



Meeting of the SWAG Network Brain and Central Nervous System Site Specific Group (SSG)
Wednesday, 14th November 2018, 12:30-17:00
Spire Specialist Care Centre, 300 Park Avenue, Aztec West, Bristol, BS32 4SY

Chair: Mr Venkat Iyer (VI)

NOTES
(To be agreed at the next SSG 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 25th April 2018, the notes were accepted.

Actions progress:

Patient experience survey: The survey has been delayed due to recent service and staff changes. Now that staffing levels have returned to normal and there is additional administrative support, it will be distributed to all patients after surgery and the data will be reviewed at the next meeting.

NBT CNS
Team

It is hoped that a separate survey can be completed for the patients receiving treatment at the BHOC.

Standard wording for palliative patients on MDT outcomes: Following liaison with a Consultant for Palliative Medicine, standard wording has now been developed for recording palliative MDT outcomes. This includes a link to further information on the Macmillan website.

Buddying systems for patients: Development of a buddying system for patients is on the agenda of the Brain Tumour Support charity for the coming year.

Gloucestershire team attendance: Apologies have been sent from the Gloucestershire team. New team members need to be added to the distribution list.

HD

Acute therapy service: Prehabilitation referral numbers are still relatively low due to the quick turnaround time to first treatment. Data collection on those patients who have been referred should be continued to assess how the process can help with the organisation of required aides post-surgery. It is not clear how to fund the service at present, as physiotherapy funding is linked to inpatient activity, and management are reluctant for this to be reviewed due to the current pressures on delivering rehabilitation.

It may be possible to screen patients by using validated telephone screening tools and getting a tariff for the activity. Electronic Holistic Needs Assessments could be modified for this purpose. It would be ideal if 2 hours per week could be allocated to provide the service with 1 Allied Health Professional (AHP) completing the assessment on behalf of the others. Macmillan could be approached to see if funding such a service may be of interest. The new Macmillan Physiotherapist Jane Masters will be contacted for her opinion.

3. Clinical guidelines

3.1 NICE Guidance: Brain tumours (primary) and brain metastases in adults

Please see the presentation uploaded on to the SWCN website

Presented by Venkat Iyer

The NICE guidance, published in July 2018, had been reviewed to identify areas for potential service developments.

Investigation of suspected glioma: NBT Service is in line with guidance apart from testing IDH-wildtype glioma specimens for TERT promoter mutations to inform prognosis; this is something to aspire to in the future.

Management of glioma: NBT Service is in line with guidance, although some incidental findings of a low grade glioma would be monitored rather than surgically resected in asymptomatic patients.

Treatment of low grade glioma with radiotherapy and 6 cycles of PCV for patients over 40 or with residual tumour was recommended; it was recognised that this should not be seen as a specific rule but should be given due consideration.

Management of Grade III Glioma: Systemic treatment of anaplastic glioma has been informed by the results of the CATNON trial.

Management of Grade IV Glioma: Treatment with radiotherapy and adjuvant temozolomide remains the same; a lower dose is recommended for patients over 70, or best supportive care if performance status is poor.

Treatment with bevacizumab and tumour treating fields is no longer recommended for new or recurrent glioma.

Results from the OPTUNE trial had shown a 3-4 month survival benefit for primary glioblastomas, but it was probably not considered a cost effective treatment; the effect on quality of life associated with having to wear electrodes and carry the medical device for 18 hours a day had not been measured as part of the trial.

Techniques for resection of glioma: The recommendation to offer 5-aminolevulinic acid (5-ALA)-guided resection as an adjunct to maximise resection at initial surgery will be implemented. A pilot study of the technique will be considered.

Follow up: A baseline MRI within 72 hours of surgical resection and 3 months after completion of radiotherapy is recommended. The standardised follow up schedules in the guidance were considered beneficial and straight forward.

4. Clinical opinion on network issues

4.1 Clinical Leads' meeting and MDT reforms

Please see the presentation uploaded on to the SWCN website

Presented by Venkat Iyer

Following review of the Cancer Research UK MDT Effectiveness Report by each SSG, and Professor Martin Gore's appointment by the National Cancer Transformation Board to reform MDTM working arrangements across the UK, an inaugural meeting of the SWAG Cancer Clinical Leads was held on Monday 16th July 2018 to define a loco-regional approach to MDT meeting reforms.

A presentation from Cognitive Scientist Tayana Soukup Acencao gave details of 3 tools that can be used to improve MDT streamlining. The presentation will be circulated and SSG members will be contacted to see who may be interested in attending a training day on use of the tools. People receiving the training would have to review at least 1 alternative MDT.

HD

It was recommended that a 10 minute break should be introduced in meetings after a period of 1 hour of discussion, or after 20 patient discussions, to prevent cognitive fatigue and the negative effect that this can have on the quality of decision making. It was also recommended that MDT Chairs visit alternative MDT meetings (contact Helen Dunderdale to discuss funding) to compare styles. In addition, it is planned to address the varied quality of triage systems by the development of online referral proformas with mandatory fields like the Bristol Neuro-Oncology Group form. Additional recommendations are detailed within the presentation. The group will meet again in approximately 6 months to discuss progress.

SWAG Breast and Colorectal MDTs are participating in an MDT streamlining pilot. Information is being collected on the length of time taken for patient discussions prior to implementing pre-determined standards of care for patients who meet certain criteria.

Consultant Neuro-radiologist Marcus Bradley is investigating methods to streamline image importing processes.

The need to promote equal contributions from MDT members was emphasised, especially to ensure that the people who have met the patients are able to communicate patient preferences.

4.2 Neuro-oncology study day

A study day on brain tumours for non-neuro-oncology clinicians will be held on Monday 11th March 2019 at the Spire, Aztec West. This will include a variety of talks on management of symptoms and side effects post discharge from hospital care, including a video that has been produced to guide people through the patient experience. It is hoped that General Practitioners (GPs) will attend as queries are often received on how to manage these patients in the community; information on the day will be disseminated via the regional Macmillan GPs. An application for Continued Professional Development accreditation will be made.

4.3 SWAG Cancer Alliance update

Please see the presentation uploaded on to the SWCN website

Presented by Amelia Randle (AR)

Cancer Alliances (CA) were set up across the country 18 months ago (Somerset, Wiltshire, Avon and Gloucestershire cancer services in this region) to deliver the following ambitions defined by the National Cancer Taskforce until at least 2020: Prevention, Early Diagnosis, High quality Cancer Services, Living With and Beyond Cancer.

Prevention sits under the general remit of Public Health England but, for cancer, the CA are identifying teachable opportunities where education on preventative behaviour can be encouraged. This has been called 'making every contact count'.

For early diagnosis, the CA was invited to submit bids for transformation funding for specific projects. The cancer sites with the highest incidence and poor survival outcomes were prioritised, and bids were successful for implementing the diagnostic phase of the National Optimal Lung Cancer Pathway, and Faecal Immunochemistry Testing for colorectal cancer. The CA has since been instructed by the National Board to improve 62 day performance to ensure continued funding of the projects.

The Brain and CNS service did not tend to breach cancer waiting times. Grade III and IV gliomas are tracked only. A new 28 day faster diagnosis standard is due to be introduced in April 2019, aiming to be compliant with the standard by April 2020. This will involve collecting an extra dataset on all patients referred via the Two Week Wait or screening pathway to confirm when and how a patient is told if they have been cleared or diagnosed with cancer. It is hoped that a method can be found that will not create additional work for the MDT coordinator.

The other priorities for the CA are to help streamline multidisciplinary team meetings, implement the new national radiotherapy service specification (the service for Brain and CNS cancer in RUH Bath is vulnerable due to the required number of patients in the draft specification), and form a radiotherapy network to standardise care, develop an Alliance workforce plan for key cancer professionals, and integrate the new Genomics service into existing pathways.

