London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: 15.00 and 17.00 on Friday 7th July
Venue: MS Teams
Chair: Craig Gerrand

1. Welcome and Introductions

Apologies were received from:
Mabs Ahmed
Palma Dileo
Jonathan Hannay
Tanya Joseph
Chris Stone
Julie Woodford

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
Sirolimus for EHE - SS MA and CB to work together on this. MA leading on this. GF to ask for update	MA	Sep 22	Oct 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	Oct 23
PS review updates and add any changes to the LSESN second opinion policy	PS	Dec 22	Oct 23
VK to present the TGCT Pathway at the next meeting	VK	July 23	Oct 23
SAG to sign off diagnostic clinic specification document and principles.	SAG	July 23	17th July

Update on action re cut off age for rapid diagnostic pathway
SM confirmed that the non-site specific diagnostic clinics will accept patients from 16 years. Paediatric patients already follow a rapid pathway.

3. Tenosynovial Giant Cell Tumour referrals

RJ spoke on this topic and stated that patients that have been treated at the London sarcoma service have been coming to the Royal Marsden asking for a second opinion about clinical trials and systemic treatment and they felt their care was disjointed. VK said that there is an increasing room for oncologists to start getting involved with these diseases that have previously only been managed by surgeons. There have been clinical trials with some

molecular targeted agents that have shown positive results and therefore patients wish to explore these options. VK is working on a pathway across UCLH and RNOH regarding the management of these patients and hoping that this can be presented at the next meeting. Once the LSS pathway is in place this should reduce the number of patients being referred to RMH for second opinions. RMH recommend that patients are referred to RNOH for surgery.

Action: VK to present the TGCT Pathway at the next meeting

4. 2WW Referrals Pathway

SM – Slides were circulated with the papers showing progress on actions. The key thing is to ask the SAG to sign off the diagnostic service specification. Version 10 has been circulated for the SAG to agree. The only outstanding item and not ready to be signed off is the pathology section. SM spoke about direct access to ultrasound in primary care. There have been number of conversations and DM has met with some MSK radiologists and sonographers who have an interest in sarcomas to try and understand the issues of how they could provide a better report to be helpful for GPs. In September they will be approaching the Imaging group get them on board and obtain their support on the first part of the pathway. The other piece of work is around the 2ww forms and to finalise any changes or upgrades to the 2ww form which will direct GPs to a local diagnostic clinic. This will enable to GP to direct their patient to the nearest service for their patient which is why we are trying to place these local diagnostic services strategically all-around London in all 5 ICBs.
One of the key next steps is communication to GPs to ensure that they are aware that the diagnostic services are available. All of the diagnostic services have been asked to self-assess against the specification. There is an implementation group that meets regularly with attendance from cancer alliances , TCST and the providers to oversee the implementation.

GF - The SAG needs to agree diagnostic specification document that has been circulated as well as the principles on Slides 10 and 11.

Action – SAG to sign off document and principles. To be given deadline until 17th July and then Chairs action to sign off.

The geography of referrals and diagnostic clinic pathways was discussed. It was agreed that a GP can refer to any sarcoma diagnostic service. All diagnostic services will have a main MDT that they link into, but they will have the facility to refer to either centre for treatment as appropriate.

CPL at C&W needs to be able to link to the LSS MDT as well as the RMH MDT for patients that live closer to RNOH, for example in Harrow.

AH discussed the Kingston clinic which is working well for RMH and asked that this is not closed whilst these other clinics are being set up. EB agreed with AH and emphasised that Kingston must remain open until new pathways are introduced and embedded. She also agreed with the proposal that patients follow the pathways based on geographical location as it supports care closer to home.

Issues with pathology:
There were issues with pathology with the Croydon pathway which they are trying to avoid with the new pathways being introduced. We need to streamline the process where pathology is taken in the local centre, sent to the specialist centre and then the results returned back to the local clinic.

DSt noted that in the current specification document is states that biopsy should not be done locally without discussion with the sarcoma centre, and he does not believe that this is necessary. AH added that only the highly suspicious cases should be sent to the centre, the centres do not need to be referred all other pathology. Patients with medium/high suspicion of sarcoma should have biopsy at RNOH for LSS pathway as then they have access to WGS. Patients with low suspicion of sarcoma can have a biopsy at a local clinic.

Southampton pathway:
PS explained that they now only have one surgeon, whereas they previously had two. They are trying to set up a nurse-led diagnostic clinic. There are discussions within Wessex Cancer Alliance regarding how the 3 diagnostic clinics could be aligned (Southampton, Bournemouth, Portsmouth). The volume of cases that go through the Portsmouth service might not be big enough to meet the numbers required in the specification.
AH noted that the Portsmouth clinic and pathway is working well and so would not want this to be removed. HR added that Portsmouth numbers do not currently meet the minimum in the specification document so asked the SAG if the number of clinics need to remove in Wessex or if the SAG is happy that they have lower numbers. AH feels strongly that the clinic continues to run as patients are treated well and rapidly and are an asset to the network.

5. Sarcoma Pathways Updates

CG and GF noted that the pathways which are in progress are spinal sarcoma, including the pathway for children presenting as an emergency, head and neck, and gynae. Hopefully they will be ready to sign off at the next SAG meeting.
There was a very productive meeting with Great Ormond St, and they are close to having a pathway finalised for children which will then be distributed to A&E departments. It will help with showing where children with spinal cord compression can be referred and treated. There is an ongoing discussion about where spinal sarcomas should be treated in the London Sarcoma Service. RNOH is the commissioned centre, and some cases are going to Queen Square at UCLH therefore they are trying to define the optimal pathway for patients. From a SAG point of view and in line with the service specification, there is not enough volume for two centres in London providing complex spinal care such as for sacrectomies.

6. NHS Commissioning Update

SM – There is no change in terms of delegation. From a commissioning perspective they have now commissioned the diagnostic services at Chelsea and Westminster, Croydon and the Royal Marsden. The clinics have been provided with pump-prime funding to ensure infrastructure is in place.

7. WGS Progress Reports

CG – From an RNOH point of view they are embedding it into normal practice but there are still improvements to be made. They are reporting monthly on the number of patients that are consenting and for the last few months it has been between 20%-40%. They have also been consenting patients retrospectively and submitting these patients diagnosed in the last

few years. FA stated that there is a slight delay from the GLH to provide reports, but they have been submitting cases and they hope to catch up soon on the reporting side of things.

RJ will ask KT for an update after this meeting. Currently patients are not being consented at RMH.

SS – There was a workshop due to be held on 20th July to discuss accessing WGS in a timely manner, challenges faced etc. This has been cancelled because of the Drs strike but will be rearranged in September. There is a development at UCLH that may be relevant for the RMH patients also. The Royal Brompton can help UCLH with accessing WGS for patients that have resection of lung metastasis.

8. **Trials**

A trials list for each centre was circulated with the papers.

9. Any Other Business:

GF asked whether the SAG would like a face to face meeting in December 2023 as has previously been suggested. The SAG agreed that this would be a good idea, with the option of joining on Teams also. It was agreed that UCLH would be a good venue as it is central for all. SM added that a room at NHS England at Waterloo could be used if finding a room at UCLH is an issue.

Dates of the next meetings 2023:

- Friday 13th October 3-5pm
- Friday 8th December 3-5pm

Attendees:

Andrea Cronin (AC)	North East London Cancer Alliance
Andrea Napolitano (AN)	Consultant Medical Oncologist, RMH
Andrew Hayes (AH)	Consultant Surgeon, RMH
Ann Courtness (AC)	NHS Lambeth CCG
Avinash Pilar (AP)	Consultant Medical Oncologist, UCLH
Cerys Propert-Lewis (CP)	Sarcoma ANP, C&W
Charlotte Benson (CB)	Consultant Medical Oncologist, RMH
Craig Gerrand (CG)	Consultant Surgeon, RNOH- CHAIR
Daniel Mercer (DM)	Cancer Diagnostics Support Manager - TCST
David Sallomi (DSa)	Consultant Radiologist, ESH
Dirk Strauss (DSt)	Consultant Surgeon, RMH
Eleanor Bateman (EB)	RMH

Fernanda Amary (FA)	Consultant Histopathologist, RNOH
Franel Le Grange (FLG)	Consultant Clinical Oncologist, UCLH
Gemma French (GF)	SAG Project Manager
Georgina Wood (GW)	Consultant Medical Oncologist, UCLH
Hel Havard (HH)	Consultant Surgeon, RNOH
Helen Ruane (HR)	Programme Manager, Wessex Cancer Alliance
Jo Coleman (JC)	Advanced Nurse Practitioner, RNOH
Karen Marus (KM)	RMH
Lee Baylis (LB)	Consultant Surgeon, RNOH
Margaret Adejolu (MA)	Consultant Radiologist, RMH
Nate Hill (NH)	Workforce Lead and Senior Project Manager, RM Partners
Peter Simmonds (PS)	Consultant Medical Oncologist, SUHT
Robin Jones (RJ)	Consultant Medical Oncologist, RMH
Sandra Strauss (SS)	Consultant Medical Oncologist, UCLH
Sue Maughn (SM)	Head of Cancer, NHS England London
Vasilios Karavasilis (VK)	Consultant Medical Oncologist, UCLH