Haematological Cancer Clinical Advisory Group

Tuesday 6th February 2024, 13:00-17:00

DoubleTree by Hilton Bristol North, Woodlands Lane, Bradley Stoke, Bristol, BS32 4JF / MS Teams

REPORT	ACTIONS

1. Introductions: Welcome and farewell update

Consultant Haematologist S Otton is deputising for R Lush. Future Chairmanship will be discussed later in the meeting.

Please see the list of attendees and apologies available on the SWAG website here.

2. Review of last meeting report and actions

As there were no amendments or comments following distribution of the report from the meeting on Thursday 23rd February 2023, the report was accepted as finalised.

Since the COVID-19 pandemic, the meeting schedule was reduced to one a year; it is planned to return to 6 monthly meetings this year.

Actions:

2.1 Genomic Medicine Service Alliance (GMSA)

The GMSA took an action to improve turnaround times, which has since been addressed.

Action: The process of uploading reports to HILIS still needs to be optimised. — **GMSA Team**

Members need to ensure that they have the right level of access to HILIS to view the reports.

2.2 Two week wait suspected haematological cancer referral proforma

Haem CAG recommended including ethnicity coding on the forms to facilitate work identifying and addressing inequalities. A patient's gender at birth and current gender could also be included for the same purpose.

Action: To feedback alterations required on the suspected cancer referral forms to Integrated Care Board Leads. — **H Dunderdale**

There is Haematology Advice and Guidance on both REMEDY and the SWAG website that need to be aligned. Somerset also have standardised replies to Advice and Guidance questions.

Action: To look at the web-based availability of advice and guidance and align / promote the use of these to GPs. — **Helen Dunderdale/Claire Burney**

CAG members often attach CAG guidance when responding to Advice and Guidance, with a message such as 'please refer to the attached schedule'. There has been feedback from GPs that they would prefer an individualised reply rather than the standardised information.

Action: Out of Hospital Lead for the Cancer Alliance, Amelia Randle, will be asked to promote use of the standardised information via the Primary Care Networks (PCNs). — **Amelia Randle**

A copy of the suspected referral proforma designed by the Peninsula team has been requested to compare data fields, aiming to optimise the SWAG version.

2.3 Quality of Life Surveys:

To date, it has not been possible to gather information for the group to review and make tangible actions from QoL surveys. This will remain on the work programme as a potential future agenda item, should information be made available from research trials.

2.4 CNS lymphoma pathway

A working group which includes members of the Bristol Neuro-Oncology Group (BNOG) has been formed to optimise the suspected CNS lymphoma pathway.

The pathway does seem to have improved since the first meeting.

Action: Draft guidance has been produced and will be shared with Haem CAG in the near future. — **BNOG Team**

BNOG use the 'refer a patient' portal for referrals: Signpost | Neurosurgery MDT | North Bristol NHS Trust

Consultant Oncologist Lorna Hawley attends BNOG as the bridge between the MDTs, and it is planned for Nikesh Chavda to attend on an ad hoc basis to discuss relevant cases.

2.5 Lymphoma Bone Protection Standard Operating Procedure

The Somerset Lymphoma Bone Protection SOP had been circulated to the group for ratification. As no comments have been received, it will be adopted as a SWAG wide document and uploaded to the website. — **AGREED**

All other actions will be addressed in the meeting today.

2.6 CAR-T

A recent update to lymphoma clinical guidelines recommends early discussion of CAR-T for patients with high-risk mantle cell lymphoma, which is thought to be due to the speed with which the disease can progress.

Action: MDT teams will incorporate this into MDT meeting decision making and the CAR-T team welcome these discussions. **Haem CAG**

2.7 CNS Prophylaxis Guidelines

Action: Consultant Haematologist Nikesh Chavda will update the treatment guidance to reflect the most recent evidence using the ASH flowchart; indications have been reduced to a small number of patients **Nikesh Chavda**

3. Research

3.1 Clinical Research Network update

Please see the presentation uploaded on to the SWAG website

Presented by Research Delivery Manager Claire Matthews and Consultant Haematologist Sally Moore

National clinical trial recruitment from April 2023-January 2024 shows that 6,026 patients have been recruited to haematological cancer trials across 18 research networks. This is on track to be similar to 2022/23 where 7,968 patients were recruited. The majority were interventional with an even split between non-commercial and commercial trials.

Heat maps show the majority of recruitment across the UK occurring in London and Manchester. For SWAG, Bristol and Musgrove are the hot spots.

There are 66 trials open across the region, 14 of which opened in the last 12 months; a further 12 are in set-up. The full list of trials open and in set-up will be circulated.

Question 58 in the National Cancer Patient Experience Survey 'Cancer research opportunities were discussed with the patient' scored below average across SWAG, but higher for haematology in comparison with the national average, being 57% in comparison with 41%.

This is felt to be related to the timing of these conversations, which often happen at the point of diagnosis and can be forgotten amidst all the information given at that time.

It is also thought to be due to the language used to describe research. Not all patients will know that a clinical trial is a research opportunity.

Patient Representative feedback is to let the patient know that research trials have been considered, even if the outcome is that there is no eligible trial available. Patient Representative Victor Barley has found that there are advantages to taking part in research, even if you are on the standard care arm of the trial.

A website is now available where patients can proactively register their interest in participating in research: https://bepartofresearch.nihr.ac.uk

and there is also e-learning for staff to help facilitate research conversations: https://learn.nihr.ac.uk/.

Results from the Participant in Research Experience Survey are documented within the presentation.

The NIHR 6-month Associate Principal Investigator (PI) scheme is still open to any interested clinician who doesn't have research in their current role. It allows associates to work alongside current PIs on studies (as documented in the presentation) signed up to the scheme.

Any PI interested in getting help from an associate while helping their personal development is to get in touch.

The second cohort of the Principal Investigator Pipeline Programme (PIPP) to support research nurses, midwives and dentists to become PIs, is due to commence in March 2024.

The Clinical Research Networks (CRNs) are transitioning into Research Delivery Networks (RDNs) to reflect that there are increasing amounts of research in non-clinical settings. The primary purpose of the RDNs remains the same: to support delivery of high quality research and increase the capacity and capability of future research. The networks are dropping from 15 to 12. The West of England will expand to include Dorset and Salisbury and will be renamed South West Central.

NIHR website links and team contact details are available within the presentation. Dr Sally Moore is the Research Sub-Specialty Lead for the CAG.

Discussion:

It would be ideal if the list of open trials could be shared on a monthly basis.

The CRNs are not resourced to provide this information.

Other CAGs have set up WhatsApp groups to share details of who is opening which trials across the region.

Action: Consultant Haematologist Sanne Lugthart will seek funding and resources to improve information on the clinical trials available across the region and local lists of open trials will be shared. **Sanne Lugthart**

The list of trials in the CRN presentation contained errors. The information was sourced from the EDGE system.

Regional collaboration on the ideal site to open new trials will improve SWAG's reputation to compete for trial site status.

4. Service development

4.1 Managing Staff Fatigue

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Psychologist Mike Osborn

Haem CAG are invited to contact Dr Osborn with any questions that may arise following the presentation.

CAG members are encouraged to think about how to manage the potential risk of psychological fatigue caused by workload pressures, which has always been high risk, but is currently at much higher risk than usual due to the exponential increase in treatment load. Provision of intensive treatment and support to ill and distressed patients has increased 8 fold over the last decade, as demonstrated in a recent presentation by Prof Mark Beresford.

Attention should be drawn to the accumulative every day small behaviours and brief experiences that can have a critical impact on our health and immune system, rather than focusing on more profound critical incidences.

Culturally, complaining about small everyday stresses, such as car parking or problems with IT systems, can be perceived as trivial. However, recognising the impact of these issues can have the biggest return on improving your quality of life, as it is prolonged duress that makes threat defence responses dominate which, in turn, can cause fatigue. Threat defence responses also do not automatically stand down once work has finished, and it can be helpful to arrange a quiet reunion with those that you live with when you return home.

