SCHEDULE 2 – THE SERVICES

A. Service Specification

Service Specification No.	170122S
Service	Sarcoma (all ages)
Commissioner Lead	
Provider Lead	

1. Scope

1.1 Prescribed Specialised Service

This service specification (the "Specification") covers the provision of care for people with sarcoma cancer, including bone sarcoma, soft tissue sarcoma and gastrointestinal stromal sarcomas (GIST).

1.2 Description

The scope of specialised services is defined within the Prescribed Specialised Services Manual (the "Manual"). The Manual describes the following commissioning arrangements for sarcoma:

- Primary malignant bone sarcoma service, or bone sarcoma, which is designated as a highly specialist service; and
- Sarcoma service, which covers soft tissue sarcoma and GIST and is designated as a specialised service.

Sarcoma is a rare form of cancer and the provision of services is concentrated into a small number of centres, each within a defined sarcoma network (the "Network"). The Network must be governed through a Sarcoma Advisory Group (SAG). An example of a generic sarcoma pathway can be found in Appendix 1.

Sarcoma services are organised and delivered through designated Specialist Sarcoma Centres; each of which hosts a sarcoma multi-disciplinary team (MDT). There are currently fifteen Specialist Sarcoma Centres, ten of which currently host a soft-tissue sarcoma MDT and five of which host a combined bone and soft tissue sarcoma MDT. Each Specialist Sarcoma Centre is responsible for delivering comprehensive sarcoma services, as defined in the Service Specification, to the Network population.

Sarcoma (soft tissue and GIST)

The Manual states that NHS England commissions all care for adults provided by specialist cancer centres, including services provided on an outreach basis as part of a provider network, for rare cancers. Sarcoma is included within the definition of rare cancers set out within the Manual, with the exception of some soft-tissue sarcoma surgery which is appropriate to undertake in local centres, in accordance with Network agreements.

All care is defined as including cancer-related activity from referral to specialist centre to discharge including diagnostics, chemotherapy, radiotherapy, surgery and any long-term follow-up. In addition, it also includes specialist palliative care and survivorship, when provided by a Specialist Cancer Centre.

Fifteen of the specialist cancer centres in England have been designated as a Specialist Sarcoma Centre. They are therefore able to provide specialist care, as described within the Specification, for sarcoma (excluding bone sarcoma).

Primary malignant bone tumours service (bone sarcoma)

The Manual states that NHS England wholly commissions primary malignant bone tumours services for adults and young people, including outreach when provided as part of a provider network. The service must provide diagnosis and surgery for primary malignant bone cancers, such as osteosarcoma, chondrosarcoma and Ewing sarcoma.

Five of the specialist cancer centres in England have been designated as Primary Malignant Bone Tumours Services. They are therefore able to provide specialist care, as described within the Specification, for bone sarcoma. Each of these providers is also designated as a Specialist Sarcoma Centre.

Sarcoma services for children, teenagers and young adults

The Manual states that NHS England commissions services for children and young people (CYP) with cancer. Therefore, NHS England is the responsible commissioner of such services for sarcoma in this age range. The organisation of sarcoma services for this age range is complex and involves both sarcoma MDTs and specialist MDTs operated by both Children's and Teenager and Young Adult (C/TYA) Principal Treatment Centres, as set out within NHS England's service specifications for both Children's Cancer and Teenage and Young Adult Cancer Services. The Sarcoma Service Specification sets out how these joint arrangements will work and should be read in conjunction with NHS England's service specifications for C/TYA Cancer Services.

1.3 How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners

Clinical Commissioning Group (CCGs) commission diagnostic services for suspected soft tissue sarcoma where these are located outside specialist sarcoma centres. Network agreements must describe both the agreed sarcoma pathways within the Network, together with a list of the designated practitioners in each Local Sarcoma Unit.

2. Care Pathway and Clinical Dependencies

2.1 Sarcoma overview

Sarcomas are rare cancers that develop in the muscle, bone, nerves, cartilage, tendons and blood vessels and the fatty and fibrous tissues. Sarcomas fall into three main categories:

(i) Bone sarcoma
(ii) Soft tissue sarcoma
(iii) Gastrointestinal stromal tumours (GIST)

There are around 100 different sub types of sarcoma and about 3,800 new cases of sarcoma are diagnosed each year in the UK, which makes up approximately 1% of all cancer diagnoses.

The most common sites for both soft tissue and bone sarcomas are within the extremities (23% of soft tissue sarcomas and 52% of bone sarcomas). However, sarcomas arise in all parts of the body producing specific clinical scenarios and challenges to management.

Survival at five years for soft tissue and bone sarcomas is 55% (data for 2006-2010) and 56% (2001-2005) respectively, but there is considerable variation within this determined by histological subtype, stage and age.

Most people with bone tumours present with pain and/or swelling. Pathological fracture is a less common presentation feature. It is not uncommon for symptoms to have been present for some time before medical attention is sought or further investigations/referrals are initiated. Most occur in the bones of the extremity; however craniofacial, pelvic and axial skeletal tumours all occur and present specific management challenges. The treatment required is dependent on diagnosis and stage of the disease. Treatment

modalities used include surgical treatment and/or further treatment such as chemotherapy and radiotherapy.

GISTs are mesenchymal tumours of the gastrointestinal tract. There are approximately 700 new cases per year in the UK. Presentation is generally with bleeding or pain with most primary tumours arising in the stomach and can also affect the small bowel and other intra-abdominal sites. There is variation in behaviour which is to an extent predicted by size, histological features and tumour DNA mutational analysis. About 60% of people with GISTs will be successfully treated by surgery. Others may have more aggressive sarcomas and benefit from drug therapies, such as tyrosine kinase inhibitors which target KIT oncogene and other molecular abnormalities.

Given the different sub-types and rarity of sarcoma, care is characterised by the need for complex multimodality assessment and therapy that involves pre-intervention evaluation - clinical, radiological, pathological and multidisciplinary; complex surgery for resection and reconstruction aimed to preserve function; further pathological assessment including margin description; complex radiotherapy; intensive chemotherapy; unique rehabilitation needs; and palliative care. The developing role of molecular pathology in the diagnosis and treatment of sarcomas is now recognised and must be included in management algorithms.

Sarcomas are a multitude of diseases with many unique and some shared characteristics. Their overall rarity and the multiplicity of presentation features determine that they are unfamiliar in routine clinical care. Management is frequently complex and pathways of care are complicated and individualised.

2.2 Service model

Sarcoma care is delivered through organised Sarcoma Networks, co-ordinated through Sarcoma Advisory Groups (SAGs). The service model is based on partnerships between Specialist Sarcoma Centres and Local Units. Each SAG must include a Specialist Sarcoma Centre which hosts a sarcoma MDT, together with a number of designated Local Sarcoma Units that are able to deliver some elements of sarcoma care.

All people with a suspected or confirmed diagnosis of sarcoma must be referred to the Specialist Sarcoma Centre for review by the sarcoma MDT. The role of the Specialist Sarcoma Centre and the MDT is described further in sections 2.2.2 and 2.2.4.

Treatment for people with sarcoma may be delivered in the Centre or in other cancer centres as defined by network protocols developed and agreed by the SAG. All surgery for bone sarcoma must be delivered in one of the five designated bone sarcoma Centres or according to pathways defined and approved by the SAG hosting the bone tumour MDT and agreed with all relevant adjoining SAGs. However, while most people with soft tissue sarcoma should also be treated in a designated Specialist Sarcoma Centre (for soft tissue), surgery for some forms of soft tissue sarcoma cancer (e.g. gynaecology, head and neck) that requires the surgical expertise of other MDTs may be performed by designated practitioners outside of the Specialist Sarcoma Centre, by agreement of the SAG.

In addition, chemotherapy and radiotherapy services for sarcoma may be delivered outside of the Specialist Sarcoma Centre, by agreement of the SAG.

Follow-up care for people with sarcoma may be delivered in either the Specialist Sarcoma Centre or Local Units, in line with SAG-agreed pathways.

2.2.1 Sarcoma Advisory Groups (SAGs)

The SAG represents the sarcoma network. The SAG must be hosted and supported by a constituent provider, usually the Trust designated as a Specialist Sarcoma Centre, within the sarcoma network. The provider will be responsible for hosting the management function and supporting the overall network functioning.

The SAG is the primary source of clinical opinion for sarcoma services and must include representation from each designated Specialist Sarcoma Centre and MDT, Local Sarcoma Units, C/TYA Principal Treatment Centres, commissioners, Service Users/public representatives, and the Genomic Laboratory Hub.

The SAG will:

- Agree the network service configuration including designation of the Specialised Sarcoma Centre and Local Sarcoma Units, together with the designation of all practitioners who may be involved in delivery of planned care for people with sarcoma. Any changes to the configuration of services within a network must be approved by the local commissioner and implemented in accordance with public involvement duties appropriate to the NHS;
- Agree network wide treatment protocols and pathways, including procedures for whole genome sequencing (WGS), other molecular pathology testing, and follow-up care;
- Plan services at the network level including clinical trial co-ordination and referral and communication processes between providers; and
- Ensure provider participation in the national audits and facilitate audits within the Network.

Adjoining SAGs must work together to ensure that pathways for people that may be served by either of two or more network services are clear. Network pathways must ensure a comprehensive service for people with any type of sarcoma.

