

## 1. Introduction

The Paediatric Society of New Zealand was contracted by the New Zealand Ministry of Health to develop a care framework and clinical guidelines for children's and young people's palliative care in New Zealand. Development of clinical guidelines which address each component of the continuum of care was beyond the scope of this project. Instead, the project focus was development of a suite of clinical guidelines for care at end-of-life. It is anticipated that, in the future, further clinical guidelines will be developed to address care at other stages of the continuum.

## 2. Methodology

### 2.1 Aim and objectives

The aim of the project was to develop, for secondary and tertiary providers of paediatric palliative care services: (1) a care framework in which to embed clinical guidelines; and (2) clinical guidelines for end-of-life care. Specific objectives were to:

1. Design robust development methods and processes
2. Develop a care framework
3. Define components of end of life clinical guidelines
4. Develop agreed end-of-life clinical guidelines

### 2.2 Project approach

The project was conducted over 15 months in three consecutive phases. Phase 1 comprised: (1) project planning and appointment of governance and clinical reference groups; (2) review of literature regarding care pathways and end-of-life clinical guidelines; and (3) design of a development method. Phase 2 consisted of development and agreement of a care framework. Phase 3 comprised: (1) definition of components for end-of-life clinical guidelines; and (2) development of agreed end-of-life clinical guidelines.

### 2.3 Project personnel

The project was conducted by Dr Elizabeth Bennett and Dr Emily Chang. Dr Ross Drake and Ms Karyn Bycroft acted as project advisers, providing clinical advice and support throughout the project. Members of the New Zealand Paediatric Palliative Care Clinical Network provided a further sounding board and several members reviewed the draft documents. Final clinical review was provided by three Australian reviewers. Details of project personnel are given below:

<b>Project staff</b>	
Dr Elizabeth Bennett	Independent consultant
Dr Emily Chang	Consultant Paediatric Palliative Care Service Starship Children's Health, Auckland DHB
<b>Project Advisory Group</b>	
Dr Ross Drake	Consultant Paediatric Palliative Care and Complex Pain Services Starship Children's Health, Auckland DHB
Ms Karyn Bycroft	Nurse Practitioner Paediatric Palliative Care Service Starship Children's Health, Auckland DHB
<b>Project Reference Group (Paediatric Palliative Care Clinical Network Group)</b>	
Ms Karyn Bycroft	Nurse Practitioner Paediatric Palliative Care Service Starship Children's Health, Auckland DHB

Ms Renee Clements	Child Health Clinical Nurse Specialist MidCentral Health
Dr Vicki Culling	Consumer representative Trainer in perinatal and infant loss Vicki Culling Associates, Wellington
Dr Ross Drake	Consultant Paediatric Palliative Care and Complex Pain Services Starship Children's Health, Auckland DHB
Dr Amanda Lyver	Paediatric Oncologist Canterbury DHB
Mr Stephen Parkinson	Psychotherapist True Colours Children's Health Trust, Hamilton
Dr Deb Rowe (Ngai Tahu)	Nurse Consultant, Auckland DHB Lecturer, University of Auckland
Ms Rachel Teulon	Child and Adolescent Clinical Nurse Specialist Nurse Maude Specialist Palliative Care Team, Christchurch
Ms Mollie Wilson	CEO Paediatric Society of New Zealand
<b>NZ Clinical Reviewers</b>	
Ms Karyn Bycroft	Nurse Practitioner Paediatric Palliative Care Service Starship Children's Health, Auckland DHB
Ms Renee Clements	Child Health Clinical Nurse Specialist MidCentral Health
Dr Ross Drake	Consultant Paediatric Palliative Care and Complex Pain Services Starship Children's Health, Auckland DHB
Dr Amanda Lyver	Paediatric Oncologist Canterbury DHB
Ms Rachel Teulon	Child and Adolescent Clinical Nurse Specialist Nurse Maude Specialist Palliative Care Team, Christchurch
<b>Australian Clinical Reviewers</b>	
Dr Anthony Herbert	Director Paediatric Palliative Care Service, Division of Medicine Children's Health Queensland Hospital and Health Services, QLD
Dr Jenny Hynson	Medical Director Victorian Paediatric Palliative Care Program The Royal Children's Hospital, VIC
Dr Martha Mherekumombe	Consultant in Paediatric Palliative Care Department of Pain Medicine and Palliative Care The Children's Hospital at Westmead, NSW

