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

Meeting of the SWAG Network Colorectal Site Specific Group (SSG)
09:30-15:00, Wednesday, 10th January 2018
Holiday Inn Taunton, Deane Gate Avenue, Taunton TA1 2UA

Chairs: Mr Michael Thomas (MT) & Ms Julie Burton (JB) **ACTIONS**

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 South West Clinical Network website here.

2. Review of previous notes and actions

As there were no amendments or comments following distribution of the minutes of the meeting on Wednesday 7th June 2017, the notes were accepted.

Actions:

Standardised radiology reporting: Further to the previous presentation on standardised reporting, Consultant Radiologist Eric Loveday (EL) will circulate details to radiology colleagues across the region aiming to reach a consensus prior to the next meeting. **EL**

Swindon team attendance at SSG: The Swindon team have been invited to join the meeting for networking purposes.

Surgical and Oncology treatment summaries from Anal Cancer Service: Methods to improve communication to referring provider Trusts on anal cancer treatment in the Bristol Royal Infirmary are currently being investigated. **MC/MT**

Taunton Service DVD: The DVD provides patients with an insight into each hospital department involved in the treatment pathway; this will be made available to the team at UH Bristol who will consider producing a similar resource. **HD**

Continual Professional Development (CPD) Accreditation: A retrospective CPD application for the meeting is underway. **HD**

3. Living With and Beyond Cancer (LWBC)

3.1 LWBC update and risk stratification of patient follow up

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), for the implementation of the LWBC Recovery Package. Work will begin on Breast, Colorectal and Prostate cancer patients; risk stratified pathways for colorectal cancer patients need to be in place by the end of 2018/19.

The National Board will collect metrics on the provision of two holistic needs assessments (HNA) to patients; one within 31 days of diagnosis, and one within 6 weeks of completing treatment. Metrics also include the offer and uptake of Health and Wellbeing (H&WB) events, provision of treatment summaries and a GP cancer care review.

Funding will be used to recruit Cancer Support Workers to assist with delivery of HNA and H&WB activity, development of a Digital Patient Information Portal and of the Somerset Cancer Register (SCR)/ InfoFlex to support data collection, implementation of 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 group is Dr Dorothy Goddard. Further details on the governance of the project and structure of the Cancer Alliance are documented within the presentation.

Colorectal risk stratified pathways have been drafted. An initial draft was discussed at the last SSG and has subsequently been revised according to advice from the Yeovil team (who have approximately 70% of patients on a self-management pathway and a system for open access), and has been recirculated. It was recognised that patients may move between the risk-stratified groupings according to clinical needs, and that there may be local variation on surveillance investigation types. The pathway will be circulated for final agreement within the next two weeks. End of treatment summaries that had also been circulated received positive feedback and will be adopted. As advised by CNS Mia Fox, an individualised end of treatment summary will be provided for patients with early rectal cancer. **CN**

Work is underway to identify a provider to develop the Digital Patient Portal; a patient representative is involved and clinical representatives are now required. Consultant Radiologist Eric Loveday agreed to assist in the assessment. **EL**

A robust surveillance investigation tracking system is needed to ensure that those patients referred to self-management are not lost to follow up. Patients who are non-compliant with attending surveillance appointments are moved back on to nurse-led follow up. Bespoke databases are currently used in some centres. Ideally the Somerset Cancer Register would be reconfigured to accommodate this information; this will be raised with the South West Cancer Alliance Manager Jonathan Miller (JM) who is liaising with the SCR team. **HD/JM**

It was noted that Health and Wellbeing events were offered across the region in varying formats. The different approaches will be assessed to decide how these might be standardised and attendance optimised.

Completion of HNA at the end of treatment was already progressing well across the region; while the early HNA was not formally completed, the CNS team do informally

discuss needs at that point in the pathway. Completion may prove difficult due to the rapid process of treatment for colorectal cancer patients and it was important to recognise that patients may require an HNA at points in the pathway that differ from the standard metrics.

4. Service Development

4.1 Cancer Alliance Faecal Immunotherapy Test update

Please see the presentation uploaded on to the SWCN website

Presented by Lynne Kilner (LK)

The National Cancer Transformation Board has awarded transformation funding to the South West Cancer Alliances (CA) to improve the earlier diagnosis of colorectal and lung cancer. To achieve this for colorectal cancer, the CA has made a commitment to introduce the faecal immunotherapy (FIT) test for the patients referred to as low risk but not no risk, as indicated in and to comply with NICE suspected cancer referral guidelines (2015). Further details are documented within the presentation.

The CA FIT steering group convenes monthly to agree the protocols and processes required to implement the change. Funding has now been received after a six month delay and is currently being held by the Bristol CCG while the proposal for approaching potential laboratories is ratified. It is hoped that FIT can be made available in a phased approach from April 2018, provided an agreement can be reached with local organisations on the processes. NICE recommends three potential kits for the test, all equally effective; the laboratory undertaking the contract will decide which one to purchase. Once the infrastructure for delivery of FIT has been established, it is hoped to extend its use to other parts of the patient pathway, should evidence from the Cancer Vanguard show that it is a robust alternative to diagnostic and surveillance interventions.

5. Patient Experience

5.1 National Cancer Patient Experience Survey (NCPES) Results

Please see the presentation uploaded on to the SWCN website

Presented by Julie Burton (JB)

The NCPES 2016 results, posted to inpatients and day case cancer patients between April and June 2016 and published in July 2017, were reviewed in comparison with the national average and 2015 results. The region was noted to have equal to or greater than the average national response rate. As the results were over a year old, it was necessary to think back to the service that was being delivered at that time and take note of any subsequent changes. Results for Weston were not available as only 19 responses had been received and 21 responses were needed for each question to be published.

The following questions from a total of 50 in the survey from before, during and after

cancer treatment, had been picked out for discussion.

Question 9: *How do you feel about the way you were told you had cancer?* Results showed all Trusts performing well, with UH Bristol making a significant improvement between 2015 and 2016. Many of the other questions showed the same; this could be attributed to the appointment of a 3rd CNS to the team, demonstrating the qualitative value of the CNS role.

Many of the questions were open to interpretation; a patient may perceive that they were told about their diagnosis at the point of endoscopy for example.

Question 10: *Did you understand the explanation of what was wrong with you?* Results from NBT showed a significant improvement in this area. This was thought to be due to the provision of patient information booklets and, in particular, the clinician's familiarity with the contents of the booklet and making it bowel cancer specific rather than generic. It was also thought to be due to the CNS time spent in clinic. The user representative member of the group, Jackie Mifflin (JM), noted that the diary supplied by the Yeovil team had been very useful.

Question 11: *When you were told you had cancer, were you given written information about the type of cancer you had?* The results from this question contradict the results from Question 10, showing how the survey questions may often be misinterpreted.

Question 16: *Were you involved as much as you wanted to be in decisions about your care and treatment?* Showed universal regional improvement.

Question 17: *Were you given the name of a CNS who would support you through your treatment?* There had been a slight drop in these results, although no drop in CNS workforce. This could be due to CNSs going into uniform, sharing the contact with patients and merging with other teams; if this was the case, it was likely to deteriorate further in future. It was noted that an insignificant percentage change looked very significant in graph form. Also, it is known that there is a limit to the amount of information that a patient can take in after receiving their diagnosis. JM concurred, having not retained anything after receiving a positive diagnosis, and she had ensured that her daughter attended consultations with her for the first couple of months to provide a 'second pair of ears'.

It was considered advisable to ask a patient what they understand is happening at the beginning of each consultation so that the level of information that needs to be reiterated can be assessed.

Question 18: *How easy or difficult has it been to contact your Clinical Nurse Specialist?* Had very positive, encouraging results.

Question 26: *After your operation, did a member of staff explain how it had gone in a way you could understand?* The significant improvement in results from UH Bristol and NBT was thought to be due to the CNS team attending the ward to visit patients post-op.

Question 29: *Did you have confidence in the doctors treating you?* Showed a positive result for the Taunton team.

Question 38: *Were you given clear written information about what you should or should not do after leaving hospital?* Engagement in the Enhanced Recovery Programme was thought to have improved results to this question in NBT and UH Bristol. Since the last results, YDH have produced relevant patient information leaflets.

Question 39: *Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?* Had a mixed response that did not tally with the results of the previous question.

Question 49: *Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?* Taunton performed particularly well in comparison to other Trusts; it was not clear how this had been achieved. This should improve with the completion of HNAs.

Question 55: *Have you been given a care plan?* Received positive responses; this was thought to be related to the care plans generated after completion of HNAs. It was recognised that a patient's interpretation of the questions may differ because of the word choice used; for example, the question about research versus a question about a clinical trial.

Question 58: *Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?* Had a good response from across the region.

Question 59: Overall, how would you rate your care (out of 10)? The majority of Trusts improved or maintained positive feedback in comparison with the previous year.

The majority of comments received in the free text part of the survey were positive.

WGH have arranged for a survey using the same questions to be given out locally; the main problem with getting responses was the number of questions. The Cancer Alliance is investigating how to improve results from the questions relating to primary care. It is hoped that the direct to test system, available in NBT, would show an improved response to the question on the length of time patients had to wait for the first test.

Events held for MDT members to communicate how to make appropriate suspected cancer referrals to GPs have proved very helpful.

A National Cancer Diagnosis Audit was undertaken to understand why referrals take longer in certain regions. Macmillan is launching a Significant Event Analysis (SAE) toolkit to help GPs improve early diagnosis of cancer.

5.2 User representative/CNS update

The User Representative member of the group was alerted to possible symptoms of cancer after reading an article in the Daily Mail in April 2016, after which an appointment was made with her GP and she then entered the rapid patient pathway from diagnosis to treatment, including a challenging 6 months of chemotherapy. After writing to the Daily Mail to thank them for the article, they published her story.

One of the most reassuring appointments in the pathway was noted to be the post treatment follow up appointment; the biggest fear for patients is the potential for recurrence, knowing that there was a surveillance schedule over the next 5 years was very benefit.

JM decided to get a job within the hospital environment, and has found that the work has provided her with a beneficial outlook on life which has aided her recovery. An account of the experience of having a stoma has been written for publication on the Bowel Cancer UK website and, with bowel cancer becoming more prevalent in younger people, volunteer work has also been undertaken for the charity to raise awareness in the region.

The ability to talk openly about the cancer treatment, especially stoma care, has improved the capacity to come to terms with the experience, as has adopting a humorous approach. Talking frankly with friends and family also helped alleviate the fear of bringing up the subject and also works to help spread awareness.

JM was thanked for sharing her experience with the group.

5.3 CNS Update

Incorporating the workload associated with implementing the recovery package with other priorities and limited resources, over a significant period of time, has been difficult to manage to date. The CNS team are looking forward to the appointment of Band 4 Support Workers to improve the workload balance.

6. Clinical guidelines

6.1 Significant Polyp and Early Colorectal Cancer (SPECC) Workshop

Please see the presentation uploaded on to the SWCN website

Presented by Ann Lyons

The following subjects were discussed in the workshop:

- Definition of significant polyps (>20mm) and the role of the MDT
- Endoscopic aspects of recognition and definition
- Triple assessment for rectal lesions
- Significant lesions on MRI
- CT colonoscopy
- MDT case study

- Endoscopic excision
- Transanal excision (Wolf TEM technique and TAMIS)
- X-ray brachytherapy (Papillion technique – to raise the possibility of offering this within the region with Stephen Falk). **HD**

There was no consensus over resection versus organ preservation with pre-operative radiotherapy. Patients opting for organ preservation should enrol in the STAR-TREC trial, although it was unclear if the trial would complete successfully. Caution was required on decision making with patients due the lack of evidence; an intensive follow up regime of endoscopic biopsies, ultrasound and MRIs would be required to detect possible recurrent disease. A presentation on pathological complete response post neoadjuvant radiotherapy will be requested for discussion at the next meeting. **HD**

There was an interesting discussion about endoscopic submucosal dissection versus endoscopic mucosal resection and the benefit of a non-piecemeal resection.

Resources from the workshop are available on the Pelican Foundation website here.

An SSG straw poll on the management of significant polyps across the region showed variation in practice. It was the recommendation of the group that significant polyps (>20mm) should be discussed and tracked in conjunction with the cancer MDT and gastroenterologist colleagues; a letter to this effect will be written on behalf of the SSG for escalation to operational management teams. **Agreed HD/MT**

7. Network Issues

7.1 100,000 Genomes Project and mainstreaming genomic medicine

Please see the presentation uploaded on to the SWCN website

Presented by Catherine Carpenter-Clawson (CCC)

The West of England GMC had received their first result for a cancer patient on Monday. Many interesting results have been returned for patients in the rare disease arm of the project; patients with multiple polyps would be eligible to be consented to this group.

At a meeting in December 2017, an update was provided on the 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. Locally, the colorectal pathway is open in North Bristol Trust, UH Bristol and RUH Bath. 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 re-procurement 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.

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 explored. Areas where further evidence on whole gene sequencing 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.

Applications can be made to access results for relevant projects in the future.

7.2 Surveillance guidelines for Lynch positive patients

Please see the presentation uploaded on to the SWCN website

Presented by Michael Thomas

Lynch syndrome, also known as hereditary non-polyposis colorectal cancer (HNPCC), is a complex syndrome to define. It refers to a number of genetic abnormalities that mean a patient has a predisposition to develop cancer in different sites, the most common of which are uterine, gastric, and colorectal. Testing for these abnormalities can sometimes be misinterpreted in the press as 'screening for Lynch'.

Previous guidelines stated that all patients under the age of 50 should be tested for the abnormalities. NICE has now published guidelines recommending that all patients with colorectal cancer are tested; a business case is currently under review in NBT to see how this can be delivered across the region.

GP colleagues have requested surveillance guidelines for people who have been identified with these genetic abnormalities.

There was an initial discussion on the following draft guidelines:

- All people with a Lynch syndrome mutation are referred to a clinical geneticist for genetic counselling and provision of information to families about the condition
- All people with a Lynch syndrome mutation are recommended to take aspirin if tolerated (evidence of the benefit is strong; the dose is uncertain, but longitudinal intake has been found to be important)
- All people with a Lynch syndrome mutation are to be offered total colonic surveillance at least every 1-2 years from the age of 25, or 2–5 years before the youngest age of diagnosis of CRC in the family if diagnosed before age 25 years. Considerations: Start at age 30 years in MSH6 and 35 in PMS2 families
- Annual colonoscopy in MMR mutation carriers
- All women diagnosed with a Lynch syndrome mutation should be referred to the gynae service for discussion of potential risks.

Further evidence needs to be gathered from the genetics team to develop the guidelines further, particularly for the other at risk cancer sites. The draft guidelines will be sent to Consultant Geneticist Alan Donaldson for his opinion.

A Freedom of Information request has been sent to the Clinical Team and the Bristol Clinical Commissioning Group on provision of the test for all CRC patients, and this will be updated with the details sent by Consultant Pathologist Newton Wong, who has submitted the business case mentioned. The recommendation of the group is to implement the NICE guidelines; however, the feasibility of funding for the service was uncertain. The level of risk associated with not providing the service needs to be established. **MT/HD**

8. Coordination of patient care pathways

8.1 Straight to test referrals

It was not possible to standardise straight to test referral processes across the region due to disparities in the hospital information systems available; it will need to be adapted at Trust level, rather than as a network, while ensuring that a positive patient experience is the same across the region. There was thought to be transformation funding allocated to develop straight to test pathways; this will be explored further.

9. Research

9.1 Clinical trials 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. A spreadsheet of all the trials available across the region will be distributed. It was increasingly important to demonstrate that the NHS can conduct effective research to be eligible to open trials run by the pharmaceutical industry, by reducing study set up time and recruiting within estimated times and to target. It would be ideal if expressions of interest for rare cancers could be formulated as a network group. Recruitment could then be sourced from across the region and the centres in which they open could be rationalised.

The recruitment target per 100,000 population for colorectal cancer is 3; this will increase by 10% year on year. Recruitment to date is exactly on target, and is comparable with far larger centres. Recruitment on time to target has improved over the last 12 months due to improved data ratification processes.

SSG members can contact DR if they would like to undertake training on use of the online resources for research; links to these are available in the presentation.

Information on open trials including eligibility criteria will be made available on the SWCN website for review within the MDT.

10. Quality indicators, audits and data collection

10.1 National Bowel Cancer Audit (NBOCA)
Please see the presentation uploaded on to the SWCN website

Presented by Jonathan Randall (JR)

The NBOCA Annual Report states that the data is sourced from April 2014/15. However, the data included appears to reflect 2015/16 activity; the NBOCA will be contacted for confirmation. The mortality data, which is the cumulative number of cases since the data collection began, shows all centres in the region are within expected parameters. The dataset is likely to increase over time; all are to be aware of validating their data for use as an early warning system if indicated.

10.2 Data for regional audits/transfer of patients post treatment/AOB

The SSG Support Service is applying for access to the 5 data dictionaries available from Public Health England Office for Data Release for the purpose of automating processes for network audits. This will include data from HES, SACT, RT and the Cancer Registry. SSG members are asked to identify ideas for useful audits using these datasets. **HD**

A standard operation procedure for ensuring the handover of patients to their referring centres post-treatment, was circulated for agreement. This was deemed suitable for the majority of patients; as previously discussed, a different system will be optimised for the handover of anal cancer patients.

Generic email addresses for SWAG CNS team:

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Date of next meeting: Wednesday 27th June 2018

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