Fatigue and exhaustion differs from tiredness, as it is an indication that the brain has depleted resources to the primitive brain, which

interrupts the ability to regulate your mood and find things interesting, pleasurable or amusing, which can undermine your confidence.

Because hospital staff are high functioning and used to high performance work in stressful environments, the response to fatigue is likely to be more fight than flight and result in irritation, annoyance and reduced tolerance for being critiqued.
This cognitive disruption, which is as real as the brain fog caused by chemotherapy, causes moral injury to NHS staff as you are all working very hard but also feel the need to apologise for the things that have not been possible to achieve, leading to misplaced guilt.

The talk is not presuming that everyone is feeling these pressures in the same way or at any given time but is simply to raise consciousness of the risk of cognitive fatigue.

To help mitigate or manage this risk, staff are encouraged to make deliberate and active steps to review what it is that you personally need, and to regularly incorporate these needs into your daily routine with benign self-compassion and complete moral authority.

Composure and civility should be prioritised and incivility called out. It is advised to 'strike when the iron is cold' to try to maintain your balance of composure below 4 to 5 out of 10 as once the adrenaline becomes higher than this, it can take significantly more time to dissipate. Even if anger and aggression is righteous, it is never helpful.

Fatigue management cannot be reduced to a test of will power, control or strength, but rather it is a test of flexibility and adaptability.

There is a psychological paradox of fatigue management, in that the virtues of a person working in the hospital environment exactly match fatigue risk factors.

Maintaining a healthy team culture is the most protective factor to ensure social safety.

In summary, CAG members are asked to prescribe for themselves the advice that a feisty compassionate colleague would recommend.

4.2 Specialist Integrated Haematological Malignancy Diagnostic Service (SIHMDS)

Presented by Consultant Haematologist Alastair Whiteway

Since the departure of Laboratory Manager Paul Virgo, some of the network interaction had paused. The working group has now been reinvigorated, with the aim to meet every three months with representatives from all sites. The next meeting will be held in March 2024 to incorporate feedback from a national meeting, which is due to convene in February 2024.

An internal working group continues to problem solve any issues raised about the SIHMDS and welcomes feedback from CAG members.

Currently, the group is working on improving the diagnostic terminology within HiLIS so that this includes the full range that people wish to use; negotiations are underway with management to ringfence time for IT support to add the WHO/other definitions. In the interim, there is a free text box that can be used.

Molecular diagnostic work is going to be reorganised across the region, with the workload due to be taken on by the Severn Laboratory. The lab team have been working to minimise the impact of this increase in activity. Any delays can be alerted to the lab via the generic email.

There is also a risk to the haemato-pathology service due to the national shortage of pathologists. The most recent trainees decided to relocate to other hospitals and current trainees are being encouraged to stay. However, due to the inherent challenges particular to haemato-pathology, it is particularly difficult to fill vacancies.

Action: SIHMDS to raise the priority of filling the haemato-pathology posts. **Alastair Whiteway**

Discussion:

The Somerset Team have had excellent support from SIHMDS members in the Myeloid MDTs.

Turnaround times have improved now that administrative support has been sourced to upload the genetics reports to HiLIS.

Reports will not export in to the Integrated Care Environment (ICE) system until everything has been signed off in HiLIS. Further work needs to be undertaken to improve HiLIS's interaction with other systems.

4.3. Genomic Medicine Service Alliance (GMSA)

Presented by Consultant Geneticist Chris Wragg

NPM1 monitoring service will be launched this month in Bristol.

Those patients who are currently monitored or who have rare and unusual NPM1 transcripts will continue to be monitored by Consultant Haematologist Richard Dillon and his team.

Severn Laboratory will monitor new patients who are not rare/unusual and triage all results to the correct team.

Results will go onto HiLIS. The reports have been designed to look the same as those produced by Richard Dillon.

Duplicate testing has been undertaken to standardise practice.

