1. Introduction

Soft Tissue Sarcomas (STS) are rare tumours arising in mesenchymal tissues, and can occur almost anywhere in the body. Their rarity and the heterogeneity of subtype and location mean that developing evidence-based guidelines is complicated by the limitations of the data available. However, this makes it more important that STS are managed by teams, expert in such cases, to ensure consistent optimal treatment is commenced within a given timeframe

Due to the heterogeneous sites of origin of STS, it is difficult to clearly define the clinical features of the disease. Any patient with a soft tissue mass that is increasing in size, or has a size more than 4 cm, whether or not it is painful, should either be referred for an urgent ultrasound scan, or referred directly to a sarcoma diagnostic centre, and should be considered to be malignant until proved otherwise

The more of these clinical features present, the greater the risk of malignancy with increasing size being the best individual indicator. In addition, deeper lying masses are more likely to be sarcomas.

East Midlands Sarcoma Service (EMSS) - Leicester Diagnostic Services

This service is currently supports the development of efficient pathways for the investigation of suspected sarcomas. It involves EMSS Clinicians and the Clinical Nurse Specialist (CNS) to provide information to local primary care teams, or to radiology services on the initial investigation and onward referral of patients with soft-tissue masses, and effective pathways to make direct suspected-cancer referrals when required. All suspected cases are discussed at the weekly sarcoma MDT (multidisciplinary team) meeting

The purpose of the combined Consultant and CNS Sarcoma Clinic is to provide patients with a safe evidence based service to:

- coordinate diagnostic investigations,
- discuss treatment options,
- monitor progress after treatment and during recovery,
- conduct surveillance for tumour recurrence and assess for metastasis.

Patients are referred from a variety of sources, including, GPs, clinicians, radiology flag, multidisciplinary teams (MDT), hospital referrals within the East Midlands region including, Northamptonshire, Kettering and Leicestershire, Nottinghamshire and Lincolnshire.

The Sarcoma CNS will conduct consultations either via attendance at out-patients department, on an inpatient ward/unit or via a Sarcoma telephone clinic (RATC)

The Sarcoma CNS will enable patients to be followed up by a highly experienced and trained Registered Nurse. Please see section 6 for Training undertaken.

This is nationally practiced at the 15 NICE accredited sarcoma units in the UK by sarcoma specialist nurses.

There are benefits to the service as the patient is seen by their keyworker (CNS) who provides a comprehensive holistic needs assessment whilst maintaining continuity of care as well as providing a more cost effective service overall.

This document outlines the arrangements for the management of patients following referral to the sarcoma service with a diagnosis of sarcoma and other rare tumours. These include borderline malignant and pre-malignant tumours such as: atypical lipomatous tumours, solitary fibrous tumours, peripheral nerve sheath tumours (in patients with NF1 and NF2) Desmoid-Type (Aggressive) Fibromatosis, patients with other rare potentially life threatening tumours seen, with the discussion and agreement with the managing consultant. This document also includes seeing patients undergoing diagnostics when referred on the 2 week wait pathway and other referral sources (radiology flag, consultant upgrade, referral from EMSS and other MDTs) with a potential malignant diagnosis. (See guide for primary care ultrasound screening Appendix1)

Guidance for suspected musculoskeletal malignancy in fracture clinic (see Appendix 2) is also made available in fracture clinics as an aid memoire for clinicians.

Whilst these guidelines primarily refer to the diagnostic and surgical pathways they also include the management of patients requiring oncological treatments and surveillance who are managed by the Sarcoma Oncologist in the Trust. Please see 3.2.4. – Macmillan Sarcoma Clinical Nurse Specialist Telephone Clinic (APTC)

2. Scope

This document applies to all consultants, junior medical staff, nursing staff and administration staff responsible for the care of Sarcoma patients University Hospitals of Leicester NHS Trust (UHL).

3. Recommendations, Standards and Procedural Statements

3.1. Aims of the Service

To provide safe and cost effective combined clinics agreed with the patient and sarcoma consultant in accordance with the British Sarcoma Guidelines 2016 for Soft tissue and bone follow up guidelines

Appendix 2 Guidance for clinicians in Fracture Clinic for suspected musculoskeletal malignancy

Hyperlink – press on link for UK guidelines for the management of soft tissue sarcomas

https://clinicalsarcomaresearch.biomedcentral.com/track/pdf/10.1186/s13569-016-0060-4.pdf

Hyperlink BSG Guidance for screening of soft tissue masses in the trunk and extremity

http://www.britishsarcomagroup.org.uk/wp-content/uploads/2019/01/BSG-guidance-for-ultrasound-screening-of-soft-tissue-masses-in-the-trunk-and-extremity-FINAL-Jan-2019.pdf

- To provide an effective and safe service to identify and act on any new symptoms that may require clinical review, abnormal or worrying radiology, informing the named consultant and other MDT members as needed.

- To communicate the outcome of the clinic to both the patient and General Practitioner.
- To provide information and education to patients on self –management regarding their condition and to explain the rationale for on-going surveillance in the clinic.
- To offer a risk stratified follow up service individualised to the patient's disease and appropriate circumstances. This potentially reduces cost and time to patients and the service (Thus improving the patient experience).

3.2 Profile of Consultant/Sarcoma CNS clinic

The clinic is for attending patients requiring clinic consultations for a new patient episode, follow up information of investigations being arranged and the giving of results in person or telephone follow up (with the patients consent). In addition, the clinic is for patients requiring dressings and wound review, possible recurrence, standard sarcoma/tumour surveillance.

The clinic takes place once a week for 1 session on a Monday and Tuesdays afternoon. Both clinics run concurrently with a consultant and CNS clinic. But when the sarcoma surgeon who is on leave, the CNS ensures medical supervision and advice/review of cases is sought through other medical colleagues,

The Telephone clinic – is allocated 5 slots per week, clinic code RATC (Robert Ashford Telephone clinic)

Face to face slots are allocated 5 minutes per slot. Clinics are coded as follows:

RASC, RASCN, RASC2WW, RASCREG, RASCDR, RATC and RASCT- Tuesday follow up clinic.

Patients can be referred to the clinic by a Consultant Surgeon. The referring clinician is responsible for ensuring that the patient meets the inclusion criteria, these will be new patients and follow-up patients at their first appointment undergoing diagnostics referred on a 2ww pathway where sarcoma is suspected. On the Tuesday clinic, the patient seen will be post treatments requiring standard sarcoma follow up appointments.

Follow-Up Schedule

Soft Tissue Sarcoma Reference

Hyperlink UK guidelines for the management of bone sarcoma

https://sarcoma.org.uk/sites/default/files/uk_guidelines_for_the_management_of_bone_sarcomas_0.pdf

Hyperlink –UK guidelines for the management of soft tissue sarcomashttps://clinicalsarcomaresearch.biomedcentral.com/articles/10.1186/s13569-016-0060-4

See Appendix 1 EMSS Follow-Up Strategy for Soft Tissue Sarcomas

Year 1 – 2 patients will be reviewed every 3 monthly frequently if clinically indicated

Year 2 - 5, patients will be reviewed 6 monthly

Year 5 -10 years, patients will be reviewed annually

Year 10 - Discharged from routine follow-up

Patients can be seen at short notice should they be experiencing new symptoms. They can contact the Clinical Nurse Specialist (CNS) via telephone to arrange this.

3.2.1. Inclusion Criteria

- Patients with new soft tissue lump
- Patients with other rare benign tumours and pre-malignant borderline tumours (with a potential to become malignant requiring close follow up.
- Post treatment patients (surgery, radiotherapy, chemotherapy and other medication)

3.2.2. Exclusion Criteria

- Patients with proven benign tumours.
- Other malignant tumours that are not sarcoma – will be referred to relevant clinical team
- When the consultant states patient should not be reviewed in clinic
- Patient choice not to be followed-up by the CNS in clinic

3.2.3. Process Summary

1. The referring clinician within the sarcoma team will request an appointment (new / follow up) for RATC or RASCT clinic on the outcome sheet after the patient has been seen at their consultant review or discussed with the CNS following MDT and if results can be given via telephone clinic instead of a follow up appointment
2. The Clinic Coordinator is responsible for booking the patients appointment
3. The clinician can only refer patients who meet the inclusion criteria and must discuss exceptions with the Clinical Nurse Specialist (CNS) prior to booking the patients appointment
4. The patient will be given information about the clinic and what to expect in consultation with the CNS
5. The patient will leave the clinic with their next appointment or an outcome agreed with the clinic staff.
6. The Clinic Coordinator will prepare medical records for the clinics.
7. On attending clinic, the following assessments may be made:
    - Assessment of post-operative recovery including: pain, wound healing, management of other related symptoms to radiotherapy, chemotherapy and/or surgery
    - Inspection and examination of signs of recurrent tumour, symptoms including: new lump, pain/discomfort skin changes, mechanical problems, deformity, swelling, lymphoedema, altered sensation, referred pain, cement issues, prosthesis issues
    - Assessment for symptoms that may indicate relapsed disease, including: unintentional weight loss, loss of appetite, fatigue, anaemia failure to thrive, breathlessness, new persistent pain/discomfort and other constitutional symptoms
8. Other investigations if indicated in consultation with the Consultant will be taken to include:

    Routine blood tests to monitor Full Blood Count, Urea and Electrolytes, Liver Function Tests, CRP, Clotting, other Tumour markers

    Imaging, X-ray, Ultrasound, MRI, CT scan, Bone scan, PET CT
9. An Electronic/Paper Holistic Needs Assessment (eHNA) will be offered to the patient if appropriate by offering the patient a passcode to complete this at home
10. The CNS record the offer of an eHNA on the Trust Cancer Patient Information System and provide a subsequent care plan should the patient complete their eHNA.

11. Clinic letter will be dictated by the Clinical Nurse Specialist (CNS) within 48Hours.
12. A copy of the letter is sent to the patients GP and the patient and a copy is filed in the patient's medical record also copying in the referred of out of Trust.
13. If patient results are stable and no new symptoms are reported the CNS will schedule the patient's next appointment in line with the agreed follow up schedule, as per sarcoma follow up guidelines.
14. If the patient has reported symptoms, the Clinical Nurse Specialist (CNS) will organise appropriate investigations in consultation with managing consultant. The outcome of the consultation and conversation will be documented in the clinic letter.
15. If the patient required immediate assessment based on clinical findings, in consultation of the managing clinician, the patient may be referred to the next available sarcoma clinic slot

    Dictated letters to the GP will include;

- Diagnosis
- Treatment
- Managing Consultant
- Summary of Consultation
- Action required by GP
- Further follow up schedule for patient

16. A chest radiograph form will be given to the patient for their next appointment The outcome sheet from Outpatients will be handed to the clinic coordinator to make the next follow up date of the next appointment.
17. The clinic will continue when the CNS has planned leave and only patient information and support needs will be met by the covering CNS (Neuro-Oncology).The medical team will see the patients.
18. If there is no medical presence available for the sarcoma clinic, clinics lists are either reduced or cancelled. If there is a reduced clinic the consultant and CNS agree in advance the patients to be seen. Any advice needed in the managing consultant's absence the CNS would seek advice and support from sarcoma colleagues in Nottingham or the registrar working with the sarcoma team as part of their rotation.

<u>Triggers for discussion with Consultant</u>

- Signs of significant wound infection, formation of a seroma or other wound issues
- Uncontrolled and / or increasing pain
- New or worsening symptoms
- Unexplained weight loss with no intention or reason
- Unrelated symptoms CNS should suggest patient should self-refer to GP and alert GP of symptom in letter

4.0. Macmillan Sarcoma Clinical Nurse Specialist Telephone Clinic (APTC)

This is a joint telephone clinic developed by the CNS and Consultant Oncologist to support patients who need advice and potential interventions and tests that can be agreed without attending a face to face appointment.

The telephone clinic slots are made available weekly (5 slots) and booked as required by the Oncologist and / or CNS based upon valid clinical reason warranting a telephone review/consultation.

The Oncologist and CNS will discuss and agree a patient's management plan if any tests and investigations are required and communicate the outcome of the discussion with the patient over the telephone.

A letter will be dictated by the Clinical Nurse Specialist (CNS)within 7 working days.

A copy of the letter is sent to the patients GP and the patient and a copy is filed in the patient's medical record.

All letters dictated to the GP will include;

- Diagnosis
- Treatment
- Managing Consultant
- Summary of Consultation
- Action required by GP
- Further follow up schedule for patient

The Clinic coordinator will be contacted to add the patient to LJS11 clinic

4.1 Inclusion criteria

- Patients in current sarcoma follow up who may develop new symptoms and need investigation earlier than a scheduled OPA. Patient may call thus adding patient to this APTC
- Patients on oral medications, who need a clinical assessment to check the effectiveness of the drug and potential side effects
- Patients discussed at the Sarcoma MDT – who require information about next steps, tertiary referral, more investigations
- Results over the phone – providing the patient is happy to receive news in this format.

All issues and concerns raised via the telephone clinic are discussed with the Oncologist responsible for the patient.

If the CNS is on planned leave, the slots are not utilised. Any patient queries are directed to the Oncologist.

If the consultant is on leave, then the CNS seeks advice from the Oncologists working within the sarcoma team or from the wider team with EMSS.

5. Discharge

At the end of year 10 post treatment follow up, patients, classed as cured (malignant/benign), will be discharged for management within Primary Care. The clinical nurse specialist (CNS) will generate a treatment summary in discussion with the managing consultant which will be given to the patient in clinic, a copy will also be sent to the will set to the GP along with the discharge letter.

Patients will be given open access to the clinic in the long term and encouraged to communicate with their GP

6. Education and Training

The CNS responsible for the nurse led clinic will have specialist knowledge, skills and experience in caring for patients who require follow –up following sarcoma treatment to provide patients with a safe guideline based service to monitor their progress and recovery post treatment.

In order to provide specialist care in this rare cancer, CNS training undertaken will include:

- University accredited consultation skills course
- Completion of all skills and competencies signed off.
- Imaging Couse to be able to view and interpret plain films x-ray's under supervision of the Sarcoma Consultant / Radiologist
- Completion of the Trust non-medical imaging referrer's course
- Completion of Non-medical prescribers course

This is nationally practiced at the 16 NICE accredited sarcoma units in the UK by sarcoma specialist nurses.

The CNS must ensure that they adhere to The NMC Code (2015) and recognise and work within the limits of their competence.

CPD will be undertaken to increase knowledge of the sarcoma specialty and develop clinical expertise. This can be achieved through the following:

- Attending relevant study days/courses/conferences
- Visits to/observation of specialist clinics at other centres
- Feedback/audit from colleagues and patient satisfaction
- Reflective practice
- Revalidation of competencies

7. Monitoring and Audit Criteria

Key Performance Indicator	Method of Assessment	Frequency	Lead
Patient experience	Patient survey / audit	Three yearly	Clinical Nurse Specialist
Number of Holistic Needs Assessments completed	Analysis from Macmillan eHNA	Annually	Clinical Nurse Specialist
Number of Care Plans completed	Analysis from Macmillan eHNA	Annually	Clinical Nurse Specialist
7 of days between consultation and sending clinic letter.	Finalisation of the letter on DIT3	Annually	Clinical Nurse Specialist

8. Key Words

CNS Clinical Nurse Specialist
GP General Practitioner
EMSS East Midlands Sarcoma Service
STS Soft Tissue Sarcoma
HNA Holistic Needs Assessment

<table>
<tr><th colspan="3">CONTACT AND REVIEW DETAILS</th></tr>
<tr><td>Author / Lead Officer:</td><td>Anita Pabla, Macmillan Sarcoma Clinical Nurse Specialist</td><td>Executive Lead: Andrew Furlong, Medical Director</td></tr>
<tr><td>Details of Changes made during review:</td><td colspan="2"></td></tr>
</table>

East Midlands
Sarcoma Service

APPENDIX 1 TO UHL GUIDELINE B37/2020

EMSS FOLLOW-UP STRATEGY FOR SOFT TISSUE SARCOMAS

Stage of Disease	*Year*	*Disease Monitoring*
Localised Extremity Tumour treated by surgery +/- radiotherapy		
ALT	Year 1 – 2	3 monthly Clinical Examination for year 1 and 6 monthly for year 2. Consider MRI 3/12 post-surgery for large, deep, impalpable tumours as baseline Surveillance MRI as clinically indicated.
GRADE I TUMOURS $ (Excluding ALT)		
	Year 1	6/52 post-operative check 3 monthly Clinical Examination & CXR MRI 3/12 post-surgery for impalpable tumours as baseline
	Year 2	6 monthly Clinical Examination & CXR
	Years 3+	Annual Clinical Examination & CXR for minimum of 10 years
GRADE II AND III TUMOURS $		
	Year 1	6/52 post-operative check or 4/52 post-radiotherapy check 3 monthly Clinical Examination, CXR Baseline MRI 3 months after completion of treatment
	Year 2*	3 monthly clinical examination & CXR
	Years 3-5*	6 monthly clinical examination & CXR
	Years 6-10*	Annual clinical examination & CXR

$ Surveillance MRI in addition to other surveillance where indicated: eg. Tumours at high risk of local recurrence, Tumour sites difficult to assess clinically and where surgical margins are compromised by anatomy (neurovascular bundle etc)

* Where treatment has been multi-modality, appointments should be alternated between Sarcoma Surgeon and Sarcoma Oncologist

East Midlands
Sarcoma Service

EMSS FOLLOW-UP STRATEGY FOR RETROPERITONEAL SARCOMAS

Abdominal, Retroperitoneal & Gynaecological Sarcomas post-surgery		
GRADE I	Year 1-2	6 monthly clinical examination Annual CXR CT chest/abdo/pelvis if clinically indicated
	Year 3-10	Annual clinical examination & CXR CT chest/abdo/pelvis if clinically indicated
GRADE II & III	Year 1	3 monthly clinical examination and CXR Baseline CT chest/abdo/pelvis at 3 months post-surgery then at 12 months
	Year 2 - 4	6 monthly clinical examination and CXR CT chest/abdo/pelvis at 24 & 36 months
	Year 5 - 10	Annual clinical examination & CXR CT chest/abdo/pelvis if clinically indicated

East Midlands
Sarcoma Service

EMSS STAGING STRATEGY FOR SARCOMAS

Baseline Investigations	
ALT	CXR Only
Upper Limb Sarcomas	CT Chest
Lower Limb, Intra-Abdominal and Retroperitoneal Sarcomas	CT Chest / Abdomen & Pelvis
Additional Staging for Specific Pathological Subtypes	
Rhabdomyosarcoma	Isotope Bone Scan
Soft-Tissue Ewing's Sarcoma	Isotope Bone Scan
Angiosarcoma	Brain Imaging
Clear Cell Sarcoma	Brain Imaging
Sarcoma of Soft Parts	Brain Imaging
Myxoid Liposarcoma	WB MRI

Whole Body MRI & PET-CT Indications

Investigation	Indications
WB-MRI	Myxoid liposarcoma Unusual metastatic pattern
PET-CT	Pre-ablation Pre-metastatectomy NF1 for occult / assessment of MPNST

All requests for WB MRI and PET-CT should be ratified by the MDT

Guidance for clinicians in Fracture Clinic for suspected musculoskeletal malignancy.

Suspected Primary Bone Malignancy

- Radiograph whole bone
- CXR
- Bloods: FBC, U&E, LFT, BONE profile, LDH, CRP & Clotting: INR and APTT
- Request 2ww MRI whole bone
- Email cancercentresarcoma@uhl-tr.nhs.uk patient details. Copy Mr Ashford & Anita Pabla
- Refer to Specialist Centre: RNOH Stanmore) or ROH (Birmingham). Electronic referrals can be found on their hospital websites

Suspected Primary Soft Tissue Sarcoma (Worrying lesions – not a large lipoma)

- Red flag symptoms: >4cm, deep, painful, growing, PMH cancer, worrying features on USS
- Examine lymph node basin
- US whilst in clinic if possible (telephone I/P radiology Hub on ext 6969)
- Bloods as above
- Request MRI as 2ww
- Email cancercentresarcoma@uhl-tr.nhs.uk patient details. Copy Mr Ashford & Anita Pabla
- For advice telephone Anita Pabla (Sarcoma CNS): 07949678934
- Ensure follow up appointment booked in Mr Ashford's clinic.

Suspected Bone Metastases (non-spinal)

- Examine patient: Lymph nodes, breasts, thyroid. Look for a primary, if not known to have one.
- Bloods: Full set of bloods to include FBC, U&E's, Bone profile, LFT's, LDH, Lactate, CEA, CA125 (female only) PSA (male only). Also myeloma screen blood test (use immunology form and request SFL (Serum free Light chain).
- Imaging:
  - Request a chest x-ray if suspicious for lung cancer (smoking history, breathing problems, cough).
  - Whole bone radiograph
  - Request Cancer 2WW CT CHEST, ABDOMEN AND PELVIS: (Must write Cancer 2WW) on the radiology request form.

If known cancer : Email relevant cancer centre mailbox on global email, cc Lara Mitchell & Mr Ashford
If no known primary: Email cancercentrecup@uhl-tr.nhs.uk cc. Lara Mitchell & Mr Ashford

- Book patient to be seen back in your clinic for results in 2/52.

Are you listing/admitting patient for theatre? Please ensure bone biopsy taken (not just reamings) for histological diagnosis

Ring Metastatic Bone Disease CNS if needed for advice: 07960 868428 (Monday Tuesday, Wednesday, Friday 9am-5pm)

Ring Acute Oncology For Advice if needed: 07908 178232 (Monday- Friday 9am-5pm, outside of hours bleep Oncology SPR on call).

How to organise cancer 2ww scans

Fax request to 3349 then telephone ext 2263 to confirm receipt of request and to allocate appointment. You will need a recent eGFR
Do this whilst patient is still in clinic and give them the appointment.

Leicester Orthopædics