GIG CYMRU NHS WALES
Cyd-bwyllgor Comisiynu
Joint Commissioning Committee

Soft Tissue Sarcoma

Service Specification: SS149

Document Information	
Document Name	Soft Tissue Sarcoma
Document No	SS149
Document Purpose	Service Specification
Publication Date	November 2025
Version No	2.0
Commissioning Team Author	Cancer and Blood
Target Audience	Chief Executives, Medical Directors, Directors of Finance, Chief Pharmacists, Wales Cancer Network, Sarcoma MDT, clinicians treating sarcomas
Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Document Update Information	Updates made further to scheduled review include: • epidemiology • references • revised quality indicators and KPIs • clarification of scope of specification • correction of minor errors and inconsistencies

Contents

Abbreviations

AHP	Allied Health Professional
BSG	British Sarcoma Group
CSG	Cancer Site Group
DF	Desmoid Fibromatosis
GIST	Gastrointestinal Stromal Sarcomas
HNA	Holistic Needs Assessment
IPFR	Individual Patient Funding Request
MDT	Multi-disciplinary Team
NICE	National Institute for Health and Care Excellence
NWJCC	NHS Wales Joint Commissioning Committee
PROM	Patient Reported Outcome Measure
RT	Radiotherapy
SACT	Systemic Anti-Cancer Therapy
SOP	Standard Operating Procedure
STA	Soft Tissue Sarcoma
TYA	Teenagers and Young Adults

Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission Soft Tissue Sarcoma services for all age groups in accordance with the criteria outlined in this specification.

In creating this document NWJCC has reviewed the requirements and standards of care that are expected to deliver this service.

Welsh Language

NWJCC is committed to treating the English and Welsh languages on the basis of equality, and endeavour to ensure commissioned services meet the requirements of the legislative framework for Welsh Language, including the Welsh Language Act (1993), the Welsh Language (Wales) Measure 2011 and the Welsh Language Standards (No.7) Regulations 2018.

Where a service is provided in a private facility or in a hospital outside of Wales, the provisions of the Welsh language standards do not directly apply but in recognition of its importance to the patient experience, the referring health board should ensure that wherever possible patients have access to their preferred language.

In order to facilitate this, NWJCC is committed to working closely with providers to ensure that in the absence of a Welsh speaker, written information will be offered and people have access to either a translator or 'Language-line' if requested. Where possible, links to local teams should be maintained during the period of care.

Decarbonisation

NWJCC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning activities. Where possible and taking into account each individual patient's needs, services are provided closer to home, including via digital and virtual access, with a delivery chain for service provision and associated capital that reflects the NWJCC commitment.

Disclaimer

NWJCC assumes that healthcare professionals will use their clinical judgement, knowledge and expertise when deciding whether it is appropriate to apply this document.

This document may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to

the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, or Local Authority.

NWJCC disclaims any responsibility for damages arising out of the use or non-use of this policy.

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of Soft Tissue Sarcoma (STS) services for people of all ages resident in Wales. This service will only be commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and applies to residents of all seven Health Boards in Wales.

1.1 Background

Sarcomas are rare cancers that can develop in the muscle, bone, nerves, cartilage, tendons, blood vessels and the fatty and fibrous tissue. Due to their rarity and the diversity of presentational features, on average a general practitioner may only see one sarcoma in their career[1]. Management of sarcoma is often complex and pathways of care are complicated and often individualised.

Sarcomas fall into the following main types:

- Soft tissue sarcoma
- Bone sarcoma
- Gastrointestinal stromal sarcomas (GIST)

There are also a number of associated "intermediate" conditions that fall within the remit of sarcomas, such as atypical lipomatous tumours[2].

Soft Tissue Sarcomas can arise in a variety of anatomical sites which result in specific clinical scenarios and sometimes very challenging approaches to management. Anatomical sites that sarcomas can appear in are:

- Limb and trunk
- Head and neck
- Gynaecological
- Intra-abdominal including retroperitoneal
- Chest wall and lung
- Breast
- Cardiac/large vessels
- Skin

[1] UK guidelines for the management of sarcoma (2024)
[2] Sbaraglia M, Bellan E, Dei Tos AP. The 2020 WHO Classification of Soft Tissue Tumours: news and perspectives. Pathologica. 2021 Apr;113(2):70-84. doi: 10.32074/1591-951X-213. Epub 2020 Nov 3. PMID: 33179614; PMCID: PMC8167394

Bone Sarcoma
The bone sarcoma service is also commissioned by NWJCC but is outside the scope of this specification. Bone sarcoma services are highly specialised and are delivered for the population of Wales at designated centres in NHS England. All suspected primary bone tumours (prior to consideration of biopsy) should be referred to a designated supra-regional bone sarcoma service: Birmingham Royal Orthopaedic Hospital (South and West Wales) or Greater Manchester and Oswestry Sarcoma Service (GMOSS) (North Wales). All patients with bone sarcoma should have their care plan confirmed by a bone sarcoma MDT and treatment delivered under the bone sarcoma MDT's guidance.

GIST
Although GIST tumours are a type of soft tissue sarcoma, management of these patients in Wales is governed by different treatment and referral pathways and is not therefore included in this specification.

Intra-abdominal (including retroperitoneal and complex pelvic soft tissue)
The retroperitoneum is deep in the abdomen and pelvis, behind the abdominal lining, where organs such as the major blood vessels, kidneys, pancreas and bladder are located. Treatment of intra-abdominal, retroperitoneal and pelvic sarcomas is highly specialised and is therefore not included in this document. Patients from South and West Wales are referred to the Midlands Abdominal & Retroperitoneal Sarcoma Unit (MARSU) in Birmingham and patients from North Wales are referred to GMOSS.

