



London and South East
Sarcoma Network

Supra Network Sarcoma Advisory Group (SAG)

Annual Report

2014-2015

Hosted by



Sarcoma Advisory Group members agreed this Annual Report by email in June 2015

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This report is a summary of the SAG's achievements, challenges and activities during the period April 2014 to March 2015. However, latest information prior to Peer Review upload has been provided for a fuller understanding of SAG's progress.

Achievements:

- Regular meetings of a highly effective London and South East Sarcoma Network SAG with strong representation from both sarcoma MDTs within the region
- Refresh of the LSESN communication directory, with LSESN Hospital Trust sarcoma leads checked and confirmed. Effective communication to shared care clinicians within LSESN via email and website updates. Communication details checked and refreshed.
- Development of newsletter to further improve communication within the LSESN
- Continued maintenance of the LSESN website
- Patient representation at SAG meetings
- Continued leadership in sarcoma clinical trials (Phase I-III) with international reputation. Successful joint clinical trials meeting

Challenges:

- Hosting arrangements and administrative support for SAG meetings
- Late diagnosis and information provided to GPs
- Local rehabilitation services
- Increasing number of referrals of suspected sarcoma with low pick up of malignancy and increased non-specialist workload at both centres. Difficulties in obtaining support to develop and roll-out of a diagnostic clinic model within the LSESN

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2 SAG meetings

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The SAG has met three times between April 2014 and March 2015 on the following dates: 18/07/2014, 24/10/2014 and 20/02/2015. The meeting is co-chaired by Mr Andrew Hayes, Consultant Surgeon at Royal Marsden Hospital and Prof Jeremy Whelan, Consultant Oncologist, ULCH. Both chairs were present for all three meetings. The location of the meeting was rotated between the two sarcoma centres.

The core membership attendance is shown in the table below. Extended membership attendance can be found in the appendix. Meeting papers are also distributed to other stakeholders as appropriate.

SAG Attendance 2014/15					
CORE MEMBERS			Meeting Dates		
Name	Position	Trust	18/07/14	24/10/14	20/02/15
MDT Lead Clinicians from associated MDTs					
Prof Jeremy Whelan	Lead Clinician, Sarcoma MDT	London Sarcoma Service	Present	Present	Present
Prof Ian Judson	Lead Clinician, Sarcoma MDT	Royal Marsden Hospital	Apologies	Present	Present
Core Nurse Members from associated MDTs					
Julie Woodford*	Nurse Consultant, RNOH	London Sarcoma Service	Apologies	Apologies	Apologies
Rolyn Alvarado*			Apologies	Present	Present
Alison Dunlop*	Clinical Nurse Specialist, RMH	Royal Marsden Hospital	Present	Present	Present
Co-Chairs of the SAG					
Prof Jeremy Whelan	Consultant Medical Oncologist	London Sarcoma Service	Present	Present	Present
Mr Andrew Hayes	Consultant Surgeon	Royal Marsden Hospital	Present	Present	Present
User Representatives					
Tricia Moate	Patient Representative	Patient of RMH/RNOH	Present	Present	-Present

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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	Present	Present	Present
Prof Ian Judson	Consultant Medical Oncologist	Royal Marsden Hospital	Apologies	Present	Present
Specialised Commissioning Group Members					
Angela Newman			Apologies	Apologies	Present
Named Managerial/Administrative Support					
Catherine Pulicani	PA	Royal Marsden Hospital	Present	Present	Present
Gemma French	Project Manager	London Sarcoma Service	Present	Present	Present
Melissa Morris/Catriona Liebenberg	Project Manager	London Cancer Alliance	Present	Present	Present

* also nominated members responsible for users' issues and information for patients and carers

3 Annual Review

The Co-Chairs of the Sarcoma Advisory Board Mr Andrew Hayes and Prof Jeremy Whelan met with the Chief Medical Officer for London Cancer Prof Kathy Pritchard-Jones and Clinical Director for London Cancer Alliance Dr Shelley Dolan on 4th June 2014 and presented the sarcoma pathway and the work programme to the London Cancer Board.

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The SAG agreed to participate in the following audits during the year 2014/15:

1. Retroperitoneal Follow-Up Audit
2. Patient Experience Audit
3. Cancer Outcomes and Services Dataset, Clinical Indicators and Cancer Waiting Times Data

Retroperitoneal Follow-Up Audit

The SAG has agreed to carry out a joint audit of the follow-up practices of retroperitoneal sarcomas. This audit will be led by Dr Beatrice Seddon at UCLH and Dr Aisha Miah at the Royal Marsden Hospital. The audit has been discussed at SAG meetings in July 2014, October 2014 and January 2015.

Patient Experience Audit

The RNOH/UCLH sarcoma MDT carried out a patient experience survey in 2013 which looked at some of the national cancer patient survey questions in more detail and asked additional questions relevant to our service. The results of this survey were presented at the SAG in January 2014. Members of the SAG commented positively on the success of the survey, and it was noted that this would allow a more comprehensive view of patient experience than that is available from the NCPES. The Royal Marsden has recently carried out the same survey on their patients and will present their results at the next SAG meeting in September 2015.

Cancer Outcomes and Services Dataset, Clinical Indicators and Cancer Waiting Times Data

The collection of COSD and difficulties in collecting staging data was discussed at the SAG meeting in July 2014. The SAG will regularly discuss the submission of this data, and will review the data at meetings over the coming year. At the July SAG meeting various data metrics were presented showing data across London, including COSD.

The clinical Indicators for Sarcoma (Service Profiles) were discussed at the SAG meetings in July 2014 and the data was compared to other national sarcoma MDTs at the SAG in October 2014.

Cancer waiting times data and delays in patient pathways at both centres were discussed at the SAG meeting in October 2014. This data will be reviewed at the SAG at least annually.

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5 Clinical Trials

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The SAG discussed an annual clinical trials report from each of the MDTs.

A report to show the list of clinical trial inclusions and recruitment for The London Sarcoma Service (including TYA trials) and The Royal Marsden Sarcoma Service (including TYA trials) was noted and approved by the SAG at a clinical trials meeting on 22/05/2015. See *appendix* reports. In addition, joint unit research meetings were instigated in 2011 and have been held 3 monthly, after the SAG meeting, to review portfolios, and discuss rationalising opening of trails across the two sites. It has been agreed that for trials where recruitment is likely to be low, best use of resource is to open at just one site, and cross refer patients. The SAG agreed that both centres were recruiting well and that all eligible patients were being offered entry into clinical trials and that current recruitment levels should be maintained. Both centres continue to have their own regular trials meeting.

6 Activity Data

London Sarcoma Service

Referrals:

- 4796 suspected sarcoma referrals received from April 2014 to March 2015
- 13% increase in referrals compared to previous year:

Year	No. of refs	% change	
2012/13	3747	13.2%	27.9%
2013/14	4240		
2014/15	4796		

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MDT Activity:

Number of cases discussed in MDTs, April 2014 to March 2015:

MDT	TOTAL
New	5221
Existing	1743
VTC	1471
BTAP	668
Abdominal	631
Thoracic	235
SUHT	60
Radiology	144
TOTAL	10173

Sarcoma Diagnoses:

The following are cases of sarcoma discussed at the MDT for the first time in the patient's case history. They are newly diagnosed sarcomas, and do not include recurrences (April 2014 to March 2015):

	TOTAL
Bone	151
Soft Tissue	307
Viscera	44
TOTAL	502

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Royal Marsden sarcoma Service

Referrals (GP and other):

	2014/15												
	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Total
GP referrals	44	34	49	57	47	58	58	52	44	44	42	53	582
Other referral types	96	83	84	128	106	122	101	95	103	99	98	98	1213
All referrals (total)	140	117	133	185	153	180	159	147	147	143	140	151	1795

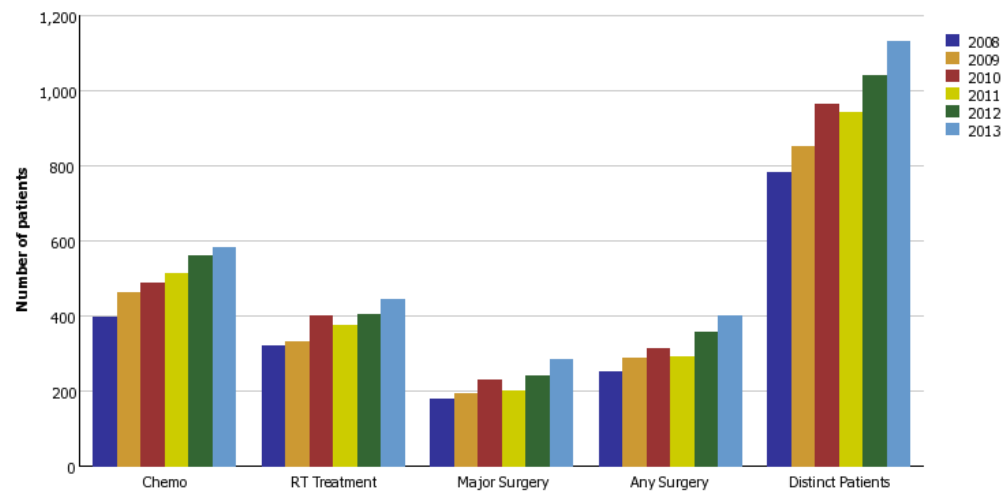
Service activity data:

Treatment breakdown (2013 data only):

Number of patients	Chemotherapy		Radiotherapy				Brachytherapy / Isotope Therapy		Major Surgery		Any Surgery		Distinct Patients		
	Chemo	No Chemo	RT Treatment	Number of RT treatments	Number of RT Courses	No RT Treatment	Brachytherapy / Isotope Therapy	No Brachytherapy / Isotope Therapy	Major Surgery	Number of Major Operations	No Major Surgery	Any Surgery	Number of Operations	No Surgery	Total
2013	581	551	446	4841	623	686	1	1131	284	299	848	401	498	731	1132

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Patterns of increase across different treatment modalities:

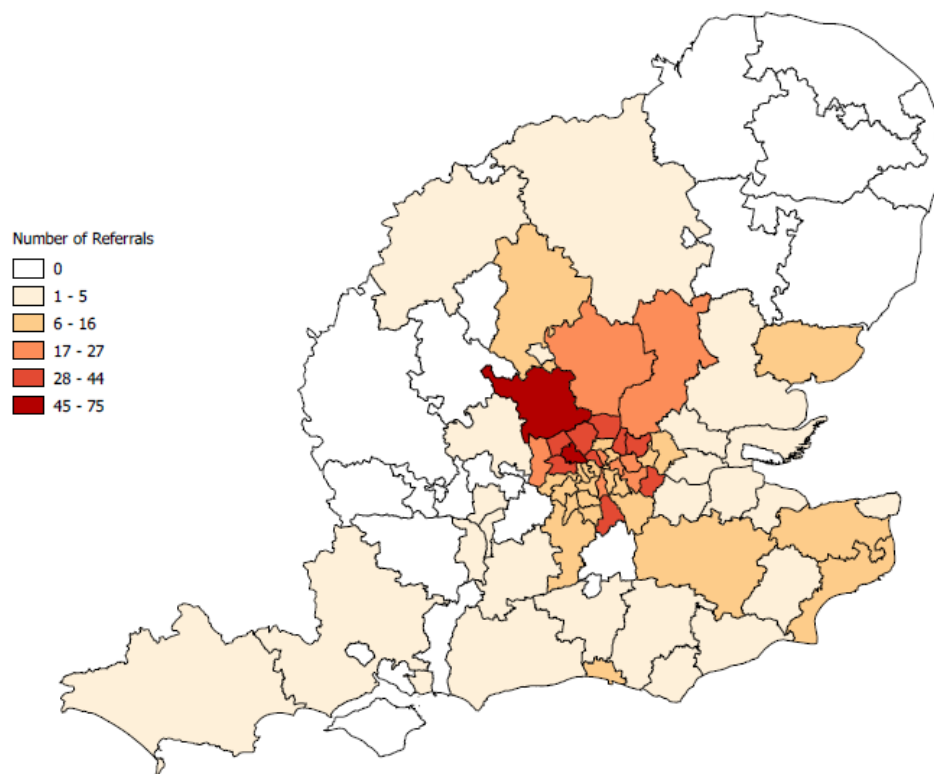


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Referral Mapping:

Referrals to both centres come from the London and South East Network and beyond, are fairly evenly distributed to the two centres as can be demonstrated from the following referral maps:

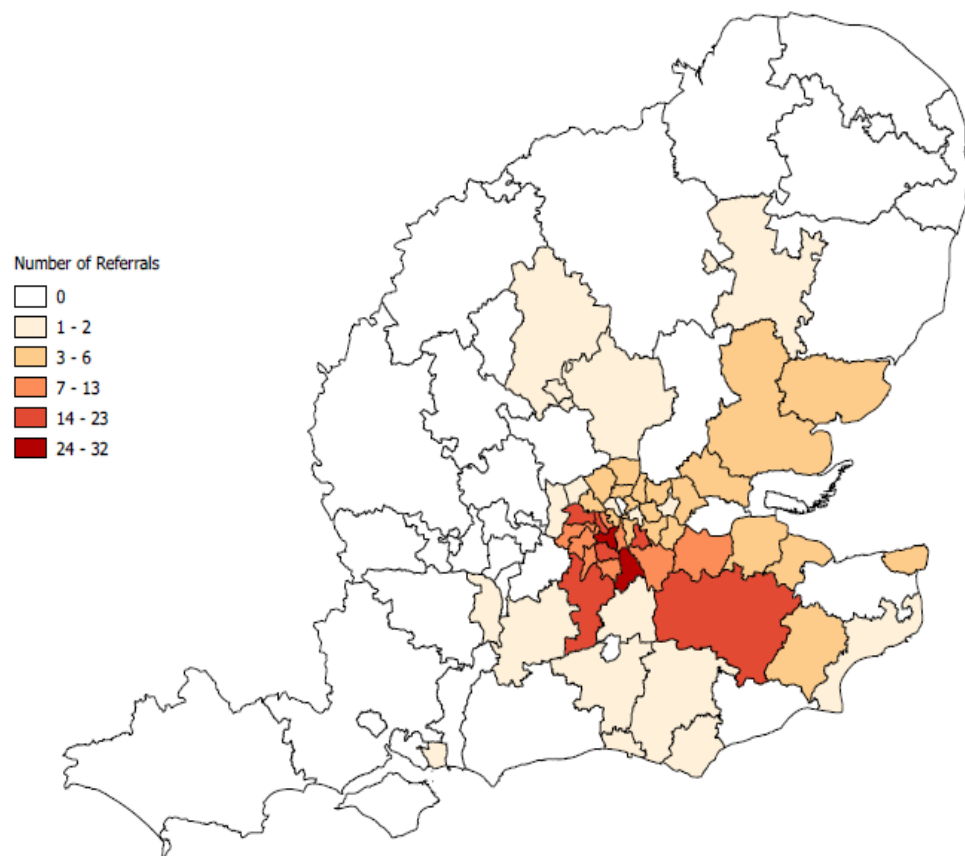
The London Sarcoma Service: Two Week Wait Referrals 01/04/2013 – 31/03/2014



London Sarcoma Service	
Brent , Herts Valley	45-75 referrals
Barnet, Bexley, Camden, Croydon, Ealing, Enfield, Harrow, Redbridge, Waltham Forest	28-44 referrals
East and North Hertfordshire, Greenwich, Hillingdon, Islington, Lambeth, Newham, Tower Hamlets, West Essex	17-27 referrals

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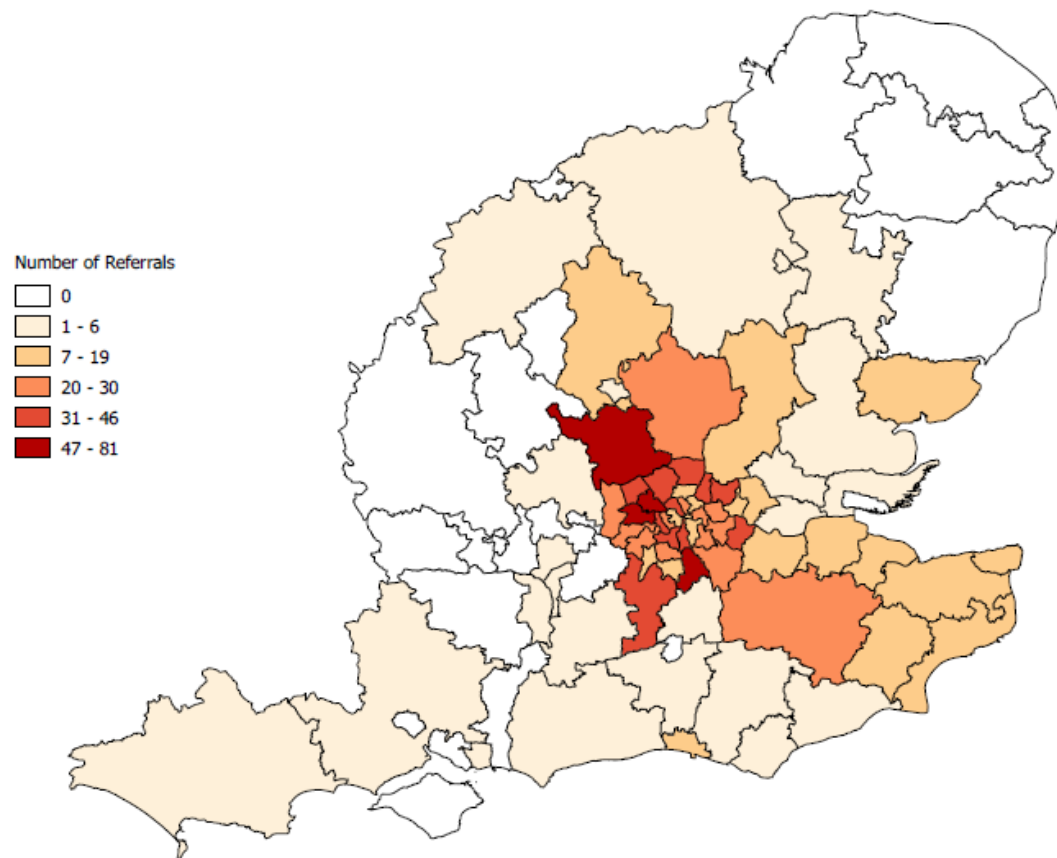
The Royal Marsden Service: Two Week Wait Referrals 01/04/2013 – 31/03/2014



Royal Marsden	
Croydon, Wandsworth	24-32 referrals
Ealing, Hammersmith and Fulham, Lewisham, Merton, Surrey Downs, West Kent	14-23 referrals

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The London Sarcoma Service and Royal Marsden Service: Combined Two Week Wait Referrals 01/04/2013 – 31/03/2014



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7 Cancer Waiting Times Performance

The two MDTs collect the agreed SAG minimum dataset for Cancer Waiting Times.

All 2WW referrals for suspected bone sarcoma should go directly to RNOH. 2WW referrals for suspected soft tissue sarcomas of limb and trunk should go directly to RNOH or RMH. 2WW referrals for suspected soft tissue sarcomas of non-limb/trunk for example head & neck, retroperitoneal, abdominal, pelvic, urology, breast, and skin should go directly to UCLH or RMH. The majority of 2WW suspected sarcoma referrals therefore go to RNOH or RMH, hence the low numbers referred to UCLH described in the table below. The London and South East Sarcoma Networks has agreed referral guidelines which indicate the location for referrals and we are currently revising our 2WW referral form to make this clearer.

The majority of oncology treatments for any bone and soft tissue sarcomas take place at UCLH and RMH, as described in the MDT Operational Policy and in the agreed pathways. There a small number of exceptions where oncology treatment is given by other trusts called shared care providers. Designated chemotherapy and radiotherapy departments and practitioners have been agreed as detailed in the SAG constitution document.

All surgery for bone sarcoma takes place at RNOH, with the exception of head and neck surgery which takes place at UCLH. Surgery for soft tissue sarcoma of the limb and trunk takes place at RNOH and RMH and for non-limb/trunk takes places at UCLH and RMH.

Summary of Performance Apr 14 - Mar 15

Royal National Orthopaedic Hospital:

Target	Number	Breaches	% Target Met	Target Threshold
14 Day to First OPA	1074	36	97%	93%
62 Day Urgent GP Referral to Treatment	48*	2.5*	95%	85%
31 Day First Treatments	128	4	97%	96%
31 Day Subsequent Drug Therapy	n/a	n/a	n/a	98%
31 Day Subsequent Surgery	166	4	98%	94%
31 Day Subsequent Radiotherapy	n/a	n/a	n/a	94%
31 Day Subsequent Other	n/a	n/a	n/a	Not Set
62 Day Consultant Upgrades	48*	0.5	99%	Not Set

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* accountable number of patients (patients are shared between trusts)

From April 2014 to March 2015 RNOH met all the cancer waiting times targets.

University College London Hospital:

Target	Number	Breaches	% Target Met	Target Threshold
14 Day to First OPA	45	7	84%	93%
62 Day Urgent GP Referral to Treatment	20*	3.5	83%	85%
31 Day First Treatments	137	1	99%	96%
31 Day Subsequent Drug Therapy	374	0	100%	98%
31 Day Subsequent Surgery	24	0	100%	94%
31 Day Subsequent Radiotherapy	189	1	99%	94%
31 Day Subsequent Other	26	0	100%	Not Set
62 Day Consultant Upgrades	15	0	100%	Not Set

* accountable number of patients (patients are shared between trusts)

UCLH met all cancer targets from April 2013 to March 2014 with the exception of the two week wait and 62 day referral to treatment targets. There were 7 two week wait breaches all due to patient choice and with only a relatively small number of total two week waits (45) this meant the performance dropped below the target threshold of 93%. There were 3.5 breaches of the 62 day referral to treatment target (a total of 7 patients). These breaches were unavoidable due to late referrals to the sarcoma service (4 referrals were received after day 60), and complex diagnostic pathways where the patient was referred to various specialities prior to the sarcoma team.

Combined data for The London Sarcoma Service (RNOH + UCLH):

April 2014 to March 2015:

Sarcoma GP 2WW Referrals: 1,119

Sarcoma 31 Day First Treatments New Cancers: 265

Sarcoma 31 Day Subsequent Treatments: 779

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Royal Marsden Hospital:

		No. TWR breach	TWR breaches	TWR day total	% compliance
TWR referrals	Q4	90	7	97	92.78%
	Q3	97	6	103	94.17
	Q2	94	5	99	94.95%
	Q1	75	4	79	94.94%
	TOTAL	356	22	378	94.18%

		No. 31 day breach	31 day breaches	31 day total	% compliance
1st treatment	Q4	31	2	33	93.94%
	Q3	42	2	44	95.45%
	Q2	54	0	54	100%
	Q1	43	0	43	100%
	TOTAL	170	4	174	97.70%
Subsequent treatment	Q4	91	0	91	100.00%
	Q3	94	1	95	98.95%
	Q2	92	2	94	97.87%
	Q1	78	2	80	97.50%
	TOTAL	355	5	360	98.61%

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		No. 62 day breach	62 day breaches	62 day total	% compliance
Urgent GP referrals to treatment	Q4	7.5	2	9.5	78.95%
	Q3	12	3.5	15.5	77.42%
	Q2	14.0	4	18	77.78%
	Q1	8.5	2.0	10.5	80.95%
	TOTAL	42	11.5	53.5	78.50%
Consultant upgrade	Q4	0	0.5	0.5	0%
	Q3	0	0.5	0.5	0%
	Q2	0	0	0	0%
	Q1	0	0	0	0%
	TOTAL	0	1	1	0%

The Royal Marsden receives a high number of referrals from other Trusts including providing a diagnostic service for suspected sarcomas referred directly from primary care. Unfortunately owing to the rarity of the tumour type, when patients initially present at other Trusts, a sarcoma is not usually initially suspected. This often has a knock on impact on the length of the pathway and the patients' time from first presentation to treatment. During the course of 2014 the service has worked hard to improve performance and regularly reviews CWT breaches, pathway issues and how to improve the process of referrals from other Trusts where initial diagnostics have taken place elsewhere. The service will continue to focus on improving performance and is exploring alternative approaches to urgent referral diagnostics to address the increasing workload within the service.

