

East Midlands 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)
Rainbows	Leicester, Leicestershire, Rutland Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire	Charity/ part NHS (15%)
Royal Derby Hospital (RDH) Kite team CCN	Southern Derbyshire	Commissioned service to commence this year
A community palliative care team is provided by the coordinated working of several organisations commissioned by Nottingham and Nottinghamshire ICS 1. Nottinghamshire Healthcare NHS Foundation Trust provides the community children’s nursing team who provide an on call end of life care service. 2. Nottingham University Hospitals NHS trust provide a	Nottingham city, Nottinghamshire and Bassetlaw	NHS

^[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>

specialist palliative care nursing and bereavement team within Nottingham children's hospital. This service also supports the community services when children die at home. NUH also provides the regional oncology service which includes POONs and a CLIC Sargeant family support service. They also provide a weekly children's palliative care clinic for children with severe disability and life limiting or life threatening conditions at the child development centre and a 24/7 on call service 7 days per week of community disability paediatricians on call for end of life care in the community.

.3.Sherwood forest hospitals provide a session per week of disability paediatrician with special interest in palliative care who also contributes to the on call rota above.

4. a specialist family support service for the Nottingham and Nottinghamshire ICS district is commissioned and provided by Barnardos. 2 specialist family support workers provide practical and emotional support to children with non oncology LLCs and

<p>their families including siblings. They take the key worker role in the early stages of the journey when nursing needs are not high.</p> <p>5. 24hr home sitting service can be accessed from fast track continuing care funding. This is provided by a number of nursing care agencies</p> <p>6. A children's community respiratory physiotherapy service is commissioned from Notts healthcare including a rapid response to children at home with severe disabilities and recurrent chest infections.</p>		
<p>St Andrew's Hospice</p>	<p>Hull, East Riding of Yorkshire, North Lincolnshire, North East Lincolnshire, Lincolnshire</p>	<p>Charity/NHS</p>
<p>United Lincolnshire NHS Hospital Trust- Dedicated Specialist Palliative Care Team within Childrens Community Services</p>	<p>Lincolnshire</p>	<p>NHS</p>
<p>Leicestershire Partnership NHS Trust Has a Palliative Care Lead Nurse and Community Paediatrician (limited to 2 PA's) to support the Diana Community Children's Service provide care support to families and 24/7 End of Life care</p>	<p>Leicester, Leicestershire and Rutland</p>	<p>NHS</p>
<p>Northampton General Hospital This standard is not met. There is no dedicated Paediatric Palliative care service. Paediatric</p>	<p>West Northamptonshire</p>	<p>NHS</p>

<p>Oncology consultant who has level 3 experience in Paediatric palliative care provides some care outside her job plan and support CCN and McMillan team. This is not an equitable service. CCN team are commissioned to provide 24/7 for 2 weeks when the need is triggered. However medical support is available at the good will of the Lead Oncology consultant.</p> <p>This consultant is in the process of initiating a countywide project supported by CCG to produce a business case to develop and commission a specialised palliative care service in Northamptonshire county (Northampton, Kettering, Corby and Wellingborough)</p>		
<p>Kettering General NHS Foundation trust CCN provide care support to families and 24/7 End of life care. However there is no Medical support Northampton consultant has provided some support if it is an Oncology patient living in that area. Service is not equitable.</p>	<p>North Northamptonshire</p>	<p>NHS</p>

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)
Rainbows hospice Provide a family support service to children referred to the hospice and have a counsellor	Leicester, Leicestershire, Rutland Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire	Charity/part NHS (15%)
Kite team of community nurses in Derbyshire RDH will try to support children and families on their caseload but there is no commissioned family support service	South Derbyshire	
-CCNs provided by Nottinghamshire Healthcare NHS Foundation Trust -Specialist family support workers provided by Barnardos and also Rainbow's hospice -Bereavement team provided from Nottingham children's hospital	Nottingham and Nottinghamshire ICS area	Commissioned by ICS
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS
United Lincolnshire NHS Hospital Trust- Dedicated service for addressing CYP grief and loss within Childrens Community Services Lincolnshire.	Lincolnshire	NHS Lincolnshire ICS
Leicestershire Partnership NHS Trust Diana Child and family support service offers	Leicester, Leicestershire and Rutland	NHS – Leicestershire ICS

pre and post bereavement support		
Northampton General Hospital CCN provide some support. There is no MDT nor specialist family support service to provide the care. This is a work in progress	West Northamptonshire	NHS
Kettering General Hospital Foundation Trust CCNs provide some support but there is no specialist family support service nor MDT . This is a work in progress	North Northamptonshire	NHS

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.

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being Charityfunded (NHS, local authority or charitable)
Rainbows Hospice have advice from a consultant in paediatric palliative care available for in patients during normal working hours		Charity/Part NHS (15%)

^[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.

<p>St Andrew's Hospice A specialist doctor is available for advice during normal working hours</p>	<p>Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire</p>	<p>Charity/NHS - H@H /community nursing core business hours 9-5, 7 days a week. Telephone nursing support 24/7,</p>
<p>United Lincolnshire NHS Trust- Dedicated Childrens Community Nursing team to provide end of life care 24/7 within Childrens Community Services. Can access specialist doctor advice in normal working hours from Rainbows or St Andrews hospices</p>	<p>Lincolnshire</p>	<p>NHS commissioned by ICS and charity funding for hospices</p>
<p>Northampton General Hospital This standard is not met. There is no dedicated Paediatric Palliative care service and no specialist palliative care doctor support</p> <p>Same as answer to Q1</p>	<p>West Northamptonshire</p>	<p>NHS</p>
<p>Kettering General NHS Foundation trust CCN provide care support to families and 24/7 End of life care. There is no Medical support .</p> <p>Same as answer to Q1</p>	<p>North Northamptonshire</p>	
<p>Nottinghamshire healthcare provide a community nursing service which can be activated to provide 24/7 support. There is a 24/7 rota of disability community paediatricians with expertise in end of life care who support end of life care at home. Advice from a specialist paed palliative care consultant is available during</p>	<p>Nottingham and Nottinghamshire ICS area</p>	<p>NHS commissioned by ICS with consultant PPC advice via charity funded hospice</p>

Normal working hours from rainbows hospice		
Leicestershire partnerships provide 24/7 community nursing. There is advice from a disability community paediatrician and consultant in paediatric palliative care within normal working hours	Leicestershire and Rutland	ICS commissioned and also charity via hospice

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)
Rainbows Have specialist nursing for patients within the hospice and will provide telephone nursing advice 24/7. There is GP support 24/7 for children in the hospice but consultant support is not available 24/7	Leicester, Leicestershire, Rutland Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire	Charity (15%)
St Andrew's Hospice Out reach home visits of specialist nurses for 24/7 end of life care Telephone nursing support 24/7 there is no consultant support out of hours	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS - Home visits for End of Life 24/7, Telephone nursing support 24/7, Medical support as above
United Lincolnshire NHS Trust- Childrens Nursing care available 24/7 within Childrens Community Services. There is no consultant support 24/7	Lincolnshire	NHS ICS funded
Northampton General Hospital This standard is not met. There is no dedicated Paediatric Palliative care service. . Same as to Q1	West Northamptonshire	NHS
Kettering General NHS Foundation trust	North Northamptonshire	NHS

Not met		
Same as to Q1		
Nottinghamshire healthcare trust provide 24/7 CCN service and there is 24/7 on call doctor support from community disability paediatricians with a special interest but there is no specialist Paediatric palliative care consultant support out of hours in our region.	Nottingham and Nottinghamshire ICS	NHS Nottingham and Nottinghamshire ICS funded

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)
Rainbows Have specialist nursing and consultant palliative care support during normal working hours	Leicester, Leicestershire, Rutland Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire (Nursing & Specialist GP)	Charity/part NHS (15%)
St Andrew's Hospice Have specialist nursing and specialist doctor support during normal working hours but not consultant in paed palliative care	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS - H@H/Community Nursing support core business hours 9-5, 7 days a week. Telephone Nursing support 24/7. Specialist Doctor available during business hours
United Lincolnshire NHS Trust provide nursing care within Childrens Community Services Doctor support for symptom management mostly comes from local paediatricians not a palliative care consultant	Lincolnshire	NHS
Northampton General Hospital This standard is not met. There is no dedicated Paediatric Palliative care service.		

Same as to Q1		
Kettering General NHS Foundation trust Not met Same as to Q1		
Nottinghamshire healthcare provide CCN 24/7 for support with symptom management NUH provide oncology symptom management and have a pain team and the disability community paediatricians provide advice on symptom management for children with disability and LLCs. There is no consultant in paediatric palliative care	Nottingham and Nottinghamshire ICS	ICS commissioned

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)
Rainbows	Leicester, Leicestershire, Rutland Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire (Nursing & Specialist GP)	Charity/Part NHS (15%)
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
Northampton General Hospital This standard is not met. There is no dedicated Paediatric Palliative care service. Same as to Q1		

Kettering General NHS Foundation trust Not met Same as to Q1		
There is no consultant in paediatric palliative care support 24 hours a day in the East Midlands region		

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)
Rainbows	Leicester, Leicestershire, Rutland Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire	Charity
St Andrew's Hospice	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS
United Lincolnshire NHS Trust- dedicated team within Childrens Community Services	Lincolnshire	NHS
Northampton General Hospital	West Northamptonshire	NHS
No service		
Kettering General Hospital Foundation Trust	North Northamptonshire	NHS
No service		
This is available in Nottinghamshire, leicestershire and Lincolnshire but not Derbyshire nor Northamptonshire		

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)
Rainbows offers short breaks but limited to 15 days per year unless child is at end of life	Leicester, Leicestershire, Rutland Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire	Charity
St Andrew's Hospice limited service unless at end of life	Hull, East Riding, North Lincolnshire, North East Lincolnshire, Lincolnshire	Charity/NHS
United Lincolnshire NHS Hospital Trust- dedicated team within Childrens Community Services	Lincolnshire	NHS ICS funded

^[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.

Northampton General Hospital Children are able to access respite with local respite homes or Rainbows Hospice	West Northamptonshire	NHS
Kettering General Hospital Foundation Trust Children are able to access respite with local respite homes or Rainbows Hospice	North Northamptonshire	NHS
Derbyshire continuing care service		ICS funded
Nottinghamshire short breaks are provided through children's continuing care funding		ICS funded