NHS

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

Meeting of the Head and Neck Cancer Clinical Advisory Group (CAG, formerly SSG)

Tuesday 2nd April 2019, 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.

The Site Specific Group Service has been rebranded as the Clinical Advisory Group (CAG) Service. Service improvement requirements identified by the CAG are escalated to the SWAG Cancer Alliance Board.

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 18th September 2018, the notes were accepted.

Actions:

Living With and Beyond Cancer (LWBC - now called Personalised Care and Support): End of Treatment Summaries will be circulated by LWBC Lead Catherine Neck (CN) for comments from the group. CN will be contacted to see if this has been completed. **HD**

Re-design of thyroid follow up pathways: Risk stratified follow up has been implemented for patients with low risk thyroid cancer and a tracking system is now in place. This may negate the need for separate work on a network audit of compliance with thyroid clinical guidelines; HD will liaise with Clinical Nurse Specialist Donna Graham to see if this is the case. **HD**

RIG service: Training has been completed and the service is now available in UH Bristol.

Patient Information Leaflet to outline the services available across the region: The need for this information is no longer thought to be necessary.

Set up of Sentinel Lymph Node Biopsy (SLNB) Service in UH Bristol: A Consultant Radiologist with extensive experience in nuclear medicine has been appointed. Set up of the SLNB service will be revisited when he has commenced in post.

Head and Neck follow up audit: The audit has yet to be completed; action abandoned.

Teleconferencing pre-operative assessment clinics (POAC): The infrastructure for POAC via teleconferencing is in situ between Bristol and Bath, and works well for

thoracic patients, reducing the need to travel between centres. CNS Fiona Mackay has previously raised the possibility of making use of this for head and neck cancer patients with the pre-operative assessment team, but it has yet to progress. The Head and Neck anaesthetist team will be asked to look into this potential service development.

Anaesthetist Representatives

Follow up safety net system: The Innovation Panel in RUH Bath has been asked by Natalie Heath (NH) to consider implementing the same safety net system as that set up in UH Bristol. The follow up issues experienced in Bristol are not thought to be happening in RUH and so it may not be required.

NH

Mortality and Morbidity case discussions: No case discussions have been submitted on this occasion.

Adoption of TNM 8th Edition dataset from 1st April 2018, with continued recording of TMN7: Recording of both TNM datasets is due to come to an end in the near future, although this needs to continue for those patients receiving radiotherapy, as the current guidelines are based on TNM7.

3. Research

3.1 Clinical research 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 recruitment target per 100,000 population for head and neck cancer is 1.5 due to the low number of trials on the portfolio. This has been exceeded 8-fold in the West of England for 2018/19, but recruitment is expected to fall once the Head and Neck 5000 follow up trials have closed, making it really important to open new observational studies.

Head and Neck trials are recruiting well in comparison to cancer overall. This is in part due to the Head and Neck 5000 study team providing support for the collection of data to those centres with a lack of research resources.

Recruitment to time and target is going exceptionally well in North Bristol Trust. Recruitment to the complex low recruiting studies in the Bristol Haematology Oncology Centre is well within expected targets.

The PATHOS target may need to be reviewed and made more realistic. Streamlining MDT discussions could help to allow more discussion of relevant research trials. Simplifying the consenting process for patients by providing an A4 summary sheet for each study was raised as a possible solution. An audit of the patients who declined to consent could be undertaken to determine the obstacles to recruitment and recommend relevant changes. A list of these patients can be obtained from the Edge system and support for compiling audit

data can be provided by CAG Manager Helen Dunderdale (HD). **HD**

Further investment in the surgical research nurse team is required as they are currently inundated with trials.

Feedback from the Patient Representatives emphasised the difficulty for patients who are faced with additional information associated with research at about the same time as their diagnosis. The decision to contribute to science by taking part in Head and Neck 5000 had however been straight forward.

It is possible to apply to Macmillan to fund research nurse time for 1 day per week for particular projects. Another potential solution would be to join forces with the trials unit in the Bristol Dental Hospital. The flow of funding associated with recruitment would need to be transparent; this will be investigated further. **ST**

RUH Bath recently opened LITEFORM in time to recruit 2 patients prior to closure of the trial on Thursday. The requirements of the trial will take an extra hour per week per patient. Taunton is the most successful recruiter to LITEFORM and will be contacted for advice on how to manage the extra workload. **RUH Bath team**

An expression of interest will be made in a genome dysplasia trial which is currently in set up.

Several early phase studies will become available for non-responders: OBERON, NICO and POPPY; the capacity for oncology to open such trials is limited.

A trial to risk stratify follow up using PET-CT is due to open in UH Birmingham; the results could lead to an increase in out-patient capacity.

An EU observational study recently adopted onto the NCRI portfolio will look at patients that present with late stage disease and personal circumstances; it is thought that Head and Neck patients will be included in the patient cohort.

Ideas for more surgical research trials in the future are required.

4. Clinical opinion on network issues

4.1 Multi-Disciplinary Team Meeting reforms

Presented by Ceri Hughes

Videoconferencing facilities have much improved since a technician recently optimised the system in RUH Bath. The long term difficulties with using the system have not impacted on patient safety to date, although this didn't mean that there is no risk. The long term problem has had a detrimental effect on morale by reducing the ability to work collaboratively. The importance of having access to the right technical expertise as soon as problems occur is essential.

CH and Barry Main will attend the MDT Assessment Tool Training Day on Wednesday 19th June 2019. The tool helps improve interactions in the MDT environment. The invite will be forwarded to Stuart Gillett. **HD**

The national vogue is to develop pre-determined standards of care to enable some cases to be discussed outside the Cancer MDTMs. This is not felt to be appropriate for Head and Neck patients, although there are other methods that could be deployed to streamline discussions prior to the meeting, especially if there is additional pathology and radiology preparation time and the meeting starts earlier on Tuesday morning. The possibility to extend the time of the MDT will be revisited. **CH**

5. Patient experience

5.1 Patient choice over treatment options: advice and information

Presented by Ralph Openshaw (RO)

Feedback was provided both from recent patients, and from personal experience, about the difficulty of being given choice over treatment options with no clear steer from the medical expert on the preferable option. It was asked that the group clarify if it would be possible for patients to be asked if they want a choice, or for the MDT to decide on the treatment option, and if it was reasonable to ask the medical expert giving the options 'what would you do'?

Providing patients with choice is a national initiative that originated from patient feedback which supports the statement 'no decision about me without me'; the importance of not prejudicing patients either way when discussing a matter of clinical equipoise is incorporated in medical training.

Evidence to date on the current head and neck treatment options shows that each are as likely to be of benefit and consistent with competent medical care; further research is required before the medical team can make a definitive recommendation but, at present, surgery or radiotherapy are both considered the right thing to do.

Prejudices can be seen to exist in some centres, where radiotherapy is overwhelmingly favoured. Having the discussion with both the surgeon and oncologist at the clinic appointment could help to address this.

Performance status and other factors from an anaesthetic point of view need to be part of the discussion; this information should be available within the MDT to add strength to the MDT recommendation, which would require additional MDT preparation time for the Bristol team. It is usually possible to gather the information prior to the MDT in Bath due to smaller patient numbers. A business case to reform the MDT, including preparation time, will be discussed with the relevant Divisional Managers. **CH**

5.2 National Cancer Patient Experience Survey (NCPES) / Personalised care and support (Living With and Beyond Cancer)

Results from the NCPES 2017 for UH Bristol and RUH Bath were overall very positive, with the majority of scores above the national average; a few were under by 1-2%. Results specifically for head and neck cancer were not sufficient to be analysed separately, didn't include patients having radiotherapy, and would

be difficult to separate from RUH Bath as care was frequently shared across the two sites. Areas identified for potential improvements (although evidence from the survey was dated and a lot of work has already been undertaken to address these issues) include the following:

- Access to financial support and free prescriptions
- Too many people in the clinic room, which some patients can find intimidating
- Parking
- Insufficient numbers of experienced staff on the wards.

Improved communication with Max Fax dentists was identified as an area for improvement.

Previously, thyroid patients managed in NBT had felt quite abandoned after treatment, but a system is now in place to track and provide support to these patients from diagnosis onwards. To date, this has already picked up 4 patients that otherwise would not have been identified. It was noted that this work would not be reflected in the next NCPES results, which had been sent to patients in Spring 2018.

Results on the question on discussing worries and fears should be much improved now that Cancer Support Workers are providing patients with Holistic Needs Assessments.

A one page local patient experience survey is routinely posted to inpatient and day-case patients by the CNS team in Bath. This is currently being reviewed and will be shared with the Bristol team as it will be helpful to distribute the same survey across the 2 centres so that services can be compared and best practice shared. The survey will also be shared with the patient representatives for their opinion on the content. It would be ideal if a survey could be provided to patients in clinic, either via iPad or to post their form into a box within the waiting area.

RUH CNS Team

HD

5.3 Adjust, Adapt and Plan Event

Please see the presentation uploaded on to the SWCN website

Presented by Ruth Hendy (RH)

A significant amount of work has been achieved to be able to implement the requirements of the Living With and Beyond Cancer (LWBC, now Personalised Care and Support) since receiving Cancer Transformation Funding, and the subsequent employment of Cancer Support Workers and other Health Care Professionals. Holistic Needs Assessments are now routinely provided within 31 days, Health and Wellbeing (H&WB) events are held at the end of treatment, provision of end of treatment summaries is gradually improving, and work is underway to encourage GPs to conduct Cancer Care Reviews.

H&WB events have historically been tailored to patients having curative treatment. A 'next steps' day for patients with a poor prognosis has been recognised as an area of unmet need and a project to set up such events has

been underway in UH Bristol over the past year. The first pilot event was held on Monday 4th February 2019 in the Education and Research Centre, University Hospitals Bristol NHS Foundation Trust, and received positive patient feedback.

Clinical Nurse Specialists can refer both male and female patients treated in UH Bristol who have a prognosis of between 6-36 months.

It has 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. It will be constantly reviewed and shaped according to patient feedback. 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.

It is now hoped to plan a generic 2 hour first step event for patients at the point of diagnosis, to be held every 2 weeks.

Enhanced Recovery Lead Nurse Rory Spanton will be invited by CNS Rob Buller (RB) to give a presentation on the Enhanced Recovery Programme at a future meeting.

RB

6. Coordination of patient care pathways

6.1 28 day faster diagnosis standard: Radiology update

Please see the presentation uploaded on to the SWCN website

Presented by Mandy Williams (MW)

The imminent introduction of the faster diagnostic standard has the potential to dramatically increase referrals of scans for benign symptoms, due to the need to give all patients referred via the two week wait pathway a diagnosis within 28 days.

An audit of the referrals from January to March 2019 was undertaken. The service is operating at full capacity and outsourcing non-urgent scans whenever possible to continually manage the backlog; it is not possible to outsource scans for patients on the cancer pathway.

Results showed that it was very rare for cancer to be found on imaging for those patients with no signs of cancer identified on clinical examination; it is therefore appropriate to remove patients from the cancer pathway at this point and instead request an urgent or routine scan. This will allow patients who have suspicious lesions to be prioritised. Standardised wording for clinic letters will be circulated by Cancer Manager Hannah Marder, and Consultant ENT and Max Fax surgeons will provide the junior medical team with information to ensure compliance with this process; the presentation will be used for this purpose.

Agreed

HM

Consultant Surgical Team

7. Quality indicators, audits and data collection

7.1 Head and Neck Audit (HANA) update

Presented by Hannah Marder (HM)

There have still been no outputs or benefits from participating in HANA since it replaced the DAHNO audit in 2015, despite submitting the dataset from 2014-2016. A request for additional retrospective data has now been received. Investing the time in this request, when there is no guarantee of any benefit is not considered to be good use of the teams' time.	**Agreed**
Formal feedback on HANA will be sent to BAHNO as the funding body from the CAG.	**HM**
A local audit dataset to review at future meetings will be agreed. Some of the information required will be available on the Cancer Stats website, which can be accessed from NHS computers: https://cancerstats.ndrs.nhs.uk/cosdl3/alliance	**ST**

8. Any other business

There have been numerous issues with booking PET-CT requests that have caused delays in the patient pathway. This will be escalated to the Cancer Alliance Board.	**HM**

Date of next meetings: To be confirmed.

-END-