Reference: **FOI.ICB-2526/218**

Subject: **Palliative care for children and young people with life-limiting and life-threatening conditions**

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

QUESTION	RESPONSE
1. Does your ICB have a children's palliative care service specification? (Yes/No). If yes, please attach a copy to your response to this request.	Please see response to Q8.
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 request.	Yes, please find enclosed (Document 01)
3. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition and their parents or carers have opportunities to be involved in developing an advance care plan? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.	Yes, the BRHC (Bristol Royal Hospital for Children) Palliative Care Service in conjunction with Lifetime and Children's Hospice South West (CHSW) (Charlton farm) - charity organisation. Specifications provided in response to Q8.
4. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition have a named medical specialist who leads and coordinates their care? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.	Partially, the BRHC and CHSW (charity organisation) have palliative care consultants at end of life. Children with life-limiting or life- threatening conditions will have a named community paediatrician and lifetime nurse. If a child is under oncology for cancer they will be under the care of a named oncologist and CLIC nurse.

5. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition, their parents or carers and their siblings are given information about emotional and psychological support, including how to access it? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.	Yes, Sirona - lifetime psychologist's service End of life emotional /bereavement support can be also accessed from Charlton farm and Jessie May (both charity organisations). Specifications provided in response to Q8.
6. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification	Yes, the BRHC palliative care service in conjunction with Lifetime, CHSW and Jessie May (both charity organisations). Specifications provided in response to Q8.
7. In your local area, does your ICB commission services which ensure siblings and 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? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.	Yes, the BRHC palliative care service in conjunction with Lifetime, CHSW and Jessie May (both charity organisations). Specifications provided in response to Q8.
8. In your local area, does your ICB commission services which ensure 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? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification. Note: 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	Yes, advice can be sought from CHSW and Jessie May. Sirona – Lifetime community nurses in hours. If oncology patient, will also have support from CLIC nurses. Service specifications enclosed for Lifetime (Doc 02), CHSW (Doc 03) and Jessie May (Doc 04).

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. Note: NHS England state that specialist children's palliative care teams should be led by specialist medical consultants. These specialist consultants are vital because they: i. Have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum. ii. The ability to manage the full range of symptoms experienced as disease and illness progresses. iii. Lead and develop services within their region. iv. Enable, support, teach and train other health care professionals.	
9. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition and their families have access to regular short breaks for respite? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.	Yes, CHSW and Jessie May - service specifications enclosed as per question 8.

The information provided in this response is accurate as of 17 November 2025 and has been approved for release by David Jarrett, Chief Delivery Officer for NHS Bristol, North Somerset and South Gloucestershire ICB.

Mapping exercise for Children's Palliative care- BNSSG

NICE 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 relavent 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 palce to supportCYp 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 visting 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 resilence	3	Resource limited to BRHC inpatients & Lifetime
Care is coordinated	Every CYP is cared for by a defined multidiciplinary 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 referal 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 is 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 resilence	4

ICS Domain Scores for Ambition 4 ("Care is coordinated")	BNSSG
Every CYP is cared for by a defined multidiciplinary 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 referal 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 is 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 Starling	Priority level to focus on in the next 5yrs 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 themself are not in use	4	4		
1	NICE	Infants, children and young people with a life-limiting conditions 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 providers who are invovled in developing ACPs do so in partnership with families				4	4		
			All CYP in the last year of life have an opportunity to undertake an ACP	No provider organisations have processes in place to identify which CYPF 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 clincial proformas to prompt clinicians to consider advance care planning.				4	4		
			The locality records and communicates decisions around CPR that is consistant and shared across all care settings	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.			A system that enables access to up to date ACPs wherever the CYP is	3	3		
			The locality use a recognised ACP template and have a process for sharing this information with relevant parties	Different templates in use - CYPACP, Wishes document, ReSPECT (for YP approaching transition to adult services). NICUs use ACPs (usually wishes) 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	Lack of a ACP template used consistently across the locality	2	2		
1	NHSE	1.1 People are identified as likely ro 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**	Examples of places where EOL care planning takes place: - HaemOncBMT Palliative Care Forum (UHBW HOB MDT, UHBW PPCBST, CHSW, Jessie May routinely attend with other SW PPC 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 UHBW/CHSW transfer SOP - Patient specifc EOL care planning meetings - if this care is taking place in hospital the PPCBST 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 taken - 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 caseload			No system in place to identify CYP across the locality who may be approaching EOL	4	4		
			CYP with LLC can be identified within a locality area	No system in place to identify CYP across the locality			No system in place to identify CYP with LLC across the locality	0	0		
3	NHSE	3.3 personalised and community focused approach	**CYP in the last year of life have a personalised care plan or multi agency plan**	Palliative care plans take the form of advance care plans, symptom management plans. These are developed in response to clinical need (e.g. unstable symptoms, a wish to avoid hospital and therefore to approach symptoms differently to usual pathways). CYP under the care of Lifetime 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			There is no palliative care plan that can be used across organisational boundaries	4	4		
			Tools are in place to measure patient outcomes aginst personaly defined goals	No BRHC and Charlton Farm are recruiting sites for the CPOS study			No tool in place to measure patient outcomes against personally defined goals	1	1		
			Information about PEOL services is easily accessible to patients and the workforce	Information is available: On organisation's websites for individual providers On 'Remedy' - the ICB's GP Referral Support Tool https://remedy.bnssg.icb.nhs.uk/children-young-people/end-of-life-care-children/end-of-life-care-children/				4	4		
			Choice of place of care is promoted	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	Launch of the Starling Serive EOL at home pilot	Evaluate Starling Service pilot and secure sustainable funding for ongoing provision	Sustainable funding for EOL at home provision beyond March 2024	5	4		

			CYP have access to multidisciplinary assessment, support and financial support packages	Each PPC provider organisation makes these assessments according to their own offer and processes. There is no cross organisation assessment			No system for making or sharing multidisciplinary assessment, support or financial packages across the locality	2	2		
			Proportion of CYP (known to services) who have an advance care plan	Each provider can identify the number of CYP known to them who have an ACP				4	4		
2	AMBITIONS	**Each person gets fair access to care**	**There is Local data availible and reviewed relating to child death**	Data collected as part of the CDOP process is reviewed within that process and themes shared through the reports generated by CDOP				4	4		
			Data is shared across the region to inform and plan services	BNSSG end of life group				4	4		
1	NHSE	1.3 equitable access to PEOLc for all, focussing on locally indentified under-served populations	**The Locality understands palliative care services, population and needs and uses it to plan future services.**	Local needs assessment has been done as part of the Starling project				4	4		
			There is representation at a strategic level of all ages, faiths and cultural groups	No				1	1		
1	NICE	Infants, children and young people with a life-limiting condition have a named medical lead to coordinate care	**PEOL services are based on a locality needs assessment**	Local needs assessment has been done as part of the Starling project				4	4		
			The views and experiences of CYP and parents are sought about the services they use	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 UHBW PPCBST in 2016 and 2019 The Starling Service has been developed with input from service users - we have a lived experience representative on our Paeds 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 recevied from across the locality would help us to improve the care we deliver	4	4		
			There is equal access to bereavement care	All providers have a bereavement offer - these vary by organisation. Access to support in bereavement is not equitable currently - it depends on 1. whether the family was known to providers in life 2. what the circumstances of their death/disease were (eg. enables access to support from specific charities) 3. Where they died (eg death at BRHC means access to BRHC bereavment support team) The Starling pilot has enabled alignment and coordination of care provided in the first two weeks following the BCYP's death and development of a bereavement holistic needs assessment tool which will be trialled during the pilot.	Trialling a holistic bereavement needs assessment tool as part of the Starling Service pilot in the hope that this will move us closer to a goal of better joined up support in bereavement	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 beravement support cross the locality	4	3		
2	NHSE	2.1 high qaulity PEOLc for all, irrisprective of diagnosis or condition	**All children have access to a named medical specilaist who leads EOL care**	Variable according to which service the CYP is known to. All will ahve 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				4	4		
			There is equal access to community nursing care at EOL	With the Starling Service pilot - yes. Without this - no		Evaluate Starling Service pilot and secure sustainable funding for ongoing provision		5	3		
			There is equal access to specialist medical care	Specialist medical care is available as follows: At EOL at 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 core offer In hospital: 4 days/week only and not OOH				4	3		
2	NHSE	2.3 High quality PEOLc across systems	**There is a process to share Learning from child death**	Child death review process which all providers input into				4	4		
3	AMBITIONS	**Maximising comfort and wellbeing**	**Locality has accessible and resonsive services to address emotional distress**	Hospice and bereavement offer from services				4	4		
			Locality has accessible and resonsive services to address spiritual distress	Hospital chaplain				3	3		
			Locality has accessible and resonsive services to address social distress	BNSSG				3	3		
			Skilled and competent workforce is availible to manage/ address physical distress & symptom control	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				4	4		
			Systems are in place to recognise children who may be approaching EOL	Relies on individual clinicians/teams				3	3		

			Prescribing & dispensing medications is availible out of hours	With Starling Service - yes. Starling prescribers will prescribe and medicines will be dispensed via UHBW. 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	5	4		
			There are mechanisms in place for anticipatory prescribing	With Starling service - yes. For patients not under the care of the Starling Service hospice & hospital PPC teams may develop Symptom Management plans and do anticipatory prescribing				5	4		
6	NICE	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	**CYP have access to 24-hour children's nursing care at EOL (visiting)**	With launch of Starling Service Pilot (3/7/23-31/3/24) this will be available	Starling Service Pilot launch July 23		Without sustainable funding for the Starling Service this will not be available beyond March 24	5	4		
1	NHSE	1.2 patients and carers can access Eol care and advice they need, whatever time of day	**CYP have access to symptom management advice (in hours)**	Only through: PPCBST - nursing advice M-F 9-5, medical advice M-Thurs 9-5 Charlton Farm Medical Team (if on hospice caseload)			medical cover only available days per week	4	4		
			CYP have access to symptom management advice for EOL (Out of hours)	With launch of Starling Service Pilot (3/7/23-31/3/24) this will be available for BCYP receiving EOL care at home. OOH EOL symptom management advice for hospital inpatients is only available from core teams (no specialist PPC support OOH). OOH EOL Symptom management advice is available for inpatients at Charlton Farm		not availible in the Hospital BCH	Without sustainable funding for the Starling Service this will not be available beyond March 24	4	3		
		1.2 staff can access Eol care and advice they need, whatever time of day	**24/7 specilaist palliative care consultant advice is avialible**	Specialist PPC Consultant advice is available 4 days/week for hospital inpatients only. Nothing OOH			0.6 of the 1.2WTE PPC Consultant workforce is funded through the Matched funding for the Starling Service which will end in March 24	4	3		
			Home visiting is availible from a named medical specialist lead at EOL	With launch of Starling Service Pilot (3/7/23-31/3/24) this will be available			Without the Starling Service medical specialist home visiting will be limited. A small number of community paediatricians may offer this, some hospital based specialisits out of goodwill (but few)	5	4		
4	NICE	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.	**Every CYP is cared for by a defined multidiciplinary team which can be adjusted as the needs of the CYP change**	Yes				5	4		
1	NHSE	1.2 staff can access Eol care and advice they need, whatever time of day	**The generalist workforce has access to advice from specialists in CYP palliative care**	Specialist support accessible through: BRHC PPCBST (only for hospital inpatients and only M-F 9-5) Charlton Farm Hospice Team for patients on the hospice caseload (Medical 9-5 M-F unless EOL and in house or under Starling Service) Nursing 24/7				4	3		
			Symptom management guidelines are accessible	BNSSG teams are encouraged to access national guidelines (Basic Symptom Control guidelines, APPM formulary). There are some clinical guidelines that have been developed within provider organisations (eg UHBW pain guideline) but these are not shared across organisations				4	4		
			Locality has a rapid transfer process in place to enable transfer to preferred place of care whilst dying.	Yes, Joint UHBW/CHSW/WATCh SOP describes process				5	4		
3	NICE	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.	**Support with grief and loss is availible to families**	Yes - all providers offer this				4	4		
3	NHSE	Improving sustainability	**Workforce have access to support to enable resilience**	BNSSG				4	4		
			The locality has arrangements in place for professionals to talk about their thoughts and feelings with colleagues when a CYP they are caring for is approaching EOL or has died.	debriefs							
		3.2 the workforce is for for purpose	**Information about emotional and psychological support is accessible to CYP**	BNSSG							
			CYP and family can access expert psychological intervention to help with distress, coping and building resilence	lifetime psychologist and BCH psychologist			limited capacity	4	4		
			Support is in place to suport siblings of CYP requiring palliative care.	hospice only.				3	3		
4	AMBITIONS	**Care is coordinated**	**EPaCCS sytem is in place and accessible across settings**	No. RePESCT Plus has been launched for adults, not CYP				2	2		
			Information can be shared between services/ settings in a timely way	By Email only				3	3		
4	NICE	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.	**Data/ informaiton is gathered relating to CYP with PEOL and used to coordinate care across the area**	Starlings project				4	3		
			There are mechanisms for coordinating care are in place	starling project for home EOL				4	4		
			There is a single point of referal for PEOL services or pathway in place	No - it is hoped that the Starling Service pilot will support joint working and in time, the development of a single point of entry				1	1		
			Health social care, education and voluntrary sector care is coordinated	?							
			EOL care is coordianted by a lead professional/ key worker	yes				5	4		
			The locality has CYP PEoLC as a core componant within the All Ages ICS Operational Plan.	There have always been informal links with this group and we had hoped to continue these if the group continues				4	4		
5	AMBITIONS	**All staff are prepared to care**	**There is a strategy is in place for educating the MDT workforce for PEOL care**	No strategy for the locality except for educaiton related to Starling - joint training delivered for teams from across all organisations with programme planned across the duration of the pilot.	Contributing to regional education project			4	4		

3	NHSE	3.2 the workforce is for for purpose	**Wellbeing interventions are in place to support resillence and compassionate care in the workforce**						4	4		
4	NICE	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.	**There is equal access to relevant education and training opportunities for the workforce**	?					3	3		
			There are strong and defined leadership roles for CYP PEOL in the locality	Leadership roles relating to planning and delivery of the Starling Service (Project Management, Nursing, Medical, Psychology, Pharmacy). Funding for these roles ends March 24. Contribution to the work of the paed pall EOL care board has always taken place as part of people's usual roles				Temporary post	4	4		
3	NHSE	3.1 PEOLc is sustainably commissioned		?				Risk of starling service not being sustainable	3	3		
2	NHSE	2.2 a confident workforce with the Knowledge, skills and capability to deliver high quality PEOLc.		?					3	3		
6	AMBITIONS	**Each community is prepared to help**	**The locality supports public discussion about Death and dying**	?								
3	NHSE	3.3 personalised and community foucsed approach	**The locality promotes building community capacity such as using volunteers**	?								
5	NICE	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.	**The locality has a dedicated work programme aimed at building community capacity e.g. Developing the social prescribing offer, promotion of the Dying Well Community Charter, or through the nourishing of**	?								
			The locality has a clear referral process from all key providers to Social Prescribing Link Workers, for all ages	?								
	Other		**Number of children support at home for EOL care in the last 12 mths**									
			Number of children who died in hospital/ hospcie supported Community nursing for EOL care in the last 12 mths	?								
			In 2022, how many times did you activate on call for end of life care support in your area?									
			Numbers of deaths 2019/20	**43**								
			Number of deaths 2020/21	**41**								
			Number of deaths 2021/22	**39**								

Red
Amber
Green

0
1
2
3
4
5

Action Plan	
Action plan lead	
Action plan date	
Monitoring and reporting	

Key to RAG Scoring:

- ● *(G)* Fully Completed
- ● *(A)* Partially Completed – actions still to be completed but due to be completed within timescale
- ● *(R)* Not Completed – unlikely to be completed within timescale or significant risks to compliance

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

Ambition	**Issue**	**Current Ambition rating**	**Action**	**Target delivery date**	**Update/ Evidence**	**Revised Ambitions rating**	**Progress RAG**

Service Specification:
Bristol, North Somerset and South Gloucestershire Community Children Nursing and Psychology Service- November 2019

This specification must be read along with the overarching specification which applies to all services

1. Population Needs

1.1 National / local context and evidence base

NHS Bristol, North Somerset and South Gloucestershire Clinical Commissioning Groups (BNSSG) aspire to commission comprehensive community nursing services that will support out-of-hospital services for children with a community nursing or psychology need. Commissioners expect this service to play a key role in achieving outcomes for all children.

Commissioners recognise that community children's nursing services are fundamental to improving urgent care, through minimising unplanned hospital admissions and reducing the number of days that children and young people spend in hospital.

Emerging evidence on the efficacy of community children's nursing suggests that the provision of care at home is both cost effective and beneficial for children, young people and families' emotional wellbeing and quality of life.

NHS Bristol, North Somerset and South Gloucestershire Bristol, North Somerset and South Gloucestershire community children's nursing services will be required to deliver care that is evidence based and clinically safe, effective and efficient, and consistent with national and local policy, clinical guidelines and NHS Standards.

The Provider will be required to ensure the services adhere to NHS Bristol, North Somerset and South Gloucestershire Clinical Commissioning Groups (BNSSG) principles for children's community health services, which are outlined in the overarching specification.

1.2 Policy Context and Legal Compliance

The provider must comply with all relevant policy and legal compliance, including but not limited to:

- Human Rights Act 1988
- Equality Act 2010
- Health Acts 1999 and 2006
- Health Bill 2009
- Health and Social Care Act 2012

- Care Standards Act 2000
- Safeguarding Vulnerable Groups Act 2006
- Vetting and Barring Scheme
- CQC Compliance
- CQC Safeguarding Standards
- Public and Patient Involvement requirements
- Children Acts 1989 and 2004
- Working Together to Safeguard Children (2015)
- NHS at Home: Community Children's Nursing Services (2011)

The provider must be familiar with and adhere to the principles and processes contained within:

- The Children and Families Act 2014
- Supporting pupils at school with medical conditions (Department for Education 2015, updated 16 August 2017
- The National Framework for NHS Children's Continuing Care.
- Statutory guidance on making arrangements to safeguard and promote the welfare of children under section 11 of the Children Act (2004).
- Safeguarding Children and Young People: Roles and Competencies for Health Care Staff 2014.
- Information Sharing: Guidance for Practitioners and Managers.
- NHS Employment Check Standards.
- NHS Equality Delivery Scheme (EDS) – the provider should implement the EDS2 and aim to be performing at no lower than amber in the first year.
- NHS Commissioning Outcomes Framework.
- Joint Health and Wellbeing Strategies – Bristol, North Somerset and South Gloucestershire
- Children and Young People Plan/Partnership Strategies/Anti-Poverty Strategies – Bristol, North Somerset and South Gloucestershire
- South West Safeguarding and Child Protection Procedures 2013.
- The NHS Long Term Plan - 2019

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**	✓

The Community Children's Nursing & Psychology Service will contribute with other services to the following the Commissioning Outcomes Framework, NHS Outcomes Framework and Public Health Outcomes Framework. However the service is not solely responsible for achieving these outcomes and they will not form part of the monitoring framework for the service.

Domain	**Outcome**
Preventing premature death	Improving childhood mortality for long-term health conditions, including asthma, diabetes and epilepsy
Improving quality of life	Improving the number of children with long term conditions who have a co-ordinated package of care, quality assessment, access to key working and a multi-disciplinary care plan
	Improving progress towards a child and family's person-centred goals
	Reducing school absence for children with long term conditions, complex needs, disabilities and life-limiting conditions
	Increasing the number of children who report that their pain is managed
Protection from avoidable harm	Reducing the rate of catheter-associated and catheter - related bloodstream infections in children
	Increasing the number of children and families who receive appropriate equipment in a timely way to support their long-term condition, complex health need, disability or life-limiting condition

Ensure a positive experience of care	Increasing the number of young people in transition that have a defined and agreed plan for handover of care to adult services
	Increasing the number of children who die in the place of their choice
	Increasing the number of children and families who feel they have more control over improved personalised services
	Improved access and availability of services
	Increasing the number of children with diabetes who achieve required national quality standards
	Reducing the average length of stay in hospital for children
	Reducing the number of children attending hospital for less than 24 hours
Protection from avoidable harm	Reducing the number of medication errors
	Reducing the rate of unplanned hospital admission for constipation and urinary tract infection
	Reducing the number of serious incidents

2.2 Local defined outcomes

In addition to the outcomes defined in the overarching specification and associated appendix, the community children's nursing & psychology service will be expected to deliver care that focusses upon the improvements it can make to children, young people and families in terms of clinical effectiveness and enhanced emotional and social benefits:

- Parents are confident that they have the skills to care for their child or young person through a genuine partnership with health professionals.
- Schools are confident that they have the skills to care for their children and young people through a genuine partnership with health professionals.
- Children and young people are admitted to hospital only when it is clinically unsafe for them to stay at home, acknowledging the preferences of parents, children and young people.
- Children and young people in need of a comprehensive care package will experience fewer hospital admissions and fewer

accident and emergency department attendances for crisis management.

- Parents have easy and reliable access to the emotional and psychological support required to provide optimal care for their family. Provided by the nursing and psychology professionals, based on specific need within service resource.
- Families, school and health professionals have easy and reliable access to the equipment and training required to provide optimal care for their children and young people.
- There is genuine and realistic choice about end-of-life care, acknowledging the preferences of parents, children and young people.

3. Scope

3.1 Aims and objectives of service

The overarching aim of the community children's nursing & psychology service is to provide specialist support and clinical interventions to any child or young person with health needs that can be managed at home, at school or in community locations.

The key objectives of the service are to:

- Assess children and young people's symptoms, recognise sickness or deterioration and take the first steps in the management of conditions, including informing GPs or hospital paediatricians as appropriate.
- Provide care and treatment to prevent hospital admission and expedite discharge for ill children. Examples of clinical interventions include:
  - Intravenous drug administration, port flushes
  - Tracheostomies, oro/naso-pharyngeal suction
  - Gastrostomies, enteral and parenteral medication
  - Invasive and non-invasive ventilation
  - Catheter care
  - Unstable seizure management
  - Tissue Viability Assessment and assessment of wound management where required.
- Provide care to children and young people at home, at school and in community locations within the core hours of 8am to 6pm

Monday to Friday, and flexibly on Saturday, Sunday and Bank Holidays

- Work with the Bristol, North Somerset and South Gloucestershire children's palliative care community to support seven day working, as required, for end-of-life care.
- Co-ordinate the care planning and management of children with long term conditions, disabilities and complex needs to prevent accident and emergency department attendances and unplanned admissions
- Co-ordinate the care planning and management of community palliative care and end-of-life needs
- Facilitate and support access to hospital care when necessary, for children with nursing needs who are normally cared for a home
- Provide reliable and sustainable care packages for children and young people who are technology dependent
- Provide training for parents and carers, children and young people and schools to support the self-management of long term conditions, complex conditions and disabilities
- Provide nursing care and home and school support workers, based upon assessed need, for families eligible for Children's Continuing Care
- To provide nursing and psychology interventions for children and young people with life limiting and life threatening conditions and to support their families. To provide clinical input into palliative and end of life care for children.
- Provide wellbeing and psychological support for families of children and young people on caseload with palliative care and end-of-life needs, and very complex conditions
- Provide a Disposable Supplies Ordering Service to health visitors / school nurses and families of children in Bristol, North Somerset and South Gloucestershire. Sirona care & health hold the disposables budget for Bristol and South Gloucestershire.
- Deliver the Paediatric Continence Pathway for Bristol, North Somerset and South Gloucestershire, including oversight of health visitor / school health nurse continence assessment and management plans, ordering and supply of continence products and the provision of specialist continence training to C&YP & their families.

