

Submission Information

Guidance for Integrated Paediatric Palliative Care Services in New Zealand: Draft for consultation

You are invited to provide your feedback on *Guidance for Integrated Paediatric Palliative Care Services in New Zealand: Draft for consultation*. Feedback and comments received during the consultation period will be considered as part of the analysis of submissions and will inform the implementation of the Guidance. Please use the following submission form to complete your submission and note:

Only submissions written in, or attached to, this form as electronic or hard copy will be accepted.

Making your submission

All submissions must be received no later than **5 pm on 28 November 2011**.

Please complete the submission form electronically and email to:
cancerteam@moh.govt.nz

We would prefer electronic submissions to assist in managing responses. If you are unable to send your submission electronically, please post your completed submission form to:

Cancer Team
Ministry of Health
PO Box 5013
WELLINGTON

Marked: 'Submission – Paediatric'

All submissions will be acknowledged by the Ministry of Health.

When commenting on the draft document, please be as specific as possible and where appropriate, support your comments with evidence or suggested alternatives. You can choose to answer some or all questions.

Your submission may be requested under the Official Information Act 1982. If this happens, the Ministry of Health will release your submission to the person who requests. If you are an individual, as opposed to an organisation, the Ministry will remove your personal details before releasing your submission if you tick the following box.

Provision of personal information is optional.

I **do not** give permission for my personal details to be released to persons under the Official Information Act 1982.

Submission Form

Name of person making submission or contact person if submission is on behalf of organisation/group: (required) Marilyn Head

Postal address: (required) New Zealand Nurses Organisation

PO Box 2128

Wellington 6140

Phone: 04 494 6372

Contact email: marilynh@nzno.org.nz

Are you submitting this as?

(Tick one box only in this section)

an individual (not on behalf of an organisation)

on behalf of a group or organisation

name of organisation: New Zealand Nurses Organisation

other (please specify)

Submission questions

1. Do you have general comments on the overall draft document such as on readability, language and structure? Please make suggestions for each issue you identify.

The document is highly readable, well structured and clear. Even so, we suggest that the distinction between leading and providing *specialist support* for locally delivered services as opposed to providing *specialist services* may need emphasising. NZNO strongly supports nationally consistent service delivery for paediatric palliative care, and agrees that Starship hospital is an appropriate lead agency for the development of systems, including education, and specialist support for paediatric palliative care services throughout Aotearoa New Zealand.

However, NZNO is concerned with both the process and the aim of the guidance project. We appreciate the difficulties posed with a short timeframe, but question the necessity for such a timeframe which has precluded comprehensive consultation, reflection and engagement in this specialised area of health. The lack of consultation with providers in the South Island in particular (only Canterbury is listed) has not allowed input from areas whose geography and population profiles are markedly different from those in the North Island where consultation was focused and from where it is proposed the service be led. Similarly, "patient and family centred services" require consultation with families and patients. We acknowledge the experience and expertise of those consulted, but the point of consultation is to get firsthand source information rather than inferred information. National consultation is necessary for the development of a national service and clear communication pathways need to be established from the outset.

Secondly, it was true that paediatric palliative care service had been 'left behind', but steps have been taken to address service gaps - in Christchurch, for example, the appointment of a palliative nurse from paediatrics who liaises between families, Christchurch the hospital and primary care, has been very successful and "collaboration between members of the paediatric workforce and shared training" is part of the South Island Regional Health Services Work plan agreement between the South island District Health boards (DHBs). It would be unfortunate if a new 'solution' were found to a problem that is already in the throes of being addressed. We note, for instance, the Ministry of Health's summary of the review's finding that: "Many families of children with palliative care needs, having no access to specialist care services, *rely on local primary health care, community services and non-government organisations (NGOs).*" (my italics) NZNO believes that it is entirely appropriate to rely on local primary care services etc. for palliative care; there may be a need for upskilling and co-ordination/communication, but that is where responsibility for delivery of paediatric palliative services should lie. Collaborative practice which ensures continuity of care for the family as well as the child is essential. Members are somewhat apprehensive that the Starship hospital lead will blur the distinction between acute services which may need hospital provision and palliative care services which generally do not.

There is a risk that Starship's high profile may create a demand for direct care from Starship, the impression that other services are inferior, or a subtle shift in focus and funding back on to acute hospital care rather than community centred palliative care. NZNO suggests that managing expectations and being absolutely clear that home or hospice delivery of palliative care is the priority which is supported by Starship's national specialist services will be necessary to avoid a siloed service, unrealistic expectations or, worse, families being uprooted to access palliative care for their children.

