

Association for
Paediatric
Palliative
Medicine

Online Catalogue of Posters
presented at the APPM Conference
16-17 November 2023 - Part 1

There are 33 posters in all. If you wish to contact the author, please email
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1

**STaRS (Siblings Together are Really Stronger)
Research Study**

**Dr Helena Dunbar
Director of Service Development**

Together for Short Lives

When my sister's
bed is empty ↓



↑ bad dreams
for me

Sometimes I have
to leave school

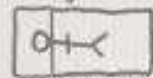


to take my brother
to hospital



Anxious about
my brother

At night my
sibling sometimes



goes to hospital
suddenly and I
get scared

STARS PROJECT

Siblings Together are Really Stronger

Dr Helena Dunbar

Director of Service Development Together for Short Lives,
Honorary Senior Research Fellow De Montfort University



Context: Siblings of children with life-limiting conditions (LCC) are sometimes overlooked – their experiences rarely explored. However, evidence suggests they have concerning vulnerabilities compared to their peers, i.e. more prone to mental health, learning and social difficulties¹. These vulnerabilities can escalate in teenage years, putting them at increased risk of social exclusion and disadvantage in adulthood².

Study aim: To explore, through the lens of siblings of children with life-limiting conditions, how they wanted to promote their own welfare and wellbeing and give them an opportunity to highlight their concerns, worries, needs and requirements.

"I have responsibility at home alongside homework; my routines have to work around my brother and sister"

Methods: Qualitative participatory methods were used to explore the experiences of nine LCC siblings, aged 9-14 years. Data was gathered via creative activities, combined with conventional focus group questioning. Wellbeing and resilience psychometric data was also collected.

Results: The participants described how they coped resiliently with family adversity and caring responsibilities. They struggled with the reality of how different their lives were to their peers. They also worried about their sibling when they were very sick or in hospital. It was during these times they often felt unsupported and anxious because their parents needed to prioritise their sick sibling.

"I think about things that probably my friends got to do as a child but maybe I didn't."

They reported that one way to make their lives easier would be if their schools had a better awareness of their challenges, so they could receive the learning assistance required.

Conclusion: STARS findings cannot be generalised to a larger population of LCC siblings; however, the findings provide insight into their unique difficulties. The worthiness of exploring more widely these children's needs is highlighted, so they are no longer overlooked.

2

**Audit of preferred place of death in a tertiary
children's hospital**

**Adrienne Rushton
Lead Nurse**

**Dr Jessica MacWilliams
Paediatric Palliative Care Consultant**

Alder Hey Children's NHS Foundation Trust

Audit of Preferred Place of Death (PPD) vs Actual Place of Death (APD) in a Tertiary Children's Hospital

Adrienne Rushton, Lead Nurse, Palliative and Bereavement Care

Background

In January 2020, the Care Quality Commission (CQC) recommended an annual audit of preferred place of care for patients known to the Alder Hey Specialist Palliative Care Team (SPCT). The SPCT look annually at the deaths of children known to the team to identify what proportion of those children died in their preferred place of care and if they didn't die in their preferred place of care, why this might be the case.

Aims

- To identify the preferred and actual place of death of neonates, infants, children and young people known to the SPCT.
- To explore any themes when children do not die in their preferred place of death and identify steps to improve this.

Methods

The SPCT maintain a log of the PPD and APD of all children they support. Records were examined for a 3 year period between January 2020 and December 2022.

Findings

- Over 3 years, the mean % of children who died in their PPD was 79.7%
- Over 3 years, of the 16 patients with an unknown PPD, 62.5% were too sick to move and be offered choice, 25% were unexpected deaths and 12.5% had no record of a PPD
- Numbers of deaths in 2022 were proportionately higher after a 2 year period of stability
- Over the 3 year period, deaths from malignancy were stable whilst non malignant deaths increased each year
- Referrals to SPCT increased year on year, more than doubling from 30 to 65 p/year

Conclusion

- Alder Hey is unable to offer home as a PPD for discontinuation of invasive ventilation
- Solutions to this barrier would offer real choice in PPD
- Early discussions about PPD should lead to a reduction in the number of children where the PPD is unknown

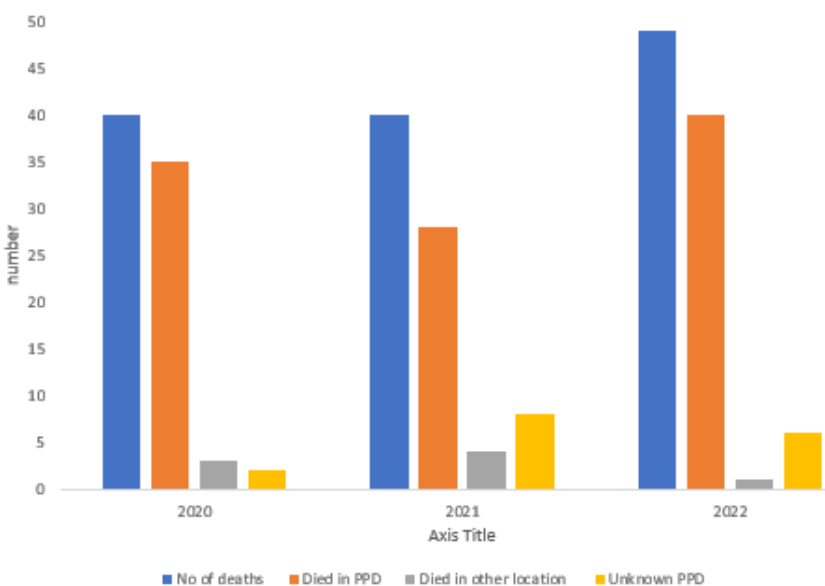


Figure 1: Preferred place of death and outcomes

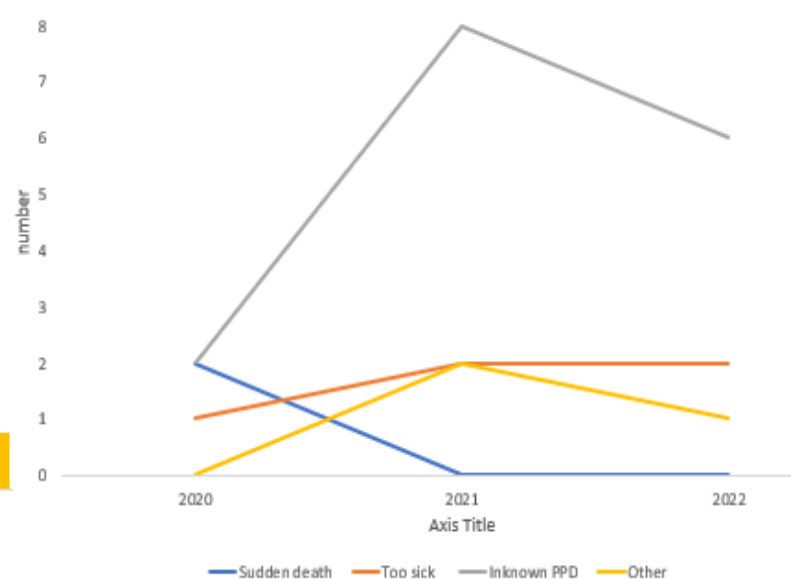


Figure 2: Reasons unable to fulfil PPD

References:

Care Quality Commission. (2020) Alder Hey Children's NHS Foundation Trust Inspection Report. Available at <https://api.cqc.org.uk/public/v1/reports/adcfba60-7c2d-43f6-9d93-f7792b1ceb77?20210113011646> (Accessed 7 November 2023)



3

**Review of Specialist Palliative Care Team
Systems for Recording Patients' Advance
Care Plans**

**Dr Melissa Mok
Paediatric Palliative Medicine Registrar**

**Dr Jessica Clarke
Paediatric Palliative Medicine Registrar**

Alder Hey Children's NHS Foundation Trust

Review of Specialist Palliative Care Team Systems for Recording Patients' Advance Care Plans – A quality improvement project (QIP) in a UK tertiary paediatric hospital

J Clarke, M Mok, S Holt

Background

The CQC 2018 report for Alder Hey identified that many Advanced Care Plans (ACP) were out of date and difficult to access, leading to a risk of suboptimal patient care. The Specialist Palliative Care Team (SPCT) devised changes to the system for all stages of advance care planning including electronic storage.

The aim of this QIP was to determine compliance to the implemented ACP system.

Methods

This regional audit retrospectively reviewed all patients in the SPCT workload with an ACP. The date of the latest ACP was identified and evidence of a review in the past 12 months was reviewed. Electronic Healthcare Records (EHR) were checked for an ACP. Paediatric secretaries for patients out of area were contacted to review local notes and identify if 1) the ACP was available, and 2) the most up to date version was available.

Conclusion

This audit demonstrated suboptimal compliance in all domains (Figure 1).

Recommendations

A new standard operating procedure for completing ACPs highlighting the following tasks:

- 1) Identifying a responsible clinician who will review and make any necessary updates to the ACP on an annual basis (if required).
 - 2) Ensuring new or updated ACPs are uploaded to EHR and that any existing outdated ACPs are archived.
 - 3) Ensuring that updated ACPs are sent to local hospitals if the patient has shared care with more than one hospital or other health provider.
- A repeat audit cycle is required following implementation of these recommendations to ensure improved compliance with the standards.

