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

Newsletter Issue 4, 20th August 2020

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Welcome to our Summer edition of the C-POS newsletter. Over the last few months the C-POS study has adapted to new ways of working, most notably by conducting remote interviews over the phone or via video software. We are delighted to have spoken to more families and commissioners over this time and are now very close to our targets for our stakeholder groups. This phase of the study closes for recruitment on the **30th September 2020.**

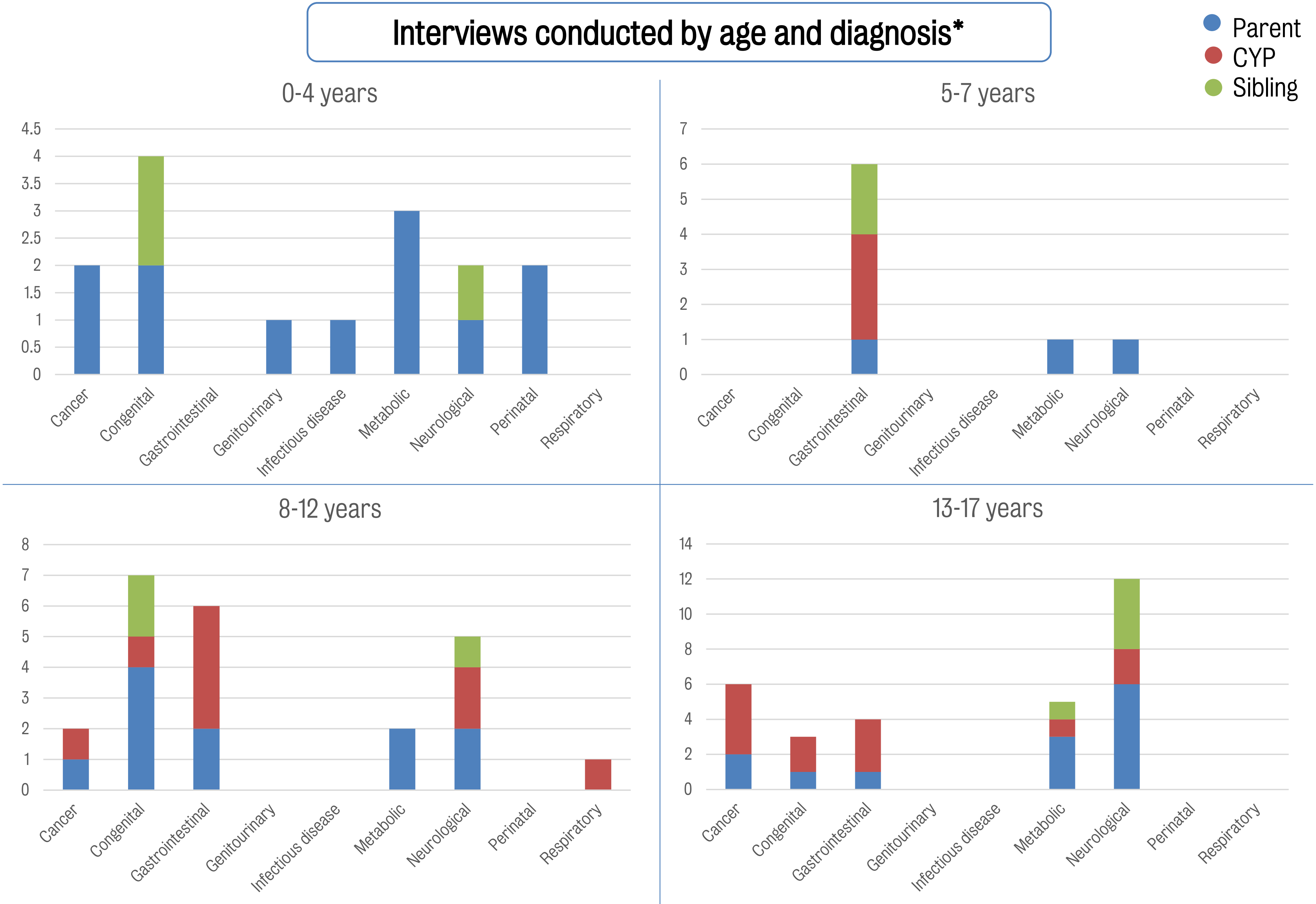
We have now completed interviews with 24 children, 39 parents, 15 healthcare professionals, 13 siblings and 11 commissioners. We are working with our clinical sites to recruit **6 more children** and **4 more commissioners** before the study closes.

We also presented our project at the Great Ormond Street Young People's Advisory Group. They enjoyed hearing about the project and made suggestions about the practicality of the C-POS measure. The team came away with really useful ideas to take forward and we look forward to going back to the group with our main study findings. Read one member's blog about the meeting here.

> One of the things I enjoyed the most was learning about the C-POS study; this is a questionnaire to find out seriously ill children are feeling. I felt like it was both fun and important to consider how this questionnaire would be received by young and older children. YPAG had to think about how children would answer the questions and how far back the children could remember

Sandra, GOSH YPAG member

Interviews conducted by age and diagnosis*



*Conditions have been classified using ICD-10 classifications

Steering group:

We held our second steering group meeting in July which provided an opportunity to explore the initial data and themes arising from our qualitative interviews. We were joined by our new patient and public involvement (PPI) representatives who have shared their reasons for getting involved in the C-POS study.

