A large, stylized graphic on the left side of the cover, composed of a grid of blue circles of varying shades, forming the outline of the North East Yorkshire and Humber region.

Guidelines for the Management of Adult Patients with Soft Tissue Tumours & Sarcomas

2012

Version Control

This is a controlled document please destroy all previous versions on receipt of a new version.

Date Approved: April 2012

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Version	Date Issued	Review Date	Brief Summary of Change	Owner's Name
1.0	November 2009	November 2009	Original draft	Sarcoma Implementation Group
1.1	November 2009	December 2009	Updated contacts / reformatted	Sarcoma Implementation Group
1.2	December 2009	May 2010	Added referral pathway HYCCN / YCN	Sarcoma Implementation Group
1.3	May 2010	October 2010	Updated information	Sarcoma Implementation Group
1.4	October 2010	November 2010	Added physiotherapy information	Sarcoma Implementation Group
1.5	November 2010	November 2010	Amended imaging, guidelines and regional incidence figures	Sarcoma Implementation Group
1.6	November 2010	March 2011	Amended pathology, radiotherapy, physiotherapy guidelines and regional incidence figures	Sarcoma Implementation Group
1.7	March 2011	April 2012	Response to Sheffield comments	Sarcoma Implementation Group
1.8	April 2012	April 2014	Updated formatting to NEYHCA (Cancer), Added Birmingham Cancer Network Bone Sarcoma information, Updated incidence data Added Treatment algorithm Updated YCN pathway Measures revised in April 2012	Sarcoma Implementation Group

For the latest version of these guidelines please see the NEYHCA (Cancer) website
Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/sarcoma.htm>

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Foreword

A guideline is “not a rigid constraint on clinical practice, but a concept of good practice against which the needs of the individual patient can be considered.” (RCR 1990)

It therefore remains the responsibility of the practising Clinicians to interpret the application of guidelines, taking into account local service constraints and the needs and wishes of the patients.

In reviewing the guidelines, local clinicians and managers will be required to assess whether the guidance can be met, and if not what service developments need to be undertaken to achieve the ‘ideal service’ as defined by the available evidence.

Clinical guidelines refer to how a given patient should be clinically managed by which modality/ies of treatment (surgery, radiotherapy, chemotherapy, and biological therapy), imaging and pathology rather than detailed chemotherapy regimens and techniques of surgery or radiotherapy.

In the case of the IOG for sarcoma the area of clinical guidelines overlaps to a degree with the descriptions of the particular groups of patients which are subject to the different levels of care.

The responsibility for review purposes for clinical guidelines lies with the lead clinician of the Local Soft Tissue Sarcoma Multidisciplinary Team (LSTSMDT) and the Chair of the Implementation Group. For compliance, the Sarcoma Implementation Group, in consultation with the LSTSMDT should produce the agreed clinical guidelines. The individual LSTSMDT for their compliance with this measure should agree to abide by them.

Objectives & Methodology

The Manual for Cancer Services states that the “Network Site Specific Groups” should agree network-wide clinical and referral guidelines. Guidelines define structure, process and standards against which the development and quality of the service can be assessed through audit. They also allow the service to be reviewed against the ideal, in order to direct effective service development and investment, and ensure seamless care is delivered and maintained between primary, secondary and tertiary sectors.

1. Introduction

1.1 Risk Factors and Epidemiology

Sarcomas are a rare and diverse group of cancers thought to have common embryological origin. They arise from cells that make up the connective tissue structure. Sarcomas can be broadly divided into those of bone and those of soft tissue sarcoma (STS). STS are ranked the 23rd most common cancer, whereas bone is 27th. Combined, sarcomas are only the 21st most common cancer type.

During a working lifetime a general practitioner with a list size of 2000 patients may see many hundreds of benign tumours, but can only expect to see one or two patients with sarcoma. Even with secondary care the majority of patients seen with soft tissue tumours are likely to have a benign lesion, so identifying the small number of patients with sarcoma generates a considerable diagnostic workload for clinicians. Soft tissue sarcomas account for about 1% of all malignant tumours. Benign soft tissue tumours outnumber malignant by at least a factor of 100.

Delays in diagnosis for sarcomas are common. Early diagnosis would undoubtedly lead to improved outcomes in terms both of survival and of less damaging surgery being required. Many are discovered incidentally following excision of a lump, without prior suspicion. Initial excision is often inadequate and further treatment is required.

1.2 Risk factors

In most cases of soft issue sarcoma it is not possible to identify a specific aetiological cause.

- A number of genetic conditions carry an increased risk including:
 - Hereditary retinoblastoma
 - Neurofibromatosis
 - Li-Fraumeni
 - Familial adenomatosis polyposis (Gardner's syndrome)
- Lymphoedema is associated with lymphangiosarcoma, often after radical lymphadenectomy, but also in primary lymphoedema.
- Prior radiotherapy can cause late development of soft tissue sarcomas.

(Information obtained from "Improving outcomes for people with sarcoma" NICE)

1.3 NEYHCA (Cancer) Regional Incidence

Incidence and mortality rates for sarcoma in NEYHCA (Cancer) are not significantly different than the national rate. However, they are significantly higher than the best in England.

NEYHCA (Cancer) s male mortality rate is the highest in the country - significantly higher than the national rate.

There is no significant difference between NEYHCA (Cancer) s 1 and 5 year survival rates for sarcoma and the national rate/best in England.

Incidence, Survival & Mortality Rates

Sarcoma tumour site	Incidence (2006-08)			Mortality (2007-09)		
	No of cases per year	NEYHCA compared to England (ASR)	NEYHCA compared to best network in England (ASR)	No of deaths per year	NEYHCA compared to England (ASR)	NEYHCA compared to best network in England (ASR)
C40-C41: Bone and articular cartilage of limbs, other and unspecified sites	10	Lower, no significant difference	Higher, no significant difference	5	Lower, no significant difference	Higher, no significant difference
C46: Kaposi's sarcoma	1	Significantly lower. Second lowest rate in England	Second lowest rate in England	0	-	-
C48: Retroperitoneum and peritoneum	14	Higher, no significant difference	Significantly higher than best in England	10	Significantly higher. Second highest rate in England	Significantly higher. Second highest rate in England
C49: Other connective and soft tissue	31	Higher, no significant difference	Significantly higher than best in England	14	Higher, no significant difference	Higher, no significant difference

Sarcoma tumour site	One year survival (2004-08)		Five year survival (2000-04)	
	NEYHCA compared to England relative survival rate	NEYHCA compared to network with highest relative survival rate	NEYHCA compared to England relative survival rate	NEYHCA compared to network with highest relative survival rate
C40-C41: Bone and articular cartilage of limbs, other and unspecified sites	Higher, no significant difference	Lower, no significant difference	Significantly higher than national rate; highest five year survival in England	Highest five year survival in England
C46: Kaposi's sarcoma	-	-	-	-
C48: Retroperitoneum and peritoneum	Lower, no significant difference	Lower, no significant difference	Lower, no significant difference	Lower, no significant difference
C49: Other connective and soft tissue	Higher, no significant difference	Lower, no significant difference	Higher, no significant difference	Lower, no significant difference

Data Source: UKCIS downloaded Nov 2011

The main findings are:

Retroperitoneum and peritoneum (C48)

- NEYHCA (Cancer) has the second highest mortality rate in the country and this is significantly higher than the national rate.
- No significant difference between the incidence or survival rate for NEYHCA (Cancer) and the England average.
- Incidence in NEYHCA (Cancer) is significantly higher than the best network; no significant difference for one or five year survival between NEYHCA (Cancer) and the best in country.

Other connective and soft tissue (C49)

- The incidence rate is significantly higher than the best in the country.
- There is no significant difference in incidence, mortality or survival rates for NEYHCA (Cancer) and England.
- There is no significant difference in the mortality or survival rates for NEYHCA (Cancer) and the best network in the country.

Kaposi's sarcoma (C47)

- NEYHCA (Cancer) has the second lowest incidence rate in the country and this is significantly lower than the national rate.

Bone and articular cartilage of limbs, other and unspecified sites (C40-C41)

- NEYHCA (Cancer) has the highest five year relative survival rate in the country and it is significantly higher than the national rate.
- There is no significant difference in incidence, mortality or one year survival rates for NEYHCA (Cancer) and England rates, or for NEYHCA (Cancer) and the best network in the country.

2. Service Organisation & Provision

2.1 Primary Care Management

The Improving outcomes Guidance for people with Sarcoma states that:

The overriding principle for referral is that any patient with a suspected or possible 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.

Public awareness of sarcoma is low and many studies have shown that patients wait a considerable time after the onset of symptoms before seeking medical advice.

Because of their rarity, bone and soft tissue sarcoma are frequently difficult to diagnose and are characterised by late presentation and delays in diagnosis.

The clinical guidelines (NICE "Referral guidelines for suspected cancer") have defined the urgent referral criteria for soft tissue sarcomas and these may help to improve diagnostic accuracy. But, despite this, only one in ten referrals of "suspicious lumps" will be a sarcoma. Therefore there is a large diagnostic workload that has to be addressed. Current practice and service provision generally fail to address this need, and this contributes to delay and adverse outcomes for patients who do have a malignant tumour. Currently diagnostic services for patients with these "suspicious" soft tissue lumps are patchy, with few well defined diagnostic clinics outside the major treatment centres.

Features suggestive of malignancy in a lump include:
• Lump > 5cm
• Lump increasing in size
• Lump deep to the fascia
• Pain
NICE "Referral guidelines for Suspected Cancer" (www.nice.org.uk/CG027)

Patients with soft tissue lumps that do not meet the urgent referral criteria will not require referral to a diagnostic clinic

2.2 GP information

GPs should have access to the following information:

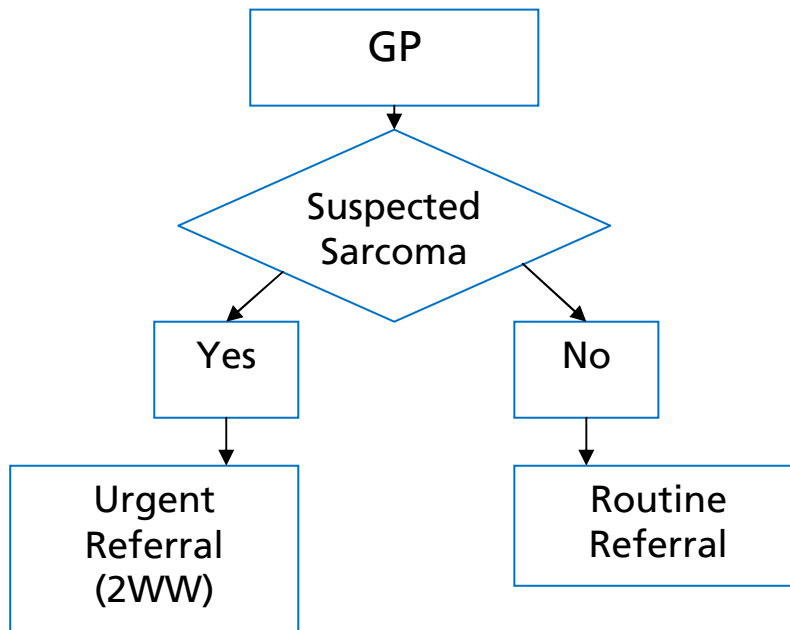
- Raising awareness of Sarcoma
- "Having a patient with Sarcoma on your list"
- Lymphodema
- Nutritional advice
- Support information for patients having problems with endoprosthetic implants
- Issues around GIST & imatinib.

Sarcoma IOG page 27

2.21 Patient Information Pathway from "IOG for people with Sarcoma", page 29

Time	Nature of Information	Responsibility
On referral to diagnostic clinic	Information on diagnostic clinic, tests it undertakes and who will be involved with the patient	Diagnostic clinic (see chapter 3 of the IOG) by post.
If sarcoma is suspected and the term is specifically used with the patient	Generic information on sarcoma	Diagnostic clinic
On diagnosis	Generic information on sarcoma. Specific information on the diagnosis (histological type, grade etc.) and the proposed treatment (if known)	Diagnostic clinic, face to face or by telephone / post if requested by patient
Confirming referral to sarcoma treatment centre	Information on sarcoma treatment centre, names of consultants / nurses who will be involved in treatment and the named key worker for the patient Specific information on the diagnosis and the proposed treatment (if known and if not given by diagnostic clinic)	Sarcoma treatment centre (see chapter 5 of the IOG) by post Local arrangements can apply
On any treatment recommendation	Generic information on that treatment (surgery, radiotherapy, chemotherapy) and any tests or imaging procedures that may accompany it. (Local or nationally published booklets may be appropriate)	Sarcoma treatment centre by post or face to face as appropriate
On referral to another sarcoma treatment centre	Reason for the referral. Information on the new sarcoma treatment centre. Identification of key worker.	Referring sarcoma treatment centre face to face or by post New sarcoma treatment centre by post

2.22 GP Information



2.3 Referral for Suspected Cancer

2.31 Background

Recognition of the North East Yorkshire & Humber Clinical Alliance (Cancer) Sarcoma Implementation Group (SIG), following release of the NICE IOG for Sarcoma means that the SIG must have a robust system for handling referrals from primary and secondary care that query a diagnosis of soft tissue sarcoma.

This group has been named the NEYHCA (Cancer) Sarcoma Implementation Group (SIG).

2.32 NEYHCA (Cancer) Acute Trusts

Within NEYHCA (Cancer) there is one established Local Soft Tissue Tumour & Sarcoma Multidisciplinary Team (LSTSMDT). This LSTSMDT is based within the Acute Trust at Hull & East Yorkshire Hospitals NHS Trust (HEYHT).

Hull & East Yorkshire Hospitals NHS Trust provides local Soft Tissue & Sarcoma cancer services for the population of Hull and the East Riding. HEYHT also provides Soft Tissue & Sarcoma cancer services to Scarborough and North East Yorkshire Healthcare NHS Trust and Northern Lincolnshire and Goole Hospitals NHS Foundation Trust.

The LSTSMDT is held at Castle Hill Hospital, Hull.

Hull and East Yorkshire Hospitals NHS Trust provides radiotherapy and chemotherapy services for Soft Tissue & Sarcoma cancers within the NEYHCA (Cancer).

2.33 Localities

- Localities within NEYHCA (Cancer) have a nominated Trust Cancer Lead.
- There are no Soft Tissue & Sarcoma cancer clinics except in HEYHT.
- All patients are referred to HEYHT.

Northern Lincolnshire and Goole NHS Foundation Trust provides diagnostic services for Soft Tissue Tumour and Sarcoma cancers for the LSTSMDT for the population of North & North East Lincolnshire & Goole. Patients are referred to HEYHT.

Scarborough and North East Yorkshire Healthcare NHS Trust provides diagnostic services for Soft Tissue and Sarcoma cancers for the LSTSMDT for the population of Scarborough, Whitby & Ryedale. Patients are referred to HEYHT.

3. Bone Sarcomas

Patients with bone sarcomas often present to primary care with no palpable abnormality, and their symptoms are often very non-specific. The symptoms of malignant bone tumours cannot be reliably distinguished from a number of benign and self-limiting conditions. The diagnosis of a malignant bone tumour relies upon timely referral of the patient for an X ray and recognition of the abnormality on the X ray.

Because of the rarity of bone tumours, failure to recognise an abnormality on an X ray or failure to identify it as being a tumour frequently contributes to the diagnostic delay for patients with bone sarcomas.

Access to expert opinion to interpret abnormal X rays is likely to be highly effective in triaging patients with abnormal X rays and deciding what further investigations are required and where these should be carried out.

"IOG for people with Sarcoma" page 36 & 37

<http://guidance.nice.org.uk/CSGSarcoma/Guidance/pdf/English>

Bone tumours fall outside the remit of the NEYHCA (Cancer) LSTSMDT. All suspected primary tumours of bone should be referred to a recognised Bone Sarcoma MDT. Current practice is to refer cases to the Royal Orthopaedic Hospital in Birmingham where a comprehensive rapid access staging, biopsy and surgical service operates.

The LSTSMDT **CANNOT** provide recommendations for a definitive overall management plan for bone sarcomas as this is the role of the specialist Bone Sarcoma MDT, but it may participate in delivering integrated non-surgical aspects of treatment.