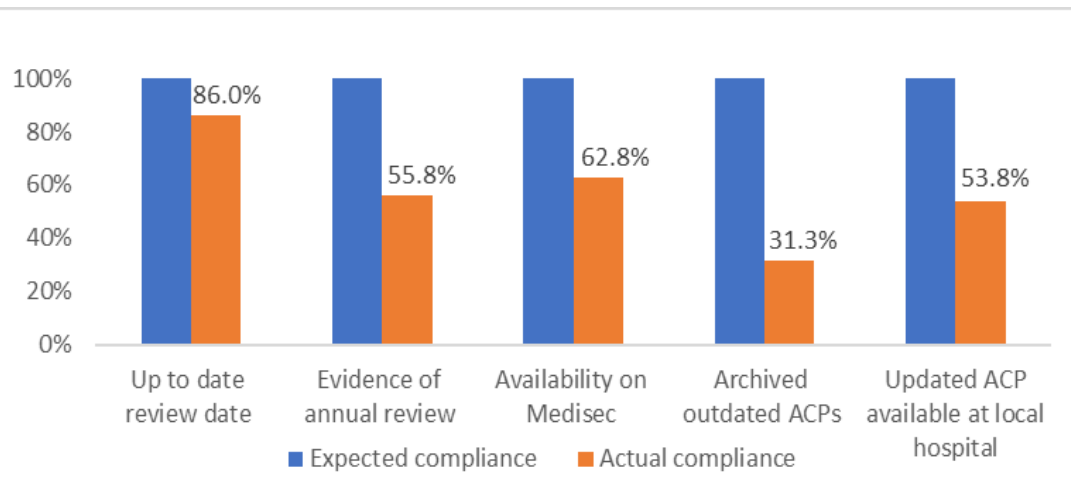


Figure 1: Compliance to ACP system

References Jenkinson, Carolyn (2018) *Alder Hey NHS Foundation Trust Inspection Report (06/02/2018)*. Care Quality Commission. [Provider section - RBS Alder Hey Children's NHS Foundation Trust \(06/02/2018\) INS2-4548378347 \(cqc.org.uk\)](#)



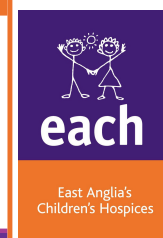
**Supporting Junior Researchers in Children's
Hospices: The Research in Hospices (RiH) Group**

**Dr Aneita Pringle
Research Lead
Shooting Stars Children's Hospice**

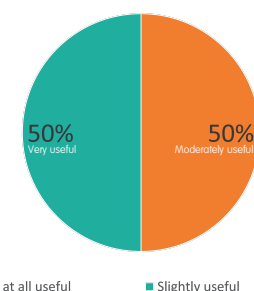
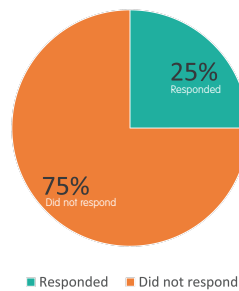
**Siobhan Butler
Research Nurse
Helen & Douglas House Hospice**

**Louise McLaughlin
Research Nurse
East Anglia Children's Hospice (EACH)**

The development of the Research in Hospices (RiH) group: Supporting junior researchers in children's hospices



Authors	Affiliations
Aneita Pringle .1 Siobhán Butler .2 Louise McLaughlin .3	1. Shooting Star Children's Hospices 2. Helen and Douglas House 3. East Anglia Children's Hospices
Background	Aim
Little research is undertaken in children's hospices due to various (lack of research governance, indemnity arrangements, research taking place in silos). Recognising these barriers and leveraging connections made through CoPPAR, this led to the development of the Research in Hospices (RiH) group. The group began in October 2022, and has grown from 3 members to 18. Attendees include professionals such as Research Managers, Heads of Care, Medical Directors, Research Associates, and Research Nurses. A survey evaluation was conducted June-July 2023.	To describe the impact of the RiH group for junior researchers and develop Terms of Reference.
Methodology	Results
<ul style="list-style-type: none"> A Microsoft Forms survey was distributed to 18 members of the RiH group. Questions included both multiple-choice as well as open-text questions Items related to (1) to preferred format of the group (meeting frequency, virtual versus face-to-face, length of meeting, etc), (2) benefits and usefulness for attendees, (3) ideas for future meetings and general feedback 	<ul style="list-style-type: none"> 6 participants completed to the survey (Figure 1). All participants reported the group as being moderately or very useful (Figure 2). The Terms of Reference were developed and discussed with the group. The final version was approved in September, 2023.



Results: Part 2

Reported attendee benefits:

- "It's ... beneficial to be able to share tips on managing studies and approaches to governance etc."
- "I feel that mutual support is the greatest benefit."
- "Good to make contacts that I feel I could call on for help."
- "Good source of networking and platform to discuss current projects."

Feedback received and acted on:

- "To share any conference/event dates at meetings or via mailing list"
- "We have shared a conference calendar to ensure awareness of opportunities."
- "Good to have time for questions and to talk with the group."
- "We set aside time at the beginning and end of each meeting to discuss concerns, bring topics of interest, and seek support."

Conclusion

- The RiH group fills a gap for junior researchers and children's hospices to become research active and support each other to build research capacity.
- Attendees report the group is useful and has benefits in terms of networking, supporting governance processes, and sharing resources and learning.
- Terms of Reference have been agreed upon and hosted on a closed Facebook group, "Research in Hospices (RiH) Group" (scan QR code)
- While the group has demonstrated a positive impact for attendees, maintaining sustainability is a priority.



If you are interested in joining, please get in touch with us aneita.pringle@shootingstar.org or sbutler@helenanddouglas.org.uk.

5

**Palliative Care Referral Tool for Babies, children
and young people receiving home parenteral
nutrition (HPN)**

**Dr Cathy Osborn
Clinical Fellow**

**Dr Emma Heckford
Palliative Care Paediatrician (supervisor)**

Children's Hospice South-West – Charlton Farm Hospice

Palliative care referral tool for babies, children and young people receiving Home Parenteral Nutrition (HPN)

Dr Cathy Osborn
Dr Emma Heckford
Dr Tony Wiskin
Lizzie Hutchinson (2023)



Background

- ☹️ HPN is the mainstay of treatment for babies, children and young people (BCYP) with intestinal failure
- ☹️ Although HPN comes with a risk of health complications and premature death, not all BCYP on HPN are expected to die in childhood (usual criteria for hospice referral).

Goals

- ☹️ Eligibility for hospice services in this group can be difficult to define
- ☹️ As yet no tool to help standardise decision-making
- ☹️ To provide a framework to inform decisions about life expectancy for those on HPN that can be applied fairly and equitably
- ☹️ To ensure that hospice resources are used in the most appropriate way.

How?

- ☹️ Local expert consensus opinion (CHSW and UHBW paediatric gastroenterology)
- ☹️ Literature review
- ☹️ Local data.

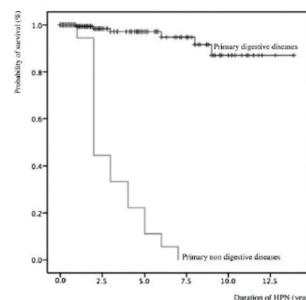


Evidence

French study - retrospective study of 251 children receiving HPN between January 2000 and December 2013

- ☹️ 86% had a Primary Digestive Disease (PDD) and 14% had a Primary Non Digestive Disease (PNDD)
- ☹️ Outcomes at end of study:
52% weaned off PN 34% still receiving PN
10% had died 7% had intestinal transplantation (all in PDD group)
- ☹️ BCYP most likely to wean = Short Bowel Syndrome (SBS) or IBD
- ☹️ In SBS the longer the bowel length the more likely the child was able to wean
- ☹️ For those weaned off HPN, mean duration was 1.9 +/- 0.4 years
- ☹️ Major morbidity factor was Intestinal Failure Associated Liver Disease
- ☹️ Death rate was significantly higher in children with PNDD (18/34 PNDD died compared with 6/217 PDD).

The graph shows the survival curves of children with primary digestive and non-digestive diseases



References: 1. Nader et al. Outcome of home parenteral nutrition in 251 children over a 14-y period: report of a single center. The American Journal of Clinical Nutrition, Vol 103, Issue 5, May 2016, Pg 1327-1336
2. Colomb et al. Long-term outcome of children receiving home parenteral nutrition: a 20-year single-center experience in 302 patients. Journal of Pediatric Gastroenterology and Nutrition. 44(3):p 347-353, March 2007
3. Wiskin et al. Prevalence of home parenteral nutrition in children. Clinical Nutrition ESPEN. 42 (2021) 138-141

Vulnerability factors

2 or more red/orange factors or answer to final question being 'yes' would predict hospice referral acceptance.

Underlying diagnosis (and therefore likelihood of premature death)

- ☹️ Primary digestive diagnosis only (NB prognosis with short bowel increases with length of functioning bowel)
- ☹️ Primary digestive diagnosis but with specific poor prognostic factors for weaning from HPN (such as extremely short bowel, pseudo-obstruction)
- ☹️ Primary non digestive diagnosis (immune deficiency, metabolic disease, cancer).

Co-morbidities

- ☹️ Minor co-morbidity (such as well controlled epilepsy)
- ☹️ Moderate co-morbidity but not meeting eligibility criteria in its own right (such as wheelchair user, child with significant neurological impairment)
- ☹️ Complex/severe co-morbidity or co-morbidities meeting hospice eligibility criteria in its/their own right (expected to die before the age of 18).

Likelihood of weaning from HPN

- ☹️ HPN currently weaning
- ☹️ Likely to wean off HPN
- ☹️ Unlikely to wean off HPN
- ☹️ Likely HPN-dependent for life.

Current/previous complications from HPN

- ☹️ None
- ☹️ Catheter-related bloodstream infections
- ☹️ Extensive vascular thrombosis
- ☹️ Intestinal Failure-associated Liver Disease (IFALD)
- ☹️ End stage liver disease
- ☹️ Awaiting intestinal transplantation.

Venous access

- ☹️ First central venous access or many alternative options available
- ☹️ Previous central venous access but several alternative options available
- ☹️ Minimal/no alternative access options available.

Hospital admissions

- ☹️ Infrequently in hospital/only admitted for elective procedures
- ☹️ Some hospital admissions but returning to baseline health in between
- ☹️ Frequent hospital admissions with overall declining health
- ☹️ Multiple/prolonged unplanned admissions including to HDU/intensive care.

In light of the factors above, would you be surprised if the child was still alive at the age of 18 years?

6

**Sunflower Course - Bringing end of life care
teaching to trainees**

**Dr Anne Haddick
Paediatric Registrar**

Belfast Trust



Sunflower Course- Bringing End-Of-Life-Care Teaching to Trainees

Haddick, Rafferty, Stefkova, Barber, Gosling, Richardson. Royal Belfast Hospital for Sick Children

Background

End-of-life care medicine is practiced in all specialities throughout paediatrics. The importance of delivering effective care to children and their families at their end-of-life is paramount. However, in Northern Ireland trainees get little experience and limited teaching in this field.

Aim

This project aimed to teach a comprehensive course to help trainees develop the skills they need when delivering end-of-life care. Therefore, having the ultimate aim to improve the delivery of palliative care in Northern Ireland.

Method

We recruited a team of enthusiastic paediatric trainees, and we were led by our Head of School in Paediatrics.

We researched topics that were pertinent in delivering effective end-of-life care.

We delivered these through a variety of methods via zoom due to covid restrictions. This was taught over a 3 day period to allow for comprehensive teaching in this important topic.

We sent out emails and made posters which we advertised in hospitals and via email, welcoming any healthcare professional that cared for children to attend.

We sent out pre and post questionnaires via survey monkey to assess trainees knowledge before and after the course, and to evaluate any improvement on day 2 and 3. This was in the form of a 5 point 'LIKERT' scale.

Topics Covered included

- Communication skills such as breaking bad news
- Advanced Care Plans
- Bereavement Support
- Hospice Services
- End-of-life Symptom Control
- Practical sessions such as setting up a syringe driver.

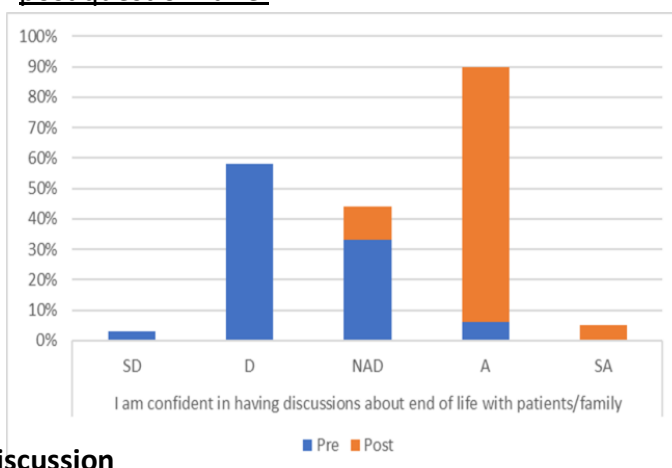
Results

We had feedback from all days of the courses. However, we only had enough data for pre and post course feedback on day 2.

Written feedback on day 1 included 'This course has been incredible!', 'very useful and so much learning from it', 'inspiring teaching session-I learnt so much and hope I can be a better doctor now for patients and their parents in these situations.'

On day 2 there were 55 participants that attended. 33 completed out the pre-questionnaire and 19 filled out the post questionnaire.

Graph showing the improvement in confidence in having discussions about end-of-life care pre and post questionnaire.



Discussion

The results clearly show that there have been improvements in participant's knowledge in understanding and delivering end-of-life care after the course.

Most participants either disagreed or strongly disagreed in their knowledge or confidence in each topic taught. This then improved to either agreed or strongly agreed after the course.

Conclusions

End-of-life care is practiced in all aspects of paediatric medicine, therefore the skills and knowledge to carry this out are essential.

This 'Sunflower Course' has helped improve Northern Ireland trainee's knowledge and ability to provide a better quality of care for patients at end of life. We aim to continue this course every 3 to 4 years and make the improvements that have been suggested



7

**Identification and exploration of the perception,
experiences and needs of key stakeholders to
develop PPCEP for nurses**

**Piyatida Theppradit
PhD Student**

**School of Nursing & Midwifery,
University of Birmingham**

The missing piece of paediatric palliative care in Thailand

Identification and Exploration of the Perception, Experiences and Needs of Key Stakeholders to Develop Paediatric Palliative Care Education Programme (PPCEP) for Nurses



Piyatida Theppradit¹, Dr. Susan Neilson², and Professor Cara Bailey³

¹ PhD candidate ² Associate Professor ³ Professor of End of Life Care School of Nursing and Midwifery, Institute of Clinical Science, University of Birmingham, United Kingdom

INTRODUCTION

The first National Health Act on palliative care was launched in 2007 but not integrated within the health care system [1]. Thirteen years later in 2020, a palliative care policy was introduced and tried to integrate palliative care services into every health care sector. There is lack of PPCEP and there are only three courses, cannot cover all content [2-4]. There is very limited in the South.

AIM

To explore the perception, and experience of nurses, oncologists, social worker, psychologist, educators; and identify the need of education programme in order to develop PPCEP for nurses in the South.

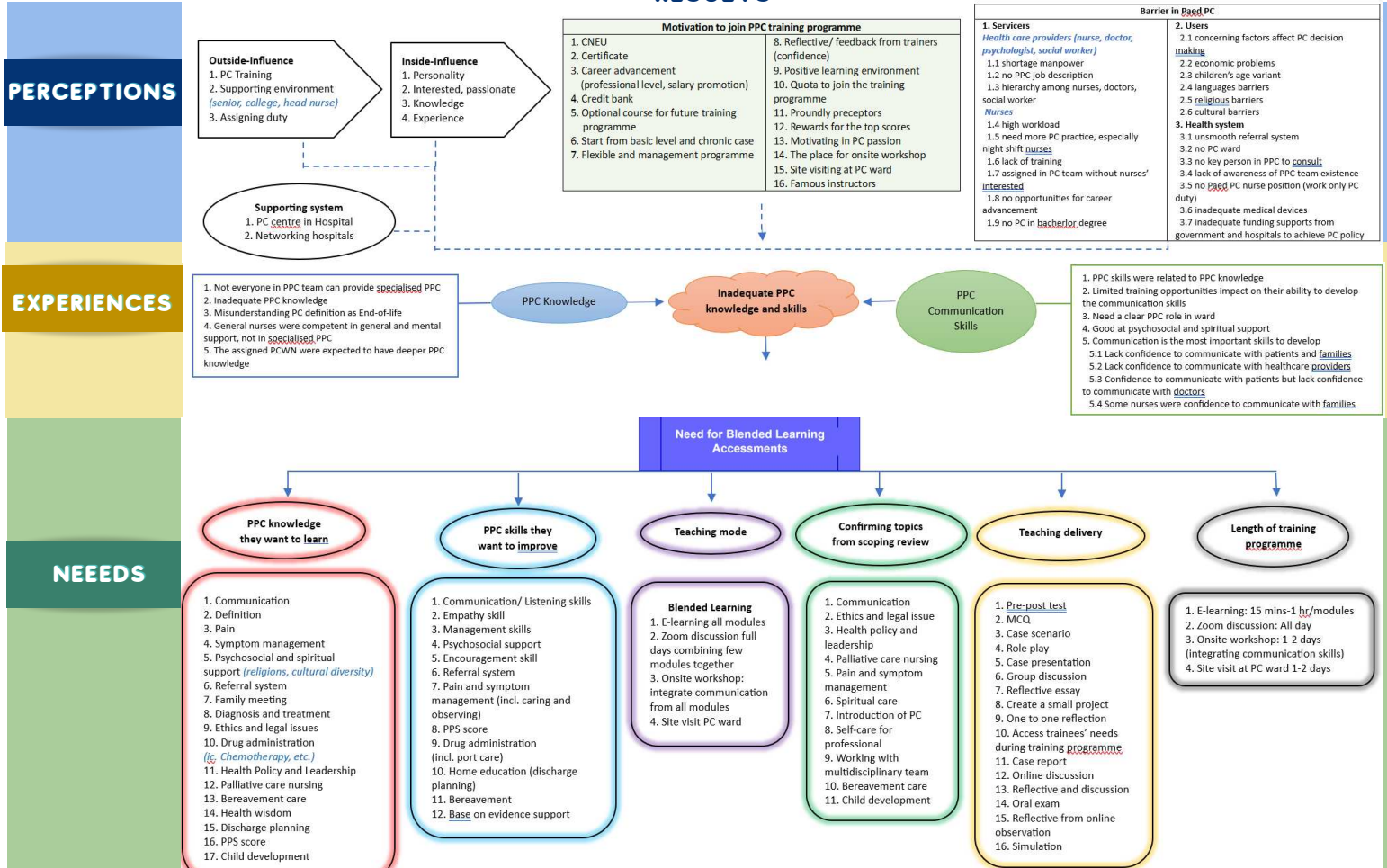
METHODOLOGY

This was an online In-depth Interview via Zoom. Data was transcribed verbatim and uploaded into the Nvivo version 2020 software programme for coding and analysing. The qualitative data analysis was undertaken using descriptive statistics and a six-phase framework for thematic analysis following Braun and Clarke's (2006).

