The London and South East Sarcoma Network

Guidance on Referral of Sarcomas

DOCUMENT CONTROL SUMMARY

Title of Document	The London and South East Sarcoma Network: Guidance on Referral of Sarcomas To be read in conjunction with pathways and guidelines found on www.lsesn.nhs.uk
Aims	To provide guidance on pathways for the management of sarcomas arising in the limb and trunk and those sarcomas arising in 'special sites'
Issued by	The London and South East Sarcoma Network Sarcoma Advisory Group
Circulation To	LSESN Sarcoma SAG – Core and Extended Members Trust Sarcoma Leads within LSESN Designated practitioners within LSESN Available to download on www.lsesn.nhs.uk
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Date of Version	January 2018
Version Number	4 Final
Approved By	The London and South East Sarcoma Network Sarcoma Advisory Group
Approval Date	January 2018
Outstanding Items	None
Date of Review	2 years - January 2020
Formal Sign-off	London and South East Sarcoma Network Sarcoma Advisory Group
Storage Pathway	UCLH - G:\Shared\Presentations and Shared Info\Sarcoma\LSS Project Manager files\LSESN & SAG\Supporting information and documents\LSESN Pathways and Guidelines\LSESN Referral Guidelines

The London and South East Sarcoma Network

Guidance on referral of Sarcomas

This guidance applies to Strategic Clinical Networks (SCNs) referring into the London and South East Sarcoma Network. The SCNs include:

Regional Team	Strategic Clinical Network
NHS England London	London SCN
NHS England South	South East Coast SCN South West SCN Wessex SCN
NHS England Midlands and East	East of England SCN Thames Valley SCN

The guidance is issued jointly by the Sarcoma Centres of the Royal Marsden Hospital (RMH) and University College Hospital/Royal National Orthopaedic Hospital (UCH/RNOH).

Services for patients with sarcoma are long established at both UCH/RNOH and RMH. Approximately 1200 sarcomas are diagnosed each year including approximately 150 bone tumours, 120 GISTs, as well as head and neck sarcomas and gynaecological sarcomas. Both centres have a strong tradition of multidisciplinary working and integrated clinical research.

The purpose of this guidance is to clarify pathways of management for sarcomas arising in the limb and trunk, and those sarcomas arising in 'special sites' which may present to other site-specific MDTs and may in some cases be managed by the sarcoma MDT in partnership with the site-specific MDT.

As defined in the NICE Improving Outcomes Guidance (IOG), all sarcoma surgery is to be carried out in designated sarcoma treatment centres. Within the London and South East Sarcoma Networks the designated treatment centres are the Sarcoma Units at UCH/RNOH and RMH as well as The Royal Free for abdominal sarcomas and The Royal Brompton for thoracic sarcomas.

Sarcomas arising in the extremity or trunk should be referred to either of the sarcoma centres or to a designated sarcoma diagnostic clinic in a local network. Both sarcoma MDTs will accept referrals for sarcomas at all sites except bone, which should be referred to RNOH/UCLH.

Intra-abdominal, including retroperitoneal, sarcomas should be referred to the sarcoma MDT at the earliest suspicion. Clinical assessment, imaging, biopsy (when indicated) and surgery will be undertaken at the sarcoma centre. Further detailed advice on the recommended care of patients with intra-abdominal sarcomas will be issued.

For those Strategic Clinical Networks that do not have a diagnostic centre, diagnostic facilities for patients with suspicious lumps are provided at RNOH, UCH and RMH. Although inevitably some patients with small, superficial, slow growing tumours may

still only be diagnosed after excision biopsy, it is strongly recommended that all such patients be referred to diagnostic centres.

Suspected bone sarcomas should be referred to the diagnostic services at RNOH. Suspected cranio-facial bone sarcomas should be referred to UCLH.

All referrals to the sarcoma MDT must be accompanied by:
- Full clinical information including patient contact details
- All imaging – digitally transferred; imaging reports; pathology reports
- Review of pathology if relevant
- Details of information already given to the patient

The sarcoma MDT is responsible for decisions on all patients regarding pre- or post-operative radiotherapy and systemic treatment. The sarcoma MDT will also provide information on follow-up after treatment. The sarcoma centre will provide specialist information and support including the allocation of key workers for individual patients.

It is anticipated that all patients with suspected or newly diagnosed sarcoma will be seen by appropriate members of the sarcoma MDT. In some instances depending on individual patient circumstances, after discussion with clinical teams at the referring hospital, it may be agreed that patient review at the sarcoma centre is unnecessary.

Some components of treatment will be delivered outside of the two sarcoma centres. This will take account of patient needs and tumour characteristics. Treatment may be undertaken in centres with which prior agreements of levels of shared care have been established and after discussion of individual patients with the sarcoma MDT. Guidance for shared care with the sarcoma centres as well as detailed site specific guidelines can be found on the LSESN website www.lsesn.nhs.uk.

The sarcoma centres provide specific information for patients, key worker support and maintain a full portfolio of clinical trials for sarcomas. The centres will undertake continuous audit of referrals and contribute to national sarcoma audit programmes.

Sarcomas arising at 'special sites'

This section of the guidance refers to sarcomas arising in the head and neck; gynaecological sarcomas; skin sarcomas; gastrointestinal stromal tumours; breast sarcomas; central nervous system sarcomas; intrathoracic sarcomas and Neurofibromatosis 1-associated sarcomas, many of which may present to or be partly managed by other site-specific MDTs. When this is the case, documented arrangements for linking with the sarcoma MDT must be in place.
This section should be read in conjunction with site-specific pathway guidelines available on http://www.lsesn.nhs.uk/sarcoma.html

Gastro-intestinal Stromal Tumours

Referral is expected to occur most often at the time of
- clinical or radiological suspicion of GIST
- biopsy proven or resected GIST

The sarcoma MDT will give access to
- radiological and clinical expertise

- expert pathology including gene mutation analysis
- expertise on use of neoadjuvant systemic treatment
- new drugs and clinical trials
- radiofrequency thermoablation and other minimally invasive techniques
- specialist surgery such as hepatic resection
- specialist key worker, information and support

It is recommended that all patients should be reviewed by a sarcoma MDT at the time of diagnosis.

Surgery for localised tumours may be undertaken in a local referring centre with appropriate surgical expertise and after agreement with the sarcoma MDT. All patients should be reviewed with pathology and imaging as above.

It is recommended that systemic therapy will be initiated only after review by the sarcoma MDT.
Systemic treatment will be administered within clinical trials where these exist or according to agreed guidelines and will be managed by the sarcoma MDT
Follow up will be in accordance with national guidelines.

Gynaecological Sarcomas

These sarcomas are often diagnosed after hysterectomy. All patients with suspected or proven gynaecological sarcomas must be discussed with, and usually referred to, the sarcoma MDT

It is anticipated that initial hysterectomy will most often be undertaken by members of the gynaecological oncology MDT either at the referring centre or sarcoma centre.

The sarcoma MDTs will manage systemic treatment, including hormonal therapy, and radiotherapy for all pure sarcomas (leiomyosarcoma, endometrial stromal sarcoma, rhabdomyosarcoma) and adenosarcomas. Mixed Müllerian tumours will be managed by the gynaecological oncology team.
Management will be undertaken in accordance with guidelines agreed across the two sarcoma MDTs.

Head and Neck Sarcomas

Sarcomas arising in the head and neck are associated with poorer outcomes than those at other sites. Management is complex and benefits from an experienced MDT. There may be a greater role for neo-adjuvant treatment for sarcomas in this site, requiring close coordination between surgeons and oncologists.

All head and neck sarcomas should be referred at the time of suspicion or biopsy.

Management will be agreed after joint discussion between the head and neck sarcoma MDT at UCH or RMH and the Head and Neck cancer MDT at the referring centre.

Place of surgery will be advised through this joint treatment planning process and in discussion with referring Head and Neck teams.

Management will be undertaken in accordance with guidelines agreed across the two sarcoma MDTs.

Thoracic Sarcomas

All patients with suspected or proven thoracic sarcomas should be referred to the sarcoma MDT. This includes patients with primary or metastatic disease.

Referral is advised at the earliest suspicion of a thoracic sarcoma and assessment, imaging and biopsy will be undertaken by the sarcoma MDT.

All patients will be discussed at the joint thoracic sarcoma MDM (weekly videoconferenced with participation from RMH, UCH and Royal Brompton Hospital). All surgery for primary thoracic sarcomas will be undertaken at the Royal Brompton Hospital by the designated thoracic sarcoma team.

All metastatectomies will be undertaken at the Royal Brompton Hospital.

Palliative procedures such as pleurodesis may be undertaken elsewhere after agreement by the thoracic sarcoma MDT.

Spinal and Intracranial Sarcomas

All patients with suspected or proven spinal or intracranial sarcomas must be referred to the sarcoma MDT.

Management will be undertaken in conjunction with spinal surgeons at RNOH or NHNN and neurosurgeons at NHNN.

Detailed guidance for the management of spinal sarcomas will be developed by the sarcoma MDTs.

Skin Sarcomas

Sarcomas arising in the dermis are rare. Subcutaneous sarcomas occur more commonly and should be managed by the sarcoma MDT as for other extremity and truncal sarcomas. The sarcoma MDT will be informed of all new skin sarcomas, excluding Kaposi's sarcoma, including details of the pathology and treatment undertaken.

The sarcoma MDT will review all new cases except fully resected Dermatofibrosarcoma Protuberans and will review all recurrences.

Management will be undertaken in accordance with guidelines agreed across the two sarcoma MDTs.

Breast Sarcomas

The sarcoma MDT will review all cases of breast sarcoma.

It is anticipated that surgery will be undertaken by local breast services after discussion with the sarcoma MDT.

Management will be undertaken in accordance with guidelines agreed across the two sarcoma MDTs.

Sarcomas associated with Neurofibromatosis 1

Sarcomas may arise in patients with known NF-1, often under the care of the regional NF service based at Guys. Sarcomas may also arise in patients with previously unrecognised NF-1 or those not under follow-up by a specialist NF service. It is recognised that NF-1 associated sarcomas present specific complexities for management.

All NF-1 associated sarcomas will be referred to a sarcoma MDT.

Surgery will generally be undertaken by core surgical members of the sarcoma MDT. In some circumstances, the peripheral nerve injury unit at RNOH (Lead – Sinisi) or neurosurgery service at GSTT (Lead - Thomas) may undertake surgery.

The sarcoma MDT will manage systemic treatment and radiotherapy.