Bone Sarcomas are referred to:

The Royal Orthopaedic Hospital NHS Foundation Trust, Bristol Road South, Northfield,
Birmingham
B31 2AP
Oncology Contact Number: 0121 685 4052

NEYHCA (Cancer) follows the Pan Birmingham Network Cancer Guidelines and referral process for Bone Sarcoma. Please press control and click on the link:

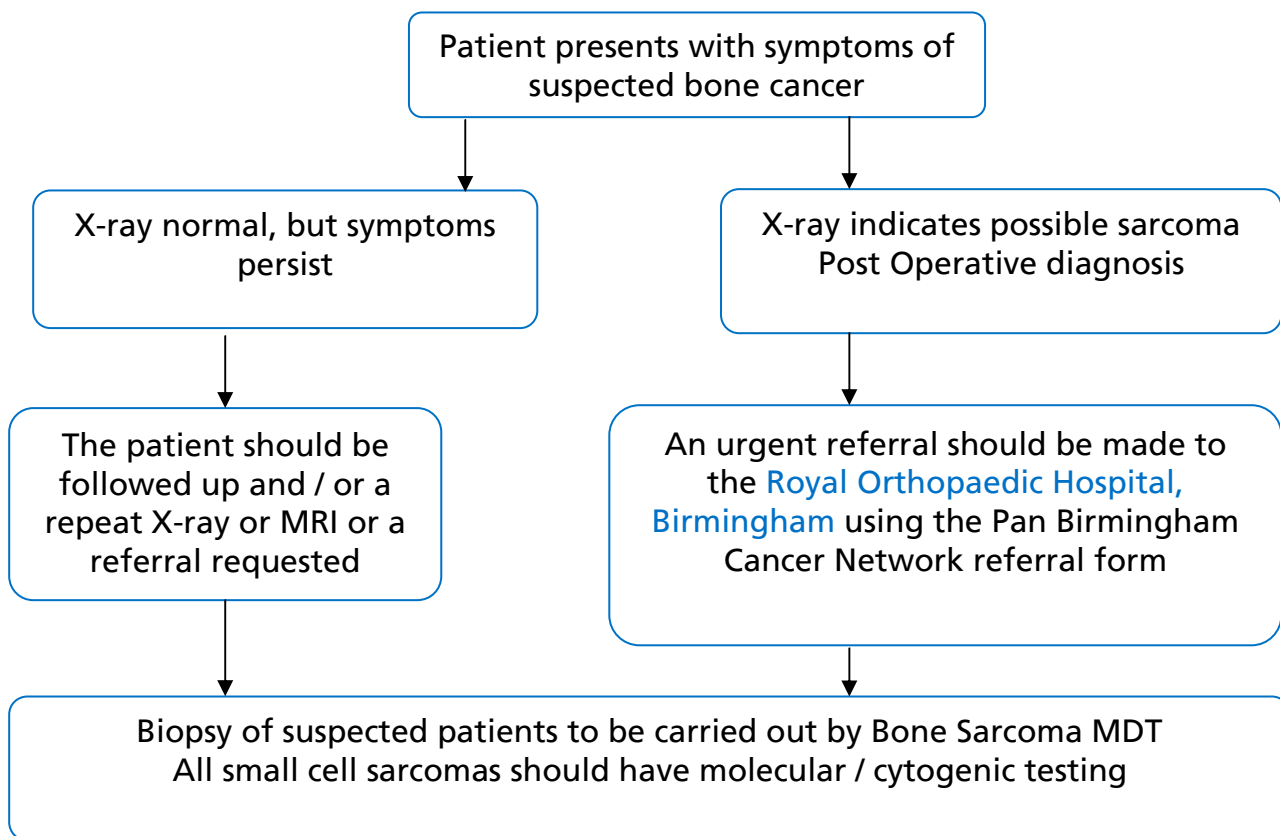
<http://www.birminghamcancer.nhs.uk/staff/clinical-guidelines/sarcoma>

The types of sarcomas most commonly seen and treated in Birmingham are:

- Osteosarcoma
- Ewing's Sarcoma
- Chondrosarcoma (non thoracic)

The Pan Birmingham Network Bone Sarcoma referral form can be found in **Appendix i**.

3.1 Bone Sarcoma Presentation Pathway



3.2 Bone Sarcoma Diagnostic & Referral Pathway

For referral / service information / referral proforma please press control and click on the following links

<http://www.roh.nhs.uk/contact>
<http://www.birminghamcancer.nhs.uk/staff/rf/gp-urgent-2-week-wait>

Initial follow up would be carried out by the Birmingham Bone Sarcoma MDT. The patient would then be referred back to the relevant team member

It is recognised that there are links with the Glasgow Bone Tumour Service (Musculoskeletal Surgical Sarcoma Services) for bone tumours arising within the facial skeleton and base-of-skull.

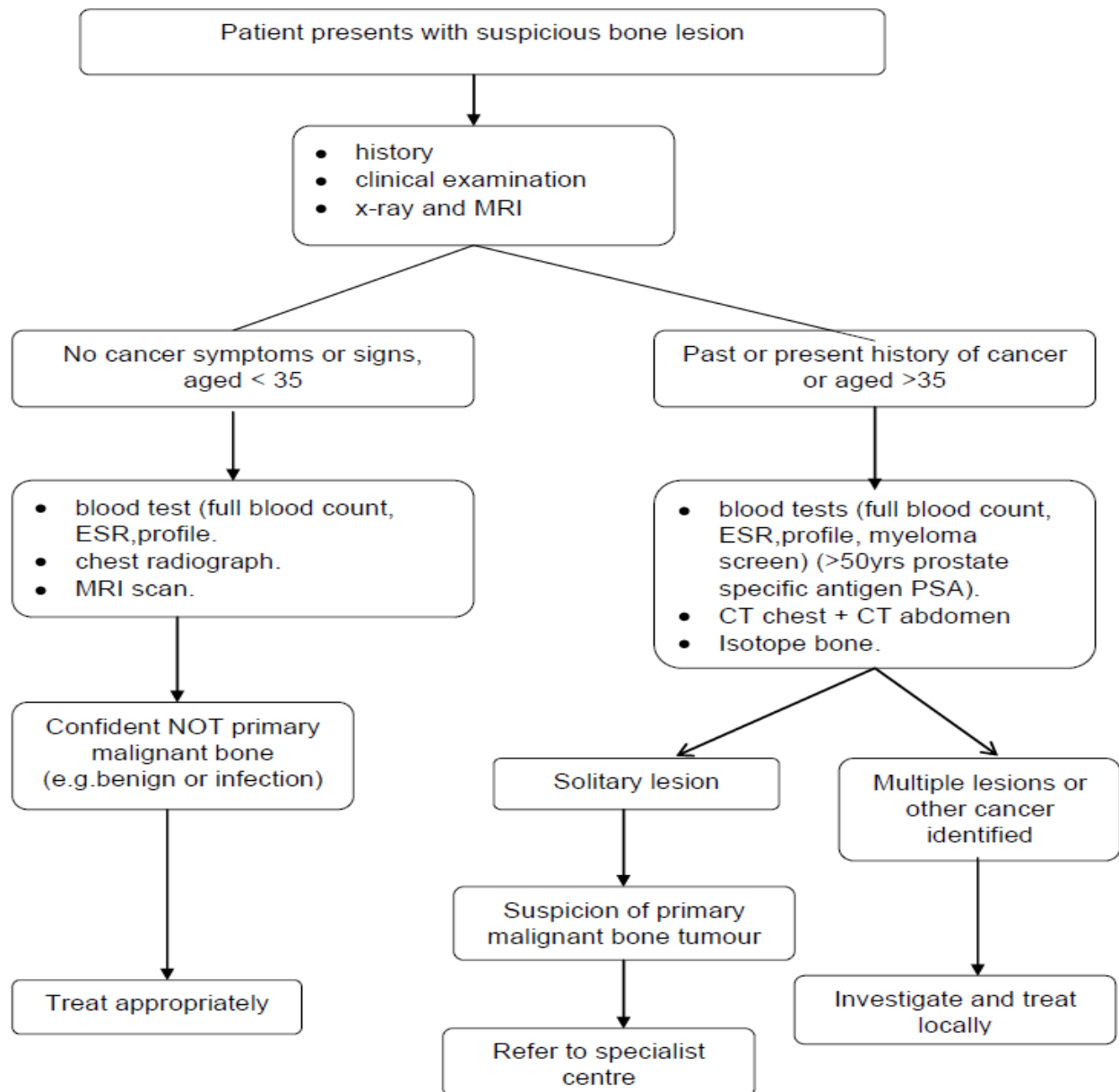
Lead clinician: Mr Mike Jane (Consultant Orthopaedic Surgeon)

Service contact address:

NHS Greater Glasgow and Clyde
Western Infirmary
Dumbarton Road
GLASGOW
G11 6NT

The investigation of a patient with a suspicious bone lesion or suspected pathological fracture should follow the algorithm shown in Figure 1.

Figure 1



All patients with suspected bone sarcoma should be referred to the specialist bone cancer multidisciplinary team in Birmingham and be seen by a specialist from this team within 2 weeks of referral.

If a primary healthcare professional has concerns about the interpretation of patient's symptoms and/or signs, a discussion with the local specialist should be considered.

- Patients with a suspected spontaneous or low impact fracture should be appropriately investigated to rule out the presence of a pathological fracture (x ray / MRI)
- Patients with increasing, unexplained or persistent bone pain or tenderness, particularly pain at rest (and especially if not in the joint), or an unexplained limp should be investigated by the primary healthcare professional urgently. The nature of the investigations will vary according to the patient's age and clinical features but should include history, clinical examination and X ray followed by blood tests (full blood count, ESR, profile)
 - In older people metastases, myeloma or lymphoma, as well as sarcoma, should be considered.

- GPs should refer patients using the urgent two week referral form (Pan Birmingham Cancer Network form in **Appendix i**) to the rapid access fax Royal Orthopaedic Hospital Birmingham. Please ensure that it is clearly indicated on the form whether the patient's symptoms are suspicious of cancer.
- Secondary care physicians should make the referral by faxing a referral letter to the rapid access fax Royal Orthopaedic Hospital Birmingham.
- If a patient has HIV disease, Kaposi's sarcoma should be considered and a referral made to an appropriate HIV treating centre if this is suspected

3.3 Bone Sarcoma Follow-Up

NEYHCA (Cancer) follow the Pan Birmingham Network Cancer Guidelines and referral process for Bone Sarcoma. Please press control and click on the link:

<http://www.birminghamcancer.nhs.uk/staff/clinical-guidelines/sarcoma>

The Pan Birmingham Network Guidelines outline Bone Sarcoma Follow Up procedures. Currently patients referred to Birmingham with a bone sarcoma will receive follow up chemotherapy or radiotherapy in Leeds.

This pathway is being discussed by NEYHCA (Cancer) and the Pan Birmingham Network as it is felt that patients could have their follow up in the specialist centre in Hull.

4. Suspected Soft Tissue Sarcoma

Established risk factors for malignant versus benign soft tissue masses are

- Size > 5 cm
- Deeply located (with respect to investing fascia)
- Rapid growth
- Recurrence after previous resection
- Pain
- Invasion of surrounding structures/ulceration of the skin

The presence of one or more the above should prompt urgent referral via the 'fast-track' two week wait cancer waiting time (CWT) process. However, these criteria are neither sensitive nor specific nor rigorously evidenced as criteria for referral (they have emerged more by consensus view).

There is a clear link between tumour size and behaviour in that larger sarcomas are more likely to metastasize (though this is in part linked to grade and rate of growth).

Later presentation of larger tumours therefore risks the need for more extensive surgery and a higher likelihood of (occult) metastatic disease.

Conversely the likelihood of benign disease increases with smaller tumour size.

Reducing the 'size cut-off' may allow earlier detection (and better outcomes) but runs the risk that referral of ultimately benign disease will overwhelms that capacity of the LSTSMDT to deal effectively with the specialist requirements of true sarcomas.

A number of clinical features, even in the presence of one of the above 'fast-track criteria', would tend to support a benign diagnosis.

- Less than 5 cm
- Superficial to deep fascia
- History and consistent signs of local trauma
- Presence of pathognomic features (punctum, Trans illumination, tenderness)
- Associated co morbidity predisposing to benign masses

Not all of these factors are addressed within the present referral criteria, nor is it simple to introduce them as they are no more rigorously evidenced than the criteria that we do use. Referring sources may lack the clinical expertise or experience to screen referrals on the basis of these clinically subjective variables.

4.1 Mechanism

All cases of suspected soft-tissue sarcoma fulfilling agreed NEYHCA (Cancer) referral criteria should be referred for the urgent attention of the LSTSMDT.

Referring organisations requiring a named contact should direct their referral to an appropriate member of the LSTSMDT, but copy the referral to the LSTSMDT co-ordinator. Failure to include the LSTSMDT co-ordinator may delay case-handling.

4.2 NEYHCA (Cancer) Sarcoma Cancer Pathway Details / Supporting Information

Referral

- GP to counsel and support patient throughout diagnostic element of pathway
- Cutaneous lesions should first follow the Melanoma/ Non Melanoma Pathways
- Suspected groin/axilla/neck lymph nodes should follow the Lymphoma Pathway
- IOG – Referral should be sent as an urgent suspected cancer if:
 - Painful
 - Increasing size
 - >5cm
 - Deep lesion (deep to the deep fascia)
 - Invasion of surrounding structures or overlying skin ulceration

Referral criteria to be regularly audited

Triage/ Diagnosis

Patients with suspicious lesions should be referred on a 2 week wait to the joint soft tissue tumour clinic.

- Same day USS
- MRI within 1 week

Results reviewed at next available MDT

US guided biopsy and CT chest are arranged to complete work up (or other test).

Patients are either seen again in clinic to discuss the MRI findings or more usually are told by phone that they need further scans (having been warned to expect a call with their MDT outcome after the MDT. These calls are made by the Sarcoma CNSs.

Patients are then seen again in clinic with biopsy results the following week.

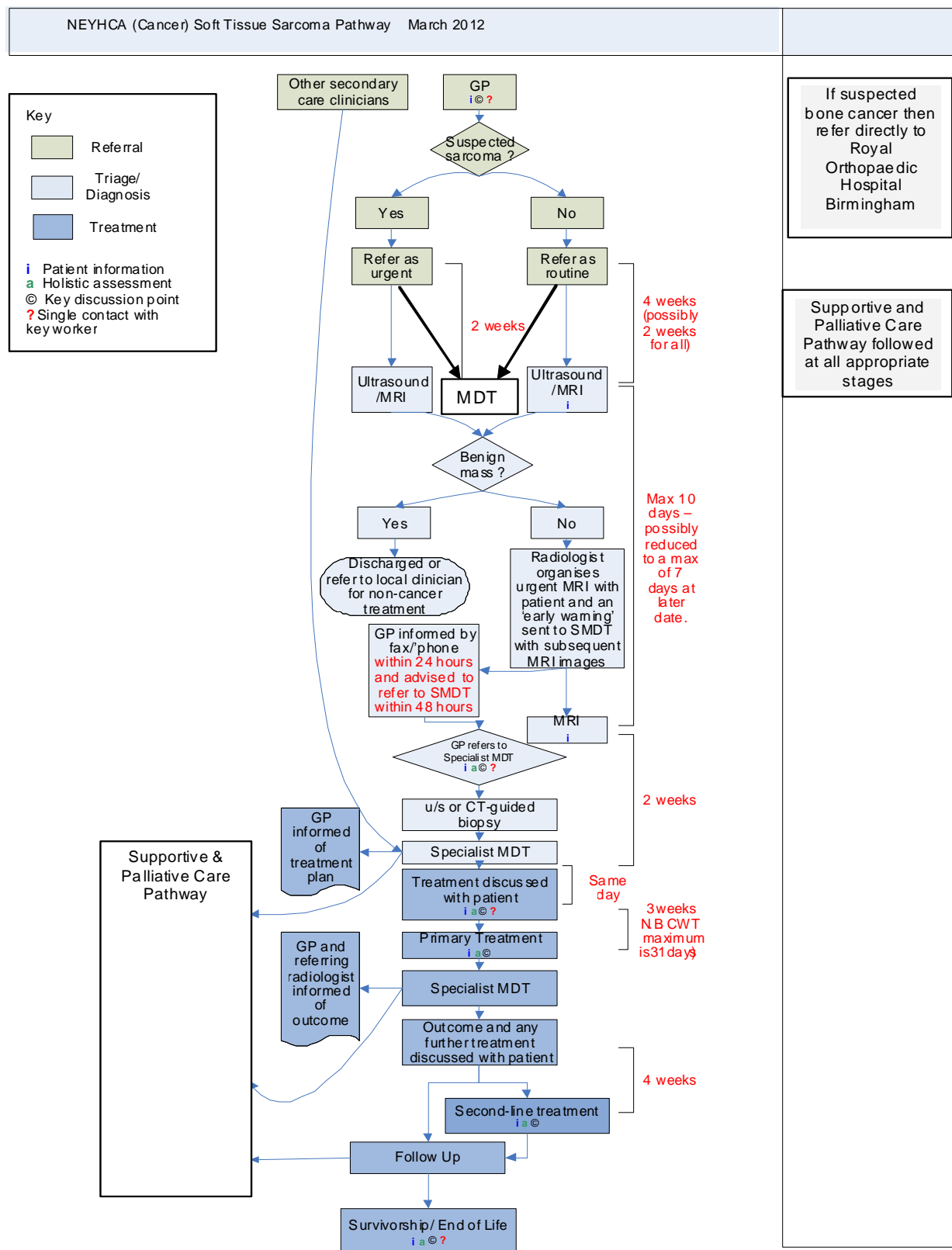
Fresh tissue to be sent to cytogenetics. (Paul Roberts, Head of Cytogenetics, Leeds Hospital)
Confirmation of Laboratory details to be checked against list in Peer Review measures (list still to be published)

Treatment

- Surgery to be undertaken at agreed Specialist Treatment Centre
- IOG – compliant membership
- Radiotherapy and Chemotherapy to be undertaken at agreed designated Centre
- Second-line treatment probably radiotherapy/ some chemotherapy

Surgical Follow-up with designated LSTSMMDT surgeon (either core or extended member depending on location of the lesion. Shared F/U care with local trust's surgeon

4.21 NEYHCA (Cancer) Soft Tissue Sarcoma Pathway April 2012



4.3 Referral Guidelines between Specialist Teams

4.31 Local Soft Tissue Sarcoma Multidisciplinary Team

Core Team	Name / Cover
Specialist sarcoma surgeons (x2)	Mr Platt, Consultant Plastic Surgeon (MDT Lead) Mr Stanley, Consultant Plastic Surgeon (SIG Member responsible for Service Improvement)
Specialist sarcoma radiologist (x2)	Dr Taylor, Consultant Radiologist Dr Bates, Consultant Radiologist
Specialist sarcoma pathologist (x2)	Dr Roy, Consultant Histopathologist (SIG Vice Chair) Dr Mathew, Consultant Histopathologist
Medical/Clinical oncologist (x2)	Professor Lind, Consultant Medical Oncologist (SIG Chair, Member responsible for Clinical Trials & research) Dr Barton, Consultant Clinical Oncologist
Clinical nurse specialist (x1)	Sharon Edwards, Sarcoma/Melanoma CNS (SIG Member responsible for patient / user issues)
MDT coordinators (x3)	Ms Janet Dent Ms Victoria Frost Ms Gill Moverley
Extended Team	Name
Physiotherapist	Ms Barbara Brown, Physiotherapist
Skin	Mr Platt, Consultant Plastic Surgeon
Gynaecology	Mr Giannopoulos, Consultant Gynaecologist
Gynaecology oncologist	Dr Bashir, Consultant Clinical Oncologist
Head and Neck	Professor Stafford, Consultant Surgeon
Head and Neck oncologist	Mr Wieczorek, Consultant Clinical Oncologist
Gastrointestinal	Mr Hartley, Consultant Colorectal Surgeon
GIST, oncologist	Dr Iqbal, Consultant Medical Oncologist
GIST, Histopathologist	Dr Justin Cooke, Consultant Histopathologist
Thoracic	Mr Cowen, Consultant Cardiothoracic Surgeon
Central nervous system	Mr Achawal, Consultant Neurosurgeon
Urology	Mr Simms, Consultant Urologist
Breast	Mr Kneeshaw, Consultant Breast Surgeon
Colorectal	Mr James Gunn, Consultant Colorectal Surgeon
AHP, rehabilitation	Dr Jayawardhana, Consultant in Disability & Rehabilitation
Specialist Palliative Care	Dr Saharia, Consultant Palliative Medicine, Oncology

4.32 Isolated Limb Perfusion

Patients are currently referred to the Royal Marsden Hospital, London as there is no provision for this service within the area. Referrals to be sent to the Royal Marsden by normal referral letter or cancer referral form, to the Central Referral Office. Mr Andrew Hayes is one of the sarcoma surgeons within that unit.

For more information please check the Royal Marsden's Website

<http://www.royalmarsden.nhs.uk/RMH/healthcare/info4gps/patientreferrals.htm>

Central Referrals Office
The Royal Marsden Hospital
Downs Road
Sutton SM2 5PT
Switchboard – 020 8642 6011 Fax: 020 8661 3143

Please note that emails are only accepted from other nhs.net addresses to ensure patient confidentiality.

Since January 2005 referrals have been accepted through the Choose and Book system. For more information please use the following link: www.chooseandbook.nhs.uk. The Trust also accepts 'requests for advice' via Choose and Book should another healthcare professional have an oncology query but has no need for a formal appointment.

Initial follow up would be carried out by the Royal Marsden Hospital. The patient would then be referred back to the relevant team member.

[All Sarcoma's arising in the skin are dealt with by the Sarcoma MDT.](#)

This is due to skin surgeons, skin histopathologist and CNS being present core members of the Specialist Skin MDT.

A copy of the HEYHT Sarcoma referral form can be found in **Appendix ii**

[4.33 Gynaecology](#)

Patients that have initially been seen by the Gynaecology MDT would be referred to the LSTSMMDT once a definitive diagnosis has been made, to allow the case to be discussed between the two groups' clinicians. A formal management plan can then be produced. Follow up treatment will be provided by the Gynaecology MDT.

[4.34 Head and neck](#)

Patients that have initially been seen by the Head and Neck MDT would be referred to the LSTSMMDT once a definitive diagnosis has been made, to allow the case to be discussed between the two groups' clinicians. A formal management plan can then be produced. Follow up treatment will be provided by the Head and Neck MDT.

[4.35 Gastrointestinal / pelvic/ retro peritoneal](#)

Patients that have initially been seen by the Upper GI / HPB MDT would be referred to the LSTSMMDT once a definitive diagnosis has been made, to allow the case to be discussed between the two groups' clinicians. A formal management plan can then be produced. Follow up treatment will be provided by the Upper GI / HPB MDT.

[4.36 GIST](#)

Patients that have initially been seen by the Upper GI / HPB MDT would be registered with the LSTSMMDT once a definitive diagnosis has been made, to allow the case to be discussed between the two groups' clinicians.

Follow up treatment will be provided by the Upper GI / HPB MDT.

Patients that have initially been seen by the Colorectal MDT would not be registered with the LSTSMDT. Once a definitive diagnosis has been made, the case may be discussed between the two groups' clinicians if necessary.

Follow up treatment will be provided by the Colorectal MDT.

4.37 Thoracic

Patients that have initially been seen by the Thoracic MDT would be referred to the LSTSMDT once a definitive diagnosis has been made, to allow the case to be discussed between the two groups' clinicians. A formal management plan can then be produced.

Follow up treatment will be provided by the Thoracic MDT for primary disease; metastatic disease will be referred to the Clinical/Medical Oncologist or referred back to the referring Consultant.

4.38 Brain & Central Nervous System (BCNS)

Patients that have initially been seen by the BCNS MDT would be referred to the LSTSMDT once a definitive diagnosis has been made, to allow the case to be discussed between the two groups' clinicians. A formal management plan can then be produced.

Follow up treatment will be provided by the Brain & CNS MDT for primary disease; metastatic disease will be referred to the Clinical Oncologist.

4.39 Urology

Patients that have initially been seen by the Urology MDT would be referred to the LSTSMDT once a definitive diagnosis has been made, to allow the case to be discussed between the two groups' clinicians. A formal management plan can then be produced.

Follow up treatment will be provided by the Urology MDT.

4.310 Breast

Patients that have initially been seen by the Breast MDT would be referred to the LSTSMDT once a definitive diagnosis has been made, to allow the case to be discussed between the two groups' clinicians. A formal management plan can then be produced.

Follow up treatment will be provided by the Breast MDT.

4.311 Soft tissue Sarcoma arising in Children and Young Adults

All age groups covered by the Improving Outcomes Guidance for Children and Young People with Cancer i.e. 0-24 years will be referred to the appropriate Principle Treatment Centre when there is a high suspicion of, or a confirmed diagnosis of soft tissue sarcoma.

(See Chapter 10 for further details)

4.312 Skin Guidelines

The following section has been added to the Skin Guidelines with reference to Sarcoma referrals:

"Sarcoma (Kaposi's and cutaneous) Patients with sarcomas involving the skin:

Patients are initially discussed by the LSMDT (HEYHT / NLGHFT / SNEYHT). Following a positive histology report the patient will be referred to a Consultant Plastic Surgeon who is a core member of a SSMDT. Follow up would be carried out by the Sarcoma SMDT"

The skin guidelines are available on the NEYHCA (Cancer) website

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/SkinNSSG.htm>

4.313 Contact numbers for Sarcoma cancer referrals to specialist teams

Tumour area / Specialty	Consultant	Secretary / Contact Number
Physiotherapist	Ms Barbara Brown	CHH 6799
Skin / plastics	Mr Platt	Elizabeth Roberts 01482 622306
Gynaecologist	Mr Giannopoulos	Pauline Holgate 01482 624098
Gynaecology oncologist	Dr Bashir	Patricia Crabtree 01482 461272
Head and Neck surgeon	Professor Stafford	Elaine Hackett, 01482 605254
Head and Neck oncologist	Mr Wieczorek	01482 461267
Gastrointestinal surgeon	Mr Hartley	Darney Wilson, 01482 623050
GIST oncologist	Dr Iqbal	Sharon Mason 01482 461299
GIST Histopathologist	Dr Cooke	01482 605307
Thoracic surgeon	Mr Cowen	Gill Morgan 01482 673578
Neurosurgeon	Mr Achawal	Lesley Hart 01482 607877
Urologist	Mr Simms	Wendy Brooksby 01482 622188
Breast surgeon	Mr Kneeshaw	Sue West 01482 622638
Colorectal	Mr Gunn	Stephanie Roe 01482 623247
AHP, rehabilitation	Dr Jayawardhana	Alison Pinnell 01482 622018
Specialist Palliative Care	Dr Saharia	Sheila Lythe CH 761306
Children / TYA	Leeds MDT	YCN – Dan Stark 0113 2068266 Sheffield - Dr Vicki Lee / Dr Jeanette Payne 0114 271 7317

4.4 LSTSMDT Co-ordinator

Purpose

The rapid and effective navigation of the patient through the pathway, from referral to the completion of the final modality of treatment, with the assistance of the sarcoma clinical nurse specialist.

Scope

All patients referred to the LSTSMDT or its core members, with a possible or proven diagnosis of soft tissue sarcoma.

Core responsibilities

1. All patients referred will be discussed by the LSTSMDT.
2. LSTSMDT discussion can only be facilitated by appropriate clinical, radiological and histopathological information.
3. It is the responsibility of the referring clinician to provide this information where it is available.
4. It is the responsibility of the LSTSMDT to confirm the diagnosis, stage and management plan based upon the information received.
5. It is the responsibility of the LSTSMDT to clearly identify who is responsible for actioning any management plan and for communicating this plan in a clear and timely manner.

4.41 Minimum data required for referral

NEYHCA (Cancer) have agreed a diagnostic pathway for suspected soft tissue sarcoma.

This pathway should be followed. HEYHT patients will be managed by LSTSMDT and as such referral with abnormal U/S (plus clinical minimum data) only is acceptable. The referral should also include core clinical data as this may influence interpretation of imaging and inform risk of biopsy.

When additional imaging and/or resection/biopsy has been performed the date and location of investigations should be provided.

Fax-back referral form

Data taken from the fax back referral form includes:

Minimum dataset

Core

- Patient identifiers and demographics including telephone number and transport needs
- Source of referral
- Lesion characteristics
- Site, size, position relative to fascia, date of onset, rate of growth, local pain
- Date and place of investigations performed to date
- Ultrasound, MRI, CT, biopsy, resection
- How much information has the patient been given on the diagnosis / potential diagnosis?

Additional minimum data (to be obtained by telephone from patient if missing)

- Risk factors
- Prior trauma, past personal or family history of soft-tissue or bone masses, history of connective tissue disease
- Diagnostic limitations
- Unable to lie flat / claustrophobic
- Anti-coagulated/bleeding diathesis

Additional data that the LSTSMDT will aim to collect:

- New confirmed soft tissue sarcoma patient per year.
- % of new cancer patients discussed at LSTSMDT meetings
- % of new cases referred as 2ww compared to national figures
- Conversion rate for 2ww cases
- Meeting with GFOCWT and CWT targets
- Number of inter hospital transfer breaches
- Average length of stay for procedure
- Pre/post operative days
- Readmission rates for complications
- Incidence of cancer
- Age standardised mortality rate, and is it falling
- 30 day mortality rate following surgery
- Hospital mortality rate post surgery
- 1,2 and 5 year survival
- Record of staging

Audit & research information

- Participation in SCG wide audit (national when available)
- % of patients entered into trials
- Evidence of patient experience audits

4.42 Referral handling

All referrals, from all sources, should be handled by the LSTSMDT office.

Direct or indirect (via LSTSMDT constituent core members) referrals should be faxed to the LSTSMDT office (01482 622353) and receipt from any source confirmed by telephone (01482 622675, LSTSMDT coordinator).

The LSTSMDT office will confirm acceptance of the referral, by telephone or e-mail, on receipt of a completed fax-back referral form.

4.43 MDT discussion

Referrals will be discussed at the first available LSTSMDT meeting. These meetings run weekly on Wednesday afternoons between 13.00 and 14.00. When pathology and imaging review are required deadlines for receipt of blocks/slides and/or films / CD-ROMs fall before this time.

- Histology preceding Monday 12.00
- Radiology preceding Tuesday 12.00

The acceptance response from the LSTSMDT office will make these deadlines clear and will indicate when, provisionally, a case will be discussed on the basis that imaging/blocks and slides are received before the given deadlines.

When it is made apparent that there is a clinical (rather than CWT) need for review and that delay will be introduced by virtue of these deadlines it may be appropriate to see the patient in a clinic or arrange suitable radiology tests prior to LSTSMDT discussion.

4.44 Clinic placement

Cancer Waiting Time Standards (January 2009)

- 2WW from Urgent GP referral for suspected cancer to date of first seen in hospital setting (Target 93%)
- 31 days from the decision to treat to first treatment commencing for all cancers (Target 96%)
- 31 days from the decision to treat to second or subsequent treatment commencing for all anti cancer drug treatments (Target 98%)
- 31 days from the decision to treat to second or subsequent treatment commencing for surgery (Target 94%)
- 62 days from Urgent GP referral first treatment commencing for all cancers (Target 85%)
- 62 days from consultant screening service referral to first treatment commencing for all cancers (Target 90%)
- 62 days from consultant upgrade to first treatment commencing for all cancers (target not yet set)

January 2010

- 2WW for symptomatic breast patients (Cancer not initially suspected) (Target 93%)

CWT '14-day' rules

Department of Health CWT rules stipulate that patients with suspected cancer must be seen within 14 days of an urgent GP referral.

This rule applies to the sarcoma service but importantly it is acceptable for the initial contact could be the radiologist performing the local imaging, and this could be in the one stop soft tissue clinic.

CWT '31- and 62-day' rules

The LSTSMDT is obligated to initiate definitive treatment within 31 days of a 'decision to treat' based upon an informed LSTSMDT discussion or within 62 days of urgent GP referral, whichever is the sooner.

Unless clinical information (that could be derived from an out-patient clinic visit) is missing that could inform a decision to treat there is no need for patients to be seen in clinic prior to LSTSMDT discussion.

Patients may not be seen prior to investigations. Information packs (postal and/or e-mail) and telephone support will be needed and this maybe given by the Clinical Nurse Specialist (CNS). Initial presentation will be subject to CWT. Patients with lower risk on clinical grounds could have a deferred appointment (provided they have had at least a U/S as 1st point of contact).

Patients with benign imaging/histology can drop off the fast track system and have a deferred appointment. They need to be informed of these decisions promptly (by telephone and letter), but need not come to clinic as the LSTSMDT is in effect offering a screening service for soft tissue masses in these situations.

4.45 LSTSMDT meeting core functions

1. All cases of suspected or actual sarcoma must be discussed at the LSTSMDT meeting
2. For all soft-tissue sarcoma diagnoses LSTSMDT to agree
 - a. Histopathological diagnosis
 - b. Disease stage
 - c. LSTSMDT management plan
 - d. Role of non-sarcoma specialist MDT/personnel if applicable
3. For bone sarcoma diagnoses LSTSMDT to agree
 - a. Need for referral to supra-regional bone sarcoma MDT at the Birmingham Royal orthopaedic Hospital
4. For patients within Teenage/Young Adult (TYA) remit, LSTSMDT to agree
 - a. Indication for shared involvement of TYA and sarcoma MDTs
 - b. LSTSMDT management plan
 - c. Role of sarcoma MDT members in plan delivery
5. For non-sarcoma diagnoses LSTSMDT to agree
 - a. LSTSMDT management plan *or*
 - b. Referral to named team/clinician *or*
 - c. Return to referring clinician stating non-sarcoma diagnosis without a recommended management plan

4.46 MDT meeting outcomes

- Imaging list
- Biopsy list
- Surgical clinic
- Radiotherapy clinic
- Systemic therapy clinic
- Recommend referral to named service
- Identification of a key worker
- Referral to Birmingham for bone sarcoma's
- Referral to Leeds Children / TYA service
- Rehabilitation pathway
- Palliative & Supportive Care services
- Discharge

LSTSMDT meeting documentation

1. All discussions minuted 'live' during the LSTSMDT meeting
2. Histology and radiology review to be *formally* documented
3. Reasoning under-pinning 'non-standard' decisions to be documented
4. Any actions arising to have a named executor and agreed time-frame
5. Handover from LSTSMDT review must be to a named clinician
6. Documentation to be maintained on LSTSMDT proforma
7. GP and referring clinician to receive a copy of the LSTSMDT decision within 24 hours.

Data-capture

8. LSTSMDT will capture data on all diagnoses and outcomes referred to it on LSTSMDT proforma
9. Core database information is held on an access database by the LSTSMDT data manager
10. Staging data to be documented. Specify grade, size, type and stage as well as post operative margin status for all cases
11. LSTSMDT will agree diagnostic and management plan
12. Executing clinicians will feed-back outcome data to the data manager
13. Case tracking (via LSTSMDT office) will ensure that dataset is maintained

Sarcoma data set structure

The LSTSMDT collects standard Registry and Cancer Waiting time data. This information is held on an access database by the LSTSMDT coordinator.

4.5 Sarcoma Clinical Nurse Specialist Guidelines

General Goals

The Sarcoma CNS is responsible for the management of a defined caseload of patients with Sarcoma, providing expert nursing advice and support to those patients with Sarcoma and other health professionals in relation to this patient group. They carry continuing responsibility for the assessment of care needs, the development, implementation and evaluation of programmes of care and the setting of standards of care.

Role of the Sarcoma Clinical Nurse Specialist

- To be present at the point the patient has first contact with the Sarcoma service. This may be during the diagnostic phase when there is a suspicion of sarcoma and the patient is undergoing investigation.
- To act as the patient's Key Worker and ensure contact details are provided to the patient and carer. To offer support and provide information (Patient Information Pathway). To direct the patient to where further information, advice and support is available.
- The CNS will perform a holistic assessment taking into account individual psychosocial, emotional, physical, spiritual, information and education needs to allow the development of a care plan to meet the needs identified in the assessment. They will coordinate the patient's movement through their care pathway.
- For those patients undergoing surgery, the Sarcoma CNS will provide support and information in the pre and post operative period. They will visit the patient whilst an in-patient and will liaise directly with the ward health care professionals ensuring follow up arrangements are in place.
- The CNS will be present at the other key discussion points (Sarcoma Pathway) that take place between the patient and medical staff regarding transitions between phases in the patient pathway: adjuvant therapy, suspected relapse, palliative and end-of-life. The Sarcoma CNS will provide support and relevant information at those points and ensure that relevant contact details are still available. They will visit those patients who require in-patient treatment and will again liaise directly with the ward health care professionals to ensure continued coordination of patients care.
- They will support the patient and their families at those times ensuring they receive the required information to enable them to participate in their care delivery.
- It maybe necessary for a small group of patients to have their surgery at another sarcoma centre and it will be the role of the CNS to ensure seamless provision of care between both hospitals.
- They will liaise with Community Services, to ensure seamless provision of care delivery. Those Community Services will include District Nurses, Macmillan Teams and Hospices.

