Soft Tissue Sarcoma Local Diagnostic Pathway

Service Specification No.	
Service	Soft tissue sarcoma Local Diagnostic Services
Commissioner Lead	NHS England region – London (for London's STS diagnostic services)
Tertiary Provider Leads	Royal Marsden Hospital/ London Sarcoma Service
Period	2023/24
Date of Review by the SAG	September 2024

1. Population Needs

Introduction

1. Sarcomas are rare cancers accounting for only 1% of all adult malignancies. Diagnosis is often delayed, and treatment is often intensive and morbid. To improve outcomes and diagnosis, treatment is centralised in specialist centres.

2. The London and South East Sarcoma Network (LSESN) comprising of The Royal Marsden Hospital (RMH) and The London Sarcoma Service (LSS) (a collaborative between University College London Hospital and The Royal National Orthopaedic Hospital) deliver all surgical treatment and oversee diagnostic, chemotherapy and radiotherapy services for patients with soft tissue and bone sarcomas in London, parts of the East of England (EoE) and South East England (SEE) regions.

3. The LSESN was established to ensure that patients who have been diagnosed with or have a suspected sarcoma can access specialist diagnostic and treatment services at one of two specialist sarcoma centres serving the network.

4. Sarcomas are categorised as either bone or soft tissue sarcomas.

5. There are multidisciplinary clinical teams for soft tissue sarcomas at RMH, and both bone and soft-tissue sarcomas at LSS.

6. The most useful initial diagnostic test for a bone sarcoma is an X-ray. However, some patients with normal x-rays and a high suspicion of bone sarcoma require an MRI before referral to a tertiary centre.

7. Diagnosis of soft tissue sarcoma usually requires an initial ultrasound carried out by an appropriately trained practitioner. For masses where there is continuing concern, MRI reported by a specialist radiologist, and biopsy carried out by an appropriately trained clinician and reviewed in an appropriate pathology laboratory.

8. The NHS England specialised services Sarcoma Service Specification Sarcoma-Service-Specification.pdf (england.nhs.uk) (2019) mandates that care is delivered through organised Sarcoma Networks, co-ordinated through Sarcoma Advisory Groups (SAGs). The service model is based on partnerships between Specialist Sarcoma Centres and Local Diagnostic Services.

9. The London & South East Sarcoma Network's diagnostic pathway document has been co-produced with the tertiary services, local diagnostic services within the SAG, and commissioners. It should be implemented in conjunction with the national service specification. Key features of the LSESN's diagnostic pathway, including the minimum number of 2ww sarcoma referrals per week and the makeup of the local diagnostic service team, are based on clinical opinion provided by the SAG in December 2022. The commissioning of London local diagnostic clinics in 2023/24 has been based on this clinical opinion. The LSESN pathway document was approved by the SAG in July 2023 and is due for review in June 2024, alongside its list of designated diagnostic practitioners.

Scope

10. This pathway document describes the specification of a local sarcoma diagnostic service (LDS), an outline of the personnel and services required to deliver the pathway, and the proposed configuration of these services within the geography of the LSESN.

11. The pathway applies to sarcoma in patients aged 16 years and over. Paediatric patients must be referred to a tertiary centre directly.

12. Any local deviation from the pathway will need to be approved via the SAG and responsible commissioner/s.

13. All pathways will be expected to be compliant with Cancer Waiting Times (CWT) guidance and providers to meet the data requirements of COSD including stage at diagnosis.

14. The service is commissioned between the relevant NHS England Region and the relevant tertiary centre. The tertiary centre sub-contracts the service to the local diagnostic service.

2. Pathway

Soft Tissue Sarcomas

15. As the geography covered by the network is large, it is important that where possible referred patients can access parts of the diagnostic pathway closer to home to minimise the need to travel to a tertiary centre.

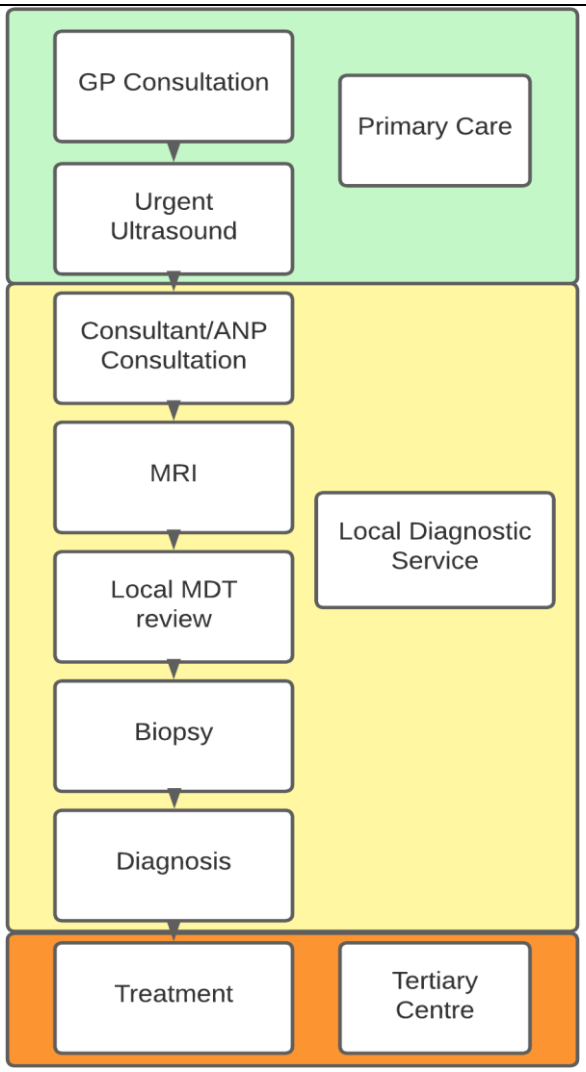


Figure 1 – Outline diagnostic pathway for suspected soft tissue sarcoma

16. The purpose of LDSs is to accept Urgent Cancer Referrals using the Pan-London Suspected Cancer referral form from GPs that include an urgent ultrasound report indicating suspicion of sarcoma. There are permissible exceptions to this policy detailed in the referral form and guidance on dealing with common scenarios is given below (see Exceptions).

17. The overriding principle of the Improving Outcome Guidance (IOG) is that any patient with a suspected or possible soft tissue sarcoma needs to follow a clear and rapid pathway to diagnosis, and those with a confirmed sarcoma need to be referred promptly to a sarcoma treatment centre for further management.

18. For soft tissue sarcomas the principal problem in diagnosis is the large number of soft tissue lumps that are indeterminate on initial ultrasound.

19. In order to exclude these patients, the diagnostic clinics will undertake a diagnostic process outlined in the flowchart below. Some variation in the process is permissible to suit local arrangements. For example, some sites choose to carry out a telephone consultation and review of imaging before arranging an MRI, some sites choose to MRI most referrals and review the MRI

report and ultrasound in an MDT before seeing them in clinic and carrying out a biopsy. In geographic areas where it is available, GPs may choose to request direct access to MRI before referring to an LDS. See Appendices 2 and 3 for details of specific pathways at existing LDSs.

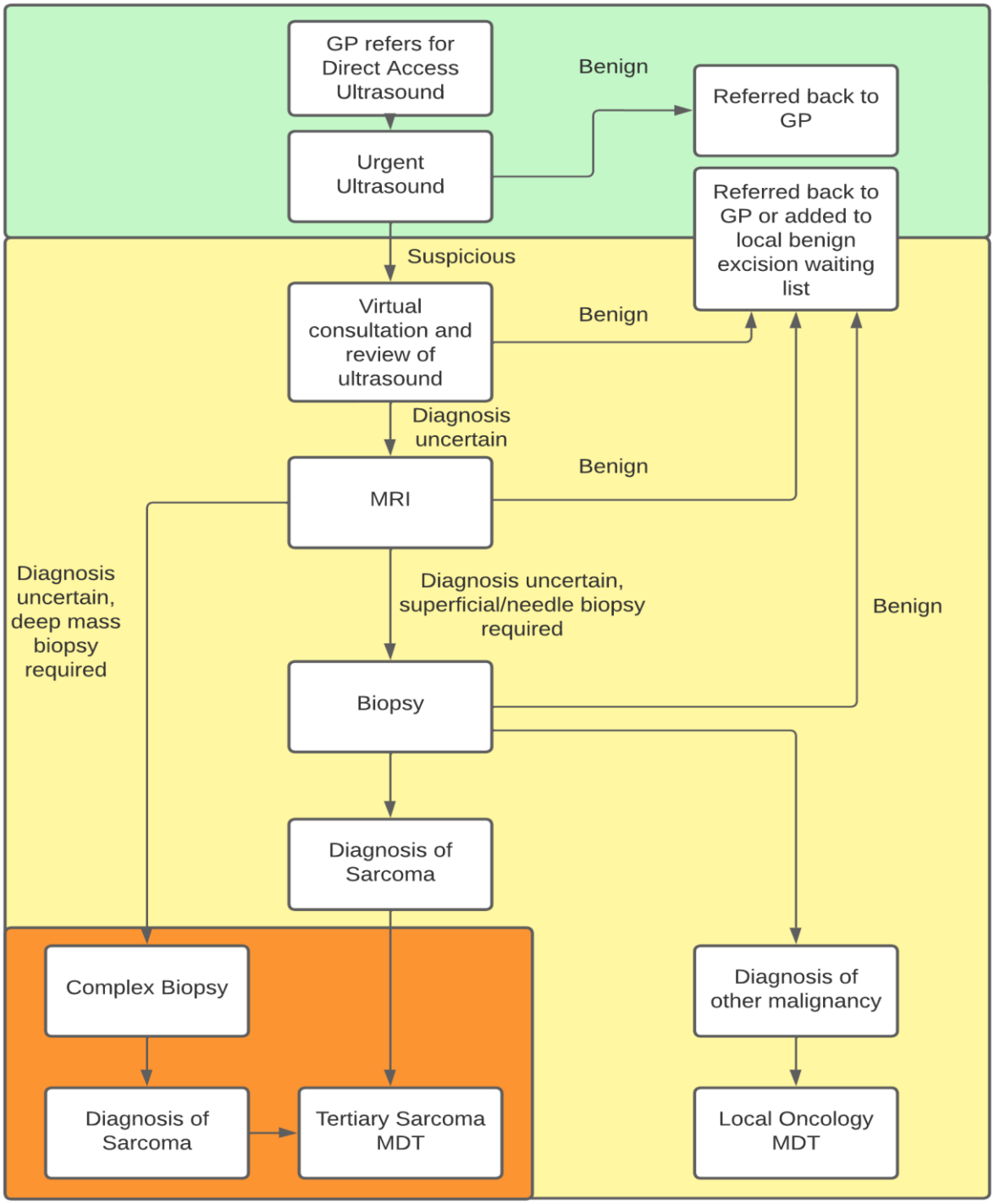


Figure 2 – Detailed diagnostic pathway

Key steps:

20. *Assessment*
    LDSs should assess referrals from the GP including accompanying imaging and carry out an initial telephone consultation with the patient.

21. *MDT*
    LDS are not expected to receive enough referrals to warrant a separate Sarcoma MDT. LDS' should make arrangements for patients to be discussed at existing MDTs (examples include rapid diagnostic clinics, colorectal, endocrine and plastics). The LDS 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 sMDT discussion. The LDS should comply with all CWT standards and FDS up to the point of transfer and transfer in line with any Inter Trust transfer policy.

22. *MRI*
    The LDS must offer on-site MRI for all patients unless the patient has had a previous MRI as part of their suspected sarcoma diagnostic process.

23. Where possible this should be offered on the same day as any biopsy and outpatient appointment to speed up the diagnostic process and reduce patient travel.

24. This MRI should be delivered as part of the LDS core offering rather than outsourced capacity.

25. *Biopsy*
    An appropriate biopsy procedure should be undertaken at the local 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.

26. In all other scenarios, the LDS should consult with a tertiary centre before carrying out the procedure and refer the patient on to the tertiary centre if the biopsy cannot safely be carried out locally.

27. Biopsies performed in a local diagnostic centre in which there is histopathological suspicion of a sarcoma are then analysed at a sarcoma centre.

28. Pathology for all sarcomas must be reviewed by a Specialist Sarcoma Pathologist for diagnostic confirmation and undertaking any appropriate molecular analysis (National Service Specification, 2019).

29. Clinicians who are appropriately trained (see Paragraph 40, below) and have received competency sign off by the tertiary centre can undertake these procedures.

30. *Breaking bad news*
Where a patient is diagnosed with cancer by the LDS, they must have a contact with the designated nurse to be informed of the diagnosis. The nurse will then become their key worker until their care is transferred to a tertiary centre for treatment.

31. *Onward referral*
Where a patient is diagnosed with cancer by the LDS, the patient should be offered the option of being referred to either tertiary centre (RMH or LSS). Similarly, if the patient requires a biopsy that must be carried out in a tertiary centre, the patient should be offered their choice of tertiary centre. In both cases, referrals should be made as inter-provider transfers (IPT).

Exceptions

32. The NICE NG12 (NICE, 2015) guidelines state that referrals for sarcoma should be accompanied by an ultrasound examination indicating possible sarcoma. There are three common exceptions.

33. *Referral without accompanying imaging (obvious pathology)*
If the evidence of malignancy is so obvious that arranging diagnostics would only delay the pathway, the patient should be referred onward to the relevant tertiary centre as soon as possible. The referral must provide as much clinical information for rapid assessment.

34. *Referral without accompanying imaging (no obvious pathology)*
It is not possible under Cancer Wait Time guidance to outright reject referrals that do not have accompanying imaging. Once the referral is received in secondary care the LDS should carry out an ultrasound and subsequent diagnostics as required to diagnose or rule out cancer.

35. *No evidence of malignancy on review of ultrasound*
If the LDS radiologist is satisfied that the accompanying ultrasound does not indicate any risk of malignancy, the patient may be discharged following a virtual consultation with a qualified professional in which a patient's full symptoms are considered (CWT version 11.1).

3. Local Diagnostic Service MDT

36. Local MDT
Each LDS will have a multidisciplinary workforce to deliver a full holistic service to patients with suspected sarcoma. Some variation in the types and grades of staff is permitted, though there are core responsibilities that must be fulfilled. These are;

- a consultant clinician who is the designated service lead

- a nurse to be present in all consultations involving breaking bad news
- an MDT coordinator to ensure full compliance with CWT rules

37. *Sarcoma Radiologist*
    A radiologist with a sub-specialty in Musculo-Skeletal (MSK) radiology that attends the local sarcoma MDT. Responsibilities include:
    - Review ultrasound reports received as part of urgent cancer referrals
    - Reporting MRIs of sarcoma patients
    - Attend local MDT and actively contribute to discussion and planning of on-going pathway

38. *Consultant surgeon with special interest in sarcomas*
    A consultant with a specialist interest in sarcomas whose wider practice includes biopsy and management of patients on urgent cancer referral pathways.
    - Provide clinical supervision for the CNS (below)
    - Deliver outpatient clinics and biopsies for patients on the sarcoma pathway.

39. It is possible for the service to be delivered entirely by radiologists if they have been certified as competent to undertake relevant biopsies by their associated tertiary service. Services should avoid having a single doctor responsible for the service to ensure resilience and cover for planned and unplanned absence.

40. *Lead Clinician*
    The service requires a lead clinician to take overall responsibility for the performance and clinical effectiveness of the local diagnostic service.

41. They will provide leadership and support to medical colleagues in the provision of specialist diagnostic sarcoma care within the trust and in collaboration with the Sarcoma MDT (at RMH or LSS), and work in partnership with the London & South East Sarcoma Network's Sarcoma Advisory Group (SAG) to contribute to the strategic development of sarcoma services within the Trust and Sarcoma Network.

42. Responsibilities are to:
    - Coordinate care for patients with suspected sarcoma referred into their service. This will include:
    - Agree policies with SAG for presentation, diagnostic, treatment and follow up pathways
    - Agree the provision of services including diagnostic clinics
    - Represent the local service at the SAG
    - Liaise with the tertiary sarcoma centre to:
        i. Establish a pathway for management of patients with sarcoma
        ii. Establish a process for registration of all new patients diagnosed within the service

iii. Establish for each patient, in discussion with the SMDT, responsibility for each component of the patient pathway.
iv. Ensure that systems are in place for the diagnosis and onward referral of patients referred with symptoms of soft tissue sarcoma of the limbs and trunk wall, and that this is to enable swift onward referral and compliance with cancer waiting time times.

- Ensure that systems are in place for patients without a sarcoma diagnosis, but with ongoing suspicion of cancer are referred onto the appropriate MDT and GP is kept informed.
- Ensuring that if a patient is given the initial diagnosis of malignancy by a member of the diagnostic clinic, the patient's GP is informed of the diagnosis by the end of the following working day
- Represent Sarcoma in the host Trust's cancer division

43. *Diagnostic Clinic Cancer Nurse Specialist/Advanced Nurse Practitioner*
A Clinical Nurse Specialist/Advanced Practitioner for sarcoma that attends the sarcoma diagnostic clinic. Responsibilities include:
    - To provide support in the pre-diagnostic phase following referral and investigations for Sarcoma
    - Communicating to patients where diagnostics have determined that they do not have cancer to complete their Faster Diagnosis Standard (FDS) pathway
    - Attend local MDT and actively contribute to discussion and planning of on-going pathway
    - Act as the key worker for patients and carers throughout the patient's pathway, communicating closely with other specialist nurses involved in the patients care
    - To provide information to patients and carers on sarcoma throughout their pathway
    - Communicate with the Sarcoma specialist MDT and treating clinicians both locally and at other Trusts.
    - To provide expert clinical advice to other health care professionals
    - To be present in all breaking bad news clinics
    - Making a complete, holistic handover of the patient from the local diagnostic service to the tertiary centre.

44. *Patient Pathway Coordinator (PPC)*
A patient pathway co-ordinator/MDT coordinator. Responsibilities include:
    - Track patients through the pathway and ensure that any delays are identified and corrected. This includes patients on inter trust pathways.
    - Arrange clinics
    - Liaise with the specialist sarcoma MDTs when patients are referred onwards to either of the specialist centres
    - Ensure that patients without a sarcoma diagnosis, but with ongoing suspicion of cancer, are referred onto the appropriate MDT and GP is kept informed.

4. Support

45. Effective working between the tertiary centres and local diagnostic services requires a combination of ongoing support and formal training. This covers training offered by tertiary centres to staff at local diagnostic services, it does not cover the training needs of the team at the tertiary centres.

Formal training

46. Biopsy – Tertiary sites must provide a method to certify that clinicians are competent to carry out needle, excision and punch biopsies and competent to assess whether a given lesion is suitable for biopsy in the LDS or requires onward referral.

47. This process will vary depending on the existing experience and practice of the incoming clinician and may encompass paper sign off of existing competence through to a period of supervised practice and instruction at the tertiary centre.

48. LDS are welcome to join/dial into tertiary diagnostic MDTs to present unusual/concerning diagnostic cases.

49. Nursing practice – with an academic partner, deliver/support the sarcoma specific components of Advanced Nurse Practice and Clinical Nursing MSc courses.

50. Placements/shadowing – All members of the SMDT should offer short periods of on-site shadowing for staff new in role at the local diagnostic services.

Ongoing support

51. Radiology – Tertiary centre radiology teams must be available to consult on imaging over the phone or responsive alternative.

52. MDT – Tertiary centre MDTs must offer informal discussion with their counterparts for unusual and marginal cases.

53. Case review – The tertiary centre MDT must communicate the outcome of unusual and marginal cases back to the referring local diagnostic service.

5. Key Performance Indicators and Metrics

54. LDS are either commissioned by Specialised Services Commissioning through sub-contract with their associated tertiary service, or by their local ICB where the LDS is not sub contracted to a specific tertiary centre.

55. The LDS will therefore submit the data outlined below for review by commissioners on the schedules described in the metric definitions for each dataset.

- Specialised Services Quality Dashboard (SSQD) Metric definitions
- Cancer Wait Times version 11.1
- Cancer Outcomes and Services Dataset (COSD) submission schedule

56. Table 1 sets out the consolidated list of metrics, and Tables 2 and 3 provide further detail of the specific measures required by SSQD and the Cancer Patient Experience Survey (CPES).

Data source	Key Performance Indicators
SSQD Soft Tissue	SARCO 1-5,15
SSQD Bone	SARCO 1-4,14
FDS	75% of patients either receive a cancer diagnosis or have it ruled out within four weeks (28 days) of an urgent GP referral
COSD	Proportion of patients diagnosed with cancer who were offered or accepted a Personalised Care and Support Plan
CPES	• Q5-9, 12 37

Table 1 – Overview of commissioning Key Performance Indicators and datasets

SSQD Code	Metric
SARC01-ST	% patients with soft tissue sarcoma discussed at the Sarcoma MDT prior to definitive treatment.
SARC02-ST	% patients with a gastrointestinal stromal tumours (GIST) discussed at the Sarcoma MDT prior to definitive treatment.
SARC03-ST	% of TYA patients with soft tissue sarcoma discussed at TYA MDT
SARC04-ST	% of patients with soft tissue sarcoma whose soft tissue sarcoma is staged using the TNM staging system prior to definitive treatment
SARC05-ST	% of patients with soft tissue sarcoma surgery undertaken outside of the designated centre
SARC15-ST	% of patients with soft tissue sarcoma with a CNS/key worker allocated.
SARC01-BS	% patients with bone sarcoma discussed at the Sarcoma MDT prior to definitive treatment.
SARC02-BS	% of TYA patients with bone sarcoma discussed at TYA MDT
SARC03-BS	% of patients whose bone sarcoma is staged using the TNM staging system prior to definitive treatment
SARC04-BS	% of bone sarcoma surgery undertaken outside of the designated centre
SARC14-BS	% of patients with bone sarcoma with a CNS/key worker allocated.

Table 2 – Detailed Specialised Services Quality Dashboard indicators

CPES Q	Metric
Q5	% patients who received all the information needed about the diagnostic test in advance
Q6	% diagnostic test staff who appeared to completely have all the information they needed about the patient.
Q7	% patients who felt the length of time waiting for diagnostic test results was about right.
Q8	% patients who felt their diagnostic test results were explained in a way that the patient could completely understand
Q9	% patients who felt that enough privacy was always given to the patient when receiving diagnostic test results.
Q12	% who said that when they were first told that they had cancer they had been given the option of having a family member, carer or friend with them
Q37	% who said they felt that they were always treated with respect and dignity while they were in the hospital

Table 3 – Detailed National Cancer Patient Experience Survey indicators

6. LSESN Diagnostic Centre Configuration

57. In order to provide safe and effective care for sarcoma patients, each local SDC should see a minimum of 500 patients/year (10 patients/week). These parameters were agreed by the LSESN at the December 2022 SAG Meeting.

58. In 2021/22, the total volume of referrals in the LSESN catchment area received 4407 referrals, indicating the need for a maximum of 9 clinics (2 in East of England, 2 in South East England and 5 in London). Table 1 outlines the current existing local diagnostic services and proposed new sites.

NHS Region	Alliance	ICBs	Local Sarcoma Diagnostic Service
East of England	East of England (south) CA	Bedfordshire, Luton and Milton Keynes	Oxford (Specialist Centre) or Cambridge
		Herts and West Essex	RNOH
		Mid and South Essex	(proposal TBC)
	East of England (north) CA	Cambridgeshire and Peterborough	Cambridge
		Norfolk and Waveney	Norwich Hospital
		Suffolk and North East Essex	(proposal TBC) or Norwich
London	NCLCA	North Central London	Royal National Orthopaedic Hospital (Specialist Centre)

			An NCL CDC (proposal tbc)
	NELCA	North East London	Mile End Hospital
	SELCA	South East London	Mile End Hospital
	RM Partners	South West London	Royal Marsden Hospital (Specialist Centre) Croydon Hospital
		North West London	West Middlesex Hospital Chelsea & Westminster Hospital
South East of England	Kent & Medway CA	Kent	Mile End Hospital or Croydon Hospital
	Surrey & Sussex CA	Surrey	Brighton Hospital or Croydon Hospital
		Sussex	Brighton Hospital
	Wessex CA	Hampshire & Isle of Wight	Southampton or Portsmouth Hospitals
		Dorset	Southampton or Bournemouth Hospitals
	Thames Valley CA	Buckinghamshire, Oxfordshire & Berkshire West	Oxford University Hospital (Specialist Centre)

Table 4 - Sarcoma Diagnostic Services, by Region and ICB

59. The Bournemouth local sarcoma diagnostic service is part of South West England SAG. However, it is recognised that a referral route does exist with RMH.

60. Oxford is also listed as a local sarcoma diagnostic service. Note that this service sits within the Thames Valley SAG and is a tertiary centre (bone and soft tissue) for that SAG.

Appendix 1 – Approving local Diagnostic Designated Practitioners

Principles

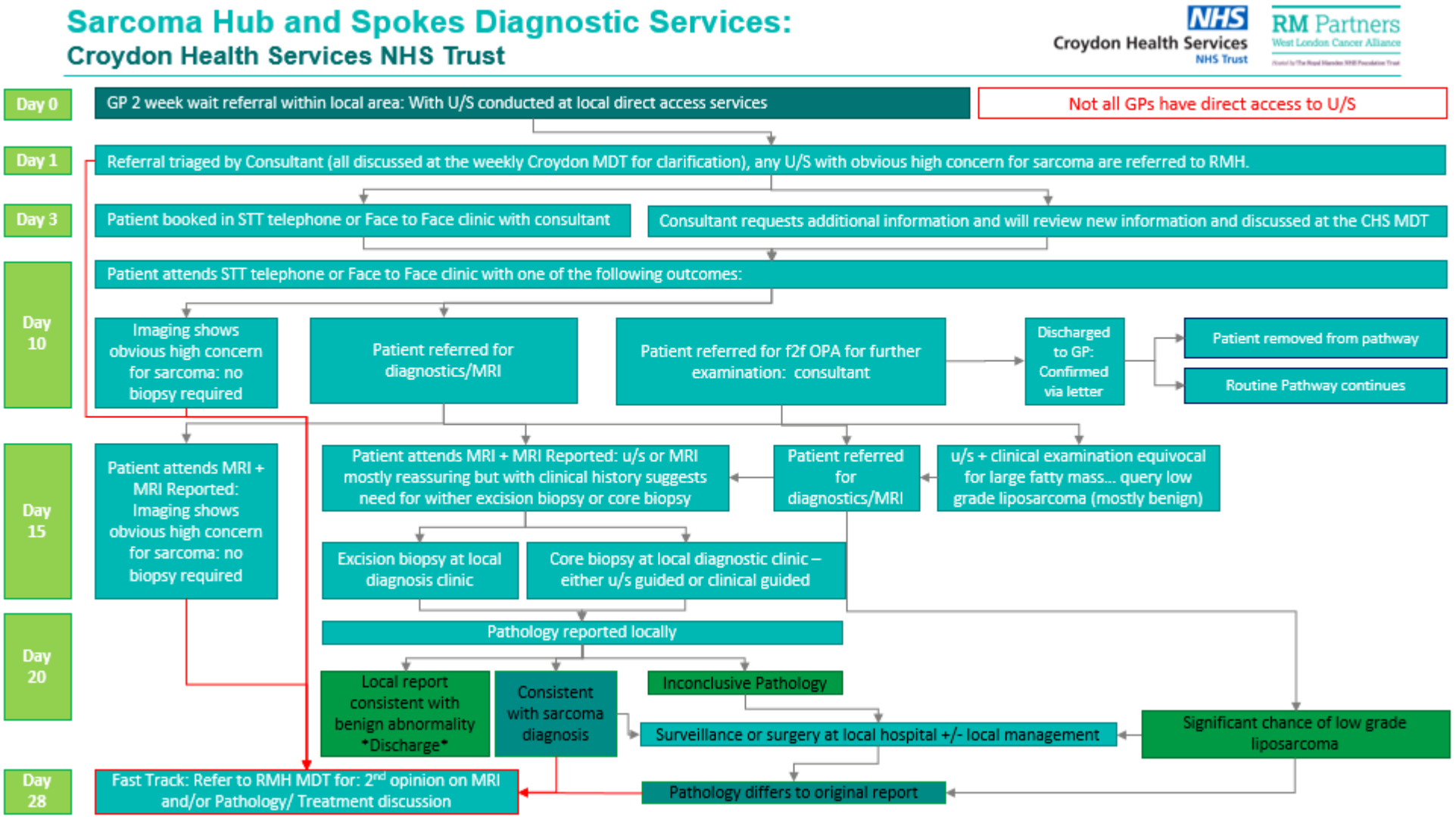
- Under 'shared care arrangements' whereby patients referred on a 2ww sarcoma pathway, patients will receive diagnostic services by a small number of named Trusts.
- Those Trusts are commissioned to deliver a local sarcoma diagnostic service (LSDS), in accordance with the LSESN's local diagnostic service pathway for suspected soft tissue sarcomas only, to support care closer to home and to reduce the diagnostic burden on the tertiary centres.
- the LSDS will provide the SAG with a named clinical lead.
- The service clinical lead or deputy will attend the SAG's quarterly meetings.
- the LSDS 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 LSDS 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.
- Diagnostic designated practitioners will be reviewed and agreed by: the Trust, the ICS' Imaging Board and the SAG annually.
- LSDS' can expect good support from and communication with the Sarcoma MDT that they are affiliated with.

Criteria for designated practitioners

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 SMDTs 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.

Appendix 2 – Local Diagnostic Centre Pathway at Croydon NHS Trust



Appendix 3 – Local Diagnostic Centre Pathway at Chelsea and Westminster NHS Foundation Trust