

**Meeting of the SWAG Network Brain and Central Nervous System Site Specific Group (SSG)
Wednesday, 25th April 2018, 12:30-16:30
Spire Specialist Care Centre, 300 Park Avenue, Aztec West, Bristol, BS32 4SY**

Chair: Mr Venkat Iyer (VI)

NOTES

ACTIONS

(To be agreed at the next SSG Meeting)

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 15th November 2017, the notes were accepted.

Actions progress:

The list of open actions will be circulated after today's meeting.

HD

Living With and Beyond Cancer (LWBC): The National Cancer Transformation Board has notified the South West Cancer Alliance that Transformation Funding will be reduced to 75% for Quarters 1 and 2, due to the recent creation of a rule that links funding to 62 day Cancer Waiting Time (CWT) performance. Recruitment to Cancer Support Worker posts in North Bristol Trust has therefore been scaled back from 8.0 to 6.2 Whole Time Equivalents, also taking into consideration the recently proposed NHS staff pay award. Development of a patient information portal has had to be put on hold. Funding may be reduced again should there be a further decline in CWT 62 day performance.

LWBC activity is being measured for prostate, breast and colorectal cancer sites. This initiative (which involved implementation of the recovery package), will be made available for all cancer patients, with generic living well days being held as an alternative to site specific events.

Redesign of the local patient experience survey: Regular local patient experience surveys are required as there are usually insufficient responses to the national survey for a site specific Brain and CNS report to be published. The action to redesign the survey, after consultation with a patient focus group, will be revisited when a full complement of Clinical Nurse Specialists have been appointed; the team is currently in a process of transition.

Multi-disciplinary training event: As above – to be revisited.

Multi-disciplinary team (MDT) reforms: A meeting of the SWAG Cancer Clinical Leads will be held on Monday 16th July 2018, seeking to agree on a loco-regional approach to MDTM reform and to share best practice prior to meeting (on another occasion) Professor Martin Gore and the NHS England Clinical Policy Managers who are developing treatment algorithms to streamline MDT discussions (where appropriate). Results will be fed back at the next meeting.

VI/HD

Information on the impact of GP direct access to MRI from the Plymouth Team:

The introduction of GP direct access to MRI in Plymouth was not thought to have made a noticeable difference in workload to date; data on MRI referral rates has been requested.

National Institute for Health and Care Excellence (NICE) Guidelines for Brain Tumours (primary) and Brain Metastases in Adults: Consultant Oncologist Alison Cameron (AC), has contributed to the development of the guidelines, which are due to be published on Wednesday 11th July 2018, and will be asked to present the recommendations at an SSG meeting in the near future.

HD

Acute therapy service update: The number of pre-operative referrals to the new service continues to be lower than expected. This was thought to be due to the fast pace of treatment for those patients diagnosed with high grade tumours plus the transitions in both CNS and Occupational Therapy teams. CNS Sarah Levy (SL) will email the NBT team when any relevant patients are identified in Yeovil prior to their pre-operative appointments, and Neuro-rehabilitation Lead, Amy Belisario, will contact Administrator Garry Pearce for the list of new patients generated each week to try and increase uptake of the service.

SL

AB

Development of a Brain and CNS scan regional protocol: A Standard Operating Procedure (SOP), which details the minimum dataset required for magnetic resonance imaging (MRI) for patients suspected or diagnosed with a brain tumour, has been developed by Consultant Neuro-radiologist Marcus Bradley (MB) for ratification by the SSG. It is hoped that this will reduce variation in the sequences performed across the region and subsequently avoid delays to the patient pathway. It was agreed that the SOP will be circulated to the radiology departmental leads across the region.

MB/HD

3. Service Development

3.1 Genomic Medicine Centre (GMC) update

Please see the presentation uploaded on to the SWCN website

Presented by Catherine Carpenter-Clawson (CC-C)

The West of England GMC received their first results for cancer patients over the last 2 months. Many interesting results have been returned for patients in the rare disease arm of the project, which is closing to recruitment in the near future.

At a meeting in December 2017, an update was provided on national recruitment to date as documented in the presentation. The recruitment of cancer patients is currently under target due to the complexities involved in processing fresh tissue.

Ultimately, the aim would be to open the pathway in all hospital sites for each disease type.

National results have shown that 65% of cases processed to date have gene variations with actionable significance.

A process of reprocurement commenced in December 2017 aiming to establish seven nationally commissioned Genetic Laboratory Hubs (GLH) by October 2018, when it is planned to transition whole genome testing from a project to standard care in the next 5-10 years.

A tailored directory of molecular markers that can be used to inform diagnosis, prognosis, and treatment decisions, will be developed and opportunities for clinical trials will be explored. Areas where further evidence on whole gene sequencing is required will be identified and patients consented accordingly.

