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

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

Thursday, 5th December 2019, 12:30-16:00

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

THIS MEETING WAS SPONSORED BY GENOMIC HEALTH

Chair: Mr Venkat Iyer (VI)

NOTES
(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 SWCN website here.

2. 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 3rd April 2019, the notes were accepted.

Information provided by the last meeting's sponsor had proved to be useful in recent clinical decision making.

Actions progress:

Redesign of patient experience survey: The survey is to be shared across the region and undertaken again in the New Year. **CNS team**

All other actions are in progress.

3. Clinical Guidelines

3.1 SWAG Clinical Guidelines and Key Documents

Please see the documents uploaded on to the SWCN website here

Presented by Venkat Iyer (VI)

The SWAG Brain and CNS Clinical Guidelines have been pared down to refer to national guidelines to meet Quality Surveillance requirements. The document could be improved if made bespoke with local information.

The SWAG Constitution is also a key document that is used to describe the service. CAG members are asked to review both documents and make comments. Word documents will be circulated. **HD/CAG members**

The Systemic Anti-Cancer Treatment Protocols, also available on the website, were considered sufficient and no additions are required.

3.2 South West Genomic Laboratory Hub Update

Please see the presentation uploaded on to the SWCN website

Presented by John McGrath (JM)

The provision of genetic and genomic test panels is now transitioning from a project to a standard NHS service. The number of laboratories has been consolidated from 25 to a network of 7 Genomic Laboratory Hubs (GLHs), all processing a core set of samples according to the same standards. North Bristol Trust (NBT) was successful in the bidding process to become one of the GLHs in partnership with Royal Devon and Exeter Trust. Each hub has been given the responsibility for processing a number of additional specialist tests, which are divided so it is clear who is doing what for each indication / disease; all cancer samples will be processed in NBT. The Director of the laboratory is Genetic Scientist Rachel Butler (RB).

National genomic test directories for rare diseases and cancer have been published here to give equity of access across the country. These define the tests that will be made available via NHS England at some point in the near future (potentially April 2020); directories will be reviewed by a panel of experts on an annual basis. This includes access to tests for inherited cancer, whole genome testing for all patients with sarcoma, leukaemia and paediatric cancers (which will include patients up to 24-years-old), and genetic panels for other tumours; panels that are due to be available for Brain and CNS tumours are detailed in the presentation. CAG are to suggest any additional tests that need to be included in future iterations of the directory.

CAG members

The South West GLH is proposing a gene panel that includes 500 genes in the hope that further relevant gene alterations and targeted therapies can be identified in the future.

Transport methods are in the process of being clarified to ensure timely receipt of samples to the laboratory.

Tests will be requested on a paper referral form until an online requesting system has been developed.

Consent is required as results are stored on a research database and will be facilitated by a standardised record of discussion forms.

A list of agreed variants will be discussed by the Genomic Tumour Assessment Boards before reporting back to the requesting MDT; patients with germline variants will be referred to the genetic counselling service and guidance for delivering initial results will be provided by GLH representatives to the clinical team.

National guidelines are being developed on the reporting of relevant variants.

Patients with similar genetic variants have been found to respond to similar therapies, which may challenge the way that we currently work to site specific protocols.

A Genomic Medicine Service Cancer Education Event will be held in Taunton on Wednesday 29th January 2020.

The North Bristol team had participated in the 100,000 genomes project; the consent and sample process had been found to be complicated; resources will be made available to simplify processes.

Educational materials are being produced to help manage public expectations.

Patient Representative Carly Monnery (CM) would have found the additional information on the genetics of her tumour of interest, and asked what the majority of patients decided to do when approached to consent for the tests. It has been found that clinicians are more concerned about the burden of putting patients through the consent process than patients, the majority of which do consent. The most common reasons for concerns have been noted to be around life insurance - there is no obligation to disclose tests results that have a predictive nature – and implications for family if a germline mutation is identified. If this is the case, an information pack can be provided for referring family members to clinical genetics. There are a series of opt-out options in the consent process that allows it to be adapted to individual preferences.

CM recently visited a laboratory in Plymouth that is currently undertaking tests on brain tumours. This is the sort of project that could link in to the GLH; any qualified researcher can apply to Genomic England to access information and maximise the opportunities for new research.

3.3 CIMPACT (The Consortium to Inform Molecular and Practical Approaches to CNS Tumour Taxonomy)-NOW, a Brief Update

Please see the presentation uploaded on to the SWCN website

Presented by Areli Cuevas-Ocampo (A C-O)

Consultant Neuropathologist A C-O is a specialist in molecular testing, and has been in post at the NBT neuropathology department for approximately 1 year.

The WHO classification of tumours of the CNS has been updated, and a comparison of the 2007 versus 2016 guidelines is documented in the presentation, which now includes molecular drivers, including IDG mutant or wildtype, and tumours that are 'Not Otherwise Specified' (NOS).

Due to the pace of change in brain tumour research, classification updates are required more frequently and gaps that arise from integrated diagnoses and new definitions need to be addressed; there have been an additional 4 updates since the 2016 version was published.

