



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

**Meeting of the Peninsula and SWAG Cancer of Unknown Primary (CUP) Clinical Advisory Group
(CAG, formerly SSG)**

Wednesday 8th May 2019
South West House, Blackbrook Park Avenue, Taunton, TA1 2PX

Chair: Tania Tillett (TT)

**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 website [here](#).

2. Review of last meeting's notes and actions

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

Actions:

Pathologist will be contacted to ask them to ensure that the Royal College of Pathologists' CUP dataset is implemented with parity across the region.

TT

3. Network issues

3.1 Trust Staffing Issues

Weston

A recruitment process is underway to replace one of the AOS/CUP Clinical Nurse Specialists (CNS) who is leaving in the near future.

North Devon

Consultant Medical Oncologist Ian Fraser has been appointed as CUP Lead. A 7-day acute nursing service is now provided.

Exeter

The workload is difficult at present due to issues with sickness and maternity leave.

North Bristol

Two nurses have recently returned from long-term absence. The future of the CUP service in North Bristol is under discussion.

Bath

No changes to report.



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Bristol

Changes with the CNS team: Emily Aston has been seconded to the Band 7 role. Cara Boyce and Sarah Ludlow are currently sharing the Band 6 role, and are also on secondment.

Gloucestershire

Advance Nurse Practitioner Amy Skelton has been appointed as the CUP lead. Funding is being sought for an additional AOS/CUP role.

Torbay

Two CNSs have been appointed.

3.2 Review of MDT Service/ Set up of Virtual MDT

A virtual monthly multidisciplinary team meeting will be piloted to discuss complex patients. When relevant cases are identified, CAG Manager Helen Dunderdale (HD) will be contacted to establish how this can be coordinated.

3.3 Cancer Research UK Systemic Anti-Cancer Therapy (SACT) consent forms

The consent forms used across the region varied, with some Trusts adopting the CRUK forms, and others developing forms in house. Some had found the CRUK forms time consuming to complete. Many Trusts are in the process of switching to e-consent, and this will be monitored before revisiting the idea of agreeing a network standardised practice.

4. Clinical Guidelines

4.1 Review of Serial Responders

Please see the presentation uploaded on to the SWCN website

Presented by Hannah Taylor (HT)

LM discussed her recent “True CUP” patients. Those patients that survive 2 or more courses of chemotherapy treatment often tend not to be “True CUP”. Sometimes this could mean that the patient is not being treated with the most appropriate treatment and patient’s diagnoses must be reconsidered if they are acting more like an alternative primary malignancy.

4.2 Highlights from the CUP Foundation Conference

Please see the presentation uploaded on to the SWCN website

Presented by Tania Tillett

The conference was divided into three sessions:

- Current optimal diagnostics for CUP tissue of origin, looking at state of the art

immunohistochemistry (IHC), using the correct IHC tests and recognising limitations of classifier assays

- Clinical and translational trials
- Optimal clinical management and focus on the future.

Molecular cancer classifiers, which can determine cancer type but not genetic alterations in cancer cells, were reducing in cost. Comprehensive profiling (NGS), which can determine genetic alterations in cancer cells but can rarely determine cancer type, was noted to be costly at present.

Further details are documented within the presentation.

A Genomics Medicine Centre is being established in Bristol in collaboration with Exeter; a member of the team will be invited to provide a presentation at a future meeting.

HD

5. Research

5.1 CUPISCO trial update

Please see the presentation uploaded on to the SWCN website

Presented by Tania Tillett

CUPISCO is open to recruitment and referrals from across the region are encouraged. Inclusion criteria are detailed within the presentation.

CUP
Team

The protocol has been amended to state that a second biopsy is no longer required for genomic testing if there is insufficient tissue in the first biopsy, as a blood sample has been confirmed to be sufficient. Albumin above 25 has been removed as exclusion criteria, and antibiotics can now be given within 2 days of commencing SACT instead of 5. Palliative radiotherapy can now be given along with the trial drug as long as this is checked with the medical monitor. It is hoped that the amendments will reduce the percentage of screening failures. Two patients have been recruited in RUH Bath to date.

6. Quality indicators, audits and data collection

A network evaluation on c-reactive protein and albumin levels in cCUP patients in relation to medium survival and performance status was proposed. An audit proforma will be circulated.

TT/MDT
Leads

7. Coordination of patient pathways

7.1 Evaluation of CUP 2WW referrals, RUH Bath

Please see the presentation uploaded on to the SWCN website

Presented by Matt Sephton (MS)

During the 12 month evaluation, undertaken from 1st August 2017 to 31st July 2018, 45 2WW referrals were received. The conversion rate to cCUP was 13%, and to primary cancer diagnoses was 73%. Further details are documented within the presentation.

Recommendations:

- The number of patients referred with full staging could be improved, despite this being a request on the referral form. This may require re-education of the referrers. This adds to inherent delays in the ability to see patients within two weeks
- The service provides a valuable means for patients who may not have another clear setting in which to be investigated, but it is more likely that another cancer will be diagnosed than CUP
- Despite only 42% of patients being seen in CUP clinic, referrals often require a lot of administration and co-ordination time that needs to be reflected in the job plans of the clinicians involved.

The poster will be circulated with details on how the data was collected.

The ownership of patients referred between MDTs needs to be clarified to streamline processes.

Although CUP is considered a minor cancer site in most job plans, a lot of work is undertaken behind the scenes. The activity should be recorded and recompensed, ideally by means of an advice and guidance tariff.

It would be helpful to look at the proportion of referrals managed by the teams in relation to the 62 day cancer waiting time target with either a primary or cCUP diagnosis.

HD

CUP
teams

8. Patient experience

8.1 Clinical Nurse Specialist update

Triage of CUP MDT referrals varied across the region, with some CNS teams triaging according to clinical history, contacting the relevant oncologist if advice is required, and ensuring that someone takes ownership of the case at the MDTM. Referral forms may need to be revised to add more information on patient preferences.

The team in Exeter regularly receive responses to their patient and family experience survey, which is sent out by post and includes a stamped addressed envelope. Feedback is generally positive aside from comments about the general service, such as car parking and waiting times, that the team have no ability to change.

8.2 Developing plans to address patient experience and inequalities

Please see the presentation uploaded on to the SWCN website



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Presented by Amelia Randle (AR)

The Cancer Alliance (CA) intends to improve access, early diagnosis and patient experience for all patients, with a particular focus on patients with protected characteristics, such as mental health problems.

The CA team recently took part in a 6 week project organised by NHS England, to assist with this process. This resulted in interviews with 6 people. Further work is now required over a 12 month timeframe to build a more comprehensive picture of the considerations for these patient groups.

AR

It is recommended that patient information should be developed relevant information in accessible, easy to read formats. For example, the Mental Health Act has been reduced into a simplified document that takes approximately 2 minutes to read. Lowering the reading age of patient information leaflets will make them accessible to a wide range of people with differing neuro-divergent characteristics.

It is recognised that people with mental health issues often neglect their physical health and find it challenging to plan ahead and comply with appointment and treatment schedules. Additional support and linking with key workers from different disciplines may be required. Any initiatives that are already in place across the alliance can be shared for compilation by HD.

9. Service developments

9.1 Management of serious non-specific symptoms: Cancer Alliance initiatives

Please see the draft plans circulated with the notes

Presented by Amelia Randle and Joe Mays

Cancer Alliances have been tasked by the National Cancer Board to spend 15% of 2019/20 funding on development of a Rapid Diagnostic Centre (RDC). The purpose of the service is to coordinate a series of tests to streamline the time to diagnosis for those patients with serious non-specific symptoms who would otherwise be referred via the suspected cancer two week wait pathway.

A national service specification has yet to be defined and, due to the rural geography of the South West, one RDC has not been proposed by the Peninsula and SWAG CA teams.

SWAG CA proposes a model based in several areas within the primary care network. Referrals would be sent for a 30 minute holistic clinical assessment and test bundle before referring on to diagnostic imaging, if deemed appropriate, after liaison with relevant secondary care teams. Examples of how this might be achieved are detailed in the draft plan, and members of the team are invited to express an interest in establishing the service.



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Peninsula CA proposes a model, based on the Oxford pilot, in several areas in secondary care imaging centres, with GPs expected to refer patients in parallel with a set of examinations available in primary care, as guided by website guidelines. The services will be piloted and evaluated.

The majority of referrals made by GPs for patients with serious non-specific symptoms, which are currently managed by the CUP service, are felt to be appropriately flagged as having rapidly progressing symptoms of concern. Clinical decision making for this patient cohort is complex and requires advanced clinical expertise.

9.2 Guidelines for the Management of Solitary Bone Lesions

Please see the presentation uploaded on to the SWCN website

Presented by Tania Tillett

Solitary bone lesions should be referred to the Oxford sarcoma service with a clinical referral letter and images from PACS via IEP: sarcoma.referrals@nhs.net

Advice on management of multiple bone metastases is documented in the presentation.

10. Any other business

CUP MDT decision making tools, developed by Consultant Oncologist David Farrugia, are available on the CUP Foundation website. MDT members are invited to express an interest in a 2 year project, partially funded by the CUP Foundation, to validate the tools.

Date of next SWAG meeting: Thursday 7th November 2019

Date of next Peninsula and SWAG meeting: Wednesday 6th May 2020