London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 20th May 2016, 15.00-17.00
Venue: The Boardroom, 3rd Floor, London Cancer, 170 Tottenham Court Road
Chair: Jeremy Whelan (JWh)

1. Welcome and Introductions

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

- CNS' @ RMH
- Kirsty Green, Clinical Business Unit Manager, RMH
- Winette van der Graff, Honorary Consultant Medical Oncologist, RMH
- Andy Hayes, Co-Chair of SAG and Consultant Surgeon, RMH
- Kate Lankester, Consultant Clinical Oncologist, Royal Sussex County Hospital
- Christina Messiou, Consultant Radiologist, RMH
- Aisha Miah, Consultant Clinical Oncologist, RMH
- Kannon Nathan, Consultant Clinical Oncologist, Kent & Canterbury Hospital
- John Pearcey, Assistant General Manager, Royal Brompton Hospital
- David Sallomi, Consultant Radiologist, East Sussex Healthcare NHS Trust
- Sandra Strauss, Consultant Medical Oncologist, UCLH
- Julie Woodford, Nurse Consultant, RNOH

2. ACTION LOG (May 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)	BMS	Outstanding
GF to upload onto LSESN website	GF	Outstanding
BMS to amend FU guidelines and send to GF	BMS	Outstanding
GF to upload onto LSESN website	GF	Outstanding
BMS to finalise chemotherapy algorithm and send to GF	BMS	Outstanding
GF to 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. GF mat cover to look at 2WW audit across SAG.	GF mat cover	Outstanding
Ask Richard Haywood for equivalent data at Norfolk and Norwich. Data not yet received	AH	Outstanding
Request radiotherapy data from NCIN. AM meeting with SS and NCRAS 06/06	AM	Outstanding
Coordinate new 'designated services' section of LSESN website. Drafted, awaiting confirmation of designated practitioners.	GF mat cover	Outstanding
PG to look at local 2WW data to identify where 2WWs are referred. Bring to next meeting	PG	September 2016
RJ and CPL to meet with RMH communications team re improving the sarcoma section on the RMH website	RJ/CPL	In progress
GH to contact EMDT colleague to enquire re feasibility of adding a PIN dropdown box	GH	Outstanding
Draft of PIN letter to be discussed at next SAG. Carry over to next meeting	JWh	September 2016
Diagnostic Clinics: GF to send July date to 3 Trusts	GF	June 2016

Generic Site-Specific Pathway to be re-drafted	JWh/GF	September 2016
Designated Practitioners: GF to give JWh the list of people who have not replied and he will contact	GF/JWh	September 2016
Add Designated Surgeons to the next SAG agenda	GF	June 2016
Designated Practitioners: GF to work with PS re amendments to SUHT list	GF/PS	June 2016
Designated Practitioners: GF to add Elliott Simms at Queens contact	GF	June 2016

3. Diagnostic Clinics

JWh gave the background information to this project. There continues to be an increase in GP referrals to RNOH and RMH, which is on burden on the centres and having an impact on the more specialised work that they can undertake.
The SAG chairs have made contact with 14 Trusts based on the heat maps of referrals into the centres. The 14 Trusts are based in the 3 areas identified as having a large number of referrals to the centres – Kent, Essex and Hertfordshire. A letter has been sent to the CEO and the Sarcoma Lead of each Trust and we have received 4 positive responses from Luton & Dunstable, Princess Alexandra, Southend and East Kent. The next step is for the SAG chairs and diagnostic teams in the linked centres to visit the Trusts and give a presentation covering national policies, existing models etc.
We have identified one date in July when SAG chairs and Trust Leads are available. It has been suggested that we send this date to the 3 Trusts in Essex and Herts to find out if they are available. We plan to do one visit before the summer break and then a further 3 afterwards.
JWh asked PS what makes the SUHT diagnostic clinic work well. PS responded that the SUHT model has an enthusiastic surgeon, keen to see lumps and bumps with a radiologist working alongside of him. PS noted that it is key to look at what each individual Trust will get out of setting up their own diagnostic clinic – some trusts will want to deal with a large benign workload and others will have an interest in the malignant work.

Action: GF to send July date to 3 Trusts

4. Review of LSESN Pathways

There are several site-specific pathways which we developed some years ago and are available on the LSESN website. A generic site-specific pathway has been produced which was projected at the meeting. It is hoped that the dissemination of this pathway might help to clarify the pathway for those who do not follow the current pathways.
The individual site-specific pathways would need to be re-visited in light of the new national sarcoma specification once it has been approved and published and so JWh asked if this generic pathway is sufficient enough to replace the individual pathways.
PG asked what the pathway refers to as for GISTs it is confusing as the pathway says that all suspected/diagnosed sarcomas are referred to a sarcoma MDT and this is not current practice. PS agreed that not all GISTs are discussed in the sarcoma MDT at SUHT also. At both Trusts some GIST patients are discussed in the GI MDT. JWh confirmed that the pathway should relate to all sarcomas as outlined in the sarcoma service specification and we need to work out how to align this with local practices. BS agreed that practices would need to be negotiated locally. There are some GISTs which the sarcoma MDT needs to know about such as large tumours and patients requiring systemic therapy. Not all patients need to be discussed at the sarcoma MDT but the sarcoma and GI MDTs need to work together to have clear procedures.
PS noted that it looks like all recurrences should be referred to the MDT within 24 hours. JWh explained

that this box does not relate solely to recurrences but all suspected/diagnosed sarcomas and 24 hours was chosen so that the pathway was measurable. PS explained that the current SUHT pathway does not follow this as if sarcoma is suspected on imaging they would then request a biopsy to confirm this before referring to the LSS Sarcoma MDT. PS questioned whether they should change the process and be referring the patient after imaging and sending the patient to RNOH for biopsy, or biopsy-ing the patient and then sending the sample rapidly to RNOH? This needs further discussion.

