National Institute for Health and Care Excellence

End of life care in children
Scope Consultation Table
Consultation 21/10/2014-18/11/2014

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
Acorns Children's Hospices	1	General	We are not convinced there is any need for changes on the basis of equality of opportunity etc. Although it is true that different groupings in society may have different prevalence of conditions requiring PPC, we are not sure that the practice of PPC needs to be different for different groups (given that it is largely based on identifying and meeting the needs of an individual and family on a whole range of axes (including ethnicity, religion and belief etc)	Thank you for your comment. We are required to consider equity for all patient groups when making recommendations. However, we acknowledge that this might not equate to differences in treatment.
Acorns Children's Hospices	2	General	The scope needs to include children with Life Threatened (LT) conditions in addition to the children with Life Limited conditions, a failure to do so would result in a scoping exercise that does not include a significant proportion of children who actively receive palliative care services. The population subgroups will also need to be revised to include children with LT conditions (section 4.1 a)	Thank you for your comment. Within the definition of life limiting conditions we will include conditions which are likely to result in an early death. Therefore some life threatening conditions or certain stages of these conditions will be encompassed by the term 'life limiting' for this guideline.
Acorns Children's Hospices	3	General	Since it is acknowledged (section 3.2b) that PPC and this guidance will cover a period outside of the end of life should the guidance title not reflect this and be called Paediatric Palliative Care rather than End of Life Care?	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person.
Acorns Children's Hospices	4	General	Include a review question on; what the clinical, psychological and cost effectiveness of palliative care support (inclusive of short-breaks and hospice intervention) for children and their families throughout their journey as identified in the TfSL Core Care Pathway	Thank you for your comment. A review question has been drafted to address palliative care support and if evidence is found in relation to the Together for Short Lives pathway and this meets the requirements of the protocol then this will be considered.

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Acorns Children's Hospices	5	4.2 a	Is there a need to explicitly consider the care that is provided (particularly by the voluntary sector) that is not NHS commissioned?	Thank you for your comment. The remit of this guideline is to cover, "All settings in which NHS commissioned healthcare is provided." Therefore, services provided by voluntary sector organisations that have not been commissioned by the NHS are outside of the remit of this guideline.
Acorns Children's Hospices	6	4.3	The key here will be to differentiate the care provided that is palliative care from that provided that fits into complex care or long-term conditions pathways – or at least be very clear where the boundaries are and how they will be addressed. The scope is wide ranging but continues to have an undue emphasis on the 'dying phase'.	Thank you for your comment. The scope of the guideline addresses care from the point of diagnosis until after death of the child or young person. The terminology used throughout the document has now been amended to better reflect the emphasis on care throughout the entire pathway.
Acorns Children's Hospices	7	4.4	Consider adding an outcome related to transition – proportion of young adults who have a service package that meets their needs and wishes. Can an outcome be added that looks at access to adequate palliative care short breaks?	Thank you for your comment. The transition from children's to adult services has now been excluded from the scope as NICE are developing guidance that covers this (www.nice.org.uk/guidance/indevelopment/gid-scwave0714). This list of main outcomes is not intended to be exhaustive. The consideration of other outcomes for inclusion in the review will be considered at the time of drafting the protocol.
Acorns Children's Hospices	8	4.5	Much the same as for section 4.3. Once again there is a great emphasis on the 'dying phase' and EOL care	Thank you for your comment. The breath of the scope covers the patient pathway from point of recognition of the life-limiting condition through to after the death of the infant, child or young person. We believe that the current set of draft questions better reflect this now that definitions within the scope have been clarified.
Association of Child Psychotherapists	1	General	Scope appears comprehensive and thoughtful	Thank you for your comment.

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Association of Child Psychotherapists	6	General	Might emphasis be given to the importance of supporting the caregivers (where appropriate) to broach and speak with their child and the child's siblings about death?	Thank you for your comment. The scope covers the support needs of the children, young people and their families/carers and it is expected that this will be addressed.
Association of Child Psychotherapists	10	General	The ACP would like to comment in general on issues of palliative care and decisions around withdrawal of intensive care for babies and very young children.	Thank you.
Association of Child Psychotherapists	11	General	The ACP asks what specialist assessment and advice can be used to help medical staff distinguish between the emotional needs and wishes of the parents, and the psychological and emotional needs of the child?	Thank you for your comment. Distinguishing between the parent and child is important. These aspects can be considered by the GDG, and would be included under two of the key issues: a) Care of infants, children and young people with a life-limiting condition and their family members or carers (as appropriate) before death. b) Assessing needs and developing a personalised care plan, including parallel care planning.
Association of Child Psychotherapists	12	General	The ACP asks how one can ascertain the wishes and needs of infants who are unable to express these verbally?	These matters will be dealt with in an age appropriate manner. In the draft review questions (which are subject to change in discussion with the GDG) we have tried to take account the need to deal with different age categories 'as appropriate'.
Association of Child Psychotherapists	13	General	The ACP asks if there is a role for those trained in infant observation to help interpret these wishes to parents and medical staff?	Thank you for your comment. The GDG is likely to consider the role of all involved in the care and assessments of infants.
Association of Child Psychotherapists	14	General	The ACP asks what specialist support is needed where there seems to be disparity or conflict between the needs of the child and the wishes of the parents?	Thank you for your comment. The needs of both the children/young person and families/carers will be considered separately and it is likely that there will be different recommendations for each group. The recommendations will be based on the best available evidence.

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Association of Child Psychotherapists	2	3.2 b	"Providing treatment and care to infants, children and young people with life-limiting conditions often involves decisions that are clinically complex and emotionally distressing, especially towards the end of their lives." Fully endorse this statement the implication of which is to draw on multi-disciplinary team working.	Thank you for your comment.
Association of Child Psychotherapists	3	3.2 c	"… but infants, children and young people with life-limiting conditions frequently need palliative care over a much longer period, often from birth … Good palliative and end of life care depends on establishing effective networking arrangements between the relevant services." Fully endorse.	Thank you for your comment.
Association of Child Psychotherapists	4	3.2 d	"… while providing psychological, social and spiritual support for them and their family members or carers (as appropriate)." Fully endorse.	Thank you for your comment.
Association of Child Psychotherapists	5	3.2 c d	I wonder if it might be helpful to stipulate the importance of specifically bearing in mind the strain on siblings and the need to acknowledge the impact on them in the context of their stage of development.	Thank you for your comment. The emotional support required by family members and carers (including siblings) will be considered within the scope of this guideline and is a key area for assessment.
Association of Child Psychotherapists	7	4.3.1 h	"The management of psychological issues in the infant, child or young person with a life-limiting condition." Might this better phrased: "The awareness, consideration and care of psychological issues in the infant, child or young person with a life-limiting condition"?	Thank you for your comment. The terminology in this question has been amended in response to stakeholder feedback and now reads as "the psychological and emotional needs of infants, children or young people with life-limiting conditions"
Association of Child Psychotherapists	8	4.3.1 g	"The management of psychological issues in family members, carers or other people who are important to infants, children and young people who have a life-limiting condition or a sudden or unexpected death." Might this be better phrased: "The awareness, consideration and care of psychological issues in family members, carers or other people who are important to infants, children and young people who have a life-limiting condition or a sudden or unexpected death"?	**Thank you for your comment. The terminology in this key issue has been amended in response to stakeholder feedback and now reads as "The psychological and emotional needs of the family members or carers (as appropriate) of infants, children and young people with life-limiting conditions".**

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Association of Child Psychotherapists	9	4.4	Might one consider "Quality of end of life" as opposed to "Quality of life"?	Thank you for your comment. The term "quality of life" is a general term that used for the measurement of patient reported outcomes. As the guidance will cover the full breadth of end of life care (from recognition of the condition through to death and following death of the infant, child or young person) the term can be applied to all stages of the clinical pathway.
Association of Paediatric Chartered Physiotherapists	1	General	A member commented that by naming the document 'end of life' some parents may find this off putting. However, this terminology is in line with many other national documents, and is primarily for professionals, and as such needs to be clear to the professionals what the guideline is for.	Thank you for your comment. The recommendations are written primarily for healthcare professionals and every effort has been made to ensure that the terminology is clear and transparent. The guidance will also be presented in a separate document that is written for members of the public.
Association of Paediatric Chartered Physiotherapists	7	General	Can equipment provision (e.g. sleep systems) and funding be covered?	Thank you for your comment. This guideline will consider all relevant interventions for which there is published clinical and cost-effectiveness evidence. If sleep systems are identified as an effective intervention the guideline development group will take account of this.
Association of Paediatric Chartered Physiotherapists	8	General	Another member commented: I feel that the scope of these guidelines should discuss infants, children and young people with life -limiting and life threatening conditions. Although Life threatening conditions are mentioned in 3.1 f) the rest of the document refers to life-limiting conditions as identified in 4.1.1 a). I think the scope is appropriately wide ranging, I am not sure that it specifically needs to discuss the areas raised in relation to equal opportunities. Paediatric palliative care is generally designed around, and specific to, the child and family needs, the equal opportunity areas raised are integral in achieving and delivering this.	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope Within the definition of life limiting conditions we will include conditions which are likely to result in an early death. Therefore some life threatening conditions or certain stages of these conditions will be encompassed by the term 'life limiting' for this guideline. The provision of end of life care begins from the point of diagnosis of the life-limiting condition through to beyond the death of the infant,

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				child or young person.
Association of Paediatric Chartered Physiotherapists	9	General	As a profession, paediatric physiotherapists are closely involved with children with life limiting conditions in every setting (community, school, hospitals and in a hospice), we often have a good handle on their symptoms, and when these change, either with slow deterioration or in an acute situation. We frequently have one of the most trusted relationships of a professional with these children and their families. We would recommend the inclusion of a paediatric physiotherapist with experience in each of these areas, and a special interest in paediatric palliative care in the GDG workshop.	Thank you for your comment. We recognise that specialist expertise beyond that already available in the guideline development group might be required. Therefore, expert advisors will be co-opted to the group as consideration of the evidence requires.
Association of Paediatric Chartered Physiotherapists	2	4.2 a	Does the role of the voluntary sector in delivery of care need to be considered, as it is heavily relied upon in many cases?	Thank you for your comment. The remit of this guideline is to cover "All settings in which NHS commissioned healthcare is provided." Therefore, the NHS commissioned services provided by voluntary sector organisations would be within the remit of this guideline.
Association of Paediatric Chartered Physiotherapists	3	4.3.1 f	Safe and effective management of pain and other symptoms relies on the knowledge of staff involved, would it be appropriate to include that the delivery of 'general palliative care' is the responsibility of all?	Thank you for your comment. The guideline will be informed by the best available evidence obtained by the systematic review and it is not possible to determine what they might recommend at this point in time.
Association of Paediatric Chartered Physiotherapists	4	4.3.1 f	Will the role of physiotherapy assessment and treatment be considered in relation to pain and spasms? Also our role in the assessment ans treatment of respiratory symptoms, as this often presents staff with challenging clinical decisions which must be backed by the MDT	Thank you for your comment. The scope allows the role of physiotherapy assessment to be considered in relation to pain and spasm and the GDG will be able to make recommendations based on the best available evidence.
Association of Paediatric Chartered Physiotherapists	5	4.3.1 l	Will the cessation of respiratory physiotherapy input be addressed, as parents often find it hard accepting this change in management?	Thank you for your comment. The decision to withhold or withdraw life-sustaining interventions is covered in section 4.3.1l within the scope. The specific topics for consideration will be prioritised by the

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				guideline development group and detailed in the review protocols.
Association of Paediatric Chartered Physiotherapists	6	4.5 f	Will physiotherapists (acute/community) be defined as a member of the MDT?	Thank you for your comment. The further detail of the constituency of the multi-disciplinary teams will be defined when reviewing the relevant evidence and formulating recommendations during the course of the guideline development.
Birmingham Children's Hospital NHS Foundation Trust	1	General	The scope of this guideline should be extended to the age of 25 across the board, reflecting the variety of conditions that would present in this age group and other NICE Improving Outcomes Guidelines such as Cancer. Failure to grasp this broader opportunity will potentially lead to confusion amongst care providers and commissioners resulting in potential fragmentation of current care provision and failure to achieve the proposed main outcomes, namely: 4.4a, 4.4b and 4.4c	Thank you for your comment. The scope of this guideline has been amended to include children and young people up to the age of 18 years. We acknowledge the importance of ensuring that people transition smoothly, and will ensure that cross-referrals to guidance under development which is addressing the transition from child to adult services (http://www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714) are made wherever possible.
Birmingham Children's Hospital NHS Foundation Trust	2	General	The guideline should look to define the relationships with local adult palliative care provision or at least stress the importance of establishing links with said services. This will be of particular importance with respect to transition.	Thank you for your comment. We acknowledge the importance of ensuring that people transition smoothly, and will ensure that cross-referrals to guidance under development which is addressing the transition from child to adult services (http://www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714) are made wherever possible.
Birmingham Children's Hospital NHS Foundation Trust	3	General	There needs to be recognition that the definition of "paediatric Services" will differ across areas, e.g. some Acute Trusts will stop paediatric services at age 16, other may extend to 18 or 21 if related to special needs provision.	Thank you for your comment. The scope of this guideline has been amended to include children and young people up to the age of 18 years only. We acknowledge the importance of ensuring that people transition

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				smoothly between services, and that the age at which paediatric services stop vary by region and this is reflected in the scope of the NICE guidance currently under development which addresses transition from child to adult services.
Birmingham Children's Hospital NHS Foundation Trust	4	General	This piece of work also needs to formally recognise the important contribution from the 3rd sector, especially in relation to formal hospice provision. There is a clear opportunity to set out guidance with respect to true multiagency working.	Thank you for your comment. The remit of this guidance is limited to "All settings in which NHS commissioned healthcare is provided", which would therefore include any third sector care that is commissioned by the NHS.
Birmingham Children's Hospital NHS Foundation Trust	5	General	There should be consideration given to a collection of a national dataset to inform the commissioning and delivery of paediatric palliative and end-of-life care.	Thank you for your comment. Service delivery is covered within the scope and the GDG could consider recommendations along these lines if they considered it appropriate
Birmingham Children's Hospital NHS Foundation Trust	6	General	Consideration should be given to the education and training for professional involved in palliative / end-of-life care.	Thank you for your comments. The education and training of staff providing end of life care is outside the remit of NICE guidance.
Birmingham Children's Hospital NHS Foundation Trust	7	3.2 G	We would challenge this recommendation and want to see the evidence supporting this recommendation. This may well be how services have grown historically, but is contrary to the Service Specification issued by NHS England E3h – Specialised Paediatric Palliative Care Services. There should not be an assumption that this will form the basis of any recommendations on service provision.	Reference to the document from Together for Short Lives is not intended as a recommendation. Recommendations on paediatric palliative care will be made by the guideline development group on the basis of evidence and current, good clinical practice.
Birmingham Children's Hospital NHS Foundation Trust	8	4.1.1 A	In considering "cancer" within the remit of the workstream, there needs to be alignment with the NICE CYP IOG specifically with respect to the age-range included on the scope.	Thank you for your comment. This guideline does not intend to make recommendations relating to the care of cancer in children and young people, but rather the aspects of care for the potentially life-limiting condition. The

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				scope has been amended so that it includes people up to and including people who are 18 years of age.
Birmingham Children's Hospital NHS Foundation Trust	9	4.3.1 A	In defining "family members", consideration should be given, specifically, to the needs of siblings.	Thank you for your comment. The scope does cover the consideration of siblings and they are included in the term "family members". The precise definition of this group will be given in the protocols, final guidance and any discussions of the evidence in the guideline.
Birmingham Children's Hospital NHS Foundation Trust	10	4.3.1 B	The concept of "parallel planning" needs to be emphasised and be a "headline" of this piece of work. Guidance specifically in terms of parallel planning should be clear within the guidelines.	Thank you for your comment. The approach to planning care for those with life-limiting conditions will be addressed, for example, under the key area "assessing needs and developing a care plan".
Birmingham Children's Hospital NHS Foundation Trust	11	4.3.1	The CGDG should look at the variety of "toolkits" available to support the delivery of palliative and end-of-life care and look to make a recommendation of a nationally agreed product.	Thank you for your comment. The scope of this guideline covers a broad range of topics related to end of life care and this would not preclude the consideration of toolkits. The specific review questions will be prioritised by the guideline development group and this suggestion will be passed to them.
Birmingham Children's Hospital NHS Foundation Trust	12	4.4 a c	Have the tools for assessing / measuring these outcomes already been defined? Will QALY's be appropriate?	Thank you for your comment. We recognise that the use of QALYs can be problematic in this area and we've amended the scope to acknowledge that the QALY may not always be a useful measure of effectiveness for analyses undertaken for this guideline, although they could be appropriate especially where interventions improved health related quality of life over a period of time. The expertise of the committee will be used to obtain relevant outcome measures for specific review questions.
Birmingham Children's	13	4.4	This is likely to vary massively: very much driven by the underlying cause / condition.	Thank you for your comment. The GDG will advise on appropriate outcomes for each

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Hospital NHS Foundation Trust		a		review
Birmingham Children's Hospital NHS Foundation Trust	14	4.4 c	It will be necessary to define a "home-based programme of care". This will need to include some of the services provided by 3rd sector in the form of "Hospice at Home" services.	Thank you for your comment. The remit of this guideline is to cover "all settings in which NHS commissioned healthcare is provided". The details about interventions under consideration will be included in the review protocol after discussion with the guideline development group.
Birmingham Children's Hospital NHS Foundation Trust	15	4.4 e	Who does this refer to and how will this be assessed.	Thank you for your comment. The outcomes for each review question will be dependent on the question and will be detailed in the review protocol. Appropriate methods of outcome measurement will be discussed with the guideline development group before reviewing of the evidence begins.
Birmingham Children's Hospital NHS Foundation Trust	16	4.5 f	What metrics are proposed to measure the parameters indicated here? With such variability that is likely to exist in practice it is difficult to foresee a measure that will be meaningful in trying to define clinical and cost-effectiveness.	Thank you for your comment. The outcomes specific to each review will be discussed with the guideline development group before drafting the protocol.
Birmingham Children's Hospital NHS Foundation Trust	17	4.5 l	See comment # 11 (The CGDG should look at the variety of "toolkits" available to support the delivery of palliative and end-of-life care and look to make a recommendation of a nationally agreed product.)	Thank you for your comment. The scope of this guideline covers a broad range of topics related to end of life care and this would not preclude the consideration of toolkits. The specific review questions will be prioritised by the guideline development group and this suggestion will be passed to them.
British Academy of Childhood Disability	1	4.1.1	The scope of patients covered is wide (covering neonatology, oncology, neurodisability and various specialties associated with end organ failure). Would it be better to try to concentrate only on some of these groups (providing, instead, separate guidance for some groups - e.g. end of life care in neonatology)? Clearly, there are some general principles that apply across all these groups but there are also various specific approaches that differ	Thank you for your comment. We recognise that the breadth of the scope is wide and will provide guidance on the general principles as addressed by the evidence. In addition, where the developers consider there are important condition-specific considerations, and the evidence allows they can decide whether to make recommendations.

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			between these groups.	
British Academy of Childhood Disability	2	4.3.1 K	In addition to point k) recognising when infants, children and young people are likely to die within a few days or hours, it would be really helpful to include: Recognise those infants, children and young people who are at increased risk of sudden and unexpected death and ensure that this has been sensitively communicated with the family and that the discussion has been recorded in the family held care plan. This is likely to include include those with complex and multiple disabilities, complex medical conditions, immunodeficiencies, complex congenital heart disease, complex congenital anomalies etc.	Thank you for your suggestions. The specific areas for consideration within a review question will be prioritised by the guideline development group during development of the review protocols.
British Academy of Childhood Disability	3	4.3.1 n	'Service delivery' for those with life limiting conditions is a very broad topic. It may be helpful to define aspects of service delivery that will be covered otherwise this could encompass most of paediatric care.	Thank you for your comments. The scope has been amended for clarity, and section 4.3.1m now states an issue which will be covered is 'the organisation of services providing the end of life care of infants, children and young people with life-limiting conditions'. The guideline development group will prioritise the areas for consideration and these will be detailed in the review protocols.
British Academy of Childhood Disability	4	4.4	Main outcomes should also include: correct identification and management of associated medical conditions in line with best evidence (e.g. constipation, endocrine issues, gastro-oesophageal reflux, drooling, epilepsies, pressure area care, spasticity, dystonia, disordered sleep, continence issues, feeding and swallowing issues,	Thank you for your comment. We believe that this is a possible topic for consideration rather than outcomes to be assessed within the current draft review questions. The diagnosis and management of the underlying life-limiting condition is outside the scope of

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			emotional, behavioural and mental health issues).	this guideline.
British Academy of Childhood Disability	5	4.5	Review questions could also include: The recognition of the group of infants, children and young people at increased risk of sudden and unexpected death, so that this risk can be communicated to families in a timely way (See Horridge K Advance Care Planning: practicalities, legalities, complexities and controversies. *Arch Dis Child* 10/2014; DOI: 10.1136/archdischild-2014-305945) How do teams ensure that infants, children and young people receive equal access to the highest standards of healthcare at all times and that assumptions are not made about their quality of life based on their appearance, disabilities, intellectual functioning or the assumptions of those who are assessing them? How do teams ensure that all infants, children and young people can continue to receive life-sustaining care and interventions in an equal way, so long as they are likely to get benefit from them? How to teams ensure that decision-making about levels of intervention with children, young people and their parent carers and families is always within an ethical and legal framework, with due regard to the Children Act Welfare Checklist and the Mental Capacity Act Best interest checklist?	Thank you for your comment. We believe that the scope of the guidance is sufficiently broad to cover this and the topic will be discussed for possible inclusion by the guideline development group. NICE is committed to ensuring equal access for all patient groups and publishes an assessment of equality considerations at the time of publishing the guidance.
British Association for Counselling and Psychotherapy	5	General	The final guideline should specify the training requirements of those carrying out psychological interventions. BACP recommends that NICE stipulates that interventions recommended in the guideline are performed by trained professionals. For example those	Thank you for your comments. Specific professional training requirements are outside the remit of the guidance. However, if supported by evidence, the guidance might stipulate that a certain intervention be delivered by professionals with a particular

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			providing psychological therapies should be registered on an Accredited Voluntary Register (AVR), and meet the Centre for Workforce Intelligence (CfWI) defined standards for psychological therapists in the NHS, which are; • to have completed one-year of recognised full-time (or equivalent part-time) psychological therapy or counselling training leading to a qualification, certification or accreditation recognised by a relevant professional or regulatory body • to have achieved a competency level that fulfils the requirements of the regulatory, accrediting or professional body • to be a member of a relevant professional or regulatory body, and continue to fulfil any accreditation or membership criteria, including meeting requirements for continuing professional and personal development, regular supervision and codes of practice • to have gained the supervised therapy experience required by the regulatory or professional body encompassing assessment, formulation, engagement, developing the therapeutic relationship, using relevant therapeutic interventions, working collaboratively with clients, and working to end therapy (CfWI, 2013) **Reference** Centre for Workforce Intelligence (2013) Improving workforce planning for the psychological therapies workforce. http://www.cfwi.org.uk/publications/improving-workforce-planning-for-the-psychological-therapies-workforce/ [Accessed 10 November 2014]	set of skills.

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British Association for Counselling and Psychotherapy	1	4.3.1	The British Association for Counselling and Psychotherapy (BACP) welcomes the draft scope for the *End of life care for infants, children and young people* clinical practice guideline. BACP supports the inclusion of the management of psychological issues and support for the patients with life limiting conditions as key issues to consider. Additionally, the inclusion of psychological support for the patients' family members, as well as initial support, assessment and care of the patients' family members and carers after the infant, child or young person has died is also welcomed. Siblings of the dying patient have double the chance of developing psychological ill health (Black, 1998; Daniels et al, 1987). Jessop et al (1988) found that mothers rates of depression increase after the death of their child. BACP recommends that psychological support, as referred to in the scope of the guideline, should include a range of counselling and psychotherapy interventions which have been proven to be effective in supporting those who are dying and their family and those grieving. For example, after a perinatal death brief counselling can significantly reduce morbidity in parents (Forrest et al, 1982), and family focused grief therapy could prevent grief in families (Kissane et al, 2006). BACP additionally recommends that the scope of the guideline includes the continuity of treatment for the family, carers and others important to the patient from palliative care into bereavement, which will enhance the effectiveness of the intervention (Kissane et al, 2006). **References**	Thank you for your comment. The recommendations will be based on the best available evidence as identified by an independent systematic review of literature. We thank you for providing us with existing recommendations for care.

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			Black, D. (1998) The Dying Child. *The British Medical Journal*, Vol316(7141), pp1376-1378. Daniels, D. Miller, JJ. Billings, AG. Moos, RH. (1987) Psychosocial risk and resistance factors among children with chronic illness, healthy siblings, and healthy controls. *J Abnormal Child Psychol*, Vol15, pp295–308. Forrest, GC. Standish, E. Baum, JD. (1982) Support after perinatal death: a study of support and counselling after perinatal bereavement. *The British Medical Journal,* Vol285, pp1475–1479. Jessop, DJ. Riessman, CK. Stein, REK. (1988) Chronic childhood illness and maternal mental health. *J Developmental Behav Pediatr*; Vol9, pp147–156. Kissane, D., McKenzie, M., Bloch, S., Moskowitz, C., McKenzie, D., & O'Neill, I. (2006). Family focused grief therapy: a randomized, controlled trial in palliative care and bereavement. *American Journal of Psychiatry*, Vol163(7), pp1208-1218.	
British Association for Counselling and Psychotherapy	2	4.3.1 l	The key issues include the decision to withhold or withdraw medical interventions. BACP notes that counselling can aid decision-making, can help parents and children reflect upon, and understand, the complicated feelings surrounding the creation of an end-of-life care plan, and can help them come to terms with the psychological consequences of the decisions they make.	Thank you for your comment. The protocol for this review question will include a description of the interventions that will be considered as agreed by the guideline development group. We thank you for your suggestion.
British Association for Counselling and Psychotherapy	4	4.3.2 e	The draft scope states that specialised management of bereavement will not be covered. The loss of a young family member is rare, as the scope states in 2012 there	Thank you for your comment. The scope of this guideline covers routine bereavement care and the social support needs of the family and/or carers. In addition, an expert

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			were only 11 deaths per 100,000 1 to 14 year olds, and results in a unique experience of bereavement. For example, Lundin (1984) found that parents who have lost a child, in comparison to widows and widowers, demonstrated greater evidence of grieving. Interventions provided should reflect this. BACP would suggest that the scope should include the specialised management of bereavement. **Reference** Lundin, T. (1984) Long term outcome of bereavement. *Br J Psychiatry*, Vol145, pp424–428.	advisor in bereavement care will be recruited to the guideline development group. The exclusion relates to long-term management of bereavement and this has now been clarified in the scope.
British Association for Counselling and Psychotherapy	3	4.4	BACP welcomes the inclusion of ‘psychological well-being, for example resilience, depression or anxiety’ as one of the main outcomes of the guideline.	Thank you for your comment.
British Pain Society	1	General	The British Pain Society endorses the scope of the proposed guideline.	Thank you for your comment.
Cambridge University Healthcare trust	2	General	Will scope include guidance to commissioners?	Thank you for your comment. The guideline will address several aspects of service provision for care of children and young people with life-limiting conditions.
Cambridge University Healthcare trust	1	4.3.1 b	Personalised care plan should include Symptom management plan, Emergency healthcare plan and resuscitation plan	Thank you for your comment. The care management plan will be informed by the best available evidence obtained from a systematic review of the literature.
Children’s Hospice Association of Scotland	1	General Title 1.1	CHAS has sought the views of several members of our team and we would urge NICE to include “palliative care” in the title. For example it could read “Palliative and end of life care for infants, children and	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person.

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			young people." This is much clearer, particularly in relation to children needing palliative care over a lengthy period of time or when being offered alongside curative options.	
Children's Hospice Association of Scotland	5	General 4.5	Feel the scope is quite hospital based in its slant also think the review questions at 4.5 are probably strong on the clinical side.	Thank you for your comment. The guideline is intended to provide recommendations for clinical practice, however we believe the draft review questions will be informed by evidence from a broad range of settings.
Children's Hospice Association of Scotland		3.2 cl	There is no mention of social care, education and the document is not as strong as it could be on the vital need to have a holistic approach to caring for a family whose child is dying. The need to individualise care, commit resources, complexity etc is essential. There is scope to include recognition of the important roles played by both education and social care in 3.2(c)	Thank you for your comments. The remit of this guideline is to cover: "All settings in which NHS commissioned healthcare is provided." Therefore, services provided by voluntary sector organisations that have not been commissioned by the NHS are outside of the remit of this guideline. However, we acknowledge the importance of a holistic approach and aim to make recommendations that address individual needs wherever possible.
Children's Hospice Association of Scotland	2	3.2 E	We would ask that children's hospices are named within voluntary services, so that sentence could read; "a significant part of children's palliative care is provided by the voluntary sector, and specifically by children's hospice organisations"	Thank you for your comment. We have amended the text to include the reference to hospices.
Children's Hospice Association of Scotland	4	4.3.1 A	4.3.1 (a) Needs to state from birth to 18 years of age. 4.3.1 (m) Needs to state the age range from 18 to 25 If those two points clarified the age range in each place, this would support and strengthen the mention of the two specific groups in section 4.1 on population	Thank you for your comments. In response: the care from birth is implied by the inclusion of infants and statement that care begins from point of recognition of the life-limiting condition (even if this occurs in the antenatal phase). The scope has been amended so that the needs of young people who are

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		4.3.1(h) 4.3.1(m)	4.3.1 (h) needs to be clearer on the specific challenges of the different age ranges and stages. This would be important. For example the emotional needs of a teenager with cancer demands a very specific skill set, as does caring for a preterm infant.	transitioning into adult care are excluded from this guideline and will instead be addressed by the NICE guidance on Transition from Children's to Adult services (in development). The population subgroups will be particular to each review and will be stated in the protocol for the systematic reviews.
Children's Hospice Association of Scotland	3	4.3.2 a 4.3.1 (o) 4.3.1 (p)	The scope suggests here **initial** bereavement support and assessment will be covered. It is not clear what "initial" is defined as. It is noted that 4.3.2 (a) says specialist management of bereavement will not be covered. This does leave the gap of bereavement support beyond the very initial period - Unless 4.3.1(p) "care of the family members or carers as appropriate after death is intended to cover this. Our experience is that the majority of bereavement support is **not** at the specialist end but goes beyond just initial support and assessment. It also needs to be explicit in listing bereavement care as available within hospitals.	Thank you for your comment. It is intended that the long-term care of the family or carer (as appropriate) is excluded from the scope of the guidance. However, routine bereavement support leading up and after the death of the infant, child or young person is covered. The exact timeframe will be defined in the protocol of the systematic review.
Children's Hospice Association of Scotland		4.4	We acknowledge and welcome the areas for developing outcomes but would suggest an additional outcome specifically about the quality or impact of bereavement support should be added.	Thank you for your comment. This list of outcomes is not intended to be exhaustive and will be dependent on the review question. The consideration of an outcome relating to bereavement support will be discussed by the guideline development group and considered for possible inclusion at the time of drafting the protocol.
Children's	6	4.5	Add review question after 4.5 (d) What are the optimal	Thank you for your comment. The remit of

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Hospice Association of Scotland		d	models of care to facilitate integrated care between NHS and voluntary providers to ensure best outcomes from babies, children and young people, as well as their families?	this guideline is to cover "All settings in which NHS commissioned healthcare is provided." Therefore, the consideration of evidence pertaining to models of care from the voluntary sector which is not NHS funded is outside of the remit of this guideline.
Claire House Children's Hospice	1	General	In general, it's great – very thorough and needs to encompass all providers of CYP palliative care and not just NHS funded or commissioned services. I think it's important to recognise that it is very hard to tell when children are dying and the challenge of recognising and responding to this unpredictability for both families and service provider. This point is made in the scope but I wonder if it needs to be stronger.	Thank you for your comment. The remit of the guideline is limited to all setting in which NHS health and social care are provided. A review question has been included to consider the signs and symptoms of impending death, however, the developers recognise that the likely time of death is often difficult to anticipate or predict. A discussion of the issues will be included in the full guideline alongside the review of evidence.
Claire House Children's Hospice	9	General	The scope should address explore the range/opportunities of collaborative and intergrated (health, voluntary sector and social) models of service provision for CYP palliative care	Thank you for your comment. The remit of this guideline is to cover: "All settings in which NHS commissioned healthcare is provided", which will include models of service provision for NHS commissioned care. Services provided by voluntary sector organisations that have not been commissioned by the NHS are outside of the remit of this guideline.
Claire House Children's Hospice	2	3.2 f	Why do hospitals with specialist palliative care teams have a specific mention but children's hospices don't? Based on an average of say 250 children per hospice in the UK, and with 50 hospice services, that's 12,500 children known to children's hospices. The total seen by SPC teams across the country is likely to be much less than that. Needs to include children's hospice in-reach, outreach and additional (free) services or other designated palliative care service providers that are not NHS commissioned.	Thank you for your comment. The remit of this guideline covers all settings in which NHS-commissioned care is provided. With regard to hospices specifically, their role is acknowledged in section 3.2h of the scope. The mention of specialised palliative care teams in hospitals was to highlight the fact that these were not always available in that setting.

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			The roots of (children's) palliative care should also be recognised – that this didn't come from the NHS but from voluntary organisations.	
Claire House Children's Hospice	3	4.2	Why is the scope for this guidance only for NHS commissioned care? Needs to include the wider voluntary and social care sector as they are clearly key and major providers in the CYP palliative care sector and therefore the scope cannot be limited to NHS services.	Thank you for your comment. The remit of this guideline is to cover, "All settings in which NHS commissioned healthcare is provided". Therefore, services provided by third sector organisations that are commissioned by the NHS will be covered by the guideline.
Claire House Children's Hospice	4	4.3.2	Only bereavement not covered? What about other additional services such as play, holistic therapies, music therapy and physio?	Thank you for your comment. The exclusion list of the scope is not intended to be exhaustive. It is possible that some of these therapies might be identified as relevant interventions when the evidence review protocol is drafted by the guideline development group.
Claire House Children's Hospice	5	4.4	Are there any long term outcomes that should be considered: Families (including siblings) able to copy in the future = less future pressure on health and social care services?	Thank you for your comment. This list of main outcomes is not intended to be exhaustive. The consideration of long term outcomes is a priority for the guideline and these will be considered for possible inclusion at the time of drafting the protocol.
Claire House Children's Hospice	6	4.5 c	Why only home-based? What about place of choice, e.g. a hospice or respite centre?	Thank you for your comment. It is expected that a hospice or respite centre (if commissioned by the NHS) would fall into the category of other settings. The exact settings that will be included in the systematic literature review will be discussed with the guideline development group and then pre-specified in the review protocol.
Claire House Children's Hospice	7	4.5 G	Why consider the impact of counselling if this is outside of the scope of the guidance?	Thank you for your comment. Counselling is considered within the remit of the scope.
Claire House Children's	8	4.6	Should other costs be formally considered, e.g. hospice services? Our costs are pretty easy to identify wheras in a	Thank you for this comment. The perspectives of costs is less about how easy

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Hospice			hospital environment they are more complicated.	costs are to identify than how the NHS should allocate its budget given competing demands on it. Any hospice care commissioned by the NHS would be formally considered if relevant to the analysis being undertaken.
Department of Health	1	General	Thank you for the opportunity to comment on the draft scope for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.
East Anglia's Children's Hospices	1	1.1	The title does not reflect the scope. The current title only refers to end of life care whereas the scope includes end of life and palliative care. The title needs to be changed to reflect this.	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person.
East Anglia's Children's Hospices	2	3.2 F	The first sentence refers to hospitals having special palliative care teams – do you mean specialist palliative care teams or dedicated palliative care teams? Does home include usual place of residence which could include residential schools. Perhaps a footnote to explain what 'home' includes would be useful and ensure all settings where children or young people live are included	Thank you for your comment. In the context of this section (now 3.2h) the term "specialist" reflects the service configuration. However, where this is unclear, the term "dedicated" will be used.
East Anglia's Children's Hospices	3	4.1 c	Please can you clarify what is meant by dying unexpectedly without a prior known life-limiting condition. Does it mean CYP who have died as a result of an acute illness, injury or trauma or does it mean those who are later found to have had a life-limiting condition on post mortem? On the assumption it is the former; the statement could be reworded to make it clearer.	Thank you for your comment. The scope has been amended for clarity and excludes infants, children and young people aged up to 18 years who die unexpectedly and do not have a known life-limiting condition, for example, accidental death. It does not include infants, children or young people who were later found to have had a life-limited condition on post mortem.
East Anglia's Children's	4	4.3.1	What does parallel care planning refer to – is it related to transition to adult services or is it related to end of life care	Thank you for your comment. The scope now states for clarity that 'Parallel planning refers

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Hospices		b	planning, resuscitation plans, anticipatory symptom management plans. Please can this be clarified? If it doesn't relate to end of life care planning this would be a gap in the scope.	to the development of plans that allow for unpredictability in the course of the condition'.
East Anglia's Children's Hospices	5	4.5 h	The sentence doesn't make sense- does it mean What interventions are safe and clinically cost effective or safe clinically and cost effective?	Thank you for your comment. This sentence has been amended for clarity.
East Anglia's Children's Hospices	6	4.5 l	Should this statement also include plans for family members or carers? I.e. 'What assessments are helpful …… for infants, CYP and their families or carers. End of life care for infants, children and young people is a family experience	Thank you for your comment. We recognise that end of life care encompasses the experience of the family/carer as well as the child or young person. Although the care plan is developed for a child or young person it does not exclude the care of the family and the recommendations will reflect that.
East Anglia's Children's Hospices	7	4.5 p	Should the statement be extended to include … 'and when this should be discussed'	Thank you for your comment. The current wording does not exclude the timing of discussions. The precise aspects of care that will be considered will be prioritised by the guideline development group and described in the review protocol.
Forgetmenot Children's Hospice	6	General	Somewhere need to highlight that many children access school and they often need guidance and support in the management of CPC provision even EOL perhaps when the child is in receipt of schooling at home.	Thank you for your comment. The remit of this guidance is limited to "All settings in which NHS commissioned healthcare is provided".
Forgetmenot Children's Hospice	1	3.1	Reference should be made to pockets in the country of higher than average rates of infant mortality and disability, with predicted increasing birth rates (CHiMAT)– as a consequence the pressure on services to deliver effective CPC can be stretched, despite other parts of the country displaying falling rates.	Thank you for your comment. The epidemiology section of the scope is intended to provide context only and would not normally go into this level of detail.
Forgetmenot Children's Hospice	2	3.2	Needs emphasising that good effective CPC spans the 24 hour period 7 days a week to ensure that preferred place of death can be achieved. Any effective partnership	Thank you for your comments. Models of multi-disciplinary care and service configuration have been included as draft

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			working falls down if commissioners don't fund community support appropriately and as a consequence children fall back into hospital at EOL as a default. Appropriate training of staff within the field of CPC is vital including Drs but also equally that of nurses and allied health professionals to meet the increasing needs of this population. CPC can be nurse and therapy led, providing an expert cost effective experience accompanied by medical input as it is required. The impact of exclusion from respite units or school if the child is in receipt of CPC especially if there is a DNAR decision been taken.	questions in the scope.
Forgetmenot Children's Hospice	3	4.3	Issues to be covered: compassionate extubation both infants and children. Compassionate extubation for young person's going through transition who may not be admitted to a children's unit but be on adult ITU and if this same process can be supported.	Thank you for your comment. Young people who are transferring to adult services are no longer covered by the scope of this guideline. A separate piece of guidance is being developed by NICE which specifically covers the transition from children's to adult services (www.nice.org.uk/guidance/indevelopment/gid-scwave0714)
Forgetmenot Children's Hospice	4	4.3	The impact of cultural differences in the delivery of CPC. How mental capacity can be incorporated into the provision of effective CPC and decision making.	Thank you for your comment. We recognise the importance of cultural diversity and how it might impact this work and will ensure this is reflected appropriately in the guidance. Similarly as stated in section 4.1.1 'infants, children and young people with complex considerations that entail specific care needs, for example those with communication difficulties' will be taken into consideration when making recommendations.
Forgetmenot Children's	5	4.4	Management of specialisms within the speciality of CPC eg management of lethal EB	Thank you for your comment. The guidance will cover aspects of end of life care and

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Hospice		f		specifically excludes the management of the underlying life-limiting condition.
Genetic Alliance UK	1	General	Nearly a third of children with a rare condition will die within their first five years of life (EURORDIS). NICE's clinical guideline therefore must ensure that the needs of infants, children and young people with rare conditions are specifically considered. Over 6000 rare conditions have already been identified. Within this group of characterised conditions there is significant variation in disease severity, rate of progression and age of onset. It is therefore important that this guideline is developed in a way that can be applied flexibly in accordance to patient need, and is not based on preconceptions of what the prognosis of a condition is likely to be. Through advances in medical research, the number of known rare conditions continues to increase. It is therefore also important to ensure any guideline on end of life and palliative care for infants, children and young people does not rely on a list of qualifying conditions which would disadvantage those with newly identified rare conditions, those with delayed diagnosis, and those who have yet to receive a diagnosis for their condition.	Thank you for your comments. The guideline will need to cover those with rare diseases as well as more common conditions. We recognise this is an important point and should be covered within the key issues as currently stated.
Genetic Alliance UK	2	General	It is thought that about half of children with learning disabilities[1] and approximately 60% of children with multiple congenital problems do not have a definitive diagnosis to explain the cause of their difficulties. As many as 50% of children who are in contact with NHS Regional Genetics Services may not get a diagnosis.[2] While the underlying cause of their conditions has not been identified, undiagnosed children can have significant health care needs and many will not survive into	Thank you for your comment. The scope will cover infants, children and young people who have a health state that is identified as life-limiting; it is not necessary that they should have a specific diagnosis. The guideline will address care from first recognition of such a condition.

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			adulthood. These infants, children and young people will require the same care and support towards the end of their lives as those who have been diagnosed with a condition that is known to be life-limiting. Identifying and addressing that need is likely to be even more challenging when the lack of a diagnosis means nothing is known about how that child's condition is likely to progress, when palliative care may be required or for how long. To ensure that all patients and families who will require end of life and palliative care or support are able to access it, it is important that this guideline is created in an environment where having a diagnosis is not necessary for accessing either the processes and services themselves, or the metrics used to estimate and evaluate the care delivered. [1] Daily et al., 2000, available at: www.aafp.org/afp/2000/0215/p1059.html [2] McLaughin et al., 2011, available at: www.ncl.ac.uk/peals/assets/publications/Peals-ResearchReportA5spreads.pdf	
Genetic Alliance UK	3	General	**Rare Disease UK** (RDUK) is a campaign initiative run by Genetic Alliance UK. It is the national alliance for people with rare diseases and all who support them. RDUK is a stakeholder coalition brought together to work with Government to develop and an implement the UK Strategy for Rare Diseases. **SWAN UK** (Syndromes Without A Name) is a patient and family support initiative run by Genetic Alliance UK. It is a UK-wide network providing information and support to families of children without a diagnosis. It works to support the development of high quality information and services for families of children affected by undiagnosed genetic	Thank you for your comments and suggestions on the consultation document. The methods for guideline development are set out in the Methods Manual www.nice.org.uk/article/PMG20/chapter/1%20Introduction%20and%20overview We consider all of the comments submitted by stakeholders and will reflect these as changes to the draft scope where appropriate. It is not usual practice to hold another stakeholder meeting to discuss changes to the scope. Once the scope is finalised it will be published online, after

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			conditions and raise public and professional awareness of undiagnosed genetic conditions and the unique challenges faced by affected families. SWAN UK is a member of 'Together For Short Lives'. On behalf of all the communities we represent, Genetic Alliance UK welcomes the development of this clinical guideline and we look forward to working with NICE and other stakeholders to support and shape its development. To this end, we would welcome clarification on when NICE intends to hold a meeting to discuss the draft scope and the comments received in this consultation. We are more experienced with NICE's processes for health technology appraisals than clinical guidelines, but look forward to an opportunity to further explore the issues we highlight in our response.	which time no further changes can be made.
Genetic Alliance UK	4	3.1 d e	To ensure NICE's assessment of recent trends in childhood mortality in England and Wales is complete, we think it is important to recognise that many of the children that are vulnerable to premature death will not have a diagnosis for their condition. It should be explored whether the undiagnosed patient community shows a similar trend in child death rates as patients with diagnosed conditions.	Thank you for comment. In 2012, 221 unexplained infant deaths occurred in England and Wales (rate of 0.30 deaths per 1,000 live births). 71% of these unexplained deaths were recorded as sudden infant deaths, and 29% were recorded as unascertained.
Genetic Alliance UK	5	3.1 f	The estimates of the number of children that may require palliative care is based on there being "300 conditions that could be classified as life-limiting or life-threatening in children and young people". As stated above, this excludes undiagnosed patients. Moreover, any form of list of qualifying conditions would be inappropriate as it has the potential to discriminate against infants, children and young people who have a genuine need for palliative or end of life care.	Thank you for your comment. This text has been used to illustrate the wide variety of diagnosed conditions that are known to be potentially included and their diverse needs.

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Genetic Alliance UK	6	3.2 b c	In line with our general comments, we seek further clarity on the statement that infants, children and young people require end of life care when they are identified as 'hours or days' from death. A more flexible approach needs be taken when identifying when a patient and their family may benefit from being given the option of palliative or end of life care, and the duration of time that care is available to them due to the inherent unpredictability and variation that exists within the rare disease and undiagnosed patient community.	Thank you for your comment. This key area and the stipulation of a few hours or days relates to the importance of trying (however uncertainly) to recognise that an infant, child or young person is likely to die in the very near future. This has been identified as an issue of central importance by family members. The timeframe given is based on that used by the NICE guideline on care of the dying adult (in development).
Genetic Alliance UK	7	3.2 e f g	As stated in the draft scope, much of the palliative care services available to children are provided privately or by charitable organisations and this can lead to variation in practice. It can also lead to discrepancies in the availability of services if an individual is not eligible for a specific hospice or care service due to the type of condition they are affected by, or the lack of a diagnosis. It would be informative if NICE could investigate current hospice admissions data to determine whether patients who are admitted have a diagnosed clinical condition or whether their access to care is based on the symptoms they present with.	Thank you for your comment. The remit of this guideline is to cover: "All settings in which NHS commissioned healthcare is provided." Therefore, services provided by voluntary sector organisations that have not been commissioned by the NHS are outside of the remit of this guideline.
Genetic Alliance UK	8	4.1	NICE must ensure that in defining the population that will be covered by this guideline it recognises the diversity of patients who will need to be able to access end of life or palliative care, and the inherent unpredictability of when that care may be required. Any form of list will be inadequate, both because of delayed diagnoses or missed diagnoses but also because of constant changes in our understanding and definition of rare diseases. Advances in intensive care and new medicines or interventions, for example, means that some patients will survive into childhood who may otherwise	Thank you for your comment. NICE is committed to ensuring equal access to care and acknowledges there must be flexibility in approach and individually-tailored care available for patients.

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			have died soon after birth, and some may now transition into adult care. NICE should ensure that this clinical guideline allows patients to access care even if their requirement for that care comes at an unexpected age or stage in their condition.	
Genetic Alliance UK	9	4.1.1 a	That the "guideline will address care from the first recognition of the condition" should be clarified to ensure that this does not mean 'from the point of diagnosis', as infants, children and young people may require palliative or end of life care before a diagnosis for their condition has been identified.	Thank you for your comment. The scope will cover infants, children and young people who have a health state that is identified as life-limiting; it is not necessary that they should have a specific diagnosis. The guideline will address care from first recognition of such a condition.
Genetic Alliance UK	10	4.1.1 a	NICE should ensure that those infants, children and young people identified as having "complex health needs" include those who have no diagnosis for their condition.	Thank you for your comment. The scope will cover infants, children and young people who have a health state that is identified as life-limiting; it is not necessary that they should have a specific diagnosis. The guideline will address care from first recognition of such a condition.
Genetic Alliance UK	11	4.3.1 c	Further to addressing the issues that families may face in making decisions about organ or tissue donation, we know from our experience of patients with rare, genetic or undiagnosed conditions that there can often be an interest in making tissue, blood or other biological samples available for research. The scope of this guideline should include how to tactfully address the issue of research involvement with families and to clearly explain the protocols that need to be navigated to make this possible.	Thank you for your comment. The recipient of the organ and tissue donation is not currently specified in the scope and therefore does not exclude donation to research.
Genetic Alliance UK	12	4.4	Further to the outcomes identified in the scope, we believe it is important to include a measure that can capture the ease with which patients and their families felt they were able to access end of life or palliative care, and whether they felt this was made available at the most appropriate time. From our work with the SWAN UK community, there	Thank you for your comment. The list of outcomes is not intended to be exhaustive and these will be discussed by the guideline development group and stated in the review protocol. We thank you for your suggestion.

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			is a general feeling that such care can sometimes be difficult to access or that there are barriers in place that prevent children with undiagnosed conditions from being eligible to receive care. It is therefore essential to measure the accessibility and timing of end of life and palliative care, as well as its quality upon delivery.	
Genetic Alliance UK	13	4.5 a	We welcome the use of symptoms and signs as a way of determining whether an infant, child or young person is likely to require end of life or palliative care, as it does not require an extrapolation from what is known about a diagnosed condition. This would otherwise create an obvious barrier to access for undiagnosed patients. We question, however, whether identifying that death is likely to occur 'within a few hours or days' gives enough time for sufficient care and support to be made available.	Thank you for your comment. This key area and the stipulation of a few hours or days relates to the importance of trying (however uncertainly) to recognise that an infant, child or young person is likely to die in the very near future. This has been identified as an issue of central importance by family members. The timeframe given is based on that used by the NICE guideline on care of the dying adult (in development).
Genetic Alliance UK	14	4.5 b k m-p	We note with concern that NICE will only conduct a literature review in order to determine the answers to their review questions. Within the rare disease and undiagnosed patient community, the availability of published literature is often limited. We would welcome the opportunity to work with NICE and other stakeholders to explore the answers to these reviews questions with the rare disease and undiagnosed patient community who may otherwise be overlooked.	Thank you for your comment. In the absence of evidence, the guideline development group can make consensus recommendations. Given the qualitative nature of some of these draft review questions, it is possible that the developers may consider the use of focus groups and other methods to help inform recommendations, and this will be considered during the development of the guideline.
Genetic Alliance UK	15	4.5 c f-h	The use of the term 'clinical effectiveness' seems inappropriate in the context of end of life or palliative care. Rather than using a measure that appears to be based on health outcomes, it may be more appropriate to measure effectiveness using the quality of life and satisfaction measures outlined in the outcomes section of the draft	Thank you for your comment. The term clinical effectiveness is a standard term that is use to evaluate aspects of clinical care, including quality of life. The outcomes considered for this question will be agreed by the guideline development group when

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			scope (4.4).	drafting the review protocol.
Genetic Alliance UK	16	4.6	The use of Quality Adjusted Life Years (QALYs) is an inappropriate tool to measure effectiveness in the context of end of life or palliative care. As above, quality of life and satisfaction measures are more appropriate outcomes to measure against the cost of the service.	Thank you for your comment. Quality of life is a key component of the QALY but we do recognise that the use of QALYs can be problematic in this area. We've amended the scope to acknowledge that the QALY may not always be a useful measure of effectiveness for analyses undertaken for this guideline
Helen and Douglas House	1	General	- Since the NICE 'Care of the dying adult' guidance is being developed simultaneously, could there be at least one GDG member (a doctor maybe) in common between both groups? This would help ensure that they are aligned where appropriate and cogniscent of each other's work? - I think there is lack of clarity as to whether this guidance is now about end of life care (whilst taking in the need for good quality palliative care and advance and parallel care planning from much earlier), or whether it is now about palliative and end of life care. If it's meant to be the former, we need to then develop separate guidance about palliative care for children. Either way, I think this needs to be spelt out more clearly in the scope which is currently open ended.	Thank you for your comment. The guideline development group will ensure that communication between groups occurs and that the guidance is aligned where possible. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person.
Helen and Douglas House	2	General	I spotted a few areas where there seemed to be errors in the text and / or rephrasing might help to clarify what is intended. I've highlighted changes needed in italics where possible: 2 (line 2) need to omit 'the' (it says '*the* end of life care for infants…). 3.1 d (penultimate line): should read: '… congenital conditions and cancers were the most common *cause* (not 'form') of death…'.	Thank you for your comments. The text has been amended in line with your suggestions where possible.

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

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			3.1 e: could clarify last sentence to read '… the proportion who die from chronic disorders falls to about 30 percent *in this age group*, although… ' (This would clarify that this sentence refers to the over 15y group). 3.1f: last line amend to read ' multiple complex healthcare needs in addition to *needs for* palliative care' 3.2 b: Last sentence could rephrase more clearly, something like: 'Infants, children and young people needing end of life care include those whose death is imminent (expected within hours of days), whether it is because of overall progression of a life-limiting condition, a sudden crisis *in the context of a* pre-existing *life-limiting* condition, or a sudden *de novo* catastrophic event'. 3.2 d: 7th line, amend to 'together with other therapies to treat the *underlying* condition (for example …' 3.2f: 1st line could clarify as 'Some hospitals *and hospices* have *specialist* palliative care teams' (unless you just mean 'special' but I'm not sure what that means in that context? Did you just mean 'designated palliative care teams' (if so, probably avoid the word 'special'? 3.2 g: Maybe line 1 could include availability, ie: 'There is variation in practice especially with respect to the *availability and* delivery of services' 4.5k: last line, how about modifying to say 'especially *towards* the end of life' (since the paragraph mentions parents and carers as well as children and young people). 4.5n: How about rephrasing as: 'What aspects of communication, *discussion* and information provision help…. ,*including the withdrawal of life-sustaining medical interventions*?' (I don't like the blanket term 'withdrawing medical care' – it's not something we do).	
Helen and Douglas House	3	3.2	Maybe add a new section to 3.2 to mention that given the epidemiology, death in childhood is rarely encountered by	Thank you for your comment. Service provision for end of life care will be

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			generalist health care professionals in the community (especially GPs). This underlines the need for accessible published guidance to support GPs and community teams, as well as for good access to specialist advice and support case by case.	addressed in the guideline and recommendations will be based on the best available evidence as identified by systematic reviews of literature.
Helen and Douglas House	4	3.2	Maybe add a new section to 3.1 or 3.2 to make mention of where children die (e.g. Craft and Killen figures), as any guidance should include discussion, planning and service provision to support children dying in the preferred place of care for the child (albeit that preference may change as death approaches).	Thank you for your comment. A draft review question has been included in section 4.5 that specifically addresses this aspect of care.
Helen and Douglas House	5	3.2 g	Maybe add a sentence at the end to say for example: 'Care available should include medically supported respite, effective symptom management, provision of care in social and medical emergencies and 'step down' care following hospital admissions to facilitate transition to home, so that hospital stays can be as short as possible.	Thank you for your comment. The scope does not set out to define possible recommendations. These aspects of care will be addressed during the evidence review and carefully considered by the guideline development group.
Helen and Douglas House	6	3.2 h	Maybe add a further brief section to highlight the issue of uncertainty re prognostication, which applies particularly in children's palliative and end of life care. Repeated surveys suggest that about 1/3 of children referred for 'end of life care' (anticipated as within hours to days) survive the immediate period when they were felt to be particularly likely to die. This points to the need for support for both health care professionals and families in handling uncertainty, and in 'parallel planning' for alternative outcomes, so that this uncertainty is embraced within planning of care.	Thank you for your comment. A draft review question has been included in section 4.5 that specifically addresses the prognosis of death and related aspects of care.
Helen and Douglas House	7	4.1.1 a	Penultimate sentence: I appreciate the emphasis on care from recognition of condition through to after death, but do we need to highlight '*with particular emphasis on planning and care for the end of life phase'*. Otherwise there is a danger that the guidance loses its focus on 'end of life	Thank you for your comment. The development of a personalised care plan is identified as a key issue in the scope (4.3.1b). Additionally 4.3.1 includes a number of areas which are directly relating to the

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			care' (which must be prepared for, yet can't be reliably predicted).	care planning of last days and hours (for example e,f,g,k and l) If appropriate, the focus of that plan and the need to alter it over time, will no doubt be considered.
Helen and Douglas House	8	4.2 a	I realise the guidance only has jurisdiction for the NHS, but does there need to be a specific mention of hospice services here? (most in the children's sector are voluntary sector organisations, but the care is provided in collaboration with NHS colleagues, and supported by some (variable) NHS funding)? I would hope that children's hospice services would want to align themselves with this guidance.	Thank you for your comment. The remit of this guideline is to cover "All settings in which NHS commissioned healthcare is provided." Therefore, the NHS commissioned services provided by the third sector/voluntary sector organisations or hospices would be within the remit of this guideline.
Helen and Douglas House	9	4.3.1 b	Maybe amend to say… 'personalised care plan, including parallel care planning, *and development of advance and emergency health care plans and symptom management plans as appropriate'*.	Thank you for your comment. The specific recommendation for how a personalised care plan should be developed will be determined by examination of the best available evidence and agreed by the guideline development group at the time of review.
Helen and Douglas House	10	4.3.1 d	This is a place to highlight equality issues, including provision of communication and information accessible for non English speakers.	Thank you for your comment. We do not highlight population groups within this section of the scope. However, NICE are committed to ensuring that guidance covers all groups equally and publish formal assessments of equality at the same time as its guidance. You can refer to the policy online at www.nice.org.uk/Media/Default/About/Who-we-are/Policies-and-procedures/NICE-equality-scheme/NICE-equality-objectives-and-equality-programme-2013-2016.pdf
Helen and Douglas House	11	4.3.1 f	Include mention of the use of symptom management plans here?	Thank you for your comment. This key area for consideration is sufficiently broad to cover the use of a symptom management plan. The specific interventions will be defined in the review protocol and recommendations will be formed on the basis of best available

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				evidence.
Helen and Douglas House	12	4.3.1 k	Suggest insert at the beginning of this: 'Recognition and management of uncertainty for health care professionals, patients and families (especially regarding prognosis)'	Thank you for your comment. This level of detail will be considered in light of the evidence that is identified by the systematic review.
Helen and Douglas House	13	4.3.1 l	Maybe add a 2nd sentence to say something like: 'Involving, supporting and communicating with children, young people and families through uncertainty and difficult decision making'. This is another point at which the equality agenda could be highlighted (provision of interpreters etc).	Thank you for your comment. The recommendations will be supported by the best available evidence as identified by the systematic review of literature. Issues relating to equity of care will be highlighted at that time also.
Helen and Douglas House	14	4.3.1 n	Service delivery should probably mention including out of hours provision especially at end of life. This is a point where there is inequality of access, so equality of access could be highlighted (geographical, socioeconomic, ethnicity).	Thank you for your comment. Models of multi-disciplinary care and service configuration have been included as draft questions in the scope. Matters of equality will be addressed by the guidance.
Helen and Douglas House	15	4.3.1 o	Add extra point? 'Use of care pathways to guide provision of high quality palliative and end of life care, for example neonatal pathway, compassionate extubation pathway, core care pathway' (such as those published by Together for Short Lives).	Thank you for your comment. It is expected that the final recommendations will be presented as part of a clinical pathway and this will be discussed within the context of the guideline.
Helen and Douglas House	16	4.3.1 p and q	Further points to highlight the equality agenda	Thank you for your comment. NICE are committed to ensuring that guidance covers all groups equally and as such publish assessments of equality alongside guidance.
Helen and Douglas House	17	4.4 d	Maybe amend to 'Whether children and young people are able to die in a place of their / their family's choice'. (One would wish to prioritise the choice of the child, but many children with life limiting illnesses are not in a position to indicate their choice).	Thank you for your comment. The text has been amended as suggested.
Helen and Douglas House	18	4.5 i j	I wondered if these 2 points could be combined as 'For infants, children and young people in the last days of life, is oral or medically assisted hydration or nutrition effective in improving quality of life?'. (You could separate out the hydration and nutrition sections, but the key issue for me is that the interpretation of 'effectiveness' at the end of life	Thank you for your comment. These two points have been kept separate for the purposes of systematic reviewing. This does not mean that the recommendations will necessarily be separated, as they will be developed following consideration of the full

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			should be clarified, namely around quality of life, balancing burdens and benefits).	evidence base.
Helen and Douglas House	19	4.5 p	The context of decision-making around organ / tissue donation should ideally be earlier, not just after death. Maybe say …. 'young person *with a life limiting condition'* rather than 'young person who has died'… ?	Thank you for your comment. We agree with your comment and have amended the text as suggested.
Helen and Douglas House	20	4.5 q	How about a further question: 'What is the role of anticipatory prescribing in the clinical care of infants, children and young people in the last days of life? (Including how this can be managed practically, arranging provision of anticipatory medication in the home etc).	Thank you for your suggestion. The draft questions will be discussed by the guideline development group and areas for consideration with be prioritised for inclusion at that time.
Helen and Douglas House	21	4.5 r	Another suggested question: What impact does the use of care pathways (such as the extubation pathway, neonatal palliative care pathway) have on the care of infants, children and young people, and on their families?	Thank you for your comment. The service delivery and planning of end of life care for infants, children and young people with life-limiting conditions will be covered by the guidance. Specific issues relating to the provision of care in line with existing care pathways will be discussed with the guideline development group in order to prioritise they key issues for review.
Jessie May	1	4.4 d	It could be that a child/young person is able to die in the place of their choosing however it would be interesting to have information about the 'quality' of that death and what contributed to that quality or otherwise.	Thank you for your comment. The list of outcomes is not intended to be exhaustive and these will be discussed by the guideline development group and stated in the review protocol. We thank you for your suggestion.
Jessie May	2	4.5 b	The preferences for place of death will be limited by the support that is available. There is a lack of 24/7 nursing care and support in the home and where this is lacking it may really be a Hobson's choice.	Thank you for your comment.
Leeds Teaching Hospitals FT	1	General	There is a lack of clarity as to whether this is a guideline for End of Life care only, or for Palliative and End of Life Care. This is to some extent addressed in the background, and it appears that the guidance is for Palliative and End of Life Care; we would welcome this, as it is extremely hard to separate the two in the care of infants, children and young people. This should be made explicit in the Title	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person.

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			of the Guideline, and it should be recognised in the resources made available to support the guideline development. It will be a major undertaking.	
Leeds Teaching Hospitals FT	2	General 4.1.1 b) and 4.1.2	To gain the most out of the inclusion of patients in transition (age 18-24), there should be a planned process which brings together more explicitly this work and the Quality Standards for End of Life Care in adults. This will help experts from each perspective to understand the other, and provide learning for end of life care for teenagers and young adults, as a collaborative partnership.	Thank you for your comment. The scope has been amended and no longer includes patients who are transitioning between children's and adult services as NICE are currently developing guidance on this topic (http://www.nice.org.uk/guidance/indevelopment/gid-scwave0714) and we will cross-refer to this where appropriate.
Leeds Teaching Hospitals FT	3	4.1.1	To address care from 'first recognition of the condition' for the wide range of life-limiting conditions that will be covered could become unmanageable. For example, cancer is included, and the guideline should not cover all aspects of care for a child with cancer. We suggest that this is addressed in section 4.3.2 'Issues that will not be covered' by stating that it will not cover condition-specific clinical management.	It is not intended that all aspects of care would be considered for any life limiting condition and the clinical management of the life limiting condition has been added to the exclusions in section 4.3.2. The general principles of care would be addressed in relation to the palliative care for the condition. It is felt that those aspects need to be considered from the earliest opportunity and the scope of the guideline begins from diagnosis of the life-limiting condition.
Leeds Teaching Hospitals FT	4	4.2	Settings should not be restricted to NHS-commissioned health care. The background recognises variability in commissioning arrangements with the voluntary sector. This guidance should cover hospices, and other voluntary sector provision. Suggest it should cover 'all settings and services in which care is provided by to the groups covered in this scope'. It is fundamental that this guideline should adopt a 'whole systems approach' across the patient pathway which may move between acute hospital care, community based care at home, and hospice or other voluntary sector provision.	Thank you for your comment. The remit of this guideline is to cover "All settings in which NHS commissioned healthcare is provided." Therefore, services provided by voluntary sector organisations or hospices that have not been commissioned by the NHS are outside of the remit of this guideline.
Leeds Teaching Hospitals FT	5	4.3.1	Management - should again start with the need for a systems based approach, across the pathway.	Thank you for your comment. We were not clear about the precise definition of a

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				'systems based approach', but took this to mean integrated provision of care across various specialities within the healthcare service and across healthcare settings. We recognise the importance of this and will make every effort to ensure that the recommendations link across the patient pathway.
Leeds Teaching Hospitals FT	6	4.3.1	Having approached this section from the viewpoint that 'this seems too big', we do not feel that there is any section which is covered by other guidance, and so feel that it needs to remain as it is, with a recognition that some sections may not be dealt with in depth, and the recommendation may be for further work to be done!	Thank you for your comment.
Leeds Teaching Hospitals FT	7	4.3.2	Include statement that the guidance will not include condition specific clinical management	Thank you for your comment. A statement has been added to 4.3.2 that "Clinical management of the underlying life-limiting condition" will not be covered.
Leeds Teaching Hospitals FT	8	4.4	Whilst recognising that all these Outcomes are important, and should be addressed by the document, measuring some of them would be extremely challenging.	Thank you for your comment.
Leeds Teaching Hospitals FT	9	4.5	We think there is work needed on some of these review questions, as it would be extremely difficult to carry out systematic reviews based on current formulations. We note that these questions will be reviewed with the guideline development group, but raise the following issues: f) Suggest that this is not included i & j) Question is wrongly formulated; not a question of how effective medically assisted hydration/nutrition are, but rather 'under what circumstances is it appropriate' or 'what considerations do children or their families consider important in making decisions/would help decision making n) Question is wrongly formulated. Medical care is not 'withdrawn', but purpose/focus may change. Therefore suggest e.g. 'decisions on advanced care planning,	Thank you for your comment. These draft review questions are yet to be discussed with the guideline development group and worked into a PICO format which is appropriate for a systematic review. Regarding 4.5f, stakeholder feedback has indicated this is an important area for inclusion. We believe that questions i and j are considering effectiveness, as we will be considering quality of life associated with these treatments and changes to other clinical outcomes. Draft review question 4.5n has been amended in light of stakeholder feedback and now has a greater emphasis on the planning aspects of this care.

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			including the cessation of life sustaining treatment and options for resuscitation decision making	
Martin House Children's Hospice	1	General	Martin House Children`s Hospice welcomed the broad scope of the planned guidance on End of life care for infants, children and young people and noted that the identified areas are ones that are of particularly important to our practice. Our comments on specific aspects of the scope are noted in the six points below.	Thank you for your comments.
Martin House Children's Hospice	2	General The title	Focusing on `End of Life` does not accurately encompass the range of what paediatric palliative care offers. It does not reflect the `flexible approach to duration` or the `importance of long term planning` as noted on page 3 (3.3b), nor does it encapsulate the point made on page 5 of the document at 4.1.1a, 'The guideline will address care from the first recognition of the condition through to care in the final phase of the condition and after death.'	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person. We acknowledge that there are differences in the accepted definition of "end of life" and will be sure to clearly define this within the guidance itself.
Martin House Children's Hospice	6	General	Guidance would be helpful on what constitutes 'sudden death', when SUDIC procedures are triggered and liaison with coroners.	Thank you for your comment. The scope has been amended for clarity and specifically excludes infants, children and young people aged up to 18 years who die unexpectedly and but have not had a do not have a known pre-existing life-limiting condition, for example, accidental death.
Martin House Children's Hospice	7	General	How will the NICE guidelines interface with other guidance eg: Together for Short Lives'?	Thank you for your comment. NICE guidance is developed independently and informed by systematic reviews. Whilst we are cognisant of existing guidance, they will make recommendations based on the best available evidence identified by the review.
Martin House Children's Hospice	3	4.3.1 d	Communication is noted in key issues that will be covered (4.3.1d 'Communication and information provision from the recognition of a life-limiting condition until after death'). It will be important to be mindful of how communication will take place with less verbal children and young people.	Thank you for your comment. The guidance aims to address the needs of this subgroup and will provide separate guidance, if appropriate.

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Martin House Children's Hospice	4	4.3.1 e	Key issue 4.3.1e, 'Identifying the preferred place of care and the preferred place of death'. This is not always static, but can change depending on a number of factors; for example, the course of the illness, specific symptoms and parents' (or carers') wishes or fears. This will also have implications for one of the suggested main outcome measures, 4.4.d ('Whether children and young people are able to die in a place of their choosing'), recognising that this can change over time, even at the very end of life and be influenced by family wishes and behaviour. It is also important to ensure that all children and families know about the range of services and options available so that they can make informed choices.	Thank you for your comments. We agree with the need to be flexible when identifying the preferred place of care and death and that this might change over time. The interpretation of the outcomes in this section will depend on the review and the review methodology used. This will be discussed with the guideline development group and detailed in the review protocol.
Martin House Children's Hospice	5	4.3.1 k	The key issue noted at 4.3.1k, ('Recognising when infants, children and young people are likely to die within a few days or hours'), is a matter of concern to many families. However the issue in palliative care is often about helping the families (and especially those of children with neuro-degenerative conditions) cope with the difficulty of knowing that this might or might not happen. (An audit carried out by Martin House in 2009 found that 30% of children who came for end of life care went home again; although half of these died within the following six months.)	Thank you for your comment. The psychological and support needs of the family or carer will be considered throughout the guideline. We recognise that there is overlap between some of the draft review questions and will ensure that the final guidance reflects the full care pathway for these individuals.
Mencap	1	4.1.1	Mencap would like to see the list in "a)" include children and young people with profound and multiple learning disabilities. Mencap has been campaigning on health issues for three decades. While progress has been made, much is yet to be done to reduce the stark health inequalities faced by people with a learning disability, and the discrimination still faced by many within our health service. Central to this is the lack of value placed on the life of someone with a learning disability. It may not be recorded	Thank you for your comment. The list of subgroups to be considered is not intended to be exhaustive and does not exclude those who are not listed. However, we believe that children and young people with profound and multiple learning disabilities can be classified as having 'infants, children and young people with complex considerations that entail specific care needs' as detailed in section 4.1.1. . NICE is committed to ensuring equality of care for those children and young people and equality analyses will be made

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			in medical notes, but it is unmistakably clear in the experiences that families of people with a learning disability have shared with us. See Mencap's death by indifference campaign and 74 lives and counting report: http://www.mencap.org.uk/deathbyindifference. Too often families have to fight to convince doctors that the lives of their loved ones are worth saving. Too often families experiefor infants, children and young people with life-limiting conditions" is a massive topic! Again, there needs to be much greater focus within the snce negative assumptions about quality of life of their loved family members. Too often assumptions are made that the life of a person with a learning disability is a burden – to both themselves and their carers – and that it would be better for everyone if they were just 'let go', much to their families' absolute desperation. It is crucial that the NICE guideline recognises the health inequalities that people with a learning disability face. Decisions about end of life must not be based on discriminatory assumptions about quality of life. We would therefore like the NICE guidelines to include a focus on children with a learning disability, specifically children with severe and profound learning disabilities.	publicly available.
Neonatal and Paediatric Pharmacists Group	3	General	We are supportive of this scope and consider that it is inclusive of the population of infants, children and young people and covers the key areas we would wish to see in the Guideline.	Thank you for your comment.
Neonatal and Paediatric Pharmacists Group	1	3.2 f	First sentence – should this read "Some hospitals have **specialist** palliative care teams"?	Thank you for your comment. The text has been amended as requested.
Neonatal and	2	4.5	Should this read "what interventions are safe and clinically	Thank you for your comment. The text in this

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Paediatric Pharmacists Group		h	cost-effective….." (i.e. remove the second "and" from the sentence)	draft review question has been amended.
NHS England	1	4.1.1	What about children with neurological conditions and learning disability? – will they come under 'complex health needs'?	Thank you for your comment. We believe that children and young people with neurological conditions and learning disability can be classified as having 'infants, children and young people with complex considerations that entail specific care needs' as detailed in section 4.1.1.
NHS England	2	4.1.2	Presumably the inclusion of 'adults aged between 18 and 25 who are in transition to adult care' relate only to adults between 18-25 whose life-limiting condition pre-dated their reaching age 18 years? I would expect adults who develop life-limiting conditions after the age of 18 years to be outside the scope of this guideline. Either way, clarification would be helpful.	Thank you for your comment. The scope of this guideline has been amended to include children and young people up to the age of 18 years. We acknowledge the importance of ensuring that people transition smoothly, and will ensure that cross-referrals to guidance under development which is addressing the transition from child to adult services (http://www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714) are made wherever possible.
NHS England	3	4.3.1 L	The common parlance relating to cardiopulmonary resuscitation would be 'to *attempt* cardiopulmonary resuscitation' rather than 'provide', in recognition of the fact that this may not be successful	Thank you for your comment. Following stakeholder feedback the wording to 4.3.1l has been amended and now reads as follows, 'Decisions regarding life sustaining interventions, including cardiopulmonary resuscitation'. The topic will be discussed with the guideline development group when determining the final review questions
NHS England	4	4.3.1 o p	There appears to be some overlap between these 2	Thank you for your comment. Following stakeholder feedback we have combined these two key areas and now appear in the scope as 4.3.1n.

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NHS England	5	4.4 d	I would suggest it's not only the place of death that is an important outcome – the place of care is also important, arguably more so – would suggest expanding this, or itemising separately	Thank you for your comment. The list of main outcomes is not intended to be exhaustive and will vary by review question. The outcomes for each review will be detailed in the review protocol for each question.
NHS England	6	4.5 n	Does this need to be age-specific?	Thank you for your comment. The subgroups that will be considered for this evidence review will be outlined in the protocol after discussion with the guideline development group.
NICE Health and Social Care Quality Programme	1	4.4 c	Could this also make reference to satisfaction with support after the person's death?	Thank you for your comment. The timeframe of the satisfaction with care will be specific to each review and defined in the review protocol.
Northern England Strategic Clinical Networks	8	General	Another important question to include is: How do teams ensure that infants, children and young people receive equal access to the highest standards of healthcare at all times and that assumptions are not made about their quality of life based on their appearance, disabilities, intellectual functioning or the assumptions of those who are assessing them? How do teams ensure that all infants, children and young people can continue to receive life-sustaining care and interventions in an equal way, so long as they are likely to get benefit from them?	Thank you for your comment. NICE is committed to ensuring that people have equal access to the highest quality of care. There are clear processes in place which ensure that recommendations address these issues which include a formal assessment of equality considerations when developing recommendations. NICE's policy can be found online at www.nice.org.uk/Media/Default/About/Who-we-are/Policies-and-procedures/NICE-equality-scheme/NICE-equality-objectives-and-equality-programme-2013-2016.pdf
Northern England Strategic Clinical Networks	9	General	Another important question to include: How to teams ensure that decision-making about levels of intervention with children, young people and their parent carers and families is always within an ethical and legal framework, with due regard to the Children Act Welfare Checklist and the Mental Capacity Act Best interest checklist?	Thank you for your comment. The guidance will cross-refer to relevant legislation as required, and notes will be included in recommendations if deemed necessary.
Northern	1	4.1.1	This is unrealistic in that the scope intends to cover "care	Thank you for your comment. We do

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England Strategic Clinical Networks			from the first recognition of the condition through to care in the final phase of the condition and after death" and is to include infants, children and young people with: • Complex health needs • Cancer • Antenatal diagnosis of life limiting condition • Neonatal intensive care needs • End organ failure This cannot be so, as this will cover all of paediatric disability, paediatric oncology, neonatology and a lot of other 'ologies' which is not possible within the scope of this guideline. It would be much more meaningful if the scope is very much more specific about the aspects that it does intend to cover, rather than this 'catch all' list. Perhaps say '….from first recognition of a life limiting condition regardless of diagnosis or lack of diagnosis'; and remove the list of broad conditions which may or may not be life limiting.	recognise the wide breadth of the scope and have recruited a diverse guideline development group in order to meaningfully prioritise the aspects of end of life care that will be considered. The guidance will cover aspects of end of life care and excludes the management of the underlying life-limiting condition.
Northern England Strategic Clinical Networks	2	4.2.1 (in addition to point k)	Recognise those infants, children and young people who are at increased risk of sudden and unexpected death and ensure that this has been sensitively communicated with the family and that the discussion has been recorded in the family held care plan. (This is likely to include those with complex and multiple disabilities, complex medical conditions, immunodeficiencies, complex congenital heart disease, complex congenital anomalies etc. etc.)	Thank you for your comment. The differing needs of those children and young people with complex medical conditions will be considered within the evidence framework and the guideline developers will make recommendations where appropriate.
Northern England Strategic Clinical Networks	3	4.2.1 n	"Service delivery for infants, children and young people with life-limiting conditions" is a massive topic! Again, there needs to be much greater focus within the scope about exactly what it intends to cover, otherwise will be in danger of covering the whole of paediatrics!	Thank you for your comments. The scope has been amended for clarity, and section 4.3.1m now states an issue which will be covered is 'the organisation of services providing the end of life care of infants, children and young people with life-limiting conditions'. . The guideline development group will prioritise the areas for consideration and these will be detailed in

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				the review protocols.
Northern England Strategic Clinical Networks	4	4.3.1 k	Recognition when an infant, child or young person likely to die within a few days or hours or are at increased risk of dying due to increased fragility or sudden deterioration of an existing condition(though they may subsequently survive)	Thank you for your comment. This key area and the stipulation of a few hours or days relates to the importance of trying (however uncertainly) to recognise that an infant, child or young person is likely to die in the very near future. This has been identified as an issue of central importance by family members. The timeframe given is based on that used by the NICE guideline on care of the dying adult (in development).
Northern England Strategic Clinical Networks	5	4.3.1 l	How to make timely decision to withhold or withdraw medical interventions, or to not provide cardiopulmonary resuscitation in the context of shared decision making, futility, best interests, ethical and legal frameworks. Also add following this – How to communicate these decisions in a timely and sensitive way	Thank you for your comment. The scope is sufficiently broad enough to cover the timing of withdrawal of care, and this will be discussed for possible inclusion with the guideline development group. Communication needs are already covered by the scope and will be relevant here also.
Northern England Strategic Clinical Networks	6	4.4	should also include: correct identification and management of associated medical conditions in line with best evidence e.g. constipation, endocrine issues, gastro-oesophageal reflux, drooling, epilepsies, pressure area care, spasticity, dystonia, disordered sleep, continence issues, feeding and swallowing issues, emotional, behavioural and mental health issues etc. Add Equitable access regardless of diagnosis or type of life-limiting condition	Thank you for your comment. The clinical management of the life-limiting conditions is excluded from the scope as detailed in section 4.3.2b. However, as detailed in 4.4f the guideline will address distressing symptoms as specified by the guideline development group when developing the review protocol. NICE are committed to ensuring equitable access to the best quality care and will publish assessments of equality at the same time as the guidance.
Northern England Strategic Clinical Networks	7	4.5	review questions, this also needs to address the recognition of the group of infants, children and young people at increased risk of sudden and unexpected death, so that this risk can be communicated to families in a timely way (See Horridge K Advance Care Planning: practicalities, legalities, complexities and controversies.	Thank you for your comment. We believe that the scope of the guidance is sufficiently broad to cover these topics and they will be discussed for possible inclusion by the guideline development group. NICE is committed to ensuring equal access for all

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
			Arch Dis Child 10/2014; DOI: 10.1136/archdischild-2014-305945) Following on from e: What service arrangements enable equitable access to end of life care Following on from f: What is the clinical and cost effectiveness of care coordination / keyworker for children and young people / does this improve satisfaction with care?	patient groups and publishes an assessment of equality considerations at the time of publishing the scope and the recommendations.
Northwest Children's Palliative Care Network	1	General	Ensure clarity about whether this guideline is JUST end of life care, or Palliative care for infants, children and young people. The document is contradictory.	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of end of life care begins from the point of diagnosis of the life-limiting condition through to beyond the death of the infant, child or young person.
Northwest Children's Palliative Care Network	2	General	We acknowledge that terminology is not always consistently used across the literature. Therefore the guideline must specify that this refers to palliative care i.e. care from diagnosis or recognition for children with life threatening and life limiting (shortening) conditions and also that it includes end-of-life care i.e. care in the last few hours and days of life for children who have a pre-diagnosed life threatening or life limiting (shortening) condition and those who die suddenly. This must also be reflected in the title e.g: "Palliative and end of life care for children"	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of end of life care begins from the point of diagnosis of the life-limiting condition through to beyond the death of the infant, child or young person. However in section 4.2.1 the scope now states that this guideline will not cover 'Infants, children and young people aged up to 18 years without a recognised life limiting condition who die unexpectedly'. Within the definition of life limiting conditions we will include conditions which are likely to result in an early death. Therefore some life threatening conditions or certain stages of these conditions will be encompassed by the term 'life limiting' for this guideline.

Stakeholder	**Order No**	**Section No**	**Comments** Please insert each new comment in a new row.	**Developer's Response** Please respond to each comment
Northwest Children's Palliative Care Network	3	General	Whilst the scope does not cover workforce training or development this must be considered in the implementation of the guidance	Thank you for your comment. Staff training is outside the remit of this guidance.
Northwest Children's Palliative Care Network	4	General	Use of the Spectrum of Children's Palliative Care Needs© would help clarify the scope of the guideline and provide helpful guidance to identify children to whom the guideline applies	Thank you for your suggestion. The scope has been amended to more accurately describe the population of infants, children and young people to which the scope applies. The provision of end of life care begins from the point of diagnosis of the life-limiting condition through to beyond the death of the infant, child or young person.
Northwest Children's Palliative Care Network	5	General	Despite the title, the guideline appears to focus primarily on the focus on end of life days and hours. The Scope as it stands does not seem to me to reflect the possible repeated episodes of end of life care nor the uncertainty of which episode is the final end of life care event. It does not adequately reflect the broader issues of diagnosis and information sharing, communication skills, holistic multiagency assessment and care planning, discharge planning, co-ordination of care, key-working and multiagency partnership working, including housing, education, social care etc which are also key elements of holistic palliative care for children	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of end of life care begins from the point of diagnosis of the life-limiting condition through to beyond the death of the infant, child or young person.
Northwest Children's Palliative Care Network	6	General	Although bereavement is a separate NICE guidline the impact of diagnosis and anticipatory grief starts from diagnosis. It is essential that the guideline emphasises the importance and relevance of anticipatory grief and pre death care and its impact on subsequent bereavement.	Thank you for your comment. Although the long term specialised management of bereavement will not be included, the care of family members and carers after bereavement is not excluded from the scope. Regarding the care needed before the death of the child or young person, the scope of the guideline allows for consideration of the aspects of care that may help family

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				members or carer to deal with the loss.
Northwest Children's Palliative Care Network	7	3.2 f	Is that meant to read Specialist palliative care teams	Thank you for your comment. The text has been amended as requested.
Northwest Children's Palliative Care Network	8	4.1.1 b	Where are children with neurodegenerative/metabolic conditions included?	Thank you for your comment. The breath of the scope is wide and section 4.1.1 does not intend to exclude these patients.
Northwest Children's Palliative Care Network	9	4.1.1 C	How can children who die unexpectedly receive palliative care? – does this describe death on intensive care? Or does it relate to bereavement care. Will it be integrated with statutory SUDC processes	Thank you for your comment. The scope has been clarified in relation to the inclusion of sudden deaths of children and young people. The scope excludes children and young people who die unexpectedly from a life-limiting condition which was not known prior to their death.
Northwest Children's Palliative Care Network	10	4.4 a	Whose quality of life does this refer to?	Thank you for your comment. This list is not exhaustive and covers both the quality of life for the children, family members and their carers. The precise definition this will be dependent on the review question and outlined clearly in each protocol.
Northwest Children's Palliative Care Network	11	4.5	Need to clarify when relating to end of life care and when whole of palliative care – is muddled	Thank you for your comment. We recognise that there are differing definitions of end of life and palliative care, and their respective timeframes. Terms within several of these questions have been amended to reflect the intended group and these will be clearly defined in the review protocols and final guidance.
Northwest Children's Palliative Care Network	12	4.5 m	This is a huge group of issues – needs to be divided	Thank you for your comment. This draft question will be informed by the guideline development group and segmented as required in order to search for the relevant evidence. This will be done at the time of

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				protocol development. This draft question is intended to be indicative of the aspects that will be considered.
Northwest Children's Palliative Care Network	13	4.5 n	Withdrawal of medical care needs to be reworded; e.g. withdrawal of ventilation/ intensive care etc or withdrawal of interventions that are no longer in the child's Best Interests	Thank you for your comment. This draft question has been reworded and now reads as "What information do infants, children and young people with life-limiting conditions and their family members or carers (as appropriate) need in order to be involved in advanced care planning, including if appropriate decisions about stopping life-sustaining treatment and attempting cardiopulmonary resuscitation?".
Oxford University Hospitals NHS Trust	1	3.2 F	Do we mean 'Specialist' rather than 'Special'? This may sound pedantic, but actually the words have become important within the definition of paediatric care. 'Specialist' services refer to Consultant-Led (Level 4) medical specialist teams; whereas 'Specialised' refers to a service specifically tailored for the needs of children with life limiting illness (but this may be a support service rather than a medical service).	Thank you for your comment. In the context of this section (now 3.2h) the term "specialist" reflects the service configuration. However, where this is unclear, the term "dedicated" will be used.
Oxford University Hospitals NHS Trust	2	3.2 g	Will we be able to specifically address the role of medically supported respite? This would include the impact on the parent's wellbeing and capacity to care, as well as the impact on the stability of the child, conferred by regular medical / nursing review.	Thank you for your comment. The role of respite care can be considered within the terms of the scope.
Oxford University Hospitals NHS Trust	3	4.2	Presumably the guidance will include third sector organisations, rather than only NHS-Commissioned care? Some charity delivered care is commissioned but most is still not (regardless of its high quality)	Thank you for your comment. The remit of this guideline is to cover, "All settings in which NHS commissioned healthcare is provided." Therefore, services provided by third sector organisations that have not been commissioned by the NHS are outside of the remit of this guideline.
Oxford University Hospitals NHS	4	4.3.2	Again, do we mean 'specialist' or 'specialised'?	Thank you for your comment. This section has been amended for clarity and now says "specialist".

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Trust				
Oxford University Hospitals NHS Trust	5	4.5 m	Maybe this would be the place to include respite?	Thank you for your comment. We believe that respite care may potentially be identified as a form of support as defined in this section of the scope. The recommendations will be based on the best available evidence as identified by the systematic literature review and all interventions will be pre-specified in the review protocol after discussion with the guideline development group.
Paediatric Chaplaincy Network	1	General	Be consistent in use of terms "spiritual and religious" – at times only one of the words is used.	Thank you for your comment. We have replaced references to "spiritual and religious" with both terms in all places.
Paediatric Chaplaincy Network	6	General	Consider including term spiritual distress.	Thank you for your comment. We believe that the term should also encompass the positive aspects of spiritual support and therefore have not amended as suggested.
Paediatric Chaplaincy Network	2	4.5 f	Chaplaincy/spiritual care should be part of all possibilities.	Thank you for your comment. The guideline development group contains a spirituality advisor and these aspects of care will considered at every stage of development.
Paediatric Chaplaincy Network	3	4.5 g	Include psycho-social and the role of chaplains and spiritual care specialists	Thank you for your comment. The guideline development group contains a diverse range of specialist members whose interests include psycho-social care including a spirituality advisor, mental health practitioner and youth worker. The scope covers these aspects of care and aims to ensure they are considered throughout development.
Paediatric Chaplaincy Network	4	4.5 l	Religious and spiritual assessments should be part of this.	Thank you for your comment. The guideline development group contains a spirituality advisor and these aspects of care will considered at every stage of development.
Paediatric Chaplaincy Network	5	4.5 o	This is an example of where religious needs to be added (see general comment above) and it would be good if spiritual was not normally the last area mentioned in a list.	Thank you for your comment. The text has been amended as suggested.

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Royal College of General Practioners	1	General	From a general practice perspective having evidence based guidance may well be of hlp in supporting the young going through palliative/end of life care. The emotional challengers are likely to be high for anyone looking after those affected and suitable guidance will be welcomed.	Thank you for your comment.
Royal College of Nursing	1	General	The RCN welcomes the development of this guidance. In terms of neonatal end of life care there are some very specific issues which don't seem to be addressed in this draft scope. There are some good documents such as the Practical guidance for the management of palliative care on neonatal units, by A Mancini, S Uthaya, C Beardsley, D Wood and N Modi. 1st Edition, February 2014. Timing of the guidelines: Will work undertaken on the development of palliative care tariff and ongoing research which is in progress into palliative care throughout the UK have some bearing on what needs to be considered, such as: • Education & training • Role of networks • Role of hospices etc	Thank you for your comments. The guideline is not intended to be exhaustive in its scope, but rather prioritises areas of need. We acknowledge the importance of these topics and believe some of these are covered by the draft review questions in section 4.5.
Royal College of Nursing	2	General	There is a lack of clarity as to whether this is a guideline for End of Life care only, or for Palliative and End of Life Care. This is to some extent addressed in the background, and it appears that the guidance is for Palliative and End of Life Care. We would welcome this, as it is extremely hard to separate the two in the care of infants, children and young people. We feel that this should be made explicit in the title of the guideline, and should be explicitly recognised in the resources made available to support the guideline development. We appreciate this will be a major undertaking.	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person.
Royal College of Nursing	29	General	To get a more diverse point of view, we feel it would be necessary to approach local groups and representatives.	Thank you for your comment. The possible inclusion of a focus group will be considered

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			There are many families in deprived areas and in varied circumstances who might attend these focus groups. This could also provide insight about religious views e.g. the use of morphine at end of life as there are religious advisers present in different communities.	during the development period and we thank you for the suggestion. A spiritual advisor has been included as a core member of the guideline development group.
Royal College of Nursing	30	General	The voluntary sector's provision is an essential part of children's palliative care and it is essential that the make-up of the guideline development group adequately reflects the range of professionals, services and organisations with expertise in this subject.	Thank you for your comment. The remit of the guideline is limited to NHS commissioned services, however we recognise that care is received in other services. A diverse range of professionals will be recruited to the guideline development group and it is expected that their experience will relevant to this setting.
Royal College of Nursing	31	General	We also feel that community children's nursing services are fundamental to the provision of high quality children's palliative care and it is essential that this is reflected in the membership of the guideline development group.	Thank you for your comment. A post was advertised for a paediatric nurse with community experience to become a member of the guideline development group.
Royal College of Nursing	32	General	Issues of diversity need to be addressed throughout the work – recognising the importance of faith and culturally sensitive care throughout the care of the child and family.	Thank you for your comment. We recognise the importance of cultural and religious diversity and how it might impact this work and will ensure this is reflected appropriately in the guidance.
Royal College of Nursing	33	General	The impact of the death of a child is felt by the whole family and so it is important that the guideline recognises the role of the family in providing care, but also in needing care, especially the care of siblings throughout the whole care trajectory, into death and bereavement.	Thank you for your comment. Although the long term specialised management of bereavement will not be included, the care of family members (including siblings) after bereavement is not excluded from the scope. Regarding the care needed before the death of the child or young person, the scope of the guideline allows for consideration of the aspects of care that may help these family members or carer to deal with the loss.
Royal College of Nursing	34	General	Although bereavement care is excluded from this guideline it is important to recognise the role of pre-bereavement care and dealing with loss and grief in the pre-death phase.	Thank you for your comment. Although the long term specialised management of bereavement will not be included, the care of family members and carers after a

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
				bereavement is not excluded from the scope. Regarding the care needed before the death of the child or young person, the scope of the guideline allows for consideration of aspects of care that may help family members or carer to deal with the loss.
Royal College of Nursing	3	General n	We feel this question needs reviewing as we believe it reads negatively. We recommend 'treatment escalation plans and treatment options' rather than withdrawal or advanced care planning.	Thank you for your comment. This question addresses advanced care planning in general however we feel it is important to include withdrawal of care, when appropriate, for clarity. The terminology has been changed so that it takes a more positive approach.
Royal College of Nursing	4	3	We noticed that some of the reference links cited here are not child specific.	Thank you for your comment. The background section of the scope is intended to provide basic context. Further details will be provided in the guidance itself.
Royal College of Nursing	5	3.1	The RCN believes that this section could benefit from reflecting on the different rates of life limiting conditions in certain ethic groups underlining a need for cultural sensitivity in service provision.	This level of detail is typically included in the review protocol. Thank you for your suggestion.
Royal College of Nursing	6	3.1a	'The death of an infant, child or young person has become an uncommon event in the UK'..... We feel that this statement can be strengthened by acknowledging the actual numbers of infants, children and young people who do still die in England	Thank you for your comment. We have provided age-specific mortality rates in section 3.1b and 3.1d
Royal College of Nursing	7	3.2b	Current practice – The RCN questions the timeline specified for imminent death ..." (expected within hours or days)" ....as many children's trajectories mean that they have crisis periods where it appears they are at the end of life and then they pull through	Thank you for your comment. This key area and the stipulation of a few hours or days relates to the importance of trying (however uncertainly) to recognise that an infant, child or young person is likely to die in the very near future. This has been identified as an issue of central importance by family members. The timeframe given is based on that used by the NICE guideline on care of

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				the dying adult (in development).
Royal College of Nursing	8	3.2c	We feel that the last sentence "These include the hospital, hospice, primary care professionals, other support providers, and specialist palliative care teams" should also include ambulance services (for planning rapid discharge at End of Life), coroner services (again in case the child dies in transit during rapid discharge but also for body to be moved after death e.g. to hospice cool room) and children's education (school is an important source of support for the child before death and the community after death.. see the support given to Steven Sutton, his family and community)	Thank you for your comment. We agree that the role of the ambulance service is an important consideration and have amended the scope as requested.
Royal College of Nursing	9	3.2d	This statement could be strengthened by acknowledging the need for short breaks to support the child and family and the role of education in the care of the child/young person	Thank you for your comment. The key areas for consideration cover the care needed to support the child and young person as well as the family and carers. The recommendations will be based on the best available evidence.
Royal College of Nursing	10	3.2f	Not only do some hospitals have special palliative care teams but the community children's nursing teams in many areas provide palliative care, and may have nurses leading on this aspect of care, especially in areas that still have 'Diana teams'	Thank you for your comment. This paragraph has been amended so that the term may include various models of care.
Royal College of Nursing	11	3.2g	Again children's education (schools) are very important to the child	Thank you for your comment. The remit of this guideline is to cover: "All settings in which NHS commissioned healthcare is provided." Therefore, services provided by organisations that have not been commissioned by the NHS are outside of scope.
Royal College of Nursing	12	4.1.1	Groups covered – adults aged between 18 and 25 will be considered in the adult guideline. However there is no provision for those young adults who are adults in terms of	Thank you for your comment. The scope of this guideline has been amended to include children and young people up to the age of

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
			age but many may have the cognitive ability of a child; they have very different needs that requires consideration. We also have an increasing group of young men for instance with DMD (Duchene Muscular Dystrophy) who will have very different needs from adults nearing end of life. We also feel that there is a need to clarify whether this is up to the 18th or 19th birthday as "up to 18" is unclear.	18 years. We acknowledge the importance of ensuring that people transition smoothly, and will ensure that cross-referrals to guidance under development which is addressing the transition from child to adult services (http://www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714) are made wherever possible. The scope excludes patients who are aged 18 years or older.
Royal College of Nursing	13	4.1.1	We feel to address care from 'first recognition of the condition' for the wide range of life-limiting conditions that will be covered could become unmanageable. For example, cancer is included, and the guideline should not cover all aspects of care for a child with cancer. We suggest that this is addressed in section 4.3.2 'Issues that will not be covered' by stating that it will not cover condition-specific clinical management.	Thank you for your comment. The scope has been amended as suggested.
Royal College of Nursing	14	4.1.1a	We suggest using 'Together for Short Lives' definitions of life-limiting and life threatening conditions	Thank you for your suggestion. We have included a section showing what the remit of the guideline is in section 3.2a and 3.2b. Within the definition of life limiting conditions we will include conditions which are likely to result in an early death. Therefore some life threatening conditions or certain stages of these conditions will be encompassed by the term 'life limiting' for this guideline.
Royal College of Nursing	15	4.1.1c	If considering infants, children and young people aged up to 18 who die unexpectedly without a prior known life-limiting condition, there is need for indication of referrals to A/E staff, coroner and CDOP at times – which should be reflected in the guidelines. Also we feel it should be taken into consideration that some of these children may be on adult ITUs who may be unaware of need to refer to CDOP	Thank you for your comment. The scope has been amended for clarity and specifically excludes infants, children and young people aged up to 18 years who die unexpectedly and were not diagnosed as having a life-limiting condition before their death. This group of patients is therefore not covered by the guidance.

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Royal College of Nursing	16	4.2	Settings should not be restricted to NHS-commissioned health care. The background recognises variability in commissioning arrangements with the voluntary sector. These guidelines should cover hospices, and other voluntary sector provision. We suggest it should cover 'all settings and services in which care is provided to the groups covered in this scope'. It is fundamental that this guideline should adopt a 'whole systems approach' across the patient pathway which may move between acute hospital care, community based care at home, and hospice or other voluntary sector provision.	Thank you for your comment. The remit of this guideline is to cover "All settings in which NHS commissioned healthcare is provided". Whilst this includes many third sector/voluntary sector organisations or hospices, it is not possible to cover those who do not receive NHS funding.
Royal College of Nursing	17	4.2a	We feel schools (school nurses) settings should also be considered.	Thank you for your comment. The remit of this guideline is to cover "All settings in which NHS commissioned healthcare is provided".
Royal College of Nursing	18	4.3.1	Management – we would suggest starting afresh with the need for a whole system approach, across the pathway. We appreciate that the breadth in reality may demand further associated guideline development in order to encapsulate the depth required. Ideally the guideline should encompass the totality.	Thank you for your comments. The scope includes the issue of service delivery and therefore whole system approaches could be considered by the GDG
Royal College of Nursing	19	4.3.1 l	This issue talks about withholding or withdrawing medical interventions. There is now more positive terminology preferred for instance 'limiting treatment' as seen in the draft RCPCH document which the RCN has been involved in. Also do not attempt CPR. Could possibly be expanded to also include withdrawal of life sustaining treatment. The RCN believe that some of these issues could be usefully presented as algorithms.	Thank you for your comment. We believe that the current terminology encompasses both limiting treating as well as withdrawing treatment, and is therefore broader in its scope. It is expected that the final guidance will be presented as part of a patient pathway and algorithms will be provided in the document where needed.
Royal College of Nursing	23	4.3.1.e	Rapid discharge plans need ambulance service and coroner to be included	Thank you for your comment. The recommendations for what to include in a rapid discharge plan will be informed by the

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				best available evidence.
Royal College of Nursing	20	4.3.1.f	We feel there might be the need to also involve the physiotherapist e.g. cough assists	Thank you for your comment. We recognise that specialist expertise beyond that already available in the guideline development group might be required, depending on which areas are prioritised by the guideline development group for inclusion. Therefore, expert advisors will be co-opted to the group as required.
Royal College of Nursing	21	4.3.1.g	There is also the need to Involve a dietician	Thank you for your comment. We recognise that specialist expertise beyond that already available in the guideline development group might be required, depending on which areas are prioritised by the guideline development group for inclusion. Therefore, expert advisors will be co-opted to the group as required.
Royal College of Nursing	22	4.3.1.j	We feel schools (school nurses) settings should also be considered.	Thank you for your comment. The remit of this guideline is to cover "All settings in which NHS commissioned healthcare is provided".
Royal College of Nursing	24	4.3.1.p	If the child dies at home, the police, coroner and undertaker may be involved, especially if the child's body is to be transferred promptly to hospice cool room. There is the need for prompt paperwork and planning as it causes unnecessary distress to the parents otherwise.	Thank you for your comment. The recommendations will be informed by the best available evidence.
Royal College of Nursing	25	4.3.2	Include the statement that the guideline will not include condition specific clinical management	Thank you for your comment. The scope has been amended as requested.
Royal College of Nursing	26	4.4	We feel there that "a good death"/"quality of death" should be included. Whilst recognising that all these outcomes are important, and should be addressed by the document, measuring some of them would be extremely challenging.	Thank you for your comment. The outcomes for each review question will be dependent on the question and will be detailed in the review protocol. Appropriate methods of outcome measurement will be discussed with the guideline development group before reviewing of the evidence begins.

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Royal College of Nursing	27	4.5	We think there is work needed on some of these review questions, as it would be extremely difficult to carry out systematic reviews based on current formulations. We note that these questions will be reviewed with the guideline development group and we would like the following recommendations to be taken into account: 1. For question (f), we suggest that this is not included. 2. For questions (i) & (j), we feel the question is wrongly formulated; as it is not a question of how effective medically assisted hydration/nutrition are, but rather 'under what circumstances is it appropriate' or 'what considerations do children or their families consider important in making decisions/would help decision making'. 3. For question (n) we feel this question is wrongly formulated (and see point raised in (5) below). Medical care is not 'withdrawn', but purpose/focus may change. Therefore we suggest, for example. 'Decisions on advanced care planning, including the cessation of life sustaining treatment and options for decision making on resuscitation options'. 4. Review questions should also include - What should we be doing in terms of competency and education for HCP's so that they can identify and prognosticate much better? 5. Review question (n) – Again, we feel this question needs reviewing as we believe it reads negatively. We recommend 'treatment escalation plans and treatment options' rather than 'withdrawal or advanced care planning'.	Thank you for your comment. These draft review questions are yet to be discussed with the guideline development group and worked into a PICO format which is appropriate for a systematic review. Regarding 4.5f, stakeholder feedback has indicated this is an important area for inclusion. We believe that questions i and j are considering effectiveness, as we will be considering quality of life associated with these treatments and changes to other clinical outcomes. Draft review question 4.5n has been amended in light of stakeholder feedback and now has a greater emphasis on the planning aspects of this care.
Royal College of Nursing	28	4.5.b	Include choice of place of body after the death e.g. hospice cool room	Thank you for your comment. The choice of place for the body after the death of the child or young person will be considered in draft review question 4.5o.

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Royal College of Paediatrics and Child Health	9	General	We think that the draft scope of the guideline is excellent. However, have one concern, which is expanded upon in 3 'linked' comments below. Broadly, the palliative care and critical care clinical community would agree with what a child with a life-limiting condition 'looks like'…as per the definition set out in the ACT (*now Together for Short Lives'*) guidance. However, the suggestion to extend the scope of the study to a child who dies 'unexpectedly' risks diverting the core focus of the group into territory which is hard to define, has a different evidence base, may demand a different approach in meeting parental needs, and similarly different stakeholders to inform discussions (e.g. the police in the case of homicide, or a coroner in the case of suicides)	Thank you for your comment. The scope has been amended to clarify that those infants, children or young people who die unexpectedly and do not have a life-limiting condition (e.g. accidental death) will not be covered by the guideline.
Royal College of Paediatrics and Child Health	1	3.1 b	No mention of important group – obstetrics. This should perhaps read … particularly in midwifery, obstetrics and neonatal …	Thank you for your comment. Your proposed change has been adopted and the sentence now reads: "This change can partly be explained by improvements in health care, particularly in midwifery, obstetric and neonatal intensive care."
Royal College of Paediatrics and Child Health	2	3.1 d	In 2012, congenital conditions and cancers were the most common form of Perhaps should be: In 2012, neonatal conditions and cancers were the most common cause of …	Thank you for your comment. As there are some neonatal conditions which are not congenital this wording will be retained.
Royal College of Paediatrics and Child Health	3	3.2 c	Hospital, hospice, primary care professionals. Perhaps should be: hospital, hospice, community care professionals	Thank you for your comment. This has now been modified to be more explicitly inclusive and refers to both primary and community care.
Royal College of Paediatrics and Child Health	4	4.1.1 a	Is there a reason for the contents of this list being so limited. Are these areas of special concern. Certainly it misses a large proportion of babies and children who might benefit from CPC. eg Congenital anomalies not amenable to treatment, severe neurological problems, etc.	Thank you for your comment. The breadth of the scope is wide and covers all life-limiting conditions. During the development of review protocols the guideline development group will discuss key patient groups to be included where relevant and appropriate, e.g.

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			Perhaps the list should extended or introduced or introduced: Subgroups to be considered include …	neonatology. Section 4.1.1 of the scope has now been amended for clarity.
Royal College of Paediatrics and Child Health	10	4.1.1 c	"infants and children and young people aged up to 18 years who die unexpectedly without a prior known life-limiting condition". We have concerns that extending the scope of the guideline to include this group of children may inadvertently cause the GDG to reflect on the end of life care of ALL children who die, and I suspect that this was not the intention of the DH when it requested NICE to undertake this project. Children who die essentially either have a known life-limiting condition or not. Hence my concern that the wording of 4.1.1.c) may inadvertently lead one to discuss the management of all children who die. The definition of 'unexpected/expected' is fraught with difficulty. Consider the child who dies from meningococcal sepsis on a PICU. That death may be entirely 'expected' from the viewpoint of the clinician. However, one can guarantee that from the viewpoint of the parent that the child's death is 'unexpected'. We understand why this additional group was mentioned at the stakeholder day, and suspect that the intention is to capture those children whose death is 'both unexpected AND unexplained' after a complete investigation. An example of this might be the infant who dies following Sudden Infant Death Syndrome (SIDS). However, there is already very clear legislation in place defining precisely what the professionals' response should be to such an event (Chapter 7, Working Together, 2013; DE). Our final concern with extending the scope of the study to 'unexpected' deaths is that these deaths often occur out of	Thank you for your comment. This section of the scope has been amended so that children who die unexpectedly and who are not know prior to death to have a life-limiting condition are excluded from the guidance.

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			hospital (eg a SIDS at home, or a road traffic death in the community). Section 4.2 a) clearly states that the scope of the guideline should be limited to NHS-commissioned settings - which we agree with. If we are to extend the scope to include ALL deaths - then the scope of the study would, by definition, have to extend to all settings where a child might die.	
Royal College of Paediatrics and Child Health	5	4.1.2 a	between 18 and 25 who Perhaps should be: between 18 and 25 with chronic or complex conditions who …	Thank you for your comment. The scope of this guideline has been amended to include children and young people up to the age of 18 years. We acknowledge the importance of ensuring that people transition smoothly, and will ensure that cross-referrals to guidance under development which is addressing the transition from child to adult services (http://www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714) are made wherever possible.
Royal College of Paediatrics and Child Health	11	4.2 a	"All settings in which NHS-commissioned health care and social care is provided". We think this is the correct scope for defining the 'setting' for the guideline. However, as explained above, if the scope of the deaths to be included extend to those who die unexpectedly, then this is incongruous with our work being limited to an 'NHS-commissioned' setting.	Thank you for your comment. The scope of the guideline has been amended for clarity and does not include sudden deaths of children or young people who do not have a life-limiting condition that was identified before their death.
Royal College of Paediatrics and Child Health	6	4.3.1 l	How to make the decision to withhold or withdraw medical interventions, or to not provide cardiopulmonary resuscitation. Should this be split into 2 parts, perhaps: 1. How to make the decision to withhold or withdraw medical interventions. 2. How to plan appropriate levels of intervention or resuscitation in the bests interests of the baby,	Thank you for your comment. We believe that the scope is sufficiently broad to cover these aspects of care however there has been a slight amendment to the wording of 4.3.1l to now read as follows; 'Decisions regarding life sustaining interventions, including cardiopulmonary resuscitation'.. The topic will be discussed with the guideline development group when determining the

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			child or young person. This then offers importance of withholding or withdrawing care. It then talks about appropriate intervention / resus and how to plan this. The second one avoids the negative connotations of "not" providing resuscitation, but rather offers a need to agree the right intervention. It also hints at need to plan this in advance, clearly with family and MPT.	final review questions
Royal College of Paediatrics and Child Health	12	4.3.1 i	"The management of psychological issues in family members…to infants, children, and young people who have a life-limiting condition or a sudden or unexpected death" (see linked comments No.1) Chapter 7, Working Together, 2013 (DE) sets out the framework for the multi-professional investigation of such deaths. The needs of the bereaved parents are central to this. The phraseology in 4.3.1.i is slightly different from that in 4.1.1.c which is likely to cause confusion if this group of children remain within the scope of the GDG. Whereas, 4.1.1.c mentions only the term 'unexpected'. 4.3.1.i uses the term 'sudden and unexpected'. Again, from a practical viewpoint, such definitions are subjective, emotive, and fraught with difficulty.	Thank you for your comment and suggestions. The terminology in the scope has been amended to clarify which infant, children and young people fall within the remit of the guideline. People who die unexpectedly and do not have a life-limiting condition are specifically excluded from the guideline.
Royal College of Paediatrics and Child Health	13	4.3.1 o	Essential support from the same professionals is offered upto 6 months after bereavement difficult to have citations as very individualised care and experience for this cohort of patients	Thank you for your comment. Although the long term specialised management of bereavement will not be included, the care of family members and carers after a bereavement is not excluded from the scope. Regarding the care needed before the death of the child or young person, the scope of the guideline allows for consideration of aspects of care that may help family members or carer to deal with the loss.
Royal College of Paediatrics and	7	4.4	There are 2 main outcome measures that might be added.	Thank you for your comment. This list of main outcomes is not intended to be

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Child Health			1. The first is certainly mentioned in 4.5: Cost effective and efficiently managed service around the needs of the child. 2. It has been pointed out that good training is patient safety and quality care for the next 30 years.CPC should now be part of education, training and continuing professional development. Either as an outcome measure or elsewhere in the document, this should be included, perhaps: Inclusion of CPC in the training and assessment strategy for all professionals involved in this care.	exhaustive. The consideration of other outcomes for inclusion in the review will be considered at the time of drafting the protocol.
Royal College of Paediatrics and Child Health	14	4.4 d	Be able to die in place of their choice with dignity	Thank you for your comment. This list of main outcomes is not intended to be exhaustive. The consideration of other outcomes for inclusion in the review will be considered at the time of drafting the protocol.
Royal College of Paediatrics and Child Health	15	4.4 e	Psychological well being of carers and child are both important	Thank you for your comment. This list of outcomes is not intended to be exhaustive and will be defined in the protocol of each review question. Whilst psychological well-being is often a component of quality of life measures, it will be considered on a question-by-question basis.
Royal College of Paediatrics and Child Health	16	4.4 f	Distressing symptoms should also include gut symptoms eg vomiting /constipation or diarrhoea	Thank you for your comment. These examples are not intended to be exhaustive and the symptoms will be defined in the protocol after being agreed by the guideline development group.
Royal College of Paediatrics and Child Health	8	4.5 i and j	Is effectiveness the right word? Should this be benefit and disadvantage? Or, should each one ask: What is the most effective and beneficial way of providing…	Thank you for your comment. The term effectiveness is a standard term that is use to encompass aspects of clinical care. The outcomes considered for this question will be agreed by the guideline development group when drafting the review protocol and will definitely include measures of quality of life,

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				as well as other measures of clinical effectiveness.
Royal College of Paediatrics and Child Health	17	4.5 a	Usually respiratory or neurological although difficult to be certain	Thank you for your comment.
Royal College of Paediatrics and Child Health	18	4.5 b	Home,hospice or relatives home has to be individuals choice	Thank you for your comment. Draft review question 4.5b aims to elicit preferences for the place of care and place of death. We recognise the need for individualised care and will ensure that the guidance appropriately reflects that.
Royal College of Paediatrics and Child Health	19	4.5 c	More relaxed environment with less medical interventions ,clinically more effective although long term cost needs to be evaluated	Thank you for your comment.
Royal College of Paediatrics and Child Health	20	4.5 d	Clinical stability before referral /transition to other services should be well planned with choice of young person and families	Thank you for your comment.
Royal College of Paediatrics and Child Health	21	4.5 e	Health and social care but important to have a lead health professional who ensures coordinated and holistic care is delivered	Thank you for your comment. Draft review question 4.5e will address the role of the multi-disciplinary team.
Royal College of Paediatrics and Child Health	22	4.5 f	Difficult to define MDT as needs of individuals will change over time and so does the support needed essential it is based on that	Thank you for your comment. The further detail of the constituency of the multi-disciplinary teams will be defined when reviewing the relevant evidence and formulating recommendations during the course of the guideline development.
Royal College of Paediatrics and Child Health	23	4.5 g	Variable according to individuals needs	Thank you for your comment. We recognise the importance of individualised care and the recommendations will reflect that.
Royal College of Paediatrics and Child Health	24	4.5 h	Pain and distressing symptoms should be addressed by not only therapeutic pharmacological intervention but also psychological interventions as parental/carer	Thank you for your comment. The specific interventions addressed by this review will be outlined in the protocol after being prioritised

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			perception will change and thresholds vary	by the guideline development group.
Royal College of Paediatrics and Child Health	25	4.5 i	Would depend on individuals needs but medicalising to prolong suffering is not in the best interest of the child	Thank you for your suggestion.
Royal College of Paediatrics and Child Health	26	4.5 k	Survey of parents ,carers will be helpful but they prefer written information and should be done by the right person for continuity of care	Thank you for your suggestion. The recommendations will be informed by the best available evidence as identified by the systematic review.
Royal College of Paediatrics and Child Health	27	4.5 m	Is and should always be family led	Thank you for your suggestion.
Royal College of Paediatrics and Child Health	28	4.5 n	Effective communication ,religious beliefs ,regular rapport building in a relaxed environment will improve outcome	Thank you for your comment. The evidence review aims to elicit best communication practices and this will be reflected in the guidance.
Royal College of Paediatrics and Child Health	29	4.5 o	Care of the body is most important and its has emotions and religious beliefs with it too and most families like to manage practical arrangements	Thank you for your comment.
Royal College of Paediatrics and Child Health	30	4.5 p	Should be addressed ahead of the event and would depend on religious beliefs	Thank you for your comment. The evidence review aims to elicit best communication practices and this will be reflected in the guidance.
Royal Manchester Children's Hospital	1	4.1.1	Your values for the ages of patients are not consistent with standard practice. You mention 'Adults aged between 18 and 25 who are in transition to adult care' will be covered by the guideline and yet standard practice is that pre-existing patients will be transitioned to adult care from their **16th** birthday, and new patients would not be taken on after this point by Paediatric services.	Thank you for comment. The scope is making a distinction between transition as a process and eventual transfer to exclusively adult care. The NICE guidance on transition from children's to adult services (in development) will cover the issue and be cross-referred to where appropriate. Care of the dying adult (in development) deals with those aged 18 years and older in adult care. The scope has been amended to reflect this.
Social Care	9	General	Should there be some reference to safeguarding arrangements where non- accidental injury and/or neglect are possibilities, particularly where there are other children	Thank you for your comment. The scope has been amended so that infants, children and young people who die unexpectedly and

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			in the family?	without a prior-known life-limiting condition are outside the remit of the guideline.
Social Care	1	3.1 f	Last line – might be helpful to change "healthcare needs" to health and care needs – as they may have complex social care needs on top of health and palliative care needs	Thank you for your comment. The scope has been amended as suggested.
Social Care	4	3.2 c	Might it be worth being more explicit about 'other support providers' and referencing particularly wider family networks and parents' support groups, although this perhaps picked up later.	Thank you for your comment. This level of detail will be included when the guideline is developed.
Social Care	2	4.1.1 b	Need to ensure that this dovetails with the transition children's to adult services guideline	Thank you for your comment. The scope of this guideline has been amended to include children and young people up to the age of 18 years. We acknowledge the importance of ensuring that people transition smoothly, and will ensure that cross-referrals to guidance under development which is addressing the transition from child to adult services (http://www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714) are made wherever possible.
Social Care	5	4.1.1 c	It says that the scope includes "Infants, children and young people aged up to 18 who die unexpectedly without a prior known life-limiting condition." – should that be *"who unexpectedly die or become terminally ill"?*	Thank you for your comment. The scope has been clarified and now states that infants, children and young people without a recognised life limiting condition who die unexpectedly are excluded from the scope.
Social Care	6	4.3.1	Possibly should include practical family/child care support, especially where there are other children to be cared for.	Thank you for your comment. This falls within section 4.5l of the current scope.
Social Care	7	4.4 d	"Or their parent choosing as appropriate"	Thank you for your comment. We acknowledge the importance of individualised care, and will ensure that this is reflected in the guidance.
Social Care	8	4.5 c	This review question and others ask about "clinical and cost-effectiveness". It should be expanded to "effectiveness and cost-effectiveness, otherwise the	Thank you for your comment. The term clinical effectiveness is a standard term that is use to evaluate aspects of clinical care,

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			effectiveness of aspects of care which are not clinically related will not be picked up.	including quality of life and aspects of care that are delivered in other settings.
The British Psychological Society	17	General	The scope document does not specifically mention post-mortem, death verification and certification for deaths at home and the need to consider cultural and religious practices relating to care of the body and funerals and the need for healthcare and administrative procedures to allow families to adhere to these wishes and traditions, such as burial within 24 hours of death. It would be useful to perhaps to define the use of the term 'child or children' to include foetus, infant, children and young people' except where the child is 18 years and above and up to 25 years of age then using the term 'young adult'. Also consider changing the use of the term incurable conditions to life-threatening or life limiting and provide consistency of terminology throughout. Overall, a tightening up of terminology and being clear about the use of terms/defining terms and criterion is needed. It is particularly important to be clear about who is doing what. For example, be more specific as to whether the recommendations specific to children's needs and those trained and expert in delivering care to children and young adults. For example, there is a world of difference between a paediatrician and a GP or a children's nurse and a community nurse. Providing 'information' is no substitute for good communication skills and care needs to be taken here as providing written information can be used as an emotionally 'distancing' technique by professionals to protect themselves from the full force of emotional distress. This is more likely to occur where staff do not	Thank you for your comment. Section 4.3.1 of the scope includes care of the infant, child or young person's body following death, in addition to section 4.5b and 4.5d which consider the family or carer's preferences and service provision after death. These draft questions will be discussed with the guideline development group and specific areas for consideration will be agreed and then outlined in the protocol. The population of the guideline has now been clarified in the revision of the scope to include infants, children and young people.

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			have adequate psychological support themselves (e.g., clinical supervision). The scope document does not specifically mention post-mortem, death verification and certification for deaths at home and the need to consider cultural and religious practices relating to care of the body and funerals and the need for healthcare and administrative procedures to allow families to adhere to these wishes and traditions, such as burial within 24 hours of death.	
The British Psychological Society	1	3.1 b	The Society believes that this does not take account of the role and development of service delivery changes in paediatric and young peoples palliative care provision which have influenced care and require sustained support.	Thank you for your comment. The guideline will address service provision for end of life care and included a draft review question in section 4.5.
The British Psychological Society	2	3.1 e f 3.1 f	The age range vacillates throughout the document and is inconsistent with Scottish definitions (transition up to 21 years of age). At 4.1.2, a statement conflicts with cut-off point of 18 years. We believe that it would be helpful and less confusing to have an agreement at the beginning of the document around age criteria and transition groups and this remain consistent throughout the document thereafter. The "severe disabilities" of this group include moderate to profound levels of physical and learning disability and other specific learning difficulties. Children and young people affected by neurodegenerative conditions. For example, Hunters Syndrome (Mucopolysacchardosis Type 11) and Niemann-Pick Disease will also experience loss of cognitive abilities (Scarpa, 2007; Vanier, 2010; NP-C Guidelines Working Group, 2009) and the guidance needs to take these factors into consideration.	Thank you for your comment. The scope has been amended to include people up to the age of 18 years. NICE is currently developing guidance for transition between paediatric and adult services (http://www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714), and this document will cross-refer whenever possible. It is expected that the guidance will consider the complex needs of the population with severe disabilities. Finally, two draft review questions were included in the scope with the aim of eliciting the support needs and psychological management of family members which includes siblings.

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			It is not unusual for there to be two or more children in a family diagnosed with the same condition. Witnessing the end of life phase of a sibling from the same condition will have particular impact on these young people (Together for Short Lives, 2013; Knebel and Hudgings, 2002) and their needs need to be considered here also.	
The British Psychological Society	3	3.2 a b	Decisions around end of life care and preferred place of care are not static and not everyone will find their needs at this time will be met in familiar surroundings. The document needs to allow for individual choice and the right to change their minds even at the last stage. Given that decisions making in end of life care is *"clinically complex and emotionally distressing"*, the guidelines should address issues of staff support, supervision and training to enable compassionate care and minimise 'burn-out'.	Thank you for your comments. We agree with the need to continue to take account of individual choice throughout care. We agree with your comment about the potentially distressing aspects of end of life care. We will consider what is necessary to deliver such care effectively. However, staff supervision and training are outside the remit of NICE guidance.
The British Psychological Society	4	3.2 c	Together for Short Lives asserts the need for palliative care at the end of life. Emerging evidence (e.g., Temple et al., 2011) demonstrates that patients assigned to early intervention palliative care show higher quality of life scores and lower depression scores and despite this group receiving less aggressive end of life treatments their median survival rates were longer.	Thank you for your comment. The need for a long-term approach to care of the child or young person and their family members and carers is recognised, and the issues you raise will be covered by the scope. The potential for benefit from early intervention palliative care would thus be considered in the guideline.
The British Psychological Society	5	3.2 d	Addressing psychological needs may require more skilled therapeutic interventions than are implied by the word 'support'. Again the NICE (2004) 4-tier model of psychological support for adults could be usefully applied and appropriately adapted here.	Thank you for your comment. A draft review question has been included which addresses psychological interventions and the guideline will cross-refer to existing guidance where appropriate.

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The British Psychological Society	6	3.2 e f	A significant proportion of the voluntary sector provision in this area is actually funded by health and social care commissioners and delivered by 'paid' staff. Therefore, the term 'voluntary sector' is misleading and changing the phrasing to 'other providers' (other than social or health care) instead is clearer and less open to misinterpretation. When treatment options are no longer possible in a PTC (e.g., TCT ward), the TYA patient may be discharged to the care of District General Hospital where boundary disputes can occur. An emphasis on across service cooperation and 'non-ownership' approaches of the patient will ease distress. Some patients and families may 'choose' to continue with trusted relationships built up over many years, these attachments and bonds if broken without consent/open discussion with forward planning will also incur unnecessary and avoidable distress. Therefore, increasing collaborative working relationships between PTC's and DGH's would be essential. This is essential as the management of care at the end of life will have an impact on how the child's family/carers then manage their own mental health into bereavement and beyond. Alongside the above are potential areas for disagreement and lack of coordination and patient choice when the very age of the child means they fall between the paediatric and adult services. Much more guidance is needed here, and clear direction.	Thank you for your comment. The remit of the guideline includes "All settings in which NHS commissioned healthcare is provided". The draft review questions include the provision of services and we recognise that this is an important consideration.
The British Psychological Society	7	3.2 g	Bereavement support is not included in the scoping exercise and the Society believes that this is a mistake both conceptually (bereavement does not simply began after a death (see above in 3.2.f)) and in terms of continuity of care and therefore providing a sense of 'being	Thank you for your comment. Although the long term specialised management of bereavement will not be covered by the guideline, the care of family members and carers after a bereavement is not excluded from the scope. In addition, a bereavement

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			held safely' by the child and their family/carers. The death of a child can impact on the mental health of the child's family and carers and significantly their surviving siblings. It will also impact on parent's ability to return to the workplace after a period of adjustment. It is therefore important to incorporate and be informed by what bereaved parents have found helpful for themselves and the surviving siblings. For example, of 45 children currently accessing one children's community palliative care team in London, 12 are from families in which there are or have been 2 or more siblings with a life-limiting condition. Witnessing the end of life phase of a sibling from the same condition will have particular impact on these young people and their needs need to be considered in the guidelines (Together for Short Lives, 2013). Further, siblings without their own physical health needs will understandable also have psychological needs and may require extra support. The charity 'Winston's Wish' has some excellent resources in this respect (see link below) is good example. http://www.winstonswish.org.uk/?gclid=CMvjipnlgcICFbCWtAodQC0AaA The terms 'emotional' and 'psychological' support are non-specific. Again it is recommended that the NICE 4-tier model of psychological support would help provide some clarity and specificity here. Further, the range of psychological interventions could be usefully and briefly explained to help providers and others understand that 'one size' does not fit all and that a range of approaches is often required. Often numerous approaches are required at one point or another and at different developmental phases for both the child and the system around them and	specialist has been recruited to the guideline development group. Regarding the 'emotional' and 'psychological' terms, these will be defined at the time of developing review protocols, at which time various types of support and psychological interventions will be considered.

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			tailored to specific needs at specific time points. This would acknowledge the 'dynamic' nature of children's developmental needs and adjustment needs as well as their families. Qualified Health Play Specialists http://nahps.org.uk may play a key role in hospital, hospice and community palliative care provision for infants, children and young people but the role of "play" and this group of professionals has not been acknowledged in this section or the wider scope document. Given the central role in memory making, infant attachment, preparation for medical procedures and quality of life at end of life, which this group would positively impact on the guidelines, should include recommendations relating to their role.	
The British Psychological Society	8	3.4 G	There is no mention of volunteers who often provide important and valued services and an absence of childhood bereavement support services. Introducing these services earlier in the document and providing consistency thereafter would allow the document, as a whole, to flow more successfully.	Thank you for your comment. The remit of this guideline is to cover "All settings in which NHS commissioned healthcare is provided". Therefore, services provided by organisations that have not been commissioned by the NHS are outside of the remit of this guideline.
The British Psychological Society	9	4.1.1 a c	The Society believes that reference to the extremely psychologically difficult diagnosis of an incurable and ultimately terminal condition in the antenatal phase for the mother and her family is required here. Particularly important is the need for an early introduction to the services that would help at this time and in preparation for what is to come. Also to ensure these are coordinated and timely and include hospice care. The term 'complex health needs' would benefit from a clear definition 'Together for Short Lives'	Thank you for your comment. We recognise the difficulties associated with the antenatal diagnosis of a life-limiting condition and it is for this reason that this group are specifically identified in the scope. We will consider the needs of family members in this difficult situation. In order to conduct a systematic literature review, a definition of 'infants, children and young people with complex considerations that entail specific care needs' as detailed in section 4.1.1 will be agreed by the guideline development group and

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			(http://www.togetherforshortlives.org.uk/) has developed useful subgroup definitions for the different types of non-cancer and non-neonatal conditions. The same organisation has developed a very useful publication which can be downloaded free entitled 'The Family Companion' which is full of useful links to agencies which may be help. http://www.togetherforshortlives.org.uk/assets/0000/1080/A_Family_Companion.pdf. Now more than ever, we require and this group of children deserve, firm definitions. This will facilitate data gathering and service planning. The language chosen should be meaningful to a whole range of different audiences, families, providers, commissioners, researchers, the general public and potential fund holders/providers. The inclusion of sudden and unexpected deaths would hopefully mean the focus will also be on providing bereavement support services and as referred to later on. We believe that there needs to be link with the introduction of sudden and unexpected deaths with the importance of appropriate and timely bereavement support and in preparation also for an expected death. The absence of reference to psychological care and family care here, though it is referred to in section 4.3.1. It would also be helpful to have some clear definition at the outset of what constitutes good psychological care (The adult 4-tier model within the NICE, 2004 guidance may again be a starting point here and as previously suggested appropriately adapted to the needs of children and their families/carers). Bereavement support should be included in the scoping exercise. The death of a child can be detrimental to mental health to all in the family particularly the parents and	detailed in the protocol. The scope has now been clarified in relation to the inclusion of sudden deaths of children and young people. The scope excludes infants, children and young people who die unexpectedly from a life-limiting condition which was not known prior to their death. We agree with your comment about the need for staff support in delivering end of life care however staff training and support is outside of the remit of this guideline..

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			surviving siblings. Given that decisions making in end of life care is *"clinically complex and emotionally distressing"*, the guidelines should address issues of staff support (who are also carers and become very close to these families), supervision and training to enable compassionate care and minimise 'burnout'.	
The British Psychological Society	10	4.3.1 d	The Society believes that information giving is not the same as good communication and may sometimes be used as a way of distancing oneself from the emotional impact of this work. Communicating in different mediums the same information works best and for children using pictures and stories is more effective than sitting down and having a conversation or asking parents to look through written information instead in the hope they will then translate for the child in the absence of professional support to do so.	Thank you for your comment. The draft review questions addresses the aspects of communication and information provision and aims to elicit best practice, which will subsequently be provided as recommendations.
The British Psychological Society	11	4.3.1 h	We would recommend changing the language around 'the management of psychological issues' be changed to a more sensitive approach of 'addressing the psychological and emotional needs…'	Thank you for your comment. This text has been amended in line with your suggestion.
The British Psychological Society	12	4	Addressing psychological needs may require more skilled therapeutic interventions than are implied by the word "support" implies. Again the 4-tier model (NICE, 2004) may be useful to refer to here. Clarification is required in relation to sudden of unexplained death only applies to children with life limiting conditions is required as this is not clear.	Thank you for your comment. The key area relevant to psychological interventions is in section 4.3.1i. The approach to care will be considered by the development group taking account of available evidence. The needs of the child or young person and of their family or carers will be addressed in separate evidence reviews and appropriate outcomes selected at that time. The needs of specific

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			Separating the outcomes to those primarily concerning the child compared to the family/carers would provide more clarity and avoid clinical risk and some governance structures. In order for all children to be included need to consider what measure will be used for those unable to communicate to ensure equality for all children as well as what measure will be used to measure depression and anxiety in children as well as they adult carers.	subgroups will be considered and evidence specific to those subgroups will be sought. The scope has been amended to clarify that sudden unexpected deaths will not be covered by the guideline
The British Psychological Society	13	4.3.1 j k	Care is often provided by multiple multi-disciplinary teams and agencies (complex systems of acute, national specialist, local hospital, community health, medical, allied health professional, social care, education and third sector networks around a family) and the guidelines should address issues of coordination, communication, consultation and how services can be integrated and work in partnership with families in care planning and delivery. Children may have more than one end of life episode of care (as indeed do many adults) and it will be important to provide guidance on how these will be recognised, when the situation changes and how that will be recognised as well as how to manage a rapidly changing situation with the child/young adult and their family/carers.	Thank you for your comment and suggestions. The scope of the guideline covers service configuration and will aim to address the issues outlined in your comment.
The British Psychological Society	14	4.3.2 a	Greater clarity is required about what is meant by "specialised management of bereavement". Palliative care services often provide bereavement services ranging from remembrance day events to therapeutic groups and individual/family therapy sessions and families often prefer to seek these services from providers who knew them and	Thank you for your comment. The routine management of bereavement will be covered by the guidance and a statement has been added to ensure this is clear to the reader. However, the long-term management of bereavement and those cases in which the care required specialist intervention are

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			their child during their illness and end of life. Given the large and complex systems of care around infants, children and young people with life-limiting conditions, if palliative care services withdraw entirely after the child's death this can represent another significant loss for the family. The circumstances of a child's death are often highly traumatising and expecting families to engage with new services/therapists at this difficult time may be further traumatising, particularly for those families in greatest distress and for whom "specialised"/expert therapeutic intervention may be necessary.	outside the remit.
The British Psychological Society	15	4.4 d	Given the association between socio-economic deprivation and child mortality, it should be clarified how services can be organised and provided most effectively in areas or boroughs where there are particularly high levels of social deprivation. For example, overcrowded housing arrangements may preclude safe provision of end of life care at home (for example storage of controlled drugs and oxygen). Some children may prefer that the decision is made for them by parents / others and this needs to be acknowledged in the guidelines.	Thank you for your comment. NICE are committed to ensuring that guidance covers all groups equally and as such publish assessments of equality alongside guidance. The scope covers service delivery for end of life care and will address these considerations.
The British Psychological Society	16	4.5 g	Some children and young people may not be able to speak to express preference and it would be helpful if the guidance addresses approaches to assessing choice and supporting communication for individuals at a pre-verbal level of functioning. Substituting "What psychological and psychopharmacological interventions are clinically and cost-effective…" in place of *"What psychological*	Thank you for your comment. The guidance aims to address the needs of this subgroup and will provide separate guidance, if appropriate. The scope has been amended to reflect your suggested wording.

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			interventions (including counselling and pharmacological interventions)" would overcome the problem that pharmacological interventions are not a subgroup of psychological interventions.	
The Royal College of Paediatrics and Child Health	9	General	We think that the draft scope of the guideline is excellent. However, have one concern, which is expanded upon in 3 'linked' comments below. Broadly, the palliative care and critical care clinical community would agree with what a child with a life-limiting condition 'looks like'…as per the definition set out in the ACT (*now Together for Short Lives'*) guidance. However, the suggestion to extend the scope of the study to a child who dies 'unexpectedly' risks diverting the core focus of the group into territory which is hard to define, has a different evidence base, may demand a different approach in meeting parental needs, and similarly different stakeholders to inform discussions (e.g. the police in the case of homicide, or a coroner in the case of suicides)	Thank you for your comment. The scope has been amended to clarify that sudden unexpected deaths will not be covered by the guideline.
The Royal College of Paediatrics and Child Health	31	General	The document rightly says that preparing for end of life may happen over a variable and unpredictable period of time, therefore end of life (the outcome of this important process) is a misnomer for the document. Perhaps "Preparing for end of life". Consent (especially if views of child and parents differ) must be covered. 4.2 Should cover local borough commissioned care e.g. health visiting. We trust NICE will refer to existing guidance e.g. BAPM, RCPCH and Bliss.	Thank you for your comment. We recognise the importance of ensuring the guidance focuses on the preparation for end of life care and this is reflected in the draft review questions. The Department of Health sets policy on consent and the guidance will refer to this where appropriate. Each recommendation is underpinned by the best available evidence which is obtained from a systematic review of published evidence and does not typically refer to existing guidance.
The Royal College of Paediatrics and	1	3.1 b	No mention of important group – obstetrics. This should perhaps read … particularly in midwifery, obstetrics and neonatal …	Thank you for comment. We have amended the text as requested.

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Child Health				
The Royal College of Paediatrics and Child Health	2	3.1 d	In 2012, congenital conditions and cancers were the most common form of Perhaps should be: In 2012, neonatal conditions and cancers were the most common cause of …	Thank you for your comment. As there are some neonatal conditions which are not congenital this wording will be retained.
The Royal College of Paediatrics and Child Health	3	3.2 c	Hospital, hospice, primary care professionals. Perhaps should be: hospital, hospice, community care professionals	Thank you for your comment. The text has been amended and now includes community care professionals in addition to primary care professionals.
The Royal College of Paediatrics and Child Health	4	4.1.1 a	Is there a reason for the contents of this list being so limited. Are these areas of special concern. Certainly it misses a large proportion of babies and children who might benefit from CPC. eg Congenital anomalies not amenable to treatment, severe neurological problems, etc. Perhaps the list should extended or introduced or introduced: Subgroups to be considered include …	Thank you for your comment. The list has been amended for clarity as it was not intended to limit the conditions or groups that would be covered.
The Royal College of Paediatrics and Child Health	10	4.1.1 c	"infants and children and young people aged up to 18 years who die unexpectedly without a prior known life-limiting condition". We have concerns that extending the scope of the guideline to include this group of children may inadvertently cause the GDG to reflect on the end of life care of ALL children who die, and I suspect that this was not the intention of the DH when it requested NICE to undertake this project. Children who die essentially either have a known life-limiting condition or not. Hence my concern that the wording of 4.1.1.c) may inadvertently lead one to discuss the management of all children who die. The definition of 'unexpected/expected' is fraught with difficulty. Consider the child who dies from meningococcal sepsis on a PICU. That death may be entirely 'expected'	Thank you for your comment. The scope has been clarified in relation to the inclusion of sudden deaths of children and young people. The scope excludes children and young people who die unexpectedly from a life-limiting condition which was not known prior to their death. As the guidance is written for healthcare professionals, we do not believe that using the term unexpected inappropriately describes the population.

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			from the viewpoint of the clinician. However, one can guarantee that from the viewpoint of the parent that the child's death is 'unexpected'. We understand why this additional group was mentioned at the stakeholder day, and suspect that the intention is to capture those children whose death is 'both unexpected AND unexplained' after a complete investigation. An example of this might be the infant who dies following Sudden Infant Death Syndrome (SIDS). However, there is already very clear legislation in place defining precisely what the professionals' response should be to such an event (Chapter 7, Working Together, 2013; DE). Our final concern with extending the scope of the study to 'unexpected' deaths is that these deaths often occur out of hospital (eg a SIDS at home, or a road traffic death in the community). Section 4.2 a) clearly states that the scope of the guideline should be limited to NHS-commissioned settings - which we agree with. If we are to extend the scope to include ALL deaths - then the scope of the study would, by definition, have to extend to all settings where a child might die.	
The Royal College of Paediatrics and Child Health	5	4.1.2 a	between 18 and 25 who Perhaps should be: between 18 and 25 with chronic or complex conditions who …	Thank you for your comment. The scope of this guideline has been amended to include children and young people up to the age of 18 years. We acknowledge the importance of ensuring that people transition smoothly, and will ensure that cross-referrals to guidance under development which is addressing the transition from child to adult services (http://www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714) are made wherever possible.
The Royal	11	4.2	"All settings in which NHS-commissioned health care and	Thank you for your comment. The scope of

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

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College of Paediatrics and Child Health		a	social care is provided". We think this is the correct scope for defining the 'setting' for the guideline. However, as explained above, if the scope of the deaths to be included extend to those who die unexpectedly, then this is incongruous with our work being limited to an 'NHS-commissioned' setting.	the guideline has been amended for clarity and does not include sudden deaths of children or young people who do not have a life-limiting condition.
The Royal College of Paediatrics and Child Health	6	4.3.1 l	How to make the decision to withhold or withdraw medical interventions, or to not provide cardiopulmonary resuscitation. Should this be split into 2 parts, perhaps: 3. How to make the decision to withhold or withdraw medical interventions. 4. How to plan appropriate levels of intervention or resuscitation in the bests interests of the baby, child or young person. This then offers importance of withholding or withdrawing care. It then talks about appropriate intervention / resus and how to plan this. The second one avoids the negative connotations of "not" providing resuscitation, but rather offers a need to agree the right intervention. It also hints at need to plan this in advance, clearly with family and MPT.	Thank you for your comment. We believe that the scope is sufficiently broad to cover these aspects of care however there has been a slight amendment to the wording of 4.3.1l to now read as follows; 'Decisions regarding life sustaining interventions, including cardiopulmonary resuscitation'. The topic will be discussed with the guideline development group when determining the final review questions
The Royal College of Paediatrics and Child Health	12	4.3.1 i	"The management of psychological issues in family members…to infants, children, and young people who have a life-limiting condition or a <u>sudden or unexpected death</u>" (see linked comments No.1) Chapter 7, Working Together, 2013 (DE) sets out the framework for the multi-professional investigation of such deaths. The needs of the bereaved parents are central to this. The phraseology in 4.3.1.i is slightly different from that in 4.1.1.c which is likely to cause confusion if this group of children remain within the scope of the GDG.	Thank you for your comment and suggestions. The terminology in the scope has been amended to clarify which infant, children and young people fall within the remit of the guideline. People who die unexpectedly and do not have a life-limiting condition are specifically excluded from the guideline.

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			Whereas, 4.1.1.c mentions only the term 'unexpected'. 4.3.1.i uses the term 'sudden and unexpected'. Again, from a practical viewpoint, such definitions are subjective, emotive, and fraught with difficulty.	
The Royal College of Paediatrics and Child Health	13	4.3.1 o	Essential support from the same professionals is offered upto 6 months after bereavement difficult to have citations as very individualised care and experience for this cohort of patients	Thank you for your comment. Although the long term specialised management of bereavement will not be included, the care of family members and carers after a bereavement is not excluded from the scope. Regarding the care needed before the death of the child or young person, the scope of the guideline allows for consideration of aspects of care that may help family members or carer to deal with the loss.
The Royal College of Paediatrics and Child Health	16	4.4 f	Distressing symptoms should also include gut symptoms eg vomiting /constipation or diarrhoea	Thank you for your comment. These examples are not intended to be exhaustive and the symptoms will be defined in the protocol after being agreed by the guideline development group.
The Royal College of Paediatrics and Child Health	7	4.4	There are 2 main outcome measures that might be added. 3. The first is certainly mentioned in 4.5: Cost effective and efficiently managed service around the needs of the child. 4. It has been pointed out that good training is patient safety and quality care for the next 30 years.CPC should now be part of education, training and continuing professional development. Either as an outcome measure or elsewhere in the document, this should be included, perhaps: Inclusion of CPC in the training and assessment strategy for all professionals involved in this care.	Thank you for your comment. This list of main outcomes is not intended to be exhaustive. The consideration of other outcomes for inclusion in the review will be considered at the time of drafting the protocol.
The Royal College of Paediatrics and Child Health	14	4.4 d	Be able to die in place of their choice with dignity	Thank you for your comment. This list of main outcomes is not intended to be exhaustive. The consideration of other outcomes for inclusion in the review will be

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				considered at the time of drafting the protocol.
The Royal College of Paediatrics and Child Health	15	4.4 e	Psychological well being of carers and child are both important	Thank you for your comment. We agree that the psychological well-being of both the child and carer is important and have included draft review questions that address psychological needs in both groups.
The Royal College of Paediatrics and Child Health	8	4.5 i j	Is effectiveness the right word? Should this be benefit and disadvantage? Or, should each one ask: What is the most effective and beneficial way of providing…	Thank you for your comment. The term effectiveness is a standard term that is use to encompass aspects of clinical care. The outcomes considered for this question will be agreed by the guideline development group when drafting the review protocol and will definitely include measures of quality of life, as well as other measures of clinical effectiveness.
The Royal College of Paediatrics and Child Health	17	4.5 a	Usually respiratory or neurological although difficult to be certain	Thank you for this information. The recommendations will be informed by the best available evidence as identified by the systematic review.
The Royal College of Paediatrics and Child Health	18	4.5 b	Home,hospice or relatives home has to be individuals choice	Thank you for your comment. Draft review question 4.5b aims to elicit preferences for the place of care and place of death. We recognise the need for individualised care and will ensure that the guidance appropriately reflects that.
The Royal College of Paediatrics and Child Health	19	4.5 c	More relaxed environment with less medical interventions ,clinically more effective although long term cost needs to be evaluated	Thank you for your comment.
The Royal College of Paediatrics and Child Health	20	4.5 d	Clinical stability before referral /transition to other services should be well planned with choice of young person and families	Thank you for your comment.
The Royal	21	4.5	Health and social care but important to have a lead health	Thank you for your comment. Draft review

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College of Paediatrics and Child Health		e	professional who ensures coordinated and holistic care is delivered	question 4.5e will address the role of the multi-disciplinary team.
The Royal College of Paediatrics and Child Health	22	4.5 f	Difficult to define MDT as needs of individuals will change over time and so does the support needed essential it is based on that	Thank you for your comment. The further detail of the constituency of the multi-disciplinary teams will be defined when reviewing the relevant evidence and formulating recommendations during the course of the guideline development.
The Royal College of Paediatrics and Child Health	23	4.5 g	Variable according to individuals needs	Thank you for your comment. We recognise the importance of individualised care and the recommendations will reflect that.
The Royal College of Paediatrics and Child Health	24	4.5 h	Pain and distressing symptoms should be addressed by not only therapeutic pharmacological intervention but also psychological interventions as parental/carer perception will change and thresholds vary	**Thank you for your comment. The specific interventions addressed by this review will be outlined in the protocol after being prioritised by the guideline development group.**
The Royal College of Paediatrics and Child Health	25	4.5 i	Would depend on individuals needs but medicalising to prolong suffering is not in the best interest of the child	Thank you for your comment. The recommendations will be informed by the best available evidence from the systematic review.
The Royal College of Paediatrics and Child Health	26	4.5 k	Survey of parents ,carers will be helpful but they prefer written information and should be done by the right person for continuity of care	Thank you for your comment. The recommendations will be informed by the best available evidence from the systematic review.
The Royal College of Paediatrics and Child Health	27	4.5 m	Is and should always be family led	Thank you for your comment. The recommendations will be informed by the best available evidence from the systematic review
The Royal College of Paediatrics and Child Health	28	4.5 n	Effective communication ,religious beliefs ,regular rapport building in a relaxed environment will improve outcome	Thank you for your comment.
The Royal	29	4.5	Care of the body is most important and its has emotions	Thank you for your comment. We

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College of Paediatrics and Child Health		o	and religious beliefs with it too and most families like to manage practical arrangements	acknowledge the importance of this aspect of care and it will be addressed within the guidance.
The Royal College of Paediatrics and Child Health	30	4.5 p	Should be addressed ahead of the event and would depend on religious beliefs	Thank you for your comment. This question will be addressed by the guideline and the timing of the communication and information provision will be considered in line with the evidence base.
The Royal College of Paediatrics and Child Health	32	4.5	We would like to see a review question to cover the effectiveness of counselling/bereavement therapies for family members - maybe this is going to be covered by the review question o) but as it stands it appears to be about what the family members view as important. We think an additional question is required and would be helpful to support commissioning of such services.	Thank you for your comment. The list of review questions is draft only, and will be discussed with the guideline development group before being worked into a format that is suitable for a systematic reviews of the literature. Specific issues relating to bereavement therapies are considered a key area of care that will be covered by the guidance. The section of the scope (now 4.3.1n) has been amended to more clearly reflect this.
Together for Short Lives'	1	General	Together for Short Lives welcomes the opportunity to comment on this draft scope. We wish to emphasise how important it is that the guideline advocates a holistic model which focuses on the wider social and spiritual elements of children's palliative care - and achieving outcomes which are important to children, young people and their families. This should be in addition to the clinical aspects of caring for children and young people with life-limiting conditions. Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including children's hospices.	Thank you for your comments and suggestions on the consultation document.

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			Hospice UK, the national body for hospice care, also supports our comments on the draft scope.	
Together for Short Lives'	35	General	We note that all the epidemiology in the scope relates to child death. To make sure it takes account of all children who need palliative care, the guideline should consider data on children and families currently living with a life-limiting or life-threatening condition. A focus on quality of life, as well as quality of death, is crucial.	Thank you for your comment. The epidemiology section of the scope is intended to provide context only. The scope of the guideline will focus on the quality of life of children and young people, their families and carers and measurement of this outcome will be of central importance to the guideline.
Together for Short Lives'	2	1	We call for the title to be amended to 'Palliative care for infants, children and young people'. On the basis that the draft scope encompasses the period between a child being recognised as having a life-limiting condition and their death, the term 'palliative care' would be more appropriate. The term 'palliative care' incorporates end of life care.	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person.
Together for Short Lives'	3	3.1 f	The scope should refer to the fact that it is not unusual for siblings in a family with the same life-limiting condition. Witnessing a sibling dying from the same condition they have will have particular impact on these young people. Their needs should be considered in the guidelines.	Thank you for your comment. The draft review questions include the management of psychological issues and support needs of family members. We recognise that this is an important consideration.
Together for Short Lives'	4	3.2 a b	In 2011, ACT and Children's Hospices UK (the two charities which went on to merge to form Together for Short Lives) held 37 'Square Table' events across England (http://www.togetherforshortlives.org.uk/professionals/resources/3962_square_table_-_local_learning_and_evaluation_report). These sought to deepen the level of shared understanding of children's palliative care. Each event brought together life-limited and life-threatened young people and their families, a range of health, education and social care professionals and providers as well as many other representatives from across the community including faith and business leaders. At these events, families of children who need palliative	Thank you for this information.

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			care gave us a vital insight into what is important to them. The most important themes they identified were as follows: • Families want to be made aware of the breadth of children's palliative care services available to them - in language which they can understand. • As many children and young people as possible should be supported to die at home if that is their or their family's choice. • Families want to have to tell their story to as few professionals and agencies as possible across health, social care and education; they want a more joined-up approach. • The best outcomes for children are achieved when parents work in partnership with professionals and volunteers; key working is essential to this. • Training and skills should be improved among generalist professionals who come into contact with children with life-limiting and life-threatening conditions. • Young people and families want smoother and better planned transitions to adulthood - with a better range of opportunities for them. • Children's palliative care services need to be better prepared to respond to increasing numbers of premature babies with complex health needs who are surviving longer due to technological advances. • Better support is needed to enable children who need long-term ventilation to spend time outside of hospital. Professor Myra Bluebond-Langner has conducted studies of end of life care and decision making in the families of children with life-limiting conditions. This has highlighted the complexity for children who may wish their parents as	

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			adults to be responsible for making this decision on their behalf. Parents may find it difficult to make an advanced care decision; it may not be possible for some to make a plan about preferred place of care for a child who may die suddenly. For others it may not also be possible to care for a child at home if there is insufficient space to provide care or store drugs and equipment. To address this complexity, health care professionals should support families to think through advanced care planning options. Training is needed to help professionals understand the systemic issues in family or group decision-making processes - and to help them communicate effectively.	
Together for Short Lives'	5	3.2 c	This section should specify that the effective networks should include community services (including community children's nurses and community paediatricians), social care services and education.	Thank you for your comment. The current wording encompasses community services and allows for the inclusion of other services also.
Together for Short Lives'	6	3.2 d	We ask that "Children's Palliative Care (CPC) aims to make infants, children and young people with an incurable condition as comfortable as possible" is altered to "Children's Palliative Care (CPC) aims to make sure that infants, children and young people with an incurable condition have the best quality of life possible."	Thank you for your comment. The reference to comfort relates specifically to the relief of distressing symptoms.
Together for Short Lives'	7	3.2 d	We ask that this paragraph uses the term 'psychological care and support' in place of 'psychological support'.	Thank you for your comment. The text has been amended to include "care".
Together for Short Lives'	8	3.2 f	We ask that the guideline uses terminology which makes clear the difference between 'special' and 'specialised' palliative care. We suggest that 'dedicated' may be a better term than 'special'. We also ask the guideline is clear whether the term 'home' includes usual place of residence.	Thank you for your comment. In the context of this section (now 3.2h) the term "specialist" reflects the service configuration. However, where this is unclear, the term "dedicated" will be used.
Together for Short Lives'	9	3.2	We are concerned that the term "emotional and psychological support" does not fully represent the range	Thank you for your comment. The text has been amended as requested.

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		g	of therapeutic mental health and relationship or family interventions that are needed and currently provided to children and their families by palliative care services. We advocate the term "emotional and psychological care and support".	
Together for Short Lives'	10	3.2 g	Qualified health play specialists (HPSs) play a key role in hospital, hospice and community palliative care for infants, children and young people. However, the role of "play" and of this group of professionals has not been acknowledged in this section or the wider scope document. Given their often central role in helping a child to understand their condition, express themselves, memory making, infant attachment, preparation for medical procedures and quality of life at end of life, the guidelines should include recommendations relating to the role of HPSs.	Thank you for your comment. A draft review question has been included which considers the communication needs of the child or young person and families/carers. The review protocol will include details about the specific methods that will be included in the review.
Together for Short Lives'	11	4.1 c	We ask that the guideline makes clear whether the term "children who die unexpectedly without a prior known life-limiting condition" refers to those who have died as a result of an acute illness, injury or trauma - or those who are later found to have had a life-limiting condition on post mortem - or both.	Thank you for your comment. The scope has been amended for clarity and excludes infants, children and young people aged up to 18 years who die unexpectedly and do not have a known life-limiting condition, for example, accidental death. It does not include infants, children or young people who were later found to have had a life-limited condition on post mortem.
Together for Short Lives'	12	4.1.1 a	We suggest that the subgroups are amended to reflect Together for Short Lives' definitions of life-limiting and life-threatening conditions. These are as follows: 1. Life-threatening conditions for which curative treatment may be feasible but can fail - such as cancer or congenital heart disease. 2. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well - such as Duchenne muscular dystrophy. 3. Progressive conditions without curative treatment	Thank you for your suggestions. Within the definition of life limiting conditions we will include conditions which are likely to result in an early death. Therefore some life threatening conditions or certain stages of these conditions will be encompassed by the term 'life limiting' for this guideline. Additionally, the scope now states for clarity that 'Parallel planning refers to the development of plans that allow for unpredictability in the course of the condition'. The list of groups in section 4.1.1

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			options, such as Batten disease. 4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.	is not intended to be exhaustive and it is expected that definition of population subgroups will be addressed at the time of protocol development.
Together for Short Lives'	13	4.1.1 a	The guidelines should address antenatal palliative care planning, therapeutic support and intervention needed by expectant parents who are hoping to carry a baby with a life-limiting condition to term. Parents who are not referred to palliative care services until the birth of their child state that it would have been more helpful to access these services during pregnancy to prepare them for parenting a child with complex needs.	Thank you for your comment. The scope of the guidance does cover the end of life support and planning required by parents who are expecting the birth of a baby with a life-limiting condition and this is mentioned in section 4.1.1 under "an antenatal diagnosis of a life-limiting condition".
Together for Short Lives'	14	4.2 a	A significant proportion of children's palliative care across the UK is provided by the voluntary and community sector. While this is funded in part from statutory sources, some services receive no funding at all from their local health and social care commissioners. We call for this guideline to recognise this. A more effective way to specify the category of service settings to which the guideline should apply are those services which are registered with regulators of health and social care and which provide: - Specialist medical input (for example, medical consultants with expertise in the child's condition). - Sustainable community children's nursing teams. - Children's hospice services. - Specialised children's palliative care. - Care in secondary or tertiary hospitals. - Emotional and psychological care and support. - Local authority children's services - social care (including services providing equipment to disabled children), education, housing and leisure. - Community paediatrics. - Primary care.	Thank you for your comment. The remit of this guideline is to cover "All settings in which NHS commissioned healthcare is provided." Therefore, services provided by voluntary and community sector organisations that have not been commissioned by the NHS are outside of the remit of this guideline.
Together for	15	4.3.1	This key issue should incorporate advanced care planning	Thank you for your comments. The guideline

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Short Lives'		b	and end of life planning.	aims to cover specific aspects of advanced care planning as well as end of life planning. This is reflected in the draft review questions in section 4.5.
Together for Short Lives'	16	4.3.1 f	Pharmacological and non-pharmacological approaches should be considered as part of this key issue.	Thank you for your comment. The specific interventions addressed by this review will be outlined in the protocol after being prioritised by the guideline development group. This suggestion for inclusion will be considered.
Together for Short Lives'	17	4.3.1 h i	We believe that "addressing the psychological and emotional needs of the infant, child or young person with a life-limiting condition" is preferable to "the management of psychological issues".	Thank you for your comment. The scope has been amended in line with your suggestion.
Together for Short Lives'	18	4.3.1 j	Short breaks (respite) are an integral part of children's palliative care and should be considered as part of this key issue.	Thank you for your comment. The role of respite care can be considered within the terms of the scope.
Together for Short Lives'	19	4.3.1 j	The support needs of infants, children and young people and their family members or carers (as appropriate) should include helping them to come to terms with a child's change in behaviour, emotional state and/or loss of cognitive ability.	The outcomes for each review will be specified in the protocol and we thank you for this suggestion.
Together for Short Lives'	20	4.3.1 l	The guideline should address the ethical decisions that need to be made relating to acute interventions and withdrawing of treatment. For example, the guideline could usefully address long-term ventilation and resuscitation.	Thank you for your comment. Section 4.3.1l of the scope specifically addresses this aspect of end of life care and a draft review question is presented in 4.5n. In addition, an ethicist has been recruited to the guideline development group to ensure ethical considerations are appropriately addressed throughout.
Together for Short Lives'	21	4.3.1 P	Care after death should incorporate verifying and certifying the death. It should also include caring for the body and helping families to plan a funeral and burial in ways consistent with their culture and faith.	Thank you for your comment. Caring for the body and making funeral arrangement will be covered by draft review question 4.5o. The scope is sufficiently broad to include the verification and certification of death and this will be discussed with the guideline

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				development group for possible prioritisation for review subject to existing guidance and legal requirements.

Together for Short Lives'	23	4.3.1	In addition to the key issues to be covered, we believe that the following should be included:
			• Nursing care - including mouth care and preventing and managing pressure ulcers.
			• Care provided by Allied Health Professionals (AHPs) - including physiotherapy.
			• Equipment - including the use of syringe drivers, oxygen, suction devices and hoists.
			• Training for professionals providing children's palliative care.
			• Effective organisational models for providing children's palliative care.
			• Collaborative and integrated working between education, health and social care agencies caring for children with life-limiting and life-threatening conditions.
			• Transfers between care settings.
			• Helping children and young people to access education, through transport, equipment and support workers with appropriate knowledge and skills.
			• Providing support to children, young people and families in making choices about care, including end of life choices.
			• Communicating with children, young people and families, particularly:
			  ○ children and young people with profound levels of learning disability and other specific learning difficulties
			  ○ children and young people affected by neurodegenerative conditions who have experienced a loss of their cognitive ability
				Thank you for your suggestions. The specific areas for consideration within the scope will be prioritised by the guideline development group in light of feedback from stakeholders. Issues relating to the needs of specific groups of patients such as those with learning or cognitive challenges, differing communication requirements, and diverse family needs, will be addressed where possible and highlighted in NICE's assessment of equality which is publically available at the time of publication. NICE's policy can be found online at www.nice.org.uk/Media/Default/About/Who-we-are/Policies-and-procedures/NICE-equality-scheme/NICE-equality-objectives-and-equality-programme-2013-2016.pdf
				
				Training for professionals is beyond the remit of NICE guidance

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			○ those for whom English is not their first language ○ those with different gendered parenting roles ○ parents who are separated. • Safeguarding. • Providing palliative care which is consistent with the culture and faith of the child, young person and their family - from the point at which a life-limiting condition is recognised or diagnosed and before, during and after death.	
Together for Short Lives'	22	4.3.1 (o)	We ask that term 'initial' is defined.	Thank you for your comment. It is intended that the long-term care of the family or carer (as appropriate) is excluded from the scope of the guidance. However, routine bereavement support leading up and after the death of the infant, child or young person is covered. The exact timeframe will be defined in the protocol of the systematic review.
Together for Short Lives'	24	4.3.2 a	We ask that the term "specialised management of bereavement" is made clearer in the scope. If this means that therapeutic work with bereaved families is not to be covered by the guideline, it would be helpful if an explanation could be provided as to why bereaved families have been excluded. Palliative care services often provide bereavement services ranging from remembrance day events to therapeutic groups and individual or family therapy sessions. Families often prefer to seek these services from providers who knew them and their child during their illness and end of life. Given the large and complex systems of care around infants, children and young people with life-limiting conditions, if palliative care services withdraw entirely after the child's death this can represent another significant loss for the family. The circumstances of a child's death are often highly	Thank you for your comment. It is intended that the long-term care of the family or carer (as appropriate) is excluded from the scope of the guidance. However, routine bereavement support leading up and after the death of the infant, child or young person is covered and this has been clarified in the scope. The exact timeframe will be defined in the protocol of the systematic review.

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			traumatising; expecting families to engage with new services or therapists at this difficult time may further traumatise them - particularly for those families in greatest distress and for whom "specialised" or expert therapeutic intervention may be necessary. Additionally, many mental health services may decline to work with recently bereaved individuals. This may leave recently bereaved families unsupported at the time of highest need.	
Together for Short Lives'	25	4.4 d	We believe that this should be amended to: "Whether children and young people are cared for and are able to die in the place of their choosing - or in the place chosen by family members, carers (as appropriate) and other people who are important to the infant, child or young person if the child or young person wants them to decide."	Thank you for your comment. We acknowledge that the choice of the family will be an important consideration for some children and young people and have amended the scope to reflect that.
Together for Short Lives'	26	4.4 d	Some children and young people may not be able to verbalise their preferences; it would be helpful if the guidance could address approaches to assessing choice and communicating with individuals who are non-verbal, either because they are too young or whose condition means they are unable to express themselves verbally.	Thank you for your comment. The guidance aims to address the needs of this subgroup and will provide separate guidance, if appropriate.
Together for Short Lives'	27	4.4	In addition to the proposed outcomes, we also believe that the following should be included: • Whether care provided is appropriate to the child or young person's age. • Whether the child, young person and their family are able to achieve the outcomes they wish to before and after the child's death; these might include: ○ accessing education or training ○ starting or maintaining a job ○ starting or maintaining a hobby ○ living independently ○ building and maintaining a social life and social networks	Thank you for your suggestions. The outcomes for each review question will be dependent on the question and will be detailed in the review protocol. Appropriate methods of outcome measurement will be discussed with the guideline development group before reviewing of the evidence begins.

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			○ having relationships. • Whether children, young people and families can access a regular short break. • Whether children, young people and families can access the treatments and equipment they need. • Whether children, young people and families are aware of the children's palliative care services available to them. • Whether children, young people and families are provided with information in language which they can understand. • The number of times that families have to tell their story to professionals and agencies across health, social care and education in order to secure the care and support they need. • Whether children, young people and families have access to a key worker. • Whether children, young people and families have access to generalist professionals who understand how to support and care for children with life-limiting and life-threatening conditions. • Whether young people experience a smooth and well-planned transition to adult services.	
Together for Short Lives'	28	4.5 b	We believe that the term "approaching the end of life" should be amended to "with life-limiting or life-threatening conditions". This would better reflect the proposed population group in 4.1.1.	Thank you for your comment. The text has been amended as suggested.
Together for Short Lives'	29	4.5 e	We believe that the term "approach the end of life" should be amended to "with life-limiting or life-threatening conditions". This would better reflect the proposed population group in 4.1.1.	Thank you for your comment. The text has been amended as suggested.
Together for Short Lives'	30	4.5 g	We would like the scope of psychological interventions considered to also include therapies based on play, music and art therapy. Group therapy and befriending models of support should also be included within the scope.	Thank you for your suggestions. The types of interventions that will be considered by the review question will be prioritised by the guideline development and stated in the

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

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				protocol.
Together for Short Lives'	31	4.5 g	"What psychological and psychopharmacological interventions are clinically and cost-effective…" should be used in place of "What psychological interventions (including counselling and pharmacological interventions*)".* This is on the basis that pharmacological interventions are not a subgroup of psychological interventions.	Thank you for your comment. The text has been amended in line with your suggestion.
Together for Short Lives'	32	4.5 l	We ask that plans for families and carers are also included in this question.	Thank you for your comment. The care of the families or carers are also included in this plan and will be covered by this draft review question.
Together for Short Lives'	33	4.5 p	We ask that this question also asks when these discussions should take place.	Thank you for your suggestion.
Together for Short Lives'	34	4.5	In addition to the review questions proposed, we also believe that the following should be included: • What is the clinical and cost-effectiveness of key working? • What is the clinical and cost-effectiveness of short breaks (respite)?	Thank you for your comment. The scope of this guideline covers a broad range of topics related to end of life care and this would not preclude the consideration of these topics. The specific review questions will be prioritised by the guideline development group and this suggestion will be passed to them.
University Hospitals Bristol NHS Foundation Trust	1	General	The purpose scope appears to be very comprehensive and covers the main issues involved in children's palliative care – it is a well-balanced document.	Thank you for your comment.
University Hospitals Bristol NHS Foundation Trust	2	General	One of the main issues in supporting a child to die at home is GP support and I wonder if this should have its own section within the scope? You may say this is covered in 4.2 (a). If we are really going to increase the number of children dying at home this needs to be address	Thank you for your comment. Issues relating to service provision will be addressed in the guideline itself.
University Hospitals Bristol NHS Foundation Trust	3	4.1.1	I wonder if the list could be put in a more logical order i.e. an antenatal diagnosis, neonatal intensive care…	Thank you for your comment. Following stakeholder feedback we have amended section 4.1.1 to more concisely identify the population covered in this guideline.

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University Hospitals Bristol NHS Foundation Trust	4	4.1.1	What is meant by complex health needs? Would this cover LTV children?	Thank you for your comment. Children and young people on long term ventilation would be considered as having 'complex considerations that entail specific care needs'. This is covered as a population subgroup in section 4.1.1
University Hospitals Bristol NHS Foundation Trust	5	4.1.1	Why only cancer children? What about renal and cardiac children? Children with cancer get a very good service, not sure cardiac or renal children do?	Thank you for your comment. The scope covers all life-limiting conditions. Cancer was thought to have specific issues that would need consideration and is a major cause of mortality in childhood and so was specifically mentioned. However, the scope has now been amended so that it is not perceived to single out specific conditions.
University of York	1	1	The guideline title is confusing as the scope of the guideline is clearly and correctly the (palliative) care of children and young people with Life-Limiting conditions not just end of life care.	Thank you for your comment. The title of the guideline has been amended to more accurately reflect the content of the scope. The provision of care begins from the point of diagnosis through to end of life and beyond the death of the infant, child or young person.
University of York	2	4.3.1	This section is written clearly but it is difficult to map the questions in section 4.5 onto these key areas. There is no mention of the different diagnostic subgroups within the LLC group which may have very different healthcare needs, it would be good to have at least oncology and non-malignant disease separated for all the questions. There are other subdivisions within the population of LLC where considerations are different including those who can communicate, those who cannot.	Thank you for your comment. The scope covers all life-limiting conditions. Cancer was thought to have specific issues that would need consideration and is a major cause of mortality in childhood and so was specifically mentioned. However, the scope has now been amended so that it is not perceived to single out specific conditions. Where a review question was relating to the management of these subgroups within the population, this has been added.
University of York	3	4.4	Outcomes in this group of individuals is very difficult and QoL is particularly difficult. You may find valid QoL measures for some subgroups within this population but not all	Thank you for your comment.

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University of York	4	4.5	Many of these review questions contain several questions or a matrix of questions which should be separated especially questions regarding clinical and cost-effectiveness. My comments on section 4.3.1 regarding subgroups are also very important in this section. There does not appear to be a specific question relating to the antenatal diagnosis of a LLC and therefore the ante and perinatal provision of care.	Thank you for your comment. The list of review questions is draft only, and will be discussed with the guideline development group before being worked into a format that is suitable for a systematic reviews of the literature. Specific issues relating to the provision of care during the antenatal period group will be discussed with the guideline development group in order to prioritise for review.