

Reference: FOI.ICB-2324/328

Subject: Palliative Care Commissioning for Children and Young People

I can confirm that the ICB does hold some of the information requested; please see responses below:

QUESTION	RESPONSE
	<p><i>Children’s palliative care</i></p> <p>“An active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of symptoms, provision of short breaks and care through death and bereavement.”</p> <p><i>Life-limiting and life-threatening conditions</i></p> <p>“Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some of these conditions cause slow deterioration over time rendering the child increasingly dependent on parents and carers.</p> <p>Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer.”</p> <p><i>End of life care</i></p> <p>“Care that helps all those with advanced, progressive, incurable illness, to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement.”</p> <p>Please note that NHS England has created a draft Children’s and Young People’s Palliative and End of Life Care Service Specification. This is available for ICBs to access here from the NHS England website.</p>

The following national standards and guidance apply to palliative and end of life care for children and young people in England:

Ambitions for Palliative and End of Life Care. Available to download from: <https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/>

Palliative and end of life care: statutory guidance for integrated care boards (ICBs): <https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/>

NICE Guidance NG 61: End of life care for infants, children and young people with life-limiting conditions: planning and management <https://www.nice.org.uk/guidance/ng61>

NICE Quality Standard QS 160: 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. <https://www.nice.org.uk/guidance/qs160>

NICE guideline NG43: 2016. Transition from children to adults’ services for young people using health or social care services <https://www.nice.org.uk/guidance/ng43>

NICE Quality standard QS140: 2016. Transition from children to adults’ services <https://www.nice.org.uk/guidance/qs140>

<p>1. Do you have a children’s palliative care service specification? (Yes/No). If so, please attach a copy to your response to this request.</p>	<p>Yes, attached original version in the contract. It is due a refresh following the publication of the SLPC national spec earlier this year and will be actioned with the new 2024/25+ contract particulars when it is published.</p>
<p>2. Has your ICB completed an Ambitions for Palliative and End of Life Care self-assessment? (Yes/No). If yes, please attach your completed self-assessment to your response to this FOI request.</p>	<p>An Ambitions for Palliative and End of Life Care self-assessment was undertaken by UHBW (University Hospitals Bristol and Weston NHS Foundation Trust) on behalf of BNSSG ICS and overseen by the Children’s Palliative Care Network. Please see enclosed.</p>

<p>3. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an advance care plan? (Yes/No)</p>	<p>Yes, advanced care plans for infants, children and young people with life-limiting conditions are discussed with their parents or carers and are also involved in the development of their care plans.</p>
<p>4. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care? (Yes/No)</p>	<p>Yes, there is named medical specialist who leads and coordinates the care of infants, children and young people with life-limiting conditions.</p>
<p>5. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition, their parents or carers and their siblings should be given information about emotional and psychological support, including how to access it? (Yes/No)</p>	<p>Yes, information and access to parents, siblings and family emotional and psychological support (EPS) is available to parents or carers and families of infants, children and young people with life-limiting conditions.</p>
<p>6. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team^[1]? (Yes/No)</p>	<p>Yes, members of the specialist paediatric palliative care team are involved in the MDT care provided for infants, children and young people with life-limiting conditions.</p>
<p>7. Do you have a children’s palliative care service specification which states that siblings and parents or carers of infants, children and young people approaching the end of life should be offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No)</p>	<p>Yes, bereavement and sibling support, symptom control, the provision of therapies including play and social activities, and advisory support to families are provided to siblings, families and parents or carers of infants, children and young people approaching the end of life and after their passing.</p>

^[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>. NICE state that the specialist paediatric palliative care team should include at a minimum:

- a paediatric palliative care consultant
- a nurse with expertise in paediatric palliative care
- a pharmacist with expertise in specialist paediatric palliative care
- experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support).

<p>8. Do you have a children’s palliative care service specification which states that infants, children and young people approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care^[2] and advice from a consultant in paediatric palliative care^[3]? (Yes/No)</p>	<p>The ICB is piloting end of life care at home service for infants, children and young people until March 2024. This includes 24-hour access to both children's nursing care and specialist advice from a paediatric palliative care medical team.</p>
<p>9. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition and their families should have access regular short breaks for respite? (Yes/No)</p>	<p>Yes, regular short breaks for respite are provided.</p>

The information provided in this response is accurate as of 4 December 2023 and has been approved for release by David Jarrett, Chief Delivery Officer for NHS Bristol, North Somerset and South Gloucestershire ICB.

^[2] We would like to capture those areas where registered nurses can provide both core and specialist children’s palliative care 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 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.

Mapping exercise for Children's Palliative care- BNSSG

<u>NICE</u>	
Statement	Description
1	Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.
2	Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.
3	Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.
4	Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.
5	Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.
6	Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

Ambitions For Palliative and End of Life Care

6 Ambitions for 2021-2026 - A framework for local action

1	Each person is seen as an individual
2	Each person gets fair access to care
3	Maximising comfort and wellbeing
4	Care is coordinated
5	All staff are prepared to care
6	Each community is prepared to help

Service Priority	Priority level to focus on in next 5 years
Green	Low priority for service
Amber	Priority area for service (non urgent or non essential for basic service provision)
Red	Urgent priority or fundamental for basic service provision

Ambitions level

Level	Locality Descriptor
Level 0	Not at all ready to achieve/anticipate barriers to achievement
Level 1	Desire to achieve this ambition in place but there are no plans currently in place
Level 2	Plans in place towards achieving this ambition
Level 3	Limited achievement across one or two organisations only
Level 4	Partially achieving (details of how or which organisations)
Level 5	Fully achieving eg across all care settings, with supporting evidence available

Grading Process

1. The self-assessment tool is structured around the Six Ambitions for Palliative & End of Life Care. All measurable NICE guideline recommendations have been included under relevant Ambitions headings in accordance with
2. Localities should assess themselves against all of the 6 ambitions and should consider how these translate to all care settings i.e. hospital, care homes, hospices, home, prisons
3. Two grading systems are used, firstly the Ambitions Level, describing the current state of progress in each of the ambitions. Secondly how much of a priority achieving this ambition is for the service.
4. Finally the NICE Standards QS160 are included to which the same ambition and service priority levels can be applied.

AMBITION STANDARD	KEY STATEMENTS - How these standards apply to BCYP	BNSSG	BNSSG notes
Each person is seen as an individual	Children, young people and their families have the opportunity to be involved in advance care planning	4	No structure/tool in place to support CYP involvement
	Consistent process for documenting and communicating advance care plan decisions	2	CYPACP and Wishes in use
	We recognise when babies, children and young people would benefit from enhanced palliative support	4	No consistent assessment process in place - but opportunities for joint assessment across teams
Each person gets fair access to care	Babies, children, young people and families with palliative care needs can access care and support from a doctor with the necessary skills, knowledge and time (wherever the care setting)	4	Not all settings for all patients all of the time. Gaps: community patients not under CHSW, hospital inpatients OOH
	Access to community nursing to support delivery of EOL care at home	5	During Starling Pilot only
	Each locality understands their local population with respect to children's palliative care and uses this for planning (e.g. knowing population of CYP with LLC in order to then assess their palliative care needs)	4	Recognise investment in Project Management and Medical & nursing lead time at ICB
	Gathering and responding to feedback from people with lived experience (children, young people, families)	4	Examples of processes to hear from service users across BNSSG but not joined up
Maximising comfort and well-being	Locality has accessible and responsive services to address physical distress and symptom control, in every setting	4	Not all settings for all patients all of the time. Gaps: community patients not under CHSW, hospital inpatients OOH
	Access to 24 hour in-person nursing care (at end of life)	5	With Starling only
	CYP have access to symptom management planning (in hours)	4	With Starling and not every day at BRHC
	CYP have access to symptom management advice for EOL (Out of hours)	4	With Starling and not OOH at BRHC
	Home visiting is available from the child's named medical lead at end of life	5	With Starling only
	There are mechanisms in place for anticipatory prescribing	5	With Starling
	Prescribing & dispensing medications is available out of hours	5	With Starling only
	Locality has accessible and responsive services to address emotional and spiritual distress	4	
	Support with grief and loss is available to families, including siblings	3	Not all organisations have a formal offer
CYP and family can access expert psychological intervention to help with distress, coping and building resilience	3	Resource limited to BRHC inpatients & Lifetime	
Care is coordinated	Every CYP is cared for by a defined multidisciplinary team which can be adjusted as the needs of the CYP change	4	
	Locality has a rapid transfer process in place to enable transfer to preferred place of care whilst dying.	5	Transfer SOP in place for UHBW to CHSW/home
	Information can be shared between services/ settings in a timely way	3	email
	There is a single point of referral for PEOL services or pathway in place	1	Hope that this practice will develop from Starling
	EOL care is coordinated by a lead professional/ key worker	5	Starling service
All staff are prepared to care	There is a strategy in place for educating the MDT workforce for PEOL care	4	Contributing to regional PPC ed strategy
	Workforce have access to support to enable resilience	4	
	There are strong and defined leadership roles for CYP PEOL in the locality	4	Reliant on fixed term funding
	Access to specialist paediatric palliative medicine advice available for professionals	4	Not all of the time in all settings
Each community is prepared to help	The locality works in partnership with individuals, groups, organisations who might be best placed to augment the social infrastructure that supports CYP with PPC needs	1	
	The locality recognises the importance of schools in providing community based support for CYP & families	4	In clinical practice

Data re numbers dying each year etc

NB Accessibility to the right support and care in every setting

ICS Domain Scores for Ambition 1 ("Each person is seen as an individual")	BNSSG
Children, young people and their families have the opportunity to be involved in advance care planning	4
Consistent process for documenting and communicating advance care plan decisions	2
We recognise when babies, children and young people would benefit from enhanced palliative support	4

