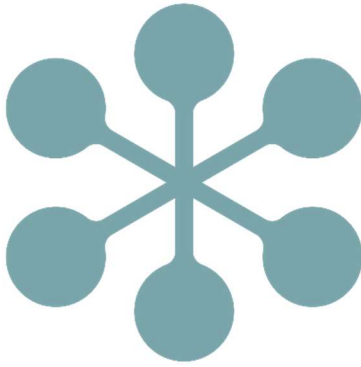


Litmus

Living with dementia mate wareware,
leading the way

The impact of peer support groups for people living
with dementia mate wareware

16 April 2024



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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, including spouses or family members (e.g., daughter/son/in-law)
Dementia Alliance International	A collaboration of like-minded individuals diagnosed with dementia providing a unified voice of strength, advocacy, and support in the fight for individual autonomy for people living with dementia
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 frequency of comments. 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 mate wareware diagnosis

Term	Explanation
People living with dementia mate wareware interviewed	Refers to people living with dementia mate wareware interviewed for this research
Tūpuna	Ancestors
Waiata	Song
Whaikōrero	Formal speaking on the marae
Whakamā	Ashamed, shy, bashful, embarrassed
Whānau Māori living with dementia mate wareware	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

We used a dementia-friendly research approach

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

- What is the impact of peer support on people living with dementia mate wareware?

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 Committee.

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 (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.

Research findings

Peer support is a structured approach of equals supporting each other

Peer support involves individuals with similar illnesses or conditions supporting each other by sharing their time and experiences.

Peer support's role in the dementia care sector is emerging

Peer support programmes tend to focus on supporting young people living with dementia care or people with a recent diagnosis. Peer support programmes has the potential to overcome isolation and offer education early in the dementia care journey. Remaining active and socially engaged enhances the wellbeing of people living with dementia care and may delay dementia symptoms.

Peer support programmes need to respond to the context of living with dementia care

To maximise the benefits of peer support programmes, early diagnosis and access to culturally safe dementia services are critical. However, early access to diagnosis and support services in Aotearoa New Zealand is challenging. Late access can diminish the benefits of peer support in navigating this life change.

Peer support programmes for people living with dementia care need to have relational safety, training in facilitation and adaptation to include the diversity of people living with dementia care.

In Aotearoa New Zealand, few formal peer support programmes exist

Internationally, many different types of peer support exist, including formal and informal, in person or online, groups and one-on-one, professional-, lay-, or peer-facilitated, community or service-led.

In Aotearoa New Zealand, peer support is informal and part of other dementia services. A few formal peer support programmes exist. Examples include one-on-one and group peer support through volunteers living with dementia mate wareware, and an online peer support group for younger people living with dementia mate wareware.

Informal peer support is beneficial

The feedback from people living with dementia mate wareware interviewed reflects the international research findings. The benefits of peer support for people living with dementia mare wareware are:

- increased social engagement and emotional support
- a sense of purpose and increased self-confidence
- ability to accept and cope with having dementia mate wareware
- new knowledge and practical advice on daily living skills
- quality of life and wellbeing benefits, and potentially maintained cognitive ability
- care partners have time for their activities.

Research in the United Kingdom found that peer support groups for people living with dementia mate wareware have a positive social return in investment for every pound (£) spent (Willis et al., 2018). Assuming these findings apply in Aotearoa New Zealand, peer support initiatives are

worthwhile investments that return positive benefits to people living with dementia mate wareware, their care partners, and dementia service organisations over their initial costs.

Te Ao Māori needs to frame the role of peer support for kaumātua living with dementia mate wareware

Living in Te Ao Māori (Māori worldview) is foundational to *oranga wairua* (spiritual wellbeing) for kaumātua (older Māori) living with dementia mate wareware. For kaumātua living with dementia mate wareware support is relational through *whānau*, *hapū*, *marae* and *hāpori* (community). The term 'peer support' is not familiar to Māori living with dementia mate wareware. However, kaumātua living with dementia mate wareware valued being in support groups with other people living with dementia mate wareware. To benefit from peer support, kaumātua living with dementia mate wareware need equity of access to dementia services, both kaupapa Māori and other culturally safe services.