In many parts of the country, it is neither appropriate nor possible, for paediatric palliative care to be delivered by specialists as it is a small part of wider general practice, district nursing, or community services. Services must balance the 'safety' that many people feel with hospital provision of acute care, with the risk of over-medicalising death which, even in tragic circumstances, is a part of life. It is essential that Starship is seen not as the remote (to three quarters of Aotearoa New Zealand) centre of paediatric palliative care services, but as the lead resource and guide for nationally consistent paediatric palliative care services. Safe pathways for community provision of paediatric palliative care must be negotiated and the budget for the service must reflect that.

The following question focuses on Part C of the draft document, *Guidance for the development of paediatric palliative care services* (beginning page 66). This sets out the proposed direction for paediatric palliative care services in New Zealand.

2. Overall, do you agree with the principles, national service delivery framework and direction as proposed in Part C?

1 Strongly DISAGREE	2	3	4 X	5 Strongly AGREE
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If you do not agree with the principles, national service delivery framework and/or direction as proposed please give details and provide suggestions of changes/improvements.

Add "as close to home as possible" to the principles or adapt the vision of the New Zealand Palliative Care Strategy (Ministry of Health 2001) to read: "*All children with palliative care needs and their families/whānau have timely access to high-quality palliative care services as close to home as possible*". This is fundamental to ensuring families receive optimum palliative care and must be explicitly stated.

Treaty of Waitangi obligations to Māori should be specifically acknowledged as a separate principle, not inferred from a principle of cultural inclusiveness or 'recommended'. "Culturally anchored" does not describe the nature of the Treaty bond. We strongly endorse clause 5.2 recommending Māori representation, but believe it should be intrinsic i.e. a principle, not just a recommendation.

Principle 6: fiscally responsible and appropriately resourced We support the inclusion of a principle based on sound economic management and limiting expectations to what can be resourced but note comments below.

13.2 The opening sentence "*The proposed national framework positions the Starship Paediatric Palliative Care Team as the national specialist service*" may be interpreted as providing services rather than providing specialist support and we suggest rewording, for example "*The proposed national framework positions the Starship Paediatric Palliative Care Team the national specialist service supporting local/regional delivery of paediatric palliative care*".

We strongly support the Framework which identifies the key delivery role in of generalist i.e. local, community-based paediatric palliative care - clearly set out in *figure 1 Paediatric palliative care system relationships* and *Table 8 Proposed paediatric palliative care service responsibilities*.

1.3 *Appoint DHB nurse coordinators and lead paediatricians* Given that this initiative is not expected to add extra costs, it is unlikely that a significant number of new appointments will be made. NZNO suggests that "Identify and appoint" may be all that is required, since we expect that some of the coordinators and paediatricians are already in place and working in this capacity.

14.6 Principle 6: Transparent funding mechanisms and operating within budget must be core objectives, but the recommendations for principle 6 could usefully include consideration of cost effectiveness, more particularly a responsibility to ensure funding equity for health services. This is particularly important with these specialist services where it is easily possible to justify considerable expenditure for very marginal benefits. This necessarily impacts on funding for other health initiatives. NZNO would like to see a recommendation to ensure *responsible expenditure* making best use of economic analysis for health care.

The guidance proposes a service delivery system that builds on existing resources and is within baselines. Section 15: *Implementation of Guidance* (page 73) indicates the organisation(s) who would take a lead role in implementing the principles and recommendations of the proposed organising framework. A suggested timeline is also provided for the phased implementation.

3. Overall, do you agree with what is proposed in the Implementation of Guidance section?

1 Strongly DISAGREE	2	3	4 x	5 Strongly AGREE
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Please provide additional comment in support, or detail the specific aspects of implementation that you disagree with.

See above re 1.3 a

We suggest that there is a role for health workforce and professional organisations to ensure practise standards and that positions align with, and health workers are covered by, Collective Agreements such as the DHB MECA where applicable. Disparate working conditions e.g. with travel time etc. must be considered to avoid burnout, unrealistic expectations etc.

Organisations such as NZNO, which represents both professional and industrial interests of nurses, can provide expertise, contacts and communication pathways. We also have a good national overview of workforce and professional issues which may impact on the roll out of a specialist service such as this.

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4. Is there anything that has been omitted from the document that you feel should be included or noted?

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If you would like to make additional comments, please add them below. Attach a separate sheet if required.

Advanced Care Planning is not mentioned and we suggest it should be part of the paediatric palliative care strategy

. <http://www.moh.govt.nz/moh.nsf/indexmh/advance-care-planning-aug11>

<http://www.advancecareplanning.org.nz/>

Thank you. Your comments are appreciated.