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

Meeting of the SWAG Network Brain and Central Nervous System Clinical Advisory Group (CAG, formerly SSG)
Wednesday, 3rd April 2019, 12:30-17:00
Spire Specialist Care Centre, 300 Park Avenue, Aztec West, Bristol, BS32 4SY

THIS MEETING WAS SPONSORED BY KYOWA KIRIN

Chair: Mr Venkat Iyer (VI)

NOTES **ACTIONS**
(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.

The Site Specific Group Service has been rebranded as the Clinical Advisory Group (CAG) Service. Service improvement requirements identified by the CAG are escalated to appropriate members of the SWAG Cancer Alliance Board.

2. A word from our sponsor

Naloxegol is approved by NICE and is now on the Bristol North Somerset South Gloucestershire formulary. It can be used for opiate-induced constipation for patients that do not respond adequately to laxatives. It does not interfere with opioid action.

3. Review of last meeting's notes and actions

Notes:

As there were no amendments or comments following distribution of the notes from the meeting on Wednesday 14th November 2018, the notes were accepted.

Actions progress:

Patient experience survey: The North Bristol Trust survey has been redesigned and distributed; a significant amount of responses have been received to date. Results will be presented by the Clinical Nurse Specialist Team at a future meeting.

A patient experience survey is also underway in Gloucestershire. This will be shared with the Bristol Haematology Oncology Centre team as it will be helpful to distribute the same survey across the 2 centres so that services can be compared and best practice shared.

The meningioma team are hoping to undertake a patient experience survey, but this is currently not possible due to workforce shortages.

Brain tumour patient reported outcome measurement (PROM) pilot project: Work on the project is ongoing; an update will be given at a future meeting.

NICE guidance on the management of glioma, meningioma and brain metastases: There is some variation in follow up schedules across the region; guidance for each tumour group will be circulated. **VI**

Gloucestershire team attendance: Attendance by the Gloucestershire team has notably improved now that additional team members are in post. Regular attendance at the NBT Neuro-oncology Multi-Disciplinary Team Meeting (MDTM) is planned for 1 day per month from May 2019. If it is not possible to attend the first MDTM of the month, attendance will be arranged for the third MDTM of the month.

Teleconferencing facilities should be made available to avoid the need to travel; the infrastructure is in place for other MDTMs.

Standard wording for palliative patients on MDT outcomes: The standard wording given to GPs, which includes a link to further information on the Macmillan website, will be shared with the Gloucestershire team.

MDTM reforms: VI and MDT Coordinator Caroline Fitzavon will attend the MDT Assessment Tool Training Day on Wednesday 19th June 2019. The tool helps improve interactions in the MDT environment. The Gloucestershire and Meningioma MDT Leads will also be invited.

General Practitioner (GP) Direct Access to MRI: The criteria for direct access to MRI scans had been ratified by the group some years ago, and it was planned that requests should be enabled by using the ICE hospital information system. As this has yet to progress, the service does not currently comply with NICE suspected cancer referral guidance; this will be escalated to the Cancer Alliance Early Diagnosis Board. **HD**

RUH Bath Service: A CNS is now in post; contact details will be shared. **HD**

4. Clinical guidelines

4.1 SWAG revised Clinical Guidelines

Presented by Venkat Iyer (VI)

The SWAG Brain and CNS Cancer Clinical Guidelines, originally adapted from the London Cancer Alliance Guidelines, has now been pared back to a simplified document containing the link to the recently published NICE guidance. Further information will be added on surgery, radiotherapy, chemotherapy, imaging and pathology, and will be circulated to all for review.

4.2 Neuropathology update

Please see the presentation uploaded on to the SWCN website

Presented by Kathryn Urankar (KU)

The neuropathology service is now fully staffed following the recent appointment of Consultant Neuropathologist Areli Cuevas-Ocampo.

New advice on examining histology and mutations together may influence prognosis and treatment decisions.

According to the Consortium To Inform Molecular and Practical Approaches to CNS Tumour Classification (cIMPACT, 2018), despite having the histological appearance of a WHO Grade II or III IDH-Wildtype astrocytic glioma, some tumours appear to follow an aggressive clinical course more comparable with glioblastomas. Three molecular features have been identified that indicate shorter survival outcomes: EGFR amplification (available in NBT), whole chromosome 7 gain 10 loss (currently not available in NBT) and TERT promoter mutations (due to be available in NBT in the near future). If one out of three is identified, the tumour is considered to have molecular features of a glioblastoma, and combined chemotherapy and radiotherapy is recommended.

The timeline for getting results to MDTs is approximately 3 weeks; work is underway to streamline these processes.

Additional tests are increasingly becoming available. Please see the presentation for further details. This area is expanding rapidly and will require additional resources. DNA methylation arrays, which are currently sent to GOSH or UCL, are good for any tumour that is not behaving as expected.

cIMPACT guidelines recommend that if an astrocytoma has an ATRX or p53 mutation, testing for 1p19Q deletions is not required.

Please see the presentation for further information on diffuse midline gliomas.

Whole genome sequencing is due to commence in July 2019 for all paediatric tumours, including low grade. The cut off age range is currently being negotiated; it is hoped that this will be 25 years. Fresh frozen tissue is required for the test. Patient friendly literature will need to be made available to assist with the consent process. Results should help to personalise treatment. Report on progress will be made at a future meeting. **KU**

NHS England has a contract with Illumina for processing the genomes.

5. Coordination of patient care pathways

5.1 Teenage and Young Adult (TYA) Service

The TYA service can now provide support to all TYA patients diagnosed with low-grade

brain tumours or non-malignant conditions requiring cancer-type therapies.

The TYA service facilitates and supports care to patients aged 16 to 24, who are recognised to be at a particularly challenging time of life to receive a diagnosis of cancer. This is an area where survival outcomes require improvement. The service improves clinical research trial uptake, treatment compliance, and provides psychological support. Further information is available on the SWCN website here.

There may be some TYA cases where it would be appropriate to consider neuro-surgery in the Bristol Royal Hospital for Children. Data on the current patient experience would need to be collected to see if this change is necessary. The need for care to be individualised was emphasised; some TYA patients would prefer to be treated in an adult setting.

6. Patient experience

6.1 Patient representative feedback

Patient Representative Carly Monnery (CM) was asked to give her personal opinion on the NBT Patient Experience Survey, as this was not available during the time of her patient experience.

The survey covered three areas in the patient pathway:

1. Prior to surgery: a positive rating would have been given to the questions relating to how sensitively the diagnosis was given. The explanation was felt to be excellent, and the information and support given on the option for surgery enabled a decision to be made with confidence.

2. Admission to hospital: Again, a positive rating would have been given to all questions. CM was definitely treated with dignity, helped with symptoms and felt supported. Information was given by the therapist, allowing adequate preparation before discharge.

3. Post-surgery: There were certain areas where improvements could be made when receiving biopsy results; it would be helpful to have a mid-tier option for rating this question. The period of time waiting in clinic for the results was a well-recognised problem. The main difficulty was communicating the different oncological treatment options, and processing the potential side effects of radiotherapy versus surveillance post-surgery for a low risk brain tumour.

The opinions of other patients who had responded to the survey matched those of CM. The experience overall was rated as excellent.

Additional comments: Being able to talk to a previous patient who had been through the same experience was invaluable when preparing to undergo an awake craniotomy. CM was put in touch with a person from a similar age group and with a similar temperament who helped her to make this treatment choice. Organisation of a patient buddying system is required; charity representatives expressed an interest in helping to set this up. **Charity Reps**

Delivering diagnoses in the most appropriate way is considered one of the most challenging areas for health professionals, particularly where areas of uncertainty exist over treatment options. Ongoing communication skill training would help; HD will investigate. **HD**

The joint surgical oncology clinics, which were hard for the clinical team to coordinate, were designed to improve the patient experience, and did meet this purpose.

6.2 Neuro-oncology therapy update

Please see the presentation uploaded on to the SWCN website

Presented by Cecily Moore

Physiotherapy and Speech and Language Therapist (SALT) representatives attend the neuro-oncology MDT to identify relevant patients that may require prehabilitation, and the CNS team contact the therapists should a patient need to be assessed in the neuro-oncology clinic. Post-operative therapy is provided on the wards.

It has been difficult to capture patients pre-operatively due to the swift process of the pathway. The 5 patients seen over the last 6 months were all assessed at short notice, 4 of which were seen in clinic and one assessed via phone. All received a baseline assessment, although this was hampered by fatigue for some, having just finished the neuro surgery clinic. A variety of aides were prescribed and patients were sign-posted to relevant community therapy teams.

Further information on the advantages and challenges of providing a prehabilitation service are documented in the presentation. It would help if more evidence of the potential benefit could be collected over the next year. Neuro-rehabilitation guidelines should be published by NICE in the coming year, and will be discussed at a future meeting. Prehabilitation may also benefit some patients diagnosed with skull base lesions. **HD**

6.3 Charity involvement updates

Brain Tumour Support (BTS) held a successful Patient and Family weekend in March 2019, with over 180 attendees, including patients with all tumour types. BTS has appointed 2 Cancer Support Workers who are working to build good relationships with the Neuro-onc team. Support Groups have now expanded to South Wales.

Collaborative work with Consultant Neuro-surgeon Neil Barua on personalised patient care is ongoing, and BTS are also working on additional Quality of Life and End of Life Projects.

Brain Tumour Charity (BTC) representative Baron Armah-Kwantreng emphasised the importance of therapist input in the management of post treatment neurological deficits. BTC was raising the profile of genomic testing through meetings with Members of Parliament. Of interest is a patient buddying system, and a family support day is due to be held in Bristol in the near future.

7. Clinical opinion on network issues / MDT services

7.1 Skull base MDT update

Presented by Richard Nelson (RN)

The Chair and CAG Manager will confirm contractual arrangements with the West of England Genomics Centre, in term of intellectual property rights between NHS England and Illumina, before consenting skull base patients for genetic analysis. **VI/HD**

The Skull Base Service, which runs in parallel with BNOG, has a clinical case mix of approximately 95% benign and 5% malignant lesions, with the majority of diagnoses being acoustic neuromas, schwannomas, and pituitary lesions.

The caseload is relatively stable but significant, and with the MDT convening every fortnight, ways to improve MDT function will be explored.

Following a Peer Review visit, the service delivery was found to be good, with high standards and a cohesive MDT. However, there are insufficient resources to meet the other quality measures. It is not possible to provide CNS support to patients throughout the patient pathway from pre-operative to follow up, deliver patient experience surveys, contribute to national audits or assess outcome measures. A Business Case is required to develop the service.

A benchmarking exercise has begun to facilitate this, and has found that the average centre of equivalent size has 4 Whole Time Equivalent (WTE) CNSs in comparison with the 1 ½ employed by NBT; this has been escalated to Martin Plummeridge as the most significant issue.

The current move to employ support workers and people in care navigator roles to provide administrative support to CNS teams, and pooling CNS teams, were raised as possible solutions, although it was recognised that particular expertise was required in each area. Lead Cancer Nurse Carol Chapman (CC) will meet with the team to assess the level of support required. **CC**

The Brain Tumour Support (BTS) Charity has a support worker who can provide assistance to patients with any kind of brain lesion. Feedback on the outcomes of referrals made to BTS is requested.

The Skull Base service will have a longer dedicated slot at one of the future CAG meetings to discuss development of the service. Patient and Charity representatives will be added to the distribution list. **HD**

7.2 SWAG Radiotherapy Service

The BHOC Consultant Clinical Oncologist team consists of 2 WTE at present. The third team member recently resigned prior to returning from maternity leave, and recent attempts to recruit have been unsuccessful. Consultant Clinical Oncologist Alison Cameron is the only person treating skull base lesions at present.

The team has therefore joined forces with Cardiff to manage the paediatric workload; this is felt to be a positive long term solution.

A short term temporary solution to streamline the workload until the trainee commences in post this time next year, is to refer Somerset patients to Royal Devon and Exeter (RD&E). The Consultant team is happy to provide this assistance for approximately 20 patients per annum. As RD&E is equidistant patients would not be disadvantaged. Funding for extra CNS support would need to be provided. A letter of recommendation supporting this solution will be sent to the Peninsula Cancer Alliance Clinical Lead Jonathan Renninson, who is the lead for setting up the regions' Radiotherapy Networks. **VI/HD**

Radiotherapy guidelines instruct Clinical Oncologists to review treatment planning collaboratively for quality assurance purposes. Permission to add this to current job plans has yet to be confirmed. A letter of recommendation supporting introduction of this QA process will be sent to BHOC Manager Sophie Baugh and Divisional Director Owen Ainsley. **VI/HD**

Patients are being referred for imaging at NBT rather than at UH Bristol due to preference for the quality of images at NBT. This has been raised as an issue by commissioners.

8. Service Developments

It is hoped to hold a neuro-oncology training day for non-neuro-oncology staff. Although previously advertised to GPs, it did not generate sufficient interest to justify going ahead. The regions' Lead Cancer Nurses have since been asked if they would support attendance by CNS/AHP teams, and positive feedback has been received. Videos have been produced by CM and another patient representative of their patient experience to kick-start the programme. A date will be set, and an expression of interest in the event will be circulated.

9. Research

9.1 Clinical research trials update

Due to time constraints, the list of current clinical research trials and trials in set up will be circulated with the notes.

Date of next meetings: Wednesday 14th August 2019 and Thursday 5th December 2019

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