Meeting of the South West Network Cancer of Unknown Primary (CUP) Clinical Advisory Group (CAG)

Wednesday 10th May 2023, 12:00-13:00, via MS Teams

Chair: Dr Tania Tillett

REPORT

ACTIONS

(To be agreed at the next CAG Meeting)

1. Introductions

Please find the list of attendees uploaded on to the SWAG website <u>here</u>.

An update on new appointments since the previous meeting was recorded in the MS Teams chat:

- Consultant Oncologist Dr A Gee has joined the team in RUH
- Consultant Oncologist Dr A Roy is now CUP Lead in PH
- Specialty Dr E Darvill is newly appointed to the CUP team in GRH
- Clinical Nurse Specialists S Cosley and T Murray have joined the team in NRT
- CNSs K Mitcham, K Irvine and D Barnes have joined C Newcombe in RDE
- Consultant Oncologist K Falconer has joined the team in UHBW
- Consultant Oncologist L Medley has no CNS and is running the service single handed.

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 11th May 2022, the report was accepted as accurate and finalised.

012/15: Identification of Poor Prognostic Support Groups plus 006/20: To raise the recommendation of provision of an Enhanced Supportive Care (ESC) with parity across the region:

This will remain a rolling agenda item as poor prognostic support groups, which provide patients with advice on will writing, having conversations with relatives and planning end of life care with input from psychologists, are not available with equity across the region. They are provided in UHBW and RUH, but not in the Peninsula, GRH or SFT.

SFT have an Enhanced Supportive Care (ESC) service which probably provides some of the same elements. ESC is not available in RUH.

ESC services have been shown to improve patient's wellness and ability to stay on active treatment for longer.



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

RDE have an ESC service that has been very successful, but ongoing funding from commissioners is not guaranteed. While on treatment, the patient will receive input from Physiotherapy, Occupational Health, the Clinical Nurse Specialist, and relevant Consultants. There is no other poor prognostic support group.

In the opinion of CUP CAG, ESC should be provided for all CUP patients at the point of diagnosis because, as well as being ideal for the patient experience, it also prevents multiple admissions.

CAG Recommendation

ESC is a more positive way to manage those young, well patients with a poor prognosis who are not ready to consider palliative / hospice input.

017/15: Patient Experience Surveys

There has not been an opportunity to undertake the action to request informal feedback on the patient experience from Cancer Support Workers due to workload pressures. This will be considered again prior to a future meeting.

009/16: Genomic Testing:

It is planned to commence reflex testing for NTRK gene fusions in cCUP, but it has not been possible to implement because a confirmed CUP diagnosis is often not known until after the MDT meeting discussion. Pick up rate for NTRK is very small.

There is also the option to send tissue for Whole Gene Sequencing (WGS).

Now that circulating tumour (ct)DNA testing is not available via the trial CUP COMP, CUP CAG need to try and make this available via other means, which is preferred as ideally gene alterations need to be identified prior to starting chemotherapy.

Action: To urgently escalate the need to fund ctDNA tests for CUP patients to the Cancer Alliance

T Tillett / H
Dunderdale

A request for urgent funding had been submitted in February 2023; no feedback has been received to date.

When comparing Next Generation Sequencing (NGS) via a blood sample versus WGS, high tumour burden gene alterations should be picked up in the blood which can be processed within days, whereas WGS turnaround times are not received in time to inform initial treatment decisions. However, it would be useful to send tissue for WGS for certain cases, for example, for solitary inguinal metastases should the disease recur after initial treatment.

It is hoped that the DETERMINE trial will open in the near future, which will aim to find new treatments for rare cancers using 5 existing licenced drugs.

006/17: To encourage reformation of an Acute Oncology Clinical Advisory Group:

It had been hoped that the AO CAG could be included in the Job Description of one of the Cancer Alliance Project Managers, but this did not progress due to changes in the workforce, and it is now considered to be more appropriate to sit under the Urgent and Emergency Care (UEC) specification while still having links with wider cancer services.



Action: J Mays will investigate what can be provided for AO services as part of the UEC specification

J Mays

005/18: Review of serial responders:

There have again been very few incidences of serial responders due to late presentations during and following the pandemic; this will be revisited in one to two years.

002/19: CUPISCO:

CUPISCO has now closed and is awaiting publication.

Action: Chief Investigator Dr Kai-Keen Shiu will be invited to present at a future meeting.

H Dunderdale

007/19: Network audit: A prospective regional audit of referrals to CUP services over a 6 month period

To be rediscussed at a future meeting.

004/20: Somerset PCN/RDS to resolve inequity in GP access to direct CT requests:

Previous feedback from Somerset CCG had confirmed that Somerset GPs did not have direct access to request CT scans via the Order Comms system, but they now have access via the new Rapid Diagnostic Service pilot, which will hopefully resolve the issue for CUP patients.

Equitable access to CT within the Peninsula Cancer Alliance region is uncertain.

National Guidance now mandates equity of access to CTs.

This has been re-escalated to Out of Hospital Lead A Randle to request that this is resolved.

005/20: SWAG and Peninsula Rapid Diagnostic Service (now more commonly referred to as the Non-Site Specific (NSS) Services) models to be presented at a future CUP CAG:

This action will be moved to the NSS CAG.

The NSS models are very different across the SWAG region. As the differences between the CUP and NSS pathways is still causing confusion for the referring GPs, further information should be made available to clearly define what is required.

NSS services are supposed to be embedded as business as usual by the end of 2023/24. At the moment they see very few people, and have limited resources; often referrals are ultimately managed by the CUP team.

It is hoped that a multi cancer detection test can be developed as a result of the



NHS-GALLERi trial, early data from which has shown a cancer pick up rate.

If the blood test is validated for roll out, it is unclear if this will be used in Primary or Secondary Care.

002/21: SFT and YDH merger and CUP service MDT:

The Trusts have now merged.

Action: An update will be requested from Consultant Oncologist E Cattell for the next CUP meeting.

H Dunderdale

003/21: Clinical Guidelines:

The SWAG Guidelines and Constitution have been updated and published on the website here; action completed. These are SWAG specific and do not include details of Peninsula services.

3. Any other business:

Roche are setting up an audit on the use of ctDNA for CUP patients, which T Tillett intends to take part in on behalf of CUP.

If successful in purchasing a stockpile of ctDNA tests, these will be distributed as required across the SWAG CUP centres. Tests can be stored at room temperature.

Date of next meeting: Wednesday 8th November2023, 10:00-13:00 via MS Teams

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