Meeting of the SWAG Network Haematological Cancer Clinical Advisory Group (CAG)

Wednesday 26th March 2025, 13:00–17:00

Aztec Hotel, Aztec West, Almondsbury, Bristol, BS32 4TS / MS Teams

This meeting was sponsored by *AbbVie UK Ltd, Accord-UK Ltd* and *Novartis Pharmaceuticals UK Ltd.*

Chair: Consultant Haematologist Randal Stronge, RUH Bath

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.

The hybrid format of the meeting is being trialled and any suggestions for the next meeting format are welcomed.

2. Review of last meeting's report and actions

As there were no amendments or comments following distribution of the report from the meeting on Wednesday 10th July 2024 the report was accepted as finalised.

2.1 Supra-regional MDTs for the diagnosis of specialised malignancies:

To clarify with Cancer Services if 90 minutes of Dr Pawade's time can formally be funded to continue providing support for the Myeloproliferative Neoplasms (MPN) MDT.

Formal arrangements for attendance of a pathologist at the supra-regional MDT has yet to be resolved.

The majority of actions on the Haem CAG Work Programme are on the agenda today.

3. Research Delivery Network Update

Please see the presentation uploaded to the SWAG website

Presented by Consultant Haematologist and Research Lead Sally Moore

National clinical trial recruitment from April 2024 to February 2025 shows that 5,995 patients have been recruited to 195 haematological cancer trials across 15 research networks.
The majority of trials were commercial and interventional. This differs in SWAG where the majority of trials are non-commercial. Recruitment has dropped in comparison with the previous year.

Heat maps that plot research activity show a good comparable amount of activity across the region.

The list of clinical trials that are open and in set-up across the region are documented within the presentation. The data is sourced from the EDGE database and is not always accurate or complete. CAG are encouraged to inform the research team if any trial information is missing.

Often, similar studies are open in multiple centres across the region, which may be appropriate for some studies where there is a lot of recruitment opportunities, whereas others may be more appropriate to open in one centre and consider cross-referral of patients.

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

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.

The free 18 month Principal Investigator Pipeline Programme (PIPP) is also available for research delivery nurses or midwives. The next cohort will open to applications later in the year.

NIHR website links and team contact details are available within the presentation.

The Clinical Research Network has been rebranded as the Research Delivery Network and the geography has expanded to include Dorset. As the Specialty Lead for Haematology, Sally Moore plans to visit all relevant hospital and community sites in the region to establish the existing research infrastructure and see how teams can collaborate to support Haematology research activity.

There are large hubs of research activity particularly in the South East, London and some more northerly centres; the ambition is for the South West region to become as competitive.

The O'Shaughnessy review on clinical trials, published in 2023, looked into why research in the UK has fallen in the ranks of international competitors for research.

A key finding was to increase the amount of commercially funded trials to support the NHS research infrastructure, which in turn will improve the infrastructure available to support non-commercial trials.

The team in the Christie increased their commercial portfolio from 15% to 80% which has increased their consultant workforce from 3 to a team of 30 over a 5 year period.

It would be ideal if Haem CAG could take a regional approach to screening and prioritising studies and optimising cross-referral.

Action: A list of the research trials open across the region will be circulated regularly to improve cross-referrals. **Sally Moore**

There are unique challenges in each centre which can hopefully be overcome with shared learning.

As data pulled from central sources contains inaccuracies, local teams will need to work together to ensure everyone is aware of all available research opportunities.

A Patient and Public Involvement (PPI) Network could challenge why research opportunities are not available within the region and drive forward improvements.

Action: To share the list of open trials in each centre at each CAG meeting. **Research Leads**

Discussion:

The Research Nurses in NBT and UHBW regularly share updates on clinical trials, and this could be extended across the region if a research lead can be identified in each centre.

Some of the Clinical Advisory Groups have WhatsApp Research Groups or have a nominated person to collate information from each centre prior to each meeting. Regional MDTs would also help promote cross-referrals.

Concern was raised over restrictions to opening trials involving PET scans in SFT due to the extra £1000 tariff added by the PET provider, which is not funded by national tariffs.
UHBW team have managed to negotiate with non-commercial study teams to provide the extra funding.

Action: A separate meeting will be held to collectively resolve the PET tariff problem. **Sally Moore/Lisa Lowry**

4. British Society for Haematology (BSH) Monoclonal Gammopathy of Undetermined Significance (MGUS) and Serum Free Light Chains (SFLC) testing

Presented by Consultant Haematologist Claire Burney

The Bristol REMEDY guidance has recently been reviewed, including the document on para-proteins and MGUS. Following discussion with Bristol colleagues, it was agreed to look into how this was being managed across the region, with the aim to reach regional consensus.

The BSH guidelines on suspected cancer referrals for para-proteins has been updated to encourage referrals from a wider cohort of patients than was previously recommended. In addition to the patients who are symptomatic of myeloma, it is now recommended to refer patients according to para-protein concentrations or abnormal light-chain ratios in the absence of other symptoms. Concern was raised that this would create a deluge in the number of suspected cancer referrals.

In response, guidelines have been drafted which propose a risk stratified monitoring strategy for opinions from the group, so that urgent suspected referral appointments are prioritised for those with symptomatic myeloma.

Those with only para-protein symptoms could be referred to a non-urgent pathway. In Bristol, this would come via the ERS system, which would allow the team to view results and triage those patients who would be appropriate to be seen with more urgency.

GRH team agree that a modified approach would be preferable.

RUH will review the guidance currently being used to see how these compare.

It is likely that suspected cancer referrals for the low-risk groups will continue to be referred, but it will still be useful to have consistent guidance agreed across the region.

Action: Haem CAG members to read the circulated guidelines and make comments prior to ratification. **Haem CAG/Alastair Whiteway**

5. Urinary Bence Jones Protein (BJP) and Serum Free Light Chains (SFLC) testing

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Haematologist Sally Moore

At a recent GP education event, it became apparent that Urinary BJP had yet to be replaced with SFLC testing and so work is underway in the community to ensure that best practice recommendations are disseminated to ensure that when a new para-protein is detected, an IFE and SFLC should be performed.

The SFLC does constitute an add-on cost to local laboratories; it is hoped that a cost saving can be made with the reduction in laboratory staff workload associated with discontinuing the manual BJP test.

Once those with MGUS have been risk stratified, low risk patients can be followed up in Primary Care.

The frequency of follow up could be specified, for example, those over 85 years of age with a 1% risk would not require further testing, whereas a patient aged 40 with a 5% risk may need to be retested on an annual basis.
This should help GPs make a cost saving by safely reducing the number of patients requiring repeat tests.

GP guidelines also recommend checking ESR, which again, is not an informative test.

New reference ranges have been proposed for SFLC, related to eGFR. It is suggested that the GP is provided with the SFLC ratio in these ranges, which should reduce the numbers of unnecessary suspected cancer referrals. It would be helpful to adopt this as practice in tandem across the region.

GPs need to be supported to monitor these patients in the most cost effective way possible.

Discussion:

It may not be possible to only report the SFLC ratio, as laboratory reports are increasingly automatically uploaded to NHS systems, but a free text comment on the meaning of the results could be added to aide interpretation.

Action: To contact the laboratory to see if reporting of SFLC ratio only would be possible.

To advise GPs not to request BJP and ESR, help source funding for SFLC, and advise where cost saving can be made in SFLC follow up. Sally Moore

6. SACT protocol update

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Haematologist Randal Stronge

Twelve NICE Technology Appraisals have been approved since March 2024, seven of which now have published protocols. A further two have been drafted and will hopefully be finalised soon. The three remaining that require a volunteer to draft are Avapritinib, Ivosidenib with Azacitidine, and Daratumumab, Bortezomib, Cyclophosphamide and Dexamethasone.

At present, Siltuximab is not available in GRH for Castlman Disease as the Pharmacy cannot accommodate it due to the short shelf life, which has led to a referral going to London. It has been accessible in UHBW, SFT and in Oxford. It may be possible to provide closer to home following contact with other regional centres.

Action: To draft Avapritinib protocol Claire Burney

To draft Daratumumab, Bortezomib, Cyclophosphamide and Dexamethasone protocol Sally Moore

Use of the Thames Valley NSSG protocols as an alternative to updating SWAG protocols was raised again as an option.

The preference for the South West SACT nurses and Pharmacists is to use the SWAG protocols for their safety checks, as the details for administration are more consistent and concise.

Additional funding for 0.2 WTE pharmacist time to update the haematological cancer protocols has been secured from the SWAG Cancer Alliance. It is planned to go out to advert soon, aiming to recruit in the next three months.

A pilot for national protocols has been approved, which is likely to be for a limited number of new agents, and available via a website that requires login details.

Protocols could be copied and pasted from NSSG and then the additional information added, which is already the process for many of them. However, it is important to ensure that the appropriate governance has been followed to ensure that these have been appropriately reviewed and updated for local use.

The new SWAG protocol format with hyperlinks is an improvement from the Thames Valley format and allows for a quick review of response rates and side effects.

It is also important that both oncology and haematology take a regional approach to protocols and that the end users are consulted.

Action: To add to SACT CAG agenda. **Helen Dunderdale**

Clinical Nurse Specialist Rebecca Hallam refers to the SWAG protocols to facilitate the consent process as they contain more accurate information. For example, one includes information on a 24 hour rest day, whereas this information is not included in the NSSG protocol.

Action: To circulate protocols for review by end users. **Network Pharmacists/Helen Dunderdale**

7. Non-Hodgkin's Lymphoma Pathways: National and local perspectives

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Haematologist Lisa Lowry

The National Cancer Programme has asked Haem CAG to look at the number of patients with high-grade Non-Hodgkin's Lymphoma that are waiting more than 62 days from referral to starting chemotherapy, to see if this can be reduced by identifying and implementing quality improvement initiatives.

Data sourced from the National Non-Hodgkin's Lymphoma Audit (2020-21) showed that the proportion of patients starting chemotherapy within the 62 day target in England was 66.1% in 2020 and 62% in 2021. This varied across the nation and across SWAG centres.

More recent data is available from 2023; data from Gloucestershire was not available. It appears that waiting times may be deteriorating, and the reasons why are being explored.

In SFT, 62 day breaches used to be regularly reviewed, and it was commonly found that the treatment start date was recorded incorrectly, which enabled appropriate adjustments to be made. It also helped to identify themes for breaches across shared care pathways. The meetings stopped during the COVID-19 pandemic, and it is thought that data accuracy will have reduced as a consequence.

It is uncertain if the data includes patients referred from all sources, such as A&E etc. and it is recognised that each organisation may have different challenges to improve the pathway.

Haem CAG aims to treat all high-grade lymphoma as urgent and address any pathway issues that are under the control of haematology services. and influence service improvements where the patient's pathway is shared with other service providers.

SFT last audited the pathway in 2018/19 and, at the time, no problems were identified with receiving prompt referrals from the colorectal cancer pathway. It is now perceived that there may be delays via this route, and this needs to be re-audited.

A known delay factor for Musgrove Park is when patients are referred from YDH and, now the Trusts have merged, improvements to the pathway should be possible.

It would be sensible to audit the most recent patient pathways rather than look at historical data.

Project Manager Trudy Gale is able to help facilitate the audit and funding is available to help embed any service improvements identified by the team.

The expectation from the National team is to see an improvement in compliance with the Cancer Waiting Time 62 day target.

Other known delays are the time it takes to arrange a scan or biopsy and then have it reported.

It will be important to liaise with the other departments where patients with lymphoma are identified.

In the BHOC, the average start time from requesting treatment to treatment commencing is 4-5 weeks which, when you factor in the delays to getting diagnostic investigations, makes it challenging not to breach the 62 day target.

The ENT pathway was improved in SFT by ensuring patients with neck lumps could have an FNA and biopsy on the same day and ENT colleagues also request the PET scan in tandem with referring to the Haem MDT.

Improvements had also been made to the radiotherapy pathway.

The first treatment can be counted as the first dose of steroids if this is before the first day of R-CHOP, or it could be a surgical procedure, if the patient presented with a bowel obstruction.

Registrars could be involved in the audit which could be rolled out as a larger piece of work via the HaemSTAR network.

The data will be available to export from the Cancer Register for all patients who progress to treatment. It would also be important to look at the data on patients who died prior to treatment commencing in case the two were related, with recognition that many patients are very frail on presentation and not suitable for treatment. Two week wait referrals and patients upgraded to the cancer pathway from the date of suspicion will both need to be included.

Action: To repeat SFT audit as a network group / design an audit proforma for the data collection and find a volunteer in each centre. **Lymphoma Leads**

8. MMR / Remote Monitoring update

Please see the presentation uploaded on to the SWAG website

Presented by Remote Monitoring Project Manager Chelsea Gilmour

In NBT, remote monitoring is being rolled out for patients diagnosed with cancer using the My Medical Record (MMR) system. The initiative is part of the NHS Long Term Plan to risk stratify patients to a follow up pathway that suits their needs, and provide rapid access to clinical support when required.

Prostate, colorectal and breast cancer were prioritised and most recently lymphoma.

MMR supports self-management, enabling the patient to take a leading role in their follow up with support from the clinical team, allows access to test results for the patient and care team to monitor if action is required, and provides tools to help the patient understand their condition.

MMR is a secure online resource developed by University Hospitals Southampton which they use to track all of their patients on follow up. It is currently the only system that offers both patient and clinician tracking.

The self-management concept is introduced to patients at a time when felt appropriate by the clinical team.

Patients with lymphoma will be sent an introduction letter with either the high grade or low grade follow up protocol as appropriate and access to a 5 minute demonstration video.

Cancer Support Workers then call the patient to ask if they are happy to be registered, then login details are provided.

Online symptom questionnaires can be completed, and it is possible to securely message the cancer support team, who reply within 48 hours.

Results from the Integrated Care Environment (ICE) feed directly on to MMR in real time.

Face to face appointments can still be arranged as and when required, although it is expected that the system will reduce the number required.

The system went operationally live for lymphoma in February 2025

and 13 patients have been registered to date and have submitted symptom questionnaires, which have been made very simple to complete with yes/no answers.

Approximately the same number of patients have been invited to use the system but have declined due to a lack of confidence using IT systems.

The next steps will involve a patient feedback and impact evaluation.

MMR also provides a robust tracking system for showing when investigations are due or overdue.

Funding has been approved to support the system in the long term and the Chronic Lymphocytic Leukaemia (CLL) pathway will be developed next.

Further details on the resources available to patients are documented in the presentation.

Discussion:

It takes between 2-3 minutes to register a patient, and an hour needs to be scheduled on a Monday and a Thursday for the Clinical Nurse Specialist to check the tracking system.

The number of messages sent to the clinical team does not appear to have overly increased, when looking at the cancer sites that have registered more patients.

There is a cohort of patients being added to the tracking system at present who are long overdue for clinical review, which is taking a long time during this initial set-up period. Once this has been completed, it is hoped that a time saving benefit will be observed.

There is a one-off cost of £10,000 to develop each new cancer site, and ongoing licence costs to maintain the system.

Project Manager support is provided until the system is embedded.

Other costs may arise when integrating MMR with other Trusts systems.

Email alerts are sent when tests results are abnormal.

9. Genomic Medicine Service Alliance Update

Presented by Consultant Haematologist Tom Coates

Plans are underway to provide a Next Generation Sequencing (NGS) panel for Lymphoma which will replace all of the separate tests, which is in the final stages of ratification.

Talks have been held recently to try and help optimise the genomic elements of the SIHMDS service, including provision of a regional lymphoma diagnostic meeting; anyone interested in attending this is encouraged to get in touch.

Discussion:

It is hoped to develop a panel for myeloma as well, although there are issues with funding streams. Funding for genetic tests from NHS England is not adequate for this year and likely to be less than the potential number of tests that could be offered next year.

The need to rationalise and prioritise the most relevant tests will be raised with the disease specific regional working groups with governance from the SIHMDS; invites will be circulated. **Tom Coates**

10. SIHMDS Service

Presented by Consultant Haematologist Alastair Whiteway

Pathology Manager Dave Fisher has left the role to undertaken a Network Manager role, and has been replaced with Nina Stock.

Monthly user group meetings are being held to ensure appropriate governance arrangements are met across the South West region.

Current workload pressures are significant, with notable pressures on flow cytometry and impacting time for review of diagnostic pathways and governance. New equipment is planned via a Manufacturing Execution System, which is expected to provide some mitigation.

Staffing has been a pressure area in NBT cellular pathology, and an example of when a dispersed approach to the SIHMDS activity works well, as activity continues to be supported in the other centres.

NBT has yet to recruit a replacement haemato-pathologist, with many of the MDTs supported by post holders in other organisations.

Digitalisation is being explored, but the current system doesn't have the resolution required for aspirates and artificial intelligence options are not developed enough to help with cellular pathology at present.

The HiLIS Laboratory Information Management System requires IT support from local IT departments and the Leeds HMDS IT team. Several requests are pending to support HiLIS functions for export of completed reports directly to local hospital information systems.

The HiLIS Diagnostic terms have been updated to WHO classification 5th edition, and the lymphoid conditions are partially updated.

Discussion:

Any HiLIS associated delays are being collated to measure the size of the problem, which seems mostly to be associated with lymphoma rather than leukaemia. HiLIS are in the process of appointing people to help make the necessary improvements.

Sometimes it will be that the report is available on HiLIS, but the individual attending the MDT is not able to comment on how to interpret results reported by another individual; turnaround times still require improvement.

Action: All issues with the HiLIS system will be re-escalated **Alistair Whiteway**

11. Clinical Nurse Specialist Break-Out Meeting

Presented by Clinical Nurse Specialist Theresa Peters

At the previous meeting, it was decided to recommence holding the separate Clinical Nurse Specialist (CNS) group. There have been numerous changes to the workforce since the pandemic and now many of the CNS team don't know each other. Two meetings have been held since, one online and one face to face, with agreement to repeat this on a regular basis for the purpose of sharing best practice, protocols, and undertaking joint projects across the region, such as provision of support groups. Having a shared contact list where the team can ask questions has already helped and can reduce duplication of work.

A one stop myeloma clinic has started in RUH and a one stop lymphoma clinic is planned as well. Patients are identified via the two week wait system, come to see the CNS, and have a bone marrow biopsy and PET scan on the same day or in the same week, with ring fenced slots that can be released and reused if the patient is not well enough to proceed with the investigations. Patient feedback will be requested to check if the speed of the pathway is well received or not.

Action: To share feedback on the patient experience of one stop myeloma clinic at a future CAG meeting, and the proposed plan for the one stop lymphoma clinic **Theresa Peters**

Associate Physicians also play a role in managing the patient pathway, and a regional overview of this would be helpful.

A project has been undertaken in Dorset to ensure all relevant tests are organised for patients referred via the two week wait pathway. **Potential Future Agenda Item**

Haematology in RUH is one of the only cancer sites that does not have a navigator to help organise and track investigations; this is all arranged by the CNS team.

The pathway for lymph nodes in the groin could be further optimised.

12. Any Other Business

Action: To review the regional guideline for the management of CLL. **Rory Mccullogh**

The venue location was felt to be convenient for the majority and will be held in a similar location next time.

A business meeting element will be added to the lymphoma education event and outputs will be fed back to the Haem CAG.

The myeloma event held yesterday went well, but more trainees could have been invited. It would be helpful to invite trainees to Haem CAG as well.

Action: To invite trainees to join Haem CAG via Amanda Clark. **Helen Dunderdale**

A regional complex lymphoma MDT would be beneficial to arrange in the SWAG region; Oxford regional MDTs are highly effective. A regional approach would also improve clinical trial recruitment. Administrative support and dedicated radiology time would be required. It may be easier to establish if arranged as an upgrade to an existing lymphoma MDT.

AGREED

A regional leukaemia meeting is now well established.

Date of next meeting: Wednesday 26th November 2025, Aerospace Bristol, Hayes Way, Patchway, BS34 5BZ / MS Teams.

-END-