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

Tuesday, 18th October 2022, 14:00-17:00

Engineers House, The Promenade, Clifton Down, Bristol BS8 3NU / Hybrid 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.

Locum Consultant Giulia Colavitti and Consultant Pathologist Naomi Carson were welcomed to the team.

2. Review of Last Meeting Report and Work Programme

It had been a year since Sarcoma CAG had met due to workload pressures.

As there were no amendments to the previous report from 19th October 2021, the report was accepted.

From the Work Programme:

Patient Experience: Post-operative Patient Information Leaflets for ward staff to give patients post discharge:

Work is underway to provide patients with a PIL on discharge from the ward, based on PILs used in Swansea. This will include the contact details of the team, details of the type of surgery undertaken and the next expected follow up appointment.

The need for this additional information was identified after review of results from the National Cancer Patient Experience Survey (NCPES). The PIL needs to be compared with the initial booklet given by the CNS team at the point of diagnosis to avoid duplication.

Although this information will also be given in a clinic letter, there is usually a 3–4-week time lag before this will be typed and posted to the patient, and so interim information is required.

The CNS team used to hold end of treatment clinics to give patients the details of their diagnosis, surgery and expected follow up, but this had stalled since the COVID-19 pandemic.

Action: To continue to develop the PIL and define who completes/provides this, and explore whether to reinstate end of treatment clinics, which could occur virtually. **CNS Team**

Personalised Care and Support (PCS – formerly known as LWBC): End of Treatment Summaries for surgery:

A standard template with generic information could be added to the bottom of the clinic letter to meet this PCS requirement for aftercare information for GPs. This may be possible now that a Patient Pathway Coordinator is in post. The process needs to be as simplified as possible to avoid causing further delays related to clinic activity. **L Wilks / Patient Pathway Coordinator**

Two Week Wait performance data:

CNS C Millman has compared the data on two week wait (2WW) breaches from the Cancer Management Team with the data on the triaged referrals and found that the 2WW does not capture all of the relevant cases and negatively skews performance.

It is also thought that data submitted to National Cancer Registration and Analysis Service (NCRAS) is also incomplete. Staging data is thought to be completed to a high standard in MDT meetings, but when the data was presented by NCRAS, it showed that it was only recorded for 50% of cases.

An attempt had been made to extract data from the Somerset Cancer Register, but the resulting report was difficult to interpret. Additional help will be sought from data analysts / Cancer Manager A Rossiter.

Action: Analysis of 2WW data will be undertaken to find the cause of the missing data. **G Ayre/ A Rossiter**

Providing feedback to straight to biopsy patients referred via the sarcoma pathway who have a non-sarcoma cancer diagnosis:

At present, patients are brought to NBT to receive their non-sarcoma diagnosis by the sarcoma plastics team, who have never met the patient and who will then refer them immediately on to the relevant cancer specialist team – most commonly Haematology.

The CCG had been contacted to see if it would be possible for the referring GP to discuss the diagnosis with the patient and inform them that they would be referred to the relevant cancer specialist team to negate the need for the patient to travel and see a clinician who will not be providing any treatment.

CCG opinion is that a clinician from the target specialty should contact the patient directly.

Referring the patient between MDTs without informing the patient first would most likely not be acceptable to the receiving MDT and so the responsibility for contacting the patient will remain with the sarcoma team, with the oncologists being responsible for contacting the patient.

Action: Sarcoma Oncologists to deliver non-sarcoma cancer diagnosis to patients diagnosed via the straight to biopsy pathway. **Sarcoma Oncologists**

Action: Straight to Biopsy Patient Information Leaflets could be developed to state that patients may expect a phone call with the biopsy results. **To be allocated**

The CNS team can also prepare patients by letting them know that this may occur when they call them to arrange the biopsy appointment.

The Radiologists also reiterate at the time of biopsy that this is a process to exclude the possibility of cancer and the results will determine who contacts the patient.

Standardised letters are sent back to the GP and patient when a diagnosis is benign, and the patient is also called by the Sarcoma CNS Team.

Retroperitoneal Sarcomas:

There is a national drive to centralise surgical treatment of retroperitoneal cancer, and discussions have been previously held to try and determine the minimum safe number of procedures to make this a viable service.

Local numbers are now being recorded as part of the Whole Genome Sequencing tracking database that are considered accurate.

