Meeting of the SWAG Brain & Central Nervous System Cancer Clinical Advisory Group

13:00-16:30, Wednesday 13th December 2023

Engineers' House, The Promenade, Clifton Down, Bristol, BS8 3NB

Chair: Mr Venkat Iyer

	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.

2. Review of last meeting's report

As there were no amendments or comments following distribution of the report from the meeting on Wednesday 17th May 2023, the report was accepted as finalised.

3. Work Programme

Personalised Care and Support (formerly Living With and Beyond Cancer (LWBC): Implementation of the recovery package.

An update on the purchase of a patient portal was requested.

NBT have set up My Medical Record (MMR) for prostate cancer patients. There were some delays caused by difficulties with linking to the Connecting Care Hospital Information System. Further funding now needs to be sought to pay for ongoing licencing costs and the full time Band 6 Project Manager prior to rolling it out to the other cancer sites. UHBW have funding for MMR until 2026 as their project start date was delayed.

Ultimately, it will be cost saving, as it saves Clinical Nurse Specialist (CNS) time and can be used to safely track surveillance requirements.

Provision of a patient portal with digitised patient information will remain on the Brain CAG Work Programme.

Other items on the Work Programme will be discussed later in the meeting today.

4. Research

4.1 West of England Clinical Research update

Please see the presentation uploaded on to the SWAG website

Presented by Research Delivery Manager Claire Matthews and Consultant Clinical Oncologist Chris Herbert

National clinical trial recruitment from April 2023 to December 2023 shows that 3,170 patients have been recruited to Brain and CNS cancer trials across 18 research networks. This is on track to be similar to 2022/23 where 4,603 patients were recruited. The majority were non-commercial with an even split between interventional and observational 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 18 trials available across the region. The full list of trials open and in set-up will be circulated.

PARADIGM is still open to recruitment, which is a Phase 1 trial with Olaparib and radiotherapy. AstraZeneca is unlikely to take this forward to a Phase 3 study due to the associated costs, therefore the Chief Investigator is looking for an alternative PARP inhibitor.

ARISTOCRAT is due to open, which involves a re-challenge of Temozolomide for relapsed GBM with or without Nabiximols.

BRAIN MATRIX is the Whole Genome Sequencing (WGS) trial for all suspected high-grade gliomas which requires BHOC to consent the patients prior to surgery and take a blood sample. This immediately caused issues as patients are currently not identified by the BHOC team until after surgery.

There is limited information on actionable gene mutations at present, with several historical trials failing to find anything to inform new treatment options.

APPROACH is in set up, which will be Protons versus Photon Radiotherapy in Oligodendroglioma cases over 25 years of age.

BHOC have expressed an interest on a trial for a Phase 1b study to assess the safety and activity of Lu-NeoB in combination with radiotherapy and Temozolomide for newly diagnosed glioblastoma with MGMT methylated and unmethylated promoter status. The practicalities of being able to meet the trial requirements are currently being assessed.

DETERMINE is opening for all cancers, which again involves gene sequencing for alterations that may respond to existing targeted therapies.

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 Brain cancer in comparison with the national average, being 60% in comparison with 41%; Brain CAG are asked to share how this was achieved.

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 Chris Herbert is the Research Sub-Specialty Lead for the CAG.

Discussion:

The high result for research discussions in NCPES is most likely due to the routine discussion of research statistics with patients as part of the treatment decision making process.

Research recruitment has recently had to stop in NBT due to a shortage of research nurses. The timeline for when this will resolve is currently unclear.

BHOC is experiencing similar issues with staff shortages.

The FUTURE GB trial in NBT compares a new type of ultrasound imaging for resection of glioblastoma with standard imaging. Recruitment has been slow, but an extension of 18 months to the trial end date has just been granted, which should hopefully allow recruitment targets to be met when the nursing shortage has been resolved. Over 15 patients have been recruited to date.

The PRIMROSE CSF trial had also opened, which is a genomics study of central nervous system disease secondary to breast cancer.

The only trial that hasn't paused, as no Research Nurse input is required, is D-Speech, which involves recording neurocranial signals to help patients with communication difficulties.