It is hoped that the haematology fusion panel will roll out in April 2024, and a similar panel will also roll out for lymphoma in Summer 2024. This should result in test results delivered in a bundle rather than separately.

Action: Feedback will be provided at a future meeting. **C Wragg/GMSA Team**

Whole Genome Sequencing WGS turnaround time has not been ideal over the last year but has since been made more efficient. Average turnaround time is now 40 days.

The intention was to use WGS results to fine tune treatment, but this has not been borne out in the findings received to date for all patients and, rather than trying to test everyone, it may be better to focus on sub-sets of patients, in particular Acute Lymphoblastic Leukaemia (ALL) where a definite benefit has been observed.

5. Patient experience

Clinical Nurse Specialist update

UHBW – Bristol site

The CNS teams at UHBW have all acquired a Band 6 and 7 post holder in the past year. As only one staff member is full time, the service is still spread a little thin.

NICE TAG funding has just been allocated to further expand the team. It is expected that 0.6 of the WTE will be allocated to lymphoma, which has the largest workload, then 0.2 to leukaemia and 0.2 to myeloma.

The Lymphoma team still run nurse-led clinics for End of Treatment and Patient Initiated Follow Up (PIFU) and hold blood cancer meetings

for patients that have been evaluated well. The Leukaemia team do MPN nurse led clinics and the Myeloma team do MGUS nurse led telephone clinics.

The Myeloma CNS has been approached by a CNS from Sydney University, who has launched an electronic Myeloma Tracker that can be populated / adapted for each patient. It can be printed and/or email to the patient and will be piloted in UHBW. This will hopefully help manage the increasingly complicated regimes for Myeloma for the patient, their CNS and for Pharmacy. It is not a prescription, but an educational prompt.

Potential future agenda item

GRH

The CNS team in GRH have a similar model with Band 6 and 7 post holders in each of the three teams, which are myeloma, lymphoid and myeloid. These need some future proofing as it is notoriously hard to recruit to these posts and find people with the particular expertise required. Two Cancer Support Workers (CSW) have been appointed which has significantly helped with provision of patient support.

One project is underway to look at frailty management, and another in the community to look at rehabilitation. The working group includes input from a psychologist, dietician and patient representatives. The first group meeting is scheduled for the Summer.

Action: The evaluation from the rehabilitation group will be shared at a future meeting.

NBT

Jo Stokes

The CNS team in NBT includes three posts, one of which is part of a project; a business case is being drafted to try and retain the post. The team did have a CSW for 2 days a week over a few months, which was very helpful, but unfortunately the post holder has now left as ongoing funding was not secured. A business case will also be submitted to try and get continued funding for the post.

A few CNS led clinics have had to be paused due to the low staffing levels.

NBT team are interested to hear how the UHBW PIFU clinics run due to the backlog of lymphoma follow up appointments. It is hoped that the introduction of My Medical Record will help to facilitate implementing PIFU.

Action: NBT Team are invited to attend UHBW PIFU meetings

UHBW – Weston site **NBT CNS team**

The CNS team also includes three CNSs with support from one CSW funded by Macmillan.

All are undertaking a variety of courses including on examining, prescribing and all are aiming to complete the blood transfusion prescribing course and non-medical prescribing. The team manage much of the transfusion workload, and this will make them more independent.

Somerset

One CNS in Somerset has been undertaking frailty assessments for AML patients who are undergoing intensive treatment. The team comprises 6 CNSs.

Lead Cancer Nurse Chris Levett is now the LCN representative for the group.

The next iteration of the National Cancer Patient Experience Survey is out for responses now; 2024 results should be available early next year.

Cancer Alliances aim to embed Personalised Care and Support activity as business as usual and so work needs to continue on completing Holistic Needs Assessments, Care Plans, and Personalised Stratified Follow Up. Work is also underway by Consultant Psychologist Jonnie Raynes to try and incorporate psychological support right at the beginning and throughout the patient pathway.

