End of life care for infants, children and young people

NICE National Institute for Health and Care Excellence

Consultation on draft quality standard – deadline for comments 5:00pm on 16 May 2017 **email:** QSconsultations@nice.org.uk

	Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly. We would like to hear your views on these questions: 1. Does this draft quality standard accurately reflect the key areas for quality improvement? If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures? Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted. 2. [Insert any specific questions about the quality standard from the Developer, or delete if not needed]
Organisation name – stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):	**Together for Short Lives**
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.	**None**
Name of commentator person completing form:	**Patrick McKenna**
Supporting the quality standard - Would your organisation like to express an interest in formally supporting this quality standard? More information.	**Yes**

Please return to: QSconsultations@nice.org.uk

Type		[office use only]	
Comment number	**Section**	**Statement number**	**Comments** Insert each comment in a new row. Do not paste other tables into this table because your comments could get lost – type directly into this table.
Example 1	Statement 1 (measure)		This statement may be hard to measure because…
1.	What the quality statement means for different audiences	All	Each quality statement refers to 'district nurses'. In the community, children with life-limiting and life-threatening conditions are cared for by community children's nurses or hospice at home nurses and not district nurses. Community children's nurses complete a different qualification to district nurses. The quality statements should instead therefore refer to community children's nurses instead of district nurses.
2.	Questions about the quality standard – question 2	All	To improve national standards of end of life care for infants, children and young people, we propose that local data that is collected should be published and collated nationally to provide a national overview.
3.	Quality statement	1	This quality statement is a key area for improvement and is achievable. It is also possible for local systems to collect data for this quality measure, as the Greater Manchester Clinical Network Audit has demonstrated.
4.	Quality statement	1	This should state 'involved in developing a quality advance care plan' and link to guidance on what a quality advance care plan looks like. We suggest that it links to the Child and Young Person's Advance Care Plan Collaborative resources page (http://cypacp.nhs.uk/documentdownloads)
5.	Quality measures – Process b)	1	As all babies will have a plan to cover their birth, this section should specify that the advance care plan (ACP) is relevant to their life-limiting condition. It should also specify that advance care plans should set out in what circumstances the baby should be resuscitated contain specific plans for resuscitation and provide for possible transfer of the baby for end of life care in a different location. The advance care plan should include plans for:

			- the period before the child is born - delivery - the period immediately after the birth. The family's preferences should be considered when developing an advance care plan. Once the baby is born, the plan should be reviewed.
6.	What the quality statement means for different audiences – Service providers	1	This list of service providers and practitioners should reflect the different settings in which the child or young person will spend time. Education settings, for example, should be informed at the earliest stage possible that an ACP is being developed for a child. They should be informed of the implications that the ACP will have for them - and what action they should take. Similarly, the list of service providers should include community paediatric services and local ambulance services.
7.	What the quality statement means for different audiences – Health and social care practitioners	1	This section should include education staff, who will be involved in supporting the child or young person. They will need to make sure that the support they provide is consistent the ACP - for example, knowing whether the child should be admitted to hospital if they collapse or if they have a Do Not Attempt Cardiopulmonary resuscitation (DNACPR) decision.
8.	What the quality statement means for different audiences – Children and young people	1	'Parents and cares' should state 'Parents and carers'. In the sentence "This may sometimes be done before a baby is born if the condition is diagnosed during pregnancy", the term 'or suspected' should be added after the term 'diagnosed'. The term 'diagnosis' is not always appropriate during pregnancy as definitive diagnoses at this stage are rare. If a child is diagnosed or suspected as having a life-limiting condition in the womb, their ACP should set out how care should be provided in several potential scenarios, which should include a stillbirth.
9.	Definitions – advance care	1	This definition should recognise that an advance care plan is not usually developed in a single conversation between a parent carer and a professional. An ACP takes time to develop. The definition should also

	plan		recognise that the child's situation may change rapidly and their ACP should be reviewed to address this. The definition should state that ACPs have no legal status.
10.	Quality statement	2	A child with a life-limiting condition needs a lead consultant and someone who coordinates their care. This is not necessarily the same person. As it is currently written, the quality statement states that the child's care will be coordinated by a 'medical specialist', which implies that this role would be carried out by a consultant. It is unlikely that a consultant will have the time available to perform a coordinating role in relation to all aspects of care – although the lead consultant will be able to coordinate medical care The family should be involved in deciding who should coordinate their child's care. This coordinating role will usually be the child's key worker. The named point of contact for a child and family will change depending on the stage of a child's life they are in. It could therefore be their: • key worker • school nurse • community children's nursing team • hospice team.
11.	Rationale	2	It is unclear whether this section seeks to make sure that a child has a named medical specialist or an individual to coordinate their care. The NICE 'End of Life Care for Infants, Children and Young People: Planning and Management' guideline states that a named medical specialist should lead and coordinate the child's care. It also states that a named individual from the multidisciplinary team should be their main contact, and that this person should coordinate their care'. These are separate roles. This section should also state that the care coordinator should lead on communication between different professionals and organisations involved in the child's care. The professional that performs the role of coordinator will require adequate time to perform their role in addition to their other roles.
12.	Quality measures – structure	2	In the sentence "Evidence of local arrangements to ensure that infants, children and young people with a life-limiting condition have a named medical specialist who coordinates their care", the word 'care' should be preceded by 'medical'.

13.	Question for consultation	2	The named medical specialist (not care coordinator) should be: • a specialist in the child's underlying condition • the lead consultant paediatrician • Community paediatrician • Palliative care consultant • hospice medical lead; or • GP.
14.	Quality statement	3	This quality statement would have a significant impact if fully implemented. However, some Child and Adolescent Mental Health Services (CAMHS) have waiting lists of up to six months. As it is currently written, this quality statement only requires that children and young people are 'given information'. We believe that this should be strengthened to state that children and young people are given access to appropriate care and support. As with Quality Statement 5, we suggest that this quality statement should address support for the whole family, including siblings (as specified by recommendation 1.1.6 of the full guidance), and parents or carers. The full guidance also specifies (recommendation 1.1.7) that 'other family members (for example grandparents) and people important to the child or young person (for example friends, boyfriends or girlfriends) may need support. This may include social, practical, emotional, psychological, and spiritual support.'
15.	What the quality statement means for different audiences – Service providers	3	This section should include schools, which play a key role in providing support for children and young people.
16.	Equality and diversity considerations	3	"Healthcare practitioners caring for children and young people with a life-limiting condition should establish if the person has a learning disability" This section should be clear that professionals do not have to carry out a learning disability assessment, but

			should instead establish the level of understanding that the child has and tailor their information they provide to them accordingly. This should happen regardless of whether the child has a diagnosed learning disability. Information could be provided using Makaton, for example, or using a pictorial leaflet for children. We therefore suggest that the statement is amended to: "Healthcare practitioners caring for children and young people with a life-limiting condition should establish the extent to which children are able to understand information about their condition and their care. They should make sure that they provide them with information which is appropriate to their level of understanding."
17.	Definitions	3	This section should define what constitutes emotional and psychological support, which should include talking therapies. The support should be provided by specialist children's teams rather than adult therapists.
18.	Quality statement	4	We suggest that this statement is widened to 'managing distress' rather than 'unresolved distressing symptoms' which is exclusively medical. The phrase 'specialist paediatric palliative care team' should hyperlink to the definition of this team. This will help to draw attention to how these teams are composed.
19.	Rationale	4	This should state that the specialist paediatric palliative care team should seek specialist paediatric pharmacy support.
20.	Quality measures – process	4	The phrase 'unresolved distressing symptoms' is subjective. Additionally, some symptoms may not be resolved but will be managed as well as possible, while some symptoms such as secretions and fitting are unlikely to be resolved. As in comment 18, we ask that this is replaced by 'distress'.
21.	Definitions – Specialist paediatric palliative care team	4	This section should state that the specialist paediatric palliative care team should work with the local children's hospice team where appropriate.
22.	Question for consultation	4	For this quality statement to be measured in practice, we suggest that there would need to be a standardised symptom assessment tool.
23.	Do you think each of the statements in this draft quality	5	There is a time and skills shortage that means that this statement is difficult to achieve. Together for Short Lives' research in 2016 (http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf) found that 17% of clinical commissioning groups (CCGs) and 70% of local authorities in England do not commission this support.

	standard would be achievable by local services given the net resources needed to deliver them?		
24.	Quality statement	5	As with Quality Statement 3, we believe that this statement should address support for the whole family, including the child, siblings (as specified by recommendation 1.1.6 of the full guidance), and parents or carers. The full guidance also specifies (recommendation 1.1.7) that 'other family members (for example grandparents) and people important to the child or young person (for example friends, boyfriends or girlfriends) may need support. This may include social, practical, emotional, psychological, and spiritual support.' This statement should state that bereavement support is offered 'at the point of diagnosis of a life-limiting condition' as grief and loss starts from the point of diagnosis. The complexity of life-limiting conditions means that many children and young people have a prognosis that will not be clearly defined and their condition may change rapidly.
25.	Rationale	5	This section refers to 'emotional and mental health problems, and relationship issues' – the meaning of which is not clearly defined. We would suggest the phrase 'mental wellbeing and the prevention of family breakdown' would be clearer and preferable to use. This section refers to 'autopsy'. The expert consensus is that 'post mortem examination' is now the preferred term to use instead. We suggest that 'genetic risk for family planning' is changed to 'plans for a future pregnancy'.
26.	Quality measures – process	5	This quality measure establishes the proportion of parents or carers who have a bereavement support plan in place. However, not all parents will want pre-death bereavement support and many will not be ready for some time after their child has died. The quality measure should reflect this.
27.	Definitions – bereavement support	5	This definition should be widened so that it includes talking therapies as part of a broader range of therapies such as art therapy.

28.	Equality and diversity considerations	5	This section states that practitioners "should establish if the child's parents or carers have any learning disabilities." They may not be qualified to carry out a learning disability assessment. Practitioners should 'assess the level of understanding and tailor the information that they provide to parents or carers'.
29.	Quality statement 6: Home care	6	We suggest that the title of this standard is amended so it is 'Care in the place that the child and their family chooses'. We suggest that the quality statement is amended to: "Infants, children and young people approaching the end of life should be able to choose where they receive their care, whether at home, in the community, in a children's hospice or in hospital. All infants, children and young people approaching the end of life should have access to 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care."
30.	Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them?	6	The current nursing workforce shortage will make this quality statement difficult to achieve. Together for Short Lives' research in 2017 (http://bit.ly/2pKTP5e) found that the nurse vacancy rate among children's hospice organisations is over 11% and has grown for each of the past two years. There is also an overall NHS nurse vacancy rate of 9% in England, Northern Ireland and Wales. There is also a shortage of community children's nurses across the UK: The Royal College of Nursing (RCN) (http://bit.ly/1QgLhZb) recommends that for an average-sized district, with a child population of 50,000, a minimum of 20 whole time equivalent (WTE) community children's nurses are required to provide a holistic community children's nursing service. The Office of National Statistics estimates (http://bit.ly/2iJOTgS) that there are 13,770,873 children aged 0-18 in England. If the RCN recommendation were to be met, this would therefore require approximately 5,508 community children's nurses. There are currently just 535 community children's nurses in England (http://bit.ly/2j2srhm). Together for Short Lives' research in 2016 (http://bit.ly/2pEd6ai) found that over a quarter of clinical commissioning groups (CCGs) do not commission out of hours' community children's nursing teams. Although this quality statement is aspiration at present, it is a key area for improvement and will support commissioners and providers to consider how to provide 24/7 paediatric nursing care at home. Several areas such as Yorkshire and Humber are working towards effective on call advice being available from level 3 and 4 palliative care consultants. Regions can work together to have sufficient numbers to provide on call advice service.
31.	Quality	6	This quality statement should promote greater choice for children and young people - and their families - over

	statement		where they receive end of life care. As it is currently written, the quality statement only offers support to those 'who are being cared for at home (see Quality measures - structure). This quality statement should instead refer to offering children and families choice over where they receive end of life care and providing support for them to do so. We therefore propose that the preferred place of death for a child or young person should be expressed in their Advance Care Plan. This should record the preferred place of death regardless of whether this is deemed possible, so that this statement can measure real 'choice'. The numerator for this measure would therefore be 'the number of children and young people with a life-limiting condition that were able to die in the place they chose' while the denominator would be 'the number of children and young people who have died'. This quality statement should also state that this support should be provided by a managed clinical network, as recommended in the full clinical guideline (recommendation 1.5.10). Together for Short Lives is currently developing a project in partnership with NHS England to support the implementation of the 'End of life care for infants, children and young people' guidance, including the development of children's palliative care managed clinical networks. This will entail conducting a benchmarking exercise with the 9 regional and 4 sub-regional Children's Palliative Care Networks, which are supported by Together for Short Lives, to establish the extent to which practice is in line with the recommendations made in the NICE guidelines. The project will then seek to bring these networks together, share best practice and provide support for the networks to adapt to become managed clinical networks.
32.	Rationale	6	This should state 'should be available in the community' to reflect the fact that children and their families should be able to choose where to receive end of life care.
33.	What the quality statement means for different audiences – service providers	6	This should include ambulance trusts. Paramedics may be called out to the child's home and should be able to access the specialist advice and manage issues to prevent unnecessary admissions.
34.	New suggested	New suggested	Together for Short Lives proposes that an additional standard 'Short breaks (respite) for children and young people' is developed.

	statement	statement	The **rationale** is that children with life-limiting conditions rely on frequent short breaks. This could be to enable them to spend time with their family, away from caring responsibilities, doing the things that other families do. Alternatively, it could be to help the child achieve some independent time away from their family to be with their peers. The importance of short breaks is recognised in the full NICE guidance. In the definitions section (page 34) it states that 'Paediatric palliative care focuses on improving the quality of life for the child or young person and supporting their family members or carers, and includes managing distressing symptoms, providing respite care, and support with death and bereavement.' Short breaks provided at or away from home for children and young people with life-limiting conditions are provided by a range of organisations, including children's hospice organisations. These short breaks may include clinical care to meet their often-complex health needs, non-clinical care, or a combination of both. They are a lifeline to these children's families and can reduce parental stress and the risk of family breakdown, which can in turn have a detrimental impact on their ability to provide care. The structure of a quality measure would include evidence of local arrangements to provide short breaks to children with life-limiting and life-threatening conditions. The process would measure the proportion of these children who report that they receive a regular short break which meet their needs. It would also measure the extent to which their families feel resilient, feel under stress, and feel able to continue caring for their child or young person following their short break. The **outcome** would be that children and young people with life-limiting and life-threatening conditions: • feel more resilient • can continue to be cared for by their families because the latter: ○ feel less stressed ○ feel less susceptible to poor health (both physical and mental) ○ do not experience the breakup of relationships between parent carers. **What this would mean for different audiences**

			Service providers (such as hospitals, hospices, GP practices and community children's nurses, other voluntary sector providers of short breaks, local authorities) ensure that systems are in place to refer parents or carers of children and young people with life-limiting and life-threatening conditions to providers of short breaks. Short break providers ensure that a range of short breaks appropriate to children's age and developmental needs are available. **Health and social care practitioners (such as secondary care doctors, nurses, GPs and community children's nurses)** are aware of referral pathways to services that offer short breaks for children and young people with life-limiting and life-threatening conditions. **Commissioners (clinical commissioning groups)** ensure that they jointly commission services that include short breaks for children and young people with life-limiting and life-threatening conditions which can meet their needs. **Children and young people** are offered short breaks which can meet their needs.

Insert extra rows as needed

Checklist for submitting comments

- Use this comment form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include section number of the text each comment is about e.g. introduction; quality statement 1; quality statement 2 (measure).
- If commenting on a specific quality statement, please indicate the particular sub-section (for example, statement, measure or audience descriptor).
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, comment forms do not include attachments such as research articles, letters or leaflets (for copyright reasons).We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.

You can see any guidance and quality standards that we have produced on topics related to this quality standard by checking NICE Pathways.

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are

Please return to: QSconsultations@nice.org.uk too long, or publication would be unlawful or otherwise inappropriate.

Comments received from registered stakeholders and respondents during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.