

# Children's Palliative Care Outcome Scale (C-POS)

Newsletter Issue 5, 7<sup>th</sup> December 2020

Partners:



Welcome to our Winter edition of the C-POS newsletter.

We are delighted to share that we finished the first phase of our study after speaking to 106 people. These interviews have highlighted the priorities of children and their families, as well as health care providers and commissioners.

We are now looking for parents and carers to complete the next round of our Delphi survey to help us identify the most important questions for the C-POS measure – closing date 21<sup>st</sup> December 2020. Please share this link with the families you work with: <https://smartsurvey.co.uk/s/CPOSDelphi/> Health and Social Care Professionals are also encouraged to take part using the link above or via the link on our Twitter: [@CYP\\_CSI](https://twitter.com/CYP_CSI).

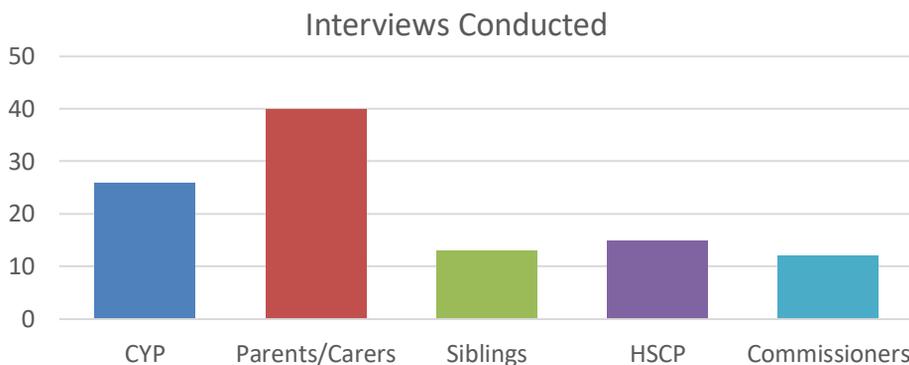
Together for Short Lives has been advocating for the development of some measures to demonstrate the impact of children's palliative care service for many years, so we're delighted that this C-POS study has been funded and has made such an excellent start. It's great to be involved as part of the advisory group and to witness the amazing range of skills and insight that this group and the core research team bring to the project. We can't wait to see the results of the next phase of the work!



Lizzie Chambers  
Together for Short Lives

## Interview Update:

In the first phase of our study, we spoke to 26 children and young people (CYP), 40 parents and carers, 13 siblings, 15 health and social care professionals (HSCP), and 12 commissioners. The interviews highlight the priorities held by children and young people, with life threatening and life limiting conditions, and their families as well as the wider health and social care teams and commissioners that work to support them.



These priorities fall into five core categories: physical symptoms, emotional and psychological concerns, social and practical factors, spiritual/existential issues, and normalcy.

The results of this phase of the study have informed the first round of our Delphi study to help generate the items to be included in the final C-POS measure.

## Welcome and Thank You:

We would like to welcome Daney Harðardóttir (left) and Hannah Scott (right) to the C-POS study team, who have joined us as research assistants.



We would also like to thank Anna Roach, who has now left the project team, for all she has contributed to the project.



## European Association of Palliative Care Conference:

In October, we presented our progress so far at the European Association for Palliative Care Conference and were awarded "1 of the 3 Best Poster Abstracts in this Category" for our Systematic Review poster.



## Steering Group:

We held our third steering group meeting virtually in November 2020. This meeting gave us the opportunity to discuss the findings from our interviews, systematic review, and round 1 of our Delphi study and make important decisions related to the design of the C-POS measure.

## Cognitive Interviews:

We are now entering Phase 2 of the C-POS study which involves testing the measure to ensure it measures the priorities highlighted by our key stakeholders as it should. To do this we will be conducting cognitive interviews with children, young people, and their parents and carers. We are expecting these to commence in the new year across 6 sites.

The Great Ormond Street Young People's Advisory Group have provided very helpful feedback on the pre-interview documentation and we have made changes in response to their suggestions.

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