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

NHS
North Central London
Cancer Alliance

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Meeting held between 15.00 and 17.00 on Friday 7th June.
Via MS Teams

Chair: Robin Jones

1. Welcome and Introductions

Apologies were received from:
Lucy McLaughlin
Rob Pollock
Sean Symons
Kelly Spiller
Nicholas Hyde
Juliet Gray
Jennifer Harrington
Charlotte Benson
Andrea Cronin
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
Sirolimus for EHE – SS, MA and CB to work together on this. MA leading on this. June 24 – RMH and UCLH pharmacists met last month and have started working on this again.	MA	Sep 22	Sep 24
PS to send updates review updates for the LSESN second opinion policy.	PS	Dec 22	Sep 24
SAG to write to host Trusts where oncologists have no CNS support (Maidstone oncologist delivering palliative chemo and radiotherapy has no CNS support)	CG/RJ	Oct 23	Jun 24
RW to lead on review of paediatric thoracic pathway	RW	Mar 24	Jun 24
SM/DB to find out if there is an orthopaedic network within the elective programme region for CG to discuss hand/foot referrals	DB/SM	Jun 24	Sep 24
SM to escalate to Simon Barton that there is still a gap in services at East of England and South East Region and the impact of the Kingston service closing	SM	Jun 24	Sep 24
SM to contact Barts re out-of-area referrals	SM	Jun 24	Sep 24
SD to send CG some examples of patients that she has needed to chase for outcomes	SD	Jun 24	Sep 24
SM to provide PS with commissioning contact in the South East Region who are looking at the issues and can help support	SM	Jun 24	Sep 24

RJ and CG to write to Cally Palmer and Simon Barton re the issues in the current hub and spoke model	RJ/CG	Jun 24	Sep 24
SM to forward Kingston correspondence to RJ and CG	SM	Jun 24	Sep 24

3. Diagnostic Clinics:

a. Clinical criteria/standards of care

It would be useful to define which patients should go to each hub. Hand tumours and nerve sheath tumours have been historically referred to RNOH. It may be useful to have a dedicated site in the future for hand and forearm tumours which require involvement from the plastic surgery and rehab teams. NP from C&W noted that they have a hand team on site but they are unable to see patients urgently and so it is then difficult for patients who are on a cancer target. CPL noted they are seeing an increasing number of hand/ suspected giant cell tumours.
It would be good to have an SOP so that the diagnostic spoke sites know where to refer patients.

Action: SM/DB to find out if there is an orthopaedic network within the elective programme region for CG to discuss this with

b. Update from each spoke

Croydon: KP who is a Consultant Radiologist at Croydon gave some feedback: they are a small unit in terms of the size of the team. Referrals have increased significantly, and it is difficult for the endocrine surgeon to triage the increasing number of referrals. Imaging facilities are in place to do biopsies but they do not have the facility to do this in clinic so there are limitations to the service which can be improved. Pathology has been a big issue for Croydon as they have to wait several weeks before results are ready.
NH added that Croydon have appointed an ANP after advertising for this post 3 times so this should help with the workload.

Chelsea and Westminster: NP, Consultant Surgeon mentioned they have similar issues to Croydon – a small team with a high volume of patients (approx. 1200 per year). A lot of patients are coming from Northwest London, and also places further afield such as Essex, Kent, Hertfordshire. They do not have the facilities to do a one stop clinic and so patients have to travel long distances more than once. NP displayed a map showing the geographical spread of referrals.
CPL noted that some patients are being referred to multiple places at the same time e.g. RNOH and ChelWest.

SM met with East of England and South East Region last week and are pushing for them to improve their referral pathways for their patients. Norfolk & Norwich and Cambridge are the only clinics in these areas at the moment.

Action: SM to escalate to Simon Barton that there is still a gap in services at East of England and South East Region and the impact of the Kingston service closing

Brighton: There was no representative from Brighton however DS noted that it is working well. They have 5 radiologists, a nurse, an MDT coordinator and it is a fully established diagnostic centre.

Barts: SD, ANP from Barts gave an update who have had around 208 referrals since going live on 6th March and only a small percentage (approx.15%) have gone to RNOH for further reviews including two malignancies. They seem to be getting their ultrasounds quickly due to having a dedicated sonographer. They have MRI, are reviewed in an MSK MDT and then referred onwards if needed. Bone sarcoma referrals and those out of the North East London area have been rejected. They are referred bone lesions which need CUP work-up – if they are in area they see the patients as they have a CUP MDT too, however if they are out-of-area they suggest referral to a local CUP MDT.
SM explained that Barts should be seeing patients from all areas, but she will speak to Barts about this separately.

Action: SM to contact Barts re out-of-area referrals
Action: SD to send CG some examples of patients that she has needed to chase for outcomes

Southampton: PS updated that SUHT face similar issues to those already described. They have had approx. 60 two-week wait referrals so far this year with many lipomas. The service is fragile as there is only one surgeon. They have had funding for the last year from the Wessex Cancer Alliance for a sarcoma pathway navigator which has been an extremely helpful post and they presented data on that at the BSG earlier this year. They are trying to obtain funding from the Trust for the post to continue but have so far only secured funding for an additional 3 months and they feel that the sarcoma diagnostic service would not be sustainable if this post is not secured. Longer term they need a second surgeon and so are in discussions to obtain funding for that. They are screening the ultrasound referrals in a virtual diagnostic clinic similar to the previous RMH model which leaves them susceptible to the same issues the RMH had.
PS noted that in Southampton all patients referred locally for ultrasound can referred for MRI the same day/a few days later and put on the urgent suspected cancer pathway by the ultrasonographer/radiographer. This doesn't happen at all cancer units in the region.

Action: SM to provide PS with commissioning contact in the South East Region who are looking at the issues and can help support

Wood Green: TJ updated that Wood Green will be going live on 17th June, for diagnostics only, for example if a patient has had an ultrasound and requires an MRI they can be referred to Wood Green for that subsequent imaging. It is a pilot for 6 months. The comms need to be agreed for this. RNOH have given Wood Green their MRI protocols for soft tissue sarcoma and they have the contact details for the RNOH trouble shooter radiologist. Ram, Consultant Radiologist from RNOH will be providing support. Mustafa from Wood Green explained that the CDC is able to do multiple diagnostics in the same day and give the results back to the GP within 24 hours.

There were no representatives from Norfolk & Norwich, Portsmouth or Bournemouth
PS noted that the SUHT team met with Bournemouth last year and are looking at whether they could do some joint working, looking at referral pathways across Dorset and Hampshire and having more cohesive working across the 2 diagnostic centres.

Concerns were raised regarding the increasing number of referrals to the spokes and the fragilities of the workforce. SM confirmed that Croydon, C&W and Barts have all received 2 years of pump prime funding in addition to the money that they receive for delivering the service. SM also confirmed that

all of the spokes have been commissioned to see patients from all over the network, not just local referrals. All spokes should be delivering the service spec that was agreed by the SAG.
Kingston have indicated that they will be closing the service. AH expressed his concerns about the loss of the service.

Action: RJ and CG to write to Cally Palmer and Simon Barton re the issues in the current hub and spoke model. NH suggested providing the data to support this e.g. numbers of patients and those waiting more than 62 days.

Action: SM to forward Kingston correspondence to RJ and CG

c. Diagnostics in the community

DB gave a brief update – they are trying to understand the level of access to ultrasound across London and the waiting times for these scans. DB has been working closely with colleagues in the regional diagnostic teams and imaging network to collate the data. Some of this data has been collected but there is still lots missing, so she is going to the imaging clinical leaders group to get their support in progressing this. Once data has been collected and analysed, she will bring it back to the SAG.

Note: NHS England met with RMH yesterday to discuss pathology delays at the spokes. RMH have not seen a decrease in pathology referrals even though the number of patients being referred have decreased significantly. RMH pathology team are going to review the data and report back to NHE about this.

4. Paediatrics Update

RW thanked the SAG for the letter which was sent to NHSE following the last meeting. NHSE have asked for an implementation plan and discussions are ongoing.

