

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 17th March 2017, 15.00-17.00

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

Chair: Andrew Hayes (AH)

1. Welcome and Introductions

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

Piers Gatenby (PG)	Consultant OG Surgeon	RSCH
Kirsty Green (KG)	Clinical Business Unit Manager	RMH
Ruth Green (RG)	Consultant Radiologist	RNOH
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
Andrew McMeeking	Transforming Cancer Services Team for London	NELCSU
Ramya Ramanujachar (RR)	Consultant Paediatric Oncologist	UHS
David Sallomi (DSall)	Consultant Radiologist	ESH
John Schofield (JS)	Consultant Pathologist	MTW
Dirk Strauss (DS)	Consultant Sarcoma Surgeon	RMH
Sandra Strauss (SJS)	Consultant Medical Oncologist	UCLH
Anne Suovori (AS)	Consultant Clinical Oncologist	PH
Winette van der Graff (WvdG)	Honorary Consultant Medical Oncologist	RMH
Justin Waters (JW)	Consultant Medical Oncologist	MTW
Rachael Windsor (RW)	Consultant Paediatric and Adolescent Oncologist	UCLH
Julie Woodford (JW)	Nurse Consultant & Lead Care Nurse	RNOH

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 will have 1 st draft in c. 2 weeks for comments.	BMS	End February 2017
Coordinate new ‘designated services’ section of LSESN website. Designated practitioners now confirmed.	GF/GK/JWh	Part complete
Review of pathology services. JWh to liaise with RJ/WvdG re drafting outline of SAG summary paper	JWh	
Suspected sarcoma diagnostic clinic initiative. Hard to get response. Lost in South Essex reorganisation. JWh to refresh request with new Chief Executive	JWh	
Atypical lipomatous tumours and CWT. Are they on 2WW pathway at RNOH? 18 week? PD to check	PD	
Sarcoma activity data for London. JWh and SJS to meet with Stephen Scott. Consider development of SAG work programme based on analysis of these data. Vanguard called for proposals on time diagnosis and quality of care.	JWh/SJS	

Previous minutes were agreed.

Matters arising:

Feedback from RM Vanguard (AH)

Current work programmes with the Vanguard and Cancer Alliances do not have immediate relevance to sarcoma services. Engagement will continue by AH and JW on respective boards.

Updating chemotherapy algorithm (CB/SJS)

An updated version is almost complete and can be uploaded to the LSESN website.

IFRs continue to be an ineffective route to access drugs. The closure of the CASPS trial present problems for patients with ASPS. No immediate solution was evident.

The availability of generic imatinib for indications other than GIST was noted and allows for treatment of patients with chordoma, PVNS and fibromatosis at affordable prices.

The meeting estimated between 4 and 7 chordoma patients per year for imatinib (2 at RMH, 2 to 5 at UCH); 4 PVNS patients per year (1 at RMH, 3 at UCH); 12 fibromatosis patients (10 at RMH, 2 at UCH).

PD mentioned a German phase II trial showing arrest of progression. Consistent prescribing practices are needed for these conditions at each Trust. This information now needs to be taken through each Trusts processes for approval.

BMS will help with PVNS.

Removal of fax numbers from network referral forms

RMH agreed removal, in line with RNOH and UCLH.

Referrals have been redirected to wrong hospitals, with GPs saying that fax machine is not working.

3. Pan London 2WW data (JWh)

NHS London data was given to JWh by Teresa Moss.

Action: GK to circulate spreadsheet.

2WW activity was light on numbers, compared to the portal data from December 2016 SAG meeting.

31 day numbers were small. There is a transfer of data issue.

The 62 day conversion rate percentage was higher for RMH. Concerns about data accuracy were voiced.

AH had spoken to Teresa Moss re lost money.

Actions:

GK/SJS to compare different sources to determine accuracy of data.

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

MS to present RMH 2WW data at next SAG

4. National Commissioning Update

JWh reported on the slow but steady process of the new sarcoma service specification.

Further updates will be given each meeting.

BMS asked about the national 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.

5. Governance

JWh introduced the Vanguard project on 2WW referral quality. This survey reviewed 2WW referrals and

fed back to a GP forum. Applicability to sarcoma was discussed, with suggestions to adapt the process, and to focus on extremities only.

There is London Cancer support available for this. It was also important to engage whenever possible with primary care and the cancer partnerships

Actions: JWo and Jo Coleman will contact Fanta Bojang from the project.

6. LSESN Website usage

December and January data had not been received, but GK noted that the number of sessions in February was 116, up from 77 in November. Average session length was up from approximately 2 minutes to 3 minutes, and the number of pages viewed per session was stable at 2.1.

85% of site visitors were new visitors.

7. Clinical Trials and Research

PD has provided an updated list of trials to GK for LSESN website.

RJ has a phase I trial for UPS and leiomyosarcoma, to open in the next few weeks, at RMH only.

RMH has funding for palliative radiotherapy trial, awaiting ethical approval

AH reported on an ILP trial to open in September

10. Any other business

The meeting agreed that Patient Representation should be a standing agenda item.

Patient representation issues raised by email from Tricia Moate:

- 1) Time to chemotherapy start at RMH. CB reported that this had just been audited. 67% of patients had been treated within 2 weeks of decision to treat.
Factors include new booking procedures, a large number of patients from a large area, and less local chemotherapy.
- 2) Communication issues – CNS from RNOH has been in contact.

New issues:

- 1) Information about ILP for GPs: Written information for an ILP patient. Verbal information was good, and CNS posted information. Could the information go with GP letters?
AH will aim to address this.
PD queried whether there was information on Sarcoma UK website.
 - 2) Access to Rehabilitation and lymphoedema services
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AH said that patients should routinely refer early for lymphoedema.
 JWh said that local services are patchy, and that we have no control over these.
 PD said that RNOH tries to see these patients on the ward.
 There can be delays with referrals and seeing local teams, for these complex patients.
 Limb radiotherapy patients have no access to physiotherapy.

- 3) Availability of Immunotherapy trials for sarcoma
 JWh said that there are trials for selective groups. Patients should ask their treating oncologist about these.
 JWh to reply to Tricia about all the points she had raised and thank her for her support of the group

- 4) Proposed new patient representative, an RMH patient, Mr Alvin Trowbridge.
 It was suggested that he could have a “buddy” regarding this at the beginning.
Action: AH to speak to CNS Alison Dunlop regarding this.

Date of next meeting: Friday 16th June 2017, 6th Floor Central (East) Meeting Room, UCLH Trust HQ, 250 Euston Road, London NW1 2PG

Present:

Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Dharmisha Chauhan (DC)	Clinical and Chemotherapy Services Pharmacist	RMH
Palma Dileo (PD)	Consultant Medical Oncologist	UCLH
Andrew Hayes (AH)	Co-chair of SAG and Consultant Surgeon	RMH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Vasilios Karavasilis (VK)	Consultant Medical Oncologist	UCLH
Jeffrey Lordan (JL)	Consultant Sarcoma Surgeon	UCLH/RFH
Gerard Kingdon (GK)	Sarcoma Project Manager	UCLH/RNOH
Anne McTiernan (AMcT)	Sarcoma Clinical Nurse Specialist	UCLH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Beatrice Seddon (BMS)	Consultant Clinical Oncologist	UCLH
Myles Smith (MS)	Consultant Surgical Oncologist	RMH
Winan van Houdt	Consultant Surgical Oncologist	RMH
Jeremy Whelan (JWh)	Co-chair of SAG & Consultant Med. Oncologist	UCLH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH