

## ***National Institute for Health and Clinical Excellence***

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### **PRESS RELEASE**

## **NICE issues guidance to improve healthcare services for sarcoma**

The National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Cancer (NCCC) have issued guidance for the NHS in England and Wales on how to improve the care of all patients with bone sarcomas and adults with soft tissue sarcomas. The guidance provides advice to those who develop and deliver cancer services on the planning, commissioning and configuration of those services.

Although there are a number of important areas of care that are common to all these tumours, the management of patients with sarcomas involves quite distinct pathways of care. Because of their relative rarity there are particular challenges in ensuring that a clear diagnosis is made quickly and that patients get speedy access to the most skilled and appropriate advice and clinical care.

Key recommendations in the guidance include:

- 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 potential sarcomas (as defined by the NICE *Referral Guidelines for Suspected Cancer*) at designated diagnostic clinics.
- All patients with a provisional histological or radiological diagnosis of bone or soft tissue sarcoma should have their diagnosis reviewed by a specialist

sarcoma pathologist or radiologist. A formal system for second opinions and review of difficult cases and molecular pathology/cytogenetic facilities should be funded by commissioners.

- A key worker, who will be a member of the sarcoma MDT, should be allocated to each patient with sarcoma.
- Patient should undergo definitive resection of their sarcoma by a surgeon who is a member of a sarcoma MDT or by a surgeon with site specific 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 with functional disabilities as a consequence of their sarcoma should have timely access to appropriate support and rehabilitation services.
- This guidance should be commissioned 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.

Sarcomas are a rare but diverse group of cancers that occur in the cells that make up the connective tissue structure, including bone, cartilage, muscle, blood vessels, nerves and fat. Occurring almost anywhere in the body, sarcomas can be broadly divided into those that affect bone and those that affect soft tissue (STS). STS are ranked the 23rd most common cancer type and bone tumours the 27th most common type (although the latter represent 4% of all malignancy in children aged up to 14years). If combined, sarcomas would be the 21st most common cancer type, with under 2,500 cases estimated each year in England and Wales.

**Andrea Sutcliffe, the Institute's Executive Lead for the guidance**, said: "This guidance highlights the importance of providing properly coordinated care for patients with a confirmed diagnosis of bone or soft tissue sarcoma. This should be done by or in conjunction with a multi-disciplinary team. The importance of a multidisciplinary team approach to the care and management of all patients with cancer is now a 'given' in the NHS. However, the guidance on sarcoma goes further by recommending that the teams become responsible not only for the management of patients but also help to establish efficient and effective pathways of care from

primary care to definitive treatment and follow-up. The guidance recommends the establishment of managed sarcoma networks to achieve the important improvements in care these patients require.”

**Dr Joe Kearney, Director of Public Health and chair of the Guideline**

**Development Group** said: "Patients with this rare tumour need specialised care to obtain the best results. This Guidance gives commissioners and clinicians sensible and practical advice as to how to develop the necessary services to deliver high quality care"

**Mr Rob Grimer, Consultant Orthopaedic Oncologist and lead clinician on the Guideline Development Group**, said: “we hope that this guidance will ensure that patients with potential sarcomas are seen and assessed quickly by experts who are familiar with this rare tumour. If we can decrease the average size of these tumours at presentation (10cm) this will dramatically improve outcomes.”

**Roger Wilson, a patient representative on the Guideline Development Group**, commented: "These guidelines will help the NHS address the main concerns of patients with sarcoma - delays in getting a diagnosis and in getting access to treatment from specialist doctors. When they are implemented we hope to see more patients diagnosed earlier, with better overall survival as a result."

**Ends**

## **Notes to Editors**

### **About NICE**

1. On 1 April 2005 the National Institute for Clinical Excellence took on the functions of the Health Development Agency to form the National Institute for Health and Clinical Excellence (NICE). NICE is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.
2. NICE produces guidance in three areas of health:
  - **public health** – guidance on the promotion of good health and the prevention of ill health for those working in the NHS, local authorities and the wider public and voluntary sector
  - **health technologies** – guidance on the use of new and existing medicines, treatments and procedures within the NHS
  - **clinical practice** – guidance on the appropriate treatment and care of people with specific diseases and conditions within the NHS.