

Northern Children's Palliative Care Network audit 2020

Response form

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

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

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
CHIPS and CCN teams with Allied Health Care Professionals	Cumbria	NHS Specialist commissioning - CHIPS
	Hambleton, Richmondshire and Whitby	CCN and AHP's - CCG
	Hartlepool and Stockton-on-Tees	
	Newcastle Gateshead	
	County Durham and Darlington	
	Northumberland and North Tyneside	
	South Tyneside and Sunderland	
POONS Paediatric Oncology Outreach Nursing Service	Cumbria	NHS Specialist commissioning
	Hambleton, Richmondshire and Whitby	
	Hartlepool and Stockton-on-Tees	
	Newcastle Gateshead	
	County Durham and Darlington	
	Northumberland and North Tyneside	
	South Tyneside and Sunderland	

^[1] This is defined in NICE guideline [NG61] 'End of life care for infants, children and young people with life-limiting conditions: planning and management':
<https://www.nice.org.uk/guidance/ng61/chapter/recommendations#multidisciplinary-team>

2. Parents or carers of infants, children and young people approaching the end of life can access support for grief and loss at home when their child is nearing the end of their life and after their death.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Paula Appleby and Rebecca – siblings and adults. The child has to have contact with Newcastle hospitals	Cumbria Hambleton, Richmondshire and Whitby Hartlepool and Stockton-on-Tees Newcastle Gateshead County Durham and Darlington Northumberland and North Tyneside South Tyneside and Sunderland	Newcastle City Council
St Oswald's Hospice Ltd	Newcastle , Gateshead, North Durham, Northumberland, North Tyneside, South Tyneside and Sunderland	Charity
Butterwick ?		
Jigsaw ?		
Child Bereavement UK	UK wide	Charity
Martin House	Referral to Martin House	
JCUH Child and Neonatal bereavement post	About to come into post - Middlesborough	
Winston's Wish	Helpline and resources – UK wide	Charity
Rainbow Trust	Region wide – sibling support	Charity

3. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care^[2] and advice from a consultant in paediatric palliative care^[3] during normal working hours.

^[2] We would like to capture those areas where registered nurses can provide both core and specialist children's palliative care in the community, to children with a range of medical complexity. We acknowledge that, where this is provided, it is done so by nurses with different roles, employed by the NHS and/or the voluntary sector. This will include specialist children's palliative care nurses providing care directly, or providing advice to other nurses providing direct care.

^[3] NHS England and NHS Improvement state that specialist children's palliative care teams should be led by specialist medical consultants. These specialist consultants are vital because they:

- have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum
- the ability to manage the full range of symptoms experienced as disease and illness progresses
- lead and develop services within their region
- enable, support, teach and train other health care professionals.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
CHIPS and CCN Teams	Cumbria	NHS Specialist commissioning _CHIPS
	Hambleton, Richmondshire and Whitby	CCG – CCN teams
	Hartlepool and Stockton-on-Tees	
	Newcastle Gateshead	
	County Durham and Darlington	
	Northumberland and North Tyneside	
	South Tyneside and Sunderland	
POONS	Cumbria	NHS Specialist commissioning
	Hambleton, Richmondshire and Whitby	
	Hartlepool and Stockton-on-Tees	
	Newcastle Gateshead	
	County Durham and Darlington	
	Northumberland and North Tyneside	
	South Tyneside and Sunderland	

4. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care 24 hours a day, seven days a week.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
POONS	Cumbria	NHS Specialist Commissioning
	Hambleton, Richmondshire and Whitby	
	Hartlepool and Stockton-on-Tees	
	Newcastle Gateshead	
	County Durham and Darlington	
	Northumberland and North Tyneside	
	South Tyneside and Sunderland	

5. Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care) during normal working hours.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
CHIPS	Cumbria	
	Hambleton, Richmondshire and Whitby	
	Hartlepool and Stockton-on-Tees	
	Newcastle Gateshead	
	County Durham and Darlington	
	Northumberland and North Tyneside	
	South Tyneside and Sunderland	
POONS	Cumbria	NHS Specialist Commissioning
	Hambleton, Richmondshire and Whitby	
	Hartlepool and Stockton-on-Tees	
	Newcastle Gateshead	
	County Durham and Darlington	
	Northumberland and North Tyneside	
	South Tyneside and Sunderland	

6. Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care), 24 hours a day, seven days a week.

7. Infants, children and young people with a life-limiting condition and their parents or carers can access emotional and psychological support at home.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Neurology	Newcastle Hospitals NHS Foundation Trust/Northern Region	NHS
Cardiology	Newcastle Hospitals NHS Foundation Trust/Northern Region	NHS
Renal	Newcastle Hospitals NHS Foundation Trust/Northern Region	NHS
Bone Marrow Transplant	Newcastle Hospitals NHS Foundation Trust/Northern Region	NHS
Diabetes	Newcastle Hospitals NHS Foundation Trust/Northern Region	NHS
Cystic Fibrosis	Newcastle Hospitals NHS Foundation Trust/Northern Region	NHS

8. Infants, children and young people with a life-limiting condition and their families can access regular short breaks for respite at home should they wish^[8].

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Jigsaw	Cumbria	
Zoe's Place/Martin House	Hambleton, Richmondshire and Whitby	
Zoe' Place/Butterwick	Hartlepool and Stockton-on-Tees	
St Oswald's Hospice Ltd	Newcastle, Gateshead, County Durham, Northumberland, North Tyneside, South Tyneside and Sunderland	Charitable, Social Care and Health – shared funding arrangement for all short breaks
Continuing Health Care – breaks in home	All areas	CCG

Please return your completed form to james.cooper@togetherforshortlives.org.uk and dan.steer@togetherforshortlives.org.uk

^[8] Short breaks may take place in the child's home or in a setting outside of the home such as a long-term care facility or hospice. It may include overnight breaks, or breaks lasting only a few hours.