A check point inhibitor trial, which is given prior to surgery for patients with small tumours, is also available. The BHOC and NBT team will need to arrange an additional step in the pathway for these patients, as with the WGS trial.

Tessa Jowell accreditation may be dependent on delivering WGS pathways in the near future.

5. Clinical Guidelines

Neuropathology update

Please see the presentation uploaded on to the SWAG website

Presented by Professor of Neuropathology Reena Kurian

Dr Kurian works alongside the Bristol Neuro-Oncology Group (BNOG) surgeons to diagnose their patients and is the neuropathologist representative on the Tessa Jowell accreditation panel.

One month ago, NBT proposed that Neuropathology merge with Cellular pathology. This will lead to a change in management and has the potential to result in a detrimental effect on turnaround time (TAT) targets. Cell path TAT is approximately 43%, whereas neuropath TAT is 100% for live patients.

This may also have an impact on BNOG retaining Tessa Jowell accreditation status.

It is not tolerable for patients with brain cancer to have delays in starting treatment should sharing neuropathology staff with cell path lengthen the

pathway. Previous work has been undertaken that shows the value of the existing model, where neuropath sits within the musculoskeletal service. It is also important to consider the effect on retention of staff; a similar merger resulted in the resignation of the Consultant Paediatric Pathologists, as they were placed into a situation where they couldn't deliver the service requirements; paediatric pathology in Bristol now needs to be outsourced.

Action: Consultant Neurosurgeons Venkat Iyer and Neil Barua will provide neuropathology with support within any relevant stakeholder meetings, as advised by Dr Kurian, to retain the service in its existing format. **V Iyer/N Barua**

Please see the presentation for an overview of the ideal diagnostic pathway.

Day 1 is when the tissue arrives at the laboratory, and the aim is to provide a working diagnosis within 5 days.

The aim is to provide all other results (aside from WGS) by Day 14 so that treatment can commence within Cancer Waiting Time targets.

The service is continually audited; results for in-house pathology tests meet targets and are within days. TAT from the genomics laboratory is improving.

Action: The percentage of gene panels processed by the Genomic Laboratory Hub within 14 days will be shared with Brain CAG. **R Kurian**

The gene panels are reliant on the surgeons providing fresh frozen tissue rather than paraffin embedded, as the paraffin fragments the DNA and can cause delays in diagnosis.

At present there are inequities in the number of samples sent for gene panel analysis by the neuro-oncology centres across the UK.

There is the argument that results have not been returned within a clinically meaningful timeframe, however, it is not until processes become embedded that all of the actionable mutations can be identified. Many clinical trials with potential new treatment options are due to open in the near future.

Data provided for Tessa Jowell on the number of samples from each centre is anonymised. Results will be fed back to individual centres prior to the February 2024 accreditation reapplication process.

The Next Generation Sequencing (NGS) gene panel now provided by Severn Laboratories is based on the National Genomic Test Directory and input from the local neuropathologists, and has been streamlined down to 11 DNA panels and 2 RNA fusion panels, as documented in the presentation.

Some results will still need to be analysed using FISH.

WGS will provide an integrated analysis of all gene variations, will identify if a tumour is germline, how the patient may respond to treatment by analysing pharmacogenomics, and tumour mutational burden, but it can't detect epigenetic or methylation changes. New Oxford Nanopore Technology is awaited which can detect these changes. It squeezes DNA through a nanopore and uses AI to interpret results. It has been trialled in Nottingham where they have been able to give an intra-operative initial diagnosis. Full analysis is still needed afterwards. NBT has got the machine but the project has stalled awaiting Dr Urankar's return from maternity leave; it will be a less expensive way to analyse DNA once established.

Regional Genomic Tumour Advisory Boards (GTABs) are available to discuss WGS results and recommend eligible trials.

Mutational burden is important to know as this could make your patients eligible for the 5G immunotherapy trial, funded by CRUK, which is due to open soon; approximately 90% of patients will be eligible for the trial. The arms are detailed in the presentation.

Action: Dr Kurian to email the record of discussion and WGS consent and request forms. — **R Kurian**

Cambridge and Birmingham are ahead of the curve with sending samples and having the infrastructure in place to get results back within a clinically relevant timeframe. The pathway now needs to commence in Bristol to show that progress is being made since the previous review.

