

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

**Meeting held between 15.00 and 17.00 on Friday 22nd March  
Via MS Teams**

**Chair: Craig Gerrard**

**1. Welcome and Introductions**

**Apologies were received from:**

Fernanda Amary  
Sue Maughn  
Peter Simmonds

**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	Jun 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	Jun 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
Spokes to be specifically invited to give updates at future meetings.	GF	Mar 24	Jun 24
CG will write to NHS England to state that the SAG did not support the under 8s moving to GOSH	CG	Mar 24	Jun 24
MMi to lead on review of paediatric thoracic pathway	MMi	Mar 24	Jun 24
CG to share spinal pathway with Queen Square for agreement	CG	Mar 24	Jun 24
RJ to meet with Mary Jo to discuss RMH staging data	RJ	Mar 24	Jun 24
RJ to discuss pathology issues with commissioners	RJ	Mar 24	Jun 24

**Items discussed not on the main agenda:**

**TGCT Pathway:**

VK presented the updated TGCT Pathway which was an action from the previous meeting.

The following amendments are to be made:

- Add missing arrow between 'Imaging' and 'BTAP'
- Add comment that appropriate or incompletely resected cases to go to BTAP. Not all patients would follow this pathway.

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Otherwise the SAG agreed to sign off the pathway

**RMH CWT performance:**

MMe presented an update on the RMH Cancer Waiting Times Performance. RMH met with SM last week to look at how the data is collected and RMH have been internally reviewing this. MMe reported that RMH performance is improving and going forward the data should look better. There is an improvement plan in place and there will be further discussions with SM about how to take this forward.

CG noted that there have been issues in pathology which may delay the patient pathway (for non-sarcoma samples going to hubs first before RMH). MMe is liaising with SM re how this can be improved. There were also delays in the pathology pathway at ChelWest. This was raised at the SAG Oversight Board last week.

3.

**Diagnostic Clinics:**

- **update from each spoke**

ChelWest – CPL gave an update that there will be an additional ANP joining in April and there is currently a part time clinical fellow. CPL is still receiving referrals on ERS from Surrey, Essex, Kent and Berkshire and there are old referral forms being used in NW London. CPL noted that some imaging is reported as needing an orthopaedic referral so she is discussing with the orthopaedic surgeons at ChelWest whether they should review these patients or if they should be referred straight to RNOH. Most referrals are now received on ERS directly to ChelWest rather than re-directs from RMH.

A lot of the spokes were not represented at the meeting.

*Action: Spokes to be specifically invited to give updates at future meetings.*

GF updated that Mile End has gone live this week and TCST are working on comms regarding this. TJ noted that CG and RJ need to agree the comms before they go out. The new referral form has not yet gone live. Once it does there will need to be more comms, changes to ERS and changes to all of the websites.

CG updated that RNOH are making good progress. They are working on communications and admin processes which allow many referrals to be signposted to more appropriate services.

AH updated that RMH have separated referrals with and without imaging and are receiving a large amount of imaging reviews

- **designated practitioners for diagnostic clinics**

GF circulated the document with the papers which details what the practitioners should do, the general principles, a list of who they are, what each site does in terms of imaging/biopsies and where the gaps are. The document was signed off. It is a dynamic document which will be updated as people come into post.

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**4. Radiotherapy and Chemotherapy Designated Practitioners**

This was discussed at the last meeting. Minor amendments have been made and the documents have been recirculated. The SAG signed off the documents.

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## 5. Paediatrics Update

There have been changes in paediatric services across London.

JC gave an update from South Thames:

NHS England has made the decision that the children's service from the Royal Marsden will in future move to the Evelina London Children's hospital (part of Guy's and St Thomas' Trust). Patients up to the age of 16 years will go to Evelina and patients over the age of 16 years will stay in the Marsden TYA service. The change to the pathway will not happen before October 2026. Sarcoma pathways for children will need to be discussed at the SAG. RJ stated they will meet internally regarding the TYA pathways.

MMi asked about the location of the drug development unit and JC confirmed that this will move with the children's service to the Evelina, but this leaves a gap for the TYA service which will need to be resolved. Surgery for under 16s happens at RNOH for limb soft tissue sarcomas.

RW gave an update from North Thames:

The paediatric cancer service at UCLH was reviewed a few years ago by Sir Mike Richards prior to the publication of the recent service specification and at that time it was deemed that the service was safe. The service specifications published in 2021 dictate that cancer patients under the age of 13 years need to be managed in a Primary Treatment Centre (PTC) that is co located with a Paediatric Intensive Care Unit (PICU). The process in North and South Thames has been slightly different due to the complexity of the super-regional bone sarcoma service and the large radiotherapy service that runs at UCLH. For over 13's it was agreed that the service would stay as it is but for under 13s to ringfence the radiotherapy and proton beam service UCLH was redesignated as an enhanced level B Paediatric Oncology Shared Care Unit (POSCU). This allows UCLH to provide care for the complex radiotherapy patients who need concurrent chemotherapy, including the many high-risk radiotherapy patients who come in from across the UK.

The number of patients under 13 years who do not need radiotherapy is very small and constitutes the bone sarcoma patients, (approx. 15-20 patients a year), and Hodgkin lymphoma patients (smaller number than bone sarcoma patients). A steering group and a clinical advisory group was set up to review the options for the service reconfigurations. The initial suggestion was that all chemotherapy patients under the age of 13 years should move to GOSH but this is not straightforward:

- There are two service specifications which apply to the bone sarcoma patient cohort (sarcoma and children's cancer) which are open to interpretation about which MDT is ultimately responsible for the patient's treatment plan
- Both bone sarcoma and Hodgkin lymphoma are diseases of older children, teenagers and young adults, and are rare in this age group (under 13s). MDT expertise and other benefits e.g. access to trials exist as the result of (and closely dependent on) the over 13s service
- UCLH'S only shortfall against the PTC specification for under 13s is PICU; bone sarcoma and Hodgkins patients are at very low risk of requiring admission to PICU
- Patients treated in the paediatric radiotherapy service have complex needs and require an experienced comprehensive multi-disciplinary team to ensure safe care during radiotherapy. Reducing the paediatric oncology service and workforce on site has the potential to destabilise or undermine UCLH's ability to provide safe care for these patients. RW also highlighted that the number of radiotherapy patients at UCLH will increase as patients will be coming from Oxford and RMH when their service moves.

RW talked through a proposal for a new pathway. This is based on a risk stratified approach: for patients with complex co-morbidities or complex therapy needs the place of care would be at GOSH; it is also proposed that all patients aged under 8 years (4/5 patients per year) are cared for at

GOSH. For other patients the place of care will remain at UCLH. The decision on the most appropriate place of care will be made by the sarcoma MDT and the paediatric bone sarcoma consultant once the patient has been seen and assessed. For patients managed at GOSH, the care would be led by one of the bone tumour paediatric consultants from UCLH.

Benefits of this proposed pathway include risk stratified care for those patients with complex underlying health conditions, improved teamwork across GOSH and UCLH paediatric oncology, improved access and integration for this patient cohort to specialist paediatric teams at GOSH if needed and paediatric radiotherapy services at UCLH would not be significantly impacted.

There are however major risks and challenges associated with moving the under 8 patients to GOSH:

- Care and outcomes are potentially negatively impacted by decentralising care and diluting specialist expertise
- Inherent risk of treating small case load at one hospital
- The pathway could lead to a more fragmented pathway for some patients
- Potential negative impact on patient experience as small number of patients are less likely to access peer support from other patients/families with similar diagnosis
- Risk that pathway requires additional resource and investment due to duplication and cross site working
- Risk that clinical information sharing is poor as information will potentially be on two versions of Epic
- Front line clinical trials will need to be opened at both sites, this may be challenging due to patient numbers

Essentially moving the patients under 8 does not necessarily meet the paediatric service specification any better than it would by not moving any of them.

