

Meeting of the SWAG Network Colorectal Cancer Clinical Advisory Group

Thursday 6th October 2022, 13:00-17:00

Engineers House, The Promenade, Clifton Down, Bristol via MS Teams

Chair: Mr Michael Thomas

REPORT

(To be agreed at the next CAG Meeting)

ACTIONS

1. Introductions

Please see the separate list of attendees and apologies uploaded on to the SWAG website [here](#).

2. Coordination of Patient Care Pathways

2.1 Implementation of Faecal Immunochemistry Test (FIT) and Management of FIT negative pathways

Please see the presentation uploaded on to the SWAG website

Presented by M Thomas

Development and implementation of the FIT testing pathway for colorectal cancer is well underway following the accumulation of work undertaken by both the Peninsula and SWAG colorectal teams over the past 4 years.

There is now increased involvement from numerous NHS bodies, accelerated by the pandemic, which has led to variation in the views over how the pathway should be implemented.

During lockdown, when access to colonoscopy was restricted, many centres adopted the North East London approach to use FIT as a mandatory test for entry into the pathway.

Colorectal CAG liaised with the Cancer Alliance about increased roll out of FIT during the pandemic and identified the need to provide education on use of the test in Primary Care, which has in part been addressed.

As a highly specific and sensitive test with a miss rate of approximately 0.4%, it is far more accurate than colonoscopy. It has now been formally integrated into referral arrangements to help prioritise those patients most likely to have colorectal cancer or adenomas and identify people at low risk.

It has been important to work closely with Primary Care to address trepidations around safety netting those patients who have a negative FIT for whom the GP still has concerns.

The CAG have decided that patients with Iron Deficiency Anaemia and symptoms of concern (although this is the area where there is still some debate) and abdominal masses are referred straight to test via the 2WW pathway; rectal and anal masses are to be referred straight to a Colorectal Out-Patient Appointment via the 2WW pathway.

Other symptoms and signs of concern, as listed in the pathway, will prompt the GP to provide the patient with a FIT test which, if positive ($\geq 10\mu\text{g/g}$), should be referred for further investigation.

The table has been agreed across clinical forums and signed off.

Where, in previous years, M Thomas and the team had been pushing for the test to be made more available, its merits have now been recognised and obstacles to its use removed.

Patient Representative S Rowley frequently encounters young patients diagnosed with late-stage disease via the colorectal cancer support group, who often have a history of symptoms and of trying to get referred 2 years prior to diagnosis and asks how this can be addressed.

In the experience of the UHBW team, GPs are now on board with using FIT more frequently for younger patients.

Colorectal CAG recognised the exponential rise of colorectal cancer in young patients some years ago after analysing data from the National Cancer Database which was subsequently published and used this evidence to enable GP access to those of 18 years plus. Data from Canada and the United States shows the same trend.

Caution was advised over drawing any conclusions on aetiological factors without sound evidence.

Consultant Radiologist P Carruthers noted that CT Colonography is missing from the list of tests on the pathway. This is used to risk stratify patients in Somerset; patients with a FIT >30 go straight to colonoscopy and those <30 lower risk patients have a CT Colonography. Contrast is given if they have abdominal pain or a mass. This has helped reduce the burden on colonoscopy resources.

This is also the process in UHBW, in particular for patients with comorbidities.

GPs in Somerset don't have direct access to book this imaging and so refer via the two week wait pathway and then these are triaged by the Secondary Care team.

Cancer Alliance Out of Hospital Lead, Amelia Randle, confirmed that the FIT pathway had now been agreed by South-West Regional Medical Director M Marsh and South West Regional Director E O'Mahony. A letter, stating that patients with a negative FIT with none of the other symptoms of concern should not be sent via the 2WW pathway, was sent to all systems leads (including Trust Leads, Chief Executives, Lead Nurses and ICB Leads) on Wednesday 5th October 2022.

Addition of CT colonography may be dependent on local resources but should be listed as an option.

Work is underway to ensure that negative FIT patients not referred to the colorectal pathway are safety netting in Primary Care or referred to the other appropriate pathway.

Action: The letter from Michael Marsh will be circulated to Colorectal CAG.

The expectation is for the pathway to be fully implemented by January 2023. An amended suspected cancer referral form is included with the letter.

H Dunderdale

BSW GP Lead, C Annesley commented that GP communications were about to be disseminated to provide FIT for all patients on the suspected colorectal cancer referral pathway, and GPs have been incentivised to provide this.

Work will need to be undertaken to ensure that the guidance on referring patients with IDA and masses straight to the two week wait pathway is continually clarified and embedded.

It was also noted that it is not possible in all centres to comply with the part of the pathway where it is recommended to refer to the non-site specific (NSS) service, as this has not been set up with parity across the region and, where services have been set up, resources are limited.

NSS services will evolve over time.

3. Clinical Guidelines

3.1 Lynch Syndrome Services

Please see the presentation uploaded on to the SWAG website

Presented by Sarah John and Siobhan John

Experienced Colorectal Cancer Clinical Nurse Specialists S John and S John (no relation) have been appointed by the South West Genomics Medicine Service, initially for one year, to embed testing and appropriate ongoing management of lynch syndrome into routine practice.

An estimated 175,000 people have Lynch syndrome in the UK, but fewer than 5% of individuals are aware that they have the condition. Since 2017, NICE has recommended that all colorectal and endometrial cancers are tested for the syndrome and the project will monitor if this is being implemented.

It is important that a biopsy is sent for MSI or dMMR testing at diagnosis to ensure that the result is received in time to inform treatment options, such as pembrolizumab for metastatic colorectal cancer, to which there is often an excellent treatment response.

Initially, it is hoped that each Lynch Syndrome Champion will undertake a baseline audit of current practice. The team will also provide educational and electronic resources, support to implement any identified improvements and workshops, and further education to optimise mainstreaming the patient pathway.

Mainstreaming pilots are initially due to commence in RD&E to train the CNS team.

The audit can be delegated to any staff member; it takes approximately two hours to complete for 30 cases.

Two audits have been completed to date which show the need to improve the rate of initial colonic biopsies.

There is also the need to improve discussion of BRAF results at MDT and referral on to genetics, and the Lynch CNS team will provide support to facilitate this aim.

50% of patients with lynch syndrome present with endometrial cancer before colorectal cancer, and so it is possible to capture these patients and their relatives early in their lynch journey.

The main issues with implementing the pathway are staffing and time.

Peninsula are managing by using immuno-histo-chemistry (IHC) testing in house, rather than sending for MSI testing to the GMC hubs. Consultant Pathologist N Wong recently confirmed that pathology services could not support this given the current shortage of resources.

MSI testing is now paid for, whereas IHC is not, which is why MSI is recommended. However around 20% of a quality biopsy sample is required to get an accurate result.

In RUH, the pathologists tend to undertake IHC testing, particularly on younger patients where it might inform if an extended resection is required or if the patient might be eligible for up front chemotherapy.

The problem is access to genetic counselling, where there is currently a year long waiting list.

It is hoped to reduce steps in the pathway and provide germline testing on site.

If there is a case of particular concern, the Genomic Laboratory hub have said that they can prioritise turnaround of certain tests. However, the waiting time for genetic services is 6 months to a year, which is frustrating for patients.

Young people can be referred to genetics at the point that they are diagnosed with a colorectal cancer rather than waiting for genetic test results to be returned.

Somerset FT are in the process of updating local pathways in preparation for the merger with Yeovil District Hospital. Similarly to RUH, it is possible to get the diagnostic information but the pathway for acting upon results requires improvement; hopefully the merger will facilitate this.

Bowel screening hubs are going to manage surveillance of lynch syndrome patients from April 2023 which will hopefully reduce the number of patients going for endoscopy.

A South-West Lynch Coordinator will be appointed to manage a regional database to track follow up and help transfer that information when people move to different areas. This will be a substantive post funded through the South-West Genomics Laboratory Hub, based at NBT; job banding is currently holding up recruitment. They will pass on the patient list to bowel screening, check their dose of aspirin and that relevant referrals are made to other cancer services (gynae for example).

Action: Lynch Syndrome Champions are to complete the baseline audit and return to S John and S John

3.2 Watch and Wait schedules for complete Clinical Response (cCR) of Rectal Cancer

Presented by Consultant Oncologist Jessica Jenkins

Lynch
Champions

Watch and wait schedules is an interesting, emerging field, with many more patients receiving a pathological or radiological complete response to treatment due to the development of neo-adjuvant therapies. This merits development of clear protocols for surveillance follow up to facilitate discussions with each patient.

In the absence of national guidelines, CAG recommends producing regional guidelines that detail the appropriate investigation type and frequency. This may vary depending on the treatment route that led to the cCR. Originally UHBW followed a 3 monthly follow up schedule of endoscopy and MRI based on the clinical trial protocol run by the Brompton; this was not felt to be feasible given current resources and increasing patient numbers.

A working group will be set up to develop the guidelines. This will include E Courtney, H Brooks, R Bamford and P Carruthers. H Dunderdale will assist with creating a patient register.