The molecular features that alter the grade of some tumours from low to high should be interpreted with caution due to the potential long term consequences of high dose treatments, and current lack of national consensus on how these cases should be managed. Many previous cases that were not treated aggressively have had long term survival outcomes.

Treatments for brain tumours have not advanced for many years due to the lack of therapies that are able to effectively penetrate the blood-brain barrier, and the heterogeneity of the tumour biology. The neuropathology department's up-to-date methods are appreciated; CAG recommends reporting the findings without stating prognostic relevance, but rather stating that 'clinical uncertainty currently exists' on how to manage this patient cohort. This advice will be shared with the neuropathology team. **AC-O**

4. Clinical Opinion on Network Issues

4.1 Multi-Disciplinary Team Meeting Activity and Survey

The Wednesday MDT generates 2-2,500 discussions per year. Data on the Brain and CNS MDT referrals, sourced from pathology, showed a significant increase in activity in comparison with previous years. In total, 422 patients were reviewed; an increase of over 70 patients from last year, 78 of which were metastatic. The number of skull base cases was relatively stable.

The cause of the increase may be attributed to the patient population living longer and the increasing numbers of older patients being suitable for treatment. Workload activity will continue to be monitored to inform service requirements.

The MDT meeting survey, circulated to provide members with the opportunity to provide feedback on how the meeting functions, received 6 responses. Response rates to these surveys, which are being circulated across the SWAG region, tend to be low when the meetings function well. Consultant Oncologist Chris Herbert concurred that the meeting ran favourably in comparison with others.

The majority of responders thought that the meeting was about the right length. There was a comment that the meeting clashed with the academic neuroscience meeting, but this was not felt to be relevant to the majority of attendees. Preparation time was felt to be adequate, as was the time spent reviewing radiology and pathology.

The amount of information on patient preferences could be improved, and video-linking with the referring clinician would be useful. Referral forms could be updated to improve the level of information provided, and encourage accurate recording of performance status.

CAG meetings could be used to provide educational input to referrers.

It was commented that some cases for stereotactic radiosurgery and gamma knife would fit the criteria to be listed for information, but not discussed as appropriate to protocolise to a standardised treatment pathway.

The skull base team is expanding and the aim is to ensure that every case is reviewed by a member of the team even if the decision is not for surgery.

The main issue with the meeting is enabling everyone to hear clearly; as this could be resolved with microphones, the possibility of purchasing the relevant equipment will be explored. **HD**

It would also be helpful if debates could be managed objectively.

5. Patient Experience

5.1 Clinical Nurse Specialist Update

The National Cancer Patient Experience Survey (NCPES, 2018), published in August, lacks specific information on Brain and CNS patients due to the low number of responses. However, results across the region show overall gradual improvements attributed to additional support provided by CNS teams.

The national deterioration in Cancer Waiting Times is reflected in the results, and men rated their experience higher than women, as do people who identify themselves as white.

Free text comments are useful to review, although none had been identified that were specific to the Bristol Neuro-Oncology Group (BNOG) service.

The NCPES is considered to be too long for the BNOG patient cohort, and the local patient experience survey has been significantly cut down and tailored by the CNS team.

NCPES will now be provided by a different company - PICKER. Lead Cancer Nurse Ruth Hendy will sit on the National Advisory Panel to contribute recommendations from SWAG CAGs to inform the redesign, and will raise the fact that the survey does not currently capture sufficient information on cancers that are more rare. Results could be used to show the benefits provided by Cancer Support Workers, completion of Holistic Needs Assessments and support from other Allied Health Professionals.

Local survey results show that BNOG scores significantly higher than the national average (93% in comparison with 77%) when patients were asked if they received their diagnosis in a sensitive manner, and report that they understand the explanation of their care, even though this is often very complicated.

A follow up telephone clinic is held on a regular basis. Calls generally take between 30-60 minutes, and receive positive feedback from patients.

Bespoke Holistic Needs Assessments (HNAs) and End of Treatment Summaries are being completed routinely in NBT, and examples were provided to CAG. These generate an income, and help track the patient pathway as they move between Trusts and provide relevant information to different health care professional teams. Numerous centres have provided positive feedback on the format and plan to adopt the same method. A summary is sent to the patient's GP, oncologist, and to the patient (if wanted) on the day of discharge.

Similar template documents for HNAs are available on the Somerset Cancer Register that can also be used for this purpose; the Macmillan template is used in UH Bristol. This does not duplicate the NBT version, but picks up any issues flagged by the team, and additional holistic needs relevant in the oncological setting. The UH Bristol team had tried to use the NBT version, but could not upload it on to the system. In Yeovil, CNS Sarah Levy completes an additional HNA for patients that are for Best Supportive Care.

Clinicians have been told to reduce the length of their correspondence to GPs due to the limited time they have to read the detail, and to only provide a headline summary of the diagnosis and plan in bold; clinic letter templates have recently been adapted to accommodate this change.

Regular oncology meetings are planned in collaboration with the skull base service to discuss service developments; the first meeting with managers convened recently to discuss the business plan, which includes the following additional team members: Band 7 Neuropsychologist, Band 5 Occupational Therapist, Physiotherapist, Clinical Nurse Specialist and a Speech & Language Therapist. It is planned to hold a one stop clinic twice a month for patients on surveillance and occasional urgent new cases.

The most significant issue in NBT is delays when waiting for scans and for results to be reported, with the full extent of this problem only coming to light recently; this was also a concern for those patients with meningioma when discharged back to Yeovil. The reasons for delays, which are most commonly due to the volume of work and shortage of radiologists, have been further exacerbated by the change to clinicians' pension contribution rate, which is a financial deterrent to working overtime.

Patient Representative CM advised that providing information for patients about the approximate waiting time for the scan and results will manage expectations on delays and maintain a positive patient experience, as opposed to not knowing what to expect.

5.2 Charity Involvement Updates

Please see the Brainstrust update circulated with the notes

Brain Tumour Support Representative Rosemary Wormington (RW) gave thanks to BNOG Administrator Gary Pearce for continuing to pass on referrals. A recent review of the service by charity partner Macmillan was very positive. An evaluation of the service provision will be presented at the next meeting.

Brain Tumour Support also attends the Peninsula CAG meeting, where the possibility of emailing MDT Outcomes to GPs was discussed. SWAG CAG recommend posting the summary within 5 days of the MDT as there are concerns that email correspondence might be missed.

6. Research

6.1 Clinical Trials Update

Please see the presentation uploaded on to the SWCN website

Presented by David Rea (DR)

The National Institute for Health Research (NIHR) has revised the high level objectives from 2019/20 as detailed in the presentation. There is an 80% patient recruitment target for both commercial and non-commercial trials. Set up targets are now 80 days for commercial studies and 62 days for non-commercial. The former 30 objectives have now been replaced with 5 harmonised objectives.

New Chief and Principal Investigators will be sought for areas of research that are currently under-represented.

Specific areas of focus for the NIHR are surgical trials, which are inherently difficult to recruit to, radiotherapy, rare cancers and Teenage and Young Adult (TYA) trials. A TYA Research Nurse has recently been appointed; the role will be based in the Bristol

Haematology Oncology Centre, but will have a network-wide remit.

Recruitment figures (sourced from EDGE), open trials, trials in set up, and open to new sites, are documented within the spreadsheet and presentation, which also includes a list of useful links for people to check for trial availability; these will be circulated and uploaded on to the SWCN website. CAG members are invited to contact the research team for further information on trials that they might wish to open.

Discussion of trial eligibility during MDT meetings has been found to be poor. Data from the Somerset Cancer Register showed that, out of 7000 outcomes across the SWAG region, approximately 5% had a documented discussion about research. This was echoed in the results from the National Cancer Patient Experience Survey. A project is currently being planned to see how this might be addressed as part of the wider work on MDT reforms.

It is recommended that teams in other regions who are successfully recruiting to the ROAM trial should be contacted to share practice.

A randomised controlled surgical trial, due to commence next year, is of interest to the BNOG team. Details will be forwarded to DR who will assist with the expression of interest process. **VI**

7. Coordination of Patient Care Pathways

7.1 Rapid Diagnostic Service (RDS)

Presented by Nicola Gowen (NG)

Progress has been made on the development of an RDS pilot to coordinate a series of tests to streamline the time to diagnosis for patients with serious non-specific symptoms (please see the presentation for referral criteria) who would otherwise be referred via the suspected cancer pathway. This aims to improve communications between primary and secondary care and prevent the delays which occur when patients are transferred from one specialist to another; the RDS will retain responsibility for the patient until an appropriate referral onwards has been identified.

Results of a national pilot of multi-diagnostic centre models, held in 10 sites across the UK, are detailed in the presentation.

Phase 1 of the RDS pilot will commence in the Primary Care Networks in Mendip and Devizes in the week starting Monday 6th January 2020, and feed in to RUH Bath.

It is hoped that expressions of interest to take part in Phase 2, which has been sent to the STP Leads in each Trust, will allow the pilot area to be widened; CAG are to contact their Cancer Manager if interested.

GPs with an extended scope will deliver the service, with agreed points of contact for advice and guidance from specialist MDTs. There is agreement for this patient cohort to be referred to CT within 7 days, which is faster than the current cancer pathway.

It is hoped that the demand for CT will not increase, as these patients would already be referred via other routes.

The pilot will be evaluated and adjusted according to local and national findings.

E-Learning will be developed to support the services.

Further detail will be sought on the cohort of patients in the RDC pilots to see if any secondary diagnoses have been recorded of brain metastases to see if the potential workload can be estimated, and to establish if patient feedback was gathered as part of the pilots. Patient feedback will be included in the SWAG evaluation. **NG**

Date of next meetings: Wednesday 11th March 2020, Thursday 13th August 2020, Thursday 12th November 2020

-END-