

**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<sup>[1]</sup>.

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)
Martin House Children’s Hospices ; Paediatric Pall Care Consultants; Clinical Psychology; Specialist nurse; Therapists; bereavement counsellors	West Yorkshire, North Yorkshire, East Yorks (Humber, Coast and Vale)	Charitable
Sheffield Children’s Hospital NHS FT Palliative Care consultant, Specialist Nurse, Community team, Psychology, Pharmacy	Sheffield (Sheffield Post code)	NHS
Calderdale & Huddersfield NHS Trust	Calderdale & Huddersfield	NHS
Airedale NHSFT	NHS Bradford District and Craven CCG and parts of East	NHS

<sup>[1]</sup> 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>

	Lancashire-including Earby, Barnoldswick and Colne	
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS
<p>Northern Lincolnshire &amp; Goole NHS Foundation Trust Children's Community Team main providers;</p> <p>North Lincolnshire- POSCU Lead Nurse, Palliative Lead Nurse, Children's Specialist Complex Needs Nurse</p> <p>North East Lincolnshire- POSCU Lead Nurse, Children's Specialist Complex Needs Nurse</p>	<p>North Lincolnshire, North East Lincolnshire- providing the patient is registered with a North Lincolnshire/North East Lincolnshire General Practitioner or Under the care of Consultant Paediatrician at Northern Lincolnshire &amp; Goole NHS Foundation Trust</p>	<p>NHS Currently Paediatric Consultant with an interest in Paediatric Palliative care- 1 PA Paediatric Palliative Lead Nurse 15 hours per week- for North Lincolnshire Patient.</p> <p>X2 WTE Complex Needs Nurses 1 covering North Lincolnshire Patients and 1 covering North East Lincolnshire Patients- Mon-Fri 8-4 service</p> <p>X2 Part-time Paediatric Oncology Shared Care Lead nurses 22.5 hours per week for North Lincolnshire and 24 hours per week for North Lincolnshire Mon-Fri service 9-5 with each nurse covering each other.</p>
<p>Forget Me Not Children's Hospice Level 3 Paediatrician, Neonatologist, GP, ANPs, EMDR Therapist, Counsellors, SUDIC Worker, Midwife, Neonatal nurse, Bereavement worker, Creative therapist, Learning disability nurses</p> <p>Bluebell Wood Children's Hospice</p>	<p>West Yorkshire</p> <p>South Yorkshire, North Derbyshire, North Nottinghamshire, North Lincolnshire</p>	<p>Charity</p> <p>Charitable/ NHS</p>

Leeds Children's Community Nursing Team	Leeds	NHS

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.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Martin House Children's Hospice	West Yorkshire, North Yorkshire, East Yorks (Humber, Coast and Vale)	Charitable
Sheffield Children's Hospital NHS FT	Sheffield	NHS
Calderdale & Huddersfield NHS Trust	Calderdale & Huddersfield	NHS
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS
Northern Lincolnshire & Goole NHS Foundation Trust- Palliative Lead Nurse, Children's Specialist Complex Needs Nurse, POSCU Lead Nurse, Bereavement Midwife Team above offer initial support for grief and loss with additional information to signpost families to further support networks	North Lincolnshire, North East Lincolnshire- providing the patient is registered with a North Lincolnshire/North East Lincolnshire General Practitioner or Under the care of Consultant Paediatrician at Northern Lincolnshire & Goole NHS Foundation Trust	NHS
Forget Me Not Children's Hospice. Counsellors, SUDIC Workers, Family Support Worker, Bereavement Worker, Sibling support worker, Creative Therapist, Midwife	West Yorkshire	Charity
Bluebell Wood Children's Hospice. <i>Counsellors, Family Support Worker, Bereavement Support Worker, Sibling support worker, Music Therapist</i>	South Yorkshire, North Derbyshire, North Nottinghamshire, North Lincolnshire	Charitable/ NHS
Leeds Children's Community Nursing Team <i>CCN Team support for child and family including</i>	Leeds	NHS

<i>play worker, link with Martin House Hospice, LTHT specialist services, community paed,</i>		
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3. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care<sup>[2]</sup> and advice from a consultant in paediatric palliative care<sup>[3]</sup> during normal working hours.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Martin House Children's Hospice	West Yorkshire, North Yorkshire, East Yorks (Humber, Coast and Vale	Charitable
Sheffield Children's Hospital NHS FT	Sheffield	NHS
Calderdale & Huddersfield NHS Trust	Calderdale & Huddersfield	NHS
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS - H@H/Community nursing – core business hours 9-5, 7 days a week. Telephone nursing support 24/7, Specialist Doctor available during business hours.
Forget Me Not Children's Hospice. ANP/Children's Nurses/Level 3 Consultant access/Neonatologist	West Yorkshire	Charity

<sup>[2]</sup> 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.

<sup>[3]</sup> 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.

