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

Newsletter Issue 14, 1st August 2023

Partners:

Welcome to the Summer edition of the C-POS newsletter

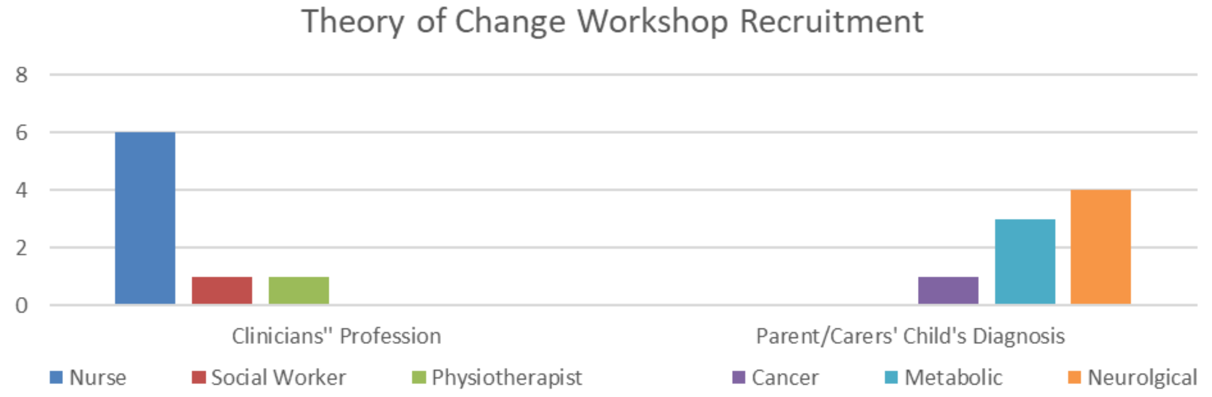
The C-POS Team have been enjoying a busy last few months. We have been working closely with clinical teams to recruit to the validation study, which is ongoing until the end of the year. Alongside this we have conducted Theory of Change workshops, attended and presented at conferences, and published papers.

In May, C-POS had a stand at the Dying Matters event at King's College Hospital. We spoke to health and social care professionals from across the hospital, and members of the public about paediatric palliative care research, and the public and patient involvement work that helps to shape it.

The annual Florence Nightingale Faculty of Nursing, midwifery and Palliative Care Awards were held in early July. The C-POS team were nominated for the Collaborative Research Excellence Award (which recognises research teams that have engaged in outstanding collaborative work, within the faculty, with impactful results) and were awarded the Research Innovation Award (which recognises the achievements of individuals or team that have demonstrated outstanding innovation in research, including new discoveries or methodologies).

Theory of Change Workshops Update

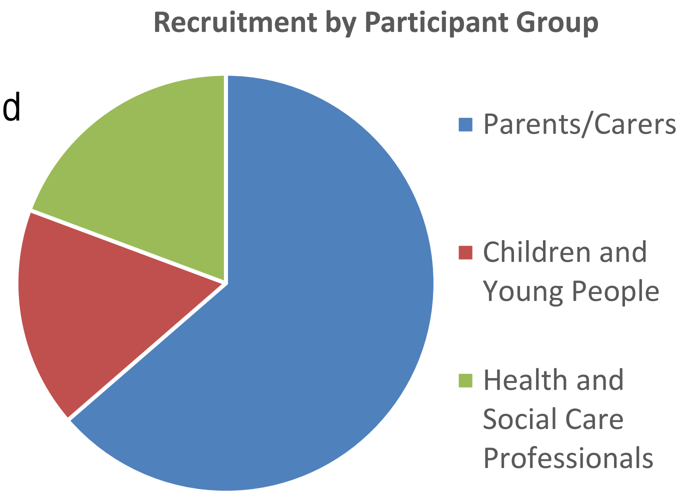
We would like to thank everyone who shared the adverts for or participated in our Theory of Change Workshops. The results have helped us to develop a preliminary plan for how we can implement C-POS into routine care to help improve outcomes for children, young people and their families.



Validation Study Update

So far 56 parents/carers, 15 children and young people, and 17 health and social care professionals have participated.

We are really grateful for the support for the study from all of our sites, and appreciate all of their hard work in recruiting children, young people and their families to take part in our study.



7th National Patient Reported Outcome Measures (PROMs) Research Conference

In June the team attended the 7th National Patient Reported Outcome Measures Research Conference in Sheffield, which focussed on PROMs Across the Lifespan.

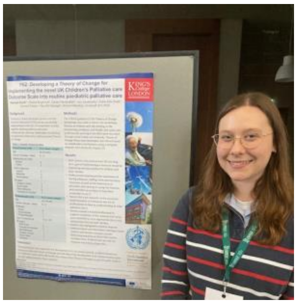
Lucy Coombes presented findings from her work on the C-POS study as part of an invited plenary session on *'The challenges relating to Measuring outcomes at the three extremes – in childhood, life-Limiting conditions and older people'*

University of Sheffield ISOQOL InSpired Health Outcomes NIHR | Research Design Service Yorkshire and Humber NIHR | Applied Research Collaboration Yorkshire and Humber Oxford University Innovation University of Oxford Clinical Outcomes

6th UK and Ireland Implementation Science Research Conference 2023

In July the team attended the 6th UK and Ireland Implementation Science Research Conference 2023 hosted at the University of Limerick in collaboration with King's College London.

Hannah Scott presented her poster on *"Developing a Theory of Change for implementing the novel UK Children's Palliative care Outcome Scale into routine paediatric palliative care"* during the Rapid-Fire Oral Presentations session.



KING'S College LONDON

UNIVERSITY OF LIMERICK OLLSCOIL LUIMNIGH | Health Research Institute

HIST Health Implementation Science and Technology

NIHR | Applied Research Collaboration South London

6th UK and Ireland Implementation Science Research Conference 2023

Centre for Evidence and Implementation

UK IMPLEMENTATION SOCIETY

frontiers | Frontiers in Health Services

KING'S HEALTH PARTNERS

RESOLVE Resolving Symptoms in Cancer

Cicely Saunders International Better care at the end of life

HULL YORK MEDICAL SCHOOL

KING'S College LONDON

POS

PALLIATIVE OUTCOME SCALE (POS + IPOS) TRAINING DAYS 15TH & 16TH MAY 2023

POS and IPOS Workshops 2023

In May the team took part in the annual POS and IPOS workshop study days.

Daney Harðardóttir and Lucy Coombes gave a presentation on the development and initial validation of the C-POS measures, including ongoing psychometric testing and implementation work.

Royal College of Paediatrics and Child Health Conference 2023

RCPCH Royal College of Paediatrics and Child Health *Leading the way in Children's Health*

In May the team attended the Royal College of Paediatrics and Child Health Conference in Glasgow.

Dr Debbie Braybrook and Hannah Scott both presented abstracts in the *Paediatric Clinical Leaders: service planning, provision and best practice* session.

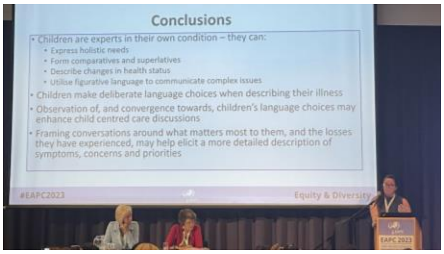
Dr Debbie Braybrook presented her abstract on *'What constitutes 'good quality care' from the perspectives of children and young people with life-limiting and life-threatening conditions'.*

Hannah Scott presented her abstract on *'Implementing child-centred outcome measures into routine practice: a systematic review'.*

European Association for Palliative Care 18th World Congress

In June the team attended the 18th World Congress of the European Association for Palliative Care in Rotterdam, the Netherlands.

As part of the Paediatric Palliative Care day Dr Katherine Bristowe and Hannah Scott presented in the session on 'The challenges of living with and dying from a life-limiting illness - the children's, parents' and professionals' experiences'


Conclusions
- Children are experts in their own condition – they can:
  - Express holistic needs
  - Form comparatives and superlatives
  - Describe changes in health status
  - Utilise figurative language to communicate complex issues
- Children make deliberate language choices when describing their illness
- Observation of, and convergence towards, children's language choices may enhance child centred care discussions
- Framing conversations around what matters most to them, and the losses they have experienced, may help elicit a more detailed description of symptoms, concerns and priorities

#EAPC2023 Equity & Diversity

Dr Katherine Bristowe presented her abstract on *"My Life Is a Mess but I Cope': An Analysis of the Language Children with Life-limiting and Life-Threatening Illnesses Use to Describe their Own Condition'*


EAPC 2023
18th World Congress
EQUITY & DIVERSITY
EAPC
15 - 17 June 2023
Rotterdam
The Netherlands

Ms Hannah May Scott
Research Assistant and PhD Candidate – Children's Palliative care Outcome Scale (C-POS)
@HannahM_Scott20 @CYP_CSI

Spiritual Concerns of Children with Life-Limiting and Life-Threatening Conditions and Their Families

#EAPC2023 Equity & Diversity

Hannah Scott presented her abstract on *'Spiritual Concerns of Children with Life-limiting and Life-threatening Conditions and their Families'.* The related article is published in the journal *Palliative Medicine* and is freely available to access online via the link: https://doi.org/10.1177/02692163231165l0. There is A brief summary podcast available on the *Palliative Medicine journal* website or through the *Apple iTunes Podcasts app:* https://traffic.libsyn.com/secure/sagepalliativemedicine/PallMed_CPOS_Spiritual_HS.mp3 & https://podcasts.apple.com/gb/podcast/sage-palliative-medicine-chronic-care/id1179036261?i=1000615997807)

The team also had two abstracts accepted as posters.


Design and administration of patient-centred outcome measures: the perspectives and preferences of children and young people with life-limiting/life-threatening conditions and their family members

Daney Harðardóttir presented a poster on '*Design and administration of patient-centred outcome measures: the perspectives and preferences of children and young people with life-limiting/life-threatening conditions and their family members'*


Development and initial validation of a novel outcome measure for use with children and young people with life-limiting and life-threatening conditions

Lucy Coombes presented a poster on the '*Development and initial validation of a novel outcome measure for use with children young people with life-limiting and life-threatening conditions'*, presenting all of her PhD work to date. This included the qualitative interview study (published in *European Journal of Paediatrics*: https://doi.org/10.1007/s00431-022-04566-w), systematic review (published in *Quality of Life Research*: https://doi.org/10.1007/s11136-021-02814-4), consensus and item generation work, and the cognitive interview study.

Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, King's College London: Research Seminar series – Research from students on the MSc programme in Palliative Care

In May Dr Nicola Ngiam, who has been working on the C-POS study in Singapore as part of her MSc studies, presented her work at the MSc Student Research Seminar.

Dr Ngiam discussed her cognitive interview study, which Evaluates the comprehensibility and feasibility of the Children's Palliative care Outcome Scale in Singapore.

INTRODUCTION

- Paediatric palliative care is unique
- Children and young people grow and develop
- Patient-reported outcome measure needed to evaluate outcome of care delivery

Publications

Our original research article exploring the preference of children and young people with life-limiting and life-threatening conditions in person-centred outcome measure design has been published online in the journal *The Patient – Patient-Centred Outcomes Research.* Key findings included the importance of designing brief measures with short recall periods and visually appealing response formats to help ensure measures are relevant, acceptable, and feasible for use. Measures should also be available in both paper and electronic formats and they should be administered in conjunction with a face-to-face interaction with a health and social care professional.

Coombes et al. Design and Administration of Patient-Centred Outcome Measures: The Perspectives of Children and Young People with Life-Limiting or Life-Threatening Conditions and Their Family Members. *The Patient – Patient-Centred Outcomes Research* (2023). https://doi.org/10.1007/s40271-023-00627-w

Our systematic review article on the implementation of child-centred outcome measures in routine paediatric healthcare practice has been published online in the journal *Health and Quality of Life Outcomes*. The review demonstrated the need for multiple strategies to facilitate implementation. Two key strategies identified include 1) educating clinicians, children and their families on using outcome measures and the benefits they can have, 2) addressing logistical and resources barriers, including time, staffing, and provision of funding and other resources such as office supplies. By addressing barriers, care and outcomes can be improved in paediatric settings.

Scott, H.M., Braybrook, D., Harðardóttir, D. et al. Implementation of child-centred outcome measures in routine paediatric healthcare practice: a systematic review. *Health and Quality of Life Outcomes* 21, 63 (2023). https://doi.org/10.1186/s12955-023-02143-9

Publications from C-POS in Turkey and Jordan

We are excited to share two new articles from research conducted by colleagues in Jordan and Turkey, led by Dr Sabah Boufkhed, with the Center for Palliative & Cancer Care in Conflict's Department of Palliative Care at King Hussein Cancer Center (Jordan) and the Department of Pediatric Oncology at Hacettepe University's Faculty of Medicine and Cancer Institute (Turkey).

The paper on *Concerns and priority outcomes for children with advanced cancer and their families in the Middle East* has been published in *Frontiers in Oncology.* The research found five areas of main concern for children receiving palliative care and their parents and caregivers: physical pain and symptoms; psychological concerns and needs; negative impact on social life; spirituality, uncertainty over the future and "Tawakkul"; and burden on caregivers and their families. The work shows the urgent need to invest sustainably in palliative care to better support patients and families, and to address structural issues like the lack of carer's leave or the lack of access to palliative care services within these countries the wider region.

Boufkhed S, et al. (2023) Concerns and priority outcomes for children with advanced cancer and their families in the Middle East: A cross-national qualitative study. *Frontiers in Oncology*. **13**, p. e1120990. https://doi.org/10.3389/fonc.2023.1120990

The paper on *Communication and information sharing with pediatric patients including refugees with advanced cancer, their caregivers, and health care professionals in Jordan*, has also published in *Frontiers in Oncology.* Four major themes were identified: 1) Hiding information between the three stakeholders; 2) Communication and sharing of clinical (physical) versus non-clinical (social, spiritual, and psychological) information; 3) Preferred communication styles such as use of a companionate approach by acknowledging patients and caregivers' suffering, building a trustful relationship, proactive information sharing, considering child age and medical status, parents as facilitators in communication, and patients' and caregivers' health literacy; 4) Communication and information sharing with refugees where they had dialect issues, which hindered effective communication. The novel findings of this study should inform better child-centered practices and better engage them in their care decisions.

Alarjeh G, et al. (2023) Communication and information sharing with pediatric patients including refugees with advanced cancer, their caregivers, and health care professionals in Jordan: a qualitative study. *Frontiers in Oncology*. **13**,p. e1118992. https://doi.org/10.3389/fonc.2023.1118992

Patient and Public Involvement

In May, the team worked with the Leeds Young Research Owls and our three bereaved parent PPI members as part of developing the next steps in the C-POS project.

Then, in July, the team met with the Great Ormond Street Hospital Young People's Advisory Group. The team fed back to the group in a 'you said, we did' style to show the group where their previous comments and suggestions had fed into the project. The team also asked for the young people's feedback on the 'map for implementing C-POS' that was developed from the Theory of Change Workshops and their thoughts on some ideas for the new study logo (coming soon!).

The C-POS team are incredibly grateful for all of the time and effort all our public involvement members have contribute to our work.

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