



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



Newsletter Issue 11, 31<sup>st</sup> October 2022

Partners:



European Commission



INSTITUTE OF CHILD HEALTH



The Martin House RESEARCH CENTRE



international children's palliative care network



Applied Research Collaboration South London

LDC Louis Dundas Centre for Children's Palliative Care

KING'S HEALTH PARTNERS



An Academic Health Sciences Centre for London

Pioneering better health for all

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

Since our last newsletter the team have been busy preparing for the validation study to open. We attended a research ethics committee on 6<sup>th</sup> October 2022 and plan to start sending out local information packs soon.

This year, July 3<sup>rd</sup> marked National Bereaved Parents Day, which aims to raise awareness, show bereaved parents they are not alone, and remember all of the children gone too soon. To recognise this, we asked our patient and public involvement (PPI) members about their experiences of joining the C-POS study, and what being a part of research meant to them. You can read about their experiences here:

<https://arc-sl.nihr.ac.uk/news-insights/blog-and-commentary/power-involvement-ensuring-parents-voices-are-heard-development>



## 5<sup>th</sup> UK Implementation Science Research Conference 2022:

In July the team attended the 5<sup>th</sup> UK Implementation Science Conference

Hannah Scott presented her abstract on *“Challenges to implementing person-centred outcome measures into routine paediatric palliative care”*.



## The Together for Short Lives Conference 2022:

In September the team attended the Together for Short Lives Conference in Manchester.

Professor Richard Harding and Daney Harðardóttir gave a presentation as part of the workshop on *“Outcome measurement in paediatric palliative care; reflecting on the current state of play and assessing future”* led by Professor Lorna Fraser and Dr George Peat from the Martin House Research Centre.



## Yorkshire and Humber Children's Palliative Care Network (YHCPCN) Annual Conference:

In September the team attended the YHCPCN Conference in Wetherby.

Dr Debbie Braybrook and Hannah Scott provided an overview of the work of the project to date and future plans for the study; including an exciting update on the validation and implementation.



## World Cancer Congress 2022:

In October the team, attended the World Cancer Congress.

Lucy Coombes presented on *“Outcome Measurement with Children Living with Advanced Cancer”* in the plenary session *“Establishing goals of care and measuring outcomes: transitioning children and young people with cancer to end-of-life care”* Chaired by Professor Julia Downing. Dr Eve Namisango also presented work from African C-POS in the session: *“What matters to children and young people at the end-of-life: Priority outcomes”*.



## Collaborative Paediatric Palliative Care Research Network:

In September the team attended a CoPPAR Network meeting and provided a progress update for the project.



The webinar the team presented at in June on working with the Great Ormond Street Hospital Young People's Advisory Group is also now available online:

[https://youtu.be/z\\_W5bhtf7ds?t=1451](https://youtu.be/z_W5bhtf7ds?t=1451) (00:24:12 – 00:53:35)

## 25<sup>th</sup> International Congress of the Portuguese Association of Palliative Care:

In September the team attended the 25<sup>th</sup> International Congress of the Portuguese Association of Palliative Care in Lisbon.

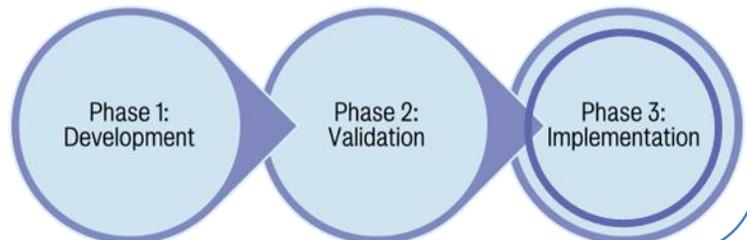
Professor Richard Harding gave a presentation on *“Paediatric Palliative Care: The Children’s Palliative Care Outcome Scale”* in the plenary session *“Paediatric Palliative Care: International Experiences and Perspectives”*



## Upcoming Implementation Workshop Plans:

To help develop a strategy for implementing C-POS into routine care, we are planning to hold a workshop in 2023.

If you would like to find out more, please contact Hannah Scott at [hannah.2.scott@kcl.ac.uk](mailto:hannah.2.scott@kcl.ac.uk)



## C-POS Validation Study:

We are excited to have had interest from over 70 sites across England, Scotland, Wales, Northern Ireland, Australia, and New Zealand. We are looking forward to working alongside the teams across the six countries to conduct robust validation of C-POS and ensure it's usefulness in practice.

We are still waiting for final ethical approval but have plans to start opening sites in the new year.

**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 →**



## Publications:



Our original research article on achieving child-centred care for children and young people with life-limiting and life-threatening conditions was recently published in the *European Journal of Pediatrics*. We recruited 106 participants - 26 children, 40 parent/carers, 13 siblings, 15 health and social care professionals, and 12 NHS commissioners. Participants reported many inter-related symptoms and concerns - physical symptoms, spiritual/existential concerns, social and practical concerns, and emotional and psychological concerns, impacting on all aspects of daily life. We also found an over-arching theme of 'pursuing normality', whereby children wanted to focus on undertaking normal childhood activities. Parents need support with the practical aspects of care in order to help their children realise this desire for normality. The full paper is open access and can be found here: <https://doi.org/10.1007/s00431-022-04566-w>

Coombes, L., Braybrook, D., Roach, A. et al. Achieving child-centred care for children and young people with life-limiting and life-threatening conditions—a qualitative interview study. *Eur J Pediatr* 181, 3739–3752 (2022).

## Contacts:

Professor Richard Harding: Principal Investigator

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

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

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

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

Inez Gaczowska: Research Project & Coordination Assistant: [inez.gaczowska@kcl.ac.uk](mailto:inez.gaczowska@kcl.ac.uk)



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



<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.