



Supra Network Sarcoma Advisory Group (SAG)

Constitution

2015

Hosted by



Date: June 2015
Version: 1
Review Date: June 2016

Sarcoma Advisory Group members agreed the constitution on 22nd May 2015

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	1 OF 31	DATE	JUNE 2015
------------------	--	-----------------	---	----------------	---------	-------------	-----------

Contents

Reference No	Subject	Page
1	Introduction	3
2	Configuration of the London and South East Sarcoma Network	3
3	Establishment of the SAG	4
4	Role of the SAG	5
5	Membership of the SAG	7
6	The MDTs	11
7	Designated Chemotherapy Service and Chemotherapy Practitioners	12
8	Designated Radiotherapy Department and Radiotherapy Practitioners	13
9	Molecular Biology/Cytogenetic Facilities	14
10	Designated GIST Histopathologists	14
11	Pathways and Guidelines	14
12	Data Collection – Minimum Dataset	29
13	Audit	30
14	Research and Clinical Trials	31

Appendix	
1	LSESN Guidance on referral of sarcomas
2	LSESN Patient Management Policy
3	LSESN Chemotherapy Shared Care Guidelines
4	LSESN Radiotherapy Shared Care Guidelines
5	LSESN Shared Care Pathways
6	Designated GIST Histopathologists
7	Clinical Trials Report for The London Sarcoma Service
8	Clinical Trials Report for The Royal Marsden
9	Extended SAG Membership Attendance
10	LSESN Communication Policy and Directory
11	Trust Sarcoma Leads

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	2 OF 31	DATE	JUNE 2015
------------------	--	-----------------	---	----------------	---------	-------------	-----------

1. Introduction

This document was compiled with the help of members of the London and South East Sarcoma Network Sarcoma Advisory Group. The document will be reviewed and updated annually. It sets out the national guidelines, together with the SAG's plans to implement them. The guidelines are specific to The London and South East Sarcoma Network and describe how the various health care professionals and organisations work together to provide care for an individual with sarcoma.

2. Configuration of the London and South East Sarcoma Network 14-1C-1011

In agreement with the North London Network Board and the London Specialist Commissioning Group (SCG) made in 2008 The London and South East Sarcoma Network (LSESN) was created to bring together two designated sarcoma centres:

- The London Sarcoma Service (LSS) (Royal National Orthopaedic Hospital (RNOH) and University College London Hospital (UCLH)) which hosts
 - a bone and soft tissue sarcoma MDT
 - a curative resection service for bone and soft tissue sarcomas
 - a retroperitoneal sarcoma service
- and
- The Royal Marsden Hospital (RMH) which hosts
 - a soft tissue sarcoma MDT
 - a curative resection service for soft tissue sarcomas
 - a retroperitoneal sarcoma service

This Sarcoma Network meets the requirement for:

- minimum number of cases (LSS serves over 150 new bone cases and 350 new soft tissue cases per year, RMH serves approx 400 new soft tissue cases per year)
- a bone MDT with surgery provided on a single site (at RNOH), designated by the Highly Specialised Commissioning Group Limb, limb girdle and truncal soft tissue sarcoma surgery consolidated onto a single site relating to each MDT (RNOH and RMH)

The two centres provide a sarcoma service to a population of approximately 17 million residents within London and the South East of England

Since 2012, the SAG and LSESN has received support from the two Integrated Cancer Systems serving London (London Cancer and London Cancer Alliance). This has included administrative support and annual review of SAG activity by the London Cancer Board, and in 2014/15 administrative and project support from the London Cancer Alliance. It has also included annual face to face review between the London Cancer Chief Operating Officer and the SAG Co-Chairs.

All primary care providers and secondary care trusts within the defined catchment population of the above will refer to

- The London Sarcoma Service MDT (RNOH and UCLH) for bone sarcomas
- The London Sarcoma Service MDT or The Royal Marsden Hospital MDT for soft tissue sarcomas

LSESN has a GP referral proforma which lists the referral criteria and contact details of the two MDTs (<http://www.lsesn.nhs.uk/files/sarcoma-2ww-form.doc>). Agreements are in place within NHS England and CCGs regarding the location of sarcoma referrals. In recognition of factors including the clinical diversity of sarcoma presentation, patient choice, and convenience of access in such a large geographical area, strict sectorisation between the two soft tissue MDTs has been avoided. Further information can be found in the IOG Implementation Plan.

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	3 OF 31	DATE	JUNE 2015
------------------	--	-----------------	---	----------------	---------	-------------	-----------

Geographical location based on former cancer networks	Bone Sarcoma	Soft Tissue Sarcoma	
	Diagnosis & Treatment	Diagnostic Clinic	Treatment Centre
North London	LSS	RNOH	LSS
North East London	LSS	RNOH	LSS
North West London	LSS	RMH	RMH
South East London	LSS	RMH	RMH
South West London	LSS	RMH	RMH
Kent & Medway	LSS	RMH	RMH
Sussex	LSS	BSUH	RMH
Surrey, West Sussex & Hampshire	LSS	RMH	RMH
Anglia	Under 16s to LSS	NNUH	RMH
Mount Vernon	LSS	RNOH	LSS
Essex	LSS	RNOH	LSS
Central South Coast	LSS	UHSFT/PHT	LSS
Dorset	-	RBCH	RMH

Sarcoma Diagnostic Clinics

11-1C-1011

The LSESN SAG has agreed designated sarcoma diagnostic clinics for soft tissue sarcomas. Primary care providers of the associated networks refer to these clinics for the initial diagnosis of soft tissue sarcoma. The clinics link into one of the two MDTs within the London and South East Sarcoma Network: and diagnosed sarcomas would be sent to these centres for treatment:

Diagnostic Clinic	MDT
Royal National Orthopaedic Hospital (RNOH)	London Sarcoma Service
Royal Marsden Hospital (RMH)	Royal Marsden Sarcoma Service
Brighton and Sussex University Hospital (BSUH)	Royal Marsden Sarcoma Service
Norfolk and Norwich University Hospital (NNUH)	Royal Marsden Sarcoma Service
University Hospitals Southampton Foundation Trust (UHSFT)	London Sarcoma Service
Portsmouth Hospitals Trust (PHT)	Royal Marsden Hospital
Royal Bournemouth and Christchurch Hospitals (RBCH)	Royal Marsden Sarcoma Service

There are no other confirmed diagnostic clinics within the LSESN, however there is the expectation that there may be more in the future. The SAG will work with Trusts who have expressed an interest in hosting a diagnostic clinic and ensure that there are clear links into a sarcoma MDT.

Trust Sarcoma Leads have been identified at each of the Trusts within the LSESN (see appendix):

3. Establishment of the SAG

11-1C-1011

The LSESN has been formed in response to the requirements of the Sarcoma IOG which recommends the creation of a managed sarcoma network in which clinicians, commissioners and cancer networks work together to develop the appropriate diagnostic and treatment pathways to serve their population.

In 2010 the two previously separate Tumour Working Groups combined to form one group that was representative of the collaborative approach that the two sarcoma centres had adopted. This combined group has taken on the role of the Supra Network Sarcoma Advisory Group (SAG) for bone and soft tissue sarcomas and is the forum for leading on LSESN operational issues. It works to ensure that care is to the standards outlined in the *Cancer Reform Strategy (2007)* and meets current guidelines

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	4 OF 31	DATE	JUNE 2015
-----------	--	----------	---	---------	---------	------	-----------

and requirements including those in the *Improving Outcomes for People with Sarcoma Manual (2006)*. The LSESN SAG is the only SAG covering the London and South East population.

Host Network

Until 2014, London Cancer has hosted the SAG. After review with both London Cancer and London Cancer Alliance, the SAG has agreed that the London Cancer Alliance will be the host network for the SAG.

4. Role of the SAG

11-1C-1041

SAG Terms of reference

Purpose

The SAG supports the goals set out in the Calman Hine report to consistently achieve the best possible outcomes for patients and to achieve this by ensuring access to a uniformly high quality of care and service provision across the LSESN.

The SAG supports the overall aim of the LSESN and facilitates the collaboration of providers of sarcoma services to provide optimum care based on best clinical practice.

The SAG endorses the Improving Outcomes Guidance for Sarcoma and aims to provide services according to these recommendations.

The SAG assumes corporate responsibility on behalf of the LSESN for co-ordination and consistency across the network in the development of pathways and guidelines, policies, audit, research and service improvement relating to sarcoma.

Quorum

A SAG meeting is quorate if representation from both RMH and LSS are present, and a minimum of four attendees plus at least one of the co-chairs.

Frequency of meetings

Meetings will be held quarterly. A summary of attendance at the SAG will appear in the Annual Report. Planned meeting dates for the following year (2015) are as follows:

- Friday 20th February RMH
- Friday 22nd May UCLH
- Friday 4th September RMH
- Friday 27th November UCLH

All meetings are 3-5pm.

Service planning

1. To agree referral and clinical guidelines for sarcoma in line with national standards and covering the whole care pathway. To subsequently review, agree and update these guidelines on an annual basis. To audit their implementation

2. To develop recommendations for cross-boundary integrated care pathways across primary, secondary and tertiary care provision. To be the primary source of clinical opinion for bone and soft tissue sarcoma for the networks associated with the SAG.

3. To advise on service provision for sarcoma and make recommendations for service improvement/reconfiguration, including the implementation of appropriate Improving Outcomes Guidance, to the Network Lead Cancer Commissioners and the Cancer Network Boards. To recommend priorities for service development to the SCG

4. To ensure decisions become integrated into constituent organisation structures and processes

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	5 OF 31	DATE	JUNE 2015
-----------	--	----------	---	---------	---------	------	-----------

5. To consult with the relevant cross-cutting network groups on issues regarding the SAG's tumour types, involving chemotherapy, radiotherapy, cancer imaging, histopathology, laboratory investigation, specialist palliative care and user involvement
6. To promote high quality care and reduce inequalities in service delivery
7. To take account of the views of patients and carers
8. To take account of opportunities for service and workforce design

Service improvement and redesign

9. To stimulate and lead service improvement initiatives for the SAG and for each individual sarcoma MDT
10. To undertake process mapping and capacity and demand analyses on a regular basis
11. To develop/approve high quality information for patients, for use across the network

Service quality monitoring and evaluation

12. To agree on priorities for common data collection in line with national priorities.
13. To receive reports on performance and cancer waiting times. To review the quality and completeness of data, recommending corrective action where necessary
14. To agree and commission Network audits in sarcoma. To subsequently review the results of these audits
15. To monitor progress on meeting national cancer measures and ensure action plans agreed following peer review are implemented
16. To monitor the quality and effectiveness of sarcoma services across the Network
17. To ensure services are evaluated by patients and carers
18. To monitor the implications of national and regional issues affecting sarcoma and develop recommendations for cross-network action
19. To report identified risks/untoward incidents to ensure learning is spread

Workforce development

20. To consider the education and training needs of teams and individuals and promote education on sarcoma across the Network
21. To maintain an awareness of activities in adjacent cancer networks
22. To consider the overall workforce requirements of the SAG, ensuring that appropriate workforce numbers and CPD are available and taking account of opportunities for skill mix changes
23. To promote links between teams through rotation of staff and to develop common recruitment strategies

Research & Development

24. To agree a common approach to research and development, working with network research teams and participating in nationally recognised studies whenever possible
25. To agree a list of clinical trials for sarcoma from the NIHR portfolio and other 'local' trials and facilitate the means by which patients may be entered

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	6 OF 31	DATE	JUNE 2015
------------------	--	-----------------	---	----------------	---------	-------------	-----------

Implementation Plans

26. To provide the ICS board(s) with an annual report of progress and activity to feed health economy clinical governance reporting processes

27. To provide the ICS board(s) with an annual work programme in the context of prioritised clinical governance, ensuring it is fed into commissioning, with agreements specifying standards, service developments and improvement, data collection, audit, research, education and training

28. To produce a service delivery plan, for approval by the ICS board(s)

5. Membership of the SAG

11-1C-1041

MDT Lead Clinicians from each MDT must ensure that MDTs are adequately represented at SAG meetings. Representatives can be drawn from the core and extended MDTs. The Chair must ensure that there is adequate representation at the SAG from each staff group on the core MDT and ensure their involvement as appropriate.

The core SAG membership is listed below:

CORE MEMBERS:		
MDT Lead Clinicians from associated MDTs		
Prof Jeremy Whelan	Lead Clinician, Sarcoma MDT	London Sarcoma Service
Prof Ian Judson	Lead Clinician, Sarcoma MDT	Royal Marsden Hospital
Core Nurse Members from associated MDTs		
Julie Woodford	Nurse Consultant, RNOH	London Sarcoma Service
Anne McTiernan	Lead Sarcoma Clinical Nurse Specialist, UCLH	London Sarcoma Service
Sam Hackett, Rolyn Alvarado	Clinical Nurse Specialist	Royal Marsden Hospital
Alison Dunlop	Clinical Nurse Specialist	Royal Marsden Hospital
Co-Chairs of the SAG		
Prof Jeremy Whelan	Lead Clinician, Sarcoma MDT	London Sarcoma Service
Mr Andrew Hayes	Consultant Surgeon	Royal Marsden Hospital
User Representatives		
Tricia Moate	Patient Representative	Patient of RMH and RNOH
Nominated members responsible for users' issues and information for patients and carers		
Julie Woodford	Nurse Consultant, RNOH	London Sarcoma Service
Cerys Propert-Lewis	Clinical Nurse Specialist, RMH	Royal Marsden Hospital
Nominated members responsible for ensuring that recruitment into clinical trials is integrated into the function of the SAG		
Dr Beatrice Seddon	Consultant Clinical Oncologist	London Sarcoma Service
Prof Ian Judson	Consultant Medical Oncologist	Royal Marsden Hospital
Administrative Support		
Gemma French	Project Manager	London Sarcoma Service
Specialised Commissioning Group Members		
Hazel Fisher	Head of Engagement and Delivery (North Central London)	NHS England

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	7 OF 31	DATE	JUNE 2015
------------------	--	-----------------	---	----------------	---------	-------------	-----------

Angela Newman	Service Specialist	NHS England
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Additional extended members of the SAG, Trust Sarcoma Leads and Designated Practitioners are distributed meeting papers, and invited to attend where possible

EXTENDED MEMBERS:							
Management Support							
Catriona Liebenberg	Service Manager	RMH					
Marvin Nyadzayo	Operational Manager	RNOH					
Chrissie O'Leary	General Manager	UCLH					
Additional Clinical members from the two sarcoma centres:							
Prof Tim Briggs	Consultant Surgeon	RNOH					
Mr Will Aston	Consultant Surgeon	RNOH					
Mr Jakub Jagiello	Consultant Surgeon	RNOH					
Mr Rob Pollock	Consultant Surgeon	RNOH					
Mr John Skinner	Consultant Surgeon	RNOH					
Prof Max Malago	Consultant Surgeon	UCLH/RFH					
Mr Arjun Shankar	Consultant Surgeon	UCLH/RFH					
Mr Dirk Strauss	Consultant Surgeon	RMH					
Mr Myles Smith	Consultant Surgeon	RMH					
Mr George Ladas	Consultant Surgeon	RBH					
Mr Simon Jordan	Consultant Surgeon	RBH					
Dr Maria Michelagnoli	Consultant Paediatric Oncologist	UCLH					
Dr Palma Dileo	Consultant Medical Oncologist	UCLH					
Dr Sandra Strauss	Consultant Medical Oncologist	UCLH					
Dr Jenny Gains	Locum Clinical Oncologist	UCLH					
Dr Aisha Miah	Consultant Clinical Oncologist	RMH					
Dr Charlotte Benson	Consultant Medical Oncologist	RMH					
Dr Julia Chisholm	Consultant Paediatric Oncologist	RMH					
Dr Robin Jones	Consultant Medical Oncologist	RMH					
Dr Shane Zaidi	Consultant Clinical Oncologist	RMH					
Dr Thillainayagam Muthukumar	Consultant Radiologist	RNOH					
Dr Asif Saifuddin	Consultant Radiologist	RNOH					
Dr Ruth Green	Consultant Radiologist	RNOH					
Dr Paul O'Donnell	Consultant Radiologist	RNOH					
Dr Charles House	Consultant Radiologist	UCLH					
Dr Eleanor Moskovic	Consultant Radiologist	RMH					
Dr Christina Messieu	Consultant Radiologist	RMH					
Prof Adrienne Flanagan	Consultant Histopathologist	RNOH/UCLH					
Dr Fernanda Amary	Consultant Histopathologist	RNOH					
Dr Roberto Tirabosco	Consultant Histopathologist	RNOH					
Prof Cyril Fisher	Consultant Histopathologist	RMH					
Dr Khin Thway	Consultant Histopathologist	RMH					
Sam Hackett	CNS	RMH					
Rolyn Alvarado	CNS	RMH					
Alison Dunlop	CNS	RMH					
Olive Griffiths	CNS	RMH					
Cerys Propert-Lewis	CNS	RMH					
Rosina Donovan	CNS	UCLH					
Deirdre Driver	CNS	UCLH					
Anne McTiernan	CNS	UCLH					
Oliver Mc Manamy	CNS	UCLH					
Joanne Coleman	CNS	RNOH					
Nicola Willis	CNS	RNOH					
Louise Gillings	CNS	RNOH					
Hannah Baldwin	CNS	RNOH					
Shared Care Members from extended MDTs							
Omar Al-Salihi	Consultant Clinical Oncologist	University Hospital Southampton NHS Foundation Trust					
Joanne Brady	Consultant Clinical Oncologist	Poole Hospital NHS Foundation Trust					
Amos Burke	Consultant Medical Oncologist	Cambridge University Hospitals NHS Foundation					
FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	8 OF 31	DATE	JUNE 2015

		Trust
Andrew Davies	Consultant Medical Oncologist	University Hospital Southampton NHS Foundation Trust
Sharadah Essapen	Consultant Clinical Oncologist	Royal Surrey County Hospital NHS Foundation Trust
Maxine Flubacher	Consultant Clinical Oncologist	Poole Hospital NHS Foundation Trust and Dorset County Hospital NHS Foundation Trust
James Gildersleve	Consultant Clinical Oncologist	Royal Berkshire NHS Foundation Trust
Rob Glynne-Jones	Consultant Clinical Oncologist	East and North Hertfordshire NHS Trust
Juliet Gray	Consultant Paediatric Oncologist	University Hospital Southampton NHS Foundation Trust
Julia Hall	Consultant Clinical Oncologist	East Kent Hospitals University NHS Foundation Trust
Charles Hamilton	Consultant Clinical Oncologist	University Hospital Southampton NHS Foundation Trust
Tamas Hickish	Consultant Medical Oncologist	The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
Gail Horan	Consultant Clinical Oncologist	Cambridge University Hospitals NHS Foundation Trust
Kate Lankester	Consultant Clinical Oncologist	Brighton and Sussex University Hospitals NHS Trust
Suat Loo	Consultant Clinical Oncologist	Colchester Hospital University NHS Foundation Trust
Craig Macmillan	Consultant Clinical Oncologist	Northampton General Hospital NHS Trust
Krishnaswamy Madhavan	Consultant Clinical Oncologist	Southend University Hospital NHS Foundation Trust
Boo Messahel	Consultant Medical Oncologist	Cambridge University Hospitals NHS Foundation Trust
Jamie Morgan	Consultant Clinical Oncologist	The Ipswich Hospital NHS Trust
Matthew Murray	Consultant Medical Oncologist	Cambridge University Hospitals NHS Foundation Trust
Kannon Nathan	Consultant Clinical Oncologist	East Kent Hospitals University NHS Foundation Trust
Anthony Neal	Consultant Clinical Oncologist	Royal Surrey County Hospital NHS Foundation Trust
James Nicholson	Consultant Medical Oncologist	Cambridge University Hospitals NHS Foundation Trust
Gary Nicolin	Consultant Medical Oncologist	University Hospital Southampton NHS Foundation Trust
Peter Ostler	Consultant Clinical Oncologist	East and North Hertfordshire NHS Trust
Sherif Raouf	Consultant Medical Oncologist	Barking, Havering and Redbridge University Hospitals NHS Trust
Peter Simmonds	Consultant Medical Oncologist	University Hospital Southampton NHS Foundation Trust
Olga Slater	Consultant Paediatric Oncologist	Great Ormond Street Hospital for Children NHS Foundation Trust
Helen Stubbings	Consultant Clinical Oncologist	Norfolk and Norwich University Hospitals NHS Foundation Trust
Anne Suovuori	Consultant Clinical Oncologist	Portsmouth Hospitals NHS Trust
Saad Tahir	Consultant Medical Oncologist	Mid Essex Hospital Services NHS Trust
Justin Waters	Consultant Medical Oncologist	Maidstone and Tunbridge Wells NHS Trust
Andy Webb	Consultant Medical Oncologist	Brighton and Sussex University Hospitals NHS Trust
Denise Williams	Consultant Paediatric Oncologist	Cambridge University Hospitals NHS Foundation Trust

Trust Sarcoma Leads

We have compiled a list of sarcoma leads for each of the trusts within the LSESN. The sarcoma leads,

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	9 OF 31	DATE	JUNE 2015
------------------	--	-----------------	---	----------------	---------	-------------	-----------

designated practitioners, core and extended members of the SAG are kept informed of any developments within the service and the work of the SAG. Each of these groups is sent the dates and papers for our SAG meetings and invited to attend. We upload pathways and documentations onto our website www.lsesn.nhs.uk and we have recently developed a LSESN newsletter which it is hoped will help improve communication across the network.

Chairman and vice-chairman

The chair is of 3 years duration and the position is appraised annually. At present the co-chairs are Mr Andrew Hayes and Prof Jeremy Whelan, re-appointed in March 2013. When a new chair is required, nominations will be made to the Clinical Director of the host ICS and a formal appointment process followed. In the event of more than one nomination being received there will be a vote to elect the chair. All members of the SAG will be eligible to vote. There is no vice-chair as the two co-chairs deputise for each other.

Between meetings, the co-chairs will action urgent items or those with prior agreement from the SAG.

The Chair(s) of the SAG will have an annual review with the Chair of London Cancer Alliance to discuss the SAG's progress over the previous year and the work plan for the coming year. The annual review will take the form of a face-to-face meeting and documentation sufficient to show that a meeting took place will be produced.

User Involvement and the Lead Nurse

11-1C-104I

The SAG always aims to include the views of patients and service users when planning and reviewing its work streams. It also ensures that services are evaluated by patients and carers through regular patient satisfaction surveys and other initiatives.

At present one user representative attends the SAG -, Tricia Moate (RMH/RNOH), however, increasing this to two users, remains a priority on the SAG Work Programme. Tricia runs sarcoma support groups in Southampton and Bournemouth and so is able to access patient and carer views and issues which are then represented to the group.

If it is not possible to have user representation at each of the SAG meetings, then the SAG defaults to the formal process for obtaining user advice and involvement. The nominated members of the SAG who are responsible for users' issues liaise with the trust user forums and the cancer network Patient Partnership Groups.

Julie Woodford, the SAG Lead Nurse and Cerys Propert-Lewis, CNS are the SAG members nominated as having specific responsibilities for user's issues and information for patients and ensuring that users' views are presented.

The Lead Nurse will take the lead for patient information and user involvement for the SAG, ensuring that all patient information is reviewed and updated on an annual basis and that user representatives are supported in the meetings and at other events. The Lead Nurse will also work with all SAG members to capture data relating to patient experience and ensure that any identified actions are implemented.

In collaboration with Sarcoma UK there is a monthly patient support group and the location of this is alternated between the two centres (RMH and LSS). The support group is advertised in clinical areas within the centres and promoted on patient and professional websites. Patients are encouraged to attend to express their views, share their experiences, gain support and learn where they can obtain more information. Clinical members are invited to give presentations and provide feedback when appropriate. CNS's will provide the link to the London Sarcoma Support Group and will recommend the group to patients where appropriate.

There is also another Sarcoma UK support group within the LSESN catchment area - Sarcoma Support South, which has bimonthly meetings in Southampton and Bournemouth. Clinicians from Southampton and Poole give presentations at these meetings.

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	10 OF 31	DATE	JUNE 2015
------------------	--	-----------------	---	----------------	----------	-------------	-----------

Research and Clinical Trials

Beatrice Seddon and Ian Judson are the SAG nominated lead members for ensuring that recruitment to clinical trials and other well designed studies is integrated into the function of the SAG.

Administrative support

Administrative support to the SAG is currently provided by the London Cancer Alliance who drafts and disseminates the minutes in advance of the meeting. This includes responsibility for keeping a record of attendance and apologies for absence to the meetings. They will liaise with the Chairs, London Sarcoma Project Manager and other members of the SAG to ensure that all issues pertaining to sarcoma and the wider cancer agenda are discussed at the SAG meeting.

The two sarcoma centres provide support to the SAG for booking rooms and meeting notifications.

The London Sarcoma Service Project Manager and lead manager at each Trust will co-ordinate the preparation of documentary evidence for annual peer review with the support of the Network management team.

Any information that requires dissemination to the SAG membership will be sent by the London Sarcoma Service Project Manager or London Cancer Alliance Project Manager and they will make relevant documentation available on the LSESN website.

6. The MDTs

The two sarcoma MDTs each have their own Operational Policy outlining core and extended membership.

SUMMARY OF MEEETINGS:

London Sarcoma Service (Bone and Soft Tissue MDT)		Royal Marsden Soft Tissue MDT					
Lead Clinician	Jeremy Whelan	Lead Clinician	Ian Judson				
<ul style="list-style-type: none"> Weekly bone and soft tissue diagnostic MDT meeting, via video teleconferencing (UCLH and RNOH) Weekly pre-diagnostic meeting at RNOH to discuss new bone and soft tissue referrals Monthly Clinical Review MDT meeting to discuss bone and soft tissue patients, with attendance from UCLH and RNOH Weekly sub-site abdominal sarcoma meeting to review patients with intra-abdominal sarcomas. Attendance from RFH via video teleconferencing Weekly radiology meeting at UCLH to review the imaging of patients that do not require surgical input, to address and answer specific management questions and to discuss second opinions. 		<ul style="list-style-type: none"> Weekly soft tissue diagnostic and management MDT meeting Fortnightly soft tissue oncology management meeting Weekly resection pathology meeting 					
<ul style="list-style-type: none"> Weekly sub-site thoracic sarcoma meeting to discuss and review referrals of chest wall sarcomas and lung metastases. Oncologists from UCLH and RMH attend as well as thoracic surgeons from RBH (via video conferencing) 							
<ul style="list-style-type: none"> Monthly Clinical Trials Meeting 		<ul style="list-style-type: none"> Weekly Clinical Trials Meeting 					
FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	11 OF 31	DATE	JUNE 2015

- Joint Clinical Trials meeting quarterly

Sub-specialisation

- Retroperitoneal surgery is undertaken at both LSS and RMH with the National Specialist Commissioning Advisory Group audit showing RMH as the largest service in England. Within the London Sarcoma Service abdominal sarcoma surgery takes place at the Royal Free Hospital whilst oncology treatment remains at UCLH. There is a weekly abdominal sarcoma MDT with attendance from RFH surgeons and UCLH oncologists.
- Thoracic surgery for sarcomas referred to both LSS and RMH MDTs is undertaken at the Royal Brompton Hospital with support of a dedicated joint extended MDT meeting
- Neurofibromatosis patients with MPNST sarcomas will be managed in conjunction with Guy's & St Thomas's Foundation Trust neurofibromatosis service

The above teams are named as extended MDT members in the Operational Policies of the LSS and RMH MDTs.

Shared management with site-specific cancer teams

There are a number of sarcomas that may present to and need management by other site-specific cancer teams. These include gynaecological sarcomas, head and neck sarcomas, central nervous system sarcomas and adult-type sarcomas arising in children. The site-specific MDTs have primary responsibility to liaise with the sarcoma MDTs to discuss the management of each patient. The key contacts for these site-specific MDTs can be found in the extended MDT membership lists in each of the MDTs Operational Policies. *See appendix for shared care pathways*

Shared Care

As many patients live some distance away from UCLH or RMH, it is not always practical to travel into London for all aspects of treatment. Wherever possible, arrangements are made with a named consultant in a local hospital to share care for any supportive therapies. Under the guidance of the cancer centres, blood analysis, antibiotic administration or blood products may be required.

A shared care folder has been developed for patients who continue treatment outside of UCLH. Further details can be found in the LSS Operational Policy.

7. Designated Chemotherapy Service and Chemotherapy Practitioners

11-1C-102I, 11-1C-107I

The SAG and the Network Board have agreed which chemotherapy services are authorised to deliver chemotherapy regimes for the treatment of soft tissue and bone sarcoma.

Designated Trust for chemotherapy
Barking, Havering and Redbridge University Hospitals NHS Trust
Brighton and Sussex University Hospitals NHS Trust
Cambridge University Hospitals NHS Foundation Trust
Colchester Hospital University NHS Foundation Trust
Dorset County Hospital NHS Foundation Trust
East and North Hertfordshire NHS Trust
East Kent Hospitals University NHS Foundation Trust
Great Ormond Street Hospital for Children NHS Foundation Trust
Maidstone and Tunbridge Wells NHS Trust
Mid Essex Hospital Services NHS Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
Northampton General Hospital NHS Trust
Poole Hospital NHS Foundation Trust
Portsmouth Hospitals NHS Trust

FILE NAME	ISSUE NO	PAGE NO	DATE
LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	1	12 OF 31	JUNE 2015

Royal Berkshire NHS Foundation Trust
Royal Surrey County Hospital NHS Foundation Trust
Southend University Hospital NHS Foundation Trust
The Ipswich Hospital NHS Trust
The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust
University Hospital Southampton NHS Foundation Trust

The SAG has named the oncologists (who are not core members of a sarcoma MDT) who should be responsible for the delivery of chemotherapy to bone and soft tissue sarcoma patients. The SAG has written guidelines which document the principles and criteria for referring patients to chemotherapy services outside the two centres (*see appendix*). These designated chemotherapy practitioners are named as extended MDT members of the relevant sarcoma MDT. They are also included as extended members of the SAG.

8. Designated Radiotherapy Department and Radiotherapy Practitioners

11-1C-102I, 11-1C-107I

The SAG and the Network Board have agreed which radiotherapy departments are authorised to deliver radical radiotherapy courses for the treatment of soft tissue and bone sarcoma:

Designated Trust for radiotherapy
Brighton and Sussex University Hospitals NHS Trust
Cambridge University Hospitals NHS Foundation Trust
Colchester Hospital University NHS Foundation Trust
East and North Hertfordshire NHS Trust
East Kent Hospitals University NHS Foundation Trust
Maidstone and Tunbridge Wells NHS Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
Northampton General Hospital NHS Trust
Poole Hospital NHS Foundation Trust
Portsmouth Hospitals NHS Trust
Royal Berkshire NHS Foundation Trust
Royal Surrey County Hospital NHS Foundation Trust
Southend University Hospital NHS Foundation Trust
The Ipswich Hospital NHS Trust
University Hospital Southampton NHS Foundation Trust

The SAG has named the oncologists (who are not core members of a sarcoma MDT) who should be responsible for the delivery of radiotherapy to bone and soft tissue sarcoma patients. The SAG has written guidelines which document the principles and criteria for referring patients to radiotherapy departments outside the two centres (*see appendix*). These designated radiotherapy practitioners are named as extended MDT members of the relevant sarcoma MDT. They are also included as extended members of the SAG.

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	13 OF 31	DATE	JUNE 2015
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9. Molecular Biology/Cytogenetic Facilities

11-1C-103I

The Network Board has nominated the following licensed laboratories which LSESN will use for cytogenetic and molecular biology investigations on sarcoma cases:

Royal Marsden Hospital

Royal National Orthopaedic Hospital

Department of Cellular Pathology, University of Birmingham Medical School (for GIST molecular analysis)

10. Designated GIST Histopathologists

11-1C-108I

The SAG has agreed the consultant histopathologists who are responsible for the final reporting and reviewing of the histological diagnosis of GIST in the SAG's catchment area

Prof. M Novelli is the specialist pathologist reporting and reviewing GIST in the LSS MDT. This has been agreed by the SAG and the clinical director at UCLH. He is named as an extended MDT member in the LSS MDT Operational Policy, as part of the abdominal sarcoma team. He is a core member of the UCLH Upper GI MDT (*see appendix*) and has taken part in the National GI Pathology EQA scheme.

Prof. C Fisher is the specialist pathologist reporting and reviewing GIST in the RMH MDT. This has been agreed by the SAG and the clinical director at RMH. He is a core member of the RMH sarcoma team as detailed in the RMH Operational Policy (*see appendix*) and has taken part in the National GI Pathology EQA scheme.

