Sarcoma 1st consultation − Stakeholder comments
9 May 2005 – 6 June 2005
National Institute for Health and Clinical Excellence

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Addenbrooke's NHS Trust		This organisation was approached but did not respond.	
Anglesey Local Health Board		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)		This organisation was approached but did not respond.	
Association of Upper GI Surgeons of Great Britain and Ireland	Paragraph 233 (Table 5)	You will not find Surgeons in the UK who spend >50% of their time resecting Sarcomas. They are too rare. This has clearly been plucked out of thin air.	There are surgeons in the UK who spend more than 50% of their time managing patients with sarcomas, but we accept that they are not likely to spend more than 50% of their time operating on them.
Association of Upper GI Surgeons of Great Britain and Ireland	Paragraph 349	It needs to be made explicitly clear here that .80% of GISTs are realated to the Upper GI tract and therefore the primary SMDT is going to be the Upper GI one. We do not accept that all GIST patients need to be transferred to a Sarcoma SMDT. The Oesophago-gastric SMDT for any Cancer Network should have all the necessary skills and information to treat GISTs and, in many cases, the diagnosis is not made until after resection (as is true of many Sarcomas)	We have clarified in the recommendations that the site-specific MDT (multidisciplinary team) has primary responsibility to liaise with the sarcoma MDT to discuss the management of each patient. While the guidance does not state that all patients with GIST need to go to the sarcoma MDT, the Guideline Development Group (GDG) feels strongly that these patients need the support provided by the sarcoma MDTs.
Association of Upper	General	We could not find a specific request for clinicians not to biopsy	We have amended the text to clarify this.

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GI Surgeons of Great Britain and Ireland		suspected Sarcomas. If it's in, apologies but this is a really important instruction.	
Bard Limited		This organisation was approached but did not respond.	
Bath and North East Somerset PCT		This organisation was approached but did not respond.	
Baxter Oncology		This organisation was approached but did not respond.	
Bedfordshire and Hertfordshire NHS Strategic Health Authority		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	General	This is a clear and accessible guideline, but would benefit from the inclusion of a glossary of terms and full reference of research material and other literature considered by the Guideline Development Group.	A glossary will be included in the second draft of the Manual and the evidence will be itemised in the Evidence Review that accompanies this guidance. Both of these will be available during the second consultation.
British Association for Counselling and Psychotherapy	Paragraph 92	We believe that information about availability and access to psychological therapy should be mentioned within Table 4: The Information Pathway. Such information would be ideally placed at the point of diagnosis and referral to a Sarcoma Treatment Centre. This should be in addition to the information provided on local and national support groups following surgery or other treatment. We would argue that by adding specific mention of psychological therapies within Table 4, this would ensure its necessity for some individuals is not overlooked. This suggestion is in line with paragraphs 81, 93 and 96, and is supported by paragraph 108, which notes that patients who received counselling found it useful.	The issue of psychological support and counselling is covered by the NICE guidance on 'Improving supportive and palliative care for adults with cancer'. We have added a cross reference to this guidance in para 73.
British Association for Counselling and Psychotherapy	Paragraphs 108–109	This sub-section would be better titled as Psychological and Psychosocial support. We were surprised at the lack of specific mention of the importance of	We have made this amendment to the text.

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		providing psychological therapy for sarcoma patients in the Manual, and would suggest that despite the frequent referral to NICE guidance 'Improving Supportive and Palliative Care for Adults with Cancer' – which does cover psychological, spiritual and emotional care – a re-titling of this paragraph would help further ensure the provision of such care is not overlooked.	
British Association for Counselling and Psychotherapy	Paragraph 233	Table 6: Membership of an extended sarcoma MDT should include mention of counsellors or psychological therapists, not just psychologists. This is partly because a range of professionals may help address the psychological needs of patients with sarcoma, and also because the guidance emphasises, in the introduction, the need to make recommendations which are practicable – there is a shortage of psychological therapists, and by widening the professional pool, there is a greater likelihood that people will get the psychological help they need.	We have included counsellors in Table 6.
British Association for Counselling and Psychotherapy	Paragraph 377	Although the NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer includes a strong emphasis on the need to ensure patients have access to psychological care, we would suggest that this term is included within this section (second bullet point), to ensure it is not overlooked.	We feel that this issue is already covered in para 378.
British Association for Dermatological Surgery		This organisation was approached but did not respond.	
British Association of Art Therapists		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 and Neck		This organisation was approached but did not respond.	

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Surgeons			
British Association of Plastic Surgeons		This organisation was approached but did not respond.	
British National Formulary (BNF)		This organisation was approached but did not respond.	
British Oncology Pharmacy Association		This organisation was approached but did not respond.	
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 for Dermatopathology		This organisation was approached but did not respond.	
British Society of Paediatric Radiology		This organisation was approached but did not respond.	
British Society of Skeletal Radiology		This organisation was approached but did not respond.	
BUPA	Paragraph 233 (Table 5)	Core membership of MDT: Ideally it would be appropriate to specify that a Sarcoma Clinical Nurse Specialist be an essential member of the Core MDT. Specialist Nurses have been included in the definition of keyworker, however in paragraph 379, the role of key worker may be undertaken by other staff, who may not necessarily have specialist knowledge in sarcoma care. Therefore having a Clinical Nurse Specialist in the Core MDT would ensure that each cancer Network or centre has at least one Specialist Nurse to provide support. Colorectal and Breast Care Guidance specifically have Specialist Nurses as part of the core MDT. Whilst the rarity of Sarcoma's may mean that there are few sarcoma specialist nurses, however every sarcoma centre should at least have access to a specialist sarcoma nurse.	We have included a clinical nurse specialist in the core MDT.
Cancer and Leukaemia in Childhood (UK)		This organisation was approached but did not respond.	

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Cancer Research UK	General	Overall this guidance will be very helpful to commissioners although some clarification where the primary responsibility of GIST tumour management should be; either the sarcoma MDT with specialist oncology, or Upper GI MDT with less sarcoma specialisation.	We have amended para 351 to clarify that the primary responsibility for GIST tumour management should be with the upper GI MDT. In some networks the subsequent oncological management of GIST patients would be with a sarcoma MDT while in other networks it would be with the upper GI MDT.
Cancer Research UK	General	The document lacks clarification with regard to important role of cancer genetic services and sarcoma patients and families.	We have added a recommendation on cancer genetic services to the chapter on follow-up.
Cancer Research UK	General	The need for integration of research in to clinical practice is essential, especially for a rare cancer, such as Sarcoma.	We feel that the guidance makes it clear that research should be carried out by all MDTs and thus will be part of clinical practice.
Cancer Research UK	General	There is no point in establishing a sarcoma MDT independent of children and young adult cancer and surgical centres. Integration with young adult cancer practices is essential in view of the age spectrum of this disease and low numbers of patients. The requirement for 50 bone tumours and 100 STS in each MDT per year means a minimum of 8 bone centres, and 10 soft tissue centres, based on the incidence figures. Clarification of the suggested centres is needed to dispel ambiguity and irrelevant argument.	Issues of chemotherapy and support services for children and young people have already been covered by the NICE guidance on 'Improving outcomes for children and young people with cancer'. To avoid duplication with this document, we have inserted a cross reference to the children's guidance. However, we have noted your point about provision of surgical services for children with sarcomas and made appropriate amendments. While noting your comments about the number of sarcoma treatment centres, it is not within the remit of this guidance to define where the suggested centres should be.
Cancer Research UK	Paragraph 183	The use of molecular pathology in essential in this group of patients. These guidelines should therefore insist that there is molecular pathology infrastructure in every one of the approximately 10 centres of pathological expertise. Storage of fresh frozen material should be mandatory, as well as cytogenetics and a molecular diagnostics lab for gene mutations, translocations and gene expression.	We agree that the use of molecular pathology is becoming increasingly important in this group of patients. It is not however, essential in every single patient, and a network of molecular pathology laboratories is probably more sensible at the present time than insisting that each sarcoma centre should have its own molecular pathology expertise in house. We believe that a needs assessment should be carried out to establish whether these facilities are required in every recognised centre or whether concentration of services at a limited number of centres is more appropriate.

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			We have identified in para 199 that commissioners should fund molecular pathology/cytogenetic facilities. We agree, however, that storage of fresh frozen material should become routine in all these laboratories subject to the provision of the Human Tissue Act 2004 and have amended para 200 accordingly.
Cancer Research UK	Paragraph 183	The recognition of the need for research in these rare tumours is welcomed. In particular the establishment of a national tissue resource would greatly aid such research. The numbers of people diagnosed with Sarcoma are still low, compared to other cancers. However, this means that the establishment of a national bank in this tumour type is realistic. In populations of this size, experience shows that the groups of involved also tend to have a co-operative approach towards research to get such a project off the ground in a meaningful scientific way. This will improve the issue of trials with appropriate molecular classification and outcome.	Thank you for these comments. Please see response to comment 5.
Cancer Research UK	Paragraph 184	The standard practice for GIST will be mutations testing of the c-kit receptor. This will inform therapeutic choices (exon 9 versus exon 11 mutations). It is no longer acceptable to use CD117 staining alone, when there are very costly implications for the appropriate use of imatinib therapy.	We accept that the diagnosis of GIST is constantly being refined. We have therefore omitted specific comment about immunohistochemical markers but have highlighted that immunohistochemistry and cytogenetic analysis is appropriate for these rare tumours
Cancer Research UK	Paragraph 185	To address the shortages of consultant pathologists in this area, the Department of Health should fund Sarcoma Pathology fellowships post CCST/FRCpath. These should be for two years and assigned to a major training centre to ensure adequate provision of childhood and adult sarcoma expertise in the UK.	We agree that sarcoma pathology fellowships would be beneficial. We have included a recommendation that the Department of Health (DH) should fund sarcoma pathology fellowships (para 200a). This is also covered in para 485.
Cancer Research UK	Paragraph 197	Paragraph 186 states that there just 26 pathologists in the England (none in Wales). This is inconsistent with the recommendation for two SSPs per MDT which would imply that there would be only 13 MDTs in the UK (and one in Wales). This point needs clarification.	We accept that ideally there should be two SSPs per MDT, but in practice there are still a limited number of pathologists interested in sarcomas and that is why we have made the recommendation in para 197. It will be up to commissioners to ensure that pathological services at sarcoma centres are safe and that isolated sarcoma pathologists have a formal collaboration with

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			at least one colleague to cover leave and to help with difficult cases.
Cancer Research UK	Paragraph 204	It should be stated explicitly in this guideline that tissue banking of soft tissue sarcoma in specialised centres should be mandatory. Long-term benefit to patients is only possible through active research and therapeutic development based on this resource.	We have altered para 200 to confirm that centres should store tissue.
Cancer Research UK	Paragraph 211	For both bone and soft tissue sarcoma, molecular and cytogenetic diagnostics are essential.	This has been dealt with in the recommendations section (para 196).
Cancer Research UK	Paragraph 233	Additional membership should include molecular diagnostic and cytogenetic staff and a plastic surgeon with specialist interest in sarcoma.	Plastic surgeons are currently included in the extended sarcoma MDT (see table 6). We do not think molecular diagnostic and cytogenetic staff are likely to be essential members of either the core or extended sarcoma MDT.
Cancer Services Collaborative 'Improvement Partnership' (CSCIP)		This organisation was approached but did not respond.	
Cancer Services Coordinating 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	Paragraph 233	The CSP feels that a specialist sarcoma physiotherapist is an important member of the Core Sarcoma MDT, particularly in large, complex cancer units where the physio will be present with the patient at all stages of their journey and thus very much a core member of the team. In addition the key worker could also be a physiotherapist (or any other professional) and the wording of this paragraph needs to be changed to reflect this	We agree that in some centres the key worker will be a physiotherapist and this has been acknowledged in para 378. We do not believe that a specialist sarcoma physiotherapist is an essential member of the core MDT in all centres.
Chartered Society of Physiotherapy	Paragraph 391	The wording should reflect that any other appropriately trained allied health professional may also be able to fulfil this role and thus should say ' clinical nurse specialists or allied health professional specialists such as physiotherapists'	We have stated previously that it will be up to individual MDTs to decide who their key worker should be.
Chartered Society of Physiotherapy	Paragraph 392	It is good to see that a specialist sarcoma physiotherapist is a member of the extended MDT but they should also play a key role in the core MDT where treatment decisions are made	We do not feel that a physiotherapist is likely to be an essential member of the core sarcoma MDT.

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Chartered Society of Physiotherapy	Paragraph 378	The CSP strongly feels that the key worker could equally be a specialist physiotherapist rather than a nurse. We would like to see the wording in brackets changed to say 'specialist nurse or other clinical specialist such as a physiotherapist'.	The nature of the key worker will vary from centre to centre and will be up to local arrangements to determine. In most centres it will be a specialist nurse that takes on this role but in other centres it could be another allied health professional. Our comment in para 378 is merely reflecting the most common scenario.
Children's and Adolescent Cancer Partnership (CACP)		This organisation was approached but did not respond.	
Chugai Pharma UK Ltd		This organisation was approached but did not respond.	
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraph 13	This guidance will be helpful to commissioners , there should however be greater emphasis on the rarity of bone and soft tissue sarcoma and how they present non specifically in the context of larger numbers of non malignant tumours or tumours that have spread to these sites	We believe that we have discussed this in paras 25–26.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraphs 17 and 124	Whilst we agree in principle with defined pathways of care, because sarcomas often present non specifically, centres could be overwhelmed by benign disease. Advice with regard to understanding referral demand and diagnostic/treatment capacity should be included in the guidance	We have suggested a number of options for diagnostic clinics to deal with the likely high number of patients that could be referred for each malignant soft tissue sarcoma. Audit of these will be essential to identify the best method of identifying sarcomas.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraphs 6, 222 and 252	Whilst we agree in principle that a patient should be managed through an MDT the literature cited in paragraph 252 showing benefit from treating more than 5 cases per year compared to treating fewer than 2 cases does not correlate with the leap to choosing figures of 50 and 100 which would appear an arbitrary figure and further evidence on establishing these numbers would be beneficial	The GDG considered at length the optimum number of patients that a sarcoma treatment centre should manage per year. We believe that a patient's care is best managed by a sarcoma MDT, and that the MDT must be of sufficient size and have sufficient members to be able to work effectively and have in-depth experience. We do not believe that a properly constituted sarcoma MDT is likely to be viable unless it treats the number of patients we have identified in the guidance. We feel that the numbers we have suggested are realistic. For a centre treating both bone and soft tissue sarcomas, the requirement for them to treat on average one new patient with bone sarcoma per week

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			is not unrealistic, given the huge variety of bone sarcomas that exist. If a centre were treating fewer than 50 cases per year, it is unlikely that the surgical team, the pathologist or the back-up team would have sufficient expertise to give those patients optimum treatment. We feel that the same argument applies for soft tissue sarcomas, which is why we have stipulated a figure of 100 new cases per year, which correlates with a population base of approximately 3–4 million.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraphs 131 and 235	The guidance highlights the need to have defined clinically managed pathways for timely diagnosis which we agree with in principle. However the suggestion of developing separate diagnostic and treatment centres could prove difficult to sustain particularly in staff motivation at the purely diagnostic centres. Promoting a diagnostic – treatment centre which defines workforce skills and experience needed at key points in the patient journey would be an effective use of resource and a local team demonstrating through audit the relevant set of skills, could be authorised to work at that level	This guidance makes it quite clear that patients with sarcomas should be treated by a sarcoma MDT and the constitution of that MDT has been defined. Diagnostic clinics will be clearly affiliated to and work in collaboration with a sarcoma MDT or may indeed be part of a sarcoma treatment centre themselves, provided they fulfil all the appropriate criteria for this.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraph 131	Many of the problems in the treatment of soft tissue sarcomas arise because of inappropriate biopsies or local resections. Any radiologist or surgeon who might be dealing with a soft tissue or bone malignancy should be made aware of the need to place the biopsy site so that it can be included in a definitive resection, if that is needed (good surgical oncological practice).	This guidance makes it very clear that patients with a suspected sarcoma should be referred to a diagnostic clinic or a sarcoma MDT for further assessment and biopsy. Biopsy or local resections of 'suspicious' lumps and bumps should become increasingly infrequent.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraph 137	The definitive treatment of bone and soft tissue malignancies other than sarcomas requires many of the same surgical and oncological skills as the treatment of sarcomas. The aim should be to encourage and develop the appropriate expertise for the treatment of bone and soft tissue neoplasia, whatever the pathology. Because of the numbers of patients, this should encourage the development, within each Cancer Network, of a diagnostic and treatment service for both bone and soft tissue malignancies (with specialist referral for designated types of case e.g. endoprosthetic replacement for paediatric bone sarcomas)	Our guidance has made quite clear that bone and soft tissue sarcomas should be treated by a sarcoma MDT, and we have identified the constitution of that MDT and the likely number of patients it will have to treat to be viable. We think it is highly unlikely that each cancer network will be able to offer both a diagnostic and a treatment service for sarcomas. Bone sarcomas have now been designated by the National Specialist Commissioning Advisory Group (NSCAG) at a limited number of centres. There is central recognition that bone sarcomas should not, in any circumstances, be treated outside these centres
Clatterbridge Centre	Paragraph	It would seem reasonable if performed by appropriately trained staff,	We believe that both diagnosis and treatment of bone

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for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	138	as in soft tissue, to allow biopsy for suspected bone biopsy	sarcomas should be carried out by a designated bone sarcoma MDT.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraphs 232, 342–349 and 357	The recognition of the wide range of situations in which sarcomas can be encountered is useful and existing successful models for network wide MDTs should be used. If a sarcoma MDT , particularly soft tissue, were based on an area larger than a cancer network it would be difficult to maintain local links with different specialist MDTs	It will be up to the sarcoma MDTs to arrange appropriate links with site-specific MDTs.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraph 233	Table 5 mentions double reporting of pathology, but this isn't reflected in chapter 4. Specialist review and double reporting by 2 specialist pathologists will require significantly more pathology sessions, this should be reflected in resource implications	Thank you for pointing out this discrepancy. We have removed this text
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraph 233	Table 6 "other designated professionals" should include vascular surgeons	We have added vascular surgeons to Table 6.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraph 235	For consistency members of the MDT should be referred to as core rather than key members	We have made this amendment to the text.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer Network)	Paragraphs 274 and 275	These paragraphs should emphasise for the convenience of patients and carers, chemotherapy and radiotherapy be provided locally, in discussion with the sarcoma MDT and local expertise would need to be developed for the monitoring of adjuvant therapy	We have amended the text to clarify how chemotherapy and radiotherapy should be provided.
Clatterbridge Centre for Oncology NHS Trust	Paragraph 332	See also: Pirayesh et al. The management of retroperitoneal soft tissue sarcoma: a single institution experience with a review of the literature. Eur J Surg Oncol 2001: 27: 491 –7	Thank you for supplying this reference, which already forms part of the Evidence Review that accompanies the Manual.
Clatterbridge Centre for Oncology NHS Trust (Merseyside and Cheshire Cancer	General	The guidance provides a useful view on the complex issue of the menagement of sarcomas of bone and soft tissues, with an emphasis on soft tissues of the extremities and paediatric bone sarcomas. It is important that sarcomas and other benign and malignant tumours	Thank you for your comments. However, benign and malignant tumours of bone and soft tissue that are not sarcomas are outside the scope of this guidance.

