

Child and adolescent cancer - Stakeholder Consultation Table - SCOPE

Stakeholder	Section number	Comments Please insert each new comment in a new row.	Developers' Response Please respond to each comment
ABPI	General	The Association of the British Pharmaceutical Industry (ABPI) welcomes the scope for the NICE Child and Adolescent Cancer Services Guideline. We believe the scope is comprehensive and have no additional comments to make. We look forward to contributing to the guideline in its development.	Thank you.
Association of Children's Hospices	4.1.2	Should the upper age range be higher? Could this be flexible as the age of diagnosis and onset of treatment will vary but some 18 – 19 year olds will be very vulnerable and would benefit from continuity of care, especially if they are approaching the terminal phase of their illness after several years with their paediatric oncologist and team.	We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a).
Association of Children's Hospices	4.3 b)	Should the Scope define what it means by the term 'Palliative Care'?	This will be covered in the forthcoming document to be published by NICE.
Association of Children's Hospices	4.3 b)	What is meant by the term 'Specialist and Community-based Palliative Care'? The phrasing suggests that there is a distinction between hospital and community-based palliative care and appears to imply that community-based care is not specialist.	This Section has been re-ordered taking your comment into account.
Association of Children's Hospices	4.3 b)	Should the Scope define 'Community-based Care' further, i.e.: Does this include hospice and day care etc or just care within the home?	This is outside the remit of the scope.
Association of Children's Hospices	4.3 b) and c)	The term 'Palliative Care' is included under both 'treatment' and Support services. Other services such as Psychology, Physiotherapy, Occupational Therapy etc are not included under 'treatment services'. Are they not 'treatments'? And if not, what is it about Palliative Care that sets this apart?	This Section has been re-ordered taking your comment into account.
Association of Children's Hospices	4.3 c)	Does the term 'Palliative care' in this section refer only to terminal/end of life care as including it with 'Bereavement Care' tends to imply that it does. The Scope should reflect the fact that 'Palliative Care' and 'Terminal Care' are not the same thing.	Palliative care will cover a whole range of aspects including terminal and end of life care.

Association of Children's Hospices	General	There is no specific reference to the work of the voluntary sector for example, children's hospice services are provided by this sector.	We have added integration to the voluntary sector under healthcare settings in Section 4.2 f)
Association of Children's Hospices	General	There is no specific reference to the role and needs of parents.	Support services for families, carers and siblings are now included in Section 4.3 e).
Association of Children's Hospices	General	There is no specific reference to the role and needs of siblings.	Support services for families, carers and siblings are now included in Section 4.3 e).
Association of Children's Hospices	General	There is no specific reference to terminal/end of life care.	Palliative care, Section 4.3 d) will cover a whole range of aspects including terminal and end of life care.
Association of Children's Hospices	General	There is no reference to spiritual needs.	Care such as spiritual care/ support/counselling/voluntary sector services will now be considered under support services in Section 4.3 e).
British Association of Oral and Maxillofacial Surgeons	4.3 a)	We believe that it would be appropriate to include O&MFS (Oral and Maxillofacial Surgery) alongside ENT under the second bullet point in this section. Those tumours affecting the head and neck region require appropriate specialist surgical services which are jointly provided by ENT and O&MFS.	This section lists some examples and is not exhaustive. These specialists would be included in the term "other specialists" in Sections 4.3 a) and 4.3 b).
British Association of Oral and Maxillofacial Surgeons	4.3 c)	We believe that this section should include general and specialist dental services (including oral health promotion) either separately or within the sixth bullet point. The use of chemotherapy in this cohort of patients commonly has a significant effect on both the oral hygiene and oral health of these patients and it is paramount as part of their management that these aspects are catered for both timely and appropriately.	Agreed, included in Section 4.3.
British Association of Oral and Maxillofacial Surgeons	General	The document is welcomed.	Thank you.
British Association of Parenteral and Enteral Nutrition	4.3 b)	Thank you for allowing us to comment on this scope. Clearly nutrition is not a treatment <i>per se</i> for these cancers but we believe that it is of great importance in the care of Childhood cancer.	Agreed, included in Section 4.3 c).

		Many of these children will become significantly malnourished from their disease itself and with this will become vulnerable and may suffer growth retardation. On top of this, chemotherapy with associated gut side effects can worsen the situation and may even necessitate parenteral nutrition support. We would therefore hope that the guidelines can address nutritional issues and the need for expert input in this area of care.	
British Dietetic Association	4.1	Either not to specify the upper age range for adolescents or specify it as 25 years of age rather than 19 years. Teenage Cancer Trust Units or adolescents treated in units attached to paediatric centres, treat adolescents from ages 13-approx 25 years age who have paediatric type tumours and are subsequently often cared for by same medical, nursing and supportive care staff as the younger adolescent age group. Therefore they should be included in the scope.	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
British Dietetic Association	4.1.2	To include some of the children with benign brain tumours who receive similar treatment to those children with malignant disease as they will require the same level of supportive care due to side effects of treatment.	We have now widened Section 4.1.1 to include some benign tumours.
British Dietetic Association	4.1.2	To perhaps include other groups of children requiring bone marrow transplantation for non-malignant reasons who are treated in the same unit as those transplanted for malignant reasons as again they are often cared for by the same medical, nursing and supportive care staff.	This is outside the DOH and Welsh Assembly Government remit for this guidance.
British Paediatric Neurology Association	4.1.2 b)	Must remove/modify exclusion of ‘benign’ tumours: Benign/malignant dichotomy is not appropriate for intracranial brain tumours whose position may make them inoperable and potentially devastating with continued slow local growth. Therefore guidance must include ‘benign’ intracranial tumours: pathologies such as optic glioma, craniopharyngioma have major associated morbidities, long term disabilities and a significant mortality and require same treatment modalities as ‘malignant’ tumours. These tumours types are particularly likely to be mismanaged precisely because they are not served as part of the mainstream of clinical ‘oncological’ provision	We have now widened Section 4.1.1 to include some benign tumours.
British Paediatric Neurology	4.3 a)	Must include referral guidelines and widen scope of range of involved specialists: Why are referral guidelines excluded? This	The Institute is in the process of updating the guideline ‘referral for

Association		<p>is one of the main issues. Historically, improvement in outcomes has for example been substantially attributable to persuading neurosurgeons that ‘surgical’ diseases like low grade glioma and craniopharyngioma require interdisciplinary management including child cancer services. It seems perverse to exclude the possibility of such guidance from the scope of the guidance. There are some curious categorisations: for example paediatric oncologists as a ‘diagnostic service’ and ‘chemotherapy’ as a ‘treatment service’ – which is actually provided by paediatric oncologists. Also it seems odd to mention general paediatricians and haematologists (and, as a separate category, specialist paediatric oncologists and haematologists) but not paediatric endocrinologists, ophthalmologists, neurologists and neurosurgeons who are frequently in an important diagnostic role for intracranial tumours</p>	<p>suspected cancers’. It is not within the scope of this guidance.</p>
British Paediatric Neurology Association	4.3 b)	<p>Must include rehabilitation services and child psychiatric services within scope, be clearer about role of psychology, and not separate ‘follow-up’ from diagnosis, treatment and support. Could also re-assort between (or amalgamate) treatment and support. Why is palliative care a ‘treatment service’ and a ‘support service’ while the word ‘rehabilitation’ does not appear at all (although some of those who would form part of such a team are mentioned as ‘other multidisciplinary services’ under ‘support services’). ‘Follow-up’ should not be a separate heading, defined by time period in relation to treatment rather than role, which is regarded as neither diagnosis nor treatment nor support. Indeed this is quite a succinct way of describing the problem with the thinking behind some current service provision. Emotional and behavioural disorders are the most common sequelae from brain tumours and child psychiatric input must be considered. ‘Psychology’ is mentioned but there are both assessment/diagnostic issues (e.g. identifying cognitive impairments) (?to be added under 4.3 a) as well as 4.3 c)) and also therapeutic roles (e.g. cognitive behavioural therapy) to be added under 4.3 b) as well as ‘support’. Also is it accurate or helpful to suggest that physios and dieticians ‘support’ while</p>	<p>This section has been re-ordered taking your comment into account.</p> <p>Rehabilitation is now included and follow up is a continuation of this but the heading is useful in clarifying the scope of the document.</p> <p>Agreed, included in Section 4.3 c)</p> <p>Agreed, now included.</p>

		<p>palliative care ‘treats’.</p> <p>In Nordic countries the care of children after tumours would be coordinated by the rehabilitation team and they even have a non-profit organisation (the CTRF) specifically dedicated to support the rehabilitation of children ‘after cancer or trauma in childhood’. Certainly the issues are very similar after head trauma and after treatment of brain tumours in childhood. The issues are rather different than after adult brain tumour in adults primarily because of the different diseases and relatively small proportion of long term survivors of adult brain tumour but also because of the primacy of neurodevelopmental and educational issues after acquired brain injury in childhood. These issues are not always understood by cancer services (nor by CRUK) even though brain tumours are the commonest type of solid tumour of childhood. These issues are central to improving outcomes in child and adolescent cancer in cases that affect the central nervous system and should be within scope.</p>	<p>Thank you, your questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this area as a clinical question.</p>
<p>British Paediatric Neurology Association (2)</p>	<p>General</p>	<p>I have been asked to comment on the scoping document on behalf of the BPNA.</p> <p>Another person has also been asked but I am afraid that the short time scale has prevented me from amalgamating my comments with any which he may separately have provided you with.</p> <p>I hope my comments will be helpful to you in deciding on the scope of the document.</p>	<p>Thank you for your comments.</p>
<p>British Paediatric Neurology Association (2)</p>	<p>4.1.2 b)</p>	<p>4.1.2 b) must remove/modify exclusion of ‘benign’ tumours</p> <p>Benign/malignant dichotomy is not appropriate for intracranial brain tumours whose position may make them inoperable and potentially devastating with continued slow local growth. Therefore guidance must include ‘benign’ intracranial tumours: pathologies such as optic glioma, craniopharyngioma have major associated morbidities, long term disabilities and a significant mortality and require same treatment modalities as ‘malignant’ tumours. These tumours types are particularly likely to be mismanaged precisely because they are not served as part of the</p>	

		mainstream of clinical 'oncological' provision	
British Paediatric Neurology Association (2)	4.3 a)	<p>4.3 a) must include referral guidelines and widen scope of range of involved specialists</p> <p>Why are referral guidelines excluded? This is one of the main issues. Historically, improvement in outcomes has for example been substantially attributable to persuading neurosurgeons that 'surgical' diseases like low grade glioma and craniopharyngioma require interdisciplinary management including child cancer services. It seems perverse to exclude the possibility of such guidance from the scope of the guidance. There are some curious categorisations: for example paediatric oncologists as a 'diagnostic service' and 'chemotherapy' as a 'treatment service' – which is actually provided by paediatric oncologists. Also it seems odd to mention general paediatricians and haematologists (and, as a separate category, specialist paediatric oncologists and haematologists) but not paediatric endocrinologists, ophthalmologists, neurologists and neurosurgeons who are frequently in an important diagnostic role for intracranial tumours</p>	
British Paediatric Neurology Association (2)	4.3 b)	<p>4.3 b) must include rehabilitation services and child psychiatric services within scope, be clearer about role of psychology, and not separate 'follow-up' from diagnosis, treatment and support. Could also re-assort between (or amalgamate) treatment and support</p> <p>Why is palliative care a 'treatment service' and a 'support service' while the word 'rehabilitation' does not appear at all (although some of those who would form part of such a team are mentioned as 'other multidisciplinary services' under 'support services'). 'Follow-up' should not be a separate heading, defined by time period in relation to treatment rather than role, which is regarded as neither diagnosis nor treatment nor support. Indeed this is quite a succinct way of describing the problem with the thinking behind some current service provision. Emotional and behavioural disorders are the most common sequelae from brain tumours and child psychiatric input must be considered.</p>	

		<p>'Psychology' is mentioned but there are both assessment/diagnostic issues (e.g. identifying cognitive impairments) (?to be added under 4.3 a) as well as 4.3 c)) and also therapeutic roles (e.g. cognitive behavioural therapy) to be added under 4.3 b) as well as 'support'. Also is it accurate or helpful to suggest that physios and dieticians 'support' while palliative care 'treats'.</p> <p>In Nordic countries the care of children after tumours would be coordinated by the rehabilitation team and they even have a non-profit organisation (the CTRF) specifically dedicated to support the rehabilitation of children 'after cancer or trauma in childhood'. Certainly the issues are very similar after head trauma and after treatment of brain tumours in childhood. The issues are rather different than after adult brain tumour in adults primarily because of the different diseases and relatively small proportion of long term survivors of adult brain tumour but also because of the primacy of neurodevelopmental and educational issues after acquired brain injury in childhood. These issues are not always understood by cancer services (nor by CRUK) even though brain tumours are the commonest type of solid tumour of childhood. These issues are central to improving outcomes in child and adolescent cancer in cases that affect the central nervous system and should be within scope.</p>	
British Paediatric Neurosurgical Group	4.1.2	To avoid the problem with distinguishing "benign" and tumours to be included, may I suggest that we substitute in section b) "benign tumours" for the phrasewith "tumours not requiring complex or multidisciplinary team therapies". This would get over tumours such as Craniopharyngiomas which technically are "benign" but require long term and very complex treatment regimes and are just the sort of tumours that we would wish to include in the document, but would be excluded with the current wording.	We have now widened Section 4.1.1 to include some benign tumours.
British Paediatric Neurosurgical Group	4.2	Whilst accepting that these are Guidelines we need to remember whom they are addressing. Many of these patients will have treatment needs that will be purchased through Specialist Commissioners. Others will be purchased through Lead Commissioners, such as Neurosurgery. and yet others will be purchased by PCT's. Putting in age limits may have financial	Thank you for drawing our attention to this potential problem. These are not clinical guidelines but service guidance for commissioners of cancer care. Part of the development process will involve

		consequences for a Hospital or organisation and the Document may lead to the need to address funding for these patients as a separate group. Do we need to raise this at this stage?	the advice and input of commissioners. We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
Chartered Society of Physiotherapy	General	Please can rehabilitation be seen as an ongoing and integral part of the care of a child with cancer and not seen as something that happens as part of ‘terminal or palliative care’?	The importance of rehabilitation is recognised in Section 3 b) and has been added as a key area of clinical management to Section 4.3 c)
Chartered Society of Physiotherapy	General	Supportive care should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment. In the NICE Supportive and Palliative Care guidelines, it encompasses: self help and support, user involvement, information giving, psychological support, symptom control, social support, rehabilitation, complementary therapies, spiritual support, palliative care, end of life and bereavement care.	We intend to address some of these important issues, several of which are now covered in Section 4.3. However it is beyond our scope to go in to too much detail. We will be suggesting to the DH and Welsh Assembly Government the need to have specialist guidance for palliative care of children.
Chartered Society of Physiotherapy	4.3 b)	We agree with this list, and would add ‘Rehabilitation’. Co-ordinated care after each of these other treatments should consider how the child returns to their usual activities at home. Nursing and allied health professionals, including physiotherapists, are integral to the multi-professional team who will assess and intervene as part of these ‘treatment services’.	Agreed, included in Section 4.3 c). Thank you, your questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this area as a clinical question.
Chartered Society of Physiotherapy	4.3 b)	The scope <i>appears</i> not to consider how care for the routine <i>side effects</i> for these medical treatments are configured, i.e. that patients have access to nursing and allied health professionals for treatment for the known side effects (for example, respiratory problems following surgery).	This section has been re-ordered taking your comments into account.
Chartered Society of Physiotherapy	4.3 c)	It is not clear what is meant by this section, who will be included, when (along the patient journey), and how. We are pleased to see physiotherapists in this list, and presume it	Section 4.5 has been revised, and we now feel that it addresses your point.

		is illustrative of other allied health professionals, and not exhaustive. Is this correct?	That is correct – it is a list of examples and is not exhaustive.
Chartered Society of Physiotherapy	4.3 d)	Does the term ‘specialist’ mean medical consultant? Please can you confirm that this ‘specialist’ follow up will include physiotherapists for the late effects of treatment and growth, etc?	No. ‘Specialist’ in this context refers to any health care professional. This section lists some examples and is not exhaustive. Physiotherapy for the late effects of treatment and growth will be considered.
Children’s and Adolescent Cancer Partnership	General	We would like to comment about the proposed involvement of service users (patients and carers), we feel that it is obviously inappropriate for children to be members of the GDG and we have similar concerns about adolescents being on the GDG. We would be very supportive of a consultation process for each section of the guideline that involves a cross-section of young patients and survivors and would be happy to assist in facilitating this via our various members’ patient / carer networks. We would suggest greater representation of service users in the GDG.	Membership of the Guidance Development Group is currently being considered. Also being considered is the most appropriate ways to involve patients and carers in the guidance development. The Patient Involvement Unit for NICE will be working with the Collaborating Centre to help facilitate appropriate patient/carer involvement.
Children’s and Adolescent Cancer Partnership	2 a)	We would like to see the Voluntary Sector acknowledged as a major funding source and provider of child and adolescent cancer services and care in England and Wales.	This section is intended to provide very brief contextual information and does not go into detail about funding sources or providers. Reference to this topic is provided in 3 d).
Children’s and Adolescent Cancer Partnership	3 a)	We would like to see the number of adolescents diagnosed with cancer each year included.	We have now included figures for the 15 to 23 years age range.
Children’s and Adolescent Cancer Partnership	3 b)	We would like to see quantification of the prognosis for adolescents rather than “often less good”.	These data will be included in the Guidance.
Children’s and Adolescent Cancer Partnership	3 c)	We would like to see overall survival rates for adolescents as well as for children.	This will be included in the background to the Guidance. Data not currently available.
Children’s and Adolescent Cancer Partnership	4 d) new section	The guideline will be integrated with other relevant NICE guidelines (e.g. Referrals for Suspected Cancer, Haem / Onc.)	Agreed - see Section 2 c). Cross reference will be made to these and other documents as appropriate.

Children's and Adolescent Cancer Partnership	4.1.1 a	We suggest the following wording "Children, adolescents and young adults diagnosed with cancer, leukaemia and related conditions as defined by the International Classification of Childhood Cancer (incorporating the amendments used by UKCCSG). We particularly welcome this inclusion as it encompasses the non-malignant life-threatening brain tumours and Langerhans cell Histiocytosis.	We have now widened the definition in Section 4.1.1. We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a)
Children's and Adolescent Cancer Partnership	4.1.2	If comments from 4.1.1 a are accepted then a and b from this section need to be excluded.	We have now widened the definition in Section 4.1.1. We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a)
Children's and Adolescent Cancer Partnership	4.2	We suggest the following wording "The guidance will cover the following NHS services and their commissioning and commissioners in England and Wales and their integration with the voluntary sector"	This document is by definition for commissioners and we can only advise on services. It is understood that the commissioners are expected to implement the guidance. We agree that the integration with the voluntary sector is important and included reference to this. See Section 4.2 f).
Children's and Adolescent Cancer Partnership	4.2 a)	We suggest the following wording "Primary care, including early diagnosis, care in the community of those receiving active treatment, rehabilitation, follow up and palliative care."	The changes have been made as suggested.
Children's and Adolescent Cancer Partnership	4.2 d) new section	Paediatric Oncology Shared Care Units (POSCU's)	Agreed. Shared Care Centres now added, see Section 4.2 b).
Children's and Adolescent Cancer Partnership	4.2 d) now becomes e)		Agreed. Shared Care Centres now added, see Section 4.2 b).
Children's and Adolescent Cancer Partnership	4.2 f) new	Voluntary sector (commissioning and partnership)	Yes we have added integration to

Adolescent Cancer Partnership	section		the Voluntary Sector, Section 4.2 f).
Children's and Adolescent Cancer Partnership	4.3 a)	We suggest the following additions to bullet point 2 (for example, ENT surgeons, orthopaedic surgeons, general surgeons, gynaecologists and general adult physicians)	This section lists some examples and is not exhaustive. These specialists would be included in the term "other specialists" in Sections 4.3 a) and 4.3 b).
Children's and Adolescent Cancer Partnership	4.3 b)	new bullet points: paediatric intensive care pharmacy supportive services (including, nutritional support and rehabilitation)	Agreed, included in Section 4.3.
Children's and Adolescent Cancer Partnership	4.3 c)	new bullet points: play and recreation peer support networks for patients and family / carers	Agreed, included in Section 4.3 e).
Children's and Adolescent Cancer Partnership	4.3 d)	bullet point 1: We suggest "need, type, frequency, location and by whom"	Agreed, included in Section 4.3 f).
Children's and Adolescent Cancer Partnership	4.3 d)	bullet point 2: We suggest the addition of orthopaedic	Agreed, included in Section 4.3 f).
Children's and Adolescent Cancer Partnership	4.3 d)	new bullet point: transition of care from paediatric to adult services	We agree. Transition between services will be covered.
Children's and Adolescent Cancer Partnership	4.3 e)	new bullet point: Administration and data management support, especially in relationship to clinical trials.	Agreed, data management included in Section 4.3 g)
Children's and Adolescent Cancer Partnership	4.4	We suggest the following "The guidance will include key criteria for audit, which will enable objective measurements to be made of the extent and nature of local implementation of this guidance, particularly its impact upon practice and outcomes for children, adolescents and young adults with cancer (to include both qualitative and quantitative outcome measurement).	We are unable to change this section, as the wording is standard in all scopes.
CLIC - Cancer and Leukaemia in Childhood	General	We would like to comment about the proposed involvement of service users (patients and carers), we feel that it is obviously inappropriate for children to be members of the GDG and we have similar concerns about adolescents being on the GDG. We	Membership of the Guidance Development Group is currently being considered. Also being considered is the most appropriate

		would be very supportive of a consultation process for each section of the guideline that involves a cross-section of young patients and survivors and would be happy to assist in facilitating this via our various members' patient / carer networks. We would suggest greater representation of service users in the GDG. We would like to see the Voluntary Sector acknowledged as a major funding source and provider of child and adolescent cancer care in England and Wales. Given that the service is based so heavily in the Voluntary Sector, it is highly vulnerable to changes in policy, and the changing financial situation.	ways to involve patients and carers in the guidance development. The Patient Involvement Unit for NICE will be working with the Collaborating Centre to help facilitate appropriate patient/carer involvement.
CLIC - Cancer and Leukaemia in Childhood	2 a)	We would like to see the Voluntary Sector acknowledged as a major funding source and provider of child and adolescent cancer services and care in England and Wales.	This section is intended to provide very brief contextual information and does not go into detail about funding sources or providers. Reference to this topic is provided in 3 d).
CLIC - Cancer and Leukaemia in Childhood	3 a)	We would like to see the number of adolescents diagnosed with cancer each year included.	We have now included figures for the 15 to 23 years age range.
CLIC - Cancer and Leukaemia in Childhood	3 b)	We would like to see quantification of the prognosis for adolescents rather than "often less good".	These data will be included in the Guidance.
CLIC - Cancer and Leukaemia in Childhood	3 c)	We would like to see overall survival rates for adolescents as well as for children.	This will be included in the background to the Guidance. Data not currently available.
CLIC - Cancer and Leukaemia in Childhood	4 d) new section	The guideline will be integrated with other relevant NICE guidelines (e.g. Referrals for Suspected Cancer, Haem / Onc.)	Agreed - see section 2 c). Cross reference will be made to these and other documents as appropriate.
CLIC - Cancer and Leukaemia in Childhood	4.1.1 a)	We suggest the following wording "Children, adolescents and young adults diagnosed with cancer, leukaemia and related conditions as defined by the International Classification of Childhood Cancer (incorporating the amendments used by UKCCSG). We particularly welcome this inclusion as it encompasses the non-malignant life-threatening brain tumours and Langerhans cell Histiocytosis.	We have now widened the definition in Section 4.1.1. We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a)
CLIC - Cancer and Leukaemia in	4.1.2	If comments from 4.1.1 a are accepted then a and b from this section need to be excluded.	We have now widened the definition in Section 4.1.1.

Childhood			We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a)
CLIC - Cancer and Leukaemia in Childhood	4.2	We suggest the following wording “The guidance will cover the following NHS services and their commissioning and commissioners in England and Wales and their integration with the voluntary sector”	This document is by definition for commissioners and we can only advise on services. It is understood that the commissioners are expected to implement the guidance. We agree that the integration with the voluntary sector is important and included reference to this. See Section 4.2 f).
CLIC - Cancer and Leukaemia in Childhood	4.2 a)	We suggest the following wording “Primary care, including early diagnosis, care in the community of those receiving active treatment, rehabilitation, follow up and palliative care.”	The changes have been made as suggested.
CLIC - Cancer and Leukaemia in Childhood	4.2 d) new section	Paediatric Oncology Shared Care Units (POSCU’s)	Agreed. Shared Care Centres now added, see Section 4.2 b).
CLIC - Cancer and Leukaemia in Childhood	4.2 d)	4.2 d) now becomes e	Agreed. Shared Care Centres now added, see Section 4.2 b).
CLIC - Cancer and Leukaemia in Childhood	4.2 f) new section	Voluntary sector (commissioning and partnership)	Yes we have added integration to the Voluntary Sector, Section 4.2 f).
CLIC - Cancer and Leukaemia in Childhood	4.3 a)	We suggest the following additions to bullet point 2 (for example, ENT surgeons, orthopaedic surgeons, general surgeons, gynaecologists and general adult physicians)	This section lists some examples and is not exhaustive. These specialists would be included in the term “other specialists” in Sections 4.3 a) and 4.3 b).
CLIC - Cancer and Leukaemia in Childhood	4.3 b)	new bullet points: paediatric intensive care pharmacy	Agreed, included in Section 4.3.

		supportive services (including, nutritional support and rehabilitation)	
CLIC - Cancer and Leukaemia in Childhood	4.3 c)	new bullet points: play and recreation peer support networks for patients and family / carers	Agreed, included in Section 4.3 e).
CLIC - Cancer and Leukaemia in Childhood	4.3 d)	bullet point 1: We suggest “need, type, frequency, location and by whom”	Agreed, included in Section 4.3 f).
CLIC - Cancer and Leukaemia in Childhood	4.3 d)	bullet point 2: We suggest the addition of orthopaedic	Agreed, included in Section 4.3 f)
CLIC - Cancer and Leukaemia in Childhood	4.3 d)	new bullet point : transition of care from paediatric to adult services	We agree. Transition between services will be covered.
CLIC - Cancer and Leukaemia in Childhood	4.3 e)	new bullet point: Administration and data management support, especially in relationship to clinical trials.	Agreed, data management included in Section 4.3 g)
CLIC - Cancer and Leukaemia in Childhood	4.4	We suggest the following “The guidance will include key criteria for audit, which will enable objective measurements to be made of the extent and nature of local implementation of this guidance, particularly its impact upon practice and outcomes for children, adolescents and young adults with cancer (to include both qualitative and quantitative outcome measurement).	We are unable to change this section, as the wording is standard to all our scopes.
College of Occupational Therapists	3	The medical treatment and follow up support are both recognised areas of need in the scope, but the area of rehabilitation is not mentioned as part of this continuum of care. It is not discussed in terms of the benefit in different stages of illness or recovery. Rehabilitation can enable the child or adolescent to adapt to and manage their condition and potentially changing levels of functional ability.	Rehabilitation is specifically mentioned in Section 4.3 c).
College of Occupational Therapists	4.1.1	We would support the proposal discussed at the stakeholder meeting (16 th May 2003) that there is a blurring or overlap in the age groups. There is often a need for increased involvement especially at transition to adult services.	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
College of Occupational	4.1.2	Children with benign tumours also have the same needs as children with malignancy especially in the follow up and	We have now widened Section 4.1.1 to include some benign tumours.

Therapists		rehabilitation phase of their illness	
College of Occupational Therapists	4.3 c)	There is no mention of active involvement from families and carers.	Agreed, included in Section 4.3 e).
College of Occupational Therapists	4.3 c)	This section mixes interventions such as practical support and palliative care, along with service providers e.g. social work and other allied health professions. To fit with NICE's position that individual professional groups are not mentioned, we would urge that rehabilitation is named here as a key intervention.	We have added rehabilitation into this section. It is usual in clinical guidelines not to name individual professional groups, however this is not the case for service guidance. Rehabilitation has now been included.
College of Occupational Therapists	4.3 c)	There is no mention of spiritual care	Care such as spiritual care/ support/counselling/ voluntary sector services are now included in Section 4.3.e).
College of Occupational Therapists	4.3 d)	This section appears very vague compared to previous ones. This section needs to define multi-agency planning, with the following in mind: the transition to adult services timely signposting to other services the use of key worker/case co-ordinator for smoother progression between stages of the illness/recovery the use of an integrated care pathways/agreed model of practice for multi-agency working quality planning with child and carers. the timely provision of equipment and resources.	We agree. Transition between services will be covered. Thank you for your comments. Section 4.3 has now been revised and we feel that it now covers the issues you have raised.
College of Occupational Therapists	Clinical Question 1	To what degree are children and adolescents affected by global or specific development issues if oncologies commence early in life? How can these be identified and supported?	Thank you, your questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this area as a clinical question.
College of Occupational Therapists	Clinical Question 2	What support or intervention is available when a child or adolescent's condition is made more complex by additional disabilities/conditions, social circumstances?	Thank you, your questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this

			area as a clinical question.
Department of Health/Welsh Assembly Government	General	<p>We would support using a pathway framework to structure this guidance (from prevention through to palliative care) as has been used for the adult guidance, recognising that the outcome is often only as good as the weakest link.</p> <p>We believe that the scope should always refer to children and adolescents unless a point is being made specifically about children i.e. we suggest that children is not used as a generic term – see para 3c below as an example.</p>	<p>Thank you for your comment. In drafting the guidance we will consider this issue.</p> <p>We agree and will not use ‘children’ as a generic term.</p>
Department of Health/Welsh Assembly Government	2 b)	<p>Please would you consider rewording part of this paragraph, as we believe it is not accurate to say that the NICE guidance documents "will have the effect of updating the [NHS Cancer] plan". We suggest you might consider inserting a comment based on paragraph 6.5 of the Cancer Plan (p57), - showing that the development of this guidance was a Cancer Plan commitment.</p> <p>Para 2b Could this paragraph also include reference to the National Service Framework (NSF) for Children, Young People and Maternity services? We believe that the generics from the NSF will need to be taken into account in the development of this guidance. The first stage of this NSF was launched on 10 April; the full NSF will be published next year and will cover many different aspects of children's lives. These include services for disabled children, ill children, children in special circumstances, child and adolescent mental health, medicines and services for all children. These will take account of the many developments in progress across government aimed at improving the lives and life chances of children including a Green Paper to be issued in the Summer on children at risk, and the establishment of pilot Children's Trusts.</p>	<p>Text amended.</p> <p>Reference to the NSF has been included.</p>
Department of Health/Welsh Assembly Government	3 b)	<p>Para 3b We believe there is no current consensus in the field about the need for separate adolescent units, 1045 the third sentence of this paragraph would appear to prejudge the issue. Please would</p>	Agreed - amendment made.

		you consider removing this sentence? The scope needs to be neutral – an alternative form of words for the end of the paragraph could be: " <i>Assessment of the service configuration which will best meet the needs of these patients is one of the objectives of this guidance.</i> "	
Department of Health/Welsh Assembly Government	3 c)	Para 3c We believe this paragraph should cover children and adolescents as patients who have been treated for cancer, as both children and adolescents may suffer from a range of late effects. Examples of this are effects on fertility and lifestyle.	We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a)
Department of Health/Welsh Assembly Government	4.1.1 a)	Population Para 4.1.1a We would advise against an arbitrary cut off point of 19 years for this guidance. We believe that one of the tasks for the group should be to advise on services for young adults (age unspecified). There may well be people in their early twenties who would prefer to be treated with adolescents rather than on adult oncology wards (where the average age of patients may be 60+).	We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a)
Department of Health/Welsh Assembly Government	4.1.1 b)	We would request that the guidance should also cover parents/siblings/family as this group is not covered in the NICE Supportive and Palliative Care Guidance. Please would you consider this point.	Agreed, included in Section 4.3 a). We will be suggesting to the DH and Welsh Assembly Government the need to have specialist guidance for palliative care of children.
Department of Health/Welsh Assembly Government	4.1.2 a)	Para 4.1.2a As mentioned above, we would not be in favour of an arbitrary cut off point as there may well be people in their early twenties who would prefer to be treated with adolescents rather than on adult oncology wards. Please would you re-consider this point?	We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a).
Department of Health/Welsh Assembly Government	4.2 a)	Para 4.2a Please would you ensure that appropriate links are made at this point to the referral guidelines which the Institute is updating?	Agree – see Section 2 c).
Department of Health/Welsh	4.3 a)	Para 4.3a It would be helpful if you could clarify what is meant by 'excluding	The Institute is in the process of updating the guideline 'referral for

Assembly Government		referral guidelines". Does it mean ensuring there is no duplication with the NICE referral guidelines?	suspected cancers'. It is not within the scope of this guidance.
Department of Health/Welsh Assembly Government	4.3 c)	Para 4.3c We suggest that support services for the family (including parents and siblings) could be included here. We also wondered if you planned to address complementary therapies here, as the supportive and palliative care guidance does not address children and adolescents?	Agreed, included in Section 4.3 e). We intend to address some of these important issues. However it is beyond our scope to go in to too much detail. We will be suggesting to the DH and Welsh Assembly Government the need to have specialist guidance for palliative care of children.
Department of Health/Welsh Assembly Government	4.3 e)	Para 4.3e Would it be possible for the guidance to address the involvement of children, adolescents and their families, both to ensure their views are taken into account in decisions about their own care but also more generally in areas such as service development?	Agreed. Support for families, carers and siblings now included in Section 4.3 e).
Department of Health/Welsh Assembly Government	Evidence	We note that you will be calling for evidence in the autumn. There are a number of pieces of work the Department will want to draw your attention. These include: a paper by a British Fertility Society-convened working group on a strategy for fertility services for survivors of childhood cancers which is due to be published shortly; work that has been carried out within the National Specialist Commissioning Advisory Group to draw up guidelines for some of the rarer children's cancers; work by the three former DH regional offices (South East, London and Eastern) to produce draft standards for paediatric oncology centres and paediatric oncology shared care units plus feedback from the peer review process that took place across these regions to assess compliance against these standards.	Thank you, these will be passed onto the Guidance Development Group to consider when they are considering the evidence.
Department of Health/Welsh Assembly	Stakeholders	In addition to the stakeholders listed on your website for this guidance we would suggest that you add:	Thank you, Cancer Voices is registered as a stakeholder.

Government		Cancer Voices who are doing work on involving service users, including children and adolescents.	
Endocrine Society and British Society of Paediatric Endocrinology	1.	Title: Outcomes should be specified as Improving “survival and its quality”	This guidance is one of the ‘Improving Outcomes’ series and as such we are not in a position to alter the title.
Endocrine Society and British Society of Paediatric Endocrinology	3 c)	The scope has the potential to be confusing in 3-4 areas: specifically The age exclusion. This implies that adult survivors of childhood malignancy are excluded once they reach 19 years. Clearly this is not intended as the scope then talks about long term consequences. The wording needs to be clarified to avoid any confusion later. (<i>see 3c Need</i>)	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a)
Endocrine Society and British Society of Paediatric Endocrinology	4.2.1	The artefactual distinction between benign and malignant tumours in childhood. Certain benign tumours are more appropriately treated in an oncology setting with chemotherapy and radiotherapy (<i>see 4.2.1. population</i>).	We have now widened Section 4.1.1 to include some benign tumours.
Endocrine Society and British Society of Paediatric Endocrinology	General	The separate scope currently being defined on brain tumours specifically. It should be made clear that childhood brain tumours (both certain benign tumours potentially requiring radiotherapy and/or chemotherapy, as well as malignant (3) above), are being considered under the child and adolescent cancer guideline to which cross-reference should be made in that document Where adult guidelines are being developed which have reference to the adult survivors of this childhood population (2. above) (i.e. osteoporosis, glucose intolerance and diabetes, heart disease etc...) these should be considered and cross-referenced in the guideline.	We agree, the scope for the guidance on brain tumours will make it explicit that it does not include children. We also agree that appropriate cross referencing between the guidelines is necessary.
Endocrine Society and British Society of Paediatric Endocrinology	3 a)	Prolonged intensive (inpatient) treatment also disrupts or halts normal endocrine and educational maturational processes, (specifically growth, puberty and peak bone mineral accretion), whilst certain tumours or their treatment may present with or cause early / precocious puberty. All later impact on adult stature, (sub)fertility, potential to obesity and bone demineralisation (with their long term consequences) and require recognition and prompt early endocrine intervention	Thank you, your questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this area as a clinical question.

		<p>Question; <u>Is early endocrine assessment and treatment important in preventing later endocrine morbidity?</u></p> <p>Question; <u>Is early and continued rehabilitation and educational support cost-effective?</u></p>	
Endocrine Society and British Society of Paediatric Endocrinology	3 b)	<p>Counselling towards consent to cancer treatment or towards fertility preservation strategies, as well as the law with respect to competency to consent (“Gillick” competence) and the Human Fertilisation and Embryology Authority (HFEA) are also important issues and needs, specific to this adolescent cohort (see consensus statement on this issue to be published in next month’s Human Fertility, lead author Ian Cooke, previous similar statements in same journal by Wallace and Walker 2001, and Archives of Disease in Childhood 2000 lead author R Grundy)</p> <p>Questions; <u>do “competent” adolescents/minors have the right to refuse cancer (life-saving) or other (life-enhancing, eg growth hormone) therapy?</u></p> <p>Question; <u>should fertility (cryo)preservation strategies be routinely offered to all adolescents deemed at significant risk of infertility and competent to consent?</u></p> <p><u>Should they be offered to pre-adolescent minors of any age?</u></p>	Thank you, we have added a section on ethical issues to the Scope. Your questions will be passed to the developer for the Guidance Development Group to consider when they are prioritising this area as a clinical question.
Endocrine Society and British Society of Paediatric Endocrinology	3 c)	<p>Although rare compared with adult cancer, survival is much greater (70%) and each child survives an average of 68 more years (cf with 10y for each adult). Hence quality of long term survival is important.</p> <p>Question; <u>what is the cost of cure in individual, public health, societal and financial terms?</u></p> <p>Over 85% survivors have a late “effect” measurable largely in endocrine (80%), but also other organ (cardiac, renal, respiratory, neurological and psychological) toxicity, more evident in the youngest at treatment and with dose intensity and time.</p> <p>It should be clear that recommendations should be applied retrospectively to current “survivors” at any age. (The present document reads as though it will exclude survivors after their 19th birthday) <i>Guidelines developed for adults should be cross-referenced here in particular those on osteoporosis and secondary glucose intolerance and the forthcoming brain tumour scope</i></p>	Thank you, your questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this area as a clinical question.

		<p><u>Question ?Is a holistic integrated and transitional service run by collaborating paediatric and adult physicians in an age-appropriate setting, and providing life-long preventative, rehabilitative and therapeutic care to patients that need it, likely to provide the best outcome?</u></p>	
Endocrine Society and British Society of Paediatric Endocrinology	4.1.1	<p>In view of the emergence of adolescent (and young adult) treatment centres, the specific recommendations for adolescents as distinct from children in the NSF for children, and the likely maturational delay and long term transitional needs of survivors (<i>see above</i>), some flexibility of ages seems necessary. We would suggest overlapping age groups e.g.;</p> <p>Children’s units : patients under 16 years Adolescent Units; patients between 13 and 25 years Adult Units; patients over 21 years NB. Note lifelong surveillance population defined in 3c need above</p>	<p>We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a)</p>
Endocrine Society and British Society of Paediatric Endocrinology	4.1.2	<p>AS 4.1.1. ABOVE PLUS</p> <p>The distinction between benign (but life-threatening) and malignant disease in children may be artefactual particularly in endocrine and brain tumours as well as other rare conditions (e.g. vascular malformations).</p> <p>Although a separate scope for brain tumours is being developed, paediatric brain tumours are more appropriately considered here, (second most common form (15%) of childhood malignancy), and cross-referenced in the other document.</p> <p>We suggest that the scope is broadened to include “benign tumours which require complex treatment pathways <u>potentially</u> including chemotherapy or radiotherapy”. This would encompass peri-pituitary tumours including craniopharyngiomas, endocrine and thyroid tumours (with familial risks) and other rare conditions. The extra load involved is small.</p> <p>Question; <u>does national registration and adherence to a national treatment guideline improve outcomes in rare (endocrine) childhood tumours?</u></p> <p><i>UKCCSG and BSPED Consensus statement on this issue due for circulation / consultation Nov 2003)</i> <i>Refer Royal College Physicians consensus guideline on Pituitary</i></p>	<p>We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a)</p> <p>Thank you for your comments - the suggested wording was particularly helpful. Thank you also for the references, which are extremely useful and will be considered during guidance development by the Guidance Development Group.</p>

		<p><i>Tumours ISBN</i> <i>Refer Royal College Physicians consensus guideline on Thyroid Tumours ISBN;</i> <i>Refer British Association of Endocrine Surgeons consensus guideline on endocrine tumours</i></p>	
Endocrine Society and British Society of Paediatric Endocrinology	4.2 a)	Care in the community should include school nurse liaison for emergency administration of any endocrine (or other) medication and detection of illness, and school special needs co-ordinator (SENCO) liaison / educational requirement during illness and rehabilitation after cure.	Amendment made to Section 4.2 g).
Endocrine Society and British Society of Paediatric Endocrinology	4.2 d)	Quaternary care examples should include endocrine tumours and specialist pituitary neurosurgery.	This issue of Quaternary referral for these and other services will be addressed during development of the Guidance.
Endocrine Society and British Society of Paediatric Endocrinology	4.3 a)	Endocrinologists are another example of “other specialists”	This section lists some examples and is not exhaustive. These specialists would be included in the term “other specialists” in Sections 4.3 a) and 4.3 b).
Endocrine Society and British Society of Paediatric Endocrinology	4.3 b)	<p>Endocrine and pituitary tumour surgery are other specialist surgical examples to be included “End-of life” care should be differentiated from “palliative” care (living with an incurable illness) pre-treatment subfertility protection strategies and after-cure fertility treatments should be considered here medium to life-long endocrine support to improve adult stature, achieve age-appropriate puberty and fertility, prevent post-irradiation secondary thyroid cancer, obesity, glucose intolerance and osteoporosis, as well as hormone replacement of deficiency states, including adult GH deficiency which may yet evolve in the cranially irradiated survivor, should be considered here. They should correspond to the NICE appraisal on growth hormone therapy where relevant In addition peri-operative fluid balance treatment guidelines after pituitary surgery should be considered here. <u>Question? Does prompt and long term endocrine surveillance and support in selected groups enhance quantity and quality of life?</u></p>	<p>These would by definition be included in the term “other specialists” in Section 4.3.</p> <p>Our definition of palliative care includes ongoing support and end of life care.</p> <p>Thank you, your questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this</p>

			area as a clinical question.
Endocrine Society and British Society of Paediatric Endocrinology	4.3 c)	<p>Transitional services for support for individual and carers for chronic disability (into adult life) should be specified here (e.g. neuropsychiatric, psychosexual, motor/sensory/intellectual impairment, rehabilitative, amputees)</p> <p><i>See also SIGN guidelines for long term follow-up of childhood cancer</i></p> <p><u>Question is there a need for transitional support services to aid rehabilitation and independence into adult life</u></p>	<p>We agree. Transition services will be covered.</p> <p>Thank you, your questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this area as a clinical question.</p>
Endocrine Society and British Society of Paediatric Endocrinology	4.3 d)	<p>Many of the patients that survive cancer therapy have medical problems that persist into or can develop in adult life. A significant majority will require <u>lifelong</u>, co-ordinated follow up by a physician with an interest in Late Effects. In some cases, postal follow up may be adequate, but information technology facilities are required to maintain contact with all patients so they can rapidly access informed support should they develop a problem. This emerging cohort of young adult patients is new to the NHS and indefinitely accruing over time as survival is further prolonged. Thus new funds will need to be diverted to support it and careful ongoing audit will be required to determine need and efficacy. Endocrinologists are the obvious choice to lead such adult care services as endocrinopathy and its related consequences (obesity, osteoporosis, secondary glucose intolerance) is the commonest problem and these specialists are also accredited in internal medicine. The follow-up should be <u>multidisciplinary</u> and comprehensive, including oncologists (paediatric or adult) and access to appropriate specialties (cardiology, fertility, pre-pregnancy and obstetric care, nephrology, respiratory, neurosurgery, orthopaedic, gastroenterology, psychology/psychotherapy/neuropsychiatry etc)</p> <p><u>Question: Are one-stop multidisciplinary late toxicity/rehabilitation services in existence in the NHS or defined in the NHS cancer plan? Are these patient pathways properly defined, appropriately funded and cost-effective?</u></p>	<p>We agree. Transition between services will be covered.</p> <p>Section 4.3 f) relating to follow up has now been revised and includes the process of transition from paediatric to adult services.</p> <p>Thank you, your comments and questions will be passed to the developer for the Guidance Development Group to consider when it is prioritising this area as a clinical question.</p>
Faculty of Dental	General	There is no reference in the scope to oral health care, this is an	Oral healthcare is now included

