Paediatric
Palliative care
NATIONAL ACTION PLAN PROJECT

Equal Voices, Shared Wisdom

A Co-Design Approach to Paediatric Palliative Care Guidelines

Palliative Care
Australia
Matters of life and death

Paediatric
Palliative Care
AUSTRALIA & NEW ZEALAND

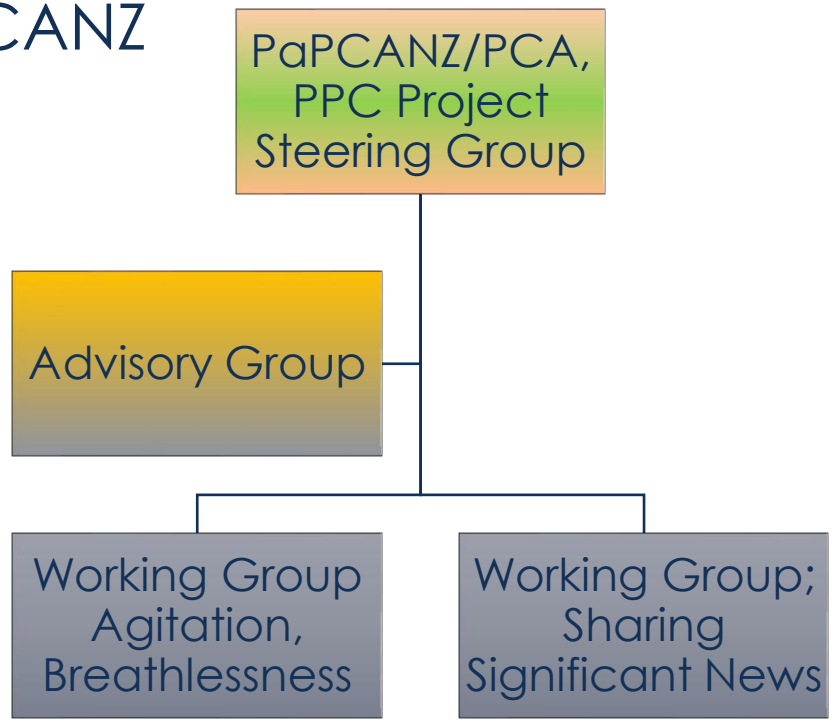
SHAPING THE FUTURE
of Paediatric Palliative Care

June 2026

Lived Experience

Background

1. Shaping the Future project, Commonwealth Government Grants
2. Partnership with PCA and PaPCANZ
3. Consumers at every level



Aims and Objectives

Project Aim;

To improve quality of life for children and their families by supporting guidance to clinical practice for health care professionals

Objective;

To review and adapt three of the topic-by-topic guidelines developed by NZCYCN for Australian practice

Important Concepts;

Consumer co-design, clinician expertise and academic rigor three-prong approach.

Integrity of content and consistency

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"Enable people with lived experience to be a part of your decision-making, don't add more advisory groups that keep people separate." Beyond Sticky Notes, Kelly Ann McKercher

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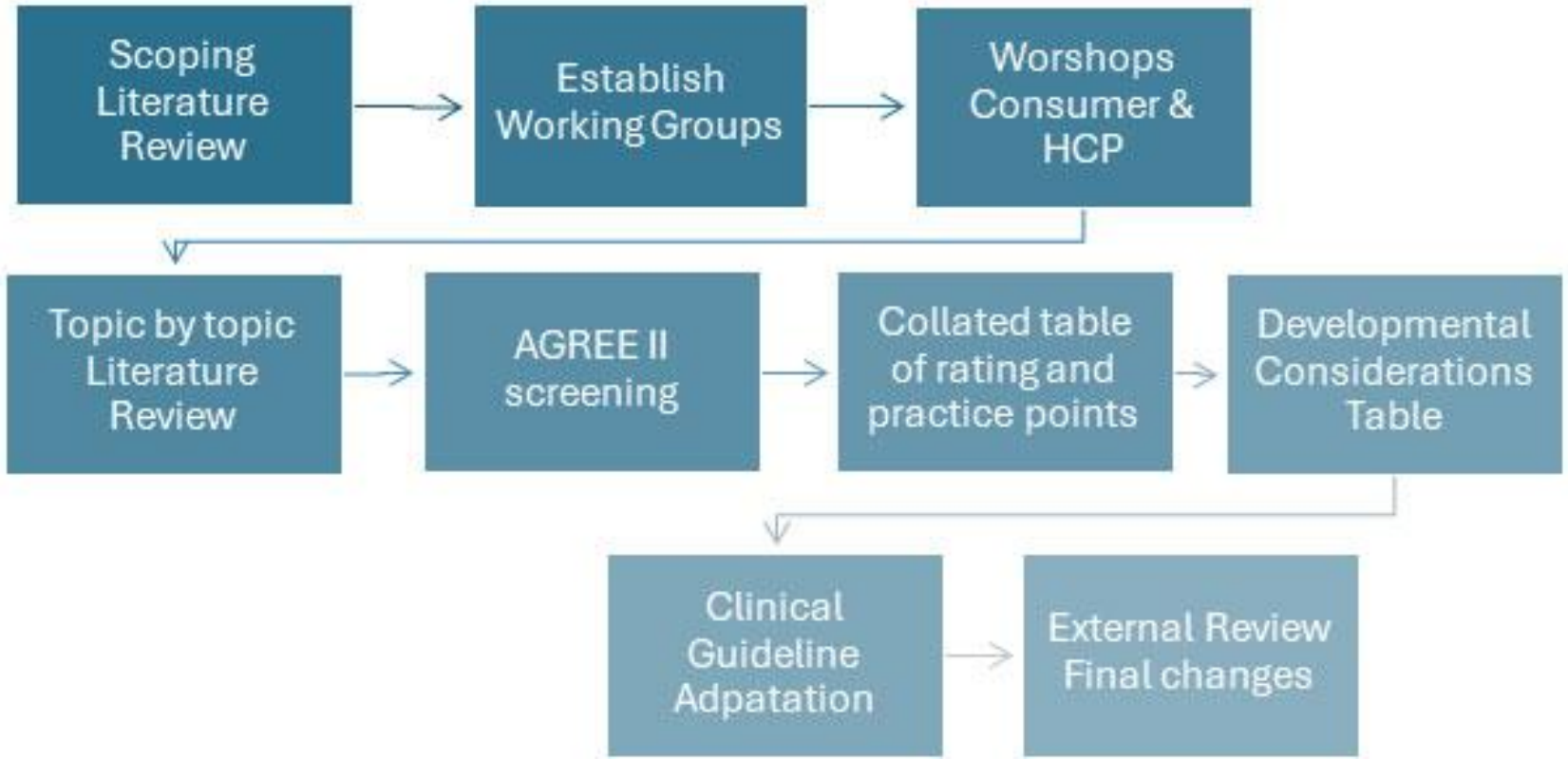
Codesign

"is a way of thinking and working, rather than a single event." *Brand, 2024*

- Share Power
- Prioritise Relationships
- Use Participatory Means
- Build Capacity

Method



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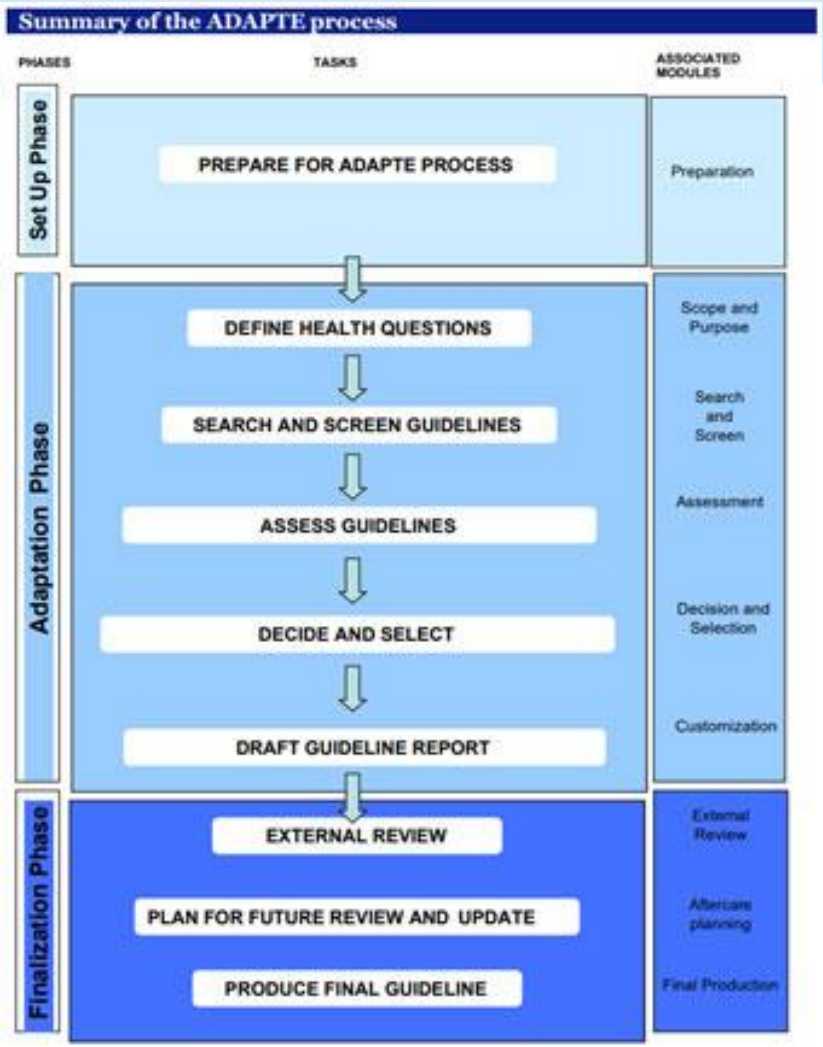
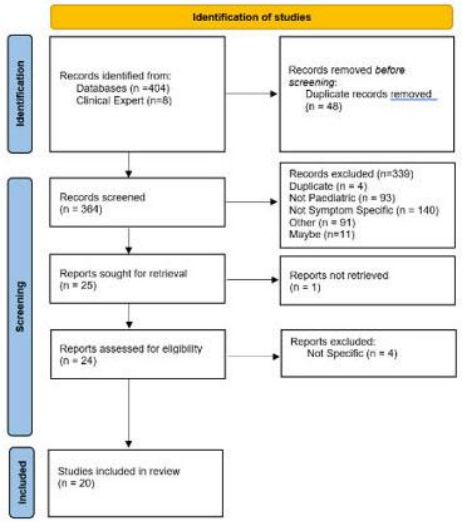
Method



For each guideline between 20 and 27 sources of literature were identified for more detailed screening using the Appraisal of Guideline Research and Evaluation (AGREE II) instrument with two-four reviewers per document following these points;

Scope and purpose

- *Stakeholder involvement*
- *Rigour of development*
- *Clarity of purpose*
- *Applicability*
- *Editorial independence*



Pivot Points

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Be **SURE** you practice these key actions;

S	**S**eek the voice of the child
U	**U**nderstand the family's current goals of care and expectations
R	**R**ecognise parent/carer role and expertise about their child
E	**E**xplore shared decision making and care partnership

Pivot Points

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Recommendations [1-7]

•Discuss with the child and family the history of the symptoms, the impact of this agitation and what words they use to describe it.
•Establish and support the family's current preferences in management wherever possible.
•Identify, assess and manage the causes and provoking factors.

