NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

End of life care for infants, children and young people

Date of quality standards advisory committee post-consultation meeting:
8 June 2017.

2 Introduction

The draft quality standard for End of life care for infants, children and young people was made available on the NICE website for a 4-week public consultation period between 18 April 2017 and 16 May 2017. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 33 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to the NICE local practice collection on the NICE website. Examples of using NICE quality standards can also be submitted.

4. For draft quality statement 2: Can stakeholders suggest who the medical specialist should be?

5. For draft quality statement 4: Can stakeholders suggest how performance would be measured in practice? Are there specific symptoms or timescales that would be more suitable as the focus of quality improvement?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Stakeholders generally felt the draft quality standard covered the key areas for quality improvement.
- Stakeholders highlighted the terms young adults and young people are used interchangeably throughout the document and requested some consistency.
- Stakeholders highlighted the statements currently refer to district nurses which should be changed to community children's nurses.
- Stakeholders felt key workers should be referenced within the quality standard.

Consultation comments on data collection

- Stakeholders commented that the complexity of data sharing between organisations and across sectors would need to be addressed at a national level.
- The need for agreed national definitions to ensure reliable data collection was highlighted.
- Stakeholders highlighted that data collection around end of life care varies by region.

Consultation comments on resource impact

- Stakeholders commented there may not be sufficient resources in place to deliver the quality statements and greater investments in palliative care are needed.
- However some stakeholders believed that some of the statements were deliverable.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- This is an important area of care.
- Currently there is no fixed standard template for advance care plans.
- Not all families may want an end of life care plan and in some cases they may not be appropriate e.g. children treated with curative intent at point of diagnosis.
- Recognising the specific issues regarding young people developing their own advance care plan should be highlighted within the supporting information.
- It was commented that education settings and ambulance trusts should be included as examples within the audience descriptors.
- The need to include infants throughout the supporting information was highlighted.
- There should be reference to the fact that an advance care plan is usually developed following a number of discussions and is not a singular activity.
- The need for staff training to ensure discussions with patients, families and carers are carried out correctly.

5.2 Draft statement 2

Infants, children and young people with a life-limiting condition have a named medical specialist who coordinates their care.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- Some commented that this should be expanded to reference a more general key worker. Others felt these functions would not be provided by one individual but instead by a range of appropriate specialists?
- References to neonatal care should be added to the statement and supporting information.
- Services should be local to the children and young person's home.
- This may already be being collected via HES.
- Resources are already in place for this statement to be implemented.

Consultation question 4

Can stakeholders suggest who the medical specialist should be?

Stakeholders made the following comments in relation to consultation question 4:

- The named medical specialists were: a specialist in the child's underlying condition, the lead consultant paediatrician, Community paediatrician, Palliative care consultant, hospice medical lead, GP.
- Other comments highlighted the named medical specialist would depend on the underlying life limiting/ life threatening condition and the person may change as the patient moves through the care pathway.

5.3 Draft statement 3

Children and young people with a life-limiting condition are given information about emotional and psychological support and how to access it.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- This is currently a major area for improvement.
- Emotional support is best delivered alongside support to parents, siblings, and carers.
- Emotional and psychological support needs to be defined within the supporting information.
- Should be rephrased to say that children and young people are ‘given access to support’ rather than ‘given information’.
- Some children e.g. those with learning difficulties, may not be able to understand information provided to them unless tailored to their needs. Another stakeholder added that the information provided needs to contain age appropriate information for the patient.
- Existing data could potentially be used to monitor referral patterns to emotional and psychological support services.
- Currently resources are not in place to support this.

5.4 Draft statement 4

Infants, children and young people approaching the end of life have any unresolved distressing symptoms assessed by the specialist paediatric palliative care team.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- An agreed definition of “unresolved” distressing symptoms is a key component of this statement.
- This should be expanded to include low mood and anxiety.
- A clear definition of specialist paediatric care team was requested.
- Currently there are not enough specialist paediatric care teams available.

Consultation question 5

Can stakeholders suggest how performance would be measured in practice? Are there specific symptoms or timescales that would be more suitable as the focus of quality improvement?

Stakeholders made the following comments in relation to consultation question 5:

- Stakeholders could not provide a definitive definition of distressing symptoms and how this could be measured.

5.5 Draft statement 5

Parents or carers of infants, children and young people approaching the end of life are offered bereavement support when their child is nearing the end of their life and after their death.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- This should refer to grief and loss support rather than bereavement support.
- The statement also needs to include siblings who would also benefit from bereavement support.
- A clear definition of bereavement support was requested.
- The process of bereavement support should begin from the point of diagnosis.
- There is a lack of funding currently available for bereavement support.

5.6 Draft statement 6

Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care.

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- This should promote greater choice for children and young people as 24 hour access to nursing care is not always available.
- Should a consultant in paediatric palliative care should be specifically referenced within the statement or could this care could be provided by another individual?
- A reference to ambulance trusts should be included within the supporting information.
- It was felt that the measures for this statement are currently feasible.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Short breaks (respite) for children and young people and their parents.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	Birmingham Children's Hospital	General	Overall, this Guidance focuses on the childhood population and does little to improve / address any issues specific to the TYA population, even though there is 'blurring of boundaries' for health care provision, especially in the 16-18 age group.
2	British Psychological Society	General	It is, perhaps, useful to note that Scottish Government guidance and policy does address the issues of care coordination and supporting families to identify and access services. Getting It Right For Every Child (GIRFEC) http://www.gov.scot/Topics/People/Young-People/gettingitright/publications/practice-guide – the approach set out to improve services for children and young people – includes the Named Person and Lead Professional roles. The role of the Named Person is to listen, advise and help a child or young person and their family, providing direct support or helping them to access other services. They can help families address their concerns early and prevent situations becoming more serious. Lead Professionals are for those families using services across two or more agencies. The Framework for the Delivery of Palliative Care for Children and Young People in Scotland (Scottish Children and Young People's Executive Group, 2012) identified that the adoption of a GIRFEC approach as a key outcome for palliative care for babies, children and young people in Scotland. Furthermore, GIRFEC underpins the recent Children and Young People (Scotland) Act 2014 which is placing statutory requirements on services regarding the way they support children with additional needs, including those with palliative care needs, and their families." (CHiSP Report, 2015) https://www.chas.org.uk/assets/0001/5573/ChiSP_report.pdf; A Matter of Life and Death, The Psychologist, vol 28 no 12 December 2015.
3	British Psychological Society	General	There are gaps in terms of services currently available versus what would be needed – staff resources would be required to achieve the quality of care indicated by the guidelines. Structurally, there would be a need for organisation and co-ordination of various clinical teams to meet, share information and plan together, which could be time intensive. There would need to be a review of staffing to ensure sufficient trained mental health professionals who can support, train, supervise, consult to other key professionals in EofL care, and who can provide direct therapeutic input for more complex cases.

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[1] PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments[1]
4	British Psychological Society	General	With regards to the resources needed to deliver this kind of quality care we believe there would need to be additional resource with significant cost implications to increase staffing in 3 main areas: 1. Access to appropriately trained mental health professionals who can either provide input directly to CYP and their families or provide training and regular clinical supervision to key professionals who may be offering this support as part of their role. 2. A requirement for administrative and data manager support in order to ensure that all data points are both collected and audited regularly. 3. Clinical governance structures would be required to be in place (such as multidisciplinary team meetings/ care planning meetings) where the holistic needs of the family are discussed, plans of care agreed/ reviewed and referral to appropriate support services made. This will be resource heavy in terms of personnel attendance and therefore would need to be accounted for when thinking about overall workload/capacity within a team.
5	British Psychological Society	General	The Society believes that overall these standards are the right markers of quality improvement and welcomes this acknowledgement. We think this is especially the case when addressing support post bereavement. We also think that access to a specialist palliative care team is essential and would agree with the definition of such. We think there needs to be greater clarity and guidance about how the relationship between the specialist team, local team and other health care professionals involved with the family is negotiated and documented. It would be helpful to have further guidance on the pathway and timing of referral/transfer between specialist palliative care teams, local teams and any professionals involved – how this is to be managed and documented.
6	British Psychological Society	General	There is currently nothing in the document acknowledging the needs of siblings, and the need to link in with education systems around both the sick child and the siblings. It may be helpful to have some way of recording whether the needs of the wider family have been assessed and the multiple systems of care surrounding a child have been considered/communicated with.
7	Children's and Young People with Cancer Clinical Reference Group	General	Whilst all the statements reflect the areas for quality improvement there seems to be little acknowledgement of the difficulties faced by patients, carers, and clinical and support services for those who are some distance from the PTC. Community nurses often play a larger part in the care when the patient is at home, and are often the only support for parent or siblings too. Not all GPs appear to be confident in supporting the care at home, whilst some are superb. POONs by the nature of distance often only able to give support when local to PTC This Quality Standard could face difficulties in its implementation, despite the very specific need. The collection of data from all the relevant services despite being difficult to access at times must be encouraged to promote progress. This information must be given in the proper way. A difficult ask at times for those not close to or in their PTC. There are instances of families being sent a general letter from the consultant to all involved discussing palliative care for the patient. This needs to be addressed and care taken that the matter has been discussed beforehand. Also giving the opportunity for choice.

ID	Stakeholder	Statement number	Comments[1]
8	Church of England: Mission and Public Affairs Council	General	Overall, we welcome this Draft Quality Statement though we believe that it is essential that it is strengthened to reflect the NICE Quality Standard for End of Life Care for Adults (2011) with regard to religious and spiritual care provision. The spiritual and religious needs of all age groups and their families and carers ought to be met as fully and as consistently as possible in all care settings. Children and young people have as wide a range of religious and spiritual care needs as adults. The needs of their families and carers are equally significant. In particular the requirements of **Quality statement 6: Holistic support – spiritual and religious** of the **Quality Standard for End of Life Care for Adults** ought to be reflected fully in the Quality Standard for End of Life Care for Infants, Children and Young People. **The Quality Standard for End of Life Care for Adults, Quality statement 6: Holistic support – spiritual and religious** states**:** ***'Quality statement*** *People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.* ***Quality measure*** ***Structure:*** *a) Evidence of local access to a range of spiritual care providers for people approaching the end of life, either in-house or through referral to appropriate providers in the community.* *b) Evidence of availability of local chaplaincy services in accordance with NHS chaplaincy: meeting the religious and spiritual needs of patients and staff Department of Health 2003* ***(This document has been superseded by 'NHS Chaplaincy Guidelines 2015: Promoting Excellence In Pastoral Spiritual and Religious Care)****.* ***Process:*** *Proportion of people identified as approaching the end of life who receive spiritual and religious support in accordance with their care plan.* *Numerator – the number of people in the denominator receiving spiritual and religious support in accordance with their care plan.* *Denominator – the number of people identified as approaching the end of life.* ***Outcome:*** *People approaching the end of life feel satisfied with the spiritual and/or religious support they have been offered and/or received.* ***What the quality statement means for each audience*** ***Service providers*** *ensure that systems are in place to offer, facilitate and provide (including sign-posting and referral) spiritual and religious support to people approaching the end of life that is appropriate to the person's needs and preferences.*

ID	Stakeholder	Statement number	Comments[1]
			Health and social care workers *offer, facilitate and provide (including sign-posting and referral) spiritual and religious support to people approaching the end of life that is appropriate to the person's needs and preferences* . ***Commissioners*** *ensure they commission services with adequate provision for offering, facilitating and providing (including sign-posting and referral) spiritual and religious support to people approaching the end of life that is appropriate to person's needs and preferences.* ***People approaching the end of life*** *are offered spiritual and/or religious support appropriate to their needs and preferences.'* We believe that it is essential that infants, children and young people and their families and carers are given the same level of support as adults. The simplest and most effective way of achieving this is to add a new Quality Statement to the six existing on the draft Quality Standard, replicating the above Quality Statement for adults (with changes to wording made to reflect mental capacity issues, when appropriate).
9	CLIC Sargent	General	CLIC Sargent welcomes the opportunity to comment on the draft Quality Standard on end of life care for infants, children and young adults. We are committed to reducing the impact that cancer has on young lives and their families, this is at no time more important than when young lives are faced with palliation and end of life care. There is only one time to get this right for each individual child, young person and their loved ones. We support all six of the Quality Statements and believe that these accurately reflect the areas for quality improvement in this area; however, we have identified some areas where we believe there will be challenges in delivery, implementation and monitoring of these Quality Statements.
10	CLIC Sargent	General	We believe that there is a challenge in the ability for local services to achieve each of these quality standards given the net resources needed to deliver them and would specifically flag concerns around the paediatric nursing workforce. Together for Short Lives' 2017 report into 'The state of children's palliative care nursing' highlighted the ongoing shortage of qualified nurses providing children's palliative care in the voluntary sector, suggesting that there is an increasing shortage of experienced nurses to care for children with rare and complex health conditions. Whilst GPs and district nurses are mentioned throughout the Quality Standard as being appropriate health professionals to deliver these standards, we would have concerns about this workforce alone being confident in managing paediatric palliative care for cancer patients, event with outreach support from specialists at the centre. There is also an issue in that district nurses will rarely deal with any patients under the age of 18.

ID	Stakeholder	Statement number	Comments[1]
11	CLIC Sargent	General	We also believe that the timely implementation of this Quality Standard is a challenge. From our experience of the implementation of NICE guidance for children with cancer, this required considerable time and support from all sectors and cancer peer reviews to ensure it was properly implemented. These systems are no longer in place due to cuts to peer review teams, and we are concerned about the extent to which this will impact the implementation of this quality standard.
12	CLIC Sargent	General	We believe that data collection on these Quality Statements will be absolutely vital in developing a baseline and seeing progress in these areas. An issue with data relating to children and young people with cancer specifically is the accessibility of data from statutory services to enable analysis. Access to data on these Quality Statements will be vital in analysing where improvements can be made and assessing performance.
13	CLIC Sargent	General	Wherever possible, we believe that young lives and families should be given information by trained, skilled professionals, so they are aware of the choices available to them; and those that are not. Information should be available in a range of formats and language, including digitally. A professional should also check an individual's understanding of the information provided.
14	Demelza Hospice Care for Children	General	Demelza Hospice Care for Children has been consulted and has inputted into the submission from Together for Short Lives (TfSL). We are fully in support of that consultation response, which is on behalf of children's hospices and children's palliative care organisations in general. Our response focusses on areas where Demelza Hospice Care for Children has a particular interest/expertise.
15	Department of Health	General	**I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.**
16	Helen and Douglas House Hospices for children and young adults	General	Overall, we feel that if the number of quality standards is limited to 6, those proposed do indeed represent important areas for quality improvement and we welcome them.
17	Helen and Douglas House Hospices for children and young adults	General	Question 2: Data Collection: Collecting the data should be technically possible going forwards, although the systems are patchy and would not yet in place for some settings, areas and standards. It could be a particular challenge across multiple sectors (statutory and voluntary) and settings, and not always economically practical. The data could give a good indication of ***quality***. Identifying appropriate '***outcome measures'*** for palliative and end of life care in this age group remains a challenge.
18	Helen and Douglas House Hospices for children and young adults	General	Question 3: Resources and services needed: This is a real challenge. Sadly I don't think the statements would be achievable by local services as currently funded or available in many parts of the country. Paediatric and young adult palliative care is already hugely reliant on voluntary sector providers, and a relatively small proportion of the costs involved are met by statutory services. The quality standards are admirable and to be welcomed, but will need greater statutory investment to be achievable. This needs to be recognised and addressed.
19	Helen and Douglas House Hospices for children and young adults	General	Although the guidance has 'infants, children and young people' in its title, can it be highlighted somewhere in the quality standards that this needs to start antenatally (e.g. from antenatal diagnosis of a life limiting condition) in some cases. This most obviously applies to advance care planning (statement 1).

ID	Stakeholder	Statement number	Comments[1]
20	Helen and Douglas House Hospices for children and young adults	General	Bizarrely the title page is headed 'End of life care for infants, children and young adults': surely this should be 'young people', to fit with the title and scope of the main NICE guidance?
21	Leeds Teaching Hospitals NHS Trust	General	The majority of these statements will be hard to measure because of the difficulty in quantifying the denominator in many organisations. In a hospital such as ours, with many different specialities, we would not be able to provide a figure for the number of infants, children and young people with life limiting conditions. The 'definition' in the guideline (*Conditions that are expected to result in an early death, either for everyone with the condition or for a specific person)* is broad, and patients are under the care of many different specialities and teams.
22	Mencap	General	Mencap were pleased to see the recognition of the support that both children, young people and their parents may require to understand information. This was included in Quality Statement 5: Emotional and Psychological Support for Parents or Carers, Quality Statement 3: Emotional and Psychological Support for Children and Young People. We would recommend that this is extended to all quality standards, including those concerned with creating support plans, as required by the Accessible Information Standard. We would also like to see the need for emotional and psychological support for siblings in the quality statements. At present, the quality standards ask for support to be "accessible, as far as possible" to people with learning disabilities. In context of the rest of the guidance, we ask that this is changed to, "accessible to people with learning disabilities, ensuring reasonable adjustments and specialist support are provided to allow individuals to both understand information and be involved in decision making to their maximum potential. Whilst support to understand information is vital, we would also like the quality statements to be explicit in their requirement for services to also support children, young people and parents with a learning disability to be supported to be involved in making decisions about the planning and delivery of care. This support may be provided through reasonable adjustments to existing services or through the provision of specialist services, or advocacy support, where necessary. We also recommend that commissioners and providers ensure they have good quality training in the needs of people with a learning disability to enable to them to plan, commission and deliver services that meet the needs of patients with a learning disability and tackling the health inequalities that people with a learning disability experience, including diagnostic overshadowing and barriers to timely interventions: this is particularly vital in the case of the named medical co-ordinator. Experience from our advice and information service, case work and past campaigns, clearly tells us that patients with a learning disability can experience several issues concerning end of life care, including: - Negative assumptions can be made about quality of life. People with a learning disability have the same right to life as everybody else, and their lives should be valued in the same way. In addition to appropriate end of life care it is vital that people with a learning disability are able to access the general healthcare services they need. Doctors should strive to preserve life, provide necessary treatment, or withhold or withdraw treatment on the same basis as they would for everyone else. Therefore, we ask that individuals working with children with life limiting conditions are trained to recognise this issue and any negative value judgements that may have been made.

