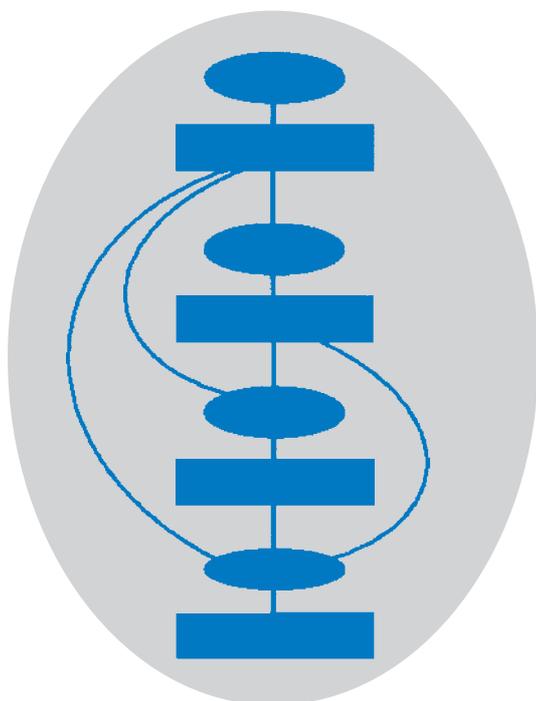


Guidance on Cancer Services

# Improving Outcomes for People with Sarcoma

Analysis of the Potential Economic Impact  
of the Guidance



March 2006

A report commissioned by the National Collaborating Centre  
for Cancer

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A report commissioned by the National Collaborating Centre for Cancer

P. Linck, D.A. Hughes and R.T. Edwards  
Centre for Economics and Policy in Health  
Institute of Medical and Social Care Research  
University of Wales, Bangor



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## **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 this document. 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 by the Manual will have cost implications.

The summary of economic implications is outlined in Table 1.

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 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 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.

**Table 1 Summary of estimated annual economic implications**

	Costs per year (£)	
	Low range	High range
Annual employment costs of a new diagnostic clinic	88,833	101,622
Average unit cost of triple assessment for patients referred to diagnostic clinics in England and Wales*		213
Average unit cost of MRI scans needed, in addition to ultrasound, to confirm diagnosis in 30% of all patients referred to diagnostic clinics in England and Wales		223.94
Employment costs of additional staff required at existing molecular pathology/cytogenetics laboratories		79,950
Core employment costs of a sarcoma treatment centre	482,399	819,039
Cost of producing information leaflets (for all patients with sarcoma in England and Wales)		26,420 (yr 1) 17,300 (subsequent yrs)
Cost of a National Implementation Group (for England and Wales)	98,443	100,843
Cost of orthotic and prosthetic appliances (per cancer network)	5,622	28,649
Employment cost of having a lead cancer registry (for England and Wales)		34,788

\* Based on cost estimates for triple assessment for the diagnosis of breast cancer

## **Improving diagnostic services**

### ***Diagnostic Clinics***

The annual opportunity cost for each diagnostic clinic operating one diagnostic session per week for 45 weeks of the year, inclusive of four training sessions per year, is estimated to be between £88,833 and £101,622. The variation is dependent upon whether the clinic is lead by a doctor or a sarcoma CNS.

These costs do not take into account the cost of any new equipment, such as ultrasound, that may be needed to provide this diagnostic service. These values represent the estimated maximum cost of staffing a new diagnostic clinic.

### ***Triple assessment***

The guidance also recommends triple assessment of all patients referred to a diagnostic clinic with a suspected soft tissue sarcoma. National Reference costs for triple assessment in the diagnosis of sarcoma are not available so costs for breast triple assessment have been used to give an indication.

The average unit cost for providing breast triple assessment is £213 with an inter-quartile range of between £150 and £242. We estimate that there would be around 20,000 new referrals per year so the cost impact of triple assessment for all of these patients would therefore be approximately £4,260,000 (inter-quartile range £3,000,000 to £4,840,000).

Triple assessment for sarcoma is likely to be more expensive as approximately 30% of the 20,000 patients referred for diagnostic tests will require an MRI scan in addition to an ultrasound, to confirm their diagnosis. The average unit cost for an MRI scan is £223.94 (inter-quartile range of between £184 and £465), therefore the additional cost for this patient group would be approximately £1,343,640 in England and Wales (inter-quartile range £1,164,000 to £2,790,000).

### ***Cytogenetics/Molecular Pathology Laboratories***

The guidance development group anticipates that additional staff will be required at the existing cytogenetic/molecular pathology facilities, to undertake the work generated as a result of implementing the guidance. It is anticipated that there would need to be an additional clinical scientist, biomedical scientist and administrative support employed at each of the laboratories. The additional employment cost per existing laboratory would be around £79,950.

### **Improving treatment**

The opportunity costs for minimum staffing levels at a sarcoma treatment centre have been estimated. The annual employment cost of the medical, nursing and other staff caring for 100 new patients per year is estimated to be between £482,399 and £819,039 per year. The cost calculations are for members of the MDT, ward nurses and outpatient nurses, but it is not inclusive of all staff who would be involved with the patients' care. Other clinical staff and the ancillary, catering or administration workforce would be an additional cost.

There is likely to be an additional requirement for some healthcare professionals, in particular, sarcoma CNS and specialist sarcoma physiotherapists. This needs to be considered by local commissioners. As with costs associated with the employment of staff at the diagnostic clinics, it needs to be emphasised that these costs represent opportunity costs because the staff involved in the treatment centres are already contracted to the NHS. However at present the staff are employed in a variety of locations rather than in designated sarcoma treatment centres.