Spinal Sarcoma
The spinal sarcoma service is commissioned by NWJCC but is outside the scope of this specification. This highly specialised service is delivered at designated NHS centres in England. All suspected primary spinal tumours (prior to consideration of biopsy) should be referred to a designated supra-regional spinal sarcoma service: a collaboration between Birmingham Royal Orthopaedic Hospital and MARSU (South and West Wales) or GMOSS (North Wales). All patients with spinal sarcoma should have their care plan confirmed by a spinal sarcoma MDT and treatment delivered under the spinal sarcoma MDT's guidance.

1.2 Epidemiology

Sarcomas make up less than 2% of all cancers diagnosed in the UK each year[3]. They constitute a heterogeneous group of tumours of mesenchymal cell origin, often with a distinct age distribution, site of presentation, natural biological behaviour and prognosis. There are more than 100 subtypes divided into two broad categories: soft tissue sarcomas and sarcomas of bone. Bone sarcomas represent a significant proportion of the cancer burden in young people under the age of 20 years. Soft tissue sarcomas may

[3] Sarcoma UK: Sarcoma incidence

occur at any age, most often in middle aged and older adults; however, as a proportion of paediatric malignancies they are relatively common comprising 7–10% of all childhood cancers. They are an important cause of death in the 14–29 years' age group.

According to Sarcoma UK, there were 5,138 sarcoma diagnoses in England in 2019, of which 4,476 were soft tissues sarcomas. Approximately 21% (927) of the soft tissue sarcomas were GIST. Extrapolating this to Wales would suggest an expected annual incidence of approximately 200 non-GIST soft tissue sarcomas per year.

The south Wales sarcoma surgical service treats in excess of 100 patients with soft tissue sarcomas per year.

1.3 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering services for people with soft tissue sarcoma (STS).

The objectives of this service specification are to:

- detail the specifications required to deliver STS services for people who are residents in Wales
- ensure equitable access to STS services
- identify centres that are able to provide STS services for Welsh patients
- improve outcomes for people with sarcoma by ensuring that all patients with suspected or confirmed STS are referred to specialist STS services and that all patients have access to the highest quality care regardless of where they live or the location of the tumour.

1.4 Relationship with other documents

This document should be read in conjunction with the following documents:

- **NHS Wales**
  - All Wales Policy: Making Decisions in Individual Patient Funding requests (IPFR).

- **Welsh Government:**
  - Wales Cancer Network: Cancer Improvement Plan for NHS Wales 2023-2026
  - Welsh Information Standards Board: Data Standards Change Notice DSCN 2020/24 National Cancer Data Standards for Wales – Site Specific - Sarcoma

- **NHS Wales Joint Commissioning Committee policies and service specifications**

- CP50 Commissioning policy: Positron Emission Tomography (PET)
- CP147 Commissioning policy: Proton beam therapy for adults with cancer
- CP148 Commissioning policy: Proton beam therapy for children, teenagers and young adults with cancer
- PP184 Policy Position: Genomic Testing
- SS86 Service Specification: Services for Children with Cancer
- SS99 Service Specification for Genomic Services

- **National Institute of Health and Care Excellence (NICE) guidance**
  - Suspected cancer: recognition and referral (NG12, published June 2015, updated October 2023)
  - Quality Standard: Sarcoma (QS78, January 2015)
  - Quality Standard: Cancer services for Children and Young People (QS55, February 2014)
  - Quality Standard: Suspected cancer (QS124, published June 2016, updated December 2017)
  - Cancer Service Guidance: Improving outcomes for people with Sarcoma (CSG9, March 2006)
  - Cancer Service Guidance: Improving Outcomes in Children and Young People with Cancer (CSG7, August 2005)

- **Relevant NHS England policies**
  - NHS England Service Specification: 170122S Sarcoma Services July 2019
  - test directory

- **Other published documents**
  - Hayes, A.J., Nixon, I.F., Strauss, D.C. *et al.* UK guidelines for the management of soft tissue sarcomas *Br J Cancer* (2024)
  - The Royal College of Pathologists, Dataset for histopathological reporting of soft tissue sarcomas May 2022
  - The Royal College of Pathologists, Best practice recommendations: The role of the cellular pathologist in the cancer multidisciplinary team September 2022

2. Service Delivery

The NHS Wales Joint Commissioning Committee will commission services for people with sarcoma, in line with the criteria identified in this specification.

NWJCC is primarily responsible for commissioning the management of treatment at the sarcoma centre by the Sarcoma MDT. The Cancer Site Group (CSG) for Sarcoma will have responsibility for the sarcoma network and ensure that there are robust pathways in place to provide a comprehensive service for patients of all ages with sarcoma. As commissioners, NWJCC will seek to ensure that the CSG and Sarcoma MDT work together with primary and secondary health care providers within health boards, as well as external MDTs to establish and implement these pathways.

2.1 Access Criteria

This specification applies to all patients with suspected or confirmed soft tissue sarcoma.

2.2 Service Description

The key elements of the STS service model are:

- All patients with a provisional histological and/or radiological diagnosis of sarcoma should have their diagnosis reviewed by the sarcoma MDT. A formal diagnosis of sarcoma is only possible where full histopathology and radiology findings are discussed in the sarcoma MDT.
- The sarcoma MDT and the CSG will take responsibility to establish and implement pathways for referral and diagnosis for people with suspected sarcoma. These pathways should be published and readily available to health care providers in both primary and secondary care respectively. For north Wales, pathways will be defined via local agreement with the GMOSS MDT.
- Designated practitioners within various health boards involved in the diagnosis and management of sarcoma will be defined by the CSG and formally linked to the South Wales Sarcoma MDT or GMOSS (see Annex iii).
- Each health board will nominate an individual who will be responsible for the sarcoma pathway within their health board and who is also a member of the CSG.
- Clinical pathways (including waiting times for diagnosis, treatment, recovery package, rehabilitation etc.) will be compliant with the single cancer pathway in Wales.
- The sarcoma MDT will be responsible for recommending an appropriate treatment plan for patients with STS and confirming place of treatment (see Annex iii).
- Planned treatment for a sarcoma must only be performed by core or extended members of the sarcoma MDT (see section 2.3 for MDT membership).
- Extended MDT members are named clinicians who provide site-specific STS treatment (e.g. head and neck, gynaecology) or other aspects of treatment

provided outside the sarcoma centre as recommended by the sarcoma MDT (e.g. chemotherapy and radiotherapy). Designation as an extended MDT member requires a number of qualifying criteria to be fulfilled as defined by the CSG and Sarcoma MDT respectively (see Annex iii).

- Children and young patients with STS will be managed via close working between a designated sarcoma MDT and paediatric and teenage and young adult (TYA) MDTs respectively.
- All patients with a suspected or confirmed intra-abdominal (including retroperitoneal) or bone sarcoma will be referred to a specialist sarcoma MDT with expertise in managing this type of tumour (as defined by the CSG) where the care plan and treatment will be confirmed and delivered as specified by the specialist sarcoma MDT.
- A formal system for second opinions and review of particularly complex cases should be established with relevant external MDTs.
- Protocols and pathways defining the relationship between the Sarcoma MDT and external as well as extended (site-specific) MDTs should be published in the Sarcoma MDT's standard operating procedure (SOP) (for inclusion in appendices when provided) including the mechanism by which outcomes are recorded and shared.
- The sarcoma MDT must publish information about their shared pathways, activity and patient outcomes, including information on site-specific sarcomas (see Annex iii).
- All patients with a diagnosis of sarcoma should have a named clinician responsible for their care and should be allocated a key worker who, with the patient's consent and agreement, takes a key role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice in relation to their cancer diagnosis. The key worker may come from any healthcare discipline involved in the patient's treatment and care and this person will usually be identified and recorded in the sarcoma MDT meeting.

2.3 Staffing

Specialist teams:

NICE guidance[4] recommends that the STS service is provided by a specialist STS multi-disciplinary team (MDT). Given the incidence of sarcoma, the MDT is likely to serve a minimum population of between 2 and 3 million. The sarcoma MDT should be expected to manage at least 100 new patients with soft tissue sarcoma per year.

MDT Membership

There should be a single named lead clinician with an agreed list of responsibilities for the sarcoma MDT who is also a core member of the MDT. Table 1 is based on NICE

[4] NICE Cancer Service Guideline 9, Improving outcomes for people with Sarcoma, 2006

guidance[3] and the NHS England Sarcoma Service Specification[5] and describes a minimum standard for core membership of the sarcoma MDT:

Table 1. Core membership of a sarcoma MDT

Staff requirements	Specification
Specialist sarcoma surgeon	Two sarcoma surgeons with a relevant surgical practice for STS i.e. spend at least 5 programmed activities of direct clinical care involved in managing sarcomas
Specialist sarcoma radiologist	Two specialist sarcoma radiologists (with a special interest in musculoskeletal and oncological imaging, this can be met by a group of named specialists). Jobs should be planned in order to be able to double report cases.
Specialist sarcoma pathologist	Two specialist sarcoma pathologists. Jobs should be planned in order to be able to double report cases.
Medical oncologist and/or clinical oncologist	Two oncologists, at least one of which should be named as having responsibility for radiotherapy and at least one of which should be named as having responsibility for chemotherapy. 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	Two clinical nurse specialists
Support staff	MDT coordinator /secretary with sufficient admin time
Palliative care specialist	A member of the specialist palliative care team

Extended MDT Membership

Each MDT should in addition have an extended team with membership as shown in Table 2, some of whom 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, including business and performance meetings.

[5] NHS England Sarcoma Service Specification, 2019

Table 2. Membership of an extended sarcoma MDT (based on NICE guidance)[6]

Staff requirements	Specification
Specialist sarcoma physiotherapist	With expertise in sarcoma *rehabilitation*.
Specialised allied health professionals (AHP)	Consisting of other relevant AHPs, such as therapy radiographers, occupational therapists, prosthetists, orthotists, dietitians 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 oncologist 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	*Named clinicians* nominated by the cancer network clinical director and approved by the MDT lead clinician

Sarcoma MDTs should ensure there are pathways in place for molecular pathology testing in partnership with the All Wales Medical Genomics Service (AWMGS) and pathology departments to ensure access to appropriate molecular testing, as defined in the National Genomic Test Directory for Cancer, for all eligible patients.

2.4 Clinical Standards

Soft tissue sarcomas can arise in a variety of sites and are usually treated by surgery, often in combination with radiotherapy and/or chemotherapy.

The management of sarcomas should be in accordance with British Sarcoma Group guidelines for the management of soft tissue sarcomas[7].

General principles

- Guidance for appropriate investigations and referral in primary care for a suspected sarcoma in children, young people and adults will be in accordance with NICE and

[6] NICE Cancer Service Guideline 9, Improving outcomes for people with Sarcoma, 2006

[7] Hayes, A.J., Nixon, I.F., Strauss, D.C.*et al.* UK guidelines for the management of soft tissue sarcomas. *Br J Cancer* **132**, 11–31 (2025). https://doi.org/10.1038/s41416-024-02674-y

British Sarcoma Group (BSG) guidance and will be approved and published by the CSG to health care providers in primary and secondary care respectively.

