



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



Newsletter Issue 7, 1st September 2021

Partners:



Welcome to the Summer edition of the C-POS newsletter. We are excited to have now opened recruitment for our cognitive interview study 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. Although recently opened, the team have already conducted 5 interviews to test different versions of the C-POS.

We are also recruiting through social media; please see details below or our twitter [@CYP_CSI](https://twitter.com/CYP_CSI) for more information.

Cognitive Interviews:

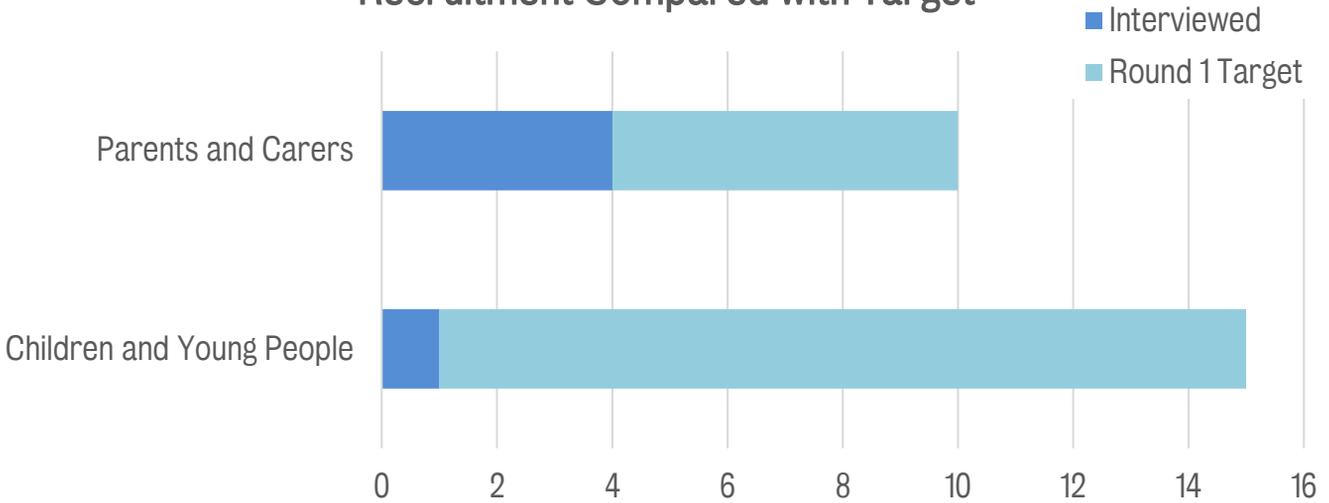
The C-POS team are looking for children and young people with life-limiting or life-threatening conditions and/or their parents/carers to help us test our new questionnaire. Participation will take approximately 1 hour and will involve you answering the questions in the measure while telling us what 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 debbie.braybrook@kcl.ac.uk
daney.haroardottir@kcl.ac.uk hannah.m.scott@kcl.ac.uk



Cognitive Interview Recruitment Progress

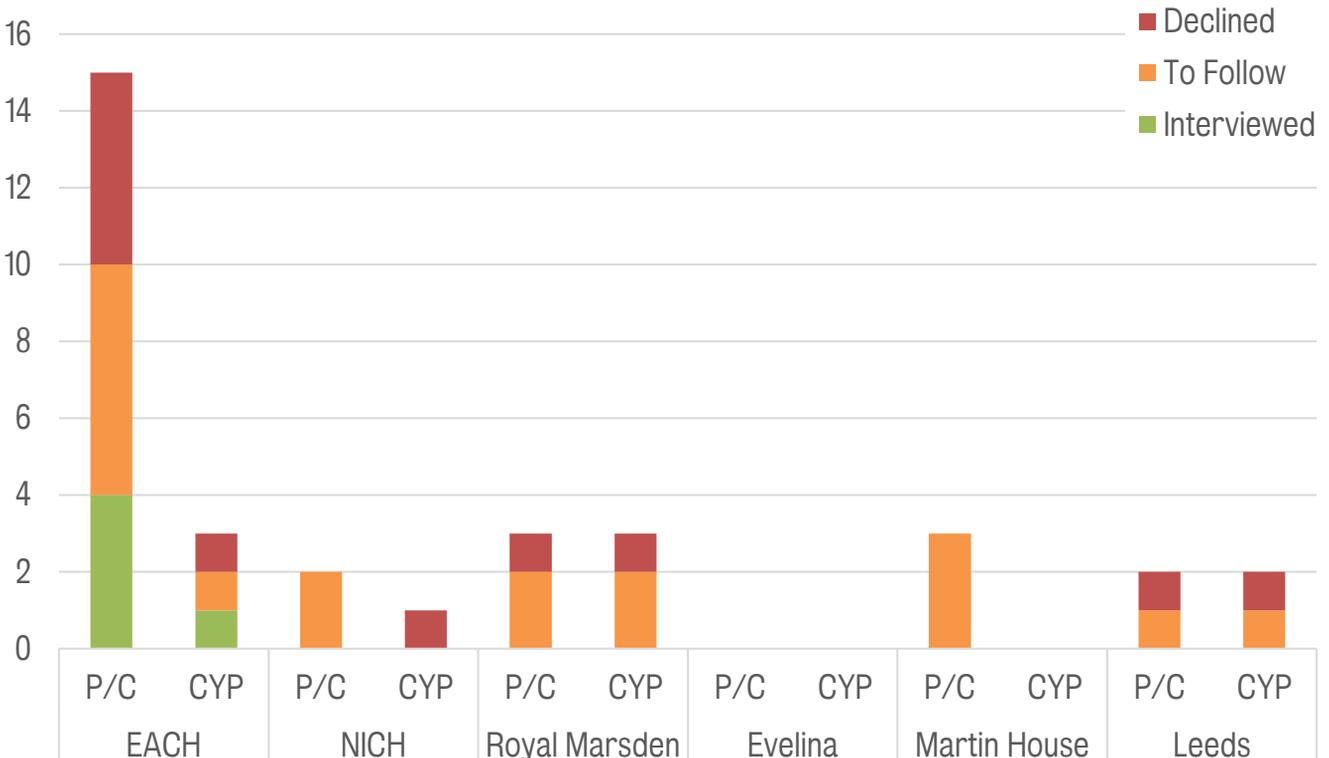
Recruitment Compared with Target



Cognitive Interview Update:

Since opening recruitment at our study sites, our recruiting teams have referred over 30 children, young people, and their parents and carers. The C-POS team have completed 5 interviews to test the C-POS versions that have been developed. We are also excited to welcome The Royal Hospital for Children Glasgow as a new cognitive interview study site and are looking forward to working with them to recruit participants from across Scotland.

Referrals by Site



New Study Site:

We are absolutely delighted at the Royal Hospital for Children, Glasgow, to be enrolled as a centre for the C-POS study. The integral role that children's palliative care services play in paediatric care has been clearly established. However, understanding what is most important to the families we serve is critical; helping to inform both care delivery and service planning. The C-POS study will deepen our understanding of what matters to families and enhance our ability to deliver individualised high-quality care through an evidenced based, validated tool.



Dr Jonathan Downie,
Consultant in Paediatric Palliative Medicine
Royal Hospital for Children, Glasgow

5th UK Patient Reported Outcome Measures Research Conference :

In June the team attended the 5th UK Patient Reported Outcome Measures (PROMs) Research Conference hosted (virtually) by the School of Health Related Research at the University of Sheffield.

From the C-POS team, Dr Debbie Braybrook presented her abstract *“if they knew what I thought was important ... that would help a lot more”*: *Methods for involving children and young people with life-limiting and life-threatening conditions in development of a paediatric palliative care outcome measure* and Lucy Coombes presented her abstract *‘Enhancing validity, reliability and participation in self-reported health outcome measurement for children and young people: a systematic review and recommendations for recall period, response scale format, and administration modality’* which has more recently been published and is available open access here: <https://doi.org/10.1007/s11136-021-02814-4>

Dr Eve Namisango also presented her abstract *‘Psychometric and measurement invariance properties of a novel outcome measure for children with life-limiting and life-threatening illness’* based on her work on the African Palliative Care Association's Children's Palliative care Outcome Scale.

As part of the conference, the team also attended a UK/Ireland Special Interest Group meeting for the International Society for Quality of Life Research (ISOQOL) and were able to take part in some really interesting discussions with other researchers and health and social care professionals from the UK and Ireland.

If you want to find out more about what happened at the conference, check out [#UKPROMS](#) on Twitter



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Clinical Outcomes



Patient and Public Involvement:

The work the C-POS team have been doing with the Great Ormond Street Hospital Young People's Advisory Group was featured in the Cicely Saunders Institute Patient and Public Involvement Summer Newsletter (pages 3-4). The newsletter can be found here: <https://www.kcl.ac.uk/cicelysaunders/patient-family-and-public-involvement/ppi-newsletter-june-update-final>.



The work of the C-POS team with the GOSH YPAG was also featured in the Great Ormond Street Hospital Patient and Public Involvement Impact Case Studies Report (pages 18-20) which can be found here:

https://media.gosh.nhs.uk/documents/PPI_Impact_Case_Studies_Report.pdf



It has been great working with the Great Ormond Street Hospital Young People's Advisory Group over the past year and we have plans to go back to them and ask for their input on the next phase of C-POS development.

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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, Professor Wei Gao, 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, Anna Roach, Michelle Ward.