*Peninsula and Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services*

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

**Wednesday 6th November 2024, 10:00-12:00**

**MS Teams**

**Chair: Tania Tillett**

| **REPORT** (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 SWAG website here.

Expressions of Interest in the role of CUP Chair would be welcomed.

**2. Review of last meeting's report and Work Programme**

As there were no amendments or comments following distribution of the report from the meeting held on Wednesday 8th November 2023, the report was accepted as accurate and finalised.

A formal report had not been produced from the meeting on Wednesday 8th May 2024, which was held for the purpose of clarifying the ordering process for ctDNA tests and discussing the multi-cancer blood test (MCBT) pilot which has since been put on hold.

**2.1 Review of MDT membership:**

CUP CAG were invited to add any changes to MDT membership into the MS Teams Chat so that the distribution list can be updated.

**2.2 Poor Prognostic Support Groups:**

UHBW and RUH continue to hold poor prognostic support groups.

In UHBW, the Adjust, Adapt and Plan events are still being held virtually as it has been difficult to return all of the groups to in-person meetings due to room availability. Feedback on the virtual method has been positive as patients can watch the videos multiple times and share these with family members although, ideally, live interaction is preferred when possible, so that any questions arising can be answered and more personalised support offered.

**Action: To share details on how to refer patients to the Adjust, Adapt and Plan Events with Vivek Mohan.** **Ruth Hendy**

**2.3 Patient Experience Surveys:**

It is notoriously difficult for the CUP teams to collate data on the patient experience. SWAG Cancer Alliance have confirmed in principle that funding and administrative support will be made available for regional patient experience surveys. Lead Cancer Nurse Chris Levett has recently been appointed and will lead on this project. It is hoped that a QR code can be developed with input from the group, which will automatically produce feedback to share within the CAG meetings. CAG Manager Helen Dunderdale will ask for CUP to be prioritised.

The Cancer Alliance have also funded a new role for the purpose of obtaining live feedback from patients across the Bristol hospitals, which is expected to generate a lot of shared learning.

UHBW have developed a generic cancer survey that can easily be adapted to incorporate cancer site specific questions, again, enabling shared learning. **Future agenda item**

**2.4 HELP CUP Programme:**

The Roche HELP CUP Programme, funded by the Cancer Alliance, is currently allowing access to circulating tumour DNA tests to patients across the region.

The CUP team can log on to the Foundation Medicine portal and select the orange 'ORDER NOW' button to get the test kit delivered.

The report comes back as a PDF which is accessible on the order platform.

There are still 41 tests available, which need to be ordered prior to the 30th November 2024 and scheduled for delivery no later than 18th December 2024. CUP members from SWAG and Peninsula are urged to register and order for as many relevant patients as possible.

Once results are received, the CUP audit proforma needs to be completed so that it is possible to keep track of the patients that have benefitted from the test.

**2.5 Reformation of an Acute Oncology CAG**

CUP have been lobbying for reformation of a South West wide Acute Oncology Group since 2014. The Cancer Alliance has now assigned Project Manager Trudy Gail to manage the group, which comprises 50 members to date and is due to convene for the first time in the new year.

**2.6 Network audit**

Two week wait referral pathway snapshot audit on the agenda.

It was also hoped to audit NTRK results and subsequent management but non have been identified to date.

**2.7 General Practitioner (GP) direct access to CT in Somerset**

The last update from Somerset ICB was that GPs could now access CT via the Non Site Specific Pathway and direct access was still not available.

**Action: To chase Somerset ICB to resolve the inequity of GP direct access to CT.** — **Helen Dunderdale**

**2.8 Provision of Cancer Supportive Care Services with parity across the region**

Provision of Supportive Care Services is still an unmet need in the RUH and has stopped in UHBW as the funding has since been withdrawn. The SFT and GRH services are still running, but not for CUP patients in GRH, although there are good links with palliative care services in the community that work well.

RDUH recognise the importance of the Supportive Care Service and have recently secured funding to appoint an additional Band 7 CNS and Consultant to the team.

Resources for Palliative Medicine in other areas remain very challenging.

Weston team can only refer patients to palliative care when they have become very symptomatic; it used to be possible to refer patients at an earlier stage. This is also the experience in Bath and other centres, where hospices are also having to restrict the patients that they can manage due to limited resources. Palliative Medicine representatives have not been available to attend the majority of MDT meetings.

**Action: To remain on the Work Programme and to raise again with ICB Leads / identify the relevant managers to escalate the problem.** — **Tania Tillett/Helen**

All other items on the Work Programme are on the agenda.

**3. Genomic Medicine Service Alliance (GMSA) update**

**Presented by Consultant Medical Oncologist Louise Medley**

Next Generation Sequencing (NGS) tests are not available at present for all CUP patients unless you are accessing the HELP ctDNA programme or can find a primary cancer site. Although the need to add CUP to the National Test Directory has repeatedly been raised, it has not been prioritised to date due to funding limitations and the need to prioritise cancers where there will be a larger impact, such as BRCA testing for prostate cancer.

The National Test Directory is due to be updated next week. CUP is not expected to be included on this occasion, but the timeline for if and when it might be will hopefully be clarified. It expected that there will be a gap from HELP finishing and genomic testing becoming accessible again.

In the next few weeks, the South West Genomic Laboratory Hub (GLH) will be automatically reporting additional genomic targets to meet the needs of the DETERMINE trial. Biopsies need to be sent as standard for both an RNA and DNA panel, whereas current practice is to send CUP only for RNA analysis for NTRK. Any RNA fusions will also be reported.

Additional targets will be included in April 2025, together with germline findings.

GLH reports have been amended to reflect these additions and include more genomic literacy and information on clinical trial eligibility.

Any questions arising can be discussed with the GLH Scientists.

**Discussion:**

Several incident forms have been raised in BHOC due to the pathology reports for BRCA results not being available to the clinical team, with the patient reporting when attending clinic that they have received their results. Ideally the results should be available on the Integrated Care Environment (ICE) along with all other blood test results. There is concern that it will lead to patients having multiple BRCA gene tests requested by different members of the breast care team.

RNA tests do get added to the end of ICE reports by pathology.

Further training on the relevance of different gene alterations would also be welcomed.

The National Genomic Test Directory is the easiest place to locate which gene alterations are relevant to the different tumour sites:
NHS England » National genomic test directory

Consultant Pathologists need to be contacted to see whose email is being entered onto the Genomic request forms to ensure that the pdf reports are emailed to all relevant parties.

Genomic test results need to be formally incorporated into MDT meetings to ensure they are discussed and documented in MDT outcomes.

Educational resources can be found here:

Welcome to Genomics Education Programme - Genomics Education Programme

Solutions to reporting the blood samples on ICE need to be sought by IT departments at individual organisations, as there is no national way to resolve this. Some Trusts have employed genomic coordinators to facilitate reporting of results.

| | |
|---|---|
| **Action: To escalate the need for reporting of germline results on Trust systems to Cancer Service Managers.** | **Helen Dunderdale** |

The governance for sign off of results needs to be clarified.

In the interim, the PDF reports should be sent to generic email addresses.

It is possible for other systems to import results to ICE, and this has been achieved between the GLH and Cambridge Hospital.

The reports generated by the GLH are very informative and CUP CAG are grateful for the work undertaken to date to improve personalised treatment options.

| | |
|---|---|
| **Action: To contact the pathology network, Jonathan Miller and the Cambridge team to see how integrating the GLH results might be achieved.** | **Helen Dunderdale** |

GMSA Managing Director: jonathan.miller@nhs.net

| | |
|---|---|
| **Action: To add an executive summary of genomic education to a future CUP meeting agenda.** | **Tania Tillett/Helen Dunderdale** |

**4. RUH 1 year snapshot audit of two week wait (2WW) referrals**

**Please see the presentation uploaded on to the SWAG website**

**Presented by Consultant Medical Oncologist Tania Tillett**

During presentation of the audit results, CUP CAG are asked to consider the referral routes into individual CUP Services and the relationship/overlap that exists with local Non Site Specific (NSS) Services. It is recognised that NSS models differ across the region and it would be opportune to learn which models work well.

RUH CUP service receive 2WW referrals for any patient with a histopathological diagnosis of cancer of unknown primary or radiological diagnosis of metastatic disease with no clear primary origin.

Solitary cancer sites are not referred.

During 1st October 2023 and 30th September 2024, the service received 24 2WW referrals, 4 of which were rejected with advice and guidance for ongoing management of non-cancer related disease provided to the referring GP; no cancers were missed. The remaining 20 referrals were all seen within 14 days, half of which went on to have a biopsy. One was benign and was discharged with reassurance. Seven of the 9 cancers diagnosed went on to have SACT. The breakdown of cancers diagnosed, and the outcomes are detailed in the presentation.

In summary, the CUP two week wait service is performing as expected, with 67% of referrals being diagnosed with cancer.

