Organisation	Docu-ment	Section number Or general	Comments Please insert each new comment in a new row.	Developers' response Please respond to each comment
ABPI	Manual	33-34, 60	The ABPI is pleased that you have responded to our comments on the two coding and data collection systems by having a paragraph in the key points (60) about this matter. However, it does not go far enough as we feel that a recommendation needs to be made to develop a system that co-ordinates the two systems to provide a comprehensive database. Clearly from paragraph 34 efforts were made by the GDG to co-ordinate the two databases by hand – a heroic effort. We believe that NICE should not miss this opportunity to make such a recommendation for the benefit of children and adolescents in the UK.	Thank you for this comment. It is undoubtedly true that for the purposes of producing comparative epidemiological analyses, synchronising of the two coding systems would be ideal. The need to consider this is implicit in paragraph 14. We have also inserted text after paragraph 60 to cover this.
Action for Sick Children				This organisation was approached to comment but did not respond.
Addenbrooke's NHS Trust				This organisation was approached to comment but did not respond.
Afiya Trust, The				This organisation was approached to comment but did not respond.
Anglesey Local Health Board				This organisation was approached to comment but did not respond.
Association for Children with Life Threatening or Terminal Conditions	Manual	General (page 8)	Could the Key Recommendations at the front include a point about the need for adequately resourced palliative care & bereavement support – as almost 25% of children and young people will die from cancer	We feel that the balance of the current key recommendations is appropriate. Other sections of the guidance contain many recommendations on bereavement support and palliative care.
Association for Children with Life Threatening or Terminal Conditions		25	Could usefully refer to those children/young people whose cancer is terminal and reflect that quality of life is also important. This is mentioned later in the document, but it would be a good point to raise early on.	Sorry but we do not feel that it is appropriate to address this issue in paragraph 25.
Association for Children with Life Threatening or Terminal Conditions		68	Could introduce the concept that supportive and palliative care also encompass a wide range of community services	This paragraph reports the finding from the survey of centres in relation to current use of hospices.
Association for Children with Life Threatening or Terminal Conditions		77	ACT's ***Guide to the Development of Children's Palliative Care Services*** quotes a study by While et al* (1996), based on OPCS mortality data 1992 for England and Wales, which states that for children aged 1-17 between 1987 and 1991, 1,100 children died each year of the following conditions: 40% from cancer 20% from heart disease 40% from other life-limiting conditions *While A, Citrone C & Cornish J (1996). A study of the needs and provisions for families caring for children with life-limiting incurable disorders. Department of Nursing Studies, King's College, London	Thank you for this. This work is referenced in the needs assessment document. Paragraph 77 has been redrafted.
Association for Children		81–85	Care Pathway section could include a reference to the now published	Thank you for this information, but unfortunately we cannot

with Life Threatening or Terminal Conditions			***Framework for the Development of an Integrated Multi-Agency Care Pathway for Children with Life-Limited Conditions***, otherwise known as the ***ACT Care Pathway***. It is a generic 'pathway' for this group of children which can be used by commissioners and providers to ensure that they have in place all the essential elements of a good system of children's palliative care, across all settings – addressing the health, social, education, emotional and spiritual needs of children and families. The needs of children are at the very centre of the Pathway and it is hoped that the document will be useful for families in helping them trace their journey through the many different agencies that will be involved in their care and support. The Pathway will provide a useful tool in the development of effective and equitable palliative care services for children and families.	incorporate this evidence at this late stage
Association for Children with Life Threatening or Terminal Conditions		192	Include parents in the MDT discussion before major therapeutic decisions are made	Parents cannot be involved in the multidisciplinary team (MDT) discussion but they are always involved in the final decisions.
Association for Children with Life Threatening or Terminal Conditions		356	Could refer to the Children's NSF work on the care of a child with acquired brain injury	The Children's National Service Framework (NSF) is cited in appendix 1
Association for Children with Life Threatening or Terminal Conditions		372	Could include other family members such as grandparents, who often provide a lot of care?	We feel this is implicit in the word 'family'.
Association for Children with Life Threatening or Terminal Conditions		Table 3 (Page 96)	Should be explicit about including spiritual and bereavement support throughout this phase, even though this point is made later on in the manual. Could include 'spiritual' in the bullet point about emotional & practical support. It's important to include bereavement in this box as it should be ongoing from the time the family receive the diagnosis that a condition is terminal – not tacked on at the end by a specialist. It facilitates timely planning for the child's death and honest communication for child, parents & professionals.	The text has been amended.
Association for Children with Life Threatening or Terminal Conditions		424	Perhaps be explicit about the need to plan ahead with the child and family for the child's death. Need to address a number of issues, including DNR, organ donation, special wishes/goals, the child's 'will', memory boxes, their wishes for their funeral/cremation etc.	This level of detail is inappropriate for service guidance.
Association for Children with Life Threatening or Terminal Conditions		425	Agree that it is important to talk with families about using the services of a children's hospice at an early stage. Parents/children may not be aware of their specialist services, eg the special cold rooms or of the wide range of support that they can provide to the whole family before, during and after the child's death.	Paragraph 425 has been amended.
Association for Children with Life Threatening or Terminal Conditions		452	Could be broadened to say that children die mainly in hospital or the community (to cover home, hospice or school) rather than just hospital and home. Bereavement support should always be provided when a terminal diagnosis has been given. There is also some evidence to suggest that what families most appreciate is bereavement support from a known and trusted	We feel the emphasis on home is appropriate here. We agree, there shouldn't be a separate bereavement service and have amended the title accordingly.

			professional (such as their keyworker) or from another bereaved parent. There is usually no need to provide a specialist bereavement service, except for those families who really need it.	
Association for Children with Life Threatening or Terminal Conditions		455	This para should include a reference to cultural aspects pertaining to death and bereavement and the need to respect each individual child/family's cultural needs.	The text has been amended.
Association for Children with Life Threatening or Terminal Conditions		109	The table of MDT members for palliative care could include children's hospice staff, community children's nurses, religious/spiritual advisor and cultural advisor.	This is a list of core attendance; other members can be co-opted as thought appropriate locally.
Association for Children with Life Threatening or Terminal Conditions		487	Could be extended to include primary care and other community services, including education	We do not think that these health professionals and others can be part of the MDT.
Association for Children with Life Threatening or Terminal Conditions		509	Could recognise recent developments in the management of chronic conditions, which could apply to children and young people to ensure continuity of care	We have referred to this issue in paragraph 505.
Association for Children with Life Threatening or Terminal Conditions		562	Recognise that schools are also a location of care for some children and young people	We disagree.
Association for Children with Life Threatening or Terminal Conditions		Table 9	Could include religious/spiritual advisers, interpreters and advocates	These are core components of any Trust. We did not feel it necessary to specify them as part of principle treatment centre.
Association for Children with Life Threatening or Terminal Conditions		601	Advise that cancer networks work in partnership with other services from the statutory and voluntary sector	We have amended the text.
Association for Children with Life Threatening or Terminal Conditions		611	This para could include a reference to PALS services, spiritual/religious advisors and interpreters	We do not feel that this level of detail is necessary.
Association of Breastfeeding Mothers				This organisation was approached to comment but did not respond.
Association of Children's Hospices	Manual	General	Within the document respite care is discussed, but there is little detail on how this might be provided. Our experience is that POONS and the Big Lottery funded Paediatric Palliative Care teams do not provide respite care at home. Social Services tend to care for children with chronic illness rather than acute episodes. Children's hospice services provide respite care for the whole family and can provide emergency as well as planned respite care.	Thankyou for your comments.
Association of Children's Hospices	Manual	452–474	Childrens hospice services provide pre and post bereavement support to siblings and their parents as well as the extended family where appropriate. They are highly skilled in supporting siblings and providing intervention and care which is appropriate to this group. It is important to recognise this resource within the local community, and for cancer networks to establish a clear knowledge of what support and specialist interventions their local children's hospice service can provide.	We agree and this is part of our recommendation in paragraph 458.
Association of Children's Hospices	Manual	19	The scope of this document as outlined in Appendix 2 is to develop service guidance for use in the NHS. Whilst this scope is clearly understood, the NHS cannot be divorced from voluntary sector provision of children's palliative care and the role that children's hospice services have in providing that care	We feel the importance of children's hospice services has been addressed in paragraphs 425 and 431 but have also added text to paragraph 421 to reflect this.

			nationally, which includes care for those children who have life threatening conditions such as cancer (ACT/RCPCH 2003). There are 37 operational children's hospices in the UK, many of whom have excellent regional working with their oncology centres and members of the oncology MDT. In light of the Childrens NSF and in particular Standard 8 we suggest that some consideration is given to this fact, and that it is reflected within the document.	
Association of Children's Hospices	Manual	68	The uptake of children's hospice care is dependent on three main issues in terms of oncology referrals. 1. The disease process, and how children's specialist respite/palliative care is viewed by oncologists and the MDT. 2. The regional availability of a children's hospice service. 3. The level of integration that cancer services have with children's community nursing teams and voluntary sector services. This paragraph suggests that children and families do not want to use children's hospices. Our experience is the reverse. Children and families have indicated that they wish that they had been referred earlier, and had been given the information about children's hospice services which would enable them to make their own choice, as opposed to professionals making that choice for them. This is consistent with the objectives of the Childrens NSF Standard 6 and 8, which states that children and families should be given the information necessary to enable them to make informed choices about their care and how/where they receive it. This is documented within the guidance as an anticipated benefit, however this will only become a reality if accurate and impartial information is given to families in a timely manner.	This paragraph reports the finding from the survey of centres in relation to current use of hospices.
Association of Children's Hospices	Manual	419	See paragraph 420 and 425 responses	
Association of Children's Hospices	Manual	420	Children with life-limiting and life threatening conditions, of which those who have cancer fall into Group 1 (RCPCH/ACT 2003), need to have information about palliative care services before the "no cure " element is experienced. Palliative care for children does not just refer to symptom control in the terminal stages of life, and is recognised as being from the point of diagnosis or recognition that the child has a life threatening condition.	We have amended paragraph 425 to read 'Children's hospices represent an important potential resource for children with cancer and their families. Information on local hospice provision should be given to families in a timely and considered fashion so that they can decide whether these services will help to meet their care and support needs.'
Association of Children's Hospices	Manual	421	Access to a range of specialist palliative care is essential, including children's hospice services, not just via oncology. As you have indicated, working with and supporting GPs is especially important, as many will want to remain involved as long as they have appropriate support and backup from specialists.	Thank you.
Association of Children's Hospices	Manual	423	Supporting children and families at this stage through a children's hospice service, which may provide care within the hospice or at home, is highly appropriate. Families should be given the choice as early as possible as to whether they wish to be referred to a children's hospice for specialist palliative care via this route.	Paragraph 425 has been amended to cover this.
Association of Children's Hospices	Manual	425	Children's hospices are not a potential resource; they are an actual resource, and it is critical that children and their families have this information at an appropriate time. Children's hospice services offer inpatient management as well as outreach, community teams or hospice at home services. They are	We have amended this paragraph.

			also an important source of pre and post bereavement care for siblings and parents. The sick child, siblings and parents will be directly supported through children's hospices. To start at the phase of terminal care is too late. Children and families do not want to meet a new group of professionals that they do not have an established relationship with, at this late stage.	
Association of Children's Hospices	Manual	427	Skilled medical support is also available through children's hospice medical directors, who may also be consultants in paediatric palliative care and through other medical personnel that work within children's hospice care.	Thank you for your comment.
Association of Children's Hospices	Manual	428	This stage of transition is well recognised within children's hospice services, and these centres need to be recognised for the specific expertise that they can offer the MDT in providing appropriate services for young people.	Thank you for your comment.
Association of Children's Hospices	Manual	431	We agree with this entirely. Transitional care planning needs to be proactive, and commence well in advance of when the support will actually be required, to ensure that there is enough time for a package of care to be organised and established across all agencies to support the young person and their family.	Thank you.
Association of Children's Hospices	Manual	437	This can only be achieved if children, young people and their families have information about all the services available to them. It is important that professionals present this in an impartial and unbiased way.	We agree.
Association of Clinical Biochemists, The				This organisation was approached to comment but did not respond.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	16	We feel that there needs to be a specific reference to addressing the shortage of Social Work expertise in this area, as well as Allied Health Professionals.	Social work is outside the scope of this guidance.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	365	We recognise that the provision of support from social care professionals has relied heavily on voluntary sector funding. However, we feel that the Statutory Authorities need to accept greater responsibility for this provision, in the light of Government policy to tackle Social Exclusion (which includes those facing bad health); The Children's National Service Framework; and Government strategy for Carers. We agree that multi-agency patterns of support are required, but suggest that greater emphasis needs to be placed on this as a priority for Statutory Authorities.	This is a descriptive paragraph. The policies cited should ensure that appropriate attention is paid to the issues raised, which are outside the scope of this particular guidance.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	369	We agree that all families with a child or young person with cancer should be offered the advice and support of a social worker to ensure that the needs of the wider family are addressed, and we refer to our comments under paragraph 365. However, the Social Work service on offer needs to be available and flexible, as well as specialist. This almost certainly means that a Social Worker needs to be placed within the cancer services, rather than located in some physically distant social work agency which may feel very threatening to service users as its priority is likely to be that of child protection rather than supportive care.	This is outside the scope of this guidance.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	372	The skills required for the assessment described in this paragraph are core professional social work skills. We therefore feel that these skills place the social worker at the heart of the psychosocial care of the patient and family.	We agree.
Association of Hospice	Manual	374–	We agree that psychological support should be a function of all members of	We agree but social work is outside the scope of this guidance

and Specialist Palliative Care Social Workers		377	the MDT, including group activities and advice regarding availability of other services. However, again we would point out that these are tasks which are at the core of the Social Work role, and examples exist of where social workers are providing these services already.	
Association of Hospice and Specialist Palliative Care Social Workers	Manual	421	We agree that provision is variable across the country, and feel that this is an issue that needs to be addressed urgently.	Thank you.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	425	It is important to note, in relation to children's hospices, that these can play an important role locally in the care of a child and the family. The hospice can offer respite care, and also support with anticipatory grief for all the family. Some have outreach nursing and support groups, even if the family do not wish to use them for respite care.	We have amended this paragraph.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	427	It is important that the multidisciplinary team in palliative care includes a Social Work service. It is also important that, as well as having appropriate links with voluntary services, the network should have appropriate links with other statutory children's services.	We have amended the text.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	432/433	We feel that Social Work should also be mentioned here, and it should be noted that Specialist Social Workers are able to offer psychological support as well as practical advice and help.	This is outside the remit of this guidance.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	612	We wish to point out that Social Workers as well as Psychology Services can play a key role in helping the healthcare professionals develop communication skills. We have examples of where social workers, alongside other disciplines, are involved in the training of health professionals in communication skills.	We agree.
Association of Hospice and Specialist Palliative Care Social Workers	Manual	615	It should be noted that a child/young person may wish to have someone to talk to outside the MDT whom they perceive to be independent of medical services and their parents. The members of the MDT will need to establish contact with local agencies that could facilitate this confidential service. We have examples of where a local children's hospice has been used for this purpose.	Thank you.
Association of Professional Music Therapists				This organisation was approached to comment but did not respond.
Association of Surgeons of Great Britain and Ireland				This organisation was approached to comment but did not respond.
Aventis Pharma				This organisation was approached to comment but did not respond.
BAPEN			BAPEN has no further comments on this Draft	Thank you.
Bard Limited				This organisation was approached to comment but did not respond.
Barts and The London NHS Trust				This organisation was approached to comment but did not respond.
Bath and North East Somerset PCT				This organisation was approached to comment but did not respond.
Bayer PLC				This organisation was approached to comment but did not respond.

