Cancer Guidance in Children and Young People – 1st Consultation – Stakeholder comments

[Please give dates of consultation]

National Institute for Health and Clinical Excellence

Organisation	Section no. or General	Comments	Developer's response
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			This organisation was approached to comment but did not respond.
Association of Breastfeeding Mothers			This organisation was approached to comment but did not respond.
Association of Children's Hospices	General	Overall this document addresses the many issues faced by children and young people with an oncology diagnosis and their families. It seeks to raise standards and provide equity of services. However the issues for those moving into the palliative care phase are only addressed at minimal levels. I do realise that those moving into palliation only represent 25% of the total but issues for these youngsters have to be dealt with effectively and in a much more rapid time frame together with the lifelong issues for their families after their death. Specific have been entered against the chapter number as requested.	Thank you. We have answered the specifics where appropriate.
Association of Children's Hospices	10	With due recognition for the young person's cognition and developmental age (e.g. the young person with Down's syndrome who develops cancer)	We acknowledge the issue. However, the wording here follows that of the NSF for children and young people, which did not make this specific distinction.
Association of Children's Hospices	19	NHS & Voluntary sector services	It was not within the remit or the scope of this guidance to address voluntary sector services.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Association of Children's Hospices	34	Is this being addressed?	Paragraph 34 has now been removed from the guidance and the key recommendation at paragraph 14 has been amended to clarify the situation.
Association of Children's Hospices	44	Essential for transition planning	Thank you for your comment.
Association of Children's Hospices	71	Education of cancer unit teams in how to introduce and describe the concept of Children's Hospice services – i.e. not just for end of life care – total holistic care in the context of the whole individual family. Many families have accepted children's hospices services just days before the child's death or in some cases after the death for use of the special bedrooms (bereavement suites), only to state later that they wished they had been offered the choice earlier not only for care & support but for fun & recreational opportunities s when these become very limited for the sick child. Like wise for sibling/ extended family support.	We appreciate the problem, but this paragraph summarises the findings of a survey.
Association of Children's Hospices	80	Good observation – support	Thank you.
Association of Children's Hospices	90	Our support is offered for the use of the statement –"Parents know their child best"	Thank you.
Association of Children's Hospices	145	Support of statement – Chemotherapy should not be administered unless in a specialist unit. Children's hospices for instance would share the issue of infrequent administration leading to inadequate skills/ accuracy & the front line clinical/ medical support during & post administration.	Thank you for your support.
Association of Children's Hospices	152	Consideration needed in terms of frequency of administration & the skills required & competency maintenance	We agree, but feel this is implicit in paragraph 146.
Association of Children's Hospices	156	See entry for 152 – perhaps development of regional community based Chemotherapy teams?	This will be a decision for local providers to make, e.g. Cancer Networks, Primary Care Trusts.

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Association of Children's Hospices	224	External support facilities such as Children's Hospices offering planned & emergency respite care. Emergency may be clinically based or may be to manage a social crisis within the family	Thank you for this comment, but we are not sure how this is relevant to management of acute febrile neutropenia.
Association of Children's Hospices	289–292	Suggestion to provide training to primary care teams e.g. health visitors to understand the complexities of nutrition in children with cancer, so as to advocate the appropriate support and/ or intervention in regard to nutrition.	We feel this is a specialist issue and health visitors would be involved in individual cases as appropriate and adequate information given at that time.
Association of Children's Hospices	351	Or when another crisis situation adds to the family's stresses – e.g. marriage difficulties/ loss of work/ another family members illness etc.	We have amended the paragraph and the recommendation now allows for additional assessments if required.
Association of Children's Hospices	399	Written information. More information/ training/ guidance for POONS teams / CCN teams/ specialist centres etc in the extended role of children's hospice services beyond end of life care. Particularly psychosocial support for the sick child/ parents/ siblings/ grandparents/ school etc. Plus the availability of ongoing post bereavement support often for several years, which is strengthened by the pre bereavement relationship.	The provision of information is a generic issue and is covered in the section on communication. This level of detail not possible in this part of the guidance.
Association of Children's Hospices	401	MDT should include wherever possible representation from the local Children's Hospice Service	It is inappropriate to include local Children's Hospice Services as co-members of the MDT. However, where they are providing care for an individual child they would be involved as appropriate in those discussions.
Association of Children's Hospices	402	Include Children's hospice services	This would be implicit in bullet point 3 – 'Multidisciplinary, multiagency services'.
Association of Children's Hospices	401, 402	Rapid access to medical/ therapeutic equipment in the community especially in the palliative phase for example specialised beds/ chairs/ hoist etc	This is highlighted in paragraph 423 but has been further strengthened in Table 3.
Association of Children's Hospices	406	Plus complimentary therapies	Complementary therapies are not commissioned by the NHS and are therefore outside the scope of this guidance.
Association of Children's Hospices	419	Please see entry against 401 & 402	It is inappropriate to include local Children's Hospice Services as co-members of the MDT. However, where they are providing care for an individual child they would be involved as appropriate in those discussions.

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Association of Children's Hospices	420	Audit of numbers of children & young people receiving care & support from Children's hospice services – in terms of community based services/ hospice based services/ planned respite/ family psychosocial support/ end of life care.	Children's Hospice Services are one of the services that could be provided, but we do not believe it is possible to be more prescriptive about the use of the service. Therefore, audit of these numbers is not possible.
Association of Children's Hospices	430, 435, 609	Only these chapters mention the necessity of staff support. I feel this should be enhanced even to the point of compulsory clinical supervision & training for identifies numbers of clinical supervisors within teams	It is not within our remit to make obligatory recommendations on supervision and/or training.
Association of Children's Hospices	440	Plus children's' hospices/ CCN teams	We have amended this paragraph to make it less prescriptive.
Association of Children's Hospices	441	At a designated time after death – not all bereavement support will require formal counselling- other styles input of emotional support is valid and will affect outcomes. Carers "satisfaction surveys" is a difficult concept within post bereavement perhaps some sort of survey based around value statements & benefits. Many bereaved carers will have different interpretations of the support they have received at different stages of their bereavement- so this should be given consideration.	We agree with your comments.
Association of Children's Hospices	Table 4	Should include: CCNs & Children's Hospice senior representative	Table 4 lists core members of the relevant MDTs. We would expect additional expertise to be accessed as necessary.
Association of Children's Hospices	Table 6	Include Children's hospice teams/ services	Table 6 lists the major roles that we feel are appropriate.
Association of Children's Hospices	520	Children's hospice services	We have amended the text to include hospices.
Association of Children's Hospices	553	Should include children's hospice services for palliative & bereavement care even at an advisory level.	We are unclear what this comment is asking for.

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Association of Clinical Biochemists, The			This organisation was approached to comment but did not respond.
Association of Hospice and Specialist Palliative Care Social Workers			This organisation was approached to comment but did not respond.
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.
Association of the British Pharmaceuticals Industry (ABPI)	12	The ABPI fully supports the recommendation that all children and young people with cancer should be offered entry into relevant clinical trials and that adequate resources to enable this to take place should be provided.	Thank you.
Association of the British Pharmaceuticals Industry	35	It is vital that the two coding systems that have grown up independently should be able to co-ordinate with one another to provide a comprehensive database.	Paragraphs 33–35 have been redrafted.
Association of the British Pharmaceuticals Industry	37	We note the incidence of childhood cancers and, in doing so, would wish to point out that puts them as a group within the incidence requirements of the Orphan Disease legislation. We would suggest that, therefore, a recommendation along the lines of "efforts should be made to determine how the Orphan Disease legislation can be used to the full in developing medicinal treatments for childhood cancer"	Thank you; this will be discussed further by the Guideline Development Group.
Aventis Pharma			This organisation was approached to comment but did not respond.
Bard Limited			This organisation was approached to comment but did not respond.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Barts and The London NHS Trust			This organisation was approached to comment but did not respond.
Bath and North East Somerset Primary Care Trusts			This organisation was approached to comment but did not respond.
Bayer PLC		No Comment	Thank you.
Bedfordshire & Hertfordshire NHS Strategic Health Authority			This organisation was approached to comment but did not respond.
Bexley Care Trust	General	The guidance is welcomed by specialised commissioners particularly in raising the profile of commissioning services for rare cancers e.g. paediatric cancers, within a competing portfolio for PCT resources.	Thank you.
Bexley Care Trust	6	Key Recommendations are very condensed compared to the detail in the recommendations and loses impact because of this.	Out of necessity the key recommendations have had to be condensed compared with the full recommendations.
Bexley Care Trust	23	Definition of children and young people. Age range is different to that defined within the NSF for children, young people and maternity services. Reference should be made to this.	Paragraph 23 makes no specific mention of an age range; however, we have extended paragraph 19 to make the decisions we took about age range clearer.
Bexley Care Trust	107–117	The diagonstic pathway for children is clear but not for older patients, e.g. over 15 year olds. It does not stipulate who should lead on management of this age group.	We acknowledge that this is difficult and believe that the document makes clear that the lead clinician will vary depending on the specific tumour type in this age group.
Bexley Care Trust	185–193	Section on CNS tumours needs to be expanded as there is an area of concern in terms of access to protocolised care.	We feel that the key issues particular to neurosurgery are covered and there are other more general recommendation on protocolised care.
Bexley Care Trust	224	Support long term audits to support national protocols but focus is on febrile neutropenia. Audit should be wider e.g. use of antifungals, antivirals, etc. This area has been flagged as an increasing Trust cost pressure year on year.	We think this is implicit in 'Compliance with protocols and guidelines'.

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Bexley Care Trust	226	Agree that any treating unit should ensure it has sufficient capacity to allow admission to a bed ….. It would be helpful to make a recommendation that bed occupancy should be no greater than…. e.g. a review of Paediatric Oncology Centres in London has just reported and the review group's medical expert advised that the optimum bed occupancy for a tertiary unit should be around 80% to allow flexibility in the system to admit urgent cases and to reduce deferred admissions for planned treatment. High bed occupancy has a knock on impact at POSCUs which cannot admit to POCs when necessary and causes out or area referrals, impacting on the whole family. The review also heard that extremely high occupancy increases stress and pressure on staff providing the service.	Each unit would have to satisfy itself that it has sufficient capacity, and bed occupancy is an important factor in this. We have included bed occupancy as a process measure.
Bexley Care Trust	Resource implications	The implications of Payment by Results and national tariff for treatment should be positive. The tariff will apply whether posts have been historically soft funded or not. The whole pathway of care should be fully funded to ensure that changes in protocols at the POC, or transferred delivery of treatment does not adversely affect another part of the care system at the POSCU or community care. Keen to see the resource sections completed within the document	We agree. The resource sections have now been added.
Bexley Care Trust	Disease specific issues	There may be disease specific issues which are not included in the document, e.g. brain tumours or teenagers with medullo blastoma not accessing trials	Thank you. We feel we have addressed these issues.
Bexley Care Trust	General	More emphasis on the psychological impact on patients and families and the necessary support infrastructure.	We feel that this has been adequately covered.
Bexley Care Trust	General	Does cancer palliative care need a separate network from palliative care given very small numbers involved. It is more important to have a clear identity and relationship to the rest of palliative care strategy/network.	We do not feel that we need to change the recommendations made.
Bexley Care Trust	General	Does not refer to complementary therapies.	Very few complementary therapies are commissioned by the NHS, and reference is made to the NICE Supportive and Palliative Care guidance where these are discussed.

[Please give dates of consultation]

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Bexley Care Trust	General	Equitable access to safe, quality services is of paramount importance. Provision should be based on incidence need and services planned accordingly.	This is the aim of this guidance.
Birmingham Heartlands & Solihull NHS Trust			This organisation was approached to comment but did not respond.
Blackburn With Darwen Primary Care trust			This organisation was approached to comment but did not respond.
Brain and Spine Foundation	General	Overall, the guidance gives an comprehensive overview of the services required to deliver high quality care to children and young people with cancer. However, we feel that that the service guidance lacks a 'child-centred' approach to service delivery which is vital to the successful delivery of high quality care	Thank you. We disagree and consider that the approach is child centred.
Brain and Spine Foundation	General	Throughout we feel the guidance could make more reference to the role of hospital play specialists, who are a vital member of multi-disciplinary teams and are often uniquely qualified to explain procedures and treatment to children and young people	The role of the play therapist is stated in several different sections of the guidance.
Brain and Spine Foundation	General	Through our own work, we have found the input of parents, children and young people invaluable. We would very much welcome the inclusion of surveys, research, audits which included their opinions and experiences to help improve services	Two specific relevant studies were commissioned for this guidance and are included in the Evidence Review.
Brain and Spine Foundation	General	Consider an additional key recommendation that services should be age appropriate. Additionally consultation with children and young people is essential at every stage of the patient care pathway to ensure that services are meeting their specific needs	We feel that this is covered in key recommendations 6 and 10. In the measurement sections there are suggestions to evaluate patient and carer satisfaction surveys.

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Brain and Spine Foundation	25	Cancer, especially brain and CNS cancer, can significantly delay the rate of psychosocial and cognitive development, but can also expose young people to life experiences and lead to greater 'maturity' earlier than in normal development. For example, having to cope with the fear of death, protecting parents and siblings from their fears and worries	Thank you. We have explicitly acknowledged this issue in the section on psychosocial care.
Brain and Spine Foundation	50	The overall success rate for treating brain and CNS cancer in children and adolescence has improved very little and whilst this is acknowledged we feel that a general statement at the beginning detracts from this very important issue. We feel that there should this should be mentioned separately (perhaps in the key points)	We have not discussed trends in survival for specific conditions, but only overall rates. We do not have survival trend data to support the description of specific diagnoses.
Brain and Spine Foundation	88	For children with brain and CNS tumours, allied health professionals can play an important role in diagnosis, for example opticians	This is too detailed for the scope of this guidance, but it has been considered by the Brain and Central Nervous System Guideline Development Group.
Brain and Spine Foundation	90	We strongly endorse the points raised here. During our work to produce an information resource for children with brain tumours, the anger and frustration from 'not being listened to' was mentioned many times by parents AND children "Everybody thought I was pretending, it might be a brain tumour but I doubt it. Not enough beds come back next week. Wouldn't let me have a scan, I hate that guy who wouldn't let me have a scan" Quote from a boy aged 12 yrs diagnosed with a brain tumour	Thank you.
Brain and Spine Foundation	116	In addition to specialist centres it is important that support staff who can explain the procedures to children and young people are mentioned as part of the service provision	We agree, and this point is covered in paragraph 612.

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Brain and Spine Foundation	117	We understand that there is an issue over whether serial scanning will continue as specified regular time intervals after treatment and during long-term follow-up. Rather than scanning at pre-set time intervals it has been suggest that patients are scanned if their clinical symptoms change. This may change the level of service provision required and is a particularly anxiety provoking issue for parents, children and young people. Would the guidance be an appropriate place to outline this issue and suggest a recommendation?	We understand the issue, but it is not possible to go into this amount of clinical detail in service guidance.
Brain and Spine Foundation	145	Suggest that this point mentions both the delivery of chemotherapy and the support staff required to explain the procedures/ treatment (e.g., hospital play specialist) to children and young people	Thank you, but we feel this is covered in paragraph 148.
Brain and Spine Foundation	171	Consider including hospital play specialists	This is not meant to be an exhaustive list.
Brain and Spine Foundation	197	Neuropsychological appraisals should be differentiated from psychological assessments. The former focuses on cognitive changes where as the latter concentrates on psychosocial issues, although there may be overlap	We agree and will add psychological appraisals to paragraph 200.
Brain and Spine Foundation	204	We support the importance of play therapists and their value in reducing distress and helping children and young people cope with their treatment "The play person can give you lots of information. When they talk to you, they explain what is going to happen. They really want to know what you think…" Quote from a child with a brain tumour	Thank you.
Brain and Spine Foundation	325	After treatment in specialist centres, many children and young people receive rehabilitation in a community setting by non-specialist health professionals. The quality of this rehabilitation would be improve if the link was stronger with the specialist centre so that non-specialist health professionals could get access to ongoing support and advice	We agree that the link with the specialist centres is important and would expect this phase of care to be overseen by the MDT.

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Brain and Spine Foundation	344	We very much endorse this statement. The practical issues which families encounter are considerable and parents often find they have to co-ordinate their child's care or liaise with a large number of different services. Anecdotally a key worker seems to ease this burden	Thank you.
Brain and Spine Foundation	349	Consider emphasising the needs of siblings in particular	We have amended this paragraph.
Brain and Spine Foundation	374	We support the statement that there should be a lead clinician who specialises in the late sequelae of cancer	Thank you.
Brain and Spine Foundation	448	Consider mentioning play therapy separately from activity coordinator/ youth worker. We understand that the former are often involved in explaining treatment etc to patients and have a very different training to activity coordinators/ youth workers	We have amended play therapist to specialist.
Brain and Spine Foundation	564–574	We strongly support the need for age appropriate information for children and young people with cancer. Our own work has shown that there is a very large gap in appropriate information for children with brain tumours. During the process of producing our own information resource, children were consulted about their experiences of information provision. Very few children had been given any information and also described how they felt excluded from communications between health professionals and parents/ carers "Mum and Dad are protective. I got told the basics and then I had to go out of the room. I didn't hear. Mum wouldn't tell me. I asked her to tell. She told me in the end. I wish they had told me in the first place" Quote from a child aged 9 with a brain tumour Children and young people may not ask their parents questions about their condition, their fears and concerns in order to protect them. All health professionals should be trained to communicate with children and young people	Thank you.

Organisation	Section no. or General	Comments	Developer's response
Brain and Spine Foundation	574	We found that consulting with parents and children significantly enhanced the quality of the information resource we produced and we are extending this model of practice to other areas of our work. Just as it is recognised that adults can be 'expert patients' so can parents, children and young people. Their input in to service development is essential	Thank you. We agree.
British and Irish Orthoptic Society			This organisation was approached to comment but did not respond.
British Association for Counselling and Psychotherapy	General	We welcome this comprehensive manual. It is clearly set out and information is easy to access.	Thank you.
British Association for Counselling and Psychotherapy	General	We notice there is no reference list. We would recommend this as an essential element of such a manual.	It will be included in the Evidence Review.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Association for Counselling and Psychotherapy	General	The guideline primarily focuses on 'psychological' services for the emotional, mental and spiritual support that young people may need as a result of diagnosis and treatment. We understand that such services often include counsellors and psychotherapists and remain disappointed that this is not specifically stated. There are a number of counselling and psychotherapy accrediting bodies in the UK that ensure high levels of practice from their accredited members in particular. For example, paragraph 350 (page 88) states: 'This should include identified psychologists…' but the practice of child psychotherapists should not be underestimated, or overlooked. Our point is also highlighted in Table 4 (page 106) 'Core membership of MDTs: Psychosocial support'. We would also stress that this population group may need ongoing therapeutic support from a counsellor or psychotherapist, and that such ongoing care may not necessarily be available in psychology departments, particular in secondary care. In addition, while psychological therapies may be available through local CAMHS units, the prevailing model may be that of treating 'mental illness', rather than provision of treatment for mentally healthy children who are trying to cope with illness and its sequelae Thus referral to CAMHS may not always be appropriate.	We cannot go into this level of detail and feel it is covered by the statement 'other psychological services'.
British Association for Counselling and Psychotherapy	323	The WHO model, the 'International Classification of Functioning' should be referenced.	This will be referenced in the document.
British Association for Counselling and Psychotherapy	354	It is worth stressing that MDTs should provide psychological and 'emotional' support, to emphasise that fear may be a particular issue for young people.	This amendment has been made to the text.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Association for Counselling and Psychotherapy	381	The second paragraph states 'There should be access to semen storage for peripubertal boys'. We would suggest that egg storage for girls should also be considered where appropriate.	We have not included egg storage at this stage, as our understanding is that it is still experimental. We have amended the text to indicate the experimental nature of this.
British Association for Counselling and Psychotherapy	404	The acronym 'POON' - as in 'POONs group' - should be written in full as the manaual does not contain an abbreviations or glossary.	The acronym POON has been written in full after its first occurrence in the guidance. It will also be in the acronym list in the guidance appendices.
British Association for Counselling and Psychotherapy	409	The acronym 'POON' should be written in full.	The acronym POON has been written in full after its first occurrence in the guidance. It will also be in the acronym list in the guidance appendices.
British Association for Counselling and Psychotherapy	422	Error in use of punctuation comma – should read: 'Although the family of a child or young person with cancer may experience…'	This amendment has been made to the text.
British Association for Counselling and Psychotherapy	431	This sentence needs explanation as it is currently non-sensical.	We have amended this paragraph.
British Association for Counselling and Psychotherapy	448 Table 4	The third bullet point under Psychosocial support MDT is inadequate: '…or other member of psychological service' should include for example members, such as a counsellor, psychotherapist, family therapist, play therapist etc. School counsellors may represent a useful resource for hospital, hospice and outreach work when a school child is diagnosed or undergoes treatment for cancer.	Thank you, but this level of detail is not possible in service guidance.
British Association for Counselling and Psychotherapy	448 Table 4	The fifth bullet point under Psychosocial support MDT 'Appropriate allied health professionals' would benefit from some examples of role titles.	We agree, but this level of detail is not possible in service guidance.

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British Association for Counselling and Psychotherapy	471	The acronym 'POON' should be written in full.	The acronym POON has been written in full after its first occurrence in the guidance. It will also be in the acronym list in the guidance appendices.
British Association for Counselling and Psychotherapy	515	Spelling mistake in third bullet point – should read: '…GCP in Clinical Trials directive.'	Thank you; an amendment has been made.
British Association for Parenteral and Enteral Nutrition (BAPEN)	287–304	Nutrition Section: We were delighted to see that nutritional management of patients was discussed as a separate section under supportive care. We would however suggest that mention should be made of the modalities available for such support i.e. oral, enteral tube and parenteral nutrition with the recommendation that the latter two should be used if necessary. This then raises the question of whether increasing dietetic resources alone is enough to ensure that all aspects of nutritional support are performed as safely as possible. Although we appreciate that PN is avoided as much as possible, it is inevitable that it is used in some patients with persistent chemo/radiative/surgical ileus related gut problems and in these cases BAPEN strongly recommends that intravenous feeding is overseen by a multidisciplinary Nutrition Support Team. This follows good evidence that such teams reduce serious complication rates related to line infection, thrombosis and metabolic upset. Thank you for giving us the opportunity to comment.	We have amended paragraphs 303 and 304.
British Association of Art Therapists	General	A great deal of thought has gone into this guideline from the medical and social perspective and this is very welcome. However, it is generally lacking some thought and consideration from the mental health perspective that has only vaguely been touched upon.	We feel that mental health has been appropriately covered.

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British Association of Art Therapists	400	The second sentence alludes to Clinical Psychologists and there is no mention of Art Therapists (or of Child Psychotherapists). In most London Teaching hospitals, representatives from these disciplines provide a significant input in supporting children and adolescents with cancer.	Thank you. We have amended this paragraph to be less prescriptive.
British Association of Art Therapists	424	This is also the case with Bereavement care and acute grief reactions from family members. Consideration should also be given to prolonged grief reactions and referrals to services like CAMHS. There is also a significant number of referrals to CAMHS for children and adolescents survivors of cancer and who may go on to experience considerable emotional and behavioural disturbance.	We have amended this paragraph to cover ongoing needs. Referral of survivors is not appropriate in a bereavement section.
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	General	Cancer in Children and young people is rare and managed in a limited number of registered centres	Thank you for the comment.

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British Association of Oral and Maxillofacial Surgeons	170	Surgery: Reference is made to head and neck surgery. There is in fact no such speciality and it may be worthwhile stressing that for the head and neck anatomical site - surgical expertise in diagnosis and treatment must be delivered by an individual and his / her team who are familiar with the specific anatomical site and pathology in children and young people. The background of this person should be very much sub-specialised and it would seem appropriate to recognise one individual rather than dilute expertise amongst the various specialities working in non-cancer surgery of the head and neck region. The specialist surgeon should be familiar with ablative and reconstructive techniques as well as issues of deformity and rehabilitation.	We have amended the paragraph.
British Association of Paediatric Surgeons			This organisation was approached to comment but did not respond.
British Dietetic Association	General	Thank you for giving the BDA the opportunity to comment on the document	Thank you.
British Dietetic Association	General	Please note the correct spelling of dietitian (not dietician).	Thank you. We have corrected the spelling.
British Dietetic Association	General	Overall the BDA considers that this is 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	General	The document also addresses issues around the roles of the principle treatment centres and shared cared centres.	Thank you.
British Dietetic Association	General	Throughout the document there is recognition of the issues of recruitment and retention of certain groups of healthcare staff within the multi-disciplinary team.	Thank you.
British Dietetic Association	290	The BDA agrees that working in general paediatrics is essential before specialising in oncology for children and young people	Thank you.

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British Dietetic Association	291	The BDA strongly agrees. The workload of dietitians working with children and young people with cancer has greatly increased with more intensive treatment protocols. Therefore this should be recognised as a specialist area of paediatrics which should be adequately funded to enable the post holders to work solely with this group of patients rather than splitting their time between different paediatric specialities. This approach would hopefully result in better recruitment and retention.	Thank you.
British Dietetic Association	300	The BDA agrees with the structure and that the provision of protocols, adequately trained staff and patient/carer information is required.	Thank you.
British Dietetic Association	636	The BDA agrees that catering services need to be addressed to ensure better provision to meet the needs of sick children. This is perhaps more of an issue in units attached to adult hospitals rather than children's hospitals; however adequate funding is required to ensure better meal provision.	Thank you.
British Fertility Society	11	refer to BFS Recs 13-27, 31, 44-46	We are not sure of the relevance of these specific British Fertility Society recommendations to paragraph 11, but where appropriate we have referenced the British Fertility Society document 'A strategy for fertility services for survivors of childhood cancer'.
British Fertility Society	12	It is also relevant to record data to make future research possible, thus Recs 4, 5, 11, 30 apply.	We are not sure of the relevance of these specific British Fertility Society recommendations to paragraph 12 but where appropriate we have referenced the British Fertility Society document 'A strategy for fertility services for survivors of childhood cancer'.
British Fertility Society	14	refer to 33, 34,	We are not sure of the relevance of these specific British Fertility Society recommendations to paragraph 14 but where appropriate we have referenced the British Fertility Society document 'A strategy for fertility services for survivors of childhood cancer'.
British Fertility Society	12	Figure A. There should be a link from Survivors to Reproductive Medicine. Rehabilitation may include Hormone Replacement therapy	Figure A was designed to be broadly illustrative of the treatment settings and is not exhaustive. This level of detail is not possible in service guidance.
British Fertility Society	68	Rec. 5	This level of detail is not possible in service guidance.
British Fertility Society	170	The BFS WP considered that a Paediatric surgeon and not a gynaecological surgeon should obtain ovarian biopsies	We have made no recommendations regarding ovarian biopsies.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Fertility Society	184	This would include follow up of the fertility implications of taking an ovarian or testicular biopsy	Thank you for your comment. However, we do not think that recommending such detailed audit is a priority in national guidance.
British Fertility Society	209–210	The impact of gonadal radiation should be recognised with respect to its long term effect on fertility. Thus 7, 11, 29, 30 apply	Thank you. This is addressed in general terms in the late effects section.
British Fertility Society	321–325	Aspects of reproduction are not mentioned. These extend to hormone replacement therapy to advice and support before future fertility treatment and treatment itself. Rec 12 applies.	We feel that this is adequately covered in paragraphs 390–418 and in the expert position paper.
British Fertility Society	326-330	A further recommendation is required to encourage provision of information from a Unit to a (future) ART Unit not only for longer term management, but also for information and support in the interim Recs 12, 30, 33, 34 apply	ART units have now been included in paragraph 404.
British Fertility Society	349-357	A recommendation is required to draw attention to future reproductive medicine services see Recs 1, 2, 3 6, 12	This is covered in the late effects section of the guidance.
British Fertility Society	365	Note Rec 6	Thank you.
British Fertility Society	366	There should also be audit of discussions and outcomes of patients' wishes with respect to reproductive choice and their being offered options Recs 1, 2, 3, 4, and outcome following death as per Recs 19, 20. Please also note Rec 9, which could also be audited.	We do not understand the relevance of the comment to this paragraph.
British Fertility Society	372	Explicit reference should be made to referral to an ART Unit, see Rec. 12.	Paragraph 372 is not a recommendation; please see paragraph 404 for reference to ART unit.
British Fertility Society	374	Explicit reference to reproductive consequences and liaison with an ART Unit is essential.see Recs 12, 29	This is covered in paragraph 404.
British Fertility Society	377	Rather than the term gynaecologist the term should be Reproductive Medicine Specialist or Assisted Conception Unit. These are quite differently trained. Today, the general gynaecologist is unable to deal with the problems that you describe. Direct referral is superior to a second hand referral. Liaison with an ART Unit develops strong links for better overall understanding of the problems, not least the impact of the Tissue Banks regulation, but also data storage and transfer. See Recs 24 - 26 and 13-23	We have amended this paragraph. We have also made reference to the ART unit in paragraph 404.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Fertility Society	380	See Rec 8 – 10, 29	This level of detail is not possible in service guidance.
British Fertility Society	381	See Recs1, 2, 5, 6,12	This level of detail is not possible in service guidance.
British Fertility Society	386	Rec. 28 applies	This level of detail is not possible in service guidance.
British Fertility Society	390	Recs 12 and 28 apply	This level of detail is not possible in service guidance.
British Fertility Society	392	Audit is required of elements referred to in Recs. 1, 2, 3, 4, 8, 9, 10, 12,16, 17, 18, 19, 29.	This level of detail is not possible in service guidance.
British Fertility Society	424	Recs. 19, 20 are relevant	This level of detail is not possible in service guidance.
British Fertility Society	Table 4	Should include, under Psychosocial support MDT, a member with experience of assisted reproduction. Under Late effects MDT, expertise or knowledge of assisted conception should be included.	Table 4 lists core members of the relevant MDTs. We would expect additional expertise to be accessed as necessary.
British Fertility Society	453	Rec. 12 is important.	This level of detail is not possible in service guidance.
British Fertility Society	463	This should include Rec. 12, ART (Assisted Reproductive Technology/Assisted Conception) Units	We do not understand the relevance of this comment to a measurement section.
British Fertility Society	Table 6	Should include under bullet 4, professionals involved with Assisted Conception.	Table 6 lists the major roles of a key worker and is not exhaustive.
British Fertility Society	480	These should be developed in conjunction with ART Units and Tissue Banks. Recs. 11, 24, 25, 26 apply.	This level of detail is not possible in service guidance.
British Fertility Society	523	The Primary Care Team must be informed of the details of the liaising ART Unit.	This level of detail is not possible in service guidance.
British Fertility Society	Table 8	Should include reference to those with the ability to assess Gillick competence, competence, in gonadal biopsy, and responsibility for liaison with Tissue Banks and with ART Units. Recs. 3, 12, 24, 26, 29 relate.	Throughout the guidance we have stressed the importance of appropriate expertise, which we feel covers this issue. We also make reference to the need to work within the relevant legal frameworks.
British Fertility Society	Table 9	Table 9 page 127: Recs 1, 2, 4, 13-15, 17, 18, 19, 24, 26 are relevant.	It is not possible to go into this level of detail in service guidance.
British Fertility Society	536	Leadership involves familiarity with and taking responsibility for all relevant recommendations of the BFS Report.	We agree, but we cannot specify all the responsibilities.

Organisation	Section no. or General	Comments	Developer's response
British Fertility Society	541	This includes longer term ART Unit liaison.	We agree.
British Fertility Society	576	Rec. 16 is relevant.	This level of detail is not possible in service guidance.
British Fertility Society	582	There is a need to inform patients and parents of the role and need for liaison with ART Units. Rec. 12 is important.	This level of detail is not possible in service guidance.
British Fertility Society	587	This will also lead to technical improvements in biopsy technique, cryopreservation and selection of material for assisted conception. Recs. 15, 17, 27 apply.	We do not understand the relevance of this comment to paragraph 587.
British Fertility Society	591	Units need to be aware of the impact of HFEA regulations, particularly as they change, as they may not be aware of the implications for many years until the tissue is required for assistedconception.	We agree and are sure that the units are aware of HFEA regulations; we have also highlighted these as part of the legal framework.
British Fertility Society	612	Rec. 12 applies. Future fertility and its discussion must not be neglected.	We have chosen examples that the Guideline Development Group felt were particularly important; the list is not exhaustive.
British Fertility Society	614	The association with assisted reproduction should not be neglected.	We are not clear on the meaning of this comment in relation to paragraph 614
British Fertility Society	622	Recs. 7-10,11, 29, 30, 31, 34 are relevant.	This level of detail is not possible in service guidance.
British Fertility Society		Page 156. The BFS Report should be referenced.	This document has been referenced in Appendix 1 of the guidance.
British Fertility Society	11	refer to BFS Recs 13-27, 31, 44-46	We are not sure of the relevance of these specific BFS recommendations to paragraph 11, but where appropriate we have referenced the BFS document 'A strategy for fertility services for survivors of childhood cancer'.
British Infertility Counselling Association	General	There are inconsistencies in the way in which parents and carers are referred to. In places, only the term 'parents' is used while elsewhere only the term 'carers' is used. This should be made consistent. We suggest that it should say 'parents, carers and/or partners' (if there is one)	Thank you; we will review the document and make the necessary amendments.
British Infertility Counselling Association	General	Some young people are living independently, some are in a long term relationship or may be married; some are parents themselves. However, situations other than those in which the child or young person is a dependent are not acknowledged. Thus, neither are the implications where this is the case	It is not possible to go into this level of detail.

Organisation	Section no. or General	Comments	Developer's response
British Infertility Counselling Association	General	There is inconsistent use of the term counselling. The term 'counselling' is used to describe a wide range of activities in this document ranging from offering medical advice to communication skills work to therapeutic counselling. We strongly suggest that its use is restricted to the provision of professional counselling services, involving a structured process of psychosocial and emotional support or therapy. Other terms should be used to describe different tasks, such as advice or guidance. Unless the purpose and content of the activity is specified in this way, confusion will continue and undermine the distinctive contribution of counsellors. By 2007, 'counsellor' will become a restricted title, and the need to formalise the distinctions in this way is therefore the more important.	We agree and have amended the document.
British Infertility Counselling Association	General	There is some inconsistency in references to multi-disciplinary work. At times, it appears that the reference is only to the NHS multi-disciplinary team whereas at others the term is used to encompass staff working outside of the NHS.	We feel we have used the term appropriately.
British Infertility Counselling Association	General	There is some inconsistency in the use of psycho-social and psychological. These terms are not interchangeable. The former should be used as the general term in order to reflect the interconnecting influences of the individual with wider family and social context. The term psychological should be used in this context only where the specific services of a psychologist or counsellor are involved. For example para 354 should refer to psycho-social support.	We agree and have amended the document.
British Infertility Counselling Association	General	As far as we could see, the first substantial reference to a service need relating to fertility does not come until the section on Long term Sequelae (para 369 and 381). We strongly suggest that guidance should be included earlier to cover the fertility-related needs at diagnosis and after. See also below (381)	We agree and in paragraph 404 we acknowledge this needs to be considered at the time of diagnosis, however it would not be possible to include this level of detail in every section.

Organisation	Section no. or General	Comments	Developer's response
British Infertility Counselling Association	General	There is a surprising lack of reference to suportive or therapeutic counselling in the guidance. This service can be provided through different services of course but the need for counselling per se should be specified so that commissioners consider how and from where it may be provided. Counselling services are increasingly commissioned in primary, secondary and tertiary settings, and are recognised to have value in all these settings.	We believe we have addressed this issue sufficiently in the guidance.
British Infertility Counselling Association	122	We were unclear whether this referred to ovarian and tissue storage or something else	This recommendation refers specifically to tumour sample storage. The issues of sperm and ovarian storage are dealt with in other sections of the guidance.
British Infertility Counselling Association	343	It is not helpful to use negative language such as 'the burden of the disease'; we suggest the alternative of 'the challenge of the disease'	This amendment has been made to the text.
British Infertility Counselling Association	343	Reference should be made here to the impact on sexual identity and the impact of relationships with potential and actual partners	We have amended this paragraph.
British Infertility Counselling Association	361	It is unclear whether the reference to treatment plans means medical treatment plans. If it does then this should be made clearer. If it means psycho-social treatment plans then the term treatment should be deleted and 'intervention' inserted	We have inserted the word 'medical'.
British Infertility Counselling Association	364	We are surprised that there is no reference to counselling services here but we are not familiar enough with the research to formally suggest its exclusion. However we are aware that people sometimes refer to their need for psychological services when they mean that they would like counselling services. This might warrant a closer look at what the needs are that are being expressed rather than what service they are requesting.	This is the evidence section and there is a lack of evidence in this area.

Organisation	Section no. or General	Comments	Developer's response
British Infertility Counselling Association	381	As stated above, the use of the term counselling can be misleading, ambiguous or unclear. In this case it is not at all clear what is meant by fertility counselling and therefore it is impossible to discern what 'appropriately trained personnel' means. We believe that anyone deemed to be at risk of fertility impairment should be advised of this at diagnosis; and that fertility storage services should be made available where appropriate. If the young person wishes to consider fertility storage then the guidance should reflect the law (Human Fertilisation & Embryology Act 1990) which states that the offer of counselling should be made before any decision is reached. In this case, counselling means the service provided by a trained infertility counsellor, not (medical) advice, guidance or information sharing. The HFEA in its Code of Practice 6th edition also states 'Treatment centres are expected to have written information which is accessible to children and young people, given by a member of staff with competence in communicating with children' (6.12). We recognise that many children & young people will not take up the offer of infertility counselling at diagnosis (even if they opt to use fertility storage). We suggest the guidance should therefore include specific reference to infertility counselling alongside reference to endocrine and fertility services	This level of detail is not possible in service guidance but the issues are referred to in the expert position paper, which will be included in the Evidence Review. We have included HFEA as part of the relevant legal framework that these services have to operate in (see paragraph 18).
British Infertility Counselling Association	424	We suggest that 'sperm donation' is an unclear term to use and that 'sperm storage' might better reflect the issue	This amendment has been made to the text.
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 Society	7	There is no mention of adequate imaging resources for staging at diagnosis and assessment of therapy. Nuclear Medicine has a role and needs to be co-ordinated across the country so that there are adequate facilities in both equipment and manpower.	These are key recommendations that do not cover specific details of all treatment service requirements.
British Nuclear Medicine Society	12	The establishment of a virtual paediatric PET centre would be important	Unfortunately the evidence to support a recommendation on the current use of PET is not available at present.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Nuclear Medicine Society	64	As there are only 17 recognised cancer centres in the UK, so there should be special care to ensure adequate nuclear medicine facilities in these 17 centres. (UKCCSG Centres).	Thank you, but it is not possible to go into this amount of detail in service guidance.
British Nuclear Medicine Society	93	Cancer networks should all have facilities for nuclear medicine for children	It is not possible to go into this level of detail in service guidance.
British Nuclear Medicine Society	118	There is no mention of general nuclear medicine facilities especially for bone scans, MIBG and facilities for investigation of the complications of chemotherapy e.g. infection WBC labelling.	Thank you. We have amended paragraph 113 to include nuclear medicine.
British Nuclear Medicine Society	130	This is only about MRI but should also include something about appropriate nuclear medicine	This paragraph was particularly aimed for neuro-oncology where a delay in diagnosis is more commonly seen due to the limited availability of CT and particularly MR imaging, which forms the initial basis for diagnostic imaging and subsequent neurosurgical management decisions. Improved and adequate access to nuclear medicine diagnostic imaging has been addressed in paragraph 113.
British Nuclear Medicine Society	Table 4	Radiologist plus Radionuclide Radiology or Nuclear Medicine is essential	Table 4 lists core members of the MDTs. We would expect additional expertise to be accessed as necessary.
British Nuclear Medicine Society	Table 9	Nuclear Medicine should be included	Given the limited need for diagnostic radioisotope investigations that are influencing management decisions, nuclear medicine is at present not required as a core component of the MDT.
British Nuclear Medicine Society	597	Research – after this paragraph: Response to treatment should mention functional imaging. Also – evaluation of PET FDG and new agents should come in here.	This level of clinical detail is inappropriate for a general recommendation.
British Nuclear Medicine Society	610	Include nuclear medicine physicians with an interest in paediatric oncology.	This list is not meant to be exhaustive.
British Nuclear Medicine Society	614 onwards	Recommendations - this has needs to train more of all members of the nuclear medicine team.	These recommendations are very general and apply to all healthcare professionals involved in the care of children and young people with cancer.
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.

[Please give dates of consultation]

Organisation	Section no. or General	Comments	Developer's response
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	General	we feel it looks good and have no additional comments to make	Thank you.
British Psychological Society, The	56	Should also include cognitive decline and associated educational difficulties, particularly in CNS tumours or treatments involving CNS chemotherapy or radiotherapy.	The text has been amended.
British Psychological Society	82	Psychological services including psychologists, psychotherapists and psychiatrists	These disciplines are not AHPs and they are discussed elsewhere in the guidance.
British Psychological Society	342	Add … psychosocial services should be integrated component of the multidisciplinary team	We agree, please see the redrafted section on MDTs.
British Psychological Society	353	Cognitive assessments should be available to all young people diagnosed with CNS tumour with ongoing followup. Acces to is not a specific enough term	We think this is implicit in the paragraph.
British Psychological Society	369	Add and gognitive etc;	This paragraph has been amended appropriately.
British Psychological Society	448	Psychological professional should be identified as key member of both late effects MDT and palliative care MDT. Essential for good pratice for psychological personnel to be part of clinical teams (ie clinical health psychology) rather than a separate referred to professional	We have included psychologist/other member of psychological services in the text.
British Psychological Society	563 onwards	Just as in paragraph 571 should have .. Psychological services should be key members of MDT given their specialist knowledge of teaching and training in communication skills.	This paragraph is meant to be introductory and the role of psychological services is covered fully elsewhere.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
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	General	Overall this guidance is comprehensive in its scope, definitions of age boundaries and treatment pathways, and in highlighting the importance of the need for excellent services which might thus come at the expense of distance. It is thus helpful to commissioners. The sections pertaining to rehabilitation and follow-up of long term survivors (a large part of the scope) could potentially, however, appear overshadowed by the acute care service need and would perhaps benefit from more specific directives in order to avoid confusion and inequities of future services :eg;	This level of detail is inappropriate for service guidance. An expert position paper on late effects is included in the Evidence Review.
		1. Recommendations on the importance of involving endocrine expertise in ensuring normal growth, puberty and bone mineral accretion to aid reproductive health and QoL in the same way as dental care is highlighted	Reference to this has now been included in the text.
		2. The service use and load of rehabilitative and late follow-up services (eg use of specialty day care endocrine beds and outpatient specialties for assessments)	Reference to this has now been included in the text.
		3. The distinction between early rehabilitation and surveillance to prevent later morbidity, and the definition of a late effect (?>5years after diagnosis).	XXX ***[add comment?]***
		4. The importance of limiting as opposed to simply monitoring the development of long term sequelae, by early pre-symptomatic surveillance and treatment of endocrine abnormalities for which good evidence exists (eg growth hormone and sex steroid replacement therapy)	We have amended the text to include the definition of late effects and the need for early referral for patients at high risk of late sequelae. Details of the ongoing care of these patients is beyond the scope of this guidance.
		5. Where such specialty MDT services should be provided	Reference to this has now been included in the text.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
		as children mature into adulthood and for which broad groups (and hence numbers) of patients tertiary/quaternary settings rather than primary care) would be appropriate. 6. Which patient and disease groups other than CNS tumours (see 197) are also high-risk and mandated for endocrinology surveillance follow-up (eg youngest, shortest, most intensively treated, receiving pelvic or cranial radiation,) of growth, puberty BEFORE the 5 year defined follow-up (at diagnosis or end of treatment) into adulthood (relates to 2.) 7. The prevalence and frequency of different organ toxicities which are heavily weighted (70-90%) towards eminently treatable endocrine deficits (both primary and secondary)to prevent morbidity 8. The value (evidence for /against) importance of holistic and alternative therapies These are important because of the length of follow-up required, (68 years survival) and the nature of multiorgan toxicity, which has important resource implications and might be better co-ordinated in designated specific centres with appropriately trained MDT personnel.	Reference to this has now been included in the text. Reference to this has now been included in the text. Recommendations regarding the use of holistic and alternative therapies are also outside the remit of this guidance.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	General	Throughout the document, the guidance effectively highlights areas where there are gaps in the evidence to support clinical practice. eg the unknown benefit to patients of routine, indefinite, non-selective, follow-up of all children in a long term follow-up clinic, without a needs-defined risk strategy	Thank you.

Organisation	Section no. or General	Comments	Developer's response
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	General	The guidance importantly highlights throughout, the importance of age-appropriate transitions, and care delivery by appropriately trained MDT professionals	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	General	The guidance makes due reference to the importance of endocrine professional support to patients, especially those with CNS tumours, and includes endocrine expertise as a requirement amongst the neuro-oncology and late effects MDT	Thank you.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	General	The absence of cross-reference to national NICE guidelines on growth hormone replacement therapy in deficient children and adults, osteoporosis (draft), RCP college guidelines on pituitary tumours and thyroid disease, BAES guidelines on the management of endocrine tumours, The BFS consensus on management of fertility preservation in minors undergoing cancer therapy and the NSF for diabetes, is notable in Appendix A	We will add the relevant documents to Appendix 1.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	General	The guidance includes recommendations for fertility counselling and semen cryopreservation in peri-pubertal males although infertility (affecting 15%) appears to be given disproportionate emphasis amongst more common and effectively treatable endocrine deficits in growth, puberty and bone mineral accretion, obesity and glucose intolerance (affecting 70-90%)	We have amended the relevant section.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	General	The guidance makes no reference to the management of children with rare endocrine tumours (eg thyroid / adrenal)	We have included thyroid tumours in the text of paragraph 485, but the other non-malignant tumours, except CNS, are outside the scope of this guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	General	Whilst we agree with the key recommendations, there appears to be an omission of specific reference to the importance of limiting morbidity by appropriate pre-symptomatic surveillance and treatment of known high risk groups, despite this being a main aspect of the scope.	We feel the topic is adequately covered and that this level of detail would not be appropriate in a clinical guideline.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	6 and 7	To avoid ambiguity, we suggest the insertion of the words 'including long term rehabilitation and follow-up' after …'funding for all aspects of care' … in first line point 6. and in penultimate para in point 7 after ' sites delivering cancer therapy …'	This is a general recommendation and we do not feel it is necessary to qualify specifics.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	56	The use of the term 'late effect' would benefit from definition. Eg Does this encompass all potential toxicities incurred at the time of diagnosis and treatment, or only those evident after 5 years from end of treatment?	'Late effect' will be defined in the glossary.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	56	Whilst we agree in principle with the broad category, we suggest the second sentence is re-worded to state that almost all/the majority patients (85%) will experience an endocrine sequelae including abnormal growth and development, bone mineral accretion, subfertility, impaired glucose tolerance.	We have added 'abnormal growth and development and bone mineral accretion' to the text
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	58	Whilst we agree with this statement, the point could be made that, unlike adult cancer, long term survival (68y) is not unusual	This is made clear in paragraph 60.

Organisation	Section no. or General	Comments	Developer's response
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	66	It is unclear how the 18 responding centres are made up (do TCT and UKCCSG units overlap or considered separately?)	One TCT overlapped with a UKCCSG centre.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	69	This statement to refer patients out of region for specialist services should include 'rare endocrine tumours of the thyroid and parathyroid, pituitary, and adrenal' in lieu of the one word 'thyroid'	We are not able to include the other non-malignant tumours, except CNS, as are they outside the scope of this guidance.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	80	It would appear to be an omission that the endocrine and other medical and nursing speciality personnel and resources required to support effective rehabilitative and surveillance specialist services are not included here	These issues are not relevant to paragraph 80, which reports the results of a survey on palliative care.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	80	Palliative care may need clarification. It appears to be symptomatic patients dying from incurable cancer as opposed to living with incurable cancer (eg CNS) or other secondary disease (cardiac dysfunction).	The definition of palliative care is given in paragraph 419.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	172	We agree with this statement which should include not only paediatric anaesthetists and intensive care facilities but also 'appropriate specialist support for the acute management of salt and water balance (endocrine, nephrology) where indicated (CNS and rare endocrine tumours)'	We feel that this is implicit in the phrase 'intensive care facilities'.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	176	Rare endocrine tumours (thyroid, parathyroid, adrenal, pituitary) should be added to the list of tumours requiring special expertise and supraregional referral and a reference to existing consensus guidelines in this area in adult (draft for paediatrics in consultation) medicine	Benign tumours are outside the scope of this guidance. Surgery for pituitary tumours is covered in the section on neurosurgery.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	189	A pituitary transphenoidal surgeon should be included in the list of specialist skills	We have added trans-sphenoidal to the list of surgeons in the text.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	287	The words 'and bone mineral accretion' could be added to growth and development in the first sentence	It is not possible to include this level of detail in service guidance.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	289	'vitamins and minerals to ensure adequate bone and dental growth' should be added to the terms 'protein and calories'	We have added 'vitamins and minerals' to the text.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	322	Whilst we agree with the statement, sound understanding of developmental processes by non-endocrine specialists is not evident in practice. Late (symptomatic) referral impacts significantly on reduced long term outcomes in terms of ultimate height, reproductive potential, bone strength and quality of life. We would urge essential **early** (pre-symptomatic) routine referral to endocrine specialist for growth and puberty assessment of **all high risk patients** (ie CNS tumours, CNS, pelvic or total body irradiation, high dose or stem cell therapy) at diagnosis or end treatment. In addition, a recommendation for endocrine review and subsequent surveillance should be made for children developing glucose intolerance or frank diabetes on steroid therapy	We agree and the text has been amended.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	349	Is this a recommendation to include availability of social work support beyond the 5 –year surveillance period? Currently such services are virtually absent from survivors' services	This is not a recommendation about timing; however, we feel that individual needs will need to be met regardless of timing.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	357	This appears to be a repeat of 349	We agree; we will remove paragraph 357.

Organisation	Section no. or General	Comments	Developer's response
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	369	Cardiac, urological, respiratory, and neuropsychological sequelae could be added to the list as well recognised but less prevalent than endocrine sequelae. Whilst we accord with the importance of fertility as a late effect, we would wish to highlight the very high prevalence (70-90%) and eminent treatability (and hence greater importance) of growth and endocrine sequelae. Their diagnostic delay compromises the **potentially preventable** detrimental effects of hypopituitarism and primary glandular dysfunction on uterine and bone growth, physical development, and quality and quantity of life.	This paragraph has been amended appropriately.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	376	The groups of those anticipated to require significant adverse effects should be listed here as those with CNS tumours, receiving high dose chemotherapy, total body, cranial or pelvic irradiation, particularly if they are very young	We have created a new paragraph to cover this.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	381	Whilst we agree with this statement we would add 'and early and prompt diagnosis and treatment of any treatment-induced sex steroid deficiency'	We have added this as an additional recommendation.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	383	We should like to see added ' training of junior oncologists in this area to enhance understanding'	Service guidance cannot make recommendations about postgraduate training.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	384	The terms 'hypopituitarism, growth, development, sexual and reproductive health' are preferred to growth and fertility. Please add importance in preventing long term mortality as well as morbidity	We have added 'growth, development, sexual and reproductive health' to this paragraph. Long-term mortality may well have an impact, but there is currently no evidence to support such a recommendation.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	386	Treatment **and Asessment** summaries are important (eg GFR, dynamic endocrine tests) for the patient-held record	We believe assessment is an integral part of treatment.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	387	We disagree with the statement that the large body of retrospective evidence is uninformative about targeting appropriate follow-up to the majority of affected survivors. It is clear that those most at risk of endocrinopathies evolving over time, who require indefinite surveillance into adult life, and for whom endocrine replacement therapy is effective, are those with CNS disease, cranial, pelvic or total body irradiation, high dose chemotherapy and those diagnosed young (prepubertally). We would urge you to consider inclusion of such a separate statement together with the proven benefits of surveillance, early therapy and pre-symptomatic HRT (eg for decreased growth velocity)	We agree that there is evidence that there are lots of endocrine problems; some that early intervention helps, but there is little evidence on how this can be delivered through a service.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	393	The definition is confusing with respect to incurable disease(s) which cause discomfort but not death (eg secondary neurodisability/paraplegia from CNS disease or chemotherapy-related chronic heart disease).	We agree and feel these are important symptoms, but we consider these are dealt with in the late effects section

Organisation	Section no. or General	Comments	Developer's response
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	449	Rare endocrine tumours (thyroid, adreno-cortical, pituitary, parathyroid, phaeochromocytoma) should be added to the list of tumours requiring specialist MDT liason (including paediatric endocrinology)	We have included 'malignant thyroid tumours' in the text of paragraph 485. The other non-malignant tumours, except CNS, are outside the scope of this guidance.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	534	Thyroid, parathyroid, adrenal and pituitary tumours should be added	We have included thyroid tumours in the text (see paragraph 485). The other non-malignant tumours, except CNS, are outside the scope of this guidance.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	612	Rehabilitation and early detection and treatment of disorders of growth, puberty and late toxicity should be included as areas for staff training	We have chosen examples that the Guideline Development Group. felt were particularly important; the list is not exhaustive.
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	627	Coding of late toxicity outcomes needs defining	Paragraph 627 refers to procedures, not outcomes. We agree with the comment, but this is outside the scope of this guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
British Society for Paediatric Endocrinology and Diabetes (BSPED) and Society for Endocrinology	Appendix A	This needs to include national NICE guidelines on growth hormone replacement therapy in deficient children and adults and, osteoporosis (draft), RCP college guidelines on pituitary tumours and thyroid disease, BAES guidelines on the management of endocrine tumours, BFS consensus on management of fertility preservation in minors undergoing cancer therapy NSF for diabetes	Thank you. We will include the relevant references.
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	General	CLIC / Sargent feel that this guidance will be very helpful to commissioners and will hopefully prove instrumental in ensuring high standards of care, equally accessible across England and Wales for all children, young people and their families. We feel that the emphasis on service provision rather than on clinical diagnosis will help to further develop the holistic approach to care for these children, young people and families, thereby improving the overall experience of children, young people and their families throughout the illness trajectory. We feel that the guidance development group are to be congratulated on the guidance and have a small number of comments detailed below.	Thank you.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	General	We would like to see acknowledgement of the vital role that the voluntary sector plays in the delivery of children and young people's cancer related services. The voluntary sector has a long history of funding posts and delivering services to this client group. We feel that we may be able to offer significant resources and knowledge, in partnership with the statutory bodies, to work towards the smooth implementation of this NICE guidance.	We have acknowledged the essential role the voluntary sector plays (see paragraph 80). The Economic Analysis that accompanies this guidance includes the voluntary sector

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	General	Throughout the document reference is made to Play Therapists and their valuable contribution. We feel that the guidance development team are in fact referring to Hospital Play Specialists and would suggest that this is changed throughout the document.	The document has been amended.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	General	In the majority of sections audits and patient satisfaction surveys are listed as being outcomes, we do not consider that, in themselves, these are outcomes.	We have amended the text.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	Key recommendations – general	We would like to see mention of the importance of the partnership between parents / carers, service providers and the young people / patients.	We feel that this is implicit throughout the guidance.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	7	We have concerns that children's and young peoples cancer services are so specialised that they should be commissioned by Specialist Commissioners for Tertiary Services rather than cancer networks and PCT's and would like to suggest that NICE consider this.	It is not the role of this guidance to advise on specialist commissioning, although we have recommended that commissioning arrangements be clarified
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	9	We fully endorse the recommendation that the concept of "Key Workers" be further developed. Families support the development of these posts, as evidenced in the recently published York report. Sargent offer some key worker type of support in some areas of the UK via their Family Support Service.	Thank you.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	14	We fully endorse the proposal to develop a national cancer registry for 15-24 year olds. Discussions between NCRI and various interested parties regarding this are ongoing, it is our understanding that Dr Ian Lewis (Leeds) is involved in these discussions.	Noted. Thank you.

Organisation	Section no. or General	Comments	Developer's response
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	73	Suggest that" More intensive treatments" becomes" More complex treatments"	We have amended the text.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	82	Refers to Play Therapists, we think you mean Play Specialists (carries through the document, see Key Rec's comment above).	Thank you. The text has been amended to 'play specialist'.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	83	We feel that more emphasis needs to be placed upon the Psychosocial Care both funded by and directly provided by the voluntary sector. The recently published York report gives a lot of detail on this (we believe a copy was sent directly to the Guidance Development team by the SPRU, please contact Susan George, Services Director at CLIC for a copy if needed).	We have consulted this report, and it is included in the Evidence Review.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	90	We feel that it is also worth noting that the use of health services by adolescents is very low and any self referral by adolescents to health services needs to be taken seriously.	This is referred to in the cited NICE GP referral guidelines for suspected cancer; space precluded more details being given.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	105	We would like to see some mention of the provision of accessible and appropriate information to children, young people and their families at the time of diagnosis and continuing through treatment.	The issues around information provision are discussed in paragraphs 610–635.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	139	We feel that a patient satisfaction survey is not in its self an outcome, it is the result of the survey that is the outcome (this carries through the document, see general comments above).	We have removed the word 'surveys'.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	148	Medical and nursing should read medical and nursing staff	We have amended the text to read 'clinical staff'.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	192	Paediatric nursing should be Paediatric Neurological Oncology Nursing.	We have amended the paragraph to reflect this.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	210	We feel that this needs to be changed and an actual time limit specified between the decision to treat with DXT and the actual delivery of it. It is our understanding that the UK, compared to other European countries, is poor at meeting these timeframes (some of which form part of specific treatment protocols).	We cannot make recommendations about specific time limits in this guidance, but in Table 2 we have referred to 'nationally agreed waiting times'. We hope that following publication of this guidance, the Dept of Health and Welsh Assembly Government will issue appropriate standards that will make clear recommendations.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	227	We feel that this implies that all patients should receive these and our understanding is that the widespread use of growth factors in particular is not actually recommended.	We have amended the text to clarify.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	254	We feel that some reference should be made to the Serious Hazards of Transfusions Report	The paragraph has been amended to include this.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	304	We are currently funding some work (chaired by Dr Barry Pizer, Alder Hey) looking at producing national, evidence based, guidelines.	Thank you. We have already contacted Dr Pizer.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	321	We feel that this describes a very medical model of rehabilitation rather than a patient focused model	The actual model we have quoted (see paragraph 341) is regarded as patient focused.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	322	We would like to see mention of education and training	We feel this is implicit in paragraph 322.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	325	We would like to see mention of neuro. Psychology as well as access to good prosthetic limbs and rapid wheelchair provision	This paragraph has been amended to include neuropsychology.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	342	We feel that this needs to be cross referenced to the recently published Children's NSF.	Thank you. We have considered the NSF recommendations in drafting the guidance.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	349	We welcome the recommendation that all families should be offered the advice and support of a social worker and would recommend that this should be expanded to include children and young people themselves.	This amendment has been made to the text.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	351	We welcome the recommendation that structured psychosocial assessment is carried out at significant points throughout the care pathway (this is consistent with the Sargent Service Framework). We would like to see the inclusion of relapse as a significant point.	This amendment has been made to the text.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	355	We would like to suggest that these sibling and family support groups be established / extended into the community.	The text has been amended.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	379	We welcome the recommendation for the provision of key workers for long term follow up.	Thank you.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	399	We would welcome the suggestion that partnerships between children's hospices and children's cancer care teams and children's community nursing teams should be developed to enhance the provision of palliative care to this group.	Paragraph 427 has been amended to include this.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	409	This section needs some reference to the ACT work on palliative care for children and young people.	This work is included in the Evidence Review that accompanies this guidance.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	422	Needs mention of the spiritual and cultural needs of families.	We have amended paragraph 455. This is also covered in the section on communication.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	424	Another specific issue we would suggest needs considering / addressing is the provision of appropriate mortuary facilities for children and young peoples families (esp viewing rooms).	A recommendation on mortuary services is outside the remit of this guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	448, Table 4	Diagnostic MDT, need a specialist nurse in here (esp. for suspected bone tumour work) Psychosocial support MDT, needs access to spiritual support	Although we agree that the attendance of a nurse at the diagnostic MDT is of value, we do not feel that participation by a nurse is a core role for the diagnostic planning of the patient. We feel that the MDT should ensure access to spiritual support when required; therefore we have not added it to the text.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	477	We would suggest the mention of a lead for teenagers and young adults.	We agree and this is in Table 9. This paragraph has also been moved to the section on place of care.
Cancer and Leukaemia in Childhood (UK) and Sargent Cancer Care for Children	521	We would like to see mention of the work / role of POONs in shared care hospitals.	We do not intend the paragraph to be prescriptive as to the location of POONs.
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.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
CancerBACUP	All	- This guidance will be very helpful for healthcare professionals in outlining the service, care and treatment children and adolescents with cancer. - However, the length and detail of the document may deter many healthcare professionals from reading it and we suggest that a shorter version should be developed. - We would also recommend the development of a version for patients, families and carers.	The breadth of the topic area meant that the resulting guidance was large. NICE no longer produce the short forms, but a version for patients and carers will be developed
CancerBACUP	Table 2	- We recommend that information about specific treatments and side-effects is age-appropriate to ensure that children, adolescents, parents or carers can understand and make an informed choice about their treatment and care.	This has been covered in the section on communication.
CancerBACUP	Care – pathway section	- Some units treating children and adolescents with cancer will have access to teachers and tutors. However, some do not which can mean that educational and schooling needs are often unmet. - We recommend that a specific section covering information about education and tutoring for children and teenagers should be included in the care pathway section. - In particular, as the guidance covers patients up to the age of 24, we would welcome the inclusion of information about tuition for patients who are university students.	We cannot make specific recommendations about educational resources.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
CancerBACUP	Continuity of care	- As the guidance states, care may need to be sustained over many years, across organisational and professional boundaries. With such a complexity of needs, a key worker is an effective approach in ensuring coordination. - However, throughout the treatment journey, the key worker may change on a number of occasions depending on the treatment and follow up. - In the section outlining the role of a key worker, we recommend that a paragraph should be included in the section outlining the role of a key worker, stating that when a key worker changes, there is a clear process of how the hand over is to be carried out, ensuring that details of the new key worker are given to the patient and family as soon as possible to ensure integration and coordination of care and treatment.	It is not possible to go into this level of detail.
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	7	Defined minimum levels of staffing, as outlined in the guidance - there is currently no numerical definition of staffing for AHPs - this would be very useful.	These are key recommendations and we are unable to give minimum numbers for most staff groups, although we have indicated which staff groups should be included in which services.
Chartered Society of Physiotherapy	323	Having attempted to look at this document on-line, it appears extremely complex and difficult to administer.	This is the currently recommended model.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Chartered Society of Physiotherapy	324	The funding/provision of specialist equipment (such as specialised buggy/ seating) is an important issue and needs to be addressed. Funding can often be the reason for delay in issuing specialised items for complex patients. Due to delays in organising assessment and purchasing equipment through official pathways, charitable funding is often approached to facilitate a safer, earlier discharge to the community from the acute services. Funding for this 'Library' type of system is rarely identified or available. Funding/provision of equipment needs to be considered in the semi-acute / community phases of rehabilitation also. In the community setting the pathways of referring for assessment are complex, as local services rarely have the same policy on which part (social services, adult or paediatric OT) of the community services carries out the assessment and subsequently funds different pieces of equipment.	We have already made a recommendation for a robust equipment strategy in paragraph 346.
Chartered Society of Physiotherapy	325	The CSP feels that social functioning should be included here. We would also like to include teachers, social workers and play therapists in the list of disciplines that contribute to the rehabilitation of these patients. It may also be appropriate to mention the necessity for a key worker to have an overview of the rehabilitation process.	This list is not meant to be exhaustive and we have now stated this in the text.
Chartered Society of Physiotherapy	327	Access to neuro-rehabilitation services for children and young people with CNS malignancy, even years after treatment has a great resource impact The CSP feels it is important to establish the need for early access to the neuro-rehabilitation team, even whilst awaiting confirmation of diagnosis.	We agree and feel that the recommendation would include this.
Chartered Society of Physiotherapy	328	Cancer networks should liaise with NHS Trusts, PCT /local health boards etc to establish robust, prompt, and equitable strategies.	We agree.

Organisation	Section no. or General	Comments	Developer's response
Chartered Society of Physiotherapy	329	Training courses to meet CPD needs of AHPs: it may be useful to acknowledge the training needs of community staff who will be treating children and young people once discharged from hospital. Possibly a designated member of each community AHP team who had a specific interest in oncology. Any AHP training course should be validated. Courses should be comprehensive due to the variety of presentation and pathology of oncology conditions.	The text has been amended.
Chartered Society of Physiotherapy	331	Benefits should also include: 1. Maximise general fitness / well being throughout a prolonged medical treatment programme. 2. Promote normal developmental progression the younger patients.3. Minimise the effects of neurological sequellae following CNS treatments.	1. We feel this is covered in the introductory paragraph. 2. This amendment has been made to the text. 3. This amendment has been made to the text.
Chartered Society of Physiotherapy	332	Appropriate provision of equipment is essential to address manual handling issues for patients and carers in the home /school situation.	We agree.
Chartered Society of Physiotherapy	334	Provision of a highly skilled and effective rehabilitation service increases the confidence of, and promotes the wellbeing of, the family unit.	We feel this covered by paragraph 350.
Chartered Society of Physiotherapy	339	Oncology outreach 'nurses' to provide rehabilitation services in the patient's home. The word nurse needs to be replaced with AHP as it is the AHPs who would need to be providing the actual rehabilitation service.	We have amended this paragraph.
Chartered Society of Physiotherapy	348	Occupational advice is often the primary role of an occupational therapist - this is most likely to be given as an out-patient; if to become in-patient staff role, this would impact on staff resources.	We agree and have not specified the service setting.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Chartered Society of Physiotherapy	448	Palliative care MDT table: This table does not list appropriate AHPs, as referenced in Page 98 para 400 - dietetics, occupational therapy, play therapy and physiotherapy are an integral part of palliative care. The treatment MDT section does not include any AHPs. Children who are in the acute specialist centres who undergosurgery/chemotherapy have acute therapy treatment needs such as reduced mobility/function of upper limbs post central venous catheter insertion, Reduced function and mobility post abdominal / thoracic surgery for biopsy/resection of primary or secondary /metastatic disease. Acute physiotherapy treatment may be indicated in acquired respiratory complications; post surgery/ due to immuno-suppression. Children who undergo Neurosurgery may have acute post op treatment needs, to address post surgery sequellae and in order to restore function and prevent physical deterioration pre discharge.	Although we agree that AHPs would have a potential contribution to make at all points of the care pathway, we believe that this is where a key worker would be able to ensure liaison with appropriate AHP services.
Chartered Society of Physiotherapy	461	A reference here would be helpful	A reference will be in the Evidence Review that accompanies the guidance.
Chartered Society of Physiotherapy	527, Table 8	Core Allied Health Professions - needs to read physiotherapists not physiotherapist	This amendment has been made to the text.
Chartered Society of Physiotherapy	General	This document has a strong emphasis on the importance of providing skilled and experienced neuro-rehabilitation for people with CNS tumours, but at no point refers to Speech and Language Therapists, who make up an essential part of the AHP team.	There is mention of speech and language therapy in paragraph 343, and speech and language therapists in paragraphs 79 and 174.
Chartered Society of Physiotherapy	General	It needs to more clearly state that Paediatric experience is essential.	We feel that appropriate emphasis is given.

Organisation	Section no. or General	Comments	Developer's response
Chartered Society of Physiotherapy	General	It is of concern as to how Trusts are going to be supported in implementing more posts or more designated posts. In the adult field there is a massive move towards charity-funded physiotherapist (i.e. Macmillan) but this does not carry on in to paediatric physiotherapy. Currently there is only 1 Macmillan paediatric physiotherapist (in Manchester). Trusts may need to take on charity funding to allow for the guidelines to be followed. Perhaps this should be pointed out in the NICE documents.	This is an implementation issue and routes of funding are outside the remit of this guidance. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
Children's and Adolescent Cancer Partnership (CACP)	209	Brachytherapy is almost unavailable for children in the UK, and hence is rarely considered. Either a service should be developed in one or two centres nationally or consideration should be given to the referral of patients to international centres (e.g. Paris, Amsterdam) where such skills exist.	Thank you. We feel that this is mostly covered within the recommendation, but have added international centres.
Children's and Adolescent Cancer Partnership (CACP)	General	We wish to congratulate the group on their work. We strongly endorse the approach they have taken and welcome the content of this document	Thank you.
Children's and Adolescent Cancer Partnership (CACP)	6	It is important to further emphasise the need for cooperation across current commissioning 'boundaries'. Ideally, we believe that services such as this should be commissioned at a regional level and that any attempt to negotiate across and within PCTs lacks clarity, is time consuming and may be counterproductive in achieving appropriate investment.	We agree. This is further explained in the text and we have made a further recommendation about commissioning in the section on service organisation.
Children's and Adolescent Cancer Partnership (CACP)	7	The overview taken by commissioners must reflect the partnership that already exists between professionals, parents and the voluntary sector	We agree.
Children's and Adolescent Cancer Partnership (CACP)	9	In referring to continuity of care 'across the whole system', it would be appropriate to emphasise that this extends beyond health care into education and social care, and that parents and users should have a forum within which their views can be heard and understood.	This is a key recommendation; we cannot go into this level of detail.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Children's and Adolescent Cancer Partnership (CACP)	11	The reference to paediatric surgery should also explicitly refer to neurosurgery	We feel that this has been covered in the section on neurosurgery.
Children's and Adolescent Cancer Partnership (CACP)	17	Although it is understood that the purpose of this guidance is primarily for commissioners (and has equal relevance for service providers) those involved in delivering or receiving the service seek reassurance about the means by which this guidance will be implemented at Network and Trust level.	Thank you for the comments, but we have no control over how this guidance will be implemented.
Children's and Adolescent Cancer Partnership (CACP)	23	Although we understand that there has been considerable discussion about the age range to which this guidance will apply, we believe that the lack of an explicit upper figure could allow undue flexibility in its interpretation and may cause difficulty at local level	We understand the concern, but our reasons are further described in amendments to paragraph 19.
Children's and Adolescent Cancer Partnership (CACP)	57	The statement that 4% of survivors develop second malignancy should be clarified as it will vary depending on underlying diagnosis and on the treatment given. It should be made clear that this is an average figure at (probably) a mean of 20 years of follow up but that individual risk can be significantly higher for some survivors	This section has been redrafted and paragraph 57 has now been omitted.
Children's and Adolescent Cancer Partnership (CACP)	63	The group had access to data from a questionnaire coordinated by CACP in 2003 (reported 2004) which identifies current concerns within UKCCSG and TCT units. We believe it would be helpful to refer to these findings and to acknowledge their source. The key conclusions of this report include the following observations: • A notable level of concern was expressed by staff about difficulties in arranging admission of patients for treatment, and about the safety of patients during their treatment, which is increasing. • Increasing complexity of patient care, nursing staff shortages and skill mix deficiencies, the changing	The CACP report will be included in the Evidence Review.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
		demands on medical staff, and, in some cases, lack of senior medical staff for this specialist work, are major factors in these concerns • Arrangements for commissioning services for children and adolescents with cancer are unclear, inconsistent and insufficiently robust to respond to unmet needs or to changes in local service requirements. • In many areas there appears to be a lack of engagement by cancer networks which have been slow to address the needs of paediatric and adolescent cancer services. • Children's and adolescent cancer services are dependent on the voluntary sector to a degree that is underestimated by health service commissioners and providers, and at a level which may challenge future sustainability.	
Children's and Adolescent Cancer Partnership (CACP)	73 and 77	Increasing activity relates not only to greater intensity of therapy (e.g. to a greater incidence of complications) but also to greater complexity and to the implementation of the majority of care according to clinical trial protocols (i.e. that even for the same length of stay, care may be more demanding on staff and other resources, independent of its intensity). Increasing in patient activity has been identified in the presence of a concurrent increase in day care activity – the commentary should reflect this 'compound' effect.	The text has been amended.
Children's and Adolescent Cancer Partnership (CACP)	82	Pharmacists should be identified within this list of AHPs	Pharmacists are not AHPs and their role is covered elsewhere in the guidance.

