UCLH Cancer Collaborative
The Cancer Alliance for north and east London

RM Partners
West London Cancer Alliance
Hosted by The Royal Marsden NHS Foundation Trust

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 12th March 2021, 15.00-17.00
Venue: MS Teams
Chair: Jeremy Whelan (JWh)

1. Welcome and Introductions

AH welcomed members to the meeting and noted the following **apologies**:

Shameen Jaunoo (SJ)	Consultant Oesophagogastric Surgeon	RMH
Beatrice Seddon (BMS)	Consultant Clinical Oncologist	UCLH
Myles Smith (MS)	Consultant Surgeon	RMH

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
JWo/SH to make contact with CNS' at RMH re PCC. (Alison) and feedback at the next meeting	JWo/SH	Dec 20	Mar 21
Whole Genome Sequencing to be added as standard item on the agenda with progress reports brought to the SAG	GF	March 21	Ongoing
A subgroup of the SAG to meet to discuss the 2WW Pathway	JWo/AH	March 21	June 21
BMS to provide update to SAG re GISTs at Mount Vernon	BMS	March 21	June 21
GF to work with PD and SG on GIST and Gynae Pathways	GF	March 21	
GF to contact RMH CNS re patient representation and add to Work Programme	GF	March 21	June 21
Letter to be drafted re pathology pathway	Ah/JWh/AF	March 21	June 21
GF to ensure the website is on the SAG Oversight Board meeting agenda	GF	March 21	June 21

Previous minutes were agreed.

Brighton surgeons were unable to attend the meeting today. It was agreed that no further discussion was needed. Await comments when GIST pathway is circulated for consultation.

3. Whole Genome Sequencing Pathway

RNOH consented their first patient for WGS last week. As advised by GOSH they will be sending one per month to begin with and will increase numbers when instructed to do so. The pathway at RNOH is that the patients are identified at the beginning of the pathway and then consented at biopsy. When requesting a biopsy for a patient the booking system asks if there is a high/medium suspicion of sarcoma. If this box is ticked there is then the option to order bloods for WGS. The CNS consents the patient. 6-8 cores are taken at biopsy and are brought fresh on ice to the histopathology lab who process the tissue as normal, assess microscopically and freeze part of the tissue. If a sarcoma is diagnosed the consent form, blood and tissue is sent to GOSH. RNOH are

cutting the tissue themselves.
RNOH/UCLH have been having monthly working group meetings for over 2 years to develop the pathway.

RMH have had a few meetings to discuss WGS and potential issues in the pathway. RMH have a different diagnostic pathway to RNOH in that the surgeons perform most of the biopsies themselves during the first OPA, as a one-stop service. This makes it difficult for the consent to be done by the CNS. The infrastructure also doesn't currently exist for the storage of tissue, the lab at RMH is a general lab not a sarcoma lab and there are no facilities to do the RNA extraction. All tissue is currently stored in formalin, not fresh/frozen so this needs a complete reorganisation of the lab.

SUHT have a different model with the pathway split into two parts. The tissue consent has been combined with the biopsy so when the patient consents for biopsy they also consent for WGS. Patients are identified pre-biopsy and their tissue is frozen. If the patient then subsequently consents for germline at this point the frozen sample is checked for tumour before sending to their GLH in Birmingham. SUHT have been freezing samples for 6 months so if any of these patients relapse they can be sent for WGS.

AF explained that Genomics England and NHS England is keen for sarcoma to make this work. As this is a rare cancer it will take years to collect the data. The 100k genome data will be published soon.

Sarcoma UK have developed a WGS factsheet which is on their website which means patients may ask for WGS.

AH asked if NHS England can provide support to Trusts for this piece of work. Investment is needed for people to be able to do the work. AF suggested that RMH look at what it is they need – map out the pathway and identify the gaps.

The SAG agreed that funding to support the collection of samples would facilitate the implementation.

JWh added that it is the responsibility of the SAG to monitor this – how easily can patients access WGS within out network, keep track of the number of patients undergoing WGS. RNOH have been working on the pathway for patients biopsied at RNOH but there is still a lot of work to do to identify how this process will work for patients biopsied outside of RNOH, even at UCLH.

Action: Keep WGS on the agenda. Work on informative progress reports to the SAG.

4. Covid-19

RNOH
During this current wave RNOH were a covid hospital for a while but the sarcoma caseload was not affected. The recent data is showing a decrease in the number of sarcoma diagnoses in this last year and so there is a concern that patients with sarcomas are not being referred to the service. There was a discussion re moving sarcoma paediatric patients to GOSH/RMH but this did not happen. RNOH is now almost covid free. There is no backlog of sarcoma patients and no breaches. They are trying to identify patients in the service who have been delayed/disadvantaged by covid but there doesn't appear to be many patients affected.

PD noted that she saw a patient with a delayed referral today and will speak to CG/JWo separately.

UCLH

PD updated that UCLH seem to have been in better shape during this wave compared to the first wave and it is pretty much business as usual for the sarcoma department. Clinicians are starting to see more face-to-face patients.
MA added that there have been no radiotherapy delays. There have been some modified regimes but generally patients have been treated in a timely manner.

RMH

RMH are also concerned about a decrease in diagnoses as they have seen their RPS diagnoses decrease. Access to chemotherapy is unchanged, they are doing more telephone clinics which increases admin time. Feeling that they are seeing some later presentations. SZ explained that there haven't been any issues re radiotherapy treatments and they have been able to use standard fractionation schedules. Patients are requesting treatment closer to home and thanked the extended MDT members for delivering treatments in a timely manner.

SUHT

SUHT have been working fairly normally and there have been no real issues. There was a previous issue in getting access to MRU but that seems to be resolved now.

5. Diagnostics

AH updated that the Kingston clinic model is working well. The Croydon diagnostic clinic started about 6 months ago. The link into the pathology service at RMH is not streamlines so they currently use St George's pathology service. It has highlighted that engagement is needed from the pathology team from the outset.
They have had a request from Chelsea & Westminster to set up a diagnostic clinic there. Work is ongoing to ensure that they are able to provide a high quality diagnostic service but there hasn't been much progress due to Covid.
RMH have a new member of the team – Jonathan Hannay, Consultant Surgeon

JWo explained that she GF, TJ and AH met with the TCST team before the 2nd wave of Covid to talk about 2WW pathways. RNOH have tried to replicate the RMH triage process as a pilot for the last few weeks and have had 248 referrals of which 68 had no imaging. 109 patients were discharged back to the GP and of these 6 were re-referred. The pilot has shown that there are lots of GPs across NCL who are saying that they do not have access to imaging.
The TCST team have asked us to develop better advice and guidance so that GPs are able to look after some of these patients before referring. TJ at RNOH has suggested that we go back to TCST once we have mapped our pathway and our ideal solutions. AH agrees with this.

Action: A subgroup of the SAG to look at the 2WW pathway

6. Service Specification Implementation

a. SAG Hosting

Jwh gave some background information that there is a requirement in the service specification for all SAGs to be hosted. It has been agreed that all 3 trusts (RMH, RNOH, and UCLH) will co-host the SAG. A SAG Oversight Board with representation from management at the 3 Trusts, local commissioning and NHS England need to meet and start the appointment process for the SAG

Chair and Deputy and Project Manager. The group was due to meet earlier this year but this was cancelled due to covid pressures. New dates have been proposed and are awaiting agreement. In preparation for this meeting new TORs have been drafted and are awaiting approval by the Oversight Board.

b. Review Workplan

GF shared the draft work program which the SAG will need to work through once the new appointments are in place. The program is missing 'ensuring guidelines are in place and updated' but this can be added. The new SAG Chairs and Project Manager will be responsible for refining the work programme and bringing to their first SAG.

c. Pathway Revision

The SAG has various pathways which are out-of-date and need to be reviewed. Some pathways are absent including spinal. GIST, H&N and Spinal are the most urgent pathways to be reviewed. It is difficult to get this work done without the Project Management support.
Sarcoma UK have recently brought to our attention that GIST patients in Hertfordshire are not following the appropriate referral pathway. BMS has been in contact with the oncologist at Mount Vernon regarding this and they will be discussing this further.

Action: BMS to provide update to SAG once discussed with MV Oncologist

MA has been working on the H&N pathway and has been in touch with AM. MA is meeting with GF after Easter and then will share the draft pathway with AM and SZ before bringing to the next SAG meeting.
PD and SG volunteered to help with the GIST pathway and PD volunteered to help with the Gynae Pathway. SS has been looking at GIST data nationally which can feed into this.
JWo will speak to RNOH team re spinal pathway

Action: GF to contact volunteers re this work and share current pathways and relevant parts from the service specification

CG is a member of the Cancer Surgery CRG and informed the group that the quality dashboard has been suspended due to Covid and is now with the Quality Surveillance team. CG has flagged that there is an old spec on the website but this is still not resolved. The H&N service specification will be published soon. JWh had previously commented on the H&N and UGI specifications when he was on the Cancer CRG but suggested that CG checks any new drafts that are circulated.

7 Patient Feedback

The SAG welcomed KC to the meeting and thanked her for attending the meeting.

KC asked about WGS and whether a recurrent sarcoma presenting at RBH would be eligible.
Recurrent sarcomas are eligible for WGS and RBH will need to be included when we are reviewing patients presenting at hospitals outside of RNOH.

AH explained that even though WGS is not available for all patients now, all patients have access to next generation sequencing and all the tests that are available at the moment.

There are currently two patient representatives on the group – KC and Alvin Trowbridge. It was suggested that we ask for more volunteers now that the group is run virtually.

Action: GF to contact RMH CNS' and Stephanie O'Neil, ANP re interested patients. Add patient

involvement into SAG Work Programme, highlighting attendance and how best to contribute to quality of care.

8. Governance

Nothing noted

9. AOB

Biopsy Pathway

AF raised an issue they have seen at RNOH with regards to biopsies at Kings Hospital being sent to Birmingham for review which delayed the patient pathway. There is no criticism of the Birmingham pathology review but concern regarding the delay to the pathway.
AF has spoken to the pathologist concerned who is quite new in post and suggests that some education and support is needed.

PS added that they regularly have samples sent to Birmingham from Portsmouth and it almost always delays the diagnostic pathway. DS suggested that PS talks to the histopathologists at Portsmouth again, RMH had a similar issue a few years go.

Action: AH and JWh to draft a letter to pathology departments in the Network with input from RNOH and RMH pathologists

There also needs to be some work done to educate histopathologists as cases are being worked up locally with tests that are inappropriate and expensive.

LSESN Website

The RMH Communications team had previously sent through some options for updating the website following a meeting with JWh and GF. GF has since drafted a paper which she was planning to take to the SAG Oversight Board when it meets, essentially asking if there is resource available to fund the improvement of the website.

Action: GF to ensure the website is on the SAG Oversight Board meeting agenda

Date and location of next meeting

Friday 11th June 2021, 15:00 – 17:00 MS Teams

Present:

Mabs Ahmed (MA)	Consultant Clinical Oncologist	UCLH
Zina Aladili (ZA)	Consultant Clinical Oncologist	Southend
Fernanda Amary (FA)	Consultant Histopathologist	RNOH
Lee Bayliss (LB)	Consultant Surgeon	RNOH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Kirstene Caine (KC)	Patient Representative	

Marc Delon	Programme Lead	NCL
Palma Dileo (PD)	Consultant Medical Oncologist	UCLH
Rebecca Exton (RE)	Consultant Surgeon	SUHT
Adrienne Flanagan (AF)	Consultant Histopathologist	RNOH
Gemma French (GF)	Sarcoma Improvement Manager	UCLH/RNOH
Spyros Gennatas (SG)	Locum Medical Oncologist	RMH
Craig Gerrand (CG)	Consultant Surgeon	RNOH
Franel le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Hel Havard (HH)	Consultant Surgeon	RNOH
Andrew Hayes (AH)	Co-chair of SAG and Consultant Surgeon	RMH
Alessandra Maleddu (AM)	Locum Medical Oncologist	UCLH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Maureen McGinn (MMc)	Senior Project Manager	RM Partners
Peter Simmonds (PS)	Consultant Medical Oncologist	SUHT
Dirk Strauss (DS)	Consultant Surgeon	RMH
Sandra Strauss (SS)	Consultant Medical Oncologist	UCLH
Khin Thyway (KT)	Consultant Histopathologist	RMH
Vanessa Topp (VT)	Deputy Divisional Director, Cancer Services	RMH
Jeremy Whelan (JWh)	Consultant Medical Oncologist	UCLH
Julie Woodford (JWo)	Nurse Consultant	RNOH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH