



# P62: Developing a Theory of Change for implementing the novel UK Children's Palliative care Outcome Scale into routine paediatric palliative care

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## Background

To ensure a newly developed person-centred outcome measure (C-POS) can be successfully implemented in the UK, it is important to draw together existing evidence and work collaboratively with key stakeholders to develop an experience-informed, evidence-based Theory of Change.

**Table 1: Sample Characteristics**

Parent/Carers (n=8)	N or mean (range)
Age	48 (43-62)
Gender (Female : Male)	6 : 2
Relationship to Child	
Mother	6
Father	2
Child's diagnosis	
Cancer	1
Metabolic	3
Neurological	4
UK region	
Greater London	3
South West	2
West Midlands	2
Yorkshire & Humber	1
Professionals (n=8)	N or mean (range)
Age	40 (35-46)
Gender (Female : Male)	8 : 0
Profession	
Nurse	6
Social worker	1
Physiotherapist	1
Years of experience	14 (1-18)
UK region	
North East	2
Yorkshire & Humber	2
East Midlands	1
Greater London	1
South West	1
Scotland	1

## Methods

The STRiDE guidance (1) for Theory of Change Workshops was used to inform the workshops. Parents of children with life-limiting or life-threatening conditions and health and social care professionals working in the NHS were recruited through social media and networks. Theory of Change Maps were developed and refined based on stakeholder contributions using a template adapted from Stories for Impact (2).

## Results

- Both parents and professionals felt the long-term goal of implementing a measure would be improving care and comfort for children and their families
- Professionals emphasised the importance of having adequate, staffing, time and monetary resources, as well as the importance of education and training on using the measure, and reminders or prompts to help them remember to use it.
- Parents felt a pre-requisite to the successful implementation of a measure was for all professionals to have an understanding of what palliative care is.
- Parents wanted a trusted professional to support completion of the measure and nurses were identified as most appropriate due to the relationship they had with families.
- Parents also highlighted a need to improve communication and information sharing to avoid children and families having to answer distressing questions or share their stories multiple times. Professionals also felt the measure may help facilitate this.

## Conclusion

These workshops have supported the development of a UK context-specific, evidence-based and experience-informed Theory of Change and will inform the development of an implementation plan for C-POS:UK. Future work will involve the review of the Theory of Change as part of a pilot study to test the Implementation Plan in practice.

### References:

(1) Breuer E, Comas-Herrera A, Docrat S, Freeman E, Schneider M, the STRiDE team. STRiDE Theory of Change Workshops: Guidance and Resources. London: Care Policy and Evaluation Centre; 2019.

(2) Stories for Impact. Theory of Change. Online; 2023 [Accessed 01 April 2023; Available from: <https://storiesforimpact.com/toolbox/theory-of-change/>].

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