London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: 15.00 and 17.00 on Friday 13th October 2023
Venue: MS Teams
Chair: Craig Gerrand

1. Welcome and Introductions

Apologies were received from:
Fernanda Amary
Charlotte Benson
Jonathan Hannay
Jennifer Harrington
Kate Lankester
Sue Maughn
Lucy McLaughlin
Rob Pollock
Anthony Skene
Sandra Strauss
Rachael Windsor

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
RJ to provide update to SAG re GISTs at Mount Vernon. RJ to speak to oncologists and surgeons at Mount Vernon: RJ subsequently spoke with Dr Muhammed Baki (Clinical Oncologist, Mount Vernon). Dr Baki confirmed that all newly diagnosed GIST patients (surgical and medical) at Mount Vernon are referred to UCLH. There is an excellent working relationship with Dr Dileo and the UCLH Team.	RJ/PD	Mar 21	Ongoing
Sirolimus for EHE – SS, MA and CB to work together on this. MA leading on this.	MA	Sep 22	Dec 23
PD to update the chemotherapy algorithm with help from SAG colleagues – using national BSG algorithm. Also talk to Alex and suggest paediatric input	PD	Dec 22	Dec 23
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	Dec 23
VK to update TGCT pathway and circulate for agreement	VK	Oct 23	Dec 23
TJ to speak to Sue re commissioning agreements as funding has been removed from some of the services at RNOH to commission some of the CDCs	TJ/SM	Oct 23	Dec 23

Marguerite to remove 2WW divert messaging at RMH	MM	Oct 23	Dec 23
RJ to go through the lists with GF, check the practitioners and amend the radiotherapy	RJ/GF	Oct 23	Dec 23
SAG to write to host Trusts where oncologists have no CNS support (Kent)	CG/RJ	Oct 23	Dec 23
GF to amend and circulate gynae pathway	GF	Oct 23	Dec 23
AH and MM to look at performance data and bring an update to the next meeting	AH/MM	Oct 23	Dec 23
GF to circulate trials lists following the meeting	GF	Oct 23	Dec 23
GF to circulate meeting dates for next year	GF	Oct 23	Dec 23

3. TGCT Pathway

VK discussed this topic, raised at the last SAG meeting due to numerous patients seeking second opinions, and it was agreed that it was more appropriate for these patients to be managed in a multi-disciplinary clinic. VK has drafted a pathway which he discussed in the meeting.

There is increasing interest for these tumours to be managed under oncologists and orthopaedics. Very recently a trial was undertaken using a CSF1 inhibitor which was very successful in terms of efficacy and symptom improvement, and it was also recruited into very quickly. There are a few more trials in the pipeline. All patients with nodular or joint involvement should be referred to orthopaedics at RNOH first and go through the new patient meeting. If it is a nodular TGCT, surgical consideration is most likely to be the best way forward. However, if it is recurrent or diffuse then this where complexity can usually develop. These patients should be discussed in the multi-disciplinary meeting with histology and images reviewed and then it can be decided what treatment/surgery is needed, including potential clinical trials. Depending on the context, follow up should be between RNOH and UCLH. VK will see TGCT patients in his clinics and there will be the opportunity for collaboration with other centres. The CNS input still needs to be agreed, it would be more appropriate for CNS support to come from RNOH.

This pathway is for more complex cases (e.g. intraarticular) – this needs clarifying on the pathway, as well as contact details adding. More straightforward cases can be done at orthopaedic hospitals.

Action: VK to circulate a refined version of the pathway for everyone to agree.

4. Diagnostic Clinics Update

TJ stated that TCST through NHS Specialised Commissioning have commissioned 5 diagnostic sites for adult soft tissue sarcomas: Chel West, West Middlesex, Mile End, Croydon and for NCL Finchley Memorial or Wood Green. All sites apart from NCL are live. It has been agreed that the site for NCL will be Wood Green and this has been approved at various boards.

For Wood Green it will be a slightly different model with no ANP or surgeon. For GPs when they suspect a soft tissue sarcoma, they will refer directly to Wood Green. Wood Green will undertake imaging and any subsequent imaging if there is a suspicion of sarcoma within 5-7days. The GP will get the imaging report and then they will refer them to the appropriate centre where the cancer pathway would start. MRI and CT should be going live at Wood Green in January.

If RNOH continue to receive referrals without imaging from NCL geography Wood Green have agreed to do the imaging for these patients.
They have appointed two MSK radiologists and Ram (Radiologist at RNOH) will be working with them to ensure that they are trained and supported.
There will need to be ongoing monitoring through the SAG Oversight Board, to ensure that the diagnostic clinics are delivering the numbers agreed etc. A risk log for the SAG needs to include the diagnostic clinics, any risks and how they are being mitigated.

Action: TJ to pick up with Sue re commissioning agreements as funding has been removed from some of the services at RNOH to commission some of the CDCs

Comms will be going out to all GPs. Currently the 2WW referrals are still going to RMH and they redirect to the spokes. The comms needs to go to GPs first before the spokes can be open on ERS.

Email addresses are needed for all sites so that centres can redirect.

AH asked if the clinicians at the centres are in liaison with the clinical teams at the new spokes.
Ram, radiologist at RNOH has been working closely with the radiologists at the spokes and was involved in the appointment of the radiographer at Mile End.

CPL noted that NH is linking the nurses together.

There is a meeting being arranged with Kingston and they will be added back to the referral form. Follow-up is in progress with the Kingston team.

Referrals are still being diverted from RMH to RNOH. It was agreed that this divert should now be removed.

Action: Marguerite to remove 2WW divert messaging at RMH

5. Designated Practitioners

GF circulated the lists of chemotherapy practitioners and radiotherapy practitioners for the network. The documents have been reviewed with the oncologists in the centres and circulated to the practitioners for agreement. There are several practitioners who have not responded (in red on the document). Some people have queried the treatment timelines given on the radiotherapy document. MA explained that all centres are currently struggling to meet the preoperative radiotherapy targets, due to the volume of treatments. This needs to be re-worded – ideally the patient should be seen within 2 weeks of referral and radiotherapy to be started within 2 weeks of consultation and within target. This should be audited. The peer review process of assessing volumes and plans to ensure there is consistency in delivery of care across the region also need adding as this is an RCR requirement.

MM noted that two paediatric oncologists from Brighton need adding.

Action: RJ to go through the lists with GF, check the practitioners and amend the radiotherapy wording. This has been completed.

Action: SAG to write to host Trusts where oncologists have no CNS support (Kent)

NH gave feedback on the work he is doing with the nurses at the various diagnostic centres and explained that for the new post being put in place at Croydon they are looking at having a joint role with sarcoma and another speciality e.g. skin/gynae. AM suggested that NH links in with Sarcoma UK as they get lots of feedback from patients regarding the challenges that they are facing locally.

CG suggested running a workshop for CNSs across the centres, diagnostic clinics and to include the designated practitioners too. UCLH ran a workshop recently with attendance from CNSs across the region, however for areas without a CNS such as Kent they were not represented.

6. SAG Pathways

- Gynae, Thoracic, Spinal, H&N

The gynae pathway which was circulated with the papers and is almost ready to be signed off. It has been sent to the SAG and also to the gynae MDTs across the network, through the alliances. The only comment GF has received is regards to whole genome sequencing – the guideline says that fresh tissue should be frozen, however not all Trusts do this at the moment. It was agreed that this should be re-worded to 'if possible'.

Action: GF to add RCOG reference to Gynae pathway and amend RMH contact details – speak to CB. To be circulated and sign off.

Thoracic pathway – to be reviewed as per recent emails. MM noted that there will be a working party looking at the children's thoracic pathway across London.

Spinal pathway – almost complete, to be signed off the next meeting. The majority of surgery will take place at RNOH, with some cases better treated at Queens Square.
AM noted that RMH receive some radiotherapy referrals who have had spinal surgery at Imperial or St Georges. It was agreed that patients with primary bone tumours or soft tissue sarcomas involving bony spine should all be referred to LSS to include having radiotherapy at UCLH. This needs adding to the pathway.

Head and neck pathway – RJ to review this

7. NHS Commissioning Update

Liz Price has prepared a SAG Workplan update which was circulated with the papers.
DM talked through the slides, most of which had already been covered.

Regarding further diagnostic sites, the East of England and Kent have been less keen on having diagnostic sites, but they are trying to make progress on getting another site in East of England. South of England pathways exist already and there are good relationships with Brighton, Portsmouth and Southampton. There are ongoing discussions with a retiring clinician on whether one of those sites is merged with another when that person leaves however it is in early-stage discussions.

Evaluation framework – Transforming Cancer Services Team (TCST) and the SAG are going to apply for a research fellow to support on some of the work, specifically looking at auditing the implementation of the diagnostic sites.

Training for sonographers – TCST have submitted a paper to Sarcoma UK asking for funding to develop a training course for sonographers.

NH has been looking at the workforce data, and the next step is now to meet with an experienced clinician to understand the skills matrix and whether different roles can cover different tasks. AH and CG volunteered to help and suggested that NH meets with a range of specialties.

Cancer Waiting Times Data
DM talked through the CWT data. The current diagnostic centres are performing well and so deserve credit for continuing to provide a good service despite concerns on pressures on capacity.
The RMH 2WW performance was discussed, AH thinks the poor performance shown may be because RMH are not seeing the patients, but reviewing the imaging which does not count as a first appointment. The FDS performance is low and it is though that this may be a recording issue.

CPL noted that at C&W not all patients are put through an MDT which could cause a problem with their FDS performance. For the patients that are put through an MDT, the Faster Diagnosis Standard (FDS) Letter is sent. However, for the others they are in a backlog of patients waiting for a letter to be sent even though the imaging has been reviewed and is benign. There are also issues as CPL is currently the only person doing this role and has no cover - this will also be an issue at Croydon and Mile End.

TJ explained that at NCL are looking at the RNOH FDS performance as it is the lowest in NCL. RNOH are currently receiving approx. 100 2WW referrals per week and the Nurse Consultant is also off at the moment.

EP raised an issue at UCLH regarding poor 62 day performance (across all specialties, not just sarcoma) and there are particular capacity issues in radiotherapy. UCLH have been receiving radiotherapy referrals from South London and would like to push these back to RMH. This needs to be looked at in detail regarding where these patients would be managed as they would already be in the RNOH/UCLH pathway, but RMH are happy to take on ad-hoc cases when UCLH are having difficulties treating the patients. AH explained that historically there has always been a cross-sector flow of patients and the SAG has never tried to change this by insisting on geographical referral boundaries. CG added that the new diagnostic pathways may change the workflows across the centres. RNOH have treated patients who have been diverted from RMH on the 2WW pathway.

Action: RMH to look at the performance data and bring an update to the next meeting (AH and Marguerite)

8. WGS Progress Reports

FA and KT sent their apologies.
CG explained that at RNOH the number of patients being consented has decreased as currently no one is employed to help with this.

9. SAG AGM and Audits

It was agreed that the SAG AGM would be postponed for now as there are lots of operational issues to focus on.

The CWT data need auditing as already discussed.

The SAG has looked previously at the data which show that patients are treated outside sarcoma centres, and it would be useful to audit these data in more detail to see if treatments are administered by SAG approved designated practitioners.

CPL suggested that the new fellow at C&W may be able to help with audits and will send GF her details.

10. Trials

Action: GF to circulate trials lists following the meeting

11. Any Other Business:

The next meeting will be face to face, followed by drinks.

Action: GF to circulate meeting dates for next year

Dates of the next meetings 2023:

- Friday 8th December 3-5pm

Attendees:

Mabs Ahmed	Consultant Clinical Oncologist, UCLH
Jo Coleman	Advanced Nurse Practitioner, RNOH
Palma Dileo	Consultant Medical Oncologist, UCLH
Gemma French	SAG Project Manager
Craig Gerrand – CHAIR	Consultant Surgeon, RNOH
Hel Havard	Consultant Surgeon, RNOH
Andy Hayes	Consultant Surgeon, RMH
Nate Hill	Workforce Lead and Senior Project Manager, RMH
Robin Jones	Consultant Medical Oncologist, RMH
Tanya Joseph	Director of Operations, RNOH
Vasilios Karavasilis	Consultant Medical Oncologist, UCLH
Alvi Khan	Senior Operations Manager, RNOH
Marguerite Meintjes	Deputy Director, RMH
Aisha Miah	Consultant Clinical Oncologist, RMH
Maria Michelagnoli	Consultant Paediatric Oncologist, UCLH
Daniel Mercer	Cancer Diagnostics Support Manager, TCST
Andrea Napolitano	Consultant Medical Oncologist, RMH
Emily Pegg	Deputy Divisional Manager, UCLH
Avinash Pilar	Locum Clinical Oncologist, UCLH
Cerys Propert-Lewis	Advanced Nurse Practitioner, C&W
Helen Ruane	Programme Manager, Wessex Cancer Alliance
Dirk Strauss	Consultant Surgeon, RMH