An Independent Review
Palliative and End of Life Care Advice and Guidance Telephone Services for Children & Young People across the North East and Yorkshire Region

Version Control Log

Version Number	Date	Author Title	Status	Approving Body	Change Tracking
V1.5	04/04/23	NECS Consultancy	Approved	NHS England North East and Yorkshire Strategic Clinical Network for PEoLC	N/A
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Contents

1.0 Executive Summary

1.1 NHS England North East and Yorkshire Strategic Clinical Network for Palliative and End of Life Care commissioned North East Commissioning Support (NECS) Consultancy to undertake an independent review of Children and Young People's (CYP) Palliative and End of Life Services across the North East and Yorkshire (NEY), with a particular focus upon which areas provide a 24/7 Advice and Guidance (A&G) telephone service.

1.2 There is now a legal obligation upon Integrated Care Boards (ICBs) as set out in The Health and Care Act (2022) and Palliative and End of Life Care: Statutory Guidance for Integrated Care Boards (2022) to commission palliative care services.

1.3 In the North East and Yorkshire region there are four recently formed Integrated Care Boards (ICBs) which are included within this review, in conjunction with the paediatric hospices in their respective localities.

1.4 The Senior Responsible Officer (SRO) for the review was Dr Yasmin Khan, with a PEoLC Steering Group formulated, consisting of NECS Consultancy and representatives of NHSE, ICBs, GPs and patients (parents).

1.5 The methodology to be deployed was agreed between the steering group and NECS Consultancy. Key Lines of Enquiry (KLOE) to be pursued were devised based upon the following deliverables:

- Understanding of population need
- Current service mapping
- Understanding of current funding provision
- Ascertain current IT solutions/Gaps in service provision
- Aligning work with current ongoing research into Hospice provision
- Establishing current governance structures
- Recommendations and next steps

1.6 Initial mapping of key stakeholders to be included within this review was undertaken per ICB and these were identified across a range of disciplines (Appendix 2). Interviews were conducted, with themes extracted for further analysis.

1.7 Thematic Analysis was undertaken and utilised for the content of the report and subsequent recommendations were made for each ICB. The following emerged as key themes across the region:

- Interoperability of IT systems and information sharing
- Workforce limitations, capacity, skills, competencies and training
- Primary Care engagement

- Geographical Challenges
- Population Health Management
- Governance for families and professionals
- Funding complexity
- Service signposting and awareness
- Numbers of children utilising Hospices and services
- Lack of Community Paediatric Teams
- Transition
- Lack of service specifications in some services

1.8 Economies of scale across ICB's were apparent in the themes and these have been articulated within the report for consideration.

1.9 It can be concluded that there are variations and inequities in service provision between localities as identified in Table 1 below.

Table 1 - CYP PEoLC Advice Line Service Provision

Organisation	24/7 Telephone A&G Line?	Hours a telephone A&G line is available	Medically led	Nurse led with support
St Andrews Hospice	✗	08:00-20:00 & Paediatric Nurse contact numbers given for OOH contact	✗	✓
Martin House Hospice	✓	24/7	✓	✗
Martin House Hospice	✓	24/7	✓	✗
Forget Me Not Children's Hospice	✓	24/7	✗	✓
Leeds Children's Hospital**	✓	24/7	✓	✗
Bluebell Wood Hospice	✓	24/7	✗	✓
Sheffield Children's Hospital	✓	Consultant on call 24/7	✓	✗
St Oswald's Hospice	✗	Through CHIPS* 08:00-18:00 Mon to Fri & 09:00-17:00 Sat to Sun	✗	✓
Zoe's Place Baby Hospice	✗	Through CHIPS* 08:00-18:00 Mon to Fri & 09:00-17:00 Sat to Sun	✗	✓
Jigsaw Hospice	✗	Through CHIPS* 08:00-18:00 Mon to Fri & 09:00-17:00 Sat to Sun	✗	✓
Great North Children's Hospital	✓ Via CYPOONS^	CYPOONS^: 24/7 CHIPS*: 08:00-18:00 Mon-Fri & 9:00-17:00 Sat-Sun	✓ Through CHIPS*	✓ Through CYPOONS^

* Children's Holistic Integrated Palliative Care Service (hosted by GNCH)
^ Children and Young People's Oncology Outreach Nurse Specialists (CYPOONS) based at GCNH
** West Yorkshire Children's Specialist Paediatric Palliative Care Team & Macmillan Nurse Specialists

Key for Table 1:

Humber & North Yorkshire ICB
West Yorkshire ICB
South Yorkshire ICB
North East and North Cumbria ICB

2.0 Next steps

2.1 Utilise a Population Health Management (PHM) approach within each ICB to clearly articulate/understand locality information, this is paramount for development of services.

2.2 Undertake service mapping/need within each ICB based on PHM findings and outcomes of this review.

2.3 Facilitative workshop between WY Leeds Specialist Palliative Team and Hospices to clearly define service specification and Model of Care for the future.

2.4 Collaborate with all ICBs to formulate service specifications for PEoLC adhering to national guidance.

2.5 Devise an IT data collection tool for all areas to collate numbers accessing hospice provision and A&G advice lines.

2.6 The findings should allow for discussion within each ICB and ultimately at commissioner level.

2.7 Recommendations should be progressed at ICB level and at scale, facilitated by NHSE.

3.0 Introduction

3.1 NHS England North East and Yorkshire Strategic Clinical Network for Palliative and End of Life Care commissioned North East Commissioning Support Consultancy to undertake an independent review of Children and Young People's (CYP) Palliative and End of Life Services across the North East and Yorkshire (NEY), with a particular focus upon which areas provide a 24/7 Advice and Guidance (A&G) telephone service.

3.2 The NHS Long-Term Plan (2019) articulates its commitments for Palliative and End of Life Care (PEoLC); this, in conjunction with NHS England's Palliative and End of Life Care National Delivery Plan 2022–2025 sets out a three-year trajectory, focusing upon improving access, quality and sustainability.

3.3 There is now a legal obligation upon Integrated Care Boards (ICBs) as set out in The Health and Care Act (2022) and Palliative and End of Life Care: Statutory Guidance for Integrated Care Boards (2022) to commission palliative care services. They must arrange for the provision of a whole system approach which ensures that the individual and their families receive and have access to the appropriate professional at the right time. This includes access to Out of Hours (OOH) Palliative and End of Life Care.

3.4 ICBs should have a clear vision of how the package of services they commission locally, deliver against the Ambitions for Palliative and End of Life Care: A National Framework for local action 2021-2026.

3.5 In the North East and Yorkshire region there are four recently formed Integrated Care Boards (ICBs). Included within this review which are:

- Humber and North Yorkshire (HNY)
- North East and North Cumbria (NENC)
- South Yorkshire (SY)
- West Yorkshire (WY)

3.6 In addition, several Children's Hospices are encompassed which provide both End of Life (EoL) and Palliative Care within the four ICB's, namely:

- St Andrews Hospice
- St Oswald's Hospice
- Zoe's Place Baby Hospice
- Jigsaw Children's Hospice
- Butterwick Hospice
- Bluebell Wood Children's Hospice
- Martin House Hospice
- Forget Me Not Children's Hospice

3.7 There are also services which operate out of tertiary centres throughout the NEY region:

- Great North Children's Hospital
- Newcastle Hospitals NHS Foundation Trust
- Leeds Children's Hospital
- Leeds Teaching Hospital NHS Trust
- Sheffield Children's NHS Foundation Trust

3.8 This review was commissioned to allow collaboration with a wide range of stakeholders, particularly those included in the children's journey from initial diagnosis of an oncological origin or for those children with a Life Limiting Condition (LLC). Personnel from Primary, Secondary, Community and Hospice providers were included in the review, in addition to families of deceased children, or those with the potential to require or currently accessing, Palliative or End of Life Services.

3.9 In addition, the aim of the report was to ascertain whether a 24/7 A&G telephone service is widely provided for clinicians and families, explore existing models of delivery and articulate where the potential for enhanced models could be initiated.

3.10 End of Life care commences for children when a life-limiting or life-threatening condition is first diagnosed and continues until death. For congenital and genetic conditions, the biggest diagnostic group of life-limiting and life-threatening illnesses among children, EoL care often begins at birth and may continue for 20 years or more (Together for Short Lives 2017).

3.11 There are increasing numbers of children living with life-limiting and life-threatening illnesses who are requiring palliative and EoL provision, predicated upon advances in medical interventions which elongate childrens' lives, the acuity of the children accessing this care and the support families need in this period. This is partly due to increases in incidence or to better diagnosis, however, better survival rates following complex surgery or very premature birth appear to be the main reason (Fraser et al 2021).

3.12 The number of children requiring EoL care is small and their needs are so complex, that services are generally commissioned on a bespoke, individual basis. Apart from children's hospices, there is not usually a 'standing' EoL service for children in the way that there is for adults.

3.13 Currently, the provision of specialist EoL care for children is variable around the country and may not reflect need. The prevalence of life-limiting and life-threatening illness is highest among certain ethnic minority groups and appears to be increasing fastest in areas of greatest deprivation, the likelihood is that this will continue to rise to 2030 in England (Fraser et al 2021).