Bluebell Wood Children's Hospice. <i>Consultant Palliative Paediatrician, Clinical Nurse Specialists, Specialist Registrar, Children's Senior Nurses</i>	South Yorkshire, North Derbyshire, North Nottinghamshire, North Lincolnshire	
		Charitable/ NHS
Leeds Children's Community Nursing Team	Leeds	NHS

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.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Martin House Children's Hospice	West Yorkshire, North Yorkshire, East Yorks (Humber, Coast and Vale)	Charitable
Calderdale & Huddersfield NHS Trust	Calderdale & Huddersfield	NHS
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS - Home visits for End-of-Life Care 24/7, Telephone Nursing support 24/7, Medical support as above
Northern Lincolnshire & Goole NHS Foundation Trust POSCU Lead Nurse - North Lincolnshire & North East Lincolnshire  POSCU Lead Nurses can provide 24/7 on call service for EOL care for oncology patients supported and led by Tertiary Centre.	North Lincolnshire, North East Lincolnshire- providing the patient is registered with a North Lincolnshire/North East Lincolnshire General Practitioner or Under the care of Consultant Paediatrician at Northern Lincolnshire & Goole NHS Foundation Trust	NHS
Forget Me Not Children's Hospice	West Yorkshire	Charity
Bluebell Wood Children's Hospice. Consultant Palliative Paediatrician, Clinical Nurse Specialists, Children's Senior Nurses – providing 24/7	South Yorkshire, North Derbyshire, North Nottinghamshire, North Lincolnshire	Charitable/ NHS

telephone advice and out of hours on call.		
Leeds Children's Community Nursing Team <i>Nursing Service offer out of hours support via good will. 365 days per year</i>	Leeds	NHS

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.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Martin House Children's Hospice	West Yorkshire, North Yorkshire, East Yorks (Humber, Coast and Vale)	Charitable
Calderdale & Huddersfield NHS Trust	Calderdale & Huddersfield	NHS
S Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS - H@H/Community Nursing core business hours 9-5, 7 days a week. Telephone Nursing support, 24/7. Specialist Doctor available during business hours
Forget Me Not Children's Hospice	West Yorkshire	Charity
Bluebell Wood Children's Hospice. <i>Consultant Palliative Paediatrician, Clinical Nurse Specialists, Specialist Registrar, Children's Senior Nurses, pharmacist</i>	South Yorkshire, North Derbyshire, North Nottinghamshire, North Lincolnshire	Charitable/ NHS
Leeds Children's Community Nursing Team	Leeds	NHS

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.

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)
Martin House Children's Hospice	West Yorkshire, North Yorkshire, East Yorks (Humber, Coast and Vale	Charitable
Calderdale & Huddersfield NHS Trust	Calderdale & Huddersfield	NHS
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS - H@H/Community Nursing, core business hours, 9-5, 7 days a week. Telephone nursing support 24/7. Specialist Doctor available during business hours
Forget Me Not Children's Hospice. Access to ANPs and Children's nurses 24/7. Access to Consultant input through Leeds General Hospital	West Yorkshire	Charity
Bluebell Wood Children's Hospice.Children's Senior Nurses – providing 24/7 telephone advice and out of hours on call.(Access to Consultant in Palliative Medicine for advice)	South Yorkshire, North Derbyshire, North Nottinghamshire, North Lincolnshire	Charitable/ NHS
Leeds Children's Community Nursing Team <i>Nursing Service offer out of hours support via good will. 365 days per year</i>	Leeds	NHS



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

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Martin House Children's Hospice	West Yorkshire, North Yorkshire, East Yorks (Humber, Coast and Vale)	Charitable
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS
Northern Lincolnshire & Goole NHS Foundation Trust  North Lincolnshire- Lead Palliative Care Nurse, POSCU Lead Nurse and Children's Specialist Complex Needs Nurse  North East Lincolnshire Children's Specialist Complex Needs Nurse and POSCU Lead Nurse  Lead/Specialist Nurses; provide parent and child with emotional support and can sign post for further psychological support.	North Lincolnshire, North East Lincolnshire- providing the patient is registered with a North Lincolnshire/North East Lincolnshire General Practitioner or Under the care of Consultant Paediatrician at Northern Lincolnshire & Goole NHS Foundation Trust	NHS
Forget Me Not Children's Hospice. Counsellors, SUDIC Workers, Family Support Worker, Bereavement Worker, Sibling support worker, Creative Therapist, Midwife	West Yorkshire	Charity
Bluebell Wood Children's Hospice. <i>Counsellors, Family Support Worker, Bereavement Support Worker, Sibling support worker, Music Therapist, Clinical Nurse Specialists</i>	South Yorkshire, North Derbyshire, North Nottinghamshire, North Lincolnshire	Charitable/ NHS
Leeds Children's Community Nursing Team	Leeds	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<sup>[8]</sup>.

<b>Name of individual professional, team or provider organisation</b>	<b>Geographical areas where this standard is being met</b>	<b>How this work is being funded (NHS, local authority or charitable)</b>
Martin House Children's Hospice	West Yorkshire, North Yorkshire, East Yorks (Humber, Coast and Vale	Charitable
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS
Forget Me Not Children's Hospice.	West Yorkshire	Charity
Bluebell Wood Children's Hospice.	South Yorkshire, North Derbyshire, North Nottinghamshire, North Lincolnshire	Charitable/ NHS
Leeds Children's Community Nursing Team <i>Provided by rapid access to Continuing Care which is part of service (maximum 60 hrs)</i>	Leeds	NHS

Please return your completed form to [james.cooper@togetherforshortlives.org.uk](mailto:james.cooper@togetherforshortlives.org.uk) and [dan.steer@togetherforshortlives.org.uk](mailto:dan.steer@togetherforshortlives.org.uk)

<sup>[8]</sup> 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.