The pathway has been reviewed by NHS England and there have not been any objections so far. RW asked for comments from the SAG, on whether they feel this proposed pathway meets the sarcoma service specification.

SAG and ODN sign off is needed before the detail can be worked through.

CG asked if anyone wanted to speak in favour of this proposed pathway. There was no response.

*Action: CG will write to NHS England to state that there was no support from the SAG for the under 8s moving to GOSH*

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## 6. SAG Pathways

### **Thoracic:**

GF circulated the pathway with the meeting papers for discussion and agreement.

SB talked through the pathway, explaining that referrals are going to RNOH for initial triage and then go to Royal Brompton for further triage and to decide whether the patient will go straight to MDT, be seen by a consultant at Royal Brompton or if they need further investigation. Some investigations are being arranged locally and some of them take place at the Royal Brompton Hospital.

The SAG is happy with the adult thoracic pathway and agreed to sign this off.

KR noted that some of the referrals are coming into the CNS inbox. SB explained that they should be going through the MDT Coordinator. To be discussed outside of the meeting.

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JC noted that the paediatric thoracic Ewing patients are being treated with chemotherapy in RMH but referred into Brompton for surgical management. As these patients are discussed in a bone sarcoma MDT it was agreed that it would be appropriate that they could have their chemotherapy elsewhere. RW highlighted that GOSH are operating on thoracic sarcoma patients without putting them through the thoracic sarcoma MDT. MMi reiterated that these patients should all be discussed in the same MDT and given the same treatment options.

Action: Paediatric thoracic pathway needs to be reviewed. MMi to lead on this

### **Spinal:**

GF circulated the pathway with the meeting papers and shared the pathway in the meeting. CG explained that there is currently a spinal bone sarcoma service at RNOH and a team at Queen Square who provide a service for some of these patients. A pathway needs to be agreed and several meetings have taken place to discuss this. The commissioners have confirmed that the diagnosis and surgical treatment of primary bone sarcomas should happen in a highly specialised commissioned hospital, which for our SAG is RNOH for this SAG. The expectations are that this is the default position and we have been trying to define which patients should go to Queen Square rather than to RNOH, but this is quite difficult to define. The circulated draft pathway states that all suspected bone sarcomas should go to RNOH for diagnosis and subsequent surgical treatment unless the MDT agrees that it would be better for the patient to be treated at Queen Square. Those present at the SAG agreed and signed off the pathway

Action: CG to share the pathway with Queen Square.

**Paediatric Spinal Pathway** – this was discussed at the last SAG meeting and now needs to go to the Operational Delivery Networks for agreement.

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## **7. Staging Data**

SS discussed the Cancer Outcome and Services Dataset for sarcoma and spoke specifically about the need for RMH to improve the collection of staging data. SS attended a COSD roadshow 3-4 weeks ago and met Mary Jo Crisp from RMH who has been tasked with helping to improve data capture at RMH. SS is happy to share different models of how staging data are captured.

This is part of a national effort to increase staging collection and if the big centres do not collect the data the numbers will never be high enough to make a difference. It has been demonstrated from the national data that we can learn a lot, but we cannot if data are not recorded.

Action: RJ to meet with Mary Jo to discuss.

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## **8. SAG Constitution and Work Programme 24/25**

GF presented the work programme for 24/25 which was agreed by the SAG. The SAG need to agree two audits for the next year. CG suggested an audit on pathway to diagnosis - there has been a national audit Britestar which we could replicate for the network.

The constitution still needs some amendments and so will be circulated once complete.

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## **9. Pathology pathway**

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RJ discussed a pathology pathway issue where gynae and thoracic sarcoma patients from Guys and the Imperial system have been referred to RMH but the pathology has gone to RNOH. The pathway needs streamlining so that when patients are referred to RMH the pathology goes straight to RMH as well.

