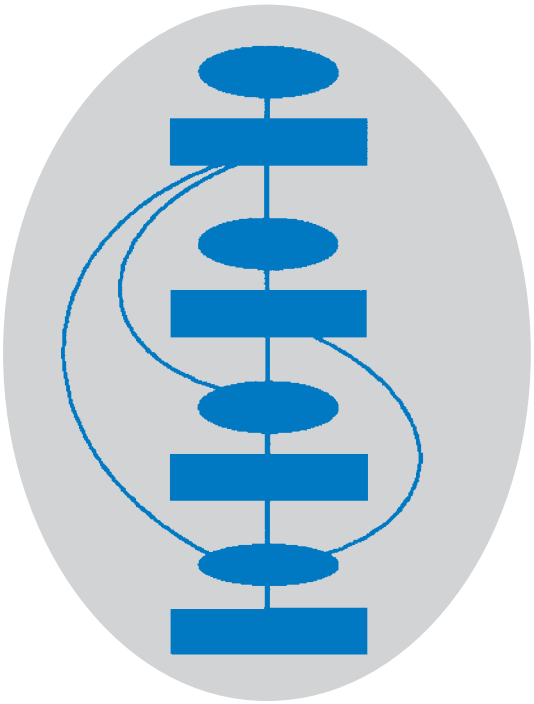
NHS

National Institute for Health and Clinical Excellence

Guidance on Cancer Services

Improving Outcomes for People with Sarcoma

An Assessment of Need for Sarcoma Services in England and Wales



March 2006

A report commissioned by the National Collaborating Centre for Cancer

Guidance on Cancer Services

Improving Outcomes for People with Sarcoma

An Assessment of Need for Sarcoma Services in England and Wales

A report to the National Collaborating Centre for Cancer

Dr Linda Mercy and Dr Joe Kearney

Dacorum Primary Care Trust

Final report submitted December 2005

Acknowledgements

We are grateful for the help of the following people in compiling this report:

Dr. Fergus Macbeth, Director of the National Collaborating Centre for Cancer (NCC-C), for commissioning the report.

Those who have shared data with us; Dr. Mike Quinn, Director of the National Cancer Intelligence Centre at the Office of National Statistics; Dr. John Steward, Director of the Welsh Cancer Intelligence Service for Wales; Dr Sara Godward, Eastern Cancer Registration and Information Centre; and Dr. Brian Cottier, Head of Cancer Service Analysis for the Department of Health.

Mr Rob Grimer and all the members of the guidance development group who gave advice on the content of the survey conducted for this report. Also to Dr Jane Halpin and Professor Carol Brayne.

The representatives of the Cancer Networks and Hospital Trusts who gave their time to complete the survey.

The team at the NCC-C for their help and assistance.

Dr. Linda Mercy, Specialist Registrar, Dacorum Primary Care Trust, Eastern Region Public Health Training Scheme

Dr. Joe Kearney, Director of Public Health, Dacorum Primary Care Trust

CONTENTS

1 Introduction

The Department of Health (England) and the Welsh Assembly Government asked the National Institute of Health and Clinical Excellence (NICE) 'to prepare service guidance for the NHS in England and Wales for sarcomas.' The National Collaborating Centre for Cancer (NCC-C) published, after consultation, a scope for the guidance in February 2004. A Guidance Development Group was established to take this work forward.

As part of this process the NCC-C requested that a needs assessment be undertaken. The purpose of this report is to inform the development of the service guidance by providing a description of the burden of disease and current service provision for patients with sarcomas.

2 Sarcomas

Sarcomas are a rare and diverse group of cancers thought to have a common embryological origin. They arise from cells that comprise the connective tissue structure, including bone, cartilage, muscle, blood vessels, nerves and fat. Sarcomas can be broadly divided into those of bone and those of soft tissue (STS).

2.1 Clinical Presentation

2.1.1 Bone Sarcomas

Bone sarcomas are relatively uncommon, estimated to account for only 0.2% of all neoplasms.[1] The age-specific frequencies of bone tumours as a group are bimodal – with the first peak occurring during the second decade of life, and the second occurring in patients older than sixty (Figure 3).

50% of these tumours arise around the knee and symptoms may include non-mechanical pain that wakes the patient at night. Bony swelling and a limp are usually late features[2].

The following are the most common histological types of malignant bone tumour:

- *Osteosarcomas*

Osteosarcomas are the most common primary tumour of bone accounting for approximately 35% of cases[3]. They occur predominantly in patients younger than twenty and in this age group 80% of tumours are located in the long bones of the extremities.[3] In patients older than 50 years, osteosarcomas of the extremities make up only 50% of cases with tumours of the pelvis and craniofacial bones increasing in frequency.

- *Chondrosarcomas*

Chondrosarcomas are malignant tumours of cartilaginous origin. They account for about 25% of bone sarcomas and the age-specific incidence of this type of sarcoma increases gradually with age. More than 50% of these tumours occur in the long bones of the extremities with other major sites being the pelvis and ribs.[4]

- *Ewing's sarcomas*

Ewing's sarcomas account for approximately 16% of bone sarcomas and are thought to have a neuroectodermal embryological origin. They occur most commonly in the bones of the extremities (48%) with the pelvis and ribs being other frequently involved sites.[3] A major peak for age-specific incidence for these tumours occurs in the second decade of life with a rapid decrease after the age of 20 years.

- *Spindle cell sarcomas*

There are a variety of other rare sarcomas of bone, for example, fibrosarcoma, malignant fibrous histiocytoma and leiomyosarcoma. These behave like osteosarcoma but typically arise in an older population.[2]

2.1.2 Soft Tissue Sarcomas (STS)

Soft tissue sarcomas are reported to account for about 1% of all malignant neoplasms[5]. Benign soft tissue tumours outnumber malignant by at least a factor of 100, and so identifying the small number of patients with sarcoma generates a considerable diagnostic workload for clinicians[6;7].

STS can occur anywhere that connective tissue is present and the signs and symptoms vary greatly depending on the anatomic site, as do the treatment options and prognosis.

- *Extremity and superficial trunk*

Extremity and superficial trunk sarcomas are estimated to account for over 50% of all STS[8;9]. The majority of these cases present with a painless mass. It can be difficult to differentiate a benign from a malignant mass but urgent referral guidelines have been published by NICE to identify patients more likely to have a malignant tumour (Table 1).[10]

Table 1 Features suggestive of malignancy in a lump

• Lump >5cm • Lump increasing in size • Lump deep to the fascia • Pain

NICE *Referral Guidelines for Suspected Cancer* 2005

- *Retroperitoneum*

Case series report that retroperitoneal sarcomas account for approximately 10-20% of all STS[11]. Most patients present with an abdominal mass, with half reporting pain at presentation. Due to the space available in the retroperitoneum these tumours may often grow to a substantial size before presenting and their overall prognosis of these patients is worse than for those with extremity sarcomas[12].

- *Viscera*

Sarcomas of the viscera present with signs and symptoms particular to the organ of origin. For example, gastro-intestinal stromal tumours (GIST), which occur primarily in the middle aged and older population, present with upper abdominal pain in 40-50% of cases[13]. Melaena, haematemesis or palpable tumour may also be presenting features. Sarcomas of the uterus often present with painless vaginal bleeding as occurs with other uterine malignancies[14].

- *Head and Neck*

Sarcomas can arise from bone, cartilage or the soft tissues of the head and neck. The majority occur in adults but, in children, 40% of soft tissue sarcomas that occur arise in the head and neck region[15]. They can present as a lump, with problems relating to compression of surrounding anatomy such as the orbit or pharynx.

Surgery and radiotherapy are difficult due to the proximity of important anatomy in this area.

2.2 Aetiology

2.2.1 Bone sarcomas

The majority of primary bone cancers develop *de novo* – however, there are some that are associated with environmental factors and others with non-neoplastic conditions or benign neoplasms[16-18].

Precursors of malignancy in bone sarcomas

- Multiple benign tumours of cartilage (e.g. Ollier's disease and Mafucci syndrome)
- Multiple osteochondromas
- Paget's disease involving several bones (polyostotic Paget's disease)
- Fibrous dysplasia and bone infarcts
- Bone cysts

Genetic Conditions

- Hereditary retinoblastoma
- Li-Fraumeni syndrome
- Rothmund Thompson syndrome

Environmental exposures

- Radiation
- Metallic and polyethylene implants

2.2.2 Soft Tissue Sarcomas

As with bone sarcomas the aetiology of most soft tissue tumours is unknown. The evolving classification, rarity and heterogeneity of sarcomas makes epidemiological studies difficult. Four recent reviews of the epidemiology of soft tissue sarcomas were identified and the findings are summarised below [18-21].

Host factors

- STS occur in the rare Li-Fraumeni syndrome where families are affected with germ-line mutations of the tumour suppressor gene p53. Other inherited disorders that predispose to STS include neurofibromatosis type 1, hereditary retinoblastoma, Werner's syndrome (adult progeria) and Gardner's syndrome (familial polyposis of the colon).
- Chronic lymphoedema, either congenital or following radical mastectomy, is also associated with lymphangiosarcomas.

Environmental factors

- External radiation therapy is a well-established cause of soft tissue sarcomas. Among patients treated for cancers of the breast, ovary, cervix, testes, non-Hodgkin's lymphoma, Hodgkin's disease and retinoblastoma, 8 to 50 fold increases in STS have been reported.

- STS have been reported after previous exposure to medicinal agents such as alkylating chemotherapeutic agents.
- Exposure to occupational chemicals such as thorotrast, herbicides, pesticides and vinyl chloride have also been associated with STS.

2.3 Trends in the Incidence of bone and STS

As tumours of the bone are comparatively uncommon, interpretation of trends is difficult – particularly in older age groups where the rarity of primary bone tumours means that any misclassification of secondary tumours could have a large impact on results. However, a study looking at cancer registry data from England and Wales between 1971 and 1992 reported no substantial change in the recorded incidence of bone cancers in the time period[22].

In contrast there have been increases in recent decades in the recorded incidence of soft tissue cancers in adults. These changes have not been attributed to changes in known risk factors, and may be due in part to the changes in reporting and coding.[22]

2.4 Survival and Prognostic Factors

2.4.1 Bone Sarcomas

Survival for patients with bone tumours has improved substantially over the last 30 years. A national study looking at the survival of adults aged 15 years or older with bone cancer of all types, found five year relative survival rates increased from 29% in 1971-75 to 51% in 1986-90[23]. The most important prognostic factors include the presence of detectable metastases at diagnosis, tumour volume, increasing age and response to chemotherapy[24].

The European cancer registry based study on survival and care of cancer patients (EUROCARE) aims to describe survival differences between European populations and the reasons for them. For adults diagnosed between 1990-1994 the survival rate for primary bone tumours in England and Wales (Table 2) were not significantly different from the average for Europe[25]. (It should be noted that small numbers are involved and there are potential differences in the quality of data available in different countries.)

Table 2 Five year survival for primary bone cancer in adults diagnosed between 1990 and 1994.

