



London and South-East
Sarcoma Network

London and South East Sarcoma Network (LSESN) Sarcoma Advisory Group (SAG)

Constitution

2024

Hosted by:

**Royal National Orthopaedic Hospital NHS Trust
The Royal Marsden NHS Foundation Trust
University College Hospitals NHS Foundation Trust**

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Sarcoma Advisory Group members agreed the constitution on 7th June 2024

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1. Introduction

This document was compiled with the help of members of the London and South East Sarcoma Network Sarcoma Advisory Group. The document will be reviewed and updated annually. It sets out national guidelines, together with the Sarcoma Advisory Group's plans to implement them and describes how the various health care professionals and organisations work together to provide care for an individual with sarcoma.

2. Configuration of the London and South East Sarcoma Network (LSESN)

The LSESN was formed in response to the requirements of the Sarcoma Improving Outcomes Guidance (IOG), published in 2006, which recommended the creation of a managed sarcoma network in which clinicians, commissioners and cancer networks work together to develop the appropriate diagnostic and treatment pathways to serve their population.

The LSESN was created in 2008 to bring together two designated sarcoma centres:

- The London Sarcoma Service (LSS) (Royal National Orthopaedic Hospital [RNOH] and University College London Hospital [UCLH]) which hosts
 - a bone and soft tissue sarcoma MDT
 - a curative resection service for bone and soft tissue sarcomas
 - a retroperitoneal sarcoma service

and

- The Royal Marsden Hospital (RMH) which hosts
 - a soft tissue sarcoma MDT
 - a curative resection service for soft tissue sarcomas
 - a retroperitoneal sarcoma service

The two centres provide a sarcoma service to a population of approximately 24 million residents within London, East of England and South East of England

The LSESN incorporates 9 cancer alliances: North Central London, North East London, RM Partners, South East London, Kent and Medway, Surrey and Sussex, East of England North, East of England South and Wessex.

The network meets the requirement for:

- minimum number of cases (LSS sees approximately 150 new bone sarcomas and 350 new soft tissue sarcomas per year, RMH sees approximately 700 new soft tissue cases per year)
- a bone MDT with surgery provided on a single site (at RNOH), designated by the Highly Specialised Commissioning Group
- Limb, limb girdle and truncal soft tissue sarcoma surgery consolidated onto a single site relating to each MDT (RNOH and RMH)

The sarcoma service specification published in 2019, maintains and builds upon the principles in the IOG and describes the provision of sarcoma services concentrated into a small number of centres, each within a defined sarcoma network and that the network must be governed through a Sarcoma Advisory Group (SAG).

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3. Establishment of the Sarcoma Advisory Group (SAG)

The NHS England 2019 sarcoma service specification states that sarcoma care should be delivered through organised Sarcoma Networks, co-ordinated through Sarcoma Advisory Groups (SAGs). This 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.

Our SAG represents the London and South East Sarcoma Network (LSESN) and includes two specialist sarcoma services as described in Section 2. The SAG must be hosted and supported by a constituent provider who will be responsible for hosting the management function and supporting the overall network functioning. NHS England (London Region) Specialist Commissioners have agreed that the three Trusts (RMH, RNOH and UCLH) may have a joint hosting arrangement for the LSESN SAG, to support resourcing and share oversight.

4. Role of the SAG

The Sarcoma Advisory Group is the primary source of clinical opinion for sarcoma services. The overall purpose of the Sarcoma Advisory Group is to ensure sarcoma services within the defined sarcoma network are being delivered and monitored using consistent and appropriate clinical protocols and guidelines and in accordance with the NHS England Specialised Commissioning Service Specification No. 170122S.

The Sarcoma Advisory Group will develop and implement a work plan to address the role and aims including:

1. Work to fulfil the aim of a sarcoma service as set out in Service Specification No. 170122S
2. Ensure that all people with a suspected or confirmed diagnosis of sarcoma are referred to a specialist sarcoma centre for review by the sarcoma multidisciplinary team
3. Agree the network service configuration including designation of the Specialist Sarcoma Centre and Local Sarcoma Units
4. Agree the designation of all practitioners who may be involved in delivery of planned care for people with sarcoma
5. Agree network wide diagnostic protocols and pathways
6. Agree network wide treatment protocols and pathways
7. Agree procedures for whole genome sequencing and other molecular pathology testing
8. Agree guidelines for follow up care
9. Ensure network pathways are available for all types of sarcoma including referral to bone tumour services where these exist outside the network
10. Agree arrangements with neighbouring SAGs for people that may be served by either of two or more network services
11. Define sites where surgery for retroperitoneal, abdominal and pelvic sarcoma will be undertaken
12. Develop and agree care pathways for children with sarcoma in conjunction with local Children's Cancer Networks
13. Support audit of
 - Unplanned procedures
 - Procedures undertaken by designated and non-designated practitioners
 - Radiotherapy

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- Chemotherapy algorithm compliance
 - Other appropriate network audits
14. Use feedback from local and national patient surveys or other sources of patient reported outcomes to improve service quality
 15. Represent the sarcoma network professional and patient community
 16. Identify specific opportunities for improving outcomes and patient experience and convert these into agreed objectives and a prioritised programme of work
 17. To gain approval for the plan of work, and provide regular reporting on its progress
 18. Remain the primary source of clinical opinion on sarcoma and other conditions covered by the sarcoma service specification
 19. Ensure that care guidelines are agreed by provider trusts, followed, and are annually reviewed
 20. To promote and develop research and innovation in the network, and to have agreed objectives in this area for the Board
 21. Monitor performance and improvements in outcomes and patient experience via the quality dashboard and other data sources, understanding deviations and assessing variation to identify unexpected or undesirable areas for action
 22. Ensure that appropriate communication occurs throughout the network including dissemination through a maintained website
 23. Discuss opportunities for improved education and training related to the sarcoma pathways and implement new educational initiatives.

Full terms of reference for the SAG can be found in appendix 1.

Frequency of meetings

The Sarcoma Advisory Group will meet quarterly on Microsoft Teams and have one face-to-face meeting per year where possible. Core members will be expected to attend the meetings and a register of attendance will be kept. A summary of attendance at the SAG will appear in the Annual Report.

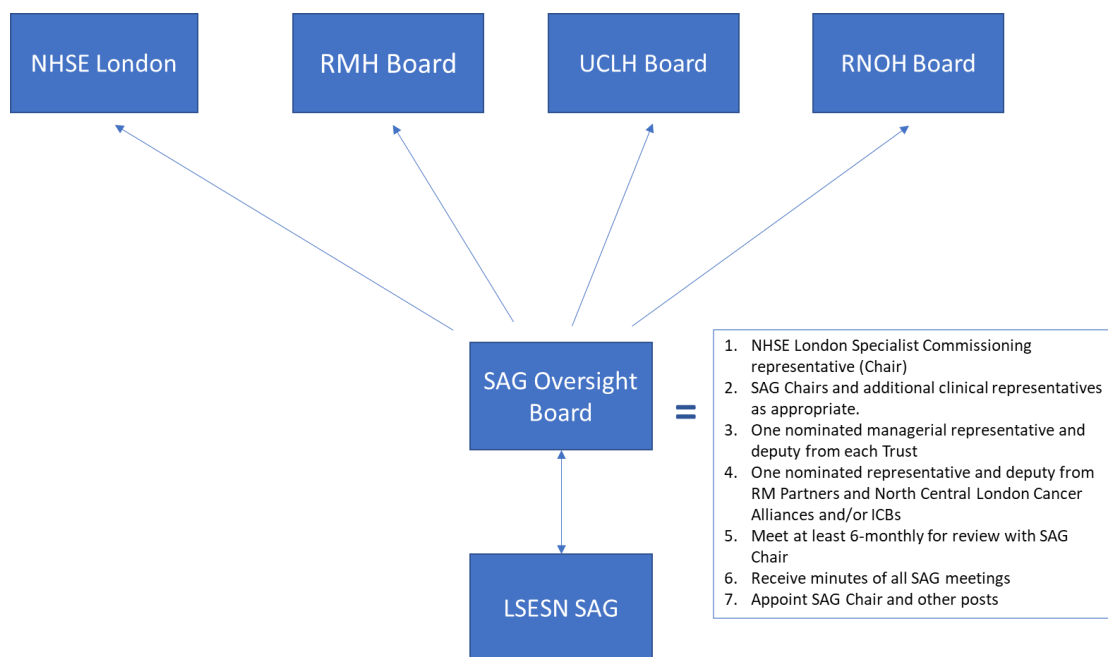
Accountability and governance

The SAG will have an Oversight Board which will include representation from each of the three host trusts as well as specialised commissioning. The SAG Oversight Board will oversee the delivery of the SAG's work plan including management of risks and issues and provide a conduit between the LSESN, the NHS England regions, cancer alliances and Integrated Care Boards.

Full terms of reference for the SAG oversight Board can be found in appendix 2.

The SAG will report through the governance framework agreed by the Trust(s) as described below:

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5. Membership of the SAG

Chair and deputy-chair

A chair and deputy chair will be appointed for a 3 year term, renewable once. The two postholders will be clinicians from both services i.e. if the chair is a member of the RMH service, the deputy will be from RNOH or UCLH and vice versa. They will also be from two different professional backgrounds e.g. surgery and oncology. New appointments will be made by nominations to the SAG Oversight Board. In the event of more than one nomination being received, an appointment process will be agreed by the SAG Oversight Board.

The chairs of the SAG will be responsible for setting the agenda for the meeting and ensuring that all relevant papers are circulated. Between meetings, the chairs will action urgent items or those with prior agreement from the SAG.

The chairs will have the support of a dedicated Project Manager. The chairs of the SAG will have an annual review as agreed with the host trust(s) to discuss the SAG Annual Report and progress over the previous year, and the work plan for the coming year.

At present the Chair is Mr Craig Gerrand and the Deputy Chair is Prof Robin Jones, both appointed in November 2021.

Quorum of the SAG Meetings

To include as a minimum: Chair, at least one each of medical and nursing members, at least one representative from each sarcoma service, a patient representative or patient advocate, and 2 others.

Core Membership of the Sarcoma Advisory Group:

To attend all SAG meetings

To receive SAG papers and SAG communications

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- Sarcoma Advisory Group Chair(s)
- Sarcoma Centres Clinical Teams, including MDT leads and identified leads for research
- Sarcoma Advisory Group Project Manager and administrative support
- NHS England London Region Specialised Commissioning Representative
- RM Partners and NCL Cancer Alliance Representatives and/or ICB Representatives
- Patient representative or advocate (at least one)
- CTYA Principal Treatment Centre Representatives

Core Sarcoma Advisory Group Members are asked to ensure that their timetable and Job Plans are adjusted or updated to ensure they are able to attend Meetings.

Extended Membership of the Sarcoma Advisory Group:

To receive SAG papers and SAG communications and to attend meetings where appropriate.

Can include but not limited to

- Sarcoma Trust Leads across the LSESN
- Sarcoma Designated Practitioners
- Representatives from providers hosting sarcoma diagnostic clinics
- Representatives from other Cancer Alliances across the LSESN (NEL, EE North and South, K&M, SEL, Surrey & Sussex, Wessex)

MDT Lead Clinicians from each MDT must ensure that MDTs are adequately represented at SAG meetings. The Chair must ensure that there is adequate representation at the SAG from each staff group on the core MDT and ensure their involvement as appropriate.

A list of core and extended members can be found in appendix 3.

User Involvement and the Lead Nurse

The SAG always aims to include the views of patients and service users when planning and reviewing its work streams. It also ensures that services are evaluated by patients and carers through regular patient satisfaction surveys and other initiatives.

