



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



Newsletter Issue 12, 31st January 2023

Partners:



Welcome to the New Year edition of the C-POS newsletter

Since our last newsletter the team have been busy preparing for the validation study to open. We are excited to share that we received ethical approval on 29th November for sites in England, Wales, and Northern Ireland. We have started the process of opening sites across these three nations and to start to recruit children and young people, their parents and carers, and the health and social care professionals that care for them to the study.



"The team at Evelina have been involved with the C-POS study since its start and are excited about continuing their involvement in the next chapter of this exciting research project. Due to the nature of the case load at Evelina London, recruitment to some arms of the study have not been easy but generally we have found our families willing and happy to engage. The C-POS team have been excellent about keeping us up to date with progress in the study and have really helpfully engaged with all the team which has helped support the team in recruiting to the study."

Dr Jo Laddie, Consultant,
Evelina Children's Hospital



5th All Island Children's Palliative Care Conference:

In November the team attended the 5th All Island Children's Palliative Care Conference in Belfast, Northern Ireland.



Professor Richard Harding, Daney Harðardóttir, and Dr Debbie Braybrook gave a presentation on the progress of the study so far. The team were also excited to be able to meet in-person with some of our study partners, including the team at Northern Ireland Children's Hospice as well as other interested clinicians across several Health and Social Care Trusts across both Ireland and Northern Ireland.



Publications:

Editorial: Knowledge, attitudes and beliefs about paediatric palliative care

We were invited to write an Editorial for the journal *Annals of Palliative Medicine* providing comment on a recently published systematic review on the knowledge, attitudes, and beliefs of healthcare professionals, parents and communities in relation to paediatric palliative care. The editorial highlights the importance of addressing misconceptions around paediatric palliative care and working to improve positive attitudes towards it from all key stakeholder perspectives.

Scott HM, Coombes L, Braybrook D, Harðardóttir D, Gaczkowska I, Harding R. Knowledge, attitudes and beliefs about paediatric palliative care. *Ann Palliat Med* 2022. <https://dx.doi.org/10.21037/apm-22-1326>

Steering Group:

Our seventh steering group meeting was held on Tuesday 10th January 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. We gave an update on the validation study including plans to start opening sites. We also presented the progress on phase 3 of the project investigating how best to implement C-POS into practice. We are grateful to all of those who attended and contributed.

C-POS Validation Study in the UK:

We are excited to have had a huge amount of interest in our validation questionnaire study. We had 42 sites included on the initial ethics application that we are the process of opening. We are currently working towards obtaining ethics for Scotland and in the process of submitting an Amendment to add an additional 25 sites.

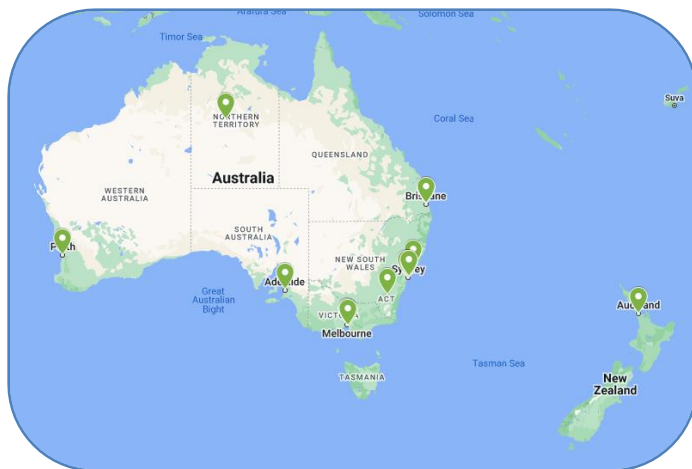
Dr Kate Renton & Christine Forster
Naomi House & Jacksplace



“Naomi House and Jacksplace, are located near Winchester Hampshire. We take children into Naomi House from across 5 counties (Hampshire and the Isle of Wight, Wiltshire, Dorset, Berkshire, West Sussex), and young adults come to Jacksplace from across the south of England. We offer charitable and funded respite, step down from hospital, end of life and bereavement support for CYP with complex life-limiting conditions and their families. Our Care team comprises of nurses, carers, play and activities workers, physio and family support. We have strong links to University Hospitals Southampton with our 2 specialist paediatric palliative care consultants, associate specialist adult palliative care doctor and physio who all work across both organisations. We are excited to be joining the C-POS study, enabling us to contribute to research which will strengthen the voices of the children, young people and families whom we support.”

Australia and New Zealand:

We are currently working with partners across Australia and New Zealand to adapt the current study protocol to their settings and hope to support them in submitting to ethics soon.



Ireland:

During their time in Belfast, the C-POS team received interest from several sites in the Republic of Ireland and plan to start working towards applying for ethics to open sites there soon.

Patient and Public Involvement:

We joined the Great Ormond Street Young People's Advisory Group again in November. The team fed back to the group on how their suggestions from the meeting in January had been incorporated into the study and the design of the C-POS measures. We then asked the group for their feedback on a short script for a video to help explain our upcoming questionnaire study to children and about the look and feel of the questionnaire. Our parent PPI members have also continued to provide really helpful insight and feedback across both the validation and implementation work.



“[The C-POS session] showed me how teamwork and ideas of very different people can build up together to create improvements in research that may eventually help future generations.”

Kornelia, GOSH YPAG member

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<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.