London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 17th September 2021, 15.00-17.00
Venue: MS Teams
Chair: Andrew Hayes (AH)

1. Welcome and Introductions

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

Fernanda Amary (FA)	Consultant Histopathologist	RNOH
Piers Gatenby (PG)	Consultant Surgeon	RSCH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Franel le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Emily Pegg (EP)	Deputy Divisional Manager - Cancer Services	UCLH
Khin Thway	Consultant Histopathologist	RMH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	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
A subgroup of the SAG to meet to discuss the 2WW Pathway. GF to ask for expressions of interest and coordinate meeting	JWo/AH/GF	Mar 21	Dec 21
BMS to provide update to SAG re GISTs at Mount Vernon	BMS	Mar 21	Dec 21
GF and JWo to approach Sarcoma UK re patient representation at the SAG	GF/JWo	Sep 21	Dec 21
Letter to be drafted re pathology pathway	Ah/JWh/GF	Mar 21	Jun 21
CS to communicate with Steve Russell re genomics at RMH	CS	Sep 21	Dec 21
GF to work with BMS and SS on data sharing template and pathway	GF/SS/BMS	Sep 21	Dec 21
GF to add to add SUHT Service Update to beginning of next agenda	GF	Sep 21	Dec 21

Previous minutes were agreed.

The Follow-Up guidelines were signed off.

3. Appointment of new chair and co-chair of LSESN SAG

Job descriptions have been circulated for the Chair and Deputy Chair of the SAG.

JWh resigned from clinical practice some time ago and has recently stepped down as Co-Chair of the SAG. AH will be resigning as Co-Chair at the end of this year.

AH formally thanked JWh for co-chairing the SAG with him for the last 10 years, for leading the work of the SAG and for bringing the two sarcoma centres together.

The new posts advertised are not too different to the posts now, although specific requirements from the service specification have been added. They have 0.5PA attached to them. There is now a SAG Oversight Board in place with representation from the 3 Trusts to ensure that the SAG is carrying out its' role effectively.

Expressions of interest are now welcome. The Chair and Deputy Chair will need to come from both MDTs i.e. the two positions cannot be covered by one MDT.

4. 2WWs

AH welcomed Dr Saker to the meeting and gave some background to the 2WW sarcoma pathway and particularly the increase in 2ww referrals over the last few years. The conversion rate for both centres has always been around 5%. The original NICE guidance was based on clinical criteria developed by Rob Grimer and included criteria such as pain, and a lump increasing in size. The national guidance to suggest the requirement of a rapid access ultrasound before urgent referral was published in 2016 and was based on published data from Leeds which showed that ultrasound is an excellent triage model for identifying sarcomas.

JWo presented some slides from a 2WW audit that she and GF and done following a meeting with LM and NCL where it was agreed to provide some data. JWo and GF looked at a 3 month period of 2WW referrals received from East and North Herts, Herts Valley, West Essex and NCL. The volume of referrals differs between these CCGs and there is also variation in the quality of the referrals received. West Essex for example generally referred patients with an ultrasound done by a consultant radiologist, often then having an MRI scan and then referring in a small number of patients to RNOH. This CCG had a higher % of sarcomas from referrals. In Herts there were some GPs indicating that they could not access ultrasound but other GPs in the same CCG or GP practice did access ultrasound. Some GPs referred up to 4 patients per week with a suspected sarcoma. NCL referred a significantly higher number of patients during the time period and so only a proportion of these referrals were looked at in detail. Ultrasound in NCL tends to be done by In Health which then usually leads to advice to refer to a specialist centre.
To summarise - the quality of referrals differs and there are more patients referred without imaging following the pandemic. Most of the patients diagnosed with sarcoma at RNOH do not come through the 2WW pathway but through other routes and still with late presentation. Access to ultrasound is variable across and within CCGs. Often imaging reports say benign but advise referral to sarcoma centre anyway. Patients are often not aware of referral to sarcoma centre but told that they have been referred for an MRI scan. There are an increasing number of patients referred with haematological lesions or metastatic bone cancer. RNOH are trying to refer patients to CUP teams but sometimes CUP teams will not see patients.
Potential solutions suggested include consistent approach to triage, access to local diagnostic hubs, advice and guidance service, directory of CUP teams and revision of 2WW form.

LM explained that NCL is in support of RNOH making changes to the pathway and advised that the 2WW form is changed as currently there is a box which says that the patient can be referred without imaging. NCL has implemented a direct access diagnostics form and now needs to understand the clinical criteria so that this form can be changed. There will need to be some communications to GPs to communicate the new pathway. LM reinforced that the pathway needs to be in line with current Cancer Waiting Times standards. The 2WW target may be reviewed if the 28 day FDS standard can be met.

AH explained that there is a box on the 2ww form to allow GPs who see an obvious sarcoma to refer patients without imaging.
The 2WW form need to be tweaked so that only useful information is included (not several pages) and that it is clear why the patient is being referred.

RMH do not accept patient referrals that do not have an attached ultrasound. Therefore their biggest issue is inappropriate referrals on the basis of an ultrasound. Quite often the ultrasound report will advise specialist referral and there is currently no other obvious route other than to the sarcoma service. RMH triage these patients and send a detailed letter to the GP of their findings and recommendations.
AH explained that RMH have been working on the 'hub and spoke' model for a number of years and have developed services at Kingston, West Mid, Croydon and hopefully Chelwest soon so that the patients with non-sarcoma lumps can been seen and treated appropriately. These diagnostic services have links with the RMH Sarcoma MDT.
NP spoke about his experience running the West Mid Diagnostic Clinic. They have seen increasing amounts of 'I cannot exclude…' in the radiology reports. He rejects about 10% of referrals because of lack of ultrasound but if the no access to U/S box is ticked he does the ultrasounds. They have an advanced diagnostic centre with the oncologists to speed up diagnoses for patients who do not meet 2ww criteria and so they see some of these patients. There a weekly meeting with radiologists (including a radiologist with expertise in sarcoma) to try to minimise use of MRI and use external ultrasound/repeat internal ultrasound where possible. Approx. 60% of their patients have some form of surgical intervention.
Sri, surgeon at Kingston gave an update re the soft tissue diagnostic service at Kingston. Sri triages the 2ww referrals. The main issue is also the ultrasound reports which state benign conditions but which cannot exclude sarcoma. Kingston will do the biopsies and if concerning will transfer to RMH MDT. Kingston also sometimes receives suspected bone referrals and will refer to RNOH as appropriate. They also have a high percentage of patients having surgery.

JP discussed examples of cases he has had where the local CUP team will not accept patients until they have had a biopsy. CG has also had this issue where it is clear that the patient has metastatic disease and not sarcoma.
CG said it would be good to have a map of local services for GPs to have and explained that RNOH are struggling to do their core business with all these other issues, and are providing a disservice for patients with sarcoma. It was discussed and confirmed by LS that GPs currently do not have a pathway for which to send the non-cancerous lesions.

5. SAG Diagnostics Subgroup

A subgroup of the SAG needs to be created to focus time on resolving the issues described above. Representation is needed from Primary Care, Diagnostic Centres, TSCT, Trust Management and Pathology

Action: GF to coordinate a Teams meeting. 45 mins, every 2 months. Circulate email re expressions of interest to join this meeting.

6. Covid-19

UCLH – BMS explained that chemotherapy and radiotherapy pathways remain unchanged.

RNOH – Sarcoma continues to be a protected pathway. RNOH are providing mutual aid lists for NCL, providing orthopaedic surgery for patients on long waiting lists, mainly from RFH. There could potentially still be impacts on the service because of isolation rules because if a household member tests positive staff are still required to self-isolate.

RMH – 10 day isolation for surgery makes it quite difficult but all treatments are continuing as normal.

7 Feedback from the SAG Chairs Group and Service Specification Implementation

The SAG Chairs Group has been meeting virtually and will be meeting face to face in Birmingham in November. This group is tasked with ensuring implementation of the sarcoma service specification uniformly across the country. AH will be attending the meeting in Birmingham.

PHE have been collating some excellent data re disparity of treatment which was presented by SS at the BSG. This will be presented and audited.

The Quality Dashboard at the end of the service specification has been reduced and has still not been signed off or being collected and so we are not measuring how services are performing against the service specification.

8. WGS Progress Reports

RNOH:

AF updated that RNOH have had a few cases put through but numbers have dropped recently. The WGS information can gives us huge amounts of data and as a rare disease it is important for us to collect this and build on the dataset.

CG updated that from June to August there were 82 sarcomas diagnosed at RNOH and 18 of these were consented for WGS. Of those 18, 14 were sent and 4 were either not suitable or not diagnosed with sarcomas. RNOH are trying to consent as many patients as possible but there are a few logistical issues which need to be worked through. There are also some concerns with interpretation of results as in the 100k genome project there was a specific MDT for these patients to be discussed.
AF explained that there is an ongoing discussion re employing someone at a national level to analyse the data. There may be some additional funding for this.
AF has sent out research consent forms to all patients missed during covid (nearly 1500 consent form). Nearly half have been returned giving consent.

RMH:

There have been no further developments at RMH. It is becoming an expectation from patients and it was agreed there needs to be engagement in the process.

Action: CS to communicate with Steve Russell re updates on this and future genomics meetings

9. Data sharing for research/audit collaborative studies across Trusts - opportunities and barriers

BMS had approached the oncology team at RMH re helping with a project at UCLH on pelvic

radiotherapy in gynae sarcomas. UCLH had an interesting finding and needed increased number of patients to verify it. After some discussion the RMH felt that they were unable to help and one of the barriers was because a data sharing agreement was needed which was going to be time consuming. This is a barrier for any hospitals to work together in audit and research. The two trusts should be working together for patient benefit. There have been similar issues for the paediatric oncology teams at UCLH and RMH to work together also. SS suggested we work towards setting up a general agreement template that needs to be submitted each time.

Action: GF to work with BMS and SS on data sharing template and pathway

AM suggested that the data is presented from both centres at a SAG meeting in future in the meantime

10. Governance

Refer to item 5
No other issues

11. AOB

GF noted that RNOH and UCLH are updating the tertiary referral form. This will be updated and communicated throughout the network soon.

PS suggested that it may be useful for SUHT to present their sarcoma diagnostic activity and plans

Action: GF to add to the beginning of next agenda

Date and location of next meeting

Friday 10th December 2021, 15:00 – 17:00 MS Teams

Present:

Yolanda Augustin (YA)		
Lee Bayliss (LB)	Consultant Surgeon	RNOH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Kirstene Caine (KC)	Patient Representative	
Jo Coleman (JC)	Advanced Nurse Practitioner	RNOH
Elliann Fairbairn (EF)	Strategy Implementation Lead	TCST
Gemma French (GF)	Sarcoma Improvement Manager	UCLH/RNOH
Adrienne Flanagan (AF)	Consultant Histopathologist	RNOH
Craig Gerrand (CG)	Consultant Surgeon	RNOH
Andrew Hayes (AH)	Co-chair of SAG and Consultant Surgeon	RMH
Hel Havard (HH)	Consultant Surgeon	RNOH
Tanya Joseph (TJ)	Divisional Head of Operations	RNOH
Caroline Macfarlane (CM)	Consultant Clinical Oncologist	SUHT/RMH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Lucy Mclaughlin (LM)	Head of Cancer Commissioning	NCL
Maria Michelagnoli (MM)	Consultant Paediatric Oncologist	UCLH

Julia Odzilli (JO)	Associate Director	TCST
Stephanie O'Neill (SN)	Advanced Nurse Practitioner	RMH
Nikhil Pawa (NP)	Consultant Surgeon	ChelWest
Jonathan Perera (JP)	Locum Consultant Surgeon	RNOH
Lance Saker (LS)	GP and Primary Care Diagnostics Lead	TCST
Beatrice Seddon (BS)	Consultant Clinical Oncologist	UCLH
Peter Simmonds (PS)	Consultant Medical Oncologist	SUHT
Parameswaren Sridhar (PSr)	Consultant Surgeon	Kingston
Chris Stone (CS)	Service Manager	RMH
Sandra Strauss (SS)	Consultant Medical Oncologist	UCLH
Julie Woodford (JWo)	Nurse Consultant	RNOH