### **Patient Perspective**

The resource implications of providing information leaflets for sarcoma patients throughout England and Wales are expected to be £26,420 for the first year and £17,300 for subsequent years. This cost assumes the

production of up to eight generic leaflets on different types of sarcoma and also the production of diagnostic clinic/sarcoma treatment centre specific leaflets.

### **National Implementation Group**

It is anticipated that the National Implementation Group would have a wide-ranging function including establishing an expert board to develop a comprehensive strategy to implement and monitor the guidance at all levels.

It is assumed that the National Implementation Group would comprise a full time manager and 1 or 2 administrative support workers, and a public health doctor and specialist commissioner (both on a sessional basis). The group would establish and facilitate a board (meeting 3-4 times a year). The estimated resource implications would be between £98,443 and £100,843 per annum.

### **Orthotic and Prosthetic Appliance Provision**

It is not known how many people who have sarcoma related amputations will require an activity limb, or indeed how many already have one. We have presented a sample of costs for patients with sarcoma who have undergone trans-femoral amputations. The annual cost estimates vary from £5,622 to £11,459 per network for 50% of trans-femoral amputees to have a water activity limb. For all sarcoma related trans-femoral amputees to have an activity limb with computerised knee and cosmesis, the cost is estimated to be between £14,054 and £28,649 per network. The cost impact of this aspect of the guidance will vary in line with patient choice.

### **Improving knowledge**

It is anticipated that there would need to be an additional full-time data manager or research officer post at the lead observatory or cancer registry that is commissioned to become holder of the national sarcoma dataset. The employment costs of a data manager (Agenda for Change Band 6 pt 30) will

be around £34,788 per year. This would vary in line with the exact requirements of the post and the experience of the data manager.

## **1. Introduction**

The Guidance has been developed to improve the provision of services for people with sarcoma. This economic analysis serves to inform commissioners, trusts and cancer networks of the resource and cost implications of implementing the recommendations in the Guidance. The Centre for Economics and Policy in Health at the University of Wales, Bangor has been commissioned to support this process by analysing the potential cost implications.

### **1.1 Scope**

The objectives of this economic analysis are to:

- Identify possible models of implementation which will vary depending both on the baseline position and on the chosen means of achieving the targets set out in the Guidance
- Identify the key economic issues and cost drivers in implementing the Guidance
- Estimate the costs of implementing the Guidance according to the different models identified and, in so doing, provide a structure and methodology that commissioners may use to do their own analysis
- Estimate the cost implications of implementing the Guidance at the diagnostic and treatment centre level.

The analysis does not aim to:

- Provide a definitive answer to the cost implications of the Guidance for specific cancer centres or cancer networks but to produce an indication of the scale of costs involved for different models
- Analyse the health outcome consequences of implementing the Guidance
- Estimate the cost-effectiveness of implementing the guidance recommendations.

## **2. Process and Methods**

### **2.1 Integration of economic analysis with cancer service guidance**

The research into the cost implications of the Guidance was carried out in parallel with the development of the guidance on *Improving Outcomes for people with Sarcoma*. One or more of the authors attended the Guidance Development Group (GDG) meetings in order to gain a full understanding of the Guidance as it developed.

### **2.2 Literature and data searching**

Literature searches were carried out by the National Collaborating Centre for Cancer (NCC-C) information specialists and the health economics team at Bangor. Searches were conducted in order to identify any existing costing exercises, audits of cancer activity, cost of illness studies or models of treatment pathways. Literature was screened for economic content and any emerging economic literature was referred to the health economics team for appraisal.

In addition to the specific research questions raised by the GDG, searches were conducted of the published economic literature relating to:

- the care of patients with sarcoma
- specific issues on the key recommendations of the guidance.

The databases searched were MEDLINE, CINAHL, NHS EED, HTA and DARE. No filters were used to restrict searches, however limitations to the searches included:

- studies in English
- publicly funded health services, i.e. similar systems to the NHS
- publications after 1990.

Unpublished data were obtained as a result of direct contact with members of the GDG, other expert clinicians, finance directors from cancer centres and trusts, as well as voluntary agencies.

## 2.3 Costs

Procedural cost data for breast triple assessment and MRI scanning were obtained using Healthcare Resource Group (HRG) costs from Payment by Results<sup>1</sup>. HRG costs are produced by every trust in the country using a very detailed method which costs all elements of patients' care including theatre time, laboratory tests, pathology tests, minutes of nursing time, minutes of consultant time, physiotherapy, X-rays, ultrasound, pharmacy and overheads (administration, heating etc.)<sup>1</sup>. Data were available for inpatient elective and non-elective cases, as well as day cases. Where HRG costs were not available, financial managers at NHS trusts or PCT/LHBs were consulted.

Staff salaries were primarily based on Agenda for Change banding for 2005/06<sup>2</sup>. The only exceptions to this were orthotists and prosthetists whose salaries were obtained from a contractor to the NHS. For each professional grade either a spine point or mid-point was chosen, upon which 20% employment on-costs plus a London weighting were added as appropriate. The consultant salary is based on a mid-point in the range for consultants of more than 7 years experience, except where stated in the text. Where calculations were based on hourly rates, salary and on-costs, leave and sickness were taken into account by assuming a 42 week year<sup>3</sup>. Further advice on calculating staffing costs was provided by the payroll managers of three NHS trusts.

The impact of the Working Time Directive is not clear at this time and has not been taken into account. However it will need to be considered by commissioners, as will Agenda for Change as it becomes fully implemented across England and Wales<sup>4</sup>.

Unpublished information from two specialist hospitals (one presented at the British Sarcoma Group conference, December 2005 and the other specifically commissioned) that treat patients with soft tissue sarcoma, suggests that the HRGs currently used for the funding of major surgery significantly underestimate 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.