Action: G Ayre will discuss with Consultant Retroperitoneal Surgeon A Mahrous the possibility of getting support from a registrar to analyse outcome data that can be used to demonstrate the quality of the service. **G Ayre/A Mahrous**

This item can be removed from the Work Programme.

Shared care pathways:

The pathways will be updated; to remain on the Work Programme.

Atypical Lipomatous Tumours (ATLs) Follow Up:

Patient Initiated Follow Up (PIFU) had previously been discussed for non-complex cases of ALT. This has yet to be formalised and is due to be discussed further at the next British Sarcoma Group (BSG) conference.

The surgical team are currently offering patients all options, from self-examination and reporting of symptoms to regular follow up appointments as the need varies from patient to patient. Some patients are very happy to be seen less and some patients need the reassurance of routine follow up.

PIFU is standard in London centres.

Complex cases will be flagged for continued follow up at MDT.

CAG will await outcomes from BSG and this item can be removed from the Work Programme.

Minor operations / See and Treat Clinic:

Previous discussions had taken place about the See and Treat Clinic, which was no longer included in the surgical job plan.

Small indeterminant lesions requiring rapid excision can now be added to the end of the Theatre list on Monday or added to Plastic Surgery Outpatients (PSOP).

However, the CNS team have found that it is not possible to book urgent suspected cancer patients into PSOP in a timely way, with patients waiting >8 weeks due to the rigid nature of the PSOP booking system.

It is not possible for suspected sarcoma to be prioritised over a suspected melanoma, with all suspected cancer needing to be prioritised in chronological order of referral as rapidly as possible.

The majority of indeterminant lesions are benign cysts, and a more appropriate pathway could be for the very small lesions to be excised by local teams.

Action: The booking system will be looked at in more detail to see if processes can be made more flexible. The pathway for small indeterminant soft tissue superficial lesion excisions will be revisited to see if they can be managed in local centres. **Surgical Team**

3. Service Update

3.1 Whole Genome Sequencing (WGS) Pathway Audit

Please see the presentation uploaded on to the SWAG website

Presented by G Ayre

A spreadsheet has been used to track all eligible patients for WGS, which is all new sarcoma diagnoses and optimise referrals for WGS, since the service commenced in August 2020 to the present date. The data could be used for any service development work.

At present, WGS is being undertaken for those patients referred directly to the plastics team, using their in-clinic biopsy, and on a small number of patients where the biopsy is not sufficient, using the resection specimen.

There have been 400 cases recorded over the two year period, 378 of which were new and 22 recurrences; 191 were high grade and 209 low grade.

Details on grade, location and if they had a biopsy are recorded, and the percentage from different body sites is detailed in the presentation.

Out of these patients, 58 had a frozen core biopsy that would be considered appropriate to consent for WGS. Half have been consented and 13 have results returned. Another 13 were not possible to consent for a variety of reasons, including insufficient DNA, which was not known prior to the primary resection.

There are 11 more patients that can potentially be consented; G Ayre is trying to arrange this when they come for follow up appointments.

Of the 13 results returned to date, one has informed clinical decision making, which turned out not to be a sarcoma. Five patients did not have actionable mutations and seven gave genetic confirmation of diagnosis, which would also have been picked up by FISH or other diagnostic methods.

Another 246 cases could have been consented, but the majority had their biopsies at other centres and it has not been possible to coordinate pathways outside the plastics team / NBT at present.

It could be possible to improve the rate of retroperitoneal cases eligible for WGS.

Action: To discuss sending retroperitoneal samples to the laboratory fresh frozen rather than in formalin — **G Ayre / A Mahrous**

Some patients didn't have a fresh sample sent to the laboratory after clinic; there are still some improvements that can be made to the local pathway. However, trying to capture all eligible patients is extremely labour intensive.

The average time from consent to return of results is 16 weeks. Some of those outstanding have been waiting for 6-9 months. Results can be prioritised if a patient relapses.

If a patient is consented immediately after diagnostic biopsy, it may be possible for pathology to predict those that are going to be insufficient for DNA and then arrange for the resection sample to be used instead. This may not be ideal if the patient has had neoadjuvant radiotherapy.

It also requires an extra step for pathology other than the standard pathway, as the pathologist needs to be available to prepare the sample rather than the pathology technician.

It is difficult to see how to improve uptake without additional resources. It is also challenging to interpret and feedback results to patients.

All centres across the country are also struggling to make the test standard care, but there is a need to better understand the genetics of sarcoma to inform development of more effective treatments.