CONCLUSION

The study has identified the missing piece of paediatric palliative care education in Thailand through stakeholder interviews. Nurses lack confidence in paediatric palliative care, particularly around emotional aspects of their work, culture, competence, and respect for dying work. They feel inadequately prepared to deliver quality care despite the increasing need for high quality palliative care. The study provides a framework for a blended learning PPCEP capturing the educational needs of nurses in order to develop their knowledge, skills and confidence for taking care their patients and their families.

RESULTS



<p>1. Experiences</p> <p>PPC Knowledge and skills</p> <p>1.1 PPC knowledge 1.2 PPC skills</p> <p>"Some nurses might think that when patients are diagnosed in the palliative care phase, there is nothing to do for those patients and no treatment. (...)" (Nurse2)</p> <p>"So, their knowledge is inadequate, and they did not have a chance to learn it as it is not a compulsory training program they had to pass. (...)"</p> <p>Among 10 nurses, only 2 were more knowledgeable than others (...)" (Nurse1)</p> <p>"We do not know it well. We had no such course when we studied for a Bachelor's degree." (Nurse7)</p> <p>"They scared, I used to ask them and they said they scared. If palliative care nurses are away, they scared to discuss about child's death with their mothers. They dare not evaluate the relatives, dare not ask questions that would hurt them, make them suffer and more grief. (...)" (Nurse1)</p>	<p>2. Perceptions</p> <p>Barriers, Influences, support systems</p> <p>2.1 Barriers in PPC 2.2 Influences in PPC 2.3 Support systems in PPC</p> <p>"[...] It is like they are not paying attention and overlook paediatric palliative care. We don't know how to manage and when we consult them it seems they are not confident in paediatric medication dose." (Nurse4)</p> <p>"I think culture has a big impact on our working style. In Thailand, the working culture is the nurse waiting for the order from doctors despite the fact that some nurses are so competent they can decide to increase pain killer drug dosage or they express their disagreement on some doctor's orders. (...)" (Doctor1)</p> <p>"Is it better than before? yes, it is, but not equally in every area. For example, 1 province is very active in referral palliative care cases. They keep us updated with the information of the child and take care of them spiritually such as inviting monks to pray for the child in palliative care at home. But in some areas, we can get the contact person at the beginning, but later we never get any update or any inquiry about palliative care. So, we have to communicate with the relatives instead. (...)" (Nurse3)</p> <p>"To be honest, no one in our ward apply to be paediatric palliative care nurse. So it necessitates to set the key person." (Nurse8)</p>	<p>3. Needs</p> <p>Co-design PPC Education Programme</p> <p>3.1 Multi dimension of learning 3.2 Space for emotion work 3.3 Learning from others (Leaders, peer supports, patients, relatives, discussion, reflection) 3.4 Motivation to join PPC Education programme</p> <p>"I think we should have e-learning lessons for self-study and then take it to on-line Zoom discussion. Then we have on-site training so that we can practise the knowledge we have learned. I think this is the way we can get the best out of this module." (Nurse3)</p> <p>"Advantages of an onsite learning platform, it would be great for attendees who can do workshops, role-play, group discussions or site visits palliative care ward in person." (Nurse2)</p> <p>"The onsite session at the end of the programme should be set around one week, I think 2-3 days it not enough for making connections and reviewing critical necessary knowledge and skills of paediatric palliative care summarisation and site visits at palliative care ward. (...)" (Nurse8)</p> <p>"Right, make it practical and simplify it, engage them, and don't let them go." (Educator2)</p>
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Contact: Piyatida Theppradit (Best), pxt924@student.bham.ac.uk



REFERENCE

[1] Thai Palliative Care Society (2016) *Palliative Care Handbook*. Bangkok: beyond enterprise.
 [2] Karunruk Palliative Care Center (2020) *Basic Certificate Course in Palliative Nursing (BCCPN)*. Available at: <https://karunruk.org/home/index.php/training2020/110-bccpn2020> (Accessed: 10 January 2022).
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 [4] Queen Sirikit National Institute of child Health (QSNICH) (2022) *paediatric palliative care*. Available at: http://www.childrenhospital-training.com/images/stories/train85/10_65/01_10_65.pdf (Accessed: 10 January 2022).

8

'It's brilliant! It's working! It's needed!' An Adult Hospice Short Break Innovation for Young Adults

**Helen Finlinson
Head of Inclusion and Development
Lead for Zest Transition and Young Adult
Palliative Care Service**

St Elizabeth Hospice

An adult hospice short break innovation for young adults

Author: H Finlinson, St Elizabeth Hospice

Introduction

A lack of short break provision after transition from children's hospice care has been described by families as like "falling off a cliff edge" (Together for Short Lives, 2015).

In response to this unmet need, St Elizabeth Hospice co-designed a pilot short break service with young adults and families - Zest Short Breaks.

The aims of the pilot were to provide weekend short breaks for two young adults at a time, in the hospice day unit which was not being utilised at weekends.

Aim

- To identify the outcomes and benefits of the service for young adults and their families
- To capture feedback to enable learning and evaluation of the new provision
- To explore the experiences of staff, including skill mix, training and support needs
- To scope the financial and service delivery implications to determine the future of the service

Method: A Service Evaluation

The evaluation process was iterative to enable improvements to the delivery model during the pilot period, as well as afterwards.

- Service user feedback
- Patients, parents/guardians and siblings
- Semi-structured questions
- Options of interview or questionnaire
- Staff feedback
- Facilitated by volunteer to enable anonymity
- Focus groups during the pilot
- Semi-structured interviews or questionnaires at end of pilot



Results

Pilot participants
15 young adults & families
18-28 years old, 9 x males, 6 x females
Majority had profound learning disability and used non-verbal communication
60 short breaks delivered (2-6/family)
All remain engaged, 1 expected death.

Service evaluation participants
10 families
3/4 cognitively able YAs (18-27yrs, 1x female, 2x males)
6 x Siblings representing 5 families (12yrs-early twenties)
10 x Parent/guardians (5x males, 5x females)
Staff - 11 x participated in focus groups during, -8x end of pilot feedback

Patient Feedback

"What I got out of it was what I wanted - to build up my independence and confidence, and a bit of fun as well!"

All three respondents had not accessed short breaks in adult care before. They were dependent on their parents for all their needs and had minimal experience of external care.

- All participants rated their experiences of short breaks as 'good' or 'excellent'
- Two said they now felt 'very confident' about taking part in short breaks and one felt 'fairly confident'

All participants highlighted the value of the service in providing:

- A break from parental care and being at home
- The opportunity for socialisation with other young adults
- Confidence building outside the family home

Areas for improvement:

- Develop facilities to reflect the younger age and complex needs of young adults
- Enable time for staff to be familiar with complex care needs
- Transport provision to enable flexible activities and outings



Staff Feedback

A service evaluation found staff:

- Felt highly motivated
- Were well supported in their roles
- Experienced job satisfaction associated with perceived benefits of the service
- Valued being part of the co-production of the new service from the beginning

"Getting such positive feedback from the parents. They put their trust in us to look after their children and to know that we have created this service for them is wonderful." (Staff member)

Key enablers:

- Importance of nurse led care and the need for high care ratios
- Benefit of the skill mix, including paediatric nurses, those recruited with complex care experience
- Experiential learning over time enabled confidence growth was evident

Parents / Guardians Feedback

Overall parents/guardians praised the standard of care received and provided positive feedback:

- Eight out of 10 rated their experience of short breaks as 'excellent'
- All parents/guardians said they were 'confident' or 'very confident' about the care provided
- Every parent/guardian wanted to continue to access the service
- Every participant would recommend the hospice short break service to families with similar needs

"As parents we have faith and trust in the service." (Parent)

Spending time with other children was the highest rated benefit:

"To be able to be mum to my other children who do unintentionally take a backseat too often." (Parent)

"It's brilliant. It's working. It's needed."

Conclusions

Limitations:

- Limited narrative voice of young adults due to nature of complex needs
- Due to time limitations, longer term benefits of service not possible to be evaluated

Implications for practice:

- Persuasive evidence for service to continue and that it is possible for an adult hospice to meet complex care needs of young adults
- Short breaks need to be enjoyable for young adults to enable families to then benefit from the respite they provide
- Co-production of services with families and staff is a key enabler for trust and confidence in service provision
- Service delivery and funding models should ensure adequate provision included for staff to have the time to:
 - learn individual care needs before providing care
 - prepare detailed care plans
 - have adequate handover times
- Services should be fully resourced to ensure personalised short breaks can be fulfilled successfully
- Quality commissioning is essential to the provision of meaningful short breaks, which can then enable families to access crucial respite support

Since the completion of the pilot and service evaluation, the Zest Short Break service has been commissioned and continues to provide valued support for families in Suffolk, with an ambition to become a regional provider for East Anglia.

Benefit identified by parents	Number of responses out of 10
Spend time with other children and family members	10
Break from the routine and time constraints of care	10
Re-charge batteries	10
Engage in a leisure activity	10
Physical rest	9
Time out for mental well-being	9
To enable opportunity for separation to reduce dependence on parent carers	9
To reduce the need for out of home placement	9
Spend time with friends	9
Spend time with partner	8
Time to reflect	8
Sleep	8
Break from the responsibility of care	8



Full Report

Full report can be accessed at:

www.stelizabethhospice.org.uk/zest/our-ambition/



Young adult hospice care

Part of the St Elizabeth Hospice family
Reg Charity No. 289154

Acknowledgements

A grant from Together for Short Lives enabled the funding of a Zest lead nurse to allow the short break service to develop.

With thanks to Dr Anna Spithis and the Cambridge Palliative and end-of-life care research group for their supervision and support.



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**The Use of Naloxegol in a Paediatric Oncology
Palliative Care Department for Management of
Opioid Induced Constipation**

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Naloxegol for the Management of Opioid Induced Constipation in Paediatric Oncology Palliative Care

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Introduction

Opioid induced constipation (OIC) is a common, well known side effect of opioid use. Opioids are frequently used to control pain and other symptoms, such as breathlessness, experienced by children with advanced cancer. Naloxegol is a peripherally acting Mu opioid receptor antagonist (PAMORA).¹ It combines with Mu receptors to inhibit the action of opioids in the GI tract, hence acting directly on the mechanism causing OIC.¹ It does not affect how opioids work in the brain or spine, enabling the GI tract to function normally while maintaining the pain relief functions of opioids.¹ Studies in Naloxegol for opioid induced constipation (OIC) have mainly been in adult non-oncology settings with limited paediatric case series' reporting on a mixture of peripherally acting mu- opioid receptor antagonists (PAMORAs) and in a paediatric intensive care setting.^{2,3} Naloxegol is recommended by the National Institute for Health and Care Excellence (NICE) and NHS Scotland as an option for the management of OIC in adults whose constipation has not responded to laxatives.^{4,5}

Aim: To collect data regarding the use of Naloxegol in our paediatric palliative care oncology population and to report any evidence of benefit and any documented side effects.

Method

A retrospective chart review was performed analysing data from all paediatric patients (<19y) with advanced cancer and receiving palliative care, from March 2017 to March 2023. Those patients on an opioid and had been prescribed Naloxegol for opioid induced constipation were included in the study. The assumption was made that OIC was a clinical concern since Naloxegol had been started. Benefit of Naloxegol was defined as having a bowel motion within 24hours of the administration of the Naloxegol and any recorded side effects (possibly) attributed to Naloxegol were recorded. Expected side effects, as per NICE guidelines, were abdominal pain, diarrhoea, nausea, headaches and flatulence.⁴

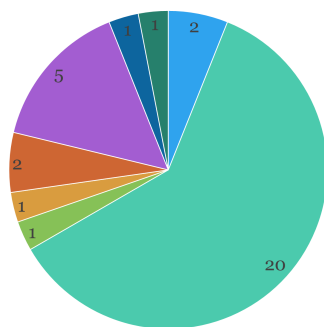
Results

A total of 144 patients with advanced cancer were identified over the time period. 38 of these children were found to have used Naloxegol.

- The sample included 21 girls and 17 boys. Mean age 11 years (4-18) on starting Naloxegol.
- 11 brain tumours, 21 solid (non-CNS) tumours and 6 haematological malignancies.
- 26 children had the number of days it took for their bowels to open after starting Naloxegol documented.

Fig 1. Laxative use once naloxegol started

- Additional laxative added at same time Naloxegol started
- Additional laxative added after Naloxegol started
- Additional laxative added at same time and then additional added after
- Dose of laxatives increased either at same as naloxegol started or after
- Laxatives added at same time as naloxegol, then dose of laxatives increased after
- Laxatives added after naloxegol and then dose of laxatives increased



Key Message

Our study is one of the largest paediatric cohort case series that has reported on Naloxegol to date. It demonstrates that Naloxegol is safe and potentially beneficial in a paediatric oncology population with advanced disease, when used in combination with other laxatives, for the treatment of OIC.

Key Findings

- 14(54%) children, who had the number of days taken to open their bowels documented, had them opened within 24h (range 0-6 days).
- An additional 8 had 'bowels opening regularly' documented after Naloxegol was commenced.
- Only 9(24%) children were deemed to have side effects.
- No correlation between the starting dose of Naloxegol and the oral morphine equivalent.
- Stepwise correlation between the starting dose of Naloxegol and age.
- Trend for those who were heavier to have had a higher starting dose of Naloxegol.
- 33(87%) children were already taking laxatives prior to commencing laxatives.
- 33(87%) children had a change to their laxative regimen at the same time as or after starting or at the same time as Naloxegol (Fig 1).

Discussion

- Naloxegol may be of benefit in children with advanced cancer experiencing OIC
- We report no additional side effects to adult studies.
- We were limited by the information that was documented in the notes about bowels opening.
- This study provides confidence in the use of Naloxegol in children with advanced cancer.
- Further guidance is required to support good paediatric prescribing practice.
- There needs to be further, prospective studies to support the efficacy, benefit and dosing of Naloxegol in managing OIC in paediatric patients.

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10

Regional Paediatric End of Life Transfer Checklist

**Dr Katherine Lang-Stevenson
Paediatric Registrar**

**Dr Carolina Perez
Supervisor**

**East of England Children's Palliative Care Managed Clinical
Network (Cambridge University Hospitals NHS Foundation
Trust, East Anglia's Children's Hospices and
Keech Hospice Care)**

Regional Paediatric End of Life Checklist

Dr Carolina Perez, Dr Amy Volans, Dr Linda Maynard, Sonya O'Leary, Dr Katherine Lang-Stevenson. In partnership with EACH and KEECH Hospices, the RAaFT team and East of England Children's Palliative Care MCN

Introduction and aim:

Following establishment of the Paediatric Palliative Care Specialist team (Regional Advice and Facilitation Team- RAaFT) in January 2022, it was identified that standardising communication, procedures and documentation for babies, children and young people (BCYP) needing end of life care in the community was essential for consistent, safe and effective care.

The aim of this study was to review the current checklists use by community and children's hospices across the region and to create a proforma which would unify regional practice (East of England).



Methods and results:

A review of the literature and current documentations from the children's hospices, (East Anglia's Children's Hospices-EACH and Keetch Hospice Care- Keetch,) was undertaken and core components were identified by key representatives from different organisations (EACH, Keetch and RAaFT). These were:

- o Reason for transfer, transfer location and lead medical professional identified.
- o Parallel planning and documentation.
- o Logistics: medications and equipment.
- o Actions on day of transfer.
- o Actions about care after death. Legal requirements and family wishes.
- o Additional information including safeguarding, infection control, family spiritual, religious or cultural needs.

The document was piloted between January 2023 and October 2023. During this period it was used on 10 occasions, 8 within Region transfers and two to receive a BCYP from a quaternary hospital outside the Region. On 1 occasion the transfer did not take place. A survey was distributed between September and October 2023 to those professionals who had used the End of Life Checklist to seek feedback what was helpful and areas for improvement.

Checklist:

Feedback:

"Used this in MDT for transfer of child from hospital to home. I send this to team in hospital in advance so they know what we are working towards before discharge."

"Helpful to show to other teams when prompting discussion around things which could be tricky such as who will order oxygen or who will do death certificate"

"Very useful, particularly with unexpected/urgent transfers."

"I love this document. EOL transfers are really stressful situations and the EOL checklist cover all the key aspects to provide a safe transfer. It also tries to standardize practice across the Region"

"Very recently it was used to support a rapid discharge home from tertiary EOL. Everyone knew what was or what needed to be done. It brought everyone together and clarified each professional's roles and requirements for safe discharge and parallel planning."

Recommendations:

1. Consider the needs of neonatal referrals (i.e postnatal care of the mother, specific equipment for this population) and those with LTV needs.
2. It works! Therefore encourage use across region.
3. Gain family experiences before/during/after the transfer to ensure their needs are captured in future checklist developments.

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11

The Value of On-Line Co-memorating Meetings as an approach to supporting the multi-agency network when a child dies.

Dr Amy Volans

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Managed Clinical Network (EACH, Keech, Little Havens
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The Value of On-Line Co-memorating Meetings as an Approach to Supporting the Multi-Agency Network When a Child Dies.

Dr Amy Volans, Consultant Clinical Psychologist and Family Therapist with the RAaFT Regional Advice and Facilitation Team East of England Children's Palliative Care Service (Cambridge University Hospital and Cambridge & Peterborough NHS Foundation Trust) working in partnership with the East of England Children's Palliative Care Managed Clinical Network. amy.volans@nhs.net

Aim:

To review staff experience, impact and outcomes of on-line "Co-memorating Meetings" as a format for providing support to multi-agency professional networks after the death of a child with palliative care needs.

Background:

NICE Guideline 61 on End of Life Care for Infants, Children and Young People with Life-Limiting Conditions (2016) includes a recommendation to *"Ensure that arrangements are in place for professionals to talk about their thoughts and feelings with colleagues when a child or young person they are caring for is approaching the end of life or has died"*.

There are multiple models for providing staff support and debriefing after the death of a child, all with limited evidence bases to inform decisions about which approach is most useful in different contexts.

The Co-memorating Approach:

Drawing on key concepts and approaches of Narrative and Systemic Therapy, Glenda Fredman (1997) developed "Co-memorating Meetings" as a model for all professionals involved in a child's care to come together to collectively "Re-member" a child who has died.

The use of hyphenation in "Co-memorating" and "Re-membering" is to emphasize the collective process of building a shared narrative of memories of the child's life and relationships that re-connects the participants as members of the network around the child and family.

The meeting format invites all professionals in the multi-agency network to reflect together on connections both between professionals and with the child and family and to celebrate new learning as "gifts" that can be taken forward in supporting the bereaved family, the professional network and other families in the future.

This approach is distinct from clinical case review and trauma debriefing. Co-memorating takes a strength-based focus to co-creating a shared narrative which connects professionals and re-connects professionals with memories of the child and family as people.

Evaluating the Co-memorating Approach, Method and Technique:

Volans (2017) reviewed 27 in-person Co-memorating Meetings convened by a community children's palliative care service for one London Borough over a 5-year period and found consensus that this approach provided effective staff support, created new learning, improved collaborative working and enabled development of individualised bereavement care for families.

The current quality improvement study explores the impact of adapting the Co-memorating Meeting approach to providing on-line staff support for the multi-agency professional network when a child dies, as part of a wider psychological consultation service for a Managed Clinical Network covering a large geographical region in the new era of virtual meetings.

Methods:

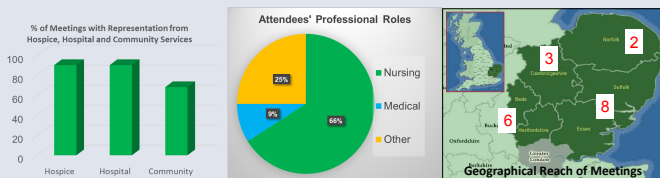
- (1) Review of attendance of all 19 online Co-memorating Meetings convened by a new NHS regional children's palliative care service over an 11-month period to assess accessibility and reach of this approach.
- (2) Thematic content analysis (Braun & Clarke, 2006) of anonymous semi-structured feedback forms completed by health, education, third-sector and social care professionals who attended the meetings.

Conclusions and Reflections:

When it is not possible to meet in-person, **on-line Co-memorating Meetings can be a valued, accessible and useful practice** in children's palliative care with potential to support all members of the multi-agency network around the child and family working across large geographical areas. Qualitative feedback suggests **Co-memorating has potential both to improve staff wellbeing and workforce retention and to improve collaborative multiagency working relationships.**

Quantitative Outcomes: Accessibility & Reach of On-Line Co-memorating

134 professionals attended **19 meetings** over an **11-month period**
(Mean attendance = 7 professionals; Median and Mode = 6; Range 3 – 16)



Qualitative Outcomes: Thematic Content Analysis of Feedback Forms

31 anonymous questionnaires returned (23% response rate)
100% rated meetings **extremely useful (18/31)** or **somewhat useful (13/31)**

What, if anything, did you find useful about the meeting?

Theme 1: Usefulness of sharing different multi-agency reflections and learning from care journey (18 statements)

"It is always useful to network with external professionals and share / reflect on practice together"

Theme 2: Usefulness of the focus on sharing memories and stories about the child and family as people (14 statements)

"The gentle reminiscing offers a different space to share memories, thoughts and relationship with the young person who has died and their family... leave the meeting with a positive memory of child."

Theme 3: Useful opportunity to celebrate collaborative multi-agency working relationship (6 statements)

"Sharing positives about the team working... work they do in support families is truly inspiring."

What, if anything, would you have liked to be different?

Theme 1: On-line Co-memorating meetings work well, no suggestions for change (22 statements)

"It always feel they are beneficial, I would not change anything."

Theme 2: Meetings would be better if more people attended (4)

"Wider attendance from teams - always tricky and difficult to obtain!"

Only 1 statement of preference for in-person over on-line video calls (1)

"Face to face would be preferable but understand the limitations of this."

Do you have a "take home message"?

Theme 1: Importance of communication and collaborative working relationships in the multiagency network (12 statements)

"made me reflect on how positive it can be for families when professionals around them communicate well & work together to meet their bespoke needs."

Theme 2: Workforce sustainability impact of an approach which highlights the positive impact for families of compassionate palliative care (6)

"I did say I would never be able to work with children again after the death of XX but after seeing the other professionals... It might now be an option in the future."

Any other comments?

Theme 1: Gratitude for facilitated time to remember together (19)

"Thank you for the opportunity to bring professionals together to share the story... and our feelings."

Theme 2: Benefits of the Co-memorating approach (7 statements)

"Is has been the only meeting I have been invited to to share positive experiences concerning a patient who has passed and it honestly made such a difference."

12

**GP Trainees Working within Non-Oncological
Paediatric Palliative Care in the North-East
and North Cumbria**

**Dr Guillaume Aubourg
GP ST3**

**Dr Helen Aspey
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Children's Holistic Integrated Palliative care Service



GP TRAINEES WORKING WITHIN NON-ONCOLOGICAL PAEDIATRIC PALLIATIVE CARE IN THE NORTH EAST AND NORTH CUMBRIA

Multi-sourced feedback after piloting GP trainee 6 month placements with CHIPS

Aubourg G, Hoskins R, Shiell A, Aspey H, Bond E, Elverson J, Boyle J, Ryan E.

Introduction

To our knowledge, it is uncommon for GP trainees in the UK to be placed within paediatric palliative care (PPC). 4 GP Trainees over two years have been placed with the Children's Holistic Integrated Palliative Care Service (CHIPS) as part of a 6 month hospice placement in the three year GP training programme. They spend two days a week with CHIPS and three days a week based at an adult and paediatric hospice (St Oswald's) mainly covering the adult inpatient unit. CHIPS care for children and young people with life limiting and life-threatening conditions (non-oncological) across the North East and North Cumbria region.

Method

Feedback questionnaires regarding the role of GP trainees in paediatric palliative care were sent to:

- Previous GP Trainees (GPST)
- GP Practices known to CHIPS
- CHIPS
- St Oswald's Hospice

RESULTS

Questionnaires focused on advantages and limitations of the GP Trainee post. Responses were summarised according to perceived benefits and challenges of the GP trainee placement by the different teams involved (Figures 1 and 2). The confidence of trainees before and after the placement in managing cases of PPC was also assessed in terms of Prescribing, assessing, communicating and seeking advice (Figure 3).

“Some of the most rewarding experiences of my career so far, and have undoubtedly made me a better GP in many areas”

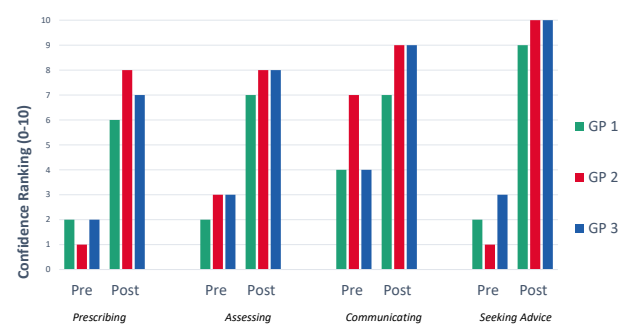
Figure 1. Summary of Benefits of the GP Trainee Role

Benefits of GP placement	
GP Trainee	<ul style="list-style-type: none"> Gained experience and confidence in managing and assessing children with neurodisabilities. Raised awareness of support services available. Awareness of challenges faced by families when accessing GP. Continuity and named GP found to be key. Improved confidence in prescribing in palliative care (APPM formulary). Knowledge of coordinating rapid discharge, role of community and GP and ongoing care of family after bereavement. “Some of the most rewarding experiences of my career so far, and have undoubtedly made me a better GP in many areas” Able to provide education and improve awareness within the rest of the GP practice.
GP	<ul style="list-style-type: none"> Useful as part of wider palliative care placement as lack of formal training in PPC. Increasing number of complex children - useful to have GPs coming through training with suitable experience.
Hospice	<ul style="list-style-type: none"> Increasing number of doctors who have broad experience in PPC can only help grow speciality/confidence. Broader training experience Experience of complex patients beneficial and has generated very good reflections
CHIPS	<ul style="list-style-type: none"> Improved CHIPS understanding of role of GP and how to collaborate and communicate effectively. Improved liaison with community services and patients known to CHIPS who also access short breaks within the Hospice. Trainees have provided objective advice on how to improve team systems and ways of working within CHIPS. Gives trainees transferable skills in communication with families and breaking bad news. With supervision, GP trainees have been able to take on an appropriate level of clinical responsibility.

Figure 2. Challenges of the GP Trainee Role

Challenges of GP placement	
GP Trainee	<ul style="list-style-type: none"> Split post = lack of continuity. Lack of exposure to oncological cases Complexity and specialist nature of service – not common to see these patients frequently once qualified, therefore always likely to need support.
GP	<ul style="list-style-type: none"> GPs would need support when it comes to using palliative medicines in paediatrics.
Hospice	<ul style="list-style-type: none"> Only 1 of 3 trainees at the hospice is able to get split post Suited better to more experienced trainees (ST2 or ST3)
CHIPS	<ul style="list-style-type: none"> Continuity can be challenging as the trainees only work 2 days with the team. Requires individual trainee to have motivation and interest in order for them to gain the most benefit and learning from the placement. Providing training every 6 months for a new GP trainee can be labour intensive for a small team.

Figure 3. Pre/Post confidence markings of various domains by each GP trainee who undertook a placement with CHIPS



Limitations

- Small sample size as new training post. It would be good to repeat in another 2 years.
- PPC is rare in terms of typical population for a GP practice.
- Aimed to get feedback from families but this was not practical. Families did not differentiate between the PPC doctors on the team and the GP trainees.

Discussion and Summary

The GP trainee post has made a positive impact on all the teams involved. All of the skills they develop are highly transferable to GP practice. The positive response of the GP trainees has encouraged CHIPS to offer training to other speciality trainees. CHIPS have gained better insight into primary care and are therefore better equipped to communicate effectively with primary care teams. The role has also facilitated better continuity for children under CHIPS who attend short breaks at the Hospice. While there are some challenges in continuity and limited availability of the post, the response has been positive with all teams. The number of children living with life threatening and life shortening conditions is increasing and therefore this training may be even more relevant to GPs of the future. One of the trainees found the placement so beneficial they have expressed interest in a split post with the team once qualified. Having a GP embedded within CHIPS on a permanent basis would be hugely beneficial and welcomed by the whole team.



13

**Places of Farewell: Bereaved Parent's Decision
Making About Their Child's Place of Death**

Gilda Davis

Senior Lecturer, Children's Nursing

University of Worcester

Places of Farewell: parent's choice about their child's place of death

Researcher: Gilda Davis

Supervisors: Dr Kerry Gaskin, Professor Gyoza Molnar, Dr Jackie Bentley



Context

The purpose of this research is to explore the choice of place for the death of a child with life limiting and/or life-threatening conditions. Deaths that are sudden and unexpected (accident, suicide, murder) have not been included.

Studies on preferred place of death have focussed on children with an oncology diagnosis
(Bluebond-Lagner et al 2013; Duc, Herbert and Heussler 2017; Johnston et al 2020)

So what?

- Different death trajectories
- Original diagnosis may change as further symptoms develop
- Conversations with health care professional about deteriorating health will be familiar to parents, so, despite these conversations, expectation is not of death

(Bogetz et al 2020)

“...and I had to let family know. So you're trying to like manage this reality and trying to let family know. And like, I remember my brother, he was in shock as well, 'cos he was like, "what? He always comes out", you know, my brother's like kind of old fashioned and all that business. Like, you know, he's sort of not a man in many words, but he was, he was even like, "oh my God", he was in shock because all he could say is he couldn't believe it because [...] always comes out, and I had to say "but this isn't the same, this was completely different".

Interview 6

“Every time that she got vented, they always asked us as well, did we want to vent her 'cos she might never come off the ventilator, but we were always like, well she's done it before.”

Interview 4

Study

The aim of this study is to explore what influences a parent's decision making when considering the place and space of death for their child, when death is expected.

Aims

- To understand the lived experience of bereaved parents when they choose their child's place of death;
- To understand the significance of space in the context of children's palliative care;
- To explore the concept of liminality within children's palliative care.

Participant selection

- Participants are the parents of children who have died and whose diagnosis prior to their death was categorised into one of the four Together for Short Lives (TfSL) diagnostic categories;
- The child had a non-oncology diagnosis;
- If the child had an oncology diagnosis, they also had another underlying condition that falls within one of the TfSL diagnostic categories;
- The parents are receiving emotional and psychological support from a hospice or another professional agency.

Child diagnosis to TfSL categories

One child was initially given a category 3 diagnosis, a subsequent additional Diagnosis was a category 2

Category 1	1	Category 2	1
Category 3	4	Category 4	3

Geography and demography

Hospice 1	3 interviews	Inner city (urban)
Hospice 2	2 interviews	Coastal farming (rural)
Hospice 3	2 interviews	Market town (semi-rural)

Participant ethnicity

Asian or Asian British	3 participants
White (English, Welsh, Scottish, Northern Irish or British)	5 participants

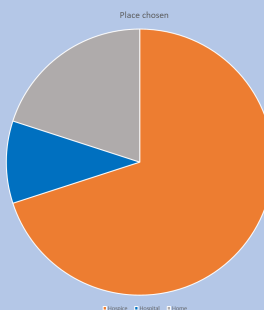
Interviews

- 7 interviews; 8 parents sharing stories about 8 children
- Parents chose where we met:
 - 5 interviews = home
 - 2 interviews = local children's hospice

Interview 4 = mother spoke about the deaths of 2 children
Interview 7 = interview included both parents

Place chosen by parents and/or child

Hospice (7)
Hospital (1)
Home (2)

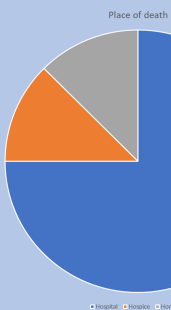


In 2 interviews there were 2 choices for place of death:

Interview 2:
Home = child choice
Hospice = parent choice

Interview 7
Home = child choice
Hospice = parent choice

Actual place of death



For four families, death occurred since March 2020, so were affected by Covid lockdowns.

Two families believe that this supported their transfer to a hospice. For three families, whilst hospital wasn't their choice, their narratives have incorporated it as an "OK" steppingstone and the culmination of their palliative journey has moved to after death and at the hospice.

For one family, the hospital death was very challenging, and although they spent a week at the hospice after, the hospital death remains the dominant experience. This family had experienced what they considered to be a good death previously and struggled with the difference.

Child data

- Child age range at death: 11 hours – 16 years
- Range of bereavement periods: 9 months – 11 years

One participant's son had died 1 year 2 months previously; however her daughter had died 11 years ago, and the participant's experience was core to this second experience



Some of the items, the visual stories, shared by parents

Themes

- **Physicality**
 - Interview 1: smelt the child's clothing before sharing with me, but "haven't been able to smell them for a long time"
 - Interview 3: "I can smell them"
 - Interview 6: could feel them his head on her shoulder, his back against her arm and his weight on her lap
- **Names**
 - "That name just didn't suit my daughter. Then I change it to, and I go into get her registered I'll change it to A. I was still in ICU and they go "if you're going to change her name, then we might as well change it now" and I go "Can I" and they go "well yeah and the paperwork will just change it". And that suited her better, 14 months and four days of life, they were gonna let her pass away in peace at the start of her life."

Interview 1

- **Continued presence**
 - Spiritual contact through psychics (interview 6)
 - Presence in dreams and seeing child getting older
 - Dreaming of child with the grandparents following their death (interview 3)
 - Dreaming of child without disability (interviews, 6, 7)
 - Presence of child through nature and symbols i.e. stars, a swirl, colour (interviews 4, 5, 6, 7)
 - Objects (interviews 1, 5, 6, 7)
 - Ashes – caskets at family home (interviews 4, 5)
- **Legacy**
 - Media reports (interviews 2, 6, 7)
 - Sports award in a child's name (interview 7)
 - Chapter in a medical textbook (interview 7)

Guilt

- Choices about surgical procedures (interviews 1, 7)
- Choices about medical procedures (interviews 2, 5, 6)
- Social situation (interview 2)

Place

- Home
 - Safe vs Home
- Hospice
 - Place bonding
- Hospital rooms
(Ellingson 2014; Pollock 2015; Bluebond-Lagner et al 2015; Dunbar et al 2019; Papadatou 2021)

Home as safe place

- Familiar
- Safe
- Ontological security
- Routine of personal and daily life
- Order and continuity that alleviate anxiety and create identity
(Relph 1976; Giddens 1991; Dunbar et al 2019)

Gender of participants

- Participant invite open to both parents, but six interviews have been with mothers only and just one interview (interview 7) with both father and mother
- Interview 5: Interview was with the mother. The father offered to stay, but made it very clear that he was doing so to support his wife, she told him she didn't want support.
- Interview 6: Interview was with the mother. We were interrupted on several occasions by the 2 adolescent sons with messages from her husband and just checking on her because (it seemed) we were being watched from another room.

Movement of the importance of the place of death

- Where death has not been able to happen in the place of choice, but the child has been moved to preferred place after, the place of death may become less important (interviews 5, 6 and 7).

Next steps

- Study is ongoing
- Data is being analysed using van Gennep's liminality model as a framework



Design

This ethnophenomenological study asked bereaved parents to share their stories about their child and their choice about where their child died.

A narrative approach has been used to interview parents.

Why narrative?

- We tell stories naturally
- Stories can help us make sense of difficult situations
- Stories can move the focus from the reality of what happened to how we make sense of what happened
- Stories can be visual as well as verbal

(Lieblich et al 1998; Riessman 2002; Bell 2013; McAlpine 2016; Tishelman et al 2016; Khwaja and Mahoney 2019; Roth 2018)

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14

**Development of a transition pathway from a
child to adult hospices in Surrey**

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'My Transition': Development of a transition pathway in Surrey

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Background	Research Aims
Transition from child to adult hospice services is better known to professionals as the 'cliff edge,' particularly for those with palliative or complex needs.	The Transition service at Shooting Star Children's Hospices in Surrey (Fig. 1) aim to develop a more unified pathway for multi-agency working and more consistent processes through engagement with service users and providers.

Methodology

A questionnaire was sent to 62 email addresses of organizations and parents/carers/professionals who had expressed interest in developing a transition pathway within Surrey. The questionnaire included 5 open-text questions seeking to better understand current ways of working including existing enablers, barriers, and what additional training is required. Responses were analyzed thematically.

Results

42% response rate (26 responses).

- Themes:
 - Barriers: absence of clear written and consistent pathways; weak equivalence of services or resources for young people between child and adult hospice care; and poor communication/handover/information-sharing between children's and adult services.
 - Enablers: a named professional or team to coordinate the transition process and to initiate the transition process early on. Recommended training topics included the services/processes that are available in adult services. Respondents emphasized the need for clear and consistent guidance and support via appropriate communication tools to share information with children and families.



Figure 1. Shooting Star Children's Hospices catchment area.

Conclusion

- A pathway ('My Transition') has been developed to support collaboration between families and professionals across Surrey.
- 'My Transition' is a living document owned by the young person or representative and includes the services given, future responsibilities of adult services with names and contacts, as well as the aspirations of the young person or their family.
- The document will function as a reference point for adult services, allowing families to record relevant professionals and their roles, and will evolve with the young adult.
- Future work will evaluate its impact.

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**Kickstarting Transition to Adult Hospice: A
Pathway to Success?**

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KICKSTARTING TRANSITION TO ADULT HOSPICE: A PATHWAY TO SUCCESS?

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1) Introduction and aim - What are we trying to achieve?

Evidence suggests that transition planning for disabled young adults requiring support into adulthood could be improved. Many find the transition process challenging, especially in the absence of clear transition pathways.

PPWH and CHAS recognised significant improvements to the transition journey of young adults living with life-limiting conditions, moving from child to adult hospice services in Scotland, were needed.

Both organisations collaborated to develop and pilot a 'coordinated approach' to transition to improve the physical and emotional health and wellbeing of young adults, reduce risks and enhance outcomes.

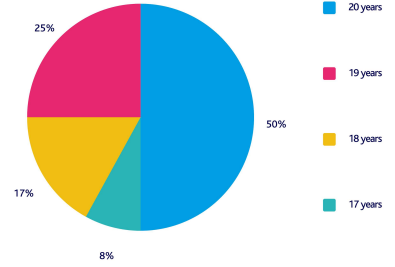
Together, they discussed their initial vision for the pilot and developed the aims illustrated in the thought cloud below



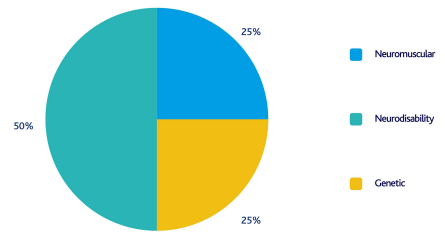
CATEGORISATION TOOL (A)	
Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, irreversible organ failures of heart, liver, kidney.
Category 2	Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.
Category 3	Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.
Category 4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.

4) The Young Adults - Who participated?

Age when added to YA pilot caseload



Diagnosis category of YA in transition pilot



Categorisation of young adult cohort

Definitions (Together for Short Lives, 2018)	Number of young adults in YA transition pathway pilot (N=12)
Category 1: Life threatening conditions for which curative treatment can be feasible, but may fail. Examples: cancers, organ failures of heart, liver, kidney, transplant and children on long term ventilation.	1 *
Category 2: Conditions where premature death is inevitable. Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA type 1.	2 *
Category 3: Progressive conditions without curative treatment options. Examples: Batten disease, mucopolysaccharidosis, and other severe metabolic conditions.	6
Category 4: Irreversible but non-progressive conditions causing severe disability and susceptibility to health complications and premature death. Examples: Severe cerebral palsy, complex disabilities such as following brain or spinal injury.	2

*Note one young adult in the transition pilot was considered as being categories 1 and 2 at the time of assessment for transition.

5) What were the outcomes?

- Twelve young adults and their families/carers participated in the 18-month pilot.
- Three declined services at PPWH
- Two young adults died during the pilot, strengthening the need for timely and appropriate transitions.
- Seven individuals accepted onto PPWH caseload: five fully transitioned, joint working continues for the remaining two.
- Young adults meeting the criteria across all 4 Categories were transitioned.



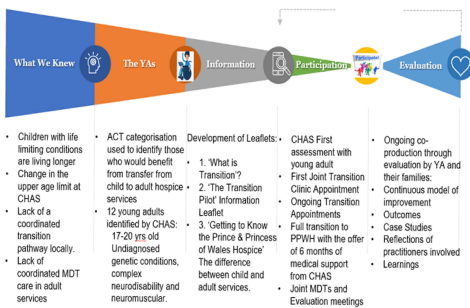
6) What are our key messages and recommendations?

- The young adult population, living with a life limiting condition, with the right to transition well and access adult hospice services, is ever increasing.
- Transition can be a lengthy, resource intensive process. Resources should consider the provision of a dedicated transition clinic, associated MDT and the ongoing training needs of staff working on transition in line with service development.
- Relationships and trust are core to transition.
- Clear pathways aid successful transition. However further development of the Transition Pathway and Categorisation Tool utilised within the pilot needs to be undertaken to determine whether it is appropriate for young adults under 18 years of age.
- Young adults identified as being within any of the four categories within the Categorisation Tool may be appropriate for adult hospice care.
- There is a need for a dedicated transition team.
- Building on the progress made in the pilot, PPWH and CHAS should secure funding to appoint a joint transition lead to work proactively across both hospices to support those in transition.
- This model is used as a 'Blueprint' for CHAS to work with other adult hospices in Scotland, advocating for the young adults' right to transition.



2) Developing a roadmap for the project - The transition Pilot Journey Map

CHAS PPWH Transition Pilot Journey Map



CHAS-PPWH PILOT TRANSITION PATHWAY	
<p>READY? Is the time right?</p>	<p>Identification of the young adult by means of:</p> <ul style="list-style-type: none"> Categorisation Age range 14-18yrs old Young adult's capacity Within PPWH catchment area (although all young adults will be considered on an individual basis). <p>Identify the needs of the young adult/family/legal responsible person (LRP) utilising GIRFEC & SHANARRI outcomes and explore their expectations of transition.</p>
<p>ON YOUR MARKS? Who is this young adult?</p>	<p>Two-way sharing of information:</p> <ul style="list-style-type: none"> Presentation and discussion at a joint pilot MDT with the consent of the young adult/family/LRP. Information leaflet shared with young adult/family/LRP. Proposed hosting an informal open evening at PPWH for young adult/family/LRP. <p>Determination of whether PPWH is the best fit:</p> <ul style="list-style-type: none"> Consider how can PPWH best support this young adult/family/LRP? <p>and/or</p> <ul style="list-style-type: none"> If appropriate, can CHAS/PPWH signpost to other suitable hospices/services?
<p>GET SET? A time of great change!</p>	<p>Formal introductions made:</p> <ul style="list-style-type: none"> PPWH staff to say "Hello" at CHAS Robin House as an informal, introductory meeting. Undertake a review during any joint transition clinic appointment. Explore potential opportunities for PPWH staff to participate in shadow shifts at CHAS.A Follow on discussions regarding remit of adult hospice care throughout any meetings. <p>Young adult/family/LRP led.</p> <p>This period will be fluid and will be time variable, allowing familiarity and trust to develop as foundations of ongoing therapeutic relationships.</p>
<p>GETTING TO KNOW YOU! Getting to know the young adult and their family</p>	<ul style="list-style-type: none"> Aim for four to six monthly clinical reviews of young adult at joint transition clinic. Explore potential for young adult to attend the Living Well Hub at PPWH. Introduction to wider PPWH MDT and services as appropriate. Final joint assessment meeting prior to full transition to PPWH adult services.
<p>Go! The time is right!</p>	<p>Final transition to PPWH young adult service:</p> <ul style="list-style-type: none"> Discharge from CHAS to PPWH If required, agreement for six months of remote medical and nursing support from CHAS. Continual assessment of need and measurement of outcomes using SHANARRI and IPOS.

3) What did we do?

- Developed a Categorisation Tool, building on the Core Pathway for Children with Life-Limiting and Life-Threatening Conditions developed by Together for Short Lives.
- Implemented a Transition Pathway consisting of operational steps to aid the multidisciplinary decision-making process and inform the young adult's transition journey.
- Identified and focused on those young adults and their families who met the criteria for Categories 2 and 3, who may benefit from participating in the pilot.
- Established joint transition MDT and clinic.
- Created a suite of information leaflets to support transition pilot.
- Tested and evaluated the Transition Pathway with Young Adults and their families who participated in the pilot.