## **2.4 Discussions with clinicians and other healthcare professionals**

Advice from members of the GDG was sought to ensure that appropriate assumptions were made for future activity, to identify data sources and to assist in the interpretation of data. In addition, doctors and/or finance managers from individual trusts were contacted to discuss resource implications of various aspects of the Guidance. Further details are included in the relevant sections. Several clinical nurse specialists (CNS) and multidisciplinary team (MDT) coordinators were also contacted to discuss their roles in MDTs and in patient-centred care. Information and advice was sought from the Department of Health (DH), cancer networks and Royal Colleges.

## **2.5 Identification of key cost issues**

The guidance development process, GDG discussions and a formal survey of GDG members identified and prioritised the key cost issues according to their potential budgetary impact. A proforma was produced to collate information on the key economic issues to be included, and the extent to which literature was available for key questions relating to this Guidance.

## **2.6 Cost analysis**

For each of the key issues identified, an estimate of the national, cancer network or diagnostic clinic/sarcoma treatment centre level resource implications has been made wherever possible. The approach adopted for each issue is detailed in the relevant section.

The costs for each cancer network will vary depending on population base, health service facilities, staffing levels and local patient activity. Estimates were based on broad working assumptions concerning future staffing configurations. Commissioners and trusts will need to make further considerations based on their local situation.

## **2.7 Sensitivity analysis**

When estimating costs, where appropriate we chose a range of  $\pm 25\%$  to reflect uncertainty in the estimate, in line with other cancer service guidance documents. There is uncertainty in our estimates, for example, in existing configurations, frequency of MDT meetings and in current and future staffing levels. In addition there may be cost savings as a result of the Guidance that are not possible to quantify at this time.

### **3. Diagnostic service**

This section includes costs relating to diagnostic services for soft tissue sarcoma. Costs relating to the diagnosis of bone sarcoma are funded by the National Specialist Commissioning Advisory Group (NSCAG) in England and by Health Commission Wales in Wales. Costs relating to a review that is currently underway by NSCAG are due to be published later in 2005<sup>5</sup>.

The Manual states that:

*“To improve the early diagnosis of soft tissue sarcoma, a clearly defined network of diagnostic clinics, linked to sarcoma treatment centres should be established. Two models are recommended to achieve this:*

*EITHER:*

- Patients with a suspected diagnosis of STS (as defined by the urgent referral criteria) would be seen within two weeks at a diagnostic clinic that is part of a sarcoma treatment centre.*

*OR:*

- Patients with a suspected diagnosis of STS (as defined by the urgent referral criteria) would be seen within two weeks at a diagnostic clinic specifically designated by their local cancer network, within the two week wait. This would be a purely diagnostic, rather than a treatment clinic, and be clearly affiliated to one sarcoma MDT.*

*These 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 STS should be rapidly referred on to a sarcoma MDT for definitive treatment, as would any cases with equivocal images or biopsy.”* (Improving diagnosis section)

The economic implications of the Improving Diagnosis section will be based on:

- the employment costs for staff at diagnostic clinics
- the costs of performing triple assessment
- the employment costs of additional staff required at cytogenetic/molecular pathology laboratories.

### **3.1 Employment costs for staff at diagnostic clinics**

The Manual recommends that all patients with a suspected diagnosis of soft tissue sarcoma should be referred to a diagnostic clinic for triple assessment. This diagnostic service would be based either at a specifically designated diagnostic clinic or at a sarcoma treatment centre.

As the Manual does not specify who should staff a diagnostic clinic, we have based our calculation of staff employment costs on a potential model of diagnostic team composition. It is acknowledged that the staff composition of some diagnostic clinics may vary from the model detailed here. These calculations have also assumed that one diagnostic clinic will serve a population of 1.5 million in England and Wales.

In this model, each team would include a specialist sarcoma pathologist, a radiologist, a sarcoma clinical nurse specialist (CNS) and administrative support. The team would be led by either a consultant level doctor or a specialist nurse. A biomedical scientist, a diagnostic radiographer and a general pathologist (to free up time for the specialist sarcoma pathologist to undertake sarcoma work) will also be required to cope with the increased workload resulting from triple assessment of all patients. Table 3.1 shows the staff employment costs of such a diagnostic clinic.

The Manual also recommends that those diagnostic clinic teams which are not based at a sarcoma treatment centre, should receive training from the treatment centre MDT. It has been assumed that 4 such training sessions will

be needed per year. Table 3.1 also shows the costs associated with training the diagnostic clinic teams.

**Table 3.1 Annual employment costs for a sarcoma diagnostic clinic**

Consultant-led clinic	FTE <sup>b</sup>	Annual Salary + 20% on-costs (£) <sup>a</sup>	Sarcoma CNS-led clinic	FTE <sup>b</sup>	Annual Salary + 20% on-costs (£) <sup>a</sup>
Consultant	0.2	19,656			
Radiologist	0.1	9,828	Radiologist	0.1	9,828
Specialist sarcoma pathologist	0.1	9,828	Specialist sarcoma pathologist	0.1	9,828
Sarcoma CNS (Band 7, pt 32)	0.2	7,623	Sarcoma CNS (pt 32)	0.4	15,245
Administrative support (Band 3/4, pt 12)	0.2	3,841	Administrative support (Band 3/4, pt 12)	0.2	3,841
Annual employment costs for staff running the diagnostic clinic		50,776	Annual employment costs for staff running the diagnostic clinic		38,742
Training sessions – 4 per year		2,561	Training sessions – 4 per year		1,805
Biomedical scientist (Band 5, pt 21)	0.5	13,460	Biomedical scientist (Band 5, pt 21)	0.5	13,460
Radiographer (Grade I or II)	0.3	9,745	Radiographer (Grade I or II)	0.3	9,745
General pathologist (Consultant Grade 1)	0.3	25,080	General pathologist (Consultant Grade 1)	0.3	25,080
Annual employment costs for additional staff needed to cover increased workload		48,285	Annual employment costs for additional staff needed to cover increased workload		48,285
<b>Total annual employment costs, inclusive of 4 training sessions per year</b>		<b>88,833</b>	<b>Total annual employment costs, inclusive of 4 training sessions per year</b>		<b>101,622</b>