ID	Stakeholder	Statement number	Comments[1]
			- We know from anecdotal evidence that people with a learning disability are not always able to access appropriate palliative care services, including effective pain management due to failures to recognise pain in patients with a learning disability, particularly those that have difficulty communicating pain. In some cases, health professionals may have incorrect beliefs about the ability of people with a learning disability to experience pain. Mencap hope that all staff involved in delivering care to children and young people with life limiting conditions are trained to recognise and resolve these issues.
23	Rainbow Trust Children's Charity	General	The key question relating to data collection is what exactly will be measured. The meaningful delivery of the quality statements would require indicators of delivery which go beyond the quantitative to involve more qualitative data collection capturing, for instance, delivery of a process over time, and the quality of planning, coordination, consultation or support that is put in place. This would mean that local systems and structures would need to have sufficient qualitative and quantitative data analysis capacity to collect the data required. Areas which provided data for the Palliative Care Funding Review may be ahead of others in terms of having the necessary expertise for data collection, although this experience may be held by individuals rather than a 'system' as such. For instance, Lynda Brooks, Macmillan Consultant in Paediatric Palliative Care at Alder Hey Hospital, led data collection efforts in the north west to feed into this review.
24	RCGP	General	• There is a fundamental bit of cognitive dissonance here. The document acknowledges that being cared for at home, and dying at home is likely to offer the best possible outcomes (Quality statement 6, page 8). The only resource widely available to support such care are primary care nurses and doctors, supported by local specialist (adult) palliative care teams. Yet the statement advises all the time the need for specialist doctors and nurses. For instance quality statement 2 is about the need for a named medical specialist. This is potentially ambiguous: do the writers included specialists in general practice in this title? Quality statement 4 is more explicit: 'assessed by the specialist paediatric care team.' Quality statement 6: '24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care'. It is up to others to report the availability of such specialist care in all areas, and the cost of developing such expertise. Assuming they are available, the result of insisting on their primacy may be that children end up being admitted to secondary care, so that they and their families are denied home care. The overarching need is to support primary care teams to provide palliative care, supported by distant, perhaps very distant, specialist expertise. That's not the language in which this document is written.
25	Royal College of Nursing	General	There is no mention of short breaks or respite care, which are very important to these families.
26	Royal College of Nursing	General	There is no mention of the involvement of Marie Curie Nurses. In order to deliver best care, a coordinated, holistic network approach to delivery is essential.
27	Royal College of Nursing	General	Each statement has a section headed "service providers" and continues by stating "such as hospitals, hospices and GP practices" This sounds like a generic statement and does not consider that this is a paediatric standard. It should include 'community paediatrics/ children's nurses' in the example.

ID	Stakeholder	Statement number	Comments[1]
			Also ensure that references to district nurses are either changed to community nurses and / or community children's nurses (this is relevant to all sections).
28	Royal College of Nursing	General	Each statement has an example in the section headed "health and social care practitioners (such as secondary care doctors, nurses, GPs and district nurses)". As previously stated, paediatric community services are very important and should be included as an example, also the term "district nurses" would normally be seen as referring to community nurses qualified and registered to care for adults. District Nurse services are not usually commissioned or qualified to care for children. Community nurses who care for children such as Community Children's Nurses or Hospice at Home Services would not see themselves as district nurses, nor would commissioners. Suggest an update of the terminology used in this document.
29	Royal College of Paediatrics and Child Health	General	We are disappointed to see no reference to the role of a 'key worker'. Over and above a designated medical specialist a key worker helps co-ordinate multiple clinic appointments, liaison with specialists. This and the medical lead role are complimentary.
30	Royal College of Paediatrics and Child Health	General	There needs to be some consistency over the use of the terms infants, children and young people throughout the document. Should we use parent(s) as there may not be 2 parents in every scenario?
31	Royal College of Paediatrics and Child Health	General	There needs to be specific reference to the UNCRC Article including articles 3, 5, 12, 13.
32	Royal College of Paediatrics and Child Health	General	Not without careful commissioning and close work with the voluntary sector (Hospices etc).
33	Royal College of Paediatrics and Child Health	General	Some of the data items are very difficult to collect, for example the issue of distressing symptoms. These are hard to define, and may come and go over a fairly short timescale. This applies to both numerator and denominator. We note "Receipt of information can be measured at key points, for example, at diagnosis, during regular reviews, and at discharge from hospital." This is potentially just the kind of unthinking administrative exercise that drives families crazy. What does it mean, anyway? Is it measuring whether parents were 'given the leaflet', or is it about whether the issue of psychological support is gently brought up in consultations from time to time?
34	Royal College of Paediatrics and Child Health	General	Yes, it does.
35	Royal College of Paediatrics and Child Health	General	Hospices are only mentioned in this document in relation to being service providers. However for children as for adults they can be a crucial pillar of the service and can in some localities be the centre for the commissioned arrangements for the care of children with life limiting illnesses. Commissioners should be encouraged to engage with a coalition of providers so that families are not offered one-size-fits all service, but rather a flexible model that can be tailored to individual families' needs.
36	Royal College of Paediatrics and Child Health	General	Yes

ID	Stakeholder	Statement number	Comments[1]
37	Royal College of Paediatrics and Child Health	General	Variable region by region (yes in the SW through the children's hospice network)
38	Royal College of Paediatrics and Child Health	General	There are not non-sufficient net resources in place to deliver these standards nor should disinvestment in other pathways provide for this. The man gap is in level 4 paediatric palliative care consultant expertise and the provision of spot purchasing to provide ad hoc 24/7 domiciliary end of life care.
39	Royal College of Paediatrics and Child Health	General	The speciality background does not matter - it could be a paediatric palliative care consultant, neurologist, community paediatrician, PIC consultant, neonatologist, general paediatrician etc. What matters is the expectations that come with being the co-ordinating specialist: single point of contact, dedicated care, regular meetings etc.
40	Royal College of Paediatrics and Child Health	General	My Qual (validated QoLtool in children with Life limiting conditions developed by Nicky Harris Childrens Hospice South West). Most important metrics are pain and distress but nil validated specifically in children. I think it is impossible to put time scales on this.
41	Royal College of Paediatrics and Child Health	General	It is good to see encouragement to record the number of children with life limiting conditions who have an advance care plan in place. The reality is that most areas don't even have systems in place to record at population level which children have a life limiting condition, leave alone which have advance care plans in place. There is now a national system in place in England for data reporting that includes reporting numbers of children with life limiting conditions – data should be flowing from all NHS providers to the Children and Young People's Health Services dataset (CYPHS) at NHS Digital. Very few NHS trusts are currently reporting such data in detail and few have systems in place to support data collection at the point of care. This guidance is an opportunity to highlight the importance of such data collection and reporting and would support the quality assurance of advance care planning.
42	Royal College of Paediatrics and Child Health	General	Overall, we applaud and support this document
43	Royal College of Physicians (RCP)	General	This is a clear and concise document which provides a good overview of end of life care for infants and young adults. However there are a number of areas which are not covered: • There is no mention or reference to transition between young adult and adult services and the fact that every paediatric palliative care service should have a clear and agreed pathway to plan for such a transition. Whilst not directly relevant to end of life care for an individual young adult without such a plan a small number of individuals are at risk of falling between paediatric and adult services. • There is no reference to joint working between adult palliative care services and paediatric palliative care services as part of the approach to meeting the quality standards. Whilst there are issues about competency and training there is a lot of mutual shared knowledge and experience that could and should be mobilised to ensure infants, children and young adults get the best possible end of life care available to them • There is no explicit reference to care being delivered as close to home as possible and the need for there to be close working links and shared care protocols between tertiary referral centres, district general hospitals, local GPs and DN teams • An explicit statement about GP and DN teams being enabled and trained to care is essential. There is currently a risk that teams who are orientated to adult care being unable to step up to provide care such as maintaining continuous subcutaneous infusions (CSCI) or changing pain relieving patches in the community, once such intervention have been

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			initiated by a specialist in paediatric palliative care. This is a particular challenge at end of life when a child or young adult may wish to be cared for at home(which may be many miles away from the specialist centre).
44	Royal College of Physicians (RCP)	General	There is no current system in place. Many of the individuals to which this document applies will be under multiple care agencies across health, social care and education. There may be issues around definitive diagnoses as well as co-morbidities. Their complexity however would imply that they will be known to key services so establishing a national agreed data base of children should be possible. Such a database would need buy in from the voluntary sector that provides a key element of care for these individuals. The complexity of data sharing between organisations and across sectors would have to be addressed at a national level, but should not be insurmountable. Getting agreed national definitions around key areas of care such as dependency, complexity and advanced care planning would be enormously beneficial going forward. There would need to be resource allocated to the collection of such data – as some organisations will not have the current IT infrastructure to prospectively collect such data.
45	Royal College of Physicians (RCP)	General	No. In most localities there is not the paediatric palliative care expertise to deliver the service in the way described without considerable investment and expansion of paediatric palliative care services both within the NHS and within the voluntary sector. In addition there is no coherent plan around the existence of specialist paediatric services with large gaps in service across the country. However if a joint model of care could be worked across adult and paediatric palliative care services could be agreed and developed, this could be deliverable with a modest increase in resource. Such a shared model of care would involve developing shared competencies around symptom management and prescribing with possibly a nominated consultant in adult palliative medicine taking a lead in developing additional skills around paediatric palliative care for a locality where no specialist paediatric palliative care service is in place. There needs to be an expansion in the number of paediatric palliative medicine consultants with at least one in each tertiary children's hospital or where there is paediatric oncology. There needs to be an expansion of paediatric clinical nurse specialist in end of life care / oncology – but I am not in a position to say how many this would need to be, There is no opportunity for disinvestment – although an opportunity for a radical reorganisation of services around the individual child and their family.
46	Teenagers and Young Adults with Cancer	General	Overall, this Guidance focuses on the childhood population and does little to improve / address any issues specific to the TYA population, even though there is 'blurring of boundaries' for health care provision, especially in the 16-18 age group.
47	**The Association of Child Psychotherapists**	General	The ACP has looked at the draft and we can only suggest a couple of small changes: **Page 9** discusses psychological care. We wondered about word resilience - although this does help children with slow and deteriorating conditions, we are aware of children

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			and young people who report being tired of being"resilient" for their families. It might be useful to think around this more and how to clarify what is meant by this. We also wondered if another line could be added to say something like 'Children will often want to protect their parents from their distress about their condition or approaching end of life and regular psychological support can enable painful but important conversations to take place safely. See: *Talking about Death with Children Who have Severe Malignant Disease in The New England Journal of Medicine Kreicbergs et al., N Engl J Med 2004; 351:1175-1186September 16, 2004:*
48	The Donna Louise Children's Hospice	General	***The current services commissioned locally would not enable the quality standards to be met.***
49	The Donna Louise Children's Hospice	General	There could be the potential locally to amalgamate some services to create one specialist paediatric palliative care team able to meet many of the standards if the commissioners would take the initiative to review and fund appropriately. For example the NHS Children's Community Nursing teams providing palliative care could potentially be transferred to and managed by the local hospice. The specialist nurse post could be a joint post between the hospital/ community and hospice as could the consultant post - all hosted at the hospice. With some investment the hospice could lead on data collection and reporting to commissioners, centralising all data collection for CPC.
50	The Donna Louise Children's Hospice	General	At present there is no way that all of these statements can be achieved locally due to the lack of specialist paediatric palliative care consultants in the Country. There are consultants with an interest, but is that what is being proposed? Therefore 24 hour access for advice at end of life will be very difficult to achieve likewise symptom review.
51	The Donna Louise Children's Hospice	General	There are no local systems in place currently to collect the proposed data. Data collection will be potentially challenging as who will actually do this? We are setting up alerts for ACP's and if referred to hospice we will know exactly who does and doesn't have an ACP, but at present no system for monitoring those who don't come to the hospice. CDOP review system could potentially collect some of this data. Without support from the commissioners it will be very challenging to put data collection systems in place that collect robust data across an area. There is potential for each individual provider organisation to collect data, but the challenge then will be who will be responsible for collating across each area? Managed Clinical Networks could have a role in this.
52	The Donna Louise Children's Hospice	General	Yes mostly, but what about offering the choice around place of death? Named medical specialist? Definition. Do they mean their local paediatrician or tertiary paediatrician? Are all of these medical specialists able to coordinate the care? Are they the correct person to always lead that information and support or should there be times when it is "handed over" to a more paediatric palliative care clinician?
53	Together for Short Lives	General	Each quality statement refers to 'district nurses'. In the community, children with life-limiting and life-threatening conditions are cared for by community children's nurses or hospice at home nurses and not district nurses. Community children's nurses

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			complete a different qualification to district nurses. The quality statements should instead therefore refer to community children's nurses instead of district nurses.
54	Together for Short Lives	General	To improve national standards of end of life care for infants, children and young people, we propose that local data that is collected should be published and collated nationally to provide a national overview.
55	United Hospitals Bristol NHS Foundation Trust	General	We feel that this quality standard accurately reflects the key areas for quality improvement
56	West Midlands Paediatric Palliative Care Network	General	Overall, this Guidance focuses on the childhood population and does little to improve / address any issues specific to the TYA population, even though there is 'blurring of boundaries' for health care provision, especially in the 16-18 age group.
57	Association of Family Therapy	1	There needs to be acknowledgement that some children may choose to know less than others, and so the importance of this being recognised in any such planning is vital - so having a discussion about the discussion is needed. (Sometimes children with chronic health conditions may not want to know a lot about what might happen, especially when it is very uncertain, and they may feel more reassured when they know that their significant others, parents etc, are taking care of this. Such decisions are of course never static and can be subject to revision, not set in stone, but should be respected and accommodated.) There is also an issue about what the parents think -there are parents who do not wish their children to know a lot of detail about eg. likelihood of death, this may have cultural aspects to it too. Again, balancing the needs of parents and child needs to be given space and time to work out a solution. Acknowledgement that there can be cultural and social differences in how families go about making decisions and who are the important people to involve in this. Asking parents or carers and children and young people about who are the important people to involve in these discussions would be a good preliminary step. This is also important because the involvement of the wider family system can help people to support each other, and also more fully understand the challenges and decisions being made. Acute hospital settings can sometimes set up a situation where parents and children can feel isolated from their usual support networks within the family and wider family members through exclusion from important conversations can find it difficult to support when they don't understand why decisions have been made in the way that they have. Some families will prefer for the parents and children to be the main decision-makers and information gate-keepers for the family and there should be space for people to indicate this, also. Family and systemic psychotherapists, for example, would have a skill set to manage complex discussions within a smaller or larger family system, and also manage conversations around very different points of view between family members. Where families may not have extended family systems available to them, there may be friends who perform this function. Asking who it is important to involve should also give space for important non-related people who support the family.
58	Birmingham Children's Hospital	1	The delivery of and provision of an Advanced Care Plan (ACP) is an area of quality improvement. It is essential that the appropriate resources are then in place to be able to deliver an ACP. There needs to be clear guidance on who will be expected to commission any services (outside of 3rd sector) for PPC and end-of-life care in order that this quality measure can be achieved.
59	Birmingham Children's Hospital	1	No. This requires a formal registration / data capture methodology to obtain accurate numbers. A national dataset for paediatric palliative care / children and young people (CYP) with life limiting / life threatening conditions would be an ideal solution here, but previous attempts at developing this have been abandoned.

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			It would be foolish for local providers to develop their own solutions here – there needs to be standardisation across the whole health / social care setting to enable NHSE to have any sense of the national picture and to make valid comparisons across all providers / commissioners. This quality measure fails to address the challenge of differences between maternity and child health services and that these are not necessarily 'joined up'
60	Birmingham Children's Hospital	1	Difficult to achieve without investment in appropriate data collection / registration processes and ensuring appropriate level of services are commissioned effectively with clear lines of responsibility / accountability. Effective support and delivery of ACP's could have an impact on other services such as PICU.
61	Bliss	1	All four audiences should include reference to infants along with children and young people. For example, "Service providers ensure that systems are in place for parents of infants with a life-limiting condition to be involved in developing an advance care plan". Throughout the document infants and babies should be mentioned alongside children and young people unless it is not relevant to include them in a specific section.
62	British Psychological Society	1	There is currently no set standard template that is being used nationally for ACPs, and although there are recommendations within the quality standard as to what is included, there is much variability in practice and so this may be hard to quantify accurately. The Society believes that data collection structures will need to be put in place that record whether the Child, Young Person (CYP) and/or parents/carers were actually involved in the ACP, not just that an ACP exists. Also, the record should show family preferences i.e. some families (for religious or cultural reasons, for example), may not wish to be involved in these conversations and may therefore refuse – there should be space for this to be noted. Documentation should also record who the conversations were with (CYP, family members, as well as which professionals) and at what stage in the process of diagnosis/treatment these conversations take place. Linked to this, it would seem important that structures (and ways of recording) need to be in place to recognise when multiple professionals have raised the topic with families and how the ACP has been shared between professional groups across all sectors.
63	British Psychological Society	1	Families can raise any aspect of an end of life discussion with a number of professionals involved in their care and although families may not necessarily engage in a full detailed discussions, it is imperative that all staff coming into contact with families approaching end of life can support / contain the family if they believe they are ready to engage in such discussions. It is therefore essential that there is a programme of training for all staff but especially with any allocated 'key' professional. This would ensure that key professionals have the capacity and professional training to enable them to do this role to a high standard i.e. manage emotive conversations, manage conversations with more than one person in the room, be able to engage with young people, deal with conflict, accurately and quickly pick up mental health concerns in parents and young people.

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			63Data collection points could include for example, attendance on specialist (tailor made) communication training, attendance at regular clinical supervision, attendance on training that helps professionals identify psychological distress, referrals made to support staff and / or mental health professionals.
64	Children's and Young People with Cancer Clinical Reference Group	1	If the young person and family are comfortable to discuss how an announcement is to be made it can be helpful later, and also making a plan to also encompass how they are to be remembered at school, clubs etc.
65	CLIC Sargent	1	We endorse this quality statement and are supportive of the approach of communicating honestly and openly with the child, young person and their family and mutually agreeing on a care plan to support the child's needs. We feel that models such as the Together for Short Lives Care Pathway or West Midlands Palliative Care Toolkit and Advanced Care Plans offer examples of good practice.
66	CLIC Sargent	1	If a child or young person is palliative for longer than six months, the advanced care plan should be reviewed to take into account any changes in the individual's wishes. New services may also be available which could lead to a different decision for care or place of death.
67	CLIC Sargent	1	When discussing end of life wishes with a young person as part of the advanced care plan, we would strongly recommend that this discussion involves a consideration of how the young person would like to be remembered digitally (i.e. on social media platforms such as Facebook).
68	CLIC Sargent	1	In addition, where a young person becomes palliative and they already have sperm, ovarian tissue or other tissue samples stored. They need to be offered the opportunity to talk about what will happen to their stored tissue after their death.
69	Demelza Hospice Care for Children	1	This quality statement is achievable. We would echo the TfSL comment that the Standard must require a high quality and effective Advance Care Plan, so that the standard will have a measurable impact, and avoid the risk of merely requiring a piece of paper to exist.
70	East Midlands Children and Young People's Palliative Care Network	1	We agree that it is important that children and young people with life limiting conditions (LLCs) have an advance care plan (ACP) from as early as possible in their lives, which includes their wishes about end of life care. And also, when a life limiting condition is diagnosed before birth an ACP should be made with parents before birth if possible. However, it is important to clarify here what is meant by an ACP. It must be emphasized that the advance care plan is not just a patient 'wishes document' but needs to include a patient- held Emergency Health Care Plan detailing the correct medical management in a life threatening deterioration and also the Resuscitation Plan, both of which will have been developed with and will be signed by the child's paediatrician. These components of the Anticipatory Care Planning documentation are medical care