We do not currently have user representatives attending the SAG meetings however the SAG is able to access a London Sarcoma Service user group for advice and involvement and can also link in with the Sarcoma UK user forum as required.

The lead sarcoma nurses at each of the centres RNOH, UCLH and RMH are the SAG members nominated as having specific responsibilities for user involvement and information and ensuring that users' views are presented.

The lead nurses above will take the lead for patient information and user involvement for the SAG, ensuring that all patient information is reviewed and updated on an annual basis and that user representatives are supported in the meetings and at other events. The lead nurses will also work with all SAG members to capture data relating to patient experience and ensure that any identified actions are implemented.

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Research and Clinical Trials

There is a Consultant Oncologist from each sarcoma service who are the SAG nominated leads for ensuring that recruitment to clinical trials and other well designed studies is integrated into the function of the SAG.

Administrative support

Administrative support to the SAG is provided by the SAG Project Manager and SAG PA who drafts and disseminates the minutes in advance of the meeting. This includes responsibility for keeping a record of attendance and apologies for absence to the meetings. The SAG Project Manager will liaise with the Chairs and other members of the SAG to ensure that all issues pertaining to sarcoma and the wider cancer agenda are discussed at the SAG meeting.

Any information that requires dissemination to the SAG membership will be sent by the SAG Project Manager or PA and they will make relevant documentation available on the LSESN website.

6. The MDTs

The two sarcoma MDTs each have their own Operational Policy outlining core and extended membership.

SUMMARY OF MEEETINGS:

London Sarcoma Service (LSS) Bone and Soft Tissue MDT		Royal Marsden Hospital (RMH) Soft Tissue MDT	
Lead Clinician	Julie Woodford	Lead Clinician	Robin Jones
<ul style="list-style-type: none">Weekly bone and soft tissue diagnostic MDT meeting (UCLH and RNOH)Weekly pre-diagnostic meeting at RNOH to discuss new bone and soft tissue referralsMonthly Clinical Review MDT meeting to discuss bone and soft tissue patients (UCLH and RNOH)Weekly sub-site abdominal sarcoma meeting to review patients with intra-abdominal sarcomas. (UCLH and RFH)		<ul style="list-style-type: none">Weekly soft tissue diagnostic and management MDT meetingWeekly pre-diagnostic meeting at RMH to discuss new soft tissue referralsFortnightly oncology management meetingWeekly resection pathology meeting	
<ul style="list-style-type: none">Weekly thoracic sarcoma meeting to discuss and review referrals of chest wall sarcomas and lung metastases. Oncologists from UCLH and RMH attend as well as thoracic surgeons from Royal Brompton Hospital RBH			

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Sub-specialisation

- Retroperitoneal surgery is undertaken at both LSS and RMH. Within the London Sarcoma Service abdominal sarcoma surgery takes place at the Royal Free Hospital whilst oncology treatment remains at UCLH. There is a weekly abdominal sarcoma MDT with attendance from RFH surgeons and UCLH oncologists.
- Thoracic surgery for sarcomas referred to both LSS and RMH MDTs is undertaken at the Royal Brompton Hospital with support of a dedicated joint extended MDT meeting
- Neurofibromatosis patients with Malignant Peripheral Nerve Sheath Tumour sarcomas will be managed in conjunction with Guy's & St Thomas's Foundation Trust neurofibromatosis service

The above teams are named as extended MDT members in the Operational Policies of the LSS and RMH MDTs.

Shared management with site-specific cancer teams

There are a number of sarcomas that may present to and need management by other site-specific cancer teams. These include gynaecological sarcomas, head and neck sarcomas, central nervous system sarcomas and adult-type sarcomas arising in children. The site-specific MDTs have primary responsibility to liaise with the sarcoma MDTs to discuss the management of each patient. The key contacts for these site-specific MDTs can be found in the extended MDT membership lists in each of the MDTs Operational Policies. Shared care pathways can be found in appendix 11.