Organisation	Section no. or General	Comments	Developer's response
Children's and Adolescent Cancer Partnership (CACP)	83	The brevity of this paragraph rather diminishes the role of 'non health services'. For 'important' substitute 'essential'?	This amendment has been made to the text.
Children's and Adolescent Cancer Partnership (CACP)	116 and 117	There is also a national shortage of paediatric radiologists – this should be highlighted (as for pathology and haematology). Difficulties in imaging babies and young children should explicitly refer to the need for anaesthetic support.	The text has been amended.
Children's and Adolescent Cancer Partnership (CACP)	126	Please define 'specialist bone tumour centre' otherwise there is a danger that centres may choose to define themselves as such.	Unfortunately this is outside the scope of this guidance. We have referred your comment to the sarcoma Guideline Development Group. for consideration
Children's and Adolescent Cancer Partnership (CACP)	142	The wide range of diagnoses and the relatively small number of children within each diagnostic group implies that, proportionately, a much larger range of chemotherapy protocols is required by paediatric oncologists. This contributes to complexity, and hence to risk.	We agree.
Children's and Adolescent Cancer Partnership (CACP)	145–153	There is an opportunity to say more here about the role of pharmacists in supervising chemotherapy prescribing	We agree that pharmacists are important in the delivery of chemotherapy and this has been mentioned in paragraph 152.
Children's and Adolescent Cancer Partnership (CACP)	158	Reduction in risk can also be achieved by the appointment of a designated pharmacist to the service	We feel that this is covered by paragraph 152, but we have included a designated pharmacist as a bullet point to paragraph 159.
Children's and Adolescent Cancer Partnership (CACP)	186	How many of the 186 neurosurgeons have a paediatric practice involving neuro oncology – this is an important statistic.	This information is not available at present.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Children's and Adolescent Cancer Partnership (CACP)	188 and 192	The appointment of designated paediatric neuro oncology specialist nurses is a very good way of maintaining communication and ensuring coordination of care, particularly when services operate on split sites	In paragraph 514 we have made a recommendation about the appointment of key workers. It may be that designated paediatric neuro oncology specialist nurses may fulfil this role.
Children's and Adolescent Cancer Partnership (CACP)	210	It would be appropriate to offer guidance about the time to start RT once a decision to treat had been made – the wording of this paragraph is too soft and will allow services to continue to fail to meet the needs of patients. Booking treatment 'slots' is frequently very difficult because of pressure on machine time and, sometimes, the availability of anaesthesia.	We are unable to make recommendations about specific time limits in this guidance, but in Table 2 we have referred to 'nationally agreed waiting times'. We anticipate that these will be available following publication of this guidance.
Children's and Adolescent Cancer Partnership (CACP)	321 et seq.	The section on Rehabilitation is very much a 'medical model' and does not adequately emphasise the importance of psycho social interventions and support	The actual model we have quoted (see paragraph 341) is regarded as patient focused. The importance of psychosocial interventions and support are covered in more detail in the section on psychosocial care
Children's and Adolescent Cancer Partnership (CACP)	324	Considerable problems exist in many parts of the country about access to wheelchairs and families are sometimes caught in unhelpful debates over funding arrangements. Children requiring artificial limbs may need to be referred to specialist prosthetics centres and not referred back to local services where experience with the needs of young amputees may be limited. Resources for provision of cosmetically and functionally sophisticated prostheses, often only available from the private sector, should be made available. A small number of children need access to specialised oculo facial prostheses.	We have already made a recommendation for a robust equipment strategy in paragraph 346. There will be specific guidance on limb prosthetics in the Sarcoma service guidance, and facial prostheses are covered in the Skin cancer service guidance.
Children's and Adolescent Cancer Partnership (CACP)	325	Reference to psychology in the context of brain tumour patients should also emphasise the requirement for specialist neuro psychology support.	We agree and we hope this will be addressed in response to our recommendation.
Children's and Adolescent Cancer Partnership (CACP)	342 et seq.	Should there be an explicit cross reference to the Children's NSF, either here, or somewhere else in this document?	The NSF will be referenced In the second draft of the Guidance.

Organisation	Section no. or General	Comments	Developer's response
Children's and Adolescent Cancer Partnership (CACP)	429	Emphasise the importance of ethnic and religious needs in this context	We feel this is implicit in paragraph 429.
Children's and Adolescent Cancer Partnership (CACP)	444	See also #6	We do not understand how this comment refers to paragraph 444.
Children's and Adolescent Cancer Partnership (CACP)	448	Add nurse to Diagnostic MDT; add spiritual support / Chaplaincy to Psychosocial support MDT	Although we agree that the attendance of a nurse at the diagnostic MDT is of value, we do not feel that participation by a nurse is a core role for the diagnostic planning of the patient. Although we agree that chaplaincy and spiritual support would have a potential contribution to make at all points of the care pathway, we believe that this is where a key worker would be able to ensure liaison with appropriate services.
Children's and Adolescent Cancer Partnership (CACP)	476	Whilst we welcome the concept of 'key worker' further thought needs to be given to what role this really represents and how this can / should be delivered	We have amended Table 7 and now feel the role of the key worker is more fully explained. The delivery is a question for local implementation
Children's and Adolescent Cancer Partnership (CACP)	526	In Table 8, it should be made explicit whether the number of consultant staff (5) refers to w.t.e. In terms of nursing establishment, it would be better to add a statement which acknowledges that the nurses for ward and day care must have the appropriate skills and competencies for this work. Overall, it might be helpful to indicate that the designated core components must address the resources needed to ensure the necessary skill mix with those required to manage work load	We have amended this table to include this. We feel that the term 'specialist trained' covers this. We think specific resource levels will be addressed by the implementation of the guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Children's and Adolescent Cancer Partnership (CACP)	554	The host network for a paediatric oncology centre which accepts referrals across a number of networks should be required to take responsibility as the 'lead' network for the service and this lead role should be acknowledged by the other networks involved.	This amendment has been made to the text.
Children's and Adolescent Cancer Partnership (CACP)		Thank you!	Thank you.
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	General	The overall principles and proposals outlined in the guidance are fully supported and will be helpful to commissioners. However, there is concern that no reference is made to additional resources required to develop AHP services in this area. Significant challenges therefore lie ahead to implement the proposals and principles.	The economic impact is covered in the Economic Analysis that accompanies this guidance.
College of Occupational Therapists	General	Acknowledgement of the important contribution of AHPs to cancer services for children and young people is praiseworthy. The document is comprehensive, practical and easy to refer to.	Thank you.
College of Occupational Therapists	General	It is unclear as to how the document relates to the NSF for Children, Young People and Maternity Services November 2004. (only reference in pain management paragraph 273)	This is referred to in paragraph 18.
College of Occupational Therapists	General	Treatments are discussed in isolation. Some children/young people require a complex combination of therapy complicating their management. Extra resources may be required, time and enhanced communication between specialist consultants and within MDT.	We feel that the integration of all aspects of care is appropriately dealt with.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
College of Occupational Therapists	General	The need for equipment is highlighted throughout the document but perhaps a definition is needed (mobility/activities of daily living/medical/nursing).	We disagree and do not see the need for this extra definition.
College of Occupational Therapists	16	The guidance highlights a gap in the evidence to support clinical practice.	Thank you.
College of Occupational Therapists	336	Existing research studies on **adults with cancer** and quality of life issues could be critiqued and where relevant, evidence extrapolated and applied when planning research studies and service for children/young people.	We agree and feel that this is stated in the document.
College of Occupational Therapists	33 and 337	Existing research studies on **children with complex health care** needs (not cancer) could be critiqued and where relevant, evidence extrapolated and applied when planning research studies and services for children/young people.	We agree and feel that this is stated in the document.
College of Occupational Therapists	338	Occupational Therapy (OT) is widely acknowledged as an effective intervention for **adults with cancer** and established models of practice/outcome measures are in use. Should be recognised as resource. OT is widely acknowledged as an effective intervention for **children with complex health care** needs. Should be recognised as resource. Evidence of a link between occupation and health is also well documented. A balanced view of evidence-based practice is needed; posts need to be established in the first instance with mechanisms to evaluate effectiveness built in. It is acknowledged that AHP input is limited and therefore likely that EBP will be very limited also, but this is not unique to AHPS. How will the shortage be addressed?	We agree and feel that this is stated in the document. We are unclear what this is referring to. However, any shortages would be the proper focus of implementation.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
College of Occupational Therapists	General 16, 81 and 82	**HIGH IMPORTANCE** The document makes reference throughout to the Allied Health Professional; the term needs to be clearly defined in line with the Health Professions Council definition/list. Where the skills of a particular profession have been identified as being needed this should be stated (as in paragraph 70).	We have amended paragraph 79 and added a definition of AHP, and the included staff in the Glossary.
College of Occupational Therapists	82	The point regarding 'having strong links to non health services' is particularly valid to OT, as OT is one of the few health professions that also work in Social Services. Increasing numbers of OT posts are joint funded and some OTs also routinely work in schools and have links with education. Accessing services can be more streamlined when this type of working is established as communication channels are in place and there are less admin/organisational barriers to overcome.	We agree.
College of Occupational Therapists	83	This needs to include joint funding posts between health, social care and education, as working across boundaries is needed.	It is outside our remit to comment on the funding of such posts.
College of Occupational Therapists	171	Whilst we agree in principle with this point, the acute rehabilitative phase, which can be crucial, may be time limited either due to lack of resources or pressure to discharge the child/young person to local services. Intensive and prolonged rehabilitation can be difficult to access; intensive rehab started in hospital may not be provided on discharge. Within both the NHS and private sector there is a lack of community rehab facilities for children and young people. Waiting lists within the community may be lengthy. Community AHPs are often inexperienced in working in this group of patients.	We agree with your comments.
College of Occupational Therapists	178	This is an important point as organising of specialist equipment; liaison with community OT services (paed/social services) needs to be planned. If done in advance it can help in establishing rapport with the child/family. May be helpful in predicting long-term functional outcomes.	We agree.
College of Occupational Therapists	197	Does this include OT functional assessments?	OT assessments have been added to paragraph 200.

Organisation	Section no. or General	Comments	Developer's response
College of Occupational Therapists	198	Does this include rehabilitation services?	Yes, this does include rehabilitation services.
College of Occupational Therapists	204	Play therapy is an involved modality and should only be carried out by a qualified play therapist and in this setting it may be that distraction techniques are required not play therapy.	Although distraction techniques are certainly required, other aspects, e.g. preparatory play, will also be needed for some patients undergoing treatment.
College of Occupational Therapists	217	Play specialists and play therapists are 2 quite different roles, need to be sure of what is required for this service. (Table 2)	We have changed to 'play specialist' throughout the guidance.
College of Occupational Therapists	324	This needs to include timely referral for equipment provision to prevent delays. It may be more helpful if this point was more specific, ie naming professionals with a specific remit. Multiagency liaison is one important aspect in avoiding delays in service provision, other factors of equal importance are the ability to fast track funding/access criteria/use of key-worker/co-location of workforce/joint funding of posts.	We have already made a recommendation for a robust equipment strategy in paragraph 346.
College of Occupational Therapists	325	Whilst we agree in principle with this point, it should be noted that neurorehabilitation is a scarce provision throughout the UK within the NHS and private organisations.	We agree and we hope this will be addressed in response to our recommendation.
College of Occupational Therapists	327	This needs to include – neurorehabilitation is a specialist service over and above what would be provided by a paediatric OT/PT/SLT service. Reference to long term treatment is a valid point but there is a gap in provision with very few facilitates available at present to offer this service.	Paragraph 327 does refer to a specialist service, but we agree that the provision is limited and hope this will be addressed in response to our recommendation.
College of Occupational Therapists	328	Strategies to include liaison with ICES regarding access criteria/priority systems. Services need to be responsive, there seems to be differences between areas - need for some standardisation.	We agree that there are differences, but this a much broader issue and is outside the remit of this guidance.
College of Occupational Therapists	329	Equally important to receiving training is opportunities for AHPs to discuss with other team members re: roles, differing views and perspectives, and philosophy of care.	We agree.
College of Occupational Therapists	331	Needs to include that: 'Timely provision' may also shorten hospital stay.	We are unable to include this as current evidence is insufficient to support this.

Organisation	Section no. or General	Comments	Developer's response
College of Occupational Therapists	332	Referrals need to be timely. Equipment may be essential for a safe home discharge.	We agree.
College of Occupational Therapists	338	Need to include a flexible rehabilitation approach as the child/young person may have a start/stop/start progression through their rehab programme. Interventions may need to be adapted as appropriate by an experienced OT.	We do not understand how this comment relates to paragraph 338.
College of Occupational Therapists	339	Outreach OT and PT need to be included.	We have amended this paragraph.
College of Occupational Therapists	348	This is not necessarily the primary role of the OT, but the role of the OT in meeting the mental health needs of the child/young person exceeds this description. For example, leading group work in anxiety/anger management/specialist expertise in grading and activity analysis to optimise function and performance in existing life roles or adapting roles.	We have amended this paragraph.
College of Occupational Therapists	397	Need to include access to OT for provision of specialist equipment who would liaise with multi-agencies.	We agree; this is highlighted in paragraph 397 but has been further strengthened in Table 3.
College of Occupational Therapists	400	Often specialist nursing teams may assume responsibility for equipment and involve OT at a late stage when an earlier referral may be more appropriate.	We are unclear of the relevance of this comment to paragraph 400 and would need clarification.
College of Occupational Therapists	448	Tables 4 and 5 need to list key AHPs.	Where AHPs are indicated as core members of the MDT we are not listing specific AHPs, because it is not possible to include this level of detail in service guidance. Where AHPs are not listed this is because we expect the key worker would be able to ensure liaison with appropriate services.
College of Occupational Therapists	519	Collaboration/partnership working is required.	We agree.
College of Occupational Therapists	617	This is very important as very few AHPs have expertise of working in this area.	Thank you.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Community Psychiatric Nurses' Association			This organisation was approached to comment but did not 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	General	Through out the guidance there are recommendations regarding "adequate resources" (eg para 227). Would it be possible for you to clarify who these types of recommendations are aimed at? Similarly, there are recommendations regarding the development of national guidance. (Eg para 225, 308). Again, would it be possible for you to clarify who you feel should be developing this guidance.	This is covered in the Economic Analysis that accompanies this guidance. National guidance could be developed either by the Department of Health/Welsh Assembly Government/NICE, or by professional societies or bodies; it would not be appropriate for us to specify which.
Department of Health	General	The jargon normally used is "specialist" centres staff etc, but "specialised" services. Please consider amending the following paragraphs and replace "specialist with "specialised": *69 For "specialist" substitute "specialised"* *339 For "specialist" substitute "specialised"* *527, Table 8, 3rd line up from bottom: For "specialist" substitute "specialised"* *527, Table 9, 6th line down from top: For "specialist" substitute "specialised"* *534 For "specialist" substitute "specialised"* *Page 155 Table, 1st box on left: For "specialist" substitute "specialised"* *Page 155 Table, 4th box on left: For "specialist" substitute "specialised"*	Thank you; we have amended the text.
Department of Health	General	Would it be possible include a list of the 17 UKCCSG centres in an annex to the guidance. .	We will insert a list of the 17 centres in an appendix.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Department of Health	General	Whilst the technical role of the oncology pharmacist is well recognised e.g. in the sections relating to chemotherapy, we believe the key clinical role of the specialist pharmacist in medicines management and clinical governance is perhaps understated. Would it be possible to address this in the next draft of the guidance.	Whilst we have emphasised the key role of the specialist pharmacists in relation to this guidance, their wider role in medicines management and clinical governance although important is beyond the scope of this guidance.
Department of Health	General	You might wish to consider collecting all the research recommendations together in an annex to ensure that they are not lost.	Thank you – we will do this.
Department of Health	6	Please would you clarify what is meant by 'strategic level' (i.e. SHA/PCT collective/networks/supranetworks)	We have deleted 'strategic level'.
Department of Health	9	Please would you clarify whether these would be paediatric key workers or general community nurses or cancer CNSs.	The issues around key worker are discussed in Table 7 and paragraph 509.

Organisation	Section no. or General	Comments	Developer's response
Department of Health	9 (also 91, 92, 191, 247, 248, 408)	The content and standard of postgraduate medical training is the responsibility of the UK competent authorities, the Specialist Training Authority (STA) for specialist medicine and, for general practice, the Joint Committee on Postgraduate Training for General Practice (JCPTGP). Their role is that of custodians of quality standards in postgraduate medical education and practice. They are independent of the Department of Health. In addition, the General Medical Council's Education Committee has the general function of promoting high standards of medical education and co-ordinating all stages of medical education to ensure that students and newly qualified doctors are equipped with the knowledge, skills and attitudes essential for professional practice. All of these bodies have a stake in ensuring that doctors are equipped to deal with the problems they will encounter in practice – including improving outcomes in children and young people with cancer. It is not practicable or desirable for the Government to prescribe the exact training that any individual doctor will receive. However, as part of the current Modernising Medical Careers initiative designed to reform postgraduate medical training and careers, all medical disciplines will review their curricula to ensure they meet all the required needs. Would you please consider whether it might be appropriate to reword any of the paragraphs referred to here to reflect the comments above?	Thank you for your information and comments, but we do not feel that we should amend these paragraphs as details of training are outside our remit.
Department of Health	10	You may wish to consider whether the split in this paragraph is necessary, as the advice seems to be the same for under 19s and over 19s.	The NSF is a legal framework in England and hence age-appropriate facilities *must* be provided for patients aged 19 years and under. However, for patients over 19 years no similar legal framework exists; therefore, we are recommending that patients *should* have the opportunity to be treated in age-appropriate facilities.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Department of Health	12	"Adequate resources - please would you clarify whether this is aimed at DH or the NHS	This is aimed at both the DH and the NHS, dependent on whether it's the distribution of current resource (NHS) or new additional resource (DH).
Department of Health	15	This paragraph might benefit by recognising that support from SHA Workforce Development Directorates is required to deliver this key recommendation, Please would you consider redrafting the paragraph to reflect this.	The guidance needs to be applicable to England and Wales and the current text reflects this.
Department of Health	16	You may wish to consider whether this paragraph would benefit by being more specific on AHPs involved	It would not be appropriate to be specific, but all the recommendations in the guidance on the structure of MDTs would imply a shortage, which needs to be addressed through workforce development.
Department of Health	22, Fig. A	The construction of this figure makes it appear that audit, communication etc are outside the remit of the multi disciplinary team (MDT). Is this intentional?	We have taken note of your comment and amended the diagram accordingly.
Department of Health	32	Please could you check whether the ONS remit includes Scotland?	For the purposes of this guidance, the ONS remit does include Scotland.
Department of Health	33	Registries take most of their coding data from pathology reports, which include the detailed Snomed morphological coding. This is used to derive the ICD10 code. If the ICCC codes are also derived from Snomed coding of pathology, there is an obvious process of translation at that level. So, whilst it may not be possible to translate ICD10 to ICCC, if the registries have the morphology coding it is perfectly possible to produce an ICD10 and an ICCC code for the same record. You may wish to reconsider the drafting of this paragraph in light of the above.	Paragraphs 33–35 have been redrafted and amended to reflect the comments made.
Department of Health	33	Please would you clarify where the estimate of 100% completeness comes from, and against what denominator?	The estimate of 100% completeness comes from a personal communication with Dr Charles Stiller. This statement has been removed from the text.
Department of Health	34	There is no register which stores additional items of data, but the registration process covers all the cases.	Paragraphs 33–35 have been redrafted and amended to reflect the comments made.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Department of Health	35	We believe this paragraph may be slightly misleading. If the data is collected using a detailed pathological coding system (e.g. Snomed in path labs) the two sets of codes are derivable directly, so the data is not actually collected twice. Therefore, could you consider redrafting this paragraph?	Paragraphs 33–35 have been redrafted and amended to reflect the comments made.
Department of Health	35	Please could you clarify the meaning of the final sentence in this paragraph?	This sentence has now been omitted.
Department of Health	39 (Figs B and C)	Would you be able to reformat the graph to include the information contained in the footnote? This would make the graphs easier to read.	Including the full titles of the ICCC classification on the *x*-axis would cause the graph to become unreadable.
Department of Health	43	'Place' is not a meaningful heading. You may wish to consider amending (eg "Comparison with other countries")	The text has been amended to 'Comparison of incidence with other countries'.
Department of Health	44	Again "person" would not seem to be very meaningful	The text has been amended to 'Variation of incidence with age'.
Department of Health	46	Typo replace 'and overall' with 'an overall.'	This amendment has been made to the text.
Department of Health	51	You may wish to reconsider this paragraph - does 'supportive care' contribute to survival. Should earlier diagnosis be included?	We disagree. Improvements in supportive care, e.g. management of neutropenic sepsis, have certainly improved survival rates. The evidence that earlier diagnosis improves survival rates is poor.
Department of Health	53	You may wish to be aware that ONS advise that survival data *by tumour type* for 15 - 24 year olds would be obtainable but is currently unpublished.	The text has been amended to reflect this.
Department of Health	58 and 59	In one paragraph, you use the term children and young people, in the other children and adolescents; you may wish to redraft to ensure consistency.	This amendment has been made to the text.
Department of Health	61	The meaning of this para is unclear, you may wish to redraft.	We have amended the text to clarify.
Department of Health	65	You may wish to consider cross-referencing the haematological guidance here.	We agree, and it is cross-referenced.
Department of Health	71	Would it be possible to refer to the reasons (if known) patients gave for rarely or never using these services.	Sorry, we do not have this information; however, it reflects the usual practice for children with cancer dying at home.
Department of Health	78	You may wish to consider referring to e-prescribing, which we believe will help with this.	This is discussed in later sections of the guidance.
Department of Health	79, last line	Would it be possible to clarify this last point – is it a recommendation, and who should do this work?	This is not a recommendation.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Department of Health	82	Allied Health Professionals (AHPs) are: Art therapists Chiropodists/Podiatrists Dietitians Drama Therapists Music Therapists Occupational Therapists Orthoptists Paramedics Physiotherapists Prosthetists/Orthotists Radiographers Speech & Language Therapists AHPs are registered with the Health Professions Council (HPC) Sonographers, play therapists and activity specialists are not AHPs and are not registered professionals. Please would you amend this paragraph to reflect the above.	We have amended the text to reflect this distinction.
Department of Health	82	Would you consider adding specialist clinical pharmacists to this section?	These are not AHPs.
Department of Health	89	Would it be possible to the original DH referral guidelines published in 2000 and the fact that NICE is updating the original guidance	The reference has been added to Appendix 1.
Department of Health	93, second line 94, first line	These paragraphs seem to be contradictory. Could you please clarify this?	These are not meant to be contradictory. We have amended the text to clarify the situation.

Organisation	Section no. or General	Comments	Developer's response
Department of Health	148	Professional colleagues advise that there are now pharmacists qualified as 'supplementary prescribers' undertaking the prescribing of chemotherapy for children in some centres. You may wish to amend this paragraph to reflect this. Small typo – 'nursing **staff** appropriately''	We have amended the text to read 'clinical staff'.
Department of Health	150	Would it be possible to amend this para to read "There must be compliance with current DH guidelines on the safe administration of intrathecal chemotherapy [HSC 2003/010]"	We have amended the text to include 'safe'. These Department of Health guidelines are also referenced in Appendix 1 of the Guidance.
Department of Health	151	please consider amending the first sentence of this to read: " All chemotherapy should be prepared in facilities by pharmacy staff in accordance with the standards specified in the Manual of Cancer Services."	We do not feel that the text needs amending.
Department of Health	164	Professional colleagues have commented that methods for monitoring compliance are "limited". We believe there is scope for further work in this area as it affects outcome. Pharmacists have an important role in counselling patients on their medication to promote compliance and concordance and liaising with other team members as necessary.	Thank you for confirming what our evidence review has suggested. In due course it will be interesting to see better evidence resulting from further work.
Department of Health	189	You may wish to consider whether there is any quantification desirable/ feasible from the evidence. Eg the urology guidance gave population size and procedure numbers for radical surgery for prostate and bladder cancers.	We searched for any evidence on the relationship between workload and outcome and found none specific to paediatric oncology. We have therefore based our recommendations on the skills required to deliver a sustainable service.
Department of Health	239.and 240	Please ensure these recommendations are consistent with current DH guidelines on the safe administration of intrathecal chemotherapy (HSC 2003/010).	We have tried to ensure that recommendations are consistent with current Department of Health guidelines. However, paragraphs 239 and 240 are not recommendations: they are background information. Please note that HSC 2003/010 does not apply to central venous access.
Department of Health	241	Would you clarify this paragraph – i.e. is it feasible to say a 'purpose designed area', as this suggests an area designed for CVC only rather than an area designed for procedures requiring similar stringent conditions.	We have changed the text to read 'an area designed for clean surgical procedures' to clarify this.

Organisation	Section no. or General	Comments	Developer's response
Department of Health	242	You might wish to add 'if required' at the end of this paragraph – the child themselves or their parents may not wish them to undergo general anaesthesia for this.	These paragraphs have now been amended.
Department of Health	245	It is the view of professional colleagues that an agreed policy for the standardisation of the care of central venous access would also reduce infection rates. You may wish to consider adding this as an anticipated benefit.	We have added 'infection rates' to the text.
Department of Health	252	Professional colleagues are of the opinion that the incidence of infection after the insertion of a CVC should be audited within each clinical network. Would you consider including this?	The text has been amended.
Department of Health	266	This paragraph mixes interventions and professionals with potential for confusion. You may wish to consider moving the sentence beginning "Play therapists" to a separate paragraph.	We feel this follows on appropriately from the first sentence.
Department of Health	281	Please would you clarify what is meant by 'timely'?	It is not within the remit of this guidance to set standards for timing of interventions. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
Department of Health	288	Investment in training places for dietitians has increased with the result that there has been a 36.5% increase in numbers of dietitians since 1997 and vacancy rates have fallen to 2.4% (Staff census Sept 2003). Services are also using skill mix eg dietetic assistants, specialist practitioners to improve recruitment and retention and to increase capacity. Would you please consider deleting this paragraph as we believe it might hinder establishment of dietetic posts to improve nutrition for this client group.	This paragraph has been redrafted.

Organisation	Section no. or General	Comments	Developer's response
Department of Health	290	This recommendation may not be specific enough about the level of training required and could be open to misinterpretation. It may also limit recruitment of dietitians who may have worked in other related areas eg adult oncology, palliative care. Provision of experience within paediatric oncology services at a junior level is important as part of succession planning for all clinical staff. Please would you consider redrafting this paragraph in light of the above comments?	We have amended this paragraph.
Department of Health	291	Would you consider rewording this paragraph to read "The skill mix of the multidisciplinary team should include a specialist dietician".	A dietitian is recognised as part of the MDT in Table 4 and the text has been amended.
Department of Health	292	You may wish to cross-refer the guidelines mentioned. This paragraph seems ambiguous – for example, one professional guideline may differ from another. Would you consider redrafting to read "The multidisciplinary team should have an agreed policy on nutritional support using evidence-based guidelines."	We agree, and they will be stated in the Evidence Review that accompanies the guidance. We have amended the text to 'staff of relevant disciplines'.
Department of Health	300	2nd bullet point – the number of staff may not reflect how the service is delivered. For example, the role of a specialist dietitian in a multidisciplinary team may include training of other staff to ensure the principles of optimum nutritional support are implemented as well as direct interventions with specific patients. Would you consider redrafting to read; "Provision of specialist dietetic advice/training/interventions."	This amendment has been made to the text.
Department of Health	301	Would you consider redrafting to read "Audit of the nutritional status of patients?"	We have inserted this in paragraph 317.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Department of Health	302	Would you consider redrafting to read "Optimum nutritional status is maintained."	This paragraph has been redrafted in response to comments from another stakeholder.
Department of Health	329	The importance and need for this type of training and development is recognised, however, ensuring appropriate provision is something to be addressed collectively by the WDCs/SHAs and the issue of support is something local trusts should be encouraged to do. This paragraph also seems to infer that CPD consists solely of training courses. The Health Professions Council is currently consulting on the requirements for CPD. The consultation document includes a range of CPD activities. Would you consider redrafting to read: "AHPs working in paediatric and adolescent oncology are supported to undertake continuing professional development. This may include support to access training opportunities unlikely to be provided locally due to the small number of professionals involved".	We have split the two paragraphs into two recommendations. Paragraph 329 is not addressed to Trusts and we would anticipate the training being organised as in paragraph 664.
Department of Health	329	Please would you consider splitting this paragraph into two recommendations – sentence 1 then sentence 2&3 as separate recommendations as we believe they are different issues?	We have split the two paragraphs into two recommendations. Paragraph 329 is not addressed to Trusts and we would anticipate the training being organised as in paragraph 664.
Department of Health	342–348	The comments on psychosocial care are welcome, but we believe it would be unsatisfactory if this led the generality of professionals to assume it was someone else's problem.	We do not think that such a perception would arise from this part of the guidance.

Organisation	Section no. or General	Comments	Developer's response
Department of Health	348	This paragraph suggests a narrow role for occupational therapist – suggesting that occupation i.e. productivity is a prime focus. The concept of occupation will vary between patients and it is the role of the occupational therapist to consider occupation holistically. 'Occupational Therapy is the therapeutic intervention that promotes health by enhancing the individual's skills, competence and satisfaction in daily occupations …to act on the environment and successfully adapt to its challenges' (Yerxa et al 1989). Occupation therefore means any way in which people spend their time – personal care (eg dressing, shopping), productivity (eg work, school), leisure (eg sports, hobbies, social life). Would you therefore consider redrafting to read: "Young people may require occupational advice. An occupational therapist, often in conjunction with other services outside of health such as careers organisations and educational establishments, can support individuals to maximise their physical, emotional, cognitive, social and functional potential."	This amendment has been made to the text.
Department of Health	375	Could you consider including 'clinician with expertise' in this list.	We feel this is implicit in paragraph 375 and further specified in Table 4.
Department of Health	376	Would you be able to advise how to distinguish between these two groups of patients?	This is now covered in paragraph 393.
Department of Health	381	This paragraph refers specifically to the storage of sperm - could you clarify whether the storage of eggs or ovarian tissue is intentionally not mentioned.	We have not mentioned egg storage, as our understanding is that it is still experimental. We have amended the text to indicate the experimental nature of this.

Organisation	Section no. or General	Comments	Developer's response
Department of Health	400 and Table 4 (after para 448)	Would you please consider including clinical pharmacists in this section. Pharmacists have a pivotal role in the provision of: • advice on symptom management, drug choice, dose, administration, alternatives routes and dosage forms • use of unlicensed medicines • provision of controlled drugs • co-ordination with outreach teams, hospital and community pharmacists to ensure timely drug provision • Information and support with syringe driver drug delivery, compatibility, mixing and choice.	We have amended the MDT section to cover this.
Department of Health	401	You will want to be aware that regions no longer exist - you may wish to redraft this recommendation to refer to SHAs or Cancer Networks.	We have amended this paragraph to clarify.
Department of Health	422	Is there any evidence to suggest whther there should be dedicated teenage cancer units, or do you feel this should be a matter for local determination?	We are not clear how this refers to paragraph 422.
Department of Health	431	Would you consider making a reference here to the NHSU development in Advanced Communication Skills programme for Senior Healthcare Professionals in Cancer Services	We will refer to this in the section on communication.
Department of Health	443	Second sentence: We believe the phrase "postcode lottery", is unclear, and causes confusion in the service. Would you consider rewording as follows: "These constraints remain real, but efforts must be made to minimise *variations in practice*."	We have made amendments to the text.
Department of Health	447	Please would you consider whether it is feasible to have 5 MDTs or whether it should be a smaller number covering these areas	The section has been amended to make it clearer that we are not talking about separate MDTs in all circumstances.

Organisation	Section no. or General	Comments	Developer's response
Department of Health	448, Table 4	Would you consider whether "**suggested** core membership" is strong enough – it might be better to say "should." Would you please consider including a clinical oncologist in the late effects MDT. Would you also consider defining the meaning of 'principle treatment centre' here – there is a definition at para 509, this could be cross referenced	We have deliberately labelled these tables 'suggested' core attendance because there is likely to be considerable local variation in the need for different health professionals and this is best left to local determination. The lead clinician in the late effects MDT would request, where necessary, an opinion from the clinical oncologist. We have cross-referenced the section that defines principal treatment centre where the term first occurs in the guidance.
Department of Health	448, Table 5	You may wish to consider whether having different types of MDT at different treatment sites is or needs to be consistent with other IOGs.	We believe that the description of MDTs in this guidance is the most appropriate for this patient group.
Department of Health	448, Table 5, point last bullet	Would you consider amending to : "AHPs such as Dietitian, Therapeutic Radiographer, Occupational Therapist, Physiotherapist."	Where AHPs are indicated as core members of the MDT we are not listing specific AHPs because it is not possible to include this level of detail in service guidance.
Department of Health	513	This paragraph mentions the need for teams to be "experienced in… the psychological needs of teenagers with cancer". This could be interpreted as having one individual in the team with specialist knowledge. Instead, every professional coming into contact with CYP with cancer needs to understand how they can promote the patient's social, emotional and mental well-being, and consider how their clinical environment can be designed to be welcoming and reassuring to young patients. Please could you consider redrafting this paragraph to ensure the meaning is clear?	We agree with your point, but think it is already clear.
Department of Health	519, Table 7	Would you consider including an identified pharmacist lead at the non-principal treatment site in this list. The provision of chemotherapy from the POSCU, some of whom do not have cytotoxic reconstitution services 'on site', is sometimes delayed because of lack of timely communication from the POC. The identification of a lead pharmacist aids communication between POC and POSCU and facilitates a better quality service.	This amendment has been made to the text.