Country	MEN Age-standardised relative survival (%) and 95% CI	WOMEN Age-standardised relative survival (%) and 95% CI
England	51.4 (46.9-56.3)	54.8 (49.8-60.3)
Wales	42.9 (28.2-65.4)	37.1 (26.6-51.8)
Europe	53.0 (48.0-58.4)	56.3 (51.5-61.6)

Data from EUROCARE-3

2.4.2 Soft Tissue Sarcomas

Five year survival is between 50% and 60% for soft tissue sarcomas as a group[26]. However, there is wide variation depending on anatomical site and histological features of the tumours. For example, the 5-year disease specific acturial survival for localised extremity STS has been reported as 79%[27], whereas the 5-year survival rate for retroperitoneal sarcoma has been reported as 50%[12]. Data from EUROCARE-3 shows that the 5 year survival for tumours coded to 'malignant neoplasm of connective and soft tissue' (ICD-9 171) in England is not significantly different from Europe as a whole.

The prognosis for patients with limb and trunk STS is based on five factors: the patient's age, the presence of metastases at the time of presentation, the size of the tumour, its depth and its histopathological grade[27]. Tumours of grade 1 are treated as low grade and those of grades 2 and 3 are treated as high grade. Patients with retroperitoneal sarcomas have a poorer prognosis largely because these tumours present so late[28].

3 Current Incidence and Mortality, England and Wales

In this section of the document recent data for incidence and mortality for England and Wales is presented.

3.1 Methods

3.1.1 Data Sources

- Cancer registration data for England was provided by the National Cancer Intelligence Centre (NCIC) and the Welsh Cancer Intelligence and Surveillance Unit (WCISU) provided data for Wales.

  The national cancer registration system aims to collect data on everyone with a cancer diagnosis. The regional cancer registries collect data that is then forwarded to the national and Welsh units. NHS hospital trusts provided the majority of the information to registries and death certificates provide fall-back information. To complete the picture information is needed from hospices, the private sector and from primary care. Different registries vary as to the extent that these further sources are included in their databases[29].

- The Office of National Statistics (ONS) produces mortality data from the statutory registration process.

3.2 Classification Systems for Sarcomas

3.2.1 International Classification of Diseases (ICD)

This system of classifying diseases, in which neoplasms are categorised by site of primary tumour, is currently in its 10th Edition[30]. Tumours of bone and articular cartilage fall into specific categories within this system. However, it is more difficult for the ICD system to classify soft tissue tumours in a meaningful way as they can occur in any anatomical site. A category exists for tumours of the connective and soft tissue (C49), however, sarcomas occurring in visceral organs are often assigned the site code for the organ, rather than to the connective tissue code[22].

The current edition of this classification has been in use since 1996 for recording incidence and since 2001 for mortality. Some large studies of cancer such as the EUROCARE study continue to use the previous edition (ICD-9). The equivalent codes for malignancies of bone and soft tissue are outlined in Table 3.

Table 3 Equivalent ICD-9 and ICD-10 codes

	ICD-9	ICD-10	
Malignant neoplasm of bone and cartilage	170	C40	Malignant neoplasm of bone and cartilage of limbs
		C41	Malignant neoplasm of bone and articular cartilage of other and unspecified sites
Malignant neoplasm of connective and soft tissue	171	C47	Malignant neoplasm of peripheral and autonomic nervous system
		C49	Malignant neoplasm of other connective and soft tissue

3.2.2 World Health Organization Classification of Tumours

Tumours can also be classified according to their histological subtypes. During development of the scope for the sarcoma guidance it was agreed that the World Health Organization (WHO) histological classification of soft tissue and bone tumours would be used (Appendix A)[16]. The WHO classifies tumours of the nervous system separately from those of soft tissue[31], but it was agreed that neurofibrosarcomas/malignant peripheral nerve sheath tumours should be added to the list of soft tissue tumours. The term malignant soft tissue tumour, as defined by the WHO classification, is used as equivalent to the term soft tissue sarcoma.

It should be noted here that the histopathological diagnosis of sarcomas is difficult. For example, in peer review studies 6-24% of registered soft tissue and bone sarcomas were considered on re-examination not to be sarcomas while agreement on sarcoma subtype in these studies was only achieved in 53-75% of cases[32]. In addition diagnostic techniques and nomenclature are evolving – a recent Danish study reviewed cases diagnosed between 1972 and 1994 and found the diagnosis changed in 57% using modern criteria and tests[33].

3.3 Identifying sarcomas for the needs assessment

It was planned to search national cancer registry data for England and Wales using the WHO histological classification. Using this approach it was hoped that all registered sarcomas and the sites in which they occur would be identified. However, the National Cancer Intelligence Centre reported that as a number of cancers are registered with non-specific codes, it is not appropriate to search the database in this way. (See Appendix B for the breakdown by histology for tumours coded to the ICD-10 categories C40, C41, C47, C48 and C49 (1996-2000 England only)).

A request was also made to the East Anglia Cancer Registry and the results of this search are presented in paragraph 3.4.

Data for England and Wales are therefore presented by ICD categories, as is the convention for cancer registry data. Because of small numbers, 5 years of data were requested from the NCIC and the WCISU. The year 2000 was the most recent complete year of data, so data from 1996-2000 was provided. Data were presented by sex and by 5 year age bands.

3.3.1 Incidence of Malignant Bone Tumours

There were on average 427 malignant tumours of bone and articular cartilage (C40 & C41) registered each year in England and Wales during 1996-2000 (Table 4).

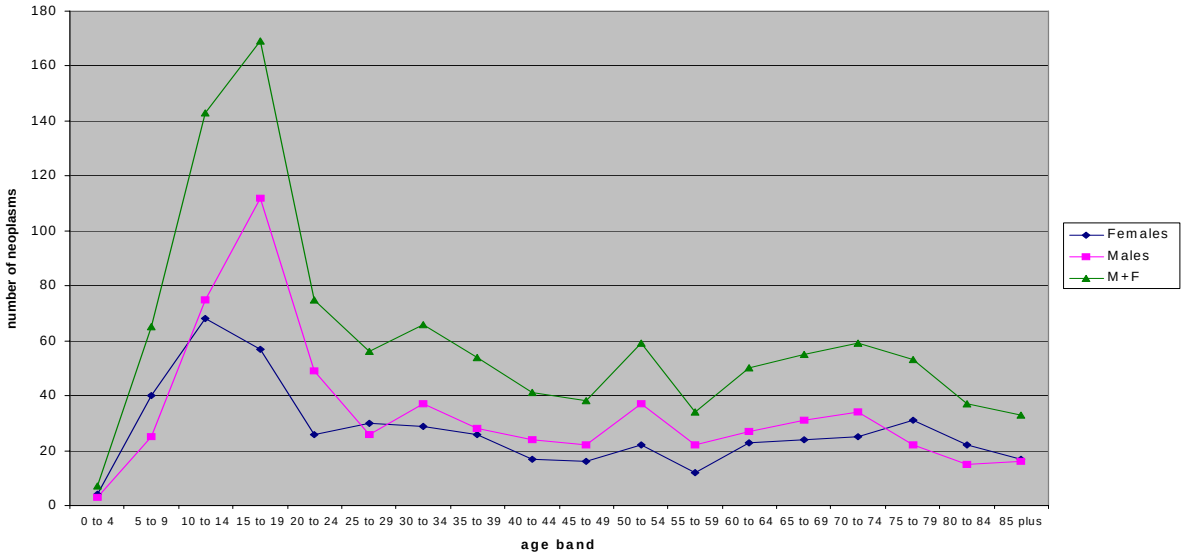
Table 4 Incidence of bone tumours in England and Wales, 1996-2000, all persons, crude rate per million population and European age standardised rates (EASR)

	Number 1996-2000	Annual Average	Crude Rate	EASR (95% c.i.)	M:F events	M:F rates
C40 Malignant neoplasm of bone and articular cartilage of limbs						
	1094	219	4.2	4.1(3.9-4.3)	1.24	1.15
C41 Malignant neoplasm of bone and articular cartilage of other and unspecified sites						
	1041	208	4.01	3.6 (3.4-3.8)	1.24	1.08
TOTAL	**2135**	**427**				

Source: Office of National Statistics

Figures 1 to 3 show the number of bone tumours occurring in each category C40 and C41 separately and combined. Figures 1 demonstrates the bimodal incidence for malignant tumours of the limbs.

Figure 1 Number of malignant neoplasms of bone and articular cartilage of limbs (ICD code C40), England and Wales, 1996-2000, by five year age groups



Source: Office of National Statistics

Figure 2 Number of malignant neoplasms of bone and articular cartilage of other and unspecified sites (C41), England and Wales, by five year age bands, 1996-2000

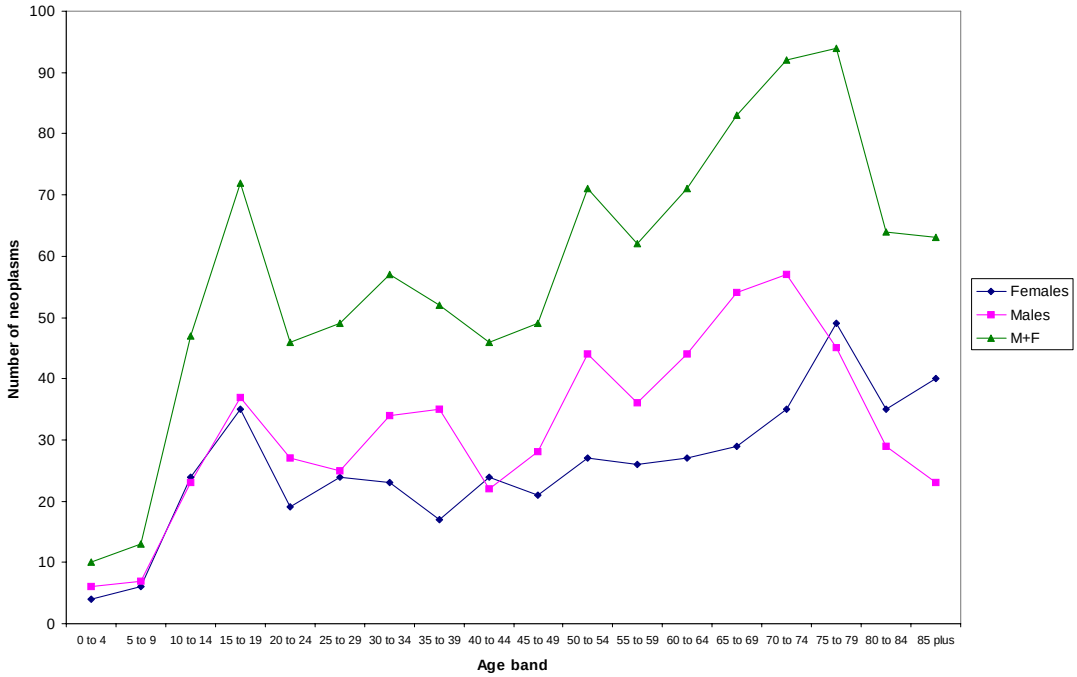
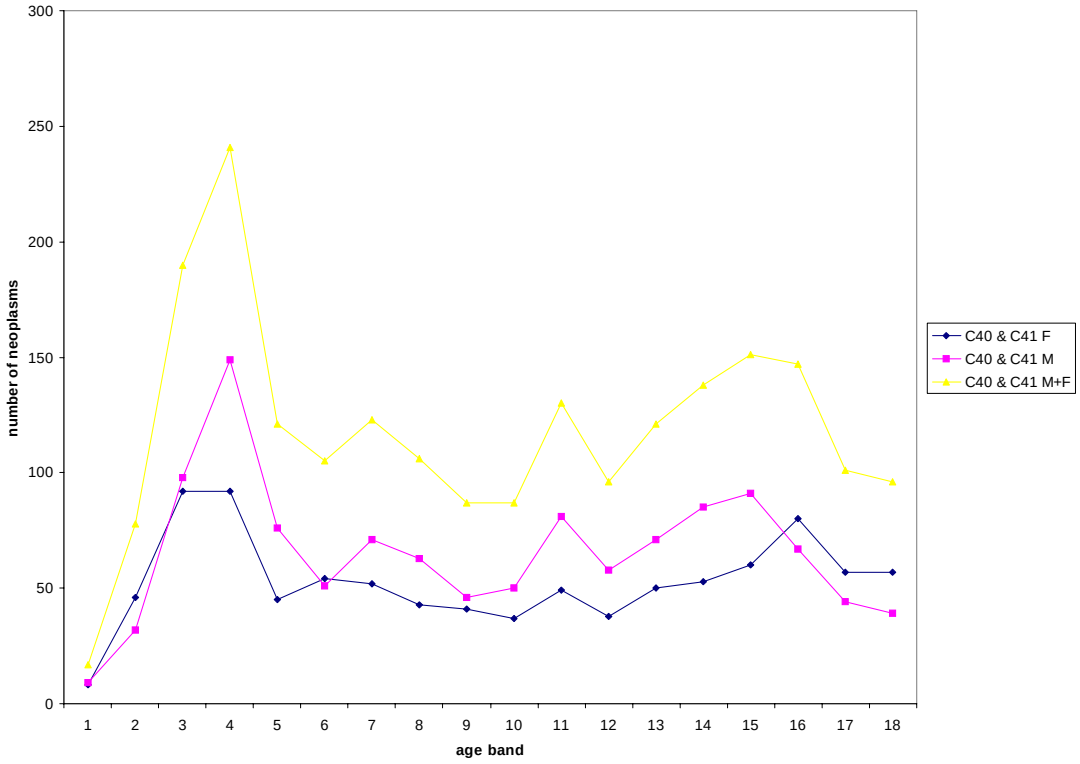


Figure 3 Number of malignant neoplasms of bone and articular cartilage of limbs (C40) and other unspecified sites (C41), England and Wales, by five year age bands, 1996-2000



Source: Office of National Statistics

3.3.2 Incidence of Malignant Soft Tissue Tumours

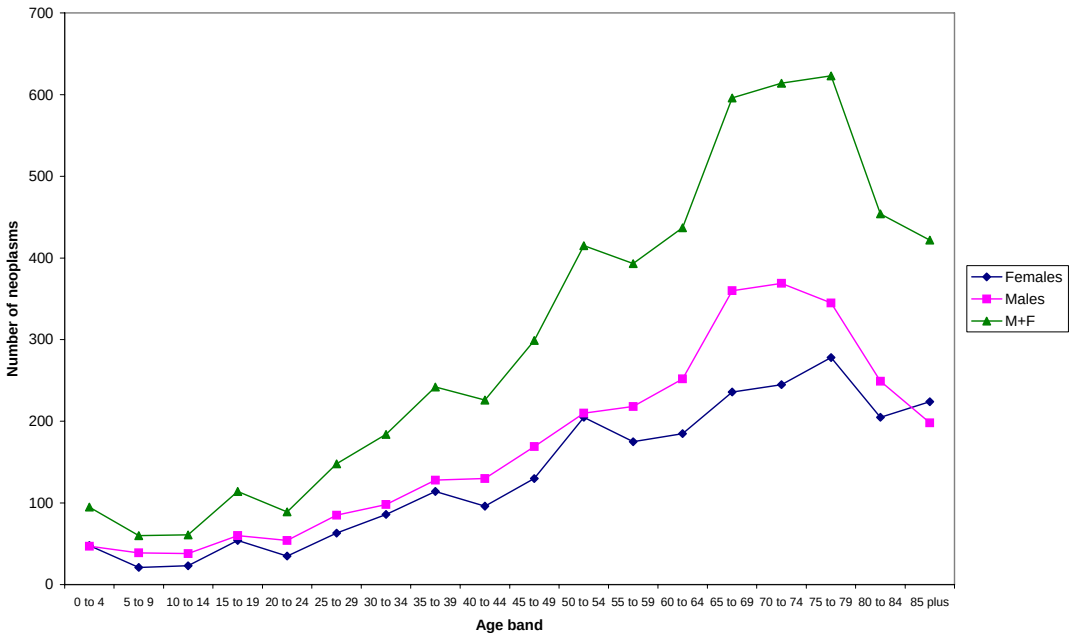
There were on average 1094 malignant neoplasms of 'other connective and soft tissue' (C49) registered each year in England and Wales during 1996-2000 (Table 5). For consistency between ICD-9 and ICD-10 the category C47 (peripheral and autonomic nerves) is included in the table.

Table 5 Incidence of soft tissue tumours England and Wales, 1996-2000, all persons, crude rate per million population, European standardised rates (EASR) and male:female ratios

	Number in 5 years	Average annual number	Crude Rate	EASR (95% c.i.)	M:F events	M:F rates
C47 Malignant neoplasm of peripheral nerves and autonomic nervous system						
	483	97	1.86	1.9(1.7-2.1)	1.1	1.0
C49 Malignant neoplasm of other connective and soft tissue						
	5472	1094	21.13	18.0 (17.5-18.5)	1.25	1.08

Figure 4 shows the total number of malignant connective and soft tissue tumours (C49) by 5 year age groups in England and Wales. The increasing incidence of these tumours with advancing age is shown.

Figure 4 Number of malignant neoplasms of other connective and soft tissue (C49), by five year age bands, England and Wales, 1996-2000



Source: Office of National Statistics

3.4 Data from the Eastern Cancer Registration and Information Centre (ECRIC)

In order to have a clearer idea about the number of tumours that might be registered in other ICD anatomical categories, a request was made to the Eastern Cancer Registry to search their data using the histology codes from the WHO classification for soft tissue tumours. The ECRIC, which covers the population of Norfolk, Suffolk, Hertfordshire and Bedfordshire, searched their database for the six years from 1996 to 2001. (1996 was chosen as a start date for the search as the 10th Edition of the ICD was adopted at this time.)

The search found 711 tumours and these were then categorised using the ICD-10 to see the proportion found in each anatomical site (Table 6). This approach will only identify tumours where the histological type has been documented. There may be tumours where this has not been recorded, and it is not known if this problem occurs equally in all anatomical sites.

The ECRIC data found that the majority of sarcomas (53%) were coded to C49, 4% to C47, 9% of sarcomas were coded to the retroperitoneum and peritoneum (C48), and 10% were found in the digestive organs and 9% in female genital organs. There were a wide variety of sites with a small number of sarcomas.

For England and Wales the yearly average of tumours in the C49 (connective and soft tissue) category is 1094. The ECRIC data found only 53% of soft tissue sarcomas were in this category. It might be estimated that, using the WHO classification, there are in the region of 2000 soft tissue sarcoma cases each year in all anatomical sites.

Table 6 Percentage of soft tissue sarcoma by anatomical site. Data from Eastern Cancer Registration and Information Centre.(1996-01)

	Number (percentage)
Other connective and soft tissue C49	380 (53%)
Digestive organs C15-C26	74 (10%)
Retroperitoneum and peritoneum C48	62 (9%)
Female genital organs C51-C57	62 (9%)
Other	38 (5%)
Peripheral nerves C47	27 (4%)
Male genital organs C61-C63	18 (3%)
Heart, mediastinum and pleura C38	18 (3%)
Kidney (except renal pelvis) and bladder C64+C67	17 (2%)
Breast C50	15 (2%)

3.4.1 Incidence of GIST

It is important to recognise that historical cancer registry data do not take into account the recent advances in the classification of gastro-intestinal stromal tumours (GIST). GIST are a form of soft tissue tumour of particular interest

because a targeted therapy (imatinib) has been developed. It has only recently been possible to classify GIST using immunohistochemistry and data on incidence are not yet available. Estimates of incidence vary widely, from 4 to 40 cases per million population, although recent data from Sweden suggest the incidence is in the region of 15 per million per year[34].

3.5 Mortality Data

The Office of National Statistics (ONS) produce mortality statistics (Series DH 2) based on information from death certificates. The cause of almost all deaths will have been certified by a medical practitioner or coroner. The published mortality statistics are usually based on a single, underlying cause of death selected by the ONS from the several causes that may be mentioned on the death certificate.

While the recording of deaths is close to 100% complete, there is the potential for error when the cause of death is recorded. However, these numbers (Table 7) do give an indication of the need for palliative care services for sarcoma patients.

Table 7 Mortality for bone and soft tissue tumours England and Wales, 2002, all persons, crude rate per Million population, European standardised rates (EASR) and male:female ratios

	Number of deaths registered	Crude Rate	EASR (95% c.i.)	M:F events	M:F rates
C40 Malignant neoplasm of bone and articular cartilage of limbs					
	35	0.67	0.6 (0.4-0.8)	2.89	3.33
C41 Malignant neoplasm of bone and articular cartilage of other and unspecified sites					
	207	3.97	3.6 (3.1-4.1)	1.59	2
C47 Malignant neoplasm of peripheral nerve and autonomic nervous system					
	21	0.40	0.4 (0.2-0.6)	1.33	1.67
C49 Malignant neoplasm of other connective and soft tissue					
	589	11.30	9.2 (8.5-9.9)	1.1	1.1

Data from Office of National Statistics (Series DH 2)

4 Hospital Activity

4.1 Present Knowledge

The diagnosis and surgical treatment of primary bone tumours are very complex and two supraregional bone tumour treatment centres were set up by the National Specialist Commissioning Advisory Group (NSCAG) in 1984 to provide ' investigation and treatment for patients who may have primary malignant bone tumours requiring endoprosthetic replacement.' It is recognised that the definition of the supraregional service is now redundant because of the many different ways in which primary bone tumours can be managed apart from endoprosthetic replacement. In 2005 NSCAG widened the definition and will commission services for the 'diagnosis and treatment of primary bone tumours'. Other units including Newcastle, Oxford, Bristol and Oswestry are now contracted to supply this service.

Management of patients with STS is not designated by NSCAG and this group of patients are treated by a range of clinicians. In many cases there is no clear pathway for patients with suspected sarcoma. Many patients with STS are still treated in district hospitals by non-specialists and delays in diagnosis are frequent despite guidelines about early referral for possible malignancy[35].

Non-surgical oncology treatment (.i.e. chemotherapy and radiotherapy) will often be carried out at a centre nearer the patient's home. This may be in a UKCCSG Centre for children or at an adult centre.

4.2 Hospital Activity Data

The following section looks at hospital activity data for patients with bone or soft tissue tumours in order to identify the main providers of care.

In England a Hospital Episode Statistic or HES record is produced for each episode of inpatient care *under a particular consultant* within a single hospital provider. Items recorded in this record include the date of admission, speciality of consultant, diagnosis (primary, subsidiary and first five secondary), the first four surgical procedure codes and date of discharge. Day surgery is included, but not outpatient attendances. In Wales the corresponding system is called Patient Episode Data for Wales (PEDW).

If responsibility for a patient is passed from one consultant to another, a separate HES record is produced for *each* of the consultant episodes. If a patient is moved from one hospital to another then a HES record is required at both hospitals. This means that several HES records could be produced for a single patient during an admission to hospital.

The HES/PEDW data used in this project were provided by Dr. Brian Cottier, Head of Cancer Services Analysis for the Department of Health. Patients recorded in the data supplied were those with a diagnosis of bone and soft tissue tumours classified according to the ICD-10. Categories for malignant tumours of bone and cartilage were C40 and C41 and the ICD-10 categories for malignant tumour of soft

tissue were C47, C48, C49 and also C38 (malignant neoplasm of heart, mediastinum and pleura). (See appendix C for a full list)

The ICD-10 categories listed above are termed 'musculoskeletal' tumours by the Cancer Services Analysis Team. It is likely that some of the patients in the soft tissue category have diagnoses other than sarcoma, but they cannot be separated in this analysis.

Sarcomas of other anatomical sites such as the gastro-intestinal tract or the uterus would account for a very small number of the tumours in these locations, so HES data for these categories were not included in the data provided.

4.3 Data Quality and Small Numbers

The following tables give data on the levels of activity within different trusts. However, given the small number of cases any variation in data quality and collection methods are likely to have a considerable impact.

The tables should therefore be viewed with consideration of their weaknesses, but are included in order to give an indication of where care is provided and who the main providers are.

Where the number of episodes is less than 6 the data cannot be published for reasons of confidentiality.

Activity for the year 1997/98 is under-reported compared to other years. This year is included where the analysis was looking to identify all possible trusts providing care in the most recent 5 year time period available (1997/98 – 2001/2).

4.4 Hospital Episodes by Cancer Network

Table 8 shows the number of Hospital Episodes recorded for all malignant 'musculoskeletal' tumours (C40, C41, C38, C47, C48 and C49) for all specialities (surgical and non-surgical) 1998/99 to 2001/2 by cancer network of the trust providing the care. While all cancer networks contain trusts treating these patients, activity varies. For example, there were 7,255 episodes recorded for the North London cancer network and 311 for the South Essex cancer network.

Table 8 Number of hospital episodes coded for malignant 'musculoskeletal' tumours by cancer network of hospital trust providing care. All specialities (98/99 to 2001/2)

CANCER NETWORK	Bone Tumours	Soft Tissue	**Total**
North London	4,708	2,547	**7,255**
Greater Manchester & Cheshire	1,915	4,454	**6,369**
South West London	1,337	3,473	**4,810**
Pan-Birmingham	2,227	1,873	**4,100**
Yorkshire	1,479	2,320	**3,799**
Northern	1,265	1,734	**2,999**
Avon, Somerset & Wiltshire	917	1,585	**2,502**

CANCER NETWORK	Bone Tumours	Soft Tissue	**Total**
North Trent	668	1,457	**2,125**
Central South Coast	937	1,176	**2,113**
West Anglia	699	1,260	**1,959**
Peninsula	662	1,255	**1,917**
Mid Trent	455	1,438	**1,893**
Merseyside & Cheshire	885	957	**1,842**
Leicestershire	721	854	**1,575**
Thames Valley	534	939	**1,473**
Lancashire & South Cumbria	213	1,235	**1,448**
North East London	404	539	**943**
South East London	331	595	**926**
Kent & Medway	289	612	**901**
West London	270	499	**769**
Norfolk & Waveney	183	521	**704**
Mid Anglia	232	451	**683**
North West Midlands	231	452	**683**
3 Counties	294	355	**649**
Humber & Yorkshire Coast	255	301	**556**
No Network Allocated	159	374	**529**
Mount Vernon	143	349	**492**
Dorset	69	409	**478**
Teeside, South Durham & North Yorkshire	118	304	**422**
Surrey, West Sussex & Hampshire	131	270	**401**
Black Country	189	210	**399**
Arden	117	265	**382**
Sussex	121	218	**339**
South Essex	157	154	**311**
Mount Vernon / West London	104	145	**249**
Derby/Burton	70	171	**241**
South West London / West London	111	124	**235**
Four Counties / Mount Vernon / Thames Valley	58	104	**162**
Northern / Teeside, South Durham & North Yorkshire	24	110	**134**
Mount Vernon / Thames Valley	45	81	**126**
Kent & Medway / Sussex	33	88	**121**
Mount Vernon / North London	50	63	**113**
3 Counties / Arden / Black Country / Pan-Birminghan	20	73	**93**
Black Country / Pan-Birmingham	7	73	**80**
Black Country / North West Midlands	27	49	**76**
Derby & Burton / North West Midlands / Pan-Birmingham	6	64	**70**
Greater Manchester & Cheshire / North West Midlands	7	55	**62**
Wales	2,079	3,287	**5,366**
Grand Total	**25,956**	**39,922**	**65,878**

4.5 Number of patients with a diagnosis of 'musculoskeletal cancer' per trust per year

The Cancer Services analysis team also provided data on the number of individual patients with musculoskeletal cancer admitted to trusts by year.

Table 9 shows the number of individual patients admitted by trust for the years 1998/99-2001/2 (all specialities). Patients are not double counted within each trust for this table, but if they were seen at more than one hospital during a year, then they would be counted for each of those hospitals.

There is a lot of variety between years. This may represent fluctuations in patient numbers, but may also indicate underlying problems with HES data collection.

Most activity was recorded at the Royal Orthopaedic Hospital, the Royal Marsden Hospital and University College London.

Table 9 Number of patients with malignant 'musculoskeletal' tumours seen at each trust, by year (all specialities).

(TOP 40 TRUSTS)

TRUST	1998-1999	1999-2000	2000-2001	2001-2002
Royal Orthopaedic Hospital NHS Trust	376	433	436	463
The Royal Marsden Hospital NHS Trust	440	345	449	404
University College London Hospitals NHS Trust	370	384	413	409
The Newcastle Upon Tyne Hospitals NHS Trust	333	349	351	346
The Royal National Orthopaedic Hospital NHS Trust	251	309	354	379
Leeds Teaching Hospitals NHS Trust	322	330	319	278
Sheffield Teaching Hospitals NHS Trust	202	233	221	222
University Hospitals Of Leicester NHS Trust	223	225	201	224
Southampton University Hospitals NHS Trust	226	195	170	171
North Bristol NHS Trust	226	177	180	170
University Hospital Birmingham NHS Trust	137	164	199	213
Oxford Radcliffe Hospital NHS Trust	154	152	171	231
Guy's & St Thomas' NHS Trust	158	154	168	141
Pennine Acute Hospitals NHS Trust	159	153	143	144
Christie Hospital NHS Trust	143	149	165	141
Addenbrooke's NHS Trust	145	142	145	159
Gloucestershire Hospitals NHS Trust	137	143	134	147
East Kent Hospitals NHS Trust	118	142	158	142
Norfolk & Norwich University Hospital NHS Trust	133	151	147	121
Lancashire Teaching Hospitals NHS Trust	131	140	153	116
Barts & The London NHS Trust	126	148	140	120
Plymouth Hospitals NHS Trust	105	139	140	142
South Tees Hospitals NHS Trust	139	118	123	140
United Bristol Healthcare NHS Trust	113	137	140	128
Central Manchester & Manchester Children's Hospitals	149	132	109	119
Southern Derbyshire Acute Hospitals NHS Trust	107	111	127	157
Moorfields Eye Hospital NHS Trust	91	147	114	138
Queen's Medical Centre, Nottingham Univ Hospital	123	125	119	116
South Manchester University Hospitals NHS Trust	115	127	129	105
Nuffield Orthopaedic NHS Trust	97	132	122	121
Nottingham City Hospital NHS Trust	123	98	122	127
Mid Essex Hospital Services NHS Trust	111	108	119	130
Barking, Havering & Redbridge Hospitals NHS Trust	153	113	97	102
St George's Healthcare NHS Trust	101	105	119	116
United Lincolnshire Hospitals NHS Trust	112	117	92	88
Royal Devon & Exeter Healthcare NHS Trust	86	103	116	104

TRUST	1998-1999	1999-2000	2000-2001	2001-2002
Brighton & Sussex University Hospitals NHS Trust	110	105	96	93
Portsmouth Hospitals NHS Trust	102	84	111	105
Royal United Hospital Bath NHS Trust	84	120	94	101
Royal Liverpool & Broadgreen Hospitals	99	87	101	107
(TOP 10 TRUSTS IN WALES)				
Cardiff and Vale NHS Trust	48	70	74	69
Swansea NHS Trust	87	64	57	40
Velindre NHS Trust	27	29	38	34
Conwy and Denbighshire NHS Trust	27	24	32	27
North West Wales NHS Trust	15	21	9	11
Carmarthenshire NHS Trust	23	21	20	16
Gwent Healthcare NHS Trust	20	19	22	25
Pontypridd and Rhondda NHS Trust	30	16	12	15
Pembrokeshire and Derwen NHS Trust	10	12	8	12
North East Wales NHS Trust	12	10	13	15

4.6 Number of patients by speciality

4.6.1 Surgical Specialities

The HES/PEDW data was then analysed by selected surgical specialities to try and identify the trusts with the greatest activity and also to see how many trusts the activity was spread over.

Table 10 shows the number of consultant episodes for malignant bone tumours (1997/8-2001/2 combined) for trauma and orthopaedic surgery, general surgery and plastic surgery. The small numbers involved mean that differences in coding practice will have had an impact, however, the data does show that activity is consistent with the expected pattern of a few trusts operating on most of these patients.

Due to the small numbers involved in some trusts, the surgical specialities selected have been combined in the table. The proportion of episodes coded under each speciality varied considerably by trust.

Table 10 Hospital episodes for malignant bone tumours (1997/8-2001/2 combined) for general surgery, plastic surgery and trauma and orthopaedic surgery

Top 20 Trusts	TOTAL
Royal Orthopaedic Hospital NHS Trust	**1,646**
The Royal National Orthopaedic Hospital NHS Trust	**724**
University College London Hospitals NHS Trust	**280**
The Newcastle Upon Tyne Hospitals NHS Trust	**153**
North Bristol NHS Trust	**86**
Nuffield Orthopaedic NHS Trust	**67**
Leeds Teaching Hospitals NHS Trust	**57**
Royal Liverpool & Broadgreen Hospitals	**54**
The Royal Marsden Hospital NHS Trust	**50**

Top 20 Trusts	TOTAL
University Hospitals Of Leicester NHS Trust	**48**
Swansea NHS Trust	**44**
Oxford Radcliffe Hospital NHS Trust	**33**
Norfolk & Norwich University Hospital NHS Trust	**31**
Mid Essex Hospital Services NHS Trust	**28**
Guy's & St Thomas' NHS Trust	**28**
Gwent Healthcare NHS Trust	**24**
Robert Jones & Agnes Hunt Orthopaedic Hospital	**22**
Cardiff & Vale NHS Trust	**22**
Royal United Hospital Bath NHS Trust	**21**
Sheffield Teaching Hospitals NHS Trust	**18**

Table 11 looks at the activity in the same surgical specialities for tumours coded to 'soft tissue'. While centres such as the Royal Marsden Hospital and the Royal Orthopaedic Hospital have a large number of episodes recorded for patients with malignant soft tissue tumours, it can be seen that recorded activity in these surgical specialities is spread more widely across trusts than it was for bone tumours. The analysis identified 65 trusts with more than 40 episodes coded over the period 1997/8 to 2001/2. 189 trusts showed at least some activity.

Table 11 Hospital episodes for malignant soft tissue tumours (1997/8-2001/2 combined) coded under general surgery, plastic surgery and trauma and orthopaedic surgery.

Top 40 Trusts	TOTAL
Royal Orthopaedic Hospital NHS Trust	756
The Royal Marsden Hospital NHS Trust	731
The Royal National Orthopaedic Hospital NHS Trust	494
The Newcastle Upon Tyne Hospitals NHS Trust	300
Leeds Teaching Hospitals NHS Trust	250
Swansea NHS Trust	238
Sheffield Teaching Hospitals NHS Trust	218
North Bristol NHS Trust	169
University College London Hospitals NHS Trust	159
Oxford Radcliffe Hospital NHS Trust	153
Guy's & St Thomas' NHS Trust	152
South Manchester University Hospitals NHS Trust	143
Cardiff & Vale NHS Trust	138
University Hospitals Of Leicester NHS Trust	130
Royal Liverpool & Broadgreen Hospitals	130
Plymouth Hospitals NHS Trust	124
Central Manchester & Manchester Children's Hospitals	122
Norfolk & Norwich University Hospital NHS Trust	116
Carmarthenshire NHS Trust	114
Nottingham City Hospital NHS Trust	108
Gwent Healthcare NHS Trust	104
Pontypridd & Rhondda NHS Trust	102
Royal United Hospital Bath NHS Trust	97
Nuffield Orthopaedic NHS Trust	86
Mid Essex Hospital Services NHS Trust	82

Top 40 Trusts	TOTAL
St Helens & Knowsley Hospitals NHS Trust	81
Lancashire Teaching Hospitals NHS Trust	80
Hull & East Yorkshire Hospitals NHS Trust	74
Royal Devon & Exeter Healthcare NHS Trust	73
Portsmouth Hospitals NHS Trust	70
Gloucestershire Hospitals NHS Trust	70
University Hospital Birmingham NHS Trust	69
Pennine Acute Hospitals NHS Trust	69
North East Wales NHS Trust	68
Conwy & Denbeighshire NHS Trust	68
Addenbrooke's NHS Trust	66
Pembrokeshire & Derwen NHS Trust	66
East Kent Hospitals NHS Trust	65
Robert Jones & Agnes Hunt Orthopaedic Hospital	64
Barking, Havering & Redbridge Hospitals NHS Trust	62

4.6.2 Clinical and Medical Oncology

Patients might receive non-surgical oncology treatment at different trusts to those where their surgery is performed. Tables 12 and 13 show the number of episodes coded to clinical or medical oncology.

Table 12 Hospital episodes coded to clinical or medical oncology (combined) for patients with malignant bone tumours (1997/98-2001/2 combined), by trust.

Top 30 Trusts	Episodes coded to Clinical and Medical Oncology Combined
University College London Hospitals NHS Trust	2,600
Christie Hospital NHS Trust	1,562
United Bristol Healthcare NHS Trust	489
Central Manchester & Manchester Children's Hospitals	482
Velindre NHS Trust	452
University Hospital Birmingham NHS Trust	423
Sheffield Children's NHS Trust	362
The Royal Marsden Hospital NHS Trust	360
Leeds Teaching Hospitals NHS Trust	274
Clatterbridge Centre For Oncology NHS Trust	270
Addenbrooke's NHS Trust	252
Sheffield Teaching Hospitals NHS Trust	222
The Newcastle Upon Tyne Hospitals NHS Trust	202
Barts & The London NHS Trust	192
University Hospitals Of Leicester NHS Trust	182
Nottingham City Hospital NHS Trust	167
Birmingham Children's Hospital NHS Trust	149
Great Ormond Street Hospital For Children	133
Hammersmith Hospitals NHS Trust	109
Lancashire Teaching Hospitals NHS Trust	103
Southampton University Hospitals NHS Trust	95
Hull & East Yorkshire Hospitals NHS Trust	90
Plymouth Hospitals NHS Trust	79

Top 30 Trusts	Episodes coded to Clinical and Medical Oncology Combined
Northern Lincolnshire & Goole Hospitals NHS Trust	76
Royal Devon & Exeter Healthcare NHS Trust	75
North Staffordshire Hospital NHS Trust	71
Norfolk & Norwich University Hospital NHS Trust	66
North West Wales NHS Trust	62
Swansea NHS Trust	60
Portsmouth Hospitals NHS Trust	60

Table 13 Hospital episodes coded to clinical and medical oncology for patients with malignant soft tissue tumours (1997/98-2001/2 combined), by trust.

Top 30 Trusts	Episodes coded to Clinical and Medical Oncology combined
Christie Hospital NHS Trust	2,853
The Royal Marsden Hospital NHS Trust	1,202
Velindre NHS Trust	1,024
Central Manchester & Manchester Children's Hospitals	1,019
University College London Hospitals NHS Trust	955
Lancashire Teaching Hospitals NHS Trust	764
United Bristol Healthcare NHS Trust	739
Leeds Teaching Hospitals NHS Trust	697
Sheffield Teaching Hospitals NHS Trust	556
University Hospital Birmingham NHS Trust	509
Addenbrooke's NHS Trust	435
Great Ormond Street Hospital For Children	417
Nottingham City Hospital NHS Trust	385
The Newcastle Upon Tyne Hospitals NHS Trust	379
Sheffield Children's NHS Trust	376
Southampton University Hospitals NHS Trust	316
Hammersmith Hospitals NHS Trust	293
Oxford Radcliffe Hospital NHS Trust	256
Plymouth Hospitals NHS Trust	251
University Hospitals Of Leicester NHS Trust	248
East Kent Hospitals NHS Trust	247
Swansea NHS Trust	230
Royal Devon & Exeter Healthcare NHS Trust	170
Barts & The London NHS Trust	169
United Lincolnshire Hospitals NHS Trust	156
Birmingham Children's Hospital NHS Trust	152
Clatterbridge Centre For Oncology NHS Trust	142
Norfolk & Norwich University Hospital NHS Trust	141
Poole Hospitals NHS Trust	121
Guy's & St Thomas' NHS Trust	118

4.6.3 Paediatric Specialities

Children and young people with sarcomas may have their hospital episodes coded under a variety of specialities. Table 14 lists hospital episodes for patients with malignant and soft tissue tumours that are coded to paediatric specialities. Paediatric surgery is combined with paediatrics due to the small numbers coded at some trusts.

Table 14 Number of consultant episodes (all types) coded to paediatrics and paediatric surgery, for patients with malignant tumours of bone and articular cartilage and soft tissue, 1998-2002.

Top 20 Trusts	Episodes coded to paediatrics and paediatric surgery
Leeds Teaching Hospitals NHS Trust	1,562
University College London Hospitals NHS Trust	1,195
The Newcastle Upon Tyne Hospitals NHS Trust	1,190
The Royal Marsden Hospital NHS Trust	1,121
Cardiff & Vale NHS Trust	810
Southampton University Hospitals NHS Trust	736
Oxford Radcliffe Hospital NHS Trust	475
University Hospitals Of Leicester NHS Trust	458
Royal Liverpool Childrens NHS Trust	445
Addenbrooke's NHS Trust	387
Queen's Medical Centre, Nottingham Univ Hospital	350
Gloucestershire Hospitals NHS Trust	283
Royal Cornwall Hospitals NHS Trust	214
The Royal Wolverhampton Hospitals NHS Trust	202
North Staffordshire Hospital NHS Trust	202
United Bristol Healthcare NHS Trust	161
Birmingham Children's Hospital NHS Trust	151
Plymouth Hospitals NHS Trust	147
Royal Devon & Exeter Healthcare NHS Trust	122
Brighton & Sussex University Hospitals NHS Trust	117
East Kent Hospitals NHS Trust	98
Northampton General Hospital NHS Trust	94
Central Manchester & Manchester Children's Hospitals	78
Chelsea & Westminster Healthcare NHS Trust	70

4.7 Main procedures performed

HES/PEDW data with details of operative procedures performed was also supplied. Several different procedures may be carried out during an episode and the data was analysed by the main procedures. A large number of codes were used by the trusts, with often only small numbers of patients coded as undergoing a particular procedure. Table 15 shows examples of procedure codes for patients with bone tumours. Procedures recorded for soft tissue tumours are often non-specific, with ‘Other operation on soft tissue’ being the most common procedure coded for soft tissue tumours (Table 16).

Table 15 Examples of operative procedure codes for patients with malignant tumours of bone and joints. Number of procedures performed 1998-2002 combined, by trust.

TRUST	Diagnos-tic puncture of bone	Extirpation of lesion of bone	Prosthetic replace-ment of bone	Total excision of bone	Other excision of bone	Other open operation s on bone	Amputation of arm	Amputation of leg	Other auto-graft of bone
Royal Orthopaedic Hospital	64	72	171	4	181	137	25	111	7
The Royal National Orthopaedic Hospital	122	115	132	*	40	13	13	44	14
University College London	83	43	42	12	12			17	9
The Newcastle Upon Tyne	42	14	12	*	20	14	6	14	*
The Royal Marsden	46			*	*		10	9	
Nuffield Orthopaedic		20	10		*	9	*	*	6
North Bristol NHST Trust		10	*	15	*	14		21	*
Univesity Hospitals of Leicester	20	*	*	*	*	*		*	*
Central Manchester and Manchester Childrens	35			*			*	*	

Table 16 Number of operations coded to ‘other operations on soft tissue’ performed on patients with malignant soft tissue tumours 1998-2002, by trust.

TRUST	Other operations on soft tissue
The Royal Marsden Hospital	359
Royal Orthopaedic Hospital	211
Royal National Orthopaedic Hospital	215
The Newcastle Upon Tyne Hospital	100
Leeds Teaching Hospital	49
Nuffield Orthopaedic NHS Trust	26
University College London Hospitals	51
South Manchester University Hospitals	52
Sheffield Teaching Hospitals	51
Robert Jones and Agnes Hunt Orthopaedic	16
North Bristol NHS Trust	45
Central Manchester & Children's	15
Royal Liverpool and Broadgreen Hospitals	25
Nottingham City Hospital NHS Trust	35
University Hospitals of Leicester	26
Plymouth Hospitals	24
Guy's and St Thomas'	24
Royal Devon and Exeter	25
Gloucestershire Hospitals	16
Portsmouth Hospitals	16

5 Service Provision

This section attempts to describe the current service provision for patients suffering from bone and soft tissue sarcomas.

5.1 Survey of Cancer Networks and Hospital Trusts

5.1.1 Background

The review of HES and PEDW data supported the understanding that while a few centres provide surgery for bone sarcomas the provision of non-surgical oncology and surgery for STS is more widespread. In order to supplement the data the Guideline Development Group agreed that a questionnaire should be sent to the cancer networks in England and also to centres in Wales. The questionnaire aimed:

- to describe referral patterns across England and Wales for both bone and soft tissue sarcomas;

- to identify trusts where biopsies and operative procedures are performed;

- to identify trusts where a specific multi-disciplinary team (MDT) is in place, including a description of:

a) the staff make-up of the MDT
b) and how often the team meets.

The questionnaire also aimed to gather information about designated beds for sarcoma patients, specialist nurse provision and recruitment to clinical trials. Locally produced guidance for primary care providers and locally produced information for patients was also sought.

5.2 Methods

The questionnaire was sent electronically to the lead clinicians for the 34 cancer networks in England and to the 3 cancer networks in Wales on 23rd April 2004. This was followed up a month later by telephone contact with the clinicians or network managers and re-sending of the questionnaire if required.

Cancer networks responded to the questionnaire in different ways. Some collected and collated responses from all the trusts in their network, while others sent out the questionnaire for the individual trusts to return themselves.

The response to the questionnaire was fairly patchy. So throughout July and August 2004 all outstanding cancer networks were contacted by telephone and an outline description of services for sarcoma patients was asked for. Thirty one out of the 37 cancer networks were able to provide some

information in the time available. In order to get further details about activity and the existence and structure of MDTs the HES data was reviewed to ensure that information was available for the 5 trusts coding the most activity for bone tumours and the 10 trusts coding the most activity for soft tissue tumours. Any trusts where no information had been received were contacted directly by telephone.

Information was therefore provided by a variety of people, including surgeons, oncologists, nurse specialists and cancer network managers.

5.3 Results

5.3.1 Diagnostic Steps

5.3.1.1 Where are patients with 'lumps and bumps' usually seen?

Only 1 trust was identified that had a specific 'lumps and bumps' clinic set up.

Comments received suggested that patients would usually be referred to the appropriate outpatient clinic depending on location of tumour.

5.3.1.2 Availability of imaging

All trusts responding reported that ultrasound guided biopsy, CT scans and MRI scans were available for their patients. Outpatient waiting times varied from less than 2 weeks for all imaging to over 3 months wait for CT and MRI scans. As expected access to PET scanners was more varied. Some trusts reported that they had no access to PET, while patients from other trusts travelled to other cancer networks for scans. Three trusts reported having PET on site, a further 3 plan to have these scanners in the near future.

5.3.1.3 Would a biopsy be taken at your hospital if a primary bone tumour was suspected?

Of 59 trusts responding to this question 11 (19%) trusts would biopsy a suspected bone tumour and 48 (81%) would not.

5.3.1.4 Would a biopsy be taken at your hospital if a soft tissue sarcoma was suspected?

Of 59 trusts responding 32 trusts (54%) would biopsy a suspected STS.

5.3.1.5 Are there locally produced referral guidelines for GPs?

Most responders suggested that the GP referral guidelines for suspected sarcoma would be used[10]. The following three areas reported some sort of locally developed guidance:

- South West Cancer Intelligence Service Sarcoma Group
- Sheffield Hospitals
- Oxford.

5.3.2 Referral Pathways and Surgery

5.3.2.1 Where are bone tumours referred for surgery?

The responses to the survey (Table 17) reflected the activity shown in the HES/PEDW data – with the largest number of cancer networks having links with the Royal Orthopaedic Hospital and the Royal National Orthopaedic Hospital.

Table 17 Trusts where patients with bone tumours are referred for surgery

Name of Centre	Number of Cancer Networks where at least one trust in the network refers to the centre. (Networks can refer to more than one centre)
Royal Orthopaedic Hospital	11
Royal National Orthopaedic	11
UCL/Middlesex	3
Nuffield Orthopaedic	2
Newcastle Hospitals	2
Avon Orthopaedic Hospital	2
Robert Jones and Agnes Hunt	1
Guy's and St Thomas	1
University Hospital Leicester	1

5.3.2.2 Where do people with STS (extremities) have surgery?

Twenty two different trusts were named as providing surgery for STS extremities, across a wide range of cancer networks.

5.3.2.3 Details of planned surgery

It was hoped that details from trusts could be used to complement HES/PEDW data. Unfortunately data was fairly incomplete for this section.

- *Planned surgery on primary bone tumours*

The number of planned operations on primary bone tumours ranged from 10 per year (1 surgeon) to 130 per year (4 surgeons).

- *Planned surgery on soft tissue sarcomas*

Reported planned operations on STS extremities and retroperitoneal sarcomas (combined) varied from 10 to 14 procedures per year in one trust up to 194 procedures per year in another.

- *Planned surgery on GIST and gynaecological sarcomas*

Few trusts were able to report activity for these tumours. The highest number of reported operations per trust on patients with GIST was 10 per year and the highest number of operations on gynaecological sarcomas was 15 per year.

5.3.3 Existing Multidisciplinary Teams (MDTs), staff and other facilities

5.3.3.1 Trusts with Sarcoma Specific MDTs

Nineteen trusts reported having a sarcoma specific MDT in place, one of the teams being non-surgical sarcoma management only. Table 18 summarises the membership of the teams.

Table 18 MDT membership

MDT Member	Frequency
Lead clinician	19
Lead oncologist/radiotherapist	19
Lead surgeon	18
Lead pathologist	17
Lead imaging	18
Psychological support	0
Nurse	13
Palliative care	2
OT	1
Physiotherapist	7
Plastic surgeon	9
Other	
Social Worker	2
Admissions Officer	1
MDT Co-ordinator	3
Data manager	2
Sarcoma Research Sister	1

Psychological support, palliative care and occupational therapy were identified as being part of the 'extended' MDT by one trust. This may be the case at other trusts but was not identified by the questionnaire.

Four teams reported routinely inviting the referring clinician to their meetings.

One team reported having teleconferencing available with another team planning to use this in the near future.

Several responders commented that non-extremity sarcomas such as those of the gastro-intestinal tract and uterus would be discussed at the relevant site specific MDT.

Twelve of the MDTs reported how frequently they met:

- 5 meet weekly
- 6 meet fortnightly
- 1 as required.

5.3.3.2 Shared Care Protocols

Two trusts carrying out surgery on patients with sarcomas reported that shared care protocols were in use when patients were referred to a trust nearer their home for chemotherapy and radiotherapy. Other respondents suggested that individual clinician to clinician discussions took place.

5.3.3.3 Nurse Specialists working with Sarcoma patients

Table 19 summarises the nurse specialists identified by the survey.

Table 19 Nurse Specialists

TRUST	
1	1 cancer nurse specialist (CNS) Sarcoma research sister
2	Sarcoma CNS
3	Lead cancer nurse in orthopaedics
4	Nurse consultant orthopaedic cancer CNS orthopaedics
5	3 x CNS
6	3 x sarcoma research 1 CNS sarcoma 1 CNS rehabilitation
7	1 CNS
8	1 CNS
9	1 CNS
10	Nurse practitioner – shared
11	Orthopaedic oncology CNS
12	1 CNS pain management and tissue viability

5.3.3.4 Patients recruited for clinical trials in the last year?

Few trusts reported recruiting patients to clinical trials for sarcoma patients in the previous year. This will of course reflect the number of trials that are recruiting during the period. Table 20 summarises the number of patients recruited to clinical trials.

Table 20 Number of patients recruited to clinical trials

TRUST	
1	20
2	10
3	7
4	2
5	2
6	1
7	1

5.3.3.5 Designated beds

Three of the larger centres reported having a dedicated ward for admissions for bone and soft tissue tumours. Two other trusts reported having six and two beds respectively.

5.3.3.6 Rehabilitation

Three ‘sarcoma specific’ physiotherapists were identified by the survey and seven MDTs reported including a physiotherapist. One centre has an intensive rehabilitation ward, but suggested, as did all other centres responding, that rehabilitation was for the most part carried out nearer to the patients’ homes.

Links to replacement limb centres were also highlighted by trusts performing surgery.

5.3.3.7 Patient Information

BACUP was the most widely used. The Christie Hospital and Leeds have locally developed information for patients.

5.3.3.8 Patient Databases

Nine of the trusts surveyed had a specific database for sarcoma patients.

5.3.3.9 Cancer Network Tumour Groups

At the time of the survey 11 networks had some form of network-wide sarcoma tumour group in place. One ‘virtual’ tumour group was also planned. Frequency of meetings varied from three to six monthly.

6 General Conclusion

Incidence

- Sarcomas are rare tumours.

- There are approximately **400** patients diagnosed with bone sarcomas in England and Wales each year.

- The incidence of soft tissue sarcomas is more difficult to estimate. They occur in locations all over the body and so do not fit easily into the ICD-10 classification system. There are also many histological types and the pathological diagnosis is difficult. There may be up to **2000** soft tissue sarcomas occurring each year in England and Wales in all anatomical locations.

- Historical cancer registry data do not take into account the recent advances in the diagnosis of GIST.

Hospital Activity

- The hospital activity data available suggests that surgery for bone sarcomas is limited to a small number of hospitals, whereas surgery for soft tissue sarcomas and non-surgical oncology is provided more widely.

Existing Multidisciplinary Teams

- 18 MDTs involving surgical teams were identified. One non-surgical MDT was also identified.

7 References

1. Ries LAG, Kosary CL, Hankey, BF et al. (1999) *SEER Cancer Statistics Review, 1973-1996.* Bethesda National Cancer Institute.

2. Grimer R (2005) Primary and secondary tumours of bone. *Surgery* 23:30-5.

3. Dorfman HD, Czerniak B (1995) Bone Cancers. *Cancer* 75:203-10.

4. Bjornsson J, McLeod RA, Listrup DM et al. (1998) Primary chondrosarcoma of long bones and limb girdles. *Cancer* 83:2105-19.

5. Storm HH (1994) Cancers of the soft tissues. *Cancer Surveys: Trends in Cancer Incidence and Mortality* 19/20:197-217.

6. Rydholm A. (1998) Improving the management of soft tissue sarcoma. *British Medical Journal* 317:93-4.

7. Rosenthal TC, Kraybill W (1999) Soft tissue sarcomas: Integrating primay care recognition with tertiary care center treatment. *American Family Physician* 60:567-72.

8. Rydholm A (1998) Improving the management of soft tissue sarcoma. *British Medical Jorunal* 317:93-4.

9. Pisters PWT, Casper WS, Mann GN et al. (2005) Soft-tissue sarcomas. In: Pazdur R, Hoskins WJ, Coia LR, Wagman LD, editors. *Cancer Management: A multidisciplinary approach.* CMP Healthcare Media.

10. National Institute for Health and Clinical Excellence (2005) *Referral guidelines for suspected Cancer: Clinical Guideline 27.* London: National Institute for Health and Clinical Ecellence.

11. McGrath PC (1994) Retroperitoneal sarcomas. *Seminars in Surgical Oncology* 10:364-8.

12. Mendenhall WM, Zlotecki RA, Hochwald SN et al. (2005) Retroperitoneal soft tissue sarcoma. *Cancer* 104:669-75.

13. Miettinen M, Sarlomo-Rikala M, Lasota J (1998) Gastrointestinal stromal tumours. *Annales Chirurgiae et Gynaecologiae* 87:278-81.

14. Gonzalez-Bosquet E, Martinez-Palones JM, Gonzalez-Bosquet J et al. (1997) Uterine sarcoma: a clinicopathological study of 93 cases. *European Journal of Gynaecology and Oncology* 18:192-5.

15. Figueiredo MTA, Marques LA, Campos-Filho N (1998) Soft-tissue sarcomas of the head and neck in adults and children: Experience at a single institution with a review of literature. *International Journal of Cancer* 41:198-200.

16. World Health Organisation (2002) *Pathology and Genetics: Tumours of Soft Tissue and Bone*. IARC Press..

17. Precancerous Conditions (1998) In: Dorfman HD, Czerniak B, editors. *Bone Cancers*. St.Louis: Mosby.

18. McClay EF (1989) Epidemiology of bone and soft tissue sarcomas. *Seminars in Oncology* 16:264-72.

19. Zahm SH, Fraumeni JFJr (1997) The epidemiology of soft tissue sarcoma. *Seminars in Oncology* 24:504-14.

20. Olsson, H (2004) An updated review of the epidemiology of soft tissue sarcoma. *Acta Orthopaedica Scandiniavica* 311 16-17.

21. Olsson, H (1999) A review of the epidemiology of soft tissue sarcoma. *Acta Orthopaedica Scandiniavica* 285: 8-10.

22. Swerdlow A, dos Santos Silva I, Doll R (2001) *Cancer Incidence and Mortality in England and Wales. Trends and risk factors*. Oxford University Press.

23. Coleman MP, Babb P, Damiecki P et al. (1999) *Cancer Survival Trends in England and Wales, 1971-1995. Deprivation and NHS Region.* . London, The Stationery Office.

24. Saeter G, Elomaa I, Wahlqvist Y et al. (1997) Prognostic factors in bone sarcomas. *Acta Orthopaedica Scandiniavica* (Suppl.) 273:156-60.

25. Santi M, Aareleid T, Berrino F, et al. (2003) EUROCARE-3: Survival of cancer patients diagnosied 1990-94 - results and commentary. *Annals of Oncology* 14(Suppl. 5): v61-v118.

26. Storm H, Hat EWG (1998) Survival of adult patients with cancer of soft tissues or bone in Europe. *European Journal of Cancer* 34:2212-7.

27. Weitz J, Anonescu CR, Brennan MF (2003) Localized extremity soft tissue sarcoma: Improved knowledge with unchanged survival over time. *Journal of Clinical Oncology* 21:2719-25.

28. McGrath P (1994) Retroperitoneal sarcomas. *Seminars in Surgical Oncology* 10:364-8.

29. Leadbeter D (2000) *Harnessing Official Statistics.* Radcliffe Medical Press.

30. World Health Organisation (2002) *International Statistical Classification of Diseases and Related Health Problems*. 10th Edition. Geneva: World Health Organisation.

31. World Health Organisation (2002).*Pathology and genetics of tumours of the nervous system.* Lyon: IARC Press.

32. Nijhuis PHA (2001) *Soft tissue sarcoma at the turn of the millenium*. University of Groningen. Thesis/Dissertation

33. Daugaard S (2004) Current soft-tissue sarcoma classifications. *European Journal of Cancer* 40:543-8.

34. Nilsson Beal (2005) Gastrointestinal stromal tumours. The incidence, prevalence, clinical course and prognostication in the pre-imatinib/mesylate era. *Cancer* 103:821-9.

35. Glencross J, Balasubramanian SP, Bacon J, et al (2003) An audit of the management of soft tissue sarcoma within a health region in the UK. *European Journal of Surgical Oncology* 29:670-5.

8 Appendices

8.1 APPENDIX A WHO Classification of Tumours of Soft Tissue and Bone

Tumours of Soft Tissue and Bone
(Fletcher CDM Unni K, Mertens K. editors (2002)
WHO Classification of Tumours
Pathology and Genetics of Tumours of Soft Tissue and Bone
Lyon France: IARC Press

Classification of Bone Tumours

CARTILAGE TUMOURS

Osteochondroma	M9210/0
Chondroma	M9220/0
Enchondroma	M9220/0
Periosteal chondroma	M9221/0
Multiple chondromatosis	M9220/1
Chondroblastoma	M9230/0
Chondromyxoid fibroma	M9241/0
Chondrosarcoma	M9220/3
Central, primary, and secondary	M9220/3
Peripheral	M9221/3
Dedifferentiated	M9243/3
Mesenchymal	M9240/3
Clear Cell	M9242/3

OSTEOGENIC TUMOURS

Osteoid osteoma	M9191/0
Osteoblastoma	M9200/0
Osteosarcoma	M9180/3
Conventional	M9180/3
chondroblastic	M9181/3
fibroblastic	M9182/3
osteoblastic	M9180/3
Telangiectatic	M9183/3
Small cell	M9185/3
Low grade central	M9187/3
Secondary	M9180/3
Parosteal	M9192/3
Periosteal	M9193/3
High grade surface	M9194/3

FIBROGENIC TUMOURS	
Desmoplastic fibroma	M8823/0
Fibrosarcoma	M8810/3
FIBROHISTIOCYTIC TUMOURS	
Benign fibrous histiocytoma	M8830/0
Malignant fibrous histiocytoma	M8830/3
EWING SARCOMA/PRIMITIVE NEUROECTODERMAL TUMOUR	
Ewing sarcoma	M9260/3
HAEMATOPOIETIC TUMOURS	
Plasma cell myeloma	M9732/3
Malignant lymphoma, NOS	M9590/3
GIANT CELL TUMOUR	
Giant cell tumour	M9250/1
Malignancy in giant cell tumour	M9250/3
NOTOCHORDAL TUMOURS	
Chordoma	M9370/3
VASCULAR TUMOURS	
Haemangioma	M9120/0
Angiosarcoma	M9120/3
SMOOTH MUSCLE TUMOURS	
Leiomyoma	M8890/0
Leiomyosarcoma	M8890/3
LIPOGENIC TUMOURS	
Lipoma	M8850/0
Liposarcoma	M8850/3
NEURAL TUMOURS	
Neurilemmoma	M9560/0

MISCELLANEOUS TUMOURS	
Adamantinoma	M9261/3
Metastatic malignancy	
MISCELLANEOUS LESIONS	
Aneurysmal bone cyst	
Simple cyst	
Fibrous dysplasia	
Osteofibrous dysplasia	
Langerhans cell histiocytosis	M9751/1
Erdheim-Chester disease	
Chest wall hamartoma	
JOINT LESIONS	
Synovial chondromatosis	M9220/0

Soft tissue tumour sites

ADIPOCYTIC TUMOURS	
BENIGN	
Lipoma	M8850/0
Lipomatosis	M8850/0
Lipomatosis of nerve	M8850/0
Lipoblastoma/ Lipoblastomatosis	M8881/0
Angiolipoma	M8861/0
Myolipoma	M8890/0
Chondroid lipoma	M8862/0
Extrarenal angiomyolipoma	M8860/0
Extra-adrenal myelolipoma	M8870/0
Spindle cell/	M8857/0
Pleomorphic lipoma	M8854/0
Hibernoma	M8880/0
Intermediate (locally aggressive)	
Atypical lipomatous tumour/	
Well differentiated liposarcoma	M8851/3
Malignant	
Dedifferentiated liposarcoma	M8858/3
Myxoid liposarcoma	M8852/3
Round cell liposarcoma	M8853/3
Pleomorphic liposarcoma	M8854/3
Mixed-type liposarcoma	M8855/3
Liposarcoma,	
not otherwise specified	M8850/3

FIBROBLASTIC / MYOFIBROBLASTIC TUMOURS

Benign	
Nodular fasciitis	
Proliferative fasciitis	
Proliferative myositis	
Myositis ossificans	
fibro-osseous pseudotumour of digits	
Ischaemic fasciitis	
Elastofibroma	M8820/0
Fibrous hamartoma of infancy	
Myofibroma / Myofibromatosis	M8824/0
Fibromatosis colli	
Juvenile hyaline fibromatosis	
Inclusion body fibromatosis	
Fibroma of tendon sheath	M8810/0
Desmoplastic fibroblastoma	M8810/0
Mammary-type myofibroblastoma	M8825/0
Calcifying aponeurotic fibroma	M8810/0
Angiomyofibroblastoma	M8826/0
Cellular angiofibroma	M9160/0
Nuchal-type fibroma	M8810/0
Gardner fibroma	M8810/0
Calcifying fibrous tumour	
Giant cell angiofibroma	M9160/0
Intermediate (locally aggressive)	
Superficial fibromatoses (palmar/ plantar)	M8821/1
Desmoid-type fibromatoses	
Lipofibromatosis	
Intermediate (rarely metastasizing)	
Solitary fibrous tumour	M8815/1
and haemangiopericytoma	M9150/1
(incl. lipomatous haemangiopericytoma)	
Inflammatory myofibroblastic tumour	M8825/1
Low grade myofibroblastic sarcoma	M8825/3
Myxoinflammatory fibroblastic sarcoma	M8811/3
Infantile fibrosarcoma	M8814/3
Malignant	
Adult fibrosarcoma	M8810/3
Myxofibrosarcoma	M8811/3
Low grade fibromyxoid sarcoma hyalinizing spindle cell tumour	M8811/3
Sclerosing epithelioid fibrosarcoma	M8810/3

SO-CALLED FIBROHISTIOCYTIC TUMOURS

Benign	
Giant cell tumour of tendon sheath	M9252/0
Diffuse-type giant cell tumour	M9251/0
Deep benign fibrous histiocytoma	M8830/0
Intermediate (rarely metastasizing)	

Plexiform fibrohistiocytic tumour	M8835/1
Giant cell tumour of soft tissues	M9251/1
Malignant	
Pleomorphic ‘MFH’ / Undifferentiated Pleomorphic sarcoma	M8830/3
Giant cell ‘MFH’ / Undifferentiated pleomorphic sarcoma with giant cells	M8830/3
Inflammatory ‘MFH’ / Undifferentiated pleomorphic sarcoma with prominent inflammation	M8830/3
SMOOTH MUSCLE TUMOURS	
Angioleiomyoma	M8894/0
Deep leiomyoma	M8890/0
Genital leiomyoma	M8890/0
Leiomyosarcoma (excluding skin)	M8890/3
PERICYTIC (PERIVASCULAR) TUMOURS	
Glomus tumour (and variants)	M8711/0
malignant glomus tumour	M8711/3
Myopericytoma	M8713/1
SKELETAL MUSCLE TUMOURS	
Benign	
Rhabdomyoma	M8900/0
adult type	M8904/0
fetal type	M8903/0
genital type	M8905/0
Malignant	
Embryonal rhabdomyosarcoma	M8910/3
(incl. spindle cell,	M8912/3
botryoid, anaplastic)	M8910/3
Alveolar rhabdomyosarcoma (incl. solid, anaplastic)	M8920/3
Pleomorphic rhabdomyosarcoma	M8901/3
VASCULAR TUMOURS	
Benign	
Haemangiomas of subcut/deep soft tissue:	M9120/0
capillary	M9131/0
cavernous	M9121/0
arteriovenous	M9123/0
venous	M9122/0
intramuscular	M9132/0
synovial	M9120/0
Epithelioid haemangioma	M9125/0
Angiomatosis	
Lymphangioma	M9170/0

Intermediate (locally aggressive)	
Kaposiform haemangioendothelioma	M9130/1
Intermediate (rarely metastasizing)	
Retiform haemangioendothelioma	M9135/1
Papillary intralymphatic angioendothelioma	M9135/1
Composite haemangioendothelioma	M9130/1
Malignant	
Epithelioid haemangioendothelioma	M9133/3
Angiosarcoma of soft tissue	M9120/3

CHONDRO-OSSEUOUS TUMOURS

Soft tissue chondroma	M9220/0
Mesenchymal chondrosarcoma	M9240/3
Extraskeletal osteosarcoma	M9180/3

TUMOURS OF UNCERTAIN DIFFERENTIATION

Benign	
Intramuscular myxoma	M8840/0
(incl. cellular variant)	
Juxta-articular myxoma	M8840/0
Deep (‘aggressive’) angiomyxoma	M8841/0
Pleomorphic hyalinizing angiectatic tumour	
Ectopic hamartomatous thymoma	M8587/0
Intermediate (rarely metastasizing)	
Angiomatoid fibrous histiocytoma	M8836/1
Ossifying fibromyxoid tumour	M8842/0
(incl. atypical / malignant)	
Mixed tumour/	M8940/1
Myoepithelioma/	M8982/1
Parachordoma	M9373/1
Malignant	
Synovial sarcoma	M9040/3
Epithelioid sarcoma	M8804/3
Alveolar soft part sarcoma	M9581/3
Clear cell sarcoma of soft tissue	M9044/3
Extraskeletal myxoid chondrosarcoma (“chordoid” type)	M9231/3
PNET / Extraskeletal Ewing tumour	
pPNET	M9364/3
extraskeletal Ewing tumour	M9260/3
Desmoplastic small round cell tumour	M8806/3
Extra-renal rhabdoid tumour	M8963/3
Malignant mesenchymoma	M8990/3
Neoplasms with perivascular epithelioid cell differentiation (PEComa)	
clear cell myomelanocytic tumour	
Intimal sarcoma	M8800/3

Additional code for Malignant Peripheral Nerve Sheath Tumours
(Kleihues P, Cavenee WK, eds.
Pathology and genetics of tumours of the nervous system
World Health Organization classification of tumours Lyon, France: IARC Press, 2000)

MPNST M9540/3

8.2 APPENDIX B Histology of Selected ICD-10 categories

The National Cancer Intelligence Centre (NCIC) was asked to provide the number of sarcomas in the following categories for England 1996-2000:

- C40 Malignant neoplasm of bone and articular cartilage of limbs
- C41 Malignant neoplasm of bone and articular cartilage of other and unspecified sites
- C47 Malignant neoplasm of peripheral nerves and autonomic nervous system
- C48 Malignant neoplasm of retroperitoneum and peritoneum
- C49 Malignant neoplasm of other connective and soft tissue

The WHO classification of malignant bone and soft tissue tumours (Appendix A) was used to identify sarcomas. Table 1 shows the total number of malignant tumours in each category followed by the number of malignant tumours with histology listed in the WHO classification. The proportion of STS was smaller than might be expected and further breakdown by histological type (Tables 2–6) found that a large number of tumours did not have a specific histological code.

In addition, a proportion of tumours in each category were not found in the WHO classification.

Table 1 Malignant tumours coded to C40, C41, C47, C48 and C49 in ENGLAND (996-2000).

	All malignant tumours (M&F)	**Malignant tumours with histology listed in WHO classification**
C40	1020	827
C41	968	643
C47	448	141
C48	1252	505
C49	5081	4096

Table 2 Bone tumours by histological type for C40 (neoplasms of Bone and Articular cartilage of limbs) ENGLAND (996-2000)

	Male	**Female**	**TOTAL for 5 years**	**Average yearly total**
Osteosarcoma	252	189	441	**88.2**
Ewing's sarcoma	74	52	126	**25.2**
Chondrosarcoma	124	127	251	**50.2**
Other specified	63	29	92	**18.4**
Sarcoma NOS	22	14	36	**7.2**
Neoplasm NOS	34	40	74	**14.8**
TOTAL	**569**	**451**	**1020**	**204**

Table 3 Bone tumours by histological type for C41 (neoplasms of Bone and Articular cartilage of other and unspecified sites) ENGLAND (1996-2000)

	Male	Female	TOTAL for 5 years	Average yearly total
Osteosarcoma	90	88	178	**35.6**
Ewing's sarcoma	71	53	124	**24.8**
Chondrosarcoma	140	119	259	**51.8**
Other specified	112	71	183	**36.6**
Sarcoma NOS	24	15	39	**7.8**
Neoplasm NOS	98	87	185	**37**
TOTAL	**535**	**433**	**968**	**193.6**

Table 4 Malignant neoplasms of peripheral nerves and autonomic nervous system (C47) ENGLAND 1996-2000

	Male	Female	Total for 5 years	Average yearly total
Malignant Peripheral Nerve sheath Tumour (MPNST)	61	65	126	**25.2**
Malignant Neurolemmoma	72	52	124	**24.8**
Ganglioneuroblastoma	15	19	34	**6.8**
Neuroblastoma	35	22	57	**11.4**
Other specified	18	21	39	**7.8**
Sarcoma NOS	8	6	14	**2.8**
Neoplasm NOS	25	29	54	**10.8**
TOTAL	**234**	**214**	**448**	**89.6**

A number of the tumours listed in C47 were coded to malignant neurolemmoma, a term that has become obsolete – with tumours now coded under MPNST. Neuroblastoma and ganglioneuroblastoma were not included in the WHO classification.

Table 5 Malignant neoplasms of retroperitoneum and peritoneum (C48) ENGLAND 1996-2000

	Male	Female	Total for five years	Average yearly total
Carcinomas and Adenocarcinomas	121	344	465	**93**
Leiomyosarcomas	80	114	194	**38.8**
Liposarcomas	76	85	161	**32.2**
Rhabdomyosarcomas	8	4	12	**2.4**
Other specified	75	67	142	**28.4**
Sarcoma NOS	66	59	125	**25**
Neoplasm NOS	69	84	153	**30.6**
TOTAL	**495**	**757**	**1252**	**250**

Table 6 Tumours by histological type for malignant neoplasm of other connective and soft tissue (C49) ENGLAND 1996-2000

	Male	Female	Total	Average annual total
Leiomyosarcomas	623	504	1127	**225.4**
Liposarcomas	480	336	816	**163**
Malignant fibrous histiocytoma	282	183	465	**93**
Rhabdoymosarcomas	135	85	220	**44**
Hemangiosarcoma	103	96	199	**40**
Synovial sarcoma	102	124	226	**45**
Extra skeletal Ewings sarcoma and pNET	43	37	80	**16**
Other specified	251	220	471	**94.2**
**Sarcoma NOS*	*592*	471	1063	**213**
(Intimal sarcoma 8800	*402*	*319*		
8801	*108*	*95*		
8802	*48*	*35*		
8803	*5*	*10*		
8804	*29*	*11)*		
Neoplasm NOS	219	195	414	**83**
TOTAL	**2830**	**2251**	**5081**	**1016**

Intimal sarcoma 8800 is included in the WHO classification.

8.3 APPENDIX C Codes and Diagnoses for HES/PEDW Analysis

Code	Actual Diagnosis	Type	Diagnosis
C380	Malignant neoplasm of heart, mediastinum & pleura, heart	Malignant	Soft Tissues
C381	Malignant neoplasm of anterior mediastinum	Malignant	Soft Tissues
C382	Malignant neoplasm of posterior mediastinum	Malignant	Soft Tissues
C383	Malig neo heart, mediastinum & pleura,mediastinum, part unsp	Malignant	Soft Tissues
C388	Malig neo, overlapping lesion of heart, mediastinum & pleura	Malignant	Soft Tissues
C400	Malignant neoplasm of scapula and long bones of upper limb	Malignant	Bone
C401	Malignant neoplasm of short bones of upper limb	Malignant	Bone
C402	Malignant neoplasm of long bones of lower limb	Malignant	Bone
C403	Malignant neoplasm of short bones of lower limb	Malignant	Bone
C408	Malignant neoplasm, overlap les bone and artic cart of limbs	Malignant	Bone
C409	Malignant neoplasm of bone and artic cart of limb, unsp	Malignant	Bone
C410	Malignant neoplasm of bones of skull and face	Malignant	Bone
C411	Malignant neoplasm of mandible	Malignant	Bone
C412	Malignant neoplasm of vertebral column	Malignant	Bone
C413	Malignant neoplasm of ribs, sternum and clavicle	Malignant	Bone
C414	Malignant neoplasm of sacrum and coccyx	Malignant	Bone
C418	Malignant neoplasm, overlap lesion bon and articular cart	Malignant	Bone
C419	Malignant neoplasm of bone and articular cartilage, unsp	Malignant	Bone
C470	Malignant neoplasm of peripheral nerve of head, face & neck	Malignant	Soft Tissues
C471	Malignant neoplasm of peripheral nerve,upp limb,incl should	Malignant	Soft Tissues
C472	Malignant neoplasm of peripheral nerve of low limb, incl hip	Malignant	Soft Tissues
C473	Malignant neoplasm of peripheral nerve of thorax	Malignant	Soft Tissues
C474	Malignant neoplasm of peripheral nerve of abdomen	Malignant	Soft Tissues
C475	Malignant neoplasm of peripheral nerve of pelvis	Malignant	Soft Tissues
C476	Malignant neoplasm of peripheral nerve of trunk, unspec	Malignant	Soft Tissues
C478	Malignant neoplasm,overlap lesion periph nerve & auton ns	Malignant	Soft Tissues
C479	Malignant neoplasm periph nerve & autonomic ns, unspec	Malignant	Soft Tissues
C480	Malignant neoplasm of retroperitoneum	Malignant	Soft Tissues
C481	Malignant neoplasm of spec parts of peritoneum	Malignant	Soft Tissues
C482	Malignant neoplasm of peritoneum, unsp	Malignant	Soft Tissues
C488	Malignant neoplasm of overlap lesion retroperit & peritoneum	Malignant	Soft Tissues
C490	Malignant neoplasm of conn and soft tiss head, face & neck	Malignant	Soft Tissues
C491	Malignant neoplasm of conn and soft tiss upp limb,inc should	Malignant	Soft Tissues
C492	Malignant neoplasm of conn and soft tiss,lower limb,inc hip	Malignant	Soft Tissues
C493	Malignant neoplasm of conn and soft tiss of thorax	Malignant	Soft Tissues
C494	Malignant neoplasm of conn and soft tiss of abdomen	Malignant	Soft Tissues
C495	Malignant neoplasm of conn and soft tiss of pelvis	Malignant	Soft Tissues
C496	Malignant neoplasm of conn and soft tiss of trunk, unsp	Malignant	Soft Tissues
C498	Malignant neoplasm, overlap lesion connective & soft tiss	Malignant	Soft Tissues
C499	Malignant neoplasm of connective and soft tissue, unsp	Malignant	Soft Tissues