Shared Care

As many patients live some distance away from LSS or RMH, it is not always practical to travel into London for all aspects of treatment. Wherever possible, arrangements are made with a named consultant in a local hospital to share care for any supportive therapies. Under the guidance of the cancer centres, blood analysis, antibiotic administration or blood products may be required.

7. Diagnostic Clinics for Soft Tissue Sarcomas of the Limbs and Trunk Wall

All primary care providers and secondary care trusts within the defined catchment population of the LSESN will refer to the London Sarcoma Service for the diagnosis and treatment of bone sarcomas.

The LSESN has a 'hub and spoke' model for the diagnosis and treatment of soft tissue sarcomas. The SAG has agreed designated sarcoma diagnostic clinics (the 'spokes') and primary care providers within the LSESN can refer to these clinics for the initial diagnosis of soft tissue sarcoma. The diagnostic clinics link into the two specialist sarcoma MDTs within the LSESN and highly suspicious/ diagnosed sarcomas are sent to these centres (the 'hubs') for treatment.

The diagnostic clinics within LSESN all function slightly differently but there are some general principles which they should follow as agreed by the SAG and outlined in the 'Soft Tissue Sarcoma Local Diagnostic Pathway' document (appendix 4). Each diagnostic clinic will be asked to self-assess against the criteria outlined in the pathway document (self assessment tool - appendix 5.) which will be reviewed by the SAG.

Key Functions of Diagnostic Clinic:

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- Assess urgent cancer referrals from GP, including any accompanying imaging
- Contact patient via telephone clinic
- Discuss suspected sarcoma patients in an appropriate MDT
- The clinic should offer on-site and timely ultrasound and MRI
- The clinic should offer a biopsy service - excision biopsies of small superficial masses, needle biopsies of nodal masses that are likely to be lymphoma and accessible soft tissue masses in selected patients at high risk of metastatic bone disease. Other biopsies should only be carried out after consultation with a sarcoma centre and referred to the centre if the biopsy cannot be carried out safely locally
- Biopsies performed in which there is histopathological suspicion/confirmed diagnosis of a sarcoma should be analysed at a sarcoma centre for diagnostic confirmation and undertaking of any appropriate molecular analysis

Key Workforce of a Diagnostic Clinic:

- A consultant clinician who is the designated service lead and takes overall responsibility for the performance of the clinic
- A nurse to be present in all consultations involving breaking bad news
- An MDT coordinator to ensure full compliance with CWT targets
- A radiologist with a sub-specialty in Musculo-Skeletal (MSK) radiology who will review ultrasound and MRI reports, and attend the local MDT
- A consultant surgeon with special interest in sarcomas to deliver outpatient clinics, carry out biopsies* and supervise the CNS
- * biopsies can be carried out by a radiologist and the clinic can be a radiology-led clinic
- A patient pathway coordinator/MDT coordinator to track patients through the pathway

Other criteria:

- The local diagnostic clinic will provide the SAG with a named clinical lead
- The service clinical lead or deputy will attend the SAG's quarterly meetings
- The local diagnostic clinic will provide a clear link to its affiliated Sarcoma specialist MDT, following the LSESN Soft Tissue Presentation and Diagnostic Pathway
- The clinic should have its staff trained and its work audited by the sarcoma MDT from the sarcoma treatment centre to which it is affiliated
- The clinic will ensure systems are in place for onward referral of patients referred with soft tissue sarcoma symptoms and that this is to enable CWTs to be achieved
- Local diagnostic services can expect good support from and communication with their affiliated Sarcoma MDT(s).

Pathway responsibility

The local diagnostic clinic retains clinical responsibility for all patients until they are either discharged back to GP with no sarcoma, referred on to another site-specific MDT if alternative cancer found or referred on to the sarcoma tertiary centre following MDT discussion. The local diagnostic clinic should comply with all Cancer Waiting Times

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standards and the Faster Diagnosis Standard up to the point of transfer and transfer in line with any Inter Trust transfer policy.