4.6 NEYHCA (Cancer) LSTSMMDT Structure

Trust / Location / Arrangements for Specialist Care	Day / Time	Lead Clinician / Phone Numbers CNS	Referring PCT / Population Approx Total Referral Catchment Population LSTSMMDT 915,100 (Oct 2009)	MDT Co-ordinators Patient Trackers Data Administrators
HEYHT (Hull and East Yorkshire Hospitals NHS Trust) LSTSMMDT Castle Hill Hospital	Wednesday 1-3pm	Mr Alastair Platt Sec Elizabeth Roberts Phone 01482 622306 Fax 01482 622353 CNS(Sarcoma) Sharon Edwards Phone 01482 622640 Urgent Referral 2WW Fax 01482 675505 MDT Fax 01482 622353	NHS Hull 262,400 NHS East Riding of Yorkshire 337,000 NHS North Lincolnshire 157,200 North East Lincolnshire CTP 158,500 NHS North Yorkshire & York (old Scarborough, Whitby & Ryedale) 162,000* Total 1,077,100	Joanne Fox Phone 01482 626726 Fax 01482 622228 Victoria Frost Gill Moverley Phone 01482 624134 Fax 01482 622353

Population sizes are approximate. Source – Mid 2009 Resident Population Estimate (2001 census based), Office of National Statistics.

**The population of NHS North Yorkshire & York that falls within the NEYHCA (Cancer) boundaries (approx 162,000) are served by the NEYHCA (Cancer) MDT, however it is recognised that some patients from Scarborough will be treated in Leeds

5. Tumour Evaluation

5.1 Imaging Guidelines

The Sarcoma imaging guidelines are also available as a separate document on the NEYHCA (Cancer) website. Please use the following link:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/NetworkImagingGroup.htm>

5.11 Diagnosis

1. Patient attends GP

Patients with suspicious lesions should be referred on a 2 week wait to the joint soft tissue tumour clinic.

- a. Same day USS
- b. MRI within 1 week

Results reviewed at next available MDT

US guided biopsy and CT chest are arranged to complete work up (or other test).

Patients are then seen again in clinic with biopsy results the following week.

Patients are either seen again in clinic to discuss the MRI findings or more usually are told by phone that they need further scans (having been warned to expect a call with their MDT outcome after the MDT. These calls are made by the Sarcoma CNSs.

2. Soft tissue Mass present and GP refers based on the sarcoma guidelines

- a. Ultrasound one stop clinic
- b. Consultant surgeon

3. Ultrasound

- a. Performed/supervised by clinician – FRCR/ RCR accredited to perform/report ultrasound (preferably muscular skeletal, and preferably the one stop clinic service).
- b. History re-taken regarding – duration, precipitants, growth, associated symptoms. Examined for position and local changes.
- c. Ultrasound machine used must be of diagnostic/medical standard with at least 6 monthly QA of electrical safety, transducer, machine and monitor quality.
- d. Ultrasound examination to assess – mass size, mass location (relation to fascia), echotexture, cyst/solid/mixed, Doppler characteristics.
- e. If diagnostic for non sarcoma (benign) (appendix 1) – report to GP.
- f. If diagnostic for non sarcoma (malignant) by history and appearances – report to GP and copy sent to relevant MDT for discussion.
- g. If diagnostic for lipoma but concerning symptoms (appendix 2) – report to GP & MRI (notify sarcoma service).
- h. If suspicious for sarcoma or indeterminate (appendix 3)–report to GP& MRI (notify sarcoma service).

4. MRI – performed within 2 weeks of Ultrasound (ideally <10 days)
 - a. Recommended protocol – appendix 4.
 - b. If claustrophobic refer to sarcoma service with ultrasound.
 - c. If diagnostic for non sarcoma (benign) (appendix 1) – report to GP.
 - d. If diagnostic for non sarcoma (malignant) (appendix 2) – report to GP and copy sent to relevant MDT for discussion.
 - e. If suspicious for sarcoma or indeterminate (appendix 4)–report to GP& MRI (notify sarcoma service).
5. Sarcoma Service
 - a. Review MR and US.
 - b. Keep biopsy appointment or
 - c. Postpone biopsy and advise LSMDT review first
6. Continue on diagnostic pathway.

5.12 Biopsy

1. Performed by LSMDT member and send to sarcoma histopathologist.
2. Image guided – dependant on anatomical location and expertise will be either ultrasound, fluoroscopically or CT guided.
3. Non-image guided (in clinic) - dependant on anatomical location and expertise, may be preferential for expediting management decisions if radiology shows no requirement for targeting focal areas of the mass.
4. Samples should be obtained using a core needle and as large as possible (typically greater than 16 gauge) but will ultimately depend on location, lesion type and patient co-morbidity.
5. At least 2 samples should be sent preserved to histopathology and 1 sample fresh to cytogenetics if possible – variations on the need for further fresh specimens will depend on level of suspicion for differing suspected tumour types.

5.13 Staging

1. Primary (local) staging will be typically addressed by the diagnostic ultrasound and/or MRI.
2. Staging CT thorax, abdomen and pelvis will be performed routinely to address metastases for highly suspicious lesions prior to known biopsy results or after positive biopsy results. Currently being audited
3. Routine CT/MRI liver, bone or PET scanning is unnecessary except for specific histological subtypes.

5.14 Relapse

1. Suspected early post treatment complications (< 4 weeks) can be initially assessed by ultrasound to detect abscess, seroma and haematoma.
2. Suspected tumour persistence or tumour recurrence will be typically best evaluated by MRI (may need contrast, see appendix 4). Alternative or additional use of ultrasound, CT, isotope bone scan and PET scanning will depend on the suspected tumour type or contraindications to MRI.
3. Biopsy may be necessary to clarify the diagnosis (same criteria as above).

5.15 Follow Up

1. CXR 6 monthly for 5 years for all high grade sarcomas. CT thorax only when clinically indicated. MRI 6 months post surgery for intermediate and high grade tumours of the limbs.
2. CT 6 months post surgery for intermediate and high grade tumours of the abdomen
3. PET scanning where clinically indicated

5.16 Benign Diagnoses

Category	Name	Description
1	Normal	No abnormality seen on ultrasound
2	Benign cyst or Ganglion cyst	Oval lesion, hypo-echoic centrally with a well defined wall and posterior acoustic enhancement
3	Benign vascular lesion	Solid or cystic structure with minor linear vascularity demonstrated on colour or power settings
4	Benign Other	Any lesion with either inflammatory characteristics or benign soft tissue mass
5	Lipoma	Homogenous hyper-echoic lesion within the dermis or deep fat planes, no flow within it on colour or power settings and causing no or minimal mass effect to the surrounding structures

5.17 Lipoma Requiring Further Evaluation

Category	Name	Description
6	Lipoma requiring further evaluation	(i) Clinically painful, enlarging , greater than 5cm in size, deep to fascia or (ii) Lipoma but mild heterogenicity on ultrasound

5.18 Indeterminate & Sarcoma

Category	Name	Description
7	Indeterminate	(i) Clinically painful or (ii) Enlarging solid mass and no Doppler flow
8	Possible sarcoma	Solid, heterogeneous lesion with distortion of surrounding anatomy and disorganized vascularity on doppler flow

5.19 MRI Protocol Guidelines

1. Mark mass with capsule(s).
2. MR imaging performed in 2 orthogonal planes, 5-6 mm slice thickness.
 - a. Axial and Sagittal or Coronal
 - b. T1 weighted (without fat suppression)
 - c. T2 without weighted with fat suppression
 - d. STIR or PD with fat saturation
3. Fast spin echo sequences can be used to reduce motion artefact.
4. Gadolinium useful
 - a. To determine solid or cystic
 - b. Identify necrotic tumour or haematoma
 - c. Patients who have had previous surgery or radiotherapy
5. If gadolinium given T1 fat saturated sequences should be performed post injection. It is NOT necessary to perform T1 fat saturated sequences pre gadolinium injection.
6. Small field of view is ideal but if very focussed should perform localiser views so subsequent clinicians involved can determine exact body positioning.

5.2 Pathology Guidelines

5.21 Introduction

This document supplements the Data set for Cancer Histopathology Reports on Soft Tissue Sarcomas, which is under consultation with the Royal College of Pathologists. Please use the following links:

Dataset for cancer histopathology reports on soft tissue sarcomas [November 2009](#)

<http://www.rcpath.org/index.asp?PageID=1619>

Dataset for histopathology reports on primary bone tumours [April 2010](#)

<http://www.rcpath.org/index.asp?PageID=1635>

All soft tissue tumour cases will be selected for review as per the national and local guidelines. There are two specialist sarcoma pathologists in the region reporting the specimens, one of whom is the nominated lead pathologist. They will contribute to the regional sarcoma MDT; participate in the National Soft Tissue EQA and in local audit.

All patients with soft tissue tumours assessed in a diagnostic clinic should have their pathology reported by a specialist soft tissue pathologist.

5.22 Specimen Types

Needle core biopsies

Open biopsies

Resection specimens – this includes large specimens, amputated limbs, limb girdle amputations, chest wall resections, retroperitoneal sarcomas and sarcomas associated with specific organs.

Fine needle Aspiration Cytology has only very limited role in the diagnosis of soft tissue sarcomas and should be avoided as far as possible.

Molecular studies - As far as possible fresh tissue should be made available to the cytogenetics department based at St. James's University Hospital for molecular studies. When fresh tissue is not available, six unstained sections on super frost slide should be sent for FISH analysis.

Specimens should be reported to an agreed time frame so as to allow appropriate clinical decision-making at a planned LSTSMdT meeting.

5.23 Clinical information required on the request form

In addition to the demographic data, the following information should be included in the request form.

1. Duration, site, size and plane of the tumour (subcutaneous, intramuscular etc.)
2. History of relevant past illnesses, radiotherapy, chemotherapy or surgery.

5.24 Preparation of specimen before dissection

1. Needle core biopsies.

Ideally, at least two samples should be provided to the histopathology department, one in formalin for histopathological examination and the other in tumour transport medium for cytogenetics. If tumour transport medium is not available, the tissue should be sent in normal saline and it should reach the Cytogenetics laboratory within four hours of the procedure.

2. Open biopsies should be sent fresh. If the specimen is large enough, small pieces of tissue can be taken for cytogenetics and also to be frozen in liquid nitrogen at -80 degree centigrade.

3. Resection specimens should be sent fresh. The specimen should be weighed, inked and measured. The specimen is then sliced. Small samples are removed for freezing and the sample for cytogenetics should be placed in tumour transport medium. The main specimen is placed in formalin for adequate fixation. Photograph of the specimen before and after slicing is desirable.

Blocks are taken to include the nearest resection margin. Lesions smaller than 5cm should be processed in its entirety. One block per cm of the longest diameter of the tumour should be ideally taken. Areas, which appear visibly different, require adequate extra sampling. In large liposarcomas, particularly of the retroperitoneum, any area with different colour or consistency should be adequately sampled to detect dedifferentiation.

5.25 Core data for soft tissue sarcoma reporting

Clinical

- Site
- Plane of the tumour

Macroscopic Description

- Type of excision.
 - Incisional
 - Excisional
 - Radical†
- Maximum tumour dimensions.
 - Measurements should be given in three dimensions.

- Presence or absence of necrosis and percentage of necrosis.
- Other features of note.
 - Ossification.
 - Calcification.

Microscopic Description

- Histological type.
 - Soft tissue sarcomas are categorised based on WHO consensus classification of 2002.
- Grade (FNCLCC) 1 / 2 / 3
- Immunohistochemistry results
- Tissue planes involved
 - cutaneous
 - subcutaneous
 - deep fascia
 - subfascial
 - intramuscular†
- Status of margins
 - marginal
 - wide
 - radical†
- Cytogenetics or Molecular studies.
- SNOMED codes T..... M.....
- Pathologist:
- Date:

5.26 Reporting of small biopsy specimens

The report should include the histological diagnosis with grade with the caveat that the excision specimen may have a higher grade. Immunohistochemical results should be included where appropriate.

Results of molecular and cytogenetic studies can be issued as supplementary reports.

Points to note:

1. Extremity pleomorphic sarcomas with myogenic differentiation have a worse prognosis compared to others. Hence immunohistochemical positivity for myogenic markers such as smooth muscle actin, Desmin, smooth muscle myosin, H-Caldesmon or nuclear positivity for Myogenin or MyoD1 should be specifically noted. The pattern of staining should be mentioned i.e. diffuse, focal or occasional.
2. Retroperitoneal high-grade sarcomas could possibly represent dedifferentiated liposarcomas, which are known to have better prognosis. In order to confirm the latter diagnosis, any fatty tissue surrounding the tumour should be sampled extensively to identify well-differentiated liposarcomatous areas.

Immunohistochemical staining for MDM2 or FISH analysis on paraffin blocks will aid in the diagnosis.

5.27 Referral for review or specialist opinion

All patients seen within NEYHCA (Cancer) with suspicion or diagnosis of sarcoma must be reviewed by a specialist soft tissue Sarcoma Team.

The complete histopathology report should be available at the LSTSMDT meeting. The reports, slides and blocks should be requested at least five days prior to the meeting and should be available at least three days before the meeting for review.

A formal report should be issued by the reviewing pathologist to the clinician responsible for the patient and also to the original pathologist.

Pathology Guidelines Appendix A: Histological types of sarcoma and SNOMED coding

Adipocytic tumours

Intermediate (locally aggressive)

- Atypical lipomatous tumour/well-differentiated liposarcoma 8851/3

Malignant

- Dedifferentiated liposarcoma 8858/3
- Myxoid liposarcoma 8852/3
- Round cell liposarcoma 8853/3
- Pleomorphic liposarcoma 8854/3
- Mixed-type liposarcoma 8855/3
- Liposarcoma, not otherwise specified 8850/3

Fibroblastic/myofibroblastic tumours

Intermediate (locally aggressive)

- Fibromatosis 8821/1

Intermediate (rarely metastasizing)

- Solitary fibrous tumour 8815/1
- Haemangiopericytoma 9150/1
- Inflammatory myofibroblastic tumour 8825/1
- Low-grade myofibroblastic sarcoma 8825/3
- Myxoinflammatory fibroblastic sarcoma 8811/3
- Infantile fibrosarcoma 8814/3

Malignant

- Adult fibrosarcoma 8810/3
- Myxofibrosarcoma 8811/3
- Low-grade fibromyxoid sarcoma/hyalinizing spindle cell tumour 8811/3
- Sclerosing epithelioid fibrosarcoma 8810/3

So-called fibrohistiocytic tumours

Intermediate (rarely metastasizing)

- Plexiform fibrohistiocytic tumour 8835/1
- Giant cell tumour of soft tissue 9251/1

Vascular tumours

Intermediate (locally aggressive)

- Kaposiform hemangioendothelioma 9130/1

Intermediate (rarely metastasizing)

- Retiform hemangioendothelioma 9135/1
- Papillary intralymphatic angioendothelioma 9135/1
- Composite hemangioendothelioma 9130/1
- Kaposi sarcoma 9140/3

Malignant

- Epithelioid hemangioendothelioma 9133/1
- Angiosarcoma of soft tissue 9120/3

Tumours of peripheral nerves

Malignant

- Malignant peripheral nerve sheath tumour 9540/3
- Epithelioid malignant peripheral nerve sheath tumour 9540/3

Chondro-osseous tumours

Malignant

- Mesenchymal chondrosarcoma 9240/3
- Extraskeletal osteosarcoma 9180/1

Tumours of uncertain differentiation

Intermediate (rarely metastasizing)

- Angiomatoid fibrous histiocytoma 8836/1
- Ossifying fibromyxoid tumour (including atypical/malignant) 8842/0
- Mixed tumour/myoepithelioma/
 - Parachordoma 9373/1

Malignant

- Synovial sarcoma 9040/3
- Epithelioid sarcoma 8804/3
- Alveolar soft part sarcoma 9581/3
- Clear cell sarcoma of soft tissue 9044/3
- Extraskeletal myxoid chondrosarcoma 9231/3
- Extraskeletal pPNET/Ewing tumour
 - Peripheral primitive neuroectodermal tumour 9364/3
 - Extraskeletal Ewing tumour 9260/3
- Desmoplastic small round cell tumour 8806/3
- Extrarenal rhabdoid tumour 8963/3
- Malignant mesenchymoma 8990/30
- Neoplasms with perivascular epithelioid cell differentiation (PEComa) None
- Intimal sarcoma 8800/3

Pathology Guidelines Appendix B: French federation of Cancer Centres System of Grading

Tumour differentiation

Score 1	Sarcoma histologically very similar to normal adult mesenchymal tissue
2	Sarcoma of defined histological subtype (e.g. myxofibrosarcoma)
3	Sarcoma of uncertain type, embryonal and undifferentiated sarcomas

Mitosis Count

Score 1	0-9 / 10 HPF
2	10-19 / 10 HPF
3	>20 / 10 HPF

Microscopic Tumour Necrosis

Score 0	No Necrosis
1	<50% tumour necrosis
2	>50% tumour necrosis

Histological Grade

Grade 1	Total score 2 or 3
Grade 2	Total score 4 or 5
Grade 3	Total score 6, 7 or 8

Tumour Differentiation Scores

Well differentiated liposarcoma	1
Well differentiated fibrosarcoma	1
Well differentiated MPNST	1
Well differentiated chondrosarcoma	1
Myxoid liposarcoma	2
Conventional fibrosarcoma	2
Conventional MPNST	2
Well differentiated malignant haemangiopericytoma	2
Myxofibrosarcoma	2
Pleomorphic "MFH" / undifferentiated pleomorphic sarcoma	2
Conventional leiomyosarcoma	2
Extraskeletal myxoid chondrosarcoma	2
Conventional Angiosarcoma	
Round cell liposarcoma	3
Pleomorphic liposarcoma	3
Dedifferentiated liposarcoma	3
Poorly differentiated fibrosarcoma	3
Epithelioid malignant schwannoma	3
Poorly differentiated MPNST*	3
Malignant Triton tumour*	3
Conventional malignant haemangiopericytoma	3
Giant cell & inflammatory MFH	3
Poorly differentiated / epithelioid angiosarcoma	3

Extraskeletal osteosarcoma*	3
Extraskeletal Ewing sarcoma / PNET*	3
Alveolar soft part sarcoma*	3
Malignant rhabdoid tumour	3
Clear cell sarcoma*	3
Undifferentiated sarcoma	3

*Grading of malignant peripheral nerve sheath tumour is of no prognostic value. Grading of embryonal and alveolar rhabdomyosarcoma, angiosarcoma, extraskeletal myxoid chondrosarcoma, alveolar soft part sarcoma, clear cell sarcoma and epithelioid sarcoma is not recommended. In practice, the following tumours are graded by definition as below:

1. Atypical lipomatous tumour / well differentiated liposarcoma, dermatofibrosarcoma protuberans, infantile fibrosarcoma and angiomatoid "MFH" are grade 1
2. Ewing sarcoma / PNET, rhabdomyosarcoma (except spindle cell and botryoid variants), angiosarcoma, pleomorphic liposarcoma, soft tissue osteosarcoma, mesenchymal chondrosarcoma, desmoplastic small round cell tumour and extra renal malignant rhabdoid tumour are grade 3.
3. Alveolar soft part sarcoma, clear cell sarcoma and epithelioid sarcoma are not graded but are usually considered as high grade for management purposes.

