

# What Matters Most

## Identifying a Core Indicator Set for Quality Pediatric Palliative Care



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# Study Team

# Background

- Several systematic/scoping reviews in last 5 years to examine indicators used to assess the impact/quality of pediatric palliative care
  - Many different indicators used (location of death was most common)
  - Different definitions of indicators used across studies
  - Different instruments used to assess indicators
  - Psychometric properties of instruments lacking
  - Primarily focused on end-of-life care
  - Few indicators rely on patient/family report



# Questions

- Are we measuring what matters or what is easy to measure?
- What matters to children, parents, HCP, administrators?
- How do we agree on a common set and common definitions of indicators?
- Do we have valid tools to measure what matters?



# Key Study Aims

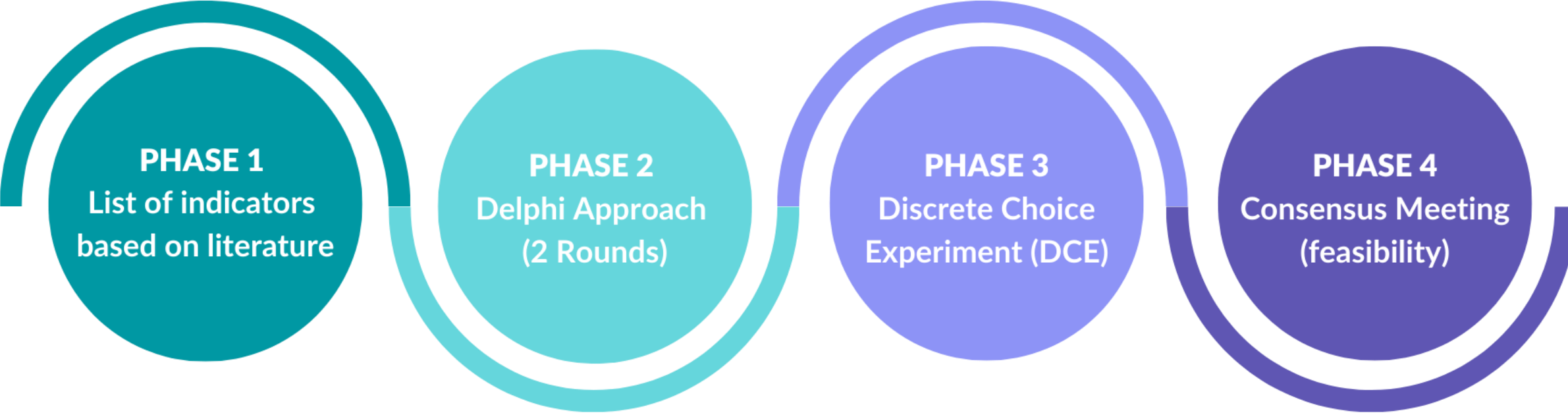


To identify and prioritize key quality domains and indicators for pediatric palliative care internationally  
Prioritize involvement and perspectives of children and families



To improve consistency in assessment and advance our ability to analyze and improve systems of care

# Methods



# Phase 1: Gather Initial List of Domains and Indicators

# Initial List of Domains and Indicators

Created from 23 documents including:

- Kim Widger – SPPC impact indicators
- Veronica Dussel & Joanne Wolfe – SPPC impact indicators
- Lorna Fraser – oncology focused indicators
- Marie Friedel - instruments to measure PPC outcomes
- Rachel Thienprayoon – domains for home-based PPC and hospice
- Jackie Boyden – indicators for home-based PPC and hospice
- Prassana Anath – indicators for EOL care in oncology
- Richard Harding & Myra Bluebond-Langner – Palliative Outcomes Scale-Peds
- Emily Johnston – quality markers for EOL care in oncology
- Sophie Ribbers – domains for PPC for children with neurological impairment
- Jori Bogetz – quality metrics for hospital-based primary PPC
- Veerle Piette – population level indicators for EOL care



# Initial List of Domains for Palliative Care

- Child Support & Outcomes
- Parent Support & Outcomes
- Sibling Support & Outcomes
- Family Support & Outcomes
- Continuity & Coordination of Care
- Communication with Healthcare Professionals
- Knowledgeable, Skilled, Compassionate Healthcare Professionals

# Initial List of Domains for End-of-Life Care

- Support for the Child
- Support for the Family
- Support for Decision-making
- Location of Care
- Discussion and Support for Location of Care
- Medical Interventions at the End of Life
- Discussions about Prognosis, Goals of Care, Advanced Care Planning, and Resuscitation.
- Bereavement Support & Outcomes

# Phase 2: Delphi Study

# Family Panel



# Healthcare Professional Panel



WHAT MATTERS MOST

# Family Panel

- Between 12 and 19 years of age **living with a serious illness** (e.g., cancer, muscular dystrophy, a serious genetic illness, etc.), **OR**
- 12 years of age or older and are a family member (parents, siblings, grandparents, etc.) of someone 19 years old or younger living with a serious illness, **OR**
- 12 years of age or older and are a family member (e.g., parents, siblings, grandparents) of someone 19 years old or younger who died from a serious illness.



# Healthcare Professional Panel

- Conduct research about **OR** are involved in providing care (either directly or through an administrative/decision-maker role)
- in any setting (e.g., home, hospital, hospice)
- to children less than 19 years of age living with a serious illness (e.g., life-threatening or life-limiting condition).



# Delphi Study: Round 1

- *How important is this indicator to the measurement of PPC quality?*



- Space to express opinions, reformulate, merge, provide a rationale for removing/adding indicators, or give any other comment.

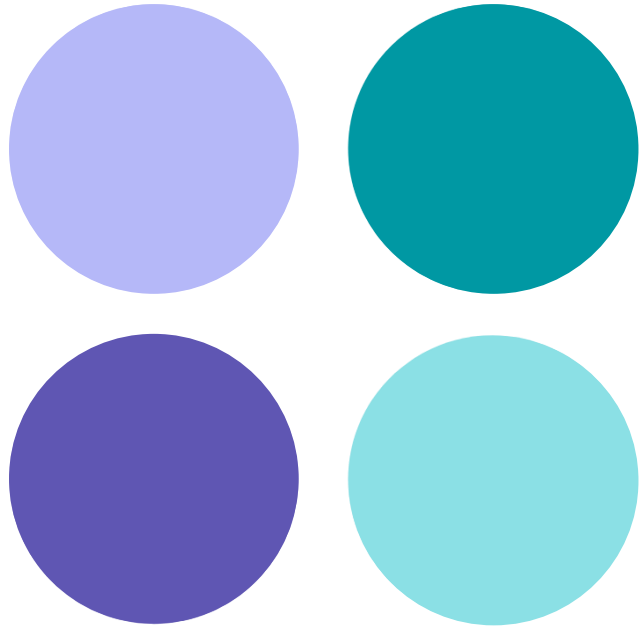
# Delphi Study: Round 2

- Review summarized scores from both panels
- Rate any newly added indicators
- Re-rate indicators where there was no consensus on importance



# Phase 3: Discrete Choice Experiment

# Discrete Choice Experiment



- Panel members will be shown a series of 4 domains / indicators at a time
- Asked to indicate the most important and least important from that group
- Results will include the domains, listed in order of importance, along with the indicators associated with each domain, also listed in order of importance for each panel

# Phase 4: Consensus Meeting

WHAT MATTERS MOST

# Consensus Meeting

- Final meeting to review study results and create core indicator sets
- GOAL: 15 to 20 indicators in 5 to 7 domains in each set
- Selection based on inclusion of:
  - 1) indicators most important to panel members (with priority given to family perspectives);
  - 2) indicators representing the most important domains of care;
  - 3) a mix of structure, process, and outcome indicators;
  - 4) patient/family reported indicators.

# Additional Steps

Our focus is **WHAT** to measure, but still need to determine **HOW** to measure

## “NUMBER OF VISITS TO THE EMERGENCY DEPARTMENT”

- which visits are counted (e.g., planned versus unplanned)?
- over what time frame (e.g., the last 30 versus 14 days of life)?

## “CHILD’S QUALITY OF LIFE”

- which is the best tool for use in this population?
- is research needed to validate an existing tool or develop a new one?

Join the family panel or  
healthcare professional panel and  
tell us **what matters most** to you.

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