Meeting of the SWAG Soft Tissue Sarcoma Site Specific Group (SSG)
Tuesday, 12th February 2019, 13:00-16:30
Engineers House, The Promenade, Clifton Down, BS8 3NB

Chair: Dr Gareth Ayre (GA)

NOTES **ACTIONS**
(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 Tuesday 9th October 2018, the notes were accepted.

Actions:

Living With and Beyond Cancer (LWBC) - Implementation of the Recovery Package: The Cancer Support Worker (CSW) allocated to the Southmead team for one day a week, who had been trained to complete electronic Holistic Needs Assessments (eHNAs), has now moved to support the Skin Cancer team. Generic Living Well days are being arranged at the beginning of the patient pathway, rather than at the end of treatment. The team 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. The preferred model, which is a requirement documented in the sarcoma service specification, would be a generic event with a disease specific add-on. The number of patients that would be likely to attend will be estimated, and GA will contact Lead Cancer Nurse Carol Chapman to discuss this further. **GA**

Dedicated physiotherapy time: A business case for a named physiotherapist for sarcoma patients has yet to progress. Physiotherapy is routinely given to inpatients, but those patients discharged as a day case can wait for a significant period of time for an appointment. GA will explore how this requirement in the sarcoma service specification can be escalated. **GA**

Lipoma referral pathways: The lipoma pathway requires a few minor amendments before sending to General Practitioner (GP) representative Nicola Harker to amend. It was agreed that this could be signed off as the regional protocol prior to obtaining national sign off. The protocol requires that a GP should arrange an MRI if recommended in an ultrasound (US) report prior to referral to the sarcoma team. This needs to be clarified on existing referral forms; GPs must be informed as the form currently states that only an US is required. **GA/HD**

GPs often refer patients without an US or MRI because they are not aware that they

have direct access to request these tests. A Directory of Imaging Centres Offering GP Direct Access to Ultrasound and MRI for Soft Tissue Lumps and Bumps has been drafted after speaking with the relevant radiology managers, informing GPs that they can request US, including the treatment centres in Shepton Mallet and Emersons Green, which have quick turnaround times. Some GPs in Clevedon are contracted to refer to North Bristol Trust rather than Weston. The Directory will be circulated when finalised. **HD**

It is not possible for GPs in Somerset to refer on to an MRI as this is not a service funded by Somerset CCG; the patient would need to be referred to a Consultant in an acute provider Trust for an MRI to be booked. A letter will be sent to the CCG to asking them to reconsider funding this service, as it can make a cost saving by reducing unnecessary clinic appointments. **HD/GA**

Implementation of Cancer Research UK MDT Recommendation: Action closed as this has been completed; for discussion on the agenda today.

Thoracic surgeon MDT attendance: Action closed; Consultant Thoracic Surgeon Doug West is forewarned whenever relevant cases need to be discussed, and the action to calculate Programmed Activity for joint cases of reconstructive surgery can also be closed as this is arranged on an ad hoc basis.

Rearrangement of radiology clinic slots: This will be considered if necessary once a 4th plastic surgeon is appointed. **HD**

Referral criteria for the Complex Cancer late Effects Rehabilitation Service: To be recirculated. **HD**

GP rare cancer masterclass: To be revisited if required after lipoma referral processes have been clarified. **NH**

Outpatient booking processes: All issues with booking clinic slots in NBT need to be documented and sent to the outpatient booking board. **NBT team**

Rearrangement of clinic slots: An optimal clinic structure template, detailing the time required for particular patient appointments, will be collaboratively designed by the surgeons, oncologists and clinical nurse specialists to assist the plastics management team with rearranging the clinic slots. **NBT team**

It was noted that the IT booking system currently did not allow alternative appointments to be booked into two week wait and urgent appointment slots.

Quality Surveillance (Peer Review) requirements: Potential dates for a Peer Review panel meeting prior to the end of March, including GA, surgical, pathology and radiology representatives from the team, will be circulated. **GA**

Principal Investigator for Kinase Inhibitor trial: Action closed.

Arrangement of South West Education Day: The level of interest in such an event will be assessed. **GA**

3. Service Development

3.1 Update on the 100,000 Genomes Project and Mainstreaming Genomic Medicine

Please see the presentation uploaded on to the SWCN website

Presented by Christopher Wragg (CW)

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 across all the provider Trusts. Work is now underway to speed up the consent and sample dispatch process to assist with mainstreaming genomics for sarcoma patients, which is expected to be commissioned nationally from August 2019. It is hoped that this will result in identification of biomarkers and the subsequent development of targeted treatments.

Sarcoma UK has promoted the initiative; an influx of requests from patients are expected imminently, however there is no funding in place at present to process the samples and the turnaround time for results, which would be unlikely to result in an actionable finding, requires improvement.

It is now necessary to work though the practical steps required to give patients the option to have the test. A network group of the experts involved in the pathway will convene to identify everything that will be required. **CW**

4. Clinical opinion on network issues / MDT service

4.1 Multi-Disciplinary Team Meeting reforms: Triaging review

Please see the presentation uploaded on to the SWCN website

Presented by Chris Millman (CM)

The Monday lunch time triage meeting, held to filter out those patients who do not require oncology and pathology input from the Sarcoma MDT, started in August 2018. The process involves accepting, downgrading or rejecting referrals based on the information provided via referral and imaging. Of the 156 referrals received over the 22 week assessment period, 91 were accepted, 34 downgraded and 34 rejected. The new process has saved 92 outpatient appointments to date, and has been shown to be safe, with no sarcoma diagnoses in the downgraded group. Of the 91 accepted two week wait referrals, 24 had a sarcoma related diagnosis. The process does increase the CNS workload and a formal arrangement for cover when CM is on leave and administrative support is required to make the process sustainable. The related activity needs to be recorded so that it can generate a tariff as an alternative to that generated by OPA bookings; details will be sent to Performance and Operations Manager Wendy Scadding (WS), and the process will be continually reviewed. **CM/WS**

4.2 Impact of the 2019 Sarcoma Service Specification for the Bristol Service

Please see the presentation uploaded on to the SWCN website

Presented by Gareth Ayre (GA)

The Bristol team submitted comments on the proposed quotas and lack of information on genomics to try to inform the content of the sarcoma service specification when the consultation was underway last year. The wording on the quotas has been adjusted and information on genomics is now included.

The finalised document has been reviewed to identify if any service changes are required for the Sarcoma Advisory Group (SAG) to become compliant. It is now a requirement that all non-musculoskeletal (MSK) sarcomas must be referred and discussed by the Sarcoma MDT. This would not override the other MDTs' responsibility for managing the patients, but provide oversight of their treatment pathways.

Firstly, a mechanism for capturing these patients needs to be established; Cancer Managers will be contacted to ask how the data can be reliably sourced. Shared Care pathways for non-MSK sarcomas have already been agreed but are not currently followed with parity across all relevant MDTs. The relevant MDT Leads will be contacted to make them aware of the new service specification and the need to refer all relevant patients; MDT Coordinators will be copied in to this correspondence. It is hoped that the benefits for improving this process would be to increase the portfolio of clinical trials available for sarcoma, ensure all patients diagnosed have access to sarcoma specific patient information, and standardise follow up pathways. **GA**

The additional MDT discussions will need to be incorporated so that attendance by MDT members can be rationalised.

Tim Whittlestone will be contacted for advice on how to further promote the retroperitoneal service. Referrals are now being received from Royal Devon and Exeter. **GA**

The service specification states that data on shared pathway activity and designated practitioners should be publically available. This could be incorporated in the SAG Annual Report. It also states that patients should receive an end of treatment summary. This routinely occurs at the end of radiotherapy. Examples of end of treatment summaries from other cancer sites will be sent to the plastic surgeons. **HD**

Information on how regularly advance communication training for MDT members is required will be sought. **GA**

MDT Coordinator Amy Dixon will be asked to keep a list of all unplanned excisions to be included in an ongoing audit by the group. **AD**

A draft Paediatric Sarcoma Shared Care Pathway will be sent to GA. **HD**

5. Research

5.1 Clinical trials update

Please see the presentation uploaded on to the SWCN website

Presented by David Rea

Recruitment figures (sourced from EDGE), open trials and trials in set up are documented within the presentation. The recruitment target per 100,000 population for sarcoma is 0.1 due to the low number of trials on the portfolio. There is work underway to try and improve recruitment of the target number of patients within the estimate timeframe.

The trial rEECur opened to recruitment last week. A trial looking at Patient Reported Outcome Measures (PROMS) will open imminently. All sarcoma patients can be registered at any point in the pathway; consent is inferred by their completion of the questionnaire provided. Research Nurse Suriya Kirkpatrick is going to coordinate sending out the questionnaires. It is hoped that they can be made available for completion by patients while waiting and then posting them into a box within the clinic, as this will improve the number of responses.

Details of a Phase 1 follow on trial from STRASS including chemotherapy will be discussed at the next British Sarcoma Group conference; the trial will be open in London and Manchester.

6. Patient experience

6.1 New Dietetic Services for Cancer Patients

Please see the presentation uploaded on to the SWCN website

Presented by Joanne Porter (JP)

SAG members can refer patients with nutritional issues as a result of cancer or cancer treatment from the BNSSG region to the cancer dietetic service in University Hospitals Bristol.

Referral criteria:

- At risk of malnutrition
- Weight gain associated with treatment
- Managing diet with side effects of treatment / cancer e.g. poor appetite, gastrointestinal, taste, dry or sore mouth, fatigue
- Dietary concerns / anxieties
- Dietary changes required as a result of operations or procedures.

Referral processes and details of similar services throughout the region are documented within the presentation.

7. Any other business

Due to time constraints, the audit of angiosarcoma and fibromatosis management guidelines will be presented at the next meeting.

Date of the next meeting: *Tuesday 18th June 2019*

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