

Wessex 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)
CCN Team Isle of Wight NHS Trust	Isle of Wight	The CCN team go onto an on-call rota – which has ring-fenced monies attached and a separate budget . The team provide care for the child at home, with on-call services 24-7 once the child is deemed at being at EoL. Care over and above the limitations of 24/7 on call CCN service, is provided via the CCG under a rapid Continuing Care assessment and package agreement.
CCN Team Guernsey	Guernsey	States of Guernsey health and social care committee -Children's community nurses Note - States of Guernsey health and social care committee is funded by a central budget from social security and taxes.
CCN Team Guernsey	Guernsey	Yes, but the specialist team are not based on island. We rely on the Southampton palliative care team who provide telephone and video support when required. NHS/charity - Southampton palliative care team

^[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>

CCN Team Jersey	Jersey	Family Nursing and Home Care (FNHC) is a Jersey charity that provides integrated nursing and home care in the community from pre-birth to end-of-life. The Community Children’s Nursing Team (CCNT) is just one of the specialist Teams within the organisation and we also provide Paediatric Palliative Care. We work in collaboration with other agencies across Jersey’s Health and Social Care such as the social work team, Hospice, the Children Development Therapy Centre and the General Hospital.
Sussex Community NHS Foundation (SCFT) – West Sussex CCN Teams divided in to North, South & West	<p>North – predominantly links with London tertiary centre, based in Crawley.</p> <p>South – care from Brighton & Hove border to Littlehampton & surrounding villages. Also some of mid Sussex (Hassocks, Henfield, Storrington). Based in Lancing.</p> <p>West – from Emsworth to Littlehampton up to Midhurst/Billingshurst. Based in Chichester.</p> <p>Must be under the care of a West Sussex GP.</p>	<p>West - NHS and local Charity funding North & South – NHS</p> <p>Within West Sussex, Specialist paediatric palliative care services are provided by the tertiary centres. These are located in London or Southampton. For Children and Young people receiving care under the tertiary centres there is access to these services. There is an identified gap in CYP palliative care management for those patients not under the care of the tertiary centres. Referrals can be made to the tertiary centres for support but this is usually within an end of life phase and not as symptoms are progressing outside of this end of life phase- e.g. palliative care management.</p> <p>NHS Commissioned care for palliative care at home is provided by the CYP Community Nursing services in partnership with the local children’s hospice. Further support from a CYP Senior clinical pharmacist is available for advice on medicines management.</p> <p>In addition to the CYPCN West Team partnership with a local charity (The Sussex Snowdrop trust) has enabled the recruitment of a CYP Palliative care CNS, Bereavement Counselling and staff to provide Short break care.</p>
Basingstoke – Hampshire Hospitals Foundation Trust (HHFT)	Hampshire – excluding Southampton & Portsmouth	NHS and Charities

Forest Holme	East Dorset (BH12-21)	75% NHS and 25% Charity
Solent NHS Trust	Southampton city & West Hampshire (SO post code areas)	This is currently funded via NHS CCG through our core Community Children's Nursing Service but there is no specific funding for palliative and end of life care. There is also no additional commissioning for increasing the service from a Mon-Fri 08:30-16:30 service to a 24/7 on-call service when required – discussions are ongoing with commissioners about the use of individual funding requests but in the long term this service requires commissioning in order to provide a sustainable offer and provide true choice of care.
Mountbatten Hospice	IoW, Southampton	Not for under 18s. 18-25s – would be cared for at home, without specialist paediatric team. Funded by Charity.
Alexander Devine Children's Hospice Service	North Hampshire (also E & W Berks & surrounding boundaries inc. S. Bucks)	Full MDT team providing nursing care, symptom management, end of life care, play specialist, music therapy & Psychological support. Medical cover from paediatricians with special interest and training in children's palliative care, pharmacist. NHS/Charity
Dorset County Hospital/University Hospital Dorset	West Dorset/East Dorset	NHS – for specialist advice they are supported by the POONS/Oncology Consultant (only for oncology CYP) or Palliative Care Consultants (in hours) at UHS. There are 3 names consultants employed by DCH who can offer end of life support at home this is predominantly for children with complex neurodisability rather than oncology diagnosis.
Hants, Southampton & IoW CCG – Hants & IoW ICS	Hants, IoW inc. Portsmouth & Southampton cities.	NHS Universal palliative care services are commissioned through local Children's Community Nursing (CCN) and allied Health professional service specifications and SLA's with medical oversight provided by DGH lead clinicians.
Virgin Care CCN Service – Wiltshire	Any child registered with Wiltshire GP.	We are funded for children with a Wiltshire GP by BSW CCG on an as and when needed basis, therefore when we

	SLA with Salisbury Hospital for children with cancer. This will cover part of Hampshire, Dorset & Somerset.	have a child requiring end of life care in the community, we then contact the CCG and they authorise that they will fund the out of hours service. This does mean that it can put excess stress of the service trying to deliver routine care to the caseload and palliative care at the same time.
St Barnabas Hospice / Chestnut Tree House	SE Hants, E Sussex, W Sussex, Brighton & Hove	Local Charity /TFSL grant Local authority
Royal Hampshire Hospitals NHS FT (RHCH)	South Hants, Winchester, Andover, Whitchurch, Eastleigh, Chandlers Ford, Bishops Waltham, Four Marks, Alresford & surrounding villages.	NHS. Provided by Children's community nursing (CCN) team in addition to their contracted hours. Support given from palliative care teams at Southampton (UHS)
Integrated CCN (iCCNS) Solent East Solent NHS Trust	Any CYP registered with a GP practice in the following post codes: PO1-6 (Portsmouth City) PO7-11 & GU30-35 (SE Hants CCG) PO12-16 & SO31 (Fareham & Gosport CCG)	This is currently funded via NHS CCG through our Community Children's Nursing Service. The iCCN service specification details the provision of nursing care and advice to support palliative and end of life care in the community, working with partners in acute and charity sectors to deliver 24/7 advice at home and supportive nursing care as able. However, there is no specifically identified funding for palliative and end of life care outside of our block contract or core working hours. In the long term this out of hours service requires commissioning in order to provide a sustainable offer and provide true choice of care.

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)
CCN Team Isle of Wight NHS Trust	Isle of Wight	Charitable via adult hospice.
Weldmar Hospice	DT1 to DT11, SP7, SP8, BH20	Charitable, Only provided to patients over 18 years old.
CCN Team Guernsey	Guernsey	States of Guernsey HSC – CCN team

		Charity – Sunflower Trust Charity – Guernsey Bereavement service.
CCN Team Jersey	Jersey	Charity - As part of our holistic assessment and approach we support families as a whole through grief and loss and tailor the care they receive to individual need. This maybe in collaboration with other agencies.
Sussex Community NHS Foundation (SCFT) – West Sussex CCN Teams divided in to North, South & West	North – predominantly links with London tertiary centre, based in Crawley. South – care from Brighton & Hove border to Littlehampton & surrounding villages. Also some of mid Sussex (Hassocks, Henfield, Storrington). Based in Lancing. West – from Emsworth to Littlehampton up to Midhurst/Billingshurst. Based in Chichester. Must be under the care of a West Sussex GP.	CYPCN North and South – CYP community nursing staff will signpost families to available support externally to the teams. CYPCN West - Specialist Bereavement counselling services available which are commissioned by local charitable funding.
Forest Holme	East Dorset (BH12-21)	Bereavement Counselling - 100% Charity Will also fund sessions at MOSAIC for families involved with Forest Holme.
Solent NHS Trust	Southampton city & West Hampshire (SO post code areas)	Our Community Children’s Nursing team (NHS funded) provides some of this service. We liaise and refer to charitable organisations such as Rainbow Trust, Naomi House, Simon Says, Child Bereavement UK for on-going support.
Mountbatten Hospice	IoW, Southampton	Charity
Alexander Devine Children’s Hospice Service	North Hampshire (also E & W Berks & surrounding boundaries inc. S. Bucks)	Charity
Dorset County Hospital/University Hospital Dorset	West Dorset/East Dorset	NHS - CCNT provide initial bereavement support, as a keyworker to support any questions parents/carers have in processes for post death and sign post to services alongside the named paediatrician, this includes a home visit if parents would like this, there is also a

		<p>wellbeing nurse within the paediatric service who is hospital based, but currently there is no local counselling or psychology support (This is for DCH). The CCNT may provide ongoing support for a few weeks, however this will then be referred or sign posted onto appropriate service as required including GP, Mosaic for siblings etc. There is currently a Gully's parents Facebook page, which is part of Gully's charity and an annual remembrance service for families.</p>
Virgin Care CCN Service – Wiltshire	<p>Any child registered with Wiltshire GP.</p> <p>SLA with Salisbury Hospital for children with cancer. This will cover part of Hampshire, Dorset & Somerset.</p>	<p>The CCN team had a psychologist who worked with the staff and child and family, however this position is currently vacant and discussions with CCG are taking place about how this will look in the future. Therefore, there is no service currently.</p> <p>It is funded by the CCG for children at end of life, but not for children with cancer as they are support with inpatient service CLIC and hospice.</p>
St Barnabas Hospice / Chestnut Tree House	SE Hants, E Sussex, W Sussex, Brighton & Hove	Local Charity /TFSL grant Local authority
Royal Hampshire Hospitals NHS FT (RHCH)	South Hants, Winchester, Andover, Witchurch, Eastleigh, Chandlers Ford, Bishops Waltham, Four Marks, Alresford & surrounding villages.	NHS and charities. We offer support in a nursing capacity, but additional grief support is sought from charities and psychologists, when available. The psychologist service is very stretched and in high demand.
Naomi House	<p>Hampshire, Wiltshire, Berkshire, Dorset</p> <p>W Surrey - GU8 6; GU9 0; GU9 7-9; GU10 1-4; GU26 6</p> <p>W Sussex - PO10 8; PO18 8; PO19 1; PO19 3; PO19 5-8; PO20 0; PO20 7-9</p>	Charitable
Julia's House Hospice	Dorset & Wiltshire	<p>Charity & CCG contract up to March 2023.</p> <p>Each family has a named nurse who will provide bereavement support for 3 years as standard if the family wants it. The families also have access to 6 funded counselling sessions per year should they want this support.</p>
Integrated CCN (iCCNS) Solent East Solent NHS Trust	Any CYP registered with a GP practice in the following post codes:	<p>NHS funded.</p> <p>Solent East iCCNS provide some of this service alongside the MDT at QAH &</p>

