North Central London Cancer Alliance

RM Partners West London Cancer Alliance
Hosted by The Royal Marsden NHS Foundation Trust

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Meeting held between 15.00 and 17.00 on Friday 17th June
Venue: MS Teams
Chair: Robin Jones

1. Welcome and Introductions

CG welcomed members to the meeting and noted the following **apologies**:
Charlotte Benson
Angshu Bhowmik
Julia Chisholm
Andy Hayes
Anisha Patel
Chris Stone
Khin Thway
Rachel Windsor

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 to add SUHT Service Update to beginning of next agenda	GF	Dec 21	Sept 22
GF and JW to establish patient expert reference group	GF/JW	Jun 22	Sep 22
Members of the SAG who are interested in joining the task and finish group for the sarcoma faster diagnosis pathway to contact Liz Price	All	Jun 22	Sep 22
RP to chase KT for WGS RMH numbers	RP	Jun 22	Sep 22
GF to circulate neurofibromatosis document. All to give comments	GF/all	Jun 22	Sep 22
Trials to be added to the agenda of the next meeting	GF	Jun 22	Sep 22

JW stated that the new SAG project manager has been appointed. Together they would like to work with the post holder to set up an expert reference group involving a couple of the patients from each of the three centres. Meetings would be held with the patients being present. One of the patients could come to the SAG meeting and speak on behalf of the expert group rather than having all patients on the call. There are two factors to consider; the impression of the person attending the SAG meeting and the impression of the SAG members having a patient participating in the meeting. JW has spoken to GF whether this is something we could do moving forward and to develop an expert patient group to take other developments to or documents that we would like them to review.

RJ and BS agreed that this is a very good idea. BS stated that teams' meetings have been a very

good access point and now that we are doing this it will be easier for patients to be part of it. PD also said that it would be great to empower the patients, give them a voice in matters and agreed with BS regarding team meetings being great to get a collective group together.

JW then ended this conversation with stating that she will pick this up with GF and they will contact Suzie Hudson who is the Macmillan Personalised Cancer Care Project Manager, and they will make connections with other services including Southampton and see if they can get something off the ground and then use that group to report patient feedback to this meeting.

Action: GF and JW to establish patient expert reference group

Children and TYA Service Specifications – Deferred until the next meeting

3. Essex Diagnostic Clinic

KM attended the SAG to discuss the Essex Diagnostic Clinic. Jeremy initially had discussions with KM in 2015/16 re setting up a diagnostic clinic in Essex. Not much progress was made, however, this has been brought to discussion again recently on the back of the establishment of the new Integrated Cancer Systems (ICS's). The proposal that has been submitted and likely to be agreed and funded is for a clinic to be set up on one Essex site in Southend for an ultrasound clinic (once a week). GF supplied data which were used for the business case. There are two MSK radiologists who could run these clinics. Pathology capacity is poor and so they do not plan to do a biopsy at this point. They will do ultrasound, ultrasound triage and then refer to RNOH as appropriate. It has been clarified with Liz Price that this can be locally commissioned as a diagnostic pathway and is not part of specialised commissioning. There will be a CNS running the clinic, Jo Hall. There will be a catchment area of 1.3 million people.
There will need to be an audit and mentorship of the use and interpretation of ultrasound for at least the first 6 months/ 1 year.
They could do a biopsy and send to RNOH for review or not do the biopsy at all.
Pete Gethin from radiology in Essex attended and explained that there are two consultant radiologists interested in getting involved in the sarcoma pathway and they have an additional ultrasound room available for this. Job plans will need to be amended to fit the sarcoma work in.
DS would be very supportive for the diagnostic clinic to have biopsy capacity also as it is essential. A lot of the soft tissue lumps indicate the possibility of several different diagnoses from ultrasound. He would recommend that if a clinic is being set up to consider incorporating a biopsy service also. He explained that this is how RMH do this with their diagnostic centres in Brighton and Norfolk - a radiologist does the ultrasound guided biopsy (and will ask RMH for advice if needed), the pathologist looks at the biopsy and if suspicious of sarcoma they send to RMH. PS explained that this happens at SUHT also and so he would echo DS's comments to have a biopsy service in the clinic if possible.

KM will speak to the pathology department to see if this could be added in the future

It is unclear whether 2WWs will be referred to this clinic or whether this will work like the pathway being set up in North Central London (NCL) where patients will be referred there for ultrasound and if suspicious of sarcoma following ultrasound review this will then be sent as a 2WW to RNOH.

KM to email SM re how the clinic will work in terms of 2WWs and she will check this

SUHT also have a pathway where GPs refer to them for ultrasound of soft tissue lumps and if this is suspicious of sarcoma the radiologist/radiographer will fast track the patient onto the 2WW pathway and they will go for review in the Sarcoma MDT as well as requesting an MRI if appropriate.

DS concluded by saying the key components to make this work are 1. A CNS/ANP to take ownership of the pathway 2. A keen and willing radiologist 3 good links with the sarcoma unit where patients can easily flow from the diagnostic unit to the sarcoma centre

4. 2WW Pathway

Liz Price has been supporting the SAG and she has prepared a report which SM will present on behalf of Liz. JW and Vanessa have met recently to discuss the difficulties in meeting the demand of the two week wait referrals. JH said that they are struggling to keep abreast of even the referrals they do triage which are highly suspicious of sarcoma. RMH are receiving 120-140 two week wait referrals a month of which between 15-17% have not even filled the form incorrectly or do not have imaging and so are rejected outright. Some which have imaging are sent straight to diagnostic MDT, half of these then come back to clinic to be seen to be biopsied. Less than 10% of the referrals received are diagnosed with sarcoma although other cancers such as lymphomas are being picked up. DS added that for the next 2/3 weeks his clinics are fully booked with confirmed sarcoma cases so it is very difficult to delay these cases for diagnostic work where only 10% will have sarcoma. The confirmed sarcoma cases must take priority.

5. Covid-19

EP said that like everybody they have changed their visiting rules. They have been more flexible however they have had a COVID outbreak on the oncology ward, so it has been closed. Patients are still told to wear a mask and there is only one visitor permitted per patient.

PS stated that in Southampton they are heading to some sort of normality but still required to wear masks in clinics and on the oncology wards although the rest of the hospital has moved away from that. They had been doing PCR on all patients coming for chemotherapy, but they have eased off on doing that. Patients are now just doing their own lateral flow test before coming in. Patients are being seen normally with family members as pre COVID.

TJ said that there will be an announcement on Monday at RNOH to say that there will be no mask wearing at all for patients or staff. However, if either party wishes to wear one that is also fine. In terms of visitors, all visitors will be allowed back to two per day.

VT said that their policies at RMH are like RNOH and UCLH. Masks are not necessary in the general hospital areas but are going to be used on a patient-by-patient risk assessment if they are high risk, not just for COVID but other respiratory diseases.

6. NHS Commissioning Update

SM presented a paper that was written by Liz price regarding an update on the project work that she has been doing. Objectives of the project are 1. Baseline mapping of London and southeast London sarcoma services against the national sarcoma service specification. 2. Map GP Direct access diagnostics (urgent ultrasound) in London. A GP that works for Cancer Research UK is

working with Transforming Cancer Services Team (TCST) to support this work and he is aware of the challenges faced. 3. Development of action plan for SAG.

The delegation of specialised services to integrated care boards (ICB) will commence from April 2023. The national team have now published a road map listing all the specialised services and the proposals for each. Both bone and soft tissue sarcomas are pathways that they think are not immediately ready for delegating to ICB. There is more work to be done at a national level before there is any decision made around what is happening in terms of sarcoma commissioning. Therefore, there is no change in the short to medium term for sarcoma.

The National Cancer program are working on faster diagnosis standard timed pathways and are thinking of developing one for sarcoma this year. If anyone is interested in joining the task and finish group with the National Cancer program about developing the sarcoma FDS timed pathway they can do.

Action: Interested members of the SAG to contact Liz Price

CG went through the SAG workplan which details the work the SAG needs to focus on. The SAG agreed with this workplan

7. WGS Progress Reports

FA stated that they have done 15 cases so far this year. CG added that it is embedded in the pathway at RNOH, and they have financial support for the next year to get people consented as part of normal practice.

Action: RP to chase KT for RMH numbers

PS stated that SUHT have consented 2 patients so far.

8. Governance

No SAG governance issues flagged.

HH asked whether we should manage the cases who have been inappropriately excised out of the service in a uniform way across the SAG.
DS feels that writing overly critical letters back to referrers can be unhelpful and put people off referring. He suggests that a supportive and educational letter is written suggesting a biopsy is taken before excision and offering advice. At RMH they write to referrers when this happens (often calling beforehand). At RNOH/UCLH these cases are audited and discussed but not often communicated back to the referrer.

9. Any other business

Neurofibromatosis pathway
GF will circulate a neurofibromatosis pathway document from Roz Ferner. Telephone numbers and contacts at RMH can be corrected. Other comments to be sent to GF.
SS clarified that this should be a pathway for both ways to and from GSTT. Patients with MPNST should have whole genome sequencing so this has been added to the pathway.

At RMH referrals are received by letter rather than a standard referral form.

Clinical Trials

Trials lists are circulated with the papers, but they are no longer discussed. There used to be a separate trials meeting after the SAG meeting with the oncologists. It would be useful if the trials teams highlighted the trials only open on one sight and those that are in set up that need support. Trials and research are on the SAG work programme.

PS noted that it would be helpful if some of the more straight forward trials are offered outside of the sarcoma centres so that patients do not have to travel.

SS noted that the payment flows for trials are complicated. Covid has changed the ways in which we work so we should contact NCRI and ask if there are any new models of working.

PD asked if trials could be run through the British Sarcoma Group. This would need further discussion.

Action: Trials to be discussed further at the next meeting – those open only at one site and those in set up

Face to face SAG meeting

It was suggested that there should be an in person meeting at Christmas

Dates of the next meetings:

- **16th September**
- **9th December**

Present:

Mabs Ahmed (MA)	Consultant Clinical Oncologist	UCLH
Fernanda Amary (FA)	Consultant Histopathologist	RNOH
Jo Coleman (JCo)	Advanced Nurse Practitioner	RNOH
Palma Dileo (PD)	Consultant Medical Oncologist	UCLH
Gemma French (GF)	Sarcoma Improvement Manager	UCLH/RNOH
Peter Gettings (PG)	Clinical Manager Ultrasound	MSEFT
Craig Gerrand (CG)	Consultant Surgeon	RNOH
Jonathan Hannay	Consultant Surgeon	RMH
Hel Harvard (HH)	Consultant Surgeon	RNOH
Amanda Heeralall (AH)	Specialised Commissioning Programme Lead	RM Partners
Nate Hill (NH)		RM Partners
Katrina Ingley	Locum Medical Oncologist	UCLH
Robin Jones (RJ)	Consultant Medical Oncologist	
Tanya Joseph (TJ)	Divisional Head of Operations	RNOH
Vasilios Karavasilis (VK)	Consultant Medical Oncologist	UCLH
Krishnaswamy Madhavan (KM)	Consultant Clinical Oncologist	MSEFT
Sue Maughn (SM)	Head of Cancer	NHSE London
Daniel Mercer	Cancer Diagnostics Support Manager	TCST
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Maria Michelagnoli (MM)	Consultant Paediatric Oncologist	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
Vanessa Topp (VT)	Deputy Director for Cancer	RMH
Julie Woodford (JWo)	Nurse Consultant	RNOH