London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 15th September 2017, 15.00-17.00
Venue: The Boardroom, Royal Marsden Hospital, 203 Fulham Road, London SW3 6JJ
Chair: Andrew Hayes (AH)

1. Welcome and Introductions

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

Piers Gatenby (PG)	Consultant OG Surgeon	RSCH
Kate Lankester (KL)	Consultant Clinical Oncologist	BSUH
Franel Le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Tricia Moate (TM)	Patient Representative	RMH/RNOH
Andrew Nicholson (AN)	Consultant Histopathologist	RBHT
Myles Smith (MS)	Consultant Surgical Oncologist	RMH
David Sallomi (DS)	Consultant Radiologist	ESH
Beatrice Seddon (BS)	Consultant Clinical Oncologist	UCLH
Sandra Strauss (SJS)	Consultant Medical Oncologist	UCLH
Winette van der Graaf(WvdG)	Honorary Consultant Medical Oncologist	RMH
Rachael Windsor (RW)	Consultant Paediatric and Adolescent Oncologist	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	Status/Due Date
Patient Management Policy is largely complete, with comments received. Needs final edit before uploading	BMS	2016	Part complete September 2017
Coordinate new 'designated services' section of LSESN website. Designated practitioners now confirmed.	GF	2016	Part complete September 2017
Review of pathology services. RJ and AH to draft 1-2 page summary document then send to JW for further drafting	RJ/AH	June 2017	September 2017
Suspected sarcoma diagnostic clinic initiative. JWh to reinitiate with GF. Possibly Kent next. Refresh plan	JWh/GF	June 2017	September 2017
Chemotherapy algorithm. Complete changes and upload	GF/JW	June 2017	September 2017
Review 2WW referral form.	GF/CK/JWh	September 2017	December 2017
Audits for shared care chemotherapy and radiotherapy: AM to speak to BMS and FLG AM to speak to SS re refreshing national sarcoma data GF to help to coordinate and share previous audits, due for presenting March 2018	AM/BMS/FLG AM GF	September 2017	December 2017 December 2017 March 2018
Guidelines to be reviewed: referral and designated practitioners	JWh/AH	September 2017	December 2017
Isolated limb perfusion trial to be presented at LSS service meeting	GF/AM	September 2017	December 2017

Olaratumab with doxorubicin for metastatic sarcoma: CB to send audit parameters to PS and BMS Audit to be presented at March meeting	CB CB/PS/BMS	September 2017	December 2017 March 2018
Adjuvant chemotherapy for soft tissue sarcomas: JWh to share draft document with RMH oncologists, discuss and feedback at the next meeting	JWh	September 2017	December 2017

Previous minutes were agreed.

Matters arising:

Updating chemotherapy algorithm

This needs to be updated further

3. Audits

a) 2WW Presentations

Nikos Memos presented an audit of 2WW referrals to the Royal Marsden Hospital from March to September 2016. Referrals were triaged every day, a new telephone clinic was set up in March 2016 and extra clinics were scheduled as and when needed. Suspected sarcoma referrals have increased by 120% to RMH over the last 4 years. The median number of referrals per week is 17. However the range is from 5 to 35 and there are 20 slots per week available to see these patients. 16% of 2WW referrals were rejected on triage. 8 extra clinics were scheduled due to lack of capacity and breaching patients. 77% of patients had a freehand biopsy. 55% of patients had an MRI. 5.7% of referrals received were then diagnosed with sarcoma and almost 70% were benign.
83% of patients were discharged in the telephone clinic. The telephone clinic has reduced the waiting time in other follow-up clinics.
A question was posed whether referrals should be rejected when the patient has not had an ultrasound (based on the new NICE guidelines).

Julie Woodford presented the 2WW model at RNOH. The London Sarcoma Service has also seen a huge increase in referrals of 218% in the last 5 years. To help alleviate the pressure on consultant clinics, RNOH have set up a nurse-led clinic to see all 2WW referrals, run by the Nurse Consultant and the Advanced Nurse Practitioner. (NB: the nurse clinic now also sees all bone 2ww referrals which were previously seen by the surgical team.) The patients seen in these clinics have been audited from November 2016 to March 2017. There were 126 patients referred on the 2WW pathway for suspected soft tissue sarcoma. The clinic is fully compliant with national guidance (93% of patients were seen within 2 weeks). The median wait from 2WW referral to OPA was 8 days. 35% of referrals had no imaging at the time of referral. Of the 65% of patients who had imaging: 74% had USS, 17% had plain film, 5% had MRI and 1% had CT scan. For 83% of patients seen in the clinic an MRI was requested and for 17% of patients a needle biopsy was requested after MDT review. 50% of patients were discharged via the telephone clinic. As part of the audit the nurses predicted the diagnosis when triaging the referral and were correct for 84%, however they feel that if the audit was to be repeated this would now be higher. Of the 126 patients audited 6 patients were diagnosed with sarcoma (5%) and 4 patients with another cancer (total of 8% cancer). 92% of patients were diagnosed with a benign condition.

All 2ww referrals are now managed within the nurse-led clinic at RNOH. The nurses plan to audit how many of the referrals they would have rejected on triage and record the postcode of the referral origin. There are on-going discussions regarding the need for biopsy and a one-stop clinic model of same day OPA and MRI/US.
JWo plans to talk to the RNOH radiologists as she believes some patients could be discharged without radiology where it is clear on the referral that there is no suspicion of sarcoma.

The group discussed the use of USS and whether this would decrease the number of MRI scans needed. RMH is unable to put in place a model that depends on MRIs upfront for the majority of patients. This would not be manageable from an imaging point of view
JWh referred to the 2WW form created with NHS London and whether we should reconsider the NICE guidelines and adapt the form. We should reach out to primary care and re-educate GPs.
RMH management feel that we should only accept forms with USS and SC noted that RMH commissioners are expecting RMH to follow NICE Guidance.

PS noted that in SUHT all GPs have rapid access to USS but this has not decreased the number of 2WW referrals received, if anything the numbers have increased. The quality of the USS is not as good and so the diagnosis is unclear. Therefore the referrals cannot be rejected on the basis of USS due to the poor quality.

Action: GF to speak to Catherine Kirk regarding the group looking at referral form and make contact with group at NHS London who created 2WW form.

b) Pre and Post-operative Radiotherapy Pathway

The group agreed that the audits that took place a few years ago looking at radiotherapy given outside of the treatment centres should be repeated. It was agreed to look at the timings of treatment, who is available to deliver treatment, any problems at the local hospitals, trials etc. The audit should be for a 2 year time period with the aim to present in March 2018. The data may support the radiotherapy given in local hospitals which is not highlighted in job plans and so it is important to see its' value.
Radiotherapy practitioners will need to be re-designated next year following the publication of the sarcoma service specification.

Action: AM to speak to BMS and FLG
Action: AM to speak to SS re refreshing national sarcoma data
Action: GF to help to coordinate

The chemotherapy audit should also be repeated, to document the numbers being done elsewhere and also the quality of the treatment given.

Action: GF to find previous chemotherapy and radiotherapy audit data and share with CB, PD, AM and BMS.

4. Guidelines due for review

- **Referral guidelines**

Action: JWh and AH to review and update prior to the next meeting. To direct queries as appropriate.

- **Designated practitioners**

Action: JWh and AH to review and update prior to the next meeting

Action: all to send GF any changes that they are aware of

5. Governance

No issues noted

6. National Commissioning Update

At the last meeting JWh reported that the draft service specification was to go out for a 60 day consultation in the summer. However this did not happen. There has been some work done nationally by NCRAS to look at the caseload of patients discussed by sarcoma MDTs and JWh also asked the SAG chairs to self-declare their numbers. Not all bone and soft tissue sarcoma MDTs discuss the minimum number of patients required.
Sandra Strauss has been appointed to an NCRAS post looking at rare cancer data.

7. Patient Representation/Feedback

AH welcomed Alvin Trowbridge to the meeting who has kindly volunteered to be a patient representative on the SAG.
AT gave feedback following a meeting with Tricia Moate which re-enforced the importance of good communication and highlighted the ongoing issue of GPs not having enough knowledge of sarcoma.

JWh gave feedback to the group on an email from Tricia which commented on our guidelines for chemotherapy and radiotherapy designated practitioners. The first issue related again to communication and informing the patient of where their follow-up will be taking place and the second related to the time frames for starting oncology treatment outside of the sarcoma centres. This will be audited as discussed in item 3.b)
The Royal Marsden Hospital has appointed 3 new clinical nurse specialists – Kelly, Karen and Angela

8. Newsletter

GF asked if she should produce an LSESN newsletter as she has done previously. It was agreed to wait until we have a firm plan for the roll-out of diagnostic clinics.

9. LSESN Website Usage Report

GF tabled the LSESN website usage report for June, July and August which shows an average of 89 sessions, an average duration of 1 min 48 secs and an average of 2.51 pages viewed per session. There were 86.6% new visitors to the site.
GF highlighted that the most viewed pages each month were the guidelines (viewed approx. once every day) followed by the pathways and so it is important that these documents are reviewed and kept up-to-date on the website.

10. Clinical Trials and Research

Clinical trial reports were tabled and discussed from both RMH and UCLH

AM discussed an isolated limb perfusion trial which is due to open in 2 years. AH noted that this will be

useful for RNOH to know and should go on the newsletter once it is produced. It was suggested that RMH attend once of the LSS research meetings held every month to present the trial.

Action: GF to arrange date for presentation

9. Any other business

1) Olaratumab with doxorubicin for metastatic sarcoma
PS noted that an audit was discussed at the last meeting and asked for an update.
CB has collected data prospectively on all patients treated with 1st line olaratumab. RMH are checking that they are adhering to the CDF rules and their auditing their toxicity rates.
PS has started collecting the information. A dataset needs to be agreed by email
Action: CB to send audit parameters to PS and BMS
Action: Audit to be presented at March meeting

2) Adjuvant chemotherapy for soft tissue sarcomas
JWh informed the group that there have been further discussions at UCLH to discuss the above. The clinical team at UCLH have agreed that to explore pathways to offer adjuvant (not neoadjuvant) chemotherapy with doxorubicin/ifosfamide adjuvantly, to patients fitting the criteria used in the recently published trial with some extension to additional patients with similar risk factors. This is being documented.
Action: JWh to share draft document with RMH oncologists and discuss with them prior to the next meeting
Action: JWh to feedback at the next meeting

Date of next meetings:
Friday 15th December 2017,
6th Floor West Meeting Room, 250 Euston Road, UCLH

Friday 16th March
The Boardroom, Royal Marsden Hospital, 203 Fulham Road, London SW3 6JJ

Present:

Imogen Batty (IB)	Nurse Practitioner	RBCH
Sofina Begum (SB)	Consultant Thoracic Surgeon	RBH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Sarah Clarke (SC)	Divisional Director for Cancer	RMH
Gemma French (GF)	Sarcoma Improvement Manager	UCLH/RNOH
Andrew Hayes (AH)	Co-chair of SAG and Consultant Surgeon	RMH
Michelle Hung (MH)	Clinical Trials Practitioner	UCLH
Simon Jordan (SJ)	Consultant Thoracic Surgeon	RBH
Catherine Kirk (CK)	Service Manager, Performance	RMH
Kelly McKibbin (KM)	Clinical Nurse Specialist	RMH
Karen O'Meara (KOM)	Clinical Nurse Specialist	RMH
Nikos Memos (NM)	Locum Consultant Surgeon	RMH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH

Caroline Ramsey (CR)	Clinical Trials Practitioner	UCLH
Peter Simmonds (PS)	Consultant Medical Oncologist	UHS
Myles Smith (MS)	Consultant Surgical Oncologist	RMH
Alvin Trowbridge (AT)	Patient Representative	
Jeremy Whelan (JWh)	Co-chair of SAG & Consultant Med. Oncologist	UCLH
Julie Woodford (JWo)	Nurse Consultant in Cancer and Supportive Care	RNOH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH