Pan London and South East Sarcoma Network Referral Guide

**SPECIALIST SARCOMA CENTRES:**

There are three SPECIALIST SARCOMA CENTRES for London:
- ROYAL MARSDEN HOSPITAL (soft tissue sarcoma at all sites)
- ROYAL NATIONAL ORTHOPAEDIC HOSPITAL (all bone sarcoma, soft tissue sarcoma of limb/trunk/spine)
- UNIVERSITY COLLEGE LONDON HOSPITAL (soft tissue sarcoma non-limb / trunk: e.g. head & neck, retroperitoneal, abdominal, urology, breast, skin)

**ADULT REFERRAL PATHWAY:**

For adults with suspected SOFT TISSUE or BONE SARCOMA:
- The GP should discuss the patient with the sarcoma team and refer the patient to the appropriate specialist sarcoma centre **USING THE PAN LONDON AND SOUTH EAST SARCOMA NETWORK REFERRAL FORM** for an appointment within two weeks.

**PAEDIATRIC REFERRAL PATHWAY:**

For children (under 16) with suspected SOFT TISSUE SARCOMA:
- The GP **MUST ALWAYS DISCUSS THE PATIENT WITH THE LOCAL PAEDIATRICIAN ON CALL** and refer the patient to the local paediatric department **USING THE PAN LONDON SUSPECTED CHILDRENS CANCER REFERRAL FORM** for an appointment within 48 hours

For children (under 16) with suspected BONE SARCOMA:
- The GP should refer the patient to the appropriate SPECIALIST SARCOMA CENTRE (RNOH) **USING THE PAN LONDON AND SOUTH EAST SARCOMA NETWORK REFERRAL FORM** for an appointment within 48 hours

**RESOURCES:**

5. Sarcoma UK [http://sarcoma.org.uk](http://sarcoma.org.uk)
## Risk Factors

### Bone Sarcoma
- Retinoblastoma, Paget’s disease of the bone, bone exposure to ionising doses of radiation, Li-Fraumeni syndrome, hereditary multiple exostoses, Ollier’s disease or Mafucci’s disease

### Soft Tissue Sarcoma
- Prior radiotherapy, Li–Fraumeni syndrome, neurofibromatosis, familial adenomatosis polyposis (Gardner’s syndrome)

## Diagnostic Imaging

### Bone Sarcoma
- Diagnostic imaging may be helpful in evaluating the clinical presentation but X-ray changes may not appear in the early stages of the disease and a normal or equivocal X-ray does not exclude sarcoma and may give false reassurance / delay diagnosis. **To establish a diagnosis CT/MRI scan is the most accurate investigation.** For adults, the GP may wish to seek advice from the radiology service and arrange further imaging if they have urgent direct access. To avoid delay, when there are clinical concerns of a bone sarcoma in adults and children, the patient should be referred urgently to the appropriate sarcoma service where imaging and tissue diagnosis will be organised.

### Soft Tissue Sarcoma
- To avoid delay, when there are clinical concerns of a soft tissue sarcoma in adults, the patient should be referred urgently to the appropriate sarcoma service where imaging and tissue diagnosis will be organised.
  - **Consider an urgent direct access ultrasound scan,** to be performed within 2 weeks, to assess for soft tissue sarcoma in adults with an unexplained lump that is increasing in size
  - **Consider a suspected cancer pathway referral,** for an appointment within 2 weeks, for adults if they have ultrasound scan findings that are suggestive of soft tissue sarcoma OR if ultrasound findings are uncertain and clinical concern persists

If the ultrasound scan does not confidently confirm a benign diagnosis, then the patient should be referred for further investigation on an urgent suspected cancer pathway referral.

**To establish a diagnosis CT/MRI scan is the most accurate investigation.**

Discussion with a specialist (for example, by telephone or email) should be considered if there is uncertainty about the interpretation of symptoms and signs, and whether a referral is needed. This may also enable the primary healthcare professional to communicate their concerns and a sense of urgency to secondary healthcare professionals when symptoms are not classical.

For children, the GP should discuss with the local paediatric service and refer for an appointment within 48 hours.
Pan London and South East Sarcoma Network Referral Guide

<table>
<thead>
<tr>
<th>REFERRAL CRITERIA:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>REFERRAL CRITERIA FOR BONE SARCOMA:</strong></td>
<td><strong>REFERRAL CRITERIA FOR SOFT TISSUE SARCOMA:</strong></td>
</tr>
<tr>
<td>- Refer the patient to a Sarcoma Diagnostic Service with abnormal imaging which is suggestive of bone sarcoma</td>
<td>- Refer the patient with a soft tissue mass to a Sarcoma Diagnostic Service with an up-to-date ultrasound or MRI which suggests soft tissue sarcoma</td>
</tr>
<tr>
<td>- Refer patients with the following clinical features:</td>
<td>- Do not have access to urgent direct access USS/MRI (within 2 weeks) and there is a high clinical suspicion of sarcoma.</td>
</tr>
<tr>
<td></td>
<td>- Recurrence following excision (please specify on the referral form)</td>
</tr>
<tr>
<td></td>
<td>- CLINICAL CONCERNS that do not meet NICE/Pan-London referral criteria</td>
</tr>
<tr>
<td></td>
<td>- The GP MUST give full clinical details in the ‘additional clinical information’ box at the time of referral.</td>
</tr>
<tr>
<td></td>
<td>- The GP MUST give full clinical details in the ‘additional clinical information’ box at the time of referral and WE STRONGLY ADVISE YOU TO DISCUSS PATIENTS WHO HAVE NO PRIOR IMAGING WITH THE SARCOMA CENTRE BEFORE REFERRAL.</td>
</tr>
<tr>
<td>o UNEXPLAINED bone swelling or tenderness with pain, especially if disturbing sleep and pain not responding to simple analgesia</td>
<td><strong>Former NICE Guidance:</strong></td>
</tr>
<tr>
<td>- Normal or equivocal x-ray but high clinical suspicion of bone sarcoma</td>
<td>Refer the following patients</td>
</tr>
<tr>
<td>- CLINICAL CONCERNS that do not meet NICE/Pan-London referral criteria (the GP MUST give full clinical details in the ‘additional clinical information’ box at the time of referral)</td>
<td>- Clinical features: UNEXPLAINED soft tissue lumps with the following features:</td>
</tr>
<tr>
<td></td>
<td>o Increasing in size</td>
</tr>
<tr>
<td></td>
<td>o Deep to fascia</td>
</tr>
<tr>
<td></td>
<td>o Fixed/immobile</td>
</tr>
<tr>
<td></td>
<td>o Painful</td>
</tr>
<tr>
<td></td>
<td>o &gt;5cm in size (i.e. about the size of a golf ball)</td>
</tr>
<tr>
<td></td>
<td>- Abnormal imaging suggestive of soft tissue sarcoma</td>
</tr>
<tr>
<td></td>
<td>- Recurrence following excision</td>
</tr>
<tr>
<td></td>
<td>- Normal or equivocal ultrasound but clinical suspicion of soft tissue sarcoma</td>
</tr>
</tbody>
</table>

**SUSPECTED SARCOMA REFERRAL TO SPECIALIST SARCOMA CENTRE**

**ADULTS (SUSPECTED BONE AND SOFT TISSUE SARCOMA): FOR AN APPOINTMENT WITHIN 2 WEEKS.**

**CHILDREN (UNDER 16 WITH SUSPECTED BONE SARCOMA): FOR AN APPOINTMENT WITHIN 48 HOURS**

April 2018

Pan London and South East Sarcoma Network Referral Guide
Please do not refer the following benign conditions using the sarcoma 2WW form:

- subcutaneous lipomas
- sebaceous cysts/epidermoid cyst
- ganglions
- giant cell tumours of the tendon sheath
- pigmented villonodular synovitis (PVNS) of a joint
- post-traumatic or inflammatory phenomena such as fat necrosis, abscess
- fibromas
- normal variant anatomy
- lymphangiomas/haemangiomas/all vascular malformations
- chest wall/rib asymmetry
- tenosynovitis of the wrist (for wrist mass)
- sternoclavicular joint degeneration