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

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

Tuesday, 26th November 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 and apologies 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 18th June 2019, the notes were accepted.

Actions:

Many outstanding actions are on the agenda today. Actions discussed:

Patient Experience - Business Case for dedicated physiotherapy time:

Permanent funding needs to be secured for Physiotherapist Jayne Masters' (JM) post to support the rehabilitation needs of sarcoma patients and maintain links with community health teams. JM's work contract, funded presently by the Personalised Care and Support Cancer Transformation Fund, has been extended by NBT until September 2020. Feedback on the service to date has been excellent.

CAG members to use the referral form enclosed with the notes and send to: cancerphysio@mdt.nhs.uk.

Patient experience feedback is continually being collected, and JM will attend a British Sarcoma Group Rehabilitation Conference in a week's time in Birmingham, where there will be the opportunity to benchmark against other national services, which could the strengthen the case for continued funding.

Physiotherapy support is required at numerous points in the patient pathway including: pre-treatment; radiotherapy; follow-up; all palliative patients; surgery and signposting.

Lead Cancer Nurse Ruth Hendy emphasised that the role of the Personalised Care and Support funded Physiotherapist is to support all cancer patients, including sarcoma. There are significant cost pressures for organisations now that continuation of Cancer Transformation funding is uncertain; Cancer Manager Terri Agnew (TA) will meet with GA outside the meeting to discuss how to progress the case. **TA/GA**

Management of lipoma audit: An audit of referral numbers and subsequent management needs to be an ongoing action; to be allocated. **To be confirmed**

MDT Service: Promotion of the Retroperitoneal Service: The service specification for retroperitoneal surgery has a target of 24 procedures per annum.

Proactive promotion of the service is required to meet the target and protect it from competitive centres; Birmingham has achieved this by promoting their service to Swansea and Oxford. The retroperitoneal surgeons could visit RD&E and other hospitals to do the same; GA will liaise with Retroperitoneal Lead Tim Whittlestone (TM) **GA/TW**

LWBC End of Treatment summaries: The aim is for CAGs to agree and sign off end of treatment templates in a set format for GPs and patients. Once agreed, they will be uploaded on to the SWCN website so that they are easy for the SWAG team to access. Radiotherapy templates have been agreed; surgical and SACT templates are outstanding. It was not clear if this would be possible for SACT as there is currently no standardised pathway. It would be more relevant to drop the 'end of' treatment for these scenarios, and send a summary for any change in modality. Examples can be found from other centres.

Having core standard information is meant to make the process easier, however people have reported to be struggling with who should complete them (sometimes several people would need to be involved) at what time point.

CNS Liz Allison has a system of copying and pasting set information into a template for germ cell patients. CNS Amy Peach completes End of Treatment Summaries on the Somerset Cancer Register.

Progress will continue within each Trust; CAG action closed.

Atypical Lipomatous Tumour (ALT) pathway: CAG agrees that a process needs to be put in place to remove diagnoses of ALT from the fast track pathway, but continue to track in a similar way to the Skin MDTs management of Basal Cell Carcinomas. GA will discuss further with the Cancer Management Team. **GA**

3. Service Development

3.1 Genomic Medicine Project Update and Consent Process

Please see the presentation uploaded on to the SWCN website

Presented by Catherine Carpenter-Clawson (CCC) and Amanda Pichini (AP)

Recruitment to the 100,000 genomes project has ended, and results are currently being processed. All project work should be completed by the end of March 2020. The Genomic Laboratory Hub will continue to send samples for all consented sarcoma patients for whole gene sequencing.

Four elements are required in the genomes biopsy sample pathway:

Pre-diagnosis:

- Fresh frozen sample (stored in the first instance in a fridge in radiology for 2 hours maximum, then sent to the laboratory, with the separate formalin sample, in clearly labelled formalin and saline pots for preparation and

storage until diagnosis confirmed)
- Blood test.

As the blood sample will be taken by the phlebotomist, it will be necessary for the MDT to clarify that an electronic germline request via ICE is required for potential sarcoma patients.

Post diagnosis:

- Signed agreement from the patient (using nationally agreed treatment discussion forms) to scan and send to genomics lab
- Completion of a paper genome request form to be scanned and emailed to the lab.

It is important to emphasise to patients that it is not possible to process all samples due to sample size or tissue necrosis.

The request form will ideally be streamlined and developed into an e-form in the near future.

