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

Meeting of the Head and Neck Site Specific Group

Tuesday 13th March 2018, 08:30-13:30, The Conference Room, Trust Headquarters, Bristol Royal Infirmary, BS2 8HW

Chair: Mr Ceri Hughes (CH)

	NOTES	ACTIONS

1. Welcome and apologies

Please see the separate list of attendees and apologies uploaded on to the South West Clinical Network website here.

2. Review of last meeting's notes and actions

As there were no amendments or comments following distribution of the notes from the meeting on Tuesday 12th September 2017, the notes were accepted.

3. Quality indicators, audits and data collection

3.1 British Association of Head and Neck Oncologists (BAHNO) Surveillance Audit (2018)

Please see the presentation uploaded on to the SWCN website

Presented by Joseph Sinnott (JS)

BAHNO has invited UK head and neck cancer centres to participate in a national audit to examine follow-up practices. This will be used to develop a research programme to improve current practice. It includes all consultations for the surveillance of treatment-completed head and neck cancer, excluding primary thyroid malignancy.

Permission to undertake the audit has been granted by the relevant Caldicott Guardians and a 2 week retrospective audit of practice has already been completed. The next stage, which is a 4 week prospective audit, is due to commence on Monday 16th April 2018 until Friday 11th May 2018. It is hoped that as much data as possible can be gathered from each team by completion of a simple audit proforma, which will be made available in the notes of those patient notes who are attending follow up clinics. No patient, consultant or individual unit will be identifiable from the data, which will be scanned and uploaded for analysis to a central database.

JS will liaise with MDT Coordinator Zoe Robinson (ZR) to obtain the schedule of all follow up clinics for patients treated with curative intent, including those managed by the Clinical Nurse Specialists (CNSs) and Oncologists. If there are any queries or registrars interested in assisting with the audit, please contact JS: Joseph.Sinnott@UHBristol.nhs.uk or Ram Balakumar in RUH Bath. **JS**

The complete guidelines for the audit will be circulated. **HD**

3.2 Head and Neck National Audit (HANA) update

When the Data for Head and Neck Oncology (DAHNO) audit was replaced with HANA, BAHNO agreed to provide day to day support for running the audit in terms of governance and accountability; this offer has now been withdrawn and, although BAHNO continues to encourage members to continue to collect data on Head and Neck patients, the HANA dataset is no longer mandatory. Data collection for the Cancer Outcomes Services Dataset (COSD) and other key data items will continue to be collected by ZR.

Cancer Manager Hannah Marder (HM) and CH will write to the HANA to establish if/when any outputs from the dataset sent to date might be produced and ask for an update on the future of the audit platform. **HM/CH**

4. Clinical opinion on network issues

4.1 Sentinel Lymph Node Biopsy (SLNB) / MDT Service

A business case for running a SLNB service in UH Bristol has been produced and reviewed by Trust managers; it would involve purchase of specific equipment and is now being considered by the Clinical Commissioning Group. Over the past year, node detection techniques have advanced, with the gynaecology surgeons now using the fluorescent marker indocyanine green as an alternative to the nuclear marker; a case using the technique will be observed by the Max Fax surgeons in the near future. CH will attend the 8th International Symposium on Sentinel Node Biopsy in Head and Neck Cancer Consensus Conference on 20th April 2018 for further information. **CH**

4.2 Radiologically Inserted Gastrostomy (RIG) service

Consultant Radiologist Huw Roach (HR) has been designated to provide the RIG service at UH Bristol after 10 supervised cases have been undertaken in RUH Bath. There are approximately 2-3 cases per month and, with 3 undertaken to date, it is estimated that the service will be able to take referrals in late summer; the equipment required has already been procured.

Recently, numerous delays to patient treatment pathways have been caused by the cancellation of Percutaneous Endoscopic Gastrostomy (PEG) insertions; it may be that waiting list managers did not recognise that the procedure related to the cancer pathway. It is hoped that a new system to flag these and RIG procedures as urgent can be put in place. The RUH Bath team have developed a robust protocol for management of these patients which, over time, has become a highly efficient service; this will be shared with the Bristol team along with any associated data on patient numbers and length of stay. **RUH team**

5. Patient experience

5.1 Complex Cancer Late Effects Rehabilitation Service (CCLERS)

The Complex Cancer Late Effects Rehabilitation Service (CCLERS) is a new national specialist rehabilitation service for people experiencing unresolved persistent

pain, and reduced physical function, due to the consequences of treatment for cancer of any tumour site. CCLERS is funded by NHS England and managed by RUH.

Referral criteria:

- Unresolved persistent pain and reduced physical function due to the consequences of treatment for cancer (any tumour site)
- Already seen by local pain and rehabilitation services (i.e primary/ secondary physiotherapy services) without improvement and/or deterioration in symptoms
- Considered complex/highly complex by local/regional services due to physical and/or psychological needs
- Completed cancer treatment > 12 months ago (excluding hormone therapy).

An information leaflet with the contact details for referrals to the service will be circulated. The service providers will be invited to give a presentation at the next meeting. **HD**

It was noted that this was a separate service from the fatigue clinic in the RUH.

5.2 CNS Medway Clinical Notes and CNS update

An electronic system has been and will continue to be developed by the CNS team in UH Bristol with assistance from IM&T, to record the CNS notes in real time on Medway as an alternative to the previous system of continuation sheets in paper records.

The notes were accessible to all relevant team members via the home tab (house symbol) on individual patient records, where they can see the latest contact and advice given, and access the most relevant contact details for patients. The records for clinics have a red symbol, and the records for communications have a green symbol; they are automatically ordered chronologically with the most recent at the top. Emails sent can be cut and pasted directly into the system. Multiple checklists have also been built within it for pre, peri, post treatment and palliative care. It will be possible to upload wound photos at some point and the data entered can be exported into Evolve and other hospital information systems.

It is not possible for the systems to be accessed across RUH and UH Bristol; there was no overarching system to manage datasets in the NHS and this solution was a step in the paper-light direction that was working well for the CNS team. A similar solution was also working well in RUH, where all information could be viewed on one screen.

It was recommended that the CNS team consider using dictation systems to minimise administrative time, and speak with IT about the possibility for systems to be made accessible between Trusts. **CNS teams**

6. Clinical guidelines

6.1 TNM Eighth (TNM8) Edition for Head and Neck Cancer

Please see the presentation uploaded on to the SWCN website

Presented by Miranda Pring (MP)

The new stage classifications, published in December 2017, sub-categorises staging of head and neck cancer. This initial review will focus on the following changes:

- HPV +ve oropharyngeal malignancy
- Modification of T for Oral Squamous Cell Carcinoma (SCC)
- Modification of N category and sub-classification into 'non-viral' and viral related head and neck cancers and CUP.

The Oral SCC stage now looks at depth of invasion as a prognosis indicator.

Clinical N stage versus Pathological for Oral SCC (applies also to other non-viral) takes into account involvement of extra-nodal extension (ENE) as a prognostic indicator.

TNM8 mandates p16 IHC in decision making rather than ISH; the majority of laboratories have access to p16, which is inexpensive and easy to interpret.

There are 2 different staging systems for clinical and pathological staging; the clinical staging is divided into the blue sections within the presentation.

Removal of the pT4b stage could make a significant psychological difference to a patient when informing them of the extent of their disease.

For cancers of unknown primary, there must be histological confirmation of SCC in a lymph node, with a core biopsy being prioritised; cytology should also be sent.

It was noted that treatment had affected the nuances of staging, aligning with prognosis for the first time. Please consult the presentation for further details.

In general, patients are informed of the classification of disease, but are not routinely informed of the stage; this was considered complex information to explain and absorb at the time of diagnosis. The user representative members felt that the amount of information given would vary according to the needs of the individual; knowing the area and size of disease area would for the most part suffice, but some patients would want to know every detail.

Clinical decision making would not be changed by the new guidelines and it was agreed that the TNM8 dataset will be adopted from the 1st April 2018. The Somerset Cancer Register had been adapted to enable the appropriate data entry; datasets from the Royal College of Pathology were not available at present. A sentence on TMN7 will continue to be reported over the next couple of years to assist with its interpretation and to satisfy reporting requirements of existing

Agreed

research trials.

A free Apple mobile application for TNM8 is available. **Application to download**

6.2 Case discussions

1) A recurrent pleomorphic adenocarcinoma previously treated with radiotherapy and surgery that progressed during a further course of radiotherapy was given a further boost, resulting in a breakdown of tissue and osteonecrosis. After intensive wound management, it was repaired with a Pectoralis Major flap which failed after one week. Further procedures have now been declined. The area continues to be managed with wound dressings. Learning points: in light of the recurrent nature of the disease and associated comorbidities, the treatment decision were not considered controversial; the risks associated with re-irradiating an irradiated patient and extensive flap surgery over an irradiated recipient bed were recognised. The potential role of hyperbaric oxygen therapy in such cases will be discussed once the results of a related research study have been reported.

2) Carotid artery injury related to radiotherapy: treatment was not considered controversial. The resulting injury was an unusual occurrence but a well-recognised side effect.

7. Coordination of patient care pathways

7.1 Yeovil District Hospital (YDH) MDT referrals

Thyroid patients can be referred from YDH for treatment by the Bristol Team if the patient chooses to travel for all of their treatment in the Bristol area. Patients should otherwise be managed by Mr Richard Wight in the Poole MDT.

7.2 Follow up safety net system

For discussion at a future SSG meeting. **HD**

8. Living With and Beyond Cancer (LWBC)

8.1 LWBC transformation funding

Please see the presentation uploaded on to the SWCN website

Presented by Catherine Neck (CN)

The National Cancer Transformation Board has awarded transformation funding for two years to the South West Cancer Alliances (CA), to increase roll out of the Recovery Package. Funding will be used to recruit Cancer Support Workers to assist with delivery of Holistic Needs Assessments (HNAs) and Health and Wellbeing activity, development of a Digital Patient Information Portal and of the Somerset Cancer Register (SCR)/Infoflex to support data collection, implementation of a psychological training programme for all relevant MDT members, improvements in quality for primary care support, and enhancement of cancer rehabilitation services.

The Clinical Lead for the LWBC working group is Dr Dorothy Goddard. Further details on the governance of the project and structure of the Cancer Alliance are documented within the presentation.

The LWBC working group has been instructed to implement risk stratified follow up pathways for breast, colorectal and prostate cancer, but the scope has not been limited to these cancer sites and work is already underway on the thyroid pathway.

Cancer Treatment Summary Templates are being developed at the request of General Practitioners due to their need to keep up to date on the evolving requirements of cancer treatments. Drafts will be circulated for comment. **CN/HD**

Changes have already been made to the SCR to incorporate the HNA and some of the other metrics. It is hoped that the SCR, which is also accessible to GPs, can be adapted in a more timely way now that the SWAG Cancer Alliance has taken a national lead on its development.

A significant amount of funding has been allocated to additional Band 4 Support Workers, with 25 due to be employed across the SWAG region.

Work is underway to identify a provider to develop the Digital Patient Portal in a similar format to the Teenage and Young Adult *I Am* system. This will give patients access to health and wellbeing information, online HNAs, and ideally link with hospital information systems so that patients can see their appointments and other relevant information.

Project Management support will be available in Trusts to develop the most beneficial processes for individual centres.

8.2 Holistic Needs Assessments (HNAs)

The National Board has decided to collect metrics on the provision of two HNAs for patients; one within 31 days of diagnosis, and one within 6 weeks of completing treatment. Initially, this will be rolled out to patients who have had breast, colorectal or prostate cancer. Other cancer sites will be included; lung and gynae patients are going to be prioritised in UH Bristol and implementation will be discussed with individual teams. The purpose of the 31 day target is to give patients the opportunity to raise relevant priorities at the beginning of the pathway; tools to capture this discussion will be developed and ratified by the LWBC working group. There are fields within the SCR that can be used to record if an HNA has been offered and declined. The targets will not commence on Day 1, but would be assessed at the end of Years 1 and 2. The take home message is to gain recognition for work that is already being completed.

9. Research

9.1 Clinical trials update

Please see the presentation uploaded on to the SWCN website

Presented by Steve Thomas (ST)

Recruitment figures (sourced from EDGE), open trials and trials in set up are documented within the presentation. The national recruitment target for Head & Neck cancer is currently 1 per 100,000 of the population served. This has been surpassed for 2017-18, with the 8 studies open recruiting 219 participants to date, 60% of which are Head & Neck 5000 follow up patients.

Recruitment to time and target 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). Recruitment targets would ideally be set as a network rather than by individual centres and up to date information on open trials could be made available via the SWCN website.

The SAVER trial, which is a Phase II chemo-preventative trial with a focus on prevention of oral cancer, is in set up in UH Bristol, and could also be opened in RUH. The Lightform trial could potentially be opened in RUH.

It would be useful to use the SSG research slot to launch new trials.

10. Service Development

The 100,000 Genomes Project

Please see the presentation uploaded on to the SWCN website

Presented by Catherine Neck (CN)

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 CCC: 07732 561067, Ubh-tr.wegmc@nhs.net.

Recruitment to the project will remain open until September and the pathways for processing samples are already embedded for other cancer sites; SSG members are encouraged to look into recruiting head and neck cancer patients.

Date of next meeting: Tuesday 18th September 2018

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