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

Meeting of the SWAG Network Cancer of Unknown Primary (CUP) Site Specific Group (SSG)

Tuesday, 6th November 2018, 10:00-13:30
Milne Walker Seminar Room, Level 7, Bristol Royal Infirmary, Upper Maudlin St, Bristol BS2 8HW

Chair: Dr Tania Tillett (TT)

	Notes	Actions
	(To be agreed at the next SSG Meeting)	

1. Welcome and apologies

Please see the separate list of attendees and apologies uploaded on to the SWCN website here.

2. Review of previous notes and actions

As there were no amendments or comments following distribution of the notes from the meeting on Wednesday 9th May 2018, the notes were accepted.

Patient Experience Survey: Data collection continues to be challenging; to remain a rolling agenda item.

CUP1 Trial: The Chief Investigator will be invited to the next meeting in May 2019.

Acute Oncology: To encourage the Cancer Alliance to reform an Acute Oncology Service Specific Group. **HD**

3. Network Issues

3.1 Review of MDT membership changes/services

RUH Bath: No changes since the previous meeting.

North Bristol Trust: Clinical Nurse Specialists (CNSs) Lucy Henderson and Olivia Rabjohns are now in post as well as Lisa Lilly-White.

UH Bristol: Consultant Oncologist Helen Winter has joined the team. Samantha Wells is on extended leave and Stephanie Jones has been seconded to the Band 6 post.

Taunton: The 3 Upper GI nurses provide cover for the CUP service along with Consultant Oncologists Emma Cattell and Jo Botten.

Yeovil: Consultant Oncologist Erica Beaumont is providing cover for the service along with 1 CNS.

3.2 CUP requirements from the Acute Oncology Service Specification

Please see the presentation uploaded on to the SWCN website

Presented by Tania Tillett

The document *Clinical Advice to Cancer Alliances for the Commissioning of Acute Oncology Services* was reviewed for advice on how to develop CUP services. Although mentioned briefly, there was nothing specific that could be used to influence clinical commissioning groups' decision making.

4. Patient experience

4.1 Patient Information Packs/CNS update

The content of each Trust's patient information packs were compared. Information leaflets from Macmillan, Jo's Friends, local citizen's advice contacts, blue badge applications, CNS contact cards and counselling services are available. The CNS team tend to tailor the content to meet the needs of the individual.

RUH has a 1 page document, sourced from the Plymouth team, which details the tests that have been undertaken, the next expected tests, and where and when the next follow up appointment will be held. This will be circulated with the notes. **HD**

Provision of patient information needs to be documented on relevant hospital information systems such as the Somerset Cancer Register.

Cancer Research UK has developed national standardised consent forms (here) for Systemic Anti-Cancer Therapy (SACT). Although they take some time to complete, they are regularly updated, reducing the work burden of updating local forms, and ensure compliance with the latest consent guidance. They help to emphasise the burden and risks associated with treatment in a formalised way. They can be printed for signing and scanned into local systems.

Consultant Oncologist Vivek Mohan (VM) will discuss the possibility of using the forms in UH Bristol with the Chemotherapy Lead. **VM**

4.2 Adapt, Adjust and Plan pilot event

Presented by Emily Aston (EA)

A 'next steps' day for patients with a poor prognosis has been recognised as an area of unmet need. A project to set up such events has been underway in UH Bristol over the past year. The first pilot event will be held on Monday 4th February 2019 in the Education and Research Centre, University Hospitals Bristol NHS Foundation Trust. Clinical Nurse Specialists can refer both male and female patients treated in UH Bristol who have a prognosis of between 6-36 months.

It will have a similar format to the 'Living Well' events, with practical talks from a poor prognosis perspective on managing fatigue, finances, advanced care planning

and Will writing. There will also be one to one breakout sessions for 10-15 minutes with a CNS, and the opportunity for follow up phone calls.

Feedback from the patients attending this event will be used to evaluate the format of future events and will be reviewed at the next meeting. **EA**

It is hoped that the event can be extended to patients across the Alliance on a regular basis once funding and an appropriate venue have been secured.

It may be possible to hold similar events in Dorothy House Bath, or the Southmead Wellbeing Centre. Online forums are sometimes used by patients, but these are not always helpful. CRUK has an online facility for patients to ask nurses questions, which was considered preferable.

Provision of the pilot event received positive feedback from the group.

4.3 Function of the Gold Standard Framework

Please see the presentation uploaded on to the SWCN website

Information supplied by General Practitioner and Cancer Alliance Clinical Lead Amelia Randle.

The Gold Standard Framework (GSF) is a mandatory model to improve end of life care in the community. The majority of patients are identified and tracked on the GSF pathway when relevant information is received via hospital letters or alternatively by direct patient contact. For UH Bristol, this would be via the Poor Prognosis Letter (PPL) discussed at the previous meeting. There is an action box on the template letter for GPs in RUH which is used to document a new diagnosis of incurable cancer. The importance of making the wording of a poor prognosis explicit to GPs while also considering that the letter will go to the patient, and be seen by family members, was emphasised. It was noted that the UH Bristol PPL did not go to the patient.

The process in the Park Medical Practice is to track patients using 3 categories: active treatment, prognosis months (flagged amber), or prognosis weeks/days (flagged red). Please see the presentation for further information and the end of life checklist.

Considering the current workload pressures on GPs, the capacity to read through and manage all relevant patients in a timely manner is unknown. Clear documentation of the predicted prognosis will assist the process.

Yeovil CNS Abbey Evenett had recently observed a GSF meeting at a local Practice, where the District Nurses flagged any patients that they were concerned about to the Practice Multi-Disciplinary Team (MDT).

The process for approaching patients with Do Not Attempt Resuscitation (DNAR) orders was often happening too rapidly after a patient has been given their diagnosis. It is psychologically preferable for the patient to have more time to

assimilate what is happening. How this might be addressed will be investigated by the CNS teams.

5. Clinical guidelines

5.1 Histopathological reporting of CUP

Please see the presentation uploaded on to the SWCN website

Presented by Leigh Biddlestone (LB)

The Royal College of Pathologists published standards and a dataset for histopathological reporting of CUP and Malignancy of Unknown Origin (MUO) in July 2018 after an extensive consultation period. Reporting CUP requires a change of mind set as the approach involves the exclusion of certain diagnoses. The document contains useful algorithms to assist with the process. It is also essential to have details on imaging, and the clinical picture, including past medical history, tumour markers and MDT discussions sent with the pathology request.

Biopsies require careful handling to preserve as much spare tissue sections as possible for immunohistochemistry (IHC) testing, which should be rationalised to use the most common markers first, after the initial MDT discussion, rather than doing an extensive panel upfront.

Increased use of IHC testing has revealed where it can be inaccurate, and raised awareness of various anomalies.

The confirmed CUP reporting proforma works as an aide memoire. It will be difficult to confidently exclude results from the various categories as, for example, a teratoma could have all types. The dataset is now embedded in the RUH Pathology Systems.

It was often found that patients who may appear to have a primary are referred to the CUP MDT if the histology is uncertain, but are not necessarily confirmed as a CUP. Pathologists need to liaise with MDT colleagues to manage these cases, which should be discussed with the referring clinician and include oncology colleagues to avoid delays to patient pathways.

The expected time frame for excluding lymphoma or small cell from a request flagged as urgent would be 24 hours; it is acceptable to ring the laboratory to speak with the relevant pathologist. IHC would be available the next day. The requirement to flag relevant requests as urgent needs to be clarified with all people who can make requests.

There have been some issues with missing patient information on referrals made via the ICE system. This will be escalated to the ICE manager. **HD**

5.2 Chemotherapy protocols

The most frequently used chemotherapy protocols for CUP are listed in a CUP specific section on the SWCN website. This included the statement 'The site specific chemotherapy protocols on the SWCN website can be used for CUP patients, as agreed by the CUP MDT'.

After reviewing the list it was decided to add Paclitaxel weekly as per the gynae-oncology protocol.

An audit of anti-cancer treatment for confirmed CUP serial responders will be repeated; the data collection template will be circulated. **TT/HD**

6. Research

6.1 CUPISCO trial

Please see the presentation uploaded on to the SWCN website

Presented by Matt Sephton

CUPISCO, a Phase II Randomized Study Comparing the Efficacy and Safety of Targeted Therapy or Cancer Immunotherapy Versus Platinum-Based Chemotherapy in Patients With Cancer of Unknown Primary Site, opened in RUH Bath 2 weeks ago. The timelines and inclusion criteria make recruitment complicated. All patients require a CT or MRI of the head (patients with Brain and CNS metastases are excluded), and women will need to have a mammogram. Patients are not eligible if they have recurrent disease, which is considered to be any previous cancer diagnosis within 5 years prior to screening. Please see the protocols for the full list of inclusion and exclusion criteria.

CT scans are required frequently during treatment and patients would need to be willing to travel to Bath for all research related activity. The recruitment target is 8 and the trial will remain open for 18 months. SSG members are to refer relevant patients and demonstrate how SWAG centres can collaborate to generate trial activity.

7. Coordination of patient care pathways

Guidelines on the management of patients with solitary bone lesions are required to avoid delays to patient treatment and improve the patient experience, which can be affected when referred between the Spinal, Haematology and CUP MDTs. A volunteer from the Haematology SSG and the Spinal team at NBT will be sought to assist with the development of the guidelines. **HD/TT**

The quality of primary care two week wait referrals was noted to be universally poor. Taunton and Yeovil do not take two week wait referrals for CUP, receiving the majority of patients via the Upper GI MDT, and do not offer GPs direct access to CT.

8. Quality indicators, audits and data collection

8.1 SWAG and Peninsula CUP / MUO coding audit

Retrospective data on all cases coded as ICD-10 80 from the 1st February 2018 to 1st May 2018 had been requested to assess if the code is being used consistently. Data was received from 7 centres. The data from Taunton appeared to show that the code was being used appropriately. There was missing information on the number of MUOs in RUH Bath; this will be investigated further. The team in Plymouth will be asked to confirm the number of cases in this period, as these were significantly higher than the other centres. The audit had highlighted a few cases coded in error which have now been corrected. There are a number of CUP cases not discussed by the CUP MDT because they are low risk and are appropriately managed by the Head and Neck MDT. Data from the audit will be circulated. **TT** **HD** **HD**

An audit of two week wait referrals will be piloted in RUH Bath. **TT**

9. Any Other Business

MDT Leads will set up a virtual regional MDT to discuss complex cases when required.

Date of next meeting: Wednesday 8th May 2019, venue to be confirmed

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