Strategic oversight for improving population cancer outcomes will be exercised by Cancer Alliances. This body will take a whole population, whole pathway approach to provide a focus for improvement and leadership on cancer in defined geographies. Cancer Alliances can support the sharing of best practice across multiple Networks, as well as address unnecessary variation across them. This is alongside existing arrangements described within the contract for quality surveillance and performance monitoring.

2.2.2 Specialist Sarcoma Centres

Specialised Sarcoma Centres will host the MDT who will provide diagnostic, treatment and follow up services in conjunction with its respective Local Sarcoma Units. Sarcoma MDTs will ensure up to date information about their shared pathways, activity and Service User outcomes, including information on site-specific sarcomas, is publicly available.

Diagnosis of suspected primary bone tumours and the surgical treatment of primary bone tumours are delivered across England by five designated centres which provide cover across all regions in England for the national caseload and which host combined bone and soft tissue sarcoma MDTs.

2.2.3 Local Sarcoma Units

Trusts providing sarcoma care in conjunction with the Specialist Sarcoma Centres will be defined by the SAG. The principle underlying these arrangements is the delivery of safe, effective specialist care as locally as possible rather than local care as safely as possible, while recognising the diversity of clinical need inherent in a sarcoma population.

Services outside the Specialist Sarcoma Centre can include diagnostic services for suspected soft tissue sarcoma, primary surgical resection by designated members of the sarcoma MDT of some visceral sarcomas (e.g. uterine sarcoma) and delivery of some chemotherapy and radiotherapy, by designated members of the Sarcoma MDT, in accordance with recommendations from the Sarcoma MDT and approved by the SAG. Specialist Sarcoma Centres must ensure that services available at each designated Local Sarcoma Unit, together with details of designated practitioners in each Unit, are published on service websites with information about pathways.

2.2.4 Sarcoma MDT

The principal role of a Sarcoma MDT is to determine a care plan for all people with bone and soft tissue sarcoma and to be responsible for its delivery either by members based at the Specialist Sarcoma Centre or by designated practitioners working at Local Sarcoma Units or by C/TYA Principal Treatment Centres following care pathways agreed with the SAG. The MDT will be constituted and organised in accordance with the updated measures associated with this Specification and in line with the Sarcoma Improving Outcome Measures (2014).

Sarcoma MDTs must publish information about their shared pathways, activity and Service User outcomes, including information on site-specific sarcomas.

Sarcoma MDTs must include key workers so that all people with a sarcoma can be supported by an allocated key worker with specialist knowledge of sarcomas and their treatment.

Sarcoma MDTs must ensure there are pathways in place for molecular pathology testing in partnership with the Genomic Laboratory Hub and pathology departments to ensure access to WGS and other appropriate molecular testing, as defined in the National Genomic Test Directory for Cancer, for all eligible patients.

The development of experience and expertise required of individual clinicians and other staff to treat people with sarcoma is a major investment for all Specialist Sarcoma Centres. Each Centre must ensure that a programme of training and a succession planning strategy is in place.

Designated Local Sarcoma Units and Designated Practitioners deliver defined areas of care in conjunction with the sarcoma MDT. These include:

- Practitioners involved in the diagnosis of suspected soft tissue sarcomas presenting to rapid access diagnostic clinics linked to sarcoma MDTs;
- Practitioners working in other MDTs to which sarcomas may present. These include: breast, head and neck, brain and CNS, urology, gynaecological, gastro-intestinal, lung, skin MDTs. Management of sarcomas arising in these sites must be in accordance with pathways agreed and monitored by the sarcoma MDT in conjunction with the SAG; and
- Practitioners delivering chemotherapy and radiotherapy services when this is deemed appropriate by the Sarcoma MDT to be undertaken outside the Specialist Sarcoma Centre.

Sarcoma MDTs must ensure there are strong working relationships in place between the MDT and Local Sarcoma Units. Referral and communication processes between the MDT and Local Sarcoma Units must be documented in the MDT's operational policy.

A soft tissue sarcoma MDT should manage the care of at least 100 new cases of soft tissue sarcoma per year. If a sarcoma MDT manages the care of both bone and soft tissue sarcoma, it needs to manage the care of at least 50 new cases of primary bone sarcoma per year and at least 100 new cases of soft tissue sarcoma per year.

Additional service volume considerations for specific anatomic sites are detailed further in the specification.

2.3 Care pathway

2.3.1 Diagnosis

All suspected soft tissue sarcomas will be referred to either a specialist sarcoma centre, a linked diagnostic service at a designated Local Sarcoma Unit, or to a C/TYA Principal Treatment Centre, according to locally defined pathways as agreed with the Sarcoma Advisory Group (SAG). Pathways must accommodate tumours arising in all ages and at all anatomic sites; for children, pathways must be jointly agreed by C/TYA Principal Treatment Centres.

All suspected primary bone tumours will be referred to one of the five designated centres in England.

2.3.2 Laboratory medicine

Histological confirmation of tumour is required before treatment with chemotherapy or radiotherapy. The pathology services must:

- Comply with ISO15189:2012 (as per the UK Accreditation Service) and the Human Tissue Authority (HTA).
- Comply with Royal College Dataset for the Histopathology Reporting of Bone and Soft Tissue Sarcomas.

- Provide acute diagnostics services and clinical pathology opinion 24 hours a day 7 days a week (e.g. blood sciences and microbiology).
- Have access to digital pathology and networked services, including remote working.
- Have in place Blood management guidelines.
- Participate in and encourage clinical trial activity.
- Provide a framework for staff education

Pathology for all sarcomas must be reviewed by a Specialist Sarcoma Pathologist for diagnostic confirmation and undertaking any appropriate molecular analysis.

2.3.3 Treatment

The management of sarcomas must be in accordance with British Sarcoma Group Guidelines.

Surgery holds a position of critical importance for the majority of newly diagnosed sarcomas. For many, it is curative by itself, for others it is a vital part of multimodality therapy given with the intent of cure. For others, repeated and often complex surgical operations may play a valuable part in palliation. The costs of inappropriate or inadequate surgery can be very high for people with sarcoma, resulting in excess lifelong morbidity and reduced survival chances.

Sarcoma services must be structured and managed to reduce the number of unplanned excisions and to ensure that all resections of sarcomas are undertaken by surgeons who are core or designated members of the Sarcoma MDT. Audit of procedures undertaken by designated and non-designated surgical practitioners will be undertaken routinely using national data sets.

Treatment decisions for delivering radiotherapy must be made by the Sarcoma MDT. It is recognised that people may live at some distance from a Specialised Sarcoma Centre, and it may not be possible for them to travel for treatment, particularly for palliative radiotherapy. In such instances, after consultation with the Service User, radiotherapy may be delivered by a designated practitioner at a radiotherapy centre that is closer to home. The decision to delegate treatment to a designated practitioner is a balance between the need for radiotherapy, particularly radical, to be planned and delivered in a large volume centre, and the choice of an individual Service User to minimise their travelling and inconvenience. Designated practitioners will mostly deliver palliative radiotherapy, and some selected radical radiotherapy.

Specialised Sarcoma Centres will undertake regular audits of radiotherapy for sarcomas treated both at the centre and by designated practitioners. Services must be delivered in line with the Service Specification for Radiotherapy.

Treatment decisions on the use of chemotherapy for individuals with sarcoma are the responsibility of the Sarcoma MDT. Services must be delivered in line with published NHS England Service Specifications, Clinical Commissioning Policy and Algorithms.

In cases where chemotherapy and radiotherapy are delivered outside of the Specialist Sarcoma Centre, the sarcoma MDTs must have clear arrangements in place for liaison with designated practitioners and re-discussion at MDTs during treatment (for example using video-conferencing).

People with sarcomas arising in specific anatomic sites or with very rare sarcoma subtypes will be managed according to detailed pathways for these sarcomas agreed by the SAG and described in the Specification.

Atypical lipomatous tumours are common low grade tumours closely related to benign lipomas. Surgery is frequently curative and recurrence, if it occurs, can be successfully managed in most cases by repeat surgery.

There are a number of associated benign or so-called ‘borderline’ conditions that appropriately fall in the remit of sarcoma services, the commonest example is desmoid fibromatosis (DF). At diagnosis or suspected diagnosis, all people with DF must be referred to a Specialist Sarcoma Centre for diagnosis and management according to pathways agreed by the SAG.

Sarcoma MDTs must publish information about their sarcoma pathways (including where these may involve travel to a more distant Specialist Sarcoma Centre) and provide liaison points for referring clinicians to discuss suspected or confirmed sarcomas for all types of sarcoma.

2.3.4 Follow-up, rehabilitation, survivorship, palliative and end of life care:

The SAG must agree, in conjunction with Sarcoma MDTs, follow-up guidelines and also define when follow up is appropriately undertaken in Local Sarcoma Units. Short and long-term morbidity of sarcoma is considerable for many people. Individual rehabilitation plans should be prepared for all Service Users and access provided to therapies. Follow-up pathways for long term toxicities should be agreed by the SAG.

Sarcoma MDTs must have effective communication and referral processes with associated hospital and community palliative care services.

A Treatment Summary must be completed at the end of each acute treatment phase and a copy sent to both the service user and their GP, in line with the Recovery Package specified by the Independent Cancer Taskforce Report (2015).

