

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

**Date:** Friday 27<sup>th</sup> November 2015, 15.00-17.00

**Venue:** 6<sup>th</sup> Floor East Meeting Room, 250 Euston Road, UCLH

**Chair:** Prof Jeremy Whelan (JWh)

**ACTION LOG (November 2015), including outstanding actions from previous meeting**

<b>ACTION</b>	<b>Owner</b>	<b>Status/Due Date</b>
CL to enquire re possibility of publishing patient survey results on LSESN website	CL	outstanding
BMS to talk to Jeff Lordan re retroperitoneal follow-up audit	BMS	Outstanding – JWh to pick up through regular abdominal sarcoma meetings
BMS to send Patient Management Policy to GF (incorporating CB comments)	BMS	Outstanding – to do next month
GF to circulate Patient Management Policy and upload onto LSESN website	GF	outstanding
BMS to amend FU guidelines and send to GF	BMS	Outstanding – to do next month
GF to circulate FU guidelines and upload onto LSESN website	GF	outstanding
BMS to finalise chemotherapy algorithm and send to GF	BMS	Outstanding – to do next month
GF to circulate chemotherapy algorithm and upload onto LSESN website	GF	outstanding
RNOH to replicate 2WW audit taking place at RMH	JWo	GF gave CL feedback. JWo to talk to Myles Smith
Update LSESN 2WW form and upload onto LSESN website	GF	February
Respond to EofE SCN re 2WW form	JWh	February
Discuss paediatric sarcoma 2WW referrals at CTYA network meeting	JWh	February
Ask John Bush if the SAG can use the Brighton data in our diagnostic clinic promotion ‘brochure’	KL	January
Ask Richard Haywood for equivalent data at Norfolk and Norwich	AH	January
Set up diagnostic clinics meeting for end of January	GF	January
Let GF know if any news to be included in newsletter	all	December
Request radiotherapy data from NCIN	?	February
Coordinate new ‘designated services’ section of LSESN website	GF	February
Obtain RMH trials data for LSESN website	GF	December
Add trials to end of SAG agenda and invite Rose and Galina to attend	GF	February
Re-establish sarcoma nursing forum	JWo	February
Coordinate the SAG CDF consultation response	VK	February
Add Governance to SAG agenda	GF	February
Circulate future dates of meetings to SAG	GF	February

## 1. Welcome and Introductions

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

- Rolyn Alvarado, Clinical Nurse Specialist, Royal Marsden Hospital
- Charlotte Benson, Consultant Medical Oncologist - Royal Marsden Hospital
- Amos Burke, Consultant Paediatric Oncologist, Adenbrookes Hospital
- Alison Dunlop, Clinical Nurse Specialist, Royal Marsden Hospital
- Catriona Liebenberg, Clinical Business Unit Manager, Royal Marsden Hospital
- Aisha Miah, Consultant Clinical Oncologist, Royal Marsden Hospital
- Rob Pollock, Consultant Surgeon, Royal National Orthopaedic Hospital
- Beatrice Seddon, Consultant Clinical Oncologist, University College London Hospital
- Myles Smith, Consultant Surgeon, Royal Marsden Hospital
- Denise Williams, Consultant Paediatric Oncologist, Addenbrookes Hospital

## 2. Minutes from the meeting held on 04<sup>th</sup> September 2015

The minutes of the last meeting were accepted as an accurate record of proceedings.

Simon Jordan gave an update regarding the thoracic pathway. George Ladas and Simon Jordan had their theatre capacity cut by 25% but are now back up to full capacity as of last week. SJ has also raised concerns to the RBH board regarding cancer waiting times and the board have agreed to support the team with additional resource. RBH are expecting to employ an additional Consultant Surgeon. SJ is auditing the communication from RBH to referring trusts, e.g. sending letters and discharge summaries and will report back to the SAG. John Pearcey, the AGM at RBH now has weekly teleconference meetings with the MDT Coordinators at RMH and UCLH to discuss patient tracking and this seems to be working well.

### Actions log - September 2015

JWh and members reviewed the action log from the last meeting and noted that the following were complete:

ACTION	Owner	Status
GF to update referral guidelines, circulate and upload onto LSESN website	GF	Complete. Noted that the LSESN website was unavailable but is working again. RMH IT fixed the problem and continue to host.
JWh to circulate bone sarcoma guidelines to SAG for approval	JWh	Complete, no further comments received. GIST and ST guidelines in development
GF to upload ALT Pathway onto LSESN website	GF	Complete
GF to amend and circulate SAG Work Programme	GF	Complete
AH to draft covering letter re diagnostic clinics	AH	Complete
GF and JWh to complete NICE shared care database application	GF/JWh	Complete

### 3. 2WW Form/NICE 2WW Guidelines

JWh and GF are meeting with the Transforming Cancer Services Team on 11<sup>th</sup> December to discuss the new 2WW guidelines and form. There has been email correspondence between various clinicians and NICE regarding the new guidelines but the NICE response has been that they will not be reviewing the guidelines again in the short term.

AH noted that by reaching out to local units to provide diagnostic services this would provide easy access to imaging in line with the new guidelines.

The SAG reviewed the current LSESN 2WW form – minor changes are needed as discussed.

**Action:** GF to update LSESN 2WW form and upload onto LSESN website

JWh noted that East of England SCN have also created their own sarcoma 2WW form.

**Action:** JWh to respond to EofE SCN.

JWh noted a recent incident where a suspected sarcoma had been referred on a paediatric 2WW form and was seen initially by the general paediatric team even though a suspicion of sarcoma was clearly indicated on the form. There is a CTYA network meeting in January which JWh is attending and the Paediatric 2WW form is on the agenda.

**Action:** JWh to discuss at CTYA network meeting

### 4. Local Diagnostic Services

It was agreed at the last meeting that the SAG would target a few trusts with a letter and a brochure. AH has drafted a letter which the SAG signed off with no further changes required.

**Action:** KL to ask John Bush if the SAG can use the Brighton data in our diagnostic clinic promotion 'brochure'

**Action:** AH to ask Richard Haywood for equivalent data at Norfolk and Norwich

Heat maps were produced in 2014 showing the areas with the highest number of referrals.

It was agreed that a diagnostic clinic working party should be formed to discuss the letter, brochure, heat maps, and previous diagnostic clinic templates. The working group is to include JWo and additional RNOH member if necessary, JWh, AH and additional RMH member if necessary, GF.

**Action:** GF to set up meeting for end of January

### 5. Work Programme

The updated Work Programme was circulated prior to the meeting. Another newsletter is to be circulated shortly.

**Action:** Let GF know if any news to be included

Site-specific referrals and protocols were discussed under the audit section of the Work Programme and it was agreed that it would be useful to repeat the chemotherapy and radiotherapy audits of referrals for treatment outside of the centres.

SS noted that the NCIN and radiotherapy databases are now linked so it would be possible to see where radiotherapy is given nationally. It would be easier to obtain radiotherapy data than chemotherapy data so it was suggested to audit the radiotherapy practice first. Aisha Miah is the radiotherapy link for the NCIN and has been doing the national audit.

KL added that it would be useful to look at the differences in timeliness from surgery to start date of radiotherapy depending on whether radiotherapy is given in the centres or at outside trusts. Although Clinical Oncologist to Clinical Oncologist referral (centre to treating trust) is best practice it means that there is a delay in starting radiotherapy as the Clinical Oncologist at the treating trust sees the patient first before booking the treatment.

**Action:** ? to request radiotherapy data from NCIN

TM noted that patients who are treated outside of the centres are sometimes unclear whether the treatment they are receiving is the same as the treatment they would receive at one of the sarcoma centres. It was suggested to have a section on the LSESN website for 'designated services' to include photos of the designated practitioners so that patients can see that the designated practitioners are part of the team at the centres.

**Action:** GF to coordinate new section of LSESN website

The trials section of the LSESN website needs updating. GF is awaiting an update from RMH but has had no response from Annie Woodbourne. It was noted that Annie no longer works at RMH and the trials contact should be Galina Petrikova.

**Action:** GF to forward email to Robin Jones

Phase I trials should include wording to say 'ask your oncologist' as this list changes regularly.

It was agreed that regular trials meeting between the two centres should be re-established. Trials will be added to the end of the SAG agenda.

**Action:** GF to add trials to end of SAG agenda and invite Rose and Galina to attend

JWo added that there also used to be a regular sarcoma nursing forum which hasn't met for some time.

**Action:** JWo to re-establish sarcoma nursing forum

KL noted that there is now a part-time sarcoma CNS at Sussex who should be included in any sarcoma nursing correspondence and passed the details onto JWo.

KL fed back that the sarcoma workshop at the RMH in the summer was very good and that in future it would be useful to have some 'site-specific' sessions i.e. clinical oncology, radiology etc.

## 6. National Commissioning Update

JWh updated the SAG that progress of the Sarcoma CRG has slowed in producing a sarcoma specification. Another draft has been produced which needs to be finalised.

The chemotherapy algorithm is complete and has been circulated for consultation to SAGs with feedback received from some. The algorithm has been written to include drugs which are in the Cancer Drugs Fund and so would not currently be approved.

**7. AOB**

a) Cancer Drugs Fund

The CDF consultation document was circulated prior to the SAG. The response to the consultation is due in February. JWh suggested that the SAG should respond collectively, SAG members agreed.

**Action:** VK to coordinate the SAG response

b) Patient Feedback

TM raised two patient concerns:

- i) Patient was told she had a recurrence and there was no CNS/Key worker in the room. The patient was very distressed. AH explained that there is a CNS resource issue. The SAG suggested that the patient raise the issue with PALs at the treating trust as it may help the case for more CNS' if a patient raises these concerns
- ii) Two patients who both had GISTs – one who had surgery at RMH and one who had surgery at their local hospital. TM questioned whether all GIST surgery should take place at a sarcoma centre. JWh noted that we have a LSESN GIST pathway but it is not clear whether it is always followed. The NICE Quality Standard indicates who should be operating on these patients and that surgery should be done by designated surgeons. The SAG needs to reflect on how it fulfils a governance role and how we influence best practice. To be discussed in future meetings.

**Action:** GF to add Governance to SAG agenda

c) Dates of next meetings

It was agreed that the next meeting would be on 26<sup>th</sup> February at RMH.

**Action:** GF to circulate all future dates to SAG

Present:

Jeremy Whelan (Chair)	Consultant Medical Oncologist	UCLH
Gemma French	Project Manager	RNOH/UCLH
Peirs Gatenby	Consultant Surgeon	Royal Surrey County Hospital
Andrew Hayes	Consultant Surgeon	RMH
Robin Jones	Consultant Medical Oncologist	RMH
Simon Jordan	Consultant Thoracic Surgeon	RBH
Vasilios Karavasilis	Consultant Medical Oncologist	UCLH
Kate Lankester	Consultant Clinical Oncologist	Royal Sussex County Hospital
Tricia Moate	Patient Representative	RNOH/RMH
Chrissie O'Leary	General Manager, Oncology	UCLH
Sandra Strauss	Consultant Medical Oncologist	UCLH



NORTH AND EAST

Rachel Windsor  
Julie Woodford  
Shane Zaidi

Consultant Paediatric Oncologist  
Nurse Consultant  
Consultant Clinical Oncologist

UCLH  
RNOH  
RMH