## 2.4 Development process

Clinical guidelines may be developed in several ways. Methods include: (1) *de novo* development; (2) use of the evidence base of existing guidelines to develop new guidelines; (3) adaptation of an existing guideline; and (4) adoption of existing guidelines.

We carefully assessed each of these methods. For reasons of best use of available resources, this project adapted existing guidelines for the New Zealand context. Selection of a process was based on three key considerations: (1) the paediatric palliative care evidence base is not well-developed and existing guidance and standards appear to be based on clinical consensus rather than robust evidence bases; (2) the project required a practical, streamlined approach which took account of limited resources; and (3) a key feature of high-quality guidelines is a rigorous and transparent development process.

Following a review of several guideline development processes, we used two internationally-developed instruments to guide the development process. The ADAPTE instrument guided the overall

development process, while the AGREE II instrument was used to: (1) assess the quality of existing guidelines; and (2) the quality of guidelines developed by this project.

We assessed 28 English-language policy and guidance documents. All but four were publicly-available and permission was gained to include those. Using the AGREE II tool, we assessed these documents for quality, currency, content and consistency, and selected 16 for inclusion as source guidelines. These are:

- ACT (Association for Children's Palliative Care). 2009. *A Neonatal Pathway for Babies with Palliative Care Needs*. 1<sup>st</sup> ed. Bristol: ACT (Association for Children's Palliative Care)
- ACT (Association for Children's Palliative Care). 2011. *Children's Palliative Care Handbook for GPs*. 1<sup>st</sup> ed. Bristol: ACT (Association for Children's Palliative Care)
- Auckland District Health Board. Allow natural death- te wa aroha. In: Auckland District Health Board. 2010. *Starship Children's Health Policy and Procedure Manual*. Unpublished document of Auckland District Health Board
- Auckland District Health Board. Pain management and analgesia overview. In Auckland District Health Board. 2011. *Starship Children's Health Clinical Practice Manual*. Unpublished document of Auckland District Health Board
- British Association of Perinatal Medicine. 2010. *Palliative Care (Supportive and End of Life Care), A Framework for Clinical Practice in Perinatal Medicine: Report of the Working Group 2010*. Unpublished document of the British Association of Perinatal Medicine
- Children's Health Queensland Hospital and Health Service. 2014. *A Practical Guide to Palliative Care in Paediatrics*. Brisbane: Queensland Government
- Hain, Richard. 2013. *Symptom Management in Paediatric Palliative Care: On-line Edition*. Available at: <http://paed.pallcare.info> Accessed 1.5.14
- Jassal, Satbir Singh (ed). 2008. *Basic Symptom Control in Paediatric Palliative Care: The Rainbows Children's Hospice Guidelines*. 7<sup>th</sup> ed. Unpublished document of The Rainbows Children's Hospice Guidelines
- Mancini A, Uthaya S, Beardsley C, Wood D and Modi N. 2014. *Practical Guidance for the Management of Palliative Care on Neonatal Units*. Unpublished document of the Royal College of Paediatrics and Child Health and the Chelsea and Westminster Hospital NHS Foundation Trust
- Paediatrics and Child Health Division of the Royal Australasian College of Physicians. 2008. *Decision-Making at the End of Life in Infants, Children and Adolescents: A Policy of the Paediatrics and Child Health Division of The Royal Australasian College of Physicians*. Unpublished document of The Royal Australasian College of Physicians
- Texas Pediatric Society. 2014. *Palliative Care Toolkit*. Available at: <https://txpeds.org/palliative-care-toolkit> Accessed 4.5.14
- The Children's Hospital at Westmead. 2005. *Palliative Care Practice Guideline*. Unpublished document of the Children's Hospital at Westmead
- The Children's Hospital at Westmead. 2009. *Guideline: Pain Management-CHW*. Unpublished document of the Children's Hospital at Westmead
- Together for Short Lives. 2012. *A Guide to End of Life Care: Care of Children and Young People Before Death, At the Time of Death and After Death*. Bristol: Together for Short Lives
- West Midlands Paediatric Palliative Care Network. 2011. Toolkit. Available at: <https://wmppcn.wordpress.com/wm-toolkit/> Accessed 6.6.14
- World Health Organization. 2012. *WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses*. Geneva: World Health Organization