Bedfordshire & Hertfordshire NHS Strategic Health Authority				This organisation was approached to comment but did not respond.
Bexley Care Trust				This organisation was approached to comment but did not respond.
Birmingham Heartlands & Solihull NHS Trust				This organisation was approached to comment but did not respond.
Blackburn With Darwen PCT				This organisation was approached to comment but did not respond.
Brain and Spine Foundation	IFP	General	The language is easy to understand and technical/ medical terms explained well. Could the text be broken down in to bullet points or in smaller chunks.	Thank you for your comments. We have considered this when rewriting some sections.
Brain and Spine Foundation	IFP	2	This section is a bit too simplistic (although I acknowledge the need to be concise). Perhaps consider putting in a sentence to say that putting NICE guidance in to practice takes time because…but this is being monitored and signpost to The Healthcare Commission?	We have reworded this section to clarify that it is the NICE recommendations specifically that the NHS is putting into practice.
Brain and Spine Foundation	IFP	4	What the service guidance covers is a bit confusing, as if the difference between this and clinical guidance. Could it be made clearer?	We have made some changes to make this clearer.
Brain and Spine Foundation	IFP	17	Phrase 'communication issues' is not clear	We have made amendments to the text.
Brain and Spine Foundation	IFP	18	Could the sentence 'Patients and carers should be involved'…be made into a separate point/ recommendation?	We have made changes to the text (additional text at the end of the Caring for children and young people with cancer section).
Brain and Spine Foundation	Manual		We have no further comments.	Thank you.
British and Irish Orthoptic Society				This organisation was approached to comment but did not respond.
British Association for Counselling and Psychotherapy	IFP	General	This looks clear and straight-forward – presuming the information in brackets pointing the reader to the corresponding Manual text is to be removed in the final edition.	Yes, that is correct. Thank you for your comments.
British Association of Art Therapists				This organisation was approached to comment but did not respond.
British Association of Dermatologists, The				This organisation was approached to comment but did not respond.
British Association of Head and Neck Oncologists				This organisation was approached to comment but did not respond.
British Association of Oral and Maxillofacial Surgeons			BAOMS has reviewed the document as part of the 2nd consultation phase and has no further comments to make.	Thank you.
British Association of Paediatric Surgeons				This organisation was approached to comment but did not respond.
British Dental Association	Manual	General	It is welcomed that oral and dental care are mentioned in this document as it is an aspect of care that is often overlooked.	Thank you.
British Dental Association	Manual	320	The primary care dentist involved should have the necessary knowledge and training to deliver this ongoing care. Not all GDPs will have the necessary	This is a descriptive statement only.

			knowledge and skills or a special interest in this patient group.	
British Dental Association	Manual	324	We need more than the provision of emergency dental treatment for teeth with poor prognosis at the start of chemotherapy. Patients need not only emergency dental care but ongoing continuing care throughout the course of their cancer treatment and beyond provided by a dentist with an interest and knowledge of caring for oncology patients. The dentist needs to be supported by PCD's who can assist the dentist in the delivery of prevention and oral care.	We have expanded paragraph 326 to cover this.
British Dental Association	Manual	326	All oncology treatment centres should have a named dentist to whom they refer patients for advice treatment or to co-ordinate such treatment with colleagues local to the patient.	We feel that the current recommendation is as explicit as we can make it.
British Dental Association	Manual	328	We need more than guidance for young adults who cannot afford to pay for NHS dentistry. Whilst it is accepted that if recommendation 324 is in place then prevention and ongoing care should reduce the amount of damage caused to the dentition, there will always be patients who fall through the net. One suggestion would be that following advise from the named dentist in recommendation 326 the patients' PCT should support their dental care.	We have amended the text.
British Dental Association	Manual	General	An additional recommendation would be to add that there is a clear referral pathway for children undergoing or have undergone oncology treatment from paediatric dentistry to adult special care dentistry once the child reaches adulthood.	We have amended paragraph 326 to cover this.
British Dental Association	Manual	335	More appropriate for the patient to be cared for by a paediatric dentist or special care dentist depending upon age.	We have amended the text to reflect this.
British Dental Association	Manual	338	Funding needs to be found to support all the recommendations not just a named dentist.	The text has been amended.
British Dietetic Association	Manual	General	As for when previously reviewed overall it is considered to be a useful document. Throughout the document areas which need addressing are highlighted e.g. adequate levels of capacity and equipment to treat increasing numbers of children and young people with cancer on increasing intensity protocols.	Thank you.
British Dietetic Association	Manual	General	Throughout the document there is recognition of the issues of recruitment and retention of certain groups of healthcare staff within the multidisciplinary team.	Thank you.
British Dietetic Association	Manual	303	There are different modalities for delivering nutritional support. Would perhaps be better to state, All of which require access to appropriate personnel and facilities. Although aseptics and specialist pharmacy staff are required for provision of TPN, diet cooks, milk kitchen staff, pharmacy technicians, medical physics staff etc are required for other methods of nutritional support.	We have amended the text.
British Fertility Society				This organisation was approached to comment but did not respond.
British Infertility Counselling Association				This organisation was approached to comment but did not respond.
British Liver Trust				This organisation was approached to comment but did not respond.
British National Formulary (BNF)				This organisation was approached to comment but did not respond.
British Nuclear Medicine	Manual	21	With advancement in technology, so the introduction of PET/CT imaging is	The issue of PET has been covered in paragraphs in 115 & 133.

Society			highly likely to change the current imaging protocols in certain types of cancer. This is a major challenge that needs to be taken into account.	
British Nuclear Medicine Society	Manual	75	There is no mention here of the use of imaging facilities. Virtually every child with cancer has some form of imaging.	This is based on data provided by the DOH, listing the 10 most commonly performed procedures coded using OPCS-4. No comprehensive data on use of imaging were available to us.
British Nuclear Medicine Society	Manual	90	Cancer care networks should also ensure that there are appropriate imaging services specifically for children. This includes routine nuclear medicine studies as well as the evaluation of PET/CT. This is especially important for the younger child.	This issue is covered by paragraph 113 and 126 and we do not feel that it is appropriate to make a separate recommendation at this point.
British Nuclear Medicine Society	Manual	100	The resource implications for nuclear medicine (including PET) have not been taken into account.	We are unclear how this comment relates to this section.
British Nuclear Medicine Society	Manual	113	If there is no nuclear medicine consultant in the paediatric oncology team then the paediatric radiologist should have the appropriate training in nuclear medicine.	We agree and feel this is implicit in the paragraph.
British Nuclear Medicine Society	Manual	Table 9	This should include expertise in nuclear medicine / radionuclide radiology	We have amended Table 9.
British Nuclear Medicine Society	Manual	209	PET/CT is likely to have a significant role in radiotherapy planning of the treatment of childhood cancers in the future. This should be considered in the context of this guidance and attention should be drawn to the need for further research in this area.	PET has already been covered in other sections of the guidance.
British Nuclear Medicine Society	Manual	636 – 646	There is a need to evaluate the role of PET/CT in children with cancer. This can only be done on a national basis as the numbers involved are small. This does not require all children to come to one single PET centre but rather have a co-ordinated agreed protocol of which children will undergo PET/CT at which stage of their disease. This requires the formation of a 'national children's PET/CT centre' that could be a virtual centre if adequately funded. Having established the role of PET/CT, this modality is highly likely to become the yard stick to assess the effectiveness of therapy on an individual patient with certain malignancies as well as assess effectiveness of new therapies. It should be noted that PET tracers other than FDG (Fluoro-deoxyglucose) the most commonly used PET tracer – need to be assessed in certain paediatric tumours and therefore it is important that at least one national centre, if not more, needs on-site access to a cyclotron for the production of such tracers.	This level of detail is not possible in service guidance and PET is mentioned in paragraph 115.
British Oncology Pharmacy Association				This organisation was approached to comment but did not respond.
British Orthopaedic Association				This organisation was approached to comment but did not respond.
British Paediatric Neurology Association				This organisation was approached to comment but did not respond.
British Paediatric Pathology Association				This organisation was approached to comment but did not respond.
British Paediatric Psychiatry & Psychology Group				This organisation was approached to comment but did not respond.
British Psychological				This organisation was approached to comment but did not

Society, The				respond.
British Psychosocial Oncology Society				This organisation was approached to comment but did not respond.
British Society for Haematology				This organisation was approached to comment but did not respond.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	General	The second consultation draft of this guidance has given more prominence and thus appropriate balance to the areas of rehabilitation, psychosocial care and follow-up of long term survivors as identified in the scope.	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	General	It is now fully comprehensive and clarifies areas of potential confusion and inequities in future long term follow up services. It also delineates the need for investment in staffing capacity, specifically to the area of late rehabilitation (352) and supportive care, the future workforce development, training and service delivery needs in more detail and throughout the acute and longer term patient journey.	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	General	It makes specific reference to the need to incorporate endocrine specialty services in the late effects MDT skill mix (398, 484, 569) and also to acute (eg neuro-oncology) services	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	General	The large and important majority of comments made to the previous consultation have now been fully incorporated. These include: 1. The importance of early and timely endocrine (341) referral and treatment for normal growth, development, puberty and bone mineral accretion (55, 405, 408) and to prevent morbidity (357). It also qualifies the negative consequences of delays in referral, inadequacies of multi-agency liaison (342) and importance of a tertiary endocrine service to the oncology MDT (196) 2. The definitions and distinction between early rehabilitation (341, 345) / surveillance (to prevent morbidity) and late effects /supportive care (227, 362, 394 and glossary) - these being separate from palliation services (419) 3. The more accurate representation (411) of the scope of late effects affecting most (50-90%) survivors other than just fertility (15%) (399-401) 4. Addresses the inequity of resources to support rehabilitation and surveillance (352, 358, 417, 448) and gaps in training of such staff (407, 483, 662, 670) 5. Makes clear the groups at high risk of endocrine toxicity (393) - especially all neuro-oncology survivors (343) – and qualifies the importance of endocrine support, clear treatment summaries and care plans (403, 410), to prevent morbidity years after treatment (345, 352), & consequent resource implications (206-8)	Thank you for your detailed comments.

			6. Makes specific recommendations to include robust surveillance of groups at high risk (399) and age appropriate transition to adult services (502) and the skill mix of key workers and MDT services which include endocrinology (400, 401) • Makes specific cross-reference to other NSF guidance and NICE guidelines on growth hormone replacement (675-8), fertility (404), SIGN guidance on late effects, listing other relevant paediatric and adult endocrine or surgical guidelines on management of endocrine and pituitary tumours and fertility preservation in minors. • Makes reference to the need for quaternary services and/or specialised MDT's (including adult liaison in rare tumours; the list includes thyroid cancer (67, 179, 485) and pituitary transphenoidal expertise (193) but other endocrine tumours have not also been specified.	
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	General	It makes estimates of future investments required to develop workforce to a streamlined consistent standard (388, 389) in each centre	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	24 and 27	Perhaps it should be specified whether the services survey specifically included questions about needs for late rehabilitation/support services	Sorry but we are unclear as to how this comment relates to paragraphs 24 and 27.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	59	It should be stated why increased survival has implications for service development …. 'Due to late morbidity' (which can be limited by early surveillance and intervention)	Paragraph 59 is a summary of paragraph 55, which gives a detailed account of the implications increased survival has for services.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	342	We agree with the reference to assessment by suitably qualified and experienced professionals	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	350	The words 'hypopituitarism' should be added to the neurological sequelae following CNS tumours.	This is not relevant to this section.
British Society for Paediatric Endocrinology and	Manual	371, 383	Agree with these strong recommendations for structured psychosocial assessments at defined points in the care pathway, especially for CNS tumours. These might be easily combined with endocrine assessments at the	Thank you.

Diabetes (BSPED) And Society for Endocrinology			same points.	
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	391	The estimates of survivors (50-90%) experiencing at least one, usually endocrine, toxicity should be included with estimates of subfertility (15%), to emphasise the balance of need and provision	This estimate is already included.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	392	For late follow-up, the word 'significant' should preface '…. Others need MDT hospital based care ' .	We have amended the text.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	408	The words 'hypopituitarism' should be included with growth and development, and 'late mortality' (from such hypopituitarism) mentioned.	This statement relates to outcome rather than cause because it is in the anticipated benefits section.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	414	The word 'timely' referral should be added to 'appropriate specialist' in line 4.	We have amended the text.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	417	Agree with this statement regarding resource	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	483	Agree with this statement about separate late effects MDT's.	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	485	Could words 'other endocrine tumours' be added to thyroid cancers (requiring specialist MDT'S)?	No. These are outside the scope of this document.
British Society for	Manual	502	Should endocrinologists not be added to the national shortage of MDT	This list is not meant to be exhaustive.

Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology			members for rehab services and for the CNS MDT?	
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	569	Should not endocrinologists be included in young people's MDT as well as children's (table 10)?	This paragraph refers to what should be present in a principle treatment centre, not an MDT.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Manual	576	Endocrine tumours should be named as part of rare tumours if possible (see 485).	These are outside the remit of this guidance.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	IFP	General	This is concise and necessarily broad but the use of the word cancer precludes certain tumours which are life-threatening and considered under the guidance. Would the term 'life-threatening tumours or cancer' be more explicit? The suggestions below are aimed at highlighting important rehabilitative issues, not currently obvious.	The term 'cancer' is used throughout the guidance and the IFP because the majority of children and young people to whom the guidance refers have malignant tumours. The guidance does make clear that services for patients with some specific non-malignant tumours are also discussed but we do not believe a change is needed in the IFP.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	IFP	5	The words '..but also disrupt normal growth and pubertal processes'.. should be added to end of penultimate sentence.	We disagree. The issues of growth delay, etc. are covered in the guidance and it is unnecessary to add this phrase (which does not really fit well) to what is simply giiven as an example of why this group has specific needs.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	IFP	12	The words 'in an age-appropriate setting throughout their treatment and pronged follow-up ' could be added to end second sentence.	'…through their treatment and long-term follow-up' added. The need for age-appropriate settings is covered in paragraphs 6, 7 and 22 and so we have not added it here.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	IFP	20	The words 'rehabilitative and' should precede 'social care' in the second sentence.	Wording changed to 'This support should include liaison with organisations that provide social care and rehabilitation and ensuring that educational needs are met, for example through liaison with schools and colleges.'
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for	IFP	21	The words 'and its surveillance' should be inserted after 'treatment for cancer…' and ' and access appropriate rehabilitative and support services' should be added right at the end.	Text changed to: 'Treatment for cancer and follow-up care may last a long time, over which a child's or young person's physical and emotional states may change, not only as a result of having cancer but also as a natural part of growing up. Key workers should be able to help the child or young person and their family adjust to

Endocrinology				these changes and access appropriate rehabilitation and support services.’
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	IFP	24	The word ‘developmental’ should be added after ‘social’.	Text changed to: ‘All health professionals at centres that care for children or young people with cancer must understand the specific needs of this group of patients. These include their social, developmental and emotional needs as well as their educational needs.’
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Needs Assessment		This was extremely thorough, interesting and appropriate to inform the service needs and guidance recommendations which appear to have fully incorporated this evidence.	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) And Society for Endocrinology	Evidence		Detailed list of evidence presented.	Thank you.
British Society of Paediatric Radiology				This organisation was approached to comment but did not respond.
British Thyroid Association				This organisation was approached to comment but did not respond.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	General	CLIC Sargent feel that the Guidance Development team are to be congratulated on the second draft of the guidance which in our opinion reads more clearly than the first draft and appears to have taken into account the majority of our previous comments. We feel that it would be useful if where social workers sit in the document remained consistent (at one point they are allied health professionals and at another others).	Social workers are not allied health professional (AHPs) but we can’t find the place in the guidance where they are referred to as AHPs.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	General 80	Whilst we acknowledge that the paragraph and economic analysis goes someway to acknowledge the vital role of the voluntary sector plays we feel that this needs to be strengthened	We will revise the Economic Analysis.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	9	We feel it is unclear which professionals can be considered as key workers. The key worker most appropriate for a child / young person / family is likely, in many cases, to alter throughout the illness trajectory.	This is made clear in the section on keyworker and also in the footnotes to Table 4-6.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	14	We suggest that this is such a vital issue that it MUST be addressed as a matter of urgency.	We are unable to use the word ’must‘ in the Guidance unless it is a Government directive.
Cancer and Leukaemia in Childhood (UK)	Manual	2	We welcome the widening of the scope to include children and young people.	Thank you.

and Sargent Cancer Care for Children				
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	32	We do not feel that the registration of cancer cases covered by this guidance should remain voluntary.	Cancer registration is governed by legislation. The same systems operate throughout the UK for all age groups.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	339	We are pleased that there is recognition that the need for rehabilitation can be urgent and that the need for emotional , social and educational rehabilitation are acknowledged alongside physical rehabilitation.	Thank you.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	342	We feel that it should be acknowledged that bottlenecks exist in the provision of appropriate equipment and this is often as a direct result of the multi agency input required.	We feel that this is already covered in the text.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	344	We feel it would be helpful to acknowledge the potential of identifying a key worker at this stage.	We have added a new recommendation to cover this.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	351	It needs to be acknowledged that funding must be available to provide the actual equipment.	The text has been amended.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	369	We feel that children with cancer need to be recognised as “children in need” in order to ensure that they and their families have more equitable access to social work support even when voluntary service do not exist.	This is outside the scope of this guidance.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	377	We welcome the recommendation that all families and young people should be offered benefits advice.	Thank you.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Manual	427 / 428	We would like to see more distinction made between the palliative care needs of children, adolescents and young people.	We believe that the existing distinction is sufficient.
Cancer Black Care				This organisation was approached to comment but did not respond.
Cancer Research UK				This organisation was approached to comment but did not respond.
Cancer Services Collaborative 'Improvement Partnership' (CSCIP)				This organisation was approached to comment but did not respond.
Cancer Services Co-ordinating Group				This organisation was approached to comment but did not respond.
Cancer Voices				This organisation was approached to comment but did not respond.

CancerBACUP				This organisation was approached to comment but did not respond.
CEMACH				This organisation was approached to comment but did not respond.
Cephalon UK Ltd				This organisation was approached to comment but did not respond.
Changing Faces				This organisation was approached to comment but did not respond.
Chartered Society of Physiotherapy	Manual	General	We welcome the opportunity to comment on the final draft of the guideline, though on this occasion have no further comments to make in addition to those already given in the first round of consultation.	Thank you.
Children's and Adolescent Cancer Partnership (CACP)				This organisation was approached to comment but did not respond.
Christian Lewis Trust - Cancer Care for Children				This organisation was approached to comment but did not respond.
Clatterbridge Centre for Oncology NHS Trust				This organisation was approached to comment but did not respond.
College of Occupational Therapists	Manual	General	Comments on previous draft dealt with adequately and amendments made as appropriate.	Thank you.
College of Occupational Therapists	Manual	General	Overall this second draft looks very comprehensive with useful provisional recommendations for stakeholders.	Thank you.
College of Occupational Therapists	Manual	Figure A Page 11	Diagram. The diagram seems more like a care process than a care pathway.	Thank you but we do not feel a change is necessary.
College of Occupational Therapists	Manual	Table 4 Page 108	Table 4 should read 'appropriate AHP's' rather than 'dieticians and other appropriate AHP's'.	We disagree because we need to mandate dieticians.
College of Occupational Therapists	Manual	175/6	Is Improving Outcomes in Children and Young People with Cancer: The Research Evidence available yet? (CD Rom) cited page 175/6. This would be a useful resource for professionals to access as soon as possible.	The Evidence is currently available on the NICE website. It will be available on CD-ROM when the guidance has been published.
College of Occupational Therapists	Manual	Appendix 7 Glossary of Terms Page 202	No definition of **Occupational Therapist** included. One is needed please and provided below: An occupational therapist will work with a person to design a programme of treatment based on the individual's unique lifestyle, environment and preferences. They will consider the importance of how a person's physical, mental and social needs will impact on their recovery process and help them to achieve the goals that are most important to them.	Thank you. We will add a definition to the glossary.
Community Psychiatric				This organisation was approached to comment but did not

Nurses' Association				respond.
ConvaTec				This organisation was approached to comment but did not respond.
Department for Education and Skills				This organisation was approached to comment but did not respond.
Department of Health	Manual	General	Whilst we accept that the clinical pathway is important, but could you consider whether it makes more sense to re-organise the report to address - service organisation first, then pathway, then issues such as research. At the moment you read information about the pathway without understanding the context within which this will be set i.e. Multi-Disciplinary Teams (MDTs) are mentioned but it is not until you read the later chapters that you actually know what these MDTs consist of and will do.	We disagree.
Department of Health	Manual	General	Please could you consider including more detail in the “E sections” on resource implications. A lot of these sections say things like “Dedicated funding should be made available for …..” This is a recommendation rather than an implication. It would be more helpful to have an indication of the resource required to do that. Including more detail would be in line with similar sections in other Guidelines produced by NICE.	More details will be included in the resource implications sections of the final guidance.
Department of Health	Manual	General	We recognise that there is little robust evidence on volume/outcome for cancer in children and young people, but one of the main purposes of this guidance is to provide information for commissioners on service configuration even if this has to be based on consensus – is there anything that can be added in the support this – we would be grateful for your advice on the following: - Are there roughly the 'right' number of paediatric centres - and how well are they located geographically to meet the needs of the population? - Ditto for young people. - Should shared care services normally be available in any District General Hospital (DGH) providing paediatric services - or is there a throughput needed to maintain an adequate level of expertise? - Should a shared care model be developed for young people? - There are several references to 'age appropriate' facilities, but no mention of what these would look like for young people - and whether they are currently available ie. could you clarify if you are recommending teenage cancer units and if so where - in every centre, shared care unit etc.? (Para 544 onwards is particularly relevant to the above) -	We believe that there is sufficient information in the guidance to inform commissioners regarding a sustainable, safe and effective service. We look forward to the Dept of Health providing strong support in the implementation of this guidance.
Department of Health	Manual	General	We feel that not all of the main issues are addressed in the guidance. For example, commissioners may not know from this whether there are the optimal number of children’s services and whether they should be advocating teenage centres – this needs to be tackled. [See 3rd set of General comments	We believe that there is sufficient information in the guidance to inform commissioners regarding a sustainable, safe and effective service. We look forward to the Dept of Health providing strong support in the implementation of this guidance.

			above for other examples]	
Department of Health	Manual	7 Bullet 5	Could you clarify if you meant to refer to particular standards here? If not, please could you consider using a different term?	We have removed the term ‘minimum standards‘ from the text.
Department of Health	Manual	36/38	Could you consider including actual numbers of new cases p.a. for patients aged 0 - 14 and 15 - 24, as well as age standardised incidence rates. This would be useful for commissioners of services. Could these be separate for England and Wales please?	These data are available in the needs assessment document as detailed in appendices 1, 2 and 4. Unfortunately, we are unable to present the data for England and Wales separately.
Department of Health	Manual	Figures B (after para 37), C (38) and D (46)	Again, could you consider including numbers of patients in the different ICCC groups. This would be helpful for commissioners.	We appreciate that these data are helpful for commissioners. The needs assessment supporting the guidance contains numbers of patients by ICCC in appendices 1, 2 and 4.
Department of Health	Manual	62	Please could you consider having a cross reference to appendix 3 (17 UKCCSG Centres). Could you also consider having a list of the 8 Teenage Cancer Trust Units and a map showing both UKCCSG and TCT centres/units. Is there any information on the numbers of patients referred to the 17 UKCCSG centres and 8 TCT units p.a? - This would give a measure of throughput (and variation).	A cross-reference to appendix 3 has been included and a list of the Teenage Cancer Trust centres has also been added to appendix 3. The needs assessment contains a map showing the UKCCSG centres and their dominant catchment areas (5.6.7). It was not possible to include a similar map for TCTs. A survey of the UKCCSG centres and TCT units conducted for the needs assessment collected data on new patient referrals (Table 28).
Department of Health	Manual	63	Would it be possible to cross refer to the *Improving Outcomes in Haematological Cancer* guidance here.	It is not appropriate to cross-reference other service guidance in this descriptive chapter.
Department of Health	Manual	63	Would it be possible to state how many shared care centres are there are and how these relate to UKCCSG centres? Would you consider a possible additional appendix.	These data are available in the needs assessment report (section 6.3.2.12 and Table 40).
Department of Health	Manual	65	Could you please clarify what happens at the 10 paediatric centres which do not have neurosurgery within 8 miles?	Unfortunately we do not know. This section therefore describes what we do know.
Department of Health	Manual	71	Para 71/Figure E. If 1997/8 is excluded there does not appear to be a major upward trend in inpatient bed day rates (except possibly among 0 - 4 year olds). Please could you check this.	Figure E refers to paragraph 72. No figure has been presented for Paragraph 71. The word ‘episode’ was in error and should read ‘bed days’, which may account for the confusion here. We have enhanced paragraph 72 with the aim of clarifying this point.
Department of Health	Manual	73	It would be useful to have the absolute bed day numbers separately for 0 - 14 and 15 - 24 year olds. Please would you consider adding these.	The text has been altered to include this. The data are provided in Table 14 of the needs assessment. The full table was not included in the manual due to its size.
Department of Health	Manual	74	Figure F. In contrast to the inpatient bed figures, the day case rates do appear to have risen considerably - yet in the text the rise is said to be small. Please could you check this.	Thank you. We agree with this and have amended the paragraph accordingly.
Department of Health	Manual	76	Could you clarify who would carry out this work?	We suggest that funding would be required for this work, which would then allow competitive bids to be made from health service research institutes.
Department of Health	Manual	76	It would be useful to see the figures for variations by SHA. Please could you clarify what makes you think this is due to differences in coding.	This data is presented in Table 26 of the needs assessment. In stating the possible reasons for the variation, we accepted the expert advice of Dr Brian Cottier (DOH)(personal communication)

