

**London and South East England Sarcoma Network Sarcoma Advisory Group Minutes**

**Date:** 15.00 and 17.00 on Friday 8<sup>th</sup> Dec

**Venue:** In person Room 5.10S Frankin, NHS England and NHS Improvement – London, Wellington House 133-155 Waterloo Rd, London, SE1 8UG

**Chair:** Robin Jones

**1. Welcome and Introductions**

**Apologies were received from:**

Thankamma Ajithkumar  
Jonathan Hanny  
Franel le Grange  
Kate Lankester  
Lucy McLaughlin  
Aisha Miah  
Sarah Slater  
Myles Smith  
Justin Waters  
Rachael Windsor

**2. ACTION LOG including outstanding actions from previous meeting. All other actions from previous meeting were completed and have been removed.**

<b>ACTION</b>	<b>Owner</b>	<b>Date Added</b>	<b>Due Date</b>
Sirolimus for EHE – SS, MA and CB to work together on this. MA leading on this. MA to feed back.	MA	Sep 22	Mar 24
PD has been contacting Alex and Adam re updating the Chemotherapy Algorithm to be signed off at the SAG chairs meeting at BSG. PD is updating the LSESN algorithm in parallel. PD will be asking for help. MM to help with paediatric part.	PD, MM	Dec 22	Mar 24
PS review updates and add any changes to the LSESN second opinion policy. GF to chase and get sign off before adding to website	PS	Dec 22	Mar 24
VK to update TGCT pathway and circulate for agreement	VK	Oct 23	Mar 24
CS to send RMH ERS messaging to TJ so that she can ensure that the RNOH messaging is aligned	CS	Dec 23	Mar 24
SAG to write to host Trusts where oncologists have no CNS support (Kent)	CG/RJ	Oct 23	Dec 23
SM to bring update to the SAG re RMH CWT Performance once she has spoken to Jo Champness	SM	Dec 23	Mar 24
SM to organise implementation group meeting for next week	SM	Dec 23	Dec 23
CG to review the comments on the adult spinal sarcoma pathway and also to update SM on	CG	Dec 23	Mar 24

progress before her follow-up meeting with RNOH and UCLH Medical Directors.			
RJ to speak to Khin re process for identifying WGS patients at RMH	RJ	Dec 23	Mar 24
GF to send updated trials list with the minutes	GF	Dec 23	Mar 24
GF to speak to Sarcoma UK re the trials hub on their website	GF	Dec 23	Mar 24

### 3. NCPES Results

KM presented the RMH NCPES results. Out of 1509 respondents in the RMH survey; 57 were sarcoma patients compared to 56 patients in 2021. 25 questions had an improved score, 3 responses stayed the same and 29 questions had a worse score.

The easing of lockdown restrictions has seen an improvement in some of the questions.

EPIC should improve the provision of patient information.

The CNS team are now fully staffed following a Trust-wide review which should also improve results.

AS presented the RNOH and UCLH results. There were only 37 patients who responded for RNOH, and 19 for UCLH. 33 results were better at RNOH than in 2021, 21 at UCLH. 3 were the same and RNOH, and 1 was the same at UCLH. 19 were worse at RNOH and 27 were worse at UCLH.

Diagnostic tests, support from main contact person, deciding on best treatment, care planning, support and care from hospital staff scored well. Areas in need of improvement include finding out you had cancer, treatment, long term side effects and living with and beyond cancer.

At UCLH there are lots of teams involved such as abdominal and head and neck teams and so a questionnaire is being developed to try to gather more specific information. The CNS team will start doing end of treatment summaries next year. End of treatment summaries are already done at RNOH after surgical treatment.

### 4. Diagnostic Clinics Update

GPs are still not able to refer into the Chelsea and Westminster Fulham site - patients are continuing to be diverted from RMH.

Mile End will not officially be going live until 1<sup>st</sup> January.

TJ shared concerns that RNOH are in the process of updating their GP communications and Electronic Referral Service (ERS) and were not aware that Mile End was not live.

AH explained that previously RMH have had oversight of the referrals coming in and have redirected as appropriate but is concerned whether all the processes are in the place for the hubs to receive referrals directly. AH noted the importance of having an administrator at RMH who triages the referrals and escalates to the clinical team as appropriate and would like this to continue during the transition to referrals going automatically to the hubs.

Action: SM to organise a diagnostic implementation group meeting next week.

CS gave a presentation on the hub and spoke system at RMH and showed how the geography of the referrals going to RMH had changed since the spokes have gone live. Referrals from South West London in particular have decreased dramatically, from 230 in 2018/19 to 23 in 2023/23.

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SM noted that referrals cannot be rejected and has organised a meeting to get further clarification on redirecting referrals.

CPL noted that the communications for GPs need to be clear for NW London on which sites are open, which will have redirects etc. Sue noted that this will be clarified in the meeting next week.

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**5. Designated Practitioners  
Radiotherapy and Chemotherapy**

RJ and GF have met to review the chemotherapy and radiotherapy designated practitioners and have had confirmation from all but two people. The list will be circulated once finalised.

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**6. SAG Pathways  
Spinal (adult and children)**

Adult spinal sarcoma pathway:

CG was hoping to have an adult sarcoma spinal pathway to sign off today but unfortunately this is not ready. There is a draft pathway which has gone out to spinal surgeons in the region for comment. Essentially the model is that the diagnosis and surgery for primary bone sarcomas goes to the commissioned centre (RNOH) and there needs to be a discussion on which cases may go elsewhere.

DC mentioned that there has been some discussion about the commissioning of Queen Square for spinal surgery. Up to now Queen Square and RNOH have shared the surgery for primary tumours in the thoracic and lumbar spine. There have been many discussions on whether Queen Square is commissioned to do those surgeries even though they have been doing them in the past. AN gave an update to this and stated that QS met with CG last week and there are a few comments from NHNN around the pathway that has been circulated and some iterations that they would like to be made in regard to the current sarcoma specification and commissioning guidance that they have received.

Action: CG to review the comments on the pathway and also to update SM on progress before her follow-up meeting with RNOH and UCLH Medical Directors.

Paediatric spinal sarcoma pathway:

MM presented the paediatric spinal pathway which is different to the adult pathway as the diagnoses are different. The development of the pathway started because of a serious incident where a Ewing sarcoma presented in a child who became paralysed very quickly and the aim of the pathway is to limit the numbers of these incidents.

Primary bone sarcomas should go to RNOH spinal team. If there is cord compression and the tumour is intradural the patient should go to neurosurgical team at GOSH and if the tumour is extradural the patient should still go to RNOH. These cases are very rare and most of these children will present to an emergency department which could be anywhere in London. The pathway therefore needs to be clear for all A&E departments across the region.

There has been agreement of the pathway between RNOH and GOSH. There will be a Morbidity and Mortality discussion about a recent patient who did not follow the pathway. There now needs to be a mechanism for this pathway to be signed off by the Operational Delivery Networks and be communicated to local hospitals so that everyone is clear of the pathway.

Pathways attached for information.

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## 7. NHS Commissioning Update

CWT performance was discussed at the last SAG and RMH were asked to bring an update to this meeting. SM has also raised this through the RMH Quality group and is expecting a full update from Jo Champness back to the RMH Quality Group as well as talking about it at the SAG.

As discussed, there will be a refreshed implementation group meeting next week regarding the diagnostic centres. SM noted that TCST are also trying to get an ultrasound fellow to work across London who will upskill sonographers and those that undertake lumps and bumps ultrasound.

Sarcoma was listed to be retained as a nationally commissioned service and there is still no change to this.

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## 8. Updates from Regions outside of London

GF updated that for East of England they are having meetings to talk about how they are going to progress with having a hub in their region They are also looking at the Norfolk and Norwich site to see if they are compliant with the SAG pathway.

The Southeast region are also meeting and looking at the governance routes of how they can set up a hub. Both East of England and the Southeast region have said they will come to the next SAG meeting in March to present an update on progress.

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## 9. WGS Progress Reports

FA gave an update on the Whole Genome Sequencing pathway at RNOH. There is still a turnaround time of more than 6 weeks as there was a shortage of clinical scientists to do the analysis at the GLH (GOSH). There is now a clinical scientist dedicated to sarcoma and so this should improve.

The consenting of patients has declined at RNOH as the person that was dedicated to consent patients at RNOH has left the post. There needs to be more engagement from the clinical team.

Khin has given RJ an update for RMH – the pathway has taken a while to set up due to the multiple specialities in the histopathology department at RMH. It would be helpful to have someone to do the consenting, but this would require more resource. CG noted there are also process issues at RNOH and so RMH may be an advantage as they have EPIC in place and so could have an oversight of patients missing consent etc. There is no clear pathway at UCLH yet and one of the issues is that WGS cannot be ordered on EPIC. This need to be built on EPIC and is taking some time. This should be investigated at RMH.

At RNOH they try to take the tissue at biopsy, but if consent and bloods are missed there is the possibility to do this at resection and use the frozen tissue

Action: RJ to speak to Professor Thway regarding process for identifying patients at RMH

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## 10. Trials

Action: GF to send updated trials list with the minutes

SS noted that the Sarcoma UK website is not up to date for trials.

Action: GF to speak to Sarcoma UK, GF to circulate our lists to them or use the link to our website.

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## 11. Any Other Business:

AH and the SAG thanked CS for all his hard work over the last 6 years as it is his last day at RMH.

### Dates of the next meetings 2024:

- Friday 22<sup>nd</sup> March, 3-5pm
- Friday 7<sup>th</sup> June, 3-5pm
- Friday 6<sup>th</sup> September, 3-5pm
- Friday 6<sup>th</sup> December, 3-5pm

### Attendees:

Margaret Adejolu	Consultant Radiologist, RMH
Mabs Ahmed	Consultant Clinical Oncologist, UCLH
Fernanda Amary	Consultant Histopathologist, RNOH
Charlotte Benson	Consultant Medical Oncologist, UCLH
Lee Bayliss	Consultant Surgeon, RNOH
David Choi	Consultant Neurosurgeon, Queen Square, UCLH
Jo Coleman	Advanced Nurse Practitioner, RNOH
Andrea Cronin	NHS North East London Cancer Alliance
Palma Dileo	Consultant Medical Oncologist, UCLH
Adrienne Flanagan	Consultant Histopathologist, RNOH
Gemma French	SAG Project Manager
Helen French	Sonographer, Southeast Ultrasound
Craig Gerrand	Consultant Surgeon, RNOH
Hel Havard	Consultant Surgeon, RNOH
Andrew Hayes	Consultant Surgeon, RMH
Nate Hill	Workforce Lead and Senior Project Manager, RM Partners
Jodie Hooker	Sonographer, Southeast Ultrasound
Katrina Ingley	Consultant Medical Oncologist, UCLH
Robin Jones (CHAIR)	Consultant Medical Oncologist, RMH
Tanya Joseph	Director of Operations, RNOH
Sue Maughn	Head of Cancer, NHS England London
Kelly McKibbin	Lead Sarcoma Clinical Nurse Specialist. RMH
Maria Michelagnoli	Consultant Paediatric Oncologist, UCLH
Ashley Nwanze	General Manager, Queen Square, UCLH
Emily Pegg	Deputy Divisional Manager, UCLH
Avinash Pilar	Locum Clinical Oncologist, UCLH

Cerys Propert-Lewis	Advanced Nurse Practitioner, ChelWest
Helen Ruane	Programme Manager, Wessex Cancer Alliance
Catarina Santos	Clinical Nurse Specialist. RMH
Parag Sayal	Consultant Surgeon, Queen Square, UCLH
Ariana Silva	Lead Sarcoma Clinical Nurse Specialist, UCLH
Peter Simmonds	Consultant Medical Oncologist, SUHT
Fay Smith	Sonographer, Southeast Ultrasound
Christopher Stone	Service Manager, RMH
Dirk Strauss	Consultant Surgeon, RMH
Sandra Strauss	Consultant Medical Oncologist, UCLH
Georgina Wood	Consultant Medical Oncologist, UCLH
Julie Woodford	Nurse Consultant, RNOH
Shane Zaidi	Consultant Clinical Oncologist, RMH