London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 16th September 2016, 15.00-17.00
Venue: The Boardroom, RMH,
Chair: Andrew Hayes (AH)

1. Welcome and Introductions

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

- Rose Ellard, Senior Research Nurse, UCLH
- Gemma French (GF) Project Manager RNOH/UCLH
- Tricia Moate (TM) Patient Representative RMH/RNOH
- Chrissie O'Leary (COL) Oncology General Manager UCLH
- Beatrice Seddon (BS) Consultant Clinical Oncologist UCLH

2. ACTION LOG (September 2016), including outstanding actions from previous meeting. All other actions from previous meeting were completed and have been removed.

ACTION	Owner	Status/Due Date
BMS to send Patient Management Policy to GF (incorporating CB comments)	BMS	Outstanding
GF to upload onto LSESN website	GF	Outstanding
BMS to amend FU guidelines and send to GF	BMS	Complete
GF to upload onto LSESN website	GF	Complete
BMS to finalise chemotherapy algorithm and send to GF	BMS	Complete
GF to upload onto LSESN website	GF	Complete
RNOH to replicate 2WW audit taking place at RMH. Explore if similar audits are being done at other diagnostic clinics within the network. GF mat cover to look at 2WW audit across SAG.	GF mat cover	Outstanding
Ask Richard Haywood for equivalent data at Norfolk and Norwich. Data not yet received	AH	Outstanding
Request radiotherapy data from NCIN. AM meeting with SS and NCRAS 06/06	AM	Meeting held
Coordinate new 'designated services' section of LSESN website. Drafted, awaiting confirmation of designated practitioners.	GF mat cover	Part complete
PG to look at local 2WW data to identify where 2WWs are referred. Bring to next meeting PG confirmed that this Guildford audit had taken place and updated on this. 7 suspected sarcoma cancer referrals to the centre. 2 were seen locally and then referred to the centre)	PG	September 2016 Action complete
RJ and CPL to meet with RMH communications team re improving the sarcoma section on the RMH website	RJ/CPL	In progress
GH to contact EMDT colleague to enquire re feasibility of adding a PIN dropdown box	GH	Outstanding
Draft of PIN letter to be discussed at next SAG. Carry over to next meeting	JWh	Complete
Diagnostic Clinics: GF to send July date to 3 Trusts	GF	Complete
Generic Site-Specific Pathway to be re-drafted	JWh/GF	Complete
Designated Practitioners: GF to give JWh the list of people who have not replied and he will contact	GF/JWh	Complete

Add Designated Surgeons to the next SAG agenda	GF	Complete
Designated Practitioners: GF to work with PS re amendments to SUHT list	GF/PS	Complete
Designated Practitioners: GF to add Elliott Simms at Queens contact	GF	Complete

3. Review of Pathology Services

There was an open discussion about specialist pathology services in the Network. There was consensus amongst the network that the workload continues to increase.

A number of issues were discussed across the network, in particular highlighting;

- molecular diagnostic turnaround times (2 weeks on average at RMH compared to 3 days at RNOH)
- Concerns relating to an insufficient portfolio of molecular diagnostic tests specifically at RMH in the context of a rapidly expanding field of molecular diagnostics
- mono-specialist Pathologists, where a number of pathologists within the network focus only on Sarcoma pathology whereas RMH pathologists cover both Sarcoma and Head and Neck
- workforce numbers and how the staffing establishments in both centres and with reference to other centres nationally
- The importance of clinical fellows to succession planning
- second opinions and the financial reimbursement of these referrals
- The arrangement for thoracic pathology were viewed as satisfactory (AN)

RMH expressed their desire to reinstate a clinical fellow position to complement the 2 consultants and at some point have the capacity within the pathology department to mono-specialise in sarcoma.

AH and JWh summarised the key points as:

- There is an inadequate and slow molecular diagnosis service at RMH. Samples being sent to RNOH make up for this shortfall in service.
- The pathology workload and complexity has increased and staffing has not kept track with that increase.
- There has been instances of delayed diagnosis across the network which has resulted in a change of therapy given
- there is a requirement to review both activity and HR establishment and benchmark these against other sarcoma pathology service to identify what is required in terms of investment to secure a stable service for the future.

JWh expressed that the aim of the SAG is to help support sustainable high quality specialist sarcoma pathology services in whatever ways possible. The SAG should also look for ways to promote national discussion. A position paper outlining the issues raised at this meeting and suggested solutions would be valuable. Robin, Winette and Jeremy agreed to create a draft for input from pathology colleagues.

Action: Draft position paper –RJ, WvdG, JWh

Funding regarding second opinions and internal recharges to pathology at RMH – KG will review this and discuss with the pathology management

4. Suspected sarcoma diagnostic clinic initiative

JWH explained that they had targeted some Trusts based on referral density and geography in relation to treatment centres. The visit to Southend as the first Trust in this initiative had been positive but feedback was awaited. JWH is following this up.

AH suggested that RMH could organise the second visit to one of the Trusts which had expressed interest in Kent.

KG explained that a RMH challenge at present is the increasing number of TWR referrals to the sarcoma unit; the number has increased by 120% over the last 4 years. In accordance with the new NICE guidelines (2015) it is recommended that an ultrasound should be carried out prior to referral for adult sarcoma referrals via an urgent TWR. Following an audit carried out by the Sarcoma Clinical Fellow from March – July 2016, 47% of referrals were not referred with an ultrasound
In order to help with the capacity constraints at RMH, KG explained that the unit is considering rejecting referrals, when patients are referred on a sarcoma TWR inappropriately early (i.e. without US) or not clinically appropriate to RMH sarcoma service (i.e. bone sarcoma). In these cases notification will be given back to the GP or referring Trust by the medical team, with discussion if this is necessary.
Discussion followed noting that this was in direct conflict with the SAG's work with commissioners through 2015-16 to revise the London 2WW pathway and that further consideration involving all providers and NHS London was essential before any further change.

JWh suggested keeping this item on the agenda.

Action: Review progress at next meeting

5. **National Commissioning Update**
The draft combined service specification remains under consideration with NHSE.

Action: Feedback any updates to SAG

6. **Atypical Lipomatous tumours and CWT**
RNOH explained that they were reviewing pathways for atypical lipomatous tumours and whether these should not be reported / treated in line with cancer waiting times targets.

KG explained that as these are a cancer diagnosis, although, may not be clinical urgent, RMH will continue to track and treat these patients in line with CWT targets.

7. **Governance**
JWH presented an audit of real time recording in MDT meetings of pathway deviations conducted by UCLH/RNOH, called Practice Improvement Notifications or PINs.

JWH discussed the tabled Practice Improvement Notification letter as a possible step in closing the audit loop by providing feedback to referrers. It was agreed that other approaches may be more valuable in achieving a balance to ensure educative rather than punitive.. Agreed that the criteria for PINs could be refined to allow more consistent categorisation and so allow more structured and generic feedback in the future. The need to meet Duty of Candour responsibilities was acknowledged.

Continue collection of data IN LSS and re-discuss in 2017

8. **LSESN Website Usage Report**
Not discussed

9. Clinical Trials and Research

CB discussed the tabled RMH research trials and explained that there has been little new development since the last discussion, and all information is available via the documents. Trial activity data was also presented for UCLH/RNOH.

10. AOB

JWH confirmed that although there have been 2 recruitment campaigns; UCLH had not been successful in recruiting to Gemma French's maternity leave cover.

Present:

Jeremy Whelan (Chair) (JWh)	Consultant Medical Oncologist	UCLH
Andrew Hayes (AH)	Co-Chair of SAG and Consultant Surgeon	RMH
Charlotte Benson (CB)	Consultant Medical Oncologist	RMH
Franel le Grange (FLG)	Consultant Clinical Oncologist	UCLH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Peter Simmonds (PS)	Consultant Medical Oncologist	UHSFT
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH
Kirsty Green (KG)	Clinical Business Unit Manager	RMH
Winette van der Graff (WvdG)	Honorary Consultant Medical Oncologist	RMH
Fernanda Amary (AF)	Consultant Medical Histopathologist	RNOH
Aisha Miah (AM)	Consultant Clinical Oncologist	RMH
Vasilios Karavasilis (VK)	Consultant Medical Oncologist	UCLH
Andrew Nicholson (AN)	Consultant Histopathology	RBHT
Piers Gatenby (PG)	Consultant OG Surgeon	RSCH
Shane Zaidi (SZ)	Consultant Clinical Oncologist	RMH
Cyril Fisher (CF)	Consultant Histopathology	RMH
Kin Thway (KT)	Consultant Histopathology	RMH
Robin Jones (RJ)	Consultant Medical Oncologist	RMH
Julie Woodford (JW)	Nurse Consultant & Lead Care Nurse	RNOH
Susan Rogers (SR)	General Manager, RNOH	RNOH
Dirk Strauss (DS)	Consultant Medical Oncologist	RMH