- Cancer waiting times are recorded in accordance with the single cancer pathway in Wales.
- Where surgery is performed inadvertently outside of the designated Sarcoma Centre, patients must be referred post-operatively to the Sarcoma MDT. The sarcoma MDT must maintain a prospective audit of such cases.

Limb and Trunk Soft Tissue Sarcoma

Diagnosis

To improve the early diagnosis of soft tissue sarcomas, a clearly defined network of diagnostic clinics linked to sarcoma treatment centres should be established. Models of care can be structured as follows:

- The diagnostic pathway for patients with a suspected diagnosis of STS will be compliant with the Single Cancer Pathway in Wales.
- Patients with a suspected diagnosis of soft tissue sarcoma (criteria as defined by the CSG) would be seen within 2 weeks at a diagnostic clinic specifically designated by the sarcoma MDT. This would be a purely diagnostic, rather than a treatment clinic, and would be clearly affiliated to the sarcoma MDT.
- Nurse-led clinics, which are implemented according to national standards and by local agreement, are included in this model. However, there must be a named consultant to provide advice and take ownership of the patient for clinical governance purposes.
- Diagnostic clinics should undertake triple assessment including clinical assessment, imaging and biopsy if clinically indicated by appropriately trained individuals. Ideally these assessments should all be performed on the same day in order to facilitate rapid diagnosis of sarcoma. Biopsy samples should be made available for genetics via pathology where appropriate and agreed by the MDT.
- Biopsies should be carried out by an appropriately trained radiologist or surgeon.
- The diagnostic clinic should provide adequate patient information and have a mechanism to support the patient and answer any queries during the diagnostic phase.
- Patients identified as having a suspected soft tissue sarcoma either radiologically and/or histologically should be rapidly referred on to a sarcoma MDT.
- Patients will remain under the care of the referring consultant or nominated health board lead for sarcoma until the MDT accepts and takes over care.
- Clear lines of communication must be established and shared between the sarcoma MDT, referring clinician, the patient and their GP. The Sarcoma MDT should make it clear who is responsible for any further care or management, including who is taking responsibility for any investigations that need to be performed.

- Written protocols will be established by the sarcoma MDT and the CSG for the structure and function of the diagnostic clinics to include patient information leaflets.

Staging

- All staging investigations required by the MDT to make a recommendation for treatment should be performed in line with the Single Cancer Pathway guidelines.

Treatment

- Treatment plans (surgery, systemic therapy, radiotherapy) for all patients with limb and trunk soft tissue sarcoma should be agreed by the sarcoma MDT.
- Patients with fibromatosis or other soft tissue tumours of borderline malignancy should be referred to a sarcoma MDT for diagnosis and management advice.

Surgery

- All patients with limb and trunk soft tissue sarcoma should undergo definitive surgical resection at a soft tissue sarcoma treatment centre.

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 by the lead clinician in the soft tissue sarcoma MDT. Audits of compliance with these protocols will need to be demonstrated.
- The provider of chemotherapy and radiotherapy services should be:

Either

  - at a soft tissue sarcoma treatment centre

or

  - at a centre with a nominated medical and/or clinical oncologist who is a member of an 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 Sarcoma MDT and the CSG respectively.

Or

  - at a principal treatment centre for children or young people as described in the NICE guidance on Improving outcomes in children and young people with cancer.
  - all patients with soft tissue sarcomas should be offered entry into the relevant clinical trials.

Soft Tissue Sarcomas Requiring Shared Management

Soft tissue sarcomas can occur at a wide variety of sites in the body. For adults, the diagnosis and treatment plan must be agreed with the sarcoma MDT prior to commencement of any treatment. For children and young patients, the treatment plan should be made and delivered by the paediatric oncology MDT; the sarcoma MDT should be informed of the plan. There are a number of sarcomas that may present to and need management by other site-specific cancer teams.

These sarcomas include:

- gynaecological sarcoma
- head and neck sarcoma
- chest wall/intrathoracic sarcoma
- skin sarcoma
- gastro-intestinal stromal tumours (GIST)
- breast sarcoma
- cardiac/large vessel sarcomas

Gynaecological Sarcoma

- Approximately 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 to the sarcoma MDT must be undertaken.
- 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 patients have been staged for sarcoma.

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. Specialist head and neck sarcoma care should be delivered by a service with associated reconstructive support as designated by the sarcoma MDT and CSG.
- Patients with suspected head and neck sarcoma must be referred, according to guidelines developed by the sarcoma MDT, to a designated head and neck diagnostic centre. Head and neck and sarcoma MDTs must work jointly and to ensure patients can access all necessary expertise and support.

Chest Wall/Intrathoracic Sarcomas

- 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 sarcoma MDT must agree pathways appropriate to this tumour location.
- 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 in designated services.

Skin Sarcomas

- Sarcomas of the skin have a more favourable prognosis than either subcutaneous or deep soft tissue sarcomas. However, aggressive subtypes have a tendency for local recurrence leading to additional treatment morbidity if initial management is inadequate.
- Patients with suspected skin sarcoma must be referred according to guidelines developed by the sarcoma MDT.

GIST

- Patients with GIST must have their care/ treatment plan confirmed by a specialist GIST or Upper GI MDT and will have treatment delivered by services designated by that MDT.