Referral form

A GP urgent cancer referral form has been created for London GPs which lists the referral criteria and contact details of the sarcoma diagnostic clinics and the two sarcoma centres. In recognition of factors including the clinical diversity of sarcoma presentation, patient choice, and convenience of access in such a large geographical area, strict sectorisation between the two soft tissue MDTs has been avoided.

Local Cancer Alliances outside of London have adopted their own referral forms using the same national referral criteria.

A list of diagnostic clinics can be found in appendix 6.

8. Designated Practitioners for Local Diagnostic Services

The SAG has agreed the designated practitioners who will be responsible for the local diagnostic services as described above. The list of diagnostic clinic designated practitioners (see appendix) will be reviewed and agreed by the Trust, the ICS' Imaging Board and the SAG annually.

All designated diagnostic practitioners (consultant surgeons, consultant radiologists and advanced nurse practitioners) will:

- have completed sarcoma specific training by one of the LSESN's tertiary centres
- participate in ongoing CPD and clinical audits conducted by the SAG
- attend a minimum of two sarcoma MDTs per year
- confirm that sarcoma clinics, number of PAs, SAG meetings and two SMDT meetings are included in their job plans
- have their hospital, profession, name and contact details included on the SAG's designated diagnostic practitioner register
- confirm that their cancer clinical director has approved all of the above.

9. Designated Chemotherapy Service and Chemotherapy Practitioners

The SAG has agreed which chemotherapy services are authorised to deliver chemotherapy regimens for the treatment of soft tissue and bone sarcoma. The SAG has named the oncologists (who are not core members of a sarcoma MDT) who should be responsible for the delivery of chemotherapy to bone and soft tissue sarcoma patients. The SAG has written guidelines which document the principles and criteria for referring patients to chemotherapy services outside the two centres (appendix 7). These designated chemotherapy practitioners are named as extended MDT members of the relevant sarcoma MDT. They are also included as extended members of the SAG.

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10. Designated Radiotherapy Department and Radiotherapy Practitioners

The SAG has agreed which radiotherapy departments are authorised to deliver radical radiotherapy courses for the treatment of soft tissue and bone sarcoma:

The SAG has named the oncologists (who are not core members of a sarcoma MDT) who should be responsible for the delivery of radiotherapy to bone and soft tissue sarcoma patients. The SAG has written guidelines which document the principles and criteria for referring patients to radiotherapy departments outside the two centres (appendix 8). These designated radiotherapy practitioners are named as extended MDT members of the relevant sarcoma MDT. They are also included as extended members of the SAG.

11. Pathways and Guidelines

The LSESN follows the national guidelines for the management of sarcoma as detailed in the Sarcoma Service Specification. The LSESN has agreed referral guidelines and a Patient Management Policy. The LSESN SAG has agreed patient pathways which both MDTs have adopted. All pathways and guidelines can be found in appendix 9-11 and on the LSESN website www.lsesn.nhs.uk.

Chemotherapy Treatment Algorithms

The SAG, in consultation with the Network Chemotherapy Group has agreed a list of acceptable chemotherapy treatment algorithms, which will be updated bi-annually. The latest list can be found in appendix 13 and on the LSESN website www.lsesn.nhs.uk

TYA Pathways

The *Improving Outcomes Guidance (IOG) for children and young people with cancer* (2005) and subsequent *Teenage and Young Adults Cancer Measures* (2012) recommend that patients aged 16–18 are managed at a principal treatment centre (PTC) for teenager and young adult (TYA) cancers and that those aged 19–24 are given the choice of being managed at a PTC or a TYA designated hospital.

All patients within this age range, regardless of place of care, should be referred to the TYA MDT at the relevant PTC. Referral to the MDT should be made using the TYA referral form.

The chairs of the SAG and the chairs of the relevant TYACNCG have agreed the pathways for sarcoma. These agreements have been communicated to the LSESN. The Sarcoma MDTs work in conjunction with the TYA MDTs at the specialist centres to agree the management of TYA patients with sarcoma.

The TYA MDT at UCLH is the Principal Treatment Centre responsible for delivering and overseeing the care of teenagers and young adults within the North Thames Network, which covers the following areas:

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- ICS London Cancer
- ICS London Cancer Alliance (North West London only)
- East of England (EoE) Strategic Clinical Network

In agreement with the Improved Outcomes Guidance for Children and Young People (2005), the Sarcoma MDT team and TYA MDT at UCLH will be jointly looking after the patients of 13 to the end of their 24th year. In general,

- TYAs of 13 to the end of their 18th year should be treated at the UCLH TYA PTC;
- TYAs of 19 to the end of their 24th year should be offered the choice of treatment in the UCLH TYA PTC or in a TYA designated hospital.

The Principal Treatment Centre for TYA for South Thames is The Royal Marsden Hospital.

All cases, even those who choose to be treated outside of either the PTC or a designated hospital, are reported to the PTC and discussed at the TYA MDT meeting. The treatment plan of all case is jointly agreed by the Sarcoma MDT and TYA MDTs according to the relevant agreed clinical guidelines.

Discussion at the TYA multidisciplinary team (MDT) is in addition to the specialist MDT; key functions of the TYA MDT are to agree the treatment plan of the specialist MDT, ensure cancer registration and provide a psychosocial care plan. Members of the specialist MDT or TYA service at the PTC or TYA designated hospitals are invited to attend the TYA MDT either remotely or in person.

The Clinical Lead of relevant Sarcoma MDT will have the final responsibility for:

- The diagnostic process
- Production of a treatment summary for each patient to be provided within six months of completion of first line treatment
- Production of a follow up care plan for each patient which describes the pathway as applied to their individual case
- Monitoring of disease recurrence and late effects care arrangements

The Clinical Lead of the TYA MDT at UCLH will have the final responsibility for:

- ensuring that age appropriate support and environment is available for each patient
- advising on age appropriate clinical trials relevant to the patient

Please note that the above arrangements are under review following implementation of the Principal Treatment Centres Service Specification.

12. Data Collection

The SAG area-wide agreed minimum data set for bone and soft tissue sarcoma comprises of the following data items:

- Cancer Waiting times monitoring
- which is taken from National Cancer Waiting Times Monitoring Dataset Guidance, version 12.0

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<https://www.england.nhs.uk/wp-content/uploads/2023/08/PRN00654-national-cancer-waiting-times-monitoring-dataset-guidance-v12.pdf>

- Cancer Outcomes and Services Dataset (COSD)
- which can be found here
http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

Note: Both MDTs collect and submit data on soft tissue sarcomas. The LSS MDT also collects and submits data on bone sarcomas.

Other Trusts within the catchment area of the London and South East Sarcoma are also responsible for submitting data for cancer waiting times and the cancer outcomes and services dataset. Referring trusts submit data on the referral and diagnostic details where applicable. The diagnostic and treatment part of the pathway is uploaded at RNOH/UCLH or RMH and links to the original referral using the NHS number. The Trust responsible for the patient at any one time is responsible for collecting and submitting the data at that point in the patient pathway.

Data collection is discussed at the SAG as appropriate, and will often focus on national as well as LSESN data, for example when looking at referral maps or location of treatment.

13. Audit

The SAG will agree an audit project each year. Each of the MDTs will participate in the audit and the results will be presented at one of the SAG meetings. Details can be found in the SAG Annual Report.

14. Research and Clinical Trials

Both MDTs are involved in a number of local and nationally approved trials. All trials are ethically approved.

The SAG will discuss and share a trials report at each meeting from each of its MDTs to include the trials currently open, pending and recently closed. This information will also be circulated to all members of the SAG and regularly updated on the LSESN website. <https://www.lsesn.nhs.uk/trials.html>

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