



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

**Meeting of the SWAG Network Colorectal SSG  
10:00-16:00, Wednesday, 14<sup>th</sup> October 2015**

***The Monks Yard, Horton Cross Farm, Horton Cross, Ilminster, Somerset, TA19 9PT***

**This meeting was sponsored by MERCK SERONO, NORGINE and ABBVIE PHARMACEUTICALS**

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

**2. Review of last meeting minutes**

Section 8.1 on user representative involvement was amended following advice from Rowland Hackett (RH). As there were no further amendments or comments following distribution of the minutes from the meeting on the 22<sup>nd</sup> April 2015, the notes were accepted.

**3. Genomic Medicine Centre Bid**

**Please see the presentation uploaded on to the SWSCN website**

**Presented by Axel Walther (AW)**

A world-leading programme to increase the use of genomic and genetic technologies is currently being established across the UK to sequence 100,000 genomes from patients with cancer and rare disorders. The first bid to host a Genomic Medicine Centre in the West of England failed due to a lack of engagement with clinical teams. To date, there are 15 centres in place across the UK and 18 are required. A West of England GMC partnership board has been formed consisting of members from each Trust and chaired by Sean O'Kelly. They are committed to securing a successful outcome now that a second 'Wave 2' opportunity has arisen. The genomic centres could potentially transform the NHS by predicting diseases, developing therapies, and improving outcomes. The centre would be hosted by UH Bristol, with support from the other Trusts. The pre-application questionnaire was recently submitted by the appropriate deadline. A 'dress rehearsal' bid will be submitted next week, prior to a final submission. The bid proposes that 10% of patients should be consented to the biobank although higher recruitment levels would be desirable.

There are many practical implications in hosting the service. Currently, no process is available to feedback results to the patient, and the consent process will take a significant amount of time. It has not yet been decided who would do this. A

pathway needs to be designed and validated. This should include a process for when and how many biopsies are taken, how the tissue samples are prepared prior to sending to the laboratory in North Bristol Trust (either fresh, frozen or paraffin embedded), and how to integrate the samples into a local bio-repository for research. The laboratory staff are confident that they can process the number of samples generated without creating a bottleneck in the pathway. If a small sample is taken that is difficult to analyse, the diagnostic biopsy will always be prioritised over the GMC sample.

A potential tissue collection pathway (within the presentation), showed how the extra tasks might be incorporated in to the existing routine. The service will be rolled out in stages, starting with breast cancer patients, at some point after January 2016. It was not to be thought of as a temporary trial, but as providing the opportunity to install the processes that will transform how future care is delivered. There are still processes that require validating on a national level before this can be achieved.

**HD**

Consenting patients for genetic tests was considered highly complex. The existing patient information and consent forms were to be removed from the website as amendments were required.

#### **4. Anal intraepithelial neoplasia (AIN) Grade III and perianal skin intraepithelial neoplasia**

**Please see the presentation uploaded on to the SWSCN website**

**Presented by Mike Thomas (MT)**

#### **Squamous cell carcinoma (SCC)**

Combined chemotherapy and radiotherapy research trials for SCC of the anus have shown local failure rates between 14-37%, 5 year overall survival between 72-89% and 5 year colostomy-free survival between 70-86%.

Results of the ACT II trial have shown that 5-FU plus mitomycin is to remain the standard of care, but 5-FU plus cisplatin is also considered to be an acceptable approach. The results did not support giving induction or maintenance chemotherapy as no particular clinical benefit was evident.

Salvage abdominoperineal resection (APR) is the preferable treatment for patients with persistent or recurrent disease after chemo-radiotherapy, although the rate of wound complications after this procedure occur in a significant proportion of patients, with most taking over 8 months to recover, and the complications have a significant impact on quality of life. A relapse rate of 40% was reported from the UKCCCR trial.

**AIN**

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The specific pathway for treatment of patients with AIN III was displayed, as indicated in the presentation. Treatment of multifocal disease was particularly challenging to excise. An image that demonstrated this was shown to the group; it is only patients with <30% circumference involvement are treated with a local excision. Patients with >30% circumference involvement are considered for treatment with Imiquimod.

HIV health care providers in San Francisco have been screening patients with HIV for AIN since the 1990's, as it was thought that this patient group would have an increased risk of AIN progressing into anal cancer. However, trends in occurrence of AIN were shown to increase year on year from 2000-2009, but the occurrence of anal cancer remained stable. Continued surveillance is required to evaluate the impact of screening, and to assess the effects of the human papillomavirus vaccination on the prevention of human papillomavirus-related AIN and anal cancer.

Outcomes of surgery for AIN are documented within the presentation.

### **The AIN service at the Bristol Royal Infirmary**

The service currently consists of the following:

- Dedicated anal neoplasia clinic
- 2 dedicated anal cancer surgeons
- Histopathology by an expert
- Same person seeing the patient on almost every visit
- AIN I-II 6/12 month OPD visit no intervention if no change or new disease
- AIN III 3/12 review in OPD if worried urgent EUA and either excision biopsy or incision biopsy
- Support by plastic surgeon and dermatologist
- Support by 2 ½ CNS.

The clinic has been running twice a month for the past 10 years, and will soon be held weekly. Another surgeon needs to be appointed to the service. The importance of having an experienced Histopathologist in the team was emphasised, as was the need for the same clinician to follow up patients to assess for any changes. Consultants from plastic and dermatology were available to provide support when considering more challenging excisions. An addition to the Clinical Nurse Specialist team would be beneficial as they are overworked at present. Further encouragement was needed to increase attendance by Senior Trainees.

Aspirations:

- Review all histology of new cases

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- Request enthusiastic colleagues to help expand the service
- Increase the use of local plastic surgical intervention.

SSG members were asked to consider joining the service.

Visual decision making was the strategy used to determine when it was appropriate to excise a lesion.

The prostate targeted biopsy method was found to be proficient for biopsy of intra anal lesions.

The HPU vaccination programme was considered a good subject for further research.

The removal of early disease that look concerning was not considered overtreatment if confident that the lesion could be removed safely. It was considered appropriate that surgeons outside the central service could perform this surgery, as long as histology was sent to the anal cancer MDT for review. The overall delivery of the service was to remain under the remit of the UH Bristol team.

## **5. Cancer Strategy update**

To be discussed at the next SSG meeting.

## **6. Radiotherapy Late Effects Service**

**Please see the presentation uploaded on to the SWSCN website**

**Presented by Helen Dunderdale (HD) on behalf of Karen Morgan (KM),  
Macmillan Consultant Radiographer**

KM runs a late effects service in the Beacon Centre, Taunton, to provide rehabilitation for people dealing with the consequences of pelvic radiotherapy. The provision of the service is linked to the survivorship initiative to assist making follow up more sustainable. Potential side effects from pelvic radiotherapy are listed in the presentation. New radiotherapy techniques that aim to minimise the consequences of treatment often involve giving a low dose bath around critical organs. The long term outcomes of these treatments are not yet known, as is the case with new chemotherapy and immunotherapy treatments. As survival rates improve, consequences may also increase, making it necessary to plan ahead to address this. Late effects can occur at any stage in the patient's lifetime, from 6 months post treatment to many decades later.

The Macmillan Consultant Radiographer post is funded by Macmillan for 3 years, with guaranteed Trust pick up at the end of pump priming.

During the first year the consultant radiographer set up the following:

- Established a Steering Group

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- Understanding of pathways
- Established mentorship
- Identified patient needs
- Undertaken RMS training in the management of lower GI consequences
- Developed patient information
- Implemented late effects service at Taunton
- Undertaken sPROM of all radical pelvic patients
- Highlighted service to GPs and established referral criteria.

A patient reported outcome measure of all patients who had undergone RT between May 2009 and June 2014 was undertaken. Results confirm the unpredictable and sporadic nature of radiotherapy late effects.

The late effects service accepts referrals from Clinical Oncologists, Clinical Nurse Specialists who run nurse led follow-up clinics, and GPs. The service is seeing an increasing numbers of referrals – the majority of these are patients post pelvic RT.

The importance of assessing and documenting pelvic health prior to treatment as a base line measurement was emphasised. The model of care that has been devised will be adapted as and when new evidence emerges from updated clinical guidelines, and as advised by patient feedback. There has been positive patient feedback about the service.

If you have any questions or have patients to refer, please contact KM.

## **7. Mandating structured reports**

### **Presented by Eric Loveday (EL)**

The way radiology reports for colorectal cancer are structured requires consensus; this would have to be agreed outside the SSG meeting as an insufficient numbers of radiologists were present. The current reporting system in North Bristol Trust was considered very basic, with unsearchable data fields. Examples of proformas with defined data fields were provided for the group. Reports structured in a predictable, repeatable way, would have the following potential benefits:

- Consistency
- Quality
- Compliance
- Comparability
- Support research
- Improved outcomes
- Use of existing tools.

Proformas that combined mandatory fields with a free form reporting option were considered ideal. The radiological requesting process could be improved using the

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same approach. The consistency of a standardised form would benefit patients who wish to access their reports. Individual Trusts' information technology requirements would need to be taken into consideration when adopting or developing forms.

All SSG members present supported this approach. A meeting of the colorectal radiologists will convene to agree the structure of the reports, and establish how this can be implemented.

**Agreed**

### **8. Network audit update**

Ann Lyons (AL), the audit lead, was not available to give an update on the progress of the MDT decision making audit in NBT. The inclusion criteria had not yet been agreed and concern was raised about the resources required to conduct it. A simplified version was proposed, which would involve discussion of sample cases by each MDT within the region to compare decision making. This will be fed back to AL and the Pelican group will be contacted to see if they can supply the group with sample patient data.

**MW / AL**

It was noted that feedback was not being routinely received on images sent for assessment to centres for research trials. This will be investigated by Diana Tait (DT) from the Royal Marsden Hospital.

**DT**

### **9. Regional NBOCAP Funnel Graph**

It was agreed to look at the 90 day mortality figures from the National Bowel Cancer audit by Trust, within each SSG meeting, so that appropriate support could be provided if a centre became an outlier. None of the Trusts within the region were outliers following comparison with Trusts in other areas, but the percentage mortality figure reported for Taunton was considered inaccurate. Corrected data had been submitted to NBOCAP, which would have lowered this percentage, but it would only be changed in the report if a Trust was identified as an outlier. A representative from NBOCAP has been invited to attend the next SSG meeting to discuss the new audit platform.

### **10. Deferral of Surgery (Watch and Wait Study), Management of Rectal Cancer**

**Please see the presentation uploaded on to the SWSCN website**

**Presented by Dr Diana Tait**

The deferral of surgery study was inspired by a Brazilian colorectal team, led by internationally renowned surgeon Angelita Habr-Gama, in response to patients who chose to decline surgery for rectal cancer. Current UK guidelines recommend that surgery takes place six weeks after neoadjuvant chemo-radiotherapy (CRT). This presents a dilemma, as up to 24 % of patients who undergo CRT have been found to have a complete pathological response in the specimen excised. Whether a complete response to treatment can be safely identified and

monitored and if surgery can then potentially be safely deferred or avoided for patients where cancer becomes undetectable on imaging, requires further investigation. The maximum tumour response time following CRT needs to be established to achieve this. This is monitored using MRI imaging to grade tumour regression using the tumour regression grading (TRG) techniques validated in the MERCURY Experience study. Compelling data has been collected so far, with an audit of 95 patients showing that significantly more tumours were downgraded in the group of patients having surgery at 8 weeks rather than 6 weeks. This part of the trial is now closed and will be analysed.

Patients are now being consented into the next part of the trial, which is to use MRI to identify and monitor patients for deferral of surgery.

Eligibility criteria:

- MRI defined complete response: TRG 1-3 at 4-8 week post-radiotherapy scan, followed by mrTRG 1-2 at second MRI scan, carried out 8-12 weeks after radiotherapy
- TRG 1-3 at 4-8 week post-radiotherapy scan, followed by mrTRG 1-2 at second MRI scan, carried out 8-12 weeks after radiotherapy. But with nodal disease, requiring adjuvant chemotherapy for nodal disease whilst on the trial.

Patients have to be consented at 10 weeks to arrange imaging at 12 weeks to establish if they are eligible for the trial. 36 patients have been consented so far, with a further 23 required. A patient is recruited approximately every 6-8 weeks. Recommendations and conclusions that have been drawn so far are as documented in the presentation.

The TRIGGER trial is currently under development. This aims to see if mrTRG can be used to stratify between good and poor responders following chemo-radiotherapy in rectal cancer.

Eligible patients who were motivated to travel to the Royal Marsden could be referred from the South West region.

There is an international Watch and Wait database ([here](#)) that is open for everyone to use, for patients who have declined surgery but are not on trial. Such patients should be followed up as recommended by the study protocol, minus the PET CT scan, as this was funded by the trial.

It was noted that implementing mrTRG as standard practice in centres other than the Royal Marsden would be difficult, due to the differing quality of the imaging equipment and radiological expertise.

The risk of extra radiation exposure from the increased imaging involved in the trial had been deemed acceptable by the various research governance bodies.

## 11. The Normal Unpleasant Psychology of Cancer Recovery

Please see the presentation uploaded onto the SWSCN website

### Presented by Mike Osborn (MO)

Research on the psychology of cancer recovery was conducted over a two year period, which is particularly pertinent to colorectal cancer patients due to the distress caused by stomas and the worry / gut link.

There is a need to dispel folklore beliefs and cultural ideas associated with cancer, to assist patients in managing their expectations. Frequently, confusion and negative self-critical feelings emerge, such as guilt and shame about the time they are taking to recover, adding to the unpleasant experience that has been inflicted upon them during treatment.

Processing the psychological effects of cancer treatment often only begins once treatment has finished and people may hide how they are feeling about it to protect the people around them. The burden on the brain caused by undergoing chemotherapy, known as 'chemo fog', can undermine everyday confidence. The intense fatigue, which is the inevitable, primal, protective reflex response to anxiety, plus metabolic fatigue, is unavoidable. People often think that they need to push through the fatigue using will power, which only results in increasing the levels of fatigue. The presentation contains pictorial representations of the different kinds of emotions that people might experience. What can help patients is to be prepared for what is to come, and realise that feeling some or all of these emotions is a normal, inevitable consequence which requires managing with a flexible approach. Patients are to be encouraged to treat themselves with the same patience, compassion, respect and dignity that they would give to a friend, and look forward to some kind of comfort, and peace of mind in the future.

The ideal time to broach this subject with patients should be guided by the information that they want and can absorb at a given time, provided in a candid, open and honest manner. When people are seen very intensely during treatment, and then move into follow up, they often feel very lost. Health and Wellbeing days can help with this, but more are needed, and often some people need more individual care. To assist with spreading the message of the normal unpleasant psychology of cancer, MO has developed films that can be prescribed to patients, prior to moving into follow up, in the hope that treating misery can become routine. Access to the films can be granted by emailing MO. These are going to be available on the Macmillan website in the near future, but it would be more beneficial if prescribed for a patient via direct contact rather than direct them to a link on a website.

SSG members  
/ MO

## 12. User Representative input

### Presented by Rowland Hackett (RH)



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SWAG Cancer User Involvement

The SWAG SSG User Involvement Brief is available on the SWSCN web site. The SWAG user group are currently not meeting, and there is no feedback about its future. The SWSCN website has been updated to include the SWAG user involvement pages; this is not yet accessible due to a software problem. SWAG user representatives have been recruited to all SSGs.

At the last SSG meeting, RH asked if SWAG would adopt Trust based cancer user involvement groups as established for the Peninsula Cancer Network. This had been raised at the Cancer Operational Group (COG) by HD in August. It was decided that the next COG meeting in October would focus on user involvement and discuss this subject. HD will feedback the conclusions from that meeting to the group.

HD

Yeovil District Hospital Patient and Public Involvement

RH contacted YDH Chief Executive Paul Mears on behalf of Colon-aid, the Yeovil District Bowel Cancer Support Group, to express concerns over relocation of the Colorectal/Stoma & Breast Care teams. The move has now taken place, with office and admin located in a building across the road from the main hospital building. Stoma Care has shared access to an examination room and a store room for stoma care supplies on Level 2, and their in-patients are on Level 7, which is both inconvenient and inefficient. This is supposed to be a short term solution to ensure the provision of additional beds for a Winter Pressures Ward. The impact on staff morale and patient access for same day appointments to deal with bleeding, skin conditions, leakages, etc. will be monitored.

Wider Concerns

Concern was raised about the increased demands for GP surgeries struggling to meet current demands, who are now being asked to take on follow up from secondary care and provide 24/7 access to patients. Many patients with chronic conditions already have to wait for an appointment with their GP.

**13. CNS update / implementation of the recovery package**

Expressions of interest were invited for the role of Colorectal CNS SSG Lead who would coordinate collaborative patient experience agenda items for SSG meetings. The role could be rotated every 2-3 years. An email will be sent to the CNSs in the region by HD.

Well-being events are being coordinated across the region on a regular basis. Weston is holding their first meeting next week; some are colorectal specific and some generic. Positive feedback has been received and a DVD is hoped to be developed to send to non-attenders.

### **15. NICE referral guidance and referral form**

Jonathan Miller (JM) is amending the 2WW referral forms to reflect the new guidelines. The CCGs have asked for a delay in the development of site specific forms while opinions are sought from SSGs on a new Cancer Concern referral form. This is one generic form for all suspected cancer referrals, but was not considered fit for purpose due to the lack of information deemed necessary for triaging purposes. There was no information to help the GP triage straight to test, and it would not be possible to audit the quality of referrals made, although the level of concern section was considered useful. The form was thought to be a backwards step and development of the site specific form was recommended. Feedback will be sent to JM by HD.

**HD**

Amelia Randle (AR), General Practitioner (GP), is part of a working group overseeing implementation of the new NICE referral guidelines over the next 5-10 years. The group is working collaboratively with secondary care and patients, and is currently working on the lung and breast cancer pathways.

The results of a recent audit, undertaken to establish the number of patients who were aware that they had been referred to eliminate the possibility of cancer, had shown that one third of patients were not aware. AR explained the challenges of raising this with some patients in the primary care setting. It was recognised that this was a complex issue, as was the imperative that GPs follow National referral guidance to the letter.

### **16. Bowel Cancer Screening: Pathology Reporting**

The network guidance is for cancerous polyps to be double reported.

**Date of next meeting: Wednesday 27<sup>th</sup> April 2016**

**-END-**