				that clinical coding and data quality were of significance.
Department of Health	Manual	106	Would it be possible for 'currently in crisis' to be changed to something less emotive, such as ' has severe shortages across the country'	We agree and have amended the text.
Department of Health	Manual	114	Please could you clarify what is being recommended here.	This is not a recommendation.
Department of Health	Manual	122	Would it be possible to make recommendations for the longer term, i.e. once these staff are available?	We have amended the text.
Department of Health	Manual	142 - Last bullet	We believe the term metronomic prescribing may not be readily understood. Please could you consider amending.	This is a precise term and is referenced in the glossary.
Department of Health	Manual	149	This seems to be repeating para 146. Could you please clarify?	These are two different recommendations; one is about people and the other is about the environment. However, we have amended the text to clarify.
Department of Health	Manual	151	This is not the correct title of the guidelines. Could you please amend as at Appendix 1, 32.	We have amended the text.
Department of Health	Manual	151	Please could you consider whether it would be helpful to add the word 'full' before compliance.	We have amended the text.
Department of Health	Manual	153	Could you consider if it would be useful to put a caveat on this recommendation i.e. this would be the icing on the cake but getting the basics right needs to be the priority.	We feel that a caveat is already in place in this recommendation.
Department of Health	Manual	161/164	Please could you consider whether it would be better to use the term e-prescribing, rather than ETP, which is being used to refer to electronic transmission of prescriptions (e.g. from primary care to pharmacies).	We have amended the text.
Department of Health	Manual	178	Please consider whether this should be the case for all treatment	This is covered by paragraph 486.
Department of Health	Manual	179	Could you clarify whether this para refers to adult sarcoma MDTs, as these may not yet be in place as the Guideline on sarcomas is not yet out?	We are not envisaging separate paediatric sarcoma MDTs.
Department of Health	Manual	190	Talks about neurosurgery and notes that some centres see very few cases each year. Could you clarify whether you believe that is acceptable and whether services should be consolidated?	This is outside the remit of this guidance.
Department of Health	Manual	192	Could you consider recommending that the MDT should subsequently discuss the decision made at the earliest opportunity	We have amended the text.
Department of Health	Manual	193	Please could you clarify what constitutes "a surgeon experienced in paediatric CNS tumour surgery"? The British Association of Paediatric Neurosurgeons have made recommendations on this.	We have now included a recommendation that the definition of specialist expertise in paediatric CNS tumour surgery should be considered urgently.
Department of Health	Manual	209	Please could you consider giving the term HSCT in full.	The text has been amended.
Department of Health	Manual	234	Please could you consider whether this should apply to all patients, regardless of age?	As written it applies to all patients within the scope of this document.
Department of Health	Manual	323	Would it be possible to clarify who is developing these recommendations?	The British Dental Association & the Royal College of Paediatrics & Child Health.
Department of Health	Manual	328	Could you clarify what this guidance should be about	We have amended this recommendation to clarify.
Department of Health	Manual	328	Could you consider whether there should there be a stronger recommendation about dental care for young adults who have had a diagnosis of cancer.	We have made the recommendation stronger.
Department of Health	Manual	371	Would it be possible to include survivors here - i.e. living with the long term	The text has been amended.

			effects of the disease/treatment and psychological support?	
Department of Health	Manual	393	Could you consider adding radiotherapy to the chest here?	We have amended the text.
Department of Health	Manual	399	Would it be possible to be more specific about what you want the NHS to do?	It is not possible to go into this level of detail in service guidance.
Department of Health	Manual	402.	Please could you consider cross-referencing to later sections on key workers.	We do not feel that this is necessary.
Department of Health	Manual	427	A palliative care network for adults is an integral part of the cancer network as a whole and not a separate entity. This guideline is focusing on children and young people with cancer - a “paediatric palliative care network” as described would provide services beyond cancer and this might be outwith the remit for this Guideline although there would obviously be lessons for provision of palliative care services for children more generally. For the purposes of this guideline, we believe it is important that such any paediatric palliative care network is embedded within the cancer network as a whole. Could you consider reflecting this?	We cannot be more specific. Inevitably children with palliative care needs will require resources from cancer networks and from children’s services more generally. These issues should be picked up during the implementation phase.
Department of Health	Manual	428 Bullet 2	Could you consider whether children might want to be involved in decisions, possibly via the parents?	We do not understand this question and feel that this topic is already covered in paragraph 428.
Department of Health	Manual	431	Could you clarify whether the authors have a view on how the need for hospice and respite services for teenagers and young adults could best be met?	This is an issue for local implementation bearing in mind the principles contained within this guidance.
Department of Health	Manual	433	Would you consider adding that referrals can be out of network if need be.	This has been amended in the text.
Department of Health	Manual	434	Could you consider who should develop the proposed training pathway. Possibly the Royal College of Paediatrics and Child Health with the Royal College of Physicians?	We would not wish to specify this within the guidance but obviously the bodies referred to would have a role.
Department of Health	Manual	435.	Could you clarify whom you believe is best placed to develop the guidelines?	We believe this is for the DH to commission.
Department of Health	Manual	459	Again, please could you cross-reference subsequent key worker section.	We are not cross-referencing in detail throughout the guidance.
Department of Health	Manual	483	"It is not necessary for each member of the MDT to attend all meetings." We can understand this - but who could you clarify decides and how it should be assessed for peer review.	We have amended the text.
Department of Health	Manual	484 - Table 4	Please clarify whether these are separate MDT meetings for diagnosis, treatment and psychosocial support? Can you clarify how this is meant to work in practice?	We are deliberately leaving this to local determination to allow the flexibility required. See paragraphs 482–484.
Department of Health	Manual	480	Please could you clarify at what level this should be coordinated – i.e. is network level too low?	We cannot clarify this because the commissioning arrangements are unclear and we feel this is an issue for the implementation of the guidance.
Department of Health	Manual	484	If there is a "case to consider" for a separate MDT for late effects could you consider stating the views of the guidance developers?	We have amended the text in paragraph 484 and 486 to make this more explicit.
Department of Health	Manual	485	Please could you clarify how this links with pathway MDTs in table 4?	The liason would be via the lead oncologist in the care pathway MDTs, as needed for individual patients.
Department of Health	Manual	502	Could you consider whether this needs to be in the recommendations – this would be more in line with other NICE Guidelines	We have amended the paragraph 488 to include a recommendation on administrative support.
Department of Health	Manual	508/514	If key workers change over time (which we support), could you consider if/how this needs to be decided, recorded and communicated.	This is a matter for implementation.
Department of Health	Manual	569 - Table 9	Last two bullets – Please could you clarify if this means a principle treatment centre must have these on site?	The guidance states there should be immediate access to these services; it does not mean they have to be on site.
Department of Health	Manual	596	Would it be possible to state whether you envisage this being done within an	This is for local determination at the implementation phase.

			existing cancer network or at a supranetwork level?	
Department of Health	Manual	597	First bullet – could you please clarify if you are proposing 3 separate leads ie. one for children, teenagers and young adults, or one lead covering the group as a whole?	We have amended the text to clarify.
Department of Health	Manual	617/624	Please could you clarify what is meant by a national template?	We have removed this term from the text.
Eisai Limited				This organisation was approached to comment but did not respond.
Eli Lilly and Company Ltd				This organisation was approached to comment but did not respond.
Faculty of Dental Surgery				This organisation was approached to comment but did not respond.
Faculty of Public Health				This organisation was approached to comment but did not respond.
General Medical Council				This organisation was approached to comment but did not respond.
Gloucestershire Hospitals NHS Trust				This organisation was approached to comment but did not respond.
Gorlin Syndrome Group				This organisation was approached to comment but did not respond.
Great Ormond Street Hospital for Children NHS Trust	Manual	70	It would be helping to state what the aim of including this information is. The data given here needs further clarification or explanation for a commissioner to be able to apply it to a population. If it is just meant to give an overview of the size of the service it would still need something to compare it to e.g. levels in adults as a whole. Also the units being used need to be clearer. It says 3684 episodes per million - is this inpatient, and day case, outpatients combined and per million of the total pop aged 0 to 24 (or only pop with cancer) It says hospital episode rates decline with age - does this mean inpatient only or IP and Dc together.. It says highest in 0 to 4 but then the illustration given says 0 to 24 years – is it actually 5 per 1000 for 0 to 4 or is it not given.	The aim is to give an overview of total hospital activity in children and young people with cancer. Comparative data for adult services were not available as our terms of reference required us to conduct a needs assessment for the 0–24 year age range. Rates were calculated for all episodes, which includes day cases, ordinary admissions, and a comparatively small number of regular day attenders, mother and babies, and not known. The denominator used was the total ONS mid-year population of 0–24 year olds (and not just those with cancer). Paragraph 70 has been redrafted to clarify the above. The '0 to 24' is a typographical error and should read '0–4'.
Great Ormond Street Hospital for Children NHS Trust	Manual	72	Again clarification would be helpful in this section. Inpatient episode rates are given which implies it means how often a patient uses an inpatient bed. For example 10.7 inpatient episodes per 1000 population on average but Figure E is labelled bedday rates which suggests patients have an average inpatient stay of 10.7 days which is a different statistic.	Thank you for this comment. The word 'episode' was in error and should read 'bed days', which may account for the confusion here. We have enhanced paragraph 72 with the aim of clarifying this point.
Great Ormond Street Hospital for Children NHS Trust	Manual	73	The information is clear but not of value for planning as services are not planned across the whole age range but by age band. It would be more helpful to provide some sort of age split eg 0 to 14, 15 to 19 and 20 to 24.	The text has been altered to include age group data. Please see Table 14 of the needs assessment for the full set of data.
Great Ormond Street Hospital for Children NHS Trust	Manual	74	The first line refers to day beds stating 2.1 per 1000 – is this 2.1 beds or 2.1 day cases. Also Figure F appears to be about numbers of day cases not beds. Again giving rates across the whole age range is not that meaningful – a summary by age band would be clearer.	This refers to day case bed days. Figure F also refers to day case bed days. A summary by age band is available in Table 18 of the needs assessment.
Great Ormond Street Hospital for Children NHS Trust	Manual		It would be helpful to give rates using the same units eg always use 1000s rather than sometimes millions in the graphs, to make the info easier to compare. Sorry to go on about this but if the intention is it should be used to help with planning it needs to be clearer. I appreciate the difficulties in getting	Thank you for this comment. We have used rates per million for the epidemiological data as the numbers are small. However, we will amend the hospital activity data to consist ently use rates per 1000, as the numbers are larger.

			the data in the first place.	
Guys and St Thomas' Foundation Trust	Manual	General	The Second Consultation Draft is an excellent overview and will provide sound basis for commissioning services. However in a small number of sections the necessary emphasis on children's services overshadows what might be necessary and appropriate for adolescents and young adults. We feel this should be particularly addressed in the sections highlighted below.	We feel that we have achieved the appropriate balance between children's services and those for adolescents and young adults. We hope all your concerns have been addressed by our responses to your comments below.
Guys and St Thomas' Foundation Trust	Manual	105 *105 continued*	Pathology: "The requirement for histopathological diagnosis of tumours in young people is very similar" might be interpreted as requiring services anchored on paediatric pathology. We believe that a Young Persons' Unit would be most appropriately supported by the broad expertise available an adult tertiary pathology department, with particular expertise in the diagnosis of lymphomas, sarcomas and germ cell tumours. However there should be adequate experience of diagnosing other tumours which occur in adolescents and clear pathways for second opinions as needed (eg for bone tumours). An appropriate "recommendation" paragraph should also be added after 117.	We have amended the text to include this.
Guys and St Thomas' Foundation Trust	Manual	112	Haematology Diagnosis: The above criticism equally applies to this brief paragraph. The haematologist supporting an adolescent and young adult service must have particular expertise in the diagnosis of acute leukaemias and lymphoblastic lymphomas. They should be experienced in the diagnosis, monitoring and management of <u>both</u> paediatric and adult lymphoid and myeloid malignancies. The laboratory needs access to specialist immunophenotyping, cytogenetics and molecular genetics, as outlined elsewhere.	We agree and feel this is covered by paragraphs 111 and 112. This is covered in paragraphs 118 and 121.
Guys and St Thomas' Foundation Trust	Manual	Table 10	Core Components (Young people) - Medical personnel: This should mirror the recommendations in Table 9 (Children). ie.1. Designated lead clinician 2. Identified Unit oncologist for each major tumour type treated 3. Lead haematologist The haematologist managing 15 to 24 year olds needs to be an adult clinical haematologist, but with experience in managing adolescent leukaemias and lymphoblastic lymphomas, which have biological overlap with their paediatric counterparts.	We have added a lead haematologist to the table.
Guys and St Thomas' Foundation Trust	Manual	Table 10	Under Core AHPs: Include Educational advisor / coordinator. A significant proportion of this age group will be in secondary or higher education.	This is outside the remit of this guidance.
Guys and St Thomas' Foundation Trust	Manual	546	We strongly disagree with the implication in the statement that patients over 16 "may be treated within a paediatric oncology service, …. or to adult units", which implies that patients of 16 and younger <u>must</u> be treated in a paediatric unit. Teenagers of 15 and 16 at the time of diagnosis, as well as older adolescents, need to be part of an adult hospital, not only because their general <u>medical</u>	This paragraph is a statement of the current situation. However, we have also added 'At present' at the start of the paragraph.

			management is best served by adult physicians, but equally importantly for their self esteem as maturing individuals. Furthermore their follow up would need to be transferred to an adult oncology/haematology setting, and initial treatment within a children's service would ensure an undesirable break in continuity of care. This age group, above all, should wherever possible be treated in a specialist teenager / young adult unit attached to an adult haematology / oncology unit. However there should be close affiliation to a children's hospital to provide appropriate psychological support and input from related AHPs for both the patient and their siblings, as described elsewhere in the manual.	
Healthcare Commission				This organisation was approached to comment but did not respond.
Help Adolescents with Cancer				This organisation was approached to comment but did not respond.
Help the Hospices				This organisation was approached to comment but did not respond.
Hertfordshire Partnership NHS Trust				This organisation was approached to comment but did not respond.
Institute of Physics and Engineering in Medicine				This organisation was approached to comment but did not respond.
Joint Committee on Palliative Medicine				This organisation was approached to comment but did not respond.
King's College Hospital NHS Trust	Manual	General	Colleagues from the adult haemato-oncology department have expressed concern that the document does not address the issue of patient choice, particularly for teenagers who are around 16-years old and over. These individuals may choose to be treated in an adult unit for many reasons such as being closer to home than the designated cancer centre. The management of these individuals will therefore be determined by the team of the adult unit in discussion with the patient.	We feel that the document does address the issue of patient choice.
Leeds Dental Institute	Manual		I had circulated these to all consultants in pediatric dentistry but have received no comments so far. I have looked carefully at the dental part of this document and feel that it is excellent and does not need any further modification.	Thank you.
Leeds Teaching Hospitals NHS Trust	Manual	General	It would be helpful if this document could be seen in the context of both The Children Act 2004 and the Children's NSF. A statement to this effect could usefully be inserted into the Foreword and Key recommendations. This would make this guidance more palatable to commissioners and would allow for greater consistency rather than paediatric oncology being seen in isolation. Comments have been added to this effect below.	We agree and have included reference to the Children's NSF in the key recommendations. In addition, both documents are referenced in Appendix 1.
Leeds Teaching Hospitals NHS Trust	Manual	14	This recommendation appears to have been somewhat weakened since the first consultation. Whilst a statement to the effect that issues should be addressed within the structures of National Cancer Registries is welcomed and pertinent, the weakening of the recommendation to create a Register for 15-24 year olds is not. Appropriate registration has underpinned much development in paediatric oncology and it is difficult to see why NICE should	We do not feel that the recommendation has been weakened as a result of the text change.

			be only half-heartedly recommending a similar mechanism and resource for the older teenagers and young adults.	
Leeds Teaching Hospitals NHS Trust	Manual	32 and 60	Appropriately recognises the difficulties of not having a Registration system for 15 – 24 year olds.	Thank you.
Leeds Teaching Hospitals NHS Trust	Manual	90	This recommendation is less than clear and appears to add an unnecessary step for all patients of referral to a secondary care paediatrician. Surely the principle to adopt here should be that children reach the most appropriate expertise as rapidly as possible. Examples: a child with a GP initiated blood film that demonstrates clear evidence of leukaemia could be referred to the specialist centre immediately. A child with painful leg lump could be referred directly to an orthopaedic surgeon. This is not to decry the role of shared care but to point out that children and young people might enter the pathway at many different points and that the principle should be as above, rather than the ‘principles of shared care’.	The text has been amended to clarify.
Leeds Teaching Hospitals NHS Trust	Manual	104–112	It would be helpful if this section emphasised the need for paediatric pathologists to work in collaboration with other pathologists that have specific tissue or system expertise in order to provide optimal diagnostic input for tumours of children and young people. Examples – Neuropathology, bone pathology.	We have inserted a new paragraph to emphasise this.
Leeds Teaching Hospitals NHS Trust	Manual	113–116	Could be a clearer statement in this section about the requirement for anaesthetic sessions for paediatric radiology and for play therapy support for patients undergoing these procedures.	We agree; this is addressed in the key recommendations (paragraph 11) and also in paragraph 177.
Leeds Teaching Hospitals NHS Trust	Manual	170	Why limit this recommendation to centres without electronic prescribing systems. A better statement might be ‘ dedicated funding should be made available for provision and maintenance of electronic prescribing systems’	Thank you. This paragraph has now become a recommendation.
Leeds Teaching Hospitals NHS Trust	Manual	171–181	The section on surgery only makes passing reference to diagnostic biopsies and little to the importance or complexity of this. As pointed out in earlier section on pathology, accurate diagnosis often depends on detailed pathology, cytogenetics, and increasingly molecular techniques. These require adequate tissue collected appropriately in a way that won’t interfere with, and is consistent with, subsequent definitive surgery. It is an omission not to have a section or paragraph about this, in particular that any suspected malignancy should not be subject to ‘occasional practice biopsy’. Essentially, it would be appropriate to include recommendations that any biopsy in a child should be undertaken after discussion with the specialist diagnostic team and agreement reached about surgical approach, volume of tissue and appropriate samples to satisfy diagnostic requirements. This may also include samples for biological or translational research.	Thank you. This is already mentioned in paragraph 171 and we have amended paragraph 175 to make this clearer.
Leeds Teaching Hospitals NHS Trust	Manual	339 – 389	These sections on rehabilitation and psychosocial care appear to completely ignore the Children’s NSF and the Children Act 2004. Whilst the principles are generally sound, both the above documents recommend the use of the Common Assessment Framework for multi-agency assessment and support of children and young people. This would be equally appropriate for children and young people with cancer.	We have included a reference to the Common Assessment Framework after paragraph 340.
Leeds Teaching Hospitals NHS Trust	Manual	411 and 417	Given the apparent lack of evidence to support the contention that long term follow up programmes improve outcomes for children and young people, it is	Long-term sequelae do give rise to problems. We agree that evidence on outcomes is not yet available but this guidance is

			difficult to see how the guidance can recommend resourcing fully staffed MDTs for the follow up and management of long term sequelae. Surely this should be addressed, as other areas, by recommending the need for studies of health service provision aiming to discover best methods of undertaking surveillance programmes and managing sequelae.	attempting to outline good practice until such time as this evidence is accrued.
Leeds Teaching Hospitals NHS Trust	Manual	427 – 449	Having stated the need for a strong community nursing infrastructure, most of this section appears to undervalue this resource by relying heavily on developing and funding POONS and a centralised model of provision of care. This is inconsistent with the Children's NSF (Standard 6) and would be more consistent if there was much greater emphasis on the need to resource strong community nursing teams to work in collaboration with POONS and other key workers. This should be promoting the development of robust local children's clinical networks rather than a centralised oncology model.	We have amended the text.
Leeds Teaching Hospitals NHS Trust	Manual	475 – 481	This section on Service Organisation is less than clear. It would be strengthened by a statement that successful outcomes for children and young people with cancer is dependent on both effective cancer services and effective services for children and young people. Organisations therefore need to bring commissioning arrangements for children together with those of cancer to meet this guidance. This should be a responsibility of Strategic Health Authorities to oversee compliance. This section might also be strengthened by reference to the Children Act and Children's NSF, ensuring that the 5 key outcomes and 11 standards are encompassed within this guidance. This could also be usefully included in the Foreword and Key Recommendations at the beginning of the document.	We have amended the text.
Leeds Teaching Hospitals NHS Trust	Manual	559 – 569 Table 8	Shared Care section does not discuss or mention the requirement for local Trust Management and Commissioners (PCTs) to agree levels of care and buy-in to local contribution to the oncology patient pathway. The table does identify 'funding' but this might be better framed as organisational and local health economy commitment to the service. The recommendations in this section would again be strengthened (and NSF consistent) in arguing for strong local provision of community children's nursing teams in all areas.	We have amended the text.
Leeds Teaching Hospitals NHS Trust	Manual	636 – 658	The emphasis on the importance of clinical trials and recognition of the need for relatively higher proportions of children and young people to enter clinical trials is welcomed. Similarly welcomed is the recommendation to develop appropriate clinical trials for older teenagers and young adults. The research section however fails to address research areas that may well benefit this client population. 1 – the potential importance of biological studies and translational research in improving outcomes for cancer. This is of particular importance given the relative rarity and life years impact of cancer in this population. Research in this group raises difficult practical and ethical issues including the need to obtain adequate samples at diagnosis, definitive treatment or relapse; consent to clinical trials and consent to biological studies. These areas need to be acknowledged and resourced, particularly with data managers, research nurses and time for senior clinical investigators.	Amendments have been made to the text.

			2 – Health Services Research. This guidance identifies that there are large deficits in evidence based practice of oncology in children and young people. A section that brought these together and identifies this as an area for future research might aid research funding decisions. Example: the need for outcome based data resulting from different models of care for teenagers and young adults: the need to examine outcome benefits from Long term follow up programmes.	
Let's Face It				This organisation was approached to comment but did not respond.
Leukaemia Research Fund				This organisation was approached to comment but did not respond.
Lymphoma Association				This organisation was approached to comment but did not respond.
Macmillan Cancer Relief	Manual	General	We are pleased to have been invited to comment on the second consultation of the above Guidance, and hope that you will find the comments which follow helpful.	Thank you.
Macmillan Cancer Relief	Manual	General	We were pleased to see that many of the comments and recommendations we made on the previous draft have been incorporated into the latest draft of the Guidance, and we therefore feel that many of our key concerns have been addressed. However, we would like to repeat our concerns about the implementation of the Guidance. Whilst we accept that NICE has no power to oversee the implementation of the recommendations, we do believe that NICE could play an important role in ensuring that the Departments of Health in England and Wales work with relevant groups to discuss the implications, to ensure that adequate resources are made available, and to clarify responsibility for implementing the recommendations	It is not within the remit of the Guideline Development Group (GDG) to advise how this guidance will be implemented and whether adequate resources are available. However, we will feed back your helpful comments to NICE for their consideration.
Macmillan Cancer Relief	IFP	General	We would also like to make a general comment on the draft information for the public which has been prepared for this round of the consultation. Whilst acknowledging that format and content may well be dictated by NICE protocols, we feel that much could be done to improve the scope of the information provided and the language used. The focus of the leaflet is largely on healthcare issues, whilst many of the key areas of interest to patients and their families will be practical support needs to care for children and young people in their own homes. We have highlighted in particular in our response to the first draft of the Guidance the financial issues resulting from a cancer diagnosis in a child or young person, and are pleased that this has been addressed in the second draft. However, practical and financial support should feature more in the public information document. Furthermore, we would like to see greater emphasis in this document to how communication and information needs can be better supported, and how patients and their families can be helped to support themselves, including opportunities for self-management.	Thank you for your comments. IFP documents directly reflect the information in the manual. For cancer service guidance they describe the key recommendations in the manual. We have added text about the need for good communication and appropriate information.
Macmillan Cancer Relief		General	You may be interested to know that Macmillan Cancer Relief worked with other charities to develop public information in respect of the NICE Supportive and Palliative Care Guidance, and a copy of the leaflet which was produced is attached. This has been very well received. Macmillan is closely involved	Thank you. We will discuss this with NICE and the GDG.

			with a number of other charities with a focus on children and young people, and we would be pleased to work with others to develop a similar leaflet to support this Guidance, if this would be helpful. In the meantime we look forward to the final publication of this Guidance and the implementation of the recommendations.	Thank you.
Medicines and Healthcare Products Regulatory Agency (MHRA)				This organisation was approached to comment but did not respond.
Merck Pharmaceuticals				This organisation was approached to comment but did not respond.
Move4Health				This organisation was approached to comment but did not respond.
National Alliance of Childhood Cancer Parent Organisations	Manual	General	We have no further comments, other than it was very difficult to relate the responses to our previous comments, because of changes in numbering of paragraphs. Consideration should be given as to how NICE can facilitate this in the future.	Thank you. We will feed back your comments and concerns to NICE.
National Alliance of Childhood Cancer Parent Organisations	IFP	9	Consider inserting 'treatment ***provision*** should', for clarity	'provision' now inserted.
National Alliance of Childhood Cancer Parent Organisations	IFP	11	Consider inserting 'for ***adult*** patients' for clarity	'adults' now inserted.
National Alliance of Childhood Cancer Parent Organisations	IFP	16, 20	Consider inserting '***or paediatric haematologist'*** where appropriate for clarity.	'paediatric haematologist' added in paragraph 16.
National Alliance of Childhood Cancer Parent Organisations	IFP	23	Consider inserting 'some ***appropriate*** treatment' to focus the recommendation on competence and capabilities.	'appropriate' added.
National Alliance of Childhood Cancer Parent Organisations	IFP	34	'considered' is a weak word. Replace with 'implemented to reflect Guideline better.	We do not think that 'implemented' accurately reflects the recommendation. The manual states 'Experts should be commissioned at a national level to consider the issues related to the registration of cancers in 15–24 year olds, including the potential value of a dedicated register'. It does not say that the register should be implemented. Heading changed to: 'A register of all cancers in people aged 15–24 should be urgently considered' to better reflect key recommendation.
National Alliance of Childhood Cancer Parent Organisations	IFP	35	'consider whether' is also weak for the same reasons.	As above.
National Cancer Alliance				This organisation was approached to comment but did not respond.
National Cancer Network Clinical Directors Group				This organisation was approached to comment but did not respond.