	PO1-6 (Portsmouth City) PO7-11 & GU30-35 (SE Hants CCG) PO12-16 & SO31 (Fareham & Gosport CCG)	UHS. They deliver a holistic approach to EOL care for the CYP and family, encompassing their psychosocial, emotional, physical, and spiritual wellbeing. 2 post bereavement visits are usually offered by the iCCNS. The CYP and family can access support from iCCNS and the wider MDT throughout their EOL journey. There is no current specifically funded role or provision for supporting staff for managing grief and loss with CYP and families. ICCN's do not undertake any formal education or training.
--	---	--

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 funded (NHS, local authority or charitable)
CCN Team Isle of Wight NHS Trust	Isle of Wight	NHS block funding.
CCN Team Guernsey	Guernsey	Southampton paediatric palliative care consultant available by phone. States of Guernsey HSC – CCN team NHS/Charity – Southampton palliative care team
CCN Team Jersey	Jersey	Charity - The CCNT for both the core and palliative care caseload routinely work Monday-Friday 9-5 and are contactable by

^[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.

		landline, mobile phones and email. At times when end-of-life care is being provided we have a dedicated mobile phone for that particular family to use to ensure responses are timely and well managed. Visits and contacts are arranged as required – in advance or short notice. There is always and paediatric consultant on-call for advice and/or the Specialist UK teams can be contacted in hours.
Sussex Community NHS Foundation (SCFT) – West Sussex CCN Teams divided in to North, South & West	North – predominantly links with London tertiary centre, based in Crawley. South – care from Brighton & Hove border to Littlehampton & surrounding villages. Also some of mid Sussex (Hassocks, Henfield, Storrington). Based in Lancing. West – from Emsworth to Littlehampton up to Midhurst/Billingshurst. Based in Chichester. Must be under the care of a West Sussex GP.	CYPCN North and South - NHS funded CYPCN West - NHS and local charity commissioning CYPCN services provide nursing care at home within normal working hours (mon-Fri 8-6), including weekends and bank holidays (8:30-13:15). This care is for core and palliative/EOLC care Access to specialist children’s palliative care team/ consultant challenging if CYP not under UHS or tertiary centre Additional commissioning in CYPCN West for a whole time equivalent Children’s Palliative Care Nurse Specialist to support holistic care and management of CYP palliative care.
Basingstoke – Hampshire Hospitals Foundation Trust (HHFT)	Hampshire – excluding Southampton & Portsmouth	Consultants in Paediatric palliative care and POONs support in hours Non oncology Patients specialist palliative care consultant advice available in hours.
Forest Holme	East Dorset (BH12-21)	100% NHS through University Hospitals Dorset NHS Foundation Trust
Alexander Devine Children’s Hospice Service	North Hampshire (also E & W Berks & surrounding boundaries inc. S. Bucks)	Clinical Nurse Specialist service - NHS/Charity Nursing Team – Charity Paediatricians with Special Interest and training in CPC– NHS/Charity (Specialist Consultant – not funded / Good will)
Dorset County Hospital/University Hospital Dorset	West Dorset/East Dorset	NHS/Charity - this is again lead by the CCNT and named consultant, Julia’s House will support as required. However we do not have a separate EOL/Palliative service here

		<p>at DCH and it is provided by the core CCNT so this has implications to the service delivery for the rest of the CCN caseload/service whilst on call for EOL Care. We can contact our on call paediatrician or paediatrician with a special interest in palliative care or oncology, however this is not 24/7. If we require specialist advice we would contact the UHS Specialist Team in hours.</p> <p>The support offered by consultants during this time is over and above their normal working time so has implications/knock on effect for other work.</p>
Hants, Southampton & IoW CCG – Hants & IoW ICS	Hants, IoW inc. Portsmouth & Southampton cities.	<p>Commissioned through local CCNT service specification.</p> <p>CCNT NHS HLOW CCG commissioning Consultant in Paediatric palliative care funded through charitable sector, small contribution through NHS match funding scheme and Specialist Commissioning.</p>
Virgin Care CCN Service – Wiltshire	<p>Any child registered with Wiltshire GP.</p> <p>SLA with Salisbury Hospital for children with cancer. This will cover part of Hampshire, Dorset & Somerset.</p>	<p>The answer is yes to they have access to a children's Nurses, but there is not always access to a specialist nurse in palliative care.</p> <p>For oncology patients in the South of Wiltshire there is support from the POONs at Southampton Hospital. Children who have been receiving cancer treatment In the north of Wiltshire are supported by CLIC nurses and they do not involve our service at end of life.</p> <p>There is no palliative nursing support for children who are end of life with other conditions across the whole of Wiltshire. The CCN team will support any child at end of life and have developed skills and expertise from delivering this care and they will access support from local hospital or tertiary centres, this is mainly medial support.</p> <p>Patients cared for at Salisbury Hospital have access to consultant Paediatric Palliative Care advice in hours.</p>
St Barnabas Hospice / Chestnut Tree House	SE Hants, E Sussex, W Sussex, Brighton & Hove	<p>Local Charity /TFSL grant</p> <p>Local authority</p>
Royal Hampshire Hospitals NHS FT	South Hants, Winchester, Andover,	<p>NHS.</p> <p>This is provided in addition to usual</p>

