London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: 15.00 and 17.00 on Friday 31st March
Venue: MS Teams
Chair: Robin Jones

1. Welcome and Introductions

RJ welcomed the group and noted the following apologies:
Hugh Janes
Jonathan Hannay
Sandra Strauss

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 RJ and PD to speak to Beatrice and pick up on this. GF to forward him email trail with Beatrice and original email of issue raised by Sarcoma UK	RJ/PD	Mar 21	Jun 23
GF to speak to abdominal surgeons to find out if this is still required on the agenda and update SM	GF	Sep 22	Jun 23
Sirolimus for EHE - SS MA and CB to work together on this. MA leading on this.	MA	Sep 22	Jun 23
PD to Update the chemotherapy algorithm with help from SAG colleagues – GF to speak to PD re using BSG guidelines instead	PD	Dec 22	Jun 23
PS review updates and add any changes to the LSESN second opinion policy	PS	Dec 22	Jun 23
SM to speak to NWL ICB re RNOH receiving 2WW referrals without imaging	SM	Mar 23	Jun 23
SM to speak to cancer alliances regarding the cut off age for the rapid diagnostic pathways	SM	Mar 23	Jun 23

NWL Lumps and Bumps document:
The SAG chairs reviewed and approved this document outside of the meeting.

Patient Expert Group:

GF met with the Patient Experience Lead at Sarcoma UK yesterday to get her advice on how to move this forward. Sarcoma UK have a large group of around 100 patients which they use for lay reviewing and input on various projects. It was felt that unless we have a specific task we need patients to do on a regular basis we could tap into their group as and when needed. Sarcoma UK would be happy to advertise and use a cohort of their patients when we need help on specific projects. We have 4 patients at RNOH which we can use for London specific feedback and this number is likely to grow as RNOH run more HOPE courses and patients volunteer to help with this.

The SAG agreed that this was a sensible approach.

3. 2WW Referrals

Mutual aid still in place at RNOH for RMH. RNOH received 25 referrals in December and continue to take 5-6 referrals per week until end of April when it will be reviewed again. Lots of referrals are going to Croydon and ChelWest. RMH team still needing to do lots of imaging reviews.
RNOH receiving referrals from NWL with no imaging with GPs saying that they cannot get imaging locally. TJ asked if this could be taken forward ICB to ICB.

Action: SM will take this forward and pick up with NWL ICB.

AH asked about SE London and Kent who have said they do not wish to set up local diagnostic clinics, despite previously saying they could help with this in a meeting. SM noted that potentially these patients could go to Mile End or Croydon.

2WWs discussed further in item 6.

4. Feedback from SAG Chairs Meeting

CG spoke about the recent SAG Chairs meeting which is a forum where all of the SAG Chairs meet. The rationale for starting it was the publication of the service specification, initially launched with Jeremy Whelan's instigation, with Sarcoma UK supporting it. It was felt there was no reliable mechanism in NHS that would allow updating of the specification and so the forum is used to talk about how people are implementing the specification in the first instance and then think about what the next iteration should be.

AH, GF and SS also attended the meeting. SS presented national data, particularly on retroperitoneal sarcomas and Anant Desai presented data which showed the relationship between volume and outcome, also presented at BSG. The data show that there is a solid argument for reducing the number of centres that do retroperitoneal sarcoma surgery. This does not affect the two centres in London (RMH and UCLH) but there are other centres in the country who are not currently doing enough cases and whose outcomes are not as good as higher volume centres. The mechanism for this is through highly specialised commissioning but this would be a long process. Of interest, a number of retroperitoneal cases were shared between centres and surgical teams asked how they would treat them – the take home message was that if one centre says it is not resectable another centre may not agree, and there is also sometimes inter-centre disagreement.
Other topics covered included early diagnosis and Rob Turner has been working with Sarcoma UK on their early diagnosis pathways and developing standard for ultrasounds. There was also a suggestion that the SAG chairs could develop a nationally timed pathway for sarcoma rather than wait for the national programme to do that. This is on the Sarcoma UK workplan from the meeting.
Updated BSG guidelines are being published and will go on the BSG website soon for comment.

5. Children and TYA Service Specifications

RW and JC both spoke regarding this topic.

JC stated that there are new national service specifications for children cancer which were published in November 2021. The TYA service specifications were written at the same time but not yet published.

The main points from the children's cancer specification were in regard to Principal Treatment Centres, this is Royal Marsden and St Georges in South Thames and UCLH and GOSH for North Thames. The key point is that there should be colocation of paediatric intensive care with other paediatric oncology services. As a result of that there is now a process for South Thames through NHS England which Hazel Fisher has been leading on. It is a very lengthy and a detailed process. There are two organisations that have bid for the service going forward in South Thames - St George's (which is currently a joint PTC with RMH) and Evelina Children's Hospital which does not have oncology care at the moment. The expectation is that the service will move off the RMH site in 3-5 years. Evelina came ahead of St Georges in the scoring process but both organisations will be having public consultations in the summer and then NHSE will make a final decision towards the end of the year on which will be the final site for Children's PTC in South Thames. JC confirmed that it is only the London PTCs that are affected as all the other PTCs have PICU onsite.

The second piece of work that is going on is around the shared care hospitals. There is a significant reorganisation around shared care. They are trying to devolve more straightforward infusional chemotherapy to our shared care hospitals around the region and so the principal treatment centres do more complex chemotherapy and there is access to high quality care delivered close to home for more of our patients.

Rachel talked about North Thames. UCLH are a joint PTC with GOSH and the service specification has quite significant implications for care of the under 13s at UCLH because they do not have collocated paediatric intensive care although do have intensive care for over 13s. UCLH has the biggest cohort of patients under 13s for radiotherapy (photons and protons). There are options, and the appraisal process is being worked through from one end of the spectrum of transferring care of all under 13s to GOSH as the PTC to the other end of the spectrum of working out whether care can remain at UCLH but still fit the service specification. UCLH has been designated as an enhanced level B POSCU by NHS England which means infusional chemotherapy can be given under the POSCU banner even if not under the PTC banner, but they now need to establish a level 2 HDU. The process for the non-radiotherapy patients under 13 years is still ongoing and we need to work out how the children's and sarcoma specifications work together.

PS asked about the transition from paediatrics to TYA to adults. The age cut off will be 16 years whether St Georges or Evelina. It is anticipated there will still be a TYA service at RMH but it is not known until the TYA service specification is published. Once this is published and the paediatric provider is chosen they will need to work together on transition.

6. NHS Commissioning Update

SM gave an update following the discussions at the workshop in November and the work they have been doing to try to resolve some of the issues raised.
SM showed a map which shows where the 21/22 2ww referrals were coming into London from which was a widespread geography from ICBs throughout London and SE and there were also around 100 referrals that come from other parts of the UK. There was a discussion at the last SAG meeting regarding the reasonable number of patients for local diagnostic services to see and it was agreed that a minimum number of 10 per week would be needed to maintain a good level of quality and expertise. This would result in two diagnostic services in the East of England and five in London and another two in SE England.

SM updated that specialised commissioners have given the go ahead to support and move forward with developing the local diagnostic service at Barts (Mile End). There have also been discussions between Julie, Tanya and colleagues from the RNOH in support of Barts to enable them to do this. They are also working with RM Partners re establishing a tariff for their diagnostic clinics.

Before Christmas a survey was sent to all of the diagnostic clinics that currently exist to establish how they are run and TCST are now working up a specification to outline what the services should look like.

DM spoke about the work he is doing on the urgent ultrasound protocol. There have been workshops held with radiologists across the network to discuss the issues and possible solutions. The local diagnostic services should improve the pathway, but will not fix all of it. Sarcoma UK are developing a poster for sonographers. TCST want to develop a template for sonographers to help sonographers use the correct language in reports re risk.

JC asked for clarification re the age of patients that will be included in the rapid diagnostic clinic and asked if it would include over 16s.

Action: SM to ask cancer alliances what the age cut offs are for these rapid diagnostic pathways

7. WGS Progress Reports

FA updated that there has been good progress at RNOH – they are sending approx. 8 cases a week which includes prospective cases and some legacy cases. They have made less progress in terms of discussing the results. The GTABs are happening every fortnight but the results are slower to come back so there is a delay on reporting cases. The turnaround time is around 3-4 months due to staffing issues at the GLH (was 6 weeks at the beginning of the year). Genomics England know about the difficulties and has been trying to employ more people to report cases. JW added that a standard has been added to the service that all newly diagnosed patients would be offered WGS, also if they recur. There are still difficulties in embedding the pathway at UCLH.

At RMH there has been an issue setting the process up in the lab, RJ has spoken to Adrienne about this. It is work in progress, to be re-reviewed at the next SAG meeting.

JC asked if the plan is that there would be a single sarcoma GTAB across London. RW explained that there is a fortnightly GTAB at LSS and they plan to trial joining the Addenbrookes meeting which is run really well. FA explained that they have tried to join this meeting before, but they do not have the time to discuss their own cases or the capacity to add on LSS cases at the moment.

PS agreed that it would be a good idea to have a regional forum to discuss actionable mutations. A national meeting would be sensible for sarcoma due to the low numbers. GF updated that at the National SAG Chairs meeting the idea of having a national GTAB was discussed, and Sarcoma UK agreed to work on this. FA added that Adrienne has been putting a grant together to get funding for a scientist to be dedicated to sarcoma to facilitate this at a national level.

8. **Trials**

RJ spoke regarding trials – the trials lists were enclosed with the SAG papers. He suggested that in future that maybe they can streamline the opening and recruitment of trials across the network, but this is a bigger topic outside of this meeting.

9. Any Other Business:

Designated Practitioners
AM raised that the Designated Practitioners lists need updating and asked if GF could work with the oncologists on updating these and meet separately to do this. Also, noted that Anthony Neal, Clinical Oncologist at Guildford has retired.

RNOH Restructure
TJ flagged that there has been a restructure at RNOH, and TJ has a new role from Monday. TJ will continue to attend the SAG, but Luke Martin will be taking over from TJs current role and will attend this meeting also.

Dates of the next meetings 2023:

- Friday 16th June 3-5pm
- Friday 15th September 3-5pm
- Friday 8th December 3-5pm

Attendees:

Fernanda Amary (FA)	Consultant Histopathologist, RNOH
Lee Baylis (LB)	Consultant Surgeon, RNOH
Charlotte Benson (CB)	Consultant Medical Oncologist, RMH
Julia Chisholm (JC)	Consultant Paediatric Oncologist, RMH
Jo Coleman	Advanced Nurse Practitioner, RNOH
Palma Dileo (PD)	Consultant Medical Oncologist, UCLH
Gemma French (GF)	SAG Project Manager
Craig Gerrand (CG)	Consultant Surgeon, RNOH
Andrew Hayes (AH)	Consultant Surgeon, RMH
Tanya Joseph (TJ)	Divisional Head of Operations, RNOH
Robin Jones (RJ)	Consultant Medical Oncologist, RMH - CHAIR
Franel Le Grange (FLG)	Consultant Clinical Oncologist, UCLH
Sue Maughn (SM)	Head of Cancer, NHS England London
Virginia Melesi (VM)	Head of Transformation Programmes, EofE Cancer Alliance
Daniel Mercer (DM)	Cancer Diagnostics Support Manager - TCST
Aisha Miah (AM)	Consultant Clinical Oncologist, RMH
Paul O'Donnell (PO)	Consultant, Radiologist, RNOH
Jonathan Perera (JP)	Consultant Surgeon, RNOH
Imran Raza (IR)	Consultant Surgeon, UCLH
Helen Ruane (HR)	Programme Manager, Wessex Cancer Alliance

Peter Simmonds (PS)	Consultant Medical Oncologist, SUHT
Dirk Strauss (DS)	Consultant Surgeon - RMH
Rachael Windsor (RW)	Consultant Paediatric Oncologist, UCLH
Julie Woodford (JW)	Nurse Consultant, RNOH
Shane Zaidi (SZ)	Consultant Clinical Oncologist, RMH