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			plans developed by the child's paediatrician and are the most important elements, without which the child is at risk of being subjected to the wrong medical care in an emergency which may be inappropriately invasive or not invasive enough. The wording here emphasises the importance of including the child's wishes which is important where possible, however most children with life limiting conditions are either too young or too disabled to express their wishes. Therefore the ACP is usually developed by their paediatrician with their parents and has to be a plan of best care that is based on the best interests of the child as judged by the medical team in discussion with the parents, not just on the parent's wishes.
71	East Midlands Children and Young People's Palliative Care Network	1	There is usually a great deal of uncertainty about the prognosis for a child with a life limiting condition, particularly when a condition which is likely to be life limiting is picked up on a scan during pregnancy, or scans in early life. The scans can be wrong. We would suggest changing the wording here to: a)Evidence of local arrangements to ensure that, when a condition which is likely to be life threatening is diagnosed in a baby during pregnancy the parents are involved in discussions about the likely prognosis, parallel planning for the possible different scenarios and the development of an advance care plan, including a parent- held emergency care plan and resuscitation plan for the baby. b) Evidence of local arrangements to ensure that children and young people with LLCs are involved in discussions about their likely prognosis, parallel planning for the possible different scenarios and the development of an advance care plan, including a patient- held emergency care plan and resuscitation plan. c)Evidence of local arrangements to ensure that the parents of infants, children and young people with LLCs are involved in discussions about the likely prognosis, parallel planning for the possible different scenarios and the development of an advance care plan, including a patient- held emergency care plan and resuscitation plan.
72	East Midlands Children and Young People's Palliative Care Network	1	The development of an Advance Care plan is usually a process not a 'one off event'. Therefore, at any given time many of the plans will be incomplete. It needs to be clear here whether it is the number of ACPs that have been started or the number completed that is being measured. And what does a complete ACP include? The anticipatory care planning process usually begins with the development of the medical Emergency Health Care plan and the Resuscitation Plan as this is often the most urgent element and will influence the other decisions about place of care, organ and tissue donation etc. Children and their parents may not be ready to discuss or decide regarding plans about care of the body after death, post mortem etc until very late in the patient journey, so the ACP will often be incomplete during the child's life, however the Emergency Health Care Plan and Resuscitation Plan must be made by the paediatrician as soon as a potential life threatening deterioration is recognised as likely. When a life limiting condition is diagnosed in a very sick neonate the time to develop the ACP

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			may be very short indeed and there may only be time to agree the resuscitation plan and the plan for care of the body after death. The ACP should be complete prior to the child actually dying. We would suggest changing the wording to: a)Proportion of infants, (including neonates), children and young people who died of a Life limiting condition (LLC) with evidence of anticipatory care planning, including a medical emergency care plan, and a resuscitation plan in place and patient/ parent wishes documentation in place. This is possible to measure. Ref. Blundell PDM, Wolff T. End-of-Life Planning Documentation and Location of Death in Children with Life-Shortening and Life-Threatening Conditions. Clinical Audits 2015: http://www.clinicalaudits.com/index.php/ojca/article/viewArticle/443. b)Proportion of pregnancies where a condition which is likely to be life limiting is diagnosed in the baby in which there is evidence of anticipatory care planning before birth, including an emergency care plan, patient/ parent wishes and a resuscitation plan for the baby. This could be measured by flagging all the pregnancies where the baby is expected to have a LLC on the electronic notes system and checking for the planning documentation and Resus Plan at the birth of the baby.
73	East Midlands Children and Young People's Palliative Care Network	1	Experience of care of children and young people with a life limiting condition. Children and parents can be asked if they have anticipatory care planning documents and whether they were involved in their development. However databases of children with life limiting conditions are rarely available in order to establish the denominator, so data collection will be patchy. It would be very useful if children with life limiting conditions had to be flagged on GP databases in the same way that adults are currently. Hospitals will be encouraged to collect data on children with LLCs once there is a specific tariff for end of life care in children.
74	East Midlands Children and Young People's Palliative Care Network	1	Advance Care Plan (ACP) It needs to be clearer here regarding what an ACP is, including a minimum acceptable level of planning demonstrated. Is the advance care plan a 'wishes document' as suggested by the wording here –'It usually covers the concerns and wishes of children and young people about their care'? Or is it a set of anticipatory care planning documentation which includes the medical

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			care plan developed with the child and parents/ carers by their paediatrician which describes best medical care for that child including the Emergency Health Care Plan for a life threatening deterioration and the Resuscitation Plan for when the child stops breathing, which must be signed by the paediatrician and should be with the patient at all times? The latter is essential for best care of the child. In the East Midlands we prefer a modular approach to anticipatory care planning. We introduce the family held Emergency Health Care and Resuscitation Plan first. This is a medical care plan. Then we introduce a separate patient and family wishes and choices document. This has a different legal status to the Emergency Care and Resuscitation Plan and so should be a separate document. Lastly we introduce the anticipatory symptom management plan which is again a separate document in the modular set which is only needed in the last days of life. The latter is also not a wishes document. It is a medical care plan.
75	Leeds Teaching Hospitals NHS Trust	1	In some cases (e.g. oncology patients) it would not be appropriate to develop an Advanced Care Plan at diagnosis, as they are likely to be treated with curative intent, and yet fall within the definition of life limiting conditions
76	Martin House, Hospice care for children and young people	1	We agree that it is often valuable to offer the opportunity to do (and subsequently revise as appropriate) an ACP, but we do not consider it appropriate to see it as compulsory. Some young people and their families do not wish to have one and this should be respected. In addition they may have preferences about when, and with whom, they have ACP discussions. A measure might be whether or not the opportunity to do one has been offered and by whom.
77	Paediatric Chaplaincy Network GB&I	1	Neither spiritual nor religious support is included in AP
78	Rainbow Trust Children's Charity	1	This depends very much on what indicators for reaching the standard are set. The creation of an Advance Care Plan should be a process involving reviews at intervals, as suggested by Recommendations 38 and 39 of the NICE guideline. Data collection should not focus on the one-time involvement of children and parents/ carers in the development of the plan, but rather should assess whether a plan is developed in detail, and reviewed over time, using a process that enables meaningful input from children and parents/ carers at each point. The ability to collect this data will therefore depend on local expertise and systems which are likely to vary.
79	Rainbow Trust Children's Charity	1	This definition should recognise that an advance care plan should not be a single conversation between a parent / carer and a professional but needs to be a process with regular reviews, especially as an infant, child or young person's condition can change quickly.
80	Royal College of Anaesthetists and Association of Paediatric Anaesthetists of Great Britain and Ireland	1	Clarity is required with respect to advanced care directives when an anaesthetic or surgical procedure becomes necessary as part of a child's care during the end of life process. Usually a DNAR directive would be suspended during a surgical procedure, however this would have to be considered on a case by case basis and anaesthetists should be involved in the multidisciplinary planning of such interventions.

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81	Royal College of Nursing	1	There should be recognition that developing an Advance Care Plan (ACP) usually takes place over a number of discussions and is not a single activity. This is unlikely to be achievable in hospital services – RCN guidance (2015) makes reference to a 2014 RCN survey, where nurses say they wanted more education and information around caring for people at the end of life *Getting it right every time: Fundamentals of nursing care at the end of life* https://www.rcn.org.uk/professional-development/publications/pub-004871 There should also be reference to the legal status of ACPs.
82	Royal College of Nursing	1	The statement is a key statement and is measurable if one is measuring if each child who should have an Advance Care Plan (ACP), has one. There might be a slightly different question to the statement though about whether the child and family are involved in developing it. An example would be the outcome of an audit carried out in the Greater Manchester area. This would be achievable.
83	Royal College of Nursing	1	Within the quality measures, as per comment above, we are surprised that there is no recognition about the specific issues re young people developing their own plans. This is important and should be included.
84	Royal College of Nursing	1	Within the rationale section, the reference to infants needs to be a range of options to cover the different potential outcomes – a stillborn infant/a living infant.
85	Royal College of Nursing	1	Within the audiences section – This needs to include ambulance trusts and education teams.
86	Royal College of Nursing	1	Ensure that the CYP only receives one ACP and not one for each organisation they visit for example hospices, acute trusts and community when the organisations are developing their own for the CYP.
87	Royal College of Paediatrics and Child Health	1	Advance care plans are fine, but not every family wants one, and there is often a protracted process by which a family moves from not wanting it to being happy with engaging with it. It would be wrong to expect that there would be universal uptake if offered.
88	Royal College of Paediatrics and Child Health	1	Suggest substitute and/or for and, e.g. "…….with a life-limiting condition and/or their parents or carers are involved in developing an advance…."
89	Royal College of Paediatrics and Child Health	1	We agree that it is important that children and young people with life limiting conditions (LLCs) have an advance care plan (ACP) from as early as possible in their lives, which includes their wishes about end of life care. And also, when a life limiting condition is diagnosed before birth an ACP should be made with parents before birth if possible. However, it is important to clarify here what is meant by an ACP. It must be emphasized that the advance care plan is not just a patient 'wishes document' but needs to include a patient- held **Emergency Care Plan** detailing the correct medical management in a life threatening deterioration and the **Resuscitation Plan**, both of which will have been developed with and will be signed by the child's paediatrician. These components of the Anticipatory Care Planning documentation are vital otherwise the child is at risk of being subjected to the wrong medical care in an emergency which may be inappropriately invasive or not invasive enough.

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			Most children with life limiting conditions are either too young or too disabled to express their wishes. Therefore the ACP is developed by their paediatrician with their parents and has to be a plan of best care that is based on the best interests of the child not just on the parent's wishes. Care needs to be taken with respect to information sharing; and it should be recognised that advanced care planning is not a single event; plans may change over time; following development of discussions and clinical change in the child. All agencies need to have access to the correct information at the right time. The safest place for the "master copy" which should be dated and signed is with the child and carers at all time. However there needs to be a robust system of alert warning to the existence of the ACP; and where to find it. Each area/region may have different mechanisms for this – in some regions where there is a locally agreed format for emergency health care plans, there is acknowledgement that there should only be a single copy of the plan, which should be signed in ink and follow the child across settings. This is to avoid the dangers of 'version control', risking an old version being acted upon when a new version is available with different content. In other areas this may not be so easy; and in this situation the master copy should be with the parents and of course dated, but there should be copies with other agencies, most importantly the ambulance service. If for whatever reason the parent doesn't have the master copy with them (understandable in an emergency) or the parent is not there, then at least there is something available. If the parent does have the master copy, they are able to say if the local copy is outdated. Reference: Horridge KA. Advance Care Planning: practicalities, legalities, complexities and controversies. *Arch Dis Child.* 2015; 100:380-385 Horridge K. Advance care planning matters. *Dev Med Child Neurol.* 2016; 58(3):217
90	Royal College of Paediatrics and Child Health	1	There is usually a great deal of uncertainty about the prognosis for a child with a life limiting condition, particularly when a condition which is likely to be life limiting is picked up on a scan during pregnancy, or scans in early life. The scans can be wrong. We would suggest changing the wording here to: a) Evidence of local arrangements to ensure that, **when a condition which is likely to be life threatening** is diagnosed in a baby during pregnancy the parents are involved in **discussions about the likely prognosis, parallel planning for the possible different scenarios and the development of an advance care plan, including a parent- held emergency care plan and resuscitation plan for the baby.** b) Evidence of local arrangements to ensure that children and young people with LLCs are involved in **discussions about their likely prognosis, parallel planning for the possible different scenarios and the development of an advance care plan, including a patient- held emergency care plan and resuscitation plan.** c) Evidence of local arrangements to ensure that the parents of infants, **children and young people with LLCs** are involved in **discussions about the likely prognosis, parallel planning for the possible different scenarios and the development of an advance care plan, including a patient- held emergency care plan and resuscitation plan.**

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91	Royal College of Paediatrics and Child Health	1	The development of an Advance Care plan is usually a process not a 'one off event'. Therefore, at any given time many of the plans will be incomplete. It needs to be clear here whether it is the number of ACPs that have been started or the number completed that is being measured. And what does a complete ACP include? The anticipatory care planning process usually begins with the development of the medical Emergency Care plan and Resuscitation Plan as this is often the most urgent element and will influence the other decisions about place of care, organ and tissue donation etc. Children and their parents may not be ready to discuss or decide regarding plans about care of the body after death, post mortem etc. until very late in the patient journey, so the ACP will often be incomplete during the child's life. When a life limiting condition is diagnosed in a very sick neonate the time to develop the ACP may be very short indeed and there may only be time to agree the resuscitation plan and the plan for care of the body after death. The ACP should be complete prior to the child actually dying. We would suggest changing the wording to: **a) Proportion of infants, (including neonates), children and young people who died of a LLC with evidence of anticipatory care planning, including medical emergency care plan, a resuscitation plan and patient/ parent wishes documentation in place.** This is possible to measure. Ref. Blundell PDM, Wolff T. End-of-Life Planning Documentation and Location of Death in Children with Life-Shortening and Life-Threatening Conditions. Clinical Audits 2015: http://www.clinicalaudits.com/index.php/ojca/article/viewArticle/443. **b) Proportion of pregnancies where a condition which is likely to be life limiting is diagnosed in the baby in which there is evidence of anticipatory care planning before birth, including an emergency care plan, patient/ parent wishes and a resuscitation plan for the baby.** This could be measured by flagging all the pregnancies where the baby is expected to have a LLC on the electronic notes system and checking for the planning documentation and Resus Plan at the birth of the baby.
92	Royal College of Paediatrics and Child Health	1	Experience of care of children and young people with a life limiting condition. Children and parents can be asked if they have anticipatory care planning documents and whether they were involved in their development.

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			However databases of children with life limiting conditions are rarely available in order to establish the denominator, so data collection will be patchy. **It would be very useful if children with life limiting conditions could be flagged on GP databases in the same way that adults are currently.** Hospitals will be encouraged to collect data on children with LLCs once there is a specific tariff for end of life care in children.
93	Royal College of Paediatrics and Child Health	1	Advance Care Plan (ACP) It needs to be clearer here regarding what an ACP is, including a minimum acceptable level of planning demonstrated. Is the advance care plan a 'wishes document' as suggested by the wording here –'It usually covers the concerns and wishes of children and young people about their care'? Or is it a set of anticipatory care planning documentation which includes the medical care plan developed with the child and parents/ carers by their paediatrician which describes best medical care for that child including the Emergency Care Plan for a life threatening deterioration and the Resuscitation Plan for when the child stops breathing, which must be signed by the paediatrician and should be with the patient at all times? The latter is essential for best care of the child.
94	Royal College of Paediatrics and Child Health	1	Need to also discuss and plan the holistic needs of the infant, child or young person, their wishes and needs that do not relate exclusively to medical treatment. The RCPCH &Us Voice Bank 2016 has captured concerns that medical teams and health care professionals do not seek to understand elements relating to school, friends, family, relationships, life goals and aspirations - event for the most unwell. Maintaining a sense of the bigger picture is vital.
95	Royal College of Paediatrics and Child Health	1	Advance care plans should also include those who are of importance to the patient. This could be a sibling, best friend, grandparent or teacher, managing the wider holistic wishes and needs of them as an individual.
96	Royal College of Paediatrics and Child Health	1	Unless local data collection is guided by a standardised proforma, it will be difficult to compare results, given different methods of collecting and defining both numerator and denominator data.
97	Royal College of Paediatrics and Child Health	1	A standard way of recording the advance plan, with recommended items to collect, discuss and record would also help with comparison.
98	Royal College of Paediatrics and Child Health	1	These discussions should also be recorded in a way that means that agreements (and who was involved) are readily available to all staff within an organisation
99	Royal College of Paediatrics and Child Health	1	The denominator would be each baby who dies in a neonatal unit – given the relatively small numbers, perinatal review should identify those in whom death was predictable.
100	Teenagers and Young Adults with Cancer	1	The delivery of and provision of an Advanced Care Plan (ACP) is an area of quality improvement. It is essential that the appropriate resources are then in place to be able to deliver an ACP. There needs to be clear guidance on who will be expected to commission any services (outside of 3rd sector) for PPC and end-of-life care in order that this quality measure can be achieved.
101	Teenagers and Young Adults with Cancer	1	No. This requires a formal registration / data capture methodology to obtain accurate numbers. A national dataset for paediatric palliative care / children and young people (CYP) with life limiting / life threatening conditions would be an ideal solution here, but previous attempts at developing this have been abandoned.

ID	Stakeholder	Statement number	Comments[1]
			It would be foolish for local providers to develop their own solutions here – there needs to be standardisation across the whole health / social care setting to enable NHSE to have any sense of the national picture and to make valid comparisons across all providers / commissioners. This quality measure fails to address the challenge of differences between maternity and child health services and that these are not necessarily 'joined up'
102	Teenagers and Young Adults with Cancer	1	Difficult to achieve without investment in appropriate data collection / registration processes and ensuring appropriate level of services are commissioned effectively with clear lines of responsibility / accountability. Effective support and delivery of ACP's could have an impact on other services such as PICU.
103	Together for Short Lives	1	This list of service providers and practitioners should reflect the different settings in which the child or young person will spend time. Education settings, for example, should be informed at the earliest stage possible that an ACP is being developed for a child. They should be informed of the implications that the ACP will have for them - and what action they should take. Similarly, the list of service providers should include community paediatric services and local ambulance services.
104	Together for Short Lives	1	This section should include education staff, who will be involved in supporting the child or young person. They will need to make sure that the support they provide is consistent the ACP - for example, knowing whether the child should be admitted to hospital if they collapse or if they have a Do Not Attempt Cardiopulmonary resuscitation (DNACPR) decision.
105	Together for Short Lives	1	'Parents and cares' should state 'Parents and carers'. In the sentence "This may sometimes be done before a baby is born if the condition is diagnosed during pregnancy", the term 'or suspected' should be added after the term 'diagnosed'. The term 'diagnosis' is not always appropriate during pregnancy as definitive diagnoses at this stage are rare. If a child is diagnosed or suspected as having a life-limiting condition in the womb, their ACP should set out how care should be provided in several potential scenarios, which should include a stillbirth.
106	Together for Short Lives	1	This quality statement is a key area for improvement and is achievable. It is also possible for local systems to collect data for this quality measure, as the Greater Manchester Clinical Network Audit has demonstrated.
107	Together for Short Lives	1	This should state 'involved in developing a quality advance care plan' and link to guidance on what a quality advance care plan looks like. We suggest that it links to the Child and Young Person's Advance Care Plan Collaborative resources page (http://cypacp.nhs.uk/documentdownloads)
108	Together for Short Lives	1	As all babies will have a plan to cover their birth, this section should specify that the advance care plan (ACP) is relevant to their life-limiting condition. It should also specify that advance care plans should set out in what circumstances the baby should be resuscitated contain specific plans for resuscitation and provide for possible transfer of the baby for end of life care in a different location. The advance care plan should include plans for: • the period before the child is born • delivery

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			- the period immediately after the birth. The family's preferences should be considered when developing an advance care plan. Once the baby is born, the plan should be reviewed.
109	Together for Short Lives	1	This definition should recognise that an advance care plan is not usually developed in a single conversation between a parent carer and a professional. An ACP takes time to develop. The definition should also recognise that the child's situation may change rapidly and their ACP should be reviewed to address this. The definition should state that ACPs have no legal status.
110	United Hospitals Bristol NHS Foundation Trust	1	This standard is deliverable with investment in training to encourage an understanding of advance care planning amongst all healthcare professionals and the development of skills to expand the number of professionals who feel able to have these conversations with families
111	United Hospitals Bristol NHS Foundation Trust	1	We feel that this statement should read: 'Infants, children and young people with a LLC and their parents or carers are *given the opportunity* to be involved in developing their Advance Care Plan
112	United Hospitals Bristol NHS Foundation Trust	1	This is measurable; in our local area we collect this data on form B's as part of the CDR process
113	University Hospital Birmingham	1	The team has concerns regarding advanced care planning, currently we offer a bespoke, patient centred responsive advanced care plan to our TYA population, we feel that a generic 'tick box' approach may in fact be counterproductive to young people especially if introduced at an inappropriate stage. Most of our patients are initially treated with curative intent and it would be inappropriate to enforce documentation upon them at a stage when it is not clinically appropriate and the plan may well become irrelevant. We propose the plan should not be mandated in all patients at diagnosis and if a tool is recommended it would be helpful if a draft national document was put forward to avoid duplication of work around the country and enable equity of access to the document. Furthermore, this standard would be difficult to achieve without further funding and investment. The document could come in to effect when a TYA is transitioned into palliative treatment/end of life care. To ensure same conversations are not being had by multiple HCP's with the TYA with regards to their wishes (which has caused distress to TYA's in the past who have to have these difficult conversations multiple times), the document could be a guide for discussions with the TYA. Some wish to speak openly about their care and wishes at the end of their life whilst others do not wish to know much about their prognosis.
114	West Midlands Paediatric Palliative Care Network	1	The delivery of and provision of an Advanced Care Plan (ACP) is an area of quality improvement. It is essential that the appropriate resources are then in place to be able to deliver an ACP. There needs to be clear guidance on who will be expected to commission any services (outside of 3rd sector) for PPC and end-of-life care in order that this quality measure can be achieved.
115	West Midlands Paediatric Palliative Care Network	1	No. This requires a formal registration / data capture methodology to obtain accurate numbers. A national dataset for paediatric palliative care / children and young people (CYP) with life limiting / life threatening conditions would be an ideal solution here, but previous attempts at developing this have been abandoned. It would be foolish for local providers to develop their own solutions here – there needs to be standardisation across the whole health / social care setting to enable NHSE to have any sense of the national picture and to make valid comparisons across all providers / commissioners.

ID	Stakeholder	Statement number	Comments[1]
			This quality measure fails to address the challenge of differences between maternity and child health services and that these are not necessarily 'joined up'
116	West Midlands Paediatric Palliative Care Network	1	Difficult to achieve without investment in appropriate data collection / registration processes and ensuring appropriate level of services are commissioned effectively with clear lines of responsibility / accountability. Effective support and delivery of ACP's could have an impact on other services such as PICU.
117	Association of Family Therapy	2	The terminology in this statement keeps changing: 'medical contact', 'medical specialist', 'health professional'. Who might be the best person to fulfil this role will depend on the intended scope of the role. To co-ordinate the person needs to be an integral part of the team providing care, and able to discuss issues with the whole team. As well as medical doctors, other members of the team should be able to take a care co-ordination role (for example, liaison nurses, social workers, clinical psychologists, systemic and family therapists), but if this role is more about medical decision-making than ensuring the child and family's decisions are respected then this aspect should be specified within the statement. Outside of an acute hospital team, a hospice team (including those who support home-based care) should also be able to support care co-ordination between team members to ensure families have a named contact. Where primary care and community teams may be offering support alongside other work they are doing which does not pertain to end of life care it is important that they have easy access to specialist teams who can support their core end of life skills, including effective communication and involvement of the family regarding end of life care.
118	Association of Paediatric Chartered Physiotherapists	2	Again this meets an area of need Data should be collectable This will require investment in staff to achieve as 'coordination' takes up a lot of time and can't just be added to a day job. It would be sensible for the key person to be the profession that would most be involved with the child/ young person. Often for those with more complex needs, physiotherapists are very involved in their postural management, respiratory management, manual handling and have built up trusting relationships with parents. NOTE: Again there are times that children's hospices becomes a fixed point for the families and it would be good for that to be in place for all with life limiting conditions not just those that access hospice services. It would also benefit professionals as having a point of contact is useful to liaise with and could help coordinate multi- agency input too.
119	Birmingham Children's Hospital	2	This should be an easy data item to obtain via HES? The more pertinent question is – Is the named medical contact the most appropriate for that individual young person / family? This would be difficult to define.
120	Birmingham Children's Hospital	2	Yes
121	Birmingham Children's Hospital	2	Please see comment # 4
122	Birmingham Children's Hospital	2	Should depend a little on the underlying life limiting / life threatening condition. Should be done in collaboration with community / primary care services local to the CYP / Family.

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123	Children's and Young People with Cancer Clinical Reference Group	2	A named medical specialist should be a quality standard for any child with a chronic or acute condition. This is not just relevant for end of life care.
124	CLIC Sargent	2	We support this quality statement. It is important to ensure that the named medical specialist is able to have frank discussions with the child or young person, and use accurate terminology to support their understanding of their prognosis. We would recommend that this individual be based on the lead clinician or specialist nurse, however this responsibility can be noted in the advanced care plan to be deferred for the individual the child, young person or family choose.
125	Demelza Hospice Care for Children	2	We agree that a family should have an identified contact individual who is responsible for co-ordinating care across all agencies. However, to work in practice we suggest the following amendments are made: • This individual may not always (or often) be the lead medical practitioner. They can be any professional with the responsibility for co-ordinating care. • The lead individual may change depending on the particular episode of care, for example in co-ordinating care during the end of life period. • The lead individual should be identified within a team of relevant practitioners/agencies. • The lead practitioner should know the family and be an active part of the child/family's care provision. This role cannot be designated as a back-office administrative function.
126	East Midlands Children and Young People's Palliative Care Network	2	Infants (including neonates), children and young people with a LLC have a named medical specialist who coordinates their care. We suggest adding the wording: This will usually be the child's consultant paediatrician**.** It should be acknowledged that it is difficult for teams to provide a named paediatrician when the child is an inpatient on the neonatal (NICU) or paediatric intensive care units (PICU) because the doctors there work in shifts. We suggest adding the wording: Teams on intensive care units, NICU and PICU should make every effort to identify a named paediatrician who is going to be able to provide continuity of care for that child whilst on the unit and involve a named paediatrician for long term support as soon as appropriate.

ID	Stakeholder	Statement number	Comments[1]
			Hospital teams may discharge a child for end of life care at home. We suggest adding the wording: Children receiving end of life care at home should continue to have a named medical specialist who coordinates their care and regularly reviews the child.
127	East Midlands Children and Young People's Palliative Care Network	2	There are rarely any databases of children with life limiting conditions to provide the denominator. It may be possible to identify children with LLCs under the care of a particular medical team and use that as a sub group denominator.
128	East Midlands Children and Young People's Palliative Care Network	2	Children and families could be asked whether they had a named medical specialist but also about the level of continuity and coordination of care they are receiving.
129	Esoteric Practitioners Association (EPA)	2	The particular needs of patients with learning difficulties are naturally addressed when relationships between family and healthcare professionals are therapeutically established. If we approach families with openness, care and respect we can learn alongside them whilst we bring our expertise. It is our duty to do this as health workers, but with the humility and respect of hearing, listening and working alongside those who have been at the heart of a patient's care.
130	Helen and Douglas House Hospices for children and young adults	2	Yes, infants, children and young people with a life limiting illness should have a named medical specialist who coordinates their care. In relation to question 4: However, it is important to recognise that this person could well ***change*** with time. For example, towards the end of life, a paediatric palliative care specialist or GP (specialist generalist) may be more likely to assume that role, whereas earlier in the disease trajectory, this may be coordinated by a disease specialist (e.g. paediatric oncologist, paediatric neurologist). The important issue is that it is clear who is coordinating care at each stage
131	Leeds Teaching Hospitals NHS Trust	2	This is a key area for quality improvement. The named medical specialist may come from different disciplines. In some locations this may be the child's named consultant, in other areas a named senior nurse or nurse specialist. Because this involves the coordination of care should this be a key worker role?
132	Martin House, Hospice care for children and young people	2	We recognise and support the value of a named medical specialist.
133	Rainbow Trust Children's Charity	2	Each infant, child or young person will have a specialist consultant for their particular condition. However, we question whether a 'named medical specialist' will be the right person to coordinate all aspects of their care. Recommendation 57 of the NICE guideline suggests that a named individual from the multidisciplinary team could be their main contact, so there is some confusion as to what is intended. Realistically, in light of resource and time constraints, we do not think a medical specialist would usually be appropriate to coordinate the detail of all aspects of care.

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134	Rainbow Trust Children's Charity	2	We query whether there is sufficient resource for a medical professional to take on the coordination of an infant, child or young person's care in all parts of the UK. For instance, the report, '*The State of Child Health: The Paediatric Workforce*',[2] from the Royal College for Paediatrics and Child Health (April 2017) notes that, '*There is a serious shortfall in the paediatric workforce. Numbers have failed to keep pace with patient numbers leading to dangerous pressure on an already stretched service…'There are substantial vacancies at consultant and trainee levels'.* However we aware of good practice examples. For example, in Surrey there is a good working relationship between the Paediatric Oncology Outreach Nursing (POON) team, the consultant at the Royal Marsden Hospital, and palliative care providers such as Shooting Star Chase Hospice.
135	Royal College of Nursing	2	It seems odd to suggest that a consultant will be acting as a key worker – and how realistic is this? Also "key working" approaches usually advise that families should have involvement in deciding who should coordinate care – this sounds more as if this should be a lead medical specialist to coordinate their medical care. The original statement in the NICE guidance is "named medical consultant who leads and coordinates their care", the word "leads" has been left out in this quality standard (QS). This changes the meaning. It is now two statements rolled into one; about a named medical consultant and about coordinating care. Indeed in the guidance (1.5.7) it states "think about a named individual from the MDT to act as first point of contact for the family". In the QS, towards the end of the statement, it states "infants, children and young people have a healthcare professional (HCP) who is their main contact and who coordinates their care". So is it a HCP from the MDT or is it the lead consultant who coordinates care? In reality it is often the specialist nurse who coordinates care, although the consultant leads on care. The activities are not the same. Having someone from MDT to coordinate care is a key statement.
136	Royal College of Nursing	2	In view of previous comments, we suggest that the quality statement should either be expanded to more general keyworker activities or become more specific to a medical practitioner coordinating their medical care
137	Royal College of Nursing	2	With regards to how achievable this quality statement is: There should be a medical specialist who might be the specialist in the child's underlying condition, or the referring general paediatrician from the referring district general hospital or hospice medical lead or GP. It is, therefore, a key achievable statement to have a named medical consultant, however, there should also be a level 4 paediatric palliative care consultant who leads on the palliative care but this is aspirational in some regions.
138	Royal College of Paediatrics and Child Health	2	It is great to see the statement about the importance of establishing if the child has a learning disability or not. This is very welcome, but is increasingly challenging as educational psychology services across the UK are being dessimated and privatised or cut altogether. Reaching an accurate diagnosis of learning disability is thus getting harder. Anything this guidance can do to acknowledge this and to promote the services required to accurately diagnose learning disability would be most welcome.

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[2] http://www.rcpch.ac.uk/workforce

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139	Royal College of Paediatrics and Child Health	2	We feel that having a named paediatrician is good, as is having some specialist nursing input: generally community paediatric nurses have these skills and would be involved with a family in which a child had a life threatening or life limiting condition (though there are other specialist children's nurses who deal with children with cancer).
140	Royal College of Paediatrics and Child Health	2	Infants **(including neonates),** children and young people with a LLC have a named medical specialist who coordinates their care. We suggest adding the wording: **This will usually be the child's consultant paediatrician, but also may be the GP OR a secondary care specialist, dependent on local circumstances and the needs of the child and family**. Care needs to be taken to ensure that support is offered at all levels of care in a co-ordinated fashion: Primary care (GP/HV), secondary care – Paediatrician and Tertiary specialists. Duplication must be avoided; but it is also important that there is clear allocation of roles and responsibilities. There is sometimes a tendency for some secondary and tertiary specialists to take on aspects of care that could/should be delivered by the primary care team. This section is an opportunity to encourage team working across the layers of the health system and to empower the GP to fulfil their important role in the team. It should be acknowledged that it is difficult for teams to provide a named paediatrician when the child is an inpatient on the neonatal (NICU) or paediatric intensive care units (PICU) because the doctors there work in shifts. We suggest adding the wording: **Teams on intensive care units, NICU and PICU should make every effort to identify a named paediatrician who is going to be able to provide continuity of care for that child whilst on the unit and involve a named paediatrician for long term support as soon as appropriate.** Hospital teams may discharge a child for end of life care at home. We suggest adding the wording: **Children receiving end of life care at home should continue to have a named medical specialist who coordinates their care and regularly reviews the child.**
141	Royal College of Paediatrics and Child Health	2	There are rarely any databases of children with life limiting conditions to provide the denominator. It may be possible to identify children with LLCs under the care of a particular medical team and use that as a sub group denominator.
142	Royal College of Paediatrics and Child Health	2	Children and families could be asked whether they had a named medical specialist but also about the level of continuity and coordination of care they are receiving.
143	Royal College of Paediatrics and Child Health	2	The RCPCH &Us Voice Bank 2016 endorse the need for a single point of contact for families and children who have a life limiting condition. This needs to be equally accessible to patient and parent/carer as the discussions and questions may not be mutually exclusive. Children and young people have shared that they withhold questions and comments from discussion with their clinicians for fear of upsetting their parents/carers. pg8 - the single point of contact may operate at two levels, clinical and pastoral. The child/young person should decide who their pastoral lead is.
144	Royal College of Paediatrics and Child Health	2	This is essential. There should also be some measure of how regularly meetings are held to discuss / review any advance plans. The named contact should be the local consultant paediatrician (unless it is very unlikely that a child or young person would be admitted anywhere except a tertiary centre)

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145	Royal College of Paediatrics and Child Health	2	Suggest add “or neonatal consultant”, e.g. “……….with a life-limiting condition have a named medical specialist or neonatal consultant who coordinates…..”
146	Royal College of Physicians (RCP)	2	Our experts suggest this is not one individual but a clearly defined referral pathway organised around a region or specialist paediatric centre or a number of localities working as a cluster– with a consultant in paediatric palliative medicine overseeing the region or cluster working with nominated local consultant paediatricians and local consultants in adult palliative medicine who then work with the individual infant, child or young adult’s GP. Alongside this would be any local hospice provision available. It is important that providing end of life care to an infant, child or young adult is a relatively rare event and for many doctors will be a once in a career event so the services established to support such care have to be sustainable and highly flexible.
147	Teenagers and Young Adults with Cancer	2	This should be an easy data item to obtain via HES? The more pertinent question is – Is the named medical contact the most appropriate for that individual young person / family? This would be difficult to define.
148	Teenagers and Young Adults with Cancer	2	Yes
149	Teenagers and Young Adults with Cancer	2	Please see comment # 4
150	Teenagers and Young Adults with Cancer	2	Should depend a little on the underlying life limiting / life threatening condition. Should be done in collaboration with community / primary care services local to the CYP / Family.
151	The Donna Louise Children’s Hospice	2	The medical specialist should be someone who has experience, expertise and specialist knowledge in paediatric palliative care with knowledge of the child’s condition (without necessarily being an expert in that specific condition). The paediatric Palliative Care Consultant?
152	Together for Short Lives	2	It is unclear whether this section seeks to make sure that a child has a named medical specialist or an individual to coordinate their care. The NICE ‘End of Life Care for Infants, Children and Young People: Planning and Management’ guideline states that a named medical specialist should lead and coordinate the child’s care. It also states that a named individual from the multidisciplinary team should be their main contact, and that this person should coordinate their care’. These are separate roles. This section should also state that the care coordinator should lead on communication between different professionals and organisations involved in the child’s care. The professional that performs the role of coordinator will require adequate time to perform their role in addition to their other roles.
153	Together for Short Lives	2	The named medical specialist (not care coordinator) should be: • a specialist in the child’s underlying condition • the lead consultant paediatrician • Community paediatrician • Palliative care consultant • hospice medical lead; or

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			- GP.
154	Together for Short Lives	2	A child with a life-limiting condition needs a lead consultant and someone who coordinates their care. This is not necessarily the same person. As it is currently written, the quality statement states that the child's care will be coordinated by a 'medical specialist', which implies that this role would be carried out by a consultant. It is unlikely that a consultant will have the time available to perform a coordinating role in relation to all aspects of care – although the lead consultant will be able to coordinate medical care The family should be involved in deciding who should coordinate their child's care. This coordinating role will usually be the child's key worker. The named point of contact for a child and family will change depending on the stage of a child's life they are in. It could therefore be their: - key worker - school nurse - community children's nursing team - hospice team.
155	Together for Short Lives	2	In the sentence "Evidence of local arrangements to ensure that infants, children and young people with a life-limiting condition have a named medical specialist who coordinates their care", the word 'care' should be preceded by 'medical'.
156	United Hospitals Bristol NHS Foundation Trust	2	This standard is deliverable. We feel that this specialist should have suitable experience in caring for children and the capacity to be responsive to their needs. Most usually this will be the child's paediatrician.
157	West Midlands Paediatric Palliative Care Network	2	This should be an easy data item to obtain via HES? The more pertinent question is – Is the named medical contact the most appropriate for that individual young person / family? This would be difficult to define.
158	West Midlands Paediatric Palliative Care Network	2	Yes
159	West Midlands Paediatric Palliative Care Network	2	Please see comment # 4
160	West Midlands Paediatric Palliative Care Network	2	Should depend a little on the underlying life limiting / life threatening condition. Should be done in collaboration with community / primary care services local to the CYP / Family.
161	Association of Family Therapy	3	There is some evidence in the literature about the need for emotional and psychological support to extend to the wider system. It might be useful to keep in mind that a) such support needs to be offered to siblings, not just the affected child, and that b) a systems approach is warranted because the life-limiting/life-threatening condition impacts the whole family system. This is further evidenced in Standard 6 which implies further emphasis on home-based care, where siblings would will be impacted on a daily

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			basis by the illness/condition. Parents / carers may need support with this as often their focus will be primarily on the child with a life limiting condition; siblings or other children living in the household may pick up on this focus and be silent about their own wishes and preferences and fears. Medical family therapists are a key specialty to be offering this kind of support. Reference: Malcolm, C., Adams, S., Anderson, G., Gibson, F., Forbat, L. (2014) A relational understanding of sibling experiences of children with rare life-limiting conditions: findings from a qualitative study. Journal of Child Health Care. 18(3): 230-40. Acknowledgement that some children and young people (and some other family members) will find the support of experts by experience more useful and relevant than professional support. Such information should include systems of peer / family support where these are in existence.
162	Association of Paediatric Chartered Physiotherapists	3	Huge area of need Data collection seems reasonable Finding and coordinating the different services that do/could offer this would be vital and would be an area of work prior to achieving this standard. NOTE: increasing the opportunities for services to develop and deliver this is important. unsure of how much there is out there for children and young people.
163	Birmingham Children's Hospital	3	*Access* to emotional and psychology support is the most important aspect of this QS, that would demonstrate real quality improvement. Given the wide variety of platforms via which people now access information, *provision* of information is not a useful quality measure.
164	Birmingham Children's Hospital	3	Referral patterns to emotional and psychological support services could be monitored. Existing data sources should be able to provide this; however, the question will be around accessing such data across primary, secondary and tertiary service providers.
165	Birmingham Children's Hospital	3	Without effective commissioning of such services, this QS is not achievable. defining commissioning responsibility - this will continue to form a barrier to effective commissioning of a service until NHSE clearly stipulates who is responsible for what without ambiguity, alongside standards regarding what should be available for patients across both the community and inpatient. In the same vain we would expect clarity regarding any onus on paediatric / TYA providers to ensure appropriate palliative input alongside acute care where that provider is being funded for treating an array of non-malignant, life-limiting conditions for which the requirement for palliation should be inherent.
166	British Psychological Society	3	While this statement identifies the need and significance of psychological support, it is weighted in favour of sign-posting to psychological services and does not identify the need for both generalist and specialist practitioner/applied psychologists in its provision. The statement should include a recognition that CYP should be given access to and information about psychological support services. Provision of such services is uneven across the country and a challenge to commissioners and policy-makers is needed to promote the need for this quality provision from practitioner/applied psychologists. This seems to be encapsulated in the "quality measures; Structure section" which mentions evidence that children can access local support and the need for commissioners to commission services but would be better captured in the wording of the quality statement itself.
167	British Psychological Society	3	

ID	Stakeholder	Statement number	Comments[1]
			The Society believes that there is a need to define what "emotional or psychological support" means e.g. may need to break this down into different levels of support available e.g. by profession: chaplaincy, specialist practitioner/applied psychology etc.; by ease of access; by intensity of input etc.
168	British Psychological Society	3	As with the NICE guidance this statement recommends care and support to the CYP rather than considering the whole family. Psychological coping of the parents are only considered in terms of bereavement/pre-bereavement, rather than recognising the impact of parental mental health and coping on child wellbeing. There is no recognition of the needs of siblings.
169	British Psychological Society	3	Local structures are not in place to collect this data/to resource implication
170	British Psychological Society	3	This statement will be hard to measure. Does it mean that the amount of young people accessing psychological supports will be measured (this is certainly measureable) or that an attempt will be made to capture the incidence of unmet /total need in the population, (this would have clear resource implications) and also be very challenging to measure.
171	Children's and Young People with Cancer Clinical Reference Group	3	Incidence of psychological problems in children and young people' is very generic. Most if they are aware will have an episode of distress – is this a psychological problem? This should be rephrased. What age are you measuring for psychological distress – infants would need psychology. Perhaps the measure should be that the child and family receive information at key stages. The measure should be proportion given information The provision for bereavement and psychology services for 16-18 year olds is variable within regions and patients may have a difficulty in terms of access. Emotional and psychological support is vital to the young person. Often their only opportunity to speak frankly about their prognosis. Every young cancer patient should have consistent and easily accessible support. The teams within the service should always be encouraged to build a relationship with the young person, whether play specialists, CLIC, a specialist nurse. These relationships can also provide comfort to the parents that their child is not so isolated from peers.
172	CLIC Sargent	3	We support this quality statement around emotional and psychological support. CLIC Sargent's soon to be published data on the emotional costs of cancer highlights that young cancer patients disproportionately experience anxiety and depression in comparison to their peers. Whilst it did not specifically investigate the needs of those at the end of life stage, our research found that 41% of young cancer patients we spoke to did not access support for the mental health impact of their cancer diagnosis. Therefore, it is vital that children and young people are able to access emotional and psychological support consistently across the country.
173	CLIC Sargent	3	As part of the emotional and psychological support offered, it is important for children and young people to know that there is someone in the care team, with whom they have a trusting relationship, who they can have open and frank discussions with. To

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			support their emotional needs, young people may need to discuss the loss of their imagined life and future experiences – such as falling in love, experiencing sex, or concern for friends and family after they have gone.
174	CLIC Sargent	3	It is vital that information on emotional and psychological support is provided in age appropriate language, ideally having been written by children and young people. It is worth noting that written information is unlikely to be read by younger children, therefore more creative means must be used when engaging with this age group. Information can be more accessible when transmitted through a safe means such as digital, or through the use of an app or 'game' in which a younger child could engage in the conversation. There is interest in digital games for this age group, as it is something they can access where they live, at a time suitable for them.
175	CLIC Sargent	3	We would comment that the equality and diversity considerations for children with learning disabilities are currently too loose. Health and social care professionals should draw on the expertise of professionals who are already in the child's life and who understand their unique learning and communication needs to communicate in a manner that the child or young person will connect with and understand. The same statement does not take cultural diversity or wishes into account. The statement should reflect that there are different spiritual and cultural needs of child, young person and family and they should be discussed and understood to ensure end of life care and wishes can be met.
176	CLIC Sargent	3	We believe that emotional and psychological support initially should come from professionals who are trained in paediatrics and have a strong knowledge of child development. We would also flag that for children and young people with cancer, cancer play specialists, social workers and faith leaders can and do provide valuable psychological support to children, young people and families, using recognised interventions and techniques, and these professionals should be considered by MDTs when considering appropriate emotional and psychological support.
177	Demelza Hospice Care for Children	3	This quality statement as written covers two separate issues: access to emotional support, and the need for children and young people to be given information about such support. We believe that these aspects should be separated so that this standard covers the availability of support only. The requirement for information about services should perhaps be combined with Quality Statement 1, which is about care planning. This standard should therefore cover appropriate emotional support being available and accessible, which includes access within a reasonable waiting time (some services have waiting lists of over six months). We find it very unhelpful that this standard about emotional support to children and young people is separate from the standard about emotional support to parents and carers. Emotional support is best delivered in a whole-family context, and should be inclusive of support to siblings, and potentially other family members and people close to the family. It would be very helpful for the standard to include a definition of what emotional support should be available. This should include talking therapies, creative arts therapies (Health and Care Professionals Council registered Art, Music and Drama), and peer support. Families should have the choice of accessing all these forms of support.

ID	Stakeholder	Statement number	Comments[1]
178	East Midlands Children and Young People's Palliative Care Network	3	a)Incidence of psychological problems in children and young people with LLCs will be very difficult to define and measure. b)Experience of care – is this about receiving the information? or receiving the service? Or the effectiveness of the service? The latter is the most important, but hardest to measure. Data collection will be affected by lack of denominator of children with LLCs.
179	East Midlands Children and Young People's Palliative Care Network	3	There are generally services available in all areas to provide emotional support to children and young people but they rarely have the specialist expertise to support children facing death nor severely disabled children with LLCs. Access to a child psychologist is very limited in many areas of the country. We suggest adding wording: Children and young people (CYP) with LLC can access emotional and psychological support services with specialist expertise and capacity to provide a prompt response and continuity of support if there is on- going need. Information about emotional and psychological support services for children and young people with a life limiting condition, and how to access it, is available in a range of formats.
180	East Midlands Children and Young People's Palliative Care Network	3	Most children living with a LLC will be severely disabled and often they will have severe learning difficulties or they will be too young to understand information about emotional and psychological support and how to access it. We suggest the following wording: Proportion of children and young people with a life limiting condition (or their parents/carers where appropriate) who are given information about emotional and psychological support and how to access it. - in a format that they can understand. The denominator, children and young people with LLCs will be unknown in most districts but may be identifiable for some specific client groups e.g. children using the local hospice, children on long term ventilation who are attending neuromuscular clinic.
181	Esoteric Practitioners Association (EPA)	3	It is commonly understood that it is often harder for the families observing the end of life than it is for the person experiencing it. They can feel helpless and not able to do anything. As HCPs a simple awareness of this would mean that we would be sensitive to keeping the families and carers in the big picture of what is going on, and also be aware of how their reactions might affect the care given to the child dying. In addition to that observers distress can lead to over prescribing. Is it possible that there are times when we resort to medication unnecessarily, or too soon – affecting the presence and emotional equilibrium of the child? It is difficult to balance the side effects of sedatives, however if we overly treat the pain and anxiety so much that they are unconscious and unaware of the experience, do we not rob them of the opportunity to prepare for passing over and to enjoy their last times with themselves and their families?

ID	Stakeholder	Statement number	Comments[1]
			Having read the recommendation we absolutely accept that managing pain is a priority, however there are many other symptoms (anxiety, depression etc.,) that don't always require medication. We understand the concern regarding depression and psychosis. For the family seeing their child distressed or mentally stressed, as well as in pain is an incredibly difficult experience, but we pose a question to consider: Are there instances where we are medicating because we are uncomfortable with the symptoms and feel helpless because we feel unable to do anything? It can be quite difficult to balance the side effects of the sedatives we use to treat pain, anxiety and depression. The question then becomes, are we treating patients so much that they are not conscious? For the person dying, even for a child it is their death and in many ways it is important that they are as conscious as is feasibly possible rather than numbed out and beyond awareness. These are the final days with yourself, family and world to get ready for passing over. When young people go into a reaction to the drugs they are already on, it may be wise to pause on giving them more drugs and come back to body techniques to support with presence because they are at the end of their life. Accepting the symptoms of end of life rather than fighting them. Our concern is that the first response in this section is to go to the psychiatric doctors, which who will only be offering medication to placate the symptoms of psychosis and depression. Rather than this being the first port of call, we suggest a more holistic and complementary approach, supporting the young person to be in their body, to be present with their breath and thoughts. Hand massages will also help with this and will alleviate anxiety. When young people go into a reaction to the drugs they are already on, it may be wise to pause on giving them more drugs and come back to body techniques to support with presence because they are at the end of their life. Accepting the symptoms of end of life rather than fighting them. We propose that in some cases the psychosis is a reaction to the environment, as stated previously, when we are nearing death we are extra sensitive to the vibration of the environment, this includes the emotions of others. There most often will be an excess intensity in parents' emotions ranging from anger, grief, bewilderment, distress etc., all of these feelings are affecting the child. If we can learn to let go and be present during the end of life we will be able surrender to the process. Children are naturally present – they don't have that long term view that adults measure life with – children have an acceptance of how things are. Therefore if we support the parents and carers to accept what is occurring, to not fight it and need for the child to have no distress, rather than seeing it as part of the end of life process, the child will be empowered to be as present as possible at their end of life, which would support everyone. We can as practitioners medicate because we want to alleviate symptoms of pain, it is our first reaction to relieve pain and distress, this is heightened when the patient is a young person or child – but if we pause and ask the question who are we medicating for? Is it possible we are medicating for the parents, carers and not for the children? Often the person who is dying is more at ease with the process than those caring for them. To bring awareness to this would support with how we medicate and treat. The cost savings could be huge in terms of medication and intervention.

ID	Stakeholder	Statement number	Comments[1]
182	Esoteric Practitioners Association (EPA)	3	It is interesting to note that in the briefing paper there is a limited reference to the health care professionals – the focus in this section is about family. Healthcare professionals become part of the family and are vital and clearly need to be well taken care of. They need supervision and practical guidance that is built in as an everyday support. If we do not put into place practical support we see these professionals becoming burnt out with predictions that half the work force will leave in the next ten years.[1] This of course has huge cost implications, and investment in the well being of these workers is money well spent. Reference [1] http://www.ascopost.com/News/19602
183	Martin House, Hospice care for children and young people	3	We welcomed the guidance in End of life care for infants, children and young people on emotional and psychological distress, crises and potential relationship difficulties etc (1.2.22) and that children, young people and parents may need expert psychological intervention (1.2.23) and urgent access to psychological services (1.2.24). However the focus of this quality statement on `giving information about emotional and psychological support` raises concerns. `Emotional support` is part of many health professionals jobs, but is different from specialist psychological services in children`s palliative care. We have found that if specialist psychological help is available it is extremely well used. However in practise there is limited specialist psychological help available to give information about.
184	Rainbow Trust Children's Charity	3	In our view this should be rephrased to say that children and young people are 'given access to support' rather than 'given information'.
185	Rainbow Trust Children's Charity	3	For children and young people at the end of life, support needs to be provided swiftly given the speed at which their condition may deteriorate. In our experience there is often unmet need in this area. It is not clear that local services in all areas can provide emotional and psychological support to children and young people at present. Alongside the support that some palliative care organisations and hospices can provide (which will be dependent on where a child or young person lives), the main source of statutory support would be from local Child and Adolescent Mental Health Services (CAMHS). However, research suggests that these often have lengthy waiting lists. The average wait for routine appointments for psychological therapy for children and young people was 32 weeks in 2015/16, and significant inequalities in access are known to exist.[3] The organisation Young Minds report[4] that CAMHS are turning away 23% of children referred to them for treatment by concerned parents, GPs, teachers and others.
186	Rainbow Trust Children's Charity	3	As per comment 4, this depends on what indicators are set for achieving this standard. It would be simple to record that a leaflet has been provided to each relevant child or young person but this would not be meaningful if support is not in fact easily and quickly available.

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[3] *The Five Year Forward View for Mental Health: A report from the independent Mental Health Taskforce to the NHS in England, February 2016* https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf

[4] https://youngminds.org.uk/about-us/media-centre/mental-health-stats/

ID	Stakeholder	Statement number	Comments[1]
187	Royal College of Nursing	3	This is a key statement but it is very aspirational and might not be achievable. It should be noted that siblings may need emotional and psychological support and need to be mentioned.
188	Royal College of Nursing	3	This statement is unlikely to be achievable – there are no sufficient CAMH services. It also feels inappropriate to separate child's issues from family (statement 5) – we suggest combining the two statements. Also ensure that the statement makes reference to school services as they have an important role in recognising distress/referring to CAMHS too.
189	Royal College of Paediatrics and Child Health	3	Most children living with a LLC will be severely disabled and often they will have severe learning difficulties or they will be too young to understand information about emotional and psychological support and how to access it. We suggest wording: **Proportion of children and young people with a life limiting condition (or their parents/carers where appropriate) who are given information about emotional and psychological support and how to access it.** **- in a format that they can understand.** The denominator, children and young people with LLCs will be unknown in most districts but may be identifiable for some specific client groups e.g. children using the local hospice, children on long term ventilation who are attending neuromuscular clinic.
190	Royal College of Paediatrics and Child Health	3	It is welcome that there is emphasis on encouraging access to emotional and psychological support for children with life limiting conditions. In reality in many places in the UK, child and adolescent mental health services are overstretched, have long waiting lists and timely access to the support required is challenging.
191	Royal College of Paediatrics and Child Health	3	There are generally services available in all areas to provide emotional support to children and young people but they rarely have the specialist expertise to support children facing death nor severely disabled children with LLCs. Access to a child psychologist is very limited in many areas of the country. We suggest adding wording: **CYP with LLC can access emotional and psychological support services with specialist expertise and capacity to provide a prompt response and continuity of support if there is on- going need.** **Information about emotional and psychological support services for children and young people with a life limiting condition, and how to access it, is available in a range of formats.**
192	Royal College of Paediatrics and Child Health	3	a) Incidence of psychological problems in children and young people with LLCs will be very difficult to define and measure. b) Experience of care – is this about receiving the information? or receiving the service? Or the effectiveness of the service? Data collection will be affected by lack of denominator of children with LLCs.
193	Royal College of Paediatrics and Child Health	3	Should this read 'Children and young people, and their parents…"
194	Royal College of Paediatrics and Child Health	3	The measure should not be whether it is offered, but whether it is offered and either not needed or is taken up. Offering a service that is not appropriate for that person/family or that is not accessible is not helpful.

ID	Stakeholder	Statement number	Comments[1]
195	Royal College of Speech and Language Therapists	3	The RCSLT advise that when a child has a significant swallowing problem or a condition where there is a progressive deterioration of the swallow, access to a paediatric speech and language therapist may be required. In many instances, these children may already be known to speech and language therapy services. In addition, children in these situations may have compromised communication skills and to ensure quality of life and ongoing quality of interaction with the family and close friends, speech and language therapists can provide appropriate methods of support. Some of these methods may be alternative forms of communication, e.g. a communication book, or programming an electronic aid, but this can enable families to sustain productive methods of communication.
196	Teenagers and Young Adults with Cancer	3	*Access* to emotional and psychology support is the most important aspect of this QS, that would demonstrate real quality improvement. Given the wide variety of platforms via which people now access information, *provision* of information is not a useful quality measure.
197	Teenagers and Young Adults with Cancer	3	Referral patterns to emotional and psychological support services could be monitored. Existing data sources should be able to provide this; however, the question will be around accessing such data across primary, secondary and tertiary service providers.
198	Teenagers and Young Adults with Cancer	3	Without effective commissioning of such services, this QS is not achievable. defining commissioning responsibility - this will continue to form a barrier to effective commissioning of a service until NHSE clearly stipulates who is responsible for what without ambiguity, alongside standards regarding what should be available for patients across both the community and inpatient. In the same vain we would expect clarity regarding any onus on paediatric / TYA providers to ensure appropriate palliative input alongside acute care where that provider is being funded for treating an array of non-malignant, life-limiting conditions for which the requirement for palliation should be inherent.
199	The Donna Louise Children's Hospice	3	This will initially require recognition on the part of the professionals that a child has a life limiting condition – education required. What information would / could be given if there are no services available to provide emotional and psychological support? What services are currently commissioned to provide this?
200	Together for Short Lives	3	This section should include schools, which play a key role in providing support for children and young people.
201	Together for Short Lives	3	This quality statement would have a significant impact if fully implemented. However, some Child and Adolescent Mental Health Services (CAMHS) have waiting lists of up to six months. As it is currently written, this quality statement only requires that children and young people are 'given information'. We believe that this should be strengthened to state that children and young people are given access to appropriate care and support. As with Quality Statement 5, we suggest that this quality statement should address support for the whole family, including siblings (as specified by recommendation 1.1.6 of the full guidance), and parents or carers. The full guidance also specifies (recommendation 1.1.7) that 'other family members (for example grandparents) and people important to the child or young person (for example friends, boyfriends or girlfriends) may need support. This may include social, practical, emotional, psychological, and spiritual support.'

ID	Stakeholder	Statement number	Comments[1]
202	Together for Short Lives	3	"Healthcare practitioners caring for children and young people with a life-limiting condition should establish if the person has a learning disability" This section should be clear that professionals do not have to carry out a learning disability assessment, but should instead establish the level of understanding that the child has and tailor their information they provide to them accordingly. This should happen regardless of whether the child has a diagnosed learning disability. Information could be provided using Makaton, for example, or using a pictorial leaflet for children. We therefore suggest that the statement is amended to: "Healthcare practitioners caring for children and young people with a life-limiting condition should establish the extent to which children are able to understand information about their condition and their care. They should make sure that they provide them with information which is appropriate to their level of understanding."
203	Together for Short Lives	3	This section should define what constitutes emotional and psychological support, which should include talking therapies. The support should be provided by specialist children's teams rather than adult therapists.
204	University of Essex	3	The Rationale states that 'Emotional support can help children and young people to cope with their distress and build resilience' (lines 3-4 of p. 9). However feedback from the Briefing Document (Appendix, Comment n°16, 'Around Communication') emphasises the empowering role of acceptance in emotional support. Indeed, some particularly difficult situations are not resolved through resilience alone because there is no possibility of 'bouncing back'. In such cases, fostering acceptance may be more appropriate to support the child's or young person's emotional well-being. Suggestion for modification: 'Emotional support can help children and young people to cope with their distress and build resilience or acceptance'.
205	West Midlands Paediatric Palliative Care Network	3	*Access* to emotional and psychology support is the most important aspect of this QS, that would demonstrate real quality improvement. Given the wide variety of platforms via which people now access information, *provision* of information is not a useful quality measure.
206	West Midlands Paediatric Palliative Care Network	3	Referral patterns to emotional and psychological support services could be monitored. Existing data sources should be able to provide this; however, the question will be around accessing such data across primary, secondary and tertiary service providers.
207	West Midlands Paediatric Palliative Care Network	3	Without effective commissioning of such services, this QS is not achievable. defining commissioning responsibility - this will continue to form a barrier to effective commissioning of a service until NHSE clearly stipulates who is responsible for what without ambiguity, alongside standards regarding what should be available for patients across both the community and inpatient. In the same vain we would expect clarity regarding any onus on paediatric / TYA providers to ensure appropriate palliative input alongside acute care where that provider is being funded for treating an array of non-malignant, life-limiting conditions for which the requirement for palliation should be inherent.

