

Meeting of the SWAG Network Colorectal Clinical Advisory Group (CAG)

Wednesday, 4th March 2020, 09:30-14:00

Holiday Inn, Bristol City Centre

THIS MEETING WAS SPONSORED BY AMGEN AND NORGINE

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

NOTES

(To be agreed at the next CAG 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

Notes:

As there were no amendments or comments following distribution of the minutes of the meeting on Wednesday 5th June 2019, the notes were accepted.

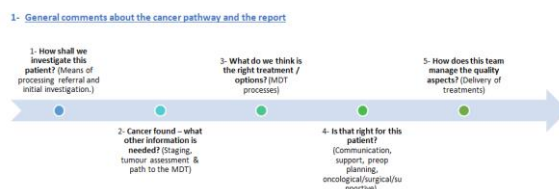
3. Coordination of Patient Pathways

3.1 Cancer Alliance project update

Presented by Michael Thomas (MT)

Cancer Alliance Clinical Leads Melanie Feldman (Peninsula) and MT (SWAG) have been to Trusts across the South West to look at what is being done well. Some centres are models of excellent practice. Quality of care was seen as outstanding by patients overall. However, there were also some individual problems. Where problems are most significant it is often due to clinician and management denial of problems. If the clinical and management teams work together, the 28 day pathway is deliverable. Overall MT has learned some novel ways to deliver the 28 day pathway.

The pathway involves a five steps; breaking the pathway down focusses on processes at each stage to enable changes. The first part is how teams can process referrals, particularly two week wait referrals. There has been a dramatic increase in the number of referrals which will continue. There is now a 4% risk of treating cancers in an appropriate time. The case-by-case approach has worked until now because of the hard work of clinical professionals. However, projected referrals will continue to increase and due to sheer numbers services can no longer cope. If smaller Trusts are struggling, larger Trusts stand no chance of delivering.



In terms of investigating the patient, NBT and UHB have worked to get GP practice buy-in with diagnostics such as colonoscopies and CPC. This has taken 4-5 years to overcome problems.

Patients where cancer is found are not the real problem; it is the 95% of cases which do not have cancer. The radiology team in Torbay have innovated their service and if they can see nothing of concern on the scan, they remove patients from the cancer pathway as soon as they are assessed. One progressive team were taking responsibility for flexible sigmoidoscopies. Even dubious CTCs can be removed from the register but still be discussed at MDTs. Each Trust must develop some way to remove patients from the Cancer Register. A Navigator role is key and Trusts that have one already have made efficiency improvements. This cannot be done by clinicians so the message is for CAG members to talk with their Trust managements to introduce a Navigator role. This has been proven to take 2-3 days off the pathway.

In terms of MDT processes, radiology teams have been supportive in making changes which have shaved up to one week from the pathway. Colorectal Nurse Specialists should all receive training so they can organise MRI and PET scans; again where this happens, up to one week is saved.

Most Trusts are doing the right investigations and offering appropriate treatments for patients. One Trust is problem solving missed targets; this is due to having only one pathologist and one Trust does not have enough clinical / medical oncologists.

Concerns were raised about GPs arranging cross-sectional imaging for incidental adenomas or splenic arterial aneurysms. There is a need to determine hospital or GP responsibilities. Across the South West, accountability is at a 50 / 50 ratio. Problems in the second part of the pathway are individual to each Trust.

MT will arrange circulation of an extract from documentation. The update may be in time for the next CAG meeting.

MT, HD

4. Clinical Guidelines

4.1 Diagnosis, Treatment and Outcomes of Young Adults with Colorectal Cancer Study

Please see the presentation uploaded on to the SWCN website

Presented by David Messenger (DM)

The rationale for developing a large-scale study is that it is proof of a concept. The primary aim is to assess the feasibility of capturing data for people under 50-years-old who are diagnosed with colorectal cancer. Information about young adult colorectal cancers is largely population-based at the moment.

Incidence rates have been higher in more developed countries. Projected total colorectal cancer rates are set to increase from 1.4 million in 2012 to 2.2 million by 2030 globally.

In the USA incidence is beginning to drop, connected with a reduction in mortality

rates. This is partly due to screening, which is part of the private healthcare system. However, total reductions are masking an increase in younger adult cases. There has been an exponential increase in rates in adults born after 1950. Furthermore, rates are almost four times higher in adults born in the 1980s and 1990s versus those born in the 1950s.

In England colorectal cancer cases are increasing, while rectal cancer cases are decreasing slightly. From 2010, there has been a slight drop due to the introduction of screening.

European published information (Viuk et al, Gut 2019) has been widely reported in the media. The most rapid increase, at 8% year on year, is seen in people in their 20s. The caveat when discussing this data is it was compiled from multiple datasets across 20 countries and assessed proximal colon cancers only. English data groups distal (which are reachable with flexible sigmoidoscopy) and proximal colon cancers. Projections are mirrored across gender and socioeconomic status.

Since the 2000s there has been a 10% year on year increase in distal colon cancers. Rates in the South West are currently at 90 per 100,000 population. Nationally rates are at 70 per 100,000. This may be due to the slightly older population in the region. 2041 projected incidences are based on ONS population data with the 2015 increase rate applied. There is a three to four year lag on receiving data.

Regionally the population is expected to increase by 15%-20% in the South West due to internal migration. Nationally cities such as Bristol, Birmingham and Milton Keynes are expected to see highest rates according to NHSE&I projections.

The study is sponsored through UHB and has two phases. Phase one is a review of a cohort of patients from UHB, NBT and RUH. Phase two will review patient data from remaining hospitals within the SWAG region. It may be possible to incorporate Peninsula patients in this phase. This should produce a total cohort of 860 patients and each phase is expected to have a three month duration. Surgical trainees would collect the data under the guidance of a nominated consultant lead. The REDCap database is currently in development, to enable paperless data entry.

Jackie Mifflin, Patient Representative, asked if any preventative education was being done. There is none currently but the Bristol Health Integration Team (HIT) hopes to combine science, hospital and community to do this. Evidence-based research will support development of preventative education in future.

Through her work for Bowel Cancer UK Jackie also commented that people go to their GPs with certain symptoms but are misdiagnosed. She feels symptom identification should be included in curricula as a preventative measure. CAG members supported the need to raise awareness and have experience of young patients who have had up to 18 month investigatory periods before being seen acutely. FIT tests might help to reduce incidence of late diagnosis. However, these are only accessible to the over 50 age range currently.

4.2 Service Developments on Frailty Assessments

Presented by Jonathan Randall (JR)

Since last year's presentation the focus has been to identify patient frailty earlier. The use of CT colonogram will also be discussed. Interventions are still considered on a case by case basis.

Work has been done to instil frailty into clinical discussions. Teams are starting to assess patients for their frailty; at UHB the Rockwood Frailty Score is embedded into practice. This provides a clear description and visual guide, easily understandable to patients. Assessments take place two weeks before the patient is admitted. The age at which patients are assessed is somewhat controversial – at 65 to 70-years-old. Patients within the 1-3 score range are still relatively fit.

A recent audit showed that CTCs are mentioned on 16% of request forms on ICE (hospital referral system) at UHB.

CT colonograms are done through the 2 week wait clinic. Straight to test colonoscopies have been introduced at UHB.

The patient experience feedback indicates 75% out of 306 patients felt vulnerable during the process. Patients have to drink a contrast at home and have to be mobile enough to lie on their side and their front to have scans in two different positions. 8 out of 11 patients thought it was better than they expected. 3 out of 11 thought it was about the same as expected. Side effects include discomfort, nausea and the bad taste of the contrast. 80% of patients were able to turn; 10% found it difficult. There was one perforation from tube insertion. 31% of patients needed further tests. Radiologist feedback was there can be interpretation difficulties due to camera position in the sigmoid or rectum. Sigmoid thickening can also have an effect.

From these scans, 4 patients were found to have cancer and 41 had polypectomies.

RUH discussed having 19 patients on a frailty pathway; of these there is a 20% mortality rate which is much higher than the 3% national average. Patients have a frailty score of ≥ 4 ; due to the score they are offered physiotherapy sessions and some Fitbits are available, although there have been data upload issues. They are flagged at MDT and seen within five days. CAG members are keen for this to be an agenda item at the next meeting.

Ed Courtney

UHB still CTC around a quarter of patients with a frailty score between 5 and 7. From a straight-to-test point of view minimal preparation could be implemented from 4+. Follow through data for patients that are not operated on would be useful, to inform counselling patients. Slow growing tumour patients often only need a watch and wait approach.

GP education is needed so that they understand what a colonogram is and what the process involves. Standardisation of frailty scoring methods is still needed and assessments need to be objective; YDH use WHO performance status which is too simplistic and not considered by CAG members to be as robust as Rockwood. Sarcopenia is a hot topic and Jonathan Hewitt and Kathryn McCarthy at Cardiff have undertaken research on frailty.

5. Patient Experience

5.1 Interventions for Intractable Cancer Pain

Please see the presentation uploaded on to the SWCN website

Presented by Nilesh Chauhan (NC)

Provision of a Complex Cancer Pain Service fits in with the aforementioned Enhanced Supportive Care project.

There are a number of innovative interventions available via the UH Bristol Pain Management Team for end of life care:

- Neurolytic saddle blocks for intractable perineal pain, which involves an injection of phenol into the spine. This temporarily destroys the perineal nerves (they can regrow) for approximately 3 months, and can enable patients to sit up comfortably in bed and reduce the risk of lung infections. Side effects can include damage to the bladder and bowel nerves, causing incontinence, and foot-drop. These can be used when patients are still receiving radiotherapy.
- Cordotomy for uncontrolled pain below C4 which is particularly suitable for patients with mesothelioma and chest wall pain; the Portsmouth service has ended but patients can be referred to Liverpool. The service may be run in London soon.
- Intrathecal Drug Delivery (IDD, funded by NHS England) for patients with severe cancer pain below the diaphragm (approximately 5-15% of cancer patients) with a life limiting illness that require pain management for 3 months or more and can tolerate an anaesthetic. This is a cost-effective alternative to systemic drugs that allows small doses of drugs to be applied directly to CNS receptors via a catheter placed in the spine. A randomised controlled trial (RCT) of opioids versus IDD shows IDD as preferable in terms of reduced toxicities and improved survival. The catheter can be refilled (approximately once every 3 months) in the outpatient pain clinic.

Peripheral nerve blocks are also available. MDT members are encouraged to ask cancer survivors if they have residual pain, as there are thought to be previous patients with unmet pain management needs that could be addressed.

Patient Information Leaflets have been developed that detail the benefits versus risks of each intervention.

The pain management team hold a monthly MDT on the first Wednesday of the month with the palliative care team. At present, referrals are restricted to the Bristol area, with a plan to set up a network service at some point in the future.

It is not uncommon for patients to have unexplained pain in the early stages of recovery. If investigations show no obvious pathology, they should be referred to the pain team. For patients with true neuropathic pain, low dose amitriptyline may be helpful, but can take a couple of months before patients begin to get relief from symptoms.

The IDD pump is only licenced for use with morphine. Baclofen has been found to corrode the pump mechanism. Pumps cost £20,000.

To refer Bristol patients, please email: Bethany.wright1@nhs.net

The group was made aware of a menthol cream used by the Royal Marsden for post-chemotherapy neuropathy and peripheral neuropathy patients. A paper was published about this and NC will forward this for circulation.

NC, HD

5.2 Complex Cancer Late Effects Rehabilitation Service

Please see the presentation uploaded on to the SWCN website

Presented by Jane Cook (JC)

The CCLERS is a highly specialised national service, based at RUH Bath, for adults with persistent pain and reduced physical function following their cancer treatment.

Please see the presentation for patient eligibility criteria and details of a case study that demonstrates the benefits that the service can provide during the 2 week residential programme with the multi-disciplinary team; any Health Care professional can refer in to the service, which is free to any patient registered with a GP in the UK.

The service is relatively new and must be promoted across the country to ensure all relevant patients can have access to rehabilitation. Patient numbers are currently 15-20 per annum and there is capacity to help more patients.

Patient outcomes pre and post treatment had significantly improved across a longer period of time due to continued contact after the 2 week residential programme; patients are contacted at 3, 6 and 12 months, and are also able to re-contact the service independently at any time.

Local services are available, such as pain clinics, but a pathway for addressing multiple late effects is not available in each locality.

CAG members are asked to identify and refer relevant patients, provide feedback on the content of the presentation, and suggest any other useful information that could be included.

5.3 Patient Experience Watch and Wait

Please see the presentation uploaded on to the SWCN website

Presented by Sarah John (SJ)

Patient experience information was gathered from 6 patients on a Watch and Wait pathway since 2015. One patient was added in 2018 and one has been added in 2020. Patients had previously received neo-adjuvant chemotherapy and were assessed as in complete remission following treatment.

Of the 6 patients, Sarah had been able to contact 3. The Watch and Wait protocol is a big commitment for patients, who have scans and tests (such as flexi-sigmoidoscopies and MRIs) every three months for the first two years. All 6 patients recruited were retired; the youngest was 65 and the oldest was 80.

Overall satisfaction was pretty good. Patients had confidence in the service and a programme of dates. For clinicians and nurses, managing tests has been problematic

as it has been difficult to get endoscopies done on time. Radiology has not been so difficult. Only one patient had to chase tests.

Pelican Centre run through questions and answers are included as part of the uploaded presentation.

6. Research

6.1 Clinical Trials Update

Please see the presentation uploaded on to the SWCN website

Presented by David Rea (DR)

MT highlighted as introduction the lack of colorectal surgical trials currently offered. A list of open trials, trials in set up, and trials open to new sites, are documented in the presentation. These will be circulated and uploaded to the website.

HD

Newer trials include:

I-TRAC is open at UHB. Stephen Falk is PI. This is for stage 2/3 colorectal cancers looking at cell free tumour DNA analysis. The trial aims to improve CTDNA detection and relapse prediction.

POLEM is also open at UHB. Participants have one of two gene mutations: mismatch repair or POLE.

The Wessex Fit-4-Cancer Surgery (WESFit) trial is a prehabilitation trial for abdominal surgery patients. This is funded by NHS England now and sponsored by Southampton. Pre-operative patient identification is needed. Patients are randomised into one of four groups: a control group; one has a personalised exercise programme; one has psychological support; and the final group has both exercise and psychological support. The trial aims to collect a large sample from 1,560 patients over three years. DR is advised to link with Hannah Wilson.

DR

CAG members are keen to consider CPET testing. Details will be circulated. YDH are trying to do this and have a CPET machine. The problem area is providing psychological support up front; there is psychological support provision in place following treatment.

HD

The STAR-TREC surgical trial for early stage rectal cancer is still open. NBT have this open through charitable funding; UHB do not have this trial because of pathology issues. This highlights the need to look at cross-site trial sharing.

DR will circulate updates from MCRI of proposed trials as soon as he has information.

DR

7. Living With and Beyond Cancer (LWBC)

7.1 Prehabilitation Guidance

Please see the presentation uploaded on to the SWCN website

Presented by Catherine Neck (CN)

This item was not presented at the meeting.

7.2 Implementation of Faecal Immunochemical Testing (FIT) Update

Please see the presentation uploaded on to the SWCN website

Presented by Alison Wint (AW)

The project has been open across SWAG and Peninsula Cancer Alliances and is for low risk patients compliant with NG12 guidance. These patients are not eligible for the two week wait pathway. Exeter has yet to complete follow-on evaluation but the project is shortlisted for an HSJ award.

FIT is acceptable to patients and GPs feel confident in using it. Of 450 patients tested, 14% had a FIT positive result. 8% of patients tested did have colorectal cancer. 8% were not referred and it is unclear if this was patient choice.

The Rapid Diagnostic Service (RDS) pilot will use FIT as one of the filter tests and will be accepting slightly younger patients; the current project age range is the over 50s. RDS will test the over 40s. Somerset CCG representation queried that FIT was a filter test and will check with the Project Manager to discuss inclusion.

CAG raised concerns of the drive to introduce protocolised medicine and not every presentation fits a protocol. The question was raised regarding patients who have a negative FIT result but are losing weight. First-line primary care testing includes thyroid function testing, chest X-ray and basic blood screening tests. This group might be eligible for an acute referral.

It was also queried whether initial FIT negative patients with symptoms would be suitable for a repeat FIT. Perhaps at the time of testing a tumour might not be bleeding. If patients continued to be symptomatic this should be considered. FIT 10 is a more sensitive test and more consistent than FOB.

Concern following earlier presentations recommended the need to reduce the age threshold. The 2041 projected figures of 30% of colorectal cancer patients would be younger than 30-years-old were discussed. Internal migration forecasts were raised, with Bristol being a city expected to see massive population increases. Some patients use Apps, such as LetsGetChecked.com, to test their own symptoms and for genetic testing. A FIT test is available for £49.

7.3 Any Other Business

No other issues were raised for discussion during this meeting.

Date of next meeting: To be confirmed via Doodle Poll

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