

# C-POS\*UK

Children's Palliative Care  
Outcome Scale UK



Newsletter Issue 15, 21<sup>st</sup> December 2023

Partners:



European  
Commission

King's College  
Hospital  
NHS Foundation Trust



US  
UNIVERSITY  
OF SUSSEX



European Research Council  
Executive Agency  
Established by the European Commission

together  
for  
short  
lives



The  
Martin House  
RESEARCH CENTRE



INSTITUTE OF CHILD HEALTH



The University  
Of  
Sheffield.



NIHR

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 Winter edition of the  C-POS\*UK newsletter

The C-POS team have had a busy few months and we are excited to share the latest updates with you. You may have noticed the newsletter looks slightly different this month as we have a new logo. We have worked with our parent patient and public involvement members, the Great Ormond Street Hospital Young Person's Advisory Group, and a graphic designer to design a new logo for the study, which we are excited to now be able to share with you all.



# C-POS\*UK

Children's Palliative Care  
Outcome Scale UK

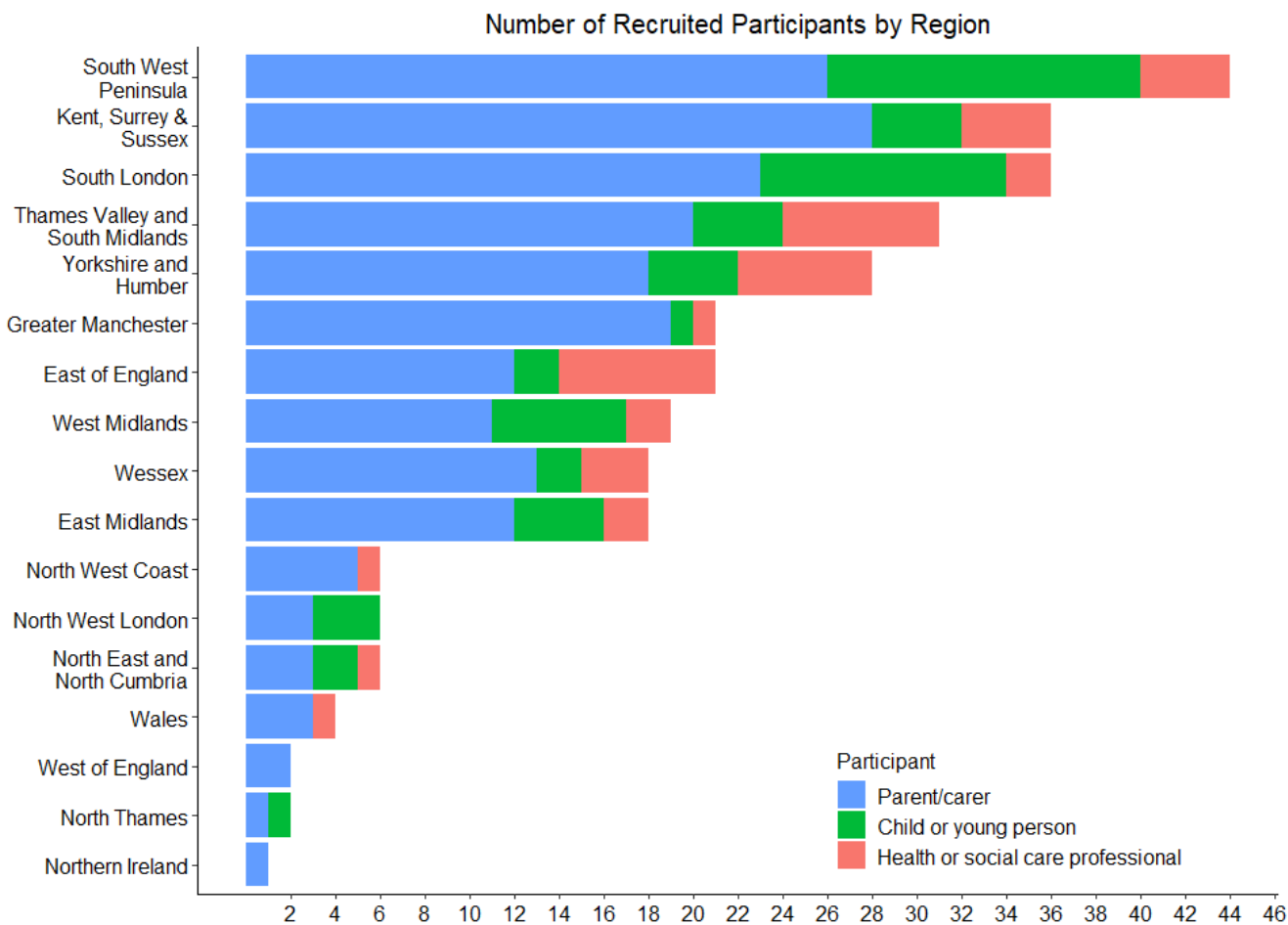
We are also thrilled that the King's College London Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care 2023 Year in Review Highlights featured our work on spiritual, existential, and religious concerns of children and young people with life-limiting and life-threatening conditions. You can read more about this work here:

<https://www.kcl.ac.uk/nmpc/year-in-review>

## Validation Study:

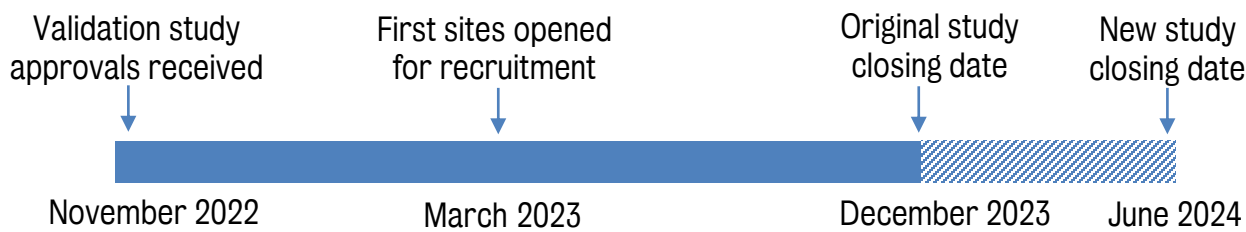
Recruitment to the validation study has been increasingly successful in the past few months. This is thanks to the incredible commitment of our partners and participating sites who keep introducing the study to their patients – thank you for all your work.

So far, a total of 301 participants have participated in the study, this includes 201 parents, 59 children and young people, and 41 health and social care professionals.



Our aim is to recruit 600 participants – so we are halfway there! We are excited to continue to work with you to reach that target in the new year now that a 6-month recruitment extension has been secured allowing us to continue recruitment until the end of June 2024:

### Updated study timelines:



## Steering Group:

Our eighth steering group meeting was held on Monday 25<sup>th</sup> September 2023. 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 on how we can continue to improve recruitment to the ongoing validation study. We also presented the progress on phase three of the project investigating how best to implement C-POS into practice and presented our new study logo. We are grateful to all of those who attended and contributed.

## Global Health and Palliative Care Project:

In September the team visited Kampala, Uganda to collaborate with researchers, clinicians, and children and young people working together as part of the Global Health and Palliative Care (GHAP) project. Professor Julia Downing and Dr Eve Namisango have both previously undertaken work to develop and validate the first Person-Centred Outcome Measure for children with life-limiting and life-threatening conditions in sub-Saharan Africa. As part of this work, a number of challenges for developing outcome measures for this population were identified, including the need for different versions for different cognitive abilities, and difficulties in proxy reporting. The UK C-POS team faced similar challenges in the development and validation of the first Person-Centred Outcome Measure for children with life-limiting and life-threatening conditions in the UK and were invited to join the GHAP team in Uganda to share learning and strengthen the work on both measures. Additionally, Lucy Coombes and Professor Lorna Fraser joined Professor Julia Downing in presenting the GHAP webinar on Global Paediatric Palliative Care Research.



## Publications:



Our original research article on achieving consensus on the priority items to include in outcome measures for children and young people with life-limiting and life-threatening conditions has recently been published online in the journal *Palliative Medicine*. We conducted a modified Delphi survey, worked with a young person's advisory group, and held an item generation meeting with key expert stakeholders. We found important differences in priority outcomes between children and young people,

parents and health and social care professionals. Health and social care professionals prioritised physical symptoms, whereas parents prioritised psychosocial and practical concerns. Children prioritised items related to living a 'normal life'. Five versions of C-POS have been developed that reflect the variation in age/developmental stages of children and young people with life-limiting and life-threatening conditions and allow for parent/carer proxy reporting if required.

Coombes et al. Achieving consensus on priority items for paediatric palliative care outcome measurement: Results from a modified Delphi survey, engagement with a children's research involvement group and expert item generation. *Palliative Medicine*. (2023). <https://doi.org/10.1177/02692163231205126>

## Nursing IN PRACTICE

Our original research article on the spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions, which was published in *Palliative Medicine* back in June of this year was recently featured in *Nursing in Practice*. The NiP article provided recommendations for how nursing professionals can deliver spiritual care for children with life-limiting and life-threatening conditions and their families, based on the findings of the research.

Scott HM. Spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions: A qualitative interview study. *Palliative Medicine*. 2023;37(6). <https://doi.org/10.1177/02692163231165101>

Scott HM. Delivering spiritual care for children with life-threatening conditions. *Nursing in Practice*. 2023. <https://www.nursinginpractice.com/clinical/paediatrics/spiritual-care-for-children-with-life-threatening-conditions/>

## Association for Paediatric Palliative Medicine Paediatric Palliative Care Conference 2023:

In November the team attended the Association for Paediatric Palliative Medicine conference in Birmingham.

Association for  
Paediatric  
Palliative  
Medicine

Daney Harðardóttir presented a poster on 'Key strategies for recruiting children and young people with life-limiting or life-threatening conditions and their families to participate in research'.



## Rays of Sunshine Study Days:

Throughout September the C-POS team joined the Rays of Sunshine Team at King's College Hospital as part of their team study days.

The C-POS team gave an introduction to outcome measurement and then presented an overview of the C-POS study.



## 10th European Tay-Sachs and Sandhoff Family Conference 2023:

In November the team attended the 10th European Tay-Sachs and Sandhoff Family Conference.

Hannah Scott was invited to give a presentation '*Introducing the Children's Palliative care Outcome Scale (C-POS)*' outlining development work and ongoing validation and implementation research.



## 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://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, Professor Sir Alan Craft, Dr Finella Craig, Dr Jonathan Downie, Professor Julia Downing, Dr Helena Dunbar, Dr Clare Ellis-Smith, Professor Bobbie Farsides, Professor Sara Fovargue, Professor Lorna Fraser, Dr Jay Halbert, Julie Hall, 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, Jane Morgan, Professor Fliss Murtagh, Dr Eve Namisango, Cheryl Norman, Dr Sue Picton, Dr Christina Ramsenthaler, Anna Roach, Ellen Smith, Michelle Ward, Dr Mark Whiting.