Shared Care Pathway for Soft Tissue Sarcomas Presenting to Site Specialised MDTs
Gastrointestinal stromal tumours – Version 1

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 Soft Tissue Sarcoma MDT.

Specialist services for soft tissue sarcomas (excluding limb and external trunk wall) are provided by the Sarcoma Units at University Hospitals Birmimgham.

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 Specialist Soft Tissue 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 West Midlands SAG referral guidelines (see www.birminghamcancer.nhs.uk)

1) Notification

All GIST patients presenting to a local upper or lower GI MDT should be notified to the Specialist Soft Tissue 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.

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 local MDT and SSTSMDT 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 SST 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.

5) Follow up

Follow up arrangements will be discussed and agreed between the local Upper GI MDT and the SSTMDT. This will include details of frequency, purpose and location of follow up.

6) Summary of roles and responsibilities

	Role and Responsibility	
	Specialist Upper GI/Lower GI MDT/Clinic	**Sarcoma MDT/Clinic**
Presentation	Assess new cases of suspected upper GI and lower GI cancer Notify Sarcoma MDT of all new cases of GIST	
Diagnosis	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
Treatment	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.

Follow up	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

7) Palliative Care

Palliative care services will be made available to all patients as deemed appropriate by the MDT.

8) Clinical Trials

Wherever possible, patients who are eligible should be offered the opportunity to participate in National Institute for Health Research portfolio clinical trials and other well designed studies.

Where a study is only open at one Trust in the Network, patients should be referred for trial entry. A list of studies available at each Trust is available from Pan Birmingham Cancer Research Network. Email: PBCRN@westmidlands.nhs.uk

Patients who have been recruited into a clinical trial will be followed up as defined in the protocol.

9) Staging

Staging data for 70% of all cancers (90% of stageable cancers) should be collected electronically and transferred to the West Midlands Cancer Intelligence Unit (WMCIU).

All Trusts

a. The Trust should send electronic extracts from their histopathology system regularly to the WMCIU
b. The Trust should send imaging extracts for cancer patients electronically to the WMCIU regularly, or establish remote access for the WMCIU to their radiology information system and / or data warehouse

c. Data extracts should be sent in line with the cancer registry dataset / cancer outcomes and services dataset guidance

For cancers **diagnosed clinically** or those that have not had surgery

a. Clinical stage is recorded on the MDT database
b. Staging extracts for all patients are sent to the WMCIU within 6 months of diagnosis

For those with **invasive cancer who have had surgery**

a. MDTs record the full cancer registry dataset onto their MDT database at the time of discussion at the MDT meeting.
c. Staging extracts for all patients are sent to the WMCIU within 6 months of diagnosis

10) Performance Status

All patients should have their performance status recorded onto the MDT database at the MDT. This should be done using the WHO classification which will ensure it is in line with the cancer outcomes and services dataset guidance

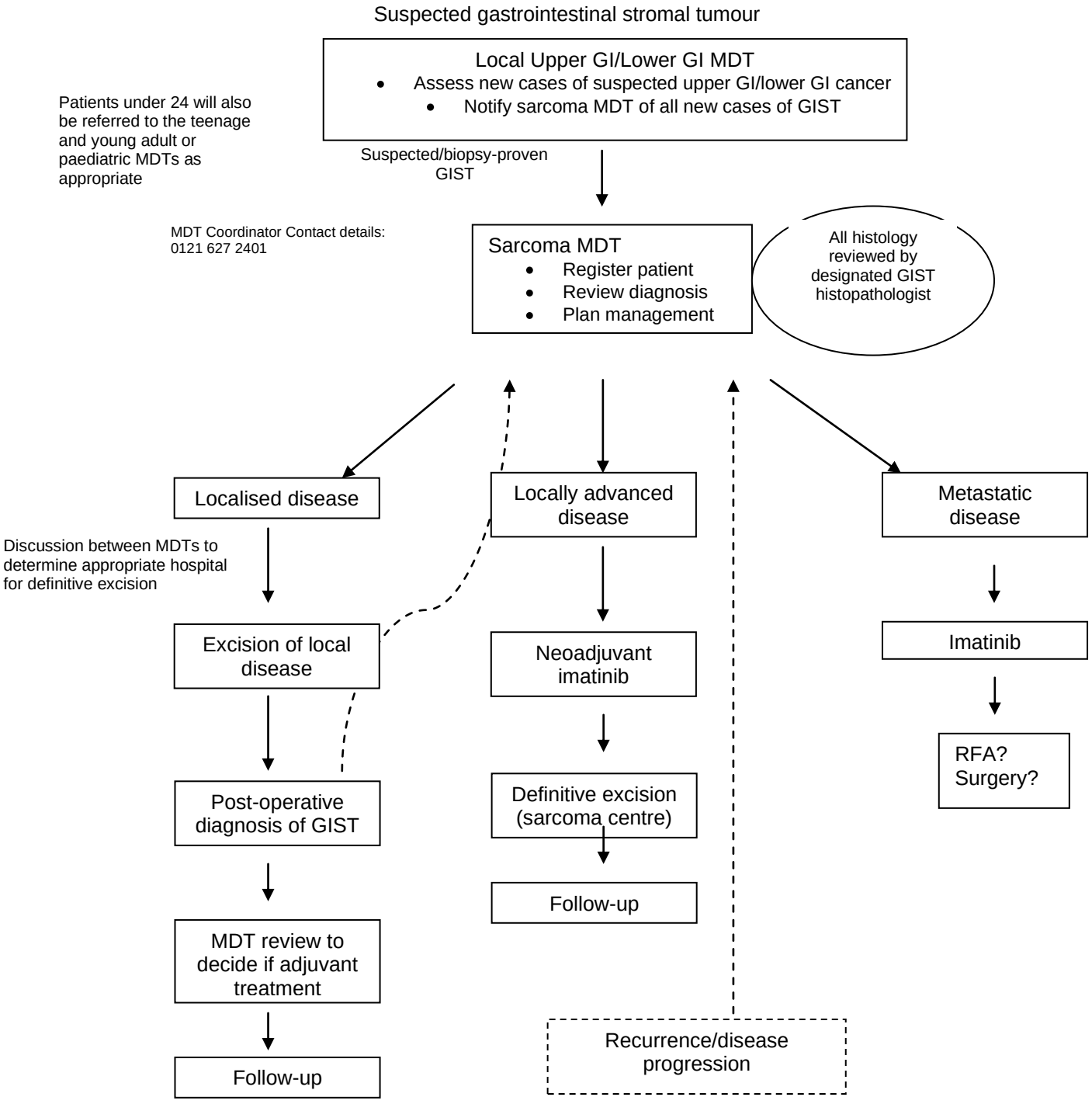
11) References

1. 2012 London and South East Sarcoma Network – referral guidelines for sarcoma http://www.lsesn.nhs.uk/files/lsesn-referral-guidelines.pdf

2. National Cancer Peer Review Programme, Manual for Cancer Services: Sarcoma Measures National Cancer Action Team, Part of the National Cancer Programme Version 1.1 http://www.dh.gov.uk/health/2011/08/sarcoma-measures

3. The Manual for Improving Outcomes for People with Sarcoma (2006) www.nice.org.uk/csg**sarcoma**

Pathway Summary:



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