The fastest sequencing turnaround time to date has been six weeks, so genome analysis will not be replacing standard care for the time being.

The Genomics Tumour Board will be available to help with complex queries. National Guideline Documents are currently being developed.

The consent process simplified:

- Consent for whole genome sequencing should remain similar to the consent processes already embedded in the cancer pathway
- Focus on how to describe a genome in one sentence using simple, succinct language. Example wording: 'Your genome is found in almost every cell in your body and it is the instructions for making you'
  'We would like to analyse your genome to try and find out more about your cancer/disease'
- Sufficient, appropriate information in different formats (written/oral/pictoral) needs to be provided and reinforced at key points in the pathway
- Communicating sharing of biological samples: The Human Tissue Authority and other relevant bodies recognise that genomic and molecular analysis can be diagnostic and undertaken as part of the routine diagnostic pathway
- Communicating storage of information: For data to be held in a genetic research database (in compliance with the Data Protection Act) there is a separate consent choice / process
- Communicating why a blood and tumour sample are required: The majority of cancers will be due to changes over time, occurring after birth (somatic, identified from tumour), whereas a small proportion will be inherited, present before birth (germline, identified from blood); all cancer is of genetic origin
- Communicating results: There may be no or uncertain findings, to confirm how findings will be fed back, and to confirm that rarely there may be findings that concern the wider family.

This is not an exhaustive list; further information is within the presentation.

A common question from patients is concern about life insurance. There is no obligation to disclose tests results that have a predictive nature.

The genomic team will be available to assist with complex questions that may arise.

Data stored for further research will be de-identified and could be viewed nationally or internationally by approved researchers, who would have to request specific permission from hospitals/centres if data would be used for further research.

The majority of patients consent to additional research options for altruistic reasons, and in general only decline for specific reasons, such as not wishing to support studies on animals. CAG members would aim to combine the consent discussions on sample analysis and additional research.

If implications are identified for the wider family, it would be appropriate to refer on to the clinical genetics counsellors for further discussion, including mapping out a family tree, identifying where people live and facilitating liaison with local teams.

Retesting at relapse would be appropriate as the tumour signature might change.

Written information to facilitate consent is currently being reviewed to ensure that it is compatible with easy read guidance. The documents will be made available before the pathway officially opens.

Patient Representative Michael Fowle (MF) felt that, due to the amount of information that already has to be absorbed at the point of diagnosis, patients may not feel in a position to consent to genetic testing at that time. The aim is to limit information to the core things needed at this point. A one page check list with enough information to consent would be useful; discussion about different mutations etc. could occur at a later date.

The appropriate way to have the conversation will be adapted according to experience in the initial few months.

Useful links to information on the website are within the presentation, which will be circulated. **HD**

4. Clinical Guidelines

4.1 Desmoid-Type Fibromatosis: Update on Management Guidelines

Please see the presentation uploaded on to the SWCN website

Presented by Gareth Ayre (GA)

European Society for Medical Oncology (ESMO) guidance on the management of desmoid-type fibromatosis was published in February 2019, which introduced new recommendations based on a paper published in 2017.

Desmoid and aggressive fibromatosis are considered the same disease.

Diagnosis is achieved via biopsy with immunohistochemistry staining.

Upfront treatment is rarely indicated, with only half of patients progressing within 5 years and 20-30% of patients having spontaneous regression.

The tumours commonly occur at period of change in hormonal state, and can resolve afterwards.

Indications for surgery at diagnosis may be for cosmesis. The only other indication would be for an abdominal desmoid causing obstruction or perforation.

Surgery on progression may be an option if it is likely to control disease, with function preservation being the priority.

A Desmoid Fibrosis: Local Recurrence Free Survival after Surgery nomogram is available online here: https://www.mskcc.org/nomograms/sarcoma/desmoid

The Watch and Wait protocol advises that there should be 2 successive scans showing progression before a decision to treat is made.

Management algorithms and the various treatment options, which have no definitive order, are detailed within the presentation. In the event that patients run out of options, there is a clinical trial available at the Royal Marsden which can give the opportunity to access new therapies.

Management in the paediatric setting is also based on doing the least harm. Hormonal and non-steroidal treatments are generally ineffective in the younger age range; spontaneous regression has been observed in children when they reach teenage.

Some younger patients receive chemotherapy for large tumours.

Although not technically cancer, low grade tumours can have significant impact on patients, and patients would benefit from ongoing holistic care provided by the CNS team.