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Network)		presenting in bones and soft tissues and in other age groups are not neglected in this guidance	
College of Occupational Therapists	Paragraph 92, Table 4 (page 34)	Reference is made to specific information about support for prosthetic limbs, perhaps information is warranted regarding information about rehabilitation services or support services other than just prostheses, e.g. wheelchairs, community rehabilitation, home modifications, driving etc.	We agree, and have amended Table 4.
College of Occupational Therapists	Paragraph 233, Table 5 (page 60) Paragraphs 388 and 392, also Paragraph 401 (pg. 93)	We are pleased to see the inclusion of a specialist physiotherapist as one of the key members on the extended MDT, however would query the absence of a specialist occupational therapist. We believe the specialist OT would have an important role in considering the likely long-term functional implications of treatments, e.g. amputation within the context of the patients' home environment and occupational roles. Seems to support the inclusion of a specialist OT on the extended MDT, and paragraph 420 demonstrates a commitment to the type of outcomes that will be focussed on by OT's. We do not believe therefore that including the OT on the list of other specialised staff who may form part of the extended MDT is sufficient (see table 5 pg 60), as we believe their role in promoting best rehabilitation outcomes is essential.	We have re-worded table 6 to highlight the role of allied health professionals
College of Occupational Therapists	Paragraphs 321, 339 and 373	Perhaps instead of only considering patient limb function the guidance should be considering overall functional status as part of the outcomes to be considered with sarcoma patients. Many patients with poor outcomes in terms of limb function may still have positive overall rehabilitation outcomes with effective rehabilitation programs (incorporating compensatory approaches). Again the outcomes that seem to be valued in paragraph 420 appear to support the benefits of these broader (and more meaningful) functional rehabilitation outcomes being strived for.	Assessing function and quality of life is very complex and it is likely that there will not be initial consensus about how this data should be collected. We have recommended that clinics should collect the minimum National Cancer Dataset, and further refinements with generalised consensus about what data should be collected are likely to be of value in the future. Comorbidity is a very significant factor in many patients with soft tissue sarcoma and a reliable standard should be agreed for collecting this data as well.
College of Occupational Therapists	General	Given the scarcity of good evidence regarding the benefits of rehabilitation, supportive and palliative care, should one of the recommendations be that resources are allocated to enable this type of research to be undertaken? Perhaps this is beyond the scope of this document, but would seem like a good idea.	We are unable to make specific comments about allocation of resources for research but we strongly support the College of Occupational Therapists in applying for research grants to assess the benefits of their services for patients with sarcomas.

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Coloplast Limited		This organisation was approached but did not respond.	
Countess of Chester Hospital NHS Foundation Trust		This organisation was approached but did not respond.	
Department of Health	General	Would you please consider whether it would be useful for this document have a glossary/list of abbreviations.	A glossary and list of abbreviations will be included in the second draft of the Manual. This will be available during the second consultation.
Department of Health	Paragraph 5	It would be helpful if you could clarify this recommendation - are you recommending funding at a local level? Central funding of pathology second opinions and review is not in line with the principles of a devolved NHS. DH guidance to the NHS *Modernising Pathology Services* encourages the development of larger pathology networks, one benefit of which is to support improved access to specialist expertise.	We have modified the text to clarify that the funding should come from commissioners.
Department of Health	Paragraph 8	You may wish to consider recommending that surgeons with site specific skills need to be consulted by sarcoma MDTs are extended members of the MDT.	This is already covered in the last row of Table 6.
Department of Health	Paragraph 11	Would you please consider amending to read " patients with functional disabilities should have a timely access..."	We have amended the text.
Department of Health	6 (and 273)	Your draft recommends that bone sarcoma MDTs should see a minimum of 100 new cases per year, or 50 new cases if also treating soft tissue sarcoma. It is widely accepted that bone sarcoma must be treated in centres with plenty of relevant experience, but we feel that the specific choice of threshold (50 / 100 new cases per annum). We feel that this recommendation requires a fuller justification from the evidence than is presented at paras 280 - 282.	The GDG considered at length the optimum number of patients that a sarcoma treatment centre should manage per year. We believe that a patient's care is best managed by a sarcoma MDT, and that MDT must be of sufficient size and have sufficient members to be able to work effectively and have in-depth experience. We do not believe that a properly constituted sarcoma MDT is likely to be viable unless it treats the number of patients we have identified in the guidance. We feel that the numbers we have suggested are realistic. For a centre treating both bone and soft tissue sarcomas, the requirement for them to treat on average one new patient with bone sarcoma per week is not unrealistic, given the huge variety of bone sarcomas that exist. If a centre were treating fewer than 50 cases per year, it is unlikely that the surgical

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			team, the pathologist or the back-up team would have sufficient expertise to give those patients optimum treatment. We feel that the same argument applies for soft tissue sarcomas, which is why we have stipulated a figure of 100 new cases per year, which correlates with a population base of approximately 3–4 million.
Department of Health	Paragraphs 12 and 328	The draft recommends that NSCAG should consider funding centres for management of abdominal and pelvic soft tissue sarcomas. NSCAG advises ministers on the designation and commissioning of services - this is a much more comprehensive process than 'funding', including for example agreeing service specifications and standards and monitoring patient outcomes and patient satisfaction with the service. Would you please consider whether it is appropriate to amend these recommendations to properly reflect the role of NSCAG .	Thank you for clarifying the situation. We have changed the phraseology from 'funding' to 'commissioning'.
Department of Health	Paragraph 17	You may wish to consider adding "and outcomes" after " key to improving care"	We have made this amendment to the text
Department of Health	Paragraph 20	You may wish to consider if the term "managed sarcoma network" is appropriate otherwise it will lead to confusion with the overarching "cancer networks" .	We are happy with the term 'managed sarcoma network' and do not envisage it being confused with 'cancer network'.
Department of Health	Paragraph 46	Would you please consider amending to read "surgical treatment is often disabling even when amputation has not been performed and patients require rehabilitation, including physiotherapy and occupational therapy, to recover optimum personal and social functioning including return to work."	We have made this amendment to the text.
Department of Health	Paragraph 77	We are not clear at what point or points information is given. Typically, it is at the point of diagnosis when patients are under great stress and unable to take in information. There are also other points (first treatment, continuing treatment, relapse, palliative care) when it is difficult for patients to assimilate what is being said. You may wish to consider extending the bullet points to include benefits advice, support groups and audiotaped consultation.	We are aware of the difficulty of patients assimilating information at certain points. This is one of the reasons why we have highlighted the problems and in particular given an information pathway in Table 4, documenting what information should be given at what stage. We have confirmed that written information should always back up verbal information. We have also confirmed the importance of self-help groups and social support in para 96.
Department of Health	Paragraph 80	Please consider adding an example such as CancerBACUP.	Current NICE rules mean that we are not allowed to name the materials of a specific voluntary organisation.

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Department of Health	Paragraph 85	We would be grateful if you could clarify whether the information for GPs referred to in this paragraph has been developed or is to be developed and by whom.	Information for GPs on referral guidelines for suspected cancer has recently been published by NICE. Further information about specific problems related to sarcomas is not currently available.
Department of Health	Paragraph 86	You may wish to consider making a reference to the chapters on information and communication in the NICE Supportive and Palliative Care guidance	Thank you for this suggestion. We have made a cross reference to chapters 3 and 4 of the guidance on 'Improving supportive and palliative care for adults with cancer'.
Department of Health	Paragraph 88	You may also wish to recommend a written record is backed up with an audiotape of the consultation. This would also be helpful for patients who are sight impaired or have difficulty reading.	We have included audio tapes in this recommendation.
Department of Health	Paragraph 89	You may wish to consider how the work of the Cancer Services Collaborative Improving Partnerships Program on national information protocols will fit into this.	Thank you. We will consider this.
Department of Health	Paragraph 92	Would you please consider redrafting table 4 as it seems to suggest that where no treatment is available that the patient need not be met face to face- this may be unacceptable to many patients and families who would want to meet with the specialist team and discuss why there was no treatment available.	We have amended Table 4.
Department of Health	Paragraph 95	You may wish to consider listing appropriate national or international trials here e.g. EORTC	We have inserted a cross reference to the research section of chapter 10.
Department of Health	Paragraph 96	Please consider including a reference to NICE Supportive and Palliative Care guidance.	We have added a cross reference to the NICE 'Supportive and palliative care' guidance in para 73.
Department of Health	Paragraph 99	We agree with the principle of a significant event analysis for significant delay – but given the median for delays at paragraph 155/156, it would be helpful if you could consider clarifying what constitutes "significant."	We have defined in para 99 that a significant event is one that affects a patient's management.
Department of Health	Paragraph 101	Please consider replacing "patients *will benefit* by helping and being helped by others in similar conditions" with "*may benefit*."	We have made this amendment to the text.
Department of Health	Paragraphs 105,107 and 112	Please consider whether there are any recommendations that should be made as a result of these paragraphs.	We do not think any particular recommendations can be made as a result of these paragraphs, but we have made the comment that MDTs should be responsible for providing accurate information and that this is likely to be done on a national basis.
Department of Health	Paragraph	Given that this is such a rare disease, you might wish to consider	We have no information about how a public

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
	128	further the implication of public awareness campaigns in terms of benefit versus unnecessary burden on GPs/public anxiety. Re. raising awareness in primary care, what useful approaches to raising awareness might be suggested to GPs.	awareness campaign might lead to an increased burden on GPs of lumps and bumps. It is hoped that a research project in the next year or so could be completed on this subject.
Department of Health	Paragraph 133	You may wish to consider expanding this paragraph to specify who is in an diagnostic team and what population should they cover.	Rather than highlighting who should be in a diagnostic team or what population they should cover, we have merely specified what we believe are the key steps in diagnosis, i.e. triple assessment.
Department of Health	Paragraph 134	Please consider recommending what training a diagnostic team should have.	In general, a diagnostic team should be proficient in the skills required for triple assessment. As there is no actual 'model' at the moment, the MDTs will have to come to a consensus with the diagnostic clinics as to how much training is required. What is identified will depend on the staff of these clinics.
Department of Health	Paragraphs 131–137	Would you please clarify if you are suggesting new networks of diagnostic clinics rather than utilising existing provision – if the latter can you clarify the likely impact on workforce supply and training	It is likely that there will be new diagnostic clinics. These clinics would, however, be clearly identified as diagnostic clinics for potential sarcomas and would replace the current somewhat haphazard referral pathways for patients, many of whom are seen by clinicians and district general hospitals in a variety of clinics.
Department of Health	Paragraph 183	Please would you consider whether the funding/commissioning of two laboratories for cytogenetics and molecular pathology should feature in the key recommendations.	We have amended the key recommendations to include this.
Department of Health	Paragraph 187	Would you please consider amending to read "The Department of Health now requires NHS pathology laboratories to enrol in a laboratory accreditation scheme."	We have made this amendment.
Department of Health	Paragraph 194	Please would you consider amending as this is incorrect – there is no such category as conditional accreditation. We suggest that the paragraph should read "There should be at least conditional approval."	We have made this amendment to the text.
Department of Health	Paragraph 199	You might wish to know that this is not in line with the principles of a devolved NHS. Local pathology services and networks should put in place any necessary arrangements to ensure access to relevant specialist expertise. You may wish to consider amending to reflect this	We have changed the recommendation about funding to confirm that commissioners should arrange funding.
Department of Health	Paragraph	The MDT catchment population falls into specialist commissioning.	We have added new paragraphs highlighting this

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
	224	You might want to consider specifically asking networks to plan through their Specialist Commissioning Groups.	issue after para 226 and made recommendations after paras 12 and 228.
Department of Health	Paragraphs 227 and 231	You may wish to consider merging these two paragraphs.	Thank you. These two paragraphs have been merged.
Department of Health	Paragraph 233 (page 60)	Would you please consider amending wording at bottom of table 5 to read "Each MDT should in addition have an extended team with membership as shown in table 6, some of whom may work as part of the core team, for example as key workers."	Thank you. We have made this amendment to the text.
Department of Health	Paragraph 235	Bullet 5 – Please could you clarify which national standards you are referring to. Bullet 9 - we are not aware that there is a national audit for sarcoma underway. Could you please clarify who is co-ordinating this or are you recommending that once takes place?	We have named these standards There is no national audit programme for sarcomas currently available, but we have recommended in para 481 that the National Clinical Audit Steering Group should be asked to provide guidance on developing this along with networks and sarcoma MDTs.
Department of Health	Paragraph 233 (page 60, Table 6, third row down)	Please would you consider changing text to: "Specialist sarcoma allied health professional (AHP)".	We have adopted the term 'specialist allied health professional'.
Department of Health	Paragraph 233 (page 60, Table 6, second column, third row down)	Would you consider inserting: "Adequately trained specialist AHP, such as physiotherapist and occupational therapist."	The text has been amended in response to a comment from another stakeholder.
Department of Health	Paragraph 233 (page 60 Table 6, second column, fourth row down.)	Would you please consider changing text to: "Consisting of other relevant AHPs, such as physiotherapists , occupational therapists,prosthetists, orthotists, dieticians plus access to psychologists and other services such as artificial limb and equipment services."	Thank you. We have amended the text.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Department of Health	Paragraph 274	We would be grateful if you could use the correct title "Manual for Cancer Services 2004", not "Manual of Quality Measures for Peer Review 2004",	We have amended the text.
Department of Health	Paragraph 275	You may wish to note that peer review is now based around cancer networks rather than cancer centres - please consider modifying sentence to reflect this.	We do not understand how this comment relates to para 275.
Department of Health	Paragraph 275	You may wish to consider modifying the phraseology in this paragraph. Organisations don't tend to be members of the MDT, individuals do.	Thank you for your comment. We have amended the text to clarify
Department of Health	Paragraph 293	Would you please consider adding the 3-year local recurrence rate to the outcome measures for bone sarcoma as a measure of the surgical component of care (we suggest inserting this after paragraph 293).	We have added '3-year local recurrence rate' to para 292.
Department of Health	Paragraph 305	Is the "Preferred provider," - the preferred provider for the MDT to refer or is it about patient choice? If the former, won't there be clear referral pathways to providers so "preferred providers" already accommodated? We would be pleased if you would consider clarifying this paragraph.	We have deleted the term 'preferred'.
Department of Health	Paragraph 354	Would you be able to remove this paragraph as there is a legal requirement to do this.	We have removed this paragraph.
Department of Health	Paragraph 355	Would you please consider amending this paragraph to read "clinical trials are needed for the full evaluation of imatinib, other novel agents and the role of PET scanning in this condition."	We have amended the text as suggested.
Department of Health	Paragraph 350	Would you please consider redrafting this paragraph. "In conjunction" may be too vague, it may be more helpful to recommend explicit pathways so patients are either discussed in 1 or both MDTs and that within sarcoma "networks" there is written agreement between MDTs (as in 352).	Thank you for your comments, but we feel that this paragraph is satisfactory as is. However, we have made more specific comments about treatment pathways in para 352.
Department of Health	Paragraph 356	Dietetic support should be available for patients who have undergone major abdominal surgery. You may wish to consider making reference here to the current NICE guidance consultation - Nutrition Support in Adults: oral supplements, enteral and parenteral feeding	Thank you. We have amended the text.
Department of Health	Paragraph 376	Many patients also have specific needs for orthoses, prosthetic limbs and for a wide spectrum of rehabilitation services. You may wish to consider whether table 6 adequately reflects this.	We feel Table 6 adequately covers this. The remainder of chapter 8 also makes more specific recommendations
Department of Health	Paragraph 378	You may wish to consider whether a list of Key worker competencies would be useful here.	We do not feel that adding a list of key worker competencies is necessary.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Department of Health	Paragraph 389	Would you consider amending to read "rehabilitation helps the patient maximise the benefits of surgery and chemotherapy and aims to improve physical, social and emotional outcomes both during and following treatment."	We feel that the text is appropriate as is.
Department of Health	Paragraph 391	You may wish to consider amending to read " clinical nurse specialists or key workers with appropriate experience and training can be helpful in managing problems during the start of treatment, including side-effects of chemotherapy and problems with nutrition, particularly in patients with GIST."	We have made amendments to the text.
Department of Health	Paragraph 392	You may wish to amend to read "a specialist sarcoma allied health professional should be a member of the extended sarcoma MDT."	We feel that the text is appropriate as is.
Department of Health	Paragraph 401	Would you please consider amending to read "provision of adequately trained specialist allied health professionals, such as physiotherapists and occupational therapists, as part of the extended sarcoma MDT."	We have made this amendment to the text.
Department of Health	Paragraph 410	Energy requirements may also be a factor, for example Waters et al found that energy cost of prosthetic walking is related to the amputation level. "Reference quoted in Broomhead P, Dawes d , Hale C, Lambert A, Shepherd R,Quinlivan D. (2003). Evidence Based Clinical Guidelines For The Physiotherapy Management Of Adults With Lower Limb Prosthesis". You may wish to include this information in this paragraph.	Thank you for drawing this paper to our attention. It has already been included in the Evidence Review, that accompanies the Manual.
Department of Health	Paragraph 428	Please consider rewording to read "... need for specialist palliative care input for some patients and there should be access to specialist palliative care teams within the hospital and community."	We have made this amendment to the text.
Department of Health	Paragraph 432	You might wish to consider omitting "with treatment" from this paragraph.	We have made this amendment to the text.
Department of Health	Paragraph 433	You may wish to consider referring to the NAO report Improving the Patient Journey, which showed that when patients felt able to complain, this correlated with an increase of feeling that they were treated with dignity and respect.	Thank you for your comment, but we feel this is generic information and that it is not appropriate to quote it in this guidance.
Department of Health	Paragraph 435	Would you please consider inserting "specialist" before palliative care.	We have made this amendment to the text.
Department of Health	Paragraph 437	Please would you consider inserting "specialist" between "shared" and " palliative " in the heading and before "palliative care " in the first sentence of this paragraph	We have made this amendment to the text.

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9 May 2005 – 6 June 2005

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Department of Health	Paragraph 440	It would be helpful if you would consider inserting "specialist" before palliative care.	We have made this amendment to the text.
Department of Health	Paragraph 445	Would you please consider making reference to the NICE Supportive and Palliative Care guidance, as it supports this approach.	We have inserted a cross reference in para 445.
Department of Health	Paragraph 446	In the Outcomes section - you might wish to consider referring to the findings of that NAO report "Tacking Cancer: Improving the Patient Journey".	Thank you for your comment, but we feel this is generic information and that it is not appropriate to quote it in this guidance.
Department of Health	Paragraph 233 (page 60, Table six, line 5)	Please consider rephrasing specification to read "including palliative care nurses and appropriately trained ward staff. As "	We have made this amendment to the text.
Department of Health	Paragraph 454	Please consider specifying who should agree the follow up protocol, DH does not feel that this would be a role for commissioners. Equally, national agreement is not consistent with a devolved NHS.	We have amended the recommendation.
Department of Health	Paragraph 453	You may wish to consider amending to read "long-term follow-up will be needed for many patients, especially those who have received a prosthetic replacement or had a childhood cancer, because of the risk of late complications and changing needs."	Thank you for your comment but we feel that the text is appropriate as is.
Department of Health	Paragraph 481	We would be pleased if you would clarify who is responsible for the National Clinical Audit Steering group.	We have amended the text to 'National Clinical Audit Support Programme'.
Department of Health	Paragraph 484–486	Would you please note that generally and specifically in paragraphs 484 - 486 the implication is that there is very little CPD/training in sarcoma care. If this is the case there are significant implications behind the recommendations which could require further training programmes.	It is indeed the case that currently there is very little specific training in sarcoma care available.
Eisai Limited		This organisation was approached but did not respond.	
Faculty of Public Health		This organisation was approached but did not respond.	
Guerbet Laboratories Ltd		This organisation was approached but did not respond.	
Healthcare Commission		This organisation was approached but did not respond.	
Help Adolescents with Cancer		This organisation was approached but did not respond.	
Hinckley & Bosworth Primary Care Trust		This organisation was approached but did not respond.	

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Hull and East Yorkshire NHS Trust		This organisation was approached but did not respond.	
Institute of Biomedical Science		This organisation was approached but did not respond.	
Intra-Tech Health Care Ltd		This organisation was approached but did not respond.	
Joint Committee on Palliative Medicine		This organisation was approached but did not respond.	
Leeds Teaching Hospitals NHS Trust		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		This organisation was approached but did not respond.	
Medical Research Council Clinical Trials Unit		This organisation was approached but did not respond.	
Medicines and Healthcare Products Regulatory Agency (MHRA)		This organisation was approached but did not respond.	
Middlesbrough Primary Care Trust		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 Clinical Directors Group		This organisation was approached but did not respond.	
National Cancer Research Institute – Sarcoma Clinical Studies Group	General	The guidance development group are to be congratulated on pulling together the disparate evidence on this heterogeneous group of tumours. If fully implemented, this guidance could make a huge difference to the quality of service for sarcoma patients, and improve	Thank you for your comments.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		outcomes.	
National Cancer Research Institute – Sarcoma Clinical Studies Group	General	Although the guidance is welcomed, it is unfortunate that there is only a small evidence base for most of the recommendations. A statement of the levels of evidence for recommendations would have been welcomed although it is appreciated that this may form part of future drafts.	The evidence will be included in the Evidence Review that accompanies this guidance. This will be available during the second consultation.
National Cancer Research Institute – Sarcoma Clinical Studies Group	General	The recommendation for national data collection and audit is welcomed, as is the recommendation for national tissue banking, as these will form a major resource for research.	Thank you for your comments
National Cancer Research Institute – Sarcoma Clinical Studies Group	General	The GDG might consider a mechanism for communication between sarcoma MDTs to discuss particularly difficult or unusual cases.	While we agree that communication between sarcoma MDTs is to be encouraged, this often happens already on an informal basis. We have made recommendations that complex cases should be referred on to MDTs with more specialised expertise but do not feel that it is within the remit of this guidance to make these links any more formal.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 3	This recommendation should include "all patients OF ANY AGE with a SUSPECTED diagnosis…"	Thank you for your comment. We feel that these issues have been addressed in paras 3 and 4. In particular, by stating 'all patients' we clearly mean patients of any age.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 6, 228 and others	The recommendation for a minimum number of patients treated is not based on firm evidence, and this need to demonstrate experience in managing a minimum number of patients is somewhat at odds with the concept of diagnostic centres. The diagnostic process is often difficult and relies on experienced clinicians, radiologists and pathologists. Enforcing the closure of units which do not meet the somewhat arbitrary volume targets will have consequences for patient care which should be carefully considered (see paragraph 83, "crucial treatment decisions…"). It would be conceptually better to have quality of care targets for units to meet, based, perhaps, on national audit.	Our recommendations for a minimum number of patients to be treated is based on the establishment of properly constituted sarcoma MDTs. A diagnostic clinic will be working in collaboration with a sarcoma MDT and in effect will be a rapid diagnostic clinic. We appreciate that this is a novel concept for diagnosis of potential soft tissue sarcomas and will need to be audited. We have therefore made recommendations in para 481 about auditing of sarcoma treatment centres. We accept that some small units treating sarcomas may need to close, but we feel that it is unlikely that these units currently have a properly constituted sarcoma MDT.
National Cancer Research Institute – Sarcoma Clinical	Paragraph 32–34	Introduction: there are too many hedges here (we think, we have tried, etc). A more positive tone (we have addressed…) would give a stronger message.	These paragraphs have been rephrased in a more positive way.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Studies Group			
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 25–61	Background: there is no evidence of a systematic or critical review of the literature here, indeed most of the figures and statements are unsupported by any references. One example (para 39) states that Ewing's sarcoma "is reported to occur almost exclusively in the white population," whereas a published report shows that it is the commonest bone cancer in Bombay.	References will be inserted where appropriate. We have also deleted the sentence 'These tumours are reported to occur almost exclusively in the white population' from para 39.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 59	"excising the tumour with as wide a margin …as possible" is not strictly true. A better formulation might be "complete excision of the tumour".	The text has been amended.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 76	Although MANY patients wish to receive the best possible treatment, the guidelines should consider those who are old and frail, and for whom travelling a long distance might be inappropriate (the elderly or infirm). Mechanisms to discuss these patients at an appropriate MDT would be welcomed.	Thank you for this comment. The GDG discussed at length the issue of travelling. There was a general consensus that the vast majority of patients would prefer to get the right treatment at the right place, and would be willing to travel for this (para 76). The concentration of expertise in specialist centres does mean that there will be no surgical skills outside of these centres for the surgical management of these patients. We have, however, acknowledged that chemotherapy and radiotherapy can be given at more local centres with the prior agreement of the sarcoma MDT (paras 302–306).
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 80	There is considerable difficulty in continuously monitoring internet sites. Are the group suggesting that NICE, DoH or NCRN should host such a site and be responsible for linked sites?	We agree that there are difficulties in continuously monitoring Internet sites. It is unlikely that NICE, DH or the NCRN would host such a site and be responsible for it. It is likely, however, that each individual MDT will choose selected sites. It may be that an organisation, e.g. the British Sarcoma Group, would take on this role.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 86	It is difficult to satisfy the requirements of the NICE Guidance on Improving Supportive Palliative Care for Adults with Cancer if the diagnosis is given by phone, eg. involvement of patients and carers in decision making, provision of interpreters, assessing information needs, etc. This states (para 3.17) that "A diagnosis should be communicated… in a comfortable, quiet area, with privacy and without interruption, preferably in the company of a close relative or friend (if	We agree that it may be difficult to satisfy the NICE guidance if a diagnosis is given by phone, but this will be up to local MDTs to arrange in conjunction with patients, and to monitor and audit carefully. Because of the distances some patients are likely to travel, agreement to receiving a telephone diagnosis simply to confirm what they have been told during a visit to

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		the patient so wishes) and in the presence of a specialist nurse where possible." If the diagnosis is to be given by phone, it should be stipulated that the patient should be able to phone the specialist at a time when the patient is comfortable, quiet and their carers are present (if desired). Diagnoses should only be given by phone by an individual whom the patient has already met face-to-face.	the hospital will be acceptable in some circumstances.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 90, 103	There is considerable evidence that patients with other tumour types value audiotapes of consultations in which the diagnosis and management options are discussed. This service should be available in every sarcoma centre.	We have amended para 88 to include audio tapes.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 92 (Table 4)	Information should refer to treatments RECOMMENDED by the MDT, and should include discussion of alternative treatments, in order for the patient to reach an informed decision.	We note your comments that we should insert 'recommended treatment' as opposed to 'proposed treatment'. We have taken it for granted that alternative treatments will always have been discussed with the patient.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 96	Support should be offered to patients AND CARERS.	We have made this amendment to the text.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 108–109	The specific rehabilitation and psychosocial needs of patients with functional impairment following surgery or radiotherapy should be addressed. These include return to work/school, social and sexual relationships.	These issues have been addressed in chapter 8. It is not appropriate that they should be addressed in this section, which describes the evidence
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 122	In addition to increasing public awareness, GPs and A&E staff need to be made more alert to the possibility that sarcoma can mimic injury.	It will be up to MDTs, hopefully in collaboration, to increase public and professional awareness of sarcomas
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 125	It would be worth restating the urgent referral criteria here. The bone tumour criteria do not appear anywhere in this document. What proportion of sarcomas currently present through the 2WW pathway?	Thank you. We have re-stated the urgent referral criteria. We have no data to identify what proportion of sarcomas currently present through the 2-week wait pathway.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 128	A cost-effectiveness analysis of a publicity campaign should be undertaken before this is embarked upon.	We hope that a research project assessing the impact of a publicity campaign on GP attendances with lumps and bumps will be carried out. It will then be possible to do a cost-effectiveness study
National Cancer	Paragraph	The imaging required should be stated: plain XR and US, CT or MR.	We have specifically not identified the optimum

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Research Institute – Sarcoma Clinical Studies Group	133	"Patients suspected of having a STS should be rapidly referred on to THE SARCOMA MDT for definitive BIOPSY and treatment…"	imaging that should be carried out for assessment of soft tissue lumps and bumps because we hope that further research will clarify this.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 136	"These patients should be referred directly to THE DESIGNATED NETWORK SARCOMA MDT."	We have amended the text to state that patients should be referred to the sarcoma MDT designated by that cancer network.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 144–147	Anticipated benefits: biopsy by a sarcoma specialist surgeon will ensure that appropriate samples are sent for molecular pathology and that it is possible to include the biopsy site and track in the definitive resection.	Thank you for these comments but we feel that the anticipated benefits are dealt with adequately in paras 144–147.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 148–168	Full references and grading of the evidence are required.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 188–200	Recommendations should include: Because of variability within sarcomas, an incisional biopsy or resection specimen is preferred to make a diagnosis. Core biopsies are recommended when performed by sarcoma specialists. Fine needle aspirates are not recommended.	These recommendations are too clinical for service guidance.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 193	Pathology reports should use a defined tumour classification (eg. WHO classification 2002) and grading (eg. Trojani). They should include the size of the tumour and the margins in each plane. Use of a consistent reporting proforma nationally would facilitate referral between centres, audit and comparison of outcomes in different centres.	We have amended the text to include tumour classification and grading systems.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 196	Funded access to molecular pathology and cytogenetic analysis is welcomed.	Thank you.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 205–211	Full references and grading of the evidence are required.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
National Cancer Research Institute – Sarcoma Clinical	Paragraph 212–219	The availability of molecular pathology and the proportion of complete pathological reports should be audited.	Thank you for this comment. We have changed para 212 accordingly

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Studies Group			
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 225	This applies to both bone and soft tissue sarcomas. Patients referred for surgery to a bone sarcoma MDT may receive other treatment modalities via a Network Sarcoma MDT.	Thank you. We have made amended para 225.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 227	A definition of "managed" might be useful. Some patients may be discussed by MDTs but "managed" closer to home, by clinicians who are not members of an MDT (eg those with advanced disease, or not fit enough for surgical or other treatment). It is worth emphasising that this includes all ADULT & PAEDIATRIC patients.	We have specifically used 'managed' as opposed to 'treated' because we feel that the sarcoma MDT should make the key decisions, which it may or may not thereafter implement locally.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 228	Not all bone sarcoma patients are fit, willing or need to travel to a supra-regional bone sarcoma MDT. These include frail patients and those with far advanced disease. They should not be denied access to the designated Network sarcoma MDT, which can co-ordinate their care locally. A sarcoma MDT should therefore manage (say) 100 new sarcoma patients per year, including all subtypes. As the radiotherapy and chemotherapy regimens are comparable in STS and bone sarcomas, the numbers-needed-to-treat for a bone sarcoma MDT presumably refers to resections.	This guidance does not recommend that every network should have a sarcoma MDT. We have clearly defined the constitution of a sarcoma MDT and we make very clear that a bone sarcoma MDT should be managing more than 50 new cases per year. An MDT not managing that number would not be accredited as a bone sarcoma MDT. The GDG discussed at length the issue of travelling. There was a general consensus that the vast majority of patients would prefer to get the right treatment at the right place, and would be willing to travel for this (para 76). The concentration of expertise in specialist centres does mean that there will be no surgical skills outside of these centres for the surgical management of these patients. We have, however, acknowledged that chemotherapy and radiotherapy can be given at more local centres with the prior agreement of the sarcoma MDT (paras 302–306).
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 232	Each sarcoma MDT should have WRITTEN AGREEMENTS with relevant site specific MDTs to cross-refer patients.	We agree that the awareness of the special expertise of MDTs does need to be more widely available. However, we have already made specific comments about the cross-referral of patients in chapter 7 (paras 350 onwards).
National Cancer Research Institute –	Paragraph 233 (Table	Specialist sarcoma surgeons should be TRAINED SURGICAL ONCOLOGISTS with a major clinical interest in sarcomas. Their	We do not feel that it is possible to include a trained surgical oncologist when there is no formal training

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Sarcoma Clinical Studies Group	5)	primary specialty might be general surgery, plastic surgery or orthopaedics. What is the evidence for surgeon volume, and what is meant by ">50% of their time managing sarcomas", particularly in view of the significant benign to malignant soft tissue tumour ratio? Why not consider "appropriate training, experience, and audited results"? Other "Improving outcomes" groups have recommended a minimum number of resections.	programme currently available. We believe, however, that surgeons spending more than 50% of their time managing patients with sarcomas are likely to be appropriately skilled. We agree that there is no evidence for surgeon volume apart from evidence from other groups such as the colo-rectal surgeons, indicating that increasing surgical volumes leads to lower complications and better outcomes. We would agree that in the fullness of time your definition of appropriate training, experience and audited results would be appropriate, but these are not available at the moment and thus a surrogate of time spent involved with sarcomas has been used.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Table 6	Each extended sarcoma MDT should include a NAMED THORACIC SURGEON with experience of pulmonary metastectomy.	Table 6 already specifies that there should be a designated thoracic surgeon.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 242–252	Full references and grading of the evidence are required.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 254	Evidence should be provided of the specialist sarcoma training, experience and continuing professional development for each core member of the sarcoma MDT.	Evidence about individuals training experience and continuing professional development should be part of their annual appraisal or personal development plan.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 257	Evidence should be given of the proportion of patients fully staged and with a pathological diagnosis prior to definitive treatment.	This would be part of a centre's annual audit.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 266	The stated median age of 21 years is not consistent with the data in figure 2, which suggests a median age over 30.	Thank you for identifying this discrepancy. We have deleted this text.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 267	It should be acknowledged that some bone sarcomas are inoperable and radiotherapy is the preferred local treatment for others.	We have clarified the fact that some cases may not be operable.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 274	The provider of chemotherapy services should be… • A medical oncologist with specialist sarcoma training, experience & continuing professional development • A member of an accredited sarcoma MDT. To "be guided by the bone sarcoma MDT on the treatment regimen" will require the bone sarcoma MDT medical oncologist to provide a detailed evidence-based protocol.	In most situations, chemotherapy will be provided at the bone sarcoma treatment centre. In certain situations, chemotherapy will be given at other centres and the guidance makes clear that the bone sarcoma MDT would give specific advice about the regime that was most appropriate. This is likely to be based on current accepted clinical practice.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 275	The provider of curative radiotherapy services should be… • A radiation oncologist with specialist sarcoma training, experience & continuing professional development • A member of an accredited sarcoma MDT. To "be guided by the bone sarcoma MDT on the treatment regimen" will require the bone sarcoma MDT radiation oncologist to provide a detailed evidence-based protocol.	We have clarified the requirements of providers of curative radiotherapy services. Issues of training and CPD are covered in para 484.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 280–285	Full references and grading of the evidence are required.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 300	The MDT does not decide treatment: it makes treatment recommendations which are then discussed with the patient.	The role of the MDT is to decide on optimum treatment for a patient. The patient may decide to accept or reject this treatment, and the treatment may need to be modified following discussion with the patient. We do not wish to diminish the power of the patient in deciding their actual treatment – this is the same for every single aspect of medicine.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 301	A pathological diagnosis and full staging evaluation should be obtained before proceeding to surgery. Definitive surgical resection should be expanded. For example: The aim of surgery is wide excision or compartmental resection, which should include the biopsy track and scar. Reoperation is recommended in the case of marginal (<2cm) or incomplete excision.	This information is too clinical for service guidance.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 302–306	Specific evidence-based recommendations can be made. For example: Adjuvant radiotherapy is recommended when compartmental resection or amputation has not been achieved. In selected patients, pre-operative radiotherapy may be offered. Adjuvant chemotherapy is not routinely recommended. Evidence suggests that it may delay local	This information is too clinical for service guidance.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		or distant recurrence, but the effect on survival is uncertain. Palliative chemotherapy can improe symptoms and quailty of life of selected patients with locally advanced or metastatic sarcoma.	
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 304	Curative-intent chemotherapy and radiotherapy should only be given by members of sarcoma MDTs.	We believe that curative intent chemotherapy and radiotherapy should only be given by members of the sarcoma MDT or by members of the extended sarcoma MDT (para 304).
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 306	The indications and referral arrangements for isolated limb perfusion should be included.	This information is too clinical for service guidance.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 307–308	A major advantage of treatment at a sarcoma centre is the presence of nursing staff, pharmacists, radiographers, physiotherapists, occupational therapists, social workers, etc with training and experience in meeting the needs of sarcoma patients.	We agree this is a significant point and have amended the text accordingly.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 310–313	Full references and grading of the evidence are required.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 324–331	It is not clear how many patients with abdominal and pelvic STS would require or be eligible for referral to a super-specialised team. Simply implementing the more general recommendations in this guidance for centralising sarcoma treatment through MDTs would lead to a major improvement in the management of these tumours.	It is not anticipated that all sarcoma MDTs would necessarily be able to treat pelvic and abdominal soft tissue sarcomas. Given the relatively low number of these sarcomas, there may well be a case for super-specialisation.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 332–334	Full references and grading of the evidence are required.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 339	Improved treatment of abdominal and pelvic STS is unlikely to result in changes in limb function.	Thank you for your comments. We have amended the text.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 342	"JOINT management" is an unfortunate term here. How about SHARED or COMBINED management?	We agree and have changed 'joint' to 'shared'.

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National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 350	Written agreements should exist between sarcoma MDTs and site-specific MDTs to ensure speedy exchange of information about patients of interest to both.	We believe that the ideal way to optimum care in patients requiring shared care is to have common treatment pathways. We have modified para 352 accordingly.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 359–363	Full references and grading of the evidence are required.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 373	Improved treatment of sarcomas requiring joint management may actually result in changes in limb function, but this is probably not intended here.	We have deleted 'limb function'.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 380	The key worker will likely change during the patient pathway if this extends from biopsy through definitive surgery to long term survival or death. Consideration should be given to how these transitions should be managed by the MDT and transmitted to the GP, patient and carer.	This guidance confirms the likely benefit of a key worker. However, we do not feel it is within the remit of this guidance to give definitive advice about how transitions should be made as patients progress through their treatment pathway.
National Cancer Research Institute – Sarcoma Clinical Studies Group	Paragraph 454–455	Each sarcoma MDT should have a protocol for the management of late effects of treatment, eg. infertility, growth delay, osteoporosis.	This is too much clinical detail for service guidance.
National Cancer Research Institute (NCRI) Clinical Studies Group and National Cancer Research Network (NCRN)		This organisation was approached but did not respond.	
National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)		This organisation was approached but did not respond.	
National Patient Safety Agency		This organisation was approached but did not respond.	
National Public		This organisation was approached but did not respond.	

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Health Service – Wales			
NHS Direct		This organisation was approached but did not respond.	
NHS Information Authority (PHSMI Programme)		This organisation was approached but did not respond.	
NHS Modernisation Agency, The		This organisation was approached but did not respond.	
NHS Quality Improvement Scotland		This organisation was approached but did not respond.	
North of England Bone and Soft Tissue Tumour Service	General	The guidance is welcomed as a means of ensuring uniformity of practice and in making explicit the need to refer to specialist centres, particularly vis a vis soft tissue sarcomas.	Thank you for your comments.
North of England Bone and Soft Tissue Tumour Service	General	Formally promoting audit may provide a fillip to its local funding and practical support.	Thank you for your comments.
North of England Bone and Soft Tissue Tumour Service	General	Nationally based data collection and tissue banking would provide a major resource for research, trial recruitment, etc.	Thank you for your comments.
North of England Bone and Soft Tissue Tumour Service	General	As a corollary to the above, a formal means for collaboration between MDT's would be useful for the management of particularly problematic or unusual cases.	While we agree that communication between sarcoma MDTs is to be encouraged, this often happens already on an informal basis. We have made recommendations that complex cases should be referred on to MDTs with more specialised expertise but do not feel that it is within the remit of this guidance to make these links any more formal.
North of England Bone and Soft Tissue Tumour Service	General	As a group we (our case nos. are close to the specified minima) are concerned lest the emphasis on case numbers become too proscriptive. Linked to this we have some reservations about the development of Diagnostic Centres; in serving our geographical region they may be counter-productive as they would be inimical to maximizing patient nos. in particular centre(s).	We note your concerns about the development of diagnostic clinics. This would not deplete the number of sarcomas you saw because by definition all diagnosed sarcomas would be referred on to you. The aim of the diagnostic clinic is to speed up the process of diagnosis for the local community and to ensure that patients are then referred on to the appropriate sarcoma treatment centre. It will be up to local networks to link with the sarcoma treatment centre in

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			establishing the best system of diagnostic services for that area.
North of England Bone and Soft Tissue Tumour Service	Paragraph 196	Promotion of a funded molecular biology/cytogenetic service as a sine qua non would be of benefit.	We have revised our recommendations on the funding of this.
Northumberland Care Trust		This organisation was approached but did not respond.	
Novartis Pharmaceuticals UK Ltd	General	We fully support the view that GISTs are important enough to warrant particular attention in the manual. GISTs represent a major subset of all sarcomas (roughly one third) and have different requirements to other soft tissue sarcomas with respect to diagnosis, treatment and necessary expertise. Consequently, clearer guidance could be provided if the manual were to define three distinct areas; bone sarcomas, GISTs and other soft tissue sarcomas, each with its own specific section in the document. The layout of a manual structured in this way will avoid confusion, be more user friendly and facilitate implementation. Most of our comments below aim to provide more specific advice with respect to GISTs.	Thank you for your comments. The GDG discussed at length the place of GIST in this guidance. While accepting that numerically there are a large number of GIST patients, many of them will be dealt with by upper GI MDTs and will not necessarily come to a sarcoma MDT. The recommendations for the management of patients with GIST were very similar to the recommendations for other types of soft tissue sarcoma. Hence they have been included in that section of the guidance.
Novartis Pharmaceuticals UK Ltd	General	We fully support the provision of a summary of key recommendations at the front of the manual. However, we propose that this section is extended to also provide a summary of all other recommendations. It is very important that all recommendations are presented together, at the front of the document for ease of reference. It would also be helpful to users to group the recommendations according to sarcoma type ie bone, GIST and other soft tissue sarcomas. This will make the manual more user friendly and facilitate implementation.	Thank you for your comments. The format of this guidance follows that of the other 'Improving outcomes' guidance produced by NICE, which does not include a summary of all recommendations at the front of the manual. However, we will be including a list of all recommendations on the CD that accompanies the published guidance.
Novartis Pharmaceuticals UK Ltd	Paragraph 3	In order to make provision for GISTs this key recommendation should be amended as follows, "All patients with a confirmed diagnosis of bone sarcoma, soft tissue sarcoma or GIST should have their care supervised by or in conjunction with a sarcoma MDT or appropriate site specific MDT."	The GDG feels that the current recommendation is appropriate as is.
Novartis Pharmaceuticals UK Ltd	Paragraph 5	In order to make provision for GISTs this key recommendation should be amended as follows, " All patients with a provisional histological or radiological diagnosis of bone sarcoma, soft tissue sarcoma or GIST should have their	In this guidance we have included GISTs under soft tissue sarcomas. Therefore we do not feel that this amendment is necessary.

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		diagnosis reviewed by a sarcoma or site specific pathologist or radiologist…"	
Novartis Pharmaceuticals UK Ltd	Paragraph 7	In order to make provision for GISTs this key recommendation should be amended as follows, "A key worker who will be a member of the sarcoma or site specific MDT should be allocated to each sarcoma patient."	It is not within our remit to comment about guidance for site-specific MDTs not treating sarcomas. We have thus not been able to make this change.
Novartis Pharmaceuticals UK Ltd	Paragraph 8	As there are a limited number of sarcoma MDTs, it may be unrealistic and impractical to expect that GIST patients can be managed jointly by a sarcoma MDT and a site specific MDT in every case. It would be more practical to suggest that patients are either managed by a sarcoma MDT or a specialist site MDT if appropriate eg for GIST patients, a GI MDT. In order to allow for this, the recommendation should be amended as follows, "Patients should undergo definitive resection of their sarcoma by a surgeon who is a member of a sarcoma MDT or by a surgeon with site specific skills who is a member of a site specific MDT with experience in treating GISTs."	We feel that the generic recommendation we have given in para 8 applies to GIST patients as well.
Novartis Pharmaceuticals UK Ltd	Paragraph 9	As the treatment of non-resectable and metastatic GISTs is primarily medical therapy rather than chemotherapy or radiotherapy, paragraph 9 should be amended as follows; "Medical therapy including targeted therapy, chemotherapy and radiotherapy are important components of the treatment of some patients and should be carried out at designated centres by appropriate specialists as recommended by a MDT." A further sentence could also be added to clarify who should manage the medical treatment of GISTs as specified in NICE Guidance No. 86. We propose the addition of the following sentence, " The medical management of GISTs should be supervised by cancer specialists with experience in the management of patients with unresectable and/or metastatic GISTs."	We believe that para 9 successfully deals with the issue of who should manage patients with GIST. We accept that clarifying who should manage unresectable and/or metastatic GISTs is an important issue and have added a new recommendation to chapter 7.
Novartis Pharmaceuticals UK	10	In order to account for all MDTs this key recommendation should be amended as follows,	It is not within our remit to comment about guidance for site-specific MDTs not treating sarcomas. We have

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Ltd		"All sarcoma and site specific MDTs…"	thus not been able to make this change.
Novartis Pharmaceuticals UK Ltd	Paragraph 32	Paragraph 32, comments on the widely varying estimates of incidence of GISTs. The addition of the following paragraph would go some way to explaining why this is the case and how this may be addressed in the future. "The recent development of KIT immunohistochemical staining techniques has facilitated the diagnosis of GISTs. Evidence has shown that a significant number of benign or malignant gastrointestinal mesenchymal tumours were reclassified as GIST when tested using the CD117 immunohistochemical staining technique. Studies are currently ongoing in Scotland and England, which would help to identify patients with GIST and establish the true incidence of these tumours."	We feel that the definitive paper about incidence is one we quote from Sweden. It would be imprudent to comment on work in progress that is still unpublished.
Novartis Pharmaceuticals UK Ltd	Paragraph 59	As the treatment of GISTs differs from that of other soft tissue sarcomas we recommend the addition of a further short paragraph to address this omission. We propose the following sentence, "Surgery with wide local excision is the primary treatment for GISTs. Imatinib is the treatment of choice for patients with unresectable or metastatic GIST."	We believe this is adequately covered in para 349.
Novartis Pharmaceuticals UK Ltd	Paragraph 61	For completeness a paragraph should be added regarding the prognosis and survival of GIST patients. We propose the following paragraph, "Five year survival for patients with completely resected GIST ranges between 30-80% (depending on prognostic factors of size and mitotic rate). Before the advent of imatinib, the median survival of patients with metastatic and/or unresectable disease was only 12 months. Median survival has not yet been reached in the pivotal study of imatinib in metastatic and/or unresectable GIST after a follow-up of 34 months."	We note the survival of patients with GIST and we have made an appropriate change to para 60.
Novartis Pharmaceuticals UK Ltd	Paragraph 68	A recent survey of current management pathways for GISTs was conducted jointly by the Association of Upper GI Surgeons (AUGIS) and Novartis. The 65 GI surgeons from the UK who responded see a total of 455 GISTs each year. Based on the estimated incidence of	Thank you for this information, which as far as we are aware is not yet in the public domain or published.

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		800-900 new cases in the UK per year, the UK responders see around half of the total number. Results from this survey revealed that almost all GISTs are discussed within an MDT setting and most are discussed in specialised MDTs (GI or upper GI MDT 80% and sarcoma MDT 12%). Details of this survey were published in the Spring 2005 AUGIS Newsletter.	
Novartis Pharmaceuticals UK Ltd	Chapter 3	As this chapter covers more than just bone and extremity soft tissue sarcomas the title of this chapter is inaccurate and should be amended as follows; "Chapter 3 – Improving diagnosis of bone sarcomas, soft tissue sarcomas and GISTs" The diagnosis of GISTs have been omitted from this section. It is important that the diagnosis of GISTs are addressed in this manual as this is an area where specific guidance is particularly needed. GISTs are often overlooked or mis-diagnosed and therefore guidance would be particularly helpful to clinicians as well as improving the overall outlook for GIST patients.	We have not dealt with the early diagnosis of GIST as we have not identified any evidence that is specific for GISTs. As most GISTs present with non-specific upper abdominal symptoms, this will have been covered by the NICE guidance 'Referral guidelines for suspected cancer' and by the NICE guidance on 'Improving outcomes in upper gastro-intestinal cancers'. We have amended para 351 to clarify that the primary responsibility for GIST tumour management should be with the upper GI MDT. In some networks the subsequent oncological management of GIST patients would be with a sarcoma MDT while in other networks it would be with the upper GI MDT.
Novartis Pharmaceuticals UK Ltd	Paragraph 130	In order to make provision for GISTs this paragraph should be amended as follows, "Networks should ensure that GPs and hospital doctors are aware of the diagnostic pathways for patients with features suggestive of bone, soft tissue sarcoma or GIST."	Most, if not all, patients with GIST will be diagnosed following a biopsy carried out by an upper GI surgeon and the case will already have been discussed at an upper GI MDT when the diagnosis is made. It therefore does not seem necessary to suggest that GPs and hospital doctors are aware of the diagnostic pathway.
Novartis Pharmaceuticals UK Ltd	Paragraph 137	A paragraph should be added after 137 that clarifies the situation with respect to GISTs. We propose the following paragraph, "The recommendations above also apply to GISTs whose management should be supervised by a site specific MDT." It should be noted that a panel of UK opinion leaders (including pathologists, surgeons, radiologists and oncologists), in collaboration with Novartis, have produced guidelines for the management of	Thank you for offering to provide these guidelines. We are not producing management guidelines on any tumours but on service provision.

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		GISTs. A copy of these guidelines can be provided on request.	
Novartis Pharmaceuticals UK Ltd	Paragraph 142	In order to make provision for GISTs this paragraph should be amended as follows, "…for review of these images by specialist sarcoma or site specific radiologists at a sarcoma or site specific MDT."	This paragraph is specifically dealing with suspicious X-rays of bone sarcoma and thus it is not relevant to make any comments about GIST.
Novartis Pharmaceuticals UK Ltd	Paragraph 143	In order to make provision for GISTs this paragraph should be amended as follows, "All patients with a possible diagnosis of bone sarcoma, soft tissue sarcoma or GIST should have the diagnosis confirmed by a specialist sarcoma or site specific pathologist."	This is dealt with in para 190.
Novartis Pharmaceuticals UK Ltd	Paragraph 184	In order to clarify the significance of KIT expression we propose that the following sentence replaces the last sentence of this paragraph, " Other tumours such as angiosarcomas and seminomas may also be positive for CD117, but can be distinguished from GISTs by histological and chemical means."	This is too clinical for service guidance.
Novartis Pharmaceuticals UK Ltd	Paragraph 225	As there are a limited number of sarcoma MDTs, it may be unrealistic and impractical to expect that patients can be managed jointly by more than one MDT. It would be far more practical to suggest that patients are either managed by a sarcoma MDT or a specialist site MDT with experience in treating GISTs, if appropriate eg for GIST patients a GI MDT. Paragraph 225 should therefore be amended as follows to reflect this, "... Other MDTs will need to consider the management of the patient eg GI MDTs for GIST."	We have amended para 351 to clarify that the primary responsibility for GIST tumour management should be with the upper GI MDT. In some networks the subsequent oncological management of GIST patients would be with a sarcoma MDT while in other networks it would be with the upper GI MDT.
Novartis Pharmaceuticals UK Ltd	Paragraph 233	This paragraph details the core membership of a sarcoma MDT. In line with our comments above, the core membership of a GI MDT for GISTs should also be specified. The staff requirements for a GI MDT could be listed as follows, - specialist GI surgeons - specialist GI radiologists - specialist GI pathologists and - oncologists.	Specifying the composition of a GI MDT is outside the scope of this guidance.
Novartis	Paragraph	In order to provide better clarity we would like to propose that	Thank you for this comment. We have merged these

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Pharmaceuticals UK Ltd	227 and 231	paragraph 227 and 231 are combined as follows, " All patients with a sarcoma must have their case discussed and managed by an appropriately qualified MDT for that condition/site." If this amendment were adopted paragraph 227 could be deleted.	two paragraphs.
Novartis Pharmaceuticals UK Ltd	Paragraph 232	Due to the relatively small number of sarcoma MDTs in existence, it may be impractical to envisage that joint discussions will always take place between sarcoma and site specific MDTs. We therefore suggest the following amendment, "It is proposed that other MDTs could take on the management of certain specialised sarcomas such as ……."	We feel this is already clear throughout this guidance, particularly in reference to GIST.
Novartis Pharmaceuticals UK Ltd	Paragraph 349	This paragraph incorrectly states that the role of imatinib is not fully understood. However, the role of imatinib in the treatment of GISTs has been clearly established, is widely published and is fully outlined in NICE Technology Appraisal Guidance No.86. which is acknowledged in the manual. This misleading statement should therefore be removed.	Thank you for this comment. We have removed this statement from the guidance.
Novartis Pharmaceuticals UK Ltd	Paragraph 368	Due to the relatively small number of sarcoma MDTs in existence, it may be impractical to envisage that joint discussions will always take place between sarcoma and site specific MDTs. A more realistic aim would be to have either a sarcoma MDT or a specialist MDT. This could be reflected in the manual by the following statement, "Proportion of patients with these tumours whose management has been discussed at the sarcoma or site specific MDTs."	We have made this amendment to the text.
Nuffield Orthopaedic Centre NHS Trust		This organisation was approached but did not respond.	
Pfizer Limited	Paragraph 349	We support the increased role of PET scanning in the management of GIST. PET scans are more accurate than CT at diagnosing metastatic disease and can be used to monitor response.	We agree that the role of PET scanning requires clarification and further research in many aspects of sarcoma care.
Pfizer Limited	Paragraph 362 and 363	PET scanning has an important role in evaluating the response to treatment	We feel that the guidance already covers this adequately.
Pfizer Limited	Paragraph 373	Patient limb function is not a primary outcome for the patients referred to in this section.	We have deleted 'limb function'.

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Pfizer Limited	Paragraph 451	Effective patient follow up is especially important given the availability of imatinib for metastatic or inoperable GIST.	Thank you for your comment.
Princess Alexandra Hospital NHS Trust		This organisation was approached but did not respond.	
Richmond and Twickenham PCT		This organisation was approached but did not respond.	
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	Excellent first draft for guidance in improving outcomes for people with sarcoma. Our team has several comments and hopes these will be addressed in the next draft.	Thank you.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	Our team agrees with an evidence based approach. However, apart from a few references in the introduction no 'evidence' has been referenced. We have marked the references we are particularly interested in below (paragraph number).	The evidence will be included in the Evidence Review that accompanies this guidance. This will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	The guidance is on improving outcomes in patient with sarcoma. The document however completely ignores how these patients present. Patients with a musculoskeletal tumour present to their Doctor with either a swelling or pain. Guidance should be given on the workup of **all** patients with suspected sarcomas. **Ensuring that a disciplined diagnostic approach is adhered to in all patients with a suspected sarcoma is the first step in optimising care of these patients.** Only then can outcomes be improved.	The NICE guidance on 'Referral guidelines for suspected cancer' already covers how patients present and what warning features should indicate prompt referral for further investigation. However, we have reiterated the relevant referral criteria at paras 52 and 129.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	**Multi Disciplinary Team (MDT)** • We feel that patients should be discussed at the MDT of a designated sarcoma unit **before and after the biopsy**. The radiologist can advise and ascertain that all appropriate imaging has been performed. • After appropriate imaging, in some cases, biopsy might not be required and the patient can be reassured. • Biopsy is preferably performed image guided and the approach should be agreed between radiologist, pathologist	Thank you for your detailed comments. The guidance makes clear that triple assessment with clinical imaging and pathological input is essential to obtain a correct diagnosis. Clearly, the clinical and radiological assessment will have happened prior to biopsy and ideally these clinicians will have communicated their findings to each other, to identify the optimum area to biopsy. It is not necessary for a specific MDT to discuss this prior to biopsy except in the most complex cases and local MDTs will have different arrangements for this. We do not feel it is within the

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		and surgeon. • Following biopsy, the team should have assessment of: 1. Diagnosis and behaviour of the tumour (pathology) 2. Extent of the tumour (radiology) 3. Likely response to oncological treatment (oncologist) 4. Patient concerns and treatment options for this particular patient (surgeon and clinical nurse specialist) • Reconstructive methods vary from locality to locality and performing the operation jointly with a site specific surgeon is much more likely to improve functional outcome. The oncological surgeon advising on the margins of excision and the site specific surgeon on the functional restoration. We believe this will improve the patient's functional outcome.	remit of this guidance to define the exact workings of the MDT.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	• We are disappointed that the guidelines do not address training of future generations of Doctors / specialists. • It is important to train new surgeons and make them familiar with the principles of treatment. This allows them to recognise possible sarcomas and refer appropriately. Early appropriate referral would certainly improve outcome. • Unfortunately, the draft guidelines give no guidance on teaching and training the next generation of surgeons and other specialists. Without training and early referral, the outcomes are likely to remain exactly as they are!	Thank you for your comments. The guidance already identifies the need for appropriate training in para 485. However, we have added an extra commitment of the MDT to encourage training in chapter 5.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	• The guidelines recommend a "hub and spoke" model with multiple diagnostic centres feeding into a few treatment centres. We feel that a diagnostic centre detached from a treatment centre is frankly dangerous. • Modern cancer management in the United Kingdom has placed the MDT meetings as the core activity. It is plain that a diagnostic centre will lack key input from a complete MDT. Furthermore, when discussed at the British Bone and Soft Tissue Tumour Panel 18 months ago, it was felt that the NICE-proposed minimum qualification for acting as a diagnostic bone tumour pathologist (namely, "successful"	The aim of this 'hub and spoke' model is to provide a diagnostic service nearer to the patient's home. It will not be needed in every cancer network and in some instances the diagnostic clinic will be at the sarcoma treatment centre. Where a 'local' diagnostic clinic is needed, the guidance clearly states that it should be affiliated with a sarcoma MDT from a sarcoma treatment centre and that the sarcoma MDT will be responsible for ensuring the competence of the diagnostic clinic (see paras 131–134). We have also recommended that these clinics will need to be

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		participation in the UKNEQAS scheme for orthopaedic pathology) was **insufficient** for that individual to claim to be an "expert" bone pathologist. Rather, participation in a full MDT meeting was suggested as a minimum standard. • We urge NICE to consider this suggested minimum standard.	audited to see how effective they are. We accept that the guidance is recommending a new model but we believe it has considerable advantages over the current system where soft tissue lumps and bumps get referred to anyone and there is no clear protocol for their early sorting and diagnosis. Thank you for your comments about a minimum criterion for an expert bone and soft tissue pathologist. We agree that it is insufficient for an expert to merely participate in the UK NEQAS scheme and have amended the text to clarify that an expert should also be part of a regular sarcoma MDT.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	• There is clear published evidence why a "hub and spoke" model should not be adopted: **Mankin et al,** The hazards of biopsy in patients with malignant primary bone and soft tissue tumors. Journal Bone Joint Surgery, 64-A: 1121-1127, 1982. **Mankin et al,** The hazards of the biopsy, revisited. Journal Bone Joint Surgery, 78-A: 656-662, 1996. **Springfield D, Rosenberg A,** Biopsy: Complicated and risky Journal Bone Joint Surgery, 78-A: 639-643, 1996. • These important, and often quoted papers, provide clear evidence for the key statement: **"Errors, complications and changes in the course and outcome were two to twelve times greater (p<0.001) when the biopsy was done in a referring institution instead of in a treatment centre."** • An important principle is that the biopsy should be performed by the surgeon or surgical team that intend to perform the definitive surgical procedure. We strongly urge the NICE group to reconsider its proposal to dissociate the diagnostic	Thank you for providing these references, all of which were included in the evidence reviewed by the GDG when writing this guidance. This guidance clearly recommends that possible bone sarcomas should only be biopsied in a bone tumour treatment centre (see para 140). In the case of soft tissue lumps, the diagnostic clinic will undertake biopsies under the guidance of its affiliated sarcoma MDT, and in particular under the guidance of a specialist soft tissue sarcoma pathologist (see paras 191 and 192). The diagnostic clinics will effectively be 'supervised' by the sarcoma MDT who will be able to instruct them in the ideal method of biopsy of soft tissue tumours. Mankin's papers are well known to the GDG but we feel that the model recommended in the guidance is completely different from that which was described by Mankin et al., where biopsies were done at district general hospitals by non-specialists.

