

London and South East Sarcoma Network  
Shared Care Pathway for Soft Tissue Sarcomas Presenting to Site  
Specialised MDTs  
Gastrointestinal stromal tumours

**Background**

This guidance is to provide direction for the management of patients with gastrointestinal stromal tumours (GIST) that may present through upper GI or lower GI cancer services, and to define the relationship that should exist with the specialist sarcoma MDT. This guidance refers to the care of patients in the London and South East Sarcoma Network and therefore recognises that specialist services for soft tissue sarcomas are provided by the Sarcoma Units at the Royal Marsden Hospital and the London Sarcoma Service provided through joint working of UCLH and RNOH. Both units have specialised dedicated MDTs for patients with GIST within their services.

GIST is a rare tumour with less than 1000 cases in the UK each year. Presentation can range from small localised tumours managed by surgery alone, to large advanced metastatic tumours requiring complex multi-modality treatment. It is apparent that treatment within a team with experience of GIST is essential for these patients, as management is often not straightforward. Therefore, all newly diagnosed cases of GIST should be referred to the sarcoma MDT, to review the diagnosis and plan management. The sarcoma MDT provides:

- Clinical and radiological expertise
- Expert pathology review 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

The primary aim of this pathway is to ensure early discussion with a specialist GIST sarcoma MDT. Surgery for localised tumours may be undertaken in a local referring centre with appropriate surgical expertise and after agreement with the sarcoma MDT. If this occurs, then further review in the sarcoma MDT after surgery will be required to determine if there is any indication for adjuvant treatment, and to recommend on follow-up schedule. For patients with locally advanced disease, discussion will be required to determine if there is a need for neoadjuvant systemic therapy prior to surgery. For patients with metastatic disease at diagnosis, systemic therapy should only be initiated after review by the sarcoma MDT.

The rarity of GISTs, their clinical diversity, and the complexities of their management argue for close co-operation between GI and sarcoma MDTs, and for centralisation of care. Where patients are receiving combined modality treatment, especially with neoadjuvant systemic therapy (imatinib), receiving all treatments at a single institution has many advantages for patients and treating teams. Regular multidisciplinary clinical review when patients are on treatment and co-ordination between surgeon and oncologist is essential. This is especially true for rectal GISTs.

**Principals**

This guidance is being developed in accordance with the relevant measures in the Manual for Cancer Services: Sarcoma Measures, the Manual for Cancer Services: Upper GI Measures and Manual for Cancer Services: Colorectal Measures. They are also written in accordance with the LSESN referral guidelines (see [www.lsesn.nhs.uk](http://www.lsesn.nhs.uk)) and the LSESN Patient Management Policy.

**1) Notification**

FILE NAME	SHARED CARE PATHWAY FOR GASTROINTESTINAL STROMAL TUMOURS PRESENTING TO SITE SPECIALISED MDTs: UPPER GI/LOWER GI	ISSUE NO	1	PAGE NO	1 OF 3	DATE AUTHOR	18.10.11 Beatrice Seddon
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All GIST patients presenting to a local upper or lower GI MDT should be notified to the sarcoma MDT nominated in the local network upper GI and lower GI cancer operational policy.

2) Review by Sarcoma MDT

a) Pathology

All GISTs will have pathology review undertaken by the nominated specialist GIST pathologists (for details see MDT operational policies), for both resected tumours to allow allocation of risk stratification, and metastatic disease. Gene mutation analysis will be performed as indicated in the LSESN Patient Management Policy.

b) Management

Management of all newly diagnosed GISTs will be discussed with the sarcoma MDT. Early referral from the time of suspicion or biopsy is recommended.

3) Site of Definitive Treatment

Discussion between MDTs will take place to determine the appropriate hospital for definitive excision of early stage disease. In general, surgical excision as part of multimodality treatment is best performed within a single MDT, such that patients receiving neoadjuvant imatinib will ideally be managed at the sarcoma centre.

Systemic therapy will be undertaken at the sarcoma centre, or by designated practitioners as agreed by the SAG. When appropriate clinical trials are running at the sarcoma centre, patients should be offered the opportunity to participate and be treated at the sarcoma centre.

4) Recurrence

All recurrent GISTs or those progressing on systemic therapy will be discussed and reviewed by the sarcoma MDT. Patients with metastatic disease who progress on first line imatinib should be treated at the sarcoma centre for subsequent therapies. When appropriate clinical trials are running at the sarcoma centre, patients should be offered the opportunity to participate.

	Role and Responsibility	
	Specialist Upper GI/Lower GI MDT/Clinic	Sarcoma MDT/Clinic
<b>Presentation</b>	Assess new cases of suspected upper GI and lower GI cancer Notify Sarcoma MDT of all new cases of GIST	
<b>Diagnosis</b>	Refer all cases of GIST for pathology review and gene mutation analysis Refer all new cases of GIST for review by sarcoma MDT	Review pathology of all new cases of GIST Arrange gene mutation analysis Clinical review of selected cases
<b>Treatment</b>	Excision when agreed by upper/lower GI and sarcoma MDT's	Consider definitive excision of all GISTs; need for adjuvant imatinib; need for neoadjuvant imatinib; initiation of imatinib for metastatic disease.
<b>Follow up</b>	Follow up according to national UK GIST guidelines	Follow up in accordance with national UK GIST guidelines, and sarcoma follow up guidelines of all patients treated by the sarcoma MDT

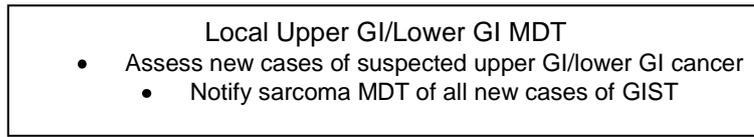
**Pathway Summary:**

Suspected gastrointestinal stromal tumour

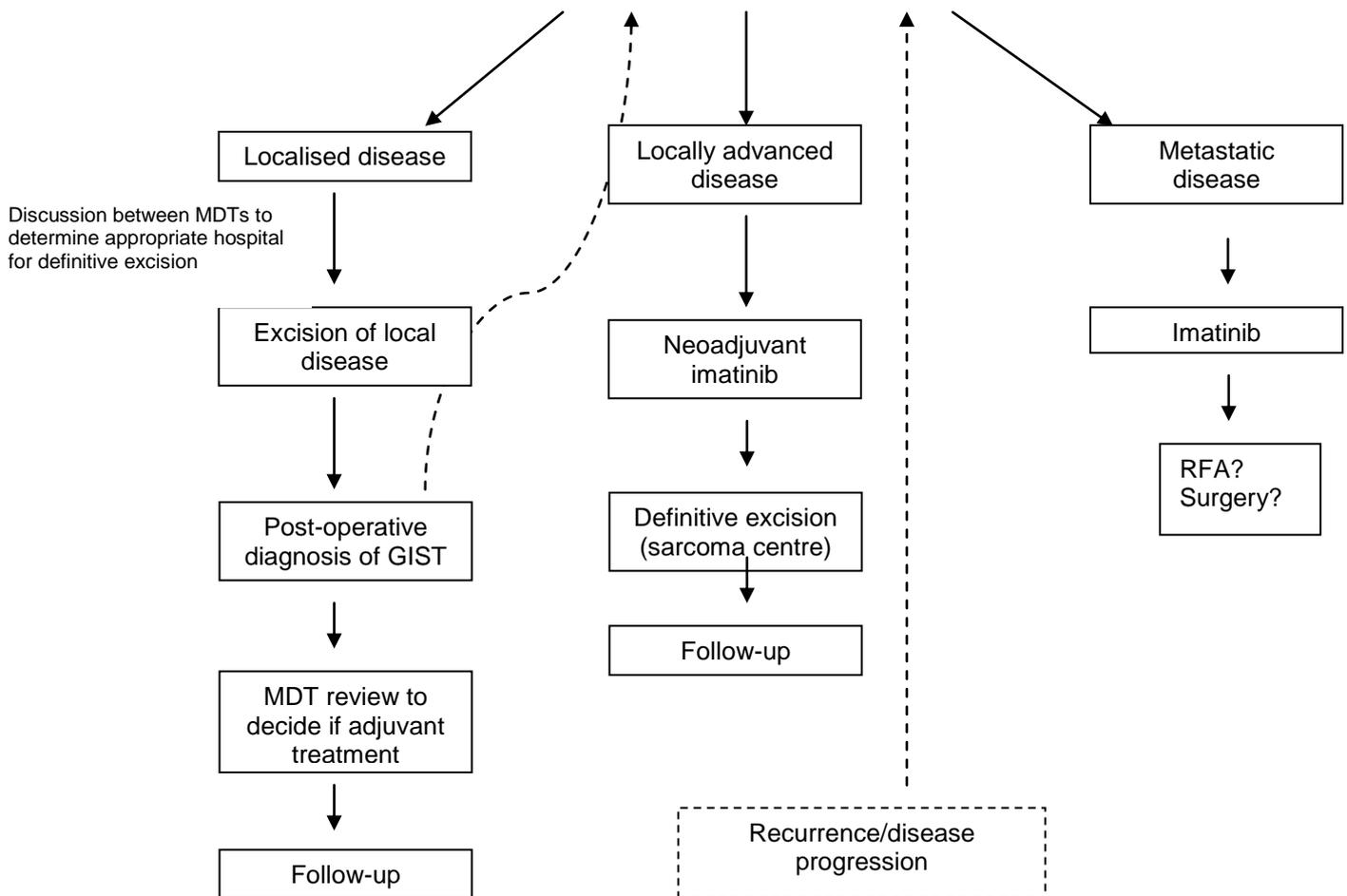
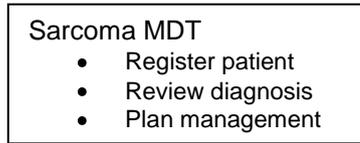
Patients under 24 will also be referred to the teenage and young adult or paediatric MDTs as appropriate

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Suspected/biopsy-proven GIST



Follow Up according to national UK GIST guidelines and LSESN sarcoma follow-up guidelines (for those patients treated by sarcoma MDT)