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

Meeting of the SWAG Soft Tissue Sarcoma Clinical Advisory Group (CAG)
Tuesday, 2nd February 2021, 14:00-15:45 via MS Teams

Chair: Gareth Ayre

NOTES
(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 South West Clinical Network (SWCN) Website which will be deactivated on the 31st March 2021. After this date, all documents will be available on the new SWAG Website.

2. Review of previous report and actions

As there were no amendments or comments following distribution of the report from the meeting on Tuesday 20th October 2020, the notes were accepted.

Previous actions

Many of the open actions are on the agenda. Actions discussed:

Action 003/16: Funding for a dedicated Sarcoma Physiotherapist:

Permanent funding for Physiotherapist J Masters' post has been agreed. Action closed.

Action 013/17: Development of post-operative Patient Information Leaflets for Ward Staff to give patients prior to discharge:

To remain as an open action for the NBT Clinical Nurse Specialist (CNS) team.

NBT CNS Team

Action 002/19: The need for General Practitioner (GP) equity of access to booking local MRI scans when flagged as required after initial assessment of a suspicious lesion via ultrasound:

The above was raised with the Cancer Alliance (CA) Early Diagnosis Group but could not be prioritised initially, as the CA needed to prioritise direct access to scans as per NG12 guidance. This has been raised again and will be followed up with the CA as it is even more relevant to prevent patients having to travel long distances for an MRI that could be performed locally, during the COVID-19 pandemic.

G Ayre / H Dunderdale / Cancer Alliance

Action 005/19: MDT service: Promotion of retroperitoneal service:

It is not clear if the number of retroperitoneal surgical cases is sufficient to meet the requirements to maintain a service, as published in the most recent retroperitoneal service specification, and if all opportunities to promote the service have been explored. This will be discussed further with Consultant Surgeon A Mahrous.

G Ayre

006/19: End of Treatment Summaries for surgical cases

E Internello forwarded the End of Treatment Summary used for patients with lung cancer, which is added as an addendum to the end of treatment clinic letter. This can be adapted for the sarcoma service and contain standard information that can be pre-populated with high grade and low grade information for GPs and patients. The request to provide this extra generic information in a set format came from the Personalised Care and Support project (previously known as Living With and Beyond Cancer).

Project Manager E Bedggood is currently providing support to teams for cancer pathway projects and can help produce the template in collaboration with the Plastic Surgeons. **E Bedggood/ R Khundkar / P Wilson**

Action 006/20: To discuss how the CNS Led Sarcoma Triaging Service will be recompensed by the Finance Department

The CNS team have confirmed that a triaging tariff of £25.00 per patient is generated when the activity is recorded on the Lorenzo hospital system. Further discussions are underway with the Finance Department on how to ensure that activity for investigations that happen remotely, for example, direct to biopsy patients, are also recompensed. The action is to remain open until this is resolved.

3. MDT Service – Optimisation of the Sarcoma Clinic:

Please see the presentation uploaded on to the SWAG website

Presented by G Ayre

The problems to be resolved and ideas to optimise the clinic, identified at the clinic reconfiguration workshop in November, are listed in the presentation.

Since the dedicated Sarcoma MDT Coordinator has left this post, the meeting has been covered by multiple different Coordinators. This has meant that the MDTM list has not been optimised, causing the meeting to overrun and the clinic to start late. Cancer Service Performance Manager C Kemp is aware of the problems and plans to allocate a permanent Coordinator to the team in the near future. Any issues in the interim are to be reported on DATEX and to C Kemp.

Ideal structure for Tuesday morning clinic:

- 10 am huddle led by the CNS team to highlight complex patients or those that need to see a specific Doctor
- Clinic Nurse is to write the name of the specific Doctor that a patient needs to see on the clinic front sheet
- The rest of the clinic is managed as a pooled list
- Face to face notes are added to the clinic box when the patient is ready to be seen
- Patients having phone call appointments are added to a separate box in order of time.

