



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



Newsletter Issue 10, 10<sup>th</sup> June 2022

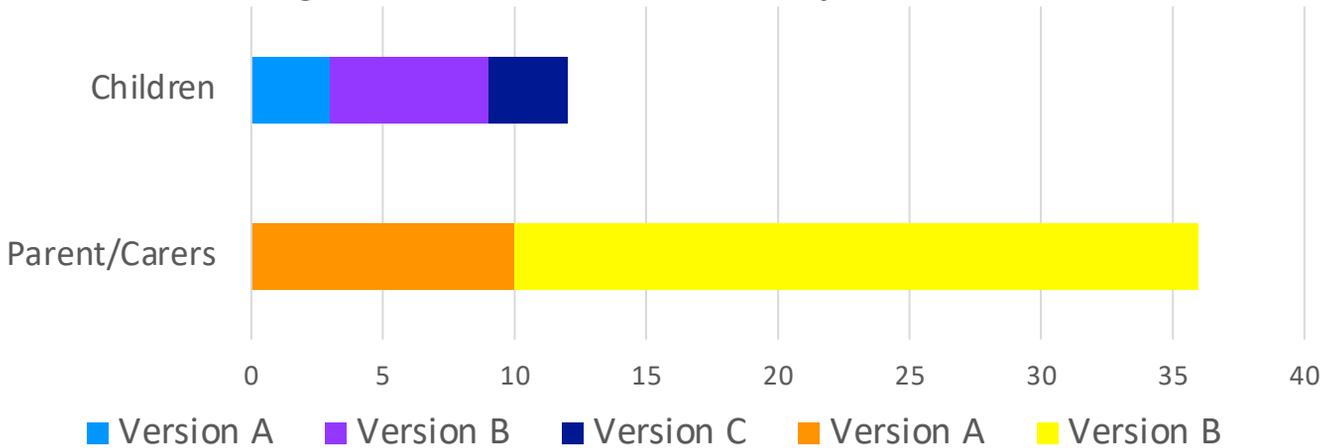
## Partners:



## Welcome to the Summer edition of the C-POS newsletter

Since our last newsletter the cognitive interview study has closed. We are really grateful for all of the support from our study sites in recruiting 48 participants to help us test the different versions of the C-POS. Cognitive interviewing helped to make changes and refine the prototype C-POS versions, especially to be inclusive of CYP who are non-verbal.

### Cognitive Interview Recruitment by C-POS Version



We are excited to begin our validation study to further test the questionnaires with children and their families across all four UK nations in the coming months.

**If you would like to join the C-POS validation study as a site, please contact the team using the details on the last page.**

## 12<sup>th</sup> World Research Congress of the European Association for Palliative Care:

In May the team attended the 12<sup>th</sup> World Research Congress of the European Association for Palliative Care Online.

Hannah Scott presented her abstract on *“The Impact of COVID-19 on Palliative Care for Children within the UK”* in the COVID-19 Oral Abstract Session.

The related short report was also recently published in the *Journal of Pain and Symptom Management* is freely available as part of Elsevier’s COVID-19 collection: <https://doi.org/10.1016/j.jpainsymman.2022.02.330>.

Hannah also had a poster presenting her research on *“Challenges and incentives for integrating person-centred outcome measures into routine paediatric palliative care: health, social care and commissioner perspectives”* which was awarded 1 of the 5 best poster abstracts in its category.



Lucy Coombes presented her abstract on *“Comprehensibility, Comprehensiveness and Acceptability of a Novel Paediatric Palliative Care Outcome Measure: A Cognitive Interview Study with Children and Families”* in the Quality, Measurement and Relationships Oral Abstract Session as part of the Paediatric Palliative Care day of the conference.

Lucy also had a poster reporting on PPI work the team had been doing with the Great Ormond Street Hospital Young People’s Advisory Group: *“Enabling children to take patient and public involvement roles in paediatric palliative care research”*. Further details of the work the team have been doing with the Great Ormond Street Hospital Young People’s Advisory Group have been published in the Cicely Saunders's Institutes most recent Patient and Public Involvement Newsletter which can be found here (page 4): <https://www.kcl.ac.uk/cicelysaunders/patient-family-and-public-involvement/ppi-newsletter-june-update-final-2022.pdf>

Lucy also presented in the EU Funded Projects Webinar to give an overview on the progress of the C-POS project to date; including the findings of the Cognitive Interview study and the next steps for the validation study.

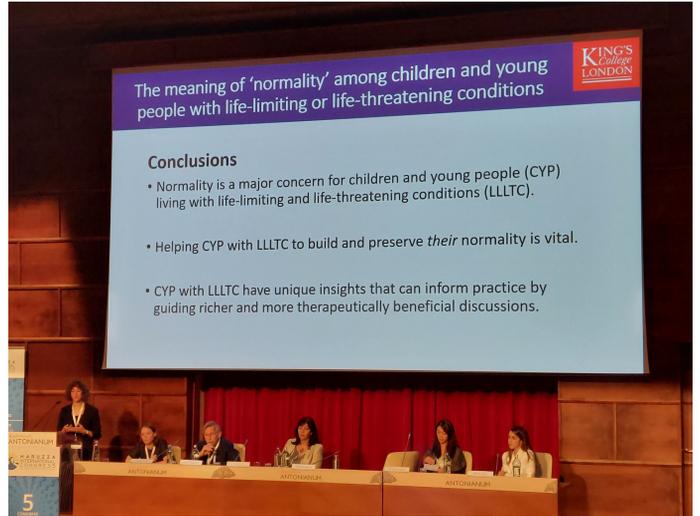


## 5<sup>th</sup> Maruzza International Congress on Paediatric Palliative Care:



In May the team attended the 5<sup>th</sup> Maruzza International Congress on Paediatric Palliative Care in Rome.

Dr Debbie Braybrook presented her abstract on *“The meaning of ‘normality’ among children and young people with life-limiting or life-threatening conditions”* in the working session on Quality of Life.



Anna Roach presented her abstract titled *“We don't know what's happening because we're not there'- What matters to siblings of children with serious illness?”* in the working session on Siblings.

## Collaborative Paediatric Palliative Care Research Network (CoPPAR) and Association for Paediatric Palliative Medicine (APPM):

The Team have also presented at a number of CoPPAR events and webinars over the last few months and also presented at the APPM study day 2022.



## The sixth National Patient Reported Outcome Measures (PROMs) Annual UK Research Conference:

In June, Daney Harðardóttir presented her abstract on *“Patient-centred outcome measure design: the perspectives and preferences of children and young people with life-limiting or life-threatening conditions”* in the Oral Abstract Presentation session.



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## Steering Group:

Our sixth steering group meeting was held on Wednesday 11<sup>th</sup> May 2022. This was a great opportunity for us to meet and discuss the progress on the project so far and gain feedback from our steering group members. We also presented our plans for the next phase of the C-POS project and received helpful suggestions which we have incorporated. We are grateful to all of those who attended and contributed.

## Welcome and Thank you:

We would like to welcome Inez Gaczowska to the C-POS study team who has joined us as a Research Project and Coordination Assistant.

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



## Contacts:

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<https://www.kcl.ac.uk/research/c-pos>

**Steering group:** Dr AK Anderson, Dr Jo Bayly, Lydia Bate, Professor Myra Bluebond-Langner, Dr Debbie Box, Dr Katherine Bristowe, Dr Rachel Burman, Lizzie Chambers, Professor Sir Alan Craft, Dr Finella Craig, Aislinn Delaney, Dr Jonathan Downie, Professor Julia Downing, Dr Clare Ellis-Smith, Professor Bobbie Farsides, Professor Sara Fovargue, Professor Lorna Fraser, Jane Green, Dr Jay Halbert, Julie Hall-Carmichael, Professor Irene Higginson, Dr Michelle Hills, Dr Mevhibe Hocaoglu, Dr Vanessa Holme, Dr Gill Hughes, Dr Jo Laddie, Angela Logun, Dr Steve Marshall, Dr Linda Maynard, Andrina McCormack, Dr Catriona McKeating, Lis Meates, Professor Fliss Murtagh, Dr Eve Namisango, Dr Veronica Neefjes, Cheryl Norman, Dr Sue Picton, Dr Christina Ramsenthaler, Anna Roach, Ellen Smith, Michelle Ward, Dr Mark Whiting.