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 18th September 2020, 15.00-17.00
Venue: MS Teams
Chair: Andy Hayes (AH)

1. Welcome and Introductions

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

Kirstene Caine (KC)	Patient Representative	
Palma Dileo (PD)	Consultant Medical Oncologist	UCLH
Piers Gatenby (PG)	Consultant Surgeon	RSCH
David Sallomi (DS)	Consultant Radiologist	ESHT
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
GF to bring LSESN website update to next meeting once quotes received	GF	Sep 20	Dec 20
GF to circulate RM Partners data slides with miniutes	GF	Sep 20	Dec 20
BMS to revise follow-up guidelines, with help from PD, PS, CG, HH, MM, SG	BMS	Jun 20	
JWo to circulate patient feedback paper	JWo	Jun 20	Sep 20
MK to take GIST discussion back to Chief Exec and feedback at next SAG meeting	MK	Sep 20	Dec 20
GF to add TCST 2WW Meeting feedback to next agenda	GF	Sep 20	Dec 20
GF to add RMH Update of Developing Diagnostic hubs to next agenda	GF	Sep 20	Dec 20
GF to circulate NCPES results to core members of SAG	GF	Sep 20	Dec 20
SS to work with RMH volunteers on designated surgery practitioners spreadsheet	SS	Sep 20	Dec 20
SS to look at paediatric pathway data	SS	Sep 20	Dec 20

Previous minutes were agreed.

3. SAG Hosting

The SAG needs to be hosted by a Trust. An MOA has been drafted for the 3 Trusts (RNOH, RMH and UCLH) to co-host the SAG. RNOH and UCLH have signed the MOA. Signature is awaited from RMH. Defined hosting of the SAG will provide us with a reporting and management structure and financial support. Once the MOA has been signed off there will need to be an appointment process for the Chair, Deputy Chair, Project Manager and Admin support. It is hoped that the Oversight

Group would have met and started the appointment process before the next SAG meeting in December.
CS has chased for the signature at RMH and would anticipate having this by early next week.

3. Brighton GISTs

Shameen Jaunoo and Mansoor Khan, Consultant UGI Surgeons at Brighton attended the SAG to discuss GIST surgery at Brighton.

The attached letter summarises the discussion

Letter from AH to Brighton Sep 20.pdf

Action: MK will take the comments from this meeting back to his Chief Executive and feed back at the next SAG meeting in December

4. Covid 19

CG updated that RNOH are trying to resume to business as normal. 2WW referrals had decreased during Covid and they are now seeing long waits and patients with late presentations. JWo noted that they are recently seeing even more inappropriate referrals than pre-covid. For many 2WW referrals the GP has ticked the box to say no access to local imaging and there have been some referrals which have quoted the c the signs guidelines.

RMH 2WW numbers are back to what they were pre-covid and they are also seeing later presentations at diagnostics. RMH have a strict consultant triage process and will not see patients without prior ultrasound imaging. They are able to see fewer patients at follow-up due to social distancing measures but expressed that the format of FU needs to change in the longer term.

SS noted that at UCLH CT Chest scans were delayed in a small number of patients. There were difficulties obtaining local chest x-rays for patents which took 1 hour of admin time per patient and it was decided that this was not sustainable in the long term. Telephone clinics worked for some patients but not others. BMS explained that there is a significant admin burden converting face-to-face clinics to telephone/video clinics. The Consultant has to go through the clinic list to identify which patients need which appointments and then the admin staff have to call the patients to rearrange the appointments. UCLH now has a lower threshold for bringing patients into clinic as they experienced some poor consultations during lockdown.

RMH also faced similar difficulties and did not do chest x-rays locally. CB explained that they have also had issues getting local blood results for oral treatments and agreed with BMS that telephone appointments are not necessarily quicker or more efficient for staff.

RNOH have been more successful at organising local chest x-rays bit had admin support to chase results. Longer term this may need a band 4 support worker for clinics.

PS updated that at SUHT all FU appointments are defaulted to telephone clinics and once the patient is phoned if it is felt that they would benefit from a face to face appointment this is arranged. He shares others views that for new patients it is better to have face-to-face clinics. PS has been involved in the testicular pathway at SUHT which has had success obtaining local tests and results. SUHT employed dedicated admin support for this, including tracking patients to ensure that they attend appointments.

Since the last SAG JWo has had a 2WW meeting with TCST who have suggested that we could provide some advice and guidance so that GPs can hold the patients. A follow-up meeting is being arranged which AH would like to attend.

Action: GF to add feedback from TCST meeting to next SAG agenda
Action: GF to add Developing Diagnostic hubs (RMH update) to the next SAG agenda

5. FU Guidelines

A revision of the LSESN Follow-Up Guidelines is still outstanding. BMS is hoping to draft at the end of this month and the will circulate to those who volunteered last month for review. JWo asked if the different models of FU care could also be addressed in these guidelines.

Action: BMS to contact GF re when to put back on the agenda

6. National SAG Chairs Group

AH updated that the SAG Chairs have recently met virtually which went well. They are meeting again in December and will report back to this meeting. Current projects include a small research protocol.

7. Patient Feedback, including NCPES

No feedback has been received from the patient representatives of the SAG.

JWo summarised the recent National Cancer Patient Experience results. 57 patients completed the survey at both RNOH and RMH, however only 20 patients completed the survey at UCLH and so UCLH data has been excluded due to the sample being too small.
At RNOH improvements were seen regarding communication, which may reflect the change in practice that the Consultant now gives the diagnosis at RNOH, not the registrar. RNOH did not score very well on patients being asked to participate in research. The freetext comments provided more useful information, and were mostly positive.

Action: GF to circulate NCPES results to SAG

7. Governance

No issues raised. To remain as a regular agenda item.

8. AOB

Virtual BSG Conference 2021
AH updated that the BSG Conference next year will now be a virtual conference and encouraged all members of the Sarcoma MDTs to register. The registration fees are very small due to the conference being virtual. AH reminded the group that the BSG relies on the registration fees to continue running as an organisation.

Designation of specialist centres
SS has been working with NCRAS for the last few months on sarcoma coding and needs greater

granularity around anatomical sites. SS presented the spreadsheet which delineates each site-specific surgical service (e.g. extremity, retroperitoneal, skin, breast etc.) and this needs to be finalised so that the data be analysed. There are 6 years of data available. LSS has reviewed the spreadsheet and SS would now like help from RMH. SS would like to finalise this is the next few weeks before disseminating nationally. It was also noted that the data is from 2013-2018 and so the timing of centre designation needs to be considered.

Action: SS to work with DS on retroperitoneal sarcomas, AM on gynae and head & neck sarcoma. PS will look at designation for SUHT.

JWh noted that once this work is complete we need to refresh our designated practitioner list and guidelines.

MM asked if we can look at the pathways for children. Particular areas of concern are head & neck, thoracic and spinal. JWh agreed that we need to use the SAG forum for reviewing paediatric pathways.

Action: SS to look at national paediatric data

Date and location of next meeting

Friday 11th December, 15:00-17:00 MS Teams

GF to set and circulate dates for 2021

Present:

Mabs Ahmed (MA)	Consultant Clinical Oncologist	UCLH
Fernanda Amary (FA)	Consultant Histopathologist	RNOH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Carl Francis	Senior Transformation Project Manager	NHSE
Gemma French (GF)	Sarcoma Improvement Manager	UCLH/RNOH
Craig Gerrand (CG)	Consultant Surgeon	RNOH
Andrew Hayes (AH)	Co-chair of SAG and Consultant Surgeon	RMH
Shameen Jaunoo	Consultant Surgeon	BSUH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Tanya Joseph (TJ)	General Manager, Sarcoma & JRU	RNOH
Nicola Keay (NK)	Consultant Medical Oncologist	SUHT
Mansoor Khan (MK)	Consultant Surgeon	BSUH
Franel le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Maria Michelagnoli (MM)	Consultant Paediatric Oncologist	UCLH
Maureen McGinn (MMc)	Senior Project Manager	RM Partners
Emily Pegg (EP)	Deputy Divisional Manager	UCLH
Beatrice Seddon (BMS)	Consultant Clinical Oncologist	UCLH
Peter Simmonds (PS)	Consultant Medical Oncologist	SUHT
Sunil Skaria (SSk)	Consultant Clinical Oncologist	Ipswich
Chris Stone (CS)	Service Manager	RMH
Dirk Strauss (DS)	Consultant Surgeon	RMH

Sandra Strauss (SS)	Consultant Medical Oncologist	UCLH
Jeremy Whelan (JWh)	Co-chair of SAG & Consultant Med. Oncologist	UCLH
Rachael Windsor (RW)	Consultant Paediatric Oncologist	UCLH
Julie Woodford (JWo)	Nurse Consultant	RNOH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH