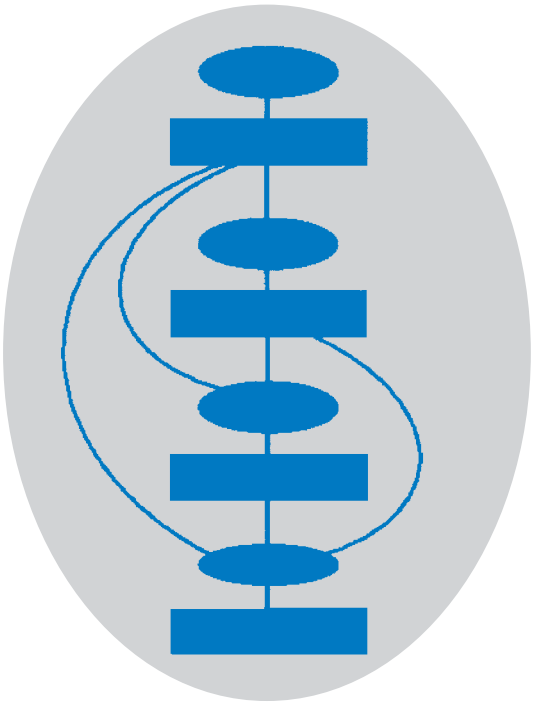
NHS

National Institute for Health and Clinical Excellence

Guidance on Cancer Services

Improving Outcomes for People with Sarcoma

List of All Recommendations



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Developed for NICE by the National Collaborating Centre for Cancer

Guidance on Cancer Services

Improving Outcomes for People with Sarcoma

List of all Recommendations

Contents[1]

[1] The chapter numbers in this contents list refer to chapters in the manual 'Improving Outcomes for People with Sarcoma', available from the NICE website (www.nice.org.uk/csgsarcoma).

Key Recommendations

- All patients with a confirmed diagnosis of bone or soft tissue sarcoma (except children with certain soft tissue sarcomas) should have their care supervised by or in conjunction with a sarcoma multidisciplinary team (MDT).

- Cancer networks should arrange diagnostic services for the investigation of patients with suspected soft tissue sarcomas (as defined by the National Institute for Health and Clinical Excellence (NICE) 'Referral guidelines for suspected cancer') at designated diagnostic clinics. All patients with a probable bone sarcoma (usually following X-ray examination) should be referred directly to a bone tumour treatment centre (see Chapter 6) for diagnosis and management.

- All patients with a provisional histological and/or radiological diagnosis of bone or soft tissue sarcoma should have their diagnosis reviewed by a specialist sarcoma pathologist and/or radiologist who are part of a sarcoma MDT. Commissioners should fund a formal system for second opinions and review of difficult cases, and molecular pathology and cytogenetic facilities.

- A soft tissue sarcoma MDT should meet minimum criteria (as defined in Chapter 5) and manage the care of at least 100 new patients with soft tissue sarcoma per year. If a sarcoma MDT manages the care of patients with both bone and soft tissue sarcoma, it needs to manage the care of at least 50 new patients with bone sarcoma per year and at least 100 new patients with soft tissue sarcoma per year.

- All patients who are managed by a sarcoma MDT should be allocated a key worker (see Chapter 8).
- Patients should undergo definitive resection of their sarcoma by a surgeon who is a member of a sarcoma MDT or by a surgeon with tumour site-specific or age-appropriate skills, in consultation with the sarcoma MDT.
- 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 sarcoma MDT.
- Patients should be informed about relevant clinical trials and supported to enter them.
- All sarcoma MDTs should participate in national audit, data collection and training.
- Patients with functional disabilities as a consequence of their sarcoma should have timely access to appropriate support and rehabilitation services.
- The National Specialist Commissioning Advisory Group should consider commissioning designated centres for the management of retroperitoneal and pelvic soft tissue sarcomas.
- This guidance should be implemented by primary care trusts (PCTs)/local health boards (LHBs) working collaboratively through their specialist commissioning groups, in close consultation with cancer networks. A National Implementation Group should be considered for both England and Wales.

Chapter 2 - Patient perspectives

Diagnosis

- A diagnosis or other significant news should be communicated by a senior doctor or specialist nurse who has enhanced skills (as defined in Chapters 3 and 4 of the NICE guidance on 'Improving supportive and palliative care for adults with cancer'[2]). Communication should be face to face unless there is specific agreement with the patient about receiving confirmation of a preliminary diagnosis by telephone or in writing.

- All patients with a suspected or confirmed diagnosis of sarcoma should be allocated a key worker (see Chapters 5 and 8).

- Patients should be offered a permanent written and/or audio record of their diagnosis and of any important points relating to the consultation. Their key worker and their contact points should be identified in writing and this information should also be supplied to their GP.

Information

- Commissioners and provider organisations should ensure that at every diagnostic clinic/sarcoma treatment centre information is available that:
  - is specific to that centre
  - describes the tests/treatments it provides
  - describes the individual patient's diagnosis or disease stage

[2] National Institute for Clinical Excellence (2004) Improving supportive and palliative care for adults with cancer. *NICE cancer service guidance*. Available from: www.nice.org.uk/ page.aspx?o=110005

- is age-appropriate (see the NICE guidance on 'Improving outcomes in children and young people with cancer'[3]).

- Information should be provided in a variety of formats (for example, print/audio) and supported by information about access to online resources. Information should be written in language to which patients can directly relate. They should have as much information as they want, in a format that they can understand.

- All information should be developed and reviewed with the involvement of patients with sarcoma.

- Table 4 maps the scope of the information which should be made available to patients at each stage in the disease and treatment pathway, and indicates which organisation(s) should be responsible for ensuring the patient has access to that information.

[3] National Institute for Health and Clinical Excellence (2005) Improving outcomes in children and young people with cancer. *NICE cancer service guidance.* Available from: www.nice.org.uk/CSGCYP

Table 4 The information pathway

Time	Nature of information	Responsibility
On referral to diagnostic clinic	Information on diagnostic clinic, tests it undertakes and who will be involved with the patient	Diagnostic clinic (see Chapter 3) by post
If sarcoma is suspected and the term is specifically used with the patient	Generic information on sarcoma	Diagnostic clinic
On diagnosis	Generic information on sarcoma. Specific information on the diagnosis (histological type, grade etc.) and the proposed treatment (if known)	Diagnostic clinic face-to-face or by telephone/post if requested by patient
Confirming referral to sarcoma treatment centre	Information on sarcoma treatment centre, names of consultants/nurses who will be involved in treatment and the named key worker for the patient	Sarcoma treatment centre (see Chapter 5) by post
	Specific information on the diagnosis and the proposed treatment (if known and if not given by diagnostic clinic)	Local arrangements can apply
On any treatment recommendation	Generic information on that treatment (surgery, radiotherapy, chemotherapy) and any tests or imaging procedures that may accompany it. (Local or nationally published booklets may be appropriate)	Sarcoma treatment centre by post or face-to-face as appropriate
On referral to another sarcoma treatment centre	Reasons for the referral	Referring sarcoma treatment centre face-to-face or by post
	Information on the new sarcoma treatment centre. Identification of key worker	New sarcoma treatment centre by post

Time	Nature of information	Responsibility
After surgery or other treatment	Specific information on individual follow-up procedure, self-monitoring information, healthcare support and sarcoma-specific support	Sarcoma treatment centre by post or face-to-face as appropriate
	Confirmation of the named key worker for that patient together with contact details	
	Specific information on support for prosthetic limbs or endoprosthetic implants	
	Details about relevant rehabilitation services including provision of mobility aids, home adaptations and referral to local rehabilitation services	
	Details of generic local and national support groups and other support resources	Sarcoma treatment centre or patient support centre, face-to-face or by post
If targeted therapy is proposed (e.g. imatinib for GIST)	Generic information on the therapy and the applicable condition. Specific information relevant to the patient's own condition	Sarcoma treatment centre face-to-face, with copies by post to GP
In the event of advanced disease (whether at diagnosis or later)	Specific information on the nature of the advanced condition. Generic information will also be appropriate when metastatic disease is diagnosed	Sarcoma treatment centre face-to-face
When a clinical trial is proposed	Generic information on clinical trials. Specific information on the proposed trial	Sarcoma treatment centre face-to-face. Further information may come from trials unit by post

Time	Nature of information	Responsibility
When no treatment other than palliative is available	Generic information on palliative care and pain control	Sarcoma treatment centre/palliative care centre face-to-face and GP

- Generic information may include publications from national cancer charities and other voluntary sector providers, and this should be provided by the diagnostic clinic/sarcoma treatment centre.

- When an existing clinical trial is not being conducted at the patient's own treatment centre, participation in that trial should be offered to the patient at another treatment centre.

- Details of clinical trials for sarcoma should be available at every sarcoma treatment centre (see the recommendations on research in Chapter 10 'Improving knowledge').

Support

- Patients and their carers should be offered appropriate support as follows:
  - psychological support
  - spiritual support
  - social support through contact with others facing similar situations – self-help groups
  - practical healthcare support relating to treatment
  - benefits advice.

- The development of sarcoma-specific self-help groups should be encouraged.

- Patients should be supported in providing feedback to the sarcoma multidisciplinary team (MDT) to aid understanding of their service and patient needs, and to institute any changes.

General

- Sarcoma treatment centres should collaborate so that duplication of resources to develop patient information leaflets/packs, Internet sites, information for GPs, etc. is minimised.

- In the event of a delay or alteration in diagnosis that affects the management of a patient's condition, a 'significant event analysis' should be undertaken and the lessons learnt from this should be fed back to both relevant clinicians and MDTs. The patient should be informed by a senior doctor with appropriate skills (as defined in Chapters 3 and 4 of the NICE guidance on 'Improving supportive and palliative care for adults with cancer'[4]).

[4] National Institute for Clinical Excellence (2004) Improving supportive and palliative care for adults with cancer. *NICE cancer service guidance.* Available from: www.nice.org.uk/ page.aspx?o=110005

Chapter 3 - Improving diagnosis of bone and extremity soft tissue sarcoma

Referral guidelines

- Commissioners should consider methods of increasing public awareness of the signs and symptoms of worrying lumps and the consequent need to attend a GP.

- Commissioners should ensure that GPs are aware of and comply with the urgent referral criteria in the NICE 'Referral guidelines for suspected cancer'.[5]

- Networks should ensure that GPs and hospital doctors are aware of the diagnostic pathways for patients with signs and symptoms suggestive of bone or soft tissue sarcoma.

Referral pathways: patients with extremity, trunk, and head and neck soft tissue sarcomas

- To improve the early diagnosis of soft tissue sarcomas, a clearly defined network of diagnostic clinics linked to sarcoma treatment centres (see Chapter 5) should be established. Two models are recommended to achieve this:

  either

  1. patients with a suspected diagnosis of soft tissue sarcoma (as defined by the urgent referral criteria) would be seen within 2 weeks at a diagnostic clinic that is part of a sarcoma treatment centre

  or:

[5] National Institute for Health and Clinical Excellence (2005) Referral guidelines for suspected cancer. *NICE clinical guideline no. 27.* Available from: www.nice.org.uk/027

2. patients with a suspected diagnosis of soft tissue sarcoma (as defined by the urgent referral criteria) would be seen within 2 weeks at a diagnostic clinic specifically designated by their local cancer network. This would be a purely diagnostic, rather than a treatment clinic, and would be clearly affiliated to one sarcoma MDT (see Chapter 5).

- Anyone with a possible sarcoma should be referred to a diagnostic clinic for biopsy. Biopsy should not be done outside these clinics.

- Each cancer network should designate a diagnostic clinic for their patients who meet the urgent referral criteria. This would either be part of a sarcoma treatment centre or established locally, as described above.

- The diagnostic clinics (in either model) should undertake triple assessment including clinical assessment, imaging and biopsy of all patients. There would be no requirement for a surgeon or oncologist to be part of such a team, but the members of the diagnostic team should be trained by and work in close collaboration with members of the affiliated sarcoma MDT. Patients identified as having a soft tissue sarcoma should be rapidly referred on to a sarcoma MDT for definitive treatment, as would any cases with equivocal images or biopsy.

- A diagnostic clinic separate from a sarcoma treatment centre should have its staff trained and its work audited by the sarcoma MDT from the sarcoma treatment centre to which it is affiliated.

- Appropriate imaging facilities should be available to comply with national access standards (as defined in the 'NHS Cancer Plan'[6] and the 'Wales National Cancer Standards'[7]).

- Some patients with a soft tissue sarcoma will be diagnosed following excision of a lump thought to be benign but which turns out to be malignant. These patients should be referred directly to the sarcoma MDT designated by that cancer network.

- Patients whose lump turns out to be benign should be referred locally for appropriate management.

- Commissioners and networks should work together to ensure that there are clear referral pathways from both primary and secondary care through to a designated diagnostic clinic and for patients with proven sarcomas on to the affiliated sarcoma treatment centre.

- An audit of all elements of the referral pathway should be carried out.

Referral pathways: bone sarcomas

- All patients with a probable bone sarcoma (usually following X-ray examination) should be referred directly to a bone tumour treatment centre (see Chapter 6) for diagnosis and management.

- Appropriate imaging facilities should be available to comply with national access standards (as defined in the 'NHS Cancer Plan'[8] and the 'Wales National Cancer Standards'[9]).

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[6] Department of Health (2002) *The NHS Cancer Plan*. Available from: www.dh.gov.uk (accessed 3 January 2006)

[7] Welsh Assembly Government (2005) *Wales National Cancer Standards*. Available from: www.wales.gov.uk/subihealth/content/cancer/national-standards-e.htm

- The biopsy of patients with a possible bone sarcoma should only be carried out at a bone tumour treatment centre.

- Patients with X-ray abnormalities that are most likely to be due to a secondary malignancy or a benign process should be referred to the local orthopaedic service for further investigation. Networks should consider formalising service provision for this latter group.

- An audit of all elements of the referral pathway should be carried out.

- Some patients with a bone sarcoma will be diagnosed following surgery. These patients should be referred directly to the sarcoma MDT designated by that cancer network.

Radiology review

- If a plain X-ray shows abnormalities that could be a bone sarcoma, there should be clear arrangements for review of these images by specialist sarcoma radiologists at a sarcoma MDT. This service should be recognised and funded appropriately.

Histopathology review

- All patients with a possible diagnosis of bone or soft tissue sarcoma should have the diagnosis confirmed by a specialist sarcoma pathologist (see Chapter 4).

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[8] Department of Health (2002) *The NHS Cancer Plan*. Available from: www.dh.gov.uk (accessed 3 January 2006)

[9] Welsh Assembly Government (2005) *Wales National Cancer Standards*. Available from: www.wales.gov.uk/subihealth/content/cancer/national-standards-e.htm

Chapter 4 - Improving Pathology

- All primary malignant bone tumours should either be first reported or reviewed by an SSP-bone. An SSP-bone is a pathologist who regularly reports bone tumours and these form a significant component of their workload. He or she should successfully participate in the bone part of the bone and soft tissue pathology EQA scheme, and be part of a properly constituted sarcoma MDT.

- All soft tissue sarcomas should either be first reported or reviewed by an SSP-soft tissue. An SSP-soft tissue is a pathologist who regularly reports soft tissue tumours and these form a significant component of their workload. He or she should participate in the soft tissue part of the bone and soft tissue pathology EQA scheme and be part of a properly constituted sarcoma MDT.

- All GISTs should be reported or reviewed by an SSP with experience in GIST who successfully participates in the bone and soft tissue pathology EQA scheme, or a tertiary GI specialist who successfully participates in the GI pathology EQA scheme.

- All patients with soft tissue tumours assessed in a diagnostic clinic (see Chapter 3) should have their pathology reported by:
  either
  - an SSP-soft tissue

  or
  - a pathologist nominated by the sarcoma MDT as part of the local diagnostic referral pathway who has formal links to an SSP.

- All malignant soft tissue tumours should be reviewed by an SSP-soft tissue prior to management recommendations by the sarcoma multidisciplinary team (MDT).

- Pathology reports should include all the information required by the Royal College of Pathologists' histopathology dataset for soft tissue sarcomas once it is available. They should use a defined tumour classification (for example, the World Health Organization (WHO) classification 2002) and grading (for example, the Trojani grading system).

- The Royal College of Pathologists should be asked to expedite production of a histopathology dataset for bone and soft tissue sarcoma, and should be invited to give guidance on situations where molecular diagnosis is of value.

- There should be at least conditional CPA approval for the laboratory in which the SSP and those with a specialist interest work.

- There should be formal documented audit of the work of the SSPs and the nominated pathologists.

- The SSPs should have ready access to molecular pathology and/or cytogenetics facilities.

- All sarcoma MDTs (see Chapter 5) must have at least one, or ideally two, SSPs. Where there is only one SSP, formal links with an SSP in another centre should be established for the purposes of consultation, audit and cross-cover.

- The additional work of reviewing cases by SSPs should be recognised in their job plan.

- Commissioners should fund:
  - a formal system for second opinions and review of difficult cases
  - molecular pathology and cytogenetics facilities.

- All pathology laboratories in centres treating bone or soft tissue sarcomas should store tissue in appropriate facilities for research (subject to the provisions of the Human Tissue Act).