3.2 Service model

The community children's nursing & psychology service will comprise of the Community Children's Nursing Team managed by University Hospitals Bristol NHS Foundation Trust and the Lifetime Nursing and

Psychology Service managed by Sirona care & health. It is the responsibility of Sirona care & health as prime provider for the CCHP contract to ensure that all policies and pathways for the services are aligned and that the services work together to maximise capacity and avoid duplication.

The service will be embedded within, and delivered from, community locations within each CCG area, including GP Practices, schools and homes

The service is led by registered children's nurses and psychologists with extensive experience of community care, supported by assistant practitioners and health support workers

The service has clear, locally agreed protocols for medical leadership with GPs and Bristol Children's Hospital.

The service will be informed by clear, locally agreed pathways which defined the community children's nursing contribution for:

1. Children and young people with acute and short-term conditions
2. Children and young people with long term conditions which require clinical, nursing and psychology support, where this is not provided by an any other dedicated children's specialist community nursing team
3. Children and young people with disabilities and complex conditions, including those requiring Children's Continuing Care
4. Children and young people with life-limiting and life-threatening illnesses, including those requiring palliative care and end of life care

There is access to diagnosis-specific advice and guidance and specialist community children's nurses

The service includes nurses trained as nurse prescribers

Where appropriate, the team will provide support to children with complex health needs in both mainstream and special school settings

The team will work collaboratively with Children's Continuing Care nurse assessors in Bristol, North Somerset and South Gloucestershire CCGs to plan personalised care packages

Included within this specification are nursing, homecare and school support services for children eligible for Children's Continuing Care in

Bristol, North Somerset and South Gloucestershire. This element of the service will be annually negotiated, ring-fenced and structured with a tolerance threshold to manage fluctuations in the number of children eligible for Continuing Care.

3.3 Homecare

The Lifetime Homecare service will develop and provide bespoke packages of care for children who meet the Children's Continuing Care criteria. All eligible families will be offered a Personal Health Budget which they may choose to use as a notional budget with the Lifetime Homecare Service

Key deliverables for this service will be to:

- Provide reliable and sustainable care packages for children and young people who require a continuing care packages, (including those who are care technology dependent) using outcome based person led care plans. Enabling children and young people to be cared for in a place of their choice and to have an improved quality of life.
- Provide services that can be purchased by personal budget holders.
- Co-ordinate the care planning and management of children with complex and continuing care needs to prevent accident and emergency department attendances and unplanned admissions.
- To pro-actively assess, support and care for children and families in a variety of settings enabling children to live and die in their preferred place of care.
- To provide a comprehensive training programme to enhance skills and confidence across a range of organisations to enable children with exceptionally complex health needs and/or technology dependency to access a wide range of settings for short breaks and education.
- To build positive relationships with families in order to demonstrate that children, young people and their carers are satisfied with the services they receive and are fully involved as partners in the delivery of care.
- To maximise continuity of carer and minimise the number of missed shifts and shifts covered by agency staff, while recognising that there will be a need to prioritise the care of the most complex children.

3.4 Equipment

The service will be responsible for ordering equipment which is required to support the health needs of children on their caseload. Equipment which is required to meet social care or education needs will be referred to the local authority. The service is not responsible for ordering medical equipment which is solely for use in an education setting.

Equipment should normally be ordered through the BNSSG Integrated Community Equipment Service (ICES) contract.

Medical equipment for children being discharged from hospital onto the Lifetime caseload, and which is not available through the ICES contract will be ordered by UHB/NBT and funded by the CCG. Of the Lifetime caseload on-going maintenance will be the responsibility of the Lifetime Service. Of the UHB caseload on-going maintenance will be the responsibility of UHB MEMO Department.

The budget for this service includes consumables for this equipment.

3.5 Referrals

Referrals to the community children's nursing & psychology service can be made by:

- GPs
- Health Visitors
- School Health Nurses
- Acute and community paediatric health services
- Schools and Early Years settings
- Children's Social Care and Preventative Services

Referrals can be made in writing, by telephone, email and or by an Electronic Patient Record. The services will work towards managing all referrals electronically.

The community children's nursing & psychology service will work with Bristol; North Somerset and South Gloucestershire Local Authority areas to develop systems and protocols for receive referrals through their Single Points of Entry.

The community children's nursing & psychology service will make onward referrals to other professionals as appropriate.

3.6 Acceptance criteria

All children and young people, from birth to their eighteenth birthday, who are registered with a Bristol, North Somerset and or South Gloucestershire GP

For young people aged between 16 and 18, with acute and short term conditions in the absence of co-existing long term conditions, complex needs or disabilities, community nursing needs should be met by adult district nursing services.

The teams will not accept new referrals after a child's 18th birthday but will remain responsible for the transition to adult services of children on the caseload.

Where known to a child through a clinical pathway, Specialist nurses will be available where required to provide Specialist clinical advice and information regarding management of conditions, to community nursing teams providing clinical nursing care in the community setting.

3.7 Exclusion Criteria

Referrals for families solely requesting psychology support, where no nursing need is identified

3.8 Response times and prioritisation

The service will meet the following response times:

- Assessment and triage of referrals (urgent and routine), including hospital discharge and end of life packages within 24 hours of referral.
- Assessment and Triage of Acute hospital discharge will require same day (in working hours assessment). Urgent response times will be monitored and adjusted in negotiation with commissioners as demand and capacity evidence is analysed.
- Assessment for SEN Education, Health and Care Plan – within local EHCP pathway requirements, currently within 6 weeks of referral.

3.9 Workforce

In addition to the workforce requirements in the overarching specification, in order to deliver flexible, equitable and accessible community nursing & psychology services to children and young people & their families, the service will have sufficient workforce capacity and skill mix.

The Provider will therefore ensure that:

- There are adequate numbers of appropriately skilled and qualified staff to support care and clinical symptom management
- Staffing establishment is based upon guidance and local population need
- Community children's nurses provide support, advice, supervision and competency-based training for non-registered carers who provide care for children with Children's Continuing Care needs
- Within the available resource, the Psychology service will psychological supervision to staff working within the Lifetime

Service and CCN team UHB. In turn, the UHB Consultant psychologist in long term conditions provides clinical supervision to the Sirona psychologist (BNSSG).

- The team is available to give expert advice and support to other professionals caring for children with nursing needs
- A supervision policy is in place that ensures staff have regular access to appropriately skilled clinical and safeguarding supervision
- Sustainability is actively pursued to ensure that there are minimal breaks in care for children and young people
- Staff have the ability to raise issues of concern regarding potential risks to children and young people's safety and clinical care.
- The service should be overseen by a qualified children's nurse holding a community qualification.
- Team members may include:
    - Children's Community Nurses
    - Children's Nurses
    - Trained carers for children with Continuing Care needs
    - Psychologists and Therapists
- The service will include one post as Bristol, North Somerset and South Gloucestershire 's Lead Nurse for Disability
- The service will include one post as Bristol, North Somerset and South Gloucestershire 's Specialist Continence Nurse
- Children needing end-of-life care must have access to nurses with additional skills in palliative care management
- The Provider will work with other Bristol, North Somerset and South Gloucestershire providers of acute, palliative and end-of-life children's nursing services, and the University of the West of England, to support and expand the Rotational Nurse Scheme

3.10 Safeguarding

Safeguarding requirements are covered in the overarching specification.

3.11 Equality and Diversity

In addition to the Equality and Diversity section in the overarching specification.

- Equality Impact Assessment must be undertaken and documented as part of any service review process or if any change is made to the provision of the service which could impact on those in receipt of the service.

- All staff employed by the community children's nursing services will recognise and respect the religious, cultural and social backgrounds of children, young people and parents, in accordance with legislation and local and national good practice. This is particularly important for carers who are working in the child's home.
- The Community children's nursing services will ensure that they have access to appropriate translation services and resources to enable equity of access and understanding

3.12 Interdependence with other services / providers

In addition to the interdependences section in the overarching specification, seamless provision is essential to meeting the needs of children, young people and families.

The community children's nursing services will therefore:

- Children's Community Nursing and Psychology Services will work in partnership with children, young people, parents and carers to develop agreed health outcomes as part of a personal care plan. Services will be required to work effectively with a range of local services to deliver the evidence based, progressive and specialist elements of the service
- Work closely with their colleagues in specialist roles at Bristol Royal Hospital for Children, such as the Diabetes Specialist Nurses. They also liaise with the public health School Nursing service which has a focus on the wider health and wellbeing needs of children and young people aged 4 – 19
- Strive to become an integrated part of GP led primary care networks by attending care planning meetings, regular face-to-face discussions with GPs and other members of the primary care health team
- Have collaborative working relationships with NHS 111 and GP out-of-hours providers in each CCG area
- Have a collaborative working relationship with the Local Authority Special Educational Needs and Disability Services, contributing to the integrated assessment and management of children and young people with Education, Health and Care Plans and those eligible for Children's Continuing Care
- As part of the collaborative working arrangements with the Local Authority Special Educational Needs and Disability Services,

provide training to short break providers. This activity will attract additional funding on a case by case basis.

- Actively engage in communication with Bristol Children's Hospital and other acute health services to ensure that full and prompt handovers of care are facilitated and the interface with clinical nurse specialists is maximally effective
- Align service delivery in mainstream and special schools with the developing Core Offer for School Health Nursing

3.13 Service Developments

As previously described, commissioners view the comprehensive community nursing service as the bedrock of out-of-hospital services for children, and recognise its fundamental role in improving urgent care through minimising unplanned hospital admissions and reducing the number of days that children spend in hospital.

Commissioners aspire to grow and develop the service, subject to availability of resources, to:

- Provide care to children and young people at home and school and in community locations from 8am to 10pm.
- Provide 24/7 access to telephone advice and support for families and carers on the service caseload, with the ability to make out-of-hours home visits as necessary. Where possible within existing resource the service will offer out of hours support during the end of life phase for children on the caseload.
- Provide wellbeing and psychological support for families of children and young people with long term conditions, complex needs and disabilities

The Provider is required to support this aspiration through:

- Providing robust local data to support the case for increased investment in community nursing
- Proactively identifying opportunities for innovation and the development of new community pathways that reduce dependence upon secondary care
- Developing the evidence base for safe community management of children and young people with acute and short-term conditions

4. Applicable Service Standards

4.1 Applicable national standards (e.g. NICE)

4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

4.3 Applicable local standards

5. Applicable quality requirements and CQUIN goals

5.1 Applicable Quality Requirements

As set out in the main contract and quality and performance framework

5.2 Applicable CQUIN goals

None applicable to this contract

Appendix One – Local Definitions

Palliative

- Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. (Together for Short Lives)

Life threatening/Life limiting conditions

- Life-threatening conditions for which curative treatment may be feasible but can fail
- Conditions where premature death is inevitable Progressive conditions without curative treatment options
- Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health
  (Together for Short Lives)

Long term conditions

- Long term conditions or chronic disease are conditions for which there is currently no cure and which are managed with drugs and other treatment. (The Kings Fund)

Disabilities

- A Physical or mental impairment that has a substantial and long term negative effect on your ability to do normal daily activities.
  (Equalities Act 2010)

Complex Needs

- A diagnosis of an illness, disability or sensory impairment and needs a lot of additional support on a daily basis.
  (NHS)

SCHEDULE 2 – THE SERVICES

A. Service Specifications

1. Population Needs

1.1 National/local context and evidence base

In England, the prevalence of children with life-limiting conditions rose from 32,975 in 2001/2 to 86,625 in 2017/18 (Fraser et al, 2020). It is estimated that there will be between 67.0 and 84.2 per 10,000 children, and their families, living with such conditions in England by 2030.

Palliative care is provided to infants, children and young people with a wide range of life-limiting or life-threatening conditions (in excess of 300). Some will have severe disabilities and multiple and particularly complex healthcare needs related to their condition, as well as palliative care needs. However, up to 15% of children and young people with palliative care needs do not have a definitive underlying diagnosis.

Access to palliative care should not depend on diagnosis or overall prognosis and can be provided at any stage of a child or young person's illness.

Services with the competencies to offer paediatric palliative care will support and care for children and young people and their families at any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement.

The needs of children and young people living with more complex and/or long-term conditions that are life-limiting or life-threatening cannot be met by the capabilities of their core team alone. They need input from a workforce with specialist palliative care skills and experience.

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 National Institute for Health and Care Excellence (NICE): End of Life Care for Infants, Children and Young People Quality Standard [QS160]

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.

2.3 National Palliative and End of Life Care Partnership Framework: Ambitions for Palliative and End of Life Care 2021 – 2026

1. Each child and young person is seen as an individual.
2. Each child and young person gets fair access to care.
3. Maximising comfort and wellbeing.
4. Care is co-ordinated.
5. All staff are prepared to care.
6. Each community is prepared to care.

2.4 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

Children's Hospice South West (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 enter and 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 young people 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 support or non-complex grief,
  - emotional and practical support, including advocacy,
  - parent/carer support,
  - 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.

Core services for children and young people diagnosed with a life-limiting or life-threatening illness will be delivered around an MDT model. The provider must ensure services communicate to achieve seamless care that works to the agreed personalised care and support plan.

The key objectives of the core PEoLC MDT are:

- ensure a personalised care and support plan, and where applicable, an advance care plan, are offered, agreed and followed by all services in regard to care and support plan and deliver symptom control
- for each child or young person identify a care co-ordinator or key worker who is responsible for co-ordinating their care
- all relevant services to meet the needs (physical, emotional and psychological) of the child or young person are engaged and available for access as appropriate
- the equipment and resources needed to support the child or young person are available at the right time and in the right place
- all medicines and prescribing are available when needed, with appropriate specialist support as required
- all transfers of care are planned and plans communicated, e.g. discharge planning
- short breaks or respite within age appropriate settings are offered
- professionals (universal and core) have the relevant training and skills, and know when to seek specialist advice.

The provider must ensure provision for:

- healthcare professionals from primary, secondary or tertiary services, including specialists in the child or young person's underlying life-limiting or life-threatening condition and members of the specialist palliative care team, and where available hospice professionals or members of palliative care charities
- social care practitioners
- education professionals
- family representatives
- spiritual advisors
- allied health professionals (eg physiotherapists, occupational therapists and psychological therapists)
- short breaks and respite providers
- voluntary sector groups and services
- children’s continuing care nurses or assessors
- equipment services
- carer services
- equality inclusion leads.

The make-up of the MDT should be adjusted as appropriate to the changing needs of the child or young person.

3.1.3 Key service characteristics

The provider must:

Service characteristic	Link to ambitions framework
Referral	
1. Have defined referral criteria that include specialist level palliative care (SLPC) for: a. the child or young person with progressive life-limiting illness and with or without co-morbidities, where the focus of care is on quality of life, including complex symptom control b. the child or young person with unresolved needs that cannot be met by the current team. These needs may be physical, psychological, social and/or spiritual, e.g. complex symptoms, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions c. the specialist service can be offered alongside the active treatment of an underlying condition.	Ambition 2
2. Have a referral process that includes an auditable system for prioritisation linked to patient outcomes.	Ambitions 2 and 4
3. Accept referrals based on need rather than diagnosis.	Ambition 2
Assessment and care	
4. Provide medical and nursing cover to allow assessment, advice and active management seven days a week, and 24-hour telephone advice. This may require a collaborative arrangement between a number of service providers and joint commissioning, working towards provision of 24-hour access to SLPC advice from a consultant in palliative medicine, including face-to-face assessment where necessary.	Ambitions 2, 3 and 4
5. Have timely access to the medication and equipment needed for specialist-level inpatient or home-based care.	Ambitions 2, 3 and 4
6. Work in partnership with the child or young person, those important to them and their carers to develop and support personalised care planning, including identifying and recording personal preferences, and helping them navigate to services that will deliver the required information and care, at any time of day or night it is needed.	Ambitions 1 and 4
7. Identify and assess the needs of the family and those important to the child or young person, including their psychological and social needs; support and prepare them for the caring role at whatever level; and facilitate access and signposting to other services, including pre-bereavement and bereavement.	Ambitions 1, 3 and 6
8. Respond to those with protected characteristics in a sensitive and inclusive way, including by providing access to advocacy, translation and interpretation services.	Ambitions 1 and 2
9. Use a multidisciplinary approach to care, with a competent workforce with recognised expertise in SLPC and using evidence-based best practice. Children and young people must be regularly reviewed and discussed by the MDT, as defined by local operational policy.	Ambitions 3 and 5
Co-ordination and partnership working	
10. Work in partnership with other services and the third sector to meet the child or young person's needs, ensuring that assessments and personalised care planning are reliably communicated to and co-ordinated with other services involved with the child or young person in a timely fashion.	Ambitions 1 and 4
11. Access and use an electronic palliative care co-ordination system to facilitate this co-ordination, as such systems become available locally, and where the individual agrees to its use.	Ambitions 1 and 4
12. Have a defined operational policy for multidisciplinary and partnership working to include arrangements for MDT meetings, and communication across care settings and organisational boundaries within a quality and governance framework.	Ambitions 4
Leadership and governance	

13. Have specialist level and diverse palliative care clinical leadership at senior strategic level within the organisation (eg senior management team level).	Ambition 5
14. Have a suitably resourced quality, IT and governance framework, which should include: • audit and quality improvement methodology • patient-centred outcome and experience measures and user feedback (in keeping with the requirements of the Accessible Information Standard) • data collection and sharing to aid service improvement at local and national level • adequate access to electronic clinical information, including pathology and imaging • arrangements for engagement in research in line with the service's objectives • arrangements for all staff and volunteers to be appropriately trained and supported to give competent, reliable, confident and compassionate care.	Ambitions 1, 2, 4, 5 and 6
15. Be configured and established to lead and/or contribute to the delivery of education, training and continuing professional development to the wider workforce regarding best practice in palliative and end of life care.	Ambition 5
16. Use the growing evidence base to enable the development of innovative practice; share and celebrate good practice.	Ambitions 3 and 5
17. Contribute to and encourage public involvement and engagement in developing compassionate, understanding communities, including through raising local awareness, practical support and planning for future care.	Ambition 6

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.

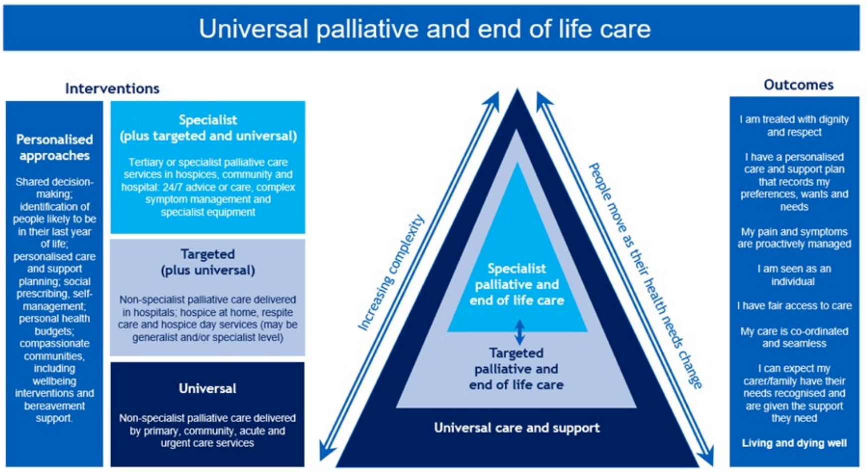
The hospice service may be delivered in different ways through a menu of services designed to deliver specialised individual packages of care, tailored to an individual child. Hospices have always aspired to the highest standards for this group of children and this specification is supportive of that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

The provider must work within the local universal palliative and end of life care model. As an enhanced palliative service, the provider must engage closely with other providers to ensure:

- the child or young person's story does not need to be told more times than necessary,
- the child or young person's key health and wellbeing needs are identified and addressed effectively, and
- all professionals involved in the child or young person's care are aware of personalised plans agreed with the child, young person, their family and/or carer.

The model is not a stepped approach. It is flexible with each service area's involvement fluctuating through a child or young person's journey in response to need. Each tier of provision depends on the others to ensure a holistic approach to the health, wellbeing, emotional, social and spiritual needs of the child or young person and their families and carers. No single provider can provide for all these needs.

Figure 1: Relationship between services



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.

3.2.3.1 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.

The needs of the family (including siblings) need to be assessed and where possible addressed. Ensuring carers are adequately supported is important to enable the child or young person’s management in a home environment where desired.

The provider must ensure:

- processes are in place to assess the needs of the family and loved ones and, where possible, to address them
- the carers are adequately supported to enable management in a home environment where desired
- where there are opportunities to do so, the family is offered training to enable self-management within the family.

The provider must ensure every member of the team receives support and an opportunity to feedback and discuss what is happening (e.g. access to professional psychological support for staff and standards for debriefs). Professionals as well as volunteers should have access to ongoing health and wellbeing support and supervision.

3.2.3.2 Communication

The provider must ensure:

- there is a key contact for the child or young person and family who knows them and the system well
- the child or young person's story is only told once to each service
- professionals communicate well with each other and work well as a team
- the child or young person and their family are listened to about what works for them and what is important (in keeping with the requirements of the Accessible Information Standard)
- next steps in treatment and care are always well communicated in advance
- arrangements are accessible for those whose first language is not English.

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.

3.2.7 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.

3.2.8 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.

3.2.9 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

3.2.10 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.

3.2.11 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
- 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

The provider must also ensure a care plan completed with risk assessment, where appropriate. Personalised care and support planning (PCSP) involves a series of facilitated conversations with children and young people, or those who know them well, to explore the management of their health and wellbeing within the context of their whole life and family situation. This process recognises the individual's skills and strengths, as well as their experiences and the things that matter most to them. It identifies issues and actions to resolve these. PCSP should be central for children and young people receiving PEoLC services. It is an essential tool to integrate the services the child or young person accesses so they have one joined-up plan that covers their health and wellbeing needs.

The provider must:
- implement a process for recording conversations, decisions and agreed outcomes in a way that makes sense to the child or young person and their family
- ensure personalised care planning is proportionate, flexible, inclusive, equitable and co-ordinated. and adaptable to a person's health condition, situation and care and support needs
- ensure what matters to the individual is documented, their plan is directed towards these concerns, and all the necessary elements that would make the plan achievable and effective are included.

NICE (NG61 and QS160) recommends consideration of **advance care planning (ACP)** for every child and young person with a life-limiting condition. This should be offered to all families and completed where agreed appropriate to do so. The key principles of a PCSP apply but with additions pertinent to supporting a child or young person in palliative care.]
The provider must implement processes for:
- collecting demographic information about the child or young person and their family, including up-to-date contact information for:
    - the child or young person's parents or carers
    - the key professionals involved in care
- providing a statement about who has responsibility for giving consent and evidence of parental responsibility
- providing a summary of the life-limiting condition
- agreeing an approach to communicating with and providing easy read and jargon-free information to the child or young person and their parents or carers
- summarising an outline of the child or young person's life ambitions and wishes; for example, for:
    - family and other relationships
    - social activities and participation
- including education preferences and an Education, Health and Care plan if relevant
- incorporating religious, spiritual and cultural beliefs and values into their care
- agreeing a treatment and prescribing plan and objectives
- providing a record of significant discussions with the child or young person and their parents or carers including:
    - preferred place of care and death
    - organ and tissue donation
    - management of life-threatening events, including plans for resuscitation or life support

    - specific wishes, e.g. for their funeral and care of their body
- providing details of any systems that provide early help, to avoid a crisis or handle an emergency
- agreeing a distribution list for the advance care plan
- agreeing a record of parallel planning (where applicable)
- agreeing discharge planning agreements from acute hospital to community
- use of social media accounts.

3.2.12 Information Sharing

Choice and decision-making must be underpinned by good information. The child or young person and their family need to have this and to be supported to use it. Information can support self-management if provided in the right way and at the right time. As such, professionals should appropriately share information, as well as direct children and young people to support organisations that can provide further relevant information and support.

A child or young person and their family need to have a copy of any plan they have agreed to, so that they can review, change and update it to ensure the plan guides a person-centred approach. Subject to the child or young person's consent, or if they lack mental capacity in their best interests, the plan should also be shared with all those who may be involved in their care.

