London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Meeting held between 15.00 and 17.00 on Friday 16th September
Venue: MS Teams
Chair: Robin Jones

1. Welcome and Introductions

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

Palma Dileo
Craig Gerand
Sue Maughn
Aisha Miah
David Sallomi

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 22
GF to add SUHT Service Update to beginning of next agenda	GF	Dec 21	Dec 22
GF and JW to establish patient expert reference group	GF/JW	Jun 22	
DM to send MP the list of all the providers with direct access to imaging across London	DW	Sep 22	Dec 22
GF to find out when KD can attend to present the relocation of abdominal sarcoma surgical service from RFH to UCH	GF	Sep 22	Dec 22
Sirolimus for EHE - SS MA and CB to work together on this	SS/MA/CB	Sep 22	Dec 22
GF to add second opinion policy to next agenda	GF	Sep 22	Dec 22
GF looking for volunteers for SAG Pathway Programme	GF	Sep 22	Dec 22
GF to send out final NF1 document for completeness	GF	Sep 22	Dec 22

3. C the signs

Miles Payling who works for C the Signs with Bea Bakshi spoke on her behalf. MP went through how the C the Signs system works. There are two basic function - the risk assessment side of the system and the practice dashboard. The practice dashboard is the follow up mechanism so that you can track patients through to see whether they are diagnosed with cancer or not or safely excluded. If you suspect cancer, you can quickly launch the risk assessment tool within the context of the patient. It's integrated with all the primary care electronic health records. MP then went through how you use the system regarding identifying the symptoms which will then generate the pan London 2ww referral form. Certain fields are mandatory and must be competed for the user

to submit the form. The system also knows the availability of access to local diagnostics in each area.

MP said that they can make amendments to this system. DS showed some concern as referrals are high and not sure if this will help the cause.

Action: Daniel mercer to send MP the list of all the providers which direct access to ultrasound across London so that he can check this against the work that he has been doing

MP also presented data showing only 2.6% of sarcoma 2ww referrals are then patients who are diagnosed with a sarcoma and 48.6% of patients diagnosed with a sarcoma are detected through other 2ww pathways. The most common features in a presentation when a sarcoma pathway is recommended are bone pain and unexplained lump increasing in size.

4. Update from Southampton

Deferred to next meeting as PS was not in attendance.

5. Relocation of abdominal sarcoma surgical service from RFH to UCH

Deferred to next meeting as KD was not in attendance.

Action: Gemma to find out when KD can attend to present this.

6. National Cancer Patient Experience Survey Results

KM presented the Royal Marsden Survey results. The Marsden scored higher than average expected range in 22 questions. For 4 questions, the Marsden scored less or below the national range and these included that the patient found it easy to contact their key worker and that the patients' family/carers were involved in decisions about their care. A lot of the poorer scores can be explained by COVID and the restrictions that were in place at that time. Questions around diagnostic tests scored well, in high 90s and the CNS questions did very well. KM stated that overall the results are about the same as the last survey that was reported. They must take into consideration the impact that COVID still had on healthcare last year. Hoping for better results from the next survey.

AS from UCLH spoke regarding their survey results. For 2021 there were 17 results higher than the national sarcoma average, 2 which scored the same and 34 which were worse. Questions in regarding CNS care and staff providing relevant information and care all scored of 90-100%. AS went through points on what they are doing to get these results. 1. Give CNS/Keyworker details, 2. Patient pack with all information, 3. Consultant documenting the CNS/Keyworker at every first meeting with patient and 4, Post chemo call. Results below national average included family or carer involvement in decisions about treatment and having an opportunity to talk with the team. This was scored so low due to COVID restrictions but hoping for better results next year as they are now encouraging family and carers to attend the outpatient appointments. They are also trying to make sure they are present during the ward rounds. Other results below national average included patients being able to discuss their needs and concerns prior to treatment and patients being able to discuss options for managing the impact of any long-term side effects. The UCLH

sarcoma team have therefore have now started HNA's to help this and their ANP has started the end of treatment consult, which they hope will help with these results and improve the quality of care for patients. Overall UCLH experience scored 9.1 compared to a national average of 8.4.

JW spoke for RNOH. The pandemic has had an impact on patients having access to doctors, opportunities to discuss fears. RNOH scored better around actual giving of diagnosis and sharing the diagnosis which was prioritised during the pandemic to make sure they could do that as sensitively as possible. Patients reported quite a low level of cancer care reviews by GP. They have introduced end of treatment summaries prompting the GP to undertake cancer care review.

7. 2WW Pathway

JW stated that both centres are continuing to struggle with the volume of 2WW referrals. Daniel Mercier works with Liz Price from the Transforming Cancer Services London cancer team. They have been looking at the diagnostic pathway at a whole SAG and the specific issues with ultrasound access and developing some of the sarcoma diagnosis services that exist in some of the outlying hospitals and regions.
AH stated that the Marsden and way below their cancer waiting times targets. The linked diagnostic centres which are currently operating are Croydon, Kingston, and Brighton, all of which provide good services for their CCG's, but there's great geographical patches which are not covered and so those referrals (which are substantial) come to the Marsden. The Marsden are trying to engage another centre (Chelsea & Westminster) that will run a diagnostic service on patients that the Marsden have originally triaged, like a clinical triage system which allows them to reject patients based on an ultrasound report by saying they think they can be managed elsewhere. The Marsden can then see the known and high-risk sarcomas and lower risk sarcomas would ideally go to Chelsea and Westminster. This is not in place yet but is in process of sorting this out and hopeful to start at the end of September. Currently patients who are low risk are put on a waiting list, so they are on the cancer pathway, and they receive a letter that states this. The Marsden surgeons are running waiting list initiative clinics.

TJ discussed the inconsistency across the network as RMH are rejecting patients without imaging and RNOH have not had sign-off from NCL to do that and so it is not equitable for patients. RNOH are also being referred patients who have been rejected from the Marsden. Not all CCGs have Community Diagnostic Clinics set up and so RNOH have been told on that basis they can't reject referrals without imaging.

8. Mutual Aid

- Not Discussed

9. Referral principles across the SAG

- Covered this during the 2WW discussion

10. Sirolimus for EHE

MA spoke regarding the use of sirolimus in epithelioid hemangioendothelioma (EHE). They do not have access to it, it is not approved by NHS England and now they are trying to get funding locally for this from using the high-cost drug function committee and it is being signed off by the clinical

director which is not sustainable long term. Cost of drug is £600 a month. MA suggested a joint application to NHS England about long term funding for this. SS suggested we need a strategy, it's a lot of pressure and work, it's a national problem and maybe the BSG could get involved. Charlotte Benson said she would happily work with someone at UCLH to do this.

Action: Sandra, Mabs, Charlotte to work on an application together and link in with the EHE patient group

11. Children and TYA Service Specifications

Deferred to the next meeting**.**

12. WGS Progress Reports

AF stated that they have appointed a new genomics coordinator at RNOH called Katie Butler who is settling into the team and will be going back and consenting patients retrospectively as well as setting up processes for consenting patients prospectively.

Action: Robin to get an update on WGS at RMH from Khin

13. Trials

RJ noted that the SAG should focus on the trials that are only open at one site so that we can help with recruitment.

SS said the NIHR are trying to close lots of trials now once recruitment numbers are met.

14. NHS Commissioning Update

Defer to next meeting

15. Any Other Business:

Charlotte Benson said that for the next meeting can we discuss the second opinion policy because they have had a few issues with second opinions coming across and then setting patient expectations of being seen. It will be good to reaffirm that policy and to discuss it at the next meeting.

Action: GF to add second opinion policy to agenda

HH gave a reminder about the EMSOS conference taking place in London next month. Would be great to have as many of the SAG team there as possible. Visit website, sign up and come to the dinner.

Gemma French is looking for volunteers to lead on the pathways for SAG work programme. There are several pathways: Bone, soft tissue, breast, skin, GIST, urology, thoracis, spinal. If anyone would like to volunteer to lead on the pathways, they can let Gemma know.

Action: Any interested of volunteers to contact Gemma

Dates of the next meetings:

- 9th December

Attendees:

Mahbubl Ahmed (MA)	Consultant Clinical Oncologist, UCLH
Fernanda Amary (FA)	Consultant Histopathologist, RNOH
Charlotte Benson (CB)	Consultant Medical Oncologist, RMH
Jo Coleman (JC)	Advanced Nurse Practitioner, RNOH
Rebecca Exton (RE)	Consultant Surgeon, Salisbury Trust
Adrienne Flanagan (AF)	Consultant Histopathologist, RNOH
Gemma French (GF)	SAG Project Manager
Jonathan Hannay (JH)	Consultant Surgeon, RMH
Heledd Havard (HH)	Consultant Surgeon, RNOH
Andrew Hayes (AH)	Consultant Surgeon, RMH
Nate Hill (NH)	Workforce Lead and Senior Project Manager, RM Partners
Katrina Ingley (KI)	Locum Medical Oncologist, UCLH
Robin Jones (RJ)	Consultant Medical Oncologist, RMH - CHAIR
Tanya Joseph (TJ)	Divisional Head of Operations, RNOH
Vasilios Karavasilis (VK)	Consultant Medical Oncologist, UCLH
Franel Le Grange (FLG)	Consultant Clinical Oncologist, UCLH
Kelly McKibbin (KM)	Clinical Nurse Specialist, RMH
Lucy McLaughlin (LM)	Head of Cancer Commissioning, NCL
Daniel Mercer (DM)	Cancer Diagnostics Support Manager - TCST
Aisha Miah (AM)	Consultant Clinical Oncologist, RMH
Maria Michelagnoli (MM)	Consultant Paediatric Oncologist, UCLH
Miles Payling (MP)	C the Signs
Emily Pegg (EP)	Deputy Divisional Manager - UCLH
Ariana Barradas da Silva (AS)	Clinical Nurse Specialist, UCLH
Dirk Strauss (DS)	Consultant Surgeon - RMH
Sandra Strauss (SS)	Consultant Medical Oncologist, UCLH
Vanessa Topp (VT)	Deputy Director for Cancer, RMH
Julie Woodford (JW0)	Nurse Consultant, RNOH
Shane Zaidi (SZ)	Consultant Clinical Oncologist, RMH