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Cancer Society of New Zealand submission on the Health New Zealand, Te Whatu Ora consultation on the Proposed National Model for Integrated Adult Palliative Care in Aotearoa New Zealand.

About the Cancer Society of New Zealand

The Cancer Society of New Zealand (Cancer Society) is the country's leading organisation dedicated to reducing the incidence and impact of cancer in Aotearoa, New Zealand. We are committed to working with communities and decision makers by providing leadership and advocacy in cancer control, with core services in information and support, research, and cancer prevention. The Cancer Society's Equity Charter guides our commitment to reducing cancer inequities and supports our vision of a cancer free future.

This submission has been prepared by Amanda Dodd, Advocacy and Public Affairs Lead, in collaboration with Cancer Society colleagues. It has been approved by Rachael Neumann, Head of Advocacy and Public Affairs, Kate Gregory, Medical Director and Nicola Coom, Chief Executive.

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The Cancer Society of New Zealand

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Cancer remains the leading cause of death in Aotearoa, New Zealand. One in three of us will receive a cancer diagnosis in our lifetime and 9,500 people will die from cancer each year.ⁱ Cancer will remain a significant contributor to increasing palliative care demands.

The Cancer Society envisions a future free from cancer. To realise this vision, our Strategic Plan prioritises four areas all relevant to the proposed National Integrated Adult Palliative Care Model of Care (Model of Care). These are:

1. Providing community support
2. Advocating for better outcomes
3. Supporting research and innovation
4. Partnering for impact

We are using these four strategic areas to shape our feedback on the proposed Model of Care.

Providing community support

The Cancer Society is pleased to see **community engagement and compassionate communities** as part of the core components of this model. The Cancer Society plays an important role in enhancing wellbeing and providing rehabilitation services to support people living with cancer and their whānau. The Cancer Society provides co-ordinated whānau led/tailored support aimed at enhancing physical, emotional, social, and spiritual wellbeing.

Whilst every person's cancer journey is unique our teams across the mōtu provide timely access to culturally appropriate information and support, empowering decision making for treatment, recovery, return to work and re-integration into daily life. At times this includes practical support such as enabling access to transport to treatment, accommodation, counselling and a range of support groups and wellness programmes.

Our teams work alongside other health professionals to help people living with cancer navigate health and community services to access the support they need most. This wholistic support is highly aligned with the concept of compassionate communities.

Given that the compassionate communities component is likely to lie outside of publicly funded health services, we strongly advocate for partnering with organisations like our own (with strong reach into local communities) to foster community involvement and create enduring collaborations between community groups and health providers.

Specialist palliative care knowledge is crucial to building compassionate communities that support care for people and their whānau through all life stages, especially during serious illness, dying, death, and bereavement. To best support individuals and whānau accessing palliative care, individuals, whānau and community service providers wishing to engage in community support for palliative care would benefit from sustained funding and appropriate oversight for training, education, and guidance.

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Cancer Society is encouraged to see the role of navigators or kaiāwhina recognised as an integral part of this Model of Care. These roles are critical to support everyone during their cancer journey; however, they are especially important to reach and support our Māori and Pacific peoples and their whānau navigate the health system. They can also provide effective support for people who are experiencing disadvantage or poverty. Our own cancer teams across the mōtu connect people living with cancer to a wide range of supportive care services, including accessing clinical expertise to connect people to primary and specialist palliative care as appropriate.

As the Model of Care continues to develop, the Cancer Society strongly advocates for appropriate funding for the continuation of navigation and supportive care services working alongside palliative care to:

- reflect the strong international evidence and widespread recognition of the vital role they contribute to improving health outcomes, and
- meet rising demand, driven both by increased engagement with palliative care systems and the projected growth in life-limiting conditions such as cancer.

Cancer Society also encourages Health New Zealand | Te Whatu Ora to engage with families who have experienced/are experiencing palliative care, to embed their lived experience into the development of future phases of the Model of Care development.

Advocating for better outcomes

Whilst the Cancer Society strives to address the preventable causes of cancer and increase access to screening and early detection and treatment, we are equally focussed on strengthening cancer care. The Cancer Society advocates for access to supportive, palliative and end-of-life care to enable people with cancer to access timely, high-quality care and support.

We are heartened to see equity at the forefront of the proposed Model of Care as one of the seven guiding principles. Given the proposed Healthy Futures (Pae Ora) Amendment Bill 2025 seeks to remove the equity principles from the Pae Ora (Healthy Futures) Act 2022, we strongly support upholding equity principles in palliative care to address recognised disparities and achieve equitable outcomes for all individuals and communities, many of whom will be affected by cancer.

Whilst a national Model of Care seeks to reduce inequities, providing holistic and culturally responsive palliative and end of life care, we are mindful that uniformity in service delivery has not met the needs of many population groups. This Model of Care acknowledges that Māori and Pacific peoples experience higher rates of chronic conditions at an early stage, and if we take a cancer lens, we see consistent disparities in cancer outcomes, especially for Māori and Pacific communities. We note and support the inclusion of whānau-centred and culturally responsive and appropriate services enabling proportionate responses to the palliative care needs of individuals and whānau, but again, assert that the lived experience of whānau should shape how services are developed in response to needs.

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Whilst **regional palliative care networks** will seek to enable adaptations to meet local needs, we advocate for a mechanism to share learnings across other community services outside of, but connected to, primary and specialist palliative care settings, including Non-Governmental Organisations (NGOs). This will be of particular importance to the one quarter of the population living in rural areas. ⁱⁱ

The Cancer Society welcomes a focus on whānau support and education but recognises that not all people have supportive or wide whānau networks to provide care for whānau members and access to wrap around services are particularly important in these circumstances.

Supporting research and innovation

The Cancer Society is committed to strengthening research and innovation across the cancer continuum, from prevention to survivorship and end of life. By adopting new evidence, treatments, and care models earlier, we aim to improve outcomes, quality of life and fairer access for all New Zealanders. Acknowledging the pivotal role research could play in reducing inequities in palliative care outcomes, the Cancer Society strongly urges Health New Zealand | Te Whatu Ora to elevate the role of research within the proposed model, making space for generation of new knowledge to better care for those accessing palliative or end of life care. We recommend that a horizon scanning function is integrated within quality improvement and evaluation to keep abreast of new findings on palliative care and its integration into practice.

We support **regular feedback mechanisms** to incorporate feedback from individuals and whānau on services received, as this is a sound process in identifying where the greatest unmet needs are. The palliative workforce also needs a supportive environment to understand the importance of research and have support to conduct research. Partnering with the regional research office and relevant national clinical networks, e.g. the Cancer National Clinical Network, could support refinement of research questions and link staff to expertise to support research project planning and conduct within palliative care.

Partnering for impact

Cancer Society supports **interdisciplinary collaboration** as a core component of primary palliative care services. We prioritise strengthening cross-sector collaboration to support coordinated efforts that reduce duplication, identify and close gaps in care, and ensure seamless services for those we support, many of whom will require primary or specialist palliative care at some point in their cancer experience.

However, while the proposed Model of Care acknowledges the importance of this collaborative approach, it places primary responsibility with a person's enrolled general practitioner (GP). This presents challenges, as not all individuals requiring palliative care are registered with a GP practice, nor do all have an ongoing relationship with one. Furthermore, we recognise the increasing pressures faced by GP practices and the barriers patients encounter in accessing timely appointments. Barriers to accessing primary care have increased with one quarter of all adults not seeing their GP for a medical problem due to appointment wait times. ⁱⁱⁱ To meet the growing demand and ensure equitable access to care, additional workforce capacity is

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essential, particularly given the Model of Care emphasis on an expanded role for GP teams in coordinating primary palliative care.

Thought Exchange question - What is the most important change you believe is needed to improve palliative care services for all adults in Aotearoa New Zealand?

