

London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 20th February 2015, 15.00-17.00

Venue: Boardroom, The Royal Marsden NHS Foundation Trust

Chairs: Mr Andrew Hayes and Professor Jeremy Whelan (JWh)

ACTION LOG (February 2015)

Ref	ACTION	Owner	Status
F1	Review email distribution list against list on inovem	(CL/GF)	
F2	Update email distribution list to reflect sarcoma leads within all providers in network	(GF)	
F3	Agenda items for May meeting – peer review documentation, workplan for 15/16, RMH survey feedback	(CL/GF)	
F4	Agenda items for August meeting – follow up audit results	(CL/GF)	
F5	SAG constitution – review and confirm any further changes / amendments	(JW/AH)	
F6	Contact Sussex LAT to establish contacts for Sussex diagnostic service commissioning arrangements	(AN)	
F7	Explore potential workshop arrangements / invitees and content of workshop	(JW/AH)	
F8	Develop newsletter content for network communication	(JW/AH)	
F9	Co-ordinate network newsletter for network – development and circulation	(CL)	
F10	Circulate workshop invite once content and format agreed	(CL)	
F11	Undertake audit within agreed parameters – All patients with a new diagnosis undergoing primary resection in 2012, scope to include follow up in local hospitals where information can be obtained	(AM)	
F12	Present follow up audit findings at August SAG meeting	(AM/BS)	
F13	Undertake audit within agreed parameters – All patients with a new diagnosis undergoing primary resection in 2012, scope to include follow up in local hospitals where information can be obtained	(AM)	
F14	Present follow up audit findings at August SAG meeting	(AM/BS)	
F15	Update chemotherapy guidelines to reflect agreed changes	(BS/JW)	
F16	Circulate chemotherapy guidelines to SAG for virtual sign off once updated	(CL/GF)	
F17	Amend pazopanib protocol to include authors	(GF)	
F18	Arrange for pazopanib protocol to be uploaded onto SAG website	(GF)	
F19	Amend wording in guidelines to reflect abdo-pelvis imaging for GIST follow up	(GF)	
F20	Include final follow up guidelines in SAG newsletter	(CL)	
F21	Write to Colchester re. pathway issues and reference patient pathway delays to date	(JW/AH)	
F22	Write to units regarding sarcoma provision for RX / CT treatment post centre	(JW/AH)	
F23	Finalise gynae trial recruitment letter for circulation to specialist gynae MDTs	(CB/PD)	

Ref	ACTION	Owner	Status
F24	Circulate gynae trial recruitment letter to specialist gynae MDTs	(CL/GF)	
F25	Arrange meeting with Shelley Dolan, Claire Dowling and SAG Chairs to review work programme and future resource arrangements	(CL)	

1. Welcome and Introductions

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

- Chrissie O’Leary, General Manager – University College Hospitals NHS Foundation Trust
- Rob Pollock, Consultant Surgeon – The Royal National Orthopaedic Hospital NHS Trust
- Stephanie Johnson, Operational Manager – The Royal National Orthopaedic Hospital NHS Trust
- Dr Sallomi, Consultant Radiologist – Eastbourne District General Hospital

2. Minutes from the meeting held on 24th October 2014

The Group discussed the updated SAG constitution that had been prepared by MM. JW expressed concerns that the current version did not highlight where changes had been made from the previous version.

The Group agreed that given the timetable for the peer review process for sarcoma in 2015 (July deadline for uploads to the CQUIN website) peer review documentation and requirements should be considered at the May meeting.

The Group agreed the following items to be added to the May agenda:

- SAG constitution – updates for 2015
- SAG workplan for 15/16

The Minutes of the October 2014 meeting were accepted as an accurate record.

Actions log - October 2014

The Group reviewed the actions arising from the last meeting:

- Retroperitoneal follow up audit – undertaken and results presented at the February meeting
Noted as an agenda item for discussion within the meeting. Action from October meeting agreed as closed.
- SJ to produce a draft letter to Sarcoma UK to ensure patients do not receive two surveys
SJ gave her apologies to the meeting. An update from SJ will be sought offline given confusion regarding the survey in question. To be actioned ahead of the May meeting.
- CPL and AD to bring RMH patient survey feedback to the next meeting
Outstanding. To be put on the agenda for the May meeting.
- SJ to update 2 week wait rule form for RNOH with GF and include spine box as an option. GF to liaise with web manager at RMH to upload to SAG website.
Update complete. GF to liaise with web manager at RMH to upload. IYG agreed to act as point of contact from RMH to support GF.
- MM to identify CCG leads and local area commissioning leads
The Group discussed the record of this action and agreed that this was in reference to the identification of local leads within the wider network. AN confirmed that given changes in NHSE the identification of local commissioning leads was difficult and not all CCGs had named leads for sarcoma.

3. Diagnostic services

The Group discussed the limited progress on the development of diagnostic services across the network.

The Group discussed the challenges faced by the network regarding the establishment of diagnostic services within the network and how to address these.

Key points of discussion included:

- Proposed workshop on potential service models and treatment pathways to improve engagement
- Appropriate methods of communication with relevant sarcoma leads
- Potential questionnaire to sarcoma leads to facilitate network development and better understanding of current provision
- Identification of sarcoma leads – ideally radiologists – key to initiating discussions
- Commissioning support required prior to dialogue with senior trust personnel within the network
- Progress required regarding identification and understanding of commissioning arrangements in place in areas (e.g. Norfolk and Brighton) where diagnostic services have been established and work well

4. Audit – retroperitoneal follow up

AM provided an update on the development of the audit of retroperitoneal follow up protocols, specifically the difference in practice between the two providers: clinical review and indication at follow up in comparison to clinical indication and imaging at follow up. The Group agreed that it would be key to identify any difference in outcomes for patients undergoing follow up in each centre

The Group discussed the parameters of the audit and the overarching objective – to develop standardised protocols for follow up in this patient cohort.

The Group agreed the scope of the audit and agreed that AM and BS would provide feedback on the audit in 6 months.

5. Chemotherapy guidelines

The Group discussed the chemotherapy guidelines – specifically in the context of the recent decisions by the Cancer Drugs Fund (CDF) to rescind funding for some regimens.

JW updated the Group on the work currently being undertaken by the CRG to develop an algorithm for national use. The Group noted that clinical trials were excluded from the national algorithm work.

The Group noted that the chemotherapy guidelines would be available on the SAG public website.

The Group formally noted the pazopanib protocol included for circulation, and noted that owing to changes by the CDF, this drug would no longer be available for NHS patients post March 2015.

6. Follow up guidelines

The Group noted the production of the follow up guidelines, specifically commenting on the required amendment regarding GIST follow up.

The Group agreed an amendment to the guidelines to reflect abdo-pelvis imaging and that the publication of the follow up guidelines should be included in the network newsletter.

7. Sarcoma CRG update

JWh provided an update from the Sarcoma CRG. Key highlights included:

- Service specification for sarcoma currently in development
- National chemotherapy algorithm under development
- Accountable commissioner leaving – highlighting continued change and instability in the wider system. Awaiting confirmation of replacement.

8. Any Other Business

Essex and pathway issues:

AM updated the Group on recent issues when referring patients back to local providers for radiotherapy and palliative care. She highlighted the delays in the pathway and the impact on patients from both a quality of care and patient experience perspective.

The Group discussed these issues and their concerns. Those present noted that in many cases, personal contacts were the only way to ensure that the pathway operated robustly and patients were not delayed. It was noted that there was currently lack of clarity regarding the relevant RX lead for sarcoma.

The Group agreed the following actions:

- Write to Colchester re. pathway issues and reference patient pathway delays to date (JW/AH)
- Write to units regarding sarcoma provision for RX / CT treatment post centre (JW/AH)

Gynae trial recruitment:

CB updated the group on the continuation of recruitment to the gynaecological clinical trial. She advised that a letter was currently in development to be circulated to the gynae specialist MDTs within the network providing them with more information.

Project management support

CL advised the Group that she would be leaving the LCA in May 2015 to take up the post of Service Manager at RMH. This post would include the management of the sarcoma service.

She confirmed that discussions regarding future support to the SAG and network were ongoing and would provide an update at the next meeting.

Present:

Jeremy Whelan (Chair)	Consultant Medical Oncologist	UCLH
Andrew Hayes (Chair)	Consultant Surgeon	RMH
Gemma French	Project Manager	UCLH
Caitriona Liebenberg	Project Manager	LCA
Ieuan Yusuf-George	Assistant Service Manager	RMH
Tricia Moate	Patient Representative	
Dirk Strauss	Consultant Surgeon	RMH
Aisha Miah	Consultant Clinical Oncologist	RMH
Christina Messiou	Consultant Radiologist	RMH
Charlotte Benson	Consultant Medical Oncologist	RMH
Alison Dunlop	Clinical Nurse Specialist	RMH
Beatrice Seddon	Consultant Medical oncologist	UCLH
Ian Judson	Consultant Medical Oncologist	RMH
Rolyn Alverado	Clinical Nurse Specialist	RMH
Sandra Strauss	Consultant Medical Oncologist	UCLH
Nicola Beech	Macmillan Advanced Nurse Practitioner	Croydon University Hospital