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

Meeting of the SWAG Soft Tissue Sarcoma Site Specific Group (SSG)
Tuesday, 9th October 2018, 13:00-16:30
Engineers House, The Promenade, Clifton Down, BS8 3NB

This meeting was sponsored by Kyowa Kirin **ACTIONS**

Chair: Mr Paul Wilson (PW)

NOTES
(To be agreed at the next SSG meeting)

1. Welcome and apologies

Please see the separate list of attendees uploaded on to the South West Clinical Network (SWCN) website.

2. Review of previous notes and actions

As there were no amendments or comments following distribution of the minutes from the meeting on 5th June 2018, the notes were accepted.

Actions:

Living With and Beyond Cancer (LWBC) - Implementation of the Recovery Package:
The team in North Bristol. An additional physiotherapist and technician have been appointed to provide rehabilitation for cancer patients. The time that they can allocate to sarcoma patients will be Trust has access to a Cancer Support Worker (CSW) one day a week. The post holder will be trained to complete electronic Holistic Needs Assessments (eHNAs) with patients established next week when Clinical Nurse Specialist Chris Millman has raised the need for the physio to attend the pre-operative clinic. LWBC transformation funding for the posts has been provided for 2 years, starting 8 months ago. After this period, a sustainable solution for commissioning the posts will be arranged.

The Bristol Haematology Oncology Centre (BHOC) has 4 CSWs that have been trained to complete eHNAs, and will have access to a dietician employed specifically for cancer patients in the near future.

Sarcoma patients have not been participating in the generic *Living Well* events provided in the Trusts; it was thought that sarcoma specific events may be preferable. The events, which are routinely offered to all patients, have been evaluated well, and can be tailored to different patient needs where appropriate.

Distribution of the SWAG Lipoma Pathway

Please see the presentation uploaded on to the SWCN website

Presented by Brathaban Rajayogeswaran (BR)

The document '*Ultrasound screening of soft tissue masses in the trunk and*

extremities - a BSG guide for ultrasonographers and primary care' has been distributed to the musculoskeletal radiologists and trained sonographers in the radiology departments across the region. This details the clinical features typical of a subcutaneous lipoma that are suitable for observation in primary care:

- Soft lipomatous consistency
- Smooth edges
- No pain
- No recent growth.

A request for special funding would be required before removal of a benign lipoma could be arranged.

Deep, painful, enlarging lesions should be investigated further with an MRI scan. Please see further details within the lipoma pathway presentation.

The wording 'subcutaneous' needs to be added to the pathway, and a few other minor amendments are required. **BR**

The Macmillan General Practitioners have asked that a separate document be provided specifically for GPs. Once the final amendments have been made, a word version of the document will be sent to GP Representative Nicola Harker (NH) for this purpose. **HD/NH**

It was noted that sonographer core training includes identification of soft tissue lumps and bumps.

The regional imaging centres that can accept GP direct referrals for ultrasound and MRI, and the approximate waiting times, will be confirmed. **HD**

The non-urgent pathway for GP referrals needs to be clarified as there are only referral forms for sarcoma on the North Bristol Trust website, and referrals made via this route can then be audited. This should reduce the number of benign referrals currently made to the NBT sarcoma service which can then be safely be monitored in primary care.

The service in Oxford is also inundated with referrals of lipomas, as was the service in Swansea where a 5 year audit of lipomas had been undertaken. As a result, lipomas were no longer routinely excised in the Swansea centre.

Nurse led lumps and bumps clinics have been set up in some centres to help manage the workload. Evidence of cost savings associated with such clinics will be shared. **HD**

It is advantageous to have a baseline measurement of lipomas so that a patient who might perceive that a lesion has grown, can be reassured that it is unchanged when rescanned, although it was recognised that methods of measurement may vary.

Dedicated physiotherapy time: The business case written for a named sarcoma physiotherapist has not progressed since the last meeting.

3. Clinical opinion on network issues / MDT service

3.1 Multi-Disciplinary Team Meeting reforms

Please see the presentation uploaded on to the SWCN website

Presented by Adam Dangoor

Following review of the Cancer Research UK MDT Effectiveness Report by each SSG, and Professor Martin Gore's appointment by the National Cancer Transformation Board to reform MDTM working arrangements across the UK, an inaugural meeting of the SWAG Cancer Clinical Leads was held on Monday 16th July 2018 to define a loco-regional approach to MDT meeting reforms. It was recognised that all MDTs had a certain group of benign patients that they had to manage.

A presentation from Cognitive Scientist Tayana Soukup Acencao gave details of 3 tools that can be used to improve MDT streamlining. It was recommended that a 10 minute break is introduced for meetings after a period of 1 hour, or after 20 patient discussions, to prevent cognitive fatigue and the negative effect that this can have on the quality of decision making. It was also recommended that the MDT Chairs visit alternative MDT meetings to compare styles. In addition, it is planned to address the varied quality of triage systems. The group will meet again in approximately 6 months to discuss progress.

The plan to have a Monday lunch time triage meeting for the Sarcoma MDT has been revisited. It had been possible to filter out 15 new patients that did not require oncology and pathology input. This will free up time to discuss more complex cases, and it may be possible on some occasions to finish earlier and start the clinic earlier. The triage meeting would need to be formally documented on Trust systems to ensure that the service is recompensed appropriately. To facilitate this process, import of imaging from other centres would need to be coordinated within a timeframe for the radiologists to complete a review beforehand. The existing process for this will be clarified together with MDT Coordinator Amy Dixon. **PW**

3.2 Highlights from the plastic surgery away day

The sarcoma service was reviewed at the away day, when the need for a fourth Consultant to join the team was again emphasised. This has now been approved by the relevant resourcing approvals panel and should go out to advert in the next 2-3 months. This will maximise the number of operation lists which can be scheduled for Monday, Wednesday, Thursday and Saturday. Major cases can be undertaken with 2 Consultants at all times, reducing stress and increasing efficiency, and there will be more flexibility to support joint cases.

3.3 Outpatient booking systems

There has been a multitude of problems with the booking of outpatient appointments since the system for doing so has been centralised. This had led to delays in the patient pathway which have been flagged on the Trust risk register. This will be escalated to the outpatient appointment board by Cancer Manager

Samuel Wadham (SW). In the interim, if there are any safety concerns with getting a timely appointment, the team are to email the Cancer Management team, who also have access to the outpatient booking system. **SW**

The time slots for clinic appointments need to be revised. The follow up discussion post diagnosis is the most complex and requires the longest slot. This will be escalated to Plastic Manager Casper Fons (CF), as will the need to look at the postcodes of new patients travelling from outside Bristol, and time their appointments to ensure that they can see the radiologists who are present in clinic from 10:30-13:00. **HD/CF**

The Oxford service discusses new patients in the MDT from 8-10:30, which is followed by the new patient clinic that has 8 dedicated biopsy slots. Plastics, orthopaedic and oncology have a joint clinic. The clinic coordinator looks at patient postcodes and coordinates the times so that patients can avoid the rush hour traffic. Radiotherapy, which may be arranged preoperatively, is scheduled in the afternoon. Patients are called later on that day to let them know if they need to attend the following week, and are given options for a time slot at that point. The time slot for the first follow up appointment also needs to be extended; this is also an issue in Birmingham.

Referrals to the service in Swansea service frequently occur after the work up has been completed. Diagnosis is most often given over the phone. Although this differs from the other centres' processes, giving a diagnosis in a timely manner has been found to reduce patient anxiety. It was thought that patients should be asked how they would prefer to receive results.

3.4 Confirmation of Christmas service arrangements

It is planned to hold the MDT on the 31st December and hold a provisional MDT list on the 21st as an alternative to the 24th as it was not possible to cancel any meetings currently due to the pressure to meet the Cancer Waiting Times 62 day target. Both clinics will go ahead as planned, but slots will not be allocated to patients on routine long term follow up.

4. Service development

4.1 General Practitioner rare cancer masterclass

The action to hold a GP educational event is to be put on hold until the lipoma pathway guidelines have been revised and circulated to primary care, to see if referrals to the service can be improved first via this route. It was recommended that Macmillan GP Nicola Harker ensure that any meeting organised for GPs is formally accredited with CPD points. It would be beneficial to include the Oxford GPs in the distribution of the revised guidelines and invite them to the masterclass should the event go ahead.

4.2 100,000 Genomes Project and Mainstreaming Genomic Medicine

Please see the presentation uploaded on to the SWCN website

Presented by Christopher Wragg (CW)

The 100,000 Genomes Project is due to end in March 2019. The next step is to provide the analysis as a mainstreamed patient care for some cancer sites, including sarcoma. The aim is to find more information on existing biomarkers, seek new ones, and link with molecular stratified clinical trials. A return of results pathway is being developed to ensure that any actionable findings are returned to the patient's MDT in a timely manner to assist clinical decision making. The consent process would need to be simplified to assist with mainstreaming, as the current process is significantly time consuming.

Result turnaround time requires improvement. It was noted that a result had yet to be returned from the first patient (a sarcoma patient) consented into the project. Results had been returned for some of the breast cancer patients after a year, but they were no longer being actively managed, although they could still be of use if the patient was to relapse. A standardised letter will be sent to the MDT when the result indicates that there are no actionable findings.

An appropriate process for transporting the tumour sample to the laboratory fresh, rather than fixed in formalin, within an hour and a half, still needs to be established, as this currently requires the CNS to physically take it from theatre and walk across with it.

From the 1st October 2018, NHS England commissioned 7 Genetic Laboratory Hubs. Genomic Medicine Centres will support the transition from a project to clinical practice. The South West Genetic Laboratory will be based in Bristol and work in partnership with the Exeter laboratory, processing samples from Cheltenham down to the Isle of Scilly.

A national directory of funded tests has been made available.

Five sarcoma patients have been recruited to date. Christine Millman (CM) will cease recruitment at the end of this month. Further resources are required to assist with the sample processing pathway.

5. Quality surveillance

5.1 Quality surveillance requirements

As the Sarcoma MDTs in Plymouth and Exeter are likely to join forces regular communications with the teams need to be improved to ensure practice can be shared across the South as well as with Oxford and Swansea.

The next requirement for Quality Surveillance is to complete an internal validation report. This requires reviewing and updating key documents for the service including the Operational Policy, Annual Report and Work Programme, before Friday next

week. An earlier reminder is required to start the Peer Review process, which is difficult to review in a short period of time. PW and Cancer Operations Manager Christine Nagle will discuss this at a meeting tomorrow. **PW/CN**

6. Living With and Beyond Cancer (LWBC)

6.1 Atypical Lipomatous Tumour (ALT) information days

Inspired by the educational support events for basal cell carcinoma held by the Skin CNS team, the Sarcoma CNS team are considering planning ALT education days and patient initiated follow up (PIFU) as an alternative to conventional follow up. This could free up a significant number of follow up clinic bookings. The cohort of patients that can be safely stratified to this pathway will be clearly defined.

Results from a follow up audit undertaken in Swansea showing an ALT recurrence rate of less than 5% at around 5-8 years, will be shared. **HD**

The team in Oxford had found that the most cost effective follow up is to offer an MRI scan (costed at £45.00) at a fixed point to provide reassurance prior to discharge.

A national patient information leaflet and online educational video could be produced to support the PIFU initiative.

7. Patient experience

7.1 National Sarcoma Forum update and CNS review

An additional CNS is due to start in mid-November 4 days per week to provide cover for Rebecca Peach's (RP) maternity leave. There will be an opportunity to try and maintain this post when the leave ends.

The South West CNS team, including Oxford, meet 3 times a year, and plans to present their work at the next British Sarcoma Group due to take place in London on Monday 25th February 2019. A South West team dinner will be planned to coincide with the BSG.

There have been some referrals that had been sent to the Oxford team for their opinion but had resulted in being managed in Oxford rather than in Southmead. The request for an opinion rather than management will be clearly documented on future requests. In Wales, patients are offered the choice of being referred for the management of bone sarcoma in either Oxford or Birmingham.

An additional retroperitoneal surgeon has joined the team in NBT which can now provide a full service, with a clinic every morning. Contact details will be circulated and the Consultants in Oxford and Wales will be invited to make referrals once the service specification has been completed.

8. Research

8.1 Clinical trials update

Recruitment figures (sourced from EDGE), open trials and trials in set up are documented within the presentation. The West of England Clinical Research Network is currently struggling to meet cancer recruitment targets due to its size in comparison to other networks.

The metrics for measuring performance are being revised and may provide ways to recompense research activity according to incidence and prevalence. Heat maps and different models to accurately calculate this are being developed. The recruitment target per 100,000 population for sarcoma is 0.1 due to the low number of trials on the portfolio.

A Phase III trial to examine the themes that patients say are important is being set up. Recruitment should be straightforward as it will be open to any sarcoma patient at any point in the pathway.

There is a new kinase inhibitor which will be compared with chemotherapy for fibromatosis in the relapse phase. A local Principal Investigator needs to be identified.

A trial is open in Oxford looking at circulating DNA for chordoma sarcoma. Patients do not need to travel to enter the trial as a blood sample can be taken locally.

9. Any other business

Funding is available to pay for the nursing team to attend the BSG conference next year.

A South West Education Day will be arranged in the next year.

Paul Wilson has stepped down from the role of Chair of the Sarcoma SSG, and the role will now be undertaken by Consultant Oncologist Gareth Ayres.

Date of the next meeting: Tuesday 12th February 2019

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