The lack of oncologists was recognised as a major workforce issue.

Transformation funding has also been given to implement the Living With and Beyond Cancer (LWBC) Recovery Package initiative, by employing Cancer Support Workers and additional AHPs to assist CNS teams.

As the clinical arm of the Cancer Alliance, the site specific groups are invited to propose ideas for using core funding for service improvements.

BNOG would like to offer GPs direct access to diagnostic scans as part of the two week wait pathway This has been discussed and agreed by the SSG a couple of years ago. How the Cancer Alliance might help with moving this forward will be explored.

5. Living with and Beyond Cancer (LWBC)

AR

5.1 Adapt, Adjust and Plan pilot event

Please see the presentation uploaded on to the SWCN website

Presented by Carol Chapman

A 'next steps' day for patients with a poor prognosis has been recognised as an area of unmet need. A project to set up such events has been underway in UH Bristol over the past year. The first pilot event will be held on Monday 4th February 2019 in the Education and Research Centre, University Hospitals Bristol NHS Foundation Trust. Clinical Nurse Specialists can refer both male and female patients treated in UH Bristol who have a prognosis of between 6-36 months.

It will have a similar format to the 'Living Well' events, with practical talks from a poor prognosis perspective on managing fatigue, finances, advanced care planning and Will writing. There will also be one to one breakout sessions for 10-15 minutes with a CNS, and the opportunity for follow up phone calls.

Feedback from the patients attending this event will be used to evaluate the format of future events and will be reviewed at the next meeting.

It is hoped that the event can be extended to patients across the Alliance on a regular basis once funding and an appropriate venue have been secured.

6. Patient experience

6.1 National Cancer Patient Experience Survey (NCPES) Results 2017

Please see the presentation uploaded on to the SWCN website

Presented by Carol Chapman

The cohort of patients who responded to the survey includes all who attended hospital as an inpatient or outpatient with a cancer related condition between April and June 2017. SWAG results compared with the national average are documented within the presentation. It was not possible for Brain and CNS specific results to be published due to the number of responses being less than 20. NBT's results had remained stable and

UH Bristol had improved. The region did well with the provision of a named clinical nurse specialist who would support them through treatment. Patient experience for Brain and CNS Cancer was normally ranked as one of the worst, but had greatly improved this year.

6.2 Patient representative input

Please see the presentation uploaded on to the SWCN website

Presented by Carly Monnery (CM)

Background: A seizure in September 2017 led to a patient's private consultation with a neurologist in Bath, who initially thought that it could be due to fatigue. Results of a scan showed a low grade glioma resulting in referral to the BNOG team in October 2017 where the treatment options of surgery or active monitoring were offered. After considering this for a couple of weeks, it was decided to opt for surgery, and an awake craniotomy was performed in January 2018.

Recovery was rapid and the patient experience was overall positive.

What went well: The process from the initial consultant, being fully informed with all relevant support, reassurance and information given by the BNOG team, and appointments being booked according to expectations. There was room to ask questions and bring family along to do the same. The pre and post-operative consultations with speech and language therapists (SLT), occupational health (OT) and the anaesthetist were structured very well and gave confidence prior to surgery. It was also very helpful to speak with previous patients who had gone through the same surgery, which helped with decision making. CM would be happy to be asked to do this for future patients.

What could have gone better: It had been difficult to identify areas for improvements due to the positive experience, but after some thought, it was felt it would be helpful if pre-operative appointments could be booked together on the same day to reduce the burden of travel, especially as patients are restricted from driving. The feedback given to relatives and friends post-surgery should ideally be quick to reduce their anxiety; relatives had waited for 2 days before they knew that the surgery had been a success. There was a long wait (3-4 months) for post-operative appointments in the local area (SLT/OT) after discharge from Southmead Hospital. The decision making to opt for further oncological treatment was hampered by the awareness that the service was under pressure with reduced capacity, leading to long appointment waiting times, the quantity of information that has to be processed on side effects and other pros and cons. Also the age of the data used to help inform decision making was about 20 years old and it was unclear if it was still relevant. After a period of confusion and a lot of personal research, a decision not to have further treatment at this stage was made, and this was felt to be fully supported by the team.

The BNOG service had been running with a reduced CNS team over the last 18 months. Now that a full team was in post, improving patient experience initiatives can be undertaken. It was recognised that treatment options were more complex for lower grade tumours due to increased choice.

CM has taken part in producing a patient experience video for the neuro-oncology study day.

6.3 Patient Reported Outcome Measures (PROMS) project

Please see the presentation uploaded on to the SWCN website

Presented by Neil Barua (NB)

A surgical specific PROMS tool needs to be validated to identify where interventions are required to ensure optimal disease free survival. The BNOG team have trialled 2 existing PROMS to date: NeuroQoLs and FACT-Br. These have been reviewed by the Brain Tumour support group and the following feedback now needs to be considered:

- The 3 main categories of patient priority are family, friends and work
- PROMS needs to be short – 2 pages max – FACT-Br will be adapted as was considered more manageable
- Optimal timing post-op is difficult (particularly for high grade patients) repeated measures would be advisable
- Risk of overloading patients with paperwork
- Patients do not see surgical episode as separate from oncological treatment
- Technology could be used to improve accessibility, but people who don't have access must have an alternative way to access PROMS
- Different tools may be required for low grade and high grade.

6.4 Charity involvement updates

NB

Brain Tumour Support (BTS): An additional Support Worker has been appointed to cover Somerset, freeing up capacity for a support group to be set up in the Bath area. The next BTS Patient and Family Weekend Event will be held from Friday 22nd to Sunday 24th March at Whittlebury Hall Hotel and Spa, near Silverstone. CNS Bea Coghlan and 1 or 2 other colleagues are coming along to support this event, which the team will encourage patients to attend; the last event received very positive feedback. The most recent Annual Report is available. Collaborative working with the CNS team on making referrals to the charity had stalled due to recent staff shortages and will recommence now that the posts have been filled.

Brain Tumour Charity (BTC): Funding has been made available for 10 low grade CNS posts; 4 have been appointed to date. Any hospital that can prove a need for posts can contact BTC for the eligibility criteria. The process from applying to appointing is envisaged to take 6 months. A memorandum of understanding that the Trust will continue funding the posts after the initial period of funding by BTC will be required.

A project to compare and contrast brain tumour pathways across the region, looking at a dataset going back 10 years, is currently underway.

The branding of the charity is being updated.

7. Quality indicators, audits and data collection



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

7.1 Public Health England Quality Dashboard

Please see the presentation uploaded on to the SWCN website

Presented by Jodie Eveleigh

A Brain Tumour Data Dashboard containing the most up to date data from Public Health England is available to view on the BrainsTrust website [here](#).

7.2 Cancer Stats website

The Cancer Outcomes and Services Dataset (COSD) entered into the Somerset Cancer Register within the MDT and submitted to the National Cancer Registration and Analysis Team on a monthly basis, is available to view on NHS computers by registering on the Cancer Stats website: <https://cancerstats.ndrs.nhs.uk/cosd13/alliance>

Data completeness sent from Trusts can be viewed by selecting 'Level 2' from the COSD drop down menu. The dataset can then be filtered by tumour group, Trust and year to look at the monthly submissions in detail.

The registration team add missing information to the dataset by accessing a variety of information systems, including pathology, radiology, systemic anti-cancer therapy, cancer waiting times etc. Ideally the dataset would be completed in full prior to submission. This more complete dataset can be viewed by selecting 'Level 3' from the COSD drop down menu, filtered as above, and compared with other Trusts. The most recent data available to date is Quarters 1 and 2 for 2017.

Requests for a more complex analysis of the data can be sent to the analytical team: NCRAEnquiries@phe.gov.uk

Date of next meeting: Wednesday 3rd April 2019

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