# **Terms of Reference for the National Dementia Mate** **Wareware Leadership and Advisory Group**

## **Background**

Dementia mate wareware is having and will increasingly have a significant social and economic impact in New Zealand. The dementia population is currently 69,713 and is expected to more than double to 167,483 by 2050, with an associated $5.92 billion total economic cost.

The National Dementia Mate Wareware Leadership and Advisory Group (DLG) is part of the Dementia Mate Wareware Ecosystem that works collaboratively to deliver effective governance of the development of dementia services. The Ecosystem comprises of the DLG and the Dementia Mate Wareware Network.[[1]](#footnote-1)

## **Purpose**

The purpose of the DLG is to provide national leadership across the dementia sector and government through advice to Te Whatu Ora - Health New Zealand (Te Whatu Ora),[[2]](#footnote-2) the Te Aka Whai Ora - Māori Health Authority (Te Aka Whai Ora), the Public Health Agency (PHA) and the Manatū Hauora - Ministry of Health (the Ministry) on future improvements to dementia supports for people with dementia and their whānau and carers.

## **Strategic alignment**

The DLG will take strategic direction from the New Zealand Health Plan, the [New Zealand Health Strategy](https://www.health.govt.nz/publication/new-zealand-health-strategy-2016), the [Healthy Ageing Strategy](https://www.health.govt.nz/publication/healthy-ageing-strategy), [Whakamaua: Māori Health Action Plan 2020- 2025, Ala Mo’ui: Pacific Health](https://www.health.govt.nz/publication/whakamaua-maori-health-action-plan-2020-2025), the [Disability Action Plan](https://www.odi.govt.nz/disability-action-plan-2/), and other strategies as advised to the DLG by the National Director, Commissioning, Te Whatu Ora.

## **Objectives**

1. Provide national leadership and strategic advice in matters relating to people with dementia mate wareware, their carers and whānau and the supports they receive.
2. Ensure the strategic direction for dementia mate wareware care in Aotearoa New Zealand is in line with the objectives of the Dementia Mate Wareware Action Plan.
3. Provide strategic advice to support the development of the Te Whatu Ora and Te Aka Whai Ora dementia implementation programme.
4. Provide strategic guidance on approaches to dementia mate wareware prevention, diagnosis, and support in line with best practice.
5. Provide strategic advice that is informed by input from the Dementia Mate Wareware Network, including Māori, Pacific and other stakeholder based groups and individuals, subject matter experts and consumer representatives.
6. Share and promote best practice and collaboration across regions and nationally through the Dementia Mate Wareware Network.
7. Share and promote best practice nationally through the Dementia Mate Wareware Network.

## **Approach**

All DLG members will work together in line with the above objectives to provide robust and well informed advice to ensure that dementia mate wareware supports are in line with the objectives of the Action Plan. This will include quarterly reports to the National Director, Commissioning, Te Whatu Ora and the National Director, Commissioning, Te Aka Whai Ora and the Manager, Healthy Ageing, Te Whatu Ora on progress against Te Whatu Ora and Te Aka Whai Ora dementia work/implementation plan

All advice will be received in good faith by Te Whatu Ora, Te Aka Whai Ora, PHA and the Ministry, which between them retain ultimate responsibility for policy, service development and funding decisions in relation to the future supports for people with dementia and their whānau and carers.

Advice from the DLG will be based in collective decision making and through consensus wherever possible. In the event consensus cannot be reached, the item will be put to a vote. A quorum of five of seven members, including the Chair, must agree for decisions to be made.

The DLG will facilitate solutions through other relevant stakeholders as required. If a particular issue requires more focused work a specific working-group and sub-groups will be established through the Dementia Mate Wareware Network to address the issue in more detail and report back to the DLG.

Overarching systemic challenges will be identified by the DLG and prioritised through reporting to Te Whatu Ora and Te Aka Whai Ora. Challenges will be addressed through a combination of stakeholder engagement and working groups.

In addition, members from the Dementia Mate Wareware Network can raise issues for consideration by the DLG as part of their regular meeting agenda. The DLG is committed to ensuring it enables meaningful and timely engagement with consumers and consumer organisations across all its activities and decision making.

