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 6th December
5.10s Franklin, 5th Floor, Wellington House, 133-155 Waterloo Road, London, SE1 8UG
and via MS Teams

Chair: Robin Jones

1. Welcome, Introductions and Apologies

Julia Chisholm
Andrea Cronin
Julia Hall
Jennifer Harrington
Daniel Holyoake
Julie Kerr
Gail Murray
Femi Odewale
Kelly Spiller
Anne Suovuori
Ramya Ramanujachar

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	Mar 25
SM/DB to find out if there is an orthopaedic network within the elective programme region for CG to discuss hand/foot referrals – They would like another follow up meeting with CG.	DB/SM	Jun 24	Mar 25
SM to invite AH to the Pan-London Imaging Clinical Leadership Group meeting	SM/AH	Dec 24	Jan 25
GF to send PS the diagnostic clinic guidelines	GF	Dec 24	Jan 25
SM to speak to Sharon Hodgson re the agreed commissioning arrangements and costings for the diagnostic spokes in London	SM	Dec 24	Mar 25
SM to discuss pathway for 16/17 year olds with the Children's network	SM	Dec 24	Mar 25
RJ to discuss the pathway for 16/17 year olds with RMH Children's service	RJ	Dec 24	Mar 25
CG to draft a position statement re metastatic bone disease to go on the SAG website	CG	Dec 24	Mar 25
RW to feed back the SAG discussion to the H&N teams, and bring the pathway back to the next SAG for sign off	RW	Dec 24	Mar 25
RW to feed back this discussion to the thoracic	RW	Dec 24	Mar 25

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RW to ask Ramya Ramanujachar how the pathway works at SUHT for under 13 chest wall bone sarcoma patients.	RW	Dec 24	Mar 25
FLG to share the national skin guidelines	FLG	Dec 24	Mar 25
Skin Pathway - criteria for sarcoma pathologist review to be agreed, and wording to be amended	GF	Dec 24	Mar 25
SAG to carry out thoracic audit	?		
Volunteers needed to review the two guidelines: patient management policy and hospital referral guidelines	All SAG	Dec 24	Mar 25
CG/RJ to write to NHS England on behalf of the SAG to express concerns on the impact changes to WGS funding	CG/RJ	Dec 24	Mar 25
The SAG to work with Genomics England to look at what should be added to the current panel tests if patients cannot have whole genome sequencing and also ensure that the clinical teams see the results of the panel	?		
The SAG to work with Genomics England to agree which patients would fall under this 'exceptional circumstances' for WGS	?		

3. GP Urgent Referrals and Diagnostic Clinics:

Urgent suspected referral form and guidance

AH gave some background information to how the 2WW service currently works at RMH. RMH are not listed as a diagnostic spoke on the new urgent cancer referral form. AH discussed the new guidance that accompanies the new form which asks the GPs to distinguish between low and high suspicion of sarcoma on the basis of an ultrasound report which he did not think was reasonable.

LS offered that GP are able make these distinctions based on the reports. The form has only been live for 6 weeks and so it will take some time for us to see a change in practice.

CG explained that the form and guidance was signed off on behalf of the SAG following previous discussion in good faith. It had been agreed that some patients should be able to be directly referred to the hubs if they have a high suspicion of sarcoma, including for example fungating or recurrent tumours, and this is what the guidance was intended to reflect. The primary care directors across the alliances were also happy to sign off this form and guidance.

AH explained that RMH want to be removed from ERS as a sarcoma diagnostic spoke, but expressed concerns that this would mean GPs were not able to refer patients with a highly suspicious sarcoma.

NHSE are meeting with RMH next week. Depending on the outcome of that meeting, the 2WW form could be brought back to the SAG for revision. It may be possible to develop different criteria for referrals to the hubs

if the commissioners agree.

SM noted that there are new radiology guidelines out to consultation which will mean that radiologists are able to upgrade a referral and request further imaging without referring the patient back to the GP. PS explained that this is how the pathway works at Southampton.

SM has a slot at the Pan-London Imaging Clinical Leadership Group on 13th January and invited AH to attend this group to discuss the sarcoma pathway and the challenges faced.

