NHS 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 9th December
Venue: MS Teams
Chair: Craig Gerrand

1. Welcome and Introductions

CG led meeting and welcomed SAG.

Apologies:
Mr Jonathan Hannay - Consultant Surgeon, RMH
Nicola Beech – Programme Director, Surrey and Sussex Cancer Alliance
Myles Smith – Consultant Surgeon, RMH
Lucy McLaughlin – Head of Cancer Commissioning, NHS North Central London
Gail Murray – Commissioning Manager, East of England Cancer Alliance
Paul O'Donnell - Consultant Radiologist, RNOH
Rachael Windsor Consultant Paediatric Oncologist, UCLH
Angela Wong, Chief Medical Officer, North East London Cancer Alliance
Fernanda Amary, Consultant Histopathologist, RNOH
Amanda Heeralall, Specialised Commissioning Programme Lead, RM Partners

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 RP and PD to speak to Beatrice and pick up on this. GF to forward him email trail with Beatrice and also original email of issue raised by Sarcoma UK	RP/PD	Mar 21	Mar 23
GF and JW to establish patient expert reference group	GF/JW	Jun 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	Mar 23
Sirolimus for EHE - SS MA and CB to work together on this	SS/MA/CB	Sep 22	Dec 22
PD to Update the chemotherapy algorithm with help from SAG colleagues	PD	Dec 22	Mar 23
Workforce to be added to a future agenda once more detailed data available	GF	Dec 22	Mar 23
CB, PS and PD to review and update the LSESN second opinion policy	CB, PS, PD	Dec 22	Mar 23

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

- Deferred to next meeting. Abdominal surgeons to be invited to the next meeting.
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4. Update from Southampton

Peter Simmonds updated that they are currently having discussions in the Wessex Cancer Alliance about diagnostic pathways. Tony Skene, a surgeon who runs the diagnostic service in Bournemouth is planning to retire soon and there is no obvious candidate to take over that service in Bournemouth. They are negotiating within the alliance to try see if they can get some resource to expand the diagnostic service in Southampton so that they can deliver a pan alliance diagnostic service across the Dorset, Hampshire and West Sussex patch. There are 3 diagnostic services in operation - Southampton, Bournemouth, and Portsmouth, and they are looking to try and consolidate that into one or two diagnostic services within the next year. This would not involve Southampton taking all the patients but rather overseeing the clinics elsewhere.

They have secured some extra funding from Macmillan for an additional clinical nurse specialist post so they will have 3 nurses working 4 days a week which is much needed extra support.

AH asked for clarification if all radical radiotherapy will take place at Southampton with palliative radiotherapy available at Bournemouth and Poole. PS noted that there is some flexibility depending on patient circumstances.

5. Feedback from Sarcoma Workshop/Commissioning Update and Network TWR referrals

AH gave some background information to give context to the current situation. For many years the Marsden has been seeing large numbers of benign patients within essentially the four surgeon treatment unit, seeing a far greater number of patients than their capacity. Previously the RMH triaged GP referrals and if there was no ultrasound the referral would be 'rejected' unless there was an obvious clinical need. The RMH clinicians would also read the ultrasound reports of patients referred with imaging, make an assessment and write to the patient if they felt confident that the patient didn't have a sarcoma. Despite this there were still more referrals than capacity and so an additional level of triage was introduced where referrals were categorised on urgency of needing to see patients and patients were not seen within 2 weeks.
There have recently been 2 serious incidents and 2 patients died on a pathway of non-sarcomatous malignancy but with a referral based on their index lesion which would have been recognised. On the basis of this RMH were forced to call a critical incident in November and they are no longer triaging referrals and writing letters to patients to say that the patient is at low risk of a sarcoma.

Vanessa Topp explained that the RMH has not been meeting the 2WW target for some time but now that the clinicians are not triaging the demand and capacity mismatch has grown. Patients are currently seen at about 5-6 weeks after referral and so RMH have been asking for mutual aid. The local hubs at Chelsea & Westminister and Croydon are taking on more referrals and Sue and team coordinated the workshop with the long-term plan of setting up more diagnostic hubs.
TJ expressed concerns re the current situation at RMH and the knock-on effect at RNOH. RNOH are already seeing an increase in referrals because of an alert that is on the GP systems re capacity issues at RMH. RNOH are trying to clear the RMH backlog but do not have the capacity to see all of the sarcoma referrals which would have gone to RMH.

Sue and the team have shared a paper that has been written in conjunction with RMH and went to the London Region specialist oversight group, the Southeast region was also part of the discussions. There are several issues to tackle including the acute capacity issue and growing backlog at RMH and the

mutual aid across the 2 centres. A pathway workshop was facilitated at short notice because of this acute issue. There is now interest at a regional medical director level in London and in the South East region.
Following review of the new cancer waiting times guidance all 2WW referrals coming into the two centres have to be managed the same way – all referrals need to be accepted and following review of ultrasound there needs to still be a conversation with the patient before discharge. Cerys noted that for her straight-to-test clinic she speaks to all patients first when she receives the referrals and takes their clinical history. There has been communication to all primary care providers across the London, South and East region re the importance of ultrasound before referral and the necessity to have a good report from the ultrasound. It was agreed in the workshop that the aim is to expand the number of diagnostic clinics across the region. Sue and team have already had discussions with Kent and are meeting with Essex soon. The SAG needs to think about how many clinics are needed and where they need to be. Which clinicians need to be involved in the clinic and what is a minimum number of patients that should be seen to ensure that the quality of the clinics is maintained. They are also working with the regional ultrasound leads and have asked them to look at a protocol for sonographers who are doing suspected soft tissue sarcoma ultrasounds with an algorithm of 4 scenarios.
The SAG discussed the requirements of a diagnostic clinic with those already running clinics and it was agreed that a surgeon, radiologist(s)and/or sonographer, a nurse specialist and an administrator was required. It was agreed that 10-20 patients a week should be a minimum number per clinic.
DS shared the following useful information: To establish a local diagnostic service, the following is required:

- Local lead consultant to provide oversight and clinical decision making for the 2WW cases (radiologist or surgeon with general/plastic/orthopedic surgical training).
- Advance nurse practitioners/junior doctors/health care workers involved in assessment of patients
- Ability to provide ultrasound guided biopsies on site
- Access to MRI
- Access to local pathology to report core needle biopsies, excision biopsies and local excisions.
- Administration support/patient pathway monitor/coordinator

2 LSESN Second Opinion Policy

The policy hasn't been revisited since 2018 and CB has recently received a complaint when a patient was referred to her from UCLH and she followed the policy and wrote back to the patient as there wasn't an alternative treatment to offer. CB therefore feels that we need to be clear about what we offer, and PD agreed and asked how we could make sure that the patient is aware of the policy. The team agreed that this was important and that it should be reviewed and signed off. The main reason that we would transfer patients from one centre to another is if one of the centres offered a trial that this other doesn't. It can get complicated when the patient sees a consultant privately.

Patients will often call Sarcoma UK for advice on second opinions and so it may be worth discussing this with them.
KI also wondered if there is something on the Marsden website regarding a second opinion.
PS suggested that the policy is updated to include SUHT also.
The policy is on the LSESN website and mentioned on the referral form

Acton: CB, PS and PD to review and update the LSESN second opinion policy

7. WGS Progress Reports

KT gave a brief update for the Marsden. The lab has made a lot of inroads with molecular pathology colleagues to get infrastructure set up. Essentially the infrastructure is in place but as it is a multi-speciality lab they cannot go live until it has been agreed by the other specialities. Clinical consent is a separate issue.

CG spoke on behalf of RNOH and stated that they are making progress. They are trying to get through a backlog of patients who haven't been consented but whose tissue is frozen. Katie Butler who is working at RNOH for a year is retrospectively consenting these patients and trying to embed the consenting process as part of normal practice. In terms of GTAB, results are coming through and clinicians have been encouraged to attend the GTAB to try and get a better understanding of what the reports really mean. Patients are now asking about WGS and asking about the results and the differences it may make to their treatment.

SS has recently attended a meeting at the house of commons to understand and talk through some of the hurdles of implementing WGS across the country. Finding the resource to implement this is challenging. Sarcoma UK are now encouraging patients to ask about it which puts a pressure on the centres to deliver this.

8. Trials

The list of open trials has been circulated with the meeting papers.
PD mentioned that communication in regard to trials is always quite clear between the centres and noted to patients. SS mentioned that the Afatanib for Chordoma trial is closed which means that there are no chordoma trials in the country. She has had a few queries re applying for compassionate access for this drug and wonders whether the SAG should be working together on access to drugs for patients and national policies for this. This is currently done on an ad hoc basis for the SAG. RJ also stated that one of the things tying in with the workload is that the RMH have a lot of patients on trials from all over the country and patients on compassionate access programs from all over the country. It seems to be very difficult for people to get compassionate access programs open at their hospitals and even to get clinical trials open. Big centres such as Birmingham are not opening certain trials and that's very worrying. He suggested that maybe we can try help in terms of getting trials and compassionate access programs open elsewhere in the country. PD stated how difficult it is getting compassionate access at UCLH and a national policy for this would be very helpful.
PD noted that the chemotherapy algorithm needs updating, and compassionate access drugs could be added to this

Action: PD to update the chemotherapy algorithm with help from SAG colleagues

All of these issues re access to chemotherapy and trials could be discussed at the upcoming national SAG Chairs forum and at BSG. It was felt it was important to raise this at a national NHS England level. SS will try to do this through her new clinical lead role.

9. Any Other Business:

Daniel and Liz have been mapping the workforce data across the SAG. GF summarised their findings and asked what the SAG thought about the data. There are no gaps in consultant surgeons from January next year, although three posts were previously covered by locums with difficulty to recruit. There are two oncologists down and no radiology issues. There are histopathology issues and unsuccessful recruitment. No issues for physio and OT, no cancer support worker at the Marsden. Difficulties recruiting to ANP posts. GF asked if this reflected what was felt about workforce across the SAG.
IR raised the risk re abdominal surgery as currently Arj Shankar is the only surgeon operating on retroperitoneal sarcomas at RFH and IR is still a locum post.

PS stated that the SAG is wider than just London so GF will feed that back.
AH asked that this is discussed in detail at a future meeting, showing what resources are currently in place (i.e. PAs for each post) as well as what gaps there are, and it is done across the SAG and not just in London.

Action: Workforce issues to be added to agenda.

Dates of the next meetings 2023:

- Friday 17th March 3-5pm – CHANGED TO 31ST MARCH
- Friday 16th June 3-5pm
- Friday 15th September 3-5pm
- Friday 8th December 3-5pm

Attendees:

Mahbubl Ahmed (MA)	Consultant Clinical Oncologist, UCLH
Lee Bayliss (LB)	Consultant Surgeon, RNOH
Charlotte Benson (CB)	Consultant Medical Oncologist, RMH
Jo Coleman (JC)	Advanced Nurse Practitioner, RNOH
Mimi Cvitanovic (MC)	Cancer Pathway Manager, RNOH
Palma Dileo (PD)	Consultant Medical Oncologist, UCLH
Gemma French (GF)	SAG Project Manager
Craig Gerrand (CG)	Consultant Surgeon, RNOH, CHAIR
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
Tanya Joseph (TJ)	Divisional Head of Operations, RNOH
Franel Le Grange (FLG)	Consultant Clinical Oncologist, UCLH
Cerys Propert-Lewis (CPL)	Advanced Nurse Practitioner, ChelWest
Sue Maughn (SM)	Head of Cancer, NHS England London
Virginia Melesi (VM)	Head of Transformation Programmes, East of England Cancer Alliance
Daniel Mercer (DM)	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)	Consultant Surgeon, RNOH
Imran Raza (IR)	Locum Consultant Surgeon, UCLH
Peter Simmonds (PS)	Consultant Medical Oncologist, SUHT
Helen Ruane (HR)	Programme Manager, Wessex Cancer Alliance
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
Georgina Wood (GW)	Consultant Medical Oncologist, UCLH
Julie Woodford (JW)	Nurse Consultant, RNOH
Shane Zaidi (SZ)	Consultant Clinical Oncologist, RMH