

DRAFT FOR CONSULTATION

NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE

SCOPE

1 Guidance title

Service guidance for improving outcomes in sarcoma

1.1 Short title

Sarcoma

2 Background

- a) The National Institute for Clinical Excellence ('NICE' or 'the Institute') has commissioned the National Collaborating Centre for Cancer to develop service guidance on improving outcomes in sarcoma for use in the NHS in England and Wales. This follows referral of the topic by the Department of Health and Welsh Assembly Government (see Appendix). The guidance will provide recommendations for service provision that are based on the best available evidence.
- b) The Institute's service guidance will support the implementation of the National Service Frameworks (NSFs) in those aspects of care where a Framework has been published. The guidance will support current national initiatives outlined in the NHS 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*. Cross reference will be made to these and other documents as appropriate.

The guidance will also refer to other NICE documents currently under development, including *Referral guidelines for suspected cancer*, *Supportive and palliative care*, *Child and adolescent cancer*, *Head and neck cancers*, *Haemato-oncology*, *Skin tumours including melanoma*, and *Tumours of the brain and central nervous system*. Cross reference will be made to these and other documents as appropriate.

3 Clinical need for the guidance

- a) Sarcomas are a rare and heterogeneous group of tumours. They may arise in either bone or soft tissue. There are between 1500 and 2500 new cases of bone and soft tissue sarcoma and gastro-intestinal stromal tumours (GIST) per year in the United Kingdom, accounting for 1% of malignancies in adults and 6% of malignancies in childhood.
- b) Soft tissue sarcomas involve the connective tissues and usually present as a swelling in any part of the body, including the limbs, trunk and head and neck. There are many histological types with a range of clinical behaviours from local invasion to distant metastasis. Because these tumours are rare, the diagnosis is frequently not suspected at presentation and subsequent management can be variable. Bone sarcomas present with bone pain, often with swelling – the commonest, with a peak incidence in adolescence, is osteosarcoma. GIST presents most commonly with gastro-intestinal bleeding.
- c) Treatment generally consists of surgery, combined with radiotherapy and chemotherapy. In particular, the role of imatinib in the treatment of GIST has recently been recognised.

4 The guidance

- a) The guideline development process is described in detail in three booklets that are available from the NICE website (see 'Further information'). *The Guideline Development Process – Information for Stakeholders* describes how organisations can become involved.
- b) This document is the scope. It defines exactly what this service guidance will (and will not) examine, and what the developers will consider. The scope is based on the referral from the Department of Health and Welsh Assembly Government (see Appendix).
- c) The areas that will be addressed by the guideline are described in the following sections.

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4.1 Population

4.1.1 Groups that will be covered

- a) Adults with:
 - a. bone sarcoma
 - b. chordoma of the sacrum
- b) Adults with soft tissue sarcoma, including:
 - head and neck sarcoma
 - chest wall sarcoma
 - dermatofibrosarcoma protuberans (DFSPs)
 - retroperitoneal sarcomas
- c) Adults with gastro-intestinal stromal tumours (GIST).

4.1.2 Groups that will not be covered

- a) Children and adolescents with bone and soft tissue sarcomas.
- b) Adults and children with:
 - benign sarcomas
 - metastasis from tumours at other primary sites
 - uterine sarcomas
 - malignant mesothelioma
 - chordoma of other sites apart from the sacrum.

4.2 Healthcare setting and services

- a) Primary care, including diagnosis, treatment and follow up.
- b) Secondary care, including the role of cancer networks and multidisciplinary teams (MDTs).
- c) Tertiary care in cancer centres and specialist surgical units (for example, thoracic and plastic surgery).

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- d) Quaternary care in specialist regional or national units for selected patients (for example, bone tumour surgery).

4.3 Clinical management

The following key areas of clinical management will be included, because they have direct implications for service delivery.

- a) Services for diagnosis and staging (excluding those being addressed as part of the updated referral guidelines), including:
- primary care
 - surgical services in secondary care
 - pathology departments
 - diagnostic radiology departments.

In addition, the guidance will address the important issue of data collection and registration of sarcomas.

- b) Treatment services, to include treatment in the following settings.
- surgical services – district general hospitals (DGHs), cancer units, cancer centres, specialist surgical units and quaternary centres
 - oncological services – cancer units and cancer centres.
- c) Follow-up (need, frequency, type, location and by whom).
- d) Specific elements of supportive and palliative care that meet the particular needs of patients with bone and soft tissue sarcoma.
- e) Rehabilitation and support of patients with bone and soft tissue sarcoma, including the role of specialist nurses, physiotherapy, occupational therapy and disablement services.
- f) Information resources for patients, carers and family members.
- g) Health service research and clinical trials on service delivery.

4.4 Audit support within the guidance

The guidance will include key criteria for audit, which will enable objective measurements to be made of the extent and nature of local implementation of this guidance, particularly its impact upon practice and outcomes for adults with sarcoma.

4.5 Status

4.5.1 Scope

This is the draft scope, which is subject to a 4-week period of consultation with stakeholders. After the consultation, the scope will be re-drafted and submitted to the Guidelines Review Panel and then to the Institute's Guidance Executive for approval. Once approved, it will be posted on the Institute's website.

4.5.2 Guidance

The development of the service guidance recommendations will begin in February 2004.

5 Further information

Information on the guideline development process is provided in:

- *The Guideline Development Process – Information for the Public and the NHS*
- *The Guideline Development Process – Information for Stakeholders*
- *The Guideline Development Process – Information for National Collaborating Centres and Guideline Development Groups.*

These booklets are available as PDF files from the NICE website (www.nice.org.uk). Information of the progress of the guideline will also be available from the website.

Appendix – Referral from the Department of Health and Welsh Assembly Government

The Department of Health and Welsh Assembly Government asked the Institute:

“To prepare service guidance for the NHS in England and Wales for sarcoma. This would form part of the “Improving cancer outcomes” series and NICE will be expected, as in previous topics in the series, to involve DH and NAW closely in the development of the guidance. In particular, DH and NAW should be alerted at an early stage to any issues in the developing guidance, which are likely to lead to significant changes in the current service provision.”