Complete Summary

GUIDELINE TITLE

Improving outcomes for people with sarcoma.

BIBLIOGRAPHIC SOURCE(S)

National Collaborating Centre for Cancer. Guidance on cancer services: improving outcomes for people with sarcoma. London (UK): National Institute for Health and Clinical Excellence (NICE); 2006 Mar. 138 p.

GUIDELINE STATUS

This is the current release of the guideline.

COMPLETE SUMMARY CONTENT

SCOPE
METHODOLOGY - including Rating Scheme and Cost Analysis
RECOMMENDATIONS
EVIDENCE SUPPORTING THE RECOMMENDATIONS
BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS
IMPLEMENTATION OF THE GUIDELINE
INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES
IDENTIFYING INFORMATION AND AVAILABILITY
DISCLAIMER

SCOPE

DISEASE/CONDITION(S)

Sarcoma

GUIDELINE CATEGORY

Counseling
Evaluation
Management
Treatment

CLINICAL SPECIALTY

Family Practice
Internal Medicine
Oncology

Orthopedic Surgery
Pathology
Pediatrics
Physical Medicine and Rehabilitation
Plastic Surgery
Psychology
Radiation Oncology
Surgery
Thoracic Surgery

INTENDED USERS

Advanced Practice Nurses
Allied Health Personnel
Health Care Providers
Hospitals
Nurses
Pathology Assistants
Patients
Physical Therapists
Physicians
Psychologists/Non-physician Behavioral Health Clinicians

GUIDELINE OBJECTIVE(S)

- To develop service guidance on sarcomas for use in the National Health Service in England and Wales
- To improve the care of all patients with bone sarcomas and adults with soft tissue sarcomas
- To support current national initiatives outlined in the *National Health Service Cancer Plan*, the Calman Hine Report, the Cameron Report, the *Manual of Cancer Service Standards for England* and the *All Wales Minimum Standards for Cancer Services*

TARGET POPULATION

- All patients with malignant bone tumours and those tumours of unspecified, borderline and uncertain behaviour as defined by the World Health Organization (WHO) classification (*World Health Organization Classification of Tumours: Pathology and Genetics of Tumours of Soft Tissue and Bone*, IARC Press, Oxford, 2002, ISBN 9283224132)
- All patients with malignant soft tissue sarcoma and those tumours of unspecified, borderline and uncertain behaviour as defined by the WHO classification, excluding Kaposi's sarcoma because this is included in the *Service Guidance for Skin Tumours, Including Melanoma* (www.nice.org.uk/pdf/Skin_scope.pdf)
- All patients with gastrointestinal stromal tumours

Groups that will **not** be covered:

Adults and children with:

- Benign bone and soft tissue tumours as defined by the WHO classification
- Metastases to bone and soft tissues from tumours at other primary sites

INTERVENTIONS AND PRACTICES CONSIDERED

Patient Perspectives

1. Diagnosis
    - Communicating diagnosis to patient
    - Assignment of a key worker
2. Information
    - Availability of information
    - Scope of information: the information pathway
3. Support
    - Psychological
    - Spiritual
    - Social
    - Practical healthcare
    - Benefits advice
4. General
    - Collaboration among treatment centers
    - Significant event analysis

Diagnosis/Evaluation

1. Referral guidelines
2. Referral pathways
    - Extremity, trunk, and local head and neck soft tissue sarcoma
    - Bone sarcomas
3. Radiology review
4. Histopathology review
5. Pathology
    - Pathology report requirements
    - Pathology review
    - External quality assurance

Management/Treatment

1. Delivery of care by a multidisciplinary team (MDT)
    - MDT membership and roles
2. Bone sarcomas
    - Surgery
    - Chemotherapy and radiotherapy
3. Limb, limb girdle and truncal soft tissue sarcomas
    - Surgery
    - Chemotherapy and radiotherapy
    - Referral for patients with retroperitoneal and pelvic soft tissue sarcoma
4. Soft tissue sarcomas requiring shared management
5. Supportive and palliative care
    - Allocation of a key worker
    - Physiotherapy and rehabilitation
    - Orthotic and prosthetic appliance provision

- Specialist palliative care and support services

6. Follow-up of patients
    - Fulfillment of protocols for each tumour type
    - Regular imaging
    - Access to cancer genetic services

MAJOR OUTCOMES CONSIDERED

- Patient/parent/carer satisfaction
- Quality of life
- Survival rate
- Recurrence rate
- Diagnostic accuracy
- Morbidity and mortality associated with treatment
- Amputation rate
- Symptom control
- Functional status

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Sources of Evidence

The members of the Guidance Development Group (GDG) were asked to consider the issues covered in the project scope and to submit research questions covering these issues.

The National Collaborating Centre for Cancer (NCC-C) information specialist constructed search strategies to identify published evidence for the research questions set by the GDG. In most cases the main search strategy, provided in Appendix A of the original guideline document, was combined with more specific terms to identify relevant studies. The literature searching period ended on the 3rd of February 2005. Relevant evidence submitted by GDG members or stakeholders after this date, however, was included.

The titles and abstracts of studies identified by the literature searches were initially screened for relevance by the information specialist and then by the NCC-C researcher. Copies of potentially relevant papers were then obtained for critical appraisal. Studies cited in these papers were also considered for inclusion if relevant. GDG members and stakeholders were also asked to submit relevant evidence.

Given the scarcity of evidence for many of the research questions, abstracts were included as evidence if their results were not published elsewhere, but were

considered to have a high risk of bias. Similarly papers not in English or French were appraised on the basis of their English abstract if available, but again were considered to have a high risk of bias.

Expert Position Papers

The GDG identified areas where there was a requirement for expert input. These areas were addressed by the production of a position paper by a recognized expert. Experts were identified by asking relevant registered stakeholders for a suitable nomination to deal with a particular topic area. Three position papers, on prosthetic rehabilitation of the post tumour amputee, the management of people with head or neck sarcoma and the management of gastrointestinal stromal tumours, were presented at the GDG meetings for discussion and are included as Appendices B and C in the technical companion titled *Improving Outcomes for People with Sarcoma. The Evidence Review* (See the "Availability of Companion Documents" field in this summary).

Health Economic Evidence

Economic evidence was extracted from the evidence tables, where it existed and was supplemented with searches performed by the Centre for the Economic and Policy in Health, University of Wales Bangor. This evidence informed the Health Economics Report, *Improving Outcomes for People with Sarcoma: Analysis of the Potential Economic Impact of the Guidance*. (See the "Availability of Companion Documents" field in this summary.)

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Levels of Evidence

1++ High quality meta-analyses, systematic review of randomised controlled trials (RCTs), or RCTs with a very low risk of bias

1+ Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias

1- Meta-analyses, systematic review of RCTs, or RCTs with a high risk of bias*

2++ High quality systematic reviews of case-control or cohort studies. High quality case-control or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal

2+ Well conducted case-control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal

2- Case-control or cohort studies with a high risk of confounding, bias, or chance and a significant risk that the relationship is not causal*

3 Non-analytic studies (for example, case reports, case series)

4 Expert opinion, formal consensus

*Studies with a level of evidence "-" should not be used as a basis for making a recommendation.

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Synthesizing Evidence

Studies were critically appraised using the methodology from the National Institute for Health and Clinical Excellence (NICE) *Guideline Development Methods* 2005. (See "Availability of Companion Documents" field in this summary.) Each study was graded using the NICE hierarchy of evidence and the quality checklists and relevant data were entered into an evidence table. The tables recommended for use in the NICE methodology manual were modified to accept the type of studies identified for service guidance. Owing to practical limitations the final selection of studies, critical appraisal and data extraction were undertaken by a single researcher. Evidence tables were circulated to the Guidance Development Group (GDG) members for comments. Finally the evidence for each research question was summarised in the form of a considered judgement form (modified from the Scottish Intercollegiate Guideline Network [SIGN] methodology).

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Informal Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Drafting and Agreeing Recommendations

The Guidance Development Group (GDG) members were allocated specific topic areas and asked to review the relevant evidence tables and draft recommendations for the service guidance. Once an early draft of the guidance was produced, the GDG members were asked to review the draft document. Members were asked to consider whether the recommendations were justified from the evidence presented and whether they were sufficiently practical and precise to allow health service commissioners and the relevant front line

healthcare professionals to implement them. The absence of high quality evidence for the majority of the research questions made the grading of the recommendations impractical.

Group support consultants from the University of Glamorgan assisted the GDG in a number of ways. An interactive group support system, which allowed anonymous polling of the group, was used during meetings to help the group reach consensus, to resolve conflicts and to vote for key recommendations. A questionnaire about the GDG members' feelings on the group process was issued after each meeting and the group support consultants provided feedback to the GDG Chairperson following each session on aspects of the group process.

Writing of the Guidance

The Chair and Clinical Lead of the GDG coordinated the first formal draft version of the guidance in accordance with the decisions of the GDG. The draft guidance was circulated for consultation according to the formal NICE stakeholder consultation and validation process prior to publication.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

Potential Economic Impact of the Guidance

Executive Summary

The economic consequences of the recommendations of the "*Guidance on Cancer Services: Improving Outcomes for People with Sarcoma*" in England and Wales are set out in *Improving Outcomes for People with Sarcoma: Analysis of the Potential Economic Impact on Guidance* (see the "Availability of Companion Documents" field in this summary). The analysis focuses on those aspects of the key recommendations that are likely to be of greatest consequence in terms of cost and this varies according to type of sarcoma. Bone sarcomas are currently treated centrally, whereas soft tissue sarcomas are treated more disparately. Moving to a more centralised service as proposed in the original guideline document will have cost implications.

The summary of economic implications is outlined in Table 1 in *Improving Outcomes for People with Sarcoma: Analysis of the Potential Economic Impact on Guidance* (see the "Availability of Companion Documents" field in this summary).

There is some uncertainty around the estimates presented and there will be variation between costs for different diagnostic clinics and sarcoma treatment centres. Therefore sensitivity analyses were conducted to account for uncertainty in the estimated costs. Further assessments will be needed at cancer network level and/or National Health Service (NHS) trust level to determine the exact cost implications. Work is currently being carried out in the NHS in England, in

connection with 'Payment by Results', to develop a better understanding of costs of treatment and care. This may help these assessments in the future.

Information from two specialist hospitals that treat patients with soft tissue sarcoma, suggests that the Healthcare Resource Groups (HRGs) currently used for the funding of major surgery significantly under-estimate the true costs of the procedure and inpatient care. Although these HRGs have not been used in this economic assessment, it is important that commissioners take this into account when calculating the overall costs of services.

For further details of the economic implications of the guidance, see Appendix 2 of the original guideline document.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

The guideline was validated through two consultations.

1. The first draft of the guideline was consulted with Stakeholders and comments were considered by the Guideline Development Group (GDG).
2. The final consultation draft of the Full guideline, the Evidence Review, the Economic Analysis, the Needs Assessment, and the Information for the Public were submitted to stakeholders for final comments.

The final draft was submitted to the Guideline Review Panel for review prior to publication.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

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 National Institute for Health and Clinical Excellence (NICE) guidance "Improving supportive and palliative care for adults with cancer"). 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 in the original guideline document).

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 general practitioner (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
- is age-appropriate (see the National Guideline Clearinghouse [NGC] summary of the NICE guidance Improving Outcomes in Children and Young People with Cancer)

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.

The Table below titled "The Information Pathway" 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.

Table. 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 in the original guideline document) 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 in the original guideline document) by post
	Specific information on the diagnosis and the proposed treatment (if	Local arrangements can apply

Time	Nature of Information	Responsibility
	known and if not given by diagnostic clinic)	
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 Information on the new sarcoma treatment centre. Identification of key worker	Referring sarcoma treatment center face-to-face or by post New sarcoma treatment centre by post
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
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

GP, general practitioner; GIST, gastrointestinal stromal tumour

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" in the original guideline document).

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 general practitioners (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').

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 NGC summary of the NICE Referral Guidelines for Suspected Cancer in Adults and Children.

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 in the original guideline document) 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

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 in the original guideline document.

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 *National Health Service (NHS) Cancer Plan* and the *Wales National Cancer Standards*).

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 in the original guideline document) for diagnosis and management.

Appropriate imaging facilities should be available to comply with national access standards (as defined in the *NHS Cancer Plan* and the *Wales National Cancer Standards*).

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 in the original guideline document).

Improving Pathology

All primary malignant bone tumours should either be first reported or reviewed by a specialist sarcoma pathologist (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 external quality assurance (EQA) scheme, and be part of a properly constituted sarcoma multidisciplinary team (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 gastrointestinal stromal tumours (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 gastrointestinal (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 in the original guideline document) 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 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 Clinical Pathology Accreditation (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 in the original guideline document) 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 recognized 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.

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 in the original guideline document). 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
- GISTs
- 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 the table below.

Table. 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 in the original guideline document)
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*	Sufficient to allocate a clinical nurse specialist/key worker for each patient (but a minimum of two) – see Chapter 8 in the original guideline document
Support staff	MDT coordinator and secretarial support
Palliative care specialist	A member of the specialist palliative care team

* 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 the table below, some of whom (for example key workers) may work as part of the core team.

Table. Membership of an Extended Sarcoma MDT

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* and the *Wales National Cancer Standards*) are achieved
- Have operational policies for the diagnosis and treatment of patients
- 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 in the original guideline document)
- 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

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 Department of Health's *Manual for Cancer Services 2004*
b. Be **either**
    - A principal treatment centre for children or young people (likely to be a United Kingdom Children's Cancer Study Group Centre (UKCCSG) or a teenage cancer unit)

      or

    - An adult cancer centre with a formal relationship with a bone sarcoma MDT

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 Department of Health's *Manual for Cancer Services 2004*
b. Be **either**
    - At a radiotherapy centre for children and young people that meets the criteria in the NICE guidance "Improving Outcomes in Children and Young People with Cancer" 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
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.

Improving Treatment: 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 in the original guideline document).

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 Department of Health's *Manual for Cancer Services 2004*.
b. Be **either**
    - At a soft tissue sarcoma treatment center

      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 of the original guideline document) 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 "Improving Outcomes in Children and Young People with Cancer"

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

- 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 of the original guideline document) 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.

National Specialist Commissioning Advisory Group (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 positron emission tomography (PET) scanning in GIST.

Dietetic support should be available for patients who have undergone major abdominal surgery (see the NICE guidance "Nutritional Support in Adults").

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.

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 allied health professionals (AHPs) should be members of the extended sarcoma MDT (see Chapter 5 in the original guideline document).

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 Prosthetic and Amputee Rehabilitation Centre (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 "Improving Supportive and Palliative Care for Adults with Cancer").

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.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting each section of the guidance is specifically stated in the technical companion titled *Improving Outcomes for People with Sarcoma. The Evidence Review*. (see the "Availability of Companion Documents" field in this summary).

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

In general, the guidance may lead to significant and lasting changes in the care of patients with sarcoma that improve not only the clinical outcomes, but also the experience of the patients and their families.

Refer to the original guideline document for anticipated benefits upon implementation of guidelines under the following topics:

- Patient Perspectives
- Improving Diagnosis of Bone and Extremity Soft Tissue Sarcoma
- Improving Pathology
- Improving Treatment: Sarcoma Multidisciplinary Teams
- Improving Treatment: Bone Sarcomas
- Improving Treatment: Soft Tissue Sarcomas: Limb, Limb Girdle and Truncal Soft Tissue Sarcomas
- Improving Treatment: Soft Tissue Sarcomas: Retroperitonral and Pelvic Soft Tissue Sarcomas
- Improving Treatment: Soft Tissue Sarcomas: Soft Tissue Sarcomas Requiring Shared Management
- Supportive and Palliative Care: The Key Worker
- Supportive and Palliative Care: Physiotherapy, Occupational Therapy and Rehabilitation
- Supportive and Palliative Care: Orthotic and Prosthetic Appliance Provision
- Supportive and Palliative Care: Specialist Palliative Care
- Follow-Up of Patients
- Improving Knowledge

POTENTIAL HARMS

Not stated

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

The Measurement sections of the guidance list "structures," "processes," and outcomes" directly related to the recommendations and suggest ways in which implementation of guidance can be measured. The topics may feed into any peer review process, may be subjects for regular or ad hoc clinical audit, or be the subject of other forms of assessment such as patient surveys. Resource implications are also provided for each section of "The Care Pathway."

IMPLEMENTATION TOOLS

Patient Resources

For information about availability, see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care
Getting Better
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

National Collaborating Centre for Cancer. Guidance on cancer services: improving outcomes for people with sarcoma. London (UK): National Institute for Health and Clinical Excellence (NICE); 2006 Mar. 138 p.

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2006 Mar

GUIDELINE DEVELOPER(S)

National Collaborating Centre for Cancer - National Government Agency [Non-U.S.]

SOURCE(S) OF FUNDING

National Institute for Health and Clinical Excellence (NICE)

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

All guideline development group (GDG) members made and updated any declarations of interest.

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) format from the National Institute for Health and Clinical Excellence (NICE) Web site.

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- National Collaborating Centre for Cancer. Guideline Development Methods: Information for National Collaborating Centres and Guideline Developers. London (UK): National Institute for Health and Clinical Excellence (NICE); 2005 Feb. 89 p. Electronic copies: Available from the National Institute for Health and Clinical Excellence (NICE) Web site.
- National Collaborating Centre for Cancer. Improving outcomes for people with sarcoma. Analysis of the potential economic impact of the guidance. London (UK): National Institute for Health and Clinical Excellence (NICE); 2006 Mar. 40 p. Electronic copies: Available from the National Institute for Health and Clinical Excellence (NICE) Web site.
- National Collaborating Centre for Cancer. Improving outcomes for people with sarcoma. The evidence review. London (UK): National Institute for Health and

Clinical Excellence (NICE); 2006 Mar. 267 p. Electronic copies: Available from the National Institute for Health and Clinical Excellence (NICE) Web site.

- National Collaborating Centre for Cancer. Improving outcomes for people with sarcoma. An assessment of need for sarcoma services in England and Wales. London (UK): National Institute for Health and Clinical Excellence (NICE); 2006 Mar. 48 p. Electronic copies: Available from the National Institute for Health and Clinical Excellence (NICE) Web site.
- National Collaborating Centre for Cancer. Improving outcomes for people with sarcoma. List of all recommendations. London (UK): National Institute for Health and Clinical Excellence (NICE); 2006 Mar. 36 p. Electronic copies: Available from the National Institute for Health and Clinical Excellence (NICE) Web site.

PATIENT RESOURCES

The following is available:

- Health services for people with sarcoma. Understanding NICE guidance – information for the public. National Institute for Health and Clinical Excellence (NICE), 2006 Mar. 4 p.

Electronic copies: Available in Portable Document Format (PDF) from the National Institute for Health and Clinical Excellence (NICE) Web site.

Print copies: Available from the National Health Service (NHS), 11 Strand, London, WC2N 5HR. Response Line 0870 1555 455, ref N0988.

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

NGC STATUS

This summary was completed by ECRI on November 15, 2006. The information was verified by the guideline developer on December 21, 2006.

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