NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Sarcoma

Output: Prioritised quality improvement areas for development.

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Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for sarcoma. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development source(s) referenced in this briefing paper is:

- Sarcoma. NICE Cancer Service Guidance (2006).
- Skin tumours including melanoma. NICE Cancer Service Guidance (2010)

2 Overview

2.1 Focus of quality standard

This quality standard will cover the diagnosis, treatment, support and follow up of sarcoma in children, young people and adults.

2.2 Definition

Sarcomas are a rare and diverse group of cancers thought to have a common embryological origin. They arise from cells that make up 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.

Soft tissue sarcoma (STS)[1]

Soft tissue sarcoma is cancer that develops in the soft tissues of the body. The term soft tissue is used to describe all of the supporting tissue in the body apart from the

[1] NHS Choices Soft tissue sarcoma

bones – this includes fat, muscle and deep skin tissues. Cancer can develop in any of these cells.

Soft tissue sarcoma does not usually cause symptoms in the early stages. As the sarcoma grows, a lump may be noticeable and this may be painful if it presses against surrounding tissue and nerves.

Types of STS[2]

There are over 50 different types of soft tissue sarcoma, depending on where in the body they are located. The following are some common anatomical sites where STS can occur:

a) extremity and superficial trunk: the majority of patients with STS of the extremities and superficial trunk present with a mass which is usually painless. It can be difficult to differentiate a benign from a malignant mass.

b) retroperitoneum: most patients present with an abdominal mass, with half reporting pain at presentation. Because of the space available in the retroperitoneum, these tumours may often grow to a substantial size before presenting, and the overall prognosis is worse for people with retroperitoneal tumours than for those with extremity sarcomas.

c) viscera: sarcomas of the viscera present with signs and symptoms particular to the organ of origin. For example, GIST [gastrointestinal stromal tumour], which occur primarily in the middle-aged and older population, present with upper abdominal pain in 40–50% of cases. 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.

d) 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. They can present as a lump, with problems relating to compression of the surrounding anatomy such as the orbit or pharynx. Surgery and radiotherapy are difficult because of the proximity of important anatomy in this area.

One particular type of soft tissue sarcoma, Kaposi's sarcoma, develops from skin cells. It is more common in people who have a weakened immune system, including people with HIV.

[2] National Institute for Health and Care Excellence (2006), Guidance on Cancer Services Improving Outcomes for People with Sarcoma The Manual, March 2006.

Fibromatosis is a benign but infiltrative and destructive condition that simulates soft tissue sarcoma in its physical signs and site of origin, and often in its rate of growth[3].

Bone sarcoma[4]

Primary bone cancer is a tumour that starts growing inside a bone. Cancer that spreads from another part of the body into surrounding bone is known as secondary bone cancer.

The most common symptom of bone cancer is bone pain that usually gets worse over time and can feel more painful during the night.

Types of bone cancer[5]

All types of bone cancer are very rare. The following are the most common histological types of malignant bone tumours:

a) osteosarcoma: the most common primary malignant bone tumour. It occurs predominantly in patients younger than 20 years, in whom 80% of tumours occur in long bones of the extremities. In the older age group osteosarcomas may arise secondary to radiation or Paget's disease.

b) chondrosarcoma: the incidence of this type of malignant bone tumour increases gradually with age. More than 50% of these tumours occur in long bones of the extremities. They may also occur in the pelvis and ribs.

c) Ewing's sarcoma: the major peak for age-specific incidence occurs in the second decade of life with a rapid decrease after the age of 20 years. These tumours typically arise in the axial skeleton (pelvis, scapula, rib) or in the diaphysis (main or mid-section) of long bones.

d) spindle cell sarcomas: these are a variety of other rare sarcomas of bone, for example fibrosarcoma, malignant fibrous histiocytoma and leiomyosarcoma, which behave just like osteosarcoma but typically arise in an older population.

2.3 Incidence and prevalence

Collectively bone and STS account for around 1% of all malignancies diagnosed in the UK[6]. Incidence figures show there were 3,272 new cases of STS during 2010 in

[3] Service Specification: Cancer Soft Tissue Sarcoma (Adult). NHS England (2013)
[4] NHS Choices Bone cancer (sarcoma)
[5] National Institute for Health and Care Excellence (2006), Guidance on Cancer Services Improving Outcomes for People with Sarcoma The Manual, March 2006.

the UK[7] and 559 new cases of bone sarcoma in 2011[8]. Crude incidence rate for STS shows that there are 54 new STS cases for every million males and 51 for every million females in the UK[7]. For bone sarcoma crude incident rates indicate 1 new bone sarcoma case for every 100,000 males and nearly 1 for every 100,000 females in the UK[8].

STS

Soft tissue sarcomas (STSs) account for about 1% of all malignant tumours. Benign soft tissue tumours outnumber malignant by at least a factor of 100. 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. Soft tissue sarcomas increase in frequency with age.

Bone sarcoma[7]

Bone sarcomas are estimated to account for 0.2% of all malignant tumours, but represent 4% of all malignancy in children aged up to 14 years. The age-specific frequencies of primary bone sarcomas are bimodal – the first peak occurring during the second decade of life, associated with the growth spurt, and the second occurring in patients older than 60 years. They are more common in males than in females.

2.4 Management

As sarcoma is so rare, most GPs and non-specialist doctors will only see a few cases in their working lifetime. The NICE Referral guidelines for suspected cancer

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[6] National Cancer Intelligence Network (2013), Bone and Soft Tissue Sarcomas; UK Incidence and Survival: 1996 to 2010, November 2013, Version 2.0, West Midlands: PHE Knowledge & Intelligence Team.

[7] Public Health England Knowledge and Intelligence Team (West Midlands). Personal communication cited in http://www.cancerresearchuk.org/cancer-info/cancerstats/types/soft-tissue-sarcoma/incidence/#source2

[8] Data were provided by the Office for National Statistics on request, July 2013. Similar data can be found here: http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/index.html cited in http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bone/incidence/

Data were provided by ISD Scotland on request, May 2013. Similar data can be found here: http://www.isdscotland.org/Health-Topics/Cancer/Publications/index.asp cited in http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bone/incidence/

Data were provided by the Welsh Cancer Intelligence and Surveillance Unit on request, June 2013. Similar data can be found here: http://www.wales.nhs.uk/sites3/page.cfm?orgid=242&pid=59080 cited in http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bone/incidence/

Data were provided by the Northern Ireland Cancer Registry on request, June 2013. Similar data can be found here: http://www.qub.ac.uk/research-centres/nicr/CancerData/OnlineStatistics/ cited in http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bone/incidence/

provide recommendations regarding the signs of possible sarcoma and where to refer patients for further investigation.

Although several areas of care are common to both tumour types, the management of patients with bone and soft tissue sarcomas involves distinct pathways of care.

Bone sarcoma[9]

The identification of bone sarcoma symptoms in primary care should lead to referral for an X-ray, which in turn may lead to the suspicion of bone malignancy. In this case, the patient should be referred directly to a bone sarcoma treatment centre for diagnosis. As primary malignant bone tumours are so rare and the number of expert staff who can provide the service is small, NHS England commissions services for adults and adolescents with suspected and confirmed primary malignant bone tumours from Highly Specialist Primary Malignant Bone Tumours Centres. Five centres of care have been designated[10]:

- Oxford University Hospitals NHS Trust
- Royal National Orthopaedic Hospital NHS Trust
- The Newcastle Upon Tyne Hospitals NHS Foundation Trust
- The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust
- The Royal Orthopaedic Hospital NHS Foundation Trust.

Bone sarcomas are predominantly treated with a combination of surgery and chemotherapy. Radiotherapy can also be a key part of a curative treatment, for example for some patients with Ewing's sarcoma. Surgical treatment aims to completely remove a primary tumour while preserving the limb and limb function. However, surgical treatment is often disabling with patients requiring rehabilitation, including physiotherapy and occupational therapy. Some patients require lifelong provision of orthotic and/or prosthetic appliances. In the UK, prostheses are provided by Disablement Service Centres (DSCs), a sub-set of which match the template for specialist Prosthetic and Amputee Rehabilitation Centres (PARC) proposed by the British Society of Rehabilitation Medicine (BSRM) in 2003.

The majority of surgical treatment of bone cancers is conducted at specialist bone sarcoma centres, with radiotherapy and chemotherapy provided more widely.

Most primary malignant bone tumours occur in adolescents or children. While complex surgery will be carried out at a centralised specialist centre, these patients will often receive their non-surgical treatment at a principal treatment centre for children and young people.

[9] NHS Choices: Map of Medicine Bone sarcoma
[10] Manual for Prescribed Specialised Services 2013/2014. NHS England.

STS

The NICE Referral guidelines for suspected cancer provide referral guidelines and criteria to identify patients more likely to have a soft tissue sarcoma. However, the majority of referred patients are likely to have a benign lesion, so identifying the small number of patients with sarcoma generates a considerable diagnostic workload for clinicians. Many STSs are discovered incidentally following excision of a lump, with no prior suspicion that it could be a sarcoma. Very often this initial excision is inadequate and further treatment is required. Many patients are still treated in district hospitals by non-specialists. However, several trusts have a multidisciplinary (MDT) team in place.

Sarcomas are a diverse group of tumours which can occur almost anywhere in the body. Therefore MDTs from different disciplines may need to work together in managing treatment. For rarer sarcomas, referrals to specialised MDTs may be necessary. For example, people with gynaecological sarcomas and sarcomas of the gastrointestinal tract are often managed by specialty multidisciplinary teams.

Cancer networks and sarcoma services

The areas covered by sarcoma centres/MDTs will not always have common boundaries with existing cancer networks – a sarcoma MDT may cover several networks or part of more than one network. Commissioners therefore need to determine the territories of sarcoma MDTs with respect to both soft tissue and bone sarcomas[11]. Overall co-ordinating functions are also required by sarcoma services in a designated area – which may include multiple MDTs as well as additional services such as chemotherapy, radiotherapy and soft tissue diagnostic clinics. Network site specific groups (Sarcoma Advisory Groups [SAGs]) assist in this function.

[11] National Cancer Peer Review Programme. Manual for Cancer Services: Sarcoma measures.