Non-pharmacological management

Work with the child and family to;

•Ensure that the child is safe from physical injury and that basic care needs are met.
•Provide care in a calm, peaceful environment with a parent or trusted adult present.
•Position comfortably and consider the temperature, sound, light and smells in the child's room.
•Encourage family to reassure child by using touch and talk to the child.
•Provide family psychological, cultural and emotional support.
•Use senses that are still intact such as hearing (e.g. play favourite music, read stories), and familiar smells (e.g. child's own blanket or soft toy).
•Introduce therapies as available, such as music, massage.
•For neonates, use swaddling, tucking, skin-to-skin contact, non-nutritive sucking.
•Offer spiritual and existential support.

Pharmacological management

Work with the child and family about their expectations and preferences keeping in mind that there is often a balance between alertness and complete control over agitation

Results

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- Powerful family-centered voices into what advice is given to clinicians about practice.
- Transformation of how the guidelines look and feel, including the priority placement of these statements in the guideline themselves- which now lead with voice of the families.

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Codesign

- Share Power
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EMPOWERING QUESTIONS

Rachel Callander

- What would help you feel comfortable and respected in this research or co-design project?
- What would help you feel that your experiences and perspectives are truly seen and valued by researchers?
- What does it look like for you to feel genuinely heard when sharing your experiences or ideas in a research setting?
- Are there any boundaries, topics, or approaches that researchers should be mindful of to ensure participation feels safe and supportive?
- What types of support or options (for example breaks, choice of format, support person, or follow-up support) would help make participation feel emotionally safe?
- How would you like researchers to communicate about the purpose of the project and how parents' contributions will be used?
- Help me understand how best to support you, as you participate in this research How do we repair, when things get hard?
- Is there anything that doesn't make sense?
- What needs further clarifying or explanation- there's no such thing as a silly question.
- What should we ask you?
- What would you like us to know about you and your family?

Reflection

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- Partner at **inception** of any idea with consumers
- **Budget** to pay well for the consumer's time and expenses
- Make the **time and tone** so that the consumer feels their place and respect at the table
- Allow time to support and educate the consumers
- Be transparent and **stop-listen-digest** the new perspectives
- Be aware of **language** which is unhelpful and exclusive
- Expect to be challenged in long held assumptions and **embrace the pivot**
- Be capable of **sensitivity and perception** in the wellbeing of the consumer

References

Clinical Guidelines

Agitation - management in the palliative paediatric patient

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Date last published: July 2025

This clinical guideline is written for health care professionals who provide care to children with life-limiting diagnoses. It is intended to inform clinical practice through concise best practice advice. Please contact your Paediatric Palliative Care Service for further advice.

This guideline has been adapted with approval from the PSNZ New Zealand Paediatric Palliative Care Clinical Network Clinical Guidelines.

Definition [1]

"Agitation or irritability is used to describe unpleasant psychological and physical arousal, often in circumstances in which the underlying etiology remains unclear. It refers to a complex set of symptoms and signs that are distressing to the patient, their family and caregivers. Agitation/ irritability may consist of psychological symptoms, physical symptoms and autonomic changes."

In this clinical guideline the word "child" is used for brevity but refers to neonate, baby, child and/or adolescent. There are developmentally appropriate considerations for each. The word "parent" is used interchangeably to represent the legal guardian of the child.

https://www.stillbirthcre.org.au/wp-content/uploads/2026/03/A-Guide-to-Partnering-with-Parents-in-Research.pdf

https://paediatricpalliativecare.org.au/paediatric-palliative-care-clinical-guidelines/

https://paediatricpalliativecare.org.au/methodology/

Brand, G., Sheers, C., Hansen, A., Stephens, G., Dart, J., Shannon, B., & Bonnamy, J. (2025). How to … Co-design Education With Healthcare Consumers. *The Clinical Teacher*, *22*(2), Article 70039.

McKercher, K. A. (2020). *Beyond sticky notes : co-design for real : mindsets, methods and movements* (Edition One.). Beyond Sticky Notes.

Borgstrom, E., & Barclay, S. (2019). Experience-based design, co-design and experience-based co-design in palliative and end-of-life care. *BMJ Supportive & Palliative Care*, *9*(1), 60–66. https://doi.org/10.1136/bmjspcare-2016-001117