

**National Institute for Clinical Excellence**  
**Sarcoma scope - Stakeholder Consultation Table**  
**20 October – 18 November 2003**

<b>Stakeholder</b>	<b>No.</b>	<b>Section number</b>	<b>Comments</b> Please insert each new comment in a new row.	<b>Institute's Response</b> Please respond to each comment
Acute Care Collaborating Centre			This organisation was approached but did not respond.	
Association for Palliative Medicine of Great Britain and Ireland			This organisation was approached but did not respond.	
Association of Hospice and Specialist Palliative Care Social Workers			This organisation was approached but did not respond.	
Association of Surgeons of Great Britain and Ireland			This organisation was approached but did not respond.	
Association of the British Pharmaceuticals Industry (ABPI)	1	General	The Association of the British Pharmaceutical Industry (ABPI) has no comments to make.	Thank you.
Bard Limited			This organisation was approached but did not respond.	
Bard Limited – 2nd contact			This organisation was approached but did not respond.	
Baxter Oncology			This organisation was approached but did not respond.	
Boehringer Ingelheim Ltd			This organisation was approached but did not respond.	
Brighton & Sussex University Hospitals Trust			This organisation was approached but did not respond.	
British Association for Counselling and Psychotherapy			This organisation was approached but did not respond.	
British Association of			This organisation was approached but did not respond.	

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Art Therapists				
British Association of Art Therapists – 2nd contact			This organisation was approached but did not respond.	
British Association of Head and Neck Oncologists			This organisation was approached but did not respond.	
British Association of Oral and Maxillofacial Surgeons			This organisation was approached but did not respond.	
British Association of Otolaryngologists, Head & Neck Surgeons			This organisation was approached but did not respond.	
British National Formulary (BNF)	1	4.3	Suggest the mention of current pharmacological treatment options for sarcoma, also the use of drugs after administration of primary drug therapy such as those used to treat side effects or for symptom control.	Thank you. The role of this work is to provide general service guidance rather than provide specific advice on individual drugs and other therapies unless there are significant service or cost implications. We feel the general issues of pharmacological treatment will be dealt with when we review oncology services (Section 4.3b).
British National Formulary (BNF)	2	4.3	The use of complementary or alternative therapies in sarcoma could also be mentioned.	Thank you. We cannot review the role of complementary therapy <i>per se</i> and it is not a primary issue within the scope. However, it will be covered with the interface with non-NHS providers.
British Oncology Pharmacy Association	1	4.1.2	The scope of this draft does not cover children and adolescents with bone and soft tissue sarcomas. Guidance on child and adolescent cancer is due in March 05 and that on sarcomas in Sept 05. It is not clear how much collaboration there is between the two working groups, but, particularly as the peak incidence of this rare group of tumours is in adolescents and as all patients' primary management is likely to be by the same clinicians, it seems entirely logical that the sarcoma guidance should cover patients in all age groups. If this is not to be the case, the two sets of guidance should be clearly cross-referenced.	Thank you. We have revised the scope (Sections 4.1.1 and 4.3) in the light of your comment and we will ensure that collaboration between the Child and Adolescent Service Guidance Guideline Development Group and the Sarcoma Guideline Development Group is effected.

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British Oncology Pharmacy Association	2	4.1.2	Inclusion of gynaecological sarcomas would also be entirely logical. If this is not to happen, once again the sarcoma and gynaecological cancer guidance documents should be cross-referenced.	Thank you. We have revised the Scope (Sections 4.1.1 and 4.3) in the light of your comment.
British Oncology Pharmacy Association	3	General	To classify these rare tumours only by site of occurrence may lead to misleading omissions since they can occur in almost any part of the body. It may be more appropriate to classify them by histological type.	Thank you. We agree and we have modified the Scope in Section 4.1.1.
British Orthopaedic Association			This organisation was approached but did not respond.	
British Psychological Society, The			This organisation was approached but did not respond.	
British Psychosocial Oncology Society			This organisation was approached but did not respond.	
British Society of Paediatric Radiology			This organisation was approached but did not respond.	
BUPA	1	4.3g	Will the health services research and clinical trials on service delivery include health economics studies?	Thank you. Yes, and this is implicit within 'Health Service Research'.
Cancer and Leukaemia in Childhood (UK)			This organisation was approached but did not respond.	
Cancer Research UK	1	4.1.1	Adults with peripheral nerve sheath tumours and neurofibromatosis type 1, including plexiform neurofibroma should also be included in the groups that will be covered. This is an emerging area and a complex disease.	Thank you. We have revised the Scope (Section 4.1.1) in the light of your comment.
Cancer Research UK	2	4.1.2	As adolescent sarcoma essentially falls within the adult population and are treated in adult centres in the main, especially from age 13–14.	Thank you. We have revised the Scope (Sections 4.1.1 and 4.3) in the light of your comment and we will ensure that collaboration between the Child and Adolescent Service Guidance Guideline Development Group and the Sarcoma Guideline Development Group is effected.
Cancer Research UK	3	4.1.2	Although childhood sarcomas are outside of the scope of this Guidance, the role of paediatric oncologists and bone surgeons in contributing to this guidance should not be overlooked. There is a lot that can be learnt from these specialists regarding the impairment of growth during treatment and the storage and molecular classification of tumour types in adults.	Thank you. We have changed the Scope to include some aspects of the management of Child and Adolescent Cancer. Further, the issue of growth impairment is within the Scope of Child and Adolescent Guidance. The issue of storage and molecular classification of

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				tumour types will be dealt with in Section 4.3a.on pathology.
Cancer Research UK	4	4.3	Services for diagnosis and staging should specifically include PET scanning.	Thank you. The issues of PET scanning will be covered in Section 4.3a.
Cancer Research UK	5	4.3	When considering the important issues of data collection and registration of sarcomas, the issue of banking by pathology departments of tissue material, for diagnostic and investigative work, should be an absolute standard of care.	Thank you. These issues will be covered in Section 4.3.
Cancer Research UK	6	4.3	Specific consideration should be given to early phase oncology trial units with a focus on sarcoma. This should be rolled out across the UK, to relieve the pressure of just having one unit responsible for all of this work.	Thank you. The remit of this guidance is to inform commissioners on service delivery and not to advise on clinical trials and research infrastructure.
Cancer Research UK	7	4.3	The role of Genetic services should be addressed. Family histories may on occasion uncover predispositions for rare cancers.	Thank you. We have modified the Scope in 4.3c to include some aspects of surveillance.
Cancer Research UK	8	4.3	An emphasis within this scope should be on the importance of multi-disciplinary clinics, with plastic, orthopaedic and abdominal surgeons discussing and managing cases together, from diagnosis to palliation.	Thank you for your comment, which will be passed on to the GDG for their consideration.
Cancer Services Co-ordinating Group			This organisation was approached but did not respond.	
Cancer Voices			This organisation was approached but did not respond.	
CancerBACUP			This organisation was approached but did not respond.	
Chartered Society of Physiotherapy			This organisation was approached but did not respond.	
Children's and Adolescent Cancer Partnership (CACP)			This organisation was approached but did not respond.	
Chronic Conditions Collaborating Centre			This organisation was approached but did not respond.	
College of Occupational Therapists	1	4.1.2	Can it be clarified whether HIV related sarcomas, that is, Kaposi's Sarcoma, would be covered in this guidance?	Thank you. No, this is specifically excluded because it is included in the Scope of the Guidance for Skin Cancer.
College of Occupational Therapists	2	4.3b	Should the developers consider identifying Hospices specifically as centres for intervention?	This is covered by Section 4.3d.
College of Occupational	3	4.4	We would like to ensure that rehabilitation outcomes (for example, changes to functional status or quality of life) are identified in addition to	Thank you. We will pass this comment on to the GDG.

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Therapists			outcomes such as survival rates.	
Coloplast Limited			This organisation was approached but did not respond.	
Department of Health	1	4.3a	Pathology services (particular histopathology) play an important role in the diagnosis and staging of a number of sarcomas. The new guidelines, <i>Modernising Pathology Services</i> (to be published imminently) describe the direction of travel of NHS pathology services. One of the main themes emerging from these guidelines is the integration of pathology into the wider health community, networking across NHS-trusts with services not confined to individual pathology departments. Colleagues from the Department's Pathology Modernisation Programme will be able to provide further information on this.	Thank you for your helpful comment, and we will act on your suggestion.
Department of Health	2	4.3a	Diagnosis of a number of sarcomas within the scope would require the input of endoscopy services. Is this included under 'surgical services in secondary care'? Perhaps it might be advisable to address this as a discreet diagnostic discipline, given that endoscopy is not exclusive to secondary care/surgical service areas.	Thank you. Endoscopy services should be included under diagnostic services in Section 4.3a.
Eisai Limited			This organisation was approached but did not respond.	
Faculty of Public Health			This organisation was approached but did not respond.	
Help Adolescents with Cancer			This organisation was approached but did not respond.	
Joint Committee on Palliative Medicine			This organisation was approached but did not respond.	
Limbless Association			This organisation was approached but did not respond.	
Macmillan Cancer Relief			This organisation was approached but did not respond.	
Marie Curie Cancer Care	1	General	Marie Curie Cancer Care does not wish to comment specifically about the scope of this guidance.	Thank you.
Marie Curie Cancer Care	2	4.3d	The Supportive and Palliative Care Guidance makes key recommendations for the care of patients throughout their cancer journey. They are applicable to any tumour type. It is unlikely that there is a significant body of evidence which is specific to palliative care for sarcomas; this guidance should not seek to restrict its scope and should make reference to the Supportive and Palliative Care Guidance in its entirety.	Thank you. We will be making clear cross reference to this Guidance (Section 2b).
Medicines and Healthcare Products			This organisation was approached but did not respond.	

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Regulatory Agency (MHRA)				
Mental Health Collaborating Centre 1			This organisation was approached but did not respond.	
Mental Health Collaborating Centre 2			This organisation was approached but did not respond.	
National Alliance of Childhood Cancer Parent Organisations			This organisation was approached but did not respond.	
National Cancer Alliance			This organisation was approached but did not respond.	
National Cancer Network Lead Clinicians Group			This organisation was approached but did not respond.	
National Cancer Research Institute - Sarcoma Clinical Studies Group			This organisation was approached but did not respond.	
National Cancer Research Institute (NCRI)	1	3a, b and c	Gastrointestinal stromal tumours (GIST) are selected out as a specific entity in parts a, b and c. While we agree that GIST should be included in the guidance for sarcoma there is an over-emphasis in these sections.	Thank you. We have changed Section 4.1.1 and have separately specified GIST because it is not included in the WHO classification of soft tissue sarcomas. ( <i>World Health Organization Classification of Tumours: Pathology and Genetics of Tumours of Soft Tissue and Bone</i> , IARC Press, Oxford, 2002, ISBN 9283224132).
National Cancer Research Institute (NCRI)	2	3b	GIST may present with a range of abdominal symptoms of which bleeding is but one, and not the commonest.	Thank you. We have amended the Scope accordingly.
National Cancer Research Institute (NCRI)	3	3c	We believe this section should include reference to both the clinical heterogeneity of these diseases, the complexity of their management and the need for an experienced multidisciplinary team. We do not see any value in picking out one specific treatment, Imatinib, in this section and believe this is inappropriate.	Thank you. We have amended Sections 3b and 3c of the Scope accordingly.

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National Cancer Research Institute (NCRI)	4	3c	We would be pleased to see a statement here acknowledging that perhaps two-thirds of patients with bone and soft tissue sarcomas may be cured with appropriate treatment and also an acknowledgement that there is a significant proportion of young patients affected who are at risk considerable long term consequences of treatment.	Thank you. Although the issues of the long-term consequences of chemotherapy and radiotherapy are being addressed by the Child and Adolescent GDG, the particular issues around surgical management and its long term consequences are clearly within this Scope (Section 4.3).
National Cancer Research Institute (NCRI)	4	4.1.1	Selectivity of this section is a little baffling. In comparison with other cancers, there are many, many types of soft tissue tumour. Some benign tumours are as complex to manage and indeed carry very major morbidity and mortality. Such tumours are frequently, and we believe appropriately, managed by the same team who manage clearly malignant sarcomas. One approach to the confusion of diseases, we would suggest, would be to use as guidance the World Health Organization Classification of Tumours Volume on Tumours of Soft Tissue and Bone (IARC press, Lyon, 2002).	Thank you. We have amended the Scope (Section 4.1.1).  We feel that the management of purely benign bone and soft tissue tumours is outside the scope, but we will consider the management of tumours of intermediate malignancy, as defined in the <i>World Health Organization Classification of Tumours: Pathology and Genetics of Tumours of Soft Tissue and Bone</i> , IARC Press, Oxford, 2002, ISBN 9283224132.
National Cancer Research Institute (NCRI)	5	4.1.1a	Chordoma of the sacrum accounts for most cases of this disease. These are generally managed by orthopaedic surgeons skilled in the treatment of other bone sarcomas. Craniofacial and higher spinal chordomas are less common and usually managed outside of sarcoma multidisciplinary teams. We are doubtful whether this is always in the patients best interests and would be pleased if the guidance development could consider appropriate care of all other patients with chordoma, particular to ensure access to new treatments.	Thank you. We have changed Sections 4.1.1 and 4.1.2 and chordomas (apart from base of skull tumours which are included in the Brain and CNS Tumours Guidance) are now included in the Scope.
National Cancer Research Institute (NCRI)	6	4.1.1b	The selection of four subtypes of sarcoma is unhelpful. For instance, why should DFSP be selected rather than any other rare type of soft tissue sarcoma? It may be clearer to leave this section simply as all soft tissue sarcoma.	Thank you. We have changed Sections 4.1.1 and 4.1.2.
National Cancer Research Institute (NCRI)	7	4.1.1c	We believe it is helpful to separately emphasize that GISTs are covered in this section.	Thank you for your comment.
National Cancer	8	4.1.2	We have very real concerns about developing a service guidance that	Thank you. We have revised the Scope

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Research Institute (NCRI)			<p>excludes consideration of children and adolescents with bone and soft tissue sarcoma. These are relatively common tumours in children and adolescents and in particular most high grade bone sarcomas occur in those aged under 25 years. We do not believe that age-defined barriers are helpful as they do not reflect either the clinical or biological features of these tumours or the functioning of well-developed specialist multidisciplinary teams which are tumour, rather than age specific. This is especially true for bone sarcomas but there are very good reasons to be concerned with regard to soft tissue sarcoma as well. The commonest soft tissue sarcoma in children is rhabdomyosarcoma which is relatively uncommon in adults. However, the other subtypes of sarcoma more often seen in adults do also occur in children. It is becoming increasingly recognized that there has been too little cross talk between paediatric and adult oncologists dealing with sarcomas to the possible detriment of adult patients with rhabdomyosarcoma and children with non-rhabdomyosarcomatous tumours. Perpetuating this artificial divide must be avoided in this guidance. Finally, we recognize that a similar exercise to develop service guidance for children and adolescent cancer is also being conducted. However, it is our understanding that this is principally aimed at ensuring that such cancers occurring in this age group are dealt with in an age specific environment but are not aware that it will concentrate on the details of each tumour type occurring in the younger patients. Furthermore, we understand that this guidance will encompass patients up to the age of twenty-four and therefore will exclude the majority of patients with high grade bone tumours. Therefore, we believe that all patients, regardless of age, with bone and soft tissue sarcomas should be covered by the sarcoma guidance but that appropriate notice should be taken of the other aspects of providing care for children and adolescents with due reference to the age specific guidance.</p>	<p>(Sections 4.1.1 and 4.3) in the light of your comment and we will ensure that collaboration between the Child and Adolescent Service Guidance Guideline Development Group and the Sarcoma Guideline Development Group is effected.</p>
National Cancer Research Institute (NCRI)	9	4.1.2b	<p>'Benign sarcomas' is an oxymoron. There are however important benign conditions which in our opinion should be covered by this guidance. In particular we believe that the rare condition of fibromatosis should be covered by the guidance. In addition we believe that consideration should be given during the development of the guidance to inclusion of advice regarding management of several others tumours using the WHO classification as a guide.</p>	<p>Thank you. We have amended Section 4.1 in the Scope.</p>
National Cancer	10	4.1.2b	<p>Uterine sarcomas should not be excluded from the service guidance for</p>	<p>Thank you. The changes in Section</p>



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Research Institute (NCRI)			sarcomas. While recognizing that these tumours often present to gynaecological oncologists, in most specialist centres best practice can be seen as an extension of the sarcoma multidisciplinary team and close working relationships exist. These tumours should be managed according to the principles of sarcoma management rather than those for the management of epithelial gynaecological cancers. Finally these are not covered in the Improving Outcomes for gynaecological cancer except a mention they should be treated in the Cancer Centres rather than Units.	4.1.1 of the Scope mean that we will be addressing the care of these patients.
National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)			This organisation was approached but did not respond.	
National Guidelines & Audit Patient Involvement Unit			This organisation was approached but did not respond.	
National Guidelines & Audit Patient Involvement Unit			This organisation was approached but did not respond.	
National Guidelines & Audit Patient Involvement Unit			This organisation was approached but did not respond.	
National Public Health Service			This organisation was approached but did not respond.	
NCC for Cancer			This organisation was approached but did not respond.	
NHS Information Authority, (PHSMI Programme)			This organisation was approached but did not respond.	
NHS Quality Improvement Scotland			This organisation was approached but did not respond.	
Novartis Pharmaceuticals UK Ltd	1		I can confirm that we do not have any comments at this stage.	Thank you.
Nursing & Supportive Care Collaborating Centre			This organisation was approached but did not respond.	

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Pfizer Limited			This organisation was approached but did not respond.	
PharmaMar	1	3	There are different chemotherapy options for treating sarcomas, and new treatments will be available in the future, therefore PharmaMar suggest to mention all agents within this section, or to exclude imatinib mesylate as the treatment for just one type of sarcoma.	Thank you. The role of this work is to provide general service guidance rather than provide specific advice on individual drugs and other therapies unless there are significant service or cost implications. We have removed reference to imatinib in Section 3.c
PharmaMar	2	4.1.1	PharmaMar suggest to include other Sarcomas types.  There are more than 50 histological subtypes of sarcomas, and only a few have been considered (bone sarcoma, chordoma of the sacrum, head and neck sarcoma, chest wall sarcom, DFSPs, retroperitoneal sarcomas, and GIST). None of these is extremity sarcomas, and 40% of STS develop in the lower extremities.  Sarcomas arising in the fat (liposarcoma) muscle (leiomyosarcoma, rhabdomyosarcoma) , the joints (synovial sarcoma), nervous system (Ewing's sarcoma) and others should be also included in order to give a broader perspective of the disease, since the STS subtypes distribution is thought to be approximately: Leiomyosarcoma: 29% Malignant Fibrous Histiocytoma: 20% Liposarcoma: 8% Fibrosarcoma: 6%	Thank you. We have modified the Scope in Section 4.1.1.
PharmaMar	3	4.1.2	Patients with metastasis from tumours at other primary sites are not covered. PharmaMar assumes that this refers to metastasis from other tumour types and not to metastasis from a soft tissue sarcoma. PharmaMar considers that advanced soft tissue sarcoma is a group of interest that should be also considered	Thank you. Yes, this refers to metastasis from other tumour types. Advanced soft tissue sarcoma will be covered by this Guidance and this has been clarified in Section 4.1.1.
PharmaMar	4	4.1.2	Why uterine sarcomas have been excluded from the analysis? We believe they should be included in the Scope.	Thank you. We have changed the Scope to include them in Section 4.1.1.
PharmaMar	5	General	PharmaMar is currently conducting a 'Cost of Metastatic Soft Tissue Sarcoma in the UK' in order to assess the cost per patient for managing Soft Tissue Sarcoma from diagnosis to death from the perspective of the UK National Health System. Results will be published in 2004 and may be of interest for adding information on the impact of soft tissue sarcomas on	Thank you. We will be most grateful if you would forward a copy of this to the National Collaborating Centre for Cancer.

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			the healthcare setting and services.	
Primary Care Collaborating Centre			This organisation was approached but did not respond.	
Royal College of Anaesthetists			This organisation was approached but did not respond.	
Royal College of General Practitioners	1	General	<p>Sarcomas are rare cancers which present in primary care once in a GP lifetime. Other conditions, such as injuries and soft tissue infections, present commonly. Accordingly, the aspect of guidance of most pressing concern to general practitioners will be directed at making the distinction between these conditions early and reliably. The principles involved will need to be compellingly presented; the one sarcoma case that a GP might ever encounter may well present 10 years or more after the guidance has been seen.</p> <p>The College will be interested in reviewing guidance on the early diagnosis of these rare conditions in this light.</p>	<p>Thank you. This issue is being dealt with in the NICE <i>Referral Guidelines for Suspected Cancer</i> (Section 2b).</p> <p>The early drafts of the relevant sections of this guidance will be made available to this Guideline Development Group.</p>
Royal College of General Practitioners Wales			This organisation was approached but did not respond.	
Royal College of Nursing (RCN)		General	I find it surprising that children and adolescents with bone tumours are not covered, as this is the majority of the patients treated. If they are grouped in more general guidance on children's tumours they will not get sufficient coverage and exposure, as they are so rare.	Thank you. We have revised the Scope (Sections 4.1.1 and 4.3) in the light of your comment and we will ensure that collaboration between the Child and Adolescent Service Guidance Guideline Development Group and the Sarcoma Guideline Development Group is effected.
Royal College of Paediatrics and Child Health			This organisation was approached but did not respond.	
Royal College of Pathologists	1	4.1.1c	Why include GIST and exclude all other internal organ-based sarcomas? The clinicians involved in GIST diagnosis, the surgeons involved in its treatment and the pathologists in its diagnosis are very different to those managing adult bone and soft tissue sarcomas.	Thank you. We have revised the Scope to include all Sarcomas (Section 4.1.1).
Royal College of Pathologists	2	4.1.1a	Adamantinoma and desmoplastic fibroma should be specifically included.	Thank you. We have revised the Scope in Sections 4.1.1 and 4.1.2 according to the WHO Guidelines ( <i>World Health</i>

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				<i>Organization Classification of Tumours: Pathology and Genetics of Tumours of Soft Tissue and Bone</i> , IARC Press, Oxford, 2002, ISBN 9283224132). This includes adamantinoma but not desmoplastic fibroma as a malignant tumour.
Royal College of Pathologists	3	4.1.1b	Fibromatosis should be specifically included.	We have revised the Scope in Sections 4.1.1 and 4.1.2 according to the WHO Guidelines ( <i>World Health Organization Classification of Tumours: Pathology and Genetics of Tumours of Soft Tissue and Bone</i> , IARC Press, Oxford, 2002, ISBN 9283224132) and this includes fibromatosis.
Royal College of Physicians of London			This organisation was approached but did not respond.	
Royal College of Psychiatrists	1	3	Patients with sarcoma may suffer chronic pain or disfigurement as a result of the sarcoma or treatment e.g. amputation. There may be significant psychological sequelae including body image problems.	Thank you. We will pass your comment on to the Guideline Development Group.
Royal College of Psychiatrists	2	4.3b and d	Services may also include psychological medicine or liaison psychiatry teams both in treatment and in supporting rehabilitation	Thank you. We will pass your comment on to the Guideline Development Group, but we feel this would already be included under 4.3d.
Royal College of Psychiatrists	3	General	<p>There are increased rates of psychiatric morbidity and psychological problems in patients with cancer/tumours which may affect the presentation, course and outcome.</p> <p>Patients experiencing disfiguring tumours or undergoing treatments which are painful, unpleasant or disfiguring are at increased risk of psychiatric/psychological problems. Patients with sarcoma fall within this group.</p> <p>It is important that patients' psychological needs are identified and that these are met.</p>	Thank you. We will pass your comment on to the GDG.
Royal College of Radiologists			This organisation was approached but did not respond.	

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Royal College of Surgeons of England			This organisation was approached but did not respond.	
Royal College of Surgeons of England – 2nd contact			This organisation was approached but did not respond.	
Royal College Patient Liaison Groups			This organisation was approached but did not respond.	
Royal Pharmaceutical Society of Great Britain			This organisation was approached but did not respond.	
Sarcoma UK	1	4.1.2a	We would like to see some clarity on the definition of 'adult', 'child' and 'adolescent' so that the particular (sometimes unique) needs of sarcoma patients in the teenage/young adult group can be fully and properly addressed. It will almost certainly be inappropriate to make such definitions purely on the basis of age. Cross reference to the still developing Childhood Cancer Guidance will be necessary to ensure that all sarcoma patients are appropriately covered. Better to have an overlapping statement than to create a gap by default.	Thank you for your helpful comment. We have revised the Scope (Sections 4.1.1 and 4.3) in the light of your comment and we will ensure that collaboration between the Child and Adolescent Service Guidance Guideline Development Group and the Sarcoma Guideline Development Group is effected.
Sarcoma UK	2	4.1.2b	We would question the exclusion of uterine sarcoma. While we recognise that the initial diagnosis of these tumours will usually lie within the gynaecology speciality and should be appropriately dealt with there, it is not unknown for patients to fail to be diagnosed with sarcoma, only being diagnosed once metastases are present. Their care and treatment should then come within the context of a specialist sarcoma MDT where the latest knowledge of sarcoma (and access to clinical trials) is located. There is the real potential for a 'gap' in patient care to occur by default should this group of patients not be considered in this guideline process.	Thank you. The changes in Section 4.1.1 of the Scope mean that we will be addressing the care of these patients.
Sarcoma UK	3	4.3a and b	The diagnosis of sarcoma following surgery for some other suspected condition is a major concern. The excision of a lump is common, the recognition that some lumps are malignant too often comes later. This is as likely to happen under private healthcare arrangements as under the NHS. While patients may continue treatment under privately funded care some will return to the NHS. The interface between the NHS specialist sarcoma services and private healthcare providers using surgeons unfamiliar with sarcoma, its diagnosis and the most appropriate surgery,	Thank you. This guidance is aimed at NHS commissioners and will be made freely available to the private sector. Wherever care is commissioned from the NHS, it should comply with this guidance.

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			should be considered.	
Sarcoma UK	4	4.3b, c and e	Long-term (lifetime) support for the maintenance and repair of prostheses should be included as most appropriate under one or more of these sub-headings.	Thank you, we feel this is covered by 4.3e.
Sarcoma UK	5	4.3f	Information AND support.	Thank you. We have changed the wording of 4.3f.
Sarcoma UK	6	4.3f	Cancer information is sometimes seen as an end in itself. In fact it is inseparable from the context of support because information is the core requirement in making choices. This is crucial for sarcoma as the issue of 'choice' is one that sarcoma treatment often involves – the extreme example perhaps being amputation versus limb salvage, balancing future risks versus future disability. The need for information which enables choices to be made, and for support when considering and making such choices, is inextricably linked and of utmost importance.	Thank you. We feel these issues are adequately covered in Sections 4.3d and 4.3e.
Scottish Intercollegiate Guidelines Network (SIGN)			This organisation was approached but did not respond.	
Sheffield Teaching Hospitals NHS Trust			This organisation was approached but did not respond.	
Society and College of Radiographers			This organisation was approached but did not respond.	
Teenage Cancer Trust, The			This organisation was approached but did not respond.	
The Royal Society of Medicine	1	General	This comment comes from a past President of our Section of Oncology, and therefore represents a personal view. The past President was concerned about the limits of the consultation. For example, children and adolescents are specifically excluded from this guidance as are adults with a variety of types of tumour which are important, such as chordomas at sites other than the sacrum.	Thank you. We have revised the Scope (Sections 4.1.1 and 4.3) and we will ensure that collaboration between the Child and Adolescent Service Guidance Guideline Development Group and the Sarcoma Guideline Development Group is effected.
UK Children's Cancer Study Group			This organisation was approached but did not respond.	
Welsh Assembly Government (formerly National Assembly for Wales)			This organisation was approached but did not respond.	

Stakeholder	No.	Section number	<b>Comments</b> Please insert each new comment in a new row.	<b>Institute's Response</b> Please respond to each comment
Wessex Cancer Trust			This organisation was approached but did not respond.	
Women's & Children's Collaborating Centre			This organisation was approached but did not respond.	