



**Meeting of the Peninsula and SWAG Network Cancer of Unknown Primary Site Specific Group
(SSG)**

Wednesday 9th May 2018, 10:00-14:00

South West House, Blackbrook Park Avenue, Taunton, TA1 2PX

Chair: Dr Tania Tillett (TT)

NOTES

(To be agreed at the next SSG Meeting)

ACTIONS

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 SWAG meeting on the 7th November 2017, the notes were accepted.

3. Network issues

3.1 Review of MDT membership changes/services

Plymouth: The recent appointment of an additional Band 6 Clinical Nurse Specialist (CNS) has increased the team to 2.5 Whole Time Equivalent (WTE) posts. Palliative Medicine representatives now regularly attend the Multi-Disciplinary Team (MDT) meetings.

Exeter: There are now 3 Consultants with CUP included in their job plans. The nursing team had been understaffed for some time, but the senior nurse is returning from maternity leave and a full time Band 6 has been recruited. The Quality Surveillance indicator for Palliative Medicine attendance at the MDT has not been achieved due to staff shortages.

Bristol: Vivek Mohan is the only permanent Consultant providing the CUP service in both UH Bristol and North Bristol Trust (NBT). Locum Consultant Lucia Angelelli has recently started at the Bristol Haematology Oncology Centre, and is providing assistance with CUP and numerous other cancer sites. UH Bristol has 2 CNSs. In NBT, Sarah Colsey is due to go on maternity leave; cover has been arranged. A Band 6 CNS is also due to commence a 3 month secondment from the Emergency Department.

North Devon: The full time Lead CUP CNS post is currently vacant. Negotiations are underway to appoint an additional Band 6 CNS. The Consultant Lead for CUP is currently a visiting Consultant.

Yeovil: There is no Palliative Medicine representation at the CUP MDT, although a Palliative CNS is about to be appointed. The Consultant Oncologist that replaced Matthew Sephton has now left, as has the CUP CNS.

Torbay: Two full time CNSs are in post. Palliative Medicine representatives attend the MDT. There are usually 2 or 3 Consultants available to manage the service.

Bath: Consultant Oncologists Tania Tillett and Matthew Sephton jointly provide the CUP service. The CNS team have 2 sessions allocated to CUP patients; an increase in session time is required. The service is aligned with the Hepato-pancreato-biliary service. There is no Palliative Medicine representation in the MDT; this had not been found to be detrimental to patient care, with appropriate palliative care referrals routinely being made to the Hospice.

Representatives from Gloucestershire and Cornwall were not available to give an update at today's meeting. It was thought that Cornwall was struggling to appoint a Clinical Lead and have appointed a Band 7 CNS.

3.2 Comparison of Acute Oncology and CUP service interfaces

Acute Oncology and CUP are 2 separate teams in RUH Bath. The majority of referrals to the CUP service are received via the two week wait referral process and aim, where possible, to reduce involvement of the acute oncology team in the management of new cancer diagnoses. Once diagnosed, the majority of patients are referred on to the appropriate pathway; a recent audit showed that 50% of referrals are transferred to site specific MDTs.

The CUP suspected cancer proforma, which states that evidence of metastases should be present for referral into the service, will be circulated.

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Referrals are frequently received from General Practitioners (GPs) who are concerned for patients with vague symptoms, for example, rapid weight loss. In such cases, the GP is contacted and advice provided on the next tests to request. The CUP team will continue management of the referral if cancer is detected or assist the GP to refer the patient on to the correct service. The majority of patients managed in this way, (which used to be managed by the on-call consultant), are found to have cancer or some other disease, and it is hoped that the service can decrease the time to diagnosis.

Although recognised as an unmet need for GPs, there was concern about the capacity and suitability for each of the AO and CUP teams to provide an advice and guidance pre-oncology service. The service had been trialled in Exeter, run by the Upper GI team, and it had been decided that GP education or production of standardised advice could be an appropriate alternative. GP capacity was recognised as an obstacle to progress when using these methods.

A pilot of a similar early warning service commenced in the BHOC in April 2018. This is run by the on-call consultant of the day between 10 and 11am to provide advice for GPs on the management of vague symptoms. There is no administrative support for the service and contact is made using the on-call's personal mobile phone. The AO/CUP service is combined and Consultant Oncologist Lucia Angelelli also manages patients with lung and colorectal cancer.

A patient information leaflet has been developed by the AO CNS team in [North Devon/South Devon](#), to ensure that patients admitted via AO know the most appropriate CNS team to contact. All CNS team details are included in the leaflet

and the relevant one is pointed out to the patient prior to discharge. The CNS team is then informed of the patient's admission and advised to expect a call from them. Where there is a gap in the provision of a site specific CNS (for example, there is no CNS team for the patients with brain cancer), the patient is kept under the care of the AO team until treatment has been planned.

The CNS team in Southmead Hospital look after patients from all cancer sites depending on the availability of site specific CNSs. This often involves cold calling the patient if it has not been possible to make contact while they were in the hospital, which can at times be a challenging way to introduce patients to CNS support.

The AO and CUP team are combined in Torbay; the team had previously been asked to provide an advice and guidance service. As there was currently no capacity to undertake this, calls from primary care are managed daily by the acute medical on-call team. It was noted that any such advice and guidance activity should be documented so that services can be appropriately recompensed for the activity.

Acute Oncology is increasingly called on to provide assistance to all cancer sites, being the only safety net available for underinvested cancer services, and having to manage the majority of complications. Further investment is required.

4. Patient Experience

4.1 Identifying differences in the experiences of care between patients diagnosed with metastatic cancer of known and unknown primaries

Presented by Richard Wagland (RW)

Please see the presentation uploaded on to the SWCN website

Patient experience surveys are frequently attempted across the region, more often than not getting few responses. It was difficult to know when to approach this cohort of patients with surveys. The team in Taunton had received a good response to a postal survey sent to both patients and relatives; a uniform approach across the region has yet to be put in place.

A qualitative research study was undertaken (published [here](#)) to identify the differences in experiences of care between patients with a cancer of unknown and known primaries. This was in response to evidence from a previous study which showed that CUP patients had a lower level of understanding about their diagnosis, a higher level of anxiety, and a greater number of tests in comparison with known primary diagnoses. A larger scale comparison was required. To achieve this, data was extrapolated and analysed from the 2013 National Cancer Patient Experience Survey. This identified 9 questions that had measurably different answers for the CUP cohort, as documented in the presentation.

The results were felt to reflect the way that CUP was most frequently managed. For example, it was less likely that a CUP patient would have surgery, more likely that their GP would inform them of their diagnosis, and less likely that there would be any treatment options.

Some findings raised questions about the validity of the data, which was sourced by filtering the NCPES data by IC-10 Codes 77-80, as the majority of the patient experience results were similar to that of known primaries, and were more positive than expected. It also seemed to suggest that CUP patients are more likely to have lymphoedema; it was assumed that this was a data error.

It was concluded that a prospective, observational cohort study was required for a more complete understanding of the issues facing CUP patients. The challenge would be gaining ethics approval to conduct such a study, which could require confirmation that the patient would be likely to survive for a particular length of time.

Despite national recommendations to use IC-10 codes C77-80 for coding CUP, the regional CUP teams have been instructed to use C80 only, as C77-79 were used by cancer management teams to report activity on patients diagnosed with metastatic disease. The process in Royal Devon and Exeter Trust differed again, where the team had been instructed to code all cancers without a biopsy, plus myeloma and lymphoma as CUP.

The CUP team would be keen to collaborate in future projects, particularly to assess management of psychological effects as treatment becomes increasingly targeted. It was noted that the CUP Foundation are willing to fund research projects.

4.2 Poor prognosis information letter

Presented by Colette Reid (CR)

Please see the presentation uploaded on to the SWCN website

The Palliative Care Team in University Hospitals Bristol was granted an award by the British Medical Journal (BMJ) in 2017 for implementing an innovative project that has improved patient care for patients and their carers. The project, which commenced in 2010/11 as part of a Clinical Commissioning Group (CCG) service improvement initiative, aimed to improve the communication of poor prognosis information to General Practitioners (GPs). An electronic letter was developed with help from IT to keep it separate from other electronic discharge letters. It can be completed at any time during a patient's admission or clinic appointment in less than 5 minutes. Junior medics have been trained to complete the template letter, which contains details of prognostic criteria of relevance to the particular patient's condition. The letter, which is never printed or sent directly to the patient, is sent directly to the GP via the Egton Medical Information System (EMIS), to ensure the GP knows that the patient may be in their last year of life and require tracking on the Gold Standard Framework (GSF (best supportive care)) Register. Positive feedback on this process has been received from patient focus groups, with people stating that this is what they would expect to occur as a matter of routine.

The use of the letter is continually audited, results of which can be found in the presentation.

The information provided via the poor prognosis letter permits GPs to arrange home visits to relevant patients and has improved discussion of their wishes. The rate of patients who died in hospital was seen to drop, which could indicate that the process has facilitated management of appropriate admissions and enabled patients to have more say in choosing their preferred place to die.

This process is also of use within the Trust, for example, it has helped to avoid an ITU admission, keeping a bed open for a patient whose surgery was dependent on the availability of that bed.

The median survival of patients for whom the letter had been generated was 31 days, indicating that prognostication was still overcautious. Further work was needed to ensure all teams used the letters, the majority of which were completed on admission in comparison to within clinic.

Ideally, if the patient was thought to be ready to discuss the poor prognosis letter, then this would be broached with them, but it was important that this did not become a barrier to the Junior medic completing it prior to this. It could also be completed by Clinical Nurse Specialists.

Since the awards ceremony, there have been numerous requests from other centres to share and adopt use of the letter. It was noted that implementing this service improvement takes a lot of time and effort; engaging the junior medical colleagues is the key to its success.

5. Clinical guidelines

5.1 Chemotherapy protocols

A brief paragraph stating that any site specific chemotherapy protocols on the SWCN website can be used for CUP patients, as agreed by the CUP MDT, will be added to the website. A list of 5 or 6 of the most frequently used protocols, with the indication stated in brackets next to it, will be listed below this statement.

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6. Research

CUPISCO trial

Please see the presentation uploaded to the SWCN website

Presented by Tania Tillett

CUPISCO is a Phase II randomized, active-controlled, multi-centre study comparing the efficacy and safety of targeted therapy or cancer immunotherapy, guided by genomic profiling versus platinum-based chemotherapy, in patients with cancer of unknown primary site who have received three cycles of platinum doublet chemotherapy. Inclusion and exclusion criteria are documented in the presentation. All patients need a mammogram and clear CT head. The extensive list of drugs included in the trial, which is funded by ROCHE pharmaceuticals, is currently going through the national ethics approval process. Treatment needs to commence using double agents, but can be reduced to a single agent, and is to

continue until there is a loss of clinical benefit. There is a tight window to send the histology to the molecular tumour board in either Switzerland or the USA. Regular CTs need to be arranged locally and coordinated with clinic visits.

CUP EM trial

CUP EM, initiated by Dr Harpeet Wasan, is awaiting ethical approval. It aims to recruit 77 patients to test the benefit of immunotherapy in CUP and find biomarkers in the patients who benefit from immunotherapy.

The trial will be run from Hammersmith, and opened in Guys/St Thomas's and The Royal Marsden.

7. Coordination of patient care pathways

Trust referral routes and processes

The teams in Plymouth, RD&E and Taunton do not have a two week wait referral system for CUP. UH Bristol does have this (as does RUH Bath, mentioned previously) and uses this regularly to triage patients to site specific MDTs.

GP direct access to book CT scans for patients varied across the region, especially in Devon, with many GPs calling the CUP team in RD&E to arrange the scan to be booked. It was thought that this was sometimes due to GPs preferring not to request the CT as they do not want to action the result. A meeting has been arranged with the Cancer Alliance to see if this can be addressed. A lot of work has gone into GP education, including sending information to GPs by name.

There was a bleak picture for patient access to GPs in Plymouth at present. Multiple practices are closing and/or amalgamating, moving from 13 practices to 7, and with many incidences of long term sickness, GPs are moving to phone triage patients.

Some hospitals are piloting a more formalised Advice and Guidance service for GPs, for those patients who do not fulfil the 2WW criteria; progress will be fed back at a future meeting.

8. Quality indicators, audits and data collection

Network audit ideas

A retrospective audit of 3 months of cases coded as IC-10 80 will be undertaken to see how many were sent via the CUP MDT, and which were considered either CUP or MUO. A data collection sheet will be circulated for agreement prior to the next meeting.

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It was noted that patients diagnosed with some palliative conditions were not immediately accepted under the care of community palliative care services when discharged from secondary care, as they did not meet the referral criteria of being at risk of imminent deterioration. There was some concern that these patients needed a safety net, and a potential business case for CUP CNSs to track these patients was raised as a possible solution.

This had been discussed at a previous meeting where GP representative Amelia Randle explained that the GP GSF register should function as the safety net. A presentation of the GSF system will be arranged at a future meeting.

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9. Any other business

Ideas for the next agenda:

- CUP1 Trial results
- Royal College of Pathology CUP dataset
- Development of a system to provide histology with background information, for example, inclusion of radiology request details to help when deciding which ImmunoHistoChemistry tests would give the most useful information
- Acute Oncology commissioning document.

Date of next meeting: Tuesday 6th November 2018

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