London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 10th December 2021, 15.00-17.00
Venue: MS Teams
Chair: Andrew Hayes (AH)

1. Welcome and Introductions

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

Fernanda Amary (FA)	Consultant Histopathologist	RNOH
Marc Delon (MD)	Programme Lead	NCL
Jonathan Hannay	Consultant Surgeon	RMH
Myles Smith (MS)	Consultant Surgeon	RMH

2. ACTION LOG including outstanding actions from previous meeting. All other actions from previous meeting were completed and have been removed.

ACTION	Owner	Date Added	Due Date
BMS to provide update to SAG re GISTs at Mount Vernon	BMS	Mar 21	Dec 21
GF and JWo to approach Sarcoma UK re patient representation at the SAG	GF/JWo	Sep 21	Dec 21
Pathology letter to be sent to all pathology leads	GF	Dec 21	Mar 22
CS to arrange a WGS meeting	CS	Dec 21	Mar 22
Project Manager and Chairs to discuss data sharing template	CG/RJ	Dec 21	
GF to SUHT Service Update to beginning of next agenda	GF	Dec 21	Mar 22
GF to set up a 2ww subgroup meeting	GF	Dec 21	Mar 22
Galleri trial - AH to contact Christina Messiou for her opinion on this and whether the quality of the MRI scans will be sufficient. CS contact the Galleri trial team once confirmation received from Christina Messiou	AH/CS	Dec 21	Mar 22
SM to give a commissioning update at the next meeting. GF to add to agenda	SM/GF	Dec 21	Mar 22
GF to add Children and TYA Service Specifications to the next agenda and ensure JC can attend	GF	Dec 21	Mar 22
GF to add NCPES to the agenda for the next meeting	GF	Dec 21	Mar 22
GF to add HNA outcomes to the next agenda	GF	Dec 21	Mar 22

Previous minutes were agreed.

Outstanding actions:

Sarcoma UK patient representation
Action: GF to follow up with JW

Pathology letter:
A letter was drafted by Jeremy but not yet sent. GF shared her screen to show the letter. The SAG agreed with the content and that the letter should still be be sent. Any additional comments to be sent to GF.

Action: GF to arrange for letter to be sent, dated from the date of the SAG meeting.

Data sharing template:
Action: For the new Project Manager and Chairs to discuss

SUHT
Action: PS asked for this to be added to the March agenda

3. Appointment of new chair and co-chair of LSESN SAG

Interviews took place last month and Craig Gerrand was appointed as new Chair of the SAG and Robin Jones was appointed as Depity Chair of the SAG.
AH thanked the new Chairs and for those who set up the interview panel. The new SAG structure will provide more support than the SAG has had in the past which will be very helpful.

CG and others offered thanks to AH for his work for the SAG over the last 10 years.

4. Feedback from 2WW subgroup

JW gave feedback from the first 2ww subgroup meeting. Both services agreed that we need to continue to work together to improve the 2ww pathways. Both centres want to expand the use of diagnostic clinics. RNOH are having early discussions with Essex and RMH keen to explore this with Kent. RNOH have been working with NCL to improve access to ultrasound for GPs.
RMH are having issues with the ultrasound reports recommending MRI and therefore needing to do lots of MRIs. This is the same at RNOH, and this is usually done following a telephone consultation with a nurse. Some patients are discharged following a standard FDS letter. More recently the Consultant has been writing to the patient following review of the scan result where appropriate.

AH suggested that dates are set for future meetings and that minutes are taken. The project manager will be able to support this once in post.

Action: GF to set up a meeting in the new year on a Wednesday that AH is not operating.

5. GRAIL sponsored NHS-Galleri Trial

SS gave an update on the Galleri Trial. It is a cancer screening study where blood is taken and markers can be found that indicates that patients may have a bone or soft tissue sarcoma.
8 cancer alliances are taking part in the study and Kent and South East London are the alliances relevant for our sarcoma network. If a patient gets a positive sarcoma marker from the blood test they will be seen by a research nurse are then referred locally for imaging (diagnostic hub in Kent or GSST) and if imaging shows a suspicion of sarcoma they will be referred to the sarcoma centre on a 2WW. The majority would go to RMH due to the patients being from Kent/SE London, however it is anticipated that numbers would be very small. If nothing suspicious is found the sarcoma centre would not be involved and the research team would manage the patient and

repeat bloods.
The question for discussion is what diagnostic imaging should be used. This was also raised recently at the SAG chairs meeting as other alliances are involved The suggestion is that whole body MRI should be used as it will not be known where in the body the sarcoma is and the patient will not have any symptoms, however it was questioned if this would accurately capture GI sarcomas.

The SAG agreed that a whole body MRI seemed the most appropriate imaging.

Action: AH to contact Christina Messiou for her opinion on this and whether the quality of the MRI scans will be sufficient
Action: CS contact the Galleri trial team once confirmation received from Christina Messiou

6. Covid-19

No particular changes in either service at the moment

7 Feedback from the SAG Chairs Group and Service Specification Implementation

CG and AH attended the SAG Chairs meeting.
The first SAG dedicated chairs meeting was approx. 2 years ago when the service specification was published which Sarcoma UK helped fund. There have been a few virtual meetings since, chaired by Anant Desai. The recent meeting was in Birmingham funded by Sarcoma UK with representation from all SAGs either in person of virtually.
3 major issues were discussed – 1. Centralisation, particularly with regards to site-specific sarcomas. 2. Research (and the NCRI) and 3. Whole Genome Sequencing.
The presentation on centralisation focused particularly on retroperitoneal sarcomas and whether the number of centres should be reduced. Volume and outcome relationships were discussed. There were similar discussions for thoracic and head & neck sarcomas.
There were also discussions re Early Diagnosis. Sarcoma UK are very engaged with policy and the tools to help services.
NCRI is being restructured but for sarcoma it is hoped things will continue as they are now as they are a small, specialised group. As a sarcoma community they would like to work towards a sarcoma network working closely with NCRI. They want to improve the integration between clinicians, researchers and NCRI.

Our SAG now needs to apply the discussions to our network and the work that we need to do.

The dashboard id due to go live on 10th January. It will contain the metrics by which are services will be judged.

SM gave an update re the commissioning arrangements of sarcoma:
NHSE currently has 3 levels of commissioning – highly specialised nationally commissioned, regionally commissioned and CCG commissioned. If the bill goes through as expected some highly specialised nationally commissioned with be retained but regionally commissioned will go and be delegated to ICS's. More guidance expected in January. In London a Task & Finish group is being established with the 4 cancer alliances and 5 ICSs as well as the quality leads and radiotherapy and SACT leads to start thinking about what that will mean in practice for cancer. The first task & finish meeting will be in the new year. They are aware that for sarcoma it is complex pathway which involves multiple ICS's.

Action: SM to give an update at the next meeting

8. WGS Progress Reports

KT gave an update from an RMH histopathology perspective. RMH histopathology are very keen to support the team in doing this and understand its importance. However the main difficulty so far has been the short staffing in histopathology, which is a national issue in histopathology labs. There is not adequate staffing and this is compounded by the fact that at RMH they are a general tumour pathology lab which has to deal with all the specialities at the RMH, there isn't a specific musculoskeletal bone and soft tissue lab like at RNOH. The pathology workload after the first year of covid has increased by 30% and it is difficult to run the normal diagnostic service with shortages in histopathologists and admin staff. There have been discussions with the lab manager re extra funding for more biomedical scientists to deal with the 30% increase in workload. Any external sources of funding would be welcomed.

CS explained that Steve Russell is no longer in the same post.

AH noted that at the recent SAG chairs meeting there was a presentation which showed that there were findings which did influence treatment and that it wasn't just a research model for the future, there were findings which were impacting on patient care.

JW provided an update from RNOH. There have been 0 patients consented for the last 2 weeks. RNOH are trying to approach all patients which a high suspicion of sarcoma. The majority of patients who have been approached have consented to treatment and there have only been a few patients who have declined. GF has received positive patient feedback via an online survey.

AH suggested that at RMH they collect and freeze the tissue from the resectional specimen as a starting point.
RNOH would be happy to share the patient information and pathways that they have with the RMH.

Action: CS to arrange a meeting with Steve Russells replacement. GF would be happy to attend this meeting to share learning from RNOH.

9. Paediatric and TYA Sarcoma Services in London

The children's cancer service specification has been published which says that for children's services there must be an onsite PICU. The children's service at RMH will need to be moved from RMH to a site that has a children's intensive care unit. Patients will need to be sent to RNOH but the numbers will be very small. The change to the pathway will not happen straight away and will take 2-3 years to set up. Further discussion will be needed between JC and CG.

MM noted that paediatric pathways for bone sarcomas already go to RNOH and so it would just affect the soft tissue sarcomas currently treated by RMH and so numbers should be small.
The children's service specification needs to be aligned with the sarcoma service specification. A piece of work needs to be done on the pathway and agreed by the SAG .JC wanted to also use this as an opportunity to explore having pan a London Children's Sarcoma MDT rather than separate MDTs. Currently patients are discussed in the LSS Sarcoma MDT/RMH Sarcoma MDT and the GOSH MDT which is quite fragmented and so it would be sensible to look at how this pathway could be

improved.
There also needs to be discussions on the children's sub-speciality sarcomas e.g. childhood H&N, chest wall and spinal sarcomas for which there have never been any formal pathways agreed.

RW, MM, JC and Olga Slater to continue discussions

The TYA Service Specification has yet to be published

Action: GF to add to the next agenda to discuss update as well as an update on the TYA service specification

10. Patient Feedback

AH asked KC for her opinion on the best way to communicate with patients re getting the results of scans. KC felt that if patients were given a set time for an appointment for a video clinic this would be better as they could ensure that a family member/friend was present.

JW added that the NCPES results have been published. The last survey was voluntary due to the pandemic. RNOH have improved in a number of questions, where questions have deteriorated was due to the pandemic e.g. whether patients could bring family to appointments.

Action: GF to add NCPES to the agenda for the next meeting

JW updated that HNAs are now embedded at RNOH and they can pull out the patients main concerns at diagnosis and it wold interesting to compare the results at RMH

Action: GF to add HNA outcomes to the next agenda

11. Governance

Nothing noted

12. AOB

Clinical Trials

BS noted that UCLH have just opened a PVNS TGCT trial of an oral drug for any patients for which surgery would be difficult and asked all surgeons to contact BS with any appropriate patients.

Date and location of next meeting

TBC

Present:

Lee Bayliss (LB)	Consultant Surgeon	RNOH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH

Kirstene Caine (KC)	Patient Representative	
Julia Chisholm (JC)	Consultant Paediatric Oncologist	RMH
Jo Coleman (JCo)	Advanced Nurse Practitioner	RNOH
Palma Dileo (PD)	Consultant Medical Oncologist	UCLH
Gemma French (GF)	Sarcoma Improvement Manager	UCLH/RNOH
Craig Gerrand (CG)	Consultant Surgeon	RNOH
Franel le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Andrew Hayes (AH)	Chair of SAG and Consultant Surgeon	RMH
Robin Jones (RJ)	Consultant Medical Oncologist	
Tanya Joseph (TJ)	Divisional Head of Operations	RNOH
Sue Maughn (SM)	Head of Cancer	NHSE/I London
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Maureen McGinn (MM)	Senior Project Manager	RM Partners
Lucy Mclaughlin (LM)	Head of Cancer Commissioning	NCL
Maria Michelagnoli (MM)	Consultant Paediatric Oncologist	UCLH
Anisha Sejal Patel-Ladva (AP)	Sarcoma PA	UCLH
Emily Pegg (EP)	Deputy Divisional Manager	UCLH
Jonathan Perera (JP)	Locum Consultant Surgeon	RNOH
Beatrice Seddon (BS)	Consultant Clinical Oncologist	UCLH
Ariana Silva (AS)	Lead Sarcoma CNS	UCLH
Chris Stone (CS)	Service Manager	RMH
Dirk Strauss (DS)	Consultant Surgeon	RMH
Sandra Strauss (SS)	Consultant Medical Oncologist	UCLH
Khin Thway (KT)	Consultant Histopathologist	RMH
Vanessa Topp (VT)	Deputy Director for Cancer	RMH
Rachael Windsor (RW)	Consultant Paediatric Oncologist	UCLH
Julie Woodford (JWo)	Nurse Consultant	RNOH