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London Sarcoma Support Group

The London Sarcoma Support Group has been developed so that meetings alternate between the Royal Marsden Hospital and the London Sarcoma Service (RNOH) every month. 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.

Patient Representation at SAG

At present one user representative attends the SAG -, Tricia Moate (RMH/RNOH). Tricia also runs sarcoma support groups in Southampton and Bournemouth and so is able to access patient and carer views and issues.

National Cancer Patient Experience Survey

The National Cancer Patient Experience Programme Survey 2014/15 provided useful feedback for both MDTs within the LSESN.. All three trusts have produced an action plan and are working on improving results for the next survey. A

Patient Experience Audit

The RNOH/UCLH sarcoma MDT carried out a patient experience survey in 2013 which looked at some of the national cancer patient survey questions in more detail and asked additional questions relevant to our service. The results of this survey were presented at the SAG in January 2014. Members of the SAG commented positively on the success of the survey, and it was noted that this would allow a more comprehensive view of patient experience than that is available from the NCPES. The Royal Marsden has recently carried out the same survey on their patients and will present their results at the next SAG meeting in September 2015.

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9 Distribution of Pathways and Guidelines

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The SAG has asked each network to nominate sarcoma leads within their network/trusts. Using this list we have created a communication directory which we have used to inform referring networks and trusts of any developments within the service over the last year. We have distributed all bone, soft tissue and site-specific shared care pathways to these trust/network sarcoma leads as well as clinical guidelines and lists of designated chemotherapy and radiotherapy practitioners. We have also uploaded pathways and documentations onto our website www.lsesn.nhs.uk and we have emailed the leads when new items have been added to the website.

The SAG has also asked for required agreements for our shared care pathways for soft tissue sarcoma from the chairs of the site-specific NSSGs in each of our 12 referring networks, and agreements from each designated oncologist's clinical director. However, it has proved very difficult to obtain all of the required agreements and this will require further work over the coming year.

10 Mortality Rates

London Sarcoma Service:

Mortality data is discussed on a regular basis at the London Sarcoma Service governance meetings. Deaths within 30 days of treatment were reviewed at meetings on 13th November 2014 and 14th May 2015.

Surgery: There were 2 deaths within 30 days of sarcoma surgery at RNOH between April 2014 and March 2015. Both patients were reviewed at the sarcoma governance meeting in May 2015 and it was agreed that the deaths could not be prevented and that the surgery carried out was appropriate.

Chemotherapy: There were 4 deaths within 30 days of chemotherapy treatments between April 2014 and March 2015. All cases were discussed at the sarcoma service governance meeting (3 in November 2014 and 1 in May 2015). In 3 of the cases, treatment was being given for palliation of advanced disease. Patients had received information about the pros and cons of chemotherapy in these circumstances, especially the risks. There were shared care arrangements with local hospitals for management of complications of chemotherapy. In 1 case the patient died unexpectedly due to other causes.

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Radiotherapy: There were 6 deaths within 30 days of radiotherapy treatment between April 2014 and March 2015. All cases were discussed at the sarcoma service governance meeting (2 in November 2014 and 4 in May 2015).

All patients were receiving palliative radiotherapy for advanced metastatic disease, for pain relief, treatment of brain metastases, or treatment of spinal cord compression. As such, all patients were expected to have died shortly after radiotherapy was completed.

Royal Marsden Hospital:

Mortality rates by treatment modality - 2014

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total
Surgery	1	1	1	1	0	0	0	1	1	0	0	1	7
Chemotherapy	3	1	3	4	0	2	1	1	2	1	1	4	23
Radiotherapy	0	0	0	0	1	0	0	0	0	0	0	0	1

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