**Meeting of the SWAG Network Brain and Central Nervous System (CNS) Clinical Advisory Group (CAG)**

**Wednesday, 11th November 2020, 13:00-15:00 via MS Teams**

**Chair: Mr Venkat Iyer (VI)**

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| **NOTES**  **(To be agreed at the next CAG Meeting)**  **1. Welcome and apologies**  Please see the separate list of attendees and apologies uploaded on to the SWCN website [here](http://www.swscn.org.uk/networks/cancer/site-specific-groups/aswg-site-specific-groups-2/brain-central-nervous-system-ssg/).  **2. Review of notes and actions**  **Notes:** As there were no amendments or comments following distribution of the notes from the meeting on Thursday 5th December 2019, the notes were accepted.  **Actions progress:**  **Personalised Care and Support (previously known as Living With and Beyond Cancer) – implementation of Patient Information Portal:** Purchase of a system is underway in North Bristol Trust.  **Action: An update will be requested from Cancer Manager Terri Agnew.**  **To provide administrative support for network audits:** H Dunderdale had previously made an application to the National Office for Data Release for patient identifiable data on brain tumour presentations and outcomes. The application has now been amended to request pseudo-anonymised data, as it is not feasible to produce the documents required to progress the original application. It is hoped that the data will be made available soon.    **To send a letter of recommendation to relevant managers to introduce a quality assurance (QA) process for Clinical Oncologists to review treatment planning collaboratively in line with radiotherapy guidelines:** Consultant Oncologists C Herbert and A Cameron have now been allocated time for QA of treatment planning; action completed.  **Action: A letter of support from the group for the RUH and GRH teams would be useful when discussing job planning in the near future.**  **Implementation of CRUK MDT recommendations:** MDT-Mode Assessments have been undertaken in three recent Neuro-Onc MDT meetings. A need for a microphone has been identified, the cost of which can be reimbursed from the CAG budget.  **Action: MDT-Mode results will be presented at a future meeting.**  **3. Clinical Opinion of Network Issues**  **3.1 Updates from Each Centre**  **RUH**  **Please see the presentation uploaded on to the SWCN website**  Consultant Oncologist M Beresford, who is currently the only oncologist assigned to provide neuro-oncology treatments in RUH, now has assistance from Clinical Nurse Specialist (CNS) T Langton, who produced the presentation shown today. The workforce limitations have not been problematic to date; the main issue is that it has not been possible to attend the Neuro-Onc MDTM, as it is at the same time as the Breast MDTM. There is a drive to recruit further oncologists in the near future.  Number of new referrals:   * 2018 = 17 * 2019 = 38 * 2020 = 22 so far.   Patients currently on treatment or follow up surveillance:   * Total number of patients = 48 * On treatment = 9 * Follow up Surveillance = 39 * Glioblastoma (GBM) Grade 4 = 19.   Average survival for patients treated at the RUH in the last two years for GBM Grade 4 is 13.9 months, with the range between 1 and 79 months; this is marginally better than the latest published data.  Average survival for patients receiving surgery, 6 weeks Rads/TMZ plus adjuvant TMZ is 28 months  For patients who had no treatment, the average survival is 4 months.  **Action: A radiotherapy planning project is underway in collaboration with a physicist, auditing organs of risk and levels of tolerance to help refine treatment parameters; this will be presented at the next meeting.**  In recognition that M Beresford is currently the only neuro-onc oncologist in RUH, and is also job planned to support 3 other cancer sites, the teams in BHOC and Cheltenham offer their support if and when required (in particular for those patients in bordering areas), acknowledging that it is ideal for patients in the Bath region to receive treatment and support close to home from the RUH team. If a patient is admitted for treatment to another centre, clear communication is required between teams should the patient be admitted as an emergency in RUH between treatments, so that they are known to the local team.  RUH has a brand new Oncologist Centre, and it would be counterintuitive not to continue to provide the neuro-oncology service to the patient population.  Patient satisfaction data is available and considered very positive, which can be sourced from CNS T Langton prior to a future meeting.  **GRH**  The Cheltenham Oncology Centre serves a community of approximately 1 million people, including South Wales and Stroud. The team comprises 2 neuro-oncologists, 2 Clinical Nurse Specialists, and support from Psychology, a Speech and Language therapist, Endocrinology and Palliative Medicine.  Consultant Oncologist J Bailey has now returned from maternity leave, allowing S Elyan to step down from providing cover.  All MDT outcomes are uploaded on to an electronic record.  While patients are provided with good quality therapeutic support in the hospital setting, access to neuro rehabilitation in the community requires improvement.  The number of new referrals is approximately 70 patients each year, the majority of which are High Grade Gliomas.  Average survival is also marginally better than the latest published data.  Patient experience outcomes across the Trust are positive; the CNS Team were planning a local questionnaire which has been delayed due to the COVID-19 pandemic.  **UHBW**  The neuro-oncology team comprises A Cameron, C Herbert, G Casswell and L Hawley. A second CNS has also joined the team. The team conduct a formal peer review of treatment planning for all glioma cases which takes place each week.  Data on activity sourced from the Somerset Cancer Register, shows a total of 1142 patients diagnosed with glioma seen in the Cameron and Herbert clinics in 2019/20, of which 109 were new, and the rest were in follow up. 559 patients have been seen during 2020 between April and end of August.  A bid has been submitted to the Above and Beyond Charity by A Cameron to fund a neuro rehabilitation team, comprising 1 Occupational Therapist, 1 Physiotherapist and 1 Speech and Language Therapist, with the intention of providing an outpatient based service to facilitate access to community services.  A regional solution for delivery of craniospinal radiotherapy in the South West is needed, as A Cameron is currently the only person providing this treatment.  **Action: To escalate to the Radiotherapy Network Group**  **NBT**  The Bristol Neuro Oncology Group (BNOG) service managed 400 surgical cases in financial year 2019/20, the vast majority of which were glioblastomas.  Since the C-IMPACT guidelines have been adopted, the number of glioblastomas identified as IDH-wildtype is significant, with 91 out of 96 having these features, of which 57 were MGMT unmethylated. Treatment discussions are complicated, with many young patients falling into the Grade 4 category.  The most common metastases are lung, breast, colon and melanoma.  During the first wave of the COVID pandemic, surgical practice remained unchanged as the neuro-oncology theatre lists were preserved, although there was a substantial drop in referrals to the MDT.  Activity and histological sub-types from the Skull Base and Pituitary MDT (April 2019 to March 2020) are documented in the presentation.  A new UK based, multicentre randomised controlled trial, FUTURE-GB is due to commence. This will compare standard care versus navigated ultrasound for GBM.  An additional skull base surgeon has joined the team who is trained to perform endo-nasal surgery.  Challenges to the service include understanding the new molecular tumour classifications, and the expected COVID second wave, which may lead to a lack of ICU capacity and cancer surgery cancellations; the intention is to preserve capacity for Priority 1 and 2 cases.  **4. Clinical Guidelines**  **4.1 Radiological Challenges in Neuro-Oncology**  **Please see the presentation uploaded on to the SWCN website**    **Presented by Becky Hunt**  The neuro-oncology radiology team comprises B Hunt, P Smith and F Williams.  The majority of centres do follow the standardised imaging protocols recommended, although there is some discrepancy with the images sent from YDH, which makes comparing subsequent images very difficult.  **Action: Clinical Nurse Specialist S Levy will feed this back to the YDH Radiologists to see if this can be harmonised across all centres**  The protocol on the ideal imaging for Skull Base is due to be updated and will be disseminated in the near future.  The optimal time to submit imaging for review prior to the MDTM is by Monday lunch time. Often imaging is received after this time, and with 40-50 MRIs to review each week, including multiple previous scans for follow up patients, this can be challenging to complete in time for the MDTM.  A new PACs system should eventually improve workload by allowing images to be automatically imported where centres share the same system. At the moment, this has been very difficult to use due to problems logging in to the system.  The Diagnostic Radiologist workforce is understaffed and does not have sufficient resources at present to manage the workload and complete sub-speciality work such as oncology planning within ideal timeframes; any time-saving initiatives are crucial.  **Action: CAG members are to encourage local teams to import imaging to the NBT team at the earliest opportunity. NBT Neuro-Radiologists will formalise timely image-sharing guidance**  Future advances may include spectroscopy if more time and appropriate resources are made available. A scanner is not set up for this yet as it is currently used only as a research tool.  Increased capacity for Radiologist input into oncology planning is recommended by CAG.  There is an expectation that neuro-radiologists provide 24/7 cover for NBT and BHOC to prioritise the A&E workload. This results in time spent waiting for an emergency which could be spent on oncology planning; it may be appropriate to add some flexibility to Job Plans to facilitate this.  **Action: Neuro-Radiologists to discuss Job Plans with Clinical Lead for Imaging M Bradley**.  Advances in oncology planning will emerge with the development of Artificial Intelligence software. Bristol has access to BRAINLAB Technology, and recommends that this is made available in the other centres.  **Action: M Beresford will contact the NBT Team to arrange a discussion with the Radiotherapy Physicist Team in RUH.**  **4.2 Management of Brain Metastases**  **Please see the presentation uploaded on to the SWCN website**    **Presented by Ribhav Pasricha (RP)**  Metastases are the most common intracranial tumour, with data from Cancer Research UK estimating a rate of approximately 16,000 cases per year, which is often an indicator of end stage disease and limited life expectancy. There is currently no effective measure to prevent brain metastases. Details of the recommended investigations, factors to consider when deciding on management options, and treatment options are detailed within the presentation.  **5. Research**  **5.1 West of England Clinical Research Network**  **Please see the presentation uploaded on to the SWCN website**    **Presented by Claire Matthews**  Research Delivery Manager for Cancer, C Matthews, undertook the role 1 week following D Rea’s move to work on the COVID-19 trials.  Update since March 2020:  All NIHR research activity has been paused and is now focused on Urgent Public Health (UPH) Research to develop vaccines and therapies for coronavirus since the pandemic began. Set up and delivery has been expedited across all research systems. There are currently 67 UPH trials open; of these 47 opened in the West of England Clinical Research Network.  Many research staff were also redeployed to clinical duties from March 2020.  In May, a restart framework was introduced aiming to restore the full portfolio while continuing to support COVID-19 research.  NIHR Guidance has been issued on how to protect research activity during the second wave, including that research staff funded by the NIHR will not be deployed to clinic duties except in exceptional circumstances.  The original high level objectives for research during 2020/21 have been suspended and replaced with objectives related to the UPH trials.  Details on the progress for restarting trial activity across cancer as a whole, and specifically for Brain and CNS cancer trials, which compares favourably with other cancer sites, is documented within the presentation.  Further information is available on the NIHR website. If any CAG members have questions about trials, please contact claire.matthews@nihr.ac.uk or Research Leads  N Barua and C Herbert.  **6. Patient Experience**  **6.1 Clinical Nurse Specialist Update**  **Please see the presentation uploaded on to the SWCN website**  **Presented by Belinda Coghlan**  The NBT team comprises two CNSs and Neuro-Oncology Cancer Support Worker G Pearce.  The CNS team had received 206 referrals via the MDT from 01/11/2019-31/10/2020; the majority were diagnosed with high grade glioma. Support was provided for 20 cases for palliative care; 21 cases had opted for surveillance. The ‘other inconclusive’ group of patients included those with undiagnosed metastases or lymphoma. Referrals had substantially decreased in comparison to last year.  The number of patients on surveillance and frequency of surveillance imaging as at October 2020 has been calculated; details are within the presentation.  A CNS led telephone clinic has been established this year, certain aspects of which can generate an income. General calls about signposting are not included in the tariff.  Throughout March and April during the pandemic, it was noted that calls to the team were markedly reduced, with patients not wanting to be a burden on the service, resulting in a spike of activity in May.  Results from the National Cancer Patient Experience Survey (NCPES) showed positive patient feedback. The local patient experience survey was not repeated this year due to COVID, but it is hoped to repeat this next year, and move towards making this available to complete electronically and use all available tools to gather sufficient information to inform improvements.  Surveillance intervals had been lengthened for some patients which, while this did not follow NICE guidance, was mostly for elderly patients or those with low grade glioma due to patient choice.  **6.2 Patient Experience during the COVID-19 Pandemic**  Presented by Carly Monnery    Surveillance scan, August 2020           The waiting time for the actual scan was significantly less, and the whole process far swifter and improved         Although initially told that there would be a delay of 8-10 weeks for the scan to be reported, the actual reporting time was 6 weeks, after which a phone call was received to book a face to face appointment.    Face to face appointment           Despite the requirement to wear masks and restriction to bring only 1 family member, the face to face appointment was very beneficial, supportive, and informative to enable decision making on future treatment options, with detailed notes being made by the CNS that could be shared with other family members after the event.    Virtual follow up appointment           The virtual video follow up appointment, which involved being sent login details to an NHS system that was straight forward to join, allowed a second opportunity to consolidate the information given in the face to face clinic with the extended family present, and with the benefit of not having to travel.    Scan waiting times were much improved during the Summer as all non-urgent scans had been delayed and cancer prioritised, with very little reporting backlog. Now that normal services have resumed, the backlog has increased again due to reduced capacity caused by compliance with COVID-19 guidelines. There is concern about delays that will be caused by the second wave of the pandemic. The team are using scanning facilities in the Nuffield and Spire, endeavouring to keep the backlog under control, but there is a lack of radiologists to complete reporting turnaround. Cancer is always prioritised; all cancer follow up requests need to be flagged as such rather than shown as routine follow ups.  **7. Any Other Business**  A new SWAG website is currently being developed. SACT protocols and CAG documents will be transferred on to the site, and a link will be circulated when the website goes live.  Brainstrust representative H Bulbeck confirmed that the charity had remained open and available to patients throughout the pandemic. A monthly webinar programme and 15 coaching-led workshops have been run to date this year. These cater to caregivers, family members, paediatric services, as well as adult patients. The first meningioma event will be held tomorrow, Thursday 12th November 2020. The website <https://brainstrust.org.uk/> has an area for healthcare professionals with a range of resources that can be ordered online.  **Action: Brainstrust update will be circulated.**  **Date of next meeting: Spring 2021 – date to be confirmed**  **-END-** | **ACTIONS**  **H Dunderdale**    **H Dunderdale**  **H Dunderdale**    **M Beresford**  **H Dunderdale**  **S Levy**  **CAG**  **Neuro-Radiologists**  **AGREED**  **Neuro-Radiologists**  **M Beresford**  **H Dunderdale** |