It is hoped to reduce the turnaround time for results to 20 days. Online training is available; for more information on this and any other queries, please contact CC-C: 07732 561067, Ubh-tr.wegmc@nhs.net.

Recruitment to the project will remain open until September; six patients with brain cancer have been recruited to date. Funding to process samples for paediatric patients with medulloblastoma and some specific adult brain tumours (to be clarified) will continue after this date.

Data from the project will be accessible for academic purposes in the future.

The possibility for patients to have access to an electronic copy of their genome will be explored.

CC-C

Despite the reduced CNS service and the complex consenting process, 2 patients have been recruited in the past month.

4. Research

4.1 Clinical trials update

Please see the presentation uploaded on to the SWCN website

Presented by David Rea (DR)

Recruitment figures (sourced from EDGE), open trials, and trials in set up are documented within the presentation. The national recruitment target for Brain & CNS cancer is currently just 0.2 per 100,000 of the population served due to the sparse national portfolio. Brain and CNS recruitment in the region was the highest in comparison with the other 15 networks for 2017/18, totalling 72 participants over 8 studies.

Recruitment to time and target for cancer studies has improved from 17% 18 months ago to 73% to date, which will result in an increase in income to the network from the

National Institute for Health Research (NIHR).

Principal Investigators will be invited to use the research section of the SSG meetings to launch new trials. Information on open trials and those in set-up will be added to the SWCN website.

DR/HD

5. Patient experience

5.1 Charity involvement

Brainstrust: In response to results from a patient experience workshop, which generated 80 questions relating to the patient pathway (42 of which were related to quality of life), Brainstrust are working in collaboration with Public Health England (PHE) to create a data dashboard, due to be launched in the second week of May 2018. This will be available in the public domain for the purpose of providing patients with greater insight into their condition and treatment. For example, it could help manage people's expectations about the number of chemotherapy cycles that are typically tolerated.

Data would only be published if there is sufficient information for it to be considered anonymous.

The group are invited to request data fields that would be considered helpful for inclusion in the dashboard; a link to the dashboard will be circulated and an update on the data will be given at the next meeting.

HB

The clinical team have made several attempts to try to access regional patient data from PHE for the purpose of regional audits; these are still continuing. Helen Bulbeck (HB) will investigate the feasibility of facilitating such requests.

HB

Brain Tumour Support (BTS): An overview of the year's achievements, published in the BTS Annual Report, was circulated, and the new Brain Tumour Support Worker for Somerset, Sarah Erskine, who has replaced Amanda Love, was introduced. An additional Support Worker for the Bath region is due to be recruited in the near future. It is hoped that both post holders can work closely with Trust based Cancer Support Workers to avoid duplication of work.

Details on the next Patient and Family Weekend, due to be held in March 2019, will be circulated in the near future and will include a request for guest speakers from the team.

The collaborative work with Bristol Haematology Oncology Cancer Information Centre, which involves the CNS team asking for patients' consent to pass on their contact details to BTS to offer their service, is working well. A cohort of patients has been identified that have not traditionally been provided with support from the charity, due to the progressive nature of their disease; the majority of patients are usually offered support at the end of acute treatment. Referral processes will be reviewed to ensure that support can be offered nearer to the point of diagnosis for these patients, where deemed appropriate by the CNS team.

RW/CNS
Team

The Brain Tumour Charity (BTC):

The Annual BTC Conference will be held on September 19th 2018 at the University of Birmingham. Over 130 attendees are expected. The theme of the conference is *Difficult Conversations within the Neuro-Onc world*; there will be 3 symposiums plus a panel of experts and three symposiums. Access on line by typing *The Brain Tumour Charity Nurses & Allied Health Professionals Conference* into [Eventbrite](#). Early Bird tickets are available at a cost of £30.00, and Year 3 Nursing and AHP students due to qualify in September 2018 or Spring 2019 are invited to attend at a cost of £18.00.

6. Quality indicators, audits and data collection

6.1 Brain tumour patient reported outcome project

Please see the presentation uploaded on to the SWCN website

Presented by Helen Spear (HS)

Consultant Neurosurgeon Neil Barua (NB) has commenced a pilot neuro-oncology specific Patient Reported Outcome Measures (PROMs) project from the neurosurgical perspective. Three priorities for assessment were identified after consultation with a patient support group: family, friends and work. A questionnaire has subsequently been developed, limited to 2 sides of A4 as recommended by the patient group, the results from which will be reviewed in 6 months to ensure that the process can appropriately assess the needs of the neuro-oncology population; an update will be given at an SSG meeting in the near future.

NB

6.2 Brain and CNS presentation audit

Caldicott Guardian permission has been granted from University Hospitals Bristol NHS Foundation Trust to allow data to be obtained from the Public Health Office for Data Release (ODR) for the regional presentation audit of Brain and CNS patients, first proposed in November 2016. An application was then submitted to the ODR for data from 1st January 2013-31st December 2017 from the following data dictionaries:

- Hospital Episode Statistics
- National Cancer Registry
- Systemic Anti-Cancer Therapy Dataset
- Radiotherapy Dataset
- Cancer Waiting Times Dataset.

Feedback from the application has confirmed that further information is required, including a clinical audit protocol and Caldicott Guardian permission from each Trust within the region. Work on a draft protocol has commenced which will include Venkat Iyer, Christopher Herbert, Marcus Bradley and Samuel Wadham as named investigators.

Assistance from a statistician will be sought to complete the analysis plan prior to distributing copies to the investigators for their opinions.

HD

7. Review of MDT changes/service

7.1 RUH Bath and regional service update

Consultant Oncologist Samir Guglani (SG) from Cheltenham Hospital hopes to be systematically engaged in the neuro-oncology MDT when staff shortages are resolved in March 2019; no locum cover is available in the interim. It may be possible to attend via Webex if this is reinstated in NBT.

Discussions are underway with Specialist Commissioners on the closure of the primary Brain and CNS service in RUH Bath due to a shortage of Consultant Oncologists; recent attempts to appoint to the posts have been unsuccessful.

35 new patients were managed by RUH last year, and there will be a considerable number of follow up patients requiring ongoing management.

The team in Cheltenham and Consultant Oncologist Christopher Herbert (CH) from the Bristol Haematology Oncology Centre are willing to take on the RUH work as long as it is resourced appropriately, but it is not possible to undertake the work immediately due to staffing shortages in both services. There was some concern that the RUH service could suddenly stop before a plan was in place; this will be recorded on the SSG Risk Register. It was noted that notice to terminate a service was usually at least 3 months.

Venkat Iyer, Sam Guglani and Christopher Herbert will arrange a preliminary meeting to discuss a potential systematic work-up and plan of action which will be shared with their associate management teams.

HD

When considering management of the workload, it was recognised that patient choice could influence how this would be split between the centres.

VI

8. Coordination of patient care pathways

8.1 North Bristol Trust Skull Base Quality Surveillance (Peer Review) visit

The most recent Quality Surveillance Self Declaration had triggered a visit from NHS England Quality Surveillance team. A formal written report of the visit is pending, but verbal feedback on the day of the visit was mostly very positive. No immediate risks were identified. One serious concern on the provision of nerve monitors in Theatres has already been addressed, and the team is in the process of deciding the ideal specification for 2 additional microscopes.

There was positive feedback on the quality of the MDTs proactive approach.

Concern was raised that the Clinical Guidelines had not been signed off at a network level. These were currently saved as a draft on the website.

A need for continuity of care between Trusts was also noted.

The Skull Base service had been underrepresented at the SSG for many years; it was

also necessary to identify a relevant patient representative to attend. This will be formally fed back to the MDT. The full Quality Surveillance report and action plan will be presented at the next meeting.

**Skull Base
MDT
members**

8.2 St Peter's Hospice/Palliative Care Services

Please see the presentation uploaded on to the SWCN website

Presented by Liz Attwood

St Peter's Hospice (SPH) services focus on optimising quality of life, improving symptoms, helping people adjust to their diagnosis and prepare for the future. The service is available to the population in the Bristol North Somerset South Gloucestershire region and some of the area covered by Bath and North East Somerset, covering geography of 500 square miles with a population of over 900,000; 80% of referrals have a cancer diagnosis.

The service includes the following:

- Access to a multi-disciplinary clinical advice team, who triage patients within 1-2 days
- Provision of assessment, support and advice from the CNS team at home
- Complex assessment and clinical management medical team
- Hospice at home, where the CNS team are in residence for end of life, respite and family support
- Inpatient unit (currently based in Keynsham Chocolate Quarter while being rebuilt in Brentry) for short term assessment and complex assessment of holistic needs.

Day services include a 12 week programme on managing fatigue and breathlessness (for lung cancer and non-malignant fatigue), psychological therapies, bereavement support, social work, complementary therapies, and occupational and physical therapy.

The large group of Hospice volunteers play a vital role in supporting the clinical teams.

Referrals are made by primary or secondary care and are contacted to see if the patient is at the point where they want assistance and meet the relevant criteria, and the referral urgency can be assessed. Most referrals receive ongoing care from the CNS team, although some are discharged. Continued bereavement support is offered to family members. This is just part of the story of the service, with many other interrelated meetings and interactions. 80% of the service is funded by the Charity and 20% of funding (which has recently been reduced) is funded by the CCG.

9. Any other business

Referral criteria for the Complex Cancer Late Effects Rehabilitation Service (CCLERS) and the Macmillan Fatigue Service in RUH Bath will be circulated.

Dates of next meeting: To be confirmed

-END-

DRAFT