Litmus

Living with dementia mate wareware, leading the way

Research to understand the influence of people living with dementia mate wareware in the planning and delivery of their services

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Contents

Research Team

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Report glossary

Term	Explanation
Aroha and manaakitanga	Acceptance of illness and behaviour change
Care partners	People who support people living with dementia mate wareware, including spouses or family members (e.g., daughter/son/in-law)
Dementia Alliance International	A collaboration of like-minded individuals diagnosed with dementia mate wareware providing a unified voice of strength, advocacy, and support in the fight for individual autonomy for people living with dementia mate wareware
Dementia friendly	Dementia friendly is an Aotearoa New Zealand that is an open and inclusive society. A friendly place where people living with dementia mate wareware can exercise their right to feel valued and safe, and where they can contribute to and participate in their communities, and where they get the help and support they need.
Dementia service organisations	Refers to the local Alzheimers organisations and other organisations providing services to people living with dementia mate wareware who were interviewed for this research.
Family or whānau	Whānau or extended family provide support but are not the primary care partner
Hapori	Community
Hapū kawa tikanga	The development of relationships in marae encounters

Term	**Explanation**
Kai	Food
Kaikaranga	Call
Kaitiakitanga	Caregiving
Kaumātua	An older Māori woman or man who has status as an older person within the whānau
Kaumātua group	Group for older Māori woman or man who has status as an older person within the whānau
Kaupapa Māori service	Kaupapa Māori service is a service by Māori, with Māori, for Māori, as Māori. The service is informed by tikanga Māori, or Māori ways of doing things.
Kuia	Elderly woman, grandmother, female elder
Mate wareware	Te reo Māori term for dementia
Most, some, and few	Refers to the participants who took part in the research and indicates the frequently of comment. The terms do not refer to all people living with dementia mate wareware
Ngā pūtake	Causes
Ngā rongoā	Protective factors
Ngā ratonga	Dementia services
Oranga wairua	Spiritual wellbeing
People/person living with dementia mate wareware	Someone with a dementia diagnosis

Term	Explanation
People living with dementia mate wareware interviewed	Refers to people living with dementia mate wareware interviewed for this research
Te Ao Māori	Māori world view
Tūpuna	Ancestors
Waiata	Song
Whaikōrero	Formal speaking on the marae
Whakamā	Ashamed, shy, bashful, embarrassed
Whānau Māori living with dementia	People living with dementia mate wareware who are Māori and their care partners and whānau
Whenua	Land, territory
Younger person with dementia mate wareware	Younger person with dementia mate wareware is a term for all types of dementia mate wareware with symptoms that begin before a person is 65 years old.

Research summary

This section is a summary of the research question, methods, and findings.

Research question and method

This research informs change for people living with dementia mate wareware to live their best lives

Alzheimers New Zealand's Lived Experience Advisory Group wanted lived experience research to answer the following research question:

- What influence do people living with dementia mate wareware have on services that support them to best meet their needs?

We used a dementia-friendly research approach

We involved people living with dementia mate wareware and care partners at all research stages. We have ethics approval from the Health and Disability Ethics Committees.

The research involved:

- a brief literature review
- a stocktake survey with 10 dementia service organisations supporting people living with dementia mate wareware
- 12 qualitative interviews with staff and managers from six dementia service organisations

  29 qualitative interviews with people living with dementia mate wareware using the six dementia service organisations.

Research findings

We all benefit when people living with dementia mate wareware are involved

When actively involved in improving dementia services, people living with dementia mate wareware, dementia service organisations, and society gain positive benefits. People living with dementia mate wareware have improved self-esteem, quality of life, and more connection to their community. Their involvement and influence reduce stigma and create more responsive services and dementia-friendly communities.

Locally, dementia service organisations are asking people living with dementia mate wareware for service feedback, but their influence is limited

Local dementia service organisations are asking people living with dementia mate wareware to provide feedback about their services via surveys and discussions. However, people living with dementia mate wareware have limited influence on service improvements or involvement in advisory groups or boards. The barriers undermining their participation and influence are:

- Delays in receiving a diagnosis mean people living with dementia mate wareware have reduced cognitive and physical capabilities, which decreases their ability and confidence to influence the services they use.
- Local dementia service organisations have limited resources and time to use processes and tools that enable people living with dementia mate wareware to be involved.
- Local dementia service organisations may seek care partner input rather than people living with dementia mate wareware due to cognitive decline.

- Local dementia service organisations do not have the resources to act on service improvements suggested by people living with dementia.
- Local dementia service organisations struggle to identify people living with dementia mate wareware who want to be on their advisory groups or Board.

Some people living with dementia mate wareware are influencing organisations they engage with

Nationally, Alzheimers New Zealand has deliberately worked to support people living with dementia mate wareware to have involvement and influence on their Board and in co-producing their services. People living with dementia mate wareware have influenced national research, policies, reviews, guidelines and development of information and services.

Internationally, Dementia Alliance International is an example of people living with dementia mate wareware leading and running an organisation. Both organisations have created enabling environments to maximise the influence of people living with dementia mate wareware.

More resources are needed to strengthen the influence of people living with dementia mate wareware on the services they use

The involvement and influence of people living with dementia mate wareware can be enabled by:

- continuing to work to reduce the stigma and exclusions of people living with dementia mare wareware within society
- ensuring people living with dementia mate wareware have early access to diagnosis and dementia services to create the choice of involvement

- creating pathways to build confidence through mentoring or peer support, to enable people living with dementia mate wareware to give feedback and step into advisory and governance roles
- ensuring dementia services have the training, time, and resources to create an enabling environment to support people living with dementia mate wareware to be involved and influence services
- building a culture of co-production with people living with dementia mate wareware
- sharing innovative practices across dementia service organisations on creating a culture of co-production with people living with dementia mate wareware
- having appropriate support and processes to enable people living with dementia mate wareware to contribute and be heard (e.g., notes, visual aids, pre-meeting briefings, support people)

Te Ao Māori needs to frame the influence of kaumātua with dementia mate wareware

Living in Te Ao Māori is foundational to oranga wairua for kaumātua with dementia mate wareware. Seeking to enhance the influence of kaumātua with dementia mate wareware needs to be done from a Te Ao Māori perspective. Further, kaumātua need equity of access to dementia services, both kaupapa Māori and other culturally safe services.

More research is needed with Pacific peoples

Due to recruitment challenges, only one Pacific care partner was interviewed. The research cannot, therefore, determine the influence of Pacific peoples living with dementia mate wareware in the dementia services they use. Pacific peoples need a voice and influence in the design and delivery of their services. Research by Pacific researchers for Pacific peoples living with dementia (and their carer partners) is critical to inform service design.

Introduction

Aotearoa New Zealand needs research on living with dementia

Dementia mate wareware is a growing health challenge

In 2020, around 70,000 people in Aotearoa New Zealand had dementia mate wareware. The number of people living with dementia mate wareware is increasing due to our ageing population. By 2050, over 170,000 people will have dementia mate wareware. This increase is expected to be particularly marked in Māori, Pacific peoples, and Asian populations, resulting in inequities (Deloitte and Alzheimers New Zealand, 2016). Dementia mate wareware impacts more women than men (Ma'u et al., 2021).

Stigma around living with dementia mate wareware continues

People living with dementia mate wareware face discrimination (Batsch, Mittelman, & Alzheimer's Disease International, 2012). They face barriers to accessing support and services and exercising their human rights. Due to stigma and dementia affecting cognitive functions, people living with dementia mate wareware are often excluded (Smith et al., 2019). More action is being called to achieve a dementia-friendly world (Carter & Rigby, 2017; Górska, Forsyth, & Maciver, 2018; World Health Organization, 2017).

Alzheimers New Zealand's mission is a dementia-friendly Aotearoa New Zealand

A dementia-friendly Aotearoa New Zealand is where organisations, communities, health services and national policies support people affected by dementia mate wareware.

A dementia-friendly Aotearoa New Zealand is where people living with dementia can feel valued and safe, contribute to their communities, and get the help and support they need.

Alzheimers New Zealand advocates for people living with dementia mate wareware to make decisions about their lives and the design and governance of services supporting them. Actively involving people living with dementia mate wareware in decision-making aligns with the Pae Ora Act 2022, the Dementia Mate Wareware Action Plan (Alzheimers New Zealand et al., 2020), the United Nations Convention on the Rights of Persons with Disabilities, and the World Health Organisation's Global action plan on the public health response to dementia (2017-2025).

Alzheimers New Zealand supports 13 member organisations

Local Alzheimers organisations support people living with dementia mate wareware in their community. They offer a range of services for people living with dementia mate wareware, including:

- individualised support
- day programmes and activities
- networks and partnerships with other health and social care providers
- referrals to specialised services such as clinical, psychological, social, physical, or financial support
- raising awareness about dementia mate wareware
- education for people living with dementia mate wareware
- education for other health care providers.

Local Alzheimers organisations are funded through Te Whatu Ora/Health New Zealand, private donations, fundraising events, grants, corporate partnerships, and other charitable donations.

Alzheimers New Zealand's Lived Experience Advisory Group wanted lived experience research to improve dementia services

People living with dementia mate wareware on Alzheimers New Zealand's Lived Experience Advisory Group (the Advisory Group) developed the Dementia Declaration (Alzheimers New Zealand's Lived Experience Advisory Group, 2019). The declaration states people living with dementia mate wareware live their best possible lives when: *'We have control over our lives; we have support to make decisions that are important to us'*.

The Advisory Group wanted lived experience research to understand the involvement and influence people living with dementia mate wareware have on the dementia services they use.

The research will be used for policy and service improvements

The research findings will inform the work of Alzheimers New Zealand and member organisations, and other organisations providing dementia service. The research will also be used to inform government agencies in their policies and funding decisions to support people living with dementia mate wareware.

We used a dementia-friendly research approach

We answered a key research question

- What influence do people living with dementia mate wareware have on services that support them to best meet their needs?

Appendix 1 has detailed research questions.

We involved people living with dementia mate wareware and care partners at all research stages. We set up a Research Advisory Group to guide the research. Members included people living with dementia mate wareware, care partners, staff from Alzheimers New Zealand, and researchers.

Appendix 2 lists the Research Advisory Group members.

We used a mixed-method research approach:

- A brief literature review of research to inform the research.
- A stocktake survey with 10 dementia service organisations supporting people living with dementia mate wareware.
- 12 qualitative interviews with staff and managers from six dementia service organisations.
- 29 qualitative interviews with people living with dementia mate wareware (9 Māori, 1 Pacific person and 11 Pākehā) using the six dementia service organisations.

The interviews were conducted in Northland, Auckland, Eastern Bay of Plenty, Wellington, Nelson, and Christchurch.

Appendix 3 has the detailed methods. Appendix 4 has the survey data.

We have ethics approval

We followed informed consent processes. Interviews were in person, audio-recorded and transcribed verbatim, with participants' permission. The Health and Disability Ethics Committees approved the research (Application ID: 2023 EXP 18263).

We used an integrated analysis process

We had an internal analysis workshop to discuss key insights. We shared the early findings with the Research Advisory Group at a sensemaking workshop in December 2023. The Research Advisory Group and Alzheimers New Zealand reviewed the draft report before finalisation.

We have presented the findings in three sections: 1) non-Māori and Pacific participants, 2) whānau Māori and 3) Pacific peoples. Some whānau Māori and Pacific peoples' findings are also reported in the impact of peer support groups for people living with dementia mate wareware research (Smith et al., 2024).

We acknowledge the research has limitations

The report presents the feedback from people living with dementia mate wareware and dementia service organisations interviewed for this research. The research does not include all experiences or preferences of people living with dementia mate wareware. Further research is needed with whānau Māori living with dementia mate wareware in urban areas, Pacific peoples living with dementia mate wareware, and people living with dementia mate wareware not engaged with dementia services.

The influence of people living with dementia mate wareware on dementia services they use

The influence of people living with dementia mate wareware on dementia services they use

This section has the findings on the involvement and influence of people living with dementia mate wareware on the dementia services they use. The findings are presented at three levels:

- locally focusing on Alzheimers organisations and other organisations offering dementia services interviewed for this research
- national focusing on Alzheimers New Zealand’s work to increase the influence of people living with dementia mate wareware in their organisation
- international focusing on Dementia Alliance International where people living with dementia mate wareware governed and lead the organisation.

The findings draw from interviews with non-Māori and non-Pacific peoples living with dementia mate wareware across the five regions, the provider survey and the literature reviewed. We have presented Māori and Pacific peoples' feedback separately, so their voice is heard.

Access barriers to diagnosis and dementia services decrease opportunities to be involved

In Aotearoa New Zealand, the process to get a dementia mate wareware diagnosis is varied and slow. People living with dementia mate wareware may wait over 12 months to get a diagnosis.

On diagnosis, access to information about dementia mate wareware and dementia services can be challenging. People living with dementia mate wareware do not know what services are available or how to access them (Smith et al., 2019).

Without access to diagnosis and dementia services, people living with dementia mate wareware cannot be involved in or influence the design, delivery, or governance of dementia services. The research findings are therefore based on people living with dementia mate wareware who have access to dementia services and accept their dementia mate wareware diagnosis.

People living with dementia mate wareware want influence in their lives and services they use

Research has shown people living with dementia mate wareware can feel they have little control in their lives. People living with dementia mate wareware want to make choices about their lives and shape the best services they use to meet their needs (Smith et al., 2019).

The rights of people living with dementia mate wareware to make their choices are recognised internationally (United Nations, 2017). The World Health Organisation's global action plan says people living with dementia mate wareware should be empowered and involved (WHO, 2017).

More locally, people living with dementia mate wareware stated they want control over their lives (Alzheimers New Zealand's Lived Experience Advisory Group, 2019).

The Aotearoa New Zealand dementia mate wareware action plan reinforces their declaration by calling for collaboration with people living with dementia mate wareware (Alzheimers New Zealand et al., 2020).

We all benefit when people living with dementia mate wareware are involved

International research highlights the personal, services and community benefits of involving people living with dementia mate wareware in decisions.

At a personal level, people living with dementia mate wareware who are involved in and able to influence services they use reported:

- improved self-esteem, identity, and dignity (Rodgers, 2018).
- increased satisfaction, quality of life and sense of empowerment (van Corven, 2022a; van Corven, 2022b, McConnell, 2019)
- broadened support networks and connection to their community (Han, 2016; Rodgers, 2018).

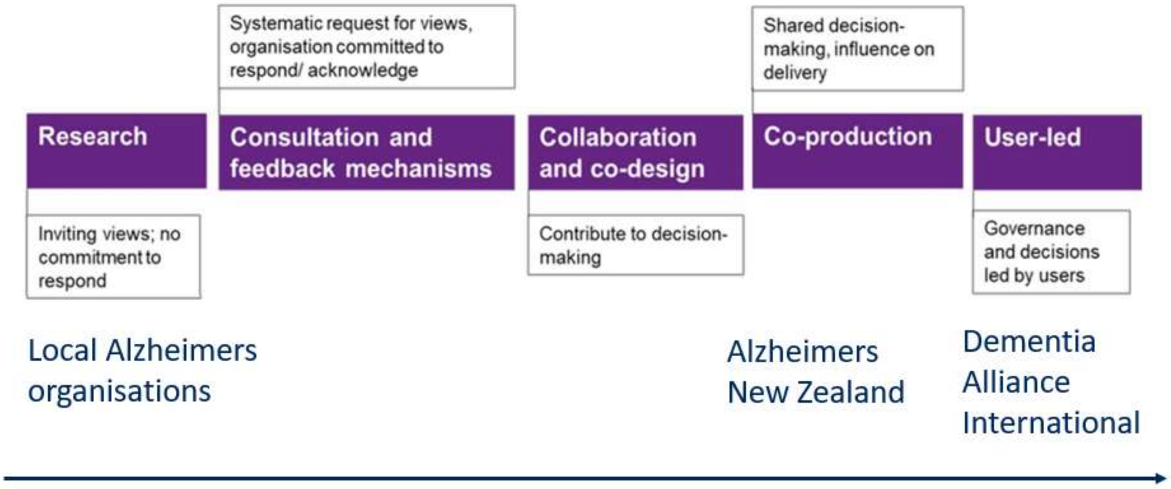
At a service level, the involvement of people living with dementia mate wareware created more responsive and dementia-friendly services (Smebye, 2012; Hung, 2021).

At a community level, their involvement reduced stigma. Family, friends, dementia service organisations gained a deeper understanding of the value of working with people living with dementia mate wareware (Daly et al., 2018). Through this change process, the involvement of people living with dementia mate wareware helps to create inclusive and respectful communities (van Corven, 2021; Rodgers, 2018).

Different levels of involvement and influence exist

People living with dementia mate wareware highlighted different levels of involvement in dementia services they use. These levels were mapped on the New Philanthropy Capital's spectrum of user involvement (Man, 2019). Figure 1 shows how users can be involved and influence services. At one end of the spectrum, users have limited influence when asked to take part in research or service feedback. On the other end, users can significantly influence services and their design through direct leadership or co-production.

Figure 1: A spectrum of user involvement approaches



Source: (Man, 2019)

People living with dementia mate wareware interviewed in this research highlighted three levels of involvement and influence:

- Local dementia service organisations ask people living with dementia mate wareware for feedback about their dementia services. However, people living with dementia mate wareware have only limited influence on service improvements. Only a few examples existed of people living with dementia mate wareware being on dementia services' boards or advisory groups.
- Nationally, Alzheimers New Zealand has deliberately worked to support people living with dementia mate wareware to have involvement and influence on their Board and in co-producing their services
- Internationally, Dementia Alliance International offers an example of people living with dementia mate wareware leading and running this organisation. People living with dementia mate wareware are effectively influencing the organisation's direction and focus. However, their ability to affect societal change to be dementia friendly is limited.

Each involvement and influence levels are described below.

Local dementia service organisations are asking people living with dementia mate wareware for service feedback, but their influence is limited

Dementia services offer a range of services to support people living with dementia mate wareware

People living with dementia mate wareware and their care partners access a range of services from their local dementia services (Smith et al., 2019). Dementia service organisations offer a range of services, with the most common services including support groups, information, and education services about living with dementia mate wareware, and cognitive stimulation programmes (Appendix 4, Table 5 has the overview of services available).

People living with dementia mate wareware are positive and grateful for their services

People living with dementia mate wareware interviewed had positive feedback on the dementia services they use. They liked the ability to socialise, share a meal with other people living with dementia mare wareware, and gain insights on living their best possible life.

> Given me a bit more confidence. I enjoyed that [support group] because it helped with my memory and built confidence for me. (Person with dementia mate wareware)

A lack of services and service choices exist for people living with dementia mate wareware (Smith et al., 2019). People living with dementia mate wareware are grateful for the services they received.

Most people living with dementia mate wareware interviewed were unwilling to offer negative feedback on the dementia services they use. Their hesitancy may reflect concern they might lose the service if criticised.

People living with dementia mate wareware are asked for feedback on the dementia services they use

People living with dementia mate wareware were asked by dementia service organisations for feedback on the services they use. These organisations asked for their input when starting the service, through surveys, and on what activities to do in groups.

A few are asked about their needs at the start of the service

A few people living with dementia mate wareware recalled being asked by dementia service organisations about their life, interests, and hobbies when starting the service. They assumed their feedback informed the types of services offered. However, most people living with dementia did not know how the providers use their feedback. Dementia service organisations interviewed noted they use these sessions to get to know the person living with dementia mate wareware.

Dementia service organisations are using surveys and interviews to get service feedback

All dementia service organisations who completed the stocktake survey (10 out of 10) said they interviewed or surveyed users on the service (Appendix 4, Table 6). They use the survey results to assess whether their services met users' needs. The surveys may also be used to provide feedback to funders, like Te Whatu Ora/Health New Zealand.

> We usually do a survey once every six months to check in and make sure they're happy with how things are going. The general surveys are pretty positive. (Dementia service organisation)

Some people living with dementia mate wareware liked completing the surveys to have a say and support the service. Those who completed the surveys did not know how the dementia service organisations use the survey results. One care partner interviewed felt their feedback was not being used to make changes.

> I do all the surveys they send through, but I don't see much change. (Care partner)

Other people living with dementia mate wareware did not recall getting the surveys. The latter may reflect their care partner completed the survey.

People living with dementia mate wareware influence group activities

People living with dementia mate wareware were also asked for feedback when attending a group activity or support group. These discussions tended to be at the activity level (e.g., song choice, discussion topics).

A few people living with dementia mate wareware provided examples of working with dementia service organisations to directly address issues arising in group activities. One person with dementia mate wareware noted another group member was struggling, and they asked the provider to get additional support for them. As a result, the group could engage more effectively by ensuring the group members received the needed support.

Some people living with dementia mate wareware were not enabled[1] to provide service feedback

People living with dementia mate wareware are diverse, and not all want to give feedback

Having dementia mate wareware affects people differently (Smith et al., 2019). In this context, the level of involvement and influence people living with dementia mate wareware want varies.

Some people living with dementia mate wareware are confident in giving feedback

Some people living with dementia mate wareware who were interviewed felt confident and comfortable providing feedback. Those who were more confident to engage had been involved in similar feedback processes before their diagnosis. People living with dementia who were more recently diagnosed or younger people living with dementia mate wareware found the feedback processes easy to use (e.g., doing an online survey).

Other people living with dementia mate wareware are not enabled by dementia service organisations to be involved

Some dementia service organisations are not using processes that remove barriers and create an environment for all people living with dementia to give feedback on their services.

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[1] Enable/enabling refers to providing the means for people living with dementia mate wareware to attain their goals by removing barriers and creating an environment where they can succeed independently.

People living with dementia mate wareware shared a range of reasons for not being able to provide service feedback:

- they did not understand what was wanted
- they needed more time to think and respond
- they felt the engagement process was unsafe
- they felt the provider knew best
- they felt their feedback would not be valued.

> I would need the confidence and to feel safe to speak to the group. (Person living with dementia mate wareware)
>
> I need more information to offer meaningful suggestions. (Person living with dementia mate wareware)
>
> [These dementia service organisations] have been doing it a while, and probably know what works. I have never done this before, so I don't know what works. (Person living with dementia mate wareware)

Some health and support organisations are not enabling input from people living with dementia mate wareware

A few people living with dementia mate wareware also highlighted their frustration with their lack of involvement in decision-making with health care professionals and care homes.

These organisations tend to be engaging with families and care partners and not creating opportunities for people living with dementia mate wareware to be involved. Examples given included a family member being moved into a mental health unit during COVID-19; a care home placing conditions about using dementia services not in their facility).

These people living with dementia mate wareware were frustrated by the lack of involvement, which undermined their sense of self-autonomy and choice.

People living with dementia mate wareware who provided feedback had increased self-autonomy and self-esteem

People living with dementia mate wareware who provided service feedback felt listened to, included, and valued. Those who were included in decisions about activities noted a sense of agency, a recognition of their passions and a contribution to their group.

> It was me that started it off. We were talking about music and I'm into my music, very much so. I started saying about different singers. We all joined in. Everybody started saying the ones they've heard of over the years. It was good, a lot of fun. They're such a great group. (Person living with dementia mate wareware)

Some people living with dementia mate wareware said giving feedback on services reinforced their sense of independence. As one person explained, they felt they were losing their independence as the effects of dementia mate wareware were changing their family role and contribution.

> I feel like I have lost my independence because I have to rely on or ask people to take me somewhere. So [the feedback forms] makes me feel like I still have some independence and that's really important. (Person with early onset dementia mate wareware)

Perceptions of service influence differ between people living with dementia mate wareware and dementia service organisations

People living with dementia mate wareware felt they had limited service influence

People living with dementia mate wareware acknowledged they were asked for input. Their feedback was influencing activities within their support groups. However, they did not know how they feedback was used. A few mentioned not seeing any service changes based on the feedback they have given their dementia service organisations.

Dementia service organisations felt people living with dementia mate wareware did influence their services

Most dementia service organisations surveyed (8 out of 10) agreed people living with dementia mate wareware influence decisions about their services (Appendix 4, Table 7). They noted feedback from people living with dementia mate wareware had resulted in the setup of younger onset dementia group and new activity-based groups (e.g., music group, walking group, more outings).

> We design and implement services based on need and feedback we hear from our clients and carers - both through formal surveys and informal feedback. (Dementia service organisation)

Some dementia service organisations noted that limited time and resources constrained their ability to respond to service requests. As one noted, they only act on requests with no financial implications.

> People living with dementia mate wareware influence our decisions within the bounds of resources available to us. Strongly influence our decisions if extra resources are not required. (Dementia service organisation)

Dementia service organisations are not co-designing services due to limited resources

Dementia service organisations noted they do not co-design their services due to time and resource constraints. In the stocktake survey, no dementia service organisation (0 out of 10) were running workshops to consult with people living with dementia mate wareware to develop services (Appendix 4, table 3).

> We do encourage as much as possible. We still don't have, and I think most places still don't have people actually designing it. Because that takes a lot more hands-on coordination. Time. And if you want them (people living with dementia mate wareware) to be at the forefront with us behind, it is going to take a lot more time and resources to do that. (Dementia service organisation)

Enabling processes, trust and confidence support people living with dementia mate wareware to be involved

People living with dementia mate wareware want various ways to provide feedback on the services they use. Examples given include surveys, one-on-one chats, and group discussions. People living with dementia mate wareware want time to reflect on the feedback sought. They want to know their voice is heard and their contributions are valued. Some want the support of family and care partners to provide feedback.

Dementia service organisations also reflected on the importance of having trusting relationships. They highlighted the need to build confidence and create a sense of community to support people living with dementia mate wareware to provide feedback.

Service access barriers and stigma prevent meaningful engagement with people living with dementia mate wareware

Dementia service organisations noted the challenges of getting a dementia mate wareware diagnosis and accessing dementia services. People living with dementia mate wareware come to their services after a significant reduction in cognitive and physical capability, such as affected speech. As a result, they feel people living with dementia mate wareware struggle with the feedback processes used. Further, some these dementia service organisations note asking people in denial about their diagnosis is upsetting, so they do not ask them.

> We need to invite them to join us at this planning level much earlier on in their journey of dementia when they might feel they have the confidence to contribute. By the time, they start engaging with us in the day facility, they are not willing and often not able to participate in meetings and planning groups.
> (Dementia service organisation)

Dementia service organisations also noted that care partners' voices have more influence on service design. The focus on care partner feedback reflects the perceptions that people living with dementia mate wareware in their services cannot contribute due to the progression of dementia.

No dementia service organisations spoke of trialling innovative ways to include the voice of people living with dementia mate wareware in service design. A few organisations are seeking more training on engaging more effectively with people living with dementia mate wareware within their current resources.

> Better training for organisations about how to comfortably seek feedback about what people living with dementia mate wareware want when we know we are already stretched in terms of resources. (Dementia service organisation)

A few dementia service organisations noted the stigma towards people living with dementia mate wareware. They noted some organisations supporting older people do not want to include people living with dementia mate wareware in their services; let alone give them a voice in their services. They are working to educate these agencies.

> There's some groups that that don't like people living with dementia going because of health and safety reasons. We are trying to get over those stigmas. For us to educate the community so they're kinder and more open. (Dementia service organisation)

A few dementia service organisations are supporting people living with dementia mate wareware to take on governance roles

A few dementia service organisations (3 out of 10) had people living with dementia mate wareware on their boards or offering guidance to the management team (Appendix 4, table 3). Service feedback suggests a lack of interest.

> We would love to start an advisory group but have not yet found much interest in this; we plan on reviewing it again next year and gauging interest in commencing one. (Dementia service organisation)

No people living with dementia mate wareware who were interviewed were on the advisory boards of their local dementia organisation. The next section discusses the role and influence of people living with dementia in governance roles.

People living with dementia mate wareware govern and co-produce services for Alzheimers New Zealand

Alzheimers New Zealand ensures a person with dementia mate wareware is on their Board

Alzheimers New Zealand is a national umbrella organisation representing people living with dementia mate wareware nationally. Over time, Alzheimers New Zealand has shifted to increase the involvement and influence of people living with dementia mate wareware in their organisation. This shift reflects their vision of creating a dementia-friendly Aotearoa New Zealand. Since 2006, Alzheimers New Zealand has had a person with dementia mate wareware on their Board.

A risk identified of not having a person with dementia mate wareware is the Board may be more focused on care partners' needs.

The Board member with dementia mate wareware contributes to and influences Alzheimers New Zealand's Board decisions

A Lived Experience Advisory Group was set up to support the Board and the Board member living with dementia mate wareware. The Lived Experience Advisory Group is made up of people living with dementia mate wareware, and care partners.

The Lived Experience Advisory Group helps the Board identify important issues for people living with dementia mate wareware. Having the Lived Experience Advisory Group offers the Board and the Board member with dementia mate wareware access to support and diversity of input from a range of people living with dementia mate wareware.

Feedback indicates the Board and Chief Executive actively work to include and listen to the Board member with dementia mate wareware and the Lived Experience Advisory Group.

> They listen and ask if they are doing the right thing. Often, she'll give me the background and explain why they're looking at doing something. There's always that opportunity for discussion.
> (Person living with dementia mate wareware)

The Board also has a relationship with the Mate Wareware Advisory Rōpū. The Rōpū provides insight into the experience, needs and expectations of whānau Māori living with dementia mate wareware.

The Board member supported by the Lived Experience Advisory Group are co-producing new services and influencing strategic directions at a national level

The Board member with dementia mate wareware working with the Lived Experience Advisory Group have influenced the following national strategic activities:

- development and dissemination of the Dementia Declaration (Alzheimers New Zealand's Lived Experience Advisory Group, 2019).
- involved in shaping and commenting on strategies, Ministerial briefings, operational plans, and annual plans.
- led inquiries into diagnosis and complaint processes with General Practice New Zealand, the Health and Quality Safety Commission and the Aged Care Commissioner
- co-produced through workshops and review processes an online education programme for people living with dementia mate wareware
- identified and co-produced research to explore issues of importance to people living with dementia (Smith et al., 2019).
- contributed to abstracts and presented at conferences nationally and internationally.

> This year, we've produced a new online education programme for people with dementia mate wareware. That had a working group of people living with dementia mate wareware who worked alongside the software company to design that. They had workshops on what was needed, they reviewed the Alpha and Beta versions, their feedback was included so that it was the programme that they said they wanted. (Alzheimers New Zealand)

A supportive environment has strengthened the influence of people living with dementia mate wareware

Initially, the Board involvement of people living with dementia mate wareware was opportunistic. People living with dementia mate wareware were invited through care partners to be involved in the organisation. On reflection, their initial involvement was more at the consultation and feedback end of the user involvement spectrum. Over time, Alzheimers New Zealand has actively worked to create an enabling environment to ensure people living with dementia mate wareware can maximise their Board influence.

Key enabling strategies include:

- having recruitment criteria and terms of reference for all Board members and the Lived Experience Advisory Group's roles to ensure people understand the role and are interested in contributing to national-level issues for people living with dementia mate wareware.
- ensuring Board members with dementia mate wareware receive accessible papers early, have time to consider, create space during meetings for their contribution, ensure travel arrangements are supportive and enable their support person to attend if needed
- having the Lived Experience Advisory Group to support the Board members by identifying issues to consider and reviewing proposed strategies and public documents
- succession planning for all Board members recognising the need to revitalise and refresh the Board over time to remain focused on the long-vision of a dementia-friendly Aotearoa New Zealand.

> Changing personnel in advisory groups is a common issue. Everyone reaches a point where they can no longer contribute, whether due to lack of time, interest, or ability. While the reasons may vary, the challenge is not unique to the dementia space but a normal part of managing any group. (Alzheimers New Zealand)

Working in the shared governance and co-production space has challenges

Recruitment issues exist in identifying people to be involved at the national level

Identifying people living with dementia mate wareware who want to be on the Board or Lived Experience Advisory Group can be challenging. Not all people living with dementia mate wareware want these roles. However, some people may not know of these opportunities or lack the confidence to step into the roles. Pathways are needed to support people living with dementia mate wareware to gain confidence and experience to take on these roles.

Retaining focus on strategic directions

A balance is needed to support people living with dementia mate wareware to act and influence while remaining focused on the group's purpose. Some people may want to join the group to gain support from others living with dementia mate wareware. However, the Board and the Lived Experience Advisory Group are not peer support groups. A person charged with a task may prefer their priority over the group's agreed deliverables. These unrealised expectations and differing priorities can disrupt the group.

> We have faced challenges finding the right balance between shaping the work and holding the pen. At times, bringing things back to where the Advisory Group had intended, rather than where the person in charge of the task might have taken it. (Alzheimers New Zealand)

People living with dementia mate wareware set up and lead Dementia Alliance International

Dementia Alliance International provides a unified voice of strength, advocacy and support for the rights, individual autonomy and improved quality of life of people living with dementia mate wareware.[2]

People living with dementia mate wareware are the key influencers of Dementia Alliance International

In 2014, Dementia Alliance International was established by people living with dementia mate wareware from different countries. People living with dementia mate wareware govern and manage Dementia Alliance International. The organisation mentors people living with dementia mate wareware to step into roles to run and support the organisation.

Dementia Alliance International has some influence internationally

People living with dementia mate wareware in Dementia Alliance International are influencing international policy (e.g., World Health Organisation, United Nations). However, as the founder reflected, after ten years of advocacy, progress in reducing stigma and creating dementia-friendly communities is slow. Positively, some change is happening.

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[2] Home | Dementia Alliance International

People living with dementia mate wareware are involved in identifying research and being members of research teams.

People not living with dementia mate wareware now support Dementia Alliance International to ensure sustainability

Over time, people who do not have dementia mate wareware were invited to support the organisation’s governance and management. These people are non-members. This shift reflects the need for support to avoid overburdening members living with dementia mate wareware.

Improvements are needed for people living with dementia mate wareware to have greater influence

Overall, the findings show in Aotearoa New Zealand local dementia service organisations are learning how to involve people living with dementia mate wareware to influence and improve their services within their current resources. Feedback from Alzheimers New Zealand and Dementia Alliance International offers insights into how to create an enabling environment to increase their level of involvement and influence.

> We’ve been through that in the disability community and the mental health community. We are still going through it in the dementia sector. We’re still having to make the case for the unique voice of people living with dementia is important in its own right. (Alzheimers New Zealand)

The involvement and influence of people living with dementia mate wareware can be enabled by:

- continuing to work to reduce the stigma and exclusions of people living with dementia mare wareware within society

- ensuring people living with dementia mate wareware have early access to diagnosis and dementia services to create the choice of involvement
- creating pathways to build confidence through mentoring or peer support, to enable people living with dementia mate wareware to give feedback and step into advisory and governance roles
- ensuring dementia services have the training, time, and resources to create an enabling environment to support people living with dementia mate wareware to be involved and influence services
- building a culture of co-production with people living with dementia mate wareware
- sharing innovative practices across dementia service organisations on creating a culture of co-production with people living with dementia mate wareware
- having appropriate support and processes to enable people living with dementia mate wareware to contribute and be heard, including:
    - discussion notes, visual aids, follow up notes and engagement.
    - time to consider, and breaks and refreshments to maintain energy
    - pre-meeting briefings and face-to-face meetings
    - support people.

The Dementia Engagement and Empowerment project offers resources on involving people living with dementia as advisors.[3]

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[3] DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf (dementiavoices.org.uk).

The influence of Māori living with dementia mate wareware on dementia services they use

The influence of Māori living with dementia mate wareware on dementia services they use

This section presents the feedback from whānau Māori living with dementia mate wareware on their involvement and influence on dementia services they use.

Feedback from Māori needs to be considered through the lens of a Māori world view (Te Ao Māori). Research by Dudley et al. (2019) and Menzies et al. (2021) provide insights into how Māori understand and experience dementia mate wareware.

Living in Te Ao Māori is foundational to oranga wairua for Māori living with dementia mate wareware

Dudley et al. (2019) found living and functioning in Te Ao Māori is critical for oranga wairua (spiritual wellbeing) for Māori living with dementia mate wareware. Their research highlighted Māori have different interpretations of dementia mate wareware. For some, dementia mate wareware is related to a loss or change; for others, the intergenerational impact of colonisation; for others, a spiritual journey of growing old and preparing to join tūpuna (ancestors). They noted a collective whānau-centred perspective highlighting how dementia mate wareware affects individuals, whānau, hapū and the community (Dudley et al., 2019).

Five categories were identified that explained dementia mate wareware from a Māori perspective: ngā pūtake (causes); ngā rongoā (protective factors); aroha and manaakitanga (acceptance of illness and behaviour change); kaitiakitanga (caregiving); ngā ratonga (dementia services) (Dudley et al., 2019). This research has drawn on the categories of ngā rongoā (protective factors), aroha and manaakitanga (acceptance of illness and behaviour change), and ngā ratonga (dementia services) to understand the feedback of whānau Māori living with dementia mate wareware about their influence on services and the role of peer support.

Kaumātua with dementia mate wareware retain influence

Interviews with kaumātua with dementia mate wareware reflect findings in Dudley et al.'s (2019) research. Kaumātua hold a place of honour and deep respect with whānau, hapū and Iwi. Kaumātua with dementia mate wareware continue to influence and contribute to their whānau, hapū, Iwi, and communities.

Kaumātua with dementia mate wareware who were interviewed continued to contribute to their cultural roles such as on the marae, through whaikōrero (formal speaking on the marae), waiata (song), as kaikaranga (caller). Cultural processes and activities keep kaumātua culturally engaged and enable them to influence whānau, hapū and on the marae. As Dudley et al. (2019) highlighted, ongoing engagement in cultural activities is a protective factor promoting wellbeing (ngā rongoā).

Support is relational through whānau, hapū, marae and hapori (community)

Kaumātua with dementia mate wareware who were interviewed highlighted the critical role of whānau, hapū and hapori (community) support. Whānau supported kaumātua with dementia mate wareware to redefine their roles based on their changing abilities. One kaumātua shared how his role and whānau contribution changed when he could no longer drive or do heavy lifting due to the effects of dementia mate wareware. With the support of his whānau, he continued to provide kai (food) by fishing and gardening. In this context, whānau aroha and manaaki enable a sense wellbeing for whānau Māori living with dementia mate wareware.

Kaumātua with dementia mate wareware spoke of the importance of kaumātua groups on the marae. They liked connecting with other kaumātua in a familiar place where they felt loved and respected. For example, one kaumātua spoke in length about cherished memories of whenua (land) belonging to tūpuna and whānau.

> It's important for people or families that are living with dementia to come together and support each other. I reckon they should be with people like us. We get on as a family. (Māori living with dementia mate wareware)

Kaumātua with dementia mare wareware living on their own also highlighted the importance of the support from their hapori (community), marae and whānau to live well. They shared how hapori (community) supported them by ensuring they were safe, well, and had food and company.

> It's good for us to make sure we've got that whānau connection and support uncle on his journey. (Māori care partner, Northland)

Kaumātua living with dementia mate wareware had varied access to ngā ratonga (dementia services)

Understanding the level of influence of kaumātua on dementia services assumes Māori have access to them. Evidence shows Māori face inequity of access to health services, and even when access is equitable, they receive lower-quality care (Ministry of Health, 2019).

Kaumātua need access to kaupapa Māori and culturally safe dementia services

As Dudley et al. (2019) noted, ngā ratonga (dementia services) are important to reduce whānau Māori stress in caring for Māori living with dementia mate wareware. They advocated that whānau Māori living with dementia mate wareware need equitable access to culturally competent support services and help to understand dementia mate wareware.

Inequitable access to dementia services and information exists for whānau Māori in rural areas

Kaumātua with dementia mate wareware living in urban or provincial areas are more likely to have access dementia services, including education sessions, community advisors, and day programmes. However, the extent to which whānau Māori living with dementia mate wareware are equitably accessing dementia services in these areas is unknown, compared to non-Māori.

In contrast, whānau Māori living in Te Tai Tokerau (Northland) spoke of access barriers to dementia services. They highlighted a lack of awareness of dementia services and information for whānau Māori living with dementia mate wareware. They felt information on living well with dementia mate wareware was not promoted or readily accessible. Others spoke of services not feeling welcoming for Māori living with dementia mate wareware.

For those living in rural towns, access to dementia services in provincial areas was challenging. Whānau Māori living with dementia mate wareware said they could not access these services due to financial constraints and travel barriers. They were unable to afford travel and food costs. Coffee groups held in public cafés left them feeling whakamā (ashamed) of being unable to afford coffee and uncomfortable talking freely in a public café.

Inequities limit kaumātua from influencing services and engaging with others with dementia mate wareware

Access barriers undermine the ability of whānau Māori to influence dementia services. Focus is needed, therefore, on increasing access to dementia services tailored to the needs of kaumātua with dementia mate wareware. Further, information about dementia mate wareware needs to be available where whānau Māori gather (e.g., marae, sports clubs).

Improvements are needed in seeking feedback from whānau Māori involved in dementia services

Some kaumātua with dementia mate wareware were asked to provide service feedback

Whānau Māori give feedback on services they use to influence the design and management of dementia services. Some kaumātua with dementia mate wareware were also invited to provide feedback to frontline staff or via online surveys on services used.

No whānau Māori living with dementia mate wareware who took part of this research had been asked to support the management or governance of the dementia services they use.

Feedback processes do not enable whānau Māori to provide meaningful input into dementia services

Feedback tended to be individualised and not whānau-centred

Feedback on dementia services tends to seek input from an individual; either the person with dementia mate wareware or their care partner. Dementia service organisations tended to use Western approaches such as surveys or forms to seek feedback from people living with dementia mate wareware. Whānau-centred approaches seeking to hear the range of whānau perspectives on service development and delivery were infrequently used (e.g., hui on marae).

Feedback processes did not support all voices of kaumātua with dementia mate wareware

Some kaumātua with dementia mate wareware liked being asked to give feedback as they felt included in the service. However, others did not feel comfortable giving feedback. They worried they would say the 'wrong' thing or be seen as ungrateful for the service. Others felt they did not have anything to contribute or know how to identify service improvements.

> I'd probably ask the wrong question, that's the only difference. So, when I'm a bit loose, I could come up and say anything and I wouldn't even know what I'm talking about. (Māori living with dementia mate wareware)

Kaumātua with dementia mate wareware did not criticise the process that is used to get their feedback. However, their responses suggest the feedback processes are not creating safe spaces for kaumātua with dementia mate wareware to contribute to service improvement. People living with dementia personally benefit from influencing positive change in their services. Therefore, consideration is needed on how to enable the voice of whānau Māori to improve services and offer insights into making services more welcoming to Māori.

> It would be nice to have more Māori imagery. Because a lot of Māori, they like to see their own culture, sit around somewhere, and know what they're looking at. (Māori living with dementia mate wareware)

A few dementia service organisations were working to increase whānau Māori involvement in their services

A few dementia service organisations with Māori staff are working to enable culturally appropriate feedback from whānau Māori living with dementia mate wareware. For example, in Eastern Bay of Plenty, Māori staff are engaging with whānau Māori living with dementia mate wareware, kaumātua groups and their local marae. They are seeking feedback on the appropriate use of karakia (prayers), waiata (song), poi or hosting kapa haka (concert) groups during the day programme. The existing relationships of Māori staff enabled this feedback together with their understanding of the wellbeing benefits of cultural activities for Māori.

In Eastern Bay of Plenty, Māori staff, whānau Māori and kaumātua groups have been involved in co-developing a cognitive stimulation therapy programme based on Te Reo Māori and Te Ao Māori.

The influence of Pacific peoples living with dementia mate wareware on dementia services they use

The influence of Pacific peoples living with dementia mate wareware on dementia services they use

Due to recruitment challenges, we only interviewed one Pacific care partner. The research cannot, therefore, determine the influence of Pacific peoples living with dementia mate wareware in the dementia services they use.

More research is needed led by Pacific researchers working with Pacific peoples living with dementia mate wareware. This section draws across the literature and feedback from one Pacific care partner to highlight themes that may inform future research.

Pacific peoples are diverse

Pacific peoples make up 8% of Aotearoa New Zealand's total population. Most are born in Aotearoa (66%) (Statistics New Zealand, 2023). In Aotearoa New Zealand, Pacific peoples come from at least eight Pacific nations, including Samoa, Cook Islands, Tonga, Niuea, Fiji, Tokelau, Tuvalu, and Kiribati (Thomsen, et al., 2018). Collectively, Pacific peoples share many similarities (e.g., family, religion, values) and as many differences (e.g., language, culture, worldview) (Thomsen, et al., 2023).

For Pacific peoples, their cultural identity is central to their wellbeing

Pacific peoples have a holistic perspective on health and wellbeing. They emphasise the collective's physical, mental, spiritual, social, and economic wellbeing (Minister of Health, 2023; Thomsen et al., 2023; Pasifika Proud, 2024).

If these holistic aspects are imbalanced, Pacific peoples' wellbeing can be adversely impacted (Pulotu-Endemann, 2001). The principle of the vā is central to these values in guiding reciprocity and respect in relational spaces (Anae, 2016).

A lack of awareness and stigma exists about dementia mate wareware

Estimates for dementia mate wareware prevalence for Pacific peoples aged sixty plus is 6.3% compared with 5.4% for Māori and 3.7% for European (Cheung et al., 2022). Over time, the number of Pacific peoples living with dementia mate wareware will increase, and so will the need for appropriate services.

Limited research has been done with Pacific peoples living with dementia mate wareware. Research completed has shown Pacific languages do not have a word for dementia mate wareware (Fa'alau, et al., 2022). In Pacific communities, stigma exists around mental health and dementia mate wareware (Hartson, 2023). The Pacific care partner interviewed highlighted the hidden nature of living with dementia mate wareware.

> Because the Samoan community's quite small, we didn't want other people to know our business, particularly dementia mate wareware. Dementia mate wareware is the unknown. (Pacific care partner).

The Pacific care partner also shared the lack of resources and information available to help Pacific peoples understand dementia mate wareware.

> There were no resources in Samoan to read. (Pacific care partner).

Pacific peoples can have difficulties accessing diagnosis and dementia services

Pacific peoples living with dementia mate wareware face access barriers to cognitive impairment and dementia services (Tippett et al, 2022). Barriers identified to dementia services include a lack of information on services available or how to access them, communication and language barriers, and financial barriers. (Symon et al., 2021). Pacific peoples living with dementia mate wareware may also face access barriers due to the absence of family support, not being computer savvy or having access to the internet.

The Pacific care partner also highlighted a lack of respite services tailored to meet the needs of Pacific peoples living with dementia mate wareware.

> I was looking for some Pacific-based or multi-cultural-based activities that he could attend to give my Mum a break. In terms of resources in the community, there were none to support people going through dementia mate wareware. (Pacific care partner)

Ideally, they want relevant services for Pacific peoples by having Pacific staff who can speak Pacific languages and offering cultural activities.

> I think what would help is cultural activities. Let's do a bit of weaving, flower arrangements, singing, and dancing with Pacific music and music they know. (Pacific care partner)

More resources in Pacific languages are needed, including written material, videos, and communications through Pacific media.

> I'd like to see pamphlets or videos online to help our people and support them in understanding. It's no fault you might be getting memory problems so let's see the GP. (Pacific care partner)

Conclusion – living with dementia mate wareware; leading the way

Increasing the involvement and influence of people living with dementia mate wareware in the services they use has multiple benefits. People living with dementia mate wareware experience improved quality of life, self-esteem, and community connections. Dementia service organisations deliver services that meet the needs of people living with dementia mate wareware. Society benefits from dementia-friendly communities.

Dementia service organisations are involving people living with dementia mate wareware to have a say on the services they offer. However, people living with dementia mate wareware have limited influence due to existing barriers. Barriers include a lack of early diagnosis and service access, dementia service organisations' resource limitations, and ongoing stigma and exclusion.

The prevalence of dementia mate wareware is increasing for Māori and Pacific peoples. However, Māori and Pacific peoples face ongoing inequities in accessing diagnostic and culturally informed information and services. These access inequities diminish their ability to influence the design and delivery of dementia services.

Dementia service organisations need more resources to create an enabling and culturally safe environment so people living with dementia mate wareware can meaningfully influence dementia services and live their best lives.

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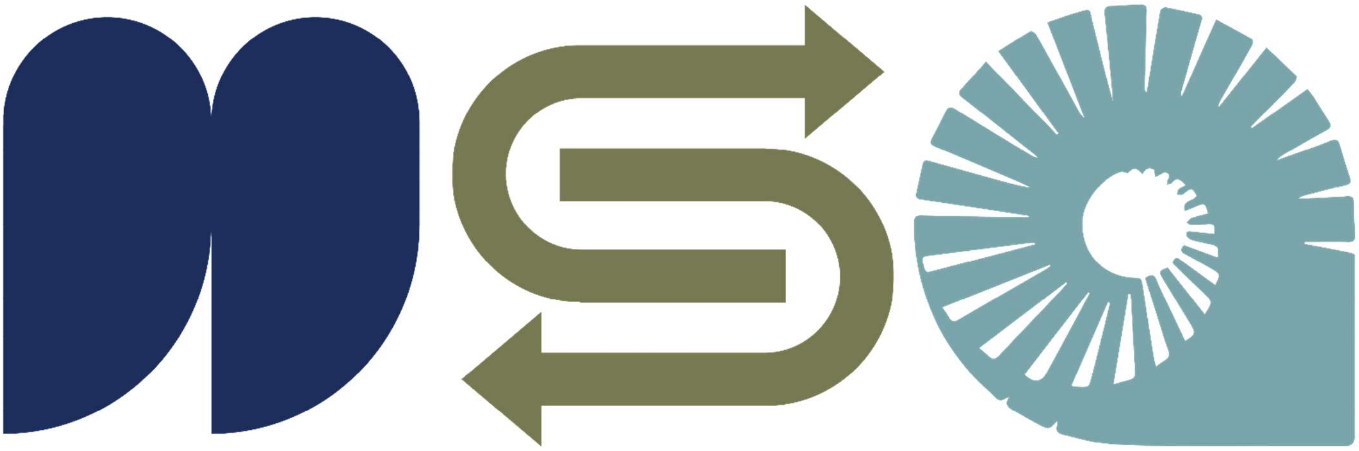
Appendices



Appendix 1: Research questions

The key research question and associated questions were:

1. What influence do people living with dementia mate wareware have on services that support them to meet their needs best?
    - What services do people living with dementia mate wareware use to meet their needs?
    - How are people living with dementia mate wareware involved in these services?
    - How does feedback from people living with dementia mate wareware influence decisions about the services?
    - What changes have been made based on their feedback?
    - What enables people living with dementia mate wareware to be involved in and influence the services they use?
    - What stops people living with dementia mate wareware from being involved in and influencing the services they use?
    - What improvements are needed to support people living with dementia mate wareware to influence their services?

Appendix 2: Research Advisory Group

We established a Research Advisory Group to provide advice to the research team. The Group advised on the research design, tools, and reviewed the draft report.

Table 1: Members of the Research Advisory Group

Name	Organisation	Role
Alister Robertson	Alzheimers New Zealand 's Lived Experience Advisory Group Dementia Alliance International	Chair Dementia Alliance International
Elizabeth Duke	Alzheimers New Zealand 's Lived Experience Advisory Group	Lived Experience
Riki Rollerston	-	Māori care partner
Sisavaii Poa-Talataina	Alzheimers New Zealand 's Lived Experience Advisory Group	Pasifika researcher and care partner
Dr Jean Gilmour	-	An expert in dementia mate wareware and research
Lyneta Russell	Alzheimers New Zealand	Clinical advisor

Appendix 3: Detailed research method

In 2023, the research was designed based on briefings, a brief review of literature and hui with the Research Advisory Group. Alzheimers New Zealand, the Research Advisory Group and the Health and Disability Ethics Committee reviewed the research plan.

A brief review of literature was completed

A brief literature review was completed to inform the answers to the following questions:

- What are the benefits or impacts for people living with dementia mate wareware from being involved and influencing the design, delivery and governance of their support services?
  - What factors limit and enable their involvement?
  - What factors limit and enable their influence?

A stocktake survey was completed by 10 dementia service organisations

The stocktake survey offered a point-in-time assessment of the current inclusion of people living with dementia mate wareware in their services. The stocktake identified services offered and the involvement and influence people living with dementia mate wareware have on these services.

The stocktake survey was developed using the research questions. The stocktake survey was on SurveyMonkey and distributed via email or completed during interviews.

Dementia service organisations were asked to complete the stocktake survey. The survey was sent to all Alzheimers New Zealand's organisations (n=13) and other dementia service organisations (n=2). A response rate of 66% was achieved (i.e., 10 out of 15 organisations completed the survey).

