

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 9th December 2016, 15.00-17.00

Venue: 6th Floor East Meeting Room, 250 Euston Road, London NW1 2PG

Chair: Jeremy Whelan (JWh)

1. Welcome and Introductions

JWh welcomed members to the meeting and noted the following apologies:

Rolyn Alvarado (RA)	Clinical Nurse Specialist	RMH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Amos Burke (AB)	Consultant Paediatric Oncologist	CUH
Sharadah Essapen (SE)	Consultant Clinical Oncologist	RSCH
Kirsty Green (KG)	Clinical Business Unit Manager	RMH
Andrew Hayes (AH)	Co-Chair of SAG and Consultant Surgeon	RMH
Kate Lankester (KL)	Consultant Clinical Oncologist	BSUH
Christina Messiou (CM)	Consultant Radiologist	RMH
Tricia Moate (TM)	Patient Representative	RMH/RNOH
Andrew Nicholson (AN)	Consultant Histopathology	RBHT
Chrissie O’Leary (COL)	Oncology General Manager	UCLH
Ramya Ramanujachar (RR)	Consultant Paediatric Oncologist	UHS
David Sallomi (DSall)	Consultant Radiologist	ESH
Peter Simmonds (PS)	Consultant Medical Oncologist	UHS
Myles Smith (MS)	Consultant Surgical Oncologist	RMH
Dirk Strauss (DS)	Consultant Medical Oncologist	RMH
Anne Suovori (AS)	Consultant Clinical Oncologist	PH
Winette van der Graff (WvdG)	Honorary Consultant Medical Oncologist	RMH
Rachael Windsor (RW)	Consultant Paediatric and Adolescent Oncologist	UCLH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH

2. ACTION LOG (December 2016), including outstanding actions from previous meeting. All other actions from previous meeting were completed and have been removed.

ACTION	Owner	Status/Due Date
BMS to send Patient Management Policy to GF (incorporating CB comments). Requires significant overhaul. BMS to propose updated strategy. New action	BMS	End February 2017
GF to upload onto LSESN website	GF/GK	No longer applicable
RNOH to replicate 2WW audit taking place at RMH. Explore if similar audits are being done at other diagnostic clinics within the network.	GF/GK	No longer applicable
Ask Richard Haywood for equivalent data at Norfolk and Norwich. Data not yet received	AH	No longer applicable
Coordinate new ‘designated services’ section of LSESN website. Drafted, awaiting confirmation of designated practitioners.	GF/GK/JWh	Part complete

Minutes were agreed

3. Review of pathology services

JWh commented on the valuable discussion at the previous meeting. A brief summary paper from the SAG would be an important record of the relevant issues.

Action: JWh to liaise with RJ/WvdG re drafting outline of SAG summary paper

4. Suspected sarcoma diagnostic clinic initiative

JWh had no more to report currently apart from learning that Southend had completed an audit.

AF concerns were noted to ensure the integration of histopathology in to the more detailed level of planning if a satellite diagnostic service begins to emerge.

IB reported that Bournemouth samples go to Bournemouth lab first, then to RMH if suspicious. There is no specialist pathologist at Bournemouth.

Action: JWh to follow up Southend feedback.

GK to check with AH and KG if any progress had been made on second trust visit.

Review progress at next meeting.

5. Atypical lipomatous tumours and CWT

Removal from cancer wait targets for ALTs is included in the new national draft service specification but this is still some months from approval.

6. Sarcoma Activity Data for London

SJS presented a large quantity of data, from 2WW, COSD and other sources collated by the informatics resource in the Cancer Vanguard.

Observations:

2WWs:

High percentage first seen on target, but 62 day target for treatment is challenging.

JWh queried whether outliers in audit could represent poor data quality or inappropriate care. SJS reports that the morphological codes are for sarcomas.

High numbers of chemo patients at UCH (377). Is this true? PD asked if children were included.

COSD:

Staging completion target is 70%. UCLH and Stanmore are at c. 80%. Others in audit are low, including RMH. However, RMH are up to 40% on level 3 data (2014).

Performance statuses all close to 70%.

CNS meeting status recording: CNSs at RMH do this on EPR. Data managers/MDT co-ordinators at UCH get information from clinic letters. The England average for this is 25%.

MDT discussion recorded: Mostly high. Concern re 60% recorded at RMH. Data on whether specifically sarcoma MDT not available here. MDT recording also higher on level 3 data.

Discussion of routes to diagnosis. A&E route is a problem for sarcoma, but not worse for London than elsewhere in country.

JWh: A significant number of patients are treated outside the specialist sarcoma centres. It would be helpful to understand how e.g. Guy's/Bart's patients fit into pathways.

RJ expressed concern re recording of MDT discussions and staging at RMH.

Discussion of possibility at RNOH of feasibility of not recording electronically surgical admission data without recording of performance status or staging, thus improving data capture.

Portal access for data: Password can be obtained from stephenscott@nhs.net (Head of Informatics, London Cancer Alliance)

Action: JWh and SJS to meet with Stephen Scott.
Consider development of SAG work programme based on analysis of these data

7. National Commissioning Update

JWh reported progress on a new service specification.

Provided the various approval checkpoints are successfully negotiated approval is expected in about 6 months.

BMS asked about the chemotherapy algorithm. JWh reported that Sarcoma CRG submitted to chemotherapy CRG December 2015, and that he had learnt from the chair of the chemotherapy CRG that it should come under consideration within the next 6 months.

UCH chemo algorithm was updated in Summer 2016. Work will be required to align this but should wait until after discussions planned for January about new data on adjuvant chemotherapy for soft tissue sarcoma.

8. LSESN Website Usage Report

GK reported that the number of sessions per month per month is down (from 131 in August to 81 in October), but average session duration is up from 47 seconds in August to 2 minutes 9 seconds in October, and number of pages per session is slightly up too.

BMS commented that over 80% of users each month are new users, and that numbers will always be small. The site is not intended for patients.

JWh commented that utility to access pathways could be enhanced, so that referrers can immediately find the appropriate pathway by anatomical site and associated specific contacts, a -"Where Should I Send This Sarcoma?" page, with options by anatomical location.

PD proposed adding descriptions of trials.

Action: PD to take on trial descriptions. JWh/GK to consider allocating anatomical sites in accordance with new service specifications.

9. Clinical Trials and Research

10. Any other business

- 1) JWh presented an email from TM:
 - a) Chemotherapy Capacity issues at RMH?
RJ reported that RMH is at capacity.
AM reported 2½ to 3 week waits, to start chemotherapy .
 - b) Communications at Stanmore
JW asked who the patient is.
IB offered to ask TM this.

Action: GK to forward email to RJ and AM. JWh will reply to TM. JW will feed back to TM re communication issue, and capacity.

- 2) SJ reported that Mr George Ladas is retiring from the NHS at the end of January 2017. RBH are looking for a locum, with a view to substantive appointment. In the meantime, Mr Lim and Michael Dusmet can help.
The SAG agreed to consolidate the thoracic MDT meetings weekly on Mondays, starting in January/February.
JWh requested guidance on referring patients. SJ asked to be main point of contact. He will also approach his Harefield colleagues.

Action: GK to discuss with MDT co-ordinators moving to weekly Mondays (completed)

- 3) JWh: Cancer Vanguard investigating quality of 2WW referrals from Camden, first lung and now other tumour types. He will contact Fanta Bojang to meet.

Date of next meeting: Friday 17 March 2017, Royal Marsden Hospital, Boardroom.

Present:

Jeremy Whelan (Chair) (JWh)	Consultant Medical Oncologist	UCLH
Imogen Batty (IB)	Clinical Nurse Specialist	RBCH
Adrienne Flanagan (AF)	Consultant Histopathologist	RNOH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Palma Dileo (PD)	Consultant Medical Oncologist	UCLH
Simon Jordan (SJ)	Consultant Thoracic Surgeon	RBH
Gerard Kingdon (GK)	Sarcoma Project Manager	UCLH/RNOH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Piers Gatenby (PG)	Consultant OG Surgeon	RSCH
Beatrice Seddon (BMS)	Consultant Clinical Oncologist	UCLH
Sandra Strauss (SJS)	Consultant Medical Oncologist	UCLH
Julie Woodford (JW)	Nurse Consultant & Lead Care Nurse	RNOH