All electronic systems for sharing health-related preferences must be able to record and then share an individual's preferences at the end of life. There should be ambitious local targets for the rollout of systems for sharing digital records and electronic patient care co-ordination systems (EPaCCs or equivalent) should be implemented to support this.

3.3 Population covered

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

	GP Registered Population 0-17 January 2017	**Number of Children Receiving Service 1st April 2017**
Bristol	103,134	69
North Somerset	42,995	17
South Gloucestershire	55,588	24
Total	**201,717**	**110**

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 NHS Bristol, North Somerset, South Gloucestershire or Bath and North East Somerset areas.
- 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 or South Central Child Protection procedures. **:** http://www.proceduresonline.com/swcpp/

4. Applicable Service Standards

4.1 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)*

4.2 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

CHSW Head Office
Little Bridge House
Redlands Road
Fremington
Barnstaple
EX31 2PZ

01271 325270

SCHEDULE 2 – THE SERVICES

A. Service Specifications

1. Population Needs

1.1. National/local context and evidence base.

In England, the prevalence of children with life-limiting conditions rose from 32,975 in 2001/2 to 86,625 in 2017/18 (Fraser et al, 2020). It is estimated that there will be between 67.0 and 84.2 per 10,000 children, and their families, living with such conditions in England by 2030.

Palliative care is provided to infants, children and young people with a wide range of life-limiting or life-threatening conditions (in excess of 300). Some will have severe disabilities and multiple and particularly complex healthcare needs related to their condition, as well as palliative care needs. However, up to 15% of children and young people with palliative care needs do not have a definitive underlying diagnosis.

Access to palliative care should not depend on diagnosis or overall prognosis and can be provided at any stage of a child or young person's illness.

Services with the competencies to offer paediatric palliative care will support and care for children and young people and their families at any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement.

The needs of children and young people living with more complex and/or long-term conditions that are life-limiting or life-threatening cannot be met by the capabilities of their core team alone. They need input from a workforce with specialist palliative care skills and experience.

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 National Institute for Health and Care Excellence (NICE): End of Life Care for Infants, Children and Young People Quality Standard [QS160]

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.

2.3 National Palliative and End of Life Care Partnership Framework:

Ambitions for Palliative and End of Life Care 2021 – 2026

1. Each child and young person is seen as an individual.
2. Each child and young person gets fair access to care.
3. Maximising comfort and wellbeing.
4. Care is co-ordinated.

5. All staff are prepared to care.
6. Each community is prepared to care.

2.4 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 service.
- 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

1.1.1 Aims of the service

Jessie May Trust (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 Bristol, North Somerset and South Gloucestershire catchment area.

The Provider will provide a range of services, which should include short breaks, emergency and end of life care, within the child's home, 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)

1.1.2 Objectives of the service

To enter and 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 who are eligible for care in line with 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 support or non-complex grief,
    - emotional and practical support, including advocacy,
    - parent/carer support,
    - 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.

Core services for children and young people diagnosed with a life-limiting or life-threatening illness will be delivered around an MDT model. The provider must ensure services communicate to achieve seamless care that works to the agreed personalised care and support plan.

The key objectives of the core PEoLC MDT are:

- ensure a personalised care and support plan, and where applicable, an advance care plan, are offered, agreed and followed by all services in regard to care and support plan and deliver symptom control
- for each child or young person identify a care co-ordinator or key worker who is responsible for co-ordinating their care
- all relevant services to meet the needs (physical, emotional and psychological) of the child or young person are engaged and available for access as appropriate
- the equipment and resources needed to support the child or young person are available at the right time and in the right place
- all medicines and prescribing are available when needed, with appropriate specialist support as required
- all transfers of care are planned and plans communicated, e.g. discharge planning
- short breaks or respite within age appropriate settings are offered
- professionals (universal and core) have the relevant training and skills, and know when to seek specialist advice.

The provider must ensure provision for:

- healthcare professionals from primary, secondary or tertiary services, including specialists in the child or young person's underlying life-limiting or life-threatening condition and members of the specialist palliative care team, and where available hospice professionals or members of palliative care charities
- social care practitioners
- education professionals
- family representatives
- spiritual advisors
- allied health professionals (eg physiotherapists, occupational therapists and psychological therapists)
- short breaks and respite providers
- voluntary sector groups and services
- children’s continuing care nurses or assessors
- equipment services

    - carer services
    - equality inclusion leads.

The make-up of the MDT should be adjusted as appropriate to the changing needs of the child or young person.

1.1.3 Key Service Characteristics

The Provider must:

Service characteristic	**Link to ambitions framework**
Referral	
1. Have defined referral criteria that include specialist level palliative care (SLPC) for: a. the child or young person with progressive life-limiting illness and with or without co-morbidities, where the focus of care is on quality of life, including complex symptom control b. the child or young person with unresolved needs that cannot be met by the current team. These needs may be physical, psychological, social and/or spiritual, e.g. complex symptoms, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions c. the specialist service can be offered alongside the active treatment of an underlying condition.	Ambition 2
2. Have a referral process that includes an auditable system for prioritisation linked to patient outcomes.	Ambitions 2 and 4
3. Accept referrals based on need rather than diagnosis.	Ambition 2
Assessment and care	
4. Provide medical and nursing cover to allow assessment, advice and active management seven days a week, and 24-hour telephone advice. This may require a collaborative arrangement between a number of service providers and joint commissioning, working towards provision of 24-hour access to SLPC advice from a consultant in palliative medicine, including face-to-face assessment where necessary.	Ambitions 2, 3 and 4
5. Have timely access to the medication and equipment needed for specialist-level inpatient or home-based care.	Ambitions 2, 3 and 4
6. Work in partnership with the child or young person, those important to them and their carers to develop and support personalised care planning, including identifying and recording personal preferences, and helping them navigate to services that will deliver the required information and care, at any time of day or night it is needed.	Ambitions 1 and 4
7. Identify and assess the needs of the family and those important to the child or young person, including their psychological and social needs; support and prepare them for the caring role at whatever level; and facilitate access and signposting to other services, including pre-bereavement and bereavement.	Ambitions 1, 3 and 6
8. Respond to those with protected characteristics in a sensitive and inclusive way, including by providing access to advocacy, translation and interpretation services.	Ambitions 1 and 2
9. Use a multidisciplinary approach to care, with a competent workforce with recognised expertise in SLPC and using evidence-based best practice. Children and young people must be regularly reviewed and discussed by the MDT, as defined by local operational policy.	Ambitions 3 and 5
Co-ordination and partnership working	
10. Work in partnership with other services and the third sector to meet the child or young person's needs, ensuring that assessments and personalised care planning are reliably communicated to and co-ordinated with other services involved with the child or young person in a timely fashion.	Ambitions 1 and 4
11. Access and use an electronic palliative care co-ordination system to facilitate this co-ordination, as such systems become available locally, and where the individual agrees to its use.	Ambitions 1 and 4
12. Have a defined operational policy for multidisciplinary and partnership working to include arrangements for MDT meetings, and communication across care settings and organisational boundaries within a quality and governance framework.	Ambitions 4
Leadership and governance	
13. Have specialist level and diverse palliative care clinical leadership at senior strategic level within the organisation (eg senior management team level).	Ambition 5

14. Have a suitably resourced quality, IT and governance framework, which should include: • audit and quality improvement methodology • patient-centred outcome and experience measures and user feedback (in keeping with the requirements of the Accessible Information Standard) • data collection and sharing to aid service improvement at local and national level • adequate access to electronic clinical information, including pathology and imaging • arrangements for engagement in research in line with the service's objectives • arrangements for all staff and volunteers to be appropriately trained and supported to give competent, reliable, confident and compassionate care.	Ambitions 1, 2, 4, 5 and 6
15. Be configured and established to lead and/or contribute to the delivery of education, training and continuing professional development to the wider workforce regarding best practice in palliative and end of life care.	Ambition 5
16. Use the growing evidence base to enable the development of innovative practice; share and celebrate good practice.	Ambitions 3 and 5
17. Contribute to and encourage public involvement and engagement in developing compassionate, understanding communities, including through raising local awareness, practical support and planning for future care.	Ambition 6

1.2 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 in either a residential establishment or within a child's own home. 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.

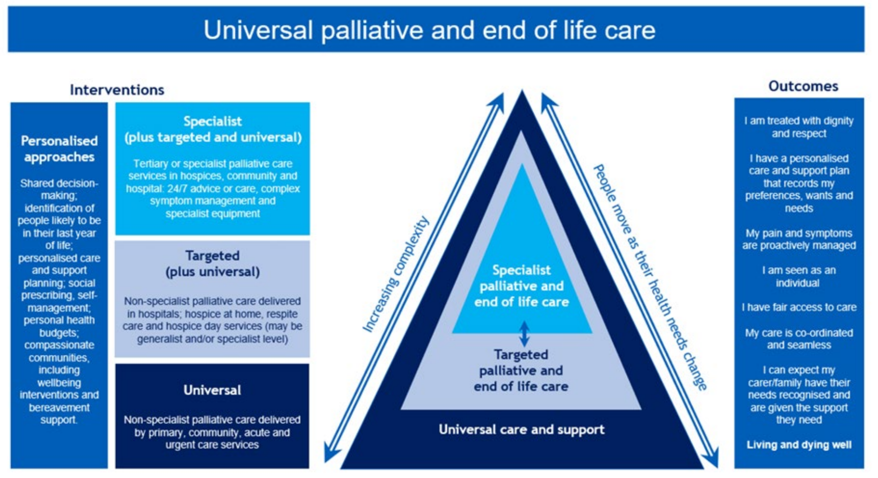
The service may be delivered in different ways through a menu of services designed to deliver specialised individual packages of care, tailored to an individual child.

The provider must work within the local universal palliative and end of life care model. As an enhanced palliative service, the provider must engage closely with other providers to ensure:

- the child or young person's story does not need to be told more times than necessary,
- the child or young person's key health and wellbeing needs are identified and addressed effectively, and
- all professionals involved in the child or young person's care are aware of personalised plans agreed with the child, young person, their family and/or carer.

The model is not a stepped approach. It is flexible with each service area's involvement fluctuating through a child or young person's journey in response to need. Each tier of provision depends on the others to ensure a holistic approach to the health, wellbeing, emotional, social and spiritual needs of the child or young person and their families and carers. No single provider can provide for all these needs.

Figure 1: Relationship between services



1.2.1 Environment

Services are normally provided in community settings including the family home.

1.2.2 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.

3.2.3.1 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 services which are flexible enough to meet the support needs of all family members. A named member of the team (key worker) should be responsible for maintaining contact with family in order that support continues between visits. The frequency of this contact will depend upon the needs of individual families.

The needs of the family (including siblings) need to be considered and where possible addressed. Ensuring carers are adequately supported is important to enable the child or young person's management in a home environment where desired.
The provider must ensure:

- processes are in place to assess the needs of the family and loved ones and, where possible, to address them
- the carers are adequately supported to enable management in a home environment where desired
- where there are opportunities to do so, the family is offered training to enable self-management within the family.

The provider must ensure every member of the team receives support and an opportunity to feedback and discuss what is happening (e.g. access to professional psychological support for staff and standards for debriefs). Professionals as well as volunteers should have access to ongoing health and wellbeing support and supervision.

3.2.3.2 Communication

The provider must ensure:

- there is a key contact for the child or young person and family who knows them and the system well
- the child or young person's story is only told once to each service
- professionals communicate well with each other and work well as a team
- the child or young person and their family are listened to about what works for them and what is important (in keeping with the requirements of the Accessible Information Standard)
- next steps in treatment and care are always well communicated in advance
- arrangements are accessible for those whose first language is not English.

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.

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.

3.2.7 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 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.

3.2.8 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.

3.2.9 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

3.2.10 Workforce

An appropriate skill mix will be maintained and reviewed regularly, 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 provider 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.

3.2.11 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 system to allow Client information to be kept electronically
- 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 the family hand-held record and the clinical record.

The provider must also ensure a care plan completed with risk assessment, where appropriate. Personalised care and support planning (PCSP) involves a series of facilitated conversations with children and young people, or those who know them well, to explore the management of their health and wellbeing within the context of their whole life and family situation. This process recognises the individual's skills and strengths, as well as their experiences and the things that matter most to them. It identifies issues and actions to resolve these. PCSP should be central for children and young people receiving PEoLC services. It is an essential tool to integrate the services the child or young person accesses so they have one joined-up plan that covers their health and wellbeing needs.

The provider must:

- implement a process for recording conversations, decisions and agreed outcomes in a way that makes sense to the child or young person and their family
- ensure personalised care planning is proportionate, flexible, inclusive, equitable and co-ordinated. and adaptable to a person's health condition, situation and care and support needs
- ensure what matters to the individual is documented, their plan is directed towards these concerns, and all the necessary elements that would make the plan achievable and effective are included.

NICE (NG61 and QS160) recommends consideration of **advance care planning (ACP)** for every child and young person with a life-limiting condition. This should be offered to all families and completed where agreed appropriate to do so. The key principles of a PCSP apply but with additions pertinent to supporting a child or young person in palliative care.]
The provider must implement processes for:

- collecting demographic information about the child or young person and their family, including up-to-date contact information for:
  - the child or young person's parents or carers
  - the key professionals involved in care
- providing a statement about who has responsibility for giving consent and evidence of parental responsibility
- providing a summary of the life-limiting condition
- agreeing an approach to communicating with and providing easy read and jargon-free information to the child or young person and their parents or carers
- summarising an outline of the child or young person's life ambitions and wishes; for example, for:
  - family and other relationships
  - social activities and participation
- including education preferences and an Education, Health and Care plan if relevant
- incorporating religious, spiritual and cultural beliefs and values into their care
- agreeing a treatment and prescribing plan and objectives
- providing a record of significant discussions with the child or young person and their parents or carers including:
  - preferred place of care and death
  - organ and tissue donation
  - management of life-threatening events, including plans for resuscitation or life support
  - specific wishes, e.g. for their funeral and care of their body
- providing details of any systems that provide early help, to avoid a crisis or handle an emergency
- agreeing a distribution list for the advance care plan
- agreeing a record of parallel planning (where applicable)
- agreeing discharge planning agreements from acute hospital to community
- use of social media accounts.

3.2.12 Information Sharing

Choice and decision-making must be underpinned by good information. The child or young person and their family need to have this and to be supported to use it. Information can support self-management if provided in the right way and at the right time. As such, professionals should appropriately share information, as well as direct children and young people to support organisations that can provide further relevant information and support.

A child or young person and their family need to have a copy of any plan they have agreed to, so that they can review, change and update it to ensure the plan guides a person-centred approach. Subject to the child or young person's consent, or if they lack mental capacity in their best interests, the plan should also be shared with all those who may be involved in their care.

All electronic systems for sharing health-related preferences must be able to record and then share an individual's preferences at the end of life. There should be ambitious local targets for the rollout of systems for sharing digital records and electronic patient care co-ordination systems (EPaCCs or equivalent) should be implemented to support this.

3.3 Population covered

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

	GP Registered Population 0-17 January 2017	**Number of Children Receiving Service 1st April 2017**
Bristol	103,134	69
North Somerset	42,995	17
South Gloucestershire	55,588	24
Total	**201,717**	**110**

3.4 Any acceptance and exclusion criteria

This service is commissioned for children and young people with life-limiting and life-threatening conditions up to the age of 19. Children who are expected to live past the age of 19 at the point of diagnosis will not normally be accepted by the service.

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 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 be included in the agreed contract activity for the relevant provider. 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 and 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 NHS Bristol/North Somerset or South Gloucestershire 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 or South Central Child Protection procedures: http://www.proceduresonline.com/swcpp/

4 Applicable Service Standards

4.1. 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)*

4.2. 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

Jessie May Trust,
35 Old School House,
Kingswood Foundation Estate,
Britannia Road,
Kingswood,
Bristol,
BS15 8DB