GMSA Programme Manager, A Juett, is working on ways to remove challenges, including making the consent process less onerous.

The Peninsula team are hoping to replicate the Bristol pathway as, despite concern over missing patients, the Bristol team have one of the most advanced pathways in England at present.

Addenbrooke's process for fresh frozen tissue sampling works particularly well, due to the resources put in place to support involvement in research; the slides from a recent talk will be circulated.

There was a large study published by Stanmore that looked at >300 cases recruited as part of the 1000 Genomes project; very few results led to therapeutic outcomes.

At present, there is one treatment that has been shown to be working well in local cases, which is Larotrectinib for NTRK fusion. As Next Generation Sequencing (NGS) is available to identify NTRK fusion, G Ayres has arranged for all metastatic patients in follow up to be tested where an appropriate tissue sample was available. Not all results are back yet, with >30 received to date; going forward, all relevant patients should get this focused testing.

Once the NBT pathway has been optimised with all patients being captured, the team will look into getting frozen samples from the other centres. However, it is not possible to achieve this with existing resources.

Action: The GMSA team will work on the practicalities of a transport route for samples coming from Somerset FT. **A Juett**

Funding to support WGS Genomic Activity, which mainly impacts Oncologists' workloads, is due to cease at the end of 2023, with the costs then expected to be absorbed by the Trusts. However, additional funding for clinical time is required if the service is going to develop any further; clinical services are still trying to recover from the affects of the COVID-19 pandemic.

It may be possible to secure further funding in recognition of the extra pressures caused by the pandemic and with the evidence of the progress to date so that equality of access to WGS can be achieved.

Action: G Ayre and A Juett to discuss the extra resources required to expand the WGS pathway **G Ayre/A Juett**

The samples that did not get sent to the laboratory from radiology could be resolved by providing a reminder to the wider radiology team.

There are some cases that have not been possible to send due to situations where it is only possible to take one sample due to pain or anxiety, and then the tissue needs to be prioritised for diagnostic purposes and is put in formalin. In general, the WGS is taken first and stored in an empty pot.

Sarcoma UK helpline receives many calls from patients who know that WGS should be offered and they haven't been able to get it in their treatment centre.

Work will continue to try and optimise the number of patients who can get WGS or at a minimum NGS for NTRK.

4. Coordination of Patient Care Pathways

4.1 Provision of Local Imaging Services, Update from Gloucestershire Commissioners

Presented by G Ayre / H Dunderdale

Following the recent issues with GP access to ultrasound in Gloucestershire, the commissioners were contacted, and it was confirmed that GPs do have access to urgent musculoskeletal ultrasound via the private company PML. However, the PML Manager was not aware that this was stipulated in their contract; this misunderstanding has since been resolved, and the individual GP practices flagged by the team that thought US was not available, have been contacted by CCG Lead S Haque.

Some of the issue had been about the wording for the requests, with GPs asked to request an 'Urgent Ultrasound' rather than a 2WW Ultrasound.

Action: Details will be further clarified, as will the actual turnaround time for provision of the US; reassurance is required that this should be within two weeks as stipulated in NICE guidance. **H Dunderdale**

Gloucestershire Commissioners have asked for the number of referrals received overall, and the proportion that have a GL postcode.

GPs in Gloucestershire do not have access to request an MRI once this is indicated as required after an US is suspicious of Sarcoma. The only option at present is to refer to Birmingham or North Bristol.

Action: To raise the need for GP access to request MRI in the Gloucestershire region with Gloucestershire CCG. **H Dunderdale**

Radiology departments in the region need an update on the guidelines for lumps that are appropriate to be referred on to MRI.

B Rajayogeswaran is currently refreshing the guidelines to clarify the pathway. It currently states that, if a lesion is ≥7cm, arrange an MRI and refer, rather than refer if the MRI is abnormal. It will also recommend management with a repeat US after 6 months for lumps with certain features.

RUH outsource a lot of imaging, and currently there is an automatic process where, if the patient is referred to MRI, they are automatically referred to the Sarcoma Service before this has been reported.

When the guidelines are reissued, it will be made clear that the referral should only be made based on an abnormal MRI being reported.

Action: The updated Lipoma Pathway will be circulated to CAG (including GP representative G Beard to proof read from a GP perspective), uploaded to the website and will most likely be presented at BSG. **B Rajayogeswaran**

4.2 Proposal of Trial of Direct to Test (DTT) Ultrasound (US) at NBT

Presented by G Ayre / B Rajayogeswaran

The Sarcoma Service is keen to introduce a DTT US pathway, local to NBT, as has been achieved in the testicular diagnostic pathway, to facilitate meeting the 28-day diagnostic pathway.

Currently, GPs can refer to radiology for an urgent US but not for a two week wait (2WW) US. Referrals are searched for words such as Sarcoma or Cancer and triaged to the next available slot, which may not always be within two weeks.

For the testicular pathway, the GP makes a 2WW referral via the Integrated Care Environment (ICE) which goes straight to the US booking team, who call the patient within 2 days to arrange an appointment by 10 days. A Patient Information Leaflet (PIL) is posted once the booking has been made.

For Sarcoma, the sonographer would need to be provided with very clear criteria on the features that should trigger an MRI to be booked. Once booked, the CNS Team and MDT Coordinators should be informed.

If none of the criteria are met, the sonographer can inform the patient that they have a benign lump and the patient will not need to be seen in clinic.

Further discussion is required to ensure all potential ramifications on the service are considered. Provision of quality patient information upfront will be essential.

This may help reduce some of the benign referrals referred to the Sarcoma MDT.

Action: G Ayre, B Rajayogeswaran, CNS Team and surgeon to meet to define pathway **G Ayre**

5. MDT Service / Changes

5.1 Clinic Configuration / Booking Systems / CXR Reporting

Presented by G Ayre

Clinic reconfiguration is underway, with the templates for appointments being updated in the next few weeks; this is not for further discussion today.

Chest x-ray surveillance still needs to be optimised by tracking that these are undertaken prior to clinic, flagged as Category 7 instead as requested as routine, and reported back to the requesting clinician in time for the result to be entered into the patient's clinic letter.

Some centres track surveillance via the MDT Coordinator. Ideally this should be managed by the clinical booking system, but there was no confidence in the system at NBT. The system in BHOC works well.

The administrative process could be improved to ensure that all patients who have come via a sarcoma clinic are automatically filed in the urgent radiology reporting folder.

It is hoped that a new system will be developed that will create an alert when a scan is due, but this won't be available for some time.

To mitigate the risk of reports getting missed, should the referring clinician be a registrar that has since moved on, all chest x-ray surveillance scan reports could be copied to a generic email address as well as the referring clinician.

Action: To circulate CNS email address to radiology **B Rajayogeswaran**

Booking processes will be discussed further outside the meeting today.

5.2 MDT Meeting Streamlining Proforma for Lipomatous Tumours

Action: A standardised Lipomatous Tumour protocol will be developed so that MDT discussions can be streamlined. **G Ayre**

The follow up after a stable scan at 6 months will be clarified; guidelines will be sought for the CAG to follow.

Action: A team meeting will be arranged in 6 weeks to try and progress the actions from the CAG meeting. **G Ayre/All**

6. Research

6.1 Clinical Trials Update

Please see the presentation uploaded to the SWAG website.

Presented by A Dangoor

National and regional recruitment figures are detailed within the presentation; regional recruitment trends mirror the national picture.

There are seven trials open with the region and an additional paediatric trial.

RAGNAR is closed to recruitment.

ICONIC is a recently opened trial for osteosarcoma; the team have recruited two patients.

rEEcur assesses different regimens for Ewing's sarcoma relapsed disease.

SPECTA (Screening Cancer Patients for Efficient Clinical Trials Access) is a genomics trial for multiple cancer types.

A 6 month Associate Principal Investigator (PI) NIHR certified scheme is available to any clinicians interested in research who do not have this as part of their main job role. The role involved working alongside the PI of a study. FaR-RMS, which is an overarching study for newly diagnosed and relapsed rhabdomyosarcoma in both adult and paediatric patients is signed up to the scheme.

Results from the Participant in Research Experience Survey (PRES) for 2021/2, which had nearly 2,000 responses from 97 studies across 22 specialties, including cancer, were rated well; 93% indicated they would take part in research again. 93% also felt they had received all the information they needed. 92% felt researchers had valued their contribution. Comments included: research participation was easy and well organised, research staff were friendly and professional, and participants felt they were contributing to improve healthcare for others.

Recommendations include improving access to test results and contact details of the research team and access to parking and appointments out of working hours. The CRN will be looking at ways to address these issues.

Useful links and contact details for the Research Delivery Team are within the presentation.

