

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

**Meeting held between 15.00 and 17.00 on Friday 6th September
Via MS Teams**

Chair: Craig Gerrard

1. Welcome and Introductions

Apologies were received from:

Andy Hayes
Lucy McLaughlin
Fernanda Amary
Stephanie Bell
Rob Pollock
Sean Symons
Nikhil Pawa
Sue Dexter

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	Dec 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 needs to sign off draft letter	CG	Oct 23	Dec 24
RW to lead on review of paediatric thoracic pathway- To review draft pathway at the next meeting	RW	Mar 24	Dec 24
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	Dec 24
SM to email Sharon about meeting with Peter to support the Southampton diagnostic clinic.	SM	Sep 24	Dec 24
RW to provide update of thoracic head and neck pathway.	RW	Sep 24	Dec 24

**3. Diagnostic Clinics:
Update from each spoke.**

Croydon – not in attendance

Chelsea and Westminster – CPL updated that they are reviewing some local processes, including the ordering of MRIs. A new CNS has started in post. Patients are still being referred from Kent and Essex.

Brighton – not in attendance

Barts – SD has sent apologies and sent an update to GF. Since going live at the beginning of March they have had 429 referrals, 49 which have been referred onto RNOH and 4 confirmed malignancies. There continues to be issues with Pathpoint and chasing outcomes of the MDT. They are taking upgrades from sonographers as well as referrals from GPs, to avoid delays. They have weekly MDT meetings and MRI scans are generally organised quickly. Demand is currently exceeding capacity as they originally thought the hub was for referrals from North East London, but they are now taking referrals from across London. This is having a big impact on other workload.

SM noted that she has been having conversations with Barts regarding the recording of sarcoma activity, as it is currently being recorded as Non Site Specific. The funding for the CNS is to support sarcoma activity.

Southampton – On average they see 22 two week wait referrals per week through their diagnostic service. This is a single surgeon service and they are trying to get funding for a nurse led diagnostic service so that capacity is not an issue. They already have 2 CNS that work in the service who are keen to take this on, but they have not yet got an agreement for funding to develop this model. They are still running part of the diagnostic services through a virtual service which is not ideal and has led to problems elsewhere, but they have no other practical way of delivering the service at the moment.

SM mentioned that Sharon in the Southeast region can help with issues in this pathway. PS has been trying to meet with Sharon.

Action – SM to email Sharon about meeting with Peter.

Wood Green – MH stated that they have not had many referrals since going live. He gave an example of a patient in Southend who is having an MRI at Wood Green as the GP was unable to organise this locally. SM noted that if the local provider cannot do the MRI scan then other diagnostic services have to do it. MH also mentioned that GP's have received Comms but feels regular comms out to the GP's would be helpful as they have not yet seen a large uptake. Wood Green are seeing more referrals for MRI's than ultrasounds.

Bournemouth – CG welcomed the team from Bournemouth. AS who is senior surgeon at Bournemouth spoke about their rapid access diagnostic clinic with one stop biopsies. They do ultrasounds, triage and rapid access to MRI's.

IB, CNS gave some figures: in 2022 they have had 257 new patients with a total of 34 malignancies, 21 of which were sarcomas. In 2023 they received 245 referrals and 9 malignancies (these data require cross-referencing). In 2024 they have had 258 referrals so far (so already more than 2023) with at least 5 sarcomas.

MT, Consultant Surgeon noted that their conversion rate to cancer is around 13%, 8% for sarcoma. They cover the whole of Dorset and so patients come from long distance. Patients normally have an ultrasound before referral. Only a minority have patients have not had an ultrasound before referral. Diagnosed soft tissue sarcomas are referred onto RMH.

Norfolk and Norwich – NS explained that they work in a similar way as Bournemouth as a diagnostic MDT sending confirmed or highly suspicious lesions onto the Royal Marsden. They do some surgery locally for patients who do not want to travel, they have two plastic surgeons who will operate on sarcomas. These cases are discussed in the RMH MDT first.

They ask that an MRI is done before a GP referral and the radiologists in the region have agreed to this. This has been put into their guidelines in the last 6 months.

4. Referrals and conversion rates

SM discussed referral and conversion rates. Her team were asked to look at the data by North West London, particularly the team and Chelsea and Westminster who were inundated by a significant number of referrals, to see how their referral and conversion rate compares to other ICBs across London. SM presented a table of conversion rates from the faster diagnosis data (number of GP urgent referrals and number of cancer treatments). Conversion rate should be around 3% to prompt earlier diagnosis. The rates all differ across London but there is not a huge variation, other than in NW London which has a much higher number of referrals and a lower conversion rate. They are going to have further conversations with North London ICB to try and understand why GPs are referring double the number of FDS pathways to the closest other ICB in London.

5. Paediatrics Update

RW updated that there is a thoracic and head and neck pathway in process and hopefully these will come back to the next SAG meeting for review. Awaiting final review from NHSE of the bone tumour pathway for patients under the age of 13 years.

Action – RW to provide update of thoracic head and neck pathway at the next meeting

6. NHS Commissioning Update

SM noted that sarcoma will be retained as a nationally commissioned service - there are no plans for this to be delegated to local commissioning.

7. WGS Progress Reports

RMH – Khin is on annual leave

RNOH – Fernanda is on annual leave

PS mentioned there was a paper published a few months ago by BJC (with Fernanda as co-author) and which is worth a read. This is a publication on the introduction of whole genome sequencing, how it can be achieved and how it can be useful for sarcoma patients:

Watkins JA, Trotman J, Tadross JA, Harrington J, Hatcher H, Horan G, Prewett S, Wong HH, McDonald S, Tarpey P, Roberts T, Su J, Tischkowitz M, Armstrong R, Amary F, Sosinsky A. Introduction and impact of routine whole genome sequencing in the diagnosis and management of sarcoma. *Br J Cancer*. 2024 Sep;131(5):860-869. doi: 10.1038/s41416-024-02721-8. Epub 2024 Jul 12. PMID: 38997407; PMCID: PMC11368954.

8. Trials

The list of open trials at both centres was circulated with the meeting papers.

9. Any Other Business:

MPNST Pathway

GF circulated the pathway with the papers. UCLH have been working on this pathway with Guys and St Thomas, it has been agreed internally and now needs to be signed of as a SAG. RMH need to add their referral contact details. Otherwise, no further comment and the pathway was agreed.

SAG Chairs

The SAG Chair and Deputy Chair is a 3-year tenure which for RJ and CG finishes in December this year. The SAG Oversight Board will be asking of expressions of interest. Please can everyone have a think about these role and email SM, CG or RJ if interested.

Nursing

CPL gave thanks to AS and GF for the regional sarcoma and AHP meetings that they have organised. RMH will be organising the day next year.

Thoracic sarcoma pathway

SS mentioned there've been some issues for lots of patients along this pathway and thought it would be helpful to audit what happens to our patients across all ages. This has been spoken about outside the SAG meetings. GF noted that the SAG agreed to do two audits as part of the work programme for 24/25. It was agreed that this could be one of the audits, looking at for example the role of protons and the location of treatment. Further work needed to agree the purpose of the audit, the timeframe, age range etc.

There has been discussion on auditing the patients that are treated outside of the centres, however, it was agreed that this would be difficult to do and would rely on other Trusts providing us with information. SS noted that they are looking at these data nationally. There still needs to be another agreed audit, previously it was suggested to do a pathology audit.

Primary Care representation at SAG

GF noted that we do not currently have primary care representation at the SAG and asked whether this would be helpful. CG thought that this would be helpful if the right person was interested. We could ask for volunteers through the cancer alliances. We could also go to the GPs with specific questions rather than them needing to attend the meetings, for example to ask whether the new GP forms are working.

Dates of the next meetings:

- Friday 6th December, 3-5pm – F2F

Attendees:

Mahbubl Ahmed (MA)	UCLH
Suzanne Barrett (SB)	UHD
Imogen Batty (IB)	UHD
Charlotte Benson (CB)	RMH
Alexandra Blowers (AB)	RMH
Meghna Chhertri (MC)	CUH
Julie Chisholm (JC)	RMH
Jo Coleman (JC)	RNOH

Andrea Cronin (AC)	NHS NEL
Katy Ellis (KE)	UCLH
Gemma French (GF)	SAG
Craig Gerrand (CG)	RNOH
Mustafa Hassan (MH)	WHT
Nate Hill (NH)	RMP
Katrina Ingleby (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
Andrea Napolitano (AN)	RMH
Ashley Nwanze (AN)	UCLH
Marvin Nyadzayo (MN)	RNOH
Emily Pegg (EP)	UCLH
Jonathan Perera (JP)	RNOH
Avinash Pilar (AP)	UCLH
Ariana Barradas da Silva (AS)	UCLH
Nicholas Sheppard (NS)	NNUHFT
Peter Simmonds (PS)	SUHT
Anthony Skene (AS)	UHD
Dirk Strauss (DS)	RMH
Sandra Strauss (SS)	UCLH
Mark Tatterton (MT)	UHD
Michelle Wilkinson (MW)	RMH
Rachel Windsor (RW)	UCLH
Julie Woodford (JW)	RNOH
Hayley Yeomans (HY)	WCA
Shane Zaidi (SZ)	RMH