Welcome to together for short lives

FUTURE PROOFING FUTURE MODELS OF CARE

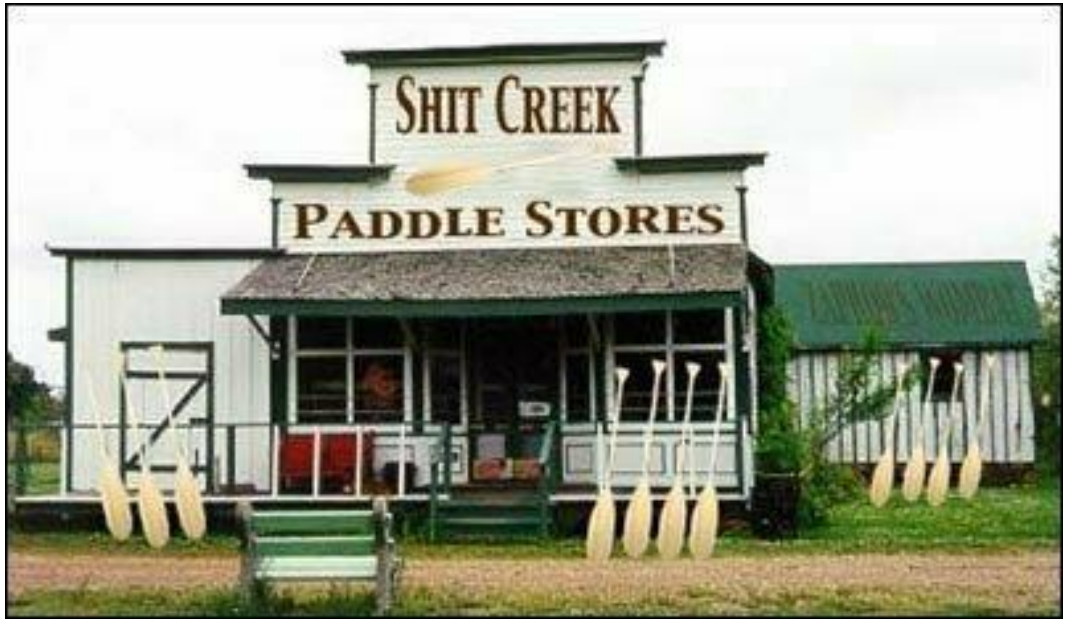
Hilary Cass

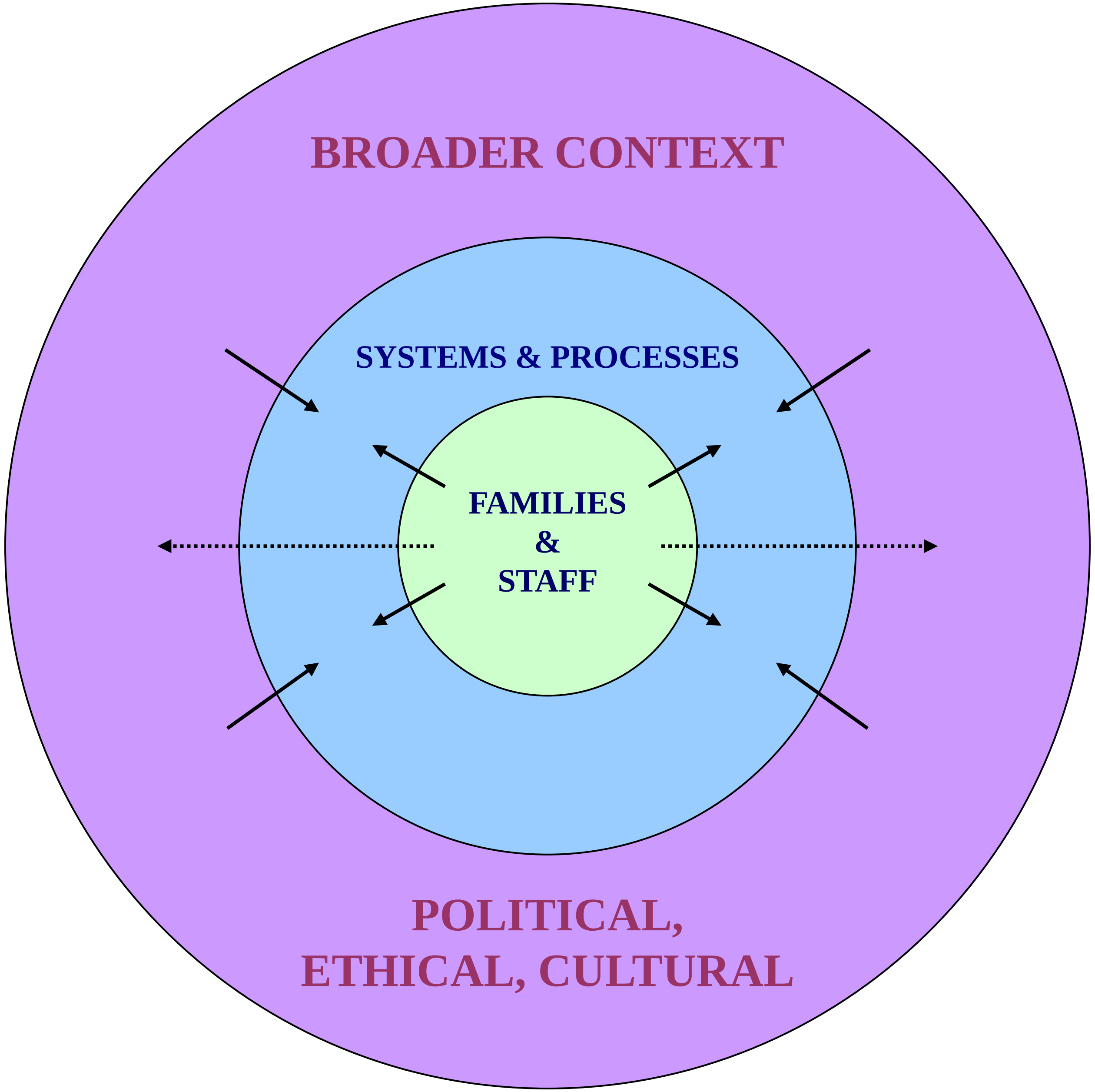
Chair, TfSL

LESSONS FROM A CASE HISTORY

- Shortfalls in clinical staffing
- Unacceptable ambulance wait times
- Inadequate information about risk
- Failure to manage chronic pain
- Failure to diagnose mental health problems
- Shortfalls in equipment
- Conflict with family
- Avoidable death

DON’T MENTION THE POLITICS. STAY UPBEAT!





BROADER CONTEXT

SYSTEMS & PROCESSES

FAMILIES
&
STAFF

POLITICAL,
ETHICAL, CULTURAL

CHILDREN AND FAMILIES

FAMILIES WITH CHILDREN WITH LIFE LIMITING CONDITIONS ARE AT RISK

- Economically
- Socially
- Physical and mental health

- How do we empower families?
- How do we support families?
- How do we lobby for and with families?

NHS AND SOCIAL CARE WORKFORCE WORKFORCE

STAFF

80/20 rule – TRAINING OF FRONT LINE STAFF

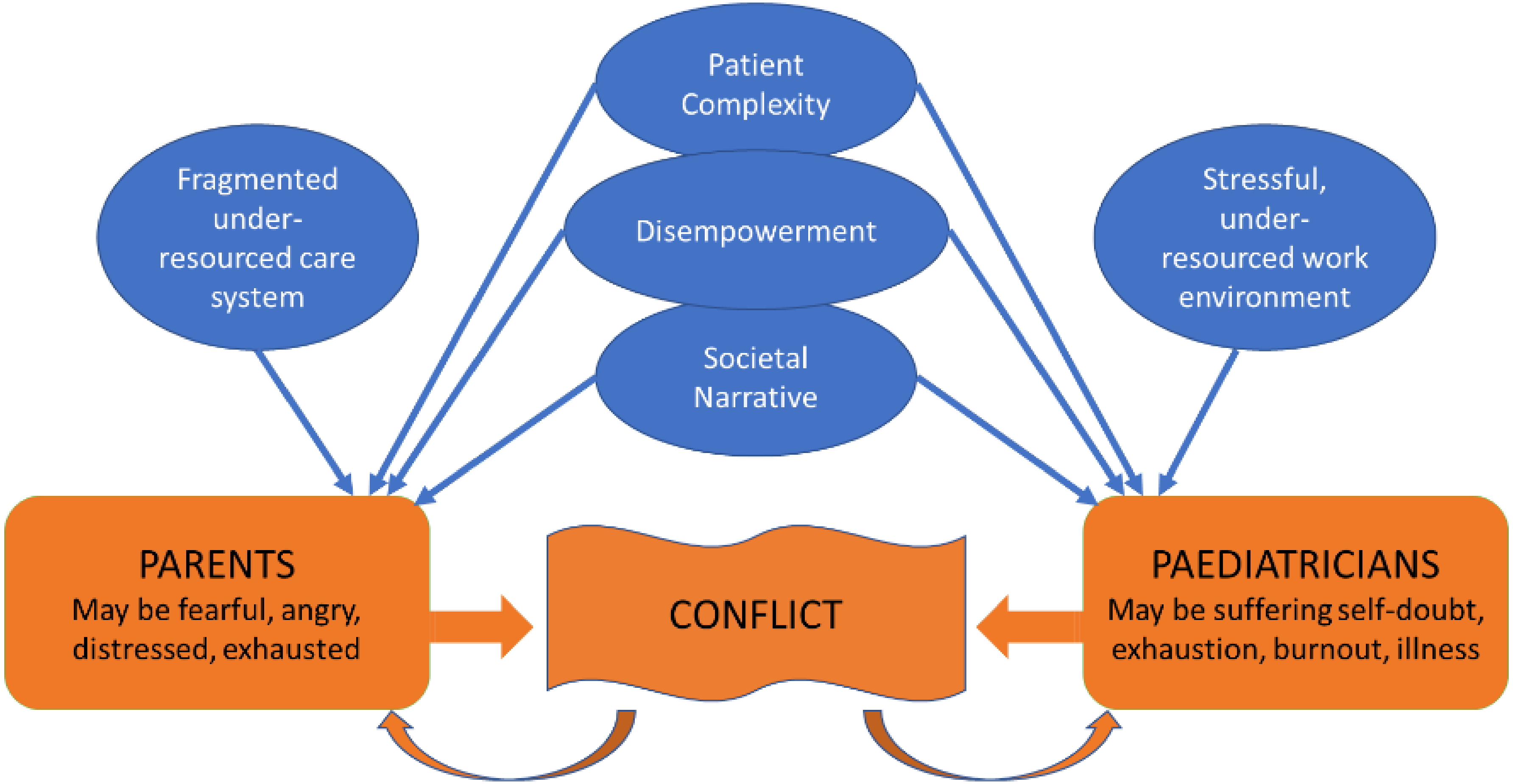
- **Advanced communication skills**
- **Recognising and de-escalating conflict**

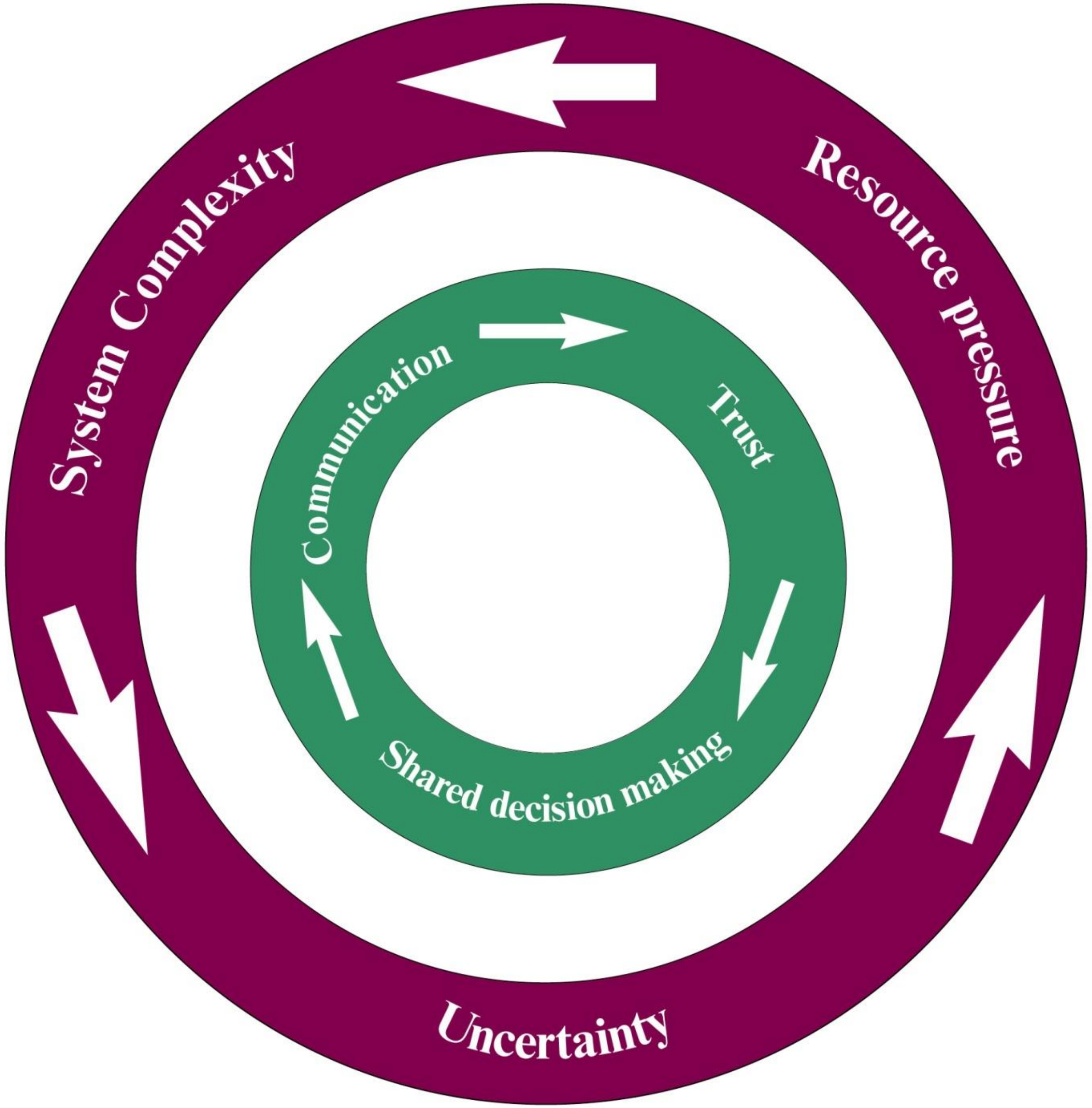
SPECIAL INTEREST DOCTORS / NURSE SPECIALISTS

- **We need to attract more staff into complex care AND find mechanisms to train**

SPECIALIST CONSULTANTS

- **We need to increase numbers**
- **We need to ringfence time for them to support the broader workforce**


Patient Complexity
Fragmented under-resourced care system
Disempowerment
Stressful, under-resourced work environment
Societal Narrative
PARENTS
May be fearful, angry, distressed, exhausted
CONFLICT
PAEDIATRICIANS
May be suffering self-doubt, exhaustion, burnout, illness


System Complexity
Resource pressure
Uncertainty
Communication
Trust
Shared decision making

HOSPICES

- We need to make hospices an essential part of the pathway of NHS care, not a luxury / add-on (lessons from Covid?)
- The more we can embed through commissioning and shared staffing, the greater the interdependence
- We need to be clear about the core offer
- Shared core features do not stifle individual innovation and unique characteristics

SYSTEMS

NETWORKS

- Strength comes through collaboration and shared working
- We fragment at our peril

NHS STRUCTURES

- NHS structures are the most transient aspect of our models
- They may not be fit for our purposes (e.g. ICB footprint) – so we have to have our house fully in order to manage inadequacies of commissioning structures

WHO ARE WE SERVING AND HOW DO WE COLLABORATE?

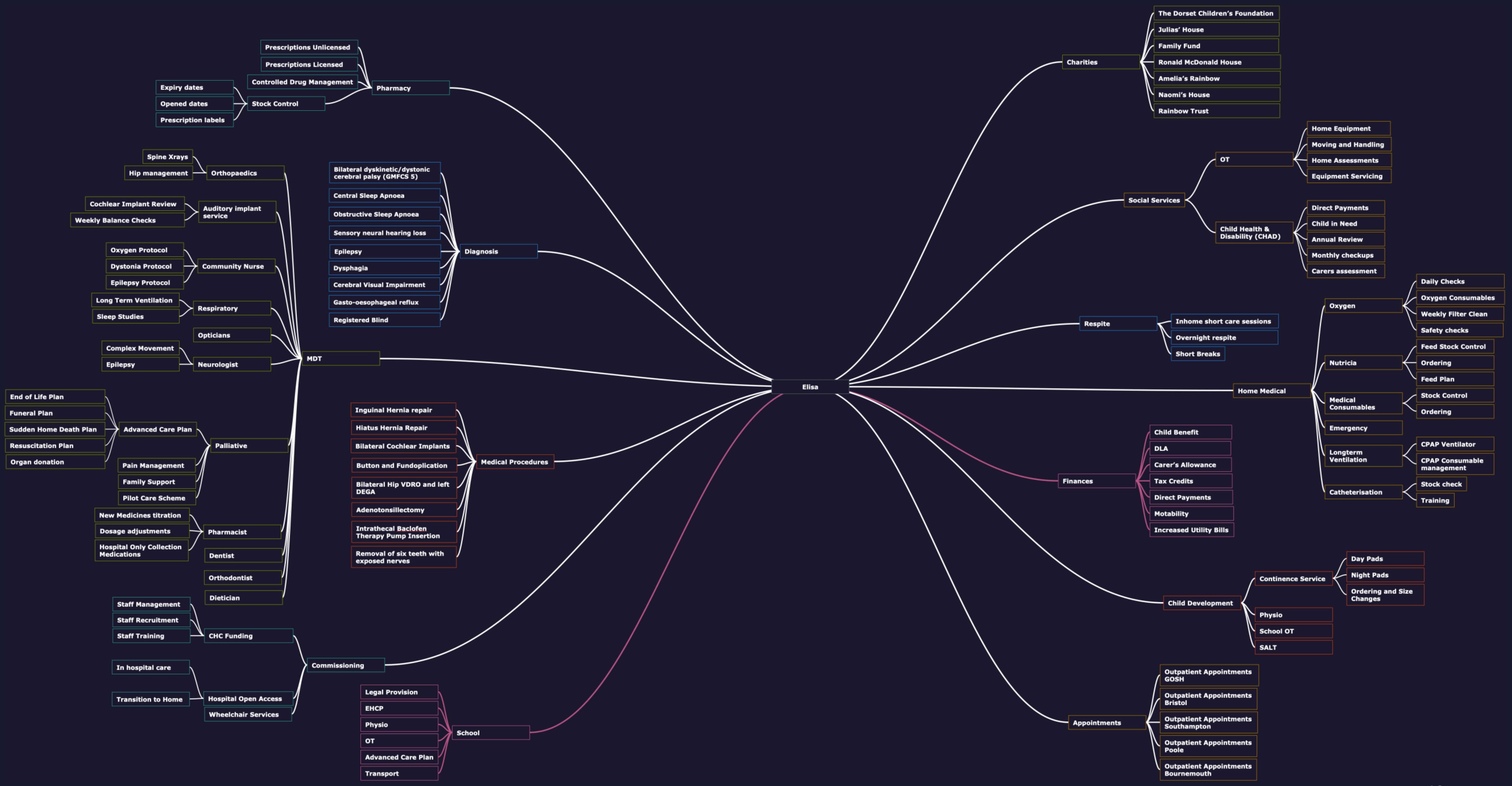
- **Children with life limiting conditions?**
- **Children with palliative care needs?**
- **Children with disability?**
- **Children with medical complexity?**

INDIVIDUAL CONSTITUENCIES OR A LARGER MOVEMENT WITH OTHER ORGANISATIONS / CHARITIES?

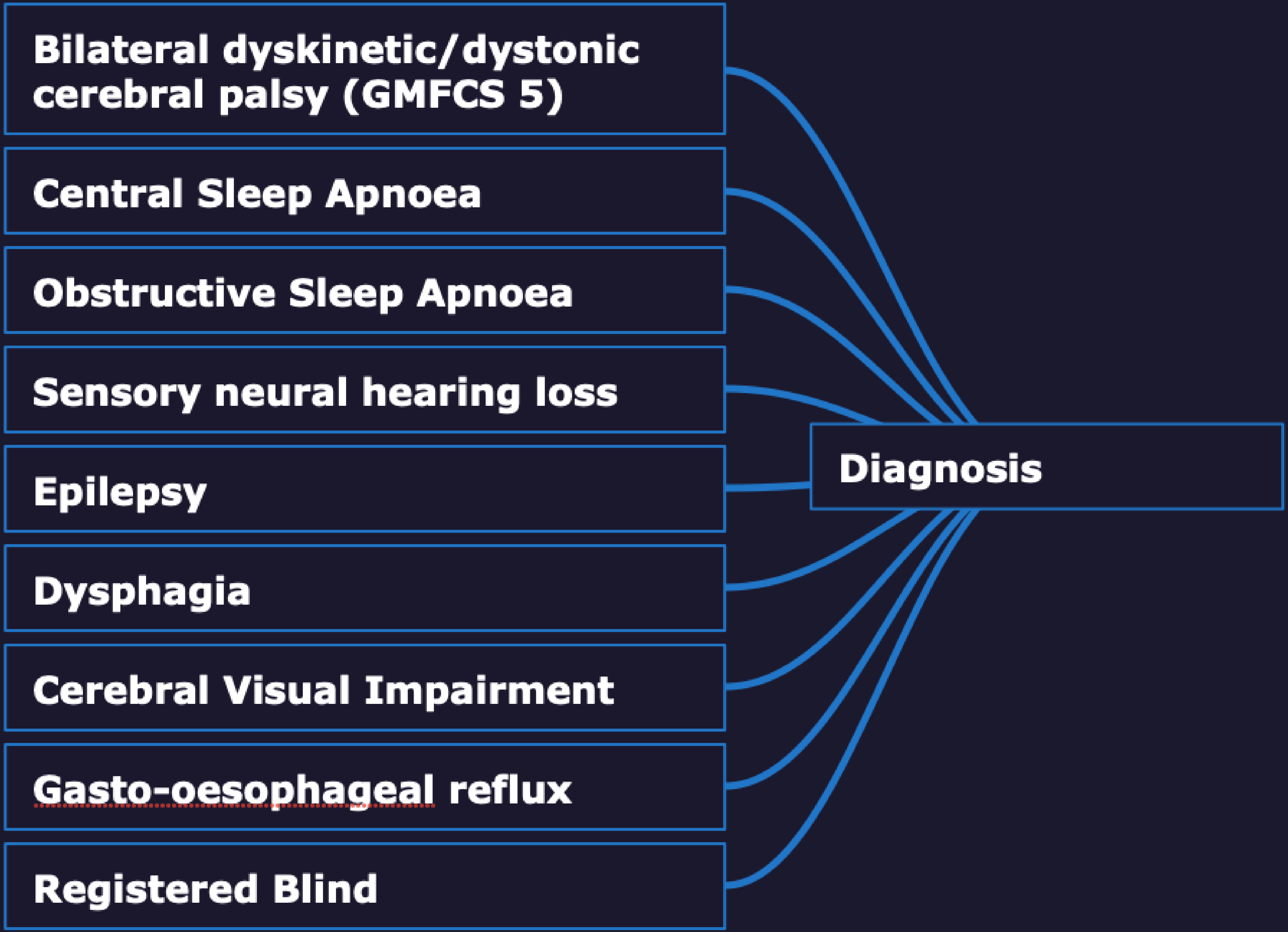
Mapping Chaos

Dan McEvoy

- Bilateral dyskinetic/dystonic cerebral palsy (GMFCS 5)
- Central and Obstructive sleep Apnoea
- Sensory neural hearing loss
- Epilepsy
- Dysphagia
- Cerebral visual impairment
- Gastro-Oesophageal reflux



- Elisa
  - Pharmacy
    - Prescriptions Unlicensed
    - Prescriptions Licensed
    - Controlled Drug Management
    - Stock Control
      - Expiry dates
      - Opened dates
      - Prescription labels
  - Diagnosis
    - Bilateral dyskinetic/dystonic cerebral palsy (GMFCS 5)
    - Central Sleep Apnoea
    - Obstructive Sleep Apnoea
    - Sensory neural hearing loss
    - Epilepsy
    - Dysphagia
    - Cerebral Visual Impairment
    - Gasto-oesophageal reflux
    - Registered Blind
  - MDT
    - Orthopaedics
      - Spine Xrays
      - Hip management
    - Auditory implant service
      - Cochlear Implant Review
      - Weekly Balance Checks
    - Community Nurse
      - Oxygen Protocol
      - Dystonia Protocol
      - Epilepsy Protocol
    - Respiratory
      - Long Term Ventilation
      - Sleep Studies
    - Opticians
    - Neurologist
      - Complex Movement
      - Epilepsy
    - Palliative
      - Advanced Care Plan
        - End of Life Plan
        - Funeral Plan
        - Sudden Home Death Plan
        - Resuscitation Plan
        - Organ donation
      - Pain Management
      - Family Support
      - Pilot Care Scheme
    - Pharmacist
      - New Medicines titration
      - Dosage adjustments
      - Hospital Only Collection Medications
    - Dentist
    - Orthodontist
    - Dietician
  - Medical Procedures
    - Inguinal Hernia repair
    - Hiatus Hernia Repair
    - Bilateral Cochlear Implants
    - Button and Fundoplication
    - Bilateral Hip VDRO and left DEGA
    - Adenotonsillectomy
    - Intrathecal Baclofen Therapy Pump Insertion
    - Removal of six teeth with exposed nerves
  - Commissioning
    - CHC Funding
      - Staff Management
      - Staff Recruitment
      - Staff Training
    - Hospital Open Access
      - In hospital care
      - Transition to Home
    - Wheelchair Services
  - School
    - Legal Provision
    - EHCP
    - Physio
    - OT
    - Advanced Care Plan
    - Transport
  - Charities
    - The Dorset Children's Foundation
    - Julias' House
    - Family Fund
    - Ronald McDonald House
    - Amelia's Rainbow
    - Naomi's House
    - Rainbow Trust
  - Social Services
    - OT
      - Home Equipment
      - Moving and Handling
      - Home Assessments
      - Equipment Servicing
    - Child Health & Disability (CHAD)
      - Direct Payments
      - Child in Need
      - Annual Review
      - Monthly checkups
      - Carers assessment
  - Respite
    - Inhome short care sessions
    - Overnight respite
    - Short Breaks
  - Home Medical
    - Oxygen
      - Daily Checks
      - Oxygen Consumables
      - Weekly Filter Clean
      - Safety checks
    - Nutricia
      - Feed Stock Control
      - Ordering
      - Feed Plan
    - Medical Consumables
      - Stock Control
      - Ordering
    - Emergency
    - Longterm Ventilation
      - CPAP Ventilator
      - CPAP Consumable management
    - Catheterisation
      - Stock check
      - Training
  - Finances
    - Child Benefit
    - DLA
    - Carer's Allowance
    - Tax Credits
    - Direct Payments
    - Motability
    - Increased Utility Bills
  - Child Development
    - Continence Service
      - Day Pads
      - Night Pads
      - Ordering and Size Changes
    - Physio
    - School OT
    - SALT
  - Appointments
    - Outpatient Appointments GOSH
    - Outpatient Appointments Bristol
    - Outpatient Appointments Southampton
    - Outpatient Appointments Poole
    - Outpatient Appointments Bournemouth



Bilateral dyskinetic/dystonic cerebral palsy (GMFCS 5)

Central Sleep Apnoea

Obstructive Sleep Apnoea

Sensory neural hearing loss

Epilepsy

Dysphagia

Cerebral Visual Impairment

Gasto-oesophageal reflux

Registered Blind

Diagnosis

Medical Procedures

- Inguinal Hernia repair
- Hiatus Hernia Repair
- Bilateral Cochlear Implants
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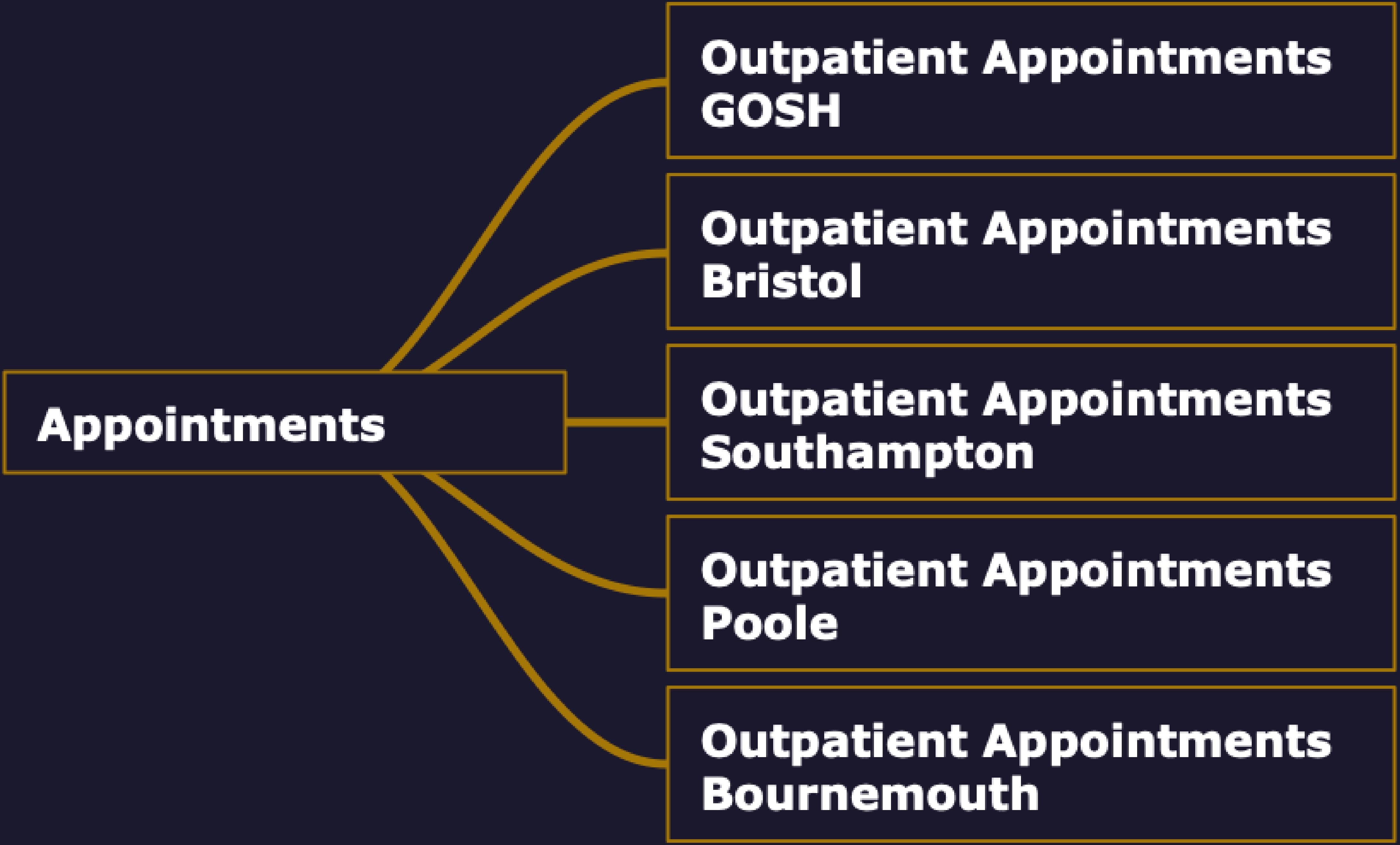

Appointments

Outpatient Appointments GOSH

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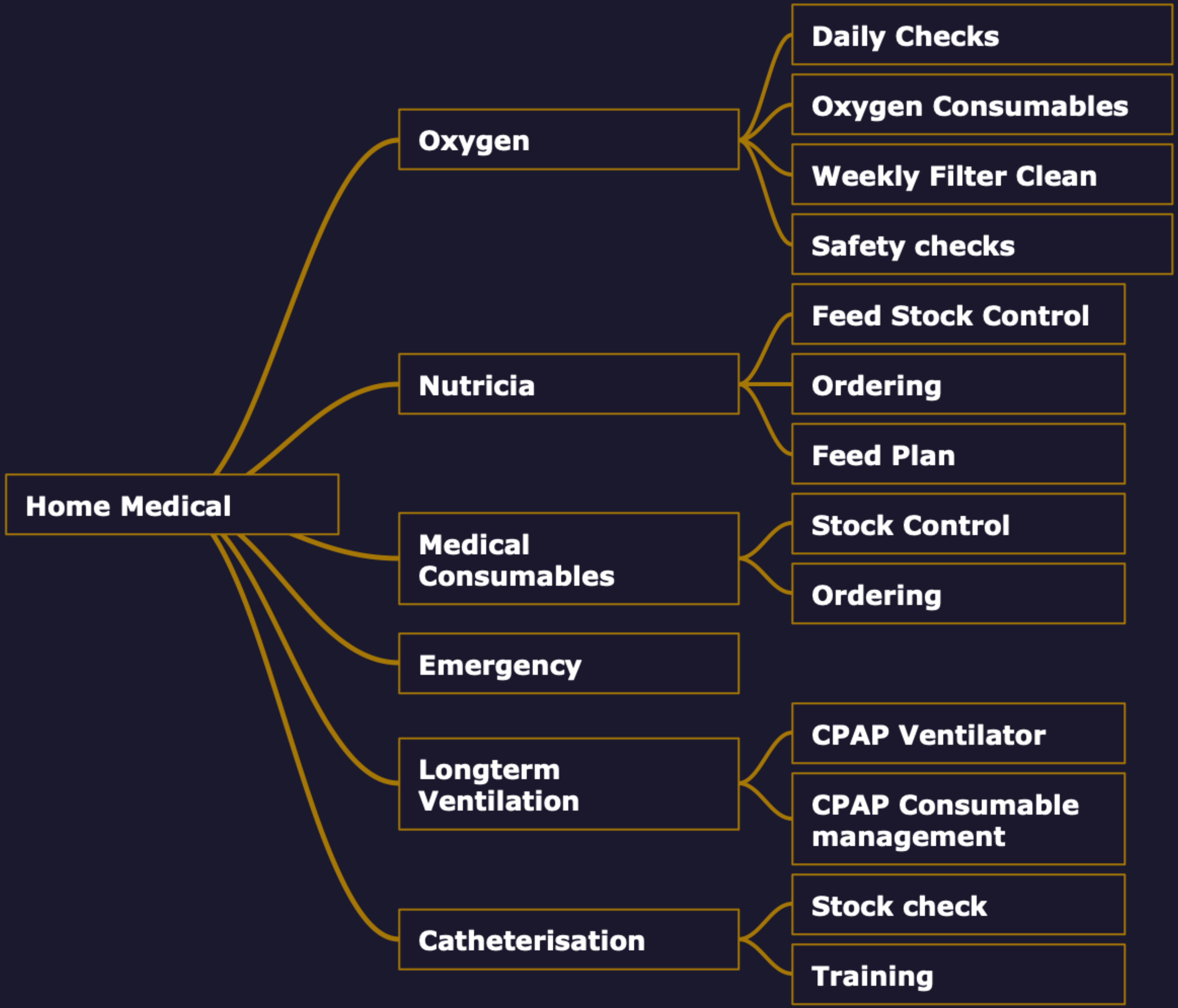
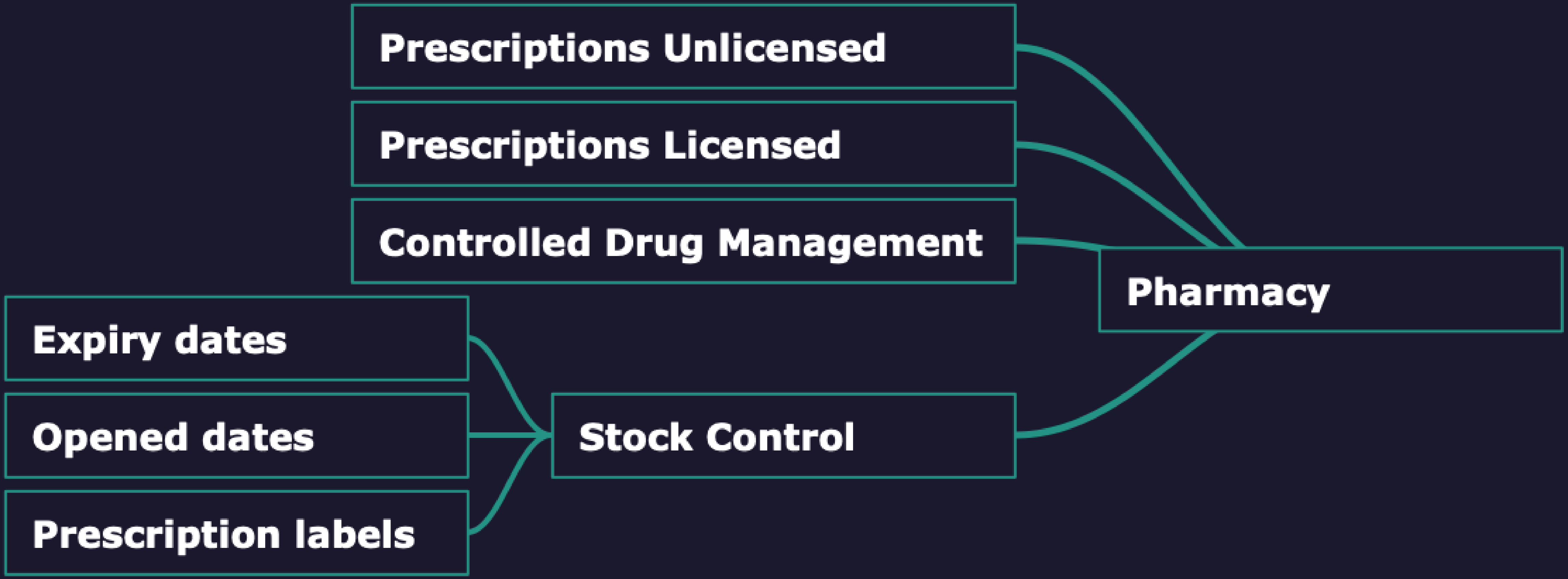


- **Home Medical**
  - **Oxygen**
    - **Daily Checks**
    - **Oxygen Consumables**
    - **Weekly Filter Clean**
    - **Safety checks**
  - **Nutricia**
    - **Feed Stock Control**
    - **Ordering**
    - **Feed Plan**
  - **Medical Consumables**
    - **Stock Control**
    - **Ordering**
  - **Emergency**
  - **Longterm Ventilation**
    - **CPAP Ventilator**
    - **CPAP Consumable management**
  - **Catheterisation**
    - **Stock check**
    - **Training**



Prescriptions Unlicensed

Prescriptions Licensed

Controlled Drug Management

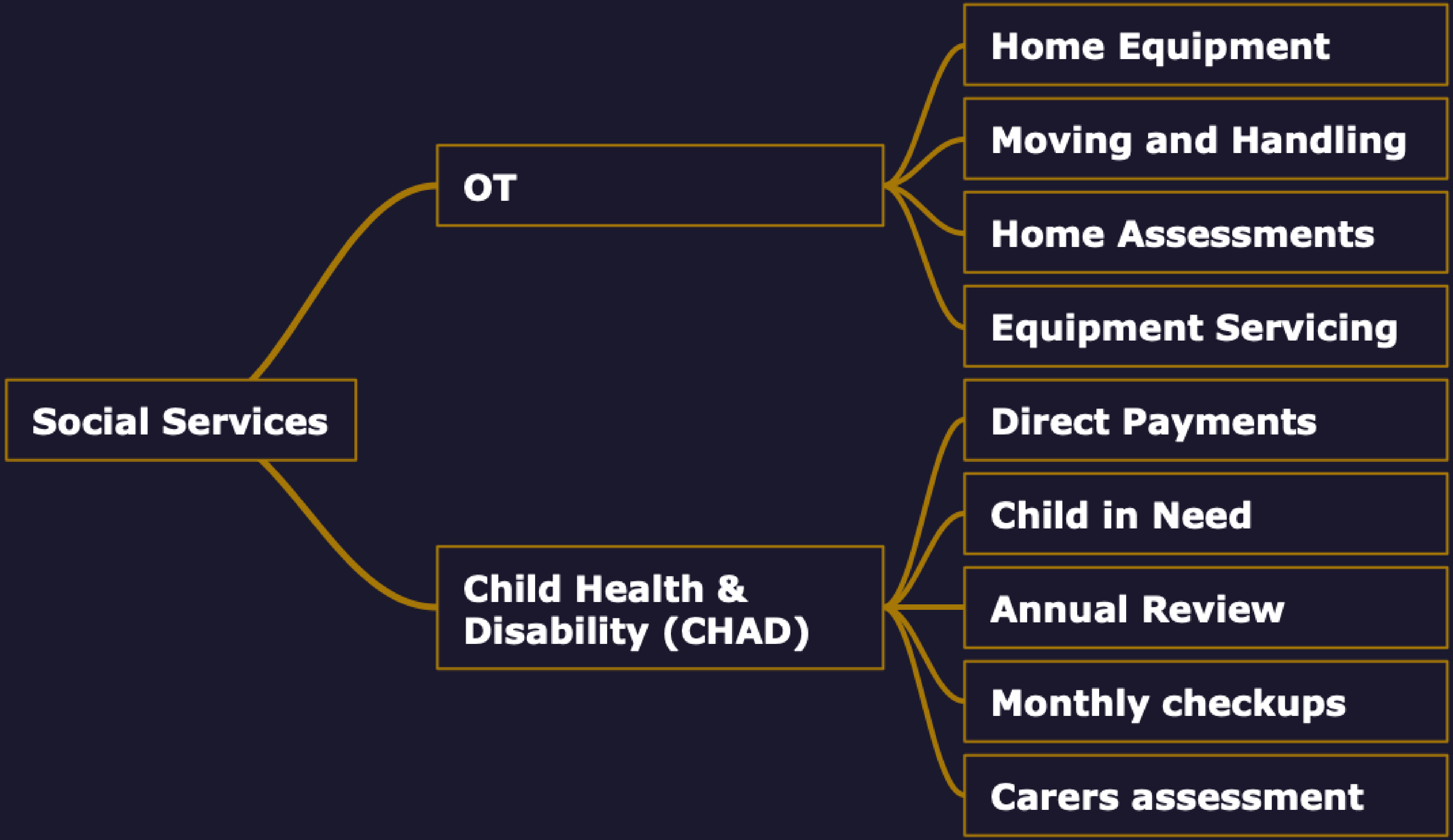
Pharmacy

Expiry dates

Opened dates

Prescription labels

Stock Control



- **Social Services**
  - **OT**
    - **Home Equipment**
    - **Moving and Handling**
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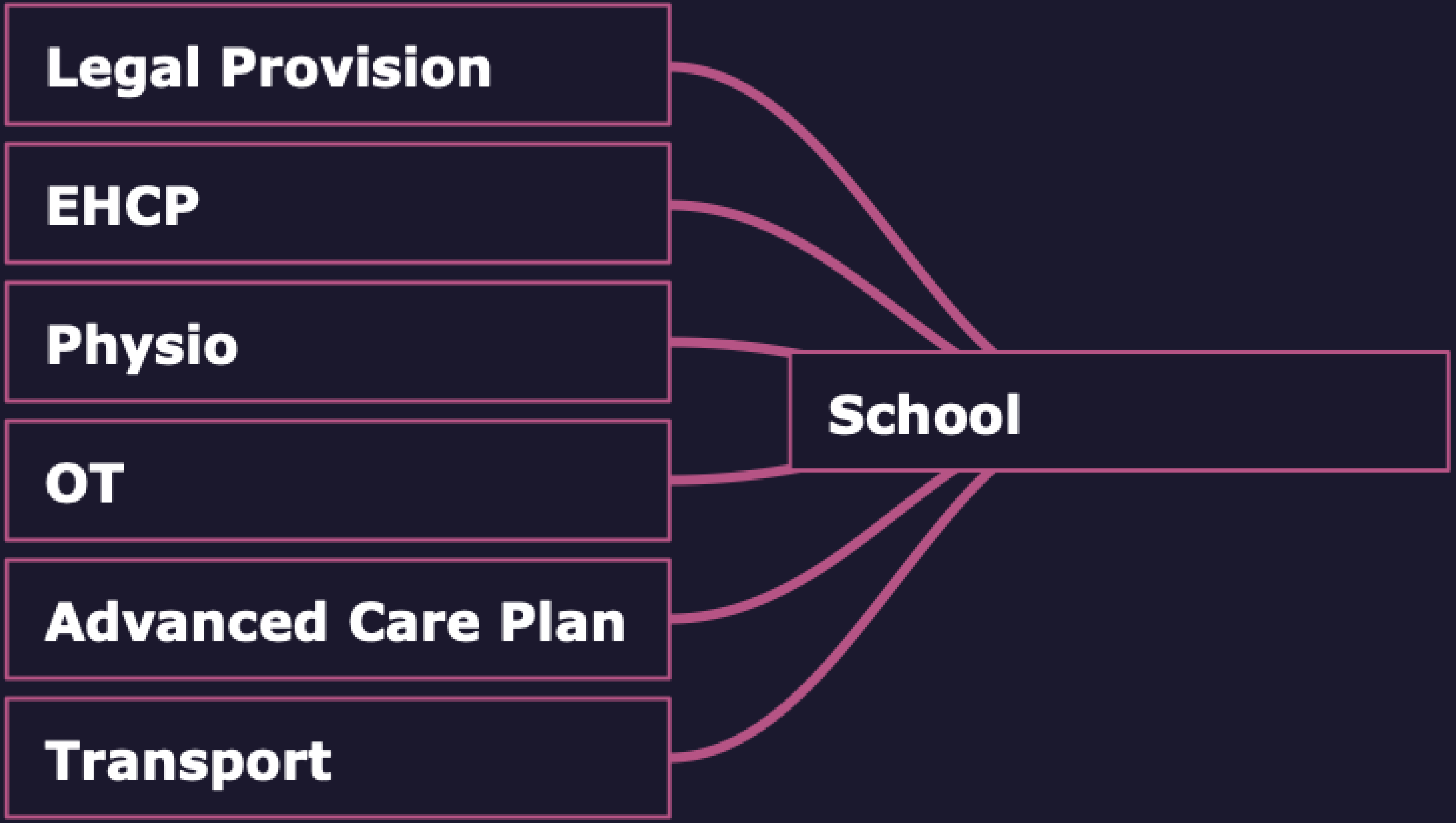
    - **Equipment Servicing**
  - **Child Health & Disability (CHAD)**
    - **Direct Payments**
    - **Child in Need**
    - **Annual Review**
    - **Monthly checkups**
    - **Carers assessment**



Legal Provision

EHCP

Physio

OT

Advanced Care Plan

Transport

School

Respite

- Inhome short care sessions
- Overnight respite
- Short Breaks

Finances

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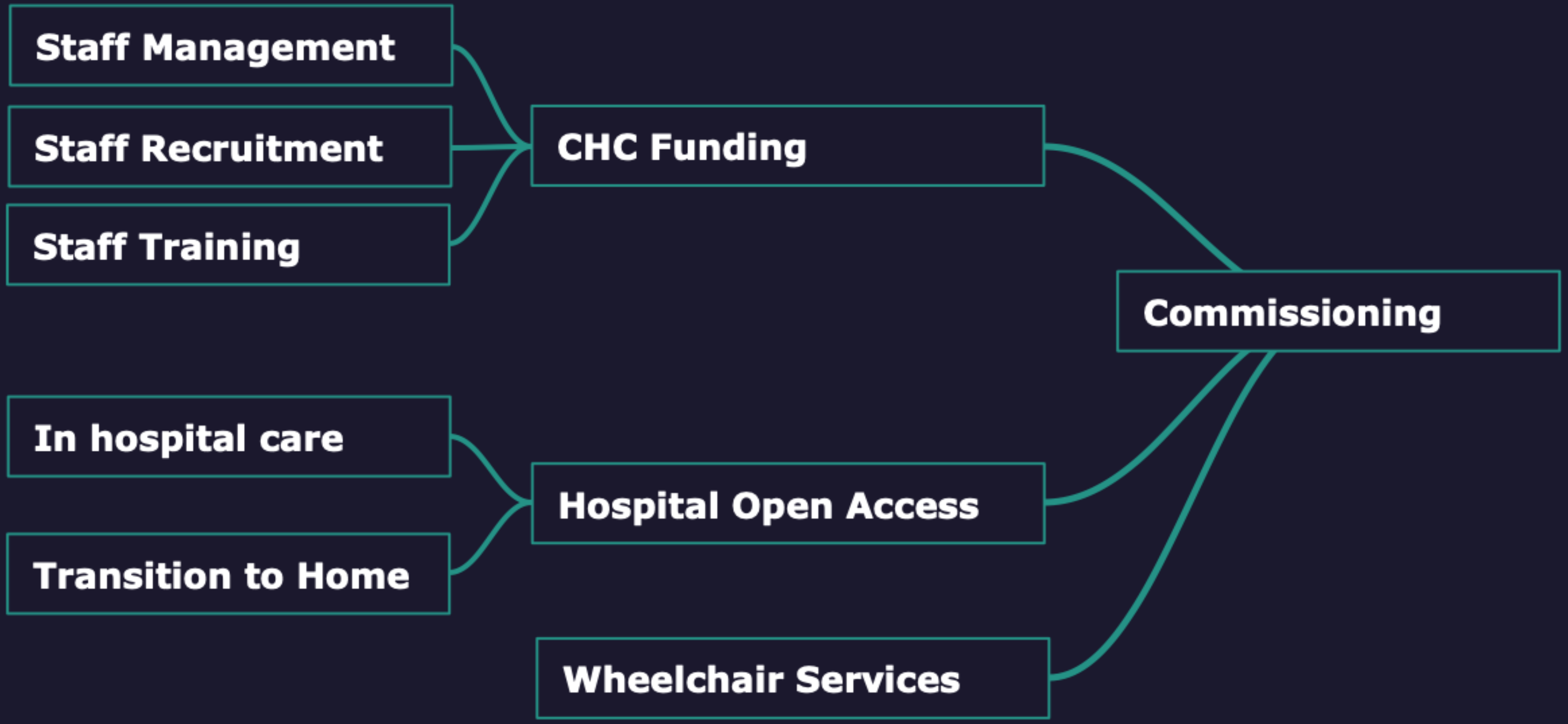
- DLA
- Carer’s Allowance
- Tax Credits
- Direct Payments
- Motability
- Increased Utility Bills



Staff Management

Staff Recruitment

Staff Training

CHC Funding

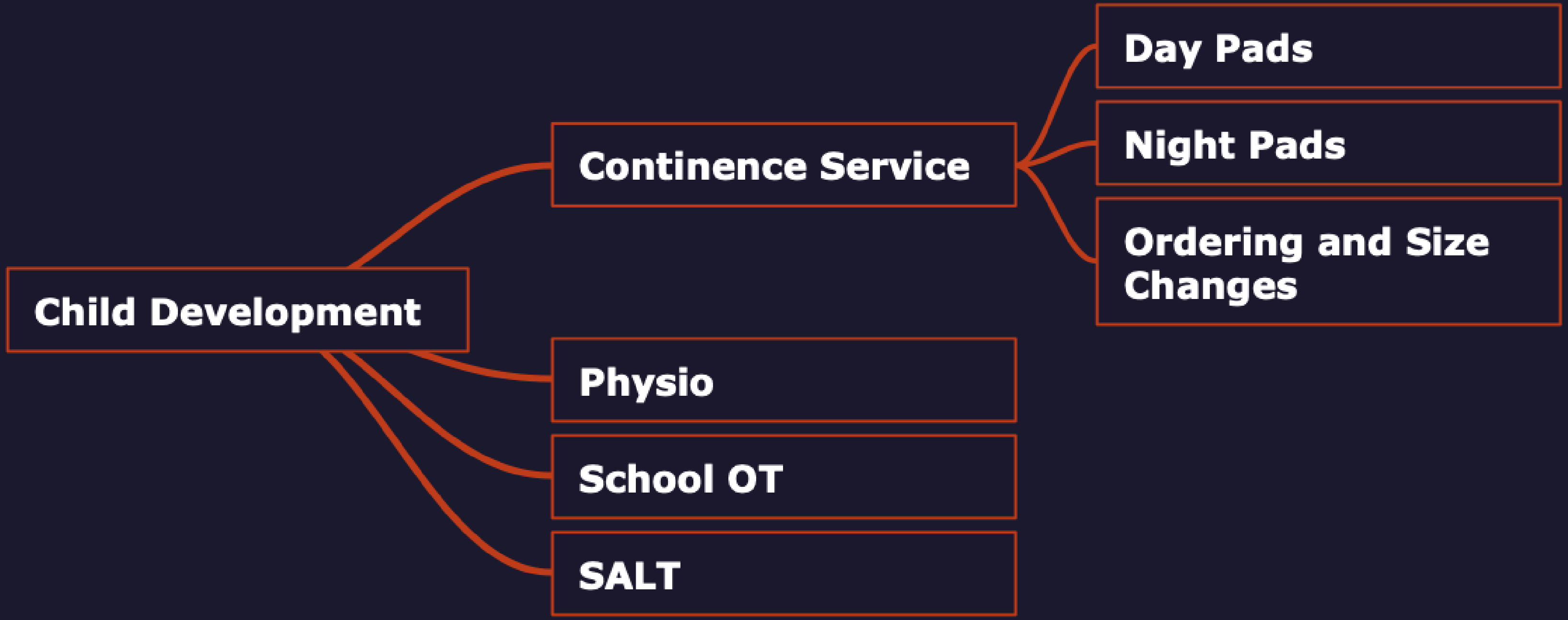
In hospital care

Transition to Home

Hospital Open Access

Wheelchair Services

Commissioning



Child Development

Continence Service

Day Pads

Night Pads

Ordering and Size Changes

Physio

School OT

SALT

Charities

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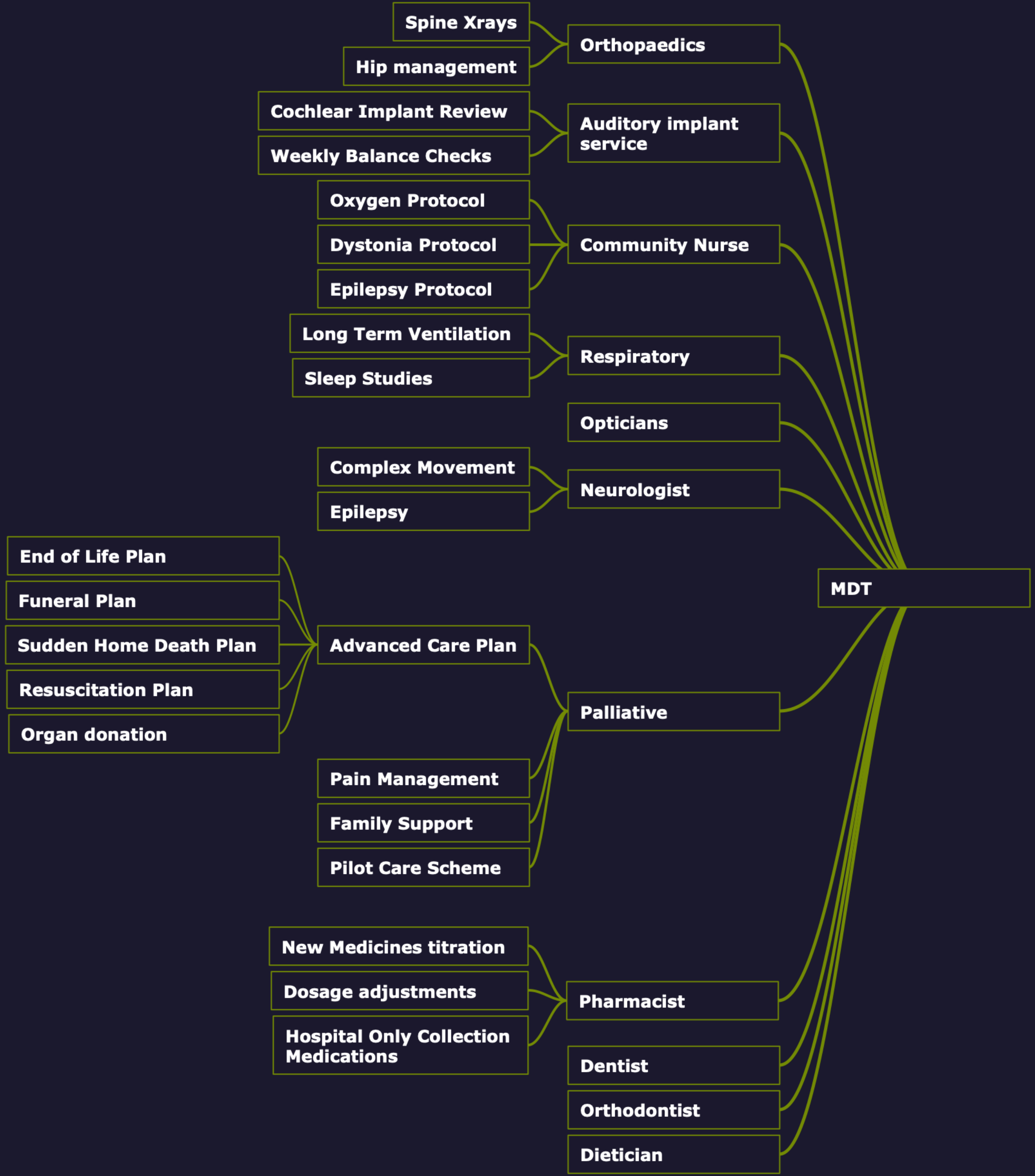

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    - Pain Management
    - Family Support
    - Pilot Care Scheme
  - Pharmacist
    - New Medicines titration
    - Dosage adjustments
    - Hospital Only Collection Medications
  - Dentist
  - Orthodontist
  - Dietician

See the whole child.

Conversations are more about Elisa as a whole. Not just her diagnosis.

MAR Charts

These go everywhere. It means that no matter what service Elisa is accessing they have an up to date record of her daily meds. So School, care, respite have the same information.

MAR charts are updated bi-weekly. It means any medication changes can be implemented quickly. No waiting for bottle labels to be changed, or paperwork to be sent.

It can also be used for basic level of trend analysis on when Elisa has rescue meds.

And if anything happens all the information needed to support Elisa is in one place. For us as parents it gives us peace of mind.

Consistent Communication

Parents are consistently telling the same story. Every meeting starts with a history lesson. A lot of parents can feel lived trauma from this.

Now centralized and consistent communication means everyone is up to date.

Meetings are more productive. More focused. As parents we feel things are progressing.

Our Complex Child

A bespoke solution for children with complex needs.

Landing page gives a brief overview of the child

Links to protocols

And a Med diary

Clicking a med opens the MAR page allowing the person administering the meds to sign and accept the med

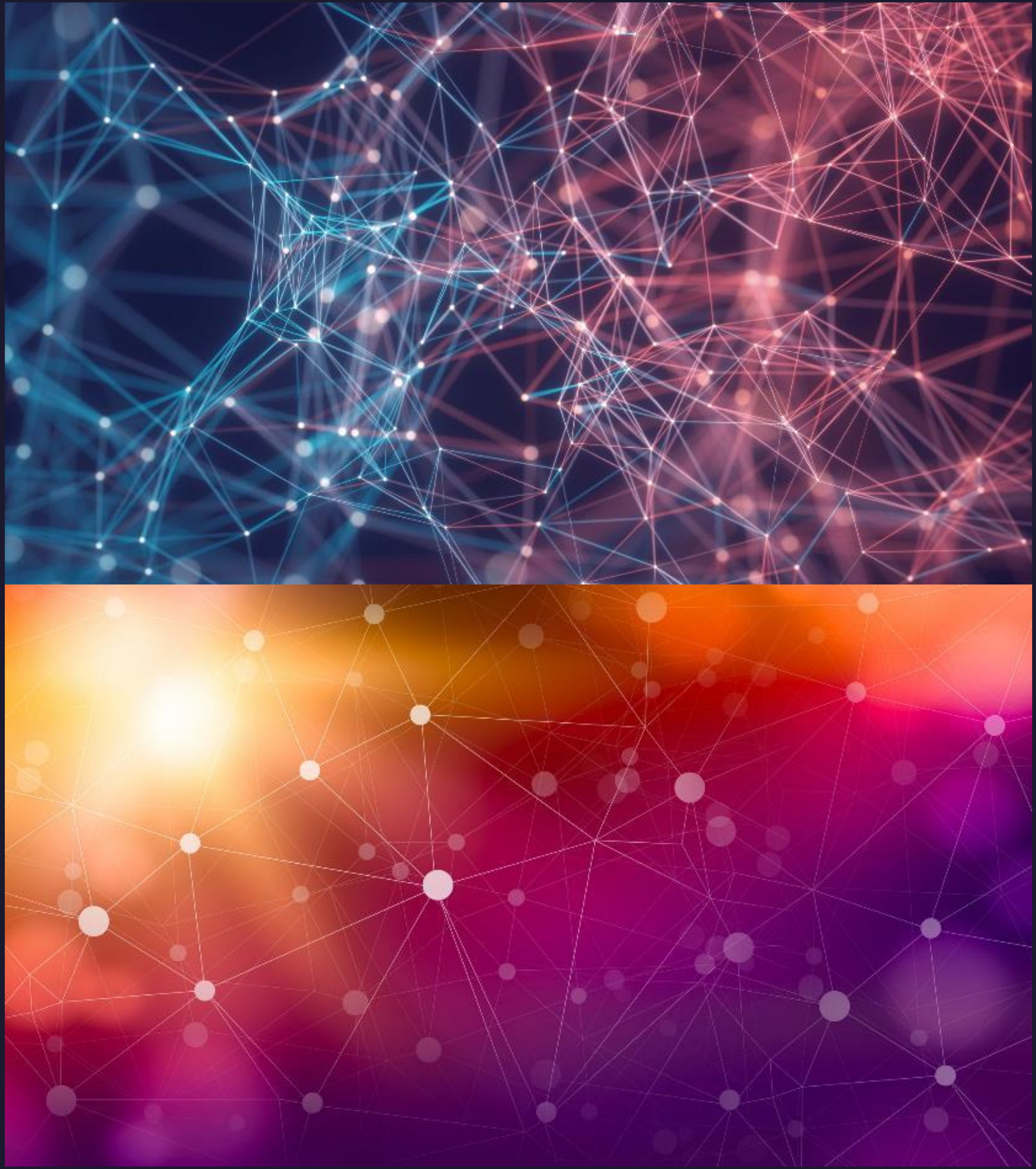
Daily trend analysis

Seamlessly updates can be pushed out by community palliative care team.

Thank You

Dan McEvoy

dan@thedcf.org



Welcome to together for short lives

/togetherforshortlives @togetherforshortlives @Tog4ShortLives #TFSLConference

Family support Hub

Our Support Hub is there for anybody caring for a child with a serious illness. The support we offer includes:

Helpline and live chat

We offer confidential emotional support and information on a range of issues, so that families can spend less time searching for help and more precious time together as a family. Open Monday - Friday, 9am-4pm.

☎ **0808 8088 100**

✉ **helpline@togetherforshortlives.org.uk**

togetherforshortlives.org.uk

Voices for Families: expert legal advice when it matters

Somebody caring for a child with a serious illness could benefit from free expert legal advice, they can reach out to our helpline: 0808 8088 100

Online support group

Our Facebook group is a supportive community that allows families caring for a seriously ill child to connect, share and support one another.

They can join the group here:
togetherforshortlives.org.uk/familyfacebook

Or scan the QR code:

/togetherforshortlives @togetherforshortlives @Tog4ShortLives

#TFSLConference

Collaborative Paediatric Palliative Care Research Network

CoPPAR

Association for Paediatric Palliative Medicine

The Martin House RESEARCH CENTRE

together for short lives

The Martin House RESEARCH CENTRE

In partnership with UNIVERSITY of York

Outcome measurement in paediatric palliative care: reflecting on the current state of play and discussion of the next big questions for outcome measurement

Presenting: Lorna Fraser, Richard Harding, Daney Harðardóttir, Linda Maynard, Jo Cohen,

11.45-11.50. Welcome

11.50-11.55. Brief introduction to the workshop (LF)

11.55-12.15. Update from the CPOS team (RH, DH)

12.15-12.35. A hospice perspective (LM, JC)

12.35-13.00. Q&A panel discussion on ‘what are the next big questions for outcomes’ (LF, RH, DH, LM, JC)

13.00. Close

@CYP_CSI

together for short lives

Cicely Saunders International
Better care at the end of life

King's College London

Patient Centred Outcomes in Paediatric Palliative Care: the Children's Palliative care Outcome Scale (C-POS) Study

Professor Richard Harding

Daney Harðardóttir

European Research Council
Executive Agency
Established by the European Commission

European Commission

NIHR | Applied Research Collaboration South London

Outcome measures

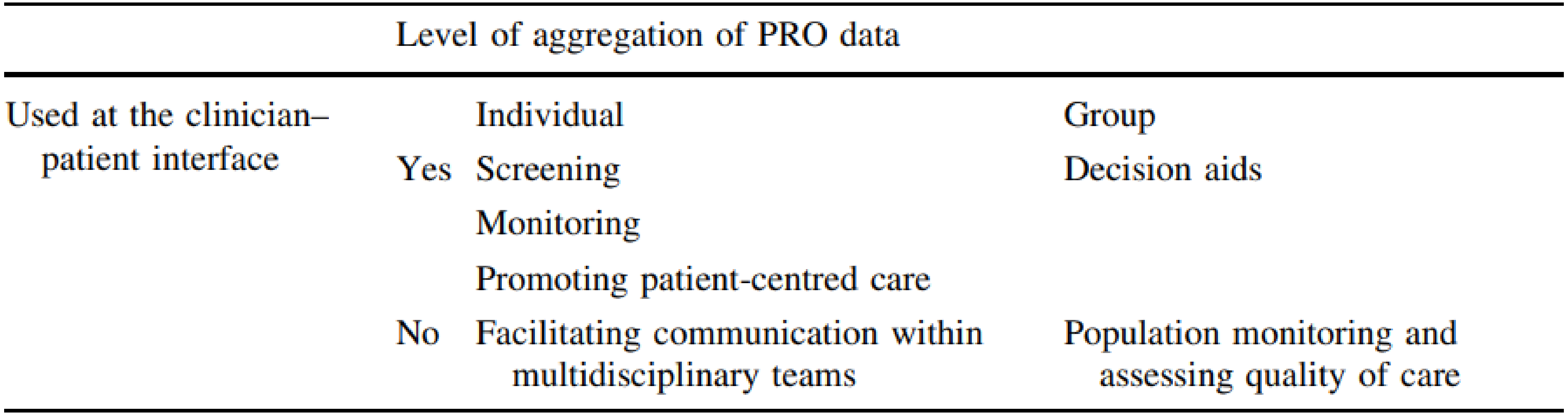
- **Outcome measures** assess the change in health or well-being of a patient and/or their family that has occurred due to intervention by a health or social care professional

- 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)[1]
  - 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, the data can be used
  - When considered at the individual and group level
  - Within and outside clinician-patient interaction[2]



		Level of aggregation of PRO data	
Used at the clinician–patient interface		Individual	Group
	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[3]

- Developing a valid and reliable outcome measure for the paediatric palliative population has been identified as both a research and clinical priority[4,5]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

[3] Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr AJ. The routine use of patient reported outcome measures in healthcare settings. BMJ. 2010;340:c186.

[4] 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.

[5] 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.

Children’s Palliative care Outcome Scale (C-POS)

KING’S College LONDON

- There is currently no ‘ideal’ outcome assessment measure for use in 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.

PALLIATIVE MEDICINE

Review Article

Palliative Medicine
2016, Vol. 30(10) 935–949

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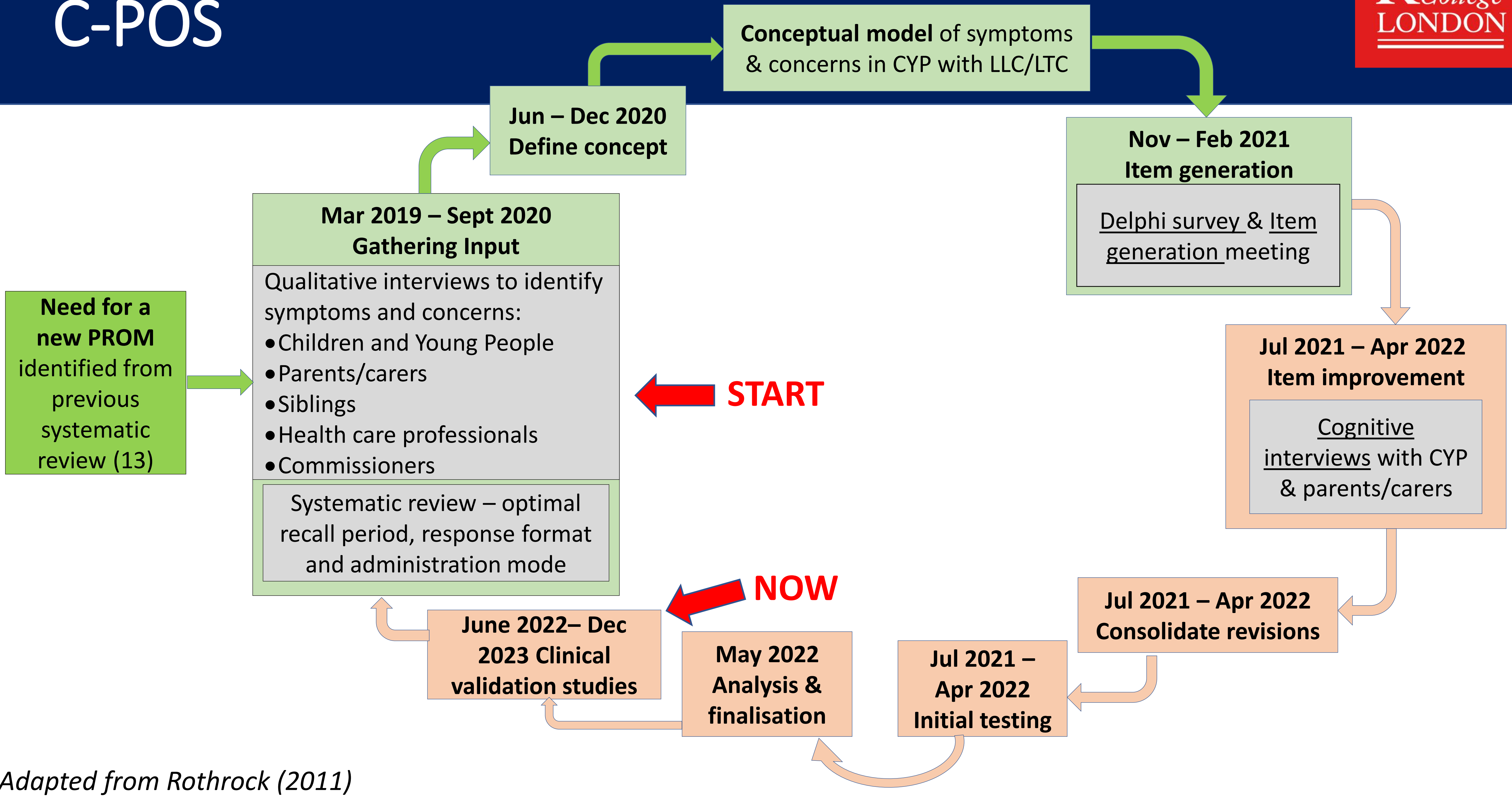
DOI: 10.1177/0269216316649155
pmj.sagepub.com
SAGE

Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use

Lucy H Coombes[1], Theresa Wiseman[2,3], Grace Lucas[2], Amrit Sangha[2] and Fliss EM Murtagh[4]

C-POS



Need for a new PROM identified from previous systematic review (13)

Mar 2019 – Sept 2020
Gathering Input

Qualitative interviews to identify symptoms and concerns:

- Children and Young People
- Parents/carers
- Siblings
- Health care professionals
- Commissioners

Systematic review – optimal recall period, response format and administration mode

START

Jun – Dec 2020
Define concept

Conceptual model of symptoms & concerns in CYP with LLC/LTC

Nov – Feb 2021
Item generation

Delphi survey & Item generation meeting

Jul 2021 – Apr 2022
Item improvement

Cognitive interviews with CYP & parents/carers

Jul 2021 – Apr 2022
Consolidate revisions

Jul 2021 – Apr 2022
Initial testing

May 2022
Analysis & finalisation

June 2022– Dec 2023 Clinical validation studies

NOW

Adapted from Rothrock (2011)

Aims and Objectives

Aim

To develop a child and family-centred outcome measure that can be used by children and young people (CYP) and their families affected by life-limiting/life-threatening conditions (LLLTC), and to test its psychometric properties.

Phase 1 – Development

1. Identify CYP, their families, professional and commissioner priorities for outcomes of care and measure completion methods (qualitative interviews).
2. Systematic review on optimal recall period, response format and administration mode in CYP measure completion.
3. Delphi survey to establish priorities for items to be included in C-POS.
4. Generate initial C-POS version(s).

Phase 2 – Validation

5. Cognitive interviews to determine the extent to which CYP can participate, and their interpretation and completion of the proposed items.

6. Refine C-POS and finalise ready for subsequent reliability and validity testing.

7. **Determine test-retest reliability, internal consistency, construct validity and responsiveness.**

Phase 3 – Implementation

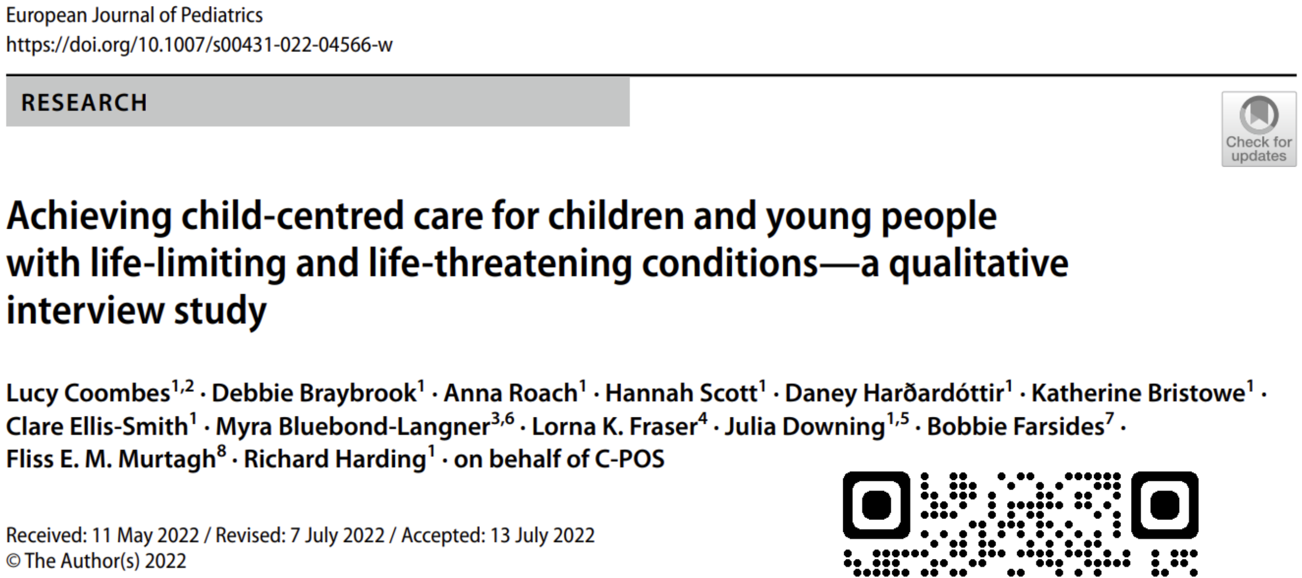
8. Develop implementation guidance for routine practice & hold launch workshop for children, families and clinicians

9. Adapt existing online POS translation protocol and implementation guidance for wider European implementation of the novel C-POS.

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
- One of the largest qualitative interview studies conducted with children with a range of life-limiting and life-threatening conditions in the UK.



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] · Debbie Braybrook[1] · Anna Roach[1] · Hannah Scott[1] · Daney Harðardóttir[1] · Katherine Bristowe[1] · Clare Ellis-Smith[1] · Myra Bluebond-Langner[3,6] · Lorna K. Fraser[4] · Julia Downing[1,5] · Bobbie Farsides[7] · Fliss E. M. Murtagh[8] · Richard Harding[1] · on behalf of C-POS

Received: 11 May 2022 / Revised: 7 July 2022 / Accepted: 13 July 2022

Development – Qualitative Interview Study

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

Physical

Cultural beliefs and needs
Life unlived
Uncertainty of the future
Living a full life
Meaning of life

Spiritual/ Existential

Psycho-Emotional

Emotions
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

Normality

Not knowing any different
Returning to normality
Adjusting to a new normal

COVID-19

Impact on Pediatric Palliative Care

JPSM

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)

*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 – Systematic Review

Quality of Life Research
https://doi.org/10.1007/s11136-021-02814-4

Check for updates

Enhancing validity, reliability and participation in self-reported health outcome measurement for children and young people: a systematic review of recall period, response scale format, and administration modality

L. Coombes[1,2] · K. Bristowe[1] · C. Ellis-Smith[1] · J. Aworinde[1] · L. K. Fraser[3] · J. Downing[1,4] · M. Bluebond-Langner[5,6] · L. Chambers[7] · F. E. M. Murtagh[8] · R. Harding[1]

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.

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

- Steering group held February 2021
  - Health and social care professionals
  - Academics (including clinical)
  - Patient and public involvement

- Items for C-POS versions selected and first versions of measures drafted
  - <2 years* parent proxy version (8 questions about the child; 5 about the family).
  - 2-17 years* parent proxy version (8 questions about the child; 5 about the family).
  - 5-7 years* - Mercury (8 questions, simple language)
  - 8-12 years* - Saturn (8 questions)
  - 13-17 years* - Neptune (8 questions, more grown-up language)

* Or cognitive equivalent

Validation - Cognitive Interview Study

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.

- Recruitment complete: 48 interviews conducted (36 parents/carers; 12 CYP)
- Recall period tested: Children 5-17 – yesterday or today
  Children 8-17 years – past week
  Parents – past week
- Response formats tested: Children 5-12 years

Never	Sometimes	All of the time
☐	☐	☐
😀	😐	☹

Children 8-17 years

Never	Almost never	Sometimes	Often	All of the time
☐	☐	☐	☐	☐
😀	🙂	😐	🙁	☹

Parents/carers

Never	Almost never	Sometimes	Often	All of the time
☐	☐	☐	☐	☐

Validation - Cognitive Interview Study

- Cognitive interviewing helped to refine the prototype C-POS versions, especially to be inclusive of CYP 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.

- This study highlights the importance of conducting cognitive interviews when developing outcome measures as several problems with questions were identified, allowing us to strengthen face and content validity.

Final Versions

A Parent/carer version A – younger and non-communicative children

B 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

Next Steps - Validation Study

Following cognitive testing revised C-POS versions are now ready for psychometric testing

Aim - To determine the psychometric properties of C-POS, a novel child and family-centred outcome measure for children, young people, and their families facing life-limiting and life-threatening conditions.

Objectives:

I. To determine the construct, structural, and convergent/discriminant **validity** of the novel C-POS
II. To determine the **internal consistency** of the novel C-POS, as well as test-retest and inter-rater **reliability**
III. To determine the **responsiveness** of the novel C-POS

Validation Study - Definitions

- **Validity** refers to the degree to which an instrument measures the construct(s) it claims to measure

- **Reliability** refers to the degree to which the measurement is free from measurement error (e.g. stability of scores for those that have not changed)

- **Responsiveness** is the measure’s ability to detect change over time

Validation study - Process

- The C-POS validation study will be:
  - An electronic survey study (with paper option)
  - Administered at two timepoints (approx. 2 weeks apart) to assess test-retest reliability and responsiveness.
- Alongside C-POS participants will be asked about:
  - Children's phase of illness, to allow for known-group-comparisons of C-POS scores
  - Symptoms and HRQoL, to test convergent and discriminant validity of C-POS
  - A global change question at timepoint 2, to determine responsiveness and stability of responses.
- Where families consent, healthcare professional will be asked to complete a clinician-proxy C-POS, to assess inter-rater reliability

Validation Study - Flowchart

STEP 1 Clinical team:

a) Identify child & family and introduce to study
b) Send contact details, and other basic info for potential participants to research team

STEP 2 Research team:

c) Contact family & provide study materials

STEP 3 Child/ family:

d) Complete measures twice (1 & 14 days)

STEP 4 Clinical team:

e) complete C-POS once (if family agrees)

PPI work with Children and Young People

July 2020

Virtual meeting to gain input on optimal recall period and response format for C-POS

October 2020

E-mail correspondence to enable co-development of participant information sheets for the cognitive interview study

March 2021

Virtual meeting. Members were asked to choose their top outcomes for inclusion in C-POS from the 28 items used in rounds 2 and 3 of the Delphi survey. They also provided input into naming of versions.

January 2022

Wording of global change item for validation study, version names, feedback on use of emojis to anchor response scale.

Future Directions - Implementation

Aim - To identify the mechanisms and processes in integration of a person-centred outcome measure into routine practice in paediatric palliative care and the benefits of the use of the C-POS for CYP with LLLTC, their families, and HSCPs

Hannah Scott (Research Assistant) won NIHR ARC South London Award to conduct PhD study - "Implementing the Children's Palliative care Outcomes Scale (C-POS) into routine clinical practice in paediatric palliative care"

Output: Guidance documents and strategy for integrating the validated C-POS measures into routine clinical practice in paediatric palliative care across the UK.

Study team looking into applying for ERC Proof of Concept Grant

NIHR | Applied Research Collaboration South London

International collaborations

- African C-POS has been developed by Dr Eve Namisango, new NIHR funding starting 2022 for implementation

- Similar studies being conducted in Turkey and Jordan, refugee children ESRC funding

- MSc student in Singapore cognitively testing C-POS

- Key paediatric palliative care providers in Australia and New Zealand to participate in validation of C-POS

C-POS Partnerships

KING'S College LONDON

KING'S College LONDON

HULL YORK MEDICAL SCHOOL

The Martin House RESEARCH CENTRE

In partnership with UNIVERSITY of York

UCL INSTITUTE OF CHILD HEALTH

LDC Louis Dundas Centre for Children's Palliative Care

US UNIVERSITY OF SUSSEX

European Commission

erc European Research Council Executive Agency

Established by the European Commission

Cicely Saunders International

Better care at the end of life

The University Of Sheffield.

Newcastle University

Lancaster University

together for short lives

icpcn international children's palliative care network

African Palliative Care Association

APCA

Relieving Pain and Suffering

YOUNG PERSONS' ADVISORY GROUP

YPAG

CHANGING RESEARCH FOR THE BETTER

GenerationR young people improving Research

DLF

Fabian's childhood cancer trust

King's College Hospital NHS

NHS Foundation Trust

NHS The Leeds Teaching Hospitals NHS Trust

Martin House children's hospice

Northern Ireland Children's Hospice

each East Anglia's Children's Hospices

Evelina London

The ROYAL MARSDEN NHS Foundation Trust

NHS Great Ormond Street Hospital for Children NHS Foundation Trust

NHS Greater Glasgow and Clyde

CHaS

Addenbrooke's NHS

NHS Trust

NHS Bradford Teaching Hospitals NHS Foundation Trust

forget me not children's hospice

Leicester Children's Hospital

Chestnut Tree House {Children's Hospice Care}

NHS Hertfordshire Community NHS Trust

NHS Maidstone and Tunbridge Wells NHS Trust

NHS East Lancashire Hospitals NHS Trust

A University Teaching Trust

NIHR | Applied Research Collaboration South London

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Developing Outcomes in Children’s Hospices

Jo Cohen

Director of Strategy & Partnerships

Shooting Star Children’s Hospices

Shooting Star
Children’s Hospices

Dr Linda Maynard

Consultant Nurse Children’s Palliative Care,
Assistant Director Specialist Services

East Anglia’s Children’s Hospices (EACH)

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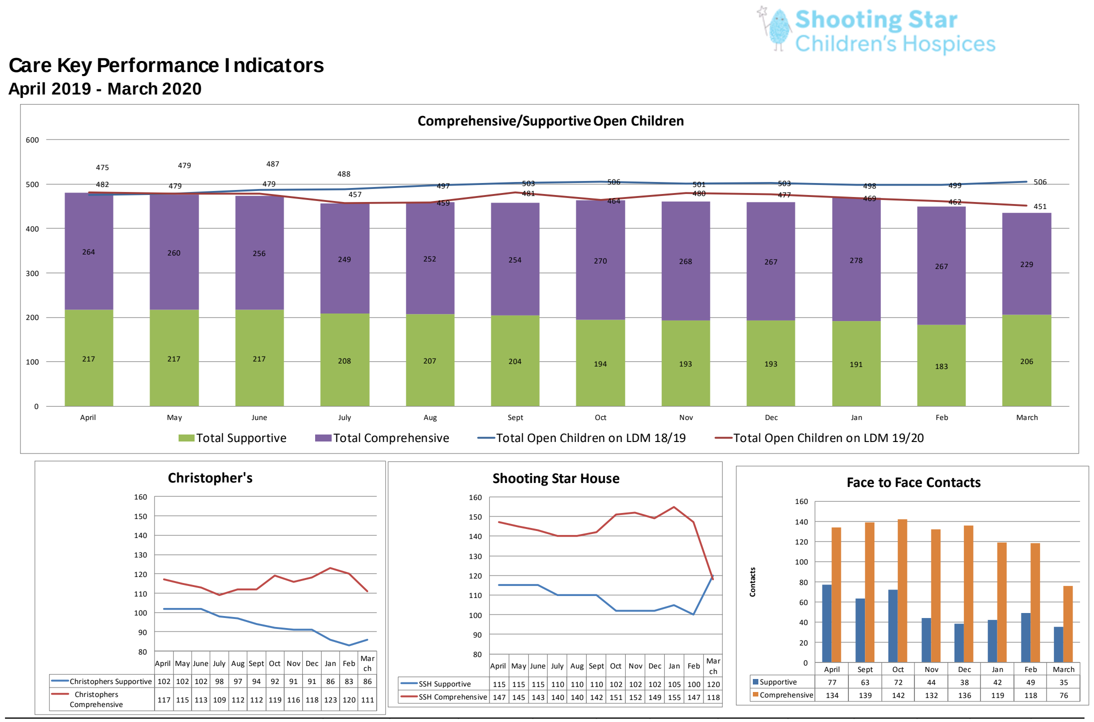
East Anglia’s
Children’s Hospices

SSCH 2021 Outcomes Project

- The hospice has not ever collected data on what requests have been made for our services, only on the volume and nature of the services that we provide.
- After changes to the service in July 2020 it was decided to start collecting data on the outcomes that we were offering families who came to us with requests for support.
- This represents our response to requests for support which have come to our weekly MDT and Family Huddle meetings. These requests can come from families directly via our Family Support Line or from external professionals or internal professionals.



Christopher's

	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March
Christophers Supportive	102	102	102	98	97	94	92	91	91	86	83	86
Christophers Comprehensive	117	115	113	109	112	112	119	116	118	123	120	111

Shooting Star House

	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	March
SSH Supportive	115	115	115	110	110	110	102	102	102	105	100	120
SSH Comprehensive	147	145	143	140	140	142	151	152	149	155	147	118

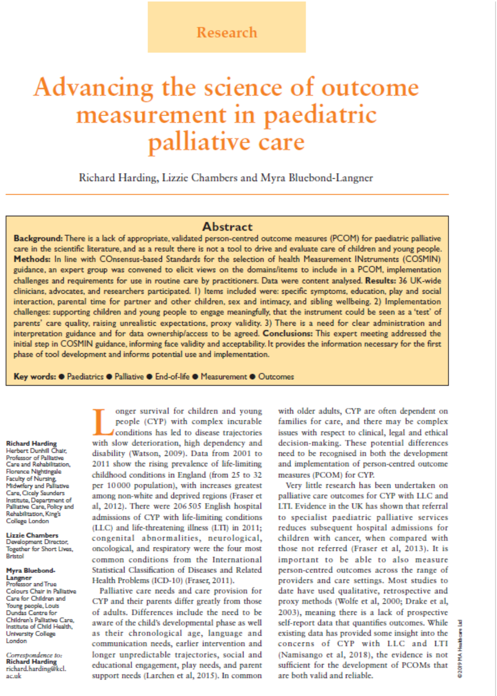
Face to Face Contacts

	April	Sept	Oct	Nov	Dec	Jan	Feb	March
Supportive	77	63	72	44	38	42	49	35
Comprehensive	134	139	142	132	136	119	118	76

Shooting Star Children's Hospices

SSCH 2021 Outcomes Project

- All new requests for support for existing families, emergency requests or requests for families who have just had an initial assessment having joined the service will come through these two meetings.
- In the absence of a standardised children's outcome scale we decided to use the research so far from the CPOS group and use the categories that they had identified in their paper "Advancing the Science of Outcome Measurement in Paediatric Palliative Care" Harding, Chambers, Langer 2019.



Research

Advancing the science of outcome measurement in paediatric palliative care

Richard Harding, Lizzie Chambers and Myra Bluebond-Langner

Abstract

Background: There is a lack of appropriate, validated person-centred outcome measures (PCOM) for paediatric palliative care in the scientific literature, and as a result there is not a tool to drive and evaluate care of children and young people. **Methods:** In line with COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidance, an expert group was convened to elicit views on the domains/items to include in a PCOM, implementation challenges and requirements for use in routine care by practitioners. Data were content analysed. **Results:** 36 UK-wide clinicians, advocates, and researchers participated. 1) Items included were: specific symptoms, education, play and social interaction, parental time for partner and other children, sex and intimacy, and sibling wellbeing. 2) 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. 3) There is a need for clear administration and interpretation guidance and for data ownership/access to be agreed. **Conclusions:** This expert meeting addressed the initial step in COSMIN guidance, informing face validity and acceptability. It provides the information necessary for the first phase of tool development and informs potential use and implementation.

Key words: ● Paediatrics ● Palliative ● End-of-life ● Measurement ● Outcomes

Richard Harding
Herbert Dunhill Chair, Professor of Palliative Care and Rehabilitation, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, King's College London

Lizzie Chambers
Development Director, Together for Short Lives, Bristol

Myra Bluebond-Langner
Professor and True Colours Chair in Palliative Care for Children and Young people, Louis Dundas Centre for Children's Palliative Care, Institute of Child Health, University College London

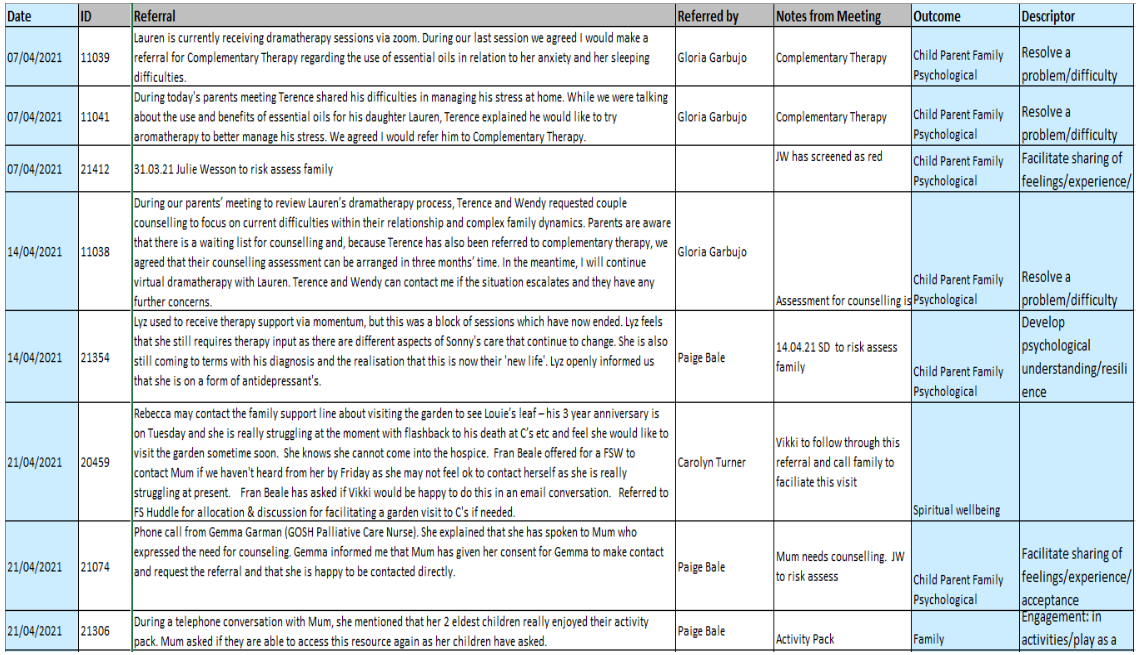
Correspondence to:
Richard Harding
richard.harding@kcl.ac.uk

Longer survival for children and young people (CYP) with complex incurable conditions has led to disease trajectories with slow deterioration, high dependency and disability (Watson, 2009). Data from 2001 to 2011 show the rising prevalence of life-limiting childhood conditions in England (from 25 to 32 per 10 000 population), with increases greatest among non-white and deprived regions (Fraser et al, 2012). There were 206 505 English hospital admissions of CYP with life-limiting conditions (LLC) and life-threatening illness (LTI) in 2011; congenital abnormalities, neurological, oncological, and respiratory were the four most common conditions from the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (Fraser, 2011).

Palliative care needs and care provision for CYP and their parents differ greatly from those of adults. Differences include the need to be aware of the child's developmental phase as well as their chronological age, language and communication needs, earlier intervention and longer unpredictable trajectories, social and educational engagement, play needs, and parent support needs (Larchen et al, 2015). In common with older adults, CYP are often dependent on families for care, and there may be complex issues with respect to clinical, legal and ethical decision-making. These potential differences need to be recognised in both the development and implementation of person-centred outcome measures (PCOM) for CYP.

Very little research has been undertaken on palliative care outcomes for CYP with LLC and LTI. Evidence in the UK has shown that referral to specialist paediatric palliative services reduces subsequent hospital admissions for children with cancer, when compared with those not referred (Fraser et al, 2013). It is important to be able to also measure person-centred outcomes across the range of providers and care settings. Most studies to date have used qualitative, retrospective and proxy methods (Wolfe et al, 2000; Drake et al, 2003), meaning there is a lack of prospective self-report data that quantifies outcomes. While existing data has provided some insight into the concerns of CYP with LLC and LTI (Namisango et al, 2018), the evidence is not sufficient for the development of PCOMs that are both valid and reliable.

SSCH 2021 Outcomes Project



Date	ID	Referral	Referred by	Notes from Meeting	Outcome	Descriptor
07/04/2021	11039	Lauren is currently receiving dramatherapy sessions via zoom. During our last session we agreed I would make a referral for Complementary Therapy regarding the use of essential oils in relation to her anxiety and her sleeping difficulties.	Gloria Garbujo	Complementary Therapy	Child Parent Family Psychological	Resolve a problem/difficulty
07/04/2021	11041	During today's parents meeting Terence shared his difficulties in managing his stress at home. While we were talking about the use and benefits of essential oils for his daughter Lauren, Terence explained he would like to try aromatherapy to better manage his stress. We agreed I would refer him to Complementary Therapy.	Gloria Garbujo	Complementary Therapy	Child Parent Family Psychological	Resolve a problem/difficulty
07/04/2021	21412	31.03.21 Julie Wesson to risk assess family		JW has screened as red	Child Parent Family Psychological	Facilitate sharing of feelings/experience/
14/04/2021	11038	During our parents' meeting to review Lauren's dramatherapy process, Terence and Wendy requested couple counselling to focus on current difficulties within their relationship and complex family dynamics. Parents are aware that there is a waiting list for counselling and, because Terence has also been referred to complementary therapy, we agreed that their counselling assessment can be arranged in three months' time. In the meantime, I will continue virtual dramatherapy with Lauren. Terence and Wendy can contact me if the situation escalates and they have any further concerns.	Gloria Garbujo	Assessment for counselling is	Child Parent Family Psychological	Resolve a problem/difficulty
14/04/2021	21354	Lyz used to receive therapy support via momentum, but this was a block of sessions which have now ended. Lyz feels that she still requires therapy input as there are different aspects of Sonny's care that continue to change. She is also still coming to terms with his diagnosis and the realisation that this is now their 'new life'. Lyz openly informed us that she is on a form of antidepressant's.	Paige Bale	14.04.21 SD to risk assess family	Child Parent Family Psychological	Develop psychological understanding/resilience
21/04/2021	20459	Rebecca may contact the family support line about visiting the garden to see Louie's leaf – his 3 year anniversary is on Tuesday and she is really struggling at the moment with flashback to his death at C's etc and feel she would like to visit the garden sometime soon. She knows she cannot come into the hospice. Fran Beale offered for a FSW to contact Mum if we haven't heard from her by Friday as she may not feel ok to contact herself as she is really struggling at present. Fran Beale has asked if Vikki would be happy to do this in an email conversation. Referred to FS Huddle for allocation & discussion for facilitating a garden visit to C's if needed.	Carolyn Turner	Vikki to follow through this referral and call family to faciliate this visit	Spiritual wellbeing	
21/04/2021	21074	Phone call from Gemma Garman (GOSH Palliative Care Nurse). She explained that she has spoken to Mum who expressed the need for counseling. Gemma informed me that Mum has given her consent for Gemma to make contact and request the referral and that she is happy to be contacted directly.	Paige Bale	Mum needs counselling. JW to risk assess	Child Parent Family Psychological	Facilitate sharing of feelings/experience/acceptance
21/04/2021	21306	During a telephone conversation with Mum, she mentioned that her 2 eldest children really enjoyed their activity pack. Mum asked if they are able to access this resource again as her children have asked.	Paige Bale	Activity Pack	Family	Engagement: in activities/play as a

- **What were we hoping to find using the data?**
- We were hoping to understand what was being requested by families and professionals and then to see if our service offer was correct based on those requests.
- What is the most asked for service?
- What is the least asked for service?
- What is the implication for how we provide services currently and do we need to change the resources we allocate?

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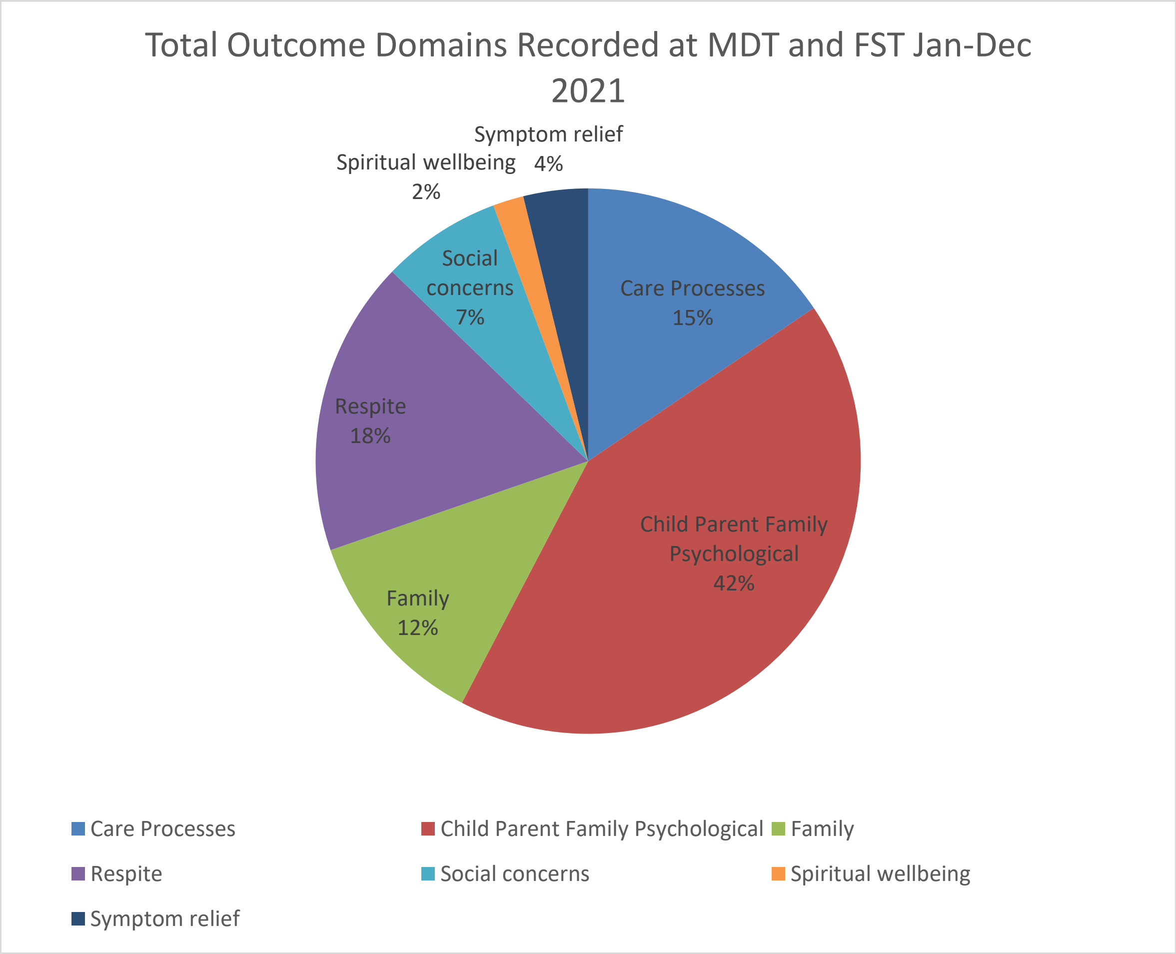
SSCH 2021 Outcomes Project

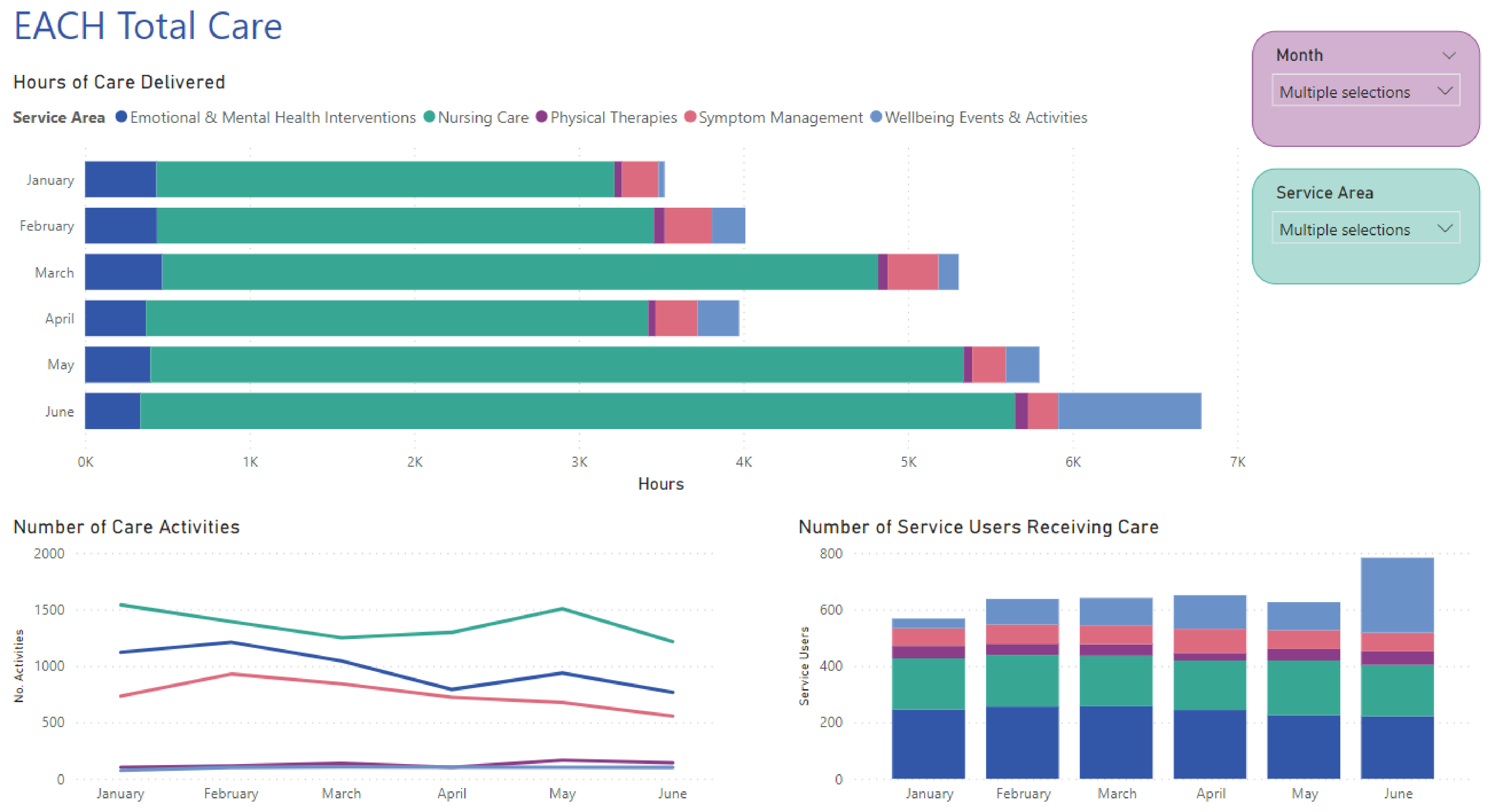


- What did the results show?
- There is a separate Specialist MDT which discusses children’s symptoms in depth
- The domains accurately represent our service provision and enabled us to tweak the job roles of the newish Family Support Workers and provide additional training and support
- We have developed an “on-boarding” process for new families which staggers the information we give them about the service over a longer time period and has an outcome template

Shooting Star Children’s Hospices

EACH Care Model

EACH Service Line Reporting



EACH Total Care

Month: Multiple selections

Service Area: Multiple selections

Quality of Care: Personalised Goals

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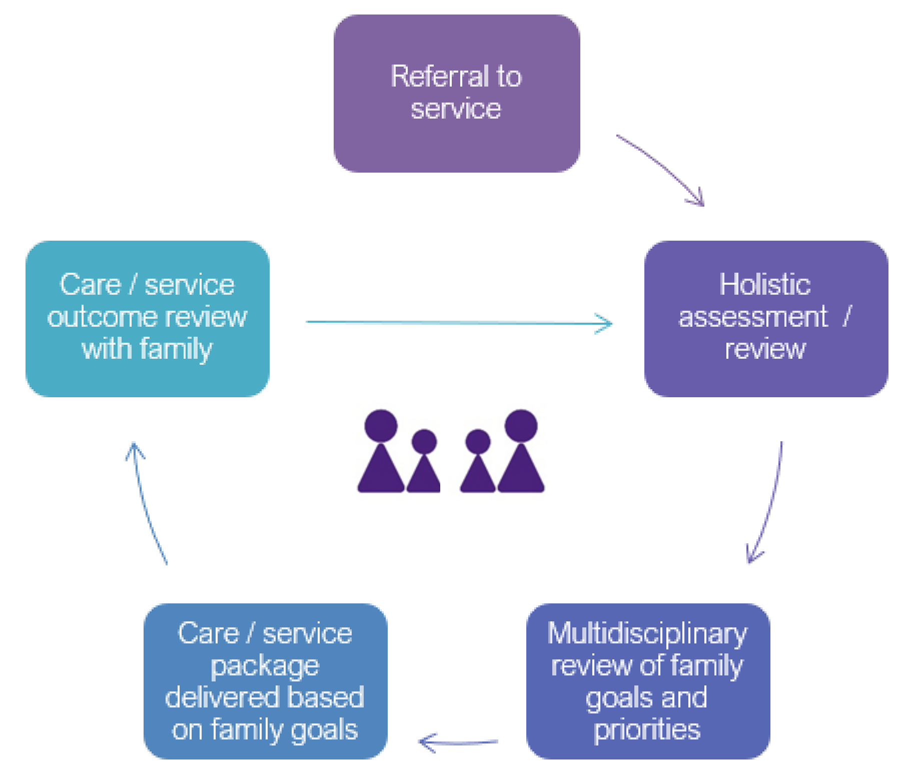
Holistic Assessment Process



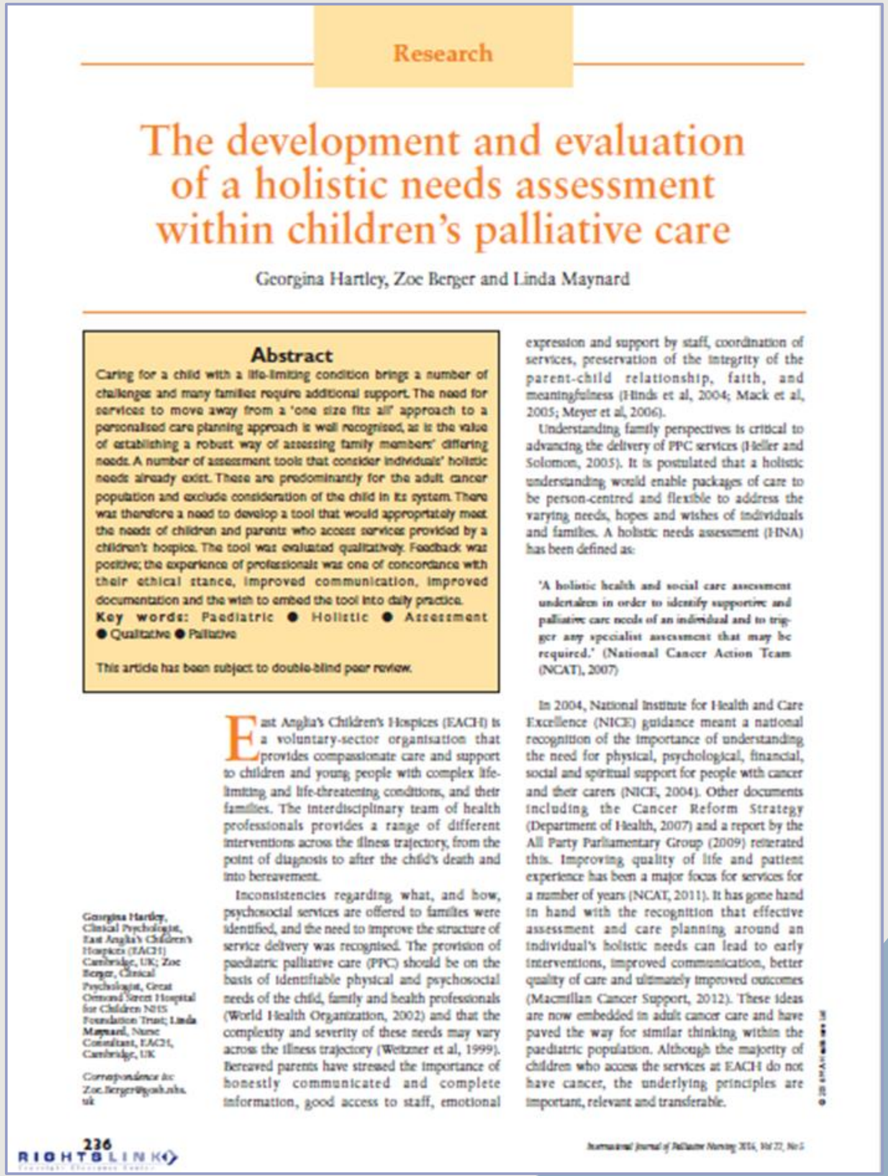
Referral to service

Holistic assessment / review

Multidisciplinary review of family goals and priorities

Care / service package delivered based on family goals

Care / service outcome review with family



Research

The development and evaluation of a holistic needs assessment within children's palliative care

Georgina Hartley, Zoe Berger and Linda Maynard

Abstract

Caring for a child with a life-limiting condition brings a number of challenges and many families require additional support. The need for services to move away from a 'one size fits all' approach to a personalised care planning approach is well recognised, as is the value of establishing a robust way of assessing family members' differing needs. A number of assessment tools that consider individuals' holistic needs already exist. These are predominantly for the adult cancer population and exclude consideration of the child in its system. There was therefore a need to develop a tool that would appropriately meet the needs of children and parents who access services provided by a children's hospice. The tool was evaluated qualitatively. Feedback was positive; the experience of professionals was one of concordance with their ethical stance, improved communication, improved documentation and the wish to embed the tool into daily practice.

Key words: Paediatric ● Holistic ● Assessment ● Qualitative ● Palliative

This article has been subject to double-blind peer review.

East Anglia's Children's Hospices (EACH) is a voluntary-sector organisation that provides compassionate care and support to children and young people with complex life-limiting and life-threatening conditions, and their families. The interdisciplinary team of health professionals provides a range of different interventions across the illness trajectory, from the point of diagnosis to after the child's death and into bereavement.

Inconsistencies regarding what, and how, psychosocial services are offered to families were identified, and the need to improve the structure of service delivery was recognised. The provision of paediatric palliative care (PPC) should be on the basis of identifiable physical and psychosocial needs of the child, family and health professionals (World Health Organization, 2002) and that the complexity and severity of these needs may vary across the illness trajectory (Weitzner et al, 1999). Bereaved parents have stressed the importance of honestly communicated and complete information, good access to staff, emotional expression and support by staff, coordination of services, preservation of the integrity of the parent-child relationship, faith, and meaningfulness (Hinds et al, 2004; Mack et al, 2005; Meyer et al, 2006).

Understanding family perspectives is critical to advancing the delivery of PPC services (Heller and Solomon, 2005). It is postulated that a holistic understanding would enable packages of care to be person-centred and flexible to address the varying needs, hopes and wishes of individuals and families. A holistic needs assessment (HNA) has been defined as:

> 'A holistic health and social care assessment undertaken in order to identify supportive and palliative care needs of an individual and to trigger any specialist assessment that may be required.' (National Cancer Action Team (NCAT), 2007)

In 2004, National Institute for Health and Care Excellence (NICE) guidance meant a national recognition of the importance of understanding the need for physical, psychological, financial, social and spiritual support for people with cancer and their carers (NICE, 2004). Other documents including the Cancer Reform Strategy (Department of Health, 2007) and a report by the All Party Parliamentary Group (2009) reiterated this. Improving quality of life and patient experience has been a major focus for services for a number of years (NCAT, 2011). It has gone hand in hand with the recognition that effective assessment and care planning around an individual's holistic needs can lead to early interventions, improved communication, better quality of care and ultimately improved outcomes (Macmillan Cancer Support, 2012). These ideas are now embedded in adult cancer care and have paved the way for similar thinking within the paediatric population. Although the majority of children who access the services at EACH do not have cancer, the underlying principles are important, relevant and transferable.

Georgina Hartley, Clinical Psychologist, East Anglia's Children's Hospices (EACH) Cambridge, UK; **Zoe Berger**, Clinical Psychologist, Great Ormond Street Hospital for Children NHS Foundation Trust; **Linda Maynard**, Nurse Consultant, EACH, Cambridge, UK

Correspondence to: Zoe.Berger@gosh.nhs.uk

The Network

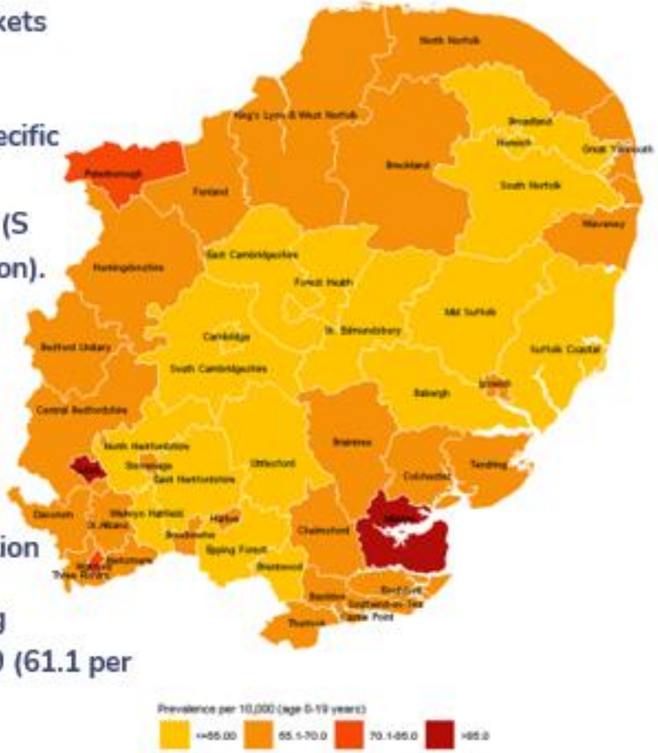
Area: 19,120 km^2

Predominantly rural, pockets of urban areas

White British (>85%), specific areas of multi-ethnic population & deprivation (S Essex, Peterborough, Luton).

Child Population: 1.4 million

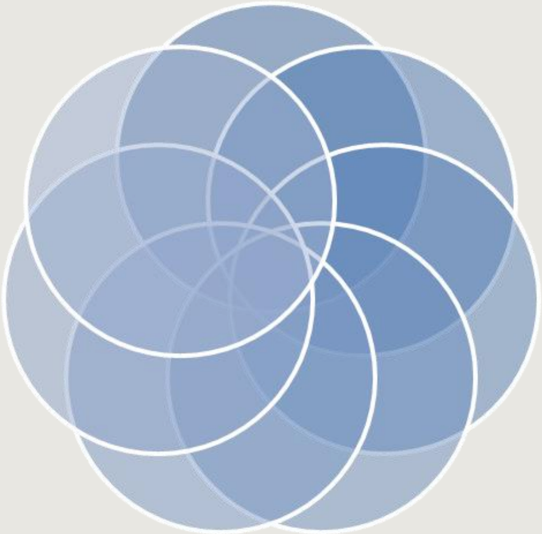
Children with life-limiting conditions estimate 8,989 (61.1 per 10,000).



1 Tertiary Centre

6 Integrated Care Boards

1 Children's Hospital



4 Children's Hospice Services

3 Level 3 NICU

7 Community Nursing Services

15 District General Hospitals

Thank you & Questions

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What are the next big questions for outcomes in the context of paediatric palliative care?

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Tag us in and use the hashtag **#TSFLConference**

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#TFSLConference

How many eligible children miss out on paediatric palliative care? An analysis of local death data and a survey of paediatric staff perceptions and barriers to referral

Dr Hannah Opstad
Paediatric Consultant, St George’s Hospital
&
The Noah’s Ark team

NOAH’S ARK
Children’s Hospice

Background:

- Paediatric hospices/palliative care services play a **key role** in supporting children & families with LLC
- It can be difficult to identify all children who may benefit from this support
- Epidemiological studies have sought to estimate prevalence of children with LLC by looking at NHS digital data from hospital admissions, but there are limitations around coding

Estimating unmet need & identifying referral barriers

- We analysed the local death data over a 6-year period to identify the cause and location of death and determine which children would have potentially met criteria for a hospice referral

- We also sought to identify the perceptions of paediatric staff of hospice care and identify referral barriers at this point
- Our hypothesis = many children with LLC are known to paediatricians but are not referred on to their local hospices

Aims

- To identify the causes and locations of child deaths in the local population
- To determine which children would have potentially met criteria for a hospice referral

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- To develop a greater understanding of paediatric staff perceptions of hospice care
- To identify barriers to hospice care referral by paediatric care teams

Design

- Records of local death data (2015-2021) were analysed:
  - Cause of death
  - Location of death
  - Underlying past medical history
- These were checked against eligibility criteria for hospice referral
- Accidental deaths/suicide at home were not included in the death-at-home data

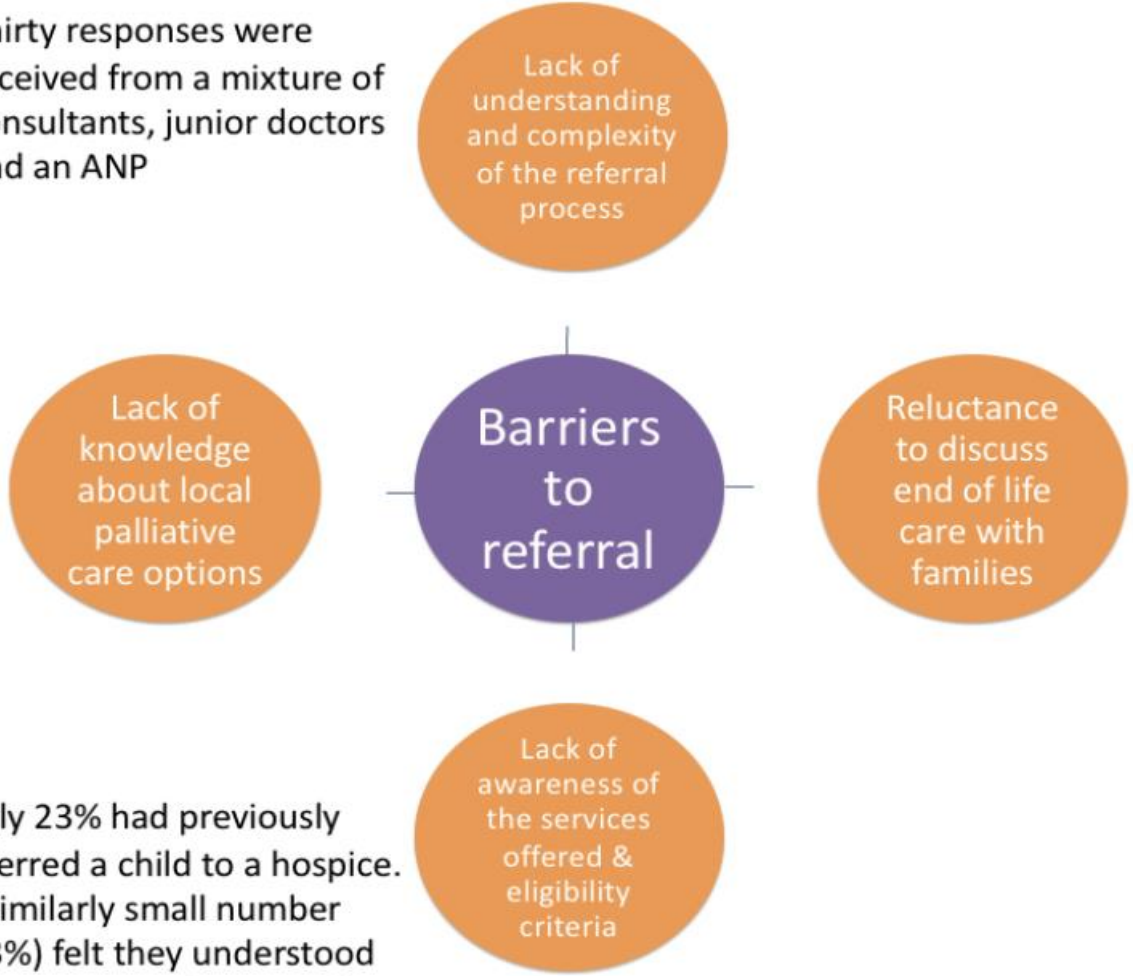
- A survey of ten questions was distributed
- The survey was shared within the paediatric departments at two North London district general hospitals (DGH), a tertiary neonatal intensive care unit and a tertiary hospital neurology department

Results:

- Over the six-year period analysed there were an average of **26** deaths per year for CYP from all causes.
- The highest number of planned deaths at home in a year was 6 in 2015.
- A total of 4 children died in a hospice.
- Between 5 and 18 children were found to meet hospice referral criteria each year (an average of 10/year), with conditions including:
- Cancers, complex congenital anomalies, Genetic & Rare conditions, Cerebral palsy with recurrent respiratory infections
- 139 of the 154 total deaths occurred in hospital (90%) from all causes, but 43 (28%) of those deaths were in children with LLC and were expected.
- Just 19 children (12%) had a planned death at home or in a hospice setting over the six-year period analysed.

Results

- Thirty responses were received from a mixture of consultants, junior doctors and an ANP



Barriers to referral

Lack of understanding and complexity of the referral process

Reluctance to discuss end of life care with families

Lack of awareness of the services offered & eligibility criteria

Lack of knowledge about local palliative care options

- Only 23% had previously referred a child to a hospice. A similarly small number (23%) felt they understood the criteria and process for hospice referral, while the majority were unsure.

- 90% reported that they had cared for, but not referred, a child who would have benefitted from hospice care.

- 97% of the clinical staff surveyed said that, having read the referral criteria and seeing the range of services offered, they would be more likely to refer a child to a hospice in future.

Conclusions:

Our findings suggest, given that **90%** of paediatric staff surveyed stated that they had previously looked after children who were eligible for hospice care but not referred, **the main barrier to referral is paediatric staff correctly identifying the need for palliative care and appropriately referring these children on**.

Conclusions:

- This data suggests the vast majority of children die in hospital, even where death is expected, with only 12% having a planned death at home/hospice.
- There are an average of 26 deaths per year locally, from all causes, but an average of 10 of those children per year potentially meet eligibility criteria for hospice referral (38%).
- This data supports the hypothesis from epidemiological studies that there is **unmet need** within the local population.
- There is clearly need for greater awareness amongst paediatric teams, as well as families, of the services offered by local hospices.
- More research is needed in this area to identify family perceptions of hospice care and ascertain whether there is an element of preferential choice for a hospital-based death, and if so why…

References:

- Williams, J., Horsley, A., 2015. Audit of Children's palliative care services in the East Midlands and identification of the gaps in service provision. East Midlands Strategic Clinical Network [online]. Available from: https://www.england.nhs.uk/mids-east/wp-content/uploads/sites/7/2018/03/childrens-palliative-care-report-2015.pdf [accessed 16/10/2021]
- Opstad, H. 2021. Why eligible children can miss out on paediatric hospice care: A study of paediatric staff perceptions and barriers to referral. Noah's Ark Hospice Survey.
- Fraser, L., Gibson-Smith, D., Jarvis, S., Normal, P., Parslow, R., 2020. Estimating the current and future prevalence of life-limiting conditions in children in England. *Palliative Medicine*. [online ahead of print]. Available from: 10.1177/0269216320975308.
- Health & Social Care Information Centre, 2015. A Guide to Linked Mortality Data from Hospital Episode Statistics and the Office for National Statistics. *Health & Social Care Information Centre* [online]. Available from: https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/linked-hes-ons-mortality-data. [accessed 16/10/2021]
- Capita, 2014. The quality of clinical coding in the NHS. *Capita Health and Wellbeing Limited* [online]. Available from: https://www.chks.co.uk/userfiles/files/The_quality_of_clinical_coding_in_the_NHS.pdf

> "This is a place of life, of light, of joy and of play. This is a place that can let your children be more than the difficulties they face and are labelled with. This is a place where specialist care is offered, a place for families to connect, a place where the most precious of memories will be made."

ROSE, GRANDMOTHER AND SOLE GUARDIAN OF BEN (WHO DIED IN 2014) AND OF SOPHIE WHO CURRENTLY BENEFITS FROM OUR CARE.

Welcome to together for short lives

How do Children with Medical Complexity Die? A Scoping Review

Together for Short Lives Conference
7 September 2022

Dr Grace Ng, HCA Hospice, Singapore
Dr Marie-Helene Bourassa, MUHC, Canada
Dr Hema Patel, MUHC, Canada

Content

Background

Methods

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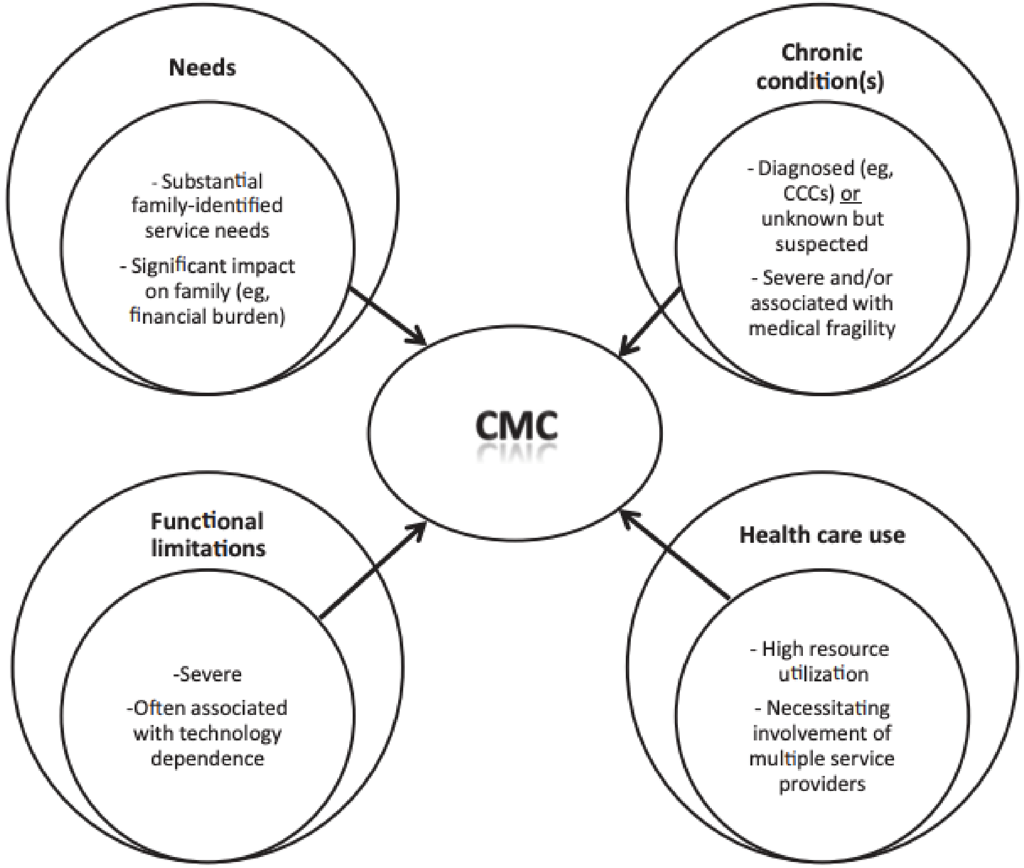
Q&A

Background

Who is the Child with Medical Complexity?

Children with Medical Complexity[1]

1) Substantial health care needs
2) Chronic condition(s)
3) Functional limitations
4) High health care utilization



Needs

- Substantial family-identified service needs
- Significant impact on family (eg, financial burden)

Chronic condition(s)

- Diagnosed (eg, CCCs) or unknown but suspected
- Severe and/or associated with medical fragility

CMC

Functional limitations

-Severe

-Often associated with technology dependence

Health care use

- High resource utilization
- Necessitating involvement of multiple service providers

End of Life in CMC

- Growing cohort, at risk of childhood death[2]
- End of life in CMC is poorly understood[3]
- Lack of knowledge leads to communication gaps and distress[3]

Aim

To synthesize current literature and to describe the characteristics of end of life in CMC

Methods

- **Scoping review**
  - To map existing literature, identify key concepts and gaps in current research[4]
  - Conducted in accordance with PRISMA-Scr
- **Search strategy**
  - Databases: MEDLINE, CINAHL, PsycINFO, Scopus and Embase
  - Grey literature: Google Scholar
  - Not limited by language, date, or study design

Inclusion and exclusion criteria

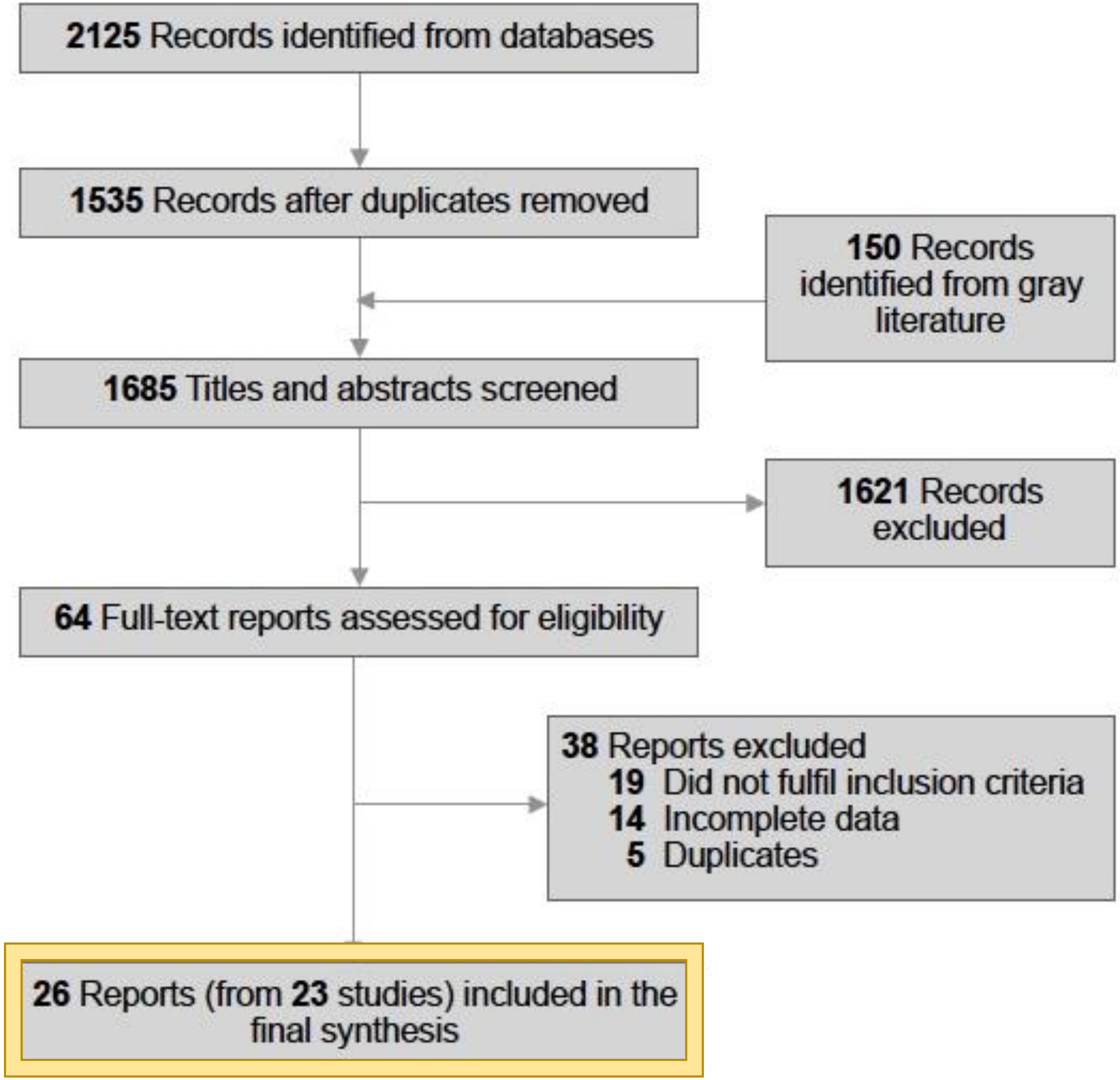
Inclusion

If study participants were:
- 0 to 21 years old
- Fulfilled definition of CMC by Cohen et al[1]
- At end of life[5]

Exclusion

If study participants were ONLY:
- Healthcare workers
- > 21 years old
- Cancer patients

Selection of articles



2125 Records identified from databases

1535 Records after duplicates removed

150 Records identified from gray literature

1685 Titles and abstracts screened

1621 Records excluded

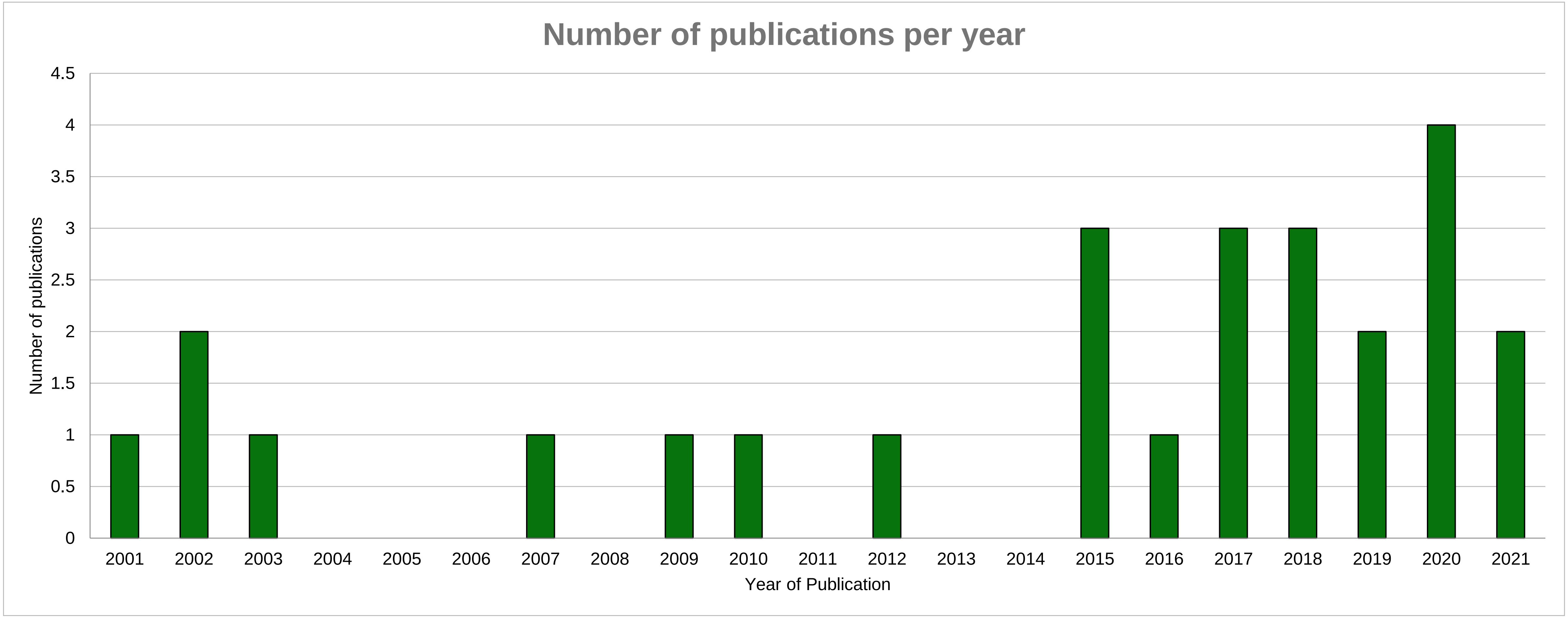
64 Full-text reports assessed for eligibility

38 Reports excluded
- **19** Did not fulfil inclusion criteria
- **14** Incomplete data
- **5** Duplicates

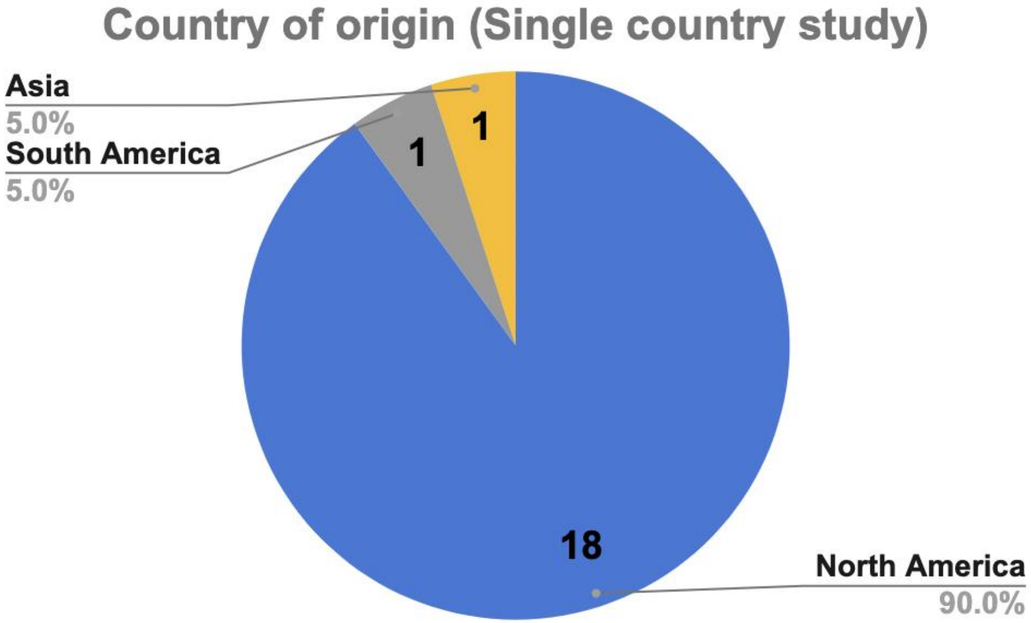
26 Reports (from **23** studies) included in the final synthesis

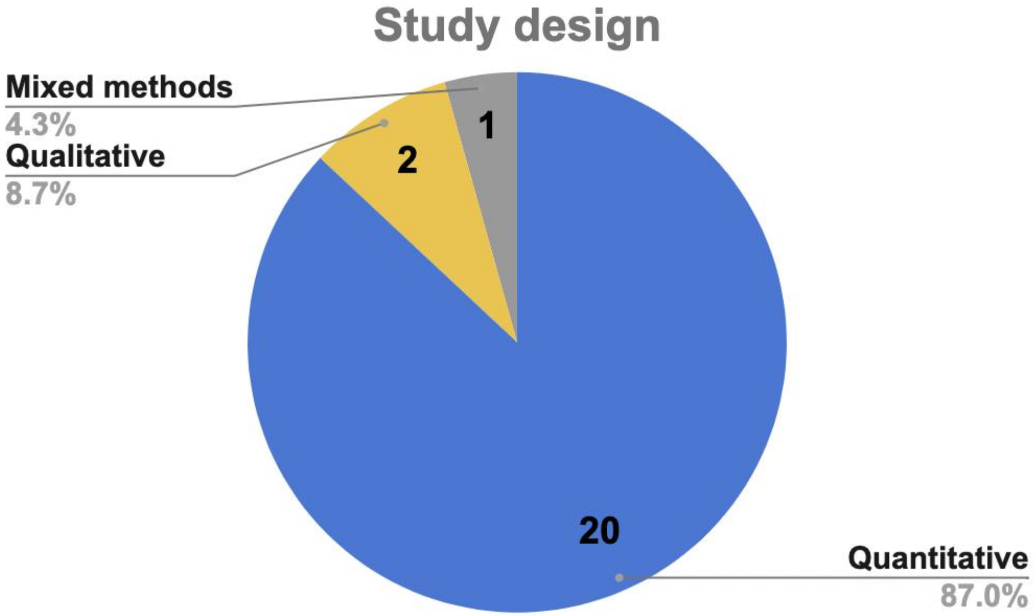
Results

Characteristics of included studies



Characteristics of included studies





Study Outcomes

1. Place of death
2. Interventions received or withdrawn
3. Health care use
4. Communication & End-of-life experiences

1. Place of Death

- Most frequently studied outcome (52%).
- Majority of CMC deaths (81%) occurred in the hospital.

Place of death	Weighted percentage (%)	Range (%)
Hospital	81	34 – 92
Intensive care unit (ICU)	44	24 – 53
General ward	58	6 – 64
Emergency department (ED)	5	4 – 14
Home	15	0 - 50

2. Interventions Received or Withdrawn

- The most frequently studied intervention received was that of mechanical ventilation.
- CMC were more likely to be mechanically ventilated and to be ventilated for a longer duration as compared to non-CMC[7].

Percentage of life-sustaining intervention received in CMC				
Study timeframe	**Ventilation (%)**	**CPR (%)**	**Surgery / Procedure (%)**	**Hemodialysis (%)**
Last 30 days of life	24	11	-	4
Last year of life	37	-	70	-
Terminal admission	76	-	41	-
Last 48 hours of life	14	-	-	-

3. Health Care Use

- CMC were hospitalised more and longer than non-CMC at end of life, with the rate of hospital admission rising nearing death[6].

4. Communication and End-Of-Life Experiences

Communication

- Prognostic uncertainty
- Perception of child's quality of life
- Chronic illness experience
- Recognition of parental expertise

4. Communication and End-Of-Life Experiences

Communication

- Prognostic uncertainty
- Perception of child’s quality of life
- Chronic illness experience
- Recognition of parental expertise

“It was really hard to gauge … whether [son] was going to give us two weeks or the extra year and a half that he did.”[3]

4. Communication and End-Of-Life Experiences

Communication

- Prognostic uncertainty
- Perception of child’s quality of life
- Chronic illness experience
- Recognition of parental expertise

> *“Their automatic assumptions… this is all the things she has wrong with her, oh, her life at home is horrible, she has a painful life, she probably lays in bed, all day, she does nothing. And we’re like, what, they doesn’t describe her at all.”*

4. Communication and End-Of-Life Experiences

Communication

- Prognostic uncertainty
- Perception of child’s quality of life
- Chronic illness experience
- Recognition of parental expertise

> *“[Our son] had a lot of medical problems during his short life, but we always expected him to have a normal life span. He was a pretty tough guy and we thought he had already been through the worst of his medical crises.”*

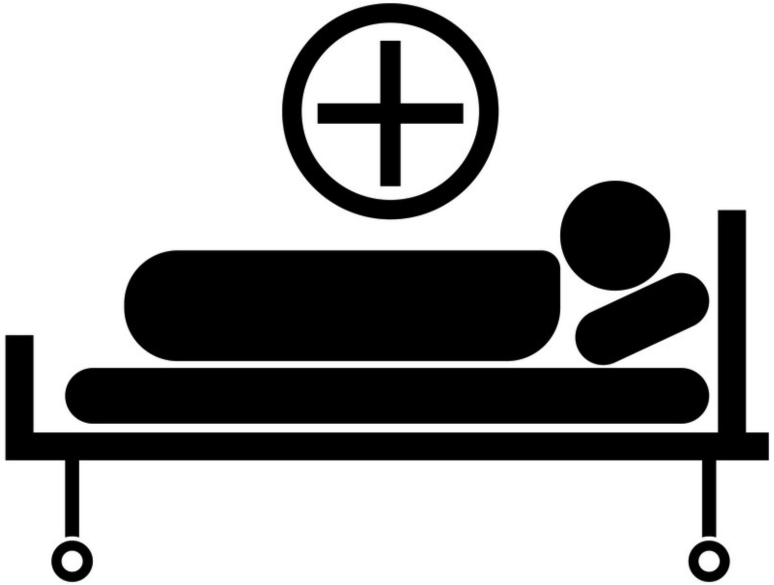
4. Communication and End-Of-Life Experiences

Communication

- Prognostic uncertainty
- Perception of child's quality of life
- Chronic illness experience
- Recognition of parental expertise

"They have to listen to parents, like I didn't want her poked a million times. I knew where the best place was… I think things could have been done very differently if they would have listened to me…"

4. Communication and End-Of-Life Experiences



End-Of-Life

- Surprised at child’s death
- Multiple losses

4. Communication and End-Of-Life Experiences

“It came as, a shock, even though knowing that every day was a gift with [son], because I didn’t realize how quickly things could happen.”[3]

End-Of-Life

- Surprised at child’s death
- Multiple losses

4. Communication and End-Of-Life Experiences

“We were so involved in the medical world throughout my son’s life… When he died, that all suddenly stopped since there is now no reason to go to the hospital. It’s like falling off a cliff.”

End-Of-Life

- Surprised at child’s death
- Multiple losses

4. Communication and End-Of-Life Experiences

COMPASSION

Communication

- Prognostic uncertainty
- Perception of child’s quality of life
- Chronic illness experience
- Recognition of parental expertise

End-Of-Life

- Surprised at child’s death
- Multiple losses

“We were overwhelmed by the kindness and respect from the staff. There was one very special nurse who had cared for my son at the end who came in to be with us after he died even though she was not on duty. She helped us wash his body and allowed us to go with him when she brought the cart to the morgue. For this kindness we will forever be grateful.”

Discussion

Summary & Implications

- CMC do die differently
- Increased in-hospital deaths, healthcare use, more intensive interventions
- Reflective of their lived experiences of unpredictability in illness trajectory, chronic illness experience, previous survival of multiple life threatening events
- Helpful in informing our approach to communication and providing end of life care

Limitations and recommendations

- Excluded studies with ONLY healthcare providers
- Studies from other countries, more qualitative studies
- Other gaps identified: ethical issues, patient perspectives, end of life care in the home and community

References

1) Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529-538. doi:10.1542/peds.2010-0910
2) Lindley LC, Mixer SJ, Mack JW. Home care for children with multiple complex chronic conditions at the end of life: The choice of hospice versus home health. Home Health Care Serv Q. 2016;35(3-4):101-11.
3) Bao D, Feichtinger L, Andrews G, Pawliuk C, Steele R, Siden HH. Charting the Territory: End-of-Life Trajectories for Children With Complex Neurological, Metabolic, and Chromosomal Conditions. J Pain Symptom Manage. 2021;61(3):449-55.e1.
4) Pham MT, Rajić A, Greig JD, Sargeant JM, Papadopoulos A, McEwen SA. A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Res Synth Methods*. 2014;5(4):371-385. doi:10.1002/jrsm.1123
5) Feudtner C, Christakis DA, Zimmerman FJ, Muldoon JH, Neff JM, Koepsell TD. Characteristics of deaths occurring in children's hospitals: implications for supportive care services. Pediatrics. 2002 May;109(5):887-93. doi: 10.1542/peds.109.5.887. PMID: 11986451.
6) Committee on Approaching Death: Addressing Key End of Life I, Institute of M. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press (US)
7) Feudtner C, DiGiuseppe DL, Neff JM. Hospital care for children and young adults in the last year of life: a population-based study. BMC Med. 2003 Dec 23;1:3. doi: 10.1186/1741-7015-1-3. PMID: 14690540; PMCID: PMC317390.

Acknowledgements

- Co-investigators Dr Marie-Helene Bourassa, Dr Hema Patel
- Patients and families

Thank you!
Any questions?

graceN@hcahospicecare.org.sg

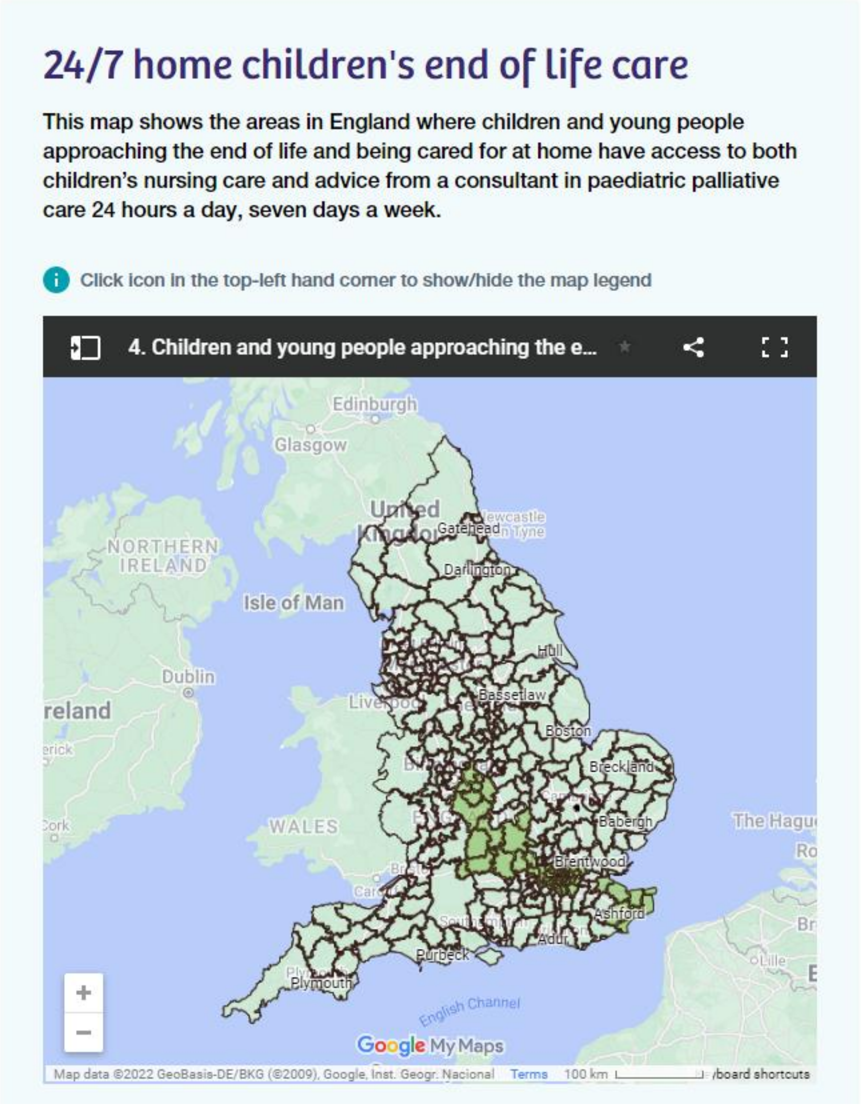
Mapping children's palliative care service provision

James Cooper
Head of Public Affairs and Policy
Together for Short Lives

www.togetherforshortlives.org.uk/247maps

Mapping children’s palliative care

1. What we mapped.
2. Why we did it.
3. How we did it.
4. What we found.
5. How we used it.



24/7 home children's end of life care

This map shows the areas in England where children and young people approaching the end of life and being cared for at home have access to both children’s nursing care and advice from a consultant in paediatric palliative care 24 hours a day, seven days a week.

Click icon in the top-left hand corner to show/hide the map legend

4. Children and young people approaching the e...

What we mapped

- Where seriously ill children and their families in England can access palliative care which meets National Institute for Health and Care Excellence (NICE) quality standards: **where the standards are being met** (shaded in **green**) and where they are not (unshaded).

- The **number** of children and children and young people aged 0-24 with life-limiting conditions per integrated care system (ICS) area; the darker the shading, the higher the number of cases.

- The **prevalence** of life-limiting and life-threatening conditions per 10,000 children and young people aged 0-24 per ICS area; the darker the shading, the higher the prevalence.

- Whether local NHS clinical commissioning groups (CCGs) were **commissioning** services to meet a standard (available on certain maps).

What we mapped (continued)

- Where **inpatient children's palliative care services** are located; these include children's hospitals and children's hospices. Descriptions about each service are available by clicking on the pins in the map, in addition to information about how children and families can access them.

- Where **Westminster parliamentary constituencies** are located.

Why we did it

- To understand the extent to which the National Institute for Health and Care Excellence (NICE) children's palliative care **standards** are being met across the UK.

- To enable **families** caring for seriously ill children to make **informed choices** about the children's palliative care they decide to access.

- To enable the UK Government, NHS England and other decision makers to **better plan, fund and fill the gaps** in children's palliative care provision across the country.

NICE quality standards

1. Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an **advance care plan**.
2. Infants, children and young people with a life-limiting condition have a **named medical specialist** who leads and coordinates their care.
3. Infants, children and young people with a life-limiting condition and their parents or carers are given information about **emotional and psychological support**, including how to access it.
4. Infants, children and young people with a life-limiting condition are cared for by a **multidisciplinary team** that includes members of the specialist paediatric palliative care team.
5. Parents or carers of infants, children and young people approaching the end of life are offered support for **grief and loss** when their child is nearing the end of their life and after their death.
6. Infants, children and young people approaching the **end of life** and being cared for at **home** have **24-hour access** to both **children's nursing care and advice from a consultant** in paediatric palliative care.

How we did it 1: CCG FOIs

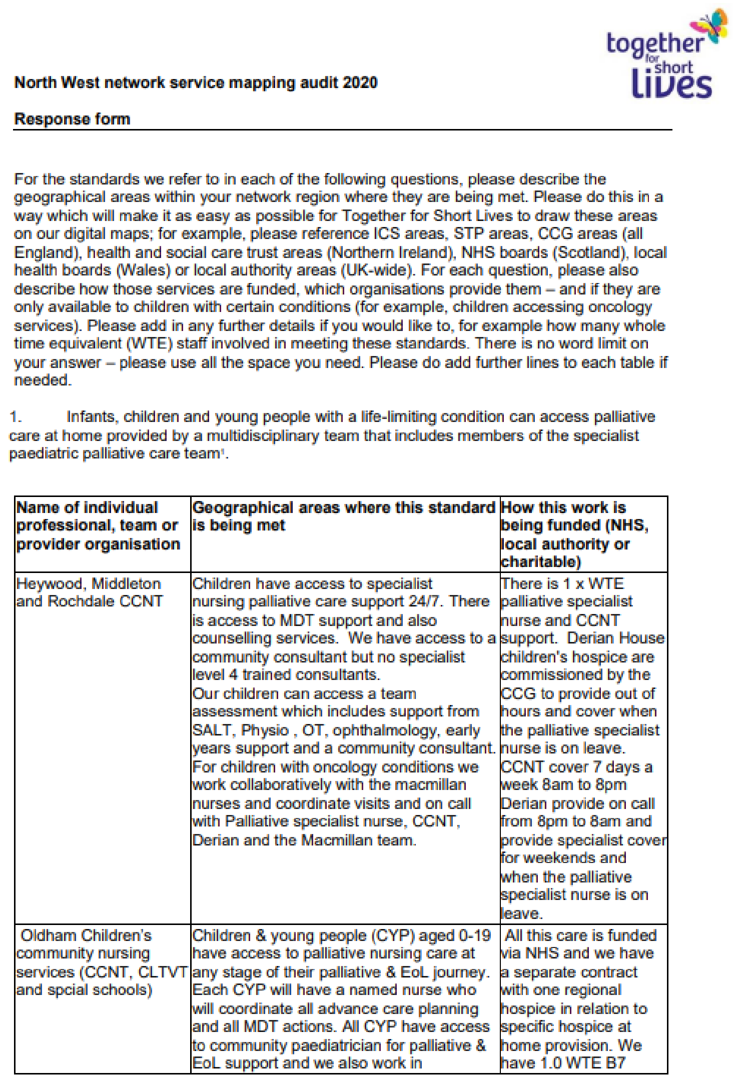
1. Do you have a children’s palliative care **service specification**? (Yes/No). If so, please attach a copy to your response to this request.
2. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an **advance care plan**? (Yes/No)
3. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition should have a **named medical specialist** who leads and coordinates their care? (Yes/No)
4. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should be given information about **emotional and psychological support**, including how to access it? (Yes/No)
5. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition should be cared for by a **multidisciplinary team** that includes members of the specialist paediatric palliative care team? (Yes/No)

How we did it 1: CCG FOIs

6. Do you have a children’s palliative care service specification which states that parents or carers of infants, children and young people approaching the end of life should be offered support for **grief and loss** when their child is nearing the end of their life and after their death? (Yes/No)
7. Do you have a children’s palliative care service specification which states that infants, children and young people approaching the **end of life** and being cared for at **home** should have **24-hour access** to both **children's nursing care and advice from a consultant** in paediatric palliative care? (Yes/No)
8. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition and their families should have access **regular short breaks for respite**? (Yes/No)

How we did it 2: network information

We issued an **online form to children's palliative care networks** in England. This data requests asked where in regions key standards of children's palliative care are being met in the community – by the NHS, the voluntary sector or a combination of both.



North West network service mapping audit 2020

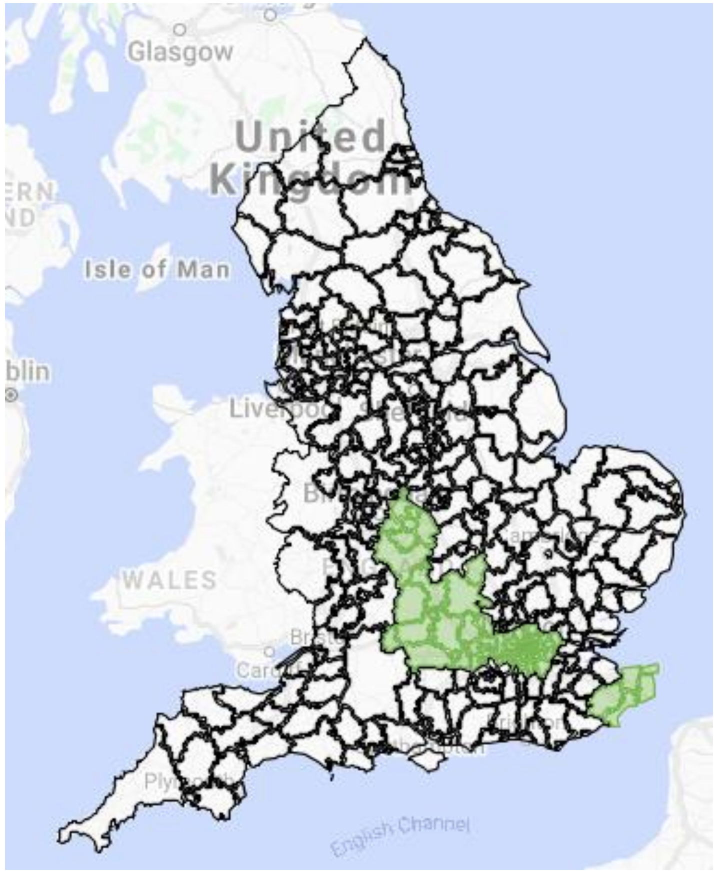
Response form

For the standards we refer to in each of the following questions, please describe the geographical areas within your network region where they are being met. Please do this in a way which will make it as easy as possible for Together for Short Lives to draw these areas on our digital maps; for example, please reference ICS areas, STP areas, CCG areas (all England), health and social care trust areas (Northern Ireland), NHS boards (Scotland), local health boards (Wales) or local authority areas (UK-wide). For each question, please also describe how those services are funded, which organisations provide them – and if they are only available to children with certain conditions (for example, children accessing oncology services). Please add in any further details if you would like to, for example how many whole time equivalent (WTE) staff involved in meeting these standards. There is no word limit on your answer – please use all the space you need. Please do add further lines to each table if needed.

1. Infants, children and young people with a life-limiting condition can access palliative care at home provided by a multidisciplinary team that includes members of the specialist paediatric palliative care team[1].

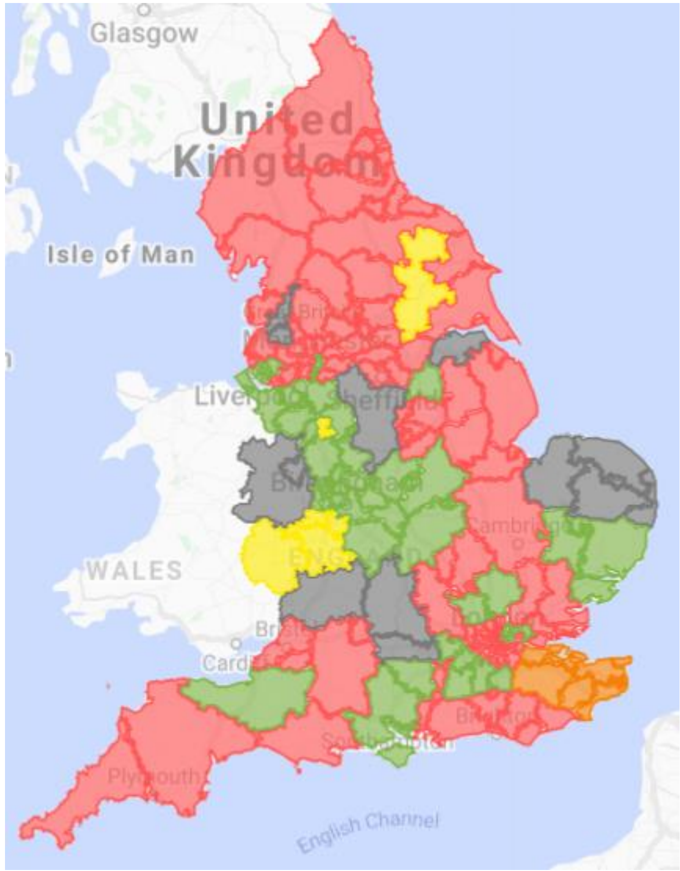
Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Heywood, Middleton and Rochdale CCNT	Children have access to specialist nursing palliative care support 24/7. There is access to MDT support and also counselling services. We have access to a community consultant but no specialist level 4 trained consultants. Our children can access a team assessment which includes support from SALT, Physio , OT, ophthalmology, early years support and a community consultant. For children with oncology conditions we work collaboratively with the macmillan nurses and coordinate visits and on call with Palliative specialist nurse, CCNT, Derian and the Macmillan team.	There is 1 x WTE palliative specialist nurse and CCNT support. Derian House children's hospice are commissioned by the CCG to provide out of hours and cover when the palliative specialist nurse is on leave. CCNT cover 7 days a week 8am to 8pm Derian provide on call from 8pm to 8am and provide specialist cover for weekends and when the palliative specialist nurse is on leave.
Oldham Children's community nursing services (CCNT, CLTVT and spcial schools)	Children & young people (CYP) aged 0-19 have access to palliative nursing care at any stage of their palliative & EoL journey. Each CYP will have a named nurse who will coordinate all advance care planning and all MDT actions. All CYP have access to community paediatrician for palliative & EoL support and we also work in	All this care is funded via NHS and we have a separate contract with one regional hospice in relation to specific hospice at home provision. We have 1.0 WTE B7

24/7 end of life care at home: nursing & PPM



Provided

Green: Yes, standard being met
White: No, standard not being met.



Commissioned

Green: Yes, CCG specifies 24/7
Red: No, CCG does not specify 24/7
Yellow: Unclear whether 24/7 specified
Orange: CCG partially specifies 24/7
Grey: Specification currently in development.

What we found

- The extent to which seriously ill children and their families can access services which achieve these standards is very patchy and depends on where they live.

- Of particular concern is children and families' access to **end of life care at home, 24 hours a day, seven days a week**, provided by nurses and supported by advice from consultant paediatricians who have completed sub-specialty training in paediatric palliative medicine (also known as GRID training).

- While this standard is met in just over half (54%) of local authority areas in England during normal working hours, **it is not being met four fifths (81%) of local authority areas 24/7**.

- This means that the 24/7 standard is not being met in nearly **four fifths (79%) of integrated care system (ICS) areas**.

- It is only being met fully in three ICS areas (7%). It is being partially met in six (14%) ICS areas.

Areas where all standards are met

Local authority	Standards met	Annual prevalence of life-limiting conditions per 10,000
Warwickshire	• All standards met	60
Buckinghamshire	• All standards met	58
North London Central	• All standards met	68
North West London	• All standards met	72
North East London	• All standards met	72
South West London	• All standards met	70
South East London	• All standards met	69

Areas with the greatest challenges

Local authority	Standards met	Annual prevalence of life-limiting conditions per 10,000
Gloucestershire	• Standard 7	64
Derbyshire	• Standard 8	61
Northamptonshire	• Standard 3 • Standard 8	67

Workforce shortages

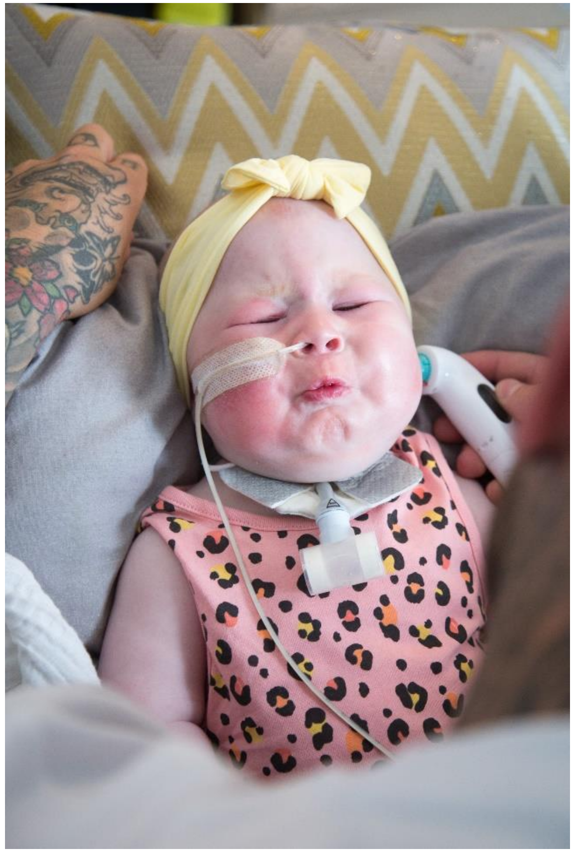
- There are currently too few nurses, paediatricians and other professionals with the skills and experience to provide children’s palliative care in hospitals, children’s hospices and in the community.
- 5,500 CCNs should be working in England according to RCN modelling. Yet there are only 713 community children’s nurses employed by the NHS in England.
- There are 18 GRID-trained specialist paediatric palliative medicine (PPM) consultants in the UK, when the Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 are needed.
- In 2022, the average vacancy rate for roles equivalent to Agenda for Change bands 2-9 inclusive (including nurses) for children’s hospices charities in England is 18.4%.
- Other vacancies among AHPs, social workers and other professions.

Workforce shortages

- We estimate that there at 10 sites across the UK that could provide GRID and special interest (SPIN) training in PPM to consultant paediatricians – and there are many who wish to undertake this training.

- However, only one whole time equivalent (WTE) GRID training place is being funded in the UK in 2022.

- We estimate that there is a funding gap of **£2.26million** in investment in GRID and SPIN training – in addition to other funding gaps in educating and training other professionals, including children's nurses.



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Funding gap

- We estimate that the NHS should spend approximately £385million every year to meet the NICE children's palliative care standards.
- Yet it will be spending only £84million every year on children's palliative care by 2023/24.
- We therefore estimate that there will be a **£301million gap in NHS spending** on children's palliative care in 2023/24.

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24/7: recommended policy actions

1. The government should make sure that, using NHSE's children's palliative care service specification, NHSE and Health Education England (HEE) work with stakeholders to develop a plan to **use the existing children's palliative care workforce as effectively as possible**, which includes organising services into NHS-commissioned children's palliative care operational delivery networks (ODNs).

2. When the government settles the health workforce education and training budget with the NHS, it should include funding to expand the children's palliative care workforce. This should include an aspiration to **increase spending on specialist paediatric palliative medicine GRID and SPIN training to £2.26million per year**, proportionate to an expansion in the overall medical education and training budget. Ministers should also make sure that the additional 50,000 nurses that the government has committed to by the end of this parliament includes children's nurses with the skills and experience to provide palliative care to children in hospitals, children's hospices and at home.

24/7: recommended policy actions

3. As the government increases NHS funding by a total of £10.8billion in the period to 2024/25, it should make sure that the NHS invests **an additional £301million in children's palliative care in England every year** to meet the funding gap for services. This NHS should also maintain existing funding streams for the long term, including children's palliative care match funding and the Children's Hospice Grant.

4. We call on the Secretary of State for Health and Social Care to use their new powers in the Health and Care Act 2022 to **direct NHSE** to make sure that all seriously ill children in England and their families should be able to choose to receive palliative care at home, 24 hours a day, seven days a week, if it is in their best interests. This should build on the legal duty on integrated care boards (ICBs) in the Health and Care Act to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.

24/7: recommended policy actions

5. **Integrated care partnerships (ICPs)** should take our findings into account as they determine the health and healthcare needs of their population. **Integrated care boards (ICBs)** should commission children's palliative care services in a way which meets the NICE standards. NHSE should regularly monitor the extent to which ICPs and ICBs do this through the new strategic clinical networks (SCNs) – and **hold them to account** if they fail to do so.

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10
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Improving access to palliative and bereavement care for all communities

forget me not
children's hospice

Learning Objectives

1. Consider the barriers to families accessing support
2. Learning from the implementation of a south Asian family support role
3. Consider how to develop a role to focus on key communities

Who Are We?

- Children's hospice; based in Huddersfield supporting children with palliative care needs and their families.
- We cover the West Yorkshire region (Bradford, Calderdale, Kirklees, Leeds and Wakefield)
- Nurse and therapy led; incorporating BCYP care, SUDIC and family support services.

What was the challenge?

- The referenced research clearly states that there are many more people from diverse communities who need to access our services, however they cannot in many cases because of cultural challenges, lack of awareness or fear.

- As an organisation, we need to be adaptive to the cultures and communities that we serve, and representative of these communities.

- The **"Make Every Child Count"** study, (2020 L Fraser), concludes that the prevalence of children with a life-limiting condition is rising and is predicted to continue rising beyond 2030.

- Prevalence is highest amongst the most deprived groups and has risen across all ethnic groups with the highest increase coming from children of Pakistani origin with children from black and other Asian groups also having higher prevalence than the white population.

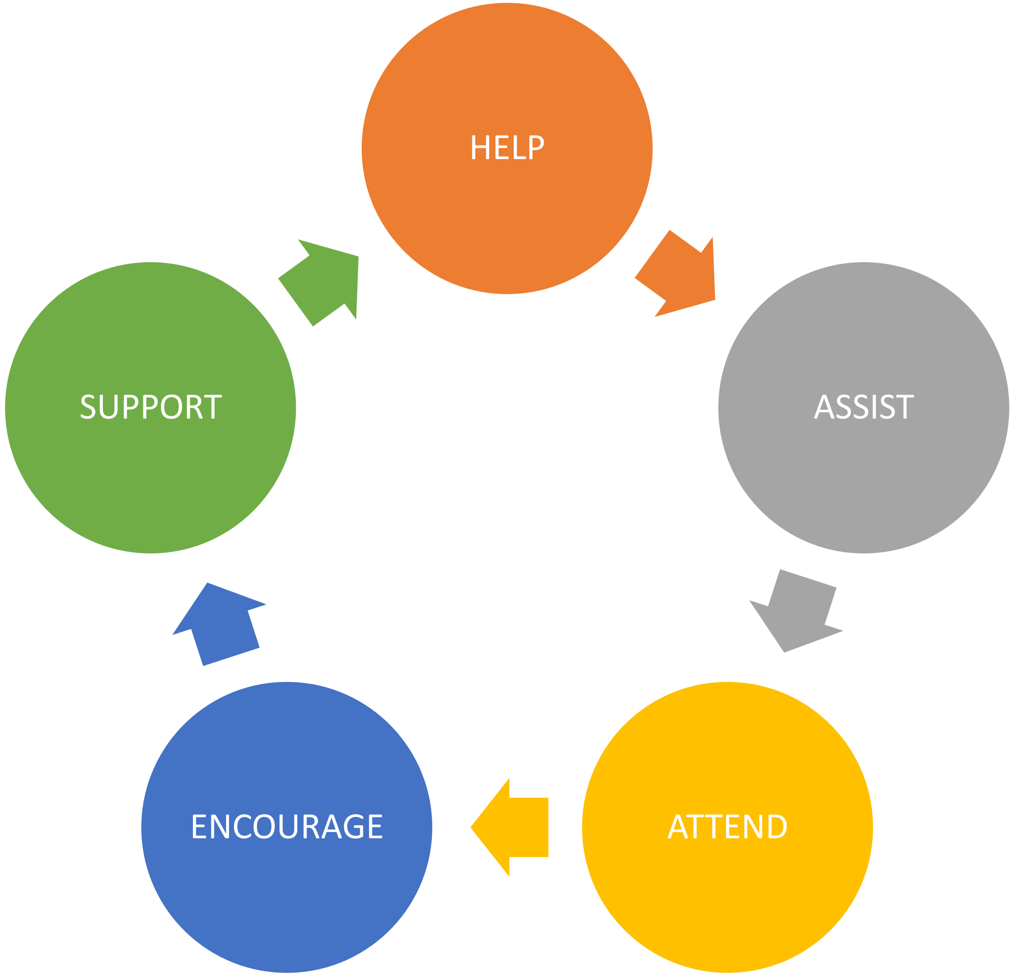
- Our footprint covers one of the highest prevalence per 10,000 population, in the country.

How we addressed this

Within care…

We introduced a specialist support worker to focus purely on supporting South Asian families, which included establishing and running culturally specific peer support sessions, one to one support, translation and some outreach.

South Asian Support Worker



Family story

What impact has this role had?

- Increase in the numbers of families from South Asian community (currently make up 62% of our BCYP caseload).
- Increase in the numbers of South Asian families accessing bereavement support.
- Partnership working with local Imam, promoting conversations around end-of-life care and limitation of treatment.
- Increase in the numbers of BCYP with completed advance care plans, including ReSPECT.
- Increasing numbers attending ‘Spice and Sparkle’ peer support group.

Emergence of a further challenge…

…As the numbers of Asian families being supported grew, it became increasingly apparent that our supporter base was representative neither of the families whom we were supporting, nor of the communities which we serve.

To continue the journey, we wanted to tackle this challenge too…

- Development of an EDI strategy.

- Recruitment of a **Community Engagement Officer**, with lived experience as a member of the South-East Asian community.

Undertaking the following activities, which will form part of the ongoing legacy from this project;

- Raising awareness and building critical relationships with groups and individuals in our south Asian communities
- Income Generation
- Education
- Support
- Inclusion & Accessibility

Outcomes so far…

- Formation of key, influential relationships.
- Both roles actively creating and stewarding relationships with community groups and places of worship.
- Currently working on several high value projects.
- Synergies between roles, working together on awareness raising initiatives.
- Incredible media presence across several Asian media and press platforms, communicating the services offer, and cultural challenges for families accessing hospices.
- Income now being generated from local diverse communities (incremental).
- Campaign to promote charitable support and giving during Ramadan.

- Improved provision of culturally appropriate support for families from diverse communities.
- Stronger, meaningful relationships with other charitable organisations, religious settings, schools and groups generating increased access to services and referrals.
- Delivery of services that are truly inclusive, reflective and adaptive to the needs of our local communities.
- Families feel better prepared for a life beyond the death of their child.
- South Asian families feel more in control and better able to make informed choices about their child’s care.
- South Asian families facing or living with the loss of a child are supported to help each other and benefit from improved mental health and emotional wellbeing

The future?

- Recent addition to the family support team; Eastern European support worker

First steps

- Contacting GP surgeries to raise awareness of role.
- Attending an outreach day at a GP surgery in Bradford to speak with representatives of the Eastern European community.
- Feature piece in WYCANN (West Yorkshire Children's Additional Needs Network) newsletter.
- Working with marketing to publicise role.
- Attending acute units to raise awareness.
- Meeting Paediatricians across region.

together for short lives

Talk about the conference on your **socials**

Tag us in and use the hashtag **#TSFLConference**

/togetherforshortlives @togetherforshortlives @Tog4ShortLives

#TFSLConference

Working across Boundaries to Enable Choice: Outcome and Process Learning from a pan-ICS area Extended Hours Community Children's End of Life Nursing Care pilot project

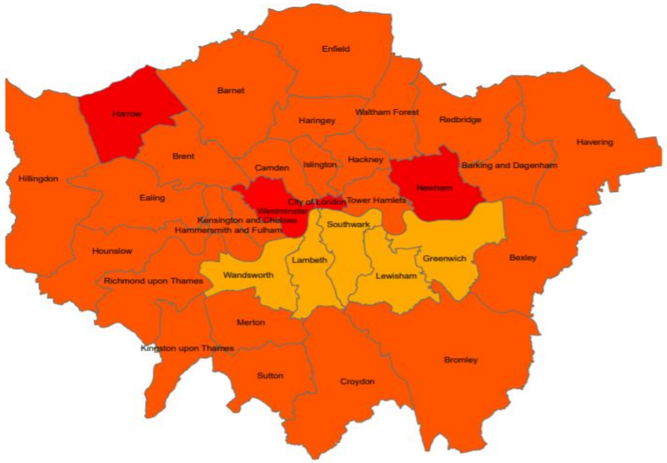
Dr Amy Volans   amy.volans@nhs.net

Clinical Psychologist & Family Therapist, BCYP Co-Lead for NHSE London Region PEoLC SCN

Together for Short Lives Conference 7th September 2022

Core Project Team: Marie Trueman-Abel, Kath Evans, Eileen White, Adila Ahmed, Hazel Dean, Rebecca Daniels, Carmela Scott, Scott O'Brien, Gareth Noble, Natascha Turner-Dyer

London: prevalence of BCYP with PEoLC needs



BCYP with life limiting conditions in London in 2017
14,360 (65.45 per 10,000 children)

Increasing prevalence year on year up to 2017
Changing distribution of highest prevalence

Wide range of palliative care conditions
Biggest increases in prevalence of “congenital” conditions
Under 1 year olds are the largest group

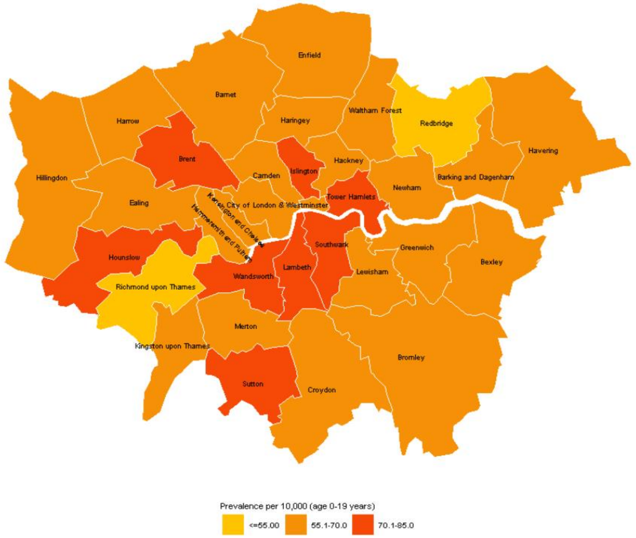


Figure 15 Prevalence per 10,000 of children (aged 0-19) with life-limiting conditions by Local Authority in London Government Office Region for 2017

amy.volans@nhs.net

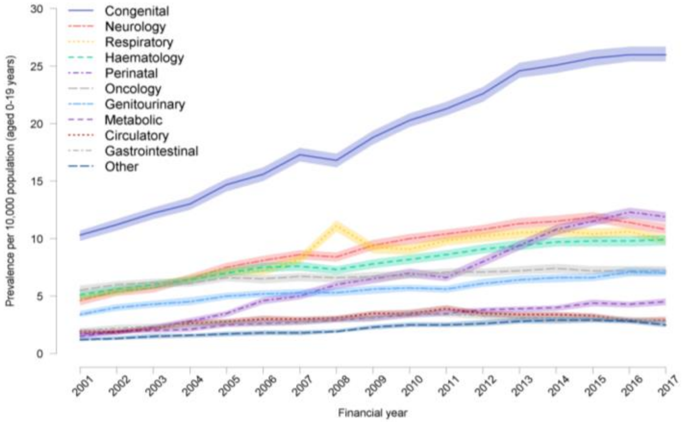
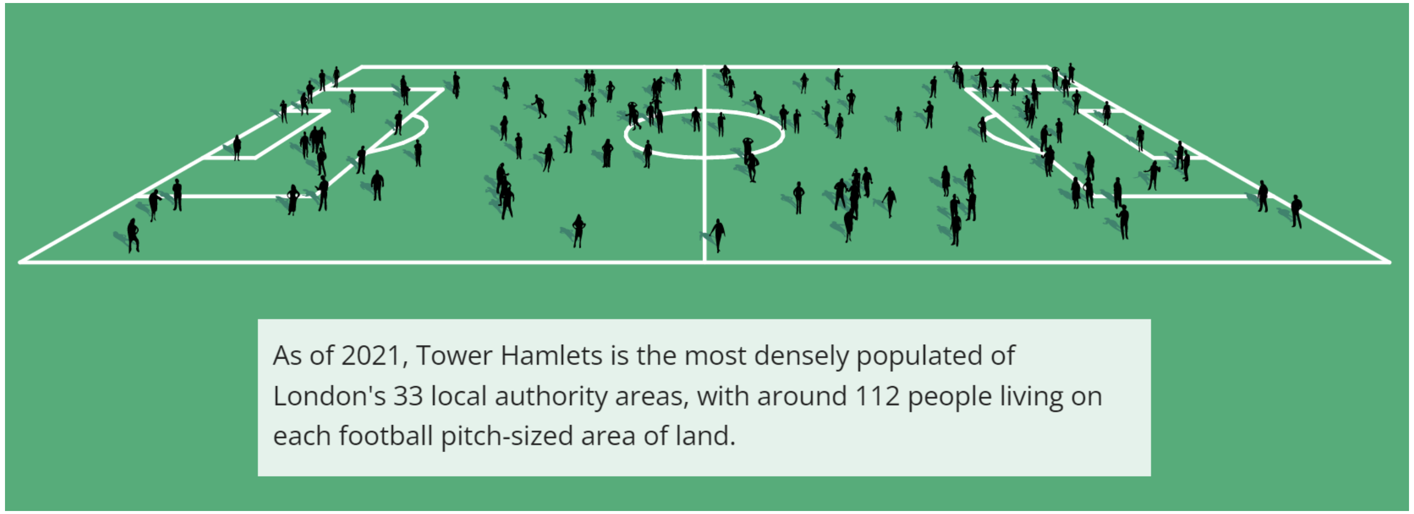
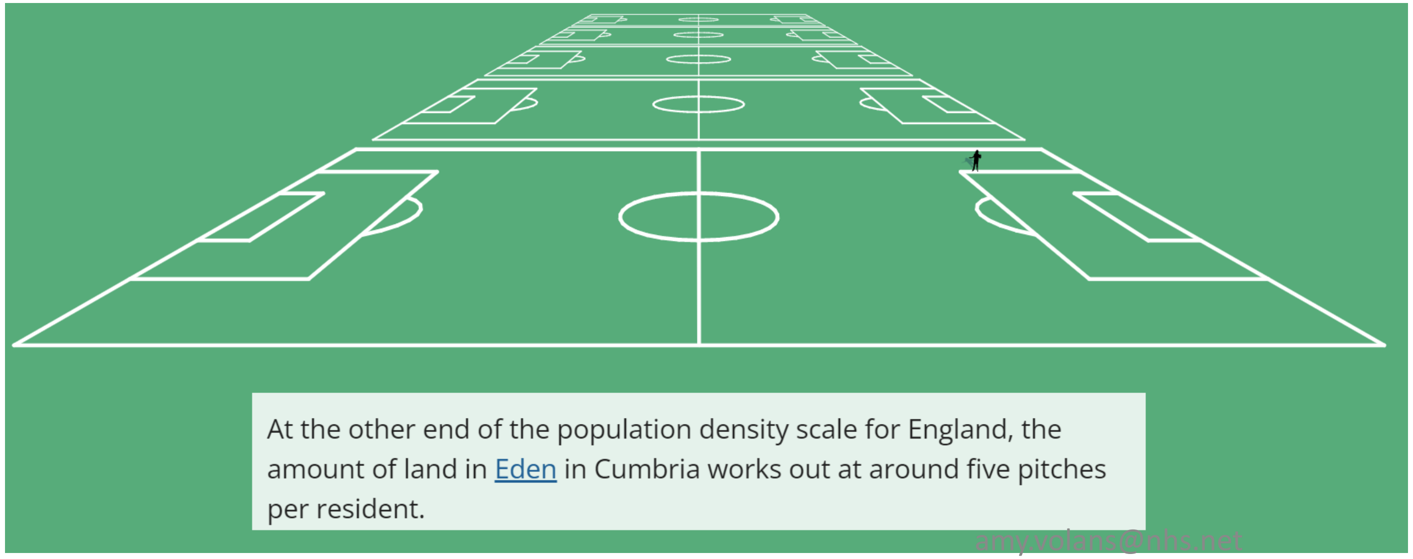


Figure 11: Prevalence per 10,000 of children (aged 0-19) with life-limiting conditions by diagnosis in London Government Office Region

London: densely populated urban area



As of 2021, Tower Hamlets is the most densely populated of London's 33 local authority areas, with around 112 people living on each football pitch-sized area of land.



At the other end of the population density scale for England, the amount of land in Eden in Cumbria works out at around five pitches per resident.

33 Local Authorities

Geographical size: 1,569 km^2

Population size: 9 million (16% of UK)

0-19yrs population: 2.1 million

Birth rate: 116,000 in 2020

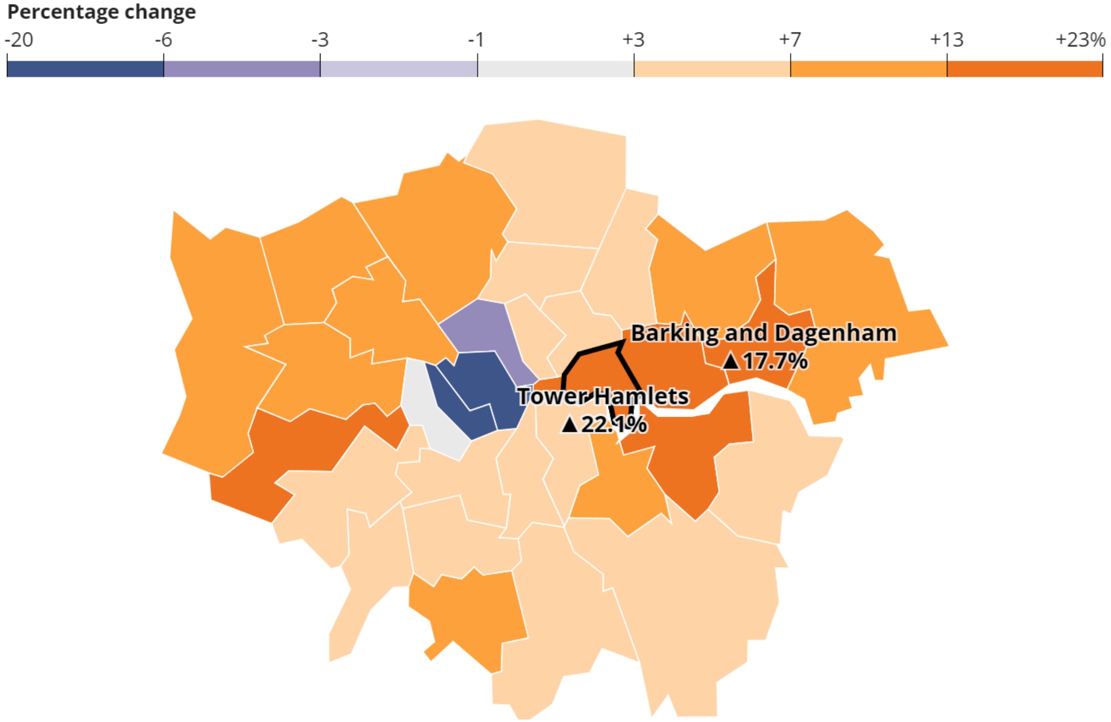
Mobile: 200,000 in-migrants in 2020

Most diverse region ethnicity & religion
(43.4% White British, 14.4% Muslim)

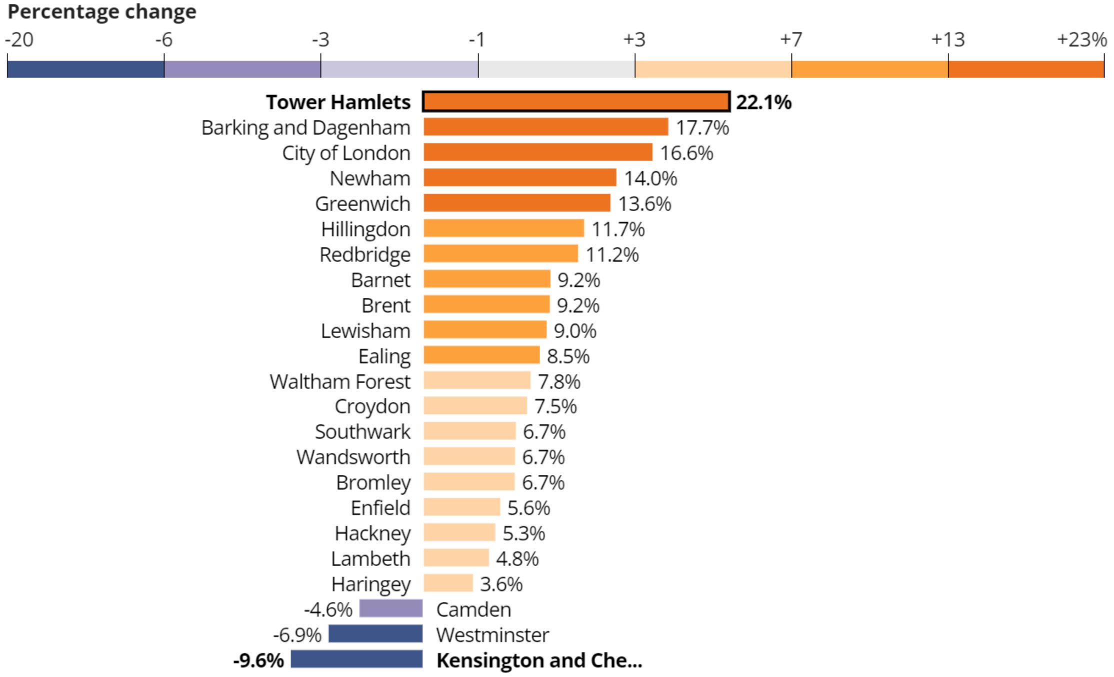
Languages: 100+ in every Borough

London: rapidly changing population

Population change of local authority areas in London between 2011 and 2021

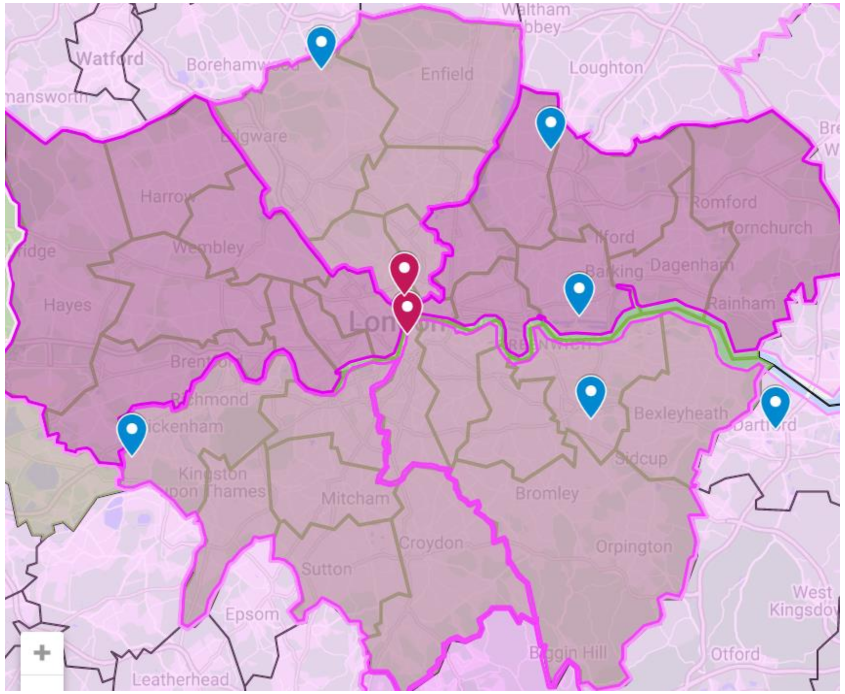


Population change of selected local authority areas in London between 2011 and 2021



amy.volans@nhs.net

33 London Boroughs, 5 ICBs



North East – Barking & Dagenham, City of London, Hackney, Havering, **Newham**, Redbridge, Tower Hamlets, Waltham Forest

North West - Brent, Ealing, Harrow, Hillingdon, **Hammersmith & Fulham**, Hounslow, **Kensington & Chelsea** and **Westminster**

North Central - Barnet, **Camden**, Enfield, **Haringey** and **Islington**

South East – Bexley, Bromley, Greenwich, Lambeth, Lewisham and Southwark

South West - **Croydon, Kingston upon Thames, Merton, Richmond, Sutton** and **Wandsworth**

amy.volans@nhs.net

London: Inequality of access to BCYP PEoLC

- In 2021, Children in 22 of 33 London boroughs had no guaranteed access to weekend Children's Community Nursing (CCN) services to support End of Life Care (EoLC) at home.

- Without this, BCYP in hospital cannot choose to go home for EoLC, and BCYP dying at home may have to be admitted to hospital.

- Services in 67% of boroughs of London not meeting access recommendations and standards set out for care at home in (1) NICE NG61 EoLC for ICYP Guidelines (2) NICE QS160 EoLC for ICYP Quality Standards or (3) new NHS PEoLC CYP Service Specification requirements for BCYP with PEoLC

amy.volans@nhs.net

Impact on BCYP, Families and Workforce

- CCN support is essential for safe provision of controlled drugs and analgesia via syringe drivers and CADD pumps in the home. Without CCN support at weekends, children in hospital cannot be discharged to home for EoLC, and children dying at home may have to be admitted to hospital to manage distressing symptoms that could have been managed at home with CCN support.

- In some areas, the good will of CCNs employed to work Monday to Friday has enabled EoLC at weekends, but this is at a high cost to the wellbeing of the workforce and this is not sustainable while recruitment and retention in nursing is in crisis (there are currently 88,000 vacant nursing posts across the UK).

amy.volans@nhs.net

Ambitions for change

- Most CCN services are commissioned to serve one borough, but demand at any one time did not justify funding permanent CCN EoLC weekend posts in every borough.

- The move to multi-borough Integrated Care System (ICS) commissioning in 2021/2 highlighted inequity of extended hours community BCYP EoLC provision within ICS areas and presented opportunity to pilot pan-ICS area weekend BCYP EoLC nursing-at-home CCN and hospice posts.

- NHSE, SCN and LCPCWG priority – Access to 24/7 BCYP EoLC at Home

amy.volans@nhs.net

Opportunity for change

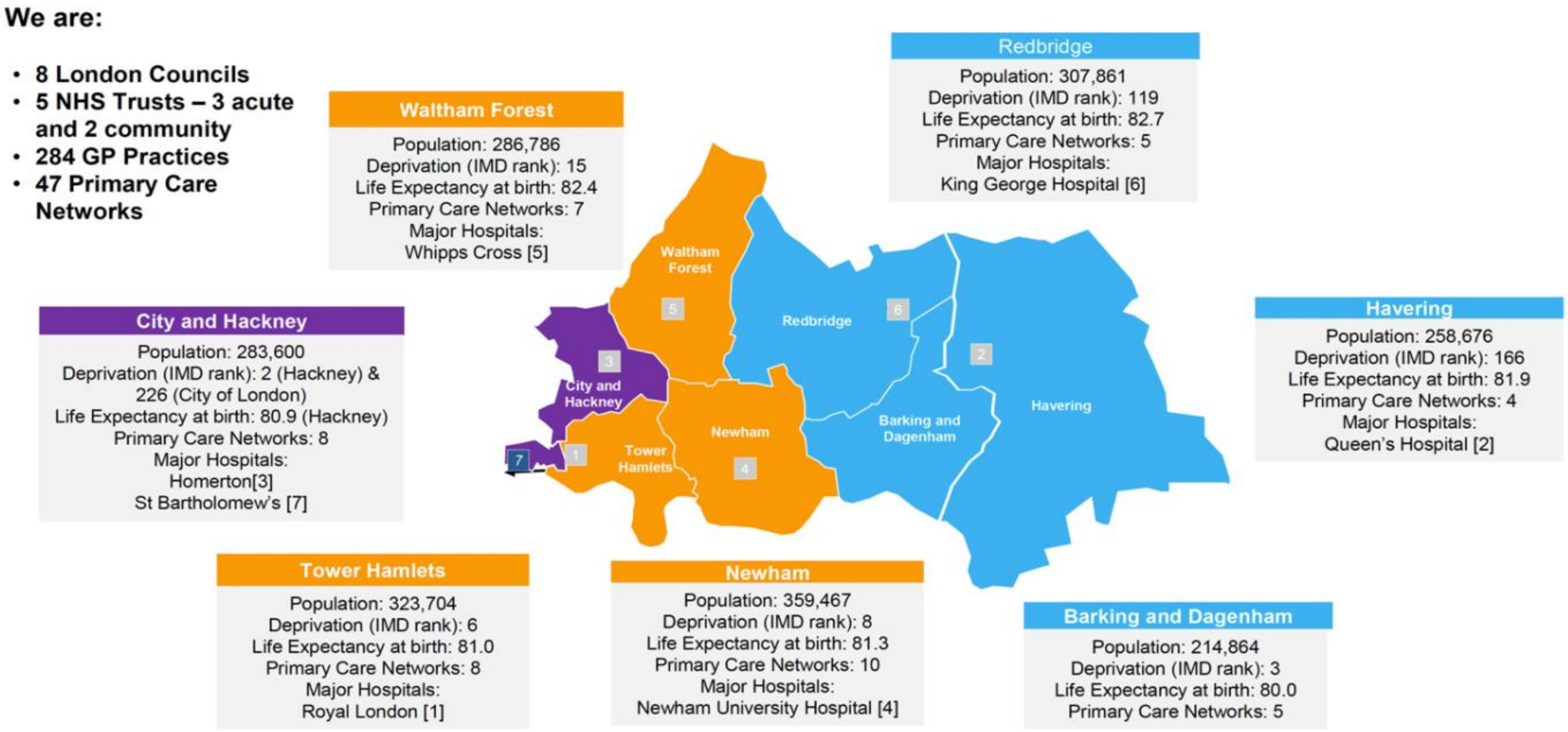
- NHSE Matched funding surplus expression of interest December 2021
- Short deadline and non-recurrent funding
- Rapid development of ideas and engagement with stakeholders
- NEL collaboration and commitment towards change BCYP EoLC
- Proposal developed, agreed, signed off and submitted to NHSE PEoLC
- 28 submissions nationally for only £250,000 in total
- Not awarded – caution re: non-recurrent funds for clinical service
- Benefits of engagement, collaboration and awareness raising
- Proposal ready when PEoLC SCN identified funding surplus – Awarded

amy.volans@nhs.net

North East London

- Population of approximately 2 million which is growing rapidly (13% growth predicted over next 10 years)
- 20 – 30% of the population in each borough aged between 0 and 19 years old.
- Fraser et al (2020) reported a total prevalence of 3,343 BCYP with PEoLC needs in NE London in 2017, with over 55 cases per 10,000 0-19 year olds
- There is a high prevalence of underserved populations in NEL.
- 5 of the 8 Boroughs of NEL are in the bottom 20% for the Index of Multiple Deprivation and 30% families are living in poverty.
- The ethnic make-up of the boroughs within NEL varies, with greatest diversity in Newham where 72.4% of residents identify as BAME and 41.4% of residents have a first language other than English.
- NEL also has a diverse health and care workforce.

North East London



We are:

- **8 London Councils**
- **5 NHS Trusts – 3 acute and 2 community**
- **284 GP Practices**
- **47 Primary Care Networks**

Waltham Forest

Population: 286,786
Deprivation (IMD rank): 15
Life Expectancy at birth: 82.4
Primary Care Networks: 7
Major Hospitals:
Whipps Cross [5]

Redbridge

Population: 307,861
Deprivation (IMD rank): 119
Life Expectancy at birth: 82.7
Primary Care Networks: 5
Major Hospitals:
King George Hospital [6]

City and Hackney

Population: 283,600
Deprivation (IMD rank): 2 (Hackney) &
226 (City of London)
Life Expectancy at birth: 80.9 (Hackney)
Primary Care Networks: 8
Major Hospitals:
Homerton[3]
St Bartholomew's [7]

Havering

Population: 258,676
Deprivation (IMD rank): 166
Life Expectancy at birth: 81.9
Primary Care Networks: 4
Major Hospitals:
Queen's Hospital [2]

Tower Hamlets

Population: 323,704
Deprivation (IMD rank): 6
Life Expectancy at birth: 81.0
Primary Care Networks: 8
Major Hospitals:
Royal London [1]

Newham

Population: 359,467
Deprivation (IMD rank): 8
Life Expectancy at birth: 81.3
Primary Care Networks: 10
Major Hospitals:
Newham University Hospital [4]

Barking and Dagenham

Population: 214,864
Deprivation (IMD rank): 3
Life Expectancy at birth: 80.0
Primary Care Networks: 5

NE London Services for BCYP PEoLC

5 hospitals with children's wards

Royal London, Newham, Whipps Cross, Queens and Homerton

7 Children's Community Nursing Services

Barking & Dagenham, City & Hackney, Havering, Newham, Redbridge, Tower Hamlets and Waltham Forest

2 Children's Hospices

Haven House and Richard House Children's Hospices

Tertiary Palliative Care

Provided by Great Ormond Street and Evelina Children's Hospitals' PEoLC teams

ICB/ICS Support

All Age Palliative and End of Life Care Programme – feeding in plans for BCYP to ensure represented and visible in wider all age plans, incl. Ambitions Framework Self Assessment

BCYP Palliative and End of Life Partnership Group – network for involved and interested Clinicians and partners across hospices, community nursing and community palliative teams, acute, primary care, tertiary centres etc.
Sub-group of overarching babies, children and young people (BCYP) NEL programme
Leading on bid development e.g. 7 day EOL nursing support

Children's hospice working group – both local hospices plus commissioners, finance, business and contract leads. Focus on sustainability of hospices, understanding needs, increasing access and support, aligning hospice core offer and planning use of match funding.

Lead commissioners from borough team in ICB (placed based partnerships) for hospices to support BCYP programme aims and implementation of palliative and end of life care plans.
Feeding in plans including investment into all age Palliative and EOL and BCYP programmes

Paediatric Palliative Care Needs Assessment in North East London

June 2022

Alasdair Gleed, Research Director
agleed@djsresearch.com

Emma Lay, Research Manager
elay@djsresearch.com

Head office: 3 Pavilion Lane, Strines,
Stockport, Cheshire, SK6 7GH

+44 (0)1663 767 857
djsresearch.co.uk

JN8421

CDOP death review data shows majority of BCYP deaths North East London occur in hospital

Less than 10% of deaths occur at home and yet the majority of deaths are expected.

2020-21	**WELC**	**BHR**
	Location	**Location**
	Home 13	Home 1
	Public place 4	Public place 0
	Other 3	Other 0
	Hospital 76	Hospital 8
	Hospice not recorded	Hospice 1
2021-22	**WELC**	**BHR**
	Location	**Location**
	Home 7	Home 4
	Public place 3	Public place 3
	Abroad 3	Abroad 0
	Hospital 72	Hospital 49
	Hospice not recorded	Hospice 0

Pilot Project Proposal

1-year pilot project to develop a weekend specialist outreach nursing service to support EoLC at home for BCYP across North East London ICS area.

- Recruit, train and support 2 x 0.6wte Band 6 CCNs to provide BCYP with PEoLC at home on weekends and bank holidays.
- 2 post holders working (1) Friday to Sunday and (2) Saturday to Monday to ensure cover for weekends and bank holidays, peer support and comprehensive handover between weekday and weekend staff to ensure continuity of care for BCYP and families.
- One-month intensive training package at outset and follow-up monthly supervision support provided by, in combination, Great Ormond Street Palliative Care Team, Haven House Children's Hospice and Newham Diana Children's Community Palliative Care Team
- **Initial Plan:** pan-ICS post holders to be hosted by Haven House Hospice as 7 day palliative care service to provide a clinic base and team support for the new post holders who would be lone workers visiting families at home. **Updated:** 1 post HH, 1 post ELFT Diana

amy.volans@nhs.net

Aims and anticipated long term benefits:

- Enabling more BCYP to die at home when this is their preference
- Reducing EoLC hospital bed days
- Reducing EoLC readmission rates
- Increasing numbers of CCNs in London with skills to manage PEoLC at home
- Reducing burnout/stress-related sickness and improving retention of CCNs employed for regular office hours
- Sharing learning across London via LCPCWG
- Developing an evidence base for future service development and scoping funding sources to extend successful aspects of the project.

amy.volans@nhs.net

Process Learning and Outcome Evaluation

Process learning from overcoming challenges of setting-up a multi-borough pan-ICS area pilot,

(a) steps in the process of setting-up the pilot (engaging key stakeholders, writing a business case, securing funding, operational planning, recruitment, training, service delivery),

(b) facilitators, barriers and how challenges were overcome.

Planning evaluation of Impact and Outcomes

amy.volans@nhs.net

Current NEL EoL Nursing at Home Provision

Service	NHS Trust / Charity	Electronic Record System	Days/wk
Barking & Dagenham CCNS	BHR @ Queens	??tbc	5
City & Hackney CCNS	Homerton Health	RiO	7
Havering CCNS	BHR @ Queens	??tbc	5
Newham CCNS	ELFT	RiO	5 7 from Oct'22
Redbridge CCNS	NELFT	RiO	5
Tower Hamlets CCNS	Barts Health	EMIS	7
Waltham Forest CCNS	NELFT	RiO	6
Haven House Children's Hospice	Charity	Care Database	7
Richard House Children's Hospice	Charity	Care Database	7

Pilot Project Working Group

Collaboration – ICB/S, SCN, Barts, ELFT, Hospices

Core Working Group

Marie Trueman-Abel (Head of Commissioning & Transformation, Maternity & Children) - NHS North East London

Kath Evans (Director of Children's Nursing/Chair of Children's Board) - Barts Health and (BCYP Clinical Lead) NE London ICS

Eileen White (Director of Care) Adila Ahmed - Haven House Children's Hospice

Hazel Dean (Lead Nurse), Rebecca Daniels (Community Matron), Carmela Scott (Diana Team Lead) – ELFT, Newham CCNS

Amy Volans (Clinical Psychologist and London BCYP Co-Lead for PEoLC SCN) – ELFT and NHSE London Region PEoLC SCN

Scott O'Brien (Director of Care) - Richard House Children's Hospice

Gareth Noble (Acting Associate Director of People) - NHS North East London, NE London Health and Care Partnership

Natascha Turner-Dyer (Transformation and Innovation Project Manager) - North Thames Paediatric Network

Engagement with CCN Matrons

amy.volans@nhs.net

Haven House children's hospice

East London NHS NHS Foundation Trust

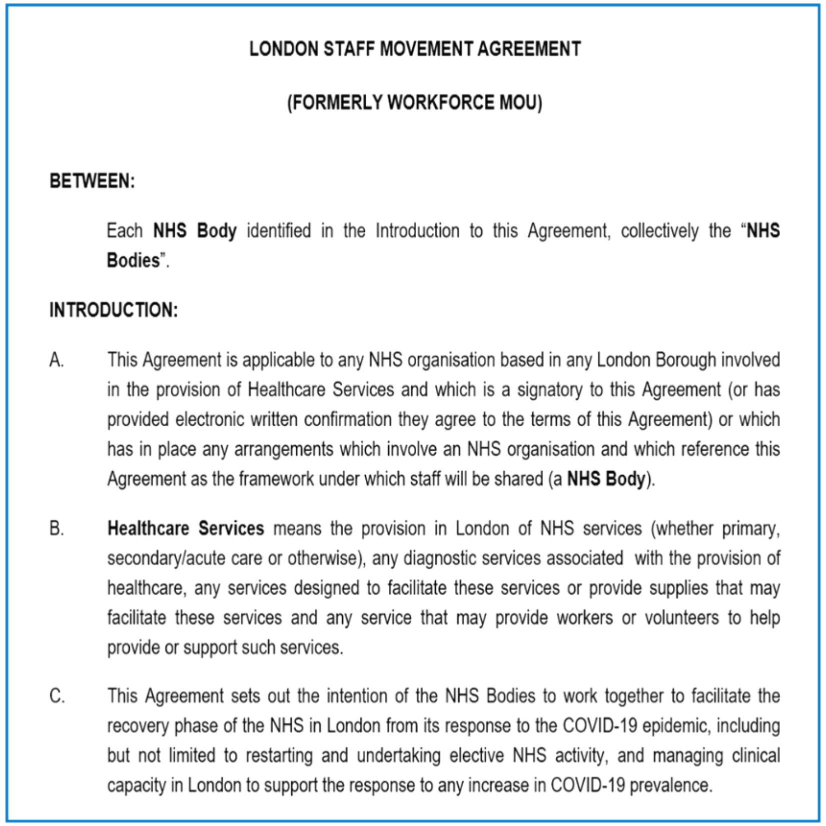
NHS Barts Health NHS Trust

NHS England London

NHS North East London

North East London Health & Care Partnership

Contracts



LONDON STAFF MOVEMENT AGREEMENT

(FORMERLY WORKFORCE MOU)

BETWEEN:

Each **NHS Body** identified in the Introduction to this Agreement, collectively the "**NHS Bodies**".

INTRODUCTION:

A. This Agreement is applicable to any NHS organisation based in any London Borough involved in the provision of Healthcare Services and which is a signatory to this Agreement (or has provided electronic written confirmation they agree to the terms of this Agreement) or which has in place any arrangements which involve an NHS organisation and which reference this Agreement as the framework under which staff will be shared (a **NHS Body**).

B. **Healthcare Services** means the provision in London of NHS services (whether primary, secondary/acute care or otherwise), any diagnostic services associated with the provision of healthcare, any services designed to facilitate these services or provide supplies that may facilitate these services and any service that may provide workers or volunteers to help provide or support such services.

C. This Agreement sets out the intention of the NHS Bodies to work together to facilitate the recovery phase of the NHS in London from its response to the COVID-19 epidemic, including but not limited to restarting and undertaking elective NHS activity, and managing clinical capacity in London to support the response to any increase in COVID-19 prevalence.

Employed by host organisations
1 Haven House and 1 ELFT Diana Team

Work across 5 NHS Trusts & 2 Charities

Staff Movement Agreement
Adapting agreement developed for NHS staff movement during pandemic to incorporate Hospices and allow movement across ICB/S area

amy.volans@nhs.net

IT systems access and equipment

- 8 separate services using 4 different electronic record systems
- NHS Laptop
- NHS remote access
- NHS Smartcard
- Mobile Phone

amy.volans@nhs.net

Travel and Parking

- Business parking permits cost hundreds of pounds for each borough
- Many areas permit holder parking only, very limited pay to park / free
- Congestion Charge
- Ultra Low Emission Charge for older vehicles

amy.volans@nhs.net

Training and education needs

- Training needs to be confirmed once skill mix of new employees known
- Support from GOS for training was factored in to the budget for the pilot
- Verification of BCYP death training – look at joining up RH HH DT and Pilot Nurses
- Catheter training –link with RH and DT
- Barts have practice educator at RLH – Kath to link Scott with Chloe
- CADs, Syringe Pumps, Talking to families when death is a likely outcome
- NEL BCYP PEoLC training and education priorities strategy in development

amy.volans@nhs.net

Induction and resource pack

- Contacts for GOS, all CCNs, Hospices, Wards, CDOP, Undertakers, Chaplaincy
- Out of Hours GP process
- Death certification process
- Notification of death forms
- Care of the body and memory making resources
- Help with funeral costs info
- Bereavement support info
- Smartcard application (if person recruited doesn’t already have one)
- Meeting with all CCNs in NEL
- Meeting with both hospice teams and GOS team
- Visit and intro to all 5 hospitals (children’s, neonatal and maternity wards/units)
- Training and competency sign off plan

amy.volans@nhs.net

Recruitment

- Job descriptions and person specifications
- Adverts – jobs webpage, twitter, TfSL jobs webpage
- Interview Panels

Barriers

- Exploring Outer / Inner London Weighting
- Exploring car pool electric vehicles

Opportunities

- Match funding surplus funded universal training program – increase interest in the sector and post from recruitment market

amy.volans@nhs.net

Haven House children's hospice

East London NHS Foundation Trust

Barts Health NHS Trust

NHS England London

NHS North East London

North East London Health & Care Partnership

Measuring Outcomes: Baseline Data Collection

- Weekend admissions for EoL
- Delayed discharges to home – number of extra bed days
- KPIs
- Nursing activity
- Ratio of home deaths to BCYP with home as preferred place of care
- Number of delayed EoLC discharges and extra EoLC “bed days” in hospital
- Avoided hospital attendance, admission/readmission during EoL

amy.volans@nhs.net

Data to collect once post holders in post:

Weekend BCYP EoLC at Home Nursing Activity data collection template

Date	Day	Child#	Borough	Visit (mins)	Tel. (mins)	Liaison (mins)	Documentation (mins)	Tasks (mins)	Travel (mins)

Weekend BCYP EoLC at Home Pilot referral data collection template

Child #	DoB	Borough	Referral Date	Discharge Date / Start of EoLC at home	Date of Death	Place of death	Duration of EoLC at home	Number of weekend/BH contacts

amy.volans@nhs.net

Planning experience measures

Adapt the gathering feedback from families survey for 3-6 months after death

https://www.healthylondon.org/wp-content/uploads/2019/09/Gathering-Feedback-When-Child-Dies_Sept-2019_final-1.pdf

Feedback from the workforce

amy.volans@nhs.net

Haven House children's hospice East London NHS Foundation Trust NHS Barts Health NHS Trust NHS England London NHS North East London North East London Health & Care Partnership

Key Learning: Collaboration & Integrated Care

- Resisting pull to silo working when systems are under pressure
- Strong network and commitment to BCYP PEoLC from commissioners, SCN, clinical leads, NHS and Hospice managers and clinicians
- Focus on core purpose – Ambition for all BCYP to have choice at EoL
- Necessity to work together to achieve choice, access and quality care
- Facing workforce and funding challenges together – everyone is working with skeleton staff and limited resources, stronger together
- Creative solutions, support and sustainability from working together

amy.volans@nhs.net

Thank You

Dr Amy Volans   amy.volans@nhs.net
Clinical Psychologist & Family Therapist, Newham Diana Children's Community Palliative Care Team, ELFT
BCYP Co-Lead for NHSE London Region PEoLC SCN

North East London Health & Care Partnership | Haven House children's hospice | East London NHS Foundation Trust | Barts Health NHS Trust | NHS England London | NHS North East London

North East London Health and Care Partnership is our integrated care system, which brings together NHS organisations, local authorities, community organisations and local people to ensure our residents can live healthier, happier lives.

www.northeastlondonhcp.nhs.uk | Follow us on Twitter @nelhcp

North East London Health and Care Partnership
Citizen's Panel

Join our Citizen's Panel and help us shape health services in north east London.
Help create services that work for you and others in your area and get your voice heard.
enquiries@northeastlondonhcp.nhs.uk

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The Martin House RESEARCH CENTRE

In partnership with UNIVERSITY of York

Regional perspectives on the coordination and delivery of paediatric end-of-life care in the UK: a nested qualitative study

Dr Andrew Papworth, Martin House Research Centre, University of York

Dr Julia Hackett, Martin House Research Centre, University of York
Gabriella Walker, Parent Co-applicant, ENHANCE Study
Professor Bryony Beresford, Social Policy Research Unit, University of York
Professor Lorna Fraser, Martin House Research Centre, University of York

The ENHANCE Study

To identify and investigate different models of providing EOLC for infants, children and young people, in terms of outcomes and experiences for children and parents, and resource use and costs to families and the NHS

First workstream:
- National surveys (UK) of EOLC providers (PICU, NNU, TYA) to identify differences in EOLC provision
- Interviews with PCN Chairs

Regional Palliative Care Networks

Palliative Care Networks were established to facilitate the coordinated working of professionals and organisations that deliver palliative care to children

There were 16 Networks across the UK at the time of data collection

The Network Chairs (and co-Chairs) are well placed to talk about inequity in end-of-life care within their region

Aim

- To explore the views of the Chairs of the regional Palliative Care Networks (PCNs) on the coordination and delivery of end-of-life care for children in the UK

Methods

- Semi-structured interviews (n=16) with 19 of the Chairs/co-Chairs, representing 15 of the 16 regional PCNs
- Interviews took place between October and December 2021 and were analysed thematically

1. Communication during end of life care
2. Getting services and staff in the right place
3. Staffing numbers, experience and confidence
4. Funding of services
5. Linking up healthcare provision

1

2

3

4

5

Communication during end of life care

> “Sometimes [with] the oncology children or the cardiac [children, the curative focus means] there isn’t the recognition that actually that child is now palliative, [and they die] quite suddenly in an acute placement, which actually may not be the [preferred] choice of place of death.”
>
> Participant 2

1

2

3

4

5

Communication during end of life care

"[I]f we can do something positive, it's changing that culture slightly, so we [have] those conversations about what parents would want"

Participant 5

"[H]e was pain-free, very comfortable, in the arms of his mummy and daddy, so that is a tick and [a] star, I think, for everybody that was involved. It was very good."

Participant 11

1
2
3
4
5

Getting services and staff in the right place

- High intensity care is often required
- End-of-life care services cover large areas that may only have small numbers of children requiring this type of care

Getting services and staff in the right place

1
2
3
4
5

This relationship may not always be intuitive:

"From my experience, [for] families who live in a more rural area, the local community are much more prepared to support them than families that are [...] in an urban area."

Participant 7

1
2
3
4
5

Staffing numbers, experience and confidence

Staff shortages and its wide range of impacts:

“I’m aware of a number of really challenging cases where staff have been put in really difficult positions.”

Participant 15

1

2

3

4

5

Funding of services

- Funding is difficult to obtain and often inconsistently provided
- Many services and posts are not statutory funded
- Affects coordination of service care provision
- Lack of standardised outcome measures = more difficult to demonstrate the benefits of end-of-life care to commissioners

1
2
3
4
5

Funding of services

"EOLC still relies very heavily on individual goodwill and nurses don't get paid for it […] if it goes on for more than a couple of weeks, they get exhausted."

Participant 1

"We don't just go: […] "There's nobody to do it, oh well [let's] go home." We'll actually try and do something about it to sort it for the family"

Participant 11

1
2
3
4
5

Linking up healthcare provision

Data sharing and care coordination

> “One of those children who died [was] discharged [to our service] and [they had] had five different appointments in the next eight weeks with different people, or different tests [back in the city centre; this] for a child that lived 50 miles away.”
>
> Participant 14

1
2
3
4
5

Linking up healthcare provision

Success achieved through good communication, secondments, networks, informal links:

“I’ve got [someone] in my team who also works for a cancer service [and my trainee] is based at the hospital. [Them] being there, boots on the ground, are more likely to spot people that need a referral.”

Participant 4

Cross-cutting factors

- Small numbers of children
- Standards, definitions, outcome measures
- Diagnosis

Conclusions

- Communication between health professionals and children and/or their families is important
- The staffing shortage is an important issue that needs to be addressed
- Coordination of care is being achieved successfully in a number of different ways, but a lot of this work is conducted informally
- Over-reliance on ‘goodwill’ and charitable funding

Impact on the ENHANCE Study

- Components of care rather than models
  - Multidisciplinarity of core team
  - Unit/ward layout
  - Availability of community services

- WS2 aims to explore the experiences of EOLC for health professionals and bereaved parents
- WS3 aims to explore outcomes for parents and their children

Welcome to together for short lives

each

East Anglia’s
Children’s Hospices

‘This is going to hurt’

How the pain of ‘birthing’ an alternative wellbeing service during covid restrictions brought unintended consequences.

Jules Gibson-Cranch
Locality Wellbeing Lead
East Anglia’s Children’s Hospices

Our hospice organisation has three sites and covers a huge area including; Cambridge, Suffolk, Norfolk and half of Essex

each

East Anglia's Children's Hospices

March 2020

each

East Anglia's
Children's Hospices

- Pandemic announced
- Restrictions started
- Use of PPE for care workers, nurses, doctors etc
- Counsellors, therapists, and other wellbeing support workers were asked to work from home.

For some the unimaginable happened…..

East Anglia's Children's Hospices

East Anglia's
Children's Hospices

Counsellors and therapists could not meet face to face with their clients

As if that wasn't bad enough...

Staff slowly grappled with the idea that they were going to have to learn and use IT in a way that (for some) they had never done before.

We were in... uncharted territory!

East Anglia's
Children's Hospices

It brought up a lot of different responses from staff…….

East Anglia's
Children's Hospices

or some....

Initial focus points

- Supporting staff's bewilderment, anxiety and discombobulation
- Working as a tri site wide team to look at the options we had with on line wellbeing support
- Gathering information from tec, online information, professional bodies and local sources.
- Staff training and experience in the use of on line systems (Teams/Zoom) & increasing IT capacity / equipment
- Drawing up new or adapting current therapeutic / other contracting for online work
- Envisaging pitfalls
- Supporting staff to create a suitable environment at home to work
- Robust Wellbeing Duty System

Well begun is half done!

- The pre-planning pay off
- The 'Nike' moments
- Managing the unimaginable
- New reach into unexpected places.

Unintended Consequences

- More efficiency (time and money)
- Squeezing more in – poor breaks between sessions (creating a feeling of needing to 'prove' they are doing enough.
- Huge increase of staff IT skills and literacy (able to pass on confidence to clients)
- Staff anxiety (not wanting to return / anxiety of illness/ sep of care team)
- Development of staff wellbeing newsletters / better communication
- Connectivity issues (Power cuts / poor Wi-Fi etc)
- Increase in availability of clinical supervisors
- Loss of working space at the hospice as it was engulfed by PPE!
- Fantastic development of resources.

EOL, Memory Making & Spiritual Care

each

East Anglia's Children's Hospices

Innovation in EOL and bereavement support

- New ideas to offer memory making on line
- Covid safe packs sent to families with the offer of on line or phone session support to utilise
- Support for nurses and carers to undertake keep sake making
- Clown Dr's 'window', garden and on line sessions
- Email / letter therapy
- Encouraging / supporting and helping families to 'hold' their loved ones
- Bespoke music sessions at EOL including recordings and use of tech

Blended approaches

- Using technology to stream live and deliver sessions face to face simultaneously
- Developing / refurbishing outside spaces to deliver sessions
- Opening up to small face to face groups and 1-1 sessions
- Larger scale outdoor family events
- Creating new 'rules' for on line working and taking breaks
- Re-designing hospice space to become multi-functional
- Improved I.T and communication equipment and support

It’s the cake not the icing….

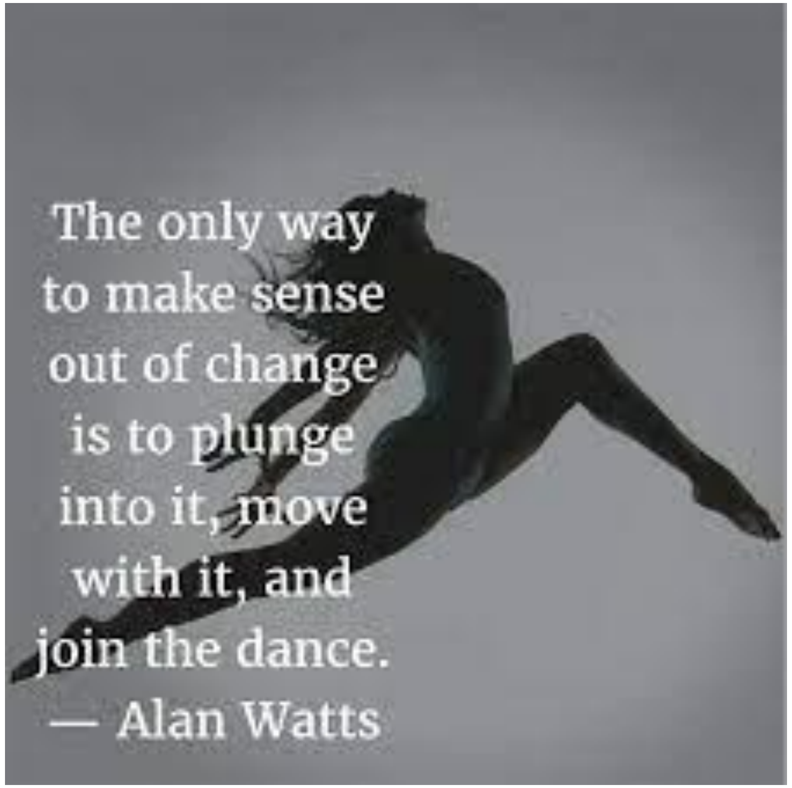
each

East Anglia’s
Children’s Hospices

The positive responses we get from families following the support they get at our hospices is the icing on the cake. The cake is the day to day work. The very hard tasks that we are all asked to perform again and again. The attendance at meetings, the protocols, the endless conversations about what to do next…………and how to solve another impossible problem. This really is the work – putting it all together, with colleagues, over and over and retaining our respect for each other, and for the children and families as we try to find the best way forward. It can be labourious, and we can I guess at times, if we’re honest, all think that we should just get on with it ourselves and not spend so much time talking and planning. The effort is worth it. It produces better results and despite the frustrations, by and large it is much more enjoyable and creative than going it alone and working in isolation. **The mix of perspectives and ideas IS the thing and it’s always worth struggling with the tensions in order to hold the network of ideas and experiences together.**

Peter Honig 2022

We made it!



The only way
to make sense
out of change
is to plunge
into it, move
with it, and
join the dance.
— Alan Watts

Thank you for listening!

Any questions?

Helen & Douglas House

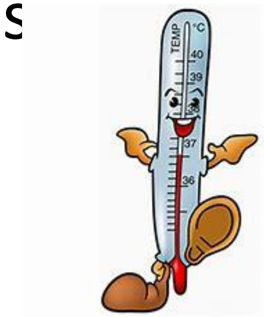
your local children's hospice

Developing a tool to support the contextualised assessment of medically complex paediatric palliative care patients across settings

Lucy Butters RN, Children's Hospice Nurse HDH
Emily Harrop, Medical Director HDH
Becky Holbrooke, RN (Child) MSc, Paediatric Nurse, OUHT

Introduction

- Paediatric palliative care patients are **complex** with **evolving clinical pictures**
- They are cared for in a **range of different settings**
- Their agreed **goals of care** and **escalation plans** are very individual and change over time
- **Monitoring** their clinical condition is important for their care
- **Interpreting** monitoring or clinical assessment needs to be **contextualised**
- Our patients often do **not have average clinical baseline** observations



Individualised Care

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your local children's hospice

- **Responding appropriately to a change in the child's condition requires:**
  - Awareness of stage of illness
  - Agreed goals of care / escalation plans
  - Usual baseline (clinical condition and any observations)

- The tool allows the child's situation to be put in to **context** and **shared** between clinicians to facilitate a **patient and family centric** response that falls **within the child's best interests** in a **timely** way.

- **Goals include:**
  - Reducing child and family anxiety
  - Supporting confidence and resilience among healthcare workers in different settings

Resources Included

- NICE Guidance NG61 – End of Life Care for Infants, Children and Young People
- Children & Young Persons Advance Care Plan document / ReSPECT
- The Spectrum of Children's Palliative Care Needs
- Paediatric Early Warning System (PEWS)
- Situation, Background, Assessment, Recommendation (SBAR) tool

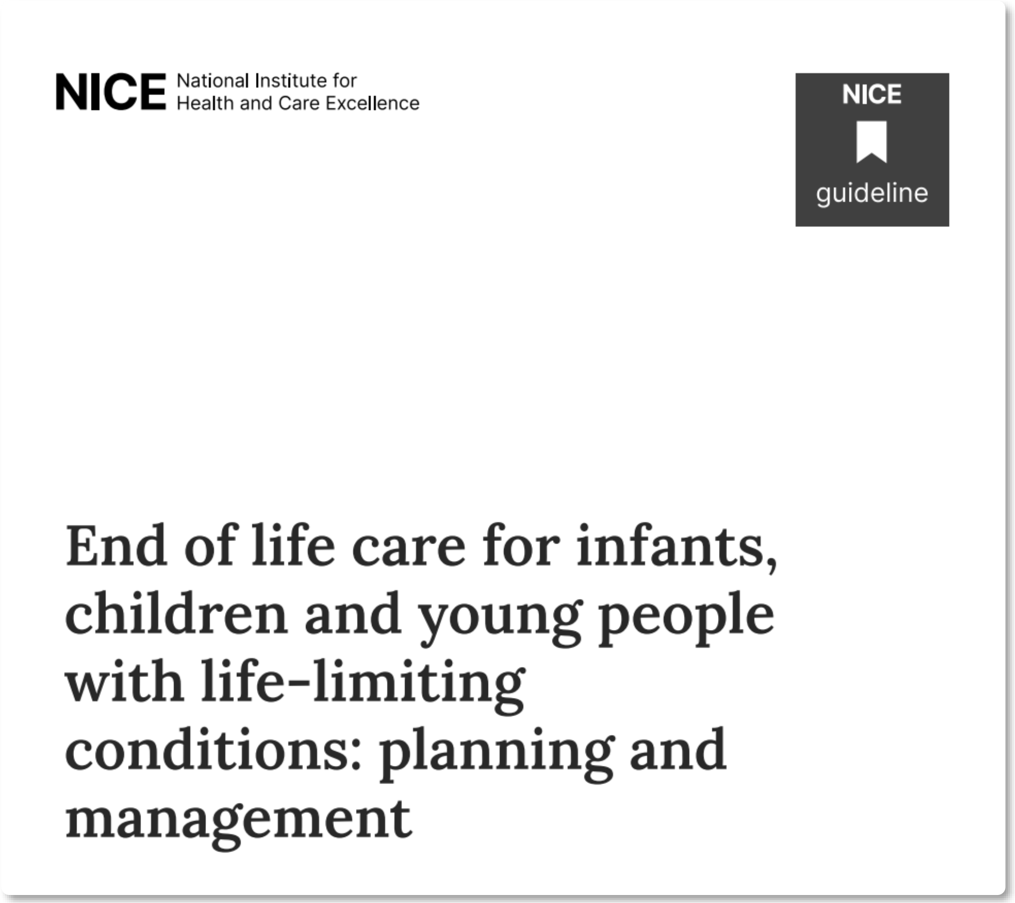
End of life care for infants, children and young people with life-limiting conditions: planning and management

NICE guideline [NG61] Published: 07 December 2016 Last updated: 25 July 2019

Helen & Douglas House
your local children's hospice

Guidance is given on:

- Transferring child or young person to their preferred place of care
- Recognising that a child or young person is likely to die within hours or days
- Provision of respite to stable children
- Management of challenging symptoms
- 24/7 access to care
- Managed clinical networks working together



NICE National Institute for Health and Care Excellence

NICE guideline

End of life care for infants, children and young people with life-limiting conditions: planning and management

The Spectrum of Children's Palliative Care Needs

A prognosis based framework for children and young people who have palliative care needs

Helen & Douglas House
your local children's hospice

Categories of life-limiting and life-threatening conditions of children with palliative care needs are vast as are their outcomes. These categories involve:

- Life-threatening conditions where curative treatment may be feasible but may fail
- Conditions where premature death is inevitable
- Progressive conditions without curative treatment options
- Irreversible but non-progressive conditions causing severe disability and complex health needs, increasing risk of life-threatening events

Withdrawal of life-sustaining treatment: For children whose treatment is merely life sustaining but cannot restore health, causes unacceptable suffering or is unlikely to prolong their life much longer.

Children can move through the colours of the spectrum in sequence, but often this is flexible and can alter quickly, the Decision Tool helps to direct decisions and open discussions by looking at where the child's health is at the time decisions need to be made, in combination with any Advance decisions that have been made.

Children who are likely to have palliative care needs

Diagnoses are likely to fit into one or more of the categories of children requiring palliative care, published by ACT (now Together for Short Lives) www.togetherforshortlives.org.uk

Children who are diagnosed or recognised to have a potentially life shortening (fatal) condition before their 18th birthday.

Survival into adulthood is likely.

Would you be surprised if this child died as a result of this condition or problem?

Children whose death before adulthood (18th birthday) is not unexpected.

May live for many years.
Care needs may be similar to other children who have complex chronic conditions.

Would you be surprised if this child died before adulthood (their 18th birthday)?

Children who have increasing instability or progressive deterioration.

Death is not unexpected in months to years.

Would you be surprised if this child died within the next few months to years?

Children who are critically ill.

Survival is not expected beyond the next few weeks.

Would you be surprised if this child was alive in a few weeks time?

Children who die.

Children who are not expected to have palliative care needs

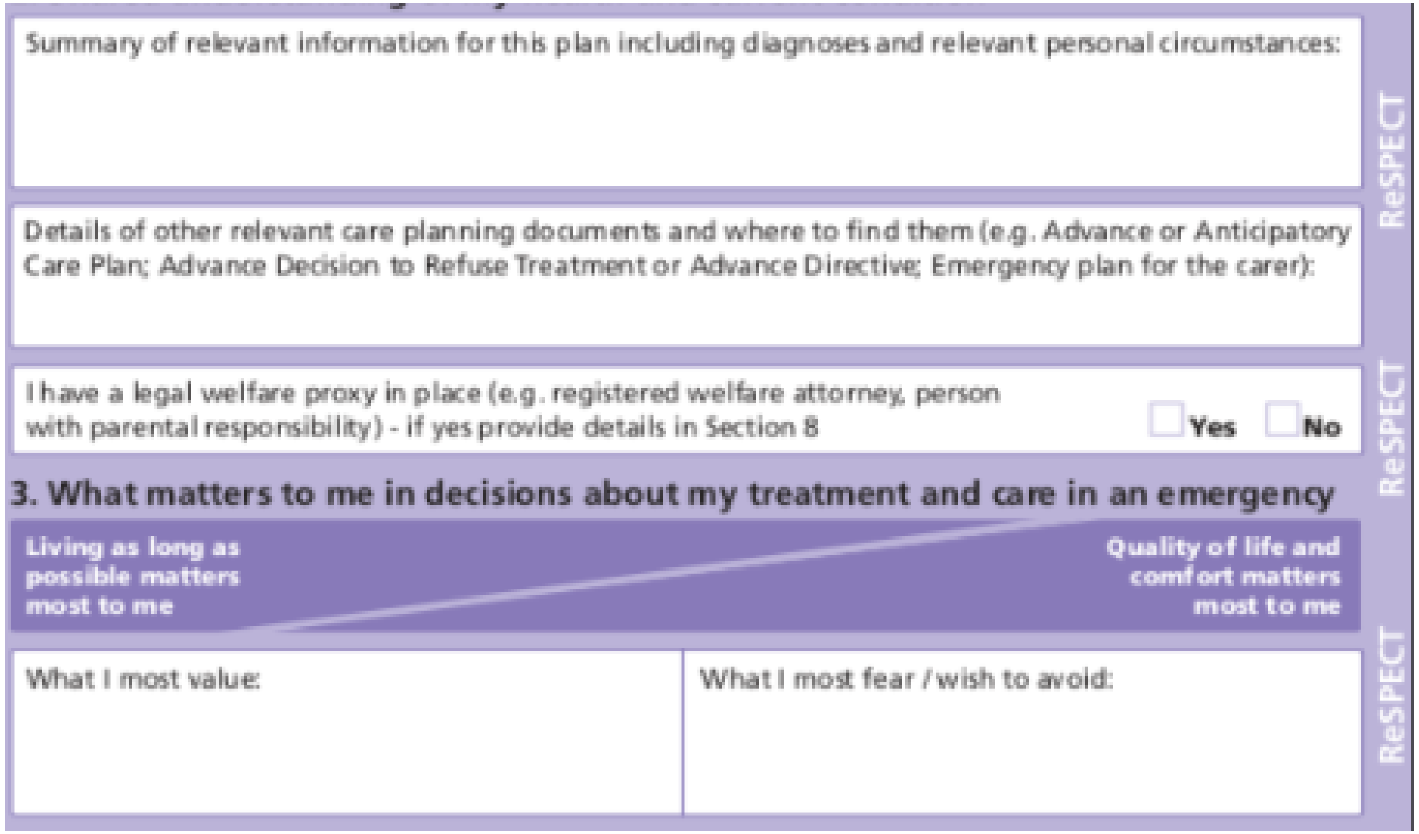
Children living with significant health needs and/or disability, but whose risk of dying is comparable to that of the general population.

Children who recover and whose risk of dying is comparable to that of the general population.

Advance Care Planning with ReSPECT

Many children with palliative care needs have or would benefit from having a completed Children and Young Person's Advance Care Plan (CYP-ACP), including ReSPECT decisions. The benefit of having this includes:

- Forward planning for any event; calmer more composed ability to make balanced decisions in child's best interests by families and professionals during an acute illness
- The ReSPECT document works with Decision Support Tool for Paediatric Palliative Care Patients to respond with appropriate monitoring, escalation and treatment in line with child's health goals and child and family's priorities



Summary of relevant information for this plan including diagnoses and relevant personal circumstances:

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ Yes ☐ No

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me	**Quality of life and comfort matters most to me**
What I most value:	What I most fear / wish to avoid:

Pediatric Early Warning Score Card

PEWS is a tool designed to effectively recognise and respond to the acutely deteriorating child or young person.

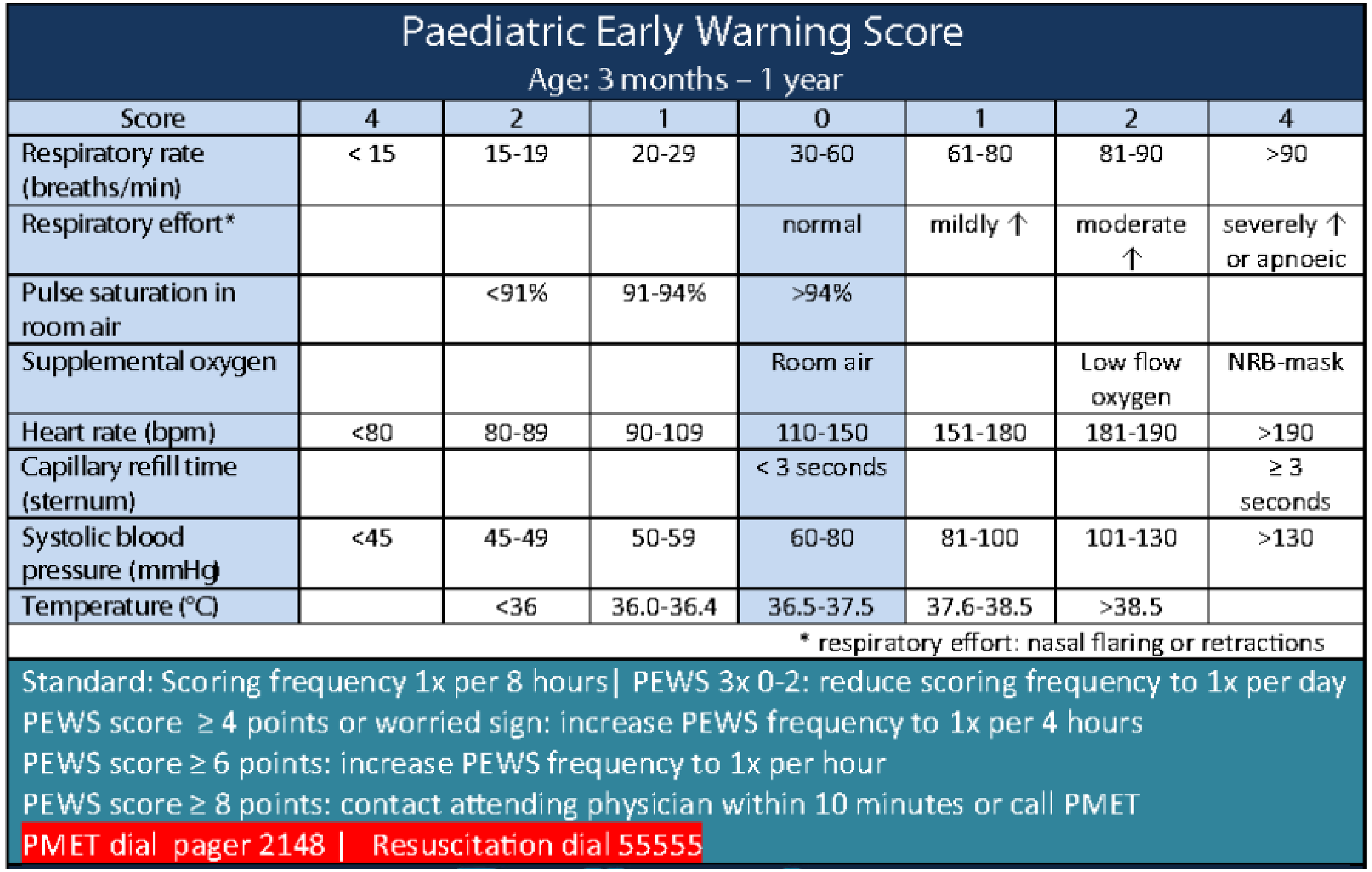
Practical use:

- To triage workload
- Identify potential children at risk of deterioration and increase team awareness and timely reviews.

In the population of paediatric palliative care it is essential for the child's usual baseline vital signs when well are known, and for parents and guardians to be able to provide context into how their child is compared to their usual state.

This is so professionals can:

- Create individualised PEWs for that child's baseline so care is escalated only when appropriate
- Simplify monitoring to what is appropriate and relevant
- Prevent unnecessarily long hospital admissions
- Reduce the amount of monitoring and intervention to only what is required and is beneficial to the child and their family
- Reduce child/family anxiety associated with ongoing monitoring and interventions



Paediatric Early Warning Score

Age: 3 months – 1 year

Score	4	2	1	0	1	2	4
Respiratory rate (breaths/min)	< 15	15-19	20-29	30-60	61-80	81-90	>90
Respiratory effort*				normal	mildly ↑	moderate ↑	severely ↑ or apnoeic
Pulse saturation in room air		<91%	91-94%	>94%			
Supplemental oxygen				Room air		Low flow oxygen	NRB-mask
Heart rate (bpm)	<80	80-89	90-109	110-150	151-180	181-190	>190
Capillary refill time (sternum)				< 3 seconds			≥ 3 seconds
Systolic blood pressure (mmHg)	<45	45-49	50-59	60-80	81-100	101-130	>130
Temperature (°C)		<36	36.0-36.4	36.5-37.5	37.6-38.5	>38.5	

* respiratory effort: nasal flaring or retractions

Standard: Scoring frequency 1x per 8 hours | PEWS 3x 0-2: reduce scoring frequency to 1x per day

PEWS score ≥ 4 points or worried sign: increase PEWS frequency to 1x per 4 hours

PEWS score ≥ 6 points: increase PEWS frequency to 1x per hour

PEWS score ≥ 8 points: contact attending physician within 10 minutes or call PMET

PMET dial pager 2148 | Resuscitation dial 55555

SBAR

NHS Improving Quality

Helen & Douglas House
your local children's hospice

The SBAR process consists of four standardised prompts that help staff to anticipate the information needed by colleagues and formulate important communications with the right level of detail

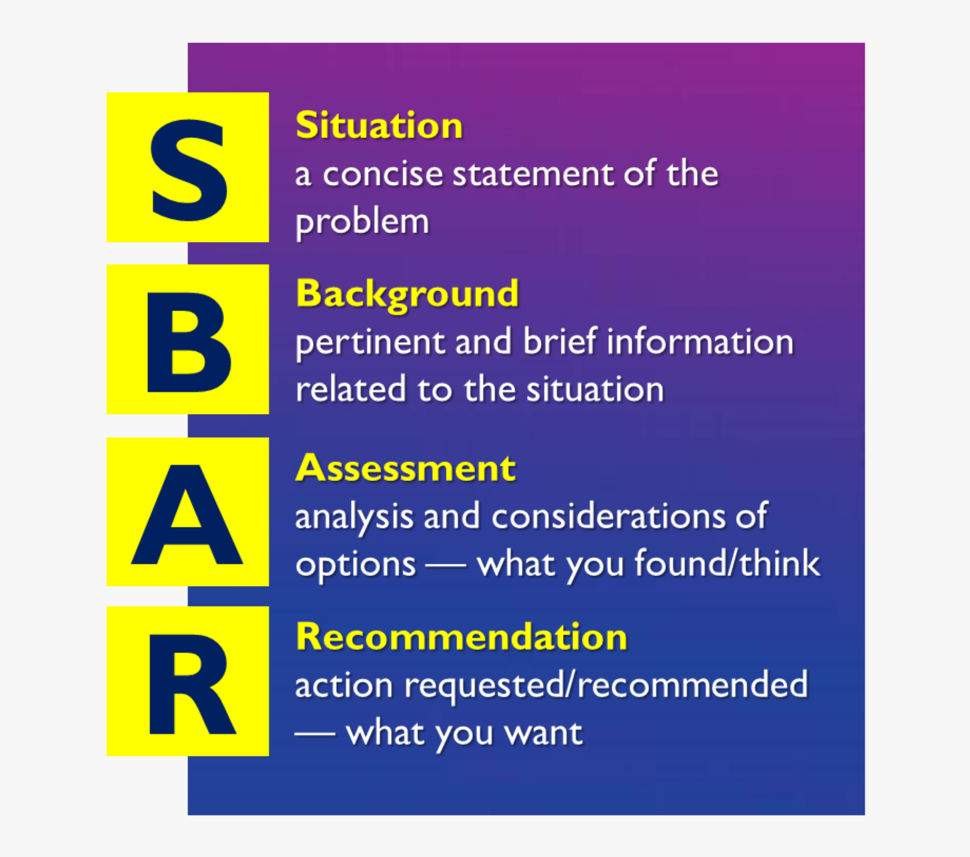
SBAR can be used very effectively to escalate a clinical problem that requires immediate attention, or to facilitate efficient handover of patients between clinicians or clinical teams

(SBAR Implementation and Training Guide, 2017)

Use with paediatric palliative care patients can communicate their usual baseline observations if these aren't within expected parameters, and any ReSPECT wishes.

In the children's hospice:

- Used to communicate with ambulance services who attend to support a child receiving End of Life Care at home
- Used between hospice staff and hospital staff to handover when transfers take place between settings
- Used between Community nurses and hospice staff when supporting decision making in the community
- Often children who are unstable or critically ill have symptom management plans written by Doctors at the hospice, professionals should be made aware of these and them made available if transfer of care is taking place

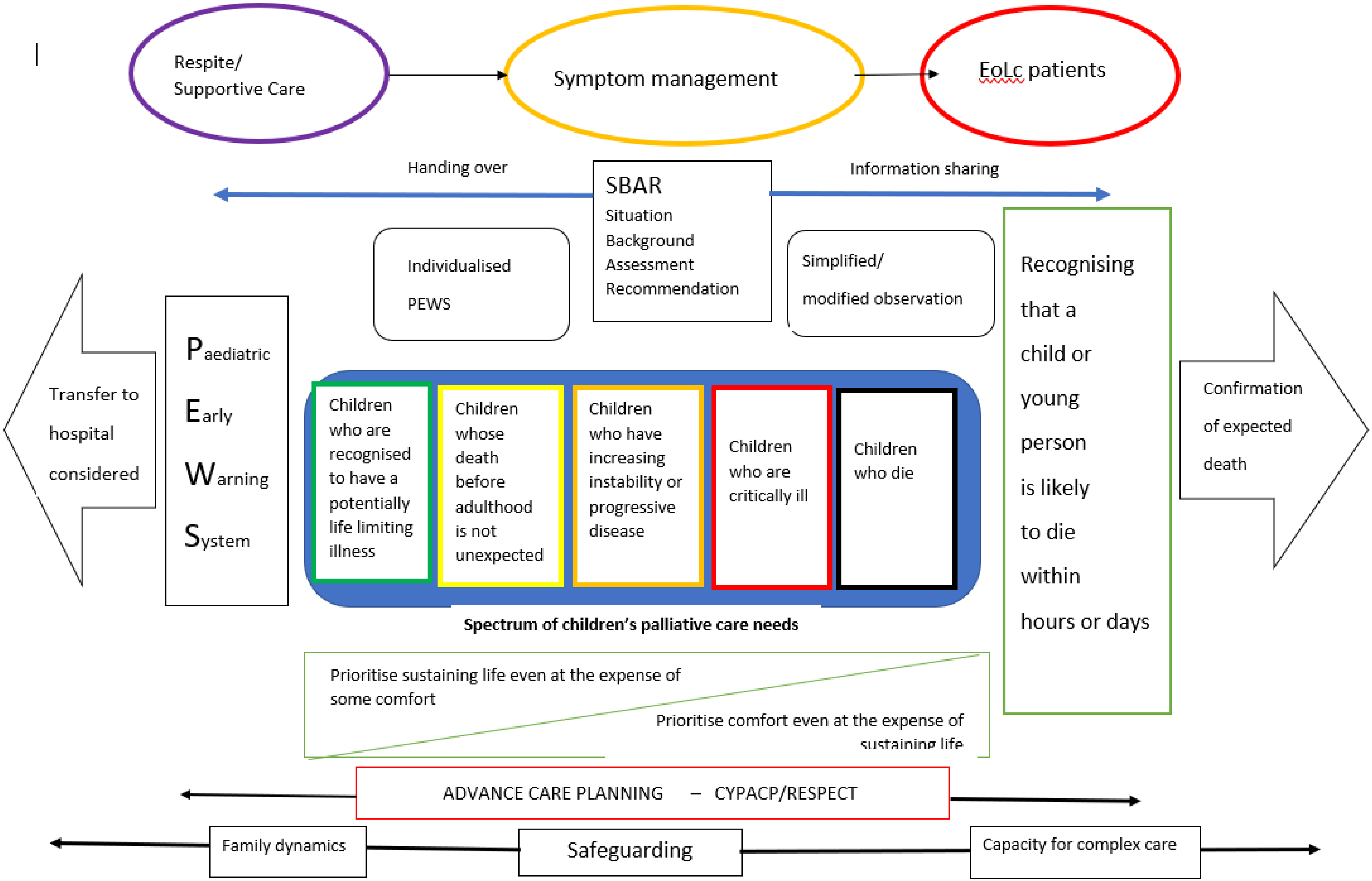


S **Situation**
a concise statement of the problem

B **Background**
pertinent and brief information related to the situation

A **Assessment**
analysis and considerations of options — what you found/think

R **Recommendation**
action requested/recommended — what you want



Respite/
Supportive Care

Symptom management

EoLc patients

Handing over

SBAR
Situation
Background
Assessment
Recommendation

Information sharing

Individualised
PEWS

Simplified/
modified observation

Transfer to hospital considered

Paediatric
Early
Warning
System

Children who are recognised to have a potentially life limiting illness

Children whose death before adulthood is not unexpected

Children who have increasing instability or progressive disease

Children who are critically ill

Children who die

Spectrum of children's palliative care needs

Recognising that a child or young person is likely to die within hours or days

Confirmation of expected death

Prioritise sustaining life even at the expense of some comfort

Prioritise comfort even at the expense of sustaining life

ADVANCE CARE PLANNING – CYPACP/RESPECT

Family dynamics

Safeguarding

Capacity for complex care

DECISION SUPPORT TOOL FOR ASSESSING PAEDIATRIC PALLIATIVE CARE PATIENTS

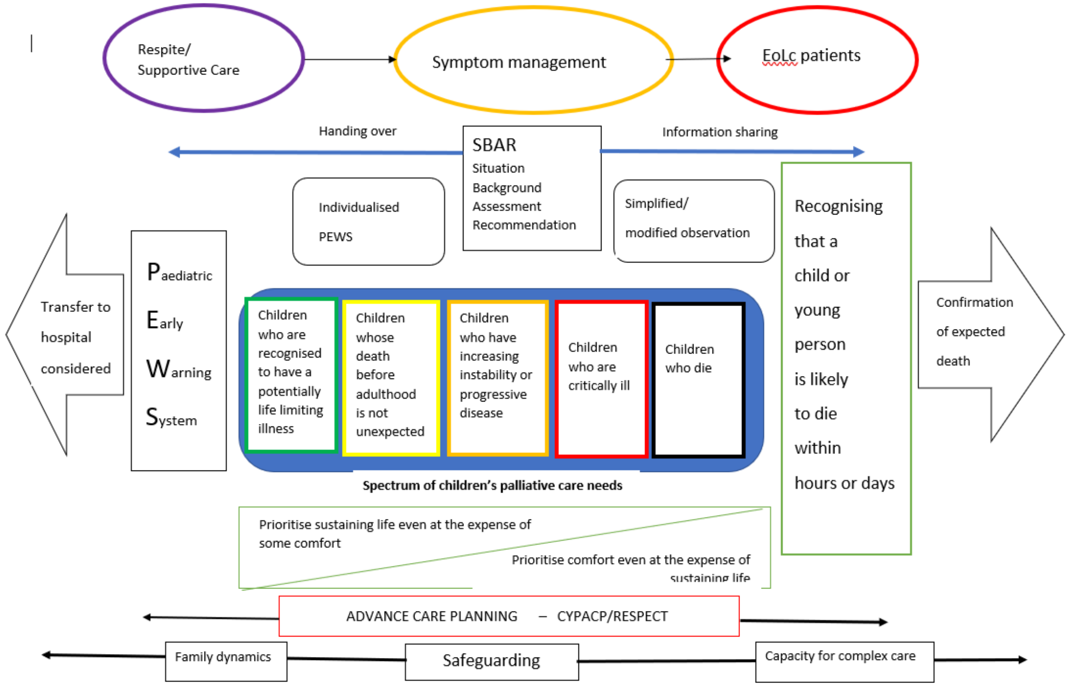
Case Study One

Matt (pseudonym).

Diagnosis: Metastatic neuroblastoma

First contact with hospice:
Initially: Increasing instability (orange), receiving treatment in hospital, continued on oral chemotherapy, parents and siblings in separate countries, remained for full resuscitation. Pain was his primary symptom. Attending hospice for symptom management, returning to hospital between as no fixed abode. Language barrier.

When unwell: If vital observations out of range, and source of infection identified or required investigation, would be transferred to hospital for treatment and IV route utilised and care escalated as necessary until family reunited.



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DECISION SUPPORT TOOL FOR ASSESSING PAEDIATRIC PALLIATIVE CARE PATIENTS

Case Study One Continued

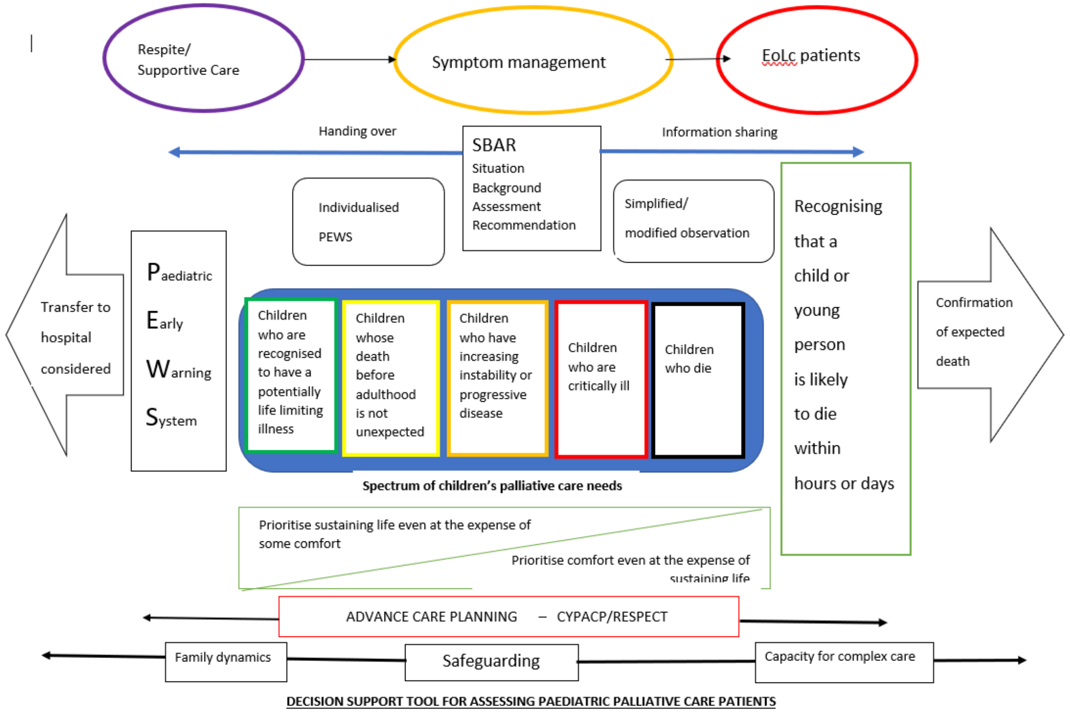
Helen & Douglas House
your local children's hospice

Matt (pseudonym)

Change of direction with decision tool:
Matt identified as critically ill, not expected to survive beyond a few weeks. Further management to be in hospice or home. Transfers escalated pain. Regular pyrexia, caused by disease progression. Decision for observations to be responsive instead of routine, treatment with medication to lower fever. Family open to potential for treatment with oral antibiotics if other symptoms of infection present however Matt made it clear side-effects of antibiotics were not tolerable to him.

Family wished to keep him comfortable. Recognised Matt was in his last days of life, family felt unable to care for him at home and language barrier increased difficulty for providing symptom management advice over the phone. Care in last days and after death supported in the hospice.

SBAR used to communicate with oncologists and community nurses throughout.



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DECISION SUPPORT TOOL FOR ASSESSING PAEDIATRIC PALLIATIVE CARE PATIENTS

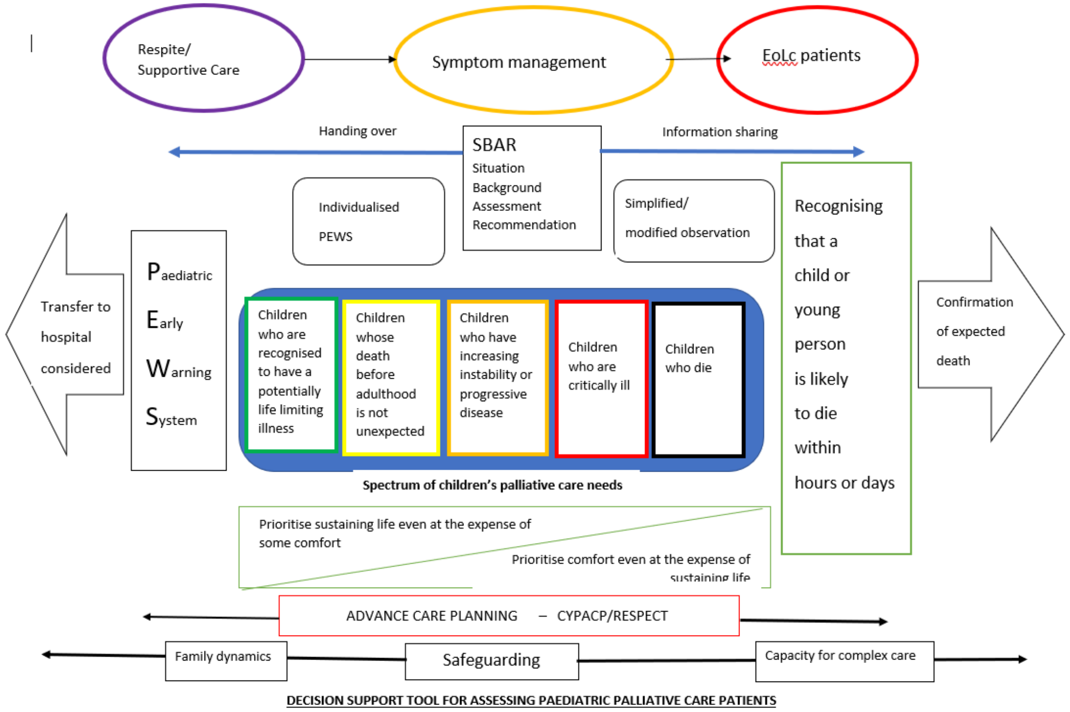
Case Study Two

Justin (pseudonym).

Justin had Duchenne muscular dystrophy and a genetic condition. Communicated using adapted Makaton.

Visited the hospice for respite over number of years, fell into ‘green’ category. For full resuscitation and transfer and treatment to hospital when required. PEWS appropriate for his baseline observations.

In 2021 experienced multiple episodes of respiratory illnesses and heart failure that caused increasing number of, and intensity of, hospital admissions, resulting in prolonged admission invasively ventilated in PICU.



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DECISION SUPPORT TOOL FOR ASSESSING PAEDIATRIC PALLIATIVE CARE PATIENTS

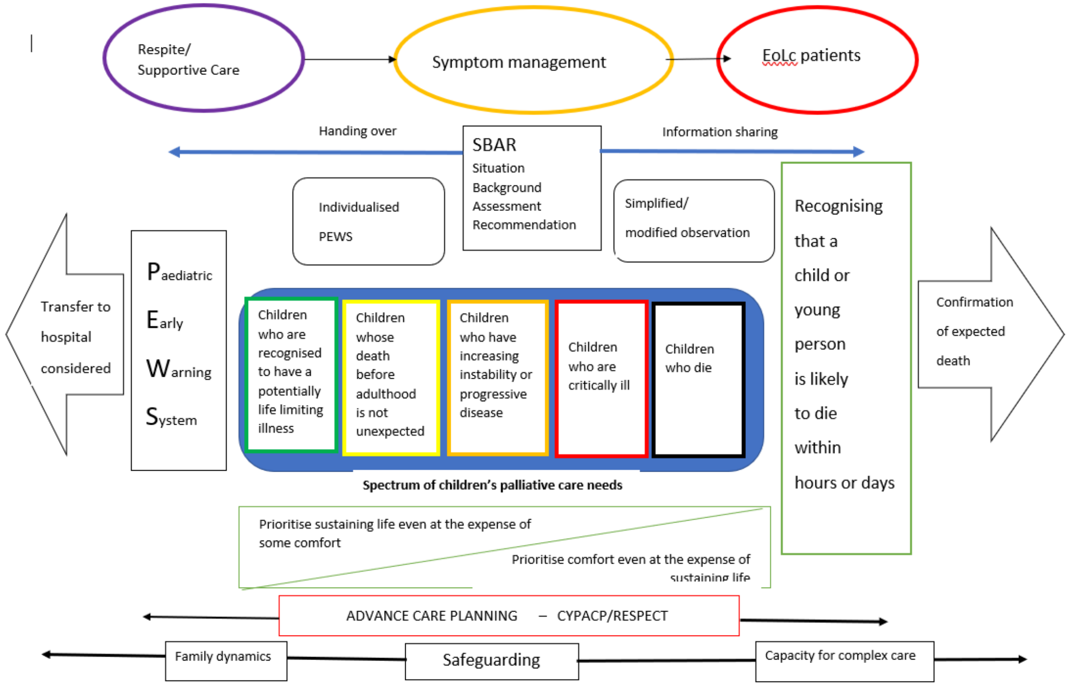
Case Study Two Continued

Helen & Douglas House
your local children's hospice

Justin (pseudonym).

Intubation and constant intervention felt not to be in his best interests by his family, improved enough to use non-invasive ventilation (NIV) but clinically deteriorated with any time off, and greatly distressed when on NIV. Justin signed clearly and repeatedly that he wanted to go home, and see his dogs. Family reviewed his Advance Care Plan, not for resuscitation or escalation unless reversible, and not to be intubated or have NIV as Justin found this intolerably distressing.

Justin returned home, as was his main wish, and lived for another 6 months in 'orange' with symptoms well managed and increased support until another chest infection, commenced oral antibiotics and oxygen at home and had further support with symptom management before dying peacefully at home which was his preferred place of care & death.



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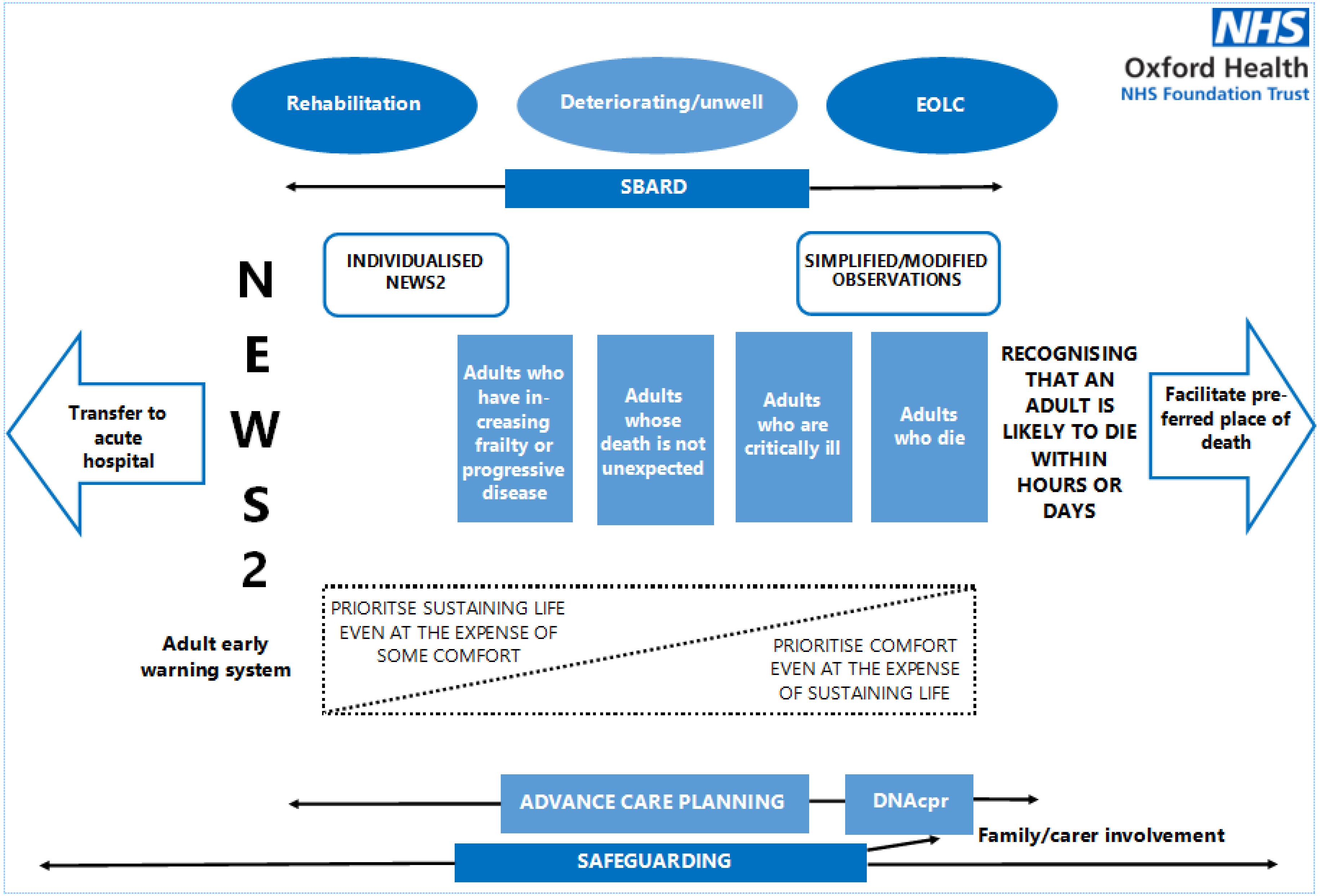
DECISION SUPPORT TOOL FOR ASSESSING PAEDIATRIC PALLIATIVE CARE PATIENTS

Ways to use the tool

- To facilitate **MDT discussions** about escalation ahead of time
- To allow staff to make a **child centred decision in real time**, whatever the setting
- To **support discussions** between clinical staff out of hours / on-call
- To **support handover** of plans between teams when patients move settings
- For **professional development** of non-specialist staff

Discussions around the need for a tool to support decision making for PPC patients has been noted on the TfSLs Clinical Forum.



NHS
Oxford Health
NHS Foundation Trust

Rehabilitation
Deteriorating/unwell
EOLC

SBARD

INDIVIDUALISED NEWS2

SIMPLIFIED/MODIFIED OBSERVATIONS

N
E
W
S
2

Adult early warning system

Transfer to acute hospital

Adults who have increasing frailty or progressive disease

Adults whose death is not unexpected

Adults who are critically ill

Adults who die

RECOGNISING THAT AN ADULT IS LIKELY TO DIE WITHIN HOURS OR DAYS

Facilitate preferred place of death

PRIORITSE SUSTAINING LIFE EVEN AT THE EXPENSE OF SOME COMFORT

PRIORITISE COMFORT EVEN AT THE EXPENSE OF SUSTAINING LIFE

ADVANCE CARE PLANNING

DNAcpr

Family/carer involvement

SAFEGUARDING

As part of an ‘all ages’ approach to palliative care, the tool was adapted to support care homes

It helps them to know which assessments to use and when to consider transferring elderly patients to acute care

All of the tools used to develop the Decision Support Tool are available online.

Would any of you like to pilot the tool and give us some feedback?
Please email lbutters@helenanddouglas.org.uk and/or
eharrop@helenanddouglas.org.uk

Developing an online feel-good resilience group

William Mackenzie

Rainbow Trust Children's Charity

Rainbow Trust: Our History

In 1986, Bernadette Cleary provided emotional support and comfort to a friend whose 12-year-old daughter had terminal cancer.

We have eight existing care teams and our online service.

We Can Offer

A wide range of support tailored to the family’s needs:

- Support in hospital
- Support at home
- Transport to and from hospital
- Support for parents
- Sibling support
- Drop-in groups
- Bereavement support
- Referrals can be made via professionals and self-referrals on our website.

Pandemic Impact

- 58% of families tell us that their mental health is worse or much worse than pre-pandemic
- 54% of families tell us they feel more isolated than pre pandemic

“I just feel numb quite frankly, just totally numb to everything”

Our Resilience group

Building resilience enables the children and young people attending have the ability to adapt well to adversity, trauma, tragedy, threats, or even significant sources of stress. It can help the child or young person manage stress and feelings of anxiety and uncertainty.

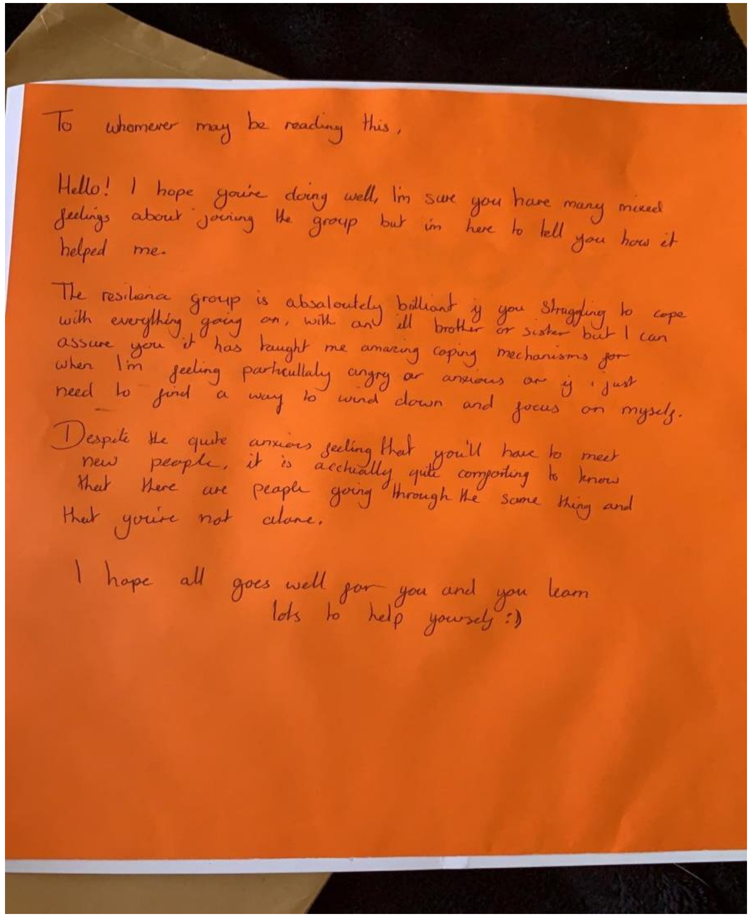
Aims

- To help children and young people to become experts in their own resilience
- To help children and young people come to terms with their experiences
- To help children and young people develop a positive lifestyle and coping strategies
- To help children to live more skillful, less impulsive lives.

The course

- Pre group assessment
- Getting to know us
- Getting to know me
- Believe in yourself
- Accepting how you feel
- Being mindful of our reactions
- Respecting ourselves and making positive choices
- After care

Week 7 – I did it :)



To whomever may be reading this,

Hello! I hope you're doing well, I'm sure you have many mixed feelings about joining the group but im here to tell you how it helped me.

The resilience group is absaloutely brilliant if you struggling to cope with everything going on, with an ill brother or sister but I can assure you it has taught me amazing coping mechanisms for when I'm feeling particullaly angry or anxious or if i just need to find a way to wind down and focus on myself.

Despite the quite anxious feeling that you'll have to meet new people, it is acctually quite comforting to know that there are people going through the same thing and that you're not alone.

I hope all goes well for you and you learn lots to help yourself :)

RAINBOW TRUST
SUPPORTING FAMILIES WITH A SERIOUSLY ILL CHILD

Young people’s feeling week1

- Stressed
- Tired
- Excited
- Sad
- Confused
- Nervous
- Anxious
- happy

Young people's feelings week7

- Peaceful
- Calm
- A little bit tense
- Tired
- Self motivated
- Happy
- Positive
- Knowing when to stop
- Confident

Next Steps

- Interactive web page to go alongside the group
- This intervention will be rolled out across all care teams within Rainbow Trust.
- We are aiming for this intervention to become part of our core offer at Rainbow Trust Children's Charity.

Thank you!

Any Questions?

William Mackenzie
Advanced Practitioner
0161 628 2194 / 07825 601359
william.mackenzie@rainbowtrust.org.uk

Sean Tansey
Family Support Manager
0161 628 2194 / 07827 878205
sean.tansey@rainbowtrust.org.uk

The Martin House RESEARCH CENTRE

In partnership with UNIVERSITY of York

Understanding parent experiences of end of life care for children: a systematic review and qualitative synthesis

Laura Barrett, Lorna Fraser, Jane Noyes, Jo Taylor, Julia Hackett

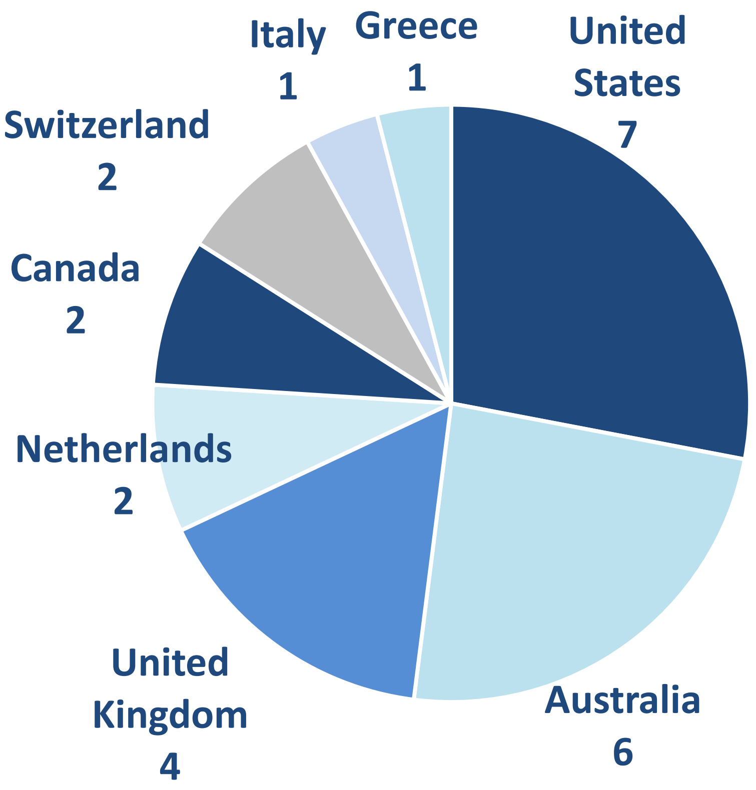
Background

- ~ 21 million children world-wide would benefit from palliative care (1)
- Nearly 8 million babies and children die each year (2)
- Delivery of end-of-life care differs considerably across countries
- Common recognition that parents need support
- Need to understand how parents’ experience the care their child receives
- Body of primary qualitative evidence – no recent systematic review

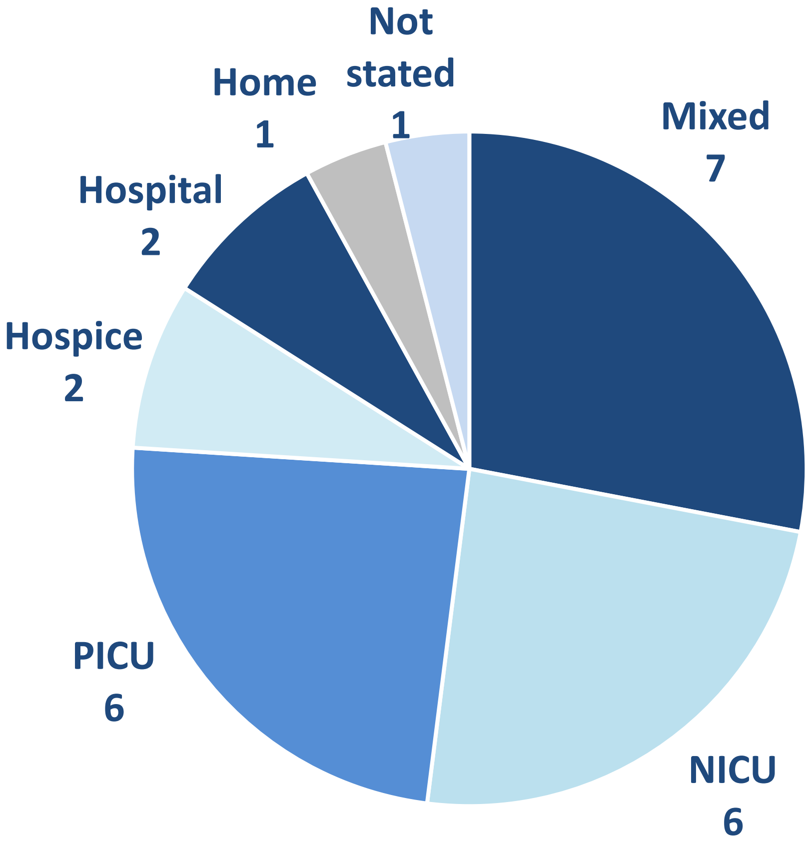
Methodology and results

- Searched for qualitative studies of parents experiences of end-of-life care of their child
- 5 databases and references - 9,200 papers
- After screening 95 papers fit inclusion criteria
- All appraised for methodological quality and data richness
- Applied purposive sampling framework - 25 papers based on 21 studies
- Thematic synthesis of over **470 parents' experiences**
- Confidence in findings assesses by GRADE-CERQual
- Consulted with parents

Sample characteristics

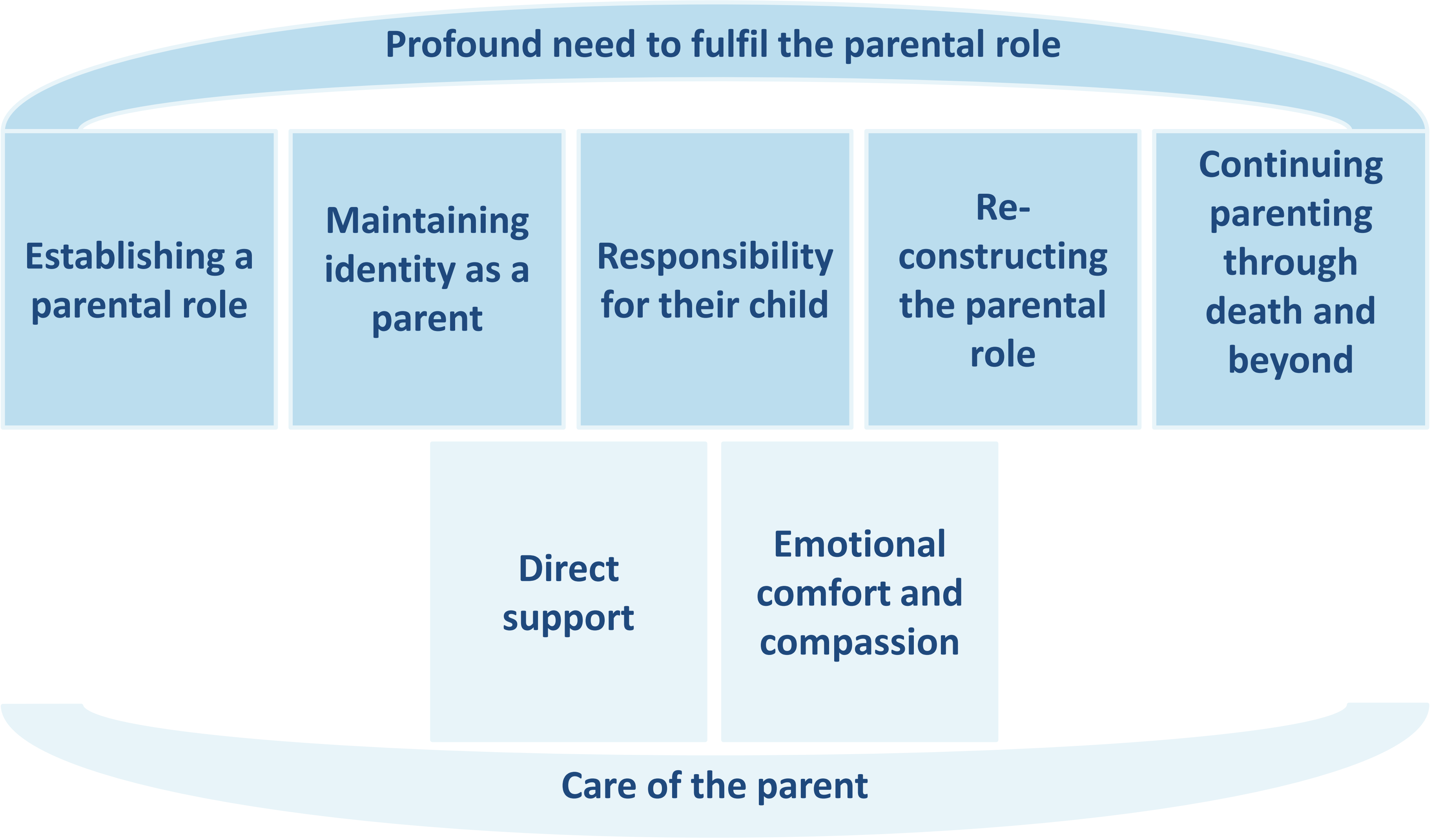


Country of study



Care setting

Overview of themes



Profound need to fulfil the parental role

Establishing a parental role

Maintaining identity as a parent

Responsibility for their child

Re-constructing the parental role

Continuing parenting through death and beyond

Direct support

Emotional comfort and compassion

Care of the parent

Establishing a parental role

- Parents with babies in the NICU needed to **establish** themselves as parents

"I pretty much did everything. Like I said, they made sure that I knew I was his mother… they pretty much made sure I stayed his mom; (Mother).

"In a certain way, he never really was our child, because you haven't been able to do normal things with him. You couldn't hold him, you couldn't tend to him. We had started with baby massage. Only once. Then he got worse again and didn't like the touch anymore." (Father)

Maintaining identity as a parent

- Parents with children in intensive care and other hospital settings needed to navigate **maintaining** their parental role while their child's health needs were also met

"When we were at home, we used to clean his peritoneal catheter but when we were in the PICU the clinicians would say: "You don't do anything, and please go out of the room." (Parents)

"What I missed the most was doing the daily things that moms do. I know that it's not easy to do these things in a PICU but even the possibility of staying there longer and holding his hand was something" (Mother)

Responsibility for their child

- For most parents there was a fundamental need to feel fully informed and to represent the child and their best interests, and ultimately be **responsible** for their child
- This role was seen as central to their identity as parents

"He's [our] responsibility. I know [the hospital] cares about him but I need to know that I'm doing everything as a parent." (Mother)

"It's the hardest role I've ever had. I did not like having to do it. But I wouldn't trust anyone else with that decision" (Mother)

Reconstructing the parental role

- Some parents **reconstructed** their role when they understood and accepted their child had reached the end of their life, moving from ‘doing’ to ‘being’
- A shift in treatment or setting gave some a feeling of getting their child ‘back’

“When you are at home you can shut the door and no-one is telling you that your child is ill, when we brought Sally home that was our time” (Mother).

