The Paediatric Society of New Zealand
Te Kāhui Mātai Arotamariki o Aotearoa

NZCYCN
New Zealand Child & Youth
Clinical Network

1 May 2025

PSNZ submission on the National Paediatric Palliative Care Model of Care

This letter provides feedback on potential future national services for tamariki, rangatahi/children, young people and their whānau/families.

PSNZ has supported the process for establishing a model of care for Aotearoa New Zealand from inception.

The strategy of PSNZ is to enable health care systems to provide appropriate levels of care equitably and as close to home as is possible. In palliative care this is even more important. Palliative care must be readily available to provide care in the home.

We endorse a kaupapa Māori approach that upholds Te Tiriti o Waitangi and addresses long-standing inequities. Māori make up nearly 25% of paediatric palliative deaths, yet face poorer access to care.

To change this, Māori must be involved from the outset, through co-design with Iwi Māori Partnership Boards and investment in culturally safe, whānau-centred services. Option 3, with four hubs, best reflects the geographic and cultural reality of Māori communities and offers the most equitable path forward.

Multiple conditions in the 0-24 age group result in the need for palliative care. Diagnoses broadly include congenital abnormalities, chronic health, neurodevelopmental, and oncological conditions. Acutely, general paediatricians, neonatologists, and other specialists deal with end-of-life sporadically across the workforce. All of the above value specialist paediatric palliative care input from clinical nurse specialists and palliative care clinicians.

Paediatricians treat young people up to age 16 or 18. Those aged 16-24 are a particular age group who are highly likely to benefit from the services proposed for a Hub and specialist approach to support the rangitahi/ whanau, their GP or adult hospital specialist teams.

To breach the current gap, community agencies (in Waikato) and philanthropically (in Wellington) have developed care that strives to meet the needs of their communities. This perpetuates inequity and variation by locations in New Zealand.

PSNZ want a Child and Youth palliative care model of care that is responsive to clinical need, engages locally with clinicians involved with the family and provides expert care by trained medical, nursing and allied health specialists when needed.

Within the proposed models only option 3 - Clinical Service Network and 4 hubs - can be developed further to meet the needs of all pēpi, tamariki, rangatahi and whānau in Aotearoa. The NZCYCN Paediatric Palliative Care Clinical Network who participated in this process only support option 3.

A phased approach may be needed, building on the excellent nursing/community team in Waikato, where a specialist is currently in training. There is a service in Wellington that needs to move to be funded by Te Whatu Ora. The predominantly CNS team in Christchurch could be developed with more team members and a trainee supervised by the Wellington Hub. The services within existing multidisciplinary teams vary significantly and currently have different levels of whānau support, especially for Māori and other ethnicities, sibling and post-bereavement support, and these can be supported once the funding is approved.

The multidisciplinary team needs to include clinical nurse specialists, psychologists, support workers, Māori Liaison, social workers, specialist PPC physicians, other allied health (occupational therapist/physiotherapist), administration support, and management oversight. Nurse practitioner positions will be a useful addition to the team and are not currently in place. This will require significant resources and planning for their training. Access to Child and Adolescent Psychiatry services should be managed regionally. Will funding for a PPC Kaiwhakarite / lead Paediatrician in non-Hub centres be included in the national model?

Education and training are also very important. Currently the NZCYCN Paediatric Palliative Network hold monthly education sessions accessible nationally. Will this be a role of the new PPC National Network?

Option 2 - Clinical Service Network and two hubs is inequitable as an endpoint in terms of delivering equitable care nationally. It could be an interim stage toward phasing to option 3. Currently, there is a Paediatric care specialist in Wellington. Having the second hub in Wellington is an interim step, while providing a trainee opportunity for the Waikato trainee and a new one for Christchurch. This model will be less able to provide an afterhours service.

Option 1 - PPC Clinical Service Network is virtually status quo with some coordination function. This is not supported as will not meet the needs of many who require general and specialist service in New Zealand.

In the current national network context, option 1 should include a funded co-lead position (min 0.2 FTE each). 1.0 FTE programme management is noted, and administration in each of the 4 Hubs (0.5 FTE each).

The PSNZ agrees that a nationally consistent structure is required and is encouraged to see that a national network is part of each of the three options.

It is not clear where Palliative care “networks” will be placed within Te Whatu Ora. We understand it is likely to be within Performance, Funding Outcomes (PFO), previously called Commissioning rather than within the umbrella of the Office of the Chief Clinical Officer (OCCO). This appears to fragment the strategy for clinical leadership to be within national clinical networks that are under OCCO.

A collaborative approach of the 4 Hub team of Specialists could provide after-hours service to deliver 24-hour cover in an integrated way. This will provide advice to support communities across the motu. The workforce coverage needs to be carefully considered, as specialists are often not working full-time. A minimum roster of 1 in 5/6 is suggested, and can include registrars in training under supervision. The proposal was short on details and costs for this important component of a national service, currently not provided even in Auckland. A 4 Hub model will be able to support a sustainable after-hours roster.

Due to this complexity, there are areas not covered within the model of care document that require clarity:

- Who will provide the reports perspective within Te Whatu Ora?
- Will these functions have clinical oversight?
- Who will review their funding annually?
- Who will evaluate progress and the service provision?

Governance is crucial for ensuring a quality service that is sustainable.

We note that the recently updated (2022) clinical resources for Paediatric Palliative Care developed by the Paediatric Palliative Care Clinical Network funded by the NZCYCN were not in the references (Page 7) and should be included. Starship - Paediatric Palliative Care Clinical Guidelines.

To summarise, PSNZ firmly believes that Option 3 is the only sustainable and equitable path forward for paediatric palliative care in Aotearoa.

Ngā mihi,

Associate Professor Nicola Austin, Chair of NZCYCN Governance Group, Neonatal Paediatrician

Pam Henry, Programme Director, Paediatric Society of New Zealand

On behalf of Te Kāhui Mātai Arotamariki o Aoteoraoa | Paediatric Society of New Zealand