<sup>a</sup> Totals rounded to the nearest £

<sup>b</sup> Calculated based on a clinic seeing 10-12 patients per diagnostic session

The annual opportunity cost for each clinic operating one diagnostic session per week for 45 weeks of the year, inclusive of four training sessions per year, is estimated to be between £88,833 and £101,622. The variation is dependent upon whether the clinic is lead by a doctor or a sarcoma CNS. In practice there will also be variation depending upon the salary point of the healthcare professionals involved and the exact staff composition of the team.

The costs presented here do not take into account the cost of any new equipment, such as ultrasound, that may be needed to provide this diagnostic service. These values represent the estimated maximum cost of staffing a new diagnostic clinic. However, in practice, it is likely that the staff required to provide this diagnostic service are already employed by the NHS. In this case, the estimated costs represent opportunity costs of re-deploying these existing staff to provide the diagnostic service. However, where there is a shortfall of staff within the NHS then the estimates for these staff would represent an additional employment cost. The cost of training for these new staff members should also be taken into account.

### **3.2 Costs of triple assessment**

The guidance recommends triple assessment of all patients referred to a diagnostic clinic with a suspected soft tissue sarcoma. National Reference costs for triple assessment in the diagnosis of sarcoma are not available. However, the available costs for triple assessment in breast cancer (HRG code J26op)<sup>6</sup> give an indication.

Breast triple assessment includes clinical examination, imaging (mammogram and/or breast ultrasound) and biopsy (fine needle aspiration (FNA), mammography guided FNA, core biopsy) at the same attendance. The average unit cost for providing this assessment is £213 with an inter-quartile range of between £150 and £242, based on submissions from 97 trusts.

Although there is considerable uncertainty about the workload of individual diagnostic clinics and the total numbers nationally, we estimate that there would be around 20,000 new referrals per year. The cost impact of triple assessment for all of these patients would therefore be approximately £4,260,000 (inter-quartile range £3,000,000 to £4,840,000).

Triple assessment for sarcoma is likely to be more expensive than for breast cancer. Approximately 30% of the 20,000 patients referred for diagnostic tests will require an MRI scan in addition to an ultrasound, to confirm their diagnosis. The average unit cost for an MRI scan is £223.94 (inter-quartile range of between £184 and £465), therefore the additional cost for this patient group would be approximately £1,343,640 in England and Wales (inter-quartile range £1,164,000 to £2,790,000).

It should be noted however that in many diagnostic clinics, triple assessment of patients with suspected sarcoma is already being carried out..

### **3.3 Cytogenetic/molecular pathology facilities**

The Manual states that

*“Commissioners should fund:*

- *A formal system for second opinions and review of difficult cases*
- *Molecular pathology and cytogenetics facilities.”* (Improving Pathology section).

The guidance development group have identified that additional staff will be required to undertake the work generated as a result of implementing this recommendation. It is anticipated that there would need to be an additional clinical scientist, biomedical scientist and a secretary employed at each of the four existing cytogenetic/molecular pathology laboratories. The additional employment cost per laboratory would be around £79,950 as shown in Table 3.2

**Table 3.2 Annual employment costs of additional staff required at the existing cytogenetic/molecular pathology laboratories**

	<b>FTE</b>	<b>Annual salary plus 20% on-cost</b>
Clinical scientist (Band 7, pt 35)	1.0	£43,338
Biomedical scientist (Band 5, pt 21)	1.0	£26,920
Secretary (Band 3/4 Pt 12)	0.5	£9,692
<b>Annual cost per laboratory</b>		<b>£79,950</b>

#### **4. Improving treatment: Multidisciplinary teams (MDTs)**

A key recommendation states that:

*“A soft tissue sarcoma MDT should meet minimum criteria and manage the care of at least 100 new patients with soft tissue sarcoma per year...”*

The sarcoma MDT should either be based in a single hospital or in several geographically close and closely affiliated hospitals, which would constitute the sarcoma treatment centre. A soft tissue sarcoma MDT is likely to serve a population of 2-3 million people and a bone sarcoma MDT a population of 7-8 million.

In order to estimate the costs for providing a safe and sustainable service for the care and treatment of patients with sarcoma, minimum staffing levels have been estimated and are discussed below. These healthcare professionals will in the main already be employed by the NHS. The objective in undertaking this exercise is to enable commissioners to consider infrastructure, staffing levels and patient flow for their local treatment centre. It is acknowledged that there will be differences between centres in line with case mix, the complexity of disease and stage of treatment, and, for some sarcomas, the age of the patient.

##### **4.1 Methods**

Minimum staffing levels have been recommended by the GDG for a sarcoma treatment centre to provide a safe and sustainable service for at least 100 new patients with sarcoma per year. NHS staff salary pay-scales, obtained from the Department of Health<sup>2</sup> were used to calculate the current staffing cost 2005/06; in the case of orthotists and prosthetists, salaries were obtained from a contractor to the NHS (see Section 2 for further information).

##### **4.2 Cost of staffing at sarcoma treatment centres**

The full time equivalent (FTE) staffing levels, together with an estimated annual employment cost for staff dedicated to the care of patients with sarcoma are outlined in Table 4.1. It is anticipated that clinical and other

specialist posts would be filled by two or more individuals to ensure adequate leave and sickness cover. It is likely that the staffing levels will exceed the minimum in some settings depending on activity levels, case mix, intensity of treatment and types of referral to the centre.

**Table 4.1 Annual employment costs of minimum staffing level at a sarcoma treatment centre managing 100 new patients per year**

<b>Staff requirements</b>	<b>Minimum FTE<sup>a</sup></b>	<b>Annual Salary + 20% on-costs (£)<sup>b</sup></b>
Specialist sarcoma surgeons	1	98,280
Specialist sarcoma radiologists	0.6	58,968
Sarcoma specialist pathologist	0.4	39,312
Medical oncologist	0.3	29,484
Clinical oncologist	0.3	29,484
Paediatric oncologist	0.1	9,828
Administrative support for consultants (Band 3/4, pt 12)	2	38,410
Key worker (Based on nursing salary Band 7 Pt 32) <sup>c</sup>	2	76,227
Palliative care specialist (Based on nursing salary Band 7 Pt 32 or consultant)	0.2	7,623 to 19,656
Specialist sarcoma physiotherapist	1	32,484
Specialised AHP – occupational therapist	0.1	3,426
Specialised AHP - orthotist	0.1	3,248
Specialised AHP - prosthetist	0.1	3,272
Ward nurses (Band 6 pt 27)	5	160,214
Clinic nurses (Band 6 pt 27)	1	32,043
<b>MDT Support staff</b>		
MDT coordinator (band 4 pt16)	0.5	11,291
Secretarial support Pt 12	0.5	9,602
<b>Total</b>		<b>643,198 to 655,231</b>
<b>Sensitivity analysis ± 25%</b>		<b>482,399 to 819,039</b>

<sup>a</sup> FTEs not necessarily 1 individual

<sup>b</sup> Costs are rounded to the nearest pound

<sup>c</sup> Costs presented for the key worker are based on a sarcoma CNS taking this role. However the key worker role can be done by any member of the sarcoma MDT.

The annual employment costs of the medical, nursing and other staff caring for 100 new patients per year is estimated to be between £643,198 ( $\pm 25\%$ , £482,399 and £803,998) and £655,231 ( $\pm 25\%$ , £491,424 and £819,039). The variation is dependent upon whether the palliative care specialist is a nurse or a consultant. The cost calculations are for members of the MDT, ward nurses and outpatient nurses, however it is not inclusive of all staff who would be involved with the patients' care. Other clinical staff and the ancillary, catering or administration workforce would be an additional cost. These factors would need to be considered by commissioners.

In addition to the staff listed in Table 4.1, there would be a need for palliative care nurses for sarcoma patients. However it is likely that patients would prefer to receive their palliative care at a local hospital rather than at a regional sarcoma treatment centre, the costs of which are included in the economic review of the NICE guidance on *Improving Outcomes In Palliative And Supportive Care*<sup>7</sup>.

As a result of this uncertainty, together with variation in remuneration for all personnel, a sensitivity analysis of  $\pm 25\%$  has been applied. The estimated annual range of opportunity costs for staffing a sarcoma treatment centre caring for 100 new patients per year is between £482,399 and £819,039.

It needs to be emphasised that these costs represent opportunity costs as the staff involved in the treatment centres are likely to already be contracted to the NHS. As with the diagnostic clinics, local commissioners will need to consider the opportunity costs of any increase in existing staffing levels.

### **4.3 MDT meetings**

It is assumed that there will be an opportunity cost to enable staff to attend MDT meetings. Meeting costs could be derived by estimating the time spent attending meetings by different staff multiplied by their hourly rate (salary and on-costs). Although MDT meetings are usually conducted out of normal working hours<sup>8</sup> the costs calculated here are based on MDT meetings being

conducted during paid hours of work. The new consultant contract formally places MDT work within programmed activities. These costs have therefore not been calculated.

There is likely to be an additional requirement for some healthcare professionals, in particular sarcoma CNS and specialist sarcoma physiotherapists, either of whom could be designated key workers. Additional specialist sarcoma training will be required, such as the training modules offered by the University of Central England in conjunction with the Royal Orthopaedic Hospital. The cost of each module is around £220<sup>9</sup>. If all nursing staff and AHPs took one module the cost per treatment centre would be £2,420.

## 5. Patient perspective

The Guidance recommends that:

*“Patients should be offered a permanent written and/or audio record of their diagnosis and of any important points relating to the consultation. Their key worker and their contact points should be identified in writing and this information should also be supplied to their GP”.* (Patient perspectives section)

Evidence about techniques to improve communication between patients and healthcare professionals is reviewed in the NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer*<sup>7</sup>. It also reviewed the evidence about the quality of information, but no evidence on the uptake of offers of letters or audio records was identified. A separate literature search was conducted by the NCC-C but no further evidence was forthcoming on this topic (for literature search methods see Section 2).

The economic implications of this section will be based on costs relating to patients being offered a permanent record of diagnosis (including both written and audio formats) and the costs of patient information leaflets. The information leaflet requirement will include generic leaflets on sarcoma and also leaflets specific to diagnostic clinics or sarcoma treatment centres.

In England and Wales there are approximately 2400 new patients per year diagnosed with bone and soft tissue sarcomas (background section). Of these approximately 132 patients will be diagnosed with bone and soft tissue sarcoma in Wales. This is a crude estimate based on the proportion of people in Wales compared with England applied to sarcoma incidence. These data are used to calculate the cost estimates presented in this chapter.

## 5.1 Costs of patient letters at diagnosis

In England, all patients with cancer currently receive a written record of their diagnosis<sup>8</sup>. This is currently not the case for Wales<sup>10</sup>. However, not all patients in England are currently offered an audio record of diagnosis. The resource implications will therefore consider the cost of:

- an individualised letter or audio record at diagnosis only for all patients in Wales;
- and an audio record for all patients at diagnosis in England.

The costs of having a permanent record of diagnosis of sarcoma are based on the clinical and clerical time that would be required, as calculated in previous NICE service guidance<sup>7</sup>.

The Guidance recommends that each patient with a diagnosis of sarcoma be sent a letter or an audio record of their consultation explaining the diagnosis and the key points of the consultation. An individualised summary of the main points of the diagnostic consultation would involve around 6 minutes of consultant time and 12 minutes of secretarial time to transcribe the letter and to transfer the consultant's voice recording from the digital format to CD. Postage and stationary costs would be additional but the patient may prefer to have it sent electronically via email, in which case the costs would be reduced.

**Table 5.1 Annual costs of providing a permanent record of diagnosis for all patients with sarcoma in England and Wales**

	<b>Cost calculation</b>	<b>Cost (£)</b>
Individualised written and audio summary of consultation	Consultant time- 6 minutes (Mid Pt Consultant Contract)* Secretarial time: 12 minutes* CD Stationary and postage	6.24 1.97 0.20 0.30
<i>Total for 1 permanent record</i>		<i>8.71</i>
<b>Cost for one permanent record for all patients with sarcoma in Wales</b>	(132 * £8.71)	<b>1,150</b>
<b>Cost of one permanent audio record of consultation for all patients with sarcoma in England</b>	Cost of CD £0.20, 2268 patients	<b>454</b>
<b>TOTAL FOR ENGLAND AND WALES PER CONSULTATION</b>		<b>1,604</b>

\* Employment costs as multidisciplinary team section

In Wales, where patients currently do not receive a written record of their consultations, the resource implications will be £1,150 for all patients to receive a written and audio record of their diagnosis. In the interests of good communication there may be more than one time point per patient pathway where a permanent record of the consultation may be advantageous. Examples of such time points can be found in the patient perspective chapter in the Manual.

In England, for all patients with sarcoma to receive an audio record of their diagnosis the cost would be £454. This assumes that these patients would already have funds allocated for written records. In view of the lack of evidence<sup>7</sup> concerning uptake of letters or audio records, together with the low costs, we have not attempted to estimate what the uptake will be.

The cost of a digital voice recorder, required to produce an audio record of consultations, is approximately £100. Each diagnostic clinic would require 2 such recorders for use by staff.

There is a degree of uncertainty surrounding this estimate as some doctors may already be giving their patients a permanent record in a format which best meets their needs.

## **5.2 Information for patients with sarcoma**

Evidence collected for the Manual suggests that there is a need for simple leaflets including basic factual information on sarcoma to be readily available for patients with sarcoma in England and Wales. In addition, there is a need for leaflets containing specific information about the diagnostic clinic/sarcoma treatment centres.

The charity CancerBACUP produces high quality generic and specific booklets about all aspects of cancer and these are free to cancer patients (£1.95 to others). In 2004 they recorded outgoings of £86,726 for publications in their annual report<sup>11</sup>. The sarcoma-specific booklets they produce relate to bone, soft tissue and Kaposi's sarcoma. Hospitals do not carry a stock of patient information publications, patients are advised to request them directly from the charity, although not all patients do this<sup>12</sup>.

In order to estimate costs for producing the information recommended in the Manual, Sarcoma UK were contacted and the results are outlined below.

### **5.2.1 Generic leaflets on sarcoma**

This cost is based on producing generic introductory leaflets on specific types of sarcoma that guide the patient to other sources of information. The leaflets would be available for patients in England and Wales. All diagnosed patients should have the opportunity to receive a leaflet.

The costs of producing a tri-fold or A5 4-page leaflet is around £1,400 in the first year and around £600 annually to maintain stocks with a 3 year updating of the leaflet<sup>12</sup>. These figures include costs for design and development, printing and distribution. Many printers require a minimum print run of 5000 to ensure sufficient supplies of leaflets for the first two years. It is anticipated that there would be up to 8 different generic leaflets produced giving a total of

£11,200 set up costs and £4,800 annual costs in subsequent years. A summary of these data is presented in Table 3.2.

### **5.2.2 Diagnostic clinic/sarcoma treatment centre-specific leaflets**

The Guidance recommends that:

*“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 patients’ diagnosis or disease stage*
- *is age-appropriate (see the NICE guidance on Improving Outcomes in Children and Young People with Cancer)”. (Patient perspective section)*

A simple one page black and white information leaflet on a specific sarcoma sub-type could be developed and distributed to sarcoma clinical nurse specialist (CNS) and consultants. The format could be standardised for all centres with specific information appropriate to each centre in England and Wales. The design would require input from the clinicians and sarcoma CNS and the leaflet could be printed from a CDROM or the internet when required.

The set-up costs for all centres in England and Wales have been estimated to be around £3,220 (with annual costs of £500) again assuming a 3-year redesign and re-pressing of the CDROM<sup>12</sup>. The set up costs include the cost of design and development, hardware and distribution and are presented in Table 5.2.

### **5.3 Total costs for the production of information leaflets for patients**

The total annual costs of designing, producing and distributing generic and diagnostic clinic/treatment centre-specific patient information leaflets are summarised in Table 5.2. The quality and the consistency of the content could be ensured by having centrally produced material. Nationally produced materials would also minimise duplication. The overhead cost of production, if

produced centrally, is around £12,000 per year (estimate provided by Sarcoma UK).

**Table 5.2. Total costs for the production of information leaflets for patients with sarcoma in England and Wales**

	<b>(£)</b>
Set-up for eight generic leaflets	11,200
Set-up for CDROMs for diagnostic/treatment centre specific leaflets	3,220
Annual overheads	12,000
<b>Total for year 1</b>	<b>26,420</b>
Annual cost in subsequent years for eight generic leaflets	4,800
Annual cost in subsequent years for CDROMs for diagnostic/treatment centre specific leaflets	500
Annual overheads	12,000
<b>Total for subsequent years</b>	<b>17,300</b>

The actual total costs may be less due to economies of scale. Sarcoma UK estimate that the costs for England and Wales would be between £20,000 to £25,000 for the first year with on-going annual costs of around £15,000.

## 6. National Implementation Group

The Guidance recommends that:

*“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 in England and Wales.” (Multidisciplinary team section)*

The economic implications of establishing a National Implementation Group to ensure that the Guidance is implemented is presented below.

A National Implementation Group would have wide-ranging functions including the establishment of an expert board to develop a comprehensive strategy to implement and monitor the Guidance at all levels.

It is assumed that the National Implementation Group would comprise a manager and two administrative support workers (all working full time); a public health doctor and a specialist commissioner (each working 1 day per week). The costs associated with the employment of these staff members is shown in Table 6.1. The employment costs include 20% on-costs (details are included earlier in section 2, Methods).

**Table 6.1 Employment costs of the National Implementation Group**

<b>Profession (Grade and FTE)</b>	<b>Annual employment cost (£)</b>
Manager (Band 7 pt 28-32)	34,897
Public health doctor (Consultant grade 1, 0.2 FTE)	16,720
Specialist commissioner (Band 7 pt 32, 0.2 FTE)	7,588
Administrative support (Band 2/3 pt 7)	16,433
Administrative support (Band 3/4 pt 12)	19,205
<b>Total*</b>	<b>94,843</b>

\* (Rounded to the nearest £)

The resource implications of the expert board would be, primarily, in expenses paid to the healthcare professionals, patients and commissioners who would attend approximately three or four meetings a year. It is assumed that there would be 12-15 board members from across England and Wales. The estimated costs for each meeting are based on the costs related to the current GDG meetings where expenses for each meeting are around £100 per member. The cost estimates are between £3,600 and £4,500 per year for 12 or 15 members meeting on three occasions. For quarterly meetings, the cost of attendance would be between £4,800 and £6,000 per year for 12 and 15 members, respectively.

The annual employment cost for staff of the National Implementation Group and expenses for board members is between £98,443 (based on 12 board members and 3 meetings) and £100,843 (based on 15 board members and 4 meetings). In addition there would need to be provision for accommodation and equipment. This will vary according to location and will require further investigation by commissioners. It is anticipated that the group would need to be in-situ for at least 3 years and it is likely that there would be an ongoing function to ensure delivery and monitoring of services for this patient group.

## 7. Orthotic and Prosthetic Appliance Provision

The Guidance recommends that for those patients who need limb amputation:

*“Special activity limbs should be provided where appropriate and proven technological improvements should be made available”.*

(Supportive and Palliative Care section)

There were 145 limb amputations in 2003/04 in England and Wales as a result of a primary neoplasm<sup>13</sup>. This represents 7% of all the new sarcoma patients per year<sup>14</sup>. Table 7.1 details the numbers of amputations as a result of neoplasia obtained from the National Amputee Database<sup>13</sup>.

The supportive and palliative care section of the Guidance sets out current provision and proposals for the provision of prosthetic appliances for patients with sarcoma in England and Wales. As the majority of patients who require such appliances are young (median age 21 years), they will require life-long access to specialist rehabilitation services and may want specialist activity limbs.

Current prosthetic provision in the UK is variable - a survey undertaken by the Audit Commission in 2000<sup>15</sup> found 25% of patients fitted with prosthetic limbs found them unusable. There is evidence that non-use of prosthetics is related to the weight of the appliance, inability to wear with some clothing and appearance. Improvements to the service had been reported in the subsequent report.<sup>16</sup>

At present Disablement Service Centres (DSC) provide prostheses in the UK. There are 44 DSCs in the UK of which 14 match the template for specialist Prosthetic and Amputee Rehabilitation Centres (PARC) proposed by the British Society of Rehabilitation in 2003. The guidance recommends that sarcoma patients are referred, for pre-amputation assessment, to centres matching the PARC template. These centres have the necessary expertise and facilities to cope with all the intricacies of comprehensive prosthetic/amputee rehabilitation.

**Table 7.1 Numbers of amputations; by cause of neoplasia for England and Wales 2003/04<sup>13</sup>**

		England				Wales			
Level of Amputation		Neoplasia	Neoplasia	Neoplasia – Benign	Neoplasia – No Additional Detail	Total Neoplasia	Neoplasia	Neoplasia	Total Neoplasia
		– Malignant – Secondary	– Malignant – Primary				– Malignant – Secondary	– Malignant – Primary	
Upper Level Amputations	Forequarter	-	4	-	-	4	-	-	-
	Shoulder disarticulation	-	6	-	-	6	-	-	-
	Trans-humeral	-	16	-	-	16	-	-	-
	Trans-radial	-	3	-	-	3	-	1	1
	Wrist disarticulation	-	1	-	-	1	-	-	-
	Partial hand	-	5	-	1	6	-	-	-
	Upper Digits	-	2	-	-	2	-	-	-
<b>Total Upper Level</b>		-	<b>37</b>	-	<b>1</b>	<b>38</b>	-	<b>1</b>	<b>1</b>
Lower Level Amputations	Hemi-pelvectomy	-	1	-	1	2	-	-	-
	Hip disarticulation	-	8	-	-	8	-	2	2
	Trans-femoral	3	38	-	11	52	-	1	1
	Trans-tibial	2	25	1	5	33	1	2	3
	Ankle disarticulation	1	-	1	-	2	-	-	-
	Partial foot	-	2	-	-	2	-	-	-
Double lower amputation	-	1	-	-	1	-	-	-	
<b>Total Lower Level</b>		<b>6</b>	<b>75</b>	<b>2</b>	<b>17</b>	<b>100</b>	<b>1</b>	<b>5</b>	<b>6</b>
<b>TOTAL NEOPLASIA</b>		<b>6</b>	<b>112</b>	<b>2</b>	<b>18</b>	<b>138</b>	<b>1</b>	<b>6</b>	<b>7</b>

Sarcoma-related amputations represent around 3% of all amputations in England and Wales<sup>13</sup> and the majority of these patients (n =106) have lower limb amputations, primarily either trans-femoral or amputations at the hip. The Guidance recommends that, when appropriate, sarcoma-related amputees be offered specialist activity limbs in addition to a conventional limb.

Private prosthetic companies are increasingly introducing advanced technological components for prosthetic limbs, particularly computerised knee joint units, carbon fibre prosthetic feet and silicone high-definition cosmesis, as well as water activity limbs. The artificial limb components of such prosthetics would enhance the capability and quality of life of the user. They are designed for specific stages of an individual's life (such as child or adult), activity levels and mobility grades, specialist activities (for example swimming, running, cycling) and the body weight of users.

Not all patients who have had amputations will have enough function to benefit from an activity limb. The ability of an amputee to benefit from activity limbs is less with a higher proximal level amputation. If the amputation is at the hip, functionality for day to day living is usually as much as can be aimed for; at trans-femoral level there is likely to be a more active profile, depending on the muscle and quality of the amputation<sup>16</sup>. There will be a wide variation in type of limb required by each patient and consequently the cost.

The prosthetic service in the NHS is contracted to external companies. There is no central database that collects information on prescription of prosthetics and thereby the associated costs. The Purchasing and Supply Agency (PSA) have been approached for cost bandings for activity limbs for people who have had trans-femoral, trans-tibial and trans-humeral amputations. The type of activity limb that this group of people might require would enable them to swim, cycle, run or dance. The PSA are in the process of conducting an analysis to determine the costs involved in producing and fitting prosthetic appliances, unfortunately this work has not been completed in time for inclusion in this analysis. Therefore the cost calculations are based on data from a private prosthetic company<sup>17</sup>.

In view of the individual differences in requirements between patients, the costs presented are for patients with sarcoma who underwent trans-femoral amputation in England and Wales in 2003/4<sup>13</sup> (n=53). The costs detailed are based on two types of activity limb; a water activity limb costing around £8000 and a limb with a computerised knee and cosmesis costing up to £20,000<sup>15</sup>. Details are presented in Table 7.2. Other types of speciality limb may fall between these two cost examples.

In 2001 the government allocated £4 million to enable all patients in England who require artificial limbs to have silicone cosmesis. In 2002, just £10,000 of the £1.3 million additional first year money had been spent for this purpose<sup>16</sup>. This allocation will have improved since the Audit Commission report was written. However, in view of the low allocation, the cost of cosmesis, around £2,000 per limb, has been included in our upper estimate (Table 7.2).

**Table 7.2 Costs of two types of activity limb for sarcoma-related amputees in England and Wales**

	Estimated cost per activity limb (£)	If all 53 patients require an activity limb (£)	Estimated cost per cancer network (£)	If 50% (n=26 patients) require an activity limb (£)	Estimated cost per cancer network (£)
Modular water activity knee	8,000	424,000	11,459	208,000	5,622
Limb with computerised knee and cosmesis	20,000	1,060,000	28,649	520,000	14,054

It is not known how many people who have sarcoma-related amputations will require an activity limb, or indeed how many already have them provided by the NHS. At present there is no central recording system for prescriptions of prosthetic limbs and without this monitoring uptake is very difficult.

We have presented the costs for two scenarios. If all anticipated sarcoma related trans-femoral amputees in England and Wales (based on our assumption of n=53) require an activity limb the cost would vary between a minimum of £424,000 for a water activity limb to a maximum of £1,060,000 for a limb with a computerised knee and cosmesis. If just half of all patients request an activity limb the costs would vary between £208,000 for a water activity limb to £520,000 for one with a computerised knee. As a guide the range in costs are also presented at a cancer network level, assuming a total of 37 networks in England and Wales.

The cost of activity limbs is from a private supplier and it is likely to be an over-estimate for people with sarcoma who have had trans-femoral amputations. However it does not include the costs associated with providing activity limbs for people who have had amputations at other levels. The cost impact of this aspect of the guidance will vary according to patient choice and the existing provision of appliances.

## 8. Improving knowledge

The guidance states that:

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

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

*Public health observatories or cancer registries should act as the data repository of the agreed dataset and a lead observatory or cancer registry should be commissioned as repository of a national dataset which could then become a national sarcoma register “(Improving knowledge section)*

The economic implications of this section of the guidance will be low. The chapter outlining the cost impact of MDTs recommends that each MDT should have a coordinator and clerical support to ensure that there is complete recording of comprehensive patient data. In view of the low incidence of sarcoma and the increasing automation of cancer registries, it is unlikely that any additional costs will be incurred at more than one registry as a result of this recommendation.

It is anticipated that there would need to be an additional full-time data manager or research officer post at the lead observatory or cancer registry that is commissioned to become holder of the national sarcoma dataset. The employment costs of a data manager (Agenda for Change Band 6 pt 30) will be around £34,788 per year<sup>4</sup>. This would vary in line with the exact requirements of the post and the experience of the data manager.

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