Sector-specific guidance: Hospices for children and young people

This includes all hospice services which care for babies, children and young people and their families. Hospices for children and young people may also care for young adults, up to the age of 30 and beyond. Some hospices will also provide a service for adults of any age, in which case the sector-specific guidance for hospices for adults should also be used.

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. They take a holistic approach to care, providing physical, emotional, social and spiritual care, and aim to meet the needs of both the child or young person and their family through a range of services.

Services may be delivered in an inpatient unit and/or at home, and may include:

- 24 hour end of life care
- support for the whole family
- bereavement support
- 24 hour access to emergency care
- specialist short break care
- 24 hour telephone support

- practical help, advice and information
- provision of specialist therapies, including physiotherapy, hydrotherapy, play and music therapy
- provision of information, support, education and training to carers.

Areas to inspect and inspection methods

The inspection team should carry out an initial visual inspection of each area. Your observations should be considered alongside data/surveillance to identify areas of risk or concern for further inspection.

Most hospices for children and young people provide a lot of care outside the building, and you should make sure that these services are included in the inspection. However not all hospices provide services in the community as they are developed to respond to local need and are shaped by local commissioning and availability of other services. Each hospice will have a different combination of services.

The lead inspector should have a good understanding of the services provided by the hospice before the inspection, through relationship management meetings, reviewing the previous inspection report and PIR, and the hospice website. If more information on the service is needed, the lead inspector should arrange a call with the Registered Manager before the inspection. This will ensure that the inspection can be planned effectively to include all aspects of the service while causing minimum disruption to people using the service.

Hospices for children and young people provide a significant amount of care in the evenings and at weekends, as children and young people are often at school during the day. Inspection teams should consider the extent to which they can reflect this in their planning.

A variety of methods should be used to gather and review a range of evidence before and during the inspection including:

- Review of recent inspection reports and any action plans
- Review information submitted via the PIR
- Review information held on CRM, for example communication with the hospice, change of Registered Manager, other notifications, information received from people who use the service or staff, safeguarding alerts or other concerns
- Assessment of governance arrangements and assurance about quality across the hospice, including care provided in community settings
- Observations of care and environment, including individual and communal rooms, and therapeutic areas
- Seeking feedback from children, young people and their families who use services, through interviews, observation, comment cards, and telephone calls*
- Shadowing one or two home visits (inspectors should recognise that this may not always be possible due to the needs of children

and their families, and ensure that the impact on the child and family involved is minimised where possible)

- Tracking a patient journey through talking to a range of different professionals involved in the child or young person's care (ensure this doesn't lead to an excessive burden on one staff member)
- Review of patient care records
- Review of data and feedback provided by the provider and other local services and agencies, including community groups, CCGs and partner organisations working with the hospice
- Feedback from a range of staff and volunteers through interviews and focus groups

*Children and young people who are cared for by children's hospices are often not able to communicate, and inspection teams should consider how to understand children's experience of care most effectively and appropriately. Hospice staff should be able to advise on appropriate communication strategies and provide support.

The inspection team should ask hospice staff and/or families to let them know immediately If they feel that a child or young person who is being interviewed is becoming unwell or distressed during the interview, as they will be better able to identify this at an early stage.

Throughout this guidance, where reference is made to families, we intend a broad definition which includes all those who are important or significant to the child or young person, for example parents, siblings, grandparents, step-families, carers, or the young person's partner. The needs of the whole family should be reflected in the planning and delivery of care, although this may be in different ways and at different times.

Interviews/focus groups/observations

You should conduct interviews of the following people at every inspection:

- Senior Management Team, including non-clinical members of the team and the named person responsible for health and safety
- Trustee if available (may be by phone)
- Registered manager or senior person in charge
- Medical support (may be outsourced)
- Nursing and clinical staff
- Care and support staff
- Allied health professionals (e.g. physiotherapists, occupational therapists, speech and language therapists, music therapists, art therapists)
- Inpatient and community teams
- Family support teams (e.g. counsellor, financial advisor, bereavement support worker, carer support, social worker, sibling support,

family events team, complementary therapist, family liaison, play therapist)
- Children and families – bear in mind that it may be difficult to arrange interviews, and that many children and young people cared for by the hospice are likely to be non-verbal.

You could gather information about the service from the following people, depending on the staffing structure:

- Cultural support worker
- Social worker
- Youth worker
- Catering staff
- Cleaning staff
- Maintenance staff
- Safeguarding lead
- Volunteers
- Chaplaincy
- Bereavement coordinator
- Transition lead
- Pharmacy (usually external to the hospice, arrangements will vary)
- Local NHS acute and community services
- Gold Standard Framework meeting participants

Links to useful documents:

- NICE guideline NG61: End of life care for infants, children and young people with life-limiting conditions: planning and management https://www.nice.org.uk/guidance/ng61
- NICE guideline NG61: tools and resources https://www.nice.org.uk/guidance/ng61/resources
- NICE Quality Standard QS60 – End of life care for infants, children and young people https://www.nice.org.uk/guidance/qs160
- NICE neonatal guidance
- RCPCH guidance - Making Decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html

- Together for Short Lives - A care pathway for children with life-limiting and life-threatening conditions http://www.togetherforshortlives.org.uk/professionals/resources/3021_a_core_care_pathway_2013_free_download_available
- Together for Short Lives - A Transition care pathway for young people with life-threatening and life-limiting conditions - http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/transition_care_pathway
- Together for Short Lives – A perinatal pathway for babies with palliative care needs http://www.togetherforshortlives.org.uk/professionals/resources/11598_perinatal_pathway_for_babies_with_palliative_care_needs
- Together for Short Lives - A Care Pathway to Support Extubation within a Children's Palliative Care Framework - http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/extubation_care_pathway
- Together for Short Lives - A Standards framework for children's palliative care - http://www.togetherforshortlives.org.uk/professionals/resources/3687_standards_framework_for_children_s_palliative_care_2015_free
- Together for Short Lives – Medicines Management Toolkit - http://www.togetherforshortlives.org.uk/professionals/resources/4602_medicines_management_toolkit
- Long Term Ventilated Children's Forum ???
- Pharmacy guidance on transcribing ???
- Spotting the Sick Child - https://spottingthesickchild.com/

Safe

By safe, we mean people are protected from abuse* and avoidable harm.
*Abuse can be physical, sexual, mental or psychological, financial, neglect, institutional or discriminatory abuse.