The Aspirant Cancer Career, Education and Development (ACCEND) workforce programme are looking for an 8a Implementation Lead and have recently sent out an Expression of Interest email advertising the role, which could be a CNS or other Allied Health Professional. It is recognised that Trusts are at very different points in implementing workforce strategies.

6. Clinical guidelines

6.1 Review of outstanding protocols

Please see the presentation uploaded on to the SWAG website

Presented by Network Pharmacist Kate Gregory

The SACT protocol work team comprises Consultant Oncologist Jeremy Braybrooke, Network Pharmacist Kate Gregory, and CAG Manager Helen Dunderdale, plus input from the site-specific specialists that

create the initial drafts, that are then ratified and uploaded to the SWAG website.

Since the previous Haem CAG, 6 new protocols have been uploaded and 4 existing protocols reviewed and updated.

A Myeloma working group was held in November which led to a number of updates including trialling a new protocol template.

The list of outstanding protocols requiring updates is included in the presentation. CAG members are asked for volunteers to review them.

Protocol	Volunteer
Loncastuximab and Glofitamab	Lisa Lowry
Zanubrutinib CLL	Nikesh Chavda
Sorafenib	Caroline Besley
Ibrutinib plus venetoclax	Sophie Otton
Zanubrutinib for treating Waldenstrom's macroglobulinaemia	Laura Percy
Venetoclax with low dose cytarabine	To check with Priyanka Mehta
Venetoclax with low dose cytarabine	Rebecca Frewin
Midostaurin	To send to Leukaemia experts
Carfilzomib with dexamethasone and lenalidomide	Sally Moore
Brentuximab, vedotin with cyclophosphamide	Nikesh Chavda
Brentuximab vedotin	Nikesh Chavda

Action: To add Epcoritamab to the list

Numerous protocols are overdue for review, with some requiring a quick check to confirm that they are still suitable and others requiring a more extensive update.

Kate Gregory

At the last Haem CAG, it was suggested that the original authors review existing protocols, but it was difficult to know where to start and which

protocols to prioritise. Haem CAG were asked to suggest different approaches to take forward the protocol updates.

The Oxford team meet once a year to review the protocols in real time and divide the workload between them, which means they never go out of date.

The chemotherapy nurses highly value the protocols and how they help with safety checks.

Action: Lymphoma team to meet face to face first to start the process in May/June 2024 — **Sophie Otton/Helen Dunderdale**

ALL and AML protocols will go back to original authors — **K Gregory**

Feedback is requested on the new protocol format, to which all existing and new myeloma protocols will be transferred, once agreed. Details are within the presentation. It is hoped that they will enable easier treatment navigation, reduce toxicities, and help with the consent process.

A number of new indications for myeloma are on the horizon and protocols will be required.

A link to protocols from the National Amyloidosis Centre could be added to the website.

The protocol work will continue to ensure that processes are as safe as possible for workers who are least familiar with SACT therapies.

7. Any other business

Action: The lymphoma risk stratified follow up pathway needs to be recirculated for review — **H Dunderdale**

Referrals for benign haematological teams have exponentially increased over recent months.

Oxford model OXCOM have an automated process where benign conditions (CLL and MGUS) are risk stratified by the laboratory into low, intermediate and high risk. If high risk, the patient is screened by a Benign Haematological Conditions Clinical Nurse Specialist who will decide if they need to be seen by a clinician. Intermediate risk are managed by the CNS with clinic telephone calls, and low risk are managed entirely by the laboratory.

The process in UHBW is to send a letter to GPs that details the vaccines required for CLL, the follow up schedule, and confirms that the

diagnosis has been logged with the hospital. It is hoped that this will be well received.

Somerset invite the patient to clinic to provide them with information about their condition, then discharge them back to Primary Care.

Action: To establish a dialogue with GPs on promotion of Advice and Guidance documents and provide a workshop on management of low risk conditions in Primary Care **Helen Dunderdale**

It may be possible to include an automated response on the bottom of laboratory reports.

There is also an application to help GPs interpret haematological conditions called Buku Medicine.

Date of next meeting: Wednesday 10th July 2024

-END-

App to Download