

**Meeting of the SWAG Soft Tissue Sarcoma Clinical Advisory Group (CAG)
Tuesday, 22nd June 2021, 14:00-15:30 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 new SWAG [Website](#).

CAG has two new members: Consultant Plastic Surgeon R Clancy and Consultant Clinical Oncologist T Spencer. It was also acknowledged that this will be Consultant Oncologist P Wilson's final Sarcoma CAG after 18 years' service in UHBW. she will continue to work in the BHOC for one day per week.

2. Review of previous report and actions

As there were no amendments or comments following distribution of the report from the meeting on Tuesday 2nd February 2021, the notes were accepted.

Previous actions

The majority of open actions are on the agenda. Actions discussed:

Action 005/16: Service Development: Implementation of a pathway for sending samples for Whole Genome Sequencing (WGS):

This is to remain as a rolling agenda item until WGS is embedded as standard practice.

WGS lead pathologist N Wong confirmed that samples need to be fresh and shrink-wrapped rather than formalin-fixed.

The extra work involved for the Consultant Pathologists needs to be recognised, as they need to drop other tasks to prioritise harvesting the fresh tissue samples.

Action: Consultant Pathologist F Maggiani will be contacted to get her thoughts on how to manage this additional workload.

G Ayre

Currently, all samples submitted have been post biopsy rather than surgical resection. The aim is to record all patients who are eligible as an MDT outcome and then add to the operation list 'please send sample for genetics'.

Action: R Clancy will be the nominated surgeon, as available in Theatre on Mondays and Wednesdays, to put the processes in place to send samples post-surgical resection for the relevant patients

R Clancy

Not all patients have biopsies within clinic, with some occurring in the radiology department. Consultant Radiologist B Rajayogeswaran has made all colleagues aware of WGS requirements if a sarcoma is suspected, and 'please take a dry sample for WGS' should be written on ICE request forms as a reminder.

Once processes have been optimised to ensure that patients are not missed in these 2 areas in NBT, a pathway for patients having biopsies in other centres will be explored, starting with the BRI.

Action: The number of samples submitted will be re-audited to see if any eligible cases are being missed.

G Ayre

There are 2 consent processes, one using paper forms and the other is an online request form. It currently seems easier to use the paper process as this involves adding the patient's pre-filled information sticker, signing it and passing to the clinic nurse to scan and email, but the online process will be evaluated to see which is quicker.

It was confirmed that when tissue is at room temperature, NHSE guidance is that the sample needs to be sent to the lab within 2 hours but, if refrigerated at 4 degrees, it needs to be sent to the lab within 48 hours.

Action 012/17: MDT Service: clinic reconfiguration

As previously discussed, the group are looking into developing templates to make sure that adequate time slots are arranged for clinic appointments.

The role of pathway coordinators has also been discussed to manage the problems where clinic slots are being booked inappropriately.

Cancer Manager T Agnew has been looking into this and has put a few pathway coordinators in to place using SWAG funding this year. The role is to support the patient after the initial appointment with the next steps in the pathway to ensure they have everything ready for the MDT and beyond.

A template job description is in place that can be adapted; Skin and Sarcoma have been identified as the next services that would benefit from such a role and once final sign off is complete on the funding from the SWAG Cancer Alliance (CA), discussions will take place on how to appoint someone to the team.

It is important to note and make transparent to the post holders that funding from the CA is non-recurrent and for one year only. As well as needing to collect evidence on proof of concept for the role, additional funding must be found for the roles to continue.

In a previous role, Consultant Surgeon R Clancy had seen the benefits of the navigator role, which showed evidence-based reduction in complaints, and improvements in service efficiency that transformed the service.

The role has a different remit from the Cancer Support Worker role, which provides patients with support by directing them to the resources identified as necessary following completion of Holistic Needs Assessments, whereas the navigator coordinates the pathway in terms of getting patients the right appointments/procedures at the right place in the pathway.

Action: A focus group will be set up to adapt the navigator job description to fit the service needs within the confines of a Band 3 role. This will include the CNS team, R Clancy, G Ayre, Service Manager and T Agnew.

**G Ayre, T Agnew,
CNS Team**

013/17: Patient Experience: Post-operative information for ward staff to give to patients

**C Millman / R
Peach**

The action is still underway, but has been delayed by workload pressures caused by the COVID-19 pandemic.

Action 014/17: Systemic Anti-Cancer Therapy (SACT) Protocols

Please see the presentation uploaded on to the SWCN website

Presented by H Dunderdale on behalf of K Gregory

Network Pharmacist K Gregory has recently been appointed to replace S Murdoch, and would like a regular slot at each CAG meeting to provide SACT updates.

The National Chemotherapy Group intend to hold a meeting in the near future to discuss producing protocols that will prevent these having to be drafted by each centre.

In the interim, the SWAG protocols will be updated. There are two on the website that need to be reviewed:

- Doxorubicin Single Agent
- Trabectedin.

Doxorubicin Single Agent will not require any changes. Doxorubicin and Olaratumab can be removed as no longer in use. Consultant Medical Oncologist A Dangoor will review Trabectedin and the other outstanding protocols and send this to K Gregory who has 1 day per week assigned to provide the protocol development service. She has produced a protocol request form to simplify the process of drafting new protocols.

Action: H Dunderdale to email A Dangoor the protocols list and request form for direct update with K Gregory

**H Dunderdale / A
Dangoor**

Action 002/19: Coordination of patient care pathways: General Practitioner direct access to MRI after indicated as necessary on ultrasound :

The CA was emailed on 10th June 2021 requesting an update after it had been identified that Somerset CCG is an outlier in not allowing GPs direct access to book MRI after indicated as necessary following ultrasound. This has been added to the

agenda of the CA Delivery Group and circulated to CCGs.

SWAG CA

Action: SWAG CA to take forward with Somerset CCG

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

The minimum number of surgical retroperitoneal cases for sarcoma recommended in the sarcoma service specification is 24 per. This is based on little evidence and, as numbers are likely to be lower in NBT, data needs to be gathered on outcomes to demonstrate the quality of the service as a means to secure it.

Consultant Retroperitoneal Surgeon A Mahrous has requested 5 years of data on relevant patients from the coding team. As this may not capture all activity due to the variation used with surgical coding, Cancer Services and Pathology will also be contacted to help gather the data.

Action: To present retroperitoneal surgical outcome data at a future CAG meeting

A Mahrous

Action 006/19: Personalised Care and Support (PCS, formerly LWBC) Initiatives: End of Treatment Summaries for surgical cases:

Project Manager E Bedgood is providing support to teams for cancer pathway projects and can help produce the end of treatment template in collaboration with the Plastic Surgeons. This can then be added as an addendum to clinic letters in the least onerous way possible.

This has come at the request of GPs that want to know exactly what action to take should alert symptoms present, such as information on referring straight back to sarcoma services in the event that symptoms of recurrence are identified.

The simplest solution will be sought to add the least burden to clinic workload but satisfies PCS requirements.

Action: R Clancy will meet with E Bedgood on Wednesday 23rd June 2021 for further discussion.

R Clancy

Action 005/20: Coordination of Patient Care Pathways: Straight to biopsy guidelines:

Two solutions have been discussed for those patients who have attended NBT for a straight to biopsy test, but are not diagnosed to sarcoma, as an alternative to the patient travelling back to the centre to be given the result by a member of the sarcoma team:

1. Produce a patient information leaflet that clarifies that the patient will be referred on to the appropriate service according to the diagnosis
2. For the GP to deliver the diagnosis if not previously seen in clinic

A letter has been drafted to CCGs to request their feedback.

Action: H Dunderdale will forward the letter to G Ayre to proof read prior to sending to the CCGs

H Dunderdale

Action 006/20: Quality surveillance: Impact of 2019 Sarcoma Service Specification: Shared Care Pathway activity and designated practitioners in SWAG:

The shared care pathways will all be reviewed and updated, in particular for breast cancer, where it has been shown that sarcoma of the breast would benefit from being treated by the NBT sarcoma service.

Action: G Ayre to update Shared Care Pathways and circulate

G Ayre

Action 007/20: MDT Service: CNS Led Sarcoma Triaging Service:

A presentation on the triaging service will be given at the next CAG meeting when 2 years of data on the referral numbers and appointments saved will be available.

The process is going well and, although more difficult to manage during the periods when C Millman and R Peach are on leave, there are plans in place to mitigate any risks to the process.

Positive feedback has been received from the patients, who appreciate getting the phone call after referral, a contact number, and a smoother pathway by saving clinic appointments with referrals straight to biopsy for example.

A poster is being produced for the British Sarcoma Group (BSG) to promote the benefits of the service.

Action: CNS Led Triaging Service update to be added to the agenda of the next CAG meeting

C Millman / R Peach

3. MDT Service – Post-COVID Recovery:

Radiotherapy and Chemotherapy remain unaffected by COVID.

All high grade sarcomas have been prioritised appropriately, but plastic surgery lists have been affected with a reduction in slots across the board; recovering this theatre time is still under negotiation.

The fortnightly See and Treat list for minor surgery has been suspended and it is unclear if this will be reinstated, as the preference would be to move these procedures to a list in a theatre with the correct light, staff and tourniquet control.

See and Treat clinics had not been listed in R Clancy's job plan, although these had been advantageous for those patients who required excision of indeterminate lesions which were too small to biopsy but had been identified in the Radiology MDT as suitable for low risk surgery. These patients can otherwise wait for a considerable period and breach cancer waiting times.

Action 006/21: The surgical team will make enquiries about an additional minor ops list for this purpose.

Surgical team

There appeared to be some discrepancies in the data collected for the purpose of assessing Cancer Waiting Time (CWT) performance. If these indeterminate lesions were tracked, this may flag the issue around waiting times and give evidence of the

need for an additional theatre list.

As far as Cancer Manager T Agnew is aware, Cancer Services were tracking all relevant cases as defined in CWT rules, but are awaiting a dataset back from the team so that this can be cross-referenced with the CWT data to ensure this is correct.

Action: CWT dataset will be discussed further outside the meeting today.

T Agnew / CNS team

It is no longer possible for the CNS team to downgrade the two week wait referrals identified as low risk for cancer which will result in an increase in CWT breaches.

4. Coordination of Patient Care Pathways

4.1 Chest X-ray Review

Presented by C Millman

Chest x-ray reports not being actioned

It is necessary to refine the current system for informing patients of chest x-ray results to ensure that this occurs in as timely a way as possible.

At present, there is currently no automated system to chase up results, which are currently posted back to the supervising consultant's desk.

It is hoped that the pathway navigator role will resolve this but, in the interim, all chest x-ray requests made by the team need to be requested as Category 7 (urgent), which the radiologists will then report within approximately 5 working days. The result then needs to be checked and added as an addendum to the Clinic Letter before any Clinic Letter is sent out.

Action: To feedback the process for chest x-ray results to registrars

Surgical team

4.2 Sarcoma / ALT Follow Up Ranges and Patient Initiated Follow Up (PIFU) Patient Information

Registrar R Slade had drafted a follow up guidance schedule which was edited by G Ayre to include set intervals rather than a range, retroperitoneal follow up, and post metastasectomy chest surveillance in line with London guidance (6 monthly CT follow up for the first 2 years followed by CXR standard follow up). This was considered the reasonable thing to do if the patient's performance status indicated that they were fit for further thoracic surgery.

R Clancy had also made a follow up guidance poster that was used in Swansea .

Action: The ALT follow up poster will be adapted to include the information that is missing when compared to the document produced by G Ayre, and will then be sent out for ratification by the group.

G Ayre / R Clancy

Self-directed follow up for ALT was also under discussion in line with London guidelines, where the patient is seen post-surgery and then discharged with PIFU

advice.

The CNS and AHP team from BSG are running a project to develop a nationally recognised standard PIL and video for this purpose, which should be made available prior to the next BSG conference.

The Bristol / Swansea team are also gathering information from all centres to seek consensus for ALT follow up to put to BSG.

It may be possible to adopt the London guidance prior to the conference; this will be discussed further with the surgical team. It will most likely be PIFU by patient selection rather than blanket guidelines for all ALT patients. This remains open for future discussion.

**Future agenda
item**

5. Quality Indicators, Audit and Data Collection

5.1 National Cancer Registration and Analysis Service (NCRAS) Data

Please see the presentation uploaded on to the SWAG website

Presented by G Ayre

Data on Sarcoma diagnoses and treatment, sourced by NCRAS from numerous data dictionaries by S Strauss with support from Sarcoma UK, was presented at a recent meeting. This showed activity from 2013-2018, allowing comparison with centres across the country.

Sarcoma data was often limited as International Classification of Disease coding was based on body site rather than histological sub-type but, with in-depth analysis, they have managed to extract some interesting information on over 20,000 diagnoses split by tumour site.

This has shown significant variations in survival outcomes where treatment happens in a specialist centre (hosting the specialist MDT) in comparison with non-specialist centres.

For retroperitoneal tumours, treatment for the majority of patients between the ages of 15-75 was surgical, with numbers falling after that age with preference for supportive care rather than active treatment due to the morbid nature of the surgery.

When looking at patient numbers across the country, only London exceeds the number required in the Service Specification (84), Birmingham just meets the target (24), and Bristol sits at the middle of the pack with approximately 12 cases per year, which is somewhat reassuring, as the service is not an outlier in comparison with other centres.

Survival data shows a 62% versus 46% difference between specialist centre versus non-specialist centre management, supporting the need for surgery to take place in specialist centres, and emphasising the need to collect local outcome data and ensure all documentation is up to date to demonstrate the quality of the service.

For breast tumours, the data also indicated that surgery should be arranged in

specialist rather than regional centres, where they are more likely to have a biopsy prior to surgery and therefore more likely to have one operation rather than two. Again SWAG services for management of breast surgery are mid-table. G Ayre will contact all breast cancer centres in the region to discuss updating the shared care guidelines in line with the findings from the data.

For soft tissue sarcoma of the extremities, results are also mid-table. It would be helpful to increase data collection of staging information and performance status. If a tumour is over 5 cm, high grade tumours have a significant survival advantage in receiving surgery at a specialist centre.

This is exactly the information that we need to make publicly available and would be useful to obtain and review in every meeting and publish in our Annual Report on the website.

NBT now has a Business Analyst who can access sarcoma data, and data is also available from the database managed by the new Cancer Support Worker. A separate meeting will be held to see what can be sourced for review prior to the next meeting.

Action: G Ayre, T Agnew, and CNS team to meet to discuss data requirements from Business Intelligence

G Ayre, T Agnew

6. Patient Experience

6.1 CNS Update

The main focus is on collecting the data to provide a more formal review of the triaging process and in conjunction reviewing existing Job Plans in terms of a workload analysis to see what other activities, such as completion of Holistic Needs Assessments, are feasible.

Results from a patient questionnaire, which are on the whole very positive, will be available to present at the next meeting.

A sarcoma patient was interviewed by Lead cancer Nurse L Wilks about the experience of treatment and diagnosis during the COVID-19 pandemic. Feedback could be arranged at a future CAG meeting.

7. Research

7.1 Clinical Trials Update

The research portfolio is very quiet at present due to the pause caused by the pandemic, during which trials staff were redeployed to the wards; REECUR for relapsed Ewing's' sarcoma remains open.

There are no surgical trials in the pipeline and three oncology trials:

- Far RMS
- OLI
- ICONIC .

8. Any other business



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

It would be useful to reinstate joint Sarcoma educational meetings in conjunction with Oxford, Wales and the Peninsula which were held regularly up to five years ago.

Any members interested in coordinating such meetings are to contact G Ayre.

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

**G Ayre / H
Dunderdale**

User representative M Fowle is willing to join the Pathway Navigator focus group should a patient perspective be required.

A social evening will be arranged as soon as lockdown restrictions have been eased, potentially on a Tuesday evening, for team building and an opportunity to say farewell to Paula Wilson.

Date of the next meeting: Tuesday 19th October 2021, potentially face to face meeting at Engineers' House (date, time and location to be confirmed)

-END-