A national sarcoma research meeting, regularly held a couple of times a year, has highlighted to the NIHR the current challenges with accessing funding to open new trials and the effect this is having on attracting interest from pharmaceutical companies, when the process is much slicker in other countries.

Sarcoma UK has developed a good database of trials and it is hoped to get access to another website for information on early phase trials.

An extract had been received on a survey of retroperitoneal sarcoma treatment, due to be presented at CTOS in Vancouver, that showed some variation in treatment intent. It was thought to show that in 9/21 cases you may be offered either radical or palliative treatment. However, the data could be skewed depending on how the neoadjuvant treatment had been recorded.

There were also some differences in surgical approaches which needed further interpretation by the retroperitoneal surgeons.

A new TYA Trials Coordinator has been appointed to focus on non-interventional trials.

Consultant Surgeon T Bragg plans to do a UK survey on the management of lipomatous tumours, which will be useful to review in a future meeting. **Future agenda item**

Two surgical trials had been discussed at BSG; one on fluorescence assisted surgery and another on Vacuum dressings. The surgical team had expressed interest, but several obstacles, including access to training and research approval processes, had halted progression to date.

7. Clinical Guidelines

7.1 Systemic Anti-Cancer Therapy (SACT) Protocols

Presented by H Dunderdale

Six SACT protocols are available on the website. Network Pharmacist K Gregory has sent an update which will be circulated.

Action: H Dunderdale to circulate SACT protocol update to oncologists **H Dunderdale**

8. Quality Indicators, Audits and Data Collection

8.1 BritE StAr Audit

Please see the presentation uploaded on to the SWAG website

Presented by G Colavitti / M Rice

Consultant Surgeon G Colavitti and Specialist Registrar M Rice are taking part in the national BritE StAr audit to assess national compliance with current BSG and NICE suspected cancer guidelines for pelvic and appendicular sarcomas.

Prospective data will be collected on all bone and soft tissue sarcomas from the SCR between 5th September 2022 and 27th November 2022 for submission by December 2022.

The national results will then be peer reviewed to make recommendations to enhance care and then the audit will be repeated once the changes have been embedded.

Action: M Rice to report regional findings at next Sarcoma CAG Spring 2023 **M Rice**

9. Patient Experience

9.1 National Cancer Patient Experience Results (2021)

There were 27 responses from Sarcoma patients in the 2021 NCPES survey published in July 2022. Five scores have been identified for the group to discuss, all of which are around communication and could be related to wearing masks.

Action: H Dunderdale to circulate NCPES Presentation to CAG members **H Dunderdale**

9.2 Prehab to Rehab Update

The Sarcoma Allied Health Professional working group has developed quality standards that show the benefits of prehabilitation and rehabilitation.

UHBW and NBT have a joint service evaluation dashboard, created by J Masters, that will be used to check that the quality standards are being met and record the benefits of the interventions received. This will be correlated with other information, such as length of hospitals stay to inform a business case to ensure funding for dedicated AHP support is continued.

Length of stay is increased by 2-3 days for post operative patients requiring physiotherapy over the weekend when there is no funding for ward cover. This needs to be included in the business case.

Action: To discuss weekend physiotherapy cover business case with J Masters **J Masters**

9.3 Clinical Nurse Specialist Update

Please see the presentation uploaded to the SWAG website

Presented by the CNS Team

The CNS team have been exceptionally busy with numerous complex cases of young adults.

Following implementation of the triaging protocol to streamline the patient pathway in August 2019, the CNS team have triaged over 3247 patients. This has reduced the number of two-week wait breaches, ensures that patients attend the right outpatient appointment with appropriate investigations and a plan in place, has reduced the number of outpatient appointments and MDT discussions required. CNS contact details are given early on in the pathway. The patient and GP experience has much improved.

Seven breaches had been reported between 1 April and 1 September 2022, most of which were caused by factors outside the control of the sarcoma service and one was processed one day after the two week wait deadline.

The triaging process will be audited and further developed to include the lipoma protocol. The resulting database can be used to inform service improvements.

CAG recognised that the CNS triaging work has dramatically improved the patient pathway, which is especially noticeable at the Tuesday clinic.

10. Any other business

Since the COVID-19 pandemic, Sarcoma MDT has lost the room previously allocated to another service. Another room is being sought in the hope that hybrid meetings can be held soon.

BSG will take place in March 2023 in Cardiff.

Sarcoma CAG will be held 6 monthly from now on instead of the previous schedule of three meetings a year.

Date of the next meeting: To be determined via Doodle Poll

-END-