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

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

Tuesday, 19th October 2021, 14:00-16:00 via MS Teams

Chair: Gareth Ayre

NOTES **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 Actions

Due to increasing numbers of COVID-19 among key staff, the face to face option for the meeting has been cancelled. The situation will be assessed again in February 2022.

As there were no amendments or comments following distribution of the report from the meeting on Tuesday 22nd June 2021, the report was accepted.

Previous actions

Several of the open actions are on the agenda.

013/17: Patient Experience: Additional surgical information:

Production of additional surgical information for patients will be looked into further; it is hoped to provide a Patient Information Leaflet (PIL) to take home at the time of consent.

It would also be helpful to look more widely at the information given across the board. For example, the London Group have a wide selection of PILs on their website.

A generic leaflet could be produced with sections that can be removed if not relevant to that particular patient.

The action had arisen following feedback from patient satisfaction surveys which indicated that some patients didn't fully understand their surgical procedure, the long term implications, and who to contact afterwards with any queries about future appointments.

Current discharge summaries often don't have these details or information on subsequent appointments, so it is hoped that a treatment summary could also incorporate this information.

Patient Representative M Fowle reported having a comprehensive briefing post-surgery while on the ward.

Resources can be made available in Cancer Services to develop a prototype.

A generic leaflet is felt to be the best option which, in combination with the clinic letters already provided after the informed consent process, should provide sufficient information prior to treatment.

In addition, development of the end of treatment summary is also underway.

Action 013/17: Cancer Services will liaise with R Clancy and the CNS team to develop the surgical information leaflet — **R Clancy/CNS Team/Cancer Services**

Action 002/19: Coordination of patient care pathways: A letter will be sent to Somerset CCG to ask them to consider funding direct access to MRI: This action has been paused awaiting feedback from the Cancer Alliance and remains open. — **SWAG Cancer Alliance**

004/19: Impact of 2019 Sarcoma Service Specification / Publication of data on shared pathway activity and designated practitioners in the SAG Annual Report:

G Ayre has discussed data quality with G Kemp to make sure that the service meets Quality Review standards. The data is required to publish the number of referrals received, the number of patients treated, and the modality of treatment in the Annual Report; this has not yet been possible to achieve.

G Ayre will meet with T Agnew to look at the availability of data.

Action: G Ayre meeting with T Agnew, Cancer Services — **G Ayre / T Agnew**

005/19: Promotion of retroperitoneal service:

The need for data on patient numbers is still outstanding. T Whittlestone has now been appointed as Medical Director at NBT, which may mean A Mahrous needs additional clinical cover. G Ayre will discuss both issues with A Mahrous.

Action: G Ayre to discuss retroperitoneal service cover with A Mahrous — **G Ayre/A Mahrous**

006/19: LWBC: End of treatment summaries for surgery: R Clancy met with E Bedggood to discuss development of surgical treatment summaries, and will be meeting with her again to refine how this is done. Completion of treatment summaries needs to be embedded in the Somerset Cancer Register; as this is very difficult to do in clinic time, an alternative way of recording them is being sought.

A standard low grade and high grade template to copy and paste on to the end of clinic letters had been proposed previously to satisfy the GP/CCG requirement for the treatment summary. This can be discussed alongside the provision of pre-operative information.

005/20: Coordination of Patient Care Pathways: Straight to biopsy guidelines need to be refined for delivery of results that are not sarcoma. A standardised letter to GPs will be drafted to see if this may be an acceptable solution: H Dunderdale has drafted a letter to the CCGs for their opinion on asking the referring GPs to provide the result, and await their responses. If not considered appropriate, G Ayre and A Dangoor may be best placed to deliver the diagnosis before referring on to the appropriate team.

Action 001/21: Patient Initiated Follow Up (PIFU) for Atypical Lipomatous Tumours (ALT):

Previously, the team had been waiting for some national guidance and development of a national PIL but, in the interim, CAG could follow London guidelines to discharge low risk patients to self-examine, with contact details for the team if needing to re-present with alert symptoms. Those patients who are thought to find self-examination difficult or have a more high risk disease (which is thought to be the minority) will remain on a follow up schedule.

Action: PIFU for ALTs will be explored further. **G Ayre/C Millman**

002/21: Reporting of Chest X-Rays:

The delays with x-ray reporting times seem to have resolved now that requests are being categorised appropriately. Reports are being received in time to add an addendum with the result to the bottom of clinic letters.

There have been some recent incidences where patients have not gone for their x-ray when requested, which then requires some chasing to resolve.

Any reports where a lesion initially may have been missed get reported back to the radiology audit system for educational review.

Action 003/21: ICE MDT referral form:

NBT Cancer Services have developed a draft form which was reviewed at the last meeting; this will be pursued after today's meeting.

Action: G Ayre to progress implementation of draft ICE referral form, which should improve the quality of information from referrers **G Ayre**

Action 006/21: The surgical team will make enquiries about an additional minor ops list for 'See and Treat'.

As the 'See and Treat' clinic was not in R Clancy's Job Plan, it was considered preferable for the minor operation list to be moved to the beginning of the Monday and Wednesday main operations list.

The waiting list for such patients was currently about 3 months if requiring a General Anaesthetic. Patients who require a biopsy under local anaesthetic do not have to wait as long.

The team are inundated with these small indeterminate lesions, which most often require an excision; the way that they are managed needs to be re-evaluated.

008/21: To Identify a Sarcoma Educational Meetings' lead to set up joint regional educational meetings (with support from H Dunderdale):

Action: R Clancy, G Ayre and H Dunderdale to develop an online event with input from Plymouth and Swansea — **R Clancy, G Ayre, H Dunderdale**

3. MDT Service / Changes

3.1 MDT Streamlining

The MDT last week involved discussion of 68 cases which is not possible to manage within the allocated 2 hours; it is predicted that case numbers will continue to rise.

Many presentations are very similar and generate similar outcomes; it is possible that these could be managed in a more efficient way. As it is not possible to move the radiology meeting to another day, and splitting the meeting would be less than desirable for the majority, it is proposed that protocols are developed for cases that meet set criteria to eliminate the need for a full formal discussion.

The following were raised as potential cases suitable for streamlining:

- Indeterminate solid lesions which can go straight to surgery and come back for MDT discussion only if malignant
- Lipomatous tumours with certain clinical features, to be defined by a focus group comprising a surgeon, radiologist, and CNS.

MDT Streamlining Clinical Lead S Falk will be consulted about the process.

NBT Clinical Lead M Plummeridge is also in the process of reviewing MDT meetings and creating guidelines, and could assist with the process.

Action: CNS, Surgeon and Radiologist to meet to agree criteria for cases that can be streamlined. — **CNS/Surgeon B Rajayogeswaran**

Any complicated lesion will need to stay on the MDTM.

Some of the unnecessary MDT referrals are due to a misinterpretation of the management of lipoma flow chart. RUH still tend to refer patients following a normal MRI when the lesion is causing pain, when the surgery could be undertaken by a local general surgeon.

Action: Consultant Radiologist B Rajayogeswaran to clarify the management of lipoma guidelines with the RUH team. — **B Rajayogeswaran**

It is not feasible for the protocol to cover every scenario, or have a rigid rule about the size of the lesion, as it will depend where it is. It is expected that the protocol will be modified over time.

Existing guidelines can be used as a baseline:

https://britishsarcomagroup.org.uk/wp-content/uploads/2019/01/BSG-guidance-for-ultrasound-screening-of-soft-tissue-masses-in-the-trunk-and-extremity-FINAL-Jan-2019.pdf

T Agnew and the Cancer Services team will be involved in the process.

The Sarcoma MDT has now been held virtually for 18 months. Hybrid meetings were attempted at the beginning, but the audio in the room wasn't clear enough for those dialling in.

A business case has since been submitted to update the audio-visual equipment, microphones, PCs and software in all MDT meeting rooms. Three rooms are currently being renovated. One has been completed and this will be tested over the next few weeks to see if any further adjustments need to be made before this is rolled out to all other rooms.

If there are issues in the room where the sarcoma MDT is held, there is a hotline that can be contacted to get instant assistance from IT.

The team will wait until the renovations are complete before attempting a hybrid meeting again.

UHBW would like to do the same.