Lydia Bate, PPI member:

I became involved with the Royal Marsden's End of Life Care PATCH Group after losing my son Fabian, who was treated at the Royal Marsden from 2006 until the end of 2014. Fabian was known and loved by the teams who cared for him at the Marsden and GOSH throughout his treatment for Acute Lymphoblastic Leukaemia. It has been good to give back a little and to help others who are journeying the unspeakable path of losing a child. It is a privilege to now be invited into the C-POS Steering Group, due to the valuable work they are pursuing in this very sensitive area of support for both child and family affected by life-limiting illness.

Fabian's legacy lives on in 'Fabian's Childhood Cancer Trust' (FCCT),based near Hampton Court, set up in his memory to help families who have a child diagnosed with cancer. We raise funds to help out on the ward at the Marsden, and elsewhere with 'Treat Bags' that are filled with toiletries and treats for parents. We help to bring a little 'cheer' to the wards from time to time by arranging different experiences, including 'Strictly Come Dancing' performer visits and gifts for the children at Christmas. FCCT have also been able to supply families from the Marsden with Legoland tickets, offer fingerprint jewellery, and donate craft materials for the Memory Day at our local Children's Hospice.

We have ties with the Irving laboratory at the Wolfson Childhood Cancer Research Centre, Newcastle University, where Professor Julie Irving leads research into relapsed childhood Acute Lymphoblastic Leukaemia. We raise funds to support this work and provide scientific instrumentation for the Irving laboratory. (The Wolfson Centre works closely with the Children's work at the Royal Marsden in Surrey).

I also help run a community Bereavement support cafe and 'The Bereavement Journey' course at St. Marys Molesey where local people have the chance to talk with trained 'listeners' at the cafe. (Princess Alice Hospice run the training we have received). 'The Bereavement Journey' is a 6 week course available nationally, which offers support for the bereaved.

https://m.facebook.com/FabiansCCT/
http://www.fabianstrust.org.uk/

Fabian's
childhood cancer trust
www.fabianstrust.org.uk

Angela Logun, PPI member:

My daughter Daniella passed away from a brain tumour in 2016. Our lived experience caring for Dannie was painful and gave us first hand insight into the gaps in the availability of wellbeing support to families with childhood brain tumours. Today, we have set up the Daniella Logun Foundation in Dannie's memory, to provide holistic wellbeing support to families with childhood brain tumours, from the point of diagnosis. We are members of Together For Short Lives and were delighted to participate in the KCL C-POS research study. The King's College C-POS research team work with multiple local and national stakeholders to develop a tool that will measure the symptoms of children with life-limiting conditions and the concerns of their families. The opportunity to sit at the table at the C-POS steering group meeting means the we have a timely opportunity to humbly provide on-going patient-insight & input as well as influence this change opportunity for the wellbeing of many families with life-limiting childhood illnesses.

Unfortunately, ideal CYP measures do not currently exist. This is therefore an exciting and innovative opportunity that focuses on the measurement of the holistic wellbeing priorities of these CYP & their families during the child's care. Families will be able to identify and prioritise their child's care outcomes with their child's healthcare professionals. Clinicians will be able to conduct more thorough assessments and monitoring and this will help commissioners remain patient centred and CYP outcomes based.

The Daniella Logun Foundation believe that when a child is diagnosed with a brain tumour (or life limiting condition) medial care takes over and the wellbeing of the family is (inadvertently) neglected. This emotional trauma plays out for life and the KCL C-POS project is a positive step in the right direction to help change this. We are grateful for a seat at the table.

Website: www.thedaniellalogunfoundation.org
Twitter: @DaniellaLogun
| Instagram: daniellalogun |
Facebook: TheDaniellaLogunFDN

THE DANIELLA LOGUN FOUNDATION
Supporting Children & Young People with brain tumours and their families

Contacts:
Professor Richard Harding: Principal Investigator: pa-richardharding@kcl.ac.uk
Lucy Coombes: PhD Student: lucy.coombes@kcl.ac.uk
Anna Roach: Study Coordinator: anna.e.roach@kcl.ac.uk
Dr Debbie Braybrook: Research Associate: debbie.braybrook@kcl.ac.uk

@CYP_CSI

Steering group: Dr AK Anderson, Lydia Bate, Professor Myra Bluebond-Langner, Dr Katherine Bristowe, Dr Rachel Burman, Lizzie Chambers, Professor Sir Alan Craft, Dr Finella Craig, Professor Julia Downing, Dr Clare Ellis-Smith, Professor Bobbie Farsides, Professor Lorna Fraser, Professor Sara Fovargue, Dr Ann Goldman, Jane Green, Julie Hall-Carmichael, Professor Irene Higginson, Dr Michelle Hills, Dr Jo Laddie, Angela Logun, Dr Steve Marshall, Dr Linda Maynard, Professor Fliss Murtagh, Dr Eve Namisango, Dr Sue Picton, Dr Pat Sartori, Professor Gao Wei