Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services

Meeting of the SWAG Soft Tissue Sarcoma Clinical Advisory Group (CAG)

Tuesday, 23rd April 2024, 14:00-17:00

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

Chair: Gareth Ayre

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.

2. Review of Last Meeting Report and Work Programme

As there were no amendments to the previous report from 17th October 2023, the report was accepted as finalised.

From the Work Programme:

Action: To continue to develop Patient Information Leaflets (PILs) for high and low grade sarcomas and Atypical Lipomatous Tumours (ALTs) in the next few months. — **CNS and Surgical team**

The PILs will contain the post-operative information required at the point of discharge from the ward, including the next expected follow up investigations and appointments, and contact details for the team. This is in addition to the post-surgery End of Treatment Summary which will be attached to the corresponding clinic letter and sent at a later date.

Action: to develop SWAG Systemic Anti-Cancer Therapy (SACT) Protocols for Sarcoma.

The majority of SACT protocols have now been drafted; it is anticipated that this action will be complete prior to the next meeting.

Action: Review of Cancer Waiting Time (CWT) Data.

Further attempts have been made to address the long term problem with inaccurate CWT data sourced from the Somerset Cancer Register as it does not capture the number of cases discussed by the MDT and dramatically skews CWT performance measures. Data on the actual number of case discussions is recorded in a separate spreadsheet.

A meeting will be arranged with Cancer Managers to try and resolve the discrepancy, which typically shows that the MDT diagnose between one to four

sarcomas per month, whereas the actual figure is approximately 12 sarcomas per month.

The data discrepancy could be due to the different source of referrals into the service, which can be made via the two-week wait referral pathway or from an alternative MDT. It may also be due to the way that sarcomas are coded on the SCR. National guidance dictates that the first code refers to the site of origin, for example breast, skin, gynae etc. with soft tissue sarcoma added as a secondary code.

Action: SWAG Cancer Alliance Managing Director Ruth Carr will explore if the Cancer Alliance can help resolve the CWT data discrepancy. **R Carr**

Action: To optimise Rehabilitation Services for sarcoma patients. **J Masters**

There is still a gap in provision of physiotherapy at the weekend across all specialties in NBT; Physiotherapy Lead Jayne Masters has added this unmet need to the physiotherapy business case.

Post operatively, patients are now being admitted to the plastics ward where the dedicated physio team are based rather than the generic surgical ward.

All other items on the Work Programme are on the agenda today or to be revisited at a future meeting.

3. Lipomatous Tumour Pathway Guidance

Please see the PDF Document uploaded on to the SWAG website

Presented by Consultant Musculoskeletal Radiologist Brathaban Rajayogeswaran

The pathway guidance has been revisited as the team are still receiving a large number of MDT referrals for lipomas.

After the first imaging modality of ultrasound, if the lipoma is found to be superficial <7m with no rapid growth or pain, this is sent back to the GP with instructions to repeat the ultrasound in 12 months if the lesion is deep. If it has increased by >5cm at this point, then a referral can be made to the Sarcoma MDT.

If the lesion shows symptoms of concern on ultrasound, the referrer should arrange an MRI and refer to the Sarcoma MDT in parallel.

If the lesion is painful, deep or has atypical features, the referrer should arrange an MRI; please see the pathway document for details of ongoing management.

Discussion had taken place with Commissioners about arranging repeat scans for the lesions that are deep with no concerning features. It was fed back that GPs would

not be able to coordinate this, however, this is being achieved with guidance from the CNS team.

It is hoped that the revised pathway will help prevent delayed diagnoses of sarcoma, which, as raised in the most recent National Sarcoma Advisory Group, is a common problem across all services due to the benign workload. The pathway will be piloted in SWAG prior to sharing with the National SAG.

Gloucestershire Commissioners have informed Sarcoma CAG that GPs in Cheltenham and Gloucester are not commissioned to refer patients for MRI scans, and any referrals sent to NBT that require an MRI should be re-directed to Birmingham, or NBT should arrange the MRI. However, the NBT triaging team have found that many Gloucestershire GPs can refer patients for MRI scans.

Actions: Regional radiologists will be signposted to the guidance and asked to add clear next step guidance to reports so that this will be appropriately relayed to the patients GP.

To upload the new pathway to the NBT website.

To raise with the National SAG for potential adoption across sarcoma services.

To contact Consultant Radiologist and Peninsula SAG Chair Priya Suresh for insights into the Peninsula pathway. **B Rajayogeswaran**

4. Education

4.1 Soft Tissue Pathology Concepts

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Pathologist Naomi Carson

The aim of the presentation is to address frequently asked questions of soft tissue pathology, which is a very niche, specialised field, consisting of 54 people across the UK and Ireland.

The questions ‘is it benign or malignant’, and ‘is it high grade or low grade’ are difficult to answer due to the nature of the pathology which sometimes defies definition.

Carcinomas and Sarcomas are very different as it is not possible to predict how a sarcoma will behave from the morphology of the cells. Immunohistochemistry (IHC) and molecular testing are required more often than for any other malignant diagnostic pathway, which is why sarcoma has the longest reporting turnaround times.

Medical negligence claims related to soft tissue pathology cost the NHS a significant amount each year; every effort needs to be made to ensure that these are only reported by experienced soft tissue specialists who are aware of the extra testing requirements. Of note, it is difficult to gain experience in a low volume and highly complex field, and several years may pass between seeing certain tumour types. Fortunately, the Royal Marsden have a team of dedicated soft tissue specialist pathologists for second opinions on tumour classification in these cases, which are usually returned within one week.

It is not possible to tell the Sarcoma MDT if a tumour is high or low grade until the specific tumour diagnosis is known. While it is sometimes possible to state with confidence that some tumours are high grade if they have all the relevant features, such as necrosis and mitotic reactivity, the detailed diagnosis is still required.

There will always be a degree of uncertainty as not all soft tissue tumours have been categorised. New soft tissue subtypes are being found all the time, and it is necessary to identify all the nuanced specific differences to retain the credibility of the service and to facilitate development of specific treatments in the future. Further research is required as these tumours are biologically very different from each other and cannot simply be classified as high or low grade. Examples of different sarcoma traits are documented in the presentation.

Sarcoma CAG are recommended to keep a copy of the WHO Soft Tissue and Bone Tumours (Version 5) available in their departments for a quick reference guide.

Discussion:

The Cancer Waiting Time Faster Diagnosis Standard (FDS) states that a patient should be given their diagnosis within 28 days and, as patients really struggle with the wait, there is a need to manage their expectations.

IHC has to be done in stages. When a sample comes to the laboratory, it is processed overnight and cut on Day 2. Day 3-4 will be the first round of IHC, presuming that it is then the weekend, Day 7-8 will be the second round of IHC. At least another 4 days will pass before this has been double reported and, if it is not possible to tell what it is at that point, it will then be sent for an RNA panel, which will take at least 2 weeks. Results of RNA panels can take up to 4 weeks at present as the Genomic Laboratory is under significant pressure.

The 28 day target is not felt to be appropriate for the tumours that require RNA testing. This could be fed back to the National CWT team.

Patients will be brought back to clinic once the diagnosis has been confirmed rather than being booked for a standard two week follow up.

Action: Pathology to communicate expected timeframes for results to the MDT **Consultant Pathologists**

Pathology reports can sometimes be difficult to interpret when there is a statement such as 'this cannot be excluded as a low grade lipomatous tumour'.

Action: To draft consistent wording for the pathology reports **N Carson**

5. Service Developments

5.1 Genomic Medicine Service Alliance (GMSA) Update

Presented by South West Genomic Practitioner Sarah Haywood

The rolling Whole Genome Sequencing (WGS) audit continues. There is nothing significant to update following discussion of the findings in the previous meeting.

The South West have sent 83 patients for WGS to date, 31 of which were sent from NBT, most of which were sarcoma, and 43 from UHBW which were mainly paediatric.

The message from the GMSA is to prioritise standard care tests and send samples for WGS whenever feasible.

The Peninsula Sarcoma Team have queried whether to send biopsy or surgical resection samples for WGS. NBT Sarcoma team exclusively send biopsy samples as many patients have pre-operative radiotherapy and, although it is possible to send irradiated specimens, the failure rate is significantly higher. This had been discussed with the Peninsula team on a previous occasion, when concerns were raised about taking additional diagnostic biopsies. However, this has not been found to cause any problems for the NBT team over a 4 year period.

Consent is arranged after it has been confirmed that the biopsy is adequate to process.

Resources are available on the SW GMSA website to facilitate the consent process.

The sarcoma request form has changed since October 2023, with the number of gene panels increasing from 55 to 114.

TYA patients are also under the remit of Sarah Haywood. Patients aged under 16 with bone sarcoma are referred to Birmingham and patients over 16 are referred to Oxford.

Sarcoma CAG are asked to involve the TYA team as early on in the pathway as possible for patients over 16 so that they can offer all patients WGS and tissue banking; this is a priority for the Children, Teenage and Young Adult Operational Delivery Network (ODN). A clinical genetic checklist is going to be developed for TYA. There are also plans to develop a genetic testing patient information section on the My Sunrise Application (a system available to Peninsula patients, but not in SWAG at present).

Discussion:

With the pathway for biopsy working well, the remaining challenge is identifying patients who have had an inadequate biopsy or a biopsy in another centre who then need a sample to be taken at the point of surgical resection.

Action: To arrange a separate meeting with the surgical team and Navigator to see how surgical resection samples can be sent from Theatre for WGS. **G Ayre/H Hilton**

Action: A generic letter will be drafted for patients to communicate when germline mutations have not been identified. **To be allocated/GMSA**

An appropriate clinic appointment will be made for patients who have had a germline mutation identified.

It has not been possible to coordinate sending retroperitoneal samples for WGS to date due to the time that samples are sent to the laboratory, which is usually after 5pm on a Friday.

Sarcoma CAG will continue to endeavour to offer WGS to all patients whenever feasible.

6. Research

6.1 SWAG Clinical Trials update

Please see the presentation uploaded on to the SWAG website

Presented by Research Delivery Manager Claire Matthews

National clinical trial recruitment from April 2023 to March 2024 shows that 3,103 patients have been recruited to Sarcoma cancer trials across 18 research networks which is just slightly below recruitment in 2022/23 where a total of 3,136 patients were recruited.

75% of the trials were non-commercial, 57.1% of the total were interventional, 35.7 % observational and 7.1% both.

Heat maps of trial activity show the majority of research happening at the Royal Marsden, Christie and Leeds.

There are 5 trials open across the SWAG region and 1 in set up in Salisbury for metastatic Leiomyosarcoma.

Currently there are no first line Ewings Sarcoma trials available for adults; it is hoped to open INTER-EWINGS-1 in the BHOC in the near future.

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 was hoped to set up the trial Sarco-SIGHT to look at the use of fluorescence guided surgery at NBT; the majority of sarcoma centres are taking part. A considerable amount of time and effort was dedicated to completing and submitting the research and ethics forms to try to open the trial but, despite repeated chasing, no response had been received from the R&D department. Other centres reported that set up was achieved with assistance from dedicated research staff. The trial ends in 2026, and it would still be ideal for Bristol to be involved to maintain the reputation of a pioneering service.

The DETERMINE (Determining Extended Therapeutic Indications for Existing Drugs in Rare Molecularly Defined Indications Using a National Evaluation Platform) Trial is also open, which is the first UK national precision medicine trial in rare cancers, such as angiosarcomas, and is testing a range of therapies specifically targeting key genetic changes in cancer cells. It will explore whether treatments approved for use in some cancer types can target identifiable genetic alterations in other cancer types and provide new treatments options for those who might not have any left. Drugs that show promising results will be accelerated for Cancer Drug Fund (CDF) assessment and NHS approval.

A target panel is required for the majority of patients prior to enrolling in the trial which currently involves patients travelling to Cardiff or Oxford.

Arm 2 is not currently open in BHOC due to technical difficulties; this is the ideal treatment option for angiosarcomas.

The Royal Marsden are exploring opening a trial to shorten the radiotherapy course and give a higher dose each day to see if this can be reduced to potentially a 3 week or even 1 week course; the current course is 5 weeks pre-op and 6 weeks post op. The aim would be to compare 5 weeks versus 3 weeks pre-op and 6 weeks versus 3.5 weeks post-op. The trial would look at local recurrence and outcomes. The potential risk would be increased toxicity, although the overall dose given will be the same.

As long as patients will have the same recovery time prior to surgery, the surgical team are supportive of the trial.

The complication with opening trials at BHOC is coordinating with the NBT research team to help collect the necessary data. This would probably involve opening the trial in both centres.

The same process has been researched for treatment of breast cancer, resulting in a reduction from the original 5 week course to a 3 weekly schedule, which has since been reduced again to 5 fractions and significantly reduces the burden of travel for patients.

Question 58 in the National Cancer Patient Experience Survey 'Cancer research opportunities were discussed with the patient' scored below average across SWAG in comparison with the national average. There is no specific figure for sarcoma due to the low number of responses to the survey.

Patient Representative feedback is to let the patient know that research trials have been considered, even if the outcome is that there is no eligible trial available.

A website is now available where patients/anyone can proactively register their interest in participating in research, and there is also e-learning for staff to help facilitate research conversations: https://learn.nihr.ac.uk/.

Results and actions from the Participant in Research Experience Survey (PRES) are documented within the presentation.

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.

Any PI interested in getting help from an associate while helping their personal development is to get in touch.

The second cohort of the free Principal Investigator Pipeline Programme (PIPP) to support research nurses, midwives and dentists to become PIs commenced at the beginning of March 2024.

The Clinical Research Networks (CRNs) are transitioning into Research Delivery Networks (RDNs) from the 1st October 2024 to reflect that there are increasing amounts of research in non-clinical settings. The primary purpose of the RDNs remains the same: to support delivery of high quality research and increase the capacity and capability of future research. The networks are dropping from 18 to 12. The West of England will expand to include Dorset and Salisbury and will be renamed South West Central.

NIHR website links and team contact details are available within the presentation.

Action: To promote the need for a dedicated research nurse or physio to coordinate research across both centres once the CRN transition has been completed and future funding opportunities have been clarified.

C Matthews

7. Patient Experience

7.1 Clinical Nurse Specialist (CNS) update

A new WTE CNS has joined the team, as has part time Navigator Hannah Hilton. After an initial training period, this will help to further optimise the patient pathway by clarifying the arrangements that each team member is responsible for enacting upon.

Hannah Hilton has picked up the existing tracking process from the previous coordinators and will work with Sarcoma CAG to incorporate additional elements to track where the team will find this of most benefit.

A Standardised Operational Procedure could be drafted to enable appropriate tracking and actions following x-ray surveillance reports. However, the processes for flagging x-ray results have significantly improved since this was previously raised.

There is concern that patients can access information on their diagnosis via the NHS app prior to a clinic discussion with a member of the MDT, and the distress that this may cause. It is thought that this is updated with the MDT outcomes sent through to Primary Care, and it is hoped that a note can be added to suppress publication until the diagnosis has been relayed in person.

7.2 Prehab to Rehab update

Presented by Physiotherapist Chris Flower

The majority of patients for prehab services are being identified via the Tuesday Sarcoma Clinics. Referrals can also be made using ICE or by email. Urgent referrals are seen either on the day or within the week. Rehab follow up is arranged automatically for anyone having major surgery.

Patients need to be referred for prehab at the earliest point possible in the pathway to optimise health outcomes from their exercise prescription. Patients can tend to withdraw from normal activities when awaiting test results and the final diagnosis due to fear of causing additional damage. The prehab service aims to address these fears and reinforce that activities can still be undertaken to retain fitness levels prior to treatment.

Feedback from patients and the sarcoma team has been positive and it is hoped that the service will seamlessly continue despite imminent changes to the team.

8. Coordination of patient care pathways

8.1 Oxford Optimal Referral Pathway

Please see the presentation uploaded on to the SWAG website

Presented by Oxford University Hospitals Consultant Orthopaedic Oncology Surgeons, Thomas Cosker and Harriet Branford-White

As well as Tom Cosker and Hattie Branford-White, the Oxford team includes Mr Duncan Whitwell, Professor Max Gibbons and Mr Ather Siddiqi.

The team work closely with the SWAG Sarcoma CAG to optimise referral processes for primary bone tumours and to ensure that the National Oxford Bone Tumour Service is meeting all the requirements of the referring centres.

A National Peer Review of the service is being held on 3rd July 2024 and will review these working relationships, which are well established, with Harriet Branford-White attending the Tuesday Sarcoma Clinic every month for over three years.

Oxford receives referrals from all centres across the South West region. Medium grade and above bone tumours are followed up for 10 years, so the clinic in Bristol is important to reduce the burden of travel for patients.

Bone tumour referrals have been increasing over the last 5 years; conversion rate from suspected referral numbers to cancers diagnosed are consistently approximately one third, with greater than 92 cases confirmed in the last year.

The service has been streamlined to ensure that referral processes are as refined as possible.

All patients >16 with a suspected bone cancer need to be referred with local imaging including a plain film and MRI sent to Oxford PACs, and an MRI proforma emailed to sarcoma.referrals@nhs.net.

Feedback from some patients is that they were not aware they were being referred or expecting a phone call from the sarcoma service, and referrers are encouraged to clarify this to patients.

For patients in a more acute situation, who may be inpatients with a suspected bone tumour, the team should call 0300 304 7777 and ask to be put through to the Orthopaedic Registrar on call at the Nuffield Orthopaedic Centre (NOC) on Bleep 7404 to highlight the referral, summarise the case, and leave contact details.

A review will then rapidly take place, which may involve arranging a biopsy on the ward or a direct transfer to the NOC.

The outcome will be telephoned through within 24 hours in the week, or on Monday if a weekend referral.

If bone cancer is confirmed, the patient is listed onto the following MDT meeting and the Oncologists from Bristol and elsewhere in the South West join to take part in the case discussion.

Discussion:

The Bristol based Oxford clinic was very much appreciated and offers patients a preferable service in comparison with other neighbouring bone cancer centres.

When patients are repatriated to Bristol for chemotherapy, it would be ideal if the pathology and radiology reports were included with the MDT outcome.

When GPs use the incorrect form to refer for suspected bone cancer and this comes via the CNS triaging team in Bristol, GPs are informed to re-refer using the Oxford form and, in parallel, the CNS team flag the referral to the Oxford MDT Coordinator.

This process was helpful and ideally should be sent to the generic referral email address to ensure rapid review.

Sarcoma CAG are invited to contact the team with further suggestions for optimising communications between the two centres.

Delays can occur with importing images across PACS systems across the region.

Action: PACS teams will be contacted to see how import of images can be optimised. **G Ayre**

Patients who contact the Bristol CNS team in error, when they should have been referred to the Oxford CNS team, should be given the Oxford Sarcoma CNS generic email, which is monitored on a daily basis: sarcomaspecialistnurses@oxnet.nhs.uk

9. Network Audits

A Pleomorphic Dermal Sarcoma (PDS) audit of outcomes has been undertaken and results will be shared. At present, the recommended follow up surveillance is chest x-ray. However, a recent study in Scandinavia has recommended cross-sectional imaging follow up to monitor for PDS metastatic occurrences.

Action: To share local PDS outcome data / investigate changing follow up surveillance **Giulia Colavitti**

Sarcoma CAG members are invited to propose subjects for future audits.

10. South West Education Day

Peninsula, Oxford and Welsh teams have confirmed that they would be interested in holding a joint education event, which will be arranged once the new chairmanship of Sarcoma CAG has been confirmed. The plan would be to host the first event face to face in Bristol, potentially in the Aerospace centre, with the option to dial in. Registrars will be encouraged to participate. Ideally it should be held 6 months after the British Sarcoma Group (BSG).

11. Any other business

A case discussion clarified the ongoing need to safety net high risk follow up surveillance.

Date of the next meeting: Tuesday 21st January 2025

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