

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

Thursday, 7th November 2019, 10:00-14:00

Milne Walker Seminar Room, Level 7, Bristol Royal Infirmary, Upper Maudlin St, Bristol BS2 8HW

Chair: Dr Tania Tillett (TT)

NOTES

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 Work Programme

As there were no amendments or comments following distribution of the notes from the meeting on Wednesday 8th May 2019, the notes were accepted.

Work Programme:

Review of MDT membership:

RUH Bath: Consultant Oncologist Matt Sephton has left the team and moved to Taunton; CUP is no longer part of his job plan. Clinical Nurse Specialist (CNS) Ali Rossiter has 0.2 Whole Time Equivalent (WTE) allocated to CUP. The team is currently under resourced. Consultant Pathologist Leigh Biddlestone provides a dedicated CUP service. There is no support available from Palliative Medicine.

UH Bristol: Consultant Oncologists Helen Winter and Vivek Mohan provide cover across the two Bristol Trusts with Consultant Oncologist Tom Wells joining the MDT meeting from Weston via teleconferencing, supported by CNS Ceri Tucker.

NBT: CNSs Lucy Henderson and Olivia Rabjohns provide the CUP and Acute Oncology Service (AOS), working closely with Palliative Medicine, which helps to get Registrar's involved. Consultant Pathologist Francesca Maggiani provides a dedicated CUP service. The team also join the MDT meeting via teleconferencing. Patients are added to the MDT via the use of a proforma. If the patient is well enough, radiology are asked to specify if there is a site suitable for biopsy.

Glos: The team consists of Consultant Oncologist David Farrugia, Radiologist Jez Green, Pathologist Raul Fulmali, and 2 CNSs providing cross cover for both CUP and AOS services. An MDT is held every 2 weeks to discuss approximately 3 patients. Patients are managed by the AOS service until biopsy results are reported, and referred on to CUP (if this is the patient's preference) if the biopsy is inconclusive. Some patients are added by other MDTs. The CNS/AOS Team ask the Consultant Oncologist on call to request biopsies. Results are given in a CNS led clinic.

Patient experience: Patients are often referred by their GP and have not been informed that they have a finding suspicious of a malignancy (CUP referral criteria)

on their scan result. The first indication that this might be the case is when the patient finds that they are sat in an oncology clinic. There is a need for ongoing education for staff from primary care through to ward care on delivering diagnoses, and having appropriate and realistic discussions about patients' wants and needs when considering ongoing treatment. Working in parallel with the palliative medicine team would be ideal. This will be investigated by Lead Cancer Nurse Ruth Hendy (RH).

RH

RH picked out themes from comments in the most recent National Cancer Patient Experience Survey (NCPES, 2018) on palliative care in UH Bristol. The same could be repeated across the other SWAG organisations. Of note, patients felt that earlier conversations about poor prognoses would have resulted in different choices over treatment options.

In general, results from the NCPES were encouraging, gradually becoming more positive year on year. The survey is now being redesigned and RH has volunteered to take part in the National Advisory Group, and can take forward any changes that the team would like to recommend. The difficulties in getting feedback from this patient cohort have been recognised but alternative such as the provision of simple comment cards or approaching relatives had not highlighted any practical ways to improve services.

RH

CUP1: The Chief Investigator has been invited to provide a presentation at the May 2020 meeting.

Development of a solution for coding CUP on the Gloucestershire Hospital Information System: Resolved; cases are coded as IC-10 80, and the list is audited on a regular basis.

Confirmed CUP (cCUP) case discussions: To revisit at a future meeting. It may be possible to get a diagnosis using blood samples to identify circulating tumour cells in the future. Blood versus tumour are being compared to validate tests; the majority of CUP patients would have a plethora of such cells. This will be considered further with Genomic Laboratory Hub representatives.

GLH

Reformation of Acute Oncology Group: This has previously been escalated to the Cancer Alliance Board, where it was recommended for the Trusts to provide this in line with the CAG service; it is not currently feasible to add this to the remit of the CAG service which currently comprises 12 groups, rising to 14 from next year. An Acute Oncology CNS group, organised by Consultant Oncologist Sharath Gangadhara, already convenes. The potential to expand this into a network group will be investigated.

HD

Two week wait referrals: UH Bristol receive approximately 2-3 referrals a week, and RUH Bristol approximately 4-8, a third of which are usually recurrence of a previous cancer which can then be diverted to the appropriate team. The workload involved in triaging such patients is not currently recognised or recompensed, but does add value to the patient pathway.

Action?

There is a need to educate people about the proper management of cases with reversible, treatable rapidly deteriorating diseases such as young men with germ

cell tumours or cases of lymphoma.

Action?

Royal College of Pathology Dataset, 8th edition; implementation with parity across the region: The dataset is now provided in RUH, but has yet to be implemented in UH Bristol and Gloucestershire, and will be kept on the Work Programme until parity is achieved.

CUPISCO trial update: The trial is open in RUH and is expected to open in Torbay in the near future. RUH is the number one recruiting centre globally, with eight patients recruited to date, having received referrals from across the region. CAG are requested to continue to refer all eligible patients.

CAG members

Network audit ideas: The network evaluation on c-reactive protein and albumin levels will be abandoned as it was not possible to establish the baseline criteria based on current information. Instead, a prospective regional audit of referrals to CUP services over a 6 month period will be undertaken in the new year. An audit proforma will be circulated. Completed forms can be scanned and emailed to HD for collation.

TT/HD

A publication on the Teenage and Young Adult pathway, written by the Paediatric Oncologist Rachel Dommert and CNS Jamie Cargill, will be circulated.