ICS Domain Scores for Ambition 2 ("Each person gets fair access to care")	BNSSG
Babies, children, young people and families with palliative care needs can access care and support from a doctor with the necessary skills, knowledge and time (wherever the care setting)	4
Access to community nursing to support delivery of EOL care at home	5
Each locality understands their local population with respect to children's palliative care and uses this for planning (e.g. knowing population of CYP with LLC in order to then assess their palliative care needs)	4
Gathering and responding to feedback from people with lived experience (children, young people, families)	4

ICS Domain Scores for Ambition 3 ("Maximising comfort and wellbeing")	BNSSG
Locality has accessible and responsive services to address physical distress and symptom control, in every setting	4
Access to 24 hour in-person nursing care (at end of life)	5
CYP have access to symptom management planning (in hours)	4
CYP have access to symptom management advice for EOL (Out of hours)	4
Home visting is available from the child's named medical lead at end of life	5
There are mechanisms in place for anticipatory prescribing	5
Prescribing & dispensing medications is available out of hours	5
Locality has accessible and responsive services to address emotional and spiritual distress	4
Support with grief and loss is available to families, including siblings	3
CYP and family can access expert psychological intervention to help with distress, coping and building resilience	4

ICS Domain Scores for Ambition 4 ("Care is coordinated")	BNSSG
Every CYP is cared for by a defined multidisciplinary team which can be adjusted as the needs of the CYP change	4
Locality has a rapid transfer process in place to enable transfer to preferred place of care whilst dying.	5
Information can be shared between services/ settings in a timely way	3
There is a single point of referral for PEOL services or pathway in place	1
EOL care is coordinated by a lead professional/ key worker	5

ICS Domain Scores for Ambition 5 ("All staff are prepared to care")	BNSSG
There is a strategy in place for educating the MDT workforce for PEOL care	4
Workforce have access to support to enable resilience	4
There are strong and defined leadership roles for CYP PEOL in the locality	4
Access to specialist paediatric palliative medicine advice available for professionals	4

ICS Domain Scores for Ambition 6 ("Each community is prepared to help")	BNSSG
The locality works in partnership with individuals, groups, organisations who might be best placed to augment the social infrastructure that supports CYP with PPC needs	1
The locality recognises the importance of schools in providing community based support for CYP & families	4

Ref	Standard	Statement	How this standard relates to babies, Children & Young People	Evidence Summary	Working on	Future plans	Identified Gaps	AMBITIONS level 0-5	Ambitions level without Starting	Priority level to focus on in the next Sys RAG	Action		
1	AMBITIONS	Each person is seen as an individual	CYP are involved in developing an advance care plan.	All providers who are involved in developing ACPs reference involving CYP and families in developing ACPs 'where appropriate'			Specific tools/templates/documents that support engagement of the YP themselves are not in use	4	4				
1	NICE	Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.	Parents and carers are involved in developing an advance care plan (including perinatal) All CYP in the last year of life have an opportunity to undertake an ACP The locality records and communicates decisions around CPR that is consistent and shared across all care settings The locality use a recognised ACP template and have a process for sharing this information with relevant parties	All providers who are involved in developing ACPs do so in partnership with families. No provider organisations have processes in place to identify which CYP may benefit from being offered the opportunity to advance care plan. All rely on individual clinicians to identify patients & families, or for families to self identify. One provider uses reminders on clinical proformas to prompt clinicians to consider advance care planning. Decisions about CPR are shared using ACPs (using a variety of ACP templates). It is the responsibility of the professional updating or developing the plan to disseminate the version for use by email. Sharing of ACPs with schools and Rainbows Family Support Service often relies on the families doing this. Different templates in use - CYPACP, Wishes document, ResPECT (for YP approaching transition to adult services). NICUs use ACPs (usually written for babies who are being discharged from the units, otherwise plans are documented in the inpatient clinical record		Planning to begin process of moving over to using CYPACP (with ResPECT) as BNSSG ACPing template as next focus for BNSSG Pall & EOL care board	A system that enables access to up to date ACPs, wherever the CYP is lack of a ACP template used consistently across the locality	4	4	3	3		
1	NHSE	1.1 People are identified as likely to be in the last 12 mths of life and are offered personalised care and support planning	The locality has clear processes in place for planning end of life care, including identifying who may benefit CYP with LLC can be identified within a locality area	Examples of places where EOL care planning takes place: - H&A/MD/MT Palliative Care Forum (UHW/ H&A/MD/MT, UHW/PCBST, CHW, advice may routinely attend with other SW CPC teams & shared care teams attending on a case by case basis) - Patient specific EOL care planning meetings when CYP are moving location (eg hospital to hospice or home) - following the UHW/CHW transfer SOP - Patient specific EOL care planning meetings - If this care is taking place in hospital the PCBST should be involved and involved community PPC providers invited to ensure care is joined up and opportunity for community teams to provide in reach support team - During Starling Service pilot there will be a defined process (meeting structure, attendance, documentation) to follow when planning the delivery of EOL care at home There is no system in place across the locality to identify which CYP may be approaching EOL Nurse led meeting to discuss cascade No system in place to identify CYP across the locality			No system in place to identify CYP across the locality who may be approaching EOL No system in place to identify CYP with LLC across the locality	4	4	0	0		
3	NHSE	1.3 personalised and community focused approach	CYP in the last year of life have a personalised care plan or multi agency plan Tools are in place to measure patient outcomes against personally defined goals Information about PEOC services is easily accessible to patients and the workforce Choice of place of care is promoted CYP have access to multidisciplinary assessment, support and financial support packages Proportion of CYP (known to services) who have an advance care plan	Palliative care plans take the form of advance care plans, symptom management plans. These are developed in response to clinical need (eg. g. unstable symptoms, a wish to avoid hospital and therefore to approach symptoms differently to usual pathways). CYP under the care of Lifeline have a care plan which is often shared with other providers to inform the development of their own care plans. There is no system in place to develop care plans that can be used by all providers in different settings (although this has been identified as a gap in the past). The Starling Service will use care plans that all partner organisations have developed together and commit to using No BBHC and Charlton Farm are recruiting sites for the CPOS study information is available. On organization's website for individual providers On 'Remedy' - the ICE's GP Referral Support Tool https://remedy.bring-itb.nhs.uk/children-young-people/end-of-life-care-children/end-of-life-care-children/ Enabling choice of place of EOL care has been an identified priority - hence focusing on the launch of the Starling Service pilot. Choice of place of care will be promoted with the launch of the Starling pilot. Each PPC provider organization makes these assessments according to their own offer and processes. There is no cross organisation assessment Each provider can identify the number of CYP known to them who have an ACP	Launch of the Starling Service EOL at home pilot	Evaluate Starling Service pilot and secure sustainable funding for ongoing provision	There is no palliative care plan that can be used across organisational boundaries No tool in place to measure patient outcomes against personally defined goals	4	4	1	1		
2	AMBITIONS	Each person gets fair access to care	There is Local data available and reviewed relating to child death Data is shared across the region to inform and plan services	Data collected as part of the CDOP process is reviewed within that process and themes shared through the reports generated by CDOP BNSSG end of life group				4	4	4	4		
1	NHSE	1.3 equitable access to PEOCs for all, focusing on locally identified under-served populations	The locality understands palliative care services, population and needs and uses it to plan future services. There is representation at a strategic level of all ages, faiths and cultural groups	Local needs assessment has been done as part of the Starling project No				4	4	1	1		
1	NICE	Infants, children and young people with a life limiting condition have a named medical lead to coordinate care	PEOC services are based on a locality needs assessment The views and experiences of CYP and parents are sought about the services they use	Local needs assessment has been done as part of the Starling project There is no cross locality system that enables views & experiences of services users to be heard. We have heard from services users that this is something they would find useful - and would appreciate the opportunity for organisations to act as 'listening ears' for each other Engagement events with professional and family stakeholders have been hosted by UHW/PCBST in 2016 and 2019 The Starling Service has been developed with input from service users - we have a lived experience representative on our Pacts Pall & EOL Care Board and the development of the model of care has been informed by interviews with bereaved parents			A process by which service users can provide feedback about the care they have received from across the locality would help us to improve the care we deliver	4	4	4	4		
1	NICE	There is equal access to bereavement care	All children have access to a named medical specialist who leads EOL care There is equal access to community nursing care at EOL There is equal access to specialist medical care	Variable according to which service the CYP is known to. All will have a medical lead at the time of delivery of EOL care but that individual's availability, skills, confidence and knowledge may not meet the CYP's need as far as delivering EOL care is concerned With the Starling Service pilot - yes. Without this - no Specialist medical care is available as follows: At EOL, in home: Available when Starling Service is running but not when it isn't At home not EOL: Possibly may access outreach support from Charlton Farm medical team but this support is not commissioned or part of the hospice care offer In hospital: 4 days/week only and not OOH	Trialling a holistic bereavement needs assessment tool as part of the Starling Service pilot in the hope that this will meet us closer to a goal of better joined up support in bereavement The Starling pilot has enabled alignment and coordination of care provided in the first two weeks following the BCP's death and development of a bereavement holistic needs assessment tool which will be trialled during the pilot.	All providers of bereavement support for families of CYP in BNSSG working more closely in partnership in a more coordinated way	Consistent and coordinated approach to the delivery of bereavement support across the locality	4	3	4	3		
2	NHSE	2.1 high quality PEOCs for all, irrespective of diagnosis or condition	All children have access to a named medical specialist who leads EOL care There is equal access to community nursing care at EOL There is equal access to specialist medical care	Variable according to which service the CYP is known to. All will have a medical lead at the time of delivery of EOL care but that individual's availability, skills, confidence and knowledge may not meet the CYP's need as far as delivering EOL care is concerned With the Starling Service pilot - yes. Without this - no Specialist medical care is available as follows: At EOL, in home: Available when Starling Service is running but not when it isn't At home not EOL: Possibly may access outreach support from Charlton Farm medical team but this support is not commissioned or part of the hospice care offer In hospital: 4 days/week only and not OOH		Evaluate Starling Service pilot and secure sustainable funding for ongoing provision		4	4	5	3		
2	NHSE	2.3 high quality PEOCs across systems	There is a process to share Learning from child death Locality has accessible and responsive services to address emotional distress Locality has accessible and responsive services to address spiritual distress Locality has accessible and responsive services to address social distress Skilled and competent workforce is available to manage/ address physical distress & symptom control Systems are in place to recognise children who may be approaching EOL Prescribing & dispensing medications is available out of hours	Child death review process which all providers input into Hospital and Bereavement offer from services Hospital chaplain BNSSG Provision is patchy across the locality. At home: For CYP who are not at EOL. If they are known to Charlton Farm the hospice team will provide medical advice to their local teams At BRHC: Symptom advice is available 4 days/week - none Relies on individual clinicians/teams With Starling Service - yes. Starling prescribers will prescribe and medications will be dispensed via UHWH. The community & hospice based teams were facing considerable challenges in accessing medicines from community pharmacies				4	4	4	4	3	3
3	AMBITIONS	Maximising comfort and wellbeing	Skilled and competent workforce is available to manage/ address physical distress & symptom control Systems are in place to recognise children who may be approaching EOL Prescribing & dispensing medications is available out of hours	Provision is patchy across the locality. At home: For CYP who are not at EOL. If they are known to Charlton Farm the hospice team will provide medical advice to their local teams At BRHC: Symptom advice is available 4 days/week - none Relies on individual clinicians/teams With Starling Service - yes. Starling prescribers will prescribe and medications will be dispensed via UHWH. The community & hospice based teams were facing considerable challenges in accessing medicines from community pharmacies			Without sustainable funding for the Starling Service this will not be available beyond March 24	4	4	3	3		

Red	0
Amber	1
Green	2
	3
	4
	5

SCHEDULE 2 – THE SERVICES
NHS Bristol, North Somerset and South Gloucestershire ICB
Specialist Children Palliative and End of Life Care

A. Service Specifications

1. Population Needs

1.1 National/local context and evidence base

Children’s palliative care is concerned with the treatment of children with life-limiting or life-threatening conditions by maintaining quality of life, not just in the dying stages, but also in the weeks, months and years before death. It is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (ACT 2008).

Better Care Better Lives (Department of Health, 2008) recognises the specialist skills and expertise of the voluntary sector, particularly children’s hospices, in palliative care and end-of-life care. The document also recognises the needs of families to access specialist short breaks, whether at home, in a children’s hospice or other voluntary sector provider, or in the community. This service model is based on the guidelines for best practice by Children’s Hospice UK 2008.

National Policy

- Children Act (2004)
- Standards for Better Health (2004)
- Our Choice, Our Care, Our Say (2006)
- Better Care Better Lives (DH 2008)
- Healthy Lives, Brighter Futures (DCSF, DH 2009)
- Working together to safeguard children (HM Government 2010)
- National Framework for Children and Young People’s Continuing Care (DH 2010)
- NHS at home: children’s community nursing services (DH, 2011)
- Getting it right for Children and Young People: Overcoming cultural barriers in the NHS so as to meet their needs (DH, 2010)
- Achieving Equity and Excellence for Children (DH, 2010)
- NHS Five Year Forward View (2014)
- Children and Families Act (2014)

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	
Domain 2	Enhancing quality of life for people with long-term conditions	
Domain 3	Helping people to recover from episodes of ill-health or following injury	
Domain 4	Ensuring people have a positive experience of care	
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	

2.2 Local defined outcomes

- Children and young people with palliative care needs and their families will have their emotional and physical challenges mitigated by the care and support they receive by the services delivered by the hospice.
- Families and children report that their social, cultural, spiritual, physical and emotional needs are met.
- It can be demonstrated that the child/young person is pain free or pain is minimised as far as possible.
- The child and family are supported to improve the quality of their lives through access to specialist clinical and psychological expertise, either for regular interventions, in an emergency or for respite care.
- Parents and children report that they are well informed about their conditions and the support/services available to them both within the hospice and within their own local area.
- Parents and siblings have a positive experience in the last days/hours of their child's (sister or brother's) life through the provision of timely interventions and support.
- The child and family will expect clear links and regular information exchange to be made with the named professional (key worker) in the child's local community.
- Close family involvement around choice of place of death, including use of the Wishes document

3. Scope

3.1.1 Aims of the service

The Provider will offer high quality care and support to children and young people with life limited or life-threatening illnesses, who are registered with a GP within the catchment area for NHS BNSSG.

The Provider will provide a range of services, which should include short breaks, emergency and end of life care, which will include various leisure and therapeutic activities and facilities to help children to be comfortable.

The Provider will work in the context of the wider network of services and support commissioned and provided by the NHS and other partners for these children and families.

Care definitions (ACT and RCPCH, 1997)

- Group 1 – Life-threatening conditions for which curative treatment may be feasible but can fail (cancer, irreversible organ failures)
- Group 2 – Conditions with long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death possible. (cystic fibrosis, muscular dystrophy)
- Group 3 – Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. (Batten's disease, mucopolysaccharidosis)
- Group 4 – Conditions with severe neurological disability which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not usually considered progressive. (severe multiple disabilities, such as following brain or spinal cord injuries)

3.1.2 Objectives of the service

To build a collaborative relationship with NHS Commissioners which will enable care to be available to local children with palliative care needs. This will include children and who are eligible for care in line with the local eligibility criteria for Continuing Care for Children and Young People.

The Provider will offer eligible children and young people high quality services, including but not restricted to:

- End of life care and support
- Short breaks care and support
- Emergency/crisis support
- Associated care such as bereavement and sibling support, symptom control, the provision of therapies including play and social activities, and advisory support to families.

These services may be agreed with NHS commissioners as part of a care package.

3.2 Service description/care pathway

The provider will deliver children's palliative care in accordance with the "ACT Integrated Multiagency Care Pathway for Palliative Care for Children (2004)". This pathway has been agreed as the most appropriate model for NHS palliative care delivery.

The service will provide holistic, family centred care. It is anticipated that the model of delivery will be as non-medicalised as possible within the parameters of the child's medical and nursing needs.

The hospice service may be delivered in different ways through a menu of services designed to deliver specialised individual packages of care, tailored to an individual child. Hospices have always aspired to the highest standards for this group of children and this specification is supportive of that trend continuing, with clear and transparent requirements that enable demonstration of their high quality work.

3.2.1 Environment

The hospice will provide a safe, homely and appropriate environment which facilitates privacy, relaxation and enjoyment but with the provision of specialist equipment such as hoists, soft play, sensory equipment and communication aids to support the care offered, where required.

An appropriately furnished area for young people/older service users, facilities for siblings and other family members and a range of leisure activities may also be made available.

3.2.2 Care

The care offered will aim to meet the social, cultural, spiritual, physical and emotional needs of the child/young person and their family. The team will endeavour to meet the needs of families from all cultural and ethnic backgrounds taking into account the customs, values and spiritual beliefs of the child and his/her family. The confidentiality, privacy and choice of the child/young person will be respected. The team will promote welfare and protection for children/young people (Children Act 1989) and may provide advocacy where needed. (Children Act 2004 and National Service Framework for Children, Young People and Maternity Services 2004). The care given will be guided by the wishes of the individual child/young person and their family, whether in the children's hospice or in the community. Care will be provided in partnership with the child and family in a spirit which acknowledges their right to confidentiality and choice and recognises the child's individual needs, whilst preserving dignity.

3.2.3 Support

Appropriate support will be made available to meet the needs of the family members and those closely involved with the child/young person and family.

The provider should aim to develop facilities and services which are flexible enough to meet the support needs of all family members. Particular and appropriate facilities and care should be provided for the child/young person's siblings staying in the hospice. A named member of the team (key worker) should be responsible for maintaining contact with a family in order that support continues when a child is at home between visits. The frequency of this contact will depend upon the needs of individual families.

3.2.4 Symptom Control

Symptom control will aim to promote comfort and enhance quality of life.

Collaboration with paediatricians, paediatric palliative care consultants, GPs, specialist nurses and other professionals will ensure that every effort is made to control distressing symptoms and provide choices of management. The child/young person should be involved in all decisions relating to care, and consent for any invasive procedures should be obtained. Symptom control requires frequent evaluation in order for it to be effective.

Forward planning which anticipates a change in need is often required to facilitate effective medicines management within the hospice and community settings. Advanced Care Plans should be discussed and documented. All care, whether conventional or complementary, will be given by staff with appropriate knowledge and experience, aimed at enhancing quality of life for the child and his or her family.

3.2.5 End of life care

Care will be continued during the terminal phase of a child's illness and following death if it is the choice of the child/young person or family. The spiritual care offered to the child and family at this stage will be appropriate to their individual wishes.

When death occurs within the children's hospice there should be facilities for the child's body to remain there until the funeral if this is the family's wish. The family can then spend as much time with their child after death as is helpful. Unless the service offered is "hospice care at home", accommodation should be available for the family to remain at the children's hospice during this time. A team member must be available to give support and information to the family as well as practical help if desired with organising the funeral and any other issues relating to the death. Sensitive, emotional support is essential for all close members of the family and the other children and families in the children's hospice at the time.

3.2.6 Bereavement

After death, bereavement care will be available to the family with support being an integral part of that care, respectful of cultural and religious needs.

Staff working with bereaved families must have access to supervision/support. Staff will have appropriate skills and experience and work closely with other agencies who may offer support in the family's own locality.

3.2.8 Transition and Discharge processes

It is recognised that packages of support may vary to that predicted and as a result, plans may need to be reviewed more regularly than quarterly. Similarly children/families may wish to be discharged at their choice and it will be the responsibility of the lead NHS professional and commissioners to find alternative provision if this is needed.

A number of children previously not expected to survive until adulthood are now living longer and reaching adulthood. Where this occurs, the service will support the smooth transition to adult services. Given the small number of young people, this may require conversations with commissioners of both adult and children's services. This requires early co-operative planning and delivery across health, social care and education services which is supportive without compromising the need for the young person's increasing independence.

The provider should ensure that they have a clear policy identifying transition arrangements to adult services.

3.2.9 Response time and prioritisation

The provider should respond to urgent referrals within 48 hours. If capacity prevents this then they will liaise with the referrer/lead professional and commissioner to prioritise while alternative provision (if appropriate) is sought elsewhere.

3.2.10 Self-care and patient carer information

The provider will be involved in the review and evaluation of care packages for children on their case load with other professionals, at each contact throughout the illness and at the request of the patient or carer.

When larger multiagency meetings are needed the provider is expected to be involved. These meetings will be to review packages of care. The date of the next review will be set and recorded.

Multiagency review of the care plan will include:

- The relevance and appropriateness of current care package
- The effectiveness of care plans
- Any newly identified needs
- Patient satisfaction with the care
- Modality and frequency of all therapies and support
- Activities of daily living/social care support
- Medication – how monitored/reviewed
- Pain plans
- Risk assessment procedures and crisis/urgent response

3.2.11 Workforce

An appropriate skill mix will be maintained and reviewed regularly, for both inpatient and outreach activity in order to deliver a service which meets the population needs.

- All trained staff are registered with the appropriate Professional body with membership and registration audited regularly to ensure compliance
- Non-professional staff must undertake training to ensure they have a minimum set of competencies to undertake their role.
- Staff should have access to a process which enables them to raise, in confidence, concerns over any aspect of service delivery that could affect the quality of patient care.
- Staff should have undertaken training for Lone Working, if applicable
- Mandatory training including CPR, manual handling, infection control, child protection must be undertaken and delivered in accordance with the Provider's policies.
- Support and train students to ensure future workforce and capacity.
- All staff should be skilled in adult and paediatric resuscitation.
- Also see requirements for safeguarding.

3.2.12 Record Keeping

The following must be delivered as a minimum:

- Record management policy, which ensures as a minimum adherence to Data protection Act, confidentiality and regular audit of records.
- Work towards a system to allow client information to be kept electronically
- Care plan completed with risk assessment where appropriate
- All visits/activity must be recorded in a legible, timely and accurate manner
- Clear process for moving and tracking records to be in place
- Clear process of working towards the development of joint records
- The provider will have policies and procedures in place to reduce risk of errors resulting from poor information recording and sharing. This will include timely sharing of information between family hand-held records and the clinical records

3.3 Population covered

The funding agreement for this service specification covers all children who reside in the BNSSG and are registered with a Bristol, North Somerset, and South Gloucestershire GP.

3.4 Any acceptance and exclusion criteria

This service is commissioned for children and young people with life-limiting and life-threatening conditions, usually up to the age of 18, although there will be provision up to 19 in certain circumstances, to be agreed on a case-by-case basis.

Children and young people will not be removed from the caseload if their prognosis changes, unless they become ineligible for the service against the agreed criteria.

3.4.1 Referral criteria

A consultant paediatrician or children's community nursing team manager will need to make a referral (or endorse a referral) in order for a child to be included within the activity for this contract.

Any new referral to the Hospice for which funding from the NHS is being requested will be approved by the Commissioning Manager or Children's Continuing Care Nurse Manager. It is expected that an holistic assessment, including health, social care and any specialist assessment will have been completed by the provider, jointly with other services if appropriate

The provider will develop a package of support with the child / family, and sharing this and its costing with the Commissioning Manager. Once agreed this will then be included in the agreed contract activity for the relevant commissioner. Any admissions or accepted cases for services of children that fall outside the agreed package of support will require authorisation by a commissioning manager in advance, unless as a result of urgent/end-of-life/crisis support.

If the referral to the hospice is not deemed to be meeting a need as described above, the services provided by the hospice will not be included in the agreed contract activity. The provider may choose to provide a package of care funded through other income.

It will be the responsibility of the Provider to undertake regular reviews of the need of the child or young person to ensure that the service is meeting the outcomes identified and that they meet the criteria for provision of support under this Contract.

3.4.2 Out of hours / End of Life

In a crisis/immediate-end-of-life/emergency situations new referrals may be made directly to the provider. However the commissioning manager / Children's Continuing Care Nurse Manager will be informed of this action at the earliest opportunity by both the provider and the referring clinician.

In exceptional circumstances where a commissioner cannot be contacted (such as out of normal business hours or bank holidays) the referrer (consultant paediatrician or children's community nursing team manager) may at their clinical discretion arrange appropriate hospice admission. However, a notification in writing discussion with a commissioner **must** take place as soon as possible thereafter (i.e. no later than 72 hours). It is anticipated that this scenario would only apply to immediate end of life care or a health/social crisis situation where the only alternative to this hospice placement is a hospital admission over a weekend/bank holiday.

3.4.3 Acceptance criteria

The service will be available to children and young people with life-limiting or life-threatening conditions and their families.

3.4.4 Exclusion criteria

- Young people over the age of 18 will not normally be accepted and should be discussed with the local commissioner in advance of their 18th birthday
- Children or young people not registered with a GP in the BNSSG area.
- Children or young people not meeting the referral criteria specified in Section 3.4.1
- Children or young people referred and admitted to any of the provider's services without being subjected to the agreed referral pathway and panel process. These patients will not have funding agreed by NHS commissioners.

It is acknowledged that the hospice may choose to provide services to a child or young person and their family who do not meet the NHS criteria and requirements in Section 3.4.1. This arrangement is separate to any NHS agreement and may be funded charitably at the discretion of the hospice.

3.5 Interdependencies with other services and providers

The provider will make available specialist expertise and advice to children's community nursing teams and paediatric teams within the child's local area.

The provider will link with all relevant NHS, social care and independent providers in and out of the Local Authority as required ensuring continuity of care for children and their families.

Sub-contractors

The Provider must notify the NHS Commissioners if it intends to use subcontractors when delivery of care cannot be met through the organisation's own service capacity.

If nursing agencies are used to augment capacity then the Provider must supply NHS Commissioners with details of these agencies, and the contractual arrangements.

Whole system relationships

The Provider will work collaboratively with NHS commissioners and other providers to ensure that referrals of locally eligible children go through the agreed referral pathway as outlined in section 3.4.1.

Safeguarding Children and Young People and Vulnerable Adults

The Provider must ensure that they meet the quality standards of all the required policies and procedures relating to safeguarding.

- All staff must be in receipt of child protection training and updating, on a minimum 3 yearly basis, at an appropriate level to their role
- All staff are compliant with Care Quality Commission Standards.
- All staff working with children and young people will have undertaken an enhanced or appropriate Criminal Records Bureau check, checked on a three yearly basis
- The provider should have an identified Named lead professional for safeguarding children within the organisation.
- All staff to have regular checking of their registration on annual basis
- All staff with patient contact will access CP supervision on a regular basis (minimum 3 monthly)
- All staff must adhere to National legislation with regards to safeguarding and local LSCB policies, including that pertaining to safer recruitment
- Mechanisms for ensuring that allegations towards staff pertaining to safeguarding issues are fully investigated must be in place and adhered to, including informing the relevant commissioner.
- Processes should be in place for managing allegations against staff and any incidents or complaints relating to any aspect of safeguarding children, including informing the relevant commissioner
- A clear process to ensure all children who do not attend for whom there are safeguarding concerns are flagged with the safeguarding team.
- The Hospice must have child protection policies and procedures in place that comply with the South West Child Protection procedures.

<https://swcpp.trixonline.co.uk/>

4. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

The services provided will be subject to inspection by the Care Quality Commission.

All services will be required to meet the following:

- Care Quality Commission Essential Standards of Quality and Safety
- NSF Standards for disabled and ill children
- Relevant NICE guidelines

- Children Act (2004) section 11 and other safeguarding legislation
- PEAT (patient environment assessment tool)
- All service provision should be delivered in an appropriate, safe, child/young people centred environment, which promotes effective care and optimises health outcomes
- Essence of Care –Privacy and dignity
- “You’re Welcome”
- Adherence to all hospice policies including Serious Untoward Incident reporting, management of emergencies, Risk Management, Complaints. Diversity, safety notices/alerts, CQC. *(For a list of policies refer to the main body of the contract)*

3.2 Applicable local standards

for the area in which the hospice provides services

- Local Safeguarding procedures
- Local Area Agreement
- Locally applicable NHS or multi-agency policies and procedures
- Children and Young People’s Plan

5. Applicable quality requirements and CQUIN goals

5.1 Applicable Quality Requirements (See Schedule 4A-D)

5.2 Applicable CQUIN goals (See Schedule 4E)

Not applicable

6. Location of Provider Premises

7. Individual Service User Placement