C-POS:UK

Children's Palliative Care Outcome Scale UK

Newsletter Issue 16, 30th April 2024

Partners:

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Better care at the end of life

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Welcome to the Spring edition of the C-POS:UK newsletter

Firstly, we are thrilled to be able to say **CONGRATULATIONS** to Lucy Coombes.

Lucy Coombes has played a very key part within the C-POS project. Lucy joined the project as a PhD student in 2018 and led all the development work and the initial validation work as part of her PhD.

In December 2023, she successfully defended her thesis and so, we are thrilled to say: **congratulations Dr Coombes!**

Dr Coombes will continue to support the C-POS work as part of the study steering group.

We are also saying **THANK YOU** and **GOODBYE** to Inez Gaczkowska

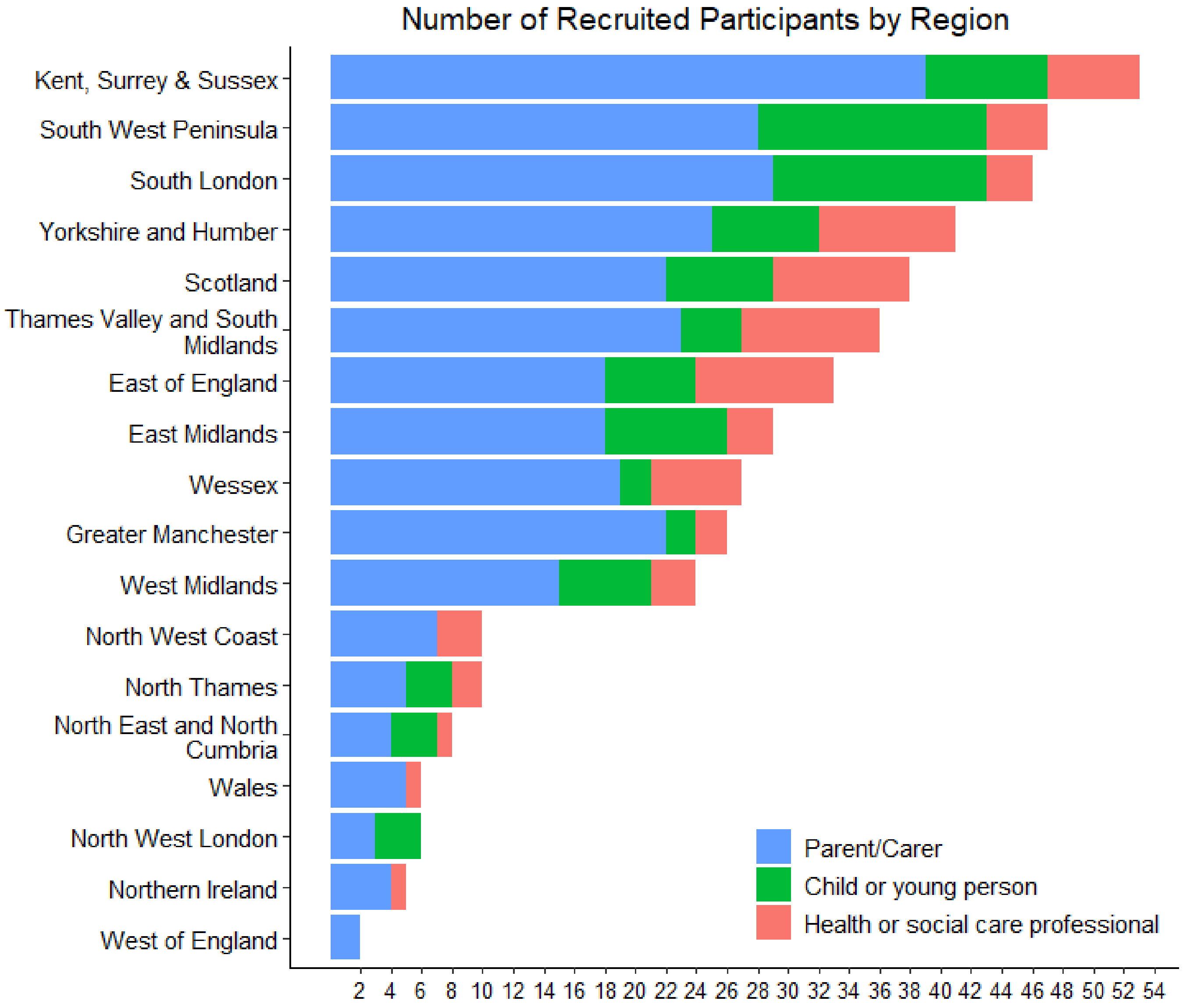
We would like to thank Inez Gaczkowska, who has now left the C-POS team, for all she has contributed to the project.

We wish you well in all you do next, Inez!

UK Validation Study:

Since starting back in January, recruitment to the validation study has continued to increase towards our target thanks to the incredible commitment of all our partners and participating sites. We reached a huge milestone of 400 participants earlier this year, making us one of the largest primary data paediatric palliative care studies ever! We are also excited to have now opened all of our sites in Scotland meaning we are now recruiting children and their families from all four nations of the UK.

So far, a total of 447 participants have participated in the study, this includes 88 children and young people, 288 parents/carers, and 71 health and social care professionals.



We are still trying to reach our target of 600 participants and are so grateful to all the health and social care professionals working across our 76 UK sites who are still recruiting for us until the study closes on 31st July 2024.

Validation Study in Australia and New Zealand:

We are really excited to finally have ethical approval to begin opening sites for the validation study in Australia. We are currently planning our site visits with the teams to open the sites for recruiting soon.

We are also continuing to work with the team in New Zealand to receive ethical approval and look forward to opening the study there soon.

Seedcorn Funding

From the implementation work that has been ongoing as part of the C-POS project, we identified several strategies and resources that may support implementation into routine care. One such resource that parents, professionals, and children have told us would support this is short videos, that explain what C-POS is and what the benefits are.

We submitted an application for Small Grant Seedcorn Funding led by Hannah Scott and were successful. We are currently working with a media production company informed by our research finding and the views of our valued PPI members (Jane, Lydia, and Angela) to begin work on developing some short videos that once produced will be able to be shared widely and help to facilitate the future implementation of the C-POS measures into routine care.

We also hope these videos may also lead to greater awareness of C-POS globally, leading to increasing interest for translation and cross-cultural validation of C-POS, as has occurred with the POS/IPOS family of measures in adult palliative care.

Welcome:

We would like to welcome Nazihah Uddin (right) to the C-POS team. Nazihah has joined the project as a research assistant.

Publications:

Our original research article analysed the language that children and young people use to describe their own life-limiting or life-threatening condition has recently been published in the journal *Palliative Medicine.* We conducted a secondary discourse analysis of the transcripts of 26 interviews with children and young people where they were asked about the symptoms and concerns that mattered most to them. The language children and young people use positions them as experts in their condition. They can provide rich detailed descriptions of symptoms and holistic assessments of their own health status, using adjectives and medical terminology, alongside their preferred terms for their body. To facilitate child-centred discussions about preferences and priorities, we recommend healthcare professionals sensitively frame conversations about losses/differences, and what matters most, to elicit detailed descriptions of symptoms and concerns and then converging their language towards the child or young persons.

Bristowe et al. 'My life is a mess but I cope': An analysis of the language children and young people use to describe their own life-limiting or life-threatening condition. Palliative Medicine. 2024. https://doi.org/10.1177/026921632412339

Our original research article on the benefits, risks, barriers, and facilitators to implementing person-centred outcome measures into routine care for children and young people with life-limiting and life-threatening conditions has recently been published in the journal *Palliative Medicine.* We conducted 106 interviews with children and young people, family members, health and social care professionals, and commissioners of paediatric palliative care services. All participants were supportive of future implementation of person-centred outcome measures into care. Perceived benefits of using person-centred outcome measures include enhanced understanding of what matters to patients and families, improved communication and collaborative working and standardised data collection and reporting. To reduce risks and barriers children and families must be involved in measure development and implementation strategies should be designed collaboratively with professionals.

Scott HM, et al. What are the anticipated benefits, risks, barriers and facilitators to implementing person-centred outcome measures into routine care for children and young people with life-limiting and life-threatening conditions? A qualitative interview study with key stakeholders. Palliative Medicine. 2024. https://doi.org/10.1177/02692163241234797

Conferences:

The Sydney children's Hospitals Network

In March to the team attended the **Sydney Children's Hospitals Network Paediatric Palliative Care Symposium**, in Sydney, Australia. Dr Debbie Braybrook presented alongside Dr Anthony Herbert, who has been supporting the psychometric validation study in Australia, on "*Children's Palliative Care Outcome Scale – applying to the Australian context*".

6th All Island Children's Palliative Care Conference

In April the team attended the **6th All Ireland Children's Palliative Care Conference** in Portlaoise, Ireland. Professor Lorna Fraser presented an oral abstract on behalf of Daney Harðardóttir on "*Development and psychometric evaluation of the novel Children's Palliative care Outcome Scale (C-POS)*".

Also in April, the team attended the **18th Current Issues in Palliative Care National Conference** in London. Dr Lucy Coombes presented on "*Outcome measurement in paediatric palliative care*" as part of the Paediatric Palliative Care Break-out session

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