Breast Sarcoma

- Soft tissue sarcomas may arise de novo within the breast or as a consequence of previous radiotherapy for breast cancer. 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 Sarcoma MDT.
- Women with suspected breast sarcoma must be referred to a sarcoma MDT and treatment delivered by services designated by the MDT.

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.

General standards for sarcomas requiring shared management

- The care of patients with soft tissue sarcomas requiring shared management should be managed by the appropriate site-specific MDT or the MDT for children in conjunction with the sarcoma MDT.
- All TYA patients diagnosed with sarcoma should be referred to the TYA MDT in parallel for psychosocial support.
- Each site specific MDT, the MDT for children and MDT for teenagers and young adults, will include a named individual who is part of the extended membership of the sarcoma MDT.
- The site-specific MDT has primary responsibility to liaise with the sarcoma MDT to discuss the management of each patient.
- The Sarcoma MDT has a responsibility to ensure that there are effective communication pathways between relevant MDTs as part of shared management to allow timely access to advice regarding patient management and to clarify under what circumstances patient care should be transferred from one team to the other.
- Specified treatment care plans, taking into account currently available clinical trials, should be used.
- The sarcoma MDT has responsibility to ensure written protocols are in place to establish the responsibilities of each specific MDT in the implementation of care plans.
- Surgery for non-rhabdomyosarcoma soft tissue sarcomas in teenagers and young adults should only be undertaken by a surgeon with appropriate expertise, and in age-appropriate facilities, after review at a designated sarcoma MDT.

2.5 Follow up/Rehabilitation/Survivorship/Palliative and End of Life Care

The recurrence risk for most high grade sarcomas is highest in the first 2-3 years after completion of treatment. For low grade sarcomas, recurrence is well-recognised to occur even after many years of disease-free survival and follow-up schedules and treatments must be guided by sarcoma sub-type. The following principles should apply:

- Patients must be educated at the end of treatment about the potential manifestations of recurrence and advised about self-detection of local recurrence. A treatment summary should be completed in collaboration with the patient and a copy sent to their General Practitioner. This includes support via self-management programmes as per local agreement and according to national standards.
- Follow up care for people with sarcoma may be delivered in either the specialist sarcoma centre, local health boards or by members of the extended MDT who provided treatment in line with pathways and protocols agreed by the CSG and Sarcoma MDT.
- Agreed protocols should include mechanisms for immediate re-referral to the sarcoma MDT.

- A recovery package, which is appropriate to the identified needs of the patient, should be implemented in line with the cancer delivery plan for Wales.

Key elements of the recovery package include:

- A treatment summary should be completed at the end of each acute treatment phase and a copy sent to both the patient and their GP.
- A holistic needs assessment and a written individualised care and support plan at key points across the pathway.
- Information on likely side-effects of treatment and how best to manage these, including those that might appear sometime later.
- Potential markers of recurrence/secondary cancers and information on what to do in these circumstances.
- Key contact point for rapid re-entry if recurrence suspected or if serious side effects become apparent.
- A cancer care review to discuss ongoing needs and completed by the GP or practice nurse.
- Access to patient education and support events to help prepare the person for the transition to self- management (including advice on healthy lifestyle and physical activity).
- Signposting to rehabilitation, work and financial support services.

Rehabilitation pathway

- For some patients who are successfully treated, the morbidity including long term sequelae is considerable. The survivorship needs of sarcoma patients must be addressed by appropriate surveillance schedules and support as well as access to appropriate rehabilitation resources. Sarcoma surgery has short and long term impact on patients in different ways depending on the site and complexity of the surgery undertaken.
- There should be appropriate assessment of patients' rehabilitative needs across the pathway and the provider must ensure that high quality rehabilitation is provided in line with the network agreed sarcoma rehabilitation pathway.
- Ongoing rehabilitation and supportive care will be provided locally wherever possible. This will be co-ordinated by the therapist in liaison with the key worker.
- Patients with functional disabilities as a consequence of their sarcoma must have timely access to appropriate support, rehabilitation and limb fitting services if appropriate.

Symptom care and end of life care pathway:

- The sarcoma service should have clear pathways agreed for patient care at the end of life. This will include services within hospitals, community services and services in the voluntary sector.

- Following a referral from the sarcoma MDT, local palliative care teams 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 standards 'End of life care for adults with life-limiting conditions' and 'End of life care for infants, children and young people with life-limiting conditions'.

Patient experience and outcomes:

- The CSG and the Sarcoma MDT will develop a mechanism to incorporate patient reported experience measures (PROM's) and patient reported outcome measures (PROM's) routinely. This will help inform future service development with a view to improving the patient experience and outcomes.

2.6 Children, Teenagers and Young People

Children

Services for children should be delivered in accordance with the standards set out in NWJCC service specification SS86 Services for Children with Cancer.

Specific additional requirements for sarcoma:

- The paediatric oncology MDT has primary responsibility for recommending and delivering a treatment plan. This plan should be ratified by the sarcoma MDT but such ratification should not be allowed to result in a delay in treatment.[8]
- The sarcoma advisory group (CSG) should have adequate representation from the paediatric oncology MDT and will be responsible for developing locally agreed referral pathways and agreed communication policies together with childhood cancer care providers.
- The paediatric oncology MDT has core expertise for rhabdomyosarcomas which is the commonest STS in children below the age of 10 years. However early discussion within a month of diagnosis with the sarcoma MDT is required for extremity tumours and all non-rhabdomyosarcomas for whom the benefits of specialist diagnostics and surgery may be considerable. The care plan for patients with non-rhabdomyosarcoma STS should be confirmed by a sarcoma MDT.
- Flexible, workable systems should provide appropriate staff and facilities to allow all diagnostic procedures to be undertaken quickly within routine working hours, and there should be protected time for theatre access and adequate paediatric surgical, radiological and anaesthetic sessions.
- Pathological specimens, suspected of being a sarcoma, should be urgently reviewed for definitive diagnosis by a paediatric or specialist sarcoma pathologist or a pathologist with a special interest in sarcoma.

