

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 16th June 2017, 15.00-17.00

Venue: 6th Floor Central (East) meeting room, UCLH HQ, 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:**

Amos Burke (AB)	Consultant Paediatric Oncologist	CUH
Palma Dileo (PD)	Consultant Clinical Oncologist	UCLH
Piers Gatenby (PG)	Consultant OG Surgeon	RSCH
Kate Lankester (KL)	Consultant Clinical Oncologist	BSUH
Franel Le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Christina Messiou (CM)	Consultant Radiologist	RMH
Tricia Moate (TM)	Patient Representative	RMH/RNOH
Tony Skene (TS)	Consultant Surgeon	RBCH
Myles Smith (MS)	Consultant Surgical Oncologist	RMH
Dirk Strauss (DS)	Consultant Surgical Oncologist	RMH
Sandra Strauss (SJS)	Consultant Medical Oncologist	UCLH
Anne Suovori (AS)	Consultant Clinical Oncologist	PH
Rachael Windsor (RW)	Consultant Paediatric and Adolescent Oncologist	UCLH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH

2. ACTION LOG (June 2017), including outstanding actions from previous meeting. All other actions from previous meeting were completed and have been removed.

ACTION	Owner	Status/Due Date
Patient Management Policy is largely complete, with comments received. Needs final edit before uploading	BMS	Part complete September 2017
Coordinate new 'designated services' section of LSESN website. Designated practitioners now confirmed.	GF	Part complete September 2017
Review of pathology services. RJ and AH to draft 1-2 page summary document then send to JW for further drafting	RJ/AH	September 2017
Suspected sarcoma diagnostic clinic initiative. JWh to reinstate with GF. Possibly Kent next. Refresh plan	JWh/GF	September 2017
Atypical lipomatous tumours and CWT. ALTs are not on 2WW/62 day pathway.	PD	Completed
Sarcoma activity data for London. Data requires cross-checking.	GF	December 2017
Chemotherapy algorithm. Complete changes and upload	GF/JW	September 2017
New patient representative to be contacted	JWo	July 2017

Previous minutes were agreed.

Matters arising:

Updating chemotherapy algorithm

Action: RJ will check with Dharmisha, pharmacist, re generic imatinib application.

BMS met Martin Forster (Chemotherapy lead, UCLH) and is due to meet Kevin Sullivan (Head of Operations, UCLH Cancer Services).

Action: BMS to follow-up. JWh will ask GF to assist in version control and finalising

Removal of fax numbers from network referral forms

These have all now been removed.

AH reported that some referrers unable to get through to one fax machine, will fax inappropriately to any other number they have.

AH/JWh to meet Teresa Moss to discuss Transforming Cancer Services interest

The data should be clarified first.

2WW referral quality project

This is moving forward at RNOH

3. Patient feedback/representation

Action: GK to give details of proposed new representative to JWo, for introductory contact

Noted new NCPES results are expected soon.

4. Governance

Peer review updates

Self-assessments have been submitted from both centres. The process has changed significantly and is reliant on individual Trusts taking responsibility for internal validity of responses. QI's not received from NHS QST

RM partners have written to AH for update on the SAG.

5. National Commissioning Update

The Sarcoma Specification was approved on 27/06/17 by the Cancer Programme Of Care Board, but is to go out for further public consultation for 60 days over July-August specifically to seek responses on an updated impact assessment. Previous versions had been assessed as having "no financial impact".

The meeting discussed the difficulties of obtaining accurate data on sarcoma activity. JWh had written to SAG chairs for their figures, and asking about impact. Half of SAGs have replied, stating no impact. NHS England recognise the importance of SAGs, but the governance of SAGs is not uniformly established. There are additional approval points for the specification but it may be potentially published by March 2018.

A further meeting of national SAG chairs meeting is being considered for Autumn 2017. Meanwhile the LSESN SAG should develop an action plan for responding to the new specification.

6. RMH 2WW data

AH suggested Nikos Memos for presentation of this data in the September SAG meeting.

The RNOH 2WW clinic is now nurse-led. RMH provides a post-biopsy telephone clinic.

The totality of 2WW data needs review. PS can provide Southampton 2WW data.

7. LSESN Website Usage Report

Number of monthly sessions, March to May 2017, remained stable at around 100 per month, dipping to 66 in April. The proportion of users who are new visitors averages 87%. Average session duration is between 1.5 and 2 minutes, and the average number of pages viewed per session is between 2 and 2.5.

8. Clinical Trials and Research

CRN Sarcoma sub-speciality leads:

RJ has replaced Professor Judson as South London CRN sub speciality lead.

In North and North-East London tumour types have been amalgamated under a lead not necessarily a sarcoma specialist. Darren Hargrave is current lead, but a replacement will be needed.

PS is CRN lead for sarcoma in Wessex.

A North-East London lead is needed. JWh will feed back to CRN lead that this is under active consideration.

9. Any other business

- 1) Olaratumab with doxorubicin for metastatic sarcoma has now been added to the Cancer Drug Fund list.
Audit of 1st line treatments in LSESN proposed. How many patients in three months have started on olaratumab, and how many on doxorubicin or other regimens? Look at all patients starting 1st line treatment for metastatic soft tissue sarcoma.

Discussion of need for consistent selection of patients for options including combination treatment

Action: RJ and BMS will produce a concise guidance document

Written information would be valuable for patients. Sarcoma UK could produce a Patient Information Sheet. **Note added after meeting: Sarcoma UK have already produced an information leaflet.**

- 2) PS raised the referral pathway in which patients are referred from Portsmouth to RMH and then to Southampton. This can be a slow process, and patient experience could be improved. Meeting conclusion: early communication between RMH and Southampton to allow more rapid initiation of treatment at Southampton when appropriate, with palliative radiotherapy only at Portsmouth.

Date of next meetings:

Friday 15th September 2017,



NORTH AND EAST



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

Friday 15th December

Room to be confirmed, UCLH HQ, 250 Euston Road, London NW1 2PG

Present:

Jessica Bate (JB)	Paediatric Oncologist	UHS
Andrew Hayes (AH)	Co-chair of SAG and Consultant Surgeon	RMH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Gerard Kingdon (GK)	Sarcoma Project Manager	UCLH/RNOH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Beatrice Seddon (BMS)	Consultant Clinical Oncologist	UCLH
Peter Simmonds (PS)	Consultant Medical Oncologist	UHS
Winette van der Graaf (WvdG)	Professor of Personalised Oncology	RMH
Jeremy Whelan (JWh)	Co-chair of SAG & Consultant Med. Oncologist	UCLH
Julie Woodford (JWo)	Nurse Consultant in Cancer and Supportive Care	RNOH