

East of England 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)
NNUHFT	Norfolk, Suffolk	NHS
(Level 3 NICU-hence patients from out of area treated on NICU at NNUHFT)		No commissioned palliative care service within acute Trust; access is via regional service-expertise medical by part time palliative care consultant employed by Addenbrookes Hospital however due to retire July 2021; support for individual patient via named consultant-access to equitable standards may not be enabled as most have no palliative care training
Keech Hospice Care	Bedfordshire, Hertfordshire & Milton Keynes	Part NHS funding from all areas. Charitable funding
Children's Community & Specialist Nursing Team (Luton Team) Cambridgeshire Community Services NHS Trust	Luton & South Bedfordshire	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

Norfolk Community Health and Care (NCH&C) Children's community nursing team. Monday – Friday 8am – 5pm, can offer home visiting where capacity allows but in partnership with other agencies we would not lead on palliative patients.	Norwich, North Norfolk, South Norfolk	NHS
Children's Community Specialist Nursing Service Cambridgeshire and Peterborough (CCS & CPFT)	Cambridgeshire and Peterborough (CCS & CPFT)	NHS
EACH provides palliative care in the home as required to all infants/children/young people with a life-limiting condition that meet EACH's eligibility criteria. Care is provided by members of the multidisciplinary team including the EACH Symptom Management Nursing Service (specialist team).	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grants NHS England Children's Hospice Grant X1 LA grant Child specific continuing care funding Charitable donations Approx 15 % statutory funding
The Specialist MCN Team provide out of hours support for children at home as required.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grant
Cambridge University Hospitals NHS Trust (CUH) provide a specialist level (4) children's palliative care.	East of England Counties of Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex	NHS Specialised Commissioning via CUH Tertiary centre
Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing and	North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood CCG, Thurrock CCG	NHS, Charitable donations, Grants

chaplaincy visits in the home, in conjunction with the relevant local Paediatric Community Nursing teams.		
East and North Hertfordshire: Community Children's Nursing Team Monday- Friday 9-5 provides community nursing care. Continuing Care team provides carer support for individual CYP who meet Continuing Health Care criteria and have an agreed package of home care	CYP who reside in and have a GP in East and North Hertfordshire	NHS
Paediatric Community Nursing Team; Essex Partnership University Trust provides 24/7 service provision.	CYP who reside in Southend CCG and Castlepoint, Rochford & Rayleigh CCG	NHS
NELFT children's community Nursing Team including a palliative care specialist nurse for 0-19year olds	CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford	NHS
Children's community nursing team 8:30-18:30 mon-fri 9:00-3:00 sat Queen ELizabeth Hospital King's Lynn	CYP living in west Norfolk and Fenland area of Cambridgeshire Norfolk and Wavney CCG	NHS
	Countywide across Essex and East London	Charitable

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	Geographical areas where	How this work is being
professional, team or provider organisation	this standard is being met	funded (NHS, local authority or charitable)
NNUHFT	Norfolk/suffolk	NHS
Keech Hospice Care Supportive Care team –	Bedfordshire Hertfordshire and Milton Keynes	No in house bereavement services for this age group; access is via charitable organisations(EACH/Nelson's journey/BLISS) Charitably funded
Family support worker, Art therapy, music therapy		
Children's Community Specialist Nursing Service Cambridgeshire and Peterborough (CCS & CPFT) - Part-time Family Support Worker in place.	Cambridgeshire (CCS)	NHS
The EACH multi- disciplinary team, including nurses; care assistants; and wellbeing support practitioners (e.g. Counsellors, Family Therapist, Art and Music Therapists) provides universal level of grief and loss support during end of life, after death, and in bereavement. Emotional health intervention is provided based on assessed need.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grants NHS England Children's Hospice Grant X1 LA grant Child specific continuing care funding Charitable donations Approx 15 % statutory funding
The MCN provides support for staff providing direct care.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grant
CUH consultant in Children's Palliative Care provides support	East of England Counties of Norfolk, Suffolk, Cambridgeshire and	NHS Specialist Commissioning

for staff providing direct care.	Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex	
Little Havens Childrens Hospice The Wellbeing team has a counselling and support service for families including parents, carers, siblings and children nearing the end of life	North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood CCG, Thurrock CCG	Charitable donations, Grants
CYP and families under the care of East and North Hertfordshire NHS Trust can be referred to a Children's Clinical Psychologist for support: appointments may be in the hospital or virtual video calls. The Community Children's Nursing team give informal emotional support during end-of-life care and bereavement, Monday-Friday 9-5	CYP who reside in and have a GP in East and North Hertfordshire	NHS
CYP and families under the Care of EPUT can be referred to a children's psychologist provided by the Acute Southend hospital. Also access to counselling available pre covid via the local children's hospice Little Havens. The paediatric community nursing team also provide informal emotional support during end of life care and bereavement.	CYP within Southend and castlepoint, rochford and rayleigh CCG's	NHS
NELFT children's community Nursing Team which includes a palliative care specialist nurse. Provide a 08:30 19:00 service 7 days a week and on call 24/7	CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford	NHS

Children's Community Nursing team Queen Elizabeth Hospital King's Lynn	CYP living in West Norfolk and fenland area of Cambridgeshire.	Support provided by East Anglian Children's Hospice. Local Charity such as Nelson's Journey
RTCC provide emotional and practical support before and after bereavement for as long as the family needs us.	Countywide across Essex and East London	Charitable

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^{1[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 funded (NHS, local authority or charitable)
NNUHFT	Norfolk/Suffolk	Acute Trust not funded for this service, hence no service currently
Keech Hospice care	Bedfordshire, Hertfordshire and Milton Keynes	Nursing care and children's hospice doctors available for advice and visits – part NHS funding and Charitable funding. Consultant access through tertiary centres. Tertiary centre funding
Children's Community & Specialist Nursing Team (Luton Base)	Luton & South Bedfordshire	NHS In conjunction with care provided from Keech Hospice Care

^[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.

- 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.

^[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:

0 1 11 11		T T
Cambridgeshire		
Community Services NHS Trust		
NCHC Children's	Norwich, North Norfolk, South	NHS
Community Nursing	Norfolk	INIIS
Team – offer in hours	Nortoik	
nursing support in		
partnership with other		
agencies		
Children's Community	Cambridgeshire and	NHS
Specialist Nursing	Peterborough (CCS & CPFT)	
Service		
Cambridgeshire and		
Peterborough (CCS &		
CPFT).		
EACH provides nursing	Norfolk & Waveney CCG	NHS CCG Grants
care for CYP being cared	Ipswich & East Suffolk CCG	NHS England Children's
for at home, including	West Suffolk CCG	Hospice Grant
access to the EACH	North East Essex CCG	X1 LA grant
Symptom Management Service and advice from	Cambridgeshire & Peterborough CCG	Child specific continuing care funding
the CYP's consultants	Mid Essex CCG	Charitable donations
and the specialist	West Essex CCG	Chartable donations
palliative care consultant	1100t 2000x 000	Approx 15 % statutory
(CUH).		funding
CUH children's palliative	East of England Counties of	NHS specialist
Care consultant provides	Norfolk, Suffolk, Cambridgeshire	NHS specialist commissioning
Care consultant provides support to EACH for	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire,	
Care consultant provides support to EACH for nursing care for CYP	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home,	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire,	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and	
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home.	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend	commissioning
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood	commissioning NHS, Charitable
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice Little Havens may be	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend	commissioning NHS, Charitable
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice Little Havens may be able to provide limited	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood	commissioning NHS, Charitable
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing care, in	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood	commissioning NHS, Charitable
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing care, in conjunction with the	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood	commissioning NHS, Charitable
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing care, in conjunction with the relevant local Paediatric	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood	commissioning NHS, Charitable
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing care, in conjunction with the relevant local Paediatric Community Nursing	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood	commissioning NHS, Charitable
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing care, in conjunction with the relevant local Paediatric Community Nursing teams during normal	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood	commissioning NHS, Charitable
Care consultant provides support to EACH for nursing care for CYP being cared for at home, including the EACH Symptom Management Nursing Service and advises the CYP's consultants. This role also provides direct advice and support to CYP and families at home. Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing care, in conjunction with the relevant local Paediatric Community Nursing	Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood	commissioning NHS, Charitable

Where children are under the care of tertiary palliative care team there is 24 hour access to a Specialist palliative care nurse and doctor		
Community Children's Nursing Team provides nursing care Monday- Friday 9-5 for CYP approaching the end of life. This is also done in collaboration with local hospice e.g. Daily syringe driver changes. Advice from consultant in paediatric palliative care would come from hospice or tertiary centre	CYP who reside in and have a GP in East and North Hertfordshire	NHS
EPUT PCN team provide 24/7 service provision in collaboration with the tertiary symptom management team from the tertiary centres and the local shared care palliative consultant from southend hospital.	Southend ccg and castlepoint , rochford and rayleigh ccg.	NHS
NELFT children's community nursing team including a palliative care specialist nurse. Provide a 08:30 19:00 service 7 days a week and on call 24/7	CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford	NHS
CCNT team based at Queen Elizabeth Hospital King's Lynn. 8:30-18:30 mon-fri 9:00-15:00 sat No out of hours or on call	CYP with a West Norfolk GP and fenland area of Cambridgeshire	Supported by East Anglian Children's Hospice, QEH paediatrician who has a special interest in Palliative care. Nurses within the team have extra training in palliative care.

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	Geographical areas where this	How this work is being
professional, team or	standard is being met	funded (NHS, local
provider organisation		authority or charitable)

NNUHFT	Norfolk/suffolk	acute Trust not funded for
		this service-hence no
1/ 1 11	B (6 11: 11 (6 11: 1	service currently
Keech Hospice Care	Bedfordshire, Hertfordshire and Milton Keynes	Nursing care including visits 24/7. On call telephone support from hospice doctors 24/7 advice and support where hospice leading on end of life care Charitable funding only Consultant advice and telephone support via designated tertiary centres where leading on end of life care. Tertiary funding
Children's Community & Specialist Nursing Team (Luton Base)	Luton & South Bedfordshire	NHS- Adhoc oncall support from specialist nurses. Unable to sustain 24/7 provision without working in collaboration with on call service provided by Keech Hospice Care Consultant support via Tertiary Centres.
NCHC Children's Community Nursing service, in office hours nursing support only. Telephone support from palliative consultants via EACH	Norwich, North Norfolk, South Norfolk	CCNT – NHS EACH – Charity funding
Children's Community Specialist Nursing Service Cambridgeshire and Peterborough (CCS & CPFT) - Office hours unless local 24 hr on-call is agreed in conjunction with EACH. Palliative consultants via EACH.	Cambridgeshire and Peterborough (CCS & CPFT)	NHS
EACH provides nursing care in the home 24/7 including an EACH Symptom Management Nursing Service on-call service.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grants NHS England Children's Hospice Grant X1 LA grant Child specific continuing care funding Charitable donations Approx 15 % statutory funding

The MCN provides a specialist palliative care rota out of hours (including the CUH) including weekends and bank holidays for the region.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grant
Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing care, in conjunction with the relevant local Paediatric Community Nursing teams during normal working hours Where children are under the care of tertiary palliative care team there is 24 hour access to a Specialist palliative care nurse and doctor	North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood CCG, Thurrock CCG	NHS, Charitable donations, Grants
Community Children's Nursing team covers Monday-Friday 9-5 only. Occasionally able to provide out-of-hours support in collaboration with local hospice, but dependant on staffing capacity at time – this isn't a commissioned service. CYP would use hospice 24-hour line or specialist symptom management team for out-of-hours symptom advice	CYP who reside in and have a GP in East and North Hertfordshire	NHS
EPUT PCN team provide 24/7 service provision NELFT children's community nursing team including a palliative care specialist nurse 2 days a week. Provide a 08:30 19:00 service 7 days a	Southend ccg and castlepoint, rochford and rayleigh ccg CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford	NHS NHS
week and on call 24/7		

CCNT team based at	CYP with a West Norfolk GP and	Supported by East Anglian
Queen Elizabeth	fenland area of Cambridgeshire	Children's Hospice, QEH
Hospital King's		paediatrician who has a
Lynn.8:30-18:30 mon-fri		special interest in
9:00-15:00 sat		Palliative care. Nurses
No out of hours or on call		within the team have extra
		training in palliative care.

