Meeting of the SWAG Network Sarcoma Clinical Advisory Group (CAG)

Tuesday 28th January 2025, 13:00-17:00

Engineers' House, The Promenade, Clifton Down, Bristol, BS8 3NB/ MS Teams

Chair: Mr Thomas Chapman

REPORT (To be agreed at the next CAG Meeting)	**ACTIONS**

1. Welcome and apologies

Please see the separate list of attendees and apologies uploaded on to the SWAG website here.

2. Review of last meeting's report and actions

As there were no amendments or comments following distribution of the report from the meeting on Tuesday 23rd April 2024, the report was accepted as finalised.

3. Patient Experience

3.1 Clinical Nurse Specialist (CNS) update, changes over the past year and going forward

Please see the presentation uploaded on to the SWAG website

Presented by CNS Sally Lovell

The CNS team has increased to three since February 2024, now providing 2.2 Whole Time Equivalent (WTE) and providing cover every day, with three available every Tuesday for the MDT meeting and Clinic.

The team also have joint Cancer Support Worker (CSW) and Navigator Hannah Hilton, who joined the team in January 2024, whose hours have since dropped to 0.5 WTE to undertake a course in Genetic Counselling. The Navigator part of the role has since been advertised, but it has not been possible to find a suitable applicant to date.

Funding for continuation of navigator posts is not available at present across NBT.

Additional administrative support is provided by Sharon Grant.

Over the past 12 months, the team has reduced turnaround time of benign letters sent following MDT discussion from 11 weeks to within 2 weeks. The delay was not known about until this was recently investigated. The letters are now completed electronically, which has helped to streamline the process.

There had been issues with patients being able to view their MDT outcome on the NHS App prior to receiving an appointment to discuss their diagnosis. This has hopefully been mitigated, with one incident occurring over the last 6 months, now that a statement has been added to the GP letter not to add the outcome on to the app until the patient has been informed.

The number of Holistic Needs Assessments (HNAs) offered has increased from 16 in 2023, to 107 in 2024, and the number completed has increased from 9 in 2023 to 64 in 2024.

Having a third nurse has also enabled the CNS team to visit inpatients, attend PDC appointments, respond to more patient phone calls and enquiries, triage in a timely manner, attend specialty Out Patient Appointments ((OPAs)Thoracic/Urology/Neurosurgery/T&O) to support patients across the pathway.

Future plans include set up of CNS led follow-up clinics once triage competencies have been completed.

End of Treatment Summaries are also in production with draft copies agreed for both Plastics and Retroperitoneal patients. These are now with the Personalised Care and Support Lead for Cancer for conversion into an electronic version on care-flow.

The CNS team continue to triage two week wait, routine MDT and tertiary referrals to either be rejected, accepted to the main MDT, or accepted to the radiology MDT.

In 2024, the CNS team triaged a total of 1348 referrals with 233 patients diagnosed with a Sarcoma, in comparison with 2023, when 1204 referrals were triaged with 206 patients diagnosed with a Sarcoma.

It is hoped that the triage process helps to optimise service provision. For the 807 patients that were triaged to the radiology MDT instead of the main MDT, 430 did not require an OPA. An additional 150 referrals were rejected as they did not meet the referral criteria or did not have the appropriate imaging performed, with the total number of OPA's saved in 2024 being 580.

For the patients that do get an appointment, the triage process helps to guide who requires an urgent or routine slot and also ensures that the patient has had all relevant investigations prior to their appointment.

It is hoped that the new SWAG lipoma pathway can be ratified and letter templates amended so that the associated workload can also be streamlined.

The team in Wales have drafted a more radical lipoma pathway and the plan is that both are presented at the British Sarcoma Group for consensus in the pathway session.

NBT no longer want to store documents such as the lipoma pathway on the website and instead wish to add links that lead to REMEDY.

It is also possible to add any relevant links on to the SWAG website.

GPs in Gloucestershire can now request MRI directly once indicated on ultrasound via the new Community Diagnostic Centre (CDCs). Musgrove GPs are not able to order directly, but an arrangement is in place for the Somerset team to book the MRI.

Regional radiologists who are familiar with the lipoma pathway should report back to GPs with instructions to repeat scan a small lipoma in 12 months and will hopefully stop recommending referral of lipomas to the sarcoma service.

It is expected that the new CDCs will go through a learning curve where feedback on appropriate management of lipomas will need to be shared.

The team have also drafted a template rejection letter bearing the Consultants name and, if it is agreed to use this, it is hoped that it will add more credibility to the triage decision.

4. Clinical guidelines

4.1 Surveillance Chest Imaging Standard Operating Procedure (SOP):
For Ratification

An SOP has been drafted by Hannah Hilton on sending 'No Abnormality Detected' Chest X-Ray Letters, to enable this to be completed by the navigator without input from the Consultant Surgeons to reduce the associated workload and allow more time for review of the x-rays with abnormalities.

The potential for the SOP to include the other imaging modalities where no abnormality is detected will be investigated, but due to outsourcing of imaging, this may not be possible as the reporting radiologist might not follow a standardised reporting format which could be open to interpretation.

Action: To add to the SOP that it has been authorised by Thomas Chapman and the Sarcoma CAG **Hannah Hilton**

It may be possible to arrange for staging CT scans where these are reported as stable as waiting for the results of these scans causes patients a lot of anxiety.

Action: To optimise communication of Staging CT reports to patients. **CNS Team**

5. Clinical opinion on network issues

5.1 MDT Meeting Arrangements

Presented by Tom Chapman / All

At a recent meeting with Cancer Services, it was tentatively agreed that the team would be provided with funding for a Band 3 administrator to support the MDT Coordinator. Currently, the Sarcoma MDT Coordinator is the only MDT Coordinator who does not have a Band 3 to provide support with patient tracking and cross-cover.

It is thought that Cancer Services consider the Sarcoma MDT to be smaller than the other Cancer MDTs and that no cross-cover is required, so the complexity of the meeting was explained. Referrals are received from a wide geography, scans being reported in multiple different centres, the intricacies involved with recording pathological and genomic results, and a vast amount of sifting is required to find the sarcomas amongst all the benign referrals.

When the Sarcoma MDT Coordinator is on leave and another MDT Coordinator provides cover, the meeting overruns and creates problems with tracking the actions. This could be resolved if there was a more regular substitute who could be trained to be familiar with the MDT processes and terminology.

The problem is also providing cover at short notice as only a few MDT Coordinators in NBT start work at 08:00.

Action: To follow up potential provision of a Band 3 administrator with Cancer Services. Thomas Chapman

At the last meeting, the inaccuracy of the Cancer Waiting Time data held by Cancer Services in comparison to the number of diagnoses documented in a spreadsheet held by the Sarcoma MDT was discussed, and Cancer Alliance Managing Director Ruth Carr took an action to look into the discrepancy. This has since been handed over to Programme Manager Niki Gowen who has spoken with Cancer Manager Anna Rossiter and the Somerset Cancer Register about the issue. An update is expected soon.

Sarcoma data collection is a national issue due to problems with standardised coding, and it is unlikely that this can be resolved by the Somerset Cancer Register at any point soon, which is why it is necessary to keep a separate spreadsheet.

It is challenging to keep this up to date as it involves duplication of work. It would be ideal if the spreadsheet could be made more user friendly.

It should be recognised that the local databases do not work and a national database should be provided as an alternative.

Action: To raise as an ongoing issue with Cancer Services and the Cancer Alliance following every meeting. Helen Dunderdale

The time of the MDT meeting is an ongoing issue as the room needs to be vacated by 10:30 due to another MDT scheduled immediately afterwards.

It is hoped that the lipoma pathway may streamline MDT meeting discussions.

One idea would be to group the case discussions for skin sarcomas at the beginning of the meeting, as these rarely need any input from radiology, although this would make coverage for pathology difficult at present until the team are fully staffed.	**Potential MDT Streamlining Initiative**
Booking an alternative meeting room could also be explored.	
The only way for complicated cases of sarcoma to be streamlined would be to have job planned preparation time to fully prepare each case prior to the meeting and prevent cases being deferred for further information to the next MDTM.	
An extra column could be added to the MDT list to include the name of the oncologist responsible for gathering the patient information required to reach the MDT outcome.	
Any other ideas to further streamlining the MDT would be welcomed.	
Action: To audit the MDT Meeting to demonstrate the number of cases deferred for further information.	**To be allocated**
To negotiate job planned preparation time for the MDT meeting.	**Thomas Chapman**
The problem will be finding the time to arrange this around other clinical commitments. A potential time slot could be available to Thomas Chapman every other Monday.	
Changing the MDT referral deadline to Thursday at 5pm would allow for more preparation time.	
The import of images causes many delays. There is regional agreement to buy a regional PACS system that each Trust will move on to when their existing PACS contracts run out. This is the system already used in Bristol. Gloucestershire will move onto the system next year, RUH Bath will hopefully move next, followed by Somerset who have the longest existing PACS contract.	

6. Quality indicators, audits and data collection

6.1 Retroperitoneal Service

Please see the poster uploaded on to the SWAG website

Presented by Consultant Retroperitoneal Surgeon Ahmed Mahrous

NHS England are planning to centralise retroperitoneal services and reduce the number of centres following production of the Sarcoma Service Specification, which states that services should undertake a minimum of 24 procedures per year (per centre, rather than surgeon), have two surgeons, and regularly audit outcomes.

Data from large centres show an increase in positive patient outcomes with a low risk of recurrence; further data analysis is currently underway to ensure that this is accurate.

NBT and Plymouth are keen to retain the service and NBT have recently audited patient numbers and outcomes from January 2016 to December 2023. 24 cases were excluded as, although they technically involve the same procedure, they did not fit the criteria for excision of retroperitoneal sarcoma.

Results are documented within the poster that was presented to BAUS in June 2024 and concluded that outcomes were comparable with expected overall and disease free survival in previously published cases.

It has not been possible to compare outcome data with the latest data from Birmingham as this has yet to be released.

NBT is teaming up with Plymouth to ensure that the service works as one across the South West with sufficient patient numbers.

It is expected that provision of cross-cover, MDT discussions, timely treatments and delivery of results within Cancer Waiting Time targets will be scrutinised.

The related imaging is being outsourced as radiologists within NBT are finding reporting of retroperitoneal disease increasingly challenging.

The potential for the retroperitoneal cases to be listed on the MDT at a time suitable for the Plymouth Surgeons to join is being explored; it is anticipated that this will be 1-2 cases every other week.

At present, cases are discussed with Consultant Surgeon Salah Albuheissi, who provides cross-cover, the Vascular MDT, or the team in Birmingham.

There is a need to formalise cross-cover arrangements and case discussions via the MDT to protect the service.

Action: To liaise with Retroperitoneal Surgeons in other centres to access outcome data and promote the Bristol service via attendance at the BSG. Ahmed Mahrous

To send a link to the NBT Sarcoma MDT to the Consultant Retroperitoneal Surgeons in Plymouth. Adam Dangoor

7. Service developments

7.1 Genomic Medicine Service Alliance / WGS Update

Presented by Genomic Healthcare Professional Sarah Haywood

As raised in previous meetings, it has not been logistically possible to send retroperitoneal samples for Whole Genome Sequencing (WGS) as they don't have a pre-operative biopsy to send, and sending the sample to the laboratory from theatres is almost impossible due to the timing of the theatre list on a Friday afternoon.

This problem may have been resolved as WGS is now being reserved only for mystery tumours.

The Next Generation Sequencing (NGS) panel is far quicker and includes the actionable variants that oncology needs to know about. NHS England are still offering WGS to all patients under 25 years of age, but GMSA representative Sarah Haywood confirms that they have moved away from recommending sending for all sarcomas; WGS is available for any solid tumour if all other standard options for diagnosis have been exhausted.

WGS is also still available for all Brain and CNS tumours.

The request for consenting to WGS would come from Consultant Pathologist Naomi Carson when encountering an unusual tumour with unpredictable high grade features. This can come with a potential cost saving as, if benign, the patient can be discharged with no further investigations required.

It is hoped that the current RNA panel will expand to include the rare translocation tumours that can only be identified via WGS at present.

There are still undescribed tumours that need to be discovered.

The current pathway for sending a second core biopsy to the laboratory for WGS will remain in place. All patients under 25 years of age and under will be consented and the others will be kept in storage should it become necessary to send for WGS in the future. **AGREED**

The Consultant Radiologists only save the second core biopsy for cases that look suspicious of a sarcoma.

There was never any funding associated with taking and storing the biopsy. NHS E fund the WGS testing process.

Consultant Pathologist Mohamed Ahmed is joining pathology, brings a lot of experience and will be a great addition to the team.

Work is underway to improve pathology turnaround time (TaT), but this is always going to be delayed awaiting the gene panel, which makes it impossible to meet the 28 day Faster Diagnostic Target (FDS). When raised if this could be recognised in the regional Cancer Access policy it was not agreed.

The laboratory are upgrading the immunohistochemistry (IHC) machines which should improve TaT for those results and new IHC tests have been introduced that should also improve TaT.

Attempts are made to expedite processing the sarcoma samples but, with 80,000 specimens processed last year, it is challenging for the lab to work in a tailored way.

7.2 Systemic Anti-Cancer Protocols (SACT)

SACT protocols for sarcoma are now available on the SWAG website here:
Protocols Archive - SWAG Cancer Alliance

8. Innovation

8.1 Micro-surgery / Microscope

The Plastics Department will soon have access to a new microscope that will enable an increase in micro-surgery productivity. At present, accessing a high quality microscope can be challenging if they are needed for trauma cases and in other theatres at the same time as the sarcoma list. The purchase is well overdue to resolve this issue, which had been raised on the risk register and with Managers many times.

9. Research

9.1 South West Central Research Delivery Network update

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Medical Oncologist Adam Dangoor and Study Support Manager Claire Matthews

The Research Delivery Network is a new organisation established in October 2024. It used to be the Clinical Research Network but has transitioned to improve support provided to researchers by making this more consistent across the country, and to reflect the growing portfolio of non-clinical trials.

Instead of monitoring trial performance on an individual basis, the organisation will take a more strategic view of the research provision.

The networks have dropped from 15 to 12. The West of England has expanded to include Dorset and Salisbury and has been renamed South West Central.

National clinical trial recruitment from April 2024 to January 2025 shows that 2,058 patients have been recruited to 26 sarcoma trials across 14 research networks. The majority were non-commercial and observational. Recruitment has dropped in comparison with the previous year.

The trials open and in set up in the SWAG region are documented in the presentation.

FaR-RMS is for relapsed Rhabdomyosarcoma, which has a new chemotherapy induction arm to look at the addition of irinotecan versus standard care; ICONIC is for Osteosarcoma; rEECur is for relapsed Ewings; it has recruited well and is due to close soon.

INTER-EWING-1 is the next iteration of the international Euro-EWING trials to improve outcomes in newly diagnosed Ewings Sarcoma.

It has not been possible to progress Sarco-SIGHT in NBT to date, which is a randomised controlled trial of fluorescence guided sarcoma surgery versus standard of care as, despite putting in a lot of time to try and get it set up, it had not been possible to get authorisation.

A website is available where patients can proactively register their interest in participating in research:
https://bepartofresearch.nihr.ac.uk

The NIHR 6-month Associate Principal Investigator (PI) scheme is still open to any interested clinician who doesn't have research in their current role. It allows associates to work alongside current PIs on studies (as documented in the presentation) signed up to the scheme.

The free 18 month Principal Investigator Pipeline Programme (PIPP) is also available for research delivery nurses or midwifes. The next cohort will open to applications later in the year.

NIHR website links and team contact details are available within the presentation. Dr Adam Dangoor is the Research Lead for the CAG.

10. Surgical Case Discussion

The presentation is available to Sarcoma CAG core members on request

Presented by Consultant Plastic Surgeons Giulia Colavitti and Rachel Clancy

The potential to work towards appointing a Clinical Fellow may be a future goal as this could raise the profile of the service. However, the training opportunities for the registrars need to be maximised and this may have an impact on their exposure to the full range of surgical experience.

At present, three registrars are covering four Consultants. A Clinical Fellow post may also need to be combined with another specialty, such as skin, as there are only theatre lists on Monday and Wednesday, and then Tuesday MDT and clinic.

An additional session could involve MDT meeting preparation time on the Friday and an additional research session on the Thursday. The duration of Clinical Fellow posts is usually 6 months.

Now that the surgical team are increasingly doing more complicated high profile cases, it could be carefully integrated to protect registrars training opportunities.

Case discussion:

A forequarter amputation with shoulder reconstruction was undertaken for an extremely painful rapid growing high grade sarcoma, which is a procedure that causes pain, deformity and a huge body imbalance and requires a shoulder reconstruction using the elbow. It was a 7 hour case but was completed with no complications, a 1 week inpatient stay, and a good outcome at first clinic appointment.

Action: To have surgical case reviews as a regular slot at the CAG meeting	**Giulia Colavitti/ Rachel Clancy**

The content of Patient Information Leaflets (PIL) versus the information in End of Treatment Summaries (EoT) needs to be reviewed and optimised. The idea was that the patient left the ward with a booklet on what to expect next, but some of this content in the draft version may be duplicated in the EoT summary.

Action: To optimise the Atypical Lipomatous Tumour (ALT) PIL and follow up processes/flow sheet for all low grade conditions.	**Thomas Chapman/Surgical team**

WHO Guidance on Classification of Tumours lists the risk of recurrence for each sub-type and access to the document can be arranged by departments for £100 per year.

Action: To arrange funding to access the WHO Guidance with the Plastics Manager	**Thomas Chapman**

11. Abstracts and posters for BSG

The registrars are presenting four posters at BSG on different surgical cases, and the CNS team are also presenting on triaging processes.

12. Any Other Business

Surgical management of bone tumours of the chest have recently been rediscussed between the OUH and UHBW teams.

UHBW have a large cardiothoracic surgical team who are experts in chest wall surgery and manage multiple referrals from across a large region; it is ideal for patients to have their surgery closer to home.

Previous discussions have resulted in agreement that Chondrosarcomas are managed locally, which has been the arrangement for the last 15 years. These should be registered with the Oxford Bone MDT.

It is the suggestion of the Oxford team that the UHBW Thoracic Surgical team join the Oxford Bone Cancer MDT on an ad hoc basis when relevant cases need discussion. It is held on a Monday morning between 9 and 11.

Consultant Cardiothoracic Surgeon Doug West agrees on the benefit of forging closer links between UHBW and will join the Oxford Bone MDT.

Action: To undertake a review of recent patient outcomes **Doug West**

Action: To send a link to the Oxford Bone MDT to the UHBW Cardiothoracic Team **Thomas Cosker**

An alert can be sent by the MDT when the section on bone tumours of the chest is due to commence.

It would be helpful if it could be arranged for information to be automatically forwarded from Oxford to Bristol on the images, pathology and discharge summaries undertaken on Bristol patients.

Consultant Orthopaedic Oncology Surgeon Thomas Cosker is always available to contact with any patient queries.

It would also be helpful if the Bristol Clinic run by Consultant Orthopaedic Oncology Surgeon Hattie Branford White could forge links with the NBT CNS team to help manage any queries about booking of local investigations.

Oxford team sadly report that Consultant Orthopaedic Surgeon Max Gibbons is on long term sick leave.

Consultants Ather Siddiqi and Muhammad Riaz are in post, so the team can continue to provide a complete service.

It is planned to hold a South West Sarcoma Education Event in the near future and Sarcoma CAG are asked to gather ideas for agenda items.

Date of next meeting: Friday 10th October 2025

-END-