National Cancer Research Institute (NCRI) Clinical Studies Group and National Cancer Research Network NCRN				This organisation was approached to comment but did not respond.
National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)				This organisation was approached to comment but did not respond.
National Council for Hospice and Specialist Palliative Care Services		General	The National Council has no comments specifically to make on this draft document. Please note that the organisation has changed its name from National Council for Hospice and Specialist Palliative Care Services to **National Council for Palliative Care**	Thank you. We have noted the change in name.
National Patient Safety Agency				This organisation was approached to comment but did not respond.
National Public Health Service - Wales				This organisation was approached to comment but did not respond.
National Youth Advocacy Service				This organisation was approached to comment but did not respond.
Neonatal & Paediatric Pharmacists Group (NPPG) and BOPA				This organisation was approached to comment but did not respond.
NHS Modernisation Agency, The				This organisation was approached to comment but did not respond.
NHS Quality Improvement Scotland				This organisation was approached to comment but did not respond.
North East London Strategic Health Authority				This organisation was approached to comment but did not respond.
Novartis Consumer Health (Novartis Medical Nutrition)				This organisation was approached to comment but did not respond.
Novartis Pharmaceuticals UK Ltd				This organisation was approached to comment but did not respond.
Ortho Biotech				This organisation was approached to comment but did not respond.
Pfizer Limited				This organisation was approached to comment but did not respond.
Plymouth Hospitals NHS Trust				This organisation was approached to comment but did not respond.
Princess Alexandra Hospital NHS Trust				This organisation was approached to comment but did not respond.
Queen Mary's NHS				This organisation was approached to comment but did not

Trust				respond.
Richmond & Twickenham PCT				This organisation was approached to comment but did not respond.
Rotherham Primary Care Trust				This organisation was approached to comment but did not respond.
Royal College of Anaesthetists				This organisation was approached to comment but did not respond.
Royal College of General Practitioners				This organisation was approached to comment but did not respond.
Royal College of General Practitioners Wales				This organisation was approached to comment but did not respond.
Royal College of Nursing (RCN)	Manual	General	The document is a comprehensive and much awaited piece of work and the GDG have achieved a great deal in a short space of time. However, we remain anxious that the emphasis appears to be on medicine i.e. workload pressures, workforce development needs, rather than across other disciplines all of whom face similar challenges and shortfalls. In particular nursing issues surrounding this group i.e. recognised standards for staffing levels, skill mix, education etc. mean that across the country capacity in principal treatment centres, shared care centres and community teams is compromised for all ages for the simple fact there are not enough nurses with the appropriate skills to administer the care prescribed in clinical trials, and we would welcome this message being sent to commissioners who will be required to make decisions using this document as guidance.	We feel these issues are addressed in Tables 9 and 10. Recruitment and retention of nurses are also mentioned in the workforce development section.
Royal College of Nursing (RCN)	Manual	General	It would be useful if the guidance was explicit about whether or not the published cancer service quality measures (2004) for chemotherapy, radiotherapy and supportive and palliative care apply to services for children and young people, or whether specific standards for paediatric/young people’s practice will be published.	The current cancer service quality measures for chemotherapy, radiotherapy and palliative and supportive care only apply to adult services, with the exception of intrathecal chemotherapy. Specific standards for children and young people with cancer will be written following publication of this guidance.
Royal College of Nursing (RCN)	Manual	General	Difficult to track whether or not previous comments have been addressed due to paragraph numbering changes, nor did it help that the index did not correlate with the actual page numbers in the document.	Thank you. We will feed back your comments and conerns to NICE regarding the consultation process.
Royal College of Nursing (RCN)	Manual	7	Agree with recommendation that ‘principal treatment centres are able to provide a sustainable range of services, with defined minimum levels of staffing, but at present only medical staffing levels are addressed. The pressure on principal treatment centres, shared care units, and community services due to lack of adequate nursing staff is often quoted. Often this is most acutely felt in inpatient facilities, guidance for clinical professionals and service managers does exist in the document “Defining staffing levels for children’s and young people’s services” (RCN 2003) adoption of this guidance would provide commissioners and those who must implement the recommendation of this guidance with a measurable standard. Suggest shared care arrangements should identify not only lead clinician but also *a lead nurse.*	We have now included the RCN document ’Defining staffing levels for children’s and young peoples needs‘ in appendix 1 of the guidance, and referenced this document in paragraph 568. The lead nurse is included in Table 8 and we have also added this to paragraph 7.

Royal College of Nursing (RCN)	Manual	15	Workforce development should be responsibility of Strategic Health Authority so suggest amend to 'need for trained specialist staff across all disciplines, able to work with children and young people with cancer, *should be supported by Strategic Health Authority workforce development directorates*	This topic is covered in paragraph 664.
Royal College of Nursing (RCN)	Manual	19	Guidance on upper age limit would be helpful to commissioners and providers in developing services for young adults. Would it be possible to add such a statement as, 'the generally accepted view is that this may appropriately include young people with cancer under 25 years of age'?	This issue was discussed at length during the scoping of this guidance and it was felt that it was not possible to define an upper age limit, as already indicated in paragraph 25. However, further explanation on why this has not been defined has now been added to paragraph 19.
Royal College of Nursing (RCN)	Manual	63	The last sentence of this paragraph seems to be in the wrong place should it be in paragraph 65?	Thankyou! We have now moved it to paragraph 65.
Royal College of Nursing (RCN)	Manual	90	In view of wide range of possible diagnoses and age range, clearly not appropriate for all patients with suspected cancer to be referred first to secondary care paediatricians. Cancer networks should ensure that there are clearly documented and well publicised local arrangements for referral of children and young people with suspected cancer from primary care to named clinicians or to specified clinics with adequate specialist time to see urgent referrals. Referral pathways should be developed and agreed locally by clinicians from primary, secondary and tertiary care as to how tertiary oncology services can be accessed by primary and secondary care clinicians (this is in accordance with 'The Referral for Suspected Cancer Clinical Guideline' due for publication March 2005 which covers children, young people and adults). These arrangements should be well publicised to all health professionals and should include the availability of telephone advice and named specialists	The text has been amended to clarify.
Royal College of Nursing (RCN)	Manual	98	The referral and subsequent wait for some patients in this guidance will be subject to the 2 week wait cancer target could this be mentioned here?	It is not within the remit of this document to define Standards; however, where Standards are available these should be applied.
Royal College of Nursing (RCN)	Manual	126 & 127	Suggest separate recommendation on imaging in general and need for diagnostic radiographers and staff who have been trained in dealing with children and young people. These procedures will frequently require the use of either sedation or general anaesthesia although the input of a play specialist may help to avoid this.	We feel that these issues are covered in other sections of the guidance.
Royal College of Nursing (RCN)	Manual	164	Aim of electronic prescribing of chemotherapy not improved compliance of patients, but reduction of risk, for which there is evidence (see 161)	We agree. This is a statement about the evidence.
Royal College of Nursing (RCN)	Manual	170	Suggest this becomes a specific recommendation rather than a resource implication to add wait to its implementation by commissioners.	Thank you. We have amended the text and this is now a recommendation.
Royal College of Nursing (RCN)	Manual	196-197	Is there any more that can be said about the over 15s? This section very much focussed on children, and paediatric services, feel there needs to be more about teenagers/young adults with CNS tumours?	This will be addressed in the service guidance on CNS tumours.
Royal College of Nursing (RCN)	Manual	233	IOG and quality measures for adults with haematological malignancy is very specific about care of neutropaenic patients, requiring isolation/filtration facilities and nurse to patient ratios of 1:2. This would be very useful in relation to children with profound/prolonged neutropaenia – i.e. a wider group in children than adults. Such clarity in this guidance would assist some units who struggle to justify and maintain adequate care environments and (particularly) staffing levels for 'high risk' children/young people.	The text has been amended.
Royal College of	Manual	304	Suggest adding recommendation that *Nutritional support should be*	We have amended the text.

Nursing (RCN)			*adequately resourced across treatment settings, including home enteral feeding.*	
Royal College of Nursing (RCN)	Manual	305	Dieticians working with young adults do not require paediatric training.	We have amended the text.
Royal College of Nursing (RCN)	Manual	344	Rehabilitation an area where clearly need engagement with children's services and networks as well as cancer network, therefore it is suggested to amend this recommendation to "*There should be clear, agreed routes of referral for rehabilitation, including self referral, throughout the patient pathway and agreed across cancer and children's networks. Rehabilitation should extend into the community setting where the involvement of community paediatricians may be beneficial".* Equipment is frequently essential to rehabilitation, and can be cause of dispute among service providers, should be addressed with new recommendation, suggest; *Funding arrangements for basic and specialist equipment such as wheelchairs and adaptation to the home should be clarified and agreed between health and social care providers*.	The text has been amended. We have added a recommendation on funding for rehabilitaiton equipment.
Royal College of Nursing (RCN)	Manual	421	Very focussed on services for children, and needs more reference to teenagers and young people. Palliative care for teenagers and young adults require special provision, which may entail the development of partnerships between children's and adult services. Macmillan teams, GPs, district nursing teams and hospice care recommendation for specialist palliative care made Improving Supportive and Palliative Care for Adults with Cancer NICE 2004) may be useful for commissioners to provide such services.	We have amended the text to emphasise this.
Royal College of Nursing (RCN)	Manual	425	Hospice care specifically designed to meet the needs of young people are being developed, but it should be mentioned that adult hospices can be an important resource for young people.	This is addressed in paragraph 431.
Royal College of Nursing (RCN)	Manual	427	Paediatric palliative care networks should probably be at SHA level. These networks should address paediatric palliative care as a whole…this is an area where links need to be with other children's services.	Thank you, but we feel this is a matter for the implementation phase.
Royal College of Nursing (RCN)	Manual	428	Welcome recognition here of different services needed for young people however palliative care for young people is at present ill defined we would welcome a further statement that encourages collaboration across disciplines with and without Cancer Networks following the model suggested in number 90 we also recommend adding the following g statement: • *24 hour access to specialist advice and support to patients, their carers and local health and social care professionals*	We have amended paragraphs 427 and 428 to refer to Table 3.
Royal College of Nursing (RCN)	Manual	430/439	24 hour palliative care advice rotas should not exclusively be the responsibility of POONs – can include SpRs, consultants and potentially other experienced nurses. This decision about designated 'on-call' staff can be made by principle treating centres. Supportive and Palliative Care for Adults with Cancer (NICE 2004) requires specialist palliative care teams to develop a 9-5, 7-day visiting on-call service, to agreed network wide criteria, this would this also improve the quality of care to children and young people and support CCNs and GPs.	We have amended the text to clarify.
Royal College of	Manual	479	Meaning of the 2nd sentence is unclear – please clarify.	We have amended the text to clarify.

Nursing (RCN)				
Royal College of Nursing (RCN)	Manual	491	Statement should also apply to young adults, not just teenagers.	The text has been amended.
Royal College of Nursing (RCN)	Manual	493	Meaning of 'referral culture' is not clear – please explain.	We have removed this from the text.
Royal College of Nursing (RCN)	Manual	510 & 511	POONS are not always the most appropriate professional group to fulfil role of key worker especially for older teenagers and young adults. The development of appropriate models of care will be required (with additional resources) for outreach and specialist nursing teams across treatment settings to meet the needs of specific groups of patients.	The text has been amended.
Royal College of Nursing (RCN)	Manual	555	Add statement to clarify what 'responsive to their needs' means – suggest "as described above" (554).	We have made an amendment to the text to clarify.
Royal College of Nursing (RCN)	Manual	10, 571 & Table 9/10	Guidance is prescriptive about MDTs for principle treatment centres for TYA's but vague about facilities. Would it be possible to define minimum facilities that are considered 'age-appropriate' for teenagers/young adults? Suggest : 1. Offers care in same environment as/opportunity to meet other young people with cancer, i.e. not in same ward/room as young children or older adults - applies to inpatient and day care facilities 2. somewhere for parents/relatives to stay, • recreation room where relatives/friends can visit, • quiet/study room. • Treatment room for day case chemotherapy • Facilities to prepare food/drinks • Consultation/discussion room	We have added references to the appropriate documents in the guidance.
Royal College of Nursing (RCN)	Manual	580	Appropriate training needs to be provided for all staff to provide safe 24 hour care, i.e. nursing staff & junior/middle grade medical staff, not just those in the MTD.	We have amended the text.
Royal College of Nursing (RCN)	Manual	597	Cancer Networks should establish network-wide (or 'pan-network') groups for children's and young people's cancer services to deliver the IOG i.e. same remit as Network site-specific groups (NSSG's).	This is for local determination.
Royal College of Nursing (RCN)	Manual	607 & Appendix 1 No 37	Is the reference correct? The Manual of Cancer Standards 2004 identified does not exist. As stated in 1st consultation response -there is a Manual of Cancer Standards 2000 and there is a Manual of Quality Measures for Peer Review 2004 (which is the updated 2000 Cancer Standards).	The reference is correct.
Royal College of Nursing (RCN)	Manual	636	Clinical trials are vital to this population but other paradigms and approaches to research can reveal the complete dimension of care and support needed and we would welcome mention of these to balance the document and recognise their value to care.	We have added an additional paragraph to cover this.
Royal College of Nursing (RCN)	Manual	646	Suggest that there should also be local and national funding for research into supportive, palliative care, patient, family involvement families and quality of life	We have amended the text.
Royal College of Nursing (RCN)	Manual	668	There is a shortage of programmes in TYA cancer care as this is perceived to be uneconomic due to low demand. We need support from service commissioners/WDCs for HE establishments to develop them.	We feel this is implicit in this paragraph.

Royal College of Nursing (RCN)	Manual	685	Access to education for 'sick children' over 16 yrs in hospital/at home is not statutory – provision is up to the discretion of LEA's and very variable across the country. Can you say something to encourage them to provide support to TYAs in full time education? – Tutorial support and/or liaison with schools/colleges/universities.	This is outside our remit.
Royal College of Nursing (RCN)	Economic evaluation		It is unclear how many new teenage/young adult units are envisaged – staffing costs are given for 8, and under place of care 10 are costed.	The economic report has been revised to make it explicit where additional costs are needed.
Royal College of Nursing (RCN)	Evidence review	194	Reference to chapter by Edwards and Hooker. This work is now published – please update citation.	The text has been amended.
Royal College of Nursing (RCN)	IFP	16	The key worker here could imply this is a specific person rather than a role that one (or more as needed over time) of the HCPs in the relevant MTD will take on. Therefore the last paragraph in 20 should be moved to avoid confusion	We do state in paragraph 20 (which paragraph 16 contains a cross-reference to): 'The key worker may change from time to time depending on the stage of treatment and the needs of the child or young person.' This seems to address your concern.
Royal College of Nursing (RCN)	IFP	23	Some "tests" i.e. FBC, CT scans etc. are and will be undertaken at primary and secondary care facilities at part of diagnosis and throughout treatment, therefore the first line might be misleading to users.	The first sentence of this paragraph has been changed to: 'NICE recommends that children who may have cancer should have their care managed by a principal treatment centre.'
Royal College of Ophthalmologists				This organisation was approached to comment but did not respond.
Royal College of Paediatrics and Child Health				This organisation was approached to comment but did not respond.
Royal College of Pathologists	Manual	General	In general. the guidance document deals with the relevant issues in a straghtforward manner; thank you	Thank you.
Royal College of Pathologists	Manual	105–112	This section illustrates well the specialist nature of paediatric pathology and the paragraphs 109, 110 and 111 are of particular importance	Thank you.
Royal College of Pathologists	Manual	119–124	These paragraphs appear non-controversial and highlight the need for tissue/DNA storage in paediatric solid tumours and leukaemias	Thank you. Your comment has been noted.
Royal College of Pathologists	Manual	126	This paragraph states explicitly that the diagnostic procedures should be undertaken within routine working hours; we fully support this recommendation	Thank you.
Royal College of Pathologists	Manual	129–133	We agree entirely with the anticipated benefits of accurate and timely diagnosis	Thank you.
Royal College of Pathologists	Manual	138 (also: 666)	We would like to add to these paragraphs that the resources should be available for an increased number of consultant paediatric pathology/paediatric haematology posts in specialist centres staffed by singlehanded specialists	Thank you. We have amended the text.
Royal College of Pathologists	Manual	Appendix 6.4	Dr Neil Sebire is a Consultant Paediatric Pathologist at the Great Ormond Street Hospital for Sick Children (and not a Consultant Anaesthetist from Birmingham); please amend accordingly	Thank you. We will amend Dr Sebire's title.
Royal College of Physicians of London				This organisation was approached to comment but did not respond.
Royal College of Psychiatrists	The Manual	433	In response to the first draft, we commented that although psychology is a key discipline, others experienced in psychological services/mental health eg nurses and psychiatrists may be appropriately involved either on a regular	We have amended the text.

			basis or because of their specific skills. A more inclusive term has now been used in the document eg 'member of psychological services' , and this is welcomed. However, the term 'clinical psychology' appears in this paragraph. Otherwise, the College is very satisfied with the revised guidance.	
Royal College of Radiologists	Manual	General	Among the key recommendations, we note the omission of any reference to the fact that radiotherapy is of major importance in the management of many children with cancer. We recommend the inclusion of a statement such as: “Timely access to fully equipped and staffed specialist paediatric radiotherapy services is essential for the care of many children with cancer”.	We feel this is covered by paragraph 7 which refers to the minimum staffing levels required by a principal treatment centre (of which radiotherapy is an important component).
Royal College of Radiologists	Manual	Table 2	We feel it is important that cross cover is only truly meaningful if there are within one centre two (or more) clinical oncologists with programmed activities in paediatric radiotherapy who are involved in the core MDT. It is not really acceptable for cross cover to mean an arrangement for a colleague in a separate UKCCSG centre to be called upon to help if required, or for a colleague in the same centre to be asked to cover if paediatric radiotherapy is not a normal component of his/her day-to-day practice. We therefore suggest that the opening two bullet points of table two are replaced by: “More than one consultant clinical oncologist with appropriate sub-specialisation in paediatric radiotherapy including membership of the UKCCSG and programmed activities for paediatric radiotherapy specified in the job plan, to enable consultant cross cover arrangements”.	The text has been amended.
Royal College of Radiologists	Manual	223	Paragraph 223 would be better rephrased as: “Provision of adequate resources and staff including more than one specialist paediatric consultant clinical oncologist with programmed activities for paediatric radiotherapy to assure compliance with waiting time requirements and cross cover arrangements”	We are unclear how this comment relates to a measurement section.
Royal College of Radiologists	Manual	226	Paragraph 226 would be better rephrased as: “… access to paediatric clinical oncologists and radiographers with paediatric training and experience”.	Thank you. We have amended the text.
Royal College of Speech and Language Therapists	IFP	39	Please insert ‘**and language’** between ‘speech’ and ‘therapy’ to read ‘speech and language therapy’	This has been added.
Royal College of Speech and Language	Manual	16 & general	We welcome the mention of the need for specific attention to address the shortage of allied health professional expertise here and throughout the	Thank you.

Therapists			document.	
Royal College of Speech and Language Therapists	Manual	181	We would suggest that some of the AHPs who might be involved (e.g. those mentioned in paragraph 174) are listed in this paragraph	We did not feel that it was necessary to list these in this paragraph.
Royal College of Speech and Language Therapists	Manual	200	It would also be important to assess speech and language skills to ensure quality of life in terms of the child or young person's ability to communicate and learn. We recommend that '**and speech and language therapy assessments** is inserted after 'occupational therapy assessments' and before 'to ensure …'	We have amended the text.
Royal College of Speech and Language Therapists	Manual	344 and 347	Speech and language therapists are specialists in communication disorders. They work to assess, diagnose and develop programmes of care to maximize the communication potential of their clients. They also work to support clients with swallowing, eating and drinking difficulties. However since we are not likely to be core members of the MDT for Children and Young People with cancer, we are concerned that our role might not be fully understood by the some of the members of the MDT, and would like to suggest that AHPs also provide training to other members of the MDT to ensure all members of the MDT are clear about the contributions each can make to improving the outcomes for children and young people with cancer. This would also support the recommendations made in paragraphs 8 and 9 and others related to trained staff.	We agree and have now included a definition in the glossary. We would expect all members of MDTs to have ongoing discussion about each other's roles.
Royal College of Speech and Language Therapists	Manual	348	We welcome the recommendation for support to allow staff to access training opportunity although we are concerned about if /how this would happen in practice.	Thank you for your comments.
Royal College of Speech and Language Therapists	Manual	351	We are concerned that there is no mention of funding of equipment and as such would result in distressing delays in obtaining equipment especially if at the palliative care stage.	The text has been amended.
Royal College of Speech and Language Therapists	Manual	612	As specialists in developing communication skills, speech and language therapists could also play a role also in training others to communicate sensitively and effectively and especially in allowing sufficient time to do so.	Thank you for your comment.
Royal College of Speech and Language Therapists	Appendix 7 Glossary	192	The glossary is welcome. However, we note that with the exception of occupational therapists core allied health professional groups are listed, and wonder if there should be a short description of all the AHPs listed for clarity. A suggested description for speech and language therapists might be 'A specialist trained in the assessment and management of communication and swallowing difficulties'	We have included speech and language therapists in the glossary.
Royal College of Surgeons of England				This organisation was approached to comment but did not respond.
Royal College Patient Liasion Groups				This organisation was approached to comment but did not respond.
Royal Liverpool Children's NHS Trust	Manual	General	A very useful document I am pleased it recognises the emotional support provided by various professionals and as a Psychologist I am also pleased it recognises the need to increase resources for Clinical Psychology and	Thank you.

			Neuropsychology.	
Royal Liverpool Children's NHS Trust	Manual	636	It is extremely important of course to appropriately research the effectiveness of treatments for various childhood cancers. Please don't forget that one of the roles of Psychologists is to research psychological issues and interventions which could be done on a multi-centre fashion the document mentions a lack of evidence base but does not from my reading address this.	We have added an additional paragraph to cover this.
Royal National Orthopaedic Hospital NHS Trust				This organisation was approached to comment but did not respond.
Royal Society of Medicine	Manual	General	Among the key recommendations, we note the omission of any reference to the fact that radiotherapy is of major importance in the management of many children with cancer. We recommend the inclusion of a statement such as "Timely access to fully equipped and staffed specialist paediatric radiotherapy services is essential for the care of many children with cancer."	Same as comment 2 lines above – ensure response is identical.
Royal Society of Medicine	Manual	In Table 2	We feel it is important that cross cover is only truly meaningful if there are within one centre two (or more) clinical oncologists with programmed activities in paediatric radiotherapy who are involved in the core MDT. It is not really acceptable for cross cover to mean an arrangement for a colleague in a separate UKCCSG centre to be called upon to help if required, or for a colleague in the same centre to be asked to cover if paediatric radiotherapy is not a normal component of his/her day to day practice. We therefore suggest that the opening two bullet points of table two are replaced by: "More than one consultant clinical oncologist with appropriate subspecialisation in paediatric radiotherapy including membership of the UKCCSG and programmed activities for paediatric radiotherapy specified in the job plan, to enable consultant cross cover arrangements."	The text has been amended.
Royal Society of Medicine	Manual	223	would be better rephrased as: "Provision of adequate resources and staff including more than one specialist paediatric consultant clinical oncologist with programmed activities for paediatric radiotherapy to assure compliance with waiting time requirements and cross cover arrangements."	We are unclear how this comment relates to a measurement section.
Royal Society of Medicine	Manual	226	would be better rephrased as: "....access to, paediatric clinical oncologists and therapy radiographers with paediatric training and experience."	Thank you. We have amended the text.
Samantha Dickson Research Trust, The				This organisation was approached to comment but did not respond.
Scottish Intercollegiate Guidelines Network				This organisation was approached to comment but did not respond.

(SIGN)				
Serono Pharmaceuticals Ltd				This organisation was approached to comment but did not respond.
Sheffield Children's NHS Trust				This organisation was approached to comment but did not respond.
Social Care Institute for Excellence (SCIE)				This organisation was approached to comment but did not respond.
Society and College of Radiographers	Manual	General	Overall this guidance document appears comprehensive, clearly addressing the workforce needs for this group of patients and as such will be very helpful to commissioners.	Thank you.
Society and College of Radiographers	Manual	General	It is encouraging that workforce development and CPD needs are clearly highlighted for all staff groups.	Thank you.
Society and College of Radiographers	Manual	211, 213 and table 2660	Whilst we are pleased to see that therapeutic radiographers are recognised within this guidance document there must be consistency of terminology when referring to this group of staff. This is important, as therapeutic radiographer is the protected title under the Health Professions Order (2001) and **not** therapy radiographer. We would therefore expect that this is rectified following this iteration	The text has been amended.
Society and College of Radiographers	Manual	205	We believe that it is vital to understand how the radiographers' role has developed since radiography became an all-graduate profession more than a decade ago, if the most effective use of their diverse skills is to be made. We believe that your definition for both diagnostic and therapeutic radiographers are too narrow and very out dated. As such we would wish to see this new definition of a Diagnostic Radiographer be used, "Diagnostic radiographers are responsible for providing safe and accurate imaging examinations and, often, resultant reports in a wide range of clinical environments, using a variety of imaging modalities and techniques so that appropriate management and treatment of patients and clients can proceed. The identification, evaluation and monitoring of systemic diseases, skeletal and soft tissue abnormalities and trauma are the major focus of diagnostic radiography. Significantly, radiographers provide this service throughout the 24-hour day, often working alone or in inter-professional care teams. Hence they need to be prepared to deal with medical emergencies which may arise during examination and treatment." Similarly the following definition adopted when describing a therapeutic radiographer " Therapeutic radiographers are responsible for providing safe and accurate high-energy radiation treatments to individual patients with cancer and for the patient's physical, psychological well being prior to, during and following radiotherapy. This is a continuum of care, which, involves complex technical skills in pre-treatment localisation, target delineation, planning and dosimetry, technique development,	We have separately defined diagnostic and therapeutic radiographers in the glossary but did not feel that the level of detail ***[Add 'you suggest' after 'level of detail'?]*** was appropriate.

			management and verification of the treatment process.”	
Society of British Neurological Surgeons				This organisation was approached to comment but did not respond.
South & Central Huddersfield PCTs				This organisation was approached to comment but did not respond.
Specialist Child and Adolescent Mental Health Service				This organisation was approached to comment but did not respond.
Tameside and Glossop Acute Services NHS Trust				This organisation was approached to comment but did not respond.
Taunton and Somerset NHS Trust	Manual	General	Although we have made a number of comments and suggestions we should like to note we feel the document is a very good step in producing guidance.	Thank you.
Taunton and Somerset NHS Trust	Manual	General	Although there is better clarity in the second draft than the first, it is suggested the authors have under estimated what actually may take place in a shared Care Centre.	The emphasis of the guidance has been on advising what can be delivered in a shared care centre.To what extent care is delivered is a matter for local determination.
Taunton and Somerset NHS Trust	Manual	General	Surprised there is so little reference to the spiritual needs of the child/family, particularly in the sections on palliative and bereavement care. It appears no learning has been sought from the supportive and palliative care guidance. If these are being included in the involvement of allied health professionals, please recognise that chaplaincy staff are not included in the DOH definition of Allied Health Professionals. They are an important part of the team and thus should be included.	Spiritual needs are now included in Table 3 under core elements for palliative care and additional information is provided in paragraphs 455 and 461.
Taunton and Somerset NHS Trust	manual	545	Major underestimate of the amount and complexity of paediatric oncology undertaken by some shared care centres. Some provide all chemotherapy except high dose methotrexate from diagnosis onwards, and all supportive care. Suggest take out most of final sentence and replace with: Thus some episodes of care, including for example the management of some complications of treatment including febrile neutropaenia, and delivery of chemotherapy, may be undertaken closer to home.	Thank you; we have amended the text.
Taunton and Somerset NHS Trust	IFP	General	We liked this, clear and concise and user-friendly. Thankyou.	Thank you.
Teenager Cancer Trust Multidisciplinary Forum	Manual	General	Although we welcome some of the changes we feel that little notice has been taken of our initial comments on the first draft. This remains a very professional and POC focussed document with little regard for the POSCUs or community teams. It is not a child or family centred document and focuses on treatment rather than holistic needs. The new section on communication is welcome.	We have ammended the text to emphasise community teams.
Teenager Cancer Trust Multidisciplinary Forum	Manual	General	Improved but still insufficient awareness of social and financial needs of families, could be missed if only sections of document are read, as confined to supportive care section	We hope that the entire document will be considered by commissioners when implementing this guidance.
Teenager Cancer Trust Multidisciplinary Forum	Manual	General	Little mention of travel difficulties	We have tried to acknowledge the difficulties faced by patients and families with regards to travel to access services throughout the guidance.
Teenager Cancer Trust	Manual	General	No mention of spiritual issues or cultural needs	Spiritual needs are now included in Table 3 under core elements

Multidisciplinary Forum				for palliative care and additional information is provided in paragraphs 455 and 461.
Teenager Cancer Trust Multidisciplinary Forum	Manual	General	It would be helpful if this document could be seen in the context of both The Children Act 2004 and the Children's NSF. A statement to this effect could usefully be inserted into the Foreword and Key recommendations. This would make this guidance more palatable to commissioners and would allow for greater consistency rather than paediatric oncology being seen in isolation. Comments have been added to this effect below.	We agree and have included reference to the Children's NSF in the key recommendations. In addition, both documents are referenced in Appendix 1.
Teenager Cancer Trust Multidisciplinary Forum	Manual	General	It would be useful if the guidance was explicit about whether or not the published cancer service quality measures (2004) for chemotherapy, radiotherapy and supportive and palliative care apply to services for children and young people, or whether specific standards for paediatric/young people's practice will be published.	The current cancer service quality measures for chemotherapy, radiotherapy and palliative and supportive care only apply to adult services, with the exception of intrathecal chemotherapy. Specific standards for children and young people with cancer will be written following publication of this guidance.
Teenager Cancer Trust Multidisciplinary Forum	Manual	14	This recommendation appears to have been somewhat weakened since the first consultation. Whilst a statement to the effect that issues should be addressed within the structures of National Cancer Registries is welcomed and pertinent, the weakening of the recommendation to create a Register for 15-24 year olds is not. Appropriate registration has underpinned much development in paediatric oncology and it is difficult to see why NICE should be only half-heartedly recommending a similar mechanism and resource for the older teenagers and young adults.	We do not feel that the recommendation has been weakened as a result of the text change.
Teenager Cancer Trust Multidisciplinary Forum	Manual	19	Guidance on upper age limit would be helpful to commissioners and providers in developing services for young adults. Would it be possible to add such a statement as, ' the generally accepted view is that this may appropriately include young people with cancer under 25 years of age'.	This issue was discussed at length during the scoping of this guidance and it was felt that it was not possible to define an upper age limit, as already indicated in paragraph 25. However, further explanation on why this has not been defined has now been added to paragraph 19.
Teenager Cancer Trust Multidisciplinary Forum	Manual	32 and 60	Appropriately recognises the difficulties of not having a Registration system for 15 – 24 year olds.	Thank you.
Teenager Cancer Trust Multidisciplinary Forum	Manual	90	This recommendation is less than clear and appears to add an unnecessary step for all patients of referral to a secondary care paediatrician. Surely the principle to adopt here should be that children reach the most appropriate expertise as rapidly as possible. Examples: a child with a GP initiated blood film that demonstrates clear evidence of leukaemia could be referred to the specialist centre immediately. A child with painful leg lump could be referred directly to an orthopaedic surgeon. This is not to decry the role of shared care but to point out that children and young people might enter the pathway at many different points and that the principle should be as above, rather than the 'principles of shared care'.	The text has been amended to clarify.
Teenager Cancer Trust Multidisciplinary Forum	Manual	104–112	It would be helpful if this section emphasised the need for paediatric pathologists to work in collaboration with other pathologists that have specific tissue or system expertise in order to provide optimal diagnostic input for tumours of children and young people. Examples – Neuropathology, bone pathology.	We have inserted a new paragraph to emphasise this.
Teenager Cancer Trust Multidisciplinary Forum	Manual	113–116	Could be a clearer statement in this section about the requirement for anaesthetic sessions for paediatric radiology and for play therapy support for patients undergoing these procedures.	We agree; this is addressed in the key recommendations (paragraph 11) and also in paragraph 177.

Teenager Cancer Trust Multidisciplinary Forum	Manual	170	Why limit this recommendation to centres without electronic prescribing systems. A better statement might be ‘ dedicated funding should be made available for provision and maintenance of electronic prescribing systems’	Thank you; we have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	171–181	The section on surgery only makes passing reference to diagnostic biopsies and little to the importance or complexity of this. As pointed out in earlier section on pathology, accurate diagnosis often depends on detailed pathology, cytogenetics, and increasingly molecular techniques. These require adequate tissue collected appropriately in a way that won’t interfere with, and is consistent with, subsequent definitive surgery. It is an omission not to have a section or paragraph about this, in particular that any suspected malignancy should not be subject to ‘occasional practice biopsy’. Essentially, it would be appropriate to include recommendations that any biopsy in a child should be undertaken after discussion with the specialist diagnostic team and agreement reached about surgical approach, volume of tissue and appropriate samples to satisfy diagnostic requirements. This may also include samples for biological or translational research.	Thank you. This is already mentioned in paragraph 171 and we have amended paragraph 175 to make this clearer.
Teenager Cancer Trust Multidisciplinary Forum	Manual	206–208	Rehabilitation often takes place in DGHs and this has resource implications that should be added here	We have amended the text to note that rehabilitation occurs in different settings and costs will be incurred across these.
Teenager Cancer Trust Multidisciplinary Forum	Manual	223	There should be a mention of the problems of transport or accommodation for daily RT treatment, especially when recommending specialist sites which may be a considerable distance from home	This issue is mentioned in paragraph 364 and covered by the recommendations in paragraphs 369 and 377.
Teenager Cancer Trust Multidisciplinary Forum	Manual	233	IOG and quality measures for adults with haematological malignancy is very specific about care of neutropaenic patients, requiring isolation/filtration facilities and nurse to patient ratios of 1:2. This would be very useful in relation to children with profound/prolonged neutropaenia – i.e. a wider group in children than adults. Such clarity in this guidance would assist some units who struggle to justify and maintain adequate care environments and (particularly) staffing levels for ‘high risk’ children/young people.	The text has been amended.
Teenager Cancer Trust Multidisciplinary Forum	Manual	305	Dieticians working with young adults do not require paediatric training.	We have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	339 – 389	These sections on rehabilitation and psychosocial care appear to completely ignore the Children’s NSF and the Children Act 2004. Whilst the principles are generally sound, both the above documents recommend the use of the Common Assessment Framework for multi-agency assessment and support of children and young people. This would be equally appropriate for children and young people with cancer.	We have included a reference to the Common Assessment Framework after paragraph 340.
Teenager Cancer Trust Multidisciplinary Forum	Manual	411 and 417	Given the apparent lack of evidence to support the contention that long term follow up programmes improve outcomes for children and young people, it is difficult to see how the guidance can recommend resourcing fully staffed MDTs for the follow up and management of long term sequelae. Surely this should be addressed, as other areas, by recommending the need for studies of health service provision aiming to discover best methods of undertaking surveillance programmes and managing sequelae.	Long-term sequelae do give rise to problems. We agree that evidence on outcomes is not yet available but this guidance is attempting to outline good practive until such time as this evidence is accrued.
Teenager Cancer Trust Multidisciplinary Forum	Manual	419–451	This section is improved but there still appears an over emphasis on the POONs and tertiary centre outreach rather than the skills and expertise of the community teams. Many are now NOF funded for 24 hour support. A greater	The approach that we have taken is that palliative care ‘should be tailored to the choices of the patient and family & take into account variations in local service provision’.

			emphasis and advice on network groups here would be useful.	
Teenager Cancer Trust Multidisciplinary Forum	Manual	430/439	24 hour palliative care advice rotas should not exclusively be the responsibility of POONs – can include SpRs, consultants and potentially other experienced nurses. This decision about designated 'on-call' staff can be made by principle treating centres. Adult IOG requires specialist palliative care teams to develop a 9-5, 7-day visiting on-call service, to agreed network wide criteria. I think this would this also improve the quality of care to children and young people and support CCNs and Gps.	We have amended the text to clarify.
Teenager Cancer Trust Multidisciplinary Forum	Manual	427–449	Having stated the need for a strong community nursing infrastructure, most of this section appears to undervalue this resource by relying heavily on developing and funding POONS and a centralised model of provision of care. This is inconsistent with the Children's NSF (Standard 6) and would be more consistent if there was much greater emphasis on the need to resource strong community nursing teams to work in collaboration with POONS and other key workers. This should be promoting the development of robust local children's clinical networks rather than a centralised oncology model.	We have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	460	Clear local policies should be in place as the treatment centre may not be the best service to provide ongoing bereavement support and services can end up being duplicated	We have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	475 – 481	This section on Service Organisation is less than clear. It would be strengthened by a statement that successful outcomes for children and young people with cancer is dependent on both effective cancer services and effective services for children and young people. Organisations therefore need to bring commissioning arrangements for children together with those of cancer to meet this guidance. This should be a responsibility of Strategic Health Authorities to oversee compliance. This section might also be strengthened by reference to the Children Act and Children's NSF, ensuring that the 5 key outcomes and 11 standards are encompassed within this guidance. This could also be usefully included in the Foreword and Key Recommendations at the beginning of the document.	We have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	483 table4	Community nurses should be included in the MDT at the palliative care stage. Physios also need to be on the MDT	We disagree.
Teenager Cancer Trust Multidisciplinary Forum	Manual	491	Statement should also apply to young adults, not just teenagers	The text has been amended.
Teenager Cancer Trust Multidisciplinary Forum	Manual	509–510	Community nurses may often be the key-worker rather than the outreach nurse and should be mentioned here	We have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	559–569 Table 8	Shared Care section does not discuss or mention the requirement for local Trust Management and Commissioners (PCTs) to agree levels of care and buy-in to local contribution to the oncology patient pathway. The table does identify 'funding' but this might be better framed as organisational and local health economy commitment to the service. The recommendations in this section would again be strengthened (and NSF consistent) in arguing for strong local provision of community children's nursing teams in all areas.	We have amended the text.

Teenager Cancer Trust Multidisciplinary Forum	Manual	571 & Table 9/10	Guidance is prescriptive about MDTs for principle treatment centres for TYA's but vague about facilities. Would it be possible to define minimum facilities that are considered 'age-appropriate' for teenagers/young adults ? Suggest : ● Offers care in same environment as/opportunity to meet other young people with cancer, i.e. not in same ward/room as young children or older adults - applies to inpatient and day care facilities ● somewhere for parents/relatives to stay, ● recreation room where relatives/friends can visit, ● quiet/study room. ● Treatment room for day case chemotherapy ● Facilities to prepare food/drinks ● Consultation/discussion room	We have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	580	Appropriate training needs to be provided for ward staff to provide safe 24 hour care - not just designated MDT members, ie nursing staff & junior/middle grade medical staff.	We have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	593	Specialist oncology wards or designated shared care wards	Specialist oncology wards
Teenager Cancer Trust Multidisciplinary Forum	Manual	596-609	This helps to clarify of the role of Cancer networks. Our network feels it has no official role with the children's work and all the directives come directly from the POCs. As each POSCU in the network aligns to a different POC there is no clear network view. If the guidance is to be peer reviewed in the future there is an urgent need for national guidance to the networks of their responsibility.	Thank you.
Teenager Cancer Trust Multidisciplinary Forum	Manual	610–635	This is a very welcome section on communication	Thank you.
Teenager Cancer Trust Multidisciplinary Forum	Manual	612	Communication skills training needs to cover issues specific to children and young people and their parents, as well as generic principles.	We have amended the text.
Teenager Cancer Trust Multidisciplinary Forum	Manual	636 – 658	The emphasis on the importance of clinical trials and recognition of the need for relatively higher proportions of children and young people to enter clinical trials is welcomed. Similarly welcomed is the recommendation to develop appropriate clinical trials for older teenagers and young adults. The research section however fails to address research areas that may well benefit this client population. 1 – the potential importance of biological studies and translational research in improving outcomes for cancer. This is of particular importance given the relative rarity and life years impact of cancer in this population. Research in this group raises difficult practical and ethical issues including the need to obtain adequate samples at diagnosis, definitive treatment or relapse; consent to clinical trials and consent to biological studies. These areas need to be acknowledged and resourced, particularly with data managers, research nurses and time for senior clinical investigators. 2 – Health Services Research. This guidance identifies that there are large	Amendments have been made to the text.

			deficits in evidence based practice of oncology in children and young people. A section that brought these together and identifies this as an area for future research might aid research funding decisions. Example: the need for outcome based data resulting from different models of care for teenagers and young adults: the need to examine outcome benefits from Long term follow up programmes.	
Teenager Cancer Trust Multidisciplinary Forum	Manual	662	Palliative care awareness should be essential in training, with recognition of when to refer so services are provided equitably. There is evidence that it is professionals who block referral to palliative care and hospices, not families	These are examples; the list is not exhaustive.
Teenager Cancer Trust Multidisciplinary Forum	Manual	685	Access to education for 'sick children' over 16 yrs in hospital/at home is not statutory – provision is up to the discretion of LEA's and very variable across the country. Can you say something to encourage them to provide support to TYAs in full time education ? – tutorial support and/or liaison with schools/colleges/universities.	This is outside our remit.
Teenager Cancer Trust Multidisciplinary Forum	Economic evaluation		It is unclear how many new teenage/young adult units are envisaged – staffing costs are given for 8, and under place of care 10 are costed.	The economic report has been revised to make it explicit where additional costs are needed.
Teenager Cancer Trust Multidisciplinary Forum	Evidence review	194	Reference to chapter by Edwards and Hooker. This work is now published – please update citation.	The text has been amended.
Thames Valley Strategic Health Authority				This organisation was approached to comment but did not respond.
The Association for Family Therapy				This organisation was approached to comment but did not respond.
The Leukaemia Society UK				This organisation was approached to comment but did not respond.
The Medway NHS Trust				This organisation was approached to comment but did not respond.
The Royal Society of Medicine				This organisation was approached to comment but did not respond.
The Royal West Sussex Trust				This organisation was approached to comment but did not respond.
UK Association of Cancer Registries				This organisation was approached to comment but did not respond.
UK Brain Tumour Society				This organisation was approached to comment but did not respond.
UK Childhood Leukaemia Working Party				This organisation was approached to comment but did not respond.
UK Children's Cancer Study Group				This organisation was approached to comment but did not respond.
UK Pain Society				This organisation was approached to comment but did not respond.
University College				This organisation was approached to comment but did not

Londons Hospital NHS Trust				respond.
Welsh Assembly Government (formerly National Assembly for Wales)	Manual	General	Thank you for giving the Welsh Assembly Government the opportunity to comment on the guideline. We are content with the document as drafted and have no further comments to make at this stage.	Thank you.
Wessex Cancer Trust				This organisation was approached to comment but did not respond.
Wyre Forest Primary Care Trust				This organisation was approached to comment but did not respond.
Young Minds				This organisation was approached to comment but did not respond.