Pathology Guidelines Appendix C: Translocations & Other Genetic Abnormalities in Sarcomas

Histological Type	Translocation Or Rearrangement	Fusion Gene or other feature
Alveolar soft part sarcoma	t(X;17)(p11;q25)	<i>ASPL-TFE3</i>
Angiomatoid fibrous histiocytoma	t(12;22)(q13;q12) t(12;16)(q13;p11) t(2;22)(q33;q12)	<i>EWSR1-ATF1</i> <i>FUS-ATF1</i> <i>EWSR1-CREB1</i>
Clear cell sarcoma	t(12;22)(q13;q12)	<i>EWSR1-ATF1</i>
Clear cell sarcoma (GIT)	t(2;22)(q33;q12)	<i>EWSR1-CREB1</i>
Dermatofibrosarcoma protuberans	t(17;22)(q21;q13) Ring form of chromosomes 17 & 22	<i>COL1A1-PDGFB</i>
Desmoplastic SRCT	t(11;22)(p13;q13)	<i>EWSR1-WT1</i>
Epithelioid sarcoma	Abnormalities of 22q	<i>INI1</i> inactivation
Ewing sarcoma/PNET	t(11;22)(q24;q12) t(21;22)(q12;q12) t(2;22)(q33;q12) t(7;22)(p22;q12) t(17;22)(q12;q12) Inv(22)(q12;q12)	<i>ESWR1-FLI1</i> <i>EWSR1-ERG</i> <i>EWSR1-FEV</i> <i>EWSR1-ETV1</i> <i>EWSR1-E1AF</i> <i>EWSR1-ZSG</i>
Extraskeletal myxoid chondrosarcoma	t(9;22)(q22;q12) t(9;17)(q22;q11) t(9;15)(q22;q21)	<i>ESWR1-NR4A3</i> <i>TAF1168-NR4A3</i> <i>TCF12-NR4A3</i>
Fibrosarcoma, infantile	t(12;15)(p13;q26) Trisomies 8, 11, 17 & 20	<i>ETV6-NTRK3</i>
Inflammatory myofibroblastic tumour	2p23 rearrangement	<i>ALK</i> fusions with various genes
Leiomyosarcoma	Deletion of 1p	
Liposarcoma Well differentiated Myxoid/round cell Pleomorphic	Ring form of chromosome 12 t(12;16)(q13;p11) t(12;22)(q13;q12) Complex	<i>FUS-DDIT3</i> <i>ESWR1-DDIT3</i>
Low grade fibromyxoid sarcoma	t(7;16)(q33;p11)	<i>FUS-CREB3L2</i> <i>FUS-CREB3L1</i> (rare)
Malignant rhabdoid tumour	Deletion of 22q	<i>INI1</i> inactivation
MPNST	Complex	
Myxofibrosarcoma	Ring form of chromosome 12	
Rhabdomyosarcoma Embryonal Alveolar	Trisomies 2q, 8 & 20 t(1;13)(p36;q14) t(2;13)(q35;q14)	<i>LOH at 11P15</i> <i>PAX7-FKHR</i> <i>PAX3-FKHR</i>
Synovial sarcoma	t(X;18)(p11;q11) t(X;20)(p11;q13)	<i>SS18-SSX1</i> <i>SS18-SSX2</i> <i>SS18-SSX4</i> (rare) <i>SS18L1-SSX1</i>

GIT indicates gastrointestinal tract; SRCT, small round cell tumour; PNET, primitive neuroectodermal tumour; MFH, malignant fibrous histiocytoma; MPNST, malignant peripheral nerve sheath tumour; LOH, loss of heterozygosity

6. Sarcoma Physiotherapist

6.1 General goals

To provide a seamless, patient-centred physiotherapy service for adults with bone and soft tissue sarcoma that can be accessed from initial contact and at any stage during their treatment pathway.

6.1.1 Role of the Sarcoma Physiotherapist

- To work as a core member of the LSTSMMDT, providing soft tissue and bone sarcoma patients (as in- and out-patients) with Specialist physiotherapy input from diagnosis and along their treatment pathway including surgery, radiotherapy, chemotherapy and during palliative treatment.
- To ensure that each sarcoma patient is able to access physiotherapy that is specific to their individual needs at the optimum time and provided by the most appropriate physiotherapist. This process involves a combination of both direct physiotherapy input and appropriate colleague liaison.

6.2 Rehabilitation

Cancer rehabilitation aims to maximise the patients' ability to function, to promote their independence and to help the patient adapt to their condition. By optimising their quality of life and developing self-management skills, our patients can take an active role in adjusting to life with and after cancer.

Although rehabilitative interventions are often considered primarily in terms of their physical and functional impact on patients, they can also have major psychological, social, economic and spiritual benefits.

The benefits of good rehabilitation services delivered in a timely manner at appropriate points on the patient pathway can be the prevention, or reduction of problems that often lead to increased length of hospital stay or readmissions due to crisis at home. Maintaining or increasing the patient's independence and ability to self manage reduces the need for alternative and possibly costly health and social service input.

For the purpose of this document rehabilitation refers to the interventions provided by the four allied Health Professions Occupational therapy, Physiotherapy, Speech & Language therapy, Dietetics and lymphoedema:

AHP services available locally:

- Colorectal
- Gynaecology
- Head & Neck
- Brain & CNS
- Lung (Breathless clinic already included)
- Sarcoma
- MSEC
- Upper GI / pancreatic & oesophageal

6.21 Rehabilitation Pathway

Following National Guidance, NEYHCA (Cancer) is in the process of producing a rehabilitation pathway for the Sarcoma Implementation Group, once agreed this will be available on the NEYHCA (Cancer) website and a link will be added to these guidelines.

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/rehab.htm>

Appropriate patients should be assessed by the sarcoma service physiotherapist and have an individualised rehabilitation plan agreed.

6.3 Physiotherapy for Sarcoma Patients

6.31 Pre- Operative

- LSTSMdT to inform Clinical Lead Physiotherapist: Amputee Rehabilitation (x6799 CHH) when a patient has been identified as requiring surgery to remove a tumour which will affect their mobility
- The Physiotherapist will attend the LSTSMdT meeting when a patient has been identified as possibly requiring a lower limb amputation. Pre operative physiotherapy assessment of patients having a lower limb amputation is essential to ensure support and information is provided to the patient, and preparations are in place to facilitate early discharge from hospital post surgery e.g. ordering of a wheelchair.
- The physiotherapist will liaise with the extended LSTSMdT re ongoing rehabilitation
- Patients requiring surgery other than an amputation: The Physiotherapist will flag up the admission of other patients being admitted to hospital for surgery which will affect mobility, to the relevant physiotherapy team.

6.32 In-Patient

Patients will be assessed post-operatively to enable identification of a physiotherapy treatment plan.

- Patients requiring physiotherapy following amputation of the lower limb will be managed by the Amputee Rehabilitation Physiotherapy team (x6799 CHH, based on Ward 2 CHH)
- Patients for palliative care who require physiotherapy will be managed by the Oncology physiotherapy team (bleep 545)
- Other patients will be assessed in the first instance by the physiotherapist on the appropriate ward and referred to other specialist physiotherapists if required

6.33 Out-Patient

- Patients who require on-going physiotherapy as an out patient will be referred to the appropriate out-patient service, at discharge, by the physiotherapist that has been treating them on the ward

NB// There is no specialist Physiotherapy service for Sarcoma patients therefore the Physiotherapist or other key worker involved will have access to other members of the multidisciplinary team for advice or onward referrals. Interventions will be tailored to the patient's needs and should be delivered as close to the patient's home as possible as limited by the geographic availability of other specialist services. Each Physiotherapy department will complete their own outcome measure based on the service provided.

7. Treatment

7.1 Preoperative therapy

Preoperative external beam radiotherapy (EBRT) should be considered for intermediate to high grade tumours where wide local excision (not marginal excision) is deemed possible. Surgery should take place 4-6 weeks post EBRT. Post-operative wound complications are more likely and myocutaneous-flap reconstruction may need to be considered in some cases. If marginal resection and/or permanent functional compromise secondary to potential wound complications is likely postoperative EBRT should be used.

7.2 Primary inoperable disease

7.21 Systemic therapy

Neo-adjuvant

There is no routine role for neo-adjuvant systemic therapy dependant on subtype. Amputation remains a definitive procedure but where this is deemed inappropriate (consider rehabilitative potential and metastatic risk based upon tumour characteristics) systemic therapy (regimen dictated by tumour histopathological sub-type) can be tried neo-adjuvantly. Consideration should be given to likely postoperative function as surgical resection and postoperative radiotherapy fields are likely to be large.

Primary therapy

When amputation is not possible (non-limb tumours) or appropriate, primary systemic therapy can be effective for local symptom control and extension of progression-free and overall-survival. Regimen should be dictated by tumour histopathological sub-type. Consideration should be given to consolidation radiotherapy on completion.

7.22 Isolated Limb Perfusion

Patients are currently referred to the Royal Marsden Hospital, London as there is no provision for this service within the area. Referrals to be sent to the Royal Marsden by normal referral letter or cancer referral form, to the Central Referral Office. Mr Andrew Hayes is one of the sarcoma surgeons within that unit.

For more information please check the Royal Marsden's Website

<http://www.royalmarsden.nhs.uk/RMH/healthcare/info4gps/patientreferrals.htm>

Central Referrals Office
The Royal Marsden Hospital
Downs Road
Sutton SM2 5PT
Switchboard – 020 8642 6011 Fax: 020 8661 3143

Please note that emails are only accepted from other nhs.net addresses to ensure patient confidentiality.

Since January 2005 referrals have been accepted through the Choose and Book system. There is more information at www.chooseandbook.nhs.uk.

The Trust also accepts 'requests for advice' via Choose and Book should another healthcare professional have an oncology query but has no need for a formal appointment.

Initial follow up would be carried out by the Royal Marsden Hospital. The patient would then be referred back to the relevant team member.

7.23 Radiotherapy

Primary radiotherapy can be curative for small tumours in exceptional circumstances. Dose will be limited by risk of toxicity to adjacent tissues and organs as well as patient fitness.

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

7.3 Surgery

7.31 Limb conservation vs. amputation

The primary goal of sarcoma surgery is local tumour control. Surgical goal should be resection of tumour with an unadulterated cuff of surrounding normal tissue or intact fascial plane. Planned positive or close margins can be managed adjuvantly as part of a combined modality approach with no apparent impact upon overall sarcoma specific survival.

7.32 Limb conservation

When limb conservation is being considered due thought must be given to post-operative function in terms of not only loss of local tissue and neurovascular compromise but also impact of late adjuvant therapy effects.

7.33 Amputation

If amputation is considered then the rehabilitative potential of the patient needs to be considered as does the absolute risk of sarcoma related death.

7.34 Reconstruction

Concerns over wound closure should not compromise surgical margins. Reconstructive considerations should be made pre-operatively. When periosteal stripping of long bones has been performed to get tumour clearance prophylactic intra-medullary nailing should be scheduled to follow adjuvant radiotherapy. (Dependant on extent of periosteal stripping)

7.35 Metastasectomy

Resection of limited or oligo-metastatic sites should be considered in fit patients as a survival advantage may be conferred. Prognostic factors should be considered in each case. PET scanning where clinically indicated

7.4 Adjuvant therapy

7.41 Radiotherapy

Post-operative radiotherapy as a means to improve local tumour control and facilitate limb preservation should be considered unless pre-operative radiotherapy was used.

Tumour size, grade, location relative to deep fascia, resection margins and nature of surgery are relevant to decision making. All cases should be discussed pre-op and extremity cases considered for inclusion in VORTEX and post-op at the LSTSMDT meeting and all relevant imaging, operative and histopathological reports should be available.

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

7.42 Systemic therapy

There is no role for routine use of adjuvant systemic therapy. Specific exceptions exist for paediatric-type histopathologies (see sections below). They may be an indication to offer discussion of adjuvant systemic therapy to those patients with high risk of systemic relapse, though the threshold for offering this is undefined.

Adjuvant Chemotherapy

Over the years there have been up to 18 randomised control trials of doxorubicin based chemotherapy in patients with complete resection of soft tissue sarcoma. In 1997 a meta-analysis was carried out which concluded that adjuvant chemotherapy improved local and distant disease free recurrence but not overall survival ¹. A subsequent meta-analysis in 2008 included 4 more randomised trials and this did show a statistically and clinically significant improvement in overall survival ². Needless to say most of these patients had grade III sarcomas. Therefore, it would be appropriate to offer patients with high grade resected sarcomas with adjuvant chemotherapy.

Neo adjuvant Chemotherapy

This should never be used where a curative resection can be achieved. Primary chemo can be given for cases which are truly inoperable.

Summary

The most current version of the chemotherapy regimens for Sarcoma can be found on the NEYHCA (Cancer) website. Please use the following link:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

7.5 Treatment for inoperable & metastatic disease

7.51 Active supportive care

Response rates to anticancer therapy in advanced disease are less than 20%. Supportive care should address all active symptoms. For patients not on active treatment appropriate links with community support should be established.

This may not always need to involve specialist palliative care. Access to LSTSMDT for advice should remain, even if routine review has been discontinued.

7.52 Surgery

Macroscopically incomplete resection is not usually advocated. However, this may be necessary for bleeding or obstructive/compressive symptoms. Consolidation non-surgical anticancer therapy should be actively considered.

7.53 Radiotherapy

Radiotherapy can be an effective means of local symptom control. Higher dose regimens may improve progression free survival. Regimen selection should be appropriate to tumour site, disease stage and patient fitness.

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

7.6 Systemic therapy

Systemic therapy may improve overall survival as well as effect improvements in symptom control. Survival gains are seen predominantly in those with an objective tumour response. Such responses may be only slowly evident on imaging. Continuation of systemic therapy should be provisional upon patient tolerance, subjective benefit and objective disease response.

7.61 Chemotherapy for adult soft tissue sarcoma

Adult soft tissue sarcoma is a notoriously chemo-insensitive disease. Historically only 3 drugs are thought to show any activity in this disease (with the exception of GIST). These are doxorubicin, Ifosfamide and DTIC (dacarbazine).

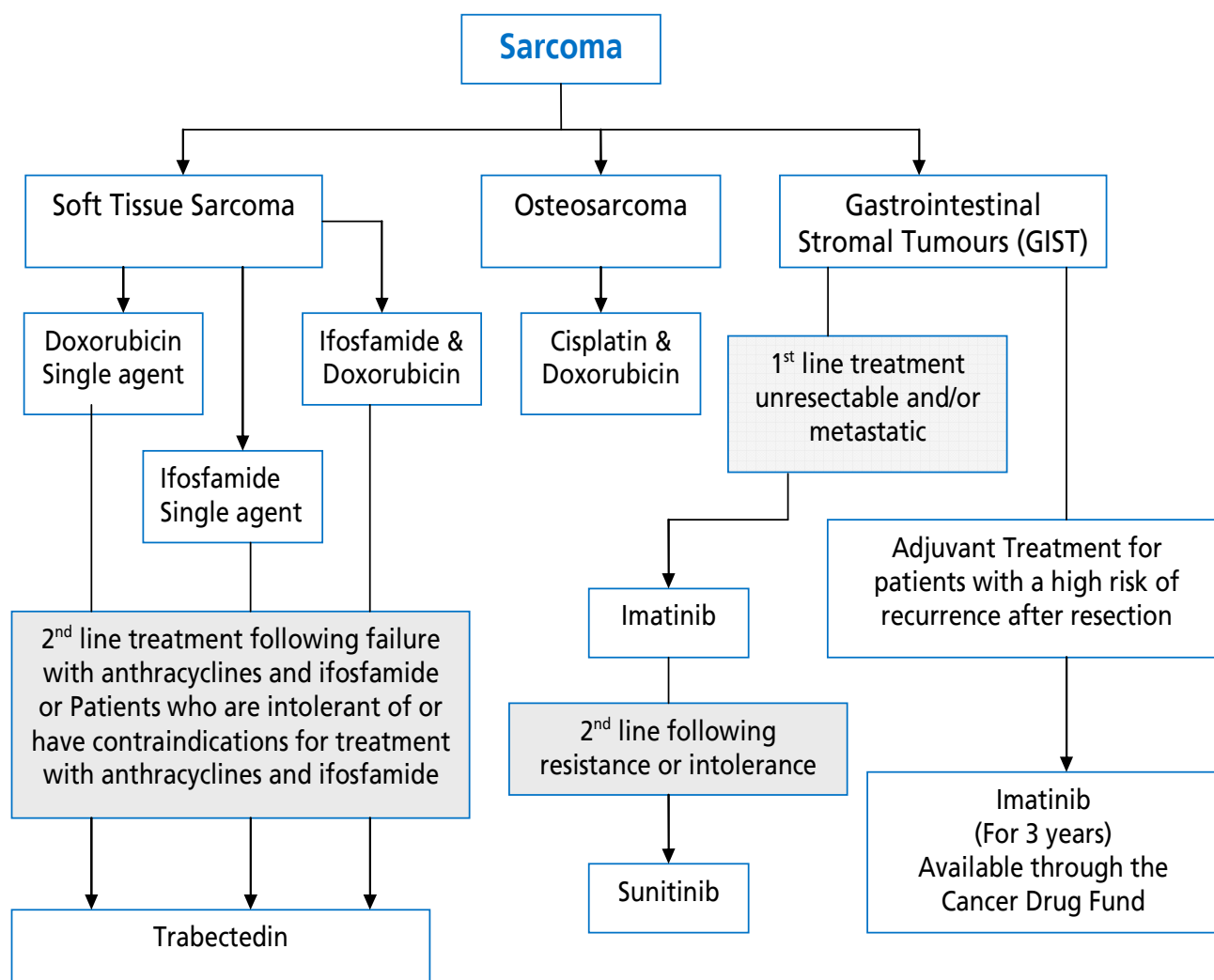
Over the years a number of randomised trials comparing single agent doxorubicin with doxorubicin combinations have been performed. Response rates of about 20% and median overall survival of 12 months are consistently reported.

To date none of these combinations have shown any advantage over single agent doxorubicin³. Therefore first line treatment should be with doxorubicin. If the patient is fit enough, Ifosfamide can be considered as second line, although the responses rate in this setting is only 8%. Alternatively, dacarbazine has similar activity, but can be given as an outpatient, with less toxicity. Trabectedin has shown some activity in liposarcoma and leiomyosarcoma patients who have failed doxorubicin and Ifosfamide and is NICE-approved for these patients⁴. There is an opinion that myxoid liposarcoma and synovial sarcoma might benefit from a combination of doxorubicin and Ifosfamide.

Systemic treatment as per outlined in the regimens on the NEYHCA (Cancer) website: Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

7.7. Treatment Algorithm for Sarcoma



8. Treatment Specific Recommendations

8.1 Children, Teenagers & Young Adults

All age groups covered by the Improving Outcomes Guidance for Children and Young People with Cancer i.e. 0-24 years will be referred to the appropriate Principle Treatment Centre when there is a high suspicion of, or a confirmed diagnosis of soft tissue sarcoma. (See Chapter 10 for further details)

8.11 Malignant soft tissue tumours: Limb: Non-metastatic

Clearly operable (limb preservation)

Wide local excision should be considered in all cases. Pre-operative RT should not be used if the lesion is likely low grade or if resection likely to be intralesional. If pre-operative RT is to be used, consideration should be given to the method of defect closure and the downstream functional consequences of post-operative wound complications. Consideration should be given to re-excision if margins following primary excision are R1 or R2 (i.e. an overall R0 excision should be the goal). If pre-op RT is not used consideration should be given to post-op RT given resected tumour grade, margins, size and relationship to deep fascia. European consensus guidelines should be followed. It is helpful for post-op RT planning if surgical clips are placed at the cranial and caudal extent of the surgical bed.

European consensus on adjuvant RT for resected STS					
Characteristic				Standard	Individualised
Locally recurrent	Grade (FNLC)	Level (fascia)	Size (cm)		
-	Lo	Sup	Any	WLE	
	Lo	Deep	≤5	WLE	
-	Lo	Deep	>5	WLE	WLE + RT
-	Int/Hi	Sup	Any	WLE	
-	Int/Hi	Deep	≤5	WLE	WLE + RT
-	Int/Hi	Deep	>5	WLE + RT	
+	Lo	Any	Any	WLE + RT	
+	Int/Hi	Any	Any	WLE + RT	

Borderline operable (limb preservation)

If WLE not deemed possible on pre-operative staging, consideration should be given to high risk limb preservation or planned marginal resection.

8.12 Planned marginal resection

A planned marginal resection may carry relapse risk only slightly higher than WLE, but clip placement at the site of anticipated close margins and careful operative and histopathology reporting are needed to guide a higher dose of adjuvant RT.

Higher dose radiotherapy carries a greater risk of late functional morbidity and this should be considered if this combined modality approach is to be deployed.

Pre-operative radiotherapy is not known to improve resectability and should not be used in this context as optimal management of positive surgical margins in this context is unclear.

8.13 Amputation

For synovial sarcomas and myxoid liposarcomas chemotherapy response rates are such that neo-adjuvant combination systemic therapy with doxorubicin and ifosfamide can be considered. If there is no objective response after 4 cycles of treatment (or if progressive disease is identified at any stage) the patient should proceed directly to surgery. In selected cases isolated limb perfusion may have a role. Post-operative RT is usually required. Functional implications of aggressive CMT should be considered. Prior to amputation consideration should be given to the likelihood of metastatic failure.

8.14 Adjuvant chemotherapy

Refer to page 47 in chapter on Treatment.

8.2 Limb: Metastatic

Aggressive local surgery should be avoided in patients with known inoperable metastatic disease. Systemic chemotherapy should be considered. If systemic therapy not deliverable or disease becomes refractory consider palliative radiotherapy. Palliative surgery should be reserved for control of difficult local symptoms.

8.21 Systemic therapy

Patients for systemic therapy should be of WHO PS 2 (high-functioning 2) or better without medical co-morbidities that would compromise safe drug delivery. Physiological safety testing is mandatory. All patients require baseline CT and repeat imaging after every second cycle. Poor tolerance / excess toxicity in the absence of an objective response of CT should prompt discontinuation.

Refer to page 48 in chapter on Treatment.

8.22 Surgery for Metastases

Patients with limited volume metastatic disease that responds to systemic chemotherapy should be considered for resection of both local and metastatic sites of disease provided that the surgery would clear all macroscopically evident tumours.

Refer to page 46 in chapter on Treatment.

8.3 Trunk

8.31 Operable non-metastatic

Guideline is as for limb tumours. Wide margins may be more difficult to achieve and en-block resection of chest/abdominal wall with myocutaneous flap, mesh or methylmethacrylate reconstruction may be required.

Underlying lung, abdominal organs or spinal cord will likely limit the delivery of full adjuvant radiotherapy (RT) doses using external beam radiotherapy and consideration should be given to the use of preoperative RT or brachytherapy.

Radiotherapy

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

8.32 Inoperable non-metastatic or metastatic disease

Guideline is as for limb tumours with the caveat that the benefit of adjuvant chemotherapy is very unclear. This may be because of the high preponderance of malignant peripheral nerve sheath tumours (MPNST), a less chemo-sensitive histological subtype, on the chest wall and the high rates of local tumour recurrence (for the reasons outlined above).

Systemic treatment as per outlined in the regimens on the NEYHCA (Cancer) website:
Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

8.4 GIST

See separate guideline – in the Upper GI Guidelines which can be accessed via the following link
Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/UGINSSG.htm>

8.5 Retroperitoneal & Pelvic Sarcomas

8.51 Resectable non-metastatic

Retroperitoneal sarcomas are often large and infiltrative. Local recurrence even after extensive surgery is common.

There is no role for routine use of adjuvant RT outside a clinical trial. In some situations (typically posterior abdominal wall or abdomino-pelvic resections when margins are close within a restricted anatomically identifiable areas not directly abutting radiosensitive normal tissues) adjuvant RT should be considered. A minimum dose of 50 Gy in 30# should be used. Delivery of this dose (or higher) may be facilitated if delivered pre-operatively.

Pre-operative RT should focus on areas of likely positive margins and may require that a dose gradient (non-uniform distribution) be accepted across the tumour to spare normal tissues and/or reduce operative problems.

Tumour resection should be undertaken by the appropriate site specific team after discussion with the LSTSMDT. There is no role for neo-adjuvant therapy but post-operative radiotherapy should be considered after review within the LSTSMDT. The magnitude of adjuvant benefit is unclear and consideration should be given as to the nature of the surgical margins (wide, marginal or intralesional). Technical RT delivery should be undertaken by the appropriate site specific team.

Low-grade uterine sarcomas often express oestrogen receptors. Anti-oestrogens have been used empirically, but there is no good evidence for their routine use.

Radiotherapy

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

Systemic treatment

Systemic treatment as per outlined in the regimens on the NEYHCA (Cancer) website: Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

8.52 Unresectable or metastatic

Systemic chemotherapy delivered as described for limb/trunk. If clear response on imaging, reconsider surgery. Inoperable disease post-chemotherapy should be consolidated with radiotherapy.

Progressive (and/or metastatic) disease requires palliative dose radiotherapy for symptom control only Stable disease or better to consider high dose-palliative or pseudo-radical dose radiotherapy.

Radiotherapy

Radiotherapy Regimens as above

Systemic treatment

Systemic treatment as above

8.6 Head & Neck

8.61 Resectable non-metastatic

Tumour resection should be undertaken by the appropriate site specific team after discussion with the LSTSMDT. There is no role for routine neck dissection. There is no role for neo-adjuvant therapy but post-operative radiotherapy should be considered after review within the LSTSMDT. Resection margins are expected to be marginal and/or involved.

Standard RT planning margins are not likely to be attainable but due care in considering tissue planes that have not been compromised should be employed. RT doses as for trunk/limb. Technical RT delivery should be undertaken by the appropriate site specific team.

Radiotherapy

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

Systemic treatment

Systemic treatment as per outlined in the regimens on the NEYHCA (Cancer) website:
Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

8.62 Unresectable or metastatic

Unresectable but non-metastatic disease should be treated with primary radiotherapy using pseudoradical doses.

Neo-adjuvant combination chemotherapy may be considered for synovial sarcoma and myxoid liposarcoma as described in limb/trunk. Neo-adjuvant therapy is not otherwise recommended.

Metastatic disease should be managed as described in limb/trunk. If unfit for chemotherapy and minimal systemic disease (i.e. locally progressive disease will/may be unacceptably morbid within the patient's expected life-span) then consider surgical resection and/or high dose RT for local control.

Radiotherapy

Radiotherapy Regimens as above

9. Soft Tissue Tumours of Vascular Origin

9.1 Angiosarcoma

9.11 Operable non-metastatic

Often arises on a background of soft-tissue field change. Wide excision with generous margins is indicated followed by wide-field adjuvant radiotherapy. Radiotherapy constraints may mean that radical surgery (amputation) is required.

For radiotherapy regimen please refer to the HEYHT Q Pulse system – link as above

9.12 Unresectable or metastatic

Systemic therapy is indicated with doxorubicin or paclitaxel. Photography of index lesion (with measurement) may be helpful for cutaneous disease. Palliative radiotherapy as described for limb/trunk. Doses may be limited by prior RT. Pulmonary metastases are commonly sub-pleural and cystic with a higher than average risk of spontaneous pneumothorax. Consider intervention (VATS pleurodesis or palliative RT) for such lesions.

Radiotherapy

Radiotherapy Regimens as above

Systemic treatment

Systemic treatment as per outlined in the regimens on the NEYHCA (Cancer) website: Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

9.2 Kaposi's sarcoma, HIV associated

KS is always incurable in this context, but long term control can be achieved in some patients. All patients should have their prognostic score (see BHIVA guideline) calculated. The mainstay of treatment is HAART, and for many patients, no additional treatment is required.

Care should be exercised regarding KS flare post-induction with HAART. Local treatments (RT or intralesional treatments) can be given for cosmesis or to control local symptoms. Systemic chemotherapy is indicated for visceral disease or disease persisting despite HAART (see BHIVA guidelines).

Radiotherapy

Local palliative radiotherapy for symptoms with close follow-up prior to systemic therapy may be appropriate. If systemic therapy indicated then treat sequentially. HAART, whilst still effective, should continue.

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

Poor immune reconstitution on HAART (rising viral load/falling CD4 count) is poorly prognostically and close liaison with the treating HIV team is required (to arrange viral resistance studies, assess compliance with therapeutic drug monitoring and supervise antiretroviral therapy changes/revisions) as KS likely to be more rapidly progressive and systemic anticancer therapy will have a more important role than antiretrovirals.

9.21 Chemotherapy

Systemic treatment with 1st line liposomal doxorubicin or 2nd line paclitaxel as outlined in the regimens on the NEYHCA (Cancer) website.

Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

Radiotherapy

Useful for isolated lesions and/or larger contiguous areas associated with local pain/ulceration. Not usually helpful for nodal disease.

Radiotherapy Regimens as above

9.3 Classical / endemic

Usually limited to feet/lower limbs. Systemic disease unusual. More radiosensitive than HIV associated. Low dose hypofractionated therapy appropriate to site and field

Radiotherapy

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

9.4 Epithelioid haemangioendothelioma

9.41 Operable non-metastatic

Manage as for low grade sarcoma. Adjuvant therapy may be indicated based upon tumour site/margins.

9.42 Unresectable or metastatic

Systemic therapy is indicated on symptomatic progression. Progression often slow so prolonged pre-treatment phase possible.

Systemic treatment

Systemic treatment as per outlined in the regimens on the NEYHCA (Cancer) website: Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

If response and non-metastatic but still inoperable consider radical radiotherapy.

Radiotherapy

Radiotherapy Regimens as above

9.5 Rhabdomyosarcoma in Adults (24 years plus)

Treat as generic sarcoma

9.6 Children, Teenagers & Young Adults

All age groups covered by the Improving Outcomes Guidance for Children and Young People with Cancer i.e. 0-24 years will be referred to the appropriate Principle Treatment Centre when there is a high suspicion of, or a confirmed diagnosis of soft tissue sarcoma.
(See Chapter 15 for further details)

10. Borderline / Non-malignant Soft Tissue Tumours

10.1 Desmoid tumour

Manage as for low grade sarcoma. Wide surgical excision if possible. If surgery would cause major functional deficit consider primary radiotherapy or marginal resection and observation. Adjuvant radiotherapy useful after R1/R2 resection of recurrent disease. Systemic options include NSAID, antioestrogens, consider chemotherapy, imatinib.

Radiotherapy

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

Systemic treatment

Systemic treatment as per outlined in the regimens on the NEYHCA (Cancer) website: Please press control and click on the link below:

<http://www.hyccn.nhs.uk/NetworkGuidelinesAndPublications/ChemotherapyAndPharmacy.htm#CR>

10.2 Dermato-fibrosarcoma protruberans

Manage as for superficial low grade sarcoma.

Symptomatic or Dermato-fibrosarcoma protruberans > 5 cm should be excised with a wide local margin. Adjuvant therapy not indicated.

10.3 Stromal Tumours of Uncertain Malignant Potential (STUMP)

Manage as for low grade sarcoma. Adjuvant RT not proven. Not usually indicated unless surgical options on relapse excessively difficult.

10.4 Lipomata

Symptomatic or lipomata > 5 cm should be marginally excised. Adjuvant therapy not indicated. All resected lipomata should be submitted for both histopathologic and cytogenetic analysis.

10.5 Thoracic Chondrosarcoma

Patients will be reviewed by the Lung (Thoracic) MDT and consider for surgery. The patients that could be considered for local resection will include:

- De-differentiated chondrosarcoma
 - Manage as for osteosarcoma
- Mesenchymal chondrosarcoma
 - Manage as for Ewing's sarcoma
- Chondrosarcoma NOS

The patients post surgical intervention will be managed by the Local Soft Tissue Sarcoma MDT

10.51 Localised

No role for systemic therapy. Primary surgical excision. No routine role for adjuvant radiotherapy. Consider RT if R1 or R2 resection, pathological fracture or extraosseous spread and no scope for further surgery.

Radiotherapy

Radiotherapy Regimens are accessed via the local HEYHT Q Pulse system. This system requires a user name and password. Please press control and click on the link below to be taken to the login page of Q Pulse

<http://hri-qpulse/QPulse5Web/UI/Open/Login.aspx?ReturnUrl=%2fQPulse5Web%2fDefault.aspx>

11. Follow-Up

11.1 General

Follow-up for treated sarcoma patients incorporates scheduled screening for local and systemic relapse, for the early and late consequences of local and systemic therapies and the provision of psychological support.

No study has clearly shown an improvement in overall outcomes as a consequence of routine follow-up, though most agencies recommend follow-up as a component of survivorship care. A careful balance must be struck between opportunity gain arising from follow-up and the patient anxiety potentially provoked by it.

As symptomatic relapse may occur between scheduled follow-up appointments it is essential that patients are informed of how to make contact with the sarcoma service so that unscheduled review can be arranged.

11.2 Components of scheduled follow-up care

Clinical assessment

Relapse and toxicity screening enquiry (local, end-organ and systemic) and physical examination. Toxicity recording ideally with CTCv3/4.

Imaging

Local:

There is no role for baseline post-treatment local imaging unless either (a) abdominopelvic primary or (b) non-abdominopelvic site but difficult to follow clinically. Clinical circumstance will dictate modality, notionally CT for abdo/pelvis and MRI for other sites.

Systemic:

Chest x-ray.

Laboratory tests

There is no specific marker for sarcoma relapse at this time.

Routine haematology, biochemistry (U&E, LFT, Bone) is indicated if:

- Patient has received systemic therapy.
- Patient has had radiotherapy with potential effect upon end-organ function (essentially any non-limb site).
- Primary tumour was abdominopelvic

Specific tests of end-organ function

- TESS score should be completed for limb sarcomas.
- A post-treatment echocardiogram should be performed 3 months after completion of any adjuvant anthracycline containing regimen.
- An endocrine profile is required if post-treatment endocrinopathy is possible.

11.3 Scheduling

11.31 Non-abdominopelvic tumours

Group	Nature	Local relapse risk	Systemic relapse risk
1	Benign without complex surgery	-	-
2	Benign with complex surgery	-	-
3	Low grade malignant	Intermediate	Low
4	High grade no adjuvant RT	Intermediate	Intermediate
5	High grade needing adjuvant RT	Intermediate	High

Group	Sub-group	Clinical assessment	Local imaging frequency	Lung imaging frequency
1-2	All	Discharge post surgery	Not needed	Not needed
3	All	6 monthly to 5 years	Not routinely required	Not needed
4-5	Limb	3 monthly year 1, 4 monthly year 2, 6 monthly to 5 years, annual to 10 years	MRI scan at 6 months post op. No more scans unless indicated	CXR every six months (CT thorax only when indicated)
	Abdo-pelvic	To coincide with CT or 6 month intervals	Baseline post treatment. No other routine imaging.	CXR each visit if G2/3

11.32 Abdominopelvic tumours

Non-GIST tumours are at high risk for local failure (manage as for group 5 above). Aggressive imaging-based follow-up is not considered useful. Baseline CT with imaging on clinical progression.

11.33 GIST risk groupings

Size	<5cm		6-10cm		>10cm	Any
Mitoses/50hpf	<5	6-10	<5	>5	Any	>10
Risk	Low		Intermediate		High	

GIST	Low	To coincide with CT or 6 month intervals	CT 3, 12, 24, 36 months	CT CAP imaged
	Intermediate	To coincide with CT or 6 month intervals	CT 3, 6, 12, 24, 36 months	CT CAP imaged
	High	To coincide with CT or 6 month intervals	CT 3, 6, 12, 18, 24, 36 months	CT CAP imaged

11.34 Procedure on suspected relapse

Patients with suspected relapse of the basis of either history and physical findings or screening investigation should be re-imaged with the definitive imaging method (U/S and MRI or CT for local relapse and CT for systemic relapse) and re-discussed at the LSTMDT meeting to agree a relapse management plan. Confirmatory biopsy may be required.

11.35 Follow-up post-relapse

Patients follow-up should be 're-zeroed' at the time of completion of relapse management and they should enter follow-up based upon the disease risk group as defined above.

11.36 Follow-up for patients who have exhausted effective anti-cancer treatment

There may be no practical benefit to patients in travelling into the specialist sarcoma clinic if there is no possibility of sarcoma specific intervention. Adequate generic supportive and palliative measures may be delivered at a community and local district hospital level. Routine appointments are not usually necessary provided adequate lines of communication and responsibility have been established closer to the patient's home.

It is recognised that sarcoma is a rare disease and that this may provoke some anxiety in the locally based palliative care teams. It is essential that a central route of access for information provision and discussion remain open and that this is clearly communicated. Scheduling of routine appointments, if still felt to be necessary, should be based upon the patient's individual needs and anticipated disease trajectory.

12. Palliative Care

12.1 Generic

Unfortunately not all patients with sarcomas are cured. Palliative care is the active total care of patients and their families by a multi professional team when the patient's disease is no longer responsive to curative treatment (World Health Organisation, *Technical Series 804*, Geneva 1990).

It addresses physical, psychological, social and spiritual concerns. The majority of palliative care in the UK is provided within the clinical setting in which the patient is routinely managed, particularly primary care, rather than by specialist services.

However, specialist palliative care services are needed by a significant minority of people. Involvement of specialist services may be appropriate at various stages of the illness and treatment, including at an early stage whilst patients are undergoing disease modifying treatment, if they have significant symptom control issues e.g. severe pain. In this situation support may be for a limited period of time and then re-accessed in the future.

Specialist palliative care advice and support is available in hospital and in the community, both in patients' homes and in an outpatient and specialist day care setting. In addition some patients benefit from an inpatient admission to a hospice / specialist palliative care unit for symptom control, rehabilitation and complex discharge planning or terminal care.

A multi professional approach is key to high quality Specialist Palliative Care, with involvement of specialist clinicians, nurses, physiotherapists, occupational therapists, other Allied Health Professionals, social work and spiritual care. In addition there is access to Family Support Services, complimentary therapies and bereavement care.

Services are delivered locally and information on all services is available on www.hospiceinformation.info In addition further information about local support is available on the NEYHCA (Cancer) website, www.hyccn.nhs.uk Useful guidelines on symptom management, assessing supportive and palliative care needs and breaking bad news are also available on Yorkshire Cancer Network website, www.yorkshire-cancer-net.org.uk

12.2 Specific

Patients who will need a palliative care pathway are identified through the weekly Multidisciplinary Team. The reasons for curative treatment options not being appropriate are discussed and a management strategy is proposed.

Following discussions with patients and their families a plan of treatments and care will be organized. This may include singularly or in combination: surgery, radiotherapy or chemotherapy and symptom management, with referrals to specialist services as appropriate. Referrals to community services would also be instigated as appropriate.

Patients will continue to be reviewed by the clinical team as required. Referral to specialist palliative care can be facilitated through any team member, but is often undertaken by the CNS as they have developed links with the community palliative care nurses throughout the region and the hospices in Hull, Grimsby, Scunthorpe and Scarborough.

Specialist Palliative Care Teams can provide access to a range of services including:

- Day care
- Admission for symptom relief
- Rehabilitation
- Terminal care
- Bereavement counselling
- Pain clinics / Pain Management
- Complementary therapies (e.g. reflexology, aromatherapy)
- Lymphoedema Management services
- Psychological support
- Help with benefits and social care issues.

(Plus, all patients have access to Specialist Palliative Care Advice via telephone support)

The Specialist Palliative Care Team are available to all health care professionals for telephone advice or will visit patients at home or in a hospice to offer clinical advice and guidance where needed. Patients are given contact numbers to gain direct access to the team.

12.3 Key Workers

The patient should be allocated a key worker, given their key workers contact details and the parameters of the key workers role. This should be clearly documented and communicated to the patient, carers and relevant professionals. The patient should be made aware if their key worker changes (which may well happen as the disease process develops).

The key worker can be either a specialist or generalist (e.g. GP or District Nurse) with whom the patient has regular contact and who has received the relevant training and been assessed as competent.

Patients can also be admitted to their local hospitals or hospices for palliative and terminal care if appropriate. The members of the multidisciplinary Specialist Palliative Care Team are available to visit and advise on specific clinical difficulties. Please press control and click on the links below:

www.dovehouse.org.uk

www.lindseylodgehospice.org.uk

www.standrewshospice.com

www.stcatherineshospice-nyorks.org

www.macmillan.org.uk

(for information regarding benefits / social care advice)

<http://www.direct.gov.uk/en/index.htm> / www.macmillan.org.uk

Further information and details of Specialist Support Groups can be found on the NEYHCA (Cancer) website and in the Local Service Directory

12.4 Summary of Specialist Palliative Care Services Available Throughout the Region

Hull

- Marie Curie Nurses.
- Out of Hours nursing (East and West Hull)
- AHP services
- Palliative Care Consultant / out patient clinic
- Lead Palliative Care Nurse
- Dove House Hospice (In Patients / Day Care / Lymphoedema)
- Community Palliative Care Macmillan / Clinical Nurse Specialists (CNS) - All PCTs
- Hospital-based Palliative CNS Specialists
- GP Macmillan Facilitators
- Macmillan Day Care
- Chaplain / spiritual worker

Grimsby

- St Andrew's Hospice (In Patients / Day Care / Lymphoedema / out of hours for North East Lincs)
- Community Palliative Care Macmillan / CNS (All PCTs)
- AHP services
- Palliative Care Consultant
- Hospital-based Palliative Care Macmillan / CNS
- Marie Curie Nurses – home nursing
- Lead GP x 2 / Nurse in Palliative Care
- GP Macmillan Facilitator
- Out of Hours Sitting Service
- Chaplain / spiritual worker

Scunthorpe

- Lindsey Lodge Hospice. (In Patients / Day Care / Lymphoedema / Breathlessness Clinic)
- Community Palliative Care Lead GP / CNS (All PCTs)
- AHP services
- Hospital based Palliative Care Macmillan / CNS
- Specialist Palliative Care Social Worker
- Dedicated Occupational Therapy Service
- Dedicated Dietician
- Dedicated Pharmacist
- Marie Curie Nursing – North Lincs
- Chaplain / spiritual worker

Scarborough

- St Catherine's Hospice (In Patients / Day Care / Lymphoedema)
- Palliative Care Consultant / out patient clinic
- Community Palliative Care Macmillan / CNS (All PCTs)
- AHP services
- Hospital-based Palliative Care Macmillan / CNS (Scarborough District General Hospital)
- GP Macmillan Facilitator
- Marie Curie Nursing
- Bereavement Support Services
- Chaplain / spiritual worker

Bridlington

- Macmillan Unit with 'GP' beds
- Neighbourhood Care Team (AHP services)
- Palliative Care Clinic
- Community Palliative Care CNS (All PCTs)
- Chaplain / spiritual worker

(Plus all sites have Specialist Palliative Care Multidisciplinary Teams and all patients have access to phone support & advice)

13. Patient Information

“A higher priority should be placed on improving information for patients, face-to-face communication with health professionals and co-ordination and continuity of care. We also need to do more to support patients through their survivorship.”

Cancer Reform Strategy 2007

Patients should be offered a permanent record or summary of all consultations at which their treatment options are discussed, this should include clear verbal and written information about the following:

- The disease (on diagnosis)
- The nature and implications of diagnosis (where appropriate).
- The treatment options, and their effects (positive and adverse)
- Assessment of the outcome, and information on symptoms which may signify recurrence
- Relevant follow up (discharge) arrangements
- Information on patient involvement groups and support groups, including AHP support.
- If necessary, the patient should be offered a tape of their consultation

MDTs should be involved in patient exercises, in conjunction with Peer Review measures, to ascertain if patients have been offered:

- A key worker
- Information for patients and carers (written or otherwise)
- The opportunity of a permanent record or summary of consultation at which their treatment options were discussed

These exercises should be presented and discussed at LSTSMDT meetings, the teams should implement actions resulting -from their findings.

Patient Information from National Information Pathways and local information meeting National Standards should be made available to all patients. Information should be available in languages and formats understandable by relevant local minority groups including; ethnic groups, those with alternative sexuality, and people with disabilities.

Information offered should be appropriate to the patients' needs at that point in their patient journey, (e.g. type of lesion, type of treatment, local services and any choice within them) and should be offered at all stages of the patient pathway. It should cover both physical and psychosocial issues. The information offered and given should be recorded in the patient notes.

Patient Information should include names and contact details of key personnel involved in the patients care. Upon diagnosis, every patient should be given the contact details of a key worker in line with local Key Worker Policy. A chemotherapy or oncology nurse should be available to advise, inform and support patients needing chemotherapy or radiotherapy.

Patients should have access to a team of professionals who have been trained in advanced communication skills. Emotional support should be available to the patient at any stage in their pathway of care. Patients should be encouraged to bring someone with them to provide support at diagnostic clinics / appointments at which distressing news may be communicated. Patients should be given time and support to reflect on their treatment options before having to make a decision.

The service should have defined access to social workers, Allied Health professionals, chaplains, pain control and palliative care professionals, whether provided by hospital staff, the Hospices or within the Trust by the Special Palliative Care Team. Services should also aim to develop access to a range of psychological support and appropriate complimentary therapies.

Carers have a key role in supporting patients and may need information to enable them to fulfill this role optimally. However, patient-specific information should only be provided to carers within the context of protecting patient confidentiality and with the patient's consent.

CNSs Contact Details		
Name	Hospital	Telephone Numbers
Sharon Edwards	Castle Hill Hospital, Castle Road, Cottingham East Yorkshire, HU16 5JQ	Bleep Switchboard 01482 875875 or by direct telephone to 01482 622640

Patient Involvement Groups / Self Help Group information can be found on the NEYHCA (Cancer) website and in the Local Service Directory. Please press control and click on the link below:

<http://www.hyccn.nhs.uk/patientexperience/prosservices.htm>

Patient Information Pathway – details can be found on the NEYHCA (Cancer) website (Includes Social Care & Benefit Advice in the Local Service Directory)
<http://www.hyccn.nhs.uk/patientexperience/prospathways.htm>

Support Groups – details can be found on the NEYHCA (Cancer) website / Local Service Directory

Written information leaflets given

Sarcoma UK

- Sarcoma UK who are we?
- Want to understand sarcoma
- Following surgery – some questions answered
- Advanced sarcoma
- GIST support UK
- Sarcoma newsletters

Macmillan leaflets

- Understand soft tissue sarcoma

HEYHT leaflets

- Surgical procedures
- Information about different scans, (MRI/CT/US/etc).
- Information about radio and chemotherapy.
- Aftercare
- Oncology health centre

14. Audit & Research

A NEYHCA (Cancer) audit project is an audit project related to the cancer site or sites of the Implementation Group and the activities of its MDT. The same audit project should be carried out by all MDTs for that cancer site across NEYHCA (Cancer), each team's results being separately identified.

The minimum progress needed for the Implementation Group's compliance is that the Implementation Group in consultation with the MDTs agrees at least one NEYHCA (Cancer) audit project with the NEYHCA Cancer Management Group, with any necessary sources of funding agreed with commissioners or from elsewhere. The individual MDTs for compliance with this measure should agree to participate in the audit.

NEYHCA (Cancer) groups may deal with more than one MDT or MDTs of more than one level of specialisation, so each individual MDT may not have the same role in an audit or be able to participate in all its aspects.

The MDT / SIG should annually review the progress of the project or present the results of the completed audit project to the Implementation Group for discussion at one of their meetings

Audit priorities include:

- Access to information sources and information about the quality of patients' experiences
- Access to appropriate supportive care for patients undergoing disfiguring treatment
- Offer of entry into clinical trials for appropriate patients.

14.1 Audit & Research Criteria

- All units should have policies or guidelines for care, with the guidelines developed through consultation between Cancer Units and cancer Centres. These guidelines will form the basis for audit and evidence of relevant data collection should be demonstrated. The main issues to monitor include clinical throughput, morbidity, pathology and monitoring of outcomes. The results will then be used to evaluate implementation of these guidelines and identify problem areas where further education and/or resources need to be targeted.
- Audit should take place across all of the NEYHCA (Cancer) area, including the Cancer Centre and all related Units. The Chair of the Sarcoma Implementation Group and the Chair of the NEYHCA Cancer Management Group should agree at least one audit project per year.
- All members of the Local Soft Tissue Sarcoma Team should attend regular audit meetings.

14.2 Research

The LSTSMDT should produce a written response annually to the Implementation Group's approved list of trials and other well designed studies, which fulfils the following:

- For each clinical trial and other well designed study the MDT should agree to enter patients or state the reason why it will not be able to;
- The remedial action arising from the MDT's recruitment results, agreed with the Implementation Group.
- All patients, including those younger than 19 years of age, should be given the opportunity, if appropriate, to take part in clinical trials.
- In terms of research, there is an urgent need for larger studies on the experiences of patients with sarcomas. In particular there is a need to look at the impact on quality of life of living with surveillance for future cancers.
- Studies are also needed to determine the benefit of self- or clinician-conducted surveillance. There is a need to gain a better understanding of the needs of patients with advanced disease and/or those requiring major and/or disfiguring treatment.
- Research should also be undertaken to assess the impact of interventions to reduce psychological morbidity and to improve psychosocial well-being.
- Cancer Centres / Units should be encouraged to participate in surgical and non-surgical randomised controlled trials, particularly national trials. Primary Care Trusts should endeavour to secure the provision of additional resources needed to participate in clinical trials. There should be a single NEYHCA (Cancer) list of clinical trials and/or studies into which the MDTs should give priority for patient entry.

The Manual for Cancer Services states that cancer sites which have standards based on Improving Outcomes Guidance (IOG), the parameters to be audited should be drawn from the "Measurement" sections of the relevant IOG.

14.3 Minimum Dataset & Collection Policy

A minimum dataset and collection policy has been agreed across NEYHCA (Cancer). The Sarcoma Implementation Group endorses the NEYHCA (Cancer) policy for cancer data collection and storage:

- All data items should be collected at the most appropriate point on the patient pathway
- Provider Trust to agree locally the most appropriate personnel and systems for the collection and storage of the agreed minimum dataset.
- Collection of clinical data items will be supported by appropriate clinical input from core members of the MDT
- Provider Trusts are responsible for the collection, storage and upload of data items in the Going Further on Cancer Waiting Times dataset.

- Action plans to be developed between NYCRIS and Acute Trust to determine the transition process between 2008 and 2011 for the collection and electronic submission of the cancer registry dataset.
- Data items should be stored appropriate an electronic format to allow upload into approved national systems and databases.
- Storage and transfer of patient identifiable information should adhere to all relevant National guidance and local Trust policies.
- Full details of the key points in this policy should be specified in the MDT key documents

A data manager / MDT Co-ordinator has been employed to collect the agreed NEYHCA (Cancer) minimum dataset in agreement with the NEYHCA (Cancer) MDS collection policy. A record of all patients with known or suspected sarcoma should be kept.

The Implementation Group has agreed a policy with the LSTSMDT specifying common priorities for data collection in line with national priorities e.g. cancer waiting times

This policy is specified in the LSTSMDT key documents

- Which type of team should collect which portion of the MDS
- When each data item should be captured on the patient pathway
- How the data will be stored and managed within all appropriate local data systems

15. Teenagers & Young Adults

15.1 IOG Key Principles

Who does this apply to?

- All patients aged 16-24 with cancer
- (2 age groups 16-18 years and 19-24 years)

What needs to happen?

- All patients aged 16-18 years inclusive should be referred to a Principal Treatment Centre (Young People) for treatment
- All patients aged 19-24 years inclusive should be offered referral to a Principal Treatment Centre (Young People) for treatment.
- All patients aged 16-24 years inclusive should be discussed at both a site-specific MDT meeting and a TYA MDT meeting.
- Referral of patients to a PTC (Young People), or review by both a site-specific and a TYA MDT should not be allowed to delay the start of urgent cancer treatment.
- For each patient, a lead medical clinician should be identified, who will have overall responsibility for their treatment.

Ref: Children & Young People's Improving Outcomes Guidance - Implementation - August 2008

Why?

- The 2005 NICE IOG on Children and Young People mandates this model of decision-making and care (key principles)
- These young people have particular needs in terms of communication, supportive care and environment of care, that are best served by referral
- The particular spectrum of diseases between MDTs
- This is what young people want to happen, when asked

When does referral need to happen?

- As soon as you are aware of (or have a high suspicion of) a diagnosis of cancer & in time for the TYA team to be involved in decisions about pattern and place of care i.e. before the management plan is negotiated with the patient.

How is this referral made?

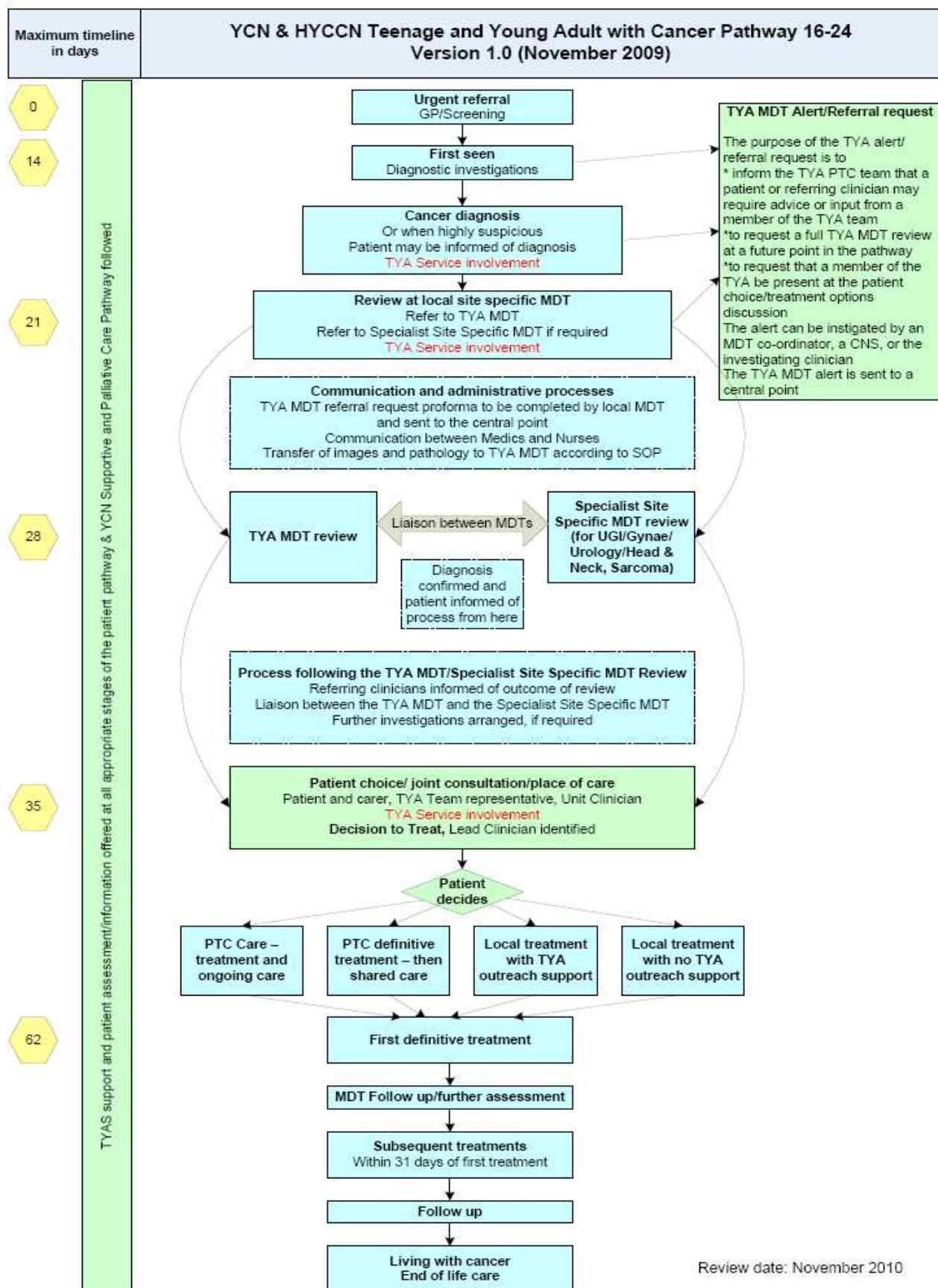
- Referral to be made using process agreed in the Standard Operating Procedure (Set up in conjunction with the Yorkshire Cancer Network)

15.2 Standard Operating Procedure

To view a copy of the Standard Operating Procedure please check the NEYHCA (Cancer) website. Please press control and click on the following link

<http://www.hycn.nhs.uk/NetworkGuidelinesAndPublications/CYA.htm>

15.3 Pathway for Teenagers & Young Adults with Cancer (Yorkshire Cancer Network (YCN) & NEYHCA (Cancer))



Appendix (i) Birmingham Bone Sarcoma Referral Form

URGENT REFERRAL FOR SUSPECTED BONE SARCOMA

If you wish to include an accompanying letter, please do so.

On completion please FAX to the number below.

Fax: 0121 685 4146



Network

Pan-Birmingham

Cancer

These forms should only be used for suspected cancer and in conjunction with the NICE Referral Guidelines for Suspected Cancer, June 2005

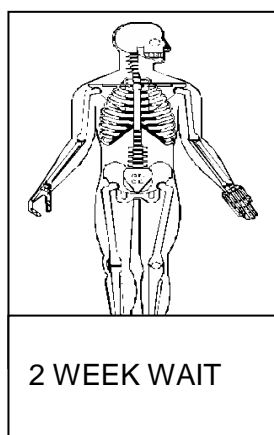
Patient Details Number)

GP Details (inc Fax

Surname Forename D.O.B. Address		Gende	
Postcode Telephone NHS No Hospital No Interpreter? Y / First Language:			Date of Decision to Date of Referral GP Signature
<u>Relevant Information:</u> (Check as appropriate) Suspected diagnosis: Sarcoma of Bone Site _____ X-ray carried out <input type="checkbox"/>		<u>Other investigations:</u> Bone Scan <input type="checkbox"/> If so, where _____	
Clinical Details: History/Examination/Investigations..... Medication.....			
<u>For Hospital Use</u>		<u>(Referral Data)</u>	
Date received_____		Date 1 st appointment booked_____	
Date of 1 st appointment_____		Date 1 st seen_____	
Clinic Attending_____			
Specify reason if not seen at 1 st appointment offered_____			
Final Diagnosis_____ Malignant / Benign			
Was the referral appropriate Yes No (if no please give reason)_____			
Hospital	Tel		Fax
Royal Orthopaedic Hospital	0121 685 4021		0121 685 4146

Appendix (ii) HEYHT Sarcoma Referral Form

PATIENTS NAME.....HOSPITAL NUMBER.....



Revised
11/02

HIGH RISK OF CANCER REFERRAL FOR SUSPECTED SOFT TISSUE SARCOMA

IF A PRIMARY BONE TUMOUR IS SUSPECTED PLEASE DISCUSS THE INDIVIDUAL CASE WITH THE ON-CALL CONSULTANT ORTHOPAEDIC SURGEON PRIOR TO FAXING THIS FORM.

PLEASE COMPLETE ALL SECTIONS AND FAX TO **01482 675505**

THE CENTRAL REFERRAL POINT TELEPHONE NUMBER IS 01482 604308

PATIENT DETAILS	GP DETAILS
Name:	Name:
D.O.B.	
Address:	Address:
Post Code:	Post Code:
Tel No:	Tel No:
Hospital No.	Contact No:
NHS No:	(Direct line of person booking i.e. GP/Secretary/ Receptionist)
Is patient instructed to self book?	Y / N
Contact No:	Contact Time:
Is Language Line needed? Y / N	Language:

IS THE PATIENT AWARE OF THE POTENTIAL DIAGNOSIS? Y / N

Has this patient been seen before by a Sarcoma Specialist/ Y / N
Orthopaedic Specialist? Y / N

PATIENTS NAME.....HOSPITAL NUMBER.....

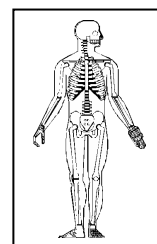
Name of Consultant Date seen:...../...../.....

SUSPECTED DIAGNOSIS (PLEASE TICK BOX)

DIAGNOSIS SUSPECTED

Soft Tissue Sarcoma

Primary Bone Tumour*



*** Please ensure that the On-Call Consultant Orthopaedic Surgeon has been telephoned.**

Comments

HISTORY

Location

Yes No

Swelling

Pain

Increase in size

CLINICAL EXAMINATION

Sizecms

Yes No

Deep to fascia

RADIOLOGY

Not Done

Suspicious of Bone

Tumour

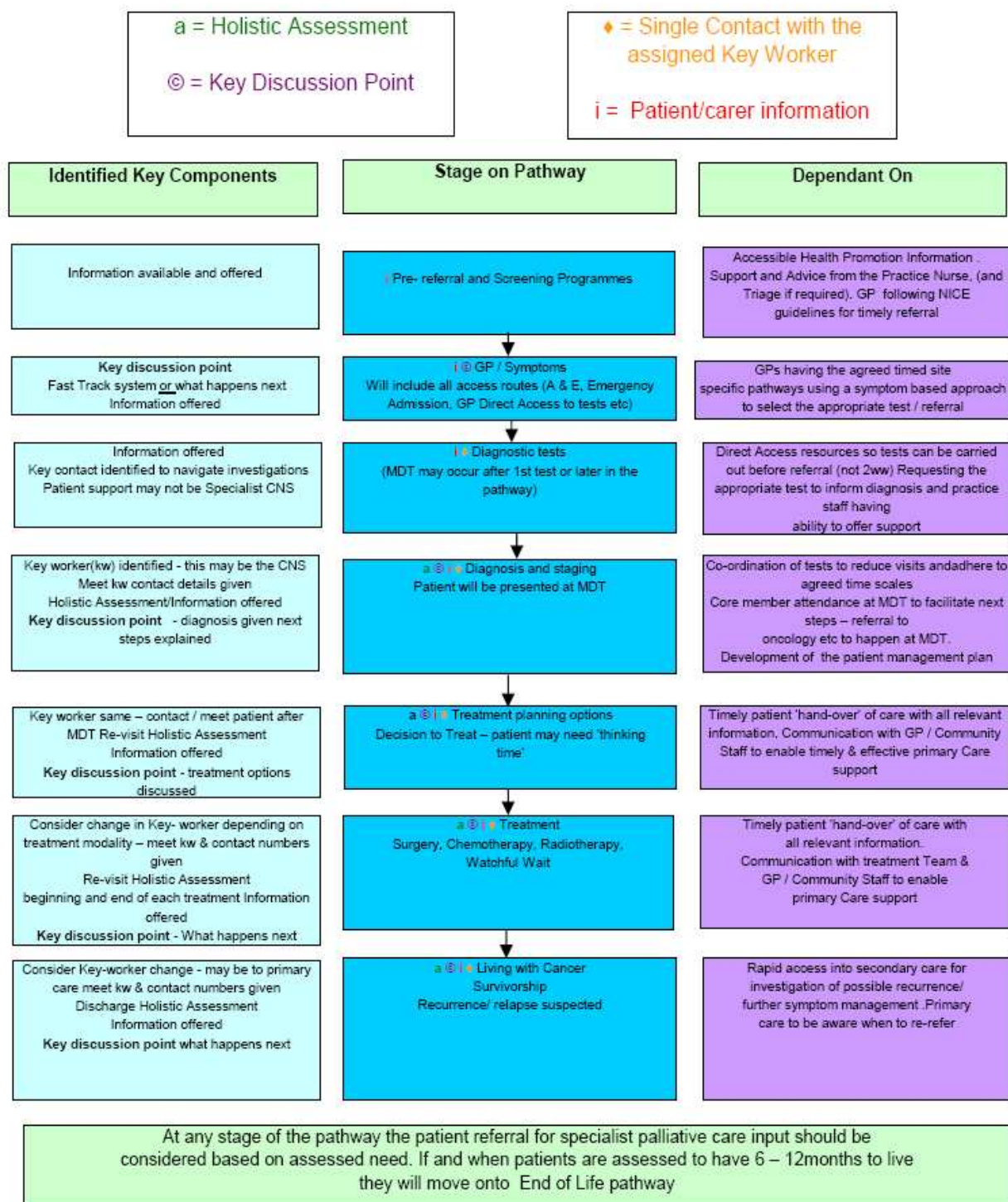
MEDICAL HISTORY / DRUGS / ALLERGIES / ANY OTHER COMMENTS:

Signature of G.P..... Date of Referral:/...../.....

Appendix (iii) Supportive Care Pathway

NEYHCA (Cancer) HIGH LEVEL SUPPORTIVE CARE PATHWAY

The pathway has four key components identified that would significantly improve the patients' experience



adapted from YCN supportive care pathway

Appendix (iv) Sarcoma Implementation Group Members List (Updated January 18th 2012)

Members full name	Job Title
Hull and East Yorkshire Hospitals NHS Trust	
Dr Rachael Barton	Consultant Clinical Oncologist
Dr Joanna Bates	Consultant Radiologist
Ms Barbara Brown	Clinical Lead Physiotherapist
Ms Debrah Butler	Divisional General Manager for Ortho, Trauma, Plastics and Neurosurgery
Ms Sharon Edwards	Clinical Nurse Specialist Skin & Sarcoma
Mrs Victoria Frost	Data Manager
Ms Joanne Fox	MDT coordinator / Data Manager
Ms Lorraine Laws	Business Manager Neurosurgery
Professor Mike Lind	Professor of Medical Oncology
Dr Bipin Mathew	Consultant Histopathologist
Ms Gill Moverley	MDT Assistant
Mrs Margaret Parrott	Trust Lead Cancer Manager
Mr Alastair Platt	Consultant Plastic Surgeon
Ms Wendy Quinn	Head of Service Surgery 1
Dr Anu Roy	Consultant Histopathologist
Mr Paul R Stanley	Consultant Plastic Surgeon
Dr Damien Taylor	Consultant Radiologist
Ms Helen Wright	Cancer Research Business Manager
Northern Lincolnshire and Goole Hospitals NHS Foundation Trust	
Ms Kathy Dent	Lead Research Nurse
Miss Louise Hobson	Trust Cancer Manager
Ms Trudy Nurse	Senior Research Nurse
Miss Deborah Whitehead	Macmillan Lead Cancer Nurse
Scarborough and North East Yorkshire Healthcare NHS Trust	
Mr Steve Bilton	Business Manager
Mrs Sarah Kent	Lead Research Nurse HYCCRN
Mrs Christine Norris	Cancer Manager
North East Yorkshire & Humber Clinical Alliance	
Mr Srdjan Ljubojevic	Cancer Research Network Manager
Mrs Sue Reid	Network Support Manager
Ms Julie Taylor-Clark	NEYHCA Director for Cancer & Vascular

The Sarcoma Implementation Group Executive Team

Chair

Professor Mike Lind

NEYHCA (Cancer) Medical Director

Vice Chair

Dr Anu Roy

Consultant Histopathologist HEYHT

MDT Lead

Mr Alastair Platt

Consultant Plastic Surgeon HEYHT

Member Responsible for User / Patient Information

Ms Sharon Edwards

Clinical Nurse Specialist Skin & Sarcoma HEYHT

Member Responsible for the integration of Service Improvement

Mr Paul Stanley

Consultant Plastic Surgeon HEYHT

Member Responsible for Recruitment into Clinical Trials

Professor Mike Lind

NEYHCA (Cancer) Medical Director

Management & Administration support provided by the NEYHCA (Cancer) Office

Mr Pete Townsend

NEYHCA (Cancer) Assistant Director / Executive Lead
NEYHCA (Cancer)

(Any of the NEYHCA (Cancer) management can provide support in Mr Townsends absence)

Mrs Sue Reid

Network Support Manager NEYHCA (Cancer)

Mrs Joanne Graham

Administrative Assistant NEYHCA (Cancer)

Mrs Jo Richardson

Administrative Assistant NEYHCA (Cancer)

Ms Sue McKie

Administrative Assistant NEYHCA (Cancer)

Guidelines Agreed (Clinical, Imaging & Pathology)

Agreement of the North East Yorkshire & Humber Clinical Alliance (Cancer) Guidelines for the Management of Adult Patients with Soft Tissue Tumours & Sarcomas by the Sarcoma Implementation Group

These guidelines have been developed by the Sarcoma Implementation Group, taking into account NICE Guidance and the IOG and are the standard for care for Sarcoma patients in NEYHCA (Cancer).

The guidelines are discussed and circulated within NEYHCA (Cancer) as per the agreed consultation process. All members are given the opportunity to assist in the publication of the guidelines / comment.

The guidelines have been formally agreed by the Sarcoma Implementation Group at a quorate meeting. Those present at the meeting agree the document on behalf of the group. Those not present at the meeting accept the groups' decision. The guidelines agreement sheet has been signed by the Chair, the NEYHCA (Cancer) Medical Director MDT Lead, Imaging Group Chair and Pathology Group Chair.

The guidelines were originally emailed out to the group on the 11th of October 2010. Final amendments were made and the guidelines were discussed again at the meeting on the 17th of November 2010.

Further comments were made by North Trent Cancer Network (NTCN), these were addressed by the group and the guidelines were amended accordingly.

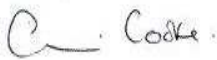

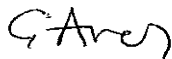

These amendments were emailed out to the group and agreed in March 2011. The guidelines were deemed as read and accepted by the Sarcoma Implementation Group as policy and procedure. The Guidelines were agreed at the March 2011 Cancer Network Board meeting. The Chair of the CNB signed the agreement sheet on behalf of the group.

In February 2012 further amendments were made to the guidelines and they were also reformatted with the new NEYHCA (Cancer) branding. These were only minor changes, for purpose of clarity in the guidelines. The Sarcoma measures were updated in April 2012 and changes have been made to accommodate these changes where possible.

It was not necessary to take these changes to the NEYHCA (Cancer) Cancer Management Group. The group agreed amendments to the guidelines via email in April 2012

The guidelines will be reviewed in 2014, unless new guidance is published before then.

Sign Off Sheet

Agreement of the NEYHCA (Cancer) Guidelines for the Care of Adult Patients with Soft Tissue Tumours & Sarcoma		
Title	Name	Date Agreed
		
Chair of NEYHCA Board / Cancer Management Group (CMG)	Mrs Allison Cooke	9/5/2012
		
Chair of the Sarcoma Implementation Group, NEYHCA (Cancer) Medical Director	Professor Mike Lind	20/4/2012
Please see original copy of signature sheet		
LSTSMdT Lead – Hull & East Yorkshire Hospitals NHS Trust	Mr Alastair Platt	20/4/2012
		
Chair of the NEYHCA (Cancer) Imaging Clinical Expert Group	Dr Ged Avery	20/4/2012
		
Chair of the NEYHCA (Cancer) Pathology Clinical Expert Group	Dr Carol Hunt	20/4/2012
These Guidelines have been agreed by the Sarcoma Implementation Group		20/4/2012