Action: Set up a Working Group to develop regional watch and wait guidelines; H Dunderdale to assist with the patient register

At present there are delays with organising surveillance. Watch and Wait patients should be put on a dedicated endoscopy list as any delays could result in missing the window of salvage treatment. Watch and Wait patients tend to proactively chase their investigations if there are delays from what was expected.

E Courtney/H
Brooks/R
Bamford/P
Carruthers/H
Dunderdale

The management of surveillance (CNS team or Consultants) varies across the patch and the Watch and Wait guidance will seek to address this as well.

Follow up protocols varied across the region.

Action: The previously agreed risk stratified follow up protocol will be recirculated and current follow up practice established.

3.3 Systemic Anti-Cancer Therapy (SACT) Protocol Update

Presented by H Dunderdale on behalf of K Gregory

M Thomas/H
Dunderdale/
L Macklin

After SACT protocols have been reviewed by the specialist Oncologists, they are signed off by Consultant Oncologist Jeremy Braybrooke and Network Pharmacist Kate Gregory. They are then version controlled and uploaded on to the SWAG website and updates are sent to the regional Lead Pharmacists.

The chemotherapy nurses rely on the resource to help with administering the therapies. There are currently 348 protocols on the website, and website activity over the last 12 months show 27,000 new users, with just under 300 people accessing it every day. The majority of users are our colleagues in London, but it is used widely across the UK and also internationally.

Of the 19 protocols for colorectal cancer, 17 require review. In most cases this should be a quick check to ensure they are still current. K Gregory asks for volunteers to undertake the work.

Although there may be national protocols at some point which will replace the need to do this work, there is no clear steer as to when this might happen and, for the time being, the nurses need this service.

It was agreed that the Bevacizumab protocol can be archived. Although some of the other protocols were not used that frequently, they were considered relevant to keep.

H Brooks volunteered to review the protocols.

Action: H Brooks to liaise with K Gregory to update outstanding colorectal protocols H Brooks

4. Research

4.1 NIHR Clinical Research Network (CRN) Update

Please see the presentation uploaded to the SWAG website

Presented by C Matthews

Research Delivery Manager C Matthews manages the cancer portfolio for West of England CRN. Consultant Oncologist S Falk is the Research Sub-Specialty lead for UGI.

National clinical trial recruitment from April 2021- March 2022 shows that 8,550 patients were recruited plus 4,992 this year to date, which looks like the previous years target is likely to be exceeded.

A comparison between national and regional recruitment levels from pre-covid to present day shows a very similar pattern of recovery.

There are 34 open colorectal trials across the SWAG region, with hot spots for recruitment identified on a regional map.

The presentation contains 14 trials that have opened in the last few years, many of which are struggling to recruit. FIT for Lynch Syndrome is on track to meet its recruitment target.

Action: A full list will be circulated to CAG members with further information on trial eligibility/availability across the region for comments from CAG.

Eight studies are in set-up at various sites across the region.

H
Dunderdale/C
Matthews

An NIHR 6-month Associate Principal Investigator (PI) role is open to any interested clinician who doesn't have research in their current role. It allows associates to work alongside current PIs on studies (as documented in the presentation) signed up to the scheme.

Any PI interested in getting help from an associate while helping their personal development is to get in touch.

The National Participant in Research Experience Survey (PRES, 2021/22) undertaken by the CRN received 1924 responses from a wide range of studies: a significant increase from the previous year. 93% of participants would consider taking part in research again and 92% felt the researchers valued their participation.

Positive comments include support from research staff who provided great communication, that participation was easy and well organised, and that it helped to contribute to improving healthcare for others.

Recommendations include improving car parking facilities, some areas for improving communication, availability of test results, clear contact information for the study team, and clinic times out of working hours / at weekends.

NIHR website links and team contact details are available within the presentation.

5. Patient Experience

5.1 Feedback of common issues from CRC Support Group

Presented by S Rowley

Newly appointed Patient Representative for Colorectal CAG, S Rowley, has a number of patient advocacy roles across Gloucestershire and beyond.

Background information on personal experience of colorectal cancer was provided along with his previous career as a scientist, internet and creative developer.

Prior to COVID-19, S Rowley undertook management of the Bowel Cancer Support Group which is available online and now has >3000 members.

The group is working with NHS England to ensure that it is responsibly managed by helping to develop accredited guidelines on the provision of online support.

There are several members who are healthcare professionals with cancer.

The support group is a source of national information on patients' experiences with colorectal cancer and cannot be interpreted as the experience received from centres in the SWAG region.

The most common problems raised:

- Anxiety, particularly during the referral period. This could be mitigated by optimising communication at the diagnosis and pre-treatment phase
- 'Scanxiety' (anxiety caused by waiting for scan results) is also hugely problematic, especially when there are delays in receiving results letters, which is an issue at the moment
- Timely assessment of mental health needs. A patient information leaflet is being reviewed in Gloucestershire to sign-post people to psychology support services
- Difficulties understanding the use of the FIT test
- Timely referral of younger patients
- Difficulty managing bowel preparation and the effect this has on your gut.

On a positive note, roll out of prehabilitation services (exercise and nutrition advice) seems to be increasing, which can help people gain control over their diagnosis. Kent and Medway and Manchester NHS Trusts are proactively enrolling all patients into prehab sessions regionally, including in community settings.

Other frequently raised problems:

- Post-operative issues including knowledge about adhesions and how to avoid getting incisional hernias when getting out of bed for the first time
- Advice on activities to undertake at home
- Advice on when driving is possible
- The lack of biomarker / lynch syndrome testing
- Side effects of SACT treatment, in particular Dexamethasone
- Availability of rehabilitation programmes
- Handover of information to palliative care.

As well as the support group, additional areas of interest include:

- Circulating tumour DNA during and post chemotherapy
- Lidocaine as an anti-inflammatory during treatment
- Personalised medicine
- Reduction of peripheral neuropathy (icing trials for example, which have been paused during COVID)
- Lifestyle approaches to support conventional therapy.

Involvement in the co-creation/production of products for patients is also of interest.

Discussion:

It is probable that a support group hosted on Facebook would capture a select audience; it would be helpful to explore additional ways to engage the wider population of patients.

Median age of the support group, which includes patients relatives and often their children, is 45 years. If additional funding was available, focussed advertising would be undertaken to improve uptake.

The continued success of bowel cancer peer support groups is often found to be dependent on Consultant and Clinical Nurse Specialist involvement thus ensuring confidence in the groups as a useful forum.

Provision of Prehabilitation is dependent on funding; as there is a huge National drive to embed this, it is hoped that this will be possible in the near future. There are sustainable models developed by some integrated care systems that could be reproduced locally if it is possible to get support from senior colleagues.

Optimising the provision of information and support by, for example, producing videos on specific surgical procedures to complement the information already given in clinic appointments, is recommended.

Action: Colorectal CAG to investigate production of patient information videos co-designed with Patient Representatives.

H Dunderdale

Initially, H Dunderdale will contact Cancer Alliance Comms Team

Colorectal CAG will actively work to look at ways to improve the patient experience in light of the points raised.

5.2 National Cancer Patient Experience Survey Results (2021)

Please see the presentation uploaded on to the SWAG website

Presented by H Dunderdale on behalf of Lead Cancer Nurse C Levett

The annual survey, which is commissioned and managed by NHS England, has been redesigned, so it is not possible to directly compare results from surveys discussed in previous meetings.

It is undertaken to monitor progress in cancer care and drive local quality improvements.

The SWAG region had 3,319 responses, 443 of which were for colorectal cancers. Only 1.5% of responders recorded their ethnicity as other than white.

The SWAG overall rating of care was 9.0, compared to the national average of 8.9, and the majority of scores either matched with or were above the expected range in comparison with the national average.

There are a number of questions that in general score lower and, as there is variation between tumour sites, the Cancer Alliance asks CAGs to assess their data and make recommendations for improving these areas.

Unfortunately, it was not possible to filter this iteration of survey for tumour specific patient comments, which historically had been found to be the most useful data. Following feedback, this will be made available in the next set of results.

The highest scores for colorectal cancer included provision of enough privacy when given diagnostic test results, advice from the main contact person was often helpful and the care team reviewed the patient's care plan with them.

Of the 6 lowest scores, 4 relate to out of hospitals activity.

There are 2 relevant for discussion by CAG:

1. People could get further advice or a second opinion before making decisions about their treatment options
2. Cancer research opportunities were discussed with the patient.

Question 1 is raised frequently by the CRC support group, with patients finding it difficult when asked to make decisions about treatment options such as, to have chemotherapy or not, or to continue after a certain number of cycles, when they are unaware of the information that might help inform the decision, such as biomarkers, scan responses etc.

Oncologists routinely provide as much information as possible to help patients make informed decisions about their treatment options, which will have been discussed and documented as an MDT meeting outcome and relayed to the patient.

Although some clinicians routinely offer the option to get a second opinion, this is not thought to be embedded in standard practice and it unlikely that patients will be aware that this is an option. It could also involve additional travel.

The overall positive outcomes from the NCPES are felt to be due to the roll out of Personalised Care and Support initiatives such as Holistic Needs Assessments and Wellbeing advice; continued roll-out is recommended.

SWAG observations for improvements:

- Improve communication between shared care centres and all care providers
- Improve information giving (particularly around immunotherapy side effects)
- Improve access to support from Primary Care and community settings.

Overall people who score a less positive experience are younger, female, from BAME communities or from the least deprived areas.

CAG are asked to recognise each other's areas of good practice and discuss and agree priorities for improvements and consider nominating a Patient Experience Lead.

Sometimes it is the wording of the questions that caused confusion, for example, a patient representative previously stated that they had been in a clinical trial but had never been asked to participate in research.

6. Review of MDT membership changes / meetings / service

6.1 MDT-Mode Baseline Survey Results, Yeovil District Hospital

Please see the presentation uploaded on to the SWAG website

Presented by H Dunderdale

A baseline audit was undertaken in 2020 using the validated metric for the observation of decision-making tool MDT-Mode, developed by Behavioural Scientist Tayana Soukup and Consultant Urologist Ben Lamb during their PhD on improving MDT meetings.

Resources relating to their PhD can be found on the SWAG website [here](#).

It has been found that the audit cycle may need to be completed several times over the course of 2-3 years until the MDT meeting is considered completely optimised.

Three meetings were observed on 6th October 2020, 20th October 2020 and 10th November 2020. A total of 47 patients were discussed across the three meetings. The average discussion time per patient was 3.04 minutes with a minimum of 20 seconds and maximum of 6 minutes.

The average discussion time is greater than the majority of other MDT meetings (of which there have been 24) assessed to date.

Deferrals due to pathology were very low in comparison with other MDTs, as were the cases discharged to benign pathways.

The majority of information and contributions on history, imaging, pathology scored 5 (maximum score).

The majority of contributions from chair, surgeon, oncologist, nurse, histopathologist scored 5.

The percentage of information on psycho/social (44%), comorbidities (70%) and patient's view (54%) is high in comparison to other MDT meetings assessed to date.

Nurse contribution (63%) was high in comparison to other MDT assessed to date.

The percentage of case discussions where clinical trials are mentioned is significantly higher than any other MDT meeting assessed to date (22% in comparison with 0%-6.7%).

In conclusion, it was found that increased average discussion time improves the quality of decision making and discussion of clinical trials; having job planned MDT preparation time increases average discussion time.

Potential points for Yeovil MDT to consider:

- There were a number of outcomes to assess fitness in clinic; would it be possible to add a frailty assessment to the MDT proforma?
- Some MDTs remove surveillance scans prior to the meeting if no change has been reported; would this be possible / appropriate if additional planning time was scheduled?

Rockwood Frailty Score has been added to the MDT proforma in UHBW.

Following the audit, YDH have also added the Rockwood Frailty Score on to the two week wait proforma, which then feeds in to the Somerset Cancer Register.

YDH are also hoping to embed prehabilitation where frailty is identified.

SFT have also incorporated frailty scores in their referral documentation.

As YDH have a lot of imaging which is outsourced to non-specialist radiologists and the average size of the meeting is small in comparison to other centres, it is an appropriate forum to continue providing a second review of imaging.

As NBT has direct to test referrals, sometimes patients on the list have yet to be seen and so it is not possible to capture patient centred information at that point in the pathway.

CRC MDT Leads are to contact H Dunderdale if they would like an MDT-Mode assessment to be completed.

YDH have been able to use the data to inform improvements.

7. Any other business / date of next meeting

The Work Programme will be reviewed outside the meeting to close relevant actions, five of which have been concluded during the meeting today.

Immunotherapy update: In the metastatic setting, 1st line Pembrolizumab is being used for patients identified with Microsatellite Instability (MSI) with very good responses. MSI diagnoses make up approximately 45% of all Colorectal Cancer diagnoses, and do not respond well to chemotherapy, making this an important additional treatment option.

In October last year, NICE approved combination immunotherapy in the metastatic setting for 2nd line treatment following results from the Phase 2 Checkmate 142 study which showed an objective response rate of 70% and beneficial survival outcomes.

At ASCO, data was presented on an immunotherapy trial for rectal cancer; all patients involved had a complete response after 6 months of treatment.

At ESMO, data was presented on immunotherapy for Stage III colon cancer patients who had two cycles of immunotherapy. All progressed to surgery, many had a complete pathological response after 5 weeks of treatment.

These new therapies are considered game changing.

Everyone was thanked for their contributions to the meeting.

Date of next meeting: To be confirmed via Doodle Poll in the next six months

-END-