Details of the Royal Marsden trial will be forwarded to Consultant Paediatric Oncologist Helen Rees. **GA**

Follow-up is probably required for approximately 10 years depending on the particular case and if there is symptomatic progression. Post-surgical patients are seen in a dedicated fibromatosis clinic.

5. Coordination of Patient Care Pathways

5.1 Paediatric Shared Care Pathway

Presented by Helen Rees (HR)

The Sarcoma Service Specification (2019) states that all paediatric cases should be reviewed by the Sarcoma MDT; the process in the majority of other centres is for paediatric-oncology to video link in to the sarcoma MDT to liaise with the adult

sarcoma plastic surgeons.

In the Bristol Royal Hospital for Children, paediatric sarcomas have routinely been reviewed as part of the paediatric solid tumour MDT, and an established pathway with paediatric surgical input is in place.

In the event that a less common adult type of cancer is diagnosed by paediatrics, the MDT Lead consults adult colleagues on an informal basis.

A shared care pathway has now been drafted to formalise the process for review of adult-type sarcomas. For these patients, a representative from the paediatric team could either join the MDT in person or via WebEx, or discuss the relevant case prior to the meeting with a member of the adult team to present on their behalf.

Review by the paediatric pathologist team needs to be included in the pathway. Pathology is then routinely sent to Manchester rather than the NBT pathologists. HR will liaise with the Paediatric Pathologist and Francesca Maggiani to review this process and include the NBT MDT via the pathology route.

The shared care pathway will be amended and circulated to all for ratification. **HD**

5.2 Clinic Reconfiguration

Presented by Tom Wright (TW)

Previously, the clinic was organised into several streams, with patients put on the list to see individual surgeons for continuity of care. This had not proved to be efficient, with some Consultant lists becoming overbooked, and others under booked. This has now been reconfigured into a single list, with patients being seen in time sequence by the next available person in most cases, unless it is clear that they ought to be seen by another colleague when reviewing their electronic record. It would be helpful if there was a way to flag such patients on the master list prior to the start of clinic. The new process has been found to be beneficial by the majority of Consultant Surgeons; feedback has been requested and is pending from the clinic nurses. CNS feedback has identified the need to document which clinic room to which each patient has been taken.

The need to allocate different time slots to different appointment types (sarcoma new, sarcoma first follow up (needs to be longer), and sarcoma follow up) has yet to be resolved; CNS Chris Millman is negotiating with management to resolve this.

The new configuration will continue with ongoing feedback to identify any problems and potential solutions. A paragraph to remind clinic staff how the new process works could be added to the list, including an option to record suggestions for improvements.

In the view of Patient Representative MF, the further away a patient is from treatment, the less important it is to see the same clinician. However, the seating area in clinic is an issue, with insufficient space in the sub-waiting areas for all patients and their family member. This is a well-recognised design fault due to the quantity of clinics running at the same time in the outpatient area.

6. Patient Experience/Living With and Beyond Cancer

6.1 CNS Update

Please see the presentation uploaded on to the SWCN website

Presented by the CNS Team

CNS Becky Peach (BP) gave apologies from Christine Millman (CM), who is planning to train BP (who has returned 3 days per week) to assist with the MDT triage process in the near future.

Last week's pre-MDT radiology triage meeting halved the numbers on the main MDT list, with more referrals not being offered an outpatient appointment than were offered, which should result in immediate benefits to the way the service is managed.

The need to capture triaging activity and also track referrals sent via non two week wait routes, will be discussed further with management. Oversight of the whole pathway needs to be planned to ensure that the new administrator role, appointed for three hours per day, can assist with triaging patients to the right clinic and operation list, which will assist with meeting cancer waiting time performance.

Fantastic feedback was received from the most recent patient experience survey. This will be adapted to try and get more useful information on patients treated across sites in Oxford and Taunton for example.

Results from the National Cancer Patient Experience Survey showed 37 responses from sarcoma patients across the region, but as scores were below 21 responses for individual centres, these could not be published. Lead Cancer Nurse Ruth Hendy is a member of the National Clinical Advisory Panel that will be reviewing methodology of future surveys, and plans to raise the issues relating to rare cancer sites. It is hoped that outpatients will be included in the cohort of patients sent the survey in a future iteration.

6.2 Any Other Business

The West of England Clinical Research Network has appointed a Teenage and Young Adult Research Nurse to work across the region.

Date of the next meeting: Tuesday 24th March 2020

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