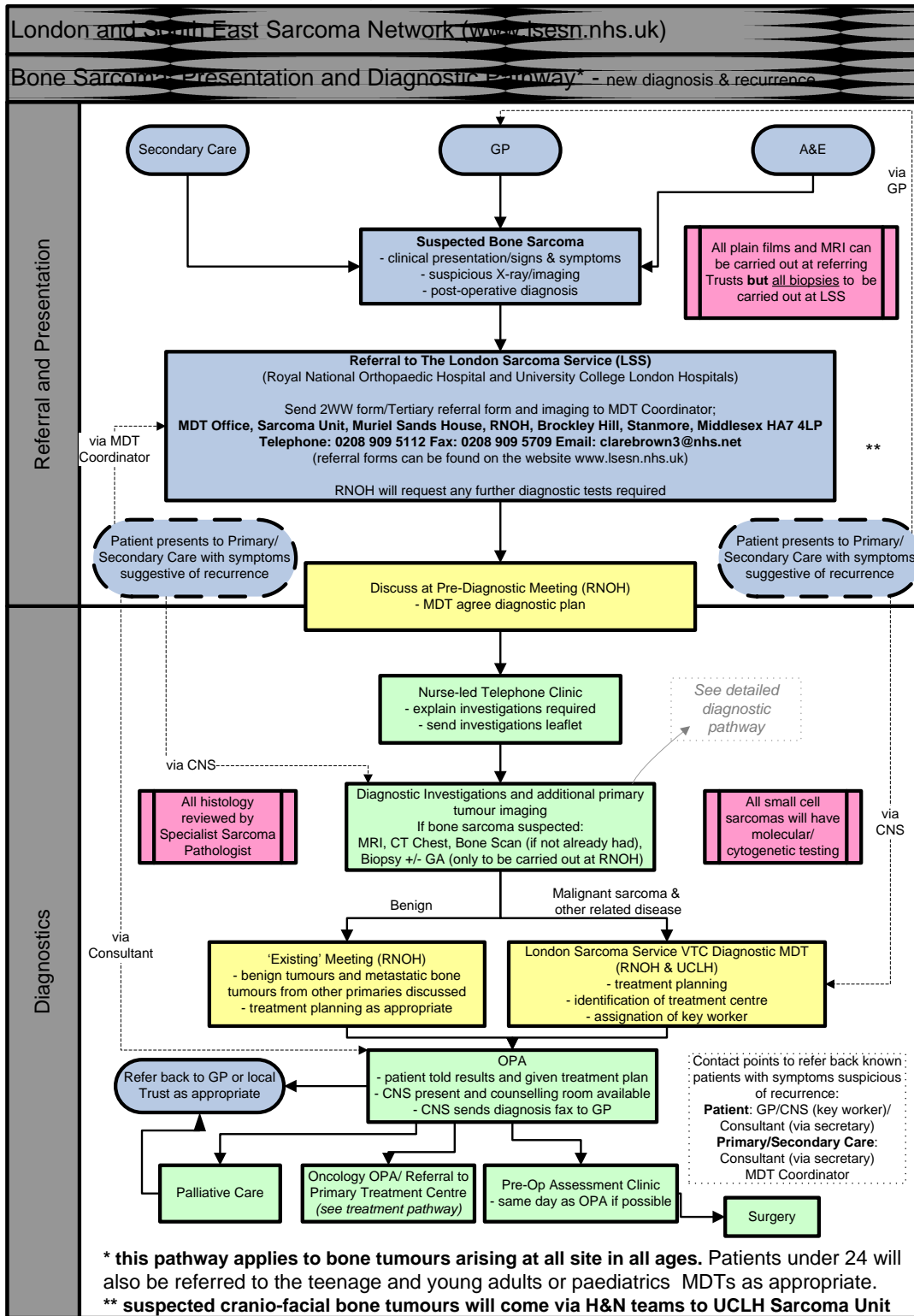
11. Pathways and Guidelines

11-1c-109I to 11-1c-117I

The LSESN follows the national guidelines for the management of sarcoma as detailed in the Sarcoma IOG. The LSESN has agreed referral guidelines and a Patient Management Policy (*see appendix*). The LSESN SAG has agreed patient pathways which both MDTs have adopted:

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	14 OF 31	DATE	JUNE 2015
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Bone Sarcoma Presentation and Diagnostic Pathway:



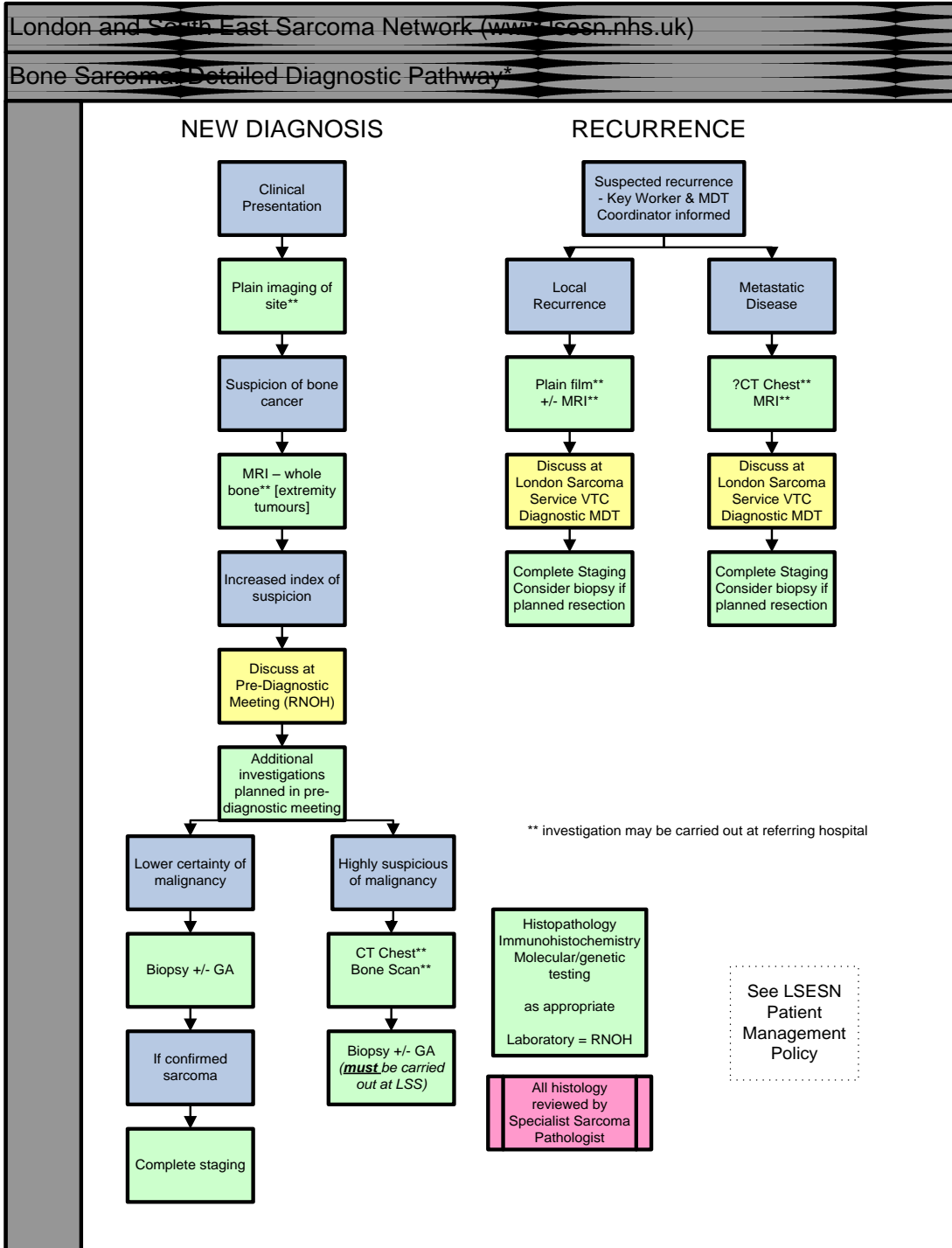
Key:

- MDT discussion
- Clinic/Diagnostics/Treatment
- Process
- Important information

FILE NAME	LSESN BONE SARCOMA: PRESENTATION & DIAGNOSTIC PATHWAY	ISSUE NO	2	PAGE NO	1 OF 1	DATE	NOVEMBER 2014
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FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	15 OF 31	DATE	JUNE 2015
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Bone Sarcoma Detailed Diagnostic Pathway:



* this pathway applies to bone tumours arising at all sites in all ages

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

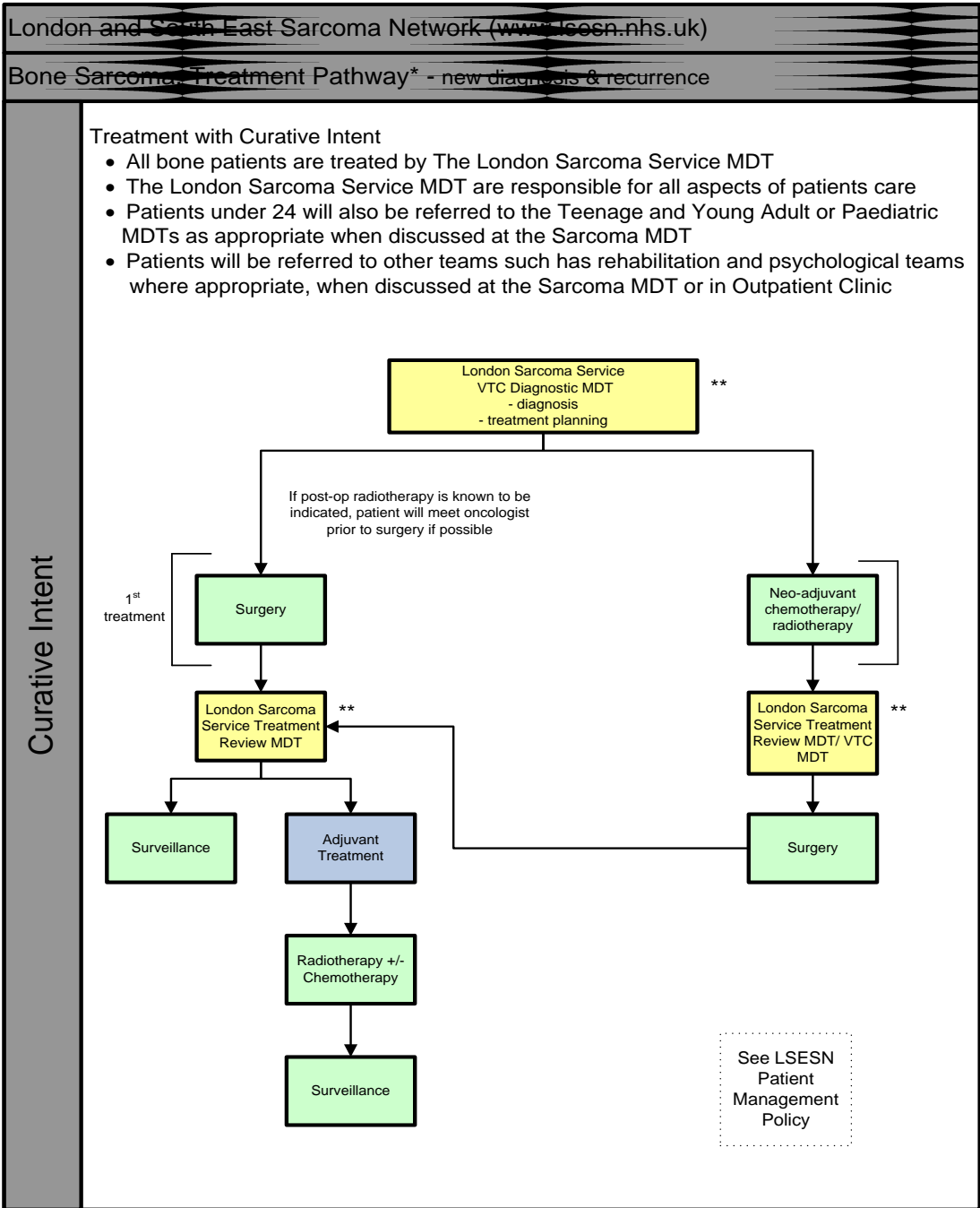
Key:

- MDT discussion
- Clinic/Diagnostics/Treatment
- Process
- Important information

FILE NAME	LSESN BONE SARCOMA: DETAILED DIAGNOSTIC PATHWAY	ISSUE NO	1	PAGE NO	1 OF 1	DATE	NOVEMBER 2014
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FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	16 OF 31	DATE	JUNE 2015
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Bone Sarcoma Treatment Pathways:



* this pathway applies to bone tumours arising at all sites in all ages

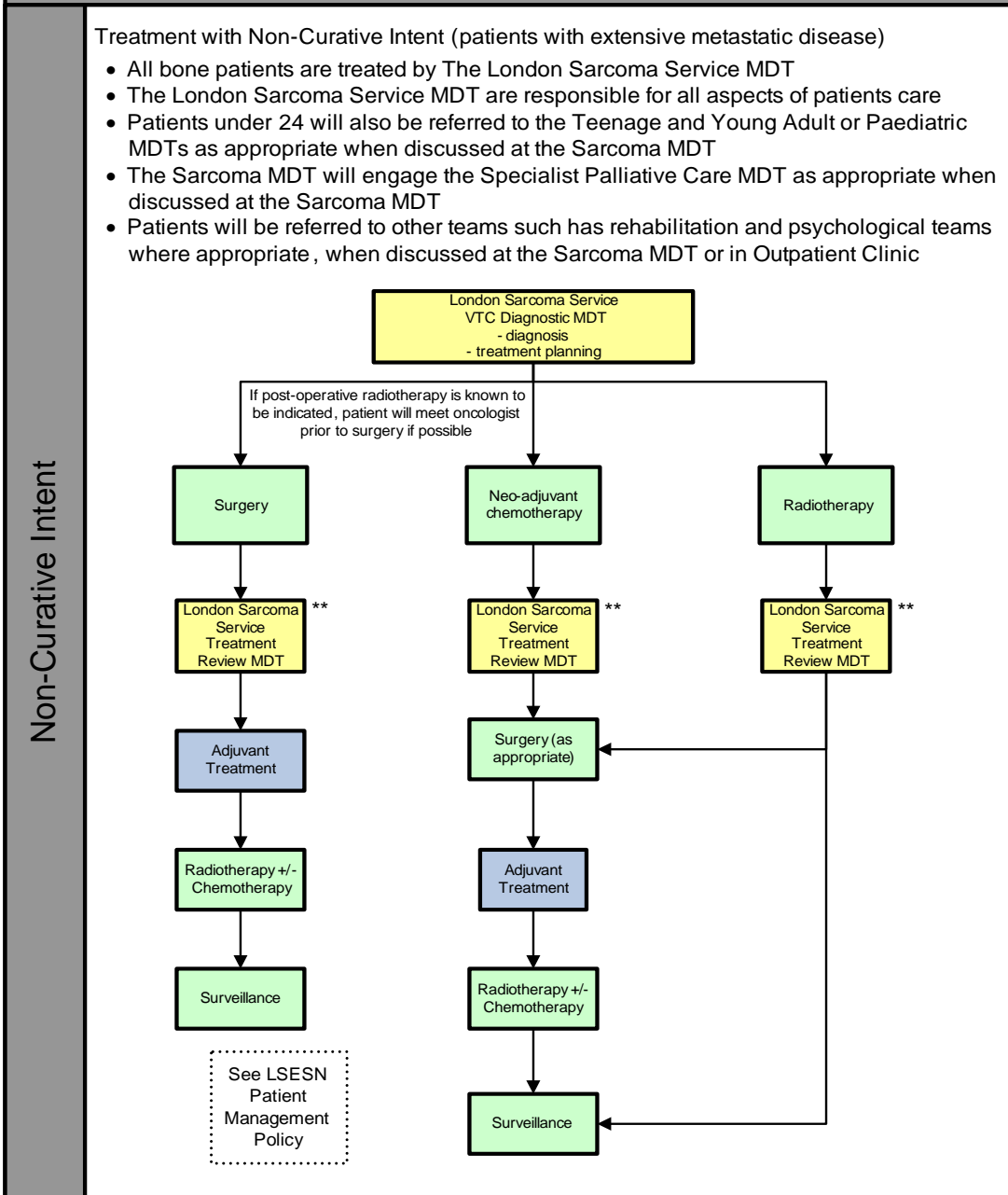
** Note: Cranio-facial bone tumours are also discussed in the UCLH Head & Neck MDT at these points

Key:

- MDT discussion
- Clinic/Diagnostics/Treatment
- Process
- Important information

FILE NAME	LSESN BONE SARCOMA: TREATMENT PATHWAY	ISSUE NO	1	PAGE NO	1 OF 2	DATE	NOVEMBER 2014
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FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	17 OF 31	DATE	JUNE 2015
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* this pathway applies to bone tumours arising at all sites in all ages

** Note: Cranio-facial bone tumours are also discussed in the UCLH Head & Neck MDT at these points

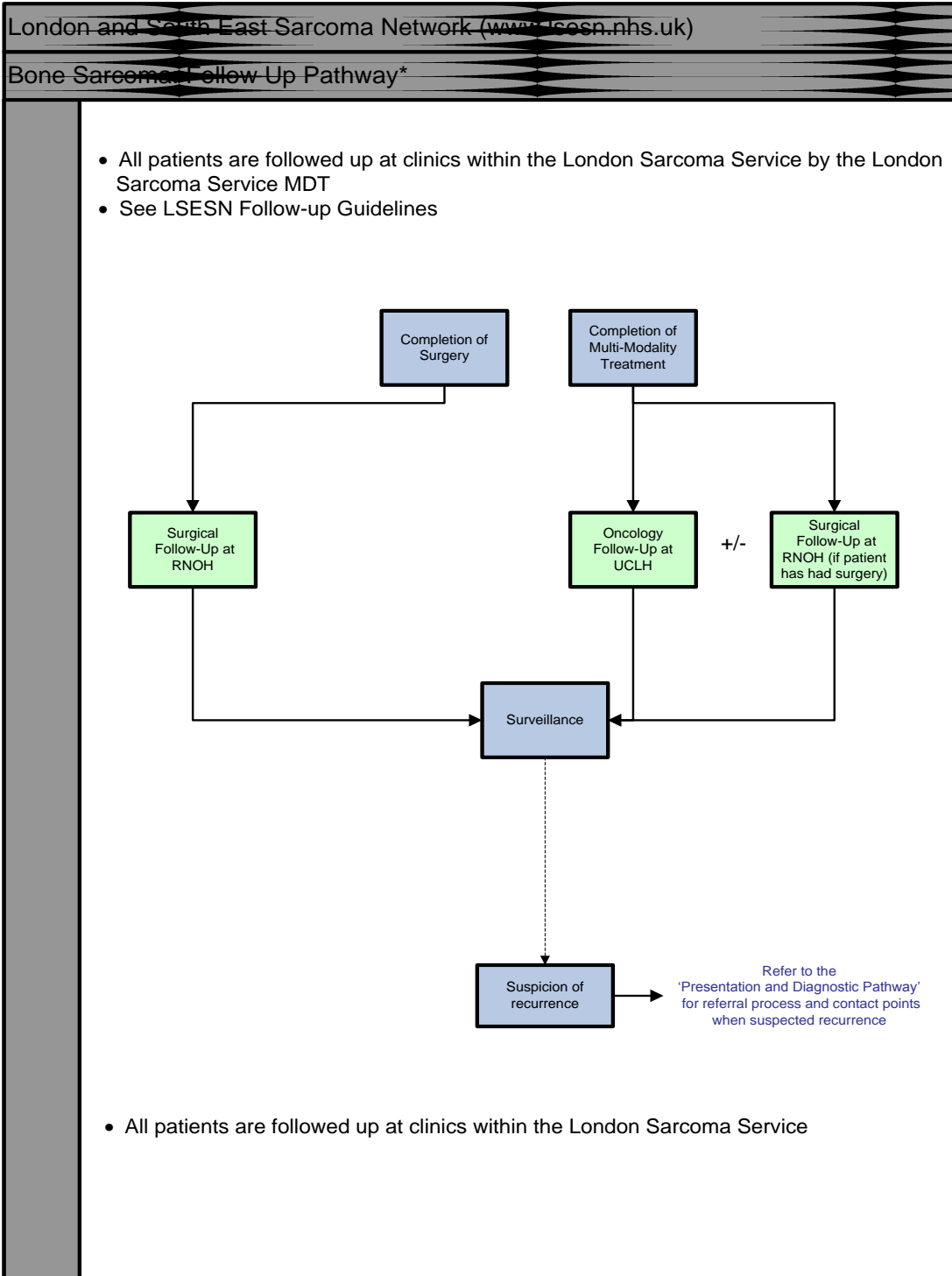
Key:

- MDT discussion
- Clinic/Diagnostics/Treatment
- Process
- Important information

FILE NAME	LSESN BONE SARCOMA: TREATMENT PATHWAY	ISSUE NO	1	PAGE NO	2 OF 2	DATE	NOVEMBER 2014
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FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	18 OF 31	DATE	JUNE 2015
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Bone Sarcoma Follow-Up Pathway:



* this pathway applies to bone tumours arising at all sites in all ages

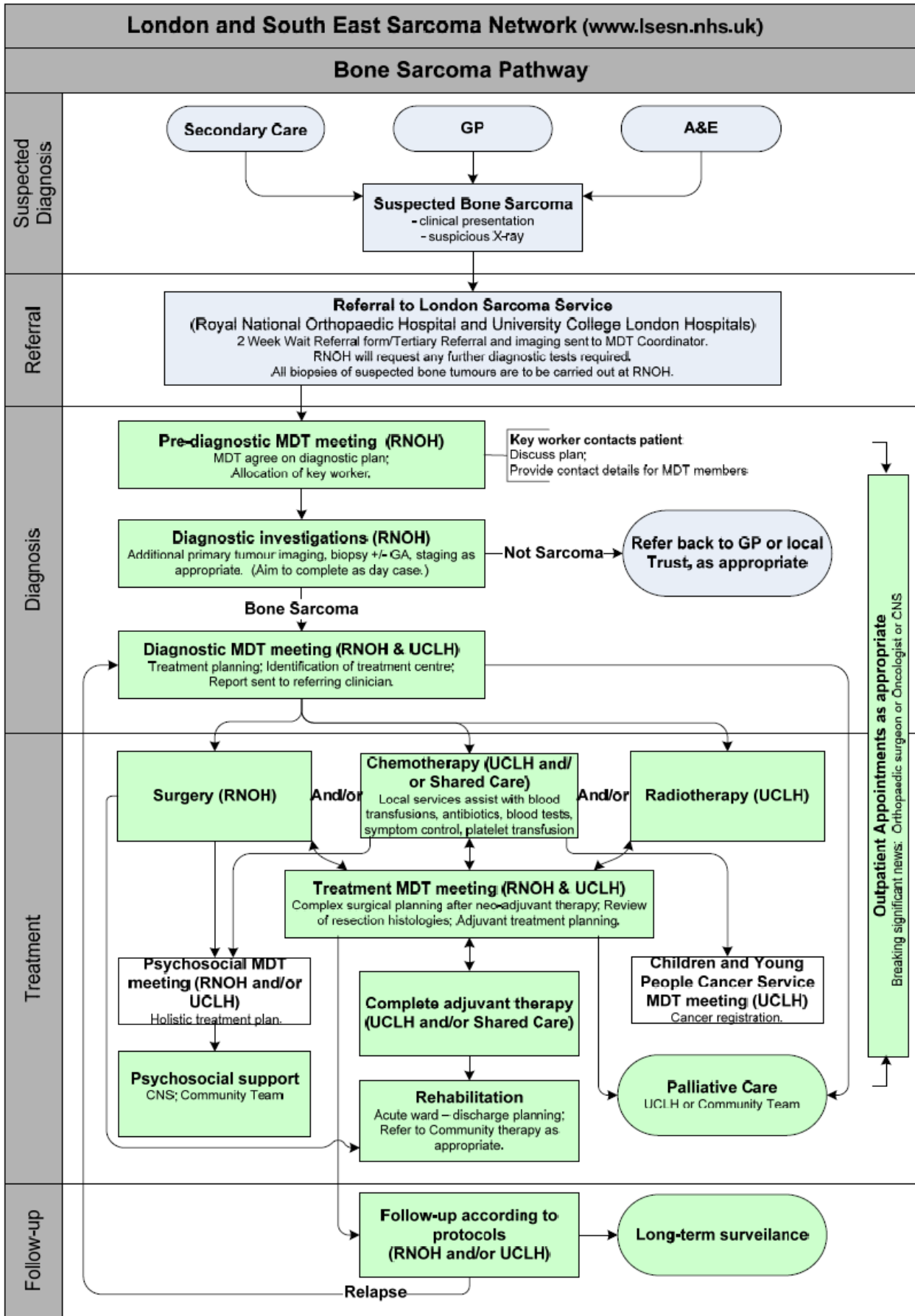
Key:

- MDT discussion
- Clinic/Diagnostics/Treatment
- Process
- Important information

FILE NAME	LSESN BONE SARCOMA: FOLLOW-UP PATHWAY	ISSUE NO	1	PAGE NO	1 OF 1	DATE	NOVEMBER 2014
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FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	19 OF 31	DATE	JUNE 2015
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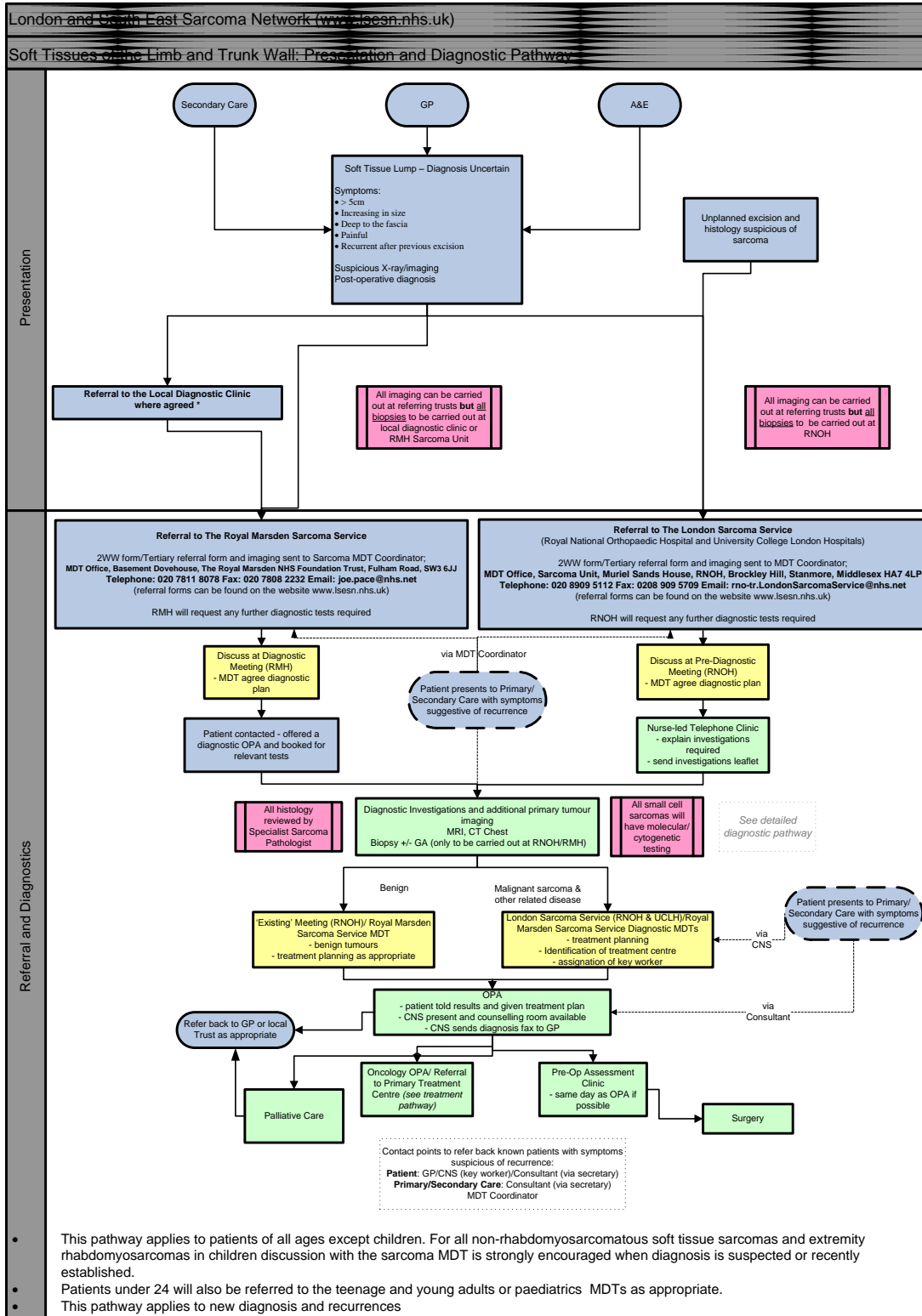
Complete Bone Pathway:



Version 1.2 (2010)

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	20 OF 31	DATE	JUNE 2015
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Soft Tissue Sarcoma Presentation and Diagnostic Pathway:



- This pathway applies to patients of all ages except children. For all non-rhabdomyosarcomatous soft tissue sarcomas and extremity rhabdomyosarcomas in children discussion with the sarcoma MDT is strongly encouraged when diagnosis is suspected or recently established.
- Patients under 24 will also be referred to the teenage and young adults or paediatrics MDTs as appropriate.
- This pathway applies to new diagnosis and recurrences

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	21 OF 31	DATE	JUNE 2015
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*** Agreed local diagnostic clinics within SAG:**

Brighton and Sussex University Hospitals NHS Trust (BSUH)

Royal Sussex County Hospital Diagnostic Clinic

Patients diagnosed with sarcomas at the diagnostic clinic are then referred to the Royal Marsden Sarcoma Service

Sarcoma Diagnostic Clinic Contact details:

2WW form/Tertiary referral form sent to Fax: 01273 694886 or email: Madalyn.Betsworth@bsuh.nhs.uk

Referral forms can be found on the sussex cancer network website <http://www.sussexcancer.nhs.uk/professionals/agreed-scn-guidelines/sarcoma/>

Any queries contact Maddy: 01273 696955 ext 7962

Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH)

Norfolk and Norwich University Hospital Diagnostic Clinic

Patients diagnosed with sarcomas at the diagnostic clinic are then referred to the Royal Marsden Sarcoma Service

Sarcoma Diagnostic Clinic Contact details:

Fax: 01603 286876

Referral forms can be found here http://nww.knowledgenorfolk.nhs.uk/cancer/soft_tissue_sarcoma.htm

Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust (RBCH)

Royal Bournemouth Hospital Diagnostic Clinic

Patients diagnosed with sarcomas at the diagnostic clinic are then referred to the Royal Marsden Sarcoma Service

Sarcoma Diagnostic Clinic Contact details:

Fax: 01202 704470 Tel (for enquiries): 01202 704741

Referral forms can be found here <http://nww.dorsetcancernetwork.nhs.uk/referral.htm>

University Hospitals Southampton Foundation Trust (UHSFT)

University Hospitals Southampton Diagnostic Clinic

Sarcoma Diagnostic Clinic Contact details:

Fax: 02380 795176, Email: margaret.burton@uhs.nhs.uk


Portsmouth Hospitals Trust (PHT)

Portsmouth Hospitals Diagnostic Clinic

Sarcoma Diagnostic Clinic Contact details:

Phone: 023 9228 6000

Key:

 MDT discussion

 Clinic/Diagnostics/Treatment

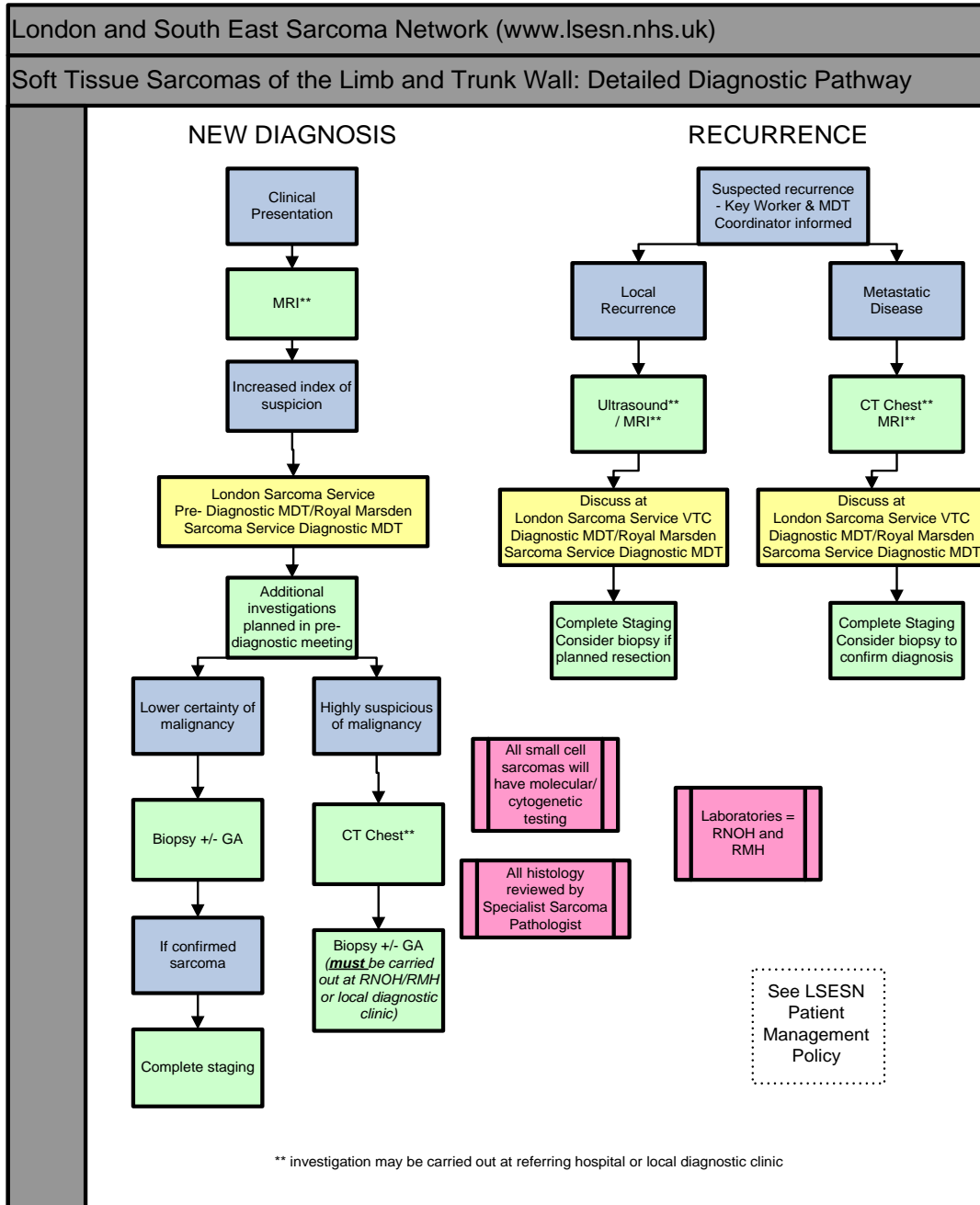
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 Important information

FILE NAME	LSESN SOFT TISSUE SARCOMA: PRESENTATION & DIAGNOSTIC PATHWAY	ISSUE NO	1	PAGE NO	1 OF 1	DATE	NOVEMBER 2014
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FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	22 OF 31	DATE	JUNE 2015
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Soft Tissue Sarcoma Detailed Diagnostic Pathway:



- This pathway applies to patients of all ages except children. For all non-rhabdomyosarcomatous soft tissue sarcomas and extremity rhabdomyosarcomas in children discussion with the sarcoma MDT is strongly encouraged when diagnosis is suspected or recently established
- Patients under 24 will also be referred to the teenage and young adults or paediatrics MDTs as appropriate.
- This pathway applies to new diagnosis and recurrences

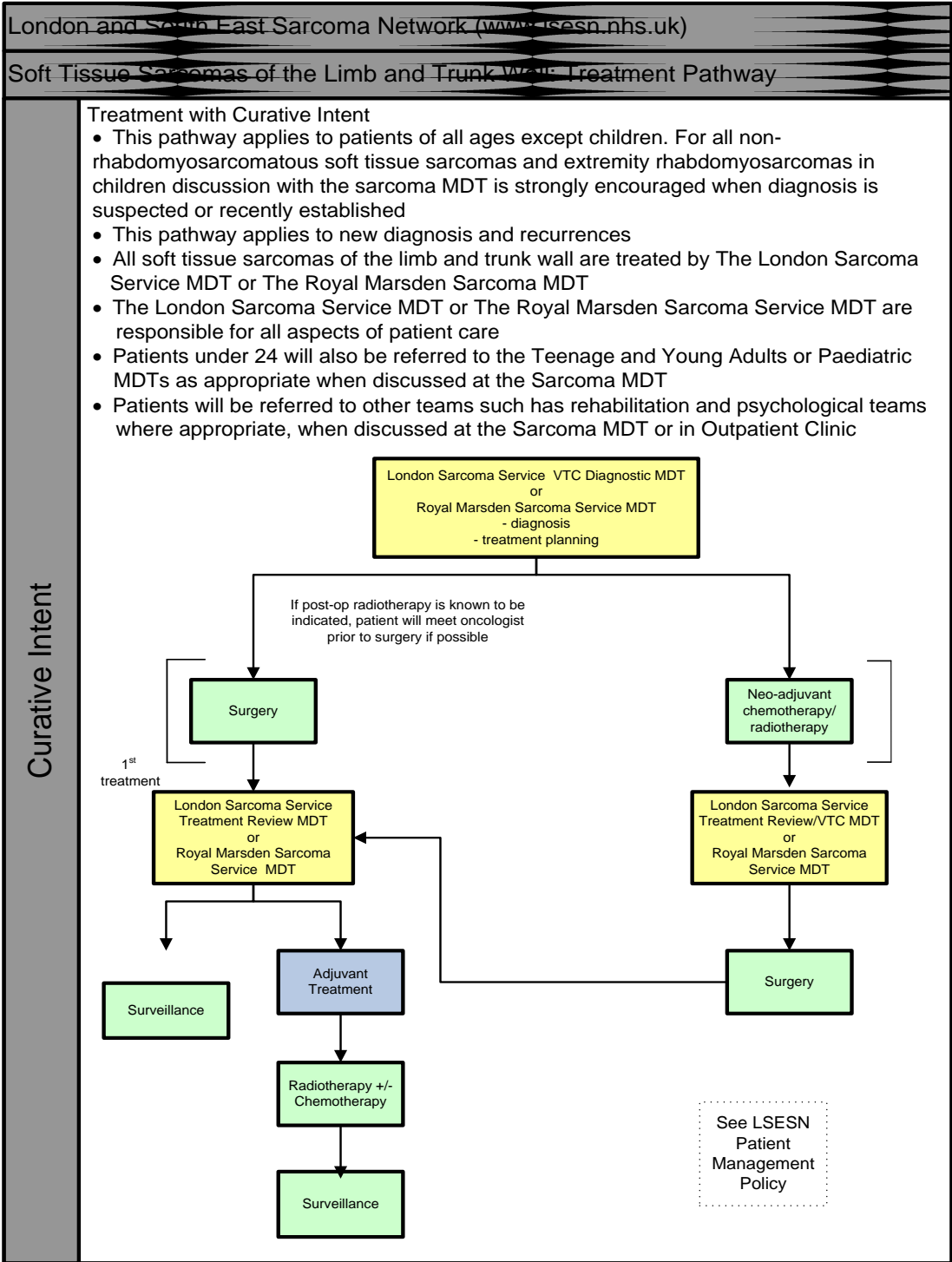
Key:

- MDT discussion
- Clinic/Diagnostics/Treatment
- Process
- Important information

FILE NAME	LSESN SOFT TISSUE SARCOMA: DETAILED DIAGNOSTIC PATHWAY	ISSUE NO	1	PAGE NO	1 OF 1	DATE	NOVEMBER 2014
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FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	23 OF 31	DATE	JUNE 2015
-----------	--	----------	---	---------	----------	------	-----------

Soft Tissue Sarcoma Treatment Pathways:



Key:

- MDT discussion
- Clinic/Diagnostics/Treatment
- Process
- Important information

FILE NAME	LSESN SOFT TISSUE SARCOMA: TREATMENT PATHWAY	ISSUE NO	1	PAGE NO	1 OF 2	DATE	NOVEMBER 2014
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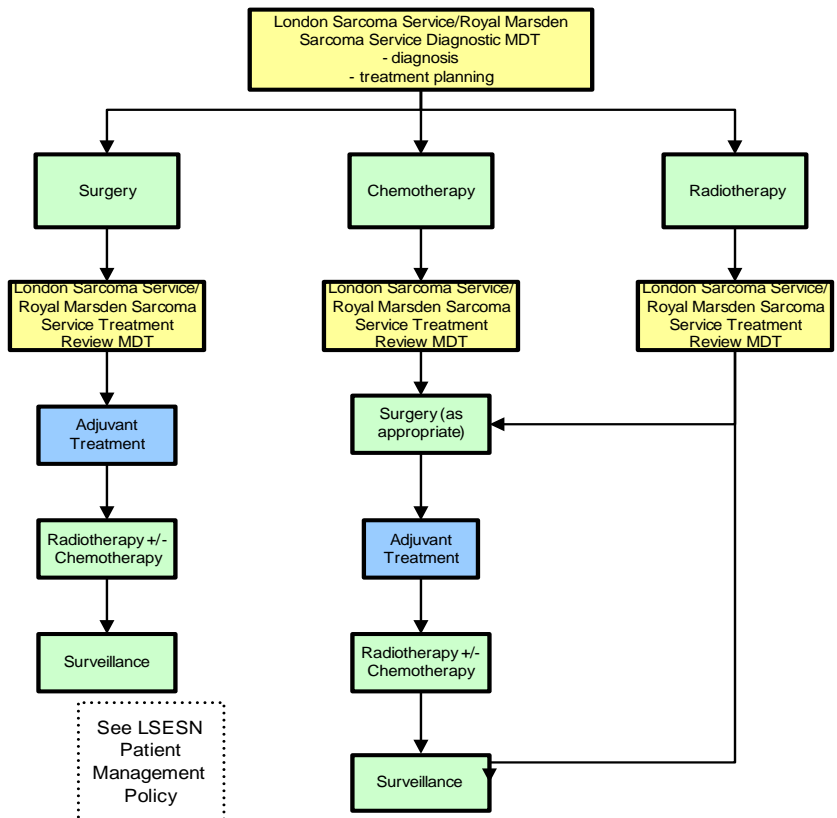
FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	24 OF 31	DATE	JUNE 2015
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Soft Tissue Sarcomas of the Limb and Trunk Wall : Treatment Pathway

Non-Curative Intent

Treatment with Non-Curative Intent (patients with extensive metastatic disease)

- This pathway applies to patients of all ages except children. For all non-rhabdomyosarcomatous soft tissue sarcomas and extremity rhabdomyosarcomas in children discussion with the sarcoma MDT is strongly encouraged when diagnosis is suspected or recently established
- This pathway applies to new diagnosis and recurrences
- All soft tissue sarcomas of the limb and trunk wall are treated by The London Sarcoma Service MDT or The Royal Marsden Sarcoma Service MDT
- The London Sarcoma Service MDT or The Royal Marsden Sarcoma Service are responsible for all aspects of patient care
- Patients under 24 will also be referred to the Teenage and Young Adults or Paediatric MDTs as appropriate when discussed at the Sarcoma MDT
- The Sarcoma MDTs will engage the Specialist Palliative Care MDTs as appropriate when discussed at the Sarcoma MDT
- Patients will be referred to other teams such as rehabilitation and psychological teams where appropriate, when discussed at the Sarcoma MDT or in Outpatient Clinic



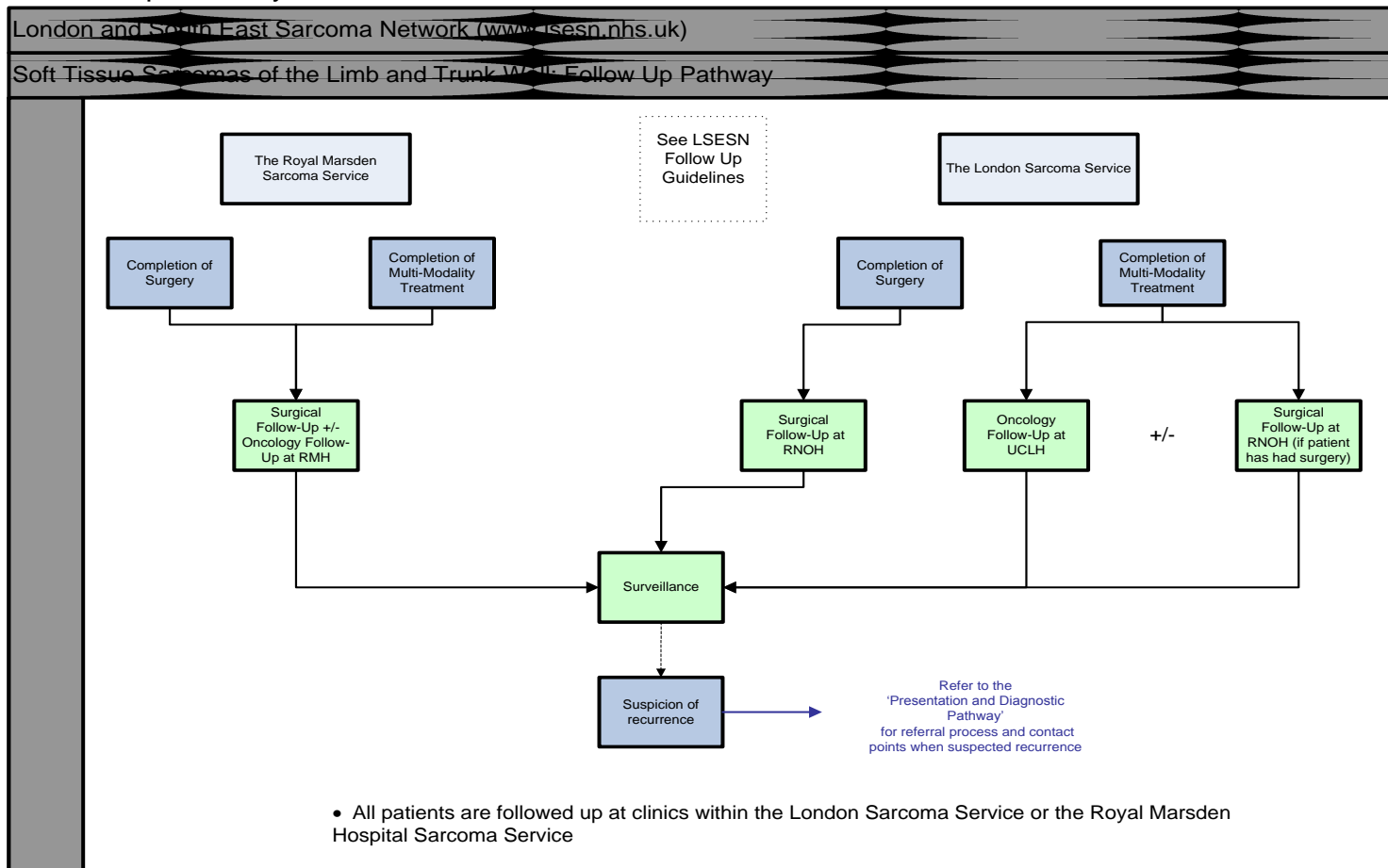
Key:

- MDT discussion
- Clinic/Diagnostics/Treatment
- Process
- Important information

FILE NAME	LSESN SOFT TISSUE SARCOMA: TREATMENT PATHWAY	ISSUE NO	1	PAGE NO	2 OF 2	DATE	NOVEMBER 2014
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FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION 2014	ISSUE NO	1	PAGE NO	25 OF 31	DATE	JUNE 2015
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Soft Tissue Sarcoma Follow-Up Pathway:

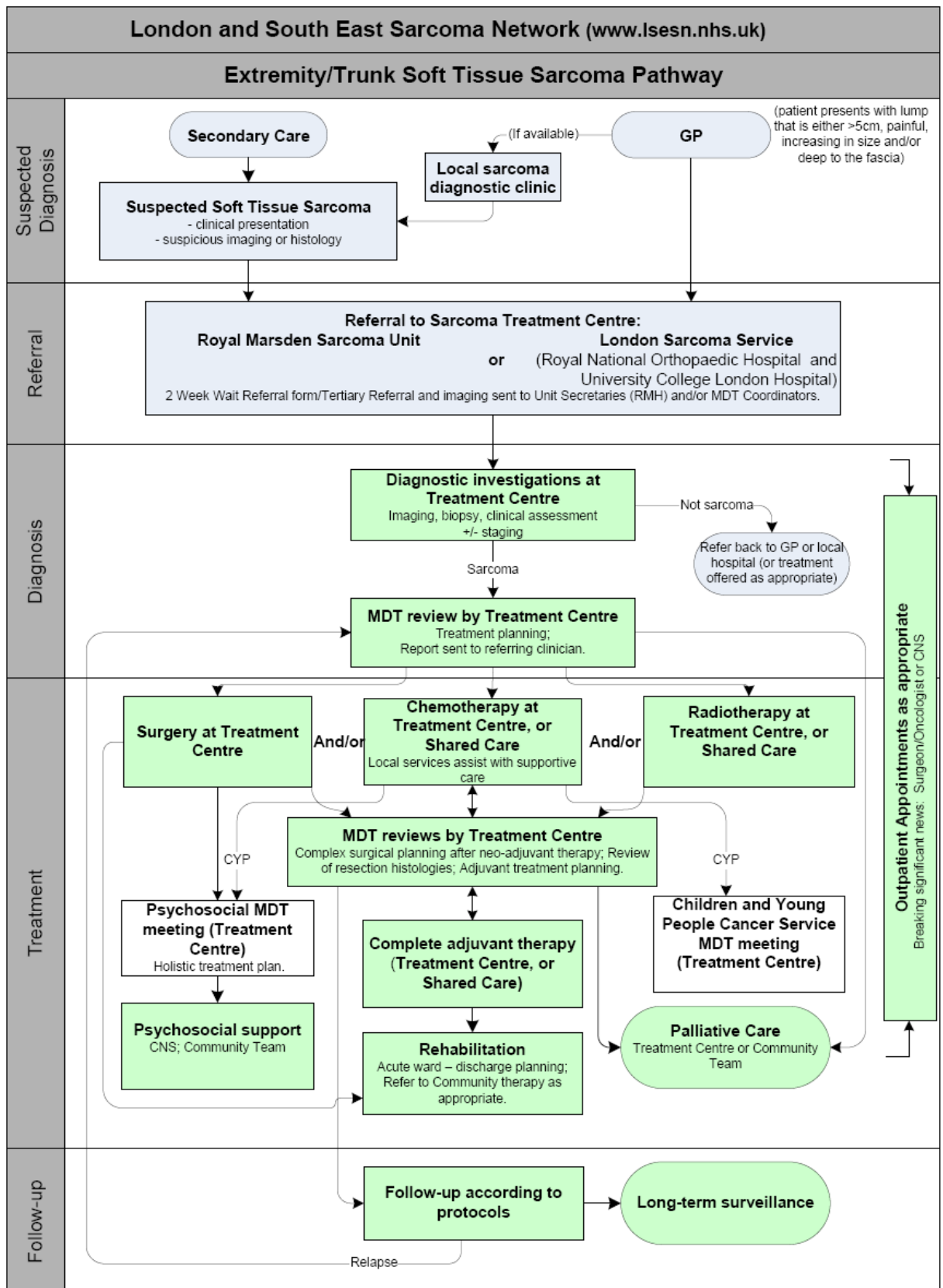


Key:

MDT discussion
 Clinic/Diagnostics/Treatment
 Process
 Important information

FILE NAME	LSESN SOFT TISSUE SARCOMA: FOLLOW UP PATHWAY	ISSUE NO	1	PAGE NO	1 OF 1	DATE	NOVEMBER 2011
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Complete Soft Tissue Pathway:



Shared Care Pathways and guidelines can be found in the *appendix*.

Chemotherapy Treatment Algorithms

11-1C-112I

The SAG, in consultation with the Network Chemotherapy Group has agreed a list of acceptable chemotherapy treatment algorithms, which will be updated bi-annually.

TYA Pathways

11-1c-115I to 11-1c-116I

The *Improving Outcomes Guidance (IOG) for children and young people with cancer* (2005) and subsequent *Teenage and Young Adults Cancer Measures* (2012) recommend that patients aged 16–18 are managed at a principal treatment centre (PTC) for teenager and young adult (TYA) cancers and that those aged 19–24 are given the choice of being managed at a PTC or a TYA designated hospital.

All patients within this age range, regardless of place of care, should be referred to the TYA MDT at the relevant PTC. Referral to the MDT should be made using the TYA referral form.

The chairs of the SAG and the chairs of the relevant TYACNCG have agreed the pathways for sarcoma. These agreements have been communicated to the LSESN. The Sarcoma MDTs work in conjunction with the TYA MDTs at the specialist centres to agree the management of TYA patients with sarcoma.

The TYA MDT at UCLH is the Principle Treatment Centre responsible for delivering and overseeing the care of teenagers and young adults within the North Thames Network, which covers the following areas:

- ICS London Cancer
- ICS London Cancer Alliance (North West London only)
- East of England (EoE) Strategic Clinical Network

In agreement with the Improved Outcomes Guidance for Children and Young People (2005), the Sarcoma MDT team and TYA MDT at UCLH will be jointly looking after the patients of 13 to the end of their 24th year. In general,

- TYAs of 13 to the end of their 18th year should be treated at the UCLH TYA PTC;
- TYAs of 19 to the end of their 24th year should be offered the choice of treatment in the UCLH TYA PTC or in a TYA designated hospital.

The Principal Treatment Centre for TYA for South Thames is The Royal Marsden Hospital.

All cases, even those who choose to be treated outside of either the PTC or a designated hospital, are reported to the PTC and discussed at the TYA MDT meeting. The treatment plan of all case is jointly agreed by the Sarcoma MDT and TYA MDTs according to the relevant agreed clinical guidelines.

Discussion at the TYA multidisciplinary team (MDT) is in addition to the specialist MDT; key functions of the TYA MDT are to agree the treatment plan of the specialist MDT, ensure cancer registration and provide a psychosocial care plan. Members of

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION	ISSUE NO	1	PAGE NO	28 OF 31	DATE	JUNE 2015
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the specialist MDT or TYA service at the PTC or TYA designated hospitals are invited to attend the TYA MDT either remotely or in person.

The Clinical Lead of relevant Sarcoma MDT will have the final responsibility for:

- The diagnostic process
- Production of a treatment summary for each patient to be provided within six months of completion of first line treatment
- Production of a follow up care plan for each patient which describes the pathway as applied to their individual case
- Monitoring of disease recurrence and late effects care arrangements

The Clinical Lead of the TYA MDT at UCLH will have the final responsibility for:

- ensuring that age appropriate support and environment is available for each patient
- advising on age appropriate clinical trials relevant to the patient

12. Data Collection – Minimum Data Set	11-1c-119I
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The SAG area-wide agreed minimum data set (MDS) for bone and soft tissue sarcoma comprises of the following data items:

- Cancer Waiting times monitoring
- which is taken from National Cancer Dataset, Waiting Times Subset, version 7.0
<http://www.nwlc.nhs.uk/Downloads/Cancer%20Intelligence/Part%206%20National%20Cancer%20Dataset%20-%20Waiting%20Times%20Subset%20-%20Version%207.0.pdf>
- Cancer Outcomes and Services Dataset (COSD)
- which can be found here
http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

Note: Both MDTs collect and submit data on soft tissue sarcomas. The LSS MDT also collects and submits data on bone sarcomas.

Cancer Waiting Times

These data items are collected and uploaded to the relevant database by the MDT Coordinator and Cancer Management team within each Trust.

As per national requirements the data is uploaded retrospectively on the 25th working day of the next calendar month to the Open Exeter Database

Within The Royal Marsden Sarcoma Unit:

- i) The RMH MMP database: covers ‘referral to treatment’ and ‘decision to treat to treatment’ pathway data items for soft tissue sarcoma patients treated at RMH, including subsequent treatments. Data is uploaded from this database to the national Open Exeter database according to the designated national timetable

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION	ISSUE NO	1	PAGE NO	29 OF 31	DATE	JUNE 2015
------------------	---	-----------------	---	----------------	----------	-------------	-----------

Within The London Sarcoma Service

- i) The MDT Coordinator at UCLH enters data into the UCLH Infoflex database and the Cancer Waiting Times Data Manager uploads reports from this system onto Open Exeter. The UCLH Infoflex database covers 'referral to treatment' and 'decision to treat to treatment' pathway data items for bone and soft tissue sarcoma patients referred to and/or treated at UCLH.
- ii) At RNOH data is entered onto the RNOH Infoflex database during and before/after the MDT meeting by the MDT and the MDT Coordinator uploads reports from Infoflex onto Open Exeter. The RNOH Infoflex database covers 'referral to treatment' and 'decision to treat to treatment' pathway data items for bone and soft tissue sarcoma patients referred to and/or treated at RNOH.

Cancer Outcomes and Services Dataset (COSD)

RNOH, UCLH and RMH provide monthly data on all cancer diagnoses electronically to the Thames Cancer Registry within 25 days after the end of the month
The data items for the COSD are submitted from various data sources:

- Trust Patient Administration Systems (PAS)
- Infoflex data reports (RNOH and UCLH)
- Using data submitted to Open Exeter (for the GFOCW dataset)
- Trust Pathology systems
- Trust Radiology systems
- Varis (Radiotherapy system)

Other Trusts within the catchment area of the London and South East Sarcoma network use various databases and systems to upload patients onto Open Exeter for Cancer Waiting Times and to submit data to the Thames Cancer Registry. Referring trusts submit data on the referral and diagnostic details where applicable. The diagnostic and treatment part of the pathway is uploaded at RNOH/UCLH or RMH and links to the original referral using the nhs number. The Trust responsible for the patient at any one time is responsible for collecting and submitting the data at that point in the patient pathway.

Data collection is discussed at the SAG as appropriate, and will often focus on national as well as LSESN data, for example when looking at referral maps or location of retroperitoneal surgery.

13. Audit

11-1c-119I

The SAG will agree an audit project each year. Each of the MDTs will participate in the audit and the results will be presented at one of the SAG meetings. Details can be found in the SAG Annual Report.

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION	ISSUE NO	1	PAGE NO	30 OF 31	DATE	JUNE 2015
------------------	---	-----------------	---	----------------	----------	-------------	-----------

Both MDTs are involved in a number of local and nationally approved trials. All trials are ethically approved.

The SAG will annually discuss a report from each of its MDTs to include:

- Details of the MDT's trials portfolio including the extent of local provision of the national portfolio
- The MDTs recruitment to the portfolio, including the extent of delivery against the locally agreed timescales and targets
- The MDTs programme for improvement for the above, as proposed to the SAG

The MDTs should agree a final programme for improvement at the SAG discussion meeting.

The MDT reports will include the above points for TYA patients and this part of the reports will be discussed with the teenage and young adults' cancer network co-ordinating group (TYACNCG). The MDT will agree the final programme for improvement for TYA clinical trials with the TYACNCG.

The discussion at the SAG will be minuted.

Joint review will take place at LSESN research meetings occurring after each SAG.

FILE NAME	LONDON & SOUTH EAST SARCOMA NETWORK: CONSTITUTION	ISSUE NO	1	PAGE NO	31 OF 31	DATE	JUNE 2015
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