More research is needed with Pacific peoples living with dementia mate wareware

Due to recruitment challenges, only one Pacific care partner was interviewed. The research cannot, therefore, determine the perceptions of Pacific peoples living with dementia mate wareware about the impact of peer support. 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 mate wareware is critical to inform service design.

Research conclusions and future directions

Peer support programmes have a positive impact on helping people living with dementia become more aware to cope with their diagnosis, be connected, strengthen their wellbeing and contribute to others. Deliberate, structured and planned peer support programmes have an important role alongside other dementia services, such as cognitive stimulation programmes.

Creating a more structured approach to peer support for people living with dementia become more aware aligned with best practice requires:

- a shared understanding of peer support reflecting the diversity of people living with dementia become more aware and their needs
- improved access to early diagnosis to create pathways to the protective aspects of peer support
- increased focus on capability building for volunteers with dementia become more aware and developing them as peer support leaders
- a more structured and purposeful approach to building diagnosis acceptance and dementia become more aware knowledge
- focus on linking people living with dementia become more aware to their community in ways that demonstrate their contribution.

Introduction



Aotearoa New Zealand needs research on living with dementia mate wareware

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 higher 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 mate wareware 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. 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, 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 research to understand the impact of peer support

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 impact of peer support on people living with dementia mate wareware. This research explored the types of peer support available and its benefits for people living with dementia mate wareware.

In this research, peer support was defined as people living with dementia mate wareware receiving support from others living with the condition in formal and informal places where they come together.

The research will be used for policy and service improvements

The research findings will inform the work of Alzheimers New Zealand, member organisations and other organisations providing dementia services. 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 is the impact of peer support on people living with dementia mate wareware?

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-methods 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 influence of 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 impact of peer support on people living with dementia mate wareware



The impact of peer support on people living with dementia mate wareware

This section describes the findings on the impact of peer support for people living with dementia mate wareware. The findings are presented across three areas:

- Peer support's value through defining peer support in the dementia mate wareware sector, the types, challenges and known benefits.
- The types of peer support offered in Aotearoa New Zealand, alignment with best practices and the benefits for people living with dementia mate wareware using them.
- Future directions and improvements for peer support programmes for people living with dementia mate wareware in Aotearoa New Zealand.

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

Peer support's role in the dementia mate wareware sector is emerging

Peer support is based on equals supporting equals

Peer support involves individuals with similar illnesses or conditions supporting each other by sharing their time and experiences (NSF Consulting, 2023).

Peer support is *'a system of giving or receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful'* (Mead, 2001: p135). Peer support has been used in the mental health and disability sectors.

Peer support is a structured approach

Engaging with peers is a normal part of day-to-day life. Peer support is more than friends supporting friends with common health conditions. Peer support is a structured approach with the following best practice principles:

- **user-led** by disabled people and their families and based on their lived experience
- **focused on capacity building** with training provided to peer support leaders to increase their knowledge and confidence
- **facilitated through a community organisation** to connect disabled people and have processes to build relationships
- **semi-structured and purposeful** organised around information-based content balanced with, as relationships grow, informal support
- **community-based** to establish and maintain links between disabled people and community organisations, other health and social services and other community services (Chronic Illness Alliance, 2015; NSF Consulting, 2023; Davy et al., 2018).

Peer support approaches need to respond to the context of living with dementia mate wareware

Getting a dementia mate wareware diagnosis and accessing peer support and other services is challenging

People may not seek or receive a dementia mate wareware diagnosis until their symptoms are more advanced. On diagnosis, people living with dementia mate wareware may struggle to access services and peer support to understand their diagnosis (Smith et al., 2019). As a result, people living with dementia mate wareware can miss out on early education through peer support to help them come to terms with their diagnosis.

Peer support programmes tend to focus on supporting young people living with dementia mate wareware or people with a recent diagnosis. People living with more advanced symptoms of dementia mate wareware can be overlooked or find it harder to engage in peer support programmes (Sullivan et al., 2022).

Peer support can overcome social isolation

After diagnosis, people living with dementia mate wareware can become isolated as friends and family pull away (Smith et al., 2019). Peer support programmes can overcome isolation. Remaining active and socially engaged is important for the wellbeing of people living with dementia mate wareware and may delay dementia mate wareware symptoms (Söderlund et al., 2022).

People living with dementia may need tailored peer support

Peer support groups for people living with dementia may have different characteristics than peer support groups for other disabled people. People living with dementia can feel vulnerable engaging with others due to stigma and concerns about their reception. Relational safety is important within peer support programmes. People living with dementia need relational safety to foster personal growth by expressing their changing self and capabilities (Sullivan et al., 2022).

Peer support groups for people living with dementia need to have appropriate structures and functional supports. Peer support groups for people living with dementia can benefit from professional facilitation or backbone support functions. This support can enable people living with dementia with memory or language issues to engage more fully through the scaffolding of communications and maintain relational safety (Sullivan et al., 2022, Toms et al., 2015).

Peer support approaches need to meet diverse needs

Peer support programmes need to accommodate and adapt to the diversity of people living with dementia (e.g., age, gender, ethnicity, disease stage) (Sullivan et al., 2022).

Peer support is not clearly defined in the lifespan support continuum

The role of peer support within the wider health and social services programmes for people living with dementia mate wareware is not clearly defined (Sullivan et al., 2022). This disconnect highlights the lifespan continuum of support services to enable people living with dementia mate wareware to live their best lives does not formally exist.

A range of peer support models exist with different structures and functions

Different types of peer support programmes for people living with dementia mate wareware include:

- Formal support groups facilitated by a person trained to support people living with dementia mate wareware to explore experiences, coping mechanisms or deliver cognitive stimulation sessions.
- Informal support groups may be lay or peer-facilitated or part of a day programme delivered by professionals to provide regular social interaction and a source of information for people living with dementia mate wareware.
- Online support groups may be peer or care partner facilitated using online-based discussion forums to enable people living with dementia mate wareware to ask questions, share experiences, and receive advice and support from others.
- Specific peer support groups may be formal and informal set up for people who share a similar background (e.g., women, Māori), enjoy similar activities (e.g., walking, coffee, art), or shared belief (e.g., marae, church) to enjoy a shared experience and support each other.

- Community support groups are set up to create more connections through the opportunity for people living with and without dementia mate wareware to meet in a community setting.
- One-on-one face-to-face or online interactions with a peer with dementia mate wareware to socialise and support each other (Toms et al., 2015, Health Innovation Network South London. 2015).

The Nesta and National Voices literature review (not dated) found the most promising types of peer support for people living with dementia mate wareware to be:

- face-to-face groups run by trained peers which focus on emotional support, sharing experiences, practical activities and education
- one-to-one support offered face-to-face or by telephone
- online forums, particularly for improving knowledge and anxiety
- offered regularly (such as weekly) for three to six months.

The evidence base on the benefits of peer support for people living with dementia mate wareware is growing

Assessing the benefits of peer support for people living with dementia mate wareware is challenging due to the different types of approaches.

Qualitative evidence highlights benefits for people living with dementia mate wareware through engaging in peer support programmes. However, quantitative evidence is lacking (Sullivan et al., 2022).

Based on the qualitative evidence, peer support for people living with dementia mate wareware has:

- interaction benefits of increased social engagement and emotional support
- personal benefits of a sense of purpose, increased self-confidence, and ability to accept and cope with having dementia mate wareware
- new knowledge and skills benefits of practical advice and day-to-day living skills, new or restarted hobbies
- quality of life and wellbeing benefits, and potentially maintained cognitive ability or slowed decline (Health Innovation Network South London, 2015, Sullivan, et al., 2022; Jorgensen, 2022; Scott, 2017; Goeman et al., 2016; Söderlund et al., 2022).

Peer support tends to be informal and opportunistic in Aotearoa New Zealand

Peer support is not a familiar term

People living with dementia mate wareware interviewed are not familiar with the term 'peer support'. Dementia service organisations interviewed know the term and appreciate its value in supporting people living with dementia mate wareware.

Peer support tends to be included in other services

All dementia service organisations surveyed offered peer support opportunities through existing day programmes or groups (Table 1). All dementia service organisations surveyed said peer support was important for people living with dementia mate wareware.

We've got nurturing clients. They're good to tee up with some newer clients. They take them under their wing, they'll buddy up with them, they'll reassure them and help them navigate the day. It gives them a meaningful purpose, knowing that they can support their peer. (Dementia service organisation)

Table 1: Types of peer support offered in Aotearoa New Zealand

Types of peer support offered	Out of 10 dementia service organisations surveyed
Group – social interaction	●●●●●●●●
Group - cognitive stimulation	●●●●●●●●
Support groups	●●●●●●
Group – education	●●●●●●
One-on-one peer support	●●
Online group	●

The dementia service organisations highlighted peer support tends to be included in an existing group rather than a separate planned initiative. The groups tend to be facilitated by dementia service organisation staff and in some cases supported by volunteers living with dementia mate wareware. The staff facilitate the sessions to ensure people living with differing communication needs are included.

This lady, she needed time to get her words out. At the beginning, the group used to jump in. They learned to wait and give her time. It was so joyful watching her because she's part of the group. (Dementia service organisation)

The staff work to create a relationally safe environment. They noted people living with dementia may be aware that they can feel judged in other groups with people who do not have dementia.

It's about being with people like yourself that make you feel safe. There's another group that meets regularly. We've tried encouraging our people to go along to that group. But, often, they'll say that no one talks to them, or they can't follow the conversation because they can't remember it. Their confidence is dampened. In the groups we're running, they feel more confident. It doesn't matter if they don't remember. (Dementia service organisation)

Dementia service organisations were also mindful to meet the diverse needs of people living with dementia may be aware. Dementia service organisations recognise that not everyone wants to join group activities and ensure other activities are available (e.g., gardening).

Generally, it seems a really good, positive thing. People are happy for it. Occasionally, you get the odd one that is just not for them. Prior to dementia, they may not have been a particularly social person, so you can't expect them to be thrown into this environment and think that this is great. (Dementia service organisation)

People living with dementia may be aware said the peer groups were important to them. People living with dementia may be aware see the groups as safe spaces to express themselves as they want.

This [group] is my lifeline. There's people who express themselves when they want to and don't go, you know mute, as they do sometimes. (Person with dementia may be aware)

Few formal peer support initiatives exist

Some peer support groups emerge out of other group activities

One dementia service organisation noted how a peer support group emerged from a cognitive simulation programme for women. On completion of the group, the women keep in touch and get together socially. They noted the importance of the group as the women lived rurally and were at risk of social isolation.

Some people living with dementia mate wareware preferred to attend groups with people they identified with (e.g., women, men, younger people, Māori, and Pacific peoples). This preference reflects the discomfort people living with dementia mate wareware can feel when they engage with people they do not identify with. They are concerned that they will not be accepted or be able to contribute.

People living with dementia mate wareware volunteer to support others

A few dementia service organisations offered one-on-one peer support through their volunteers living with dementia mate wareware (volunteers). Volunteers tend to be identified through their interactions in a group setting and their desire to support others who receive a dementia mate wareware diagnosis.

The volunteers do not receive formal training for the role. However, they do receive support, as needed, from dementia service organisations. The volunteer roles are supervised to ensure a good fit between the volunteer and the person they are supporting. The latter demonstrates processes to manage the relational aspects of peer support in practice.

We have a volunteer coordinator. She gets feedback from carers. She also makes sure the volunteer match is working okay and that there aren't any issues. A regular communication to check that it's all going fine. (Dementia service organisation)

Volunteers support new people living with dementia mate wareware coming to support groups. They help the new person in feeling at ease and understanding the activities.

It takes new people a little while to create those friendships. That's where the volunteers are brilliant. It's just bringing people together. They can talk and introduce them. (Dementia service organisation)

A volunteer living with dementia mate wareware interviewed said they enjoyed the social interaction and the opportunity to help others.

Well, people seem to need to talk. I feel because people will confide, they are enjoying it. I try to encourage people to talk about it [dementia]. (Volunteer with dementia mate wareware)

An online peer support group exists for younger people living with dementia mate wareware

This online group is led and run by younger people living with dementia mate wareware (those who were diagnosed with dementia mate wareware before the age of 65 years old). People living with dementia mate wareware who live in rural areas liked the online peer support because they could access the group.

Young people living with dementia mate wareware liked to connect with others in their age group. They liked the opportunity to ask questions about dementia mate wareware. They also benefitted from sharing tips on living well with dementia mate wareware and finding out what other online resources were available.

The group gave younger people living with dementia mate wareware a sense of hope and built confidence they could cope with future changes.

The whole point of coming into the early onset peer support group for me is to ask questions like what do we think about driving? How are people coping? How do people remember? Do you use lists? What apps do you find useful? What peer support do you get in your area? (Younger person with dementia mate wareware)

One drawback is the need for more facilitation to stop some members from dominating the group and reducing the benefit to others.

Dementia service organisations noted that not all people living with dementia mate wareware are comfortable with online groups due to challenges using online technology and lack of internet access. Online groups tend to suit younger people living with dementia mate wareware.

In Aotearoa New Zealand, peer support initiatives have some alignment with best practice principles

Best practice principles note that peer support for people living with dementia mate wareware is a deliberate, structured, and planned process.

In Aotearoa New Zealand, peer support initiatives are organically emerging through existing services. These peer support initiatives tend to align with two best practice principles:

- **User-led** - Peer support initiatives tend to be led by people living with dementia mate wareware.

- **Facilitated through a community organisation** - Peer support is facilitated through dementia service organisations. Staff encourage peer support by facilitating the conversations and activities in a supportive and safe environment.

Peer support initiatives are not well aligned with other best practice principles.

- **Capability-building** - People living with dementia mate wareware offering peer support do not receive formal training for the role.
- **Semi-structured and purposeful** - Peer support offered is unstructured and informal and not based on agreed information content.
- **Community-based** - Peer support offered creates connections within the dementia service organisation. Feedback indicates more limited work in linking people living with dementia mate wareware to their wider community.

In Aotearoa New Zealand, resources barriers inhibit the development of structured peer support programmes

Dementia service organisations acknowledged the importance of peer support. However, due to limited resources, their staff are not available to enable peer support activities, training, and scaffolding of conversations. In rural areas, the cost of transportation was also highlighted as a barrier to attending peer support groups. Some groups charge a fee, which creates an access barrier for some people living with dementia mate wareware.

Informal peer support is beneficial to people living with dementia mate wareware and their care partners

Both people living with dementia mate wareware and dementia service organisations highlighted the benefits gained from peer support. The benefits identified mirror those in the literature.

People living with dementia mate wareware make new friends and are accepted

People living with dementia mate wareware noted they had lost friends following their diagnosis. They worried about engaging with people who did not understand dementia and might judge them. The peer support groups' activities enable them to make new friends.

Making friendships. It's really important. Because the majority of my friends aren't my friends anymore. They can't cope with me, so I don't have anything to do with them. That's why I started going to [name]. (Younger person with dementia)

People living with dementia mate wareware said that in the peer support groups, they felt safe to be themselves. This reflects other people living with dementia mate wareware understanding and accepting of their dementia symptoms.

I think it's the feeling of all being in the same boat. We argue how much we are in the same boat because some of us have more difficulties than others—the sense of helping each other. At the one I went to yesterday, there was one stage where one of the ladies in the group was close to tears. I think the invisible support when somebody is distressed. (Person with dementia mate wareware)

People living with dementia mate wareware found engaging with others with dementia mate wareware normalised having the condition.

I like the companionship. At the beginning, my family were worried about me having Alzheimer's. But there's no big deal about it. There's no worry about it. [The group] makes it normal. That going to the group makes what I've got okay. (Person with dementia mate wareware)

People living with dementia mate wareware gained a sense of purpose and confidence

Volunteers living with dementia mate wareware spoke of a sense of purpose of helping others. They enjoyed the ability to give back to their community and support other people living with recent a diagnosis who are anxious.

It's just caring for others. They ask me for a friendship. I went and visited this lady, and we had lots of laughs. (Person with dementia mate wareware)

Some people living with dementia mate wareware spoke of struggling with getting out of the house. The support groups offered a sense of structure to their week and day.

I think it's made a big difference for me. I tend to withdraw from the world so getting out there and meeting people living with similar challenges as me. It has made me feel that I'm not the only one with the thing. (Person with dementia mate wareware)

An opportunity to understand dementia mate wareware and gain new skills

Through the peer support groups, people living with dementia mate wareware learnt about their health condition and how to cope. Interacting with others living with dementia mate wareware offered insight into what may lie ahead. Engagement in the groups increased their connectedness and put their life now and in the future into a more positive perspective.

They are all a bit older than me and further along the path of dementia. But they're all vocal, they can still talk. It's given me a wee bit of reassurance that, touch wood, I'm going to be like I am now for quite some time. It's not a fun place to be, but it's not as bad as it could be, and that's something. (Person with dementia mate wareware)

Some people living with dementia mate wareware were encouraged to try new activities or take up old hobbies. These activities and the group interaction offered a sense of purpose and reinforced that they could continue to contribute meaningfully.

He hadn't played the piano for at least a year and when he came here, within a fortnight, he was playing the piano at home. It's brilliant – he plays the piano once a week. (Care partner)

This is so important. People put people in a box when they hear you've got dementia and think right that's it - party's over. No, it's not. I love hearing that life's not over. I can try this. I can do that. Discover hidden talents. Take ideas at home like the clay. (Dementia service organisation)

The activities and engagement offered wellbeing benefits

A few people living with dementia mate wareware noted that engaging in peer support group activities helped to support their cognitive and physical wellbeing. Attending the group was also seen by dementia service organisations as reducing the anxiety of people living with dementia mate wareware.

Probably friendliness and testing my ability to keep up with my brain, which I know is becoming more rusty. Because that's the main result of Alzheimer's. (Person with dementia mate wareware)

It reduces anxiety and stress for people living with dementia, they feel more connected and helps them socially, mentally and emotionally. (Dementia service organisation)

Care partners have a break from caring

A few people living with dementia mate wareware mentioned attending the support group offered their care partner time to engage in their hobbies.

[Care partner] spends a lot of time looking after me. It's good for her to have a break. (Person with dementia mate wareware)

An opportunity for more structured peer support in Aotearoa New Zealand

Peer support, both one-on-one or part of groups, has benefits for people living with dementia mate wareware and their care partners. This research cannot determine which models of peer support for people living with dementia mate wareware offer the greatest benefit. However, social return on investment research completed in the United Kingdom found that:

peer support groups for people living with dementia, regardless of size or structure, provided personal and social value to people living with dementia, their carers and volunteers supporting the group, with a social value ranging from £1.17 to £5.18 for every pound (£) invested. (Willis et al., 2018).

Assuming these findings apply in Aotearoa New Zealand, peer support initiatives are worthwhile investments that return positive benefits to people living with dementia mate wareware, their care partners, and dementia service organisations over their initial costs.

Health and disability resources are limited. The potential investment in peer support needs to be considered in the lifespan continuum of support. Research indicates the value of peer support for people living with dementia mate wareware after diagnosis and for young people living with dementia mate wareware.

The lack of dementia mate wareware support, particularly in rural areas, highlights the potential to enable people living with dementia mate wareware to play a key role in providing in-kind contributions (Willis et al., 2018).

In this context, a case can be made for a more structured approach to peer support for people living with dementia mate wareware aligned with best practices. This approach would require:

- a shared understanding of peer support within the diversity of people and needs of people living with dementia mate wareware
- improved access to timely diagnosis to create pathways to the protective aspects of peer support
- increased focus on capability building for volunteers living with dementia mate wareware and potentially developing peer support leaders
- a more structured and purposeful approach to build diagnosis acceptance and early access to the positive benefits of peer support
- focus on linking people living with dementia mate wareware to their wider community in ways that are safe and demonstrate their contribution.

Health Innovation Network South London (2015) offers insights into running a peer support group.

The impact of peer support for Māori living with dementia mate wareware



The impact of peer support for Māori living with dementia mate wareware

This section presents feedback from whānau Māori on peer support. 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 with dementia mate wareware

Dudley et al. (2019) found living and functioning in Te Ao Māori (Māori worldview) 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 pūtaka (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 the impact role of peer support.

Kaumātua living with dementia mate wareware contribute to their whānau, hapū, and Iwi

Interviews with kaumātua living 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 living with dementia mate wareware continue to support and contribute to their whānau, hapū, Iwi, and hapori (community).

Kaumātua living with dementia mate wareware who were interviewed for this research continued to contribute in 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 living with dementia wareware who were interviewed highlighted the critical role of whānau, hapū and hapori support. Whānau supported kaumātua living 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 manaakitanga (acceptance of illness and behaviour change) enable a sense wellbeing for whānau Māori living with dementia mate wareware.

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

Evidence shows Māori face equity 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 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 living with dementia mate wareware living in urban or provincial areas are more likely to have access to dementia mate wareware 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 mate wareware 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 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 mate wareware 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 engaging with others with dementia mate wareware

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

Whānau Māori valued being in support groups with other people living with dementia mate wareware

The term peer support is not well known

The term 'peer support' was unfamiliar to kaumātua living with dementia mate wareware. As discussed, kaumātua living with dementia mate wareware gain collective support through whānau, hapū and hāpori (community), particularly through the marae.

I don't know how most Māori think about peer support, that word in particular. What I do know about us, is our whānau relationships and how we support one another – that whānau support. (Māori with dementia mate wareware)

Kaumātua living with mate wareware found groups with others living with mate wareware beneficial

Kaumātua living with dementia mate wareware felt accepted and their confidence to cope increased

Kaumātua living with dementia mate wareware who were interviewed and are part of groups with other people living with dementia mate wareware found these groups useful. Those accessing groups with other people living with dementia mate wareware liked the ease of acceptance as members understood their condition. The group's acceptance helped build their confidence to cope with the changes they faced.

Everyone understands that we have got dementia and that we are a bit forgetful here and there. (Māori with dementia mate wareware)

Kaumātua living with dementia mate wareware learnt about dementia

Kaumātua living with dementia mate wareware shared attending these groups helped them to understand more about living with dementia mate wareware. Other group members shared tips for living well and offered reassurance when changes were challenging. Kaumātua, recently diagnosed with dementia mate wareware, particularly appreciated hearing these tips (e.g., using a diary and writing lists to help with forgetfulness).

There's a few things that you learn from others. Because you're listening and you understand what they come out with. (Māori with dementia mate wareware)

Kaumātua living with dementia mate wareware enjoyed socialising and connecting

Kaumātua living with dementia mate wareware enjoyed the socialising and the group activities. Kaumātua living with later-stage dementia mate wareware felt these groups and the activities lifted their mood.

It's enjoyable. We have a few laughs. (Māori with dementia mate wareware)

Whānau appreciated the groups offered cognitive health activities

Whānau appreciated attending the group gave their kaumātua living with dementia mate wareware independence. They also noted the groups created a safe environment for their kaumātua living with dementia mate wareware to do cognitive health activities.

We're quite a busy household. I'm working. I wanted to ensure Uncle had his independence. But also a service that could help him with cognitive learning. (Care partner, Northland)

The impact of peer support for Pacific peoples living with dementia mate wareware



The impact of peer support for Pacific peoples living with dementia mate wareware

Due to recruitment challenges, we only interviewed one Pacific care partner. The research cannot, therefore, determine the perceptions of Pacific peoples living with dementia mate wareware on the value of peer support.

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).

Estimates for dementia prevalence for Pacific peoples aged sixty plus is 6.3% compared with 5.4% for Māori and 3.7% for Europeans (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 (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. Dementia 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 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 may also face access barriers due to the absence of family support, not being computer savvy or not 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.

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. (Pacific care partner)

Ideally, they want relevant services for Pacific peoples by having Pacific staff who can speak Pacific languages and offer 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

Peer support programmes have a positive impact on helping people living with dementia mate wareware to cope with their diagnosis, be connected, strengthen their wellbeing and contribute to others. Deliberate, structured and planned peer support programmes have an important role alongside other dementia services such as cognitive stimulation programmes.

Peer support in Aotearoa New Zealand tends to be informal and included in other dementia services with only some alignment with best practice. The research shows the benefits and potential return on investment of more structured peer support in Aotearoa New Zealand, with people living with dementia mate wareware leading this work.

Creating a more structured approach to peer support for people living with dementia mate wareware aligned with best practice requires:

- a shared understanding of peer support reflecting the diversity of people living with dementia mate wareware and their needs
- improved access to early diagnosis to create pathways to the protective aspects of peer support
- increased focus on capability building for volunteers with dementia mate wareware and developing them as peer support leaders
- a more structured and purposeful approach to building diagnosis acceptance and dementia mate wareware knowledge
- focus on linking people living with dementia mate wareware to their community in ways that demonstrate their contribution.

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Appendices



Appendix 1: Research questions

The key research questions and associated questions were:

1. What is peer support impact on people living with dementia mate wareware?
 - What is the contribution and value of peer support group to the lives of people living with dementia mate wareware?
 - What types of support groups make a positive difference for people living with dementia mate wareware?
 - What support groups exist in Aotearoa New Zealand for people living with dementia mate wareware, and how do they align with best practice?

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 2: 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 is the impact of peer support on people living with dementia mate wareware?
 - What is the contribution and social value of peer support?
 - What types of peer support make a positive difference?

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 whether peer support groups are used and their purpose.

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 and dementia service organisations completed qualitative interviews

The voice of people living with dementia mate wareware was critical to understanding the impact of peer support.

We completed interviews across five locations

The site selection was based on urban and rural locations, North and South Island and areas with high Māori populations. The sites also reflected areas where dementia service organisations had the 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 the five regions (Table 3). 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 4). 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 organisation supported younger people living with dementia mate wareware.

Table 3: 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 ¹

Table 4: Location of the dementia service organisations interviewed

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

¹ 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 living 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 aware of 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,b, 2014)

Interviews were mainly face-to-face with a couple held virtually and by telephone. Most interviews were held in people's homes or comfortable and safe location. We audio recorded interviews if people provided consent. The interviews lasted up to 30-40 minutes. People 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 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 dementia 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 dementia service organisations. 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 dementia service organisations in regions where more Pacific peoples live not having the capacity to take part in the research.

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 5: 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 6: Type of services offered by dementia service organisations

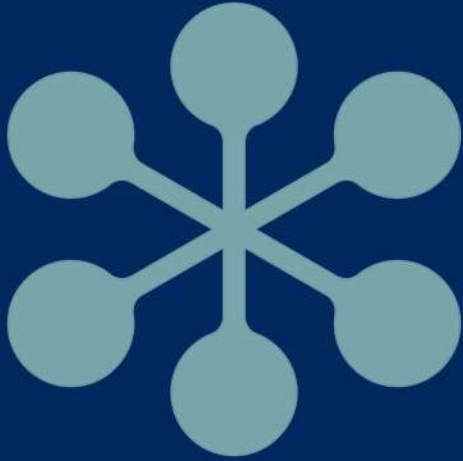
Types of services offered	No. of dementia service organisations	% of dementia service organisations
Base	10	10
Social connections	10	100%
Information and resources about living with dementia	9	90%
Cognitive stimulation programmes	9	90%
Support groups (staff facilitated)	9	90%
Support and navigation services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

Table 7: Type of peer supports offered by dementia service organisations

Type of peer support offered	No. of dementia service organisations	% of dementia service organisations
Base	10	10
Group – social interaction	10	100%
Group - cognitive stimulation	9	90%
Support groups	7	70%
Group – education	6	60%
One-on-one peer support	2	20%
Online group	1	10%

Table 8: Dementia service organisations rating on how important peer support services are to people living with dementia mate wareware

Response	No. of dementia service organisations	% of dementia service organisations
Base	10	10
Very important	9	90%
Important	1	10%
Somewhat important	-	-
Not important	-	-
Not at all important	-	-



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