“We washed her ourselves and put on her clothes. It was wonderful. We finally had her without tubes. Free..” (Mother)

Continuing parenting through death and beyond

- Finally, it was important that parents were able to **continue** to enact their role as their child died and beyond

"In the end he died quietly. On daddy's lap. I said: He was born from my womb, he may go from daddy's lap" (Mother)

"the most powerful photo that we've got is one where my wife is holding (baby). And you can just see the heartbreak on her face. At the time I felt bad taking that photo. But I'm very glad we did, because as I said, it kind of reminds you that it did really happen. The pain was real. And her existence was real. " (Father)

Care of the Parent

- Parents that were well cared for felt more enabled to be a parent

> ***Looking after us, so we could better look after Ethan (Parent)***

- Parents valued professionals who provided direct and practical support
- Emotional support and compassion offered by HCPs was acknowledged and much appreciated

Conclusion

- All services delivering end-of-life care for children need to **recognise the importance** for parents of being able to fulfil their parental role and **consider how their service can enable this.**
- What the parental role consists of, and how it is expressed, **differs for individual parents** and can **shift**.
- **Policy and practice guidance** should acknowledge the need to enable parents and to support them in parenting at the end of their child’s life.

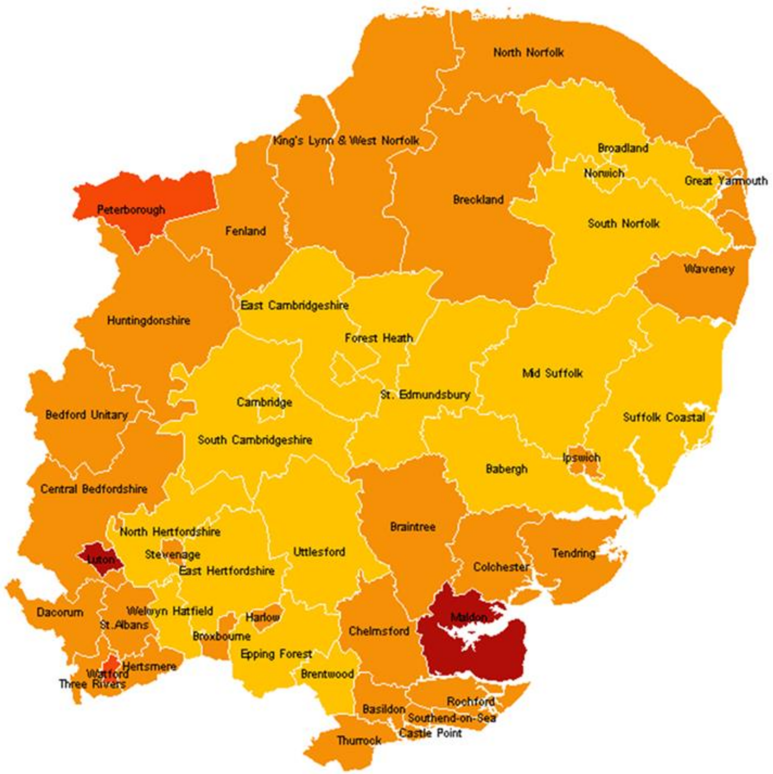
The Value of the Senior Specialist Pharmacist Role in a new Regional Paediatric Palliative Care Service.

Stephanie Smith

- Senior Paediatric Pharmacist
- Rheumatology Network pharmacist for CHEERS
- Palliative care pharmacist for RAaFT:

Regional Advice and Facilitation Team. East of England symptom management and palliative care service.

New Regional Service



- Child Population (aged 0-19 years) 1.4 million

- Children with life-limiting conditions est. 8,989 (61.1 per 10,000)

- Area of 19.120 km^2

- 6 ICS areas:
- Bedfordshire, Luton and Milton Keynes
- Cambridgeshire and Peterborough
- Hertfordshire and West Essex
- Mid and South Essex
- Norfolk and Waveney
- Suffolk and North East Essex

East of England Children's Palliative Care
Managed Clinical Network

MCN Managed Clinical Network
...promoting coordinated quality care

Working in Partnership with

5 children's hospices

1 Tertiary Centre – (CUH)

1 Children's Hospital (Norwich)

3 Level 3 NICUs (Cambridge, Luton & Norwich)

15 District General Hospitals

7 Children's Community Nursing Services

The Case for a Regional Tertiary Service

6 month gap after retirement of Addenbrookes' Paediatric Palliative Care Consultant

No other Consultants in Paediatric Palliative Medicine in East of England

NICE guidelines and QSAC standards for all BCYP with PEoLC to have access

Increasing prevalence, particularly neonatal/antenatal and transition

No previous tertiary specialist nurse, pharmacy or psychology provision

Range of MDT models in other tertiary services nationally

To enable ICS and EoE PEoLC SCN Region to meet Ambitions for BCYP and their families

New Service Specification for BCYP PEoLC

The Team

- Dr Carolina Perez, Consultant in Paediatric Palliative Medicine
- Dr Elena Cattaneo, Consultant with Special Interest in BCYP PEoLC
- Dr Gemma Barnard, Consultant in Paediatric Oncology
- 1.0wte Vacancy Consultant in Paediatric Palliative Medicine
- Julia Boom, Specialist Support Nurse
- Juliet Nobel, Clinical Nurse Specialist
- Stephanie Smith, Senior Paediatric Pharmacist
- Dr Amy Volans, Consultant Clinical Psychologist & Family Therapist
- Dhilip Subramani, Data Coordinator
- 0.2wte PEoLC Play Specialist support and training role

RAaFT

Regional Advice and Facilitation Team
East of England Children's Palliative Care Service

Linking with existing structures

- **Weekly Regional BCYP PEoLC MDT meetings**
- MCN regional Out of Hours On-Call
- **MDTs and "round robin" emails**
- **Monday On Call Handover Meeting**

- MCN Point Prevalence Study
- EACH Training Needs Analysis projects
- MCN Regional Clinical Forum and Steering Groups
- APPM Specialist Group

- EoE Children, Teenagers and Young People with Cancer ODN
  Symptom Management and Palliative Care working groups
- EoE Neonatal ODN
- APPM Specialists Group

RAaFT

Regional Advice and Facilitation Team
East of England Children's Palliative Care Service

RAaFT

Regional Advice and Facilitation Team
East of England Children's Palliative Care Service

Developing the new RAaFT service

- Service user involvement – naming the service
- Implementation meetings
- Regional Away Day
- EPIC build (electronic prescribing system)
- Interim manual data collection
- Data summaries and submissions to NHSE
- RAaFT referral pathway development
- RAaFT policy development
- MCN collaborative Training Strategy
- Planning launch event

Referrals to RAaFT
January to May 2022

- 13 oncology referrals
- 26 non-oncology referrals
- Non-oncology referrals from:
  NICU, Foetal Medicine, PICU, Neurology, Keech, EACH, Little Havens, WellChild Nurse, Children's Wards

- 6 oncology deaths

(3 Home, 2 Hospice, 1 PICU)

- 10 non-oncology deaths

(2 Home, 1 NICU, 1 Labour Ward, 5 Hospice, 1 Hospital)

- 18 Symptom Management Plans
- 9 Advanced Care Plans

RAaFT
Regional Advice and Facilitation Team
East of England Children's Palliative Care Service

Regional Baby Child and Young People (BCYP) Palliative and End of Life Care (PEoLC) Pharmacy Service Survey

- Circulated to all 35 professionals on the meeting invitation list for the regional MDT meetings
- 7 responses, which is likely to be representative of number of professionals who have contacted the pharmacist for consultation in the last 6 months

Regional BCYP Palliative Care Pharmacy Service Survey

- **How useful has your experience of the new BCYP PEoLC Pharmacy Service been?**
- 5/7 Extremely useful
- 2/7 Somewhat useful

- **How accessible have you found the BCYP PEoLC Pharmacy Service?**
- 4/7 Easy to access
- 3/7 Neutral

- **How has the new BCYP PEoLC Pharmacy Service impacted on reviewing Symptom Management Plans?**
- 5/7 Extremely helpful
- 2/7 Somewhat helpful

Regional BCYP Palliative Care Pharmacy Service Survey

- **How has the new BCYP PEoLC Pharmacy Service impacted on the process of discharging BCYP with palliative care needs from hospital to home/hospice for end of life care?**
- 6/7 Extremely helpful
- 1/7 Somewhat helpful

- **How has the new BCYP PEoLC Pharmacy service impacted on medication wastage?**
- 2/7 reduced wastage
- 3/7 no impact on wastage
- 2/7 unsure

- **What methods of communication would work best for you for accessing the Regional Children's Palliative Care Pharmacy Service?**
- 5 – email
- 5 – Wednesday regional meeting
- 4 – telephone
- 2 – via CNS

What, if anything, do you find most useful about accessing the BCYP PEoLC Pharmacy Service?

- Advising us on syringe driver combinations
- Quick response to pharmacy questions and timely supply of medications for patients at the point of discharge
- Answers to queries when needed, very responsive.
- No pharmacist linked to our service so support needed.
- Her advice regarding drugs interactions and syringe driver compatibility
- Rapid response to medication queries in end of life
- That the service is there to utilise if required.
- Prompt response. Very useful resource as has access to information which local DGH pharmacies may not have.

Key themes in what was “useful” about the new service

Source of Advice and Information

- Advice re: drug interactions
- Advice re: syringe driver compatibility and combinations
- Advice re: medication supply issues
- Access to information local DGH pharmacies may not have

Accessible and Responsive

- Rapid/prompt/efficient response
- Answering urgent medication queries at end of life
- Knowing how to access if/when needed
- One place to access advise for all patients in region

Effective for Improving the Quality of Patient Care

- Good outcomes when advice followed
- Enabling rapid discharge with all medications on the symptom management plan
- Rapid access to medications hard to access for end of life care in the community

What, if anything, would you like to be different about the BCYP PEoLC Pharmacy Service?

- Difficult to define at the moment as our needs have been minimal. However, working with a pharmacist in another service has been invaluable so I think the potential is great
- Helpful to have allocated cover for leave periods
- Available every day

Do you have an example you could share of a useful outcome of accessing the BCYP PEoLC Pharmacy Service that would have not have been possible / been a lot more difficult to achieve before the new service.

- Queries regarding compatibility of medications in syringe driver. Other source for support would be GOSH but not a GOSH patient. Advice regarding medications and effectiveness.
- There was a question around compatibility of drugs in a syringe driver or dilution requirements of a drug in a syringe driver. Although we didn't directly ask the question ourselves the Raft team were able to gather the info very quickly from the attached pharmacist. On previous occasions a lot of time would have been used to gain the answer and this would have likely been from an adult focused pharmacist.
- Transfer end-of-life transfers to the hospice. The patient got all the meds from the SMP.
- Incompatible drugs in a syringe driver. Following Steph´s advice, the syringe driver was changed.

Do you have an example you could share of a useful outcome of accessing the BCYP PEoLC Pharmacy Service that would have not have been possible / been a lot more difficult to achieve before the new service.

- Discussions regarding using Dexamethasone with several other drugs in a syringe driver

- Accessing a supply of oral Ketamine for a patient having end of life care as an inpatient in hospice on same day, where community access would have taken a number of days. Medication was very effective so quick access was really helpful

- Rectal administration of clonidine with clear guidance and instructions in a timely manner.

- Accessing information about the availability of drugs which GP surgeries were advising were out of stock and being willing to supply these if required.

Thank you for taking the time to share your thoughts and reflections. Please use the space below for any other comments.

- Excellent in supporting discharge home and provision of SMP medications which have been difficult to access in the community or from the local hospitals who are anxious regarding dispensing these medications.
- For me, Steph´s role is key within the team. Her expertise and knowledge help us to provide safe care to our patients. Most of our patients are on multiple medications and having access to Steph is amazing as she can check doses, incompatibilities, etc.
- So far has been really helpful, I would consider if consultant and pharmacy input into SMP's will potentially deskill CNS's and it can be difficult to implement and advise if you are unclear of rationale
- I think as the service grows there could be potential for more use of the service. When dealing with DGHs it will be so helpful when asking for JIC meds if we can put the local pharmacist in touch with BCYP PEoLC service for reassurance and guidance.

Response to feedback.

You Said, We Did!

- Upskilling the nursing workforce - drug interaction and syringe driver education and training sessions for nurses delivered and content being refined and developed in response to feedback from those initial sessions
- Improving access to resources – exploring access for all nurses to online database of palliative care drugs
- Improving access to the service – raise regional awareness that CUH paediatric pharmacy team does provide cover when post holder is on leave
- Improving access to the service – discussing with CUH pharmacy lead whether the paediatric service could be extended to weekends
- Improving access to the service – plan a program to raise awareness across regional pharmacy services about service offered by RAaFT

Two other important Quality Improvement projects which are underway

- Updated CUH Symptom Management Plan template in development
- Standardising discharge – Electronic prescribing template for discharge and inpatients.

Review of numbers of Advice/support contacts , Symptom Management Plans and To Take Out medication prescriptions for BCYP with PEoLC that senior specialist pharmacist contributed since January 2022

Phone calls (From outside of RAaFT team)	SMP's clinically reviewed by pharmacist	Discharge medication for EolC from CUH
Average of 3 calls a week. Common themes: • Syringe driver compatibility • Stock shortages/supply • Formulation queries • CD requirements • Dose checks • Risk assessments – shelf life	• 19 • Non – oncology: 9 • Oncology: 10 Including dose checking, interactions, formulation choice (need for dilution), polypharmacy review.	• 9 To Take Out medication prescribed and clinically reviewed by the paediatric pharmacy team on EPIC.

Thank you for your time

Any questions?

Thank you to the RAaFT team especially Amy Volans for supporting me with the questionnaire.

RAaFT

Regional Advice and Facilitation Team
East of England Children's Palliative Care Service

RAaFT

Regional Advice and Facilitation Team
East of England Children’s Palliative Care Service

Introducing RAaFT

RAaFT - Regional Advice and Facilitation Team
East of England Children’s Palliative Care Service

Team Telephone: **01223 217677**

Team email:
cuh.add-tr.paedpalliativecare@nhs.net

Office: Rosie Hospital
Cambridge University Hospitals NHS Foundation Trust
Monday – Friday 08:30 -16:30

together for short lives

Talk about the conference on your **socials**

Tag us in and use the hashtag **#TSFLConference**

/togetherforshortlives @togetherforshortlives @Tog4ShortLives

#TFSLConference

A collaborative approach for the delivery of palliative care

Hospice Advanced Clinical Practitioners establishing hospital in-reach services

Lynn Grayson – Director of Clinical Services

derian

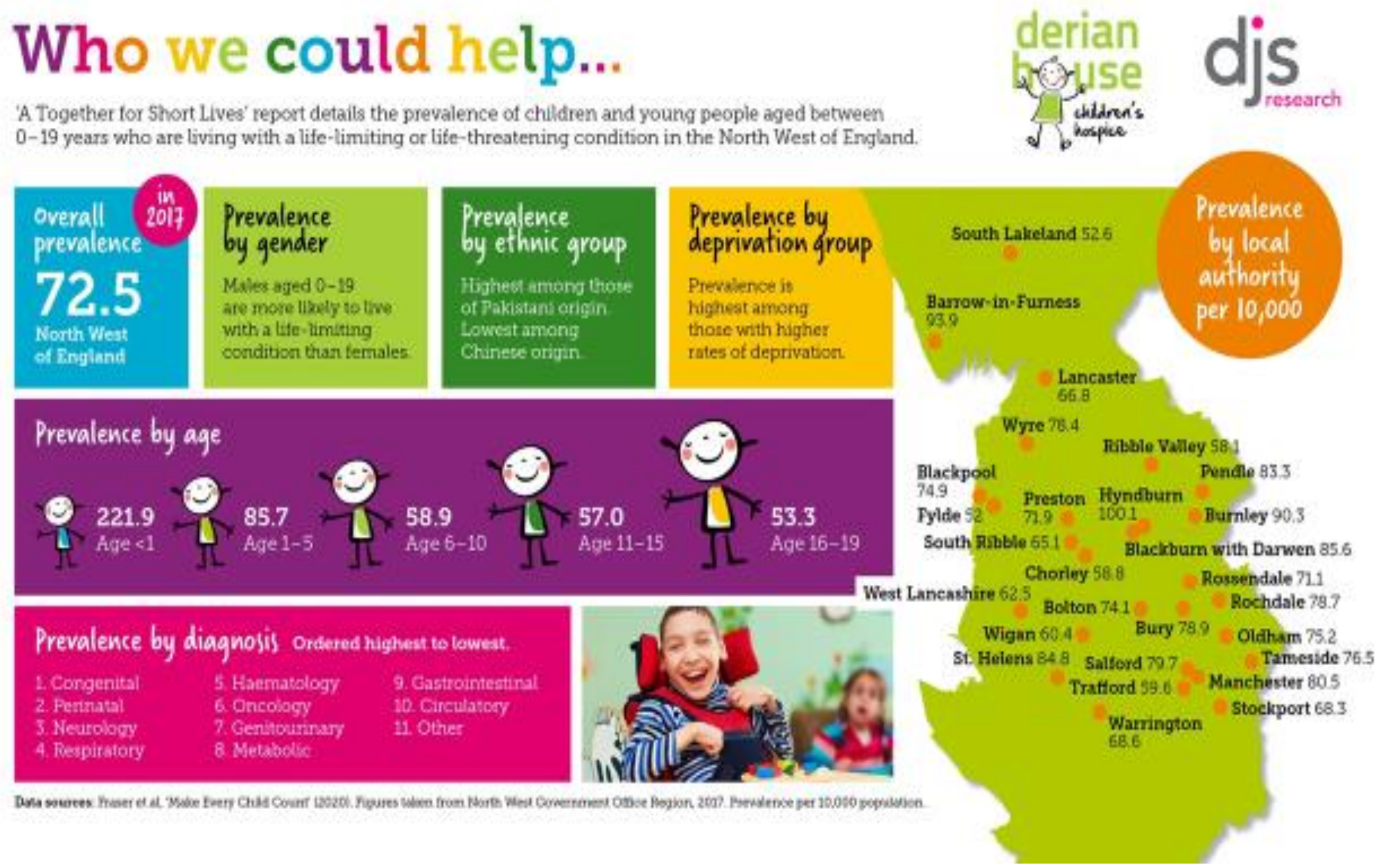
deliver outstanding care
engage with everyone
respond to change
innovative in our approach
aim for the highest standards
nurture and develop our people

derian house
children's hospice

Background

- Location
- Needs Assessment
- Strategy development
- Matched funding opportunity
- COVID……

In numbers



Who we could help...

'A Together for Short Lives' report details the prevalence of children and young people aged between 0–19 years who are living with a life-limiting or life-threatening condition in the North West of England.

Overall prevalence in 2017

72.5
North West of England

Prevalence by gender

Males aged 0–19 are more likely to live with a life-limiting condition than females.

Prevalence by ethnic group

Highest among those of Pakistani origin. Lowest among Chinese origin.

Prevalence by deprivation group

Prevalence is highest among those with higher rates of deprivation.

Prevalence by age

221.9 Age <1
85.7 Age 1–5
58.9 Age 6–10
57.0 Age 11–15
53.3 Age 16–19

Prevalence by diagnosis Ordered highest to lowest.

1. Congenital
2. Perinatal
3. Neurology
4. Respiratory
5. Haematology
6. Oncology
7. Genitourinary
8. Metabolic
9. Gastrointestinal
10. Circulatory
11. Other

Prevalence by local authority per 10,000

South Lakeland 52.6
Barrow-in-Furness 93.9
Lancaster 66.8
Wyre 78.4
Ribble Valley 58.1
Blackpool 74.9
Pendle 83.3
Preston 71.9
Hyndburn 100.1
Fylde 52
Burnley 90.3
South Ribble 65.1
Blackburn with Darwen 85.6
Chorley 58.8
Rossendale 71.1
West Lancashire 62.5
Bolton 74.1
Rochdale 78.7
Wigan 60.4
Bury 78.9
Oldham 75.2
St. Helens 84.8
Salford 79.7
Tameside 76.5
Manchester 80.5
Trafford 59.6
Stockport 68.3
Warrington 68.6

Data sources: Fraser et al. 'Make Every Child Count' (2020). Figures taken from North West Government Office Region, 2017. Prevalence per 10,000 population.

Aim

- Provision of reactive palliative care service irrespective of place of care
- Smooth transition between hospital, home and hospice
- Earlier referrals for specialist palliative care
- Provision of specialist advice
- Supporting families to plan for future needs
- Working collaboratively to reduce length of stay in hospital

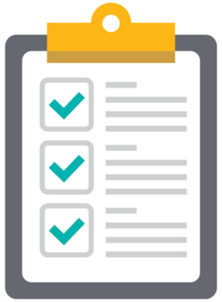
Making it happen

- Key players involved
- Honorary contracts
- Medical lead support
- Establishing roles & responsibilities

Role & Responsibilities

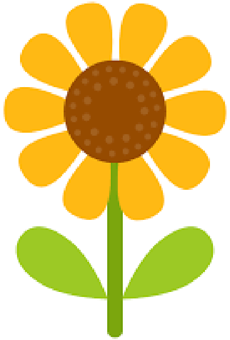
Training and education

Facilitated
early referrals



Advance
Care Plans

Participate in
ward rounds



End of Life Care
support

Care reviews

Challenges

- Establishing honorary contracts
- Relationships and engagement
- Perceptions of other providers
- Managing expectations

Successes

- Honorary contracts with acute trust
- Information sharing to identify CYP for direct referral to Derian House
- NHSE Exemplar Site
- Recognition of the contribution of Hospices in the region
- Outcome measures

- **Improving access**
- **Improving quality**
- **Improving sustainability**

Next Steps

- Sharing learning
- Growing team
- Formal training & education programme
- Consultant post
- Establish pathways for service and care provision
- Roll-out model
- Commissioning and funding

Learning points

Family support Hub

Our Support Hub is there for anybody caring for a child with a serious illness. The support we offer includes:

Helpline and live chat

We offer confidential emotional support and information on a range of issues, so that families can spend less time searching for help and more precious time together as a family. Open Monday - Friday, 9am-4pm.

☎ **0808 8088 100**

✉ **helpline@togetherforshortlives.org.uk**

togetherforshortlives.org.uk

Voices for Families: expert legal advice when it matters

Somebody caring for a child with a serious illness could benefit from free expert legal advice, they can reach out to our helpline: 0808 8088 100

Online support group

Our Facebook group is a supportive community that allows families caring for a seriously ill child to connect, share and support one another.

They can join the group here:
togetherforshortlives.org.uk/familyfacebook

Or scan the QR code:

/togetherforshortlives @togetherforshortlives @Tog4ShortLives

#TFSLConference

Helen & Douglas House

your local children's hospice

Celebrating 40 years of Helen & Douglas House

Clare Periton

Chief Executive Officer

Beginning 1982

Helen House

1980s

Duchess opens happy hospice

HELEN House is vibrant with co our and sunshine . . . its love an happiness is practically tangible.

These were the feelings of t Duchess of Kent when she arrived Oxford to open the world's first hospi for chronically sick children.

In a short ceremony at the home Leopold Street, Oxford, today she unveile the placque and told Mother Frances — t nun who has spearheaded the campaign build the £½m hospice — that she had create something very special.

She said: "I understand totally your lo for children and feel very privileged, b humble, to be here with you."

The Duchess then made the day of thre year-old Catherine, sister of Helen, the litt girl who gives her name to the hospice.

Presents

After receiving a bouquet from Catherine the Duchess offered her a flower from it.

Picking the bigggest Catherine whispered "I'll give it to mummy to put in a vase."

After giving presents for the home and fo Helen's family the Duchess was then show round Helen House and was able to meet th eight children who are staying at the hospic as well as Helen.

She was introduced to many of the staf and builders who have made the project possible.

Also there to meet the Duchess was the Lord Lt. Sir Ashley Ponsonby and his wife, the Lord Mayor of Oxford, the Rev. Tony Williamson and his wife, and the nuns of All Saints' Convent where the hospice has been built.

Today's official opening marks the end of a two-year struggle to raise the money for the hospice.

The campaign began in August, 1980, when the nuns, who belong to the order of the Anglican Society of All Saints, launched the appeal.

Within a year they raised

The Rt Rev Patrick Rodger blesses the entrance of Helen House. Picture by Chris Love.

World's first hospice for children opens

by Jayne Belcher

he world's first children's hospice as been officially opened in Oxford.

The Helen House Hospice, in the rounds of All Saints Convent in eopold Street, Oxford, was blessed esterday by the Bishop of Oxford, e Rt Rev Patrick Rodger.

In a short religious ceremony he as asked by Mother Frances Domiica, who spearheaded the campaign, bless the building. He then went om room to room to give his blessg.

The opening marked a long, hard wo-year struggle to raise £500,000 for e hospice and furnishings and it eant a remarkable fund-raising feat.

The hospice, will provide a shortay home for up to eight chronically ck children.

The face of Mother Frances eamed with success and yet even she ould hardly believe the day had ome.

"I have not really had a chance to ink back on it all as we have been ipping over paint pots for the past w weeks.

"I'm just very thrilled and more rateful than I can say to all the eople who helped. I look forward to aring for the children we have been lanning for," she said.

The bishop was also overjoyed at e event. "It's wonderful to see it in

Mother Frances

bricks and mortar. It has been in our hopes and prayers for such a time.

"I have been concerned with hospices for adults in my last diocese in Manchester and I know what a network of love and care they became. I am sure that is already the case for the Helen Hospice."

The idea for the hospice came afte Mother Frances nursed a brain-dam aged child called Helen from Abing don. She is now six and is expecte to come to the hospice for sho periods.

Her three-year-old sister Catherine who laid the foundation stone las October, was present at the cere mony.

The Lord Mayor of Oxford, th Rev Tony Williamson, and his wif were also among those present.

The hospice will be open to th public to wander around from toda until Tuesday. The first child is ex pected on November 15 and the Duchess of Kent is also due to visi at some stage to meet children and parents.

The campaign began in Augus 1980 when the group of nuns, The Anglian Society of All Saints launched an appeal for £400,000 t pay for the building.

Within a year they raised th money and a further £100,000 to pa for furnishings. It is estimated it wi cost £100,000 a year to run an already just over £¼m has been raise for future bills.

The long, hard fund-raising battle i from over as large sums of mone still have to be raised yearly to kee the building open.

- 1978 Helen is diagnosed with a brain tumour and the family meet Sister Frances
- 1980 The first meeting to discuss the building of the world's first children's hospice is held and fundraising starts
- 1981 building started and on 30th November 1982 Helen House opens

1990s

ears and the smiles

Duchess of Kent brings happiness to her 'other family'

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a nine minute programme after the ITN evening news. It showed her at a children's hospice in Oxford. It was extraordinarily moving.

The Duchess' work with children is, of course, nothing new, and as Patron of the National Society for Cancer Relief she has been involved with the work of hospices all over the country for several years. But until the programme not many people were aware of Helen House Hospice or of its heartrending, tireless work with children who are terminally ill.

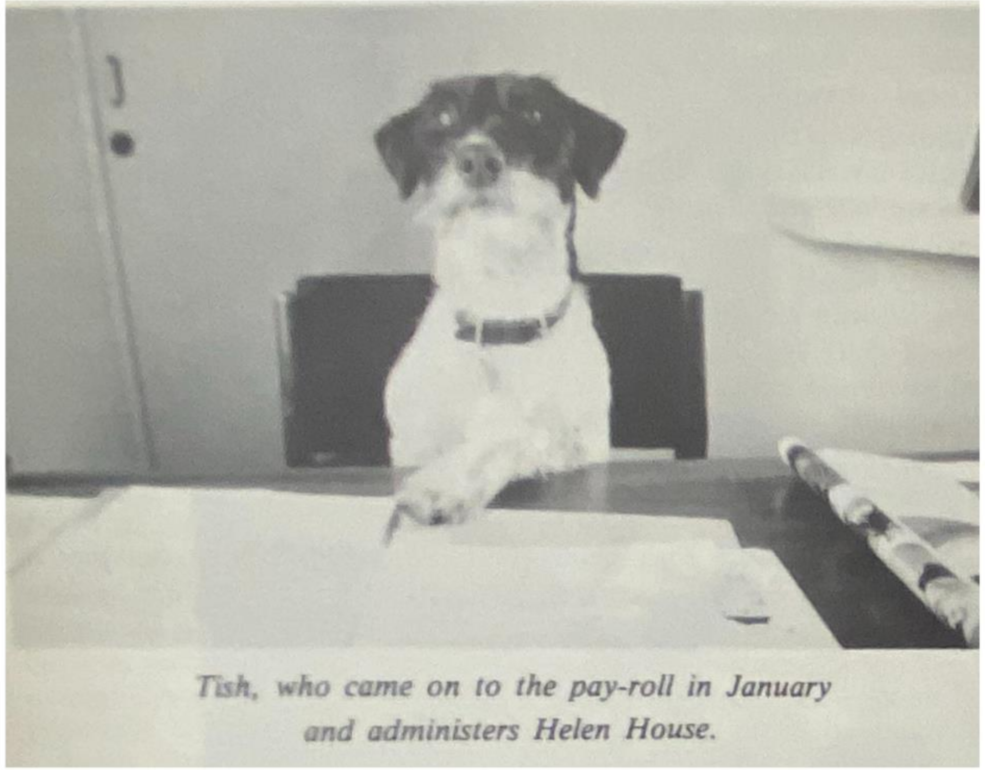
Suddenly, by the dramatic and powerful medium of television, people across the country were made aware of the needs of that institution – the only hospice for children in the world.

The Duchess herself came across as an extraordinarily concerned and caring woman, with a gentle ability to talk to and empathise with youngsters whose future can only be counted in weeks.

"I've been to so many hospices",

Although she has three children — the Earl of St Andrews aged 23, Lady Helen Windsor aged 21 and Lord Nicholas Windsor aged 15 – the Duchess, who married Prince Edward, Duke of Kent twenty-four years ago, had hoped to have a larger family. Tragically, eight years ago at the age of 44 she suffered a miscarriage. The resulting bouts of depression have, from time to time, forced her to withdraw from public life. She is no stranger to suffering and this manifests itself in an ability to communicate with and feel the suffering of others, particularly children. It is not an understatement when she says, "I'm not very robust".

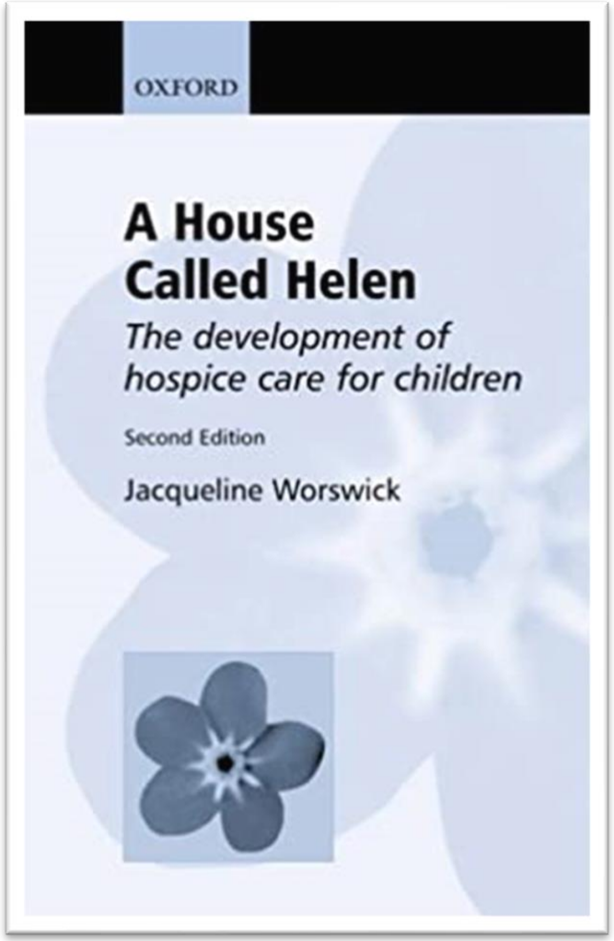
In spite of this the Duchess manages superbly. As well as her huge commitment to charity work, which includes her being a qualified Samaritan – she insisted on doing the training when she became Patron – she runs two homes (a working apartment in York House, St. James's and a Georgian House, Anmer Hall in Norfolk), is



Tish, who came on to the pay-roll in January and administers Helen House.

- During the 80s and 90s HRH The Duchess of Kent was our Patron and regularly visited.
- She gifted a Silver Cross pram which is still used in the hospice today
- Tish the scruffy mongrel, was a member of the Helen House team from 1983 - 1994

A House Called Helen



OXFORD

A House Called Helen

The development of hospice care for children

Second Edition

Jacqueline Worswick

- First edition 1993
- Second edition 2001
- Authoritative account of how Helen House came in to being
- Guiding philosophy of children's hospice care

Sharing the learning

> Dev Med Child Neurol. 1990 Apr;32(4):341-6. doi: 10.1111/j.1469-8749.1990.tb16946.x.

A survey of signs, symptoms and symptom control in 30 terminally ill children

A M Hunt [1]

Affiliations + expand

PMID: 2110086 DOI: 10.1111/j.1469-8749.1990.tb16946.x

Abstract

The notes of 30 terminally ill children with various diagnoses were searched for reports of symptoms that had occurred during their last month of life. All had stayed at Helen House, a hospice for children, for part or all of that time. The results were analysed for symptom frequency and resistance to treatment. Over four-fifths of the children were recorded as having pain in the last month of life. In a smaller number, symptoms such as muscle spasm and excessive secretions proved particularly difficult to control. The identification of symptoms in brain-damaged and young children, and the control of some of the more resistant symptoms, are discussed.

Decade	Sharing the learning
1980s	6 publications
1999s	2 publications
2000	1 publication
2010	18 publications
2020	15 publications so far….

2000s

Low-key visit boosts Douglas House campaign

CLINTON BACKS CITY HOSPICE

By Peter Unsworth

BILL Clinton rode into Oxford to support the Douglas House hospice campaign and won scores more friends among the young and old.

He showed that six months out of office had done nothing to reduce his popularity or his ability to win friends.

The private visit was heralded a great success by Sister Frances Dominica, founder of Helen House children's hospice.

The previous evening, he had been guest speaker at a fundraising dinner Chislehampton Manor. It is hoped the £4m project to build Douglas House, a hospice for young adults, will be one of the beneficiaries.

During his visit, he made an impassioned plea for governments worldwide to support the work of hospices. He said: "What we see here will be the norm one day. Today Helen House and Douglas House are at the cutting edge."

A 30-minute scheduled visit stretched to almost an hour and a half, delaying his trip to Chequers for lunch with the Prime Minister, Tony Blair.

As his motorcade left the hospice grounds in Leopold Street, east Oxford, he ordered his car to stop so that he could talk to residents.

"I'll be back," was his parting shot. From the Comeback Kid, that was undoubtedly a promise.

● Clinton insists on a scene – Page 3

the former US president a hug

Picture: Andy Cooper

ROYAL VISIT

Queen's visit the crowning glory for Douglas House

Cheering welcome for royals

The Queen officially opened Oxford's Douglas House respite centre on a visit to the county yesterday. **Victoria Owen and Alfred Artley** report

THE Queen's visit to Douglas House was described as the crowning glory for dedicated staff and fundraisers who worked hard to ensure the respite centre became a reality.

Dozens of guests, from young people to celebrities, were invited to yesterday's event, and many more braved the cold outside to catch a glimpse of the royal party as they arrived.

Sister Frances Dominica, founder of the house for 18 to 40-year-olds, was overjoyed the 50-minute visit went smoothly.

She said: "It was lovely. Her Majesty seemed genuinely delighted. She understood what a need there is for this group of young people and how that need *just* isn't being met.

"She was impressed by many things, but most of all the thing she enjoyed was meeting the young guests."

The Queen arrived at Douglas House, in Magdalen Road, east Oxford, at 11.30am, cheered by about 50 people waiting behind barriers in the street and welcomed by elderly residents from St John's home.

Two-year-old Jimmy Gladwin was left beaming as she thanked him for presenting her with a bouquet of snowdrops.

Elizabeth Shuray, a gardener at St John's, had already had a hectic morning when the Queen arrived, after taking part in an emergency operation to cut holly tree branches which kept snagging the Royal Standard.

Her hard work was rewarded by Prince Philip, who joked with her about the weather.

Ms Shuray, 54, said: "It's such a glorious moment for the residents. They were really looking forward to it."

Once inside the house, the Queen shook hands with dignitaries, including city councillor Val Smith and her husband, Work and Pensions Secretary Andrew Smith MP, before being given a guided tour and meeting young guests and their families.

Robert Heywood, 20, of Carterton, generated howls of laughter during his conversation with the Queen in the music room.

He said: "I just said that my idea for Douglas House was to include a bar and she said it was very important!"

Valerie Bell, whose late son Douglas' name was used

Turn to Page 11

ALL SMILES: The Queen at Douglas House in Oxford

ANTAS SET TO SWELL CITY STR

Road, the Parks, St Cross Road and Holywell Street along the way. The route will be closed to traffic from 9am to noon. Hip-hop dancers from local group Dance Rhythms will get the Santas warmed up.

Fox FM drivetime presenter Adam Ball said: "I would like to thank everyone who has given up time to run, help and spend their Sunday morning supporting two great local charities."

As an incentive for runners to collect as much as they can, adult runners

- Our first shop opens in Oxford
- Bill Clinton & Sir Trevor Macdonald help raise money to open Douglas House
- HRH The Duchess of Cornwall becomes Patron
- HRH The Queen opens Douglas House for young adults
- Our first Santa run in Oxford
- The Volunteering team was set up

2010s

- Our first inhouse Medical Consultants were appointed
- Our siblings are invited to 10 Downing Street
- The Helen House garden is turned into a beach for a child's last wish
- We were awarded the Queen's Award for Volunteering



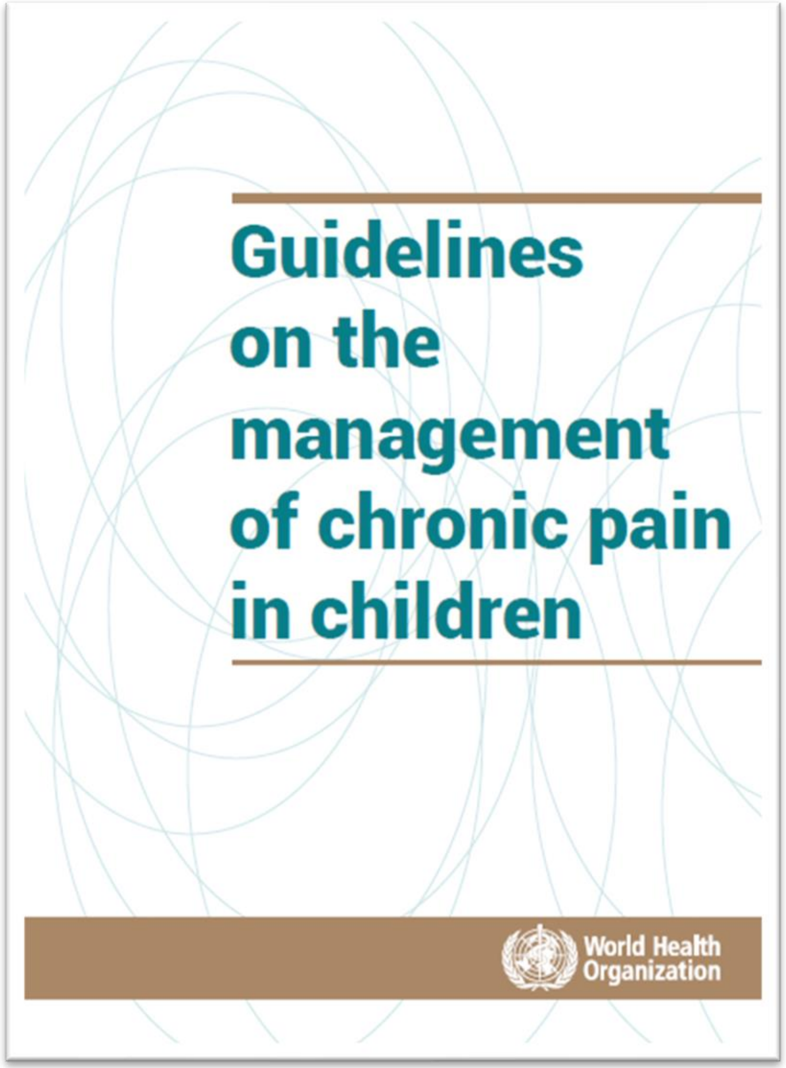
Contributing to Guidance

Helen & Douglas House
your local children's hospice

Visual summary: End of life care for children and young people

World Health Organization

NICE
National Institute for Health and Care Excellence



Guidelines on the management of chronic pain in children

World Health Organization

2020s

- We delivered hampers to our families packed and delivered by our wonderful volunteers
- COVID struck but the hospice stayed open to care for children
- HRH The Duchess of Cornwall kept in touch with us through zoom calls and visited our new garden

Helen & Douglas House
your local children's hospice

40 years

40 years of
world class
hospice care
for children
1982-2022

What does it mean to all of us?

Palliative care has been accepted as a basic Human Right for Children by the United Nations

Thank you!

See you tomorrow for day two

/togetherforshortlives @togetherforshortlives @Tog4ShortLives

#TFSLConference