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		work up from surgical treatment.	
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	The current draft NICE guidelines: 1. Will limit the number of centres treating sarcoma patients based on an arbitrary figure of the number of patients being treated. There is no convincing evidence that: a. These figures are correct, and b. Threshold selected correlates with improved outcome. 2. Will create diagnostic units charged with diagnostic workup and a biopsy of suspected cases and refer the proven cases of sarcoma to the designated sarcoma centres. There is no evidence that supports implementing this system to improve outcomes. There is however definite evidence to the contrary. **The diagnostic biopsy needs to be done in the treatment centre.** **Mankin et al,** The hazards of biopsy in patients with malignant primary bone and soft tissue tumors.	The GDG considered at length the optimum number of patients that a sarcoma treatment centre should manage per year. We believe that a patient's care is best managed by a sarcoma MDT, and that MDT must be of sufficient size and have sufficient members to be able to work effectively and have in-depth experience. We do not believe that a properly constituted sarcoma MDT is likely to be viable unless it treats the number of patients we have identified in the guidance. We feel that the numbers we have suggested are realistic. For a centre treating both bone and soft tissue sarcomas, the requirement for them to treat on average one new patient with bone sarcoma per week is not unrealistic, given the huge variety of bone sarcomas that exist. If a centre were treating fewer than 50 cases per year, it is unlikely that the surgical team, the pathologist or the back-up team would have sufficient expertise to give those patients optimum treatment. We feel that the same argument applies for soft tissue sarcomas, which is why we have stipulated a figure of 100 new cases per year, which correlates with a population base of approximately 3–4 million. Thank you for drawing our attention again to the work of Mankin et al. about the hazards of biopsy. We have previously responded to you identifying our belief that the situation we are suggesting is completely different from that which was described by Mankin, where biopsies were done at district general hospitals by non-specialists.

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		Journal Bone Joint Surgery, 64-A: 1121-1127, 1982. **Mankin et al,** The hazards of the biopsy, revisited. Journal Bone Joint Surgery, 78-A: 656-662, 1996. **Springfield D, Rosenberg A,** Biopsy: Complicated and risky Journal Bone Joint Surgery, 78-A: 639-643, 1996. 3. Contradict the review findings of NSCAG. NSCAG's review of its funded services and outcome figures from the two originally designated centres treating primary malignant bone sarcomas resulted in: a. In change in remit based on recognising the importance of diagnosis and not just the treatment of bone sarcomas in a designated centre and b .Increasing the number of designated centres for this to happen from two to six. This took place after the NICE committee was formed.	NSCAG has extended the service definition for bone tumours without an evidence base, accepting that bone tumours do require diagnosis in specialist centres. NSCAG is fully aware of this guidance and is awaiting final publication before making a definitive decision as to the future of its funding.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	General	The relationship between a minimum number of sarcoma patients that need to be treated by a centre to ensure a good "outcome" is not convincingly made. If there is as yet no evidence on this it should be declared as such. **Identifying a gap in knowledge is the first step towards acquiring it!**	The aim of this document is to improve outcomes for patients with sarcomas. Outcomes can be measured in a variety of ways and we have recommended in para 481 that audit should be carried out for both bone and soft tissue sarcomas.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 6	• We would be interested to read the evidence regarding the stipulated number of patients required to be treated to ensure "competence". It also seems peculiar that 100 soft tissue sarcomas can 'compensate' for 50 bone sarcomas. We would be interested in reading the argumentation and evidence. • The document refers several times to Swedish figures. The total population of Sweden is approximately 9 million (2004). Under the draft guidance presented for the United Kingdom, Sweden should have at the most (if any) one bone sarcoma	The GDG considered at length the optimum number of patients that a sarcoma treatment centre should manage per year. We believe that a patient's care is best managed by a sarcoma MDT, and that MDT must be of sufficient size and have sufficient members to be able to work effectively and have in-depth experience. We do not believe that a properly constituted sarcoma MDT is likely to be viable unless it treats the number of patients we have identified in the guidance.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		centre!! However, there are at least three sarcoma centres in Sweden. Clinical outcomes in Swedish units are comparable to the United Kingdom. • There are several other countries in Europe that have centres of excellence that, in terms of outcome figures, compare favourably to the United Kingdom. However these units see fewer patients (Leiden (The Netherlands) and Belgium unpublished data) than suggested in this document. • In 2004, NSCAG commissioned six designated centres for the diagnosis and surgical treatment of malignant primary tumours of bone. These units have all been thoroughly inspected by the NSCAG advisory team and commissioned as centres of excellence. Under the proposed guidance, four of the six units (2/3) would be inadequate (NSCAG DATA). We find this incongruous. • As the NICE committee was formed before the setting up of these NSCAG centres, there is only limited consultation input from the newly appointed centres. • The suggested minimum limit of 50 malignant primary tumours of bone would restrict the number of current centres of excellence. We feel this is not in the best interest of the patient. Local availability of the service and ability to request a second opinion are both important to the patient. • It is regrettable that the focus is on the number of patients treated rather than availability of expertise and quality of outcome (see 292 – 295). • To diagnose 20 patients with a malignant primary tumour of bone, the unit requires to evaluate at least 100 patients suspected of having the disease (NSCAG DATA). This figure is likely to be much higher for soft tissue sarcoma. The expertise required however, is very much the same!	We feel that the numbers we have suggested are realistic. For a centre treating both bone and soft tissue sarcomas, the requirement for them to treat on average one new patient with bone sarcoma per week is not unrealistic, given the huge variety of bone sarcomas that exist. If a centre were treating fewer than 50 cases per year, it is unlikely that the surgical team, the pathologist or the back-up team would have sufficient expertise to give those patients optimum treatment. We feel that the same argument applies for soft tissue sarcomas, which is why we have stipulated a figure of 100 new cases per year, which correlates with a population base of approximately 3–4 million. We are aware of the situation in Sweden but note that each of the three centres quoted has a properly constituted sarcoma MDT. There are of course more doctors per head of population in Sweden, and it may be that they can afford to have a properly constituted MDT treating fewer patients. We are unable to comment about the centres of excellence in Leiden and Belgium as their outcomes have not been published. NSCAG is aware of the provisional findings of this guidance and has responded to us. Their comments will be taken into account in the second draft. NSCAG is awaiting final publication of this guidance before reaching a definitive conclusion about the constitution of bone tumour treatment centres in the UK. The minimum limit of 50 malignant primary tumours of bone is based upon the likely patient catchment population for the formation of a properly constituted sarcoma MDT. If an MDT is treating fewer than 50 primary malignant bone tumours per year, it is not

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		• If numbers are going to be used in this guidance; it seems more sensible to concentrate on the total number of patients who present with **suspected** sarcoma. **The work up and expertise required of the MDT is exactly the same.** • Patients present with a possible musculoskeletal tumour. After work up, this can turn out to be benign, sarcoma, or more commonly metastatic carcinoma. **The expertise required to establish a diagnosis however is identical.** **Metastatic disease:** • The knowledge of the MDT and the technical surgical skill required to deal with patients with metastatic bone disease from carcinomas is identical to patients with bone sarcomas. The methods of surgical reconstruction (which includes endoprosthetic replacement) and surgical principles are similar (Bauer, JBJS 87-B May 2005, 608).	likely to be able to justify the costs of a properly constituted MDT as defined in this document, nor is that MDT likely to retain sufficient expertise. We agree that at the current time there is probably a 5:1 ratio between patients referred with a suspected primary bone malignancy and those actually having one. Hopefully, as algorithms for investigation become more widespread and utilised, this ratio will decrease. We accept, however, that part of the role of a bone tumour treatment centre is to expedite efficient diagnosis of patients with peculiar lesions of bone. Many will not turn out to have malignancy and thus do not require the skills of the sarcoma MDT. Paras 138–141 have identified the referral pathways for bone sarcomas and the necessity for networks to consider formalising service provision for patients who are most likely to have metastatic or benign disease. Metastatic disease is outside the scope of this guidance.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 27	Please supply source of figure 1 and reference.	We have inserted this information.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 49	Please supply reference of the national study. Please supply source of figure 3.	This information will be added.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 61	Please supply source of figure 5.	This information will be added
Robert Jones and	Paragraph	NSCAG only commissions 'the diagnosis and **surgical** treatment of	We feel that your definition is incorrect as at some

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Agnes Hunt Orthopaedic and District Hospital NHS Trust	63	**malignant** primary bone tumours'.	centres they pay for non-surgical treatment of primary malignant bone tumours as well.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 104	Please supply reference of the 'systematic review'.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 105	Please supply reference of the observational study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 106	Please supply reference of the survey.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 107	Please supply reference of the survey.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 108	Please supply references of the three systematic reviews.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 109	Please supply references of the two observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt	Paragraph 110	Please supply references of one systemic review and seven observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Orthopaedic and District Hospital NHS Trust			the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 112	Please supply references of the two American observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	133	• Diagnostic clinics undertaking 'triple assessment' are proposed. It is suggested that 'triple assessment' refers to: o Clinical Assessment o Imaging o Biopsy. Please confirm that this is indeed what is proposed. • If it is, it goes totally against the evidence produced by Mankin et al that categorically concluded that the biopsy should be done in the place where the patient will receive the necessary treatment. • It is proposed that the teams in the diagnostic clinics do **not** require a surgeon or oncologist. We strongly oppose this proposal as it is likely to end up in disaster! • It is not stated who the members of the diagnostic team would be. It implies the introduction of nurse specialists. We strongly oppose this. • It is our experience that patients with a swelling would like to see a surgeon and discuss their concerns. • Patients are often referred to specialist units by other specialists (orthopaedic and general surgeons). It is inappropriate that a referral is made to a person who is not suitably qualified and experienced. • Assessment of patients with suspected soft tissue sarcoma is difficult and complex. There are many conditions that present as **possible** sarcoma and the patient should be assessed accordingly. • If the MDT is only going to look at radiological images without	We believe that triple assessment with clinical assessment, imaging and biopsy is essential for patients with both bone and soft tissue tumours. The guidance makes it very clear that patients with potential bone sarcomas should be referred directly to a bone sarcoma MDT. This guidance is, however, making a different recommendation for patients with suspicious lumps and bumps, in the recognition that only approximately 1 in 10 patients with a suspicious lump meeting the referral guidelines for suspected cancer will turn out to have malignancy. We are suggesting that for these patients there may be scope for local diagnostic clinics, which will run under the supervision of the sarcoma MDTs. We accept that there is no evidence that these will prove successful and they will clearly need to be closely monitored and audited. However, as they will be working with the sarcoma MDT, their success or otherwise should rapidly become apparent. We do not think that the hazards mentioned by Mankin et al. will be of any relevance because the diagnostic clinics will be set up specifically to do biopsies under the guidance of the sarcoma MDT. There will be different configurations of diagnostic clinics, but whoever runs them will need appropriate training. We would reiterate that this person need not necessarily be a surgeon (it could, for instance, be an interested GP).

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		proper assessment by a surgeon, failure is likely. Furthermore, patient's concerns are not addressed. This certainly can't be in the best interest of the patient! • **We feel that an 'MDT' as proposed, assessing radiological images in isolation from patient contact is a recipe for disaster and does not have the best interest of the patient at heart.** • Biopsy should be done by the surgeon or team who will perform the definitive procedure. ***Mankin et al,*** *The hazards of biopsy in patients with malignant primary bone and soft tissue tumors.* *Journal Bone Joint Surgery, 64-A: 1121-1127, 1982.* ***Mankin et al,*** *The hazards of the biopsy, revisited.* *Journal Bone Joint Surgery, 78-A: 656-662, 1996.* ***Springfield D, Rosenberg A,*** *Biopsy: Complicated and risky* *Journal Bone Joint Surgery, 78-A: 639-643, 1996.* • We recommend that every patient is discussed at MDT **before and after biopsy**. In the pre biopsy MDT imaging can be discussed and ascertained all appropriate imaging has been performed. In certain cases biopsy might not be required. • Biopsy is preferably performed image guided. Surgeon and radiologist should agree on the approach at the pre biopsy MDT. The pathologist also needs to know the details concerning the sampling site to aid correct interpretation. • **Discrepancy between histology and biopsy: needs expertise to note it!** Example: cartilage tumours	
Robert Jones and Agnes Hunt Orthopaedic and	Paragraph 148	Please supply references of the several observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
District Hospital NHS Trust			
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 149	Please supply references of the Belgian and Dutch studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 150	Please supply references of the 5 studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 151	Please supply references of the several observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 152	Please supply references of the two UK studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 153	Please supply source of the unpublished observational study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 154	Please supply source of the UK survey and reference of the American study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS	Paragraph 155	Please supply references of the several observational studies and one American study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Trust			
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 156	Please supply references of the American and Belgian studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 158	Please supply references of the several studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 159	Please supply reference of the UK study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 160	Please supply reference of the Scandinavian study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 161	Please supply references of the two studies and the Dutch population based study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 162	Please supply references of the two observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 163	Please supply references of the three observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 164	Please supply reference of the UK study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 166	Please supply source of the audit.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 167	Please supply references of the seven observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 168	Please supply references of the observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 205	Please supply references of the evidence and source of the audit.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 206	Please supply references of the nine studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 207	Please supply references of the ten studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and	Paragraph	Please supply references of the six studies.	This will be included in the Evidence Review that

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Agnes Hunt Orthopaedic and District Hospital NHS Trust	208		accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 209	Please supply reference of the study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 211	Please supply references of two observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	233	• The MDT should have a lead clinician. • Recommendation regarding pathologist appears to be driven by current availability of pathologists rather than what is clinically required. Pathologists practising in this extremely difficult and complex field of pathology should not be working in isolation from specialist radiologists, oncologists and surgeons. Every MDT should have at least two pathologists to provide specialist opinions. • Pathologists who provide second opinions (secondary reporting) should also be members of an MDT and should not be working in isolation. • We do not feel a palliative care specialist with a special interest in sarcoma is realistic (see 429). • The specialist nurse should be part of the Core MDT rather than the extended MDT. • At least one therapist (physiotherapist or occupational therapist) should be member of the core MDT rather than the	We agree that a clinical lead should be part of the MDT and we have altered para 230 accordingly. We agree that ideally all MDTs would have two pathologists, but we are aware that this is not currently practicable. We have covered this topic in more detail in chapter 4. We agree that a pathologist reporting bone and soft tissue sarcomas should be a member of an MDT and should not work in isolation, and we have altered paras 188 and 189 accordingly. A palliative care specialist with a special interest in sarcoma is not likely to be a member of every sarcoma MDT, but when available would be a member of the extended sarcoma MDT. We agree that a specialist nurse would usually be a part of the core MDT, and it is most likely that a specialist nurse would take on the role of the key worker. We have modified Table 5 accordingly.

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		extended MDT.	The GDG was not convinced that a therapist was an essential member of the core MDT.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 243	Please supply references of the observational studies and audit.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 244	Please supply references of the studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 245	Please supply references of the studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 247	Please supply reference.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 249	Please supply references of the observational and cohort studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 250	Please supply reference of the cohort study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS	Paragraph 251	Please supply references of the Dutch studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.

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Trust			
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 252	Please supply reference of the Scandinavian study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 273	Please supply evidence (see 6).	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 280	Please supply reference of the cohort study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 281	Please supply reference of the observational study in Swedish patients.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 282	Please supply reference of the small Australian study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 283	Please supply reference of the cohort study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 284	Please provide source of the unpublished observational study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 285	Please supply references of the systematic review and small randomised controlled trial.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 292–295	• We agree with proposed outcome measures of survival, amputation rate, chemotherapy related toxic deaths and patient satisfaction. However we feel there should also be an assessment of: o Infection rate o Local recurrence rate o Functional Assessment o Quality of Life • The **surgical** treatment of bone sarcomas is commissioned by NSCAG due to its specialist nature. • **Overall** survival is largely controlled by the nature of the tumour and the response to chemotherapy and largely controlled by oncological treatment. • The main factors under **surgical** control are o Amputation rate o Local recurrence rate o Infection rate • We feel it is important to assess these parameters as a measure of surgical success. • Particularly in bone sarcomas, where frequently large endoprosthetic replacements of bone are being inserted, it is important to minimise infection risk. Patients who have had cytotoxic chemotherapy are immunosuppresed and have an increased risk of infection. Adequate surgical facilities should be available to minimise the risk of infection. **The use of an ultra clean air theatre is absolutely essential.** • The treating hospital should have a proven low incidence of infection in total hip and knee replacements. We suggest an	You correctly identify that NSCAG commissions services for the surgical management of bone sarcomas. NSCAG is likely to provide guidance on items that should be audited between different bone sarcoma treatment centres.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		infection rate of 1% for primary joint replacements as an absolute maximum. • Specialist hospitals were introduced prior to the antibiotic era to combat infection. With the introduction of antibiotics their popularity has diminished. However, nowadays MRSA is endemic in most hospitals; especially 'super hospitals' with intensive care units and medically ill patients. Hospital acquired infections are much less likely to occur in specialist orthopaedic units. • Our unit regrets that there is no guidance of infection in the outcome assessment of bone sarcomas.	
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 310	Please supply reference of the recent UK study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 311	Please supply references of the studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 312	Please supply references of the five studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 313	Please supply references.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS	Paragraph 320, 321, 322	Overall survival, local control, complication rates, limb function, quality of life and patient satisfaction are suggested as outcome measures. However, no scoring systems or functional evaluation systems are referred to. In comparing outcomes meaningfully, it is important to use	The ability to compare outcomes is going to become increasingly important but actually recording these and deciding what outcome measures to use is not straightforward. This guidance has recommended that

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Trust		the same outcome measure. We feel complications related to radiotherapy, skin flap / graft problems and amputation rates should also be recorded.	the minimum National Cancer Dataset should be collected, and once this can be accurately achieved it is likely that a national audit of more complex measures, e.g. functional evaluation, will be commenced.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 332	Please supply references.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 333	Please supply references.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 334	Please supply references.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 363	Please supply references of the five observational studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 382	Please supply references of the two randomised controlled trials.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 398	Please supply references of the two review papers and case reports.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and	Paragraph	Please supply reference of the audit commission report (2000).	This will be included in the Evidence Review that

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Agnes Hunt Orthopaedic and District Hospital NHS Trust	417		accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 418	Please supply reference of the updated audit commission report (2002).	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 420	Please supply reference of the cohort study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 429	• It is unrealistic and not justified to recommend a palliative care specialist with a special interest in sarcomas. Palliative care, in its nature, should be provided locally (in the patient's community). Sarcomas are rare tumours and it is unlikely that a palliative care network has more than a few patients with sarcoma. • Furthermore, from palliative care point of view, it is unlikely to make much difference if the patient has sarcoma or carcinoma as the underlying course for their musculoskeletal disability.	We have altered para 429 to point out that palliative care specialists with an interest in sarcomas will not always be available for all centres
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 436	Please supply references of the seven systematic reviews.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 437	Please supply references of the systematic reviews.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and	Paragraph 438	Please supply reference of the randomised controlled trial.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
District Hospital NHS Trust			
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 458	Please supply reference of the review paper.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 459	Please supply source of the American survey and the UK NCRI study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 460	Please supply reference.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 462	Please supply reference of the observational study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 463	Please supply reference.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 464	Please supply source of the unpublished observational study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS	Paragraph 465	Please supply reference of the small cross sectional study.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Trust			
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 466	Please supply references of the cross sectional studies.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 476	Please confirm what data should be collected and what coding should be used. We would recommend the World Health Organisation's classification of musculoskeletal tumours. Details and database can be downloaded from www.paulcool.com.	Please see para 477, which details the data that should be collected.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 477	A national agreed data set on sarcoma is suggested. However, there is no recommendation on what data should be collected. We feel NICE should advice on this and suggest a minimum dataset.	We recommend reference to www.paulcool.com. Further information will also be in the Evidence Review that accompanies the Manual.
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust	Paragraph 501	Please supply source of the audit.	This will be included in the Evidence Review that accompanies the Manual and will be available during the second consultation.
Royal College of Anaesthetists		This organisation was approached but did not respond.	
Royal College of General Practitioners	General	The RCGP has evaluated your request for commentators on this topic, and is happy in this instance to rely on the advice given by our specialist and nursing colleagues.	Thank you.
Royal College of General Practitioners Wales		This organisation was approached but did not respond.	
Royal College of Nursing	General	Easy to read and follow guidance. Good cross reference to Children and Young Persons' Cancer Improving Outcome Guidance.	Thank you.
Royal College of Nursing	Paragraph 3	All patients with a confirmed diagnosis of cancer **MUST (not should)** have their care supervised by or in conjunction with a sarcoma MDT	The use of the word 'must' in NICE guidance is restricted to government priorities and targets (e.g. the 2-week wait).
Royal College of	Paragraph	Joint working **BOTH** within and across cancer networks	We have made this amendment to the text.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Nursing	13		
Royal College of Nursing	Paragraph 22	Why have the team not given definitive advice?	This sentence has been removed from para 22.
Royal College of Nursing	Paragraph 71	Training needs to include training for nurses & Allied Health Professionals and how essential it is for all disciplines. Recommendation for communication skills, general oncology & treatment care of dying symptom management.	Thank you for your comment. This para describes the current situation regarding training. The recommendations on training can be found at paras 484–486.
Royal College of Nursing	Paragraph 92 (Table 4)	Term sarcoma - this should be encouraged and a definition of sarcoma, cancer	A glossary will be included in the second draft of the manual. This will be available during the second consultation.
Royal College of Nursing	Paragraph 96	Benefits expand in relation to paediatrics length of treatment and education.	This has been dealt with by the NICE guidance on 'Improving outcomes for children and young people with cancer'.
Royal College of Nursing	Paragraph 99	Add to 99 - Cancer network managers should be responsible for patient process mapping.	Please explain the meaning of the term 'patient process mapping'.
Royal College of Nursing	Paragraph 101	Add **many** patients **may** benefit by both helping and being helped (it is a very sweeping statement in its current form especially as on page 37 paragraph 109, 9% patients found it difficult to interact with other patients.)	We have amended the text to read 'Patients **may** benefit …'.
Royal College of Nursing	Paragraph 103	Communication - 103 - *recorded copy of consultations* does that mean taped or written?	The text has been amended to clarify that it means both a taped and a written copy of the consultation.
Royal College of Nursing	Paragraph 110–112	Commissioners need to consider long term follow-up transport arrangements, disability and difficult geographical journeys.	This has been dealt with in the resource implications.
Royal College of Nursing	Paragraph 119	Outcomes could include patient diaries questionnaire patient focus groups	We agree.
Royal College of Nursing	Paragraph 120	Resource implications should include TRANSPORT	Thank you for your comments.
Royal College of Nursing	Paragraph 128	Referral guidelines for bone sarcoma - GP to order early x-ray sooner rather than later	This suggestion is already in the NICE 'Referral guidelines for suspected cancer'.
Royal College of Nursing	Paragraph 131 (Point 2)	Need to increase awareness of "waiting times clock ticking" maximum 62 days from urgent GP referral to treatment for all cancers necessitating speedy referral to specialist centre.	We accept the importance of the waiting times charter for patients with cancer. It will be up to the sarcoma MDT to liaise with its referring organisations about inappropriate referrals. This has been dealt with in paras 479 and 483.
Royal College of	Paragraph	Process - plus timeliness of scans	We feel that the timeliness of the scans will be

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Nursing	176		covered by the NHS targets for diagnosis and treatment of patients with cancer, as stated in para 174.
Royal College of Nursing	Paragraph 228	Do figures relate to the number of patients with suspected sarcoma or a confirmed diagnosis of sarcoma?	The figures relate to confirmed diagnosis of sarcoma.
Royal College of Nursing	Paragraph 233 (Table 5)	Specialist sarcoma pathologist current peer review states a minimum of 2 pathologists at MDT.	We agree that ideally all MDTs would have two pathologists but we are aware this is not currently practicable. We have therefore taken a pragmatic approach and defined that ideally there should be two pathologists.
Royal College of Nursing	Paragraph 233 (Table 5)	Under oncologist how much is a " significant portion" subjective statement	We have amended the text to specify that the medical/clinical oncologists should each spend a minimum of 3 Pas involved in the management of sarcomas.
Royal College of Nursing	Paragraph 235 (Bullet point 12)	Informing GP should include within 48 hours for diagnosis as per Manual of Quality Measures for Peer Review 2004.	Informing GPs within 24 hours is one of the national cancer standards, which should be adhered to and which is mentioned in para 5.
Royal College of Nursing	Paragraph 257	Process - " first opportunity" too woolly	Thank you for highlighting this. We have changed the wording
Royal College of Nursing	Paragraph 394–395	Add in specialist physiotherapy input for long term function follow-up assessments facilitation of gaining maximum function for those undergoing limb salvage	We have added achievement of maximum function for those patients undergoing limb salvage to the anticipated benefits.
Royal College of Nursing	Paragraph 384	Provision of a key worker-needs to include guidance on caseload as this will be important in considering the resource implications for staffing these posts.	The number of cases that could be handled by an individual key worker is likely to vary between treatment centres and there is little available evidence on which to base any definitive recommendation. The number of key workers required will be based on existing caseload and future caseload.
Royal College of Nursing	Chapter 8 Supportive and Palliative Care	Supportive care needs to include guidance on the importance of the social worker and recommendations for the provision of adequate numbers of oncology social workers to provide patients and families with emotional, financial, practical and educational support.	While agreeing that social workers should be available for patients with sarcoma, this is a generic recommendation that has already been covered by the NICE guidance on 'Improving supportive and palliative care for adults with cancer'. This document has been cross-referenced in this guidance.
Royal College of	Paragraph	The recommendation should include guidance on access to home	Guidance about palliative care is already available in

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Nursing	431	care services so that palliative care packages can be organised to meet patients wishes to be cared for at home. Currently these services are inadequate, require intense and lengthy negotiations and often patients have to be admitted to nursing homes due to the lack of funding\availability of care services.	the NICE guidance on 'Improving supportive and palliative care for adults with cancer'. We have inserted a cross-reference to this guidance in para 431.
Royal College of Nursing	Paragraph 486	Training 486 - add nurses, key workers and Allied health professionals training also essential	We have added a recommendation to cover this.
Royal College of Nursing	General	Other general comment is regarding the care of young people and the availability of resources to meet their needs in the form of the capacity and availability of young persons' units as there seems to be a problem with access and waiting times to be admitted for chemotherapy, plus a review of the palliative care provision for young people who would be too old for children's hospices.	This is not within the scope of this guidance and has been dealt with by the NICE guidance on 'Improving outcomes in children and young people with cancer'.
Royal College of Nursing	General	Consider that the document is comprehensive and will be helpful to the commissioners. Although evidence was sparse with regard to some of the issues discussed, it is understood that in-depth searches were carried out.	Thank you. The evidence will be included in the Evidence Review that accompanies this guidance. This will be available during the second consultation.
Royal College of Paediatrics and Child Health		This organisation was approached but did not respond.	
Royal College of Pathologists	General	Overall this guidance is well set out and clearly written. However a document such as this requires that appropriate references be given for any cited published studies. Virtually no references have been included.	The references will be included in the Evidence Review that accompanies this guidance. This will be available during the second consultation.
Royal College of Pathologists	Paragraph 5 (Key Recommendations)	"Second opinions and review of difficult cases should be funded". I strongly support this, however, I do not think it appropriate to invoice for every case, as this would require a large amount of secretarial time by those invoicing/paying. It should be organised at a national level, possibly yearly retrospectively, so that the specialist pathology units submit their costs to a national body on an annual basis with costs for cases agreed in advance, at a national level. Any department may be a little underpaid or over paid, but this would be better than vast amounts of clerical time being spent trying to follow each case.	We have clarified that commissioners should be responsible for funding specialist second opinions. The exact mechanism by which this is done remains to be resolved, and it is not within the remit of this guidance to do this.
Royal College of Pathologists	Paragraph 77	Maybe the specialist centres should have a joint, or possibly independent up-to-date web site in which appropriate, accurate, useful information is made available. This would possibly help to counteract	Providing accurate and up-to-date information is going to be one of the responsibilities of the sarcoma MDTs. It is likely that this information will become available

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		some of the misinformation provided on the internet. This web site/sites would be linked to other relevant sites.	over the Internet and that MDTs will collaborate in ensuring that the data provided are consistent.
Royal College of Pathologists	Paragraph 107	Are we satisfied that the information given to teenagers was inappropriate? This may sound patronising but the information given may well have been the appropriate information but patients may not appreciate it at the time they are provided with this information. It is also possible that the info was appropriate but could be delivered in a different manner.	The study (which has now been referenced) identified that the teenagers themselves felt that the information was not appropriate. No judgement was made as to whether it was actually appropriate or not.
Royal College of Pathologists	Paragraph 183	NSCAG has recently funded a clinical scientist post at the Royal Orthopaedic Hospital, Birmingham and a technician for molecular genetics at the Royal National Orthopaedic Hospital. Therefore it is incorrect to say that there are no established laboratories. However, as a consequence of new targeted therapy, which has developed in parallel with new diagnostic markers, diagnostic molecular pathology is a fast growing area and is still insufficiently supported at the present time. One possibility of ensuring that appropriate funding goes into new diagnostic techniques, is linking the pharmacy budget with the diagnostic budget in NHS hospitals.	Thank your for informing us about the funded unit at ROH and RNOH – we have amended para 183. It is not within the remit of this guidance to comment about linking pharmacy and diagnostic budgets.
Royal College of Pathologists	Paragraph 188	A specific number of bone tumours and new soft tissue sarcomas should be stipulated for a pathologist before they are designated as specialists. The minimum number should be possibly 100 soft tissue sarcomas or neoplasms of low malignant potential and 100 primary bone tumour [to include benign and malignant neoplasms].	We have amended the definition of a specialist sarcoma pathologist to include being a member of a sarcoma MDT (see paras 188 and 189).
Royal College of Pathologists	General	It probably requires at least two years of subspecialty training in histopathology before individuals are comfortable taking responsibility for even the most straightforward of connective tissue neoplasms and up to five years before they have the experience in breadth and depth of knowledge to take responsibility for the vast majority of diagnostic decisions. On that basis, future planning for replacement consultants in subspecialty areas must be undertaken and costed. Similar experience and training is almost certainly warranted in oncology and surgery. This means that 5 years prior to a consultant specialist retiring, the specialist units should be appointing the sucessors.	Thank you for your comments. This issue has been covered in para 485. We accept that this is a generic problem for many other specialised areas of medicine but it is outside the scope of this guidance to provide specific detailed advice on how it should be dealt with.
Royal College of Physicians of London		This organisation was approached but did not respond.	
Royal College of Psychiatrists		This organisation was approached but did not respond.	

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Royal College of Radiologists (Faculty of Clinical Oncology)	General	This document proposes recommendations for the management of both bone and soft tissue sarcoma (STS). Because bone sarcomas are very rare, they are generally already managed in specialised centres, generally supraregional. As stated in the forward on page 3, STSs are also rare, although not so rare as bone sarcomas and it is hoped that continued evolution of the MDT system for their management will lead to improved outcomes. It is estimated that currently approximately 50% of patients with STS are managed at a DGH rather than a cancer centre. Of major concern are potential delays to diagnosis, and also the potential for inappropriate management of their primary disease. Because of the rarity of sarcomas, it is not clear whether implementation of an improved MDT network will reduce delays to diagnosis.	One of the aims of the guidance is to improve the speed of diagnosis of patients with sarcomas and hopefully thus decrease the size at which they are currently diagnosed, leading to improved outcomes. This will need to be audited. This has already been identified in para 169.
Royal College of Radiologists (Faculty of Clinical Oncology)	General	An inherent problem is the very small number of malignant cases in comparison with the huge number of patients with 'lumps and bumps' in general practice, or even general surgical or orthopaedic practice. Early diagnosis will probably remain problematic for many patients.	The recent publication of the NICE guidance on 'Referral guidelines for suspected cancer' should, with this guidance, help improve early diagnosis of potential sarcomas. We believe that having an identifiable referral pathway for suspicious lumps and bumps is likely to be the single factor that speeds up diagnosis.
Royal College of Radiologists (Faculty of Clinical Oncology)	Paragraph 4	It is stated that the minimum recommended number of STSs should be >100 per year. It is also stated later in the document that this will apply to a centre serving a population of approximately 2-3 million. This number will probably exclude many, possibly the majority of cancer centres, and in certain parts of the UK raises the issue of supra-regional services for soft tissue sarcoma. In fact in some areas of the UK geographic consideration will make it impossible to comply with these recommendations. Therefore the issue of precise patient numbers needs to be questioned and discussed further. The main issue will be whether patient numbers per se are important, or whether it is the development of expertise with adherence to agreed, preferably national protocols that is more important. The corollary of this is that the network of paediatric oncology centres will individually handle diagnostic groups comprising very small	The GDG believes firmly that the optimum management of a patient with a sarcoma is through a properly constituted sarcoma MDT. Given the requirements to constitute that MDT, the MDT will need to serve a minimum population, which we have identified to be approximately 2–3 million for soft tissue sarcomas. There is currently only one cancer network that has a population base greater than 3 million, but three have a population base greater than 2.5 million and all of these are likely to be able to host a sarcoma MDT. Other cancer networks are likely to combine to rationalise the scare resources available for treating this rare tumour type. Certainly at the moment there are many cancer centres and cancer networks that do not specifically treat sarcomas. The GDG believes that getting the correct treatment is

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		numbers. However adherence to national treatment protocols via the United Kingdom Children's Cancer Study Group (UKCCSG) has maintained a good outcome, despite small patient numbers. Setting the population base for a bone sarcoma MDT at approximately 7 million may well require an increase in the number of bone sarcoma MDTs in the UK.	important for patients and accepts that this may mean that patients may have to travel to receive it, although the distances involved are not likely to be great. We accept that children treated at UKCCSG centres have very good outcomes with very low numbers, and this is largely because of the commendable organisation of the UKCCSG and the strict protocols it adheres to. These are currently lacking for soft tissue sarcomas. The formation of specific sarcoma MDTs and treatment centres will, however, bring greater standardisation of care for patients with sarcomas to the UK, which is likely to be beneficial.
Royal College of Radiologists (Faculty of Clinical Oncology)	General	Linking of Centres The linking of small and large cancer centres providing limited (e.g. palliation) and comprehensive (e.g. radical surgery/radiotherapy) services respectively is a new departure for cancer centres and requires further discussion. An alternative approach may be to consider the initial assessment and surgery being performed in the major centre, with adjuvant radiotherapy being administered in the smaller centre, given according to agreed protocols. Radiotherapy involves daily visits generally for at least six weeks, and therefore travelling long distances daily may be a problem for many patients. Provided the smaller centre has access to modern 3-dimensional conformal planning facilities and the treatment is planned and delivered according to agreed protocols then this would seem to be an appropriate solution. In addition palliative chemotherapy may not need to be delivered only in the larger centres, again provided this is administered according to agreed protocols. The issue of staff numbers for a rare tumour type could be at least partially dealt with by considering access to video-conferencing facilities.	We feel that our recommendations in paras 304–306 were specific on this matter. We are not clear on the meaning of your comment about issues of staff numbers – please clarify. Videoconferencing facilities may have a role in communicating with members of the extended sarcoma MDT but it will be up to individual MDTs to make arrangements for this if required
Royal College of Radiologists (Faculty	General	Radiotherapy Facilities	Thank you for your comments. The level of detail you have supplied is not appropriate for service guidance.

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of Clinical Oncology)		The requirements for radiotherapy facilities should be more explicitly stated. This should include mould room facilities, full range of linear accelerators, including electron facilities, and also 3-D conformal planning and delivery technology. It should also be stated that radiotherapy should be deliverable in a timely manner according to nationally agreed waiting time targets. Radiotherapy should start within 4 weeks of the patient agreeing to it and being fit to receive it (JCCO guidelines, RCP, 1993). Radiotherapy delivery should be accompanied by support of a team including specialist nurse and physiotherapist. Intensity Modulated Radiotherapy (IMRT) may be relevant in the future for some sarcomas arising in difficult sites such as chest wall or the abdomen. It should probably be stated that major sarcoma treatment centres should be working towards implementation of IMRT, although its precise future role is not yet well defined.	However, we have inserted a cross reference to the 'Manual for cancer services 2004'.
Royal College of Radiologists (Faculty of Clinical Oncology)	Paragraph 233 (Table 5)	Medical and clinical oncologist – at least one of each – is this always necessary? In view of the relative limitations of chemotherapy for STS, therefore from the perspective of the RCR, the statement that there will always need to be at least one medical oncologist may need justification. The question of medical oncology input could be decided according to local policy. A clinical oncologist with the relevant site specialist expertise could provide input into decision making for patients requiring systemic therapy. Each MDT will need probably at least two clinical oncologists. In order to provide seamless cover at times of absence it will probably be necessary for an MDT, particularly one in a large area to have input from two clinical oncologists. Radiotherapy for STSs is often complex, and in the era of oncology site specialisation, other oncologists may have become 'deskilled'. Therefore it seems unlikely that appropriate input can be provided by any less than two clinical oncologists.	We accept your comments about the variation in the delivery of chemotherapy in different centres and have changed the staff requirements and specification accordingly. We do, however, believe that there should be a minimum of two oncologists involved in a sarcoma MDT and that each should have 3 PAs involvement with sarcoma patients per week.
Royal College of Radiologists (Faculty of Clinical Oncology)	General	Adolescent/young adult practice Sarcomas arise in a population of patients who span the age range across the boundary from paediatric through adolescent to the young adult age group. An important issue, which has not been dealt with, is	Thank you for your helpful comments about this age group. We have amended the guidance to mention the management of soft tissue sarcomas in children and young adults, but it will be up to the individual MDTs to decide who is the best person to treat each

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		the issue of how adults with 'paediatric' type tumours should be managed. Simply applying paediatric protocols may not be appropriate, and these patients demand the expertise of adult and paediatric oncologists. At what age level should a paediatric oncologist be 'actively involved' as opposed to consulted. A significant issue is also the involvement of paediatric oncologists and/or the adolescent oncology team in patients with low grade sarcomas managed by excision alone. These patients may have psychosocial issues which and may well benefit from input from the team.	patient. In some situations paediatric oncologists manage the young adult population, while in others the adult oncologists will manage this age group over 16. This guidance states that the appropriate oncologist should be consulted in these cases, but it is not possible to make more specific recommendations.
Royal College of Surgeons of England		This organisation was approached but did not respond.	
Royal College Patient Liasion Groups		This organisation was approached but did not respond.	
Royal Liverpool Children's NHS Trust		This organisation was approached but did not respond.	
Royal Marsden Hospital NHS Trust	General	The comments outlined in this document represent the combined views of the Sarcoma unit at the Royal Marsden Hospital (RMH). All members of the unit have read the guidance and these comments have been written after a unit meeting held on 3/6/05 to discuss this guidance	Thank you.
Royal Marsden Hospital NHS Trust	Paragraph 12	The RMH Sarcoma unit would strongly support key recommendation 12 (NSCAG funding for a small number of centres managing abdominal and pelvic soft tissue sarcoma) and would apply for status as a designated centre. RMH has financial and clinical audit data on a significant cohort of such patients that could be made available to NSCAG if required.	Thank you for your comments.
Royal Marsden Hospital NHS Trust	General and specifically paragraphs 125,131, 132,133, 224 and 228	One of the general concerns that the RMH sarcoma unit had with the guidance related to the relationship between diagnostic centres and treatment of soft tissue sarcoma in specialist centres. The guidance correctly advocates that the treatment of STS should be centralised within groups managing a high volume of disease (at least 100 cases /annum) The necessary expertise suggested in Table 5 is significant (2 surgeons with >50% workload in sarcoma, 2 radiologists, one or two pathologists, one medical and one clinical oncologist). Clearly such expertise must be directed principally in the management of malignant disease. In established units such as our	We accept that there will be many different models for running diagnostic clinics. You correctly identify that the aim of this guidance is to try to get patients with sarcomas identified at as early a stage as possible. Unfortunately, there are no good models for these diagnostic clinics currently in practice outside of a sarcoma centre. The guidance makes this clear and, hopefully, audit will identify what the best model is. The guidance does not make a specific

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		own where such expertise does already exist, in fact the malignant caseload is much greater than 100 cases/annum with 458 new sarcoma cases being registered at RMH last year, the majority with primary disease. The referral base for this practice covers the whole of the South of England spanning many cancer networks, as well as including patients from further a field. In practical terms the diagnostic workload for this referral pattern is substantial. The RMH unit feels that the estimation in paragraph 125 that 1 in 10 patients referred appropriately to a diagnostic centre would have a sarcoma is a considerable under-estimation of the benign to malignant ratio. Furthermore the comment in paragraph 133 that there would be no requirement for a 'surgeon or oncologist' to be a part of the diagnostic centre fails to address the fact that there are major treatment implications for the 9/10 patients diagnosed with a benign but symptomatic mass. Most of these patients will still require surgery or at the very least ongoing follow up. In paragraph 131, model 1 would completely undermine the role of the treatment centre because of the huge ratio of benign to malignant cases. Furthermore as the aim of the guidance is (correctly) to centralise sarcoma treatment in major specialist centres, these centres will receive patients from a number of cancer networks. Although it might be possible for a treatment centre to have a specific relationship with a diagnostic centre serving there own cancer network, this diagnostic centre would only provide a small proportion of patients to the treatment centre. It is difficult for major treatment centres to work in close collaboration with all referring diagnostic centres (para 133) and we feel that the guidance should make this clear. There should be no stipulation implied for a treatment centre to also serve as a diagnostic centre (para 224), although that service may need to be provided within the network in a distinct separate unit.	recommendation that a sarcoma treatment centre should also act as a diagnostic clinic, although many will choose to do so. We feel it is, however, the responsibility of the treatment centre to work with the local diagnostic clinics to ensure a smooth patient pathway and early diagnosis. We accept that some patients who are referred to the diagnostic clinic will have benign conditions needing further treatment and some will have malignant but non-sarcomatous conditions also needing treatment. However, the scope of this guidance only covers those patients with sarcoma and thus is unable to make recommendations on how patients identified at the diagnostic clinic as **not** having a sarcoma should be further managed.
Royal Marsden Hospital NHS Trust	303, 304	Paragraph 303 indicates that curative radiotherapy should normally be delivered in the treatment centre. In fact the arrangement described in paragraph 304 in which radiotherapy is administered by a local	We have amended chapter 7 to clarify the arrangements for the provision of chemotherapy and radiotherapy.

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		affiliated clinical oncologist is not uncommon, and may be come more common with centralisation of surgery in major centres. Outpatient attendance for a 6 week course of fractionated radiotherapy may be logistically impossible for certain patients, particularly elderly patients. Given the fact that the guidance gives fairly precise stipulations about the number of patients treated by an MDT, there should be some consideration given to providing some guidelines about the number of cases treated by that affiliated clinical oncologist. Clearly these could only be guidelines and not didactic rules as the reason for local radiotherapy is principally because of important individual patient factors. Hence there would have to be some inherent flexibility.	
Royal Marsden Hospital NHS Trust	Paragraph 268	Lacks cross reference to the NICE guidance for paediatric and young people with cancers with respect to the need for age appropriate treatment facilities in the younger age group.	Thank you for your suggestion. We have inserted text and a cross-reference to the NICE guidance on 'Improving outcomes for children and young people with cancer' after para 266.
Royal National Orthopaedic Hospital NHS Trust		This organisation was approached but did not respond.	
Royal Pharmaceutical Society of Great Britain		This organisation was approached but did not respond.	
Sarcoma UK		This organisation was approached but did not respond.	
Scottish Bone and Soft Tissue Sarcoma Network	General	The caseload requirements recommended are not appropriate for the geographically widespread population of Scotland.	NICE guidance does not cover Scotland, and thus this guidance was not produced with the Scottish population in mind.
Scottish Bone and Soft Tissue Sarcoma Network	General	Many of the recommendations are rather general and anodyne. The specifics of treatment are not dealt with in any detail.	This is service guidance for commissioners and thus does not cover the specifics of treatment.
Scottish Bone and Soft Tissue Sarcoma Network	General	The references to GIST are very widespread throughout the document. There is a need to integrate the existing GIST guidelines more into these general sarcoma guidelines.	We have referenced the NICE technology appraisal about the use of imatinib in GIST, but have not made any reference to treatment guidelines as that is outside the scope of this guidance.
Scottish Bone and Soft Tissue Sarcoma Network	General	Should MDTs discussing adult and paediatric cases separately be integrated?	A paediatric oncologist is a core member of the bone sarcoma MDT and thus should be available when cases of bone sarcomas in children are discussed.

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			Soft tissue sarcomas arising in childhood are rare and frequently will present through other site-specific MDTs. We have amended the text to cover this.
Scottish Bone and Soft Tissue Sarcoma Network	Paragraph 128	For a rare tumour, the yield by having a major campaign would be low especially as the symptoms are often non-specific and can be in any part of the body. It would seem much more sensible to see how we can raise awareness in health professionals, especially as significant delays seem to occur even when the patient gets into the health care system.	It is unclear at the moment to whom education campaigns should be directed, but our guidance makes clear that GPs should be encouraged to comply with urgent referral criteria.
Scottish Bone and Soft Tissue Sarcoma Network	Paragraph 228	No evidence is quoted to justify these caseload requirements. See next comment.	The GDG considered at length the optimum number of patients that a sarcoma treatment centre should manage per year. We believe that a patient's care is best managed by a sarcoma MDT, and that MDT must be of sufficient size and have sufficient members to be able to work effectively and have in-depth experience. We do not believe that a properly constituted sarcoma MDT is likely to be viable unless it treats the number of patients we have identified in the guidance. We feel that the numbers we have suggested are realistic. For a centre treating both bone and soft tissue sarcomas, the requirement for them to treat on average one new patient with bone sarcoma per week is not unrealistic, given the huge variety of bone sarcomas that exist. If a centre were treating fewer than 50 cases per year, it is unlikely that the surgical team, the pathologist or the back-up team would have sufficient expertise to give those patients optimum treatment. We feel that the same argument applies for soft tissue sarcomas, which is why we have stipulated a figure of 100 new cases per year, which correlates with a population base of approximately 3–4 million.
Scottish Bone and Soft Tissue Sarcoma	Paragraphs 249–252	In fact, the only evidence quoted here suggests that about 10 new diagnoses per annum might provide a sufficient workload to maintain	The GDG considered at length the optimum number of patients that a sarcoma treatment centre should

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Network		generic expertise and a satisfactory outcome.	manage per year. We believe that a patient's care is best managed by a sarcoma MDT, and that MDT must be of sufficient size and have sufficient members to be able to work effectively and have in-depth experience. We do not believe that a properly constituted sarcoma MDT is likely to be viable unless it treats the number of patients we have identified in the guidance. We feel that the numbers we have suggested are realistic. For a centre treating both bone and soft tissue sarcomas, the requirement for them to treat on average one new patient with bone sarcoma per week is not unrealistic, given the huge variety of bone sarcomas that exist. If a centre were treating fewer than 50 cases per year, it is unlikely that the surgical team, the pathologist or the back-up team would have sufficient expertise to give those patients optimum treatment. We feel that the same argument applies for soft tissue sarcomas, which is why we have stipulated a figure of 100 new cases per year, which correlates with a population base of approximately 3–4 million.
Scottish Bone and Soft Tissue Sarcoma Network	Paragraph 378–387	1. Nice idea, but given the huge geographical dispersal of the Scottish population, how are we to manage this? Two central workers who do most of their work on the telephone? 2. Patients receiving chemotherapy or radiotherapy through an extended MDT should be supported by a named key worker at the relevant cancer centre.	This guidance is for England and Wales, not for Scotland. We do feel, however, that key workers have been shown to be very valuable members of the MDT in England and Wales and a lot of their work on behalf of patients is indeed done over the telephone. We would urge Scotland to consider adopting our model. The important point is that a patient treated at a sarcoma treatment centre will have a key worker. If the patient was then referred on for chemotherapy/radiotherapy elsewhere, that key worker would hand over the patient to another key worker at the other centre
Scottish Bone and	Paragraphs	Specialist palliative care services and follow-up should be provided as	We are unable to comment about practice in Scotland.

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Soft Tissue Sarcoma Network	428–449	close to home as possible (in practice, one of the five Scottish centres).	
Scottish Bone and Soft Tissue Sarcoma Network	Paragraph 454–470	There is little data on follow-up. I can see the logic of follow up to assess local control since local relapse may be salvageable (and anyway we want local control figures for audit of our local management policies). There seems to be an inconsistency in the recommendations about other investigations; there is "consensus" about the use of Chest X-ray (CXR) regularly (how often?) in patients at "high risk". There is then mention of one study where resection of pulmonary mets was largely in patients in whom they were detected asymtomatically. What is the evidence that resection on pulmonary mets improves outcome? If it does, it is likely to be in patients with "intermediate risk" sarcomas - high grade aggressive tumours would tend to produce multiple irresectable mets. I suspect that regular CXRs serve only to shorten disease free survival (and increase patient anxiety for the result). Two studies in breast cancer (a tumour with more therapeutic options for metastatic disease se than sarcomas) failed to show any advantage in terms of survival by regular staging for mets. Can we question even the use of CXRs?	Thank you for your detailed comments. We have changed para 454 to suggest that research should be commissioned to provide evidence for the follow-up protocols required for each tumour type.
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	General	Very positive document providing recommendations for the re-organisation of service for this rare group of tumours (who undoubtedly do require significant specific clinical expertise to improve outcomes).	Thank you.
Society and College of Radiographers	Paragraph 9 (Key Recommendations)	For radiotherapy and chemotherapy- "should be carried out at designated centres by appropriate specialists as recommended by a Sarcoma MDT". This will importantly place emphasis on Commissioners to discuss with Cancer Networks which centres within their network should perhaps be" the designated centre". This will need to be weighed against the issues also raised re patient travelling times to the expertise. (Discussed in Chapter 2)	We agree.
Society and College	Paragraph	With regard to a nominated clinical oncologist, we would argue that	We do not think it is realistic that every treating centre

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
of Radiographers	275	there should be a second clinical oncologist available too for backup, again this person must have expertise in the treatment of sarcomas.	should have two clinical oncologists with expertise in radiotherapy for bone sarcomas. Radiotherapy is not usually required as an emergency and there is usually considerable planning about the timing of radiotherapy which will allow for annual leave, sickness, etc.
Society and College of Radiographers	Paragraph 304	With regard to a nominated clinical/medical oncologist, we would again argue that a second clinical oncologist/medical oncologist should be available too for backup, again this person must have expertise in the treatment of sarcomas.	We do not think it is realistic that every treating centre should have two clinical oncologists with expertise in radiotherapy for bone sarcomas. Radiotherapy is not usually required as an emergency and there is usually considerable planning about the timing of radiotherapy which will allow for annual leave, sickness, etc.
Society and College of Radiographers	Paragraph 475	Support fully the need for specific training for all those involved and the need for CPD, funding and time must be made available to support this. We would also like to see the training focussed within the MDT (& extended team) environment and directly linked to outcome goals.	Thank you for your support.
South Warwickshire General Hospitals NHS Trust		This organisation was approached but did not respond.	
South West Cancer Intelligence Service	General	The majority of responses from the Tumour Panel members focus on the number of cases expected to be managed per Unit. They are reported as general comments because they relate to the MDT process, geographical proximity, quality of care and clinical workload. Much of the sarcoma guideline document is sensible and, like similar documents covering other sites, aims to achieve improvements in outcome through standardisation of the MDT process. The main issue that needs to be debated is: what is the best balance between the number of cases managed by an MDT and the reasonable local care of patients with these diseases. Although there is some (patchy) evidence for the benefit of volume of throughput through a unit and outcome, in most cases the comparisons deal with much smaller numbers than eg 100 soft tissue and/or 50 bone tumours per year. It is an unreasonable assumption that the benefit continues to increase the higher the number. The contrary arguments include the valid concerns about required travelling distances for treatment for patients	The GDG considered at length the optimum number of patients that a sarcoma treatment centre should manage per year. We believe that a patient's care is best managed by a sarcoma MDT, and that MDT must be of sufficient size and have sufficient members to be able to work effectively and have in-depth experience. We do not believe that a properly constituted sarcoma MDT is likely to be viable unless it treats the number of patients we have identified in the guidance. We feel that the numbers we have suggested are realistic. For a centre treating both bone and soft tissue sarcomas, the requirement for them to treat on average one new patient with bone sarcoma per week is not unrealistic, given the huge variety of bone sarcomas that exist. If a centre were treating fewer than 50 cases per year, it is unlikely that the surgical team, the pathologist or the back-up team would have

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		who may be elderly, receiving intensive therapy (and so potentially not fit to travel because neutropenic etc), dependent (and so unable to travel without provoking family disruption) or disabled. I fully support the concept of the MDT, the named individual supervising each patients care, the interaction between smaller and larger MDTs etc, but one must consider that effectively dividing the country into 5-6 units treating bone tumours is probably inappropriate and 10-12 units treating soft tissue sarcoma is certainly inappropriate. It might be pointed out that the numbers suggested are much higher than required for a unit treating acute leukaemia (more complex and intensive regimens, similar cure rate), or salvage therapy for high grade lymphoma (more complex and intensive regimens, similar cure rate) etc. There may be a case for greater centralisation of sarcoma surgical services to ensure that there is appropriate experienced cover for surgeons who spend a substantial amount of their time carrying out this type of work, but this would be feasible without so centralising the other aspects of care.	sufficient expertise to give those patients optimum treatment. We feel that the same argument applies for soft tissue sarcomas, which is why we have stipulated a figure of 100 new cases per year, which correlates with a population base of approximately 3–4 million. The number of sarcoma treatment centres that we have suggested to serve the country is not unreasonable, given the rarity of these types of tumours. We must emphasise that the presence of a properly constituted MDT for making treatment decisions is one of the principal aims of this document. We agree that in certain geographically diverse locations of the UK chemotherapy and radiotherapy need not be centralised, and this has been dealt with in paras 304 and 305.
South West Cancer Intelligence Service	General	There should be some flexibility of scale for the local commissioners and a robust peer review process that examines outcomes- the current peer review is all about compliance with guidelines. If the guidelines are based on false assumptions then the peer review will be fatally flawed.	We agree that examining outcomes and auditing these is essential. We have suggested in paras 481–482 that multicentre audit will be beneficial and we have invited the National Clinical Audit Steering Group to support this.
South West Cancer Intelligence Service	General	Overall satisfied by the guidelines, I would suggest that there is some flexibility for the 100 cases of Soft Tissue Sarcoma (STS) needed to be a centre so that geographical isolation (i.e. the SW Peninsula) can be taken into account for the benefit of patients	As we have stated in para 222, we would anticipate that a soft tissue sarcoma MDT would service a population of somewhere between 2 and 3 million. It is likely that at the present time, within this population, many soft tissue sarcomas are managed outside of a sarcoma MDT. Thus identifying these patients and ensuring that they are managed by the sarcoma MDT will increase numbers to the requisite level.
South West Cancer	General	It needs to be made clear to NICE that they need to consider	The aim of this guidance is to try to identify where

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Intelligence Service		suspected sarcomas as well as proven ones. Very few units can claim 100 proven soft tissue sarcomas a year but there are an awful lot of suspected cases which need skilled assessment. It is unrealistic to expect all the fast track referrals to go to a very few centres which are likely to be a very long way away from the patients home.	patients with suspected sarcomas should be referred. There is abundant evidence that currently the biggest delays are in patients being referred to non-specialist centres that have no expertise in managing potential sarcomas. It is the belief of the GDG that having diagnostic clinics with interested personnel will do more to speed the early diagnosis of sarcomas than any other single measure.
South West Cancer Intelligence Service	General	I am concerned at the suggestion that units doing less than 100 sarcomas per year should discontinue. Current teams seeing less than the required number will discontinue the service. This will remove individuals with an interest in sarcoma from offering a local service. Is there evidence that a surgeon doing 100 per year does them better than a surgeon doing 25 per year? Removing the local sarcoma team will close down the local diagnostic service which will probably return to being dissipated over a number of general/orthopaedic etc surgeons. I doubt this will improve the early diagnosis of sarcomas. It will also remove a mechanism for treating benign masses which will again tend to be distributed over the generality of surgeons rather than in the hands of individuals with an interest in the subject. I think the number limit is short sighted and may be harmful some instances. Poor practise arises where individuals dabble with 1 or 2 sarcomas per year outside and MDT. This certainly should be discontinued but not at the expense of smaller sarcoma teams that provide a local service	We accept that there may be some units, treating only a few sarcomas per year, that are likely to have to discontinue the service they offer. We believe, however, that the benefit of having patients managed by a properly constituted sarcoma MDT with all the support services available and with in-depth knowledge of the whole spectrum of bone and soft tissue sarcomas will be advantageous to the patients. We have not been able to identify evidence that a surgeon doing 100 cases per year does better than a surgeon doing 25 per year, but we feel there is evidence that patients managed by a properly constituted MDT are more likely to be managed appropriately, and better outcomes achieved, than patients managed outside of such an MDT. The aim of the 'local' diagnostic clinics is to provide a local service for rapid diagnosis of suspicious lumps. There may be scope for these diagnostic clinics to be run by groups that are currently treating sarcomas. Their expertise will be welcomed. Dealing with the benign lumps is outside the scope of this guidance.
South West Cancer Intelligence Service	General	Overall this guidance will be very helpful to commissioners although some clarification where the primary responsibility of GIST tumour management should be; either the sarcoma MDT with specialist oncology, or Upper GI MDT with less sarcoma specialisation.	We have amended para 351 to clarify that the primary responsibility for GIST tumour management should be with the upper GI MDT. In some networks the subsequent oncological management of GIST patients would be with a sarcoma MDT while in other networks

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			it would be with the upper GI MDT.
South West Cancer Intelligence Service	General	The document lacks clarification with regard to important role of cancer genetic services and sarcoma patients and families.	We have added a recommendation on cancer genetic services to the chapter on follow-up.
South West Cancer Intelligence Service	General	There is no point in establishing a sarcoma MDT independent of children and young adult cancer and surgical centres. Integration with young adult cancer practices is essential in view of the age spectrum of this disease and low numbers of patients. The requirement for 50 bone tumours and 100 STS in each MDT per year, means a minimum of 8 bone centres, and 10 soft tissue centres simply based on the incidence figures. Clarification of the suggested centres would be essential in order to dispel ambiguity and irrelevant argument.	Issues of chemotherapy and support services for children and young people have already been covered by the NICE guidance on 'Improving outcomes for children and young people with cancer'. To avoid duplication with this document, we have inserted a cross reference to the children's guidance. However, we have noted your point about provision of surgical services for children with sarcomas and made appropriate amendments. While noting your comments about the number of sarcoma treatment centres, it is not within the remit of this guidance to define where the suggested centres should be.
South West Cancer Intelligence Service	Paragraph 12	A significant number of sarcomas can be identified using the ICD10 codes: C47: also connective, subcutaneous and other soft tissues, peripheral nerves. C48: retroperitoneum and C38 1&2: mediastinum. It does not appear that these codes have been used in the document's present calculation of cases.	We have covered this in paras 30–31.
South West Cancer Intelligence Service	Paragraph 131	Considering the heterogeneous group of tumours open to misinterpretation as benign lumps and the rarity of the disease and therefore the inexperience of GPs in diagnosing the disease, one must keep in mind the likelihood that cases will not necessarily all be referred as urgent as it has been shown with other rare cancers. It will take time before all possible cases of STS are referred correctly to the proposed "diagnostic" clinics. Alternative plan might have to be put in place in order to retain some expertise at individual Trust level to diagnose the missed patients.	The aim of our guidance, along with the recent NICE 'Referral guidelines for suspected cancer', is to highlight the correct patient pathway for patients with a possible sarcoma. We hope that this will apply not just to GPs but also to hospital practitioners who will see a patient with a lump and, rather than investigating themselves, will refer to a diagnostic clinic. It will be up to networks to publicise the location and timing of these diagnostic clinics.
South West Cancer Intelligence Service	Paragraph 152	Our audit, undertaken in the South West, looking at a cohort of patients diagnosed in 2000 shows the following median waiting times in weeks o GP referral to first hospital appointment: 2.8 o GP referral to first treatment: 9.4	Thank you for this information. We will review it.
South West Cancer	Paragraph	It is not longer optional to avoid the use of molecular pathology in this	We agree that the use of molecular pathology is

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Intelligence Service	183	group of patients. It would be a fundamental error not to insist that there is molecular pathology infrastructure in every one of the approximately 10 centres of pathological expertise. Storage of fresh frozen material should be mandatory, as well as cytogenetics and a molecular diagnostics lab for gene mutations, translocations and gene expression	becoming increasingly important in this group of patients. It is not, however, essential in every single patient, and a network of molecular pathology laboratories is probably more sensible at the present time than insisting that each sarcoma centre should have its own molecular pathology expertise in house. We believe that a needs assessment should be carried out to establish whether these facilities are required in every recognised centre or whether concentration of services at a limited number of centres is more appropriate. We have identified in para 199 that commissioners should fund molecular pathology/cytogenetic facilites. We agree, however, that storage of fresh frozen material should become routine in all these laboratories subject to the provision of the Human Tissue Act 2004 and have amended para 200 accordingly.
South West Cancer Intelligence Service	Paragraph 184	The standard practice for GIST will be mutations testing of the c-kit receptor. This will inform therapeutic choices (exon 9 versus exon 11 mutations). It is no longer acceptable to use Cd117 staining alone, when there are very costly implications for the appropriate use of imatinib therapy	We accept that the diagnosis of GIST is constantly being refined. We have therefore omitted specific comment about immunohistochemical markers but have highlighted that immunohistochemistry and cytogenetic analysis is appropriate for these rare tumours
South West Cancer Intelligence Service	Paragraph 185	There should be a department of health supported Sarcoma Pathology fellowships (one per year) post CCST/FRC path. These should be for two years and assigned to a major training centre to ensure adequate provision of childhood and adult sarcoma expertise in the UK.	We agree that sarcoma pathology fellowships would be beneficial. We have included a recommendation that they should fund sarcoma pathology fellowships (para 200a). This is also covered in para 485.
South West Cancer Intelligence Service	Paragraph 197	With 26 pathologists in the UK, and two per centre, this means 13 centres. Please clarify, as the essential focus is pathological support?	We accept that ideally there should be two SSPs per MDT, but in practice there are still a limited number of pathologists interested in sarcomas and that is why we have made the recommendation in para 197. It will be up to commissioners to ensure that pathological services at sarcoma centres are safe and that isolated sarcoma pathologists have a formal collaboration with at least one colleague to cover leave and to help with

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			difficult cases.
South West Cancer Intelligence Service	Paragraph 204	Any notion that tissue banking of soft tissue sarcoma in specialised centres is optional should be immediately and unequivocally refuted in the NICE statement. There will be no long term benefit to patients without active research and therapeutic development based on this resource.	We have altered para 200 to confirm that centres should store tissue.
South West Cancer Intelligence Service	Paragraph 211	For both bone and soft tissue sarcoma, molecular and cytogenetic diagnostics are essential.	This has been dealt with in the recommendations section (para 196)
South West Cancer Intelligence Service	Paragraphs 221–225	It may be worth questioning the inefficiency factor which probably increases the larger the MDT. Although concentration of expertise is desirable, coverage of a large number of cases by a centralised MDT will inevitably mean 1) scarce experts using scarce time travelling 2) a high proportion of attendees having no direct input, knowledge or responsibility for a particular case. This may be counterproductive, making it difficult for the group to focus on certain aspects of the case not necessarily well represented (eg co-morbidity)in a 'thumbnail sketch' The ideal size for an MDT is not well worked out for rare cancers. For common tumours such as breast, 100 -200 annual cases are easily reached by the local team so that an MDT is held locally and a high proportion of attendees are involved directly in each case. Further, coverage of a high number of breast cases is relatively easy because many cases are straightforward and little discussion is required. This is not the case for sarcoma, where many aspects of treatment are controversial. My fear is that we will have for sarcoma an unwieldy MDT with excellent diagnostic input but insufficient time to cover clinical management issues properly. This group will be expected to make treatment recommendations which will either require the patient to travel long distances (sometimes needlessly) or will be 'handed down' to the local team who will have become de-skilled by the centralisation process. The local team will not then be well-placed to question the central recommendation which may in fact have been made somewhat 'on the hoof' in a busy meeting	The aim of the sarcoma MDT is that the specialists will all be working in or close by that particular centre. The centre will have sufficient cases to justify the existence of an MDT and thus there will be sufficient number of cases to be discussed at the regular MDT meetings to ensure that the experts are, first, aware of the patients who are under their care and, second, have sufficient work and input to justify their attendance at that MDT. If a clinician is not involved in the care of patients it is unlikely they would be seeing sufficient number of patients to justify being a member of that MDT in any case. We note your concerns about the size of an MDT, but the whole aim of this guidance is to ensure that members of the team are actively involved in the care of the patients at a sarcoma treatment centre. We note your comments about the breast MDT seeing 100–200 cases per year, and this is similar to the number that we have suggested for a sarcoma MDT. For a team seeing this many sarcomas, treatment protocols will become refined and thus decisions will become relatively straightforward. The guidance makes clear that treatment should not be 'handed down' to the local team, apart from by certain centres that are affiliated to and approved by the sarcoma MDT. These clinicians will be part of the

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		with little insight into the individual being discussed. This is less of a problem for some younger patients for whom radical curative treatment is the clear aim. It becomes a bigger problem for older patients, patients at relapse and for diseases where cure is relatively unlikely. Even in breast cancer (sometimes held up a role-model) the management of recurrent disease is too complex and 'individual' to cover properly by most MDTs.	extended sarcoma MDT.*[*
South West Cancer Intelligence Service	Paragraph 232	Should not urological sarcoma be included in this list?	This list is not exhaustive and urological sarcomas are so rare that we have not included them.
South West Cancer Intelligence Service	Paragraph 233	Additional membership should include molecular diagnostic and cytogenetic staff and a plastic surgeon with specialist interest in sarcoma	A plastic surgeon is included as a member of the extended sarcoma MDT (see table 6). We do not think molecular diagnostic and cytogenetic staff are likely to be essential members of either the core or extended sarcoma MDT.
South West Cancer Intelligence Service	Paragraph 349	I consider that calls for yet more centralisation of therapy for metastatic GIST is inappropriate. The response of GIST to imatinib is exciting and interesting, and the potential for further research studies is clear. However this does not make metastatic GIST a particularly difficult disease to manage. Imatinib is a well tolerated tablet; it would be plainly silly to have elderly GIST patients travelling 100 miles to have a repeat CT scan and pick up their next months supply of tablets. The importance is in the diagnosis - MDTs must be competent to diagnose GIST and this can be audited quite easily	We have amended para 351 to clarify that the primary responsibility for GIST tumour management should be with the upper GI MDT. In some networks the subsequent oncological management of GIST patients would be with a sarcoma MDT, while in other networks it would be with the upper GI MDT.
South West London Strategic Health Authority		This organisation was approached but did not respond.	
Sussex Cancer Network	Ch 4 esp 188	National initiative will be need to develop specialist pathologist capacity	We agree. The Royal College of Pathologists is already addressing this.
Sussex Cancer Network	Ch 7	Plastic surgery input needed for patients with skin sarcomas	A plastic surgeon is included as a member of the extended sarcoma MDT (see Table 6) and will thus be available for dealing with not only skin sarcomas but also complex reconstruction issues.
Sussex Cancer	Ch 9	Orthopaedic follow-up will be required for patients with prosthetic	The need for long-term follow-up for these patients is

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Network		devices.	covered in para 453 and a recommendation is made in para 454.
Sussex Cancer Network	7	A designated key worker- presumably a CNS in most cases- is welcome. However in view of distance patient is likely to live from specialist centre and MDT a local contact would also be a good idea.- see 393 for instance of need.	Thank you. As you have identified, it will be the role of the key worker in conjunction with the therapist to liaise about local services.
Sussex Cancer Network	12	…designated *and coordinated* centres….	We believe that any centre recommended by NSCAG will have to be coordinated with other centres recommended by NSCAG.
Sussex Cancer Network	20	Where existing referral routes to specialist centres are working well they need to be maintained and strengthened.	Where clear routes of referral exist we would not want to interfere with them, and it may well be that these routes of referral become transformed into diagnostic clinics. They could, however, become part of the managed sarcoma network.
Sussex Cancer Network	88 and 83	These could be contradictory. Younger patients or their parents may want to know a great deal of information, whilst some elderly patients may not want their diagnosis in writing.	We do not discriminate in any guidance by age, and the overriding issue is to ensure that patients receive as much information as they want and can handle at an appropriate time.
Sussex Cancer Network	123, 128,130	There is a huge amount of education required for both GPs and the public. Sarcoma so rare GP likely only to see on in whole career, so maintaining public awareness is impossible. Better to include 'beware of new and unusual lumps' in health promotion messages.	The new diagnostic clinics should, in collaboration with the sarcoma MDTs, work towards methods of increasing awareness in their local population of suspicious lumps and bumps. This has been addressed to a certain extent by the recently published NICE 'Referral guidelines for suspected cancer'.
Sussex Cancer Network	125	These need to go faster than 2WW timescale if identified as possible sarcoma- red flag system?	Nothing in this guidance precludes direct referral to a sarcoma treatment centre of patients who appear to have an obvious sarcoma. If the system works, however, there will be increasing speed of referral of patients with sarcomas and fewer patients will have classic red flag signs because they will be detected earlier.
Sussex Cancer Network	130	Draft is generally weak on advice regarding structure of referral pathways, probably because guideline team were as stumped for solutions as everyone else.	We feel that we have been clear in making recommendations about diagnostic referral pathways but accept that there is virtually no evidence at the present time about the optimum configuration of

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			these. Hopefully, improved pathways will be developed following implementation of this guidance.
Sussex Cancer Network	131	Don't like the either/or. All patients with possible sarcoma, at whenever stage this is identified, should go straight to the specialist centre, even if it means a journey.	We have discussed the issue of diagnostic clinics at length within the GDG and feel that the options that have been suggested are entirely appropriate and give scope for local solutions
Sussex Cancer Network	134	What is difference between 'possible' and 'suspected'? Not clear	A suspected sarcoma is one that meets the criteria in the NICE 'Referral guidelines for suspected cancer'. A possible sarcoma is any lump that could possibly be a sarcoma.
Sussex Cancer Network	141	Secondary malignancies need a faster track than probable benign lesions given orthopaedic waiting lists	We agree with this, but it is outside the scope of this guidance.
Sussex Cancer Network	142	Funding for second opinions of both X-rays and biopsies must be identified locally, so there is no delay in this process, and there needs to be a system for rapid access to second opinions from specialist centres- preferably digitally	It is likely that suspicious bone X-rays will be referred to a bone sarcoma treatment centre, which by definition is currently funded by NSCAG. NSCAG is likely to include funding for this service. We accept that digital transfer of images is becoming increasingly frequent and centres need to be able to deal with this. Funding of pathological second opinions is a complex matter and we have suggested in para 199 that commissioners should fund this.
Sussex Cancer Network	222 and 228	Specialist MDT populations are much too small given rarity of these tumours- 5 million for soft tissue and 10 million for bone, to give max of 8 bone teams and 10-11 STS teams in E&W.	Thank you for your comments. We feel happy with the population size we have suggested, accepting that some units will treat more than the number. We would not recommend that they should treat any fewer than the numbers we have recommended.
Sussex Cancer Network	304	Videoconferencing will be essential if local oncologist is to be involved in specialist MDT for certain patients.	Videoconferencing facilities may have a role in communicating with members of the extended sarcoma MDT but it will be up to individual MDTs to make arrangements for this if required.
Sussex Cancer Network	306	The second 'or' should be 'and', as all networks will need ability for palliative treatments from time to time.	We feel that the text is appropriate as is.
Sussex Cancer Network	344	Number of H&N MDTs will decline when H&N IOG is implemented- this is one reason why that should proceed ASAP	Thank you.
Sussex Cancer	350/1	Videoconferencing will be essential	Videoconferencing facilities may have a role in

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Network			communicating with members of the extended sarcoma MDT but it will be up to individual MDTs to make arrangements for this if required.
Sussex Cancer Network	455	What imaging? Too vague: ? role of MRI and PETCT?	This has been left deliberately vague because the optimum follow-up investigations and frequency has not yet been clarified.
Sussex Cancer Network	473	Register is imperative- this is too weak. Central funding necessary.	Please see para 478.
Tameside and Glossop Acute Services NHS Trust		This organisation was approached but did not respond.	
Teenage Cancer Trust, The		This organisation was approached but did not respond.	
Thames Valley Strategic Health Authority		This organisation was approached but did not respond.	
The Neurofibromatosis Association		This organisation was approached but did not respond.	
The Royal Society of Medicine		This organisation was approached but did not respond.	
The Royal West Sussex Trust		This organisation was approached but did not respond.	
UKCCSG	General	Overall the document is well written and particularly clear for patients with bone tumours. Our understanding is that the guidance is applicable to both adults and children, clarification is therefore required in many sections to understand the differences in service provided for children and the rationale behind that. There is an assumption through the document of the typical presentation of sarcomas in adults. This is different to the majority of sarcomas that occur in children (i.e. rhabdomyosarcomas) and this should be acknowledged.	Thank you for your comments. We have changed para 3 to clarify who is covered by this guidance. In recognition of the fact that shared care is sometimes needed for soft tissue sarcomas in children, we have added a section on this to chapter 7 confirming that on these occasions surgery should be carried out in age-appropriate facilities by site-specific surgeons. We are grateful to you for clarification of the other items in your comments, and we have made appropriate changes.

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UKCCSG	3	This key recommendation does not apply to children. For example we would consider that it would be inappropriate for a child with a rhabdomyosarcoma eg orbit or bladder prostate to be discussed in the Sarcoma MDT.	We appreciate fully that childhood soft tissue sarcoma, particularly rhabdomyosarcomas, are dealt with almost exclusively by paediatric oncologists in conjunction with paediatric surgeons adhering to very strict protocols. We have clarified the fact (as previously outlined in the scope documentation) that our guidance does not cover children and young adults with these types of tumours, and we have added cross references to the NICE guidance on 'Improving outcomes for children and young people with cancer' throughout this guidance.
UKCCSG	5	Is it necessary for all paediatric patients to have their diagnosis reviewed by specialist sarcoma pathologists or radiologist? There are specialists in diagnosis of paediatric sarcomas who are different to those working in the adult field (*XXX to expand this comment)*.	We believe that all patients with a bone sarcoma, no matter what age, should have that diagnosis reviewed by a sarcoma specialist pathologist as defined in para 5 of the key recommendations and explained in greater detail at para 188.
UKCCSG	8	It is not necessarily appropriate that the definitive resection of the sarcoma should be a member of a Sarcoma MDT. Many paediatric surgeons will be a member of a Paediatric MDT rather than a Sarcoma MDT.	We have amended the text to clarify this.
UKCCSG	20	In the background section, there was a lack of description of paediatric practice. Some acknowledgement of this would be appropriate if this document is intended to cover the treatment of sarcomas in children.	We have added text to the introduction to cover this.
UKCCSG	28	There is no reference to the paediatric coding (Birch classification) within this section.	Cancer registry data were only coded using ICD10 for both children and adults. Birch coding was therefore not used for the epidemiological analysis. We have inserted a footnote in the Manual to clarify this.
UKCCSG	84	It is not true that many sarcoma trials in children are in the palliative context. The majority are developed with curative intent.	We note your comments about chemotherapy trials and we have changed the wording so that it makes no mention of palliative.
UKCCSG	221–226	There is no mention of the Paediatric MDT at which the majority of patients with sarcomas (rhabdomyosarcoma) would be considered. We suggest the following wording. "Sarcomas occurring in children and young people should be discussed at a Paediatric MDT where	We appreciated that soft tissue sarcomas in children are managed extremely well by the present system and we would not wish to interfere with that. We do, however, make recommendations about shared

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		consideration will be given to taking advice from a Sarcoma MDT or other site specific MDT as appropriate".	working, particularly with the non-rhabdomyosarcoma adult-type soft tissue sarcomas that arise in children and that may require surgical skills available in sarcoma centres.
UKCCSG	227	See paragraph 3. This is not appropriate for all paediatric sarcomas.	We have clarified the fact (as previously outlined in the scope documentation) that our guidance does not cover children and young adults with these types of tumours.
UKCCSG	230	Should this be job plan rather than job description?	We agree and have made this amendment.
UKCCSG	247	There are 17 UKCCSG Paediatric Oncology Centres in England and Wales.	This paragraph reports the results of a cohort study that quoted the number of UKCCSG centres as 20. To avoid confusion, we have deleted this number.
UKCCSG	274	The wording Teenage Cancer Trust Unit should be replaced by the wording used in the Child and Adolescent Cancer Guidance.	We do not think a change is needed. The terminology is correct.
UKCCSG	293	Is the higher amputation rate in patients treated with curative intent a good or bad outcome?	Amputation rate is largely a reflection of the extent of disease at time of diagnosis, and thus may be a reflection on delays in diagnosis. In general, therefore, a high amputation rate is a bad outcome as it implies that the tumours presenting are large and often present late. Some centres may electively do a greater proportion of amputations, but this has not been shown to lead to better outcomes.
UKCCSG	297	Mention should be made here of paediatric rhabdomyosarcomas.	We do not think this is necessary in a very general introductory paragraph.
UKCCSG	302–304	Again a recognition of the Paediatric MDT structure should be made.	The text has been amended.
UKCCSG	342	Small point - The title Soft Tissue Sarcomas Requiring Joint Management, is a little misleading as it implies limb sarcomas!	The title has been amended to 'Soft tissue sarcomas requiring shared management
UKCCSG	350	Would it be possible to add the words 'or paediatric' after site specific before MDT in this paragraph	The text has been amended.
University College London's Hospital NHS Trust			
University Hospital Birmingham NHS Trust			
Welsh Assembly	General	Thank you for giving the Welsh Assembly Government the opportunity	Thank you.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
Government		to comment on the guideline. We are content with the technical detail of the evidence supporting the provisional recommendations and have no further comments to make at this stage.	
Wessex Cancer Trust		This organisation was approached but did not respond.	
West Lincolnshire PCT		This organisation was approached but did not respond.	
West Midlands Specialised Services Agency	Paragraph 6 (Key Recommendation)	**Service configuration** The recommendation should be strengthened with the view to: • Ensuring that rarer cancers (e.g.GIST) within this group are referred to national centres. • Avoiding duplication of infrastructure. It is clear from the description of the epidemiology of these conditions that there is a group of sarcomas which make up the majority (about 68%). These are cancers of the bone and extremities. This group will share a need for a common resource (surgeons, rehabilitation etc…) The remainder of cancers are a heterogenous group each of which will require a different group of specialists to be involved and possible different rehabilitation needs. It appears neither practical nor cost effective to duplicate this expertise at a number of centres. Although the consultation document refers to the need for super-specialist MDTs and the possible role of NSCAG they are not picked up in the headline recommendations and as such the recommendations are open to interpretation risking duplication of infrastructure. It should be possible to determine, from the epidemiology how many teams are needed to manage sarcomas at the less common sites (pelvic and abdomen, CNS, skin etc). It is likely that nationally only one or two centres might be needed for each site. In the interests of planning it would seem sensible that the authors of this report undertake the above exercise and specify, in their recommendations, how many centres are needed for each of the rarer	Thank you for your comments. The GDG did consider how far we could plan for the rarer soft tissue sarcomas. We decided on priority of establishment of the treatment centres as in the guidance, with an expectation that future cooperation between the centres would result in the super-specialisation you suggest. Your point about national planning is also well made and can be applied to the entire guidance.

Stakeholder Organisation	**Section number Or general**	**Comments**	**Developer's response**
		groups. It would also seem sensible to task NSCAG with identifying those centres at the outset rather than have every region go through the exercise. National planning is undoubtedly required. It might also be more cost effective to have fewer centres for the more common group of sarcomas but have each centre develop the capacity to treat both bone and soft tissue sarcomas of the extremities (namely 150 patients per year). A rapid calculation would indicate only about 11 centres might be needed + national centres for the rarer sarcomas (which could link in with these). To suggest about 22 centres for STS with the capacity to treat all types of STS + 7 centres for bone (presumably combined with the STS centres) + development of teams within these which specialise in rarer cancers seems excessive.	