

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 04th September 2015, 15.00-17.00

Venue: The Boardroom, Royal Marsden NHS Foundation Trust, Fulham Road, London, SW3 6JJ

Chair: Mr Andrew Hayes (AH)

ACTION LOG (September 2015)

ACTION	Owner	Due Date
CL to enquire re possibility of publishing patient survey results on LSESN website	CL	November
BMS to talk to Jeff Lordan re retroperitoneal follow-up audit	BMS	November
GF to update referral guidelines, circulate and upload onto LSESN website	GF	November
BMS to send Patient Management Policy to GF (incorporating CB comments)	BMS	November
GF to circulate Patient Management Policy and upload onto LSESN website	GF	November
BMS to amend FU guidelines and send to GF	BMS	November
GF to circulate FU guidelines and upload onto LSESN website	GF	November
BMS to finalise chemotherapy algorithm and send to GF	BMS	November
GF to circulate chemotherapy algorithm and upload onto LSESN website	GF	November
JWh to circulate bone sarcoma guidelines to SAG for approval	JWh	November
GF to upload ALT Pathway onto LSESN website	GF	November
GF to amend and circulate SAG work programme	GF	November
AH to draft covering letter and brochure re diagnostic clinics	AH	November
RNOH to replicate 2WW audit taking place at RMH	JWo	November
GF to add Sarcoma 2WW form/guidelines to the next agenda	GF	November
GF and JWh to complete NICE shared care database application	GF/JWh	November

1. Welcome and Introductions

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

- Piers Gatenby, Consultant Surgeon, Royal Surrey County Hospital
- Kate Lankester, Clinical Oncologist - Royal Sussex County Hospital
- Craig Macmillan, Consultant Clinical Oncologist, Northampton General Hospital
- Angela Newman, Service Specialist, NHS England London
- Chrissie O’Leary, General Manager - University College Hospitals NHS Foundation Trust
- David Sallomi, Consultant Radiologist, Eastbourne District General Hospital
- Sandra Strauss, Consultant Medical Oncologist, University College Hospital
- Helen Stubbings, Consultant Clinical Oncologist, Norfolk and Norwich University Hospital

2. Minutes from the meeting held on 22nd May 2015

It was noted that there was a factual inaccuracy in the minutes – the action log on page 1 should say May 2015. Otherwise, the minutes of the last meeting were accepted as an accurate record of proceedings.

Actions log - May 2015

AH and members reviewed the action log from the last meeting and updated the following:

ACTION	Owner	Status/Due Date
Explore potential workshop arrangements / invitees and content of workshop	JW/AH	On Work Programme
Write to Colchester re. pathway issues and reference patient pathway delays to date	JW/AH	JW/AH have discussed – new personnel in place in Colchester. No further action for now.
Write to units regarding sarcoma provision for RX / CT treatment	JW/AH	Incomplete
CL to speak to MN/JWo re the management of referrals at RNOH	CL	Incomplete
Contact Sarcoma UK re support/sponsorship of LSESN sarcoma diagnostic engagement event.	JWo	Incomplete

3. Audit

a) RMH Patient Survey

CB presented the results of the RMH patient survey on behalf of Cerys Propert-Lewis and the CNS'. WG asked why the waiting times in clinic are so long. RMH Oncologists and surgeons explained that this is due to space in clinic and the volume of patients. Seeing your consultant was rated as the most important factor at RMH (and also at RNOH/UCLH). Provision of written information scored lower than some of the other questions. When asked if patients were told sensitively of their diagnosis a proportion of patients said no. JWh explained that it is not always clear which hospital patients are referring to when answering this question. The majority of patients indicated that they were happy to travel to RMH for appointments and treatment; however, some patients would prefer to be followed up locally. Generally patients at RMH reported a good experience, with 10 being the most common rating given and there was a variety of positive comments.

AH thanked CPL and CB for their hard work.

TM asked if it was possible to publish the results of the survey online. It was felt that the LSESN website would probably be the best place to publish the results. CL explained that she would need to check if this was possible.

JWo noted that a new national patient survey has just been announced. The surveys will be circulated shortly to patients treated in April to June of this year.

b) Retroperitoneal Follow-Up

BMS has not had the capacity to carry out the retroperitoneal follow-up audit. AM has done some work on this at RMH. The group discussed whether Jeff Lordan at RFH could carry out this audit for LSS. BMS will talk to Jeff. If it is not possible this audit will be postponed.

AM noted that the oncologists have drafted new guidelines and that they have audited against these guidelines. They haven't changed practice or acted on the data. Patients have varied follow-up at RMH.

JWh explained that the SAG needs to do a network audit as it is a peer review requirement. The SAG needs to think about what resources are available and what can be done collectively.

4. Clinical Documents Review/Update

a) Referral Guidelines

GF has updated the referral guidelines following the comments made at the last meeting. The SAG signed off the updated guidelines pending some minor changes. Guidelines to be circulated and uploaded on the LSESN website.

b) Patient Management Policy

CB and BMS have reviewed and amended the guidelines. To send to GF for circulation and uploading onto the LSESN website

c) Follow-up Policy

BMS to amend GIST section of follow up policy

d) Chemotherapy Guidelines

BMS has updated the chemotherapy algorithm. Reference to clinical trials has been removed (as they change regularly) and replaced with a more general sentence. References have been updated. Changes to CDF funding were discussed and reflected in the document.

The SAG signed off the document pending minor changes to be made. BMS to finalise and send to GF

e) National Bone Sarcoma Guidelines

JWh explained that there are currently national guidelines for bone, soft tissue and GIST sarcomas. The guidelines are being updated, supported by Sarcoma UK. It is extremely valuable to have updated guidelines to be able to refer to in the service specification. The bone guidelines are out for consultation. JWh to circulate to the SAG for approval. They have already been circulated via the BSG earlier in September. Soft tissue and GIST guidelines will follow.

5. Atypical Lipomatous Tumours Pathway

The ALT pathway was circulated with the SAG papers. The pathway was developed by LSS and has been shared with RMH as an opportunity to be adopted by the SAG. The pathway is to be uploaded onto the LSESN website.

6. Feedback of RMH Study Day and future educational meetings

IJ reported that the study day at RMH went very well and very positive feedback was received on all speakers. There was a wide spectrum of attendees. The RMH plan to repeat the event in 2 years' time. Both events will be recorded as network educational events.

7. Work Programme

The SAG reviewed and amended the work programme. GF to update and circulate to SAG.

Diagnostic clinics were discussed. It was agreed that a letter would be sent to the chief executives and sarcoma leads of the trusts which have a high proportion of referrals (to be identified from the heat maps) with a 'brochure' promoting diagnostic clinics. It was also noted that the Royal College of Radiologists hold an MSK meeting every September which is attended by radiologists and clinical oncologists. It was suggested that sarcoma diagnostic clinics is presented at the meeting next year. MS and CL are looking at the quality of sarcoma 2ww referrals received by RMH. JWo suggested that this work is replicated at RNOH.

Sections on retroperitoneal sarcoma surgery and follow-up protocols to be removed.

8. 2WW Form

New NICE referral guidelines for sarcoma have been published. The Transforming Cancer Services for London Team held a workshop in July to look at the impact of the new guidelines on the London Cancer and London Cancer Alliance catchment area. Four GPs attended the sarcoma discussion, one of which has recently re-formatted the 2WW forms in London Cancer. The attendees agreed that the current 2WW form should not be changed in response to the new NICE guidelines and that there was insufficient evidence to support the new proposals. Lots of GPs do not have access to USS and so this would delay the patient pathway. This was fed back to the Transforming Cancer Services for London team.

This will also need to be addressed as part of the SAG work project on diagnostic clinics. To be discussed further at the next meeting, including reviewing the LSESN 2WW form and the new NICE guidance.

9. National Commissioning Update

The next CRG meeting is on the 17th September. The meeting will be used to discuss the draft of the single service specification for sarcoma which is almost ready to be circulated for consultation. The CRG have also developed a chemotherapy algorithm which will be adopted nationally.

10. Hosting and Support of SAG

JWh met with London Cancer Alliance last week. LCA will continue to host the SAG and identified areas where they have particular expertise such as Informatics, R&D, Education and Training.

11. Any Other Business

a) Regorafenib

IJ informed the group that regorafenib is still on the CDF list.

b) Thoracic Pathway

JWh expressed his concerns re the capacity of surgery at RBH. The AGM from RBH was present and explained that there have been recent problems due to theatres undergoing major works and so reducing theatre capacity. RBH plan to employ another thoracic surgeon in the next financial year. They have introduced a weekly sarcoma meeting with attendance from the new sarcoma coordinator and the team are meeting with the MDT Coordinators at UCH soon. Hopefully these actions will improve the pathway.

CB noted that communication with RBH could be improved, particularly regarding receiving letters back from RBH. BMS agreed and added that UCH do not receive the discharge summary.

c) NICE Shared Care Database

NICE would like to use our LSESN website and documentation as evidence of how NICE guidance has been applied. GF and JWh to complete the application

Present:

Andrew Hayes (Chair)	Consultant Surgeon	RMH
Charlotte Benson	Consultant Medical Oncologist	RMH
Gemma French	Project Manager	UCLH
Winette van der Graaf	Honorary Consultant Medical Oncology	RMH
Ian Judson	Consultant Medical Oncologist	RMH
Caitriona Liebenberg	Clinical Business Unit Manager	RMH
Aisha Miah	Consultant Clinical Oncologist	RMH
Tricia Moate	Patient Representative	RNOH/RMH
Marvin Nyadzayo	Interim Operational Manager	RNOH
John Pearcey	AGM Lung Division	RBH
Rob Pollock	Consultant Surgeon	RNOH
Beatrice Seddon	Consultant Clinical Oncologist	UCLH
Myles Smith	Consultant Surgeon	RMH
Dirk Strauss	Consultant Surgeon	RMH
Jeremy Whelan	Consultant Medical Oncologist	UCLH
Julie Woodford	Nurse Consultant	RNOH
Shane Zaidi	Consultant Clinical Oncologist	RMH