Examples of data to be considered when making judgements:

- Mandatory training data
- Safeguarding training data
- Actual staffing numbers compared to establishment
- Staff vacancy rates and use of bank/agency staff
- Records audit and other safety audit results
- Safety performance measures – e.g. reported incidents

Key lines of enquiry: **S1**		
S1. How do systems, processes and practices keep people safe and safeguarded from abuse?		
Prompts	**Professional standard**	**Sector-specific guidance**
Report sub-heading: **Mandatory training**		

• S1.1 How are safety and safeguarding systems, processes and practices developed, implemented and communicated to staff[1]?
• S1.5 Do staff receive effective training in safety systems, processes and practices?
	• Providers should have regard to the statutory guidance Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children (March 2015)
	• This guidance references the intercollegiate document *Safeguarding Children and Young People: Roles and competencies for Health Care Staff* published in March 2014, which sets out that as a minimum level required for non-clinical and clinical staff who have some degree of contact with children and young people and/or parents/carers should be trained to level 2 and all clinical staff clinical staff working with children, young people and/or their parents/ carers and who could potentially contribute to assessing, planning, intervening and evaluating the needs of a child or young person should be trained to
		• Is there a structured induction programme that all staff complete when they commence employment?
		• What are the mandatory training rates for staff working in the hospice and where are the gaps?
		• Have health professionals received training in the identification and management of an acutely sick child e.g. Spotting the Sick Child?
		• Have all clinical staff received training in basic life support specific to children?
		• Have staff received training to make them aware of the potential needs of people with:
		  • mental health conditions
		  • learning disability
		  • autism

[1] Throughout this guidance, where reference is made to staff, inspectors should consider whether the KLOE or prompt should apply equally to volunteers.

	level 3 in safeguarding. • Education on Spotting the Sick Child should be promoted for all staff • NICE guideline [NG51] Sepsis: recognition, diagnosis and early management	
Report sub-heading: **Safeguarding**		
• S1.1 How are safety and safeguarding systems, processes and practices developed, implemented and communicated to staff? • S1.2 How do systems, processes and practices protect people from abuse, neglect, harassment and breaches of their dignity and respect? How are these monitored and improved? • S1.3 How are people protected from discrimination, which might amount to abuse or cause psychological harm? This includes harassment and discrimination in relation to protected characteristics under the Equality Act. • S1.4 How is safety promoted in recruitment practice staff support arrangements, disciplinary procedures, and ongoing checks? (For example Disclosure and Barring Service checks). • S1.5 Do staff receive effective training in safety systems, processes and practices? • S1.6 Are there arrangements to safeguard	• Safeguarding Children and Young People: Roles and Competencies for Health Care Staff' (March 2014) • Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children (March 2015) • This guidance references the intercollegiate document *Safeguarding Children and Young People: Roles and competencies for Health Care Staff* (March 2014) which sets out minimum levels of safeguarding training for staff as above. • Female genital mutilation multi-agency practice guidelines published in 2016 • DH Female Genital Mutilation and Safeguarding: Guidance for professionals March 2015 • Guidelines for physicians on the	• How are children and young people respected, their views heard? Are they supported with their individual needs? • How is safety promoted in recruitment and induction of volunteers and their ongoing support, including DBS checks? • Do volunteers have training and an awareness of safeguarding appropriate to their role? Do they know what action to take if they identify a safeguarding concern? • Does the service ensure that all staff are trained to appropriate level set out in the intercollegiate document *Safeguarding Children and Young People: Roles and competencies for Health Care Staff* published in March 2014 and are familiar with Government guidance *'Working Together to Safeguard Children.* • Do staff know how to identify and report abuse and neglect? • Are all clinical staff working directly with children level 3 safeguarding trained?

adults and children from abuse and neglect that reflect relevant legislation and local requirements? Do staff understand their responsibilities and adhere to safeguarding policies and procedures, including working in partnership with other agencies? • S1.7 Do staff identify adults and children at risk of, or suffering, significant harm? How do they work in partnership with other agencies to ensure they are helped, supported and protected?	detection of child sexual exploitation (RCP, November 2015) • Providers should have regard to the statutory guidance 'Working Together to Safeguard Children'. (2015) and Facing the Future (RCPCH, 2015) Standard 10 • Providers should have regard to safeguarding children from abuse linked to faith or belief https://www.gov.uk/government/publications/national-action-plan-to-tackle-child-abuse-linked-to-faith-or-belief • Multi-agency statutory guidance on female genital mutilation 2016 • Prevent duty guidance for England and Wales	• Is there safeguarding supervision (nurses) and peer review (doctors) in place for all staff? • What system is in place to check whether all children are subject to a child protection plan? • What arrangements are in place to support the care of looked after children, for example when the hospice is named as place of care under a court order? • What wider safeguarding protocol/guidance is in place - how are safeguarding issues talked about, who manages them, are lessons learned etc.? • How are staff supported to contribute to external safeguarding meetings and processes? • Have there been any local safeguarding/serious case reviews? If so, how have they been responded to? • Do staff have an awareness of the specific safeguarding risks relevant to children with a physical and/or learning disability, including the increased risk of abuse for disabled children and the barriers to protecting them? What action is taken to manage this? • How does the hospice manage the increased risk presented by a family member who is a Schedule One

		offender and ensure the safety of children and young people in the hospice? • Do staff receive specialist training appropriate to their role e.g. safeguarding of disabled children, trafficking, female genital mutilation? • Do staff have an awareness of child sexual exploitation and understand the law to detect and prevent maltreatment of children? • Are there arrangements in place to safeguard children or young people with, or at risk of, Female Genital Mutilation (FGM)? • What are the arrangements for chaperones? What training have staff received?
Report sub-heading: **Cleanliness, infection control and hygiene**		
• S1.1 How are safety and safeguarding systems, processes and practices developed, implemented and communicated to staff? • S1.8 How are standards of cleanliness and hygiene maintained? Are there reliable systems in place to prevent and protect people from a healthcare-associated infection?	• NICE QS61 Infection prevention and control	• Is the hospice visibly clean and clutter-free (given it is a child-friendly environment e.g. children's toys should be accessible)? • Do staff adhere to the bare below the elbows policy, as well as utilising appropriate protective equipment such as gloves and aprons to carry out procedures and personal care activities? • How does the service educate CYP and parents/carers on infection control practice?

		• What are the hand hygiene audit results? • How does the service support staff to maintain cleanliness and hygiene when working in community settings? Do staff have the equipment they need? • How is this audited? • How does the hospice minimise the risk of infection which could present a risk to children and young people being introduced to the hospice e.g. by visitors?
Report sub-heading: **Environment and equipment**		
• S1.1 How are safety and safeguarding systems, processes and practices developed, implemented and communicated to staff? • S1.9 Does the design, maintenance and use of facilities and premises keep people safe? • S1.10 Does the maintenance and use of equipment keep people safe? • S1.11 Do the arrangements for managing waste and clinical specimens keep people safe? (This includes classification, segregation, storage, labelling, handling and, where appropriate, treatment and disposal of waste.)	• Health and Safety Executive (HSE) FAQs about PAT • Maintaining portable electrical equipment in low-risk environments (HSE leaflet)	• Is specialist equipment needed to provide care and treatment in the child's home identified based on an assessment of needs, and requested in a timely way? Is it appropriate and fit for purpose so that children and young people are safe? • Is the hospice environment safe for the age of children and their siblings? • Is there consideration of a suitable environment for children and young people with ASD/ADHD, sensory, behavioural or mental health needs? • Is specialist equipment for all age ranges, including that required for resuscitation, available and fit for purpose? • How are the age range and cognitive

		abilities of children and young people being cared for in the hospice at a particular time reflected in the hospice environment? • Are syringe pumps maintained and used in accordance with professional recommendation?
Key line of enquiry: S2		
S2. How are risks to people assessed, and their safety monitored and managed so they are supported to stay safe?		
Prompts	**Professional standard**	**Sector-specific guidance**
Report sub-heading: **Assessing and responding to patient risk**		
• S2.5 Are comprehensive risk assessments carried out for people who use services and risk management plans developed in line with national guidance? Are risks managed positively? • S2.6 How do staff identify and respond appropriately to changing risks to people who use services, including deteriorating health and wellbeing, medical emergencies or behaviour that challenges? Are staff able to seek support from senior staff in these situations?	• Spotting the Sick Child	• How do staff plan for and manage behaviour that challenges to ensure the safety of the child or young person, and of others? • How are staff supported to identify and manage an acute deterioration of a child's condition? What procedure is in place for identification and to facilitate the right care for the child? • Do staff know what action to take, both in the hospice and in the community? • Are there systems in place to monitor the condition of a child whose condition may be deteriorating unexpectedly? • What are the arrangements for transfer if a child required urgent acute care?

		• How do staff ensure that a child with an infection is cared for effectively and that the risk to other children in the hospice is managed? • Is there effective risk assessment, action planning and review in place which is understood by the child or young person and their family and supports patient choice?
Report sub-heading: **Nurse and medical staffing**		
• S2.1 How are staffing levels and skill mix planned and reviewed so that people receive safe care and treatment at all times and staff do not work excessive hours? • S2.2 How do actual staffing levels and skill mix compare with the planned levels? Is cover provided for staff absence? • S2.3 Do arrangements for using bank, agency and locum staff keep people safe at all times? • S2.4 How do arrangements for handovers and shift changes ensure that people are safe? • S2.7 How is the impact on safety assessed and monitored when carrying out changes to the service or the staff?	Royal College of Nursing Defining staffing levels for children and young people's services N.B. This guidance is not a recognised standard for hospices and hospices will not necessarily be using it fully. Royal College of Nursing Competences: palliative care for children and young people Association for Paediatric Palliative Medicine Combined Curriculum in Paediatric Palliative Medicine	• What tools are used to plan and allocate staff levels and mix? • Has the service considered the RCN standards on staffing levels in relation to the service they provide? • Do caseloads/staff numbers match plans? • Do the skill mix and competencies of staff on duty, including Healthcare Assistants with additional skills, reflect the needs of children and young people being cared for at that time? • Is there a qualified children's nurse on duty for each shift? How does the hospice ensure that it has access to appropriate medical input? • How does the hospice ensure that there is effective communication with and input from the named medical specialist for the

		child or young person?

Key line of enquiry: **S3**

S3. Do staff have all the information they need to deliver safe care and treatment to people?

Prompts	**Professional standard**	**Sector-specific guidance**
Report sub-heading: **Records**		

• S3.1 Are people's individual care records, including clinical data, written and managed in a way that keeps people safe?
• S3.2 Is all the information needed to deliver safe care and treatment available to relevant staff in a timely and accessible way? (This may include test and imaging results, care and risk assessments, care plans and case notes.)
• S3.3 When people move between teams, services and organisations (which may include at referral, discharge, transfer and transition), is all the information needed for their ongoing care shared appropriately, in a timely way and in line with relevant protocols?
• S3.4 How well do the systems that manage information about people who use services support staff, carers and partner agencies to deliver safe care and treatment? (This includes coordination between different
	• Records management code of practice for health and social care
	• Records are clear, accurate and legible. All concerns and actions taken as a result are recorded. Information relevant to keeping a child or young person safe is recorded and available to other clinicians providing care to them. GMC guidance Protecting children and young people: doctors' responsibilities
	• Information Commissioner's Office General Data Protection Regulation
		• Are there systems to flag the particular needs of a child on their records, including child protection, and is this widely understood?
		• What does the service do to ensure that information is up to date and relevant?
		• Are arrangements for timely sharing details of hospice care with other professionals and agencies involved in the child's care, including social care, working effectively both ways?
		• Do records contain details of the child's emotional, social and spiritual needs alongside their physical health needs, in addition to
		  • mental health needs
		  • learning disability needs
		  • behavioural needs
		  • autism needs?
		• Do staff have access to patient-specific

electronic and paper-based systems and appropriate access for staff to records.)		information, such as care programme approach (CPA) care plans, positive behaviour support plans, health passports, communication aids? Do they use or refer to them? • If an electronic records system is in place, how does the hospice manage appropriate access to the system by temporary staff?
Key line of enquiry: **S4**		
S4. How does the provider ensure the proper and safe use of medicines, where the service is responsible?		
Prompts	**Professional standard**	**Sector-specific guidance**
• S4.1 How are medicines and medicines related stationery managed, i.e. ordered, transported, stored , and disposed of safely and securely (including medical gases and emergency medicines and equipment)? • S4.2 Are medicines appropriately prescribed, administered and/or supplied to people in line with the relevant legislation, current national guidance or evidence base where these exist? • S4.3 Is individualised advice provided about medicines in line with current national guidance or evidence base where it exists? • S4.4 How does the service make sure that people receive their medicines as intended,	• Nursing and Midwifery Council NMC - Standards for Medicine Management • Together for Short Lives Medicines Management Toolkit • Association for Paediatric Palliative Medicine Master Formulary 2017 • NICE NG46 Controlled drugs: safe use and management • The Controlled Drugs (Supervision of Management and Use) Regulations 2013 • Controlled Drugs (Supervision of management and use) Regulations	• Are allergies clearly documented in the prescribing document used? • Is the child's weight clearly documented and are all prescriptions appropriate for the child's weight? • Are nursing staff aware of policies on administration of controlled drugs as per the Nursing and Midwifery Council – Standards for Medicine Management? • What pharmacy input does the hospice have? • What are governance arrangements around supply of medicines from an

and is this recorded appropriately? • S4.5 Are people's medicines reconciled in line with current national guidance on transfer between locations or changes in levels of care? • S4.6 Are people receiving appropriate therapeutic drug and physical health monitoring with appropriate follow up in accordance with current national guidance or evidence base where these exist? • S4.7 Are people's medicines regularly reviewed including the use of 'when required' medicines? • S4.8 How does the service make sure that people's behaviour is not controlled by excessive or inappropriate use of medicines?	2013 Information about the Regulations • NG5 Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes • Medicines Act 1968 • NHS England Security of prescription forms guidance	external source? How are medicines ordered and handled on receipt? • How is the use of medicines off-license managed? • How does the hospice ensure that medicines are administered safely when they are caring for a child in their own home? • How are controlled drugs handled to ensure compliance with legislation? To include storage, prescribing, preparation, administration, documentation and destruction. • Are SOPs, policies and guidance in place with regard to all aspects of handling medicines where appropriate? • Are medicines stored safely and securely and also in line with manufacturers guidance? E.g. how is the cold chain guaranteed? Do cupboards meet requirements? • Do prescribers have access to evidence based and up to date resources to ensure safe prescribing? • Is there evidence of local intelligence network (LIN) reports being submitted on time and attendance at meetings? • Are medicines disposed of safely and medicines requiring disposal segregated safely?

		• Are records of destruction maintained? • Are the relevant training and competency assessment of all staff handling medicines offered/assessed? • When children or young people transfer to another care setting is information with regard to their medicines communicated to the relevant teams/hcps in a timely manner and in a format to ensure reduction of errors? • Is medicines reconciliation carried out by a trained and competent healthcare professional? • Does the Hospice have a Medicines Safety Officer, how does their role add to the governance of medicines within the organisation? • How does the Hospice deal with drug alerts and recalls?
Key line of enquiry: **S5 & S6**		
S5. What is the track record on safety? S6. Are lessons learned and improvement made when things go wrong?		
Prompts	**Professional standard**	**Sector-specific guidance**
• S5.1 What is the safety performance over time?	• A never event is a *serious*, *wholly preventable* patient safety incident that has the *potential to cause serious*	• Has the hospice reported any Never Events? • Are Serious Incidents (SIs) reported in

• S5.2 How does safety performance compare with other similar services? • S5.3 How well safety is monitored using information from a range of sources (including performance against safety goals where appropriate)? • S6.1 Do staff understand their responsibilities to raise concerns, to record safety incidents, concerns and near misses, and to report them internally and externally, where appropriate? • S6.2 What are the arrangements for reviewing and investigating safety and safeguarding incidents and events when things go wrong? Are all relevant staff, services, partner organisations and people who use services involved in reviews and investigations • S6.3 How are lessons learned, and themes identified and is action taken as a result of investigations when things go wrong? • S6.4 How well is the learning from lessons shared to make sure that action is taken to improve safety? Do staff learn from reviews and investigations by other services and organisations?? Do staff participate in learning led by other services or organisations? • S6.5 How effective are the arrangements to respond to relevant external safety alerts, recalls, inquiries, investigations or reviews?	*patient harm or death, has occurred in the past and is easily recognisable and clearly defined.* ○ Revised never events policy and framework (2015) ○ Never events list 2015/16 ○ Never Events List 2015/15 - FAQ • CQC guidance Duty of Candour • NMC/GMC Openness and honesty when things go wrong: the professional duty of candour • Where there are safeguarding concerns an Individual Management Review or Root Cause Analysis should have been completed to contribute to a multi-agency Serious Case Review • Child deaths should be reported through the Child Death Overview Panel ref 'Working Together to Safeguard Children' • Serious Incidents (SIs) should be reported and investigated using the Serious Incident Framework 2015.	line with the serious incident framework? • How are minor and moderate incidents reviewed to identify themes and learning? What action is taken as a result? • Have any safeguarding incidents been reported? Is there an audit trail of evidence and action taken? Were other agencies involved appropriately? • How is learning disseminated? – Any evidence of change to practice as a result? • How does the hospice respond to national patient safety alerts? • Is there evidence in incident investigations that duty of candour has been applied?

Effective

By effective, we mean that people's care, treatment and support achieves good outcomes, promotes a good quality of life and is based on the best available evidence.

Examples of data to be considered when making judgements:

- Local monitoring data of patient outcomes – e.g. are care goals being met, benchmarking data
- Local and relevant national clinical audit results
- Appraisal rates
- Uptake of training and development opportunities
- Consent records and audits

Key line of enquiry: **E1**

E1. Are people's needs assessed and care and treatment delivered in line with current legislation, standards and evidence-based guidance to achieve effective outcomes?

Prompts	Professional standard	Sector-specific guidance
Report sub-heading: **Evidence-based care and treatment**		
• E1.1 Are people's physical, mental health and social needs holistically assessed, and is their care, treatment and support delivered in line with legislation, standards and evidence-based guidance, including NICE and other expert professional bodies, to achieve effective outcomes?	• 'You're Welcome', the Department of Health's quality criteria for young people friendly health services • NICE Guideline NG61 End of life care for infants, children and young people with life-limiting conditions: planning and management	• How are the needs of the family of a child or young person, including their siblings, grandparents, and others who are important to the child, recognised and assessed, and arrangements put in place to meet their needs? How are these arrangements reviewed over time?

• E1.2 What processes are in place to ensure there is no discrimination, including on the grounds of protected characteristics under the Equality Act, when making care and treatment decisions? • E1.3 How is technology and equipment used to enhance the delivery of effective care and treatment and to support people's independence? • E1.4 Are the rights of people subject to the Mental Health Act 1983 (MHA) protected and do staff have regard to the MHA Code of Practice? • E1.7 Are people told when they need to seek further help and advised what to do if their condition deteriorates?	• NG61 Tools and resources • NICE Quality Standard QS60 End of life care for infants, children and young people • NICE Quality Standard QS27 Epilepsy in children and young people • NICE Clinical Guideline CG107 Autism spectrum disorder in under 19s: support and management • NICE pathway Spasticity in children and young people overview • Spasticity in children and young people overview - NICE Pathways • NICE Public Health Guideline PH28 Looked after children and young people • Together for Short Lives - A care pathway for children with life-limiting and life-threatening conditions • Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)	• Are parents or carers of children and young people who are approaching the end of life offered support for grief and loss when their child is nearing the end of their life and after their death? • How does the service adapt the care provided to a child or young person and their family as their needs change over time? • How are the emotional, spiritual and social needs of children and young people identified, assessed and met? • How does the hospice help children and young people to maintain a good quality of life, and provide choice about how their care needs are met? • How are the symptoms experienced by children and young people assessed and managed appropriately, including seizures and symptoms experienced at the end of life? • How does the service adapt to meet the changing needs of children and young people and their extended families in times of change or crisis? • Are relevant NICE guidelines and quality standards followed, for example: EOLC for infants, children and young people? • Do children have a clear personalised care plan which reflects their complex needs, is up to date and in line with relevant good-practice guidance, and sets out clear goals for the child? (A

		sample of care plans should be reviewed) • Do all children who have been diagnosed with a life-limiting condition have an Advance Care Plan which the hospice has access to? • Do children have a ReSPECT summary plan or equivalent to guide decision-making in the event of an emergency? • How does the service review, update and share plans when young people reach the age of 16 and their medical care is transferred to adult services? • Are other relevant national guidelines being followed, such as Promoting the Quality of Care of Looked After Children and Young People, and Special Educational Needs and Disability Code of Practice?
Report sub-heading: **Nutrition and hydration**		
• E1.5 How are people's nutrition and hydration needs (including those related to culture and religion) identified, monitored and met? Where relevant, what access is there to dietary and nutritional specialists to assist in this?	• NICE Guideline NG61 End of life care for infants, children and young people with life-limiting conditions: planning and management	• Does the hospice manage the nutrition and hydration of children and young people who are approaching the end of life in line with NG61?
Report sub-heading: **Pain relief**		
• E1.6 How is a person's pain assessed and managed, particularly for those people where	• NICE Guideline NG61 End of life care for infants, children and young people	• Does the hospice manage the pain of children and young people who are

there are difficulties in communicating?	with life-limiting conditions: planning and management • Paediatric Pain Profile • DisDAT (Disability Distress Assessment Tool)	approaching the end of life in line with NG61? • Where relevant do children and young people's care plans include an appropriate pain assessment and management plan? • Do staff use strategies and tools to assess and respond to the pain experienced by children and young people who have communication difficulties or are non-verbal e.g. the paediatric pain profile, DisDAT? • How is the pain of children and young people who are being cared for at home managed 24/7? • Are anticipatory medications prescribed appropriately in children and young people identified as approaching the end of life?

Key line of enquiry: **E2**

E2. How are people's care and treatment outcomes monitored and how do they compare with other similar services?

Prompts	**Professional standard**	**Sector-specific guidance**
Report sub heading: **Patient outcomes**		
• E2.1 Is information about the outcomes of people's care and treatment (both physical and mental where appropriate) routinely collected and monitored? • E2.2 Does this information show that the intended outcomes for people are being	Note – there is no nationally agreed outcomes framework for hospice care for children and young people.	• Is there a clear approach to monitoring, auditing and benchmarking the quality of the services and the outcomes for children and young people receiving care and treatment? • Does quality and outcome information

achieved? • E2.3 How do outcomes for people in this service compare with other similar services and how have they changed over time? • E2.4 Is there participation in relevant quality improvement initiatives, such as local and national clinical audits, benchmarking, (approved) accreditation schemes, peer review, research, trials and other quality improvement initiatives? Are all relevant staff involved in activities to monitor and use information to improve outcomes?		show that the needs of children and young people are being met by the hospice? • Does the hospice have a strategic approach to monitoring outcomes, including future development to improve outcome monitoring? • Does quality and outcome information reflect the breadth of the service provided – including spiritual, social and emotional aspects of care • Is quality and outcome information used to inform improvements in the service? • What outcome data is used in reporting to CCGs or other commissioners? • How is outcome data shared with other partners in the system? • Does the hospice participate in regional or national audits, and/or regional or national benchmarking programmes? • Do providers with more than one service benchmark the quality of care in their services internally? *Consider available data about patient outcomes. Also use pathway tracking to help assess this KLOE.*
Key line of enquiry: **E3**		
E3. How does the service make sure that staff have the skills, knowledge and experience to deliver effective care, support and treatment?		

Prompts	Professional standard	Sector-specific guidance
Report sub heading: **Competent staff**		
• E3.1 Do people have their assessed needs, preferences and choices met by staff with the right skills and knowledge? • E3.2 How are the learning needs of all staff identified? Do staff have appropriate training to meet their learning needs to cover the scope of their work and is there protected time for this training? • E3.3 Are staff encouraged and given opportunities to develop? • E3.4 What are the arrangements for supporting and managing staff to deliver effective care and treatment? (This includes one-to-one meetings, appraisals, coaching and mentoring, clinical supervision and revalidation.) • E3.5 How is poor or variable staff performance identified and managed? How are staff supported to improve? • E3.6 Are volunteers recruited where required, and are they trained and supported for the role they undertake?	• Safeguarding Children and Young People: Roles and competencies for Health Care Staff: Intercollegiate guidance March 2014. Intercollegiate document • Royal College of Nursing Competences: palliative care for children and young people	• Do all staff (including volunteers) caring for children and young people have the qualifications, skills and competencies they need? • Do they have regular appraisals and training plans to support this? • Is there a competency framework in place which reflects RCN guidance on competencies for palliative care for children and young people? • How does the service ensure that staff are enabled to provide appropriate care for children and young people from neonates to young adults/adults (depending on the service)? • How does the service ensure that staff able to provide appropriate care to children and young people with cognitive impairments? • How does the service ensure that staff have training in medicines management appropriate to their role? • Are there hospice policies in place that detail resuscitation training requirements? • Do staff have the skills, knowledge and experience to understand, identify and manage issues arising from a child or young person's ○ mental health condition

		○ learning disability ○ autism
Key line of enquiry: **E4**		
E4. How well do staff, teams and services within and across organisations work together to deliver effective care and treatment?		
Prompts	**Professional standard**	**Sector-specific guidance**
Report sub-heading: **Multidisciplinary working**		
• E4.1 Are all necessary staff, including those in different teams, services and organisations, involved in assessing, planning and delivering care and treatment? • E4.2 How is care delivered and reviewed in a coordinated way when different teams, services or organisations are involved? • E4.3 How are people assured that they will receive consistent coordinated, person-centred care and support when they use, or move between different services? • E4.4 Are all relevant teams, services and organisations informed when people are discharged from a service? Where relevant, is discharge undertaken at an appropriate time of day and only done when any necessary ongoing care is in place?	• NICE Guideline NG43 Transition from children's to adults' services for young people using health or social care services • Together for Short Lives - A Transition care pathway for young people with life-threatening and life-limiting conditions	• Does multidisciplinary working support effective care planning and delivery for children and young people with complex needs and disabilities? • Does multi-disciplinary working include all necessary professionals and extend to include other aspects of children's lives, including nurseries, education and social care? Do these arrangements help plan and deliver care, treatment and other support to children and young people in a holistic and joined up way? • How does the hospice work with local partners, including social care, to ensure continuity of care for children, young people and their families? • How does the service ensure that plans are in place to manage the transition of children and young people to an adult hospice if appropriate, and ensure that the transition is managed effectively? • Is there evidence of multi-disciplinary/ interagency working when required? • Do staff participate in relevant external

		meetings and share information appropriately e.g. Gold Standard Framework meetings?
Key line of enquiry: **E5**		
E5. How are people supported to live healthier lives and where the service is responsible, how does it improve the health of its population?		
Prompts	**Professional standard**	**Sector-specific guidance**
Report sub-heading: **Health promotion**		

• E5.1 Are people identified who may need extra support? This includes:
  • people in the last 12 months of their lives
  • people at risk of developing a long-term condition
  • carers
• E5.2 How are people involved in regularly monitoring their health, including health assessments and checks, where appropriate and necessary
• E5.3 Are people who use services empowered and supported to manage their own health, care and wellbeing and to maximise their independence?
• E5.4 Where abnormalities or risk factors are identified that may require additional support or intervention, are changes to people's care or treatment discussed and followed up
		• How does the hospice support the families of infants and young children to ensure their children receive immunisations, routine checks and other input from the health visitor and GP?
		• How does the hospice support families and carers to maintain their own health and wellbeing?

between staff, people and their carers where necessary? • E5.5 How are national priorities to improve the population's health supported? For example, smoking cessation, obesity, drug and alcohol dependency, dementia and cancer.		
Key line of enquiry: E6		
E6. Is consent to care and treatment always sought in line with legislation and guidance?		
Prompts	**Professional standard**	**Sector-specific guidance**
Report sub-heading: **Consent, Mental Capacity Act and Deprivation of Liberty Safeguards**		
• E6.1 Do staff understand the relevant consent and decision making requirements of legislation and guidance, including the Mental Capacity Act 2005 and the Children's Acts 1989 and 2004 and other relevant national standards and guidance? • E6.2 How are people supported to make decisions in line with relevant legislation and guidance? • E6.3 How and when is possible lack of mental capacity to make a particular decision assessed and recorded? • E6.4 How is the process for seeking consent monitored and reviewed to ensure it meets legal requirements and follows relevant national guidance? • E6.5 When people lack the mental capacity	• BMA Children and young people tool kit • Gillick competence • GMC Guidance – 0-18 years assessing capacity to consent • My adult – still my child: a guide for parents and carers of adults (16+) who may not be able to make decisions • Resuscitation Council UK Decisions relating to Cardiopulmonary Resuscitation	• Is valid consent to treatment obtained for children and young people who are under 16 with their involvement, either directly where they are judged to be Gillick competent or from a person with parental responsibility where the child cannot give or withhold consent? • How does the team support children and young people and their parents to make decisions about care? • How do staff ensure that decisions are made in the best interests of young adults who are in the care of their parents but whose parents do not have parental responsibility because they are aged 18 or over? How are any orders which may be in place reflected in decision-making? • How is decision-making managed when

to make a decision, do staff ensure that best interests decisions are made in accordance with legislation? • E6.6 How does the service promote supportive practice that avoids the need for physical restraint? Where physical restraint may be necessary, how does the service ensure that it is used in a safe, proportionate, and monitored way as part of a wider person centred support plan? • E6.7 Do staff recognise when people aged 16 and over and who lack mental capacity are being deprived of their liberty, and do they seek authorisation to do so when they consider it necessary and proportionate?		the parents of a child or young person disagree? • How is decision-making managed when the local authority has parental responsibility for a child or young person? • How are such decisions documented, evidenced and shared appropriately? • Are DNACPR decisions made appropriately and in line with national guidance? Is this audited?

Caring

By caring, we mean that the service involves and treats people with compassion, kindness, dignity and respect.

Examples of data to be considered when making judgements:

- Service level patient experience feedback - e.g. Friends and Family test results, local patient experience surveys
- Relevant staff survey feedback

Key line of enquiry: C1, C2 & C3

C1. How does the service ensure that people are treated with kindness, dignity, respect and compassion, and that they are given emotional support when needed?

C2. How does the service support people to express their views and be actively involved in making decisions about their care, support and treatment as far as possible?

C3. How is people's privacy and dignity respected and promoted?

Generic prompts	Professional Standard	Sector-specific guidance
Report sub-heading: **Compassionate care**		
• C1.1 Do staff understand and respect the personal, cultural, social and religious needs of people and how these may relate to care needs, and do they take these into account in the way they deliver services? Is this information recorded and shared with other services or providers? • C1.2 Do staff take the time to interact with	• Registered nurses working with children will need additional training, education and supervision to demonstrate competence in: - understanding and upholding the rights of children, young people and their families in all areas of the health care system - communicating with children and	• How does the service ensure that they understand and meet the needs of the child or young person's family, both in the hospice and in the community? • Do staff care for the whole family when they are staying at the hospice or are using hospice services with their child? • How does the whole team demonstrate a caring approach in

people who use the service and those close to them in a respectful and considerate way? • C1.3 Do staff show an encouraging, sensitive and supportive attitude to people who use services and those close to them? • C1.4 Do staff raise concerns about disrespectful, discriminatory or abusive behaviour or attitudes? • C3.1 How does the service and staff make sure that people's privacy and dignity needs are understood and always respected, including during physical or intimate care and examinations? • C3.2 Do staff respond in a compassionate, timely and appropriate way when people experience physical pain, discomfort or emotional distress?	young people to understand their needs, involving them and their parents/carers in decision making and facilitating children to care for themselves as much as they are able or wish to - assessing children and young people in terms of their clinical needs based upon knowledge of their different levels of physical and emotional maturity and development - recognising actual and potential physical health and mental health problems and deterioration in health status Royal College of Nursing guidance on Defining staffing levels for children and young people's services	providing care to the child or young person and their family, including in the child's home? • Does the environment reflect the individual wishes and preferences of the child or young person, for example through personalisation of rooms for the individual child? • Do staff ensure that the environment meets the changing needs of children and young people, for example for relaxation or stimulation? Do staff ensure that children are seen as children first and foremost, with their individual physical, emotional and social needs recognised and responded to? • How do staff ensure that the privacy and confidentiality of children and young people are appropriately respected? • Are staff trained and supported in managing children and/or parents with behavioural or mental health disorders? • How do staff respond to children and young people who might be frightened, confused or phobic about medical procedures or any aspect of their care?
Report sub-heading**: Emotional support**		

• C1.5 Do staff understand the impact that a person's care, treatment or condition will have on their wellbeing and on those close to them, both emotionally and socially? • C1.6 Are people given appropriate and timely support and information to cope emotionally with their care, treatment or condition? Are they advised how to find other support services? • C2.7 What emotional support and information is provided to those close to people who use services, including carers, family and dependants?		• Do parents feel confident leaving their child in the care of the hospice, both in an inpatient unit and their own home? • How do staff recognise and support the broader emotional wellbeing of children and young people with complex needs, their carers and those close to them? • What support is available for parents, siblings and others close to the child? • What support is available to families who are facing bereavement or who have been bereaved? • Do children and young people with life limiting conditions receive social, practical, emotional, psychological, and spiritual support? • If a child or young person becomes distressed in an open environment, how do staff assist them to maintain their privacy and dignity? • How are children and young people supported to access and maintain their education and maintain their social networks? • What arrangements are in place to refer people for carer's assessments or to further information and support for carers? • How does the service work with voluntary agencies to support families?
Report sub-heading**: Understanding and involvement of patients and those close to them**		

• C2.1 Do staff communicate with people so that they understand their care, treatment and condition and any advice given? • C2.2 Do staff seek accessible ways to communicate with people when their protected equality or other characteristics make this necessary? • C2.3 How do staff make sure that people who use services and those close to them are able to find further information, including community and advocacy services, or ask questions about their care and treatment? How are they supported to access these? • C2.4 Are people empowered and supported, where necessary, to use and link with support networks and advocacy, so that it will have a positive impact on their health, care and wellbeing? • C2.5 Do staff routinely involve people who use services and those close to them (including carers and dependants) in planning and making shared decisions about their care and treatment? Do people feel listened to, respected and have their views considered? • C2.6 Are people's carers, advocates and representatives including family members and friends, identified, welcomed, and treated as important partners in the delivery of their care? • C3.3 How are people assured that	• GMC Guidance and resources for communicating with people with communication difficulties • Information Commissioner's Office General Data Protection Regulation •	• Are staff observed to be communicating appropriately with children and young people and their families? • Are there communication plans in place for children and young people to support their communication and enable staff to recognise and understand their feelings, emotions, symptoms and needs, and respond appropriately? • How do staff use appropriate tools and strategies for communication with children and young people who are non-verbal? • Do staff have access to communication aids to help children and young people to become partners in their care and treatment? • Is information and support provided in a child-friendly format? • How are children and young people and their families involved in developing their care plan? • How do staff communicate with families to support their involvement in planning and making decisions about the care of a child or young person? • How do staff ensure that children, young people and their families can access the information they need, including from other services? • What support is given and how are young people and their families

information about them is treated confidentially in a way that complies with the Data Protection Act and that staff support people to make and review choices about sharing their information?		involved before and during transition to an adult hospice? • How are children and young people supported to keep in touch with their friends and family when they are in the hospice?

Responsive

By responsive, we mean that services meet people's needs

Examples of data to be considered when making judgements:

- Waiting times for access to the service
- Service level complaints data

Key line of enquiry: **R1 & R2**

R1. How do people receive personalised care that is responsive to their needs?

R2. Do services take account of the particular needs and choices of different people?

Prompts	Professional standard	Sector-specific guidance
Report sub-heading: **Planning and delivering services which meet people's needs**		
• R1.1 Do the services provided reflect the needs of the population served and do they ensure flexibility, choice and continuity of care?	• Children and young people's experience of health services are captured as part of service development, monitoring and evaluation Department of Health,	• Is the service proactive in meeting the needs of children and young people from their whole community, reflecting diversity at the individual level? • What arrangements are in place to

• R1.2 Where people's needs and choices are not being met, is this identified and used to inform how services are improved and developed? • R1.3 Are the facilities and premises appropriate for the services that are delivered?	You're welcome: Quality criteria for young people friendly health services, 2011 • Steps have been taken to ensure that service provision, environment and atmosphere are young people friendly. Department of Health, You're welcome: Quality criteria for young people friendly health services, 2011	help address inequalities and to meet the diverse needs of local children and young people? • What arrangements are in place to access translation services? • What engagement and involvement of children and young people and their families has there been in the design and running of the services? • What facilities are available for families e.g. accommodation, refreshments etc.? • How does the service work with other health, social care and education providers or agencies to meet the needs of children and young people in the local area? • Does the hospice understand the needs of their local community and are they proactive in meeting the identified needs? • Are any gaps in the service provided locally identified and action taken to try to address the gaps?
Report sub-heading: **Meeting people's individual needs**		
• R1.4 How does the service identify and meet the information and communication needs of people with a disability or sensory loss. How does it record, highlight and share this information with others when required, and gain people's consent to do so? • R2.1 How are services delivered, made	• Reasonable adjustment for children or young people with disabilities under the Equality Act 2010 • NICE Guideline NG61 End of life care for infants, children and young people with life-limiting conditions: planning and management • RCPCH guidance - Making Decisions	• Do children's records contain sufficient detail to enable staff to meet their individual needs and deliver individualised care? • How does the holistic care provided to children and families reflect their cultural context? • How are the needs of children and

accessible and coordinated to take account of the needs of different people, including those with protected characteristics under the Equality Act and those in vulnerable circumstances? • R2.2 How are services delivered and co-ordinated to be accessible and responsive to people with complex needs?[2] • R2.3 How are people, supported during referral, transfer between services and discharge? • R2.4 Are reasonable adjustments made so that people with a disability can access and use services on an equal basis to others? • R2.5 Do key staff work across services to coordinate people's involvement with families and carers, particularly for those with multiple long-term conditions? • R2.6 Where the service is responsible how are people encouraged to develop and maintain relationships with people that matter to them within the service and wider community? • R2.7 Where the service is responsible, how are people supported to follow their interests and take part in activities that are socially and culturally relevant and appropriate to them, including in the wider community and, where appropriate to have access to	to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice	young people being met: ○ at different ages? ○ when receiving end of life care? ○ where English is not their and/or their parents first language? ○ for looked-after children? ○ for children with child protection orders? ○ if they are children of asylum seekers? • How are the changing needs of children and young people monitored and regularly reviewed? • What arrangements are in place to enable access to the service of children, young people and families in vulnerable circumstances? • How are the needs of children and young people who may be vulnerable because of their circumstances understood, and a plan developed and delivered to meet their individual needs? • How does the service meet the needs of children who are looked after or care leavers, and improve their health outcomes? • How does the hospice support children and families to have discussions and make decisions about place of care when the child or young person is

[2]. For example, people living with dementia or people with a learning disability or autism.

education and work opportunities? • R2.8 How are services delivered and coordinated to ensure that people who may be approaching the end of life are identified, including those with a protected equality characteristic and people whose circumstances may make them vulnerable, and that this information is shared? • R2.9 How are people who may be approaching the end of their life supported to make informed choices about their care? Are people's decisions documented and delivered through a personalised care plan and shared with others who may need to be informed? • R2.10 If any treatment is changed or withdrawn, what are the processes to ensure that this is managed openly and sensitively so that people have a comfortable and dignified death?		approaching the end of life, and about place of death? How are these decisions documented and shared? • How do hospice staff offer support for grief and loss to the families of children and young people when their child is nearing the end of their life and after their death? • Is care after death managed sensitively and in a way which respects the wishes of families while following the appropriate process? • Do staff ensure that families have an understanding of the practical arrangements needed after the death of their child e.g. the involvement of the child death overview panel? • Does the service deal effectively with the child death overview panels in their local areas?
Key line of enquiry: **R3**		
R3. Can people access care and treatment in a timely way?		
Prompts	**Professional standard**	**Sector-specific guidance**
Report sub-heading: **Access to the right care at the right time**		
• R3.1 Do people have timely access to initial assessment, test results, diagnosis, or treatment? • R3.2 Can people access care and treatment		• Is the service able to meet the needs of children and young people who can benefit from their service at the point that they need it? • Does the service raise awareness

at a time to suit them? • R3.3 What action is taken to minimise the length of time people have to wait for care, treatment, or advice? • R3.4 Do people with the most urgent needs have their care and treatment prioritised? • R3.5 Are appointment systems easy to use and do they support people to access appointments? • R3.6 Are appointments care and treatment only cancelled or delayed when absolutely necessary? Are delays or cancellations explained to people, and are people supported to access care and treatment again as soon as possible? • R3.7 Do services run on time, and are people kept informed about any disruption? • R3.8 How is technology used to support timely access to care and treatment? Is the technology (including telephone systems and online/digital services) easy to use?		among local clinicians of the role of hospice care for children and young people with life-limiting or life-threatening conditions, in order to ensure children and families who can benefit from their service are referred appropriately? • Does the hospice have effective processes in place to manage admission to the service? • Do children and young people have to wait to access the service (review activity reports/KPIs)? Is there an action plan in place if needed? • How does the service manage demand during busy periods e.g. school summer holidays? • Is there an effective urgent access pathway in place so that children and young people can be discharged home to die?
Key line of enquiry: **R4**		
R4. How are people's concerns and complaints listened and responded to and used to improve the quality of care?		
Prompts	**Professional standard**	**Sector-specific guidance**
Report sub-heading: **Learning from complaints and concerns**		
• R4.1 How well do people who use the service know how to make a complaint or raise	• The NHS constitution gives people the	• Is there a child friendly complaints process appropriate for CYP of

concerns and how comfortable do they feel doing so in their own way? How are people encouraged to make a complaint, and how confident are they to speak up? • R4.2 How easy is it for people to use the system to make a complaint or raise concerns? Are people treated compassionately and given the help and support, through use of accessible information or protection measures if they need to make a complaint? • R4.3 How effectively are complaints handled, including to ensure openness and transparency, confidentially, regular updates for the complainant, a timely response and explanation of the outcome, and a formal record? • R4.4 How are people who raise concerns or complaints protected from discrimination, harassment or disadvantage? • R4.5 To what extent are concerns and complaints used as an opportunity to learn and drive improvement?	right to ➢ Have complaints dealt with efficiently and be investigated. ➢ Know the outcome of the investigation. ➢ Take their complaint to an independent Parliamentary and Health Service Ombudsman. Receive compensation if they have been harmed. • Department of Health, You're welcome: Quality criteria for young people friendly health services, 2011	different age ranges to easily access and use? • Are children and young people who are not able to communicate verbally supported to express their views, including negative views about the service? • Are staff in the service aware of any relevant complaints and action needed to make improvements? • Does the hospice make children, young people and their families aware of how to complain? • How does the hospice ensure they learn from complaints effectively? • Is there a process for capturing and learning from negative feedback which is not submitted as a complaint?

Well-led

By well-led, we mean that the leadership, management and governance of the organisation assures the delivery of high-quality person-centred care, supports learning and innovation, and promotes an open and fair culture.

Examples of data to be considered when making judgements:

- Relevant feedback from children, young people and their families
- Relevant staff survey feedback

Key line of enquiry: **W1**

W1. Is there the leadership capacity and capability to deliver high-quality, sustainable care?

Prompts	Professional standard	Sector-specific guidance
Report sub-heading: **Leadership of service**		
• W1.1 Do leaders have the skills, knowledge, experience and integrity that they need – both when they are appointed and on an ongoing basis? • W1.2 Do leaders understand the challenges to quality and sustainability, and can they identify the actions needed to address them? • W1.3 Are leaders visible and approachable? • W1.4 Are there clear priorities for ensuring sustainable, compassionate, inclusive and effective leadership, and is there a leadership strategy or development programme, which includes succession planning?	•	• Is the relationship between senior leaders, including trustees, and operational staff effective? • How do trustees (or equivalent) ensure they meet their governance responsibilities and have a good understanding of quality and safety of care? • Do staff, particularly those working in the community, feel connected to other teams within their service and to the organisation as a whole?

Key line of enquiry: **W2**

W2. Is there a clear vision and credible strategy to deliver high-quality sustainable care to people who use services, and robust plans to deliver?

Prompts	Professional standard	Sector-specific guidance
Report sub-heading: **Vision and strategy for the service**		
• W2.1 Is there a clear vision and a set of values, with quality and sustainability as the top priorities? • W2.2 Is there a robust, realistic strategy for achieving the priorities and delivering good quality sustainable care? • W2.3 Have the vision, values and strategy been developed using a structured planning process in collaboration with staff, people who use services, and external partners? • W2.4 Do staff know and understand what the vision, values and strategy are, and their role in achieving them? • W2.5 Is the strategy aligned to local plans in the wider health and social care economy, and how have services been planned to meet the needs of the relevant population? • W2.6 Is progress against delivery of the strategy and local plans monitored and reviewed, and is there evidence to show this?		• Is the strategy in line with national recommendations and direction of travel for hospice care for children and young people? • Was the hospice strategy developed with engagement from the local community and developed to reflect their needs? • Does the strategy recognise current and future funding arrangements and enable prioritisation?
Key line of enquiry: **W3**		
W3. Is there a culture of high-quality, sustainable care?		
Prompts	**Professional Standard**	**Sector-specific guidance**
Report sub-heading: **Culture within the service**		

• W3.1 Do staff feel supported, respected and valued? • W3.2 Is the culture centred on the needs and experience of people who use services? • W3.3 Do staff feel positive and proud to work in the organisation? • W3.4 Is action taken to address behaviour and performance that is inconsistent with the vison and values, regardless of seniority? • W3.5 Does the culture encourage, openness and honesty at all levels within the organisation, including with people who use services, in response to incidents? Do leaders and staff understand the importance of staff being able to raise concerns without fear of retribution, and is appropriate learning and action taken as a result of concerns raised? • W3.6 Are there mechanisms for providing all staff at every level with the development they need, including high-quality appraisal and career development conversations? • W3.7 Is there a strong emphasis on the safety and well-being of staff? • W3.8 Are equality and diversity promoted within and beyond the organisation? Do all staff, including those with particular protected characteristics under the Equality Act, feel they are treated equitably? • W3.9 Are there cooperative, supportive and	• CQC guidance Duty of Candour • NMC/GMC Openness and honesty when things go wrong: the professional duty of candour	• What processes and procedures does the provider have in place to ensure they meet the duty of candour? For example, training, support for staff, policy and audits. • What measures are taken to protect that safety of staff who work alone and as part of dispersed teams working in the community? • How is the lone working policy implemented? • What arrangements are in place to ensure staff can raise concerns safely e.g. whistleblowing policy? • Is there a focus on improving health outcomes embedded in the culture of the hospice?

appreciative relationships among staff? Do staff and teams work collaboratively, share responsibility and resolve conflict quickly and constructively?		

Key line of enquiry: **W4, W5 & W6**

W4. Are there clear responsibilities, roles and systems of accountability to support good governance and management?

W5. Are there clear and effective processes for managing risks, issues and performance?

W6. Is appropriate and accurate information being effectively processed, challenged and acted upon?

Prompts	**Professional Standard**	**Sector-specific guidance**
Report sub-heading: **Governance, Risk management and quality management**		
• W4.1 Are there effective structures, processes and systems of accountability to support the delivery of the strategy and good quality, sustainable services? Are these regularly reviewed and improved? • W4.2 Do all levels of governance and management function effectively and interact with each other appropriately? • W4.3 Are staff at all levels clear about their roles and do they understand what they are accountable for, and to whom? • W4.4 Are arrangements with partners and third-party providers governed and managed effectively to encourage appropriate interaction and promote coordinated, person-centred care? • W5.1 Are there comprehensive assurance	•	• Is feedback from people who use services and their families regularly discussed at divisional and Board meetings? What recent actions have been identified as a result, and how is progress tracked? • What quality and risk information about the service is reviewed by the Board and what assurance is provided about the quality of information being considered? • Are there clear lines of accountability within the service? • Are there clear lines of accountability for arrangements for safeguarding children and support for children who are looked after? • Does the hospice have plans in place to ensure continuity of care in an

systems, and are performance issues escalated appropriately through clear structures and processes? Are these regularly reviewed and improved? • W5.2 Are there processes to manage current and future performance? Are these regularly reviewed and improved? • W5.3 Is there a systematic programme of clinical and internal audit to monitor quality, operational and financial processes, and systems to identify where action should be taken? • W5.4 Are there robust arrangements for identifying, recording and managing risks, issues and mitigating actions? Is there alignment between the recorded risks and what staff say is 'on their worry list'? • W5.5 Are potential risks taken into account when planning services, for example seasonal or other expected or unexpected fluctuations in demand, or disruption to staffing or facilities? • W5.6 When considering developments to services or efficiency changes, how is the impact on quality and sustainability assessed and monitored? Are there examples of where financial pressures have compromised care? • W6.1 Is there a holistic understanding of performance, which sufficiently covers and integrates people's views with information on quality, operations and finances? Is		emergency, for example where they may be unable to use the hospice building, working with local partners if appropriate?

information used to measure for improvement, not just assurance? • W6.2 Do quality and sustainability both receive sufficient coverage in relevant meetings at all levels? Do all staff have sufficient access to information, and do they challenge it appropriately? • W6.3 Are there clear and robust service performance measures, which are reported and monitored? • W6.4 Are there effective arrangements to ensure that the information used to monitor, manage and report on quality and performance is accurate, valid, reliable, timely and relevant? What action is taken when issues are identified? • W6.5 Are information technology systems used effectively to monitor and improve the quality of care? • W6.6 Are there effective arrangements to ensure that data or notifications are submitted to external bodies as required? • W6.7 Are there robust arrangements (including internal and external validation) to ensure the availability, integrity and confidentiality of identifiable data, records and data management systems, in line with data security standards? Are lessons learned when there are data security breaches?		

Key line of enquiry: **W7**		
Are the people who use services, the public, staff and external partners engaged and involved to support high-quality sustainable services?		
Prompts	**Professional Standard**	**Sector-specific guidance**
Report sub-heading: **Public and staff engagement**		
• W7.1 Are people's views and experiences gathered and acted on to shape and improve the services and culture? Does this include people in a range of equality groups? • W7.2 Are people who use services, those close to them and their representatives actively engaged and involved in decision-making to shape services and culture? Does this include people in a range of equality groups? • W7.3 Are staff actively engaged so that their views are reflected in the planning and delivery of services and in shaping the culture? Does this include those with a protected characteristic? • W7.4 Are there positive and collaborative relationships with external partners to build a shared understanding of challenges within the system and the needs of the relevant population, and to deliver services to meet those needs? • W7.5 Is there transparency and openness with all stakeholders about performance?		• Does the hospice work in partnership with other services providing care to children and young people to ensure they effectively meet their needs? • How do staff seek to understand the experience and views of children and young people who may be cognitively impaired and unable to communicate? • What techniques and tools are used with children and young people to get their feedback on the quality of the service, where this is possible? • How are the families of children and young people involved in shaping and improving the service and culture? • Is feedback from people who use services and the public reviewed by teams and used to inform improvements and learning? • How are the views of staff in the service sought and acted on? • Is feedback from staff reviewed by teams and used to inform improvements and learning?

Key line of enquiry: **W8**		
W8. Is there transparency and openness with all stakeholders about performance?		
Prompts	**Professional standard**	**Sector-specific guidance**
• W8.1 In what ways do leaders and staff strive for continuous learning, improvement and innovation? Does this include participating in appropriate research projects and recognised accreditation schemes? • W8.2 Are there standardised improvement tools and methods, and do staff have the skills to use them? • W8.3 How effective is participation in and learning from internal and external reviews, including those related to mortality or the death of a service user? Is learning shared effectively and used to make improvements? • W8.4 Do all staff regularly take time out to work together to resolve problems and to review individual and team objectives, processes and performance? Does this lead to improvements and innovation? • W8.5 Are there systems to support improvement and innovation work, including objectives and rewards for staff, data systems, and processes for evaluating and sharing the results of improvement work?		• What improvements have been made to the service in the last year, or since we last inspected? • What innovations is the hospice involved in and what has been the impact of this innovation on the quality of care received by children and young people who use the service? • Are there any issues in relation to the future sustainability of services?