Organisation	Section no. or General	Comments	Developer's response
Department of Health	524	Urgent referrals should thus be taken directly to principle centres (not local hospitals). It would be beneficial if you could take a view on this (also para 94)	Thank you. We have made changes to paragraph 91.
Department of Health	Table 8	Play Therapists are not AHPs. Please consider amending	We have amended this.
Department of Health	Table 9	Activity Co-ordinators are not AHPs. Please consider amending.	This amendment has been made to the text.
Department of Health	554	Could you consider whether paediatric tumours should be regarded as 'specialist commissioning' and so recommend it be commissioned at level 2?	We have made a recommendation that clarification is required on commissioning arrangements.
Department of Health	565	You may need to be aware that this has already been taken forward in medical training. Communication skills are a defined competency in the curriculum for the new Foundation Programmes (replacing in August 2005 the existing PRHO year and first year of SHO training). These skills will have to be demonstrated by all trainees in order to progress with their training.	Thank you for this information.
Department of Health	597	Please could you clarify whether this is aimed nationally or locally?	The guidance is aimed both nationally and locally, and the wording has been amended.
Department of Health	610	There are also particular issues around recruitment and retention of specialist hospital pharmacists (eg in oncology and paediatrics) too. You may wish to amend this paragraph to reflect this.	This amendment has been made to the text.
Department of Health	614 onwards	Please would you update this paragraph to refer to SHA Workforce Development Directorates not WDCs	This amendment has been made to the text.
Department of Health	616	See comment on para 13.	We could not find the comment to paragraph 13.
Department of Health	626	You may wish to consider whether the requirements for this need to be defined and built into the overall agenda for registration within NPfIT (in England). You may also wish to check if this is the same issue in Wales. If the PEDW data has morphology coding attached, it may be easier to identify the cases and produce an ICCC code already?	We are not clear what is being asked. If the suggestion is that we scope the requirements, then this is outside the scope of this guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Department of Health	635	Would you consider redrafting this paragraph as follows: 'Hospital facilities must meet requirements for good infection control and clinical teams should actively involve the Director of Infection Prevention and Control and other members of the Infection Control Team in service audit and development. It would be desirable for each lead oncology centre to designate a lead clinician for infection control.'	Your first sentence has been included in the guidance. With regard to your second suggested sentence, our understanding is that every trust is already required to designate a lead clinician for infection control so every principal treatment centre should already access to such a clinician.
Department of Health	636	Would you consider amending this paragraph to read: 'Hospital catering services should meet the particular nutritional needs of sick children however these arise – clinical, cultural (eg halal, kosher) or personal (eg vegetarian)'	We have added the following text to the paragraph: 'these may arise from clinical, cultural or personal needs'.
Department of Health	Appendix A	Please include references to the original GP guidelines, the HSC on intrathecal chemotherapy and Implementing a scheme for Allied Health Professionals with Special Interest – Department of Health 2003	Thank you. We will include the omitted references.
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	7	Local and national voluntary support groups need to be included in partnership in local service delivery planning.	We agree; however, this guidance can only advise on the commissioning of NHS services.
Gorlin Syndrome Group	8	In planning each child's care the multi development team must be aware and signpost parents to any relevant support group.	We agree, but cannot make such detailed recommendations.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Gorlin Syndrome Group	67	The scope needs to map and consider the lack of resources for rarer cancers e.g. PDT	This mapping exercise is outside the remit of this guidance.
Gorlin Syndrome Group	General	The scope needs to consider the provision for travel and accommodation support to families who have to travel to access services.	The text has been amended to cover these issues.
Gorlin Syndrome Group	General	Otherwise very comprehensive	Thank you.
Great Ormond Street Hospital for Children NHS Trust	General	Broad agreement with the NICE Guidance	Thank you.
Great Ormond Street Hospital for Children NHS Trust	General	Implications of "Payment by Results" should be positive but the impact on POCs and shared care needs to be incorporated in the resource section which will be part of Final document	This is now addressed in paragraph 2.
Great Ormond Street Hospital for Children NHS Trust	General	View that the section on CNS tumours needs to be expanded as an area of concern in terms of access to protocolised care.	Thank you for your comment. This will be addressed during the second consultation phase.
Great Ormond Street Hospital for Children NHS Trust	General	Emphasis on need to consider alongside NSF for children and relationship with disease site specific guidance.	We have tried to take into consideration such important guidance as the NSF.
Great Ormond Street Hospital for Children NHS Trust	General	The diagnostic pathway for children is clear but not for older patients, eg over 15 year olds. It does not stipulate who should lead on management of this age group.	We recognise that this a complex issue, and feel this is covered in the guidance
Great Ormond Street Hospital for Children NHS Trust	General	The issue of different guidance for children and young people covering different age groups e.g. NSF different to NICE.	We have further amended the guidance to draw attention to these anomalies.
Great Ormond Street Hospital for Children NHS Trust	General	Support long term audits to support national protocols but focus is on febrile neutropenia should be wider e.g. antifungals	This is now included.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Great Ormond Street Hospital for Children NHS Trust	General	More emphasis on the psychological impact on patients and families and the necessary support infrastructure.	We believe that given the time constraints and the size of the document we have addressed these issues adequately.
Great Ormond Street Hospital for Children NHS Trust		Does cancer palliative care need a separate network from palliative care given very small numbers involved. It is more important to have a clear identity and relationship to rest of the palliative care strategy / network??	Thank you for your comment, but we feel that the wording is appropriate as is.
Great Ormond Street Hospital for Children NHS Trust		Does not refer to role of complementary therapies.	Complementary therapies were not included in the scope that was decided at the beginning of the process.
Great Ormond Street Hospital for Children NHS Trust		Summary is very condensed compared to detail in the recommendations, looses impact because of this.	We are not clear what summary this refers to, but out of necessity the key recommendations have had to be condensed compared with the full recommendations.
Great Ormond Street Hospital for Children NHS Trust	6 and 20	It says in para 20 a principle is **"the aim is for safe and effective care as locally as possible, not local services as safely as possible"** – In the para 6 this phrase has been shortened which gives the opposite meaning! The summary needs to include the full wording as per para 20	We agree and have amended the text to correct this.
Great Ormond Street Hospital for Children NHS Trust	38 and 39	The 2 tables showing incidence of cancers have poor visual impact – the tables should be split if necessary to allow bar labels to be included.	Thank you for this suggestion, but we feel that including bar labels would make the figures difficult to read.
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.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
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	140	Reference to treatment should include palliative care as in the broader sense of symptom control which may be important at the time of diagnosis. It may also be a key determinant of the patient/family's 'satisfaction' with the diagnostic/treatment process, unrelated to chemotherapy etc	We agree. This is discussed in the sections on palliative care and supportive care.
King's College Hospital NHS Trust	227	Should include **'antibiotics'** these need to be adequately resourced as well – current protocol drugs tazocin etc constitute significant part of departments' drugs budget	We have added antibiotics to paragraph 234.
King's College Hospital NHS Trust	240	Should include '**timing of insertion'**.	This amendment has been made to the text.
King's College Hospital NHS Trust	255	Should include a comment to the effect that special blood product requirements for patients determined by the POC should be explicit in communication to the shared care centre. Patients transferring to hospital units other than their POC and POSCU for other interventions need the information to be clear especially requirements for irradiated products.	We have amended paragraph 267 to cover this.
King's College Hospital NHS Trust	277	Other causes of vomiting should be considered. Involve palliative care team for advice if refractory	We have amended the paragraph.
King's College Hospital NHS Trust	326	Important to include community paediatricians at this stage who often have to 'pick up the pieces' for years to come	We have amended this paragraph to include community paediatricians.
King's College Hospital NHS Trust	349	Very patchy postcode provision for older teenagers.	We hope this guidance will address this.

Organisation	Section no. or General	Comments	Developer's response
King's College Hospital NHS Trust	371	Services for young children are fairly well-organised but for older teenagers/ young adults there is a problem with long-term follow-up - ? need identified specialists with 'an interest' linked to each cancer centre	We feel that this is implicit in this paragraph and it is further covered in paragraph 397 and the section on continuity of care.
King's College Hospital NHS Trust	393	It is not helpful to consign palliative care to when therapy is not given with curative intent – the expertise the team can provide is just as important when therapy is given with full curative intent and there are problems with symptom control. The switch from curative to non-curative treatment can occur very quickly in some situations and it is good if the palliative care team have already met the patient/family as part of the MDT caring for the patient.	The section on supportive care addresses the issues of symptom control during treatment.
King's College Hospital NHS Trust	395	Most of the home care in this setting is provided by the community childrens nurses who know the patient, not the POONs who only have limited contact, usually at diagnosis	We agree and feel that we have recommended a sound infrastructure, but have amended the paragraph to emphasise this point.
King's College Hospital NHS Trust	431	This should be changed to 'bereavement support' not 'bereavement counselling'. Bereavement Counselling is a specific skill, the generic would be support and is more appropriate to a general communication skills training package.	This amendment has been made to the text.
King's College Hospital NHS Trust	524 and 527	This sounds unrealistic – if all the children with a suspected diagnosis of cancer came to the POCs for investigation they would be overwhelmed – surely the part of the function of the local hospital is to intiate and expedite prompt diagnosis (with the provisos of surgical/histopathology expertise etc) in discussion with the POCs	We have amended this paragraph.
King's College Hospital NHS Trust	General	Most respondents commented that whilst they agreed with the spirit of the guidance, they awaited the resource implications of this document with interest.	Thank you. The resource implications have been added to the second draft.
Leeds Teaching Hospitals NHS Trust			This organisation was approached to comment but did not respond.
Let's Face It			This organisation was approached to comment but did not respond.

Organisation	Section no. or General	Comments	Developer's response
Leukaemia Research Fund	142	A specific caution should be included about the lethal danger of injection of vincristine into the spine; this error has occurred on a number of occasions with fatal results.	We have made specific reference to the guidelines on intrathecal chemotherapy in paragraph 151.
Lymphoma Association			This organisation was approached to comment but did not respond.
Macmillan Cancer Relief	General	We welcome the recognition that children and young people with cancer have particular needs unrelated to their specific cancer which must be addressed during their care. We are pleased that the guidance has been developed around the care pathway, but feel that more could have been included to reflect the totality of people's needs during their experience of cancer. We have recently published the *'Principles of People-Centred Care'*, which describes all aspects of information and support which people affected by cancer have identified to help them deal with their cancer experience. A copy of this document is sent separately by post. Our response is also informed by calls to our helpline received from young people or their parents, which have highlighted the type of information and support required by people coping with cancer in a child or young person.	Thank you for this document. We have tried to take these issues into account.
Macmillan Cancer Relief	General	Whilst we welcome this recognition, children and young people are very different groups. They have different developmental and psychological needs, their level of understanding and ability to communicate needs and wishes differ, they experience differing levels of parental influence and control, and can participate in the care and decisions about their treatment to varying degrees. All these factors need to be borne in mind when designing appropriate services.	We believe that, as far as possible in a document of such broad scope, we have taken these issues into account.
Macmillan Cancer Relief	General	Little reference is made to what young people have said they need or to describe what the current situation is. We strongly recommend that consultation takes place with children, young people and their carers and that this is used to inform the next stage of developing the guidance.	Consultation has taken place and is included in the Evidence Review.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Macmillan Cancer Relief	General	Much greater emphasis and recognition needs to be given to the role played by families, particularly parents, in the delivery of care to their children. There could be more emphasis on patient/family involvement in decision making (e.g. making them aware of options and supporting them to make meaningful choices about their treatment and care).	We agree that the parents' role is important, but there is no more that we can recommend in service guidance, rather than clinical guidelines.
Macmillan Cancer Relief	General	The document makes occasional reference to the needs of people from black and minority groups, but much more emphasis should be given throughout the document to recognition of the needs of these communities, and also to addressing the needs of disadvantaged groups.	We disagree and feel that appropriate emphasis has been given.
Macmillan Cancer Relief	General	We would welcome advice on how the implementation of these guidelines is going to be funded, and whether additional resources will be made available to deliver the desired service as outlined in this guidance.	Implementation of this guidance is not within our remit. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards. The economic impact will be addressed in the Economic Analysis that accompanies this guidance.
Macmillan Cancer Relief	General	We are also interested to know how implementation will be supported: i.e. whether there are incentives/benefits for relevant professionals or organisations to implement the recommendations, how they can be supported to deliver the guidance, and how the benefits to patients can be demonstrated.	Implementation of this guidance is not within our remit. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards
Macmillan Cancer Relief	General	The document states several times in section D of each chapter, describing measurement, that audits and surveys are outcome measures. These are not outcomes. Outcome measures would show that problems have been alleviated, for example "Pain relief is more effective", "Survival rates improve", "Blood and blood products are administered safely", and appropriate outcome measures should be identified in the guidance.	The measurement sections are intended to describe methods for measuring outcomes and audits, and surveys are the methods to be used.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Macmillan Cancer Relief	General	Macmillan Cancer Relief increasingly focuses its service development on a model of integrated care, which links up people's health care, social/practical care with their own ability to manage their condition and situation. We would like to see this approach reflected in the guidance, and in particular it needs to be reflected in the remit and role of the key worker. The delivery of care to children and young people with cancer presents an especially relevant opportunity for 'professional' deliverers of care to work in partnership with patients and their carers.	We feel the document addresses these issues sufficiently.
Macmillan Cancer Relief	2	This states the reason for changing the title from 'children and adolescent cancer', but the terms 'child and adolescent' are used frequently throughout the document.	Thank you; we will review the document and make the necessary changes.
Macmillan Cancer Relief	23–24	Whilst recognising the difficulties of definition for the terms 'child' and 'young people', we believe it would be helpful for the guidance to specify the age groups which are being described.	We understand the concern but our reasons are further described in amendments to paragraph 19.
Macmillan Cancer Relief	73, 108, 113, 141	We are concerned about the implications for implementation of this guidance of the shortage of specialists which has been identified. This will also be exacerbated by the fact (para 141) that regimes are becoming increasingly complex. This, together with improved survival (para 73) rates, will also put increased pressure on the workforce.	We acknowledge this concern.
Macmillan Cancer Relief	143, 152	It will be essential to ensure that families are adequately trained in administering treatment regimens at home, which should also include training in dealing with any side-effects, or how to deal with non-compliance with treatment by their children. It will, of course, be essential to ensure that domestic and/or family circumstances are appropriate to the delivery of treatment regimes in the child's or young person's home.	We agree and feel that our recommendations cover this.
Macmillan Cancer Relief	153, 162	It is not clear from the document whether consultation has taken place with children and young people to inform the guidance. We believe that this would be beneficial, particularly with respect to identifying methods to improve compliance in young patients, and would be especially productive in the teenaged group.	Details of the consultation exercises will be available in the Evidence Review.

Organisation	Section no. or General	Comments	Developer's response
Macmillan Cancer Relief	210	It would be helpful if the guidance indicated what the minimum time required to start radiotherapy should be.	We cannot make recommendations about specific time limits in this guidance but in Table 2 we have referred to 'nationally agreed waiting times'. We anticipate that these will be available following publication of this guidance
Macmillan Cancer Relief	264–266, 277–278, 287, 288	Training could be given to parents and/or other family members to enable them to assist with pain management, control of nausea and vomiting, and the nutritional aspects of a diagnosis. **NB**: The document refers to 'dieticians'. The spelling preferred by the profession is 'dietitian'	We have mentioned this in paragraph 610 and have inserted a recommendation (paragraph 616) regarding provision of appropriate training. The spelling of dietitian has been corrected
Macmillan Cancer Relief	321–334	There is generally little emphasis on the importance of education/training for families on self-management. Rehabilitation as described here is a very medical model and is mentioned solely as the remit of AHPs. It does not recognise the important contribution of families/parents. Of course this means that family members should be adequately and appropriately supported to care for their children at home.	We do not agree that we have limited the statement in this way. We have also inserted an additional paragraph (616) to reflect the need of families for training.
Macmillan Cancer Relief	342–364	Whilst we welcome the recognition of the importance of psychosocial care for patients, their carers and other family members, we believe that this section could be considerably strengthened. Support to meet the social needs of children and young people is particularly important. The particular needs of the young parent or guardian (i.e. someone of 16-24 years old) of children or young people with cancer should be considered, as they are likely to need additional support compared to that given to families.	We appreciate the specific issues mentioned, but we felt that it was only possible and appropriate to provide broad guidance on psychosocial issues.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Macmillan Cancer Relief	355	Greater recognition should be given to the role of support groups, and in particular for peer support. Evidence from calls to our CancerLine demonstrates that young people want to have contact with their peers who are going through similar experiences. There is a range of ways in which this may be facilitated, for example via websites, telephones and 'pen pal' services. This section also needs to recognise the needs of people from different cultures or whose preferred language is not English, and also those who from disadvantaged groups.	Thank you, but we feel that the wording is appropriate as it is. This is covered in paragraph 617.
Macmillan Cancer Relief	357	There is minimal reference to issues relating to access to benefits. Issues relating to benefits following a cancer diagnosis are complicated, and social workers may not be best placed to understand the complexity (357, 359). We strongly recommend that all families of children diagnosed with cancer should be offered benefits advice by a benefits / welfare rights specialist at the point of diagnosis, as per the NICE Guidance on Supportive & Palliative Care.	This has been covered in the NICE guidance on Supportive and Palliative Care and a paragraph has been inserted to cover this
Macmillan Cancer Relief	368	Sentence should read "Over 1200 survivors of childhood **cancer**…"	This amendment has been made to the text.
Macmillan Cancer Relief	379, 470	With respect to the role of a key worker, we believe that there may be many models for addressing the issues identified and that this recommendation should be kept under review to take account of new models of care which may be developed. This is a role which may be well suited to delivery by voluntary sector organisations.	We agree and hope that this comes across in the guidance.

Organisation	Section no. or General	Comments	Developer's response
Macmillan Cancer Relief	393	The core elements of palliative care (Table 3) should apply at all stages of a person's care following diagnosis. Most of the principles described are fully applicable at earlier stages of a person's care and reflect good practice in delivering cancer services. The concept of the 'total approach' provided by palliative care (para 393) is equally applicable throughout a person's experience of cancer. The total care approach described here should be the guiding principle for care delivered from diagnosis onwards.	We have amended the paragraph to reflect this.
Macmillan Cancer Relief	395	The correct term is the Paediatric Oncology Outreach Nurse Specialist (POONS), and this term or its acronym should be used consistently throughout the document. POONS are well placed to be the key worker from diagnosis onwards throughout the disease trajectory, and to bridge the gap between hospital and home and tertiary and secondary care.	We agree.
Macmillan Cancer Relief	397	Family members can also contribute to the palliative care of children dying at home, but will need training and support to do so.	We agree and this has been strengthened in Table 3.
Macmillan Cancer Relief	404	The document may need to offer guidance on the number of POONS posts required per patient numbers. There are workforce implications for the roles required of the POONS: As treatment regimes become more intensive and the length of palliative care becomes more protracted, pressures of work will increase on POONS over a prolonged period of time. This is a particular problem for lone postholders and could lead to inequality of care. Ideally POONS work closely with paediatric community nurses to support families at home. However provision of these teams is patchy, and commissioners should recognise the importance of establishing such teams as a recognised part of the oncology package.	The Guideline Development Group felt it was more appropriate to specify the level of service rather than attempt to specify any numbers.
Macmillan Cancer Relief	422	We would strongly support the provision of pre-bereavement services for families in addition to bereavement counselling following death.	We agree and feel this is covered in this paragraph.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Macmillan Cancer Relief	448	Table 4 includes the need for a key worker as a member of the MDT. Our experience shows that children and young people welcome having "someone to talk to" who can listen and address their concerns and provide support. This person could be any one of a range of professionals.	We agree, thank you for the comment.
Macmillan Cancer Relief	448	We support the role that education professionals might play in the care of a child or young person with cancer. One of the comments often made by young people with cancer is they want 'life to return to normal... to be treated normally'. An education professional liaison between their school and family could facilitate this need.	We agree, this is the role of the teacher.
Macmillan Cancer Relief	448	Consideration should also be given to how best the care, information and support needs of children with a pre-existing disability or special needs can be met. There are also implications for the care of a child or young person whose parent(s) may have a disability.	We agree and think this is implicit in addressing individual needs of child and young person.
Macmillan Cancer Relief	507–508	We would strongly favour the development of cancer services specifically for teenagers which will deliver age-appropriate care. It is not appropriate for the older age group to be treated in a children's or an adults' ward.	We agree and hope that this guidance addresses this issue.
Macmillan Cancer Relief	510	There are critical issues relating to additional costs incurred by hospital travel and hospital parking given the long distances families have to travel to get to specialist paediatric centres (so accommodation costs may also be incurred). Additional expenditure on childcare for siblings may also be necessary. This will be of particular importance for those people living in rural and/or isolated communities. We recommend that all families should be advised about the Hospital Travel Costs Scheme and other transport concessions and that cancer centres should make financial provision for families' visiting, parking, and overnight stay costs.	We have now included these issues in paragraph 364.

Organisation	Section no. or General	Comments	Developer's response
Macmillan Cancer Relief	513	For health care professionals to be able to communicate effectively with children and young people they need to have a clear awareness of how an illness can affect a young person's developing independence, schooling and education, sense of identity and growing sexuality, peer relationships and family dynamics. They should receive appropriate training in communication skills to help them achieve this. Such training should also include help with communicating with people from minority groups and people with disabilities.	This issue is covered in the section on communication.
Macmillan Cancer Relief	563–576	We believe that the provision of well-supported, appropriate information, delivered at the right time, is an essential part of the care of children and young people with cancer and their families. This section could be improved in relation to the specific needs of children and young people, as opposed to the generic communication skills needed by health professionals.	We agree with the issue and believe this has been covered adequately.
Macmillan Cancer Relief	563	Siblings and grandparents are mentioned in 572, but should be flagged here (as this is the start of the section and the needs of the broader family members are often overlooked).	We feel it is implicit that the broader family members are included in this paragraph.
Macmillan Cancer Relief	564	This paragraph should begin "Information **should** be provided" (rather than "Information *can* be provided"). Templates for information resources should be in a range of formats. More emphasis should be given to the "age appropriate communication style and language" linked to children's very diverse understanding according to age, development and cognitive skills. This guidance reads as if it could be applied to adults, without recognising children's unique requirements and how the use of image, new media etc are more accessible to certain age groups. Children and young people would like publications which they can read to understand about cancer, its treatment and the side effects. This will enable them to make informed choices and to feel in control. Families also have information needs.	This is not a recommendation and therefore the wording is correct. We feel we have referred to the needs of children and young people in the recommendations. We agree and feel that our recommendations cover this.

[Please give dates of consultation]

Organisation	Section no. or General	Comments	Developer's response
Macmillan Cancer Relief	571	Regarding communication with children and young people, youth counselors should be included as key members of the multidisciplinary team (unless this role is covered by clinical psychologists).	This list is not meant to be exhaustive and contains selected examples.
Macmillan Cancer Relief	573	Free helpline telephone services for children and young people with cancer would be helpful.	This was not an issue specifically addressed by the Guideline Development Group.
Macmillan Cancer Relief	583	As we do not do a comprehensive trawl of websites, this citation of the directory as an evidence base is not accurate. We would suggest rewording it as follows: "The evidence from the **Macmillan Cancer Relief** [not Macmillan Cancer Fund, please!] directory of information materials indicates that there are few good quality information materials that have been produced specifically for children. Online and published information materials need to be evaluated carefully."	This amendment has been made to the text.
Macmillan Cancer Relief	584	Second bullet point – reword: "Availability of appropriate information **in a range of formats** for children and young people and their families of all ethnic groups." Third bullet point: the environment for children is designed differently. This should say the environment should be supportive when communicating about cancer, prognosis etc.	This amendment has been made to the text. This bullet point is not a recommendation: it is an area for measurement.
Macmillan Cancer Relief	585	First bullet point – reword: "**Assessment** of patient's and family members' understanding of the information received and whether communication needs are being fulfilled." Surveys are not a very sophisticated tool for measuring communication.	This amendment has been made to the text.
Macmillan Cancer Relief	611–612	It is important that training in communication/information-giving skills is included.	Communication/information skills are included in this list.
Macmillan Cancer Relief	628–632	In addition to professionals working with children and young people having knowledge of child protection issues and undergoing CRB checks, they also need to be very aware of issues regarding confidentiality and parental responsibility.	Confidentiality is a wider issue than just within child protection, but both this and parental responsibility are implicit in 'robust child protection arrangements'.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Macmillan Cancer Relief	633–634	Regarding education for patients, effective collaborative working between health and education is essential. POONS again provide liaison with schools to facilitate reintegration back into school. However the bigger issue again is the patchy provision of services again leading to inequality for individual patients. Parents are burdened with ongoing fighting for resources, statementing etc at an already difficult time. Schools also welcome information, resources and support services available locally which can help them support children with cancer (and their siblings).	We understand the problem, but cannot make recommendations on educational standards and resources. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards
Macmillan Cancer Relief		Little reference is made to benefits advice etc, which is surprising considering that para 357 states that travel for treatment and care is "well accepted", (and again in para 510). May we suggest that more research/audit is carried out in this area. Travelling long distances for treatment may indeed be well accepted (because the necessity is accepted), but the financial cost may be considerable, which in turn adds to the considerable burden the family are already carrying.	A paragraph has been inserted in the section on psychosocial care to cover this issue.
Macmillan Cancer Relief		The document has no reference to spiritual care, and this needs to be included.	Reference to spiritual care has now been included in the section on bereavement and its importance has been stated throughout the document.
Macmillan Cancer Relief		There is a tendency throughout the document to rely on the adult recommendations in respect of palliative care, and research needs to be carried out to discover whether these adult guidelines/recommendations are indeed appropriate for this population.	We recognise this and have tried where possible to address specific needs of children and young adults. We recognise this may be an area for further consideration for the Department of Health and Welsh Assembly Government in future.
Macmillan Cancer Relief	7	Para 7: We suggest that "where appropriate" is deleted from the first sentence, as it appears to diminish the impact of the document by suggesting that commissioners may choose to ignore this guidance. This may not be the intended meaning, and perhaps a rewording would make it clearer.	This amendment has been made to the text.
Macmillan Cancer Relief	78	Para 78 states that administration of chemotherapy has not been well recorded and I feel that stronger leadership re what should be done about this regrettable situation should have come from the NICE guidelines.	We have amended the paragraph.

Organisation	Section no. or General	Comments	Developer's response
Macmillan Cancer Relief	271	Para 271 states that effective pain management will lead to improved compliance with procedures and improved quality of life. We would strongly suggest that this order is reversed, and that the first objective of effective pain management should be to improve quality of life. It should be a secondary point that it will influence compliance.	Thank you for your comment, but we feel the wording is appropriate left as it is.
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	General	Clearly a great deal of work gone in to do justice to a very extensive topic area, particularly given the lack of commissioner input.	Thank you.
National Alliance of Childhood Cancer Parent Organisations	General	Should there be some comments regarding user and carer involvement in implementation, in the same way that the adult cancer guidelines has done/did.	It is not within the remit of the guidance to comment on implementation. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
National Alliance of Childhood Cancer Parent Organisations	General	There are a whole barrel-load of comments about timeliness – shouldn't this be quantified wherever possible and where there is no evidence of what is meant in the comment.	It is not possible for this guidance to set out specific standards on times. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
National Alliance of Childhood Cancer Parent Organisations	General	Because of the comparative rarity of children's cancers, audit data should be collected on a national basis where appropriate and mechanisms set up to ensure this happens.	Some outcome data are already collected on a national basis and we have made a recommendation on this in paragraph 14
National Alliance of Childhood Cancer Parent Organisations	General	The key recommendations vary from the general and open to wide interpretation to some more specific. They probably warrant being more consistent or at least 'sharpening up' – example of para. 6 below.	Some of the key recommendations are of necessity broad, but some amendments have been made.

Organisation	Section no. or General	Comments	Developer's response
National Alliance of Childhood Cancer Parent Organisations	Key recommendations	There are no key recommendations as to the contribution from, and liaison with, the voluntary sector providers. There is no key recommendation regarding parents' contribution, support or role in care.	The key recommendations have to address the issues for commissioners.
National Alliance of Childhood Cancer Parent Organisations	6	Whether the term 'adequate' needs further qualification/quantification as this will mean or be interpreted as something different in different areas.	We have removed 'adequate' from the text.
National Alliance of Childhood Cancer Parent Organisations	Fig. A	The Care Pathway is very complex and not explained and would be largely incomprehensible to the lay reader. The Care pathway composed by the Children's and Adolescent Cancer Partnership is clearer.	We have amended the figure.
National Alliance of Childhood Cancer Parent Organisations	25	Age range warrants further specification	We have not specified a specific upper age limit, the reasons for which are further described in amendments to paragraph 19.
National Alliance of Childhood Cancer Parent Organisations	50	Although overall survival is 75%, there are large variations between solid tumours, especially CNS tumours, and this should be reflected here, and as an emphasis on the contribution of care to improving outcomes in specific childhood cancer groups, and to supporting patients and their families.	The variations in survival are described in detail in the full needs assessment. Paragraph 50 has been amended to read: 'The probability of survival varies with diagnosis. Lower survival is achieved, for example, in certain classes of brain and spinal tumours (43%), chronic myeloid leukaemia (44%) and neuroblastoma (55%), whilst 100% survival is reported for thyroid carcinoma.'
National Alliance of Childhood Cancer Parent Organisations	52	The fact that England and Wales outcomes appears to be approximately 8% lower than some other European countries, in spite of differences in data collection and analysis, should be the subject of more research and clarification. NICE should be assisting in achieving the best, and 8% (or 10% more survivors) is unacceptable without good reason.	We agree. Research is ongoing and the aim of this guidance is to improve the service in England and Wales.

Organisation	Section no. or General	Comments	Developer's response
National Alliance of Childhood Cancer Parent Organisations	56	Late Effects – does this need to say more about transition, which is more than discharge to a GP for onward referral, these are people who warrant specialist input and follow-up in many cases. Given that commissioners do cover all services for all ages they should be expected to do more to assure smooth transition and ongoing care. Families would want to see more clarity and definition of commitments here or at an appropriate place in the Guideline and in Key recommendations.	We agree and this is covered in paragraphs 505 and 517.
National Alliance of Childhood Cancer Parent Organisations	61 and 62	What is the significance of and differences between, these two points? It is not clear and therefore, although a critical area of need for patients, may be missed by Commissioners.	Thank you. This paragraph has been redrafted to ensure the two points are different.
National Alliance of Childhood Cancer Parent Organisations	67	We welcome the recognition of the current disparity of specialised services for children and the desire of this Guideline, through Key Recommendations, to produce more uniformity, without loss of specialist quality of care.	Thank you.
National Alliance of Childhood Cancer Parent Organisations	68	Access to all of these services, whether provided by the NHS or by the voluntary sector, should not be limited in a modern developed society. What other essential services for children with cancer are limited. These should be clearly identified, so that Commissioners can focus on their improvement	This paragraph summarises the results of a survey performed for this guidance.
National Alliance of Childhood Cancer Parent Organisations	69	What other specialist services are referred out of the region and how variable is this across regions? As for 68 above, this should be clearly described and should form the basis of clear target standards to be achieved.	Further details are available in the full report included in the Evidence Review.
National Alliance of Childhood Cancer Parent Organisations	70	Psychology and psychiatry tend to be towards the 'heavy therapy' end of psychosocial support;. Consideration should be given to professional counselling support and support/supervision for befriending networks for patients and families.	This paragraph summarises the findings of a survey.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
National Alliance of Childhood Cancer Parent Organisations	71	The support provided for the patients and their families in the home palliative and terminal care setting is recognised as very variable. Remedial actions and targets should also be clearly defined. Maybe, with appropriate funding, more could be made of the highly specialised support services offered by the children's hospice setting. These paragraphs could acknowledge more about the role of parents and non-NHS carers, including the role of the voluntary/charitable sector, social care and education, particularly in terms of psycho-social care and support.	This paragraph summarises the findings of a survey. Palliative care is covered in more detail later in the guidance.
National Alliance of Childhood Cancer Parent Organisations	72	How many of the Centres have been excluded from the analysis on the grounds of less than 2,500 episodes of care per annum? Does this make any difference in the analysis of needs and services?	All centres were included in the analysis. However, Trusts with less than 2,500 episodes were excluded from the results tables for reasons of space.
National Alliance of Childhood Cancer Parent Organisations	Fig. E	The activity is notably lower in the 10-14 age group.	Thank you.
National Alliance of Childhood Cancer Parent Organisations	Fig. F	The day case activity is notably higher in the groups covering 0-9, which should be reflected in recommendations for service provision and support for families, e.g. there are often other children in the family who have needs and put additional pressure on families.	This is descriptive figure and is for background information.
National Alliance of Childhood Cancer Parent Organisations	79	We welcome the recognition of the need to get better quality of data to assist the analysis of need and standards across the country.	Thank you.
National Alliance of Childhood Cancer Parent Organisations	82 and 83	We welcome the acknowledgement of the importance of AHPs. However, the importance and contribution of the voluntary sector and parents themselves (and thus their need for appropriate support) is under recognised and is not translated into clear recommendations and deliverables.	We understand and have acknowledged the importance of the voluntary sector and parental contribution, but making recommendations on this is outside our remit. Some voluntary sector economic issues are considered in the Economic Analysis, which is included in the Evidence Review.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
National Alliance of Childhood Cancer Parent Organisations	88–96	Whether these sections are appropriate for this Guideline, as opposed to that for Referal for Suspected Cancer, and a general cross-reference statement and Key recommendation is more appropriate, merits consideration. It is important to have an all-encompassing set of recommendations and deliverables across this whole area, especially to reduce delay for CNS tumours. Alternatively, these sections need to be cross-referenced and lined up with the Referral Guidelines for Suspected Cancer in Adults and Children. The current wording of these sections is not entirely coincident.	We have given this issue due consideration. The NICE GP Referral Guidelines for Suspected Cancer are clinical guidelines and for the present guidance we have highlighted the service issues.
National Alliance of Childhood Cancer Parent Organisations	88	It will be particularly disturbing for parents to read that deaths occur before diagnosis or at diagnosis that could be avoided; yet no data is provided to back this up, or as to the extent of this.	We agree, but this is taken from the Evidence Review in the NICE GP Referral Guidelines for Suspected Cancer.
National Alliance of Childhood Cancer Parent Organisations	102	We welcome the proposal to have clear Guidelines for internal referral from secondary paediatric services (including ENT and orthopaedics) to prevent the delays that occur between symptoms and diagnosis.	Thank you.
National Alliance of Childhood Cancer Parent Organisations	112	We welcome the recognition that paediatric specialist pathology services are crucial to the outcomes for our children and that there is a critical resource problem that needs to be resolved urgently	Thank you.
National Alliance of Childhood Cancer Parent Organisations	114	Where does the 'specialised input for the preparation and assessment of specimens' come form? Is this addressed in recommendations?	Thank you. We have added appropriate wording to paragraph 118.
National Alliance of Childhood Cancer Parent Organisations	121	What is the coverage and availability of this across the country? Should there be a recommendation about provision of these modern techniques now and increasingly for the future?	The recommendation covers this point.
National Alliance of Childhood Cancer Parent Organisations	127	We welcome the recommendation for a clear pathway for reaching diagnosis accurately and swiftly.	Thank you.

Organisation	Section no. or General	Comments	Developer's response
National Alliance of Childhood Cancer Parent Organisations	141	We welcome the recognition that delivery of chemotherapy to children is complex and more prone to error than in adults. Recommendations for minimising this, and standardising practices across the country need to be clearly defined in this Guideline and resources identified to deliver them.	The section on chemotherapy makes several recommendations on the safe delivery of chemotherapy.
National Alliance of Childhood Cancer Parent Organisations	153	This recommendation will need some explanation to patients and/or their parents. Delivery will need to take into account the wide range of understanding and emotion in parents of children diagnosed with cancer to make this realistic.	We will suggest that this recommendation is expanded and explained in the patient version of the guidance.
National Alliance of Childhood Cancer Parent Organisations	Omission ?	Should there be a recommendation about making available and for consistent use etc. of drugs not licensed for use in children, that will cover safe and effective practices until drugs licensed for children become more routinely available?	Our recommendation that care should be given within the context of protocols should go some way to address these issues.
National Alliance of Childhood Cancer Parent Organisations	166	Is it envisioned that there should be central reporting of incidents, in order to obtain a more robust data set for something that is infrequent, so that practice improvements can be identified earlier if necessary?	We are making no specific recommendations on central reporting of such incidents. This is just a suggested topic for local or regional audit.
National Alliance of Childhood Cancer Parent Organisations	192	What is the definition of 'younger' in this recommendation?	We have removed the word 'younger'.
National Alliance of Childhood Cancer Parent Organisations	194	Education for whom?	This paragraph has been removed.
National Alliance of Childhood Cancer Parent Organisations	197	Long term assessment of health and psycho-social status should also include an assessment of any additional support needs for the patient and their family.	Additional support needs for the patient and their family are included in long-term assessments.
National Alliance of Childhood Cancer Parent Organisations	210	We welcome the recognition that delays occur in the provision of radiotherapy treatments to children with cancer, and the attempt to address this problem.	Thank you.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
National Alliance of Childhood Cancer Parent Organisations	219	We welcome the recommendation to gather data on effects of delays and on patient/parent satisfaction, as supporting the patient, while coping with family life, is a big strain on parents.	Thank you.
National Alliance of Childhood Cancer Parent Organisations	222	Parents will be concerned that there is an avoidable cause of mortality and morbidity.	We understand this, but we hope the recommendations in the guidance will significantly reduce the risks.
National Alliance of Childhood Cancer Parent Organisations	224	Will this be monitored nationally, or just at local Centres?	We would foresee this being monitored locally.
National Alliance of Childhood Cancer Parent Organisations	230	What is meant by 'community based therapy below risk episodes'?	There is a typo here; it should read 'community based therapy for low risk episodes'.
National Alliance of Childhood Cancer Parent Organisations	240	If removal of CVCs is potentially hazardous, there should be similar recommendations as to who does it and their training level (see 250).	We have amended paragraph 259; please also see paragraph 251 where this issue is addressed.
National Alliance of Childhood Cancer Parent Organisations	277	Diarrhoea is also very distressing for patients and their families. Should anything be included in this section and potentially in Nutrition (287 onwards)?	We have amended the paragraph to include diarrhoea.
National Alliance of Childhood Cancer Parent Organisations	306, 312	We welcome the recognition that dental treatment is a financial burden that limits its availability to patients, and therefore leads to avoidable problems. There needs to be financial provision that recognises the problem for these patients in an environment where there are fewer and NHS dentists available.	Thank you. As you say, we have identified the problem but we cannot make specific financial recommendations.
National Alliance of Childhood Cancer Parent Organisations	321 – 325	Should there be more reference to the problems that exist around wheelchairs and limb prosthetics?	There will be specific guidance on limb prosthetics in the Sarcoma service guidance

Organisation	Section no. or General	Comments	Developer's response
National Alliance of Childhood Cancer Parent Organisations	334	The responses should be co-ordinated appropriately to deliver maximum benefit to patients and their families.	We agree.
National Alliance of Childhood Cancer Parent Organisations	339, 364	There is an emphasis on psychology provision, which is often seen as 'treatment', as though patients/parents have something wrong with them. Some consideration should be given to provision of appropriate professional counselling support, especially around certain parts of the pathway, such as bereavement, that is less 'treatment' and more supportive focused. The need for co-ordination of support needs to be clearly stated.	These amendments have been made to the text.
National Alliance of Childhood Cancer Parent Organisations	355	We welcome the recognition of the value of peer support. Commissioners should consider what resources, both human and financial, could be provided to facilitate this.	We agree: this is an issue for Commissioners at implementation.
National Alliance of Childhood Cancer Parent Organisations	372, 373, 389	We welcome the recognition of the great need for dealing with long term sequelae, and in particular the need for effective co-ordination of medical care and support across disciplines and across facilities, that are appropriate to the age of the patient and the condition being managed. We see this as an essential Deliverable from this Guideline. The Recommendations address these, but will need to be implemented and audited to make them meaningful to patients and families.	Thank you. We agree.
National Alliance of Childhood Cancer Parent Organisations	381	We welcome the recognition that fertility counselling should be considered at diagnosis, as there is currently unacceptably widespread gaps in this service.	Thank you.
National Alliance of Childhood Cancer Parent Organisations	396	GP's should have a named contact to provide 24hr palliative care guidance, as it is they who often have to deal with crisis outside hours when parents need help immediately.	We agree, but this level of detail is not possible in service guidance

Organisation	**Section no. or General**	**Comments**	**Developer's response**
National Alliance of Childhood Cancer Parent Organisations	397	The recognition of making specialist equipment available and in a timely manner should be emphasised. Parents do not need to have to fight for it at a time when every moment with their child is precious and needs to be stress free.	We agree: this is highlighted in paragraph 397 but has been further strengthened in Table 3.
National Alliance of Childhood Cancer Parent Organisations	400	Professional counsellors also have a role.	We have amended this paragraph to make it less prescriptive.
National Alliance of Childhood Cancer Parent Organisations	411	Appropriate support needs to be provided for these key workers and their associates, who work in emotionally draining situations.	Support for all staff is addressed elsewhere in this guidance.
National Alliance of Childhood Cancer Parent Organisations	419, 430	Consideration should be given to providing respite care for families caring for dying children at home, to provide parents with some relief if they want or need it.	This amendment has been made to the paragraph 446.
National Alliance of Childhood Cancer Parent Organisations	422	Bereavement support should not be provided by staff who are not experienced in bereavement counselling. They can do more harm than good.	We agree.
National Alliance of Childhood Cancer Parent Organisations	424	What is the bereavement suite?	'Bereavement suite' is a generic term for the facilities in which a body can be viewed.
National Alliance of Childhood Cancer Parent Organisations	424	Should include those families about to experience the death of their child.	We disagree. Paragraph 424 refers specifically to needs after death.
National Alliance of Childhood Cancer Parent Organisations	426	Should include young adult hospices.	This amendment has been made to the text.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
National Alliance of Childhood Cancer Parent Organisations	428	What is the definition of appropriate period for bereavement support, and who decides?	These are clinical decisions decided by the relevant health care professionals at the time.
National Alliance of Childhood Cancer Parent Organisations	Omission	Consideration should be given to support needs of siblings.	The text has been amended.
National Alliance of Childhood Cancer Parent Organisations	436	What provision of bereavement care outside the main UKCCSG Centres e.g. shared care centres?	This is an evidence section, which quotes the evidence that was available.
National Alliance of Childhood Cancer Parent Organisations	444	Consideration needs to be given to the level of commissioning that should be appropriate for specific services, or even services overall. There should be more definition and recognition of the key contribution made by the voluntary sector and for integrating this contribution into the overall cancer journey for families and patients.	A recommendation about the need to address commissioning arrangements has been made. We recognise the contribution the voluntary sector makes to cancer care; this has been described in the text and further detail is given in the Economic Analysis that accompanies this guidance.
National Alliance of Childhood Cancer Parent Organisations	Table 4	No mention of role of parent/carer, anaesthetist, paediatric pathologist, voluntary sector or other agencies who may reasonably be involved. There is no mention of the GP in the palliative care setting. What about a MDT structures for late-effects, palliative care and psychosocial needs?	Table 4 lists core members of the relevant MDTs. We would expect additional expertise to be accessed as necessary.
National Alliance of Childhood Cancer Parent Organisations	461	Is the Danish experience comparable and if so, what are the underlying reasons/facilities/services behind their success? Are they incorporated in the recommendations of this Guideline?	Yes, the Danish experience was comparable and the findings were taken into consideration in framing the recommendations.
National Alliance of Childhood Cancer Parent Organisations	552, 554	How will this work in practice? What are their deliverables and performance targets?	The detailed arrangements will vary across the country and we cannot specify performance targets.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
National Alliance of Childhood Cancer Parent Organisations	565	Breaking bad news requires special attention in training.	We agree, but this level of detail cannot be specified in service guidance.
National Alliance of Childhood Cancer Parent Organisations	572	The support needs of siblings also need addressing.	This is dealt with in paragraphs 372 and 375.
National Alliance of Childhood Cancer Parent Organisations	602	The issue of 'do children do better I trials' needs to be addressed with better data, that takes into account the type of cancer, as well as the availability of trials and what type of trial. It is very worrying that having to enrol your child into a trial to get the best care is an essential option.	We understand the problem, but paragraph 602 is a summary of the evidence.
National Alliance of Childhood Cancer Parent Organisations	631	Parents should also be made aware of how to make a complaint. Should something be said about communicating the guidelines to patients, parents/families?	This amendment has been made to the text. Awareness of the guidelines is implicit in paragraph 631.
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.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
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			This organisation was approached to comment but did not respond.
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.
NCC for Cancer			This organisation was approached to comment but did not respond.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	67	The reference to transplant centres that take referrals from other centres is slightly misleading as the list is incomplete. Transplant centres offering a referral service should be JACIE accredited	We have changed to 'JACIE accredited centres'.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	70	Pharmacy support also needs to increase in a number of UKCCSG centres and also in shared care centres where the degree of pharmacist input and expertise is highly variable – it needs to be appropriate to the level of care being delivered in the centre.	This paragraph summarises the findings of a survey.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	82	Specialist clinical pharmacists need to be added to this section	These are not AHPs.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	142	Issues are not just of poor palatability and tablet strengths. Suitable oral liquids may not be available at all to enable us to give accurate doses to young children eg lomustine, hydroxycarbamide, temozolamide, cis retinoic acid. We would also add: • fluid volume • management of central lines • wide ranges of doses used eg methotrexate • complexity of treatment protocols as reasons why there are particular risks of error in giving chemotherapy to children	We have now included fluid volume, wide ranges of dose used and complexity of treatment protocols in paragraph 142.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	146	There seems to be a shift towards the out-sourcing of parenteral chemotherapy as the requirements of the MCA make it increasingly difficult and costly for Trusts to maintain services on-site. If this para. is to stand it must be recognised that there is a shift in the opposite direction, specifically with respect to the preparation of chemotherapy, and the implications of this need to be addressed. If this document is to set a standard which effectively requires on-site preparation then this needs to be taken up with the MCA and other regulatory bodies. Alternatively, if the standard is to ensure timely and efficient provision of chemotherapy then there needs to be an acknowledgement that this can be achieved without the availability of on-site facilities - although it is not without it's problems!	We have made a small amendment to the text, but feel that the details of where and how the service is provided are outside the remit of this guidance.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	148	With reference to the prescribing of chemotherapy, in line with current government policy, there is a legal framework for supplementary prescribing by other healthcare professionals. The prescribing of chemotherapy could be done by pharmacist supplementary prescribers, some of whom already exist. The current wording in this paragraph appears prohibitive for this.	We have amended the paragraph accordingly.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	148	The pharmacist's pivotal role in clinical checking of chemotherapy prescriptions reduces errors and the prevention of toxicity and side effects.	We agree and have amended paragraph 152.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	150	The addition of 'safe' to both prescribing and administration would cover hazards associated with chemotherapy for staff, carers and patient's	We have amended the text to include 'safe'.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	151	This paragraph does not accurately reflect current or future practice within aseptic units. Chemotherapy is prepared in facilities meeting national standards under the supervision of Pharmacists trained and accredited for this work. As a further comment, trained staffs other than Pharmacists undertake the majority of aseptic manipulations.	We do not understand the comment and feel that the paragraph is appropriate.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	155	At this point some benefit might be derived for children by stating that having preparation facilities meeting national standards with proper capacity plans would also avoid unnecessary delay and maximise treatment compliance. Also in those units where there is a preponderance of Chemotherapy preparation for adults there is a genuine risk that the needs of the child might be subordinated to those of the adult service.	We have amended paragraph 156 to include 'preparation facilities'.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	157	Improve quality of life for patients/carers	This amendment has been made to the text.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	158	Reduction in risks can also be achieved by; - having appropriate checks at all stages of prescribing, preparation and administration - maintaining up to date (accessible) medication records	We agree.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	160	Whilst there is evidence that ETP may reduce prescribing errors, there is much good evidence to show that Pharmacist involvement in the prescribing process reduces risk to patients. As an example in one hospital of 1100 patients which regularly undertakes a weekly audit of interventions using the Hind * Hatoum scoring system data shows; • 2000 monitoring events • 600 interventions • approx 2.5 per patient • *150+ at a level of 4, 5 or 6 which would have triggered a critical incident report at the 'major harm level'. (150 at the 4 or 5 level -representing loss of major organ system and 1 to 2 fatalities prevented) • Ref: Hatoum HT, Hutchinson RA, Witte KW, Newby GP. 1988 Evaluation of the contribution of clinical pharmacists: inpatient care and cost reduction. Drug Intell. Clin Pharm; 22:252-9). As a further example the Lenerd error auditing project across south east region showed pharmacists errors reported using NPSA grading criteria - this showed;1% catastrophic11% majorand10% of total almost certain to reoccur.	Thank you for this information. It is in the Evidence Review that accompanies the guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	163	We suggest this paragraph is removed. It adds nothing as it stands and we find it hard to envisage how ETP itself can have any direct impact on patient compliance	This is part of the evidence assessment that will be included in the Evidence Review that accompanies this guidance.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	164	Methods for monitoring compliance are "limited". There is scope for further work in this area as it affects outcome. Pharmacists have an important role in counselling patients on their medication to promote compliance and concordance and liaising with other healthcare team members as necessary.	Thank you for confirming what our evidence review has suggested. In due course it will be interesting to see better evidence resulting from further work.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	165	At present there appears to be a climate where many Shared Care Units (POSCUs) have no easy access to current protocols. This has been highlighted in the recent Peer Review of several POSCU's in SE region.	Thank you for this information. We hope that our Guidance will improve this situation.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	225	National guidance would have to be non-drug specific – organism prevalence and patterns of resistance are variable in different locations. The management of febrile neutropenia is an important issue, but there are other clinical areas that would also benefit from national guidance eg anti-fungal therapy	We agree and feel that these issues would be implicit in the development of national guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	245	An agreed policy for the standardisation of the care of central venous access would also reduce infection rates.	We have added 'infection rates' to the text.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	252	The incidence of infection after the insertion of a CVC should be audited within each clinical network.	The text has been amended.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	287	It is inexplicable why Parenteral Nutrition has not been mentioned here, the enteral route is not the only route by which nutrition is delivered in paediatric oncology. For example children with mucositis post chemotherapy and frequently post BMT will have periods of TPN feeding, supplied and supported by the pharmacy department.	We have amended paragraphs 303 and 304.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	288	There is also a shortage of trained pharmacists (see para 610). Dieticians are not always involved in nutritional decisions involving Parenteral Nutrition.	Following comments from another stakeholder we have re-drafted this paragraph.

Organisation	Section no. or General	Comments	Developer's response
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	288	Addenda; The achievement of optimal Parenteral nutrition is a multidisciplinary task involving clinician, dietician, and pharmacist with experience in this area. This should be included here or with an additional paragraph. As examples; - TPN patient (3 months) with limited IV access, multiple IV antibiotics, IV chemotherapy, no oral route available, sub-optimal nutrition, discontinuity of Registrars. Required careful manipulation of PN formulation and administration balanced against other IV needs. Eventually received full nutrition, slow transfer to oral feeding, discharge home, and continuation of treatment through to transplant. This involved clinicians, dietician, and a pharmacist. - 12month old patient with single lumen on TPN requiring IV chemotherapy with hydration incompatible with TPN. Detailed discussion required between Registrar and Pharmacist to ensure safe administration of chemotherapy and maintenance of TPN	We agree that this is a multidisciplinary task. Like all aspects of care, we think it should be overseen by an MDT, hence our emphasis on such teams (see the MDT section of the guidance). We did not feel that more detailed guidance was within the remit of this document.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	292	This paragraph does not go far enough in how adherence to guidelines can be achieved. (e.g.; BAPEN) With respect to ensuring that Parenteral Nutrition meets national guidelines the availability of a Paediatric Parenteral Nutrition team and the active daily involvement of clinician, pharmacist and dietician trained and experienced in this area is essential.	We cannot advise on the much broader and difficult issue of compliance with national guidelines. This will be covered in the implementation of this guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	395	Interpreting and predicting drug effects in a palliative patient requires access (by the key worker') to support and advice from a pharmacist experienced in paediatric palliative care	We have included specialist pharmacists in the palliative care MDT.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	400 (see also 448)	Clinical pharmacists need to be included in this section. Pharmacists have a pivotal role in the provision of: • advice on symptom management, drug choice, dose, administration, alternatives routes and dosage forms • use of unlicensed medicines • provision of controlled drugs • co-ordination with outreach teams, hospital and community pharmacists to ensure timely drug provision Information and support with syringe driver drug delivery, compatibility, mixing and choice.	We have amended the MDT section to cover this.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	408	The inclusion of training for pharmacists wishing to develop expertise in this area should also be made available. They are often consulted over drug decisions where limited evidence is available but active decisions over possible drug/dose/route choices need to be made.	We have amended this paragraph to include all relevant clinical staff.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	448, Table 4	Clinical pharmacists need to be included in this section. Pharmacists have a pivotal role in the provision of: • advice on symptom management, drug choice, dose, administration, alternatives routes and dosage forms • use of unlicensed medicines • provision of controlled drugs • co-ordination with outreach teams, hospital and community pharmacists to ensure timely drug provision • Information and support with syringe driver drug delivery, compatibility, mixing and choice.	This amendment has been made to the text.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	416	Do the guidelines referred to in the first sentence relate to the model of care/care pathway in general or to medicines in particular? If it is for medicines, then this should be stated. Whilst medicines guidance in this context does have a low evidence base in children, they are, in the majority, based upon experience and the doses checked as a minimum.	We have clarified which guidelines we are referring to.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	519	Table 7 requires the addition of 'an identified pharmacist lead at the non principal treatment site'. The provision of chemotherapy from the POSCU, some of whom do not have cytotoxic reconstitution services 'on site', is sometimes delayed because of lack of timely communication from the POC. The identification of a lead pharmacist would aid communication between POC and POSCU and facilitate a better quality service.	This amendment has been made to the text.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	527, Table 8	In a principal centre the designated Pharmacist should be detailed as – 'Designated Paediatric Oncology' pharmacist. This is to ensure that they have training and/or experience in this area.	This amendment has been made to the text.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	527, Table 8	Immediate access should be available to – 'Paediatric Nutrition team'	We would expect the dietitian to interface with the paediatric nutrition team.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	527, Table 9	In a principal centre the designated Pharmacist should be detailed as – 'Designated Paediatric Oncology' pharmacist. This is to ensure that they have training and/or experience in this area.	We agree and have amended the text appropriately.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	527 Table 9	Immediate access should be available to – 'Paediatric Nutrition team'	We would expect the dietitian to interface with the paediatric nutrition team.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	551	Points 3,4,5 Should this read; 'to avoid any necessary delays to……….'	No, this is inappropriate for a measurement section.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	596	There must also be adequate resources provided for pharmacy compliance with the EU directive	This guidance cannot make recommendations regarding the resources to implement EU directives.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	610	There are particular issues around recruitment and retention of specialist hospital pharmacists (eg in oncology and paediatrics) too. Big salary differences between the hospital service compared to community and industry pharmacists are a major contributing factor to the national shortage of hospital pharmacists generally. This, and other capacity planning issues were highlighted in the recent (October 2004) briefing paper to 'National Chemotherapy Advisory Group' by BOPA (British Oncology Pharmacists Association) – copy attached	We have included specialist hospital pharmacists, but cannot comment on the issue of salaries.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	General	The general thrust of the document, if followed, will move forward the provision of Children's Cancer Services.	Thank you.

Organisation	Section no. or General	Comments	Developer's response
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	General	Whilst the technical role of the oncology pharmacist was well recognised e.g. in the sections relating to chemotherapy, the key clinical role of the specialist paediatric oncology pharmacist in medicines management and clinical governance is rather understated	Whilst we have emphasised the key role of the specialist pharmacist in relation to this guidance, their wider role in medicines management and clinical governance, although important, is beyond the scope of this guidance.
Neonatal and Paediatric Pharmacists Group (NPPG) and British Oncology Pharmacy Association (BOPA)	General	There are however some omissions which might improve the document. As an example; **Nutrition** fails to mention the use of Parenteral Nutrition as part of overall Nutritional support. It mentions no other professionals in this context. National Bodies (e.g.; BAPEN – British Enteral and Parenteral Nutrition Group) recognise that having specialist Nutrition teams composed of several professions enhances the nutritional care of parenterally fed patients.	Space precludes us detailing all methods of nutritional support; however, we have amended the section on nutrition
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.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Ortho Biotech			This organisation was approached to comment but did not respond.
Patient Involvement Unit for NICE			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 Trust			This organisation was approached to comment but did not respond.
Richmond & Twickenham Primary Care Trusts			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	General	This guidance is welcomed by the RCGP Wales as a document which identifies the importance of early referral from Primary Care in improving outcome in children and young people with cancer and identifies the role of Primary Care in the pathway of care.	Thank you.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of General Practitioners Wales	6	As many areas of Wales are rural, we would support the principle that underpins the guidance is that of age appropriate, safe and effective care *as locally as possible.*	Thank you.
Royal College of General Practitioners Wales	20	Again in view of the rurality of Wales, we would agree that there needs to be a sustainable balance between centralisation and decentralisation.	Thank you. We agree.
Royal College of General Practitioners Wales	57	In view of the fact that the risk of second malignancy, which can occur many years after the primary diagnosis, is estimated to be between four to six times the risk in the general population, the general practitioner has an important role in maintaining cancer databases, using appropriate computer codes and operate possibly operate recall systems for follow up. This is particularly important if the patient moves from one practice area to another. The general practitioner needs to be aware of the increased risk of a second malignancy and have a low threshold for investigation and referral. This information should be included in the educational process in creating a local common care pathway.	We agree and hope that further education will be possible through written communication between professionals and patient-held records.
Royal College of General Practitioners Wales	90	We would agree that persistent parental anxiety should be sufficient reason for investigation and/or referral – but also recognise that parental anxiety is common and that inappropriate investigation would not be in the child's best interest.	Thank you. This is a quote from the GP referral guidelines for suspected cancer.
Royal College of General Practitioners Wales	92	We would agree that specific education for professionals in primary and secondary care in the recognition and referral of suspected CNS malignancy and other solid tumours in children and young people should be established and ideally the educational process should be shared at a local level, thus aiding the communication issues involved.	We feel that it is implicit in paragraph 92 that education will be cascaded locally.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of General Practitioners Wales	96	There are already established pathways for urgent referrals from Primary to Secondary Care. Many trusts use "Safe Haven" fax numbers for urgent cancer referrals. It would be appropriate that the same system be used for children and young people cancer as introducing an alternative method of referral such as telephoning the consultant may be unnecessary and confusing. This is not to suggest that telephoning a consultant in addition may not be appropriate.	Thank you. We have deleted paragraph 96.
Royal College of General Practitioners Wales	102	We would agree that clearly documented and well publicised local guidelines and protocols for initial referral should be established. Ideally, members of both Primary and Secondary care should be involved in the production of these local guidelines.	Thank you.
Royal College of General Practitioners Wales	224	The protocol for the management of febrile neutropenia should include presentation and diagnosis in the primary care setting and a written protocol kept in all surgeries and out of hours on call centres.	Because of the nature of the condition, the appropriate protocol should instruct patients to go directly to principal treatment centre or shared care centre.
Royal College of General Practitioners Wales	371	We recognise that the general practitioner has an important co-ordinating role, especially when a number of consultant and other health care professionals are involved.	We agree.
Royal College of General Practitioners Wales	373	It is important to recognise the role of the general practitioner in providing longitudinal care and also as a record keeping of information over time.	Thank you. We have recognised this.
Royal College of General Practitioners Wales	395	Many general practitioners undertake palliative care and some will have developed a special interest, gaining skills and knowledge through the Diploma in Palliative Care and Diploma in Palliative Care for Children. Many of the principles of palliative care are underpinned by the core values and generalist skills of a general practitioner. We feel that the general practitioner, working as part of a multidisciplinary team, has an active role to play in palliative care of our patients and their families.	The text has been amended to include the role of the general practitioner.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of General Practitioners Wales	447	It may be appropriate to include the general practitioner in the MDT	Thank you for your comment, but although GPs are obviously essential for one-off meetings about individual patients, we do not feel that they need to be a core member of the MDT.
Royal College of General Practitioners Wales	553	Cancer Care Networks should include Primary Care representation.	We agree, but specifying representation is outside of the remit of this guidance.
Royal College of General Practitioners Wales	614	As well as addressing the training and educational needs of the staff, their emotional and support needs should also be addressed.	This topic is addressed in the section on psychosocial care.
Royal College of General Practitioners Wales	622	There is a need to co-ordinate the coding used in Primary and Secondary care to facilitate research across the pathway.	We agree, but this is outside the scope of the guidance.
Royal College of Nursing (RCN)	General	This is a welcomed and timely document which is concise and well written hopefully it will be helpful to commissioners of children's and young people's cancer services at all levels.	Thank you.
Royal College of Nursing (RCN)	General	It was felt that it should be explicit that the document covers only England and Wales.	This is stated in paragraph 5.
Royal College of Nursing (RCN)	General	Frequent mention of education / training provision was mentioned but again no guidance as to who would provide it and how it would be paid for.	It is not possible to comment on who undertakes training within this guidance. The funding of training will be addressed in the implementation of this service guidance.
Royal College of Nursing (RCN)	General	Reference to The Children's NSF would add weight to some of the recommendations particularly in relation to environment.	This document is referenced.
Royal College of Nursing (RCN)	General	The use of ambiguous words such as timely, rapidly, adequate, properly trained, detracts from the concise nature of care needed for this group of patients and will be difficult to measure.	We recognise the ambiguity in these terms, but it is not the role of this document to set cancer standards or standards for professional training. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Nursing (RCN)	General	Throughout the document we hear about properly trained, adequate numbers of staff we do recognise that different units have different needs and hence staffing levels are difficult to state but we do think we can be clear about what we mean by "properly trained" in relation to nursing (and other fields). Can we not be specific about general and specialist education, national competencies and required CPD?	It is not the role of this document to define standards for professional training. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
Royal College of Nursing (RCN)	General	We look forward to the resource document as we feel this will enable many of our questions in this area to be answered.	Thank you.
Royal College of Nursing (RCN)	6	Who decides and measures what is age appropriate, safe and effective?	Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
Royal College of Nursing (RCN)	7	Clinical standards for lead nurses should also be established in shared care arrangements.	It is not within our remit to set standards. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
Royal College of Nursing (RCN)	7	Excellent to see recognition of the need for network leads for children, teenagers and young adults with cancer, maybe it comes later but there would seem to be a missed opportunity to really stress the role a nurse can play if placed in this position: in relation to organisation of care and care delivery.	Thank you. We feel the core role of the nurse is a key theme throughout this guidance.
Royal College of Nursing (RCN)	11	Anaesthetic time for radiotherapy, and painful procedures	This amendment has been mad e to the text.
Royal College of Nursing (RCN)	78	A solution to the problem of inadequate coding would be welcomed by the GDG.	We agree.
Royal College of Nursing (RCN)	90	It should also be noted that adolescents rarely attend primary care and if they do their problems should be taken seriously by health care professionals (HCP).	Thank you. This is a quote from the GP referral guidelines for suspected cancer.
Royal College of Nursing (RCN)	116	It was felt that this paragraph should include…competency of staff to deal with children and young people, access to general anaesthetics and child and young people friendly environment.	We agree, and these points are covered in the treatment section of the guidance.
Royal College of Nursing (RCN)	127	We welcome a pathway for suspicious lumps and inclusive scans but feel this would be more helpful if this was national rather than local.	We feel this pathway should be within a Cancer Network.
Royal College of Nursing (RCN)	130	We were surprised the shortage of radiologists was not mentioned in this section.	Thank you. We have added radiologists to paragraph after 103.

Organisation	Section no. or General	Comments	Developer's response
Royal College of Nursing (RCN)	140	The increased use of chemotherapy has lead to an increased complexity in the level of care needed by children and young people with cancer this has subsequently had an impact on capacity and a need to re-evaluate the competency of all staff groups caring for these patients especially in nursing.	We agree.
Royal College of Nursing (RCN)	144	Dedicated computerised chemotherapy prescribing is mentioned, there is no evidence to support its use in clinical practice but we would have thought that consensus on clinical practice would be supportive of the initiative that clearly requires finance to support implementation and evaluation…good to see it recommended but how far this can be put in place through cost is a concern.	We agree, and have now made a specific recommendation that there should be national strategies to address this issue.
Royal College of Nursing (RCN)	145	Suggested levels of competence would be welcomed.	This is outside the scope of this guidance.
Royal College of Nursing (RCN)	161	A recommendation of further research into this area, related to skills, experience and evaluation of education and training of parents and non-specialist paediatric oncology nurses would be extremely helpful.	We agree that further research is necessary because of the lack of evidence, but we cannot make a recommendation on this.
Royal College of Nursing (RCN)	192	How young is younger? Specify	We have removed the word 'younger'.
Royal College of Nursing (RCN)	Table 2	Support of a play specialist, it would be helpful if this statement were stronger access and active involvement not just support which is a fairly weak statement.	We feel that the use of the word 'support' is appropriate.
Royal College of Nursing (RCN)	Table 2	We would welcome if these staff have APLS or EPLS skills	We think that the MDT is appropriately constituted; if local MDTs wish to include additional members this is appropriate.
Royal College of Nursing (RCN)	221	Fatigue is mentioned here, which is great to see it acknowledged but there is evidence available to suggest it has a detrimental effect on children and young people and may influence quality of life, a greater presence in the guidelines would be worthwhile, raise the profile that needs to feature in communication with children and young people and their parents from diagnosis	We agree that fatigue is an important issue in these patients, but in view of the lack of good evidence of therapeutic interventions, apart from good clinical care, we do not feel that additional service recommendations can be made.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Nursing (RCN)	244	Great to see mention of parent/child choice about CVAD. We wonder also whether we can emphasise the role of parents and patients in self-management of lines and taking an active role education and support required for this. This is common place in some centres but not all, some national guidelines would help.	We have added a new paragraph 616 to cover this issue.
Royal College of Nursing (RCN)	257	SCHOT guidance could be mentioned here	The SCHOT report is what is meant by national surveillance report and is referenced in the Appendices of the Evidence Review that accompanies this guidance.
Royal College of Nursing (RCN)	279	National guidance on the management of nausea and vomiting would be welcomed.	We agree, but it is not within the remit of this guidance to provide clinical guidelines on the management of nausea and vomiting.
Royal College of Nursing (RCN)	292	Resources to support nutrition at home and in shared care i.e. enteral feeding, community dieticians etc would be welcomed.	Whilst we acknowledge the importance of support nutrition at home and in shared care, resources will be required to implement the whole of this guidance. Specifying where these resources should be provided is outside our remit.
Royal College of Nursing (RCN)	308	National evidence based guidelines for oral care are being developed not should.	Thank you. We have amended this paragraph
Royal College of Nursing (RCN)	312	We welcome this statement but would like its message to be made stronger that the exemption of young people for dental treatment be made	We cannot strengthen this recommendation.
Royal College of Nursing (RCN)	321	We feel this section could be made more holistic in tone at the moment it is quite a medical model of care presented.	The actual model we have quoted (see paragraph 341) is regarded as patient focused.
Royal College of Nursing (RCN)	339	Does this refer to the age of the nurses or their client group?	This paragraph has now been amended.
Royal College of Nursing (RCN)	355	To include provision outside the principle treatment centre?	We have amended this paragraph.
Royal College of Nursing (RCN)	368	Resources and care pathway for the transition to adult services for those who need continuing care but are no longer children. /young people would be timely as this group will continue to grow and their needs will become more apparent in the future.	Thank you, we agree.
Royal College of Nursing (RCN)	381	The feasibility of the key worker is questioned here without further guidance.	This comment is about key workers, but this paragraph is about fertility counselling. The role of the key worker has been considered in detail elsewhere in the guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Nursing (RCN)	417	Requirement for adequate provision of trained paediatric oncology outreach nurses, yet we know from the ENB document that this is very variable and absent from many university portfolios there needs to be a stronger recommendation for delivery, access and evaluation of such education. Mentoring and training posts could be highlighted as training opportunities.	Paragraph 417 is a summary of the evidence not a recommendation. These issues are highlighted in paragraphs 660 and 666.
Royal College of Nursing (RCN)	421	Audit of symptom control is crucial, a recommendation of the need for robust studies in symptom control and patient and family experience is required.	We agree and have added a paragraph (436) to cover this.
Royal College of Nursing (RCN)	423	Bereavement may also be provided by a social worker or psychologist, counsellor or through a befriending approach by other trained bereaved parents. There is also no mention in this section about the need for family friendly mortuary services to be available in treatment centres.	We have not specified the professional status of the individuals providing bereavement support. A recommendation on mortuary services is outside the remit of this guidance.
Royal College of Nursing (RCN)	Table 4	Specialist nurses are involved in diagnostic MDTs and should be included here Treatment MDT should include a lead nurse Ward nurse and specialist nurses would need further definition Palliative care MDT, need to mention paediatric oncology outreach nurse specialist and other nurse specialist roles Pharmacists are often very involved in palliative care	Table 4 lists core members of the relevant MDTs. We would expect additional expertise to be accessed as necessary. We have, however, made amendments to Table 4 to include some other healthcare professionals.
Royal College of Nursing (RCN)	Table 5	Identified lead nurse should be included here	Table 5 lists core members of the MDT at other treatment sites. We would expect additional expertise to be accessed as necessary.
Royal College of Nursing (RCN)	Table 6	Excellent expression of the role of the key worker, we are anxious that key worker may in some treatment centres be non-specialist and not a healthcare professional' this would detract from the role and potentially offer a less robust standard of care. It will be important that the key worker liases with all relevant experts and that includes other professionals and voluntary organisations.	We agree.

Organisation	Section no. or General	Comments	Developer's response
Royal College of Nursing (RCN)	Table 8	We are disappointed not to see more refined clinical standards for nursing staff in this section. There is evidence for such standards produced by the RCN and PONF and would welcome its inclusion here, capacity in all treatment centres is often reduced due to lack of nurses (both numbers and appropriately skilled).	It is not our remit to set or refine standards. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
Royal College of Nursing (RCN)	General	We would welcome further clarification as to what a "specialist nurse" is, it is used throughout the document in various sections yet the person it is describing remains unclear, how will any treatment centre know they have them if they don't know what they are?	We agree that this needs further clarification, but this is outside the scope of this guidance. We would welcome a definition from the Royal College of Nursing.
Royal College of Nursing (RCN)	552--562	We welcome the promotion of inclusion child/young peoples cancer with Cancer Networks (though please see the comments below from one of our members)	Thank you.
Royal College of Nursing (RCN)	563–586	Support & agree with this section. Time to develop such resources will be a problem, as we move constantly closer to environment where patient activity and costs are the main focus.	We agree.
Royal College of Nursing (RCN)	587–608	The role of clinical trials, access and clinical outcome is of course crucial. It is a missed opportunity not to highlight the role of other types of research: qualitative, evaluation etc in order to reveal a complete picture of care, patient and family experience, meaning of symptoms, quality of life etc.	This is a background statement and it is not possible to go into this level of detail in this section.
Royal College of Nursing (RCN)	610	Nurses are listed, but can we be more specific about types and what we know about recruitment difficulties that need to be addressed: i.e. specialist and non-specialist: experienced and less experienced: recruitment into specific roles such as management and more senior positions.	It is not possible to include this level of detail.
Royal College of Nursing (RCN)	609–622	We agree with the statements made here however would like to see commissioners calling for greater collaboration nationally on the provision of training/education in harness with the universities and NMC.	Thank you, but we do not feel that we need to change the recommendations that we have made.