(RHCH)	Whitchurch, Eastleigh, Chandlers Ford, Bishops Waltham, Four Marks, Alresford & surrounding villages.	caseload.
Naomi House	Hampshire, Wiltshire, Berkshire, Dorset W Surrey - GU8 6; GU9 0; GU9 7-9; GU10 1-4; GU26 6 W Sussex - PO10 8; PO18 8; PO19 1; PO19 3; PO19 5-8; PO20 0; PO20 7-9	Charitable / NHS
Julia's House Hospice	Dorset & Wiltshire	Charity & CCG contract up to March 2023. We work collaboratively with the local CCN's in both Dorset & Wiltshire to provide EoL care in the place of the family's choosing. We liaise with each child's consultant/CCN/CNS to provide that care within a prescribed plan.
Integrated CCN (iCCNS) Solent East Solent NHS Trust	Any CYP registered with a GP practice in the following post codes: PO1-6 (Portsmouth City) PO7-11 & GU30-35 (SE Hants CCG) PO12-16 & SO31 (Fareham & Gosport CCG)	The iCCNS offer a community-based palliative and end of life service by working alongside Queen Alexander Hospital (QAH) and University Hospital Southampton (UHS), Specialist Nurses, Paediatricians (with an interest in Palliative care) & Palliative Consultants to provide a joined-up approach to care. iCCNS support the completion of advanced care plans, administration and review of symptom management and attend MDT and Palliative meetings, acting as advisors and advocates for the CYP & family. There is no specifically identified funding for palliative and end of life care outside of our block contract and core working hours. In the long term this out of hours service requires commissioning in order to provide a sustainable offer and provide true choice of 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 professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
CCN Team Isle of Wight NHS Trust	Isle of Wight	CCN team out of hours provision - Funded via ring-fenced monies for paediatric palliative care.

		<p>2 x General Paediatric consultants have 1 PA each.</p> <p>On-call General paediatric consultant paid for by NHS under existing acute block funding agreement.</p> <p>There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.</p>
CCN Team Guernsey	Guernsey	<p>The CCN team works Monday – Friday 8-6 but are paid ‘on-call’ for end of life work carried out at weekends and late evenings. States of Guernsey HSC – CCN team</p> <p>There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.</p>
CCN Team Jersey	Jersey	<p>Charity - The CCNT expand their working hours when providing end-of-life care and the dedicated mobile phone becomes an ‘on-call’ phone so as support is prompt and over the 24hr period. We can then contact local consultants for advice and/or support or directly contact UK based teams.</p> <p>There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.</p>
<p>Sussex Community NHS Foundation (SCFT) –</p> <p>West Sussex CCN Teams divided in to North, South & West</p>	<p>North – predominantly links with London tertiary centre, based in Crawley.</p> <p>South – care from Brighton & Hove border to Littlehampton & surrounding villages. Also some of mid Sussex (Hassocks, Henfield, Storrington). Based in Lancing.</p> <p>West – from Emsworth to Littlehampton up to Midhurst/Billingshurst. Based in Chichester.</p> <p>Must be under the care of a West Sussex GP.</p>	<p>All CYP Community nursing teams in West Sussex provide a 24/7 on call for end of life care as required. This may be in partnership with the local children’s hospice. – it is funded via NHS and charity commissioning.</p> <p>CYP Community nursing provide care at home – if this is the preferred place of care/death.</p> <p>A 24hr on call service is available for those who are expected to die imminently. This may be in partnership with the local children’s hospice.</p> <p>There is not 24hr on call for patients with a life threatening /life limiting condition who may have a change in condition but are not assessed as being in an end of life care phase. This care would be managed by the acute trusts or tertiary centres via open access arrangements , 999 or GP/111 referral</p>

		There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.
Basingstoke – Hampshire Hospitals Foundation Trust (HHFT)	Hampshire – excluding Southampton & Portsmouth	NHS - No extra funding or extra time allowed for these patients so CCN has to manage around the normal caseload. There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.
Forest Holme	East Dorset (BH12-21)	Unsure – would be provided through University Hospitals Dorset NHS Foundation Trust 100% NHS
Solent NHS Trust	Southampton city & West Hampshire (SO post code areas)	We provide a 24/7 service alongside the paediatric palliative care team and offer a visiting service. This is currently funded via NHS CCG through our core Community Children's Nursing Service but there is no specific funding for palliative and end of life care. There is also no additional commissioning for increasing the service from a Mon-Fri 08:30-16:30 service to a 24/7 on-call service when required – discussions are ongoing with commissioners about the use of individual funding requests but in the long term this service requires commissioning in order to provide a sustainable offer and provide true choice of care. There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.
Alexander Devine Children's Hospice Service	North Hampshire (also E & W Berks & surrounding boundaries inc. S. Bucks)	Clinical Nurse Specialist service - NHS/Charity Nursing Team – Charity Paediatrician with Special Interest in palliative care – Charity (Specialist Consultant – not funded / Good will)
Dorset County Hospital/University Hospital Dorset	West Dorset/East Dorset	NHS/Charity - this is again lead by the CCNT and named consultant, Julia's House will support as required. However we do not have a separate EOL/Palliative service here at DCH and it is provided by the core CCNT so this has implications to the service delivery for the rest of the CCN caseload/service whilst on call for EOL Care. We can contact

		<p>our on call paediatrician or paediatrician with a special interest in palliative care or oncology, however this is not 24/7. If we require specialist advice we would contact the UHS Specialist Team.</p> <p>There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.</p>
Hants, Southampton & IoW CCG – Hants & IoW ICS	Hants, IoW inc. Portsmouth & Southampton cities.	<p>CCN 24/7 commissioned however recognition in the HIOW CCN Review paper 2018 that CCNT were not funded to sufficient capacity to deliver all 4 elements of the national recommendations to include PEOLC. CCNT/MDT can apply for Continuing Care Fast Track funding to support PEOLC . CCN as above re commissioning Fast Track monies funded through HIOW CCG Continuing Care.</p> <p>There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.</p>
Virgin Care CCN Service – Wiltshire	<p>Any child registered with Wiltshire GP.</p> <p>SLA with Salisbury Hospital for children with cancer. This will cover part of Hampshire, Dorset & Somerset.</p>	<p>Yes they have support from children's nursing care but there is not a consultant in paediatric palliative care available 24 hours a day seven days a week across the whole of Wiltshire.</p> <p>Children's Community Nurses are funded by the CCG as stated above on an as and when needed basis.</p> <p>There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.</p>
St Barnabas Hospice / Chestnut Tree House	SE Hants, E Sussex, W Sussex, Brighton & Hove	<p>Local Charity /TFSL grant</p> <p>Local authority</p>
University Hospital Southampton (UHS) – Hospital Palliative Care Team	Wessex region - Tertiary centre for neurosurgery, oncology, cardiology, CF, PCD which can include all of the Southern region (i.e. Guernsey, Falklands).	<p>16 and over in Mountbatten Hampshire catchment have access to 24/7 palliative medical advice via UHS consultants.</p> <p>NHS; SLA with Guernsey & Jersey; Charitable SLA with Mountbatten Hampshire.</p>
Royal Hampshire Hospitals NHS FT (RHCH)	South Hants, Winchester, Andover, Whitchurch, Eastleigh,	<p>NHS.</p> <p>Nursing care is provided as an on call service in addition to the normal workload.</p>

	Chandlers Ford, Bishops Waltham, Four Marks, Alresford & surrounding villages.	Telephone advice available by POONS service for oncology patients. No equivalent service for non- oncology patients.
Julia's House Hospice	Dorset & Wiltshire	Charity & CCG contract up to March 2023. We work collaboratively with the local CCN's in both Dorset & Wiltshire to provide EoL care in the place of the family's choosing. We liaise with each child's consultant/CCN/CNS to provide that care within a prescribed plan. There is no access to consultant in paediatric palliative care out of hours or weekends for end of life care.
Integrated CCN (iCCNS) Solent East Solent NHS Trust	Any CYP registered with a GP practice in the following post codes: PO1-6 (Portsmouth City) PO7-11 & GU30-35 (SE Hants CCG) PO12-16 & SO31 (Fareham & Gosport CCG)	This is currently funded via NHS CCG through our Integrated Community Children's Nursing Service. The iCCN service specification details the provision of nursing care and advice to support palliative and end of life care in the community, working with partners in acute and charity sectors to deliver 24/7 advice at home and supportive nursing care as able. However, there is no specifically identified funding for palliative and end of life care outside of our block contract or core working hours. In the long term this out of hours service requires commissioning to provide a sustainable offer and provide true choice of care. 24/7 EOL care is initiated as required for the CYP. Our iCCN service works in partnership with the Consultant Paediatrician at QAH who provides 24/7 telephone advice and home visiting support for all aspects of palliative & EOL care, including verification of death as requested by iCCNS. There is no access to consultant in paediatric palliative care out of hours or weekends for end of life 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	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
---	---	--

organisation		
CCN Team Isle of Wight NHS Trust	Isle of Wight	<p>CCN team – block funded as part of acute NHS paediatric provision. 2 x Paediatric consultants have 1 PA each. On-call paediatric consultant paid for by NHS under existing acute block funding agreement.</p> <p>Paediatric Palliative Care Consultants at University Hospitals Southampton provide in hours symptom management advice/support over phone, virtually or in person if needed as long as the child is under the palliative care team.</p>
CCN Team Guernsey	Guernsey	<p>Southampton paediatric palliative care consultant available by phone. States of Guernsey HSC – CCN team NHS/Charity – Southampton palliative care team</p>
CCN Team Jersey	Jersey	<p>Charity</p> <p>Paediatric Palliative Care Consultants at University Hospitals Southampton provide in hours symptom management advice/support over phone, virtually or in person if needed as long as the child is under the palliative care team.</p>
<p>Sussex Community NHS Foundation (SCFT) –</p> <p>West Sussex CCN Teams divided in to North, South & West</p>	<p>North – predominantly links with London tertiary centre, based in Crawley.</p> <p>South – care from Brighton & Hove border to Littlehampton & surrounding villages. Also some of mid Sussex (Hassocks, Henfield, Storrington). Based in Lancing.</p> <p>West – from Emsworth to Littlehampton up to Midhurst/Billingshurst. Based in Chichester.</p> <p>Must be under the care of a West Sussex GP.</p>	<p>NHS & local charity funding Local children’s Hospice</p> <p>Paediatric Palliative Care Consultants at University Hospitals Southampton provide in hours symptom management advice/support over phone, virtually or in person if needed as long as the child is under the palliative care team.</p>
Basingstoke – Hampshire Hospitals Foundation Trust (HHFT)	Hampshire – excluding Southampton & Portsmouth	<p>NHS - the oncology patients definitely do. But for the non oncology patients, they do not receive the same support and advice.</p>

		Paediatric Palliative Care Consultants at University Hospitals Southampton provide in hours symptom management advice/support over phone, virtually or in person if needed as long as the child is under the palliative care team.
Forest Holme	East Dorset (BH12-21)	provided through University Hospitals Dorset NHS Foundation Trust 100% NHS
Solent NHS Trust	Southampton city & West Hampshire (SO post code areas)	We provide children's nursing care, this is funded by the NHS as part of the CCN service. The Nursing team have access to advice from paediatric palliative care consultants from the tertiary hospital (NHS).
Alexander Devine Children's Hospice Service	North Hampshire (also E & W Berks & surrounding boundaries inc. S. Bucks)	Clinical Nurse Specialist service - NHS/Charity Nursing Team – Charity Paediatricians with Special Interest in palliative care – NHS/Charity (Specialist Consultant – not funded / Good will)
Dorset County Hospital/University Hospital Dorset	West Dorset/East Dorset	NHS - Yes we will support Symptom management at home however If a CYP is not EOL we only provide a Monday-Friday 9-5pm service, this does not include Bank Holidays.
Hants, Southampton & IoW CCG – Hants & IoW ICS	Hants, IoW inc. Portsmouth & Southampton cities.	As per Q4 CCNT / MDT can refer the CYP to Continuing Care for eligibility and funding consideration. HIOW CCN and Continuing Care funding
Virgin Care CCN Service – Wiltshire	Any child registered with Wiltshire GP. SLA with Salisbury Hospital for children with cancer. This will cover part of Hampshire, Dorset & Somerset.	Children across the Wiltshire have access to a CCN Mon-Friday 9-5 who can access support from the palliative care team at the child's tertiary centre.
St Barnabas Hospice / Chestnut Tree House	SE Hants, E Sussex, W Sussex, Brighton & Hove	Local Charity /TFSL grant Local authority
Royal Hampshire Hospitals NHS FT (RHCH)	South Hants, Winchester, Andover, Whitchurch, Eastleigh, Chandlers Ford, Bishops Waltham, Four Marks, Alresford & surrounding villages.	Through continuing care, if the child has additional carers in place. NHS - Nursing care from CCN's. NHS - Advice from POONS service, if the child has cancer. Palliative care Consultant if referred to that team.

		<p>Non oncology patients have support from their consultant but how extensive that is depends on the individual Consultant.</p> <p>Paediatric Palliative Care Consultants at University Hospitals Southampton provide in hours symptom management advice/support over phone, virtually or in person if needed as long as the child is under the palliative care team.</p>
Naomi House	<p>Hampshire, Wiltshire, Berkshire, Dorset W Surrey - GU8 6; GU9 0; GU9 7-9; GU10 1-4; GU26 6 W Sussex - PO10 8; PO18 8; PO19 1; PO19 3; PO19 5-8; PO20 0; PO20 7-9</p>	<p>Charitable / NHS</p> <p>Paediatric Palliative Care Consultants provide in hours symptom management advice/support over phone, virtually or in person if needed as long as the child is under the palliative care team.</p>
Integrated CCN (iCCNS) Solent East Solent NHS Trust	<p>Any CYP registered with a GP practice in the following post codes: PO1-6 (Portsmouth City) PO7-11 & GU30-35 (SE Hants CCG) PO12-16 & SO31 (Fareham & Gosport CCG)</p>	<p>This is by NHS as part of our block contract for the ICCNS.</p> <p>The iCCN service specification details the provision of nursing care and advice to support palliative care in the community, working with partners in acute and charity sectors QAH Paediatrician, UHS Palliative Consultants and where appropriate Solent Community Paediatricians work collaboratively to ensure good symptom management for the CYP and Family. The ICCNS works with the Consultants and MDT to implement symptom management within the community for all CYP who are palliative or have life limited conditions/illness.</p> <p>ICCNS empower CYP & families to learn skills such as medication administration. They deliver teaching to education settings/nurseries to minimising the impact of their condition/prognosis on their life.</p> <p>The coordination of symptom management is more challenging for CYP who do not have an Oncology diagnosis and are not known to the UHS Palliative Team. Paediatricians at QAH are required to manage this.</p>

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)
--	---	--

CCN Team Guernsey	Guernsey	<p>The CCN service will go 'on call' at end of life. In other cases the patient will be admitted to Frossard ward (the Guernsey paediatric ward) out of hours for symptom management.</p> <p>No access to Consultant in Paediatric Palliative Care for advice/support out of hours or at weekends.</p>
CCN Team Jersey	Jersey	<p>Charity/NHS - Out of hours they can phone Robin Ward (our local children's ward) for advice or seek review in A&E. There is always a paediatric Consultant on-call locally who can provide support.</p> <p>No access to Consultant in Paediatric Palliative Care for advice/support out of hours or at weekends.</p>
Forest Holme	East Dorset (BH12-21)	<p>Unsure – would be provided through University Hospitals Dorset NHS Foundation Trust 100% NHS</p>
Solent NHS Trust	Southampton city & West Hampshire (SO post code areas)	<p>As Q5.</p> <p>This is currently funded via NHS CCG through our core Community Children's Nursing Service but there is no specific funding for palliative and end of life care. There is also no additional commissioning for increasing the service from a Mon-Fri 08:30-16:30 service to a 24/7 on-call service when required – discussions are ongoing with commissioners about the use of individual funding requests but in the long term this service requires commissioning in order to provide a sustainable offer and provide true choice of care.</p> <p>There is currently no access to non-oncology palliative care from a paediatric consultant outside of normal working hours.</p>
<p>Sussex Community NHS Foundation (SCFT) –</p> <p>West Sussex CCN Teams divided in to North, South & West</p>	<p>North – predominantly links with London tertiary centre, based in Crawley.</p> <p>South – care from Brighton & Hove border to Littlehampton & surrounding villages. Also some of mid</p>	<p>NHS & local charity funding</p> <p>Local children's Hospice</p> <p>As Q4: Palliative care team/ Palliative care consultant: CYP not always receiving specialist children's palliative care if not under tertiary centre or UHS. Access may be available to palliative care team service – this may not be Consultant but may be CNS.</p>

	<p>Sussex (Hassocks, Henfield, Storrington). Based in Lancing.</p> <p>West – from Emsworth to Littlehampton up to Midhurst/Billingshurst. Based in Chichester.</p> <p>Must be under the care of a West Sussex GP.</p>	<p>No access to Consultant in Paediatric Palliative Care for advice/support out of hours or at weekends.</p>
Alexander Devine Children's Hospice Service	<p>North Hampshire (also E & W Berks & surrounding boundaries inc. S. Bucks)</p>	<p>Clinical Nurse Specialist service - NHS/Charity Nursing Team – Charity Paediatrician with Special Interest in palliative care – Charity (Specialist Consultant – not funded / Good will)</p>
St Barnabas Hospice / Chestnut Tree House	<p>SE Hants, E Sussex, W Sussex, Brighton & Hove</p>	<p>Local Charity /TFSL grant Local authority</p>
Integrated CCN (iCCNS) Solent East Solent NHS Trust	<p>Any CYP registered with a GP practice in the following post codes: PO1-6 (Portsmouth City) PO7-11 & GU30-35 (SE Hants CCG) PO12-16 & SO31 (Fareham & Gosport CCG)</p>	<p>The iCCNS do not provide a 24 hour 7 day a week symptom management provision unless a CYP is end of life. However, our service is available between 10am-6pm at weekends/BH to reduce hospital attendance if the CYP requires nursing support to replace NGT, syringe driver, administer medications or take bloods. CYP & families would have 'open access' to the Children's Unit at QAH for their specific need or would contact the specialist unit/ward at UHS.</p> <p>No access to Consultant in Paediatric Palliative Care for advice/support out of hours or at weekends.</p>

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)
Weldmar Hospice	DT1 to DT11, SP7, SP8, BH20	Charitable. Only provided is patients is over 18 years old and is known to the service.
CCN Team Guernsey	Guernsey	We do provide emotional support but do not have extensive training and would encourage referral to a specialist if

		psychology input was required. States of Guernsey HSC – CCN service
CCN Team Jersey	Jersey	Charity - This maybe in collaboration with other agencies once a need has been identified.
Sussex Community NHS Foundation (SCFT) – West Sussex CCN Teams divided in to North, South & West	North – predominantly links with London tertiary centre, based in Crawley. South – care from Brighton & Hove border to Littlehampton & surrounding villages. Also some of mid Sussex (Hassocks, Henfield, Storrington). Based in Lancing. West – from Emsworth to Littlehampton up to Midhurst/Billingshurst. Based in Chichester. Must be under the care of a West Sussex GP.	NHS, local charity commissioning and charitable organisations. CYPCN services provide families with access to emotional and psychological support as part of their nursing care. Advanced communication skills is a core element of community nursing. If the needs of the family exceed the skill and competency of Community nursing, the teams will signpost families to appropriate psychological support. Such as CAMHS, Time to talk, Bereavement charities. Within CYPCN West there has been additional charitable funding for bereavement services
Basingstoke – Hampshire Hospitals Foundation Trust (HHFT)	Hampshire – excluding Southampton & Portsmouth	Charity - Yes but it often depends on the diagnosis. We rely on Charitable support CLIC sargent for the Oncology families and the psychology team at the PTC.
Forest Holme	East Dorset (BH12-21)	100% charity
Solent NHS Trust	Southampton city & West Hampshire (SO post code areas)	NHS This is provided as part of our CCN service but is not sufficient and access to psychological support as well as specially trained counsellors for CYP, siblings and family members would be beneficial.
Mountbatten Hospice	IoW, Southampton	Charity – no age restriction.
Alexander Devine Children’s Hospice Service	North Hampshire (also E & W Berks & surrounding boundaries inc. S. Bucks)	Charity
Virgin Care CCN Service – Wiltshire	Any child registered with Wiltshire GP. SLA with Salisbury Hospital for children with cancer. This will cover	As per Q2. The oncology service provide psychology support to children with cancer.

	part of Hampshire, Dorset & Somerset.	
St Barnabas Hospice / Chestnut Tree House	SE Hants, E Sussex, W Sussex, Brighton & Hove	Local Charity /TFSL grant Local authority
Royal Hampshire Hospitals NHS FT (RHCH)	South Hants, Winchester, Andover, Whitchurch, Eastleigh, Chandlers Ford, Bishops Waltham, Four Marks, Alresford & surrounding villages.	NHS Limited psychological support due to resources available. Additional support is provided by various charities.
Naomi House	Hampshire, Wiltshire, Berkshire, Dorset W Surrey - GU8 6; GU9 0; GU9 7-9; GU10 1-4; GU26 6 W Sussex - PO10 8; PO18 8; PO19 1; PO19 3; PO19 5-8; PO20 0; PO20 7-9	Charitable
Julia's House Hospice	Dorset & Wiltshire	Charity & CCG contract up to March 2023. Each family has a named nurse who will provide bereavement support for 3 years as standard if the family wants it. The families also have access to 6 funded counselling sessions per year should they want this support.
Integrated CCN (iCCNS) Solent East Solent NHS Trust	Any CYP registered with a GP practice in the following post codes: PO1-6 (Portsmouth City) PO7-11 & GU30-35 (SE Hants CCG) PO12-16 & SO31 (Fareham & Gosport CCG)	This is provided as part of our CCN service but is not sufficient and access to psychological support as well as specially trained counsellors for CYP, siblings and family members would be beneficial. iCCN's have no formal training in this area.

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)
CCN Team Isle of Wight NHS Trust	Isle of Wight	Block funded service offering respite to children with life-limiting conditions that meet the Continuing Care threshold and are open to CC. Respite provision is monitored and commissioned via the CC process.
CCN Team Jersey	Jersey	Charity, local authority - There is a

^[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.

		referral and assessment process for short breaks which is led by the social work team. If families wish, a referral can be made and assessment made of what maybe the best provision. Within the CCNT we also have a paediatric palliative care worker who provides home respite and outside activities for the child/young person and also their siblings.
Sussex Community NHS Foundation (SCFT) – West Sussex CCN Teams divided in to North, South & West	North – predominantly links with London tertiary centre, based in Crawley. South – care from Brighton & Hove border to Littlehampton & surrounding villages. Also some of mid Sussex (Hassocks, Henfield, Storrington). Based in Lancing. West – from Emsworth to Littlehampton up to Midhurst/Billingshurst. Based in Chichester. Must be under the care of a West Sussex GP.	CYPCN West - in partnership with The Sussex Snowdrop trust are able to provide short break care – this is based on a model of play and development, rather than providing clinical care to CYP. Short break Support workers funded by local charity provide short breaks at home - focused on a model of play/ development rather than clinical respite care. Local Children’s hospice also provide outreach. Children’s Continuing care can provide respite at home if the CYP meets the appropriate criteria - this is not managed by SCFT.
Basingstoke – Hampshire Hospitals Foundation Trust (HHFT)	Hampshire – excluding Southampton & Portsmouth	NHS - Continuing health care allows for respite at home.
Mountbatten Hospice	IoW, Southampton	18-25 yrs – funded by charity
Sebastian’s Action Trust	Hampshire (also Berks, Surrey, Oxon & Bucks)	Charity.
Alexander Devine Children’s Hospice Service	North Hampshire (also E & W Berks & surrounding boundaries inc. S. Bucks)	Charity
Hants, Southampton & IoW CCG – Hants & IoW ICS	Hants, IoW inc. Portsmouth & Southampton cities.	Only if the CYP is eligible for Continuing Care or open to Social Care. If eligible HIOW CCG Continuing Care fund domiciliary care and Personal Health Budgets that the family could choose to spend on a hospice break. Local Authority if eligible could fund.
Virgin Care CCN Service – Wiltshire	Any child registered with Wiltshire GP.	This is provided by a range of services, some from hospice and some from social care funding.

	SLA with Salisbury Hospital for children with cancer. This will cover part of Hampshire, Dorset & Somerset.	
St Barnabas Hospice / Chestnut Tree House	SE Hants, E Sussex, W Sussex, Brighton & Hove	Local Charity /TFSL grant Local authority
Julia's House Hospice	Dorset & Wiltshire	Charity & CCG contract up to March 2023. Every family is given 200 hours per year respite, which can be used in the community or at the hospices in the form of regular respite at home or sessional support in the hospice. The hours do not come in to consideration when providing EOL care.

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