Action: SM to invite AH to this meeting

Update from each spoke
Croydon – not present
ChelWest – CPL noted that the ultrasound reports are often very vague. Healthshare are not commissioned to do MRI, they are only commissioned for ultrasound. Some ultrasound reports suggest sending a non-urgent referral to a sarcoma centre (for example large lipomas), some say to refer to plastic surgery (e.g. foot surgeon), and some say to refer to orthopaedics (for a soft tissue lesion). The new urgent GP referral forms are being used for North and South West London. Essex have their own form. There is currently a 20 day wait for MRI, and similar wait for biopsy.
Royal London – the sonographer upgrades patients and the ANP will review in clinic and order the MRI. They are receiving lots of out-of-area referrals from Kent and Essex, whose patients do not want to travel for an MRI. Approximately 10% of referrals received are going to RNOH so they are seeing and discharging many patients. SM continues to try and work with the East of England region regarding provision in Essex. There have been difficulties obtaining engagement in Kent and South East London.
Wood Green – there has been some improved uptake from GPs in directing patients to Wood Green for MRI scans. They are having an issue with appropriateness of referrals for MRI. They are also encouraging GPs to get imaging done locally before referral to RNOH. In the last 2 weeks they have had approximately 12 referrals for MRI for suspected soft tissue sarcomas. The Wood Green diagnostic service is a pilot service, and meetings are being arranged to discuss the long term plan for the service.
SUHT – no specific issues. They are running a virtual diagnostic triage, where they decide if patient needs further imaging or refer to GP following review of imaging similar to the previous RMH pathway. This is on the Trust risk register.

Action: GF to send PS the diagnostic clinic guidelines
Action: SM to speak to Sharon re the agreed commissioning arrangements and costings for the diagnostic spokes in London

Portsmouth – not present
PS noted that SUHT are in discussions with Portsmouth regarding them linking into the SUHT MDT
Brighton – not present
Norfolk and Norwich – not present

Pathway for 16 and 17 year olds
Some of the diagnostic spokes to do not accept referrals for patients under 18 years. There has been a recent case of a 17 year old patient who was bounced around between spokes and hubs.
ChelWest see these patients, but the other spokes do not.

Action: SM to discuss with Children's network
Action: RJ to discuss with RMH Children's service re what happens at RMH

Statement re bony mets

SM gave an example of a recent patient who had been referred to RNOH with suspected metastatic bone disease who couldn't been seen by non-specific site pathway locally and asked is RNOH the best place to be referred. CG explained they should be seen by local metastatic bone lead/non site-specific pathway but this is not always available and RNOH receives many such referrals.

Action: CG to draft a position statement to go on the SAG website.

RW noted there have been issues with paediatric patients being referred to RNOH on the bone pathway who have widespread metastatic bone disease and RNOH have done a biopsy and then there have been difficulties transferring the patient back to RMH/GOSH

Direct access to MRI – request from Brent LMC – not discussed
Issues in pathway – not discussed

4. Desmoid follow up guidelines and pathway.

Deferred to the next meeting.

5. First line chemotherapy in metastatic LMS.

Deferred to the next meeting.

6. Pathways for sign off:

Paediatrics update
RW explained that for the under 13s bone sarcoma pathway, the response from NHS England to sign off the pathway agreed with GOSH is awaited.

Head and Neck Paediatric Pathway
UCLH is the designated H&N bone sarcoma service for adult patients, which consists of adult surgeons with no paediatric expertise and under 13s cannot be supported at UCLH as it does not have a PICU.
At GOSH there is an extensive surgical H&N team who perform soft tissue sarcoma and reconstructive surgery but not bone sarcoma surgery, but they have a PICU and so these patients need to be treated at GOSH.
There are only 2/3 patients under the age of 13 years per year.
RW and GF have met with the GOSH and UCLH teams several times to work through this pathway. RW asked for the SAG recommendation for this pathway.

The SAG agreed that all suspected and confirmed head and neck sarcomas should go through the UCLH Sarcoma H&N MDT. Surgery for sarcoma patients under 13 years of age would usually be at GOSH and older patients at UCLH. However, decisions should be made on an individual case basis for example to involve an adult surgeon in a case at GOSH if there was agreement amongst surgeons at the UCLH Sarcoma MDT that it would be to the patients benefit.

Action: RW to feed back this discussion to the H&N teams, and bring the pathway back to the next SAG for sign off

Thoracic Paediatric Pathway

RW and GF have been meeting with the GOSH and RBH teams. UCLH and RMH patients are operated on at the Royal Brompton. Currently if GOSH receive a chest wall sarcoma referral the patient stays at GOSH, and

receives treatment there, including surgery. The patients then normally come to UCLH for PBT/radiotherapy. RW asked for the SAG opinion on this pathway.

The SAG agreed that all bone thoracic sarcoma surgery (for all ages) should be at the SAG designated centre which for our sarcoma network is the Royal Brompton. All patients with suspected and confirmed sarcomas of the chest wall should be redirected to the Royal Brompton Sarcoma MDT. This is in line with the sarcoma service specification. Surgical expertise should be concentrated and there should not be two centres doing surgery for a small number of cases.

Action: RW to ask Ramya Ramanujachar how the pathway works at SUHT for chest wall bone sarcoma patients under the age of 13 years.

Action: RW to feed back this discussion to the thoracic teams, and bring the pathway back to the next SAG for sign off

Adult Pathways:
GF circulated the pathways with the papers for the meeting.

H&N Adult
This has been agreed by the UCLH and RMH H&N teams. The SAG agreed to sign off this pathway.

Skin Pathway
This has been agreed by the UCLH and RMH Skin teams. There is one additional comment to add and GF will speak to Myles Smith regarding this.
AM asked if it was appropriate for all skin pathology to be reviewed by the sarcoma pathologist. This is not done at RMH but is at UCLH. Therefore clarification is needed. PS noted that they do not send all of their skin sarcomas to the UCLH/RMH Skin sarcoma MDT but the pathway reads that they should be.
FLG has been contributing to new national guidelines regarding skin sarcomas.

Action: FLG to share the national guidelines
Action: Criteria for sarcoma pathologist review to be agreed, and wording to be amended as above.

Thoracic
The SAG agreed the pathway.
Regarding chest wall Ewing sarcomas SS noted that UCLH offer ambulatory care which may be easier for eligible patients.
There is a new pathway in place between RBH and UCLH. SS thanked SM for helping with commissioning discussions with the managers at RBH.
SS noted that the SAG had agreed to audit the thoracic patients.

Action: SAG to carry out thoracic audit

7. Guidelines to be updated:

GF noted that the patient management policy and the referral guidelines for hospitals were last updated in 2018 and asked for clinical volunteers to help update these.

Patient Management Policy:
- Update to include clear details about diagnostic panels and WGS eligibility.

Hospital Referral Guidelines:

- AM noted that it would be helpful to add the minimum dataset when transferring patients between our hospitals.

Action: Volunteers needed for the two guidelines

9. NHS Commissioning Update and SAG Workplan update

A slide pack was circulated with the papers, including updated performance data.
The overall numbers of 2ww referrals have remained stable but ChelWest are getting an increase in referrals. The new form launched in October should help redistribute the referrals. Kingston has officially closed their service. SM continues to engage with East of England re opening a diagnostic spoke in their region.

10. WGS Progress Reports

RJ noted that NHS England will no longer be funding whole genome sequencing for patients over age 25 years.

Action: CG/RJ to write to NHS England on behalf of the SAG to express concerns on the impact of this.

Action: The SAG to work with Genomics England to look at what should be added to the current panel tests if patients cannot have whole genome sequencing and also that the clinical teams see the results of the panel (because they do not currently).

The group confirmed that children and young people (up to age 25 years) are eligible for whole genome sequencing as part of their care. This change confirms that teenagers and young adults (16-25 years) are included, which was not always clear previously.
For patients older than 25 years, WGS is only allowed in special circumstances.
The team discussed the need to decide what qualifies as a “special circumstance” to ensure this is applied fairly.

Action: The SAG to work with Genomics England to agree which patients would fall under this ‘special circumstance’.

11. Trials

GF circulated the trials lists with the papers for the meeting.

12. Any Other Business:

Dates of the next meetings 2025:

- Friday 28th March, 3-5pm
- Friday 6th June, 3-5pm
- Friday 26th September, 3-5pm
- Friday 19th December, 3-5pm

Attendees:

Mahbubl Ahmed (MA)	UCLH
Fernanda Amary (FA)	RNOH
Lee Bayliss (LB)	RNOH
Charlotte Benson (CB)	RMH
Daisy Beserve (DB)	NHS England London
Ghias Bhattee (GB)	LNW
Alexandra Blowers (AB)	RMH
Lee Chesham (LC)	UCLH
Sue Dexter (SD)	BH
Rebecca Exton (RE)	SUHT
Gemma French (GF)	SAG
Craig Gerrand (CG)	RNOH
Mustafa Hassan (MH)	WHT
Hel Havard (HH)	RNOH
Andy Hayes (AH)	RMH
Katrina Ingley (KL)	UCLH
Robin Jones (RB)	RMH
Vasilios Karavasilis (VK)	UCLH
Franel Le Grange (FG)	UCLH
Cerys Propert-Lewis (CPL)	CWH
Sue Maughn (SM)	NHS England London
Lucy McLaughlin (LM)	NCL
Aisha Miah (AM)	RMH
Laura Mooney (LM)	UCLH
Ashley Nwanze (AN)	UCLH
Avinash Pilar (AP)	UCLH
Imran Raza (IR)	UCLH
Ariana Barradas da Silva (AS)	UCLH
Lance Saker (LS)	GP/Cancer Research UK
Peter Simmonds (PS)	SUHT
Sarah Slater (SS)	BH
Dirk Strauss (DS)	RMH
Sandra Strauss (SS)	UCLH
Bryn Thomas (BT)	RMH
Rachel Windsor (RW)	UCLH
Hayley Yeomans (HY)	WCA
Shane Zaidi (SZ)	RMH