

London and South East England Sarcoma Network Sarcoma Advisory Group

Date: Friday 17 January 2014, 15:00-17:00

Venue: Boardroom, 3rd Floor, 170 Tottenham Court Road, London W1T 7HA

Chair: Professor Jeremy Whelan and Mr Andrew Hayes

ACTION LOG

Action	Owner	Date Agreed	Status/Due Date
CB and SS to produce LSESN guidance on use of dexrazoxane for metastatic soft tissue and bone sarcomas	Charlotte Benson and Sandra Strauss	25 October 2013	By April 2014
BS to make additions to research strategy and send back to ML	Beatrice Seddon	17 January 2014	By January 2014
ML to coordinate completion of the sarcoma research strategy	Mark Linch	25 October 2013	By January 2014
BS to amend follow-up guidelines and re-circulate final version	Beatrice Seddon	17 January 2014	29 April 2014
ST to ensure final follow up guidelines to be published online	Sonja Tattermusch	17 January 2014	29 April 2014
JWo to produce draft of PIS for atypical lipomas	Julie Woodford	17 January 2014	29 April 2014
BS and AM to lead on audit of follow-up of retroperitoneal sarcomas	Beatrice Seddon and Aisha Miah	25 October 2013	Friday 17 January 2014
JWh to share with Cerys Propert-Lewis approval documentation for patient experience survey from UCLH to speed up approval processes at RMH	Jeremy Whelan	25 October 2013	Friday 17 January 2014
CPL to implement patient experience survey with help from JWo at RMH	Cerys-Propert Lewis	17 January 2014	On-going
AM and AH would work together to create an audit proforma retroperitoneal sarcomas	Aisha Miah and Andrew Hayes	17 January 2014	29 April 2014
CF to enquire about LCA 2ww referral form strategy and report back at the next meeting	Catriona Fox	17 January 2014	29 April 2014
to circulate 'save the date' email for study day on Tuesday 29 April	LC admin team	25 October 2013	On-going
All SAG members to register their interest at https://llesn.eventbrite.co.uk	All members	17 January 2014	29 April 2014

ST and SF to produce draft newsletter	Sonja Tattermusch Catriona Fox	17 January 2014	29 April 2014
CF to liaise with data department at LCA	Catriona Fox	17 January 2014	29 April 2014
CF to present metrics data at next meeting of SAG	Catriona Fox	17 January 2014	29 April 2014

1. Welcome and Introductions

JW welcomed members of the board and apologies were heard. Introductions were made, JW noted that Catriona Fox, Project Manager at London Cancer Alliance has joined the board and that this was a positive development for the board and for partnership working across the geographical area.

2. Minutes from the meeting on 25 October 2013

The minutes of the last meeting were accepted as an accurate record of proceedings. JW and members reviewed the action log from the last meeting.

Research Strategy:

The research strategy had been discussed at the last meeting. The Group heard that ML had completed a first draft which was now with BS for comments and would be finalised by the end of the following week. The strategy would be shared with both London Cancer and London Cancer Alliance and form the basis for wider conversations regarding general interests in research collaboration.

ACTION: BS to make additions to research strategy and send back to ML
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3. Sarcoma CRG update

JW and AH updated the SAG members on the recent work of the Sarcoma Clinical Reference Group which is currently producing a service specification for soft tissue and bone sarcomas based on the latest clinical evidence on best practice. JW confirmed that the deadlines for these documents are challenging but that this is a real opportunity to develop patient-focussed services. An important workstream would be to support local trusts in improving their diagnostic services to avoid reduplicating tests at the centre and avoid unnecessary delays to the patient pathway.

4. Follow-up guidelines for sarcomas

BS presented the latest draft for the follow up guidelines and thanked members for the comments she had received. BS noted the amendments made since the previous meeting. The aim of the guidance is to standardize practice whilst still ensuring that there is sufficient flexibility to make individualised clinical decisions. BS invited further comments and informed members that there will be one more set of amendments made before these guidelines are finalised and circulated. This was agreed by the SAG.

ACTION: BS to amend guidelines and re-circulate final version
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There was discussion around re-occurrence of sarcomas and TM noted that this is one of the biggest fears for a patient. The SAG agreed that there needs to be more information and explanation to the patient around this. The SAG has already done work on atypical lipomas and the next step, to produce patient information and consistent clinical care across the two centres should be followed through. It was also noted that there is a need to manage patients' expectations early, particularly in some cases where follow-up is not clinically needed or there treatment will not significantly enhance patients' condition.

It was suggested that elements of the guidelines could be audited to check compliance and best practice. It was agreed that AH and AM would work together to create an audit pro forma for retroperitoneal sarcomas.

ACTION: AM and AH would work together to create an audit proforma for retroperitoneal sarcomas

The group agreed that the guidelines would be reviewed annually and confirmed that they should be available online.

ACTION: Final follow up guidelines to be published online

ACTION: JWo to produce draft of PIS for atypical lipomas

5. Patient Experience Survey RNOH/UCLH

JWo gave a presentation on the patient experience survey from UCLH/RNOH. This survey was used to drilldown on the NCPES results. There were 98 patients surveyed, and most of them were within 3 years of follow up. It was noted that patients were less concerned with waiting times and wanted the right amount of time with the consultant. There were several key challenges noted from the survey; improving access to consultants, ensuring access to a CNS, utilising the holistic needs assessment and improving emotional support.

Members 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. JWo commented that UCLH plan to re-survey patients next year, as it did provide a very useful dataset. There was discussion around patient experience focus groups, members from RMH stated that they would like to complete this survey and would use their patient focus group to input on this.

ACTION: CPL to implement patient experience survey with help from JWo at RMH

6. 5min updates

- **Commissioning update**

ST informed members that AN, commissioning representative had given her apologies for today's meeting. The group agreed that to ensure adequate commissioning support, invitations to join the SAG would be extended to commissioners from Strategic Clinical Networks outside of London.

- **2ww referral form**

ST informed members that the 2ww referral form for sarcoma is being re-issued within the *London Cancer* geography. CF explained that LCA had unfortunately been unable to take this forward at the moment and is currently developing a strategy with regards to all 2ww referral forms relevant to the LCA geography. It was suggested that the SAG may write an open letter to GP practices emphasising the importance of using the most recent version of the form; however, it was agreed that this would be very research intensive.

ACTION: CF to enquire about LCA 2ww referral form strategy and report back at the next meeting

7. Planning for Study Day: 29/04/2014

The group discussed the study day planned for 29/04/2014, the suggestions for the agenda include: diagnosis and treatment options available locally and at the centres, treatment of GIST and gynaecology sarcomas, and recommended follow up guidance. It was agreed that this would be an afternoon session in the hope that many attendees will register. It was requested that another save the date email be circulated.

ACTION: LC admin team to re-circulate save the date email to the SAG and extended list

ACTION: all SAG members to register their interest at <https://llesn.eventbrite.co.uk>

• **SAG Newsletter**

The group discussed content for a SAG newsletter: update on follow up guidelines, research strategy and the study day.

ACTION: ST and CF to produce draft newsletter
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8. AOB

JW and AH informed members that they had met with Shelly Dolan and Kathy Pritchard-Jones, Chief Medical Officers for London Cancer Alliance and *London Cancer*. The purpose of the meeting was to discuss the developments of the SAG and long-term strategies for the sarcoma pathway in London and South East England. Members heard that the main work would be to ensure consistent approaches to sarcoma diagnosis, treatment and follow-up across local trusts and between the two centres. The Group noted that it will be important to obtain adequate data around current patient flows which was agreed to be provided by LCA. CF explained that the LCA data team will be working towards this.

ACTION: CF to present metrics data at next meeting of SAG
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Attendees

Name	Role	Trust/Organisation
Jeremy Whelan	Co-Chair	UCLH
Andrew Hayes	Co-Chair	RMH
Aisha Miah	Clinical Oncologist	RMH
Beatrice Seddon	Consultant Clinical Oncologist	UCLH
Catriona Fox	Project Manager	LCA
Charlotte Benson	Consultant Medical Oncologist	Royal Marsden
Chrissie O’Leary	Manager	UCLH
Ian Judson	Professor of Cancer Pharmacology, Head of the RMH Sarcoma Unit	Royal Marsden
Julie Woodford	Clinical Nurse Specialist	RNOH
Mark Linch	Consultant Medical Oncologist	Royal Marsden
Palma Dileo	Consultant Clinical Oncologist	UCLH
Rob Pollock		RNOH
Sonja Tattermusch	Pathway Manager	<i>London Cancer</i>
Tricia Moate	Patient Representative	--

Apologies

Name	Role	Trust/Organisation
Angela Newman	Commissioner	NHS England
Dirk Strauss	Consultant Surgeon/Oncologist	Royal Marsden
Ian Vousden		UCLH
Jennifer Hunt		Royal Marsden
Kate Lankester	Consultant Clinical Oncologist	BSUH
Maria Michelagnoli		UCLH
Rosemary Radband		RNOH

Name	Role	Trust/Organisation
Sandra Strauss	Consultant Medical Oncologist	UCLH