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

Meeting of the SWAG Soft Tissue Sarcoma Clinical Advisory Group (CAG, formerly SSG)
Tuesday, 18th June 2019, 13:00-16:30
Engineers House, The Promenade, Clifton Down, BS8 3NB

Chair: Dr Gareth Ayre (GA)

	NOTES (To be agreed at the next CAG meeting)	ACTIONS

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 Tuesday 12th February 2019, the notes were accepted.

Actions:

Living With and Beyond Cancer (LWBC) activity update: As discussed at the last meeting, the team had previously held disease specific events at the end of treatment, every 6 months, with a Psychologist and Physiotherapist; support ceased as they were not considered to be sustainable, and now generic 'Living Well' events are held for all patients with cancer near the beginning of the patient pathway. Sarcoma specific information will continue to be provided by the Clinical Nurse Specialist team and a Cancer Support Worker who will be appointed in the near future. Action closed.

Dedicated physiotherapy time: A business case for a named physiotherapist will be drafted using evidence to demonstrate the value of the service, which is due to be piloted over the next 6 months.

MDT Service - Implementation of CRUK MDT Recommendations: The pre-MDT radiology triage meeting, held on a Tuesday morning, is working well, and allows more time to discuss cases of sarcoma. The main risk is ensuring that outcomes are communicated to the referring General Practitioner. This has been managed by creating template letters, and the Plastics Administrators can then be instructed to send the appropriate version. Administrative support is required to assist with the process, which is currently managed solely by CNS Chris Millman (CM). The feasibility of funding an administrator using the nursing budget from the Temporary Staffing Bureau will be explored, and a business case for a permanent Band 3 administrative post will be drafted to assist with managing the patient pathways. **GA/CM**

MDT service – documentation of problems with outpatient bookings:
Outpatient appointment clinics could be utilised more efficiently; there are still problems with making requests for appointments using the centralised booking system. The following potential solutions were discussed:

- Increase clinic preparation time
- Ring-fence slots for new patients requiring ultrasound/biopsy, checking postcodes to take travel time into account
- Send patients on long term follow up to general clinics
- Separate benign / Atypical Lipomatous Tumour (ALT) follow up from sarcoma
- Organise nurse-led follow up clinics for ALT, potentially twice a week
- Allocate appropriate time slots for first, second, and follow up appointments
- With assistance from a patient pathway administrator, telephone people who do not need to attend clinic to avoid unnecessary visits.

Clinic nurses will be included in the plan to pilot potential service improvements. The clinic list will be reviewed at the end of the next MDT to start the process. **MDT members**

Impact of 2019 Sarcoma Service Specification: MDT Lead Gareth Ayre will arrange to speak with all relevant site specific MDT Leads about the sarcoma shared care pathways and the need to publish details of the activity. Data will be collected from pathology and published in the CAG Annual Report.

Promotion of retroperitoneal service: The 2019 Sarcoma Service Specification states that the recommended caseload for retroperitoneal sarcoma is 24 cases per annum. The retroperitoneal surgical service performs this number of cases, but the majority of diagnoses are benign. The service needs to be promoted across the South West and Wales to ensure that all appropriate cases are referred. Referral pathways are already in place for patients with retroperitoneal germ cell malignancies.

Advance communication training requirements: The Lead Cancer Nurses were contacted to see how often advance communication training needs to be repeated. This has yet to be defined. Action closed.

End of treatment summaries: Radiotherapy End of Treatment Summaries are routinely completed by the Radiographers. Chemotherapy End of Treatment Summaries are going to be imported into the Medway Hospital Information System so that these can easily be added as an addendum to the clinic letter. It is difficult to produce a generic surgical summary as the treatment is so variable, but a simple addendum could be created to add to clinic letters which could contain links to related web pages. Consultant Surgeon Paul Wilson (PW) will discuss this with the Plastic Administrators. Physiotherapist Jayne Masters will be included in the design process. **PW**

A recent meeting with finance confirmed that the tariff for triage activity or follow up via telephone call is £20.00 in comparison to £140.00 for a face to face clinic. This is not felt to reflect the amount of preparation time required to undertake this activity, which can improve breach rates; Commissioners will be asked to reconsider

the tariff.

3. Service development

3.1 Genomic Medicine update

Please see the presentation uploaded on to the SWCN website

Presented by Catherine Carpenter-Clawson (CC-C)

In December 2018, the UK reached its goal of sequencing 100,000 genomes. Over 3,550 samples, of which 2,643 were for rare diseases, were collected by the West of England Genomics Centre (which consisted of a virtual body of GMC champions who consented patients and coordinated the necessary pathways in collaboration with the clinical teams) across all the provider Trusts. Results are now being returned for analysis en masse; the first results for sarcoma were returned yesterday.

Transition from a project to a standard NHS service with continued involvement from the GMC team is now underway by reducing the number of laboratories from 25 to a network of 7 Genomic Laboratory Hubs, all processing a core set of samples according to the same standards.

North Bristol Trust was successful in the bidding process to become one of the GLHs in partnership with Royal Devon and Exeter Trust. Each hub has been given the responsibility for processing a number of additional specialist tests, which are divided so it is clear who is doing what for each indication / disease.

National genomic test directories for rare diseases and cancer have been published (here) that define the genetic and genomic tests that will be made available via NHS England at some point in the near future (potentially April 2020); directories will be reviewed by a panel of experts on an annual basis. Whole genome sequencing for all patients with sarcoma is included.

A dedicated Genomics Tumour Advisory Board has been proposed to review the analysis of all results for patients with sarcoma; the next meeting will convene in mid-July 2019.

Dr Dan Nelmes has been appointed as the GLH Clinical Lead for cancer, and will be in touch with representatives from the MDT to discuss the resources required to set up a local sustainable pathway; potential dates will be circulated by CC-C in the near future. There will be national standardised resources available for consent, sample handling guidance and result management. **CC-C**

CAG will consider the ideal frequency and format of the Genomics Tumour Advisory Board, which could be held nationally or regionally.

4. Patient experience / Living With and Beyond Cancer

4.1 Pilot Sarcoma Outpatient Physiotherapy Service

Please see the presentation uploaded on to the SWCN website

Presented by Jayne Masters (JM)

From May 2019 until June 2020, Macmillan is funding dedicated outpatient physiotherapist time to patients with musculoskeletal soft tissue sarcoma.

Patients will be seen in clinic pre-operatively to evaluate their baseline function, identify those patients where prehabilitation might be appropriate, and start to develop a physio care plan for those patients likely to have significant post-operative rehabilitation needs. The aim will be to implement rehabilitation requirements prior to discharge, and then liaise closely to facilitate its continuation in the community, plus management of late effects. The service is funded for 2 days per week, so it is essential to target the physio time in the right clinics to capture all relevant patients.

A referral form has been developed to email to the physio team. Patients are also able to self-refer.

JM is gathering information from sarcoma physio services in other centres, such as the Royal Marsden, and will evaluate the service via patient experience questionnaires, review of case studies and clinical outcomes to measure improvements in physical function, reductions in length of stay and readmissions, to inform a business case to continue the service.

Patient experience and improvement in Quality of Life is felt to be the key measure of the service, which has been identified as an unmet need by the sarcoma service for many years; the waiting times for rehabilitation to commence in the community have been a particular problem for patients.

Further details on the structure of service provision are within the presentation, and any suggestions for improvements from the group are welcomed.

4.2 CNS update

CNS Liz Allison (LA) has undertaken an audit on systemic anti-cancer therapies which can be presented at the next meeting. **LA**

CNS Chris Millman has annual leave with no planned cover to triage referrals in July 2019. The MDT will be made aware and the issue will be raised with Martin Plummeridge. **GA**

5. Coordination of patient care pathways

5.1 Clinical review of cancer waiting time targets

The NHS National Cancer Programme has asked for a clinically-led review of NHS Access Standards. For cancer, it is proposed that a new 28 day Faster Diagnostic Standard (FDS) to communicate a definitive cancer / not cancer diagnosis for patients referred urgently, will replace the current two week wait referral standard.

The standard will not be suitable to apply to patients with a likely ALT diagnosis due to the turnaround time for analysis of FISH results. Specific wording to remove these patients from the 28 day pathway will be proposed. **GA**

5.2 General Practitioner Direct Access to book MRI scans

Not all GPs within the region have direct access to book an MRI for soft tissue lumps and bumps after an ultrasound result indicates that this is required. Ideally, patients will receive diagnostic imaging locally prior to referral to reduce the burden associated with travelling to NBT. Radiology Departments in Taunton and UH Bristol have confirmed that bookings need to be made by an appropriate specialist. The number of patients needing to travel specifically for an MRI to rule out sarcoma will be recorded by Consultant Radiologist Brathaban Rajayogeswaran (BB) to assess the scale of the problem. The need for an MRI will be copied into the MDT triage meeting outcomes on the Somerset Cancer Register to allow a booking to be made by GPs on behalf of the specialist MDT. **BB**

Recent referrals from Bath have been made using a previous version of the suspected cancer referral form. This will be escalated to the relevant managers. **HD**

The lipoma management document has now been finalised and can be sent to GP representative Nicola Harker to adapt as a GP version. **HD**

5.3 Review of non-MSK sarcoma shared care activity

Shared care activity will be monitored on a 6 monthly basis to ensure all relevant patients are reviewed by the STS MDT. A data query for this purpose is in the process of being set up with Severn Pathology Services. **GA**

A fibromatosis combined clinic with oncology and plastics input is now being held on the first Tuesday of every month, and a patient support event is being arranged.

6. Quality indicators, audits and data collection

The previous audit of wound healing complications in patients with sarcoma radiotherapy, excision and flap reconstruction will be repeated in the near future. **Surgical team**

A retrospective database of patients with fibromatosis has been collated, which will be used by Consultant Oncologist Paula Wilson for a future audit; due to time constraints, the fibromatosis guidelines will be presented at the next meeting. **GA/PaW**

6.1 Audit of Head and Neck Angiosarcoma referred to Bristol 2009-2018

Please see the presentation uploaded on to the SWCN website

Presented by Gareth Ayre

Between 1st January 2009 and 31st December 2018, 12 cases of head and neck angiosarcoma were extracted from the pathology database. Details on patient disease factors, surgical and oncological management are documented within the presentation.

Treatment recommendations:

- Complete resection aiming for 1cm peripheral margin
- If fascia uninvolved, then this is an acceptable deep margin
- If fascia involved then periosteum should be taken
- Pre or post-op RT for almost all patients
- Definitive RT +/- concurrent taxane for patients who are unresectable or medically inoperable.

Date of the next meeting: *Tuesday 15th October 2019*

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