NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: End of life care for infants, children and young people

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 9 February 2017

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for end of life care for infants, children and young people. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development source

The key development source referenced in this briefing paper is:

End of life care for infants, children and young people: planning and management. NICE guideline NG61 (2016).

2 Overview

2.1 Focus of quality standard

This quality standard will cover end of life care for infants, children and young people aged up to 18 years who have a life-limiting condition. It will also cover providing support to family members and carers.

2.2 Definition

End of life care is defined within NG61 as care that covers a wide range of life-limiting conditions. It begins when a life-limiting condition is diagnosed (potentially in the antenatal stage) and continues even if a child is having treatment for the underlying condition, and it will, in the event of the death of a child or young person, continue to include the immediate bereavement support of their family. It covers the physical, emotional, social and spiritual elements of end of life care, and focuses on improving the child or young person's quality of life and supporting their family and carers.

2.3 Incidence and prevalence

It is estimated that almost 50,000 children and young people aged 19 years or under in the UK (40,000 of these in England) are living with a life-limiting condition at any time, and may therefore need end of life care. They may have widely varying needs, as there are over 300 conditions that could be classed as life-limiting or life-threatening in this age group. Some of these children and young people also have severe disabilities and multiple complex health and care needs, in addition to end of life care needs. The importance of support for children and young people with life-limiting conditions is an area that these guidelines try to emphasise. Complications of pre-term birth, particularly respiratory and cardiovascular conditions, account for about half of infant deaths. Congenital anomalies account for about a further third.

2.4 Management

There is wide regional variation in paediatric end of life care practice, combining a broad range of health and other care services, including 40 hospitals, hospices, primary care and community professionals, ambulance services, dedicated palliative care teams, and other support providers. Specialist end of life care services for children may be delivered in a variety of settings. Consultant-led teams may be found within some children's hospices, as well as in tertiary children's hospitals, and also within community-based services. Hospices and community services offering a specialist service will often offer 'in-reach' to local hospitals, as well as supporting end of life care in hospice, schools and at home. Services thus span statutory and charitable sectors (for example hospices). Core end of life care skills exist in most local community teams, among children's community nurses and general paediatricians/general practitioners.

Children, young people and their parents, families or carers may have varied and differing ideas about what represents good end of life care. They may also have differences of opinion with each other and what is a priority for them, and at various stages, over time, their priorities may change.

2.5 National outcome frameworks

Table 1 shows the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS outcomes framework 2016–17

Domain	**Overarching indicators and improvement areas**
2 Enhancing quality of life for people with long-term conditions	***Overarching indicator*** 2 Health-related quality of life for people with long-term conditions** **Enhancing quality of life for carers** 2.4 Health-related quality of life for carers
4 Ensuring that people have a positive experience of care	**Improving the experience of care for people at the end of their lives** 4.6 Bereaved carers' views on the quality of care in the last 3 months of life

3 Summary of suggestions

3.1 Responses

In total 14 stakeholders responded to the 2-week engagement exercise 09/12/2016 – 23/12/2016.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 2 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 2 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Advance care planning	Mencap, TSL, SCMx5, RCGP,NHSE, EPA, TCT, NCD
Clinical management • Managing pain and Agitation	NHSE, EPA, SCMx2
Emotional and psychological support for the child • Anxiety and depression • Severe psychiatric disorder	SCM. RCP
Emotional and psychological support for the family • Bereavement support	NHSE, CBN, PAMIS, RTCC, RCP, TSL, EPA, SCMx2
Home care • Care at home • 24/7 Nursing/specialist support	TSL, RGHC, SCMX3
Key contacts • Named worker • Access to a Level 4 Consultant	Mencap, TSL, RCGP, NCD, SCMX2
Additional areas • Managed clinical networks • Training for healthcare professionals • Clinical and psychosocial debrief	TCT, Mencap, RCN, RCGP, NCD

Suggested area for improvement	Stakeholders
CBN, Childhood Bereavement Network EPA, The Esoteric Practitioners Association Mencap NCD, National Clinical Director, Children, Young People and Transition to Adulthood NHSE, NHS England PAMIS RCGP, Royal College of General Practitioners RCN, Royal College of Nursing RCP, Royal College of Psychiatrists RGHC, Rennie Grove Hospice Care RTCC, Rainbow Trust Children’s Charity SCM, Specialist committee member TCT, Teenage Cancer Trust TSL, Together for short lives	

3.2 Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 757papers were identified for end of life care for infants, children and young people. In addition, 47 papers were suggested by stakeholders at topic engagement and 25 papers internally at project scoping.

Of these papers, 5 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 Advance care planning

4.1.1 Summary of suggestions

Advance care planning

Stakeholders highlighted that absence of a comprehensive cross-setting advance care plan can impact on consistency and coordination of care and result in the wishes of infants, children and young people in end of life care, and their family, not being followed. Stakeholders therefore highlighted the importance of involvement of in the development of advance care plans and in shared decision making.

The importance of discussing an advance care plan with parents during the pregnancy if there is an antenatal diagnosis of a life-limiting condition was also highlighted. It was felt currently babies are often referred to palliative care services only after birth.

4.1.2 Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 3 to help inform the committee's discussion.

Table 3 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Advance care planning	**Advance Care Planning** NICE NG61 Recommendations 1.2.5 and 1.2.6

Advance Care Planning

NICE NG61 Recommendation 1.2.5

Develop and record an Advance Care Plan at an appropriate time for the current and future care of each child or young person with a life-limiting condition. The Advance Care Plan should include:

- demographic information about the child or young person and their family
- up-to-date contact information for:
  - the child or young person's parents or carers and
  - the key professionals involved in care
- a statement about who has responsibility for giving consent

- a summary of the life-limiting condition
- an agreed approach to communicating with and providing information to the child or young person and their parents or carers
- an outline of the child or young person's life ambitions and wishes, for example on:
    - family and other relationships
    - social activities and participation
    - education
    - how to incorporate their religious, spiritual, and cultural beliefs and values into their care
- a record of significant discussions with the child or young person and their parents or carers
- agreed treatment plans and objectives
- education plans, if relevant
- a record of any discussions and decisions that have taken place on:
    - preferred place of care and place of death
    - organ and tissue donation (see recommendation 1.2.17)
    - management of life-threatening events, including plans for resuscitation or life support
    - specific wishes, for example on funeral arrangements and care of the body
- a distribution list for the Advance Care Plan.

Advance Care Planning

NICE NG61 Recommendation 1.2.6

Begin discussing an Advance Care Plan with parents during the pregnancy if there is an antenatal diagnosis of a life-limiting condition. For each individual think about who should take part in the discussion, for example:

- obstetricians
- midwives
- neonatologists
- specialists in the life-limiting condition
- a member of the specialist paediatric palliative care team (see recommendation 1.5.4).

4.1.3 Resource impact

The resource impact for this area could not be specifically assessed, however the time taken to ensure the recommendations on care planning are implemented could be part of the work of the multidisciplinary team. The capacity needed can be assessed locally in the resource impact template.

4.1.4 Current UK practice

A local audit of ‘expected’ deaths in children with life-shortening and life-threatening conditions between 1st April 2012 and 31st September 2013 was carried out in 2014[1]. It looked at end of life care planning for 42 neonates and 32 children over 28 days old:

- 79% of neonates and 91% children had documented end of life plans.
- 6% of neonates and 47% of children had personal resuscitation plans
- 17% of neonates and 53% of children had a preferred placed of death identified which was achieved in 86% and 76% of cases respectively.

A study by together for shorter lives on end of life care for children with life-limiting conditions and their families was carried out between July 2011 and June 2012[2]. It looked at how well the needs of the children and their families were being met by supportive and palliative care services in the West Midlands:

- 68% of parents felt they did not have sufficient opportunities to plan future care for their child
- 56% of parents felt they did not have sufficient opportunities to plan care for their child around the time of death
- 46% of parents felt they did not receive sufficient information about services and how to receive them

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[1] End-of-Life Planning Documentation and Location of Death in Children with Life-Shortening and Life-Threatening Conditions, Blundell PDM, Wolff T (2015).

[2] The Big Study for Life-limited Children and their Families* – Final research report, together for short lives (2013)

4.2 Clinical management

4.2.1 Summary of suggestions

Managing pain and agitation

Children and young people receiving end of life care often experience pain and agitation. Effective management, both pharmacological and non-pharmacological, can help to improve quality of life. Stakeholders including NHS England therefore highlighted the management of pain and agitation as a key priority area for infants, children and young people.

4.2.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Managing pain and agitation	**Managing agitation** NICE NG61 Recommendation 1.3.38

Managing agitation

<u>NICE NG61 Recommendation 1.3.38</u>

If a child or young person who is approaching the end of life needs treatment for agitation:

- identify and if possible treat any medical or psychological conditions that may be contributing to it
- think about non-pharmacological interventions, such as:
    - calm speaking, reassurance, distraction, and physical contact such as holding and touch
    - changes to the environment to make it more comfortable, calm and reassuring, to reduce noise and lighting, to maintain a comfortable room temperature, and to provide familiar objects and people and relaxing music
    - religious and spiritual support if this is wanted and helpful
- think about pharmacological interventions (beginning with low doses and increasing if necessary). Drugs to think about using include:
    - benzodiazepines, such as midazolam, diazepam or lorazepam
    - neuroleptics, such as haloperidol or levomepromazine.

4.2.3 Resource impact

The resource impact for this area could not be specifically assessed, however the time taken to ensure the recommendations on symptom management are implemented could be part of the work of the multidisciplinary team. The capacity needed can be assessed locally in the resource impact template.

4.2.4 Current UK practice

A study by together for shorter lives on end of life care for children with life-limiting conditions and their families was carried out between July 2011 and June 2012[3]. It looked at how well the needs of the children and their families were being met by supportive and palliative care services in the West Midlands:

- 16% of parents reported that their child's needs related to relief from pain and discomfort were not sufficiently met.

A National End of Life Care Intelligence Network (NEoLCIN) report that looked at any available new information on end of life care in 2011/12[4] for all patients in England found:

- 91% of people (including adults) had anticipatory prescribing of medications for five key symptoms that may occur in last hours or days of life (pain, agitation, respiratory tract secretions, nausea and vomiting and breathing difficulties)
- Between 93% and 99% of patients (including adults) who had documented routine on-going assessment individuals were recorded as 'comfortable' for goals related to symptom control.

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[3] The Big Study for Life-limited Children and their Families* – Final research report, together for short lives (2013)

[4] What do we know now that we didn't a year ago? New intelligence on end of life care in England, National End of Life Care Intelligence Network (2012)

4.3 Emotional and psychological support for the child

4.3.1 Summary of suggestions

Anxiety and depression

Stakeholder's highlighted that anxiety and depression are treatable conditions experienced by children and young people who are receiving end of life care. The presence of anxiety and depression may be missed or underestimated because it is expected that they might struggle with their emotions in this context or it may be diagnosed as an adjustment disorder.

Severe psychiatric disorder

Stakeholders highlighted that children and young people can develop psychotic illnesses co-morbidly or it can be caused by treatment provided during end of life care such as high dose steroids. It was commented that clinicians treating these children and young people need to be able to access specialist psychiatric services for children and young people without delay through paediatric liaison psychiatry teams who can provide assessment, diagnosis and treatment of psychosis.

4.3.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Anxiety and depression	**Managing agitation** NICE NG61 Recommendation 1.3.36
Severe psychiatric disorder	No recommendations identified

Managing agitation

<u>NICE NG61 Recommendation 1.3.36</u>

If a child or young person becomes agitated as they are approaching the end of life, look for causes and factors that may be contributing to this, including:

- medical disorders and conditions such as pain, hypoxia, anaemia, dehydration, urinary retention or constipation
- psychological factors such as fear, anxiety or depression
- adverse effects from medication.

4.3.3 Resource impact

The resource impact for this area could not be assessed due to variations in local practice and access to services. The workforce required to ensure the recommendations on emotional and psychosocial support are implemented could be assessed as part of the costs of the multidisciplinary team. The capacity needed can be assessed locally in the resource impact template.

4.3.4 Current UK practice

Anxiety and depression

A study by together for shorter lives on end of life care for children with life-limiting conditions and their families was carried out between July 2011 and June 2012[5]. It looked at how well the needs of the children and their families were being met by supportive and palliative care services in the West Midlands:

- 22% of parents felt their child's need to access psychological or emotional support was not sufficiently met

Severe psychiatric disorder

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

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[5] The Big Study for Life-limited Children and their Families* – Final research report, together for short lives (2013)

4.4 Emotional and psychological support for the family

4.4.1 Summary of suggestions

Bereavement support

Stakeholder's highlighted the importance of bereavement support for family and carers following the death of a child or young person from a life-limiting condition. Stakeholders commented that there is currently variation in the availability of bereavement support particularly psychological bereavement support and support for parents affected by stillbirth or neonatal death.

4.4.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Bereavement support	**Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person** NICE NG61 Recommendation 1.4.2 to 1.4.5

Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person

NICE NG61 Recommendation 1.4.2

When a child or young person is approaching the end of life, discuss the bereavement support available with their parents or carers and provide them with written information.

NICE NG61 Recommendation 1.4.3

When a child or young person is approaching the end of life, talk to their parents or carers about available psychological bereavement support groups.

NICE NG61 Recommendation 1.4.4

Offer bereavement support from a professional with appropriate expertise to the parents or carers both before and after the death of a child or young person

NICE NG61 Recommendation 1.4.5

When planning bereavement support for parents or carers:

- talk to them about the support that is available and explore with them what they would find helpful and acceptable
- think about what support different professionals could provide, for example:
  - their GP
  - healthcare professionals who know the child or young person and are involved in their care
- think about the role of individual professionals in providing specific aspects of support
- inform the multidisciplinary team about the support plan.

NICE NG61 Recommendation 1.4.6

When making a bereavement support plan with parents or carers, discuss possible options with them such as:

- opportunities to talk to the professionals caring for the child or young person, to:
  - discuss memories and events
  - answer any concerns or questions they may have
- home visits from the healthcare professionals caring for the child or young person
- bereavement support groups.

4.4.3 Resource impact

The resource impact for this area could not be specifically assessed, however the time taken to ensure the recommendations on bereavement support are implemented could be part of the work of the multidisciplinary team. The capacity needed can be assessed locally in the resource impact template.

4.4.4 Current UK practice

A report by Together for Short Lives (2016)[6] looked at a series of freedom of information requests made to local authorities and NHS clinical commissioning groups (CCGs) in England during April 2016.

- 83% of CCGs and 30% of local authorities said they commission emotional and psychological support (including bereavement care) for children and young people.
- Of these 61% of CCGs and 16% of local authorities said they commission these services out of hours and at weekends.

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[6] Commissioning children's palliative care in England, together for shorter lives, 2016

A study by together for shorter lives on end of life care for children with life-limiting conditions and their families was carried out between July 2011 and June 2012[7]. It looked at how well the needs of the children and their families were being met by supportive and palliative care services in the West Midlands:

- 22% of parents felt their child’s brothers and/or sisters need to access psychological or emotional support was not sufficiently met.

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[7] The Big Study for Life-limited Children and their Families* – Final research report, together for short lives (2013)

4.5 Home care

4.5.1 Summary of suggestions

Care at home

Stakeholders commented that infants, children and young people should have the option of receiving end of life care at home where this is appropriate. Stakeholders highlighted evidence that suggests higher satisfaction with care in people who received end of life care at home as opposed to in hospital.

24/7 nursing and specialist support

Stakeholders commented on the importance of 24/7 nursing and specialist support for infants, children and young people receiving end of life care at home. It was highlighted although NICE guidance recommends paediatric nursing care should be available at any time (day and night) there remains high variation in the availability of this across the UK. Stakeholders suggested that this prevents infants, children and young people from being offered choices related to preferred places of care and death at the end of their lives.

4.5.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Care at home	**Care at home** NICE NG61 Recommendation 1.5.10
24/7 Nursing/specialist support	**Care at home** NICE NG61 Recommendation 1.5.9

Care at home

NICE NG61 Recommendation 1.5.10

Services should have agreed strategies and processes to support children and young people who are approaching the end of life and are being cared for at home. These services should be based on managed clinical networks, and should collaborate on care planning and service delivery.

Care at home

NICE NG61 Recommendation 1.5.9

For children and young people with life-limiting conditions who are approaching the end of life and are being cared for at home, services should provide (when needed):

- advice from a consultant in paediatric palliative care (for example by telephone) at any time (day and night)
- paediatric nursing care at any time (day and night)
- home visits by a healthcare professional from the specialist paediatric palliative care team (see recommendation 1.5.4), for example for symptom management
- practical support and equipment for interventions including oxygen, enteral nutrition, and subcutaneous and intravenous therapies
- anticipatory prescribing for children and young people who are likely to develop symptoms.

4.5.3 Resource impact

The resource impact work for the guideline identified two areas where there could be a resource impact relating to home care. These are:

- rapid transfer arrangements – cost per transfer £1,100 to £2,700 [recommendation 1.5.8]
- care at home – cost to be assessed locally [recommendation 1.5.9].

Table 8 illustrates the estimated potential resource impact of providing services for a population of 1.5 million. It is anticipated that some of these costs will be met from using existing resources differently. The resources released are unlikely to be cash releasing.

Table 8 Potential resource impact of providing end of life care for infants, children and young people for a population of 1.5 million

Description	£000s
Illustrative costs:	
Rapid transfer arrangements	53
Day and night care at home (see appendix 5)	381
Total illustrative costs	**434**
Illustrative resources released:	
Reductions in critical care bed days	-1,037
Unplanned admissions	-98
Total illustrative resources released	**-1,135**
Potential resource impact	**-701**

Commissioners and providers should decide together whether the resources released are cash releasing or help manage demand for paediatric critical care beds.

A more detailed analysis of the illustrative costs and resources released can be found in the resource impact tools for the guideline.

4.5.4 Current UK practice

Care at home

A report by the Royal College of Paediatrics and Child Health[8] looking at child deaths in the four UK countries between 2001 and 2010 found a small but consistent decrease (approximately 5%) in the proportion of children who died during an admission, and concurrent increases in the proportion of children who died out of hospital (approximately 10%). The decrease in the proportion of deaths occurring during a hospital admission was largest for children with cancer/blood conditions.

A National End of Life Care Intelligence Network (NEoLCIN) report looked at information from a survey of children's hospice providers carried out in 2010/11[9]. Data was collected from 35 children's hospice providers in the UK and found:

- Of the 729 reported deaths just over 30% occurred at home.

24/7 Nursing/specialist support

A study by together for shorter lives on end of life care for children with life-limiting conditions and their families was carried out between July 2011 and June 2012[10]. It looked at how well the needs of the children and their families were being met by supportive and palliative care services in the West Midlands:

- 94% of CCGs commission community children's nursing (CCN) for children with life-shortening conditions.
- 73% for CCGs when asked if they commission a CCN service for children with life-shortening conditions out of hours and at weekends.

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[8] Overview of child deaths in the four UK countries, Royal College of Paediatrics and Child Health CHR-UK Programme (2013)

[9] What do we know now that we didn't a year ago? New intelligence on end of life care in England, National End of Life Care Intelligence Network (2012)

[10] The Big Study for Life-limited Children and their Families* – Final research report, together for short lives (2013)

4.6 Key contacts

4.6.1 Summary of suggestions

Named worker

Stakeholders highlighted that infants, children and young people who are receiving end of life care will often have complex or multiple needs and be in contact with multiple members of staff. Poor communication between health care professionals can lead to strain on families who have to repeat information and take responsibility for information sharing. This can also impact on the limited time clinicians have to spend with patients. Having a named worker as part as a central point of contact in a multidisciplinary team can therefore help to ensure a positive experience.

Access to level 4 Consultant

Stakeholders highlighted that end of life care can be complicated and doctors can be uncertain of how to manage children approaching the end of their lives. Access to a level 4 Consultant is therefore important to ensure high quality care for infants, children and young people.

4.6.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 9 to help inform the committee’s discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Named medical specialist	**Multidisciplinary team** NICE NG61 Recommendation 1.5.7
Access to a Level 4 Consultant	**Multidisciplinary team** NICE NG61 Recommendation 1.5.4

Multidisciplinary team

NICE NG61 Recommendation 1.5.7

Think about having a named individual from the multidisciplinary team to act as a first point of contact for the child or young person and their parents or carers.

NICE NG61 Recommendation 1.5.4

The specialist paediatric palliative care team should include at a minimum:

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

4.6.3 Resource impact

The resource impact for this area could not be specifically assessed, however the time taken to ensure the recommendations on care planning are implemented could be part of the work of the multidisciplinary team. The capacity needed can be assessed locally in the resource impact template.

4.6.4 Current UK practice

Named medical specialist

A study by together for shorter lives on end of life care for children with life-limiting conditions and their families was carried out between July 2011 and June 2012[11] in the West Midlands. Parents were asked whether they had a named person to contact if they needed help and advice (to find out if they had a care co-ordinator or key worker). There was a mixed response: some parents did whilst others said they never had a named person to contact. This information was followed up and where the families could identify a named person, services were perceived as better.

Access to a Level 4 Consultant

A report by Together for Short Lives (2016)[12] looked at a series of freedom of information requests made to local authorities and NHS clinical commissioning groups (CCGs) in England during April 2016:

- 72% of CCGs said they were commissioning specialist medical input for children and young people with life-shortening conditions.
- 60% of CCGs said they were commissioning this care out of ours and at weekends.

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[11] The Big Study for Life-limited Children and their Families* – Final research report, together for short lives (2013)

[12] Commissioning children's palliative care in England, together for shorter lives, 2016

4.7 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 9 February 2017.

Managed clinical networks

A stakeholder felt there should be funded and managed clinical networks, to enable equitable access to children's palliative care needs. It was felt this should be built on existing clinical networks, in each region and supported by a statutory sector partner, such as CCGs to give the networks authority and influence. This is not covered within the source guidance and is out of scope for the quality standard.

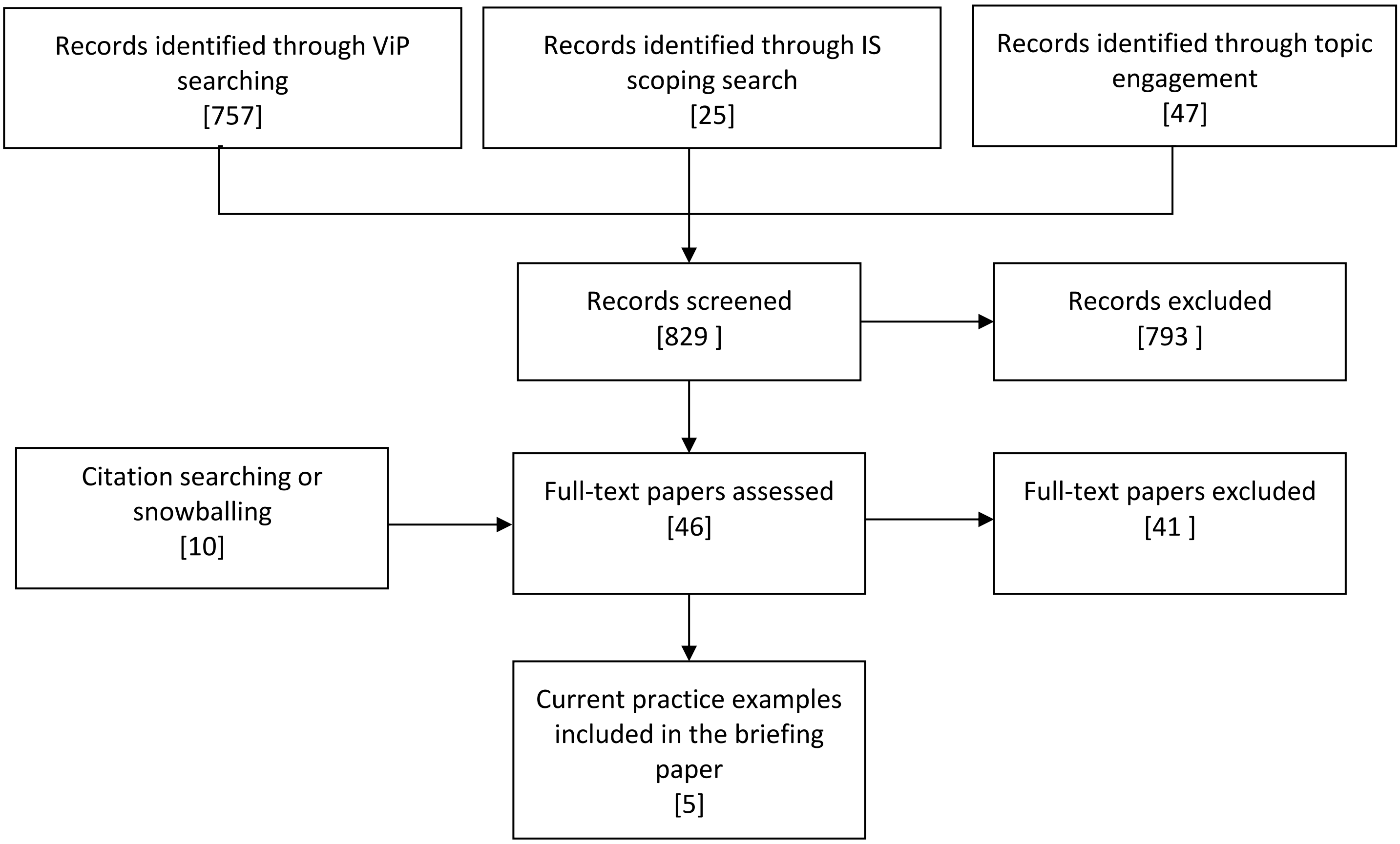
Training for healthcare professionals

A stakeholder felt there is a need for training for healthcare staff on the needs of patients with a learning disability and their families: including communication tools and techniques, together with information and resources for ensuring reasonable adjustments are made where required. Another stakeholder felt there is limited access to specific education for staff on how to support people with profound and multiple learning disabilities and their family carers through bereavement and loss. Quality statements do not usually focus on training. The aim is to identify the actions and interventions that should be the focus of quality improvement. Training would then be one method to help deliver improvement.

Clinical and psychosocial debrief

A stakeholder felt all organisations involved in the death of a child or young people should carry out a thorough clinical and psychosocial debrief to help ensure that lessons are learnt in order to develop and improve practice. This is out of scope for the quality standard.

Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Advanced care planning					
1	Mencap	Key area for quality improvement 1	Ensure families, children and young people affected by life-limiting conditions have good quality, comprehensive information to the services available to them at all stages, from diagnosis to bereavement.	The Together for Short Lives report highlights that the distribution of information for families on the services available to them is often inconsistent. Anecdotal evidence from families with children with complex needs often reflects that they have had to find services themselves, rather than receiving comprehensive information from health and social care staff.	Please refer to: The Big Study for Life-limited Children and their Families: Final research report Together for Short Lives, June 2013 http://www.togetherforshortlives.org.uk/assets/0000/4435/TfSL_The_Big_Study_Final_Research_Report__WEB_.pdf
2	NCD	Proactive parallel planning in all children with life-limiting conditions at point of diagnosis (rather than towards end of life). This would set a precedent for neurologists, fetal cardiologists etc to have those difficult discussions much earlier in the pathway of care than currently occurs. It is this lack of parental/child ‘preparation’ that sometimes leads to unrealistic expectations and criticisms when things ‘go wrong’			Most of the key reports relating to this area are on the Together for Short Lives website. I think the most influential document published in the last 10 years has been Professor Sir Alan Craft’s

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
3	NCD	Adoption of a universal Advance Care Planning document that describes concepts such as 'End of Life medical lead', 'Key worker' and the 'Team around the Child'			
4	NHS England	Involving the child or young person in decisions about care and treatment			
5	NHS England	Recognising when a child or young person is likely to die within hours or days			
6	RCGP	Key area for quality improvement 1	Involving children and young people with life limiting conditions and their parents or carers in decision making and care planning throughout their care.	Involving children and young people is vital to ensure there is as much choice available to the focus of the care and support services. These need to be focused around what is important to the person and those close to them, whether this is place of care, symptom control or decisions around treatment.	The US National Comprehensive Cancer Network recommends that teenagers and young adults are involved in decision making from an early age, given age appropriate information and permission to share it with others offering genuine choices. Check these quality statements are addressed in care plan and CDOP process
7	RCGP	Key area for quality improvement 4	Decisions about care should always consider what it is the best interest of the child or the young person		Check these quality statements are addressed in care plan and CDOP process
8	RCGP	Key area for quality improvement 2	A UK standard written, shared advance care plan should be a core element of a child's or young person's end of life care which prominently records their wishes and preferences.	This should act as a prompt for health care professionals and families as well as being easily recognisable and accessible to health care professionals who are unfamiliar with the children and young people. This plan should be be	Check these quality statements are addressed in care plan and CDOP process

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				available to the Child Death Overview process. At present there are multiple different format care plans that are not recognisable by care staff. There needs to a standard simple format that is recognised by community ,ambulance and hospital staff. Children and young people often travel great distances to regional centres but may die in a local children hospital. Shared care that are recognised at least regionally but preferably nationally is important. The care plans should be vailable and easily produced from Electronic Palliative Care Co-ordination Systems (EPaCCS)	
9	SCM 1	Key area for quality improvement 1 Improve care and support for parents & carers & improved working with parents & carers, especially as child approaches death & following child's death	. There is good evidence that HCPs working in positive partnerships with parents leads to better care for children in their life-times; less stress for children; less stress for HCPs and parents/carers and long-term better outcomes in terms of parents in terms of both mental and physical health following the child's death.	Extent HCPs work with parents & carers & support they get varies patchy England. In worst case scenario HCPs hostile to parents who have different view of child's best interests. Hostility between HCPs distressing to dying child; has negative impact on parents' ability to care for child; parents traumatised which can have long term health, economic & social implications. Also distressing the HCPs	Eg http://jme.bmj.com/content/early/2012/08/24/medethics-2011-100104.short Also my PhD on end of life decision making; conflict with parents cited by consultant paediatricians as the biggest difficulty they face in making end of life decisions. Conflict particularly acute See also http://ascopubs.org/doi/abs/10.1200/jco.2006.10.0743 between PICU consultants and parents
10	SCM 2	All children heading towards EOL should have an Advance Care Plan that is reviewed regularly	Allows us to get the views of child and family to plan care.	NICE guidance	

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11	SCM 3	Consistent use of ACP	Planning enable families to be more in control and make decisions in advance of critical events	Making decisions in a rush can lead to poor decisions	NICE Guideline
12	SCM 4	Key area for quality improvement 2 **Advanced Care Planning for infants, children and young people with life-limiting conditions.**	**Recommendation 1.2.5 of NICE End of Life Care for Infants Children and Young People states that:** Develop and record an Advance Care Plan at an appropriate time for the current and future care of each child or young person with a life-limiting condition. The Advance Care Plan should include… *(see full list of content in recommendation in the guidance)*	At present, there are large areas of the UK (including London) where there is no agreed format for Advanced Care Plans for ICYP that is recognised across all healthcare setting that the ICYP may access, or where Advanced Care Plans currently in use to do not include all the content areas listed in the recommendation. Absence of a comprehensive cross-setting Advanced Care Plans can impact on consistency and coordination of care, ICYP and family wishes not being followed and families being asked to complete different Advanced Care Plans type documentation when they access different services which can be extremely distressing given the sensitivity of the content of an Advanced Care Plans. Absence of comprehensive Advanced Care Plans may also mean that CYP and their families are not given the opportunity to discuss their wishes about some key areas of care.	Unpublished information – I co-chair the London Children's Palliative Care Network (affiliated to Together for Short Lives) and also work clinically in London and from this have awareness of the lack of comprehensive, cross-setting Advanced Care Plans for ICYP. *Please note, here I have used "ICYP" as an abbreviation for Infants, Children and Young People*
13	SCM 4	Key area for quality improvement 5 **Advance Care Planning with parents during the pregnancy if there is an antenatal diagnosis of a life-limiting condition.**	**Recommendation 1.2.6 of NICE End of Life Care for Infants Children and Young People states:** Begin discussing an Advance Care Plan with parents during the pregnancy if	This is a developing area of practice across the UK and there is a need to increase awareness in antenatal screening services, obstetrics services and other midwifery and maternity services about using the NICE Guidance on End of Life Care for Infants, Children and Young People when there is a an	Unpublished information based on communication with the London Neonatal Palliative Care Network *http://www.londonneonatalnetwork.org.uk/neonatal-complex-and-palliative-care/guidance/*

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			there is an antenatal diagnosis of a life-limiting condition. For each individual think about who should take part in the discussion, for example: obstetricians midwives neonatologists specialists in the life-limiting condition a member of the specialist paediatric palliative care team (see recommendation 1.5.4).	antenatal diagnosis of a life-limiting condition. At present, babies are often referred to palliative care services after birth and the opportunity to provide planning, information and access to emotional and psychological support during pregnancy is missed.	*Please note, here I have used "ICYP" as an abbreviation for Infants, Children and Young People*
14	SCM 5	Develop and record and advance care plan	Low to moderate evidence was found to support the impact of this on patient care during the guideline development process. The experience of the guideline committee also strongly supported timely planning	There is wide variation in practice nationally, with numerous different documents in use and limited consensus about the timing and nature of such plans. Available evidence suggests that timely planning supports family / patient choices being achieved at end of life.	See NICE Guidance recommendation on ACP and associated evidence (rec 1.2.5) Example of ACP documents in use: http://cypacp.nhs.uk/ Care planning was a key area identified in the Together for Short Lives work on Outcome Measures: http://www.togetherforshortlives.org.uk/professionals/resources/7968_towards_outcomes
15	Teenage Cancer Trust	Key area for quality improvement 1 Young people should have access to a smooth transition to adult end of life care, evidenced in section 1.2.3 of the guideline.	There is good evidence to suggest that transition is a difficult time for teenage and young adult cancer patients: the situation at end of life is no different. An	Young people report negative experiences of transition through treatment, with less than 50% of children and their families who are preparing for their transition feeling as involved as they would like .	The Department of Health's 2008 report, Better Care, Better Lives, emphasised the need for a better transition process at the end of life.

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			improvement in transition would create a better patient experience.	Transition has to be managed by both paediatric and adult services, something which is not represented in the 2015 NICE guidance, Care of the Dying Adult. This will make it difficult to accurately coordinate services.	
16	The Esoteric Practitioners Association (EPA)	1. Communication	The quality standard is well set on a functional level, taking into account the information sharing, but there is another depth here: the quality in the person sharing the information, their ability to hold the family and patient and allow them the space to express, feel and make choices without imposition. We understand that 55% of communication is body language, 38% is tone of voice (which also comes from our body) and 7% is the actual words spoken. Therefore how we walk into a room, how we open/close doors, move and sit are all integral in other people's experiences. Working with children it is important to be aware of the impact of the quality of our interactions and the way we communicate because our non-verbal signals are received very directly so. Children, maybe more than adults, read these signals	The NHS's 7 Cs (compassion, care, competence, communication, courage, commitment, consistency) are a great theoretical foundation for care; but without supporting carers to develop these qualities, they come across as just another set of rules for staff to have to adhere to. We need to support staff to develop the understanding of these values and to incorporate them in their own lives so that they can be shared with experience. As carers, if we appreciate the fact that children do read between the lines of what we say as it were (all our non-verbal cues and the quality of our presence) and honour it in our interactions with them, the therapeutic relationship can be based on respect and understanding rather than sympathy (an emotion which is generally accepted as positive, but actually puts and keeps the child in a victim or weak position, rather than being empowered by our acceptance, unconditional support, clarity and responsible approach to the situation).	Many professionals feel anxious about communicating about death, being unsure of their own feelings and wobbly about such a sensitive subject. There is an unacknowledged tension and lack of reconciliation around death. Complaints received about end of life care show lack of skills around communication being a key factor. https://www.medicalprotection.org/uk/casebook/casebook-may-2013/we-need-to-talk-about-death-complaints-about-end-of-life-care We need more support within work hours for all those involved with end of life care to discuss, talk, develop understanding and share about death and dying. In an article written by someone living with breast

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			very astutely because they are less intellectualised.	Beyond the careful management of all symptoms and the physical needs of a child who is dying, if we can consider developing our awareness of the emotions we bring to our work - particularly here we have focused on sympathy and its impact - we can then provide the space for the child to be with themselves in the moment, held and supported to come to their own understanding.	cancer the impact of sympathy is clearly outlined http://www.unimedliving.com/living-wisdom/living-wisdom-category/warning-sympathy-hurts-and-can-be-harming-to-your-health.html 'When you communicate with your child, you might choose your words carefully, but most communication is without words.' http://raisingchildren.net.au/articles/body_language_tone_of_voice.html
17	Together for Short Lives	Every family receives disclosure of child's prognosis in face-to-face discussion and is treated with respect, honesty and sensitivity	Sharing the news that a child has a life-limiting condition with a family is undoubtedly one of the most difficult tasks that any professional has to face. However, many parents still report that they are treated clumsily or insensitively and this experience stays with them for a long time. Recommendations 1.1.12 and recommendations 1.1.13 emphasises importance of communication when the life-limiting condition is first recognised.	A BMA survey of doctors (January 2016) found that 'junior doctors and medical students in particular expressed a desire for more training in discussing the end of life and dying with patients'. Many young doctors felt that they were 'thrown in at the deep end' and expected to learn how to have these discussions by experience (p51).	BMA (2016). *End-of-life-care and physician assisted dying*. Available at: https://www.bma.org.uk/collective-voice/policy-and-research/ethics/end-of-life-care

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18	Together for Short Lives	Every child and family should be offered an Advance Care Plan, which is developed together with the multi-disciplinary team and reflects the views of all those that the child and their family deem to be important. This should involve all agencies involved in supporting the child and family and should include an end of life care plan.	Advance Care Plans (ACPs) allow children, young people and their families to communicate their wishes for life and wishes for end of life, alongside management of acute and intercurrent illnesses. They can help families and professionals think about choices at the end of life and set out what actions should be taken when a child develops potentially life-threatening complications. Recommendations 1.25 to 1.2.15 highlight the importance of ACPs. Recommendation 1.2.14 states that 'all children and young people with life-limiting conditions should have an Advance Care Plan in their medical record.'.		[Further research required to evidence this]
Managing pain and agitation					
19	NHS England	Managing distressing symptoms, in particular pain and agitation			
20	SCM 3	Specialist medical advice out of hours	Supports local teams to manage ICYP better	Symptom management can be complex and expert advice is likely to improve this	NICE Guideline
21	SCM 5	Access to specialist paediatric palliative care services - including management of distressing symptoms	Recommendation based on experience and opinion of the guideline committee	There is inequity in access to specialist paediatric palliative care services, and this needs to be addressed on a regional basis. Economic analysis was supportive of this.	Whilst the recommendation was based on opinion and experience of the committee the following article gives some context for the complexity and difficulty in medicating children in their choice of setting at the end of life:

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					Jamieson L, Wong ICK, Craig F, Christensson N, Brombley K, Tuleu C and Harrop E (2016) Palliative Medicines for Children: a new Frontiere in paediatric research, J Pharm Pharmacol. 2016 Oct 13. doi: 10.1111/jphp.12615. [Epub ahead of print] Review. Access to specialist symptom management was also identified in the Together for Short Lives work on Outcomes: http://www.togetherforshortlives.org.uk/professionals/resources/7968_towards_outcomes
22	The Esoteric Practitioners Association (EPA)	4. Non-pharmacological management of symptoms	There is developing awareness of the many ways that symptoms of all kinds (agitation, pain, respiratory distress, anxiety…) can be ameliorated – we know that the patient's immediate surroundings, their dignity, nutrition, the quality of communication and information sharing amongst many other things, all have an impact. What we feel is missing in the guideline and in our observations at work is the implementation of these emergent understandings and the support for a much wider remit of approaches to the management of symptoms.	We know that the efficacy of pain relief is hugely affected by a wide range of factors including the tension, fear, anxiety, cultural experience of the patient, to name but a few. It is important to emphasise the impact of all the non pharmacological interventions. These include the power of touch, relaxation, the quality of our breath, the significance of the setting and environment (lighting, music, temperature, privacy…), how much intervention/support is provided and the way other people interact with us. When considering end of life care, this is not about restoring health, but for	Time stretched and unsupported to develop their understanding and experience of the power of the quality of touch and other non-pharmacological interventions, staff still rely heavily on pharmacological solutions for symptoms. We need to support with and educate staff and carers about the impact of non-pharmacological practices, for them to embrace them as part of the holistic care of an infant, child or young person who is

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				infants, children and young people to have an experience of their situation where they feel empowered, held, supported, heard and understood.	dying. It is hard to deliver it if you have not experienced it. ‘The goal of complementary and alternative medicine (CAM) in professional nursing practice and palliative care aims to reduce suffering and enhance patient comfort, promoting dimensions of healing in the face of life-limiting illness. Complementary and alternative medicine has been around for centuries.’ http://hpna.advancingexpertcare.org/wp-content/uploads/2014/09/Complementary-Therapies-in-Palliative-Care-Nursing-Practice-position-statement-FINAL-0411.pdf In a position statement from The American Massage Therapy Association it was identified that massage relieves pain. https://www.amtamassage.org/statement6.html
Anxiety and depression					

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
23	Royal College of Psychiatrists	Key area for quality improvement 1 Anxiety and depression in children and young people who are receiving end of life care	Anxiety and depression are treatable conditions which can present in children and young people who are receiving end of life care. This may be missed or underestimated because it is expected that they might struggle with their emotions in this context or it may be diagnosed as an adjustment disorder.	Addressing mental health disorders in this context is important because it can be treated by psychological therapies and/or psychotropic medication. Screening tools can be used to support diagnosis	NICE guidelines Depression in children and young people; identification and management Strengths and Difficulties questionnaire

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24	SCM 4	Key area for quality improvement 3 **Emotional and psychological support and interventions for infants, children and young people with life-limiting conditions and their families.**	**Recommendation 1.2.26 of NICE End of Life Care for Infants Children and Young People states:** Provide information to children and young people and their parents or carers about the emotional and psychological support available and how to access it. **The full guidance also recommends:** 71. Be aware that children and young people and their parents or carers may need support, and sometimes expert psychological intervention, to help with distress, coping, and building resilience.72. Be aware that siblings will need support to cope with: their brother's or sister's condition and death; the effects of their parents' or carers' grieving.73. Be aware that other family members (for example grandparents) and people important to the child or young person may need support.	Currently, provision of emotional and psychological support and interventions for ICYP, their family (parents/carers, siblings and wider family) and other people important in their lives varies widely across the UK. In some areas, qualified psychological practitioners and/or psychotherapists are employed within children's palliative care services. Where this is the case there is variation in whether the therapist has capacity to work directly with families or is employed in a consultation capacity to support and advise other health professionals only. In other areas, there is no integrated provision. In areas where psychological support is provided by non-palliative-specialist community mental health services, families may not be able to access early intervention support to build coping and resilience and adults and children will access separately adult and children mental health services and not have coordinated family care.	Unpublished information – I coordinate the national special interest group via the British Psychological Society and my information about variation in service provision comes from mapping exercises we have conducted within the group. *Please note, here I have used "ICYP" as an abbreviation for Infants, Children and Young People*
Severe psychiatric disorder					
25	Royal College of Psychiatrists	Key area for quality improvement 3 Severe psychiatric disorder in child or young person receiving end of life care e.g. psychosis	Children and young people can develop psychotic illnesses co-morbidly or it can be caused by treatment provided for end of life care e.g. the use of high dose steroids.	Clinicians treating these children and young people need to be able to access specialist psychiatric services for children and young people for on site Paediatric Liaison Psychiatry teams who can provide assessment, diagnosis and treatment of psychosis	NICE guidelines Psychosis and schizophrenia in children and young people: recognition and management

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Bereavement support					
26	Childhood Bereavement Network	Support for siblings before the death	The time before a death in the family is often the time of most stress and anxiety for children and young people (Penny and Stubbs, 2015). Siblings may be taking on significant caring responsibilities which impact on their own wellbeing and schooling. Many siblings' daily lives are very affected by the responsibilities within the family. The degree to which children are prepared for a death and have a chance to build positive memories and say goodbye to their sibling varies.	There are examples of excellent practice in support for siblings, both those who qualify as young carers and those who do not, but are very deeply affected by their sibling's condition and treatment. However, these are not universally provided and some siblings needs remain overlooked. Evaluations of this support are currently limited.	VOICES survey could be adapted to collect information on care before and around the death of children and young people. This could include care for the siblings in the family.
27	Childhood Bereavement Network	Support for siblings after the death	Life changes greatly for families following the death, with altered patterns of caring responsibilities and family organisation. Children bereaved of a close family member are at increased risk of a range of negative outcomes across their physical and mental health, education and relationships (Penny and Stubbs, 2015).	Some siblings will manage the impact of the death with the support of their family, friends and school and other networks, but many can benefit from meeting other bereaved children and young people and some will need specialist support. Some siblings can access support after the death from the hospice or palliative care team, others may be supported by a general community child bereavement service if one is available, but some areas lack such a service or there may be a long wait for support.	As above
28	NCD	A re-invigorated discussion with Primary Care colleagues (GPs) regarding their role in the follow-up of bereaved parents			

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29	NHS England	Care and support for parents, carers and siblings			
30	PAMIS	Bereavement and loss education and support for those involved in end of life care for infants, children and young people with profound and multiple learning disabilities.	Currently there is limited access to specific education for staff on how to support people with profound and multiple learning disabilities and their family carers through bereavement and loss. This is a stark inequality and isolates and ignores an already marginalised group of people. A lack of awareness by professionals about chronic sorrow and the impact leads to long lasting negative impact on family carers' health and well-being. Appropriate education has led to better support for both family carers but also for people with a profound and multiple learning disability	Many paid carers and professionals have not received the necessary training or support to enable them to provide appropriate high quality and person centred support to individuals with profound and multiple learning disabilities to enable them to understand bereavement or loss. This is a complex area and may be the reason for a lack of information and education in this area. In addition family carers have reported a lack of empathy and understanding from staff when they lost a child with profound and multiple learning disabilities.	Please see PAMIS Bereavement and Loss resource http://www.pamis.org.uk/_page.php?id=70 and training
31	Rainbow Trust Children's Charity	Key area for quality improvement 1 Families of infants, children and young people who are approaching the end of life are offered a plan for bereavement support in response to their needs and preferences	The NICE guideline on End of Life Care for Infants, Children and Young People includes 5 recommendations related to the provision and planning of bereavement support (recommendations 81-85).	Evidence or information that care in the suggested key areas for quality improvement is poor or variable and requires improvement? There is currently uneven provision of bereavement support, and health and care provided are not sufficiently prepared to handle the complexities of caring for bereaved families. For example, the need for a bereavement	If available, any national data sources that collect data relating to your suggested key areas for quality improvement? Please see the following sources which document uneven access to bereavement support:

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				pathway for parents affected by stillbirth or neonatal death has been recognised by the Department of Health, which has asked the charity Sands to develop a comprehensive bereavement care pathway, in partnership with other charities and experts. The gap in provision was highlighted in a 2016 survey of maternity units by Sands which found that resources for bereavement care in maternity units are insufficient to meet demand in some areas. Of the Trusts and Health Boards that responded to a survey, 38% of the maternity units they cover do not have a specialist bereavement midwife based at them. Bereavement care training is mandatory in only 46% of Trusts and Health Boards. Where this training is mandatory, two thirds carry out training annually, and of those, 86% allocate only an hour or less for training. A separate piece of research found that 17% of clinical commissioning groups and 68% of local authorities do not commission bereavement support at present.	· The need for a bereavement care pathway and improved information about bereavement support is evidenced in 'Beyond Awareness to Action: Tackling baby loss in the UK', All-Party Parliamentary Group on Baby Loss October 2016 www.lullabytrust.org.uk/file/APPG-on-baby-loss---Beyond-Awareness-to-Action-Tackling-baby-loss-in-the-UK-FINAL-WEB-VERSION.pdf · Sands survey 2016 findings in 'Sands briefing for Baby Loss Awareness Week 2016', available at http://www.uk-sands.org/sites/default/files/Parliamentary%20briefing%20BLAW%202016.pdf · For research on the gaps in commissioning of bereavement support see Together for Short Lives survey findings,

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					'Commissioning Children's Palliative Care in England' http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf
32	Royal College of Psychiatrists	Key area for quality improvement 2 Emotional distress and mental health disorders in siblings of children and young people receiving end of life care	Siblings can become distressed and develop mental health disorders in the context of end of life care for a child I their family.	The needs of siblings need to be considered in this situation. Some can be overly involved in their sibling's care, miss out on their education and social opportunities or develop mental health disorders in their own right before or after the death of their sibling.	We are not aware of research or work in this area but primary and secondary care services can be contacted to consider the needs of siblings as well as through education and third sector organisations e.g. Cruise, Seasons for Growth.
33	SCM 4	Key area for quality improvement 4 **Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person from a life-limiting condition: Bereavement Support.**	**NICE End of Life Care for Infants Children and Young People Guidance states:** 1.4.2 When a child or young person is approaching the end of life, discuss the bereavement support available with their parents or carers and provide them with written information. 1.4.3 When a child or young person is approaching the end of life, talk to their parents or carers about available **psychological bereavement support groups**.1.4.4 Offer bereavement support from a professional with **appropriate expertise** to the parents or carers both before and after the death of a child or young person.	Currently there is wide variation across the UK in the provision of bereavement support for different members of the family (siblings, parents, carers, wider family and friends). Psychological Bereavement Support Groups are not available in many areas but are recommended in the guidance. There is wide variation in the expertise of professionals currently providing bereavement support and lack of standardisation or guidance on what constitutes "appropriate expertise". Parents/Carers who accessed children's services for support during their child's life not be able to access these services after their death if there is no longer a child living in the family, so they experience a difficult transition and delay in accessing bereavement support if their care has to be transferred to adult	Unpublished information – information from discussions with national psychology special interest group about coordination of bereavement support after the death of a child with a life limiting condition.

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			1.4.5 When planning bereavement support for parents or carers: talk to them about the support that is available and explore with them what they would find helpful and acceptable.	services if there is no locally agreed bereavement pathway for these families.	
34	SCM5	Access to emotional support for the child and family	Palliative care for children needs to embrace the needs of the whole family. This is not consistently offered.	Based on low to moderate evidence from qualitative studies within the recent NICE guidance.	Background data in this report: http://togetherforshortlives.ouryear.org/ See NICE blog by Stephen Harrison & Paul Nash for extra context The ChISP report outlines a recent assessment of the psychosocial needs of children in Scotland with life limiting illnesses: http://www.chas.org.uk/assets/0001/5573/ChiSP_report.pdf
35	The Esoteric Practitioners Association (EPA)	3. Care and support of carers (family, guardians and professionals)	The care and support of carers has a direct impact on the care and well-being of the patients. The care and support of carers is of paramount importance, preventing ill health for those committed to taking care of others.	Currently we live within a framework of belief that the patient comes first; that our needs are second to theirs and we are congratulated when we put ourselves last. The facts are on the table, this is an unsustainable model. Our NHS is close to collapse as we continue to dismiss the needs and true value of carers.	It is well known that clinicians experience distress and grief in response to their patients' suffering' 'Given the lack of adequate focus on the importance of caring for one's self in the training of future oncologists and palliative medicine physicians, those practicing in these fields should develop a self-care plan.'

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					https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3974630/ ‘At the University of Texas Health Science Center, we encourage physicians to use self-care strategies to maintain personal well-being throughout their professional lives. We also hold self-care rounds twice a month to give the medical staff an opportunity to talk about how their professional lives are affecting their personal lives.’ http://www.ascopost.com/issues/march-25-2015/avoiding-burnout-and-maintaining-well-being-while-caring-for-seriously-ill-patients/ ‘Strong evidence shows that NHS organisations that support the health and well-being of their staff achieve a range of positive outcomes. The level of health and well-being of the workforce is a key indicator of organisational performance and patient outcomes. The evidence makes it clear that cultures of engagement, mutuality, caring, compassion and respect for all - staff, patients and the public -

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					provide the ideal environment within which to care for the health of the nation. When we care for staff, they can provide outstanding professional care for patients.' https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216380/dh_128813.pdf
36	Together for Short Lives	Every child and their family should be asked who is important to them. The social, practical, emotional, psychological and spiritual needs of these people should be assessed and met, including a plan for bereavement support in response to their needs and preferences.	The death of the child is not the end of the care pathway for families. They may experience grief for many years to come and may need support along the way. The NICE guideline on End of Life Care for Infants, Children and Young People includes 5 recommendations related to the provision and planning of bereavement support (recommendations 1.4.2 to 1.4.6). Many children and young people will receive support from a range of people, including siblings, boyfriends/girlfriends, wider family members, or foster carers. Recommendations 1.1.6 and 1.1.7 stipulate that the needs of those important to the child of young person be recognised and they should be supported.	There is currently uneven provision of bereavement support, and health and care provided are not sufficiently prepared to handle the complexities of caring for bereaved families. For example, the need for a bereavement pathway for parents affected by stillbirth or neonatal death has been recognised by the Department of Health, which has asked the charity Sands to develop a comprehensive bereavement care pathway, in partnership with other charities and experts. The gap in provision was highlighted in a 2016 survey of maternity units by Sands which found that resources for bereavement care in maternity units are insufficient to meet demand in some areas. Of the Trusts and Health Boards that responded to a survey, 38% of the maternity units they cover do not have a specialist bereavement midwife based at them. Bereavement care training is	Please see the following sources which document uneven access to bereavement support: · The need for a bereavement care pathway and improved information about bereavement support is evidenced in 'Beyond Awareness to Action: Tackling baby loss in the UK', All-Party Parliamentary Group on Baby Loss October 2016 www.lullabytrust.org.uk/file/APPG-on-baby-loss---Beyond-Awareness-to-Action-Tackling-baby-loss-in-the-UK-FINAL-WEB-VERSION.pdf · Sands survey 2016 findings in 'Sands briefing for Baby Loss Awareness Week 2016', available at

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				mandatory in only 46% of Trusts and Health Boards. Where this training is mandatory, two thirds carry out training annually, and of those, 86% allocate only an hour or less for training. A separate piece of research by Together for Short Lives found that 17% of clinical commissioning groups and 68% of local authorities do not commission bereavement support at present.	http://www.uk-sands.org/sites/default/files/Parliamentary%20briefing%20BLAW%202016.pdf · For research on the gaps in commissioning of bereavement support see Together for Short Lives survey findings, 'Commissioning Children's Palliative Care in England' http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf
Care at home					
37	SCM 4	Additional developmental areas of emergent practice **Service Delivery: Care at Home for infants, children and young people approaching end of life.**	**Recommendation 1.5.10 of NICE End of Life Care for Infants Children and Young People states:** Services should have agreed strategies and processes to support children and young people who are approaching the end of life and are being cared for at home. These services should be based on managed clinical networks, and should collaborate on care planning and service delivery.	There is currently wide variation across the UK in whether strategies are in place across services to enable infants, children and young people to access end of life care at home and there is a need for collaborative working at the strategic level to ensure this is in place for all age groups, including infants which requires involvement of neonatal services in strategic planning.	

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38	Together for Short Lives	Every child and family diagnosed in the hospital setting receives an agreed transfer plan involving hospital, community services and the family	Children and families should be offered, where possible, the choice of being care for at home during their life and their end of life care. Recommendations 1.5.9, 1.5.10 and 1.5.11 stipulate that services should have agreed strategies and processes and paediatric nursing teams for in place for children to be cared for at home.		[Further research required to evidence this]
24/7 Nursing/specialist support					
39	Rennie Grove Hospice Care	All children have access to 24/ 7 specialist palliative / end of life care at home	Children and families can only truly have choice of place of death if service delivery is adequate. By this it needs to be readily available, responsive and of high quality	TFSL freedom of information request from CCGs in 2016 showed that there is little consistency or even understanding of how End of Life Care for children is commissioned.	Together for Short Lives Interactive commissioning map
40	SCM 3	Provision of 24/7 nursing support	Out of hours nursing support enables ICYP to remain at home	Promotes choice of place of care	NICE Guideline

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41	SCM 4	Key area for quality improvement 1 **Care at home for infants, children and young people approaching the end of life**	**Recommendation 1.5.9 of NICE End of Life Care for Infants Children and Young People states that:** For infants, children and young people with life-limiting conditions who are approaching the end of life and are being cared for at home, services should provide (when needed): - paediatric nursing care at any time (day and night) - practical support and equipment for interventions including oxygen, enteral nutrition, and subcutaneous and intravenous therapies Without the provision of this care and practical support, it may not be possible to meet the child and families' wishes for preferred place of care and place of death.	At present 24/7 nursing care in the home is not available/cannot be arranged at short noticed in many regions/areas. Absence of 24/7 nursing care impacts on the provision of multiple practical interventions in the home which can only be provided by qualified nurses or doctors. Together, this prevents many infants, children, young people and their families from being offered real choice about preferred place of care and death at end of life.	See the Together for Short Lives "round the clock care" campaign http://www.togetherforshortlives.org.uk/news/8709_seriously_ill_children_need_care_around_the_clock
Named worker					
42	Mencap	Key area for quality improvement 2	Children and young people with a life limiting condition should have a named contact to co-ordinate their health and social care. The Together for Short Lives report shows that where families had access to a named individual to contact they reported a better experience of EOL services.	People with complex and/or multiple needs will often be in contact with multiple members of staff. Communication can be poor between health care professionals, leading to strain on families who have to repeat information and bear responsibility for information sharing. This can also impact on the quality of care provided as clinicians have limited time to spend with patients.	Please refer to: Living and Dying With Dignity Report, Mencap, (2008) http://socialwelfare.bl.uk/subject-areas/services-client-groups/adults-disabilities/mencap/1488752008_living_dying_dignity.pdf

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			The CIPOLD report recommended people with complex and/or multiple health conditions should have access to a named health care co-ordinator.	People with a learning disability consistently report that it is helpful to have a single contact who knows their needs and can offer appropriate communication support in healthcare settings.	The Big Study for Life-limited Children and their Families: Final research report, Together for Short Lives, (2013) http://www.togetherforshortlives.org.uk/assets/0000/4435/TfSL_The_Big_Study_Final_Research_Report__WEB_.pdf Confidential Inquiry into the Premature Deaths of People With Learning Disabilities (2013) http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf
43	RCGP	Key area for quality improvement 3	Name a medical specialist who leads on and coordinates the child or young person's care	Continuity of care is essential for end of life care	Check these quality statements are addressed in care plan and CDOP process
44	SCM 3	Consistent multidisciplary team working	This ensures all professionals are up to date, and involved in planning care	Promotes a more holistic view of child and family, and results in better coordination	NICE Guidelines
45	Together for Short Lives	Every family receives a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition and should have their needs reviewed at appropriate intervals	The needs assessment forms the introduction to the care team which will play a central co-ordinating role. It provides an opportunity for the child and family's hopes, wishes and concerns to be heard and for their full range of needs to be explored. Recommendation 1.2.5 states that Advance Care Plans should record the child or young person's ambitions and wishes, for		[Further research required to evidence this]

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			example on ‘family and relationships’, ‘social activities’ and ‘education’ etc.		
Access to level 4 consultant					
46	NCD	24/7 Consultant Palliative Care provision within regional hospices			
47	SCM 2	Every EOL child should have access to a Level 4 Paediatric Palliative Medicine Consultant	EOL can be complicated and other doctors are often uncertain of how to manage children who are EOL	In NICE and TfSL guidelines	
Additional areas					
48	[Royal College of Nursing]	Key area for quality improvement 1 There should be (funded) managed clinical networks, to enable equitable access to children’s palliative care needs, building on the existing clinical networks, in each region, supported by a statutory sector partner, such as CCGs or tertiary centre to give the networks authority and influence.	Most regions in England have children's palliative care clinical networks, often set up with support from the then Strategic Health Authorities (SHAs) and after the 2010 reorganisations, some continued to be supported by the Strategic Clinical Networks (SCNs). That has also ended now. Despite this, the clinical networks have had considerable impact on the standard and equity of care available for children with palliative care needs. Royal College of Paediatrics and Child Health (RCPCH) (2012) describes a clinical network as a linked group of professionals working in a coordinated manner, unconstrained by existing and professional boundaries, to ensure equitable provision of high quality, clinically effective	The Scottish Office (1999) and National Service Framework for Children (2004) state that a managed clinical network allows whole pathway for the child to be delivered by a number of NHS organisations and partner agencies working together in an integrated management structure with clear governance arrangements. RCPCH (2012) suggests a funded managed clinical network has a more formal management structure to support the delivery of care, to have defined objectives and to have a clear governance framework. They acquire authority and influence. Cancer, Cardiac and Stroke Networks have demonstrated working in collaboration can be a successful method to improve services in order to improve outcomes for service users. Diabetes UK says that managed networks can deliver high-quality, cost-effective care through	RCPCH (2012) The Way Forward: Strategic Clinical Networks http://www.rcpch.ac.uk/node/570/system/files/protected/page/Implementing%20Networks%20in%20the%20new%20NHS%207%204%2011.ppt

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			services. To further develop high standard equitable care across all settings and to implement the recommendations of the NICE guidance, the networks need the authority of managed clinical networks. Those networks in Scotland and Wales already have access to this authority, whilst East of England has a Managed Clinical Network (MCN). All the networks should be equal in this authority. We would want groups of CCGs to join together to commission regional children's palliative care managed clinical networks to give the existing clinical networks authority and governance as well as the funding to become a managed network by employing a network manager and some admin support and other costs.	effective commissioning, organisation and monitoring of services. This calls for having in place the right commissioning structures, effective procedures and clear channels of communication through working in active partnerships through managed networks funded by commissioners from groups of Clinical Commissioning Groups (CCGs) to give them authority and influence.	
49	[Royal College of Nursing]	Key area for quality improvement 2 **There needs to be clarity and commissioning of services for those diagnosed aged 16years and 17years, as well those already diagnosed who need to move up to adult services.**	There is good evidence that planned and coordinated care of children aged 16 to 17 year olds who fall between adult and children's services is important to ensure that they do not fall between services or be missed out. This is particularly important for end of life care for this group of people, their parents and families.	NICE guidance recommends effective management of the transition from children's to adults' services. However, we are aware that currently, there is variation in the implementation of the NICE guidance, particularly in applying the overarching principles of transition. At present these young people often fall between services, being too old for children's wards and children's community nurses, but not old enough for adult district nurses or physicians for	NICE NG61: End of life care for infants, children and young people with life-limiting conditions: planning and management https://www.nice.org.uk/guidance/NG61/chapter/Recommendations#advance-care-planning NICE NG43: Transition from children's to adults' services

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				example after being in adult ITU. .They need expert, high quality, commissioned services as every age group does, but often have no services and depend on the goodwill and hard work of the paediatrician. They need expert treatment and support from the moment of diagnosis (Teenage Cancer Trust).	for young people using health or social care services https://www.nice.org.uk/guidance/ng43 Transition from children's to adults' services https://www.nice.org.uk/guidance/QS140
50	Mencap	Key area for quality improvement 3	Training for healthcare staff on the needs of patients with a learning disability and their families: including communication tools and techniques, together with information and resources for ensuring reasonable adjustments are made where required.	Patients with a learning disability experience barriers to accessing health care services. Diagnostic overshadowing and communication difficulties can prevent diagnoses and treatment occurring in a timely manner. The CIPOLD report documents failures to make reasonable adjustments in a significant number of cases, alongside delays in treatment and diagnosis. As a corollary there can be delays in referral to palliative care for patients with a learning disability, sometimes stemming from a lack of awareness of the needs of a person with a learning disability. Healthcare professionals are not always trained in how to communicate effectively with a person with a learning disability. Family members frequently report feeling 'shut out' of decision making processes and not listened to by decision makers.	Please refer to: Confidential Inquiry into the Premature Deaths of People With Learning Disabilities (2013) http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf Death by Indifference: 74 Deaths and Counting, Mencap (2012) https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf

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51	Mencap	Key area for quality improvement 4	Decisions about life sustaining treatment must be made objectively without judgement on the quality of a person's life based solely on their disability. Training for healthcare professionals must reflect the potential for meaningful lives and relationships for children with a learning disability and complex health needs.	Deaths of patients with a learning disability can be seen as 'inevitable' or 'expected' (Learning, candour and accountability, CQC, 2016). This may mean that decisions made in the patients 'best interests' to withhold or deny treatment are clouded by prejudice and pre-existing notions of negative outcomes for people with a learning disability.	Please refer to: Learning, Candour and Accountability, CQC (2016) https://www.cqc.org.uk/content/learning-candour-and-accountability Death by Indifference: 74 Deaths and Counting, Mencap (2012) https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf
52	NCD	Provision of 'spot' commissioning to enable children at end of life to be discharged home to die. This requires rapid access funding to provide key workers and skilled community nursing to operate at short 24h notice. Currently It is almost impossible to get a child home to die because a) the resources don't exist in the community and b) where they do, it is very difficult to uplift the funding to provide 24 hr care			

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53	NCD	Creation of national Standards for Bereavement Care to include a service specification, validated training, and commissioned pathways of support			
54	RCGP	Key area for quality improvement 5	All organisations involved in the death of a child or young people should carry out a thorough clinical and psychosocial debrief to help ensure that lessons are learnt in order to develop and improve practice.	Children and young people can the potential to severely affect staff who may struggle to continue care of other patients and them selves. Support should be available within the organisation	
55	Royal College of Paediatrics and Child Health is submitting comments on behalf of the following members: dr. Eugen Strehle, Consultant Paediatrician	Key area for quality improvement 1	Whole document	Our commenter has advised that they are satisfied with the content of the overview document for this quality standard.	

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56	SCM 1	Key area for quality improvement 2 Parity of care for disabled children, particularly those with severe physical or learning disabilities, with life limiting conditions.	Report after report has shown that disabled children & their families with life limiting conditions face barriers to accessing parity of care in many parts of UK & families face lack of support following child's death	Providing less than optimum care intentionally or otherwise as a result of a child's disability is unlawful and in breach of HCPs' professional codes of conduct. Disabled children receiving less than optimum care causes great distress to the children; their families and to HCPs. At the extreme it can contribute to premature death of child. It also has significant financial and morale implications for the health services if investigations and litigations result from poor health care, as well as causing considerable avoidable stress to families.	For example:- http://www.ncepod.org.uk/cn.html Also http://www.cqc.org.uk/content/learning-candour-and-accountability And https://www.disabilitymatters.org.uk
57	SCM 2	Health care professionals should have access to 24/7 telephone support from specialist in PPC	Part of government policy. Will reduce unnecessary admission to hospital	Government policy which is now being implented particulalry in adults.	
58	Teenage Cancer Trust	Key area for quality improvement 2 Young people should be able to receive care from specialised staff at the end of life, as seen in section 1.1.9 of the guideline.	Staff should have the skills to communicate age-appropriate information with children and young people.	Children and young people require age-appropriate information: staff should have the necessary skills to create open, frank and honest discussions with the young person and their families, creating a better experience and environment .	Please see the following for examples of the need for specialised communication: Dr Anne Grinyer, and Zephyrine Barbarachild, Teenage and young adult palliative and end of life care service evaluation, 2011 Together for Short Lives: A Guide to End of Life Care, 2012
59	The Esoteric Practitioners Association (EPA)	2. Self Awareness	Self awareness is important because our relationship with ourselves affects everything we do, say, think and feel.	We need to be more aware of, and honest about, what we feel about certain cultural beliefs, religious rules, social expectations, hidden opinions and	This is a level of awareness that is not sought in society. We accept a level of function that does not challenge our

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			If we do not take responsibility for ourselves we are potentially imposing our behaviour on others without consideration. It is a simple formula: the more developed our self-awareness the more able we are to be sensitive to others.	reactions and the impact these have on the way we communicate with others, often without us realising. We need to be more alert about what we carry - those insidious habitual reactions – that affect us and those around us every day. We need to provide training and support for professionals to explore and articulate their belief systems in the absolute understanding that they do affect our every interaction. Beyond function and box ticking (the compulsory Equality and Diversity updates) to deepened awareness and honesty about our ingrained prejudices.	deeper more hidden prejudices and beliefs. 'Stereotyping patients according to their age, race, weight, socioeconomic status, gender or other factors can have negative impacts on their health, according to new research.' '…patients who feel judged by healthcare workers are less likely to follow medical instructions and more likely to mistrust their doctors and other healthcare providers.' http://www.fiercehealthcare.com/healthcare/healthcare-stereotyping-can-negatively-affect-patient-outcomes 'It's time for us to implement policies that enhance medical school training in cultural competency and increase the diversity of our physicians and broader health care workforce.' http://www.medicaldaily.com/group-stereotypes-negatively-impact-health-care-prejudice-leaves-some-patients-358082

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60	Together for Short Lives	(Funded) Managed Clinical Network for children's palliative care	There should be (funded) managed clinical networks, building on the existing clinical networks, in each region, supported by a statutory sector partner, such as CCGs or tertiary centre to give the networks authority and influence Most regions in England have children's palliative care clinical networks, often set up with support from Strategic Health Authorities, then, after the 2010 reorganisations, some continued to be supported by the Strategic Clinical Networks. That has also ended now. Despite this, the clinical networks have had considerable impact on the standard and equity of care available for children with palliative care needs but are hindered by their lack of authority and influence. RCPCH (2012) describes a clinical network as a linked group of professional working in a coordinated manner, unconstrained by existing and professional boundaries, to ensure equitable provision of high quality, clinically effective services. To further develop high standard equitable care across all settings and to implement the recommendations of the NICE guidance, the networks need the authority of managed clinical	The Scottish Executive (1999) and National Service Framework for Children (2004) state a managed clinical network allows whole pathway for the child to be delivered by a number of NHS organisations and partner agencies working together in an integrated management structure with clear governance arrangements. RCPCH (2012) suggests a funded managed clinical network has a more formal management structure to support the delivery of care, to have defined objectives and to have a clear governance framework. They acquire authority and influence. Cancer, cardiac and stroke networks have demonstrated working in collaboration can be a successful method to improve services to improve outcomes for service users (Diabetes UK, 2013). Cancer networks have raised standards, supported easier and faster access to services and encouraged the spread of best practice (Muscular Dystrophy UK). Diabetes UK says that managed networks can deliver high-quality, cost-effective care through effective commissioning, organisation and monitoring of services. That calls for having in place the right commissioning structures, effective procedures and clear channels of communication through working in active partnerships through managed networks funded by commissioners from groups of CCGs to give them authority and influence.	RCPCH (2012). Bringing Networks to Life - An RCPCH guide to implementing Clinical Networks. Available at: http://www.rcpch.ac.uk/system/files/protected/page/Bringing%20Networks%20to%20Life%20for%20web_0.pdf Scottish Executive (1999). MEL(1999)10: Introduction of managed clinical networks within the NHS in Scotland. Available at: http://www.sehd.scot.nhs.uk/mels/1999_10.htm DH (2004). National Service Framework for Children, Young People and Maternity Services. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199952/National_Service_Framework_for_Children_Young_People_and_Maternity_Services_-_Core_Standards.pdf Diabetes UK (2013). Service Improvement Delivery. Implementing Local Diabetes Networks. Available at: https://www.diabetes.org.uk/Documents/Reports/implementin

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			networks. Those networks in Scotland and Wales already have access to this authority. All the English regions need networks should have equal authority and influence to expand their impact to all.	Therefore, Children's Palliative Care Managed Clinical Networks, in partnership with a statutory body, whether CCGs or others (such as the emerging STPs), would have the authority to influence equitable and high standard palliative care as recommended by NICE, in all areas.	g-local-diabetes-networks-0113.pdf RCPCH (2012) Bringing Networks to Life. An RCPCH Guide to Implementing Clinical Networks. Available at: http://www.rcpch.ac.uk/system/files/protected/page/Bringing%20Networks%20to%20Life%20for%20web_0.pdf Muscular Dystrophy UK (2015). Managed Clinical Neuromuscular Networks. Available at: http://www.musculardystrophyuk.org/app/uploads/2015/10/Managed-Clinical-Neuromuscular-Networks-Guide.pdf Further evidence is available in the NICE Evidence Search: https://www.evidence.nhs.uk/Search?q=managed+clinical+networks
61	Together for Short Lives	General comment	The recommendations made in the guidance require commissioners to recognise and commission the range of services that children with life-limiting and life-threatening conditions rely on.		Together for Short Lives (2016). Commissioning children's palliative care in England. Available at: http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_pallia

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			However, Together for Short Lives' research shows that many local areas are failing to commission these services. There is also huge national variation, for example: • Just 73% of CCGs commission community children's nursing teams out of hours. • 18% of CCGs and 82% of local authorities do not commission hospice services. • Only 37% of CCGs commission out of hours community paediatrics.		tive_care_in_England_FINAL.pdf