2.5 National Outcome Frameworks

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS Outcomes Framework 2014–15

Domain	Overarching indicators and improvement areas
1 Preventing people from dying prematurely	***Overarching indicator*** 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare i Adults ii Children and young people 1b Life expectancy at 75 i Males ii Females ***Improvement areas*** **Reducing premature mortality from the major causes of death** 1.4 Under 75 mortality rate from cancer * i One- and ii Five-year survival from all cancers **Reducing deaths in babies and young children** 1.6 iii Five year survival from all cancers in children
4 Ensuring that people have a positive experience of care	***Overarching indicator*** 4a Patient experience of primary care i GP services 4b Patient experience of hospital care ***Improvement areas*** **Improving people's experience of outpatient care** 4.1 Patient experience of outpatient services **Improving the experience of care for people at the end of their lives** 4.6 Bereaved carers' views on the quality of care in the last 3 months of life **Improving children and young people's experience of healthcare** 4.8 Children and young people's experience of outpatient services
Alignment across the health and social care system * Indicator shared with Public Health Outcomes Framework (PHOF)	

Table 2 Public health outcomes framework for England, 2013–2016

Domain	Objectives and indicators
2 Health improvement	***Objective*** People are helped to live healthy lifestyles, make healthy choices and reduce health inequities. ***Indicators*** 2.19 Cancer diagnosed at stage 1 and 2
4 Healthcare public health and preventing premature mortality	***Objective*** Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities. ***Indicators*** 4.1 Infant mortality * 4.3 Mortality rate from cause considered preventable ** 4.5 Under 75 mortality rate from cancer *
Aligning across the health and care system * Indicator shared with the NHS Outcomes Framework ** Complementary to indicators in the NHS Outcomes Framework	

Summary of suggestions

2.6 Responses

In total 8 stakeholders responded to the 2-week engagement exercise [22/04/14 – 07/05/14].

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the Committee.

Full details on the suggestions provided are given in appendix 4 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
4.1 Organisation of care • Sarcoma MDTs • Pathways for sarcoma patients presenting to other cancer MDTs • Desmoid-type fibromatosis	NHSE
4.2 Specialised sarcoma sub-type services • Specialised sarcoma sub-type services • Retroperitoneal sarcoma • National Ewing's sarcoma MDT	NHSE, SCM1, SCM2.
4.3 Designated practitioners • Surgical practitioners • Chemotherapy/radiotherapy practitioners	NHSE
4.4 Diagnosis • Diagnostic pathways • Diagnostic services • GIST diagnosis	NHSE, RCGP, RCR.
4.5 Patient support • Customised information. • Key worker • Rehabilitation • End of life care	BCGS, NHSE, SCM2, SCM3.
4.6 Improving knowledge • Opportunities to participate in clinical studies • Pathology reporting of STS • Data collection	BGCS, NHSE, RCR, SCM2, SCM3.
4.7 Additional suggestions **Further guidance** • Gynaecological sarcoma treatment • Follow-up procedures • Development of a risk score for sarcoma symptoms • Guidelines for musculoskeletal (MSK) radiologists • Optimal imaging tests for staging sarcomas • Treatment of surgically inoperable sarcomas **Additional suggestions - out of scope, no supporting recommendations, do not meet technical criteria for statement development** • Regional Sarcoma Advisory Groups in place • General adherence to national guidelines • Suggested outcomes for assessing surgery/care • Treatment of GIST and NICE TAs	

Suggested area for improvement	Stakeholders
BGCS, British Gynaecological Cancer Society NHS, NHS England RCGP, Royal College of General Practitioners RCR, Royal College of Radiologists SCM, Specialist Committee Member	

3 Suggested improvement areas

3.1 Organisation of care

3.1.1 Summary of suggestions

Sarcoma MDTs

A stakeholder identified sarcoma multidisciplinary teams (MDTs) as the best site to provide a comprehensive service to sarcoma patients, from diagnosis through to definitive treatment and follow-up. The same stakeholder also highlighted considerable variation in the size, function and quality of MDTs and also the extent to which they were available to patients.

Pathways for sarcoma patients presenting to other cancer MDTs

A stakeholder also highlighted the importance of ensuring that people with sarcoma who are referred to a cancer site-specific MDT (e.g. gynaecological, gastrointestinal, skin) ultimately have their treatment and support delivered by a sarcoma MDT. Pathways and arrangements to ensure that people with sarcoma initially referred to a site-specific cancer MDT have access to a sarcoma MDT were described as poorly developed, resulting in sporadic referral and variation in treatment.

A further stakeholder raised the concern that when gynaecological cancer MDTs liaise with specialist sarcoma centres for the management of gynaecological sarcomas, this may adversely affect patient management and could lead to patients missing out on available services (e.g. palliative care).

Desmoid-type fibromatosis

A stakeholder commented that patients with desmoid-type fibromatosis should be referred to a sarcoma MDT. Expertise in the management of fibromatosis was described as limited but often concentrated in sarcoma centres.

3.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 4 to help inform the Committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Sarcoma MDTs.	NICE Guidance for Improving Outcomes in Sarcoma Section - Improving treatment: sarcoma multidisciplinary teams Section - Improving treatment: sarcoma multidisciplinary teams Sub-section section - Sarcoma MDT membership Section - Improving treatment: sarcoma multidisciplinary teams Sub-section - Role of the sarcoma MDT.
Pathways for sarcoma patients presenting to other cancer MDTs.	NICE Guidance for Improving Outcomes in Sarcoma Section - Improving treatment: soft tissue sarcomas Sub-section - Soft tissue sarcomas requiring shared management Section – Improving treatment: sarcoma multidisciplinary teams Sub-section - Role of the sarcoma MDT. Improving Outcomes for People with Skin Tumours including Melanomas. Section - Generic recommendations for patients with uncommon risk factors or rare cancers. Section - Skin sarcomas.
Desmoid-type fibromatosis	NICE Guidance for Improving Outcomes in Sarcoma Section - Improving treatment: soft tissue sarcomas Sub-section - Limb, limb girdle and truncal soft tissue sarcomas

Sarcoma MDTs

Improving treatment: sarcoma multidisciplinary teams

All patients with a confirmed diagnosis of bone sarcoma, or adults with a soft tissue sarcoma, should have their care supervised by or in conjunction with a sarcoma MDT.

Improving treatment: sarcoma multidisciplinary teams:

Sarcoma MDT membership

Each sarcoma MDT should have a core membership as shown in Table 5 [see Appendix 1].

Each MDT should in addition have an extended team with membership as shown in Table 6 [see Appendix 1], some of whom (for example key workers) may work as part of the core team.

Members of the extended team should be nominated and will bring particular expertise to the sarcoma MDT. They should attend MDT meetings as and when appropriate.

Improving treatment: sarcoma multidisciplinary teams:

Role of the sarcoma MDT

The MDT should have weekly meetings at which all core members of the team are present and their attendance is documented.

The MDT should ensure that a treatment plan is agreed and documented by the MDT for all of the following:

- newly diagnosed patients
- patients following tumour resection
- patients with first metastases and/or first local recurrence.

Pathways for sarcoma patients presenting to other cancer MDTs

Improving treatment: soft tissue sarcomas:

Soft tissue sarcomas requiring shared management

Site-specific and sarcoma MDTs need to ensure that clear pathways exist between the two MDTs, to have common treatment pathways and to clarify under what circumstances patient care should be transferred from one team to the other.

The site-specific MDT has primary responsibility to liaise with the sarcoma MDT to discuss the management of each patient. Specified care plans, taking into account

currently available clinical trials, should be used. It should be made clear to patients who their key worker is.

Improving treatment: sarcoma multidisciplinary teams

Role of the sarcoma MDT.

The MDT should have documented arrangements for linking with other MDTs to ensure coordinated management of patients with sarcomas at specific anatomical sites for which specialist input is required (for example, head and neck, uterine, retroperitoneal sarcoma and GIST).

Improving Outcomes for People with Skin Tumours including Melanomas.

Generic recommendations for patients with uncommon risk factors or rare cancers.

There should be a close liaison between the SSMDT [specialist skin cancer MDT] and the soft tissue sarcoma MDT. It is appropriate for many cutaneous sarcomas to be considered by the SSMDT but some should also be discussed at the sarcoma MDT, especially those that penetrate the superficial fascia or require chemotherapy.

Improving Outcomes for People with Skin Tumours including Melanomas.

Skin sarcomas.

Skin cancer MDTs should liaise with sarcoma MDTs in the management of patients with cutaneous sarcomas. As stated in the section on SSMDTs, it is essential for all cutaneous sarcomas to receive specialist histopathology review.

It is essential that there is close liaison between the SSMDT and sarcoma MDTs. This is particularly important for patients whose sarcomas are large or penetrate the superficial fascia or are of a histological type requiring chemotherapy (e.g. rhabdomyosarcoma, Ewing's sarcoma).

Desmoid-type fibromatosis

Improving treatment: soft tissue sarcomas:

Limb, limb girdle and truncal soft tissue sarcomas

Patients with fibromatosis or other soft tissue tumours of borderline malignancy should be referred to a sarcoma MDT for diagnosis and management.

3.1.3 Current UK practice

Sarcoma MDTs

No current practice information relevant to the proportion of people with sarcoma who are treated by a sarcoma MDT was identified.

A total of 15 sarcoma MDTs were identified in a 2012/2013 National Peer Review Report on Sarcoma Cancer Services. These MDTs deal with soft tissue sarcomas only or soft tissue and bone sarcomas. There are currently no 'bone only MDTs'. All 15 MDTs were reviewed against 'sarcoma multidisciplinary team' measures in a Peer Review cycle conducted for 2012/2013[12].

Only 47% of sarcoma MDTs comprised of a named lead clinician and named core team members for all required roles. Required core roles consisted of two sarcoma surgeons, two imaging specialists, two oncologists (with responsibility for radiotherapy and chemotherapy), two histopathologists, two clinical nurse specialists, an MDT coordinator/secretary, a nominated member with responsibility for users' and carers' information and a nominated member with responsibility for ensuring that recruitment into clinical trials and other well designed studies is integrated into the function of the MDT.

87% of sarcoma MDTs held weekly meetings; however, a lack of attendance at meetings by core members was highlighted in the Peer Review. Core members (or their arranged cover) attended at least two thirds of meetings at only 33% of sarcoma MDTs.

Pathways for sarcoma patients presenting to other cancer MDTs

The National Peer Review Programme reviewed 15 sarcoma MDTs in 2012/2013 (National Peer Review Report: Sarcoma Cancer Services 2012/2013). In this time frame, 60% of sarcoma MDTs were found to have an agreed pathway regarding their role in the shared care pathways for soft tissue sarcomas presenting to site specific MDTs[12].

No current practice information regarding adherence levels to these pathways was identified.

Desmoid-type fibromatosis

A stakeholder identified limited expertise in the management of fibromatosis, with what expertise that does exist being concentrated in sarcoma centres.

[12] National Peer Review Report: Sarcoma Cancer Services Report 2012/2013

No current practice information regarding the treatment of fibromatosis was identified.

3.2 Specialised sarcoma sub-type services

3.2.1 Summary of suggestions

Several stakeholders highlighted the benefits of specialised sarcoma services which deal with particular sarcoma sub-types.

Concentrating the treatment of rare sarcoma sub-types at higher-volume specialised centres, rather than spreading cases across national MDTs, was suggested to improve patient outcomes. Patients treated in such centres were likely to have greater access to adjuvant treatment, research studies and specialist sarcoma pathologists and radiologists.

A stakeholder also highlighted the benefit of discussing patient cases at a relevant sarcoma sub-type MDT. As sarcomas are a diverse group of tumours, discussion should be conducted by appropriate experts who understand the behaviour of the particular sarcoma sub-type. This may require referral to different MDTs depending on the sub-type of sarcoma. A stakeholder identified such scenarios as complex to manage and noted that currently there is considerable variation in practice in referral to specialised care.

A stakeholder specifically identified an advantage in concentrating retroperitoneal sarcoma cases in a smaller number of high-volume units; highlighting several studies in support of this point.

A further stakeholder also identified the importance of discussing all new patients with Ewing's sarcoma at the National Ewing's sarcoma MDT.

3.2.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 5 to help inform the Committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Specialised sarcoma sub-type services	NICE Guidance for Improving Outcomes in Sarcoma Section - Improving treatment: sarcoma multidisciplinary teams

Retroperitoneal sarcoma	NICE Guidance for Improving Outcomes in Sarcoma Section – Improving treatment: soft tissue sarcomas Sub-section - Retroperitoneal and pelvic soft tissue sarcomas
National Ewing's sarcoma MDT.	Not directly covered in the developmental sources and no recommendations are presented

Specialised sarcoma sub-type services

Improving treatment: sarcoma multidisciplinary teams

Information about the specific expertise of different MDTs should be made widely available so that cases can be referred expeditiously. Such expertise – which is not likely to be found everywhere – includes:

- gynaecological sarcomas
- head and neck sarcomas
- retroperitoneal and pelvic sarcomas
- chest wall/intrathoracic sarcomas
- skin sarcomas
- central nervous system sarcomas
- gastrointestinal stromal tumours (GIST)
- adult-type soft tissue sarcomas arising in children
- the use of isolated limb perfusion.

Retroperitoneal sarcoma

Improving treatment: soft tissue sarcomas:

Retroperitoneal and pelvic soft tissue sarcomas

Patients with retroperitoneal and pelvic soft tissue sarcoma should be referred to a sarcoma treatment centre where there is a core member of the team with special expertise in managing these tumours.

3.2.3 Current UK practice

Specialised sarcoma services

No current evidence relating to specialised sarcoma centres/services was identified.

Retroperitoneal sarcoma

One stakeholder highlighted the low annual number of new retroperitoneal sarcoma cases in England (approximately 250), noting that distribution of these cases across national sarcoma MDTs would lead to MDTs dealing with approximately 20 new cases a year. In fact, as case distribution is likely to be un-even (with, for example, the Royal Marsden Hospital dealing with an estimated 70 cases per year), many sarcoma MDTs will deal with less than 20 new retroperitoneal sarcoma cases a year.

National Ewing's sarcoma MDT

No current practice information relating to the number or proportion of Ewing's sarcoma patients treated at the national Ewing's MDT was identified.

3.3 Designated practitioners

3.3.1 Summary of suggestions

Surgical practitioners

A stakeholder identified the need for sarcoma patients to undergo planned surgery by designated surgeons, citing several examples of literature in support. These surgeons should be core members of the sarcoma MDT. This would ensure that correct operations are undertaken and improve outcomes such as reduced local recurrence and functional outcomes.

Chemotherapy/radiotherapy practitioners

A stakeholder highlighted the need for chemotherapy and radiotherapy to be delivered by practitioners designated by a Sarcoma Advisory Group. This would ensure consistent and uniform approaches to treatment and the safe delivery of appropriate care.

3.3.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Surgical practitioners	NICE Guidance for Improving Outcomes in Sarcoma Section - Key Recommendations
Chemotherapy/radiotherapy practitioners	NICE Guidance for Improving Outcomes in Sarcoma Section - Key Recommendations Section – Improving treatment: bone sarcomas Sub-section - Chemotherapy and radiotherapy Section – Improving treatment: soft tissue sarcomas Sub-section – Chemotherapy and radiotherapy

Surgical practitioners

Key Recommendations

Patients should undergo definitive resection of their sarcoma by a surgeon who is a member of a sarcoma MDT or by a surgeon with tumour site-specific or age-appropriate skills, in consultation with the sarcoma MDT.

Chemotherapy/radiotherapy practitioners

Key Recommendations

Chemotherapy and radiotherapy are important components of the treatment of some patients and should be carried out at designated centres by appropriate specialists as recommended by a sarcoma MDT.

Improving treatment: bone sarcomas:

Chemotherapy and radiotherapy

The provider of chemotherapy services should have a clinical/medical oncologist who has a specific interest in chemotherapy for bone sarcoma, nominated by the cancer network clinical director and approved by the sarcoma MDT lead clinician.

The provider of curative radiotherapy services should have a clinical oncologist who has a specific interest in radiation therapy for bone sarcoma, nominated by the cancer network clinical director and approved by the sarcoma MDT lead clinician.

There should be a formal relationship between the bone sarcoma MDT and the provider of non-surgical oncology services that is characterised by common protocols, good communication, and well defined referral pathways. These relationships should be defined in writing and approved by the cancer network director and the bone sarcoma MDT lead clinician. Audits of compliance with these protocols will need to be demonstrated.

Improving treatment: soft tissue sarcomas:

Chemotherapy and radiotherapy

There should be a formal relationship between the soft tissue sarcoma MDT and the provider of non-surgical oncology services that is characterised by common protocols, good communication, and well-defined referral pathways. This relationship should be defined in writing and approved by the cancer network director and the lead clinician in the soft tissue sarcoma MDT. Audits of compliance with these protocols will need to be demonstrated.

All cancer networks should either

• host a sarcoma MDT

or

• decide to use the services of a nearby sarcoma MDT to provide all treatment facilities

or

• have a nominated medical and/or clinical oncologist who is a member of the extended sarcoma MDT and who agrees to give curative and palliative treatments (chemotherapy or radiotherapy) according to protocols defined by the sarcoma MDT. These oncologists should be nominated by the cancer network clinical director and approved by the lead clinician on the sarcoma MDT.

3.3.3 Current UK practice

Surgical practitioners

No current practice information relating to what proportion of sarcoma surgeries are conducted by surgeons who are members of a sarcoma MDT was identified.

In 2012/2013, a National Peer Review Report on Sarcoma Cancer Services[13] reported that 53% of core surgical members of sarcoma MDTs had 5 PAs (programmed activities) per week specified in their job plans for the care of patients with sarcoma (the PAs could be a combination of direct clinical care PAs and supportive PAs).

Chemotherapy/radiotherapy practitioners

In 2012/2013, a National Peer Review Report on Sarcoma Cancer Services reported that 47% of core oncology members of sarcoma MDTs had 3 PAs (programmed activities) per week specified in their job plans for the care of patients with sarcoma (the PAs could be a combination of direct clinical care PAs and supportive PAs).

[13] National Peer Review Report: Sarcoma Cancer Services Report 2012/2013

3.4 Diagnosis

3.4.1 Summary of suggestions

Diagnostic pathways

A stakeholder highlighted the need for clear diagnostic pathways and processes to be in place to reduce time to diagnosis. This would result in earlier diagnosis and a consequent reduction in disease and related morbidity. Diagnostic pathways and process for suspected sarcoma were noted as varying nationally and the implementation of local diagnostic clinics recommended by NICE guidance (Improving Outcomes for People with Sarcoma) was descried as sporadic.

Stakeholders also noted a lack of clarity in the referral pathways GPs should use for suspected sarcomas and highlighted that one of the biggest perceived delays in sarcoma management is the time between first presentation to a medical practitioner and the occurrence of an appropriate diagnostic scan.

Diagnostic services

A stakeholder highlighted that the lack of local diagnostic clinics was an issue commonly raised by patients as a critical area for improvement.

The same stakeholder noted low positive rates of sarcoma diagnosis from referrals made to specialised sarcoma services under the two week referral system, and commented that this put undue pressure on these specialised services.

A further stakeholder emphasised the difficulties of sarcoma diagnosis in primary care; in particular, distinguishing sarcomas from the far more commonly occurring benign lesions. This was increasingly the case as fewer benign lesions are now removed in primary or secondary care (sarcomas are often only identified during removal of such benign lesions).

GIST diagnosis

A stakeholder highlighted the need for molecular diagnosis to be undertaken in all patients with gastrointestinal stromal tumours (GISTs). Molecular characterisation was noted as important information for prognosis and to guide treatment. Furthermore, the responsibility for reporting and reviewing diagnosis of GIST should only be undertaken by consultant histopathologists accredited in the national sarcoma histopathology EQA or the national GI histopathology EQA and recognised by a Sarcoma Advisory Group.

3.4.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Diagnostic pathways	NICE Guidance for Improving Outcomes in Sarcoma Section - Improving diagnosis of bone and extremity soft tissue sarcoma Sub-section – Referral guidelines Section - Improving diagnosis of bone and extremity soft tissue sarcoma Sub-section – Referral pathways: patients with extremity, trunk, and head and neck soft tissue sarcomas Section - Improving diagnosis of bone and extremity soft tissue sarcoma Sub-section - Referral pathways: bone sarcomas
Diagnostic services	NICE Guidance for Improving Outcomes in Sarcoma Section - Key Recommendations Section -Improving diagnosis of bone and extremity soft tissue sarcoma Sub-section - Referral pathways: patients with extremity, trunk, and head and neck soft tissue sarcomas
GIST diagnosis • Molecular diagnosis	Not directly covered in the developmental sources and no recommendations are presented
• Pathologist requirements	NICE Guidance for Improving Outcomes in Sarcoma Section - Improving pathology

Diagnostic pathways

Improving diagnosis of bone and extremity soft tissue sarcoma

Referral guidelines

Networks should ensure that GPs and hospital doctors are aware of the diagnostic pathways for patients with signs and symptoms suggestive of bone or soft tissue sarcoma.

Improving diagnosis of bone and extremity soft tissue sarcoma

Referral pathways: patients with extremity, trunk, and head and neck soft tissue sarcomas

Commissioners and networks should work together to ensure that there are clear referral pathways from both primary and secondary care through to a designated diagnostic clinic and for patients with proven sarcomas on to the affiliated sarcoma treatment centre.

Improving diagnosis of bone and extremity soft tissue sarcoma

Referral pathways: bone sarcoma

All patients with a probable bone sarcoma (usually following X-ray examination) should be referred directly to a bone tumour treatment centre for diagnosis and management.

Diagnostic services

Key Recommendations

Cancer networks should arrange diagnostic services for the investigation of patients with suspected soft tissue sarcomas (as defined by the National Institute for Health and Clinical Excellence (NICE) ‘Referral guidelines for suspected cancer’) at designated diagnostic clinics. All patients with a probable bone sarcoma (usually following X-ray examination) should be referred directly to a bone tumour treatment centre for diagnosis and management.

Improving diagnosis of bone and extremity soft tissue sarcoma

Referral pathways: patients with extremity, trunk, and head and neck soft tissue sarcomas

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

either

1. patients with a suspected diagnosis of soft tissue sarcoma (as defined by the urgent referral criteria) would be seen within 2 weeks at a diagnostic clinic that is part of a sarcoma treatment centre

or

2. patients with a suspected diagnosis of soft tissue sarcoma (as defined by the urgent referral criteria) would be seen within 2 weeks at a diagnostic clinic specifically designated by their local cancer network. This would be a purely diagnostic, rather than a treatment clinic, and would be clearly affiliated to one sarcoma MDT.

Each cancer network should designate a diagnostic clinic for their patients who meet the urgent referral criteria. This would either be part of a sarcoma treatment centre or established locally, as described above.

GIST diagnosis

Improving pathology

All GISTs should be reported or reviewed by an SSP [specialist sarcoma pathologist] with experience in GIST who successfully participates in the bone and soft tissue pathology EQA scheme, or a tertiary GI specialist who successfully participates in the GI pathology EQA scheme.

3.4.3 Current UK practice

Diagnostic pathways

No current data on the general awareness of primary and secondary health care professionals regarding sarcoma referral pathways was identified.

A National Peer Review Report on Sarcoma Cancer Services covering 2012/2013[14] measured the number of sarcoma MDTs with an agreed presentation pathway (with local contact points) for soft tissue sarcomas of the limbs and trunk wall. 'Presentation pathway' in this context covered the pathway of referral from all aspects of primary care to sarcoma diagnostic clinics, including the pathway of referral to the clinic when a patient presents to a hospital doctor who is not a member of a sarcoma MDT or part of the diagnostic clinic. 86% of sarcoma MDTs had such an agreed pathway.

Furthermore, the same National Peer Report measured the number of sarcoma MDTs (which dealt with bone sarcomas) with agreed presentation pathways for bone

[14] National Peer Review Report: Sarcoma Cancer Services Report 2012/2013

sarcomas. The presentation pathway in this context covers the pathway of referral from all aspects of primary care to the bone sarcoma centre. All sarcoma MDTs which deal with bone sarcoma had a pathway agreed by the lead clinician of the MDT.

Diagnostic services

A study published in 2010 noted that at that time most cancer networks had no arrangement whereby sarcoma diagnostic clinics existed separately from a sarcoma treatment centre. The study observed that many networks intended to fulfil sarcoma diagnostic requirements using diagnostic facilities in a treatment centre[15].

A retrospective case-notes review of patients referred to the Royal Marsden Sarcoma Unit between January 2004 and December 2008 looked at referral patterns in a regional sarcoma centre[15]. In this period a total of 2,746 referrals for suspected sarcoma were made. Of these, 154 referrals were made under criteria that all patients with a suspected cancer are seen within two weeks of a GP making an urgent referral ('two week referrals'). The other 2,592 referrals were following initial non-urgent local referral, with subsequent histological work or imagining suggesting a diagnosis of sarcoma. Of the 154 'two week referrals', 102 of these were referred solely on clinical criteria for suspected soft tissue sarcoma; with two of these patients ultimately found to have soft tissue sarcomas and a further one patient was found to have a cutaneous sarcoma.

The authors of this study noted that the number of 'two week referrals' in this unit has risen 25-fold between 2004 and 2008, but still accounted for approximately only 1% of all confirmed diagnoses of sarcoma treated in the unit (in 2008).

GIST diagnosis

No current practice information regarding the use of molecular diagnosis for patients with GIST was identified.

A National Peer Review Report on Sarcoma Cancer Services covering 2012/2013 reported that in 80% of sarcoma MDTs all histopathology core MDT members have completed either the national soft tissue sarcoma EQA (for MDTs dealing only with STS) or both the bone sarcoma and soft tissue sarcoma EQA (for MDTs dealing with both STS and bone sarcomas).

[15] Does the two-week rule pathway improve the diagnosis of soft tissue sarcoma? A retrospective review of referral patterns and outcomes over five years in a regional sarcoma centre. Oncology Vol 92,pages 417-421

3.5 Patient support

3.5.1 Summary of suggestions

Customised information

A stakeholder highlighted the need for better sarcoma-specific information to be provided to patients; in particular, this information should be customised to individual patients to cover their diagnosis and location.

Key worker

A stakeholder identified the benefit of access to a sarcoma clinical nurse specialist (CNS) during treatment and follow-up. Access to this resource was identified as non-existent or difficult.

A further stakeholder raised the issue that patients moving through 'unusual' routes of care during sarcoma treatment may not be effectively managed and consequently could miss out on existing services (e.g. palliation).

Rehabilitation

A stakeholder identified the need for rehabilitation support from diagnosis onwards; including rehabilitation needs assessment at key points in the pathway. The provision of prosthetics for sarcoma amputees was identified by a further stakeholder as central to rehabilitation and quality of life; with prosthetic provision protocols varying by region.

End of life care

Stakeholders highlighted the need for an end of life care plan and for clear pathways and protocols to be in place. Sarcoma patients were identified as frequently having extensive palliative needs which can be difficult to meet and require the involvement of an experienced team.

3.5.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Customised information	NICE Guidance for Improving Outcomes in Sarcoma Section - Patient perspectives Sub-section - Information
Key worker	NICE Guidance for Improving Outcomes in Sarcoma Section - Supportive and palliative care Sub-section - The key worker
Rehabilitation	NICE Guidance for Improving Outcomes in Sarcoma Section – Key recommendations Section - Supportive and palliative care Sub-section - Physiotherapy, occupational therapy and rehabilitation Section - Supportive and palliative care Sub-section - Orthotic and prosthetic appliance provision
End of life care	NICE Guidance for Improving Outcomes in Sarcoma Section - Supportive and palliative care Sub-section - Specialist palliative care

Customised information

Patient perspectives

Information

Commissioners and provider organisations should ensure that at every diagnostic clinic/sarcoma treatment centre information is available that:

- is specific to that centre
- describes the tests/treatments it provides
- describes the individual patient's diagnosis or disease stage
- is age-appropriate (see the NICE guidance on 'Improving outcomes in children and young people with cancer').

Key worker

Supportive and palliative care

The key worker

All patients managed by a sarcoma MDT should be allocated a key worker. Patients should be provided with their key worker's name and contact details.

Rehabilitation

Key recommendations

Patients with functional disabilities as a consequence of their sarcoma should have timely access to appropriate support and rehabilitation services

Supportive and palliative care

Physiotherapy, occupational therapy and rehabilitation

A specialist sarcoma physiotherapist and other specialised AHPs [allied health professionals] should be members of the extended sarcoma MDT.

Ongoing rehabilitation and supportive care should be provided locally wherever possible. This should be coordinated by the therapist in liaison with the key worker.

Supportive and palliative care

Orthotic and prosthetic appliance provision

Rapid, easy access should be provided to appropriate orthotic and prosthetic services.

The sarcoma MDT should establish formal links to a centre(s) matching the PARC template, and should refer patients for pre-amputation assessment.

End of life care

Supportive and palliative care

Specialist palliative care

A member of the specialist palliative care team should be a member of the core sarcoma MDT.

3.5.3 Current UK practice

Customised information

A National Peer Review Report on Sarcoma Cancer Services covering 2012/2013[16] reported that 53% of sarcoma MDTs provided written material for patients and carers which included customised information specific to that particular MDT. This included information about local provision of services and also information specific to the MDT's cancer site or group of cancers about the disease and its treatment options (including names and functions/roles of the team treating them).

No current practice information regarding information available from diagnostic clinics separate from sarcoma MDTs was identified.

The National Cancer Patient Experience Survey (NCPES) asks patients if, when they were told they had cancer, they were given written information about the type of cancer they had. In 2012, the proportion of patients offered information was 50%[17] - rising to 58% in the same survey conducted in 2013[18].

In the 2013 Welsh Cancer Patient Experience Survey (CPES)[19], 43% of people with sarcoma were given written information about their operation. In the National Cancer Experience Survey 2011/12[17], 55% of sarcoma patients surveyed said they were given access to written information about their operation beforehand. This was the lowest proportion of all tumour groups surveyed (13 in total). In the same survey performed in 2013, 56% sarcoma patients said that they were given written information about their operation[18].

Key worker

A National Peer Review Report on Sarcoma Cancer Services covering 2012/2013[16] reported that 93% of sarcoma MDTs had an operational policy where a single named key worker for a patient's care is identified for each individual patient, with the name and contact number of the current key worker being recorded in the patient's case notes.

Of the sarcoma patients asked in the 2013 National Cancer Patient Experience Survey[18], 86% reported that they were given the name of a Clinical Nurse Specialist.

[16] National Peer Review Report: Sarcoma Cancer Services Report 2012/2013
[17] National Cancer Patient Experience Survey 2011/12. Department of Health (2012)
[18] Cancer Patient Experience Survey 2013. NHS England
[19] Wales cancer patient experience survey 2013. Welsh Assembly Government (2013)

Rehabilitation

In 2012/2013, 73% of sarcoma MDTs had an extended membership including an AHP agreed as providing contact with rehabilitation services when such an individual was not included as part of the core MDT[20].

No current practice information regarding the availability of rehabilitation, orthotic or prosthetic services was identified.

End of life care

A National Peer Review Report on Sarcoma Cancer Services covering 2012/2013[20] reported that 73% of sarcoma MDTs had an extended team which contained a health professional who is a core member of a specialist palliative care team, when MDTs did not include such a professional as part of the core team.

[20] National Peer Review Report: Sarcoma Cancer Services Report 2012/2013

3.6 Improving knowledge

3.6.1 Summary of suggestions

Opportunities to participate in clinical studies

Two stakeholders identified the need to offer patients the opportunity to take part in clinical studies. Stakeholders noted that increased participation in such studies would raise the profile of sarcoma through greater availability of research studies and also help to improve outcomes.

Pathology reporting of STS

A stakeholder highlighted that the Royal College of Pathologists have published guidelines on the core minimum data set required for reporting STS histopathology. Following these guidelines would enable pathologists to grade and stage cancers in an accurate and consistent manner in compliance with international standards. This would ultimately provide prognostic information allowing clinicians to provide high standards of care and appropriate management for specific clinical circumstances.

Data collection

A stakeholder identified the need for up-to-date information to be available to indicate weaknesses in the provision of current services and noted the fragmented manner in which sarcoma data has previously been recorded.

A further stakeholder suggested that MDTs should be responsible for data collection and reporting.

3.6.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source(s) that may support potential statement development. These are presented in full after table 9 to help inform the Committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Opportunities to participate in clinical studies	NICE Guidance for Improving Outcomes in Sarcoma Section – Key Recommendations Section - Patient perspectives Sub-section - Information Section - Improving knowledge Sub-section - Research Section - Improving treatment: bone sarcomas Sub-section - Chemotherapy and radiotherapy Section - Improving treatment: soft tissue sarcomas Sub-section - Chemotherapy and radiotherapy
Pathology reporting of STS	NICE Guidance for Improving Outcomes in Sarcoma Section - Improving pathology
Data collection	NICE Guidance for Improving Outcomes in Sarcoma Section - Improving knowledge Sub-section - Data collection

Opportunities to participate in clinical studies

Key Recommendations

Patients should be informed about relevant clinical trials and supported to enter them.

Patient perspectives

Information

When an existing clinical trial is not being conducted at the patient's own treatment centre, participation in that trial should be offered to the patient at another treatment centre.

Details of clinical trials for sarcoma should be available at every sarcoma treatment centre.

Improving knowledge

Research

Commissioners should ensure that NCRN-adopted clinical trials for patients with sarcomas are supported locally.

All sarcoma MDTs should aim to maximise entry into trials and should work with the local NCRN to ensure this happens. They should have a nominated research lead.

The possibility of entry into an appropriate trial should be discussed with every patient who fits the inclusion criteria. Such patients should be given accurate and accessible information to inform their decision about whether to participate in the trial.

Improving treatment: bone sarcomas

Chemotherapy and radiotherapy

The provider of chemotherapy services should offer all patients with bone sarcomas entry into the relevant clinical trials.

Improving treatment: soft tissue sarcomas

Chemotherapy and radiotherapy

The provider of chemotherapy and radiotherapy services should offer all patients with soft tissue sarcomas entry into the relevant clinical trials.

Pathology reporting of STS

Improving pathology

Pathology reports should include all the information required by the Royal College of Pathologists' histopathology dataset for soft tissue sarcomas once it is available. They should use a defined tumour classification (for example, the World Health Organization (WHO) classification 2002) and grading (for example, the Trojani grading system).

Data collection

Improving knowledge

Data collection

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 (including comorbidity data). 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 the repository of a national dataset, which could then become a national sarcoma register.

3.6.3 Current UK practice

Opportunities to participate in clinical studies

In the National Cancer Patient Experience Survey (NCPES) conducted in 2013, only 34% of sarcoma patients reported that (since their diagnosis) taking part in research had been discussed with them (the result was 33% for the same question asked in 2012[21]). Of the patients who were asked, 72% went on to take part in cancer research[22].

In 2012/2013, 40% of sarcoma MDTs produced a report at least annually on clinical trials[23]. Reports included details of the MDT's trials portfolio (including the extent of local provision of the national portfolio) and also the MDT's recruitment to the portfolio, including the extent of delivery against the locally agreed timescales and targets.

Pathology reporting of STS

No current practice information regarding pathology reporting of STS was identified.

Data collection

80% of sarcoma MDTs are reported to have recorded their agreed part of an area-wide minimum dataset (MDS) in an electronically retrievable form in 2012/2013[23]. MDS are agreed by SAGs and cover at least the latest approved cancer dataset at

[21] National Cancer Patient Experience Survey 2011/12. Department of Health (2012)
[22] Cancer Patient Experience Survey 2013. NHS England
[23] National Peer Review Report: Sarcoma Cancer Services Report 2012/2013

www.isb.nhs.uk. Additionally SAGs may agree additional data items such as the cancer waiting times monitoring, including Going Further on Cancer Waits in accordance with DSCN 20/2008, to the specified timetable as specified in the National Contract for Acute Service or the National Sarcoma Dataset.

3.7 Additional areas

3.7.1 Summary of suggestions

Further guidance

Several stakeholders identified areas where further guidance is needed:

- Gynaecological sarcoma treatment

A stakeholder commented that of all site-specific tumours, gynaecological sarcomas are the least well managed. In particular, inappropriate surgical procedures conducted on misdiagnosed gynaecological sarcomas can result in shortened time to local recurrence. The stakeholder remarked that NICE guidance could be used to alert Gynaecologists to the risk of uterine malignancy in patients thought to have benign fibroids by improving recognition of relevant symptoms.

A further stakeholder highlighted the need for guidance on several specific areas of gynaecological sarcoma treatment, with guidance required for:

  - Preoperative investigations,
  - The effectiveness of adjuvant therapy in gynaecological sarcomas,
  - The optimal mode of follow-up for women with gynaecological sarcomas.

- Follow-up procedures

Several stakeholders raised the need for guidance relating to follow-up procedures and monitoring agreements.

Two stakeholders observed that follow-up practices varied and one stakeholder identified a need for consistent, uniform and evidence based approaches. A stakeholder raised a specific question as to the optimal mode of follow-up for women with gynaecological sarcomas.

A further stakeholder raised the issue that no recognised standard exists for both timing and modality for thoracic surveillance following sarcoma resection. The stakeholder observed that some centres use 3 monthly chest radiographs whereas other use CT, and, furthermore, that some patients can present late with abdominal metastatic disease – an anatomical region currently not included in surveillance.

- Development of a risk score for sarcoma symptoms

A stakeholder highlighted the difficulty of diagnosing sarcomas in primary care; particularly distinguishing sarcomas from the far more commonly occurring

benign soft tissue lesions. The stakeholder suggested the development of a risk assessment tool (such as a Hamilton Risk score) for sarcoma for patients attending their GP.

- Guidelines for musculoskeletal (MSK) radiologists

A stakeholder noted that MRI is advised for diagnostic triage where Ultrasound is inappropriate and stated that clear guidelines for MSK radiologists is required.

- Optimal imaging tests for staging sarcomas

A stakeholder commented that currently thoracic CT is part of the staging process for soft tissue sarcoma, with the addition of a radio-nuclide bone scan for bone sarcoma as a minimum standard. The stakeholder further noted that some centres are using whole body MRI as a staging tool and asked if all centres should be using this.

- Treatment of surgically inoperable sarcomas

A stakeholder suggested that MRIgFUS [Magnetic Resonance Image-guided focused Ultrasound Surgery] should be considered for treatment of surgically inoperable sarcomas.

Additional suggestions - out of scope, no supporting recommendations, do not meet technical criteria for statement development

Other areas for quality improvement suggested by stakeholders are either out of scope, have no supporting recommendations or do not meet technical criteria for statement development:

- Regional Sarcoma Advisory Groups in place
- General adherence to national guidelines
- Suggested outcomes for assessing surgery/care
- Treatment of GIST and NICE TAs

Appendix 1: Tables of Core and extended members of a sarcoma MDT

From ‘Improving Outcomes for People with Sarcoma’ [page 55]

Table 5. Core membership of a sarcoma multidisciplinary team

Staff requirements	Specification
Specialist sarcoma surgeon	A minimum of two per MDT. These surgeons should have a major clinical interest in sarcomas i.e. spend at least 5 programmed activities of direct clinical care involved in managing sarcomas.
Specialist sarcoma radiologist	At least two with a special interest in musculoskeletal/oncological imaging.
Specialist sarcoma pathologist	At least one and ideally two (see Chapter 4)
Medical oncologist and/or clinical oncologist	At least two with an interest in musculoskeletal oncology. There should be at least one clinical oncologist. The oncologist/s should each spend a minimum of three programmed activities of direct clinical care involved in the management of sarcomas.
Sarcoma clinical nurse specialist/key worker*	Sufficient to allocate a clinical nurse specialist/key worker for each patient (but a minimum of two) - see Chapter 8.
Support staff	MDT coordinator and secretarial support
Palliative care specialist	A member of the specialist palliative care team.

* Key worker may come from any of the disciplines involved in the multidisciplinary team (MDT).

From ‘Improving Outcomes for People with Sarcoma’ [page 56]

Table 6. Membership of an extended sarcoma multidisciplinary team

Staff requirements	Specification
Specialist sarcoma physiotherapist	With expertise in sarcomas
Specialised allied health professionals (AHP)	Consisting of relevant AHPs, such as therapy radiographers, occupational therapists, prosthetists, orthotists, dieticians and social workers, plus access to counsellors and/or psychologists.
Paediatric oncologist	Specifically for MDTs that treat children and young people with bone and/or soft tissue sarcoma
Specialist nurse(s)	Including palliative care nurses and appropriately trained ward staff
Affiliated medical or clinical oncologists from linked cancer centre	Nominated by the cancer network clinical director and approved by the MDT lead clinician
Affiliated diagnostic service clinicians	Nominated by the cancer network clinical director and approved by the MDT lead clinician.
Other professionals including orthopaedic, thoracic, plastic, head and neck, gynaecological, GI and vascular surgeons.	Nominated by the cancer network clinical director and approved by the MDT lead clinician.

Appendix 2: Key priorities for implementation (CSGSarcoma)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

Key Recommendations

• All patients with a confirmed diagnosis of bone or soft tissue sarcoma (except children with certain soft tissue sarcomas) should have their care supervised by or in conjunction with a sarcoma multidisciplinary team (MDT).

• Cancer networks should arrange diagnostic services for the investigation of patients with suspected soft tissue sarcomas (as defined by the National Institute for Health and Clinical Excellence (NICE) 'Referral guidelines for suspected cancer') at designated diagnostic clinics. All patients with a probable bone sarcoma (usually following X-ray examination) should be referred directly to a bone tumour treatment centre (see Chapter 6) for diagnosis and management.

• All patients with a provisional histological and/or radiological diagnosis of bone or soft tissue sarcoma should have their diagnosis reviewed by a specialist sarcoma pathologist and/or radiologist who are part of a sarcoma MDT. Commissioners should fund a formal system for second opinions and review of difficult cases, and molecular pathology and cytogenetic facilities.

• A soft tissue sarcoma MDT should meet minimum criteria (as defined in Chapter 5) and manage the care of at least 100 new patients with soft tissue sarcoma per year. If a sarcoma MDT manages the care of patients with both bone and soft tissue sarcoma, it needs to manage the care of at least 50 new patients with bone sarcoma per year and at least 100 new patients with soft tissue sarcoma per year.

• All patients who are managed by a sarcoma MDT should be allocated a key worker (see Chapter 8).

• Patients should undergo definitive resection of their sarcoma by a surgeon who is a member of a sarcoma MDT or by a surgeon with tumour site-specific or age-appropriate skills, in consultation with the sarcoma MDT.

• Chemotherapy and radiotherapy are important components of the treatment of some patients and should be carried out at designated centres by appropriate specialists as recommended by a sarcoma MDT.

• Patients should be informed about relevant clinical trials and supported to enter them.

• All sarcoma MDTs should participate in national audit, data collection and training.

• Patients with functional disabilities as a consequence of their sarcoma should have timely access to appropriate support and rehabilitation services.

• The National Specialist Commissioning Advisory Group should consider commissioning designated centres for the management of retroperitoneal and pelvic soft tissue sarcomas.

• This guidance should be implemented by primary care trusts (PCTs)/local health boards (LHBs) working collaboratively through their specialist commissioning groups, in close consultation with cancer networks. A National Implementation Group should be considered for both England and Wales.

Appendix 3: Glossary

AHP	Allied health professional
BSRM	British Society of Rehabilitation Medicine
CNS	Clinical nurse specialist
DSC	Disablement Service Centre
GIST	Gastrointestinal stromal tumours
MDS	Minimum data set
MDT	Multidisciplinary team
MSK	Musculoskeletal
NCRN	National cancer research network
PA	Programmed activities
PARC	Prosthetic and Amputee Rehabilitation Centres
SAG	Sarcoma Advisory Group
SSMDT	Specialist skin cancer multidisciplinary team
SSP	Specialist sarcoma pathologist
STS	Soft tissue sarcoma

Appendix 4: Suggestions from stakeholder engagement exercise

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
001	SCM1	Retroperitoneal sarcomas should be concentrated in a smaller number of specialist high-volume units.	There are approximately 250 new cases of retroperitoneal sarcoma annually in England and these are distributed across the 13 sarcoma MDTs. If the cases were evenly distributed, this would amount to approximately 20 new cases per MDT. We know that some units have many more than 20 new cases per year (RMH has approximately 70 new cases annually), therefore, by definition, some of the 13 sarcoma MDTs will have less than 20 cases per year. The last NSCAG assessment identified a number of units with less than 10 new cases per year. If NICE were to recommend a small number of Units performing retroperitoneal sarcoma then that would definitely lead to higher volume centres. This subject is also being discussed by the Sarcoma Clinical Reference Group (Sarcoma Service Specifications: Draft recommendations for retroperitoneal sarcoma). At a recent meeting, it was suggested	High surgeon volume and specialised multidisciplinary centres leading to improved patient outcome in major oncologic surgery has been shown in hepatobiliary/pancreatic surgery, esophago-gastric surgery and surgical oncology.[1,2] Data also exist that show better outcomes for RPS managed in centralised multidisciplinary specialist centers. Gutierrez and colleagues [3] looked at the prognostic significance of surgical case volume on outcome in 4205 patients. They found that patients with retroperitoneal sarcoma treated in a high-volume center had a lower postoperative mortality and improved overall mortality compared when treated in a low volume center. Bonvalot and colleagues [4] published results showing that intra- operative tumour rupture rate is inversely related to institutional volume in RPS and that institutional volume was a significant risk factor for local recurrence (adjusted hazard ratio 1.61 when surgery occurred in low volume centers). Van Dalen et al [5] published data demonstrating a higher rate of incomplete resections in low volume centres (38% vs. 18%, P = 0.002) compared to high-volume centre. This further translated into a survival benefit for patients treated in a high-volume	1. Chowdhury MM, Dagash H, Pierro A. A systematic review of the impact of volume of surgery and specialization on patient outcome. Br J Surg. 94(2) 145-61 (2007). 2. Learn PA, Bach PB. A decade of mortality reductions in major oncologic surgery: the impact of centralization and quality improvement. Med Care. 48(12) 1041-9 (2010). 3. Gutierrez JC, Perez EA, Moffat FL, Livingstone AS, Franceschi D, Koniaris LG. Should soft tissue sarcomas be treated at high-volume centers? An analysis of 4205 patients. Ann Surg. 245(6) 952-8 (2007). 4. Bonvalot S, Rivoire M, Castaing M, et al. Primary retroperitoneal sarcomas: a multivariate analysis of surgical factors

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			that units performing retroperitoneal sarcoma surgery should perform between 30 and 40 new cases annually.	centre. Patients treated in high-volume centers further have greater access to adjuvant treatment, research studies, specialist sarcoma pathologist and radiologist. Sarcoma surgeons in specialist high-volume centre should have skills to better select patient where a complete resection would be possible, better judgment to determine the extent of organ resection required to obtain complete resection and develop skills to be more comfortable with performing complex multi-visceral en bloc resection.	associated with local control. J Clin Oncol. 27(1) 31-7 (2009). 5. Van Dalen T, Hennipman A, Van Coevorden F, et al. Evaluation of a clinically applicable post-surgical classification system for primary retroperitoneal soft-tissue sarcoma. Ann Surg Oncol. 11(5) 483-90 (2004).
002	SCM1	Gynaecological sarcomas	Our observation is that of the site-specific tumours, gynaecological sarcomas are the least well managed. Most are only diagnosed after hysterectomy but the current trend towards minimally invasive surgery is creating an even greater problem. Myomectomy or morcellation greatly increases the risk of intra-abdominal dissemination and shortens the time to local recurrence. Although the incidence of leiomyosarcoma in resections for apparently benign fibroids is only 1:500- 1:1000, the impact of these procedures is	NICE Guidance could alert Gynaecologists to the risk of uterine malignancy in patients thought to have benign fibroids. Better recognition of relevant symptoms are safeguards to limit the risk of inappropriate surgery would represent a significant improvement for patients. It is suggested that NICE Guidance should highlight “red flag symptoms” such as a rapid increase in tumour size, increasing pain or severe haemorrhage. Such symptoms of recent onset should be a recommendation for imaging by CT or MRI. Currently, patients having surgery for fibroids are usually imaged by ultrasound alone. Such a recommendation would alert Gynaecologists and Radiologists to the possibility of	Information provided in confidence relating to why this is an important area for further guidance.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			devastating, indeed likely fatal for these women. Individual case histories suggest that for some women, a rapid increase in tumour size, increasing pain or severe haemorrhage should alert their physician to the possibility of malignancy but appropriate imaging is often not done and biopsies prior to surgery are a rarity.	malignancy and the need for pre-operative biopsy or appropriate referral of suspicious cases to a specialist sarcoma MDT	
003	SCM2	All patients with a sarcoma should have their case discussed at a relevant sarcoma MDT	Sarcomas are such a diverse group of conditions that the way a tumour behaves can be unpredictable. To ensure that each patient has correct treatment their case should be discussed by experts who understand the behaviour of that tumour	There are still many patients with a sarcoma who's case is not discussed by appropriate experts. This may mean that not all sarcoma MDTs discuss all cases eg gynae sarcomas may need referral to a different MDT than limb ones. tension and alleviate headaches.	*No additional information provided by stakeholder.*
004	SCM2	All patients should be offered opportunity to contribute to research studies	A broader portfolio of studies should be developed	The more research studies available the greater the profile of sarcomas will be raised	*No additional information provided by stakeholder.*
005	SCM2	Better information should be provided which can be customised to individual patients	Many patients with a sarcoma comment that current information does not cover their diagnosis or location.	Patients consistently mention this as a key deficiency	*No additional information provided by stakeholder.*
006	SCM2	Adherence to national guidelines	Guidelines suggest best treatment. Adherence to these is	NCIN can identify how many patients are treated with 'appropriate' therapy and	*No additional information provided by stakeholder.*

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			likely to improve outcomes	identify outlying units	
007	Royal College of Paediatrics and Child Health	Key area for quality improvement 1	Should they include the NICE/DH source of national cancer survivorship initiative as they are dealing with follow-up too?		*No additional information provided by stakeholder.*
008	The Royal College of Pathologists	I am just writing to inform you that the College does not have any comments to make on this quality standard at this stage.			*No additional information provided by stakeholder.*
009	Royal College of Nursing	This is to inform you that the Royal College of Nursing have no comments to submit to inform on the Sarcoma topic engagement at this present time.			*No additional information provided by stakeholder.*
010	Royal College of General Practitioners	Key area for quality improvement 1	Diagnosis in primary care is difficult as these tumours are less common than relatively common benign soft tissue. Due to changes in funding structures and criteria less benign lesions appear to be removed in primary and secondary care as it deemed non-essential NHS work.	Develop a Risk assessment tool such a a Hamilton Risk score for sarcoma Identify all symptoms reported to GPs before diagnosis • Identify which symptoms were relevant • Estimate the 'risk' of sarcoma for each symptom in a patient attending their GP	Does the two-week rule pathway improve the diagnosis of soft tissue sarcoma? A retrospective review of referral patterns and outcomes over five years in a regional sarcoma centre Tim D Pencavel, Dirk C Strauss, Greg P Thomas, J Meirion Thomas, Andrew J Hayes

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				http://www.tvcn.nhs.uk/earlydiagnosis/the-primary-care-cancer-risk-assessment-tool-rat/	Ann R Coll Surg Engl. 2010 July; 92(5): 417–421. doi: 10.1308/003588410X12664192075972 PMCID: PMC3180317
011	Royal College of General Practitioners	Key area for quality improvement 2	Ultrasound is being used to diagnostic triage but unless the lump is superficial or if it involves muscle an MRI will usually be advised.	Clear guidelines for MSK radiologists.	*No additional information provided by stakeholder.*
012	Royal College of General Practitioners	Key area for quality improvement 3	Lack of clarity of which specialty o GPs refer to as benign lipomas usually go to Dermatologists and sarcomas to Orthopaedics. Many 2 week wait forms are unclear about referral unless the lump is in a defined areas such as Head and neck to ENT.		*No additional information provided by stakeholder.*
013	Royal College of General Practitioners	Key area for quality improvement 4	Consider MRIgFUS for treatment of surgically inoperable sarcomas	Non invasive technique	http://www.anticancerfund.org/sites/default/files/documents/thermal_ablation_for_professionals_3.pdf
014	The Royal College of Radiologists	Key area for quality improvement 1 Recommended referral pathway for medical	The RCR notes that one of the biggest perceived delays in sarcoma management remains the time between first presentation to a medical	Current guidance for GPs is to refer to an appropriate surgeon. The RCR suggests that direct referral to an appropriate scanning service may more quickly identify those patients with a mass requiring urgent	*No additional information provided by stakeholder.*

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		practitioners presented with a soft tissue lump	practitioner with a lump and an adequate diagnostic scan – usually U/S or MR.	further investigation.	
015	The Royal College of Radiologists	Key area for quality improvement 2 Optimal imaging tests for staging a sarcoma	Currently thoracic CT is part of the staging for soft tissue sarcoma, with the addition of a radio-nuclide bone scan for bone sarcoma as a minimum standard. Some centres are also using whole body MRI as a staging tool. The RCR asks whether all centres should be using this.	This has important implications regarding the availability of MRI scanning time and Radiologist reporting time.	http://www.hindawi.com/journals/sarcoma/2013/548628/
016	The Royal College of Radiologists	Key area for quality improvement 3 Optimising image modality and frequency of surveillance following sarcoma resection	Currently there is no recognised standard for both timing and modality for thoracic surveillance, with some centres using 3 monthly chest radiographs and others using CT. Some patients also present late with abdominal metastatic disease – this anatomical region is not currently included in surveillance.	The RCR asks whether abdominal ultrasound should also be included in surveillance?	*No additional information provided by stakeholder.*
017	The Royal College of Radiologists	Key area for quality improvement 4 Incidence of unplanned positive margins post-resection of soft tissue sarcoma (STS) at Sarcoma Unit	The RCR notes that good quality surgery should minimise the chances of an unplanned positive margin. Unplanned positive margin is a definite risk factor for local and probably distant relapse.	The RCR suggests this would help to identify centres without the mean	J Surg Oncol. 2004 Feb;85(2):68-76. The prognostic significance of margin width for extremity and trunk sarcoma. McKee MD1, Liu DF, Brooks JJ, Gibbs JF,

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					Driscoll DL, Kraybill WG.
018	The Royal College of Radiologists	Key area for quality improvement 5 30 day mortality post potentially curative resection at Sarcoma Unit	The RCR notes that this should be minimal in good quality units	The RCR suggests this measure will benchmark good practice and identify outliers.	*No additional information provided by stakeholder.*
019	The Royal College of Radiologists	Key area for quality improvement 6 Incidence of amputation as the definitive local treatment for initial presentation with STS	The majority of patients should be offered limb sparing surgery. The RCR notes that it is difficult to find supporting data but estimates that amputation as the primary treatment should be <5% in STS management.	The goal in modern day sarcoma management is to offer limb sparing to the vast majority of patients. The RCR feels that better functioning multi-disciplinary teams (MDTs) should achieve this whilst higher amputation rates may reflect difficulties in MDT working or a higher frequency of difficult cases (perhaps to be seen in the much larger sarcoma units).	Lancet Oncol. 2003 Jun;4(6):335-42. Amputation for soft-tissue sarcoma. Clark MA1, Thomas JM.
020	The Royal College of Radiologists	Key area for quality improvement 7 Pathology reporting of soft tissue sarcoma	The RCPath has published guidelines on the core minimum data set required for reporting STS histopathology.	The datasets enable pathologists to grade and stage cancers in an accurate, consistent manner, in compliance with international standards, and provide prognostic information thereby allowing clinicians to provide a high standard of care for patients and appropriate management for specific clinical circumstances.	www.rcpath.org
021	NHS England	To have in place rapid and effective diagnostic pathways for suspected	The clinic-pathological heterogeneity of sarcoma coupled with its rarity creates major challenges to recognition and	Diagnostic pathways and processes for suspected sarcoma vary nationally. Local diagnostic clinics as recommended in Improving Outcomes for People with	*NICE IOG.* *CQuINS peer review reports of diagnostic*

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		sarcoma	timely diagnosis. Missed opportunities for earlier diagnosis are commonly reported and excess disease and treatment-related morbidity consequently occur.	Sarcoma, NICE, March 2006 (NICE IOG) have been only sporadically implemented. Patients commonly raise this as a critical area for improvement. The low positive rate of sarcoma diagnoses through the 2 week wait referral system puts undue pressure on specialised services. Patients with sarcoma report more commonly than those with other cancers: more visits to the GP and deterioration in health while awaiting referral.	*services www.cquins.nhs.uk* *National Cancer Patient Experience Survey* *http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey*
022	NHS England	All patients with sarcoma will be referred to specialised sarcoma services	Sarcomas vary widely in their presentation and behaviour and may present to primary care as well as multiple sub-specialities. Management is often complex. Currently there is considerable variation in referral to specialised care either random or determined by sarcoma sub type such as skin sarcomas, gynaecological sarcomas, sarcomas of the head and neck, gastrointestinal stromal tumours (GIST).	Specialised sarcoma centres will offer expert care, support and information, access to research, reporting of outcomes and so assist in reaching clinical outcome benefit. A consistent message from sarcoma patient groups and the National Cancer Patient Experience survey is the priority and importance placed on seeing a specialist.	Sarcoma UK NCIN CQuINS http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey
023	NHS England	Sarcoma MDT All patients with sarcoma will have their diagnosis, treatment and support agreed and delivered by	Patients with a sarcoma are best treated by a multi-disciplinary team of specialists that have the skills and expertise to ensure the best possible outcomes for patients. MDTs will provide	Providing a comprehensive service to sarcoma patients from diagnosis through to definitive treatment and follow up, can only be achieved through an appropriately resourced MDT core team with access to other professionals and expertise. Currently	NICE IOG CQuINS NCIN

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		a Sarcoma MDT. MDTs will be responsible for data collection and reporting.	assessment, diagnosis and treatment including surgical management, oncology and radiotherapy. The MDT will be made up of a 'core' team and other professional disciplines who are able to contribute to decision making and offer expertise	there is considerable variation in the size, function and quality of MDTs as well as the extent to which they are accessed by patients.	
024	NHS England	Patients with sarcoma will be supported throughout their treatment and follow up pathway by a sarcoma clinical nurse specialist	It is important that all patients with sarcoma are provided with support throughout their treatment and follow up plan by a sarcoma clinical nurse specialist. The value of clinical nurse patients to patients with cancer has been well illustrated through the results of the National Cancer Patent Experience Survey.	Patients with sarcoma consistently report the value of a CNS. Yet data from NCPS shows that sarcoma patients often have no or difficult access to a CNS.	http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey
025	NHS England	Sarcoma patients should undergo planned surgery by designated surgeons	Sarcoma patients should undergo planned surgery by designated sarcoma surgeons who are core members of the sarcoma MDT. Surgeons who are responsible for treating sarcomas in specialist sites should be core members of a relevant site specific MDT or a sarcoma MDT	Planned operations by specialist surgeons ensure correct operations are undertaken and give best possibility for improved outcomes including reduce local recurrence and functional outcomes.	Examples of supporting literature include i. M. Venkatesan, C.J. Richards, T.A. McCulloch, A.G.B. Perks, A. Raurell, R.U. Ashford, East Midlands Sarcoma Service, Inadvertent surgical resection of soft tissue sarcomas, European Journal of Surgical Oncology (EJSO),

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					Volume 38, Issue 4, April 2012, Pages 346-351 ii. Bonvalot S, Miceli R, Berselli M, et al. Aggressive surgery in retroperitoneal soft tissue sarcoma carried out at high-volume centers is safe and is associated with improved local control. Ann Surg Oncol. 17(6) 1507-14 (2010). iii. Gronchi A, Lo Vullo S, Fiore M, et al. Aggressive surgical policies in a retrospectively reviewed single-institution case series of retroperitoneal soft tissue sarcoma patients. J Clin Oncol. 27(1) 24-30 (2009) iv. Gutierrez JC, Perez EA, Moffat FL, Livingstone AS, Franceschi D, Koniaris LG. Should soft tissue sarcomas be treated at high-volume centers? An analysis of 4205 patients. Ann Surg. 245(6) 952-8

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					(2007), v. Bonvalot S, Rivoire M, Castaing M, et al. Primary retroperitoneal sarcomas: a multivariate analysis of surgical factors associated with local control. J Clin Oncol. 27(1) 31-7 (2009)
026	NHS England	Pathways for sarcomas presenting to other MDTs Sarcoma patients presenting to a cancer site specific MDT will have their diagnosis, treatment and support agreed and delivered by a sarcoma MDT	To ensure that all patients have access to treatment that is consistent and equitable, it is important that Trusts have in place arrangements and pathways that ensure access for patients from site specific MDTs to a specialist sarcoma MDT	Pathways for patients with sarcomas which may present to other cancer MDTs e.g. gynaecological, head & neck, gastrointestinal, skin, breast, urology, lung, are poorly developed and result in sporadic referral, treatment variation and poor patient experience. Outcomes including survival for some of these sarcomas are poor.	Peer review report CQuINS Sarcoma UK strategic priorities http://www.sarcoma.org.uk/strategy
027	NHS England	All patients with desmoid-type fibromatosis will be referred to a specialised sarcoma service	This uncommon disease is poorly understood but information emerging about its biology and the benefits of different treatment approaches have the potential to reduce the morbidity of fibromatosis.	Expertise in the management of fibromatosis is limited but often concentrated in sarcoma centres. Patients with this disease often describe a poor experience as clinicians are unfamiliar with the condition and are unaware of current approaches to treatment.	e.g. http://www.sarcoma-patients.eu/index.php/quality-care-3
028	NHS England	All new patients with Ewing sarcoma are discussed at the National	There are approximately 60 cases of Ewing sarcoma annually. This cancer is curable in approximately	Maximising access through innovation to specialists for very rare sarcoma sub groups is expected to improve outcomes. The	Gerrand et al. Early experience of recommendations by a

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		Ewing MDT	two thirds of patients. The need for radiotherapy and/or surgery is individualized in each patient as a consequence of the variety of primary tumour sites. The effectiveness of local control by surgery or radiotherapy is associated with survival. Data from a clinical trial completed in 1998 exists which indicates that UK results are inferior to other participating countries. A national Multi-Disciplinary Team has been formed in England to provide a national reference centre of expertise for the treatment of Ewing's Sarcoma of bone. The aim of the National Ewing's MDT is that all new cases of Ewing's sarcoma of bone should be discussed by a National MDT with at least two surgeons, two radiation oncologists and the patient's own treating clinician in attendance.	National Ewing MDT is a valuable paradigm.	national virtual multidisciplinary forum to recommend primary tumour treatment options in Ewing's sarcoma. Connective Tissue Oncology Society
029	NHS England	Sarcoma patients undergoing chemotherapy and radiotherapy should receive it through designated practitioners	Chemotherapy and radiotherapy are important components for the treatment of sarcomas and should only be delivered by chemotherapy and radiotherapy practitioners designated by a	To ensure consistent and uniform approaches to treatment and safe delivery of appropriate care.	CQuINS

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			Sarcoma Advisory Group		

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030	NHS England	Patients with sarcoma should be offered the opportunity to take part in appropriate clinical trials	All sarcoma patients should be offered the opportunity to take part in clinical trials if they are eligible. Sarcoma centres must provide evidence of offering participation in trials.	Outcomes including survival for most sarcomas remain unsatisfactory. Clinical trials are a vital means to improve outcomes and rates of inclusion of sarcoma patients need to be improved	NIHR Clinical Research Network, Cancer.
031	NHS England	Molecular diagnosis should be undertaken in all patients with gastrointestinal stromal tumours (GIST)	The responsibility for the final reporting and reviewing of the histological and molecular diagnosis of GIST can only undertaken by consultant histopathologists who are accredited in the national sarcoma histopathology EQA or the national GI histopathology EQA and recognised by a Sarcoma Advisory Group.	Molecular characterisation is important information for prognosis and to guide treatment.	National and international guidelines for GIST e.g. ESMO CQuINS and Manual of Cancer Measures
032	NHS England	Sarcoma patients should have their rehabilitation needs assessed at key points on the care pathway and receive support based on their identified needs	It is important that sarcoma patients are supported from diagnosis through the entire pathway with appropriate rehabilitation support. All sarcoma patients will have their rehabilitation needs assessed at key points on their pathway and receive support based on their identified needs	The functional cost of sarcoma and its treatment is high. Effective, specialist rehabilitation is highly valued for patients but variably available.	National QIDIS project – report available from Sarcoma CRG
033	NHS England	All sarcoma patients have an end of treatment summary and care plan	It is important that MDTs oversee all aspects of treatment including any follow up and monitoring	Information needs including summaries are not well provided for patients with sarcoma. Follow up practices vary. Consistent,	http://www.quality-health.co.uk/surveys/national-cancer-patient-

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		that includes agreed follow up and monitoring arrangements that are overseen by a sarcoma MDT and in accordance with guidelines	requirements as set out in the end of treatment summary and care plan.	uniform and evidence based approaches are required.	experience-survey Rothermundt C, Whelan JS, Dileo P, Strauss S, Coleman J, Briggs T, Haile S, Seddon B. What is the role of routine follow up for localised limb soft tissue sarcomas? A retrospective analysis of 174 patients. Br J Cancer 2014 1–7 | doi: 10.1038/bjc.2014.200
034	NHS England	End of life care Sarcoma services should provide end of life care in line with NICE guidance and should ensure access to services in hospitals and in the community	Sarcoma services should have clear pathways and protocols in place to support end of life care. Trusts should provide end of life care in line with NICE guidance and in particular the markers of high quality care set out in the NICE quality standard for end of life care for adults.	Palliative care needs of patients with sarcoma are frequently extensive and difficult to meet. Early involvement of an experienced team is important.	NICE QS http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13/introduction-and-overview
035	NHS England	Sarcoma Advisory Groups in place at regional level and linking to national commissioning and patient involvement	Regional Sarcoma Advisory Groups responsible for a sarcoma Network should be in place to support MDTs and produce an annual work programme informed by clinician, commissioner and patient/carer involvement and developed in partnership with	This is a key component for delivery of equitable, consistent, high quality sarcoma services. Sarcoma Advisory Groups are recognised as the primary source of clincial opinion on tumour types. They are also responsible for ensuring a standardised and consistent approach to the management of tumour	NICE IOG, Manual for Cancer Services Sarcoma Measures Version 1.0 http://www.cquins.nhs.uk/?menu=resources

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			Strategic Clincial Networks and agreed by Area Teams responsible for specialised services.	types through the development and publication of patient pathways, practice guidelines, audit, research and service improvement initiatives.	

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036	British gynaecological cancer society	Key area for quality improvement 1	Need for guidance on required Preoperative investigations +/- need for CT chest/abdo/pelvis as limited evidence base in literature.	Our members report considerable variation in practice across the country	Published literature
037	British gynaecological cancer society	Key area for quality improvement 2	Limited evidence exists to support the effectiveness of adjuvant therapy in gynaecological sarcomas	Considerable variation in adjuvant treatment exists - Can guidelines address this	information sources may include national chemotherapy data.
038	British gynaecological cancer society	Key area for quality improvement 3	Please note recent FDA guidance on use of morcellators. Can NICE include this in its review as this is potentially of significant concern that sacromas could be missed in the morcellation process of a fibroid.	This is an important area for dissemination – as morcellation of a gynaecological sarcoma considered pre-operatively to be a fibroid can result in missed diagnosis and poor outcome for patients	Published literature
039	British gynaecological cancer society	Key area for quality improvement 4	What is the optimal mode of follow-up of women with gynaecological sarcomas	Considerable variation in practice exists	Published literature
040	British gynaecological cancer society	Key area for quality improvement 5	Gynaecological cancer MDTS are now required to liaise with specialist sarcoma centres for the management of gynaecological sarcomas. This may sometimes result in patients being managed outwith usual routes of care and some members report patients potentially missing out on existing services for palliation for example.	A national framework for which patients need sarcoma MDT referral and which patients can be managed by on going gynae teams would improve care	Evidence of outcomes from HES data/MDTs and cancer registry
041	SCM3	Treatment of GIST	GIST is the most common sarcoma. There are a number of	There are issues concerning the implementation of the IOG and the TAs	NICE TA 86, 179, 209, 196 which is currently

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			NICE TAs regarding its treatment which are not mentioned in the summary document.	which should be discussed	being reviewed, and a suspended review of masitinib. A decision not to TA regorafenib has also been made by NICE.

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042	SCM3	Treatment of gynae sarcomas	Data indicate that patients with gynae sarcomas have poorer outcomes than other patients with sarcoma. The gynae sarcoma pathway is also inconsistent nationally.	NCIN is currently researching and analysing national data through the gynae and sarcoma Knowledge Intelligence Teams. Their pending report may need to be taken into account.	Forthcoming NCIN study.
043	SCM3	IOG implementation	A number of specialist treatment centres have recorded their experience post-IOG and have presented results at British Sarcoma Group conferences. These papers are of limited interest outside sarcoma and do not get published.	The practical experience of the IOG implementation and the problems encountered must be reflected in the quality standard discussion.	I would suggest that all treatment specialist units are asked to provide abstracts/papers they have researched which report their own practice base.
044	SCM3	IOG implementation has not yet settled down and weaknesses are becoming evident.	Gives indications of where current service provision has weaknesses.	Important factual information is still being analysed and published. Owing to the fragmented manner in which sarcoma has been recorded in cancer registries in the past it is important that the latest data are available.	Peer reviews are published by NHS England. Papers from the NCIN on sarcoma are also open access.
045	SCM3	Prosthetic provision for adult amputees. Sarcoma amputees number about 30 per annum.	Most of these patients have no other morbidities unlike the majority of adult amputees. Prosthetic provision protocols differ around the country and sarcoma amputees may be denied access to the latest functional technology (especially feet).	For an amputee the prosthetic limb is central to rehabilitation and to developing a ‘new’ quality of life.	Not documented as far as I am aware.