End of life care for infants, children and young people

Stakeholder consultation: 01/07/16 – 12/08/16

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

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1	Acorns Childrens Hospices	Full	General	General	A very long document with 452 pages and at least as many pages of appendices. Difficult to see how this can be useful at such length.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the ‘short guideline’ lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and follow. A short and full version aimed primarily at clinicians. NICE also produce a version called ‘information for the public’ which is a lay representation of the recommendations. In this instance there will be 2 documents: a version for families that is addressed to parents and carers, and a brief summary for young people themselves. End of life care for infants, children and young people has also been referred as a topic for a NICE quality standard which will be informed by the guideline.
372	Acorns Childrens Hospices	General	General	General	It is unclear who these recommendations will apply to. Many are very basic and should apply to all clinical relationships / encounters. Many are considerations and principles for the care of any child with a long-term illness/condition irrespective of anticipated lifespan. Other attempt to provide brief guidance on very specialised issues such as the use of medications. Rather than trying to summarise extensive guidance on symptom management should there be signposting to more comprehensive sources of guidance such as the APPM formulary or TfSL	Thank you for your comment. We agree that the scope of this guideline was substantial. However, this was finalised before the development of the guidance and stakeholders were consulted on the remit of what should be included. As a result it includes planning, communication and support needs as well as treatment of symptoms and service delivery.

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					Symptom management guidance?	
373	Acorns Childrens Hospices	General	General	General	There appears to be little mention of pyscho-social support for child, parents, siblings and wider family, this is an important component of holistic care.	Thank you for your comment. We have outlined the need for an awareness of psychological difficulties and need for support and that they may need urgent access to psychological services (see section 'emotional and psychological support and interventions'). We have also now added specific recommendations addressing ' social, practical, emotional, psychological, and spiritual support' needs of siblings and the wider family (see recommendations 1.1.6 and 1.1.7).
409	Acorns Childrens Hospices	Short	General	General	A long document - 39 pages and 137 recommendations. This will be difficult to use in practice	Thank you for your comment. The 'NICE version' will be presented digitally in clearly divided sections and, even though large, will be easier to use and navigate.
543	Acorns Childrens Hospices	Short	8	24	Would it be simpler to direct to the collaborative ACP www.cypacp.nhs.uk rather than listing all of the necessary components? Indeed could most of the recommendations concerning ACPs be replaced with a single statement that an ACP should be considered on the basis of the CYPACP guidance?	Thank you for your comment. The Committee discussed at length what an Advanced Care Plan should include, based on their experience and available guidance. The suggested ACP document was discussed by the Committee and we have now described this in the “linking evidence to recommendation section”.
757	Acorns Childrens Hospices	Short	32	17	It is disappointing that there are not stronger recommendations about the composition of a MDT to provide paediatric palliative care. It is a missed opportunity to clearly state that every child must have access to a specialist PPC team and to give clear recommendations about such access might or should be organised. I am concerned that when a recommendation suggests a MDT may include particular elements it is not very likely that they will do so based on current experience and provision. A much clearer recommendation would do more to inform	Thank you for your comment. Recommendation 1.5.3 about the multidisciplinary team (MDT) has been amended: we have added ‘Allied Healthcare professionals’ and ‘those with expertise in managing the child’s underlying life-limiting condition’ to the MDT. Recommendation 1.5.4 has also been added: this is about the ‘specialist paediatric palliative care team’ and who should be involved in it.

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					and encourage commissioners to act.	
780	Acorns Childrens Hospices	Short	33	16	As above – services must provide specialist medical and paediatric nursing as required (not should). Too many areas do not provide such services and the care of children at EOL suffers as a result.	Thank you for your comment. The NICE wording 'should' identifies a strong recommendation. 'Must' is rarely used, for instance only when there is a legal obligation for this to happen.
208	ALD Life	Full	26	36	We are concerned that this recommendation is too general and will not encompass all services involved, particularly for patients with complex conditions/disabilities. We have numerous accounts from our beneficiaries that health care equipment providers (eg. food/equipment suppliers for peg feeds, companies that service hoists and specialist bathroom equipment amongst others), hospices, educational and voluntary support services (eg. Contact A Family, visual/hearing impairment teams) have contacted bereaved parents unaware that the child has died. In particular, for children with multiple and complex conditions, the range of services involved is immense. A recommendation that informing all relevant services (and who this should include) is coordinated by a patient's multidisciplinary team leader (or appropriate alternative) would be welcome.	Thank you for your comment. We have amended the recommendation to include a statement that this should be overseen by an 'appropriate nominated member of the multidisciplinary team'.
2	Alexander Devine Children's Hospice Service	Full	General		In summary we believe the guidelines will positively support and impact on practice as they comprehensively address the scope of practice in children's palliative care. However we recognise the very limited evidence base in the field demonstrated through the process of compiling this guidance. We believe the guidance could be a strong platform for advocating the urgency and need for research in the field.	Thank you for your comment. We acknowledge that quantitative evidence was limited in this population most likely due to ethical considerations or difficulties to recruit. However, we had a fairly big evidence base on some of our qualitative reviews. Research recommendations are only made in areas where gaps are identified and are then prioritised by the Committee. Decisions about the prioritisation of research recommendations

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						were based on factors such as: the importance to patients or the population national priorities potential impact on the NHS and future NICE guidance ethical and technical feasibility. After further consideration of the topics that we addressed we have now added one further research recommendation on perinatal end of life care because we thought that the evidence for this was indeed very limited and we hope that this will inform future guidance.
3	Alexander Devine Children's Hospice Service	Full	General		We recognise that the guidelines cannot be over committed to research recommendations but we are challenged by the validity of the guidelines and recommendations for best practice if they are not based on research and a robust evidence base. Where this is the case and clearly stated in the individual sections of the guidelines – so where the review question is not answered sufficiently because there is no evidence to meet the inclusion criteria for the review - we strongly suggest that this should conclude the need for future research. The current research recommendations do not reflect the findings (and lack of evidence) in the guidelines that would suggest areas for future research.	Thank you for your comment. We acknowledge that quantitative evidence was limited in this population most likely due to ethical considerations or difficulties to recruit. However, we had a fairly big evidence base on some of our qualitative reviews. Research recommendations are only made in areas where gaps are identified and are then prioritised by the Committee. Decisions about the prioritisation of research recommendations were based on factors such as: the importance to patients or the population national priorities potential impact on the NHS and future NICE guidance ethical and technical feasibility. After further consideration of the topics that we addressed we have now added one further research recommendation on perinatal end of life care because we thought that the evidence for this was indeed very limited and we hope that this will inform future guidance.
121	Alexander Devine Children's Hospice Service	Full	16		In the diagram of supportive framework – Advance (d) care plan	Thank you for your comment. The supportive framework diagram has now been corrected.
171	Alexander Devine Children's Hospice Service	Full	21	15	We would suggest that updating the advance care plan, should include in its list of bullet points any changes / updates to condition,	Thank you for your comment. It is important to update the Advance Care Plan if there are important changes and this is addressed in the

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					decisions / outcomes as well as the administrative changes	recommendations in the Advance Care Planning section. The recommendation gives some examples, however these are not intended to be exhaustive.
184	Alexander Devine Children's Hospice Service	Full	23	41	This paragraph may imply that changes will be made to the advance care plan at the time of rapid transfer (which may be the case) but it would be helpful to emphasise here that conversations and ACP should, as far as possible have taken place prior to this critical point. It is clear elsewhere in the guidance about early conversations and planning which would have already been documented.	Thank you for your comment. Yes, as you stated, it is covered elsewhere (see recommendation 1.2.5 for instance) in the guideline and would therefore not need to be repeated in every section.
237	Alexander Devine Children's Hospice Service	Full	33		(p33/34) We do not believe the (key) research recommendations accurately reflect the findings / summary of evidence in the guidance (see later comments) or meet the inclusion factors stated for future research (3.5.1).	Thank you for your comment. We have reviewed our research recommendations and have added a further research topic on perinatal life-limiting conditions. Due to the scarcity in this topic area we have also then given this a 'key' status and have swapped this with the research recommendation on rapid transfer protocols. This is decided according to the gaps identified in our reviews and by consensus within the Committee. Even though further gaps were identified the Committee did not prioritise some of these for further research since research may be unlikely to be carried out or change the recommendations. These reasons are outlined in the relevant 'Evidence to recommendations' sections of the guideline.
238	Alexander Devine Children's Hospice Service	Full	33		(p33/34) We feel that having key research recommendations repeated in the next section (research recommendations, but with different numbering) may be confusing and not easy to cross reference.	Thank you for your comment. We agree that there was undue repetition and have therefore removed the five key research recommendations from the list of research recommendations in section 1.6 of the full guideline.
261	Alexander Devine Children's Hospice	Full	38		Guideline development – this is a clear and well-structured chapter and the themed maps	Thank you for your comment.

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	Service				offer a clear, visual representation of the identified themes.	
274	Alexander Devine Children’s Hospice Service	Full	140		We are concerned how current practice for ACP and the published guidelines will fit with the proposed Emergency health care plans in development.	Thank you for your comment. In parallel planning the Advance Care Plan should be developed to take emergencies, such as worsening symptoms into account. We are unsure whether these fit with the proposed Emergency healthcare plans since they, as you pointed out, are not finalised.
278	Alexander Devine Children’s Hospice Service	Full	181	44	We are concerned that where there is clearly very low evidence to support best practice about shared decision making and ACP – that this has not been put forward as a recommendation for future research and we would strongly recommend that it is included in the research recommendations..	Thank you for your comment. Compared to other sections in this guideline, the section on planning contained a relatively large amount of evidence. The Committee therefore prioritised those that had identified the biggest uncertainties, i.e. largest gaps in evidence. Therefore the sections of the guideline with no evidence were deemed to be more uncertain.
282	Alexander Devine Children’s Hospice Service	Full	184	14	31. Update the ACP when needed – should include significant changes as well as administrative changes (see point 3)	Thank you for your comment. It is important to update the Advance Care Plan if there are important changes and this is addressed in recommendation 1.2.11. The recommendation gives some examples, but these are not intended to be exhaustive.
283	Alexander Devine Children’s Hospice Service	Full	185		Providing end of life care to support preferred place of care and preferred place of death has significant cost and resource implications for our service as end of life care 24/7 (out of hours) is poorly resourced in our region / community with no commissioned funds.	Thank you for this comment. We do appreciate that providing 24 hour access to end of life support given current resource/capacity constraints will be challenging to implement, particularly in the short term. However, NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing support and day and night specialist telephone advice for children and young people receiving home care and

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						approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. "What-if" analysis showed that the resource impact of providing such a service would depend on the staffing configuration and the size of the population covered by such a service. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24h access to end of life support was available in some areas. Whilst this guideline does address service provision it does not specify how services should be commissioned as that will depend on the local context. NICE produce a number of tools to support implementation including resource impact reports and templates, and your comments will be considered by NICE where relevant support activity is being planned. The Guideline Committee recommendations are consistent with recent NHS England advice (e.g. 2013/14 NHS Standard contract for paediatric medicine: Palliative Care and NHS England Specialist Level Palliative Care: Information for commissioners [April 2016]). NHS England do recognise that not all palliative care services will be able to immediately meet the requirements of the service specification for specialist level palliative care for a variety of reasons (e.g.

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						historical patterns of working, workforce capacity and the ability to recruit and retain specialist staff (which may be more difficult in some parts of the country), capacity to provide education and training for staff and others, as well as the mixed funding streams they reflect) but they do state that the sample service specification is an indicator of a 'direction of travel' for such service providers, supported by their commissioners, to which they should be working.
284	Alexander Devine Children's Hospice Service	Full	185	22	We believe this may be misleading in advocating family choice. Some parents may choose hospital as their preferred place of care and death.	Thank you for your comment. We made statements about the 'costs and often unsatisfactory environment' of hospital and it leading to a preference to care in the community. Although in some cases the hospital may be the preferred place of death. We also stated that in the past it was more common that children did die in hospital and that other options were limited.
285	Alexander Devine Children's Hospice Service	Full	185	24	The challenges of NHS commissioning for community and end of life children's palliative care is far more complex than implied in this single phrase. The post code lottery of funds even in part has been clearly demonstrated by TFSL. We are not sure it is helpful to say that NHS are increasingly funding these services when some services still receive no funds at all. It would be more helpful to use the guidance as a lever to suggest that the NHS should be funding end of life care for children.	Thank you for your comment. In this introduction we set the scene that there has been a bit of a shift from place of care and death in hospital to other options over time. We have made strong recommendations in favour of choice in preferred places of care and preferred place of death and also day and night care or advice to achieve this. We therefore believe that this guideline will encourage this to happen, be it through existing or new services. We appreciate that there may be challenges implementing some recommendations given the current financial climate. With regard to the comment on funding: whilst NICE guidelines take into account resource impact, the recommendations were considered

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						to represent a cost-effective use of NHS resources. We recognise not all care is commissioned from the same budget.
293	Alexander Devine Children's Hospice Service	Full	199		The issue of organ donation is a challenging area of practice which requires greater attention in children's palliative care in relation to conversations with parents and the knowledge of HCP's. We are not sure this is explicit in this section – and again given the very limited evidence believe that investigating parent's perspective of organ and tissue donation could be a valid research recommendation.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reorganised - please see recommendations 1.2.16 to 1.2.21. Recommendation 1.2.17 has been rewritten and now includes exploring the views and feelings of the child or young person and their parents or carers on organ donation.
297	Alexander Devine Children's Hospice Service	Full	212	20	We believe that the stated issue to determine the cost of a defined MDT alongside the differing models of end of life delivery should be explicit in the research recommendations (research recommendation No. 3)	Thank you for this comment. This research recommendation relates to home based programme care versus hospital/hospice care, but the Guideline Committee thought Multidisciplinary Team composition would usually be intervention, and therefore would not normally be affected by place of care.
307	Alexander Devine Children's Hospice Service	Full	223		We do not believe the issue of rapid transfer identified as a key research recommendation is a priority for research in children's end of life care. The guidelines cover a breadth of issues with little evidence to support best practice that if we had greater knowledge would benefit and provide better outcomes for families eg service collaboration between NHS and non-statutory services; decision making with families at EOL	Thank you for your comment. The Committee members agreed a recommendation on this topic was needed because of the high variability between regions, lack of clear practices and the importance this has to both parents and children. Moreover, this topic was prioritised for health economic analysis as it would mean a change in practice. However, following this comment the Committee agreed other issues were more important priorities for research, and this question has been de-prioritised.
328	Alexander Devine Children's Hospice Service	Full	291		If the review question has yielded insufficient evidence to support the guidance we would recommend this as the research question, rather than the more focused investigation that is only looking at chaplaincy	Thank you for your comment. The review question did not identify sufficient evidence and the Committee suggested that this more focused research question is more likely to be carried out. A review question aims to

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						summarise many studies rather than describe the design of one particular research project.
365	Alexander Devine Children's Hospice Service	Full	398		In light of the importance of and emotive challenges surrounding nutrition and hydration we would support this as an area for future research especially as the guidelines state there is no evidence to meet the inclusion criteria for the review.	Thank you for your comment. We acknowledge that quantitative evidence was limited in this population most likely due to ethical considerations or difficulties to recruit. We also agree that it would be important to increase the evidence base in this topic. However, we had a fairly large evidence base on some of our qualitative reviews. Research recommendations are only made in areas where gaps are identified and are then prioritised by the Committee. After further consideration of the topics that we addressed we have now added one further research recommendation because we thought that the evidence for perinatal end of life care was indeed very limited and hope that this will inform future guidance.
65	Association of Child Psychotherapists (ACP)	Full	General		The ACP was very impressed by what we read in this guidance. It was rich in both descriptions and needs (We wondered if someone from the ACP has already been involved in the draft). At many points it registers the need for suitably qualified psychology and psychotherapy as treatment choices. We were quite hard pressed to think of what we may add, but did come up with a few thoughts/ recommendations. One was the idea of offering groups for children but more possibly young people with life limiting disease in order that they could have the possibility of sharing some of their	Thank you for your comment. We were aware of the relative lack of evidence to support specific interventions in this area for this group of children and young people. We were not therefore able to make very specific therapeutic recommendations, and consequently highlighted the need to be aware of the needs of these children and where necessary to seek expert psychological intervention. Regarding the role the MDT, a number of recommendations (1.5.1-1.5.6) highlight the diverse needs of individual children and young people and specifically recommendation 1.5.3 advises that the team may include a wide range of healthcare professionals. It does not make reference to experts in psychological therapies as it is not intended to cover all eventualities, but based

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					experiences with others. These would as mentioned in draft need to be run by suitably qualified therapists. More generally we thought (and this would tie in with being able to offer the above) that all health provisions for children and young people who have life limiting disease should have access to multi-disciplinary psychological services/ teams (to include psychology, psychotherapy and psychiatry) to best meet their and their families variable needs. So often these needs are complex and the needs of each family member may differ.	on recommendations on emotional and psychological support and interventions access to such professionals is implicit (recs 1.2.22-1.2.26)
4	Association of Paediatric Anaesthetists of Great Britain and Ireland and Royal College of Anaesthetists	Full	General		This is a huge and comprehensive guideline, (452 pages and 137 recommendations), and the authors are to be commended for the work, rigour and detail of the final document. While attempts have been made to group recommendations together to facilitate easier reference this cannot be regarded as an "easy reference guide" and while clinicians may well have time away from the bedside to digest the contents and implications, parents, carers and children may find the document relatively inaccessible. It is hoped that accompanying documentation intended for lay distribution is clear, styled so that it is easy to access and much shorter than the "Full" and "Short" guides we have reviewed.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and follow. End of life care for infants, children and young people has also been referred as a topic for a NICE quality standard which will be informed by the guideline.
275	Association of Paediatric Anaesthetists of Great Britain and Ireland and Royal College of Anaesthetists	Full	140		(p140-) Advance Care planning and DNAR. There is an excellent section on Advance planning but the DNAR element of such planning is only briefly mentioned. This is important when new professionals, for example anaesthetists, surgeons and other	Thank you for your comment. Advance Care Planning does mention the topic of resuscitation. We recognise that this is an important topic and recommendation 1.2.15 states that a resuscitation plan may require alteration, for example if a child is undergoing

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					acute care physicians become involved (Recommendation 31 for example). This has particular relevance with respect to surgery, whether related or not to the disease process where a multi-disciplinary decision needs to be made with respect to suspension or otherwise of DNAR instructions for the peri-operative period and cases will need to be treated on an individual basis. Recommendations regarding the consideration of suspension or otherwise of DNAR instructions would be helpful. The early involvement of anaesthetists in planning for surgery and for example the use of pre-operative assessment clinics is suggested such that discussions regarding advance planning and DNAR do not take place on the day of elective surgery. Planning for more urgent surgery will depend on proper and timely multi-disciplinary discussions. The following updated 2016 guidance from RCUK is recommended: https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/	general anaesthesia. The resuscitation plan for any child or young person needs to take account of many individual factors and may require review (see recommendation 1.2.7 on developing and regularly reviewing Advance Care Plans). Recommendation 1.3.1 has been rewritten: we have used positive phrasing to indicate that resuscitation should always be attempted, unless a do-not-attempt-resuscitation order is in place.
370	Association of Paediatric Anaesthetists of Great Britain and Ireland and Royal College of Anaesthetists	Full	35,105 and 148	Table 13 and 5.5.12 Theme map And figure 6	The spider diagrams on, for example on p35, table 13 and p105, 5.5 Theme map, are superficially attractive but utterly confusing. It is an attempt to summarise the previous text content into a manageable format for easy reference but I am afraid it does not work. There are other examples: p148, Figure 6 “At the centre…….” Is utterly dreadful and far too complicated. Note: the pagination is not clear here with only a 14.. as the page number, the final digit is missing as are many pages beyond 100. This may be a formatting issue	Thank you for your comment. The theme maps visually represent what was identified in the evidence. The themes are then quality assessed in the tables that follow. The Committee found them helpful and other stakeholders commented positively on them. The formatting issue with the visibility of page numbers has now been resolved - thank you for bringing the issue to our attention.

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					on the version I am viewing but should be checked.	
407	Association of Paediatric Anaesthetists of Great Britain and Ireland and Royal College of Anaesthetists	General	General	Short, p7, line 21 and onward	The list of recommendations is long, comprehensive and each one is supplemented by multiple examples and additional text. We wonder whether all this text is necessary within each recommendation, especially within the short version as much relates to what would be considered integral to the standard working practice of **any** trained medical professional and most especially within specialties such as palliative care. For example: p7, line 21, 1.1.15: When talking to parents, children and young people etc. Be sensitive, honest, realistic, give reassurance etc. Surely this is a given for properly trained practising medical professional? A shorter version of the short version might be more accessible.	Thank you for your comment. The qualitative evidence that was reviewed in detail for this guideline identified that 'sensitive, honest and realistic' communication and information was not consistently provided. The Guideline Committee therefore agreed that it was necessary to highlight this issue and therefore encourage better practice. Other such recommendations were also based on a substantial number of qualitative studies that highlighted that the 'standard' practice is unfortunately not always followed in end-of-life care because people avoid having these conversations.
408	Association of Paediatric Anaesthetists of Great Britain and Ireland and Royal College of Anaesthetists	General	Managing pain p18	Short p 18, line 17 and sequence	The section on Pain relief is appropriately comprehensive. There is a useful general overview without the need for specific instructions regarding dosing. This is appropriate given the individual nature of prescribing in this area. An additional note regarding the need to consider the continuation, suspension or modification of an analgesia regimen during any peri-operative episode would be beneficial. Again this would depend on whether the procedure was integral to the disease process or a separate intervention. The appreciation of the need to modify (or not) existing analgesia regimen would fall within the competences of most paediatric anaesthetists however complex regimens may require advice from	Thank you for your comment. With regard to 'very basic concepts and philosophy of care' we have reviewed the recommendations we have made on service delivery and have now included detailed guidance on 'specialist paediatric palliative care teams' (recommendation 1.5.4) as well as describing who may be involved in discussions about antenatal diagnosis of a life-limiting condition (recommendation 1.2.6). In recommendation 1.5.3 we state that ‘Depending on the needs of the child or young person’ the MDT may include ‘healthcare professionals from primary, secondary or tertiary services’. This does not rule out access to an anaesthetist if this was what the child or young person needed. This provides clarity about the range of

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					specialist palliative or chronic pain physicians. A recommendation to consider referral to such specialists when complex analgesia needs fall outside individual practitioners skill-set might be helpful.	professionals that may be involved in the child or young person's end-of-life care. We have also made specific recommendations about home care and how it should be provided with access to services around the clock (recommendation 1.5.9).
595	Association of Paediatric Anaesthetists of Great Britain and Ireland and Royal College of Anaesthetists	Short	12	4 and section 1.4, line 10	The section on Organ and tissue donation on page 12 raises the subject. We suggest that Section 1.4 on page 30 also includes this as a discussion item as this process will precede matters itemised from line 16 onwards. This would close the loop with respect to the organ donation process.	Thank you for your comment. Section 1.4 is directly in relation to the death of the child, i.e. directly before or after. Discussions about organ donation should be initiated at an earlier stage since it could be misinterpreted directly at the time of death or just before.
66	Association of Paediatric Chartered Physiotherapists (APCP)	Full	General	General	Experience has shown that therapists involved in end of life care/palliative care with children, often have other roles outside of this. It can therefore be challenging when intensive input is required with a child and family who are nearing the end of life in terms of the therapists remaining caseload. Hospital trusts should have a contingency plan for those therapists who have dual roles so that dedicated, none-rushed time can be given to children at end of life and their families.	Thank you for this comment. The Guideline Committee does not disagree with this but contingency plans of the type mentioned are outside the remit of this NICE clinical guideline.
67	Association of Paediatric Chartered Physiotherapists (APCP)	Full	General	General	Children with life limiting conditions often have a wide range of equipment that requires collection after death. There should be a discussion with the family with regards to when and how they want the equipment collected, for example; some families like to keep it for a while as they feel it links them to their child, others want it removed fairly swiftly. Discussions also need to occur with	Thank you for your comment. In recommendation 1.3.14 we ask healthcare professionals 'to take into account and discuss the practical considerations with them' when considering care at home. These included equipment. Without being too prescriptive about the content of these discussions the Committee agreed that the collection of equipment would usually feature in these

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					regards to whether they want a specific person to collect it or someone anonymous i.e. a driver.	discussions.
68	Association of Paediatric Chartered Physiotherapists (APCP)	Full	General	General	It should be recommended that the wider MDT has appropriate training with regards to managing families and children with life limiting conditions. Often therapists may not be part of the 'palliative team' however work very closely with the child and family over many years and therefore have many of the discussions highlighted in the draft informally. Therapists often just 'feel their way' through these discussions or signpost families to other members of the MDT. Empowering therapists with palliative care training would increase confidence in all parties when having these types of discussions. Obviously there is a cost implication to this type of training which would need to be considered.	Thank you for your comment. The issue of training (medical or otherwise) is outside the remit of this guideline. NICE guidelines assume that healthcare professionals would have the appropriate training and expertise in their area.
308	Association of Paediatric Chartered Physiotherapists (APCP)	Full	227		There does not seem to be any guidelines for what happens when a child/young person dies during a rapid transfer/ transfer. This has happened on a number of occasions when children have died on the way to the hospice. Guidelines of how to deal appropriately with this very complex situation would be beneficial.	Thank you for your comment. We agree that this is important. Recommendation 1.3.17 advises that the course of the condition may be unpredictable, and that with rapid transfer death may occur 'sooner or later than expected'. The recommendation is to discuss these uncertainties.
449	Association of Paediatric Chartered Physiotherapists (APCP)	Short	General	General	The document as a whole does not seem to be very specific to the distinct needs of the neonate and their families. Occasionally neonates are mentioned eg sucrose for pain (page 19) but the general information in the document is often not wholly appropriate for neonates	Thank you for your comment. We have changed the preamble to the guideline and removed 'where appropriate' to clarify that children and young people include neonates and infants. The Committee acknowledges that evidence in this area is scarce and has therefore written

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						another research recommendation for this topic. The new research recommendation is on the impact timely perinatal palliative care has on the experience of bereaved parents. It has been prioritised as one of the 5 key research recommendations, with the intention that this will hopefully inspire future evidence to inform a future update of this guideline. We have also highlighted the percentage of neonatal deaths in the introduction to this guideline to emphasise the importance of this group. We have however changed recommendation 1.2.6 on beginning discussions of an Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition, to now include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.
675	Association of Paediatric Chartered Physiotherapists (APCP)	Short	19	23	We feel the non-pharmacological ways to decrease pain could also include aquatic therapy, repositioning, passive movements and stretches	Thank you for your comment. These are examples for illustrative purposes and not an exhaustive list. There was no direct evidence for the effectiveness of any particular approach, but the Committee reached consensus on a few measures that would help relax children and may therefore contribute to pain reduction.
697	Association of Paediatric Chartered Physiotherapists (APCP)	Short	25	8-31	We feel it would it make more sense for the causes of respiratory distress come before the contributing factors. Physiotherapy is mentioned as 'think about…' We feel physiotherapy assessment and advice is essential in managing respiratory distress at	Thank you for your comment. We do think that the contributing factors should be considered first because they are often resolved without specific medical interventions. However, we agree that it did not match up in the preamble and have switched the order of contributing

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					end of life.	factors and causes around at this point to reflect the order of the bullet points below it.
699	Association of Paediatric Chartered Physiotherapists (APCP)	Short	26	1	We feel that the child/ young person should also be referred to a specialist physiotherapist for assessment and treatment.	Thank you for your comment. Physiotherapy is mentioned in recommendation 1.3.42. This would mean that this is carried out by a healthcare professional with the appropriate expertise to do this (such as a physiotherapist). However, we did not want to be too prescriptive about this since some types of physiotherapy could be provided by another trained healthcare professional. We have also now added allied health professionals to the Multidisciplinary Team recommendation and provided physiotherapists as an example (recommendation 1.5.3).
5	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Full	General	General	The size of the Full Guidance makes this document essentially unusable as a practical document. The existing document does not allow for the establishment of very clear standards against which 'peer review' assessment could take place.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and follow. A short and full version aimed primarily at clinicians. NICE also produce a version called 'information for the public' which is a lay representation of the recommendations. In this instance there will be 2 documents: a version for families that is addressed to parents and carers, and a brief summary for young people themselves. End of life care for infants, children and young people has also been referred as a topic for a NICE quality standard which will be informed by the guideline.
6	Birmingham Children's Hospital & West	Full	General	General	It is unclear why the upper age limit of 18 has been chosen for the definition of a 'young	Thank you for your comment. It is standard practice with NICE guidelines to consider that

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	Midlands Paediatric Palliative Care Network Group				person' when other NICE service guidelines use an upper limit of 24yrs – Children and young people with cancer: improving outcomes in children and young people with cancer. This also misses an opportunity to address the issues of transition into adult services.	children range from 0-11 years and young people from 12-18. Although there have been exceptions, extending the range to 25 years for example, young people tend to be transferred to adult care about 16 to 18 years of age. There is existing NICE clinical guidance on care of the dying adult. The guideline makes reference to the importance of transition to adult care where this arises (rec 1.2.3) and cross-references to an existing Nice Guideline on this matter.
7	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Full	General	General	The terminology of the document is unclear and confusing. The document refers to 'End of Life Care….' And yet refers to aspects of care that would be best referred to as 'Palliative Care' and not strictly 'End-of-Life'. The document does not recognise the subtle differences in definitions.	Thank you for your comment. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days. The 'Terms used in this guideline' section has been updated in the guideline and in the glossary of the full guideline. In addition, the End of Life Care definition has been reworded, and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. The terminology used was discussed and adopted at the time of scoping for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan / strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life

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						Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.
8	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Full	General	General	There is a lack of detail to support commissioners in the delivery of services or development of services where none exists.	Thank you for your comment. Resource allocation for implementation of recommendations is a matter for local commissioning. Your comments will be considered by NICE where relevant support activity is being planned.
9	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Full	General	General	Most areas discussed in the document comment on the lack of evidence to support recommendations and yet there are no recommendations about addressing this lack of evidence including the need for the development of research strategies.	Thank you for your comment. We acknowledge that quantitative evidence was limited in this population most likely due to ethical considerations or difficulties to recruit. However, we had a fairly big evidence base on some of our qualitative reviews. Research recommendations are only made in areas where gaps are identified and are then prioritised by the Committee. Decisions about the prioritisation of research recommendations were based on factors such as: the importance to patients or the population national priorities potential impact on the NHS and future NICE guidance ethical and technical feasibility. After further consideration of the topics that we addressed we have now added one further research recommendation on perinatal end of life care because we thought that the evidence for this was indeed very limited and we hope that this will inform future guidance.
10	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Full	General	General	There should be some discussion and recommendations about the establishment of an accurate data repository for palliative and end of life care delivery such as a national data set.	Thank you for your comment. We agree that such a national data set would be useful. However, the specification of a full data set is outside the remit of this guideline.
11	Birmingham Children's	Full	General	General	No specific reference made to the concept /	Thank you for your comment. We recognise

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	Hospital & West Midlands Paediatric Palliative Care Network Group				principles of parallel planning. It is a very useful concept to assist people when considering or undertaking the completion of Advanced Care Plans.	the importance of parallel planning, and have therefore added recommendation 1.1.8 to the ‘General principles’ section of the guideline, explaining the need for parallel planning in order to take account of possible unpredictability in the course of life-limiting conditions. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section of the guideline. We also slightly changed recommendation 1.2.5 on advance care planning.
12	Birmingham Children’s Hospital & West Midlands Paediatric Palliative Care Network Group	Full	General	General	Very little reference to the care and support of siblings	Thank you for your comment. We have amended the guideline and added in explicit reference to siblings and other family members in the section that precedes ‘General principles’ as an overarching theme. Two new recommendations have also been added under ‘General principles’ as overarching recommendations: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
13	Birmingham Children’s Hospital & West Midlands Paediatric Palliative Care Network Group	Full	General	General	There is no discussion about the concept of Life-limiting diagnoses being made ante-natally and the implications for ante natal care and neonatal end-of life care.	Thank you for your comment. In the 'Advance Care Planning' section we have changed recommendation 1.2.6 to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.

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						We did not identify any specific evidence for ante-natal end of life care and acknowledge that evidence is scarce. We have therefore included another research recommendation on this topic which we have prioritised as one of our 5 key research recommendations in the guideline.
14	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Full	General	General	An opportunity has been missed to introduce keyworker concepts in palliative care (they mention having 1 person towards the end, but don't use the phrase key worker).	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist has been added as recommendation 1.2.2.
15	Birmingham Children's Hospital & West Midlands Paediatric	Full	General	General	Limited discussion about the role of specialist therapeutic support interventions such a play, music and art therapy, Physiotherapy and	Thank you for your comment. Please see recommendations 1.1.9, 1.3.25 and 1.3.38 which all mention music and/or play. We did

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	Palliative Care Network Group				occupational therapy as a general concept rather than specific indications such as play therapy for pain management (pg357 Ln36)	not have any evidence for the effectiveness of these interventions and therefore were limited in the recommendations that could be made.
410	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	General	General	Much of the terminology used in the recommendations describes very basic concepts and philosophy of care that applies to all health care settings and is not specific to end-of-life care. This is a missed opportunity to define what the service could and should look like and should go beyond a description of the most basic of ideas and approaches to palliative and end-of-life care. The recommendations are at such a basic level that it is difficult to see how this document will be of any value to the wide range of professionals working in this and allied fields delivering care.	Thank you for your comment. We have reviewed the recommendations we have made on service delivery and have included further guidance on 'specialist paediatric palliative care teams' (recommendation 1.5.4) as well as describing who may be involved in discussions about antenatal diagnosis of a life-limiting condition (recommendation 1.2.6). This provides clarity about the range of professionals that may be involved in the child or young person's end-of-life care. We have also made specific recommendations about home care and how it should be provided with access to services around the clock (recommendation 1.5.9).
411	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	General	General	Most of the recommendations lack sufficient detail to be helpful to either those delivering or commissioning services, this is juxtaposed to the very detailed section on 'Managing Distressing Symptoms'. It is unclear from the document why such detail on Symptom management is needed and thus who the Guidance is ultimately aim at.	Thank you for your comment. We reviewed this issue and have now added or revised a number of recommendations related to service delivery. We have recommended a lead medical specialist in recommendation 1.2.2, added recommendation 1.5.4 about specialist paediatric palliative care teams, and clarified which professionals could be involved when a life-limiting condition is diagnosed antenatally in recommendation 1.2.6. Furthermore we revised our multidisciplinary team in recommendation 1.5.3 and care at home at any time in recommendation 1.5.9 to provide further detail on service provision. Please see the full version of the guideline which includes a sections that describe the rationale for these recommendations.
458	Birmingham Children's Hospital & West	Short	4	18-21	This statement applies to all aspects of health care delivery and is not specific to	Thank you for your comment. The focus of this recommendation is not only that the children or

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	Midlands Paediatric Palliative Care Network Group				End-of-Life care – it should not require stating in this document as this is a very basic element of caring for families.	young people and parents or carers should be involved in the decision making processes but are also supported by the multidisciplinary team if needed. Even though this is general good clinical practice it is particularly important in end-of-life care where decisions can literally be a matter of life or death. We therefore made this one of our overarching 'General principles' of the guideline. From systematic review of qualitative literature about this subject, it was often reported that this does not happen as effectively as it should in End-of-Life care (please see the chapter 5). The Committee therefore drafted these recommendations to address this.
462	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	4	14	There is evidence that repeated questioning is met with negative feedback from parents having to answer the same questions over and over. This underpins the importance of parallel and advanced care planning.	Thank you for your comment. We do not recommend repeated questioning, but there are times at which a review of the plan may be necessary. We addressed the matter of trying to recognise that a child or young person is likely to die within hour or days: recommendations 1.3.57 and 1.3.64 specifically discuss the uncertainty that surrounds such predictions and the need to discuss this fact. Therefore the importance of parallel planning is emphasised in its inclusion in the recommendation on the development of an Advance Care Plan. We recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 (explaining the need for parallel plans) to the 'General principles' section. A definition of parallel planning has also been added to the 'Terms used in this guideline' section of the short guideline. We also slightly changed recommendation 1.2.5 on advance care planning.

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476	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	5	7	There should be clear recommendations about those involved in the delivery of palliative and end-of-life care demonstrating appropriate training in advanced communication skills. There will be cost implications in delivering this training. It should be contained within the service specification for specialised palliative care teams. There needs to be an investment of time to deliver this training and this will have implications on service delivery.	Thank you for your comment. Issues around training are outside the remit of the guideline.
487	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	5	1-3	See comment # 15	Thank you for your comment. Please see our response to # 15.
489	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	5	4-6	The concept of the Keyworker / care navigator should be introduced. This role would need to be defined clearly and could possibly have cost implications.	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact'

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						and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist has been added as recommendation 1.2.2 in the guideline.
496	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	6	1	See comment # 18	Thank you for your comment. Please see recommendations 1.1.9, 1.3.25 and 1.3.38 which all mention music and/or play. We did not have any evidence for the effectiveness of these interventions and therefore were limited in the recommendations that could be made.
501	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	6	9	See comment # 17	Thank you for your comment. We did not have any evidence for the effectiveness of these interventions and therefore were limited in the recommendations that could be made. Organisations such as BAMT will be instrumental in the implementation of these recommendations in practice.
521	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	7	1	See comment # 4 example – 'be aware'	Thank you for your comment. We have reviewed the recommendations we have made on services and have included further guidance on 'specialist paediatric palliative care teams' (recommendation 1.5.4) as well as describing who may be involved in discussions about antenatal diagnosis of a life-limiting condition (recommendation 1.2.6). This provides clarity about the range of professionals that may be involved in the child or young person's end-of-life care. We have also made specific recommendations about home care and how it should be provided with access to services around the clock (recommendation 1.5.9).
544	Birmingham Children's Hospital & West	Short	8	24	There are examples of Advanced Care Planning Documents available that have	Thank you for your comment. We have referred to some such resources in the Linking

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	Midlands Paediatric Palliative Care Network Group				been developed across various regions – these should be referenced. It should not be necessary detail the components when resources already exisit that can be used.	Evidence to Recommendations section. We will pass this information to our resource endorsement team.
555	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	9	21	Recommendations needed for who will be responsible for recording education plans: SENCO, School, family.	Thank you for your comment. Responsibilities for education plans are outside the scope of this guideline.
565	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	10	8	There needs to be clarity on what this statement means.	Thank you for your comment. We have deleted this recommendation because this is now covered in the Advance Care Plan (recommendation 1.2.5) which refers to 'wishes and ambitions' and aspects of the child or young person's life as a whole.
584	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	12	23-27	See comment # 4	Thank you for your comment. Please see our response to comment # 4.
592	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	12	5-21	The document needs to make reference to national standards / guidelines for referral to Specialist Nurse for Organ Donation (SNOD) or Clinical Lead for Organ Donation (CLOD) and should include NHS BT as a stakeholder.	Thank you for your comment. We cross-refer to the NICE organ donation guideline which provides details about who should be involved in those decisions and when (rec 1.2.16). NHS blood and transplant are registered stakeholders for this guideline and have commented.
606	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	13	28	Should there be a clear recommendation that there needs to be a dedicated social worker as part of a specialist palliative care team. The source of funding for this post would be a rate limiting factor. It would need clarity on where this might be sourced: Local authority v 3rd Sector.	Thank you for your comment. Recommendation 1.5.4 has now been added about the 'specialist paediatric palliative care team' and who should be involved in it; the list includes social care practitioners.
609	Birmingham Children's	Short	13	1-22	See comment # 4	Thank you for your comment. Please see our

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	Hospital & West Midlands Paediatric Palliative Care Network Group					response to comment # 4.
619	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	14	26	Why is there a change in terminology? 'Do Not Resuscitate plan' has not been mentioned thus far in the document. There needs to be clarity of why this is different to an ACP. This then needs referencing to the updated national guidance from the Resuscitation Council on the DNACPR orders.	Thank you for your comment. There is a recommendation that specifically states that the 'Advance Care Plan should not be confused with the 'do-not-attempt-resuscitation' order' (recommendation 1.2.14). We therefore feel that this is clear.
653	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	18		(p18-27) The amount of detailed contained within this section of the document appears very much out of place given the remainder of the document significantly lacks in details with respect to all other aspects of delivering palliative and end-of-life care. Reference should be made to resources available via the Association of Paediatric Palliative Medicine (APPM).	Thank you for your comment. The Committee agreed that pain management was incredibly important in end-of-life care and that guidance in this is therefore needed. We have now recommended to 'involve the specialist paediatric palliative care team if a child or young person has unresolved distressing symptoms (recommendation 1.3.20). This team is described in recommendation 1.5.4 and also includes a pharmacist with expertise in specialist paediatric palliative care. We will pass the information about the resources available via the Association of Paediatric Palliative Medicine to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
764	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	32	10-25	The recommendations with respect to the MDT should be very clear and robust and should not be open to interpretation locally – there should be a very clear directive on the constituents of a specialist palliative care	Thank you for your comment. We have reviewed our recommendations related to this topic and have provided further details to strengthen them. Recommendation 1.5.3 about the

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					MDT. The current statement is too 'weak'. This will have significant implications dependent on the existing local arrangements. There should also be a clear statement on the role for regional paediatric palliative care networks. This will potentially be challenging for local implementation. Reference to the NHSE service specification published in 2013 should be made.	multidisciplinary team (MDT) has been amended: we have added 'Allied Healthcare professionals (for example physiotherapists, occupational therapists, speech and language therapists, and psychological therapists)' and 'those with expertise in managing the child's underlying life-limiting condition' to the MDT. We have also added another recommendation (1.5.4) about the 'specialist paediatric palliative care team' and who should be involved in it. At a minimum this team should include: • a paediatric palliative care consultant, • a nurse with expertise in paediatric palliative care, • a pharmacist with expertise in specialist paediatric palliative care, and • experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support). Regional paediatric palliative care networks will be important in the implementation of recommendation 1.5.9 which specifies the services that should be provided for children approaching the end of life and are being cared for at home. We did not specifically reference the NHSE service specification published in 2013 as these recommendations were based on a health economic analysis which showed them to be cost effective.
783	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	33	19	Define 'specialist'	Thank you for your comment. Recommendation 1.5.9 has been amended to 'specialist consultant paediatric palliative care advice (for example by telephone) at any time (day and night)'. We have decided to leave this intentionally vague since the type of specialist may vary according to the particular care that

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						is needed for the individual child. For example a child who has seizures and neurodisabilities may need a different specialist compared to a child with cystic fibrosis who is in respiratory distress.
792	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	33	9-14	There should be greater reference to the concept of parallel planning	Thank you for your comment. We are aware of the crucial importance of parallel planning, In the section addressing the topic of Advance Care Planning it was recommended that the ACP should include and record discussions and decisions regarding parallel planning of end of life care and medical care that is specifically for the underlying condition (rec 1.2.5). We have now also added an explanation of the concept of parallel planning to the guideline glossary of terms.
797	Birmingham Children's Hospital & West Midlands Paediatric Palliative Care Network Group	Short	34	1	There should be a very clear definition within the document as a whole what exactly is a 'Service'. An ideal opportunity has again been missed to specify exactly what a PPC service should be. This would give clear guidance to commissioners.	Thank you for your comment. The service that is needed is described in recommendation 1.5.9 and the recommendation that you are referring to the collaborations and networks that make this happen (recommendation 1.5.10). The exact specifications may vary according to many different factors that are difficult to define.
16	British Association for Music Therapy (BAMT)	Full	General	General	We are delighted that NICE has included the use of music and is highlighting the role it can play in the end of life care for infants, children and young people in this guideline. Music can play a fundamental role in people's lives. At such difficult times, music can be used effectively by families to support relationships. It offers a means for non-verbal expression at a time when words may be particularly difficult to access, and can provide an opportunity to experience times of well-being and capability, providing relief from pain.	Thank you for your comment.

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17	British Association for Music Therapy (BAMT)	Full	General	General	Where available, a music therapist would enhance the delivery of musical interventions for children, young people, their families and other members of staff.	Thank you for your comment. We did not have any evidence for the effectiveness of these interventions and therefore were limited in the recommendations that could be made. Organisations such as BAMT will be instrumental in the implementation of these recommendations in practice.
18	British Association for Music Therapy (BAMT)	Full	General	General	The skills of a music therapist would help to enhance the delivery of the recommendations as stated in the guidelines, in order to make the possibilities of music actively available to young people, their families and other members of staff.	Thank you for your comment. Please see recommendations 1.1.9, 1.3.25 and 1.3.38 which all mention music and/or play. We did not have any evidence for the effectiveness of these interventions and therefore were limited in the recommendations that could be made. Organisations such as BAMT will be instrumental in the implementation of these recommendations in practice.
19	British Association for Music Therapy (BAMT)	Full	General	General	In order to make this guideline more facilitative, could the guideline cite best practice resources related to musical interventions?	Thank you for your response. Your comments will be considered by NICE where relevant support activity is being planned.
20	British Association for Music Therapy (BAMT)	Full	General	General	We recognise that children and young people access music in a variety of ways through a range of services. Services, such as Jessie's Fund, are a wonderful example of best practice in providing opportunities to access to and the delivery of music-making and music therapy to children's hospices. http://www.jessiesfund.org.uk/in-childrens-hospices/	Thank you for your response. Your comments will be considered by NICE where relevant support activity is being planned.
21	British Association for Music Therapy (BAMT)	Full	General	General	Given the lack of quantitative evidence, it would be helpful for providers of end of life care for children, young people and their families, if the guideline could list services delivering best practice in providing music-making and music therapy.	Thank you for your response. Your comments will be considered by NICE where relevant support activity is being planned.
22	British Association for Music Therapy (BAMT)	Full	General	General	The British Association for Music Therapy is happy to work with NICE to produce a list of	Thank you for your response. Your comments will be considered by NICE where relevant

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					resources related to musical interventions in this area.	support activity is being planned.
23	British Association for Music Therapy (BAMT)	Full	General	General	The British Association for Music Therapy is happy to work with NICE to produce a list of services delivering best practice in providing access to and the delivery of music-making and music therapy to children and young people accessing end of life care services.	Thank you for your response. Your comments will be considered by NICE where relevant support activity is being planned.
24	British Association for Music Therapy (BAMT)	Full	General	General	The British Association for Music Therapy is happy to work with NICE in any evaluation of the evidence base for music therapy.	Thank you for your response. Your comments will be considered by NICE where relevant support activity is being planned.
169	British Association for Music Therapy (BAMT)	Full	21	8	(& General) Within hospice care there is a diverse range of professionals working with children, young people and their families. It would be extremely helpful if the guidelines explicitly state the range of professionals involved in delivering care. For example, Allied Health Professionals such as music therapists (and other arts therapists), physiotherapists, speech and language therapists, occupational therapists.	Thank you for your comment. We have amended recommendation 1.5.3 which details who the multidisciplinary team (MDT) may include: in this recommendation we have added 'Allied Healthcare professionals' and 'those with expertise in managing the child's underlying life-limiting condition' to the MDT. Recommendation 1.5.4 has also been added: this is about the 'specialist paediatric palliative care team' and lists the professionals who should be involved in it. We also amended recommendation 1.2.6 to clarify that if the condition is diagnosed during pregnancy think about involving specialists in the discussion, such as obstetricians, midwives, neonatologists, condition-specific specialists and experts from the paediatric palliative care team. We did not want to be too prescriptive about the exact professional roles that must be included because this varies according to the individual condition and the particular needs that were identified.
343	British Association for Music Therapy (BAMT)	Full	352	13	Suggested rates for music therapy sessions recommended by BAMT can be found at www.bamt.org	Thank you for this comment. We have contacted BAMT for their suggested rates for music therapy sessions and have now amended this table accordingly.

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356	British Association for Music Therapy (BAMT)	Full	364	9	Suggested rates for music therapy sessions recommended by BAMT can be found at www.bamt.org	Thank you for this comment. We have contacted BAMT for their suggested rates for music therapy sessions and have now amended this table accordingly.
412	British Medical Association	Short	General	General	It is positive to see references throughout the document to the importance of involving children and young people, as well as their parents and carers, in discussions and decisions about their care. The guideline could benefit, however, from some references to the assessment of competency as a necessary precursor to establish the level of involvement a child or young person can have in specific decisions. There should not be an assumption that a young person lacks competency to make decisions, and neither should they be approached with preconceptions about ability based on previous experiences with young people of the same age. In fact, there is a range of evidence which indicates that very seriously ill children and young people develop a far greater understanding of the implications of their choices regarding medical treatment. Information on the assessment of competency could also include specific issues such as the fact that competency is decision-specific, can fluctuate depending on a number of different factors, and that doctors have a duty to maximise decision-making capabilities. Such information should also make clear that a child or young person may lack competence, but should still be involved in discussions about their care if appropriate.	Thank you for your comment. At the beginning of the guideline there is a hyperlink to a document entitled 'Making decisions using NICE guidelines' which includes information on standards and laws (including on consent and mental capacity).
413	British Medical Association	Short	General	General	There is repeated reference throughout to ensuring that the needs of the child or young	Thank you for your comment. The Committee agreed that it would be difficult and not always

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					person and their parents or carers are considered at all stages of care. The guidelines should, however, also emphasise the importance of considering whether there are other children who will be affected by the death (e.g. siblings), and any specific needs they have which will need to be addressed. This may include determining their level of understanding of what is happening, what information they should receive, and providing them with the opportunity to ask questions. Others involved in their care (e.g., parents, grandparents, teachers) should also be made aware of what they have been told to avoid contradictory or surprising information. The loss of a sibling can cause psychological and emotional distress, which can often be overlooked by parents and healthcare professionals who are intensely focused on the needs of the child or young person at the end of life. Considering the needs of other children who will be affected by the death will therefore be particularly crucial when considering the emotional and psychological wellbeing of families, the support available to them (in particular, bereavement support), and whether there are any other services which will need to be informed of the child or young person's circumstances in order to best support them (e.g., counselling, social services, schools).	applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
414	British Medical Association	Short	General	General	The guideline views end-of-life care as a progression in a single direction. It fails to acknowledge that a child or young person may have episodes where both clinicians and	Thank you for your comment. Recommendations 1.3.5 and 1.3.6 specifically discuss the uncertainty that surrounds such predictions and the need to discuss this fact.

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					families believe they are coming to the end of their life, but who then go onto recover before suffering another illness (for example, children with progressive neuromuscular conditions who have recurrent respiratory infections). It would be helpful for the guideline to recognise the potential for this happening, and provide guidance to clinicians responding to these incidents – in particular, in supporting the child or young person and those close to them to alter advance care plans if circumstances change as a result.	We have therefore also highlighted the importance of parallel planning. This is emphasised in its inclusion in the recommendation on the development of an Advance Care Plan. We have also updated the glossary to include parallel planning.
415	British Medical Association	Short	General	General	The focus of the guideline is very much on expert palliative care, and has little reference to the role of general practitioners in end-of-life care. Although deaths in this age group are rare, and the majority of care will be provided elsewhere, GPs still have a significant role to play. GPs are often relied upon heavily by families for extra support. They are often asked to provide informal second opinions after hospital consultations, sometimes to reinterpret what has been said by a consultant. GPs will also be involved in providing ongoing care and support to parents and other family members after the death of the child or young person. More directly, significant numbers of GPs will be involved in providing out-of-hours care for children and young people being cared for at home. The need for more specialist support for those doctors is explored in more detail at point 38, below. Whilst the guideline does make some references to primary care, it may be useful	Thank you for your comment. We have referenced healthcare professionals from primary care in the MDT (recommendation 1.5.3) and directly referred to GPs as a source of bereavement support (recommendation 1.4.5). However, even though not specifically mentioned throughout the document many of the principles of communication, information provision, or symptom management could be provided through primary care.

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					to give more thought to the specific role of GPs in the end-of-life care of children and young people.	
416	British Medical Association	Short	General	General	The guideline does not provide any guidance on what to do in the event that parents struggle to accept a diagnosis and embark on a search for experimental or alternative treatments which may conflict with the provision of palliative care. Recent cases have highlighted the difficulties that arise when this is not managed properly (see, for example, the much publicised case of Ashya King). It may be useful for the guidelines to include advice on how to approach these situations.	Thank you for your comment. The link in the introductory paragraph to the short guideline entitled 'Making decisions using NICE guideline' includes information related to professional guidelines, standards and laws (including those on consent and mental capacity), and safeguarding. The situation you describe could fall in one or more of these categories. Experimental treatments that are not licensed or available in the NHS are outside the remit of this guideline.
472	British Medical Association	Short	5	2	It is encouraging to see an explicit reference to the need for children and young people and their parents or carers to have time to consider difficult decisions about end-of-life care. What will also be crucial to ensuring high-quality end-of-life care, and perhaps more challenging to implement, is ensuring that doctors also have sufficient time and space to have these types of conversations. Conveying information about terminal conditions in an appropriate way, ensuring that information is understood, and managing those conversations sensitively takes time, which at present, is not always available to doctors. Careful consideration should be given as to how time is allowed to ensure individual patient needs can be met, for example by ensuring that rotas, work patterns, and appointment times take this into account.	Thank you for your comment. Recommendation 1.1.4 refers to 'enough time and opportunities for discussion', under the 'General principles' section, in order to promote this to happen. We strongly believe that it is clear that telling children or young people and their parents or carers that death is likely to happen within hours or days is a conversation that should be given sufficient time and privacy.
490	British Medical Association	Short	5	4-6	A recent BMA project looking at experiences and perceptions of end-of-life care found that	Thank you for your comment. We agree and therefore have highlighted this as an

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					continuity of care is highly valued by patients in healthcare generally. Members of the public who had experience of the end-of-life care of a relative valued it even more so, and took great comfort from the same healthcare professional being alongside them at every step of the journey. We are concerned, however, that current healthcare systems and structures mean continuity of care cannot always be guaranteed. As well as “trying to avoid frequent changes to the healthcare professionals caring for them”, the guidelines should also stress the importance of having clear systems in place to ensure that all those involved in the care of a child or young person have sufficient opportunity to regularly share information and discuss their health and treatment. If continuity of care cannot be achieved, this at least will ensure a consistent approach is taken to treatment and communicated to the child or young person and their parents or carers.	overarching recommendation in the 'General Principles' section of the guidance.
493	British Medical Association	Short	5	7-17	Good communication was identified as an essential component of any end-of-life care approach by doctors and members of the public involved in our recent work on end-of-life care, and we therefore welcome the emphasis placed on appropriate communication in the guideline. We believe, however, that implementation of the recommendations will need to be supported by further work beyond the scope of the guideline. Facilitating open and honest discussions	Thank you for your comment. Yes, we share your view that effective communication is an essential component of end-of-life care and we are therefore providing guidance on this (see section 1.1). However, matters of education and training are outside the remit of this guideline.

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					about the end of life can be immensely challenging and requires skilled and trained input from doctors. Our recent work in this area found that many doctors lacked confidence in discussing the end of life and dying with patients. A huge number expressed a desire for more training in this area, feeling that current education and training was insufficient. In order for doctors to be able to carry out the recommendations on communication, they must receive more ongoing training and support in communication and listening skills, focusing in particular on how to respond to difficult questions, how to initiate discussions about end of life with patients and families, and how to ensure communication and information materials are appropriate for the child or young person's level of competency.	
495	British Medical Association	Short	5	8-14	Using the communication formats listed in this section are crucial to ensuring good communication which is appropriate to the age and level of understanding of the child, but have the potential to be incredibly time-consuming – as noted above at comment number 6, a lack of time was frequently cited by doctors in our research as a barrier to the provision of good end-of-life care. The guideline could emphasise the importance of ensuring doctors give themselves enough time to have these difficult conversations and to communicate difficult and complex information in a sensitive manner. Beyond the scope of the guideline, doctors must be supported by managers and employers allowing them the time and space in which to do this.	Thank you for your comment. Our evidence reviews showed that this does not currently happen in as an effective way as is should and showed that sometimes these discussions were not given sufficient time and this was distressing to all concerned. This recommendation (1.1.4) aims to promote good practice which includes sufficient time for discussions.

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502	British Medical Association	Short	6	9	The recommendation that one healthcare professional lead on communication is helpful insofar that it may, if the lead has dedicated time for this available in their role, address many of our concerns about time. It has the potential to be problematic, however, if the clinician lacks the appropriate skills or confidence in discussing the child or young person's care. We have heard concerns from our members that where single clinicians currently take on responsibility for a child or young person's care, but have then been reluctant or felt unable to discuss the child's care, there are serious implications for the child or young person and those close to them. It will also be important to ensure that other members of the team do not become reliant on that one person. The need to have urgent conversations can arise unexpectedly, and it is crucial to ensure that <u>all</u> healthcare professionals involved in the child or young person's care have the necessary skills and expertise in communicating. A team approach to end-of-life care should be emphasised.	Thank you for your comment. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care has been added; please see recommendation 1.2.2. In addition, recommendation 1.5.3 about the multidisciplinary team (MDT) has been amended: we have added 'Allied Healthcare professionals' and 'those with expertise in managing the child's underlying life-limiting condition' to the MDT. Recommendation 1.5.4 has also been added and is about the 'specialist paediatric palliative care team' and who should be involved in it.
503	British Medical Association	Short	6	9	Another factor to be taken into consideration when deciding which healthcare professional should take the lead on communication should be whether there is any long-standing or pre-existing relationship with the patient or those close to them. In some circumstances this may be the GP.	Thank you for your comment. The views of the child or young person and their parents or carers would cover factors such as existing relationships with health care professionals. A new recommendation about every child or young person with a life-limiting conditions having a named medical specialist to lead on and coordinate their care has been added (please see recommendation 1.2.2.)
515	British Medical	Short	6	1-2	Another key barrier to effective	Thank you for your comment. We would like to

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	Association				communication can be the reluctance of members of the public to talk about the end of life and dying, and the guideline should include some reference to this as a factor to be taken into consideration when thinking about how best to communicate with each child or young person and their parents or carers. Overcoming this reluctance may require more information being made available to children or young people and their families about the options available for end-of-life care, and encouraging them to discuss their preferences and wishes.	draw your attention to recommendation 1.3.2 which explicitly states that 'they may be reluctant to think about end of life care and have difficulties discussing this with professionals or with one another. Wider societal factors with regards to discussions about death (along the lines of the dying matters initiative) are outside the scope of this guideline.
520	British Medical Association	Short	7	13-14	We believe that there should be a presumption in favour of telling children and young people about their life-limiting condition, and that parents should not decide whether or what they should be told. We are concerned that these lines as currently worded place too much emphasis on parents and carers making these types of decisions and having overall control on what information is shared with children and young people. This is particularly problematic if a child is competent and should be involved in decision-making. The guideline should also cover situations where a child or young person wishes to discuss their situation with healthcare professionals without their parents or carers present, making clear that this should be accommodated where appropriate.	Thank you for your comment. We intentionally worded this recommendation using terms such as 'if appropriate and 'what they think their child should be told'. We would also like to highlight that the first recommendation in 'General principle' emphasises the 'central role' that children and young people and their parents or carers play in planning and decision making. The situation of beliefs and values and that there may be disagreement between children and young people and their parents or carers is described in recommendation 1.2.32.
532	British Medical Association	Short	8	24-26	Developing and recording an advance care plan (ACP) is vital in ensuring that appropriate care and services are organised and that the wishes of the child or young person and their family are respected. We heard from many doctors involved in our	Thank you for your comment. We have added 'at an appropriate time' to the recommendation on the development of the ACP (recommendation 1.2.5) because this may vary. We have also amended the same recommendation to 'a record of discussions

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					recent research that at present, advance care planning takes place too late to facilitate that (often due to the fact that doctors do not recognise that individuals are approaching the end of life). It would be useful for the guideline to emphasise the importance of sufficiently early advance care planning, rather than it coming at a point of crisis. The list of what the advance care plan should include is useful, but it could be helpful to emphasise that it is not necessary to complete all aspects of an ACP at the same stage. Introducing topics gradually may allow children and young people and those close to them to get used to these conversations over time and begin to feel more comfortable in discussions.	that may have taken place' to highlight that some sections are optional. We then highlight particular situations when it may need to be updated in recommendation 1.2.11. We therefore agree that this is an evolving document.
536	British Medical Association	Short	8	11	In addition to the type of information listed in this section, families should also be provided with clear instructions about who to call if they need help or advice, particularly if something unexpected happens whilst they are caring for the child or young person at home. We heard from many doctors involved in our recent research that huge numbers of inappropriate hospital admissions occur because the family are concerned by a sudden deterioration in the health of the child or young person and do not know what to do, so call an ambulance. Providing families with information about support available will play a key role in reducing those incidents. Some very good examples of this exist already, for example, where patients and their families are given a single number to	Thank you for your comment. We have added a new recommendation highlighting that every child should have a named medical specialist who is responsible for leading and coordinating their care and who would be able to provide this advice if necessary (please see recommendation 1.2.2).

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					call should they have any concerns or need medical attention or additional medication, with a rapid response from experienced staff, including out of hours. Such provision is, in our experience, not widespread, and initiatives such as this should be given greater consideration by healthcare providers. The commitment from the government in their response to the Review of Choice in End of Life Care to explore the potential for care coordinators at the end of life, who would be the first point of contact for patients and their families, is a positive step in this direction, but must be backed up by action.	
537	British Medical Association	Short	8	14	It may be useful to provide some guidance for doctors about what to do if the life-limiting diagnosis is a genetic condition. There may be other children in the family who may be affected by the same condition and so require information about options for testing, as well as emotional support. Parents may need to be offered information about genetic counselling for parents regarding the risks of similar genetic disorders in any future children.	Thank you for your comment. The topic of genetic counselling is outside the scope of this guideline.
552	British Medical Association	Short	9	22-30	The recommendation lists a number of issues on which discussions should be recorded and documented as part of the advance care plan. Decisions on many of these issues, such as preferred place of care/death, organ donation, and management of life-threatening events, will require children and young people and family members to have coherent and detailed information on the various options available to them, and there is a clear role for healthcare providers to	Thank you for your comment. We have highlighted communication and information provision in separate sections because these are critical components in end-of-life care. We have therefore not repeated this in the planning section.

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					ensure that that information is available and accessible.	
558	British Medical Association	Short	9	1-31	The recommendation provides a detailed list of the types of information the ACP should include. Much of this requires the child or young person and their families to make very difficult, and significant decisions, and one of the biggest challenges to implementation may be the lack of time and space for healthcare professionals to have these sensitive discussions and to explore the relevant options. Again, careful consideration should be given as to how time is allowed to ensure individual patient needs can be met, for example by ensuring that rotas, work patterns, and appointment times take this into account.	Thank you for your comment. Recommendation 1.1.4 refers to 'enough time and opportunities for discussion', under the 'General principles' section, in order to promote this to happen. We strongly believe that it is clear that telling children or young people and their parents or carers that death is likely to happen within hours or days is a conversation that should be given sufficient time and privacy.
569	British Medical Association	Short	10	25	At present, the biggest barrier to the sharing of advance care plans is the lack of mechanisms available for communicating information. The provision of out of hours care, ambulance call-outs, and emergency admissions to hospitals were all identified in our research as particular points where end-of-life care could break down, largely because those providing care could not access the relevant information. We heard many examples of good practice across the country – for example, integrated electronic systems or patient-held notes or “care passports” - but it was clear there was a huge amount of variability across the country. This recommendation for sharing advance care plans needs to take this variability into account.	Thank you for your comment. We have recommended that the plan should be shared with relevant professionals and services (recommendation 1.2.10). Your comments with regard to implementation tools will be considered by NICE where relevant support activity is being planned
586	British Medical Association	Short	12	23-24	As well as recognising the emotional and psychological needs of children and young	Thank you for your comment. The Committee agreed that it would be difficult and not always

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					people and their parents or carers, it is important that healthcare professionals also consider whether there are any other children or young people close to the patient who will also have emotional and psychological needs (e.g. siblings). The impact of bereavement on children and young people can be particularly damaging and they often require specialist help to process the information and to deal with the grief and other emotions they may be feeling. The guidelines could benefit from explicitly referring to the need to consider whether there are other children or young people close the patient who will be affected by the death; the provision of emotional and psychological well-being in line with that highlighted by the guidelines for parents and carers; and the provision of information about other services available.	applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
598	British Medical Association	Short	13	10	Our research with doctors found that awareness of emotional support available to children and young people and their families in their local areas was low, which could impede the implementation of this recommendation. In order for healthcare professionals to be able to provide this type of information to the child or young person and their families, employers will need to ensure that information on available services, and how to access them, are made readily available to doctors. It will also be useful to emphasise the importance for healthcare professionals to share this type of information with the child or young person and their families throughout all stages of care, not only towards the very end of life.	Thank you for your comment. Recommendation 1.2.26 asks healthcare professional to provide information about available emotional and psychological support services and how to access them. The aim of this guideline will be to promote good practice in this area.
601	British Medical	Short	13	23	As well as recognising that children and	Thank you for your comment.

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	Association				young people and their families will have various social and practical support needs, it will be important to make sure they have information about the various services available in their local area and how to access them.	Recommendation 1.2.28 describes the social and practical support needs. It is implied that the awareness of these will promote that information to help overcome these needs will be provided. The aim of this guideline will be to promote good practice in this area.
617	British Medical Association	Short	14	21-13	If a child or young person is deemed competent to make decisions about their medical care, the decision about how their beliefs and values should influence their care is important. We are concerned that the current wording of these lines defers too much to the views of parents and carers, which may not always be appropriate. Although it might sometimes to be useful to discuss options which might be mutually acceptable to both parties, decisions about care made by competent children and young people should be respected as far as possible – even where that might conflict with the views of their parents or carers. At times it may be necessary to seek a second opinion or, in extreme cases, involve the courts if there are differences of opinion. The BMA's *Children and young people toolkit* provides further detail on resolving disputes – available at www.bma.org.uk/advice/employment/ethics/children-and-young-people/children-and-young-peoples-ethics-tool-kit.	Thank you for your comment. At the beginning of the guideline there is a hyperlink to a document entitled 'Making decisions using NICE guidelines' which includes information on standards and laws (including on consent and mental capacity). We have also recommended in 1.2.32 that 'children and young people may feel differently to their parents, carers, or healthcare professionals about how their beliefs and values should influence their care' and that healthcare professional should try to make a mutually acceptable care plan and involve a facilitator or the chaplaincy service if necessary.
630	British Medical Association	Short	15	18	This should be amended to read "take into account their beliefs, values and wishes (if known) and those of their parents or carers", in recognition of the fact that some patients and their parents or carers will have very clear views about withdrawing or withholding life-sustaining treatment.	Thank you for your comment. We would like to keep this recommendation as it is, because adding 'if known' would imply that you do not have to make every effort to ascertain their wishes which would be inconsistent with other recommendations related to a discussion and record of such wishes (captured in the

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						Advance Care Plan - 1.2.5) or 1.2.29 on beliefs and values that may influence care.
649	British Medical Association	Short	17	15	This section should make a specific reference to the need to contact GPs by telephone to inform them that a child or young person is being transferred to their home as the preferred place of death. It is not enough to rely on the sharing of an ACP by e-mail or fax.	Thank you for your comment. As you highlight we do recommend that the update of the Advance Care Plan should be discussed 'with the healthcare professionals who will be involved following transfer'. This implies that this would be a face to face discussion rather than an email or fax. When referring to 'discussions' we have left it to clinical judgement how they would be conducted.
652	British Medical Association	Short	17	1-4	To allow children and young people and their families to make an informed choice about possible place of care and death, it will be important to ensure that the information provided is realistic. For example, many of the doctors involved in our research expressed a view that very few families had a realistic view of the challenges of caring for a dying person at home and what that actually involves. Many doctors also highlighted variability in terms of what services and support is available across different areas, and the difficulties that patients and their families sometimes experience in trying to navigate the different services available. Hospice care for children and young people, for example, is not available universally. There is a role for healthcare providers to make that information available and visible, so that doctors can help signpost appropriately, as well as ensuring that such services are available at the time of need.	Thank you for your comment. The principles of good information provision are described in section 1.1. It is for example stated in recommendation 1.1.18 to be 'sensitive, honest and realistic' when talking to children and young people and their parents or carers.
659	British Medical Association	Short	18	16 onwards	In addition to the distressing symptoms discussed in this section, it may be helpful to include some guidance on managing sleep problems, which are often inextricably linked	Thank you for your comment. We agree that this is an important issue. However, we had to prioritise the number of symptoms and the consensus was reached to address these four

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					with pain, anxiety, and distress.	different types (pain, respiratory distress, agitation and seizures).
662	British Medical Association	Short	18	17	Effective pain management is a crucial issue in end-of-life care: in our research, pain was consistently ranked by doctors and patients as one of the top fears and concerns about end of life and dying. How well pain was managed will have a lasting impact on family member, both in how they judge the end-of-life care provided to their loved ones, and remember their last days. There are various barriers to good pain management, particularly where the patient is being cared for in the community. Doctors and members of the public involved in our work expressed concern about access to medication in the community, particularly out-of-hours. These recommendations on pain management will therefore need to be supported by robust systems which ensure the availability of specialist advice and medication and equipment required for pain control, whenever and wherever that need arises.	Thank you for your comment. The issue of anticipatory prescribing was not included in the scope. However, where we have made recommendations about pain control we believe that this medication would be made available regardless of setting.
667	British Medical Association	Short	18	27	It may be useful to include more guidance on how to recognise signs of pain in children, as the way in which they express or vocalise this can be very different from adults. Measures such as “smiley faces” as a pain assessment tool could be mentioned explicitly here as an example.	Thank you for your comment. Recommendation 1.3.22 starts with: 'When assessing pain in children and young people: • use an age-appropriate approach that takes account of their stage of development and ability to communicate…' This therefore covers this point. The Committee did not recommend any particular tool as this was outside the scope.
670	British Medical Association	Short	19	23-24	The comfort measures outlined in this section are helpful, but we are concerned they could be interpreted by some doctors (particularly those who are anxious about using opioids) as adequate stand-alone pain relieving	Thank you for your comment. We do not think that adding ‘to help’ to this recommendation is necessary. The Committee agreed that the wording ‘Think about non-pharmacological interventions for pain management’ would be

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					measures. To avoid confusion, the stem of this section could perhaps be reworded to state “Think about non-pharmacological interventions to help with pain management.”	understood as suggesting that non-pharmacological approaches may help. Whether it is sufficient or adequate in relieving pain is then a matter of clinical judgement.
677	British Medical Association	Short	19	27	In addition to music, time spent on art, story-telling, and interaction with others can distract from pain experience. Some moderate exercise, particularly in water (where facilities allow), has also been shown to relieve some pain symptoms. Some children and young people and their parents or carers may also welcome complementary therapies (such as acupuncture, reflexology or aromatherapy) in addition to their medical treatment at the end of life, and it may be helpful for the guideline to explicitly refer to the opportunities for and appropriateness of their use.	Thank you for your comment. These are examples for illustrative purposes and not an exhaustive list. There was no direct evidence for the effectiveness of any particular approach, but the Committee reached consensus on a few measures that would help relax children and may therefore contribute to pain reduction.
679	British Medical Association	Short	20	1	Doctors in our research expressed concern that the public often had unrealistic expectations about what can be achieved in terms of pain relief at the end of life. They felt that members of the public often believed it could be relieved completely, when it was more realistic to talk in terms of “managing” or “alleviating” pain to a level acceptable to the patient. In addition to the considerations to be taken into account when tailoring pain treatment, the guideline should also include an explicit reference to exploring the child or young person’s and family’s expectations and preferences regarding pain management and how to respond to them appropriately.	Thank you for your comment. We have covered this issue in our Advance Care Plan section which states that this should include agreed treatment plans and objectives.
681	British Medical Association	Short	20	18	Opioids, although started in low dose, may need to be given in relatively large doses on an mg/kg basis for maintenance analgesia. For this reason, it may be helpful to reword	Thank you for your comment. We therefore stated in recommendation 1.3.29: When using opioids, titrate treatment to find the minimal effective dose that will relieve and prevent

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					this line to stress that opioids should be started at a low dose and then titrated appropriately to achieve pain management.	pain.
686	British Medical Association	Short	21	8-9	Although the crimes of Harold Shipman took place decades ago, there is still a considerable amount of anxiety amongst doctors about how their actions regarding pain management at the end of life will be interpreted. As a result, many of the doctors involved in our research expressed concern that some colleagues – particularly junior doctors and nurses – were too conservative in their prescribing. We are concerned that reference to "minimal effective dose" in the guideline will encourage this practice of under-prescribing, and believe that the guideline could benefit from some rewording to address the anxieties of doctors on the use of opioids. The under-treatment of pain (possibly as a result of doctors' fears and concerns) can be just as serious as the over-treatment of pain.	Thank you for your comment. As much as under-treatment, over-treatment is also not advisable. We have therefore added a further recommendation to involve the specialist paediatric palliative care team if the child or young person has unresolved distressing symptoms (recommendation 1.3.20). This team is now described in recommendation 1.5.4 and also includes a pharmacist with expertise in specialist paediatric palliative care.
724	British Medical Association	Short	30	25	A major barrier to the provision of information about bereavement services is a lack of awareness on the part of doctors on the services available in their area. This recommendation could be reworded to emphasise the importance of doctors making themselves aware of services available locally. Healthcare providers also have a role to play in raising awareness of services amongst doctors and making information about those services visible, so that doctors can signpost families. As noted above at comment number 2, it will be important for doctors to consider whether	Thank you for your comment. In recommendation 1.4.2 we describe that there should be a discussion about the bereavement support that is available which implies that they should make themselves aware of these services. In recommendation 1.4.5 we describe how to plan bereavement support including what services are available and what the parent or carers would find helpful and acceptable as well as who may be involved in providing this support. With regard to siblings we have added them in two sections at the beginning of the guideline.

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					there are any other children in the family (e.g. siblings) who will be affected by the death, and to provide information about specific bereavement support available for them. Sometimes, it is not a lack of information that will be the barrier, but the availability of local services and their ability to meet demands. At present, there are often long delays or restrictions in access. These types of services must be prioritised by service providers so that sufficient, high-quality bereavement services – including specific services for children – are available and accessible consistently across the UK.	We clarified that 'In this guideline' (on page 4) family members include for example siblings or grandparents; and we have also added in the 'General Principles' section of the guideline another overarching recommendation that reads '1.1.6 Be aware that other family members (for example siblings and grandparents) or people important to the child or young person (for example school friends, boyfriends or girlfriends) may also need support.' NICE will also publish a version of the guideline for families and another for children which will refer to some resources.
730	British Medical Association	Short	30	8-9	Privacy, and time alone with their family member, was greatly valued by members of the public involved in our work who had recent experience of bereavement. This may be particularly challenging to guarantee where the individual is being cared for in hospital, the very nature of which means they will be cared for in wards, surrounded by other patients, their family members, and a number of healthcare staff. Hospitals should take steps to ensure that their processes and procedures for the care of children and young people in the very last days of life allow for private time for them and their families. The wording of these lines could be amended to explicitly refer to the need to ensure other children and young people close to the patient (e.g. siblings, cousins, close friends) have the opportunity to have some private time as the patient approaches the end of life. This is part of the more general	Thank you for your comment. The Committee have reviewed and amended recommendation 1.3.70, about ensuring that a child or young person who is likely to die within hours or days has private time with their parents and carers. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes ‘General principles’, adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed

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					comment, outlined above at comment number 2, about the importance of considering the needs of any other children and young people who will be affected by the death.	that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
732	British Medical Association	Short	31	23-24	We are pleased to see a recommendation to give professionals involved in the care of the child or young person opportunities to talk about and explore their thoughts and feelings, as the emotional support available for doctors was a key concern amongst those involved in our research. Although professionally equipped to deal with death, the emotional toll it can have on doctors should not be underestimated – even amongst those who work in areas where they are regularly exposed to dying patients. We heard a range of examples of some of the formal and informal mechanisms available to doctors, ranging from a debrief meeting for all members of staff involved in the care of the dying patient, to time with a senior colleague to talk over tea. Very often, these mechanisms are entirely dependent on individual staff members, and in some areas are non-existent, and so we would like to see greater consistency in terms of what is available to doctors caring for dying patients. We would also like to see the use of such mechanisms expanded and normalised so that doctors access support at an early stage before their health is adversely affected.	Thank you for your comment. The members of the Committee felt strongly about this and therefore drafted this recommendation to increase the opportunities for this to happen more consistently.
758	British Medical Association	Short	32	17	Approaching the end of life can cause acute psychological distress, but trying to access specialist support urgently can be incredibly difficult. In recognition of this, “child and	Thank you for your comment. Recommendation 1.5.3 about the multidisciplinary team (MDT) has been amended: we have added ‘Allied Healthcare

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					adolescent mental health services" should be included as possible members of the multi-disciplinary team.	professionals (for example...psychological therapist)'. ' And 'those with expertise in managing the child's underlying life-limiting condition' to the MDT. Recommendation 1.5.4 has also been added: this is about the 'specialist paediatric palliative care team' and who should be involved in it.
767	British Medical Association	Short	33	19-20	We welcome information being provided to patients and families about who to contact in the event of an emergency. We also welcome the inclusion of "home visits by a healthcare professional with expertise in palliative care, for symptom management" as part of service delivery for children and young people being cared for at home. We are concerned, however, that this will be difficult to implement in practice. At present, it is difficult to guarantee the availability of specialist palliative care doctors 24/7 – particularly in rural areas. Although this could be overcome by the reorganisation of services for specialist palliative care staff to work in pooled rotas, it may be more realistic to refer to home visits from out-of-hours GPs who have direct access to specialist palliative care advice and support (e.g. via e-mail or telephone). GPs can play a critical role in providing out-of-hours care to patients at the end of life, and with access to the right advice services, could be supported to provide high-quality end-of-life care in the absence of a specialist palliative care doctor. As part of our research, we heard of many initiatives in place across the country to ensure that specialist palliative care advice for doctors is available whenever and wherever that need	Thank you for this comment. Whilst the guideline recommends (see recommendation 1.5.9) that care at home is supported by "home visits by a healthcare professional from the specialist paediatric palliative care team (see recommendation 1.5.4), for example for symptom management" the guideline does not require that all home visits require such expertise (and it does not specify that the expertise is restricted to specialist palliative care doctors). The Guideline Committee recognised that access to specialist advice on the telephone would be a means to provide specialist advice on a 24/7 basis and this is reflected in the recommendations. We agree that visits from out-of-hours GPs with direct access to specialist palliative care advice and support (e.g. via e-mail or telephone) is one way in which day and night support services could be supported. The remit of this guideline does not extend into providing details on how services should be commissioned. However, NICE do produce a number of tools to support implementation including resource impact reports and templates, and your comments will be considered by NICE where relevant support activity is being planned.

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					arises, but these are either not widely available or not widely promoted. Healthcare providers should ensure that such support is available and that information about how to access it is widely disseminated.	
769	British Medical Association	Short	33	5	We heard on numerous occasions from both doctors and members of the public, that navigating the many different services involved in a patient's care can be time-consuming and complex, and can be distressing for families at an already difficult time. The concept of having a named individual as a first point of contact and responsible for coordinating care – whether that be through the creation of a new post, or the development of existing structures – is one that we support. It will be important, however, to consider how this post is covered during periods of absence.	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) uses the term 'named individual' instead of the term 'key worker', because the latter may not be appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. The Committee chose to recommend that thought should be given to having a named individual as the 'first point of contact' and who might coordinate care. Recommendation 1.2.2 has also been added, and is about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care.
69	British Pain Society	Full	General	General	Overall the guidelines look quite comprehensive and there is some well-placed emphasis on communication and the involvement of the children, young people	Thank you for your comment. Thank you for your comment. We have reviewed this issue with the Guideline Committee and a new recommendation has been added under

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					and parents/family in decision making. What is lacking however, is a stronger guide to prompt early consultation with a pain specialist, if pain continues to be poorly controlled. Specialist input may prove to be invaluable, not just for the interventional procedures and techniques not available within other specialities, but also for the greater familiarity with a much broader range of strong analgesics and adjuvants compared to many paediatricians and palliative care specialists (in our experience). Our concern is that without specific consideration of this in the guidance, this extra avenue of expert input/intervention may be missed and then there will be no commissioned or recognised pathway to facilitate this expert input, leaving a number of children open to prolonged poorly controlled pain. We would advise its inclusion in the strongest terms.	'managing distressing symptoms'; recommendation 1.3.20 addresses the need for specialist input when symptoms are unresolved, and it precedes all symptom management recommendations. We then cross-reference to the section that described the specialist paediatric palliative care team. We felt that this should not only relate to pain but all other symptoms described in this section of the guideline.
168	Cambridge University Hospitals Trust	Full	21	37/38	This recommendation is not strong enough. It is not enough to see a statement about a DNAR in the patient's record, the doctor needs to see a copy of the actual DNAR.	Thank you for your comment. We have now amended recommendation 1.3.1 to say 'Attempt resuscitation for children and young people with life-limiting conditions, unless there is a 'do-not-resuscitate' order in place'. We feel that this would address your point.
179	Cambridge University Hospitals Trust	Full	23	15/16	This needs to be a stronger recommendation. 'Identify a named individual…'	Thank you for your comment. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care has been added; please see recommendation 1.2.2.
228	Cambridge University Hospitals Trust	Full	31	41/42/43	This implies we should always discuss starting enteral or iv fluids when a child or young person is dying. The effect of this could be to increase pressure on teams to	Thank you for your comment. We disagree with your comment. A discussion about whether medically assisted hydration is in the child's best interest (recommendation 1.2.82)

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					start iv fluids at the time of dying. I don't think it is appropriate to start this discussion in most cases, as it may well set up unrealistic expectations.	together with the awareness that this has a significant effect on care and may be a burden (recommendation 1.2.83) does not imply that this should always be initiated.
25	Child Bereavement UK	Full	General	General	We applaud that the guidelines put the child at the centre	Thank you for your comment.
26	Child Bereavement UK	Full	General	General	We applaud that the guidelines attempts to take a holistic approach	Thank you for your comment.
27	Child Bereavement UK	Full	General	General	We applaud that the guidelines acknowledge the need for flexibility and change over time	Thank you for your comment.
28	Child Bereavement UK	Full	General	General	We applaud that the guidelines advocates for consistency and continuity where possible	Thank you for your comment.
29	Child Bereavement UK	Full	General	General	We applaud that the guidelines advocate direct discussion regarding death and dying and needs/wants of the child and parents/carers	Thank you for your comment.
30	Child Bereavement UK	Full	General	General	We are concerned that throughout the document the needs of children and their parents/carers are highlighted with much less emphasis on involvement of siblings	Thank you for your comment. We have amended the guideline and added in explicit reference to siblings and other family members in the section that precedes 'General principles' as an overarching theme. Two new recommendations have also been added under 'General principles' as overarching recommendations: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all

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						individual recommendations that would follow on from that.
31	Child Bereavement UK	Full	General	General	We are concerned that the committee included 2 parents of children who had died from a life limiting condition and focus groups of children with life limiting conditions also included (done through Together For Short Lives), however no siblings were consulted or involved in the process	Thank you for your comment. Unfortunately we did not get applications from siblings of children who had died from a life limiting condition; if we had received such applications they would have been considered for the guideline committee. We have targeted children with life-limiting conditions in our focus groups since they would be at the centre of our guideline. We have amended the guideline and added in explicit reference to siblings and other family members in the section that precedes 'General principles'. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends).
32	Child Bereavement UK	Full	General	General	The guidance highlights a paucity of quality research on which to base their recommendations in general and a particular lack of research into the needs of siblings (both healthy and those with a similar condition), which is of concern	Thank you for your comment. We do agree that on the whole there was little research on siblings that we uncovered. The Committee did not draft a specific research recommendation on the topic of siblings. However, one of our research topics that was prioritised is on the identification of the emotional support needs for children and young people with life limiting conditions as well as their parents and carers. In our guideline the term parent or carer can include 'other family members (for example siblings or grandparents) or people important to them (for example friends, boyfriends or girlfriends). They are therefore not excluded

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						from this research recommendation. We have also amended the guideline and added in explicit reference to siblings and other family members in the section that precedes 'General principles'. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends).
33	Child Bereavement UK	Full	General	General	The guidelines include very little evidence regarding psychological support for children and parents/carers or of bereavement support for parents/carers or siblings.	Thank you for your comment. Yes, unfortunately the available evidence in these areas was limited which restricted the recommendations we were able to make. We have made a research recommendation on emotional support needs of children and young people as well as parents or carers (which in our context could include other family member). The study that we proposed is qualitative and therefore emerging themes could include bereavement support.
34	Child Bereavement UK	Full	General	General	This guidance is predicated on some very important conversations taking place between professionals and family members. It is our experience that the majority of professionals experience these conversations as difficult and therefore support and training for them is essential if this guidance is to fulfil its potential.	Thank you for your comment. The issue of training (medical or otherwise) is outside the remit of this guidance. NICE guidelines assume that healthcare professionals would have the appropriate training and expertise in their area.
450	Children's Heartbeat Trust	Short	General	General	In general, we would like to see recognition that the approach to supporting a family experiencing end of life care for infants, children and young people also needs to encompass siblings and understand their involvement and needs within this	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit

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					circumstance.	reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
451	Children's Heartbeat Trust	Short	General	General	Through our experience, we have found that parents and families do not want to be 'handed over' to an 'end of life' team but still would like contact with the multidisciplinary team that cared for their child throughout their lives. A high level of trust is built up between clinicians and families and often families can feel they have been abandoned and isolated when their medical team changes, especially if this is due to an end of life circumstance.	Thank you for your comment. We agree that these are important issues. We would like to highlight the overarching recommendation 1.1.5 in the 'General principles' section, which talks about continuity of care. Furthermore we have now also added recommendation 1.2.2, which is about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care.
518	Children's Heartbeat Trust	Short	7		A challenging area in practice is making sure that all members of the multidisciplinary team are talking to children and young people with the same message – that there is a consistent approach across all specialties to the information families are given.	Thank you for your comment. We agree that this is currently a problem in clinical practice. Therefore this guideline provided extensive recommendations on the role of healthcare professionals in communicating, providing information and planning of end of life care (see sections 1.1 and recommendations 1.2.5 - 1.2.15).
748	Children's Heartbeat Trust	Short	32		It is important that clinical psychology team included within the multidisciplinary team	Thank you for your comment. Recommendation 1.5.3 about the multidisciplinary team (MDT) has been

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						amended: we have added 'Allied Healthcare professionals (for example...psychological therapist)'.
417	Children's Hospice Association Scotland	Short	General		1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why: i. Dissemination of so large a document – even the 39 page summary document will be too much for most interested health care professionals to absorb, and this may or indeed not be even more the case for parents, siblings and, vitally importantly for children and young people with appropriate cognitive skills and reading abilities. ii. TRAINING – while it is not the apparent role of NICE to highlight this, our organisation feels this will UNDOUBTEDLY be the most challenging to implement and with its associated economic implications. iii. This assumes a single ACP documentation – can the guidelines promote one ACP for each child with the authority for one to be continued and developed? This would make information sharing easier and therefore more effective.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate. NICE will also produce a version for the parents or carers as well as a version for children. Issues around training are outside the remit of this guideline. Your comments with regards to implementation will be considered by NICE where relevant support activity is being planned.
418	Children's Hospice Association Scotland	Short	General		2. Would implementation of any of the draft recommendations have significant cost implications? i. These guidelines need to effectively implimented with a shift in the current cultures of practice needed, which would need to start in undergraduate	Thank you for your comment. The Guideline Committee was very much aware of the need to adopt an appropriate tone in relation to the recommendations made. There is an emphasis throughout on the importance of involving the child or young person and parents or carers (as appropriate). The Guideline Committee

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					training, and continue into postgraduate training and assessment. ii. We felt that the guidelines also felt insufficiently "warm" and if this could change they could also augment the culture change. iii. Insufficient concentration on the need for excellent holistic care to include the training, recruitment and employment of psycholoigist, professionals from CAMH areas, as well as physios and other AHPs, specialist and knowledgeable social work and educational teams iv. Training and employment of more paediatric palliative lead nurses and doctors, and the financing of 24/7 rotas which rely on more than good will to make the development of this vital area more sustainable.	gave careful consideration of the information and communication needs of the children and their families and made a series of important recommendations to this. Following the consultation we have also highlighted the importance of taking account of the needs of siblings and other family members and others important to the child or young person in these matters. We hope that this has further contributed to the intended tone of the guideline. The recommendations for around the clock services were based on a health economic analysis which found this service to be cost effective. Your comments with regards to implementation will be considered by NICE where relevant support activity is being planned.
419	Children's Hospice Association Scotland	Short	General		3. What would help users overcome any challenges? i. Ensuring that the guidelines are even more readable ii. Provision of more regional/nationally agreed ACP guideline templates, with input from "coal-face" clinicians in their development iii. The absolute need for greater training resources and in terms of the subsequent employment of appropriately employed and retained professionals iv. Publication of more examples of good practice and models of care, eg a. Employment of paediatric consultants	Thank you for your comment. NICE will produce a digital version of the short guideline which is clearly divided into sections and therefore will be easier to navigate. The ACP and what it should contain is captured in recommendation 1.2.5. The provision of training resources is outside the remit of this guideline. Your comments will be considered by NICE where relevant support activity is being planned.

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					across 2 or more sectors, do moving away from silo practice and facilitating the right professionals around the child, young person and family b. Care 24 models to safely facilitate care of children and young people in the area of choice for palliative and subsequently end of life care c. Employment of lead paediatric palliative pharmacists to work with the above v. Mention and pointers to other areas which show evidence based work in PPC, eg Rainbows, APPM Formulary, Oxford Textbook of PPC, and other key organisations such as Together for Short Lives, which itself has many excellent pieces of work….so a sign posting is absolutely vital	
460	Children's Hospice Association Scotland	Short	4	4	We prefer you to state 0-18 years old, as our experience has advised that lay readers do not recognise that neonates/infants are automatically included but numerically 0 – 1 years have the largest number of deaths for 'children' with palliative care needs. In line 14 there needs to be reference to ensure that parents of infants are specially mentioned, as they are only mentioned by inference, rather than specifically – this may be pedantic, but for organisation in Scotland this is now becoming our largest new referral cohort, and I know this to be the case also from my in-tray as Chair of the Association of Palliative Medicine (APPM).	Thank you for your comment. The bullet points are intentionally in this order. Preceding the 'General principles' section, the guideline explains that 'children and young people' includes neonates and infants'; following this we then use children and young people, starting with the second bullet.
481	Children's Hospice Association Scotland	Short	5	24	Many of the children and young people accessing specialist palliative care facilities have limited cognitive ability so this feels as	Thank you for your comment. Throughout we highlight that the care needs to be individualised and we have made specific

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					though it is more concentrated on children and young people with a fuller cognitive ability, eg those with cancer diagnoses. Can this and the surrounding sentences be tweaked to be more inclusive?	recommendations with regard to 'taking account of age and level of understanding' (rec 1.1.9) and 'any special needs' (rec 1.1.10).
497	Children's Hospice Association Scotland	Short	6	1	Somehow include the communication with care professional in terms of drawing up ACPs as this can be as challenging for some as it has to be for children, young people and parents or carers. You take this up in 1.1.11 (line 9) but it may also include who should decide, as sometimes it may be the parents, and this may not be in everyone's best interests.	Thank you for your comment. The recommendations with regard to communication and information provision are intended to apply throughout the guideline. There are therefore not repeated from then onwards.
512	Children's Hospice Association Scotland	Short	6	27	"Orally and in writing" but in the most appropriate language and concentrating that is in plain language and if for children and young people at the appropriate reading age…..or through a communicator as many children may not have the appropriate reading or cognitive ability.	Thank you for your comment. This has now been amended to 'verbally' rather than 'orally'. Age and level of understanding is covered by recommendation 1.1.9 and special needs (including communication aids) are addressed in recommendation 1.1.10.
576	Children's Hospice Association Scotland	Short	11	1	ACP section excellent but is it possible to share the ACP with members of: • Primary Health Care Team • Hospital paediatric teams, eg consultants and lead or liaison nurses, to include relevant A&E units • Community Nurse teams • Respite centre teams • Children's hospice teams • Social work teams and those managing social service packages • School and other education services	Thank you for your comment. We agree that this recommendation was phrased as if this list was exhaustive. We have revised this to clarify that the list includes examples of who the plan is shared with which means that if applicable it may be shared with fewer people than in the list or with other people not included in the list according to individual needs.

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					- Ambulance services …some of which you have.	
589	Children's Hospice Association Scotland	Short	12	24	…important for parents reading this – would, "their parents or carers may FREQUENTLY have some of all of the following:	Thank you for your comment. We prefer not to add 'frequently' because the focus of this recommendation is raising the awareness that children or young people with life limiting conditions as well as their parents or carers could have: emotional and psychological distress and crises, relationship difficulties or mental health problems. We aim to improve recognition for of these whether this is a frequent or rare for the individual person.
597	Children's Hospice Association Scotland	Short	13	6	….may FREQUENTLY experience rapid changes……	Thank you for your comment. We would like to keep this recommendation as it is, because it is the awareness that we are aiming to raise, rather than the frequency of this happening, that is the focus of this recommendation.
624	Children's Hospice Association Scotland	Short	14	26	We all commented you on your NEVER!	Thank you for your comment. We have reworded this recommendation (1.3.1). Resuscitation should now be attempted unless there is a 'do-not-attempt-to-resuscitate' order is in place.
644	Children's Hospice Association Scotland	Short	17	4	Ensure as well as all the discussions, a line is recorded in this section about the need to record the decision and reason(s), and ensure that this is in a prominent position in the child's or young person's notes, and that it is subsequently very VISIBLE, and that it continues to be highlighted at any form of handover, and with the necessary authority, more especially as new teams, in my experience, may tend to not recognise it as it has been developed in their unit. If possible, and it should be, ensure that a copy of this stays with the child or young person	Thank you for your comment. Recommendation 1.2.5 states that discussions about place of care should be documented in the Advance Care Plan. We did not want to be too specific about these discussions since each individual situation requires different discussions. However, we do also state in recommendation 1.3.12 that these preferences may change either if they change their minds or for clinical reasons or due to problems with service provision. We therefore believe that this is covered.
664	Children's Hospice Association Scotland	Short	18	18 and followin	We concur with very many areas of this but it reads very medical and needs to take into	Thank you for your comment. We have emphasised tailoring care according to

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				g	account a greater display of holistic management. All CHAS reviewers also felt that there MUST be greater signposting to other reference material, eg Rainbow's Manual and the APPM Master Formulary. This applies across all the symptoms listed: • Agitation • Seizures • Respiratory distress	individual conditions or circumstances throughout the guideline with the child or young person at the centre (please see the supportive framework diagram in section 1.3 of the full guideline). We have furthermore now recommended to 'involve the specialist paediatric palliative care team if a child or young person has unresolved distressing symptoms (recommendation 1.3.20). This team is described in recommendation 1.5.4 and also includes a pharmacist with expertise in specialist paediatric palliative care. We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement NICE will also publish a version of this guideline for families and one for children. These will refer to some resources.
701	Children's Hospice Association Scotland	Short	26	To p27, line 11	Our reviewers found this very useful but even in the shorter version, we would all have preferred to see an evidence referenced here to the GMC work on this for children and to reference the RCPCH guidelines published in 2015, as so many care professionals who I meet have no idea that there are new and, indeed, very helpful guidelines available. The danger of non-obviously cross referencing this is that the NICE guidelines are the new authorative ones.	Thank you for your comment. NICE is unable to refer to other sources of guidance unless they have been accredited by NICE or we have reviewed the evidence.
706	Children's Hospice Association Scotland	Short	27	12 and onwards	We found the following paragraphs through to 1.3.69 very useful, and also the areas covered in 1.4.	Thank you for your comment.
740	Children's Hospice	Short	31	22	Some form of words which ensures:	Thank you for your comment. The options that

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	Association Scotland				- Strategic bereavement support - Referral to other services as while (line 20) is very important, it is sometimes necessary to seek an early referral to another specialist service, whilst still staying involved.	we have referred to in this recommendation are examples and the list is not exhaustive. However, with regard to your point on referral to another specialist service we have described that people may need 'expert psychological interventions' in the section on emotional and psychological support. These may be needed as part of bereavement support if necessary.
804	Children's Hospice Association Scotland	Short	34	11	We feel that most of the work related to ACP was related to ANTICIPATORY rather than advance care plans	Thank you for your comment. The Committee decided to the term Advance Care Plan as this terminology is more widely used amongst healthcare professionals and therefore would be generally understood.
374	Children's Hospice South West	General	General	General	CHSW welcomes this new NICE guidance as it provides a benchmark for providers to aim towards and a comprehensive framework to support negotiations with commissioners to help move towards a more consistent and equitable funding of children's palliative care services across the country.	Thank you for your comment.
375	Children's Hospice South West	General	General	General	CHSW believes the guidance lacks clarity with regard to the scope of the guidance. It is not clear whether this is a document which is simply referring to care at the end of life, (which may be days/weeks) or to palliative care from the point of diagnosis or recognition of a life limiting condition to death, (which may be months/years). Whilst the title of the document simply refers to end of life, much of the guidance covers other stages in the course of the child's journey with a life limiting condition – for example referring to thinking about communicating 'when the life limiting condition is first recognised' and talking about 'care planning and support throughout the child or young	Thank you for your comment. The terminology used was discussed and adopted during the scoping stage for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.

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					person's life'. This is confusing and it also neglects to appreciate that much of the care that is delivered at the end of life is a continuation or extension of care delivered during the child's life. If this is guidance that is intended to apply for children requiring palliative care at any stage of their life limiting condition, then CHSW recommends that the title reflect this.	The 'Terms used in this guideline' section has been updated. In addition, the End of Life Care definition has been reworded, and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days.
376	Children's Hospice South West	General	General	General	The title and the section 'Who is it for' refers to 'infants, children and young people with life-limiting conditions' but makes no reference to children with life threatening conditions. The definition of life-limiting conditions used in the guidance states: 'Conditions that are expected to result in an early death, either for everyone with the condition or for a specific person'. Life threatening conditions, such as cancers, may result in an early death - but are not necessarily expected to. CHSW, as most children's hospices, provides care to children with life limiting and/or life threatening conditions and would expect any guidance for children requiring end of life care to include both groups of children.	Thank you for your comment. The terminology used was discussed and adopted during the scoping stage for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point. The 'Terms used in this guideline' section has been updated in the short guideline. In addition, the End of Life Care definition has been reworded, and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days.

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377	Children's Hospice South West	General	General	General	In general, throughout the document, the word 'children' is used. But occasionally the term paediatric is used, for example 'paediatric palliative care'. In the interests of de mystifying medical terminology and using plain English which makes guidance and literature accessible to children and their families, CHSW believes it is preferable to use the word children or children's rather than paediatric.	Thank you for your comment. We have added a definition of paediatric palliative care to the glossary. Even though 'children' is plain English, paediatric care is a commonly used term indicating a medical specialty.
463	Children's Hospice South West	Short	4	14	Whilst CHSW endorses the importance of regularly asking children and young people their views about their involvement in care, about their care etc, there needs to be greater recognition in this section about considerations to take into account with the significant number of children with life limiting conditions who have profound learning difficulties; sensory impairment; and communication difficulties.	Thank you for your comment. We agree that this is a very important matter and have therefore highlighted this in the first recommendation in the 'Communication' section of this guideline which highlights age and level of understanding and the possible formats that could be used (recommendation 1.1.9).
473	Children's Hospice South West	Short	5	4	Children and their families often need to receive support from a wide range of different services and practitioners – even if there is consistency of staff within each of these services, (providing continuity of care from that service) all the services involved need to proactively promote processes and partnerships which enable a seamless delivery of care. Otherwise, even if there is continuity of staff within individual organisations, there is fragmentation of care. CHSW believes the guidance could emphasise best practice examples of partnership working, where honorary contracts; single referral points; virtual teams for EOL care etc are used.	Thank you for your comment. We believe that this guideline will promote this issue of continuity that is highlighted in the 'General principles' section (please see recommendation 1.1.5). We will pass this information to our local practice collection team. More information on local practice can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/local-practice-case-studies
478	Children's Hospice	Short	5	8	The challenges of providing information	Thank you for your comment. We have

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	South West				and/or communicating with children with profound learning difficulties and communication difficulties is not fully addressed in this section and is a significant issue for the providers of children's palliative care.	highlighted different formats of communication depending on age and level of understanding in recommendation 1.1.9 and special needs (for instance the use of communication aids) in recommendation 1.1.10. Specific recommendations on how and when each of these would be used is outside the scope of this guideline.
482	Children's Hospice South West	Short	5	24	CHSW was concerned to note that siblings are not included in this section listing other people who might be important to children and young people. Overall, it was our impression that the needs of siblings and the support which they require is significantly under- represented in this guidance. Siblings of disabled children have been found to be almost three times more likely to have significant levels of problems in interpersonal relationships, their psychological wellbeing, school performance, or use of leisure time (as reported by parents) compared to other siblings. 245 siblings compared to 6,564 controls. Goudie et al, 2013. Over half of all young carers in the UK were caring for a brother or sister with a health or disability need. Young carers have significantly lower educational attainment at GCSE and more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19. Hidden from View, Children's Society, 2013. Sibs.org.uk would be able to provide more detailed information.	Thank you for your comment. The guideline committee felt that it would be difficult, and not always applicable, to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs, specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
504	Children's Hospice South West	Short	6	9	This recommendation will be challenging in practice because the child and their family often moves between settings, (hospital, home, hospice) and within each setting it is	Thank you for your comment. A new recommendation about every child or young person with a life-limiting conditions having a named medical specialist to lead on and

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					possible to ensure there is continuity from one (or two) lead healthcare professionals for discussions but it is not possible to ensure only one lead healthcare professional for communication across all settings. A more manageable recommendation is that the number of people involved in leading communication with the child/family is limited to one or two key people – but that there is a lead professional who is kept abreast of the communication that has taken place. This is particularly true when the EOL period stretches over a period of several weeks.	coordinate their care has been added (please see recommendation 1.2.2.)
516	Children's Hospice South West	Short	6	1 - 6	This is an example of how the guidance is confusing, in that the title suggests it is a document for the end of life phase, and then gives guidance about what is required in terms of communication: 'When the life-limiting condition is first recognised; when reviewing the Advance Care Plan; if their condition worsens; when they are approaching the end of life' – so throughout the palliative care journey. CHSW believes the guidance title should reflect what the guidance actually covers.	Thank you for your comment. The full guideline title is 'End of life care for infants, children and young people with life-limiting conditions: planning and management' which therefore includes planning which involves both communication and information provision.
538	Children's Hospice South West	Short	8	17	Transition is a hugely important issue for children during their palliative care journey – but if this is guidance for the end of life, CHSW would rarely be considering transition issues whilst planning end of life care. Parallel planning will take place, and if the child survives what is believed to be an end of life phase, transition planning will be picked up on taking up the parallel plan for care. This is another example which confuses, is this about the specific end of life period, or is it actually guidance for the whole	Thank you for your comment. We have added a recommendation about parallel planning in our 'General principles' section (recommendation 1.1.8). Due to the NICE guideline 'Transition from children's to adults' services for young people using health or social care services' (NG43) this topic was not included in the scope. We have, however, looked at whether or not they identified relevant evidence and were reassured that they had. We therefore believe that this would be covered by a cross-reference.

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					palliative care journey for a child and their family?	
540	Children's Hospice South West	Short	8	23	CHSW believes this statement: 'Develop and record an Advance Care Plan for the current and future care of each child or young person with a life-limiting condition' is too prescriptive and does not recognise the importance of working with the child and family and their wishes/choices regarding this. CHSW believes that the recommendation should state that the opportunity to discuss and develop an Advance Care Plan should be offered to everyone, but it should be acknowledged that some children and families may choose to decline this opportunity and this choice needs to be respected. The recommendation can also make it clear that it is important to return on a regular basis to the family to explore this opportunity, as children and families reach a point when they wish to do this at different stages on their journey. Refusing at one stage, does not mean they will not want this opportunity at a later date.	Thank you for your comment. The Committee recommend that every child or young person with a life-limiting condition should have an Advance Care Plan in place. The Committee have revised the bullet on the record of discussions and decisions by adding 'that have taken place' to give it an optional component (please see recommendation 1.2.5).
560	Children's Hospice South West	Short	10	4	CHSW could not locate anything in this section about the fact that the Advance Care Plan is not a legally binding document and that parents/children/young people are able to re-think and change their decisions at any time they wish to. In this section about regularly reviewing the Advance Care Plan it may be worth including guidance to make sure that children and their parents are absolutely clear that they can change their mind about choices/decisions at any time.	Thank you for your comment. We have emphasised in 'General principles' that the child or young person and their parents or carers have a central role in decision making and planning. We believe that from this it is clear that they can therefore change their minds. The way this is effectively communicated and information is provided are described in the respective sections.
567	Children's Hospice South West	Short	10	13	CHSW was not able to find any guidance in this section on Advance Care Planning about	Thank you for your comment. We would like draw your attention to the link in the

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					what to do if there are conflicts between the views of the nursing/medical team and the family – especially when it is believed the best interests of the child may be compromised. CHSW believes it would be useful to include a section covering this in the guidance.	introductory paragraph to the 'short guideline' entitled 'Making decisions using NICE guideline'. This includes information related to professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.
572	Children's Hospice South West	Short	10	28	Community Paediatricians who work with CHSW were concerned to note that Community Paediatricians were not included in the list of services/people with whom to share the Advance Care Plan – reference was only made to hospital consultants.	Thank you for your comment. This list was intended to provide some examples, and was not intended to be exhaustive.
636	Children's Hospice South West	Short	16	7	CHSW has received anecdotal evidence from parents that this choice/wish for a preferred place of care at death can be offered in too simplistic a way. The circumstances of death cannot always be predicted; sometimes the reality of care in a setting is not properly described, (for example there may be challenges accessing specialist medical advice at home or to provide 24/7 care at home, agency staff unknown to the family are used). Families have recommended questions which reflect how they would like the care to be – for example, their child will be kept comfortable and symptoms dealt with quickly, their child will be looked after by people who know them. CHSW is able to contribute the findings of a research project 'The Hospice to Home Project: The development of a model of care for integrated hospice to home service in Cornwall and Isles of Scilly' Jo Frost and Antonia Beringer CHSW and UWE 2012 which includes many parent accounts and concludes (p.34) 'Parent's primary choice is for their child to be	Thank you for your comment. We have retrieved the suggested reference. It is a very interesting report, but unfortunately it does not meet the criteria for inclusion in the review as it is not a peer-reviewed publication. The Committee acknowledged these uncertainties and unpredictabilities in their discussion, and reflected them in the recommendations (please see recommendations 1.3.10, 1.3.12, 1.3.14 & 1.3.15). They also discuss the course of the condition being unpredictable, and the need to have alternative plans (see recommendations 1.3.16 & 1.3.17).

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					free of pain and fear and any decision regarding location of care is secondary to this'. CHSW also believes that this guidance should recognise that although everyone needs to work very hard together to endeavour to enable a family to achieve their preferred place of care at death, this is sometimes not possible due to the condition of the child or events taking an unexpected turn, families need to be prepared for this eventuality.	
660	Children's Hospice South West	Short	18	16	CHSW uses a range of resources to inform the management of symptoms, in particular the 'Basic Symptom Control in Paediatric Palliative Care' manual (9.5 Ed May 2015) available from the Together for Short Lives website or Rainbows Children's Hospice. CHSW would recommend a link to existing more comprehensive guidance in this section, rather than creating an additional, abbreviated version.	Thank you for your comment. We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement NICE will publish a version of this guideline for families and one for children. These refer to some resources.
718	Children's Hospice South West	Short	30	10	CHSW is concerned that this section regarding care and support for parents, carers and healthcare professionals in relation to the death of a child or young person does not include any recommendation or information about the support needs of siblings, CHSW believes this is a worrying gap in the guidance.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g.

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						best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
721	Children's Hospice South West	Short	30	23	In CHSW's experience, when a family are in the midst of the end of life phase with their child, they are not easily able to focus or think beyond the immediate situation. Prior to the end of life phase, families will often discuss and ask questions about bereavement care and bereavement services – and this is discussed with them and written information shared so they know what is available for the future. After the child's death, the family are preoccupied with the immediate demands of all the administrative requirements and planning the funeral – it is often some time later that they feel able to reflect on and talk about their bereavement care needs. CHSW does not think this recommendation to discuss bereavement care and make a bereavement support plan should be tied to when the child approaches end of life, but should be at the time which feels right for the child/family – and acknowledges that every family is different and there is no set formula which works for everyone.	Thank you for your comment. The scope of the guideline excluded long term specialist management of bereavement. Therefore the focus of this guidance was on planning bereavement support.
735	Children's Hospice South West	Short	31	3	There is no reference to undertaking a bereavement needs assessment when planning bereavement support with parents and carers. Evidence quoted in Hospice UK's 'Guidance for bereavement needs assessment in Palliative Care' 2nd edition by Relf, Machin and Archer 2010 (page 6) states that: 'Early studies of 'bereavement	Thank you for your comment. We have not directly referred to a 'needs assessment', as we do not know which elements should be included. However, we made concrete statements about what to consider when planning bereavement support (e.g. finding out what parents or carers would find helpful, the role that different professional might have in

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					counselling' indicate that intervention only makes a measurable difference to those with 'high' levels of vulnerability or 'risk'. While 'bereavement counselling' is often used indiscriminately to mean a range of interventions, from befriending to therapy, there is now general agreement that offering therapy to those who are resilient is not helpful and may be harmful23. This view is supported by the conclusions of recent meta-analyses of the effectiveness of bereavement care that there is no evidence to support outreach support to all and that services only seem to benefit those who are 'at risk' or struggling with their grief'. The use of bereavement needs assessment helps to tailor the bereavement support offered to a family most appropriately and effectively. Whilst CHSW has not currently implemented a bereavement needs assessment, it is one of our planned developments for the future.	supporting them and other related matters - see recommendations 1.4.2 to 1.4.6). We have reviewed the evidence that Hospice UK guidance is based on. There were 5 relevant references (3, 6, 23, 24, and 25). Please see below our reasons for why these were not included in the guideline. 3. Larson DG, Hoyt WT. Grief counselling efficacy: what have we learned? Bereavement Care 2009; 28(3): 14-19. Response: discussion paper. Does not meet the criteria for inclusion in the review. The study has been added to the excluded studies list (Appendix H) 6. Schut H. Grief counselling efficacy: have we learned enough? Bereavement Care 2010; 29(1): 8-9. Response: discussion paper. Does not meet the criteria for inclusion in the review. The study has been added to the excluded studies list (Appendix H) 23. Schut H, Stroebe M. Interventions to enhance adaptation to bereavement. Journal of Palliative Medicine 2005; 8: S-140-146. Response: this is a narrative review and does not meet the criteria for inclusion in the review. The study has been added to the excluded studies list (Appendix H) 24. Currier JM, Neimeyer RA, Berman JS. The effectiveness of psychotherapeutic interventions for the bereaved: a comprehensive quantitative review.

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						Psychological Bulletin 2008; 134(5): 648-661. Response: this is a meta-analysis of both randomised controlled trials and non-randomised studies. It includes a mixed population (bereaved adults and children - unknown % - who lost a family member - 56% - or other), and data is not provided separately for bereaved parents. The study has been added to the excluded studies list (Appendix H) 25. Neimeyer RA. Grief counselling and therapy: the case for humility. Bereavement Care 2010; 29(1): 4-7 Response: this is a narrative review and does not meet the criteria for inclusion in the review. The study has been added to the excluded studies list (Appendix H)
754	Children's Hospice South West	Short	32	7	Those healthcare professionals (indeed any professional – this will not just involve health care professionals) offering bereavement support need to have expertise, but families also say that what they value is that the person knows them and knew their child – continuity from the time of caring for the child into bereavement is important to families. There are many levels of expertise, some families simply need 'be-friending' and a skilled listener, others need more specialist bereavement expertise, and others need therapeutic intervention for mental health and complicated grief issues. CHSW believes the recommendation needs to be clearer regarding levels of expertise and this could be linked to the different levels of assessed bereavement need.	Thank you for your comment. We have captured general continuity of care in an overarching recommendation in the 'General Principles' section (please see recommendation 1.1.5). The different levels of bereavement support (involving most likely different levels of expertise) are captured in 1.4.5 which mention GPs or other healthcare professionals. All of those involved should have the necessary level of expertise. However, recommendations about training are outside the remit of this guideline.
759	Children's Hospice	Short	32	17	CHSW believes that play professionals	Thank you for your comment.

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	South West				should be included in the list of multidisciplinary team members.	Recommendation 1.5.3 about the multidisciplinary team (MDT) has been amended: we have added ‘Allied Healthcare professionals’ (e.g. psychological therapists) and ‘those with expertise in managing the child’s underlying life-limiting condition’ to the MDT. We did not identify any specific evidence for play interventions and therefore cannot make a strong recommendation about 'play professionals'.
774	Children’s Hospice South West	Short	33	8	CHSW recognises the need to establish the ability to rapidly transfer children to a preferred place at the end of life, but believes that this recommendation has to be coupled with the ability for services to rapidly respond to the needs of a child for end of life care if they are transferred at short notice or unexpectedly. The real challenge to the delivery of end of life care is the unpredictable nature of demand – there can be long periods when there are no children needing end of life care, and then periods when there are a number of children needing end of life care at once. Services need to have sufficient capacity of staff and resource to respond to these varying situations. This is why partnership working at this time is so important as it expands the resource to respond.	Thank you for this comment. The Guideline Committee agree that there are challenges to providing these services and that partnership working is important. Whilst this guideline does address service provision it does not specify how services should be commissioned as that will depend on the local context, NICE do produce a number of tools to support implementation including resource impact reports and templates. Your comments will be considered by NICE where relevant support activity is being planned.
784	Children’s Hospice South West	Short	33	19	This recommendation for specialist medical advice at any time, (day or night) for children receiving end of life care at home will be challenging to deliver because there is shortfall of suitably experienced doctors and few of them provide an out of hours on call rota for the community. Much medical support in the home is provided by the GP.	Thank you for your comment. We do appreciate that providing day and night end of life support will be challenging to implement, given current resource/capacity constraints, particularly in the short term. NICE recommendations are intended to reflect the best available evidence on clinical and

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					Any medical support of this nature delivered to children and families at home is usually delivered on a 'good will basis CHSW is able to contribute the findings of a research study: '24/7 There for you: the development of a service specification for 24/7 access to specialist nursing and medical advice for parents and professionals caring for children with palliative care needs across the South West Peninsula' Jo Frost, Antonia Beringer, and Katherine Pollard CHSW and UWE June 2011. In making this recommendation, there should be greater clarity of what is meant by 'specialist medical advice'. Is this a consultant qualified at Level 4 in children's palliative medicine, or Level 3 – what exactly is meant by this? Without a clearer definition in the guidance there may be varied interpretation and, therefore, inconsistencies in practice.	cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing support and day and night specialist telephone advice for children and young people receiving home care and approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. "What-if" analysis showed that the resource impact of providing such a service would depend on the staffing configuration and the size of the population covered by such a service. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24h access to end of life support was available in some areas. Whilst this guideline does address service provision it does not specify how services should be commissioned as that will depend on the local context. NICE do produce a number of tools to support implementation including resource impact reports and templates. The recommendation has been amended to read "specialist consultant paediatric palliative care advice at any time (day and night), for example telephone advice"
786	Children's Hospice South West	Short	33	21	This recommendation for children's palliative nursing care at any time of the day or night	Thank you for this comment. We do appreciate that providing day and night end of life support

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					will be challenging to deliver in practice because there is a shortfall in qualified children's nurses, a short fall in children's community nurses and too few training posts for both roles. In addition, there is under resourcing of community children's nursing teams and children's palliative care teams to achieve this. Within the South West there is no community service which is able to routinely deliver 24/7 care in the home, there is not even a 7 day a week service. When 24/7 care is delivered for a specific end of life case – this is usually based on good will arrangements and is not sustainable for long periods of time. A more realistic objective given current financial and resource constraints may be for a 7 day a week service.	will be challenging to implement, given current resource/capacity constraints, particularly in the short term. NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing support and day and night specialist telephone advice for children and young people receiving home care and approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. "What-if" analysis showed that the resource impact of providing such a service would depend on the staffing configuration and the size of the population covered by such a service. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24 hour access to end of life support was available in some areas. Whilst this guideline does address service provision it does not does not specify how services should be commissioned as that will depend on the local context. NICE do produce a number of tools to support implementation including resource impact reports and templates. The Guideline Committee believe their recommendations are also consistent with

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						recent NHS England advice (e.g. 2013/14 NHS Standard contract for paediatric medicine: Palliative Care and NHS England Specialist Level Palliative Care: Information for commissioners [April 2016]). NHS England do recognise that not all palliative care services will be able to immediately meet the requirements of the service specification for specialist level palliative care for a variety of reasons (e.g. historical patterns of working, workforce capacity and the ability to recruit and retain specialist staff (which may be more difficult in some parts of the country), capacity to provide education and training for staff and others, as well as the mixed funding streams they reflect) but they do state that the sample service specification is an indicator of a 'direction of travel' for such service providers, supported by their commissioners, to which they should be working.
405	Children's Liver Disease Foundation	General	General	General	The target audience of this recommendation is children and young people amongst others. The current wording and format is inaccessible for this audience, therefore, consideration will need to be given to the accessibility of the guidelines to young people and children. A different document will be required which is aimed solely at this audience.	Thank you for your comment. NICE produces several versions of the guideline. A short and full version aimed primarily at clinicians. NICE also produce a version called 'information for the public' which is a lay representation of the recommendations. In this instance there will be 2 documents: a version for families that is addressed to parents and carers, and a brief summary for young people themselves.
486	Children's Liver Disease Foundation	Short	5	1.1.4	There is vague guidance regarding providing "enough time and opportunities for discussion". One particular issue within end of life care is identifying that a child is dying and communicating this to the family. There perhaps needs to be more emphasis on identifying that a child is dying or that there is a high chance that they will die and	Thank you for your comment. The Committee believe that providing time and opportunity for discussion is a clear recommendation. We have a recommendation which identifies that children and parents need support and an opportunity to discuss anxieties when a child is likely to die within hours or days (1.3.61) and giving parents and children opportunities to

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					communicating this to parents.	talk in these situations (1.3.62).
514	Children's Liver Disease Foundation	Short	6	1.1.9	Guidance regarding what to do when a child is very unwell and may die but equally when a child may also survive but is in a life threatening condition may be helpful. The guidance seems to only cover when a child is definitely going to die but discussion of end of life care may need to be initiated prior to the identification that an illness will definitely be life limiting.	Thank you for your comment. This guideline covers a population of infants, children and young people with life-limiting conditions and therefore discussions prior to the identification of an illness are outside the scope.
420	Christian Medical Fellowship	Short	General		CMF welcomes these guidelines and supports the general tone and balance of the content. In particular, we welcome the absence of any reference to a 'pathway' of care, but the repeated emphasis given to the need for ongoing communication and continuous review.	Thank you for your comment.
421	Christian Medical Fellowship	Short	General		We would like to see the scope of the guidelines extended to include **unborn** children with severe, life-threatening conditions. Development of screening techniques means that more women and their partners will be able to know earlier in pregnancy that their child has a life-threatening disorder. The availability of perinatal hospice care has been shown to reduce the number of women opting for abortion at this stage. Continuing support through the pregnancy and after birth has meant that some of these parents have been able to hold their babies after birth, if only for	Thank you for your comment. The area of unborn children with severe, life-threatening conditions was not prioritised within the scope of this guideline. However, we have amended recommendation 1.2.6 on discussing Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition, to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team. We have also changed the preamble and

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					a matter of hours. A British Parliamentary Inquiry into abortion on the grounds of disability [1]concluded that: *'….the studies have all found that around 20% of women, between one and two years after an abortion for fetal abnormality, have a psychiatric condition, usually a complicated grief reaction, a depressive disorder or post-traumatic stress disorder.*' The availability of perinatal palliative care would encourage a higher proportion of pregnant women carrying a baby with a life-threatening disorder to continue their pregnancies and avoid many of the mental disorders associated with regret. In one British study, when parents were offered perinatal hospice as an option, 40% chose to continue with their pregnancies.[2] Parents need and deserve best-practices care. Britain has a unique programme of children and baby hospices. These offer a positive, civilised response to the challenge of disability. Examples of hospices providing perinatal hospice/palliative care programs and support include The Maypole Project[3] which offers emotional psychosocial support, including prenatal support, integrated with children's hospices and children's hospitals in southeast London and Kent to ensure a holistic package of care. They support children diagnosed with a complex life-	removed 'where appropriate' to clarify that children and young people include neonates and infants. We acknowledge that evidence is scarce and the Committee have therefore written another research recommendation on perinatal palliative care. This has been prioritised as one of the 5 key research recommendations, with the intention that this will hopefully inspire future evidence to inform a future update of this guideline. We have also highlighted the percentage of neonatal deaths in the introduction to this guideline to emphasise the importance of this group. NICE produces several versions of the guideline. A short and full version aimed primarily at clinicians. NICE also produce a version called 'information for the public' which is a lay representation of the recommendations. In this instance there will be 2 documents: a version for families that is addressed to parents and carers, and a brief summary for young people themselves.

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[1] http://abortionanddisability.uk/assets/Abortion-and-Disability-Report-17-7-13.pdf

[2] Breeze AC et al. Palliative care for prenatally diagnosed lethal fetal abnormality. Arch Dis Child Fetal Neonatal Ed. 2007 Jan;92(1):F56-8.

[3] http://www.themaypoleproject.co.uk/

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					threatening or life-shortening illness and/or disability between birth and 18 years of age. Also Zoe's Place baby hospice which offers palliative, respite and terminal care for babies/infants aged from birth to five years old.[4] Whenever possible, we recommend that every parent who receives a prenatal diagnosis should be given information written by individuals who have received the same news, and experienced the same disability in their child.	
469	Christian Medical Fellowship	Short	4	11-13	The guidelines are careful to avoid the use of the term 'consent'. Clearly, the capacity to consent to treatment is dependent on age, maturity and cultural background - consent can only occur if the child fully understands and agrees. The notion of 'assent' might be useful to introduce - assent can occur if the parent/carer fully understands and the child assents by agreeing to trust the parent/carer. Occasionally a child may be too afraid, confused, or ignored to refuse assent, in which case the term assent may be misused to cover a child's refusal. In some cultures, children's rights are not emphasised – rather it is the rights of a parent or community leader that are emphasised. We suggest it is important in the model of shared decision-making, outlined in	Thank you for your comment. The matter of consent is covered in the link to 'Making decisions using NICE guidelines' which covers 'consent and mental capacity' it is otherwise too complex a legal matter to cover by individual recommendations.

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[4] http://www.zoes-place.org.uk

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					the guidelines, that the child's rights are respected at all times, even when these are counter-cultural.	
500	Christian Medical Fellowship	Short	6	7	As well as being accurate and truthful, the language employed by health professionals should be in lay terms, neutral, compassionate and person-centred. Many families facing complex and frightening problems seek wise counsel, advice and support from professionals, not just the communication of percentages and clinical facts. Health professionals should signpost families to a wide range of sources of information, including information leaflets covering all their options, and telephone and online helplines manned by trained professional counsellors.	Thank you for your comment. In recommendation 1.1.15 we describe that information should be 'clearly explained and understandable' and 'specific to the child or young person's circumstances'. We also talk about 'empathy and compassion' in recommendation 1.3.61. We therefore think that we have addressed your point within this guideline. NICE will also publish a version for the public which will sign post to sources or organisation that could provide further information.
452	Church of England	Short	General		We welcome the inclusion of '*religious, spiritual and cultural'* values and considerations throughout the document. While these ought not to be conflated, they are, nonetheless, frequently connected and form a crucial part in delivering holistic care. There are also some points within the document where we believe that specific references to religious and/or spiritual care and the role of healthcare chaplains could usefully be strengthened in order that patients and relatives receive optimal care and other health professionals receive optimal support and guidance. Under '*Recommendations for Research*' we strongly suggest either that religious and	Thank you for your comment. We have drafted a research recommendation to explore perceptions and attitudes around religion and spirituality in paediatric end of life care; when children, young people and their families would like to access religious and spiritual support (see section 8.3.10 of the full guideline).

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					spiritual care is included in research into '*Emotional and psychological support and interventions*' or is treated as a topic for research in its own right.	
574	Church of England	Short	10	25 (1.2.10)	We believe that it is important that healthcare chaplains are included in the list of professionals with whom Advanced Care Plans may be shared.	Thank you for your comment. We agree that this recommendation was phrased as if this list was exhaustive. We have revised this to clarify that the list includes examples of who the plan is shared with which means that if applicable it may be shared with fewer people than in the list or with other people not included in the list according to individual needs.
627	Church of England	Short	14	19 (1.2.31)	We are concerned that the document states, 'if *necessary* involve the chaplaincy service….'. Involvement of chaplaincy services ought to be a first rather than a last consideration.	Thank you for your comment. We believe that the person usually involved in their care may help attempt to agree a mutually acceptable plan. We have therefore added 'if necessary' because it may have been resolved at that point.
651	Church of England	Short	17 29	15 (1.3.16) 25 (1.3.67)	In this context it would be helpful if healthcare chaplains were specifically mentioned with regard to the reference to 'healthcare professionals' as their expertise could prove to be invaluable, but might be overlooked. As above.	Thank you for your comment. We intentionally kept it as 'healthcare professional' in the body of the recommendation because most of this refers to factual information. However, one of the bullets refers to 'professional who will be involved' which may well be chaplains.
729	Church of England	Short	30	26 (1.4.3)	In offering bereavement support, it is important that religious and spiritual support is offered in addition to psychological support	Thank you for your comment. We left recommendation 1.4.2 intentionally broad 'the bereavement support available' which would include religious and spiritual support where it is applicable. We would like this to be at the discretion of the healthcare professional who would be familiar with the individual background of the people involved.
746	Church of England	Short	31 32	3 (1.4.5) 17 (1.5.3)	It is important that chaplains are included in a list of prospective bereavement support health professionals.	Thank you for your comment. In recommendation 1.4.5 we intentionally described 'think about what support different professional could provide' and gave a couple

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					Chaplains ought to be included as healthcare professionals: '*spiritual/religious advisers*' may provide additional support.	of examples. These professionals would include chaplains even if they are not explicitly mentioned.
70	CLIC Sargent	Full	General	General	CLIC Sargent welcomes the opportunity to comment on the draft guideline on end of life care for infants, children and young people. We have identified some specific areas where we think the guideline could be improved but we think that the document overall is extremely well written and comprehensive. We believe that it will be an invaluable source of guidance for healthcare professionals. The short version is also extremely useful for those who do not need to possess the detailed knowledge contained in the full version.	Thank you for your comment.
124	CLIC Sargent	Full	16	Fig 1	This diagram appears fuzzy in the guideline, which makes it difficult to read. In the way the MDT and staff wraps around, we would suggest that parents / carers, siblings and people important should also wrap around the child in the diagram.	Thank you for your comment. The supportive framework diagram is a visual representation of the relationship between our topics in relation to the wider context of key life events and key transitions. Guidelines usually include a pathway, but the Committee agreed that such a linear concept does not fit the scope of our guideline. We have added explanatory text underneath the figure to describe this (see section 1.3 of the full guideline). We wanted to convey that all the people in the inner circle are important and close to the child in the centre, whereas the multidisciplinary team wraps around all of them, further away from the centre (on a different level). We agree that the figure was fuzzy and we have rectified this.
178	CLIC Sargent	Full	23	17-19	We would suggest reviewing the evidence from the CLIC Sargent and London South Bank University Children's Key Worker Service Evaluation Report (Gibson, F. et al	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting

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					2015). The value of the key worker model in palliative care can be found on pages 48-50 of this report. The Key Worker report can be found online here: http://www.clicsargent.org.uk/content/nurses	conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care has been added as recommendation 1.2.2. The report that you provided the link to was not included in the evidence review because it provided descriptive rather than comparative data. We will pass this information to the NICE local practice collection team.
247	CLIC Sargent	Full	34	5-8	Following the CLIC Sargent and London South Bank University Children's Key Worker Service Evaluation Report (2015), [redacted] is intending to publish further papers, providing greater detail on some of the areas covered in the overall Evaluation Report. See bottom of Page 62 in the Key Worker report. One of those listed is the "Key	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs,

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					Worker role in palliative care." There is already some reference in the main evaluation report that the key worker model of care helps families with decision making.	and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having an identified medical specialist has been added as recommendation 1.2.2.
248	CLIC Sargent	Full	34	12-13	CLIC Sargent would recommend that "What is the effectiveness of a home-based package of care as opposed to hospital or hospice care?" is a key research recommendation.	Thank you for your comment. We have preferred place of care as one of our key recommendations and think that this is related to your comment. The decision on the prioritisation was based on the consensus of the Committee.
249	CLIC Sargent	Full	35	39-48	We would like to see an additional note here that there are known known gaps in services for teenagers between their 16th and 18th birthday, where they fall between paediatric and adult services both in the community and in access to age appropriate hospice care.	Thank you for your comment. It is standard practice with NICE guidelines to consider that children range from 0-11 years and young people from 12-18. Although there have been exceptions, extending the range to 25 years for example, young people tend to be transferred to adult care about 16 to 18 years of age. There is existing NICE clinical guidance on care of the dying adult. The guideline makes reference to the importance of transition to adult care where this arises (rec 1.2.3) by cross-referring to an existing Nice Guideline on this matter.

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268	CLIC Sargent	Full	133	22-31	The CLIC Sargent and London South Bank University Children's Key Worker Service Evaluation Report (2015) has much evidence to offer around the importance of relationships and trust through a period of illness / disease culminating in palliative and end-of-life care. Parent quote from the evaluation, Page 49 "Eventually you have to be able to not hold yourself together... and actually have the conversations you need to have .....with somebody who actually knows where you're from. Knows how you live, where you live. I think you need some kind of bond."	Thank you for your comment. The Committee was aware of the importance of communication and a specific review question was conducted on this topic which uncovered a considerable amount of qualitative data. This review highlighted many of the matters that you raise. The importance of establishing a good interpersonal relation is for example covered by recommendation 1.1.11 (deciding who should lead on communication), recommendation 1.1.15 describes the communication styles needed (e.g. sensitive, honest and realistic) and 'empathy and compassion' has been highlighted in recommendation 1.3.60 with regard to recognising that the child or young person is likely to die within hours or days. We have retrieved the suggested reference for assessment. We agree this report provides valuable information, however it cannot be included because it is not a peer-reviewed journal article.
269	CLIC Sargent	Full	135	27-31	[redacted] (http://www.worcester.ac.uk/discover/sue-neilson-ihs.html) has completed a number of published research papers listed on the website above that would inform various parts of this document. In particular, when teaching Sue relayed a family story from her research, where a child had a sudden and quite rapid deterioration, all efforts were made to get the child home quickly at family request, and the first day at home was filled with much coming and going of community health professionals and	Thank you for your comment. We have retrieved all the publications listed on the website for assessment: Neilson S.J., Gibson F., Greenfield S. (2015) Pediatric oncology palliative care: Experiences of general practitioners and bereaved parents. Paediatric Palliative Care and Medicine 5:214. DOI: 10.4172/2165-7386.1000214. Response: This is a qualitative study aimed to examine the role of GPs in children's oncology home palliative care from the perspective of both GPs and bereaved parents. However, the questions about home based care and care

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					clinical hand-overs. The child died quickly and Mum's lasting impression was that valuable last hours at home were focused on the health professionals needs and not their own. The recommendation for time and space for the family needs to be stronger.	round the clock were looked at as intervention reviews. Therefore this study does not meet the protocol criteria. This study has been added to the excluded studies list (Appendix H). Flanagan S., Greenfield S., Coad J., Neilson S. (2015) An Exploration of the data collection methods utilised with children, teenagers and Young people (CTYPs). BMC Research Notes 8:16 DOI 10.1186/s13104-015-1018-y. Response: this is a study on methods used in paediatric research, and not relevant to any of the questions in the guideline. Neilson S., Kai J., MacArthur C., Greenfield S.M. (2013) Using social worlds theory to explore influences on community nurses' experiences of providing out of hours paediatric palliative care. Journal of Research in Nursing, 18 (5): 443-456. Response: this is a qualitative study that looked at the experiences of paediatric nurses providing out of hours palliative care within the family home to children with cancer. As above, this study does not meet the protocol criteria for inclusion. This study has been added to the excluded studies list (Appendix H) Neilson S, Kai J, MacArthur C., Greenfield S.M. (2011) Caring for children dying from cancer at home: a qualitative study of the experience of primary care practitioners. Family Practice, Oct 28 (5):545-53. Response: this is a qualitative paper that aims to explore the experiences of primary care practitioners following their involvement in the

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						palliative care of a child with cancer at home. This study was identified in the original search, but this study design does not meet the inclusion criteria indicated in the protocol. Neilson S., Kai J., MacArthur C., Greenfield S. (2010). "Developing and maintaining palliative care knowledge and skills: The experience of community children's nurses". Paediatric Nursing, 22(3): 31-36. Response: the aim of this study is not relevant to the review. NICE guidelines cannot make specific recommendations in relation to training. The West Midlands Paediatric Macmillan Team (2005). "Palliative Care for the Child with Malignant Disease". London: Quay Books, MA. Response: books cannot be included in systematic reviews
288	CLIC Sargent	Full	197	18-19	Could there be a recommendation that, for palliative and end of life care, services should cover 0-18 years, to cover the gap in options on place of care for some 16-18 year olds who fall between paediatric and adult services. Is there any evidence that more 16-18 year olds die in hospital?	Thank you for your comment. We did not directly look for evidence around whether or not 16-18 year olds die more frequently in hospital. But the whole guideline promotes that children and young adults should be cared for, and die, in the place they prefer. It is standard practice with NICE guidelines to consider that children range from 0-11 years and young people from 12-18. Although there have been exceptions, extending the range to 25 years for example, young people tend to be transferred to adult care about 16 to 18 years of age. There is existing NICE clinical guidance on care of the dying adult. The guideline makes reference to the importance of transition to adult care in line with an existing Nice Guideline on this matter (rec 1.2.3).

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292	CLIC Sargent	Full	198	8-13	We feel that there is a gap in the discussion and guidance on the communication that needs to take place, where a young person becomes palliative and they already have sperm, ovarian tissue or other tissue samples stored. They need to be offered the opportunity to talk about what will happen to their stored tissue after their death.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reorganised - please see recommendations 1.2.16 to 1.2.21. Recommendation 1.2.17 has been rewritten and now includes exploring the views and feelings of the child or young person and their parents or carers on organ donation.
295	CLIC Sargent	Full	212	28-35	There is evidence in the CLIC Sargent and London South Bank University Children's Key Worker Service Evaluation Report (2015) that specialist nurses undertaking a key worker model of care, can make a better contribution where they are valued and their role is understood in the MDT. When the model works well it was found to have positive outcomes for children and families. It is recognized that this was a realistic UK wide service evaluation and not a clinical trial and therefore will score low in terms of NICE Evidence, however, this low level evidence may be considered in the absence of anything else. [redacted], the CLIC Sargent lead on this project, and our Nurse Lead Assistant Director of Services, would be happy to talk to NICE and can liaise with [redacted] to do so if you need more detail on the evidence.	Thank you for your comment. We have looked at the report and it does not match our review protocol because it is descriptive rather than comparative. We will pass this information to the NICE local practice collection team.
296	CLIC Sargent	Full	212	28-35	[redacted] has undertaken and published a number of studies relating to the GP role in palliative care. It can be demonstrated that when GP's fear of caring for a child at end of life is acknowledged and	Thank you for your comment. We have retrieved all the publications listed on the website for assessment: Neilson S.J., Gibson F., Greenfield S. (2015)

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					they are supported by specialist teams (even remote support by phone) the GP can make a valuable contribution to home care. http://www.worcester.ac.uk/discover/sue-neilson-ihs.html Neilson S.J., Gibson F., Greenfield S. (2015) Pediatric oncology palliative care: Experiences of general practitioners and bereaved parents. Paediatric Palliative Care and Medicine 5:214. DOI: 10.4172/2165-7386.1000214. Neilson S., Kai J., MacArthur C., Greenfield S.M. (2013) Using social worlds theory to explore influences on community nurses' experiences of providing out of hours paediatric palliative care. Journal of Research in Nursing, 18 (5): 443-456. Neilson S, Kai J, MacArthur C., Greenfield S.M. (2011) Caring for children dying from cancer at home: a qualitative study of the experience of primary care practitioners. Family Practice, Oct 28 (5):545-53. Neilson S., Kai J., MacArthur C., Greenfield S. (2010). "Developing and maintaining palliative care knowledge and skills: The experience of community children's nurses". Paediatric Nursing, 22(3): 31-36.	Pediatric oncology palliative care: Experiences of general practitioners and bereaved parents. Paediatric Palliative Care and Medicine 5:214. DOI: 10.4172/2165-7386.1000214. Response: This is a qualitative study aimed to examine the role of GPs in children's oncology home palliative care from the perspective of both GPs and bereaved parents. However, the questions about home based care and care round the clock were looked at as intervention reviews. Therefore this study does not meet the protocol criteria. This study has been added to the excluded studies list (Appendix H) Flanagan S., Greenfield S., Coad J., Neilson S. (2015) An Exploration of the data collection methods utilised with children, teenagers and Young people (CTYPs). BMC Research Notes 8:16 DOI 10.1186/s13104-015-1018-y. Response: this is a study on methods used in paediatric research, and not relevant to any of the questions in the guideline. Neilson S., Kai J., MacArthur C., Greenfield S.M. (2013) Using social worlds theory to explore influences on community nurses' experiences of providing out of hours paediatric palliative care. Journal of Research in Nursing, 18 (5): 443-456. Response: this is a qualitative study that looked at the experiences of paediatric nurses providing out of hours palliative care within the family home to children with cancer. As above, this study does not meet the protocol criteria for inclusion. This study has been added to the excluded studies list (Appendix H)

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298	CLIC Sargent	Full	213	42-45	The CLIC Sargent and London South Bank University Children's Key Worker Service Evaluation Report(2015), provides evidence that the key worker model of care can reduce hospital admissions and is reprieved to save hospital and family resources. A cost benefit model has not yet been conducted as we first needed to establish whether the model did	Thank you for your comment. We have retrieved the suggested document, but unfortunately it does not meet the criteria for inclusion in the review as it not a peer-reviewed publication. The Committee discussed the importance of having a named care coordinator, and this was reflected in a number of recommendations (1.2.2 and 1.5.7)

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					improve outcomes before we could analyse the cost of the most effective model for improving outcomes. At the present time we do not have funds to conduct an economic evaluation.	
299	CLIC Sargent	Full	214	29-36	CLIC Sargent supports this approach.	Thank you for your comment.
300	CLIC Sargent	Full	214	23-28	CLIC Sargent agrees with this approach and the constitution of the MDT and named co-ordinator (Lead Professional / Key Worker) will vary by disease trajectory. However, we believe there is much in the Children's Key Worker Service Evaluation that describes what good practice looks like and the model can be adapted to need.	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care has been added; please see recommendation 1.2.2.
301	CLIC Sargent	Full	214	23-28	See [redacted] research - http://www.worcester.ac.uk/discover/sue-	Thank you for your comment. We have retrieved all the publications listed on

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					neilson-ihs.html Neilson S.J., Gibson F., Greenfield S. (2015) Paediatric oncology palliative care: Experiences of general practitioners and bereaved parents. Paediatric Palliative Care and Medicine 5:214. DOI: 10.4172/2165-7386.1000214. Neilson S, Kai J, MacArthur C., Greenfield S.M. (2011) Caring for children dying from cancer at home: a qualitative study of the experience of primary care practitioners. Family Practice, Oct 28 (5):545-53.	the website for assessment: Neilson S.J., Gibson F., Greenfield S. (2015) Pediatric oncology palliative care: Experiences of general practitioners and bereaved parents. Paediatric Palliative Care and Medicine 5:214. DOI: 10.4172/2165-7386.1000214. Response: This is a qualitative study aimed to examine the role of GPs in children's oncology home palliative care from the perspective of both GPs and bereaved parents. However, the questions about home based care and care round the clock were looked at as intervention reviews. Therefore this study does not meet the protocol criteria. This study has been added to the excluded studies list (Appendix H) Flanagan S., Greenfield S., Coad J., Neilson S. (2015) An Exploration of the data collection methods utilised with children, teenagers and Young people (CTYPs). BMC Research Notes 8:16 DOI 10.1186/s13104-015-1018-y. Response: this is a study on methods used in paediatric research, and not relevant to any of the questions in the guideline. Neilson S., Kai J., MacArthur C., Greenfield S.M. (2013) Using social worlds theory to explore influences on community nurses' experiences of providing out of hours paediatric palliative care. Journal of Research in Nursing, 18 (5): 443-456. Response: this is a qualitative study that looked at the experiences of paediatric nurses providing out of hours palliative care within the family home to children with cancer. As above,

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						this study does not meet the protocol criteria for inclusion. This study has been added to the excluded studies list (Appendix H) Neilson S, Kai J, MacArthur C., Greenfield S.M. (2011) Caring for children dying from cancer at home: a qualitative study of the experience of primary care practitioners. Family Practice, Oct 28 (5):545-53. Response: this is a qualitative paper that aims to explore the experiences of primary care practitioners following their involvement in the palliative care of a child with cancer at home. This study was identified in the original search, but this study design does not meet the inclusion criteria indicated in the protocol. Neilson S., Kai J., MacArthur C., Greenfield S. (2010). “Developing and maintaining palliative care knowledge and skills: The experience of community children's nurses”. Paediatric Nursing, 22(3): 31-36. Response: the aim of this study is not relevant to the review. NICE guidelines cannot make specific recommendations in relation to training. The West Midlands Paediatric Macmillan Team (2005). “Palliative Care for the Child with Malignant Disease”. London: Quay Books, MA. Response: books cannot be included in systematic reviews
302	CLIC Sargent	Full	214	6	CLIC Sargent would like to endorse and support this Committee assumption.	Thank you for your comment.
303	CLIC Sargent	Full	214	10-18	Page 32 of the CLIC Sargent and London South Bank University Children's Key Worker	Thank you for your comment. The guideline emphasises the importance of team work and

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					Service Evaluation Report (2015) demonstrates how the key worker model of care can help families to understand roles and who is doing what in an MDT approach to care.	specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care has been added; please see recommendation 1.2.2.
309	CLIC Sargent	Full	240	14-34	NICE have looked at this from a purely health care cost analysis approach. Our "Cancer Costs" research (to be published on the 1st of September) explores how cancer affects families financially, with travel for treatment a key cost, in addition to food, clothing and hospital car parking. Consideration of the cost to families should also be a consideration in home care. In addition, and this is perhaps more of a general point, but we've included here as it	Thank you for this comment. This guideline has followed the NICE methods manual (https://www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf) which states that 'productivity costs and costs borne by people using services and carers that are not reimbursed by the NHS or social services are not usually included in NICE analyses. NICE takes the NHS and Personal Social Services (PSS) perspective rather than a societal perspective.

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					relates to finances, but NICE may want to include something on support for funeral costs. Bereaved parents who participated in our Cancer Costs research told us that funeral costs were a significant financial concern for them. For some, this may come after a long period of treatment, remission, relapse or repeated relapses, and hit them at the point that they are already deep in debt. The guidance should perhaps reference the Social Fund should bereaved parents require financial help with funeral costs.	
311	CLIC Sargent	Full	241	23-28	We would suggest you add to these recommendations another bullet point; consider financial implications to the family on place of care.	Thank you for your comment. This recommendation refers to some examples of practical issues that may need consideration. This list is not intended to be exhaustive. However, financial needs are highlighted in the 'social and practical support' section of the guideline (please see recommendation 1.2.28).
312	CLIC Sargent	Full	243	14-21	Children and young people need to know that that there is someone in their care team, with whom they have a trusting relation, who they can have any conversation with - someone who is un-shockable. They may want and need to discuss the loss of their imagined life. Teenagers sometimes want to discuss not finding true love, not having experienced sex, or concern for friends and relations after they have gone.	Thank you for your comment. We do agree that rapport and trust is very important in end of life care. We believe that our recommendations encourage this to happen because we describe the factors that need to be considered when deciding which healthcare professional should lead on communication (recommendation 1.1.14) and that continuity of care is very important (recommendation 1.1.5). This will then promote the development of trust.
317	CLIC Sargent	Full	251	33-50, (p252)1-6	CLIC Sargent would like to note that for children and young people with cancer and associated diseases, specialist cancer play specialists, specialist social workers and faith leaders, can and do provide valuable psychological support to children, young	Thank you for your comment. Recommendation 1.5.3 about the multidisciplinary team (MDT) has been amended: we have added chaplains and allied health professionals, for example physiotherapists, occupational therapists and

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					people and families using recognized interventions and techniques. MDTs should look to these professionals more often when access to psychology services is limited, and not assume that a referral to psychology or mental health services is the first step.	psychological therapists, to the multidisciplinary team.
324	CLIC Sargent	Full	256	8-29	This is a really important point. CLIC Sargent Social Care staff, along with other charitable and voluntary organisations, support families through this difficult period. NICE may want to reference the role of the voluntary/charity sector here, and perhaps provide some signposting.	Thank you for your comment. Your comment will be considered by NICE where relevant support activity is being planned.
325	CLIC Sargent	Full	265	Fig 9	We would recommend that benefits and welfare advice is more explicit in the guidance here. If parents / carers haven't already given up work or reduced hours they may need to for a while after child dies.	Thank you for this comment. Financial resources has been added to Figure 9 now.
332	CLIC Sargent	Full	301	Fig 10	This is an excellent diagram and we would recommend to NICE that this and some of their other Theme maps are published as stand-alone support tools. This would be a valuable tool to have in any local end of life care folder.	Thank you for your comment. Unfortunately it is not currently possible for NICE to create standalone tools for all of the diagrams produced.
340	CLIC Sargent	Full	336	6	As young people are living more of their lives online we strongly recommend that the NICE guideline includes something here about creating a digital legacy with the young person. It will be important for them to think about and decide how they want to be remembered digitally. For example, Facebook already has a function where someone can assign a Legacy Contact where someone can choose another person	Thank you for your comment. We have now made reference to plans for media content as a possible help to parents, see recommendation 1.3.8.

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					to look after their account. We would like to see other social media platforms and digital companies look into taking this approach as well. More information on Facebook's Legacy Contact can be found here: https://www.facebook.com/help/1568013990080948	
329	College of Health Care Chaplains	Full	291	33	We are concerned that religious, spiritual and cultural needs will continue to go unrecognised if professionals are uncomfortable with discussing these issues and support increased inter-disciplinary work and training to overcome this.	Thank you for your comment. The Committee understands your concern. This guideline includes a specific section on spiritual and religious support as this area was identified as important to patients. The Committee placed emphasis on including a chaplain as part of the multi-disciplinary team (see new recommendation 1.5.3). It is not part of the remit of this guideline to make specific recommendations about training.
336	College of Health Care Chaplains	Full	333	26	Question 2-cost implications- with continuity of care and recording of spiritual care assessments and implementation there is likely to be a need for increased staff time	Thank you for this comment. We acknowledge that discussions involve staff time but would maintain that the recommendations covered in this section of the guideline would not have a significant cost impact for the NHS
338	College of Health Care Chaplains	Full	334	8	We are concerned that re-exploration of child's; parents' and carers' views , which is very significant , will be challenging to implement without increased chaplaincy staffing (c.f. NHS Chaplaincy Guidance 2015) p21-22; sections 11 & 12	Thank you for your comment. Costs would only increase if there is a large difference between the recommendation and current practice. We believe that over the course of a life-limiting condition chaplains currently would not only speak to children or young people and their parents or carers once, but several times (this is what has been recommended). This means that there would not be a significant change in current practice.
339	College of Health Care Chaplains	Full	335	15	Question 3-overcome challenges- good practice examples, for access to multi-faith	Thank you for your comment. Costs would only increase if there is a large difference between

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					chaplaincies, with referral processes and client load may be sought from the Paediatric Chaplaincy Network (NHS Chaplaincy Guidance p.22)	the recommendation and current practice. We believe that over the course of a life-limiting condition chaplains currently would not only speak to children or young people and their parents or carers once, but several times (this is what has been recommended). This means that there would not be a significant change in current practice.
341	College of Health Care Chaplains	Full	336	10	Question 3-overcome challenges- relevance to NHS re e.g. Muslim concerns with e.g. radical curative treatment; treatment withdrawal - Siddiq Diwan (Central Manchester University Hospitals NHS Foundation Trust) : College of Health Care Chaplains (CHCC) National Faiths co-ordinator	Thank you for your comment. It is highlighted throughout that the care needs to be individualised and the guideline recommends asking if families want to discuss their beliefs and values (for example religious, spiritual or cultural) that are important to them, and how these should influence their care (please see recommendation 1.2.29). This is therefore an inclusive recommendation applicable to any particular type of belief.
342	College of Health Care Chaplains	Full	336	10	Question 1- Research question very helpful; may be good to refer to Paediatric Chaplaincy Network for a larger scale study support by Trusts' clinical research departments as research time a challenge in smaller chaplaincy teams	Thank you for your comment. We hope the publication of this guideline will promote this research and will get such trusts involved.
461	College of Occupational Therapists	Short	4	10	**General principles** The draft guideline is very clear and helpful in its recommendations for medical and nursing needs of a child who requires end of life care. The College of Occupational Therapists is, however, concerned that the child and family's overall wellbeing and support for	Thank you for your comment. All of the suggested references have been checked to see if they met the inclusion criteria. Heath JA, Clarke NE, Donath SM, McCarthy M, Anderson VA, Wolfe J. Symptoms and suffering at the end of life in children with cancer: an Australian perspective. Medical Journal of Australia. 2010 Jan 18;192(2):71. Response: this study was identified in our search, but was excluded as it was clear from

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					involvement in daily occupations is under-represented. In a study by Heath et al (2010) titled *Symptoms and suffering at the end of life in children with cancer: an Australian perspective,* they reported: *"During the last month of life, 42% of children were reported to have been more than a little sad, 38% to have had little or no fun, and 21% to have often been afraid." (p. 73)* Similar results were seen in a study in the USA by Wolfe et al (2000): *'As would be expected, during the last month of life the majority of children had little or no fun (53 percent), were more than a little sad (61 percent), and were not calm and peaceful most of the time (63 percent), according to their parents' (p331).* A child and family's quality of life and engagement in activities (and having fun)	the abstract it did not meet the inclusion criteria listed in the protocol, as it is a qualitative study. Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, Emanuel EJ, Weeks JC. Symptoms and suffering at the end of life in children with cancer. New England Journal of Medicine. 2000 Feb 3;342(5):326-33. Response: this study was also identified in the search and retrieved full text. It was excluded because it was a survey-based study where parents report on common symptoms and related suffering in the last month of life (see Appendix H). The third reference [Children and young people with cancer: guidance for Occupational Therapists' (2010)] cannot be considered for inclusion because it is not a peer-reviewed publication. We agree that children and young people with life-limiting conditions and their parents, or carers, should have the best possible quality of life, and this is reflected in the scope of this guideline. Quality of life was included as an outcome in all reviews conducted as part of this guideline. Quality of life of the child or young person was the basis for all the recommendations, and therefore was not specifically stated as an overarching recommendation. In addition, explicit reference was made to include the children or young person's wishes in the advance care plan (see recommendation

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					during such a distressing time should be given equal priority to medical and nursing care. This is also supported in the 'Children and young people with cancer: guidance for Occupational Therapists' (2010). Thus, an additional general principle is suggested: Recognise that children and young people with life-limiting conditions and their parents or carers should have the best possible quality of life throughout end of life care. This means that they should be enabled to engage in meaningful and desired activities, such as self-care, being productive, socialising and play / leisure. To reinforce this principle, the other comments made within this response also relate to this theme.	1.2.5).
554	College of Occupational Therapists	Short	9	20	**Advance Care Planning** - **agreed treatment plans and objectives**	Thank you for your comment. We specify in recommendation 1.2.5 that the Advance Care Plan should include 'an outline of the child or young person's life ambitions and wishes' which would include activities that they desire

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					It is suggested that this be expanded to include: 'agreed treatment plans and objectives, considering the child and family's quality of life and engagement in desired and meaningful activities.'	and are meaningful for them.
602	College of Occupational Therapists	Short	13	23	**Social and practical support** It is suggested that an additional point be made in this section: 'The provision of equipment, strategies, advice and assistance to support engagement and quality of life'	Thank you for your comment. The points you raise are covered in another recommendation (1.5.9) which includes services that should provide for example 'advice from a consultant in paediatric palliative care at any time' and 'practical support and equipment'. We believe that this would have a direct positive impact on engagement and quality of life.
663	College of Occupational Therapists	Short	18	17	**Managing pain** It has been the clinical experience of the occupational therapy practitioners who contributed to this response that additional influences on pain management include:	Thank you for your comment. We have only given a few examples. The list therefore is not exhaustive. We covered possible causative and contributing factors in recommendations 1.3.21 and 1.2.22 which include emotional, environmental, social and physical.

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					fatigue, positioning and difficulty changing positions and associated breathing and feeding difficulties, muscle spasms, pressure areas and engagement difficulties.	
676	College of Occupational Therapists	Short	19	25	**Think about non-pharmacological interventions for pain management, such as:** **changes that may help them to relax, for example:** It has been the clinical experience of the occupational therapy practitioners who contributed to this response that environmental adjustments relate to more than just the reduction of noise. Visual changes (e.g. ’fiberoptic light, light projections), tactile changes (e.g. sensory toys to hold or massage), movement changes (e.g. positioning of the body to provide support and comfort, alleviate pressure areas and maximise respiration,	Thank you for your comment. We agree that the reduction of noise is only one example. However, we could not be more specific since we did not uncover any specific evidence for these possible interventions.

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					communication and engagement) have also been used to good effect. Additional techniques which have clinically been found to be useful to support relaxation include breathing techniques and guided imagery.	
691	College of Occupational Therapists	Short	24	1	**Managing seizures** It has been the clinical experience of the occupational therapy practitioners who contributed to this response that a further consideration is the posture and positioning of the child which is a further contributing factor to managing seizures.	Thank you for your comment. This is an illustrative list of examples rather all possible triggers or contributing factors.
779	College of Occupational Therapists	Short	33	15	**Home care** It is suggested that an additional point be made in this section: 'The provision of equipment, strategies, advice and assistance to ensure daily activities continue to be managed and the child remains	Thank you for your comment. We have outlined this in the social and practical support section - see recommendation 1.2.28 which specifies support needs such as equipment and advice.

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					comfortable and able to engage in suitable activities.’	
400	Department of Health	General	General	General	Thank you for the opportunity to comment on the draft 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.
422	East Anglia’s Children’s Hospices (EACH)	Short	General	General	We are pleased with this guideline and are highly supportive of its recommendations	Thank you for your comment.
423	East Anglia’s Children’s Hospices (EACH)	Short	General	General	We feel there is a lack of clarity around definitions of general and specialist levels of children’s palliative care and about end of life care	Thank you for your comment. We have added a further recommendation about the specialist paediatric palliative care team and who should be included at a minimum in the team (please see recommendation 1.5.4).
499	East Anglia’s Children’s Hospices (EACH)	Short	6	4	The concept of advance care planning may be challenging to implement because a clear definition and explanation about when this should be initiated, how this should be initiated and by whom, is required. Although there is discussion about this in the full guideline on p134 – the short version does not seem to give more detail about advance care planning until section 1.1.17. We suggest there should be cross referencing to relevant sections or a definition included in key terms p 34. In our experience advance care planning often occurs from diagnosis onwards and as the title of the guideline is End of Life Care this could therefore be	Thank you for your comment. We recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 (explaining the need for parallel plans) to the ‘General principles’ section. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section. We did not want to be too prescriptive about when this should be developed since this may vary according to individual circumstances. The 'short version' follows a set format and does not refer to sections in the 'full guideline' which has a different structure. The title of the guideline included 'planning and management' and therefore captures a longer time period

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					misleading and cause confusion.	than the final hours and days.
534	East Anglia's Children's Hospices (EACH)	Short	8	5	We feel that advance care planning would be better understood if this section came before sections 1.1.9 and 1.2.4	Thank you for your comment. We believe that this recommendation related to the type of information you may need and when. We therefore cross-referenced other sections when information provision is particularly important. We would therefore like this order to remain as it is.
580	East Anglia's Children's Hospices (EACH)	Short	11	23	We feel this statement could be used to help describe the advance care plan in key terms section to avoid confusion with do not resuscitation plans.	Thank you for your comment. We have included a recommendation that states that the 'Advance Care Plan should not be confused with the 'do-not-attempt-resuscitation' order' (recommendation 1.2.14).
618	East Anglia's Children's Hospices (EACH)	Short	14	23	We are concerned about the specific reference to chaplaincy and wonder if this could be replaced with family own or recognised faith advisor?	Thank you for your comment. The recommendation reads '….and if necessary involve the chaplaincy service or another facilitator.' Chaplaincy services represents lots of different faiths or not faith at all in the NHS and the wording leaves it open to have a facilitator of their own choosing (which could be a community member or another person of trust). Chaplain has now been added to the glossary.
633	East Anglia's Children's Hospices (EACH)	Short	15	24	Could 'taking as a whole family' be added to this recommendation to reflect a holistic / systemic approach?	Thank you for your comment. The text at the beginning of this document states: In this guideline: • 'Parents or carers' refers to the people with parental responsibility for a child or young person. If the child or young person or their parents or carers (as appropriate) wish, other family members (for example siblings or grandparents) or people important to them (for example boyfriends or girlfriends) should also be given information, and be involved in discussions about care. Therefore this applies also to the recommendation you are referring to.

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639	East Anglia's Children's Hospices (EACH)	Short	16	20	Our organisation recognises this to be a very important recommendation	Thank you for your comment.
648	East Anglia's Children's Hospices (EACH)	Short	17	13	We feel that a definition of 'rapid' in this recommendation would help its implementation perhaps in key terms p34. Implementation of this recommendation may be a challenge as it assumes that rapid transfer services are universally in place.	Thank you for your comment. We describe rapid as a situation where 'the child or young person may die soon and they are not in their preferred place of death' (see recommendation 1.3.15).
650	East Anglia's Children's Hospices (EACH)	Short	17	20	We are concerned that not all the practicalities associated with rapid transfer are documented in this recommendation. Other key pieces of information which could be recorded in the advance care plan are: for example, need to ensure that a discussion has taken place of what to do if death occurs during transportation. Do the family want to continue to destination or return to place of discharge? Who will travel with child?	Thank you for your comment. We describe rapid as a situation where 'the child or young person may die soon and they are not in their preferred place of death' (see recommendation 1.3.15) which could therefore happen in transition from one place to another. We have not gone into this much detail about where to go and with whom if death occurs during transfer. This would be down to local policies.
665	East Anglia's Children's Hospices (EACH)	Short	18	18	In our experience specific pain tools are not often well used – it would help this recommendation to be implemented if it advised to use a relevant pain tool when assessing and managing pain	Thank you for your comment. The use of specific pain tools was outside of the scope for this Guideline.
687	East Anglia's Children's Hospices (EACH)	Short	22	2	We feel it would be helpful to define 'guidance from a specialist' in this context.	Thank you for your comment. In this particular context we could not define the 'specialist' because this would depend on the child's condition and other causative factors.
692	East Anglia's Children's Hospices (EACH)	Short	24	21	As above define 'seek specialist advice' in this context	Thank you for your comment. In this particular context we could not define the 'specialist' because this would depend on the child's condition and other causative factors.
694	East Anglia's Children's Hospices (EACH)	Short	25	25	We are concerned that the advance care plan in the context of managing distressing symptoms could be misinterpreted. We would use a separate symptom management plan to outline care and anticipatory planning for	Thank you for your comment. The Committee agreed that 'a treatment plan' should be recorded in the Advance Care Plan. We believe that this should cover the circumstance and decisions specified in the symptom

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					distressing symptoms as described between pages 18 and 27 in the short version.	management sections.
695	East Anglia's Children's Hospices (EACH)	Short	25	31	Would including an antibiotic in the list of appropriate interventions be useful as sepsis is mentioned in line 23?	Thank you for your comment. The list of possible interventions chosen as examples by the Committee are meant for purposes of illustration. The decision to use antibiotic treatment in a child approaching the end of life would depend very much on individual circumstances.
702	East Anglia's Children's Hospices (EACH)	Short	26	12	We feel it would help with implementation of this recommendation if there was definition or recognition of the normal process of dying'	Thank you for your comment. There are many uncertainties of what would be the 'normal process' depending on the individual condition and symptoms of the child or young person. The complexities of recognising some of these 'normal' processes is highlighted in the section 'Recognising that a child or young person is likely to die within hours or days. We therefore think that it is impossible to provide this definition.
705	East Anglia's Children's Hospices (EACH)	Short	27	6	We support this recommendation but would describe this concept as 'feed or eating for comfort'.	Thank you for your comment. Even though the concept could be described as 'feed or eating for comfort' the Committee agreed to leave the wording as it is more easily understood.
710	East Anglia's Children's Hospices (EACH)	Short	28	27	We feel somewhat sad that showing empathy and compassion has to be recommended in a guideline	Thank you for your comment. In our summary of evidence we have identified that communication at the end of life is not always as effective as it could be. We therefore agreed that there was a need to state this to promote better clinical practice in this area.
716	East Anglia's Children's Hospices (EACH)	Short	29	17	We feel this recommendation may be easier to implement if 'in consultation with parents' was added	Thank you for your comment. We intentionally wrote this for situations where parents may not be available to be consulted with.
725	East Anglia's Children's Hospices (EACH)	Short	30	25	We are concerned that this and the following recommendation do not appear to promote resilience, self care in bereavement and promotes the need for psychological intervention. We are concerned that this may	Thank you for your comment. The Committee recommend that sometimes expert psychological interventions may be needed, as stated in recommendation 1.2.23. With regard to how this is implemented, your comments will

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					be difficult to implement as implies the need for specialist level psychological service. We suggest that a targeted or even universal level of emotional support may be appropriate for most bereaved family members.	be considered by NICE where relevant implementation support activity is being planned.
763	East Anglia's Children's Hospices (EACH)	Short	32	19, 25	We wondered why hospice professionals are described separately from other health care professionals in relation to the MDT. We are concerned that this recommendation does not describe the important relationship between statutory and voluntary services.	Thank you for your comment. This recommendation on the multidisciplinary team has been amended and hospice professionals are now included in the first bullet point we have also added 'Allied Healthcare professionals (for example physiotherapists, occupational therapists, speech and language therapists, and psychological therapists)'.
770	East Anglia's Children's Hospices (EACH)	Short	33	5	We think this recommendation should be stronger and 'identify a named individual' to act as first point of contact	Thank you for your comment. A new recommendation about every child and young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care has been added; please see recommendation 1.2.2.
775	East Anglia's Children's Hospices (EACH)	Short	33	8	We feel this recommendation could be easier to implement if there was detail given in how to complete a rapid transfer. Our organisation has experience of this and we would be willing to share our thoughts and experiences.	Thank you for your response. NICE encourage stakeholders to submit examples of good practice that demonstrate implementation of NICE recommendations. We will pass this information to our local practice collection team. More information on local practice can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/local-practice-case-studies
778	East Anglia's Children's Hospices (EACH)	Short	33	15	We are highly supportive of this recommendation	Thank you for your comment.
796	East Anglia's Children's Hospices (EACH)	Short	34	23-24	We are confused about the definition of end of life care which we feel describes a definition of palliative care	Thank you for your comment. The 'Terms used in this guideline' section has been updated: the End of Life Care definition has been reworded and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been

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						added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days. The terminology used was discussed and adopted during the scoping stage for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.
807	East Anglia's Children's Hospices (EACH)	Short	35	2	We are concerned that this definition may cause confusion in particular regarding death in the childhood period.	Thank you for your comment. The 'Terms used in this guideline' section of the short guideline has been updated: the End of Life Care definition has been reworded and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days. The terminology used was discussed and

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						adopted during the scoping stage for this guideline. The scope for this guideline was consulted on and this term was accepted by stakeholders. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.
424	East Midland's Children and Young People's Palliative Care Network	Short	General	General	The guideline frequently uses the term "Advance Care Plan". This is a term used in some children's palliative care networks but in our network we have found it to be more acceptable to children and families to take a modular approach to end of life care planning [refs 1-9]. Initially, the child's consultant paediatrician discusses and agrees a written and family held "**Emergency Care Plan**" with the child or young person and family as soon as any life threatening event can be anticipated. This written emergency care plan includes the demographic information about the child and family and the background medical information regarding the life limiting or life threatening condition, then stipulates the symptoms and signs that would signify a deterioration and the appropriate interventions and best care to undertake in an emergency situation, particularly in the case of the child stopping breathing.	Thank you for your comment. The Committee wanted to promote (1) the concept of Parallel Planning (which would take account of the uncertainties - including possible emergencies) - see recommendation 1.1.8 in 'General Principles'; and (2) that every child or young person should have an Advance Care Plan (1.2.5) which includes 'life ambitions and wishes' and a record of discussions (if they have taken place) on 'management of life-threatening events, including plans for resuscitation or life support'. The Committee preferred to have one document that could be updated rather than having many different documents at different phases during the course of the life-limiting condition. However, we have also highlighted elsewhere that this is not synonymous with a 'do-not-attempt-resuscitation' order (recommendation 1.2.14). Please see our response to comment 426 about the reasons why the references you

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					This includes the resuscitation plan (i.e. called a “Personal Resuscitation Plan” in some of our communications, but the “Personal” is not really needed, it was to distinguish it from the default resuscitation plan that would otherwise be followed). It also includes the plan for a gradual deterioration in medical condition. The plan details who to call in an emergency with contact details and where to transfer the child to i.e. whether the best and chosen place of care is home, hospital or hospice. The legal status of this document is a medical care plan and it must be signed by the child s consultant and must be agreed with those with parental responsibility. A copy stays with the child at all times. The plan is reviewed as the child's medical condition changes but has no expiry date. It includes the distribution list on the back page and has a system for version control. This **Emergency Care Plan** is much easier for the consultant to introduce to a child and family than a document called “Advance Care Plan” which has sections to fill in about death, care of the body and other post death wishes. We have a separate **Wishes and Choices** document which details the child, or young person and family wishes regarding place of death, care of the body, funeral arrangements. This can be developed after the introduction of the emergency care plan, once the family are ready to contemplate and	provided were not included in the guideline. The Committee agreed that the term ‘Advance Care Plan’ was more commonly used and understood rather than ‘Emergency care plan’ or ‘wishes and choices’.

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					talk about the death of their child. Some families will have an emergency care plan for several years before they are able or willing to look at choices regarding death. The Wishes and Choices document is developed during several discussions often with the key worker, lead nurse or the consultant over a prolonged period of time. The legal status of this is a wish list, not a medical care plan. This document remains with the family and the medical team and does not need to be widely shared. This approach was developed locally with input from hospital and community paediatricians, hospital and community nurses, the East Midlands Ambulance Service, and families of children with Life Threatening Conditions, and parents of children who have died. It has worked well over the last 10 years [refs 1-9]. The plan of management for anticipated symptoms at the end of life is written and signed by the child's consultant when it is recognised that death is imminent and the child is in the last days of life. In the guidance document the words 'Advance Care Plan' should be replaced with simply 'Care Plan'.	
425	**East Midland's Children and Young People's Palliative Care Network**	**Short**	**General**	**General**	**Which areas will have biggest impact on practice?** a) Paediatricians need to be able to identify all children with life limiting and life threatening conditions earlier, and have	Thank you for your comment. With regard to the points you raised: (a) Diagnosis (early or otherwise) of the life-limiting condition is outside the scope of this guideline. However, planning is one of the

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					earlier discussions with families about the child's probable prognosis even when there is uncertainty. There needs to be parallel planning for the child living or dying. This can be improved by paediatricians having more training, more time in their job plans, and the support of specialist paediatric palliative care consultants in a local network. Caring and care planning for children with life limiting or life threatening conditions requires more consultant paediatricians to have the knowledge, experience and time in their job plans to medically manage the children but also to have the difficult discussions and care planning meetings. b) Home visits by a health professional with expertise in children's palliative care for symptom management. This needs to be provided by a consultant led team with some visits by nurses but doctor back up. GPs generally lack knowledge in this area, confidence, and experience. The availability of paediatric community nursing teams, able to provide end of life care 24/7 is essential, but will require additional funding. Specialist medical advice should be available at any time it is needed. The best way to provide this is not clear and it is not currently funded.	central themes of the guideline and we believe that this will promote earlier initiation of these plans. We have also added a recommendation on parallel planning into our 'General Principles' section (recommendation 1.1.8). (b) We have added a recommendation on the composition of the specialist paediatric palliative care team (recommendation 1.5.4) and these may be involved in home visits if necessary (recommendation 1.5.9). Thank you for your response. Your comments will be considered by NICE where relevant support activity is being planned.
426	East Midland's Children and Young People's Palliative Care Network	Short	General	General	**References** 1. Neenan F, Wolff A, Whitehouse WP. Development of an audit tool for children's palliative care. Archives of Disease in	Thank you for your comment. We have retrieved the suggested references for assessment.

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					Childhood 2005: 90; suppl 11; A80. 2. Wolff A. 'To Resuscitate or Not'. Requested article for newsletter of British Society of Paediatric Palliative Medicine October 2005. 3. Wolff A, Hollingsworth S, Whitehouse WP. Clinical usefulness of personal resuscitation plans in children with neurodisability and life-limiting conditions. Archives of Disease in Childhood 2007; 92(suppl 1): A56-A62. 4. Wolff A. Whitehouse W. The death of DNRs: personal resuscitation plans. British Medical Journal 2009; 338: 1227. 5. Wolff A, Browne J. Minimising crisis points in paediatric palliative care: the ACT pathways in action. In Pfund R and Fowler-Kerry S (eds.) Perspectives on palliative care for children and young people: a global discourse. Radcliffe Publishing, Oxford. 2010. 6. Wolff A, Browne J. 2011 Organizing end of life care: parallel planning. Paediatrics and Child Health 2011; 21: 378-84. 7. Wolff A, Browne J, Whitehouse WP. Personal resuscitation plans and end of life planning for children with disability and life-limiting/life threatening conditions. Archives of Disease in Childhood Education & Practice 2011; 96: 42-8. 8. Wolff A, Anne Kelly A. Life-shortening	1. Neenan F, Wolff A, Whitehouse WP. Development of an audit tool for children's palliative care. Archives of Disease in Childhood 2005: 90; suppl 11; A80. Response: this is an audit tool, and therefore not relevant to the aim of the review. 2. Wolff A. 'To Resuscitate or Not'. Response: this reference could not be found. 3. Wolff A, Hollingsworth S, Whitehouse WP. Clinical usefulness of personal resuscitation plans in children with neurodisability and life-limiting conditions. Archives of Disease in Childhood 2007; 92(suppl 1): A56-A62. Response: conference abstract. 4. Wolff A. Whitehouse W. The death of DNRs: personal resuscitation plans. British Medical Journal 2009; 338: 1227. Response: this reference could not be found in the BMJ. We retrieved the following reference instead: G202 PERSONAL RESUSCITATION PLANS: THE DEATH OF DNARS?. Wolff, A. 1; Browne, J. 1; Whitehouse, W. P. 2 Archives of Disease in Childhood. 90 Supplement II:A78, April 2005. [Abstracts of the Royal College of Paediatrics and Child Health; 9th Spring Meeting; University of York, 18-21 April 2005: Ethics and law and palliative medicine joint session]. Response: However this is a conference abstract and could not be included in the review. The study has been added to the excluded studies list (Appendix H). 5. Wolff A, Browne J. Minimising crisis points

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					conditions and planning for the end of life. In Seal, Robinson, Kelly, Williams (eds.) Children with Neurodevelopmental Disabilities: the essential guide to assessment and management. Mac Keith Press, London. 2013. 9. Horridge K, Wolff A. Palliative care for disabled children and young people. Paediatrics and Child Health 2014; 24; 343-350.	in paediatric palliative care: the ACT pathways in action. In Pfund R and Fowler-Kerry S (eds.) Perspectives on palliative care for children and young people: a global discourse. Radcliffe Publishing, Oxford. 2010. Response: books cannot be included in NICE guidelines. 6. Wolff A, Browne J. 2011 Organizing end of life care: parallel planning. Paediatrics and Child Health 2011; 21: 378-84. Response: the issue of parallel planning was considered very important by the Committee members, but this is a discussion paper and does not meet the criteria for inclusion listed in the protocol. The study has been added to the excluded studies list (Appendix H). 7. Wolff A, Browne J, Whitehouse WP. Personal resuscitation plans and end of life planning for children with disability and life-limiting/life threatening conditions. Archives of Disease in Childhood Education & Practice 2011; 96: 42-8. Response: this paper was identified in the search, but it was disregarded as it was clear from the abstract that it was a discussion paper and did not meet the criteria for inclusion listed in the protocol. 8. Wolff A, Anne Kelly A. Life-shortening conditions and planning for the end of life. In Seal, Robinson, Kelly, Williams (eds.) Children with Neurodevelopmental Disabilities: the essential guide to assessment and management. Mac Keith Press, London. 2013. Response: books cannot be included in NICE

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						guidelines. 9. Horridge K, Wolff A. Palliative care for disabled children and young people. Paediatrics and Child Health 2014; 24; 343-350. Response: this is a discussion/ guidance paper and does not meet the criteria for inclusion listed in the protocol. The study has been added to the excluded studies list (Appendix H)
578	East Midland's Children and Young People's Palliative Care Network	Short	11	7	Update the care plan when needed, for example if: the child or young person s condition changes.	Thank you for your comment. The focus of this recommendation is to highlight some of the situations where further discussion may be required for illustrative purposes. Therefore it is meant to be examples rather than a list of all possible situations.
587	East Midland's Children and Young People's Palliative Care Network	Short	12	11	"and as part of advance care planning" should be deleted.	Thank you for your comment. We have now made a change to recommendation (1.2.5 the content of the Advance Care Plan) which states 'discussions that may have taken place' when talking about organ donation (making this an optional rather component). We have retained 'as part of Advance Care Planning' as it was not clear what the distribution list is for. We have also reworded recommendation 1.2.20.
673	East Midland's Children and Young People's Palliative Care Network	Short	19	7	"Gastrointestinal pain (which can be caused by gastro oesophageal reflux or constipation, or associated with diarrhoea)."	Thank you for your comment. We have now amended all of 'which can be associated with' to for example' to indicate that this is not the only possible cause.
693	East Midland's Children and Young People's Palliative Care Network	Short	25	4	Ensure parents or carers who have been provided with rescue anticonvulsant medication (such as Buccal midazolam) have had training in its use and have a written emergency care plan detailing when to give it and when to call an ambulance and when	Thank you for your comment. We have mentioned that parents need information on what do if a seizure happens at home (please see recommendation 1.3.42) and that parents or carers know how and when to use anticonvulsive therapy (recommendation

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					transfer to hospital is needed.	1.3.43). The Committee agreed that this would include information on when to call an ambulance.
708	East Midland's Children and Young People's Palliative Care Network	Short	28	6	"Intractable seizures that keep occurring even with optimal management". Should be changed to "new onset of seizures or increased frequency or severity of seizures".	Thank you for your comment. This wording was taken from the evidence and the Committee agreed that this would be clear. We feel that 'new onset of seizures or increased frequency or severity of seizures' is a slightly different concept.
752	East Midland's Children and Young People's Palliative Care Network	Short	32	4	Change to: "Update relevant documents, electronic notes systems and databases after the death."	Thank you for your comment. The Committee concluded that an electronic notes system can be classified as a type of database. The recommendation was therefore left intentionally broad, because it may be difficult to list each possible system that requires updating.
768	East Midland's Children and Young People's Palliative Care Network	Short	33	3	"Involve children and young people and their parents or carers in multidisciplinary Team Around the Child meetings whenever possible."	Thank you for your comment. We have stressed the importance of children and young people's involvement as well as their parents' involvement in decision making throughout this guideline (see for example in the 'General Principles' section recommendations 1.1.1 and 1.1.2). The particular recommendation that your comment is referring to was intentionally written in this way because there are circumstances where it may not be appropriate or when it may be distressing for the child or parent to be involved. We would therefore like to keep this recommendation as it is.
771	East Midland's Children and Young People's Palliative Care Network	Short	33	5	"All children and young people with a life limiting or life threatening condition and their parents or carers should have a named key worker to provide proactive support, act as first point of contact and facilitate coordinated care."	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs,

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						and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) uses the term 'named individual' instead of the term 'key worker', because the latter may not be appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. The Committee chose to recommend that thought should be given to having a named individual as the 'first point of contact' and who might coordinate care. Recommendation 1.2.2 has also been added, and is about every child or young person with a life-limiting condition having a named medical practitioner to lead on and coordinate their care.
35	ellenor	Full	General		The age range stated is 0-18…how does this fit with other initiatives to extend age range for some young people's services?	Thank you for your comment. It is standard practice with NICE guidelines to consider that children range from 0-11 years and young people from 12-18. Although there have been exceptions, extending the range to 25 years for example, young people tend to be transferred to adult care about 16 to 18 years of age. There is existing NICE clinical guidance on care of the dying adult. The guideline makes reference to the importance of transition to adult care where this arises (rec 1.2.3) and cross-references to an existing Nice Guideline on this matter.
36	ellenor	Full	General		We are concerned about the challenges of delivering 24hr access to end of life support widely due to current resource/ staffing issues nationally and gaps in commissioning	Thank you for this comment. We do appreciate that providing 24 hour access to end of life support given current resource/capacity constraints will be challenging to implement,

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					and the impact of a lack of paediatric consultants .	particularly in the short term. However, NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness, and the health economic analysis undertaken for this guideline suggested that such 24 hour provision could be warranted in these terms. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24h access to end of life support was available in some areas. The remit of this guideline does not extend into providing details on how services should be commissioned. However, NICE do produce a number of tools to support implementation including resource impact reports and templates and your comments will be considered by NICE where relevant support activity is being planned. The Guideline recommendations are consistent with recent NHS England advice (e.g. 2013/14 NHS Standard contract for paediatric medicine: Palliative Care and NHS England Specialist Level Palliative Care: Information for commissioners [April 2016]). NHS England recognise that not all palliative care services will be able to immediately meet the requirements of the service specification for specialist level palliative care for a variety of reasons (e.g. historical patterns of working, workforce capacity and the ability to recruit and retain specialist staff [which may be more difficult in some parts of the country], capacity

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						to provide education and training for staff and others, as well as the mixed funding streams they reflect) but they do state that the sample service specification is an indicator of a 'direction of travel' for such service providers, supported by their commissioners, to which they should be working.
37	ellenor	Full	General		The document as a whole is comprehensive and provides great clarity, it is easy to read and understand.	Thank you for your comment.
90	ellenor	Full	General	8.1	Could there be more emphasis on psychosocial issues?Although these are mentioned it remains relatively medical focussed.	Thank you for your comment. We disagree that the guideline is 'relatively medical focused'. We have large sections on planning, communication and information provision
456	ellenor	Short	General	1.1.9	Who should sign off the advance care plan?	Thank you for your comment. The Committee did not want to specify a particular person to 'sign off' this plan because it would depend on many factors, e.g. the time, the course of the condition, setting of care, type of condition.
92	Faculty of Intensive Care Medicine	Full	1.3.26		This document may need to be more explicit regarding ventilation at the end of life.	Thank you for your comment. We did address this aspect in relation to the care of those likely to die within hours or days. For example in recommendation 1.3.63 there is reference to the importance of discussing whether the treatment plan (which might relate to ventilation) should be changed, and in recommendation 1.3.68 whether any available invasive treatments might be in their best interest or any interventions they are currently receiving may no longer be in their best interest. Recommendation 1.3.68 also discusses withdrawal of a treatment (which may include ventilation). Finally there is reference to ventilation in terms of its potential impact on preferred place of care or death

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						(please see recommendation 1.3.12, bullet 2) and about the use of a rapid transfer service 'to allow the child or young person to be in their preferred place of death when withdrawing life-sustaining treatments such as ventilation.
93	Faculty of Intensive Care Medicine	Full	1.5.4		The MDT adjustments should also reflect the situation as mentioned above.	Thank you for your comment. We have made changes to the multidisciplinary team recommendations: recommendation 1.5.3 about the multidisciplinary team (MDT) has been amended - we have added ‘Allied Healthcare professionals’ and ‘those with expertise in managing the child’s underlying life-limiting condition’ to the MDT; and recommendation 1.5.4 has been added - this is about the ‘specialist paediatric palliative care team’ and who should be involved in it. We hope that this covers your comment.
96	Faculty of Intensive Care Medicine	Full	5	6	Many places will not view people post GCSEs as children and these young people will be admitted to adult wards and may, if presenting to an ED, not be referred to paediatrics at all	Thank you for your comment. It is standard practice with NICE guidelines to consider that children range from 0-11 years and young people from 12-18. Although there have been exceptions, extending the range to 25 years for example, young people tend to be transferred to adult care about 16 to 18 years of age. There is existing NICE clinical guidance on care of the dying adult. The guideline makes reference to the importance of transition to adult care where this arises (rec 1.2.3) and cross-references to an existing Nice Guideline on this matter.
103	Faculty of Intensive Care Medicine	Full	6.1.8.5	13	It may be a challenge to keep the Advanced Care Plan contemporaneous and ensure that it is regularly updated and reviewed	Thank you for your comment. This may be a challenge, but is nonetheless an important part of good clinical practice that the Committee wanted to highlight.
38	Forgetmenot Childrens Hospice	Full	General	General	This piece of work has been well received within this organisation however this service particularly offers specialist support to the	Thank you for your comment. After discussion with the Guideline Committee, we have added in the percentage of neonatal death in the

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					perinatal and neonatal period of end of life planning and management – as national stats indicate it is the biggest area of childhood death and those families requiring active support. The current draft does not appear to address the needs of this unique group of babies as such – and almost supports the idea that a separate or more clearly defined section around perinatal and neonatal EOL care management is required.	introduction to the 'full guideline' and to the context section of the 'short guideline', in order to emphasise the importance of this group. We have also changed the preamble to the guideline and removed 'where appropriate' to clarify that children and young people include neonates and infants. We acknowledge that evidence is scarce in this area and have therefore written another research recommendation for this topic which we have prioritised as one of our 5 key research recommendations in the guideline. We have changed recommendation 1.2.6 (Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition) to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.
39	Forgetmenot Childrens Hospice	Full	General	General	Little evidence about the implications of the need for catheterisation at EOL and what cost implications and lack of training there is generally when the need arises	Thank you for your comment. The use of catheterisation was not a specific topic in the scope of this guideline.
359	Forgetmenot Childrens Hospice	Full	368	9.4.5.1	It is of interest little discussion re use of oxygen at EOL and what benefit or other this may have on the child or infant. – feel requires further discussion and clarification – in which situations are feasible and others where can prolong suffering..	Thank you for your comment. We have only provided these as examples of what may be provided. This does not preclude healthcare professionals using their clinical judgement to assess whether or not this is in the child or young person's best interest. We have also added 'supplementation' to 'oxygen' in recommendation 1.3.44.
360	Forgetmenot Childrens Hospice	Full	378	19	Non invasive ventilation – it states defers to the specialist however our experience is that professionals working in acute care may	Thank you for your comment. We acknowledge that there are other ventilation methods in specific circumstances. The

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					prolong interventions and not always for the benefit to the child or baby – but more in meeting parental demands. Further section on complex tracheostomy NIV children who are dying would be very helpful to offer intensivists evidence of step down and EOL care and what that looks like.	Guideline Committee did not feel that there was sufficient existing evidence to make specific recommendations on the various transmucosal or transdermal options.
427	Genetic Alliance UK	Short	General	General	We are concerned that the guideline does not include the substantial population of infants, children and young people who need access to end of life care but who do not have a formal diagnosis for their condition. The children in families supported by SWAN UK have an undiagnosed genetic condition (a syndrome without a name) and therefore lack a diagnosis for their condition. This may be because their condition is so rare that they are the first person to be affected by it, or because their symptoms are different to how the condition usually presents and so it has not been tested for. Without a diagnosis to explain why their child is disabled it can sometimes be difficult for families to have their child's needs taken seriously, and to access the care and support they need inside and outside of the health service. Many of our members' children have been refused end of life care, despite symptoms indicating that the child is approaching the end of life. This refusal appears to be due to the lack of diagnosis with an understood life-shortening condition. Children with undiagnosed conditions need the care planning and support of palliative care services at least as much as children with more straightforward medical histories.	Thank you for your comment. We acknowledge that this is a challenging issue. We agree that the starting point of our guideline is having an identified life-limiting condition. However, if it is a condition perceived to be so severe that it is likely to be life-limiting and a prognosis has been made to this respect, then the Committee agreed that a clinician would use their clinical judgement to use this guideline. However, it would be very difficult to ever make recommendations for any undiagnosed conditions. The number of >300 conditions was used for illustrative purposes, to highlight that we would not be able to address each condition individually in this guideline, but would deal with the issue of having a life-limiting condition as a starting point.

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					We welcome the emphasis on social, practical, emotional and psychological support for decision making and advance care planning throughout this document. However, in using the WHO definition of paediatric palliative care as beginning at diagnosis of a life limiting condition, the families of undiagnosed children we support are specifically excluded. The guideline is made even less inclusive by the reference in the context to “over 300 conditions that could be classified as life-limiting or life-threatening” based on ICD10 diagnostic codes. ICD10 is of extremely limited use in the field of rare diseases, as it cannot properly distinguish the thousands of rare diseases and disorders. (By way of an example, a rare disease clinician at the Institute of Neurology, specialising in a broad range of metabolic conditions recently indicated that every case he sees would fit into one code of ICD 10.) A guideline which is unable to acknowledge the challenges of coding for rare diseases is likely to underestimate the scale of the problem, further perpetuating this oversight. We understand that it was not the intention of the guidelines authors to exclude a whole swathe of children with needs for end of life care from the support it recommends. We therefore feel there should be a strong and detailed message in this document that access to palliative and end of life care services should not rely on having a	

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					diagnostic label, to ensure that the system does not place unintended barriers to families with children with undiagnosed conditions accessing much needed support.	
704	Genetic Alliance UK	Short	27	14-20	We welcome the acknowledgement of the frequent uncertainty involved in identifying when a child or young person is likely to die within hours or days, but feel this language should be stronger. In rarer conditions where the natural history is not well understood and particularly in children with undiagnosed conditions, often little is known about prognosis and it can be impossible to judge when the child is likely to die. It is important that children are not refused access to necessary palliative care and support until they reach the very final stages, such as the signs listed. This prevents adequate advance planning and preparatory support, which might permit, for example, choice of place of death. Where there is doubt about the prognosis or proximity to death, a more generous approach which permits children with what are reasonably believed to be life limiting conditions and their families to access care and support is appropriate, and far better for all involved than setting a high bar of evidence which cannot be met in most cases of rare and undiagnosed conditions.	Thank you for your comment. We have described these uncertainties in several sections (see recommendation 1.1.18 related to providing information; recommendation 1.3.17 in preferred place of care and place of death; recommendation 1.3.56 and 1.3.63 in recognising that a child or young person is likely to die within hours or days).
791	Genetic Alliance UK	Short	33	5-7	We welcome the suggestion to consider providing a named care coordinator for children with life limiting conditions. However, this should be strengthened to a must (not a	Thank you for your comment. We have retrieved the suggested document, but unfortunately it does not meet the inclusion criteria indicated in the protocol. However, the

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					“think about”) as recommended in the UK Strategy for Rare Diseases (available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/260562/UK_Strategy_for_Rare_Diseases.pdf)	Committee appreciated the importance of having a named care coordinator. We have added a reference stating that 'every child or young person with a life-limiting condition should have a named medical specialist who leads on and coordinates their care' (recommendation 1.2.2).
40	Helen and Douglas House	Full	General	General	There seems to be relatively little emphasis on siblings, partners, and other family members (e.g. grandparents)	Thank you for your comment. We have amended the guideline and added in explicit reference to siblings and other family members in the section that precedes ‘General principles’ as an overarching theme. Two new recommendations have also been added under ‘General principles’ as overarching recommendations: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were now explicitly covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
41	Helen and Douglas House	Full	General	General	The addition of an Executive Summary to both versions could synthesise the key points and direct the reader to relevant content and implications.	Thank you for your comment. When the guideline is published on the NICE website it will be presented digitally and is therefore more user-friendly. Apart from this we currently do not include executive summaries for our guidelines.
122	Helen and Douglas House	Full	16	Figure 1	This diagram is slightly puzzling. What is its source? If used, could it be adapted to highlight key moments of care (episodes or deterioration and instability) that happen between ‘diagnosis’ and ‘dying’. Might be useful to refer to the ‘Spectrum’ tool and/or to	Thank you for your comment. The supportive framework diagram is a visual representation of the relationship between our topics in relation to the wider context of key life events and key transitions. Guidelines usually include a pathway, but the Committee agreed that

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					reflect 'stable, unstable, deteriorating, dying' phases as set out in NHS England documents.	such a linear concept does not fit the scope of our guideline. We have added explanatory text underneath the figure to describe this (see section 1.3 of the full guideline).
187	Helen and Douglas House	Full	24	All	Rapid transfer: this section could be enhanced by more guidance as to planning for what to do in the case of death during transfer.	Thank you for your comment. We believe that this is covered elsewhere already. In recommendation 1.3.17 (to raise awareness that they may die sooner or later than expected), changes in level of care in recommendation 1.3.16 and the care available in different settings in recommendation 1.3.13.
256	Helen and Douglas House	Full	36	27 General	Although the guidance excludes children dying suddenly and unexpectedly (presumably in the absence of a life limiting illness), could there be more guidance on what to do at the point of death, and particularly when children with life limiting conditions die suddenly and unexpectedly (and how to determine what is an unexpected death e.g. for CDOP purposes – there is significant confusion about this? (e.g. could insert at page 30 in short guidance and cross reference to full guidance).	Thank you for your comment. If they do have a life-limiting condition and die suddenly or unexpectedly they are not excluded from our guideline and the recommendations we have drafted would apply with respect to general planning of their condition. However, it is difficult to recommend anything for any unexpected events. We have, however, sections on social, practical, emotional and religious support which would apply to people affected by such events.
265	Helen and Douglas House	Full	48	18	..such frequency…….. doesn't make sense ?typo.	Thank you for your comment. This has now been corrected.
266	Helen and Douglas House	Full	75	1,2	? from next page	Thank you for your comment. This has now been corrected.
276	Helen and Douglas House	Full	148	Fig 6	Use of the word religious – would a better word be spiritual as this encapsulates a lot more than religion.	Thank you for your comment. The theme maps represent visually what was identified in the evidence. In most of these studies people, if they did mention these issues, referred to those beliefs as religious. We agree with your comment and have therefore in our recommendations we consistently referred to these as 'religious, spiritual or cultural' needs

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						or values. We have replaced ‘spiritual or religious advisors’ with ‘chaplains’ in recommendation 1.5.3, and recommendation 1.2.32 refers to the chaplaincy service. A definition of chaplain has been added to the section on ‘Terms used in this guideline’. Other terminology has been checked for consistency.
277	Helen and Douglas House	Full	177	40	Again – use of religious – perhaps spiritual may be a better word.	Thank you for your comment. The theme maps represent visually what was identified in the evidence. In most of these studies people, if they did mention these issues, referred to those beliefs as religious. We agree with your comment and have therefore in our recommendations we consistently referred to these as 'religious, spiritual or cultural' needs or values. We have replaced ‘spiritual or religious advisors’ with ‘chaplains’ in recommendation 1.5.3, and recommendation 1.2.32 refers to the chaplaincy service. A definition of chaplain has been added to the section on ‘Terms used in this guideline’. Other terminology has been checked for consistency.
286	Helen and Douglas House	Full	194	6	England used ?should be UK	Thank you for your comment. We have amended this accordingly.
322	Helen and Douglas House	Full	256	14	Religious ?spiritual	Thank you for your comment. We have added spiritual since we believe that both could apply in this context in the introduction to this topic. We have replaced ‘spiritual or religious advisors’ with ‘chaplains’ in recommendation 1.5.3, and recommendation 1.2.32 refers to the chaplaincy service. A definition of chaplain has been added to the section on ‘Terms used in this guideline’. Other terminology has been checked for consistency.

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334	Helen and Douglas House	Full	331	34	Whilst ? typo	Thank you for your comment. This has now been corrected.
347	Helen and Douglas House	Full	358	26	not only associated with cancer	Thank you for your comment. We agree that the wording of recommendation 1.3.22 may have been confusing and that these are not the only causes. We have therefore revised it by changing 'which can be associated with' to 'for example, associated with', to clarify that this is not an exhaustive list.
350	Helen and Douglas House	Full	358	30	Not only associated with metabolic disease	Thank you for your comment. We agree that the wording of recommendation 1.3.22 may have been confusing and that these are not the only causes. We have therefore revised it by changing 'which can be associated with' to 'for example, associated with', to clarify that this is not an exhaustive list.
361	Helen and Douglas House	Full	390	9.5.9	Research recs – 8. Current evidence base – typo – 2nd line from top. However, this The	Thank you for your comment. This has now been corrected.
362	Helen and Douglas House	Full	393	27	It is important the committee…..	Thank you for your comment. This has now been corrected.
363	Helen and Douglas House	Full	395	12	Harm? Not harms?	Thank you for your comment. This has been reviewed and does not require amendment.
364	Helen and Douglas House	Full	397	7	When it taking fluid????	Thank you for your comment. This has now been corrected.
366	Helen and Douglas House	Full	404	Table	Symptoms sometimes present – increased calmness/severity. Should it say serenity?	Thank you for your comment. This has now been corrected.
367	Helen and Douglas House	Full	407	11	Next page	Thank you for your comment. This has now been corrected.
368	Helen and Douglas	Full	408		Social withdrawal - onto page 409?	Thank you for your comment. This has now

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	House					been corrected.
378	Helen and Douglas House	General	General	General	Your question on Impact: Thankyou to all for this very impressive and excellent piece of work, which will hopefully have big impacts on care. In answer to your question on impact, I think the biggest impact will be in the areas of - advance care planning (including parallel planning), - communication (with patients, families and between colleagues across sectors) and facilitated decision-making. Thankyou for giving this plenty of attention in the guidance. - symptom management (expert, timely, and accessible (phone and face to face)) - equity of provision (24/7, all settings, all geographical areas) - and the specific areas of neonatal palliative care and transition.	Thank you for your comment.
379	Helen and Douglas House	General	General	General	Your question on Challenges to achieve impact: - in order to achieve this, the recommendations will need to have significant positive impact on commissioning, statutory funding and staff provision. (Currently there is patchy and partial commissioning and funding, patchy PPC provision, patchy staffing (challenging recruitment as well as funding) and patchy 24/7 cover. - There is particular need for staff	Thank you for your comment. We agree that staff training is outside the remit of this guideline. However, staff support is covered to some extent in recommendation 1.4.7 - 'Ensure that arrangements are in place for professionals to talk about their thoughts and feelings with colleagues when a child or young person they are caring for is approaching the end of life or has died'. The health economic analysis showed that 24/7 was cost effective and therefore supported the recommendation 1.5.9 on 'Care at Home'.

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					training and staff support. Whilst recognising this is beyond the NICE brief, if it doesn't happen, it will significantly limit any positive impact from the guidance.	
380	Helen and Douglas House	General	General	General	Your question on Cost implications: in answer to your question on cost. Yes, the recommendations will indeed have cost implications, both direct costs for more universally available care and expertise, and indirect costs for staff training, support etc. But if the recommendations lead to such care being available in all settings, there should also be NHS savings as more care could be delivered out of hospital and there could be fewer / shorter stays in its intensive settings (PICU, NICU etc).	Thank you for this comment which is consistent with the rationale outlined in the full guideline to underpin recommendations on 24h day/night care
381	Helen and Douglas House	General	General	General	Your question on what would help overcome challenges: - Using and building on current commitment, specialist expertise and goodwill in the sector. Resourcing expert professionals to share advice and expertise. - Strengthening local and regional cross sector networks and professional collaboration to share expertise, training, case by case and child centred advice and discussion, and build professional relationships - Resourcing development, publicising and updating of high standard and freely accessible expert resources to inform care (formularies, pathways, guidance), and support both generalists and specialists in providing such care. See	Thank you for your comment. That is very helpful and response will be considered by NICE where relevant support activity is being planned.

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					www.appm.org.uk and www.togetherforshortlives.org.uk for examples (e.g. APPM formulary http://www.appm.org.uk/10.html , Rainbows symptom control manual, pathways for neonatal palliative care, compassionate extubation etc.): many examples here: http://www.togetherforshortlives.org.uk/professionals/resources/p2 - Resourcing staff training at all levels (initial training and ongoing professional development), ongoing staff support (albeit outwith NICE brief). - Having a clearly designated 'advance care planning coordinator' for each locality (see comment 7). This has proved very effective where implemented: recommending it as good practice could help lever provision for this. - Support rollout of simple tools giving patients and families a voice to inform care and produce patient-generated outcome measures e.g. MyQUOLT http://www.health.org.uk/sites/health/files/Shine2012_MyQUOLT_report.pdf - Publicise the availability of apps to support communication with children, and patients with learning and/or communication difficulties. - Finding ways to share insights and build bridges between paediatric and adult palliative care sectors	

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					- Funding joint appointments (e.g. consultants, specialist nurses) working across sector e.g. 2 or 3 of hospital, hospice and community. This builds working relationships and shared learning and can enhance flexible availability of relevant expertise.	
382	Helen and Douglas House	General	General	General	In the full guideline each section of recommendations is related to a particular Review Question. For context, the short version could benefit from a brief outline of the Review Question considered and the pertinence of each for good practice in the planning and management of end of life care for this group of people. As an introduction to the short version, this would give a sense of scope and weight to the subsequent recommendations. It would also signpost the reader to the structure of the document. This could be summarised within an executive summary as well as part of an introduction.	Thank you for your comment. This layout and level of detail in the 'short' version is the standard template for NICE guidelines. The aim of this document is to summarise all recommendations. Therefore we are not able to add extra text to this.
428	Helen and Douglas House	Short	General	General	Whilst both documents are very valuable, in practice most professionals will only read the short guidance. It is worth prioritising this to ensure a) that the key messages are still clear even after revision, and b) that dissemination is thorough and ongoing. The excellent communications team have made a good start, thankyou.	Thank you for your comment.
429	Helen and Douglas House	Short	General	General	Could you make use of more frequent embedded links from the short guidance to relevant parts of the full guidance, so that people are directed efficiently to further information?	Thank you for your comment. We agree that this would be useful, but unfortunately there is no process in NICE guidelines to be able to do this at present. This short version of the guideline will however be presented digitally in clearly divided sections, which will be easier to use and follow and which will link to the

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						relevant chapters in the full guideline.
430	Helen and Douglas House	Short	General	General	The front page introduces 4 stakeholder groups: professionals, commissioners, children and young people with life limiting conditions; families and carers. To emphasise the difference /impact that you foresee the guideline has the potential to make it could be beneficial to include a punchy set of statements outlining the key implications for each of these stakeholder groups. This could form the basis of a summary check list/action plan for each of the stakeholder groups. If appropriate, each statement could take the form of 'must', 'should' or 'could'. Again this might sit within an Executive Summary.	Thank you for your comment. In NICE Guidelines the wording takes into account that some recommendations are made with more certainty than others. For example we use 'offer' to reflect a strong recommendation, usually where there is clear evidence of benefit (or 'do not offer' in case of strong evidence for harms). We use 'consider' to reflect a recommendation for which the evidence of benefit is less certain (or 'do not consider' in case of less certain harm). NICE produces several versions of the guideline. A short and full version aimed primarily at clinicians. NICE also produce a version called 'information for the public' which is a lay representation of the recommendations. In this instance there will be 2 documents: a version for families that is addressed to parents and carers, and a brief summary for young people themselves. In relation to different stakeholders, NICE do not distinguish between different stakeholder groups just the strength of the evidence.
494	Helen and Douglas House	Short	5	7 – 21 General	Could we have more guidance on communication with children and young people with communication and/or learning difficulties?	Thank you for your comment. In the 'Communication section' of the guideline, recommendation 1.1.9 refers to taking into account the age and level of understanding, and recommendation 1.1.10 addresses any special needs related to communication. This is therefore not repeated in recommendations that follow on from this.
530	Helen and Douglas House	Short	8	All	(p8-11) Advance care planning: could the guidance affirm the value of having a designated advance care planning	Thank you for your comment. We have added a recommendation on a named clinician who leads and coordinates the child or young

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					coordinator for a locality to ensure that ACPs are appropriately circulated and updated (this could be a nursing or administrative function depending on local systems). E.g. relevant to page 10 line 25 to page 11 line 16.	person's care (see recommendation 1.2.2). We believe that this would involve the Advance Care Plan and who to share it with.
806	Helen and Douglas House	Short	34	23 General	End of life care: this definition seems bizarre and I wonder if it has got distorted in editing? It is really important as it underlines the scope of the guidance which seems unclear. Most people would not consider end of life care as synonymous with 'care throughout life' (even if provision of palliative care may be relevant throughout life from diagnosis in many conditions, and for some conditions, diagnosis may not happen until near end of life). This definition and then the overall scope of the guidance need urgent clarification, and the stating clearly at the start of both documents (e.g. in general principles, page 4 of the short guidance)	Thank you for your comment. The 'Terms used in this guideline' section has been updated: the End of Life Care definition has been reworded and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days. The terminology used was discussed and adopted during the scoping stage for this guideline. The scope for this guideline was consulted on and this term was accepted by stakeholders. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.
811	Helen and Douglas House	Short	37	All	(p37-39 The recommendations for research are admirable and important. I wonder if the	Thank you for your comment. It is usually the case that the 'short version' of the guideline

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					short guidance could also include just brief headings for the other 4 research recommendations (around home based care, chaplaincy, oral / trans mucosal medication in breathlessness, subcutaneous antiepileptics), referring to the full guideline for more details. Also, should there also be mention of research prioritising exercises that have already happened in the sector which include further priority topics even though NICE has not selected all these for its short priority list.	includes only up to 5 key research recommendations. The short guideline is a summary of all of the recommendations in one document, and any other detail is to be found in the full guideline. With regard to a reference to the research prioritisation exercise, this was looked at and many of the topics fell into the proposed subjects. However, research recommendations in guidelines can only be made on areas on the scope where uncertainties or gaps in the evidence were directly identified.
814	Helen and Douglas House	Short	37	9	Research: Link is broken.	Thank you for your comment. This has now been corrected.
406	Helen and Douglas House, Trustees	General	General		Education of all paediatricians in the existence of ACP and method to communicate any necessary changes.	Thank you for your comment. The issue of training (medical or otherwise) is outside the remit of this guideline. NICE guidelines assume that healthcare professionals have the appropriate training and expertise in their area of practice.
573	Helen and Douglas House, Trustees	Short	10	1.2.5	Advance Care Plan: More emphasis on the ACP being available to hospital staff who may deal with emergency admissions. This would be facilitated by every infant/child having a ACP coordinator responsible for ensuring the ACP is up-to-date and available to all involved. The primary carer should have a copy and liaise over any inconsistencies that need rectifying.	Thank you for your comment. We do emphasise that the Advance Care Plan should contain a distribution list which we believe would include hospital staff. A new recommendation has also been added: 1.2.2, which states that every child or young person with a life-limiting condition should have a named medical specialist who leads on and coordinates their care. This would include responsibility for having an up-to-date Advance Care Plan for the child or young person.
613	Helen and Douglas House, Trustees	Short	13	1.2.25	Emphasise the need to develop and augment emotional and psychological support services. Decisions must be made how these will be funded	Thank you for your comment. Your comment seems to relate to the implementation rather than the content of the guidance. Your comments will be considered by NICE where

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						relevant support activity is being planned. NICE will also publish a version for families and one for children this will include links to relevant resources.
641	Helen and Douglas House, Trustees	Short	16	1.3.11	Preferred place of death may not be practical or appropriate. In depth discussion needs to be started early. Arrangements for alternative locations need to be very clear in ACP.	Thank you for your comment. Recommendation 1.2.5 states that discussions about place of care should be documented in the Advance Care Plan. We did not want to be too specific about these discussions since each individual situation requires different discussions. However, we do also state in recommendation 1.3.12 that these preferences may change either if they change their minds or for clinical reasons or due to problems with service provision. We therefore believe that this is covered.
682	Helen and Douglas House, Trustees	Short	20	1.3.26	Excellent emphasis on appropriate use of ‘off-label’ drugs. National data collection on this aspect of care needs to be coordinated to inform changes in licencing.	Thank you for your comment.
789	Helen and Douglas House, Trustees	Short	33	1.5.7	Clearer definition of Rapid Transfer Service is needed and agreement as to how this will be implemented and funded.	Thank you for your comment. We refer to rapid transfer in terms of the situation where it is suspected that a child or young person may die soon and they are not in their preferred place of death. How soon this is required to happen may then vary on a case by case basis. We have also changed 'rapid transfer service' to 'rapid transfer process'.
812	Helen and Douglas House, Trustees	Short	37	General	Recommendations for research must be given more emphasis in the final document. Where evidence does not yet exist much of the Guidance may be ignored by Commissioners. At a national level Ring-fenced funding needs to be prioritised for all the important aspects listed. Improvements in provision will only occur if evidence is better defined.	Thank you for your comment. Usually the 'short version' of the guideline presents up to 5 key research recommendations. We then added further research topics to the full guideline. However, research recommendations can only be made on areas in the scope where uncertainties or gaps in the evidence were directly identified. The National Institute for Health Research (NIHR) have

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						allocated funding for some NICE guideline key research recommendations.
371	Hospice UK	General	General	General	Hospice UK would like to endorse all the comments on the NICE Draft Guidance for End of Life Care for Infants, Children and Young People submitted by Together for Short Lives. We are not submitting a separate response from Hospice UK. Although we include many childrens hospices in our membership at Hospice UK, these expert organisations are also members of Together for Short Lives who have a wider paediatric stakeholder audience than us. We know that their response was based on extensive feedback from young patients, their families and professionals. We have looked at every line of their submission and fully endorse all comments.	Thank you for your comment.
123	Leeds Teaching Hospitals NHS Trust	Full	16	Fig 1	This Figure provides a useful graphic which would help frame the recommendations in the Short Version	Thank you for your comment. The short version will be presented digitally in clearly divided sections and will be easier to use and navigate. This format is unable to display graphics.
383	Leeds Teaching Hospitals NHS Trust	General	General	General	This is an extremely thorough and detailed guideline and the development group are to be congratulated. Whilst we recognise that	Thank you for your comment. This layout and level of detail in the 'short' version is the standard template for NICE guidelines. The

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					this is a particularly complex topic we feel that some of the context that is in the full document should be brought into the 'Short' version rather than it being predominantly the recommendations. The length of the full document is daunting, and we believe that some of those to whom this guidance is directed, both professionals who provide end of life care, and the commissioners of end of life services will not go to the full document; there is a risk that this will diminish the strength and impact of some of the recommendations. We will indicate particular examples in comments below. We suggest consideration should be given to expanding the 'short' version to incorporate the 'key conclusions' from the full guidance document, with explicit reference to the evidence in relevant sections in the full guideline.	aim of this document is to summarise all recommendations. Therefore we are not able to add extra text to this.
431	Leeds Teaching Hospitals NHS Trust	Short	General	General	Although the introduction to this guideline states that it is for commissioners of end of life services (as well as for service providers and service users), we feel that it is weak in the recommendations it makes for the commissioning of services, particularly in the 'short version' which we believe many commissioners are more likely to read. The section on service delivery is very brief, and refers to what services should provide, not what services should be commissioned. We will comment further below.	Thank you for your comment. We have strengthened a number of issues with regard to service delivery recommendations. We have specified that every child or young person should have a named medical specialist (recommendation 1.2.2), and also revised our Multidisciplinary Team section by adding a recommendation on 'specialist paediatric palliative care teams' (recommendation 1.5.4). We have also changed the wording from 'specialist medical advice' to 'specialist consultant paediatric palliative care advice' at any time. There was not much evidence identified for this topic so recommendations were mostly based on consensus of the Committee as well as their members'

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						experience and expertise. This limited the number of recommendations that could be made.
432	Leeds Teaching Hospitals NHS Trust	Short	General	General	The phrases 'be aware' and 'if appropriate' are used repeatedly, and weaken a number of the recommendations; see examples below.	Thank you for your comment. For a number of topics we had a large amount of qualitative evidence highlighting the views of parents or carers, children and young people.
433	Leeds Teaching Hospitals NHS Trust	Short	General	General	The guidance is for 'End of Life Care'; the focus is very much on children who have long term 'life limiting conditions' but there are children and young people (for example those with cancer) who have a 'life threatening condition', which then becomes 'life limiting'. There are others who may require a very short period of End of Life Care, following an acute illness. Although the scope of the guidance makes it clear that it excludes children who die unexpectedly, it is not clear whether it also excludes children who require a short, intensive period of palliative care at the end of life, for example following an acute and life threatening illness. We believe that these children should be included, as they and their families also require End of Life Care and bereavement support, and our experience is that this can lead to inconsistencies in care.	Thank you for your comment. These children are not excluded from this guideline and the guidance (such as recognition of the likelihood of death) applies to those children and young people as much as those with other life-limiting conditions.
471	Leeds Teaching Hospitals NHS Trust	Short	5	1	We think the recommendation should be more explicit about the fact that children & young people, and their parents & carers may have different needs and that they should have opportunities for discussion both together, and separately, and that this should take account of the personal situation and cultural beliefs of each family. This is addressed in the full guidance and supporting evidence but not in the short	Thank you for your comment. This is covered in recommendations 1.2.29 onward, under the section on 'religious, spiritual and cultural support'.

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					version.	
529	Leeds Teaching Hospitals NHS Trust	Short	7	10-14	We are concerned that the phrasing 'If appropriate' in these recommendations (which relate to asking parents or carers about the understanding of their child, and what they should be told), weakens the recommendation. They should read 'Ask the parents or carers'….with an additional bullet point to highlight the role of professionals as advocate for the child/young person in ensuring open and honest communication.	Thank you for your comment. We believe that 'if appropriate' is important in this context. There may be situations where these discussions are not appropriate, i.e. if the child is has autism or has a particular learning difficulty and asking parents about this would be justified.
545	Leeds Teaching Hospitals NHS Trust	Short	8	24 onwards	The section on Advanced Care Planning is very prescriptive. Opportunities should certainly be offered to families to develop an ACP which may (not should) include all the elements listed from line 27 on pg. 8 to 31 on pg. 9. The development of the Advanced Care Plan is a record of decisions taken with the child or young person and their family; it should be an individualised and responsive document (responsive to the needs of the individual child or young person and family). Some elements listed here may be added over weeks/months or even years of a child's life.	Thank you for your comment. We believe that all children and young people with a life-limiting condition should have a plan in place which in their case is called 'Advance Care Plan'. Recommendation 1.2.7 'develop and regularly review Advance Care Plans', and 1.2.8 'Advance Care Plans should take account of the child or young person's life as a whole' are in line with your comment.
561	Leeds Teaching Hospitals NHS Trust	Short	10	4	It is difficult to set out how 'regularly' to review and ACP. Suggest that this point is merged with 1.2.11 so that: The ACP should be reviewed and updated with members of the MDT and in discussion with the child or young person and their parents or carers if: • The child or young person's condition changes (*new bullet point*) • The care setting changes… • New professionals become involved	Thank you for your comment. The Committee considered your suggestion but preferred not to combine 1.2.7 and 1.2.12 as it was felt that the content of these related recommendations would be clearer by keeping them separate.
581	Leeds Teaching	Short	11	23	See comment 7	Thank you for your comment. Please see our

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	Hospitals NHS Trust					response to comment # 7.
588	Leeds Teaching Hospitals NHS Trust	Short	12	22	Suggest add overarching recommendation that CYP and their families/carers should be offered a Holistic Needs Assessment which should address emotional, psychological, social, practical cultural and spiritual needs	Thank you for your comment. We have described in detail what the Advance Care Plan should include some of which are related to 'wishes and ambitions' (1.2.5). The issues of emotional, psychological, social, practical, cultural and spiritual needs are addressed in recommendations 1.2.22 to 1.2.32. The Committee therefore wanted to use concrete language rather than conceptual terms.
632	Leeds Teaching Hospitals NHS Trust	Short	15	20	We believe the recommendation should be to offer the opportunity to talk to the child or young person and their parents or carers both separately and together, setting out the need to both respect the culture/dynamics of the family, whilst acting as an advocate for the child and promoting open communication.	Thank you for your comment. We have amended the text accordingly to include parents or carers in the preamble to the recommendation.
646	Leeds Teaching Hospitals NHS Trust	Short	17	11	This is one of the areas where the concise nature of the short document means that there is a lack of clarity around the recommendations which relate to ‘rapid transfer’. Need to establish what service is available to support this process (before discussing with child and family). It is not clear what a ‘rapid transfer service’ is at this point in the document, although this is set out more clearly in the recommendations on service delivery (pg. 33). Provision of such services are not consistent and we see this as an opportunity to highlight the need for equity of access to such a service. There would be a cost implication to this	Thank you for this comment. The Committee agree that there was variation in practice in terms of availability of services for Rapid Transfer and acknowledge that there is likely to be a resource impact in making access to such services available across the country. We have amended recommendation 1.5.8 (66 in the full guideline) (formerly 1.5.7, and recommendation 62 in the full guideline) as follows to provide greater clarity: "In collaboration with local hospitals, hospices, and community, primary care and ambulance services, ensure there is a rapid transfer process for children and young people with life limiting conditions to allow urgent transfer to the preferred place of death (for example from

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						the intensive care unit to their home, or other locations [such as a children's hospice])."
661	Leeds Teaching Hospitals NHS Trust	Short	18	16	Whilst we recognise that the guideline addresses some of the most common 'distressing symptoms', we believe there are some omissions which should be included, in particular Nausea and Vomiting, but possibly also raised intracranial pressure and spinal cord compression;	Thank you for your comment. We agree that this is an important issue. However, we had to prioritise the number of symptoms and the consensus was reached to address these four different types (pain, respiratory distress, agitation and seizures).
671	Leeds Teaching Hospitals NHS Trust	Short	19	6	We are concerned that by identifying one cause for different types of pain this recommendation may increase the risk that symptoms caused by other conditions may be missed; it would be better to say 'for example caused by cancer'.	Thank you for your comment. We have now amended all of 'which can be associated with' to for example'.
688	Leeds Teaching Hospitals NHS Trust	Short	22	3	We suggest adding the use of steroids (dexamethasone) to help manage pain in patients with brain tumours and the use of palliative radiotherapy in a range of solid tumours.	Thank you for your comment. Due to a lack of evidence the Guideline Committee only reached consensus on these categories as examples.
696	Leeds Teaching Hospitals NHS Trust	Short	25	31	We suggest adding an additional intervention: drainage of pleuritic fluid in some conditions (for example cancer)	Thank you for your comment. The list is not meant to be exhaustive and only list some of the medical disorders related to respiratory distress. We agree that there are many others including your example that could be mentioned but are not excluded if individual circumstances require it.
714	Leeds Teaching Hospitals NHS Trust	Short	29	18 - 24	We suggest making it explicit that discussions about dying may need to take place both separately and together with children & young people, and their parents and carers	Thank you for your comment. We describe these situations in recommendation 1.3.62 - 'When a child or young person is likely to die within hours or days: • be aware that they or their parents or carers may not express their feelings openly, and may: have intense and varied feelings such as fear, hopelessness or anger or become more accepting of the inevitability of death and give them and their parents or carers opportunities to talk.' It is left

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						to clinical judgement whether these opportunities to talk should be provided jointly or individually.
772	Leeds Teaching Hospitals NHS Trust	Short	33	5	We suggest that recommendation 1.5.6 should be stronger; children should have a key worker or 'first point of contact' to coordinate care and help the family to navigate the complexities of health and social care. It is our experience that the key worker model is valued by families.	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist has been added as recommendation 1.2.2.
777	Leeds Teaching Hospitals NHS Trust	Short	33	9	It is not clear who should lead on the establishment of a rapid transfer service; we recommend that this should be the responsibility of the palliative care/clinical networks identified in recommendation 1.5.9	Thank you for your comment. We have amended this recommendation to now read 'rapid transfer process' rather than 'rapid transfer service' which we feel would be easier to implement.
781	Leeds Teaching Hospitals NHS Trust	Short	33	16 onwards	The recommendation is not clear on which services should provide the home care which may be required. Whilst we accept that there	Thank you for your comment. We have now clarified that this refers to 'care at home' rather than 'home care' (as a particular package). We

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					are different models of provision across the country, we believe that this is a lost opportunity to advocate for more equitable access to services, particularly given the economic analysis in the full guidance which suggests that 'access to day and night' paediatric nursing care in the home is a cost effective alternative to hospital. We suggest that this should be a commissioning recommendation.	have revised the recommendation to provide more clarity about who should be involved (see recommendation 1.5.9)
794	Leeds Teaching Hospitals NHS Trust	Short	34	16 - 24	There is some inconsistency in the use of terms; 'Approaching the End of Life' is '*the phase of illness after a change…which means they are likely to die within weeks*; 'End of Life Care' is care '*throughout life' for children…with life-limiting conditions.* We believe that it is more intuitive to talk about palliative care as a continuum with End of Life '*when they are likely to die within weeks'*. We recognise that this may have been debated at length by the group.	Thank you for your comment. These terms are defined in the 'Terms used in this guideline' section. They reflect the timeframe that the recommendation is referring to (likely to die within weeks [approaching] or hours or days [dying]). This section has also been updated: the End of Life Care definition has been reworded and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days. The terminology used was discussed and adopted during the scoping stage for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a

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						fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.
798	Leeds Teaching Hospitals NHS Trust	Short	34	1	(Full p221) We support the recommendation for a collaborative approach, but believe that this should be based on a network model which should be commissioned to provide these services across a region.	Thank you for your comment. We agree as stated in the recommendation this should be 'based on established networks' the commissioning of this is outside the scope of NICE clinical guidelines.
803	Leeds Teaching Hospitals NHS Trust	Short	34	9	The examples of care which should be delivered at home should include intravenous infusions where there is appropriate IV access, and in particular the use of Central Venous Access Devices	Thank you for your comment. We recommended that services should be able to support parenteral drug administration. The list provided was not intended to be exhaustive and the examples provided are for illustrative purpose only; other examples may apply according to individual circumstances.
808	Leeds Teaching Hospitals NHS Trust	Short	35	8	**Implementation:** We believe that the area which will both have the biggest impact, and be the hardest to implement, will be access to 24 hour telephone advice, and to paediatric nursing care at 'any time' (day and night). We believe that the use of patient narratives can help overcome some of the challenges, and help service users and service providers engage the critical support of commissioners. We believe that a (commissioned) palliative care clinical network would be the most effective way to develop the collaborative working across services that would allow for creative and cost effective resources to an unpredictable and variable demand.	Thank you for this comment. We appreciate that providing day and night end of life support will be challenging to implement, given current resource/capacity constraints, particularly in the short term. NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing support and day and night specialist telephone advice for children and young people receiving home care and approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. "What-if" analysis showed that the resource impact of providing

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						such a service would depend on the staffing configuration and the size of the population covered by such a service. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24 hour access to end of life support was available in some areas. Whilst this guideline does address service provision it does not does not specify how services should be commissioned as that will depend on the local context. Resource allocation for implementation of recommendations is a matter for local commissioning but the Guideline Committee is supportive of clinical networks of the type you propose. NICE do produce a number of tools to support implementation including resource impact reports and templates. Your comments with regard to implementation tools will be considered by NICE where relevant support activity is being planned Please see also the full guideline LETR section relevant to this topic: “The Committee agreed that clinical networks in collaboration with care planning and service delivery should be established so as to properly cover population of appropriate size and that these networks might aspire to formalised partnership working between the statuary and voluntary sector.”
810	Leeds Teaching Hospitals NHS Trust	Short	36	29	In this important section on context, which identifies recommendations on how services are delivered, there is no reference to	Thank you for your comment. The 'context' section is a broad overview and provides a rationale why guidance is needed. It is not a

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					commissioners; we believe this is a significant omission.	recommendation in itself. It therefore does not provide information on every aspect related to the topic.
813	Leeds Teaching Hospitals NHS Trust	Short	37	6 onwards	**Recommendations for Research:** We believe that the topic areas selected are relevant, appropriate and address both clinical concerns and service delivery. We support these recommendations, and hope that they will encourage funding bodies to support relevant research applications.	Thank you for your comment. The National Institute for Health Research (NIHR) have allocated funding for some NICE guideline key research recommendations.
73	Martin House	Full	General	General	We value the quality and thoroughness of the guidance; in particular on communication, decision-making, emotional support and specialist psychological care and the importance of continuity of relationship.	Thank you for your comment.
74	Martin House	Full	General	General	It would have been helpful to include the needs of siblings more explicitly throughout; for example, short version p.25, line 3.	Thank you for your comment. We have amended the guideline and added in explicit reference to siblings and other family members in the section that precedes 'General principles' as an overarching theme. Two new recommendations have also been added under 'General principles' as overarching recommendations: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
75	Martin House	Full	General	General	Stronger acknowledgement would be welcome of the complexity of the situation with regard to the prediction of end of life in children and young people. With many	Thank you for your comment. We have addressed the matter of trying to recognise that a child or young person is likely to die within hour or days in recommendations 1.3.57

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					children with life-limiting conditions it is not possible to know if a specific episode is the last one. The importance of parallel planning is widely recognised in paediatric palliative care. This has implications for disease directed care and non-disease directed, or broader, care. It also has implications for awareness of the emotional toll on families (including siblings and grandparents).	and 1.3.64, which specifically discuss the uncertainty that surrounds such predictions and the need to discuss this fact. We recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 (explaining the need for parallel plans) to the ‘General principles’ section of the short guideline. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section and to the glossary of the full guideline.
91	Martin House	Full	1	1	There remains confusion about whether it is a document on \`end of life care\`, or a document addressing paediatric palliative care more broadly.	Thank you for your comment. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase ‘planning and management’ which indicates that this is not restricted to only the last days. The ‘Terms used in this guideline’ section has been updated. In addition, the End of Life Care definition has been reworded, and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. The terminology used was discussed and adopted at the time of scoping for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan / strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this

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						overall approach to end of life care at some point.
643	Martin House	Short	17	1	It is important to acknowledge and respect the children who do not want too much information. The wording, for example, might be, `Be aware that *some* children and young people…...`	Thank you for your comment. Not providing too much information is covered as a general matter of matter in the information provision section. We therefore do not repeat it in all of the recommendation that follow.
647	Martin House	Short	17	11	As above, `Be aware that some children…….may be anxious about receiving information…*or may only want a limited amount at this particular point in time*.`	Thank you for your comment. We have covered this point in recommendation 1.1.17 in the section on information provision.
656	Martin House	Short	18	13	Digital media in the form of trusted websites seems relevant, but it is not clear to what `social media` refers?	Thank you for your comment. These are examples of formats that could be used as possible ways of information provision for children or young people. The children in our focus group reported that being connected to others by social media was important to them. It is possible that information could be provided via apps or even through social media (some hospices have Facebook pages). We therefore felt that this was relevant.
685	Martin House	Short	21	31	The guidance is very prescriptive on advance care plans, and also place of care and death. Not all children with a life-limiting condition and their parents want an advance care plan, or to agree a preferred place of care or of death. It can however be helpful to provide opportunities to discuss these matters.	Thank you for your comment. This guidance aims to improve opportunities to have these discussions.
690	Martin House	Short	22	25	The feedback from a number of families is that there can be considerable pressure to donate their child`s organs and tissue. Whilst some families find this a helpful thing to do, others do not. Might the guidance reflect a less pressurising and more open approach? For example, `*Consider* discussing with the child or young person and their parents whether or not they *wish* to donate organs or	Thank you for your comment. Recommendations in the organ and tissues donation section have been reworded and reorganised; please see recommendations 1.2.17 to 1.2.22. Recommendation 1.2.18 (formerly 1.2.17) has been rewritten to form two separate recommendations, 1.2.18 and 1.2.19. Recommendation 1.2.18 in particular now includes explore the views and feelings of

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					tissue *and eligibility*.`	the child or young person and their parents or carers on organ donation.
703	Martin House	Short	26	4, 10	Timing is a key issue in this matter and varies considerably from family to family and situation to situation. The draft guidance says to talk about these matters when the child is approaching the end of life. Some parents say they feel they are betraying their child if they talk about such matters whilst their child is alive, whilst others appreciate the information. (We note that on p.252 of the full version, lines 29 and 30 the committee, `thought that information on bereavement support should be offered for parents/carers and families after the child`s death.`)	Thank you for your comment
709	Martin House	Short	28	10	The guidance on total pain management is welcome, rather than a reliance solely on pharmacological approaches to managing distressing symptoms.	Thank you for your comment.
717	Martin House	Short	29	26	For children there is often, `sleepiness and withdrawal.`	Thank you for your comment. We believe that this is captured by 'an altered level of awareness (for example reduced consciousness, alertness or responsiveness, excessive sleeping, or confusion)' in recommendation 1.3.57.
726	Martin House	Short	30	40	`A palliative care specialist` might be added.	Thank you for your comment. We are unsure where this could be added on this page. There is no line 40.
776	Martin House	Short	33	8	For children there is also, `calmness and acceptance.`	Thank you for your comment. We are unsure how to capture this in a recommendation.
88	Neonatal and Paediatric Pharmacists Group (NPPG)	Full	General	sections 9.2, 9.3, 9.4, 9.5	We appreciate that it is not always appropriate to include dosage information for medication within NICE guidelines, however many of the medicines used in this patient group will be used outside of the product licence, and dosing information may not be available in the commonly accessible	Thank you for your comment. We are unable to refer to other sources of guidance unless they have been accredited by NICE or we have reviewed the evidence. The Committee agreed that providing dosage throughout our recommendations would be difficult. If age/weight related doses are not given in the

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					resources, e.g. BNF for Children. We feel that it would be useful for practitioners to be made aware of the Association for Paediatric Palliative Medicine (APPM) guidelines which covers dosing advice. These are freely accessible via http://www.appm.org.uk/10.html	Summaries of Product Characteristics (SPC) document (which is very often the case particularly for young children and unlicensed usage), our understanding was that we could only suggest dosages if in the evidence reviewed there was compelling evidence to support them. We would therefore not usually suggest dosages. NICE are working with the BNF to make sure dosages for clinical situations like this are covered where appropriate in the future.
89	Neonatal and Paediatric Pharmacists Group (NPPG)	Full	General	section 7.1	We were disappointed to find no mention of the Pharmacist's role in either secondary, primary or hospice care. The Pharmacist plays an important role not only in the supply of vital medication but also as a member of the multidisciplinary team, advising on treatment decisions and issues such as compatibility of medicines.	Thank you for your comment. Recommendation 1.5.3 emphasises the wide range of expertise that may be required in relation to end-of-life care for children and young people with life limiting conditions, including secondary and tertiary care specialists. It does not attempt to provide a comprehensive list as this would have been unwieldy and unhelpful to clinicians. The Guideline Committee believe that the vital role of expert pharmacist advice for some children in relation to end of life care was fully recognised by clinicians.
242	Neonatal and Paediatric Pharmacists Group (NPPG)	Full	33	43	We welcome the research recommendations 1.5.4, 1.6.7 and 1.6.8.	Thank you for your comment.
310	Neonatal and Paediatric Pharmacists Group (NPPG)	Full	241	17-32	It is important to ensure that the appropriate medication is available at home. Some of our members mentioned sending children and young people home with a plaintive care box that contains essential medicine. These could then be accessed by a healthcare professional rapidly to alleviate the patient's symptoms.	Thank you for your comment. We recommend anticipatory prescribing in recommendation 1.5.9
434	NHS England	Short	General	General	This guideline is comprehensive and has	Thank you for your comment. The guideline

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					covered the key areas within the scope. However, there is a lack of reference to the impact on, and needs of, any siblings the child may have and other close family, including grandparents. This can be readily addressed by reference to these two groups of people at specific points stated below.	committee felt that it would be difficult, and not always applicable, to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
638	NHS England	Short	16	16	An additional bullet point – 'the needs of other children and young people in the family'	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings

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						were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
707	NHS England	Short	28	24-27	An additional bullet point – 'listening to any fears or anxieties that siblings and others close to the child, including grandparents, may have'	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
715	NHS England	Short	29	6	Expand the final bullet point to include 'siblings' and 'others close to the child, including grandparents'	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and

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						spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
731	NHS England	Short	30	10-12	Expand the heading to include ‘siblings’ and ‘others close to the child, including grandparents’	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes ‘General principles’, adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
127	Paediatric Intensive Care Society	Full	17	General	I am concerned that the scope of this guidance is too large. There is a confused juxtaposition between trying to give generic guidance on the management of patients with ‘life-limiting conditions’ and specific guidance on end of life care. Whilst I am fully cogniscent that the former involves planning	Thank you for your comment and the reference. The summary of all recommendations is the short version of the guideline and does not provide extra details about methods used and the evidence. This version will be presented digitally in clearly divided sections and will be easier to use and

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					for the latter, the end result is a very large document (137 recommendations) that is difficult to navigate. I suspect that an equivalent piece of work in adults would demand several separate guidelines; for example, in relation to aspects of symptom management such as 'Pain Control;.	navigate. NICE will also produce a version for the public as well as a version for children. The terminology was discussed when the scope was drafted and consulted on, and the title of the guideline includes 'planning and management' of end of life care. We agree that this is a large piece of work and therefore think that a large number of recommendations are necessary.
128	Paediatric Intensive Care Society	Full	17	General	The overarching content contained within this guidance is sensible. My concerns relate to presentation. The Recommendations are extremely difficult to follow. There is much repetition and no logical order. By design, the Recommendations section would be ordered clearly in the following sections A) Diagnosis B) The Multi-professional Team C) Advance Care Planning D) Symptom Management E) Approaching end of Life/Dying E) After death. Ordering Recommendations in this manner that logically follows the life course of the child would allow the authors to avoid repetition of themes throughout the document. Whilst it is accepted that the Full Guidance gives context to the manner in which the Recommendations are presented, most readers of NICE guidance will only read the Recommendations section and NICE should take this into account when formatting the document.	Thank you for your comment. The Committee deliberated for a long time about the order of these sections. There are over 300 conditions that could be referred to as life-limiting and the diagnosis of each condition is not the focus of this guideline. Once diagnosed children could live many years with the condition and during this time communication, information and planning are as well as support needs are the main focus. Signs and symptoms of dying is an end point rather than the starting point for this guideline and only refers to the last days or hours. This was the consensus of the Committee. The service delivery recommendations were intentionally kept at the end because this is a separate issue that would happen alongside all other topics of the guideline.
129	Paediatric Intensive Care Society	Full	17	General	The Recommendations (Guidance) are written from the perspective of a patient/parent. This has merit. However, there is a danger that this approach fails to place sufficient responsibility on health care professionals (and specifically the child's Consultant) on the responsibilities they have	Thank you for your comment. We have emphasised in this guideline the importance of putting the child and family at the centre of care. Recommendations make clear there important role in discussion planning and decision making. This is not to suggest that Health Care Professionals including the

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					towards end of life care. DH and RCPCH guidance is increasingly categorical about the expectation that every patient should have a named Consultant. Patients with life-limiting conditions are no exception and there is value in these Recommendations being clear about this at the outset. Such designation brings both responsibilities and clarity in regards to many of the Recommendations in this guidance e.g. information relating to disease prognosis at diagnosis, and advance care planning.	relevant paediatric consultant do not have a major responsibility in the care delivered.
130	Paediatric Intensive Care Society	Full	17	General	The Recommendations contain almost no reference to the term “Parallel Planning’. This term is widely recognised and frequently used by all health care professionals looking after children with life-limiting conditions. It reinforces that Advance Care planning is a normal part of treatment planning in such patients and therefore places a responsibility on all paediatricians to consider this guidance.	Thank you for your comment. We recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 to the ‘General principles’ section of the short guideline, explaining the need for parallel planning in order to take account of possible unpredictability in the course of life-limiting conditions. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section. We also slightly changed recommendation 1.2.5 on advance care planning.
131	Paediatric Intensive Care Society	Full	17	Specific Recommendation 51-54	The term Team around the Child is one that is frequently used in children with life-limiting conditions. The term references those professionals who form a safety net around the family. The NICE guidance uses the term ‘multi-professional team’. Whilst the two terms might be synonymous this guidance might instead reference a term that is already in common parlance? This section might also then logically be extended to include those recommendationsrelating to psychology, social care, and spiritual support discussed in the latter sections of the Recommendations	Thank you for your comment. Section 1.5 includes several recommendations about the team. Recommendation 1.5.4 has been added to this section, and is about who should be included at a minimum in the ‘specialist paediatric palliative care team’. The guideline uses the term 'Multidisciplinary Team' because it was agreed that this is still commonly understood by professionals and lay people. We did not want to be too prescriptive about the exact professional roles that would be included because this varies according to

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						the individual condition and the particular needs that were identified. However, all the professions that you described do fall broadly into the categories that we have provided.
132	Paediatric Intensive Care Society	Full	17	Specific Recommendation 54	This is a key recommendation. However, whilst the guidance refers to 'named individual' the common parlance is 'key worker'. The latter term is referenced in much ACP guidance and understood by health care professionals. Why is a different term used in these Recommendations? This might potentially cause confusion.	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist has been added as recommendation 1.2.2.
133	Paediatric Intensive Care Society	Full	17	Specific Recommendation 60	What is a Rapid Transfer service? Does this refer to a paediatric intensive care retrieval service or is it something specific that requires commissioning? Recommendation 62 gives some further detail but this is another example where the ordering (and clustering) of Recommendations throughout	Thank you for this comment. The Committee believe that there is variation in practice in terms of availability of services for Rapid Transfer. A paediatric intensive care retrieval service could be used to provide this service, but the recommendations do not preclude alternative arrangements. NICE clinical

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					the document could be improved. i.e.62 preceding 60. Regional critical care transport services are ubiquitous throughout England, Scotland and Wales. There are national Paediatric intensive Care Standards relating to such services that provide for benchmarking and service specification. This guidance should provide some steer as to how a proposed Rapid Transfer Service would interface with what is already in situ. Otherwise there is the potential for parallel commissioning, replication of services, and , confusion.	guidelines make recommendations on services that should be available (e.g. Rapid Transfer) but it is the responsibility of commissioners to determine how that service can best be provided in the local context. In response to this comment we have amended recommendation 1.5.8 (previously 1.5.7, recommendation 66 in the full guideline) to provide greater clarity so that it now reads: "1.5.8 In collaboration with local hospitals, hospices, and community, primary care and ambulance services, ensure there is a rapid transfer process for children and young people with life limiting conditions to allow urgent transfer to the preferred place of death (for example from the intensive care unit to their home, or other locations [such as a children's hospice])."
134	Paediatric Intensive Care Society	Full	17	Specific	There is repetition of very similarly worded recommendations e.g. 18 and 19; 20 and 22; 40 and 41. Some Recommendations e.g. 12 are so 'high-level' that they carry little value	Thank you for your comment. The Committee intentionally phrased recommendations 18 and 19 in the same way to mirror the topic of dying from the children's own (18) and the parents or carers' (19) perspective. These would be very different conversations and the Committee did not want to bundle these into one. There are also subtle but important differences in the focus of recommendations 20 and 22. One talks about the role of children or young people and parents or carers in decision making whereas the other focusses on the support that could help them fulfil this role. Similarly with recommendations 40 and 41 there is one recommendation that emphasises that the discussion should take place and the second highlights that once agreed there have to be some factors that need to be taken into

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						account. Recommendation 12 seems on first inspection 'high-level', but it refers to 'all parents or carers'. This was seen as important since there are cases when parents are separated or otherwise estranged and information should be provided accordingly.
140	Paediatric Intensive Care Society	Full	17	Specific Recommendation 14	This is a key recommendation that logically precedes those before it. It is therefore 'lost' within the other 137 recommendations. One of the main obstacles to parallel planning is the failure of health care professionals to enter into discussions with patients/parents at diagnosis. The consequence is that such discussions too frequently occur during a crisis and, in my experience therefore often led by Intensive Care Consultants i.e. the wrong setting by the wrong specialty group. I would like to see a more strongly worded Recommendation " Health care professionals should tell the child……and what it may mean for them when the condition is first diagnosed"	Thank you for your comment. We agree that this is an important recommendation and was therefore placed at the beginning of this section. However, the Committee agreed that the general principles, effective communication and information provision should be highlighted at the outset. Many of these would go on in parallel. Including 'should' in the recommendation was discussed but the Committee was in agreement that this would be too strong. This would be an individualised approach tailored to each child or young person and therefore 'should' may be too prescriptive. The digital version will make navigation of these sections easier and will therefore not get 'lost' within the other recommendations.
144	Paediatric Intensive Care Society	Full	17	Specific Recommendation 51	See below 7 but this MDT might include psychology.	Thank you for your comment. We have amended our multidisciplinary team recommendation 1.5.3 to include 'Allied Healthcare professionals', for example psychological therapists depending on the on the needs of the child or young person.
243	Paediatric Intensive Care Society	Full	34	General	There is other areas of practice that might benefit from further research but not referenced on page 34. 1. When do patients/parents wish to begin discussions regarding parallel planning. There is qualitative evidence to support that this should occur at diagnosis. However, much of this is inferred from parental	Thank you for your comment. Compared to other sections in this guideline, the section on planning contained a relatively large amount of evidence. The Committee therefore prioritised those that had identified the biggest uncertainties.

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					viewpoints and not those of children with varying capacity. 2.Does Advance Acre Planning improve quality of care at the end of life. In adults there is evidence that ACP in cancer may enhance both longevity and quality of life. However I am not aware of such evidence in paediatrics.	
253	Paediatric Intensive Care Society	Full	35	2.1	For whom is this guideline intended? See Point 1. I think this guideline should also be intended for 'Health Care Professionals looking after children with life-limiting conditions' I suspect the authors believe it to be relevant to all paediatricians and not just those involved in palliative care…they should therefore be explicit using phraseology as suggested.	Thank you for your comment. We usually target guidelines to those providing care for people with a condition, in this case a life-limiting condition. It may of course also be interesting and useful for a wider audience, but there is a balance to be struck between being too specific or too general. We would therefore like to keep this as it is.
136	Rainbow Trust Children's Charity	Full	17	3	We are concerned that this section of the guidance limits information provision to children and young people and their parents or carers. If the child receiving palliative care has siblings or would like another family member to be involved, these conversations may also include them. We suggest inserting the phrase 'and other family members'	Thank you for your comment. We have amended the guideline and added in explicit reference to siblings and other family members in the section that precedes 'General principles' as an overarching theme. Two new recommendations have also been added under 'General principles' as overarching recommendations: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
150	Rainbow Trust Children's Charity	Full	18	21	We are concerned that the guidance in this section does not address support for siblings	Thank you for your comment. The guideline committee felt that it would be difficult and not

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					and other family members and is limited to only 'parents or carers'. This is despite the fact that the support of siblings is a key practical support which families seek from services such as Rainbow Trust Children's Charity. For instance, in an internal snapshot audit of our services in May 2016, 61 per cent of the families we support who responded said that they receive sibling support from us.	always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
154	Rainbow Trust Children's Charity	Full	19	1	Care must be taken not to use confusing or overformal language which can be confusing or distressing for parents or carers.	Thank you for your comment. The focus of the recommendation that you are referring to is on the topic that should be discussed. How communication should be conducted is described in a separate recommendation (because it would therefore apply throughout). This states that amongst other examples of good communication that it should be 'clearly explained and understandable'.
156	Rainbow Trust Children's Charity	Full	19	25	This section states that children and young people and their parents or carers have a 'central role in decision-making'. We strongly believe that where possible they should be *the* decision-makers, except in situations where professionals believe that a decision taken by a child, young person or their family is not in their best interests.	Thank you for your comment. We have placed this in the 'General principles' section to highlight the important role that they have in the decision making process. We agree that where possible they should make the decision, but there are some medical issues where they may need help in decision making (which is stated in recommendation 1.1.3) and the feeling of having to make decisions in these

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						cases may be burdensome.
164	Rainbow Trust Children's Charity	Full	20	27	This section should state that neonatal medical teams should be involved in Advanced Care Plan discussions if there is an antenatal diagnosis.	Thank you for your comment. We have changed recommendation 1.2.6 (Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition) to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.
180	Rainbow Trust Children's Charity	Full	23	1	The multidisciplinary team should include the family and charities involved in the child or young person's care and support.	Thank you for your comment. We have amended recommendation 1.5.3 about who the multidisciplinary team (MDT) should include, by adding 'Allied Healthcare professionals' and 'those with expertise in managing the child's underlying life-limiting condition' to the MDT. Recommendation 1.5.4 has also been added: this is about the 'specialist paediatric palliative care team' and lists the professionals who should be involved in it. We also amended recommendation 1.2.6 to clarify that if the condition is diagnosed during pregnancy think about involving specialists in the discussion, such as obstetricians, midwives, neonatologists, condition-specific specialists and experts from the paediatric palliative care team. We did not want to be too prescriptive about the exact professional roles that must be included because this varies according to the individual condition and the particular needs that were identified. Our first general principle of this guideline refers to the 'central role of in decision-making and planning' that the children and young people with a life-limiting and their parents or carers have. This would be in collaboration with the MDT but not as a

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						member of the MDT. Charities are not usually part of a clinical MDT and were therefore not included unless they are representatives from hospices. Such professional are covered in recommendation 1.5.3.
206	Rainbow Trust Children's Charity	Full	26	10 & 12	Any siblings should be offered bereavement support as well as parents and carers.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
210	Rainbow Trust Children's Charity	Full	26	41	This should recognise that a range of professionals may be involved in bereavement support – not only healthcare professionals. We would recommend an amendment to say 'Ensure that any professionals providing bereavement support have the necessary expertise.'	Thank you for your comment. We have removed 'healthcare' and the recommendation now states 'bereavement support from a professional with appropriate expertise '.
234	Rainbow Trust Children's Charity	Full	32	19	This section should note that professionals need to be aware that it is difficult to be certain about what will happen and children	Thank you for your comment. We have addressed the matter of trying to recognise that a child or young person is likely to die

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					or young people may recover unexpectedly.	within hours or days in recommendations 1.3.57 and 1.3.64, which specifically highlight the uncertainty that surrounds such predictions and the need to discuss this fact. Related to this, we recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 (explaining the need for parallel plans) to the 'General principles' section. A definition of parallel planning has also been added to the section 'Terms used in this guideline'. This again highlights the sometimes unpredictable nature of the course of the life-limiting condition.
401	Rainbow Trust Children's Charity	General	General		The phrase 'if appropriate' is used on four occasions in the recommendations - for instance in considering when to discuss a life limiting condition with children, young people, parents or carers. A definition of 'appropriate' is required for professionals using this guidance if this is not to be a subjective judgment which undermines the principle of parents, carers, children and young people having a central role in decision-making and care planning. See, for instance, page 7 of the Short version, line 13, and page 8 of the Short version, line 15.	Thank you for your comment. We have tried to use the term sparingly and only in cases where 'appropriate' is impossible to define. For instance in 'Be aware of the importance of talking about dying, and if appropriate discuss with children and young people...' (please see recommendation 1.3.6), there may be many situations where this may not be appropriately done.
492	Rainbow Trust Children's Charity	Short	5	5-6	Question 1 – We welcome this recommendation but it may be challenging to implement in practice because of ongoing shortages in some key posts (such as Children's Community Nurses - see the Together for Short Lives 2015 Nurse Vacancy Survey), and the potentially long periods of time over which a child may be	Thank you for your comment. We have made a number of recommendations which aim to promote good practice, implementation will take time.

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					receiving treatment which mean changes in staffing may well occur.	
511	Rainbow Trust Children's Charity	Short	6	23	We would elaborate on providing information 'specific to the child's or young person's individual circumstances' to say in addition 'and in response to what they wish to know'	Thank you for your comment. This recommendation is focused on the type of information that they may require. This issue that you raised, i.e. how much they wish to know, is covered in recommendation 1.1.17. This recommendation asks healthcare professionals to explore the topics that they would like to discuss and those that they may not want information on. Being specific to the 'child's individual circumstances' is covered by recommendation 1.1.15. We agreed that this would best be captured by two different recommendations rather than trying to fit it all in one or reiterate it at every point.
549	Rainbow Trust Children's Charity	Short	8	26	The list of contents for an Advance Care Plan is comprehensive. However we would suggest that what is missing is some brief guidance on when the plan might be drawn up, with sensitivity towards the family or care-givers' feelings, and the child or young person's ability to consider their care and express their wishes.	Thank you for your comment. We have added 'at an appropriate time' to recommendation 1.2.5 on developing and recording an Advance Care Plan, because this may vary according to the sensitivities mentioned in your comment. Other matters such as 'showing empathy and compassion' are covered in recommendation 1.3.61.
550	Rainbow Trust Children's Charity	Short	8	26	We would suggest one further situation when more information or discussions may be required, which is 'family circumstances change significantly'.	Thank you for your comment. The focus of this recommendation is to highlight some situation where further discussion may be required for illustrative purposes. Therefore it is meant to be examples rather than a closed list of all possible situations.
590	Rainbow Trust Children's Charity	Short	12	24	We are concerned that the emotional and psychological needs of siblings are not recognised here alongside those of the child or young person and their parents or carers. In the full guidance, on page 244, lines 4 and 9 do highlight the needs of the whole family and the potential impact on their mental	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing

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					health. However this more holistic approach is not reflected in the Recommendations around ‘Emotional and psychological support and interventions’.	information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
604	Rainbow Trust Children’s Charity	Short	13	25	We are concerned that social and practical support considers only the needs of children and young people and their parents or carers, without specifying siblings. This is despite acknowledgment of the potential impact on siblings in the full guideline, on page 256, line 17. Practical support for siblings can include provision of transport to enable a sibling to stay in education or take part in clubs and activities to maintain some normality, or dedicated time spent with a Family Support Worker, while parents are frequently attending hospital appointments with a sick sibling as an out-patient, or visiting a sick sibling as an in-patient.	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes ‘General principles’, adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
611	Rainbow Trust Children’s Charity	Short	13	1-3	We are concerned that support and possible expert psychological intervention is only	Thank you for your comment. The Committee agreed that it would be difficult and not always

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					considered in relation to children, young people and their parents or carers. We would recommend inclusion of siblings and other close family members.	applicable to add references to siblings throughout the guideline. We have amended the section that precedes ‘General principles’, adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
615	Rainbow Trust Children’s Charity	Short	14	1	We are concerned that this list of types of social and practical support is narrowly focussed on the child or young person, and omits key areas on which many families seek assistance in our experience. For instance, parents often request help with transport to hospital appointments, transport to enable early discharge from hospital when a child or young person is in a stable condition, help to drop siblings at school or collect them when parents are attending a hospital appointment or visiting an in-patient, and practical support within the home to maintain some normality despite challenging circumstances.	Thank you for your comment. Issues such as transport related to family members are outside the scope of this guideline.
722	Rainbow Trust Children’s Charity	Short	30	23	We would recommend that bereavement support information should be offered to parents or carers at an earlier point, once a diagnosis of a life limiting illness has been	Thank you for your comment. We would like to draw your attention to recommendation 1.4.4 which reads 'Offer bereavement support from a professional with appropriate expertise to the

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					made. It would then be reintroduced at the point when a child or young person is approaching the end of life.	parents or carers both before and after the death of a child or young person.' It was agreed that 'before' should not be too prescriptive because it should be introduced to the parents or carers when they are ready for this. At the time of diagnosis the child or young person may have many years ahead of them and some parents or carers would not find this appropriate at this point.
737	Rainbow Trust Children's Charity	Short	31	3	We would urge that bereavement support considers the needs of any siblings as well as of parents or carers.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
741	Rainbow Trust Children's Charity	Short	31	22	An additional option to note is the use of family and friendship networks. For some bereaved parents or carers these may be valuable and preferred to formal expert psychological support.	Thank you for your comment. The options that we have referred to in this recommendation are examples and the list is not exhaustive. Your response will be considered by NICE where relevant implementation support activities are being planned. NICE will also publish a version of this guideline for families

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						and one for children which will refer to some resources. Please see recommendation 1.2.23 where we refer to the need for 'expert psychological interventions' that people may need (not restricted to bereavement only). We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
742	Rainbow Trust Children's Charity	Short	31	23	This is important. We welcome the recognition that professionals involved in the care of the child or young person will need opportunities to talk about and explore their thoughts and feelings. When such opportunities are provided this is likely to assist in the retention of staff which in turn will assist in the continuity of care experienced by children and young people.	Thank you for your comment.
751	Rainbow Trust Children's Charity	Short	32	2	As well as informing relevant professionals, we recommend that relevant professionals are debriefed so that the circumstances of the child or young person's death are explained.	Thank you for your comment. We would like to draw your attention to recommendation 1.4.7 which is about ensuring that arrangements are in place for professionals to talk about their thoughts and feelings with colleagues when a child or young person they are caring for is approaching the end of life or has died. Whether this is instead of a formal debrief or another less formal way is then left to the discretion of the professional involved.
760	Rainbow Trust Children's Charity	Short	32	22	We would recommend the inclusion of 'family support professionals' in this list as they do not fit into any of the existing categories noted.	Thank you for your comment. We have added a new recommendation describing a specialist paediatric palliative care team (recommendation 1.5.4) which includes 'experts in child and family support who have experience in end of life care.'
773	Rainbow Trust	Short	33	5	Question 1 - We strongly welcome the	Thank you for your comment. We believe that

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	Children's Charity				suggestion of having a named individual to act as first point of contact and to coordinate care for the child or young person and their parents or carers. We do however see this as challenging to implement in practice in light of the budgetary constraints faced by services to fund coordination roles, the ongoing shortages in some key posts (such as Children's Community Nurses - see the Together for Short Lives 2015 Nurse Vacancy Survey), and the potentially long periods of time over which a child may be receiving treatment which mean changes in staffing may occur. In selecting this individual it is important that this person has a good relationship with the family.	this is not a radical departure from current practice and hope that the publication of the guideline will encourage a consistent approach.
790	Rainbow Trust Children's Charity	Short	33	3-4	We would recommend a stronger guideline which says 'Always' involve children and young people and their parents or carers in multidisciplinary team meetings 'if they wish to be involved'.	Thank you for your comment. We have stressed the importance of children and young people's involvement as well as their parents' involvement in decision making throughout this guideline (see for example in the 'General Principles' section recommendations 1.1.1 and 1.1.2). The particular recommendation that your comment is referring to was intentionally written in this way because there are circumstances where it may not be appropriate or when it may be distressing for the child or parent to be involved. We would therefore like to keep this recommendation as it is.
800	Rainbow Trust Children's Charity	Short	34	1	Services should also consider what care and support is needed for other close family members such as siblings.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing

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						information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
48	RC(UK) Resuscitation Council UK	Full	General		The explanations of GRADE are generalizable and would be more useful if they were specific to explain how it was applied in this review. Most of what is covered in this section on GRADE hardly applies to this review given the evidence base. This would be especially useful given the wide range covered by this excellent review.	Thank you for your comment. The explanations of GRADE included in the methods section cover all potential review types, and these are the standard NICE processes as they would have been applied. Unfortunately, little evidence was found to apply these methods. In the methods section we have also included specific sections on how specific questions were addressed (for example for the sign and symptoms review).
49	RC(UK) Resuscitation Council UK	Full	General		The paucity of evidence in neonates was noted apart from Mc Haffe 2001	Thank you for your comment. We acknowledge that evidence is scarce and have therefore written another research recommendation for this topic which we have prioritised as one of our 5 key research recommendations in the guideline, which will hopefully inspire future evidence to inform a future update of this guideline
172	RC(UK) Resuscitation Council UK	Full	21	36	We are concerned that whilst appropriate to "Never Assume" there should be something about asking if it is not clear. If it is not documented but has been agreed,	Thank you for your comment. Recommendation 1.3.1 has been rewritten: we have used positive phrasing to indicate that resuscitation should be attempted, unless a

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					resuscitation when not wanted, could be just as distressing as the reverse. Why not clarify whether a resuscitation plan has been agreed as part of an ACP.	do-not-attempt-resuscitation order is in place.
258	RC(UK) Resuscitation Council UK	Full	36	31	Should this read ; All infants, children and young people as infants were not mentioned in this section.	Thank you for your comment. As stated on the outset of the guideline the wording 'children and young people' includes neonates and infants even when these are not directly mentioned. This is commonly done in NICE guidelines.
442	RC(UK) Resuscitation Council UK	Short	General		We feel that 137 recommendations is a lot to hold on to so presenting them in a more user friendly way will ensure that the pertinent points are read by a wider audience. We consider this to be an excellent piece of work. Some of the recommendations will be harder to achieve in unexpected deaths and in children where parents change their minds and end up coming to the emergency department however with good communication with the paediatricians and the wards these recommendations could be achieved. Maybe a future research question could be the awareness and adherence of acute emergency services to these recommendations.	Thank you for your comment. We believe the digitalised version will be easier to navigate once the final version is available on the NICE website. We recommended the development of a detailed 'Advance Care Plan' which would include a record of discussions about the 'management of life-threatening events, including plans for resuscitation or life support' which will make this easier to achieve. The guideline, with its extensive sections on communication, will promote good practice in this area. We did not draft a research recommendation related to this because it was not a specific key area that we covered in the scope of this guideline.
443	RC(UK) Resuscitation Council UK	Short	General		Much more accessible Recommendations divided into themes	Thank you for your comment. We believe the digitalised version will be easier to navigate once the final version is available on the NICE website.
444	RC(UK) Resuscitation Council UK	Short	General		As this is for all infants, children and young people there needs to be some differentiation between those that can communicate and those that cannot. The latter may be due to age or circumstance.	Thank you for your comment. Please see recommendations 1.1.9 and 1.1.10: the former is about taking into account age and level of understanding (for instance using pictures), and the latter highlights taking into consideration any special needs in the context of communication.

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750	RC(UK) Resuscitation Council UK	Short	32	1	1.4.8 mentions " ensure that relevant healthcare and other professionals are informed' Given that we want to cover all situations there should be mention of antemortem discussion with the coroner, which is not an unusual occurrence when an infant, child or young person is likely to die when they are on neonatal or paediatric intensive care. This will ensure that there are as few surprises as possible for families.	Thank you for your comment. The Committee was aware of such variations in practice. Recommendation 1.4.1 aimed to encourage efficient handling of practical arrangements after the death of the child, including involvement of a coroner. Local variations in practice would therefore be a matter for local discussion. This recommendation also supports the need for forward planning in relation to the registration of the child or young person's death.
805	RC(UK) Resuscitation Council UK	Short	34	20	Children = Age 0-12 this includes infants and neonates when applicable. When applicable needs defining when would neonates and infants not be included.	Thank you for your comment. We have also changed the preamble to the guideline and removed 'where appropriate' to clarify that children and young people include neonates and infants. We left this intentionally open to interpretation. There are many sections in this guideline about planning and decision making where neonates and infants would not be able to be involved, however they do need support.
225	Royal College of General Practitioners	Full	29	20	Gabapentin in particular can be given at higher doses than in BNF, but needs agreeing with specialist.	Thank you for your comment. . If age/weight related doses are not given in the BNF or Summaries of Product Characteristics (SPC) document (which is very often the case particularly for young children and unlicensed usage) we could only suggest dosages if -the evidence reviewed was compelling e to support them. We could not therefore recommend particular doses.
259	Royal College of General Practitioners	Full	36	41	Most of the NICE guidance topics that are listed as related with this guideline are not related at all, e.g. bipolar illness.	Thank you for your comment. We agree and have removed some of the listed guidelines, and also added some related guidelines (such as 'Care of dying adults in the last days of life').
436	Royal College of General Practitioners	Short	General	General	In overall the RCGP welcomes this document. The document provided a	Thank you for your comments. We highlighted the role of primary care and GPs in

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					comprehensive overview of end of life care for children. The Committee highlighted the lack of availability of evidence and also the relatively low quality of existing evidence in this area. The recommendations were pragmatic and also acceptable to mainstream practice. While GPs may not have much experience in this very specialised area, it is important to utilise their position as the global recipients of medical information from all the specialist sources involved with the patient and also their position as a family physician with experience and knowledge of the family and community. However, both versions are too long and repetitive. The RCGP recommends to remove duplication and stating the obvious to shorten it and improve the focus. Some GPs may struggle with this document. The RCGP recommends to do a one page summary as a flow chart and a table for drugs for the main symptoms at end of life- this takes one page too and would be practically useful. The RCGP recognises that seamless care is the aim but needs very hard work in all aspects to achieve this. The document also tells us about symptom control in paediatric cancer but not at a lvel that it useful.	recommendations 1.5.3 (Multidisciplinary team), 1.2.10 (sharing of the Advance Care Plan) and their role in bereavement support (recommendation 1.4.5). The title of the guideline refers to both planning and management (including service delivery) of the child and young person's life-limiting condition. We also identified a lot of valuable qualitative evidence which highlighted that communication, information and the right support is not always as effective as it could be. Therefore what it considered to be obvious by some may not consistently been done by others in clinical practice. With regard to the length of the document, the 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the ‘short guideline’ lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate. We did provided a framework diagram in the full guideline (see the supportive framework figure in section 1.3 of the document), but the Guideline Committee agreed that the topic does not lend itself to a linear pathway as you suggest.

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					The RCGP also would appreciate further detail to be included on: 1. Transition services between childhood-adolescence- adult care. 2. Links with Adult EOLC – any congruent themes linking with Ambitions Partnership work? 3. Inequalities such as: • BAME groups – evidence regarding access, language, cultural and spiritual needs etc • LGBT, both families and adolescents. Linking with supportive networks. • Learning Disabilities and Autism 4. No significant mention of mental health support pre-bereavement and following death. Significant requirement to support families – links with marital support, employment support, school support – teachers/ other siblings/ class children. This is particularly important for primary care teams. 5. Given this is a highly specialised field, it would be helpful to have specific advice on ‘transfer of care’ details – particularly with home deaths and in some areas reduced resources and potential impact on primary care both in and out of hours.	1. The topic of transition was outside the scope of this guideline because of a published Transition NICE guideline which looked for evidence in our population. We scrutinised their documents to confirm that they have looked at the relevant evidence. The principles of the transition should therefore apply to this guideline too. 2. The end of life care in adults guideline is focused on the last days or hours of life. 3. Equalities issues were considered, such as special needs (recommendation 1.1.10) and levels of understanding (recommendation 1.1.9) and there is a separate Equalities Assessment Impact form (also available on the website) that sets out the possible equalities issues identified in this guideline. 4. To address mental health issues we have included a section on 'emotional and psychological support and interventions' (recommendations 1.2.22 to 1.2.27) as well as recommendations on bereavement (see section 1.4 Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person). 5. In our section on 'preferred place of care and place of death' we describe what the discussion about the various options should include and what services should be provided if the preferred place is home.

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					6. Complexities such as guidance on having a process for safe-guarding risk assessment and to deal with difference of opinions between parents or between young person and parent. 7. In the demedicalised model of death and dying, is there an opportunity to link health and social care and their importance within compassionate communities and supportive networks? Information about this is contained in the recently published guidance to Ambition 6. The link to this is http://www.ncpc.org.uk/sites/default/files/J1448%20ncpc_strand_6_ART_NC.pdf. Smooth navigation between your community (often supported by commissioned structures) and health and social care is a key component. Understanding the importance of the caring network for both families and professionals is important as without it, staying and dying at home may become too difficult. 8. Are there workforce training requirements that could be further supported within the guidelines?	6. Complexities such as differences in opinion between children or young people and their parents is covered in recommendation 1.2.32. However, the topic of safeguarding assessments was outside the scope of this guideline. 7. In our section on 'Care at home' we describe that services should have agreed strategies and processes to support families where children or young people are cared for at home (recommendation 1.5.10). These should be based on 'managed clinical networks'. The Committee agreed that this would be based on collaboration between health and social care. However, social care provision as such was outside the remit of this guideline. 8. We assumed that the healthcare professionals would have the relevant expertise. Staff training as a topic was outside the remit of this guideline.
437	Royal College of General Practitioners	Short	General	General	(Communication) The RCGP feels that keeping updated the document may be an issue and a GP having an old copy a real worry. It would be worth it a time like an annual update in all members possessions unless they are specifically contacted between times. It could change monthly from your guidance. The document basically outlines good communication which should be a part of	Thank you for your comment. The Committee did not want to be overly prescriptive about any frequency of reviews, but made recommendations about situations that may warrant a review (recommendation 1.2.27). Communication and information provision were the two topics with the largest evidence base which highlighted that this is not as effectively done as you suggest in your comment. With regard to your suggestion about breaking

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					normal practice. The recommendations of communicate well could be much briefer as the current ones do not provide any quality improvement. Is it possible to maybe break it down into simple booklets by age periods and assume health care professionals do have training in communications skills. A sort of short booklet off the shelf approach?	the guidance up into booklets, we would like to highlight that the digital version of the guideline will do that. We believe that this will enable easier navigation between topics. GPs can keep up to date on NICE guidance by registering for our monthly newsletter and alerts for GPs and others working in primary care 'Update for primary care' https://www.nice.org.uk/news/nice-newsletters-and-alerts
438	Royal College of General Practitioners	Short	General	General	(Care drugs) The RCGP would find useful if the document provides a specific terminal care drug as hospices do. If this is to be a useful working guide it should include doses, interactions, cautions. The BNF and hospice books do it. GPs may not find this guidance practical if its not enough specific for practice.	Thank you for your comments. It is outside the remit of the guideline to make recommendations about dosages and interactions since this information is otherwise available. There was no evidence for a 'specific terminal care drug'. The Committee agreed that this would be difficult to recommend due to too many different contributing or causative factors for each individual child.
439	Royal College of General Practitioners	Short	General	General	(Organs donations) The RCGP feels that organs donation is a sensible approach. The current wording may be controversial as the public could feel that the document does not respect children or parents who do not agree with organ donation and this should be clearly supported if their view. It is important to avoid misunderstanding, some members of the public may feel as if it is written to service another part of the NHSA at present and that should never happen. Just if organ donation is appropriate and words can be found to sensitively discuss, this can be approached.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reorganised - please see recommendations 1.2.16 to 1.2.21. Recommendation 1.2.17 has been rewritten and now includes exploring the views and feelings of the child or young person and their parents or carers on organ donation.

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					The RCGP recommends to review this statement again.	
440	Royal College of General Practitioners	Short	General	General	(Decision making/Advanced care plan) The RCGP agrees with the guidance about who has the personal info and makes decision. This is excellent. The RCGP also welcomes the advanced care plan in overall. However, there is a danger that we are directing GPs to be so busy writing advance care plans that they have not time to care for the children and families. The emphasis should be on caring for these people, for being there with them on their last painful journey with their child. The RCGP recommends to revise it and make the style less wooden and more child friendly even, as we want people reading it to be child and family friendly in their contacts. How about calling "advance care planning"- "How we are going to help you and your child?" The RCGP also suggests one plan only, and each time a change is made that it is updated, and any out of date directions are removed.	Thank you for your comment. We believe that the GP is not the only person involved in writing the care plan. This could be developed by another relevant member of the Multidisciplinary team in partnership with the child or young person and their parents or carers. We did not make specific recommendations about any frequency of updating an Advance Care Plan, but suggested possible situations where this should be carried out (recommendation 1.2.27). We do not recommend another plan and therefore it is one plan only as you suggest. We believe that Advance Care Plan is the term generally used for this document. How the aims of this plan are communicated to the child or young person and their parents or carers is described in our communication and information provision sections (i.e. according to age and level of understanding and taking account of possible special needs - recommendations 1.1.9 and 1.1.10 respectively).
513	Royal College of General Practitioners	Short	6	27	Suggest change from ‘orally’ to ‘verbally’ (Page 17, in Full Guidelines).	Thank you for your comment. We have amended this accordingly.
528	Royal College of General Practitioners	Short	7	6-7	Motivational interviewing techniques may also be helpful in agreeing PPC.	Thank you for your comment. This may be helpful but we did not identify any specific

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						evidence for this. We therefore did not recommend a specific way of doing this.
562	Royal College of General Practitioners	Short	10	4	The MDT regular review should be held at the General Practice premises where appropriate to maximise GP team involvement.	Thank you for your comment. We did not want to be too prescriptive about where this should take place because this would vary according to the individual child's circumstances, condition and place of care.
570	Royal College of General Practitioners	Short	10	25	A plan needs to be communicated to ED in case of a crisis which cannot be managed at home (such as prolonged fitting). Consultants should be willing to come in to advise on these complex cases with multiple medication already.	Thank you for your comment. We have now added an overarching recommendation that precedes the symptom management section. This recommends to involve the specialist paediatric palliative care team (described in a further new recommendation 1.5.4) in case of unresolved distressing symptoms (please see recommendation 1.3.20). We also recommend that advice from a consultant in paediatric palliative care should be available at any time for children and young people with life-limiting conditions who are approaching the end of life (please see recommendation 1.5.9).
579	Royal College of General Practitioners	Short	11	7	One person (for example the leader of the palliative care team) should be responsible for changes in medication and letting everyone know. Bear in mind that the local authority may commission care assistants who are not part of health so do not have access to the medical notes so the GP may have to authorise medication separately.	Thank you for your comment. We have now added a recommendation about a named medical specialist who leads on and coordinates the child or young person's care (recommendation 1.2.2).
599	Royal College of General Practitioners	Short	13	13	Consider counselling and support for siblings too. (e.g. through STARS)	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family

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						members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
603	Royal College of General Practitioners	Short	13	24	Social care and respite care includes home carers who help the child or young person with personal care. The social care budget and provision may also be reassessed repeatedly. The clinical team need to work closely with these and support them for the child and family’s sake.	Thank you for your comment. Recommendation 1.5.10 refers to services which provide care at home should be based on 'managed clinical networks and should collaborate on care planning and service delivery'. This collaboration would include working with social care services. The social care budget in relation to this was outside the scope of this guideline.
629	Royal College of General Practitioners	Short	15	15	‘Review these needs regularly’ and document these conversations contemporaneously in the primary medical record as well as any EPACCS or other form of coordinated care plans.	Thank you for your comment. The focus of this recommendation and others that refer to 'record' something is on the action of recording rather than on where it is recorded. This is a matter of implementing the guidance and we believe that systems may still vary across regions. We therefore would not be able to mention all available options.
634	Royal College of General Practitioners	Short	15	25	After death, before the undertakers are involved, those certifying death may be asked to remove or cut tubes to enable the child’s body to be viewed by the local community. The GP should be prepared to do this, as palliative team members may not	Thank you for your comment. We are unable to cover specific details in our recommendations.

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					be able to come immediately to help with this.	
817	Royal College of General Practitioners	Short	39	5	It looks inappropriate to ask the child or young person and their parents or carers whether or not they are eligible to donate organs or tissue.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reworded and reorganised; please see recommendations 1.2.17 to 1.2.22. Recommendation 1.2.19 in particular has been reworded to read 'explain to the child or young person and their parents or carers which organs or tissues (if any) it may be possible to donate.
818	Royal College of General Practitioners	Short	39	7	The RCGP feels that when an organ or tissue cannot be donated it shall be explained just if they ask.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reorganised - please see recommendations 1.2.16 to 1.2.21. Recommendation 1.2.17 has been rewritten and now includes exploring the views and feelings of the child or young person and their parents or carers on organ donation. Recommendation 1.2.20 reads "offer to discuss this with them....if appropriate" to emphasise that discussions should not be forced with children and young people and their parents or carers.
819	Royal College of General Practitioners	Short	39	9	The RCGP does not feel that if the child or young person is eligible to donate organs or tissue, it has to be discussed with them and their parents or carers when they are ready and as part of Advance Care Planning.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reorganised - please see recommendations 1.2.16 to 1.2.21. Recommendation 1.2.17 has been rewritten and now includes exploring the views and feelings of the child or young person and their parents or carers on organ donation. Recommendation 1.2.20 reads "offer to discuss this with them....if appropriate" to emphasise that discussions should not be forced with children and young people and

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						their parents or carers.
820	Royal College of General Practitioners	Short	39	16	The RCGP does not feel that if the child or young person does not have the capacity to decide about organ and tissue donation, it should be asked to their parents or carers to make the decision.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reworded and reorganised; please see recommendations 1.2.17 to 1.2.22. The link to the 'Making decisions using NICE guidelines' documents includes information on standards and laws (including on consent and mental capacity), and safeguarding.
146	Royal College of Nursing	Full	18	4	We are concerned that occasionally there isn’t simply time to have discussions	Thank you for your comment. The purpose of drafting this recommendation was to highlight that this is not consistently done and it was agreed that every effort should be made to have these difficult discussions.
327	Royal College of Nursing	Full	289	32	If you are discussing post mortems options with the family and it is good to have a leaflet explaining the options of Post mortems - so therefore why have in brackets … only if it is going to be performed?	Thank you for your comment. The other bullet points in this list are not optional and information should therefore be offered. However, where a post mortem is not going to be conducted or being considered by the family, information about this may be confusing or upsetting for some families; this is the reason why it appears in brackets.
384	Royal College of Nursing	General	General	General	The Royal College of Nursing welcomes proposals to develop these guidelines. The RCN invited members who work with and care for children and young people and who provide care for them towards end of life to review and comment on the draft guidelines. The comments presented include the views received from our members.	Thank you for your comment.
385	Royal College of Nursing	General	General	General	Please change any mention throughout of ‘paediatric nurse/nursing’ to ‘children’s nurse/nursing’. The Nursing and Midwifery Council register now refers to ‘registered Children’s Nurse’	Thank you for your comment. Even though 'children' is plain English, paediatric care is the commonly used term indicating a medical specialty.
386	Royal College of	General	General	General	The guidelines are in line with existing	Thank you for your comment.

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	Nursing				guidelines which have not been embedded in practice. Hopefully new guidelines with NICE badging will have a stronger influence with regards to the implementation of the recommendations and development of sustainable services for the end of life care for infants, children and young people.	
387	Royal College of Nursing	General	General	General	There are some areas of good practice many of which are focused on the care of the child or young person with cancer, which are mainly funded by charities for specific conditions. Unless there is investment and additional resources are provided it would be challenging to effectively implement the recommendations.	Thank you for this comment. We appreciate that there may be challenges implementing some recommendations given the current financial climate. However, whilst NICE guidelines take into account resource impact, the recommendations were considered to represent a cost-effective use of NHS resources. We recognise not all care is commissioned from the same budget.
388	Royal College of Nursing	General	General	General	It should be noted that there is different terminology used in relation to 'approaching end of life' and 'end of life care' - one refers to weeks to end of life and the other refers to the whole life care.	Thank you for your comment. The terminology used was discussed and adopted during the scoping stage for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point. The 'Terms used in this guideline' section has been updated. In addition, the End of Life Care definition has been reworded, and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. We

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						acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days.
389	Royal College of Nursing	General	General	General	Choice of place of death and rapid transfer would not be possible without funded community children's nursing services. This also applies to the NICE Caring for the dying adult guidelines but the document emphasises the need for district nursing service.	Thank you for this comment. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/). The remit of this guideline does not extend into providing details on how services should be funded, however NICE do produce a number of tools to support implementation including resource impact reports and templates, and tour comments will be considered by NICE where relevant support activity is being planned.
390	Royal College of Nursing	General	General	General	We are concerned about the lack of bereavement and psychology support for most of the infants, children and young people requiring palliative care population - unless the CYP has cancer in which case the service is better though this is not always excellent.	Thank you for your comment. We agree and recommended bereavement support to improve the access to these services (recommendations 1.4.3 and 1.4.4).
391	Royal College of Nursing	General	General	General	It is extremely difficult to assess the dying phase in infants, children and young people who have non-oncology conditions because of the possibility of reversible causes. This is mentioned in the Full document but not in the Short version. This is a major issue in the acute children's services when a "palliative care label" has been given, so needs to be addressed. We are aware that there are similar issues in adult services.	Thank you for your comment. We have highlighted 'unpredictability in the course of the condition' and the 'uncertainties' in the recognition that a child is likely to die to raise the awareness of this issue to recommendation 1.1.8 (formerly 1.1.5). The Committee also agreed that there was a gap in the evidence and prioritised a research recommendation on this topic.
392	Royal College of Nursing	General	General	General	There is no mention of siblings and the support and information they will need from the health care professionals, their school	Thank you for your comment. The guideline committee felt that it would be difficult, and not always applicable, to add references to

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					and other relevant networks. This is important and should be considered.	siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
393	Royal College of Nursing	General	General	General	The document is EOLC (End of Life Care) for ICYP (Infants, Children & Young People). Throughout the document it refers to them being life limited conditions and not life threatened, we use both in the nationally within the field of palliative care. We just wondered what the rational was for this pure reference to End of Life Care	Thank you for your comment. The terminology used was discussed and adopted during the scoping stage for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point. The 'Terms used in this guideline' section has been updated. In addition, the End of Life Care definition has been reworded, and definitions

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						for Paediatric Palliative Care and Perinatal Palliative Care have been added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase ‘planning and management’ which indicates that this is not restricted to only the last days.
394	Royal College of Nursing	General	General	General	Advanced care plans – It is referred throughout the ACP (Advanced Care Planning) is used. Some of our members have highlighted from experience that some families don’t like using them, will they still have choice, or will the ACP just be kept with the professional?	Thank you for your comment. The Committee agreed that every child or young person should have an Advanced Care Plan. We have intentionally not specified who should keep this and how, because this may vary according to individual circumstances. All NICE guidelines are subject to patient choice.
395	Royal College of Nursing	General	General	General	Final care of the body is in section 8 - it isn’t clear if this is referring to personal care (used to be called last offices) and if so our members have highlighted that they are not sure it fits under the social and practical support - several of our members feel it is better placed in section 7 Provision of care	Thank you for your comment. Although this comment relates to practical arrangements, the guideline is divided into a timeframe and refers to 'arrangements that will be needed after the death of a child or young person'. Therefore, the Committee have decided that this would be more appropriate in the section on 'care and support for parents, carers and healthcare professionals in relation to the death of a child or young person', as it is in the short version of the guideline.
396	Royal College of Nursing	General	General	General	24/7 nursing care in the community – This will have workforce difficulties and cost implications. Perhaps as this can be used by the commissioners we will see the raise in numbers within community children’s nursing teams and the ability to work across count/ borough boarders to keep it cost effective	Thank you for this comment. We agree that there may be challenges, especially in the immediate term, implementing 24/7 nursing care in the community for the reasons you suggest. NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing support and day and night specialist telephone

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						advice for children and young people receiving home care and approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. "What-if" analysis showed that the resource impact of providing such a service would depend on the staffing configuration and the size of the population covered by such a service. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24 hour access to end of life support was available in some areas. Whilst this guideline does address service provision it does not does not specify how services should be commissioned as that will depend on the local context. NICE do produce a number of tools to support implementation including resource impact reports and templates, and your comments will be considered by NICE where relevant support activity is being planned.
397	Royal College of Nursing	General	General	General	The terminology used varies throughout. There is reference to Emotional and psychological support which is fine then it reverts to a bias of psychological support through the chapter. We have and believe that grief is a normal process and not to medicalise it. Having psychological support really does put the emphasis on medicalising grief.	Thank you for your comment. We have intentionally separated emotional and psychological support from bereavement support to highlight this subtle difference.
475	Royal College of Nursing	Short	5	6	Suggest add to last line of the sentence: '*…and introduce in a timely way to ensure*	Thank you for your comment. We agree that this is important (please see recommendation

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					the core team is known by the family'	1.5.5).
480	Royal College of Nursing	Short	5	18	Does this include looked after children (i.e. children in care)?, if so, please mention this group	Thank you for your comment. Children in care are not excluded from this guideline. We focus on care tailored to individual circumstances throughout this guideline and your point could be captured in the bullet on 'their personal and family situation'.
505	Royal College of Nursing	Short	6	9	Add the following to the bullet points: *relationship / rapport with family - although it may be the lead consultant's responsibility, healthcare professionals need to consider if they are best placed to undertake this (or undertake it in conjunction with another individual that has rapport with the CYP/ families / carers)*	Thank you for your comment. In this recommendation we state 'take account of the views of the child or young person and their parents or carers' as one of the factors when deciding on who should lead communication. The Committee believe that rapport and relationship would fall into this category.
507	Royal College of Nursing	Short	6	14	If the initial conversation is carried out jointly with consultant / clinical nurse specialist (CNS), then frequent discussions could be carried out with CNS.	Thank you for your comment. We did not want to be too prescriptive about this since this may vary on a case by case basis.
508	Royal College of Nursing	Short	6	16	As above	Thank you for your comment. We did not want to be too prescriptive about this since this may vary on a case by case basis.
510	Royal College of Nursing	Short	6	19	Add to the bullet points: *Timely [with a warning shot if giving bad news] so the parents/carers can be prepared and can bring someone with them for support*	Thank you for your comment. The focus of this recommendation is about the type of information that the child or young person and the parents or carers value. This should be taken into consideration whenever information is provided. We do describe that some children and young people and parents or carers may be anxious about receiving information about the life-limiting condition in recommendation 1.1.16.
524	Royal College of Nursing	Short	7	8	Suggest add to the end of the sentence: *'or when to potentially revisit challenging information'*	Thank you for your comment. Thank you the recommendation that you are referring to is specifically about information provision and therefore refers to topics that people may not want to know about. However, we believe that

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						we have covered in other sections how to communicate, plan or review the information needs for example at different times during the course of the life limiting condition (e.g. in recommendation 1.3.65 and 1.3.66 we refer to the difficult discussions about death and dying) .
525	Royal College of Nursing	Short	7	13	This recommendation should go further and state that if parents think the child should not be told of their condition due to mental capacity, e.g. autism and/or learning difficulties, the parents/carers' wishes should be respected as they know the child best.	Thank you for your comment. We agree and that is why we intentionally worded this recommendation using terms such as 'if appropriate' and 'what they think their child should be told' to highlight just these situations.
526	Royal College of Nursing	Short	7	18	Consider if they have any choice in where information is delivered if it is clear they do not want to attend hospital, Should it delivered be at home? What is the role of the GP?	Thank you for your comment. We intentionally did not specify where this should take place because this may vary according to individual circumstances. A GP may well be involved in this.
527	Royal College of Nursing	Short	7	26	Suggest add to the sentence : *'and agree a time to discuss further if required'*	Thank you for your comment. The recommendation is about situations or signs that there is a need to provide further information. It is implied that this should then be provided rather than delayed until another time.
556	Royal College of Nursing	Short	9	21	Suggest add: *'seek permission / ask if the family wishes a professional to discuss with school on their behalf or plan for a joint meeting'*	Thank you for your comment. We agree that the wording of this recommendation seemed rather prescriptive. We did not mean that, for example schools, would always need sight of this and we have now made it clearer ('think about which professionals and services involved in the individual child or young person's care should also share it for example' with the bullet referring to schools).
563	Royal College of Nursing	Short	10	6	Suggest add: *'Need to be conscious that repeated conversations maybe onerous if held too frequently'*	Thank you for your comment. In the guideline's General Principles recommendation 1.1.2 advises discussions about how they wish to be involved in decision making. We believe that

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						this is an opportunity to take account of their preferences regarding the frequency of such conversations.
568	Royal College of Nursing	Short	10	22	Suggest add : '*acknowledge with the family that this may be a team approach and not just one individual'*	Thank you for your comment. In the 'General principles' section, it is recommended that children or young people as well as their parents or carers have a central role, but do not have to make decisions alone (please see recommendations 1.1.1 and 1.1.3). The Committee agree that this covers the notion of a team approach.
571	Royal College of Nursing	Short	10	26	Suggest add: "…*and with the consent of the child, young person and family,* share with relevant professionals and services involved in their care…"	Thank you for your comment. In keeping with recommendation 1.2.5 and 1.2.7, the Advance Care Plan including its distribution list would be developed in discussion with the child or young person and their parents or carers. We did not state that their consent was essential because there might be rare circumstances when this was not appropriate.
582	Royal College of Nursing	Short	11	23	Suggest add: *'The purpose of the Advanced Care Plan should be discussed with the family to aid communication etc.'*	Thank you for your comment. Please see recommendation 1.2.9 which addresses this issue.
607	Royal College of Nursing	Short	13	28	Suggest add: '…*Continuing Healthcare funding / social work (disability)'*	Thank you for your comment. In this recommendation we have provided categories with illustrative examples. They are therefore not exhaustive.
614	Royal College of Nursing	Short	14	1	Practical social support could include support to care for siblings, respite care for parents in any setting including hospital and home etc.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the

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						social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
616	Royal College of Nursing	Short	14	5	Suggest add: *'…and guidance with completing benefit claims'*	Thank you for your comment. Providing guidance on how to complete benefit claims is outside the remit of this guideline.
626	Royal College of Nursing	Short	14	27	Suggest rephrase and include: "…explicitly stated in the *original record with the family'*	Thank you for your comment. We have rephrased this recommendation to clarify this issue. It now states 'Attempt resuscitation for children and young people with life-limiting conditions, unless there is a 'do not attempt resuscitation' order in place.'
637	Royal College of Nursing	Short	16	10	Suggest add: '…*and cared for after death'*	Thank you for your comment. This section is specifically related to the preferred place of care and preferred place of death. We have covered the topic of care of the body in two other sections. Recommendation 1.3.7 highlights beliefs and values and how they may influence issues such as funeral arrangements and care of the body; and recommendation 1.4.1 highlights the need for information about these issues.
640	Royal College of Nursing	Short	16	25	Suggest add: *'…don't make promises'*	Thank you for your comment. In recommendation 1.1.18 we describe that professionals should be 'sensitive, honest and realistic' when talking to the child or young person. Therefore this means 'not making promises'.
645	Royal College of Nursing	Short	17	4	This should include issues such as possible delays in getting death certificates in some	Thank you for your comment. This is covered in recommendation 1.4.1 with regard to

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					settings, especially where same day burial is important.	practical information that will be needed after the death of a child: • relevant legal considerations, including - the involvement of the child death overview panel - the involvement of the coroner - registration of the death
655	Royal College of Nursing	short	18	11	There is no rapid transfer service in most places. The guideline should state rapid transfer pathway or protocol or plan as it is normal services coming together in these circumstances in an agreed way. Not a separate service usually.	Thank you for your comment. We have now changed 'rapid transfer service' to 'rapid transfer process' to clarify this point.
657	Royal College of Nursing	Short	18	14	• The coroner in some areas may prefer to be informed in advance of expected deaths in the community. Plan timely verification and certification of death, especially for planned deaths in the community to reduce delay in moving body e.g. to a hospice cool room, after death.	Thank you for your comment. Recommendation 1.4.1 aimed to encourage efficient handling of practical arrangements after the death of the child, including involvement of a coroner. Local variations in practice would therefore be a matter for local discussion. This recommendation also supports the need for forward planning in relation to the registration of the child or young person's death.
668	Royal College of Nursing	Short	18	18 to 20	Please amend the bulleted list wordings as follows: 1.3.20 When assessing and managing pain, be aware that various factors can contribute to unrelieved pain including: • Please delete ‘causative’ and insert ‘biological factors’, for example insert stiffness, muscular spasms and delete musculoskeletal disorders or constipation • environmental factors, such as an uncomfortable or noisy care setting	Thank you for your comment. We have amended 'causative' to read 'biological'. The examples are meant to be illustrative and not comprehensive.

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					• psychological factors, such as anxiety and depression • social, emotional, religious, spiritual or cultural considerations.	
672	Royal College of Nursing	Short	19	6	Suggest add: Procedural or incident pain	Thank you for your comment. Please see recommendation 1.3.31 related to anticipatory doses of analgesia which addresses your comment. We agreed that procedural or incident pain would be covered by this. We have also included a research recommendation on pain management which partially addresses this point.
678	Royal College of Nursing	Short	19	29	Please amend and add as follows: • Delete 'local' and insert 'topical hot or cold applications' to the site of pain <<topical>> hot or cold applications to the site of pain • Insert Application of TENS	Thank you for your comment. We would like to keep 'local' since this is more easily understood. These are examples for illustrative purposes and not an exhaustive list. There was no direct evidence for the effectiveness of any particular approach, but the Committee reached consensus on a few measures that would help relax children and may therefore contribute to pain reduction.
680	Royal College of Nursing	Short	20	7	Suggest add to the bullet points: • Dry mouth	Thank you for your comment. We have added 'for example' to indicate that this is not an exhaustive list of possible side effects.
683	Royal College of Nursing	Short	21	2	Suggest add to the bullet points: Nasal fentanyl	Thank you for your comment. We recognise that such routes are used and this is acknowledged in the recommendation 1.3.27 referring to transmucosal administration. The Committee did not feel that there was sufficient existing evidence to make specific recommendations on the various transmucosal or transdermal options.
684	Royal College of Nursing	Short	21	22	Please amend as follows: Consider inserting gabapentin or pregabalin (NB shorter onset of action and twice daily	Thank you for your comment. We left this intentionally broad because there was not specific evidence for this. However, we have added an overarching recommendation to

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					dosing)	involve the specialist paediatric palliative care team if the child or young person has unresolved distressing symptoms (recommendation 1.3.20). This team is now described in recommendation 1.5.4 and also includes a pharmacist with expertise in specialist paediatric palliative care.
700	Royal College of Nursing	Short	26	3	With regards to referring patients to other specialist teams for advice - Would referring the patient to yet another team not add to the complexity for the patient? Or would you seek advice on symptom management on behalf of the patient from that specialist team or a palliative care team that would have experience of managing such symptoms, particularly in end of life, as we appreciate that most services won't advise without at least meeting the patient? Some of our members have concerns that families sometimes struggle with an overwhelming number of professionals being involved, can a CNS, Key worker or team who are already supporting the family, coordinate a wider more inclusive input regarding symptom management rather than simply deferring to yet another service	Thank you for your comment. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care has been added; please see recommendation 1.2.2. A further new recommendation has been added under 'managing distressing symptoms'; recommendation 1.3.20 addresses the need for involving the specialist paediatric palliative care team when distressing symptoms are unresolved, and precedes all symptom management recommendations.
736	Royal College of Nursing	Short	31	3	Suggest add to bullet points: '*Acknowledge there may be a delay or trigger in some feelings being experienced – which may not occur for some months after*'	Thank you for your comment. We believe that professionals with 'the appropriate expertise' (recommendation 1.4.4) in bereavement support would know that this could be the case.
738	Royal College of Nursing	Short	31	6	Include Bereavement support for siblings and for the child's friends through the schools/colleges.	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and

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						other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
739	Royal College of Nursing	Short	31	20	Need to be careful not to promote reliance	Thank you for your comment. The Guideline Committee agreed that bereavement support should be discussed and offered. Reliance is then something that the provider of this support should be aware of.
787	Royal College of Nursing	Short	33	21	This is difficult to predict and staff for 'just in case', potentially utilise the skills of multiple teams to provide out of hours support with core team providing daytime support seven days per week with an on-call system in place for advice and support.	Thank you for this comment. Resource allocation for implementation of recommendations is a matter for local commissioning, but the Committee were of a view that one way such a service could be provided is using an approach similar to that what is outlined in your comment.
788	Royal College of Nursing	Short	33	27	Important to have ‘just in case’ medicine available as this can be challenging to source/obtain medication during out of hours, in particular some paediatric preparations can have a lead time to order from community pharmacies and best supplied from hospital	Thank you for your comment. Please see recommendation 1.5.9 which specifies 'anticipatory prescribing' as one of the services that should be in place when a child or young person approaching the end of life is cared for at home.
801	Royal College of Nursing	Short	34	4	Agree that these should be based on the established clinical networks, but regional children’s palliative care clinical networks	Thank you for your comment. Yes, we agree and have amended it to read 'managed' rather than 'established.

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					would be even better if there were managed clinical networks just as the neonatal networks are across England, or the network which is in place in Wales. Could this be suggested?	
802	Royal College of Nursing	Short	34	8	Suggest add: …and *readily available equipment - syringe drivers, such equipment ideally needs to be common across provider agencies*	Thank you for your comment. We recommend equipment in recommendations 1.2.28 (social and practical support), 1.3.14 (preferred place of care) and 1.5.9 (care at home). This includes practical support and equipment for interventions including oxygen, enteral nutrition, and subcutaneous and intravenous therapies. The purpose of NICE guidance recommendations is that what is recommended should be available.
43	Royal College of Paediatrics and Child Health	Full	General		This is a tremendous quantity of work which clearly reflects the detailed and thoughtful reflections of a wide body of experienced practitioners. It seems to have sought to provide outline guidance to the key elements of managing children and young people with life-limiting conditions.	Thank you for your comment.
44	Royal College of Paediatrics and Child Health	Full	General		As with all NICE guidelines, the shorter recommendations statements, which are often perceived independent and incorrectly to be the whole of the guideline, may be misinterpreted. For example rec. 7: “When difficult decisions must be made about end of life care, give children and young people and their parents or carers enough time and opportunities for discussions.” The extensive discussion around the provision of this and negotiated way to allow this within a wide MDT and use of multiple participants is simplified, possibly too much. I can – partly deliberately - misread this as	Thank you for your comment. The evidence showed that time devoted to speak to families is critical to effective end-of-life care. The Committee felt strongly about making this particular recommendation to promote good practice in this particular area and improve satisfaction with services in what is understandably a very difficult time for the child or young person and the parents or carers.

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					"Doctors have to spend as long as families say they should with them when they say they need it." Is there a way of describing the setting of the recommendations, for example in the composition of the broad healthcare team involved in care that would offset some of this, early on in the 137 recommendations?	
45	Royal College of Paediatrics and Child Health	Full	General	General	Overall, much of this guideline is based on expert consensus rather than evidence of research and more questions are raised than answered. This is an extremely important area of clinical practice and one that requires investment if services for children and young people with life limiting conditions are to be provided in a way that is safe and sustainable.	Thank you for your comment. We acknowledge that quantitative evidence was limited in this population most likely due to ethical considerations or difficulties to recruit. However, we had a fairly big evidence base on some of our qualitative reviews. Research recommendations are only made in areas where gaps are identified and are then prioritised by the Committee. After further consideration of the topics that we addressed we have now added one further research recommendation because we thought that the evidence for perinatal end of life care was indeed very limited and hope that this will inform future guidance.
46	Royal College of Paediatrics and Child Health	Full	General	General	There needs to include a strong statement to the effect that children who are considered to be at risk of early death or to be potentially dying need to have access to experts in their condition, to ensure that they have been afforded the best possible healthcare, symptom control (fine tuning) and life chances. Who this specialist is will depend on the health condition of the child and will include a range of '-ologists'. For disabled children and young people this must include access to a paediatrician with competence in childhood disability. I think this is very important indeed, as otherwise children may	Thank you for your comment. Recommendation 1.5.3 about the multidisciplinary team (MDT) has been amended: we have added 'Allied Healthcare professionals' and 'those with expertise in managing the child's underlying life-limiting condition' to the MDT. A new recommendation, 1.5.4, has also been added: this is about the 'specialist paediatric palliative care team' and who should be involved in it. The guideline committee also amended recommendation 1.2.6 to clarify that if the condition is diagnosed during pregnancy think about involving specialists in the discussion, such as

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					be at risk of being put on palliative care pathways before all positive treatment options have been fully considered and discussed with families.	obstetricians, midwives, neonatologists, condition-specific specialists and experts from the paediatric palliative care team.
47	Royal College of Paediatrics and Child Health	Full	General	General	The guideline does not include the issues of transitioning an ACP and DNAR or modified resuscitation plan to adult services, where the law changes at 18; this particularly relates to those children who do not attain competence to consent for themselves. We recommend that transition needs to be robustly addressed, including emphasis on decision-making taking place within the framework of the Mental Capacity Act 2005, including the best interest's decision-making process for those who are assessed not to have capacity. Please see reference: Horridge KA. Advance Care Planning: practicalities, legalities, complexities and controversies. Arch Dis Child. 2015; 100:380-385 We understand that the ALSG working group are in the process of formulating guidance and The ReSPECT template is the new national form that is being piloted at the moment in four sites, one of which is South Central. It will then be reviewed and updated before final version goes live. More can be found at: https://www.resus.org.uk/consultations/respect/ The final version of this may not be complete	Thank you for your comment. The Committee members acknowledged transition is a very important issue, however it is outside the scope of this guideline. There is specific NICE guidance on transition from children's to adult's services, and we have cross-reference to that document in the care planning section.

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					in time for publication of the NICE guidance; we would recommend the guidance signposts to the Resuscitation Council website, for progress and cross referencing.	
87	Royal College of Paediatrics and Child Health	Full	General	Chapter 6	I note the evidence, both published and commissioned focus group, around the concept of advance care planning / directives and the synthesis of this information. As acknowledged in 6.1.8.2 the data is largely conceptual not specific to the practical use and content of such documents. I also note the group decided not to make a research recommendation in this area, and give an extensive list of items they felt should be included (6.1.8.5 line 44+). As a practical way of supporting the use of ACP this may be valuable, but may stifle detailed study into different quantities of information, formats and ways of developing/using the data. Could the recommendation (24) be worded in a way which reflects this “we think ACP are good and the evidence shows this, but the exact items here are suggestions based on our best guess”. ‘Should’ I associate with high quality evidence, and this appears not to be the case here.	Thank you for your comment. We acknowledge that the evidence was limited, but the Committee agreed that this was such important information that it 'should' be included as a minimum.
252	Royal College of Paediatrics and Child Health	Full	35	25, 29	Terminology: re: neurodevelopmental conditions. It would be better to say neurodisabling conditions, as the term ‘neurodevelopental conditions’ is often taken to be synonymous with autism conditions, attention deficit etc. rather than the broader range of conditions that are more likely to be	Thank you for your comment. We have now referred to nervous system conditions (including neurodisabling conditions). The term nervous system conditions was the one used in the cited report.

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					associated with life limitation e.g. cerebral palsies, chromosomal and genetic conditions etc. (although we do recognise that if the terminology is directly referenced from the 2014 report – there may need to be consistency with this.)	
254	Royal College of Paediatrics and Child Health	Full	36	27-29	The guideline covers children and young people with a life limiting condition but does not make recommendations for those who die suddenly and unexpectedly. Data from Why Children Die? And from the Child Death Review Overview Process outputs evidence that children and young people with life limiting disabling conditions are at significantly greater risk of sudden and unexpected death compared to other children and young people. This guideline should acknowledge this and address this important group, who benefit just as much from advance care planning and from being informed of the risk of sudden and unexpected death, what to do if this occurs etc.	Thank you for your comment. As highlighted in your comment, this group is not excluded from the guideline and the recommendations that have been drafted would apply to children and young people with respect to the general planning of their condition. However, it is difficult to recommend anything for any unexpected events. The Committee has, however, drafted sections on social, practical, emotional and religious support which would apply to children and young people affected by such events.
290	Royal College of Paediatrics and Child Health	Full	197	Section 6.2.9	Although there is mention of 'safety and practicality' as factors influencing choice of place of death, there is insufficient discussion about consideration of safeguarding issues. Some parent carers may not be able to recognise changes in a child's wellbeing or symptoms and the clinical MDT must be able to assess this and take this into account when considering where it is practical to deliver end of life care. The main consideration must be the best interests and wellbeing of the child or young person, rather than parental choice. The guideline does not make this clear and it would be helpful if it	Thank you for your comment. We agree that this is important. Please see the link 'Making decisions using NICE guidelines' at the beginning of the guideline, which includes information on standards and laws (including on consent and mental capacity), and safeguarding.

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					did.	
326	Royal College of Paediatrics and Child Health	Full	286	Line 38	There is limited discussion in the guideline about how children and young people with life limiting conditions can best be supported to continue their education and how their health needs can best continue to be met at nursery, school or college, nor of the need to support the staff in schools who provide daily care for them. This is really important, as the complexity of needs of children and young people with complex and life limiting conditions is increasing, with increasing technology dependencies that need to be supported in a safe and sustainable way.	Thank you for your comment. Educational support was not prioritised in the scope of the guideline and was therefore not reviewed. However, we mention 'ambitions and wishes' for example in relation to education in the Advance Care Plan section and hope that this will encourage healthcare professionals to think about such issues.
351	Royal College of Paediatrics and Child Health	Full	358	section 93	In the section on gastro-intestinal pain, there needs to be specific mention of pain from gastro – intestinal dysmotiliity and/or gastro-oesophageal reflux disease, both are very common in children and young people with complex disabling conditions and there is a separate NICE guideline for gastro-oesophageal reflux disease.	Thank you for your comment. We agree that the wording of this may have been confusing and that these are not the only causes. We have now clarified that these are just examples, and that this is not meant to be an exhaustive list.
441	Royal College of Paediatrics and Child Health	Short	General	General	This is an excellent document with much to recommend it. It is important to remember how much end of life care is provided in non-specialist settings eg. district general hospital general paediatric ward where medical and nursing staff may never have cared for a dying person before. It is therefore important that the document makes explicit in the implementation section the need for education, courses, information and ongoing updates for staff to ensure that everyone is equipped with adequate knowledge, skills and attitudes to provide these CYP and their families with high quality care.	Thank you for your comment. Your comments will be considered by NICE where relevant support activity is being planned

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474	Royal College of Paediatrics and Child Health	Short	5	4	Challenging to implement continuity in these situations given changeover of training doctors. Perhaps worth suggesting a named lead clinician who might be someone from the multidisciplinary team eg. the specialist nurse, the consultant, the physiotherapist who is their key worker (mentioned on page 33, line 5 but important to reference earlier too)	Thank you for your comment. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist to lead on and coordinate their care has been added; please see recommendation 1.2.2. Please also see recommendation 1.1.5 about the importance of continuity of care.
542	Royal College of Paediatrics and Child Health	Short	8	23	Challenging to request that all children have an Advanced Care Plan but a laudable aim. Educationally, training doctors (and I suspect many consultants) would need training to increase awareness about the existence of these and how to use them acutely, as well as the process of drawing them up.	Thank you for your comment. We believe that all children and young people with a life-limiting condition should have a plan in place which in their case is called 'Advance Care Plan'. These recommendations should help to standardise good practice. Guidance related to training and education of healthcare professionals is outside the remit of this guideline.
674	Royal College of Paediatrics and Child Health	Short	19	17	Managing pain in these children is clearly very important and there will be much educational work needed to upskill nurses and doctors working on general paediatric wards to ensure this is done well. Might it be worth adding that teams can liaise with their anaesthetic colleagues who are much more used to doing this kind of thing, as well as being in phone contact with the hospice/palliative care team if the child is in a general hospital environment and symptoms of pain are not well controlled	Thank you for your comment. We have reviewed this issue with the Guideline Committee and a new recommendation has been added under ‘managing distressing symptoms’: recommendation 1.3.20 is about involving the specialist paediatric palliative care team if there are unresolved distressing symptoms as they approach the end of life, and it precedes all symptom management recommendations.
745	Royal College of Paediatrics and Child Health	Short	31	25	It is important to be explicit here that healthcare professionals may require a debrief, discussion with colleagues also involved in the care of the child as well as access external sources of help.	Thank you for your comment. The recommendation resulted from a discussion of the evidence for social and practical support for family members when a child or young person is approaching the end of life or has died. However, the Guideline Committee recognised in this context the impact that the

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						death of a child or young person can have on healthcare professionals who have provided end of life care. Therefore this recommendation was included because it was felt important that staff welfare at this particular point in time was not overlooked.
76	Royal College of Physicians	Full	General	General	The guideline is a comprehensive review of the limited evidence currently available around the provision of end of life care for children and young adults which makes sensible recommendations based on the evidence and expertise within the group writing the guideline. The calls for further research are to be welcomed but will need national lead and momentum in light of the small numbers of deaths that any individual trust or organisation will encounter.	Thank you for your comment.
77	Royal College of Physicians	Full	General	General	It would be helpful where possible for the guideline to mirror the guideline for adults (such as the kind of medications used for common symptoms) – to reduce the clinical risk to children and young adults of not being offered any support or inappropriate support because the 2 guidelines make different suggestions (they generally do not) that general physicians feel they are unable to use transferable skills when supporting a dying child or young adult.	Thank you for your comment. The Care of the Dying Adult guideline addressed a different timeframe (the last days and hours) compared to our guideline and was more directly targeted on particular topics that occur in these final days. The Care of the Dying Adult guideline was already published and we reviewed the recommendations when we drafted ours. The timeframe for pain management in particular was considered over the course of the life limiting condition in our guideline rather than focussed on the last days or hours in the Adult guideline. Therefore the medication recommended in these two guidelines differs.
78	Royal College of Physicians	Full			**If a child or young person is approaching the end of life and has respiratory distress, breathlessness or noisy breathing:** • **explain to them and to their**	Thank you for your comments. We addressed the issues of non-pharmacological treatments in recommendation 1.3.44, in accordance to NICE guideline methodology we reviewed the age appropriate evidence which was limited.

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					parents or carers that these symptoms are common - **discuss the likely causes or contributing factors** - **discuss any treatments that may help.** - There should be clear recommendations on noisy breathing. This includes non-pharmacological such as positioning, suction, or physiotherapy (if appropriate) or the anticholinergic drugs, hyoscine, hydrobromide, hyoscine, butylbromide, or glycopyrronium, as treatment options. There is an evidence base for these in adults (although there is not sufficient to recommend one above another).	The Guideline Committee decided therefore to limit their recommendations to general advice about the possible role of these various drugs.
196	Royal College of Physicians	Full	25	25 - 27	**Be aware that continuity of care is important to children and young people and their parents or carers. If possible, avoid frequent changes to the healthcare professionals caring for them.** A comment is needed about limiting the number of health and social care professionals involved to that which is acceptable to the family and these individuals should have the knowledge and skills to deliver the care needed. Local organisations should collaborate and act on each other's assessment and recommendations around care and its delivery.	Thank you for your comment. We did not want to be too prescriptive about this because due to individual circumstances it may be in the best interest of the child to have more people involved than the family would have wished.
214	Royal College of Physicians	Full	27	26 - 30	**When a child or young person is approaching the end of life, discuss with**	Thank you for your comment. The recommendation does give some explanatory

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					their parents or carers what would help them, for example: • **important rituals** • **recording or preserving memories (for example with photographs, hair locks or hand prints).** Creation of memories can go beyond hand prints. Our experts believe that the current statement reads in a way that it may be a barrier to other approaches, such as making a cushion out of a favourite shirt or duvet.	examples of possible ways of recording memories. These are examples, the list is not exhaustive.
267	Royal College of Physicians	Full	96	General	(p96-139) The key area of communication skills and engaging in difficult conversations is well covered and comprehensive.	Thank you for your comment.
348	Royal College of Physicians	Full	358	26	**Neuropathic pain (which can be associated with cancer)** This comment should be removed as neuropathic pain occurs in a wide spectrum of diseases, not just cancer.	Thank you for your comment. We agree that the wording of recommendation 1.3.22 may have been confusing and that these are not the only causes. We have therefore revised it by changing 'which can be associated with' to 'for example, associated with', to clarify that this is not an exhaustive list.
352	Royal College of Physicians	Full	359	23 - 24	**If treatment with a specific opioid does not give adequate pain relief or if it causes unacceptable side effects, think about trying an alternative opioid preparation.** This statement should include a recommendation about seeking specialist advice early from those with either specialist paediatric palliative care knowledge or adult palliative medicine consultants who will have some training around paediatric palliative	Thank you for your comment. We have reviewed this issue with the Guideline Committee and a new recommendation has been added under ‘managing distressing symptoms’; recommendation 1.3.20 addresses the need for involving the specialist paediatric palliative cate team when distressing symptoms are unresolved, and precedes all symptom management recommendations.

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					care. There is no evidence for this but it would be sensible addition.	
354	Royal College of Physicians	Full	359	20	**Transmucosal opioids** The committee should specify that trans mucosal opioids include transdermal, sublingual, and buccal. The evidence for all is poor but does exist and these are widely used.	Thank you for your comment. We recognise that such routes are used and this is acknowledged in recommendation 1.3.27, referring to transmucosal administration. The Committee did not feel that there was sufficient existing evidence to make specific recommendations on the various transmucosal or transdermal options.
355	Royal College of Physicians	Full	359	37 - 2	(p359-360) **If you suspect neuropathic pain and standard analgesia is not helping, consider a trial with other medicines, such as:** • **gabapentin or** • **a low-dose tricyclic antidepressant (for example amitriptyline) or** • **an anti-NMDA agent (for example ketamine or methadone), used under guidance from a specialist.** It is unclear on where pregablain as a second line to gabapentin fits. It is commonly used when gabapentin is not tolerated or is ineffective.	Thank you for your comment. These are only examples of medication that could be used. The list is not exhaustive which is why we added that a 'specialist' should be involved to select the appropriate drug tailored to the individual life-limiting condition.
239	Royal College of Psychiatrists	Full	33	40-42	We agree with recommendation 3 of the key research recommendations. We do need better research in this area, as it is clear from the lack of studies available for NICE to	Thank you for your comment.

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					review	
315	Royal College of Psychiatrists	Full	250	22- 26	We agree ‘that the lack of evidence should not be interpreted as a lack of effectiveness. The recommendations reflected this lack of evidence while recognising that psychological and emotional support is important for the well-being of children and young people with life-limiting conditions and their parents and carers. The Committee were strongly of the view, based on their clinical experience and evidence in other contexts, that psychological and emotional support was likely to be cost effective’	Thank you for your comment.
316	Royal College of Psychiatrists	Full	250	31-32	We agree that the expectation was that some uplift in NHS resource use would be required to redress the inequity in access to psychological and emotional support	Thank you for your comment.
318	Royal College of Psychiatrists	Full	252	1-6	We are not sure why it is beyond the scope of the guidance to make recommendations on the importance of training, support, supervision and access to psychological consultation for healthcare professionals around talking with children and young people and families about their emotional and psychological needs. We disagree that NICE cannot recommend this as something that acute trusts, CCGs etc. need to commission i.e. access to consultation and advice for those working with end of life cases	Thank you for your comment. The issue of training is outside the remit of this guideline. NICE guidelines assume that healthcare professionals would have the appropriate training and expertise in their area.
94	Royal Marsden Hospital	Full	4	20	1.1.3 The way the language is written it suggest that “that they do not have to make decisions alone” - does this mean that parents can make decisions alone or should it always be in partnership and discussion with professionals.	Thank you for your comment. The intention is to reassure parents that children and young people's views are very important, but they are not alone in decision making. They will be a part of the decision making process with the MDT. We think this is clear in the context of

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						the full recommendation.
95	Royal Marsden Hospital	Full	4	11-13	1.1.1 There should potentially be a comment around partnership working with professionals here.	Thank you for your comment. Working in partnership with professionals is highlighted in the 'General Principles' section of this guideline (please see recommendations 1.1.2, 1.1.3 and 1.1.4). These are overarching recommendations therefore we have not reiterated this in all the remaining sections.
97	Royal Marsden Hospital	Full	5	14	1.1.6 Comments about digital media - there needs to be clarification here regarding whether the social media is relating specifically to the child or general information about social media awareness and individual.	Thank you for your comment. This was written in the context of 'thinking about the format of the information taking into account their age and level of understanding'. The bullet points then provide some examples. Digital media can be used if children who are already using them and social media was highlighted by the children in our focus group as important in their day-to-day lives.
98	Royal Marsden Hospital	Full	6	19-27	1.1.12 There is no reference to recent research around positive approach that children have requested for report information to be shared with, perhaps they should look at this. Also some comment about checking out what level of information the child is wanting as the conversation goes on.	Thank you for your comment. We agree that information should be shared with children and young people taking account of their views and this is covered in recommendation 1.1.15. The important matter of continuing this discussion is addressed in 1.1.17.
99	Royal Marsden Hospital	Full	6	4	1.1.9 The bullet point stating in “when reviewing the Advanced Care Plan” perhaps this should read “when developing and reviewing the Advanced Care Plan”	Thank you for your comment. We agree this would be an appropriate modification which will compliment recommendation 1.2.6 with regard to developing and reviewing the Advance Care Plan in discussion with them. We have amended recommendation 1.1.12 accordingly.
100	Royal Marsden Hospital	Full	6	7-8	1.1.10 This comment appears to have been repeated at 1.1.2.	Thank you for your comment. We would like the recommendations to remain as they are because one focusses on decision making the other on information provision.
101	Royal Marsden Hospital	Full	6	9-11	1.1.11 I am not sure that this point is well phrased due to the nature of many of	Thank you for your comment. We felt that this recommendation (now 1.1.14) did allow for the

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					the paediatric conditions. Different professionals may have different expertise and have the ability and expertise to discuss topics at different times throughout the palliative care process. This requires some rephrasing.	variation in individual needs, in the expertise needed and at different times in the child or young person's life. The recommendation specifically says that the decision relates to 'a particular stage in the child or young person's illness'.
102	Royal Marsden Hospital	Full	7	4-20	1.1.14 A balance should be struck here between what topics families do not want details and information on, but also the need for information to be shared. For example a sudden event, “If appropriate ask parents or carers what they think their child should be told about their condition”. This statement should be about this being aged dependent, if they are aged 16/17 the question should be addressed to them.	Thank you for your comment. We agree that this is a difficult balance. Children and young people are in the preamble to this recommendation and you would therefore always attempt to do this. The bullet that you quote is qualified by 'if appropriate' because there may be many other situations and circumstances apart from age that may influence information provision for the child or young person. Furthermore the partnership between professionals and children, young people and their parents or carers with regard to decision making is highlighted as a 'General Principle' at the beginning of this guideline.
104	Royal Marsden Hospital	Full	8	17-18	1.2.2 There needs to be a mention here around parallel planning, particularly end of life and disease specific follow up.	Thank you for your comment. We recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 to the ‘General principles’ section, explaining the need for parallel planning in order to take account of possible unpredictability in the course of life-limiting conditions. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section of the short guideline. We also slightly changed recommendation 1.2.5 on advance care planning.
105	Royal Marsden Hospital	Full	8	2-11	1.1.17 There is no discussion here about child death review process, which is an important part of information sharing prior to the death of the child.	Thank you for your comment. Providing information about the relevant legal considerations in relation to the child or young person's death are described in

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						recommendation 1.4.1. This recommendation highlights the need for information, e.g. on the involvement of the child death overview panel, the involvement of the coroner and registration of death.
106	Royal Marsden Hospital	Full	9	9-31	1.2.4 “a statement covering what information about the child or young person and their parents or carers will be shared, and with whom” - is this different from a distribution list as this is not clear to me. “an outline of the child or young person’s life ambitions and wishes” - I find that the word ambitions slightly ambiguous. In these circumstances and where is the evidence for this use of this language. “a record of significant discussions with the child or young person and parents or carers”. This implies that not all conversations should be documented which I think is not appropriate. This needs to be re-phrased to state that all conversations need to be documented. “a record of any discussions and decisions on ……………… “ - this needs to be clear not everything has to be gone through, for example, funeral arrangements may be completely inappropriate at this stage, depending upon the family. There is no statement here about reversible conditions, for example, choking that needs to be included.	Thank you for your comment. We have removed the bullet point of 1.2.5 regarding the sharing of information ('what information to be shared and with whom'). On further consideration we believe that this occasionally important matter is dealt with in the previous bullet regarding an 'agreed approach to communication'. Regarding 'ambitions and wishes' we felt that though this is broad ranging it captures the child or young person's wishes beyond their clinical care, which is of course centrally important. The recommendation refers to 'significant discussions' because we considered that it would be impractical (and sometimes inappropriate) to document all discussions that take place with HCPs. Some might be inconsequential and some might be private.
107	Royal Marsden Hospital	Full	10	19-20	1.2.9 “ensure that relevant professionals	Thank you for your comment. We have

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					can plan, develop and implement a management plan for now and the future" - this is a very loose thinking comment. It is not clear who should ensure this large holistic plan for now and in the future.	removed this bullet from the recommendation as we agree it does not contribute usefully to an explanation of Advance Care Planning.
108	Royal Marsden Hospital	Full	11	23-26	1.2.14 No comment has been made about engagement of families and the young person and some not wanting Advanced Care Plans.	Thank you for your comment. The Guideline Committee agreed that all children should have a plan in place which is called an Advance Care Plan (ACP), but we have reviewed this issue and made two changes that address your concern. First, we added a recommendation about the importance of parallel planning into the 'General Principle' section. Second, we clarified that some discussions that may go into the plan are optional components, i.e. in recommendation 1.2.5, to 'a record of discussions and decisions' we have added 'that may have taken place' because it included examples related to organ donation and management of life threatening events including plans for attempted resuscitation, therefore not everyone would need to have these discussions when the ACP is developed for the first time.
109	Royal Marsden Hospital	Full	11	1-6	1.2.10 Specialist nurse should be included in this list, both local and specialist hospitals. Disappointing since there are several nurses on the NICE committee that this was not picked up.	Thank you for your comment. We have amended the bullet in accordance with your advice to now read 'nursing services (community or specialist)'.
110	Royal Marsden Hospital	Full	11	7-14	1.2.11 Additional points need to be made • If change in medical condition • Request by family or professional	Thank you for your comment. It is important to update the Advance Care Plan if there are important changes and this is addressed in recommendation 1.2.12. The recommendation gives some examples, but these are not intended to be exhaustive.

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111	Royal Marsden Hospital	Full	12	23-27	1.2.21 There is no comment here around normal grief reaction to life limiting conditions, or comment on complex grief.	Thank you for your comment. The psychological difficulties and mental health problems mentioned are exemplary and high level. It was not intended to provide a comprehensive list of causes. The topic of bereavement is addressed later in the guideline.
113	Royal Marsden Hospital	Full	12	1-3	1.2.15 "Changed in some circumstances" - this should be part of all plans or stated within the plan around specific circumstances, for example undergoing general anaesthetic for another condition or choking.	Thank you for your comment. It is true that any plan might be subject to change, but the Guideline Committee felt strongly that this was a specifically important plan that needed to be highlighted in an individual recommendation. A resuscitation plan for a child needs to be clear in normal circumstances should be adhered to, but they felt it was important to bear in mind the fact that it might sometimes need further consideration.
114	Royal Marsden Hospital	Full	14	26-27	1.3.1 "Never assume that there is a do-not-resuscitate plan in place for a child or young person unless this is explicitly stated in their records" – this is a very odd statement and am not certain what this is.	Thank you for your comment. Recommendation 1.3.1 has been rewritten: we have used positive phrasing to indicate that resuscitation should always be attempted, unless a do-not-attempt-resuscitation order is in place.
115	Royal Marsden Hospital	Full	14	22	1.2.31 "mutually acceptable" – should read something around supporting the child rather than something being acceptable to everyone.	Thank you for your comment. The Committee agreed that it was important to give consideration to the child or young person's views on their care and to discuss an approach to try and achieve agreement if this was possible.
116	Royal Marsden Hospital	Full	14	1-3	1.2.27 "Practical support such as access to respite care" - there is no comment around sibling support. "Technical support, such as training and help with administration of drug infusions at home" – we have to be careful about this statement. It may suggest that we are happy to support	Thank you for your comment. The Guideline Committee agree that siblings also need support. A new recommendation, 1.1.6 has been added under 'General principles' detailing the social, practical, emotional, psychological and spiritual support needs specifically of siblings. The reference to 'training and help with

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					families to learn how to give opiates at home on a general basis via infusion.	administration of drug infusion' is a sub-bullet of a recommendation that refers to varying support needs that may change during the course of the life-limiting condition. This was then given as an example of such a need. We were not suggesting that everyone should do this.
117	Royal Marsden Hospital	Full	14	10-11	1.2.28 "be aware that they may need to discuss their beliefs and values more than once" – this needs to be phrased better, it sounds like we are only wanting to listen to the family once but we can put up with that if we listen to it again.	Thank you for your comment. The preceding sentence introduces this topic by asking healthcare professionals to have a discussion about beliefs and values if children or young people and their parents or carers are open for this. The Committee then wanted to highlight that once this discussion has taken place it may need to be revisited periodically because these beliefs may change over time. Therefore this second sentence directly refers back to the first and we think that together they would be interpreted in this way.
118	Royal Marsden Hospital	Full	15	25-28	1.3.6 It needs to state that not everybody wants to discuss care of body and funerals as this may encourage services to discuss inappropriately with them and they may find this distressing. This is not highlighted here disappointedly.	Thank you for your comment. In many recommendations we have highlighted that clinicians should be aware of the fact that the people involved will find it difficult to talk about dying (see particularly recommendation 1.3.1 and also 1.3.6, but also recommendation 1.2.26 with regard to emotional wellbeing). The focus of the recommendation in your comment is stating that the issue of these arrangements should be raised if possible. It is up to the discretion of individual clinicians to take into account whether the individual family is ready for this conversation.
119	Royal Marsden Hospital	Full	15	22	1.3.7 There needs to be a statement about asking open questions rather than the role of direct questions, this does not phrase very well on this statement.	Thank you for your comment. We have intentionally phrased these recommendations using open questions 'discuss what would help them' or 'take account of beliefs and values when thinking about'. We therefore think that

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						this will encourage exploration of these issues.
120	Royal Marsden Hospital	Full	15	1-4	1.3.2 It would appear that you jump from comments on DNRs to ACP – this does not flow well reading the document and is not helpful when looking to make the document user friendly.	Thank you for your comment. The Committee intentionally used this order to highlight that an ACP is not equivalent to a DNAR statement (which may or may not be part of it). They discussed that this is an issue that is still sometimes misunderstood in current clinical practice.
126	Royal Marsden Hospital	Full	16	1-6	1.3.8 Does information on child death review sit here?	Thank you for your comment. We are unsure which recommendation you are referring to. We have included 'a discussion and the provision of information' about the 'child death overview panel' in recommendation 1.3.1.
135	Royal Marsden Hospital	Full	17	29-30	1.3.16 The comment around sign posting that when professional will help with the practical administration arrangements around death, might be suggestive that there might sign post rather than do it regularly.	Thank you for your comment. The recommendation refers to the planning of rapid transfer and it states that the Advance Care Plan should be updated to include a record of 'the professionals who will help with the practical and administrative arrangements after the death.' We believe that this statement implies that once recorded they should be doing this and furthermore the Guideline Committee agreed that this would not usually happen on a 'regular' basis.
145	Royal Marsden Hospital	Full	18	18-25	1.3.20 Proxy reporting and perception of parents is not commented on, despite research on this area.	Thank you for your comment. In the first instance, the child or young person would be asked whether they are in pain in an 'age-appropriate approach that takes account of their stage of development and ability to communicate' and 'try to identify what is causing or contributing to their pain, and be aware that this may not relate to the life-limiting condition' (recommendation 1.3.22). This identification process does not preclude asking other people such as parents or carers or other multidisciplinary team members to ascertain whether the child or young person is

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						in pain. The topic of proxy reporting as a key clinical area or question was not included in the scope and therefore not separately covered.
153	Royal Marsden Hospital	Full	18	11-13	1.3.18 Comments about death on route, change of level of care from one institution to another, and level of intervention should be stated within this part of document.	Thank you for your comment. The topics you are referring to in your comment are covered in recommendations: 1.3.17 (to raise awareness that they may die sooner or later than expected); 1.3.16 (changes in level of care); and 1.3.13 (the care available in different settings).
162	Royal Marsden Hospital	Full	19	6-10	1.3.21 Additionally points around “neuropathic pain (which can be associated with cancer)” this appears odd and unhelpful, suggesting that you can only experience these symptoms. Bone pain - I note it could also be associated with metastatic cancer, I do not think this is helpful since people will start to perceive that this is the only place that children may experience and I think the brackets should be removed. This is meant to be a professional document, the brackets suggest we don’t know how to define pain and in which children.	Thank you for your comment. We have revised this recommendation by changing 'which can be associated with' to 'for example associate with' to clarify that these are just examples rather than a specific comprehensive list.
163	Royal Marsden Hospital	Full	20	8	1.3.25 Uncertain what “reduced mobility” above other more significant and important symptoms in pain management should be included in this list.	Thank you for your comment. This refers to the possible side effects of analgesia for moderate to severe pain (such as opioids); whilst most side effects including unwanted sedation and nausea usually improve over time, patients are likely to need active treatment to prevent constipation in the longer term.
173	Royal Marsden Hospital	Full	21	5-7	1.3.27 There is no statement that perhaps we should consider if the pain is opiate sensitive pain and deciding	Thank you for your comment. In recommendation 1.3.33, we recommend that in the event that neuropathic pain is suspected

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					whether to switch.	and standard analgesia is not helpful, that a trial of treatment with other agents listed (as listed in the recommendation) should be considered (recommendation 1.3.33). Recommendation 1.3.20 highlights the importance of various factors that can contribute to pain, such as musculoskeletal disorders and constipation. We have also added a new recommendation, 1.5.4, highlighting the importance of the involvement of the specialist paediatric palliative care team in case of unresolved symptoms.
174	Royal Marsden Hospital	Full	22	2	1.3.32 On page 22 of 39 – “specialist” – this should state who the specialist is.	Thank you for your comment. The Guideline Committee considered this but it was decided that based on individual causative factors it may be a different specialist depending on need. However, we have now also added a further recommendation preceding the symptom management section stating that the specialist paediatric palliative care team should be involved if there are unresolved symptoms. The specialist paediatric palliative care team is now covered in a new recommendation and also includes a pharmacist with expertise in specialist paediatric palliative care (see recommendation 1.5.4)
186	Royal Marsden Hospital	Full	23	1-18	1.3.37 Additional points should be: • Orientating the child • Visual clues for day and night	Thank you for your comment. The list of contributing factors and triggers contains examples and is not meant to be exhaustive and depends on the individual child's condition and circumstances.
200	Royal Marsden Hospital	Full	25	8-31	1.3.43 There is no comment about non pharmacological management and some comments around anxiety, there is nothing on mirroring, relaxation techniques or fans.	Thank you for your comment. The starting point for this recommendation is 'think about and if possible treat' and for each of the contributing or causal factors examples of possible treatments are provided. These are examples and it is not meant to be an

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						exhaustive list, therefore other methods could fall into these categories (for instance, fans could be an environmental change). We did not have any evidence for the effectiveness of these interventions and approaches and were therefore limited in the strength of the recommendations that could be made.
201	Royal Marsden Hospital	Full	26	23-26	1.3.50 There is no comment on metabolic rate which is reduced when dying and the reduction in renal function, therefore fluid volume management is altered. There is no comment on basic medical information.	Thank you for your comment. NICE guidelines are not meant to be text books, but are addressing areas where there is variation in clinical practice, such as for example medically assisted hydration. Comments about metabolic rate and reduction in renal function would be assumed to feature in medical training which is outside the remit of this guideline.
204	Royal Marsden Hospital	Full	26	13	1.3.46 “Approaching the end of life or is dying” – what is the difference this should be stated and clarified?	Thank you for your comment. Both of these terms are defined in the section 'Terms used in this guideline' and reflect the timeframe that the recommendation is referring to (likely to die within weeks [approaching] or hours or days [dying]). In addition, the End of Life Care definition has been reworded, and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase ‘planning and management’ which indicates that this is not restricted to only the last days.
217	Royal Marsden Hospital	Full	27	7-11	1.3.54 There is a further no comment on reduced metabolic rate – end of life or dying.	Thank you for your comment. NICE guidelines are not meant to be text books, but are addressing areas where there is variation in clinical practice, such as for example medically assisted hydration. Comments about metabolic rate and reduction in renal function would be assumed to feature in medical training which is outside the remit of this guideline.

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218	Royal Marsden Hospital	Full	28	17-19	1.3.58 There is no statement that the family should be aware of professional concern of imminent death.	Thank you for your comment. This is covered in recommendation 1.3.63.
223	Royal Marsden Hospital	Full	28	1-9	1.3.55 There is no comment or phrase used for terminal agitation which is unusual.	Thank you for your comment. We had limited research evidence on this and the list was based on consensus; we highlight throughout that there is always uncertainty about recognising whether a child or young person is likely to die within hours or days. We do list the 'altered level of awareness' as one of the signs with 'confusion' as a possible example. We believe that agitation could be described as falling into this category (recommendation 1.3.57).
227	Royal Marsden Hospital	Full	31	23-27	1.4.7 Recognise who should explore this and some may not want to talk – this needs to be clarified.	Thank you for your comment. We have modified the recommendation to advise that services involved in the care of children and young people should put in place arrangements for discussion between colleagues.
231	Royal Marsden Hospital	Full	32	17-25	1.5.3 There is no comment on pharmacist in this role which should really be emphasised and no transition-worker or professional mentioned.	Thank you for your comment. We have now added a new recommendation on the professions that should be included in the 'specialist paediatric palliative care team'. We have recommended that 'a pharmacist with expertise in specialist paediatric palliative care' is in this team.
241	Royal Marsden Hospital	Full	33	21	1.5.8 You are asking for a paediatric nursing care at all times – good luck with this since the NHS has no money and there are no community nurses to staff this level.	Thank you for this comment. The recommendation is not intended to provide 1:1 nursing care round the clock and the Guideline Committee were of the view that much home care could be organised in normal working hours. We do appreciate that providing 24 hour access to end of life support given current resource/capacity constraints will be challenging to implement, particularly in the short term.

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						NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing support and day and night specialist telephone advice for children and young people receiving home care and approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. “What-if” analysis showed that the resource impact of providing such a service would depend on the staffing configuration and the size of the population covered by such a service. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24h access to end of life support was available in some areas. Whilst this guideline does address service provision it does not specify how services should be commissioned as that will depend on the local context. NICE do produce a number of tools to support implementation including resource impact reports and templates, and your comments will be considered by NICE where relevant support activity is being planned. The Guideline Committee recommendations are consistent with recent NHS England advice (e.g. 2013/14 NHS Standard contract for

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						paediatric medicine: Palliative Care and NHS England Specialist Level Palliative Care: Information for commissioners [April 2016]). NHS England do recognise that not all palliative care services will be able to immediately meet the requirements of the service specification for specialist level palliative care for a variety of reasons (e.g. historical patterns of working, workforce capacity and the ability to recruit and retain specialist staff (which may be more difficult in some parts of the country), capacity to provide education and training for staff and others, as well as the mixed funding streams they reflect) but they do state that the sample service specification is an indicator of a 'direction of travel' for such service providers, supported by their commissioners, to which they should be working.
245	Royal Marsden Hospital	Full	34	14	I am still uncertain as to what the word "ambitions" – I think these statements and wishes should be given an explanation and I note this is "terms used" and you have not actually explained what wishes and ambitions are.	Thank you for your comment. These terms are intentionally undefined. Depending on a child's developmental age or abilities the wishes or ambitions may vary widely. For instance they could range from walking a few steps, hoping to finish GCSEs, or travelling somewhere.
246	Royal Marsden Hospital	Full	34	20	I think that perinatal/neonatal should have a separate section, rather than grouping them into the phrase – children. In all my paediatric training they were always seen as separate. No comment made about specific issues about neonatal death.	Thank you for your comment. The Committee acknowledges that evidence in this area is scarce and has therefore written another research recommendation for this topic. The new research recommendation is on perinatal palliative care and has been prioritised as one of the 5 key research recommendations, with the intention that this will hopefully inspire future evidence to inform a future update of this guideline. We have also highlighted the percentage of

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						neonatal deaths in the introduction to this guideline to emphasise the importance of this group. We have also changed the preamble to the short guideline and removed 'where appropriate' to clarify that children and young people include neonates and infants. We have changed recommendation 1.2.6 (Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition) to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.
255	Royal Marsden Hospital	Full	36	6	Starting with a joining word is poor grammar.	Thank you for your comment. The sentence begins with the title of the guideline, therefore it has not been amended.
260	Royal Marsden Hospital	Full	37	15-25	There is nothing here about priorities or what is most important to the family	Thank you for your comment. This is a brief paragraph of 'why this is important' and is not meant to be a comprehensive discussion. There is more information on the content of the research recommendation in the full guideline.
262	Royal Marsden Hospital	Full	38	13	There is no comment on bereavement in this paragraph.	Thank you for your comment. This is a brief paragraph of 'why this is important' and is not meant to be a comprehensive discussion. There is more information on the content of the research recommendation in the full guideline.
263	Royal Marsden Hospital	Full	38	22	"looked at what families want" or do you mean needs.	Thank you for your comment. This is a brief paragraph of 'why this is important' and is not meant to be a comprehensive discussion. The Committee agreed that 'need' would be captured because it is part of the review question. The text then refers to an exploration of what families may want which may also relate to what is needed. There is more information on the content of the research

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						recommendation in the full guideline.
264	Royal Marsden Hospital	Full	39	6	why only community as a reason for investigating pain	Thank you for your comment. This is a brief paragraph of 'why this is important' and is not meant to be a comprehensive discussion. It stated in this paragraph that there is some general evidence that opioids are effective. However, little evidence in the community setting. This potentially exposes children and young people who are having end of life care in the community to untreated pain or significant side effects. There is more information on the content of the research recommendation in the full guideline.
398	Royal Marsden Hospital	General	General	General	Generally I do not agree with your recommendations for research on preferred places of care. I do not think this is the biggest and most important issue. I think types of care and how we deliver services are far more important. Also symptom assessment and review of medications including efficacy.	Thank you for your comment. We have made recommendations on preferred place of care as well as symptom management. Both were considered to be important by the Guideline Committee.
446	Sands	Short	General	General	Sands is the stillbirth and neonatal death charity. We operate throughout the UK, supporting anyone affected by the death of a baby, working to improve the care bereaved parents receive, and promoting research to reduce the loss of babies' lives. Due to the very young age of the babies in situations in which Sands provides support, our responses to this consultation refer only to how they would apply to parents and their families in situations of neonatal death, or when a baby is expected to die in the neonatal period.	Thank you for your comment.

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457	Sands	Short	4	General	(p4-5) Sands welcomes the general principles outlined in recommendations 1.1.1 – 1.1.5. It is crucial to recognise that parents have a central role in decision making and care planning for their children, when a baby will or is expected to die in the neonatal period. Sensitive, empathetic care involves making sure care is individualised wherever possible, and this in turn requires active engagement with parents throughout care planning and delivery. As these general principles recognise, the needs of parents can differ greatly between families, and can change for individuals as situations develop. The need to effectively communicate with parents, listen to their wishes and feelings and to give them as much time to make often difficult decisions about care as possible is therefore crucial to ensuring that their needs are met. The recommendation that continuity of carer is an important facet of care is also welcome; effective care planning is built on establishing trust and relationships, and frequent changes of healthcare professionals can erode parents' confidence in the care process. There should be appropriate training and support structures in place to ensure that high quality care is delivered on a consistent basis.	Thank you for your comment. We hope that the guideline has reflected this sentiment. The issue of training in these matters is outside the remit of this guideline.
470	Sands	Short	5	15-21	The draft guidance rightly identifies that personal situations, cultural backgrounds and other individual characteristics can influence the way in which parents may like to be communicated with and involved in decision	Thank you for your comment. The main way not to make assumptions is asking people whether they like to discuss their beliefs which we have recommended in 1.2.29.

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					making for their children. This is an important aspect of effective communication around end of life care, and healthcare professionals need to be aware of how these factors may influence care planning and delivery. However, it is also important to recognise that all families are unique, and healthcare professionals need to avoid making assumptions about the care families may wish to receive based upon any personal characteristics alone. All parents should be offered all relevant choices and involvement in care planning. Any personal characteristics which influence the delivery of care should come out of the ongoing communication process, and it should be recognised that not all parents with the same background will want the same type of care, and that their initial positions may change as the situation develops. The need to not make assumptions about the care that is most suitable for parents based upon personal characteristics should be made clearer in the draft guidance.	
517	Sands	Short	6	7-8	This recommendation could reemphasise that potential requirements for interpreters or alternative formats of information for parents with sensory impairments may be required to ensure that information and opportunities for discussion are available for all parents.	Thank you for your comment. As you say these alternatives and needs for interpreters are recommended elsewhere and therefore apply throughout.
519	Sands	Short	7	18-20	Whilst it is important to regularly consult with parents about care for their babies, particularly as a situation develops or changes, it is also important that their wishes	Thank you for your comment. We emphasise the need for individualised care throughout this guideline and agree that this should not involve discussions if they are not required or wanted.

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					are respected. It can be distressing for parents to be repeatedly asked about an aspect of care if they have already made a firm decision, and can be interpreted as pressure being placed upon them to change their minds. There is a fine balance to be met in these situations, and healthcare professionals need to use their judgement and communications skills to ascertain when and how to revisit a decision previously made by parents.	Clinical judgment should always be applied even when guidelines are available.
531	Sands	Short	8	19-22	As with our position outlined in comment 3, it should be made clear to healthcare professionals within the guidance that they should take care not to make assumptions about the nature of care parents may want based upon their background or personal characteristics.	Thank you for your comment. Recommendation 1.2.4 is intentionally written to support your comment. Healthcare professionals are asked to explore these issues to prevent them basing their care on assumptions.
551	Sands	Short	8	9-10	Discussions on preferred place of death should cover, where possible, what arrangements could be made for transfer to a non-medical setting. Such arrangements may be difficult but possible with adequate planning, so these discussions need to happen early on in the care planning process so appropriate arrangements can be put in place.	Thank you for your comment. Discussions that may have taken place about the preferred place of care are initially recorded in the Advance Care Plan (see recommendation 1.2.5) at the time when it is first developed. We then discuss practical arrangements in recommendation 1.3.14 and the update of the Advance Care Plan if necessary in recommendation 1.3.16.
575	Sands	Short	10	10-12	As with our position outlined in comment 3, it should be made clear to healthcare professionals within the guidance that they should take care not to make assumptions about the nature of care parents may want based upon their background or personal characteristics.	Thank you for your comment. Please see recommendation 1.2.29 in which we recommend that children or young people and their parents or carers are asked whether they would want to discuss their beliefs and values that are important to them. Asking this will prevent assumptions being made.

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594	Sands	Short	12	7-15	Organ donation is less common in cases of neonatal death. Whilst some parents may want to consider this option, their expectations regarding what organs can be donated, and whether it is possible in their situation, need to be sensitively managed. Organ donation is a topic which is likely to create a variety of opinion. Whilst it is less common for parents to not be able to agree on a course of action, hospitals should have guidelines or procedures in place on how to handle these situations should they arise.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reorganised - please see recommendations 1.2.16 to 1.2.21. Recommendation 1.2.17 has been rewritten and now includes exploring the views and feelings of the child or young person and their parents or carers on organ donation.
612	Sands	Short	13	10-12	Details of relevant emotional and psychological support both within and outside of healthcare settings should be provided, including details of local charities and support services.	Thank you for your comment. We did not identify any evidence for the effectiveness of any intervention and could therefore not recommend one over any other. We did however recommend that children and young people and their parents or carers should be informed 'about the emotional and psychological support available and how to access it' (see recommendation 1.2.26). NICE will publish a version of the guideline for families and one for children which will link to relevant resources.
642	Sands	Short	16	5-6	Sands has produced a form which provides a record for staff to make sure parents are offered appropriate time and opportunities to make memories with their babies. It helps to ensure that parents are given time to reflect and decide what they want. If they have declined previous offers, it also helps to ensure that parents are not asked repeatedly if they have changed their minds (but that they know they can do so, if they wish). The	Thank you for your comment. We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement NICE will publish a version of this guideline for families and one for children. These refer to some resources.

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					form is available to download via the Sands website: http://www.uk-sands.org/sites/default/files/Creating%20Memories%20-%20Offering%20Choices.pdf	
669	Sands	Short	19	20-22	When working with babies who will or are expected to die in the neonatal period, staff should speak to parents to ascertain whether there have been any changes in behaviour or appearance that could be an indicator of pain. Babies cannot communicate their pain levels, and in some cases where parents spend a lot of time with their baby in hospital, they may be the first to notice changes. This may particularly be the case in busy units where maintaining continuity of carer is more difficult.	Thank you for your comment. Please see recommendation 1.3.22 which amongst other points mentions 'age-appropriate approach' when assessing pain. The Committee believed that asking parents about pain would fall into this category.
698	Sands	Short	26	21-24	For parents of babies who will die or are expected to die in the neonatal period, asking them if they would like to be involved in non-invasive care procedures, where appropriate, can provide appreciated bonding activities for those who would like to do so. Some parents of babies in these situations will feel helpless, and actively participating in the care of their baby can provide a bonding opportunity, a chance to make memories as a parent, and allow them to feel more engaged in the care of their baby. Examples of the type of care which may fall in to this description are detailed in this guidance (page 23, lines 5-11, and page 26, lines 17-18).	Thank you for your comment.
747	Sands	Short	31	11-12	The contribution of individual healthcare professionals to specific aspects of care emphasises the importance of strong	Thank you for your comment. This recommendation focuses on who may be involved in bereavement support. Principles of

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					communication and good relationships within multidisciplinary teams, and between specialisms. This should also be the case between primary and community care teams.	good planning are provided in section 1.2.
749	Sands	Short	32	27-28	The guidance should be clear that explanations of who is involved in the multidisciplinary team (and introductions) should take place as early as feasibly possible in the care process.	Thank you for your comment. Recommendation 1.1.20 describes that information should be provided on the membership of their multidisciplinary team and the responsibilities of each professional. The Committee did not want to be too prescriptive about the timing of this information since it may vary according to individual conditions and circumstances.
761	Sands	Short	32	4-6	In the case of neonatal deaths, it is very important that the Bounty Pack is cancelled to prevent unnecessary upset and distress. Parents may also be grateful for information about the Baby Mailing Preference Service, to help reduce the likelihood of receiving unwanted mailings.	Thank you for your comment. The Committee concluded that an electronic notes system can be classified as a type of database. The recommendation was therefore left intentionally broad, because it may be difficult to list each possible system that requires updating.
762	Sands	Short	32	7-8	Some healthcare professionals can feel nervous or uncomfortable working with bereaved parents or with the families of children who are expected to die, particularly in maternity or neonatal settings where these situations may not regularly arise for the relevant staff. Appropriate skills-based training for healthcare professionals who may work with bereaved parents should be a priority for healthcare providers. This can help healthcare professionals to both improve the care they provide to bereaved parents and to ensure they are supported working in potentially very distressing situations. In our experience, this can prove very effective.	Thank you for your comment. The issue of training is outside the remit of this guideline.

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					Between April and August 2016, 762 professionals who have taken Sands' Bereavement Care Training report that attending the training has made them feel more confident in communicating with bereaved parents and families. Improved confidence and communications skills are crucial to providing effective, ongoing care, and staff working with bereaved families should receive training specific to their needs.	
809	Sands	Short	35	9-16	The most challenging aspect of this guidance to implement will likely be the culture change that will be required to ensure all staff are aware of and comfortable with developing and implementing an effective care plan for end of life care. It requires a heightened awareness of the needs of families, and excellent communication skills to involve relevant colleagues and parents alike. It can be difficult to develop these skills, particularly for staff members who may not encounter these situations on a regular basis. However, this culture change is also likely to be the one that would have the biggest impact on practice, and to improve end of life care planning for babies in the neonatal period. There are a number of activities and approaches that can be undertaken to improve communications skills. Active, skills-based training is a critical method of improving staff's confidence in working in these situations, and multidisciplinary training can emphasise the importance of effective team communication in end of life care.	Thank you for your comment. We completely agree that communication and information provision in order to facilitate good planning is incredibly important in end of life care. Your examples as well as the qualitative evidence that we have identified supports this notion. We have strengthened recommendation 1.2.6 with respect to the antenatal diagnosis of a life-limiting condition and who may be involved in the discussion of Advance Care Plans in these situations (this could involve for example midwives, neonatologists, obstetricians and specialists). Issues related to training are outside the remit of this guideline. We did not identify any specific evidence for perinatal end of life care and we have therefore added a research recommendation on perinatal palliative care to the guideline. We will pass this information to our resource endorsement team. More information on

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					Shadowing more experienced colleagues skilled in this work can also provide practical experience of the most effective way of implementing these recommendations into everyday practice. These methods all depend on establishing a supportive working environment that provides sufficient time and resources for these activities. In cases of neonatal death, Sands provides a number of practical resources for healthcare professionals to assist them in providing high quality of care when a baby dies, or is expected to die. Our forthcoming publication *Pregnancy Loss and the Death of a Baby: Guidelines for professionals, 4th edition*, released in September 2016, provides comprehensive guidance and best practice on relevant areas, such as communication, loss and grief, care in neonatal units and postnatal care. We provide skills-based, accredited training for healthcare professionals working with bereaved parents, and offer a range of resources and template forms to assist professionals with implementing this best practice into their work. These can be accessed via the Sands website: http://www.uk-sands.org/professionals/resources-for-professionals. The Bereavement Care Network also offers healthcare professionals an online space to share ideas and best practice regarding stillbirth and neonatal death: http://bereavement-network.rcm.org.uk/	endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
79	Sebastian's Action Trust	Full	General	General	Sebastian's Action Trust welcomes and	Thank you for your comment. There was no

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					supports the development of the new guideline. As an organisation, we support life-limited and life-threatened children and their families from the point of diagnosis, through treatment and beyond. We provide a range of services to children and families, including a strong programme of wellbeing and psycho-social interventions, which meet their needs outside of direct medical support. We have had particular success in championing therapeutic services to support ongoing medical management and we are pleased to see these sorts of services championed in the guideline. In addition to those listed in the current guideline, we would like to see specific mention made of Aromatherapy as a potential intervention to aid pain management and the reduction of agitation. A key element of the use of therapeutic aromatherapy is the benefit that can also be afforded to parents and caregivers involved in the treatment, thereby contributing to the reduction of wider familial distress as referenced in the guideline. Benefits are both physical and emotional and therefore as a specific non-pharmacological intervention it meets multiple objectives in the delivery of end of life care to children and their families.	evidence for the effectiveness of aromatherapy and it was not an intervention that the Committee had prioritised in the protocol. Therefore we recommended some general changes that help children 'relax' and provided some examples of these.
344	Sebastian's Action Trust	Full	352	13	We would like to see Aromatherapy included in Table 67 as a specific non-pharmacological intervention.	Thank you for your comment. These examples are for illustrative purposes and are not intended to be an exhaustive list. There was no direct evidence for the effectiveness of any particular approach, but the Committee reached consensus on a few measures that would help relax children and may therefore contribute to pain reduction.
345	Sebastian's Action Trust	Full	355	2, 5, 30,	The lack of evidence found for non-	Thank you for your comment. NICE guidelines

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				31	pharmacological interventions is referenced in the quoted lines. Our Trust and similarly placed organisations working with life-limited/threatened children have experience and monitoring/evaluation evidence linked to such interventions and it might be beneficial to consider how this could be used to support the NICE evidence base.	only feature published peer reviewed evidence.
346	Sebastian's Action Trust	Full	357	36	We would like to see Aromatherapy included as a potential non-pharmacological intervention.	Thank you for your comment. These examples are for illustrative purposes and are not intended to be an exhaustive list. There was no direct evidence for the effectiveness of any particular approach, but the Committee reached consensus on a few measures that would help relax children and may therefore contribute to pain reduction.
353	Sebastian's Action Trust	Full	359	2	Insert Aromatherapy as a potential intervention for pain management.	Thank you for your comment. These examples are for illustrative purposes and are not intended to be an exhaustive list. There was no direct evidence for the effectiveness of any particular approach, but the Committee reached consensus on a few measures that would help relax children and may therefore contribute to pain reduction.
357	Sebastian's Action Trust	Full	364	9	Include Aromatherapy in listing of interventions costed in Table 73.	Thank you for your comment. These examples are for illustrative purposes and are not intended to be an exhaustive list. There was no direct evidence for the effectiveness of any particular approach, but the Committee reached consensus on a few measures that would help relax children and may therefore contribute to pain reduction.
358	Sebastian's Action Trust	Full	367	16	Insert Aromatherapy as a non-pharmacological intervention for the treatment of agitation as part of end of life care.	Thank you for your comment. These examples are for illustrative purposes and are not intended to be an exhaustive list. There was no direct evidence for the effectiveness of any particular approach, but the Committee

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						reached consensus on a few measures that would help relax children and may therefore contribute to pain reduction.
320	SIRONA Care and Health CIC	Full	253	33	Question 2.Although fully in support of the provision of emergency interventions and urgent access to psychological interventions this would have significant cost implications to increase staffing particularly from a community nursing psychology palliative care service and to have effective co-ordination of provision across the palliative care partnership and statutory and non-statutory agencies .However ,this may have the added benefit of more effective liaison with colleagues within CAMHS services locally..	Thank you for this comment and your support for this recommendation. The provision of emergency intervention and urgent access was not part of the service models developed for this guideline. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee were aware that access to emotional and support services was varied. They recognised that there was likely to be some uplift in NHS resources in order to implement this recommendation although no specific psychological interventions were recommended. The Guideline Committee considered that the recommendation was likely to be cost-effective but we do appreciate that with current financial constraints that all recommendations which require additional resources can be challenging to implement.
402	SIRONA Care and Health CIC	General	General	General	Although the guidance refers to Advance Care Planning encompassing a number of factors, including wishes for life, place of death, plans for the body etc for a number of professionals we are concerned that the terminology will still be interpreted by a large number of practitioners as being associated with for example a resuscitation plan Although this has been acknowledged in the guidance could the terminology be expanded to fully acknowledge the need to embrace living and have wishes for life?	Thank you for your comment. We have a recommendation that explicitly states that the Advance Care Plan should not be confused with a 'do-not-attempt-resuscitation order' (recommendation 1.2.14). We have revised one of our other recommendations to state that resuscitation should be attempted unless a 'do-not-attempt-to-resuscitate' order is in place (recommendation 1.3.1).
403	SIRONA Care and	General	General	General	Question 2.The recommendation for End of	Thank you for this comment. The

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	Health CIC				Life Care Around the clock maybe challenging for the service. In practice it would have a significant cost implication as it would require additional staff to meet this recommendation ad a significant change in the pattern of service delivery form a current model of community nursing and psychology services being provided Monday to Friday 9.00am to 5.00pm- .It would also require significant changes in practice in working with partner agencies both in the acute health setting and n the voluntary sector.	recommendation is not intended to provide 1:1 nursing care round the clock and the Guideline Committee were of the view that much home care could be organised in normal working hours. We do appreciate that providing 24 hour care given current resource/capacity constraints will be challenging to implement, particularly in the short term. NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing support and day and night specialist telephone advice for children and young people receiving home care and approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. "What-if" analysis showed that the resource impact of providing such a service would depend on the staffing configuration and the size of the population covered by such a service. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24 hour access to end of life support was available in some areas. Whilst this guideline does address service provision it does not specify how services should be commissioned as that

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						will depend on the local context. NICE do produce a number of tools to support implementation including resource impact reports and templates, and your comments will be considered by NICE where relevant support activity is being planned. The Guideline Committee recommendations are consistent with recent NHS England advice (e.g. 2013/14 NHS Standard contract for paediatric medicine: Palliative Care and NHS England Specialist Level Palliative Care: Information for commissioners [April 2016]). NHS England do recognise that not all palliative care services will be able to immediately meet the requirements of the service specification for specialist level palliative care for a variety of reasons (e.g. historical patterns of working, workforce capacity and the ability to recruit and retain specialist staff (which may be more difficult in some parts of the country), capacity to provide education and training for staff and others, as well as the mixed funding streams they reflect) but they do state that the sample service specification is an indicator of a 'direction of travel' for such service providers, supported by their commissioners, to which they should be working.
465	SIRONA Care and Health CIC	Short	4	14	It is important to ensure that families are not overwhelmed by discussions on end of life and the need to prevent a series of professionals having the same conversations .The key issue is that families have the opportunity to engage with such discussions.	Thank you for your comment. Throughout the guideline we highlight the need for individualised care. We do refer to 'opportunities to talk' (see for example recommendations 1.1.4 in 'General principles, 1.1.14 and 1.3.6) and the Committee agreed that this would be left to the clinical judgement

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						of the professional involved.
467	SIRONA Care and Health CIC	Short	4	18	There is concern that the recommendations does not fully explain or support the value in explaining to families why h discussions on end of life would be helpful	Thank you for your comment. The focus of recommendations is on the action and topic of the action. The rationale of why this is important is provided in the full guideline.
50	Teenage Cancer Trust	Full	General	General	Teenage Cancer Trust welcomes the decision to publish a separate guideline for infants, children and young people, as the discrete needs of this age group need to be addressed. However, cancer is the leading cause of death from disease for teenagers and young adults[5]; although we do not think that a disease-specific guideline on end of life care is necessary, we do think that it is imperative that the guideline be easily implemented in cancer services, as these may be the most likely to need it. When considering implementation, NICE should focus on making it fit across all cancer services.	Thank you for your response. Your comments will be considered by NICE where relevant support activity is being planned.
51	Teenage Cancer Trust	Full	General	General	Teenage Cancer Trust welcomes the emphasis placed throughout this guidance on keeping the child or young person at the centre of the discussion, and on the importance of repeated, individually-tailored communication with the patient and the family or carers. Our specialist staff are well placed to deliver end of life care to the young people who die when accessing our services; our clinical and non-clinical funded staff are trained to communicate with teenagers and young adults as well as family members and carers.	Thank you for your comment.

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[5] Cancer Research UK, Teenagers' and Young Adults' Cancer, 2013

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					The need for discussions to be had with a professional with whom the family is comfortable is core to the specialised services provided by Teenage Cancer Trust; we set this recommendation out in our 2012 Blueprint of Care[6].	
52	Teenage Cancer Trust	Full	General	General	We welcome the focus on helping a patient and their family to consider the options, benefits and disadvantages of different places of death. However, we urge NICE to consider the fact that in reality the choice can be very limited. This is in part due to regional variation, which affects all areas of teenage and young adult cancer care; in some areas even the referral rate to Principal Treatment Centres can be as low as 40%[7] which can limit young people's access to specialist staff who are able to have age-appropriate conversations regarding end of life care. Children's hospices are often the product of a local area or a personal event[8], which can mean an added level of variation and often leads to inconsistency in entry criteria or standards. In fact, the age range of some hospices for children ends at 16, whilst most adult facilities begin at 18. If there are not many local hospices, this can lead to a situation in which a 17 year old is not eligible for any hospice care[9].	Thank you for your comment. The Committee was fully aware of the difficulties in this area. Recommendation 1.3.11 advises agreement on the preferred place of death taking into account the child or young person's wishes and those of their parents or carers and also issues of safety and practicality. Recommendation 1.3.12 specifically emphasises the need to recognise what's possible when trying to accommodate preferences.

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[6] Teenage Cancer Trust, Blueprint of Care, 2012

[7] C. O'Hara, S. Khan, G. Flatt, North West Cancer Intelligence Service, 'How many teenagers and young adults with cancer are being referred to specialist care in England?', 2011

[8] Professor Sir Alan Craft and Sue Killen, Palliative Care Services for Children and Young People, 2007

[9] Dr Anne Grinyer, and Zephyrine Barbarachild, Teenage and young adult palliative and end of life care service evaluation, 2011

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					The fact that not all options will be available to the young person needs to be considered when asking health professionals to put the guideline into practice.	
53	Teenage Cancer Trust	Full	General	General	It is apparent that the Committee struggled to draw together high-quality evidence in their research around the report, which is indicative of the lack of data in this area. We urge NICE to consider the importance of data collection and analysis when addressing end of life issues in young patients; the lack of evidence makes it harder for services to make their end of life work accountable and this should be recognised as a potential problem for implementation. For example, although we know that cancer is such a significant cause of disease-related death in teenagers and young adults, up to date data on young peoples' place of death has not been published since 2011. More needs to be done to address this lack of available data and to ensure that end of life care for children and young adults is a priority.	Thank you for your comment. We acknowledge that quantitative evidence was limited in this population most likely due to ethical considerations or difficulties to recruit. We also agree that it would be important to increase the evidence base in this topic. However, we had a fairly big evidence base on some of our qualitative reviews. Research recommendations are only made in areas where gaps are identified and are then prioritised by the Committee. After further consideration of the topics that we addressed we have now added one further research recommendation because we thought that the evidence for perinatal end of life care was indeed very limited and hope that this will inform future guidance.
399	Teenage Cancer Trust	General	General		Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day[10]. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them. Through education of young people about the signs of cancer and collaborating with health professionals to	Thank you for your comment.

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[10] North West Cancer Intelligence Service (2013)

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					improve their knowledge, we work to significantly improve young people's experience of cancer. And through our own research and collaboration with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people. Around 310 teenagers and young adults die each year as a result of cancer[11]. We broadly welcome this guideline as we believe it addresses in detail many of the issues which face teenage and young adult cancer patients as well as their families at the end of life.	
539	Teenage Cancer Trust	Short	8	17	We are pleased with the inclusion of transition in the guideline, as this is often highlighted as a point of concern for young people and their families. However, we remain disappointed that this was not addressed in the 2015 guideline, Care of the Dying Adult; as the 2016 NICE guidance on transition shows, work has to be done by both adult and paediatric services to ensure a smooth transition.	Thank you for your comment. Due to the NICE guideline 'Transition from children's to adults' services for young people using health or social care services' (NG43) this topic was not included in the scope. We scrutinised the transition guideline and reassured ourselves that evidence applicable to our population was covered. Issues such as 'gap analysis' are covered by the transition guideline and would be applicable to both populations. The 'Care of dying adults in the last days of life' NICE guideline (NG31) was consulted on separately, and comments to change that guideline needed to be raised there.
756	Teenage Cancer Trust	Short	32	11	We welcome the recommendation that a young person at the end of life should be cared for by a multidisciplinary team. We currently fund multidisciplinary team	Thank you for your comment.

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[11] Cancer Research UK, Teenagers' and Young Adults' Cancer, 2013

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					coordinators to make sure that the needs of young people with cancer are fully addressed and believe that this approach leads to more age-appropriate, holistic care, including at end of life.	
313	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Full	244	4	We assume that this is meant to read 'Childhood life-limiting conditions affect the whole family at an individual and *systemic* level' (Systemic rather than systematic)	Thank you for your comment. This has now been corrected.
314	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Full	244	13	The language is very much geared toward psychology and psychological interventions. Whilst positive, this may be excluding other helpful and evidence based approaches to children and families receiving services at end of life, such as educational (see below) and it takes until page 244 line 13 to introduce the idea of 'psychotherapies'. For example the education approach Seasons of Growth. See below link https://www.goodgrief.org.au/children-and-young-people It is important that the evidence and guidance about this draws on the widest form of framing support.	Thank you for your comment. We did not identify any evidence on the effectiveness of any particular psychological intervention, and were therefore unable to make strong specific recommendations on any particular types of psychological therapies. The link that you provided seems to lead to a website were you can get training in the programme you are referring to, but does not provide any direct evidence of its effectiveness.
321	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Full	254		(p254-255) There should be a clearer statement about the need for funding to study different psychological / therapeutic interventions for children / young people / families. Since childhood health is necessarily a whole system impact, such research should incorporate the effectiveness of family systems therapy interventions.	Thank you for your comment. We agree and therefore include the research recommendation on psychological support and interventions and prioritised it as one of our key research recommendations.
466	The Association for	Short	4	7 to 9	Whilst the guideline notes that if the child or	Thank you for your comment. We have added

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	Family Therapy and Systemic Practice in the UK (AFT)				young person or their parents or carers wish, other family members or people important to them should also be given information and be involved in discussions about care, there is not sufficient explicit mention of siblings in this guideline. Siblings of children and young people who are receiving end of life care also need information and support, both during end of life care and after bereavement.	in explicit reference to siblings and other family members in the section that precedes 'General principles' as an overarching theme. Two new recommendation have also been added under 'General principles' as overarching recommendations: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee concluded that as siblings were covered by overarching recommendations, they would not need to feature in all individual recommendations that would follow on from that.
468	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	4	14 to 17	Children / young people may at times have different views and ideas to their parents / carers eg about care or whether they want to talk about dying, and it would be important to offer opportunities for children / young people to voice these.	Thank you for your comment. In recommendation 1.2.32 we do highlight that different views about care can arise between children and young people and their parents or carers and that it may be necessary to involve a 'facilitator'.
484	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	5	8 to 21	Siblings will also need information during end of life care and after bereavement. Parents / carers could be sensitively asked about whether they would like to do this, or whether they would like help with this. Parents could be given information about resources and opportunities for providing information in different formats.	Thank you for your comment. The guideline committee felt that it would be difficult, and not always applicable, to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs, specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people

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						important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
485	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	5	24 to 26	This list should include siblings and extended family members.	Thank you for your comment. The guideline committee felt that it would be difficult, and not always applicable, to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs, specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
509	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	6 7 7 7 7	18 1 to 3 4 to 5 21 to 25 26-30	Providing information: Siblings will also need information during end of life care and after bereavement. Parents / carers could be sensitively asked about whether they would like to do this, or whether they would like help with this. The guidance needs to be explicitly ensuring that the needs of siblings are thought about. The needs of siblings for information may be different to the needs of children / young	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles':

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					people and parents / carers.	1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
535	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	8	11	Siblings would benefit from knowing of resources or support, which may be available to them.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes ‘General principles’, adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
551	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	8	24 to 26	There is evidence to suggest that many clinicians do not recognise it is part of their role to conduct the Advance Care Planning. Therefore there needs to be more training and awareness raising that Advance Care	Thank you for your comment. We have retrieved the suggested document and, whist we appreciate the document provides valuable guidance, it does not meet the criteria for inclusion in our review. Training of

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					Planning is not someone else's job. Reference: Malcolm, C., Adams, S., Anderson, G., Gibson, F., Hain, R., Morley, A. & Forbat, L. (2011) The symptom profile and experience of children with rare life-limiting conditions: perspectives of their families and key health professionals. CHAS Children's Hospice Association Scotland. Cancer Care Research Centre, University of Stirling.	professionals is outside the remit of this guideline. We have edited the linking evidence to recommendation section in the full guideline to note that conducting the Advanced Care Plan should involve all the multi-professional teams.
553	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	9	9 to 10	The Advance Care Plan could include: A statement covering what information about the child or young person, their parents or carers, and their siblings will be shared, and with whom.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
591	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	12	23 to 24	This statement could be changed to, Be aware that children and young people with life-limiting conditions and their parents or carers, and *their siblings*, may have: NICE needs to be explicit about the extent to	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and

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					which the needs of siblings are to be addressed by this guideline. Parents and carers may well need support with addressing the needs of siblings, on top of supporting their child with a life-limiting condition, themselves, and sustaining family relationships.	other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
596	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	13	1 to 3	Be aware that children and young people and their parents or carers, *and siblings*, may need support and sometimes expert psychological intervention to help with distress, coping and building resilience.	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
600	The Association for	Short	13	10 to 12	Provide information to children and young	Thank you for your comment. The Committee

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	Family Therapy and Systemic Practice in the UK (AFT)				people and their parents or carers, *and siblings,* about the emotional and psychological support available and how to access it.	agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
605	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	13	13 to 15	Be aware that siblings may also need support with emotional and psychological wellbeing at times of change. Parents could be made aware that they can ask for help with this if they wish.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as

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						siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
631	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	15	8 to 12	It may also be helpful for siblings to be made aware of the care and support they can expect when the child or young person dies, and parents and carers could be given information about this to share with siblings.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
635	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	15	23 to 24	Whether they or their parents or carers *or siblings* would like support talking to each other about dying	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs

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						specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
658	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	18	16 onwards	Distressing Symptoms: Consider what information about distressing symptoms it might be helpful to share with siblings and support parents or carers to think about how they would like this to happen, eg for parents / carers to talk with siblings and / or for the multidisciplinary team to help with this, particularly if the child's preferred place of death is at home.	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
711	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	28	28 to 6 1-2 6	(p28-29) Include siblings: Be aware that they or their parents or carers or *siblings* (eg if present) may not express their feeling openly… Give them and their parents or carers *and siblings* (eg if present) opportunities to talk	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing

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						information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
712	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	28	18 to 20	(p28 or 29) Support parents and carers to be aware that siblings may have difficulty asking directly if a child or young person is dying. This could form part of an earlier conversation or plan about what siblings may need.	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
713	The Association for Family Therapy and	Short	28	24 to 25	Include siblings: When a child or young person is likely to die	Thank you for your comment. The Committee agreed that it would be difficult and not always

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	Systemic Practice in the UK (AFT)				within hours or days, support them and their parents and carers, and *siblings* (eg if present) by…	applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
720	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	30	10 to 12	Include siblings: Care and support for parents, carers, *siblings* and healthcare professionals in relation to the death of a child or young person	Thank you for your comment. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching

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						recommendations they would not feature in all individual recommendations that would follow on from that.
727	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	30	23 to 25	Discuss the bereavement support available for parents and carers and siblings / families and provide them with written information.	Thank you for your comment. Please see recommendation 1.4.2, which is about providing parents and carers with written information on bereavement support when a child or young person is approaching the end of life. The Committee agreed that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes ‘General principles’, adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
728	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	30	26 to 28	Talk to parents or carers about available psychological bereavement groups for parents or carers, siblings and families.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes ‘General principles’, adding in explicit reference to siblings and other family

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						members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
734	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	31	1 to 2	Include siblings: Offer bereavement support to parents or carers and siblings both before and after the death of the child or young person	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
744	The Association for Family Therapy and	Short	31	3 to 22	Recommend that parents or carers be made aware of the help available to them in	Thank you for your comment. The Committee agreed that it would be difficult and not always

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	Systemic Practice in the UK (AFT)				thinking about the needs of siblings for bereavement support	applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore agreed that as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
815	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	37	10 to 25	Preferred place of death It is important that a study is conducted which takes a longitudinal retrospective design in order that the longer term consequences (psychological, social, financial) be assessed. That is, let's not just focus on factors impacting decision making in the immediate pre-death scenario, but gain feedback from families whose child has died to assess the longer term repercussions (e.g. not feeling able to move house if the child died in the family home.)	Thank you for your comment. The Committee agreed this research recommendation should be addressed using a qualitative approach. This is because they concluded that it would be more useful to explore people's views in relation to place of care and death in order to understand how that affects decision-making.
816	The Association for Family Therapy and Systemic Practice in the UK (AFT)	Short	38	14 to 16	Emotional and psychological support interventions Research needs to include the emotional support needed by children and young people, and their parents or carers, and	Thank you for your comment. The Committee agreed that a research recommendation was needed in relation to emotional and psychological support. As suggested in your comment, the proposed research would address what emotional support is needed by

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					siblings, and how they would like these needs addressed	children and young people and their parents or carers, by exploring the psychological impact of living with a life-limiting condition, their attitude towards psychological support, and their experiences accessing psychological services. For further details please see the research recommendation table in the full guideline.
271	The Brain Tumour Charity	Full	138	38-39	**Recommendation 12:** In order to implement this recommendation, it will be important for commissioners to work alongside voluntary sector organisations to ensure that the parents/carers whose child is at the end of life has access to some information about this stage of care, and the options available to them. Evidence from our *Losing My Place: The Reality of Childhood with a Brain Tumour* study of nearly 300 children and young people suggests that there is some variation in the level of information provision for children and families affected by a brain tumour at the end of life. (1) Of the 69 people who responded to the statement, *“Me and/or my child received the right information about care at end of life,”* more than two-thirds (67%) either strongly agreed or agreed with this statement, although 26% either disagreed or strongly disagreed. Additionally, more than a quarter of respondents (26%) either disagreed or strongly disagreed with this statement “Me and/or my child were given a choice of end of	Thank you for your comment. It seems that the information that is provided to families is not as effective as it should be, which our review on this topic highlighted (we identified a substantial amount of qualitative evidence for this). Therefore, we have included a dedicated section on information provision in the guideline and highlighted throughout the individualised nature of end of life care. Information needs to be tailored to the individual and we recommend, for instance, that in discussions about places of care information should be provided on 'the various care settings', 'the care and support available in each setting' and 'practical and safety issues' (please see recommendation 1.3.13). We therefore believe that the guideline promotes effective communication, information provision and planning. The report mentioned in your comment does not meet the inclusion criteria as it is not a peer-reviewed journal article. It is not part of the remit of this guideline to explicitly address implementation. Your comments will be considered by NICE where relevant support activity is being planned.

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					life care options."	
272	The Brain Tumour Charity	Full	139	1-7	**Recommendation 13:** Communications is one of the seven strands of the Gold Standards Framework and with the right training for healthcare professionals involved in the care of the dying person, this recommendation has the potential to improve patient experience at the end of life. However, we think the criteria for this recommendation should be expanded to include the level of training that a healthcare professional has received in this area, especially when communicating about such a sensitive subject. The House of Commons' Health Select Committee recommended in 2015 that all staff who provide palliative and end of life care to people with life-limiting conditions should receive training in communication skills. The Committee also suggested that NHS England works with care providers to identify and roll out tailored end of life care training. (2)	Thank you for your comment. The issue of training (medical or otherwise) is outside the remit of this guideline. NICE guidelines assume that healthcare professionals would have the appropriate training and expertise in their area.
273	The Brain Tumour Charity	Full	139	8-15	**Recommendation 14-15:** We support these recommendations, as open and honest communication about the nature of a child's or young person's condition and what this means is important for building parental trust for the next stage of their care. However, evidence from van der Geest et al highlights how communication around death and dying should be tailored to individual	Thank you for your comment. Informed by the evidence, individualised communication between health care professionals and children and young people living with life limiting conditions and their parents or carers has been recommended by the Committee and reflected in the guideline, for example, recommendation 1.1.10. The review on the communication between

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					circumstances, given the different attitudes of children and their parents towards this issue. (3) They argue that clinicians can play a more active role in supporting *"…parents who feel insecure, or they can explain the possible consequences of "protecting" the child from knowledge regarding the impending death. Open, honest communication is important; however, as our data show, not all parents feel confident discussing impending death with their child."* Such variation in attitudes amongst parents, carers and young people to talking about death and dying were revealed in our survey, *Losing My Place: The Reality of Childhood with a Brain Tumour*. Nearly half (49%) of those who were willing to answer questions about dying agreed that they were not afraid of dying because of their brain tumour, whilst 30% said they were not afraid. (1)	children and young people living with life limiting conditions and their parents or carers and the health care professionals was led by the evidence that meets the inclusion criteria set out in relevant systematic review protocols (Appendix D). Van der Greest 2015 did not meet the inclusion criteria as it was mainly about the communication between parents and their child living with life limiting conditions. For details, please see excluded study list (Appendix H) We have also checked the report (Losing My Place: The Reality of Childhood with a Brain Tumour, 2016) mentioned in your comment; it does not meet the inclusion criteria as it was not a peer-reviewed journal article. The views presented in the said report have been covered by other evidence that is included in the review, and is reflected in the recommendations, in particular in the Communication section (recommendations 1.1.9 to 1.1.14) and Providing Information section (1.1.15 to 1.1.20).
279	The Brain Tumour Charity	Full	182	32-33	**Recommendation 23:** To make sure that this recommendation can be implemented, it is crucial that local authorities initiate advance planning for the care needs children who will need palliative care needs as an adult before the young person is 16, as suggested by Together for Short Lives. In particular, this recommendation should include a reference to gap analysis that is also recommended in the NICE guideline on transition from children's to adult's services.	Thank you for your comment. We agree that transition is a very important issue. With the cross-reference that we have included in this guideline readers will be directly hyperlinked to the guideline. We can confirm that the transition guideline looked at the evidence for paediatric palliative care transition and this population is therefore included in the transition guideline and now linked in with our guideline.

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					This gap analysis is crucial for identifying the needs of young people who have been receiving support from children's services, but are not able to get this support from adult services – particular attention is encouraged for young people who are being supported with palliative care. One other aspect beyond the recommendations in NICE's guideline on transition from children's to adult's services is the importance of maintaining childhood friendships, even when a child is moving from one facility to another, and even in the final stages of a young person's illness. This was highlighted in a 2010 study looking at "Palliative Care of Children with Brain Tumours: A Parental Perspective," which stressed the importance of maintaining some of the normal patterns of a child's life during their care. (4)	
280	The Brain Tumour Charity	Full	182	34-43; (p183) 1-25	**Recommendation 24:** We support this recommendation, but believe that another recommendation should be added in this area which proposes that all staff providing palliative and end of life care to people with life-limiting conditions should receive training in advance care planning. This was recommended in the House of Commons' health Select Committee report on End of Life Care last year, with the aim of ensuring that Advance Care Planning is embedded across the whole of the NHS. (2)	Thank you for your comment. The issue of training (medical or otherwise) is outside the remit of this guideline. NICE guidelines assume that healthcare professionals would have the appropriate training and expertise in their area.

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					They suggest that this training should be developed in partnerships with the National Council for Palliative Care and other non-government bodies with relevant expertise.	
281	The Brain Tumour Charity	Full	184	14-17	**Recommendation 31:** "Preferences change around place of death" should be added to the criteria in this recommendation. Evidence from a 2016 study (Pallative Medicine Journal) looking at preferred place of death for children and young people indicates that for many parents, preferences change over the period of their child's care.	Thank you for your comment. The Committee noted that preference may change over time: this was reflected in the relevant 'evidence to recommendation' sections in the guideline, as well as in recommendation 1.3.12. We also refer in one of our 'General principles' to regularly review decisions with children and young people and their parents or carers (recommendation 1.1.2). These are general overarching principles and therefore not repeated in the subsequent sections. Unfortunately, it has not been possible to retrieve the suggested document as there was not enough information provided in your reference.
287	The Brain Tumour Charity	Full	197	26-29	**Research Recommendation 1:** We think that this research recommendation should be framed differently, to look at what factors could help to facilitate choice at the end of life. In our *Losing My Place* study, of the 56 people who answered how far they agreed or disagreed with the statement, "My child died in the place they wanted to," nearly 8 in 10 respondents (78%) either strongly agreed or agreed. However, 10% of respondents either disagreed or strongly disagreed. (1) A report in Palliative Medicine journal concluded that "the opportunity to plan	Thank you for this comment. We believe that the factors that could help to facilitate choice would be an outcome of the research rather than the research itself. With this research recommendation the Committee aimed to identify the determinants of this choice. Once these have been identified it will then be easier to provide decision support. We therefore believe that both ways of framing the question would cover similar ground. For details, please also see the rationale that follows this research recommendation - "Why this is important" and details of what this study may look like in the full guideline (see section 6.2.10). We have checked the report ((Losing My

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					location of death may be a better proxy for high-quality end of life care than the actual location of death, one that is more inclusive and better aligned with palliative care principles." This would include focusing on workforce provision, which many palliative care charities argue is critical to enabling choice at the end of life. For example, the charity Together for Short Lives suggests that access to a Community Children's Nursing team is important to implementing the preference of parents/carers for a child to die at home or in their usual residence. (2)	Place: The Reality of Childhood with a Brain Tumour, 2016) mentioned in the comment) as well, because it is not a peer-reviewed journal article it does not meet our inclusion criteria set out in our review protocol (Appendix D).
291	The Brain Tumour Charity	Full	197	9-11	**Recommendation 40:** This recommendation should be expanded to include a requirement on healthcare professionals to identify any barriers to implementing such preferences.	Thank you for your comment. We believe that 'taking into account: their wishes, values, views of experienced healthcare professionals, and safety and practicality' (recommendation 1.3.10) would identify any of these barriers.
294	The Brain Tumour Charity	Full	211	1-7	**Recommendation 46:** We suggest that another criteria is added to this recommendation, to place a requirement on providers to "Explain how organ/tissue donation could help facilitate research." From our work with those personally affected by a brain tumour, we know that many patients are prepared to gift their tumour samples for research for the benefit of others in the future. As there are many types of brain tumour, some of which are very rare, we need to ensure that we learn from every patient to accelerate the advancement of more	Thank you for your comment. We recommend that professionals should talk to the child or young person and their parents and carers about organ or tissue donation (see recommendation 1.2.17). We believe that issues such as 'research' would commonly feature in these conversations and would not therefore require a separate recommendation. We did not write a research recommendation on this topic because barriers to organ donation are discussed in detail in the Organ donation NICE guideline to which we cross-refer.

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					effective treatments in the future. We need to radically increase the number of frequency of tissue samples banked for research to improve outcomes. 76% of patients who responded to a Charity survey said they would be willing to undergo an operation to collect biopsy samples from their tumour even if this surgery was not for treatment purposes and would not benefit them directly. We recommend that this section also includes a research recommendation on organ/tissue donation looking at how barriers to the collection of tissue samples from children and young people can be eliminated.	
304	The Brain Tumour Charity	Full	216	1-3	**Recommendation 54:** We think the phrase "Think about having" should be removed from this recommendation, and replaced with the imperative "Nominate." Coordination of care is critical to good patient experience at the end of life, particularly when a young person is making the transition from children's to adult's services. Indeed, if recommendation 72 on continuity of care is to be implemented, there must be an imperative on hospitals and medical centres to ensure that there is at least one healthcare professional who is consistently involved in the care of a young person. Evidence from our *Losing Myself* and *Finding Myself* reports have shown that both low-grade and high-grade adult brain tumour	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a

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					patients who have access to a clinical nurse specialist are more statistically likely to have a lower symptom interval and report a better experience of care. (5) (6)	named individual as the 'first point of contact' and who might coordinate care. The report you mention has not been included as evidence because it was on adults rather than children. A new recommendation about every child or young person with a life-limiting condition having an identified medical specialist has been added as recommendation 1.2.2.
306	The Brain Tumour Charity	Full	222	1-16	**Recommendations 55-56:** We support these recommendations, but their implementation is highly contingent on CCGs and local authorities commissioning 24/7 children's palliative care services at a local level. Together for Short Lives recently showed that 4 in 5 local authorities in England are failing to plan and fund care for seriously ill children and young people, including in the home. (7) Similarly, only 73% of CCGs commission a community children's nursing service for children with life-shortening conditions out of hours and at weekends. We recommend that CCGs and local authorities follows the recommendations of Together for Short Lives' report, *"Jointly commissioning palliative care for children and young people aged 0-25 including short breaks."* (8)	Thank you for this comment and your support for these recommendations. We recognise that providing 24/7 children's palliative care services at a local level will be challenging to implement, particularly in the short term. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24 hour access to end of life support was available in some areas. NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing support and day and night specialist telephone advice for children and young people receiving home care and approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. "What-if" analysis showed that the resource impact of providing such a service would depend on the staffing

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						configuration and the size of the population covered by such a service. NICE is unable to refer to other sources of guidance unless they have been accredited by NICE or NICE has reviewed the evidence.
319	The Brain Tumour Charity	Full	253	39-40	**Recommendation 70:** We support this recommendation. Evidence from the 2016 study, *“Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review”* highlighted how many bereaved parents would like to see improved psychosocial and spiritual support for both children and family members, and for earlier introduction to professional counselling. (9) However, the study also noted that 58% of surveyed paediatric oncologists reported “not feeling personally competent to manage depression in children,” which demonstrates the need for referral to allied healthcare professionals such as psychologists within interdisciplinary palliative teams when these issues emerge.	Thank you for your comment. We have retrieved the suggested study (Weaver 2016). Although it is a very useful study, it is a narrative review and it does not meet the criteria for inclusion. Note that the “themes” identified in this study have been addressed across the guideline (care access; cost analysis; social support, sibling care, bereavement outreach; symptom management, psychological support; communication and decision-making). This study has been added to the excluded studies list (Appendix H). We have also retrieved the study that reported that “58% of surveyed paediatric oncologists reported “not feeling personally competent to manage depression in children” (Hilden 2001). After assessment, we concluded this study does not meet the criteria for inclusion in the review, as it did not evaluate the effectiveness of psychological interventions. It does not reflect the views of children and young people or their parents. This study has also been added to the excluded studies list (Appendix H).
404	The Brain Tumour Charity	General	General	General	**Bibliography** 1. Losing My Place | The Brain Tumour Charity [Internet]. 2016 [cited 2016 Jun 23]. Available from:	Thank you for your comment. The listed studies have been retrieved and assessed for inclusion: 1. Losing My Place | The Brain Tumour Charity

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					https://www.thebraintumourcharity.org/about-us/our-publications/losing-my-place-reality-childhood-brain-tumour/ 2. House of Commons Health Select Committee. End of Life Care [Internet]. 2015. (Session 2014-15). Report No.: 5. Available from: http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf 3. Ivana M.M van der Geest, Anne-Sophie E. Darlington, Isabelle C. Streng, Erna M.C Michiels, Rob Pieters, Marry M. van den Heuvel-Eibrink. Parents' experiences of pediatric palliative care and the impact on long-term parental grief. J Pain Symptom Manage. 2014;47(6):1043–53. 4. Shayna Zelcer, Danielle Cataudella, A. Elizabeth L. Cairney, Susan L. Bannister. Palliative Care of Children wih Brain Tumours: A Parental Perspective. Paediatr Adolesc Med J [Internet]. 2010 Mar 1;164(3). Available from: http://archpedi.jamanetwork.com/article.aspx?articleid=382912 5. The Brain Tumour Charity. Losing Myself: The reality of life with a Brain Tumour [Internet]. 2015. Available from: https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/	[Internet]. 2016 [cited 2016 Jun 23]. Available from: https://www.thebraintumourcharity.org/about-us/our-publications/losing-my-place-reality-childhood-brain-tumour/ Response: this report does not meet the inclusion criteria, as it is not a peer-reviewed journal article 2. House of Commons Health Select Committee. End of Life Care [Internet]. 2015. (Session 2014-15). Report No.: 5. Available from: http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf Response: this report does not meet the inclusion criteria, as it is not a peer-reviewed journal article 3. Ivana M.M van der Geest, Anne-Sophie E. Darlington, Isabelle C. Streng, Erna M.C Michiels, Rob Pieters, Marry M. van den Heuvel-Eibrink. Parents' experiences of paediatric palliative care and the impact on long-term parental grief. J Pain Symptom Manage. 2014;47(6):1043–53. Response: this is a very interesting study, but does not clearly fit any of the reviews conducted as part of this guideline. All the issues discussed in the study (communication, continuity of care, and parental involvement) have been addressed in the recommendations 4. Shayna Zelcer, Danielle Cataudella, A. Elizabeth L. Cairney, Susan L. Bannister. Palliative Care of Children wih Brain Tumours: A Parental Perspective. Paediatr Adolesc Med

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					6. The Brain Tumour Charity. Finding Myself in Your Hands : The Brain Tumour Charity [Internet]. 2016 [cited 2016 Jan 15]. Available from: https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/ 7. Together for Short Lives. Commissioning children's palliative care in England: The results of Together for Short Lives' freedom of information requests of NHS clinical commissioning groups (CCGs) and local authorities in England [Internet]. 2016 Jun. Available from: http://www.togetherforshortlives.org.uk/assets/0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf 8. Together for Short Lives. Jointly commissioning palliative care for children and young people aged 0-25 including short breaks: A guide for local areas in England [Internet]. Available from: http://www.togetherforshortlives.org.uk/assets/0001/2093/Joint_commissioning_pallative_care_for_children___young_people_WEB_FINAL.pdf 9. Meaghann S. Weaver, Katherine E. Heinze, Cynthia J. Bell, Lori Wiener, Amy M. Garee, Katherine P. Kelly, et al. Establishing Psychosocial Palliative Care Standards for Children and Adolescents with Cancer and Their Families: An Integrative Review. Palliat Med. 2016	J [Internet]. 2010 Mar 1;164(3). Available from: http://archpedi.jamanetwork.com/article.aspx?articleid=382912 Response: this is a very interesting study, but does not clearly fulfil the inclusion criteria for any of the reviews conducted as part of this guideline. Please note the study provides only survey results, rather than qualitative data. 5. The Brain Tumour Charity. Losing Myself: The reality of life with a Brain Tumour [Internet]. 2015. Available from: https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/ Response: this report does not meet the inclusion criteria, as it is not a peer-reviewed journal article 6. The Brain Tumour Charity. Finding Myself in Your Hands : The Brain Tumour Charity [Internet]. 2016 [cited 2016 Jan 15]. Available from: https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/ Response: this report does not meet the inclusion criteria, as it is not a peer-reviewed journal article 7. Together for Short Lives. Commissioning children's palliative care in England: The results of Together for Short Lives' freedom of information requests of NHS clinical commissioning groups (CCGs) and local authorities in England [Internet]. 2016 Jun. Available from: http://www.togetherforshortlives.org.uk/assets/

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					Mar;30(3):212–23.	0001/5669/Commissioning_children_s_palliative_care_in_England_FINAL.pdf Response: this report does not meet the inclusion criteria, as it is not a peer-reviewed journal article 8. Together for Short Lives. Jointly commissioning palliative care for children and young people aged 0-25 including short breaks: A guide for local areas in England [Internet]. Available from: http://www.togetherforshortlives.org.uk/assets/0001/2093/Joint_commissioning_pallative_care_for_children___young_people_WEB_FINAL.pdf Response: this report does not meet the inclusion criteria, as it is not a peer-reviewed journal article 9. Meaghann S. Weaver, Katherine E. Heinze, Cynthia J. Bell, Lori Wiener, Amy M. Garee, Katherine P. Kelly, et al. Establishing Psychosocial Palliative Care Standards for Children and Adolescents with Cancer and Their Families: An Integrative Review. Palliat Med. 2016 Mar;30(3):212–23. Response: this is a very useful study. However, it is a narrative review and it does not meet the criteria for inclusion. Note that the “themes” identified in this study have been addressed across the guideline (care access; cost analysis; social support, sibling care, bereavement outreach; symptom management, psychological support; communication and decision-making)
71	The Faculty of Pain Medicine (FPM) of the	Full	General	General	There is clearly very little evidence directly relating to pain management in this age	Thank you for your comment.

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	Royal College of Anaesthetists				group (aside from the few studies on PCA) and the so the recommendations are sensible, as are the future research questions.	
72	The Faculty of Pain Medicine (FPM) of the Royal College of Anaesthetists	Full	General	General	If pain is poorly controlled despite following this guidance, then consultation with a pain medicine specialist would be desirable. Many paediatricians/palliative medicine doctors are not familiar with a broad range of opioids. Clonidine can be useful, as can interventional techniques on occasions.	Thank you for your comment. We have reviewed this issue with the Guideline Committee and a new recommendation has been added under 'managing distressing symptoms'; recommendation 1.3.20 addresses the need for specialist input when symptoms are unresolved, and it precedes all symptom management recommendations. NICE guideline relies upon specialists having relevant and appropriate skill set, and training needs are outside its remit.
445	The Royal College of Midwives	Short	General	General	The RCM is very pleased to see the focus throughout the document on continuity of care	Thank you for your comment.
559	The Royal College of Midwives	Short	10		"Begin discussing an Advanced Care Plan during Pregnancy ….. ". It should be clear what professionals are expected to be involved in this discussion.	Thank you for your comment. We have changed recommendation 1.2.6 (Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition) to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.
564	The Royal College of Midwives	Short	10	6	"members of the multidisciplinary team". Continuity of carer should involve one named midwife here in co-ordinating the care plan and ensuring that all professionals in contact with the family are up to date with it.	Thank you for your comment. We have revised recommendation 1.2.6 to consider discussions about and Advance Care Plan with a midwife if there is an antenatal diagnosis of a life-limiting condition.
577	The Royal College of Midwives	Short	11	1	Midwives should be included in the list here	Thank you for your comment. We agree that this recommendation was phrased as if this list was exhaustive. We have revised this to clarify that the list includes examples of who the plan is shared with which means that if applicable it

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						may be shared with fewer people than in the list or with other people not included in the list according to individual needs.
583	The Royal College of Midwives	Short	12		It would be helpful to link to sites discussing advice and ethical issues that inform the potential discussion of organ donation when there is an antenatal diagnosis of a life limiting condition, as we know some parents would be interested in this.	Thank you for your comment. Your response will be considered by NICE where relevant support activity is being planned. NICE will also publish a version of this guideline for families and one for children. These will provide links to some resources.
80	Together for Short Lives	Full	General	General	We are very concerned that the title of this guideline implies that it only refers to end of life care, rather than palliative care. End of life care for adults is defined as the last 12 months of life, however the short guidance of this guidance (p.34 line 24) defines it as 'Care throughout life for children and young people with life-limiting conditions'. This is in line with the definition of children's palliative (not just end of life) care: "Palliative care for children with life-limiting and life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement." (Together for Short Lives (2013). A Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions)	Thank you for your comment. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days. The 'Terms used in this guideline' section has been updated. In addition, the End of Life Care definition has been reworded, and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. The terminology used was discussed and adopted at the time of scoping for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan / strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.

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					It is also unclear whether the guidance refers only to those with life-limiting conditions, or if it refers to those with life-limiting or life-threatening conditions. The glossary in the full guidance defines life-threatening conditions as 'Any condition for which curative treatment is not possible or might fail' (P.441). Children with life-threatening conditions will still require palliative care as the trajectory of their condition is unknown. The guidance, however, only uses the term 'life-threatening' sporadically and it appears as though 'life-limiting' is used as a short-hand for both terms. The guidance must clarify from the offset whether this guidance applies to children with life-limiting and life-threatening conditions, or solely those with life-limiting conditions. The distinction between life-limiting and life-threatening conditions is detailed in Together for Short Lives' Core Care Pathway (Together for Short Lives (2013). A Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions).	
81	Together for Short Lives	Full	General	General	The timescales for this consultation mean that it has taken place almost entirely during school holidays. We have been told that, as a result, professionals and families may not have been made aware that it is taking place, nor had an opportunity to have their say on it.	Thank you for your comment. We were pleased that despite the summer holidays stakeholders were very engaged in the consultation process and we received a substantial amount of comments from many different sources (professional and lay / patient organisations).
82	Together for Short Lives	Full	General	General	The guidelines should signpost professionals to existing materials which provides further information on palliative care for children with life-limiting and life-shortening conditions. This should include: Together for Short Lives (2013). A Core Care Pathway for Children	Thank you for your comment. Your comments will be considered by NICE where relevant support activity is being planned.

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					with Life-limiting and Life-threatening Conditions. And: Together for Short Lives and The Rainbows Hospice for Children and Young Adults (2014). Basic Symptom Control in Paediatric Palliative Care.	
83	Together for Short Lives	Full	General	General	The guidance should make reference to the important role that Allied Health Professionals play in delivering children's palliative care. Services such as a community physiotherapy service are highly cost-effective as they can reduce hospital admissions (Wolff, A., Griffin, H., Flanigan, M., Everest, S., Thomas, D. and Whitehouse, W. (2015). Development and evaluation of a community respiratory physiotherapy service for children with severe neurodisability. *BMJ Quality Improvement Reports,* 4, doi:10.1136/bmjquality.u208552.w3411).	Thank you for your comment. The Committee agreed that allied health professionals (ACHP) play an important role in delivering palliative care, and they have now explicitly mentioned AHCP as part of the multi-disciplinary team (see recommendation 1.5.3). The study you suggest would have not been picked by the search, as it includes children with respiratory difficulties, but not approaching the end of life. This study has been added to the excluded studies list (Appendix H).
84	Together for Short Lives	Full	General	General	This guidance will have the biggest impact on neonates and young adults with life-limiting or life-threatening conditions. While prevalence of life-limiting and life-threatening conditions has increased for all age groups, it has increased most significantly for neonates and young adults (16-19 year olds) (Fraser, L., Miller, M., Hain, R., Norman, P., Aldridge, J., McKinney, P.A. and Parslow, R.C. (2012). Rising National Prevalence of Life-Limiting Conditions in Children in England . *Paediatrics*, 129(4), pp. 1-7).	Thank you for your comment and the reference. We have added a statement based on this to the general introduction.
85	Together for Short Lives	Full	General	General	We suggest that the guidance might refer to \`parents\` and the glossary might be used, as with other terms, to define \`parents\` as \`parents and other carers to whom the child or young person has a primary attachment'.	Thank you for your comment. At the beginning of the guideline we already have the following definition ''parents or carers' refers to the people with parental responsibility for a child or young person'. Other carers to whom the child or young person has a primary attachment could be 'people important to the child or

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						young person' that we have included in the same statement. However, these would not have parental responsibilities and would not be able to make decisions about the child or young person's care.
125	Together for Short Lives	Full	16	Figure 1	It is unclear where this diagram originates from as there is no reference listed and no explanatory note. We are concerned that this diagram is confusing, is of little use and will not aid those delivering children's palliative care. We suggest that it may be useful to set out in separate diagrams which (i) depict the relationships between services involved in the care of a child or young person and (ii) show the phases of a life-limiting condition; these could perhaps reflect those set out by NHS England Palliative Care Development Currency framework (stable, unstable, deteriorating and dying).	Thank you for your comment. The supportive framework diagram is a visual representation of the relationship between our topics in relation to the wider context of key life events and key transitions and was therefore based on the consensus of the group. Guidelines usually include a pathway, but the Committee agreed that such a linear concept does not fit the scope of our guideline. We have added an explanatory text underneath the figure to describe this (see section 1.3 of the full guideline).
137	Together for Short Lives	Full	17	3	We are concerned that this section of the guidance limits information provision to children and young people and their parents or carers. If the child receiving palliative care has siblings or would like another family member to be involved, these conversations may also include them. If so, their specific needs should be supported. The guideline should also recognise that young people may be in a relationship. If so, their partners should also receive information and support. The guideline should also recognise that a relatively high proportion of children with life-limiting conditions are also looked after children.	Thank you for your comment. We have amended the guideline and added in explicit reference to siblings and other family members in the section that precedes 'General principles' as an overarching theme. Two new recommendations have also been added under 'General principles' as overarching recommendations: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.

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139	Together for Short Lives	Full	17	11	This section of the guidance should address mutual pretence (situations in which the child and their parents may be avoiding discussions about end of life care even when they both know that this will be needed as a result of the child's condition). Professionals must pace these conversations sensitively and use careful judgement.	Thank you for your comment. We highlighted in several sections of the guideline the importance of children and young people as well as their carers contributing to decisions about their care (e.g. 1.3.66 and 1.3.67) and we agree that these conversations should be conducted sensitively. We have therefore devoted two sections to cover communication and information provision to provide guidance on these topics.
141	Together for Short Lives	Full	17	17	This is very important. The amount of information that parents will want to know will vary widely from family to family. A note must be kept of their wishes as imposing information on them may be unfair and insensitive.	Thank you for your comment. We agree that this is important and have therefore included the 'agreed approach to communicating with and providing information to the child or young person and their parents or carers' should be recorded in the Advance Care Plan (see recommendation 1.2.4).
142	Together for Short Lives	Full	17	22	Not all children will be able to have conversations about their condition because, for example, they are autistic and/or have a severe learning disability. The guidance should be clear that professionals must ask parents what level of information they feel is appropriate and respect their wishes.	Thank you for your comment. Please see the following recommendation (with examples of different formats for communication) 'Think about how to provide information for children and young people with life-limiting conditions, taking into account their age and level of understanding' (please see recommendation 1.1.9). We therefore do not reiterate within each new recommendation.
143	Together for Short Lives	Full	17	39	Advanced care plans will only work if they are honest and reflect views of everyone. It is appropriate to state wishes of parents as well as what professionals think will happen, even if they conflict.	Thank you for your comment. We agree that these plans should reflect the views of everyone and we have therefore made a reference to these in the recommendation on Advance Care Planning (see recommendation 1.2.5 which explicitly highlights wishes of the child or young person and other wishes for instance those of parents or carers related to the condition.
147	Together for Short Lives	Full	18	4	Often when difficult decisions need to be made there is some urgency. Families will	Thank you for your comment. We do agree that when there is some urgency there may not

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					not have much time. Therefore, early discussions should take place about what decisions need to be made when. Children, young people and families should be supported to prepare before being asked to make a decision.	be time for these discussions. However, as this is in the 'General Principles' it refers to all discussions about care. The available evidence showed that sometimes these discussions were not given sufficient time and this was distressing to all concerned. This recommendation (1.1.4) aims to improve this, but does not preclude shorter discussions if there is a specific urgent need.
148	Together for Short Lives	Full	18	7	This list should include digital apps (on either phones or tablets) that can be used to communicate with a child who has difficulty communicating verbally.	Thank you for your comment. These formats are examples of what could be used and the list is not intended to be exhaustive. However, we think that digital apps could broadly be classified as 'digital media' which we did include in our list.
149	Together for Short Lives	Full	18	11	This section should reference the important role that play specialists can have in delivering this interaction (Boucher, S., Downing, J. and Shemilt, R. (2014). The Role of Play in Children’s Palliative Care. *Children,* 1, DOI: 10.1136/bmj.h6123, P.312).	Thank you for your comment. We agree that there is a role for 'play' as a possible format of communication or providing information. However, we did not identify any evidence for ‘play’ and did not want to be too prescriptive about who would do this since this could be delivered by a 'play specialist' or another appropriately trained professional or provided informally.
151	Together for Short Lives	Full	18	21	Although this section states that professionals should ask the young person who is important to them, we are concerned that the guidance thereafter does not address support for siblings and other family members and is limited to only ‘parents or carers’. Many children and young people will receive support from a range of people, including siblings, boyfriend/girlfriend, wider family members, or foster carers.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes ‘General principles’, adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under ‘General principles’: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support

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						needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
152	Together for Short Lives	Full	18	33	It is vital that this is at the discretion of the parents or carers: while some parents will not know everything and may not want to take decisions relating to care, they must still have the choice.	Thank you for your comment. We agree that they should have a choice in the amount of information that they would like to receive (see recommendation 1.1.17 which addresses this). The emphasis of the recommendation that you are referring to is on 'all' parents. It was highlighted that for divorced or separated couples that was not always the case and therefore all parents have information needs (and that they may differ).
155	Together for Short Lives	Full	19	1	Care must be taken not to use confusing or over formal language: terminology such as ‘incompatible with life’ can be confusing, distressing and upsetting for parents or carers.	Thank you for your comment. The focus of the recommendation that you are referring to is on the topic that should be discussed. How communication should be conducted is described in a separate recommendation (because it would therefore apply throughout). This states that amongst other examples of good communication that it should be 'clearly explained and understandable'.
157	Together for Short Lives	Full	19	25	This section states that children and young people and their parents or carers have a ‘central role in decision-making’. This should be strengthened to state that children and families should be given the option of making choices in their care – and supported to do so – but should not be forced to do so.	Thank you for your comment. We have placed this in the 'General principles' section to highlight the important role that they have in the decision making process. We agree that where possible they should make the decision, but there are some medical issues where they may need help in decision making (which is stated in recommendation 1.1.3) and the feeling of having to make decisions in these cases may be burdensome.

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158	Together for Short Lives	Full	19	31	Reference should be made in this section to the '9-point checklist' in the Mental Capacity Act 2005 (Section 4). Professionals should use this checklist to deem whether the young person and/or parents are able to make decisions regarding the care of the young person.	Thank you for your comment. The 'Making decisions using NICE guidelines' contains information related to standards and laws (including on consent and mental capacity) and how this applies to NICE guidelines.
159	Together for Short Lives	Full	19	35	We are concerned that this guidance only refers to the generic NICE guideline on transition from children's to adult services. We believe that this guideline must emphasise the importance of smooth transition to adult services and the need for palliative care to be provided in a way which meets the age and developmentally specific needs of young people. Transition to adult services for young people with life-limiting or life-threatening conditions is a specific issue which can be more complicated due to the uncertain trajectory of their illnesses. Many young people will go through multiple 'end of life' phases and this makes it more difficult to plan their transition to adult services. Parallel planning is therefore vital. This is particularly relevant to young people whose condition falls into categories 2 and 3 of Together for Short Lives' categories of life-limiting and life-threatening conditions (Together for Short Lives (2015). Stepping Up. P. 10). These categories are defined as: '2. Young people with conditions where there may be long periods of intensive treatment aimed a prolonging life and allowing participation in normal activities, but where	Thank you for your comment. Transition as a topic was not included in the guideline because of the NICE guidance that was in development. We have checked the transitions guideline in detail and can say that they have identified the relevant evidence for transition of children with life-limiting conditions. Therefore their recommendations aim to apply to all groups unless otherwise specified. We acknowledge that this is an important issue and therefore in the NICE digital version the two guidelines will be hyperlinked.

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					premature death is still possible or inevitable. Examples include cystic fibrosis, Duchenne muscular dystrophy and HIV/AIDS.' '3. Young people with progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples include Batten disease and mucopolysaccharidosis.' This section of the guidance should refer to Together for Short Lives' 'Stepping Up' guidance to transition (reference above).	
160	Together for Short Lives	Full	19	37	It should be recognised that taking on the role of co-ordinating an advance care plan will require time for the professional acknowledged. This role does not need to be performed by a health professional as it could be performed by admin support, but they will require protected time to be able to deliver this. This will therefore incur an additional cost.	Thank you for your comment. The Committee agreed that this, in most cases, is current practice. It would therefore not incur a substantial amount of additional costs.
161	Together for Short Lives	Full	19	37	This section states that the Advance Care Plan should reflect the child or young person's 'life ambitions and wishes' as well as their education plan. To avoid duplication, it should state that (in England) this should form part of their education, health and care plan, if they have one in place. Children with life-limiting or life-threatening conditions may also have an individual health care plan (IHCP). Both were introduced as a result of the Children and Families Act 2014.	Thank you for your comment. The Committee was aware of the importance of planning for the child that took account of their overall circumstances and needs. We recommended therefore involvement of the child or young person and their parents or carers as appropriate in discussion and review of the Advance Care Plan (see recommendation 1.2.5) as well as sharing this with schools and other education services as appropriate (recommendation 1.2.10). It is recommended that the Advance Care Plan should be developed and reviewed by the MDT (recommendation 1.2.7) and the MDT

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						membership will, where appropriate include social and educational professionals (recommendation 1.5.3). We believe therefore that this approach should avoid duplication and take account of the child or young person's educational and other needs.
165	Together for Short Lives	Full	20	27	This section should state that neonatal medical teams should be involved in Advanced Care Plan discussions if there is an antenatal diagnosis.	Thank you for your comment. We have changed recommendation 1.2.6 (Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition) to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.
166	Together for Short Lives	Full	20	27	If there is an antenatal diagnosis of a life-limiting condition and the child or young person is not expected to live for a long period, the parents should be asked if they would like other services (including voluntary sector children’s palliative care services) to support them and be specified in their Advanced Care Plan. This will allow them to consider the services available to them locally and to plan their support.	Thank you for your comment. We have reviewed our recommendations related to the subject of antenatal diagnosis. We have changed recommendation 1.2.6 (Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition) to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team. We have also changed the preamble and removed ‘where appropriate’ to clarify that children and young people include neonates and infants. Furthermore we acknowledge that evidence is scarce and have therefore written another research recommendation on perinatal palliative care which we have prioritised as one of our 5 key research recommendations in the

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						short guideline.
167	Together for Short Lives	Full	20	31	It is unclear whether the 'specialist advice' referred to here and in other sections must be given face-to-face or whether it can be provided over the telephone. We are concerned that specialist clinicians may be required to give opinions without being able to see the child if this is not made clearer.	Thank you for your comment. We have amended this recommendation to now state explicitly who this should come from: 'consultant paediatric palliative care advice'. The recommendation also states that 'for example' the advice could be given over the phone. However, we believe that this would be at the discretion of the individual consultant to decide on a case by case basis whether or not a face-to-face consultation is necessary. We did not want to be too prescriptive about this.
170	Together for Short Lives	Full	21	11	This section states that the Advanced Care Plan should be shared with 'Respite centres'. This should be changed to 'short breaks services' to reflect the language now used in the children's disability sector.	Thank you for your comment. We believe that 'respite care' is currently still more commonly understood. A future update of this guideline may then pick up new terminology when it has become lay language.
175	Together for Short Lives	Full	22	24	It is important that professionals are sensitive to the fact that many parents will not want to discuss organ donation. Professionals working in bereavement support have reported to us that some families raise this issue during counselling and feel this conversation could have been 'softer'.	Thank you for your comment. Recommendations in the organ and tissues donation section have been reorganised - please see recommendations 1.2.16 to 1.2.21. Recommendation 1.2.17 has been rewritten and now includes exploring the views and feelings of the child or young person and their parents or carers on organ donation.
176	Together for Short Lives	Full	22	42	It should be stated that members of the multidisciplinary team must have their time funded in order to attend meetings regarding the child or young person's care. Professionals have reported to us that this time is not always funded as there is no direct patient contact.	Thank you for your comment. Multidisciplinary team meetings are part of current NHS practice and therefore attendance should be funded.
177	Together for Short Lives	Full	22	42	The guidance should provide more detail on the composition of a multidisciplinary team or signpost professionals to the existing guidance which contains this detail, i.e. Together for Short Lives (2013). A Core Care	Thank you for your comment. We have amended recommendation 1.5.3 about who the multidisciplinary team (MDT) should include, by adding 'Allied Healthcare professionals' and 'those with expertise in

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					Pathway for Children with Life-limiting and Life-threatening Conditions	managing the child's underlying life-limiting condition' to the MDT. Recommendation 1.5.4 has also been added: this is about the 'specialist paediatric palliative care team' and lists the professionals who should be involved in it. We also amended recommendation 1.2.6 to clarify that if the condition is diagnosed during pregnancy think about involving specialists in the discussion, such as obstetricians, midwives, neonatologists, condition-specific specialists and experts from the paediatric palliative care team. We did not want to be too prescriptive about the exact professional roles that must be included because this varies according to the individual condition and the particular needs that were identified.
181	Together for Short Lives	Full	23	1	The multidisciplinary team should include the family and charities involved in the child or young person's care and support.	Thank you for your comment. We have amended recommendation 1.5.3 about who the multidisciplinary team (MDT) should include, by adding 'Allied Healthcare professionals' and 'those with expertise in managing the child's underlying life-limiting condition' to the MDT. Recommendation 1.5.4 has also been added: this is about the 'specialist paediatric palliative care team' and lists the professionals who should be involved in it. We also amended recommendation 1.2.6 to clarify that if the condition is diagnosed during pregnancy think about involving specialists in the discussion, such as obstetricians, midwives, neonatologists, condition-specific specialists and experts from the paediatric palliative care team. We did not want to be too prescriptive about the exact professional roles that must be included because this varies according to the individual

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						condition and the particular needs that were identified.
182	Together for Short Lives	Full	23	15	This section should say ‘Do involve’ rather than ‘Think about involving’ in order to keep the child or young person and their parents and carers at the heart of the decision-making process about their care.	Thank you for your comment. This recommendation is intended to encourage appropriate participation of children and young people and their parents or carers in relevant multidisciplinary team (MDT) discussions. It is important to recognise that teams meet formally and informally and depending on the matters under discussion and that not all MDT members participate in every meeting. Recommendations are intended to be literally interpreted and stipulating that parents or children are involved in every meeting was not considered either practical or appropriate. Recommendation 1.5.3 about the multidisciplinary team has been amended: we have added ‘Allied Healthcare professionals’ and ‘those with expertise in managing the child’s underlying life-limiting condition’ to the MDT.
183	Together for Short Lives	Full	23	39	This section should note that planning for rapid transfer while a child is in their end of life phase can be an emotional experience for parents and other family members and that professionals should be aware that this may be a difficult time for families to make decisions.	Thank you for your comment. Rapid transfer would be necessary when it is recognised that the child is likely to die in hours or days and they are not in the preferred place of death. We have therefore covered the points you raised in the 'Recognising that a child or young person is dying' section (see for example recommendation 1.2.93 'listening to fears and anxieties' and recommendation 1.2.94 referring to 'intense and varied feelings').
185	Together for Short Lives	Full	23	41	This section should note that parallel planning should negate the need to ‘review and if necessary update the Advance Care Plan’ if there are any changes to the child or young person’s care.	Thank you for your comment. Recommendation 1.2.5 (formerly 1.2.4) has been amended: to ‘a record of any discussions and decisions’ we have added ‘that have taken place’ to indicate that this would only be

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						recorded if such a discussion has taken place and that such discussions are optional.
188	Together for Short Lives	Full	24	4	It should be noted that many families will not be ready for bereavement support immediately after the death of the child or young person. Many families may feel a sense of numbness, particularly if they have been caring for their child for a long time. For siblings, a bereavement process can take several years.	Thank you for your comment. We agree that this is the case. The bullet that you are referring to states that the care plan should cover 'support for the family after the child or young person dies'. We did not want to be prescriptive about any timeframe within this, because this would vary on a case by case basis.
189	Together for Short Lives	Full	24	9	This section does not include detail on planning in case of death during a rapid transfer. It would be helpful to add guidance for what professionals should do in these situations and what contingency planning should take place before the transfer.	Thank you for your comment. We believe that this is covered elsewhere: please see recommendation 1.3.17 (to raise awareness that they may die sooner or later than expected), changes in level of care in recommendation 1.3.16 and the care available in different settings in recommendation 1.3.13.
190	Together for Short Lives	Full	24	12	The guidance states that, when planning rapid transfer, professionals should be aware that the child may die ‘sooner or later than expected’. It should be noted in the guidance that it can be very difficult to predict when a child is going to die and that this period may extend to weeks rather than days. The guidance should acknowledge this and emphasise the need for parallel planning when considering rapid transfer.	Thank you for your comment. We recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 (explaining the need for parallel plans) to the ‘General principles’ section. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section of the short guideline. We have also reviewed recommendation 1.3.58 to emphasise this uncertainty about recognising that a child is likely to die within hours or days.
191	Together for Short Lives	Full	24	18	The term ‘rapid transfer service’ is confusing as this is not a distinct service - it is instead a process or protocol. As such transfers are rare, it does not make sense to build a service around this, but to use existing services well. ‘Rapid transfer’ should be delivered by all teams rather than by a separate ‘rapid transfer service’ team.	Thank you for your comment. We have altered the wording to recommend a rapid transfer 'process', thus clarifying that we are not advising a separate team. The guideline aims to describe good clinical care.

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					There are additional challenges in allowing a child or young person to die in their preferred place of death that should be acknowledged in this guidance. Together for Short Lives' research shows that commissioning of children's palliative care services is patchy and inconsistent across England (http://www.togetherforshortlives.org.uk/about/our_policy_work/9591_map_data). Fewer than three-quarters of CCGs commission community children's nursing out of hours and this will limit the extent to which children and young people can access palliative care in the location of their choice. The importance of access to community nursing is recognised in the NICE 'End of life care for adults' Quality Standard (0507): 'People have access to community nursing as needed, 24 hours a day, 7 days a week'. Together for Short Lives' survey of voluntary sector palliative care providers (http://www.togetherforshortlives.org.uk/assets/0001/3944/One_page_summary_TogetherforShortLives_nurse_vacancy_survey_2015_.pdf) also shows that a lack of available services is limiting the extent to which they can provide community-based care. The average nursing vacancy rate for these services is 10%, which is significantly higher than the NHS (7%). While education and training is outside of NICE's remit, it should be acknowledged that these factors may limit choice over where a child or young person is able to receive their end of life care.	
192	Together for Short Lives	Full	24	21	In some areas, coroners may prefer to be informed in advance of expected deaths in	Thank you for your comment. The Committee was aware of such variations in practice.

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					the community. Timely verification and certification should be planned in advance, especially for planned deaths in the community, to reduce delays in moving the body after death e.g. to a hospice cool room.	Recommendation 1.4.1 aimed to encourage efficient handling of practical arrangements after the death of the child, including involvement of a coroner. Local variations in practice would therefore be a matter for local discussion. This recommendation also supports the need for forward planning in relation to the registration of the child or young person's death.
193	Together for Short Lives	Full	24	33	'Practical' issues should include issues such as possible delays in getting death certificates, which vary widely across the country, especially when same day burial is important.	Thank you for your comment. In recommendation 1.4.1 we recommend having a discussion and providing information on the practical arrangements that will be needed after a child or young person's death (including registering the death). We think that possible delays would feature in the discussion.
194	Together for Short Lives	Full	24	34	The family needs to know the range of support that can be provided by statutory, voluntary and private services within the local area.	Thank you for your comments. We aimed to address this when we describe that information should be provided about the various settings and the care and support available in each setting (recommendation 1.3.13) which would include support by statutory, voluntary and private services.
198	Together for Short Lives	Full	25	13	This should be changed to read 'specialist emotional and psychological care' as the feedback from young people and families is that they find generic services hard to access in a timely manner and are limited in their ability to effectively address the issues.	Thank you for your comment. Emotional and psychological support may not always be 'specialist'. Individuals may choose support groups that may or may not be led by a specialist. The focus here is on signposting the available support whether specialist or non-specialist based on the individual need and circumstances of the people involved.
199	Together for Short Lives	Full	25	15	This section should include sexuality support for children and young people. For more information, see 'Together for Short Lives (2015). Talking about sex, sexuality and relationships'.	Thank you for your comment. The topic of sexuality support was not prioritised in the scope of this guideline and therefore is outside the remit.
202	Together for Short Lives	Full	26	4	Not all parents will be able to talk about	Thank you for your comment. It is not

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					bereavement support before their child dies. Some parents report feeling that they would be 'betraying' their child by spending time supporting their own psychological needs during this time. The guidance should reflect this by stating that professionals should be aware that not all parents will be able to have this conversation at this stage.	uncommon for the bereavement process to start long before the child or young person dies. The principles of effective communication and information provision that are applicable throughout highlight the need for an individualised approach to this. We also refer to 'the importance of talking about dying' (recommendation 1.3.6) and whether parents or carers would like support in talking to each other about this. We left room for clinical judgement on the timing of this.
203	Together for Short Lives	Full	26	10	Bereavement support should be an integral part of palliative care rather than offered as a standalone service. It should be offered to siblings, partners and wider family members who are close to the child or young person. Children, parents, siblings and other family members will also need psychological support following the death of their child. The definition of bereavement support should be more open so that it includes this support. We are aware that there is a nationwide shortage of available local services and often long waiting lists within existing support organisations for these groups. Children's hospices currently offer the most comprehensive support schemes for siblings pre and post bereavement but this is usually only available when the child that has died is known to the hospice. External referrals are generally not available.	Thank you for your comment. The Committee agreed that bereavement should not be restricted to the time after the child or young person has died (recommendation 1.4.4). This should be initiated before the death and is therefore integrated in the end-of-life care process. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.

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205	Together for Short Lives	Full	26	15	Siblings should be offered bereavement support; early years settings, schools and further education settings should be involved in providing it.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the short guideline in the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
207	Together for Short Lives	Full	26	32	This has cost and resource implications including allocation of protected time and space for provision of emotional support and it will have potential impact on ward/unit staffing levels. Staff need to be clear what they can expect in terms of support for themselves. Other than 'opportunities to talk about and explore their feelings', there is no reference to the psychological support to the teams dealing in end of life care for children and there is no guidance on debriefs for professionals following a child or young person's death. This does not capture the essential role and value of well led Clinical	Thank you for this comment. The recommendation resulted from a discussion of the evidence for social and practical support for family members when a child or young person is approaching the end of life or has died. However, the Guideline Committee recognised in this context the impact that the death of a child or young person can have on healthcare professionals who have provided end of life care. Therefore this recommendation was included because it was felt important that staff welfare at this particular point in time was not overlooked.

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					Reflection and Clinical Supervision throughout the work in terms of developing the abilities and resilience of the care staff.	
209	Together for Short Lives	Full	26	38	The bereavement key worker may have difficulty controlling this when child dies out of area and different databases are used. It will require robust communication and delegation of responsibility for local updating of records.	Thank you for your comment. We are not recommending a bereavement key worker, because the terminology is not universally used. We have, however, amended the recommendation to include a statement that this should be overseen by an 'appropriate nominated member of the multidisciplinary team'.
211	Together for Short Lives	Full	26	41	This section could be clearer, as all professionals providing bereavement support will require the necessary expertise, not just healthcare professionals. In addition, the guidance does not clarify which professionals count as bereavement ‘experts’ – this should be clarified to state that support can be delivered by people who are not experts, but who have received the appropriate training and have the necessary skills to support bereaved families. It is also not clear from the guidance what is defined as necessary expertise, which health care professionals are included in this and exactly what families can expect. To reduce inequity of provision there is a need to define ‘necessary expertise’ and outline a national minimum core bereavement support offer that can be adapted to local resources.	Thank you for your comment. We have restructured and amended this section and 'necessary expertise' no longer features in the recommendations in this section.
212	Together for Short Lives	Full	26	41	In addition to having staff with the necessary expertise, there should be a local bereavement support map setting out the services available to families.	Thank you for your comment. This can be useful to signpost as good practice when implementing this guideline. We will pass this information to our local practice collection team. More information on local practice can be found here:

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						https://www.nice.org.uk/about/what-we-do/into-practice/local-practice-case-studies
213	Together for Short Lives	Full	26	41	Where bereavement support workers care for the family after the death of a child or young person, there should be a transitional period where they attend meetings alongside those who provided end of life care for the child or young person.	Thank you for your comment. This may be helpful for some bereaved families but others may not wish to have these meetings because they may be a painful reminder. We therefore did not want to be too prescriptive about this.
215	Together for Short Lives	Full	27	26	This is very important for families and it is important to recognise that rituals can take many forms. They could include the music that is played in the child or young person's room, or the clothes that they are able to wear.	Thank you for your comment. The recommendation does give some explanatory examples of possible ways of recording memories. These are examples, the list is not exhaustive.
216	Together for Short Lives	Full	27	39	This section should consider anticipatory pain, kidney stones, gall stones, dislocated hip and the upset and depression that might be caused by a nutritional deficiency.	Thank you for your comment. We agree that the wording of recommendation 1.3.22 may have been confusing and that these are not the only causes. We have therefore revised it by changing 'which can be associated with' to 'for example, associated with', to clarify that this is not an exhaustive list.
220	Together for Short Lives	Full	28	16	The non-pharmacological interventions should include play therapy. Play therapy can 'provide a pleasurable distraction and temporary respite from painful procedures and unpleasant experiences that accompany any life-threatening or life-limiting illness' (Boucher, S., Downing, J. and Shemilt, R. (2014). The Role of Play in Children's Palliative Care. *Children,* 1, DOI: 10.1136/bmj.h6123, P.314).	Thank you for your comment. We did not retrieve any evidence on the effectiveness of any non-pharmacological interventions for pain management. The Committee agreed that the suggested non-pharmacological approaches provide illustrative examples of measures that may relax the child or young person and by means of this relaxation contribute to pain relief. These are examples and are not an exhaustive list. We have retrieved the paper for assessment. This is a discussion/ narrative paper and as such, it does not meet the inclusion criteria indicated in the protocol. This study has been added to the excluded studies list (Appendix

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						H). Play therapy was included in the protocol but no evidence was found regarding its effectiveness. However, the Committee acknowledged the importance of play and this was included in the evidence to recommendation sections in the full guideline for the management of distressing symptoms. Play was also included as a way to facilitate communication in the communication review.
221	Together for Short Lives	Full	28	32	This section should include consideration of intra-nasal opioids or opioid patches.	Thank you for your comment. We recognise that such routes are used and this is acknowledged in the recommendation 1.3.27 referring to transmucosal administration. The Committee did not feel that there was sufficient existing evidence to make specific recommendations on the various transmucosal options.
226	Together for Short Lives	Full	30	37	We believe that specialists, including paediatric specialists, should seek help and support from a paediatric palliative care specialist if they consider it to be necessary, regardless of whether the latter is available locally or not - or whether the support is provided in person or by telephone. If a paediatric palliative care specialist is not available, the advice of an adult palliative care doctor may be sought, rather than an organ specialist.	Thank you for your comment. We agree regarding the importance of palliative care. Recommendation 1.5.4 is about involving a specialist paediatric palliative team when needed. We also recommend paediatric palliative care provision when needed in the care at home setting in recommendation 1.5.9. We have not recommended that adult palliative care expertise be a substitute for children and young people as we believe paediatric expertise is crucially important.
230	Together for Short Lives	Full	31	37	We suggest taking out \`encourage\` but leave in \`support\`. Parents can put a lot of pressure on their child by \`encouraging \` them to drink at the end of life when the child does not want to do so.	Thank you for your comment. The Committee felt that 'encouragement' is a positive term, and that it does not mean food or drink should be provided even if the child does not want to have them. The term 'support' has a slightly different meaning and the Committee have therefore decided not to amend this recommendation.
232	Together for Short Lives	Full	32	7	We suggest taking out \`encourage\` but leave	Thank you for your comment. The Committee

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					in `support`. Parents can put a lot of pressure on their child by `encouraging ` them to eat at the end of life when the child does not want to do so.	felt that 'encouragement' is a positive term, and that it does not mean food or drink should be provided even if the child does not want to have them. The term 'support' has a slightly different meaning and the Committee have therefore decided not to amend this recommendation.
233	Together for Short Lives	Full	32	9	This section should include detail on how to introduce other forms of feeding, if appropriate.	Thank you for your comment. We did not identify any evidence about other forms of feeding and therefore wanted to highlight that a discussion should take place and that children or young people should be encouraged and supported to eat if willing or able to do this (please see recommendations 1.3.53 and 1.3.54). Recommendation 1.3.55 is related to children or young people who are already receiving enteral tube feeding. We could not be more specific then this because this would be based on the individual circumstance of the individual child or young person (condition, setting etc.).
235	Together for Short Lives	Full	32	28	This section should note that professionals should be aware that it is difficult to be certain about the future and children may recover unexpectedly.	Thank you for your comment. We recognise the importance of parallel planning and have therefore added recommendation 1.1.8 (explaining the need for parallel plans) to the ‘General principles’ section. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section. We also slightly changed recommendation 1.2.5 on advance care planning.
240	Together for Short Lives	Full	33	15	This section refers to ‘parents or carers’ throughout. As per our previous comments, these discussions must include whoever the child or young person deems important to them – such as a partner or other family members.	Thank you for your comment. The guideline committee felt that it would be difficult and not always applicable to add references to siblings throughout the guideline. We have amended the section that precedes ‘General principles’, adding in explicit reference to siblings and other family members, about sharing

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						information with them and involving them in discussions. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
244	Together for Short Lives	Full	34	3	Please note that this comment is jointly submitted on behalf of the Together for Short Lives and Association for Paediatric Palliative Medicine Research Group chaired by Prof Myra Bluebond-Langner PhD, Hon. FRCPCH, True Colours Chair in Palliative Care for Children and Young People. All other comments are submitted from Together for Short Lives only. We are concerned that although the NICE Guideline states that the published evidence that sits behind the clinical recommendations is lacking, there have nevertheless been 'authoritative' practice recommendations made in the guidelines, based on opinion from a relatively small number of practitioners. Given this situation we would suggest looking at some of the existing national guidance and resources which were developed with input from a wider group of experts then assembled for this report and	Thank you for your comments. We agree that we did not uncover a lot of quantitative evidence. However, there was a substantial amount of qualitative data that we were able to utilise. NICE guidelines use the available published evidence and do not, on the whole, use grey literature and as you say they are based on 'opinion' rather than data. However, the Committee were aware of national guidance and considered this in their discussion. We have added a bit of detail to the Linking Evidence to Recommendation section (please see section 9.2.7). We have 10 research recommendations, five of which are in the 'short guideline' having been prioritised by the Committee. Decisions about whether or not to make research recommendations for a particular topic are captured in the relevant Linking Evidence to Recommendation section. However, due to the scarcity of evidence in perinatal end of life care we have added a further research

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					using or at least referring to this work to underpin recommendations. Among those we would suggest are: - Jassal, S.S. (2011). *Basic Symptom Control in Paediatric Palliative Care: The Rainbows Children's Hospice Guidelines.* Bristol: ACT. - Widdas, D., McNamara, K. and Edwards, F. (2013). *A Core Care Pathway for Children with Life-limiting and Life-threatening Condition*s. Bristol: Together for Short Lives - Chambers, L., Dodd, W., McCulloch, R., McNamara-Goodger, K., Thompson, A. and Widdas, D. (2009). *A Guide to the Development of Children's Palliative Care Services*. Bristol: ACT). Neither the research recommendations that have been put forward, nor the prioritisation, reflect the commentary within the report that highlights gaps in evidence. Where review questions are identified and not included due to lack of evidence, we do not understand why these research questions are not put forward as recommendations for further research. Furthermore, the term 'infants' is not used in the research recommendations. We appreciate that it including the terms 'infants', 'children' and 'young people'	recommendation on this topic (please see the short guideline and section 6.1.10 in the Full Guideline). With regard to the references that you provided. We looked at each and have addressed below why they were not included: 1. Additional references: The suggested references have retrieved and assessed for inclusion: Jassal, S.S. (2011). Basic Symptom Control in Paediatric Palliative Care: The Rainbows Children's Hospice Guidelines. Bristol: ACT. Response: this is not a peer-reviewed publication, and therefore does not meet NICE inclusion criteria. Widdas, D., McNamara, K. and Edwards, F. (2013). A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions. Bristol: Together for Short Lives Response: this is not a peer-reviewed publication, and therefore does not meet NICE inclusion criteria. Chambers, L., Dodd, W., McCulloch, R., McNamara-Goodger, K., Thompson, A. and Widdas, D. (2009). A Guide to the Development of Children's Palliative Care Services. Bristol: ACT). Response: this is not a peer-reviewed publication, and therefore does not meet NICE inclusion criteria. 2. Research recommendations The Committee members discussed the need

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					throughout the document is cumbersome. We therefore request that the definition of terms in this documents makes clear that 'children' includes infants. There have been research prioritising exercises carried out by academics and clinicians in the field and these are not reflected in the report. For example, we would suggest that the Committee consider: - Liben S, Langner R, Bluebond-Langner M. "Pediatric Palliative Care in 2014: Much accomplished, much yet to be done." *Journal of Palliative Care* 30:4/2014; 311-316. December 2014 This article sets out unbiased recommendations for future research that will have impact on the further development of the children's palliative care sector, identifying unanswered research questions in the two key areas of communication & decision-making and pain & symptom management. We suggest that the list of references in this article would also be worth exploring. We do not agree that research on achieving preferred place of death is of high importance. Studies show (including several cited in the report) that what is more important is that conversation take place. - Bluebond-Langner M, Beecham E,	for a research recommendation when drafting the recommendations for each review question. The justification for having or not having a research recommendation is documented in every LETR (linking evidence to recommendation section) in the full guideline. 3. Use of term infants The Committee agreed not to use the term infants, as the term children already includes infants. This is a common practice in NICE guidelines. The definition included in the glossary has now been modified to emphasise that the term children includes infants. 4. Previous research prioritising exercises The Committee acknowledged the usefulness of this study (Liben 2014). However, the prioritisation was made according was done based on their discussions, and adhering to NICE processes (see https://www.nice.org.uk/about/what-we-do/science-policy-research/research-recommendations). The intended outcome is that the commissioned research will provide evidence that can be used to inform an update to the guidance or related guidance. Also when drafting research recommendations, the Committee focused on areas where there is the most chance of the research been taken up by a funding body. 5. Research recommendation of preferred place of death The suggested references have been retrieved and assessed for inclusion:

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					Candy B, Langner R, Jones L. “Problems with preference and place of death for children too” *BMJ,* DOI: 10.1136/bmj.h6123. Published 19 November 2015 - Bluebond-Langner M, Beecham E, Candy B, Langner R, Jones L. “Preferred Place of Death for Children and Young People with Life-Limiting Conditions and Life-Threatening Illnesses: A Systematic Review to Inform Policy.” *Palliative Medicine* Volume 27(8) 705 –713. September 2013 (Accepted for publication February 2013) DOI: 10.1177/0269216313483186 Moreover, what can be offered and achieved is limited by a number of factors ranging from child’s condition at end of life, through to 24/7 availability of palliative care services in the community. We would also like to see incorporated into all of research recommendations the need for prospective studies, looking at all phases of illness and in all care settings (e.g. home, hospice, hospital). It should be noted that parents do want to participate in research. - Crocker, J.C., Beecham, E., Kelly, P., Dinsdale, A.P., Hemsley, J.,	Bluebond-Langner M, Beecham E, Candy B, Langner R, Jones L. “Problems with preference and place of death for children too” BMJ, DOI: 10.1136/bmj.h6123. Published 19 November 2015 Response: this is a letter, and does not meet NICE inclusion criteria. Bluebond-Langner M, Beecham E, Candy B, Langner R, Jones L. “Preferred Place of Death for Children and Young People with Life-Limiting Conditions and Life-Threatening Illnesses: A Systematic Review to Inform Policy.” Palliative Medicine Volume 27(8) 705 –713. September 2013 (Accepted for publication February 2013) DOI: 10.1177/0269216313483186 Response: This study was identified in our search and excluded (please see list of excluded studies in appendix H). The reason for exclusion was that it included children but also young people up to the age of 25 years were included for this systematic review. Individual studies were cross-checked. 6. All research recs Research recommendations are developed using an appropriate technique to frame research question development, for example PICO (population, intervention, comparator, outcome). For further information please see: https://www.nice.org.uk/about/what-we-do/science-policy-research/research-recommendations 7. Definition for palliative care The Committee agreed that some clarity was

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					Jones, L. and Bluebond-Langner, M. (2015). Inviting parents to take part in paediatric palliative care research: a mixed-methods examination of selection bias. *Palliative Medicine,* 29(3), pp. 231-40). However, there are significant barriers to such research including clinician gatekeeping and research governance • Beecham, E., Hudson, B.F., Oostendorp, L., Candy, B., Jones, L., Vickerstaff, V., Lakhanpaul, M., Stone, P., Chambers, L., Hall, D., Hall, K., Ganeshamoorthy, T., Comac, M., Bluebond-Langner, M. (2016). A call for increased paediatric palliative care research: Identifying barriers. *Palliative Medicine,* pii: 0269216316648087). We would also recommend that, in research going forward, attention should be given to invitation and recruitment practices • Hudson, B., Oostendorp, L., Candy, B., Vickerstaff, V.H., Jones, C., Lakhanpaul, M., Bluebond-langner, M., Stone, P. (2016). The under reporting of recruitment strategies in research with children with life threatening illnesses: A systematic review. *Palliative Medicine*). Finally, and not insignificantly, we would like	needed regarding these concepts. A new definition for palliative care has been added to the glossary, based on the one suggested in the comment.

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					the definition of children's palliative care used in the glossary as well as the definition of end of life care to reflect the definitions commonly used within the sector, • 'Palliative care for children with life-limiting and life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement' (Widdas, D., McNamara, K. and Edwards, F. (2013). *A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions.* Bristol: Together for Short Lives).	
250	Together for Short Lives	Full	35	15	This section requires a definition of 'infant'. In the glossary it refers to 'children under 2' but this section discusses infant mortality, which is usually expressed as the number of deaths within the first year of life divided by all live births.	Thank you for your comment. The definition of infants can vary and this is the range we chose. We agree that in the context of 'infant death' it does make sense to have the <1 year definition and we added this in brackets to this section of the guideline. However, overall we have used the 'children under 2 years' definition' which is therefore in the glossary.

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251	Together for Short Lives	Full	35	25	This should refer to neurodisabling conditions, as the term 'neurodevelopmental conditions' is often taken to be synonymous with autism conditions (such as attention deficit disorder) rather than the broader range of conditions that are likely to be life-limiting (cerebral palsies and chromosomal and genetic conditions, for example).	Thank you for your comment. We have now referred to nervous system conditions (including neurodisabling conditions). The term nervous system conditions was the one used in the cited report.
257	Together for Short Lives	Full	36	27	This section states that the guideline covers children and young people with a life limiting condition, but does not make recommendations for those who die suddenly and unexpectedly. Data from 'Why Children Die?' and the child death review overview process outputs show that children and young people with life limiting conditions are at significantly greater risk of sudden and unexpected death compared to other children and young people. This guideline should acknowledge this and address this important group, who benefit just as much from advance care planning and from being informed of the risk of sudden and unexpected death. The guideline should set out what to do if children with life-limiting conditions die suddenly.	Thank you for your comment. As highlighted in your comment, this group is not excluded from the guideline and the recommendations that have been drafted would apply to children and young people with respect to the general planning of their condition. However, it is difficult to recommend anything for any unexpected events. The Committee has, however, drafted sections on social, practical, emotional and religious support which would apply to children and young people affected by such events.
289	Together for Short Lives	Full	197	17	Although the guideline refers to 'safety and practicality' as factors influencing choice of place of death, it provides insufficient guidance on safeguarding issues. Some parent-carers may not be able to recognise changes in a child's wellbeing or symptoms. Therefore, a multi-disciplinary team should take this into account when considering where it is in the child's best interests to receive end of life care.	Thank you for your comment. We agree that this is important. Please see the link 'Making decisions using NICE guidelines' at the beginning of the guideline, which includes information on standards and laws (including on consent and mental capacity), and safeguarding.
305	Together for Short Lives	Full	222	15	This should state 'managed clinical networks'	Thank you for your comment. We have

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					instead of 'clinical networks'. A good example is the All-Wales Managed Clinical Network.	amended recommendation 1.5.10 (formerly 1.5.9) to include suggested phrase "These services should be based on managed clinical networks,"
323	Together for Short Lives	Full	256	21	An example of an 'after death check list' would be helpful in this section. There could also be more detail about arranging who will complete the death certificate and who will confirm the death.	Thank you for your comment. We believe that this is a matter of implementation of our recommendations. We did not uncover any direct evidence on this. Your comments will be considered by NICE where relevant implementation support activity is being planned.
349	Together for Short Lives	Full	358	27	This section should include specific mention of pain from gastro-oesophageal reflux disease which is very common in children and young people with complex disabling conditions and for which there is a separate NICE guideline.	Thank you for your comment. We agree that the wording of recommendation 1.3.22 may have been confusing and that these are not the only causes. We have therefore revised it by changing 'which can be associated with' to 'for example, associated with', to clarify that this is not an exhaustive list.
369	Together for Short Lives	Full	414	21	Where it is difficult to assess if a child has entered their end of life phase, professionals have told us that they would value more guidance on how to manage infections - for example, whether to give antibiotics or not.	Thank you for your comment. The Committee had to prioritise symptoms to a manageable amount. Infections could be causing many of the symptoms that we did address, such as pain or respiratory distress. Please see the NICE guideline on sepsis, which has just been published https://www.nice.org.uk/guidance/ng51?unlid=629887382201610182172
453	Together for Short Lives	Short	General	General	There is no mention of the needs of siblings in the short version of the guidance. This is very concerning for the reasons set out in our response to the full guidelines (p.17 line 3; p.18 line 21; p.26 line 10; p.26 line 15).	Thank you for your comment. The guideline committee felt that it would be difficult, and not always applicable, to add references to siblings throughout the guideline. We have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members, about sharing information with them and involving them in discussions. Two new recommendations have also been added

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						under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). The Committee therefore felt as siblings were covered by overarching recommendations they would not feature in all individual recommendations that would follow on from that.
86	Trinity Hospice	Full	General	General	The recommendations are clear and concise but make no reference to potential transferable skills form adult palliative medicine – which may be more easily available in some localities than access to paediatric palliative care – and whilst not a replacement to such expertise – may be a better option than nothing at all.	Thank you for your comment. In keeping with our standard practice for guidance for children and young people, the evidence sought and reviewed in relation to these matters was restricted to those less than 18 years old. The recommendations made in part were derived from the expertise and experience of Guideline Committee members and as such would have taken account of accepted clinical practice.
197	Trinity Hospice	Full	25	25-27	Continuity of care – addition recommendation that the number of health and social care professionals involved in direct patient care should also be limited to a number acceptable to the child and their family.	Thank you for your comment. We did not want to be too prescriptive about this because due to individual circumstances it may be in the best interest of the child to have more people involved than the family would have wished.
219	Trinity Hospice	Full	28	16-17	Non-pharmacological pain management – many organisations will offer complimentary therapies such as aromatherapy, acupuncture and distraction which are not mentioned and this appears to be a gap	Thank you for your comment. The non-pharmacological interventions are covered in recommendations 1.3.25 & 1.3.38. There was no evidence identified for the effectiveness of the interventions that you mention in your comment. The rationale for the examples that we provided was based on the Committee's belief that stress and anxiety heighten the perception of pain.
222	Trinity Hospice	Full	28	41	Trans-mucosal opioids – I think the recommendation needs to be expanded to	Thank you for your comment. We recognise that such routes are used and this is

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					include transdermal, buccal and sub-lingual formulations so that it is clearer to non-specialists	acknowledged in the recommendation 1.3.27 referring to transmucosal administration. The Committee did not feel that there was sufficient existing evidence to make specific recommendations on the various transmucosal or transdermal options.
224	Trinity Hospice	Full	29	5	Add to the recommendation seek advice early from a specialist in paediatric palliative care or, if not accessible, an adult palliative medicine palliative medicine consultant	Thank you for your comment. We have revised the guidance to include a further recommendation that precedes the symptom management section. This now explicitly states that a specialist paediatric palliative care team should be involved if there are unresolved distressing symptoms (see recommendation 1.5.4).
229	Trinity Hospice	Full	31	1	I would suggest there is clear guidance around pharmacological measures to manage noisy breathing – hyoscine transdermal patches, glycopyrronium, hyoscine butylbromide, hyoscine hydrobromide	Thank you for your comment. We do refer to anti-secretory drugs in recommendation 1.2.76. However, there was no evidence for the comparative effectiveness of any particular drug in this population.
236	Trinity Hospice	Full	32	4-6	I think this requirement needs an addition about recognising the sensitivities of discussing food and fluids at end of life and that time needs to be given to acknowledge the emotional aspects of the subject with family.	Thank you for your comment. We have generally covered sensitivities in all areas of care and highlighted the principles of effective communication and information provision that apply throughout (see section 1.1 on 'General principles').
54	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	The size of the Full Guidance makes this document essentially unusable as a practical document. The existing document does not allow for the establishment of very clear standards against which 'peer review' assessment could take place.	Thank you for your comment. The 'full guideline' contains details of the methods used, the underpinning evidence as well as the recommendations, whereas the 'short guideline' lists the recommendations, context and recommendations for research in a more concise format. This short version will then be presented digitally in clearly divided sections and will be easier to use and navigate. NICE

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						will also produce a version for the public as well as a version for children.
55	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	It is unclear why the upper age limit of 18 has been chosen for the definition of a 'young person' when other NICE service guidelines use an upper limit of 24yrs – Children and young people with cancer: improving outcomes in children and young people with cancer. This also misses an opportunity to address the issues of transition into adult services and the gaps that exist in current service provision. There is no discussion / mention of the interface with adult palliative care services and how this should work for young people needing to transition and also the role of primary care in this scenario.	Thank you for your comment. It is standard practice with NICE guidelines to consider that children range from 0-11 years and young people from 12-18. Although there have been exceptions, extending the range to 25 years for example, young people tend to be transferred to adult care about 16 to 18 years of age. There is existing NICE clinical guidance on care of the dying adult. The guideline makes reference to the importance of transition to adult care where this arises (rec 1.2.3) and cross-references to an existing Nice Guideline on this matter.
56	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	The terminology of the document is unclear and confusing. The document refers to 'End of Life Care….' And yet refers to aspects of care that would be best referred to as 'Palliative Care' and not strictly 'End-of-Life'. The document does not recognise the subtle differences in definitions.	Thank you for your comment. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days. The 'Terms used in this guideline' section has been updated in the guideline. In addition, the End of Life Care definition has been reworded, and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. The terminology used was discussed and adopted at the time of scoping for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends

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						on their being a plan / strategy in place from the earliest opportunity. For example, Advance Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.
57	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	There is a lack of detail to support commissioners in the delivery of services or development of services where none exists.	Thank you for this comment. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/). The remit of this guideline does not extend into providing details on how services should be commissioned. However, NICE produce a number of tools to support implementation including resource impact reports and template, and your comments will be considered by NICE where relevant support activity is being planned.
58	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	Most areas discussed in the document comment on the lack of evidence to support recommendations and yet there are no recommendations about addressing this lack of evidence including the need for the development of research strategies.	Thank you for your comment. We acknowledge that quantitative evidence was limited in this population most likely due to ethical considerations or difficulties to recruit. However, we had a fairly big evidence base on some of our qualitative reviews. Research recommendations are only made in areas where gaps are identified and are then prioritised by the Committee. Decisions about the prioritisation of research recommendations were based on factors such as: the importance to patients or the population, national priorities, potential impact on the NHS and future NICE guidance ethical and technical feasibility. After further consideration of the topics that we addressed we have now added one further research recommendation on perinatal end of

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						life care because we thought that the evidence for this was indeed very limited and we hope that this will inform future guidance.
59	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	There should be some discussion and recommendations about the establishment of an accurate data repository for palliative and end of life care delivery such as a national data set.	Thank you for your comment. Recommendations about data repositories are outside the scope of the guideline
60	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	No specific reference made to the concept / principles of parallel planning. It is a very useful concept to assist people when considering or undertaking the completion of Advanced Care Plans.	Thank you for your comment. We recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 to the ‘General principles’ section of the guideline, explaining the need for parallel planning in order to take account of possible unpredictability in the course of life-limiting conditions. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section. We also slightly changed recommendation 1.2.5 on advance care planning.
61	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	Very little reference to the care and support of siblings	Thank you for your comment. We have amended the guideline and added in explicit reference to siblings and other family members in the section that precedes ‘General principles’ as an overarching theme. Two new recommendations have also been added under ‘General principles’ as overarching recommendations: 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends).
62	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	There is no discussion about the concept of Life-limiting diagnoses being made ante-natally and the implications for ante natal	Thank you for your comment. Recommendation 1.2.6 is a specific recommendation on the discussion of an

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					care and neonatal end-of life care.	Advance Care Plan with parents if there is an antenatal diagnosis of a life-limiting condition. The recommendation has now been amended to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.
63	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	An opportunity has been missed to introduce keyworker concepts in palliative care (they mention having 1 person towards the end, but don't use the phrase key worker) and to describe how this might work.	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist has been added as recommendation 1.2.2.
64	TYAC – Teenagers and Young Adults with Cancer	Full	General	General	Limited discussion about the role of specialist therapeutic support interventions such a play, music and art therapy, Physiotherapy and	Thank you for your comment. Please see recommendations 1.1.9, 1.3.25 and 1.3.38 which all mention music and/or play. We did

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					occupational therapy as a general concept rather than specific indications such as play therapy for pain management (pg357 Ln36)	not have any evidence for the effectiveness of these interventions and therefore were limited in the recommendations that could be made.
447	TYAC – Teenagers and Young Adults with Cancer	Short	General	General	Much of the terminology used in the recommendations describes very basic concepts and philosophy of care that applies to all health care settings and is not specific to end-of-life care. This is a missed opportunity to define what the service could and should look like and should go beyond a description of the most basic of ideas and approaches to palliative and end-of-life care. The recommendations are at such a basic level that it is difficult to see how this document will be of any value to the wide range of professionals working in this and allied fields delivering care.	Thank you for your comment. With regard to 'very basic concepts and philosophy of care' we have reviewed the recommendations we have made on service delivery and have now included detailed guidance on 'specialist paediatric palliative care teams' (recommendation 1.5.4) as well as describing who may be involved in discussions about antenatal diagnosis of a life-limiting condition (recommendation 1.2.6). This provides clarity about the range of professionals that may be involved in the child or young person's end-of-life care. We have also made specific recommendations about home care and how it should be provided with access to services around the clock (recommendation 1.5.9).
448	TYAC – Teenagers and Young Adults with Cancer	Short	General	General	Most of the recommendations lack sufficient detail to be helpful to either those delivering or commissioning services, this is juxtaposed to the very detailed section on 'Managing Distressing Symptoms'. It is unclear from the document why such detail on Symptom management is needed and thus who the Guidance is ultimately aim at.	Thank you for your comment. We reviewed this issue and have now added or revised a number of recommendations related to service delivery. We have recommended a lead medical specialist in recommendation 1.2.2, added recommendation 1.5.4 about specialist paediatric palliative care teams, and clarified which professionals could be involved when a life-limiting condition is diagnosed antenatally in recommendation 1.2.6. Furthermore we revised our multidisciplinary team in recommendation 1.5.3 and care at home at any time in recommendation 1.5.9 to provide further detail on service provision. Please see the full version of the guideline which includes a sections that describe the rationale for these recommendations.
459	TYAC – Teenagers and	Short	4	18-21	This statement applies to all aspects of	Thank you for your comment. The focus of this

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	Young Adults with Cancer				health care delivery and is not specific to End-of-Life care – it should not require stating in this document as this is a very basic element of caring for families.	recommendation is not only that the children or young people and parents or carers should be involved in the decision making processes but are also supported by the multidisciplinary team if needed. Even though this is general good clinical practice it is particularly important in end-of-life care where decisions can literally be a matter of life or death. We therefore made this one of our overarching 'General principles' of the guideline. From systematic review of qualitative literature about this subject, it was often reported that this does not happen as effectively as it should in End-of-Life care (please see the chapter 5). The Committee therefore drafted these recommendations to address this.
464	TYAC – Teenagers and Young Adults with Cancer	Short	4	14	There is evidence that repeated questioning is met with negative feedback from parents having to answer the same questions over and over. This underpins the importance of parallel and advanced care planning.	Thank you for your comment. We recognise the importance of parallel planning, and have therefore added recommendation 1.1.8 to the ‘General principles’ section, explaining the need for parallel planning in order to take account of possible unpredictability in the course of life-limiting conditions. A definition of parallel planning has also been added to the ‘Terms used in this guideline’ section of the short guideline. We also slightly changed recommendation 1.2.5 on advance care planning.
477	TYAC – Teenagers and Young Adults with Cancer	Short	5	7	There should be clear recommendations about those involved in the delivery of palliative and end-of-life care demonstrating appropriate training in advanced communication skills. There will be cost implications in delivering this training. It should be contained within the service specification for specialised palliative care teams. There needs to be an investment of	Thank you for your comment. Issues around training are outside the remit of the guideline.

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					time to deliver this training and this will have implications on service delivery.	
488	TYAC – Teenagers and Young Adults with Cancer	Short	5	1-3	See comment # 15	Thank you for your comment. Please see our response to # 15.
491	TYAC – Teenagers and Young Adults with Cancer	Short	5	4-6	The concept of the Keyworker / care navigator should be introduced. This role would need to be defined clearly and could possibly have cost implications.	Thank you for your comment. The guideline emphasises the importance of team work and specifically the role of multidisciplinary teams in the care of children with life-limiting conditions throughout the course of their lives. The recommendations are intended to recognise the diverse purposes of such team working depending on their individual needs, and they might well at some time in the child or young person's life involve a palliative care team. Recommendation 1.5.7 (formerly 1.5.6) does not use the expression 'key worker' because this might not seem appropriate in all settings. For example a child in the intensive care unit would be in the care of a team of healthcare professionals and it would not be common practice to refer to the lead person in that setting as a key worker. We preferred to recommend that thought be given to having a named individual as the 'first point of contact' and who might coordinate care. A new recommendation about every child or young person with a life-limiting condition having a named medical specialist has been added as recommendation 1.2.2.
498	TYAC – Teenagers and Young Adults with Cancer	Short	6	1	See comment # 18	Thank you for your comment. Please see recommendations 1.1.9, 1.3.25 and 1.3.38 which all mention music and/or play. We did not have any evidence for the effectiveness of these interventions and therefore were limited

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						in the recommendations that could be made.
506	TYAC – Teenagers and Young Adults with Cancer	Short	6	9	See comment # 17	Thank you for your comment. We did not have any evidence for the effectiveness of these interventions and therefore were limited in the recommendations that could be made. Organisations such as BAMT will be instrumental in the implementation of these recommendations in practice.
523	TYAC – Teenagers and Young Adults with Cancer	Short	7	1	See comment # 4 example – 'be aware'	Thank you for your comment. We have reviewed the recommendations we have made on services and have included further guidance on 'specialist paediatric palliative care teams' (recommendation 1.5.4) as well as describing who may be involved in discussions about antenatal diagnosis of a life-limiting condition (recommendation 1.2.6). This provides clarity about the range of professionals that may be involved in the child or young person's end-of-life care. We have also made specific recommendations about home care and how it should be provided with access to services around the clock (recommendation 1.5.9).
546	TYAC – Teenagers and Young Adults with Cancer	Short	8	24	There are examples of Advanced Care Planning Documents available that have been developed across various regions – these should be referenced. It should not be necessary to detail the components when resources already exist that can be utilised.	Thank you for your comment. We have referred to some such resources in the Linking Evidence to Recommendations section. We will pass this information to our resource endorsement team.
557	TYAC – Teenagers and Young Adults with Cancer	Short	9	21	Recommendations needed for who will be responsible for recording education plans: SENCO, School, family.	Thank you for your comment. Responsibilities for education plans are outside the scope of this guideline.
566	TYAC – Teenagers and Young Adults with Cancer	Short	10	8	There needs to be clarity on what this statement means.	Thank you for your comment. We have deleted this recommendation because this is now covered in the Advance Care Plan (recommendation 1.2.5) which refers to

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						'wishes and ambitions' and aspects of the child or young person's life as a whole.
585	TYAC – Teenagers and Young Adults with Cancer	Short	12	23-27	See comment # 4	Thank you for your comment. Please see our response to comment # 4.
593	TYAC – Teenagers and Young Adults with Cancer	Short	12	5-21	The document needs to make reference to national standards / guidelines for referral to Specialist Nurse for Organ Donation (SNOD) or Clinical Lead for Organ Donation (CLOD) and should include NHS BT as a stakeholder.	Thank you for your comment. The guideline refers to the NICE organ donation guideline in recommendation 1.2.16. NHS blood and transplant are registered stakeholders for this guideline and have commented.
608	TYAC – Teenagers and Young Adults with Cancer	Short	13	28	Should there be a clear recommendation that there needs to be a dedicated social worker as part of a specialist palliative care team. The source of funding for this post would be a rate limiting factor. It would need clarity on where this might be sourced: Local authority v 3rd Sector.	Thank you for your comment. Recommendation 1.5.4 has now been added and is about the specialist paediatric palliative care team and who should be involved in it; this includes experts in child and family support with experience in end of life care, including providing social support.
610	TYAC – Teenagers and Young Adults with Cancer	Short	13	1-22	See comment # 4	Thank you for your comment. Please see our response to comment # 4.
625	TYAC – Teenagers and Young Adults with Cancer	Short	14	26	Why is there a change in terminology? ‘Do Not Resuscitate plan’ has not been mentioned thus far in the document. There needs to be clarity of why this is different to an ACP. This then needs referencing to the updated national guidance from the Resuscitation Council on the DNACPR orders.	Thank you for your comment. There is a recommendation that specifically states that the 'Advance Care Plan should not be confused with the 'do-not-attempt-resuscitation' order' (recommendation 1.2.14). We therefore feel that this is clear.
654	TYAC – Teenagers and Young Adults with Cancer	Short	18		(p18-27) The amount of detailed contained within this section of the document appears very much out of place given the remainder of the document significantly lacks in details with respect to all other aspects of delivering palliative and end-of-life care. Reference should be made to resources available via	Thank you for your comment. The Committee agreed that pain management was incredibly important in end-of-life care and that guidance in this is therefore needed. We have now recommended to 'involve the specialist paediatric palliative care team if a child or young person has unresolved distressing

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					the Association of Paediatric Palliative Medicine (APPM).	symptoms (recommendation 1.3.20). This team is described in recommendation 1.5.4 and also includes a pharmacist with expertise in specialist paediatric palliative care. We will pass the information about the resources available via the Association of Paediatric Palliative Medicine to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
765	TYAC – Teenagers and Young Adults with Cancer	Short	32	10-25	The recommendations with respect to the MDT should be very clear and robust and should not be open to interpretation locally – there should be a very clear directive on the constituents of a specialist palliative care MDT. The current statement is too 'weak'. This will have significant implications dependent on the existing local arrangements. There should also be a clear statement on the role for regional paediatric palliative care networks. This will potentially be challenging for local implementation. Reference to the NHSE service specification published in 2013 should be made.	Thank you for your comment. We have reviewed our recommendations related to this topic and have provided further details to strengthen them. Recommendation 1.5.3 about the multidisciplinary team (MDT) has been amended: we have added 'Allied Healthcare professionals (for example physiotherapists, occupational therapists, speech and language therapists, and psychological therapists)' and 'those with expertise in managing the child's underlying life-limiting condition' to the MDT. We have also added another recommendation (1.5.4) about the 'specialist paediatric palliative care team' and who should be involved in it. At a minimum this team should include: • a paediatric palliative care consultant, • a nurse with expertise in paediatric palliative care, • a pharmacist with expertise in specialist paediatric palliative care, and • experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support).

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						Regional paediatric palliative care networks will be important in the implementation of recommendation 1.5.9 which specifies the services that should be provided for children approaching the end of life and are being cared for at home. We did not specifically reference the NHSE service specification published in 2013 as these recommendations were based on a health economic analysis which showed them to be cost effective.
785	TYAC – Teenagers and Young Adults with Cancer	Short	33	19	Define ‘specialist’	Thank you for your comment. We left this intentionally vague since the type of specialist may vary according to the particular care that is needed for the individual child. For example a child who has seizures and neurodisabilities may need a different specialist compared to a child with cystic fibrosis who is in respiratory distress.
793	TYAC – Teenagers and Young Adults with Cancer	Short	33	9-14	There should be greater reference to the concept of parallel planning	Thank you for your comment. We were acutely aware of the crucial importance of parallel planning. In the section addressing the topic of Advance Care Planning it was recommended that the Advance Care Plan should include and record discussions and decisions regarding parallel planning of end of life care and medical care that is specifically for the underlying condition (please see recommendation 1.2.5). We have now also added an explanation of the concept of parallel planning to the guideline glossary of terms.
799	TYAC – Teenagers and Young Adults with Cancer	Short	34	1	There should be a very clear definition within the document as a whole what exactly is a ‘Service’. An ideal opportunity has again been missed to specify exactly what a PPC service should be. This would give clear guidance to commissioners.	Thank you for your comment. The service that is needed is described in recommendation 1.5.9 and the recommendation that you are referring to the collaborations and networks that make this happen (recommendation 1.5.10). The exact specifications may vary according to many different factors that are

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						difficult to define.
454	University Hospitals Bristol NHS Foundation Trust	Short	General	General	Question 3: Collaboration and integration between voluntary services and NHS to provide regular respite and medical support in Wiltshire (https://www.naomihouse.org.uk/news/211-more-care-for-wiltshires-families)	Thank you for your comment. We agree that the integration between these services is very important. We have highlighted the need for collaboration between services in a recommendation on rapid transfer processes where local hospitals, hospices and community, primary care and ambulance services should work together to ensure in making transfer possible. Thank you for your response - we will pass this information to our local practice collection team
455	University Hospitals Bristol NHS Foundation Trust	Short	General	General	General comments: It was also felt that the following aspects of end of life care need to be included in the guidelines: 1. The pivotal role of GPs in providing EOLC for infants, children and young people and the importance of engaging GPs, including in bereavement support 2. The principles of parallel planning: *'Parents quickly experience the uncertainty that living with a child requiring palliative care brings, and with support, value a 'parallel planning' approach. Parallel planning for life while also planning for deterioration or death allows a child's full potential to be achieved and primes the mobilisation of services and professionals where necessary.'*	Thank you for your comment. We recommend thinking about the bereavement support that GPs could provide in recommendation 1.4.5 and that the Multidisciplinary Team may include representation of primary care professionals. We have added a recommendation highlighting the importance of parallel planning in the 'General principles' section which is therefore an overarching recommendation (recommendation 1.1.8). Furthermore we have revised the recommendation on 'antenatal diagnosis' to include the professionals who may be involved in discussing plans (obstetrician, midwife, neonatologist, condition specific specialist and an expert from the paediatric palliative care team). We acknowledge that evidence particularly in this group is scarce and have therefore added a research recommendation in the revised version. This was assigned 'key' status and will therefore also feature in the digital version of the guideline.

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					A Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions, 3rd edition, Together for Short Lives, 2013 3. The importance of good collaboration between different clinical and non-clinical services across a variety of different settings including the voluntary sector (also detailed in 'Our Commitment to you for end of life care' Department of Health 2016) 4. Support for siblings including bereavement support 5. Advice on courses of action should there be conflict between the views of the nursing and medical team and the family 6. Despite the fact that the guideline clearly states its intention to apply to neonates, it does not really address issues related to end of life care in this group. As neonatal deaths are the largest group in under 18 year old deaths this seems remiss. The issues and solutions are different. I would suggest that they either have a section explicitly addressing neonatal deaths - or exclude them from the guideline.	With regard to the specific needs of siblings, we have amended the section that precedes 'General principles', adding in explicit reference to siblings and other family members. Two new recommendations have also been added under 'General principles': 1.1.6 details the social, practical, emotional, psychological and spiritual support needs specifically of siblings, and 1.1.7 the support needs for other family members (e.g. grandparents) or other people important to the child or young person (e.g. best friends). Differences in opinions about care between healthcare professionals and families are outside the remit of this guideline. At the beginning of the guideline there is a hyperlink to a document entitled 'Making decisions using NICE guidelines' which includes information on standards and laws (including on consent and mental capacity and other legal matters). With regard to antenatal diagnosis / care, we have changed recommendation 1.2.6 (Advance Care Planning if there is an antenatal diagnosis of a life-limiting condition) to include the specialists that would be involved in these discussions, i.e. obstetrician, midwife, neonatologist, a condition specific specialist and an expert from the paediatric palliative care team.

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479	University Hospitals Bristol NHS Foundation Trust	Short	5	14	Question 1: This recommendation would be challenging to implement on the basis of confidentiality, technological availability and knowledge	Thank you for your comment. These are examples of how information and communication could be provided and the formats that could be used. Some support groups use 'digital media' and this would therefore be suitable and accessible.
547	University Hospitals Bristol NHS Foundation Trust	Short	8	24	Question 1: This recommendation would be challenging in practice as it is felt that not every family may wish to participate in developing an ACP. The opportunity to discuss and develop an ACP should be offered but it should be recognised that some families may decline the production of an ACP. It is also worth noting that an ACP is not a legally binding document and so parents/children/young people can re-think their decisions at any time if they wish to. Concern has also been expressed that without adequate communication skills and training on the use of ACPs, such documents may be used inappropriately and that the sharing of ACPs requires a robust and watertight system	Thank you for your comment. We do feel strongly that every child or young person should have a plan which in these circumstances is called the Advance Care Plan. We have revised recommendation 1.2.5 to highlight that some of the discussions may have an optional component. We have highlighted elsewhere that this plan is not the same as a do-not-attempt-resuscitation order (recommendation 1.2.14). We are well aware that this should be revisited if circumstances change. Issues related to training are outside the remit of this guideline.
548	University Hospitals Bristol NHS Foundation Trust	Short	8	24	Question 3: A standardised ACP document for use across England with clear, unified language and definitions of key terms and phrases would be useful in terms of consistency, continuity of care between different geographical settings and transition between primary, secondary and tertiary care. For example Child and Young Person's Advance Care Plan (http://cypacp.nhs.uk/about)	Thank you for your comment. The Committee discussed at length what an Advanced Care Plan (ACP) should include, based on their experience and available guidance. The suggested ACP document was discussed by the Committee and has now been described in the linking evidence to recommendation section. Thank you for your response - we will pass this information to our resource endorsement team.
723	University Hospitals Bristol NHS Foundation Trust	Short	30	23	Question 3: Use of the Child Bereavement Network national mapping of member organisations that support bereaved children (whatever the cause of death) could help	Thank you for your comment. The aim of the guideline is to promote bereavement support. In recommendation 1.4.2 we describe that there should be a discussion about the

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					overcome this. There needs to be more widespread mapping of local organisations across the UK providing parent/carer support. Greater opportunity for self-referral to services would facilitate uptake of available support.	bereavement support that is available which implies that they should make themselves aware of these and either healthcare professionals could refer or people could self-refer to these services. NICE will also publish a version of the guideline for families and another for children which will refer to some resources. We will pass this information to our resource endorsement team. More information on endorsement can be found here: https://www.nice.org.uk/about/what-we-do/into-practice/endorsement
733	University Hospitals Bristol NHS Foundation Trust	Short	31	1	Question 1: Parents/carers will often not wish to discuss bereavement issues prior to the death. This will be a barrier to providing optimal preparation for bereavement.	Thank you for your comment. From the experience of the Guideline Committee and as mentioned by other stakeholder organisation the opposite was considered to be important. To introduce bereavement support only once the child has died was considered too late. In individual cases where the family may not be ready for this suggestion, it is still left to the discretion of the relevant healthcare professional to choose the time that they consider appropriate. The need for this to happen earlier was highlighted in the rationale for this recommendation in the full guideline.
743	University Hospitals Bristol NHS Foundation Trust	Short	31	23	Question 2: This has cost and resource implications including allocation of protected time and space for provision of emotional support and it will have potential impact on ward/unit staffing levels. Staff need to be clear what they can expect in terms of support for themselves.	Thank you for this comment. We agree that support for staff has resource implications. The recommendation resulted from a discussion of the evidence for social and practical support for family members when a child or young person is approaching the end of life or has died. However, the Guideline Committee recognised in this context the

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						impact that the death of a child or young person can have on healthcare professionals who have provided end of life care. Therefore this recommendation was included because it was felt important that staff welfare at this particular point in time was not overlooked. We did not otherwise look for evidence related to interventions for staff welfare, for instance psychological support because this was outside the scope for this guideline.
753	University Hospitals Bristol NHS Foundation Trust	Short	32	4	Question 1: Bereavement key worker may have difficulty controlling this when child dies out of area and different databases are used. It will require robust communication and delegation of responsibility for local updating of records.	Thank you for your comment. The Committee concluded that an electronic notes system can be classified as a type of database. The recommendation was therefore left intentionally broad, because it may be difficult to list each possible system that requires updating.
755	University Hospitals Bristol NHS Foundation Trust	Short	32	7	General comment: . It is not clear from the guidance what is defined as necessary expertise, which health care professionals are included in this and exactly what families can expect. To reduce inequity of provision there is a need to define ‘necessary expertise’ and outline a national minimum core bereavement support offer that can be adapted to local resources.	Thank you for your comment. We have reworded this to 'appropriate' rather that 'necessary', but agree that this is a bit unclear. However, the Committee felt unable to define this since matters of training are outside the remit of this guideline.
766	University Hospitals Bristol NHS Foundation Trust	Short	33	19-23	Question 1 and 2: This recommendation would be challenging in practice as currently some children are unable to be cared for at home at the end of life because these services do not exist (including out of hours paediatric community nursing and access tospecialist paediatric palliative care advice 24/7). It is felt there are considerable challenges to the implementation of this due	Thank you for this comment. We do appreciate that providing 24/7 end of life, support given current resource/capacity constraints, may be challenging to implement, particularly in the short term. NICE recommendations are intended to reflect the best available evidence on clinical and cost-effectiveness. A costing model was produced for this guideline to compare the costs of a day and night community nursing

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					to the cost of staffing, training, recruitment and logistics of providing a 24/7 service. Services locally would need to be considerably reconfigured.	support and day and night specialist telephone advice for children and young people receiving home care and approaching the end of life with an alternative of in-patient hospital care. The results suggested that a day and night (24/7) service could be cost saving as a result of reduced hospitalisation. "What-if" analysis showed that the resource impact of providing such a service would depend on the staffing configuration and the size of the population covered by such a service. NICE guidelines aim to raise standards of patient care and reduce variation in practice (http://review2014-2015.nice.org.uk/best-practice-guidelines/clinical-guideline/) and the Guideline Committee was aware that 24 hour access to end of life support was available in some areas. Whilst this guideline does address service provision it does not specify how services should be commissioned as that will depend on the local context. NICE do produce a number of tools to support implementation including resource impact reports and templates. The Guideline Committee recommendations are consistent with recent NHS England advice (e.g. 2013/14 NHS Standard contract for paediatric medicine: Palliative Care and NHS England Specialist Level Palliative Care: Information for commissioners [April 2016]). NHS England do recognise that not all palliative care services will be able to immediately meet the requirements of the service specification for specialist level palliative care for a variety of reasons (e.g.

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						historical patterns of working, workforce capacity and the ability to recruit and retain specialist staff (which may be more difficult in some parts of the country), capacity to provide education and training for staff and others, as well as the mixed funding streams they reflect) but they do state that the sample service specification is an indicator of a 'direction of travel' for such service providers, supported by their commissioners, to which they should be working.
795	University Hospitals Bristol NHS Foundation Trust	Short	34	23-26	General comment: The definition of end of life care is thought to be incorrect. The draft guidelines define end of life care as: *'Care throughout life for children and young people with life-limiting conditions. It includes symptom management and psychological, social, spiritual and practical support'.* End of Life applies to the last days of hours of life	Thank you for your comment. These terms are defined in the short guideline, under the 'Terms used in this guideline' section. They reflect the timeframe that the recommendation is referring to (likely to die within weeks [approaching] or hours or days [dying]). This section has also been updated: the End of Life Care definition has been reworded and definitions for Paediatric Palliative Care and Perinatal Palliative Care have been added. We acknowledge that there is overlap between these terms and that definitions vary, however, the full title of the guideline includes the phrase 'planning and management' which indicates that this is not restricted to only the last days. The terminology used was discussed and adopted during the scoping stage for this guideline. The guideline embraces the care of children and young people with life-limiting conditions in relation to their anticipated limited life span. Proper preparation for care in the final months, weeks, days and hours depends on their being a plan or strategy in place from the earliest opportunity. For example, Advance

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						Care Planning was considered a fundamentally important aspect of End of Life Care, and would begin at the time of diagnosis. Palliative care may become a part of this overall approach to end of life care at some point.
138	York Teaching Hospital NHSFT	Full	17	10	I think it should say verbally not orally;	Thank you for your comment. We have amended this accordingly.
195	York Teaching Hospital NHSFT	Full	24	46-2 (p25)	Add an extra bullet point: parents and carers may also experience financial strain;	Thank you for your comment. We agree that this is important and have therefore highlighted 'financial support' in recommendation 1.2.28 in relation to 'social and practical support'.

**There were no links to, or funding from, the tobacco industry disclosed by commenters.*

Registered stakeholders