Health New Zealand
Te Whatu Ora

National Palliative Care Steering Group

Terms of Reference Version 2

Purpose

The purpose of the National palliative care steering group (the Steering Group) is to provide regular and ongoing oversight of the National Palliative Care Work Programme and recommendations to Health New Zealand - Te Whatu Ora - for national service improvements.

Health New Zealand are committed to working in partnership with Government agencies, providers of palliative care services (primary and specialist), consumers, and communities to ensure palliative and end-of-life care meets the needs of all New Zealanders and their whānau. Work will be informed by cross-agency and cross-sector input, national and international evidence, the lived experiences of people with palliative care needs and their whānau, and the priorities identified by communities.

It is acknowledged that one standard approach does not work for everyone (see Equity Definition in the Appendix A). Alongside the Equity Working Group the Steering Group will identify core values underpinning funding arrangements for palliative care services that ensure underserved populations have access to, and good outcomes from, palliative care services.

Working in partnership, the initial focus of the Steering Group will be overseeing the following key deliverables:

- providing recommendations on achieving equitable access to, and outcomes from, palliative care services for all New Zealanders
- identifying and recommending core palliative care services
- developing a national model for paediatric and adult palliative care
- proposing national adult specialist palliative care service specifications and corresponding pricing framework
- providing recommendations to sustain a clinically and culturally competent, diverse workforce that represents the community it is serving and meets service demands
- developing a national outcome and reporting framework.

These deliverables will be achieved, in part, through the establishment of working groups. The Steering Group will agree and oversee the scope, function, and deliverables of any working groups. This will initially include the establishment and oversight of the following groups:

- equity[1]
- models of care - paediatric[2]
- models of care – adult
- contracting and funding
- workforce
- measures and reporting.

[1] The following has been identified as priorities with regards to palliative care services and equity in Aotearoa: Māori, Pacific peoples, rural Māori, rural, refugee and migrant communities, people who aren't enrolled with a GP or are otherwise disengaged from health services, and with low health literacy, people who are part of Rainbow Communities, people with disabilities, people with frailty or dementia, in prison, and people experiencing homelessness. Adults with non-cancer diagnosis, high need adolescents, children, and young people as they transition into adulthood, have also been identified as priorities.

[2] "Model of Care" broadly defines **the way health services are delivered**. It outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury, or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place.

The steering group will provide recommendations and proposals to the Health New Zealand Director of Living Well, National Commissioning. The Steering Group may also be required to present to Executive Leadership Teams as appropriate.

Background

Health New Zealand holds responsibility for developing a palliative care work programme,-that supports a nationally consistent approach to planning, funding, service delivery and outcomes. This includes responding to the action in Te Pae Tata - Interim New Zealand Health Plan 2022 to:

> *Develop a nationally consistent model for paediatric and adult palliative and end-of-life care that is integrated across primary and community health and strengthens the equitable provision of palliative care across Aotearoa* (pg 63).

Commitment to Te Tiriti o Waitangi

Health New Zealand are committed to meeting our Te Tiriti o Waitangi obligations. This will be reflected in our palliative care work programme through:

a) engaging with Iwi Māori Partnership Boards as our Tiriti o Waitangi partners as appropriate
b) engaging with iwi and other hauroa Māori providers, Māori stakeholders, and palliative care focussed Māori and equity groups, as directed by and appropriate to them
c) embedding a Tiriti-dynamic health system approach through:

- **Whanaungatanga - Relationship and Connection**
  Relationships are intentional, respectful, and reciprocal.
- **Kotahitanga - Collective Action**
  Shared decision-making responsibilities equally in partnership as Tangata Whenua and Tangata Tiriti committed to creating outcomes of mutual benefit.
- **Tino Rangatiratanga - Self determination**
  The right of Tangata Whenua to participate in making decisions about their health and to have meaningful ways to decide how health outcomes might be provided for their benefit, is recognised.
- **Ōritetanga - Equal opportunity**
  Commitment to ensuring equitable outcomes for Tangata Whenua and for other under-served groups in our communities.
- **Wairuatanga - Spirituality**
  Different worldviews, belief systems, spirituality, and ways of doing, being and knowing are respected and valued.

Pae Ora (Healthy Futures) Act 2022, health sector principles:

Pae Ora legislation puts people and whānau at the centre of service design and development. We will engage with people who have experience of palliative and end-of-life services where possible, such as patients and their whānau, communities and the clinicians providing care.

As outlined in section seven of the Pae Ora Act 2022 (see appendix 1), the following guiding principles will direct and guide our work. These principles reflect our Te Tiriti obligations and help ensure that the experiences of people with palliative and end-of-life care needs are at the centre of decision making. These principles include:

- Māori and other population groups have access to services in proportion to their health needs and receive equitable levels of service and equitable health outcomes
- we will engage with Māori, and other population groups to develop services that reflect people's needs and aspirations
- we will provide opportunities for Māori to exercise decision-making authority on matters of importance to them

- we will provide choice of services to Māori and other population groups, by resourcing services to meet their needs and aspirations, providing culturally safe and responsive services, developing, and maintaining a culturally diverse workforce
- we will harness clinical leadership, innovation, technology and lived experience to continuously improve palliative care services and outcomes
- we will develop services that are tailored to peoples' physical needs, preferences, and circumstances, and provide services that reflect mātauranga Māori.

Scope

The following areas have been approved as in or out of scope.

In-scope:

- Supporting the work of the National Palliative Care Work Programme in addressing inequity in the provision and outcomes from adult and paediatric palliative care services in Aotearoa.
- How health services work together on a national level.
- Transition between paediatric palliative care, and adult palliative care services.
- Publicly (crown) funded health services.
- Recommendations to support equitable and consistent implementation of adult and paediatric palliative models of care in Aotearoa.
- Tools that enable equity, for example technology, where this relates to the National Palliative Care work programme.

Out-of-scope:

- Clinical pathways and clinical practice.
- Pharmaceuticals and medical devices.
- Local/regional decisions, solutions, and processes.
- Addressing inequity improvements and system improvements for health and disability services that fall outside of the National Palliative Care Work Programme.
- Advance care planning.
- Assisted dying.
- Work being undertaken by other teams in Health New Zealand. Rather than duplicating the work of other teams, we seek to influence their processes where they intersect with palliative care.

Membership

Health New Zealand is committed to working in partnership with Māori in the governance, design, delivery, and monitoring of health and disability services. The steering group will be co-chaired by 2 people elected from within the group, one of which will reflect the aspirations of Māori.

Members of the steering group will bring expertise and leadership in the areas of:

- primary, community and specialist palliative care services
- people with experience of receiving palliative care services
- wellbeing for Māori and Pacific people
- access to palliative care services
- equity
- research and academic communities
- health service policy, planning and funding
- workforce.

Alongside consumer and whānau voice, membership will include, but not be limited to, stakeholder sectors including hospice, hospital palliative care, aged residential care, and general practice. Membership may also include crown agencies including Health New Zealand Hospital and Specialist Services, Regional Commissioning and Manatū Hauora – Ministry of Health. Consideration will be given to ensuring diversity of cultural perspectives, clinical roles, and geographic spread.

Initial members will be appointed by the National Palliative Care Work Programme co-sponsors and Director Living Well, National Commissioning.

Health New Zealand will appoint discretionary non-voting ex-officio members as required, for example specific clinical roles, such as allied health professionals, can be brought onto the Steering and working groups as required.

Members are likely to be required to serve a minimum term of 2 years from July 2023 until June 2025. Any vacancies that occur will be filled via a nomination process, with approval at the discretion of the steering group. The group may also be disbanded at any time if Health New Zealand believes that the objectives have been fulfilled, the steering group is no longer required, or it is not meeting its intended purpose.

In many instances, membership will be contingent on a role(s) a member holds in their community or an organisation at the time of application. Members must advise the Steering Group co-chairs if their role(s) change. The Steering Group will consider on a case-by-case basis, if it is appropriate for the member to continue on the Steering Group. Members will reside in New Zealand and remain engaged with local stakeholders.

Resignations of members must be submitted in writing to the co-chairs.

Roles and responsibilities of steering group members

Steering group members are responsible for:

- bringing their expertise in palliative and end-of-life care
- acting in accordance with the principles outlined in the National Palliative Care Steering Group charter (see appendix 3)
- providing input on behalf of the sector, community and/or organisations they represent
- engaging with their respective organisations and networks and keeping them updated
- sponsoring working groups established by the steering group
- contributing to the development of recommendations and proposals.

The **co-chairs** are responsible for:

- providing leadership to the group and running efficient and effective meetings that result in clear resolutions and actions
- providing regular progress reports to Health New Zealand
- speaking on behalf of the group as required
- managing conflict of interest processes
- corresponding and working with other networks as required and acting as spokespersons for the steering group
- reviewing all input developed by the steering group and working groups and providing timely and constructive feedback before wider distribution
- assisting with conflict resolution within the steering group, working groups and with members of other organisations should such arise.

Health New Zealand is responsible for:

- leading and completing the National Palliative Care Work Programme as agreed by the Director, Living Well, National Commissioning
- providing programme management and administrative support for the co-chairs, the steering group, and working groups
- managing work programme budgets and resource requirements

- providing advice to the Minister, who then makes any final decisions with respect to budget bids and strategic direction
- responding to enquiries from media, members of the public and other interested parties
- reporting overall work programme activities and achievements to the wider palliative care sector and key stakeholders.

Meetings

Meetings will begin in August 2023 and are likely to continue until June 2025. Meetings will be held approximately monthly at the outset, and then every 8 weeks and will be approximately 2 hours. Meetings will be held via video conference, using Teams. Face-to-face meetings can be called at the discretion of the co-chairs and with the agreement of Health New Zealand.

If a member misses more than 2 consecutive meetings, they may be asked to reconsider their capacity to continue their steering group membership.

Working groups

The establishment of working groups to progress work on behalf of the steering group will be discussed and agreed with steering group members and Health New Zealand. The Steering Group will be responsible for developing a brief scoping document for each proposed new working group. New working groups can only be established if the resources to support them have been approved by Health New Zealand. The Steering Group will then be responsible for agreeing and overseeing working group memberships (including appointing co-chairs), processes, reporting, deliverables, and timeframes.

Steering Group members will act as a tuakana[3] for at least one working group to provide a direct link between the Steering Group and working groups and to ensure the working groups deliver. This will require attendance at working group meetings and completing working group activities between scheduled steering group meetings.

Quorum

A quorum of half of the total number in the steering group plus one will be required for a steering group meeting to proceed, assuming that there is appropriate representation in accordance with the agenda.

Apologies must be communicated to co-chairs in advance of the meeting, and where appropriate any comments, reports or queries forwarded to the co-chairs for inclusion in the meeting.

To minimise disruption of continuity, substitutes are generally not encouraged. However, substitutes can be invited at the discretion of the co-chairs and the member who is unable to attend.

External persons

[3] **Tuakana–teina**

The concept of a tuakana–teina relationship

The tuakana–teina relationship, an integral part of traditional Māori society, provides a model for buddy systems. An older or more expert tuakana (brother, sister or cousin) helps and guides a younger or less expert teina (originally a younger sibling or cousin of the same gender). In a learning environment that recognises the value of ako, the tuakana–teina roles may be reversed at any time. For example, the student who yesterday was the expert on te wā and explained the lunar calendar may need to learn from her classmate today about how manaakitanga (hospitality) is practised by the local hapū. (The concept of a tuakana–teina relationship / Aspects of planning / Teaching and learning te reo Māori / Curriculum guidelines / Home - Te reo Māori (tki.org.nz))

External persons may be invited to attend steering group and working group meetings at the request of the co-chairs (on behalf of the group), to provide advice, additional expertise, and assistance where necessary.

Decision-making

Decisions will be made by consensus, or if consensus cannot be reached, by majority. If consensus is not reached, dissenting positions are to be recorded and included in formal advice or viewpoints.

Conflicts of interest

Conflict of interest processes will be applied, and members will be expected to disclose any potential conflicts of interest as part of a standard agenda item.

Any potential, perceived, or actual conflicts of interest will be documented by the co-chairs in a separate conflicts of interest register.

Conflict resolution

If situations of conflict should arise between two or more steering group members, those members should attempt to resolve the conflict in the first instance. If this fails, the issue should be raised with the co-chairs. If either co-chair is part of the conflict, Health New Zealand should be involved.

Resources and budget

There is some discretionary funding to support travel and meeting costs of the Steering Group dispensed via Health New Zealand in accordance with Te Tāhū Hauora: Health Quality and Safety Commission, partners in care consumer engagement operational policy.

Members employed by government agencies or crown entities are not eligible for additional remuneration. Other members may be eligible for reimbursement in accordance with the Health Quality and Safety Commission, partners in care consumer engagement policy (see Appendix 2). This fee will cover preparation for and participation in meetings. Additional expenses incurred by any member, while fulfilling their membership responsibilities, will require prior approval from Health New Zealand and be reimbursed on an actual and reasonable basis, with receipts required.

Reporting
The Steering Group will be required to provide regular updates about what is being progressed to Health New Zealand as well as any questions or concerns relating to the deliverables of the group. The working group sponsors and co-chairs will provide regular progress reports to the Steering Group Action points, key communications and key decisions will be documented and held by Health New Zealand . These will be subject to Official Information Act requirements.

Review

The Terms of Reference will be reviewed by the steering group every 6 months to ensure they continue to be relevant and reflect the requirements of most members, sponsors, and Health New Zealand.

Appendix A


Achieving Equity in Health and Wellness
A fair health system prioritises equity
DEFINITION OF EQUITY
In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust.
Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes.
How does your decision making address equity?
What can you do?
What can we all do?
How can we support you?
Rights
Upholds the rights of people, especially under Te Tiriti o Waitangi
&
Needs
Addresses unfair differences between population groups
Currently, what works for most may not work for some
WHĀNAU CENTRED SERVICES
COMPETENT WORKFORCE
SYSTEMS
TOOLS
FUNDING
An equitable playing field is essential to improve health outcomes for Māori, Pacific Peoples, those with disabilities and other groups
Rebalance approaches and resources to meet different needs
A shared responsibility for achieving equity
See health.govt.nz/equity for more info on
Defining equity for the Aotearoa NZ context
Explaining why rights and needs are both a priority
Clarifying what equity means in practice beyond the definition
Creating a commitment to health equity as an enabler of wellbeing
Highlighting the link between Te Tiriti o Waitangi and equity
Describing specific actions to deliver equity
MINISTRY OF HEALTH
MANATŪ HAUORA

Appendix 1

Pae Ora (Healthy Futures) Act 2022

7 Health sector principles (pg 9-11)

(1) For the purpose of this Act, the health sector principles are as follows:

(a) the health sector should be equitable, which includes ensuring Māori and other population groups—
  (i) have access to services in proportion to their health needs; and
  (ii) receive equitable levels of service; and
  (iii) achieve equitable health outcomes:

(b) the health sector should engage with Māori, other population groups, and other people to develop and deliver services and programmes that reflect their needs and aspirations, for example, by engaging with Māori to develop, deliver, and monitor services and programmes designed to improve hauora Māori outcomes:

(c) the health sector should provide opportunities for Māori to exercise decision-making authority on matters of importance to Māori and for that purpose, have regard to both—
  (i) the strength or nature of Māori interests in a matter; and
  (ii) the interests of other health consumers and the Crown in the matter:

(d) the health sector should provide choice of quality services to Māori and other population groups, including by—
  (i) resourcing services to meet the needs and aspirations of iwi, hapū, and whānau, and Māori (for example, kaupapa Māori and whānau-centred services); and
  (ii) providing services that are culturally safe and culturally responsive to people's needs; and
  (iii) developing and maintaining a health workforce that is representative of the community it serves; and
  (iv) harnessing clinical leadership, innovation, technology, and lived experience to continuously improve services, access to services, and health outcomes; and
  (v) providing services that are tailored to a person's mental and physical needs and their circumstances and preferences; and
  (vi) providing services that reflect mātauranga Māori:

(e) the health sector should protect and promote people's health and wellbeing, including by—
  (i) adopting population health approaches that prevent, reduce, or delay the onset of health needs; and
  (ii) undertaking promotional and preventative measures to protect and improve Māori health and wellbeing; and
  (iii) working to improve mental and physical health and diagnose and treat mental and physical health problems equitably

Appendix 2

Te Tāhū Hauora: Health Quality and Safety Commission; Partners in Care consumer engagement operational policy

Purpose of policy

1. To ensure:
    a. Health Quality & Safety Commission staff include consumers in all relevant policies, programmes, and projects
    b. consumers are supported and engage with Commission programmes in a consistent manner.

Context

2. Consumer engagement is one of the strategic priorities for the Commission and underpins all projects and programmes. This is to ensure the Commission is driven by what matters to consumers and whānau, and by what will improve the health of communities and populations.
3. The importance of partnerships between health service organisations/health professionals and consumers, whānau and carers is now well established and documented. Benefits include improved outcomes, better experience of care, lower costs per case and increased workforce satisfaction. One way to provide excellent health care within limited resources is improved engagement with consumers, whānau and carers involving decisions about their own health care and the services they receive.

Scope

4. All Commission policy development, programmes and projects will demonstrate how they have involved and partnered with consumers. This includes those either procured or initiated by the Commission for delivery within the health sector.
5. All programme plans will include information on how consumers have been considered and included in the planning process. This will include in developing evaluation criteria.
6. All board papers will include a section on ‘implications for consumers’.
7. Consideration will always be given to including relevant consumer speakers at workshops, education and training, and other Commission hosted or sponsored events.
8. All consumer representatives will be reimbursed for their time where applicable.