Organisation	Section no. or General	Comments	Developer's response
Royal College of Nursing (RCN)	609–621	Low numbers of all staff working across the spectrum paediatric oncology care (relative to adult cancers), means that a National approach to training & workforce development makes more sense than 1 or 2 staff trying to find effective ways to develop in their local area. It could also mean that issues around the emotional investment (point 609) are shored up through peer support when linking up for training. In the long term this may help retention. See also comment on Point 15. National training, education and workforce development may however, result in additional costs either by providing Distance Learning methods or to enable staff to travel.	We have added a new recommendation to cover this.
Royal College of Nursing (RCN)	612	Palliative care needs to be listed, as does clinical nurse researchers.	We have chosen examples that the Guideline Development Group felt were particularly important and the list is not exhaustive.
Royal College of Nursing (RCN)	618	There should be access to appropriate post-qualifying education (not basic, term no longer used). However, we know that these courses are diminishing/not available in some areas, not always resourced locally for uptake, not evaluated to clearly show their relevance and impact on clinical outcome. We need more evidence to support their need in paediatric oncology and palliative care: there needs to be a recommendation of the role of cancer networks and commissioners to be creative in appropriate education provision.	We have changed the wording to 'post-qualifying'. Further work on this issue is not within our remit.
Royal College of Nursing (RCN)	Omissions	We feel that the following areas could have been included 1. The lack in some areas of adequate apherisis services 2. The role of the voluntary sector in the provision of care, funding and support in this field 3. The need for access to high dependency care as well as PICU 4. The development of new /expanded roles for healthcare professionals	1. This level of detail is not possible in service guidance. 2. This is covered in the Economic Analysis which is included in the Evidence Review. 3. This is implicit in the section dealing with this topic. 4. We feel this is adequately covered in the guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Nursing (RCN)	General	Overall extremely well researched and presented guidance which reflects the real picture and real needs of children and young people with cancer. Thank you for this comprehensive document.	Thank you.
Royal College of Nursing (RCN)	90	It should also be noted that adolescents rarely attend primary care and if they do their problems should be taken seriously by health care professionals (HCP).	Thank you. This is a quote from the GP referral guidelines for suspected cancer.
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	General	In general I was impressed by the guidance document and feel that for my specialty (histopathology) it deals with the relevant issues in a straightforward manner.	Thank you.
Royal College of Pathologists	General	I feel that the guidance appropriately highlights where there is and where there is not a definite evidence base for the recommendations.	Thank you.
Royal College of Pathologists	105–112	This section succinctly illustrates the specialist nature of paediatric pathology and paragraphs **109** and **111** are critical inclusions.	Thank you.
Royal College of Pathologists	124, 122	Should recommendation **124** be restricted to laboratories dealing with paediatric leukaemias? Increasingly DNA or RNA is extracted from solid tumours and lymphomas, and so departments dealing with these conditions will face a similar need for facilities to store cells or nucleic acid as well as tissue (recommendation **122**).	Paragraph 119 has been amended.
Royal College of Pathologists	129	This is a key recommendation; access to the full range of diagnostic techniques generally requires that the specimen be received in routine working hours. Perhaps this should be stated explicitly?	We feel this issue is adequately covered in the current text.
Royal College of Pathologists	131	I agree wholeheartedly with the anticipated benefits of accurate and more timely diagnosis.	Thank you.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Physicians of London			This organisation was approached to comment but did not respond.
Royal College of Psychiatrists	General	1. Overall the guidelines are very easy to read and well organised. Given the huge scope of the document the contributors should be congratulated on this. 2. Apart from the table on page 107 (para 440) (Psychosocial support MDT), psychological support refers solely to 'psychologist' or 'clinical psychologist'. It would be useful to be generally more inclusive in the entire document (as in the table on p107 which refers to 'psychologist or other member of psychological service') to make it explicit that although psychology is a key discipline, others experienced in psychological services/mental health eg nurses, psychiatrists may be appropriately involved either on a regular basis or because of their specific skills. 3. With regard to Psychosocial Care it would be useful to suggest that there is a Psychosocial Lead to coordinate psychosocial care and represent relevant issues at management level. 4. Throughout the document there could be more reference to the wider family and their role and support, particularly parents and siblings.	Thank you. This amendment has been made to the text. We agree and have amended Table 9. We have amended paragraph 458 to include siblings specifically.
Royal College of Psychiatrists	351	We would like to add strong support for routine structured psychosocial assessment.	Thank you.
Royal College of Psychiatrists	422–441 and 400	'Bereavement services' - There is no explicit mention of psychologist/psychological support in this section. As in the 'Palliative care' section (particularly paragraph 400) there may be some situations where such input may be necessary directly for families as well as a resource for professionals, or indeed as support for professionals.	Text has been amended in paragraph 457.

Organisation	Section no. or General	Comments	Developer's response
Royal College of Psychiatrists	448	There should be explicit mention of psychological input in both the Late Effects and the Palliative Care MDT.	This amendment has been made to the text.
Royal College of Psychiatrists	609–610	There may be a clear role for formal psychology/psychological support for staff working in this personally demanding area, and this may have implications for retention (and possibly recruitment). This could be more explicit in the document, although we appreciate that the document does not claim to cover staff training comprehensively.	Thank you, but we do not feel that we need to change the recommendations that we have made.
Royal College of Radiologists	General	This is an admirably comprehensive document and should provide the basis for improving the care of children and particularly adolescents.	Thank you.
Royal College of Radiologists	General	The commissioning sections assume that it is possible for the whole health care system to work in a co-ordinated way at a strategic level. In recent years the NHS has been particularly poor at this because of the difficulty in getting effective joint working established through PCTs. During the drafting of this document the NHS has been re-organised yet again with formation of Foundation Hospitals and the announcement of payment by results based on HRGs (Health Resource Groupings). These changes need to be recognised and addressed as the document is re-drafted. The College fully supports the aims of this document, our concern is with the difficulty, which has been experienced in commissioning care for patients with rare diseases across large populations. Cancer networks remain variably effective in this role and this is unlikely to change.	We have asked for commissioning arrangements to be clarified and we have amended other parts of the document to try to address some of these issues.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Radiologists	General	Although the document refers to the management of children and *'young people'*, much of the description of recommended services applies to the paediatric oncology model. The broader issue of management of young people is discussed, but generally in the context of considering children and young people together. In reality the models for providing care differ considerably according to age and diagnosis. As hard as it is to define an 'adolescent', another problem is related to the definition of a young adult. Many centres manage teenagers with bone and soft tissue sarcomas in 'adolescent units', but this is not the only model of care. One of the commonest groups of patients in the 20-25 year age group is the group with lymphoma. In this age group there are also significant numbers of patients with epithelial cancers. Perhaps the document should address in a separate section some of the specific needs of the age group which make their needs different from other slightly older adults such as the 25-35 age group, because all patients with cancer should receive high quality care based on MDTs with psychosocial support, etc.	We acknowledge this and these issues have resulted in considerable discussion in drafting the document. We believe that the document addresses the issues sufficiently.
Royal College of Radiologists	General	The key recommendations are interesting in that the verb predominantly used is 'should'. The only 'must' is identified in paragraph 10 in relation to age appropriate facilities. It is unclear why this is perceived to be more important than the other recommendations.	The word 'must' may only be used in NICE guidance recommendations when referring to a recommendation from a government strategic or legal document.
Royal College of Radiologists	6	Inevitably, there is a balance between local versus centralised specialist care. We do not have a St Jude's or an Institut Gustave Roussy in the UK. The issue of further specialisation within paediatric oncology centres is not really discussed, but could become an issue in the future, e.g., fewer neuro-oncology centres?	We agree, but this is not an issue for the current guidance.
Royal College of Radiologists	7	I recommend that 'commissioners <u>must</u> ensure…'	The word 'must' may only be used in NICE guidance recommendations when referring to a recommendation from a government strategic or legal document.
Royal College of Radiologists	39	I am not sure whether the figures for epithelial cancers includes CIN. If these are included this section should say so.	CIN was not included in the incident cases of epithelial cancers.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Radiologists	44	I think the final sentence is a bit misleading. The incidence in 'adults' depends hugely on age.	We have omitted 'and approaches that in adults'.
Royal College of Radiologists	52	I think the international comparisons for outcome are difficult and not adequately studied. It is not clear why outcomes in the UK may fall short of those in some other countries.	We agree.
Royal College of Radiologists	56	I think it should be made clear that sequelae relate to the effects of the cancer as well as its treatment.	We feel that the wording does not imply that late effects are solely due to treatment, and is therefore appropriate as it is.
Royal College of Radiologists	57	I think 'second primary malignancy' should read 'second primary solid tumour', as this point ignores the problem of secondary leukaemia.	The authors of the work that we are quoting used this form of words.
Royal College of Radiologists	64	The fact that there are 17 UKCCSG centres but only 8 TCT units relates to the variability in provision for teenagers and young adults with various models which might apply.	We agree.
Royal College of Radiologists	88	Maybe '*perceived* delay' would be more appropriate.	We do not agree.
Royal College of Radiologists	92	Introduction into undergraduate programmes would probably be helpful.	The guidance cannot advise on undergraduate curricula.
Royal College of Radiologists	105	The multi-disciplinary approach to diagnosis is rightly emphasised here, but I will have more to say on this in the section on surgery.	Thank you.
Royal College of Radiologists	107	This is very important, and in this age group the role of the general paediatric pathologist does not apply.	Thank you.
Royal College of Radiologists	118	The role of PET in assessment for radiotherapy and, more specifically, in planning needs to be addressed. A PET evaluation network in the UK has been discussed and would be an important rather than a 'creeping development'.	Unfortunately the evidence to support a recommendation on the current use of PET is not available at present.
Royal College of Radiologists	140	I agree this statement should be qualified. *'Radiotherapy given to children under the age of three results in greater long-term effects than for older children. Therefore radiotherapy is often avoided or delayed by the use of other modalities provided treatment outcome is not compromised,*. – or similar phrase.	The text has been amended.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Radiologists	142	It is claimed that weight loss or gain can significantly alter the correct dosage. I question the evidence for this as dosage based on weight or meter squared is at best a crude estimate. For leukaemia and lymphoma there is some evidence that the achievement of adequate myelosuppression is a key indicator of the correct dosage rather than a specific dose prescription in milligrams. Metromonic prescribing should be defined and explained.	There is some observational evidence that weight loss or gain can significantly alter the correct dosage of drugs. This will be defined in the glossary.
Royal College of Radiologists	144	There is an important omission here. It is true that only a few UKCCSG centres have dedicated computerised prescribing systems. However, most adult services have chemotherapy systems whereby pre-printed paper copies are used to standardise prescribing practice. In some cases this system has been extended into paediatrics but, elsewhere, minor resource limitations have prevented this. This document should set pre-printed prescription forms for cytotoxics as a minimum standard of practice. It should also require the existence of a quality assurance system for the recording of errors and particularly for documenting near misses, which can improve practice. Ideally, these systems should be linked to those in use for adult practice in the same institution as this applies consistency across the whole age spectrum, and the increased workforce gives better cover for absence and sickness.	We agree, and have now made a specific recommendation that there should be national strategies to address this issue.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Radiologists	145	I recommend adding the following new section: 'Ideally, a computerised prescribing system should be available. If not, then a paper-based system of pre-printed form should be in use. Ad hoc hand-written prescriptions are only acceptable in emergency, and they require careful checking.' 'A quality assurance system should be in operation with documented reviews to identify errors and near misses. There are advantages in linking such systems to adult systems within the same hospital.'	Thank you. We feel the new recommendation that we have made about electronic prescribing covers these issues and we feel it would be inappropriate to go into this level of detail in this instance. However, we have taken on board your comments regarding 'identifying errors and near misses' in paragraph 167.
Royal College of Radiologists	150	The intrathecal guidance should be highlighted separately.	We have referenced this guidance in Appendix 1 of the Guidance.
Royal College of Radiologists	153	I am unfamiliar with the concept of concordance – it should be explained.	We will define concordance in the glossary.
Royal College of Radiologists	158	Reduction in risk may also be achieved by: • Pre-printed prescription charts • Quality assurance system • Error and near miss reporting on a quarterly basis	We agree, but this list is not intended to be exhaustive, merely to relate to specific recommendations made.
Royal College of Radiologists	166	Incidents reporting should include both errors and near misses.	This amendment has been made to the text.
Royal College of Radiologists	170	This understates the importance of surgical site specialisation for young adults, where the 'paediatric oncological surgeon' model definitely does not apply. This also applies to later in this section.	We feel that the first sentence makes this very clear.
Royal College of Radiologists	175	The surgical management of tumours in children and young adults is identified as occurring in the context of the appropriate paediatric specialist MDT. It needs to be emphasised here that these cases should be discussed pre-operatively at the MDT in all cases, except in emergencies, to ensure that the patient is fully staged and that the surgery is appropriate. The aim of this is to prevent patients having inappropriate operations in the face of undetected metastases or having operations, which are not in their best long-term interests.	This amendment has been made to the text.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Radiologists	177	This advice on the management of sarcoma must be improved. If sarcoma is suspected, then the patient must be discussed in the MDT and be fully staged. The appropriateness of biopsy should be considered and in some cases the patient should be referred without a histological diagnosis to a sarcoma service for further investigation including appropriate biopsy. Failure to do this may compromise the chance of the patient having the best curative operation and may also lead to patients having inappropriate surgery in the face of metastases. This must be completely re-drafted and it should be cross-referenced to the recommendations of the NICE guidance on sarcoma, which is currently being drafted.	We are going to omit paragraph 177.
Royal College of Radiologists	188	This recommendation is to be commended and something similar should appear in the section on surgery.	We agree, and have amended paragraph 178 in the section on surgery.
Royal College of Radiologists	203	Overall the recommendations on radiotherapy are welcomed.	Thank you.
Royal College of Radiologists	204	Children may need to lie still for up to approximately 20-30 minutes, depending on the situation.	The text has been amended.
Royal College of Radiologists	203–207	I would also introduce somewhere the potential key role of the nurse in this situation. We have found nursing input extremely valuable in all aspects of paediatric radiotherapy, including general care, liaison with paediatric oncology, assistance with anaesthesia, nutrition information, and so forth., all together with other professionals including play specialists.	Thank you; this has now been highlighted as part of the role of the keyworker (see Table 7).
Royal College of Radiologists	205	This recommendation should be strengthened. Many UK CCSG radiotherapy centres now have two Consultant Clinical Oncologists sharing the workload in providing appropriate cross cover arrangements. This should be a standard of care and inappropriate cover by Junior Staff during absence should no longer be accepted.	We recognise the issue and Table 2 has been appropriately amended.
Royal College of Radiologists	206	The point about the conflict between age specific specialisation and tumour site specialisation is well made. I believe that your recommendations should advocate joint working whereby a paediatric and site-specialised Oncologist manage the patient jointly.	We feel the issue of joint working is implicit in this paragraph.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Radiologists	216	I would delete *'..but do not appear to affect overall or event free survival in patients with medulloblastoma'.* I assume this statement may relate to the outcome for the PNET-3 study. This finding may apply within the context of this study, but we are now in the era of reduced dose craniospinal RT for medulloblastoma. I think we should avoid any statement which underplays the importance of timely access to radiotherapy. Table 2. I would add appropriate specialist nursing input.	This paragraph has been amended.
Royal College of Radiologists	239	I would add that this may be necessary for daily anaesthesia for radiotherapy.	The text has been amended to include radiotherapy.
Royal College of Radiologists	277 and 279	I would add radiotherapy induced N&V as an indication for antiemetic protocols.	We have amended paragraphs 289 and 292.
Royal College of Radiologists	369	In many cases the risk of sequelae also relates to the nature of the primary tumour. I would add *'neurpsychological'* to the list well recognised sequelae.	This paragraph has been amended appropriately.
Royal College of Radiologists	370–371	It is important that there is a seamless service for long-term follow-up through 'young adult' to 'older adult' services. I would also mention that on of the greatest risks of death in the long-term follow-up is the late relapse of the original tumour. Therefore services for long-term follow-up need to have access to appropriate diagnostic services for the investigation of possible late relapse of the original primary. Table 3. I would mention specifically palliative radiotherapy so that it is not forgotten as one of the potentially useful treatments. Table 8. I would suggest 'A minimum of 2 clinical oncologists with expertise in paediatric radiation oncology.	This is covered in paragraphs 504 and 505. We have included this in Table 3. We will amend the Table to read 'at least 2'.
Royal College of Speech and Language Therapists			This organisation was approached to comment but did not respond.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Royal College of Surgeons of England	General	The College has no specific comment to make except those below.	Thank you.
Royal College of Surgeons of England	116	There should be a Paediatric Radiologist in paediatric oncology centres, trained in paediatric oncology imaging.	We agree and have amended paragraph 113.
Royal College of Surgeons of England	177	Not all solid tumours require immediate excision e.g. wilms will be needle biopsied first according to current protocols.	We are going to omit paragraph 177.
Royal College of Surgeons of England	610	Change to read ' Paediatric Radiologists + Diagnostic Radiologists' + lower down 'Clinical Oncologists and Therapy Radiographers'.	This amendment has been made to the text.
Royal College Patient Liaison Groups			This organisation was approached to comment but did not respond.
Royal Liverpool Children's NHS Trust			This organisation was approached to comment but did not respond.
Royal National Orthopaedic Hospital NHS Trust			This organisation was approached to comment but did not respond.
Samantha Dickson Research Trust, The			This organisation was approached to comment but did not respond.
Scottish Intercollegiate Guidelines Network (SIGN)			This organisation was approached to comment but did not respond.
Serono Pharmaceuticals Ltd			This organisation was approached to comment but did not respond.

Organisation	Section no. or General	Comments	Developer's response
Sheffield Children's NHS Trust	General	Whilst the difficulty of defining an upper age limit is understandable, its absence results in some internal inconsistency, as scattered throughout is an implied upper age limit of 25 years which is not made explicit.	Thank you, but it is not possible to define an upper age limit in this guidance.
Sheffield Children's NHS Trust	General	There are overlaps with the Children's NSF, particularly relating to service issues defined in the non-shaded area of Figure A. Would it be helpful to direct commissioners to this more comprehensive guidance, rather than distract them from the core treatment services for children with cancer by dealing with the more general issues in such detail here?	We feel the balance is appropriate.
Sheffield Children's NHS Trust	6	Does the term strategic level require definition – does it imply the Strategic Health Authority? Given the rarity of childhood cancers, should not the core treatment services be commissioned by Regional or sub-regional consortia?	Strategic level has been removed and we have made a new recommendation about commissioning in the section on service organisation.
Sheffield Children's NHS Trust	10	We wonder exactly what is implied by the term "age appropriate facilities" require a reference or definition	As in the NSF, this term has not been defined but is widely understood.
Sheffield Children's NHS Trust	6-13	The key recommendations do not include any recommendations on the management of long term consequences. This should be included.	This is implicit in key recommendation 8.
Sheffield Children's NHS Trust	24	Should the upper age limit of 25 for "young people" be referred to here?	We have not specified a specific upper age limit, the reasons for which are further described in amendments to paragraph 19.
Sheffield Children's NHS Trust	34 and 35	We agree that the national register of cancers for ages 15-25 should be developed as a priority as the registration and coding of tumours influences referral patterns and care, and this is currently ad hoc. Issues about growth and puberty should be addressed by specialists in this area, who are usually paediatricians and this should also include those over 16 who are treated in an adult setting who may not all have completed puberty.	Thank you for your comments.
Sheffield Children's NHS Trust	47	It perhaps should be made clear that although leukaemia is the most common cause of death in this age group, this is because it is the single most common childhood cancer and survival relative to most other cancers is very good	We have slightly changed the wording of this paragraph to try to make this point. However, to discuss leukaemias specifically would not fit with the general point we are trying to make about the effect survival rates have on mortality across the ICCC groups.

Organisation	Section no. or General	Comments	Developer's response
Sheffield Children's NHS Trust	54–55	On and off-treatment prevalence might be more useful as a better indication of service provision requirements. Leukaemia requires longer period of treatment but the off-treatment support requirements are less than many other patients such as survivors of CNS tumour after neurosurgery	To our knowledge, such data are not available.
Sheffield Children's NHS Trust	81–82	Pathology AHPs need mention here. Haematology bio-medical scientists and cytogenetics clinical scientists are important contributors to the patient's "package of care"	These clinical scientists are not AHPs. We have acknowledged this staff group throughout the guidance.
Sheffield Children's NHS Trust	114	Haematologists also report marrow aspirate and trephines which contribute to staging of solid tumours. In addition cytogenetics and molecular genetics are increasingly important to the diagnosis and staging of all cancers and deserve a separate paragraph.	We agree and have amended paragraph 111.
Sheffield Children's NHS Trust	123	……and Haemopoietic Stem Cell Transplantation.	This amendment has been made to the text.
Sheffield Children's NHS Trust	138	Audit pathology report turn-round times? Recommend laboratories have CPA accreditation.	This section has been redrafted.
Sheffield Children's NHS Trust	140	Include immunotherapy and Haemopoietic Stem Cell Transplant	We have included 'stem cell transplantation' in the text.
Sheffield Children's NHS Trust	203	Should include Total Body Irradiation for HSCT	This amendment has been made to the text.
Sheffield Children's NHS Trust	224	Antibiotic policy should be informed by local microbiological prevalence rates and resistance patterns, and reviewed on a regular basis?	We agree, but this is a clinical issue and is not part of the remit of this guidance. We would foresee this being part of the information on which local protocol is based and regularly updated.
Sheffield Children's NHS Trust	238	Regular audit of microbiology prevalence and resistance patterns? Audit of hospital acquired infections? Audit of respiratory viral infection patterns?	The measures proposed are related to recommendations. We do not feel it appropriate to make recommendations on microbiology prevalence and resistance patterns. Audit of hospital-acquired infections and respiratory viral infection patterns, although relevant, are not specific to neutropenia and are covered by other surveillance systems.

Organisation	Section no. or General	Comments	Developer's response
Sheffield Children's NHS Trust	252	Presumably includes line infections?	The text has been amended.
Sheffield Children's NHS Trust	254	Paediatric haematologists should have input into hospital transfusion committee and transfusion policies.	It is not the remit of the guidance to determine the composition of hospital transfusion committees.
Sheffield Children's NHS Trust	325	What about the role of education services – home and hospital tuition?. There should be a comment on access to local services specifically for children with a disability – the need for neurology input is highlighted, but for some of these children specific neuro-disability input might be more appropriate. Ongoing needs in terms of access to services for young people with a disability is a particular problem as they move into adulthood and appropriate support often extremely difficult to access – e.g. occupational psychologist to advise re employment, long waiting lists for young adult disability services.	We have inserted an additional paragraph (686) to include educational services.
Sheffield Children's NHS Trust	341	Educational attendance and attainment should be an important outcome measure as this can be a major deficit area for many of this group.	This amendment has been made to the text.
Sheffield Children's NHS Trust	347	? should also state … including after completion of treatment and into adult life.	This amendment has been made to the text.
Sheffield Children's NHS Trust	349	We think social work support should be available after completion of treatment and during long term follow up not just the period of active treatment. Social workers can provide valuable input in terms of employment, schooling, on going family adjustment – for example there are often later concerns in relation to new problems related to late effects of treatment.	This is not a recommendation about timing; however, we feel that individual needs will need to be met regardless of timing.
Sheffield Children's NHS Trust	351	? should also include as "significant points" the return to school, the transfer to secondary school, as well as the post16 transition.	We have amended the paragraph and the recommendation now allows for additional assessments if required.
Sheffield Children's NHS Trust	369	There is no mention of cardiac toxicity – potential significant health burden	This paragraph has been amended appropriately.

Organisation	Section no. or General	Comments	Developer's response
Sheffield Children's NHS Trust	374	These recommendations are for childhood cancer only and therefore by definition excludes those 16 years and above. Shouldn't these recommendations be extended to all young people and apply to all treatment centres, given that late effects are also an issue for young people who survive.	We agree and the text has been amended.
Sheffield Children's NHS Trust	379	Late effects Nurse Specialists could be an appropriate "key worker". There is considerable US experience using these personnel in off treatment clinics.	We agree that in this setting, the key worker may well be the Late effects Nurse Specialist but felt it inappropriate to limit the 'key worker' to this role.
Sheffield Children's NHS Trust	380	? long term follow up should be done with reference to existing guidelines (as produced by nationally).	These guidelines have been referenced in the Evidence Review that accompanies this guidance.
Sheffield Children's NHS Trust	381	Given that 15% of survivors will be rendered infertile (and hypogonadal) then access to appropriately trained personnel for both counselling and clinical management is crucial, especially for 15-24 year olds.	We agree.
Sheffield Children's NHS Trust	382	Further information sharing about late effects should also be undertaken once therapy is complete. In addition children and young people may not be aware of potential late effects that were discussed with their parents at the time of diagnosis. It is essential that these are discussed with them in a timely and appropriate manner as they mature. In particular discussion of potential implications on fertility and sexuality needs particularly careful handling and appropriate training is essential.	We agree and believe this is covered in the recommendation.
Sheffield Children's NHS Trust	392	While audit of treatment outcomes is important and needs to be ongoing because of changes in treatment other outcome measure should also be used such as evaluation of alternative models of FU care including role of Late Effects MDT and Nurse Specialist as well as models such as GP, telephone, questionnaire based FU. Audit of adherence to good practice guidelines in relation to LTFU – is FU undertaken in the way it should be, is intervention in relation to late effects timely and appropriate?	The measurement section is designed to suggest types of audit to be undertaken and the list is not exhaustive. This is just a suggested topic for local or regional audit.

Organisation	Section no. or General	Comments	Developer's response
Sheffield Children's NHS Trust	395	In practice most children with cancer who die, do so whilst remaining under the care of their haematologist/oncologist. What they require is ready access to other support services rather than referral to a separate palliative care service. A separate issue is that there are more deaths in children with leukaemia from treatment related complications than directly from disease. This group of patients more commonly die in hospital and their needs and those of their families may be different from those dying of refractory cancer.	We agree and have not recommended separate palliative care services.
Sheffield Children's NHS Trust	447–448	Perhaps the function and role of many of these MDTs can be merged into a manageable number with appropriate membership. Should the treatment MDT include microbiologist/virologist/surgeon?	Membership is indicated as a guide and all teams must work flexibly to respond to individual needs.
Sheffield Children's NHS Trust	449	Add HSCT MDT?	This is inappropriate for paragraph 449 as it is a part of treatment, not a tumour type.
Sheffield Children's NHS Trust	515	For paediatric haematologists, non-malignant haematology and laboratory workload has risen due to increase in asylum seekers, transfusion and laboratory regulation and accreditation of transplant services.	We have amended to clarify that this is not an exhaustive list.
Sheffield Children's NHS Trust	517	Shared care often relies on a highly motivated paediatrician with an interest in oncology. It would be useful to define the training required of such an individual. Should such centres treat a minimum number of patients to maintain clinical skills and expertise?	It is not within our remit to specify training requirements and there is no evidence available to specify a minimum number of patients.
Sheffield Children's NHS Trust	526 and Table 8	Should the consultant staff be 5 whole time equivalent ? There is no mention in this section or the table of minimum nursing staff numbers – should these not be defined?	This amendment has been made to the text. We are unable to define minimum numbers given the variety of shared care arrangements around the country.

Organisation	Section no. or General	Comments	Developer's response
Sheffield Children's NHS Trust	553	Should Cancer Networks be made to commit a proportion of their funding to support children and young people's services? Otherwise adult services, due to their larger size, will always take precedence. It is important to emphasise that the UKCCSG and Childhood Leukaemia Working Party function better than any other cancer network in the UK.	We cannot specify how the Cancer Networks use what limited funding they have.
Sheffield Children's NHS Trust	567	Copies of letters from clinics etc can be useful to assist in communication with families.	We agree, and this has become practice in England.
Sheffield Children's NHS Trust	568	There is no mention of the concept of Gillick competence especially with regard to informed consent.	This isn't specifically referring to consent: we would expect this to be covered by the comments on legal frameworks at the start of this guidance.
Sheffield Children's NHS Trust	584	The use of video to review consultation skills can be helpful	We agree, but this is not appropriate for a measurement section.
Sheffield Children's NHS Trust	586	Formal assessment of communication skills should be part of training requirements	This is not appropriate to a measurement section.
Sheffield Children's NHS Trust	592	Given the current reluctance of pharmaceutical companies to carry out Phase I trials in children, and the added ethical issues of such trials, this risks denying children access to innovative drugs on compassionate basis.	This recommendation does not rule out the use of innovative drugs outside a clinical trial; however, it is preferable that they are subject to proper evaluation.
Sheffield Children's NHS Trust	617	Haematology bio-medical scientist and clinical scientists are in short supply. Training in paediatric aspects of laboratory haematology for these professional groups should be mandatory.	Thank you for the comment, but this guidance cannot mandate training standards. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
Social Care Institute for Excellence (SCIE)			This organisation was approached to comment but did not respond.
Society and College of Radiographers	General	The Society & College of Radiographers welcomes and is supportive of this positive document.	Thank you.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Society and College of Radiographers	General	We feel that it is good to have nominated cancer network lead for children and also positive to identify key workers for each child.	Thank you.
Society and College of Radiographers	General	Additionally it is very helpful to have principal treatment centers identified for each cancer type including centers outside the child's cancer network if required.	Thank you.
Society and College of Radiographers	14	We welcome addressing the need for separate register for 15-24 year olds, as this is felt essential.	Thank you.
Society and College of Radiographers		It is important to have therapeutic radiographers specializing in children's treatment within RT centers; for example Newcastle have a very successful radiographer undertaking that role	There is specific mention of appropriately trained therapy radiographers in paragraph 213.
Society and College of Radiographers	Table 2	We would recommend that it would be preferable for the cases where Radiotherapy is to be used that the Paediatric therapeutic radiographer is part of the MDT team particularly the treatment team (pg 60) a full understanding of the case is required and this would be the best place to gain an overall picture.	The text has been amended.
Society and College of Radiographers		However we are concerned that treatment is not explicit within the list covered by AHP's particularly as this is a core role for therapeutic radiographers.	We are not sure to which part of the document this refers; they are specifically mentioned in paragraph 79.
Society and College of Radiographers		It is essential to add therapeutic radiographer to the treatment MDT (where RT is to be used)	We have added therapeutic radiographers to Table 2.
Society and College of Radiographers		Please add both diagnostic and therapeutic radiographers to this list who specialize in the imaging and treatment of children.	We are not clear to which list this refers, but they are both referred to in paragraph 79.
Society of British Neurological Surgeons	General	The concept of "Principal Treatment Centres" is to be welcomed and whilst chemotherapy and radiotherapy for CNS tumours may be given in any of the 17 UKCCSG Centres, as there are only about 450 new paediatric brain tumours each year surgery should ideally be undertaken in those centres with paediatric neurosurgical expertise and a multidisciplinary paediatric neuro oncology team. The paediatric neurosurgeons should also be supported by adult colleagues with special surgical skills such as transsphenoidal or spinal surgery.	This section was drafted in conjunction with a specialist paediatric neurosurgeon and we feel covers these issues.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Society of British Neurological Surgeons	9	The "key care worker" for each child is to be welcomed, but the SBNS would also emphasise the importance of ongoing input from funded paediatric neuropsychologists and clinical psychologists.	This level of detail is not possible in the key recommendations, but we have referred to this issue in more detail later in the guidance.
Society of British Neurological Surgeons	186	Paragraph 186 - contains data, which may require updating.	This information is not available at present.
Society of British Neurological Surgeons	201	Paragraph 201 - refers to "British Association of Paediatric Neurosurgeons" which should be "The British Paediatric Neurosurgical Group"	This amendment has been made to the text.
South & Central Huddersfield Primary Care Trusts			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	General	Although we have made a number of comments and suggestions we should like to note we feel the document is a very good first step in producing guidance.	Thank you.
Taunton and Somerset NHS Trust	General	It is not clear what applies to the shared Care Unit and what applies to the tertiary centres.	The Guidance sets out the responsibilities of principal treatment centres and other treatment sites. The level of service provided at each site has not been defined in detail, although a broad outline is given. Specific arrangements between principal treatment centres and other treatment sites need discussion and agreement. These need to take into account local expertise, staffing levels, facilities and the ability of each site to address the recommendations made throughout this guidance regarding the provision of care.

Organisation	Section no. or General	Comments	Developer's response
Taunton and Somerset NHS Trust	General	It is suggested the authors have under estimated what actually takes place in a shared Care Centre.	The Guidance sets out the responsibilities of principal treatment centres and other treatment sites. The level of service provided at each site has not been defined in detail, although a broad outline is given. Specific arrangements between principal treatment centres and other treatment sites need discussion and agreement. These need to take into account local expertise, staffing levels, facilities and the ability of each site to address the recommendations made throughout this guidance regarding the provision of care.
Taunton and Somerset NHS Trust	General	Surprised there is no reference to the spiritual needs of the child/family. It appears no learning has been sought from the supportive and palliative care guidance.	We have included spiritual care in the section on bereavement services. We have also extensively reference the NICE guidance on Supportive and Palliative care throughout this guidance, where appropriate.
Taunton and Somerset NHS Trust	General	Wide range of "open and vague" statements, talks about policies/ recommended levels with no actual references.	It is difficult to address this wide and non-specific comment. Supporting references will be included in the Evidence Review.
Taunton and Somerset NHS Trust	7, bullet point 4	Shared care arrangements need to encompass clinical trials teams.	We agree this is important, but arrangements for clinical trials are under the organisation of the Cancer Trials Network.
Taunton and Somerset NHS Trust	8	"Adequate resources should be provided" – this is vague what does adequate mean? Presupposes a critical mass of patients, which may not always be the case.	We cannot find a reference to 'adequate resources' in paragraph 8.
Taunton and Somerset NHS Trust	9	Does this include chaplaincy/spiritual care worker?	This is not relevant to this key recommendation.
Taunton and Somerset NHS Trust	10 10 cont'd	What is meant by "age appropriate" facilities – needs more measurable definition for <18 years age – appropriate is supported by the children's NSF. Why the increase for oncology to 19 years? Age appropriate is difficult. This is different for different children. Surely choice is a better phrase?	As in the NSF, this term has not been defined but is widely understood. The specific recommendation of 19 years comes from the NSF for children and young people. Once again we are following the recommendations of the NSF and we have explicitly said that for teenagers and young adults, choice should be offered.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Taunton and Somerset NHS Trust	15	Presupposes a critical mass of patients, which may not always be the case.	We agree, but despite this there is a need for trained specialist staff.
Taunton and Somerset NHS Trust	16	There are times when chaplaincy are included in the AHP category, in the children's hospice setting there should be a trained chaplaincy provision as part of the MDT.	Chaplaincy staff are not included in the Department of Health definition of Allied Health Professionals.
Taunton and Somerset NHS Trust	60, Table 2	Again childrens' NSF supports paediatric trained recovery nurses, however this is difficult to achieve in a DGH. First aim would be to ensure separation from post op adults.	Thank you, this paragraph is for background only.
Taunton and Somerset NHS Trust	65	This is incorrect. The provision of services may vary, from initial diagnosis only, to full chemotherapy and supportive care provision for haematological and solid tumours. In the South West, shared care centres provide services varying from initial diagnosis of malignancy to treatment of most tumours after start of treatment and some shared care centres initiate treatment for Acute Lymphatic Leukaemia.	Thank you, we have amended the text.
Taunton and Somerset NHS Trust	90	"persistent parental anxiety should be sufficient reason for investigation and/or referral" This could be translated into an excuse for all parents to demand hospital assessment, which is not practical or necessary.	Thank you. This is a quote from the GP referral guidelines for suspected cancer.
Taunton and Somerset NHS Trust	116–119	Unclear as to where diagnostic investigations should take place. Delivery of local care is optimum but restricted by lack of funding to develop.	It is very difficult to specify where investigations should take place. Because special resources and specialist clinical expertise is required, we have phrased paragraph 113 to cover this variability.
Taunton and Somerset NHS Trust	130	The limitations is not facilities for MRI per se that are difficult to access – most DGHs now have MRI scanners but instead facilities for sedated/anaesthetised MRI necessary in the <5s or those with learning difficulties are needed. Funding is difficult to obtain to ensure such investigations can be undertaken near to the child's home where possible.	We agree. This point is covered in paragraph 127.
Taunton and Somerset NHS Trust	145	Need to define "properly trained staff in an environment capable of providing the predicted level of support": - Very wide statement - Need to identify bench marking levels of staff	This is not part of the remit of this guidance. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.

Organisation	Section no. or General	Comments	Developer's response
Taunton and Somerset NHS Trust	176	Sarcomas? – bone tumour or soft tissue? need to differentiate.	We have amended paragraph 179 to specify 'bone tumours'. The decisions about specialist surgery for soft tissue sarcomas awaits the publication of the Sarcoma guidance.
Taunton and Somerset NHS Trust	177	Lumps that are unusual – this is often a retrospective finding.	We are going to omit paragraph 177.
Taunton and Somerset NHS Trust	222	Definition of neutropaenia is incorrect!	We will include a definition of neutropenia in the glossary.
Taunton and Somerset NHS Trust	225	How long do we wait for national guidance?	Unfortunately this is outside of our control.
Taunton and Somerset NHS Trust	230	"community-based therapy below risk episodes?" What does this mean?	There is a typo here; it should read 'community based therapy for low risk episodes'.
Taunton and Somerset NHS Trust	285, bullet point 1	Again needs defining and a level to which we can benchmark against.	We agree. Because we have not been able to define the levels of appropriate staffing we have removed this audit criterion.
Taunton and Somerset NHS Trust	289	Nutritional support should not only provide adequate protein and energy but it should also provide all other nutrients that are not being met through oral intake.	We have added 'vitamins and minerals' to the text
Taunton and Somerset NHS Trust	290, 291	We agree that any dietician working in the area of paediatric oncology needs paediatric experience. However specialist knowledge is also required in areas such as Neonates and TPN, which a general paediatric dietician may or may not have. It would be useful to state the kind of training or specialist roles that is required for paediatric oncology dieticians.	Our recommendation reflects our view that dietitians require paediatric training first then further oncological training.
Taunton and Somerset NHS Trust	292	Need to state which national professional guidelines on nutritional support the document is referring to.	We agree, and they will be stated in the Evidence Review that accompanies the guidance.
Taunton and Somerset NHS Trust	293	Also improves general well being and how they feel.	We have added 'improve general well being' to the text.

Organisation	Section no. or General	Comments	Developer's response
Taunton and Somerset NHS Trust	294	It would be useful to define metabolic needs, does it refer to energy metabolism, general etc.	Have amended text to 'nutritional needs'.
Taunton and Somerset NHS Trust	301	Does this refer to all dieticians or dieticians working in certain areas eg paediatrics, TPN, paediatric oncology etc.	We have amended this paragraph to clarify this.
Taunton and Somerset NHS Trust	303–306	Need to identify the role of oral and dental care within oncology services. Such services are vital and are of ten not mentioned/resourced.	We feel this is adequately covered within this section.
Taunton and Somerset NHS Trust	327	Needs to be more specific as to when/how/where such services would be best accessed/provided. Need clear guidelines as to when services needed to be provided by adult or children's services?	This will be addressed during the implementation of this service guidance. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
Taunton and Somerset NHS Trust	343	"Inevitably" – generally/often/commonly would be better	We have replaced 'inevitably' with 'often'.
Taunton and Somerset NHS Trust	401 Point 4	Define "some training" Palliative care nurse or consultant – these are quite different and not interchangeable	We understand that they are different, but in this context both may be appropriate.
Taunton and Somerset NHS Trust	404	Need to give guidance as to bench marking as to staff required to achieve 24 hour cover.	The Guideline Development Group felt it was more appropriate to specify the level of service rather than attempt to specify any numbers.
Taunton and Somerset NHS Trust	426	We would consider that chaplaincy has a role to play here.	We agree, but feel that this is included in the term 'other agencies'.
Taunton and Somerset NHS Trust	431	Understanding spiritual needs and the provision of spiritual care is a vital part of the needed skills.	We agree, but feel that this issue is covered in paragraph 456.
Taunton and Somerset NHS Trust	422	"Also occurs during treatment"; suggest "may also occur in hospital".	This amendment has been made to the text.

Organisation	Section no. or General	Comments	Developer's response
Taunton and Somerset NHS Trust	425	This is patronising – suggests that they are not able without appropriate info and support. Suggest: Many families are able and wish to take the lead in the arrangements after their child's death. Appropriate information and support should be available to assist them in this process if needed.	We disagree that this is patronising, but are happy to amend the paragraph.
Taunton and Somerset NHS Trust	448	Re palliative care MDT: The key worker is usually but not always a nurse. Important to include nursing expertise per se. Re table 5: Need to add social worker to other treatment site MDT.	Nursing expertise has been included in the palliative care MDT. We have added social workers.
Taunton and Somerset NHS Trust	506	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, with central responsibility of regional UKCCSG centre's MDT re pathology/surgery/radiotherapy/BMT/clinical trials support.	The Guidance sets out the responsibilities of principal treatment centres and other treatment sites. The level of service provided at each site has not been defined in detail, although a broad outline is given. Specific arrangements between principal treatment centres and other treatment sites need discussion and agreement. These need to take into account local expertise, staffing levels, facilities and the ability of each site to address the recommendations made throughout this guidance regarding the provision of care.
Taunton and Somerset NHS Trust	516 and Table 8	"adequate core consultant staff" – could this be defined as numbers of whole time equivalents (important for clinicians with academic contracts with reduced clinical time)	We agree and have added a footnote to Table 9.
Taunton and Somerset NHS Trust	517	"Responsible team may be from paediatric or adult services"; this should not be taken as accepting that children can be cared for on adult wards.	Paragraph 517 is about the responsible team, not facilities, and the guidance is clear that care needs to be provided in age appropriate facilities.
Taunton and Somerset NHS Trust	520	Wording not clear … may be given in community (usually at home) and during palliative care.	We have amended the text.
Taunton and Somerset NHS Trust	521	Provided also by shared care unit.	We are do not intend the paragraph to be prescriptive as to the location of POONs.

Organisation	Section no. or General	Comments	Developer's response
Taunton and Somerset NHS Trust	533	This needs clearer definition – some shared care units provide full chemotherapy and supportive care for intensive regimes such as AML or sarcoma protocols, in close communication with tertiary hospitals	The Guidance sets out the responsibilities of principal treatment centres and other treatment sites. The level of service provided at each site has not been defined in detail, although a broad outline is given. Specific arrangements between principal treatment centres and other treatment sites need discussion and agreement. These need to take into account local expertise, staffing levels, facilities and the ability of each site to address the recommendations made throughout this guidance regarding the provision of care.
Taunton and Somerset NHS Trust	572	Open to misinterpretation, unless consent is obtained we do not give information to extended families – such is the nature of families nowadays.	We disagree. Paragraph 572 is not referring to information about the child's individual treatment.
Taunton and Somerset NHS Trust	596–607	The references to "EU directive of good clinical practice", are not really the best. There is an EU directive on "use of medicines" which is transposed into law as the clinical trials regulations. There is a draft EU directive on GCP but its not out yet. Then there is the specific "Research Governance framework" – not law but the DoH umbrella framework for all these things. It is suggested the EU directive on GCP is replaced with a statement like "relevant legal and regulating frameworks.	We agree and have amended the text.
Taunton and Somerset NHS Trust	606	We would disagree, the two distinct but very important roles are strictly administration/co-or clinician and research nurse/clinical support.	We are unclear what this comment is referring to in paragraph 606.
Taunton and Somerset NHS Trust	610	Should this be paediatric nurses and not just "nurses"?	This guidance covers patients outside the paediatric age group.
Taunton and Somerset NHS Trust	609–621	Locally we do not have a problem with recruitment and retention of nurses but agree with problems in other areas. National Workforce Strategy promotes the increase of skills of support workers to overcome the national shortage. This document really only looks at the use of play specialists doing some psychological input. Need to consider other areas eg radiographers advanced skills to free up radiologists etc.	Thank you, but we do not feel that we need to change the recommendations that we have made.
Taunton and Somerset NHS Trust	General	Although we have made a number of comments and suggestions we should like to note we feel the document is a very good first step in producing guidance.	Thank you.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenage Cancer Trust, The	15	Components of both medical and nurse training relevant to young cancer patients should be developed.	We feel this is implicit in paragraph 15.
Teenage Cancer Trust, The	25	Outcomes – also include the effect on life chances due to the disease/its treatment – e.g. education interrupted or truncated employment/career opportunities no longer available – additionally exclusion from services and job opportunities due to prejudice	Although we understand the issue, we do not feel it was right to go into too much detail in this background section.
Teenage Cancer Trust, The	51 and 53	If improvement in survival in childhood malignancies is attributed to centralisation of treatment in specialist centres as well as treatment/care improvements – does this not argue for development of specialist centres, such as TCT Units for teenagers and young adults?	We agree.
Teenage Cancer Trust, The	54	Prevalence. Are there figures available for re-occurrence of cancer in young people first diagnosed when children? Need to know these numbers in order to ensure sufficient specialist facilities available.	These data were not available to us. We were not able to obtain any prevalence data for 15–24-year-olds. The NRCT may be able to provide data on such children.
Teenage Cancer Trust, The	60	Key (3) Need to enlarge upon "disease specific rates vary" as masks true picture for 15-24 year olds.	We do not have national survival rate figures for this age group and so feel unable to enlarge upon disease specific rates. Issues of data availability in this age group have been mentioned in other responses.
Teenage Cancer Trust, The	82	With reference to TCT survey considerable value placed on these services in comparison to other professions, e.g. nurses and activity co-ordinators were more popular than psychologists and psychiatrists as sources of support.	Thank you. It is made clear in the full report, which is included in the Evidence Review.
Teenage Cancer Trust, The	83	Dearth of educational support for young adults – it is essential such provision included	We agree, but this is outside the remit of this guidance.
Teenage Cancer Trust, The	312	Dental – young adults should have priority access to Hospital Dental Services or vouchers for non NHS dentists	We cannot make specific recommendations on either of these points.
Teenage Cancer Trust, The	351	It would be useful to mention here that expert fertility advice should be made available prior to treatment	This is covered by paragraph 404.
Teenage Cancer Trust, The	357	Respite opportunities should be made available/offered	We have included 'respite care' in paragraph 362.

Organisation	Section no. or General	Comments	Developer's response
Teenage Cancer Trust, The	396	Consider psychological support at this stage for both patient and family, important Recommendations – add 'appropriate skills and experience in handling teens, young adults'	We feel the importance of psychological support is recognised throughout the guidance in particular the section on psychosocial support.
Teenage Cancer Trust, The	402	Particular need for staff to be supported when dealing with Teens and young adults in palliative stage	Support for staff is important across the whole client group and has been addressed in the section on psychosocial care.
Teenage Cancer Trust, The	414	Use "should" in place of "will"?	This section is an anticipated benefit and therefore the word 'will' is appropriate.
Teenage Cancer Trust, The	419	Structure - Availability of <u>24hr</u> telephone support	This amendment has been made to the text.
Teenage Cancer Trust, The	422–425	Additional point re bereavement services Need to ensure supporting team is fully aware of religious practices, or lack of, of the patient and family prior to death in order that they can be supported appropriately. These should also be referred to in this section's recommendations	We have amended paragraph 455 and feel that this now covers these issues.
Teenage Cancer Trust, The	455	MDT need to be aware that TYA patient may have differing views from those of their patients re treatment	We agree and feel that it is covered in this paragraph.
Teenage Cancer Trust, The	468	Integration vital between different medical disciplines and between paediatric and adult clinicians	We agree.
Teenage Cancer Trust, The	584	Provision of ongoing information and support after treatment for patients and carers	This is not measurable
Teenage Cancer Trust, The	634	Re 16+ education and further education. Commissioners should expect that adequate provision be made for 16+ age group to enable patients to continue their education (which is likely to be interrupted by treatment).	We agree and feel this is implicit in the text. However, education provision is outside the remit of NHS commissioners.
Teenage Cancer Trust, The	General	Regarding the provision of education - the use of technology should be enlisted and the expectation that national service (particularly for further education and rarely studied subjects) could be delivered via a website could be a minimum standard.	We agree that this sounds interesting, but it is outside our remit.

Organisation	Section no. or General	Comments	Developer's response
Teenager Cancer Trust Multidisciplinary Forum	7	We would recommend strengthening the links to commissioning of all specialised children's services. The Children's NSF recommends the formation of a series of networks as a means of commissioning and delivering children's services. Children's cancer services should be seen as integral to this and not separate, particularly as there will be impact on provision of a number of other services i.e. PICU, surgery, pathology, nephrology etc. These should be commissioned through specialised children's networks. The expectation that services will be delivered as close to home as feasible also demands close links with local children's networks. It might also be helpful to note the potential impact of 'Payment by Results' on the commissioning process and the potential risk to centralised care.	We recognise this issue, but it is not the role of this guidance to advise on specialist commissioning, although we have recommended that commissioning arrangements be clarified. The role of cancer networks has been highlighted together with the importance of working in partnership with other children's services (paragraphs 597–601).
Teenager Cancer Trust Multidisciplinary Forum	15	There is a need for standards to be set for training and appropriate, realistic (in terms of time commitment) accredited courses and study days available	We feel this is implicit in paragraph 15.
Teenager Cancer Trust Multidisciplinary Forum	15	Components of both medical and nurse training relevant to young cancer patients should be developed.	We feel this is implicit in paragraph 15.
Teenager Cancer Trust Multidisciplinary Forum	25	Outcomes – also include the effect on life chances due to the disease/its treatment – e.g. education interrupted or truncated employment/career opportunities no longer available – additionally exclusion from services and job opportunities due to prejudice	Although we understand the issue, we do not feel it was right to go into too much detail in this background section.
Teenager Cancer Trust Multidisciplinary Forum	26	People in their early twenties may have families of their own.	Your comment is noted.
Teenager Cancer Trust Multidisciplinary Forum	51, 53	If improvement in survival in childhood malignancies is attributed to centralisation of treatment in specialist centres as well as treatment/care improvements – does this not argue for development of specialist centres, such as TCT Units for teenagers and young adults?	We agree.

[Please give dates of consultation]

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	54	Prevalence. Are there figures available for re-occurrence of cancer in young people first diagnosed when children? Need to know these numbers in order to ensure sufficient specialist facilities available.	These data were not available to us. We were not able to obtain any prevalence data for 15–24-year-olds. The NRCT may be able to provide data on such children.
Teenager Cancer Trust Multidisciplinary Forum	56	Should psychological late effects be included here?	This amendment has been made to the text.
Teenager Cancer Trust Multidisciplinary Forum	60	Key (3) Need to enlarge upon "disease specific rates vary" as masks true picture for 15-24 year olds.	We do not have national survival rate figures for this age group and so feel unable to enlarge upon disease-specific rates. Issues of data availability in this age group have been mentioned in other responses.
Teenager Cancer Trust Multidisciplinary Forum	64	Age within Teenage Cancer Trust Units not yet standardised. Guide age 15-24 yrs. Age limits dependent on where TCT Unit is based. There is a need to standardise age range for admission purposes	In response to stakeholder comments the Guideline Development Group felt that at this stage, age range should be flexible.
Teenager Cancer Trust Multidisciplinary Forum	70	Should include audiology and speech and language All of the disciplines should be trained in meeting the requirements of a young person.	This paragraph summarises the findings of a survey.
Teenager Cancer Trust Multidisciplinary Forum	71	Access to palliative care needs to include the availability and skills of community teams and the voluntary sector. The fears of referral need to be overcome. Children's hospices will accept referrals and offer support from diagnosis, they can always discharge patients. Professionals need greater awareness of the benefits of hospice and not see it only as terminal care.	This paragraph summarises the findings of a survey. Palliative care is covered in more detail later in the guidance.
Teenager Cancer Trust Multidisciplinary Forum	80	There should be useful additional epidemiology figures available from ACT	None were available at the time the needs assessment was conducted.
Teenager Cancer Trust Multidisciplinary Forum	83	Dearth of educational support for young adults – it is essential such provision included	We agree, but this is outside the remit of this guidance

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	88–90	'Refers to delays in diagnosis in under 15 yrs age group'. Teenagers and young adults also experience the same delays due to misdiagnosis of symptoms i.e., glandular fever, sports injury, osteomyelitis	This is true, but unfortunately this is outside the scope of the guidance.
Teenager Cancer Trust Multidisciplinary Forum	97	Parents cannot be held responsible for seeking advice, many presenting problems/symptoms are insidious and manifest only when advanced disease is present.	This paragraph describes the research evidence.
Teenager Cancer Trust Multidisciplinary Forum	99	The GP should acknowledge the importance of a visit from a young person **and** parent.	This paragraph describes the research evidence.
Teenager Cancer Trust Multidisciplinary Forum	132	Is this recommending diagnostic investigation in paediatric centres for young people over 16 as well as children?	This is not a recommendation but a statement relating to the evidence, which itself is not clear about the age limits in the studies.
Teenager Cancer Trust Multidisciplinary Forum	142	Significant weight loss, requiring a change in dosage as a chemotherapy risks can occur for teenagers and young adults. Section only refers to children	The text has been amended to include teenagers.
Teenager Cancer Trust Multidisciplinary Forum	148	Not aware of any nurses prescribing chemotherapy **as yet.**	We have amended the text to read 'clinical staff'.
Teenager Cancer Trust Multidisciplinary Forum	149	Need reassurance that shared guidelines with Paed. Onc Shared Care Centres(POSCUs) not imposed by Paed Onc Centres (POCs) and that funding issues of guidance considered	We cannot provide reassurance on this as it is outside of the remit of this guidance.
Teenager Cancer Trust Multidisciplinary Forum	160	Clear funding arrangements needed for this	We agree.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	161	Rarely will parents want to administer chemo, those who do require the support of nurses and written this way may imply a cost saving to commissioners. It should not be seen as affecting service delivery or a pressure to be placed on parents	We appreciate the comment, but do not feel we need to change any of our recommendations
Teenager Cancer Trust Multidisciplinary Forum	168–178	Needs to be clearer definition of the limits of DGHs in surgery but also the involvement of POSCUs, especially with care during recovery. Needs to be guidance for the non-specialist who finds a mass, who, how and when to refer, remove, biopsy etc	We understand the issue, but it is not possible to go into this amount of clinical detail in service guidance.
Teenager Cancer Trust Multidisciplinary Forum	192	Lack of resources for POSCUs when children transferred back for rehab	We acknowledge that there is a lack of resources for POSCUs and we have made recommendations that commissioning for all aspects of care, wherever they are delivered, are clarified.

Organisation	Section no. or General	Comments	Developer's response
Teenager Cancer Trust Multidisciplinary Forum	192	This refers to "younger children". Perhaps this should be changed to all children (<15 years) as the integrated care of a young person with a brain tumour requires that they are the focus of a multi-disciplinary paediatric team. Allowing some neurosurgical units to continue to operate on "older children" outside a paediatric intensive environment without multi-disciplinary consultation with the paediatric team will allow the situation to re-occur prior to introduction of the RCPCH Guidance on Brain and Spinal Tumours in Children and Young People listed in Appendix. The publication of this document was associated with a dramatic change in referral practice to children's specialist cancer centres. Lack of clarity about which age group should and should not be operated upon by paediatric neurosurgeons within this document would be inconsistent with this prior guidance and its demonstrable success in improving referral trials' recruitment and survival rates for CNS tumours. This lack of clarity may also undermine the very important statements made by this document with respect to rehabilitation which inevitably requires close liaison and working with the full range of specialist and community paediatric rehabilitation services. TYA with neural tumours are not identified in this guidance however they fall into the gap between paediatric and adult, rehab and oncology services. This is only just being recognised and focussed upon in the professional literature. The upper age limit for paediatric neurosurgery should for this reason be maintained at the general upper limit specified in the introduction to this document. A lower limit cannot be justified as in the patients' interests now that paediatric neurosurgery is established.	We have removed the word 'younger'.
Teenager Cancer Trust Multidisciplinary Forum	203–216	This is written only with regard to the technicalities of radiotherapy. There is no consideration to the difficulties for the family of transport, distance, daily treatments, need for GA, or the possible need to admit for treatment	Thank you. The issues you raise are not specific to this section but are covered elsewhere.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	204	Refers to anaesthetics but often children are <u>sedated</u> for radiotherapy, radiotherapy preparation (i.e. mould room prep) Play therapy is vital and may prevent need for anaesthesia or sedation	Thank you for your comments. We do not believe that sedation is appropriate in this setting, but we do agree that play therapy is vital.
Teenager Cancer Trust Multidisciplinary Forum	208	The assumption from this paragraph is that radiotherapy services for children and young people will be specifically commissioned separate from radiotherapy services for adults. As I understand it this is not currently the case. The JCCCO guidelines for radiotherapy / clinical oncology services do not specifically provide for children and young people. If this para is retained then recommendation for specific commissioning of radiotherapy services for children and young people should be included in recommendations for resources.	This assumption is incorrect: radiotherapy services for children and young people will be commissioned alongside radiotherapy services for adults.
Teenager Cancer Trust Multidisciplinary Forum	210	"As soon as possible" - This is a vague statement which is open to wide interpretation. There are no written standards for the accepted waiting times for commencing radiotherapy in children unlike recommendations for waiting times for radical versus palliative radiotherapy in adults. The nature of childhood cancer means that tumour progression can be rapid and speed of action may be critical in successfully initiating radiotherapy. Few clinical situations require initial treatment with radiotherapy to save life however it is relatively common for radiotherapy to be needed to provide effective palliation e.g. Brainstem Glioma. There is a diversity of practice and speed of initiation of treatment which should be subjected to standardised recommendations in view of the very severe personal consequences for families when treatment is offered for their child but not delivered prior to their death for reasons related to resource rather than clinical need. Radiotherapy is predominantly part of multi-disciplinary treatment protocols where the feasibility of initiation of radiotherapy has been taken into account in their design. The standards specified within the protocols and accepted by Ethics and R&D committees could be specified as a disease specific	It is not possible for this guidance to define waiting time standards. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.

Organisation	Section no. or General	Comments	Developer's response
		standard to be adhered to and audited against. Alternatively an arbitrary waiting time from referral to initiation of radical radiotherapy / palliative radiotherapy should be recommended with the children's disease sets in mind. This problem coupled with the problem identified in 208 results in children and young people getting radiotherapy as a result of good will and individualised dispensation within departmental prioritisation processes rather than by right. The current paediatric clinical oncology consultant body in UK are highly committed. However as sub specialisation in adult clinical oncology progresses and the paediatric cross cover arrangements expand the lack of specified priority for children may lead to a situation where their priority is unclear and the previously effective professional advocacy breaks down with disastrous consequences for the child in an overstretched busy department.	
Teenager Cancer Trust Multidisciplinary Forum	217	This should identify the need to establish the agreed standards for resources and commissioning arrangements for radiotherapy departments delivering children's and young people's services	We are not clear how this comment refers to the measurement of structure in paragraph 217; however, Table 2 clearly describes the resources needed.
Teenager Cancer Trust Multidisciplinary Forum	220	Should outline who delivers supportive care, usually POSCU oncology nurse, community nurses. Of vital importance to the family and yet given little emphasis	The draft document did not make it clear that paragraphs 220 and 221 are introductory to the whole section. Thank you for drawing this to our attention
Teenager Cancer Trust Multidisciplinary Forum	221	Do we also need to include nutrition here?	Nutrition is covered in paragraphs 302–318.
Teenager Cancer Trust Multidisciplinary Forum	225	Protocols should be written with full representation of POSCUs and community teams and not imposed by POCs	We would expect the development of protocols would be in consultation with all relevant professionals.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	241–242	CVC insertion is equally traumatic and painful for teenagers and young adults. Sedation and local anaesthetic should be offered for this age group for insertion and removal. General anaesthetic should also be offered where available.	We have amended paragraphs 250 and 251 to include teenagers and young adults.
Teenager Cancer Trust Multidisciplinary Forum	244	Choice of location of port should be included, consideration given to length of treatment and future needs. Families don't seem to get unbiased information on which to base choices. There is no consistency of when line is inserted or type and size	We have amended the paragraph.
Teenager Cancer Trust Multidisciplinary Forum	239–251	Whole section on CVC appears muddled in order and presentation	We believe that the structure is appropriate for the guidance.
Teenager Cancer Trust Multidisciplinary Forum	264	This should clarify use of pain assessment tools, and reassessment of analgesia with constant pain management for all patients.	Thank you. We understand the issue, but it is not possible to go into this amount of clinical detail in service guidance.
Teenager Cancer Trust Multidisciplinary Forum	265	Lumbar puncture and bone marrow biopsy are also a particular issue in teenage and young adult treatment for leukaemia. Young people should receive or should be offered sedation (i.e. IV Midazolam) for these procedures.	We accept that the issue of sedation in teenagers and young adults is complex, but it is not possible to go into this level of detail in service guidance.
Teenager Cancer Trust Multidisciplinary Forum	267	Collaborative approach to protocols	We feel this is implicit in the phrase 'multidisciplinary protocols'.
Teenager Cancer Trust Multidisciplinary Forum	270	There should be provision for all patients, including TYA patients of GA for painful procedures.	The existing statement covers this.
Teenager Cancer Trust Multidisciplinary Forum	277	Other causes of nausea and vomiting not considered. Advice of symptom control teams should be mentioned	We have amended the paragraph.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	287	Access to trained nutritional support team. Provide food that appeals to younger people.	We feel that the aspects of training are covered in paragraph 306. The issue of hospital catering standards is covered by national guidance (see Appendix 1).
Teenager Cancer Trust Multidisciplinary Forum	342	This has implications again for young people with their own families.	We agree.
Teenager Cancer Trust Multidisciplinary Forum	349	Need to specify that individual patient has social work support, not just 'family' as a whole.	This paragraph has been amended to include the patient.
Teenager Cancer Trust Multidisciplinary Forum	351	Can use Social Workers to assess this and refer to psychological services if needed.	We have not made a specific recommendation as to who performs psychosocial assessment.
Teenager Cancer Trust Multidisciplinary Forum	352	Do we need to include financial circumstances/ issues for families too?	We feel this is covered by the phrase 'practical support issues'.
Teenager Cancer Trust Multidisciplinary Forum	351	It would be useful to mention here that expert fertility advice should be made available **prior** to treatment	This is covered by paragraph 404.
Teenager Cancer Trust Multidisciplinary Forum	357	Respite opportunities should be made available/offered	We have included 'respite care' in paragraph 362.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	342–357	Psychosocial Care More emphasis would be useful in terms of important psychosocial issues that affect the quality of care in teenagers and young adults. It is widely documented and there is sufficient evidence to show that it is of vital importance to young people to know other people of the same age with similar diagnosis and treatment regimes. They also require time and space for socialising with other patients, support groups etc. These psychosocial interventions have direct effects on the young person's ability to cope with the hospital experience. Furthermore, nursing staff should have knowledge / expertise in adolescent development and coping strategy in order to interpret behaviour and implement psychosocial care strategies	We appreciate the specific issues mentioned, but we felt that it was only possible and appropriate to provide broad guidance on psychosocial issues.
Teenager Cancer Trust Multidisciplinary Forum	352	Sibling support essential and often over looked	Thank you.
Teenager Cancer Trust Multidisciplinary Forum	359	Access to social worker needs greater emphasis	We feel the emphasis is appropriate.
Teenager Cancer Trust Multidisciplinary Forum	369	Does not mention pulmonary not cardiac late-effects. There is an x 8 mortality from cardiac disease and x 9 excess mortality from pulmonary disease in long term survivors compared to the general population. Very little mention of second malignancies. Survivors of childhood cancer have an excess risk of 11x mortality than expected. 67% deaths are due to the recurrence of original tumour or second malignancies.	This paragraph has been amended appropriately.
Teenager Cancer Trust Multidisciplinary Forum	371	Severe challenge of follow up when now adult and follow up requires a variety of specialists which are not co-ordinated	Thank you this is covered in the section on continuity of care.

Organisation	Section no. or General	Comments	Developer's response
Teenager Cancer Trust Multidisciplinary Forum	378	Transitional services need clear pathways	We agree.
Teenager Cancer Trust Multidisciplinary Forum	381	States that sperm banking should be available for peri-pubertal males. Clearly it must be available for post-pubertal males as well.	This amendment has been made to the text.
Teenager Cancer Trust Multidisciplinary Forum	393	When does palliative care start? The support of palliative care services is relevant through the whole journey even if cure is expected. The holistic supportive approach is valuable through out	Palliative care starts when therapy is no longer given with curative intent. Further relevant points are made in the section on MDTs.
Teenager Cancer Trust Multidisciplinary Forum	395	This comment fails to recognise the palliative care expertise of community paediatric teams and other palliative care providers, it is not only provided by POONs	We have amended the paragraph to reflect this.
Teenager Cancer Trust Multidisciplinary Forum	396	Consider psychological support at this stage for both patient and family, important Recommendations – add 'appropriate skills and experience in handling teenagers, young adults'	We feel the importance of psychological support is recognised throughout the guidance in particular the section on psychosocial support.
Teenager Cancer Trust Multidisciplinary Forum	402	Particular need for staff to be supported when dealing with Teenagers and young adults in palliative stage	Support for staff is important across the whole client group and has been addressed in the section on psychosocial care.
Teenager Cancer Trust Multidisciplinary Forum	398	POONs are not always the best placed to be the key worker	This amendment has been made to the text.
Teenager Cancer Trust Multidisciplinary Forum	399	Children's hospice services should be better accessed and professional fears overcome. Referral at diagnosis should be considered when the fear of bereavement is there and support needed.	We have amended paragraph 427 to strengthen the links with appropriate hospice services, but do not feel it is appropriate for this guidance to be more prescriptive.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	404	24 hour support may come from the community teams. NOF has funded many for this purpose	Thank you.
Teenager Cancer Trust Multidisciplinary Forum	409	Needs recognition of local provision which may include a community paediatric palliative care team. It should not be assumed it can only come from tertiary centres	This is recognised and further strengthened in paragraph 421.
Teenager Cancer Trust Multidisciplinary Forum	414	Use "should" in place of "will"?	This section is an anticipated benefit and therefore the word 'will' is appropriate.
Teenager Cancer Trust Multidisciplinary Forum	419	Structure - Availability of 24hr telephone support	This amendment has been made to the text.
Teenager Cancer Trust Multidisciplinary Forum	422	There is good evidence that pre-bereavement work improves bereavement outcomes. Services should be developed to encompass this, good supportive care to the whole family. There is no mention of the child's/tya pre-death needs. There is no mention of spiritual or cultural issues. There is no mention of the differing needs of sudden death. No mention of need of child/TYA when child known to them dies.	We agree, but feel that this is covered appropriately in this and other sections of the guidance. In addition, we have amended several paragraphs to cover these issues. It is not possible to go into further detail in this guidance.
Teenager Cancer Trust Multidisciplinary Forum	422–425	Additional point re bereavement services Need to ensure supporting team is fully aware of religious practices or lack of, for the patient and family prior to death in order that they can be supported appropriately. These should also be referred to in this section's recommendations	We have amended paragraph 455 and feel that this now covers these issues.
Teenager Cancer Trust Multidisciplinary Forum	428	Needs clear pathways as to who will prove care, often at least 3 services involved, POCs, POSCU and community teams	This should be decided locally, but the key worker may have a role here

Organisation	Section no. or General	Comments	Developer's response
Teenager Cancer Trust Multidisciplinary Forum	430	Staff support/supervision for all those involved in the death of a child/TYA.	This amendment has been made to the text.
Teenager Cancer Trust Multidisciplinary Forum	442–446	Service provision needs robust guidelines/policy to ensure teenagers and young adults are recognised as a specific group with unique needs. Failure to uniform guidelines/policy with an age range will result in a continuation of the 'lottery' of care that exists today. Teenagers and young adults will continue to be cared for inappropriately on Paediatric or Adult environments. Service delivery should include Admission Policy with set criteria, including age range to ensure that young people are appropriately placed.	We agree and have made recommendations to address these issues.
Teenager Cancer Trust Multidisciplinary Forum	443	Parental choice of place of care may make this difficult to achieve	We agree.
Teenager Cancer Trust Multidisciplinary Forum	448	Separating MDTs in this way is not helpful. Diagnostic MDTs should include palliative care to challenge treatment decisions and supportive care to consider the families wider needs. No input of spiritual care givers or community services	We agree and have revised the section on MDTs to clarify.
Teenager Cancer Trust Multidisciplinary Forum	469	The key worker is not necessarily the POON from the tertiary centre. It is often better to be a local nurse and an individual and flexible decision as to who is best. The role of the key worker table 6 is too big. Initially care planning will be POON at POC but much of the list should be by the local team, either POSCU or community service.	We agree that the POON is not necessarily the key worker and feel this is reflected in paragraphs 508–512. This table has been amended to make it smaller.
Teenager Cancer Trust Multidisciplinary Forum	584	Suggest using Social workers and psychologists to provide this training.	This is not appropriate to a measurement section.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	513	Teenagers AND young adults both require the same. Management of cancer in young adults is no less complex in terms of social, psychological and educational needs	This amendment has been made to the text.
Teenager Cancer Trust Multidisciplinary Forum	521	There needs to be recognition of the expertise of local teams.	We feel that the guidance adequately demonstrates the necessary expertise.
Teenager Cancer Trust Multidisciplinary Forum	537	Communication is a huge problem and we agree with this statement	Thank you.
Teenager Cancer Trust Multidisciplinary Forum	576	Agree a good idea to have consistent information	Thank you
Teenager Cancer Trust Multidisciplinary Forum	612	It would be useful to include: - Adolescent Development/behaviour & coping strategy This is still a neglected area and often an area missed by Healthcare professionals with no expertise in caring for the young person.	We have chosen examples that the Guideline Development Group felt were particularly important and the list is not exhaustive.
Teenager Cancer Trust Multidisciplinary Forum	634	Re 16+ education and further education. Commissioners should expect that adequate provision be made for 16+ age group, to enable patients to continue their education, which is likely to be interrupted by treatment.	We agree and feel this is implicit in the text. However, education provision is outside the remit of NHS commissioners.
Teenager Cancer Trust Multidisciplinary Forum	General	There is a strong view from many respondents that a Register for TYA should be established. The majority view was that such a register should encompass 15 – 29 year olds. This should be in association with the National Cancer Registration Scheme and other Registries.	We have amended the key recommendation in paragraph 14, but have maintained that the register should only encompass 15–24-year-olds.
Teenager Cancer Trust Multidisciplinary Forum	General	Regarding the provision of education - the use of technology should be enlisted and the expectation that national service (particularly for further education and rarely studied subjects) could be delivered via a website could be a minimum standard.	We agree that this sounds interesting, but it is outside the remit of this guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	General	There are currently no specified income streams for cancer services for children and young people. There is now a specified funding stream within NCRN for children and young people identified by the funding for the UKCCSG portfolio of trials - the 35th Network. With the introduction of this document a funding stream for Children and Young people's cancer services will need to be established if there is to be progress with these priorities. The Children's NSF is extensive, complex and unfunded. Without a specified cancer funding stream this document will be limited in its effectiveness. Surely a 35th nationwide network for Children and Young People's cancer funding should be established and stop the disordered and uneven development that has dominated the existing service arrangements.	It is not within our remit to determine revenue sources. The resource implications are highlighted in the guidance and the Economics Report that accompanies this guidance.
Teenager Cancer Trust Multidisciplinary Forum	General	The document seems very focused on the needs of POCs with little regard to POSCUs and community teams	We feel the balance is appropriate.
Teenager Cancer Trust Multidisciplinary Forum	General	It does not read as a child and family centred document with the focus being on treatment rather than the needs of the child and family. There is little mention of working in partnership with families and giving choice	We feel the balance is appropriate.
Teenager Cancer Trust Multidisciplinary Forum	General	The travel difficulties for families gets minimal mention	The text has been amended to cover these issues.
Teenager Cancer Trust Multidisciplinary Forum	General	There is no mention of spiritual/cultural issues	The bereavement section has been amended to include this.
Teenager Cancer Trust Multidisciplinary Forum	General	Education gives very little mention	It is not within the remit of this guidance to advise on educational matters.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
Teenager Cancer Trust Multidisciplinary Forum	General	Overall this guidance will be very helpful to use as a tool to influence service provision for young people. However, some further attention is needed to teenagers and young people as a specific group with specific needs and service requirements.	We disagree and feel appropriate emphasis has been given.
Teenager Cancer Trust Multidisciplinary Forum	General	We would like to see more mention about patient choice.	The issues of patient choice were explored in the surveys commissioned for this guidance.
Teenager Cancer Trust Multidisciplinary Forum	General	More comments about choice and child and family centred emphasis	The issues of patient choice were explored in the surveys commissioned for this guidance.
Teenager Cancer Trust Multidisciplinary Forum	General	This is a robust document drawing together the many facets required in the provision of cancer care in children and young people.	Thank you.
Teenager Cancer Trust Multidisciplinary Forum	General	There is a lack of tumour specific recommendations. This is particularly important for TYA where there will be continued professional conflicts and a need to marry specific national tumour guidance for haematological malignancy, sarcoma and epithelial tumours with these recommendations.	This level of detail is not possible in service guidance.
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.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
The Royal West Sussex Trust			This organisation was approached to comment but did not respond.
UK Association of Cancer Registries	General	The UK Association of Cancer Registries (UKACR) is pleased to have the opportunity to read and comment on the draft guidance "Improving Outcomes in Children and Young People with Cancer". The UKACR is very supportive of the initiative and agree that the profile of cancer occurrence and cancer care in these small but important patient groups should be raised.	We welcome these comments. What is important is that accurate, complete and comparable data is collected to allow service planning and evaluation in the future. Our observations of the difficulties we encountered were in no way meant to suggest that the current system should be fragmented and we feel that your proposal represents an excellent solution to the issues raised.
	Recommendation 14	Our specific comment concerns recommendation 14: "The issues related to the registration of cancers in 15-24 year olds and the potential value of a separate register should be addressed urgently at a national level." We believe it would be of great value to create a national intelligence function to work specifically on cancer occurrence and cancer care in 15-24 year olds, but the creation of a separate <u>register</u> (data source) within a new specialist cancer <u>registry</u> (the organisation which holds the data) for this age group is not the best solution. This is because: 1. While it can be argued that childhood cancer (typically defined as 0-14 years) constitutes a unique entity in terms of biology, aetiology and epidemiology, the same does not hold true for cancer in adolescents and young adults (15-24 years). The occurrence of cancer in 15-24 year olds can best be understood as a mixture of the "older" end of the spectrum of childhood cancer (typically congenital and arising in embryonal cell populations during foetal development) and the "young" end of the spectrum of adult cancers (typically arising through somatic mutations in differentiated tissues). The analysis of cancer occurrence and cancer care in 15-24 year olds can only be conducted meaningfully with the possibility of active comparison with	We have re-phrased recommendation 14 and hope this addresses the issues you have raised.