Surgery		important area of treatment support that is of considerable value to the patient's oral comfort during treatment and their post treatment rehabilitation.	under Allied Treatment Services in Section 4.3.
Faculty of Dental Surgery	4.3 c)	Support services: An oral examination and provision of necessary oral care prior to treatment is essential to avoid acute oral disease during treatment for cancer and to initiate a preventive regimen that can minimise oral disease during oncology treatment(1)	Agreed, included in Section 4.3 c).
Faculty of Dental Surgery	4.3 d)	Follow up: Following cancer treatment that has involved radiotherapy there is evidence of long term damage to growth and development in the oro-facial region (2). In addition the patient is at greater risk of dental and soft tissue oral disease.	Thank you for your comments, which will be passed on to the Guidance Development Group to consider. Section 4.3 f) relating to follow up has now been revised.
Faculty of Dental Surgery	References	1. Fayle SA, Duggal MS, Williams SA. Dental Update 1992: May 152-159	Thank you, these will be passed onto the Guidance Development Group to consider when it is considering the evidence.
Faculty of Dental Surgery	References	2 Nasman M, Bjork O, Soderhall S, Ringden O, Dahloff G. <i>Pediatr Dent</i> 1994 : 16 : 217-23	Thank you, these will be passed onto the Guidance Development Group to consider when it is considering the evidence.
Faculty of Dental Surgery	References	Thanks. Yes, I agree with your comments. The most important thing at this stage is to make sure oral care is going to be considered. Some other refs you might wish to include to emphasise this are: Collard MM. Hunter ML. Dental care in acute lymphoblastic leukaemia: experiences of children and attitudes of parents. <i>International Journal of Paediatric Dentistry</i> . 11(4):274-80, 2001 Jul. _ Chin EA. A brief overview of the oral complications in pediatric oncology patients and suggested management strategies. <i>Journal of Dentistry for Children</i> . 65(6):468-73, 1998	Thank you, these will be passed onto the Guidance Development Group to consider when it is considering the evidence.

		<p>Meraw SJ. Reeve CM. Dental considerations and treatment of the oncology patient receiving radiation therapy. <i>Journal of the American Dental Association</i>. 129(2):201-5, 1998.</p> <p>Fayle SA. Curzon ME. Oral complications in pediatric oncology patients. <i>Pediatric Dentistry</i>. 13(5):289-95, 1991</p> <p>Shaw MJ. Kumar ND. Duggal M. Fiske J. Lewis DA. Kinsella T. Nisbet T. Oral management of patients following oncology treatment: literature review. <i>British Journal of Oral & Maxillofacial Surgery</i>. 38(5):519-24, 2000</p> <p>I have taken the liberty of pasting these into doc you sent, an amended copy of which is attached. Hope this helps and thanks very much for keeping us informed of all this.</p>	
Faculty of Dental Surgery	References	<p>You might like to add something about the 'consumer' perspective. I have research which shows that parents place a high level of importance on their children's dental care, with more than two thirds expressing a preference for this to be provided within the Paediatric Oncology Unit.*</p> <p>We also surveyed UKCCSG centres and showed that while the majority of centres carry out an oral assessment at the time of diagnosis, various health care professionals are responsible for this. A dentist routinely attended clinics in only a minority of sites. Almost a quarter of centres did not have an oral care protocol.**</p> <p>* Collard MM and Hunter ML Dental care in acute lymphoblastic leukaemia: experiences of children and attitudes of parents. <i>International Journal of Paediatric Dentistry</i> 2001; 11: 274-280.</p> <p>** Collard MM and Hunter ML Oral and dental care in acute lymphoblastic leukaemia: a survey of United</p>	Thank you, these will be passed onto the Guidance Development Group to consider when it is considering the evidence.

		<p>Kingdom Children's Cancer Study Group centres. International Journal of Paediatric Dentistry 2001; 11: 347-351.</p> <p>You might also like to use an additional recent reference:</p> <p>Duggal MS, Curzon MEJ, Bailey CC et al. Dental parameters in the long term survivors of childhood cancer compared with siblings. oral Oncology 1997; 33: 348-353.</p> <p>Otherwise fine.</p>	
Gorlin Syndrome Group	3b	A need to include children with learning difficulties	All children are included in the scope, regardless of disability.
Gorlin Syndrome Group	3c	A need for consideration of children with long term or life-long cancers from birth to adulthood including transition from child to adult services.	We agree. Transition between services will be covered.
Gorlin Syndrome Group	4.3a	Needs to include Plastic Surgeons and Dermatologists.	This section lists some examples and is not exhaustive. These specialists would be included in the term "other specialists" in Sections 4.3 a) and 4.3 b).
Gorlin Syndrome Group	4.3b	To include Plastic Surgeons and specialist treatments including Photo Dynamic Therapy and use of laser treatment.	This section lists some examples and is not exhaustive. These specialists would be included in the term "other specialists" in Sections 4.3 a) and 4.3 b).
Help the Hospices	General	<p>End of life care</p> <p>We recommend that end of life care should be covered in this guidance. Increasingly, palliative care is seen as something which should be offered from the point of diagnosis. It is important, therefore, that end of life or terminal care should be covered in its own right.</p>	Palliative care, Section 4.3 d) will cover a whole range of aspects including terminal and end of life care.
Help the Hospices	General	<p>Spiritual care</p> <p>There is currently no mention of spiritual care and, while it could</p>	Care such as spiritual care/ support/counselling/ voluntary sector services will now be

		be covered under “other multidisciplinary services”, we recommend that it be mentioned specifically to ensure that it will be covered in the guidance. We recognise that there may be some difficult issues around the provision of spiritual support for children. The guidance should, however, recognise that children have spiritual needs and include recommendations on how these should be met.	considered under support services in Section 4.3 e)
Help the Hospices	4.2.a), 4.3.b), and 4.3.c)	<p>Definition of community</p> <p>If the term community is used, it needs to be defined. In responding to the draft Supportive and Palliative Care guidance, we have found that it is often unclear whether hospice services, especially inpatient services, are considered to be community-based. If a hospice provides inpatient, day care and home care services, which of these is considered to be a community-based service? For the sake of clarity, it might be easier to avoid using the term community altogether. Alternative terms might include non-hospital, home care, day care, outpatient or non-inpatient.</p>	Amended - see Section 4.2.a).
Help the Hospices	4.3 b)	<p>Palliative care</p> <p>It is not clear what is meant by “community-based” palliative care and how this is different from specialist palliative care. There are a large number of, for example, hospice at home services which we would consider to be both community-based and specialist. To be consistent with the Supportive and Palliative Care Guidance, the last bullet point should probably read “specialist and generalist palliative care”, although we have some concerns about how clearly this distinction is defined in the second draft of the Supportive and Palliative Care Guidance. An alternative would be “inpatient, outpatient and home-based palliative care.”</p>	Palliative care is now more clearly defined within the Scope under Sections 4.3 d) and e).
Help the Hospices	4.3 b) & 4.3 c)	<p>Treatment and Support services</p> <p>Treatment and support services need to be defined. It is not clear why psychology and other multi-disciplinary services such as dieticians, physiotherapists and occupational therapists are listed as support and not treatment services. Palliative care is listed under both headings, but it is unclear whether palliative care as a</p>	This section has been re-ordered taking your comment into account.

		support service is considered to be something different from palliative care as a treatment service.	
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	General	<p>Thank you for inviting Macmillan Cancer Relief to comment on the Draft Scope for Guidance on improving outcomes in child and adolescent cancer.</p> <p>We have consulted colleagues from CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children, and would like to submit the attached joint response.</p> <p>We note that the process for ensuring the patient voice is considered at all times in preparing this guidance has not yet been agreed. CancerVOICES has piloted a successful model for informing the guidance development process using a User Reference Group in the similar consultation on Supportive and Palliative Care Guidance. CancerVOICES would be happy to coordinate a similar structure to provide a child and young people's cancer group.</p>	Thank you, this information will be passed onto the Guidance Development Group.
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	3 a)	The guidance needs to address continuity of care from the hospital to the community.	We agree – transition between services will be covered.
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	3 b)	The particular needs of adolescents needs to be addressed within the community as well as the hospital setting.	We agree – this will be addressed in the guidance.
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and	3 c)	Follow-up of young people needs also to address the psychological and social impact of their cancer.	Agreed - this has been added into Section 3 c).

Sargent Cancer Care for Children			
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	4.1.2 a)	We are very concerned that the Guidance will exclude young adults over the age of 19. We believe that adolescents and young adults up to the age of 25 have very complex medical, social and psychological needs and it is vital to examine these needs together. Many young people now continue into full-time education into their early 20s and remain within the transitional phase to adult independence well into their 20s. Current services frequently miss the needs of young people in this age range. This point is alluded to in section 3 but not followed up into the scope and age range.	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a)
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	4.1.2 b)	We recommend that the guidance consider all tumours requiring oncological intervention (surgery and treatment) as from the patient’s perspective, the distinction between benign and malignant may not be readily apparent.	We have now widened Section 4.1.1 to include some benign tumours.
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	4.2 a)	The consideration of best practice surrounding diagnosis must also include parents’ experiences of the primary care response when they initially present at a surgery. This will include sensitivity in giving information, listening to parent’s concerns and taking those concerns seriously.	Thank you for your comment. This will be considered during development of the guidance by the Guideline Development Group.
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	4.2 a)	Best practice in diagnosis should also consider methods for information sharing and networking within primary care for rarer cancers.	Thank you for your comment. This will be considered during development of the Guidance by the Guidance Development Group.
Macmillan Cancer Relief, CancerVOICES, the Teenage	4.3 a)	Specialist paediatric oncology nurses should be integral to the team	Agreed, included in Section 4.3 b).

Cancer Trust, and Sargent Cancer Care for Children			
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	4.3 b)	Specialist and community-based palliative care is of terminology, implying that specialist palliative care is separate from community based services. This section needs to consider the provision of all forms of palliative care outside of the hospital setting.	This section has been re-ordered taking your comment into account.
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	4.3 c)	Practical support must consider the needs of siblings as well as parents and the child or young person affected by cancer.	Agreed, included in Section 4.3 e)
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	4.3 c)	Educational needs are very complex for children and young people with cancer. This section must consider both the provision of information and support to all schools and support for each child with cancer. It must consider the needs of children and young people within the hospital and the community setting and the support needs of young people when they return to full-time education.	The guidance will be for the NHS, and cannot make direct recommendations for education services. Reference has been made to these in the scope at 4.3.e).
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and Sargent Cancer Care for Children	4.3 c)	Multi-disciplinary teams should also routinely include specialist paediatric nurses as well provision of complementary therapy.	Agreed, included in Section 4.3 b). We cannot review the role of complimentary therapy <i>per se</i> and it is not a primary issue within the Scope. However it will be covered within the interface with non-NHS providers, Section 4.3 e).
Macmillan Cancer Relief, CancerVOICES, the Teenage Cancer Trust, and	4.3 d)	Follow-up of young people must include the emotional and social effects of cancer addressing any impact on independence, sexuality and self-image.	Section 4.3 f) relating to follow up has now been revised.

Sargent Cancer Care for Children			
National Alliance of Childhood Cancer Parent Organisations (NACCPO)	General	<p>The scope places strong emphasis on the need for patient and carer involvement, there are two particular factors which need to be acknowledged:</p> <p>The consultation period of four weeks built into the Guideline development process is particularly favourable to the mainstream health and non-statutory organisations that have registered as stakeholders in the process. It is disadvantageous for patient/carer stakeholder groups, who are less structured and organised, making it difficult to gain a valid comprehensive input from their members and constituent groups.</p> <p>A number of charitable/non-statutory care providers are registered as patient/carer organisations (e.g. MacMillan, Sargeant), when they are clearly oriented towards business/professional care, employing a wide range of professional and management support staff. Consideration should be given to perhaps either broadening the category of professional/carer stakeholder organisations, to include these non-statutory/NHS organisations, or even to having a separate category. The latter would be more correct, in view of their overall contribution to this care sector – hospice/palliative care, play therapy, physiotherapy, OT, respite care, social work support, etc. – which frequently replace/supplements NHS care. Specialist Teenage Cancer Units should be sited close to specialist paediatric units, to ensure all aspects of continuity of care and support.</p>	<p>Thank you. The stakeholder process for the guidelines programme is self selecting and any organisation that fits the criteria is able to become a registered stakeholder. Many of the disciplines that you have listed (physiotherapy, OT etc) comment via their professional organisations. Individuals should contact their professional organisations to find out who at the organisation is coordinating responses to the guidelines. A selection of NHS Trusts and PCTs are invited to become stakeholders on each guideline also (these are randomly selected by the Institute).</p> <p>We acknowledge that sometimes a 4-week consultation is difficult for groups, but already the validation process is 6-7 months long and we are reluctant to extend this further, otherwise the guideline would be out of date by the time it was published.</p>
National Alliance of Childhood Cancer Parent Organisations (NACCPO)	General	<p>It is clearly stated that the Guidelines will be for health commissioners rather than professionals. As such, is essential to build in representation/advice from commissioners, such as Primary Care Trusts and Strategic Health Authorities into the Guideline development process. This could perhaps be done through the main development group or through incorporating this area of expertise into the proposed expert panel.</p>	<p>For all of the guidelines a selection of NHS Trusts and PCTs are invited to become stakeholders. For the cancer service guidance topics this is also extended to include Strategic Health Authorities. (A selection of these groups are randomly selected by the Institute).</p>
National Alliance of Childhood	4.1.1	<p>The upper age limit is too restrictive (22 or 24 would be more appropriate to this patient population), particularly in terms of</p>	<p>We have changed the definition to “Young people presenting with</p>

Cancer Parent Organisations (NACCPO)		potentially excluding the increasingly large group of patients and survivors requiring specialist long-term follow-up and support and also the associated issues relating to transition into adult care.	malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
National Alliance of Childhood Cancer Parent Organisations (NACCPO)	4.2	The inclusion of such a wide range of settings and services is to be commended, but Shared Care Units should be considered separately, as they impact significantly on treatment, care and support for patients and their families. In addition, the role of the charitable/non-statutory sector, community-based care and support groups, should be more explicitly acknowledged and considered.	Amendments made, see Section 4.2 b).
National Alliance of Childhood Cancer Parent Organisations (NACCPO)	4.3 4.3 b, c and d	The position of the non-statutory/charitable sector needs to be both acknowledged and clarified, particularly the role and function of palliative/hospice care. There is no reference to the physical environment, is this outside the scope of the guidance? The roles of the GP/Primary Care team/Community Children’s Nurse in treatment, support and follow up should be included.	Addressed in Section 4.2 f) and g). Yes, it is outside the scope of the document. This is now explicit in Section 4.2 a).
National Alliance of Childhood Cancer Parent Organisations (NACCPO)	4.3 c)	The direct role/involvement of parents/carers and families, particularly in terms of family/family and patient/patient support warrants acknowledgement and incorporation into the guidance. If the development of the guidelines is going to fully engage with patients/carers, then it is essential for this to be included in the scope of the guidance.	Agreed, included in Section 4.3 e).
National Alliance of Childhood Cancer Parent Organisations (NACCPO)	4.4	Any audit should include a full range of objective and qualitative measures.	Thank you, we agree.
Pharmacia	General	Pharmacia have no additional comments on the Child and Adolescent cancer scope document itself, which appears comprehensive. However, a related area not yet addressed is that of clinical trials in paediatric and adolescent cancer patients. With FDA incentives - primarily additional patent life - on drugs being tested in children, together with increasing pressure on pharmaceutical companies as a whole, it is highly likely that there will be an increased focus	Thank you, your comments have been passed to the developer.

		<p>by drug companies to perform trials in this subgroup of patients.</p> <p>This may be considered outwith the scope of guidelines aimed at NHS practice, but the Institute may wish to address this in some way in this scope - even in a limited form.</p>	
Royal College of Anaesthetists	4.3	No mention of anaesthesia in section. (Future consideration of recommendation for management to be in centre which has presence of anaesthetists skilled in paediatric work, as per various CEPOD reports?)	Agreed, see Section 4.3 b).
Royal College of Anaesthetists	4.3 b)	No mention of paediatric intensive care in Scope document (Future consideration of desirability of availability to paediatric intensive care facility?)	Agreed, included in Section 4.3 b).
Royal College of Anaesthetists	4.3	No mention of pain management in Scope document, unless implied under palliative care.	Pain management is now included under Allied Treatment Services in Section 4.3 c).
Royal College of Nursing (Paediatric Oncology Nurses Forum)	General	<p>Clearly the scope gives the broad outlines of the areas to be covered, and does so appropriately and effectively. It is not clear from the scope, however, whether issues of capacity and workforce development are to be addressed in the guidelines. We hope that they will be, as it is here that many of the variations we see in service provision originate.</p>	<p>This document is by definition for commissioners and we are only advising on the services. Workforce and capacity issues, although very important, are beyond the scope of this document.</p> <p>However the service guidance will be making recommendations on ideal staffing and configuration of services which will be of use to the commissioners.</p>
Royal College of Nursing (Paediatric Oncology Nurses Forum)	4.1.1	We believe that the age limit of 19 years is not appropriate. As is recognised in the section on 'Clinical need' in this document, services for adolescents remain poorly developed at present, and there is a clear need to address this in the guidelines. Setting an upper age limit of 19 would exclude the needs of many patients currently cared for in specialist adolescent units and those whose needs would be better met in such units. We would prefer no stated upper age limit, whilst recognising that the main thrust of the guidance would indeed address that younger population.	We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a).
Royal College of	4.1.2	Following on from the above point, to remove from this section	We have changed the definition to

Nursing (Paediatric Oncology Nurses Forum)		'young adults aged 19 or over'.	"Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a).
Royal College of Nursing (Paediatric Oncology Nurses Forum)	4.2	We would like to see here mention of the commissioning of services. The guidance is clearly directed at those who commission services for children with cancer, and we would like to see recommendations on specialist commissioning, if this would fall within the remit of the document.	This document is, by definition, for commissioners and we can only advise on services. It is understood that the commissioners are expected to implement the guidance. We agree that integration with the voluntary sector is important and we have included a reference to this. See Section 4.2 f).
Royal College of Nursing (Paediatric Oncology Nurses Forum)	4.3 b)	We would like to add Supportive Care to the section on Treatment services. (To include the management of acute side effects of treatment, including nausea & vomiting, management of infection, blood product support, pain management, nutrition and other aspects of care.)	This will be addressed within the context of Allied Treatment Services as detailed in the Scope. Reference to the acute side effects of treatment has been included in Section 4.3 b).
Royal College of Nursing (Paediatric Oncology Nurses Forum)	4.3 c)	We would like to add Play and play provision to the section on Support services, as one of the most important of the support services to both children and families. It is also important to recognise the very different demands of adolescents for recreation and appropriate facilities. We would see Pharmacy as having a particularly important role to play in many aspects of care, and would like to identify it in its own right, rather than as one aspect of the multidisciplinary team. We would also like to add Spiritual Care to the support services.	Agreed, included in Section 4.3 e). Agreed, included in Section 4.3 e). Care such as spiritual care/ support/counselling/ voluntary sector services will now be covered under support services in Section 4.3 e).
Royal College of Nursing (Paediatric Oncology Nurses Forum)	4.3 d)	We would like the section on follow up 'by Whom', to include consideration of the need for some patients for Transition to adult services.	Agreed, included in Section 4.3 f).
Royal College of Paediatrics and Child Health	General	The scope appears generally comprehensive, with one or two provisos outlined below.	Thank you.
Royal College of	General	There are some cancers that, whilst generally specific to children,	The upper age limit is to be flexible,

Paediatrics and Child Health		do occur in adults. Consideration should be given as to how these may be covered.	so that if appropriate young adults could be covered by this guidance, however the scope of this guidance does not include adults generally.
Royal College of Paediatrics and Child Health	General	The current cancer services for children and adolescents are in part reliant on the voluntary sector. This results in services that are vulnerable should funding be withdrawn, and this issue should be addressed.	The integration of current cancer services for children and adolescents with the voluntary sector is important and has been included in Section 4.4.2 f).
Royal College of Paediatrics and Child Health	General	The scope does not include the role of the inclusion of many children with malignancy in clinical research protocols in achieving and maintaining high standards of care.	Research and clinical trials are now included in the scope under Section 4.3 g).
Royal College of Paediatrics and Child Health	3 c)	Suggest insert the words “and rehabilitation” in the first sentence, which should read: “...care of children with cancer is their follow-up and rehabilitation”	Amendment made.
Royal College of Paediatrics and Child Health	4.1.1 a)	Suggest clarify the wording and insert the word “suspected” in the sentence: “Children and adolescents (below the age of 19 years) with suspected cancers, haematological malignancies, sarcomas and central nervous system tumours as defined by...”	Inclusion of the word ‘suspected’ would widen the scope beyond the remit proposed by the DH and Welsh Assembly Government.
Royal College of Paediatrics and Child Health	4.1.1 a)	Suggest inclusion of “benign central nervous system tumours”. The classification into benign and malignant is arbitrary for some CNS tumours, the prognosis for some benign tumours may be very poor, and the management issues are similar.	We have now widened the definition in Section 4.1.1.
Royal College of Paediatrics and Child Health	4.1.2 b)	“Children with benign tumours except central nervous system tumours”.	We have now widened Section 4.1.1 to include some benign tumours.
Royal College of Paediatrics and Child Health	4.2	“The guidance will cover the following NHS services and commissioning in England and Wales and their interaction with the following two sections.	This document is by definition for commissioners and we can only advise on services. It is understood that the commissioners are expected to implement the guidance.
Royal College of Paediatrics and Child Health	4.2 a)	Suggest insert: “...active treatment, follow-up, rehabilitation and palliative care.”	The word ‘rehabilitation’ has been added to the document as suggested.
Royal College of Paediatrics and	4.2 d)	Insert “and their paediatric oncology shared care units”	Agreed, change made in Section 4.2 b)

Child Health			
Royal College of Paediatrics and Child Health	4.3 a)	Suggest add in “general paediatric surgeons”.	Agreed, included in Section 4.3 a)
Royal College of Paediatrics and Child Health	4.3 a)	Since the numbers of paediatric pathologists have been decimated, their role should be included. Adult cancer services use pathologists specialised to a particular organ, but this is not appropriate in paediatric pathology. Therefore it is suggested that paediatric histopathologists and adult histopathologists should be added into the list of professionals whose role in diagnosis is included.	Paediatric pathologists are now included in Section 4.3 a).
Royal College of Paediatrics and Child Health	4.3 b)	Suggest an additional bullet point: “rehabilitation”	Agreed, included in Section 4.3 c).
Royal College of Paediatrics and Child Health	4.3 c)	There is no mention of the important role of pharmacy. Suggest insert “pharmacy”	Agreed, included in Section 4.3 b).
Royal College of Paediatrics and Child Health	4.3 d)	Suggest insert the word “type”: “need, frequency, type, location and by whom”	Agreed, ‘type’ has been added in Section 4.3 f).
Royal College of Paediatrics and Child Health	4.3 d)	The transition to adult services is important as these young people reach maturity. Suggest an additional bullet point: “the process of transition from paediatric to adult services.”	We agree, transition between services will be covered and an additional bullet point has been added.
Royal College of Pathologists	General	Draft scope consultation on Child and Adolescent Cancer Service Guidance The following comments have been made by an adviser chosen by the Royal College of Pathologists (Dr Alan Ramsey, Consultant Pathologist at Great Ormond Street Hospital for Children) on the draft scope for the above guidance.	Thank you.
Royal College of Pathologists	3 a)	Section 3. Clinical need for guidance. In paragraph a) the document indicates that the treatment of childhood cancers is "often complex". I would like to see a sentence indicating that the diagnosis of childhood cancers is also complex. The biopsy process is more difficult, diagnoses often have to be made on small amounts of material and most childhood	We agree.

		tumours require immunological and molecular techniques that are only available in specialist pathology laboratories.	
Royal College of Pathologists	4.1.2 b)	<p>Section 4.1 Population</p> <p>Paragraph 4.1.2 Groups that will not be covered.</p> <p>I have grave misgivings about the exclusions here - it seems to have been written without any idea of the practicalities of paediatric practice.</p> <p>Section b) excludes children and adolescents with "benign" tumours. Many childhood neoplasms are hard to classify as benign or malignant. Conditions such as myofibromatosis and angiomatosis are histologically "benign" yet can be diffuse and life threatening and are treated by paediatric oncologists. The same fibrous proliferation can be classed either as juvenile fibromatosis (benign?) or infantile fibrosarcoma (malignant?). Teratomas (classed as malignant) may be composed wholly of histologically benign adult-type tissue. Otherwise benign tumours when sited in of brain and spinal cord will require complex neurosurgery possibly with chemotherapy, and so should fall under the NICE guidance.</p>	We have now widened Section 4.1.1 to include some benign tumours.
Royal College of Pathologists	4.1.2 c)	<p>Sections c) and d) have similar problems. Children with immune dysfunction are prone to develop a variety of malignancies, particularly lymphoid tumours. They are also at risk of EBV-driven lymphoid proliferations. Children who have had a bone marrow transplant of any sort carry a similar risk. The proliferations and tumours developing in such patients are fully malignant and require chemotherapy. It can be difficult to separate immune disorders from neoplastic disorders in these children.</p>	<p>We have now widened Section 4.1.1 to include some benign tumours.</p> <p>This will include those children and young people who develop immune related proliferative disorders.</p>
Royal College of Physicians	General	<p>The College welcomes the opportunity to provide comment on the draft scope for the above NICE guideline.</p> <p>Having reviewed the draft scope I can confirm that this College does not have any suggested amendments that we wish the guideline development group to consider. We believe the scope, as listed, should enable the group to produce a concise guideline within the agreed boundaries.</p>	Thank you.

Royal College of Psychiatrists		<p>The Royal College of Psychiatrists, Child and Adolescent Faculty very much welcome the opportunity to comment on this important draft scope.</p> <p>In responding as a Faculty on behalf of the College, we have tapped into the expertise of our colleagues working in this field. Overall, we welcome the invitation of this NICE guideline and thought already given to the very important psychological and emotional issues for children, families and health professionals.</p> <p>Our specific comments are :</p>	Thank you for your comments.
Royal College of Psychiatrists	4.1.1	No mention of the need for follow-up to monitor for secondary malignancy.	Section 4.3 f) relating to follow up has now been revised.
Royal College of Psychiatrists	4.1.2	Specify that the age cut off will be for the time of first onset, as people over 19 are usually retained by specialist centres. Perhaps there is a need to be more specific about what is meant by "benign tumour". Not only has here been a need to reclassify certain tumours initially believed to be benign, but also, some tumours are hard to classify.	<p>We have changed the definition to "Young people presenting with malignant disease in their late teens and early twenties." See Section 4.1.1 a)</p> <p>We have now widened Section 4.1.1 to include some benign tumours.</p>
Royal College of Psychiatrists	4.3b	Should the harvesting of sperm and ovum from appropriately aged children, and the necessary counselling be mentioned? Should hospice services be mentioned?	Fertility services are covered under 4.3c) and would include the appropriate counselling. Hospice services are covered under 4.3e).
Royal College of Psychiatrists	4.3c	Liaison psychiatry at least needs to be available. Should there be mention of the McMillan service and the voluntary sector, for example the Sargent social workers clinical genetics can play an important role.	We agree that the integration with the voluntary sector is important and included reference to this. See Section 4.2 f) and 4.3 e).
Royal College of Psychiatrists	4.3d	Should there be mention of the need for psychological follow-up to support people who have experienced disfiguring/invasive procedures? They may have needs connected with poor self-esteem or personality difficulties.	Section 4.3 f) relating to follow up has now been revised.
Sargent Cancer Care for Children	3 a)	The guidance needs to cover the continuity of care from the hospital to the community, and the balance of services needed to enable children and young people to get localised support in	We agree – transition between services will be covered.

		addressing their needs, particularly Youth work and Family support	
Sargent Cancer Care for Children	3 b)	The needs of adolescents and young adults are particular and service guidance should address the specialist services to meet these both in tertiary care but also in their local communities, and consider the provision of community based provision to meet a range of needs for support and information both individually and in groups. Sargent Cancer Care has piloted a model of Youth Support including mentoring and the use of IT networking with young people. Recognition of the transitional stage in life from child to adult is of critical importance	We agree – this will be addressed in the guidance.
Sargent Cancer Care for Children	3 c)	Follow-up and support with later effects is crucial for young people, and these services are significantly under-funded. Again services need to link in to available support in the community including Psychological support	This has been added into Section 3 c).
Sargent Cancer Care for Children	4.1.2.a)	It is our view that the scope of the guidance should address the needs of young people aged 19 and over. These young people face particularly complex conditions, in services that are fundamentally missing their needs. We would argue that the scope of the guidance should cover young people up to the age of 22 at least, and preferably up to age 25, in line with discussions between UKCCSG and a number of stakeholder voluntary organisations	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a)
Sargent Cancer Care for Children	4.1.2.b)	Consideration should be given to including any tumours that require oncological interventions, rather than distinguishing between malignant and benign tumours	We have now widened Section 4.1.1 to include some benign tumours.
Sargent Cancer Care for Children	4.3 c)	Support services considered should include Youth work, Play Specialists, and creative therapists including group work	Agreed, included in Section 4.3 e).
Society and College of Radiographers	4.1	At the 16 May meeting of stakeholders a number of points for consideration were well made. In particular, that the team refer to best practice and relevant legislation taking care not to be too prescriptive in determining any age limits for inclusion/exclusion. Rather the focus should be on ensuring equity of provision and adequate access during the bridging period between child and adolescent and also beyond for those young adults with continuing care needs.	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
Society and	General	The scope appears to be inclusive. However, we would like to	We agree, transition between

College of Radiographers		suggest that integrated care is emphasised as a continuous pathway within the document and the various treatment regimes/services.	services will be covered within the scope.
Taunton & Somerset NHS Trust	4.1	It would be useful if the guidelines could incorporate some degree of flexibility re age range, to make them patient-centred rather than service-centred. E.g. children 0-16, overlapping with teenagers 13-19, overlapping with young adults 17-22 (or even up to 25). This would allow more appropriate service delivery options for the wide variety of young people, who will not easily fit into one age-defined category.	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
Taunton & Somerset NHS Trust	4.1.2 b)	Definitions based on histology will not be patient-centred; use practical criteria relating to impact on patient lives e.g. will this lump/condition require the input of an oncologist for further management? As this is service guidance rather than clinical guidelines, this definition will also correlate more closely with the use of health care resources.	We feel that this is now addressed in the revised definition. The use of a definition based on histology is the most practical in addressing the remit.
Taunton & Somerset NHS Trust	4.3 – general	Will the guidance provide information as the number of WTE expected within a clinical team, based on the % of cancers diagnosed, i.e. if a population is such it is expected the % of diagnosed cancers will be and thus XXX wte of specialist staff will be required. This proves to be helpful when developing specialist teams and ensuring appropriate skill mix within units.	It is anticipated that the guidance will provide this information. Your comments will be forwarded the Guidance Development Group for their information.
Taunton & Somerset NHS Trust	General	Will the guidance reflect areas of the National Cancer Plan to which we are working, for example treatment times from diagnosis, clinical trials and genetics.	Yes.
The Leukaemia Society (UK)	4.1.1 & 4.1.2	Variation of age. Transition is an issue. Are older children adults? When? If the age is vague in the scope long care needs could then be extended.	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
The Leukaemia Society (UK)	4.3 c)	Counselling is important and needs to be added to the list of support services.	We agree, this issue will be captured under the heading 4.3 f).
The Teenage Cancer Trust		Physiotherapy	Physiotherapy is covered in Section 4.3 c) – Support Services.
The Teenage Cancer Trust	3 b)	Needs to define adolescent age range. Teenage Cancer Trust Units can range from 13-25 yrs. However, we applaud recognition of them as a distinct group.	We have changed the definition to “Young people presenting with malignant disease in their late teens

			and early twenties.” See Section 4.1.1 a).
The Teenage Cancer Trust	3 c)	What are survival rates for adolescents and young adults?	This will be addressed in the background to the Guidance. Data not currently available.
The Teenage Cancer Trust	4.1.1 & General	If NICE are serious about adolescent/young adult facilities (3b) this is the time to break the “straight jacket” of NHS Child/adult structures and include young adults up to 25. If the status quo remains, what guidelines will adolescent/young adults follow with 18-25 group?	We have now widened the definition in Section 4.1.1. We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
The Teenage Cancer Trust	4.1.2 a)	See above	We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
The Teenage Cancer Trust	4.1.2 b)	What about brain tumours that it is known will become malignant at some point.	We have now widened Section 4.1.1 to include some benign tumours.
The Teenage Cancer Trust	4.2 a)	Include referral time from Primary Care	Thank you for your comment. This will be considered by the Guidance Development Group during development of the Guidance.
The Teenage Cancer Trust	4.2 a-c)	Needs something, consider links/gaps between stages of care	Agreed see Section 3 c).
The Teenage Cancer Trust	4.2 d)	Please define meaning of “quaternary” for us lay people	“ <i>Quaternary Centres</i> ” refer to nationally recognised centres in highly specialised areas.
The Teenage Cancer Trust	4.3 a)	Understand that referral guidelines are separate exercise but should ensure cohesion between the two.	Agree there will be cohesion between the two.
The Teenage Cancer Trust	4.3 a)	What about adult specialists working with older adolescents and young adults?	We have included general adult physicians to the list of ‘other specialists’.
The Teenage Cancer Trust	4.3 a)	What about specialist adolescent clinicians?	The second bullet point in Section 4.3 a) now includes a list of personnel– it lists just a few

			examples, other groups will be considered as appropriate.
The Teenage Cancer Trust	4.3 b)	Fertility counselling/treatment?	Agreed, included in Section 4.3 c).
The Teenage Cancer Trust	4.3 c)	Psychology and Social Work for families as well	Agreed, included in Section 4.3 e).
The Teenage Cancer Trust	4.3 c)	Education for 17+ needs addressing because no obligation in adult services.	Thank you, this comment will be passed to the developer.
The Teenage Cancer Trust	4.3 c)	Activity co-ordinators and play therapists	Agreed, included in Section 4.3 e).
The Teenage Cancer Trust	4.3 c)	Voluntary organisations such as TCT.	Care such as spiritual care/ support/counselling/ voluntary sector services will now be covered under support services in Section 4.3 e).
The Teenage Cancer Trust	4.3 d)	Late effects to include psychological effects and social impacts.	This section lists some examples and is not exhaustive. Psychological effects and social impacts will be considered.
The Teenage Cancer Trust	General	If young adults are not included this will eliminate the chance of appropriate services of 19-24 year olds and 17-19 year olds will be in adult settings. Therefore adult physicians and specialists must be included	We have now widened the definition in 4.1.1. We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a).
The Teenage Cancer Trust	4.1.1	The research for the Thames Cancer Registry concludes that the number of 15-19 year olds with cancer are equal to the number of 0-10 year olds. This alone makes the case considering them and young adults as a distinct group.	Thank-you for your comments. We hope this will be incorporated into the final Guidance. We have changed the definition to “Young people presenting with malignant disease in their late teens and early twenties.” See Section 4.1.1 a)
The Teenage Cancer Trust	General	With regard to adolescent/young adult representation on the guidelines group I do not believe that this is the best way of	Membership of the Guidance Development Group is currently

		<p>involving them. We will be in danger of tokenism and not paying enough attention to proper consultation. There is also the risk of their experience being very specific. My suggestion is that as the guidelines are produced each section where we feel that consultation is essential then we set up specific groups to be consulted on those areas. That way we can target those that have experience of that area of service delivery and we can consult with greater numbers and cross sections of the country. TCT will be happy to assist with this. In addition the Teenage Cancer Trust will be running its 3rd Conference for teenagers with cancer at the end of April 2004. I will be happy to facilitate NICE to use that in some way to consult on some/all of the guidelines. There will be 350+ 15 – 23 year olds with cancer from all around the UK attending.</p> <p>Let me know if you want to take advantage of this sooner rather than later as we are planning the content of the programme now.</p>	<p>being considered. Also being considered is the most appropriate ways to involve patients and carers in the guidance development. The Patient Involvement Unit for NICE will be working with the Collaborating Centre to help facilitate appropriate patient/carer involvement.</p>
UK Childhood Leukaemia Working Party	General	The draft scope is broad but there are some omissions, which are important. The inclusions and exclusions are appropriate	Thank you.
UK Childhood Leukaemia Working Party	4.3 a)	Haematology - immunophenotyping for leukaemia is omitted.	Agreed, included in Section 4.3 a).
UK Childhood Leukaemia Working Party	4.3 b)	Staff resources are critical at present with shortages of appropriately trained nurses and doctors. Nursing is not mentioned in this document. Whilst chemotherapy is listed, pharmacy facilities are not specifically identified. The NCRI has been established to promote the entry of patients into clinical trials, which requires both data management and research nursing. This need should be identified.	Thank you for your comments, the section to which you refer has been re-ordered taking your comments into account.
UK Childhood Leukaemia Working Party	4.3 c)	Included in support services should be laboratory services, blood transfusion service and access to ITU.	Thank you for your comment, these services will be considered as part of the project areas within clinical management.
United Kingdom Children's Cancer Study Group	3 c)	Suggest insert - Rehabilitation in "Care of children with cancer in their follow-up and rehabilitation"	Agreed.
United Kingdom	4 d)	Suggest insert - The guidance will relate to guidelines for	This has been addressed in a new

Children's Cancer Study Group		suspected cancers, haematological malignancies, sarcomas and central nervous system tumours.	Section 2 c). Cross reference will be made to these and other documents as appropriate.
United Kingdom Children's Cancer Study Group	4.1.1 a)	Suggest increase age to 21 years and below	We have changed the definition to "Young people with malignant disease in their late teens and early twenties." See Section 4.1.1 a).
United Kingdom Children's Cancer Study Group	4.1.1 a)	Classify inclusion of "benign central nervous system tumours"	We have now widened Section 4.1.1 to include some benign tumours.
United Kingdom Children's Cancer Study Group	4.1.2 b)	In exclusion "Children with benign tumours except central nervous system tumours".	We have now widened Section 4.1.1 to include some benign tumours.
United Kingdom Children's Cancer Study Group	4.2	"The guidance will cover the following NHS services their commissioning and commissioners in England and Wales and their interaction with the voluntary sector	This document is by definition for commissioners and we can only advise on services. It is understood that the commissioners are expected to implement the guidance.
United Kingdom Children's Cancer Study Group	4.2 a)	Insert rehabilitation in "Active treatment follow-up, rehabilitation and palliative care.	The word 'rehabilitation' has been added to the document as suggested.
United Kingdom Children's Cancer Study Group	4.2 d)	Insert as d) Paediatric oncology shared care units and omit "their shared care partners" from c).	Agreed. Shared Care Centres now added, see Section 4.2 b).
United Kingdom Children's Cancer Study Group	4.3 b)	Insert "Intensive care, supportive care; pharmacy and rehabilitation"	This Section has been re-ordered taking your comment into account.
United Kingdom Children's Cancer Study Group	4.3 d)	Insert type in "Need frequency type location in the home"	Agreed, 'type' has been added in Section 4.3 f).
United Kingdom Children's Cancer Study Group	4.3	Insert as e) Administrative and data management support, especially in relationship to clinical trials	Agreed, now included in Section 4.3 g).
United Kingdom Children's Cancer Study Group	4.3 d)	Add "The process of transition from paediatric to adult services"	We agree, transition between services will be covered and an additional bullet point has been

			added.
United Kingdom Children's Cancer Study Group	General	The reliance on the current cancer services for children and adolescents on the voluntary sector and the resultant vulnerability of the service should be addressed.	The integration of current cancer services for children and adolescents with the voluntary sector is important and has been included in Section 4.2 f).
United Kingdom Children's Cancer Study Group	General	The treatment of malignancies generally specific to children, which occur in adults, should be addressed.	The upper age limit is to be flexible, so that if appropriate young adults could be covered by this guidance, however the scope of this guidance does not include adults generally.
Action for Sick Children	Scope		This organisation was approached, but did not respond.
Afiya Trust, The	Scope		This organisation was approached, but did not respond.
Association for Children with Life Threatening or Terminal Conditions	Scope		This organisation was approached, but did not respond.
Association of Professional Music Therapists	Scope		This organisation was approached, but did not respond.
Association of Surgeons of Great Britain and Ireland	Scope		This organisation was approached, but did not respond.
Aventis Pharma	Scope		This organisation was approached, but did not respond.
Bard Limited	Scope		This organisation was approached, but did not respond.
Bayer PLC	Scope		This organisation was approached, but did not respond.
Blackburn With Darwen PCT	Scope		This organisation was approached, but did not respond.
Brain and Spine Foundation	Scope		This organisation was approached, but did not respond.
British Association	Scope		This organisation was approached,

of Dermatologists, The			but did not respond.
British Association of Head and Neck Oncologists	Scope		This organisation was approached, but did not respond.
British Association of Paediatric Surgeons	Scope		This organisation was approached, but did not respond.
British Fertility Society	Scope		This organisation was approached, but did not respond.
British Infertility Counselling Association	Scope		This organisation was approached, but did not respond.
British Liver Trust	Scope		This organisation was approached, but did not respond.
British Medical Association	Scope		This organisation was approached, but did not respond.
British National Formulary (BNF)	Scope		This organisation was approached, but did not respond.
British Oncology Pharmacy Association	Scope		This organisation was approached, but did not respond.
British Orthopaedic Association	Scope		This organisation was approached, but did not respond.
British Orthoptic Society	Scope		This organisation was approached, but did not respond.
British Paediatric Pathology Association	Scope		This organisation was approached, but did not respond.
British Paediatric Psychiatry & Psychology Group	Scope		This organisation was approached, but did not respond.
British Psychological Oncology Society	Scope		This organisation was approached, but did not respond.
British Psychological	Scope		This organisation was approached, but did not respond.

Society, The			
British Society for Haemato-oncology	Scope		This organisation was approached, but did not respond.
British Society of Paediatric Radiology	Scope		This organisation was approached, but did not respond.
Cancer Black Care	Scope		This organisation was approached, but did not respond.
Cancer Research UK	Scope		This organisation was approached, but did not respond.
Cancer Services Coordinating Group	Scope		This organisation was approached, but did not respond.
CancerBACUP	Scope		This organisation was approached, but did not respond.
Changing Faces	Scope		This organisation was approached, but did not respond.
Christian Lewis Trust - Cancer Care for Children	Scope		This organisation was approached, but did not respond.
Community Psychiatric Nurses' Association			This organisation registered as a stakeholder after the end of the scope consultation period.
Eisai Limited	Scope		This organisation was approached, but did not respond.
Faculty of Public Health Medicine	Scope		This organisation was approached, but did not respond.
General Medical Council	Scope		This organisation was approached, but did not respond.
Help Adolescents with Cancer	Scope		This organisation was approached, but did not respond.
Institute of Physics and Engineering in Medicine	Scope		This organisation was approached, but did not respond.
Joint Committee on Palliative Medicine	Scope		This organisation was approached, but did not respond.

Let's Face It	Scope		This organisation was approached, but did not respond.
Merck Pharmaceuticals	Scope		This organisation was approached, but did not respond.
National Cancer Alliance	Scope		This organisation was approached, but did not respond.
National Council for Hospice and Specialist Palliative Care Services	Scope		This organisation was approached, but did not respond.
National Network Lead Clinicians Group	Scope		This organisation was approached, but did not respond.
Neonatal & Paediatric Pharmacists Group (NPPG)	Scope		This organisation was approached, but did not respond.
NHS Quality Improvement Scotland	Scope		This organisation was approached, but did not respond.
North East London Strategic Health Authority			This organisation registered as a stakeholder after the end of the scope consultation period.
Novartis Consumer Health (Novartis Medical Nutrition)	Scope		This organisation was approached, but did not respond.
Novartis Pharmaceuticals UK Ltd			This organisation registered as a stakeholder after the end of the scope consultation period.
Ortho Biotech	Scope		This organisation was approached, but did not respond.
Royal College of General Practitioners	Scope		This organisation was approached, but did not respond.
Royal College of			This organisation registered as a

General Practitioners Wales			stakeholder after the end of the scope consultation period.
Royal College of Ophthalmologists	Scope		This organisation was approached, but did not respond.
Royal College of Radiologists	Scope		This organisation was approached, but did not respond.
Royal College of Speech and Language Therapists			This organisation registered as a stakeholder after the end of the scope consultation period.
Royal College Patient Liaison Groups			This organisation registered as a stakeholder after the end of the scope consultation period.
Samantha Dickson Research Trust, The	Scope		This organisation was approached, but did not respond.
Scottish Intercollegiate Guidelines Network (SIGN)	Scope		This organisation was approached, but did not respond.
Serono Pharmaceuticals Ltd	Scope		This organisation was approached, but did not respond.
Society for Endocrinology	Scope		This organisation was approached, but did not respond.
Society of British Neurological Surgeons	Scope		This organisation was approached, but did not respond.
Teenage Cancer Trust Multidisciplinary Forum	Scope		This organisation registered as a stakeholder after the end of the scope consultation period.
The Royal Society of Medicine	Scope		This organisation was approached, but did not respond.
UK Brain Tumour Society	Scope		This organisation was approached, but did not respond.

UK Pain Society	Scope		This organisation was approached, but did not respond.
Wessex Cancer Trust			This organisation registered as a stakeholder after the end of the scope consultation period.
Young Minds	Scope		This organisation was approached, but did not respond.