Paying consumers

9. The Commission pays consumers for their time. Payment will vary according to the level of involvement and whether the consumers working with the Commission have paid employment that enables them to participate within the context of their job.
10. Members of advisory groups to the Commission who are staff of a New Zealand public sector organisation, including public service departments, state-owned enterprises or Crown entities are not permitted to claim fees to attend consumer network meetings. However, reasonable expenses for all members will be met by the Commission (eg, travel, parking, and accommodation).
11. Group members who are not from the public sector will have fees and costs covered as follows:
    a. A standard $330.00 (GST excl) payment per meeting. Members are also entitled to preparation time where appropriate. Preparation time will generally be half a day for every full meeting day. In some cases, more or less may be appropriate depending upon the nature of the work to be undertaken, which covers 0.5 day of pre-reading agenda documents, preparation and one-day full meeting attendance.
    b. In some circumstances, an hourly rate of $41.25 (GST excl.) applies. *
12. Administration staff can help with the documentation needed to set up meeting fees, tax obligations and conflict of interest register.

Implementation

13. This policy was updated as at June 2022.

*The full meeting rate will be paid for full/formal working or steering group meetings. Informal meetings held between these scheduled meetings are to be charged as meeting preparation.

Appendix 3

National palliative care steering group charter

This charter outlines our commitments, key principles, and rules of engagement we will follow as members of the National Palliative Care Steering Group (the Steering Group).

We are members of a group of clinical, sector and community leaders; key people from provider organisations and people with consumer and Māori perspectives who have been selected to successfully lead the Steering Group to achieve its objectives.

We share common objectives and commitments which are outlined in this charter.

Purpose

The purpose of the Steering Group is to provide regular and ongoing oversight of the National Palliative Care Work Programme and provide recommendations to Health New Zealand - Te Whatu Ora for national service improvements.

Principles

The foundation of our agreement is a commitment to act in good faith to reach consensus decisions. We will conduct ourselves, and undertake our role, in a manner consistent with the following principles:

- we will adopt a people-centred, whole-of-system approach, that focuses of reducing health inequities and meeting future service demands
- we will support clinical and consumer led service development
- we will conduct ourselves with honesty and integrity, and develop a high degree of trust
- we will promote an environment of high quality, performance and accountability, and low bureaucracy
- we will strive to resolve disagreements professionally, constructively, and co-operatively, and wherever possible achieve consensus decisions
- we will seek to make the best use of finite resources in planning health services to achieve improved health outcomes for our populations
- we will balance a focus on the highest priority needs in our communities, while ensuring appropriate care across all our rural and urban populations
- we will adopt and foster an open approach to sharing information
- we will actively monitor and report on our achievements.

Commitments

We will work actively and in partnership with our fellow members, in an innovative and open manner, to produce outstanding results. To achieve this, we make the following commitments:

- **Shared responsibility:** We will actively address all tasks and duties of our role as members of our steering group and will comply with the operational provisions and guidance for our team.

- **Shared decision-making:** We agree that our decisions will be supported by the best available evidence. We will use our best endeavours to facilitate unanimous decisions and will not prevent a consensus being reached for trivial or frivolous reasons.

- **Shared accountability:** We agree that we will have a robust, professional, airing of views, but that once our group has reached a decision, we will all abide by that decision and support it publicly. This includes keeping confidential the views of individuals expressed during the discussion but does not prevent us sharing the issues that were balanced in reaching that decision.

- **Good faith:** We agree to openly discuss all matters that affect our ability to make firm decisions, including any conflicts of interest and any limits on our mandate (where we carry these from participant organisations), so that all members of our group are fully aware of any restrictions, caveats or further authority that may be required. We also agree not to publicly criticise individuals, organisations, or government agencies in relation to the work of the steering group.

- **Te Tiriti o Waitangi:** We agree that the Te Tiriti o Waitangi establishes the unique and special relationship between Iwi, Māori, and the Crown. Parties with Treaty obligations will honour these when participating in steering group activities.

- **Confidentiality:** To encourage the open sharing of information we agree to keep confidential matters shared on a confidential basis, to enable improved decision-making.

- **Active engagement:** We agree our members' continuous involvement in and attendance at our group meetings is critical and will make every effort to attend and participate fully as well as complete the work required between meetings in a timely way.

If a member of our Steering Group does not act in accordance with our purpose, principles and commitments, Health New Zealand ex-officio members will discuss the situation with the member involved and/or with the co-chairs. If no resolution can be achieved, then the member may be removed from the Steering Group in consultation with Health New Zealand.

Commitment to serve

Based on the above, I agree to serve as a member of the National Palliative Care Steering Group:

Signed: _____

Name: _____

Date: _____