Supportive and palliative care must be delivered in line with NICE guidance (Cancer service guideline [CSG4] - https://www.nice.org.uk/guidance/csg4) and the relevant quality markers for end of life care (Quality standard [QS13] - https://www.nice.org.uk/guidance/qs13).

2.3.5 Service User information and experience of care

All services must be patient-centred and must respond to service user and carer feedback in line with the standard set out by NICE for patient experience (Clinical guideline [CG138] - https://www.nice.org.uk/Guidance/CG138).

SAGs must demonstrate how feedback from local surveys and the National Cancer Patient Experience Survey has been used to improve service quality. Attendance at advanced communications skills training (based on the Connected training course) are recommended for all SMDT members.

Each service user must:

- Be offered a holistic needs assessment (HNA), in line with the Recovery Package specified by the Independent Cancer Taskforce Report, at key points in their cancer pathway including at the beginning and end of primary treatment and the beginning of the end of life. This should take in to account social circumstances, psychological needs, and any co-morbidities. Referral to other services should be made as appropriate.
- Receive verbal and written information that is clearly understood by patients and their families and free from jargon, and must include, as a minimum, information on the following:
    - Disease and condition;
    - Treatment, possible side-effects and aftercare;
    - Dietary advice and nutritional support;
    - Access to psychological support;
    - How to access financial support.
- Given the option of contact details for support organisations or internet resources recommended by the clinical team or national organisations.
- Be provided with an education and support event, such as a Health and Wellbeing Clinic, to prepare them for the transition to supported self-management post treatment. The event should include advice on relevant consequences of treatment, recognition of issues and who to contact. They should also be given information and support on work and finance, healthy lifestyle and physical activity.

2.4 Surgical treatment

2.4.1 Bone sarcoma

All adults, children and TYA's with bone sarcoma must have their care plan confirmed by a bone sarcoma MDT and treatment delivered by services designated by the SAG. SAGs are responsible for ensuring that clear pathways exist for the referral of all suspected bone sarcomas to designated bone tumour services.

Pathways must accommodate non-extremity tumours including those arising in the chest wall, spine and craniofacial bones, including base of skull. These pathways may recommend surgery for certain anatomical locations to be conducted on sites outside of the five designated centres. Surgery for these sarcomas must only be carried out by designated practitioners in centres defined by the SAG. When the bone tumour MDT is in another SAG, pathways must be discussed and agreed by both SAGs.

Bone sarcoma MDTs will consider referral of primary tumours deemed inoperable for alternative management, including proton beam therapy, in accordance with national Service Specifications and Clinical Commissioning Policy.

Sarcomas arising in the spine are uncommon and present particular challenges for management, influenced by age, co-morbidity, presenting features, location in the spine, histological subtype, stage and response to treatment. Bone sarcoma MDTs must incorporate designated expertise for surgical management of spine sarcomas and all cases must be discussed by the bone sarcoma MDT.

The management of craniofacial sarcomas, including base of skull tumours, will require additional expertise from specialist base of skull and head and neck MDTs. These must be aligned with a bone sarcoma MDT. Craniofacial bone sarcomas include osteosarcoma, Ewing sarcoma, mesenchymal chondrosarcoma and other less common subtypes. Management requires close cooperation between radiologist, pathologist, oncologist and surgeons as well as experience in supporting Service Users though the particular challenges experienced. The care of these very rare tumours must be in centres which have comprehensive teams for bone sarcoma and head and neck cancer surgery and where MDTs have experience based on sufficient case volume of at least ten new cases per year.

All new cases of Ewing sarcoma arising in bone must be referred to the National Ewing MDT which is an exemplar for accessing expertise in order to reach consensus on important areas of clinical uncertainty. Its aim is to discuss all new cases of Ewing sarcoma and to make a consensus recommendation to the treating MDT on surgery and radiotherapy options for primary tumour management.

The commonest sarcomas arising in the skull base region are chordoma and chondrosarcoma. Some rarer bone sarcomas, such as Ewing sarcoma and soft tissue sarcomas, can involve the skull base. While it is difficult to quantify exact numbers, there are thought to be fewer than 40 cases per year in England. There are key inter-dependencies which include disease familiarity and procedure expertise for both surgical and oncological team members and an increasingly essential link to proton beam therapy (PBT) services. Therefore, management of these rare sarcomas should be concentrated into a small number of centres, likely not more than five, where very close interaction between skull base unit and sarcoma MDT can be ensured with detailed examination of outcomes.

2.4.2 Spinal, paraspinal, complex pelvic and sacral sarcoma

These are a heterogeneous group of rare sarcomas that require highly specialised multidisciplinary assessment, treatment planning and delivery. Where possible, primary surgery remains the gold standard but is often highly morbid and recurrence common. Newer highly specialised techniques such as computer-assisted resection may improve the safety of resection. PBT has increasing importance, either as a pre- or post-operative adjunct to surgery or in some cases instead of surgery. This can require specific consideration of stabilisation techniques and post-operative PBT treatment planning.

Suspected sarcomas at these sites must be referred to a designated bone sarcoma service. Surgery must be undertaken by core or designated members of a bone sarcoma MDT.

2.4.3 Head and neck sarcoma

Due to the relative rarity of head and neck sarcomas, specialist care cannot be delivered by all head and neck services. The Head and Neck Service Specification clearly sets out that the care of such tumours will be as stated within the Sarcoma Service Specification.

It is recommended that SAGs designate no more than one head and neck service with associated reconstructive support in the Network to manage sarcomas, according to pathways determined by the SAG. Surgery for bone and soft tissue sarcoma arising in the head and neck must only be carried out by designated practitioners in centres defined by the SAG. In most areas it is recommended that there is no more than one centre in each Sarcoma Network. However, SAGs and local commissioning teams should take into account availability of clinical expertise, travel and access arrangements within their locality. This service must be compliant with the relevant service specification for head and neck cancer surgery and must regularly audit volumes and clinical outcomes.

People with suspected head and neck sarcoma must be referred, according to Network guidelines, to a designated diagnostic centre, which will be a Sarcoma Specialist Centre where head and neck and sarcoma MDTs work jointly and Service Users can access all necessary expertise and support.

Diagnoses of head and neck sarcomas made outside of the local pathway i.e. inadvertent or unplanned biopsies/excision, will be the subject of on-going audit and results disseminated within the Network.

2.4.4 Gynaecological sarcoma

About two-thirds of gynaecological sarcomas are not diagnosed pre-operatively but discovered on histopathology after hysterectomy which has been carried out for presumed fibroids or other benign conditions. Immediate referral according to the Network pathway to the Sarcoma MDT must be undertaken.

Features on imaging which are atypical for fibroids should raise the suspicion of sarcoma and prompt liaison with the identified sarcoma specialists responsible for gynaecological sarcomas within the Sarcoma MDT.

It is recognised that distinguishing between fibroids and cancer on imaging is very difficult. Laparoscopic morcellation has grown in popularity for the treatment of fibroids because it is associated with lower morbidity than with open surgical procedures. However, morcellation of a uterine sarcoma is associated with higher rates of abdomino-pelvic recurrence, and poorer progression free and overall survival than definitive surgery with hysterectomy. It is therefore contra-indicated for uterine sarcoma.

In many cases the initial management is by total abdominal hysterectomy. This may be undertaken outside the Specialist Sarcoma Centre within a designated gynaecological oncology service after staging.

People with proven gynaecological sarcoma must be referred according to Network guidelines to a Specialist Sarcoma Centre where gynaecological and sarcoma MDTs work jointly to ensure that Service Users can access all necessary expertise and support. Management of gynaecological sarcomas within Specialist Sarcoma Centres will be in accordance with national guidelines.

2.4.5 Intra-abdominal (including retroperitoneal) sarcoma

Any intra-abdominal or retroperitoneal tumour arising in adults which is not epithelial in origin must be considered to be a sarcoma.

Pre-operative/treatment biopsy is safe and must be considered when the diagnosis is uncertain. Diagnostic biopsy is necessary for tumours that are not demonstrated to be liposarcoma on imaging and often requires specialist trained interventional radiological input.

Surgery remains the primary treatment for these tumours, and is often complex and usually involves multi-visceral/structural resection with careful planning within a multi-specialist surgical team. Best outcomes are achieved with complete surgical resection of these tumours without breach of the tumour capsule or fragmentation of the tumour.

Radical resection often necessitates multi-organ resection and is associated with improved local control/oncological outcomes. However, multi-visceral resection carries the potential for increased surgical morbidity and mortality and the best outcomes for these Service Users are achieved in hospitals that routinely manage complex surgical cases and when surgery is undertaken by surgical teams who specialise in retroperitoneal sarcomas with a high caseload.

Specialist intensive care facilities with 24/7 medical cover, specialist anaesthetic and nursing staff, 24 hour emergency theatre and interventional radiology are required.

The SAG, in conjunction with local commissioners, will define sites where surgery for retroperitoneal, abdominal and pelvic sarcomas must be undertaken.

The Network will publish pathways so that people with retroperitoneal sarcoma are referred before any intervention to a sarcoma treatment centre with special expertise in managing this type of tumour. Special expertise will be defined by:

- Regular sarcoma MDT meetings which include anatomic expertise in pathology, imaging and surgery;
- Infrastructure and resource to support major intra-abdominal surgery; and
- A recommended case load including surgical resection of an average of 24 new cases of primary retroperitoneal sarcoma per annum.

All retroperitoneal, abdominal and pelvic sarcomas must be discussed pre-operatively by the sarcoma MDT. Planned surgery will be undertaken by core or designated members of a Sarcoma MDT.

Where surgery is performed inadvertently outside of the Specialised Sarcoma Centre, cases must be referred post-operatively to the Specialised Sarcoma Centre. The SAG must maintain a prospective audit of such cases.

Whilst surgery remains the standard treatment of these tumours, preoperative radiotherapy is increasingly considered for retroperitoneal sarcomas with the development and use of IMRT providing accurate therapy with reduced normal tissue toxicity to adjacent organs. The Sarcoma MDT meetings at which abdominal and retroperitoneal sarcomas are discussed must include appropriate expertise to address questions of radiotherapy and systemic therapy.

Diagnoses of abdominal and retroperitoneal sarcomas made outside of the local pathway i.e. inadvertent or unplanned biopsies/excision, will be the subject of on-going audit and results disseminated within the Network.

2.4.6 Gastro-intestinal stromal tumours

People with suspected GIST must be referred according to Network guidelines to a designated diagnostic centre. People with GIST must have their care plan confirmed by a Sarcoma MDT and treatment delivered by services designated by the SAG. The medical management of GIST cases must be supervised by cancer specialists with experience in the management of people with GIST. These specialists must participate in national audit, contribute to national/international clinical trials where available and be core or designated members of the sarcoma MDT. It is recommended that these specialists have an annual new case load to a service of 24 per annum. Management will be in accordance with British Sarcoma Group guidelines.

2.4.7 Breast sarcoma

Soft tissue sarcomas may arise de novo within the breast or as a consequence of previous radiotherapy for breast cancer. The latter are almost always angiosarcoma. De novo breast sarcomas must be managed as with other soft tissue sarcomas based on stage and histological subtype. Surgery may be appropriately undertaken within breast cancer services after discussion has occurred with a sarcoma MDT. Angiosarcomas must always be referred at suspected diagnosis to a Specialist Sarcoma Centre.

Women with suspected breast sarcoma must be referred according to Network guidelines to a designated diagnostic centre, which will be a Sarcoma Specialist Centre where breast and sarcoma MDTs work jointly and Service Users can access all necessary expertise and support. Women with breast sarcomas must have their care plan confirmed by a sarcoma MDT and treatment delivered by services designated by the SAG.

2.4.8 Skin sarcoma

Sarcomas of the skin have a more favourable prognosis than either subcutaneous or deep soft tissue sarcomas. However aggressive subtypes such as angiosarcoma occur and other histologies have a tendency for local recurrence leading to additional treatment morbidity if initial management is inadequate.

People with suspected skin sarcoma must be referred according to Network guidelines to a designated diagnostic centre, which will be a Sarcoma Specialist Centre where skin and sarcoma MDTs work jointly and Service Users can access all necessary expertise and support. People with skin sarcomas must have their care plan confirmed by a sarcoma MDT and treatment delivered by the sarcoma MDT or by services designated by the SAG.

2.4.9 Chest wall and lung sarcoma

Sarcomas may arise either in soft tissue or bone of the chest wall. The principles of management of sarcomas at other sites apply but surgical expertise for complex chest wall resection and reconstruction may not be found within the core surgical members of a sarcoma MDT. The SAG in conjunction with sarcoma MDTs must therefore agree pathways and locations of care appropriate to this tumour location.

All people with suspected or proven bone sarcomas of the chest wall must be referred to a bone sarcoma MDT. Bone sarcoma centres must have clear pathways defining access to thoracic surgery. Surgery for chest wall and lung sarcoma must only be carried out by designated practitioners in centres defined by the SAG. When the bone tumour MDT is in another SAG, pathways must be discussed and agreed by both SAGs. In most areas it is recommended that there is no more than one centre in each Sarcoma Network. However, SAGs and local commissioning teams should take into account availability of expertise, travel and access arrangements within their locality. The service must be compliant with the relevant service specification for thoracic surgery and must regularly audit volumes and clinical outcomes.

Primary sarcomas of the lung parenchyma are very uncommon and are commonly diagnosed at the time of resection of an unidentified mass. If the diagnosis is suspected or proven on biopsy, referral to a Specialist Sarcoma Centre is required in accordance with local published pathways.

People with chest wall and lung sarcomas must have their care plan confirmed by a Sarcoma MDT and treatment delivered by services designated by the SAG.

Metastatectomy and newer approaches such as percutaneous ablation of pulmonary metastases or SABR are important components of managing sarcomas. Sarcoma MDTs must define pathways for people requiring these approaches which allow multidisciplinary discussion and routine audit of procedures and outcomes.

Metastatectomy and ablation must be undertaken in centres with sufficient caseload volume to ensure at least one case per month to support maintenance of expertise throughout the MDT. Procedures must be undertaken by core or designated members of the MDT.

2.4.10 Cardiac/large vessel sarcomas

Intimal sarcomas and angiosarcomas of the heart and great vessels are a rare entity demanding specific multidisciplinary expertise in order to consider the options for an individual of combined modality treatment including cardiac surgery. The SAG in conjunction with sarcoma MDTs must therefore agree pathways and locations of care appropriate to this tumour location

2.5 Children and Teenagers and Young Adults with sarcoma

Children and TYA's with sarcoma may have specialist needs in relation to their age and the rarity of their condition.

Children
The Children's Cancer Principal Treatment Centre has the primary responsibility for the management of children with cancer, however, the needs of children with sarcoma are best met through close working between the Specialist Sarcoma Centre, which hosts the sarcoma MDT, and the Children's Cancer Principal Treatment Centre, which hosts the children's cancer MDT. In order to ensure effective communication and clinical pathways, the following arrangements must be put in place:

- Each SAG must include representation from relevant Children's Cancer Principal Treatment Centres; and
- Each SAG must develop and agree locally defined care pathways for children with sarcoma, including referral arrangements and agreed communication methods jointly with their local Children's Cancer Networks.

Children's Cancer MDTs have core expertise for management of most rhabdomyosarcomas, the commonest sarcoma in younger children. Early discussion within a month of diagnosis with sarcoma MDTs is required for extremity tumours and all non-rhabdomyosarcomas for whom the benefits of specialist diagnostics and surgery may be considerable.

All children with suspected bone sarcomas must be referred to a bone tumour diagnostic service. Surgeons operating on children with non-rhabdomyosarcomas must be core or designated members of a sarcoma MDT.

Teenage and Young Adult's
Sarcoma MDTs must be integrated with a TYA Principal Treatment Centre that meets the Improving Outcomes Guidelines (IOG) for Teenagers & Young Adults (2001) and relevant NHS England service specification for TYA Cancer Services. In order to ensure effective communication and clinical pathways, there must be:

- Clear operational policy in place defining the working arrangements between the MDTs; and
- A member of the sarcoma MDT must be part of the relevant TYA MDT(s).

All TYA referrals must be discussed at the appropriate TYA MDT for decision on care planning and treatment with clear mechanisms for tracking.

People aged 16 – 18 years with sarcoma must be treated by the TYA Principal Treatment Centre, in line with the standards set out in the TYA Cancer Service Specification. People aged between 19 and 24 years, may choose where to have their sarcoma treatment in line with the TYA Cancer Services Service Specification. Treatment must be delivered in line with network protocols and by designated centres by both the TYA Cancer Network and the SAG.

Please note that access to treatment will be guided by any applicable published NHS England Clinical Commissioning Policy.

3. Population Covered and Population Needs

3.1 Population covered by this Specification

The Specification applies to all children, young people and adults with suspected or diagnosed bone and soft tissue sarcoma.

Kaposi's sarcoma is excluded from this specification due to the origin of the condition and the limited overlap with sarcoma care.

3.2 Population needs

About 3,800 new cases of sarcoma are diagnosed each year in the UK constituting approximately 1% of all cancer diagnosis. Out of these new cases,

- 3,300 people are diagnosed with a soft tissue sarcoma (including 700 cases of GIST); and
- 500 people are diagnosed with a bone sarcoma.

In general, people with a soft tissue sarcoma or bone sarcoma tend to be younger than the majority of people with cancer; 57% of soft tissue sarcomas affect those under 65 years and about a quarter of all bone sarcomas occur before the age of 30 years.

3.2.2 Bone sarcoma

The most common types of bone sarcoma are:

- Chondrosarcoma (37% of all bone sarcoma diagnosis)
- Osteosarcoma (30% of all bone sarcoma diagnosis)
- Ewing sarcoma (14% of all bone sarcoma diagnosis)
- Chordoma (6% of all bone sarcoma diagnosis)

The first three subtypes of bone sarcoma account for over 75% of all cases. With complex intensive combined modality treatment about two-thirds of people will be cured.

Based on data from 1996-2010, the age-standardised incidence of bone sarcoma was constant at around 7.9 per million. Age specific incidence rates for bone sarcoma are bi-modal, with incidence peaks observed in teenagers and young adults, as well as the elderly.

Higher incidence rates of sarcoma were observed in males between 2004 and 2012, but in more recent years, this disparity is no longer seen between genders (Public Health England).

For bone sarcoma there is currently no association between sarcoma incidence and deprivation for either males or females in England (Cancer Research UK, 2016).

3.2.3 Soft-tissue sarcomas

The incidence of soft tissue sarcomas increases significantly with increasing age. The age specific incidence rate is highest in males aged 85 years and over where it reaches 230 per million and exceeds the rate for females by a ratio of 1.9:1. Age specific incidence rates for soft tissue sarcomas in females aged 45 to 59 years are slightly higher than those in males, due to the incidence of gynaecological sarcomas.

There was no disparity in incidence rates between males and females for soft tissue sarcoma until 2012 where females had a significantly lower incidence rate than males (Public Health England).

Based on data from 1996-2010, soft tissue sarcoma incidence rates increased significantly from 39 per million to 45 per million, although this increase may reflect improved diagnostic techniques and reporting rather than a true increase in incidence. The incidence of certain types of sarcoma has increased (such as liposarcoma, fibrobastic sarcoma, rare soft tissue variants) whilst others, primarily leiomyosarcoma, have decreased (Cancer Research UK, 2016).

Approximately 40% of soft tissue sarcomas arise in the limb and trunk. These sarcomas form the majority of cases that will be discussed and managed by a Sarcoma MDT. This sub-population includes considerable heterogeneity varying from small subcutaneous tumours carrying an excellent prognosis when treated by surgery alone to large deep high grade sarcomas which are associated with a five year survival rate in the order of 30-40%.

3.2.3 Other types of sarcoma

Sarcoma can occur in a multitude of sites. Other types of sarcoma include:

- Head and neck sarcomas: approximately 190 soft tissue sarcomas and 38 bone sarcomas diagnosed a year, accounting for less than 2% of all head and neck cancers;
- Gynaecological sarcomas: approximately 280 new cases of gynaecological sarcomas are diagnosed annually;
- Intra-abdominal sarcomas (including retroperitoneal sarcoma): about 7% of sarcomas are of gastrointestinal origin, a further 6% arise in the abdominal cavity and 5% are retroperitoneal;
- Breast sarcomas;
- Skin sarcomas; and
- Chest wall and lung sarcomas.

3.3 Expected Significant Future Demographic Changes

The incidence of bone sarcoma has been relatively stable over the last decade. If population levels stay consistent, then bone sarcoma incidence is projected to fall by 5% in the UK between 2014 and 2035 (Cancer Research UK, 2016). Data from Cancer Research UK (2016) indicates that bone sarcoma incidence is projected to be at 568 cases in 2035, equating to approximately 500 cases in England.

Incidence rates for soft tissue sarcoma are expected to be consistent with ageing population trends only although some changes may be seen in the sub-types of sarcoma being recorded.

3.4 Evidence base

This specification draws its evidence and rationale from a range of documents and reviews as listed below:

NICE

- Improving Outcomes for People with Sarcoma (NICE 2006)
- Improving Outcomes in Children and Young People with Cancer (NICE August 2015)
- NICE Quality Standard for Sarcoma (NICE January 2015)
- NICE Suspected cancer: recognition and referral (NICE June 2015)

National Cancer Peer Review

- Manual for Cancer Services, Sarcoma Measures version 1, January 2014

Other

- British Sarcoma Group Guidance for Soft Tissue Sarcoma
- British Sarcoma Group Guidance for Bone Sarcoma
- British Sarcoma Group for Gastrointestinal Stromal Tumour (GIST)

4. Outcomes and Applicable Quality Standards

4.1 Quality statement – aim of the service

The aim of the service is to improve outcomes for all people with sarcoma through:

- Ensuring access to a comprehensive service for all Service Users within a SAG-led Network, regardless of where each individual with sarcoma may live or the type of sarcoma that they have;
- Ensuring that all Service Users are referred to a specialised sarcoma service for timely diagnosis and access to expert care and management provided by trained staff;
- Ensuring that all adults, children and TYA's with either bone or soft-tissue sarcoma have their care plan confirmed by a sarcoma MDT and treatment delivered by services agreed locally by the SAG;
- Ensuring that all Service Users receive care in accordance with the most up to date Network agreed clinical protocols;
- Ensuring that treatment for sarcoma is delivered in line with national guidelines and evidence based practice, and is carried out by designated practitioners in designated centres and in accordance with Network policy;
- Ensuring that treatment and care services for sarcoma are planned and delivered in a collaborative way as part of the wider suite of services that are led and coordinated by the Cancer Alliance;
- Ensuring collaborative working between children, TYA and sarcoma MDTs;
- Ensuring that all Service Users have opportunities to participate in research;
- Encouraging Service User feedback and involvement in service delivery; and
- Ensuring continued participation in research and audit to support service improvements.

NHS Outcomes Framework Domains

Domain 1	**Preventing people from dying prematurely**	√
Domain 2	**Enhancing quality of life for people with long-term conditions**	√
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	√
Domain 4	**Ensuring people have a positive experience of care**	√
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	√

4.2 Indicators Include

Number	Indicator	Data Source	Outcome Framework Domain	CQC Key question
Clinical Outcomes - quantitative data				
101	The number of new cases per year	NCRAS	1,3,5	Effective
102	% patients discussed at Sarcoma MDT prior to definitive treatment.	NCRAS	1,3,5	Effective
103	% patients discussed at MDT prior to definitive treatment.	NCRAS	1,3,5	Effective
104	% of TYA patients discussed at TYA MDT	NCRAS	1,3,5	Effective
105	% Patients without confirmed histology prior to surgery	NCRAS	1,3,5	Effective
106	% of biopsies outside designated centre for soft tissue sarcoma	NCRAS	1,3,5	Effective
107	% of biopsies outside designated centre for bone sarcoma	NCRAS	1,3,5	Effective
108	Proportion of patients whose extremity soft tissue sarcoma is staged using the TNM staging system prior to definitive treatment	NCRAS	1,3,5	Effective
109	% patients with time to diagnosis within 30 days	NCRAS	1,3,5	Effective
110	% of excisions outside designated centres	NCRAS	1,3,5	Effective, Safe
111	Survival 1 and 5 year	NCRAS	1,3,5	Effective
112	Local recurrence rates for extremity bone sarcomas	NCRAS	1,3,5	Effective
113	Local recurrence rate for extremity soft tissue sarcomas	NCRAS	1,3,5	Effective
114	No. of patients with a second malignancy	NCRAS	1,3,5	Effective
115	No. patients who died within 30 days of treatment	NCRAS	1,3,5	Effective, Safe
116	No. of patients who died within 30 and 90 days of surgery	NCRAS	1,3,5	Effective, Safe
117	Amputation rates for extremity sarcoma	NCRAS	1,3,5	Effective

118	Proportion of patients with extremity sarcoma, who undergo curative surgical resection where R0 or planned R1 resection is achieved	NCRAS	1,3,5	Effective
119	Proportion of patients with an extremity soft tissue sarcoma which is deep and grade 2 or 3 who receive post-operative radiotherapy within 3 months of a planned marginal or wide local excision (R0 or R1).	NCRAS	1,3,5	Effective
120	% patients treated with IMRT	NCRAS	1,3,5	Effective, Safe
121	% patients with extremity soft tissue treated pre-operatively with RT	NCRAS	1,3,5	Effective
122	% patients meeting RT waiting times	NCRAS	1,3,5	Effective
123	% of patient receiving radiotherapy at designated local treatment centres	NCRAS	1,3,5	Effective, Safe
124	No. patients receiving chemotherapy outside national algorithm	NCRAS	1,3,5	Effective, Safe
125	% of patient receiving chemotherapy at designated local treatment centres	NCRAS	1,3,5	Effective, Safe
126	Proportion of patients with high or moderate risk GIST, small bowel GISTs and primary metastatic GIST who have mutational analysis within 3 months of diagnosis	NCRAS	1,3,5	Effective
127	Proportion of patients with high/moderate risk GIST who commence adjuvant imatinib within 3 months of complete macroscopic resection.	NCRAS	1,3,5	Effective
128	Proportion of children with non-rhabdomyosarcoma histologies and limb/trunk rhabdomyosarcomas discussed within 1 month of diagnosis at sarcoma MDT	NCRAS	1,3,5	Effective
129	% of patients accepted entry into a clinical trial	NCRAS	1,3,5	Effective
Patient Experience				
201	% patients seen by a Sarcoma CNS	CHI	1,3,4	Responsive, Caring
202	Proportion with recorded treatment intent	COSD	1,3,4	Responsive, Caring
Structure and Process				
301	There is a named lead clinician with responsibility for the sarcoma services	Self-declaration	2,3,5	Well led, Safe ,
302	There is an MDT that meets the requirements as specified in the national service specification	Self-declaration	1,,3,5	Well led, Safe, Effective
303	There is a weekly MDT meeting for treatment planning attended by all the relevant disciplines.	Self-declaration	1,2,3	Effective

304	There are clinical guidelines in place which, where available, reflect national guidelines	Self-declaration	1,2,3,5	Safe, Effective
305	There are area wide presentation pathways in place	Self-declaration	1,2,3,4,5	Safe, Effective, Caring
306	There are area wide investigation and treatment pathways in place	Self-declaration	1,2,3,4,5	Safe, Effective, Caring
307	There are designated practitioners who are named members of the Sarcoma MDT	Self-declaration	1,3,4,5	Safe, Effective, Caring

Detailed definitions of indicators, setting out how they will be measured, is included in schedule 6.

4.3 Commissioned providers are required to participate in annual quality assurance and collect and submit data to support the assessment of compliance with the service specification as set out in Schedule 4A-C.

4.4 Applicable CQUIN goals are set out in Schedule 4D.

5. Applicable Service Standards

5.1 Applicable Obligatory National Standards

Improving Outcomes for People with Sarcoma NICE (2006)
Improving Outcomes for Children and Young People NICE (2005)
Manual for Cancer Services Sarcoma Measures Department of Health (August 2011)
Manual for Cancer Services Acute Oncology Measures Department of Health (April 2011)
Manual for Cancer services Chemotherapy Measures (April 2013)
NICE Quality Standard for Sarcoma no 78
NICE Suspected cancer: recognition and referral
Cancer Waiting Times
National Genomic Test Directory for cancer (NHS England August 2018)

5.2 Other Applicable National Standards to be met by Commissioned Providers

British Sarcoma Group Guidance for Soft Tissue Sarcoma
British Sarcoma Group Guidance for Bone Sarcoma
UK Guideline for Gastrointestinal Stromal Tumour (GIST)

5.3 Other Applicable Local Standards

Guidelines and pathways produced and agreed by Sarcoma Advisory Groups for referral, treatment and follow-up

6. Designated Providers (if applicable)

The designated provider for the Joint Soft Tissue and Bone Sarcoma MDT/Soft Tissue MDT* [*SELECT AS APPROPRIATE AT CONTRACT STAGE] is:

[DRAFTING NOTE – AT CONTRACT STAGE SELECT A SINGLE SARCOMA MDT PROVIDER FROM THE LIST BELOW]

Joint Soft Tissue and Bone Sarcoma MDT Providers
The Newcastle Upon Tyne Hospitals NHS Foundation Trust
The Royal Orthopaedic Hospital NHS Foundation Trust

London Royal National Orthopaedic Hospital NHS Trust with University College London Hospitals NHS Foundation Trust
Oxford University Hospitals NHS Trust
Robert Jones and Agnes Hunt Orthopaedic and District Hospital NHS Trust

Soft Tissue MDT Providers
University Hospital Birmingham NHS Foundation Trust
North Bristol NHS Trust and University Hospitals Bristol NHS Foundation Trust
Plymouth Hospitals NHS Trust
Royal Devon and Exeter NHS Foundation Trust
The Christie NHS Foundation Trust and Manchester University NHS Foundation Trust
Royal Liverpool and Broadgreen University Hospitals NHS Trust Compliant
Nottingham University Hospitals NHS Trust and University Hospitals Of Leicester NHS Trust
The Royal Marsden NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust
Sheffield Teaching Hospitals NHS Foundation Trust

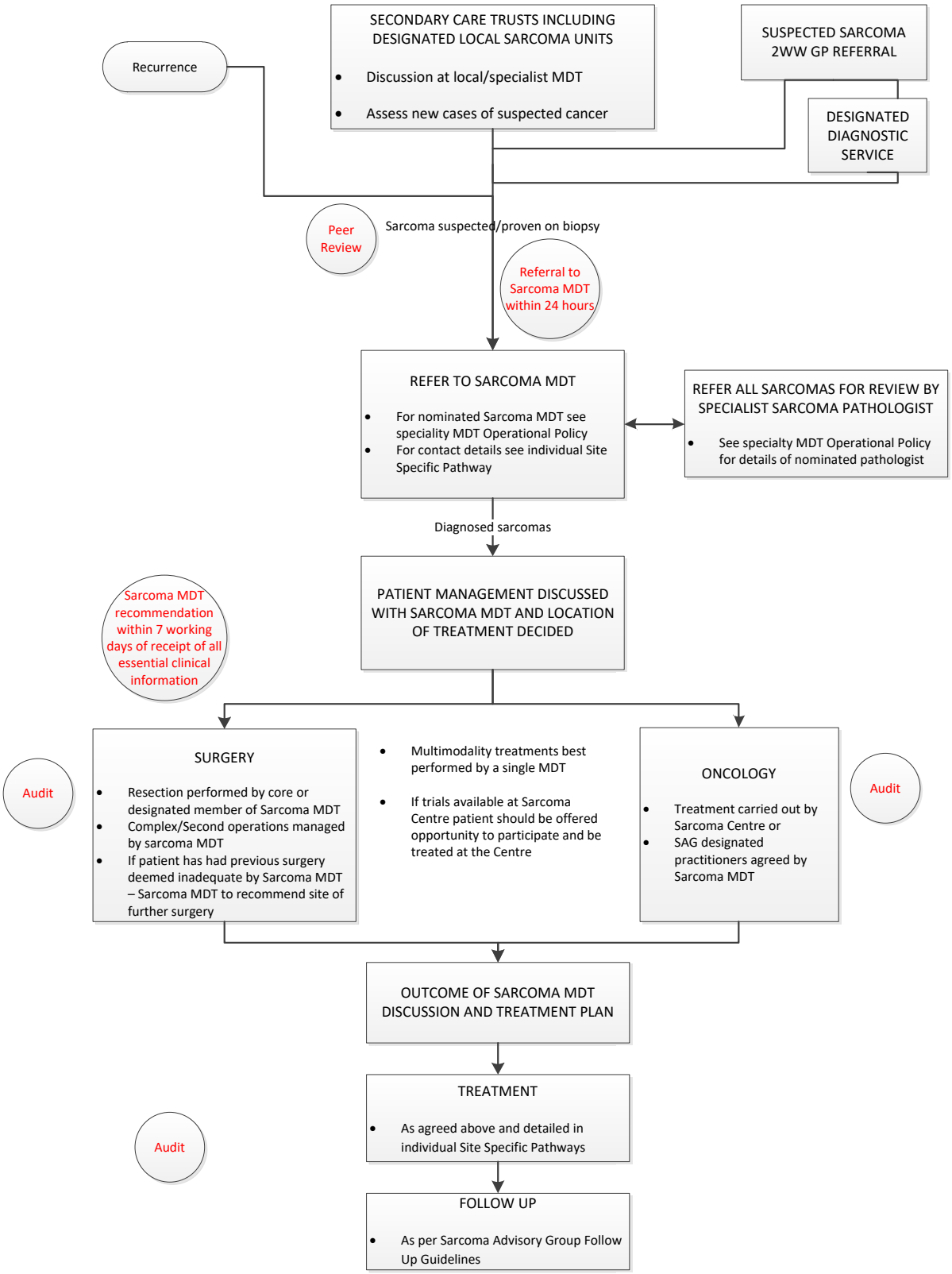
7. Abbreviation and Acronyms Explained

The following abbreviations and acronyms have been used in this document:

DF	Desmoid fibromatosis
CHI	Clinical Headline Indicators
COSD	Cancer Outcomes and Services Dataset
MDT	Multi-disciplinary team
NCRAS	National Cancer Registration and Analysis Service
NICE	National Institute for Health and Care Excellence
SAG	Sarcoma Advisory Group
SACT	Systemic Anti-Cancer Therapy
TYA	Teenage and Young Adult

Date published: ***<insert publication date>***

Appendix 1 Example Sarcoma Pathway



Please follow in accordance with 'Manual for Cancer Services: Sarcoma Measures', 'Manual for Cancer Services: Site-Specific Speciality Measures', ''SAG Referral, Diagnostic and Treatment Guidelines' and Sarcoma Service Specification 2016.

Appendix 2 Designated Sarcoma MDT members and Practitioners

A sarcoma MDT includes core members who fulfil the requirements of expertise, allocated time in job plan and attendance. Comprehensive sarcoma care is dependent on the support to the core MDT provided by other practitioners who by way of expertise or location can positively contribute to high quality specialist care. Examples include (i) surgeons whose main anatomical focus is not sarcoma but may for individual cases be the most appropriate lead or support surgeon, and (ii) oncologists able to deliver radiotherapy or SACT under the direction of the sarcoma MDT nearer to home. These latter roles are described as 'designated practitioners' in the Manual of Cancer Services for Sarcoma which also describes qualifying criteria to be fulfilled. This includes being a member of an extended sarcoma MDT. Although the term 'extended MDT member' is widely used it is loosely defined.

In this specification, all practitioners who may be involved in delivery of care for people with sarcoma must be designated to do so by the SAG in conjunction with the sarcoma MDT. The principle of designated practitioner will therefore be extended beyond oncologists to include surgeons and other specialists. This is also essential for monitoring the delivery of high quality specialist care.

Designation as a member of the extended sarcoma MDT will require

- Nomination by the sarcoma MDT or children's cancer PTC;
- A written record shared between the sarcoma MDT, SAG and employing Trust clinical line manager (clinical or Medical Director);
- A role outline for each designated practitioner, for example, including:
  - Delivery of chemotherapy in accordance with Network guidelines and following recommendation from the sarcoma MDT; and
  - Responsibility for surgical management of (site specific) sarcoma in accordance with Network guidelines and following recommendation from the sarcoma MDT.
- Designated oncologists will be expected to participate directly in the sarcoma MDT meetings either on a regular basis or for case-by-case discussion;
- Participation in the Sarcoma MDT annual review;
- Participation in pathway development and maintenance;
- Participation in audit of sarcoma cases;
- Named information to be made available to Service Users by the sarcoma MDT and SAG; and
- Designation reviewed by the Sarcoma MDT and SAG at least biennially.

Appendix 3 – QUALITY INDICATORS

Number	Indicator	Detail		Data Source	O.F Domain	CQC Key question
		Descriptor	Notes			
	Clinical Outcomes - quantitative data					
101	The number of new cases per year	The number of patients diagnosed at a trust within a calendar year. This indicator is used as the denominator to other indictors.		NCRAS	1,3,5	Effective
102	% patients discussed at Sarcoma MDT prior to definitive treatment.	Numerator - The number of tumours with a diagnosis code of (A) with an MDT discussion indicator to show the patient was discussed at MDT (A) Denominator - The total number of sarcoma patients	Patients with a newly diagnosed cancer should be discussed by a Multi-Disciplinary Team prior to definitive treatment - if possible, an MDT relevant to their diagnosis	NCRAS	1,3,5	Effective
103	% patients discussed at MDT prior to definitive treatment.	Numerator - The number of tumours with a diagnosis code of (A) with an MDT discussion indicator to show the patient was discussed at MDT (A) Denominator - The total number of sarcoma patients	Patients with a newly diagnosed cancer should be discussed by a Multi-Disciplinary Team prior to definitive treatment	NCRAS	1,3,5	Effective
104	% of TYA patients discussed at TYA MDT	Numerator - The number TYA patients with sarcoma diagnosis discussed at a TYA MDT Denominator - The total number of TYA sarcoma patients		NCRAS	1,3,5	Effective
105	% Patients without confirmed histology prior to surgery	Numerator - The number of tumours without a diagnosis code of (A) which have a basis of diagnosis of cytology, histology of metastases or histology of primary Denominator - The total number of sarcoma patients		NCRAS	1,3,5	Effective

106	% of biopsies outside designated centre for soft tissue sarcoma	Numerator - The number of biopsies outside designated centre for soft tissue sarcoma Denominator - The total number of sarcoma patients		NCRAS	1,3,5	Effective
107	% of biopsies outside designated centre for bone sarcoma	Numerator - The number of biopsies outside designated centre for bone sarcoma Denominator - The total number of sarcoma patients		NCRAS	1,3,5	Effective
108	Proportion of patients whose extremity soft tissue sarcoma is staged using the TNM staging system prior to definitive treatment	Numerator - The number of patients whose extremity soft tissue sarcoma is staged using the TNM staging system prior to definitive treatment Denominator - Total number of sarcoma patients		NCRAS	1,3,5	Effective
109	% patients with time to diagnosis within 30 days	Numerator - The number of sarcoma patients with time to diagnosis within 30 days Denominator - Total number of sarcoma patients		NCRAS	1,3,5	Effective
110	% of excisions outside designated centres	Numerator - The number of surgical excisions performed outside designated sarcoma centres Denominator - Total number of surgical excisions		NCRAS	1,3,5	effective, safe
111	Survival 1 and 5 year	Numerator - The number of patients surviving either one or five years after initial sarcoma diagnosis Denominator - Total number of sarcoma patients		NCRAS	1,3,5	Effective
112	Local recurrence rates for extremity bone sarcomas	Numerator - The number of patients with recurring sarcoma of bone extremity at provider level Denominator - Total number of sarcoma patients		NCRAS	1,3,5	Effective
113	Local recurrence rate for extremity soft tissue sarcomas	Numerator - The number of patients with recurring sarcoma of soft tissue extremity at provider level Denominator - Total number of sarcoma patients		NCRAS	1,3,5	Effective

114	No. of patients with a second malignancy	Numerator - The number of patients with a second malignancy from after a primary sarcoma malignancy Denominator - Total number of sarcoma patients		NCRAS	1,3,5	Effective
115	No. patients who died within 30 days of treatment	Numerator - The number of patients who died within 30 days of treatment for sarcoma malignancy Denominator - N/A		NCRAS	1,3,5	effective, safe
116	No. of patients who died within 30 and 90 days of surgery	Numerator - The number of patients who died within 30 days of surgery for sarcoma malignancy Denominator - N/A The number of patients who died within 90days of surgery for sarcoma malignancy Denominator - NA		NCRAS	1,3,6	effective, safe
117	Amputation rates for extremity sarcoma	Numerator - The number of patients amputated due to extremity sarcoma malignancy Denominator - Total number of sarcoma patients		NCRAS	1,3,5	Effective
118	Proportion of patients with extremity sarcoma, who undergo curative surgical resection where R0 or planned R1 resection is achieved	Numerator - The number of patients with extremity sarcoma, who undergo curative surgical resection where R0 or planned R1 resection is achieved Denominator - Total number of sarcoma patients with extremity sarcoma		NCRAS	1,3,5	Effective

119	Proportion of patients with an extremity soft tissue sarcoma which is deep and grade 2 or 3 who receive post-operative radiotherapy within 3 months of a planned marginal or wide local excision (R0 or R1).	Numerator - The number of patients with an extremity soft tissue sarcoma which is deep and grade 2 or 3 who receive post-operative radiotherapy within 3 months of a planned marginal or wide local excision (R0 or R1) Denominator - Total number of patients with an extremity soft tissue sarcoma which is deep and grade 2 or 3		NCRAS	1,3,5	Effective
120	% patients treated with IMRT	Numerator - The number of extremity soft tissue sarcoma patients treated pre-operatively with Intensity-Modulated Radiation Therapy Denominator - Total number of sarcoma patients		NCRAS	1,3,5	effective, safe
121	% patients with extremity soft tissue treated pre-operatively with RT	Numerator - The number of sarcoma patients treated with Intensity-Modulated Radiation Therapy Denominator - Total number of sarcoma patients		NCRAS	1,3,5	Effective
122	% patients meeting RT waiting times	Numerator - The number of patients who meet the radiotherapy waiting times criteria of having a first treatment within 62 days of initial diagnosis Denominator - Total number of sarcoma patients having radiotherapy		NCRAS	1,3,5	Effective
123	% of patient receiving radiotherapy at designated local treatment centres	Numerator - The number of patients receiving radiotherapy at designated local treatment centres Denominator - Total number of sarcoma patients		NCRAS	1,3,5	effective, safe
124	No. patients receiving chemotherapy outside national algorithm	Numerator - The number of patients with recurring sarcoma of bone extremity at provider level Denominator - Total number of sarcoma patients		NCRAS	1,3,5	effective, safe

125	% of patient receiving chemotherapy at designated local treatment centres	Numerator - The number of patients receiving chemotherapy outside national algorithm Denominator - N/A		NCRAS	1,3,5	effective, safe
126	Proportion of patients with high or moderate risk GIST, small bowel GISTs and primary metastatic GIST who have mutational analysis within 3 months of diagnosis	Numerator - The number of patients with high or moderate risk Gastro-Intestinal Stromal Tumour, small bowel Gastro-Intestinal Stromal Tumours and primary metastatic Gastro-Intestinal Stromal Tumours who have mutational analysis within 3 months of diagnosis Denominator - Total number of patients with high or moderate risk Gastro-Intestinal Stromal Tumour, small bowel Gastro-Intestinal Stromal Tumours and primary metastatic Gastro-Intestinal Stromal Tumours		NCRAS	1,3,5	Effective
127	Proportion of patients with high/moderate risk GIST who commence adjuvant imatinib within 3 months of complete macroscopic resection.	Numerator - The number of patients with high/moderate risk Gastro-Intestinal Stromal Tumours who commence adjuvant imatinib within 3 months of complete macroscopic resection. Denominator - Total number of high/moderate risk Gastro-Intestinal Stromal Tumours		NCRAS	1,3,5	Effective
128	Proportion of children with non-rhabdomyosarcoma histologies and limb/trunk rhabdomyosarcomas discussed within 1 month of diagnosis at sarcoma MDT	Numerator - The number of children with non-rhabdomyosarcoma histologies and limb/trunk rhabdomyosarcomas discussed within 1 month of diagnosis at sarcoma MDT Denominator - Total number of child sarcoma patients with non-rhabdomyosarcoma histologies and limb/trunk rhabdomyosarcomas.		NCRAS	1,3,5	Effective
129	% of patients accepted entry into a clinical trial	Numerator - The number of sarcoma patients accepted entry into a clinical trial Denominator - Total number of sarcoma patients applicable for clinical trials		NCRAS	1,3,5	Effective
	Patient Experience					

201	% patients seen by a Sarcoma CNS			CHI	1,3,4	Responsive, caring
202	Proportion of patients with recorded treatment intent			COSD	1,3,4	Responsive, caring
	Structure and Process - infrastructure requirements, staffing, facilities etc.					
001	There is a named lead clinician with responsibility for the sarcoma services	There should be a single named lead clinician with agreed list of responsibilities for the Sarcoma Service who should then be a core team member.	The role of lead clinician of the MDT should not of itself imply chronological seniority, superior experience or superior clinical ability	self-declaration	2,3,5	well led, safe ,

002	There is an MDT that meets the requirements as specified in the national service specification	The MDT should provide the names of the core team members for named roles in the team as follows: (1) - two sarcoma surgeons with a relevant surgical practice for each of the two sarcoma subdivisions, soft tissue and bone, that the MDT deals with (2); - two imaging specialists (3); - two oncologists, at least one of which should be named as having the responsibility for radiotherapy and at least one of which should be named as having responsibility for chemotherapy (4); - two histopathologists who should be taking part in the specialist EQA for sarcoma; (5) - two clinical nurse specialists; (6) - MDT co-ordinator/secretary; (6) Each clinical core member should have sessions specified in the job plan for the care of patients with sarcoma and attendance at MDT meetings; (6) Core surgical members of the MDT should have 5 PAs per week specified for the care of patients with sarcoma; Core oncology members of the MDT should have 3 PAs per week specified for the care of patients with sarcoma. (7)	(1) Where a medical specialty is referred to, the core team member should be a consultant. The cover for this member need not be a consultant. Where a medical skill rather than a specialty is referred to, this may be provided by one or more of the core members or by a career grade non-consultant medical staff member. All consultants responsible for the delivery of any of the main treatment modalities should be a core member of the MDT. (2) For example, for a STS/ bone sarcoma MDT, if only one of the two surgeons had a practice in bone sarcoma, then a third surgeon, who had such a practice, would be necessary. A given individual can be accepted for both the STS and bone roles provided they have a practice in both. (3) The role of the imaging specialist can be met by a group of named specialists. (4) It can be seen that one clinical oncologist plus one	self-declaration	1,,3,5	well led, safe, effective

			medical oncologist or two clinical oncologists may fulfil the above requirement. Both oncologists may have responsibility for the same modality and a given clinical oncologist may have responsibility for both modalities. (5) The role of the histopathologist can be met by a group of named histopathologists provided each meets the workload and EQA requirements. (6) Clinical sessions should be defined as relevant to their professional group. (7) The PAs may be a combination of direct clinical care PAs and supportive PAs. Where a given individuals practice is for both the STS the 5 sessions can be made up of care for both STS and bone sarcoma patients (6) The roles of the clinical nurse specialist and MDT co-ordinators can be met by a group of named specialists.			

003	There is a weekly MDT meeting for treatment planning attended by all the relevant disciplines.	The MDT should have treatment planning meetings scheduled every week unless the meeting falls on a public holiday. The attendance at each individual scheduled treatment planning meeting should constitute a quorum, for 95% or more, of the meetings. (1)The quorum for the sarcoma cancer MDT is made up of the following core members, or their cover: (2) one sarcoma surgeon; one clinical oncologist; one oncologist taking responsibility for chemotherapy; one imaging specialist; one histopathologist; one sarcoma nurse specialist; one MDT co-ordinator.		Self-declaration	1,2,3	effective

004	There are clinical guidelines in place which, where available, reflect national guidelines	The SAG should produce clinical guidelines for bone and soft tissue sarcoma (i.e. how a given patient should be clinically managed), and should include the following: - that all soft tissue biopsies should be referred either directly or for a confirmatory opinion, to a specialist sarcoma pathologist (SSP);(1) - application of appropriate molecular testing for diagnosis, prognosis and prediction in accordance with the National Genomic Test Directory - the imaging modalities and their specific indications; - the laboratory and histopathological/ histochemical investigations and their specific indications; - any aspects of the process which differ between a new diagnosis and that of a recurrence; - how a given patient should be clinically managed, usually at the level of which modality of treatment is indicated, rather than detailed regimens or surgical techniques. The SAG should produce clinical guidelines for soft tissue sarcomas presenting to site specialised MDTs (i.e. how a given patient should be clinically managed, usually at the level of which modalities of imaging and pathology investigation and which modalities of treatment are indicated, rather than detailed regimens or techniques). The guidelines should apply to at least the following sarcomas: Upper GI	(1)A SSP is defined as a histopathologist who has successfully taken part in the relevant sarcoma national EQA scheme and is a core member of a sarcoma MDT Chemotherapy treatment algorithms are dealt with in a separate measure in this section, below. Radiotherapy treatment techniques are dealt with in the Radiotherapy measures. Where there are nationally agreed requirements for clinical guidelines it is recommended that these are adopted.	self-declaration	1,2,3,5	safe, effective

		Gynaecology Head and Neck Skin Breast Lung Thoracic Urology				

005	There are area wide presentation pathways in place	The SAG should, in consultation with the MDTs and diagnostic clinic leads, agree an area-wide presentation pathway for potential sarcoma patients which specifies at least the following: - there is a named lead clinician for sarcomas in each of the referring trusts. They should be at consultant level and have specified time and a list of responsibilities for the role For soft tissue sarcomas of the limbs and trunk wall: - that patients newly presenting with symptoms urgent, suspicious of soft tissue sarcomas of the limbs and trunk wall, (appendix 1) should be referred to one of the sarcoma diagnostic clinics for the area (topic 1D); (1) - those diagnostic clinics, out of all those agreed for the area, which are agreed as able to perform biopsies of suspected sarcomas;(2) - the investigations other than biopsy which may be or are expected to be carried out by the diagnostic clinic prior to referral to the sarcoma MDT; the contact points of the locally relevant diagnostic clinics for primary care /hospital doctors, for referral of newly presenting patients; - the contact points for primary care/ hospital doctors to refer back known patients with	(1) Masses which are clinically judged to be lymph nodes would normally be expected to be referred initially to the relevant site specific MDT, depending on their anatomical site and accompanying clinical features. Neck lumps are expected to be referred to the already established 'neck lump' clinics. (2). This is following a judgment by the SAG on whether the relevant surgical staff of the clinic have the necessary expertise relating to the requirements of specifically, sarcoma biopsies. (3) This covers the referral of newly presenting patients and patients presenting with symptoms suggestive of recurrence. Referral of suspected recurrences may be to a diagnostic clinic or a core member of a sarcoma MDT.	self-declaration	1,2,3,4,5	safe, effective, caring

		symptoms suspicious of recurrence.(3) for bone sarcomas - that patients with X-rays or other images (including incidental findings) which are thought to be possibly indicative of a primary bone sarcoma, should be referred directly to the bone sarcoma MDT which is associated with the patient's network; - that patients with clinical symptoms or signs suspicious of a primary bone sarcoma should be referred directly to the bone sarcoma MDT; - that patients diagnosed post-operatively with a previously unsuspected bone sarcoma should be referred directly to the bone sarcoma MDT; the contact number for referral to the MDT; - that biopsy of suspected patients should only be carried out by the bone sarcoma MDT; and - the contact points for primary care/ hospital doctors to refer back known patients with symptoms suspicious of recurrence.				

006	There are area wide investigation and treatment pathways in place	The SAG should produce patient pathways for bone and soft tissue sarcoma – limb and trunk (i.e. the named services, hospitals and MDTs which a patient should be referred to according to named indications, during their investigation, treatment, psychological and social support, rehabilitation and follow up). The pathways should include the relevant contact points for the services, hospitals and MDTs (1,2) and cover the following: - which part of the investigational protocols may be carried out by the initial referring body, which may be carried out by the sarcoma diagnostic clinic and which should be carried out by the MDT; - which team from the, sarcoma MDT, teenage and young adults MDT (TYAMDT), or specialist palliative care MDT (SPCMDT) is responsible for which aspects of care; - at which stages in the pathway, the patient should be referred between teams; - that the treatment planning decision for any active treatment of at least any local recurrence and first distant recurrence, should be made only after discussion at the sarcoma MDT. - that any patient with metastatic carcinoma of unknown origin should be referred on for discussion by the carcinoma of unknown primary MDT. - the roles in the follow up process, of clinics outside the sarcoma centre and the sarcoma MDT; - the contact points for referral back with recurrence.	(1)This should include, where relevant, any services, hospitals or MDTs outside those associated with the SAG.	self-declaration	1,2,3,4,5	safe, effective, caring

		- for soft tissue sarcomas presenting to Site Specialised MDTs: confirmation of a care plan by a Sarcoma MDT treatment delivered by services designated by the SAG ; - that all newly presenting cases of soft tissue sarcoma, if not diagnosed initially by an SSP should be sent for histological review by an SSP and in the case of Upper GI sarcomas, the histology of all proposed cases of GIST are reviewed by one of the designated GIST pathologists, for the area. - the pathway as it should apply to retroperitoneal sarcomas - the pathway should apply to at least the following sarcomas: Upper GI Gynaecology Head and Neck Skin Breast Lung Thoracic Urology				

007	There are designated practitioners who are named members of the Sarcoma MDT	All elements of non-emergency treatment for patients with sarcoma must be delivered by core or designated members of the MDT. Designated practitioners will be named and will require: - nomination by the sarcoma MDT - a written record shared between sarcoma MDT, SAG and employing Trust clinical line manager (clinical or Medical Director) - an outline of role as a designated practitioner e.g. diagnostic clinic lead - to deliver chemotherapy and radiotherapy in accordance with Network guidelines and following recommendation for individual patient from the sarcoma MDT - to be responsible for surgical management of (site specific) sarcoma in accordance with Network guidelines and following recommendation for an individual patient from the sarcoma MDT - participation in Sarcoma MDT annual review - participation in pathway development and maintenance - participation in audit of sarcoma patients - named in information made available to patients by sarcoma MDT and SAG - designation reviewed by Sarcoma MDT and SAG at least biennially.	(1) The designated chemotherapy practitioners may be consultant medical oncologists or clinical oncologists. The designated radiotherapy practitioners should be consultant clinical oncologists. (2) A given oncologist may be designated as able to treat one or both out of soft tissue sarcoma and bone sarcoma. Palliative chemotherapy and or radiotherapy should be delivered under the care of a designated oncologist,	self-declaration	1,3,4,5	safe, effective, caring

Appendix 4 - Network Provider Configuration

TO BE INSERTED AT CONTRACT STAGE