

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

Newsletter Issue 3, April 23rd 2020

Partners:



Welcome to our Spring edition of the C-POS newsletter. Since the New Year began we have conducted a further 42 interviews which includes speaking with 13 more children. We held our first Steering Group meeting at the beginning of February which was a great chance to meet together to review aims and objectives, discuss recruitment and plan future goals and timelines. We also received ethical approval to open at Northern Ireland Children's Hospice, where we interviewed 3 children during a 3-day visit. This provided us with additional perspectives from areas outside of London and further opportunity to speak with children and explore what matters to them.

Northern Ireland Children's Hospice is passionate about delivering exceptional care and support to children and their families and so we very much welcomed the opportunity to be involved in this study in developing outcome measures for children's palliative care. We found the recruitment process straightforward as many of the children and families we approached were keen to be involved. The children especially responded positively to the interview process and were able to have some fun with this! The study team engaged exceptionally well with the children and the information leaflets they produced were invaluable in explaining the study to parents and children.

Thank you for including us in this study.

Julie Hall-Carmichael, Senior Social Work Practitioner at Northern Ireland Children's Hospice



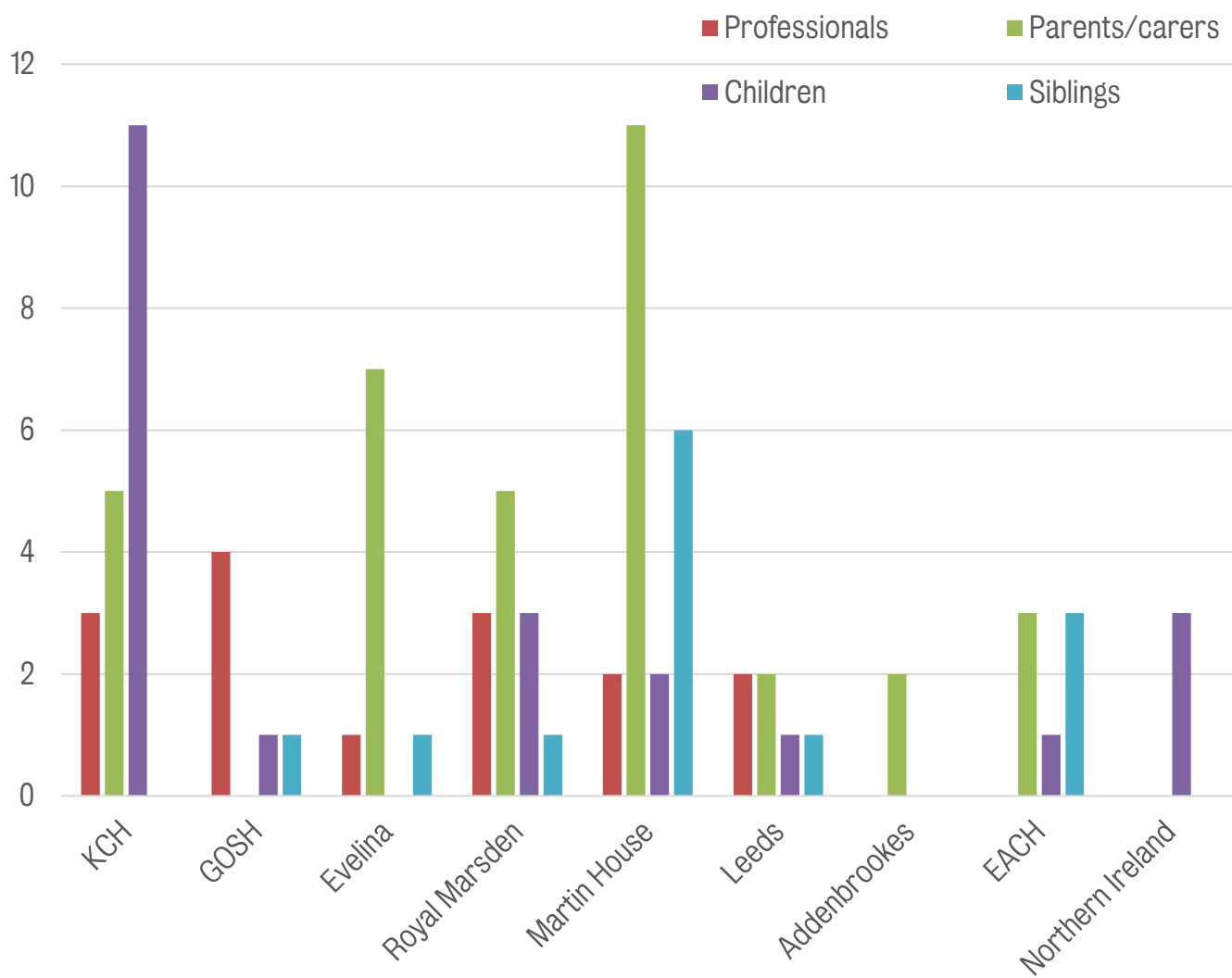
Ethics amendments:

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

Recruitment Progress

We have now completed interviews with 22 children, 35 parents, 15 healthcare professionals, 13 siblings and 9 commissioners. After an initially slow start to child recruitment there is strong evidence of an upwards curve and it has been great to explore what is important to a range of children living with different life-limiting and life-threatening conditions. Additionally, we made a decision to increase parent recruitment numbers, since opening at new sites, so we could gain more perspectives of families living outside of London.

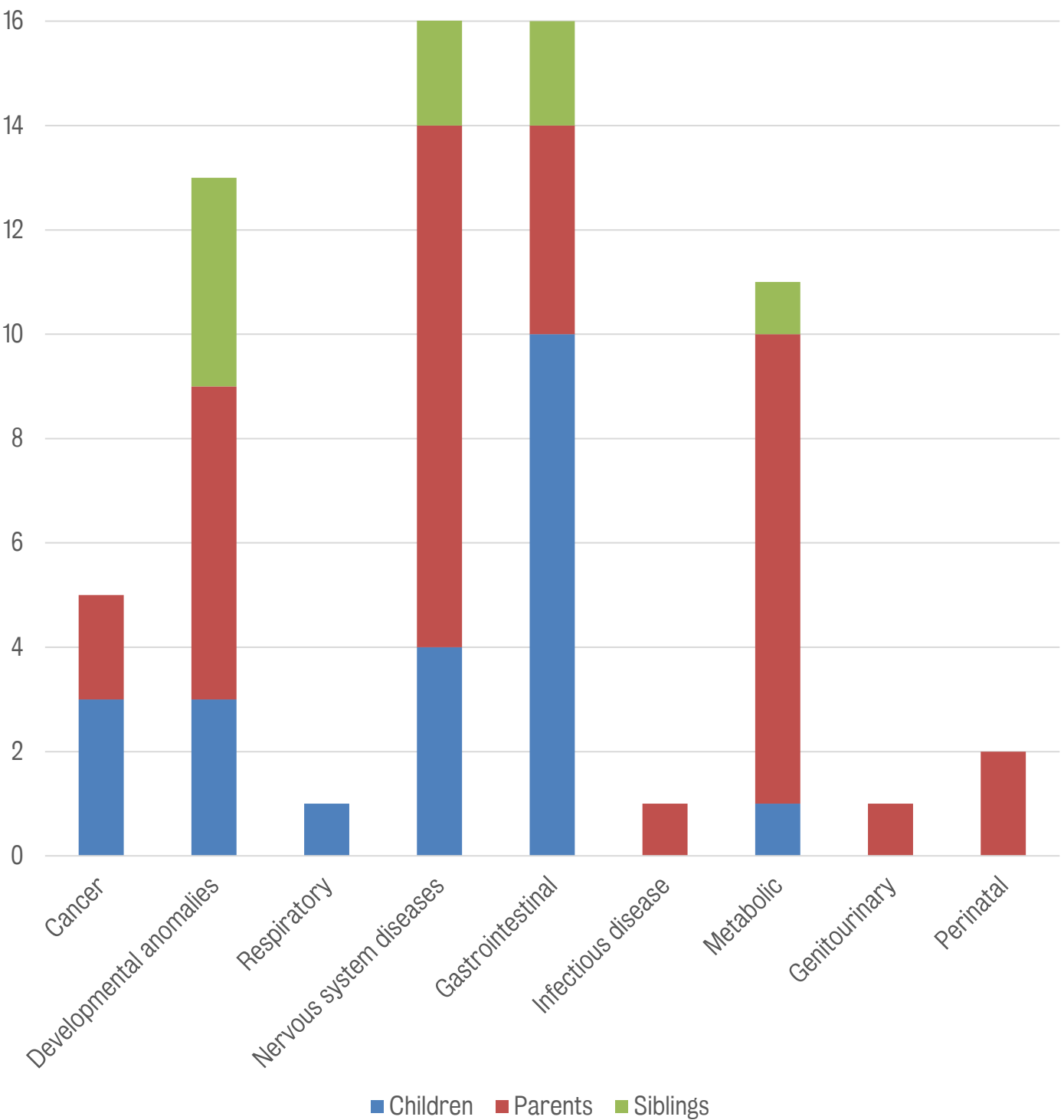
Interviews conducted by site



Recruitment by diagnosis

Current paediatric palliative care literature has largely focused on oncology patients so we have been purposively sampling to ensure we hear the experiences of families of children of different ages, living with different conditions, from different areas across the UK. Diagnoses have been grouped using ICD-11 classifications.

Diagnosis of child for child, parent and sibling interviews



PPI

We are delighted to have welcomed additional PPI (patient and public involvement) representatives to join our study group. These individuals who have had experience of caring for children with life-limiting and life-threatening conditions will be joining us for our steering group meetings, and providing feedback on patient facing documents, abstracts submissions and publications.

Additionally, we are working with the Young People's Advisory Group (YPAG) at GOSH who have provided us with opportunities to share our research and future ideas with young people there.



Steering group:

Our first closed steering group meeting was held on Monday 3rd February 2020 at King's College London. This was a great opportunity for us to meet and discuss current recruitment, ideas for moving forward and study timelines. Decisions suggested by the steering group have already been implemented as ethics amendments and we are grateful for all those who attended and contributed.

The next closed meeting is scheduled for Wednesday 15th July 2020 at the Cicely Saunders Institute with options for joining remotely.

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Steering group: Jane Green, Angela Logun, Lydia Bate, 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 Steve Marshall, Dr Clare Ellis-Smith, Professor Irene Higginson, Dr Gao Wei, Dr Sue Picton, Dr Pat Sartori, Dr Michelle Hills, Julie Hall-Carmichael.