

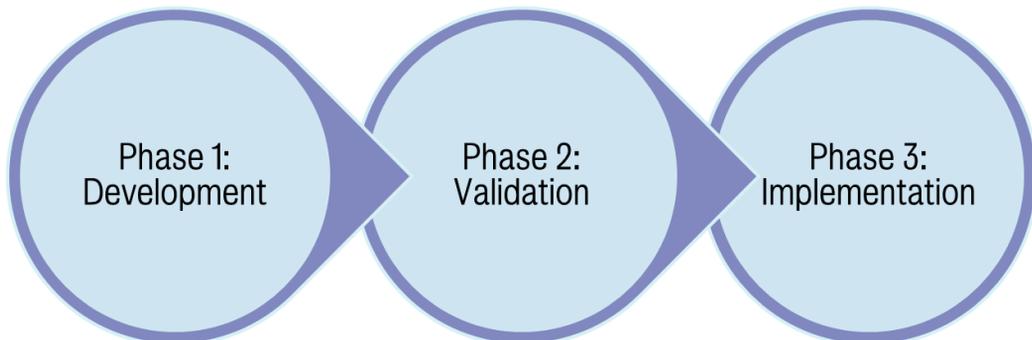
# Children's Palliative Care Outcome Scale (C-POS)

Newsletter Issue 6, 10<sup>th</sup> May 2021

Partners:



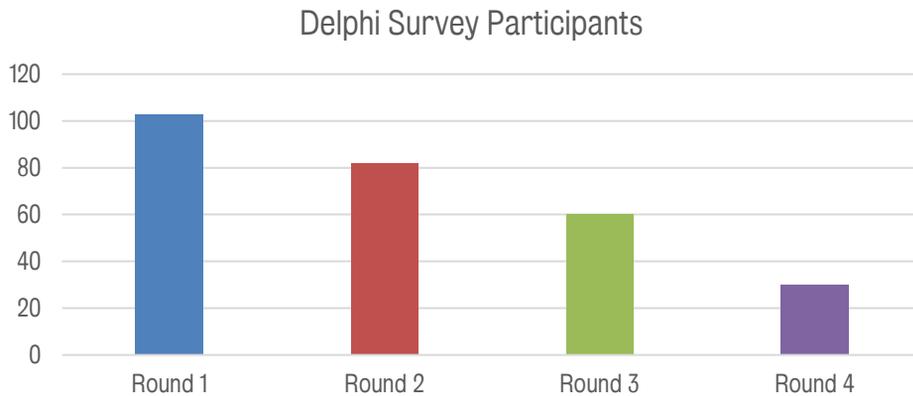
Welcome to our Spring edition of the C-POS newsletter. Since the New Year, we have closed the final round of our Delphi Survey and held our fourth Steering Group meeting. We also joined the Great Ormond Street Young People's Advisory Group for a meeting, who gave the team some really helpful ideas and suggestions to take forward. By bringing together our findings so far from the qualitative interviews, systematic review, Delphi survey, and the knowledge and insight from our steering group and the Great Ormond Street Young People's Advisory Group, initial C-POS versions have been developed.



As the study moves into Phase Two, these C-POS versions will be tested in Cognitive Interviews starting later in the Spring with our sites at The Evelina Children's Hospital, The Royal Marsden, Leeds Teaching Hospital, East Anglia's Children's Hospice, Martin House, and Northern Ireland Children's Hospice.

## Delphi Survey:

We would like to thank everyone who shared or participated in our Delphi Survey. The results have helped us to identify the most important questions to include on the C-POS to ensure that it focuses on what matters most to children, young people and their families.

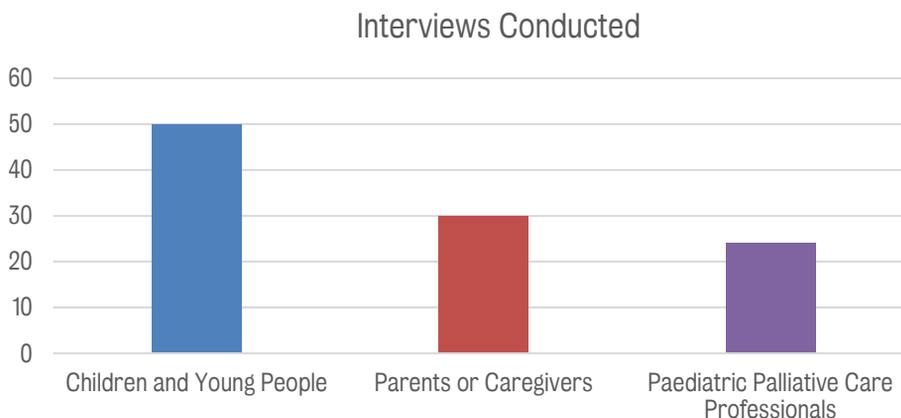


## International Update:



The C-POS study in Jordan and Turkey, led by Dr Sabah Boufkhed, is being conducted with the Center for Palliative & Cancer Care in Conflict's Department of Palliative Care at King Hussein Cancer Center (Jordan) and the Department of Pediatric Oncology at Hacettepe University's Faculty of Medicine and Cancer Institute (Turkey).

A total of 104 participants were recruited in both sites between March 2019 and February 2020. Each team interviewed 25 Children and Young People (CYP) with advanced cancer (age 5-17); 15 parents or caregivers of CYPs of any age living with advanced cancer; and 12 multi-professional paediatric palliative care professionals. The interviews were transcribed and translated from Arabic or Turkish to English.

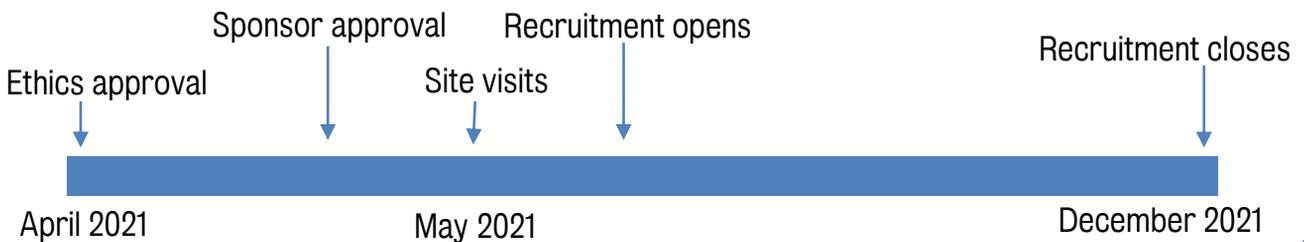


The research team (Cicely Saunders Institute, King Hussein Cancer Center and Hacettepe University) is currently analysing the interviews using an interdisciplinary, cross-country and collaborative approach. The findings will inform the development of culturally and contextually adapted versions of the C-POS.

## Cognitive Interviews Update:

The C-POS team have developed 5 initial versions of the C-POS which will be tested in cognitive interviews with children, young people and their parents from May 2021.

### Phase 2 project timeline:



## Conferences and Presentations:



One of the C-POS team was invited to the Northern Ireland Paediatric ECHO meeting in March to give an overview of patient centred outcome measurement and the science behind this. We also presented an overview of the C-POS study and the work done so far, as well as timelines for when the measure will be available for use .

This year's POS workshop theme was current concepts and new directions in measurement, and the C-POS team were invited to present. We gave an overview of the C-POS study and discussed some of the challenges we had encountered during the study so far. We were able to present some of the ways we had overcome these challenges and give some possible solutions to these that future researchers could use. The team enjoyed answering some interesting questions after their session.



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## Patient and Public Involvement:

We joined the Great Ormond Street Young People's Advisory Group again in March. We fed back to them about how their previous ideas and suggestions had been incorporated into the project and practical aspects of the measure. This time we brought our findings so far and the young people gave the team some really helpful suggestions and insight into the items they felt were important to be prioritised in the measure.

We're voicing our opinions and making important changes in how research is being done!



Laila, GOSH YPAG Member

## Publications:



Our systematic review on enhancing validity, reliability and participation in self-reported health outcome measurement for children and young people was recently published online in *Quality of Life Research*. We looked at the evidence on recall period, response format and administration modes needed to enable children to self-report their health outcomes. We found that children <5yrs cannot reliably report their own health outcomes; those >8yrs can reliably use a 3-point response format. Faces scales demonstrate better psychometric properties than Visual Analogue/Likert scales and children prefer computerised measures. We make 8 recommendations for the future development of self-reported outcome measures for children and young people. The full paper can be found here: <https://doi.org/10.1007/s11136-021-02814-4>

Coombes, L., Bristowe, K., Ellis-Smith, C., Aworinde, J., Fraser, L.K., Downing, J., Bluebond-Langner, M., Chambers, L., Murtagh, F.E.M., and Harding, R. Enhancing validity, reliability and participation in self-reported health outcome measurement for children and young people: a systematic review of recall period, response scale format, and administration modality. *Qual Life Res* (2021). <https://doi.org/10.1007/s11136-021-02814-4>

## Contacts:

Professor Richard Harding: Principal Investigator: [pa-richardharding@kcl.ac.uk](mailto:pa-richardharding@kcl.ac.uk)

Lucy Coombes: PhD Student: [lucy.coombes@kcl.ac.uk](mailto:lucy.coombes@kcl.ac.uk)

Dr Debbie Braybrook: Research Associate: [debbie.braybrook@kcl.ac.uk](mailto:debbie.braybrook@kcl.ac.uk)

Daney Harðardóttir: Research Assistant: [daney.haroardottir@kcl.ac.uk](mailto:daney.haroardottir@kcl.ac.uk)

Hannah Scott: Research Assistant: [hannah.m.scott@kcl.ac.uk](mailto:hannah.m.scott@kcl.ac.uk)



**Steering group:** Dr AK Anderson, Lydia Bate, Professor Myra Bluebond-Langner, Dr Katherine Bristowe, Dr Rachel Burman, Lizzie Chambers, Professor Sir Alan Craft, Dr Finella Craig, Professor Julia Downing, Dr Clare Ellis-Smith, Professor Bobbie Farsides, Professor Lorna Fraser, Professor Sara Fovargue, Dr Ann Goldman, Jane Green, Julie Hall-Carmichael, Professor Irene Higginson, Dr Michelle Hills, Dr Jo Laddie, Angela Logun, Dr Steve Marshall, Dr Linda Maynard, Professor Fliss Murtagh, Dr Eve Namisango, Dr Sue Picton, Anna Roach, Dr Pat Sartori, Professor Gao Wei