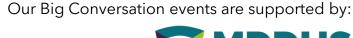
# Children's Palliative Care Outcome Scale (C-POS)

Big Conversation Thursday 13th February 2025











Our Big Conversation events are supported by:



## Welcome and introductions

Catherine Hodge, Programme Development Lead Hospice UK & Katie Tallowin, Head of Education and Professional Development - Together for Short Lives



Agenda		
14:00	Welcome and Introductions	<b>Catherine Hodge</b> , Programme Development Lead - Hospice UK and <b>Katie Tallowin,</b> Head of Education and Professional Development - Together for Short Lives
14:05	Quality and evidence in paediatric palliative care	<b>Professor Lorna Fraser,</b> Professor of Palliative Care and Child Health - Cicely Saunders Institute and School of Life Sciences and Population Health, King's College London
14:25	The Children's Palliative Care Outcome Scale (C-POS)	<b>Professor Richard Harding,</b> Executive Dean - Florence Nightingale Faculty of Nursing Midwifery & Palliative Care, Herbert Dunhill Chair of Palliative Care & Rehabilitation - Cicely Saunders Institute, King's College London
14:45	A Parent's View	<b>Angela Logun,</b> Parent Participant - C-POS, Co-Founder and CEO - The Daniella Logun Foundation
15:00	Q&A	Prof Richard Harding, Prof Lorna Fraser, Angela Logun, Dr Emily Harrop, Medical Director, Helen & Douglas House, Research Lead, Association of Paediatric Palliative Medicine and Lizzie Chambers, Programme Manager, International Children's Palliative Care Network
15:25 - 15:30	Close	Catherine Hodge and Katie Tallowin



# Quality and evidence in paediatric palliative care

Lorna Fraser King's College London















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

Prof Richard Harding on behalf of the C-POS research group







#### Outcome measures



 Outcome measures assess the change in health or well-being of a patient and/or their family that has occurred due to intervention by a health or social care professional

- Ideally outcomes are reported by the patient using patient reported outcome measures (PROMs) where this is not possible patient-centred outcome measures (PCOMs) are used as they allow for proxy-reporting (i.e. by parent/carer or staff)<sup>1</sup>
  - PCOMs can also be used to assess the needs of carers
- 1. Etkind SN, Daveson BA, Kwok W, Witt J, Bausewein C, Higginson IJ, et al. Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. J Pain Symptom Manage. 2015;49(3):611-24.

#### Outcome measures in Clinical Practice



- Collecting patient reported outcomes has several applications in clinical practice. Data can be used:
  - When considered at the individual and group level
  - Within and outside clinician-patient interaction<sup>2</sup>

Level of aggregation of PRO data			
Used at the clinician-		Individual	Group
patient interface	Yes	Screening	Decision aids
		Monitoring	
		Promoting patient-centred care	
	No	Facilitating communication within multidisciplinary teams	Population monitoring and assessing quality of care

2. Greenhalgh J. The applications of PROs in clinical practice: what are they, do they work, and why? Qual Life Res. 2009 Feb;18(1):115-23.

#### Outcome measures in Clinical Practice



- In adult practice outcome measures have been shown to:
  - Improve service quality and promote patient-centred care
  - Lead to better symptom recognition
  - Increase referrals
  - Lead to better quality of life<sup>3</sup>
- Developing a valid and reliable outcome measure for the paediatric palliative population has been identified as both a research and clinical priority<sup>4,5</sup>this will help:
  - Children and families identify priorities and outcomes of care with clinicians
  - Clinicians conduct thorough assessments and monitor outcomes
  - Commissioners ensure that commissioning is patient-centred and outcome-based

<sup>&</sup>lt;sup>4</sup>National Institute for Health and Care Excellence, End of life care for infants, children and young people with life-limiting conditions: planning and management. 2021: London.

<sup>&</sup>lt;sup>5</sup>Harding R, Chambers L, Bluebond-Langner M. Advancing the science of outcome measurement in paediatric palliative care. International Journal of Palliative Nursing. 2019;25(2):72-9.

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



- The use of outcome assessment tools is important to measure quality and effectiveness of care.
- The population of children requiring paediatric palliative care services is diverse.
- There are no 'ideal' outcome assessment tools validated specifically for use within paediatric palliative care.
  - The domains of generic health-related quality-of-life measures are not relevant to all children receiving palliative care
  - Some domains within disease-specific measures are only relevant for that specific

population.

Review Article



Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use Polliative Medicine
2016, Vol. 30(10) 935–949
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/0269216316649155
pmj.sagepub.com
SSAGE

Lucy H Coombes<sup>1</sup>, Theresa Wiseman<sup>2,3</sup>, Grace Lucas<sup>2</sup>, Amrit Sangha<sup>2</sup> and Fliss EM Murtagh<sup>4</sup>

#### Aim and methods



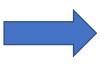
<u>Aim:</u> to develop a family- and patient-centred outcome measure for children and young people with life-limiting and life-threatening conditions and their families, and to evaluate its psychometric properties

- Multi-phase, mixed-methods study
  - Including qualitative interviews, systematic review, a Delphi survey, an item generation meeting, cognitive interviews, and a longitudinal observational study
- Following COSMIN and Rothrock guidance on outcome measure development and evaluation

Phase 1: Development



Phase 2: Validation



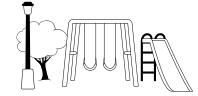
Phase 3: Implementation

## Pre-Development Work



 An expert group of 36 UK-wide clinicians, advocates, and researchers was convened to elicit views on the domains/items to include in a person-centred outcome measure, implementation challenges and requirements for use in routine care by practitioners.









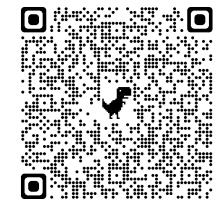




Items to be included were: specific symptoms, education, play and social interaction, parental time for partner and other children, sex and intimacy, and sibling wellbeing.

Implementation challenges: supporting children and young people to engage meaningfully, that the instrument could be seen as a 'test' of parents' care quality, raising unrealistic expectations, proxy validity.

Considerations for routine use: There is a need for clear administration and interpretation guidance and for data ownership/access to be agreed.





## Phase 1: Development



## Development: Qualitative Interview Study



**Aim** - Identify child and young person, their families, professional and commissioner priorities for outcomes of care and measure completion methods

#### 106 interviews conducted:

- -26 children/young people
- -40 parents/carers
- -13 siblings
- -12 commissioners
- 15 health and social care professionals

European Journal of Pediatrics https://doi.org/10.1007/s00431-022-04566-w

#### RESEARCH



Achieving child-centred care for children and young people with life-limiting and life-threatening conditions—a qualitative interview study

Lucy Coombes  $^{1,2} \cdot$  Debbie Braybrook  $^1 \cdot$  Anna Roach  $^1 \cdot$  Hannah Scott  $^1 \cdot$  Daney Harðardóttir  $^1 \cdot$  Katherine Bristowe  $^1 \cdot$  Clare Ellis-Smith  $^1 \cdot$  Myra Bluebond-Langner  $^{3,6} \cdot$  Lorna K. Fraser  $^4 \cdot$  Julia Downing  $^{1,5} \cdot$  Bobbie Farsides  $^7 \cdot$  Fliss E. M. Murtagh  $^8 \cdot$  Richard Harding  $^1 \cdot$  on behalf of C-POS

Received: 11 May 2022 / Revised: 7 July 2022 / Accepted: 13 July 2022 © The Author(s) 2022



## Development: qualitative interview study



Pain
Other symptoms e.g. seizures
Symptom Management
Physical appearance

Physical

Psycho-

**Emotional** 

Cultural beliefs and needs
Life unlived
Uncertainty of the future

Spiritual/

Existential

Cultural beliefs and needs
Life unlived
Uncertainty of the future

Meaning of life

COVID-19

Impact on Paediatric Palliative
Care

**OPEN ACCESS PAPER** 

**Normality** 

Not knowing any different Returning to normality Adjusting to a new normal Vol. 64 No. 1 July 2022

Journal of Pain and Symptom Management e1

**Brief Report** 

Richard Harding, BSc, MSc, DipSW, PhD

COVID-19: Impact on Pediatric Palliative Care

Check for updates

Hannah May Scott, BA(Hons), MSc, Lucy Coombes, RN (Child), BSc (Hons), MSc, Debbie Braybrook, BSc, PhD, Anna Roach, BSc, MSc, Daney Harðardóttir, BSc, MSc, Katherine Bristowe, BA(Hons), MA, PhD, Clare Ellis-Smith, BSc, PhD, Irene Higginson, OBE BMedSci BMBS PhD FMedSci FRCP FFPHM, Wei Gao, MD, PhD, Myra Bluebond-Langner, PhD, Hon. FRCPCH, Bobbie Farsides, BSc, PhD, Fliss EM Murtagh, PhD, FRCP, MRCGP, MBBS, Lorna K Fraser, MBChB, MRCPCH, MSc, MMedSci, PhD, PGCAP, and

Emotions

Sleep

Access to support Impact on family life

Memory making

Meeting others who are the same

Social/ Practical

Service provision
Friendships
Advanced Care Planning
Hobbies and play
Balancing needs of the family



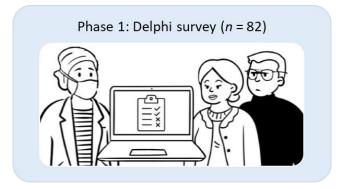
## Development: Delphi Survey



**Aim -** Obtain stakeholder consensus on which outcomes identified through interviews and previous systematic review (Namisango, 2019)\* to include on C-POS

Four rounds of a Delphi survey, with 28 adult participants completing final round

Round 4 – ranking results (top 10 outcomes)	Median rank (% ranking in top 50%)
Pain	1 (92.9)
Ability to live life to the fullest	2 (96.4)
Breathing and respiratory difficulties	3 (100)
Child/young person being able to do things they enjoy	4 (96.4)
Having sufficient support from HSCPs	5 (92.9)
Having a plan for future care	6 (89.3)
Dystonia/muscle spasms	8 (78.6)
Being supported/enabled to express emotions & feelings	9 (82.1)
Having psychological needs met	10 (78.6)
Sleeping difficulties	10.5 (89.3)





<sup>\*</sup>Namisango E, Bristowe K, Allsop MJ, Murtagh FEM, Abas M, Higginson IJ, et al. Symptoms and Concerns Among Children and Young People with Life-Limiting and Life-Threatening Conditions: A Systematic Review Highlighting Meaningful Health Outcomes. Patient. 2019;12(1):15-55.

## Development: Measurement design



**Aim:** to systematically appraise the evidence on recall period, response scale format, mode of administration and approaches needed to enable children and young people <19 years to participate in valid and reliable self-reporting of their health outcomes.

- Systematic review including 81 papers
- Supports the acceptability of C-POS and enables children and young people to self-report their health outcomes



 Data from semi-structured qualitative interviews also informed measurement design



#### 8 recommendations made:

- 1. Development should include both cognitive interview studies, and psychometric testing to enhance understanding of how children formulate answers.
- 2. 5-7 years olds should be given a dichotomous response format; those 7 years and over should be given a three-point response format.
- 3. Recall period should be kept short, no more than 48 hours for those 5-7 years.
- 4. PROMS should have a computerised version.
- 5. Proxy measures should be used for those under 5 years old.
- 6. Measures should be visually appealing, to improve acceptability.
- 7. PROM studies should be analysed and reported in developmentally appropriate age bands.
- 8. Developers should consider different versions of a measure for different age groups.

## Development: Item Generation



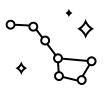
- Item generation meeting was held with the study steering group to design prototype C-POS for further testing
- 22 participants: health and social care professionals, academics (including clinical academics), bereaved parents
- Items for C-POS versions selected and first versions of measures drafted
  - $\circ$  <2 years or cognitive equivalent parent proxy version (8 questions about the child; 5 about the family)
  - 2-17 years or cognitive equivalent parent proxy version (8 questions about the child; 5 about the family)
  - 5-7 years or cognitive equivalent Mercury (8 questions, simple language)
  - 8-12 years or cognitive equivalent Saturn (8 questions)
  - 13-17 years or cognitive equivalent Neptune (8 questions, adult language)













## Phase 2: Validation



## Validation: Cognitive Interviews



**Aim -** To test the C-POS for comprehensibility, comprehensiveness and acceptability with children and young people with life-limiting and life-threatening conditions and their parents/carers.

- 48 interviews conducted (36 parents/carers; 12 children/young people)
- Cognitive interviewing helped to refine the prototype C-POS versions, especially to be inclusive of children who are non-verbal.
- Parent participants felt that some distress when answering questions was acceptable and that despite this all questions were appropriate to ask.



#### **FINAL VERSIONS**

- A Parent/carer version A younger and non-communicative children
- Parent/carer version B older children and those who can communicate
- Mercury recall of yesterday and today; 3-point response format
- Saturn recall of past week; 3-point response format
  - Neptune recall of past week; 5-point response format



## Implementation: Systematic Review



2023

**Aim -** to identify and synthesise evidence of the determinants, strategies, and mechanisms that influence the implementation of person-centred outcome measures into paediatric healthcare practice.

#### **Facilitators for implementation**

- Educating and training staff and families on how to implement and use the measure, advantages of using measures over current practice and benefits on patient care and outcomes
- Addressing logistical and resource barriers, including time, staffing, and provision of funding and resources such as
  office supplies.
- Having a comprehensive plan for implementation agreed upon in advanced by all staff involved
- Formally appointed implementation leads or implementation champions
- 'Buy-in' from staff and commitment and support from leadership

#### **Barriers to implementation**

- Lack of knowledge about how the measure may improve care and outcomes
- The complexity of using and implementing the measure
- Staff readiness and willingness to change current practice, including perceived disruption to workflows
- Lack of resources including funding and staff to support sustained used

#### **OPEN ACCESS**



# Implementation: Anticipated benefits, risks, barriers, and facilitators



2024

**Aim** - To identify the anticipated benefits, risks, barriers, and facilitators to implementing person-centred outcome measures (PCOMs) for children with life-limiting and life-threatening conditions.

106 interviews with children, families, and professionals



OPEN ACCESS



#### 8 recommendations made:

- 1. Children and families must be involved in the development of PCOMs to ensure that measure characteristics do not act as barriers to implementation
- 2. Strategies for implementation should be designed collaboratively with professionals to ensure they are optimal
- 3. The benefits of PCOMs for care should be explained to families and professionals to facilitate implementation
- 4. The professional administering the measure should be known and trusted by the child and family
- 5. Completion of the measure should be a collaborative dialogue, in which the child, family, and healthcare professional are fully involved where possible and appropriate
- 6. Professionals should respond appropriately to issues raised through completion of the measure and ensure children and families are involved and informed of any changes in care as a result
- 7. Discussions should be held with children and families to address privacy concerns, find out who they are comfortable with their information being shared with, and to explain use and benefits of information-sharing in relation to PCOMs
- 8. Once robustly and scientifically developed and validated, PCOMs should be translated to locally relevant languages, to increase usability for families where the local language is not their primary language

#### Benefits

- Understanding what is important to patients and families
- Improved communication and collaborative working
- Standardising data collection and reporting

#### Risks

- Negative impacts on care
- Person-Centred
   Outcome Measures not used as intended

#### Barriers

- Acceptability and usability for children
- Burden and Capacity
- Confidentiality and information sharing
- Language barriers

#### **Facilitators**

- Explaining the benefits and securing 'buy-in'
- Knowing and trusting measure administrators
- Language being meaningful

### International collaboration



- African C-POS has been developed by APCA & ICPCN with KCL, NIHR funding for implementation
- Similar studies being conducted in **Turkey** and **Jordan**, refugee children ESRC funding
- Key paediatric palliative care providers in Australia and New Zealand to participate in C-POS:UK psychometric validation
- C-POS:UK:
  - cognitively tested in **Singapore** by MSc student
  - translated & cognitively tested in South Korea
  - being translated & cognitively tested in Japan
  - translation and cultural adaptation in **Taiwan**
  - plans underway for **Italian** adaptation



## Conclusions and future work

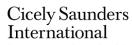


- An outcome measure for paediatric palliative care has been developed and its psychometric properties are being evaluated
- C-POS is the first patient-centred outcome measure designed for this population in the UK and it reflects the top priorities of children and families affected by life-limiting and life-threatening conditions
- Next steps are to implement the C-POS into routine clinical practice, to facilitate the assessment and monitoring of key outcomes

## **C-POS UK Partnerships**







Better care at the end of life



Newcastle together



































**All-Wales** 





University Hospitals Sussex Ashford and St. Peter's Hospitals









European Research Council Established by the European Commiss



Paediatric Palliative Care Network



























Hospital for Children Teaching Hospitals





NHS

Alder Hey Children's























**Hull University** 

Birmingham Bristol Royal Hospital



Imperial College Healthcare

North Tees and Hartlepool

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Peterborough

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Torbay and South Devon Children &









Homerton

**Tameside and Glossop Integrated Care** NHS Foundation Trust



Orthopaedic Hospital



Na Omi House

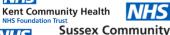
& Jacksplace

and young adults



hospices for children North West London











**Bradford Teaching Hospitals** 











The Robert Jones and Agnes Hunt







**Primary Care** 



**Royal Berkshire** 





and Social Care Trust



St Andrew's





Western Health







Angela Logun - PPI Update

13 Feb 2025

### Inspiration





Using Dannie's story inform quality improvements in Children's palliative care

- 1. Investigation
- 2. Diagnosis
- 3. Care Planning
- 4. Bereavement

#### The Problem Statement





What is the problem we are trying to solve?

When a child is diagnosed with a brain tumour/cancer, medical care takes over. Wellbeing of the child and family is inadvertently neglected.

The costs of wellbeing trauma play out for life.

#### The CPOS Scale



# Using lived experience to improve the standards of children's palliative care

- 1. Why CPOS?
- 2. Co-production
- 3. PPI Contributions





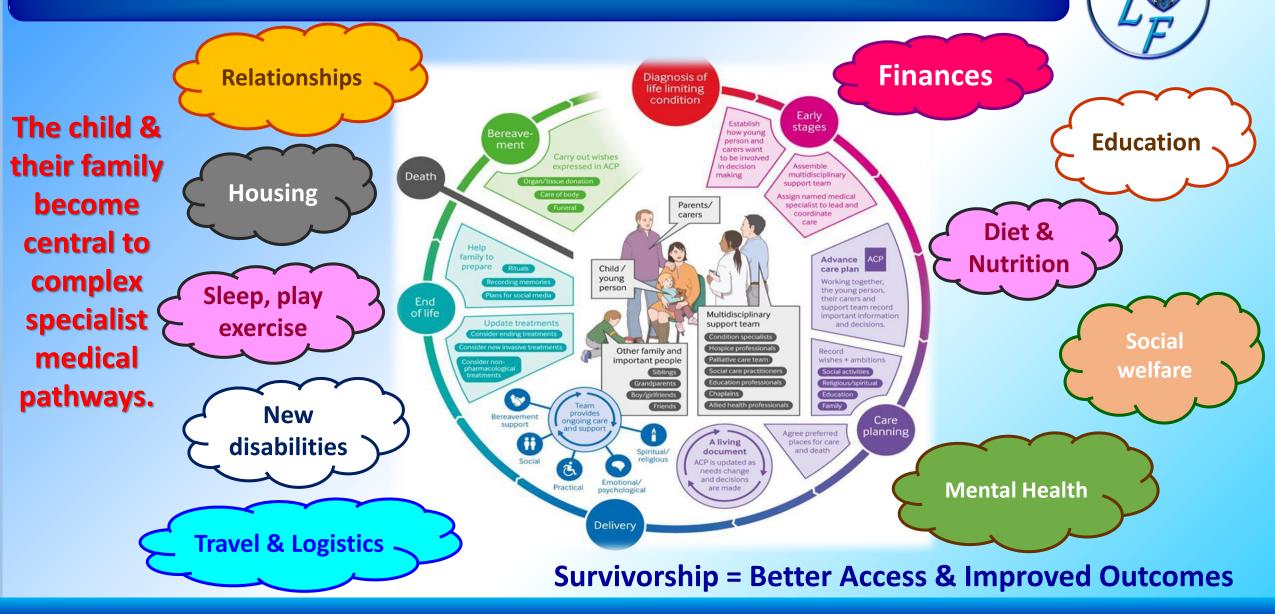
Supporting Children & Young People diagnosed with brain tumours, other cancers and their families.

Registered Charity No. 1189746 (England)

Link to the Charity

13 FEB 2025

## Holistic Wellbeing Impact & Priorities



#### What We Do



#### General

Befriending Counselling Psychological support Talking Listening



#### **Emotional:**

Validating, feelings & thoughts

**3D** 

DLF Core Families Cherry Blossom Families

Specialist

Prayer Spiritual Counselling Home & Virtual Support Christian Support Chaplaincy



## Wellbeing

Spiritual:
Faith & finding
meaning of life



Physical:
Meeting practical
care needs



Advocacy, language, meetings & paperwork

Door-Step drop - food parcels, DGB etc Lifestyle - nutrition, diet, fitness advice SEND Coordination & Litigation Support with technical jargon

#### **CPOS Value**



# Using lived experience to improve the standards of children's palliative care

- 1. Change Agent
- 2. Benefit
- 3. Beneficiaries
- 4. Take Away



### **Upcoming Events**



#### March

The Daniella Logun Foundation (DLF)

March is Brain Tumour Awareness Month (BTAM)

# Fundraising Bake Sale

**Boundary** 

House

**Cricket Field** Road. Uxbridge.

**UB8 1QG** 

Friday, 28 March 2025 1pm to 5pm

Pastries. Desserts, Cakes, Cupcakes, Homemade Delights





#### April

#### April is **DLF Fun Bike Ride**

Sat, 26 April 2025.

Start Time: TBC

Fundraising to support our Cherry Blossom families who have lost children to a childhood brain tumour or cancer.

Start: TBC

Featuring **## GREGGS** 

hrispy hreme

COSTCO



#DanniesLegacy | #familywellbeingmatters | #FaithHopeLove









December

www.thedaniellalogunfoundation.org ( ) SCAN ME

September

Twitter | @daniellalogun

... to support children with brain tumours and their families.

### Stay in Touch





# Hillingdon & the surrounding areas

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@TheDaniellaLogunFoundationDLF



www.thedaniellalogunfoundation.org

enquiries@thedaniellalogunfoundation.org







## Q&A





# Built of last



#### The Together for Short Lives conference

TOWARDS A STRONG, SUSTAINABLE FUTURE

Save the date 7 – 8 May 2025 Hilton, Manchester Deansgate







#### Clinical and Workforce Leaders Conference

## A one-day conference for those with an interest in the hospice workforce and patient care.

The 2025 conference will take place on Tuesday 29 April, Conference Aston, Birmingham.

It will look at the impact of innovation, research and collaboration on the future of work and hospice care.

Our early bird ticket rate is available to **members** who book **before 17 February 2025.** 



Scan the QR code to book



## **Big Conversations**

The Big Conversations series comprises webinars, workshops, and roundtables that enable our members to:

- learn more about key issues
- share knowledge and experience to inform our work
- discuss problems and solutions with peers
- get practical guidance to move work forward

We invite you to continue engaging with us in the months ahead, as we explore a range of important topics. Upcoming events:

- Assisted Dying: engage and support you workforce 20<sup>th</sup> February
- National Hospice Data 26<sup>th</sup> February





## Stay up to date



Scan me

Our <u>Member Update page</u> is updated regularly so you can keep up with our key work and priorities from week to week.

The page is hidden from the public and will not come up in web searches, so we'd recommend bookmarking it!



## Feedback Survey

Children's Palliative Care Outcome Scale (C-POS) 13th February 2025



Please consider sparing a few minutes to answer this survey, so that we can continue to improve future Big Conversations events:

https://forms.office.com/e/5snqRsMTsi



# Thank you