5. NHS Commissioning Update

SS discussed the quality metrics that were agreed in the service specification. No data has yet been published. SS has been liaising with Peter Johnson and the Cancer Program of Care Board. Some progress is being made and data should be released by October. The SAG will then be able to review our data.

6. WGS Progress Reports

FA updated from RNOH: since 1st January this year 117 patients have consented, 76 cases were sent to GOSH for sequencing, 16 cases were not sent due to insufficient viable tumour/sarcoma not diagnosed. 21 cases consented have are still waiting for resection to be sent as there's not enough tissue in the biopsy, and four of those are in progress. FA thanked the team, particularly the nurses for consenting the patients and the histopathology team that are cutting, analysing and sending the cases through.
KT was not at the meeting. RJ will follow up with her.

7. Trials

The trials lists from RMH and UCLH were circulated with the SAG papers.

8. Any Other Business:

SAG Constitution – needs to be signed off by the SAG. If anyone has any comments please send to GF in the next week or two, otherwise it will be assumed that it has been signed off.

The bone sarcoma pathways also need signing off. They have been submitted as evidence for the RNOH Bone Tumour Peer Review.

RNOH are being peer reviewed on 19th June. CG thanked the team for their hard work in pulling the evidence together and will bring back any learning points to the next SAG.

TJ informed the SAG that this will be her last SAG meeting as she has been appointed as COO at RNOH. The SAG thanked TJ for all of her hard work and congratulated her in her new role.

Dates of the next meetings:

- Friday 6th September, 3-5pm
- Friday 6th December, 3-5pm – F2F

Attendees:

Mahbubl Ahmed (MA)	Clinical Oncologist, UCLH
Fernanda Amary (FA)	Histopathologist, RNOH
Ariana Barradas da Silva (AS)	Lead Sarcoma CNS, UCLH
Lee Bayliss (LB)	Surgeon, RNOH
Daisy Beserve (DB)	Head of Cancer Improvement, NHSE London
Alexandra Blowers (AB)	Clinical Business Unit Manager, RMH
Lee Chesham (LC)	Sarcoma Improvement Manager, RNOH/UCLH
Julia Chisholm (JC)	Paediatric Oncologist, RMH
Sue Dexter (SD)	ANP, Barts Health
Katy Ellis	ANP, UCLH
Rebecca Exton	Surgeon, SUHT
Gemma French (GF)	SAG Project Manager
Craig Gerrand (CG)	Surgeon, RNOH
Mustafa Hassan (MH)	General Manager, Whittington Health
Heledd Havard (HH)	Surgeon, RNOH
Andrew Hayes (AH)	Surgeon, RMH
Nate Hill (NH)	Project Manager, RM Partners
Katrina Ingley (KI)	Medical Oncologist, UCLH

Robin Jones (RJ)	Medical Oncologist, RMH
Tanya Joseph (TJ)	Unit Director of Operations, RNOH
Vasilios Karavasilis (VK)	Medical Oncologist, UCLH
Sue Maughn (SM)	Deputy Director Cancer, NHSE London
Marguerite Meintjes (MM)	Deputy Director, RMH
Aisha Miah (AM)	Clinical Oncologist, RMH
Andrea Napolitano (AN)	Medical Oncologist, RMH
Kethesparan Paramesparan (KP)	Radiologist, Croydon
Nikhil Pawa (NP)	Surgeon, ChelWest
Emily Pegg (EP)	Deputy Divisional Manager, UCLH
Jonathan Perera (JP)	Surgeon, RNOH
Cerys Propert-Lewis	ANP, ChelWest
Ramanan Rajakulasingam (RR)	Radiologist, RNOH
Peter Simmonds (PS)	Medical Oncologist, SUHT
Sarah Slater (SS)	Medical Oncologist, Barts Health
Dirk Strauss (DS)	Surgeon, RMH
Sandra Strauss (SS)	Medical Oncologist, UCLH
Charlotte Travill (CT)	General Manager, ChelWest
Rachel Windsor (RW)	Paediatric Oncologist, UCLH