



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

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

Wednesday, 27th June 2018, 09:30-15:30

Penny Brohn Cancer Care, Chapel Pill Lane, Pill, Bristol, BS20 0HH

THIS MEETING WAS SPONSORED BY AMGEN, KYOWA KIRIN & MERCK SERONO

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

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 South West Clinical Network website [here](#).

2. Review of previous notes

As there were no amendments or comments following distribution of the minutes of the meeting on Wednesday 10th January 2018, the notes were accepted.

3. Living With and Beyond Cancer (LWBC)

3.1 Cancer Transformation Funding/LWBC progress

Please see the presentation uploaded on to the SWCN website

Presented by Hannah Manton (HM)

Project Manager HM has recently been appointed by the Somerset Clinical Commissioning Group (CCG) to assist with the delivery of LWBC activity, and will be working with the teams in Yeovil Hospital, Musgrove Park Hospital, Primary Care and community settings within Somerset.

Evidence has shown that many people living with and beyond cancer have unmet needs affecting their quality of life, particularly at the end of treatment; implementation of the LWBC Recovery Package, as documented in the presentation, will aim to address these needs. The SWAG Cancer Alliance (CA) has been tasked with measuring and reporting LWBC activity to the National Cancer Board for prostate, breast and colorectal cancer sites, to ensure that the Cancer Transformation Funding (CTF) given for this purpose can continue; the initiative will be made available for all cancer patients.

CTF has been used to recruit Cancer Support Workers (CSWs) across the SWAG area to assist the CNS teams with delivering LWBC, including completion of Holistic Needs Assessments within 31 day post diagnosis and 60 days post end of treatment. The definition of end of treatment needs to be clarified.

HM

Treatment Summary Templates have been developed as part of the project. These are currently being reviewed to ensure that they are fit for purpose. The Health and Wellbeing Events held in Somerset have received positive patient feedback. It is planned to provide more generic rather than site specific events.

The advice and support available for promotion of healthy living, including exercise schemes, is being mapped. In Yeovil, there is a service called *Spring*, which is a rolling 12 week exercise and advice programme for patients at any point in the pathway. A similar programme called *Energise* is available for Bristol patients. The CNS teams are keen to start a more formal prehabilitation programme; funding is required.

There is a system wide move towards encouraging preventative behaviour for all patients, and a need to provide accessible options so that patients can choose an individual approach.

PREPARE-ABC is a national trial that randomises patients, having surgery to remove part of the bowel, to a pre and post-operative exercise programme versus standard care. An audit of patient outcomes after engaging in programmes such as *Spring* would be helpful to see if healthy behaviour was sustained long term.

The CA has also agreed to implement risk stratified follow up pathways for colorectal cancer by the end of Year 2 of the CTF stream. These have been developed and circulated, and the next step will be to assess how they are put into practice. A gap analysis is underway to ensure that LWBC activity is incorporated in a consistent and sustainable way with the most efficient use of the resources available.

A Band 5 Project Support Role for Somerset is due to be advertised in the near future, and a GP Cancer Road Show Event will be held in Taunton in mid-July 2018.

4. Clinical guidelines

4.1 Complete clinical response following neo-adjuvant chemoradiotherapy for rectal cancer: surgical resection versus organ preservation

Please see the presentation uploaded on to the SWCN website

Presented by Jessica Jenkins (JJ)

The need to review evidence on resection versus organ preservation for patients with a complete clinical response following neo-adjuvant chemoradiotherapy for rectal cancer was raised at the last meeting.

Reports of excellent responses to neoadjuvant chemoradiotherapy have increased over the last decade, with a pathological complete response rate of up to 25%. This had prompted a Brazilian colorectal cancer team to pioneer the Watch and Wait approach to avoid surgery. The associated clinical trial had shown excellent results of disease free survival, and sparked interest in the international community. However, only a small number of carefully selected cases were included, and evidence from later trials was not comparable due to use of different neoadjuvant treatment doses and clinical response rates. There was also a lack of consistency in the patient

characteristics across different trials and therefore insufficient data to draw definitive conclusions, although there was enough information to aid shared decision making with clinicians and patients. Patients should be offered the opportunity to enrol in the STAR TREC or TRIGGER trials, which could provide further clarity on the best approach.

A recent presentation on the subject at the American Society of Colon and Rectal Surgeons conference in Seattle advised that the surveillance schedule for Watch and Wait should be 4 monthly MRIs for 2 years. Patients have requested this, but it is not feasible in all centres due to current radiology capacity. One centre has opted for a 6 monthly follow up with flexible sigmoidoscopy. Another centre has a cohort of patients going for 3 monthly MRIs and flexi-sig; the question of whether PET-CT should be part of surveillance was raised. An intensive surveillance schedule of some sort is essential for the management of Watch and Wait.

There was also some evidence from a study in the USA that surgery followed by adjuvant radiotherapy had better outcomes.

A review of each centre's processes will be presented at the next meeting.

MDT Leads

The CNS team in NBT are auditing the patient experience of Watch and Wait and will present their results at the next meeting.

NBT CNS Team

The user representative members of the group felt that they would have opted for surgery rather than the Watch and Wait option, due to the level of anxiety that this would generate, and thought that the age of a patient would be a significant factor in the decision making process.

There was a need for multiple opportunities to discuss treatment options repeatedly with patients, to ensure that they have retained the information given in consultations, and have a thorough understanding of the options available to them.

Development of a regional register of relevant patients will be explored for the purpose of defining a regional policy for surveillance. A register was available via the Pelican Cancer Foundation charity, from which local data can be exported. Ideally retrospective data should be collected, and all patients included. A data sharing agreement will be required; Registrars will be enlisted to assist with the data collection. Consultant Colorectal Surgeon Jonathan Ockrim (JO) will initiate the plan.

JO

The Somerset Cancer Register is developing a remote surveillance system which could tie into this work at some point; a representative will be invited to give an update on progress at the next meeting.

HD

5. Network issues

5.1 Clinical advice for the Commissioning of the Bowel Cancer Pathway

Please see the presentation uploaded on to the SWCN website

Presented by Michael Thomas (MT)

The document Clinical Advice for the Commissioning of the Whole Bowel Cancer Pathway, published by the Colorectal Cancer Clinical Expert Group in November 2017, provides guidance for Cancer Alliances, Commissioners, Acute Trusts and patient groups on the best clinical practice for patient care.

The report states that patients presenting as an emergency should have surgery under the care of a Consultant Colorectal Surgeon who is a member of a colorectal MDT, within and out of normal working hours, and that this may require collaborative working between Trusts. This was not going to be consistently achievable 100% of the time across the region given the current number of consultants, but provision of remote input/advice is feasible. It was noted that all surgeons are trained as general surgeons prior to specialising.

Increasing the number of surgeons would have an impact on the distribution of surgical resections. The guidelines state that each surgeon should undertake 30 procedures per year, although it was noted that joint and benign procedures have been included in this number.

The diagnostic service for straight to test referrals is in line with current and emerging practices. Trusts are implementing this pathway in a variety of ways according to local systems and priorities.

For those patients with investigations that do not reveal cancer but a symptomatic condition manageable in primary care, the recommendation is to provide advice on self and primary care management. A streamlined process for such communications is required.

The recommendations on adequate provision of a CNS workforce appear to make common sense.

GPs should receive notification of the diagnosis within 24 hours as a matter of routine.

The recommendation to send patients diagnosed with Inflammatory Bowel Disease (IBD) to the IBD MDT was not possible across the board; not all centres have this facility.

NICE guidance on screening all patients with CRC for Lynch Syndrome has been included in the document. Some providers are trying to absorb the related costs into the existing service, but formal funding is required.

Guidelines for the surveillance of patients with Lynch syndrome had been drafted at the last meeting. These have now been proof read and amended by Consultant Geneticist Alan Donaldson, and will be circulated for further ratification by the group prior to circulating to the Macmillan GPs and other relevant site specific groups.

HD

BRAF gene mutation tests are routinely performed in the majority of centres. It will soon become routine practice in all centres, due to the cost savings associated with some chemotherapy that has been found to be ineffective on BRAF positive colorectal cancer.

A specific chemotherapy CNS is not available in each Trust, although there are 24 hour helplines.

There was nothing controversial in the colorectal best practice timed pathways apart from the ability to meet targets with the existing endoscopy and radiology capacity; the shift to the 28 day target from referral to diagnosis will also prove challenging. The underfunded services will have funding reduced in the event that the targets are not met.

6. Coordination of patient care pathways

6.1 Straight to test referrals

This subject will be deferred to the next meeting when it is hoped that Gastroenterology colleagues will be available to attend.

7. Service development

7.1 Cancer Alliance Faecal Immunotherapy Test (FIT) project update

Please see the presentation uploaded on to the SWCN website

The two laboratories that have been appointed to analyse FIT tests (NBT and RD&E) have started to send supplies of the kits to GP Practices in the SWAG and Peninsula region. Information has been distributed to GPs on when to use FIT, including a link to this video produced by the Cancer Alliance (CA):

<https://www.youtube.com/watch?v=zb1o8ykvS6U&feature=youtu.be>

The first two samples have arrived back to the labs. There have been no positive tests received to date. Data will be gathered to assess the impact of the test over the next few months.

The Department of Health has decided on a significantly higher FIT abnormality threshold for the bowel cancer screening initiative which could increase colonoscopy workload.

FIT testing has already been rolled out in Scotland, and is working well.

8. Patient experience

8.1 User representative input

User Representative Michael Fowle shared recent experience of one of the region's colorectal cancer pathways, having undergone treatment with surgery and chemotherapy following a diagnosis in 2016. Although assigned a specific CNS contact, it was observed that the CNS team had seemed understaffed, as it was extremely difficult to get hold of anyone.

It was recommended that group sessions with other patients who have gone through similar experiences are arranged at the earliest opportunity, because this can help to alleviate concerns, as experienced on a previous cancer pathway.

Several areas for improvement were identified about administrative communications. When initially referred, the GP said that the referral was urgent and an appointment would be received within 2 weeks. When this did not occur, the process for chasing the appointment was unclear, and needed to be clarified.

A Patient Information Leaflet (PIL) on the 2 week wait referral process has been produced for this purpose and is available for GPs to print out and provide to patients but this was not given to the user representative member of the group. As a recent audit showed that 90% of patients had not been given the leaflet, this will be brought to the attention of the CCGs.

HD

After treatment, a letter was received informing the user representative that a previously booked follow up colonoscopy was postponed. There was no further information included in this correspondence, prompting a phone call to the secretary, who explained that this was due to a management decision. The lack of clarity was perturbing. Eventually a manager was contacted for more information; one of the Consultants called back and clarified that the cancellation was due to workload pressures, and that the colonoscopy would be rescheduled. Slight alterations to letters, such as including this information, or advice to administrators on how to communicate with patients on such matters, would significantly improve the patient experience.

It is important to set realistic expectations when communicating when things are due to occur, for example, patients may be told in primary care that results from a test in secondary care will be available in 1-2 weeks, when the standard reporting time is 4-6 weeks, creating a level of dissatisfaction that could have been avoided.

User Representative Jackie Mifflin has undertaken further volunteer roles, volunteering for Bowel Cancer UK, and has given several presentations on the patient experience of colorectal cancer to different organisations and at Well Being days. The reassurance given by having a clear 5 year follow up surveillance plan at the end of treatment was emphasised.



8.2 Clinical Nurse Specialist update

Please see the presentation uploaded on to the SWCN website

Presented by Julie Burton

Patient focus groups held in UH Bristol had identified that shared care across centres can have a detrimental effect on the patient experience. In response, a shared care patient information leaflet was drafted. This has yet to be implemented. It was still considered to be a good idea to add this information to existing PILs and examples of appropriate wording will be sent to Co-Chair Julie Burton.

CNS Team

A draft standard operation procedure for confirming the process for transfer of patients between organisations after treatment was discussed at the January 2018 meeting, and it was thought at the time that the CNSs team could use their generic email addresses to refer patients back for follow up. The receiving Trust could then provide confirmation for the referrer confirmation that the follow up processes were instigated. It was not apparent if this process was now in place, or if an alternative process should be put in place. Lead Cancer Nurse Carol Chapman (CC) will investigate this on behalf of the group.

CC

A South West Cancer Clinical Nurse Forum held recently had received positive feedback, with interesting, informative presentations by guest speakers. CNS teams are encouraged to attend future meetings.

The Gynae oncology team in UH Bristol has implemented risk stratified Patient Initiated Follow Up (PIFU), and developed wallet sized cards to support this, with information on how and when to re-access services; contact details for the team are on the front, and alert symptoms are on the back. Similar cards are available in NBT, with information on Macmillan on the back rather than alert symptoms. Modifications will be considered.

In UH Bristol, there will be a dearth of CNSs for a time, as 3 members of the team are due to leave within a similar time frame.

9. Quality Surveillance

9.1 Issues arising from Annual Reviews

No specific issues have been highlighted by the Trusts' Cancer Management Teams.

In response to the perception that surgical practice is becoming increasingly risk-averse, a surgical team in Glasgow has changed the way they work by referring all high risk interventions, initially deemed inoperable, for review by a designated 'high risk' surgeon. This ensures that the opportunity for surgery is offered whenever possible; approximately two thirds of the patients referred have gone on to have surgery; to date, the designated surgeon's mortality rates remain within normal ranges. A SWAG approach to management of high risk patients will be raised with the wider surgical team by Michael Thomas, for further discussion at the next meeting.

MT

10. Clinical opinion on network issues

10.1 Multi-Disciplinary Team (MDT) meeting reforms

Please see the presentation uploaded on to the SWCN website

Presented by Stephen Falk (SF)

MDT meetings need to be streamlined to cope with the increasing demand in patient number and complexities.

Key service issues identified by Peer Review:

- A lack of functional Cancer of Unknown Primary teams and robust pathways
- Lack of Clinical Nurse Specialist (CNS) resource and cover
- MDTs who do not meet minimum number requirements for surgical treatments (as defined in Improving Outcomes Guidance)
- A number of core team members not fulfilling the minimum attendance.

The MDT meeting needs to be organised to accommodate the schedules of radiology and pathology colleagues ensuring support for their capacity to attend specific slots.

When looking at time pressures in more detail, it can be seen that the number of MDT discussions had increased exponentially, whereas the number of whole time equivalent (WTE) MDT staffing groups has not. This was expected to become even more pronounced with the reduction in recruitment numbers of non-UK medics.

It is hoped that UK health services will collaborate with NICE and SIGN to identify where protocolised treatment pathways can be developed for MDTs to agree and document where deemed appropriate. Processes for improving the quality of the information recorded are required, as are more frequent operational meetings to help progress change. Please see the presentation for further recommendations.

A meeting of the Cancer Clinical Leads will be held on Monday 16th July 2018 to identify 3 or 4 points for agreement and implementation. Results will be fed back at the next meeting.

SF

11. Research

11.1 Clinical trials update

Please see the presentation uploaded on to the SWCN website

Presented by Stephen Falk

Recruitment figures (sourced from EDGE), open trials, trials in set up and trials open to new sites are documented within the presentation. The recruitment target per 100,000 population for colorectal cancer is 3. Recruitment to date for 2018-19 is slightly below target, which means that the region are recruiting well, given that the portfolio for colorectal is at present sparse.



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Long term improvement plans for research include developing the role of Principal Investigators and Chief Investigators. Over the past 5 years, there has been a fracturing of the University and NHS union, driven apart by funding. Although this has made coordinating research difficult at present, there is optimism that this will gradually repair in the near future, with provision of NIHR fellowships, academic training schemes and driven by surgical trainee research collaboratives.

Any other Business

Date of next meeting: To be decided via Doodle Poll

-END-