- Commissioners should consider funding sarcoma pathology fellowships to address the current shortages of SSPs.

Chapter 5 - Improving Treatment: Sarcoma Multidisciplinary Teams

- All patients with a confirmed diagnosis of bone sarcoma, or adults with a soft tissue sarcoma, should have their care supervised by or in conjunction with a sarcoma MDT.

- The sarcoma MDT should be expected to manage at least 100 new patients with soft tissue sarcoma per year; if the MDT also manages bone sarcomas then it should manage at least 50 new patients with bone sarcoma plus 100 new patients with soft tissue sarcoma.

- This guidance should be implemented by primary care trusts (PCTs)/local health boards (LHBs) working collaboratively through their specialist commissioning groups, in close consultation with cancer networks. A National Implementation Group should be considered for both England and Wales.

- Each sarcoma MDT should be based either in a single hospital or in several geographically close and closely affiliated hospitals, which would constitute the sarcoma treatment centre.

- There should be a nominated clinician (clinical lead) who takes responsibility for the service and this should be reflected in their job plan. The clinical lead should be a member of the core MDT.

- Information about the specific expertise of different MDTs should be made widely available so that cases can be referred expeditiously (see Chapter 7). Such expertise – which is not likely to be found everywhere – includes:

- gynaecological sarcomas
- head and neck sarcomas
- retroperitoneal and pelvic sarcomas
- chest wall/intrathoracic sarcomas
- skin sarcomas
- central nervous system sarcomas
- gastrointestinal stromal tumours (GIST)
- adult-type soft tissue sarcomas arising in children
- the use of isolated limb perfusion.

Sarcoma MDT membership

- Each sarcoma MDT should have a core membership as shown in Table 5.

Table 5 Core membership of a sarcoma multidisciplinary team

Staff requirements	Specification
Specialist sarcoma surgeon	A minimum of two per MDT. These surgeons should have a major clinical interest in sarcomas i.e. spend at least 5 programmed activities of direct clinical care involved in managing sarcomas
Specialist sarcoma radiologist	At least two with a special interest in musculoskeletal/oncological imaging
Specialist sarcoma pathologist	At least one and ideally two (see Chapter 4)
Medical oncologist and/or clinical oncologist	At least two with an interest in musculoskeletal oncology. There should be at least one clinical oncologist. The oncologist/s should each spend a minimum of three programmed activities of direct clinical care involved in the management of sarcomas

Sarcoma clinical nurse specialist/key worker[a]	Sufficient to allocate a clinical nurse specialist/key worker for each patient (but a minimum of two) – see Chapter 8
Support staff	MDT coordinator and secretarial support
Palliative care specialist	A member of the specialist palliative care team

[a] Key worker may come from any of the disciplines involved in the multidisciplinary team (MDT).

- Each MDT should in addition have an extended team with membership as shown in Table 6, some of whom (for example key workers) may work as part of the core team.

Table 6 Membership of an extended sarcoma multidisciplinary team

Staff requirements	Specification
Specialist sarcoma physiotherapist	With expertise in sarcomas
Specialised allied health professionals (AHP)	Consisting of other relevant AHPs, such as therapy radiographers, occupational therapists, prosthetists, orthotists, dietitians and social workers, plus access to counsellors and/or psychologists
Paediatric oncologist	Specifically for MDTs that treat children and young people with bone and/or soft tissue sarcoma
Specialist nurse(s)	Including palliative care nurses and appropriately trained ward staff
Affiliated medical or clinical oncologist from linked cancer centre	Nominated by the cancer network clinical director and approved by the MDT lead clinician
Affiliated diagnostic service clinicians	Nominated by the cancer network clinical director and approved by the MDT lead clinician

Other professionals including orthopaedic, thoracic, plastic, head and neck, gynaecological, GI and vascular surgeons	Nominated by the cancer network clinical director and approved by the MDT lead clinician

- Members of the extended team should be nominated and will bring particular expertise to the sarcoma MDT. They should attend MDT meetings as and when appropriate.

Role of the sarcoma MDT

- The MDT should:
  - have weekly meetings at which all core members of the team are present and their attendance is documented
  - ensure that a treatment plan is agreed and documented by the MDT for all of the following:
    - newly diagnosed patients
    - patients following tumour resection
    - patients with first metastases and/or first local recurrence
  - ensure that the written care/treatment plan draws together the provision of all components of care
  - ensure that a key worker has been allocated to each patient
  - cooperate in service development at a national and local level for patients with sarcomas
  - ensure national standards for diagnosis and treatment (as defined in the 'NHS Cancer Plan'[10] and the 'Wales National Cancer Standards'[11]) are achieved
  - have operational policies for the diagnosis and treatment of patients

[10] Department of Health (2002) *The NHS Cancer Plan*. Available from: www.dh.gov.uk (accessed 3 January 2006)

[11] Welsh Assembly Government (2005) *Wales National Cancer Standards*. Available from: www.wales.gov.uk/subihealth/content/cancer/national-standards-e.htm

- have documented arrangements for linking with other MDTs to ensure coordinated management of patients with sarcomas at specific anatomical sites for which specialist input is required (for example, head and neck, uterine, retroperitoneal sarcoma and GIST; see Chapter 7)
- comply with the information requirements of the National Cancer Dataset
- participate in any future national audit programmes for sarcoma outcomes
- participate in national and international trials
- ensure audit and education of its referring hospitals and networks
- ensure GPs are given prompt and full information about significant changes in their patients' illness or treatment
- encourage education of medical students, GPs and trainee surgeons about the diagnosis and management of sarcomas.

Chapter 6 - Improving Treatment: Bone Sarcomas

Surgery

- All patients with bone sarcoma should undergo definitive surgical resection at a bone tumour treatment centre with a properly constituted MDT.

- A bone sarcoma MDT should see a minimum of 100 new cases of bone sarcoma per year (or 50 cases of bone sarcoma if the MDT also manages 100 cases of soft tissue sarcoma).

Chemotherapy and radiotherapy

- There should be a formal relationship between the bone sarcoma MDT and the provider of non-surgical oncology services that is characterised by common protocols, good communication, and well-defined referral pathways. These relationships should be defined in writing and approved by the cancer network director and the bone sarcoma MDT lead clinician. Audits of compliance with these protocols will need to be demonstrated.

- The provider of chemotherapy services should:
  a) provide the facilities for intensive inpatient chemotherapy as described in the 'Manual for cancer services' 2004[12]
  b) be **either**
     - a principal treatment centre for children or young people (likely to be a UKCCSG Centre or a teenage cancer unit)

     or
     - an adult cancer centre with a formal relationship with a bone sarcoma MDT

[12] Department of Health (2004) *Manual for cancer services*. Available from: www.dh.gov.uk (accessed 3 January 2006)

c) have a clinical/medical oncologist who has a specific interest in chemotherapy for bone sarcoma, nominated by the cancer network clinical director and approved by the sarcoma MDT lead clinician
d) offer all patients with bone sarcomas entry into the relevant clinical trials
e) provide facilities for long-term follow-up for late effects of chemotherapy
f) be guided by the bone sarcoma MDT on the treatment regimen
g) identify an oncologist to be a member of the extended bone sarcoma MDT.

- The provider of curative radiotherapy services should:
  a) provide the facilities for radiotherapy as described in the 'Manual for cancer services 2004'[13]
  b) be **either**
     - at a radiotherapy centre for children and young people that meets the criteria in the NICE guidance on 'Improving outcomes in children and young people with cancer'[14] and that has a formal relationship with a bone sarcoma MDT

     or

     - at a cancer centre that has a formal relationship with a bone sarcoma MDT
  c) have a clinical oncologist who has a specific interest in radiation therapy for bone sarcoma, nominated by the cancer network clinical director and approved by the sarcoma MDT lead clinician

[13] Department of Health (2004) *Manual for Cancer Services*. Available from: www.dh.gov.uk (accessed 3 January 2006).

[14] National Institute for Health and Clinical Excellence (2005) Improving outcomes in children and young people with cancer. *NICE cancer service guidance.* Available from: www.nice.org.uk/CSGCYP

d) be guided by the bone sarcoma MDT on the treatment regimen
e) identify an oncologist to be a member of the extended bone sarcoma MDT.

Palliation

- The preferred provider for palliative radiotherapy and chemotherapy services should be decided by the sarcoma MDT in conjunction with the patient and agreed with local radiotherapy and chemotherapy providers.

Chapter 7 - Improving Treatment: Soft Tissue Sarcomas

Limb, limb girdle and truncal soft tissue sarcomas

- Treatment recommendations (surgery, chemotherapy, radiotherapy) for all patients with limb, limb girdle and truncal soft tissue sarcoma should be decided by a properly constituted sarcoma MDT (see Chapter 5).

- Patients with fibromatosis or other soft tissue tumours of borderline malignancy should be referred to a sarcoma MDT for diagnosis and management.

Surgery

- All patients with limb, limb girdle and truncal soft tissue sarcoma should undergo definitive surgical resection at a soft tissue sarcoma treatment centre.

Chemotherapy and radiotherapy

- There should be a formal relationship between the soft tissue sarcoma MDT and the provider of non-surgical oncology services that is characterised by common protocols, good communication, and well-defined referral pathways. This relationship should be defined in writing and approved by the cancer network director and the lead clinician in the soft tissue sarcoma MDT. Audits of compliance with these protocols will need to be demonstrated.

- The provider of chemotherapy and radiotherapy services should:
  a) provide the facilities for intensive inpatient chemotherapy and radiotherapy as described in the 'Manual for cancer services', 2004[15]
  b) be **either**
     - at a soft tissue sarcoma treatment centre

     or

     - at a centre with a nominated medical and/or clinical oncologist who is a member of an extended sarcoma MDT (as defined in Chapter 5) and who agrees to give curative and palliative treatments (chemotherapy or radiotherapy) according to protocols defined by the sarcoma MDT. These oncologists should be nominated by the cancer network clinical director and approved by the lead clinician on the sarcoma MDT

     or

     - at a principal treatment centre for children or young people as described in the NICE guidance on 'Improving outcomes in children and young people with cancer'[16]
  c) offer all patients with soft tissue sarcomas entry into the relevant clinical trials.

- The sarcoma MDT should recommend the treatment regimen.

- All cancer networks should **either**
  - host a sarcoma MDT

  or

[15] Department of Health (2004) *Manual for Cancer Services*. Available from: www.dh.gov.uk (accessed 3 January 2006)

[16] National Institute for Health and Clinical Excellence (2005) Improving outcomes in children and young people with cancer. *NICE cancer service guidance.* Available from: www.nice.org.uk/CSGCYP

- decide to use the services of a nearby sarcoma MDT to provide all treatment facilities

or

- have a nominated medical and/or clinical oncologist who is a member of the extended sarcoma MDT (as defined in Chapter 5) and who agrees to give curative and palliative treatments (chemotherapy or radiotherapy) according to protocols defined by the sarcoma MDT. These oncologists should be nominated by the cancer network clinical director and approved by the lead clinician on the sarcoma MDT.

Retroperitoneal and pelvic soft tissue sarcomas

- Patients with retroperitoneal and pelvic soft tissue sarcoma should be referred to a sarcoma treatment centre where there is a core member of the team with special expertise in managing these tumours.

- NSCAG should consider commissioning designated centres for the management of retroperitoneal and pelvic soft tissue sarcomas.

Soft tissue sarcomas requiring shared management

- The care of patients with soft tissue sarcomas requiring shared management should be managed by the appropriate site-specific MDT, the MDT for children or the MDT for young people in conjunction with a sarcoma MDT.

- The site-specific MDT has primary responsibility to liaise with the sarcoma MDT to discuss the management of each patient. Specified care plans, taking into account currently available clinical trials, should be used. It should be made clear to patients who their key worker is.

- Site-specific and sarcoma MDTs need to ensure that clear pathways exist between the two MDTs, to have common treatment pathways and to clarify under what circumstances patient care should be transferred from one team to the other.

- The medical management of patients with GIST should be supervised by cancer specialists with experience in the management of patients with GIST.

- Clinical trials are needed for the full evaluation of imatinib, other novel agents and the role of PET scanning in GIST.

- Dietetic support should be available for patients who have undergone major abdominal surgery (see the NICE guidance on 'Nutritional support in adults'[17]).

- Surgery for non-rhabdomyosarcoma soft tissue sarcomas in teenagers and young adults should only be undertaken by a surgeon with appropriate expertise, and in age-appropriate facilities, after review at a designated sarcoma MDT.

[17] National Institute for Health and Clinical Excellence (2006) Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition. *NICE clinical guideline* no. 32. Available from: www.nice.org.uk/CG032

Chapter 8 - Supportive and Palliative Care

The key worker

- All patients managed by a sarcoma MDT should be allocated a key worker. Patients should be provided with their key worker's name and contact details.

Physiotherapy, occupational therapy and rehabilitation

- A specialist sarcoma physiotherapist and other specialised AHPs should be members of the extended sarcoma MDT (see Chapter 5).

- Ongoing rehabilitation and supportive care should be provided locally wherever possible. This should be coordinated by the therapist in liaison with the key worker.

Orthotic and prosthetic appliance provision

- Rapid, easy access should be provided to appropriate orthotic and prosthetic services.

- The sarcoma MDT should establish formal links to a centre(s) matching the PARC template, and should refer patients for pre-amputation assessment.

- Special activity limbs should be provided where appropriate and proven technological improvements should be made available.

Specialist palliative care

- A member of the specialist palliative care team should be a member of the core sarcoma MDT.

- Key workers should have a major role in liaising with palliative care and support services such as hospice and Macmillan services.

- Commissioners should ensure that patients with sarcoma have easy and timely access to appropriate palliative and specialist pain management services (see the NICE guidance on 'Improving supportive and palliative care for adults with cancer'[18]).

[18] National Institute for Clinical Excellence (2004) Improving supportive and palliative care for adults with cancer. *NICE cancer service guidance.* Available from: www.nice.org.uk/page.aspx?o=110005

Chapter 9 - Follow-up of patients

- Research should be commissioned to provide evidence for the follow-up protocols required for each tumour type.
- Resources should be made available for regular imaging of patients at high risk of recurrence (as defined in an agreed protocol, for example the American National Comprehensive Cancer Network/American College of Radiology consensus-based guidelines).
- Where appropriate, access to cancer genetic services should be offered to the patient and their family.

Chapter 10 - Improving Knowledge

Data collection

- All sarcoma MDTs should collect data on patients, tumour, treatment and outcome.

- The data collected should be agreed nationally and should be based on the sarcoma subset of the National Cancer Dataset (including comorbidity data). Cancer networks should ensure that a complete dataset exists for all patients managed within their network.

- Public health observatories or cancer registries should act as the data repository of the agreed dataset, and a lead observatory or cancer registry should be commissioned as the repository of a national dataset, which could then become a national sarcoma register.

Audit

- Audit should be carried out of all elements of the referral and management pathway including standards for referral, investigation and management.

- SSPs should continue to undertake the existing EQA scheme, and networks should ensure that only specialist sarcoma pathologists who comply with this scheme report on sarcomas.

- Commissioners should ensure that networks and sarcoma MDTs audit the management of sarcoma on a regular basis, using the national dataset for comparison of compliance with management guidelines and outcomes. The National Clinical Audit Support

Programme should be asked to provide guidance on multicentre audits.

- National audits of outcome including patient satisfaction should be carried out by networks and sarcoma MDTs.

- The results of audits should be widely available to clinicians within referring units, networks and the public.

Training

- Commissioners should ensure that all those involved in sarcoma care remain up to date with current advances in sarcoma care, and can provide evidence of adequate, relevant CPD.

- Appropriate training posts should be made available nationally to train and recruit surgeons, pathologists, radiologists and oncologists with appropriate expertise in sarcoma care.

- Training should be developed and provided for all members of both the core and extended sarcoma MDTs.

- The Royal Colleges of Surgeons should be invited to make recommendations about appropriate training and certification of sarcoma surgeons.

- MDTs should ensure that they regularly provide updates for members of the extended MDT.

Research

- Improvements in the management of sarcomas require reliable evidence that interventions are effective and that they improve outcomes for patients. There is limited evidence-based information available on many aspects of the management of sarcoma,

including the optimum patient pathway and the configuration of services. It is therefore important that health service commissioners should support the well-designed clinical trials within the portfolio of the National Cancer Research Network (NCRN), which should be encouraged to investigate diagnostic pathways.

- Data from the national dataset for sarcoma should be used for research purposes to enable multicentre survival studies to be carried out on a relatively large and complete population base.

- Commissioners should ensure that NCRN-adopted clinical trials for patients with sarcomas are supported locally.

- All sarcoma MDTs should aim to maximise entry into trials and should work with the local NCRN to ensure this happens. They should have a nominated research lead.

- The possibility of entry into an appropriate trial should be discussed with every patient who fits the inclusion criteria. Such patients should be given accurate and accessible information to inform their decision about whether to participate in the trial.

- Trials of treatment for sarcoma should be designed with outcome measures that reflect quality of life, including the use of limb prostheses in bone sarcoma (assessed by patients, not just clinicians), as well as survival time and clinical measures with prognostic significance.

- Patients who are not involved in a clinical trial should be treated according to local clinical guidelines based on research evidence.