HD

3. Coordination of patient care pathways

3.1 Rapid Diagnostic Service (RDS) update

Please see the presentation uploaded on to the SWCN website

Presented by Nicola Gowen (NG)

Progress has been made on the development of an RDS pilot to coordinate a series of tests to streamline the time to diagnosis for patients with serious non-specific symptoms (please see the presentation for referral criteria) who would otherwise be referred via the suspected cancer pathway. This aims to improve communications between primary and secondary care and prevent the delays which occur when patients are transferred from one specialist to another; the RDS will retain responsibility for the patient until an appropriate referral onwards has been identified.

Results of a national pilot of multi-diagnostic centre models, held in 10 sites across the UK, are detailed in the presentation.

Phase 1 of the RDS pilot will commence in the Primary Care Networks in Mendip and Devizes, and feed in to RUH Bath.

It is hoped that expressions of interest to take part in Phase 2, which has been sent to the STP Leads in each Trust, will allow the pilot area to be widened.

GPs with an extended scope will deliver the service, with agreed points of contact for advice and guidance from specialist MDTs. There is agreement for this patient cohort to be referred to CT within 7 days, which is faster than the current cancer pathway. It is hoped that the demand for CT will not increase, as these patients would already be referred via other routes.

It was emphasised that the RDS Clinical Lead will need to give a direct verbal hand over to a named acute consultant or CNS when a patient needs to be referred on to a specialist MDT.

CUP CAG recommends that the RDS forges links with the Emergency Departments. Project Manager Nicola Gowen (NG) will investigate.

NG

The pilot will be evaluated and adjusted according to local and national findings.

E-Learning will be developed to support the services.

4. Patient Experience

4.1 Adjust, Adapt and Plan (AAP) event: Patient feedback

Presented by Mia Foxhall (MF)

The AAP event, held in UH Bristol as an alternative to Living Well events for patients with advanced cancer, has been evaluated by Clinical Psychologist Mia Foxhall. The event programme consists of 5 elements: nutritional needs, support from palliative medicine, psychological considerations, community support and managing fatigue. Long breaks are included to ensure that there are plenty of opportunities to ask questions and share experiences. There is a significant attrition rate which needs to be investigated; 55 patients have been invited to 4 events, with 32 patients (the majority having lung or haematological malignancies) and family members attending to date.

The evaluation, which people consented to at the event, involved semi-structured telephone interviews 3-5 days after the event for approximately 25 minutes with each of the 13 attendees. Thematic analysis revealed that the process was as valuable as the content of the event, with the main benefit being to help people to share their experiences, give them permission to start conversations on future wishes and adjust to their prognosis.

There is a critical period when the event is most useful to patients who are still well enough to engage in the process.

The structure of the event will be continually reviewed and amended in response to feedback, as will the process for inviting people to the event. The evaluation was undertaken due to concern about how people would feel about being invited; every person that attended said that they would recommend it, and relevant patients should be given the opportunity to attend.

It is felt that the event will help address the cultural misconceptions about the meaning of palliative care.

Further information is required on the patients that did not attend. There were a few attendees who were initially shocked to be invited and a few who did not attend as they had already had sufficient information from St. Peter's Hospice.

It would also be helpful to hold an event in Weston as travel to UH Bristol could

explain why some people did not attend.

CAG can send any further questions about the event to HD to send on to MF.

4.2 CNS Update

There have been staff shortages at both UH Bristol and NBT. The UH Bristol CNS team has provided support to NBT patients over the last 2 months and the NBT CNS has continued to make arrangements for biopsies. CNS teams are encouraged to monitor capacity. A network wide project is underway to assess CNS workloads and formalise provision of CNS numbers.

5. Service Development

Please see the presentation uploaded on to the SWCN website [here](#).

5.1 South West Genomic Laboratory Hub

Presented by Laura Yarram-Smith (LY-S)

The provision of genetic and genomic test panels is now transitioning from a project to a standard NHS service. The number of laboratories has been consolidated from 25 to a network of 7 Genomic Laboratory Hubs (GLHs), all processing a core set of samples according to the same standards. North Bristol Trust (NBT) was successful in the bidding process to become one of the GLHs in partnership with Royal Devon and Exeter Trust. Each hub has been given the responsibility for processing a number of additional specialist tests, which are divided so it is clear who is doing what for each indication / disease; all cancer samples will be processed in NBT. The Director of the laboratory is Genetic Scientist Rachel Butler (RB).

National genomic test directories for rare diseases and cancer have been published [here](#) to give equity of access across the country. These define the tests that will be made available via NHS England at some point in the near future (potentially April 2020); directories will be reviewed by a panel of experts on an annual basis. This includes access to tests for inherited cancer, whole genome testing for all patients with sarcoma, leukaemia and paediatric cancers (which will include patients up to 24-years-old), and genetic panels for other tumours. Whole genome sequencing is currently not available for CUP, but the plan will be to include all cancers in the future.

The South West GLH is proposing a gene panel that includes 500 genes in the hope that further relevant gene alterations and targeted therapies can be identified in the future; many biomarkers are emerging that could be eligible for Neurotropic Tyrosine Receptor Kinase (NTRK) gene alteration inhibitor drugs.

Transport methods are in the process of being clarified to ensure timely receipt of samples to the laboratory.

Tests will be requested on a paper referral form until an online requesting system has been developed.

Consent is required as results are stored on a research database and will be facilitated by a standardised record of discussion forms.

A list of agreed variants will be discussed by the Genomic Tumour Assessment



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

Boards before reporting back to the requesting MDT; patients with germline variants will be referred to the genetic counselling service and guidance for delivering initial results will be provided by GLH representatives to the clinical team.

National guidelines are being developed on the reporting of relevant variants.

A Genomic Medicine Service Cancer Education Event will be held in Taunton on Wednesday 29th January 2020.

Date of next meeting: Wednesday 6th May 2020

-END-