Action: To start WGS pathway by first prioritising GBM diagnoses due to the extra treatment options that may be available via the 5G trial / setting aside a 1x1x1 fresh frozen sample. — **BNOG Surgical team**

Action: To send consent forms for the MATRIX trial to surgical team to consent prior to taking the surgical and blood samples. — **C Herbert**

It may be helpful to arrange training to facilitate the consent process, in particular when explaining the consequences of identifying germline mutations. — **Potential Future Agenda Item**

The pathway for referral on to clinical genetics, for which there is a long waiting time, should also be clarified.

6. Patient experience

6.1 Prehabilitation Service Update

Please see the presentation uploaded on to the SWAG website

Presented by Physiotherapists Charly Moran and Jayne Masters, and Occupational Therapist Rosie Humphreys

The prehab service welcomes Speech and Language Therapist Maddy Farrow to the team who has extensive experience, including being part of the team for awake surgeries, which should improve continuity of care.

The first year of data from the BNNG prehab dashboard has been received, which was developed by the South Central West Commissioning Support Unit. This provides evidence of the outputs from the service.

Results were presented to the Trust Board on 28th September 2023, and at an Allied Health Professional Conference on 12th October 2023, including two patient stories. The team have since been nominated for an AHP award.

The service has been demonstrated to have the following impact:

- Reduce Length of Stay (LOS) by a mean saving of 1.5 days
- Improve the patient experience and quality of life, as demonstrated with patient reported outcome measure surveys and stories
- Reduce the burden on outpatient services
- Reduce A&E attendances within 90 days of elective discharge.

Estimated annual cost savings from the 277 bed days released are £96,673.

Data demonstrating the impact in more detail is within the presentation. Two videos of patient stories were played which emphasised the importance of the service.

A request for permanent funding for the service has been submitted for consideration in time for the 2024/25 NBT business planning round.

Given the current financial challenges, it is uncertain if investment in the service will be prioritised.

The investment required is 1.3 whole time equivalent (WTE) B7 AHP workforce (£77K). The service will halt on 31st August 2024 if substantive funding is not secured.

6.2 Brain Tumour Support (BTS) Early Intervention Pilot

Please see the presentation uploaded on to the SWAG website

Presented by CEO Tina Mitchell-Skinner

The vision for Brain Tumour Support is to ensure that no one feels alone when facing the impact of a brain tumour diagnosis. Patients and families can access support at any stage, from diagnosis to bereavement, with recognition that support requirements are unique and need to adapt to meet needs at each point in the pathway. The Support Professionals are skilled at assessing and offering individualised patient and family-led support.

Brain Tumour Support commenced an early support intervention study (which has been linked to improving QoL outcomes) in partnership with Southmead Hospital. It started with a pilot from 1st April to 30th September 2023, where patients were automatically referred to the Brain Tumour Support (BTS) team by the Southmead clinical team, with the option for patients to opt out. Patients would then be contacted by a BTS professional within 7 days or sooner if more urgent. The individual needs of patients and their families were assessed, triaged and one-to-one support offered to enable early access to specialist counselling and welfare benefits.

Of the 101 patients referred, 119 people accepted the offer of support (this includes family members), with one person declining the offer.

Evaluation of the pilot was very positive from patients, family members and the team in Southmead, and will continue.

BTS now has built connections with the skull base and prehab teams plus other MDT members to maximise the amount of patients receiving support.

Actions: The service will continue to be evaluated and learning will be shared at future CAG meetings. **T Mitchell-Skinner**

Other funders and partners will be contacted, such as the TJBCM, to consider where else early access to BTS can be rolled out in a sustainable way.

Patient Representative Carly Monnery has attended both the face to face and online counselling session and found them both immensely helpful.

Support will continue to be provided to patients and their families whenever required.

6.3 Brainstrust update

Presented by Brainstrust Representative Rosie Hurley

Clatterbridge Cancer Centre commenced a project to reduce inpatient Length of Stay (LoS) after presentation via A&E, which was usually 7-14 days before a treatment plan has been worked up. Brainstrust charity has collaborated with them to provide the patient voice and feedback. Patients are usually discharged within one day. The project is now being shared with other Cancer Alliances to see if this can be replicated in other centres. Brainstrust continues to provide support to these other centres.

Additional support is now being provided to patients with low grade non-malignant tumours. Referrals can be made by the clinical teams or directly by the patient.

Relevant Patient Information Leaflets are available on request.

6.4 Patient Representative feedback

Patient Representative Carly Monnery has recently experienced revisiting the treatment pathway again, having had repeat surgery followed by radiotherapy and chemotherapy, and has felt very well supported throughout the pathway. The only comment was that the time waiting for surveillance scans to be reported can be a difficult, long wait, usually between 6 to 8 weeks long.

A business case had previously been developed that was ready to go prior to the COVID pandemic for a one stop hot reporting clinic, where patients would have a scan and be seen 2 hours later for the results. This had been put aside during the pandemic.

Action: To revisit the potential service development of the one-stop clinic. **V Iyer**

The speech and language service has significantly improved since Carly Monnery's experience, where the waiting times had been so long that it became necessary to pay for private assistance.

7. Service developments

7.1 Updates from each centre

BHOC – Low Grade Tumours:

Please see the presentation uploaded on to the SWAG website

Presented by Neuro-Oncology CNS Emil Cano

Neuro-Oncology CNS Emil Cano had recently been appointed to provide support to patients with low grade gliomas and the majority of skull base tumours, which has been an unmet need for some time, particularly for psychological support.

The role started in February 2023 following a recommendation from the Tessa Jowell Foundation, with funding sourced from the Cancer Alliance for 1 year. Funding for a 2nd year was confirmed yesterday, so the service is now secure until March 2025.

As of the 12 December 2023, support has been provided to 154 patients.

Training to date has involved attending the Low Grade Glioma (LGG) conference/study day, Level 2 psychological skills, and Having Difficult Conversations.

QoL measures are routinely being collected.

Patient feedback on having a single point of contact has been very positive.

Further details of the service provided are documented in the presentation.

RUH:

Now all treatments have been redirected from RUH to the Bristol service. Neuro-Oncology CNS Tracy Langdon still has 35 patients on 3 monthly or 6 monthly surveillance scans and one patient on Best Supportive Care. Support is available from the Oncologists when required.

Follow up will eventually all be managed by the Bristol team.

BHOC - High Grade Gliomas:

Since 17th April 2023, the BHOC has inherited the RUH follow up patients and is taking on the new patients requiring oncological treatments, the majority of which are high grade. This has had a significant impact on workload, with 19 additional patients as of the 4th December 2023.

Consultant Oncologist Katherine Falconer is currently providing a fortnightly clinic, but her job plan will change in January 2024 to reflect the additional workload. The CNS team provide an all day clinic alongside that. Previously 80% of workload would be dedicated to high grade, which has now risen to 90%.

The CNS Team receive a high volume of phone calls from patients on a daily basis.

Historically, RUH would manage approximately 40 patients per year.

Action: To seek support for additional CNS workforce **BHOC Team**

As discussed in previous meetings, it is important to look at the patient experience across all centres using the same survey.

Action: To agree a SWAG regional patient experience questionnaire that captures information on the surgical and oncological pathways **To be allocated**

Neuro-Oncology CNS Team in Southmead now comprises an additional 2 new nurses in addition to Bea Coghlan.

A business case has been submitted to try and secure ongoing funding for one of the posts which was pump primed for 2 years by Macmillan.

There are currently 150 low grade patients on the workload who have opted for watch and wait surveillance rather than surgical or oncological intervention. The workload is being carefully reviewed to see if further resources are required.

7.2 Managing Staff Fatigue

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Psychologist Mike Osborn

Brain 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.

Discussion:

There has been input from the psychology department into staff wellbeing within the BHOC which has led to the arrangement of 5 minute huddles where team members will discuss any concerns that have arisen that day; this was considered a valuable model to follow.

8. Any other business

The Clinical Trials Unit in BHOC is starting a project to identify reasons for disproportionate uptake to research trials. It is for all tumour groups, but Brain and CNS Cancers will be targeted, aiming to broaden the population of people accessing research in the future.

Date of next meeting: Wednesday 17th July 2024

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