[8] Children should be discussed in the STS MDT within a month of diagnosis, but they will have started treatment if chemotherapy is the initial treatment modality. If surgery is required first, then the adult-style pathway will be followed.

- All hospitals with shared care arrangements should have an MDT that facilitates the interface between that centre and both primary care and the principal treatment centre.
- Diagnostic biopsies are carried out by an appropriately trained radiologist. Definitive surgery in children known to have, or suspected of having, a malignant tumour should only be carried out by surgeons appropriately trained either in paediatric oncological surgery or other appropriate surgical specialities, working in a centre with appropriate support from paediatric anaesthetists and intensive care facilities.
- Referral systems should be in place to provide easy access to a variety of other surgical specialists.
- Where possible, involvement of Allied Health Professionals (AHP's) should be planned before surgery.

Teenagers and Young adults (TYA)

- All teenagers and young adults should be referred to the TYA MDT in parallel. Note that the TYA MDT is not a treatment MDT.
- The Sarcoma MDT standard operating procedure (SOP) must have the working arrangements between these MDTs clearly stated and agreed with the host sarcoma networks.
- Centres providing care for teenagers and young adults should ensure that the skills and experience represented in the MDT are appropriate to their age-related needs. Members should be familiar with the communication issues specific to working with teenagers and young adults and their families and appropriate training and support should be available.
- Surgery for non-rhabdomyosarcoma soft tissue sarcoma in teenagers and young adults should only be undertaken by a surgeon with appropriate expertise, and in age-appropriate facilities, after review at a designated sarcoma MDT.

2.7 Interdependencies with other services or providers

Sarcoma services are commissioned as part of a network arrangement.

A comprehensive service is available for patients with any type of sarcoma and network pathways are the responsibility of the sarcoma MDT and CSG respectively.

The CSG will take responsibility that network pathways are developed with the sarcoma MDT, local diagnostic clinics and other centres which are designated within the network for the delivery of diagnostic and treatment services. The sarcoma network (CSG) will engage with local health, social care and other services to ensure that patient experiences across all aspects of sarcoma pathways are positive.

2.8 Exclusion Criteria

No specific exclusions have been identified.

2.9 Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients resident in England who are registered with a GP Practice in Wales.

2.10 Transition Arrangements

Transition arrangements should be in line with Transition from children's to adults' services for young people using health or social care services NICE guidance NG43 and the Welsh Government Transition and Handover Guidance.

Transition involves a process of preparation for young people and their families for their transition to adulthood and their transition to adult services. This preparation should start from early adolescence 12-13 year olds. The exact timing of this will ideally be dependent on the wishes of the young person but will need to comply with local resources and arrangements.

The transition process should be a flexible and collaborative process involving the young person and their family as appropriate and the service.

The manner in which this process is managed will vary on an individual case basis with multidisciplinary input often required and patient and family choice taken into account together with individual health board and environmental circumstances factored in.

2.11 Patient Pathway (Annex i)

The patient pathway is set out in Annex i.

2.12 Service provider/Designated Centre

The Soft Tissue Sarcoma service is provided by the following:

- South Wales: South Wales Sarcoma Service, Swansea Bay University Health Board.
- North Wales: Greater Manchester and Oswestry Sarcoma Service (Robert Jones Agnes Hunt Orthopaedic Hospital NHS Foundation Trust / Manchester University NHS Foundation Trust).
- Patients in mid Wales may be referred, depending referral pathways into secondary care, to either the south Wales sarcoma service, Greater Manchester and Oswestry

Sarcoma Service, or to the sarcoma service at University Hospitals Birmingham NHS Foundation Trust.

2.13 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: Individual Patient Funding Requests

3. Quality and Patient Safety

The provider must work to written quality standards and provide monitoring information to the lead commissioner. The quality management systems must be externally audited and accredited.

The centre must enable the patients, carers and advocates informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties and for children, teenagers and young adults.

3.1 Quality Indicators (Standards)

Table 4: Sarcoma Metrics

Service Specification	Indicator
To manage the care of at least 100 new patients with soft tissue sarcoma per year (soft tissue sarcoma MDT).	The number of new cases of STS managed per year.
To provide expert accurate diagnosis and staging of bone and soft tissue sarcoma utilising the most up to date validated diagnostic tools. To have pathways for referral and diagnosis in place for people with suspected sarcoma. To publish information about shared pathways, activity and patient outcomes, including information on site specific sarcomas.	% of TYA patients discussed at TYA MDT. Proportion of patients whose sarcoma is staged using the TNMG staging system prior to definitive treatment % patients from point of suspicion to diagnosis and all staging within 28 days % patients from decision to treat to treatment within 21 days A standard operating policy (SOP) should be available that describes the policies and procedures of the sarcoma MDT. This should include extended membership and the names of specified consultants delivering any aspect of the care plan. There are published patient pathways in place for referral, diagnosis and treatment including shared pathways.

