

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

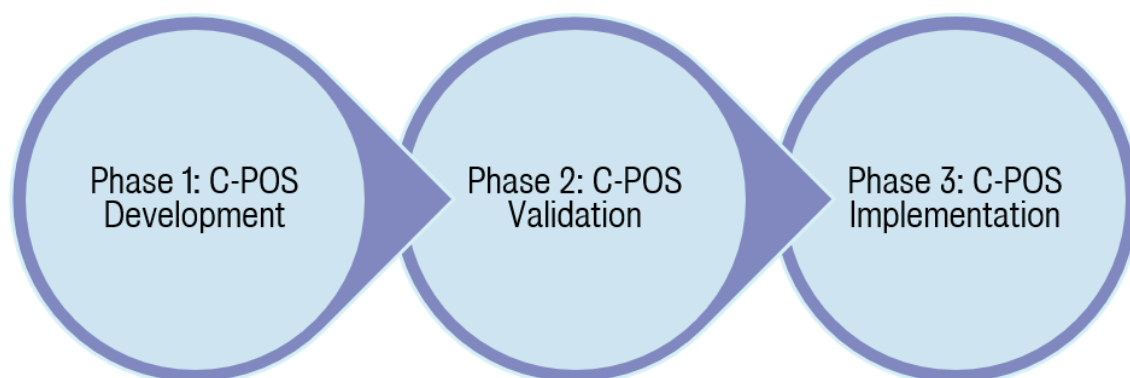
Newsletter Issue 1, 11<sup>th</sup> September 2019

## Partners:



## What is this project for?

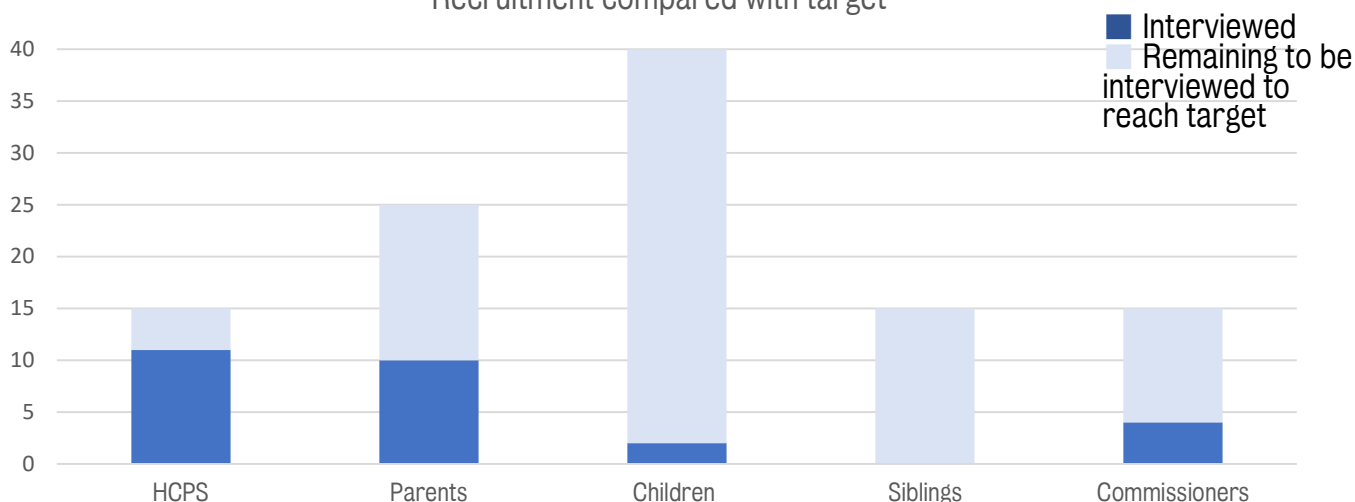
The C-POS study aims to develop a person-centred outcome measure that can be used by children, young people and families affected by life-limiting and life-threatening conditions. The study builds on existing international work and draws together a unique multidisciplinary collaboration to pioneer new methods for outcome measurement by a population currently neglected in research. The European Research Council has awarded funding for this project until early 2023.



The research team at the Cicely Saunders Institute at King's College London are currently working with the paediatric palliative care teams at Great Ormond Street Hospital, The Evelina Children's Hospital, The Royal Marsden and King's College Hospital. Interviews are underway with children and young people, siblings, parents/carers, healthcare professionals and commissioners to establish priorities for care which will inform the new measure before validation testing and implementation into routine practice.

# Recruitment Progress

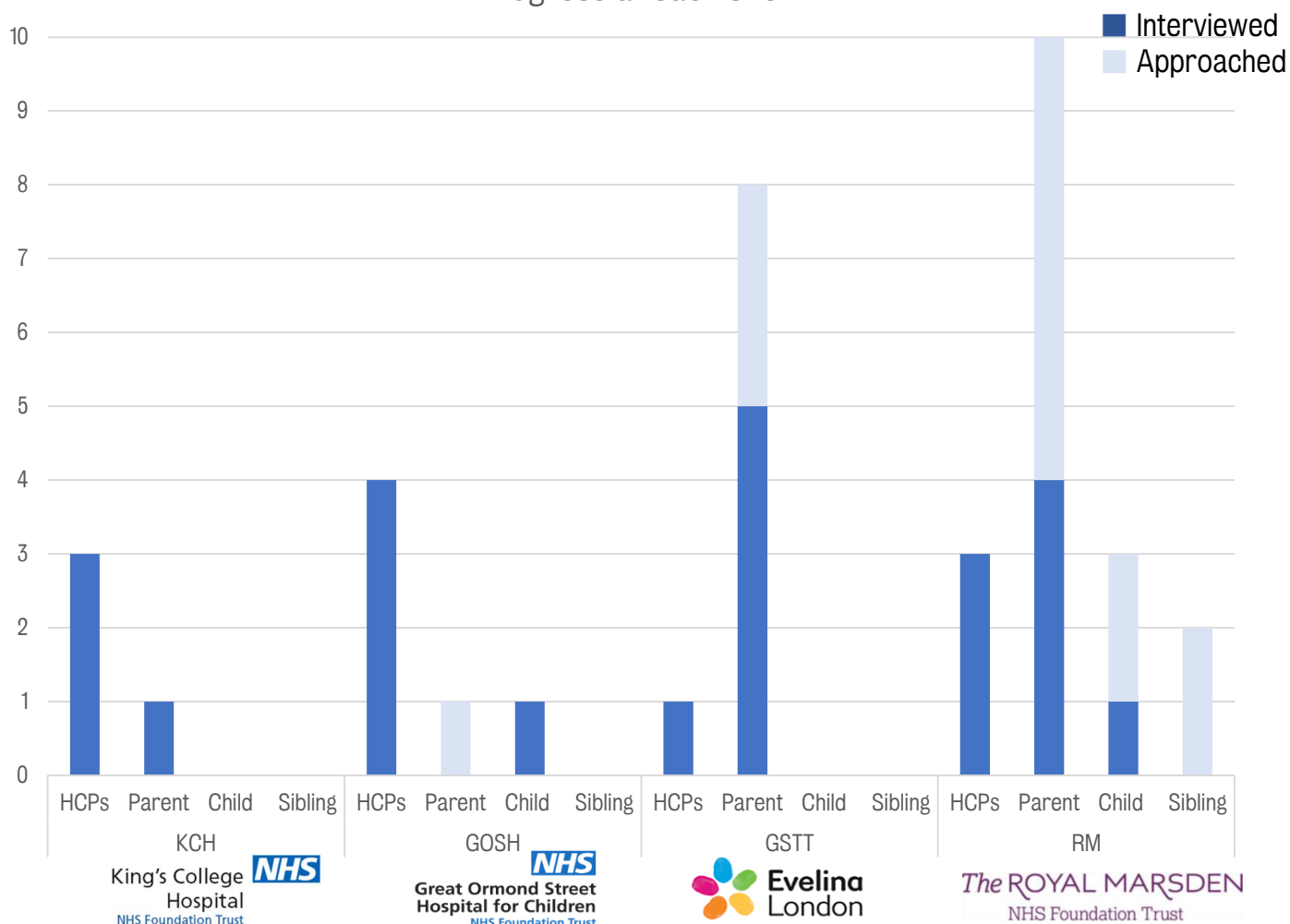
Recruitment compared with target



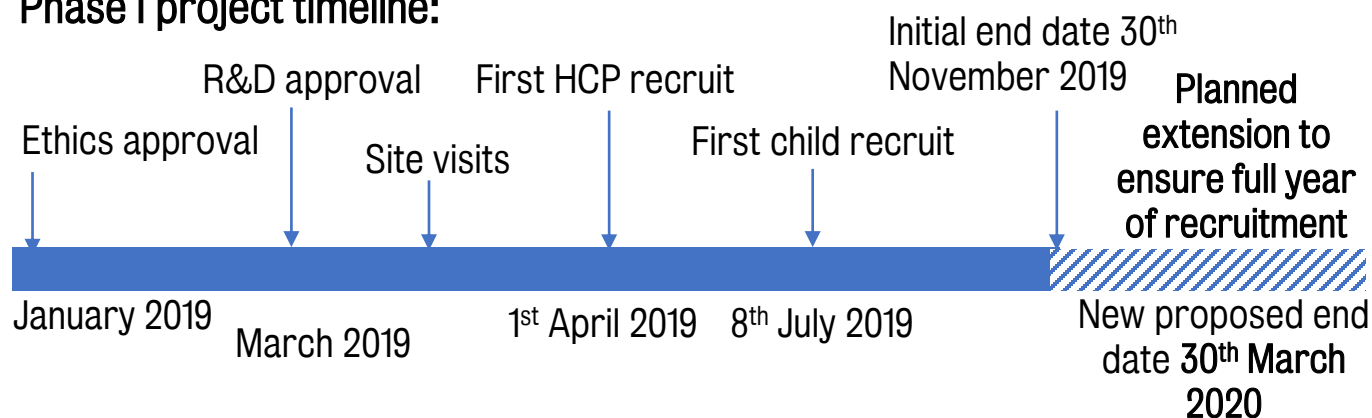
## New sites and ethics amendments:

We are opening at EACH, Addenbrookes, Martin House and LTHT which should help in recruiting more children so we can ensure their care priorities are accurately captured and included in the C-POS tool. We also have ethics approval so that non-palliative care clinicians can approach participants who have a life-limiting or life-threatening illness, as defined by Together For Short Lives, but are not under a palliative care team.

Progress at each site



## Phase I project timeline:



## International progress:

Following the development of the paediatric POS tool in Africa, the C-POS study is currently recruiting in Turkey and Jordan.

Site	UK	Turkey	Jordan	Africa (closed and complete)
Stage	Development stage			Total numbers: Development and validation stages
Date opened	March 2019	March 2019	May 2019 (not opened for children yet)	May 2009
Children recruited	2	16	-	67
Parents/carers recruited	10	13	2	75
Healthcare professionals recruited	11	8	12	23

## C-POS sites in Africa, Turkey and Jordan



Jaramogi Oginga Odinga Teaching & Referral Hospital

## News from our partners:

Evelina London Children's Hospital (ELCH) has been involved in C-POS since the original workshops over 6 years ago. As a team we have been delighted with the enthusiasm of our families to get involved. The study is discussed weekly at our MDT to ensure that it remains in everyone's minds and to ensure we are considering all families as possible recruits. All members of the team are involved in the recruitment process. In light of our caseload, it is hard to recruit children and young people but the willingness of their parents to get involved, we suspect reflects the importance that they place in palliative care for their families and their desire to help shape services of the future.

Dr Jo Laddie,  
Paediatric Palliative Care Consultant at the Evelina

We are currently very interested in speaking with commissioners of children's palliative care services who would be willing to be interviewed for the study. If you are interested or would like to learn more about the study please contact [anna.e.roach@kcl.ac.uk](mailto:anna.e.roach@kcl.ac.uk) or [lucy.coombes@kcl.ac.uk](mailto:lucy.coombes@kcl.ac.uk) for further information.



## Meetings:

We are holding our first steering group meeting on the 5th November which will be a chance to review our aims and objectives, progress, initial data interpretation and future goals and timelines with our stakeholders.

## Contacts:

Professor Richard Harding: Principal Investigator: [pa-richardharding@kcl.ac.uk](mailto:pa-richardharding@kcl.ac.uk)

Lucy Coombes: PhD Student: [lucy.coombes@kcl.ac.uk](mailto:lucy.coombes@kcl.ac.uk)

Anna Roach: Study Coordinator: [anna.e.roach@kcl.ac.uk](mailto:anna.e.roach@kcl.ac.uk)

Dr Debbie Braybrook: Research Associate: [debbie.braybrook@kcl.ac.uk](mailto:debbie.braybrook@kcl.ac.uk)



**Steering group:** Jane Green, Professor Sir Alan Craft, Professor Julia Downing, Professor Myra Bluebond-Langner, Dr Lorna Fraser, Professor Fliss Murtagh, Professor Bobbie Farsides, Dr Ann Goldman, Dr Hilary Cass, Lizzie Chambers, Dr Rachel Burman, Dr AK Anderson, Dr Jo Laddie, Dr Finella Craig, Dr Linda Maynard, Professor Sara Fovargue, Dr Katherine Bristowe, Dr Clare Ellis-Smith, Professor Irene Higginson, Dr Gao Wei