It was agreed that the principles of the national sarcoma service specification can be put into one generic site specific pathway but there will need to be some explanatory footnotes added.

Action: Generic Site-Specific Pathway to be re-drafted

5. Designated Practitioners

We currently have lists of designated practitioners for chemotherapy and radiotherapy. The national sarcoma service specification goes beyond this and also includes designated practitioners for surgery, which the SAG need to approve.
The SAG looked at the lists available on the LSESN website. Both need refreshing.

TM explained that as a patient you want to be reassured that the experience you will have at another trust will be the same as if you had been treated at a sarcoma centre. GF noted that a new section of the LSESN website has been drafted to explain this and the plan is to include a list of practitioners and their photos.

GF has written to all practitioners on the lists to ask them to confirm if they still consider themselves to be designated practitioners – about half have replied. JWh asked the SAG how we should approach this.
PS noted that there needs to be a clear link and relationship with the sarcoma MDT. The oncologists suggested that we actively contact people as they do refer patients to them successfully.

Action: GF to give JWh the list of people who have not replied and he will contact including the script re designated practitioners from the sarcoma service specification.

Action: GF to add Designated Surgeons to the next SAG agenda

Action: GF to work with PS re amendments to SUHT list

Action: GF to add Elliott Simms at Queens contact

6. Pathology

Concerns were expressed at the last SAG meeting and it was agreed that the chairs of the SAG would invite key pathologists to attend the SAG. JWh has contacted the pathologists, neither could attend today as it is a national EQA day but they all plan to attend the next meeting in September.

7. LSESN Website Usage Report

GF tabled the reports from the last 3 months and summarised the key points. There are approx. 200 sessions each month, an average of over a minute per session and an average of over 2 pages per session. Guidelines continue to be the most viewed pages.

8. National Commissioning Update

Sarcoma Service Specification:

JWh explained that the national sarcoma service specification went out for consultation and this has been completed. Several comments were made and responses to these comments are being undertaken by the sarcoma CRG. This will then go to two stages of NHS England for consideration. If NHS England feel that these responses are satisfactory the specification will go for approval. The specification could be approved in July.

Sarcoma Chemotherapy Algorithm:

The Sarcoma CRG constructed a chemotherapy algorithm and submitted this to the Chemotherapy CRG before Christmas. No response has been received from the Chemotherapy CRG to date. The algorithm includes drugs which have been removed from the CDF so could raise some issues.

Sarcoma CRG

There is no longer a Sarcoma CRG. NHS England have reorganised and reduced the number of CRGS to 5. Sarcoma will come under the Cancer Surgery CRG. This went out for consultation and all changes were accepted. It is still unclear how specialised commissioning for sarcoma will function in the future.
As a response to this JWh has invited all the Chairs of the SAGs nationally to meet at the end of June. Half of the SAGs are attending this meeting.

9. Clinical Trials and Research

RE and CB presented the trials open and in-set up at UCLH and RMH respectively.

Key points:
Announce: now open at UCH, took longer than expected. Recruited 1 patient to date. Only open to leiomyosarcoma patients from 1st April. RMH are also running this trial.
CASPS: due to close at both sites
STRASS: RMH have had a slowdown in recruitment
Create: UCH continue to recruit. Do not know planned closure date.
Enliven: Difficulties recruiting at both sites
IMRIS: open at UCH. Not open at RMH yet, due to open soon. Due to open at SUHT.
LMS Study: neither centre has done as good as expected due to screening failures.
Paragon: UCH have not recruited any patients. RMH have recruited quite a few sarcoma patients.
1202: suspended at RMH at the moment. RMH to let UCH know when it re-opens.
Adaptimmune: due to open soon at UCH. RMH can refer patients to UCH.
HGUS: due to open soon at UCH. RMH can refer patients to UCH.
Recent closures at RMH: AXI-STS, EMPRASS, VORTEX, CAMN107 and VIT 0910

10. AOB

2WW Form:
GF explained that the new Pan London 2WW Form developed by NHS England London has gone live on all GP electronic systems across London. GPs outside of London should continue to use the LSESN 2WW form. Both forms are available on the LSESN website.

Patient Feedback:
TM discussed two recent patient issues. The first patient had surgery locally and then follow-up at 1 year. They were then discharged with no further follow-up. The patient now has a recurrence. It was agreed that designated practitioners should follow the LSESN follow-up guidelines. JWh noted that there is good evidence to show that the patient is better at detecting a recurrence rather than follow-up scans but what was missing from this pathway was the information for the patient on signs and symptoms of recurrence. The patient also did not have a CNS to contact re any worries.

PS noted that it would be good to look at how follow-up is shared, for example between SUHT and RNOH.

The second patient is having palliative chemotherapy at their local hospital. The patient did not start treatment for 5 weeks after diagnosis and has had a few issues in their pathway. Blood clots were seen on a scan and the radiologist called the patient on a Saturday to inform them of this. The patient then had difficulties obtaining a prescription. The SAG agreed that normally this would have been referred to the Trust AOS team who would have liaised with the patient.

Present:

Jeremy Whelan (Chair)	Consultant Medical Oncologist	UCLH
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
Franel le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Tricia Moate (TM)	Patient Representative	RMH/RNOH
Chrissie O'Leary (COL)	Oncology General Manager	UCLH
Beatrice Seddon (BS)	Consultant Clinical Oncologist	UCLH
Peter Simmonds (PS)	Consultant Medical Oncologist	University Hospital Southampton
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH