



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

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

**10:00 – 16:00, Wednesday, 22nd April 2015, South West House, Blackbrook Park Avenue, Taunton,
TA1 2PX**

This meeting was sponsored by Merch Serono

Chair: Mr Michael Williamson (MW)

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 SWSCN website	
Representatives from Gloucestershire Hospitals were welcomed as new members of the group. Due to patient referrals going both to the Midlands and to the SWAG region from Gloucestershire Hospitals (Glos), it would be necessary for representatives from Glos to attend both the SWAG and Midlands SSG group meetings.	
2. Review of last meeting notes	
As there were no amendments or comments following distribution of the notes from the meeting on the 24 th September 2014, the notes were accepted.	
3. Clinical opinion on network issues	
3.1 Network Update	
The cancer network is no longer called ASWCS. To reflect the addition of Gloucestershire Hospitals to the network it is now called Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Services.	
The SSG Support Manager, Helen Dunderdale (HD), and SSG Support Administrator, Samantha Larsen (SL), have now been in post for 8 months. Their posts will be funded for one year by the South West Strategic Clinical Network. Funding for the posts after this year will be provided by the acute Trusts, with the cost of the SSG service divided, based on Trust size (calculated from numbers of cancer treatments), plus the number of SSGs within the region in which each Trust would participate. This has been agreed by all Trusts for the next 5 years.	
Any operational issues that are identified within the SSG meetings will be escalated to the Cancer Operational Group, and any funding issues will be escalated to the commissioning groups via the South West Strategic Network Cancer Manager, Jonathan Miller.	
Commercial sponsorship will be sought to assist with funding venues and refreshments for SSG meetings.	



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Continuous Professional Development accreditation from the Royal College of Physicians will be applied for when the SSG meetings have educational content.

HD has been nominated by the SSG Chairs as the NHS member of staff responsible for user representatives' issues and information and will provide user representatives with information prior to the meetings, supply user involvement handbooks and opportunities to attend relevant workshops. Rowland Hackett is happy to continue as the user representative of the group.

The SSG Support Manager will create drafts of the following SSG key documents by April 2015 for approval by the group by the end of June 2015:

- Constitutions
- Clinical Guidelines
- Work Plans

The SSG support team have been granted access to add content to the South West Strategic Clinical Network website:

<http://www.swscn.org.uk/networks/cancer/site-specific-groups/aswg-site-specific-groups-2/>

Once notes and actions have been uploaded, the link will be emailed to the group. Sections have also been added where it is possible to upload GP referral information, information for SSG members, and patient and public information. SSG members are to inform the SSG support team if they have any content to add to the website.

3.2 Review of MDT membership / changes

A list of the SSG delegates was circulated so that members could check that relevant colleagues had been identified. Additions were made to the list. A shortage of imaging specialist members was noted. The list will be updated and relevant radiologists will be invited to attend.

HD / SL

4. The National Survivorship Programme

Presentation by Catherine Neck (CN)

Please see the presentation uploaded on to the SWSCN website.

Due to the ever increasing population of patients living with and beyond cancer, the current follow up systems are not sustainable, therefore new methods need to be established to provide the support that patients require to lead as healthy and active a life as possible, for as long as possible. In order to achieve this, a risk stratified redesign of the follow up pathways is required, which will be based on the clinical condition and the individual needs of patients. Conventional follow up leaves patients with various needs not met, and has been found to be ineffective in the detection of recurrence, with most recurrences of disease occurring outside routine follow up. Implementation of the

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Recovery Package is recommended as an alternative. The *Recovery Package* consists of holistic needs assessments, extended treatment summaries to improve the communication between secondary and primary care, patient education and support events. Access to remote monitoring and open access back into specialist services would have to be made available. A General Practitioner Cancer Care review (CCR) also requires completion by GP practices within 6 months of the practice being notified that a person has been diagnosed with cancer, to ensure consistency and quality of care. Implementation of these changes is one of the four priorities of the commissioning groups, with the emphasis not being on making cuts, but using the money for follow up more effectively.

The group was invited to contact CN if they require any help to map follow-up pathways relating to this. Gloucestershire Hospitals are under the remit of a different Macmillan Survivorship Lead.

The presentation also introduced the Prehabilitation project. This has been piloted in Upper GI services in UH Bristol for patients having an oesophagectomy and surgery for gynaecological cancers, and in NBT for patients with kidney cancer. At the point of diagnosis, the patients have an interview with the Band 4 Macmillan cancer support workers prior to the neoadjuvant chemotherapy period of their treatment. Health and wellbeing advice is provided. The feedback from patients is that they feel very much supported. Patients have managed to maintain and improve their physical function during their treatment. CN is currently seeking funding to extend this service to other disease sites.

The issues with managing remote surveillance were discussed. The complete transfer of surveillance to primary care was not considered a possibility. Some Trusts within the network have remote monitoring IT systems which send alerts when patients' tests are due. The system within NBT was thought to have cost approximately £10,000. RUH also have a PSA tracking system that was accessible anywhere and thought to be less expensive. Due to IT issues, it was 2-3 years before the system at TST ran correctly. Weston has a remote surveillance system in place for the last ten years that works well. The various software systems in the other Trusts will be investigated by Yeovil.

It was felt that the wording associated with the Survivorship Initiative was not thought to be intuitive to the general public. For example, the terms 'holistic needs assessment' and 'key worker' might be unfamiliar and potentially confusing.

There was concern about the potential risks associated with making patients responsible for managing their own follow up. Rowland Hackett had recently attended a survivorship meeting with two other user representatives to give their opinions on three potential risk stratified pathways. They all thought it was a good idea to have your follow up tailored to suit the individual needs of patients. For example, no one wants to wait in a clinic for hours just to be told good news. If the results of a blood test or CT are reported as normal, it can be arranged with the patient how they would like to be informed, be it by letter, email or text. This frees up the capacity of the clinics and stops the patient having to wait for an unnecessary appointment.

Representatives from the individual Trusts were asked how the implementation of the

recovery package was progressing. Wellbeing events are being held in the Trusts in different formats aside from GLOS and RUH who are looking to establish this in the near future. All Trusts aside from RUH are doing the extended treatment summaries, which is work related to a CQUIN, and completing holistic needs assessments.

5. Cancer Waits: The Good, The Bad and Patient Choice

Presented by Teresa Coombes (TC)

Please see the presentation uploaded on to the SWSCN website.

The presentation brought together the collective views of the Cancer Managers. There has been a National slide in Cancer Waits Performance that has created anxiety across all areas. Cancer Managers are discussing the need to identify where the issues are occurring in the pathways with all SSGs so that unnecessary delays can be avoided. For many of the cancer sites, problems occur when patients move between Trusts, which is not so much of an issue for colorectal patients, apart from the need for access to radiotherapy. None of the SSGs are consistently achieving the 62 day target. Examples of good and challenging pathways, pathways affected by patient choice, and potential ways to problem solve the challenging pathways, were discussed as documented in the presentation. Access to endoscopy was identified as one of the biggest challenges. The group were encouraged to share best practice and rethink the current pathways to make them as streamlined as possible. TC is currently doing some work on this.

6. Clinical Guidelines

6.1 Review of any amendments to imaging, pathology, chemotherapy, surgery and radiotherapy practices:

The clinical guidelines are currently being updated and will be circulated to the MDT Chairs for their consideration prior to the end of June.

6.2 An update on the genetics of colorectal cancer, with specific regard to lynch testing:

Presented by Alan Donaldson

Please see the presentation uploaded on to the SWSCN website.

A freedom of information (FOI) request was recently sent to all of the Trusts in the network, to establish whether they were performing mismatch repair immunohistochemistry testing for Lynch syndrome in patients diagnosed with bowel cancer, who were under 50 years at time of diagnosis. This was recommended in the Royal College of Pathologists' minimum dataset guidelines for colorectal cancer (July 2014). RUH had not been routinely performing this. Alan Donaldson was invited to the group to explain its importance and give a general update on the genetics of colorectal cancer.

Tumour analysis is performed to identify those individuals for DNA analysis whose

colorectal cancer may be due to Lynch syndrome. The information may be important to the decisions made by oncologists due to the poorer response patients have to 5-Fluorouracil. Lynch syndrome (also known as hereditary non polyposis colorectal cancer) is an autosomal dominant disorder that accounts for 1-5% of all colorectal cancers. It is due to mutations in one of the mismatch repair genes and causes a 50% accelerated process from normal polyp to cancer in females, and 80% in males. The mismatch repair genes produce proteins that identify and repair DNA replication mistakes, so mutations of the genes impair this process. The Amsterdam Criteria for testing for the syndrome can be found in the presentation. The tumour is stained to look for the mismatch repair proteins. In Lynch syndrome, one of the proteins will be missing. The DNA analysis will look for microsatellite instability (MSI) present in an electropherogram trace. In normal tissue, one peak will be recorded, whereas in abnormal tissue, there will be a double peak (as shown in the presentation). There can be sporadic loss of MLH1 in 10 – 15% of all colorectal cancers; this is associated with DNA methylation and BRAFV600E in colonic tumours, but not endometrial. The advantages of testing for MSI are that it has better sensitivity and specificity than immunohistochemistry (IHC) and is able to detect BRAFV600E mutations. The disadvantages are that it is more expensive than IHC and doesn't tell you which genes are involved. Newton Wong at the Bristol Royal Infirmary does both IHC and MSI tests. Many more clinicians across the cancer sites are requesting genetic tests and the costs are being reduced.

The process for consenting patients to have DNA testing and where this should fall in the patients' pathway needs to be defined. If the results are going to inform what chemotherapy a patient may have, the potential to have the DNA testing prior to the tumour test might be necessary. With the current service, it was not thought to be possible for the geneticists themselves to consent and process the test within a short time frame. Patients under 50 could be consented at the same time that they were consented for their operation. Patients can be reassured that there is a voluntary agreement that insurance companies will not ask about genetic testing. It was decided that the results of the testing should be sent back to the MDT.

The plan for the network will be to test all patients under 50 for Lynch syndrome. The consent forms will be sent by AD to HD to publish on the website. A flow chart will be developed to show where the test will sit on the patient's pathway.

**AD /
HD**

6.3 Self-expanding metal stents usage in the region

All Trusts usage of self-expanding metal stents will be in accordance with the updated clinical guidelines.

6.4 Barium enema (BE) usage in the region

TST were still using BE when there were restrictions in the capacity to provide CT colonoscopies, but this has been resolved due to the national shortage of BE leaving no other option than to make the resources available to the radiographers. Weston also used to use BE when there were problems with capacity; this has been resolved in the same way.

6.5 The management of early rectal cancer

Presented by Jonathan Ockrim

The management of early rectal cancer was discussed in relation to MDT decision making and methods of surgical procedures. The current clinical guidelines state that all patients with early rectal cancer should be referred to the trans anal endoscopic microsurgery (TEMS) service in Bristol Royal Infirmary. Referral to Cheltenham's service needed to be added to this list.

The group were asked to consider whether it would be appropriate to offer patients a local palliative resection if that patient refuses to travel to the centres and was comorbid, but would benefit from surgery to relieve uncomfortable symptoms. In this scenario, the patient would be fully informed that the gold standard for the management of early rectal cancer would be to travel to the services at either Bristol or Cheltenham. The group agreed that they would support the decision for local surgery in this particular set of circumstances. All persons with potentially curative early rectal cancer should be referred to the specialist centres.

Agreed

The equipment to perform TEMS was considered expensive and other options were now available. For example, the equipment to perform trans anal minimal invasive surgery (TAMIS) is a totally disposable piece of kit that can be used with other equipment such as diathermy or a scalpel. There were also other platforms available. The clinical guidelines will be amended to state 'surgical resection' rather than limit performing the procedure to one platform.

MW

7. Coordination of patient care pathways

7.1 Update of NICE suspected cancer guidelines and two week wait (2WW) referral forms

The NICE guidelines for the referral of suspected cancer are currently being updated and will be published on the 23rd June 2015. The two week wait forms will have to be revised to reflect the NICE recommendations and this will provide an opportunity to standardise the form across the network. The guidelines have been based on a mathematical model that aims to increase referrals to cancer services. Statistics indicate that there will be a 15% increase in referrals per year.

7.2 Update on the colorectal pathway project

Presented by Mark Rawles

The colorectal diagnostic pathway project is running to timeline. It is fully included in the ACE programme and details will be published on the SWSCN website in the next few weeks. The initial fact finding stage is complete and the project is now moving to the next stage. Challenges have arisen around obtaining timely, accurate data from the National datasets. The intention of the project is to develop a business model that will inform commissioning intentions. Having assessed the current services across the region, there are many variations in the diagnostic pathways and good practice that will be useful to

share. The results will be presented at the next SSG meeting.

MR

7.3 Primary care referral process in North Bristol Trust

Presented by Sarah John

Please see the presentation uploaded on to the SWSCN website.

North Bristol Trust changed its colorectal referral pathway in January. Referrals can now be made through the new referral route on ICE. NBT was aware that the previous colorectal 2 week wait pathway did not meet the NICE guidelines for best practice. The Trust therefore undertook a large scale review of the pathway aiming to streamline the process, and ensure that diagnostic tests and decisions were made at the earliest possible stage, as detailed in the presentation. So far the average referral time has been reduced from 14 to 8 days and is already improving the 62 day target, and reducing the pressure on the radiology department. So far no inappropriate referrals have been received through the system.

UH Bristol and Weston also have ICE, but this is not available in the other Trusts. The CNSs at TST triage patients via their nurse led telephone clinic.

8. Patient experience

8.1 User representative input from Rowland Hackett (RH)

The web pages developed by the SWAG user involvement group have not yet been published on the SWSCN website. HD currently has to prioritise completing Peer Review documents. User involvement information will be revisited later in the summer.

HD

The user representative groups in the Peninsula operate differently from the former SWAG user group as they are based within the Trusts, and have strong links with the clinical teams and current issues. The possibility for setting up similar user involvement groups within the SWAG region was raised. This will be escalated to the Cancer Operational Group.

HD

RH was asked by Rob Lutyens, Macmillan Acute Oncology Lead Nurse, YDH, to provide patient insight into the experience, feelings and thoughts around diagnosis through to treatment. This was to be used in a series of study days to raise awareness among nurses of the whole patient pathway.

An update on the effect of the flexible sigmoidoscopy screening trial for people aged from 55 years was requested. This will be completed in the South West by the end of the year. The success of the trial will be measured in approximately 10 years' time.

8.2 Review of the National Patient Experience Survey

Please see the presentations uploaded on to the SWSCN website

The Clinical Nurse Specialists (CNSs) discussed the results from the National Patient Experience Survey, looking at Trust level best practice to be shared, Trust / network level priorities identified for pathway improvements, and the actions required to address identified priorities, as detailed in the presentations. Overall, an increased need for patient information was the most common issue, particularly on how to get financial help and information on clinical trials. The CNSs had already addressed this by adding relevant leaflets to the patient information packs. The methodology of the survey was questioned as local surveys conducted in some of the Trusts get very different results. The survey is currently out to tender.

9. Quality indicators, audits and data collection

9.1 Auditing MDT discussion recommendations versus eventual treatment

Presented by Ann Lyons (AL)

A network wide observational audit of whether MDT decisions are followed through in reality will be undertaken by looking at prospectively recorded data. Data will be collected on the patients discussed in the past 50 MDTs by going backwards from the 1st of March to identify if the decisions were implemented. The information can be gathered from the SCR or clinic letters / notes and there will also be an MDT team questionnaire. Once completed, the potential to publish the results will be explored. The audit department and various junior doctors in NBT are ready to start the data collection. A few questions are specifically for the MDT coordinator to answer. Treatment will be defined as the decision to treat for the first definitive treatment (within 31 days). This will be written into the inclusion criteria. The audit department in NBT will contact the audit departments within the other Trusts to ask for their assistance. There are still some decisions to be made on defining the inclusion criteria and AL will doodle-poll the group to facilitate agreement on these.

AL

9.2 90 day mortality statistics

A funnel graph from the National Bowel Cancer Audit Report (2014) that showed the observed and adjusted 90 day post-operative mortality (elective and emergency) by Trusts was reviewed. It had only been possible to distinguish where Gloucestershire Hospitals was placed in the graph prior to the meeting. A funnel graph of the individual Trusts results will be plotted for review at an SSG meeting in the future.

HD /
MW

9.3 Feedback from NBOCAP / data collection issues

The death rate reported by NBOCAP from TST appeared to have been corrupted. A figure of 8.7% was reported. On repeating the analysis of the data over the same period of time, a figure of 2.2% was calculated. A possible explanation was thought to be that the Trust data is compared with HES data, and if the data doesn't match up, the HES data is used for the final results. Data collection and surgeon level reporting will be explored in more

depth at an SSG meeting in the near future.

10. Service Development

10.1 Cheltenham's brachytherapy unit

Neil Borley (NB) explained that, although funding had been agreed for Cheltenham's brachytherapy unit several years ago, the service was not currently running due to low patient numbers. However, if there is a will to refer patients, and sufficient patient numbers, the service is all ready to run.

Brachytherapy is suitable when local excision from other platforms cannot be offered due to a patient not being able to tolerate a general anaesthetic, or to avoid potential unpleasant side effects from a surgical procedure. For a lesion of the right size (the maximum capacity is 4 ½ cm), it can offer the patient a complete ablation of the tumour in 1-2 treatments.

It was thought to be highly beneficial to have this different treatment option available, and several clinicians felt that they had patients who would benefit from brachytherapy.

10.2 The Enhanced Recovery Programme (ERP)

The Enhance Recovery Programme was not discussed due to time constraints in the meeting.

10.3 Training opportunities

A list of Pelican Courses that are available in 2015 was reviewed. This will be uploaded to the SWSCN website.

HD

11. Research Update

Please see the presentation uploaded on to the SWSCN website.

Maxine Taylor (MT) provided a research report that detailed the clinical trials which were open across the region, and the most recent recruitment figures. Stephen Falk has agreed to remain the research lead for the SSG. All members were encouraged to continue recruiting patients to the relevant trials.

12. Peer Review

Review of draft constitution

The MDT leads provided information that will be updated in the Colorectal Constitution. This will be circulated for proof reading prior to the end of June.

HD

13. Any other business



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It was agreed that Rob Longman (RL) will give a presentation of the management of anal cancer and AIN practice at the next SSG meeting.

RL

Date of next meeting: 14th October 2015

DRAFT