DukeNUS Medical School
Lien Centre for Palliative Care

Quality-of-care measurement for seriously ill children: working with and for the voices of families

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Program in Health Services & Systems Research

LCPC Palliative Care Conference 2022: Improving the Quality and Value of End-of-Life Care

Session: Improving quality of Paediatric Palliative Care

SingHealth DukeNUS
ACADEMIC MEDICAL CENTRE

‘Serious illnesses’: Over 21 million children identified to benefit from palliative care *annually*

together for short lives

Cat.	Description	Examples:
1	**Life-threatening conditions for which curative treatment may be feasible but can fail**	cancer, irreversible organ failures of heart, liver, kidney.
2	**Conditions where premature death is inevitable**	Cysticfibrosis, duchenne muscular dystrophy.
3	**Progressive conditions without curative treatment options**	batten disease, mucopolysaccharidoses.
4	**Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health**	severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury.

Cancer

Duchenne Muscular Dystrophy

Cerebral Palsy

Mucopolysaccharidoses

Pediatric and Adult Palliative Care: Some differences

1.Different causes of death.

A variety of childhood conditions are rare, and length of illness can **vary greatly .**

Children continue to develop.

Burden of care falls upon the whole family.

Organization of Children's palliative care services.

More aggressive care compared to adults at EoL.

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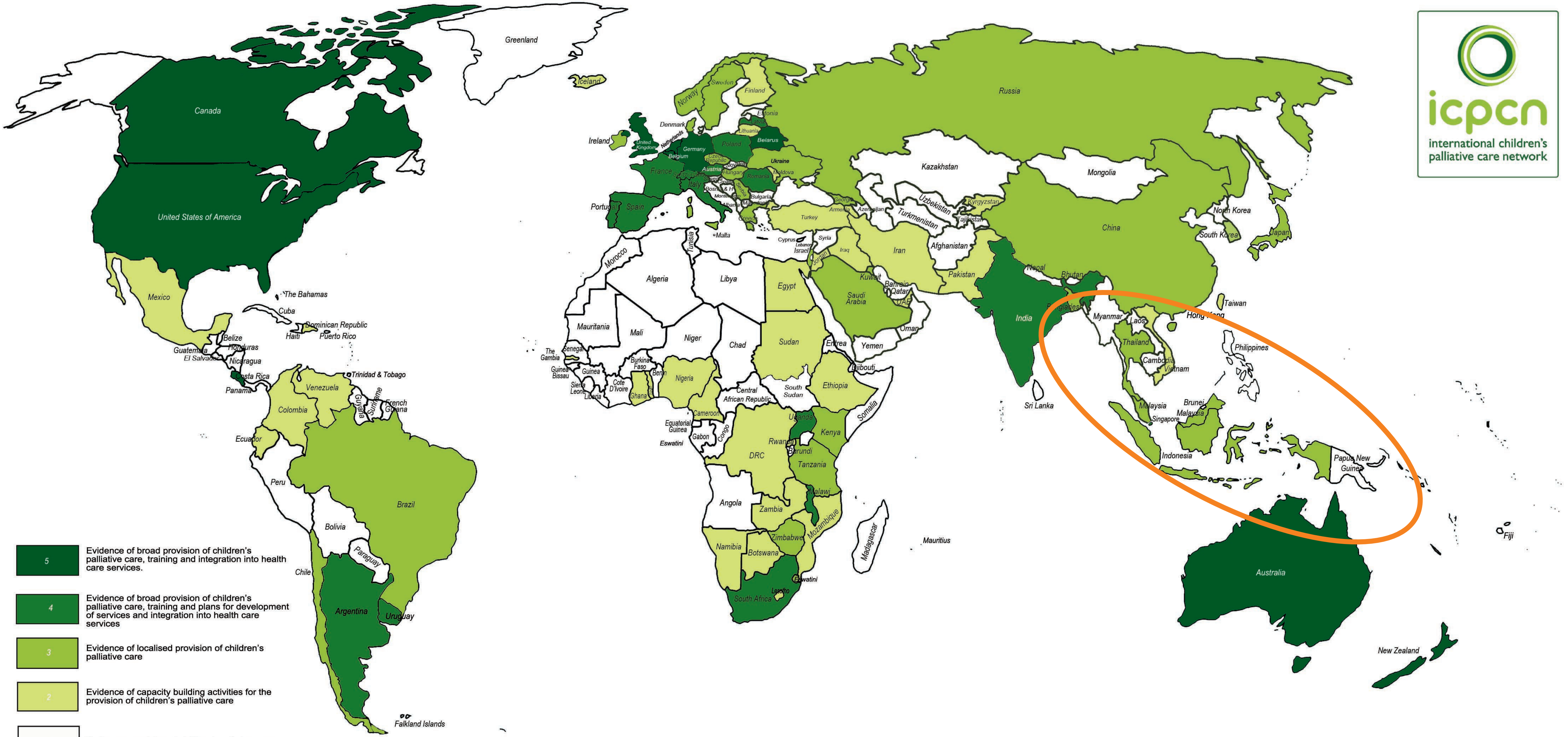
Estimated Levels of Pediatric Palliative Care (PPC) Provision Worldwide

icpcn

international children's palliative care network



5 — Evidence of broad provision of children's palliative care, training and integration into health care services.

4 — Evidence of broad provision of children's palliative care, training and plans for development of services and integration into health care services

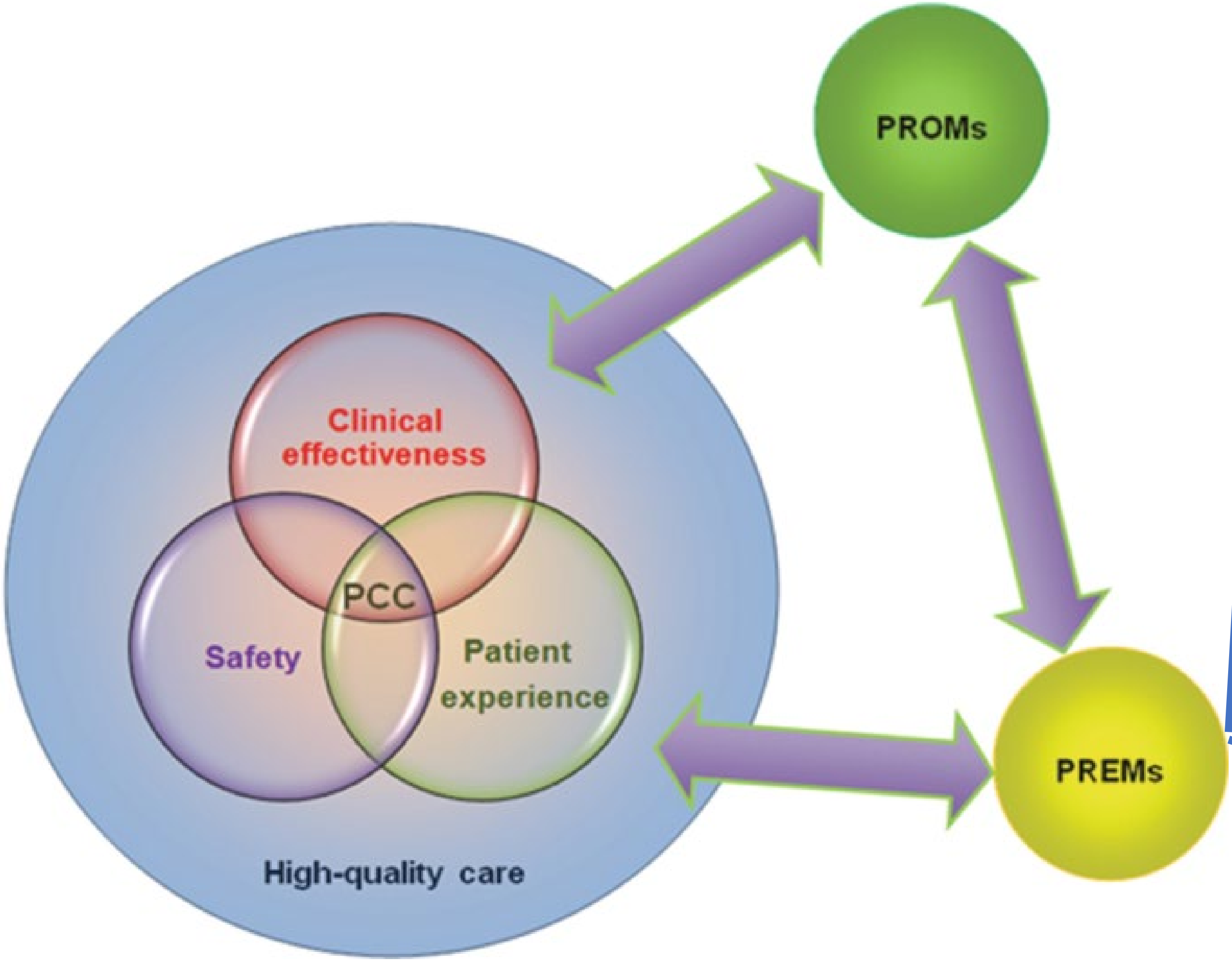
3 — Evidence of localised provision of children's palliative care

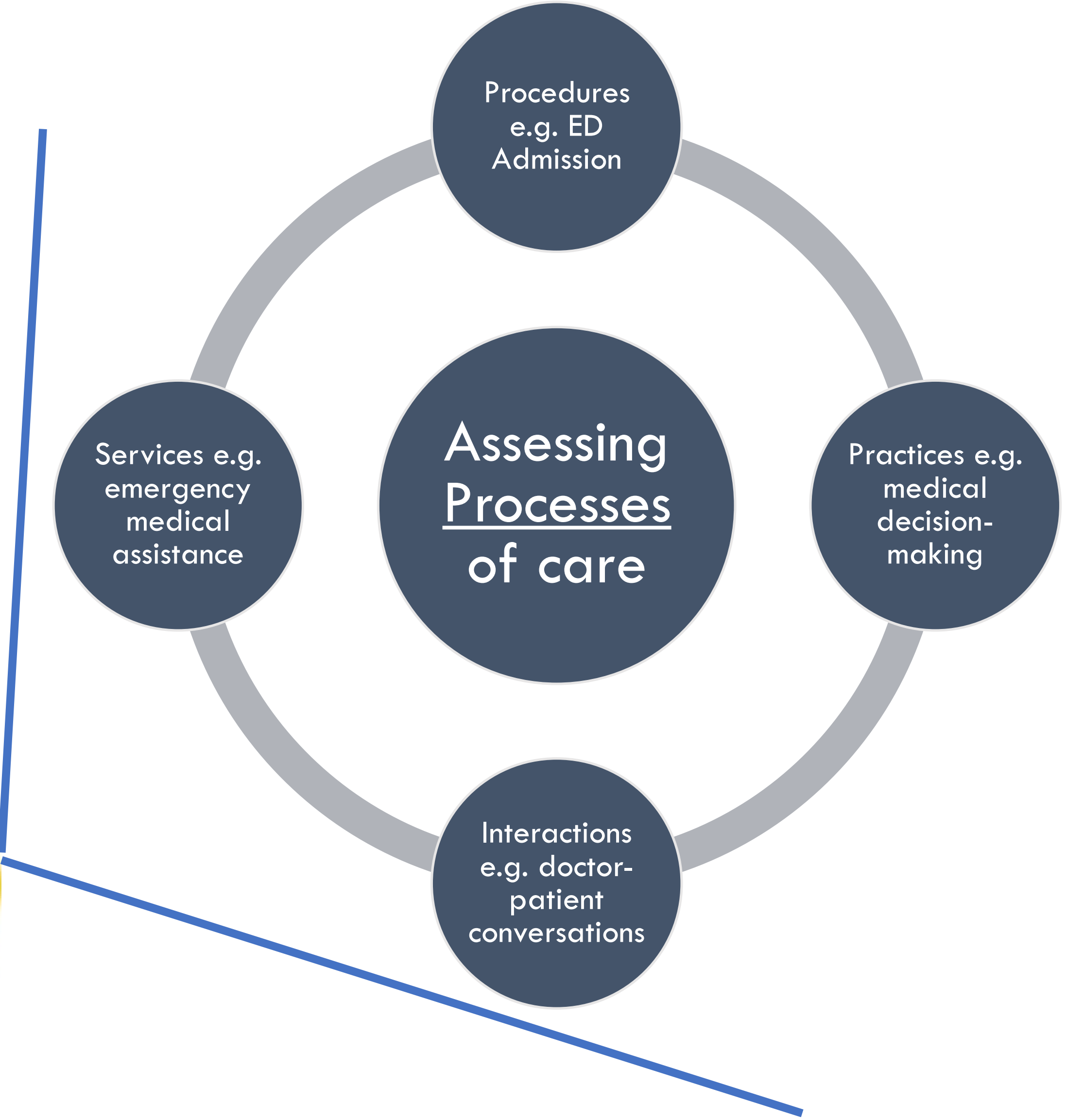
2 — Evidence of capacity building activities for the provision of children's palliative care

1 — No known provision of children's paliatve care

Updated May 2019

What is Quality-of-care? What are Quality-of-care indicators?




Assessing Processes of care

Procedures e.g. ED Admission

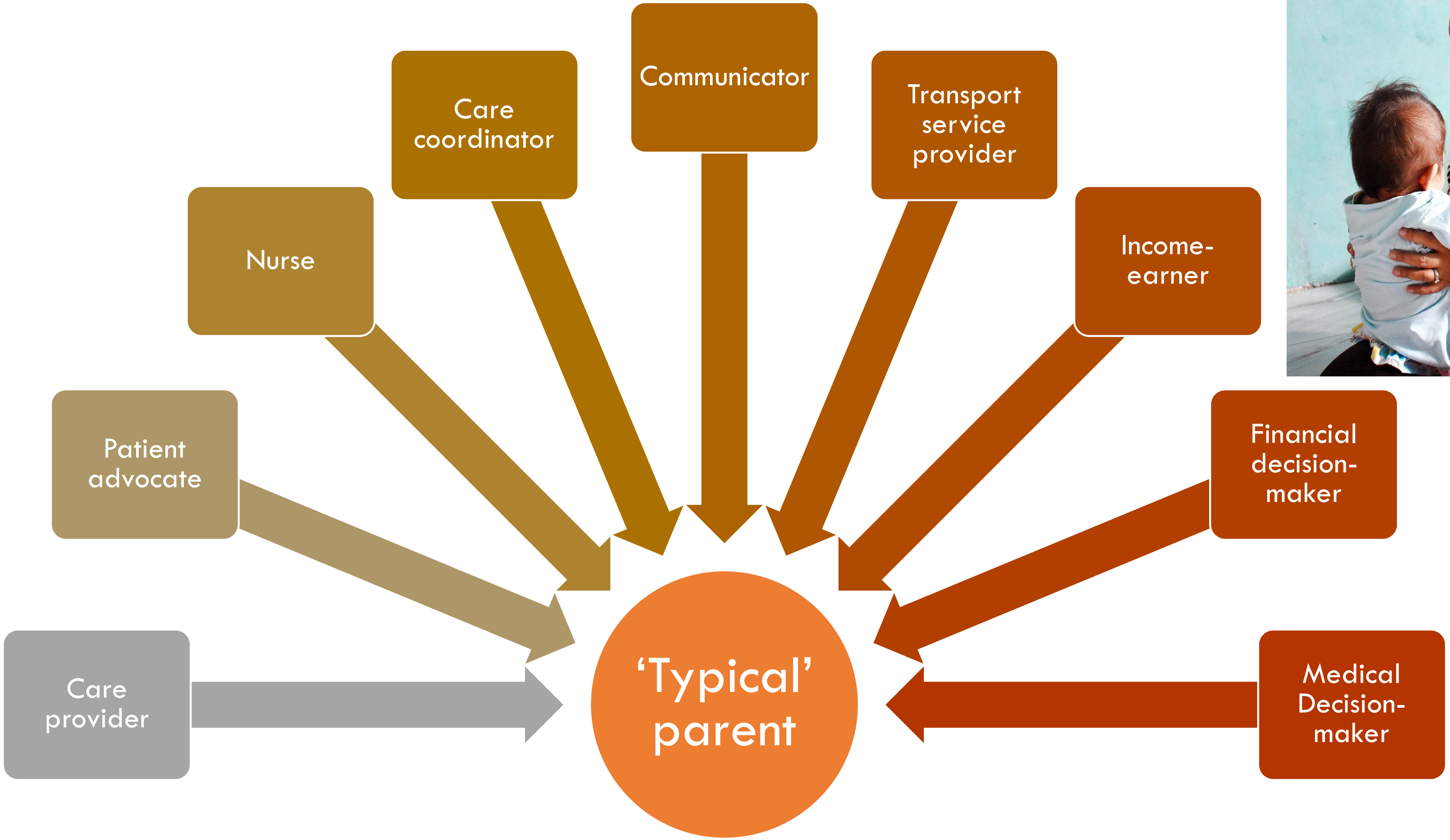
Practices e.g. medical decision-making

Interactions e.g. doctor-patient conversations

Services e.g. emergency medical assistance

Aiyegbusi, O.L., Hughes, S.E., Calvert, M.J. (2022). The Role of Patient-Reported Outcomes (PROs) in the Improvement of Healthcare Delivery and Service. In: Kassianos, A.P. (eds) Handbook of Quality of Life in Cancer. Springer, Cham. https://doi.org/10.1007/978-3-030-84702-9_20

Parents of seriously ill children: fighting on the battlefront



Care provider

Patient advocate

Nurse

Care coordinator

Communicator

Transport service provider

Income-earner

Financial decision-maker

Medical Decision-maker

‘Typical’ parent

Why Parental experience is important for high-quality care

Patient Experience

- Service and resource utilization
- Clinical effectiveness
- Patient safety

Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open. 2013;3(1).

Family-Centered Care

- Parents are integral in children's care
- Children are treated as child-parent dyads (parent's experience matters)

Ward C, Glass N, Ford R. Care in the home for seriously ill children with complex needs: A narrative literature review. Journal of Child Health Care. 2015;19(4):524-31.

Parental Roles

- Vulnerable group at risk of poor health outcomes
- Awareness and responsiveness to parental priorities

King SM, Rosenbaum PL, King GA. Parents' perceptions of caregiving: development and validation of a measure of processes. Dev Med Child Neurol. 1996;38(9):757-72.

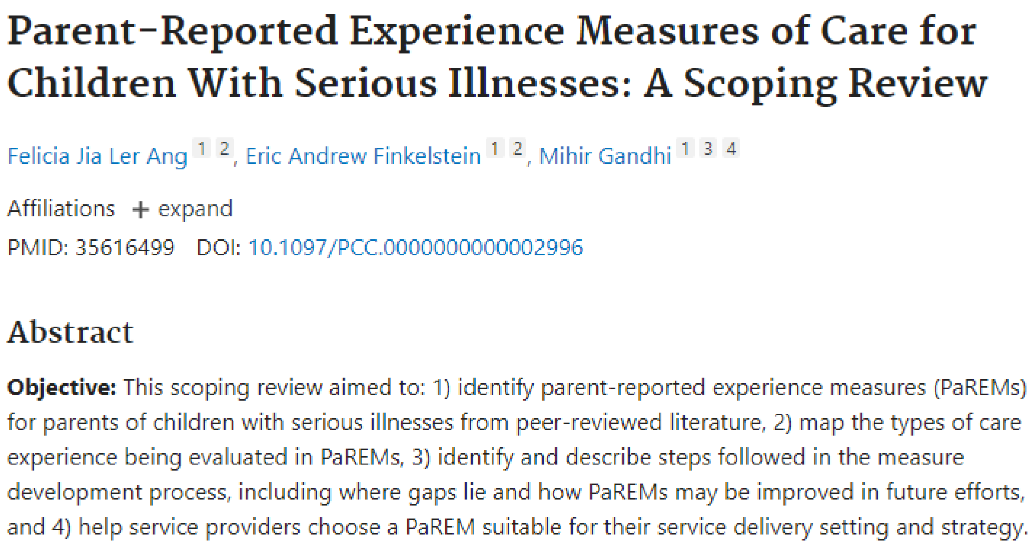
In the beginning: Unanswered questions

**Parent
Reported
Experience
Measures**

Service Providers: What Parent-Reported Experience Measures (PaREMs) can or should I use?

Researchers: What are the gaps in current knowledge & PaREMs that we need to fill?

Scoping review: Major Gaps identified in existing PaREMs



Parent-Reported Experience Measures of Care for Children With Serious Illnesses: A Scoping Review

Felicia Jia Ler Ang [1] [2], Eric Andrew Finkelstein [1] [2], Mihir Gandhi [1] [3] [4]

Affiliations + expand

PMID: 35616499 DOI: 10.1097/PCC.0000000000002996

Abstract

Objective: This scoping review aimed to: 1) identify parent-reported experience measures (PaREMs) for parents of children with serious illnesses from peer-reviewed literature, 2) map the types of care experience being evaluated in PaREMs, 3) identify and describe steps followed in the measure development process, including where gaps lie and how PaREMs may be improved in future efforts, and 4) help service providers choose a PaREM suitable for their service delivery setting and strategy.

1. **Reporting & methodological inconsistencies** highlight a need to normalize the use of measure development guidelines

2. Most measures do not evaluate **accessibility** to care, **chronic** care, and are inapplicable across the **various healthcare settings** SIC receive care

7 Recommendations for developers of PaREMs

1.Take ***6 measure development steps when developing a PaREM.***

Follow evaluative guidelines for the assessment of psychometric properties.

Follow saturation parameters for qualitative steps.

Develop measures appropriate for assessing ***multiple service providers.***

Develop measures capable of evaluating experience beyond acute care delivery to include ***long-term, chronic care.***

Include items to evaluate ***accessibility*** to care.

Increase diversity in the sociocultural ***contexts*** in which PaREMs are developed.

Project was born

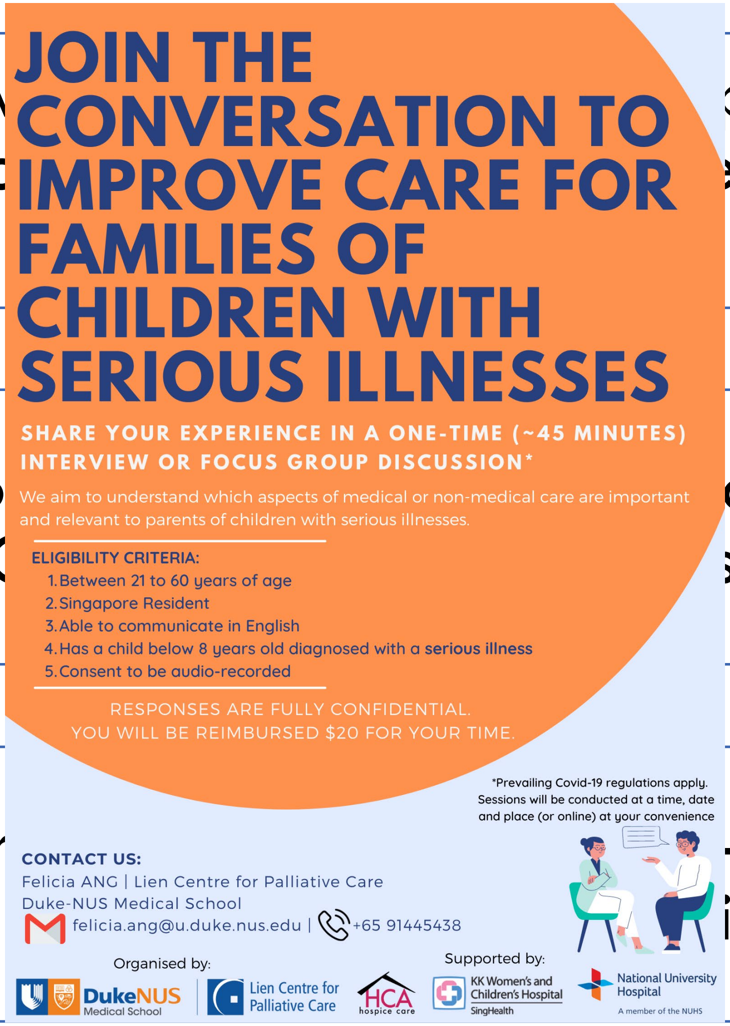
Quality-of-care measurement for seriously ill children: working with and for the voices of families

Why is this study important?
What gap does this study intend to fill?

Few parental
perspec esses are key

Not kno onceptualize
HC settings

Pr -SIC or
ings



JOIN THE CONVERSATION TO IMPROVE CARE FOR FAMILIES OF CHILDREN WITH SERIOUS ILLNESSES

SHARE YOUR EXPERIENCE IN A ONE-TIME (~45 MINUTES) INTERVIEW OR FOCUS GROUP DISCUSSION*

We aim to understand which aspects of medical or non-medical care are important and relevant to parents of children with serious illnesses.

ELIGIBILITY CRITERIA:

1. Between 21 to 60 years of age
2. Singapore Resident
3. Able to communicate in English
4. Has a child below 8 years old diagnosed with a **serious illness**
5. Consent to be audio-recorded

RESPONSES ARE FULLY CONFIDENTIAL.
YOU WILL BE REIMBURSED $20 FOR YOUR TIME.

*Prevailing Covid-19 regulations apply. Sessions will be conducted at a time, date and place (or online) at your convenience

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Organised by: DukeNUS Medical School | Lien Centre for Palliative Care

Supported by: HCA hospice care; KK Women's and Children's Hospital SingHealth; National University Hospital A member of the NUHS

Methods

Charmaz's Constructivist Grounded Theory

- Qualitative research methodology
- Seeks to understand and explore a social process where no adequate prior theory exists

Participants

- In-depth interviews with parents of young children diagnosed with a serious illness
- Purposively sampled from multiple care settings

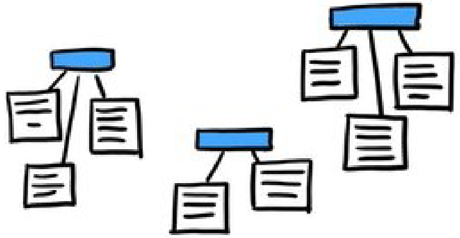
RQ1: What are the care processes parents of SIC commonly prioritize across service delivery settings and over the entire care journey?

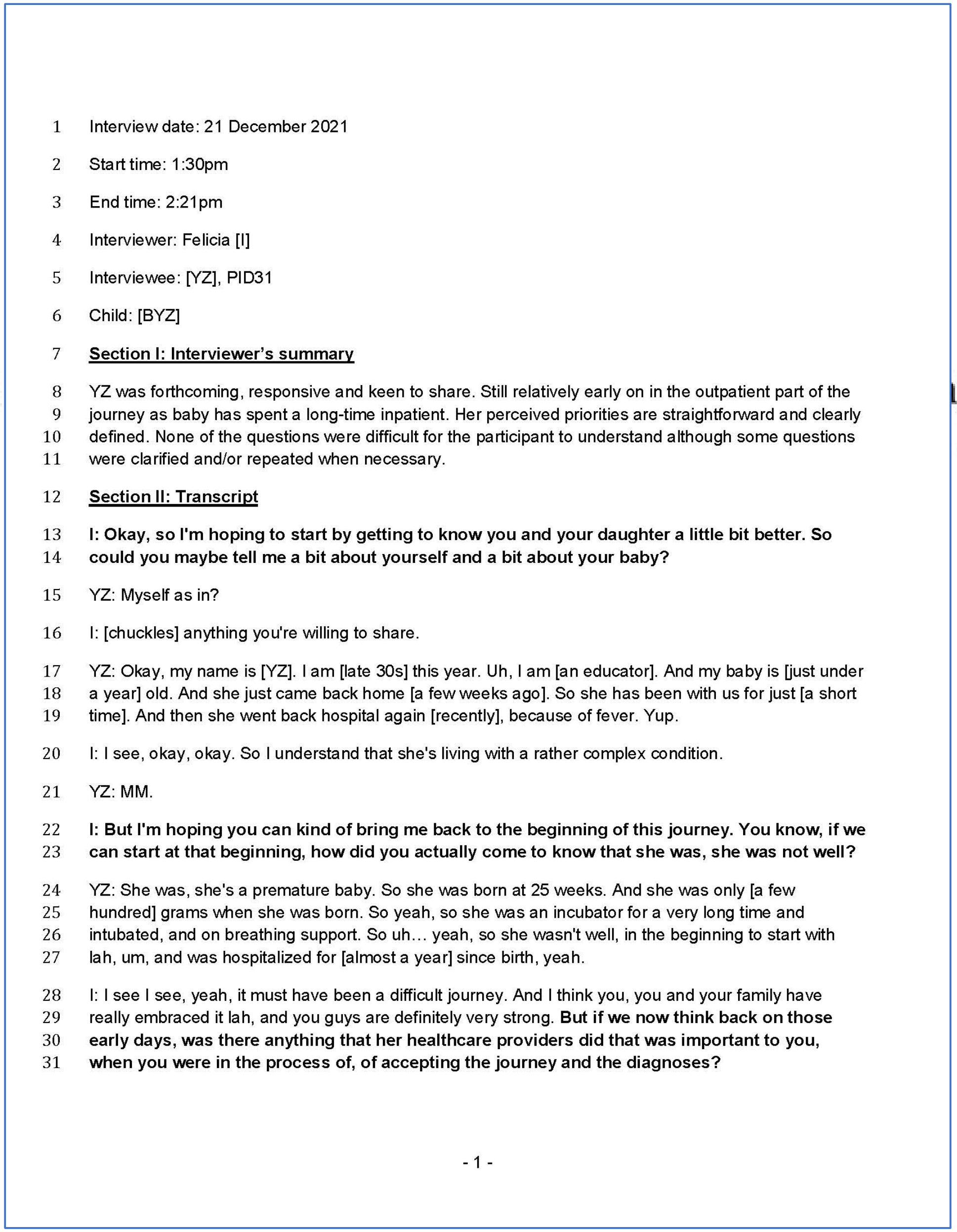
RQ2: How do these processes culminate meaningfully in a high-quality care experience?

Constant Comparative Analysis

Initial Coding

Compare snippets with snippets and create codes that connect them.





Interview date: 21 December 2021

Start time: 1:30pm

End time: 2:21pm

Interviewer: Felicia [I]

Interviewee: [YZ], PID31

Child: [BYZ]

Section I: Interviewer's summary

YZ was forthcoming, responsive and keen to share. Still relatively early on in the outpatient part of the journey as baby has spent a long-time inpatient. Her perceived priorities are straightforward and clearly defined. None of the questions were difficult for the participant to understand although some questions were clarified and/or repeated when necessary.

Section II: Transcript

I: Okay, so I'm hoping to start by getting to know you and your daughter a little bit better. So could you maybe tell me a bit about yourself and a bit about your baby?

YZ: Myself as in?

I: [chuckles] anything you're willing to share.

YZ: Okay, my name is [YZ]. I am [late 30s] this year. Uh, I am [an educator]. And my baby is [just under a year] old. And she just came back home [a few weeks ago]. So she has been with us for just [a short time]. And then she went back hospital again [recently], because of fever. Yup.

I: I see, okay, okay. So I understand that she's living with a rather complex condition.

YZ: MM.

I: But I'm hoping you can kind of bring me back to the beginning of this journey. You know, if we can start at that beginning, how did you actually come to know that she was, she was not well?

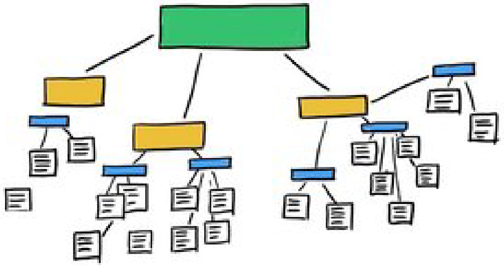
YZ: She was, she's a premature baby. So she was born at 25 weeks. And she was only [a few hundred] grams when she was born. So yeah, so she was an incubator for a very long time and intubated, and on breathing support. So uh… yeah, so she wasn't well, in the beginning to start with lah, um, and was hospitalized for [almost a year] since birth, yeah.

I: I see I see, yeah, it must have been a difficult journey. And I think you, you and your family have really embraced it lah, and you guys are definitely very strong. **But if we now think back on those early days, was there anything that her healthcare providers did that was important to you, when you were in the process of, of accepting the journey and the diagnoses?**

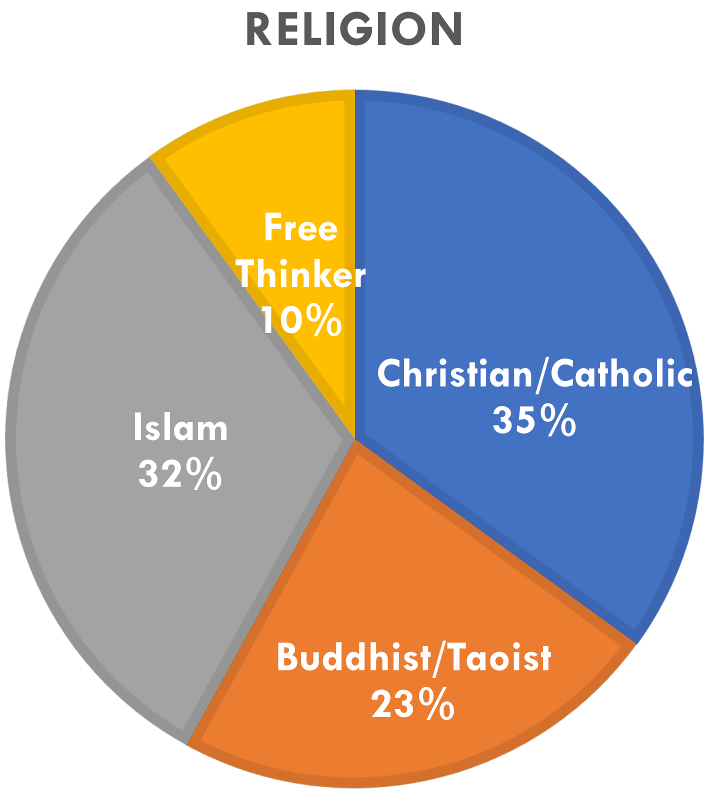
- 1 -

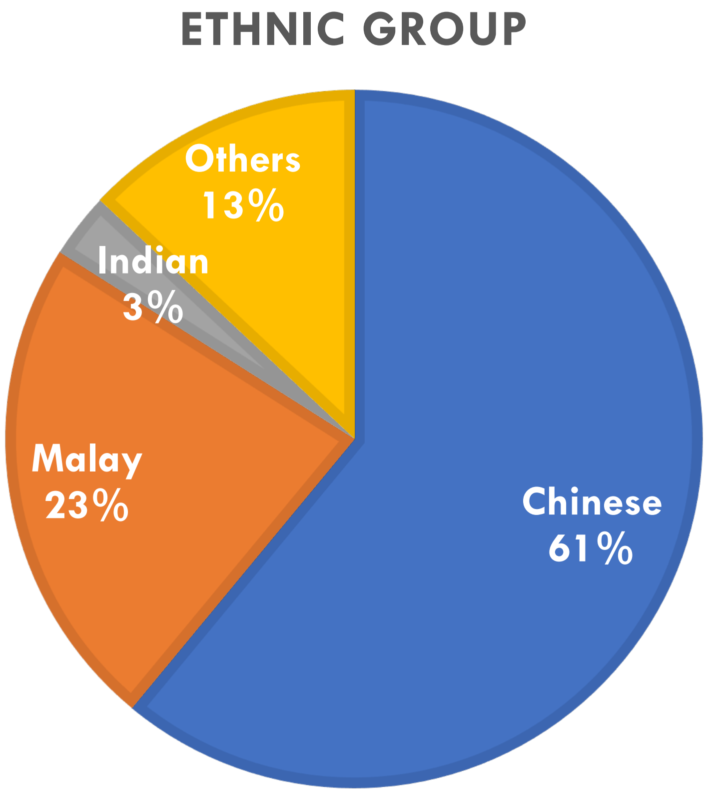
Theoretical Coding

pare categories with categories and the core category that connect them.



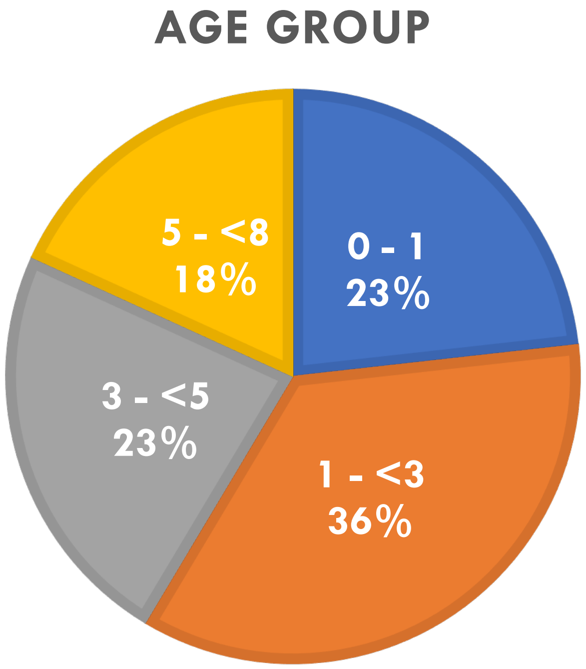
Characteristics of parents (N = 31) in stage 2

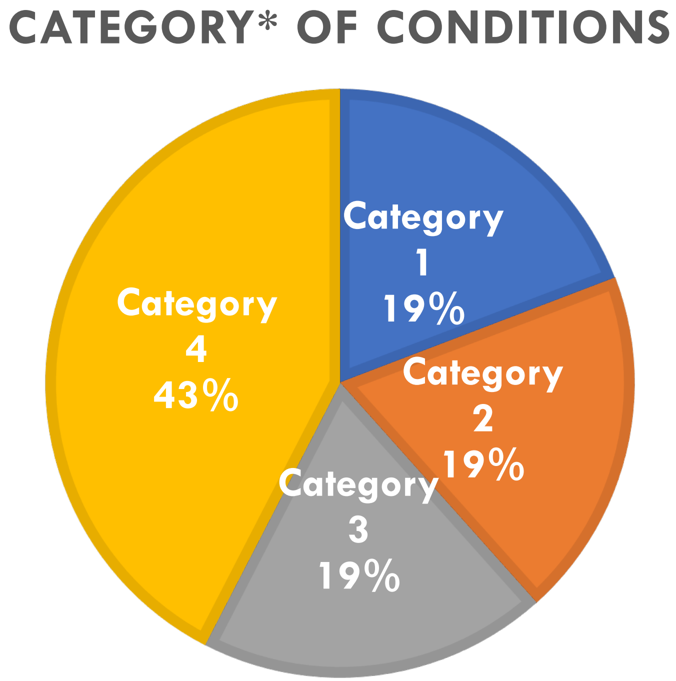




Female gender	**23 (74%)**
Mean **age**, years (SD)	**37 (6)**
Married	27 (87%)
Caregiving status	
Sole or Primary caregiver	**13 (52%)**
One of few caregivers	**12 (48%)**
Employment	
Stopped working to care for child	**5 (16%)**
Full-time job	**18 (58%)**
Homemaker	**2 (6%)**
Unemployed	**4 (13%)**
Others	**2 (6%)**

Characteristics of children (N = 31) in stage 2





Female gender	**18 (58%)**
Mean number of months since diagnosis (SD)	**28 (21)**

**Cat 1. Life-threatening conditions for which curative treatment may be feasible but can fail*

Cat 2. Conditions where premature death is inevitable

Cat 3. Progressive conditions without curative treatment option

Cat 4. Irreversible but non-progressive conditions causing severe disability

Output

RQ1: *64 Process indicators representing quality-of-care for seriously ill children

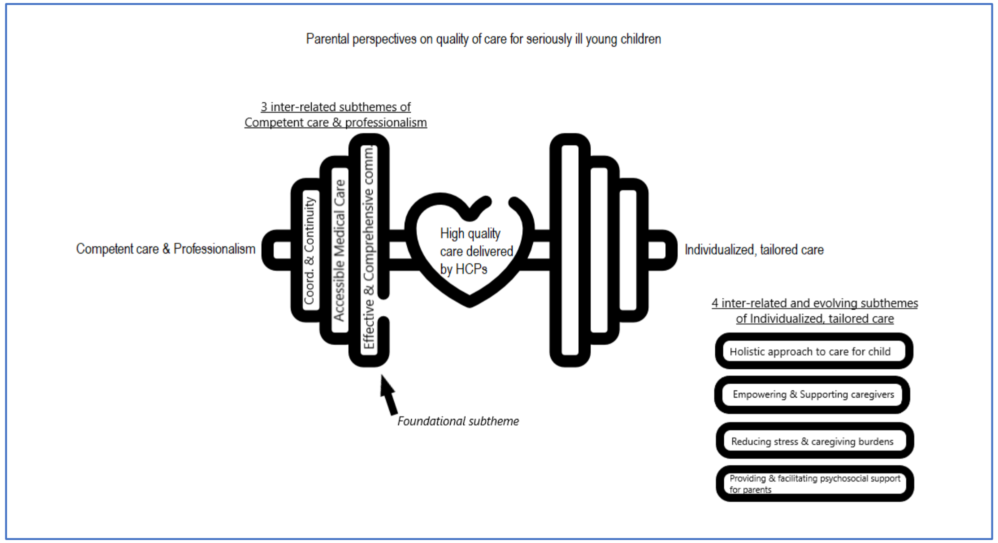
RQ2: Parent-driven framework of high-quality care delivery for seriously ill children

- ➢ inform development of PaREMs to assess quality-of-care

Applicable across healthcare settings and over illness trajectories

- ➢ opportunities for targeted multi-component interventions

Graphical evolution of theoretical framework



Parental perspectives on quality of care for seriously ill young children

3 inter-related subthemes of Competent care & professionalism

Competent care & Professionalism

Coord. & Continuity

Accessible Medical Care

Effective & Comprehensive comm

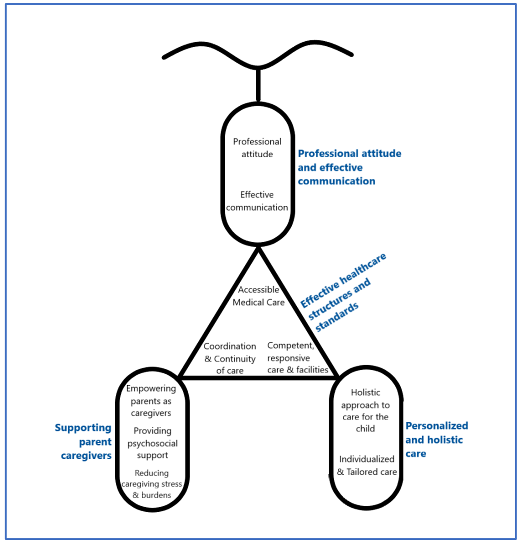
High quality care delivered by HCPs

Individualized, tailored care

Foundational subtheme

4 inter-related and evolving subthemes of Individualized, tailored care

- Holistic approach to care for child
- Empowering & Supporting caregivers
- Reducing stress & caregiving burdens
- Providing & facilitating psychosocial support for parents



Professional attitude and effective communication

Professional attitude

Effective communication

Effective healthcare structures and standards

Accessible Medical Care

Coordination & Continuity of care

Competent, responsive care & facilities

Supporting parent caregivers

Empowering parents as caregivers

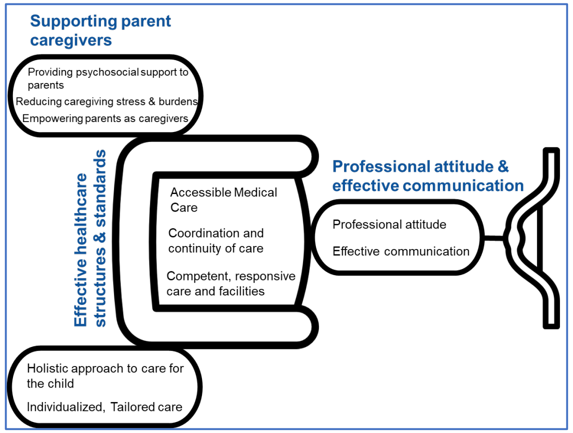
Providing psychosocial support

Reducing caregiving stress & burdens

Personalized and holistic care

Holistic approach to care for the child

Individualized & Tailored care



Supporting parent caregivers

Providing psychosocial support to parents

Reducing caregiving stress & burdens

Empowering parents as caregivers

Effective healthcare structures & standards

Accessible Medical Care

Coordination and continuity of care

Competent, responsive care and facilities

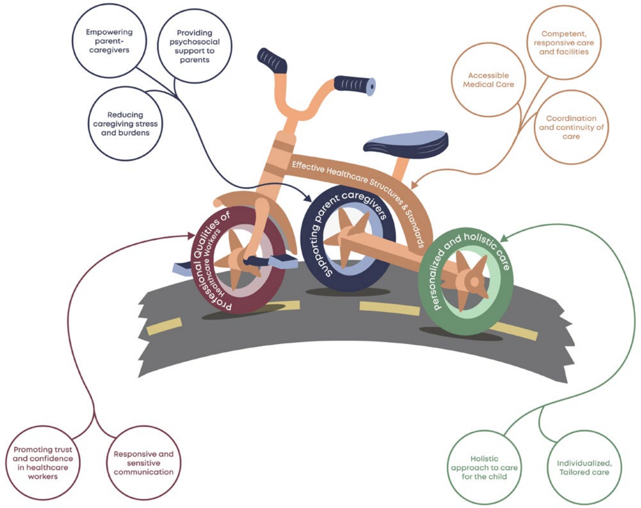
Professional attitude & effective communication

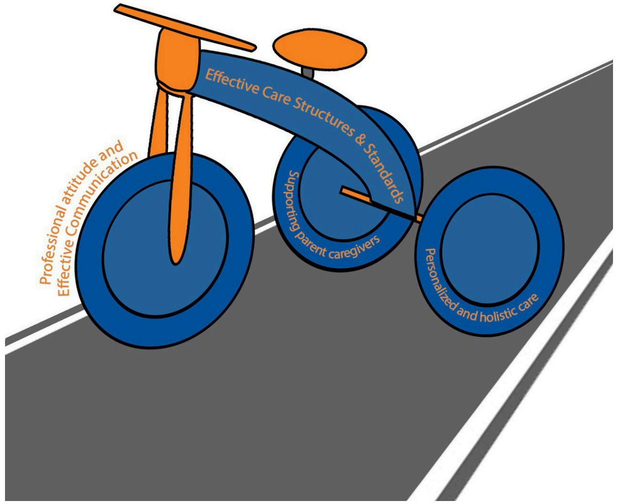
Professional attitude

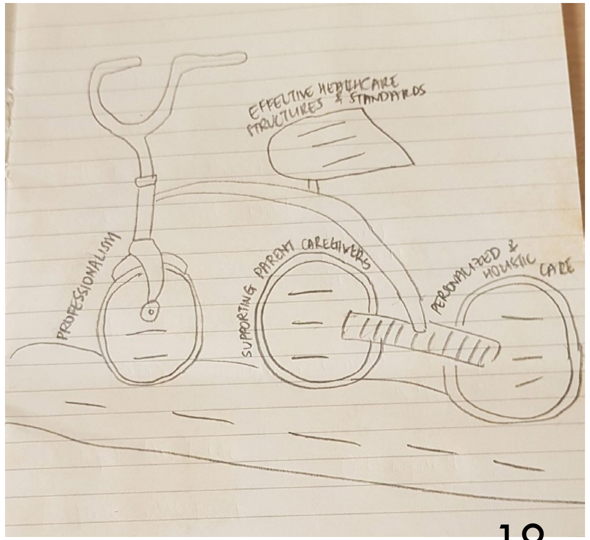
Effective communication

Holistic approach to care for the child

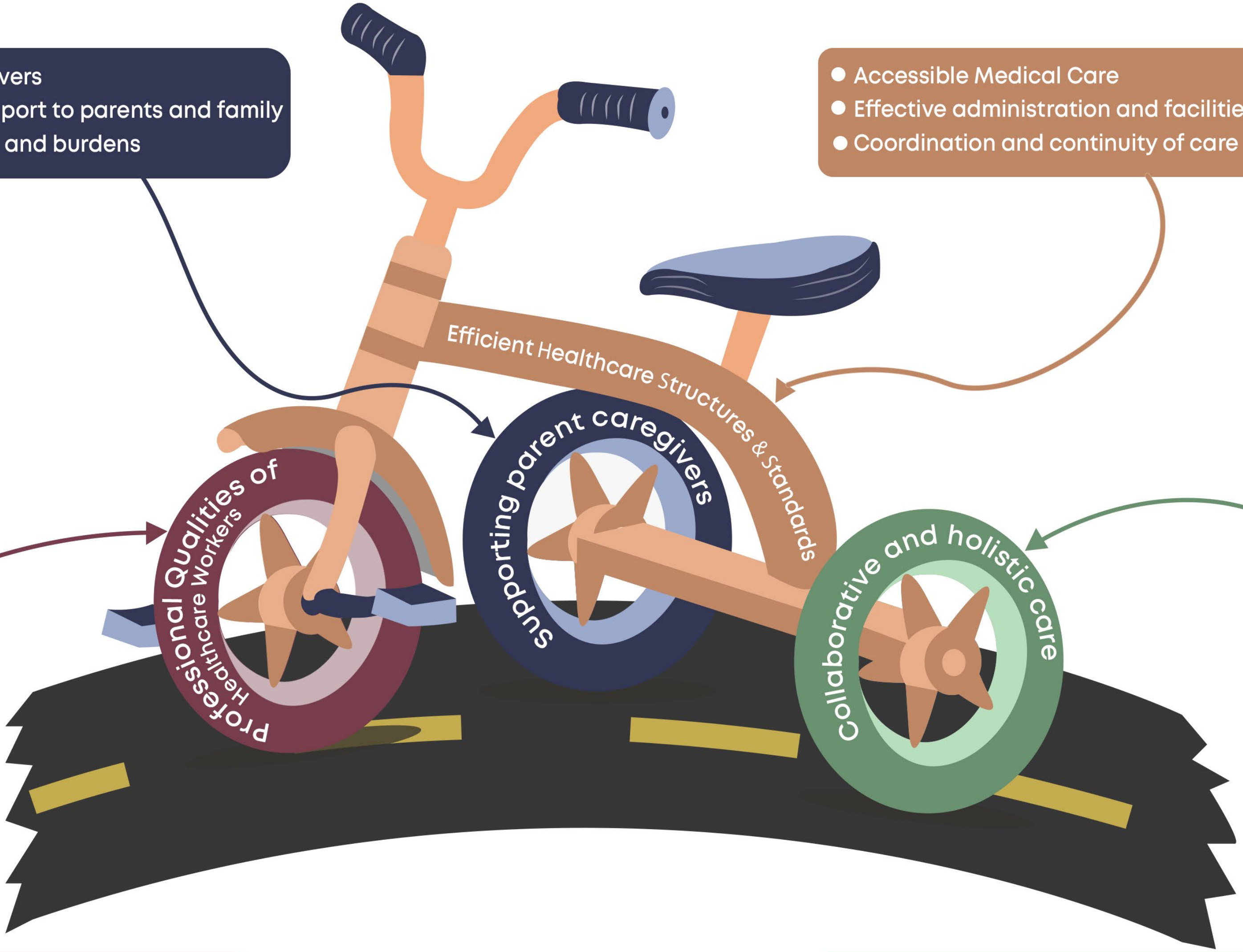
Individualized, Tailored care







PaRental perspectives on hIgh quality care for Children with sErious iLlnESSes (PRICELESS)



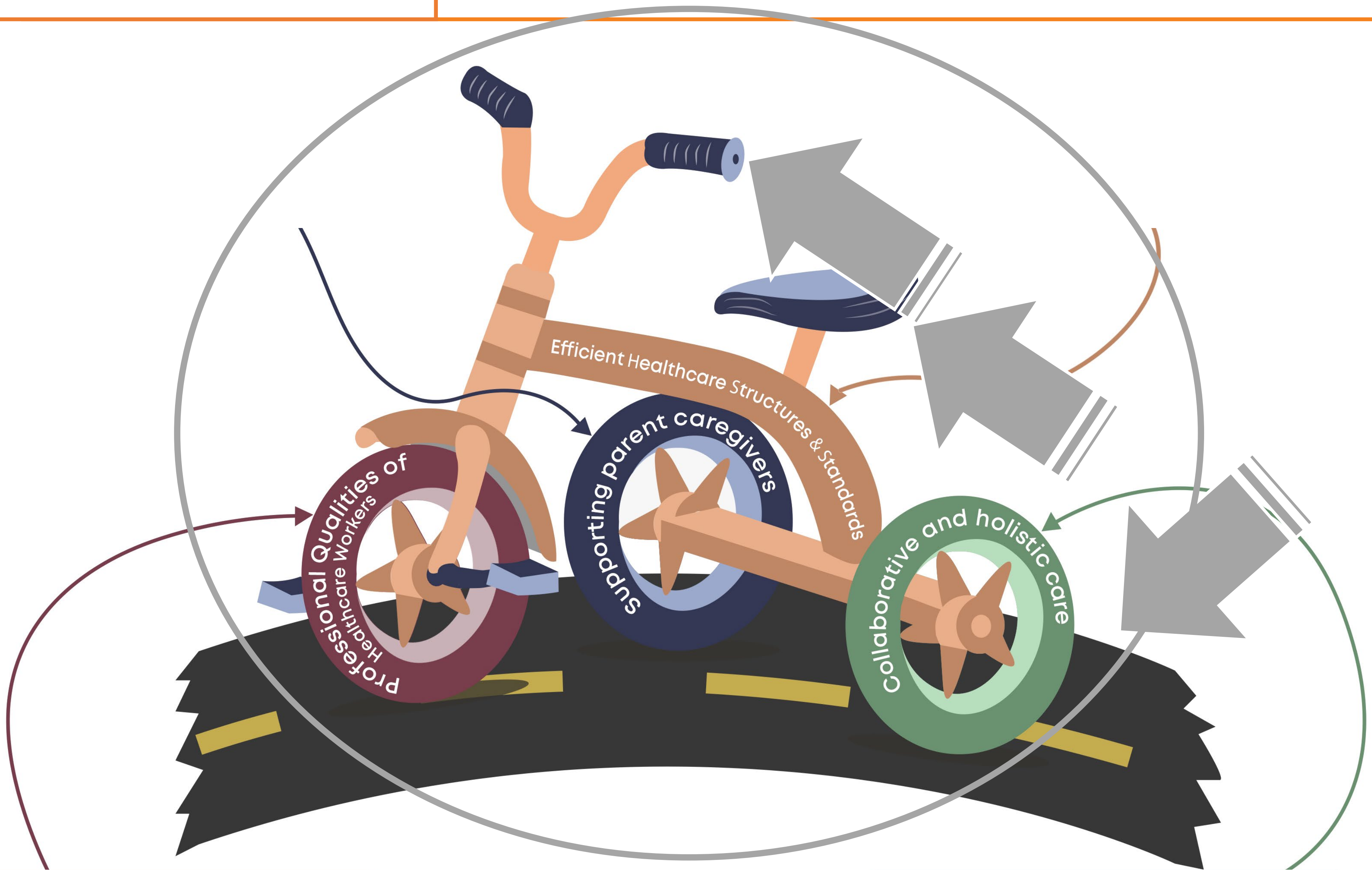
- Empowering parent-caregivers
- Providing psychosocial support to parents and family
- Reducing caregiving stress and burdens

- Accessible Medical Care
- Effective administration and facilities
- Coordination and continuity of care

- Responsive and sensitive communication
- Competency of healthcare delivery

- Holistic approach to care for the child
- Shared decision-making

7 Key components in PRICELESS

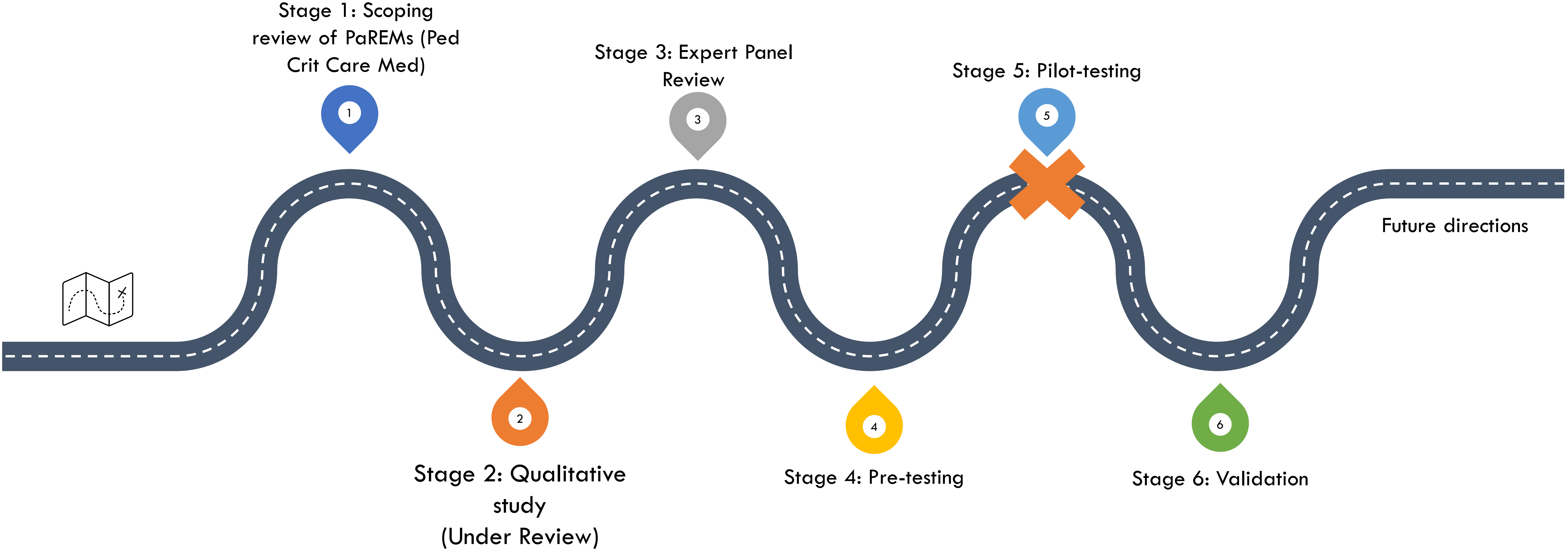


64 process indicators generated

Table 2. Summary of 64 care processes (specific, well-defined process indicators describing how particular practices, interactions, services, or procedures take place) and respective illustrative quotes constituting high-quality care from the perspective of parents of seriously ill children

Theme	Subtheme	Care process
Efficient healthcare structures & standards	Accessible Medical Care	Facilitating easy access to multi-disciplinary expertise in child's range of condition(s)
		Being approachable for parents to comfortably seek advice
		Availability of on-demand advice
		Convenient processes for parents to obtain medical equipment and supplies
		Helping parents acquire high-cost medical equipment (e.g., ventilator, suction machine, buggy)
		Provision of sufficient financial support based on individualized assessment of family's needs
	Effective administration and facilities	Allocating multiple caregivers to be present at the child’s bedside during inpatient stays
		Providing flexibility for parents to select an individualized HCW team across service delivery settings
		Attending to the child without undue delay at children’s emergency
		Providing parents with a place to be close to their child in healthcare facilities
		Taking appropriate action to reduce child’s exposure to other communicable diseases in healthcare facilities
	Coordination and continuity of care	Alignment of care and management goals across HCWs
		Communication to ensure coordination across HCWs
		Ensuring smooth transition of care across service delivery settings
		Coordinating appointments to reduce hospital visits
		A main HCW who or team which has consistent oversight over child's medical needs
		A HCW who or team which coordinates child's care between different disciplines, agencies and services
Professional Qualities of HCWs	Responsive and sensitive communication	Respecting the spiritual or religious customs and beliefs of parents
		Presenting honesty
		Making efforts to build parental trust in HCWs
		Taking responsibility and being accountable for child’s wellbeing
		Respecting the parental right to information
		Providing information on child's condition in a timely manner
		Communicating in a manner that is sensitive to parent’s needs’
		Using understandable language and methods to communicate
		Giving parents time and space to make decisions without pressurizing them
		Avoid causing parents additional stress by having an appropriate sense of urgency when communicating
	Competency of healthcare delivery	Reassuring parents of HCW's expertise in the field
		Avoiding unnecessary treatments and investigations on child
		Delivery of timely medical care
		Ability to identify and treat child's medical issues
		Providing symptom management to ensure child's physical comfort
Supporting parent caregivers	Empowering parent-caregivers	Providing anticipatory medical advice for parents to recognize when child’s condition deteriorates
		Acknowledging and affirming parents' efforts in caring for their child
		Equipping parents with skills to confidently deliver out-of-hospital care
		Providing parents with opportunities to bond with children during admissions (in the daily/ nursing care)
		Providing parents with opportunities to give back to the special needs community
		Opportunities for caregivers to advocate/speak up for their child
	Providing psychosocial support to parents and family	Showing parents genuine care and sincerity
		Supporting parents' hopes for their child
		Preparing parents for what may lie ahead
		Providing parents with a compassionate listening ear
		Providing parents with emotional/physical space to grieve
		Accessibility to parent support networks
		Attending to the psychosocial needs of the family unit resulting from child's condition
	Reducing caregiving stress and burdens	Providing options for respite care
		Provision of practical suggestions on how to reduce financial burden
		Guidance to available resources to reduce financial burden
		Help parents to avoid child’s unplanned and non-critical hospitalization
		Home visits to provide medical treatment or care
		Offer information on Specialized transport for children with mobility challenges
Collaborative and holistic care	Holistic approach to care for the child	Efforts to foster a personal relationship with the child
		Creating a child-friendly atmosphere in hospital
		Providing emotional support and encouragement to the child
		Provision of facilities or services for child's play and engagement
		Facilitating access to inclusive schools for children with special needs
		Incorporating palliative and supportive care elements into clinical management
		Recommending comfort care in clinical situations where child's prognosis is assessed to be poor
		Providing allied health support to meet parent's goals for the child
	Shared decision-making	Offering complete information on all management options for parents to make informed decisions
		Being receptive to parental input and experience for better care
		Advocating and directing care while considering family's goals and preferences
		Recognizing and conveying the benefits and burdens of technology and procedures on the child
		Supporting parents’ preferences for involvement in decision-making

Project roadmap: Quality-of-care measurement for seriously ill children: working with and for the voices of families


Stage 1: Scoping review of PaREMs (Ped Crit Care Med)

Stage 2: Qualitative study (Under Review)

Stage 3: Expert Panel Review

Stage 4: Pre-testing

Stage 5: Pilot-testing

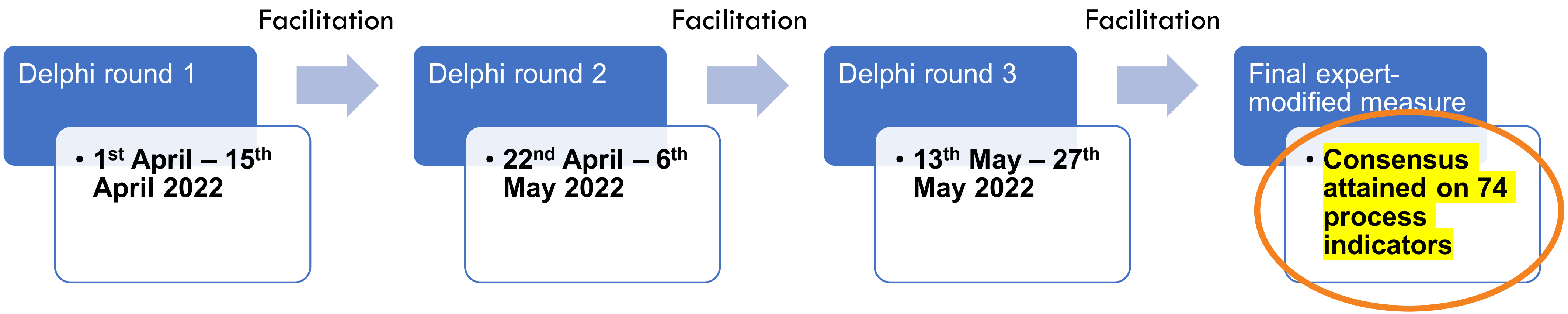
Stage 6: Validation

Future directions

Stage 3: Delphi expert panel review (n = 24)

Consensus is systematically determined by a panel of experts (digitally administered) to:

1. Assess how well indicators captures parents’ experience with various care processes (content validity)
2. Improve the relevance and coverage of indicators (content validity).



Delphi round 1
- **1st April – 15th April 2022**

Facilitation

Delphi round 2
- **22nd April – 6th May 2022**

Facilitation

Delphi round 3
- **13th May – 27th May 2022**

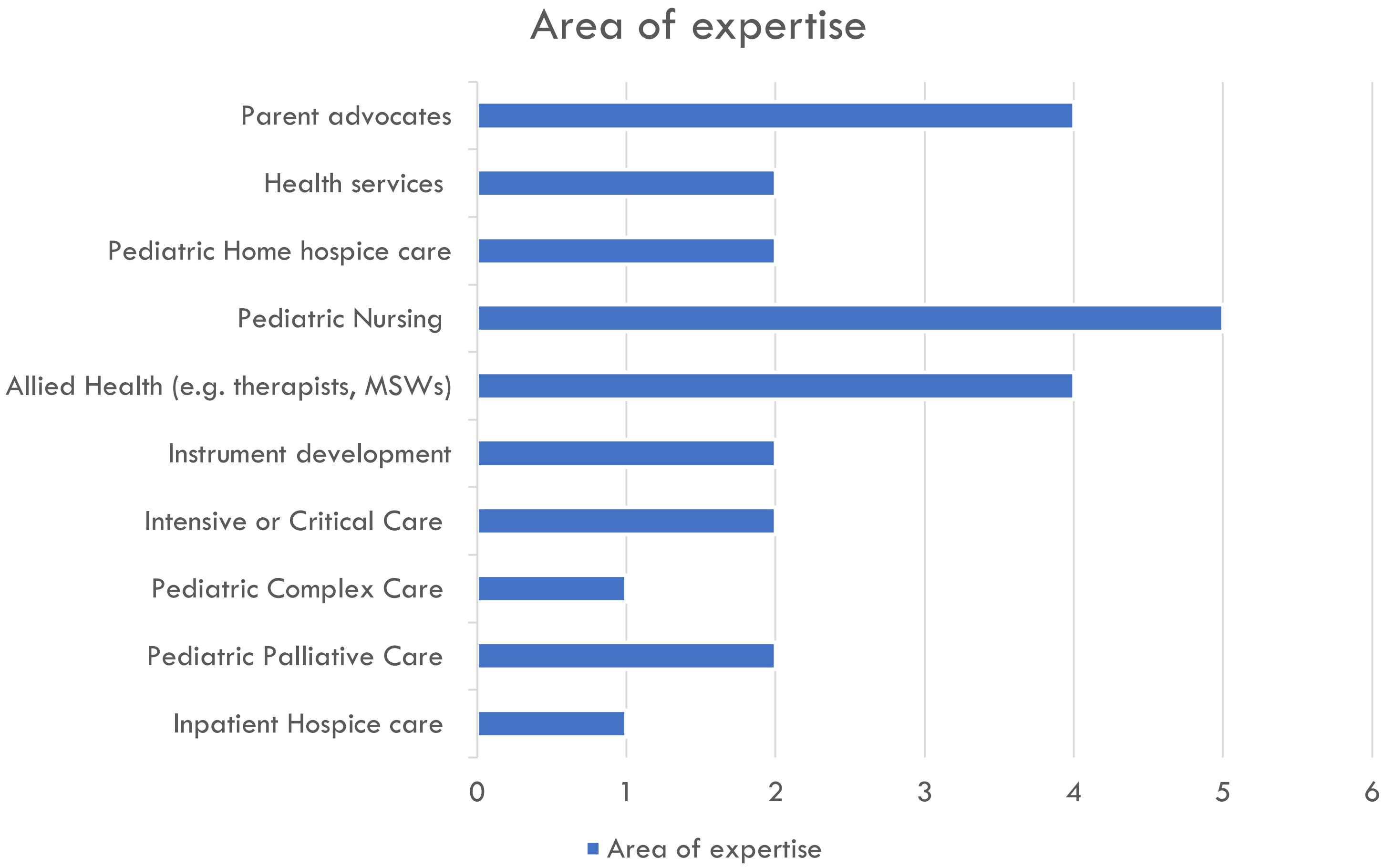
Facilitation

Final expert-modified measure
- **Consensus attained on 74 process indicators**

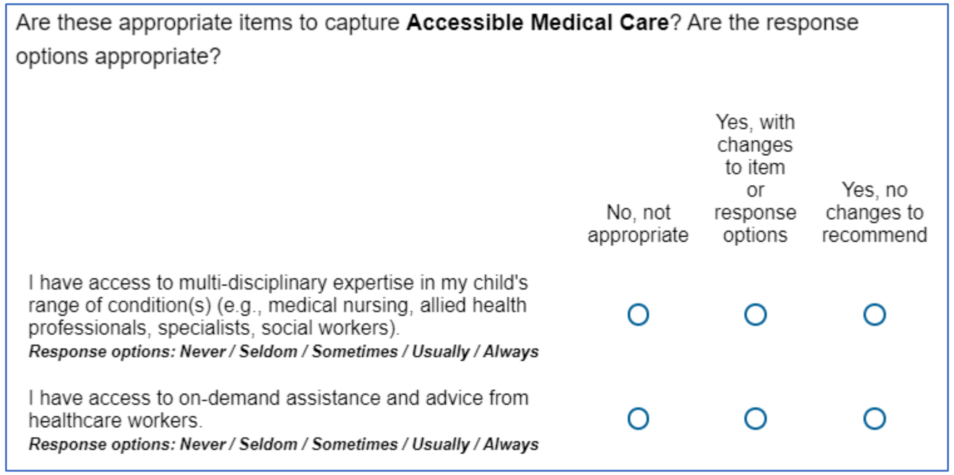
*Consensus was pre-defined as >70% for inclusion

Each item’s aggregate expert ranking, all de-identified comments and facilitators' modifications were shown in each subsequent Delphi round.

Expert panel breakdown (n = 24) in stage 3



Example of rating:



Are these appropriate items to capture **Accessible Medical Care**? Are the response options appropriate?

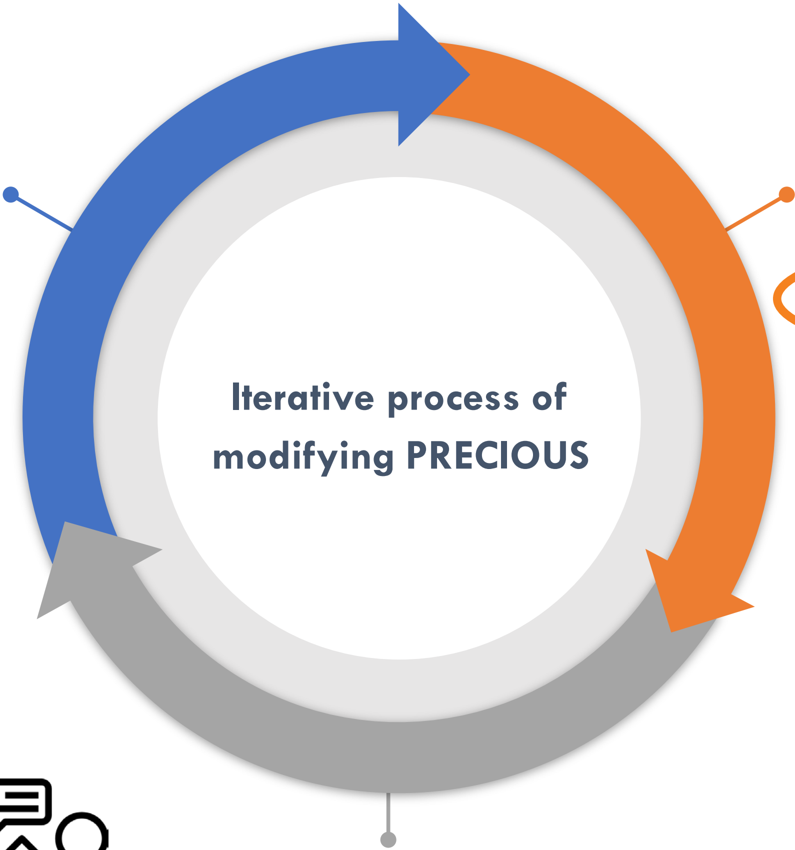
	No, not appropriate	Yes, with changes to item or response options	Yes, no changes to recommend
I have access to multi-disciplinary expertise in my child's range of condition(s) (e.g., medical nursing, allied health professionals, specialists, social workers). ***Response options: Never / Seldom / Sometimes / Usually / Always***	○	○	○
I have access to on-demand assistance and advice from healthcare workers. ***Response options: Never / Seldom / Sometimes / Usually / Always***	○	○	○

Experts rated each candidate indicator.

A free-text response was available for every indicator.

Stage 4: Pre-testing PRECIOUS with parents (n = 12)

PaRental Experience with care for Children with serIOUS illnesses (PRECIOUS)



STEERING COMMITTEE DISCUSSION
MODIFICATION OF PRECIOUS

Add, remove and refine items based on participant feedback and comprehension

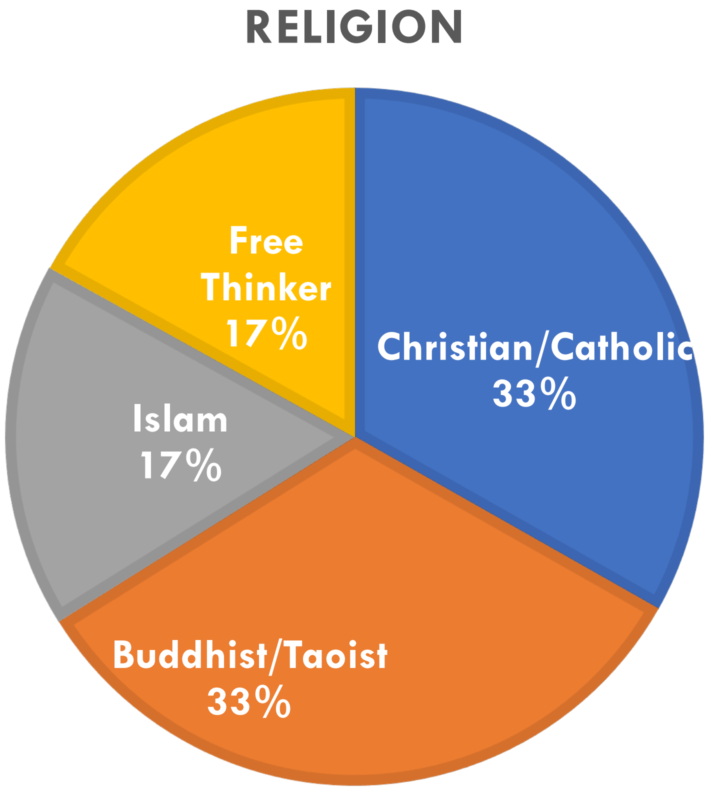
STEERING COMMITTEE OUTCOME

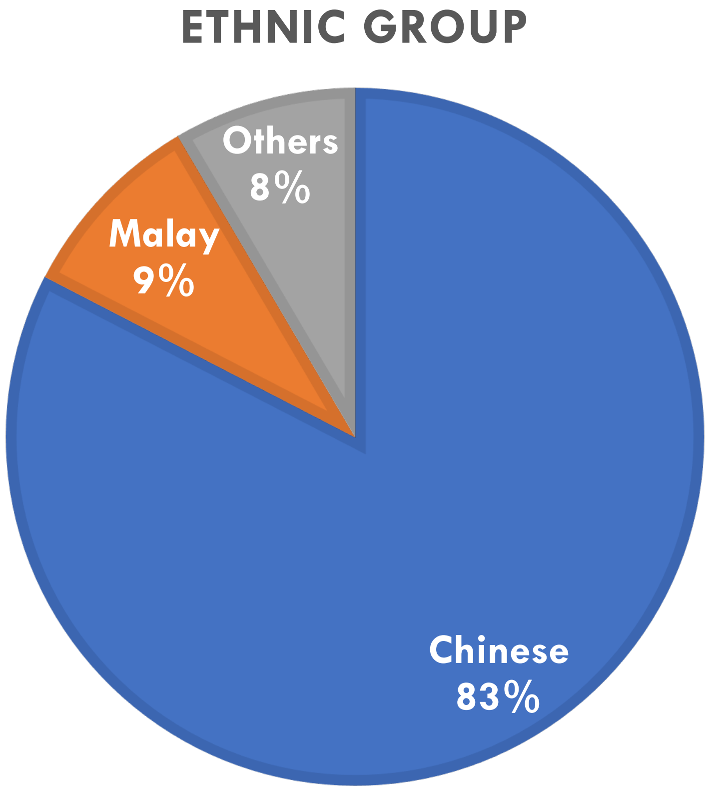
Modified PRECIOUS
57 modified process indicators retained

COGNITIVE INTERVIEW

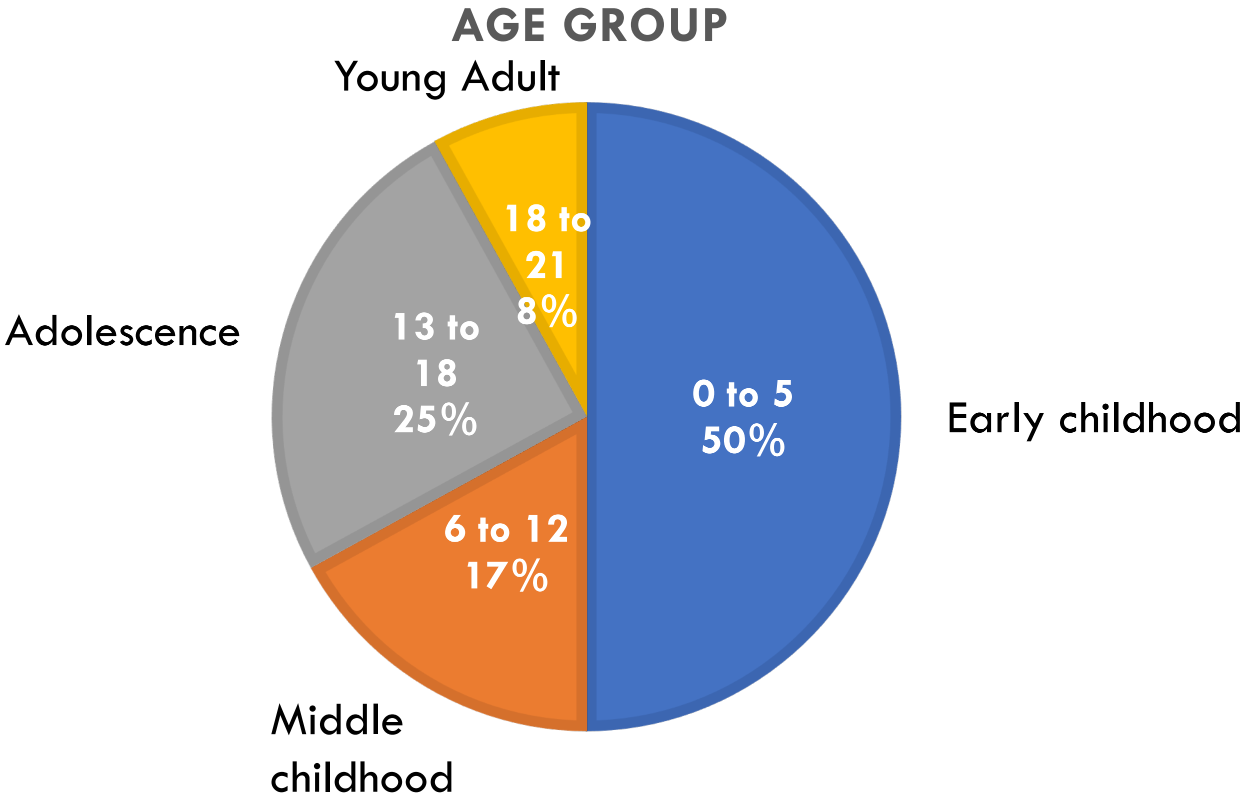
Tourangeau's four-stage model
Think-aloud approach with Verbal Probes

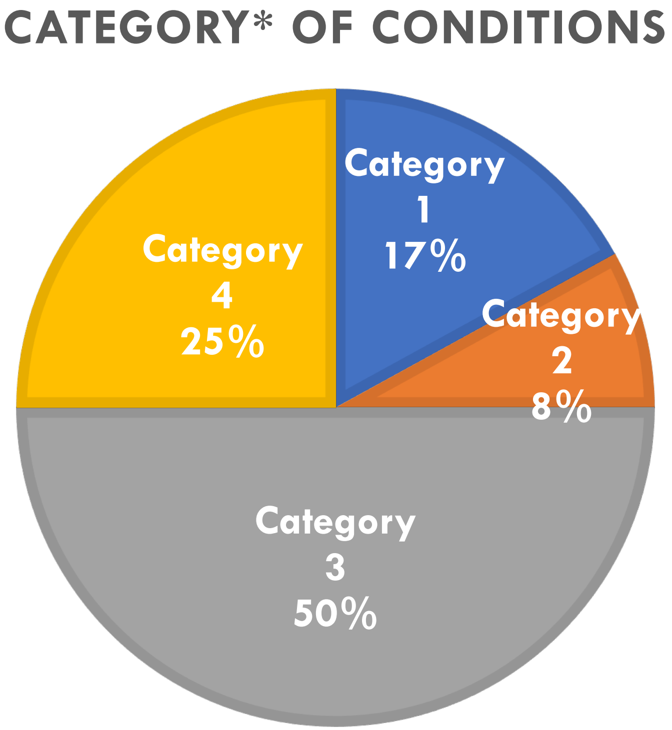
Characteristics of parents (N = 12) in stage 4





Characteristics of children (N = 12) in stage 4





*Cat 1. Life-threatening conditions for which curative treatment may be feasible but can fail

Cat 2. Conditions where premature death is inevitable

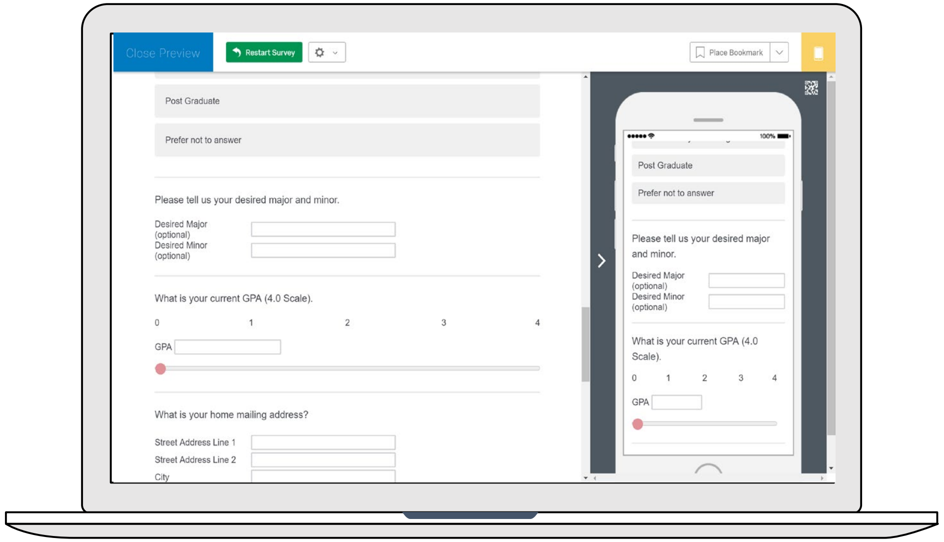
Cat 3. Progressive conditions without curative treatment options

Cat 4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health

Stage 5: Pilot-testing PRECIOUS with parents (n = 30)

Digitally-administered

- Sociodemographic details
- Caregiving details
- Child's Clinical information
- ***PRECIOUS (57 items)***
- ***Measure of Processes of Care (20 items)***
- ***Quality of Children's Palliative Care Instrument (17 items)***



Post Graduate

Prefer not to answer

Please tell us your desired major and minor.

Desired Major (optional)
Desired Minor (optional)

What is your current GPA (4.0 Scale).

0 1 2 3 4

GPA

What is your home mailing address?

Street Address Line 1
Street Address Line 2
City

Post Graduate

Prefer not to answer

Please tell us your desired major and minor.

Desired Major (optional)
Desired Minor (optional)

What is your current GPA (4.0 Scale).

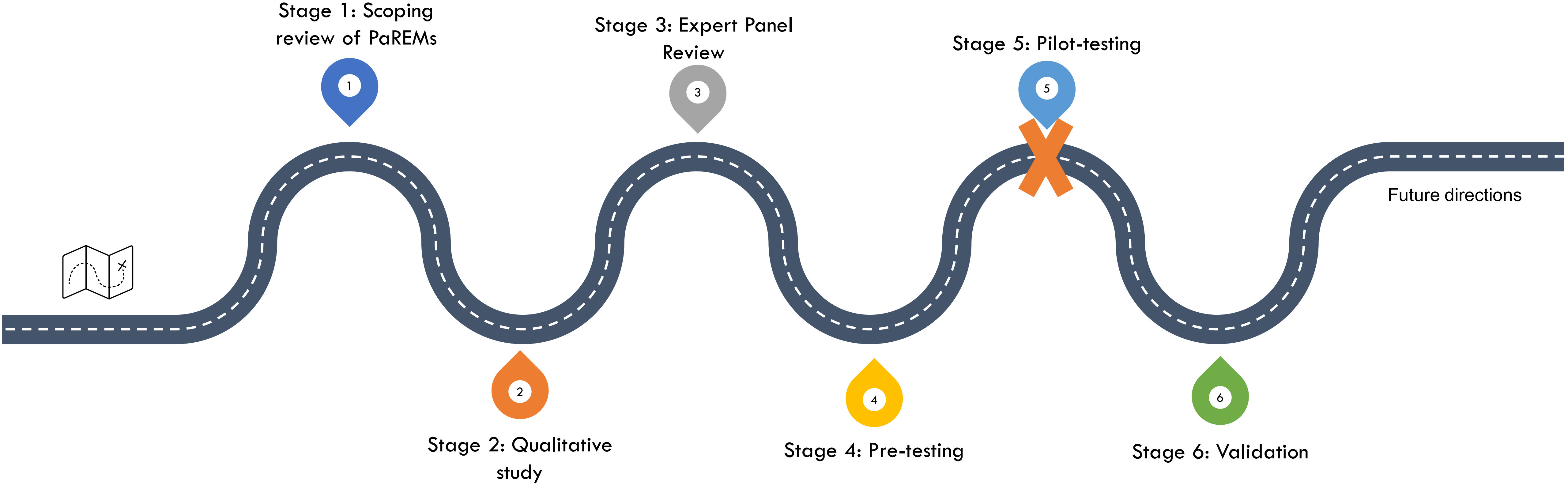
0 1 2 3 4

GPA

AIMS

- Identify key obstacles during administration or in the protocol
- Identify items/issues affecting data analysis & completeness

Project roadmap: Quality-of-care measurement for seriously ill children: working with and for the voices of families



Stage 1: Scoping review of PaREMs

Stage 2: Qualitative study

Stage 3: Expert Panel Review

Stage 4: Pre-testing

Stage 5: Pilot-testing

Stage 6: Validation

Future directions

Cross-country, Multi-centre collaboration across Malaysia and Singapore

Be part of our team!

KK Women's and Children's Hospital
SingHealth

Children's Cancer Foundation

National University Hospital
A member of the NUHS

RARE DISORDERS SOCIETY SINGAPORE

HCA hospice care

UNIVERSITI MALAYA
KUALA LUMPUR

Longitudinal survey at 2 timepoints

- Exploratory factor analysis
- Convergent validity
- Test-retest, internal consistency reliability

- 200 families of seriously ill children (≤18 years old)
- English-speaking parents
- SG+MSIA (min. 25% representation)
- Representation across all 4 illness categories

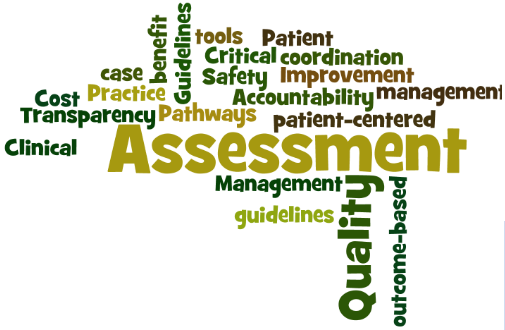
Funding Agency

SingHealth DukeNUS ACADEMIC MEDICAL CENTRE
GLOBAL HEALTH INSTITUTE

Significance of PRECIOUS

Immediate output

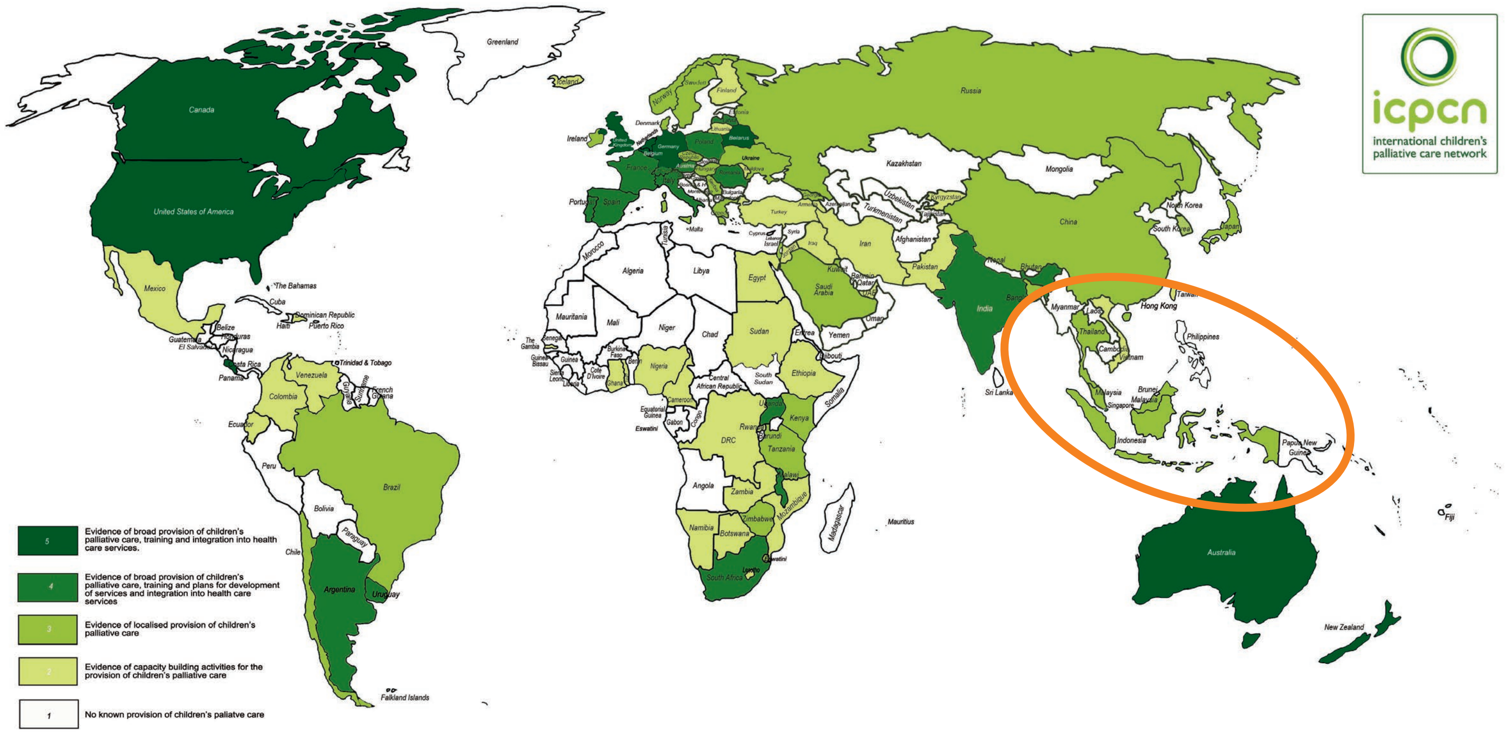
- First broad-based, widely applicable Parent-reported experience measure for SIC
- Relevant across healthcare workers, over time, and various health & social care settings



Short-term output

- Enable HCWs and researchers to…
  - identify areas for quality improvement initiatives
- track and improve own & team's practice
- monitor impact of changes or interventions

Future Directions: Expanding Regional Impact



icpcn
international children's palliative care network

- Validate the modified measure in other economic & cultural settings in SEA
- Integration into comprehensive quality indicators
- Enable standardized benchmarking, continuous evaluation and redesign of services across the region

DukeNUS Medical School

Lien Centre for Palliative Care

Mentors, Collaborators & Co-Investigators

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RARE DISORDERS SOCIETY SINGAPORE

Children's Cancer Foundation

thank you

To all families who have been part of this journey

Administrators & Representatives

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