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

Tuesday, 17th October 2023, 14:00-17:00

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

Chair: Gareth Ayre

REPORT **ACTIONS**

(To be agreed at the next CAG meeting)

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

It has been another year since Sarcoma CAG met due to workload pressures.

As there were no amendments to the previous report from 18th October 2022, the report was accepted as finalised.

Consultant Plastic Surgeon Giulia Colavitti was welcomed as a new and substantive member of the group.

From the Work Programme:

Rearrangement of the Tuesday Clinic: The clinic structure has been altered to fit the needs of radiology and is working well. Previously, errors had been occurring with the clinic bookings. These have since decreased as all patients are told to contact the team directly if they have not heard about their next appointment within an expected time frame. Theatre bookings have also improved now that the team have more oversight of these. The action can now be removed from the Work Programme.

Post-operative information for ward staff to give patients post discharge: The patient information leaflets are still in draft form and need to be reviewed by the group and signed off by NBT's communications department.

Patient information leaflets have also been developed to be handed out in follow up clinic appointments. These are simplified in comparison with Macmillan leaflets. Low grade and high grade versions are available and include details on when to expect their next Chest X-ray and MRI so the patient has ownership of their follow up pathway. These have been presented at the British Sarcoma Group (BSG) and also need to be signed off by NBT's communications department.

Treatment Summaries for Surgery: A template has been drafted to satisfy the requirements of the Personalised Care and Support initiative (formerly Living With and Beyond Cancer). This could be added to the end of the post-surgery consultation clinic letter. It is hoped that this work can be undertaken by the new Sarcoma Navigator.

Straight to biopsy guidelines need to be refined for delivery of results that are not sarcoma: The sarcoma oncologists are best placed to deliver the diagnosis before referring on to the relevant alternative cancer team; GP representatives have confirmed that it is not appropriate to be sent back to the GP to deliver the diagnosis.

The Consultant Radiologists are thought to discuss with patients at the time of their biopsy that they may be referred to an alternative team depending on the result but, when this occurs, it still tends to cause some confusion.

It is difficult to know if additional written information on this would help manage patients expectations. When arranging the straight to test biopsy, patients could be asked if they would be happy for a phone call to discuss the results or if a clinic appointment would be preferable.

In the opinion of Patient Representative M Fowle, there can be no rigid system for managing anxieties around such a pathway, and communications need to be tailored to the individual patient's responses. They may want a clinical appointment with time to ask questions and bring a family member along with them, rather than a telephone call.

Action: To ascertain if the radiology technician can routinely ask all patients if they are happy to receive results by phone call or clinic appointment and document this in their record. — **G Ayre/ Consultant Radiologists**

Shared Care Pathway for Skin Cancer Follow Up: The follow up schedule from the British Sarcoma Guidelines has been copied and pasted into the SWAG Shared Care Guidelines for Sarcoma and Skin Cancer, which has resolved the query from the skin cancer team. The Chair of the Skin Cancer Clinical Advisory Group is also going to amend the responsibilities section for surgery in consultation with the Sarcoma Plastic Surgeons. The updated document will be ratified at Skin CAG and uploaded on to the website.

Patients can be discharged to Patient Initiated Follow Up (PIFU) if assessed as being able to see a local occurrence and act upon this appropriately.

Complicated cases and different patient factors need to be considered prior to discharge.

A registrar has been tasked with gathering information on all local recurrences to see if any conclusions can be drawn from this data.	**Potential future agenda item**

Skin Cancer CAG have developed an algorithm for risk stratifying Squamous Cell Carcinoma (SCC) follow up, which may be possible for sarcoma if sufficient data can be gathered.

Follow up of Atypical Lipomatous Tumours (ALT) to move to PIFU: PIFU for ALT is working well, with patients contacting the CNS team if there are any symptoms of concern. Once the new navigator post is in place, it is hoped to hold group education events twice a year, similar to those organised by the skin cancer team, where patients are taught about symptoms of concern, how to self-examine and how to contact the team if required.

Action: An ALT PIFU information sheet from British Sarcoma Group (BSG) will be adopted when available.	**CNS Team**

Reporting of Chest X-rays: The system for reporting has improved. It was agreed at a previous meeting to request high grade follow up as Category 7. It is not felt to be necessary to flag all follow ups as urgent. This will be clarified again with the Consultant Radiologists.

Pathway for small indeterminant soft lesions: Concerns had previously been raised about the waiting times for these cases. They are now managed on the end of the Monday list in main theatres or in a slot for local anaesthetic only. If the team want surgery undertaken within a month, this is booked as Priority 2 for any theatre. If not considered urgent, surgery is booked as Priority 3.

A paper will be reviewed which has detail on how to assess the urgency of soft tissue lesions in the hand.	**Potential future agenda item**

Regional educational meeting:

The group is still in favour of organising a regional educational event. The ideal time of year would be Autumn as the BSG conference is in Spring.

Action: The Peninsula team will be contacted to see if they would be interested in participating in a regional event.	**H Dunderdale**

3. Service development

3.1 Genomic Medicine Service Alliance (GMSA) update

Please see the presentation uploaded on to the SWAG website

Consultant Clinical Oncologist Gareth Ayre and GMSA Representative Chris Wragg

The ongoing Whole Genome Sequencing (WGS) audit undertaken by G Ayre now includes over three years of data, collected between 25th August 2020 to 17th October 2023.

Turnaround time for results has been improving and is now around 18 weeks; there is still a backlog which is starting to resolve.

All new diagnoses of sarcoma are included in the audit, which is 594 cases to date; 261 were high grade, 209 low grade, 564 new cases, and 30 recurrences.

In total, 83 frozen cores have been taken, 64 of which were in eligible patients. Of those, 17 were not suitable for processing, mainly due to the need for a minimum of 30% cellularity and no more than 20% necrosis, and some other issues with the pathway. 43 went on to be consented, and 34 results have been returned; 4 people are awaiting consent. This is a significant increase in results in comparison to last year.

Of the results returned, 8 cases provided additional information. 3 patients were found to have germline mutations from the blood sample sent with the biopsy sample; 1 patient was already confirmed to have BRCA1 mutation. 3 of these have actionable mutations who would be eligible for immunotherapy in the event of relapse. Further details of the results are documented in the presentation.

In the event of diagnostic uncertainty with a case, the genomics laboratory can be asked to prioritise processing a sample.

Genomic Tumour Advisory Boards (GTABs) are held on an ad hoc basis to help interpret the findings.

Gaining actionable results for 8 out of 34 patients shows that it is a useful task to undertake and should be offered to as many patients as possible.

A plan needs to be put in place to capture all relevant patients in NBT and those biopsied in other centres. Efforts should be focused on the patients who are most likely to relapse.

Some high grade cases are missed as they are often not known about until after surgery; planning is required prior to surgery to ensure that fresh frozen tissue is sent to the laboratory.

Retroperitoneal biopsies are currently all fixed with formalin. There is some reluctance to convert to fresh frozen due to the risk of samples being left over the weekend. The barriers to changing this practice need to be investigated further as this could add another 5 cases for WGS per year.

Another option may be to introduce a pathway for patients having surgery at the Bristol Royal Infirmary for Head and Neck or Chest sarcomas. This is achieved by the Teenage and Young Adult (TYA) team as the Clinical Trial Nurse retrieves the samples from the Theatre and arranges transportation to the laboratory.

A frozen section could be taken from the resection specimen for those patients where the core biopsy is taken elsewhere, or if the core biopsy isn't suitable due to high necrosis. This would need to be flagged on the theatre list and with pathology prior to surgery. Clear instructions not to fix in formalin would also need to be included on the ICE request and extra stickers need to be added to the specimen bags that state 'Do Not Fix in Formalin'; juniors have to read this to check the patient identity label before enclosing the specimen.

It could be possible for the navigator to become involved in this process.

It may be possible to look at biopsies on irradiated specimens; there isn't the data to know if this would definitely mask mutations or not.

Guidelines on how to manage the families of patients who have had germline mutations identified need to be clarified.

It is thought that an NF1 clinic may be available in NBT, this will be explored further, but otherwise, the Clinical Genetics waiting list is greater than a year. Some mutations involve intense follow up and can be very complex. Lead Nurse for Genomics Tracie Miles has a team of 8 nurses working on these guidelines, and on the need to add results to GP alert systems so that any lesions identified are appropriately referred.

There are some published guidelines on surveillance but no associated funding.

Action: A plan will be put in place to supply guidelines for families where gene mutations have been identified. **T Miles**

It would be interesting to have sight of the guidelines provided for families by the paediatric oncology team.

The issues with staff shortages in Clinical Genetics have been apparent for a long time, with the team comprising 1.5 WTE Consultants when 8 are required. One of the postholders has also retired and then returned as there is no one to replace him.

The NBT team are one of the highest recruiters of sarcoma patients to WGS. Oxford, Cambridge and London are also doing well, but they have employed genomic advisers to lead the service. Although it is a lot of work for minimal return, it can make a big difference to the patients who have actionable mutations identified.

Any patient with metastatic disease at diagnosis and relapse can be sent for Next Generation Sequencing (NGS), which has picked up a couple of NTRK mutations which has an effective treatment option.

The RNA panel has recently changed and is now slicker and more comprehensive; turnaround time is under 10 days. This will eventually replace routine FISH testing and give additional information on 120 genes including those required for the DETERMINE trial.

Action: Details of the updated gene panel will be circulated. C Wragg

Changes will be made to the referral form as the sample requirements will differ from FISH requirements.

It is also planned for the DNA panel to become more comprehensive.

4. Research

West of England Clinical Trials Network update

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Medical Oncologist Adam Dangoor and Research Delivery Manager Claire Matthews

National clinical trial recruitment from April 2023-October 2023 shows that 1,520 patients have been recruited to sarcoma trials across 18 research networks, which looks similar to the previous year.

The majority were non-commercial trials and about one third commercial with an even split between observational and interventional.

SWAG region is recruiting very well this financial year in comparison with national recruitment.

There are 7 trials open across the region, and 2 in set-up.

The priority trial at present is FaR-RMS, which is for newly diagnosed and relapsed rhabdomyosarcoma (RMS). ICONIC is mainly a data collection trial. RECURR is relapsed Ewings; RAGNAR has now closed.

The 2 trials in set-up are due to open in Salisbury:

- PM1183-C-010-22 is a randomised controlled open label Phase IIb/III trial of Lurbinectedin in combination with Doxorubicin versus Doxorubicin alone for front line treatment of metastatic leiomyosarcoma
- Nanabis is to determine if nanoparticle cannabis-type based medicines are effective in reducing metastatic bone pain.

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 signed up to the scheme. FaR-RMS and ICONIC are enrolled in the scheme.

It would also be of interest to the group to have sight of the trials available in Cardiff.

The Clinical Research Networks are going through a period of transition. In October 2024 they will be renamed as Research Delivery Networks (RDNs) and reduce from 18 to 12 networks that will operate as one organisation across England. The changes reflect that the NIHR also manages research in local authorities and other out of hospital settings.

The West of England RDN will be renamed South West Central and include Salisbury and Swindon, Bournemouth and Dorset. It will still not include the Somerset Hospitals in SWAG, which will remain under the remit of the Peninsula RDN. The organisational structure is also expected to change but the definitive model is not known at present.

C Matthews will continue to work closely with Peninsula colleagues to report on the trials available in Somerset.

It is not possible to negotiate mapping the RDNs to the Cancer Alliances as these decisions have already been finalised by the NIHR.

The BHOC team have just been accepted to open a new trial for Ewings Sarcoma; the initial start up pack has just been received. A randomisation should be available for all patients.

5. Quality Indicators, audit and data collection

Two Week Wait data

Sarcoma CAG hope to source data to evaluate two week wait service provision at each meeting; data was provided last week for this purpose by Data Analyst Will Ellis in several different spreadsheets.

The first spreadsheet included the number of new diagnoses. This matched the number of cases recorded in the WGS audit (2023). However, the spreadsheets that include the number of two week wait (2WW) and 62 day cancer waiting targets did not tally and were difficult to interpret as patient specific information was not included.

A total of 106 2WW referrals were recorded over the same time period, 80 of which were actioned within 2 weeks (78%).

Although some patients are referred from other cancer sites, such as breast, gynae etc. the discrepancy between the number of diagnoses and number of two week wait referrals seemed to indicate that a significant amount of data was missing.

Some two week wait referrals are downgraded to routine referrals as part of the triage process.

In the 62 week wait data, 15 out of a total of 19 were treated within the target; this also strongly indicated that data was missing.

Recording of sarcoma data has been raised as a national problem.

Action: To compare WGS dataset with Cancer Waiting Time (CWT) dataset to identify the data collection issues and how these might be resolved. G Ayre/W Ellis

The CNS team have tried to resolve this previously, and one of the issues identified was differing coding methods.

It will also be useful to compare with the triaging spreadsheet.

The Brightstar audit data, which was collected over three months at a particularly quiet period, contained details of 12 patients, which also demonstrated that the CWT data is incorrect.

Ultimately, Sarcoma CAG want data that can be trusted and useful to use.

6. MDT Service / Changes

6.1 Lipomatous tumour pathway

One of the main problems with service capacity continues to be managing the quantity of benign referrals sent without appropriate imaging; the lipomatous tumour pathway needs to be further optimised.

Consultant Radiologist B Rajayogeswaran circulated an updated version of the BSG lipomatous tumour pathway document prior to the meeting. A European Consensus document had also been published last year; the content differed on who should have an MRI and be discussed by the MDT. However, the European version did give more guidance on how to manage patients following the results of the MRI.

The priority is to define who organises the MRI and when not to refer following results of an MRI that confirms a lipomatous tumour. This is not clear in the BSG guidelines which states to perform an MRI and refer to the sarcoma service.

The European guidelines recommend performing a biopsy on all patients prior to surgery; the surgeons will be asked to review this section and agree a SWAG version.

A biopsy would be useful for patients where it would be ideal not to operate, should an ALT be identified for example, but if undertaking biopsy on a patient where you would remove the lump regardless of the result, the patient is being subjected to an unnecessary intervention and straight to surgery would be preferable.

The rationale in the European guidelines is that a benign biopsy would mean surgery could be arranged locally by a non-sarcoma specialist and reduce the sarcoma surgeons' workload.

Action: To review both guidelines and agree a straightforward pathway that prioritises where MRIs need to be performed, when MRI results should trigger a referral to the sarcoma team, and when a lesion should be biopsied. **G Ayre/B Rajayogeswaran/ Surgical representative**

The impact on pathology needs to be considered.

The European guidelines have also removed the clinical features associated with pain and growth from the MRI referral criteria, which may be useful for the team to consider.

Arranging MRIs in SFT has improved. It has also improved in GRH, despite the fact that Commissioners had confirmed that this is not a funded service.

6.2 Local audits

To look at results from the Brightstar audit in the next meeting and potentially re-audit prior to the next meeting. **Potential future agenda item**

It would also be helpful to audit the retroperitoneal surgical service as this is at risk due to BSGs intention to reduce the surgical centres from 12 to 6.

The Royal Marden, UCL and Birmingham will be safe as they reach the target number of 24 cases per year. The centres currently operating in the South West are Plymouth, Bristol and Oxford; it is likely that only one will continue.

BSG have put a service specification proposal to NHS England so that centres can apply to retain the service.

The suggested centralisation comes following a survey which compared outcomes from the Royal Marsden, UCL and Birmingham with those from the other 9 centres. This showed a 10% increase in overall survival outcomes after 5 years from the three larger centres. Although observational rather than randomised, it demonstrates the benefit of operating on significantly more cases per year.

Geographically, Bristol would be the most sensible location for the SW Service. A second surgeon will need to be part of the service if Bristol decides to bid; Consultant Urologist Salah Albuheissi would adjust his job plan to incorporate this if required; there is not sufficient workload to justify this at present. Ideally, Bristol could take referrals from the Peninsula and Wales to meet the service specification numbers.

Sarcoma CAG are in favour of forward planning to comply with the service specification framework and retain the retroperitoneal service. **CAG Recommendation**

The centres permitted to continue will ultimately be decided by NHS England.

Action: Local outcome data needs to be made available to support the application to retain the retroperitoneal surgical service. **A Mahrous**

Planning should include how the team will provide remote follow up.

Additional CNS support may be required; a third CNS is going to be joining the team in the near future.

It will also make sense for the service to remain in Bristol because of the cross-over of care with paediatric/TYA patients treated at the Bristol Royal Hospital for Children.

7. Patient experience

7.1 Prehab to rehab update

Presented by Physiotherapist Chris Flower

The Cancer Physiotherapy Team are able to provide more consistent cover for the Tuesday sarcoma clinics following the appointment of C Flower, and back up has also been arranged with the inpatient Plastics Physios for further resilience.

Physiotherapist Jayne Masters, who previously provided the service, has moved to the new role of Allied Health Professionals Cancer Lead.

Prehabilitation patients are usually identified via the clinics, with the target to see people as early as possible in the pathway. Patients flagged for urgent prehab will be seen within the 2 week target to give them as much time to prepare as possible.

One of the main areas of focus is to expand the offer of prehab with parity across different cancer sites via education and exercise classes as well as individualised assessments.

The service is still considered at risk as it is funded on a fixed term two year contract across all cancer groups.

It is essential to patients and organisations for the prehab service to continue as it reduces length of stay by approximately 1.1 days. **CAG Recommendation**

Patient Reported Outcomes Measures (PROMS) are being collected for further evidence of the benefit to patients.

A BSG Lead based in Leeds, who is also a Physiotherapist, has collected a vast amount of evidence on the benefits of prehab, which could be shared.

In addition to the PROMS, a questionnaire could be developed and approved by comms to look at the impact of physio intervention. From the surgeons' perspective, it helps shorten consultation times as patients are better prepared for the impact of surgery.

Action: To develop a questionnaire for patient feedback on the impact of physio interventions. **C Flowers**

There are still delays with discharging patients due to the shortage of physiotherapy cover over the weekend.

7.2 Clinical Nurse Specialist update

Interviews are due to take place for a Whole Time Equivalent (WTE) Navigator role in two weeks' time; six applicants have been shortlisted. However, there is a problem with finding desk space. The team also advertised for a new whole time equivalent CNS; shortlisting will be undertaken this week. It is a developmental role starting on a Band 6, working towards a Band 7 after completion of Macmillan competencies.

The National Cancer Patient Experience results (2022) had a very low number of responses for sarcoma but had received some free text comments which were very positive. Previously, the team undertook separate patient experience surveys to get more responses and, once the additional post holders are in place, the plan is to do this using QR codes that patients can scan using their phone in clinic and then text their responses.

Action: To develop a QR patient experience survey and to reinstate the end of treatment clinics in response to NCPES results once the additional CNS is in post. CNS Team

Triaging the two week wait referrals, although very time consuming, has very positive feedback from patients and ensures that they arrive in the right clinic with the right tests, knowing the names of the CNS contacts.

Action: To provide another presentation on the progress of triaging at a future meeting. CNS Team

A regional CNS and AHP meeting was held two months ago, which was well attended, helpful, and is planning to convene on a regular basis.

8. Any other business

Additional patients will be coming to the BHOC from Cheltenham for radiotherapy now that Clinical Oncologist Charles Candish has stepped down from the role. The majority of patients will be referred to Birmingham, but a small number that are South of Cheltenham will be referred by Birmingham to the BHOC.

The surgical team recommend that surgery is also undertaken in Bristol for these patients so that the patient's pathway remains under the care of the same MDT, and they are treated as close to home as possible. This will be discussed further with Birmingham MDT.

Gloucestershire CCG had been contacted about the separate issue of providing MRI locally but had fed back that all Gloucestershire patients were diagnosed and treated in Birmingham. This was not felt to be the case, and Cancer Advisory Group Manager H Dunderdale has requested the postcodes of patients managed by NBT Sarcoma team, to provide evidence of the number of patients managed from the Gloucestershire region.

Action: To further investigate the number of patients who are treated in Bristol with GL postcodes. **H Dunderdale**

Action: To discuss the possibility of offering radiotherapy and surgery to patients South of Cheltenham with relevant managers. **G Ayres**

A South West Sarcoma Summit meeting was held recently, focused on management of streamlining the pathway for Teenage and Young Adult (TYA) patients due to shortages in the oncology workforce at RD&E. There is one oncologist available one day a week for all sarcoma patients, so again, additional patients may be referred from the Peninsula to the Consultant Oncologists at BHOC.

Consultant Oncologist G Ayre has undertaken the role of Sarcoma Lead now for 5 years and invites CAG members to express an interest in the role. This involves networking with the other Chairs across the region. The role can be undertaken by anyone with an interest in service development.

The BSG conference is in Leeds this year from Tuesday 27th to Wednesday 28th February 2024. Everyone is encouraged to stay for the networking dinner.

A poster will be submitted on the WGS audit. CAG members are invited to submit additional posters.

Date of the next meeting: Tuesday 23rd April 2024, Engineers House, The Promenade, Clifton Down, Bristol, BS8 3NB

-END-