Meeting of the SWAG Network Lung Site Specific Group (SSG)

09:30–15:00, Tuesday, 27th November 2018, Engineers House, The Promenade, Bristol, BS8 3NB

This meeting was sponsored by AMGEN, ASTRAZENECA, BOEHRINGER-INGELHEIM, BRISTOL MYERS-SQUIBB & MERCK

Chair: Dr Adam Dangoor (AD)

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 the 22nd May 2018, the notes were accepted. SSG members are to contact the Chair with ideas for external speakers to invite to All future meetings. Actions: Living With & Beyond Cancer (LWBC) implementation of the recovery package: Lung cancer treatment summary templates have been drafted by LWBC Lead Catherine Neck (CN), and will be circulated to the group for comments prior to CN ratifying them for use across the region. North Bristol Trust application to become a mesothelioma centre for research: HD Progress of the application will be established prior to the next meeting. Management of lung nodules: A session on management of lung nodules and agreement of a standard patient information leaflet will be arranged for the next HD/AD meeting. 3. Patient experience 3.1 Poor prognosis letter Please see the presentation uploaded on to the SWCN website Presented by Miranda Florey (MF)

The Palliative Care Team in University Hospitals Bristol was granted an award by the British Medical Journal (BMJ) in 2017 for implementing an innovative project



that has improved patient care for patients and their carers. The project, which commenced in 2010/11 as part of a Clinical Commissioning Group (CCG) service improvement initiative, aimed to improve the communication of poor prognosis information to General Practitioners (GPs).

An electronic letter was developed with help from IT to keep it separate from other electronic discharge letters. It can be completed in less than 5 minutes at any time during a patient's admission or clinic appointment. Junior medics have been trained to complete the template letter, which contains details of prognostic criteria of relevance to the particular patient's condition.

The letter, which is never printed or sent directly to the patient, is sent directly to the GP via the Egton Medical Information System (EMIS), to ensure the GP knows that the patient may be in their last year of life and require tracking on the Gold Standard Framework (GSF (best supportive care)) Register. Positive feedback on this process has been received from patient focus groups, with people stating that this is what they would expect to occur as a matter of routine.

The use of the letter is continually audited, results of which can be found in the presentation.

The information provided via the poor prognosis letter permits GPs to arrange home visits to relevant patients and has improved discussion of their wishes. The rate of patients who died in hospital was seen to drop, which could indicate that the process has facilitated management of appropriate admissions and enabled patients to have more say in choosing their preferred place to die.

This process is also of use within the Trust as, for example, it has helped to avoid an ITU admission, keeping a bed open for a patient whose surgery was dependent on the availability of that bed.

The median survival of patients for whom the letter had been generated was 31 days, indicating that prognostication was still overcautious. Further work is needed to ensure that all teams use the letters.

Ideally, if the patient was thought to be ready to discuss the poor prognosis letter, then this would be broached with them, but it was important that this did not become a barrier to the Junior medic completing it prior to this. It could also be completed by Clinical Nurse Specialists.

Since the awards ceremony, there have been numerous requests from other centres to share and adopt use of the letter. It was noted that implementing this service improvement takes a lot of time and effort; engaging the junior medical colleagues is the key to its success.

The letter contains information on the prognostic criteria specific to the disease rather than patient characteristics. There is a free text box where further information can be added.

A clear definition of median survival should help trigger when to complete the

form, which is acceptable to complete in error if a patient lives beyond a year.

The GP representatives attending the meeting had not received the poor prognosis letter to date, but would find this useful to help with family conversations.

4. Clinical guidelines

4.1 Lung Cancer Clinical Outcomes Publication (LCCOP)

The latest LCCOP, published in 2018, contains data on 2016 surgical resections.

The number of resections performed over the year indicates why the service in Royal Devon and Exeter was closed and moved to Plymouth.

UH Bristol has consistently been one of the lowest units in the country for median length of stay due to the Enhanced Recovery Programme.

The percentage of readmissions within 90 days was generally high (approximately 50%) across the country, with UH Bristol doing comparably well (approximately 30%). There was an existing patient information leaflet on after care, but more information on managing pain and complex complaints, plus ways to access the service for advice is needed. Patients also need to be aware that recovery time from surgery has been shown to be a lot longer than previously expected; symptoms of fatigue and breathlessness can continue for a year.

UH Bristol has been a positive outlier for survival outcomes in previous years, and was within normal ranges for 2016. Lobectomy rates were lower than the national average.

Resection rates looked low across the region, although it was understood that the data for the national audit has been captured differently to previous years. This raised the question about whether the criteria for surgery should be lowered. The data will be analysed to see if there is a sub-section of patients who are not being offered surgery that is being carried out by other units. Stage, Performance Status (PS) and Stereotactic Ablative Radiotherapy (SABR) rates need to be included. Resection rates need to be compared with survival rates to assess the overall benefit and what can be considered the optimal resection rate. Results will be presented at the next meeting.

Consultant Respiratory Physician Andy Low undertook an audit of patients with Stage 1 or 2 lung cancer with a PS of 1-2 to look at radical treatment. Radical treatment had been offered to 80%. No issues were identified; the majority of patients that did not have surgery were high risk and chose oncological treatment as an alternative to surgery.

Improvements could be made by optimising the patient pathway; the process for implementing the radical treatment bundle in line with the National Optimal Lung Cancer Pathway needs an accelerated timeline. Prehabilitation should be consistently offered, and surgical MDT attendance at peripheral centres needs to

Surgical team

DW / Surgical team



be optimised. The plan to move the Gloucestershire MDT to a different day to facilitate this has been put on hold until teleconferencing equipment is replaced at some point in 2019. Some patients may be deterred from going for surgery due to the need to travel.

Surgical team

A survey of the management of Stage III lung cancer is underway; results will be reviewed at a future meeting.

3.2 Adapt, Adjust and Plan event

Please see the presentation uploaded on to the SWCN website

Presented by Sophie Fox (SF)

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.

The initiative is considered to be an excellent service improvement; linking up with community care providers is recommended.

3.3 National Cancer Patient Experience Survey

Please see the presentation uploaded on to the SWCN website

Presented by Belinda Ockrim (BO)

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 only possible for results to be published for UH Bristol and Gloucestershire due to the number of responses in other Trusts being less than 20.

A quality dashboard developed by PH England and NHS England is available to view in the presentation; results that are less than the national average are



highlighted in red.

The results relating to GP access reflected the current pressures on workload capacity.

Question 5: *Beforehand, did you have all the information you needed about your test?* appeared to have scored less than the year before, but was still rated at over 90% positive.

The activity related to Living With and Beyond Cancer, including wellbeing events and the introduction of Cancer Support Workers (CSWs) should result in increased satisfaction with questions such as information on financial support.

Question 55: *Have you been given a care plan?* received low positive responses across the board. This was thought to be due to the way that care plans were labelled. For example, patients in Yeovil are given a 'Health Diary'. This is now going to be relabelled explicitly as a care plan.

The way that the questions are interpreted does not seem to reflect the reality of practice. For example, Question 47: *Beforehand, did you have enough information about your chemotherapy treatment?* should be 100% due to the in-depth informed consent process.

It was noted that the people who were sent surveys were not necessarily current patients.

5. Network issues/MDT service

5.1 MDT reforms – national and local developments

Please see the presentation uploaded on to the SWCN website

Presented by Adam Dangoor (AD)

Please see the presentation uploaded on to the SWCN website

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 Ascencao 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.

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

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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. In the interim, a generic email address will be used for all UH Bristol referrals.

North Bristol Trust has developed MDT referral proformas with mandatory fields in the ICE hospital information system. This is not accessible across all Trusts.

Additional recommendations are detailed within the presentation. The group will meet again in approximately 6 months to discuss progress. The Cancer Alliance has allocated some funding to support the work.

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 (pSOC) for patients who meet certain criteria. The national guidance gives permission to triage cases on to pSOC. The Sarcoma MDT plan to do this for lipomas, and it could be possible to do this for lung nodules, although there would need to be a robust tracking system for these patients.

It was noted that any issues with MDT videoconferencing facilities should be escalated to management teams.

The RUH Bath MDT are reducing repeat discussions by only listing those patients that have staging information available on imaging.

Bristol patients' MDT outcomes are now available to GPs on the Connecting Care information system. The identity of the person who is required to act on the next MDT outcome must be clearly documented on the system.

Lung nodules are already triaged outside the Gloucestershire MDT.

To date, Yeovil District Hospital has not been able to coordinate a suitable time and venue to meet with a radiologist to triage the MDT, which is used as a safety net to discuss all patients.

6. Research

6.1 Lung cancer trials clinical 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 West of England Clinical Research Network (CRN) is currently struggling to meet cancer recruitment targets due to its



size in comparison with other networks. The standard for recruitment to time and target was met for 2017/18, which meant that funding for the network remained stable.

The metrics for measuring performance are being revised and may provide ways to recompense research activity according to incidence and prevalence. Heat maps and different models to accurately calculate this are being developed. The recruitment target per 100,000 population for Lung is 4, and is currently on target and performing well in comparison with the percentage of cancer incidence in the region.

A spreadsheet of open trials, trials in set up, and trials that are open to new sites is available on the SWCN website <u>here</u>. It is hoped that Principal Investigators (PIs) will use the research slot on the SSG agenda to boost recruitment by promoting new and existing trials.

A South West wide research event, including colleagues from Wales, will be held at The Castle, Taunton in February 2019 to discuss trials to open, share, and encourage cross referrals. A save the date email will be sent in the near future.

The National Lung Matrix trial, a Phase II trial for patients with Stage III or IV Non-Small Cell Lung Cancer (1 or 2 biopsies required) who are willing to travel to one of the study centres (open in UH Bristol, Royal Devon and Exeter and Cardiff) for research related activity, offers the opportunity to gain access to targeted therapies for specific gene mutations.

For radiotherapy: ADSCaN, is a randomised Phase II study of Accelerated, Dose escalated, Sequential Chemo-radiotherapy in Non-small Cell Lung Cancer (NSCLC), and SARON for patients with NSCLC that has spread to no more than three areas in the body. Contact Clinical Oncologists Gareth Ayres and Charlie Comins to discuss patients that may be eligible.

7. Coordination of patient care pathways

7.1 Wythenshawe rapid diagnostic pathway

Please see the presentation uploaded on to the SWCN website

Presented by Vidan Masani (VM)

Implementation of the Manchester Rapid Access to Pulmonary Investigations and Diagnosis (RAPID) programme has enabled compliance with the National Optimal Lung Cancer Pathway. Details of how this was achieved are within the presentation; a significant Health Foundation grant was pivotal, funding a purpose built centre where the lung cancer team could pool their resources. The team has slowly increased in numbers due to diligent coding of activity to provide proof of the staffing level requirements. SWAG centres are recommended to adopt those elements of the project where it is feasible to do so. There are behavioural changes that can be made on a cost neutral basis. The team in RUH Bath have commenced work on the same process but use an electronic platform instead of a whiteboard record as used by Wythenshawe.

The numerous groups involved in lung cancer are planning to share best practice via a shared repository. Lung cancer diagnostic algorithms have been developed that split patients into 5 different groups, detailing the test bundles required. These are being adapted by the team in RUH Bath, and then will be laminated and made available in clinic rooms. These will be reviewed by the group and any comments should be sent to AD/HD.

7.2 South West Alliances' Rapid Diagnostic Pathway for Lung Cancer

Please see the presentation uploaded on to the SWCN website

Presented by Amelia Randle (AR)

The National Cancer Transformation Board has awarded transformation funding to the South West Cancer Alliances (CA) for the purpose of improving earlier diagnosis of colorectal and lung cancer. To achieve this for lung cancer, the CA has made a commitment to introduce the diagnostic phase (chest x-ray to CT scan) of the National Optimal Lung Cancer Pathway (NOLCP). Progress on delivery of the project within each Trust can been seen within the presentation, where the blue boxes indicate that a task has been completed, green that the task is underway, and orange indicating that there is an obstacle to overcome before the task can be completed.

The potential risks flagged by the project team and provider Trusts have been agreed.

The most significant waiting time in the process is for the referral to CT scan after chest x-ray; reporting waiting times had not been flagged as a problem.

All Trusts are using a version of the chest x-ray reporting tool; there was some variation in the reporting of the CX3 code, and a standardised approach needs to be clarified.

The diagnostic breakdown in the presentation will be reassessed. It could be that the NSCLC and SCLC have been transposed.

Reports on the related activity will be requested on a quarterly basis.

The Clinical Advisory Group and Steering Group have now merged and will meet on a quarterly basis to continue auditing the project.

A second stream of funding is available to assist with meeting and sustaining the 62 day cancer waiting time target. Some of this will be used to fund clinical lead posts to ensure that the clinical order of the NOLCP is implemented; a request for expressions of interest in the role for lung has been circulated. The funds are non-recurrent and cannot be spent on capital. Cancer Managers are to suggest other ways to use the money to improve 62 day performance.

Cancer Managers



It was noted that it is difficult to spend non-recurring money on things other than capital; it may be useful to purchase time for information technology support.

8. Clinical guidelines

8.1 Pathology update

Please see the presentations uploaded on to the SWCN website

Presented by Simon Rose (SR)

There is variation in the provision of reflex tests, with some laboratories testing only at the request of the oncologist. It may be appropriate to rationalise testing in some cases, and helpful to preserve a section of a small biopsy sample. However, reflex testing speeds up the process when these results are required and tissue can be optimised, with core biopsies being split over several blocks. Many of the reflex tests are required for clinical trials early on in the pathway; reflex testing will be reconsidered as the standard for SWAG.

A plan to look at retrospective cases using fluorescence in situ hybridization (FISH) tests to verify and use as positive controls will take some time to be analysed, but should eventually make the pathway quicker.

There is a plan to create pathology networks in hub and spoke models to rationalise services, with the majority of work occurring in the hubs. Networking across the region was already established to a significant degree, and given the country-wide crisis in recruiting histopathologists, the requirement to relocate the necessary staff was not thought to be viable.

From the 1st October 2018, NHS England commissioned 7 Genetic Laboratory Hubs. The South West Genetic Laboratory will be based in North Bristol, led by Head of Oncology Genomics, Christopher Wragg, and will work in partnership with the Exeter laboratory, processing samples from Cheltenham down to the Isle of Scilly. NHS England will provide funding for a range of tests. Whole gene sequencing will be available for sarcoma, paediatric and haematology, and more tumour types as evidence dictates, so that treatments can be tailored accordingly. Dr Rachel Butler is joining the Bristol team, bringing an abundance of expertise that will assist with driving this forward, including work on circulating tumour DNA.

8.2 Developments in oncological treatment for Stage III NSCLC

Please see the presentations uploaded on to the SWCN website

Presented by Gareth Ayre (GA)

Publication of the PACIFIC study data (Durvalumab after Chemoradiotherapy in NSCLC) showed a reduction in metastatic relapse, and a significant improvement in overall survival of approximately 11% at 2 years. It was possible that there was synergy in the action of radiotherapy and immunotherapy. It was speculated that



radiotherapy induced necrosis might help prime cells to make the immunotherapy more effective.

The draft NICE guidance *Lung Cancer: Diagnosis and Management* (2019) contains advice that would constitute a shift in practice. The recommendation for Stage III A-N2 NSCLC is for chemoradiotherapy with surgery, with the key benefit being progression free survival. There were uncertainties about the evidence for this recommendation, and a separate meeting will convene on Friday to decide on a response to the guidance which, it was recognised, would apply to the minority of patients as the majority would be too frail for treatment.

The most recent evidence for trimodality treatment was discussed as detailed in the presentation to assist with the regional discussion.

It was noted that the guidance said to 'consider the treatment' rather than state that this was standard care.

It was hoped that the evidence from the PACIFIC study could also be incorporated in the guidance.

8.3 Surgical update

Please see the presentations uploaded on to the SWCN website

Presented by Eveline Internullo (EI)

The Nelson Study, presented at the IASLC World Conference on Lung Cancer, showed that annual lung cancer screening, with low-dose computed tomography in high-risk patients, reduced lung cancer deaths by 26 percent in men and up to 61 percent in women (up to a 44 percent reduction overall if male and female cohorts were evenly split).

NHS England has given assurances that money will be invested in piloting a screening programme, and 10 Clinical Commissioning Groups (CCGs) have been selected based on incidence and survival rates. The surgical centre will make preparations for the potential impact of a future screening programme. The results will be presented in full at the next meeting.

Results from 2 randomised controlled trials looking at segmentectomy are due imminently and will be discussed at a future meeting.

9. Living With & Beyond Cancer (LWBC)

9.1 LWBC regional update

Please see the presentation uploaded on to the SWCN website

Presented by Belinda Ockrim

National Transformation Funding has been awarded to providers within the SWAG



region for the purpose of implementing the LWBC Recovery Package. The funding is dependent on delivering the activity, which is being measured for certain cancer sites. In North Bristol Trust this is Breast, Colorectal and Prostate, and in UH Bristol Colorectal, Gynae and Lung, although the initiative, which has funded Band 4 Cancer Support Workers (CSW) to assist the CNS team, is being made available to all cancer patients. Additional AHPs and LWBC Project Managers have also been appointed. UH Bristol is planning to provide Health and Wellbeing events earlier on in the patient pathway rather than at the end of treatment to match the model in NBT.

Teams are encouraged to complete End of Treatment summaries to provide GPs and Practice Nurses with the information they require to care for patients post discharge.

Level 2 Psychology Training for CNSs and AHPs will commence in the new year.

Patient and Public Involvement Lead Katy Horton-Fawkes is improving patient involvement in service development across the network.

10. Any other business:

Robust processes are in place for ensuring that the transfer of cancer patients between organisations after treatment routinely occurs.

Date of next meeting: Tuesday 21st May 2019

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