In the main, selected source guidelines focused either on pain and symptom management or on the more general aspects of palliative care for children and their families. Only one guideline (WHO, 2012) provided consistently evidence-based recommendations: most source guidelines drew on clinical consensus regarding best practice. Guidance regarding the psychosocial and spiritual care of

children is not strong and there is little international guidance which addresses the cultural aspects of care for the New Zealand context.

Data was extracted from the source guidelines and draft clinical guidelines were developed according to the protocols of the ADAPTE instrument. Data was extracted from the source guidelines and draft clinical guidelines were developed according to the protocols of the ADAPTE instrument. Draft guidelines were reviewed by the Project Group, the New Zealand Clinical Reference Group and three Australian reviewers, before development of the final version.

## 2.5 Development of guidelines for pain and symptom management

It is appropriate to address specific issues in development of guidelines for pain and symptom management. We point out that no set of guidelines can cover all variations required for specific patient circumstances. We emphasise the responsibility of clinicians who use these guidelines to adapt them for safe use within their institutions and according to the needs of individual patients.

The topics selected by the development group, took into account the following:

- How likely the symptom is likely to occur in a population of paediatric palliative care patients
- Level of specialist knowledge required to effectively manage a given symptom

Dosing information was largely been taken from *A Practical Guide to Palliative Care in Paediatrics* (Children's Health Queensland Hospital and Health Service, 2014). This reference was chosen because the drugs available, and prescribing practices, are similar in Australia and New Zealand.

Dosing information included in the Pain Management Guideline references the *WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses* (WHO, 2012). This reference was used because of its high AGREE II rating.

Pain and symptom management guidelines are provided for use by specialist paediatric health care professionals in New Zealand. While great care has been taken to see that the information in this section is accurate, users are advised to check drug doses carefully. Where there is uncertainty regarding the guidance provided, users are advised to seek advice. Telephone advice is available from the Palliative Care Service at Starship Children's Health.

Medication doses given in pain and symptom management guidelines are standardised by *body-weight*. To calculate the dose for a given child the weight-standardised dose is multiplied by the child's weight (or, occasionally, by the child's ideal body-weight for height). The calculated dose should not normally exceed the maximum recommended dose for an adult. For example, if the dose is 8 mg/kg (maximum 300 mg), a child of 10 kg body-weight should receive 80 mg, but a child of 40 kg body-weight should receive 300 mg (rather than 320 mg).

Calculation by body-weight in the overweight child may result in much higher doses being administered than necessary; in such cases, the dose should be calculated from an ideal body-weight for height. For WHO mean values, see [Weight, height, and gender \(mean values\)](#).

## 3. ADAPTE Instrument

The ADAPTE Collaboration is an international group of researchers, guideline developers and implementers who have developed a generic process that aims to foster and validate high-quality guidelines. The ADAPTE instrument guides a systematic development process that is flexible and adaptable to specific circumstances. It is supported by a resource toolkit and specific tools. The ADAPTE process comprises three stages, each of which has specific components:

### Setup phase

- Outlines specific tasks to be completed before adaptation process begins

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### Adoption phase

- Assists process of topic and question selection
- Guides process of searching for, and retrieving guidelines
- Guides assessment of consistency of evidence and guideline quality, currency, content and adoption
- Assists in preparing drafts of adopted guidelines

### Final phase

- Guides users through stakeholder feedback process
- Guides consultation with developers of original guidelines
- Assists in updating original guidelines
- Guides creation of final document (ADAPTE Collaboration, 2009)

## 4. AGREE II Instrument

The ADAPTE developers recommend the use of the Appraisal of Guideline Research and Evaluation (AGREE II) instrument to appraise the quality of original guidelines, in order to assess their appropriateness for adaption, as well as adapted guidelines.

AGREE II is an internationally used tool which is both valid and reliable. It is used to assess methodological rigour and transparency of development process. The tool comprises 23 items which are organised in six domains. These are:

- *Scope and purpose*, which assesses: the overall aim of guideline; specific questions or topics; and the target population
- *Stakeholder involvement*, which assesses the extent of development by appropriate stakeholders
- *Rigour of development*, which assesses: the process used to gather and synthesise evidence; and methods used to formulate recommendations
- *Clarity of purpose*, which assesses the language, structure and format
- *Applicability*, which assesses: barriers and facilitators to implementation; strategies to improve uptake; and resource implications
- *Editorial independence*, which assesses the formulation of recommendations based on competing interests

As well, an overall assessment of quality is facilitated by the tool. AGREE II recommends two to four reviewers, who complete four-point scale answers.

AGREE II comprises a comprehensive users' manual and specific tools, which include training tools. An online appraisal platform is provided on the AGREE website ([www.agreetrust.org](http://www.agreetrust.org)) (Brouwers et al, 2010)

The table below sets out: (1) the key processes and components of the international tools and the relationships between each; (2) the components which were adopted, adapted or omitted; and (3) the involvement of project teams in the development process.

ADAPTE/AGREE II PROCESS	NZ PROCESS	TOOLS AND GUIDELINES	RESOURCES
<b>Phase 1: Setup</b>			
Check whether adaptation feasible	No change	ADAPTE	Development team
Establish organising committee	Establish review group	ADAPTE	Development team
Select topic	No change	ADAPTE	Development team Project team
Identify skills and resources	No change	ADAPTE	Development

<b>ADAPTE/AGREE II PROCESS</b>	<b>NZ PROCESS</b>	<b>TOOLS AND GUIDELINES</b>	<b>RESOURCES</b>
needed			team Project team
Complete setup tasks	No change	ADAPTE	Development team
Write protocol	No change	ADAPTE	Development team
<b>Phase 2: Adaptation</b>			
Determine topic and question	No change	PIPOH instrument	Development team Project team
Search for guidelines and other relevant documentation	No change	ADAPTE	Development team
Screen retrieved guidelines	No change	AGREE II	Development team
Reduce number of required	No change	AGREE II	Development team
Assess guideline quality, currency, content, consistency	Modified assessment (reflects quality of source guidelines)	AGREE II	Development team Project Team
Assess acceptability and applicability of recommendation	Modified assessment (reflects quality of source guidelines)	ADAPTE	Development team Project team
Prepare guideline	No change	ADAPTE	Development team
<b>Phase 3: Finalisation</b>			
External review by target users	Review by Clinical Reference Group members and external reviewers	ADAPTE	Clinical Reference Group External reviewers
Consult with relevant endorsement bodies	Omit	-	-
Consult with developers of source guidelines	No change	-	Development team
Acknowledge source document	No change	-	Development team
Plan for aftercare of document	Omit (outside of scope)	-	-
Produce final document	No change	-	Development team Clinical Reference Group

## References: Development Methodology

ADAPTE Collaboration. 2009. *The ADAPTE Process: Resource Toolkit for Guideline Adaptation*. Version 2.0. Available at: <http://www.g-i-n.net>

Children's Health Queensland Hospital and Health Service. 2014. *A Practical Guide to Palliative Care in Paediatrics*. Brisbane: Queensland Government

Brouwers M, Kho ME, Browman GP, Burgers JS, Cluzeau F et al, for the AGREE II Consortium. 2010. Advancing guideline development, reporting and evaluation in healthcare. *Canadian Medical Association Journal* 182E:839-42 doi.10.1503/090449

World Health Organization. 2012. *WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses*. Geneva: World Health Organization