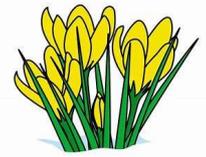


# Children's Palliative Care Outcome Scale (C-POS)



Newsletter Issue 9, 28<sup>th</sup> February 2022



## Staff Information round-up

Welcome to the first C-POS newsletter of 2022. Since our last newsletter we joined the Great Ormond Street Young People's Advisory Group again in January. The members provided some really helpful suggestions and insight into the names for the different C-POS measures. We have also had four abstracts accepted to be presented at the European Association for Palliative Care 18th World Congress Conference. Recruitment continues to the cognitive interview study through our recruitment sites and via social media, please see our twitter @CYP\_CSI for more information.

YPAG members were delighted to welcome Hannah and Debbie from KCL's C-POS study team again and see how our group's previous ideas had been incorporated into the project. The highlights of this last meeting were helping to finalise their questionnaire; including emoji chats et al, discussing the design and voting for the planets 'Mercury,' 'Saturn' and Neptune' as a novel and engaging way to distribute the different patient versions.

Oceiah, GOSH YPAG Member

## Cognitive Interview Update

### Cognitive Interview Update:

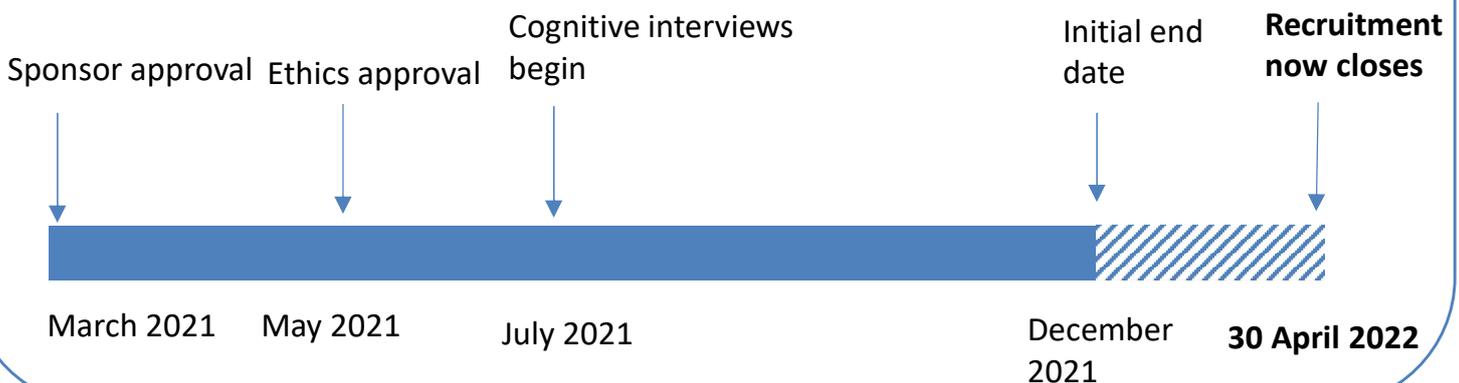
Since our last newsletter our sites have referred a further 44 participants, and the team have conducted a further 16 interviews. We are also excited to welcome a new site: Maidstone and Tunbridge Wells NHS Trust. We look forward to working with them to continue to recruit children, young people and their parents and carers.



### Ethics amendments:

We have received further approval to extend our recruitment period for the cognitive interview phase. The study will now close for recruitment on the **30 April 2022**.

### Phase 3 project timeline:



### New Study Site:

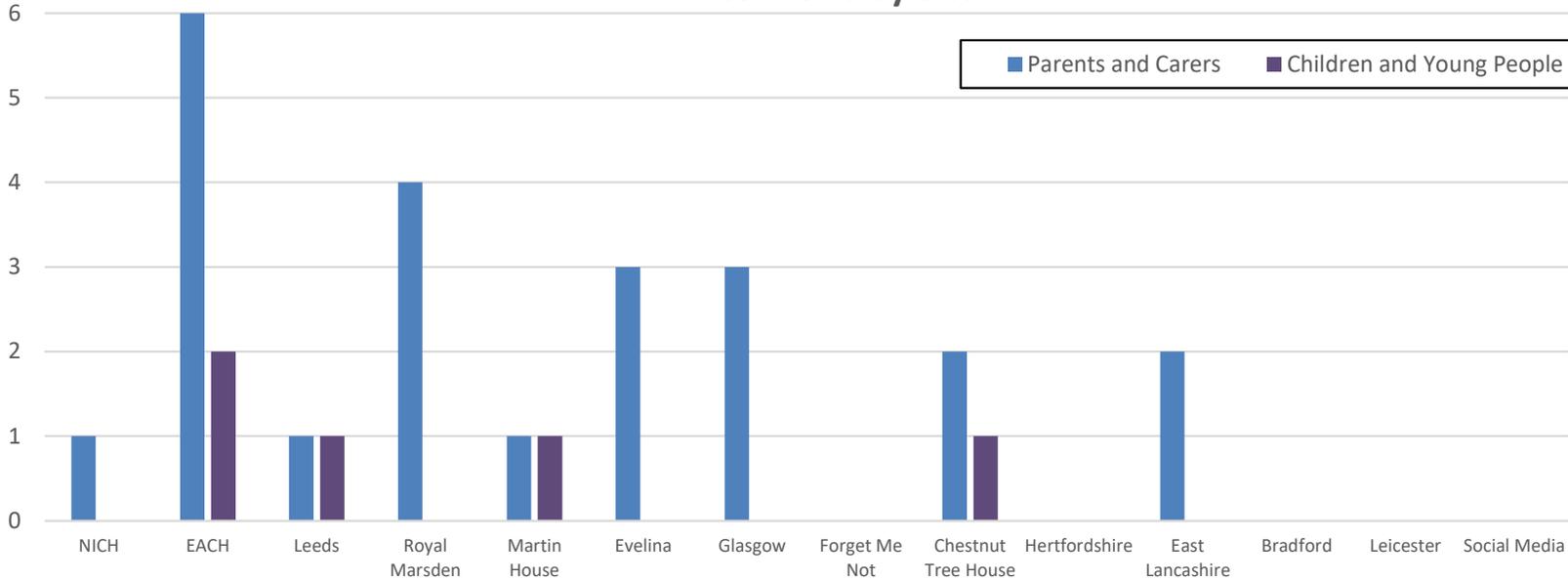
Maidstone and Tunbridge Wells NHS Trust is proud to be part of a multidisciplinary team in West Kent providing round the clock care and support to children and their families for a variety of acute and chronic healthcare problems including where appropriate palliative and end of life care. We are thus delighted to be involved in this study to develop a Children's Palliative Care Outcome Scale. So far, we have found the study team exceptionally supportive and the recruitment process simple and straightforward. Thank you very much for including us in this study.

Dr Jay Halbert, Consultant Paediatrician with a Specialist Interest in Paediatric Oncology, Maidstone and Tunbridge Wells NHS Trust

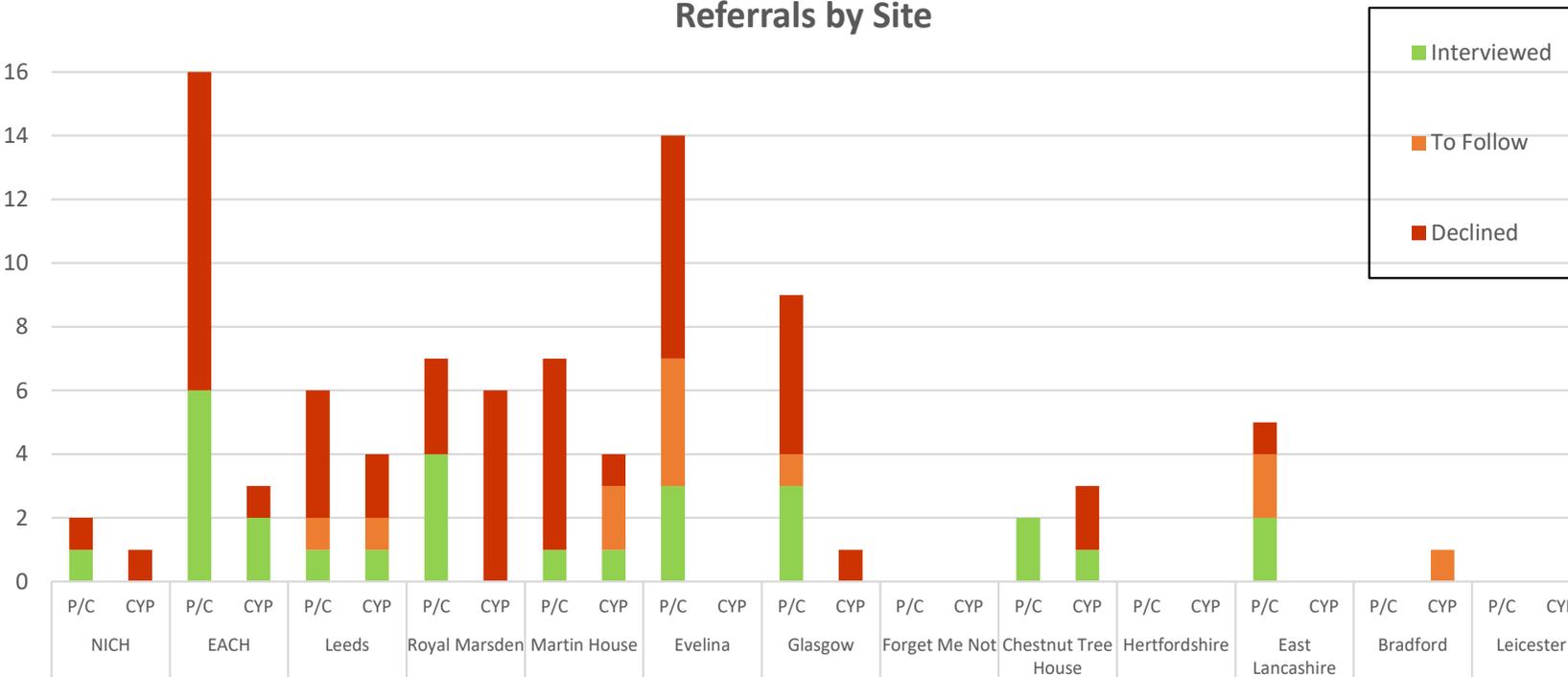


# Cognitive Interview Recruitment Update

## Interviews by Site



## Referrals by Site



## Site opening dates

	Northern Ireland Children's Hospice	24/05/2021
	EACH	07/06/2021
	Leeds	07/06/2021
	Royal Marsden	06/07/2021
	Martin House	08/07/2021
	Evelina	14/10/2021
	Greater Glasgow & Clyde	11/11/2021
	Forget Me Not Children's Hospice	15/11/2021
	Chestnut Tree House	02/12/2021
	Hertfordshire	09/12/2021
	East Lancashire	13/12/2021
	Bradford	15/12/2021
	Leicester	15/02/2022
	Maidstone and Tunbridge Wells	Opening soon

## Cognitive Interviews:

The C-POS team are looking for children and young people with life-limiting or life-threatening conditions and/or their parents/carers to help us test our new questionnaire. Participation will take approximately 1 hour and will involve you answering the questions in the measure while telling us what you think they mean and how you chose your answers. The conversation will be audio recorded and can be conducted via video calling. The questions will ask about physical symptoms such as pain that you/your child might have been experiencing, as well as how you/they have been feeling. If you are interested in participation or would like more information, then please contact the team on one of the emails below:

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



**Steering group:** Dr AK Anderson, Dr Joanne 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, Eve Malam, 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, Dr Kirtsen Wolffsohn.