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

13:00-16:30, Wednesday 17th July 2024

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 and Work Programme

As there were no amendments or comments following distribution of the report from the meeting on Wednesday 13th December 2023, the report was accepted as finalised.

An update on the nanopore pilot which should speed up the adult patient pathway will be provided at a future meeting.

The prehabilitation team are presenting their service provision to the British Neuro-Oncology Society today and have recently managed to secure an additional year of funding. It is hoped that an agreement will be made to fund the service long term.

The majority of items on the Work Programme are on the agenda of the meeting today.

3. Charity involvement

3.1 Brain Tumour Support (BTS)

Presented by Chief Executive Officer (CEO) Tina Mitchell-Skinner and Emma McKeown

Tina Mitchell-Skinner is stepping down from the role of CEO at the end of July and thanked Bristol Neuro Oncology Group (BNOG) for the support provided to BTS since its formation, and for the ongoing partnership.

Emma McKeown will undertake the role of CEO from 1st August 2024.

The early intervention pilot presented at the previous meeting has now been running for over a year and has made a huge difference to the patient experience and hopefully helped support the work of the BNOG team as well.

Feedback from the first 6 months was very positive and will continue to be collated to ensure that it remains a relevant partnership.

Since the pilot commenced on 1st April 2023, support has been provided to 250 individuals who have been directly referred to the service at the point of diagnosis, out of which 4 people declined the support. The needs of people referred at the beginning of the pathway differ from those who find the charity later on, in that more crisis counselling is requested. For example, advice is often sought on how to talk to children and colleagues. It has also increased the number of family and friends seeking support, which has enabled the charity to provide more practical advice on meeting caring needs as well as emotional support. 92% of individuals said that the service made them feel less isolated and alone.

Face to face support groups are also being held in Southmead, which are also being well received. 80 counselling sessions have been arranged over the period; at present, it has been possible to keep waiting lists low. 23 families have accessed the welfare and benefits advice service, with the service gaining access to over £180,000 in benefits.

It is hoped that the early intervention service will now continue as a permanent fixture.

Previously, patients were missed or picked up after treatment, but they are now being contacted prior to surgery. The pilot has resulted in a 52% uptake in BTS activity. The pilot has been self-funded but funding from other sources is required for this to continue.

Discussion:

Home visits and visits to schools and work places have been arranged where this has been identified as necessary.

The welfare and benefits service run by BTS is quicker than the service provided by Macmillan who have a backlog.

Support is available at any point after diagnosis, and patients often contact BTS at different stages over many years.

Action: North Bristol Trust and the Integrated Care Board (ICB) need to be made aware of the service, which is successfully addressing a huge unmet need. **H Dunderdale**

Applications will be made to funding bodies so that the service can be maintained and hopefully grow.

The service was considered an extension of the prehabilitation pathway.

Tina Mitchell-Skinner was thanked for all her work as the CEO of BTS.

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 2024 to July 2024 shows that 865 patients have been recruited to Brain and CNS cancer trials across 17 research networks. The majority were non-commercial with an even split between interventional and observational trials.

There are 13 trials available across the region. The full list of trials open and in set-up will be circulated.

The APPROACH study, which is looking at protons versus photon radiotherapy for low grade gliomas, is still in set up.

ARISTORACT is now open, which involves a re-challenge of Temozolomide for relapsed Glioblastoma (GBM) with or without cannabinoids, has yet to recruit.

PARADIGM is now coming to an end and is unlikely to go forward to a Phase 3 study due to the associated costs.

BRAIN MATRIX is the Whole Genome Sequencing (WGS) trial for all suspected high-grade gliomas. It remains difficult to recruit to as it requires BHOC to consent the patients prior to surgery and take a blood sample.

The FUTURE GB trial in NBT, which compares a new type of ultrasound imaging for resection of glioblastoma with standard imaging, is on hold due to the shortage of research nurses. This is the same for the PRIMROSE CSF trial for breast cancer metastases.

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

CAGs are being asked how they share information on the research trials that are open across the region with colleagues and patients. Some groups

regularly share a list of open trials and others have WhatsApp research groups.

The research slides from each CAG meeting are uploaded on to the SWAG website.

The Tessa Jowell Foundation keep an up to date accurate list of trials.

A website is 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/.

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 Clinical Research Networks (CRNs) are transitioning into Research Delivery Networks (RDNs) in October 2024. This is 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.

The RDN has appointed two Research Directors, Dr Helen Winter and Dr Patric Moore, and Helen Lewis-White as the Health and Care Research Director.

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:

Current research information systems do not allow teams to accurately see up to date lists of open trials across the UK filtered by specialty. It is hope that a better system will be made available when the transition has been completed as this is an unmet need.

5. Service developments

5.1 Development of non-pharmacological interventions for fatigue management in primary brain tumours

Please see the presentation uploaded on to the SWAG website

Presented by PhD Student Rachael Simms-Moore

Fatigue is a key debilitating symptom for patients with a primary brain tumour (PBT). The fatigue experienced can be physical, psychological and/or emotional and significantly reduces quality of life, limiting the ability to work, socialise or engage in activities.

Patients have expressed a preference for non-pharmacological interventions, but there are no standard options available.

To address this the PhD project has been divided into 5 key stages:

- Scoping review
- Patient and Healthcare Professional interviews
- Intervention co-design
- Proof of concept study
- Feasibility study.

Patient and public involvement is crucial throughout, and work has been undertaken with four patient research partners.

The next stage of the PhD is intervention co-design, which will focus on:

- Behavioural change
- Individual tailoring
- Holistic design
- Delivery methods.

Currently interviews are being analysed and a scoping review is being written to inform the intervention design stage. Further details on the interviews, thematic commonalities that have emerged, and the next stages of the project are documented in the presentation.

Discussion:

The first aim of the project is to understand/define fatigue in this patient group before developing an intervention strategy.

It has been incredibly difficult to recruit patients from ethnic minority groups.

The West of England Clinical Research Network is undertaking work with community groups to try and improve uptake in research, as has Cancer Alliance Early Diagnosis Manager Catherine Neck.

Feedback had been provided from a charity group that some cultures perceive being diagnosed with cancer as a form of punishment and therefore a shameful taboo subject. There is also some distrust associated with engaging in research that needs to be resolved.

Once an intervention has been developed, further attempts will be made to engage with ethnic minority groups, perhaps with assistance from the CRN/RDN.

Many cancer patients are diagnosed with depression following treatment, which may also contribute to fatigue. This will be considered as part of the research. Patients' needs are so multifactorial that the interventions developed will have to be tailored to the individual. Patients' ideas of success also vary widely.

Treatment of post-traumatic stress disorder (PTSD) also needs to be factored in as a contributor to fatigue.

5.2 South West Genomic Medicine Service Alliance (GMSA) update

Please see the presentation uploaded on to the SWAG website

Presented by Consultant Clinical Geneticist Ruth Cleaver and Genomic Healthcare Professional Sarah Haywood

When feasible, the BNOG aspire to consent all patients with brain tumours for Whole Genome Sequencing (WGS).

The South West Genomic Laboratory Hub (GLH) is made up of two partner laboratories, the Bristol Genetics laboratory at NBT and the Exeter Genomics laboratory at the RDUH.

The National Test Directory aims to offer equitable access to Genomics across England and all subtypes of brain tumour are included for WGS.
At present, it is an adjunct rather than a replacement for standard of care testing; turnaround time for WGS is approximately 3 months.

WGS involves submission of a fresh tumour sample with over 30% cellularity and less than 20% necrosis, which can be confirmed by pathology as appropriate to consent the patients. A blood sample is also required.

Once the pathway is underway, the GMSA would provide access to a Genomic Tumour Advisory Board (GTAB) to provide advice on how to interpret complex results. Clinical Geneticists and Scientists would attend along with members of the faculty.

Patients identified as having a germline mutation, which is extremely rare in brain tumours (1%) can be referred to Clinical Genetics for support and seen within 2-3 weeks of referral.

Support and resources are available from the GMSA team to ensure that the processes of what needs to happen, and by which time, are all mapped by working closely with the team to understand the patient pathway.

A website is available with information and links to training.

A brain tissue pathway has been developed and is documented in the presentation.

A more in depth stage by stage document is also available that details how to complete all of the forms.

Discussion:

Following the WGS meeting held last week, the documents have been downloaded by Brain CAG Chair Mr Iyer to clarify the practicalities.

The minimum tissue required for DNA extraction is 15mm x 2mm, which should be put in a universal container with saline soaked gauze.

Three forms then require completion and emailing to the GLH: one for WGS, a second one for germline testing, and a third record of discussion form with a signature of the patient and of the healthcare professional.

The first decision required is when the record of discussion takes place, as this could be done at the same time as the pre-operative discussion or later on in the pathway when the sample is known to be sufficient. It may be better prior to surgery, due to the potential for neurological deficit afterward.

The second decision is to define who analyses the results and relays these to the patient. Reassurance has been given that the majority of results will be normal, and the very small number of germline results will have support from genetics.

It would not be feasible for the BHOC team to arrange two new clinic appointments for the record of discussion and relaying the results due to capacity issues.

Consenting at the beginning would help but would need to be kept very simple and brief as it is difficult for patients to take on information after receiving their diagnosis, and it must be emphasised that it is unlikely to result in an actionable finding and additional treatment options.

The ambition to offer this with equity to all patients will result in a lot of extra work for the benefit of a small number of patients.

It is important to discuss and have formal consent about the potential for identification of germline variants as there is the potential for a BRAF or lynch syndrome variant to be identified that is not associated with their brain tumour, which may have consequences for family members.

The problem with consenting prior to surgery is that some of the tumour samples will not be suitable for DNA extraction and the patient will need to be informed that WGS was not achievable. It needs to be emphasised to patients upfront that a number of tumours will not be suitable to process.

As this is a new pathway, starting with gliomas prior to rolling out to all other tumours may be the most sensible approach. **AGREED**

It is possible to complete the record of discussion by telephone.

Sarcoma CAG consent patients in the next patient clinic after the biopsy has been confirmed as viable. This process is currently managed by one oncologist and is not feasible to achieve for all patients due to the workload this generates.

As patients often do not recall much information from the initial diagnostic clinic, it would be important to provide the information for review at a later date, which could ideally be sent electronically. Administrative support would be required for this to be achieved.

Patient Representative Andy Holness recommends repeating the discussion to re-confirm that this has been understood.

Although there is not an existing GTAB for brain, this can be established by the GMSA when required, to convene at a time in the week that is convenient for the BNOG team. BNOG MDT could be extended for this purpose.
NHS England are mandating roll out of the tests, which are all centrally funded. Extra funding to implement the pathway would need to be sourced from within the Trust.

Tessa Jowell Foundation accreditation is also reliant on implementing the pathway.

Cancer Alliance Clinical Director Helen Winter offers support from the Cancer Alliance to help implement the pathway.

It is anticipated that administrative support will be required.

Action: To raise the need for additional funding for administrative support from the Cancer Alliance / for further discussion with BNOG General Manager and MDT members to establish the WGS pathway.

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Details of the staff members to email with the WGS results can be entered on to the GMSA request form and brought back to the MDT.

6. Clinical Guidelines

6.1 Neuropathology update

Presented by Consultant Neuropathologist Jillian Davis

The pathology department has been going through a period of upheaval with staff shortages; 1.3 Whole Time Equivalent (WTE) Consultants are currently managing a 2.5 WTE workload.

A Clinical Fellow has been appointed to help with the day to day workload and an additional registrar is due to be appointed in August 2024. In October 2024, the situation is expected to improve, with two Consultants returning to post. However, there are also problems with staff shortages in the laboratory with several senior technicians moving on.

On a more positive note, a new Quality Manager was appointed in February 2024 who has achieved an exceptional amount in a short period and, despite the problems, the team have managed to maintain turnaround times.

New UKCAS accreditation standards have been released to which the department needs to comply by 2025. An initial transition assessment has been completed, and it is expected that this will be achieved, with the team receiving positive feedback.

The team will continue to get information on the genetic variations identified via DNA methylation.

It is hoped that the nanopore pilot, which is a relatively new technology that can be delivered alongside intra-operative assessments within 20 minutes, will commence in Winter 2024.

Digital pathology is in place and will help with networking locally and nationally for additional advice.

7. Patient experience

7.1 NBT activity update / Patient Experience Survey

Presented by Cancer Support Worker Garry Pearce

Over the past year, the service has registered referral of 222 patients from the BHOC, Cheltenham, and 8 from outside the normal catchment area. 87 patients have been referred on to the BHOC, 75 of which were high grade and 12 low grade. 34 high grade and 3 low grade were referred onwards to Cheltenham. 11 were referred on to other primary teams. An additional 33 patients were added to the surveillance list which now totals 144 patients on three monthly or 6 monthly follow up scans. All patients were offered a Brain Tumour Support referral.

All patients referred for surgery are sent a patient experience survey and 27 responses have been received to date. The majority of feedback was excellent. Two rated the service as good, and one rated the service as poor, which was related to a delayed referral to BNOG and not within the services control.

There was particular reference to the speed of the pathway.

Responses are expected to increase next year as the survey was paused temporarily this year.

Patients are given the option to complete the survey via paper or QR code and the only returns have been via the paper option.

Attempts have been made to provide the survey at different points in the pathway to improve return rates, and two weeks post operatively seems to be the optimal time. The surgical pathway is very quick and there is far less time to get responses than when the patient is on the oncological treatment pathway.

Responses compare favourably to numbers received via the National Cancer Patient Experience Survey (NCPES).

7.2 BHOC Patient Experience Survey

Results from the BHOC Patient Experience Survey which started on 3rd June 2024 have been shared. It was considered to be well designed with informative questions and had received 22 responses by 26th June 2024 which were all very positive.

7.3 What Matters to You?

Please see the presentation uploaded to the SWAG website

Presented by Andy Holness and Catherine Neck

A new strategy for Personalised Care and Support has been launched, with recognition of the work that has already been undertaken in this area.

A team has been recruited to include representatives from across all the Trusts. A launch day was held in July 2023 and a strategy on a page was produced and signed off by the Cancer Alliance Board. It has been possible to incorporate the 'What Matters to You' message into NBT's electronic patient records and the e-Holistic Needs Assessments developed by Macmillan, inspired by the Patient Representative Jo Chambers. Jo has since passed away but provided SWAG with a presentation on what mattered most to her during her cancer pathway.

The vision, mission, values and approach to the strategy are documented in the presentation.

The current pressures on the workforce are recognised and it is hoped that the strategy will help manage delivery of personalised care in the most efficient way possible while ensuring health inequalities are also addressed.

The key message is 'Your Cancer, Your Care, Your way'; 26 deliverables have been identified to support the strategy.

The first step will be to map out all of the work that is already being undertaken across the region to identify good practice to share and areas for improvements. For example, the Teenage and Young Adult service has developed a questionnaire with 'What Matters to You' questions that help the clinical team with their patients' needs.

Brain CAG were asked to consider how they might support implementation of the strategy.

Discussion:

Personalised care is felt to be routinely provided to patients with Brain and CNS cancer.

It will not be possible for all patients with Brain and CNS cancer to articulate what matters to them following surgery.

An example of incorporating 'What Matters to You' in conversations came from Jo Chambers, when a surgeon remembered to ask her how an exam went.

'What Matters to You' has also been incorporated in the UHBW strategy.

Resources are limited and emotional labour is intensive for healthcare workers. This is recognised, and the strategy will try to find ways to address this.

It is also recognised that by risk stratifying low risk follow up, all of the good news follow up has been stripped from services and only the complex follow up remains.

Date of next meeting: Wednesday 11th December 2024

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