Action: T Agnew will forward a copy of the IT business case to A Dangoor **T Agnew**

Another MDT Streamlining initiative could be to reduce the amount of routine review of imaging. This could be reviewed in clinic and brought to MDT if abnormal or discussed directly with the radiologist. **MDT Streamlining Initiative: AGREED**

3.2 Clinic Reconfiguration: Focus Group

The Tuesday morning clinic has yet to improve, and is frequently impacted by the MDT meeting overrunning.

There has been some discussion about moving follow up to a different clinic and only booking new or post biopsy follow up patients into the Tuesday morning clinic. Patients on follow up who relapse with metastatic disease will still need to be reviewed on Tuesday morning so that they have access to an oncologist.

The booking team need to consider Annual Leave when arranging the clinic; this is booked 6 weeks in advance.

A snapshot look at a month of clinics to look at the numbers of new, first appointment post biopsy, post op or routine follow up could be undertaken to see whether there are enough patients to support moving follow up out of the clinic.

Action: A focus group including G Ayre, T Chapman or T Wright, one of the CNS team, and Management will arrange a monthly rolling meeting to try to progress the reconfiguration. **G Ayre / T Chapman or T Wright /CNS's**

None face to face appointments present difficulties. There is often lack of clarity over whether a patient is going to be seen or called, especially with fibromatosis patients. A hybrid model would work for the oncologists.

From a surgical point of view, this would not be ideal for the majority of patients, who require a physical examination which may result in sending them directly for an x-ray, but may work for those patients who just need some questions answered.

Many patients are still asking if they can have a telephone follow up appointment as they did in the previous year, but the CNS team have advised the secretaries as a blanket rule that telephone appointments are no longer offered.

It is recognised that this is not as applicable for patients with fibromatosis when reviewing scans, and attempts have been made to communicate when these patients are coming in or having a telephone appointment. Further work needs to be undertaken to make sure that this is recorded in the appropriate place.

Action: A list of the patients requiring a telephone appointment, including the time that the call is expected and the patients' telephone numbers needs to be provided in advance of the clinic.

Clinic Reconfiguration Focus Group

There are examples of hybrid clinics that function well; the lung cancer clinic has 2 separate lists. Input from the clinic team will be requested.

One of the problems with running a hybrid clinic on Tuesday morning is that often the length of consultation slots are not appropriate for the type of clinic appointment.

The surgical team were asked to consider if there were certain patients where physical examination was no longer necessary and follow up could consist of a local chest x-ray and a phone call. This could be arranged with some organisation, as long as the patients were safety netted appropriately.

Action: Surgical Team to discuss the possibility of risk stratifying some follow up to local chest x-ray and telephone call.

Surgical team

4. Patient experience

4.1 Case studies: Qualitative MDT Feedback Pre & Post Physiotherapist Review of Proposed National Quality Standards for Sarcoma Rehabilitation

Presented by J Masters

J Masters would like to be part of the Clinic Reconfiguration Focus Group due to the need for some patients to have physiotherapist input at the same time as the review for surgery, and if there will need to be some liaison with physio should follow up move to a different slot.

One of the benefits of the Tuesday clinic from a physio perspective is the ability to capture all patient requirements at the same time.

The Sarcoma service has had a dedicated specialist physiotherapist since May 2019 for between 7.5 and 12 hours per week.

Prior to that, provision of physio was inconsistent, and there was no retrospective data to compare previous outcome with current data; therefore examples of qualitative data gathered on two case studies will be presented for the opinion of the group on whether physio input has benefited the service and improved outcomes.

Case Study 1:

High Grade Sarcoma, pre-operative radiotherapy, chemotherapy for lung metastases, surgery: Now independently mobile with a knee brace, frequently exercising and returning to work.

Case Study 2:

High Grade Sarcoma, surgical removal of quads: Now walking with 1 stick and returning to work and involved in cancer community exercise scheme.

Qualitative feedback:

Having physio involvement in pre and post-operative clinics is unanimously supported. It is felt to improve patient's confidence and helps manage expectations. After surgery to the axilla, it helps encourage people to get their hand moving earlier which is vital when undertaking these complex surgeries.

From an oncological perspective, it is felt to be particular pertinent for patients post radiotherapy as it increases tissue fibrosis, stiffness, and impairs function; it is positive news that the role has been made permanent.

Currently, J Masters covers prehab and rehab for numerous different cancer sites. Funding has recently been made available to pilot another physio to provide cover.

Formal clinical feedback will be requested at some point to gather evidence to support a business case to future proof the service.

British Sarcoma Group have a National sub-group of Allied Health Professionals (AHPs) who have drafted the rehabilitation guidelines circulated prior to the meeting.

Action: CAG are requested to read the draft rehab guidelines and provide feedback **CAG members**

The Quality Standard is that sarcoma patients should have access to a specialty physio throughout the patient pathway.

Currently inequity exists; it is felt that patients with bone sarcoma may not receive the same level of support at present.

Action: To use rehabilitation guidelines to define optimum AHP service provision for all sarcoma patients **G Ayre/CAG**

If J Masters is not available in clinic, please refer patients using the ICE request form so that the detail of where the patient is in their treatment pathway is provided.

4.2 CNS Update

Presented by CNS Team

Some data on triaging still needs to be validated and will be circulated after the meeting. Talks are underway about how to further refine the triaging process.

From August 2020 to July 2021, referrals have increased by 107 in comparison with the previous year.

The percentage of two week wait referrals has increased from approximately 50% to 80%.

The number of patients post triage that meet the criteria to go to clinic is still consistently less than 50%, so while we may feel like we are discussing a lot of people at the pre-MDT radiology meeting, the actual number of clinic appointments has reduced.

There is still the need to review reimbursement to the service. For triaging, the service receives a £25.00 fee per patient. The number of patients put on to the direct to test pathway, which was 90 last year, are not generating a tariff at present.
This has been raised with Management.

Triaging has softened the blow in helping to absorb these increased referral numbers in the main MDT, ensuring that the right patients get to the MDT.

As streamlining the MDT progresses, the value of the triaging process will become even more important, together with the use of protocols.

It is only possible to reject referrals that don't meet the 2WW criteria at present; it would need to be possible to create MDT streamlining protocols that allow for a more detailed filtering of cases.

It will be possible to accept a two week wait referral and then protocolise it to the appropriate pathway. This will not constitute a rejection but will be acted on by providing standardised advice.

The amount of time it takes for the CNS team to triage needs to be recognised. It is difficult to manage when one of the team is on leave. Workload should be recorded so that this can be used as evidence for additional resources.

Action: CNS team to document triaging time. **CNS Team**

5. Clinical Guidelines

5.1 Systemic Anti-Cancer Therapy (SACT) Protocols

Presented by K Gregory

K Gregory and J Braybrooke are working on creating a complete library of SACT protocols.

There are only 4 protocols available for Sarcoma at present, 3 of which are out of date and need review.

There are a number of protocols under development, some of which were drafted a while ago so will need a full review, and some have many outstanding queries to be answered.

CAG are asked for guidance on which protocols to prioritise; which are used more frequently or which ones present the highest risk if not available from other sources; and for volunteers to write them or review ones that K Gregory produces.

London and South East have numerous protocols, and it is unclear which ones to prioritise.

The most commonly used protocols are produced by Clatterbridge and the Marsden.

Action: A Dangoor to send priority list and most commonly used protocols to K Gregory to transpose into SWAG format. **A Dangoor**

N Bracknell is seeking funding to produce National protocols, but this will take some time to put in place.

London Guidelines have lowered the threshold for use of supportive drugs relating to Ifosfamide, including sodium bicarbonate, frusemide, and methylene blue for example.

Action: G Ayre and A Dangoor to agree supportive drug thresholds for Ifosfamide. **A Dangoor/G Ayre**

K Gregory will support with the process of copying and pasting Clatterbridge protocols in to SWAG format. Registrar could be tasked with helping.

6. Quality Indicators, Audit and Data Collection

6.1 Audit of the Whole Genome Sequencing Numbers

Presented by G Ayre

Data has been collected on all of the biopsy proven sarcomas diagnosed since Whole Gene Sequencing (WGS) commenced in August 2020 to see how well embedded WGS has become.

WGS has been introduced by NHS England, initially just in some cancer sites (including sarcoma) to examine the WGS of the tumour in comparison with a blood sample to identify gene alterations. The long term plan is for this to become standard of care to

offer to all cancer patients; however this is not something that can be achieved easily.

The current pathway is for any patients biopsied at the Southmead plastics clinics to have an additional core put into a dry pot, rather than formalin fix, which is then frozen and sent to the laboratory. If histology confirms a sarcoma diagnosis, the next time that a patient comes to clinic, they are approached about WGS and asked if they will sign a 'Record of Discussion' (Consent) form. A request form is then completed which involves a sticker and signature. A WGS germline blood sample request form is booked via the ICE system. The lab can then prepare the extra core and blood sample to be sent for WGS.

It is possible to also send shrink wrapped surgical specimens for WGS.

Using the triage list to look at all new and recurrent cases of sarcoma, the MDT have discussed a total of 176 biopsies since August 2020, 28 of which had a dry biopsy sample frozen, 12 of which have been consented, 6 of which have results back.

This shows at every step in the pathway that there is currently a loss of patients having samples sent for WGS.

The British Orthopaedic Oncology Society met in Bristol last week, where A Dangoor gave a talk on WGS.

Data from the 100,000 WGS project has shown how cancer diagnoses can be defined. Anyone who wants to know more can look at the videos available on the Genomics Education Website, and on the National Genomic Test Directory for eligible patients.

The aim in Bristol is to do WGS and Next Generation Sequencing (NGS), which can be done much faster with formalin fixed or fresh samples. This tests for 350 DNA and 150 RNA fusions/mutations, which are then reported to clinicians, picking out clinically relevant information. This may result in access to NICE or compassionate approved drugs and access to clinical trials.

Examples of gene alterations that can be identified include NTRK, EWSR1, ALK.

Two cases previously discussed, both with an initial poor prognosis and no further treatment options, had the NTRK alteration identified, and continue to respond to the targeted treatment, with masses continuing to reduce in size and no side effects from the drug.

It is vital to take advantage of this technology and capture more patients to consent to WGS and NGS. It is possible to use surgical resections, all of which are placed in a compressed pack suitable for processing. MDT outcomes often also state 'patient is suitable for WGS'.

There are factors that make this difficult from the perspective of pathology services. Specimens stored at room temperature need to be processed by a sarcoma specialist within 2 hours and specimens refrigerated need to be processed within 48 hours, therefore it is not practical to process every sample with existing resources. No extra resources have been allocated to provide this additional service, whereas it was for the 100,000 genomes project.

One way that uptake could be improved is if the type of samples that are going to be excised in a given week could be highlighted to the pathologist, so that it would be possible to plan for the correct pathologist to be available on that day/time. If organised in a very detailed way, this could be possible.

It is important to achieve NGS at least for the High Grade Sarcomas as soon as possible.

Action: Resources are required for a research nurse's time to coordinate sending the samples, as was the case in the 100,000 genomes project. H Dunderdale will investigate **H Dunderdale**

Action: G Ayre will be meeting with Sarcoma CAG Chairs in the near future, and will see if/how this is being achieved in other centres **G Ayre**

It was unclear if samples should continue to be sent for FISH when it was possible to send for NGS locally.

FISH can be completed in 2 weeks, but recently turnaround times have increased to a month. For lung NGS DNA locally takes 2-3 weeks and RNA approximately 4 weeks.

Current delays due to workforce issues may guide which test to prioritise; at present it was considered preferable to request both. This will mostly be for metastatic patients or young patients with concerning presentations; the decision will be made within the MDT. **AGREED**

7. Any other business

P Wilson will be on sabbatical from the end of October for 6 months.

It will not be possible for the surgical team to be compliant with Peer Review guidelines during this period, which require 2 surgical members of the team to have 5 PAs in their job plan. To mitigate this, T Chapman will be taking on 2 additional lists per month, which will reduce the impact to some extent, although it was noted that the service had run efficiently with less dedicated PAs for the past 10 years with no problems.

It may be necessary to arrange an additional sarcoma clinic to address workload pressures, operate on less lipomas, and streamline the service as much as possible.

The BSG conference is on 23rd and 24th March 2022 in Liverpool; CAG members are encouraged to submit any abstracts.

If any trainees have undertaken any projects, please inform G Ayre, as these could be added to the next agenda.

It is hoped that the next CAG meeting will be held face to face.

Date of the next meeting: April 2022; exact date to be confirmed.

-END-