

**London and South East England Sarcoma Network Sarcoma Advisory Group Minutes**

**Date:** Friday 15<sup>th</sup> December 2017, 15.00-17.00

**Venue:** 6th Floor West 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**:

Piers Gatenby (PG)	Consultant OG Surgeon	RSCH
Kate Lankester (KL)	Consultant Clinical Oncologist	BSUH
Franel Le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Zara Gross (ZR)	Cancer Strategy Implementation Lead	TCT for London
Tricia Moate (TM)	Patient Representative	RMH/RNOH
Andrew Nicholson (AN)	Consultant Histopathologist	RBHT
Chrissie O’Leary (COL)	General Manager, Oncology	UCLH
Susan Rodger (SR)	General Manager, Joint Reconstruction & Cancer	RNOH
David Sallomi (DS)	Consultant Radiologist	ESH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH

**2. ACTION LOG including outstanding actions from previous meeting. All other actions from previous meeting were completed and have been removed.**

ACTION	Owner	Date Added	Status/Due Date
Patient Management Policy is largely complete, with comments received. Needs final edit before uploading	BMS	2016	Expected end of January 2018
Coordinate new ‘designated services’ section of LSESN website. Designated practitioners now confirmed.	GF	2016	To do after re-designation following publication of service spec
Review of pathology services. RJ and AH to draft 1-2 page summary document then send to JW for further drafting	RJ/AH	June 2017	On hold June 2018
Chemotherapy algorithm – JWh to send updated version to PD and CB for further review	JWh/CB/PD	June 2017	March 2018
Audit for shared care radiotherapy AM to send template to BS	AM/BMS/FLG	September 2017	March 2018
Audit for shared care chemotherapy	PD/CB	September 2017	June 2018
Guidelines to be reviewed: referral and designated practitioners	JWh/AH	September 2017	March 2018
Isolated limb perfusion trial to be presented at LSS service meeting	AH/GF	September 2017	March 2018
Olaratumab with doxorubicin for metastatic sarcoma audit	CB/PD	September 2017	March 2018
Adjuvant chemotherapy for soft tissue sarcomas: JWh to share draft document with oncologists	JWh	September 2017	March 2018

2WW Form: Amend and circulate for approval Send tracked changes of guidelines to GF	GF all	December 2017	January 2018
2 <sup>nd</sup> Opinion Policy: comments to be sent to GF AH to look at for surgery. JWo to look at for RNOH. Alvin to look at from patient perspective. JWh to seek help from Sarcoma UK re wording	All AH JWo AT JWh	December 2017	Mid-January 2018
Adjuvant Chemotherapy – JWh to share UCH Policy	JWh	December 2017	March 2018

Previous minutes were agreed.

**Matters arising:**

Discussion re BSG having more responsibility for the updating of chemotherapy guidelines. To be used as a forum for discussing the chemotherapy algorithm. The medical oncologists agreed that this would be a good idea to meet to discuss this at the BSG in February.

PD asked whether Exemestane should be considered as 2<sup>nd</sup> line treatment and also said that UCH has put in a proposal for Propanoral for Angiosarcoma.

**Action:** JW, PD and CB to review the chemotherapy algorithm

**3. Update on Audits**

**a) Olaratumab with doxorubicin for metastatic sarcoma**

RMH and UCLH have preliminary results and will present the full audit in March. PS is also collecting the same data at SUHT.

**Action:** CB to share the RMH protocol

**b) Shared care chemotherapy and radiotherapy audits**

CB and PD are currently completing the olaratumab audit and will do the chemotherapy audit after this. AM and BS to present radiotherapy audit in March. AM to send the template to BS.

**4. Patient Feedback**

AT gave feedback on two recent patient issues:

- A patient who is on a trial and attends RMH for chemotherapy often does not start their treatment until late in the day and has to travel a long distance to get home.  
CB updated that there has been a recent meeting regarding this and MRH are looking to make improvements. However, lots of patients live far away and pharmacy has to make up drugs on the day which takes time. It was also noted that RMH are currently using a manual scheduling system and so when they move to an electronic scheduling system this will hopefully help.
- A patient who attends RNOH is not able to make his next appointment before he leaves and has to wait for a letter giving him an appointment which isn't always suitable. JWo explained that RNOH have the same scheduling problems at RMH and the clinics are full and overbooked

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meaning future appointments cannot be booked at the time of leaving the clinic. There is a work programme looking specifically at clinics and FU appointments at RNOH and so this issue will be priorities in this. PS also asked whether all follow-up appointments need to be done at RNOH or whether some can be done locally. This will also be discussed in the work programme.

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**5. Governance**

No issues noted

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**6. National Commissioning Update**

The sarcoma service specification still hasn't gone out for consultation and has been re-formatted since the last meeting. It is not clear why there is a delay. Note added after meeting: approval given 19Dec2017 for specification to be sent out for consultation in January 2018.

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**7. 2WW Form and Guidelines**

Electronic 2WW forms were developed early last year for all tumour sites as part of a project led by the Transforming Cancer Services for London team. The forms were updated in consultation with primary care and commissioners. The SAG contributed to the creating of the current form and guidelines which is hard loaded onto GP computers and so not easy to change. The form contains links to our LSESN website whose details can be easily updated.

The forms are now being updated for all tumour sites. As shown in the presentations at the last meeting sarcoma referrals are increasing for both centres and referrals to the centres are not always appropriate. Therefore, the form needs to be improved in light of this.

Two new versions of the form were circulated prior to the meeting and the SAG discussed the appropriateness of these versions. JWh also gave feedback from Zara at TCST who was unable to attend the meeting. It was agreed that there needs to be a greater emphasis on imaging prior to referral where possible and that symptoms will be included in the guidance not on the form.

Changes will be made to the form as agreed and circulated to all for approval. A contact number will be added for GPS to use for advice prior to referral.

The guidelines will be further amended to include conditions which should not be sent using the sarcoma 2ww form.

**Action:** GF to amend and circulate updated form

**Action:** all to send tracked changes of guidelines to GF

**Action:** DS to send letter to JWo that RMH use when rejecting 2ww referrals based on U/S

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**8. NCRAS Update**

SS gave an update re the re-organisation of NCRAS and informed the SAG that she has recently been appointed as the Clinical Lead for Sarcomas and Rare Cancers.

JWh noted that NHS England had previously sent data on the caseload of sarcoma services which didn't match previous data circulated. JWh then asked SAGs to self-declare their data. NCRAS have now produced data for us to correlate.

SS presented the NCRAS data (presentation attached). The data will be presented at the BSG in February.

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The presentation showed that there are issues with the national data collection as the figures presented

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are a lot lower than the figures that MDTs have declared. Cancer Waiting Times performance for the 62 day target is poor for both sarcoma centres, which reflects the national trend across all tumour sites. The data showed that there are issues with COSD data collection at RMH. However, SACT data collection at RMH was good. There is no data for HNA for either site. UCH are doing HNA's but this is not being recorded or submitted correctly.

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## 9. LSESN Website Usage Report

The latest reports have been circulated – the most commonly visited pages continue to be the guidelines, referrals and pathways and so it is important to keep these pages up-to-date. The website has been updated this week with changes to the trials page, SAG meeting dates and papers and the links.

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## 10. Clinical Trials and Research

The trials data for both centres was circulated prior to the meeting. No further discussion required.

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## 9. Any other business

### a) 2nd opinion policy

JWh discussed the draft 2<sup>nd</sup> opinion policy which was circulated prior to the meeting. The SAG agreed with this policy in principal but noted that there are two different scenarios – the patient seeking a 2<sup>nd</sup> opinion vs the consultant seeking a second opinion.

**Action:** comments on policy to be sent to GF. AH to look at for surgery. JWo to look at for RNOH. Alvin to look at from patient perspective. JWh to also send to Sarcoma UK for comment.

### b) Adjuvant chemotherapy

Practice has not changed at RMH or UCH.

**Action:** JWh to share UCH policy

### Date of next meetings:

Friday 16<sup>th</sup> March 2018

The Boardroom, Royal Marsden Hospital, 203 Fulham Road, London SW3 6JJ

Friday 15th June 2018

6th Floor West Meeting Room, 250 Euston Road, UCLH

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### Present:

Farzana Aslam (FA)	Sarcoma Data Manager	UCLH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Sarah Clarke (SC)	Divisional Director for Cancer	RMH
Palma Dileo (PD)	Consultant Medical Oncologist	UCLH
Alexandra Donkin	Clinical Nurse Specialist	UCLH



NORTH AND EAST



Gemma French (GF)	Sarcoma Improvement Manager	UCLH/RNOH
Andrew Hayes (AH)	Co-chair of SAG and Consultant Surgeon	RMH
Michelle Hung (MH)	Clinical Trials Practitioner	UCLH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Catherine Kirk (CK)	Service Manager, Performance	RMH
Nikos Memos (NM)	Locum Consultant Surgeon	RMH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Caroline Ramsey (CR)	Clinical Trials Practitioner	UCLH
Beatrice Seddon (BS)	Consultant Clinical Oncologist	UCLH
Peter Simmonds (PS)	Consultant Medical Oncologist	UHS
Myles Smith (MS)	Consultant Surgical Oncologist	RMH
Chris Stone (CS)	Clinical Business Unit Manager	RMH
Dirk Strauss (DS)	Consultant Surgeon	RMH
Sandra Strauss (SS)	Consultant Medical Oncologist	UCLH
Alvin Trowbridge (AT)	Patient Representative	
Jeremy Whelan (JWh)	Co-chair of SAG & Consultant Med. Oncologist	UCLH
Rachel Windsor (RW)	Consultant Paediatric and Adolescent Oncologist	UCLH
Julie Woodford (JWo)	Nurse Consultant in Cancer and Supportive Care	RNOH