3.14 There is a necessity to consider those children and families of a differing ethnic origin, with different beliefs, or language barriers. Fraser et al (2021) highlighted that prevalence of LLCs was highest amongst children of Pakistani origin (103.9 per 10,000) and lowest among children of Chinese origin (32.0 per 10,000) in 2017/18. This cohort of children may not have access to services or may have difficulty contacting services due to lack of information in relation to obtaining an interpreter. This is an integral element for all providers to consider, ensuring services can flex to meet the needs of all children

3.15 In addition to those children and families from an ethnic minority, there are also a multitude of other areas to consider ensuring equitable services to all; geographical boundaries, rurality, deprivation, homelessness and mental health to name a few.

3.16 Whilst all the hospices are paediatric focussed, except for St Andrews, who provide both Adult and Paediatric Services, there are varying offers to the child and their family during this difficult time. Some hospices provide respite care only and do not offer EoL provision, predominantly, due to workforce issues from both a medical and nursing perspective.

3.17 In addition to hospices, there are services for EoL provision provided by NHS Organisations and Local Authorities.

3.18 Research for Marie Curie into 24/7 PEoLC services is currently being undertaken by Julia Hackett - Research Fellow and MHRC Public Involvement Lead at Martin House Research Centre, University of York. The study is entitled 'Parent and Professional Experiences of Paediatric 24/7 End of- Life Care: A Mixed Methods Study'. The results from this have not been concluded and therefore cannot be reflected within this report.

4.0 Background

4.1 North East and Yorkshire Palliative and End of Life Care Strategic Clinical Network

4.1.1 The North East and Yorkshire Palliative and End of Life Strategic Clinical Network (SCN) was established in 2021 as part of a three-year programme funded by NHSEs National Palliative and End of life Team. The Health and Care Act (2021) resulted in the establishment of Integrated Care Boards (ICBs) across the region namely, North East and North Cumbria ICS (NENC), West Yorkshire Partnership (WY), South Yorkshire ICS (SY) and Humber and North Yorkshire Partnership (HNY).

4.1.2 Among other ambitions, the PEoLC SCN aimed to address unwarranted variation and promote equity of access to palliative and end of life services for CYP.

4.2 The Yorkshire and Humber Children's Palliative Care Network

4.2.1 The Yorkshire & Humber Children's Palliative Care Network (YHCPCN) had developed a five-year strategy (2018-2023) to provide 24/7 provision for children requiring specialist medical advice and guidance. This vision was underpinned by the Ambitions for Palliative and End of Life Care – a National Framework for Local Action 2021-2026 and NICE (NG61). However, due to the evolution of the ICBs and NEY SCN, it was clear there would be a significant amount of duplication, in addition to the ICB/SCN having an increased level of accountability into the changing architecture of the NHS. Therefore, the decision was taken to disband this network in 2021.

4.3 Funding

4.3.1 Currently there is local variation pertaining to provision of funded 24/7 Out of Hours (OOH) and EoL Children's Community Nursing Care. Inequities across the region are apparent in relation to diagnosis, with only those children diagnosed with cancer having access to the 24/7 Paediatric Oncology Outreach Teams (Nurse Led).

4.3.2 Differing hospices within the region offer varying support due to current workforce issues and therefore not all can provide 24/7 A&G. Children's Community Nursing (CCN) is not commissioned in all areas and therefore out of hours support to children and families is scarce in some areas and only provided on an ad hoc basis in others.

5.0 Scope

5.1 In Scope

5.1.1 All ICB's and Hospices identified in section 2.5 and 2.6 except for Butterwick Hospice. This is excepted based upon being currently closed to admissions.

5.1.2 All Acute Providers integral to the Paediatric Palliative Pathway.

5.1.3 All Community Paediatric Providers.

5.1.4 Families of children with Life Limiting Conditions or families of deceased children.

5.1.5 24/7 Advice and Guidance telephone lines or alternative provision.

5.2 Out of Scope

5.2.1 Butterwick Hospice.

5.2.2 Adult Hospices.

5.2.3 Wider topical issues within the palliative arena. However, it was agreed that wider determinants may be referenced and discussed within the interviews and subsequent report as intrinsically linked into the review of 24/7 A&G provision.

5.2.4 Children's sudden death.

6.0 Governance

6.1 The Senior Responsible Officer (SRO) for the review was Dr Yasmin Khan.

6.2 A PEoLC steering Group was formulated consisting of NECS Consultancy, NHSE/I, ICB representation and a Patient Representative (parent).

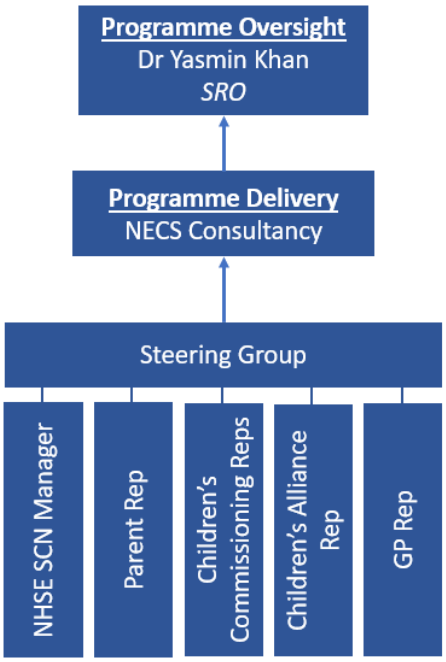

Figure 1 – Governance Structure

7.0 Methodology

7.1 A collaborative approach was agreed between the steering group and NECS Consultancy.

7.2 Formation and agreement of Key Lines of Enquiry (KLOE) to be pursued based upon the following deliverables:

- Understanding of population need
- Current service mapping
- Understanding of current funding provision
- Ascertain current IT solutions/Gaps in service provision
- Aligning work with current ongoing research into hospice provision
- Establishing current governance structures
- Recommendations and next steps

7.3 Identification of Key Stakeholders within each ICB.

7.4 Conducting qualitative interviews across four ICBs, ensuring a wide range of interviews across differing groups of clinicians, CEO's, families, NHSE, amongst others.

7.5 Thematic Analysis shared iteratively within the Steering Group.

7.6 Findings - A concise summary, inclusive of challenges/opportunities for each ICB.

7.7 Recommendations.

7.8 Cascade draft report to Steering Group members.

7.9 Quality Assurance of report (internal/external).

7.10 Publish report.

7.11 Host webinar to socialise report.

8.0 Desk Based Research

8.1 A suite of documents (Appendix 1) has been critiqued and utilised to support this report, namely:

1. Care Quality Commission. (2020). Sector Specific Guidance: Hospices for Children and Young People.
2. Fraser, L.K., et al., (2021). Estimating the Current and Future Prevalence of Life-Limiting Conditions in Children in England. Palliative Medicine.
3. Hackett, J. (Year of publication pending). Parent and Professional Experiences of Paediatric 24/7 End-of-Life Care: A Mixed Methods Study.
4. Health and Care Act (2022).
5. National Palliative and End of Life Care Partnership (2021). Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021–2026.
6. NHS England. (2019). The NHS Long Term Plan.
7. NHS England. (2022). Palliative and End of Life Care: Statutory Guidance for Integrated Care Boards (ICBs).
8. NHS England. (2022). Palliative and End of Life Care National Delivery Plan 2022–2025.
9. NICE (2016). Transition from Children's to Adults' Services for Young People Using Health or Social Care Services.
10. The King's Fund (2023). Dying well at Home - Commissioning Quality End of Life Care.
11. Together for Short Lives (2017). Commissioning Children's Palliative Care in England: 2017 Edition.
12. Together for Short Lives. (2019). Together For A Workforce in Crisis: Children's Palliative Care in 2019.
13. Together for Short Lives. (2020). Make Every Child Count: Estimating Current and Future Prevalence of Children and Young People with Life-limiting Conditions in the United Kingdom.
14. Together for Short Lives. (2022). Access to 24/7 Children's Palliative Care
15. Yorkshire and Humber Children's Palliative Care Network (YHCPCN) 5 Year Strategy 2018-2023.

9.0 Stakeholder Mapping

9.1 Initial mapping was undertaken per ICB. Key Stakeholders were identified across a range of disciplines:

- Hospice CEO's
- Consultants in Paediatric Palliative Medicine
- Consultants in Neonates, Paediatrics, Community, Acute, Paediatric Intensivists
- Clinical Directors
- GPs

- Clinical Nurse Specialists
- Nurses
- NHSE
- Patient and Parent Representatives

9.2 An engagement document was compiled to capture all interviewees inclusive of those suggested by key stakeholders during the interviews (Appendix 2).

10.0 Stakeholder Interviews

10.1 The interviews were conducted and recorded via MS Teams, with key observations and themes extracted utilising thematic Key Lines of Enquiry (KLOE) (Appendix 3) which had been agreed with the SRO Dr Yasmin Khan. All conversations were conducted confidentially with Chatham House rules and all observations have been summarised and anonymised, therefore not attributable to any individual interviewee. Over the course of the qualitative interviews more than twenty themes were captured and there were consistent themes apparent across the regions.

Table 2 – Stakeholder Interviews Completed

	Number of Interviews Completed					
Role Category	Humber and North Yorkshire	North East and North Cumbria	South Yorkshire	West Yorkshire	National and Other	**Total**
Head of Commissioning	1	2	0	2	0	**5**
Specialist Consultant in Paediatric Palliative Medicine	0*	0	0	3	1	**4**
Consultant	4	5	3	3	0	**15**
Clinical Nurse Specialist	0*	1	2	2	0	**5**
Nurse	1	0	2	0	0	**3**
Hospice CEO	1**	1	1	2	0	**5**
GP	1	0	1	0	0	**2**
Parent	1	1	1	1	0	**4**
Other	0	1	0	4	5	**10**
Total	**9**	**11**	**10**	**17**	**6**	**53**

*Covered by those in the same role based in West Yorkshire
**Not including Martin House CEO, accounted for within West Yorkshire figure

11.0 Humber and North Yorkshire ICB

11.0.1 Table 3 below summarises the services available within the ICB. For narrative pertaining to Martin House Children's Hospice, which covers both HNY and WY ICB, see Section 12.0.

Table 3 - HNY Service Summary

Organisation	Number of SPPCs^	24/7 Telephone Advice Line?	Hours a telephone advice line is available	Medically led	Nurse led with GP support	Opening hours per week
St Andrews Hospice	0	✗	08:00-20:00 & Paediatric Nurse contact numbers given for OOH contact	✗	✓	8am-8pm weekdays, 2-3 weekends per month for respite
Martin House Children's Hospice	2	✓	24/7	✓	✗	24/7

^ GRID-trained Specialist Palliative Paediatric Consultants

11.1 Infrastructure

11.1.1 After the disbanding of the Yorkshire and Humber Children's Palliative and End of Life Network, there has been a formation of a Children's PEoLC Steering Group, with four defined Task and Finish Groups covering all six places of the ICS:

- North Yorkshire
- York
- Hull
- East Riding
- North Lincolnshire
- North East Lincolnshire

11.1.2 The Palliative & End of Life Care: Babies, Children and Young People Strategy, 2023-2026 (Appendix 1, 16.), has been developed by the HYN Health and Care Partnership to direct their future ambition for paediatric palliative care across these boundaries. Further consultation with parents, children and young people is ongoing. The governance structure has been agreed.

11.1.3 ICBs should have a clear vision of how the package of services they commission locally, deliver against the Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026. Self-

Assessments should have been undertaken against the six ambitions in collaboration with system partners to ensure integration system wide.

11.1.4 St Andrews Hospice, located within Grimsby, is one provider of palliative and EoL provision. They offer care to children living in North East Lincolnshire, North Lincolnshire, Lincolnshire, Hull and East Riding, both at the Hospice and in their own homes. They can deliver care for children from the age of 0-25. They do not work to an agreed service specification.

11.1.5 Martin House is a hospice, based in Wetherby, that provides care for children and young people across Humber, West, North and East Yorkshire (for more detail see West Yorkshire ICB, section 12). This is a significant part of HNY which St Andrews does not provide for.

11.1.6 St Andrews is atypical in its Statement of Purpose, offering both paediatric and adult EoL provision, albeit, differing access times.

11.1.7 The Model deployed is Nurse Led with GP support for medical provision for paediatrics and Medically Led in the adult provision. These are specialist doctors with Palliative Medicine Diplomas who are or have been GP's.

11.1.8 Whilst adult provision is offered on a 24/7 basis, this is not equitable in paediatric services.

11.1.9 A 24/7 A&G Line is not offered within this model as the Hospice does not operate 24/7 for paediatrics, only adult services. However, if a child is at home and the Hospice is supporting for EoL, the paediatric nurse contact numbers will be given for OOH contact.

11.1.10 The Hospice at Home Team offer 'outreach' services seven days per week within the hours of 8am to 8pm. In addition to these hours the Hospice also opens for respite 2-3 weekends per month for paediatric admissions.

11.1.11 The Hospice offer a variety of services, namely, Community Support, Therapeutic sessions, Respite and EoL care.

11.1.12 Families of children who have died can access the 'Butterfly Suite' within the Hospice to allow time together with their child in the hours/days following.

11.2 Geographical Boundaries

11.2.1 St Andrews is located on the coast and therefore this poses challenges for families accessing the hospice due to locality. Difficulties encountered with recruitment of both medical and nursing personnel directly impacts upon the operational hours of the paediatric provision.

11.3 Funding

11.3.1 The Hospice has a turnover of circa £5.5 million. It has 18% combined funding for both paediatric and adult services. This equates to 5-6% for paediatrics when disaggregated. Further funding is obtained from charitable funds.

11.4 Governance

11.4.1 There is a robust governance structure within the Hospice with a Director Lead across both Paediatrics and Adult services.

11.5 Workforce

11.5.1 There are significant challenges with recruitment of nursing personnel due to the location of St Andrews. However, the Hospice is undertaking a huge workforce reform project. All roles are now evaluated and aligned as much as possible with AFC/NJC pay scales, and they offer significantly improved T&Cs – unsocial hours, on-call allowance, improved pension contributions, increased annual leave allowance, Professional Registrations paid for, bridge tolls paid for those living across the Humber and Length of Service awards.

11.5.2 The Hospice has five Specialist Doctors covering seven days a week (10 sessions Mon-Fri, plus on-site visits and on-call over the weekend) two of these Doctors work exclusively for the organisation (Adult & Children), however, they are not GRID trained within Paediatric Palliative Medicine. The three other members of the team are also GPs in the local area with additional Palliative Medicine qualifications/experience. There has been an unsuccessful recruitment campaign recently for a Palliative Care Consultant (Adult) as part of the Northern Lincolnshire Adult PEoLC Programme and this is currently being explored again.

11.5.3 A vacant CNS role will allow the Hospice to increase community support once recruited too which will impact upon operational hours.

11.5.4 Due to the lack of employed personnel, both medical and nursing, the operational hours of the Hospice have reduced, which ultimately impacts children and their families.

11.5.5 With the above challenges in question, the CEO is collaborating with a neighbouring hospice, to develop a shared offering. Provision of services are currently being reviewed, with the potential for one site to be a satellite service, whilst the other focuses upon inpatient services.

11.6 Training

11.6.1 Every professional needs to be confident and competent in their knowledge and practice, which allows them to deliver exceptional care to those children from a palliative or EoL perspective. It is vital that every organisation has a framework for their education, training and continuing professional development.

11.6.2 Continued investment in the training and development of nursing personnel is vital within St Andrews to sustain a protracted Nurse Led Model.

11.6.3 Although a collaborative approach to services is being developed and considered, it is paramount that the existing staff are trained to maintain competence and confidence; thus, enabling the Hospice to gradually increase operational hours to 24/7.

11.7 Transition

11.7.1 Failure to achieve a safe transition and deliver developmentally appropriate care can lead to disengagement and poorer outcomes. This is supported within Transition from Children's to Adults' services for young people using Health or Social Care Services, The NHS Long Term Plan (2019) and NICE Guidance (NG43).

11.7.2 Although transition from paediatrics to adult services poses difficulties for families, St Andrews has a privileged position of offering both and therefore can facilitate the transition. Whilst this is only pertinent to the children who are under the care of the Hospice, transition from one to the other can significantly impact children and their families. It is, therefore, beneficial in that it enables them to remain within the same hospice provision, albeit in different areas.

11.8 General Practitioners

11.8.1 There appears to be a gap in GP knowledge pertaining to services who can directly be involved and support the child receiving palliative care. This extends to a gap in awareness of and signposting to the services available for supporting the child and their families. However, GP's have minimal numbers of palliative children within their remit and therefore can feel vulnerable caring for these children.

11.8.2 This leaves both the children and their families in a vulnerable position, during diagnosis, whilst living with a life limiting condition, at the time of death and after a child has passed away. Sibling and parental support via bereavement counselling is paramount and GP awareness of available services are vital.

11.9 Community Services

11.9.1 Although the Hospice provides an outreach service into the community – 'The Hospice at Home Service', which operate 8am - 8pm seven days a week, this is not complemented or supported by a Community Children's Nursing (CCN) team OOH. The CCN work between 9am - 5pm Monday to Friday and 9am – 1pm Saturday. The team will provide 24/7 on-call for EoL on a rota basis once this has been identified as needed, therefore, on an ad hoc basis, based upon goodwill. This is not sustainable and depletes the 'in hours' team of personnel. These hours ultimately leave a gap in community service provision between the hours of 8pm to 9am.

11.9.2 In hours, the Hospice works very closely with the local Complex Care Team and the Children's Community teams across their catchment area.

11.10 Information Technology

11.10.1 There are problems pertaining to communication and interoperability between community teams and the Hospice, with both utilising differing systems.

11.10.2 The Hospice has initiated a system to collect and collate data and have initiated a dashboard to support a Population Health Management (PHM) approach.

11.11 Recommendations

11.11.1 Based on the information to date, collated through discussion with key stakeholders within the ICB remit, the following recommendations are made to enhance the current service provision.

1) The ICB should utilise local and national data collected and collated to demonstrate the wider societal impact of the activity of St Andrews using a Population Health Management approach.

2) A change in reporting should be made to align the delivery of Statutory services with the Integrated Care Boards emerging Assurance Framework.

3) There is a necessity for parity of service as it is evident that oncological and non-oncological children currently receive a different level of service.

4) The ICB, in conjunction with the locality hospices, should assess and review the self-assessment undertaken against the 6 principles contained within The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026 to clearly define their focus for the future.

5) Collaboration between hospices should continue to compile an Options Appraisal – Service Specification needs to be developed to support the collaborative model.

6) Devise a tiered model of on-call between St Andrews and Martin House – Inclusive of CNS/ANP and Medics - This could be further developed as a regional approach (see section 12).

7) St Andrews should continue to advertise for medical personnel to allow for an increase in operational hours – Potential for shared posts across differing boundaries if collaborating with Martin House.

8) St Andrews should continue to develop competencies and provide training for ANP's to sustain a protracted Nurse Led Model.

9) Undertake a review of services for those with language barriers/interpreting services and other inequalities as per section 3.14 and 3.15 above.

10) The ICB should instigate and offer 'Lunch & Learn' events for Primary Care – allowing GPs to be well informed of services available to them for supporting the children and families accessing palliative care and bereavement services. This could be extended to all Primary Care personnel, Social Care and Schools.

11) The ICB needs to undertake a full review of paediatric CCN Teams to ensure OOH provision is supported on a permanent basis opposed to an ad hoc. This could be a collaborative approach with neighbouring localities

12) The ICB should work in partnership with system partners to improve the limited transport linkages for families

12.0 West Yorkshire ICB

12.0.1 Table 4 below summarises the services available within the ICB.

Table 4 - WY Service Summary

Organisation	Number of SPPCs^	24/7 Telephone Advice Line?	Hours a telephone advice line is available	Medically led	Nurse led with GP/ Specialist Consultant support	Opening hours per week
Martin House Children's Hospice*	2	✓	24/7	✓	✗	24/7
Forget Me Not Children's Hospice	0	✓	24/7	✗	✓ (Specialist Consultant Support)	24/7
Leeds Children's Hospital**	1	✓	24/7	✓	✗	N/A

^ Specialist Palliative Paediatric Consultants
* GRID-trained Specialist Palliative Paediatric Consultants
** West Yorkshire Children's Specialist Paediatric Palliative Care Team & Macmillan Nurse Specialists

12.1 Infrastructure

12.1.1 As an integral part of the formation of the Children's PEoLC Steering Group and the associated Task and Finish Groups there will be a defined strategy to steer the future ambition for Paediatric Palliative Care.

12.1.2 There are two hospices based within the WY ICB localities – Martin House and Forget Me Not Children's Hospice. The main referral routes into the hospices are from the Tertiary Centres, although Forget Me Not Children's Hospice also receive a considerable number of self-referrals and referrals from CCN's, Community Paediatricians and local hospital teams.

12.1.3 Martin House is a hospice, based in Wetherby, that provides care for children and young people across Humber, North, East and West Yorkshire. It provides family-led care to children and young people with life-limiting and life-threatening illnesses, either at the Hospice or in families' own homes. In addition, they frequent Leeds Teaching Hospitals NHS Trust to support children requiring EoL intervention. The Hospice is the main provider of palliative and EoL provision. They deliver care for children from the age of 0-25.

12.1.4 The Model deployed is Medically led by two Consultants in Paediatric Palliative Medicine, in addition to a multidisciplinary team, inclusive of Clinical Nurse Specialists, Psychologist, Social Worker, Physiotherapist, Music Therapists and a Chaplain.

12.1.5 The Model has 24/7 A&G service provision for both professionals and families to access. Only families known to Martin House can access the on-call provision. Professionals contacting the Hospice for those children not known to them will be given high level advice, however, a subsequent referral would be required for further management.

12.1.6 Services provided include Specialist Short Break, Emergency Care, Symptom Control, Community Care, Advanced Care Planning and Bereavement Support. The Hospice also supports families whose child has died from a life-limiting condition but did not access hospice care, or those who have endured a child's sudden death.

12.1.7 They offer an outreach service, which is reactive in nature, based upon individual need of the child and their families. They can book home visits proactively thereafter to ensure continuity of care.

12.1.8 They are a GRID Training provider and viewed as a Centre of Excellence.

12.1.9 Forget Me Not Children's Hospice in Huddersfield deploys a Nurse Led Model. The model has 24/7 A&G provided by children's nursing staff. The care offered there is individualised for each child and family, with a team of specialist care co-ordinators co-ordinating care for them.

12.1.10 For children under 21 years old, Forget Me Not Children's Hospice offers 24/7 inpatient unit beds, emergency admission to these beds, hospice at home and in reach services to local hospitals. The Hospice provides face to face specialist palliative care advice and assessment between 9am and 5pm. It also offers specialist palliative care advice for patients in the community and for staff (Acute and Community) in collaboration with Martin House.

12.1.11 Place based commissioning arrangements are in place for maternal mental health and funded placements for respite. The Hospice also offers a region wide key worker service for SUDIC deaths, but this is not yet commissioned. The service runs in conjunction with West Yorkshire Police.

12.2 Geographical Boundaries

12.2.1 Martin House is based in Wetherby. This location can cause access challenges for families due to the lack of public transport available. There have been occasions this has prevented families from choosing the Hospice for EoL provision. There is an over-reliance upon GP arranged transport and the Palliative Care Ambulance, in addition the Rotary Club is also an option open to families.

12.2.2 Forget Me Not Children's Hospice in Huddersfield, is reasonably accessible using public transport. A small fleet of minibuses are available to support usage where required.

12.2.3 Improved links and transportation in the area would be hugely beneficial for children and families where public transport is not an option.

12.3 Funding

12.3.1 Martin House Hospice receives approximately 20% of their funding from the NHS, with 80% of income being generated from charitable monies.

12.3.2 Forget Me Not Children's Hospice receives approximately 6% of their funding from the NHS, with 94% of income being generated from charitable monies.

12.4 Governance

12.4.1 There is a robust governance structure within Martin House with a Director of Clinical Services, supported by two Deputies of Care. Six Team Leaders each lead specific areas and policy reform; ratification is deduced via a Clinical Effectiveness Committee.

12.4.2 Forget Me Not Children's Hospice employ a Finance and Corporate Service Director to oversee all aspects of the non-clinical governance arena. In particular, the understanding of the complexities in terms of charity structures and trading subsidiaries, including from an IT perspective. Clinical Governance is led by the Director of Service Delivery and Development who collaborates with the Registered Manager and a team of ANPs, a CNS, Doctors and a Physiotherapist. Pharmacy support is provided on a contract by Ashtons. The Hospice have a team of NMPs and hold a Home Office Licence for controlled drugs.

12.5 Workforce

12.5.1 Martin House is led by two Consultants qualified in Paediatric Palliative Medicine. They are supported by a Specialist Doctor in Palliative Care and a further three Speciality Doctors: specifically, one Consultant Paediatrician and two GP's. All have undertaken additional training and have a Post Graduate Diploma in Palliative Medicine.

12.5.2 The Consultants in Paediatric Palliative Medicine are employed by Leeds Teaching Hospital NHS Trust, whilst the supporting medics are directly employed by Martin House for the sessions they undertake. However, the two

consultants are funded from Martin House and the Trust recharge for this. Their job plans and working practices are not governed by Leeds governance structure.

12.5.3 All the six doctors participate on the on-call rota which allows a 24/7 medical provision to be deployed, both in terms of physically assessing a child or telephone advice to families and professionals.

12.5.4 The Speciality and Specialist doctors all possess honorary contracts with the Acute Provider to allow for them to fully participate in patients' care and advise accordingly.

12.5.5 Martin House has five Clinical Nurse Specialists (CNS) who will provide support in the community in families' homes and in local hospitals. Currently, they operate from 9am-6pm, from Monday to Saturday. The team intends to extend these hours to also cover Sundays. No night shifts are undertaken.

12.5.6 Out of Hours provision is supported by a 24/7 on-call model which is medically led. Whilst they do not attend home visits frequently, they can support both the professional or family requesting advice virtually and do participate in video consultations.

12.5.7 Forget Me Not Children's Hospice employ three doctors: one consultant paediatrician one day per week, one consultant neonatologist ½ day a week and a further consultant paediatrician with an interest in transition who also works ½ day a week.

12.5.8 Out of Hours provision is supported by a 24/7 on call model staffed by the senior nursing team inclusive of ANPs, a CNS and other seniors staff members who are NMPs. Whilst much of the activity is conducted via the phone, the team can and do go to family homes and arrange for transfers to the hospice where required.

12.6 Training

12.6.1 Every professional needs to be confident and competent in their knowledge and practice which allows them to deliver exceptional care to those children entering their final days. It is vital that every organisation has a framework for their education, training and continuing professional development.

12.6.2 Investment in training and education within both the nursing and medical personnel is well recognised with Martin House. All Clinical Nurse Specialists are non-medical prescribers or working towards this qualification.

12.6.3 Martin House is recognised nationally as a Centre of Excellence for medical training. They currently have three trainees, two completing GRID, which is a two-year programme for those doctors seeing to specialise in PPM

and one SPIN trainee. These are doctors completing additional training/obtaining experience to enable them to be a local lead or part of a network.

12.6.4 Forget Me Not Children's Hospice currently have four ANP's and a CNS, all are Non-Medical Prescribers, as are several other members of the team. Investment into the nursing personnel needs to be sustained to maintain a robust Nurse Led Model. It is this team that manages the 24/7 on-call service for existing families known to them, but they regularly receive calls from other professionals seeking specific advice and support. The Hospice will and do respond to families unknown to them when a referral has been made by a professional out of hours.

12.7 Transition

12.7.1 Failure to achieve a safe transition and deliver developmentally appropriate care can lead to disengagement and poorer outcomes. This is supported within Transition from Children's to Adults' services for young people using Health or Social Care Services, The NHS Long Term Plan (2019) and NICE Guidance (NG43).

12.7.2 Although transition from paediatrics to adult services poses difficulties for Children and Young people and their families, Martin House liaises and collaborates with the adult hospices to ensure it is seamless for the child and their family. The consultants facilitate the transfer, but they can remain involved post age 25 on a case-by-case basis, where appropriate, which can reassure the families and the adult services that they remain to have support.

12.7.3 There is a transition lead within Martin House who leads on Advanced Care Plans (ACP), Personalised Care and Support Plans and Referrals to Adult Services.

12.7.4 Forget Me Not Children's Hospice have a transition team led by a care co-ordinator. Transition starts from around age 14 with the ambition to allow for a seamless transfer to adult services. ACPs can be produced for any child of any age, this is not limited to those in transition. They aim to offer anyone on their case load the opportunity to complete an ACP, should this be required.

12.8 General Practitioners

12.8.1 There appears to be a gap in GP knowledge pertaining to services who can directly be involved and support the child receiving palliative care. This extends to a gap in awareness of and signposting to the services available for supporting the child and their families. However, GP's have minimal numbers of palliative children within their remit and therefore can feel vulnerable caring for these children.

12.8.2 Martin House medical staff liaise with GP Colleagues when required to support them in treating and supporting the child and their families.

12.8.3 Forget Me Not Children's Hospice rarely collaborate with the children's GPs but are able to on request. They liaise more frequently with CCN teams and assigned Community/Acute consultants.

12.9 Community Services

12.9.1 Although Martin House provides an outreach service into the community, this is not robustly complemented or supported by a CCN Team OOH.

12.9.2 Forget Me Not Children's Hospice have a robust 'Hospice at Home Service which extends beyond EoL Care. Families can have access 24/7 to anything delivered within the Hospice itself provided to them at their own homes, inclusive of short breaks, snowflake care and crisis care.

12.9.3 Both hospices work very closely with the CCN Teams and support services to ensure both the professional and children/families are well informed and supported.

12.9.4 There is variation in CCN teams' working hours across the localities and in the hospices. Not all work OOH or weekends and do not have overnight provision unless on an ad hoc basis. However, where OOH provision is required, Martin House and CCN personnel will collaborate and support as required.

12.9.5 Leeds Children's Hospital Macmillan Nurse Specialists – the Paediatric Oncology Nurse Specialists (POONS) - are part of the multi-disciplinary team looking after CYP with cancer and their families both in the hospital and the community. They offer a 24/7 A&G telephone line for oncology patients. This is nurse-led with support from an on-call consultant.

12.10 West Yorkshire Specialist Paediatric Palliative Team (Leeds)

12.10.1 It appears there are conflicting opinions on the introduction of a new Specialist Paediatric Palliative Care Team based out of The Leeds Teaching NHS Trust. These opinions differ in relation to whether this is the most beneficial model for the children, predicated upon whom you are discussing this with.

12.10.2 This service does not have a service specification. This has resulted in a lack of accountability and some confusion from the local CCN Teams and the Children's Hospices about what the service should provide. A service specification is being developed with the commissioners and the new team in consultation with Local

Hospices and CCN's. There are opportunities to collaborate for a medical on call which will make it less onerous for those included within the rota.

12.10.3 Certain views feel a combined, collaborative model with the monies invested into one team may have enhanced the patient journey, whilst others feel that two teams, as a separate entity, are working effectively and for the benefit of the patient. Everyone working to the same objectives, despite base location is paramount to continue the service expected for children and their families.

12.10.4 There is an opportunity to improve the medical on-call provision and relationships between the new team and the children's hospices.

12.10.5 A rota of differing personnel – Consultants in PPM, Speciality doctors and Specialist doctors, in conjunction with CNSs could support a 24/7 advice line across WY and HNY.

12.10.6 There appears to be a distinct disconnect between the Leeds team and the Hospice which alludes to being political in nature, with only the child/family lacking benefit.

12.10.7 One team of medical and nursing personnel would support annual leave, study leave, sickness, without leaving a service compromised. One consultant working unilaterally is not sustainable and not robust in the longer term.

12.11 Information Technology

12.11.1 Martin House Hospice and the community staff now use Systm1 and this has improved contemporaneous record keeping. The Acute Provider utilises a different system – PPM, which only specific medics can access and this is not interoperable with Systm1.

12.11.2 Forget Me Not also utilise Systm1 and do not articulate any interoperable problems.

12.12 Recommendations

12.12.1 Based on the information to date collated through discussion with key stakeholders within the ICB remit, the following recommendations are made to enhance the current service provision.

1) The ICB should utilise local and national data collected and collated to demonstrate the wider societal impact of the activity of Martin House and Forget Me Not Children's Hospice utilising a Population Health Management approach.

2) A change in reporting should be made to align the delivery of Statutory services with the Integrated Care Boards emerging Assurance Framework.

3) The ICB should complete a further self-assessment and subsequent next steps against the 6 principles contained within The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026.

4) Self-Assessment outcomes should be utilised to focus upon areas of development.

5) Develop a robust service specification for the West Yorkshire Paediatric Palliative Team in collaboration with local hospices and CCN Teams.

6) Consider a 24/7 advice line for professionals, children and families inclusive of CNS/ANP and medical staff from the West Yorkshire Team and the Children's Hospices over a wider geographical area – to include WY and HNY.

7) Undertake a review of services for those with language barriers/interpreting services and other inequalities as per section 3.14 and 3.15 above.

8) The ICB should instigate and offer 'Lunch & Learn' events for Primary Care – allowing GPs to be well informed of services available to them for supporting the children and families accessing palliative care and bereavement services. This could be extended to all Primary Care personnel, Social Care and Schools.

9) The ICB needs to undertake a full review of paediatric CCN Teams to ensure OOH provision is supported on a permanent basis opposed to an ad hoc. This could be a collaborative approach with neighbouring localities.

10) The ICB should work in partnership with system partners to improve the limited transport linkages for families. In addition, they could potentially fund Hospices to provide access and transport.

13.0 South Yorkshire ICB

13.0.1 Table 5 below summarises the services available within the ICB.

Table 5 - South Yorkshire Service Summary

Organisation	Number of SPPCs^	24/7 Telephone Advice Line?	Hours a telephone advice line is available	Medically led	Nurse led with GP support	Opening hours per week
Bluebell Wood Hospice	0	✓	24/7	✗	✓	4 nights respite care

^ GRID-trained Specialist Palliative Paediatric Consultants

13.1 Infrastructure

13.1.1 Bluebell Wood Children's Hospice provides respite and EoL care and symptom management. The Hospice delivers care to CYP up to the age 25 with life threatening and life limiting conditions. A substantial range of family support services are also offered.

13.1.2 The Model of service delivery is Nurse Led currently.

13.1.3 The main referral routes into the Hospice are via Sheffield Children's NHS FT, Rotherham, Doncaster and South Humber NHS FT. Sheffield Children's Hospital Paediatric Palliative Care Team works primarily with Bluebell Wood for referrals and advice and occasionally refers to Martin House and Forget Me Not Hospices in West Yorkshire.

13.1.4 The Paediatric Oncology Outreach Nurse Specialist (POONS) Team cares for oncology patients – families can call the Oncology Ward of Sheffield Children's Hospital OOH.

13.1.5 A phased reopening is currently being implemented since the temporary closure of Bluebell Wood clinical care services. The closure was undertaken to assure safety of services for children, families and staff in line with regulatory requirements.

13.1.6 The Hospice currently offers the equivalent of four nights of respite care per week. If upcoming recruitment is successful, respite care will be offered over seven nights and unplanned stays (emergency and unexpected) and post-death services will be reintroduced, with the aim to offer end of life care within twelve months.

13.1.7 The Hospice has maintained a 24/7 telephone line through which families and professionals can access on-call nurses. There is currently no medical consultant in-house, but the Hospice is in discussion with a local GP practice around potential collaboration.

13.1.8 Sheffield Children's NHS Foundation Trust provides respite care from Ryegate House.

13.2 Geographical Boundaries

13.2.1 Bluebell Wood Children's Hospice operates across South Yorkshire, North Derbyshire, North Nottinghamshire and parts of North Lincolnshire. The Hospice is a half hour drive from Sheffield Children's NHS FT and is not accessible by public transport. This poses severe difficulties for families and influences their decision for the support of the Hospice.

13.2.2 Children from Nottingham and Nottinghamshire ICS still access Doncaster Royal Infirmary or Sheffield Children's Hospital, and Bluebell Wood which is the closest hospice.

13.2.3 Improved links and transportation would be hugely beneficial for children and their families.

13.3 Funding

13.3.1 Bluebell Wood received 10% of the total £5.7m from NHS monies and 90% from charitable funds.

13.4 Governance

13.4.1 There is increased stability in the Hospice since changes in leadership have been undertaken. The current model for Bluebell Wood is care focussed.

13.4.2 There is the potential to change internal governance and strategic focus to a model that balances care, financial growth and stability.

13.4.3 A clear structure has not been designed which reveals the responsibility of local hospital consultants and which cases are appropriate for tertiary level medical care or sub regional hospice and what should be held locally. This leads to variation in care and in community provision.

13.5 Workforce

13.5.1 Significant scarcity of key Paediatric Palliative Medicine Consultants has left the Hospice compromised, hence, the closure in 2022 when their consultant moved roles.

13.5.2 Only one CNS remains who is a Non-Medical Prescriber, however, active recruitment to another post is ongoing.

13.5.3 Ongoing recruitment is required to sustain a protracted Nurse Led Model.

13.5.4 Collaboration with regional hospices may be beneficial to support development and prevent further closures.

13.5.5 Sheffield Children's NHS Foundation Trust has one individual consultant who provides OOH A&G; however, this is not sustainable long term.

13.6 Training

13.6.1 Every professional needs to be confident and competent in their knowledge and practice which allows them to deliver exceptional care to those children entering their final days. It is vital that every organisation has a framework for their education, training and continuing professional development.

13.6.2 Investment within the nursing personnel is well recognised and pursued and will be beneficial to attract further CNS to be recruited.

13.7 Transition

13.7.1 Failure to achieve a safe transition and deliver developmentally appropriate care can lead to disengagement and poorer outcomes. This is supported within Transition from Children's to Adults' services for young people using Health or Social Care Services, The NHS Long Term Plan (2019) and NICE Guidance (NG43).

13.7.2 Although transition from paediatrics to adult services poses difficulties for Children and Young people and their families, the Hospice provides, assists and conducts transition meetings for children and their families.

13.8 General Practitioners

13.8.1 There appears to be a gap in GP knowledge pertaining to services who can directly be involved and support the child receiving palliative care. This extends to a gap in awareness of and signposting to the services available for supporting the child and their families. However, GP's have minimal numbers of palliative children within their remit and therefore can feel vulnerable caring for these children.

13.8.2 Most referrals to hospices are received from specialist teams opposed to directly from GPs.

13.8.3 Most PEoLC for children in the region is held in specialities. GPs are not frequently sighted on the detail of patients with complex life limiting conditions.

13.9 Community Services

13.9.1 There are no Paediatric CCN Teams in Sheffield.

13.9.2 The Helena Specialist Nursing Team support with on-call services and community visits.

13.9.3 Sheffield Children's Hospital is both the specialist tertiary and community generalist asset in Sheffield.

13.9.4 A team of experienced Children's Community Nurses based out of Rotherham and Doncaster provide support CYP and families, including those requiring EoL care. The Doncaster team works Monday to Friday from 8am to 6pm.

13.10 Information Technology

13.10.1 The current systems and processes have evolved to meet the current need however there is significant potential for improvement.

13.10.2 Bluebell Wood operates using The Care Database. Whilst the Helena Specialist Team utilises EDMS.

13.10.3 There is no integration or interoperability with existing electronic patient record systems between the Hospice, Acute or Community Teams.

13.11 Recommendations

13.11.1 Based on the information to date collated through discussion with key stakeholders within the ICB remit, the following recommendations are made to enhance the current service provision.

1) The ICB should utilise local and national data collected and collated to demonstrate the wider societal impact of the activity of Bluebell Wood utilising a Population Health Management approach.

2) A change in reporting should be made to align the delivery of Statutory services with the Integrated Care Boards emerging Assurance Framework.

3) The ICB should complete a further self-assessment and subsequent next steps against the 6 principles contained within The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026.

4) Self-Assessment outcomes should be utilised to focus upon areas of development.

5) Devise a tiered model of on-call - Inclusive of CNS/ANP and Medics over a wider geographical area.

6) Undertake a review of services for those with language barriers/interpreting services and other inequalities as per section 3.14 and 3.15 above.

7) The ICB should instigate and offer 'Lunch & Learn' events for Primary Care – allowing GPs to be well informed of services available to them for supporting the children and families accessing palliative care and bereavement services. This could be extended to all Primary Care personnel, Social Care and Schools.

8) The ICB should undertake a full review of paediatric CCN Teams to ensure OOH provision is supported on a permanent basis opposed to an ad hoc. This could be a collaborative approach with neighbouring localities.

9) The ICB should work in partnership with system partners to improve the limited transport linkages for families.

14.0 North East and North Cumbria ICB

14.0.1 Table 6 below summarises the services available within the ICB.

Table 6 - North East and North Cumbria Service Summary

Organisation	Number of SPPCs^	24/7 Telephone Advice Line?	Hours a telephone advice line is available	Medically Led	Nurse Led with Support	Opening hours per week
St Oswald's Hospice	0	✗	Through CHIPS 08:00-18:00 Mon to Fri & 09:00-17:00 Sat to Sun	✗	✓ GP Support	24/7
Zoe's Place Baby Hospice	0	✗	Through CHIPS 08:00-18:00 Mon to Fri & 09:00-17:00 Sat to Sun	✗	✓ GP & CHIPS Support for EoL	5-6 nights per week
Jigsaw Hospice	0	✗	Through CHIPS 08:00-18:00 Mon to Fri & 09:00-17:00 Sat to Sun	✗	✓ GP & CHIPS Support	3 nights, 4 days Up to 24/7 for approx. 1-2 children
CHIPS team[1]	0	✗	Through CHIPS 08:00-18:00 Mon to Fri & 09:00-17:00 Sat to Sun	✓	✗	08:00-18:00 Mon to Fri 09:00-17:00 Sat to Sun
CYPOONS[2]	0	✓	24/7	✗	✓ Oncology Specialist Support	24/7

^ GRID-trained Specialist Palliative Paediatric Consultants
[1] Children's Holistic Integrated Palliative Care Service (hosted by GNCH)
[2] Children and Young People's Oncology Outreach Nurse Specialists (CYPOONS) based at GCNH

14.1 Infrastructure

14.1.1 Whilst there are several Paediatric Hospices within the North East and North Cumbria (NENC) the infrastructure of EoL care is different to those of the other regions.

14.1.2 The regional service is provided by the Children's Holistic Integrated Palliative Care Service (CHIPS) Team funded by Specialised Commissioning. This team offer A&G to all four hospices within NENC but not 24/7 provision.

14.1.3 The CHIPS team, hosted by the Great North Children's Hospital (GNCH) provides specialist paediatric palliative care advice and nursing care seven days per week (8am-6pm Monday to Friday and 9am-5pm Saturday to Sunday). Referrals have increased significantly since the launch of the service in January 2020.

14.1.4 The CHIPS team compromises 1.5 WTE Medical cover, 2.9 WTE Specialist Nurse and 1.0 WTE Administrative. Medics are a blend of Community Consultant Paediatricians with a special interest in Palliative care and GPs.

14.1.5 They implement a tiered on-call with CNS as first on-call, with support from a consultant should this be required.

14.1.6 Support for paediatric oncology patients is provided by the Children and Young People's Oncology Outreach Nurse Specialists (CYPOONS) based at GCNH.

14.1.7 There are four hospices offering PEoLC for CYP within NENC ICB:

- St Oswald's Hospice
- Zoe's Place Baby Hospice
- Jigsaw Hospice
- Butterwick Hospice (out of scope).

14.1.8 St Oswald's provides both Adult and Paediatric respite and EoL care. Care is provided through a Nurse Led Model with an MDT approach consisting comprising of Consultants, Doctors, Nurses, Social Workers, Spiritual Care, Bereavement Support Workers, Physiotherapists, Occupational Therapists and Complementary Therapists. There are currently 8 beds for paediatrics.

14.1.9 Zoe's Place Baby Hospice provides respite and PEoLC care to babies and infants from birth up to the age of five with life-limiting or life-threatening conditions. This is a Nurse Led Model with GP and CHIPS Team support for EoL. The Hospice is not open full time due to small referral numbers. There are six beds available and at maximum capacity five to six children can be accepted at any one time. Currently, there are 41 children and their families accessing the Hospice on a regular basis. The Hospice is opening approximately five nights per week and families can call within those hours for advice and guidance. Some children attend for day-care only (9am - 5pm). Most children and families stay for a 24-hour short break. Therefore, Zoe's place can regularly provide up to 30 overnights/24-hour respite episodes per week (six beds for five nights).

14.1.10 Jigsaw Children's Hospice is contained within Eden Valley Hospice which is an Adult Hospice. The Hospice provides one to one PEoLC for CYP with life limiting illnesses and offers support for families. Since January 2022 the service has fluctuated in terms of opening days/nights and beds available. Currently, they are open (on average) 3 nights, 4 days per week, and take on an average of two children overnight and sometimes a further child for day care. Medical cover is available from the Adult Hospice clinicians, but specialist paediatric A&G is also required. Ad-hoc A&G is sought from referring teams and CHIPS Team.

14.2 Geographical Boundaries

14.2.1 The Hospices are located around the North East and Cumbria with a significant distance between them geographically.

14.2.2 There are no PEoLC oncology services located in Cumbria, therefore paediatric patients from North Cumbria are referred to the CYPOONS Team in Newcastle.

14.2.3 St Oswald's situated in Gosforth Newcastle is the largest of the hospices within NENC.

14.2.4 Zoë's Place is situated in Middleborough, but also has hospices based in Coventry and Liverpool.

14.2.5 Jigsaw Hospice contained within Eden Valley Hospice, is based out of Carlisle.

14.3 Funding

14.3.1 St Oswald’s Hospice is funded 2/3 via Health & Social Care and 1/3 charitable funding. Their total income expected in 2022-2023 is £1,969,921

14.3.2 The NHS grant for Zoe's Place Baby Hospice was £215,000 per annum for 2022-2023. This grant covers approximately 13.9% of total costs for the Middlesborough base. This is less than 20% of their annual income.

14.3.3 Jigsaw Hospice receives part of a 20% NHS grant which the whole of Eden Valley Hospice receives. This is not disaggregated for the children's element.

14.4 Governance

14.4.1 Whilst all three hospices have structures in situ for management of the Governance arena per se, there are specific elements which would benefit from particular focus upon.

14.4.2 CHIPS provide the majority of A&G to all the hospices contained within the NENC localities. Whilst all providers agree they receive an excellent service from this team, it is not without difficulties due to geographical boundaries, particularly Middlesbrough and Cumbria.

14.4.3 Due to lack of interoperability within IT provision, there is a risk of error in the transcription of verbal conversations around prescriptions. Confirmation processes via email and letter are implemented to mitigate this, however this would be far safer if systems could be aligned and seamless.