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208	Association of Family Therapy	4	For this statement it is important to consider who defines symptoms as distressing, and how this is done. Without a definition it will be difficult to measure and in older children and young people there may be differences of opinion in the assessment of distress, and the degree to which a resolution of this distress is wanted (similarly to adult end of life care, children and young people may have different relationships to their experience of pain or distress, and to any side effects of treatments used to resolve these, and so have different wishes around their experiences of pain and distress which others in their families or care systems may have opposing views on).
209	Association of Paediatric Chartered Physiotherapists	4	Achievable How to measure when a symptom becomes unresolved? Huge need for investment for this to be achievable if via NHS. NOTE: This is what we do! But I would suggest it often falls to us as a hospice to deliver this type of care. Who and how will this be achieved by would be my question, if this is a NICE guideline should the NHS services be delivering this or would this be more of a direct link for us to deliver this area of the statement. Close development of pathways would be useful. As Physiotherapists there are many ways we can support this and AHPs would need to be part of any service. Assisting with equipment, positioning, tonal issues, mobility, access to activities, exercise, respiratory care, HYDROTHERAPY should play a part. Etc etc etc. would all be important areas of input for symptom control.
210	Birmingham Children's Hospital	4	No. The major issue with this QS, is the definition of a 'specialist paediatric palliative care team' and how this is commissioned / resourced. Much of front-line paediatric palliative care is delivered by CCN's / Community paediatricians with an interest in paediatric palliative care or possibly primary care and is not reflected in this QS. Provision of paediatric palliative care is variable across providers that this QS is almost meaningless.
211	Birmingham Children's Hospital	4	Although it should be easy to collect data on who is involved in delivery of elements of paediatric palliative care, it is difficult to see how data could be collected on 'unresolved distressing symptoms'. This would require the use of some form of unified electronic patient record and a more objective measure of 'unresolved distressing symptoms'.
212	Birmingham Children's Hospital	4	This achievement of this QS will be reliant on the definition of a 'specialist paediatric palliative care team' and effective commissioning process for this along with a clear definition of a service specification for paediatric palliative care. There remains confusion about this process and it remains unresolved despite the NHSE publication in 2013 of e03-paedi-med-pall. Based on the definition contained within this guidance, this is not deliverable.
213	Birmingham Children's Hospital	4	24/7 access to palliative care advice and provision of CCN support for families during end-of-life care are perhaps more meaningful measure of performance currently. This should be flexible and have an ability to respond to individual patient /carers needs.
214	Bliss	4	All four audiences should include reference to infants along with children and young people. It should also be noted that babies and infants may still be in neonatal services rather than paediatric and will therefore receive palliative care in the neonatal setting.
215	Bliss	4	This should include babies and infants alongside children and young people. It should also be noted that babies and infants may still be in neonatal services rather than paediatric and will therefore receive palliative care in the neonatal setting.
216	British Psychological Society	4	It is key to have the definition of a specialist palliative care team as is already there, however a clearer definition of who the "experts in child and family support" are is also needed.

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			There is need for clarity in the essentiality of psychological intervention for a practitioner/applied psychologist in the role of interventionist (patient, family) and clinical supervisor. Furthermore, the practitioner/applied psychologist may have a significant role in leadership/facilitation of the palliative care team promoting professional effectiveness and resilience in the team members.
217	British Psychological Society	4	Data collection will need to have some way of recording “unresolved” distressing symptoms – so as well as defining specific symptoms, you will also need a concrete way of defining and measuring whether they have resolved or not and a timescale for what would be classed as “resolved”.
218	British Psychological Society	4	This statement addresses specifically potential distressing symptoms from a medical/physical symptom perspective. Specific distressing symptoms should include low mood and anxiety (including fear of death) as well as more medically orientated symptoms like pain and agitation.
219	Children’s and Young People with Cancer Clinical Reference Group	4	Communication skills are not always at their best at end of life care. This is an area where those communicating with families need to be confident and that can help the young person when they need it most.
220	Children’s and Young People with Cancer Clinical Reference Group	4	The statement that the team should include a consultant paediatric specialist in palliative care does not reflect those teams who have consultant paediatrician who have expertise, or indeed consultant paediatric oncologists who also deliver palliative care with experience and expertise. This statement should be reworded to reflect these individuals who currently exist appropriately. The specialist team having pharmacist attached is important if resources allow. Consultant 24/7 support is great but there is little comment about the specialist support and value of Band 8 CNS or nurse consultant who has a different, but valuable involvement in supporting care. In fact potentially we are failing the families if they only have access to a consultant- they are not the panacea of all end of life care and specialist nurses have an equal role. Some of the people involved in NICE guidance have a very heavy consultant led service and therefore this influences their experiences. CNS value should be recognised and be available 24/7 (not a community nurse but a specialist nurse). The advice 24/7 should be from a specialist palliative team, which is both nurse, and doctor lead. Every young person should receive the same level of end of life care, if they wish to be at home that should be provided regardless of age. Hospice care can be a long way from home adding to distress. All areas should provide end of life care and pain relief at home, why should 16/17 yr olds be treated differently. ‘Rates of unresolved symptoms’ –well we don’t know how to manage a lot of symptoms including fatigue and anorexia so this that is a good measure. Perhaps- just being reviewed by a specialist service and evidence of on-going systematic symptom assessment maybe a better measure.
221	CLIC Sargent	4	We would comment that the definition of the specialist paediatric palliative care team be expanded to better reflect the role of the charity sector. We provide support to infants, children, young people and their families and work closely with other parts of the wider specialist team.

ID	Stakeholder	Statement number	Comments[1]
222	CLIC Sargent	4	It is also important to factor into this quality statement that professionals working with children, young people and their families at the end of life are trained with Advanced Communication Skills, or are working at level 3 of NICE psychological guidelines, to ensure they are competent and confident in communicating with young people and their families at this time.
223	Demelza Hospice Care for Children	4	In common with the TfSL response, we feel that this standard should be about 'managing distress', and not only 'distressing symptoms', as the latter implies that distress can only be medical. The standard would then link to the previous and next standards about emotional support, and include consideration of other forms of practical support.
224	East Midlands Children and Young People's Palliative Care Network	4	We suggest the following wording: Infants, children and young people approaching the end of life should be managed by a coordinated multidisciplinary team with expertise to assess and manage all their symptoms. Most children will remain and be successfully managed under the care of the specialist teams who they have known since their diagnosis of a life limiting condition e.g. the children's oncology service, the paediatric neurodisability team, the children's renal team. However advice from a specialist paediatric palliative care team should be available promptly when needed, particularly in the event of unresolved distressing symptoms such as pain and agitation.
225	East Midlands Children and Young People's Palliative Care Network	4	The number of children and young people assessed by the specialist palliative care team will be ascertainable, but the denominator will be difficult to ascertain.
226	East Midlands Children and Young People's Palliative Care Network	4	Symptom control / pain measures can be completed by some client groups e.g. children and young people with neuromuscular conditions or oncology problems. Post bereavement interviews with parents can give a proxy measure of symptom control at end of life, with or without specialist paediatric palliative care team involvement. Professionals can give feedback on the benefit of the involvement of the specialist palliative care team.
227	Esoteric Practitioners Association (EPA)	4	**Environment, movement and sound:** • When you are dying you are very sensitive to the energy of others. If someone is rough or too quick it will increase the pain. Health Care professionals (HCP) need to take responsibility for their movements, and to be aware of how movement in the room impacts on the child and ripples out to the parents. For example, if a child becomes more agitated because of an HCP who is not being aware of jarring or harsh movements this doesn't just affect the dying child, the parents increase in anxiety as the child becomes more unsettled.

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			• We need to be more mindful of the basic design of palliative care units and to ensure the minimum impact on the patient. For example, the lids of the bins are normally heavy and noisy and without meaning to, a HCP can slam it down, which reverberates throughout the bodies of everyone, but someone who is dying is extra sensitive to all the ways others are being in their movements. Any jarring sound is going to cause more unnecessary pain to the dying person. Practitioners need to be especially aware of how their bodies and movements can support someone or can negatively impact them. • Within this context, caring for patients is more than the healthcare professionals at the bedside. Everyone in the hospital is responsible for the patient well-being and care. For example, the cleaning team are hugely important and have just as much to offer the patient as the nursing staff if they move through the ward with care and gentleness. **The power of touch:** Gentle and considerate care supports with pain relief. The quality of touch is very important. A loving touch is so much more than just touching without harshness. https://www.amtamassage.org/ statement6.html **Self care for staff:** There is much anecdotal evidence to suggest that self care of staff affects the service users' well-being and also increases staff self worth, resilience and saves money through less staff absence. Those who work in palliative care can experience much stress and depression through watching patients suffer. Nurses often feel a sense of failure – much of their own hurts are raised too in watching young patients die and if un-dealt with, compound on their feelings of being unwell. A study supported by the NHS has shown that there is a link between staff wellbeing and improved patient care: **https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216380/dh_128813.pdf** We feel it is important to: • support practitioners to begin to go deeper with self-awareness; if you are not sensitive to yourself you can't be sensitive in your work environment. • be awarene of the impact of life-style and how this affects the quality of your care and your patients' well-being - for example getting over tired, feeling bloated from over eating, smoking, drinking, recreational drugs or on medication, will affect the care you are able to give and the care received.

ID	Stakeholder	Statement number	Comments[1]
			• develop ways to deal with stress on a practical level, so that HCP can bring more harmony to the children and families they are caring for. • deepen the quality of care for HCP so that they are supported to go beyond simply complying with policies, functioning (pushing through at the expense of their own mental and physical health) and coping. The NHS has a responsibility to take care of staff, as anything that stresses or unsettles staff has an impact on patients, particularly on children who are dying and their families.
228	Leeds Teaching Hospitals NHS Trust	4	It would be particularly difficult to provide a denominator for this statement because of the difficulty identified above of 'capturing' all cases.
229	Neonatal and Paediatric Pharmacists Group (NPPG)	4	The NPPG welcomes the recommendation to include a pharmacist with expertise in specialist paediatric palliative care as one of the essential members of specialist paediatric palliative care teams.
230	Paediatric Chaplaincy Network GB&I	4	It would improve the support to many patients and families if it read religious as well as spiritual on page 14, could read spiritual or religious. Definition of these terms are in the original NICE guideline. It would be helpful to have a definition of spiritual distress.
231	RCGP	4	• Denominator. 'the number of infants, children and young people approaching the end of life with unresolved distressing symptoms' will be impossible to count. For any clinician to record a child having distressing symptoms that, by definition they did nothing to resolve seems unlikely.
232	Royal College of Nursing	4	This needs to link to a clear definition about what specialist children's palliative care is – and what it means – it appears later in the document but should be linked here in case readers do not go any further than the headlines. We would suggest that the statement should also make reference here to specialist paediatric pharmacy support – it is found later in the document and could be missed.
233	Royal College of Paediatrics and Child Health	4	Structured debriefing of relatives as part of bereavement follow up, done sensitively and qualitatively, is the best way of measuring outcome. All the process measures imaginable are no good if the family's experience is poor.
234	Royal College of Paediatrics and Child Health	4	At this time, there are insufficient specialist paediatric palliative care teams across this UK to make this an achievable objective in an equitable way. Setting this standard is welcome to try and drive an increase in the number of paediatric palliative care specialists. At present some regions do not have palliative care specialists and in other regions most paediatric palliative care consultants are so pushed to the wall delivering front line care that they don't have the capacity to train and support other professionals to manage symptoms. The bottom line is that in a child with LLC any distressing symptom needs to be promptly addressed.

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235	Royal College of Paediatrics and Child Health	4	We suggest the wording: **Infants, children and young people approaching the end of life should be managed by a coordinated multidisciplinary team with expertise to assess and manage all their symptoms. Most children will remain and be successfully managed under the care of the specialist teams who they have known since their diagnosis of a life limiting condition e.g. the children's oncology service, the paediatric neurodisability team, the children's renal team. However advice from a specialist paediatric palliative care team should be available promptly when needed, particularly in the event of unresolved distressing symptoms such as pain and agitation.**
236	Royal College of Paediatrics and Child Health	4	The number of children and young people assessed by the specialist palliative care team will be ascertainable, but the denominator will be difficult to ascertain.
237	Royal College of Paediatrics and Child Health	4	In terms of what should be measured, it matters more to measure the number of children with unresolved symptoms and consider how these could be have been managed with appropriate resource. Symptom control / pain measures can be completed by some client groups e.g. children and young people with neuromuscular conditions or oncology problems. Post bereavement interviews with parents can give a proxy measure of symptom control at end of life, with or without specialist paediatric palliative care team involvement. Professionals can give feedback on the benefit of the involvement of the specialist palliative care team.
238	Royal College of Paediatrics and Child Health	4	We do not think that this is measurable. Who will define / decide whether a particular child/young person has unresolved distressing symptoms. Sadly, while it is much better to measure outcomes than processes, if this standard is to remain, then it would have to be about timeliness of review of distressing symptoms (e.g. nausea, agitation, pain)
239	Royal College of Physicians (RCP)	4	This is difficult but mirroring the measures for adult palliative care may be appropriate using: • death at home or outside hospital, • issue of and use of "anticipatory end of life box including drugs for common symptoms and interventions for comfort. • Number of registered advanced care plan with key out of hours organisations including ambulance service etc in a locality • VOICES bereavement survey • Nationally run and funded Hospital note audit of deaths (similar to the 60 note death audit undertaken by adult services) • Number of emergency admissions that occur in last 90 days of life – suggesting and ineffective advanced care plan or inappropriate place of care • I want great care feedback for hospice, paediatric palliative care teams
240	Teenagers and Young Adults with Cancer	4	No. The major issue with this QS, is the definition of a 'specialist paediatric palliative care team' and how this is commissioned / resourced. Much of front-line paediatric palliative care is delivered by CCN's / Community paediatricians with an interest in paediatric palliative care or possibly primary care and is not reflected in this QS. Provision of paediatric palliative care is variable across providers that this QS is almost meaningless.

ID	Stakeholder	Statement number	Comments[1]
241	Teenagers and Young Adults with Cancer	4	Although it should be easy to collect data on who is involved in delivery of elements of paediatric palliative care, it is difficult to see how data could be collected on 'unresolved distressing symptoms'. This would require the use of some form of unified electronic patient record and a more objective measure of 'unresolved distressing symptoms'.
242	Teenagers and Young Adults with Cancer	4	This achievement of this QS will be reliant on the definition of a 'specialist paediatric palliative care team' and effective commissioning process for this along with a clear definition of a service specification for paediatric palliative care. There remains confusion about this process and it remains unresolved despite the NHSE publication in 2013 of e03-paedi-med-pall. Based on the definition contained within this guidance, this is not deliverable.
243	Teenagers and Young Adults with Cancer	4	24/7 access to palliative care advice and provision of CCN support for families during end-of-life care are perhaps more meaningful measure of performance currently. This should be flexible and have an ability to respond to individual patient /carers needs.
244	The Donna Louise Children's Hospice	4	Clinical symptoms are not the only measure of quality improvement. Many of the biggest problems faced by children and families are of a Psycho-social nature, family support, emotional care and support, housing, access to education, access to therapeutic support i.e. physio therapy, speech and language etc; securing the right equipment at the right time to facilitate discharge from hospital. It is important that these issues are not overlooked.
245	The Donna Louise Children's Hospice	4	This is quite subjective. Review from staff (as part of debrief) and family (would need to be done with psychologist/ specialist support probably sometime after death) regarding any distressing symptoms. There is work underway already to develop quality measures within children's palliative care – perhaps these should be revisited and support given to develop and implement these as part of the NICE guidelines and standards. Whatever measures are developed must be developed with the input of children, young people and families, not professionally led. They must also be both qualitative and quantitative and not just medically focused. We need to be able to measure impact of interventions from the child and families experience.
246	The Donna Louise Children's Hospice	4	There is no specialist paediatric palliative care team! Unresolved distressing symptoms to be assessed by the specialist paediatric palliative care team- This includes • Paediatric palliative care consultant (is this only those with a CCT in paediatric palliative care (very few of those in the Country) or is this someone with an interest too)- this needs to be better defined • Nurse with expertise in paediatric palliative care (locally don't have one in hospital, community pall care nursing team and hospice would count) • Pharmacist with expertise in specialist paediatric palliative care- for most hospitals this is not achievable and how is "expertise" and "specialist paediatric palliative care" again defined • Experts in child and family support- achieved through the hospice, but not every life limited child is referred or has access
247	Together for Short Lives	4	This should state that the specialist paediatric palliative care team should seek specialist paediatric pharmacy support.
248	Together for Short Lives	4	For this quality statement to be measured in practice, we suggest that there would need to be a standardised symptom assessment tool.
249	Together for Short Lives	4	We suggest that this statement is widened to 'managing distress' rather than 'unresolved distressing symptoms' which is exclusively medical.

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			The phrase 'specialist paediatric palliative care team' should hyperlink to the definition of this team. This will help to draw attention to how these teams are composed.
250	Together for Short Lives	4	The phrase 'unresolved distressing symptoms' is subjective. Additionally, some symptoms may not be resolved but will be managed as well as possible, while some symptoms such as secretions and fitting are unlikely to be resolved. As in comment 18, we ask that this is replaced by 'distress'.
251	Together for Short Lives	4	This section should state that the specialist paediatric palliative care team should work with the local children's hospice team where appropriate.
252	United Hospitals Bristol NHS Foundation Trust	4	To meet this standard there would be a requirement to invest in the development of specialist paediatric palliative care teams to ensure that the team would be able to provide such an assessment around the clock and wherever the child is cared for
253	University Hospital Birmingham	4	The TYA population does not need access to specific paediatric palliative care, patients are well supported by the hospital and community palliative care team and TYA staff. Paediatric services would not support all of our TYA's currently as they would be classed as adults.
254	West Midlands Paediatric Palliative Care Network	4	No. The major issue with this QS, is the definition of a 'specialist paediatric palliative care team' and how this is commissioned / resourced. Much of front-line paediatric palliative care is delivered by CCN's / Community paediatricians with an interest in paediatric palliative care or possibly primary care and is not reflected in this QS. Provision of paediatric palliative care is variable across providers that this QS is almost meaningless.
255	West Midlands Paediatric Palliative Care Network	4	Although it should be easy to collect data on who is involved in delivery of elements of paediatric palliative care, it is difficult to see how data could be collected on 'unresolved distressing symptoms'. This would require the use of some form of unified electronic patient record and a more objective measure of 'unresolved distressing symptoms'.
256	West Midlands Paediatric Palliative Care Network	4	This achievement of this QS will be reliant on the definition of a 'specialist paediatric palliative care team' and effective commissioning process for this along with a clear definition of a service specification for paediatric palliative care. There remains confusion about this process and it remains unresolved despite the NHSE publication in 2013 of e03-paedi-med-pall. Based on the definition contained within this guidance, this is not deliverable.
257	West Midlands Paediatric Palliative Care Network	4	24/7 access to palliative care advice and provision of CCN support for families during end-of-life care are perhaps more meaningful measure of performance currently. This should be flexible and have an ability to respond to individual patient /carers needs.
258	Association of Family Therapy	5	Emotional and psychological support should be systemic too – framing this as only offered to parents/carers may inadvertently exclude the supportive nature of the sibling relationship and profound impact of the death on them. This statement should also connect up with international guidance on risk stratification and case-finding models for provision of bereavement support. That is, ensuring that the amount of support offered is tailored to the risk of poor bereavement outcomes for the family. The emotional and psychological support needs of carers and family members should not only be focused on bereavement. Whilst bereavement support is very important, support at earlier stages (e.g. during advance planning discussions, when information or circumstances change, when unexpected things happen, and a host of other reasons) before the actual end of life may be very important in helping the family to set the scene for what they see as 'a good death'
259	Association of Family Therapy	3 and 5	Emotional and psychological support for children and for parents and carers are listed as separate quality statements. It should be acknowledged that these impact upon each other, so for example, sending all off in different directions may be really unhelpful (e.g., when children and parents are given their own therapy that is separate and not co-ordinated. This is not to challenge the idea

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			that children and young people can be offered separate space for individual input, but that there needs to be consideration about how and when this is linked into the input for parents (would also include siblings and grandparents etc. here too.) Similarly there may be children who are wanting to know more than their parents are wishing to share, and working through these conflicts of opinion requires systemic input, including for example outreach to schools who may be themselves managing such dilemmas.
260	Association of Paediatric Chartered Physiotherapists	5	Area of need and requirement Should be able to find data, but wide range of agencies delivering this would need coordination Coordination and management of systems, groups, services that provide this required in order to achieve this. Difficult to manage currently NOTE: Children's hospices currently provide this, other charities will for their area e.g. SANDS however, what formal NHS support is out there I am not sure and so would need to be addressed. In addition, what does 'approaching' EOL mean? All those will a child will Life limiting condition should be supported and this starts at diagnosis.
261	Birmingham Children's Hospital	5	This should link directly with QS 1 and should be integral to development and delivery of an ACP. This is an area of cross over directly with primary care. The challenge, therefore, is accessing data from different data sources.
262	Birmingham Children's Hospital	5	See comment above re: accessing different data sources. The additional challenge will be obtaining data on families that may access this aspect of support through a 3rd sector organisation. How could this data be captured?
263	Birmingham Children's Hospital	5	A local directory of support services would be a useful tool to have available and should be deliverable without much, if any additional resource. Obtaining data on how / which services are accessed by individual carers / families might be more challenging as some of this will be via the 3rd sector route. It is perhaps an area where 3rd sector organisations have a well-defined role.
264	Bliss	5	Throughout this statement reference must be made to parents and carers of babies and infants alongside those of children and young people. These are not currently included at all, however will have specific needs for emotional and psychological support.
265	British Psychological Society	5	Bereavement services are currently patchy at best and largely provided by third sector organisations with very little NHS funded provision for bereavement support. We believe that it needs to be made clear how access to and take up of bereavement support will be measured. This is an opportunity for NICE to consider grief and bereavement work as a specialism and recommend training need for the healthcare professionals identified.
266	Children's and Young People with Cancer Clinical Reference Group	5	Bereavement support is only mentioned for parents/carers not wider family or siblings. Financial advice can be crucial at this time, managing debt, a further reduction in income and in some instances a clawback on benefit payments made earlier in time. Bereavement services are often dealt with by the hospital team and can sometimes seem age inappropriate for the families contacted.
267	CLIC Sargent	5	We would suggest that this statement's definition of 'bereavement support' is expanded to include a discussion of relevant financial support available for funeral costs. Bereaved parents who participated in our Cancer costs (2016) research told us that funeral costs were a significant financial concern for them. For some families, this may come after a long period of treatment, remission,

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			relapse or repeated relapses, and hit them at a point when they are already deep in debt. With the pressure of managing finances during their child's treatment causing considerable stress and anxiety for many families, signposting to available support from the Social Fund would be an additional means by which to support parents and carers to cope after the death of their child. It is also important to note that financial support provided to families of children with cancer, and to young people with cancer, for example through Disability Living Allowance or Personal Independence Payments, comes to an end when that child or young person dies. Therefore, easy and timely access to appropriate information on welfare and finances would be beneficial for parents.
268	CLIC Sargent	5	Bereavement support should also include information to parents and carers about peer support services during and after the death of their child, and services offered by Child Bereavement UK and the Child Death Helpline.
269	Demelza Hospice Care for Children	5	As with Quality Standard 3, we find it unhelpful that the provision of support to children/young people, and to parents/carers, is contained in separate standards, and misses out siblings and whole-family approach entirely. Otherwise our comments are identical with that of our comments on Standard 3, including the need for a clearer and wider definition of what constitutes emotional support.
270	East Midlands Children and Young People's Palliative Care Network	5	The number of children and young people approaching the end of life will not be known. It will be easier to collect the information after the death of a child with a LLC. We suggest the wording: Proportion of parents or carers of children and young people who died of a LLC who had a bereavement support plan developed with them as their child's death was approaching. Denominator will be -the number of children and young people who died of a LLC in that year. It would be helpful to further define what is meant by 'formal bereavement support' and 'bereavement support plan'. Some parents or carers will need formal bereavement counselling which needs to be available too.
271	Leeds Teaching Hospitals NHS Trust	5	Again this is very difficult to 'measure' as the definition of 'approaching the end of life' is ill defined, and there is no current means of data collection I can think of which would capture this.
272	Martin House, Hospice care for children and young people	5	It is relevant that good \`emotional and psychological support\` for parents or carers is available throughout. This would include dealing with such issues as grief, loss, bewilderment etc. However it can be unhelpful to some families to call it \`bereavement support\` before their child has died.
273	Paediatric Chaplaincy Network GB&I	5	Neither spiritual nor religious support is offered to families
274	Rainbow Trust Children's Charity	5	We recommend the inclusion of siblings, to read:

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			'Parents or carers, <u>and siblings</u> of infants, children and young people approaching end of life are offered bereavement support when <u>a</u> child is nearing the end of their life and after their death.' This would be in line with recommendation 1.1.6 of the full guidance.
275	Rainbow Trust Children's Charity	5	In Rainbow Trust's mapping of bereavement support available in the areas where our teams operate, we found that current provision is patchy. Our mapping found only two sources of local bereavement support in Cumbria, both in the southern part of the region, compared to numerous charities operating in and around Essex or Southampton, for instance. Child palliative care organisations like Rainbow Trust or children's hospices may also provide tailored bereavement support, 'tribute days' and sibling support groups, but access to these will be dependent on where a family is based. Similarly, Together for Short Lives' research in 2016 found that 17% of clinical commissioning groups (CCGs) and 70% of local authorities in England do not commission bereavement support.[5] In terms of resource requirements, bereavement support has the potential to draw upon volunteer support if appropriately trained and managed. One source of support can be other parents who have experienced having a terminally ill child. For example, in a pilot 'Face to Face' befrienders project in 2016, Rainbow Trust provided two parents (whose families our service has supported in the Southampton area) with 40 hours of accredited training in befriending skills. This drew on a model developed by Scope and adapted by Acorns Children's Hospice Birmingham, recognising that parents with a child with a life threatening or terminal illness often feel very isolated and alone. These parents are now being matched with other parents seeking support, and the training will be provided during 2017 to parents in Essex who are also interested in providing this support on a voluntary basis.
276	Rainbow Trust Children's Charity	5.	As per comments 4 and 8, this depends on what indicators are set for achieving this standard. Would providing a leaflet on bereavement support be counted as 'being offered support' (a one off, light touch interpretation of this standard) or would measurement capture a more substantial, in depth process in which options are discussed by a trained professional who can approach the topic with tact and sensitivity at different points in a family's experience of bereavement? We strongly recommend that it is the latter interpretation. However this would require appropriate qualitative data collection and the ability to collect data will likely vary in different areas.
277	RCGP	5	• This statement should include siblings as well as parents and carers. Also bereavement care should include special cultural or religious arrangements. • Under structure there is mention of formal bereavement support. Not many agencies provide such support, most are charities. It's not clear that such agencies would be included under the heading of 'formal'.
278	Royal College of Nursing	5	As per previous comment, this is a key statement but siblings and extended family members also need to be offered bereavement support.

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[5] http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf

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279	Royal College of Nursing	5	We reiterate the point made earlier that this statement needs to include siblings and the recognition that there are different levels of intervention and for it to be consistent with the universal approach of talking therapies, the ability to refer on for more therapeutic approach if required. http://childhoodberea.wpengine.com/pyramid/#.WRHoOE8kuvG
280	Royal College of Nursing	5	Grief and loss support is not just about support when end of life is near, care should start from diagnosis. As previously commented in statement 3, there is a lack of recognition of the needs of other family members e.g. siblings. Should this be grief and loss support rather than bereavement?
281	Royal College of Nursing	5	The Human Tissue authority and NHS Choices use the word 'post mortem' and not "autopsy". It would be helpful to use the same terminology as the relevant English medical terminology https://www.hta.gov.uk/sites/default/files/Post-mortem_examination_-_your_choices_about_organs_and_tissue_FINAL_v3_0.pdf
282	Royal College of Paediatrics and Child Health	5	It is almost impossible to discuss a bereavement support plan before death, even when that death is clearly imminent. You just don't know how you will feel afterwards. In fact in the early days after the death the pain is so great that you can't think about the longer term at all; all you can do is cry, and anything you had sort of planned beforehand gets chucked away. It is very nice if after a few weeks someone calls to see how you are doing, and then gradually you can think about how you might move forward and whether any external help might be valuable. For some it is, and others it isn't. It's quite nice to have the offer made a bit later too, as this shows that you haven't been forgotten.
283	Royal College of Paediatrics and Child Health	5	Encouraging the development of services to better support families emotionally is very welcome and a gap in many areas. Again, the role of the GP and primary care team should be emphasised here.
284	Royal College of Paediatrics and Child Health	5	The number of children and young people approaching the end of life will not be known. It will be easier to collect the information after the death of a child with a LLC. We suggest the wording: **Proportion of parents or carers of children and young people who died of a LLC who had a bereavement support plan developed with them as their child's death was approaching.** Denominator will be **-the number of children and young people who died of a LLC in that year.** It would be helpful to further define what is meant by 'formal bereavement support' and 'bereavement support plan'. Some parents or carers will need formal bereavement counselling which needs to be available too.
285	Royal College of Paediatrics and Child Health	5	What is meant by 'bereavement support' please?
286	Royal College of Paediatrics and Child Health	5	We feel that this is a weak section. The definition of 'bereavement support' services as 'Talking therapies aimed at supporting an individual anticipating or experiencing the loss of a loved one' is meaningless. It is important to get this right as otherwise it will impose upon commissioner an obligation they are unable to meet. What is more important is to establish a pathway of communication where by the bereaved are able to seek answers to their questions.

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287	Royal College of Paediatrics and Child Health	5	The measure should also include emotional and psychological support for siblings. There also needs to be comparison of what support is available – e.g. face to face vs telephone, timeliness, out of hours, use of alternative support such as via e-communication/social media and the length of time support is available. And, like for statement 3, a measure of uptake, as offering a service that is not wanted or not accessible is not effective.
288	Royal College of Paediatrics and Child Health	3 and 5	The emotional and psychological needs should also include siblings and their potential role as a young carer (statutory carers assessment to be offered for siblings and family members). Where emotional or psychological support is offered, it needs to be provided (from signposting to therapeutic intervention) in line with the Accessible Information Standard 2017 so that there are appropriately commissioned services meeting the communication needs of the patient.
289	Royal College of Paediatrics and Child Health	3 and 5	Whilst there is reference to LLDD, communication needs also extend to those who have sensory impairments, English as a second language or require additional communication aids such as symbols/PECS. The RCPCH &Us Voice Bank 2016 make reference to the need for appropriate communication models that includes Be short Be provided on a number of occasions – giving everything at the beginning in written or verbal form can be overwhelming Be in a variety of methods in order to support family sharing (one leaflet doesn't work for everyone) Be mindful of those with English as a second language (e.g. BSL, Polish, Urdu) Be visual with images that support the explanation not just stock photos to make it "friendly" Be making the best use of technology – email, text, WhatsApp, trust apps, websites, video stories of patients and their family experiences, social networks / chats Have language that is accessible It would be useful to include an expectation around signposting to information that is relevant to the client group e.g. Carers Trust, Contact a Family, Together for Short Lives, WellChild and ensure that local multi-disciplinary teams have access to up to date local voluntary sector/support service information.
290	Teenagers and Young Adults with Cancer	5	This should link directly with QS 1 and should be integral to development and delivery of an ACP. This is an area of cross over directly with primary care. The challenge, therefore, is accessing data from different data sources.
291	Teenagers and Young Adults with Cancer	5	See comment above re: accessing different data sources. The additional challenge will be obtaining data on families that may access this aspect of support through a 3rd sector organisation. How could this data be captured?
292	Teenagers and Young Adults with Cancer	5	A local directory of support services would be a useful tool to have available and should be deliverable without much, if any additional resource. Obtaining data on how / which services are accessed by individual carers / families might be more challenging as some of this will be via the 3rd sector route. It is perhaps an area where 3rd sector organisations have a well-defined role.
293	The Donna Louise Children's Hospice	5	There is no bereavement support commissioned for parents and carers of infant, children and young people nearing the end of their life and after their death. Any bereavement support locally (apart from oncology) is provided by charities.
294	Together for Short Lives	5	This section refers to 'emotional and mental health problems, and relationship issues' – the meaning of which is not clearly defined. We would suggest the phrase 'mental wellbeing and the prevention of family breakdown' would be clearer and preferable to use. This section refers to 'autopsy'. The expert consensus is that 'post mortem examination' is now the preferred term to use instead.

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			We suggest that 'genetic risk for family planning' is changed to 'plans for a future pregnancy'.
295	Together for Short Lives	5	As with Quality Statement 3, we believe that this statement should address support for the whole family, including the child, siblings (as specified by recommendation 1.1.6 of the full guidance), and parents or carers. The full guidance also specifies (recommendation 1.1.7) that 'other family members (for example grandparents) and people important to the child or young person (for example friends, boyfriends or girlfriends) may need support. This may include social, practical, emotional, psychological, and spiritual support.' This statement should state that bereavement support is offered 'at the point of diagnosis of a life-limiting condition' as grief and loss starts from the point of diagnosis. The complexity of life-limiting conditions means that many children and young people have a prognosis that will not be clearly defined and their condition may change rapidly.
296	Together for Short Lives	5	This quality measure establishes the proportion of parents or carers who have a bereavement support plan in place. However, not all parents will want pre-death bereavement support and many will not be ready for some time after their child has died. The quality measure should reflect this.
297	Together for Short Lives	5	This section states that practitioners "should establish if the child's parents or carers have any learning disabilities." They may not be qualified to carry out a learning disability assessment. Practitioners should 'assess the level of understanding and tailor the information that they provide to parents or carers'.
298	Together for Short Lives	5	There is a time and skills shortage that means that this statement is difficult to achieve. Together for Short Lives' research in 2016 (http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf) found that 17% of clinical commissioning groups (CCGs) and 70% of local authorities in England do not commission this support.
299	Together for Short Lives	5	This definition should be widened so that it includes talking therapies as part of a broader range of therapies such as art therapy.
300	United Hospitals Bristol NHS Foundation Trust	5	Challenging to define what is meant by the term 'bereavement support.' The definition provided in the document remains open to misinterpretation, specifically with regard to what 'talking therapies' are
301	United Hospitals Bristol NHS Foundation Trust	5	What can be reasonably expected of the NHS with regard to bereavement support provision?
302	University Hospital Birmingham	5	Some families and patients might welcome bereavement support but others would baulk at, particularly when it is labelled as such. The issue is really about naming it and some patients and families simply don't want to go there however beneficial it might be. The TYA team supports parents and patients in the end of life stages but it is bespoke and very much nuanced to where they are emotionally, psychologically and spiritually. Calling in a Bereavement specialist at a late stage could be tricky if they have not been involved before. That isn't to say that it wouldn't be beneficial if the family or patient are ready for it. It would be really good to have that specialist bereavement support available, when the team judges it appropriate, or indeed to provide those skills within the team.

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303	West Midlands Paediatric Palliative Care Network	5	This should link directly with QS 1 and should be integral to development and delivery of an ACP. This is an area of cross over directly with primary care. The challenge, therefore, is accessing data from different data sources.
304	West Midlands Paediatric Palliative Care Network	5	See comment above re: accessing different data sources. The additional challenge will be obtaining data on families that may access this aspect of support through a 3rd sector organisation. How could this data be captured?
305	West Midlands Paediatric Palliative Care Network	5	A local directory of support services would be a useful tool to have available and should be deliverable without much, if any additional resource. Obtaining data on how / which services are accessed by individual carers / families might be more challenging as some of this will be via the 3rd sector route. It is perhaps an area where 3rd sector organisations have a well-defined role.
306	Association of Family Therapy	6	This is a very relevant standard to support a full range of choice for children, young people and families. Children young people and families choosing end of life care at home should have the same access to advice and support on a 24 hour basis as those in hospital or hospices. It is likely that families will find this easier to access if they have a relationship already with the team who provide this 24 hour support.
307	Association of Paediatric Chartered Physiotherapists	6	Area of need Data available Would need massive investment, good communication and joined up working. NOTE: Many children's hospices provide this care but the service is not equitable across the country. Would be ideal to not just have access to nursing and drs but the wider MDT who can play a large and important role in end of life care.
308	Birmingham Children's Hospital	6	This links with QS 1 and QS 4. Place of death and choice of place of death is perhaps a more useful measure / comparator and may well directly relate to the availability of services to support families at home at the time of death.
309	Birmingham Children's Hospital	6	Measuring existing service provision should be easy.
310	Birmingham Children's Hospital	6	This links back to the effective commissioning of palliative and end-of-life care services and clear lines of responsibility if services are not commissioned. It is likely that increased resources / investment will be required to ensure uniformity of service provision throughout England & Wales. See also Comment # 10
311	CLIC Sargent	6	We believe there is a significant issue for 16 to 17 year olds due to configuration of community nursing, which in some areas only goes up to age 15. This can severely affect a young persons end of life experience and in particular pain relief and discomfort if they wish to die at home. It means that a disproportionate number of young people do not have a choice where they die. We would suggest a good quality measure would be to assess which areas of England provide end of life and pain relief by community or district nurses to 16 or 17 year olds and identify what steps they are taking to resolve this.
312	CLIC Sargent	6	Whilst we support this quality statement, we believe that there will be challenges in implementation by local services considering the point made above about current workforce challenges.

ID	Stakeholder	Statement number	Comments[1]
313	Demelza Hospice Care for Children	6	The title 'Home care' is unhelpful. The Standard itself seems to be clearly focussed on end of life care at home, but the term 'home care' is much wider. This Standard appears to only require measures to be taken if an authority chooses to provide access to end of life care at home. Therefore the easiest way to meet the Standard is to not provide this support (as indeed many areas do not). The standard could therefore be detrimental to the support received by families. In addition, the specific requirements of the standard are not achievable in the vast majority of areas: there are not enough available specialist consultants and community nurses for them to be directly involved in each child's care at all times. However, many areas are now able to provide quality care to children and families at end of life in their own homes through the Managed Clinical Network approach, which ensures effective deployment of the expertise of specialist consultants, nurses and other staff within local teams. We would suggest strongly that the standard is re-written, to be less specific about the staff who should be leading care in the home if that service is offered; and to be about providing choice about place of death, including at home. The Managed Clinical Network approach should be adopted by all areas, and span care at home, in hospitals, and in hospices. This aligns with existing NICE, and Department of Health, guidance
314	East Midlands Children and Young People's Palliative Care Network	6	We agree that home-based care can be preferable and improve patient experience. High quality care from a team with appropriate experience and expertise should be available at all hours of the day or night. This is not necessarily the specialist palliative care team. It is also important to children and families that the professionals caring for them, particularly in their home are a small consistent team of familiar people who they know and trust. Again this is not necessarily the specialist palliative care team. 24 hour availability of a consultant in paediatric palliative care is not currently available in most areas and there would need to be a huge financial investment to have consultants in paediatric palliative care to provide an out of hours rota even at regional level. For example, in the East Midlands region there are currently no consultants in paediatric palliative care and it would require at least 5 new consultant posts to be able to provide a regional rota for telephone advice at a cost of more than £500,000. Even with that investment they would not be able to provide a useful face to face service out of hours to such a large geographical area as the East Midlands. Also, we anticipate that the number of times they might be called is very few and therefore this would not be a good use of financial resources. We suggest the following wording: Having good anticipatory symptom management plans in the home developed in advance by the child's medical specialist, with advice from the paediatric palliative care team and / or pain specialist is essential.

ID	Stakeholder	Statement number	Comments[1]
			Infants, children and young people approaching the end of life and being cared for at home should have 24 hour access to face to face paediatric nursing care and advice from their specialist medical team. A doctor with appropriate skills who is familiar with the child and family needs to be able to provide home assessment visits 24/7. (This is more important than it being a member of the specialist palliative care team.) This can be provided by the child's consultant paediatric team working together with the child's named GP, but may require a small amount of additional funding for out of hours home visits by the paediatrician. Case example .. In Nottingham the neurodisability paediatricians are commissioned to provide 24/7 face to face support to children with complex disability having end of life care at home, approximately 5 children per year, with additional payment to the team of 2 consultant PAs i.e. £20,000 per annum. This is in addition to the generic community nursing service.
315	East Midlands Children and Young People's Palliative Care Network	6	We suggest the wording: Evidence of local arrangements to ensure that advice from an appropriately skilled consultant such as a paediatric oncologist, palliative care consultant or paediatrician with specialist training in palliative care is available 24 hours a day.
316	East Midlands Children and Young People's Palliative Care Network	6	We suggest the wording: Proportion of infants, children and young people approaching the end of life and being cared for at home who have 24 hour access to face to face support from an appropriately skilled consultant such as a paediatric oncologist, palliative care consultant or paediatrician with specialist training in palliative care.
317	Esoteric Practitioners Association (EPA)	6	It is important to note that there can be an unrealistic ideal or picture of dying at home, which can cause a lot of stress for carers, so it is important not to get caught up in that. For example, depending on the speed of transfer there may not be the right bed, equipment and so on at home, which can mean a lot of running around for the carers involved, at a time when they are feeling very fragile. Before this there needs to be a choice which has to respect the wishes of the carers. If the carers are stressed and anxious and the patient starts to manifest symptoms then this is going to be overwhelming for them to have to deal with if they are not ready, or don't have the experience to handle. It is important for the carers to accept the truth of where they are at, rather than where they wish to be. Being at home is not a 'better' way of dying necessarily. At end of life it can be quite a straight forward situation with no emergencies or medical intervention needed. Often the hospital doesn't feel like the right place for the patient to die in. However to have a nurse present to explain the process would be very helpful for the carers. We agree with your recommendation that access to 24/7 support is needed, even if on the phone. It is important for the patient and carers to be offered informed choices with awareness and to understand exactly what the choice implies, with no investment in that choice but free to change their minds depending on circumstances.
318	Esoteric Practitioners Association (EPA)	New suggested statement	In the briefing paper and in the NHS generally we are glossing over the crucial aspect of practitioner self awareness. This is where we could be focusing our CPD days.

ID	Stakeholder	Statement number	Comments[1]
			Whilst this is a quality standard document – have we really understood what this term "quality" means? Currently we are ensuring standards by systems that are ticked. For the EPA we understand that the quality is in the way the key workers live. This in itself takes care of everything, including less costs due to sick leave and less pain and tension in the bodies of both the healthcare worker and patient. Through truly self-caring the entire environment will change. In our experience this is not about grabbing a quick fix snack and a magazine during break times, it is about really taking care of and nurturing the body you take into work with you and into every aspect of your job - from emptying the bin to conversing with a bereaved parent. Developing self care through nutrition, regular exercise and sleeping patterns can build health and well being. In an approach that puts quality ahead of function, and if this quality is delivered, then we will potentially move away from the very regulated box ticking exercise that we have in place at that moment, which is based on fear and litigation, bringing it back to quality care. In the knowing and understanding that the quality is inherently in the service provided we don't have to be fearful of repercussions and blame the whole time, freeing us up to be more at ease and truly caringly responsive to the needs at hand. Until we are consistent with this there won't be consistency of quality.
319	Leeds Teaching Hospitals NHS Trust	6	This is a key area for Quality Improvement, but I do not believe the resources currently exist to achieve it. There needs to be investment in children's community nursing teams in order to achieve this.
320	Martin House, Hospice care for children and young people	6	As it is written this quality statement only refers to those, \`who are being cared for at home\`.
321	Rainbow Trust Children's Charity	6	We question whether the resources exist to offer this level of care in light of research into the paediatric and nursing workforce. Together for Short Lives' research in 2016 found that over a quarter of clinical commissioning groups (CCGs) do not commission out of hours' community children's nursing teams.[6] In addition to research from the Royal College for Paediatrics and Child Health[7], research from the Royal College of Nurses, '*The UK nursing labour market review 2016*'[8] found that half of nurses are aged 45 or over and are within ten years of being eligible for early retirement. The research also highlighted risk factors which will affect the future supply of safe staffing levels, including: the ageing workforce, rising demand, uncoordinated workforce planning, changes to student nurse funding, real terms cuts to nurse pay and the impact of Brexit on international recruitment. Looking at hospice nursing levels, a recent survey from Together for Short Lives, '*The State of the UK Children's Hospice Nursing Workforce: A report on the demand and supply of nurses to children's hospices*',[9] found that it is getting harder to recruit nurses to posts in hospices, with increasing shortages of more experienced nurses.

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[6] http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf

[7] http://www.rcpch.ac.uk/workforce

[8] https://www.rcn.org.uk/professional-development/publications/pub-005779

[9] http://www.togetherforshortlives.org.uk/assets/0001/9508/Together_for_Short_Lives_-_The_state_of_children_s_palliative_care_nursing_in_2017.pdf

ID	Stakeholder	Statement number	Comments[1]
322	Royal College of Nursing	6	What does the statement mean by "access to 24hr paediatric nursing care" Presumably care or advice in the home? The children can also access nursing care in Accident and Emergency Departments 24/7. We suggest that this statement is re-written to make it specific and more useful – e.g. access to a children's nurse – this needs to be 24/7 access to professionals with appropriate skills and experience. NB. Please do not use the term 'Paediatric Nurse' – please change this throughout to 'Children's nurse'
323	Royal College of Nursing	6	In order to provide advice 24/7 from paediatric palliative care consultant, it might be necessary to look at how rotas can be achieved such as the Hub and Spoke Method for Yorkshire and Humber, or it could be regions working together to develop a rota.
324	Royal College of Nursing	6	The statement is very aspirational in many areas due to shortage of Community Children's Nurses (CCNs) and Hospice at Home services, but the statement may prompt commissioners to consider this service across board. As with medical advice, nursing advice is equally important. Often parents just want telephone advice from a nurse, and also a CCN might want to get advice from a palliative care nurse.
325	Royal College of Nursing	6	We would also suggest the addition of 'ambulance trusts' to the audience, paramedics may be called out and should be able to access the experts and manage issues to prevent unnecessary admissions.
326	Royal College of Paediatrics and Child Health	6	We agree that home-based care can be preferable and improve patient experience. 24 hour availability of a consultant in paediatric palliative care is not currently available in most areas and there would need to be a huge financial investment to have consultants in paediatric palliative care to run an out of hours rota even at regional level. For example, in the East Midlands region there are currently no consultants in paediatric palliative care and it would require at least 5 new consultant posts to be able to provide a regional rota for telephone advice at a cost of more than £500,000. Even with that investment they would not be able to provide a useful face to face service out of hours to such a large geographical area as the East Midlands. We anticipate that the number of times they might be called is very few. This standard is therefore a very high bar to reach. Most services are currently facing austerity cuts and do not have the capacity to deliver paediatric nursing care 24/7 at home. Neither are there sufficient specialists in paediatric palliative care to deliver the backup required for safe care in the community. This standard is welcome if it can help as a lever to improve resource. Many community services are struggling++ to deliver the same quality of safe care in families' homes as can be delivered in hospital because there are not enough nurses available with the right skills, not enough doctors able to back them up, which often means actually going out to assess the child, rather than just giving advice on the phone. It would be good it this guidance could help with expansion of community children's nursing teams and of the medical competence to support this, but this does feel rather aspirational in these times of austerity.

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			More realistic standards in the current climate would be: High quality care from a team with appropriate experience and expertise should be available at all hours of the day or night. It is also important to children and families that the professionals caring for them, particularly in their home are a small consistent team of **familiar people who they know and trust.** **Having good anticipatory symptom management plans in the home developed in advance by the child's medical specialist, with advice from the paediatric palliative care team and / or pain specialist is essential.** Infants, children and young people approaching the end of life and being cared for at home should have 24 hour access to **face to face** paediatric nursing care **and advice from their specialist medical team.** **A doctor with appropriate skills who is familiar with the child and family needs to be able to provide home assessment visits 24/7.**
327	Royal College of Paediatrics and Child Health	6	Excellent but costly/unaffordable. Where is the evidence that a consultant delivered service provides better care than a consultant–led service through advance nurse practitioners.
328	Royal College of Paediatrics and Child Health	6	Not all support needs to be by a consultant in paediatric palliative care. There are many excellent paediatricians who, as part of a multidisciplinary team, including a palliative care consultant, could be the contact. We think that the measure should be of support, without being so prescriptive about who provides it.
329	Royal College of Paediatrics and Child Health	4 and 6	In practice, for some families, introducing another specialist beyond the neonatal consultant may not be practical or desired. We think that the guideline should acknowledge that neonatal consultants are (or should be!) trained and experienced in end of life care. In this field, a useful measure of quality of care would be consistency – were the family able to meet with the neonatal team prior to delivery, and were options for care discussed? We suggest that "access to a specialist in palliative care" be extended to "access to a specialist in palliative care or a neonatal consultant with experience in end of life care"
330	Teenagers and Young Adults with Cancer	6	This links with QS 1 and QS 4. Place of death and choice of place of death is perhaps a more useful measure / comparator and may well directly relate to the availability of services to support families at home at the time of death.
331	Teenagers and Young Adults with Cancer	6	Measuring existing service provision should be easy.
332	Teenagers and Young Adults with Cancer	6	This links back to the effective commissioning of palliative and end-of-life care services and clear lines of responsibility if services are not commissioned. It is likely that increased resources / investment will be required to ensure uniformity of service provision throughout England & Wales. See also Comment # 10

ID	Stakeholder	Statement number	Comments[1]
333	The Donna Louise Children's Hospice	6	There is no access to 24/7 paediatric nursing care, nor 24/ 7 advice from a consultant in paediatric palliative care as these are not commissioned! 24 hour access to advice from a consultant in paediatric palliative care at end of life- by "consultant in paed. pall care" how are they defining that? quaternary / interest in? How is that practically managed?
334	Together for Short Lives	6	This should include ambulance trusts. Paramedics may be called out to the child's home and should be able to access the specialist advice and manage issues to prevent unnecessary admissions.
335	Together for Short Lives	6	This should state 'should be available in the community' to reflect the fact that children and their families should be able to choose where to receive end of life care.
336	Together for Short Lives	6	We suggest that the title of this standard is amended so it is 'Care in the place that the child and their family chooses'. We suggest that the quality statement is amended to: "Infants, children and young people approaching the end of life should be able to choose where they receive their care, whether at home, in the community, in a children's hospice or in hospital. All infants, children and young people approaching the end of life should have access to 24-hour access to paediatric nursing care and advice from a consultant in paediatric palliative care."
337	Together for Short Lives	6	This quality statement should promote greater choice for children and young people - and their families - over where they receive end of life care. As it is currently written, the quality statement only offers support to those 'who are being cared for at home (see Quality measures - structure). This quality statement should instead refer to offering children and families choice over where they receive end of life care and providing support for them to do so. We therefore propose that the preferred place of death for a child or young person should be expressed in their Advance Care Plan. This should record the preferred place of death regardless of whether this is deemed possible, so that this statement can measure real 'choice'. The numerator for this measure would therefore be 'the number of children and young people with a life-limiting condition that were able to die in the place they chose' while the denominator would be 'the number of children and young people who have died'. This quality statement should also state that this support should be provided by a managed clinical network, as recommended in the full clinical guideline (recommendation 1.5.10). Together for Short Lives is currently developing a project in partnership with NHS England to support the implementation of the 'End of life care for infants, children and young people' guidance, including the development of children's palliative care managed clinical networks. This will entail conducting a benchmarking exercise with the 9 regional and 4 sub-regional Children's Palliative Care Networks, which are supported by Together for Short Lives, to establish the extent to which practice is in line with the recommendations made in the NICE guidelines. The project will then seek to bring these networks together, share best practice and provide support for the networks to adapt to become managed clinical networks.
338	Together for Short Lives	6	The current nursing workforce shortage will make this quality statement difficult to achieve. Together for Short Lives' research in 2017 (http://bit.ly/2pKTP5e) found that the nurse vacancy rate among children's hospice organisations is over 11% and has grown for each of the past two years. There is also an overall NHS nurse vacancy rate of 9% in England, Northern Ireland and Wales. There is also a shortage of community children's nurses across the UK:

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			The Royal College of Nursing (RCN) (http://bit.ly/1QgLhZb) recommends that for an average-sized district, with a child population of 50,000, a minimum of 20 whole time equivalent (WTE) community children's nurses are required to provide a holistic community children's nursing service. The Office of National Statistics estimates (http://bit.ly/2iJOTgS) that there are 13,770,873 children aged 0-18 in England. If the RCN recommendation were to be met, this would therefore require approximately 5,508 community children's nurses. There are currently just 535 community children's nurses in England (http://bit.ly/2j2srhm). Together for Short Lives' research in 2016 (http://bit.ly/2pEd6ai) found that over a quarter of clinical commissioning groups (CCGs) do not commission out of hours' community children's nursing teams. Although this quality statement is aspiration at present, it is a key area for improvement and will support commissioners and providers to consider how to provide 24/7 paediatric nursing care at home. Several areas such as Yorkshire and Humber are working towards effective on call advice being available from level 3 and 4 palliative care consultants. Regions can work together to have sufficient numbers to provide on call advice service.
339	Together for Short Lives	New suggested statement	Together for Short Lives proposes that an additional standard 'Short breaks (respite) for children and young people' is developed. The **rationale** is that children with life-limiting conditions rely on frequent short breaks. This could be to enable them to spend time with their family, away from caring responsibilities, doing the things that other families do. Alternatively, it could be to help the child achieve some independent time away from their family to be with their peers. The importance of short breaks is recognised in the full NICE guidance. In the definitions section (page 34) it states that 'Paediatric palliative care focuses on improving the quality of life for the child or young person and supporting their family members or carers, and includes managing distressing symptoms, providing respite care, and support with death and bereavement.' Short breaks provided at or away from home for children and young people with life-limiting conditions are provided by a range of organisations, including children's hospice organisations. These short breaks may include clinical care to meet their often-complex health needs, non-clinical care, or a combination of both. They are a lifeline to these children's families and can reduce parental stress and the risk of family breakdown, which can in turn have a detrimental impact on their ability to provide care. The structure of a quality measure would include evidence of local arrangements to provide short breaks to children with life-limiting and life-threatening conditions. The process would measure the proportion of these children who report that they receive a regular short break which meet their needs. It would also measure the extent to which their families feel resilient, feel under stress, and feel able to continue caring for their child or young person following their short break. The **outcome** would be that children and young people with life-limiting and life-threatening conditions: • feel more resilient

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			- can continue to be cared for by their families because the latter:
			  - feel less stressed
			  - feel less susceptible to poor health (both physical and mental)
			  - do not experience the breakup of relationships between parent carers.
			
			What this would mean for different audiences
			
			Service providers (such as hospitals, hospices, GP practices and community children's nurses, other voluntary sector providers of short breaks, local authorities) ensure that systems are in place to refer parents or carers of children and young people with life-limiting and life-threatening conditions to providers of short breaks. Short break providers ensure that a range of short breaks appropriate to children's age and developmental needs are available.
			
			Health and social care practitioners (such as secondary care doctors, nurses, GPs and community children's nurses) are aware of referral pathways to services that offer short breaks for children and young people with life-limiting and life-threatening conditions.
			
			Commissioners (clinical commissioning groups) ensure that they jointly commission services that include short breaks for children and young people with life-limiting and life-threatening conditions which can meet their needs.
			
			Children and young people are offered short breaks which can meet their needs.

340	United Hospitals Bristol NHS Foundation Trust	6	We agree with this aspiration but feel it is undeliverable if access to 24/7 paediatric nursing care is integral. There is a question as to whether it is essential for care around the clock to be delivered by paediatric nurses or whether there is a model where care is planned by paediatric nurses but might be delivered (e.g. out of hours) by non-paediatric trained nurses
341	United Hospitals Bristol NHS Foundation Trust	6	Agree with the statement about access to advice from a PPC consultant, however, this is not deliverable with current resources within our area.
342	West Midlands Paediatric Palliative Care Network	6	This links with QS 1 and QS 4. Place of death and choice of place of death is perhaps a more useful measure / comparator and may well directly relate to the availability of services to support families at home at the time of death.
343	West Midlands Paediatric Palliative Care Network	6	Measuring existing service provision should be easy.
344	West Midlands Paediatric Palliative Care Network	6	This links back to the effective commissioning of palliative and end-of-life care services and clear lines of responsibility if services are not commissioned. It is likely that increased resources / investment will be required to ensure uniformity of service provision throughout England & Wales. See also Comment # 10

Registered stakeholders who submitted comments at consultation

- Association of Paediatric Chartered Physiotherapists (ACP)
- Association of Child Therapists
- Association of Family Therapy
- Birmingham Children's Hospital
- Bliss
- British Psychological Society (BPS)
- Bristol Children's Hospital
- Church of England
- CLIC Sargent
- CYP CRG
- Demelza
- Department of Health
- East Midlands Children and Young People’s Palliative Care Network
- Esoteric Practitioners Association
- Helen and Douglas House
- Leeds Teaching Hospital
- Martin House
- Mencap

- Neonatal and Paediatric Pharmacists Group (NPPG)
- Paediatric Chaplaincy Network
- Rainbow Trust
- Royal College of General Practitioners (RCGP)
- Royal College of Nurses (RCN)
- Royal College of Anaesthetists and Association of Paediatric Anaesthetists of Great Britain and Ireland (RCoA APAGBI)
- Royal College of Physicians (RCP)
- Royal College of Paediatrics and Child Health (RCPCH)
- Royal College of Speech and Language Therapists
- Stoke and Staff Children's Palliative Care Network
- The Donna Lousie Children’s Hospice
- Teenagers and Young Adults (TYAC)
- University Hospital Birmingham (UHB)
- University of Essex
- West Midlands Paediatric Palliative Care Network