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)
NNUHFT	Norfolk/Suffolk	No funding for acute Trust hence no service available
Keech Hospice Care	Bedfordshire, Hertfordshire and Milton Keynes	Nursing care and advice. Hospice doctor advice available. Part NHS funding and charitable funding
Children's Community & Specialist Nursing Team (Luton) Cambridgeshire Community Service NHS Trust	Luton & South Bedfordshire	NHS
NCHC – CCNT nursing visits within office hours where capacity allows	Norwich, North Norfolk, South Norfolk	NHS
Children's Community Specialist Nursing Service Cambridgeshire and Peterborough (CCS & CPFT)	Cambridgeshire and Peterborough (CCS & CPFT)	NHS
EACH and the CUH Consultant in Children's Palliative care provides access to nursing care and advice from a palliative care consultant to manage symptoms during normal working hours.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grants NHS England Children's Hospice Grant X1 LA grant Child specific continuing care funding Charitable donations Approx 15 % statutory funding
Little Havens Childrens Hospice	North Essex CCG, South Essex CCG, Mid Essex CCG, Southend	NHS, Charitable donations, Grants

CCG, Basildon & Brentwood CCG, Thurrock CCG	
CYP who reside in and have a GP in East and North Hertfordshire	NHS
southend ccg and castlepoint, rochford and rayleigh ccg	NHS
CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford	NHS
CYP with a West Norfolk GP and fenland area of Cambridgeshire	Supported by East Anglian Children's Hospice, QEH paediatrician who has a special interest in Palliative care. Nurses within the team have extra training in palliative care.
	CYP who reside in and have a GP in East and North Hertfordshire southend ccg and castlepoint, rochford and rayleigh ccg CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford CYP with a West Norfolk GP and

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)
NNUHFT	NOrfolk/Suffolk	Acute trust no funded service
Keech Hospice Care	Bedfordshire, Hertfordshire and Milton Keynes	Nursing on call for advice 24/7. Charitable funding Hospice doctor support not available in these circumstances
EACH, the MCN and the CUH provides access to nursing care and advice from a paediatric palliative care consultant to manage symptoms, 24 hours a day, seven days a week.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grants NHS England Children's Hospice Grant X1 LA grant Child specific continuing care funding Charitable donations Approx 15 % statutory funding
CUH Consultant in Children's palliative care supports the provision of 24/7 care 7 days a week through collaboration with AECH and MCN	East of England Counties of Norfolk, Suffolk, Cambridgeshire and Peterborough, Bedfordshire, NE Hertfordshire, North, Mid and West Essex	NHS Specialised commissioning
Little Havens Childrens Hospice Little Havens may be able to provide limited palliative nursing care including symptom management, in conjunction with the relevant local Paediatric Community Nursing teams during normal working hours. Where children are under the care of tertiary palliative care team 24 hour access to advice is available	North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood CCG, Thurrock CCG	NHS, Charitable donations, Grants

Community Children's Nursing team service is Monday-Friday 9-5. Signposted to local children's hospice 24-hour advice line out of hours/for specific palliative advice, or to specialist centre	CYP who reside in and have a GP in East and North Hertfordshire	NHS
EPUT PCN Team provide 24/7 nursing care. Access to tertiary palliative care consultants out of hours and access to general paediatric consultants locally out of hours.	Southend ccg and castlepoint, rochford and rayleigh ccg	NHS
NELFT children's community nursing team. 7 days per week service 08:30-19:00 with a 24hour on call advice service. Access to consultants, palliative care and little havens hospice	CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford	NHS
CCNT team based at Queen Elizabeth Hospital King's Lynn. 8:30-18:30 mon-fri 9:00-15:00 sat No out of hours or on call	CYP with a West Norfolk GP and fenland area of Cambridgeshire	Supported by East Anglian Children's Hospice, QEH paediatrician who has a special interest in Palliative care. Nurses within the team have extra training in palliative care.
Children's Community Specialist Nursing Service Cambridgeshire and Peterborough (CCS & CPFT), No out of hours On-call service, Signposted to local children's hospice, EACH, advice line out of hours/for specific palliative advice, or to specialist centre	Cambridgeshire and Peterborough (CCS & CPFT)	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.

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)
NNUHFT	Norfolk/suffolk	Psychologists working within speciality teams-limited service offered within the Trust but no service provision in the patient home
Keech Hospice Care	Bedfordshire, Hertfordshire and Milton Keynes	Care team and Supportive care service offer psychological support in the home setting where need is identified. Charitable funding
Children's Community Specialist Nursing Service Cambridgeshire and Peterborough (CCS & CPFT) - Part-time Family Support Worker in place.	Cambridgeshire (CCS)	NHS
EACH provides access to emotional and psychological support at home for CYP and their parents / carers and families.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grants NHS England Children's Hospice Grant X1 LA grant Child specific continuing care funding Charitable donations Approx 15 % statutory funding
Little Havens Childrens Hospice Little Havens Childrens Hospice The Wellbeing team has a counselling and support service for families including parents, carers, siblings and children nearing the end of life	North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood CCG, Thurrock CCG	Charitable donations, Grants
Community Children's Nursing team refer to Clinical Psychologist at the Trust if needed – as per question 2. Would	CYP who reside in and have a GP in East and North Hertfordshire	NHS

also signpost to support from local hospice, and other relevant charities,		
or to GP for mental health issues/care		
EPUT PCN team provide informal emotional and psychological support but are able to refer onto the services available at the local hospice Little havens and to the the services at the local acute southend hospital.	Southend ccg and castlepoint, rochford and rayleigh ccg	NHS
NELFT children's community nursing team. Palliative care specialist nurse works 2 days per week. Access to our service 24/7 and refer to available support	CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford	NHS
Queen Elizabeth Hospital King's Lynn	Children and young people living in West Norfolk, Fenland area of Cambridgeshire. Norfolk and Waveney CCG	NHS Psychologists working within speciality teams, all are not commissioned.
RTCC provide emotional support to families at	Countywide across Essex and East London	Charitable

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].

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)
EACH provides access to CYP and their families for regular short breaks for respite in the home.	Norfolk & Waveney CCG Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG Cambridgeshire & Peterborough CCG Mid Essex CCG West Essex CCG	NHS CCG Grants NHS England Children's Hospice Grant X1 LA grant Child specific continuing care funding Charitable donations Approx 15 % statutory funding
Little Havens Childrens Hospice Provides a home respite care service 7 days a week	North Essex CCG, South Essex CCG, Mid Essex CCG, Southend CCG, Basildon & Brentwood CCG, Thurrock CCG	NHS, Charitable donations, Grants

Children's Community Specialist Nursing Team Cambridgeshire (CCS) Children's Complex Care Team will offer respite at EOL dependant on capacity.	Cambridgeshire including Huntingdon also Royston	NHS
CYP who meet Continuing Health Care eligibility will have an individual package of care agreed at panel and provided by the Children's Continuing Care Team.	CYP who reside in and have a GP in East and North Hertfordshire	NHS
Essex Partnership University Trust specialist school nursing service has a number of nursery nurses able to provide respite to CYP with life limiting conditions subject to assessment	Southend ccg and castlepoint, rochford and rayleigh ccg	Nhs
NELFT Children's Community Nursing team. We have a nursery nurse on the team that could provide some short respite (but not regular) if necessary and staffing/visits allow, although we have not practised this as of yet. This would not be overnight and we also have support from Little Havens for respite.	CYP that live in Brentwood, Thurrock, Basildon, Billericay and Wickford	NHS

CCNT team based at Queen Elizabeth Hospital King's Lynn.8:30-18:30 mon-fri 9:00-15:00 sat No out of hours or on call	CYP with a West Norfolk GP and fenland area of Cambridgeshire	Respite provided by EACH for children accessing their services

RTCC offers short breaks within the family home, subject to risk assessment

Countywide across Essex and East London

Charitable

^[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.