To ensure that all patients with confirmed bone or soft tissue sarcomas have access to expert care and management provided by trained staff and receive care in accordance with the most up to date agreed clinical protocols. To provide chemotherapy, radiotherapy and surgery in line with national guidelines, evidence based practice and network policy and delivered by designated practitioners who are core or extended members of a Sarcoma MDT. To be compliant with National Guidance and standards including NICE IOG and standards.	There are network wide clinical guidelines in place which, where available, reflect national guidelines and policy (as part of the SOP) There are designated practitioners who are nominated (by the CSG) extended members that deliver elements of care in different health boards. % of patients receiving chemotherapy at designated local treatment centres. Amputation rates for extremity bone and soft tissue sarcoma. Proportion of patients with extremity sarcoma, who undergo curative surgical resection where: • R0 is achieved • planned R1 is achieved Proportion of patients with an extremity soft tissue sarcoma which is deep and grade 2 or 3 who receive post-operative radiotherapy within 12 weeks of a planned marginal or wide local excision (R0 or R1). % patients with extremity soft tissue who have surgery and radiotherapy. % of patients with soft tissue sarcoma surgery undertaken outside of the designated centre. Number of patients receiving chemotherapy outside national algorithm.
To support local health boards to manage patients with sarcomas in line with national guidelines, evidence based practice and network policy.	All patients should have a clearly documented, MDT ratified management plan.
For adults, children and young people and adults with soft tissue sarcoma – to have their care plan	There is an MDT that meets the requirements as specified in the national service specification.

confirmed by a sarcoma MDT and treatment delivered by services designated by the Sarcoma Advisory Group.	There is a weekly MDT meeting for treatment planning attended by all the relevant disciplines. % patients discussed at Sarcoma MDT prior to definitive treatment. Number of patients referred for Proton Beam RT.
Compliance with Single Cancer Pathway.	% Patients treated within 62 days from point of suspicion. % Patients offered HNA and acceptance rates. % Patients with HNA's completed % Patients with recorded treatment intent % patients offered education and structured support programme
To ensure optimal physical functioning and quality of life for patients through rehabilitation and monitoring.	MDT to define and collect Patient Reported Outcome Measures and Patient reported experience measures
To ensure there is a commitment to continued service improvement and to improve outcomes for patients with sarcoma through research and audit . Clinical outcomes reporting.	Survival - 1 and 5 year Local recurrence rates for extremity soft tissue sarcomas within 2 years of sarcoma surgery. No. patients who died within 30 days of treatment (surgery, RT and SACT) No. Of patients who died within 90 days of treatment (surgery, RT and SACT) % of patients accepted entry into a clinical trial
To support patients through an allocated key worker. To provide high quality information for patients, families and carers in	% patients seen by a key worker and / or specialist cancer nurse.

appropriate and accessible formats and mediums.	
To ensure that there is involvement of service users and carers in service development and review.	Proportion of service users asked to complete patient survey Proportion of service users respond to patient survey Service users' attendance at sarcoma business meeting
To present information to the annual audit meeting (joint soft tissue and bone sarcoma MDT).	To present outcome data to NWJCC innovation and improvement days. Published outcomes should be shared with extended MDTs and other services that sarcoma feeds into. Publication of an annual report

4. Performance Monitoring and Information Requirement

4.1 Performance Monitoring

NWJCC will be responsible for commissioning services in line with this policy. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Service providers to evidence quality and performance controls
- Service providers to evidence compliance with standards of care

NWJCC will conduct performance and quality reviews on an annual basis

4.2 Key Performance Indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 2.2.

The provider should also monitor the appropriateness of referrals into the service and provide regular feedback to referrers on inappropriate referrals, identifying any trends or potential educational needs.

In particular, the provider will be expected to monitor against the following target outcomes:

Suspected Cancer Pathway Targets

- % Patients treated within 62 days from point of suspicion
- % patients from point of suspicion to diagnosis and all staging within 28 days
- % patients from decision to treat to treatment within 21 days

Diagnostic component targets

- Short to medium term (0 to 2 years) histopathology and genomics component targets:
    - From receipt of biopsy to final report available to MDT (inc. histopathology and genomics): 90% within 21 calendar days
        - Histopathology reported: 90% within 10 calendar days
        - Genomics reported: 90% within 10 calendar days
- Longer term histopathology and genomics component targets:

- From receipt of biopsy to final report available to the MDT (inc. histopathology and genomics): 90% within 14 calendar days
    - Histopathology reported: 90% within 7 calendar days
    - Genomics reported: 90% within 7 calendar days

4.3 Date of Review

This document is scheduled for review every three years, unless information is received which indicates that the policy requires revision.

If an update is carried out, this version of the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality Impact Assessment (EIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable NHS Wales Joint Commissioning Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

6. Putting Things Right

6.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for NHS Putting Things Right. For services provided outside NHS Wales the patient or their representative should be guided to the NHS Trust Concerns Procedure, with a copy of the concern being sent to NWJCC.

6.2 Individual Patient Funding Request (IPFR)

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

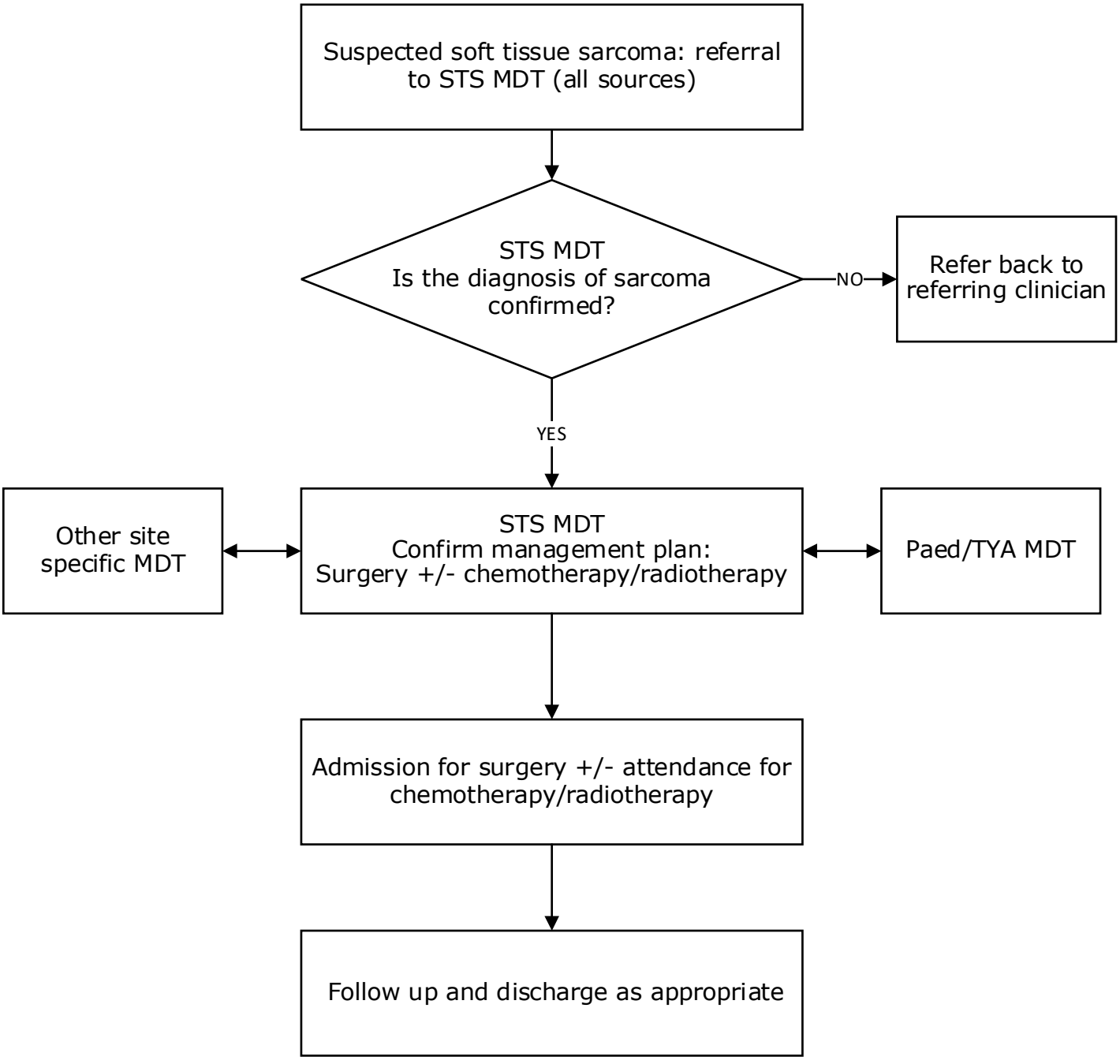
If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated.

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: Individual Patient Funding Requests.

Annex i Patient Pathway

The pathway shown below starts from the point of referral to the specialist MDT of suspected soft tissue sarcoma.



Annex ii Codes

The list of ICD codes is indicative and is not exhaustive. Additional codes may be used for contract monitoring purposes, furthermore some codes may cover indications not included within this policy.

Code Category	Code	Description
IDC 10	C40	malignant neoplasm of bone and articular cartilage of limbs
	C41	malignant neoplasm of bone and articular cartilage of other and unspecified sites
	C49	malignant neoplasm of connective and soft tissue

Annex iii Designated MDT members and designated 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:

- surgeons whose main anatomical focus is not sarcoma but may for individual cases be the most appropriate lead or support surgeon, and
- oncologists able to deliver radiotherapy or SACT under the direction of the sarcoma MDT nearer to the patient's home.

These latter roles can be described as 'designated practitioners'. Designated practitioners are members of an extended sarcoma MDT.

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

Designation as a member of the extended sarcoma MDT will require:

- Nomination by the sarcoma MDT
- A written record shared between sarcoma MDT and employing health board clinical line manager (clinical or Medical Director)
- An outline of role as a designated practitioner e.g.
    - to deliver chemotherapy 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
- Designated oncologists will be expected to participate directly in sarcoma MDT meetings either on a regular basis or for case-by-case discussion
- 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
- Designation reviewed by sarcoma MDT at least biennially.

Annex iv Glossary

Individual Patient Funding Request (IPFR)
An IPFR is a request to NHS Wales Joint Commissioning Committee (NWJCC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

NHS Wales Joint Commissioning Committee (NWJCC)
NWJCC is a joint committee of the seven local health boards in Wales. The purpose of NWJCC is to ensure that the population of Wales has fair and equitable access to the full range of Tertiary Services. NWJCC ensures that services within our portfolio are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.

Contact Us

If you have a question related to this document you can contact us using one of the methods outlined below.

If you would like this document in an alternative format and/or language, please contact us for assistance.

Email:

NWJCC consultation mailbox – nwjccconsultation@wales.nhs.uk

Telephone:

General Enquiries – 01443 433112

Website:

Contact us - NHS Wales Joint Commissioning Committee

Writing:

If you wish to contact the NHS Wales Joint Commissioning Committee, you can write to us at one of our locations below, we welcome correspondence in Welsh or English:

South Wales Offices
Unit 1, Charnwood Court, Heol Billingsley, Nantgarw, CF15 7QZ
Unit G1 The Willowford, Main Avenue, Treforest Industrial Estate, Pontypridd, CF37 5YL

North Wales Offices
Unit 3, Media Point - Unit 3, Mold Business Park, Mold, CH7 1XY
Preswylfa, Hendy Road, Mold, CH7 1PZ