**Discussion:**

RUH CUP service has experienced some complications with overlapping referrals between the Non-Site Specific (NSS) Service, in particular for patients with sclerotic lesions that are not indicative of a malignancy; it is unclear who should undertake ongoing management of these patients.

RDUH does not have a two week wait referral pathway for CUP.

Inclusion criteria for CUP two week wait referrals is radiological evidence (CT chest, abdomen, pelvis) of metastatic disease and no primary origin. All GPs in Bath have direct access to CT.

Sometimes patients are referred with a histological diagnosis, for example, if diagnosed via a skin biopsy.

TSDFT recently audited the CUP service, which also does not have a two week wait referral pathway. The service received 11 referrals with benign disease, the majority of which were bone lesions with no evidence of malignancy. It is not possible for TSDFT to redirect these referrals to the NSS team.

Sclerotic lesions are often referred to CUP via the A&E pathway; it is also not possible to redirect these to the NSS pathway in RUH.

In SFT, two CUP Clinical Nurse Specialists and an Oncologist also manage the NSS service. This model works well as they arrange the diagnostic work up in the dedicated time for the NSS pathway and then hand over any Malignancies of Unknown Origin to the CUP Service. The service accepts incidental findings directly from radiology, negating the need for the result to go back to the GP and then be referred onwards. Patients are first seen via a virtual route and so are not attending an oncology department with no prior warning.

It is not felt appropriate for a Consultant Oncologist or other cancer specialists' time to be allocated to the NSS workload due to workforce shortages and the need to protect staff time to prioritise management of patients with malignant disease; medics with a generalist skill set should manage the service.

Conversion rate from NSS to Cancer is approximately 8-10%.

UHBW had to pause the NSS service due to staff shortages and workload pressures; previously it was run solely by the CUP CNS and Consultant Oncologist. Two separate generalist medics and an additional non-cancer CNS have since been appointed, and the service has been reinstated. This is still hosted in Oncology; the preference would be for it to sit with generalist services.

UHBW have a two week wait pathway for CUP patients working alongside the AOS team. The service receives many referrals from Primary Care with no imaging; it is now possible to ask the GP to redirect these to the NSS service. There are still many patients being supported by the CUP team awaiting onward referral.

When the NSS CNS is not available, it is still the expectation that the CUP CNSs provide cover for the service, and it is uncertain if this will be sustainable.

NSS services has been set up differently across the country as the ideal model was never defined.

PH have a successful model, managed by GPs based in the hospital setting, who provide GP referrers with excellent advice and guidance. The CUP Consultant Oncologist attends their MDT, which is 40 minutes per week. Patients referred with advanced metastatic disease whose MDT outcome is Best Supportive Care (BSC) are referred straight to hospice care. Not all NSS services have an MDT, and this is a very efficient pathway with the CUP MDT held afterwards.

RDUH have had difficulty recruiting GPs to manage the service.

RUH NSS GPs are based in the community but join the CUP MDT.

GRH NSS also sits with GPs and it is possible for the CUP MDT to refer back to NSS should a patient be referred on the wrong pathway. There are good communication links between the teams, which seem to be key to successful NSS services, along with having links to refer patients onwards for management of symptoms to the appropriate non-cancer pathway.

**5. ctDNA tests results**

Twenty test results have been returned to date. WHO Performance Status (PS) was 0 for 6, 1 for 9, between 1 and 2 for 1, and 2 for 4 patients.

Outcomes show that 16 patients went on to have SACT, 1 patient had radiotherapy alone, 2 patients were for BSC and 1 patient had a primary identified and was referred for management by the appropriate team.

All but one patient proceeded to have a biopsy.

Results from the ctDNA tests have helped define the diagnosis and provide targeted SACT, plus change management, with 2 patients referred on to the DETERMINE trial.

**Discussion:**

The tests can be requested at the point of presentation in the diagnostic stage to try and determine the primary site and best treatment options. Tests have also been requested at the point of progression.

It is ideal to have both the genomic and histological diagnosis so that all relevant targeted therapies can be identified.

When the deadline has passed, it should be possible to access the test by recruiting patients to the Target National Trial. The closest referral centre is Oxford.

Eligibility criteria states that patients should have exhausted all other lines of treatment, but it is hoped to make the argument that CUP are eligible because the first line of treatment is unknown; the pathway will be tested.

**6. Any Other Business**

South West CUP Clinical Advisory Group will remain online as it covers such a large geography and attendance has improved since MS Teams became available.

**Date of next meeting: Wednesday 21st May 2025**

**-END-**