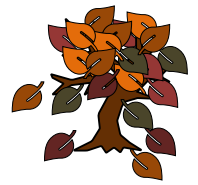


# Children's Palliative Care Outcome Scale (C-POS)



Newsletter Issue 8, 22<sup>nd</sup> November 2021

## Partners:



Welcome to the Autumn edition of the C-POS newsletter. Since our last newsletter recruitment has continued for the cognitive interview study and the team have submitted an ethics amendment for 7 new sites to join the study. In October, the team presented at the European Association for Palliative Care 17<sup>th</sup> World Congress Conference. We also held our fifth steering group meeting in which we welcomed some new members.

We are also still recruiting for the cognitive interview study through social media; please see details below or twitter [@CYP\\_CSI](https://twitter.com/CYP_CSI) for more information.

## Cognitive Interviews:

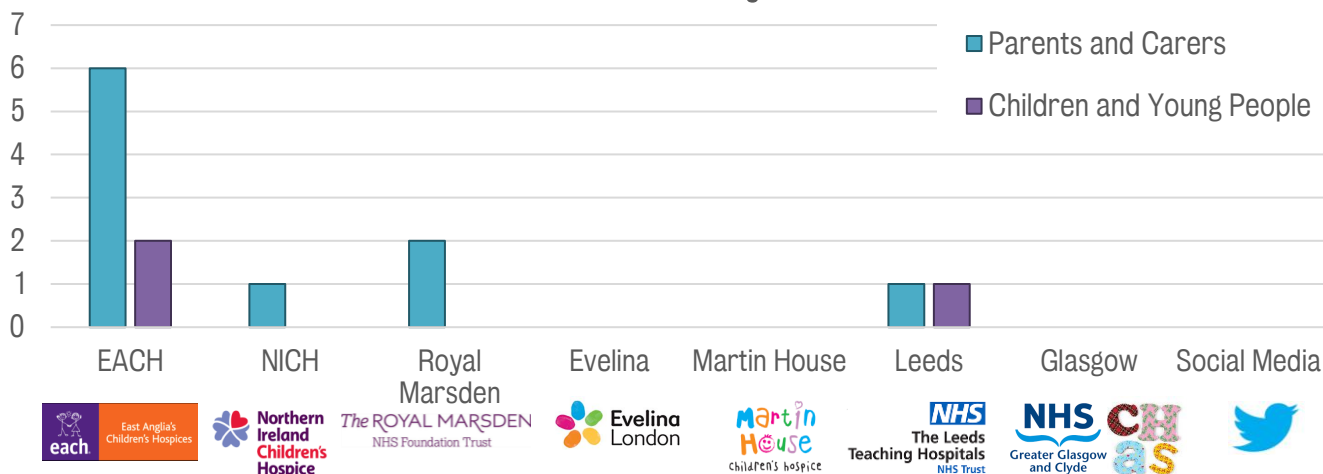
The C-POS team are looking for children and young people with life-limiting or life-threatening conditions and/or their parents/carers to help us test our new questionnaire. Participation will take approximately 1 hour and will involve you answering the questions in the measure while telling us what you think they mean and how you chose your answers. The conversation will be audio recorded and can be conducted via video calling. The questions will ask about physical symptoms such as pain that you/your child might have been experiencing, as well as how you/they have been feeling. If you are interested in participation or would like more information, then please contact the team on one of the emails below:

[lucy.coombes@kcl.ac.uk](mailto:lucy.coombes@kcl.ac.uk) [debbie.braybrook@kcl.ac.uk](mailto:debbie.braybrook@kcl.ac.uk)  
[daney.haroardottir@kcl.ac.uk](mailto:daney.haroardottir@kcl.ac.uk) [hannah.m.scott@kcl.ac.uk](mailto:hannah.m.scott@kcl.ac.uk)



# Cognitive Interview Recruitment Progress

## Interviews by Site

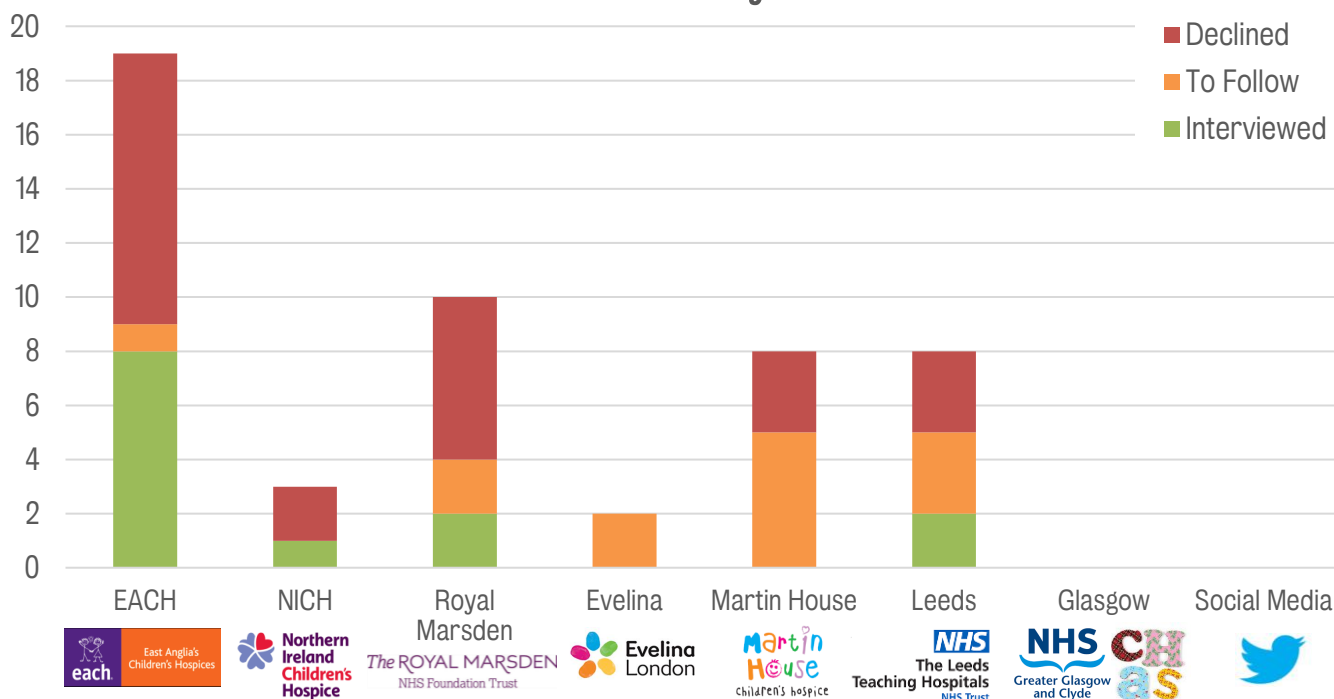


## Cognitive Interview Update:

Since our last newsletter our sites have recruited an additional 16 participants and our study team have conducted 8 further interviews to test the C-POS versions. We are also excited to welcome a number of new sites to the cognitive interview study: Bradford Teaching Hospitals Trust, Chestnut Tree House, East Cheshire NHS Trust, East Lancashire Hospitals NHS Trust/Royal Blackburn Teaching Hospital, Forget Me Not Childrens Hospice, Hertfordshire Community NHS Trust and Leicester Children's Hospital. We look forward to working with them to continue to recruit children, young people and their parents and carers.

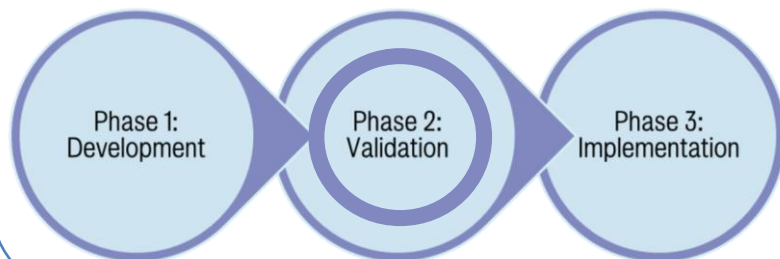


## Referrals by Site



## Upcoming Validation Study:

The next step in Phase 2, after the completion of our Cognitive Interviews study, will be to validate the developed and cognitively tested C-POS versions. The team have been working on developing a protocol for the upcoming study and will be looking for sites to take part in the new year. If you are interested in working with us as a site for the validation study, you can contact the team with the details below:



- ◆ [debbie.braybrook@kcl.ac.uk](mailto:debbie.braybrook@kcl.ac.uk)
- ◆ [daney.haroardottir@kcl.ac.uk](mailto:daney.haroardottir@kcl.ac.uk)
- ◆ [hannah.m.scott@kcl.ac.uk](mailto:hannah.m.scott@kcl.ac.uk)
- ◆ [frances.1.waite@kcl.ac.uk](mailto:frances.1.waite@kcl.ac.uk)

## European Association for Palliative Care 17<sup>th</sup> World Congress Online:

In October the team attended the 17<sup>th</sup> World Congress of the European Association for Palliative Care Online.

Hannah Scott presented her abstract on *“Existential Concerns of Children and Young people with Life-Limiting or Life-Threatening Conditions”* in the Free Communication session on Sharing learning from across the globe.

Lucy Coombes also had a poster on her research reporting on a *“Modified Delphi survey to ascertain stakeholder consensus on priority outcomes for inclusion in the Children’s Palliative Outcome Scale (C-POS)”*.

The Congress Abstract book which includes the full abstracts is available here: <https://journals.sagepub.com/doi/full/10.1177/02692163211035909>

Dr Debbie Braybrook also presented in the EU lunch session to give an update on the progress of the C-POS project to date.

We are also pleased to have been able to offer funded places for our recruiting sites to attend the conference as a thank you for their work.

**EAPC 17<sup>th</sup> World Congress Online**  
“EXPLORING NEW DIMENSIONS”  
**Interactive Online Sessions**  
6 - 8 October 2021

## Steering Group:

Our fifth steering group meeting was held virtually on Thursday 4<sup>th</sup> November. 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 next steps for the next year of the project to the group and are grateful to all those who attended and contributed for their input.

## Welcome:

We would like to welcome Frances Waite (pictured right) to the C-POS study Team who has joined us as a research project and coordination assistant.



## Contacts:

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 [@CYP\\_CSI](https://twitter.com/CYP_CSI)



**Steering group:** Dr AK Anderson, 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, Dr Ann Goldman, Jane Green, Julie Hall-Carmichael, Professor Irene Higginson, Dr Michelle Hills, Dr Mevhibe Hocaoglu, Dr Gill Hughes, Dr Jo Laddie, Angela Logun, Dr Steve Marshall, Dr Linda Maynard, Andrina McCormack, Professor Fliss Murtagh, Dr Eve Namisango, Cheryl Norman, Dr Sue Picton, Dr Christina Ramsenthaler, Anna Roach, Michelle Ward.