Adequate time slots	New Patient	First FU*	FU
Consultant	20 min	40 min	20 min
SpR	30 min	60 min	30 min

*Follow up appointment

With the post-operative ward round, 2 ½ hour MDT meeting, and 2 ½ hour clinic all occurring on the same day, the potential to move some of the workload to a different day was raised. For example, moving the clinic could be considered, or the benign MDT could be held on a different morning. Now that a third Consultant Musculoskeletal Radiologist has joined the team, it may be possible to look at changing Job Plans although, as the radiologists have lists booked every other morning than Tuesday, it may not be possible to do an alternative morning.

Action: Consultant Radiologists and Consultant Plastic Surgeons will discuss current Job Plans to see if there are any opportunities to make improvements. — **Cons. Radiologist / Cons. Plastic Surgeons**

The CNS triaging process, which takes approximately 2 hours per day, is working well, with 20-30% of referrals downgraded or redirected for further tests. It streamlines the patient pathway by ensuring that the patient is directed towards the right clinic, improves the level of information available at the MDT, and patients are grateful for the upfront CNS contact.

It would be helpful if the CNS team could have a slot each week to liaise with Radiology about queries arising from the triage process, such as appropriate management of intermediate small lesions, to prevent cancer waiting time breaches.

Action: Consultant Radiologists and CNS team to find a convenient time in the week to discuss triaging queries; Tuesdays would probably be preferable. — **Cons. Radiologists / CNS team**

One of the main challenges to organising the clinics is caused by multiple individuals booking the slots; ideally patients with sarcoma should have a separate clinic, organised using outcome forms to direct them to the correct clinic slot and format, e.g. face to face or virtual, to mitigate the risk of patients getting the wrong type of clinic letter. BHOC do not have the same issues as all bookings are made in-house.

A potential solution to this would be to appoint a Pathway Coordinator with a clear remit to optimise the pathway. — **CAG Recommendation**

A similar approach is being trialled in certain cancer pathways within SWAG, where people have been appointed to Navigator Roles. In North Bristol Trust, this is due to commence in Lung Cancer Services.

Action: R Khundkar to liaise with Respiratory Physician A Bibby, and Plastics Manager S Vaithianathan for details of the Navigator Role, and Cancer Manager T Agnew will share an example job description — **R Khundkar / T Agnew**

The potential for follow up of certain patients with Atypical Lipomatous Tumours (ALT) to be safely moved to patient initiated follow up (PIFU) will be explored and decided on an individual basis at the MDTM. A PIFU Patient Information Leaflet (PIL) has been circulated that could be adapted for this purpose. Follow up ranges are set at longer intervals in some other centres, and it would be useful to review and agree these prior to the rotation of registrars.

Action: R Khundkar and G Ayre to email information on ALT follow up ranges for the group to consider — **R Khundkar / G Ayre**

Patients with recurrences should routinely be reviewed in clinic.

4. Coordination of Patient Care Pathways

4.1 Reporting of Chest X-rays

The governance on reporting chest x-rays has been clarified following review of an issue that resulted in the following learning point:

Registrars are not to self-report to a patient that a chest x-ray looks clear before the official radiological report is available.

Patient Representative M Fowle recommends that, instead of having the x-ray prior to the follow up consultation, it is preferable to have the consultation first, followed by the x-ray, with clear information that the result will follow. — **Patient Representative Recommendation**

Action: CAG agrees with the recommendation to change the pathway from chest x-ray to consultation to consultation followed by chest x-ray, and check the results of the x-ray prior to sending the clinic letter. — **CAG members**

4.2 Review of internal ICE referral form

A Sarcoma MDT Referral Form has been drafted by R Khundkar in collaboration with C Kemp that would sit on the Integrated Clinical Environment (ICE) Hospital Information System. This will have mandatory data fields that will need to be completed before the referral can be submitted.

Action: The ICE form will be circulated for comments from the group. — **H Dunderdale**

5. Whole Genome Sequencing (WGS) Audit: 25th August 2020 – 26th January 2021

Please see the presentation uploaded on to the SWAG website

Presented by G Ayre

Core biopsies have been frozen for potential future WGS analysis over the past 5 months. A spreadsheet of all new cases identified in the MDTM is collected to support the work. There have been 75 cases during the audit timeframe, 33 of which are high grade and 42 low grade.

A total of 13 core biopsies have been frozen, 8 of which had successful DNA extraction. Of the 5 unsuccessful samples, 2 were used to test the extraction method, 2 failed due to necrosis / inadequate viable tissue, and 1 was not received by the laboratory in the required timeframe.

Of the 8 successful samples, 3 patients consented to WGS and were sent for processing. These were the first 3 cases to be submitted nationally. One result has been returned to date; turnaround time was 4 weeks.

There were 47 additional cases that would have been eligible to consent, but no frozen core biopsy was available. To increase case capture, a punch biopsy of fibromatosis or recurrent disease could be taken by the Consultant Radiologists, a pathway could be put in place to send specimens directly from theatre to the laboratory, and samples taken via CT guided biopsy in other centres could be transported to the laboratory, from the Bristol Royal Infirmary for example.

Potentially dry biopsies could be sent from the See and Treat Clinic, although the majority would be benign.

Action: G Ayre will discuss taking samples from the See and Treat Clinic with the laboratory team **G Ayre**

Resources are available from the Genomic Laboratory Hub team, including how to help implement the surgical pathway. The Plymouth team would also like to link with the SWAG CAG to share practice.

Action: Genomics Programme Manager A Juett and Genetic Counsellor A Pichini will direct the team to the GLH resources, continue to provide support, and arrange a meeting with the Plymouth team. **A Juett / A Pichini**

Patient Representative M Fowle was welcome to join the group if interested.

Thanks was given to the NBT team for the hard work undertaken to become the first centre to recruit sarcoma cases in the country.

6. Patient Experience

6.1 Prehabilitation and Rehabilitation during the COVID-19 pandemic

Please see the presentation uploaded on to the SWCN website

Presented by J Masters

The Physiotherapy Service for patients with sarcoma commenced in May 2019. The ideal aim is to deliver prehabilitation and rehabilitation to all relevant patients. Referrals can be made via the ICE Hospital Information System, or alternatively directly via email, as it is not possible for the UHBW team to access the NBT ICE system.

At present, the majority of surgical patients are being provided with rehabilitation, but it has not been possible to capture all patients to provide prehabilitation. J Masters tries to review as many patients as possible at the Tuesday clinic.

It is also aimed to provide a service to patients that are out of the area.

An overview of the evidence of how important exercise is to oncology patients is within the presentation,.

Action: Slides to be circulated. **H Dunderdale**

Since the pandemic, Lead Physiotherapist J Masters and the Physiotherapist Technical Instructor have been providing video consultations. Patients have fed back that this has helped prepare them for their treatment and facilitated faster recovery.

Currently, measuring the impact of interventions is based on Sit to Stand assessments and patient feedback. Development of a suite of outcome measures for physio interventions, particularly for those patients that have had extensive reconstructive surgery, would be a beneficial service improvement.

Action: J Masters to explore how to develop a suite of outcome measures **J Masters**

The team have all noticed an improvement in patient outcomes since the service commenced, and are very grateful that the service is now available.

6.2 CNS Update

There are no specific updates for the group at the meeting today, other than recognition that the service is particularly stretched at the moment due to workload pressure caused by the second wave of the COVID-19 pandemic, and subsequent provision of support to Critical Care one day per week.

7. Research

West of England Clinical Research Network Update

Please see the presentation uploaded on to the SWCN website

Presented by C Matthews

Research Delivery Manager for Cancer, C Matthews, undertook the role following D Rea's move to work on the COVID-19 trials.

