



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



Newsletter Issue 2, 19th December 2019

Partners:



We are delighted to have welcomed four new sites to the C-POS study. In October 2019 we opened at Martin House, Leeds Teaching Hospital Trust, East Anglia Children's Hospices and Addenbrookes Hospital. This allows insight to the experiences of families outside of London where paediatric palliative care is provided using different service models. We also hope this will boost the recruitment of children to ensure their care priorities are captured and included in the C-POS tool. Although only recently opened, we have already conducted 14 interviews recruited from our new sites.

“At Martin House we feel passionately about the importance of developing outcome measures for palliative care so this piece of research is important to us. Working within the Yorkshire and Humber Children's Palliative Care Network, piloting the new NHS England specification, has highlighted further the need for a measure of how well we are doing and the impact of what we do. Families and professionals seem genuinely interested and keen to help and it has been very straight forward to recruit to the study. Once the individuals have asked us to pass over their details the study team does all the rest!”

Dr Michelle Hills
Consultant in Paediatric Palliative Medicine
Martin House Children's Hospice and Leeds Teaching Hospitals NHS Trust

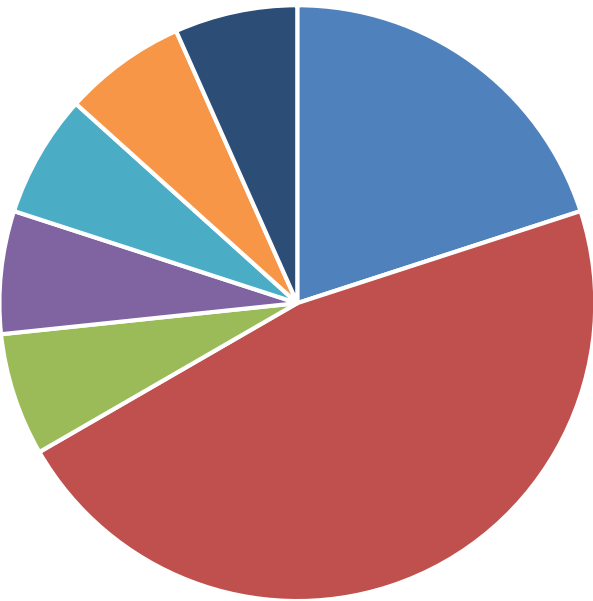
Ethics amendments:

We have received approval to extend our recruitment period so the study will now close for recruitment on the **30th March 2020**.

Recruitment Progress

We have reached our upper limit for healthcare professional interviews. We have conducted 15 interviews with a wide range of professionals, hearing their views on what is most important to families facing serious illness.

Health care professionals interviewed



- Doctors
- Nurses
- Social worker
- Chaplain
- Play therapist
- Psychologist
- Physiotherapist

Site opening dates

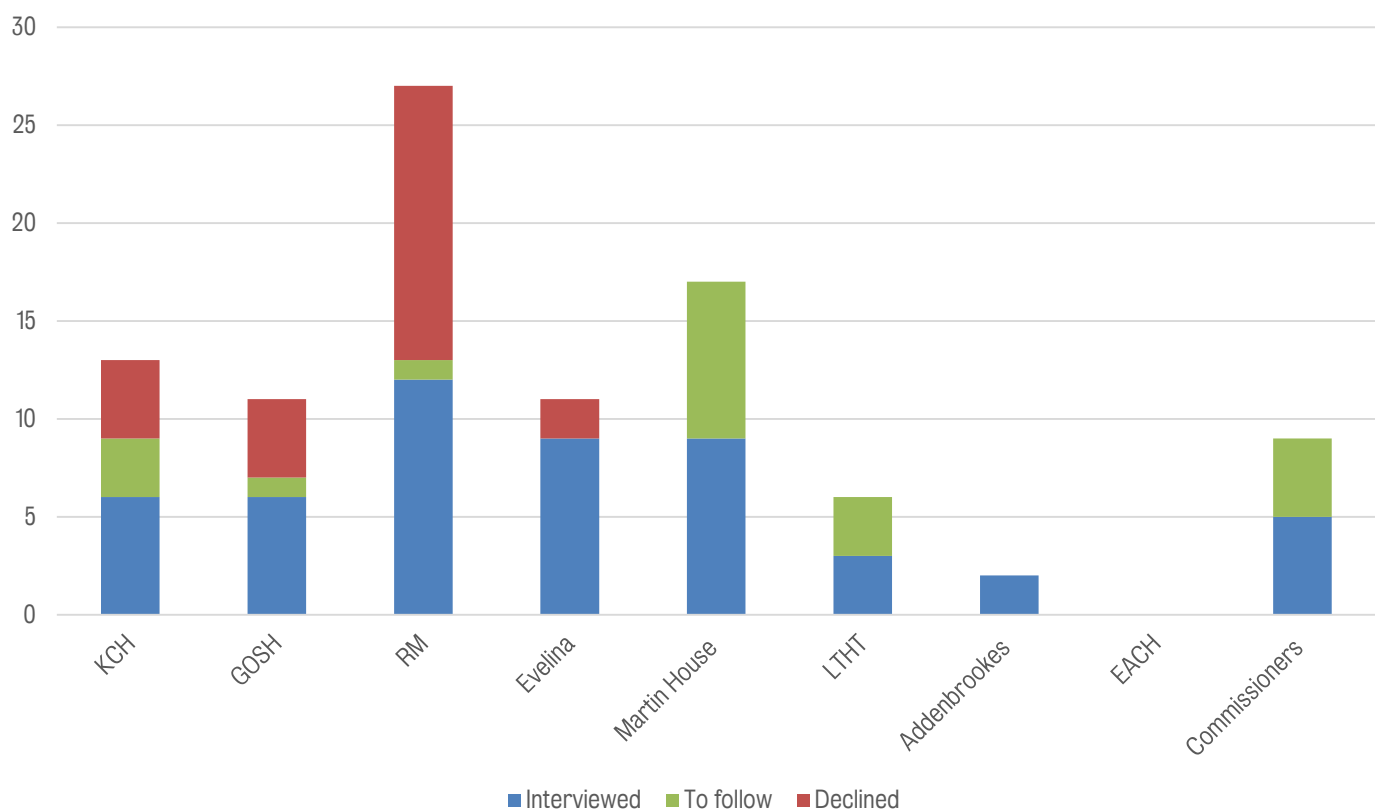
	KCH	25/01/19
	GOSH	27/02/19
	Royal Marsden	11/02/19
	Evelina	15/03/19
	Martin House	01/10/19
	Leeds	07/10/19
	Addenbrookes	28/10/19
	EACH	28/10/19

Recruitment Progress

Recruitment by site



Referrals by site



International Progress:



Our partner sites in Turkey and Jordan continue to recruit to their studies.

	Date opened:	Children recruited:	Parents recruited:	HCP recruited:
Turkey	March 2019	23	15	12
Jordan	May 2019	9	13	12

Meetings:

We are holding our first steering group meeting on **Monday 3rd February 2020 from 1-3pm** at the Cicely Saunders Institute. Representatives from each site have been invited to review the aims and objectives, progress, initial data interpretation and future goals and timelines of the project.

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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, Dr Sue Picton, Dr Pat Sartori, Dr Michelle Hills.