



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



Newsletter Issue 13, 5th April 2023

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Welcome to the Spring edition of the C-POS newsletter

Validation Study Updates

We are excited to announce that we officially opened and started recruitment to the validation study on 13th March in England, Wales, and Northern Ireland. If you would like get in touch about the C-POS validation study, please contact the team on kch-tr.cpos@nhs.net

The C-POS has been developed To identify symptoms and concerns that are important to children and their families.

The aim of the validation study is to test the measure to make sure that it works how we expect it to work, that it does so reliably, and that it can measure changes over time



Implementation Updates – Theory of Change Workshops:



To help understand how best to implement C-POS into care we are conducting workshops with parents and carers and health and social care professionals. The first of our professionals workshops ran from 27th March to 7th April and identified really important things to consider in terms of what is needed to implement C-POS, barriers to implementation and sustained use, and potential solutions to overcome the barriers identified. The parent and carer workshops will be running on 7th April and 24th April and the second health and social care professional workshop will run between 14th and 30th April. If you would like to find out more about the workshops, please contact Hannah Scott (PhD Candidate) on Hannah.2.scott@kcl.ac.uk

Publications:



Our original research article on the spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions was recently published Open Access in *Palliative medicine*. Existing research on spiritual concerns of seriously ill children primarily comes from parent/carers or health and social care professionals, however this research identified specific concerns in interviews with children themselves, as well as their family members. Themes identified included: living life to the fullest, meaning of life & leaving a legacy, uncertainty about the future, determination to survive, accepting or fighting the future, and role of religion.. This work broadens understanding of the spiritual domain for children and young people with life-limiting and life-threatening conditions. Recognition of the way children conceptualise spirituality and being able to identify their spiritual concerns is essential for child- and family-centred holistic palliative and end-of-life care spiritual concerns must be assessed beyond religious considerations. Professionals can optimise children and family's wellbeing through identification of the things that provide meaning for them, and working together to set goals and actions towards achieving them

The research was also highlighted in a King's College London news article:

<https://www.kcl.ac.uk/news/children-experiencing-end-of-life-care-have-spiritual-concerns>



Scott HM, Coombes L, Braybrook D, Roach A, Harðardóttir D, Bristowe K, Ellis-Smith C, Downing J, Murtagh FEM, Farsides B, Fraser LK, Bluebond-Langner M, Harding, R. Spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions: A qualitative interview study. *Palliative Medicine*. 2023;0(0). doi:10.1177/02692163231165101

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King's welcomes The Princess Royal to campus:

We were pleased to welcome Her Royal Highness The Princess Royal to the Cicely Saunders Institute to celebrate the 12th Anniversary of her opening of the Institute.

Members of the C-POS team were excited to share several updates on the work they have been doing with and for children, young people, their families to improve paediatric palliative care.

You can find out more about the visit here:



<https://www.kcl.ac.uk/news/kings-welcomes-the-princess-royal-to-campus>

International Collaborations

Congratulations to MSc student, Dr Nicola Ngiam, who has passed her dissertation on the C-POS study. Nicola has been working to conduct cognitive interviews with children and families at the National University Hospital in Singapore.

We are also excited to welcome Dr Eun Sook Kim, who has joined us at the Cicely Saunders Institute from Samsung Medical Centre and Catholic University of Korea in South Korea as a visiting research assistant. She is currently working on developing a protocol to translate and cognitively test the C-POS in Korean.

NIHR ARC South London Know your ARC Awards 2022:

In 2021, Hannah Scott won an NIHR ARC South London Studentship to undertake a PhD investigating how to implement the C-POS measure into routine care. All ARC-funded PhD scholarship students were invited to attend the NIHR ARC South London Know Your ARC Awards on 26th January 2023. Hannah was invited to speak about the aims of her research and the most important or exciting aspect of her work with Professor Nick Sevdalis from the Centre for Implementation Science. Hannah highlighted the importance of ensuring the voices of children and families were heard and that they were enabled to participate in research about them.

You can find out more about the event and the award winners on the ARC South London

Webiste: <https://arc-sl.nihr.ac.uk/news-insights/latest-news/congratulations-all-know-your-arc-2022-winners>



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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.