*Action: RJ to discuss with commissioners*

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## 10. WGS Progress Reports

RNOH – CG gave an update for RNOH. There has been a recent decrease in consenting for a variety of reasons but a few issues have been addressed and the pathway continues to improve.

SS spoke about the North Thames Genomic Tumour Advisory Board which occurs fortnightly on Tuesday. The meetings are very helpful, the genetic scientists are extremely knowledgeable, and the consultants are learning new things every week.

RMH – RJ explained that RMH are currently trying to improve the consenting process for the tumour bank, which will hopefully make consenting for WGS easier too.

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## 11. Trials

The trials lists were circulated with the papers.

Following discussion at the last meeting regarding the Sarcoma UK website not being up-to-date for trials GF has contacted Sarcoma UK and will be sending them the updated trials lists after each SAG meeting.

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## 12. Any Other Business:

### **Chemotherapy Algorithm:**

PD explained that the Chemotherapy Algorithm has been updated and circulated for comment amongst the SAG oncologists as well as across the country. PD has responded to the comments received and asked the SAG if these comments will delay implementing the algorithm for the SAG or whether the SAG can sign off the algorithm as it is. CB noted that Adam Dangoor is planning a meeting in a few weeks to sign it off as a national algorithm for the BSG.

The SAG agreed to sign off the main content of the algorithm. George Wood has kindly agreed to update the references.

CG noted that this is PD's last SAG meeting. The SAG thanked PD for all of her hard work and contributions.

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### **Dates of the next meetings:**

- 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:**

Craig Gerrand – Chair (CG)	Consultant Sarcoma Surgeon, RNOH
Hanny Anwar (HA)	Consultant Spinal Surgeon, RNOH
Sofina Begum (SB)	Consultant Thoracic Surgeon, Royal Brompton
Charlotte Benson (CB)	Consultant Medical Oncologist, RMH
Angshu Bhowmik (AB)	Cancer Lead, Homerton university hospital
Julia Chisholm (JC)	Consultant Paediatric Oncologist, RMH
Andrea Cronin (AC)	NHS North East London Cancer Alliance
Palma Dileo (PD)	Consultant Medical Oncologist, UCLH
Gemma French (GF)	SAG Project Manager
Nicholas Haden (NH)	Consultant Spinal Surgeon, RNOH
Heledd Havard (HH)	Consultant Sarcoma Surgeon, RNOH
Andrew Hayes (AH)	Consultant Sarcoma Surgeon, RMH
Katrina Ingley (KI)	Consultant Medical Oncologist, UCLH
Robin Jones (RJ)	Consultant Medical Oncologist, RMH
Tanya Joseph (TJ)	Director of Operations, RNOH
Vasilios Karavasilis (VK)	Consultant Medical Oncologist, UCLH
Franel Le Grange (FLG)	Consultant Clinical Oncologist, UCLH
Marguerite Meintjes (MMe)	Deputy Director Cancer Services, RMH
Maria Michelagnoli (MMi)	Consultant Paediatric Oncologist, UCLH
Andrea Napolitano (AN)	Consultant Medical Oncologist, RMH
Jonathan Perera (JP)	Consultant Sarcoma Surgeon, RNOH
Avinash Pilar (AP)	Locum Clinical Oncologist, UCLH
Cerys Propert-Lewis (CPL)	Advanced Nurse Practitioner, ChelWest
Kate Ross (KR)	Lead Cancer Nurse, Royal Brompton
Sandra Strauss (SS)	Consultant Medical Oncologist, UCLH
Khin Thway (KT)	Consultant Histopathologist, RMH
Lewis Thomas (LT)	Operational Manager, RMH
Rachael Windsor (RW)	Consultant Paediatric Oncologist, UCLH
Shane Zaidi (SZ)	Consultant Clinical Oncologist, RMH