## **Pae Ora Legislation**

The principles of Te Tiriti o Waitangi, as articulated by the Courts and the Waitangi Tribunal, provide the framework for how the dementia governance ecosystem will meet its obligations under Te Tiriti o Waitangi. The DLG will ensure its advice is aligned with and informed by the Crown’s obligations under Te Tiriti o Waitangi as expressed through the Te Tiriti o Waitangi principles.

* ***Tino rangatiratanga*** – Māori are supported to self-determine the design, delivery, monitoring and evaluation of dementia services for their population and the communities they serve.
* ***Equity*** - Dementia mate wareware services contribute to achieving equitable health outcomes for Māori.
* ***Active protection*** - to the fullest extent practicableMāori health will be protected and equitable health outcomes will be achieved for Māori accessing dementia mate wareware services.
* ***Options*** - appropriate levels of resources to be secured for the provision of dementia mate wareware services in an equitable, sustainable and culturally safe way that recognise and support the expression of hauora Māori models of care.
* ***Partnership -*** work in partnership with Māori, Kaupapa Māori providers, iwi, hapū and consumers in the governance, design, delivery and monitoring of dementia mate wareware services to contribute the achievement of equitable outcomes for Māori.

## **Equity**

Addressing inequities through ensuring everyone can achieve the same outcomes, and have the same access to services and support regardless of where they live is a priority for the Government. The DLG will have an initial focus on the priority groups identified through the Budget 2022 initiative – Māori, Pacific, rural populations and people with younger onset dementia.

## **Membership**

The membership will comprise of:

1. seven dementia sector leader positions, including the Chair.
2. four senior officials, one from each of Te Whatu Ora, Te Aka Whai Ora, the Ministry, and the Public Health Agency (PHA).

Membership is appointed by the National Director, Commissioning, Te Whatu Ora.

Composition of the membership of the DLG and any subgroups or working groups from the Dementia Mate Wareware Network should reflect the importance of our obligations under Te Tiriti o Waitangi.

### Membership term

Members of the DLG are appointed for a term of up to three years, with the option of renewal at the discretion of the National Director, Commissioning, Te Whatu Ora.

### Additional attendees at meetings

The Coordinating organisation, which provides secretariat support to the DLG and coordinates the Dementia Mate Wareware Network will attend each meeting.

Other attendees, such as subject matter experts, including people with dementia and their carers, from the Dementia Mate Wareware Network will attend to provide input into specific areas, as deemed appropriate by the Chair.

## **Roles and Responsibilities**

The DLG will:

* act in accordance with the principles of Te Tiriti o Waitangi
* ensure that the independent views of members are given due weight and consideration
* ensure fair and full participation of members
* use their specific knowledge and skills, be diligent, prepared and participate
* be respectful, loyal and supportive not denigrate or harm the reputation of the dementia mate wareware governance ecosystem.

### Chair

The Chair, and Deputy Chair, will be appointed by the National Director, Commissioning, Te Whatu Ora.

The Chair will preside at each meeting. If the Chair is unable to attend a meeting, or is required to withdraw for any reason, the Deputy Chair will preside. If neither the Chair nor Deputy Chair are available, the remaining DLG Members may elect an Acting Chair for that meeting by majority vote. If either the Chair or the Deputy Chair resigns from their position, the National Director, Commissioning, Te Whatu Ora will appoint a replacement.

The DLG Chair, in consultation with Te Whatu Ora and the Secretariat organisation, will be responsible for setting the agenda for each meeting.

Public statements about the DLG’s work will be made by the Chair (or as delegated by the Chair) or by the National Director, Commissioning, Te Whatu Ora as appropriate.

### Deputy Chair

A Deputy Chair is nominated and selected by members of the Group and from among the group members to stand in for the Chair if required.

### Dementia Leadership and Advisory Group members

Each DLG member will:

* Have a commitment to work in the best interests of dementia mate wareware services.
* Make every reasonable effort to attend all DLG meetings. If a DLG member misses more than three meetings in a row this will be taken as a resignation and a process to elect another DLG member will be undertaken.
* Devote sufficient time to become familiar with the affairs of the DLG and the wider environment within which it operates and prepare for meetings by reviewing information provided to them prior to those meetings.
* Act responsibly with regard to the effective and efficient administration of the DLG.
* Ensure that all information acquired or created for the DLG is only used for performing duties as an DLG member. In the event that any personal or health information is disclosed to any DLG member in the performance of their DLG duties it must be handled confidentially, and in accordance with the requirements of the Privacy Act and Health Information Privacy Code (where relevant).

### Coordinating organisation

The Chair and the DLG members will be supported by a Te Whatu Ora contracted organisation to ensure appropriate administrative and technical resources available. As secretariat, this organisation will support the Chair in ensuring the smooth functioning of the DLG. This includes distribution of the agenda, ensuring meeting agendas and minutes are effectively recorded and distributed, and facilitating consultation and discussion with the Dementia Mate Wareware Network.

## **Meetings**

The DLG will meet six weekly, usually via Zoom or Teams, with up to two face to face meetings per year. Additional ad hoc meetings can be called on the request of the Chair if required to manage the workload or key decisions. Members will make every effort to attend each meeting either in person or online.

## **Conflicts of interest and confidentiality**

DLG members must perform their functions in good faith, honestly and impartially, and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. Proper observation of these principles will protect the DLG and its members and ensure it retains public confidence.

Members attend meetings and undertake DLG activities as independent persons responsible to the DLG. Members are not appointed as representatives of professional organisations and groups. The DLG should not, therefore, assume that a particular group’s interests have been taken into account because a member is associated with a particular group. Each instance of potential conflict of interest must be specifically addressed, including non-members of the DLG invited to speak by the Chair.

Members are required to declare any actual or perceived interests to the full DLG. The DLG will then determine whether (or not) the interest represents a conflict, and if so, what action will be taken.

In general, no member may take part in any deliberation, discussion or decision relating to the matter in which they have a conflicting interest, unless given leave by the DLG. If the DLG allows a member with a conflict of interest to take part in any action of the DLG, it must be recorded in the minutes and in the Register of Conflicts of Interests Declarations:

* that the DLG permitted the conflicted member to take part
* the reasons for this permission being given
* a summary of what the conflicted member said in any deliberation or discussion.

The Chairperson will ask members to declare any actual or perceived interests at the start of each meeting.

## **Fees and allowances**

For dementia sector leader members, fair and reasonable costs associated with individual members participation in meetings will be met using as a reference the Department of the Prime Minister and Cabinet, Cabinet Fees Framework for Group 4, ‘All Other Committees and other Bodies’.

Members who are employed by and representing Te Whatu Ora, Te Aka Whai Ora, the Ministry, and the Public Health Agency (PHA) will not be paid fees or allowances.

Fees and allowances are considered at the time a DLG member is appointed and may be considered for a review at re-appointment.

# **Appendix One – the Dementia Mate Wareware Network**

The Dementia Mate Wareware Network is overseen by the Coordinating organisation. It has its own Terms of Reference, which can be found [here].

The Dementia Mate Wareware Network consists of dementia mate wareware stakeholder-based oversight groups, subject matter experts (SMEs) and consumer representatives. Its role is to engage with and provide advice to the DLG on specific focus areas and other related and relevant topics. The Network will include but not be limited to:

* People with dementia
* Carers and whānau
* Local Dementia and Alzheimers organisations
* National representative bodies, such as the New Zealand Dementia Foundation, Younger Onset Dementia Aotearoa Trust, Carers New Zealand,
* Kaupapa Māori health service providers
* Pacific health service providers
* Professional bodies, such as Royal Australian and New Zealand College of Psychiatrists, Royal NZ College of GPs, the New Zealand College of Primary Health Care Nurses, and Directors of Allied Health Leadership Group
* Aged Residential Care (ARC) and Home and Community Support Services subject matter experts
* Individuals working in dementia sector, including medical, nursing and allied health workers, support workers, educations, academics
* Needs Assessment and Service Coordination Association
* Whānau Ora Commissioning agencies.

1. See Appendix One for information on the Ecosystem and the Network. [↑](#footnote-ref-1)
2. When Te Whatu Ora is referred to it includes the point at which the DLG advice is received, as well as the four regional groupings, health districts and localities, which will receive advice and directions through established mechanisms. [↑](#footnote-ref-2)