People living with dementia mate wareware and dementia service organisations completed qualitative interviews

The voice of people living with dementia mate wareware was critical to understanding their influence on services and the impact of peer support.

We completed interviews across five locations

The site selection was based on a mix of urban and rural locations, North and South Island and areas with high Māori populations. The sites also reflected areas where dementia service organisations had capacity to support the research. The five regions were Northland, Eastern Bay of Plenty, Nelson/Tasman, Wellington, and Canterbury.

We completed qualitative interviews with 29 people living with dementia mate wareware in five regions (Table 2). Interviews were mainly with people living with dementia mate wareware.

We interviewed 12 staff and managers representing six dementia service organisations across the five regions and at a national level (Table 3). The dementia service organisations involved in a qualitative interview also completed the stocktake survey. Most dementia service organisations were affiliated with Alzheimers New Zealand. One dementia service organisations supported younger people living with dementia mate wareware.

Table 2: Profile of the people living with dementia who were interviewed

People living with dementia		**n=29**
Ethnicity	Māori	9
	Pacific peoples	1
	Pākehā	19
Gender	Female	16
	Male	13
Age group	Older than 65 years of age	22
	Less than 65 years of age	7
Location of residence	Northland/Whangarei	7
	Nelson	6
	Eastern Bay of Plenty	5
	Christchurch	5
	Wellington	5
	Auckland	1[4]

Table 3: Location of the dementia service organisations interviewed

Dementia service organisations	**Areas**	**n=12**
Location of organisation	Northland/Whangarei	2
	Nelson	2
	Eastern Bay of Plenty	2
	Christchurch	3
	Wellington	3

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[4] Interview with Pacific care partner to a family member with dementia mate wareware.

We used the Older Adults' Capacity to Consent to Research (OACCR) scale

We interviewed people who have a dementia mate wareware diagnosis and accepted having a dementia mate wareware diagnosis.

We mainly recruited people living with dementia mate wareware through dementia service organisations. These organisations asked people living with dementia mate wareware if they wanted to take part in the research.

A Māori community connector recruited whānau Māori in Northland. The Pacific researcher worked to connect with Pacific organisations supporting Pacific peoples living with dementia mate wareware.

We adopted a modified version of the OACCR scale to determine capacity to consent to the research (Lee, 2010). The scale asks four key questions which we used during recruitment and before starting an interview. After going through the information sheet about the research, we asked the person with dementia mate wareware:

1. What is the purpose of the research?
2. Tell me some things you may be asked about?
3. What are the things that might worry you about taking part in the research?
4. If you don't want to, do you have to take part in the research?

We adopted the following decision hierarchy:

- Informed consent was reached if a potential participant answered all four questions.
- We used supported decision making, working with care partners and families and people living with dementia mate wareware if potential participants answered 1 and 4.
- We excluded people who could not answer questions 1 and 4.

We adopted this scale as it aligns with the best practice for everybody taking part in research. No one should take part in research they do not understand, have concerns about, or do not know they don't have to take part in.

We followed DEEP guides to complete interviews (The Dementia Engagement and Empowerment Project, 2013a, 2013b, 2014)

Interviews were mainly face-to-face with a couple held virtually and by telephone. Most interviews were held in people living with dementia’s homes or comfortable and safe location. We audio recorded interviews if they provided consent. The interviews lasted up to 30-40 minutes. People living with dementia mate wareware were invited to bring a support person.

Experienced qualitative researchers completed the interviews. Maria Marama, a kaupapa Māori researcher, conducted the interviews with Māori participants. Dr Marianna Churchward, a Samoan researcher, interviewed Pacific peoples.

The researchers were flexible in their approach so people could tell their story in their way. Researchers were mindful and did not rush interviews.

People living with dementia mate wareware who took part in the research received a $60 supermarket voucher koha.

We followed a multi-stage thematic analysis process

Interviews were transcribed. Where requested, we sent people their transcripts to review.

All interviewers attended an analysis workshop to identify high-level findings. A detailed thematic analysis process followed to identify patterns and themes. We held a sensemaking workshop with Alzheimers New Zealand staff and members of the Research Advisory Group to present preliminary findings in December 2023.

We acknowledge the research limitations

The report reflects the feedback from people living with dementia mate wareware and service organisations interviewed. The report has limitations.

The findings reflect the perspectives and experiences of the people who were interviewed for this research. The sample size is sufficient for qualitative research (Hennink and Kaiser, 2022). However, the sample achieved does not represent the diversity of people living with dementia mate wareware or service organisations offering services. We have limited insight into the perceptions of Māori living in urban areas, Pacific peoples, and people living with dementia mate wareware not engaged in dementia services.

We faced significant challenges recruiting Pacific peoples living with dementia mate wareware. This challenge was partly due to service organisations in regions where more Pacific peoples live not having the capacity to take part in the research. Further, ensuring the inclusion of Pacific peoples living with dementia mate wareware would have required more time and resources for the research to offer Pacific researchers who speak Pacific languages. More research is needed to understand the diverse experiences, needs and preferences of Pacific peoples living with dementia mate wareware in Aotearoa New Zealand.

Appendix 4: Survey data tables

Table 4: Location of dementia service organisations who completed the stocktake survey

Location	**No of dementia service organisations**
Base	**10**
Northland	1
Tauranga/Western Bay of Plenty	1
Eastern Bay of Plenty	1
Gisborne/Tairāwhiti	1
Taranaki	1
Whanganui Wairarapa	1
Wellington & online New Zealand	1
Nelson/Tasman	1
Marlborough	1
Canterbury	1

Table 5: Type of services offered by dementia service organisations

Types of services offered	**No. of dementia service organisations**	**% of dementia service organisations**
Base	**10**	**10**
Social connections	10	100%
Information and resources about living with dementia	9	90%
Cognitive stimulation programmes	9	90%
Support groups (staff facilitated)	9	90%
Support and navigation services	8	80%
Peer support services	8	80%
Education programmes	7	70%
Day programmes	7	70%
Activity respite programmes	6	60%
Younger onset programmes	4	40%

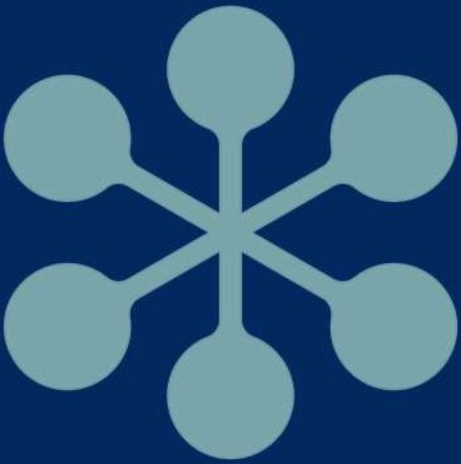
Table 6: Organisations’ views on how people living with dementia mate wareware are involved in design, implementation, and evaluation of services

Involvement type Base	No. of dementia service organisations 10	% of dementia service organisations 10
We survey or interview them about how to improve services	10	100%
They are on our organisation’s Board or governance group	3	30%
They deliver some of our services	3	30%
They offer advice and guidance to the management team	2	20%
We have an advisory group of people living with dementia	1	10%
People living with dementia lead our organisation	1	10%
We run workshops to consult with them to develop or improve services	0	0%
Other answer**	3	30%

** Other included: informal chats, journalling, family feedback, volunteering, kaumātua group feedback, clients onboarding interviews when they enter 73service to understand values, interests, hobbies

Table 7: Organisations rating on how people living with dementia mate wareware influence decisions about the design, planning, implementation and evaluation of services

Response Base	No. of dementia service organisations 10	% of dementia service organisations 10
Strongly agree	3	30%
Agree	5	50%
Neither agree nor disagree	1	10%
Disagree	1	10%
Strongly disagree	0	0%



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