14.4.4 In addition, CHIPS must contact on-call GPs to prescribe on their behalf which can be timely, whilst a child is suffering with symptom management.

14.5 Workforce

14.5.1 There is a necessity for Consultants in Paediatric Palliative Medicine within the NENC. Whilst the CHIPS team have a wealth of expertise and exceptional medics within the team, they are not GRID trained. This poses difficulties as they are not able to provide specialist training to those doctors obtaining PPM training posts nationally.

14.5.2 The nearest training provider is Martin House in Wetherby.

14.5.3 St Oswald's do not have difficulty in recruiting to posts or within training of their staff. A robust training programme is evident and implemented. They have reviewed salaries and annual leave to attempt to align with Agenda for Change which attracts applicants.

14.5.4 Whilst operating a Nurse Led Model, St Oswald's does have the support of their Adult Palliative Care Consultants and GNCH paediatricians OOH.

14.5.5 They are actively attempting to recruit to a GRID trained post collaboratively with GNCH.

14.5.6 St Oswald's are the biggest hospice regionally and employ approximately 56 staff of all disciplines, inclusive of RGN/RSCN/RLDN/Care Support staff/Associate Practitioners/Physiotherapists and Activity Co-ordinators.

14.5.7 Zoe's place has seen a reduction in the number of applicants for roles. One factor in this is competitive offers from NHS roles. The charitable organisation has recently matched salaries to Agenda for Change and offered other benefits to attract candidates. Matching NHS pensions is not currently a financially viable option.

14.5.8 Jigsaw is also experiencing marked difficulties in recruitment. Competitors are the Community Children's Nursing Team and the District General Hospitals. Historically, lesser salaries compared to NHS organisations added to this challenge, but these are now matched to Agenda for Change. The reputation of the Hospice locally has also improved.

14.6 Training

14.6.1 Every professional needs to be confident and competent in their knowledge and practice which allows them to deliver exceptional care to those children entering their final days. It is vital that every organisation has a framework for their education, training and continuing professional development.

14.6.2 As stipulated above, official specialised GRID training for medics can only be completed at Martin House in Wetherby or another provider where there are GRID trained consultants. Should St Oswald's be successful in recruiting a GRID trained consultant, this will pave the way for the future training of regional doctors.

14.6.3 St Oswald's clinical leads are embarking upon CNS training and ANP status and this has been well supported.

14.6.4 Continued investment within the nursing personnel is vital within Zoe's Place and Jigsaw to sustain a developed and protracted Nurse Led Model. Jigsaw support training with Master's Degrees, Advanced Communication Skills, Conflict Resolution, they have their own in-house training for clinical skills such as epilepsy or TPN training.

14.6.5 Zoe's Place have a new nursing care strategy to support nurses and care assistants through their clinical skills and nurse prescribing qualifications. All nurses have completed the PILS and BLS courses and completed the management of a sick child training programme. The Hospice has a robust in-house induction training programme and mentorship. External training provided throughout the year is available through Service Level Agreements with the Acute Hospital. Some of the team have training in bereavement and counselling. There is a play leader in post. The Hospice has an inhouse competency framework to ensure that Nurses and Care Assistants are skilled in Tracheostomy, Ventilation, TPN, Oxygen Therapy, IV, Sub-cutaneous and Oral Administration of Medication. These are reviewed annually.

14.7 Transition

14.7.1 Failure to achieve a safe transition and deliver developmentally appropriate care can lead to disengagement and poorer outcomes. This is supported within Transition from Children's to Adults' services for young people using Health or Social Care Services, The NHS Long Term Plan (2019) and NICE Guidance (NG43).

14.7.2 Although transition from paediatrics to adult services poses difficulties for CYP and their families, St Oswald's assists and conducts transition meetings for children and their families. A medical transitional lead supports this element. However, as most of the service provision is respite opposed to EoL, this becomes problematic from the age of 25 when childrens' services discontinue. Collaborative reviews with Case Managers from Continuing Healthcare (CHC) are undertaken to support future care.

14.7.3 Zoe's Place do not embark in transitional care due to the age constraints of the children within their care. However, they have an outcome measure for transition and the team attempt to ensure the child is transferred to a suitable care provider based upon availability. This is a home service, the Butterwick (when able) and the Baysdale unit based within Tees Esk and Wear Valley NHS Trust.

14.7.4 Jigsaw Hospice are currently advertising for a transition lead and our staff are engaging in ACP training with some facilitating discussions with families.

14.8 Primary Care

14.8.1 There appears to be a gap in GP knowledge pertaining to services who can directly be involved and support the child receiving palliative care. This extends to a gap in awareness of and signposting to the services available for supporting the child and their families. However, GP's have minimal numbers of palliative children within their remit and therefore can feel vulnerable caring for these children.

14.8.2 Most referrals to hospices are received from specialist teams opposed to directly from GPs.

14.8.3 Most PEoLC for children in the region is held in specialities. GPs are not frequently sighted on the detail of patients with complex life limiting conditions.

14.8.4 Whilst the CHIPS team can link in with primary care across the region, they have limited knowledge on geographical boundaries and infrastructure which can pose difficulties.

14.8.5 A neighbouring GP Practice partners with Zoe's Place to offer support for EoL care when required. The GP has each child at Zoë's place registered as a temporary patient and offers Primary Care support to these children. The GP contacts the Hospice daily (Monday – Friday) and visits the child, assesses and prescribes for minor health issues e.g. URTI, UTI and skin problems. This prevent the child having to be referred to James Cook University Hospital (JCUH) or have an early discharge home to see their own GP.

14.8.6 Children that go to Jigsaw Hospice for respite are under the care of their GP and in-house clinicians work in partnership for the benefit of continuity of care.

14.9 Community Services

14.9.1 Not all areas across the region have 24/7 Community Paediatric Nursing Care. There is variation in CCN teams pertaining to working patterns serving localities and hospices. Not all work OOH or weekends and not overnight provision unless on an ad hoc basis.

14.9.2 All hospices work very closely with the Children's Community Teams and support services to ensure both the professional and children/families are well informed and supported.

14.9.3 St Oswald's are currently developing an outreach service into the community. Whilst this has been funded non-recurrently in the first instance, there is hope that this will be commissioned for the future.

14.9.4 The CYPOONS team operates out of Great North Children's Hospital for oncological care and works in collaboration with the CHIPS and Hospice services.

14.9.5 The North Cumbria Integrated Care Children's Community Nursing (CCN) team offers PEoLC closer to home for patients. This team operates from 9am to 5pm, Monday to Friday.

14.10 Information Technology

14.10.1 The CHIPS Team, whilst utilising The Great North Care Record, do encounter difficulties with the IT interoperability when offering A&G and prescribing to other localities within the region. Each area is utilising different systems, now of which are interoperable. This leaves the safety of patients and prescribing of drugs compromised and at risk of transcribing errors.

14.10.2 St Oswald's hospice is utilising Systm1 within adult services and this has been cascaded to paediatrics. This is interoperable with the GPs and Community provision and therefore this has been beneficial to all clinical personnel.

14.10.3 Zoe's place uses the Care Database which GP's and physios need to be given access to individually. This is where any advice shared with families is stored. An NHS mail account is also used to relay patient identifiable information on to professionals involved. Interoperability is a long-standing challenge and causes inefficiencies for the service as staff collaborate with paediatricians in the Acute Trust around medications and clinical letters.

14.10.4 Jigsaw Hospice utilises EMIS, which algins with their local GPs (beneficial for children in respite care) but have different software to the Children's Community Team and the Acute Provider. The Great North Care Record will be accessed by Jigsaw Hospice imminently.

14.11 Recommendations

14.11.1 Based on the information to date collated through discussion with key stakeholders within the ICB remit, the following recommendations are made to enhance the current service provision.

1) The ICB should utilise local and national data collected and collated to demonstrate the wider societal impact of the activity of all three of the hospices utilising a Population Health Management approach.

2) A change in reporting should be made to align the delivery of Statutory services with the Integrated Care Boards emerging Assurance Framework.

3) The ICB should complete a further self-assessment and subsequent next steps against the 6 principles contained within The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2021-2026.

4) Self-Assessment outcomes should be utilised to focus upon areas of development.

5) The ICB should review the service specification/bid with specialised commissioners in relation to funding the CHIPS service 24/7.

6) Offer an attractive role to recruit a GRID trained consultant, which ultimately will allow trainees to be placed in the North East and be vital in both expansion of the team and succession planning.

7) Devise a tiered model of on-call - Inclusive of CNS/ANP and Medics over a wider geographical area.

8) Undertake a review of services for those with language barriers/interpreting services and other inequalities as per section 3.14 and 3.15 above.

9) The ICB should instigate and offer 'Lunch & Learn' events for Primary Care – allowing GPs to be well informed of services available to them for supporting the children and families accessing palliative care and bereavement services. This could be extended to all Primary Care personnel, Social Care and Schools.

10) Undertake a full review of paediatric CCN Teams to ensure OOH provision is supported on a permanent basis opposed to an ad hoc. This could be a collaborative approach with neighbouring localities.

11) The ICB should work in partnership with system partners to improve the limited transport linkages for families.

15.0 Economies of Scale

15.1 Whilst a full review has been undertaken across the NEY, there are viable options to enhance the current service offers.

15.2 West Yorkshire has the capabilities to collaborate across both Acute Provider/Hospices to provide a more comprehensive model. Whilst a presence within the Trust is vital, this could be a rotational role from a medical perspective and CNS. This would assist with cross covering of sickness, annual leave, whilst also building relationships within the region. A larger team could provide 24/7 telephone A&G across all the Yorkshire regions which would ensure NICE compliance.

15.3 A combined, collaborative model can only enhance the care given to children and their families whilst also offering a developmental opportunity for both medics and nursing personnel.

15.4 Martin House, Forget Me Not and St Andrews could all be included within the model above which would add additional resource to a rotational model.

15.5 A tiered rota at a regional level compromising medics and CNS/ANP could be devised which would ensure a less onerous on-call for medics and could emulate those models spanning other areas. This would also ensure compliance with working time directives for specific consultants.

15.6 The third-party call handling provider EMBRACE could be utilised within a central model of on call, building upon their expertise of call handling/transfer of critically ill patients.

15.7 Commissioners should review CCN Teams OOH and collaborate to provide a 'regional mobile team(s)' on an on-call basis. Whilst this will require a business case, inclusive of costings, this will be of significant benefit to children, families and current teams, whom, are expected to provide cover on an ad hoc basis currently, thus, depleting in hours core staffing.

15.8 Within NENC, additional funding from Specialised Commissioning would allow an increase in resource within the CHIPS Team, thus, enhancing a regional response to 24/7 A&G and ensuring compliance with NICE Guidance.

16.0 Conclusion

16.1 To conclude, the scope of this assignment was to ascertain whether 24/7 A&G telephone lines were apparent within the NEY and were the patients and families receiving a service as dictated in national mandates.

16.2 The review deduced that 24/7 wasn't widely available to all children and there is a definite inequity dependent upon location.

16.3 There are inequities between oncological and non-oncological children, with those with a cancer diagnosis receiving enhanced support and on a 24/7 basis.

16.4 In addition, the review has obtained a wealth of knowledge in relation to intricacies within the patient journey and those that pose difficulties to the teams.

16.5 Information offered has allowed recommendations to be defined both for individual ICBs and at scale.

17.0 Next steps

17.1 Utilise a PHM approach within each ICB to clearly articulate/understand locality information, this is paramount for development of services.

17.2 Undertake service mapping/need within each ICB based on PHM findings and outcomes of this review.

17.3 Facilitative workshop between WY Leeds Specialist Palliative Team and Hospices to clearly define service specification and Model of Care for the future.

17.4 Collaborate with all ICBs to formulate service specifications for PEoLC adhering to national guidance.

17.5 Devise an IT data collection tool for all areas to collate numbers accessing hospice provision and A&G advice lines.

17.6 The findings should allow for discussion within each ICB and ultimately at commissioner level.

17.7 Recommendations should be progressed at ICB level and at scale, facilitated by NHSE.

18.0 Author

Nicola Jones - Senior Manager
Simeon Nichols - Junior Consultant

19.0 Appendices

Appendix 1 – Research Documents

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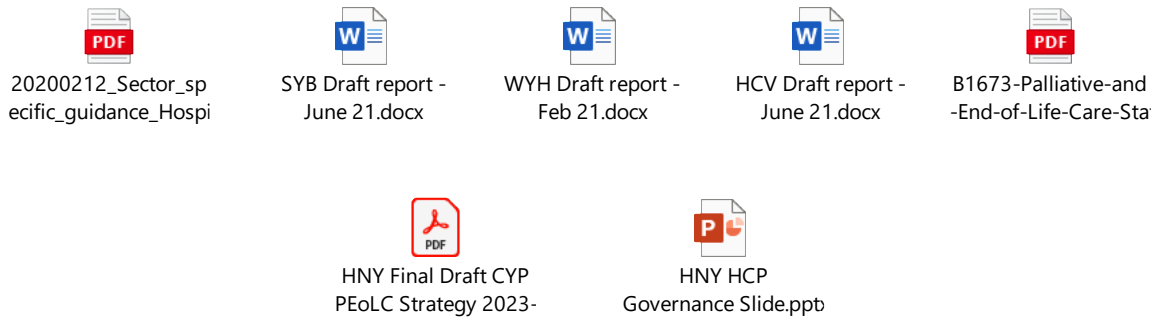

Appendix 2 – Stakeholders Interviewed

HNY Stakeholder Interviews

Interviewee	Role	Organisation
Aparna Manou	Neonatal Lead	Hull University Teaching Hospitals NHS Trust
Dr Amy Oehring	GP & GP Lead CYP & Mat	Hull CCG
Dr Chris Wood	Clinical Director Paediatric and Neonates	Hull University Teaching Hospitals NHS Trust
Dr Vijaya Hebbar	Clinical Lead Paediatrics DPoW	Northern Lincolnshire and Goole NHS FT
Emma-Jayne Ashley	Parent	
Jayne Lowther	Clinical Manager, Health & Wellbeing – Community Children's Nursing Team	City Health Care Partnership
Karen McNicholas	Secondment as CYP Program Lead	HNY ICB
Michelle Rollinson	CEO	St Andrews Hospice
Sandhya Jose	Community Paediatric Lead	Hull University Teaching Hospitals NHS Trust

NENC Stakeholder Interviews

Interviewee	Role	Organisation
David Purdue	Executive Chief Nurse, ICS lead for Children	NENC Integrated Care Board
Dr Helen Aspey	Community Paediatrician & Children's Holistic Palliative Care Service (CHIPS) Lead	Great North Children's Hospital - CHIPS team
Dr Maeve O'Sullivan	Clinical Director	James Cook University Hospital South Tees
Dr Mike Mckean	Consultant in Respiratory Paediatrics, Clinical Lead for the Child Health & Wellbeing Network (NENC ICS), Clinical Advisor for NHSIE NEY Childrens Oversight Board, Vice-President for Policy for Royal College or Paediatrics & Child Health (RCPCH)	Great North Children's Hospital - Newcastle
Jo Elverson	Specialist Palliative Medicine Consultant	St Oswald's Hospice
Jocelyn Thompson	Children and Young Adults Service Manager	St Oswald's Hospice
Lindsey Shaw	Parent	
Michelle Larkin	Head of Care	Zoe's Place Baby Hospice
Simon Gordon	Director of Strategy and Development	St Oswald's Hospice
Suzanne Garbarino-Danson	Clinical Lead	Eden Valley Hospice & Jigsaw Hospice, Cumbria
Yasmin Sultana Khan	Specialised Commissioning - Service Specialist: Women and Childrens Programme of Care	NHS England - North East and Yorkshire Region

SY Stakeholder Interviews

Interviewee	Role	Organisation
Anthony Gore	GP and Clinical Director for CYP and maternity	NHS South Yorkshire ICB
Anton Mayer	Tertiary Care Consultant	Sheffield Children's Hospital
Chris Downes	Parent	
Ellie Addison	Palliative Care CNS	Bluebell Wood Children's Hospice
Gemma Barker	Palliative Care CNS	Sheffield Children's NSH FT
Nic Marriott	CEO	Bluebell Wood Hospice
Sally Bolsover	Community Matron	Sheffield Children's NHS FT
Sally Gibbs	Consultant Paediatrician and Clinical Director for Medicine	Sheffield Children's NHS FT
Sam Rooksby	Team Lead- Long Term Conditions	Children's Care Group - RDaSH
Terry Hayes	Head of Childrens Nursing	NHS Nottingham & Nottinghamshire ICB

WY Stakeholder Interviews

Interviewee	Role	Organisation
Becki Rose	Children's Palliative Care Nurse Specialist	Bradford and Airedale Community Team
Caroline Mullins	Programme manager for the CYP and families	WY ICB
Clair Holdsworth	CEO	Martin House Hospice
Colin Holton	Clinical Director and line manager of the PC team	Leeds Children's Hospital
David Durbin	Parent	
Dr Archana Soman	Consultant in Paediatric Palliative Medicine and Clinical Lead for WY	WYCSPCC
Dr Michelle Hills	CMO for Martin House and Consultant in Paediatric Palliative Medicine	Leeds Teaching Hospital NHS Trust / Martin House Children's Hospice
Dr Ross Smith	Consultant in Paediatric Palliative Medicine	Leeds Teaching Hospital NHS Trust / Martin House Children's Hospice
Helen Storton	Clinical Nurse Specialist	Martin House Hospice
Jo Rooney	Commissioner	WY ICB
Luen Thompson	CEO	Forget Me Not
Renee McCulloch	Consultant Paediatric Palliative Medicine	The Royal Marsden NHSFT
Ruth Shaw	Children's commissioner	WY ICB
Sayma Mirza	Associate Director for Children, Young People and Families	WY ICB
Susan Picton	Oncology lead	Leeds Children's Hospital
Vicki Greensmith	Director of Clinical Services	Martin House Hospice
Zoe Richardson	Digital Project Manager	West Yorkshire ICB

National and Other ICS Stakeholders

Interviewee	Role	Organisation
Anna-karenia Anderson	APPM Chair	Medical Director for Shooting Star Children's Hospice
Davina Hartley	Senior Manager CYP PEoLC	NHSE
Dr Helena Dunbar	Director of Service Development and Improvement	Together For Short Lives
Helen Hemming	Improvement Lead, system improvement	NHSE
Noreen Sheikh-Latif	Improvement manager	NHSE
Sarah Mitchell	Associate Professor of Palliative Care, University of Leeds Regional Clinical Lead for Palliative and End of Life Care, NEY SCN National Senior Clinical Lead for Palliative and End of Life Care, NHS England	South Yorkshire ICB

Appendix 3 - Key Lines of Enquiry

Key Lines of Enquiry
CYP PEoLC NEY v0.3.c