In response to the thought exchange question posed above, we note that there is no mention of hospice funding within the draft National Integrated Adult Palliative Care Model of Care.

The reality is that hospices have a large reliance on charitable funding. As specialist palliative services, this reliance would impede implementation of the proposed model and continue to drive inequity of access to hospice services. A 2022 study identified many areas of variability in hospice services, resulting in inconsistent care across settings^{iv}.

Given the breadth of services offered by hospices in Aotearoa New Zealand, including but not limited to, advice to patients and carers, clinical and psychosocial services, education and training to other health professionals, hospice care should be given greater emphasis within the proposed model. If we take Christchurch as an example, there is only one hospice to serve the entire population and noting the projected increase in deaths highlighted in the proposed model (148% increase by 2043), there will be increased demand on hospice services. Whilst the draft Model of Care notes a small number of deaths will occur in hospice inpatient services, demand for specialist hospice services in other settings is likely to increase in line with projected increase in deaths.

A more sustainable approach to future funding for hospice care is essential to meet many of the core components of the proposed national model and facilitate coordinated palliative care for adults. For example, this could have a positive impact on the extreme pressure for bed availability that exists within the hospital system.

While the draft Model of Care presents many commendable strengths, we believe New Zealand faces significant challenges in realising its full implementation. Challenges to equitable provision of assisted dying services, grief and bereavement counselling, access to psychosocial support, home help support, sustained resourcing of advanced care paramedics (trained specifically for palliative care), support for increased continuity of care, and out-of-hours care all require adequate funding to support workforce capacity, training and education. Efforts to address fragmentation of services and support increased sector-wide collaboration are crucial to realise the potential benefits offered by a National Integrated Adult Palliative Care Model of Care.

Likewise, **additional system-wide recommendations**, including the development of National Quality Standards Framework, and Standards Framework for Aged Residential Care (ARC) will all require sustained funding to drive implementation at a national, regional, and local level.

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In summary, the Cancer Society of New Zealand recommends that:

- Sustained funding is allocated to support individuals, whānau and community service providers wishing to engage in community support for palliative care (i.e. compassionate communities) to access training and education with appropriate oversight.
- Sustained funding is allocated to drive implementation of National Quality Standards Framework and Standards Framework for ARC
- Appropriate funding is allocated for the continuation of navigation and supportive care services working alongside palliative care.
- Health New Zealand | Te Whatu Ora engage with families who have experienced/are experiencing palliative care, to embed their lived experiences into the development of future phases of the Model of Care development.
- Health New Zealand | Te Whatu Ora partner with NGOs to foster community involvement and create enduring collaborations between community groups and health providers aligned with compassionate communities.
- Health New Zealand | Te Whatu Ora uphold equity principles as a core component of palliative care to address disparities and achieve equitable outcomes for individuals, their whānau and communities, many of whom will be affected by cancer.
- Regional palliative care networks provide a mechanism to share learnings across other community services outside of, but connected to, primary and specialist palliative care settings, including the NGOs.
- Funding is prioritised for additional workforce capacity across palliative care services, but particularly for General Practice given the Model of Care emphasis on an expanded role for GP teams in coordinating primary palliative care.
- Elevate the role of research within the proposed model and integrate a horizon scanning function quality improvement and evaluation to keep abreast of new findings in palliative care and its integration into practice.
- Health New Zealand | Te Whatu Ora partner with the regional research office and relevant national clinical networks to support research project planning and conduct within palliative care.
- Increased and sustainable government funding to hospice services provision to reduce reliance on charitable funding.

Thank you for the opportunity to comment on the Proposed National Model for Integrated Adult Palliative Care in Aotearoa New Zealand.

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- ⁱⁱ Ministry of Health. 2025. Health and Independence Report 2024 – Te Pūrongo mō te Hauora me te Tū Motuhake 2024. Wellington: Ministry of Health.
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- ^{iv} New Zealand Medical Journal Te ara tika o te hauora hapori -‘Community specialist palliative care services in New Zealand: a survey of Aotearoa hospices’
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