London and South East England Sarcoma Network Sarcoma Advisory Group Minutes

Date: Friday 18th March 15.00 and 17.00
Venue: MS Teams
Chair: Craig Gerrand

1. Welcome and Introductions

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

Simon Landergan
Angela Wong
David Sallomi

CG reiterated the thanks given in the last meeting to Jeremy and Andy for running the meeting so successfully over the last 10 or more years. CG and RP hope to continue this success, with the help of a new infrastructure which is in process of being set up including the Project Manager role which is still to be advertised.

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
BMS to provide update to SAG re GISTs at Mount Vernon	BMS	Mar 21	Dec 21
GF and JW to approach Sarcoma UK re patient representation at the SAG. JW to chase Sarcoma UK for response	GF/JW	Sep 21	Jun 21
Project Manager and Chairs to discuss data sharing template	CG/RJ	Dec 21	When PM in post
GF to add SUHT Service Update to beginning of next agenda	GF	Dec 21	June 22
GF to add Children and TYA Service Specifications to the next agenda and ensure JC can attend	GF	Dec 21	Jun 22
SAG to respond to Cancer waiting time version 12 and raise at SAG Chairs meeting	CG/RP	Mar 21	Apr 21
SM to share the mechanism for feedback process on the v12 cwt guidance consultation	SM	Mar 21	Mar 21
SAG members to feedback to GF on draft 2WW form	all	Mar 21	Mar 21
2WW subgroup meetings to be restarted	Liz P	Mar 21	Jun 21
SM to send draft slides for the regional meeting next week	SM	Mar 21	Mar 21
SM to enquire re meetings between RNOH and the spec comm team	SM	Mar 21	Jun 21

SM to find out from National Programme of Care team re sarcoma service specification and whether this is what we should be working to and if the outcomes/dashboard will be published soon	SM	Mar 21	Jun 21

Previous minutes were agreed with a correction to be made to the spelling of Christina Messiou

3. SAG Workplan

CG discussed the draft workplan which was written in March 2020 and asked if anything is missing.

CG asked PS for his opinion on the SUHT relationship with the SAG. PS explained that it is important to include the diagnostic centres in the periphery as well as the two centres in London and would like that they get more traction. PS will be presenting at this meeting to highlight the volume of patients that they see.

JW suggested that we add some detail around education and that the SAG should play a part in education for primary care, radiographers etc.

4. 2WW Pathway

JW explained that the SAG now has some Project Management support from Liz Price at TCST to help the SAG with the 2WW/Diagnostic Clinic pathway. Liz has been assigned to help the SAG 1.5 days per week, she has produced a scoping document which SM shared in the meeting. SM has asked Liz to think about all the current challenges and show how she can support the SAG with these.

Some of the challenges are because of the volume of referrals and lack of direct access to ultrasound and the quality of imaging reports received. Liz's slides showed that the waiting time for ultrasounds was much longer at RNOH and shorter at the Marsden. London does not meet the faster diagnosis standard and is quite a big outlier nationally.

There is also the challenge on two week wait referrals are managed and how there is a significant difference between how the Marsden manage two week wait referrals and the RNOH, especially on what happens following review of an ultrasound report.

North Central London CCG have asked that a proposal goes to the regional specialised commissioning group on how 2WWs are managed after review of imaging. SM has a slot at this meeting next week.

Action: SM to send draft slides for the regional meeting next week

SM also noted that Cancer waiting time version 12 is out for consultation and it is important for the SAG to feedback on this proposed guidance. The proposed guidance says that a GP can refer on a direct access ultrasound but that the centre is still required to see the patient following review of this ultrasound. This goes against what the 2 centres are trying to do and so needs to be fed back as part of the consultation.

MM noted that this is her last SAG meeting, and her colleague Amanda Heeralall will be attending in future. MM has spoken to Amanda re the new proposed v12 guidance and how this goes against the current RMH pathway so she will take this forward in RM Partners.

AH explained that the current RMH model does have its issues, and 2WW performance at RMH is very poor. Jonathan Hannay is triaging the 2WWs at RMH and calls the patients. Jonathan is triaging out around 50% of 2WWs. AH has data which shows that the medical model of triaging these patients does not work and is unmanageable. A telephone consultation as suggested in the new guidance would not be a solution to the problem. AH explained that RMH need to look at what workforce is required to try and run a proper diagnostic service with an ANP. DS explained that there is a direct impact on patients with sarcoma as so much resource is spent on the 2WWs who do not have a sarcoma. The model needs to have an expanded diagnostic service and the hub and spoke model also does not solve all the problems.

AH would like some data from JW with regards to the number of clinics and ANP requirements at RNOH. JW has spoken to Jo Coleman, the ANP who runs the 2WW clinic at RNOH – she sees approx. 60 new patients per week. AH wants to know how many of these translate to ultrasound appointments and MDTs.
JW noted the problems: lack of direct access to imaging and the referrals which do come in with ultrasounds are often done by sonographers with a caveat that sarcoma cannot be excluded. We need to find out how we influence this and how to change this process.

PS added that the current practice at SUHT would also go against the new proposed guidance. SUHT also reject approx. 50% of 2ww referrals after imaging review.

SM suggested that there is feedback from other SAG chairs also on the proposed cwt guidance. TJ agreed that we should have a strong SAG and national response.

Actions:

- SAG to respond to Cancer waiting time version 12.
- To be raised at SAG Chairs meeting at BSG
- SM to share the mechanism for feedback process.

There has been a draft circulated of the new 2WW form from Julia at TCST. GF has circulated the draft to the SAG

Action:

- Feedback on form to be given to GF

TJ is concerned that the 2WW form will change again if the guidance changes and so then there will need to be another form.
SM added that there is a full-scale review of all 2WW forms. The forms can be changed fairly easily, and SM will ask them to do this if required.

Action: Liz to restart the 2WW subgroup meetings

5. Patient Feedback, including NCPES results

JW presented the patient survey results from RNOH .
Headlines:

- Opt in survey because of pandemic. Marsden, UCLH and RNOH took part
- For RNOH 32 questions got better, 14 questions got worse and 1 question stayed the same
- High score in patients accessing their CNS as there has been a lot of work around this.
- Ward scored well on respect and dignity whilst in hospital
- 71% said GP practice staff supported patients through their treatment, this hasn't scored so well in the past
- Due to pandemic the score for patients bringing someone to the hospital with them scored low.
- Patient Information, in particular financial help is something patients felt that they did not receive
- Simple things at the hospital like communication were challenging and this was down to everyone wearing masks
- Worries and fears were much higher than usual, and this is a reflection of the pandemic
- There was a disconnect between hospital and community staff working together
- Being asked to take part in cancer research scored particularly low

Current survey is out to patients at the moment. JW still chasing the free text comments as often you learn more from those. For UCLH there was a smaller number of patients taking part and so not enough data for comparison. Lots of Trusts did not have enough participants for data or did not take part.

6. HNA Outcomes

JW spoke for Suzy Hudson who is on leave, presenting her Personalised Cancer Care data. Suzy has been in post for 2 years and has achieved a significant amount – HNA's at diagnosis are now fully embedded in the service, the HOPE programme about to start, a health and wellbeing programme is running, they are just about to start end of treatment summaries and then they will look into stratifying some follow-ups. JW thought it would be useful to share some of the data that is coming out of the HNA's with regards to the patients concerns.
Patients are showing a higher number of physical concerns but there is more to select from and when Suzy has done the analysis in reality patients are actually scoring higher for emotional concerns.

Top concern that patient's flag is thinking about the future/uncertainty. At the BSG there is going to be a presentation on new research re patient worries around this.

At the end of treatment patients are scoring lower for concerns because of HNA's and care plans being done.
JW showed the concerns that have been flagged every year and those which have just appeared on certain years.
RNOH have appointed a cancer support worker who has been key to coordinating HNAs and ensuring that they are completed, and the Trust will continue to fund Suzy 2 days per week once the Macmillan funding runs out.

PS asked JW what their plans are in regards to stratified follow up. JW stated that they are struggling with surgical follow up capacity at the moment, so the plan is to set up Nurse and AHP follow-up clinics. During the pandemic they have been able to really push virtual clinics and are

getting surveillance X-rays done through primary care which has been working very well and so they are keen to continue with this.
RNOH are also looking at remote monitoring systems. RNOH use Infoflex, SM said that Somerset is a much easier system to use as they have a module which is built in to help with PCC.

7. Covid- 19

Nothing new to report. All Trusts still having issues with staff absences.

8. NHS Commissioning Update

SM gave an update on the new structure of the NHS.

Cancer services are generally commissioned at three levels: highly specialist (nationally commissioned), regionally commissioned or locally CCG commissioned. We are waiting for the bill to go through parliament. They have established task and finish groups in London to look at cancer surgical specialities and whether they could be commissioned by a single integrated care board.
For sarcoma, the current thinking is that it will remain one the few services that will still be nationally commissioned. This means that it will be considered highly specialised and remain within NHS England at a national level. Effectively there would no change in sarcoma.

TJ asked if the meetings between the highly specialised commissioning team and RNOH will be starting up again

Actions:

- SM will find out re meetings
- SM to find out from National Programme of Care team re sarcoma service specification and whether this is what we should be working to and if the outcomes/dashboard will be published soon

9. WGS Progress Reports

FA stated that the number of patients undertaking WGS is unstable – the major issue is the workforce to consent patients. They have quite a few samples frozen and so we could capture those patients in their second visit. The nurses are doing fantastic job more patients have been consented this month. Overall, there has been a good number of patients submitted.

RNOH are hoping to get charity funding for a 1-year post to help with consenting and embedding the pathway.

RMH reported that there have been changes in pathology management but there is now a meeting set up in 2 weeks' time to discuss how progress.

10. Governance

Nothing to report.

11. Any Other Business:

RNOH will be helping the RMH pathology department, and an SLA is currently being drafted. TJ thanked the RNOH pathology team for their support. RJ noted that Khin Thway is managing the workload incredibly well considering she is on her own.

RNOH have had one patient from Ukraine and all bone centres have offered support with this. RMH have not been approached to date.

Dates of the next meetings:

- 17th June
- 16th September
- 9th December