Consultant Oncologist A Dangoor continues as the Sarcoma Sub-Speciality Research Lead

In March, all NIHR research activity was paused to focus on Urgent Public Health (UPH) Research to develop vaccines and therapies for coronavirus.. Set up and delivery has been expedited across all research systems. There are currently 67 UPH trials open; of these 47 opened in the West of England Clinical Research Network.

In May, a restart framework was introduced aiming to restore the full portfolio while continuing to support COVID-19 research. NIHR Guidance has been issued on how to protect research activity during the second wave, including that research staff funded by the NIHR will not be deployed to clinic duties except in exceptional circumstances.

The original high level objectives for research during 2020/21 have been suspended and replaced with objectives related to the UPH trials.

Details on the progress for restarting trial activity across cancer as a whole, and specifically for sarcoma, are documented within the presentation.
Further information is available on the NIHR website.

The portfolio of open sarcoma trials is quite limited at present:

- NIHR – BioResource – Rare Diseases
- rEECur
- FaR-RMS (for children)
- OLIE (in set-up – for children).

It is likely that FaR-RMS and OLIE will be opened in the adult service as well.

A list of potential trials to open is listed in the presentation. If any CAG members have questions or want to express an interest in opening addition trials, please contact claire.matthews@nihr.ac.uk

The team would be interested in opening ICONIC.

8. Quality Indicators, Audits and Data Collection

8.1 Datasets

This item will be added to the agenda of the next meeting due to time constraints and the need to review data completeness.

8.2 Service Evaluation of Chest Wall Resections for Sarcoma against NICE Quality Standard 78 (2015)

Please see the presentation uploaded on to the SWCN website

Presented by A Younes Ibrahim

NICE Quality Statement: Surgical Skills states that surgeons performing planned resections of sarcomas are core or extended members of a sarcoma MDT

Outcome measures:

- 30 day mortality rate post sarcoma resection
- Recurrence within 2 years of initial surgery.

The Service Evaluation, undertaken in Spring 2020 prior to the COVID-19 pandemic, looked at the chest wall resections undertaken between December 2008 and February 2020.

Data was collected from a thoracic logbook, existing database, ICE and Clinic Letters.

20 patients were identified, the majority of whom were men; 16 had primary disease and 4 had metastatic disease. Histological grade was high for 10 cases, low for 2, and unspecific for 8, with Chondrosarcoma being the most common sub-type.

- 30 day mortality: 0/20
- Recurrence within 2 years of initial surgery: 5/20.

Overall findings show that surgery is relatively safe; there is almost 30% risk of recurrence after 2 years. This is relatively consistent with results from larger international studies.

Further data is required due to the small population size and the large amount of heterogeneity, but findings are comparable with other centres.

It is recommended that NICE considers defining acceptable recurrence and mortality

thresholds to allow centres to compare and benchmark themselves to national standards.

8.3 Targeted Treatment of Neurotrophic Tyrosine Receptor Kinase (NTRK) Fusion-Driven Sarcoma: 2 Cases

Presentation available on request

Presented by T Spencer

Larotrectinib is recommended for use within the Cancer Drugs Fund as an option for treating NTRK fusion-positive solid tumours in adults and children if:

- The disease is locally advanced or metastatic or surgery could cause severe health problems and
- They have no satisfactory treatment options.

Case 1:

High grade sarcoma and progressive disease: Sustained partial response of lung nodules, ventricular mass and brain metastases. Currently symptomatically well.

Case2:

High grade sarcoma and progressive disease: Ongoing partial response of lung nodules and no side effects to treatment.

Both cases responded rapidly and treatment was well tolerated. For Case 1, life span has been extended.

9. Any other business

The British Sarcoma Group Annual Conference will take place virtually from Wednesday 24th to Thursday 25th February 2021. J Masters and A Dangoor will be providing presentations.

C Millman and R Peach will provide a presentation on MDT triaging, and a psychologist from North Bristol Trust will also provide a talk.

It may be possible to host an online South West Sarcoma Education Event at some point later in the year.

Date of the next meeting: Tuesday 1st June 2021 (to be confirmed)

-END-