South West Clinical Network  
Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services

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

09:30–16:00, Tuesday, 15th November 2016 at The Orchard Room, Holiday Inn, Filton Road, Bristol, BS16 1QX

This meeting was sponsored by PFIZER, ASTRAZENECA, AND ELI-LILLY

Chair: Dr Adam Dangoor

Notes
(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 the last meeting notes and actions

As there were no amendments or comments following distribution of the notes from the meeting on the 24th May 2016, the notes were accepted.

Evidence for brain imaging prior to radical surgery is being collated by Alfredo Addeo (AA), and will be distributed with the aim to agree regional guidelines. Imaging with either MRI or CT is yet to be decided. Radiologist members will be encouraged to attend the next meeting to contribute to this discussion.

3. Survivorship

3.1 Living With and Beyond Cancer update (LWBC)

Presented by Catherine Neck (CN)

The essential elements of the LWBC recovery package are Holistic Needs Assessments (HNA), Health and Wellbeing events and End of Treatment summaries. Initially, the national focus has been to establish LWBC for patient groups with better survival outcomes, such as breast, colorectal and prostate cancer. Pilot work completed in Hull and Brighton has shown how LWBC could benefit lung cancer patients, who have equal and arguably more need at an earlier stage than other cancer site groups. The pilot held in Brighton identified £100,000 of savings by adapting the patient pathway. Nurse led telephone clinics reduced outpatient appointments by 25%, and reduced emergency admissions. Average length of stay fell by 2 days. Unfortunately the work did not continue.

It is recommended that HNAs, which involve a one to one appointment with the patient’s CNS, are completed at the beginning of treatment, alongside completion of care plans. Practical, social, financial and emotional advice is given; the assessment is completed using a template available on the Somerset Cancer
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Register. HNAs can reduce the need for extra follow up appointments, as patients are referred early on to the services they require. The majority of positive patient feedback has been related to having early access to physiotherapy and provision of nutrition advice, which should ideally be provided within 4 weeks of diagnosis.

The prehabilitation initiative in UH Bristol also provides early access to beneficial advice, including physical interventions. Patients are identified for this service as soon as they are referred via the two week wait pathway.

Due to time constraints, it was not possible for the CNS team to complete HNAs with all patients. The gynaecology and colorectal teams in UH Bristol have access to iPads that allow patients to pre-populate the form in the clinic waiting room, reducing the work load; these will be made available to the thoracic team. It is recommended that HNAs are repeated at every end point in the patient’s treatment pathway.

4. Clinical guidelines

4.1 Systemic Anti-Cancer Therapy (SACT) data

Please see the presentation uploaded on to the SWCN website

Presented by Alfredo Addeo (AA)

The first mandatory SACT dataset on 30 day mortality data has been published in The Lancet (September 2016). This was designed to include details on all patients from January to December 2014 who received chemotherapy for breast and lung cancer, for the purpose of monitoring the quality of clinical decision making. The publication looked at outcomes in comparison to age, toxicity and palliative or curative intent. Data can be viewed at Trust level and be compared with other Trusts. It was not possible to extrapolate useful information from the publication due to significant inaccuracies and gaps in the data collection. All cancer patients receiving chemotherapy are to be included at some point in the future. It is hoped that this will lead to provision of dedicated administrative support to improve data quality, so that it can be used to inform treatment improvements.

5. Coordination of patient care pathways

5.1 Two week wait clinics

Please see the presentation uploaded on to the SWCN website

Presented by Andy Low (AL)

The low survival rates in lung cancer in comparison to other cancer sites are compounded by patients often presenting with advanced disease. In order to improve early diagnosis, the two week wait referral system was introduced and awareness campaigns have been widely advertised. In UH Bristol and RUH Bath,
this resulted in a doubling of patient referrals between 2011 and 2016. The number of lung cancer diagnoses remains around the same. There has been an increase in inappropriate referrals, but the number of referrals diagnosed as an outpatient via the 2WW process rather than as an inpatient has increased, leading to improved chances of survival.

The national optimal lung cancer pathway recommends GP direct access to CT. In UH Bristol, the CT is performed prior to the clinic appointment. This causes logistical problems as the number of referrals per week vary; three clinics are needed each week so that this can be managed. The potential to move towards GP direct access to CT and use the CT result to triage patients off the suspected cancer pathway was raised as a possibility. This is the current process in RUH Bath, and was previously trialled in UH Bristol, but GPs found that they could not arrange the scans in a timely way.

North Bristol Trust and Royal Devon and Exeter are conducting a project to see how the pathway can be streamlined; there was resistance from General Practitioners to adopt direct access. In RUH Bath, the GP requests a CT, and if clear, the patient is sent a letter to say that there is no need for an urgent assessment and an appointment will be made in six weeks.

An ACE project looking at the lung cancer referral pathway, undertaken by Cancer Alliance Clinical Lead and Somerset GP, Amelia Randle, will be discussed at a future meeting. Whether a negative CT could negate the need for any secondary care follow up appointment will be investigated. It will be the responsibility of the Cancer Alliance to communicate conclusions of such a project to the 3000 GPs within the region.

5.2 Suspected cancer referral forms

Please see the presentation uploaded on to the SWCN website

Presented by Andy Low (AL)

Incomplete suspected cancer referral forms are received on a regular basis, which means that hospital staff have to contact referring GP surgeries to obtain further information. Mandatory data fields that would not allow referrals to be submitted until they were completed may help to solve this.

The SWAG referral form includes an option that allows GPs to refer a patient who has a normal chest x-ray but raises a high level of concern, as it was not clear from the NICE suspected cancer guidance (2015) how the GP should manage patients in these circumstances. Ideally, GP guidelines should be made available on how to triage chest x-rays.

A SWAG SSG nhs.net email has been set up for network audits: ubh-tr.SWAGSSGAudits@nhs.net
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If feasible, after processing 2WW referrals in the usual way, any incorrectly completed referral forms can be emailed to this account. Forms must be sent from another nhs.net email account to comply with Information Governance with the subject Lung referral. Feedback on the forms will be sent to the relevant CCGs approximately every three months who will then provide feedback for GP practices.

6. Patient experience

6.1 Roy Castle Lung Cancer Foundation update

Please see the presentation uploaded on to the SWCN website

Presented by Jesme Fox (JF)

The Roy Castle Lung Cancer Foundation (RCLCF), which is the only national lung cancer charity in the UK, aims to explore ways to mutually collaborate with lung cancer services. Their main priorities are:

- Research
- Patient Support and Information
- Tobacco Control
- Policy and Informing.

Applications for research funding are welcomed. Priorities include early detection and improving the patient experience. Pilot Grants for up to £25,000 and Project Grants for up to £75,000 are available. There is a two-part application process that is submitted online. The deadline for 2017 grants is the end of March 2017. Approximately 25 applications are submitted each year. At present, there is a lack of research looking at quality of life for palliative patients.

The RCLCF produces patient information booklets which can be ordered online or by phone, hold patient information days, and support groups. There are three facilitators that manage a telephone helpline. Small financial grants of up to £200.00 are available for patients. Eligibility criteria can be found here. The form should be completed by the patient’s CNS or doctor.

There is a template lung cancer CNS business case available on the website here.

Testimonials of positive experiences from either patients or carers are always welcome.

A tobacco control initiative, in collaboration with Cut Films, is underway, focusing on young people and prevention.

Several UK projects were underway, looking at the possible benefit of a lung cancer screening programme. The results from a US National screening trial and the European NELSON trial should also help to assess the benefit of such a
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scheme. Research in breath testing and biomarkers is also underway.

NICE guidelines for the diagnosis and management of lung cancer are due to be updated in the near future.

6.2 Results of the National Cancer Patient Experience Survey

There were insufficient numbers of lung cancer patients in Yeovil District Hospital and Weston General Hospital to look at site specific results. In Yeovil, results were above the national average for all questions. A significant improvement was seen in the provision of information on financial advice. There was a drop in the score relating to the question Did you have confidence and trust in the ward nurses treating you? which was being investigated. The CNS now has additional support from two nurses, which should further improve the patient experience. A low score for the question Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research? was thought to be due to research not being discussed with patients who were not eligible, and patients not understanding that being asked to participate in a clinical trial was the same thing as being asked to participate in research.

Results were low when patients were asked if they felt supported by health and social services after treatment. Collaboration and communication between primary and secondary care needs to be improved.

A speed dating event with team members from each cancer site specific group was held for GPs in Somerset, to give them the opportunity to ask questions about how to make appropriate two week wait referrals. Details of the event will be presented by Matt Sephton (MS) and Charlotte Garland (CG) at the next meeting.

In UH Bristol, comments about groups of doctors and nurses who talked in front of patients as if they were not there when performing ward rounds needed to be addressed. Positive results were received about the confidence and trust patients had in their doctors but information given by ward staff was identified as an issue; the CNS team are holding teaching sessions to resolve this.

Weston had received positive feedback on the dignity and privacy given in outpatient clinics and information given about financial assistance. The CNS team now allot specific time for patients to be involved in treatment decisions as this has been identified as an area that requires improvement, as has the need to provide more information on the next steps in the patient pathway.

RUH Bath uses a cancer tracker, which helps identify when information will be needed, rather than giving all information up front. The tracker also helps the Trust’s Cancer Support Workers triage patients to appropriate tests and streamline the two week wait pathway.

Gloucestershire are reviewing when information should be given, to reduce the amount given at the beginning of the patient pathway. A low score was given for
the question *How easy or difficult has it been for you to contact your CNS?* The CNS team was under-resourced, with only two CNSs employed across Gloucester and Cheltenham sites. The use of the RCLCF CNS template business case could be considered.

The 2016 NCPES was distributed before there was an opportunity to action the priorities for improvement identified in the 2015 survey, so it is possible that there will be no change in the next set of results.

7. Research

7.1 Mesothelioma trials

**Please see the presentation uploaded onto the SWCN website**

**Presented by Nick Maskell (NM)**

The British Thoracic Surgery Mesothelioma Guidelines will be out for consultation in the next 2-3 weeks, for publication next year.

The role of the regional mesothelioma multidisciplinary team was recently evaluated, looking at the 210 cases discussed between January 2014 and December 2015. The MDT function had provided a definitive diagnosis for 81% of patients, ensured that patients were offered and recruited into appropriate clinical research studies, and prevented the need for a post mortem for 95% of patients.

The research trials currently available across the region are documented within the presentation.

A combined mesothelioma and lung cancer clinic has been arranged, with assistance from Alfredo Addeo, every Monday in North Bristol Trust.

7.2 Clinical trials update

**Please see the presentations uploaded on to the SWCN website**

**Presented by Adam Dangoor (AD)**

AD stepped down from the role of Research Lead for the SSG. Consultant Clinical Oncologist Ashley Cox (AC) has agreed to undertake this role.

The West of England Clinical Research Network is currently ranked third in the country for recruitment to lung cancer studies in relation to the percentage of cancer incidences. The list of open trials and trials in set up will be distributed; members of the group are to check this for accuracy and inform AC if any information is missing or incorrect.
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The Javelin trial, a Phase III open-label, multicenter trial of avelumab (MSB0010718C) versus platinum-based doublet, can be offered as a first-line treatment of recurrent or Stage IV PD-L1+ non-small cell lung cancer. Patients must be willing to travel; travel expenses will be reimbursed. The Avastin trial, a multicenter, randomized, double-blind Phase III trial to evaluate efficacy and safety of BI 695502 plus chemotherapy versus bevacizumab plus chemotherapy, can be offered to patients with advanced non-squamous Non-Small Cell Lung Cancer. The Principal Investigator for both trials is David Farrugia. Contact details and eligibility criteria are within the presentations on the website.

Expressions of interest in smaller studies could be made as a network group, with different studies set up in each centre. Recruitment could then be sourced from across the region.

8. Service development

8.1 Thoracic video-link update and audit

Please see the presentation uploaded on to the SWCN website

Presented by Doug West (DW)

The pre-clinic information for patients has recently been updated on the UH Bristol website. A Quick Response (QR) matrix barcode can be shared should patients want to look at the webpages using their mobile phones, or a google search for Bristol thoracic surgery will find the pages.

The Pre-operative Assessment Clinic (POAC) via video-link between UH Bristol and North Bristol Trust has been running for 2 years. This is now being established in Gloucestershire Royal. POAC nurses discuss exercise, smoking cessation and weight maintenance to ensure that a patient’s health is optimised prior to surgery. This initiative improves the patient experience by reducing the need to travel to Bristol, and has been shown to speed up time to surgery. To date, the Consultant Anaesthetists have had no problems conducting airway assessments using the system, which has been shortlisted for a Health Service Journal Value in Healthcare Award. It would be ideal if the service could be established across the region; engagement from a local CNS to arrange the POAC timeslots is essential for it to work. A webcam would be supplied by the UH Bristol team. Aside from the initial set up costs, no additional resources are required to deliver the service.

The preparation and clinic time were equivalent to a face to face clinic appointment, and should be equally recompensed. This will be investigated by Jonathan Miller (JM) who will discuss this with the commissioning groups across the region.

JM
9. Network issues

9.1 Quality Surveillance Programme (QSP)

Please see the presentation uploaded on to the SWCN website

Presented by Ed Nicolle (EN)

Peer Review has been replaced by the Quality Surveillance Programme (QSP). It now includes many other services as well as cancer, is focused more on outcomes from existing datasets, and should prove to be less intensive. The existing Peer Review documentation will need to be updated and maintained in the event that a QSP visit is announced, but it will no longer need to be uploaded to the CQUINS website. Annual declarations will be submitted onto the new QSIS web portal. EN will check to see if the information will be made available in the public domain.

9.2 Cancer Alliance update

In order to implement the National 5 Year Forward Cancer Strategy, providers and commissioners have been instructed to form Cancer Alliances.

For the South West area, there will be 2 Cancer Alliances (CA). The SWAG Cancer Alliance matches the geography of the SWAG SSG Support Service. It has been agreed that the existing cancer steering groups, BNSSG, BANES, Somerset and Gloucestershire, will continue to convene, working to agreed terms of reference, and will nominate 2 to 3 representatives to form the Cancer Alliance board, representing primary care, secondary care and CCG members. A Clinical Lead will be appointed to Chair the group and interviews are currently underway. Membership will also include patient and charity representatives. If agreed, the SSG Support Service will provide administrative support for the CA to ensure two way communications between the CA and SSGs.

It is hoped that SSGs will be asked to participate in decision making exercises proposed by the alliance. When relevant items are on the CA agenda, SSG Chairs will be invited to contribute to these meetings.

The practicalities of how the CA will function, the availability of money and resources, and the agreed standards to deliver, are currently under discussion.

A draft report detailing the overarching priorities and site specific priorities identified by SSGs will be submitted, in the hope that this will be used to inform the Cancer Alliance Work Programme.

10. Quality indicators, audits and data collection

10.1 National Lung Cancer Audit (NLCA) update

Please see the presentation uploaded on to the SWCN website
Presented by James Withers and Ian Woolhouse (JW, IW)

New data systems have been linked to the NLCA, resulting in increased identification of lung cancer patients and additional treatments. Data will tend to be less complete for these patients, who may not have been reviewed by an MDT. Elderly care centres are to be contacted to refer all patients, even if palliative. An online reporting tool is available to enable teams to review their data completeness. To register, visit the website here. Data can be filtered by year, region and each measure. Preliminary results for the South West are documented within the presentation. UH Bristol and NBT are in the unique situation of sharing the same data system, which has caused problems with identifying where data quality requires improvement. This will be resolved next year when an additional data field will allow the Trust data to be split.

JW will be available to visit and work with teams across the region to help improve the quality of data collection.

Two Quality Improvement Leads have been appointed to set up spotlight audits. These will pick an area where they will ask units to submit 4 or 5 additional items for central analysis; constructive feedback will be provided where necessary.

11. Any other business

Members of the group are to contribute ideas for the next meeting agenda.

Date of next meeting: Tuesday 23rd May 2017