North Central London Cancer Alliance

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 11th June 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**:

Spyros Gennatas (SG)	Locum Consultant Medical Oncologist	RMH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Aisha Miah (AM)	Consultant Clinical Oncologist	UCLH
Andrew Nicholson (AN)	Consultant Histopathologist	RBH
Emily Pegg (EP)	Deputy Divisional Manager - Cancer Services	UCLH
Myles Smith (MS)	Consultant Surgeon	RMH
Beatrice Seddon (BMS)	Consultant Clinical Oncologist	UCLH
Sandra Strauss (SS)	Consultant Medical Oncologist	UCLH
Jeremy Whelan (JWh)	Co-Chair of SAG	UCLH

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
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 chase RMH CNS again re patient representation on SAG	GF	June 21	Sept 21
Letter to be drafted re pathology pathway	Ah/JWh/AF	March 21	Jun 21
GF to give feedback to BMS on behalf of the SAG re the follow-up guidelines	GF	June 21	Sept 21

Previous minutes were agreed.

3. Covid-19

UCLH:

Oncologists are seeing more and more patients face-to-face, however some patients still being seen via video/telephone consultation. Clinics are busier than ever, possibly because of an influx of referrals post-covid. No particular concerns re chemotherapy other than usual pressures in day-care and ambi-care.

RNOH:

Referrals are increasing post-covid. RNOH are putting a recovery programme in place to catch up on activity lost during the pandemic. They are planning for wave 3 (peak expected in August). More patients are being seen face-to-face but they are still trying to see as many patients as possible virtually.

RMH:
Activity has returned to normal. Virtual consultations continue (telephone and face-to-face rather than video) Referral load is high and they are seeing late presentations as predicted.

SUHT:
Activity has returned to normal following the pandemic. Workload is high.

4. Diagnostics

RNOH:
JWo – RNOH are seeing more 2WW patients referred with no imaging. They are in discussions with NCL re the difficulties of this. GP access to ultrasound varies across London. A consultant has been triaging 2ww referrals when received – some are redirected back to GPs for ultrasound. There has recently been resistance to this from GPs, which has also been discussed in NCL forums. There is now an opportunity to review the pathway and the 2WW referral form.
TJ has spoken to Lucy Mclaughlin, Head of Cancer Commissioning at NCL. RNOH are not aware of the areas which have direct access to ultrasound. Lucy is finding out which areas have Rapid Diagnostic Clinics (RDCs), obtaining a map of this and finding out what plans are in place for areas that don't have access. Lucy has also sent through the direct access diagnostic form but this does not have ultrasound for suspected soft tissue sarcoma or xray for suspected bone sarcoma on it. The form is therefore not going to meet our needs so TJ has asked if we can add this to the form – this will be picked up through the NCL imaging workstream.
TJ agrees that we need to revise our 2WW form as there is a box to tick if the GP does not have access to imaging so this therefore gives GPs the option to refer without imaging.
AH asked TJ to speak to Chris Stone as RMH had the same resistance from GPs when they first starting rejecting referrals and have resolved this working with the CCGs.
Some patients who RMH have rejected are being referred to RNOH – not as often now as previously, but this data is not being collected.

Regarding changing the 2WW form MMc advised that it should be revised with TCST involvement but that it does not necessarily need to go through the CAG.

VT has circulated a document with the SAG papers outlining the 2WW pathway at RMH. Page 2 is a diagram to show how the hub and spoke model works and page 3 shows the impact this model has had on volume of 2WW patients seen by RMH.

It would be expected that the 2WW to sarcoma diagnosis conversion rate would be higher at RMH than at RNOH due to the RMH triage process of rejecting referrals without an ultrasound unless very concerning clinical features and redirecting referrals with obviously benign lesions on ultrasound for care in local centres.

Regarding patients referred by GPS to linked diagnostic centres It was noted that if the linked diagnostic centres have a strong suspicion of sarcoma on imaging they do not do the biopsy but send the patient to RMH in order to ensure no delay in treatment

Action: SAG 2WW Subgroup to meet and include attendance from – Clinical and Managerial representation from RMH, RNOH and any RDCs – (Andrew Millar NCL Clinical Lead NCL RCDs and Ollie Gregory – NCL Programme Manager), AH, JWo, Surgeon at RNOH, managers from both Trusts, SUHT – surgeon and Louise Shariff.

5. Feedback from SAG Chairs Meeting

AH explained that when JWh was driving forward the sarcoma service specification the SAG Chairs met annually at the BSG meetings. This has now been consolidated into a group meeting virtually every 4 months. The aim of the SAG chairs meeting is to implement the service specification uniformly across all SAG regions. The meetings have been well attended and with good engagement. At the recent meeting there was an extremely helpful presentation from Sandra Strauss of the PHE data on where sarcomas are operated on, surgical outcomes, volume and outcome relationships – which showed striking data re poorer outcomes if operated on a non-sarcoma centre . The data is going to be published.
The service specification has Quality Indicators (QIs) – the measures by which all SAGs will be assessed. There was a presentation from NHS England as the dashboard for QIs has not yet been launched, two years after the specification has been published – and there doesn't seem to be any progress. The QIs are the motivation for SAGs to adhere to the service specification. The QI dashboard indicators have been reduced from 30 to 16 – AH noted these which will go through NHS England then we will need to collect the data. Designated practitioners, volume of surgery etc. that we as a SAG plan to collect and measure is no longer in the dashboard.
JWo suggested that the SAG Oversight Board could ask the SAG to collect this data so that we are prepared for when the data becomes mandatory.

6. LSESN Follow-Up Guidelines

GF has circulated the guidelines with the SAG papers. BMS has asked the SAG to review and send comments by the 2nd July. She will meet with RMH to discuss the GIST section but otherwise the guidelines are almost complete.

The SAG discussed that the guidelines say discharge at 10 years throughout, with a note that some patients may need following up for longer. It was questioned whether there could be a caveat to say that some patients can be discharged before 10 years – for low-risk or elderly patients. It was suggested that a statement is added such as 'consider early discharge for good-prognosis tumours'.

JWo discussed the Personalised Cancer Care project which is being led by Suzy Hudson at RNOH and includes personalising and stratifying follow-up and how patients could be followed remotely and referred back into the service if necessary. This discussion therefore fits in with that agenda.

KC discussed her experience and expressed her concerns if patients were discharged earlier. AH explained that the guidance would not suggest this for all patients but would allow some personalisation and flexibility depending on the tumour type, prognosis, age etc.

Action: GF to feedback to BMS that the SAG would like a more personalised structure based on the patient. The SAG agree with the general principle of10 year follow up but they would like a note to say that there is capacity for extended (as it outlined) and shortened follow up for patients who would not benefit coming into hospital regularly.

7 Service Specification Implementation

Covered in feedback from SAG Chairs Meeting

8. WGS Progress Reports

RNOH:

RNOH has been sending one case per week; it is going well so far with limited numbers due to capacity of the GLH. They have discussed and finalised one case and report and hope to increase numbers by the end of June.

RMH:

Concerns were raised at the last SAG about whether there was sufficient infrastructural /financial support for widespread implementation of WGS in RMH sarcoma patients. RMH WSG group are meeting soon to discuss progress. AH felt that one case per week is achievable and will feed back about any progress on escalation.

To remain as a regular agenda item.

9. Patient Feedback

No other feedback noted

10. Governance

SAG Hosting

AH gave background that the plan is for the SAG to be formally hosted by all three trusts, with financial support for a project manager, a chair and co-chair.
TJ updated that the SAG Oversight Board met a few weeks ago (with attendance from NCL, RMP, AH, JWh, JWo, GF, TJ, EP, CS, and NHSE) and discussed how the Board would work, the work that needed to happen next - appointing a new chair and co-chair of SAG, a part-time Band 8a Project Manager and a band 5 admin support. All 3 trusts have financial sign-off. UCLH will be the host trust for employment purposes. EP has therefore kindly taken on the next steps and has drafted a JD for the chair and co-chair, which needs to be finalised and then can be advertised. EP has identified some band 5 support within UCLH. The JD needs to be worked on for the Band 8A Project Manager - TJ, CS and EP will work on this. An SLA needs to be drafted an agreed regarding the re-charging. The SAG Oversight Board Terms of Reference needs to be finalised re attendance and accountability. TJ has given her feedback that the Board should be attended by the Chair and Co-Chair of the SAG, the Project Manager and admin support, the 3 general managers of the Trusts, a clinical representative from each of the 3 Trusts, NHSE, NCL and RMP. The purpose of the Board is to hold the Chair, Co-Chair and PM to account on delivering the work plan. The Board would then feed into the Cancer Boards at each Trusts and progress against the work plan would be updated at the SAG meeting each quarter.

AH praised JWh and all those involved on putting this new structure together.

AH has asked the SAG to look out for the adverts for the chair positions and consider whether they want to apply for the roles. There is 0.5PA allocated for each role.

11. AOB

None noted

Date and location of next meeting

Friday 17th September 2021, 15:00 – 17:00 MS Teams

Present:

Mabs Ahmed (MA)	Consultant Clinical Oncologist	UCLH
Fernanda Amary (FA)	Consultant Histopathologist	RNOH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Kirstene Caine (KC)	Patient Representative	
Marc Delon (MD)	Programme Lead	NCL
Palma Dileo (PD)	Consultant Medical Oncologist	UCLH
Gemma French (GF)	Sarcoma Improvement Manager	UCLH/RNOH
Adrienne Flanagan (AF)	Consultant Histopathologist	RNOH
Franel le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Andrew Hayes (AH)	Co-chair of SAG and Consultant Surgeon	RMH
Giulia Impelluso (GI)	Assistant General Manager, Oncology	UCLH
Tanya Joseph (TJ)	Divisional Head of Operations	RNOH
Maureen McGinn (MMc)	Senior Project Manager	RM Partners
Maria Michelagnoli (MM)	Consultant Paediatric Oncologist	UCLH
Ariana da Silva (AS)	Clinical Nurse Specialist	UCLH
Peter Simmonds (PS)	Consultant Medical Oncologist	SUHT
Chris Stone (CS)	Service Manager	RMH
Dirk Strauss (DS)	Consultant Surgeon	RMH
Vanessa Topp (VT)	Deputy Divisional Director, Cancer Services	RMH
Julie Woodford (JWo)	Nurse Consultant	RNOH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH