

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 26th February 2016, 15.00-17.00

Venue: Board Room, Royal Marsden Hospital

Chair: Andy Hayes (AH)

1. Welcome and Introductions

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

- Palma Dileo, Consultant Medical Oncologist, UCLH
- Kirsty Green, Clinical Business Unit Manager, RMH
- Dawn Holland, General Manager Cancer & Joint Reconstruction, RNOH
- Kate Lankester, Consultant Clinical Oncologist, Royal Sussex County Hospital
- Andy McMeeking, Team Manager, Transforming Cancer Services Team for London
- Chrissie O’Leary, General Manager Oncology, UCLH
- David Sallomi, Consultant Radiologist, East Sussex Healthcare NHS Trust
- Dirk Struass, Consultant Surgeon, RMH
- Denise Williams, Consultant Paediatric Oncologist, Addenbrookes Hospital
- Shane Zaidi, Consultant Clinical Oncologist, RMH

2. ACTION LOG (February 2016), including outstanding actions from previous meeting. All other actions from previous meeting were completed.

ACTION	Owner	Status/Due Date
CL to enquire re possibility of publishing patient survey results on LSESN website	GH/KG	Outstanding
If above approved CPL and JWo to provide summaries for website	CPL/JWo	Outstanding
BMS to send Patient Management Policy to GF (incorporating CB comments)	BMS	Outstanding
GF to circulate Patient Management Policy and upload onto LSESN website	GF	Outstanding
BMS to amend FU guidelines and send to GF	BMS	Outstanding
GF to circulate FU guidelines and upload onto LSESN website	GF	Outstanding
BMS to finalise chemotherapy algorithm and send to GF	BMS	Outstanding
GF to circulate chemotherapy algorithm and upload onto LSESN website	GF	Outstanding
RNOH to replicate 2WW audit taking place at RMH. Explore if similar audits are being done at other diagnostic clinics within the network	JWo	JWo to talk to Myles Smith, include CPL
Respond to EofE SCN re 2WW form	JWh	Outstanding
Ask John Bush if the SAG can use the Brighton data in our diagnostic clinic promotion ‘brochure’	KL	Outstanding
Ask Richard Haywood for equivalent data at Norfolk and Norwich	AH	Outstanding
Amend Diagnostic Clinics letter. Circulate to Trusts	GF/JWh/ AH	May 2016
Request radiotherapy data from NCIN	AM	Outstanding
Coordinate new ‘designated services’ section of LSESN website	GF	Outstanding
PG to look at local 2WW data to identify where 2WWs are referred	PG	May 2016
GF to keep Pathology as a standing item on the SAG agenda	GF	Ongoing

GF to add 'delay in receiving external pathology' to PIN dropdown menu on LSS Infoflex	GF	May 2016
JWh to write to Cyril Fisher and Adrienne Flanagan to ask them to come to the next SAG meeting	JWh	May 2016
GF to add results of pathology audit to agenda in 6 months' time	GF	September 2016
GF to keep website reports as a standing item on the agenda	GF	Ongoing
GF to include additional information on LSESN website re where patients can go to for support	GF	May 2016
RJ and CPL to meet with RMH communications team re improving the sarcoma section on the RMH website	RJ/CPL	May 2016
GH to contact EMDT colleague to enquire re feasibility of adding a PIN dropdown box	GH	May 2016
Draft of PIN letter to be discussed at next SAG. GF to add to agenda.	JWh/GF	May 2016
GF to ensure venues are booked for the next year	GF	May 2016

3. Diagnostic Clinics

AH discussed the proposal that the SAG will write to Trusts to ask whether they would be interested in setting up a diagnostic clinic. A letter has been drafted and was discussed. A selection of Trusts has been identified using the 'heat maps' which highlight the areas where the highest number of 2WWs are sent to the centres. 6 Trusts in Essex, 4 Trusts in Kent and 3 Trusts in Hertfordshire will be targeted.

Members of the SAG agreed with this plan and that the letter should be circulated to Chief Executives, Sarcoma Leads and Cancer Improvement Leads where known. Some comments were made on the letter – GF to amend.

Action: GF to amend diagnostic clinics letter and send out

4. 2WW Form

JWh explained that the Transforming Cancer Services Team (part of NHS London) is looking at the 2WW referral process for all cancers across London. They held workshops last summer following the publication of the new NICE Guidance (NG12). There have been a series of meetings since then to look at the sarcoma form. The form will be completed electronically by GPs (for all sites) and there will be no faxes from January 2017. There is no way of centrally managing the updates to the forms and GPs use different systems and once the new forms have been uploaded onto these systems they will be hard to change. We are therefore including as much information as possible on the LSESN website so that this can be hyperlinked on the forms. We will therefore be able to change for e.g. contact details easier. The new forms will 'go live' in April 2016. The form was initially changed so that all paediatric sarcomas were sent directly to sarcoma centres; however following comments from paediatricians within the networks the current pathways will remain (soft tissue sarcomas will be referred to paed, bone sarcomas will be referred to sarcoma).

NK informed the SAG that SUHT is in the process of looking at their 2WW pathway. They are also becoming overwhelmed with the number of referrals received for their soft tissue diagnostic clinic. The number of referrals is increasing and they are seeing more 'non-sarcomas'.

PG noted that RSCH is being asked to cut back on their 'lumps and bumps' clinics. The heat maps tabled show that Guildford and Waverly CCG refer very few patients to the sarcoma centres so the SAG questioned where these referrals are going.

Action: PG to look at local 2WW data

5. Pathology

JWh explained that the London Sarcoma Service has recently had a number of patients in whom there had been delays in receiving external pathology for review by LSS pathologists. RMH agreed that this is also the case for their service. The possible reasons for these delays, including opinions being sought from other pathologists outside either the London Sarcoma Service or RMH, were discussed. 3 years ago this problem was highlighted at the SAG. The SAG send a letter and the pathology referral forms to all Trust sarcoma leads (and pathology contacts where known) within the network. In 2013 the SAG approved the proposal that:

- In the event of pathology misdirected for review, the treating MDT will resend the previous SAG communications to the reporting pathologist
- In the event of delay in dispatch for review by a Specialist Sarcoma Pathologist (SSP) beyond 5 days from requesting review, a proforma will be sent from the SAG chairs drawing attention to the need for timely SSP review.

There have been no improvements since this exercise was carried out 3 years ago, and the above plan was not followed through.

It was suggested to go through the Royal College of Pathologists, but we would need to take an audit to this forum to assess the extent of the problem . A prospective audit would need to look at the date of patient review by the referring hospital, the date of review at the centre and the date the patient is seen at the centre. Medical students could potentially carry out the audit, to be completed in a time frame of around 6 months. SAG chairs to speak to pathologists first. JWo suggested that 'delay in receiving pathology' is added to the PIN dropdown options at LSS.

The second issue raised was regards to SAG engagement from pathology at the 2 centres. It was noted that both sites are served by excellent pathology services. There is a shortage of sarcoma pathologists nationally and regionally our pathologists are very busy and the SAG is unaware of any succession plans. It was agreed that over the coming year the SAG should engage with our pathologists to talk about how we sustain sarcoma pathology within London.

Action: GF to keep Pathology as a standing item on the SAG agenda

Action: GF to add 'delay in receiving external pathology' to Pin dropdown menu on LSS Inflex

Action: JWh to write to Cyril Fisher and Adrienne Flanagan to ask them to come to the next SAG meeting

Action: GF to add results of pathology audit to agenda in 6 months' time

6. LSESN Website Usage Report

GF circulated and tabled 2 monthly reports to show the general usage of the LSESN website. The RMH communications team have agreed to provide these reports every month. The SAG agreed that the information in the reports is useful.

Action: GF to keep website reports as a standing item on the agenda

7. Governance

Governance has been added as a standard item on the agenda following on from the patient feedback that TM raised at the last meeting. It was agreed that it is appropriate for the SAG to write to the sarcoma leads of the trust to note that issues have been raised but that these would be general comments rather than specific personal information. Patients are encouraged to take any concerns to the PALs department of their Trust. Prior to the SAG, JWh and AH discussed whether to add a 'contact us' button on the LSESN website which patients could use to raise concerns however it was concluded that Sarcoma UK cover this with their new support line.

TM explained that one of the patients in her support group has had a similar incident recently where they were told that they had a recurrence when they were alone and with no CNS present. AH felt that these specific issues were outside the remit of the SAG however e.g.s when patients do not follow agreed pathways (such as the recent GIST example) can be governed by the SAG.

It was agreed that we can add some additional information on the LSESN website to include that patients can seek a second opinion/advice, PALs information and the link to the Sarcoma UK support line (check with Sarcoma UK first)

Action: GF to include on LSESN website

It was noted that it is very difficult to find the contact details for the sarcoma CNS' on the new RMH website

Action: RJ and CPL to meet with RMH communications team re improving the sarcoma section on the RMH website

JWh explained that the London Sarcoma Service have a 'Practice Improvement Notification' (PIN) system within their MDT whereby errors in the pathway are logged during the MDT and can be audited. The PIN categories need to be refined and the audit needs to be repeated.

RMH agreed to explore the development of a similar process and audit results of both centres to be discussed at a future SAG meeting.

The next step would then be to send a letter from the SAG to Trusts identified in the audit.

Action: GH to contact EMDT colleague to enquire re feasibility of adding a PIN dropdown box

Action: Draft of PIN letter to be discussed at next SAG. GF to add to agenda.

9. Clinical Trials and Research

GP tabled the RMH trials data. There are currently 14 open studies, 7 academic studies and 3 observational studies. There is some overlap with the studies open/due to open at UCLH. GP highlighted the studies which are RMH only.

RE tables the UCLH trials data and discussed the trials which are open/due to open at UCLH but unavailable at RMH.

It was agreed that it would be useful to see this data at every SAG meeting. RE and GP do not need to attend every meeting but could liaise beforehand and attend the meetings which are hosted by their

Trust. Data to be presented by research leads (BS and IJ).

10. AOB

The next meeting is on 20th May at London Cancer.

Future support for the SAG was discussed as GF is due to go on maternity leave. JWh, GF and COL are due to meet with Nick Kirby, Divisional Manager for Cancer Services at UCLH to discuss the Trust support of these meetings and will feedback to RMH (GH and AH) after this meeting.

Action: GF to ensure venues are booked for the next year

Present:

Andy Hayes (Chair)	Consultant Surgeon	RMH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Rose Ellard (RE)	Senior Research Nurse	UCLH
Gemma French (GF)	Project Manager	RNOH/UCLH
Piers Gatenby (PG)	Consultant Oesophagogastric Surgeon	Royal Surrey County Hospital
Gwen Hodge (GH)	Assistant CBU Manager	RMH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Nicola Keay (NK)	Consultant Medical Oncologist	Southampton University Hospital
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Tricia Moate (TM)	Patient Representative	RMH/RNOH
Galina Petrikova (GP)	Senior Clinical Trials Coordinator	RMH
Cerys Propert-Lewis (CPL)	Clinical Nurse Specialist	RMH
Beatrice Seddon (BS)	Consultant Clinical Oncologist	UCLH
Sandra Strauss (SS)	Consultant Medical Oncologist	UCLH
Winette Van Der Graaf (WG)	Consultant Medical Oncologist	RMH
Jeremy Whelan (JWh)	Consultant Oncologist	UCLH
Julie Woodford (JWo)	Nurse Consultant	RNOH