

# Te Ōranga Ō Te Roro: kaumātua perspectives on the development of a mobile app for mate wareware (dementia) awareness

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## ABSTRACT

**AIM:** Mate wareware (dementia) presents a significant social and economic burden for Māori in Aotearoa New Zealand. Previous literature has highlighted the need to improve health literacy for Māori regarding the causes and management of mate wareware, yet there is a lack of Māori-centred educational resources. It was determined that a mobile phone application (app) could meet this need and that early consultation with Māori was required to ensure the digital solution would be culturally safe and relevant.

**METHOD:** This study explored the perspectives of kaumātua (Māori elders) regarding how to cater the mate wareware mobile app to Māori. Through a qualitative approach based on Kaupapa Māori principles, two focus groups were held with 15 kaumātua. Focus group data were thematically analysed.

**RESULTS:** The analysis identified four themes related to the content of the proposed app and its design features. “Information about mate wareware” and “Caregiver support” were prominent themes that kaumātua prioritised for inclusion in the proposed app. To ensure uptake, kaumātua emphasised that the “Access” and “Appeal” of the proposed app should be considered.

**CONCLUSION:** The findings have informed the design of the Mate Wareware app and should be considered when developing other digital health interventions for Māori.

Mate wareware, or dementia, is typically defined by cognitive decline that interferes with social or occupational functioning.<sup>1</sup> In Aotearoa New Zealand, there are an estimated 70,000 people living with mate wareware, and this is predicted to increase to 170,000 by 2050.<sup>2</sup> The prevalence of mate wareware is estimated to be much higher among Māori compared with other ethnicities<sup>3</sup> and Māori represent a greater proportion of those with early-onset dementia (19% Māori versus 8% NZ Europeans).<sup>2,4</sup> The total economic costs of dementia are greater for Māori compared to Europeans as a result of lost productivity and income due to earlier mate wareware onset in Māori,<sup>2</sup> and the costs of caring for kaumātua (elders) at home rather than having them placed in residential care facilities.<sup>5</sup> Thus, mate wareware presents a significant burden for Māori in terms of lost quality of life, increased caregiving responsibility and financial impacts.<sup>2</sup>

Research indicates Māori perspectives of the causes of mate wareware differ from Western

views. There is less focus on the physical pathology, and greater focus on spiritual, historical or social causes, and for some, a perception that mate wareware is a normal part of ageing.<sup>5</sup> In relation to protective factors for mate wareware, Māori have reported using a range of strategies to support cognitive, psychological and spiritual health, such as speaking and listening to te reo Māori (the Māori language), singing waiata (song), reciting whakapapa (genealogy), conducting whaikōrero (formal speaking on marae) and participating in raranga (weaving) and whakairo (carving).<sup>5</sup> However, longstanding health inequities<sup>6</sup> have led to Māori disproportionately experiencing obesity, hypertension and diabetes, which have increased their risk for mate wareware.<sup>7,8</sup> It has been established that Māori would benefit from greater health literacy about the causes and management of mate wareware;<sup>5</sup> however, at the inception of this project there was a lack of Māori-centred educational resources concerning mate wareware.

Mobile phone technology is one platform for building health literacy and support around

mate wareware. Māori have rapidly adopted smartphones and other internet-based technologies because of the opportunities for learning, creating a Māori voice, knowledge sharing and socialising virtually, all of which empower Māori values.<sup>9,10</sup> Mobile interventions have been successfully delivered to Māori to manage conditions such as diabetes,<sup>11</sup> alcohol misuse<sup>12</sup> and smoking cessation.<sup>13</sup> Personalisation of mobile interventions with Māori content has had positive effects,<sup>13</sup> suggesting Māori will use a tool if it is targeted for Māori specifically. Importantly, digital technology can remove barriers that prevent Māori accessing information and support.<sup>14</sup>

This paper presents the first study in a research programme and was the starting point for designing a mobile application (app) with Māori whānau (families and communities). The aim of the study was to explore the perspectives of kaumātua (Māori elders) regarding how to best design and develop the mate wareware mobile app for maximum uptake by Māori.

## Method

### Study design

This study adopted a Māori-centred research design<sup>15</sup> in that all the kaumātua were Māori and the lead researcher (MD) was Māori; however, the research team was comprised of both Māori and non-Māori researchers.<sup>16</sup> Analyses of the data were undertaken using Western-based thematic analysis and a mahi rōpū approach.<sup>17</sup> Kaupapa Māori principles underpinned the research.<sup>18,19</sup> All kaumātua provided informed written consent and ethical approval was obtained from the Health and Disability Ethics Committees (16/STH/154).

### Kaumātua

The participants were kaumātua who identified as Māori and were members of a local kaumātua rōpū (community group of Māori elders) in Tāmaki Makaurau (Auckland).

### Procedure

Kaumātua were invited to a local marae in Tāmaki Makaurau to participate in focus group interviews. Māori tikanga (protocol) was observed throughout the wānanga (meeting to discuss, deliberate and consider), beginning with a mihi whakatau (a traditional Māori welcome) followed by whakawhanaunga (people making connections). This was followed by a morning

tea break, which is part of Māori tikanga that allowed the wānanga to move from a state of tapu (sacredness) into a state of noa (without restriction). During morning tea, kaumātua had the opportunity to ask questions about the study and provide informed consent. Following this, kaumātua divided into two equal groups for the focus group discussions. The two focus groups occurred simultaneously and took approximately 90 minutes. Discussions were conducted in te reo Pākehā (English) at the request of the kaumātua. Kaumātua then re-joined as a larger group to share kai (lunch). To ensure reciprocity,<sup>19</sup> the research team then led a general discussion and question/answer session about mate wareware, and all kaumātua received a \$50 koha (gift) as acknowledgement of their participation.

### Data analysis

Focus group audio data were transcribed, coded and categorised under emerging themes (by CR) using Braun and Clarke's thematic analysis approach.<sup>20</sup> Themes were required to have been discussed more than twice by two or more different kaumātua. Themes were discussed and redefined by CR and MD, both Māori researchers. Transcriptions, codes and themes were shared with the wider research team and redefined as needed to ensure consensus.

## Results

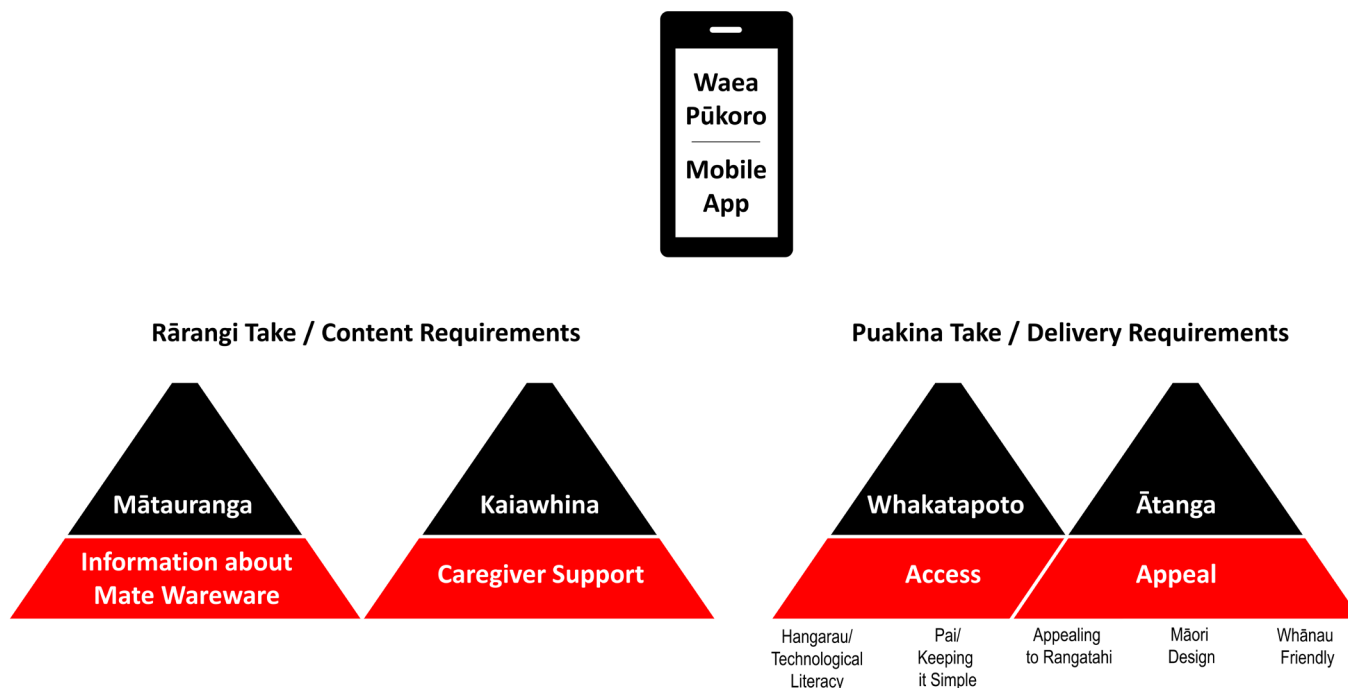
### Kaumātua

The focus groups were attended by 15 kaumātua (>60 years of age) and three whānau/family members (<60 years of age). The two focus groups included a majority of female participants, with only one or two male participants in each group. The kaumātua affiliated to a wide range of iwi in the North Island of New Zealand. All kaumātua had some understanding of mate wareware, but only one person was experiencing memory loss themselves.

### Analysis

Four themes were identified as priorities for app development: two related to app content, and two related to the design and delivery of the content and were underpinned by five subthemes. An illustration of the themes and subthemes is presented in Figure 1, and example quotes for each theme and subtheme are presented in Table 1.

**Figure 1:** Themes from qualitative analysis illustrating requirements of the proposed mobile app.



**Table 1:** Themes and example quotes.

Rārangī take/Content requirements	
Themes	Quotes
1. Mātauranga Information about mate wareware	<ul style="list-style-type: none"> <li>“What is mate wareware in simple terms, because the carers and the supporter, whānau and friends, and all they hear are Alzheimer’s or dementia, but they don’t fully understand what it is that that actually means.” – P2/G1</li> <li>“I can’t explain to them what it is ... it upsets me when I myself can’t explain it.” – P7/G1</li> <li>“Because rather than look at the symptoms first, I want to be in that preventative stage of my life if I haven’t missed the bus already!” – P3/G1</li> <li>“These apps, you know, to make our grandchildren realise the risk factors that can come or how things can help to keep our brains alive.” – P8/G2</li> </ul>
2. Kaiāwhina Caregiver support	<ul style="list-style-type: none"> <li>“Who to go to. How to get help...” – P2/G1</li> <li>“But I think one of the main things is information about where we can go for help if we’ve got any questions.” – P8/G2</li> <li>“Where you can go and where your whānau can go—not in a horrible way—for that burden.” – P12/G2</li> <li>“The thing is who looks after the carer when they are looking after someone with dementia you know nobody looks after the carer.” – P9/G2</li> </ul>

**Table 1 (continued):** Themes and example quotes.

Puakina take/Delivery requirements		
Themes	Subthemes	Quotes
3. Whakatapoto Access	Technological literacy	<ul style="list-style-type: none"> <li>“A lot of us don’t even know how to access an app ... I just learnt how to send an email ... a lot of us weren’t brought up in this IT business ... we cannot go to a normal computer class because we don’t absorb, our brains are not like sponges anymore.” – P8/G2</li> <li>“It would be nice if us kaumātua could learn how to use it ... because some kaumātua don’t have children to rely on like us.” – P15/G2</li> <li>“I don’t want to sit around and sit at home there just twiddling my fingers.” – P14/G2</li> </ul>
	Keeping it simple	<ul style="list-style-type: none"> <li>“So, perhaps a slight description of what it is in not big words but in a simple user-friendly way, first and foremost.” – P2/G1</li> <li>“I think simple is key ... if it’s going to be a whole lot of information going past the screen, I think anyone is going to want to fade off.” – P12/G2</li> <li>“While it sounds great to have it in Māori, let’s face it, a lot of our people can’t read Māori.” – P3/G1</li> <li>“I don’t know, yeah, but I think if we had a simple tool that you could just bring up information on it.” – P8/G2</li> </ul>
4. Ātanga Appeal	Appealing to rangatahi (Māori adolescents)	<ul style="list-style-type: none"> <li>“We have our grandchildren or our children having to access these apps, you know ... must be designed with our moko and our children in mind so that they think the app is interesting enough to pass it on to us. You know, or because we are never going to—we are never going to see these apps and the fact that they are going to help us.” – P8/G2</li> <li>“...My mokopuna ... they’re the ones that are going to be looking after me and they are going to have to be able to access it.” – P3/G1</li> <li>“Wouldn’t it help for the younger generation to know about it (mate wareware) too, because most of the young generation would like to know and like to find out why is nana like this? Because they don’t understand.” – P7/G1</li> </ul>
	Māori design	<ul style="list-style-type: none"> <li>“A lot of our whakataukī have been written by our elders and it is about tapping into the past then bringing me into the present. That absolutely allows me to build for the future because I’m including my elders ... a whakataukī would take care of a lot of things for me.” – P3/G1</li> <li>“I would like some sort of waiata and tikanga and things on this application (to make this) spiritually correct for me.” – P1, G1</li> <li>“Just colouring definitely is the one, because in Te Ao Māori colours/ colouring are different with meaning to each other and where it comes from.” – P4/G1</li> <li>“We should put in, like, Māori music because we always sing no matter what.” – P12/G2</li> </ul>

**Table 1 (continued):** Themes and example quotes.

	Whānau (family) friendly	<ul style="list-style-type: none"> <li>• “We have noticed that when we do a collage of whānau photos that triggers them and opens them up to kōrero (conversation), it really is a stimulator ... perhaps if there was one way to individualising? ... Once it’s personalised there’s more interest.” – P2/G1</li> <li>• “...Where your whānau could be in there as well, so maybe at first it could be individualised and then maybe whānau can talk ‘what does she need?’, ‘who is going to go now?’” – P5/G1</li> <li>• “Another aspect of keeping it whānau based is that if it is like a Facebook page, if you have other people in (placename) that are prepared to face-to-face talk to you, support you, swap stories with what is happening with your loved one, perhaps.” – P1/G1</li> </ul>
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P = participant, G = focus group

### Theme 1: Mātauranga (information about mate wareware)

*“I can’t explain to them what it is ... it upsets me when I myself can’t explain it.” – Participant 7*

Information was a prominent theme, and many kaumātua emphasised their desire to be educated on mate wareware, including the symptoms, causes and protective factors. All kaumātua had experiences with mate wareware and some reported experiencing memory loss themselves, but they struggled to understand the underlying process. The kaumātua were unaware of the modifiable risk factors for mate wareware. Some reported anecdotal ideas about the cause of mate wareware, such as the overuse of technology. Kaumātua showed a strong interest in the education of their whānau around risk factors and recognised that this would benefit future generations. Kaumātua wanted information about activities and foods that can keep the brain healthy, as well as information about normal cognitive ageing compared with the signs of mate wareware. Kaumātua also desired information on comorbid lifestyle diseases such as diabetes, heart disease and obesity.

### Theme 2: Kaiāwhina (caregiver support)

*“The thing is who looks after the carer when they are looking after someone with dementia, you know, nobody looks after the carer.” – Participant 9*

Kaiāwhina (caregiver) support was deemed

important and included caring for oneself and caring for a loved one with mate wareware. Kaumātua expressed a need for information about where to access support for older whānau members, as well as sources of support for the caregiver. It was recommended that information be displayed clearly with external links that directly transfer to supporting organisations. Kaumātua also asked for information on managing challenging behaviours with whānau with mate wareware.

### Theme 3: Whakatapoto (access)

This theme considers how people will access the mobile app and is underpinned by three subthemes: “Technological literacy”, “Keeping it simple” and “Appealing to rangatahi” (this final subtheme also aligns with theme 4, “Appeal”).

#### Technological literacy

*“A lot of us don’t even know how to access an app.” – Participant 8*

Access to technology was limited among kaumātua, and all but one reported having never used an app. Most kaumātua had access to a mobile phone but only engaged in simple tasks such as speed dialling and text messaging. One participant reported that kaumātua have a limited ability to learn about new technology due to difficulty retaining new information. Some kaumātua were not open to learning how to use a mobile app and preferred to be contacted through the landline phone or through the distribution of pamphlets. Others were interested in learning to use technology.

### Keeping it simple

*“I think simple is key.” – Participant 12*

A key requirement of the app was simplicity. Kaumātua recommended keeping the app simple and including additional prompts within the app to further assist the user. This would enable all whānau members to use the app, including tamariki (children) and kaumātua with and without thinking difficulties. Kaumātua recommended video content from medical experts and those experiencing mate wareware. Written information was recommended to be precise and presented in bullet points. Kaumātua wanted simple terminology such as “brain disease” to keep the users’ interest, rather than scientific terminology. Additional recommendations were for larger text, auditory options, colour coding and step-by-step instructions. Kaumātua stated that the app would need to be predominantly in English and complimented with te reo Māori.

### Appealing to rangatahi (Māori adolescents)

*“Must be designed with our moko and our children in mind so that they think the app is interesting enough to pass it on to us.” – Participant 8*

Given the aforementioned issues with technological literacy, the kaumātua reported that all of their interactions with technology were facilitated by their tamariki (children) and mokopuna (grandchildren). The kaumātua emphasised that the app must be interesting enough to engage the younger generation in order for them to utilise the app and pass on the information to their elders. In addition, kaumātua believed it was important to target some education towards the younger generation and that video demonstrations would increase younger users’ understanding of mate wareware. Games would also encourage the attention of younger generations. Kaumātua acknowledged that this reliance on younger whānau would disadvantage some kaumātua who do not have support to engage with the app.

### Theme 4: Ātanga (appeal)

This theme considers how to design the app to appeal to Māori and is underpinned by three sub-themes: “Appealing to rangatahi” (described under theme 3), “Māori design” and “Whānau friendly”.

### Māori design

*“...A whakataukī would take care of a lot of things for me.” – Participant 3*

Kaumātua favoured a Māori-centred app. The inclusion of karakia (prayer) and waiata (songs) were discussed; however, participants agreed that a whakataukī (Māori proverb) would suffice. The group decided the most appropriate whakataukī was “He aha te mea nui o te ao? He tāngata, he tāngata, he tāngata”; this translates to “What is the most important thing on this earth? The people, the people, the people”. Kaumātua also suggested that the choice of colours would be important, as each colour has a different meaning in Te Ao Māori (the Māori worldview).

### Whānau friendly

*“Once it’s personalised there’s more interest.” – Participant 2*

Whanaungatanga (connectedness) with whānau and iwi was repeatedly referenced by all kaumātua. Thus, there was interest in being able to personalise the app and incorporate features that facilitate the connection between whānau and the person with mate wareware. It was suggested that the inclusion of personal features such as whānau photos might trigger the memory and stimulate conversation. An app with similar features to Facebook, such as status updates and diary entries, would enable whānau members to remain connected and combine efforts to support their loved one with mate wareware.

## Discussion

This is the first study to explore kaumātua perspectives of a proposed mobile app for mate wareware awareness, and the first culturally specific digital intervention to address mate wareware in Aotearoa New Zealand. Early consultation with Māori in the design of the app was essential to ensure a meaningful and relevant intervention for Māori. This approach aligns with Te Tiriti o Waitangi principles of tino rangatiratanga and partnership, which guarantee Māori a voice in the design and delivery of healthcare interventions.<sup>21</sup> The design of a mobile app specifically targeting Māori also aligns with Te Tiriti o Waitangi principles of equity, active protection and options, which pledge a commitment to equitable outcomes for

Māori and the provision of culturally appropriate hauora (health) services.<sup>21</sup>

### App content requirements

The lives of kaumātua and their whānau are significantly affected by mate wareware, yet this research suggests kaumātua have a limited understanding of the disease process, its clinical presentation, lifestyle factors that increase risk and sources of support. The theme “Information about mate wareware” primarily focused on understanding mate wareware and modifying risk factors. However, kaumātua also wanted information on other comorbidities so that all information was in one place. This would be an advantage given the common risk factors across chronic health conditions such as cardiovascular disease, diabetes, stroke and mate wareware.<sup>8</sup> Information on risk reduction was considered a priority and is consistent with previous research where kaumātua reported limited knowledge about risk factors for mate wareware.<sup>5</sup> Lifestyle risk factors such as obesity, hearing loss, hypertension, traumatic brain injury, alcohol, social isolation, physical inactivity, smoking, depression, diabetes and air pollution account for 51% of the risk for mate wareware in Māori.<sup>7</sup> Due to longstanding health inequities and socio-economic determinants that have led to poor biological health,<sup>22</sup> Māori are disproportionately affected by lifestyle-related diseases such as diabetes, hypertension, obesity,<sup>23</sup> mild traumatic brain injury<sup>24</sup> and alcohol disorders.<sup>25</sup> Therefore, it is vital that Māori are provided with information about these lifestyle risks and ways to manage them to ensure the health of current and future generations.

“Caregiver support” was an important theme. Caring for a whānau member with mate wareware is associated with poor health and quality of life for both the caregiver and the individual with dementia.<sup>26</sup> Caregiver self-efficacy and coping strategies are an important mechanism for reducing caregiver burden,<sup>26</sup> and the proposed app has potential to provide support through self-help information and links to external support. Importantly, for Māori, whānau members tend to be cared for within the home rather than in residential care facilities,<sup>5</sup> and therefore support for this role was prioritised for inclusion in the proposed app.

### App design and delivery requirements

The findings emphasised that the design of the app should consider how Māori will “Access” the

app and whether it will “Appeal” to them. The sub-theme “Technological literacy” emphasised the challenges faced by kaumātua when accessing technology, yet there was still a strong desire for kaumātua to be actively involved in designing the app. Kaumātua acknowledged their children and grandchildren would initially help them access the app, and thus it was essential the app was “Appealing to rangatahi”. Kaumātua also expressed a desire for simplicity and prompts to help navigate the app, reinforcing the importance of “Keeping it simple”. There was a concern that some kaumātua would not have support to help them navigate the app. This is concerning, as social isolation is a risk factor for developing mate wareware.<sup>7,8</sup> Further research is required to identify how to reach individuals who live in isolation. Indeed, a mobile app solution may not be appropriate for this group; as suggested by two kaumātua, communication through landline phone calls or pamphlets may be more appropriate. In relation to the proposed app, the ability to print out a brochure from written text within the app would offer a partial solution to this problem.

Within the subthemes of “Keeping it simple” and “Appealing to rangatahi”, videos of clinicians and those with lived experience of mate wareware were considered important. This aligns with Te Ao Māori, where storytelling is a preferred medium for knowledge sharing and traditionally takes place through waiata (song), mōteatea (poetry) and kauwhau (moralistic tale).<sup>27</sup> Lived experience videos have been used in other digital health literacy resources in Aotearoa New Zealand.<sup>28,29</sup> In the wider literature, digital health education interventions often include video content; however, personal storytelling videos appear less common.<sup>30</sup> This reinforces the unique requirements of a Māori-centred mobile app.

There was a strong interest in “Māori design”. This aligns with user feedback obtained during the development of the OL@-OR@ app, a mobile app co-designed with Māori communities to support healthy lifestyle behaviours.<sup>31,32</sup> During that co-design process, feedback supported the inclusion of Māori imagery such as a kete (basket) and waka (canoe), and symbolism such as the koru, manaia and tiki patterns.<sup>31</sup> The inclusion of Māori tikanga, language and knowledge was also deemed important; however, it was cautioned that some knowledge is iwi (tribe) specific.<sup>32</sup> In other Indigenous research, culturally relevant graphics and animations have enhanced

the acceptability of digital mental health apps in Aboriginal and Torres Strait Islander communities.<sup>33</sup>

While the inclusion of te reo Māori was considered important, kaumātua noted that most Māori elders cannot speak (or read) fluent Māori as a result of the lack of Māori language learning they experienced in schools,<sup>34</sup> and recommended the app should be in English with the inclusion of common Māori words throughout. In contrast, the inclusion of te reo Māori may also support the person with mate wareware, as many Māori with mate wareware return to speaking te reo Māori, which was their first language prior to its suppression in their early years.<sup>5</sup> Providing opportunities for the individual with mate wareware to choose to speak te reo Māori affirms their cultural and ethnic identity<sup>22</sup> and is considered a source of healing and comfort by Māori.<sup>5</sup> More younger Māori speak fluent te reo Māori as a result of increased learning opportunities;<sup>34,35</sup> therefore, a full Māori version of the app should be considered in the future.

The final subtheme of “Whānau friendly” speaks to the importance of whānau relationships in Te Ao Māori.<sup>19</sup> This could be supported by offering a section of the app that could be personalised

with images, updates and a messaging feature to connect whānau members. This theme has also been highlighted in the previously described OL@-OR@ app, in which participants wanted the app to foster relationships and whānau participation.<sup>32</sup> In relation to mate wareware, social support is an essential aspect of reducing caregiver burden,<sup>26</sup> and thus a social feature in the proposed app could offer the ability to unite caregivers. This approach might alleviate the social isolation, limited social outings and whānau conflict experienced by whānau members of a person with mate wareware.<sup>26</sup>

## Conclusion

Te Ōranga Ō Te Roro is an important step in providing culturally tailored information about mate wareware for Māori. This study reinforced how important this topic is for kaumātua and identified ways to ensure the proposed mobile intervention is culturally safe and relevant. The findings have informed the design of the Mate Wareware app and should be considered when developing other digital health interventions for Māori.



**COMPETING INTERESTS**

Nil.

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