Organisation	Section no. or General	Comments	Developer's response
		patterns of occurrence and care in both younger and older age groups. There will also be issues concerning patients diagnosed at ages less than 15 years but treated at 15-24 years and diagnosed at 15-24 years but treated at older ages. A special registry function that was restricted to 15-24 year olds could not provide this necessary broader context for analysis and interpretation. 2. The data on occurrence and care in patients aged 15-24 years are already collected and quality assured by the regional cancer registries in the UKACR, and there is no unique data source about these patients that is not already used by these registries. The imminent development of the Cancer Registry Dataset, will include further extended details about referral, diagnosis and management pathways including treatment with outcome and follow-up data. 3. Clinical information about cancer patients is considered as sensitive personal data, and the unnecessary dissemination of this information through the creation of a separate cancer registers is not desirable. The UKACR member registries have been given approval by the Patient Information Advisory Group (PIAG) under section 60 of the Health and Social Care Act to receive identifiable information about cancer patients, without informed consent, for the purposes of registration. It is unlikely that PIAG would approve the establishment of further new databases that simply duplicate information held by existing registries. It is the proposal of the UKACR that it (the UKACR) takes responsibility for provision of a national database to support the analysis and intelligence functions relating to cancer occurrence and cancer care in adolescents and young adults. We would delegate this responsibility to one of the existing regional registries, which would create a national, regularly updated analysis file based on data from the regional cancer registries,	

Organisation	Section no. or General	Comments	Developer's response
		including data pertaining to all relevant age groups. The analysis file would be amended with information specifically relevant to adolescents and young adults, e.g. the Birch classification of diagnosis based on already collected tumour topography, morphology and behaviour data. The registry would assign sufficient analytical and statistical personnel to the task and actively collaborate with relevant national organisations (e.g. the newly established professional organisation 'Teenagers and Young Adults with Cancer', the Teenage and Young Adult Research Interest Group within the National Cancer Research Institute, the UK Childhood Cancer Study Group) as well as existing regional paediatric registries and relevant clinical units. Such collaborations, would provide a means of adding value to the core cancer registration dataset by providing supplementary information on e.g. clinical trial entry, long term follow-up outcomes, biological markers etc. We believe this approach would provide a competent and comprehensive cancer registration and cancer intelligence function for cancer in adolescents and young adults in a cost and resource efficient manner.	
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	General	Very supportive of this document tin general	Thank you.
UK Children's Cancer Study Group	General	Very supportive of role for a key worker in late effects	Thank you.
UK Children's Cancer Study Group	General	Very supportive of the major recommendations of the NICE guidance	Thank you.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	General and Table 8	We would suggest that there is no evidence base to suggest that each principal treatment centre should have five consultant staff at least two in paed haem, and two in paediatric oncology as a minimum. We would suggest that each principal treatment centre should be able to provide 7.2 whole time equivalent consultants to fulfil the EU directive of providing 24 hour, 7 days per week care. The UKCCSG recommends that each consultant in paediatric haematology or oncology should be responsible for between 20 and 30 new patients per year. There should therefore be specific recommendations on centre size. One consultant should have a lead responsibility for late effects.	Five have been proposed, as this is now recommended by the Royal College of Paediatric and Child Health as the minimum for an on-call number. We believe this is a minimum (5 WTE) for each centre and have stated that where more complex care is undertaken (e.g. bone marrow transplantation), or where patient numbers are high this number should be greater.
UK Children's Cancer Study Group	136	The role of FDG-PET scanning in Hodgkin's lymphoma is likely to become central to the staging and management in forthcoming international paediatric trials. Access to FDG-PET scanning for children with HL will be important in the future and requires funding.	We have already addressed the role of PET in paragraph 115.
UK Children's Cancer Study Group	188	Strong support	Thank you.
UK Children's Cancer Study Group	192	?Define younger children…	We have removed the word 'younger'.
UK Children's Cancer Study Group	349	Strong support	Thank you.
UK Children's Cancer Study Group	381	Strong support . Suggest refer to NICE fertility guidelines. Also consideration should be given with appropriate expert advice to cryopreservation of ovarian cortical strips in children and young people who are at high risk of a premature menopause.	We have amended this paragraph to refer to the NICE guidance on fertility.
UK Children's Cancer Study Group	374	Strong support	Thank you.
UK Children's Cancer Study Group	379	Role of the late effects nurse practitioner needs to be highlighted here. An urgent need is to devise appropriate training courses for this position and development.	We agree that in this setting the key worker may well be the Late effects Nurse Specialist, but felt it inappropriate to limit the 'key worker' to this role.

Organisation	Section no. or General	Comments	Developer's response
UK Children's Cancer Study Group	369	Must include cardiac dysfunction here (see my special report on late effects, submitted as evidence)	This paragraph has been amended appropriately.
UK Children's Cancer Study Group	380	Emphasise the importance of following available evidence based and best practise guidelines (SIGN and UKCCSG)	These guidelines have been referenced in the Evidence Review that accompanies this guidance.
UK Children's Cancer Study Group	395	General practitioner will have a major role here and should be involved not informed	This amendment has been made to the text.
UK Children's Cancer Study Group	General, Table 7, 517–519	The role and levels of care provided within the shared care centre need more definition. All paediatric units should be able to resuscitate an ill oncology patient and stabilise before transfer (level one care). A shared care centre must be able to assess and instigate the safe treatment of febrile neutropenia according to agreed local protocols. These centres need access to safe blood product advice and supply. All shared care centres should have a designated lead clinician for haem/onc. However, administration of chemotherapy (Level two) and in particular intrathecal chemotherapy (level three) is a major clinical governance risk. These centre require at least two paediatricians with an interest and access to expert paediatric oncological pharmacist advice. Accreditation of levels of care in shared care centres should be recommended.	The Guidance sets out the responsibilities of principal treatment centres and other treatment sites. The level of service provided at each site has not been defined in detail, although a broad outline is given. Specific arrangements between principal treatment centres and other treatment sites need discussion and agreement. These need to take into account local expertise, staffing levels, facilities and the ability of each site to address the recommendations made throughout this guidance regarding the provision of care.
UK Children's Cancer Study Group	General	The UKCCSG welcomes the publication of the NICE guidance.	Thank you.
UK Children's Cancer Study Group	General	The UKCCSG believes the guidance is very comprehensive, clear, covers important aspects and that it will substantially improve the service provided to children and young people with cancer.	Thank you.
UK Children's Cancer Study Group	General	The UKCCSG strongly supports the major recommendations of the NICE guidance.	Thank you.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	General	Regarding the commissioning of cancer services for Children and Young People - There are currently no specified income streams for cancer services for children and young people. There is now a specified funding stream within NCRN for children and young people identified by the funding for the UKCCSG portfolio of trials, the 35th Network. The UKCCSG suggest that consideration be made to creating a specific Paediatric and Young People's Cancer Network. This should stop disordered and uneven development.	It is not within our remit to determine revenue sources. The resource implications are highlighted in the guidance and the Economics Report that accompanies this guidance. We are uncertain of the level of network being proposed, but agree this is one approach to implementation, but it will be up to Commissioners to decide.
UK Children's Cancer Study Group	General	There is support for outcomes, including the opinions and views of voluntary / user groups on how to best serve the needs of these patients.	Thank you.
UK Children's Cancer Study Group	General	Suggest use definition :- POCs - Paediatric Oncology Centres; POSCUs - Paediatric Oncology Shared Care Units - local DGH providing shared care with the centres. .	We have avoided using these definitions, which apply only to the paediatric age group.
UK Children's Cancer Study Group	General	The role of the community children's nurses needs to be specified in recognition of their impact on the care pathway and as a target outcome for the PCTs who do not provide community children's nurses teams.	This amendment has been made to the text.
UK Children's Cancer Study Group	General	Whilst the difficulty of defining an upper age limit is understandable, its absence results in some internal inconsistency, as scattered throughout is an implied upper age limit of 25 years which is not made explicit.	The document has been amended to clarify why we have done this.
UK Children's Cancer Study Group	General	The UKCCSG agrees with the need for effective audit but are concerned that there is insufficient recognition that audit requires resources.	The provision of resources for audit is a local responsibility and is not within our remit.
UK Children's Cancer Study Group	General	The document recognises the importance of treating patients in an age appropriate environment. It perhaps should support the idea of choice for individuals who are at the boundaries of "paediatrics" and young adults. i.e., to be able to allow the 14 or 15 yr old some degree of choice as to which environment they feel most appropriate for them.	We believe that 'choice' is implicit in recommendations 571 and 527.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	General	The UKCCSG suggests that even greater emphasis is placed on the training of nurses and allied health professionals, as this is central to the future service.	We feel the emphasis is sufficient and space precludes a detailed description of training.
UK Children's Cancer Study Group	6	Suggest that the level is defined at which there is planning, commissioning and adequate funding. This should ideally be at a national level.	Strategic level has been removed and made a new recommendation about commissioning in the section on service organisation.
UK Children's Cancer Study Group	7	The UKCCSG suggest that consideration be made to creating a specific Paediatric and Young People's Cancer Network, as the 35th Network as has been done for the NCRN. As at present Cancer Networks' work is predominately focused around adult services, due to a simple equation of the size of populations of cancer patients. A network already exists in terms of the 22 UKCCSG services and this could provide the basis for a service Cancer Network.	We recognise the complexity of the commissioning of these services and a recommendation about the need to address commissioning has been made in the Guidance.
UK Children's Cancer Study Group	7	The UKCCSG believes the recommendation for 5 consultants per site is of great significance and should be highlighted and included in the major recommendations. The importance of an adequate nursing establishment should also be highlighted.	There is a limit to the amount of detail there should be in key recommendations and this is a recommendation in the section on Place of care.
UK Children's Cancer Study Group	*9*	The UKCCSG supports the concept of a 'key worker'. It would be helpful if the background of the key worker was identified i.e. Paediatric Oncology Nurse Specialists (POONs) or Sargent social workers. This has very significant resource implications.	The issues around the key worker are discussed in Table 7 and paragraph 509.
UK Children's Cancer Study Group	10	Suggest add in last line: "all children and young people must have access to tumour specific *or treatment specific (e.g. transplant, clinical expertise as required….).*	This amendment has been made to the text.
UK Children's Cancer Study Group	10	It should be specified that this implies an adolescent / teenage ward for those 15-19 years old	This is meant to reflect services, not just in patient facilities, and is expanded in later sections of the document.
UK Children's Cancer Study Group	11	Suggest add "*Where the surgical expertise is not available transferred to the nearest centre with that expertise should be encouraged and resourced appropriately*".	We agree and feel that this is covered in the section on Surgery.
UK Children's Cancer Study Group	12	Suggest add at the end: "adequate resources should be provided to support such trials *at all levels*".	We disagree as we feel this statement would require further clarification.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	13	Suggest add "if possible the patient should be transferred to the nearest centre where inclusion into the clinical trial is possible. The resources for this should then be transferred".	We have amended the text to clarify.
UK Children's Cancer Study Group	15	The UKCCSG strongly believes that this is a key recommendation great emphasis should be given to training of nursing and allied professional staff. Suggest that this is carried out again by a Paediatric and Young People's Cancer Network. The proposed network for children and young people would have close links to, but be separate from adult services workforce development plans.	We agree this is an important recommendation for the guidance. We are uncertain of the level of network being proposed, but agree this is one approach to implementation – it will be up to Commissioners to decide.
UK Children's Cancer Study Group	16	Suggest planning and commissioning should be at 'strategic' level; possibly a Cancer Network. Commissioning should be at a specialised level.	We have added two recommendations in the section on service organisation to cover this.
UK Children's Cancer Study Group	25	Suggest clearly define age less than 25 years.	We have not specified a specific upper age limit, the reasons for which are further described in amendments to paragraph 19.
UK Children's Cancer Study Group	47	Suggest clarify that although leukaemia is the most common cause of death in this age group, this is because it is the single most common childhood cancer and survival relative to most other cancers is very good	We have slightly changed the wording of this paragraph to try to make this point. However, to discuss leukaemias specifically would not fit with the general point we are trying to make about the effect survival rates have on mortality across the ICCC groups.
UK Children's Cancer Study Group	67	Suggest second sentence should read "many centres undertake *allogeneic* bone marrow transplantation. However some centres refer patients for this procedure". Not specifying which centres receive patents. Appropriate referral pathways should be overt. High dose, myeloablative therapy with haemopoetic stem cell rescue should be considered separately from allogeneic transplantation as it is an 'extension' of dose intensive chemotherapy rather than an immunological manipulation.	We have added 'allogeneic' to the text. This is a background section and referral pathways are dealt with elsewhere in the guidance. Therapy is referred to where appropriate in the guidance.
UK Children's Cancer Study Group	81–82	Suggest identifying specifically, pathology, haematology bio-medical scientists and cytogenetics clinical scientists as AHPs	These clinical scientists are not AHPs. We have acknowledged this staff group throughout the guidance.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	83	Suggest more detail stating that designated social workers and teachers should be part of the multidisciplinary team at all levels of the pathway.	We have added social workers to Table 4. Education is outside the remit of this guidance.
UK Children's Cancer Study Group	110	UKCCSG recognises the importance of paediatric pathologists in making the diagnosis of childhood malignancies and feels that addressing the current shortage of these critical members of the team should be a high priority.	We agree.
UK Children's Cancer Study Group	113	Should this be pathologists?	Pathologists have been included in a new paragraph 103.
UK Children's Cancer Study Group	114	Haematologists also report marrow aspirate and trephines which contribute to staging of solid tumours.	'Bone marrow aspirate' and 'trephine biopsies' have been added to the text.
UK Children's Cancer Study Group	105	Suggest cytogenetics and molecular genetics are mentioned in a separate paragraph. They are increasingly important to the diagnosis and staging of all cancers.	Paragraph 102 has been amended.
UK Children's Cancer Study Group	117	MR imaging, not MRI imaging.	This amendment has been made to the text
UK Children's Cancer Study Group	117	Suggest a comment is added about the need for, and problems with sedation and GA.	Thank you. We feel that these problems are inherent in paragraph 113.
UK Children's Cancer Study Group	118	Suggest the final sentence should read: "as it becomes more widely available, its specific indications within a paediatric setting will become clearer and its use is likely to increase."	This amendment has been made to the text.
UK Children's Cancer Study Group	121	Suggest referring to the need for some samples to be analysed in Quality Assured laboratories for some specialised tests.	The text has been amended.
UK Children's Cancer Study Group	123	Suggest ……*'and Haemopoietic Stem Cell Transplantation*.'	This amendment has been made to the text.
UK Children's Cancer Study Group	124	Suggest addition of 'and solid tumours' after paediatric leukaemias.	This amendment has been made to the text.

Organisation	Section no. or General	Comments	Developer’s response
UK Children's Cancer Study Group	126	Suggest that this statement is made more strongly.	We are unable to strengthen this statement.
UK Children's Cancer Study Group	126	Suggest that it is the investigation and treatment of ‘suspected	We do not understand the relevance of this comment to paragraph 126.
UK Children's Cancer Study Group	130	UKCCSG strongly endorses this point.	Thank you.
UK Children's Cancer Study Group	130	Suggest rapidly is defined.	It is not the within the remit of this Guidance to specify specific time standards. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards
UK Children's Cancer Study Group	130	Suggest pre-treatment MRI at the tertiary centre to include all relevant sequences e.g. spine.	We understand the issue, but it is not possible to go into this amount of clinical detail in service guidance.
UK Children's Cancer Study Group	136	Suggest the final word should read “ongoing” instead of “inconclusive. In addition emphasise that new functional imaging techniques should be subject to rigorous research studies.	We have amended the text.
UK Children's Cancer Study Group	138	Suggest include audit the time taken for the production of pathology report times.	This amendment has been made to the text.
UK Children's Cancer Study Group	140	Suggest specify in addition “myeloablative therapy with haemopoetic stem cell rescue”.	Stem cell transplantation has now been explicitly included in the text of paragraph 140.
UK Children's Cancer Study Group	142	Insert 'are' after first word (there).	This amendment has been made to the text.
UK Children's Cancer Study Group	142	Suggest add fluid volume; management of central lines and other central venous access devices; the wide range of doses used e.g. methotrexate and the increasing complexity of treatment protocols.	Amendments have been made to paragraph 142.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	144	The UKCCSG strongly suggests that computerised chemotherapy prescribing systems become a 'recommendation' rather than a general background point. This is very important in ensuring patient safety. Also we suggest that it is recommended that one system is used nationally.	We agree and have now made a specific recommendation that there should be national strategies to address this issue.
UK Children's Cancer Study Group	148	Insert 'staff' between 'nursing' and 'appropriately'.	We have amended the text to read 'clinical staff'.
UK Children's Cancer Study Group	148&152	As phrased, these points appear to contradict each other, the UKCCSG supports each point. Suggest, some comment to explain the difference between the two points.	We have amended the text to further clarify these two paragraphs.
UK Children's Cancer Study Group	151	It would be useful to define more clearly national standards of training for pharmacists preparing parenteral chemotherapy.	We agree with this statement, but it is not our remit to define standards. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
UK Children's Cancer Study Group	151	Suggest add: a 'designated pharmacist' *and pharmacy support team* should be part of MDT.	This amendment has been made to the text.
UK Children's Cancer Study Group	157	Suggest add: Quality of Life.	This amendment has been made to the text.
UK Children's Cancer Study Group	192	Strongly suggest that this paragraph should be changed to 'all children (<15 years)' rather than "younger children", as the integrated care of a young person with a brain tumour requires that they are the focus of a multi-disciplinary paediatric team. RCPCH Guidance on Brain and Spinal Tumours in Children and Young People listed in Appendix brought about a significant beneficial change in practice.	We have removed the word 'younger'.
UK Children's Cancer Study Group	203	Suggest include Total Body Irradiation for myelolablation.	This amendment has been made to the text.

[Please give dates of consultation]

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	208	The assumption from this paragraph is that radiotherapy services for children and young people will be specifically commissioned separate from radiotherapy services for adults. It appears that this is not currently the case. The JCCCO guidelines for radiotherapy / clinical oncology services do not specifically provide for children and young people. If this paragraph is retained then recommendation for specific commissioning of radiotherapy services for children and young people should be included in recommendations for resources.	This assumption is incorrect: radiotherapy services for children and young people will be commissioned alongside radiotherapy services for adults.
UK Children's Cancer Study Group	210	Suggest define "As soon as possible" The UKCCSG suggests that for those childhood malignancies where radiotherapy is a first line therapy, e.g. medulloblastoma, high grade astrocytoma and Wilms' tumour, a special case is made and these patients receive radiotherapy within two weeks.	It is not possible for this guidance to define waiting time standards. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
UK Children's Cancer Study Group	216	We are aware of the source of the evidence regarding medulloblastoma but are concerned about how this statement will be interpreted	We agree and have amended this paragraph.
UK Children's Cancer Study Group	222	Suggest reference is made to the transfer of a sick child from a shared care unit to the cancer centre.	Amendments have been made to paragraph 231.
UK Children's Cancer Study Group	224	Suggest antibiotic policy should be informed by local microbiological prevalence rates and resistance patterns, and reviewed on a regular basis.	We agree, but this is a clinical issue and is not part of the remit of this guidance. We would foresee this being part of the information on which local protocol is based and regularly updated.
UK Children's Cancer Study Group	225	Suggest national guidelines should address antiviral and antifungal therapies as well as antibiotic management.	Although the details of such national guidance are outside our control, we would expect that it would cover the use of antiviral and antifungal therapies.
UK Children's Cancer Study Group	230	Suggest national research is also needed into:- i) better, safe, prevention of febrile neutropenia ii) the use of antivirals and antifungals in this population.	Thank you, the text has been amended
UK Children's Cancer Study Group	230	Typo in second point "below" should read "for low"	Thank you for picking up this typo, which we have amended.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	232	Benefits also include a reduction in the duration of hospital admission for some patients.	This amendment has been made to the text.
UK Children's Cancer Study Group	236	Suggest add the development of national protocols for antifungal and antiviral therapies.	We agree, but believe that national guidelines will cover the use of antifungal and antiviral therapies.
UK Children's Cancer Study Group	238	Suggest add the number of PICU admission as a result of neutropaenic sepsis.	This amendment has been made to the text.
UK Children's Cancer Study Group	252	Suggest specifically mention CVC associated infections.	The text has been amended.
UK Children's Cancer Study Group	254	Suggest add' Hospitals will have a transfusion committee, *including a paediatric haematologist ….'*	It is not the remit of the guidance to determine the composition of hospital transfusion committees.
UK Children's Cancer Study Group	255	Suggest add a nationally agreed protocol for blood transfusion.	This is not within the remit of this guidance; it is currently being addressed by the British Society of Standards and Haematology.
UK Children's Cancer Study Group	325	Suggest add the roles of education services – home and hospital tuition and neuro-disability.	We have inserted an additional paragraph (686) to include educational services.
UK Children's Cancer Study Group	328 and 330	There would be substantial benefit in a Paediatric and Young People's Cancer Network.	We are uncertain of the level of network being proposed, but agree this is one approach to implementation – it will be up to Commissioners to decide. Whilst the details of the process of commissioning are not within the remit of this guidance, we have made a recommendation that clarification is required on commissioning arrangements.
UK Children's Cancer Study Group	341	Suggest add: - Educational attendance and attainment.	This amendment has been made to the text.
UK Children's Cancer Study Group	347	There is a substantial role for psychological support after completion of therapy.	Agree, amend.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	348	Occupational therapists are mentioned in respect of offering occupational Advice. It is questioned if this is the correct context rather than it being used in a much wider context in conjunction with physiotherapists in the rehabilitation of children.	The paragraph has been amended.
UK Children's Cancer Study Group	349	Suggest add in "social work support should be available after completion of treatment to provide valuable input in terms of employment, schooling, on going family adjustment".	We agree, but have not specified the timing of such support.
UK Children's Cancer Study Group	353	Suggest add in 'for all patients, particularly those with CNS tumours'	This amendment has been made to the text.
UK Children's Cancer Study Group	355	Suggest specify specific recommendations for the siblings with respect to age including youth groups.	We do not feel able to make a specific recommendation in this area.
UK Children's Cancer Study Group	369	Suggest include cardiac disorders. As more than 50% of patients receive cardiotoxic drugs and some reports indicate that 25-50% of patients receiving these drugs develop cardiac abnormalities which causes problems for cardiology departments that have to provide continuing follow-up for these patients due in part to a lack of resources and trained echo cardiologists. 10-15% of patients seen for cardiomyopathy are cancer survivors (USA survey).	This paragraph has been amended appropriately.
UK Children's Cancer Study Group	379	Suggest Late effects Nurse Specialists as the appropriate "key worker".	We agree that in this setting the key worker may well be the Late effects Nurse Specialist, but felt it inappropriate to limit the 'key worker' to this role.
UK Children's Cancer Study Group	380	Strongly suggest that long term follow up should be done with reference to existing national guidelines.	These guidelines have been referenced in the Evidence Review that accompanies this guidance.
UK Children's Cancer Study Group	381	Fertility management is a rapidly changing and very important area to young adults surviving cancer. There is an urgent need to develop national approaches, probably as part of a research protocol, for male and female children and for post pubertal girls, to store immature gametes.	We agree and hope that the amended recommendation in this guidance will promote the development of a national approach to this issue.

Organisation	Section no. or General	Comments	Developer's response
UK Children's Cancer Study Group	381	The development of formal links between UKCCSG / TCT / Young adult cancer units and Assisted Conception Units (ACU) should be widely encouraged / supported not just for the purposes of sperm-banking but to support wider discussions about technologies that may become available for female fertility preservation in the future.	We believe the adoption of this guidance will promote the necessary wider discussions.
UK Children's Cancer Study Group	382	Further information sharing about late effects should also be undertaken once therapy is complete. In addition, children and young people may not be aware of potential late effects that were discussed with their parents at the time of diagnosis. It is essential that these are discussed with them in a timely and appropriate manner as the patients mature. In particular discussion of potential implications on fertility and sexuality need particularly careful handling and staff involved in these discussions should be appropriately trained.	We agree and believe this is covered in the recommendation.
UK Children's Cancer Study Group	392	Suggest add as an outcome: - the evaluation of alternative models of FU care including role of Late Effects MDT, Nurse Specialist, GP and telephone questionnaire based FU.	The measurement section is designed to suggest types of audit to be undertaken and the list is not exhaustive. This is just a suggested topic for local or regional audit.
UK Children's Cancer Study Group	395	In practice most children with cancer who die, do so whilst remaining under the care of their haematologist/oncologist. Therefore it is important the haematologist/oncologist has access to specialist paediatric palliative care expertise and ready access to other support services, rather than referral to a separate palliative care service.	We agree and have not recommended separate palliative care services.
UK Children's Cancer Study Group	395	Suggest, the general practitioner, should continue to be involved instead of be kept fully informed. (Informing GP only may result on families missing aspects of care).	This amendment has been made to the text.
UK Children's Cancer Study Group	418	There would be substantial benefit in a Paediatric and Young People's Cancer Network.	We are uncertain of the level of network being proposed, but agree this is one approach to implementation – it will be up to Commissioners to decide. Whilst the details of the process of commissioning are not within the remit of this guidance, we have made a recommendation that clarification is required on commissioning arrangements.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	444	This point could be strengthened and stated that this may cross Trust's boundaries.	We consider this is implicit in paragraph 444.
UK Children's Cancer Study Group	448, 449	Definition of MTDs for children and young people are very helpful.	Thank you.
UK Children's Cancer Study Group	448, 449	It should be emphasised that there is major overlap between these MDTs	Thank you. We have now re-structured this section, which should clarify this.
UK Children's Cancer Study Group	448, Table 4	Suggest add surgeon to Treatment MDT.	Surgeons are only a core member of the MDT for some cancers, so we feel that they should not be added to the list.
UK Children's Cancer Study Group	448, Table 4	Suggest add microbiologist/virologist to Treatment MDT.	We have included 'microbiologist' in the text.
UK Children's Cancer Study Group	448, Table 4	Suggest add Physiotherapist as a member of the Treatment MDT. .	Physiotherapists are only a core member of the MDT for some cancers, so we feel that they should not be added to the list.
UK Children's Cancer Study Group	448, Table 4	Suggest add Psychosocial support include spiritual / chaplaincy.	We disagree. The MDT should ensure access to this support when required.
UK Children's Cancer Study Group	448, Table 4	Suggest add social worker to late effects MDT.	We disagree. The MDT should ensure access to social work support when required.
UK Children's Cancer Study Group	448, Table 5	Suggest add community children's nurse as a member of the MDT at the other site.	This amendment has been made to the text.
UK Children's Cancer Study Group	448, Table 5	Specify that 'other treatment sites' indicates shared care centres.	We disagree, because shared care centres are more applicable to paediatric settings.
UK Children's Cancer Study Group	448, Table 5	Suggest MDT 'other treatment sites' include psychologist or social worker if such centres deliver chemotherapy.	We have amended this table.

Organisation	Section no. or General	Comments	Developer's response
UK Children's Cancer Study Group	449	Suggest additional MDT for myeloablative therapy	This is an integral part of treatment.
UK Children's Cancer Study Group	515	For paediatric haematologists, non-malignant haematology and laboratory workload has risen due to increase in transfusion and laboratory regulation and accreditation of transplant services.	We have amended to clarify that this is not an exhaustive list.
UK Children's Cancer Study Group	515	Suggest addition paragraph stating the reasons why workload for nurses and Allied Health Professionals have increased – intensity of treatment and the need to provide greater levels of psychosocial and care support. The lack of paediatric training particularly since the demise of the ENB 240 has led to increased pressure to deliver good quality in-house training. The poor retention rate and retirement of senior staff in the past decade has resulted in a very junior workforce, who requires additional supervision and considerable in-house training.	We have amended this paragraph to describe why the workload of nurses and AHPs has increased.
UK Children's Cancer Study Group	517	Suggest training of a paediatrician responsible for shared care is defined	It is not within our remit to specify training requirements.
UK Children's Cancer Study Group	517	Suggest the minimum number of new patients at a shared care centre defined.	The Guideline Development Group felt that it was more appropriate to specify the level of service rather than attempt to specify any numbers.
UK Children's Cancer Study Group	526, Table 8	Suggest consultant staff should be 5 whole time equivalent.	This amendment has been made to the text.
UK Children's Cancer Study Group	526/ Table 8	Suggest the aim should be for each centre to have 7 consultants; this would fulfil the EU Directive of providing a 24 hour, 7 days a week cover. Also mention that the UKCCSG recommends each consultant is responsible for between 20-30 new patients per year	We disagree (please see your comment 119 (paragraph 526, Table 8)). We are unable to include this comment without further evidence.
UK Children's Cancer Study Group	526, Table 8	Suggest define the minimum number of nursing staff	We are unable to define minimum numbers given the variety of shared care arrangements around the country.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	526, Table 8	The UKCCSG very strongly suggests that that there are at least two clinical oncologists (radiotherapists) with expertise in paediatric oncology in each centre.	This amendment has been made to the text.
UK Children's Cancer Study Group	528	Suggest omit 'unless the requirement for specific expertise demands otherwise'.	The Guideline Development Group felt that the qualification was necessary.
UK Children's Cancer Study Group	553	There would be substantial benefit in a Paediatric and Young People's Cancer Network.	We are uncertain of the level of network being proposed, but agree this is one approach to implementation but it will be up to Commissioners to decide. Whilst the details of the process of commissioning are not within the remit of this guidance, we have made a recommendation that clarification is required on commissioning arrangements.
UK Children's Cancer Study Group	562	Alongside the whole discussion so far re working as part of Cancer Networks, this point highlights that there still isn't adequate recognition of the difficulties. The Manual of Cancer Standards 2004 identified in this guidance, does not exist. There is a Manual of Cancer Standards 2000 and there is a Manual of Quality Measures for Peer Review 2004 – both documents are orientated around adult services, the 2004 one talks specifically about the Adult Chemotherapy Unit and the 2000 one talks about children as though they are a Cancer site. Neither can be used off-the-shelf as a measurement tool without adaptation for Children's Services. It is recognised that Peer Review involves considerable time and effort, which is prolonged for staff in Children's Services if they then have to work on adapting, explaining differences and providing evidence as to why differences in paediatrics are justified.	Standards will be produced to address the recommendations in this service guidance. Compliance with these standards when finalised will be a key part of this process and the text has been amended accordingly.
UK Children's Cancer Study Group	568	Suggest mention of the concept of Gillick competence especially with regard to informed consent.	This isn't specifically referring to consent: we would expect this to be covered by the comments on legal frameworks at the start of this guidance.
UK Children's Cancer Study Group	584	Suggest add the use of video to review consultation skills. .	We agree, but this is not appropriate for a measurement section.

Organisation	**Section no. or General**	**Comments**	**Developer's response**
UK Children's Cancer Study Group	586	Formal assessment of communication skills should be part of training requirements	This is not appropriate to a measurement section.
UK Children's Cancer Study Group	609–621	Low numbers of all staff working across the spectrum paediatric oncology care (relative to adult cancers), means that a national approach to training & workforce development is more appropriate than one or two staff trying to find effective ways to develop in their local area. It could also mean that issues around the emotional investment are shored up through peer support when linking up for training. In the long term this may help retention. National training, education and workforce development may however, result in additional costs either by providing Distance Learning methods or to enable staff to travel.	We have added a new recommendation to cover this.
UK Children's Cancer Study Group	617	Haematology bio-medical scientist and clinical scientists are in short supply. Training in paediatric aspects of laboratory haematology for these professional groups should be mandatory.	Thank you for the comment, but this guidance cannot mandate training standards. Following publication of the guidance, we anticipate that the Department of Health and Welsh Assembly Government will issue appropriate standards.
UK Pain Society			This organisation was approached to comment but did not respond.
University College London Hospital NHS Trust	General	The authors are to be congratulated on an extremely comprehensive document of which I am broadly supportive. My main concern, however, is that we may miss an opportunity if the draft is left in its current format to clarify the ideal referral pathways and recommendations for management of the teenage population. Although the document includes within its term of reference older teenagers and young adults, the actual document reads and is more comprehensive for children under sixteen. Specific issues:	Thank you. We feel that we have adequately considered the needs of the teenage population for cancer care.

Organisation	Section no. or General	Comments	Developer's response
University College London Hospital NHS Trust	93	I am most concerned that we may be missing an opportunity to clarify the ideal referral pathways into tertiary and quaternary care for the teenage cancer population. I am particular concerned about teenagers and young people older than sixteen years who would not normally be referred to a secondary care paediatrician and where the point of reference for secondary services may be extremely diverse. There may be a lack of awareness of cancer in teenagers, who almost certainly contributes to delays in diagnosis in this subgroup.	We have acknowledged that there are problems with delayed diagnosis for this older age group. However, because this is a diverse group of patients it is very difficult to clarify all the 'ideal' referral pathways. We hope that the recommendations made in this document will improve this situation.
University College London Hospital NHS Trust	140	I agree that access to paediatric haematology for diagnosis and assessment of response to treatment is essential to modern paediatric practice. I think it would be helpful in this section to have some clarification about the role of paediatric oncologists in the management of paediatric haematological malignancies.	We do not believe that further clarification is necessary.
University College London Hospital NHS Trust	185	I have a major concern that the neuro-oncology referral pathway makes no recommendation for over fifteen year olds. This is a group that has limited access to paediatric/adolescent neuro-oncology MDTs, which may mean that there is a considerable teenage population that does not have access to adjuvant chemotherapy protocols or, indeed, a paediatric histopathologist familiar with bone tumour appearances more common in younger age groups. I think it is vital that we should be directive about the access to paediatric/ adolescent neuro-oncology MDT's for this vulnerable age group.	We have amended paragraph 192 to address this issue.
University College London Hospital NHS Trust	209	Presume that it is meant 'hyperfractionated guided therapy' rather than 'hypo'.	'Hypo' is correct.
University College London Hospital NHS Trust	533	It would be helpful to have some clarification about the statement of direct access to intensive care facilities; in particular whether that broadly includes access to an adult intensive care unit for stabilization pre-transfer or whether it could include access to a dedicated retrieval team with standards in place for timing of access to a children's intensive care unit.	The broader issues of access to intensive care treatment for this age group is outside the remit of this guidance; however, we have now included reference to the TROOP report and commissioned an expert paper from Dr Monica Stokes (paper included in the Evidence Review).

Organisation	**Section no. or General**	**Comments**	**Developer's response**
University College London Hospital NHS Trust	550	There is a statement about taking patients with febrile neutropenia on wards other than specialist oncology wards, which I perceive to be at odds with the recommendation in the earlier section 222-229, which looks at the provision of febrile neutropenia management in shared care units. I think it would be helpful if there was some understanding of what was meant by that statement in section 550.	The statement is a suggestion for audit of inappropriate care – i.e. managing the patients on a ward other than a specialist oncology ward.
University College London Hospital NHS Trust	Fig. A	An important group missed out of the Venn diagram is that of psychological services which I think deserves specific mention. I look forward to the next draft.	This amendment has been made to the diagram. Thank you.
Welsh Assembly Government (formerly National Assembly for Wales)	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.