# Clinical Advice for the Commissioning of the Whole Bowel Cancer Pathway

This document was produced by the Colorectal Cancer Clinical Expert Group *November 2017* 

## Clinical Advice to Cancer Alliances for the Commissioning of the Whole Bowel Cancer Pathway

Date of issue: November 2017

Date of review: May 2019

#### Prepared by:

The clinical advice outlined in this document on commissioning the whole pathway for colorectal cancer was prepared by the Colorectal Cancer Clinical Expert Group (CEG). This group is chaired by Mr Michael Machesney, Consultant Colorectal Surgeon and is co-chaired by Mr John Griffith, Consultant Colorectal Surgeon. The group also includes representation from the full range of professions involved in delivering bowel cancer services, as well as patient groups and commissioners.

#### Audience:

The audience for this document includes:

- **Cancer Alliances:** should work with commissioners and providers to ensure the whole pathway for colorectal cancer is provided within their geographical footprint.
- **Commissioners**: should ensure services for colorectal cancer are commissioned in alignment to this commissioning advice.
- Acute Trusts: should ensure services provided to colorectal cancer patients are in line with this commissioning advice.
- **Patients and patient groups:** to improve understanding of what best practice in treatment and care should be look like and therefore what they should experience.

#### Groups consulted:

This document was produced by the Colorectal Cancer CEG whose members represent a wide range of disciplines and geographical perspectives. The following organisations were invited to provide comment:

Association of Coloproctology of Great Britain and Ireland (ACPGBI) Beating Bowel Cancer Bowel Cancer UK Chemotherapy Clinical Reference Group (CRG) Hepatobiliary CRG Radiotherapy CRG Specialist Colorectal CRG Thoracic Surgery CRG

#### Purpose:

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 2

The commissioning advice outlines best clinical practice for the provision of colorectal cancer services in England. It applies to the whole patient pathway, from first contact with the NHS, to discharge from follow up or palliative care. The commissioning advice should inform discussions between commissioners and providers on quality priorities. Where commissioners and providers feel unable to deliver the standards set out in this document, they should clearly set out the reasons for this, as well as what actions will be taken to address the issues identified.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 3

## Contents

Executive Summary	6
Summary of key priorities for commissioning services for people with suspe and confirmed colorectal cancer	6
<ul> <li>2.1 National and local context</li> <li>2.2 The burden of bowel cancer</li> <li>3. Evidence needs</li> </ul>	
<ul><li>3.1 Evidence base</li><li>3.2 Why improving early diagnosis and increasing participation in screeni priority</li></ul>	ng is a 9
<ul><li>3.3 Why reducing unwarranted variation in diagnosis and treatment is a p</li><li>4. Scope of the bowel cancer service</li></ul>	-
<ul> <li>4.1 Aims and objectives of service</li></ul>	10
<ul> <li>5.1 Presentation</li></ul>	11 11 11 12
<ul> <li>5.2 Diagnosis</li></ul>	12 12 13
<ul> <li>5.2.5 Investigation protocol for primary colorectal cancer</li> <li>5.3 Multidisciplinary Team (MDT)</li> <li>5.3.1 Membership</li></ul>	14 14 15
<ul> <li>5.3.4 Workload</li></ul>	16 16 17
<ul> <li>5.3.8 Teenage and Young Adult Pathways (TYA)</li> <li>5.4 Patient notification within outpatient clinic</li> <li>5.4.1 Diagnosis and treatment options</li> <li>5.4.2 Nursing input</li> <li>5.4.3 Patient information</li> </ul>	17 18 18 18
5.4.3Patient information5.4.4Primary treatment5.4.5Pre-operative treatment for rectal cancer5.4.6Surgery for colorectal cancer	19 20

Clinical Advice for the Commissioning of	of the Whole	Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 4

5.4.7		
5.4.8		
5.4.9		
5.4.1		
5.4.1	······································	
5.4.1		
5.4.1		
5.5 C	Clinical review and surveillance	26
5.5.1		
5.5.2	2 Minimum follow-up schedule	26
5.5.3	3 Surveillance	27
5.5.4		
5.6 N	Anagement of advanced and recurrent disease	27
5.6.1	Systemic chemotherapy for potentially operable disease	27
5.6.2	2 Surgery for metastatic disease	28
5.6.3	B Palliative chemotherapy and radiotherapy	28
5.6.4	Other treatments to improve symptom control	29
5.6.5	Specialist palliative care and hospice care	29
5.7 l	nformation / data submission	30
5.8 F	Research	30
6. Cano	cer networks and population covered	30
	Cancer Alliances	
	Population covered	
	Any acceptance and exclusion criteria	
	nterdependencies with other services	
	nterdependencies with other organisations	
Appendix	. 1	35

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 5

## **Executive Summary**

This Clinical Advice for the Provision of Colorectal Cancer Services provides a summary of current best practice, and highlights areas where there have been recent advances and changes in patient management.

Colorectal cancer is the fourth most common cancer in the UK affecting both men and women, and the second biggest cancer killer. If diagnosed at an early stage it is curable. There are effective treatments for colorectal cancer at all stages of presentation. Adenomatous polyps are a premalignant condition, which if removed may prevent bowel cancer from developing.

Unfortunately, the survival prospects for patients diagnosed with colorectal cancer in England are not as good as in other countries with a developed heath care system. Net survival has been reported to be up to 15% less in England compared with, for example, Australia. These differences in outcomes are most likely due to late presentation. In England there is an increased rate of emergency presentation with about 24% of patients diagnosed following admission via Accident and Emergency (A&E) departments. More than half these patients have late stage disease.

Within England, there are also regional variations in stage at diagnosis, provision of diagnostic and treatment services and outcome. Local commissioning for much of the colorectal cancer pathway may permit provision more responsive to local need, but risks increased national variation if best practice standards are not applied.

This clinical advice describes a good practice service for colorectal cancer in England. It applies to the whole patient pathway, from first contact with either primary care, the National Bowel Cancer Screening Programme (NBCSP) or A&E, through to discharge from follow up or palliative care. The advice should inform discussions between commissioners and providers, including general practitioners, on local contacts and quality priorities. Where commissioners and providers feel unable to deliver the standards set out in this document, they should clearly set out the reasons for this, as well as what actions will be taken to address the issues identified.

## 2.1 Summary of key priorities for commissioning services for people with suspected and confirmed colorectal cancer

a. Data submission: a high quality service requires and provides good quality data. This will only be possible if commissioners and providers work together to ensure comprehensive, timely and accurate data submission. These data will permit better assessment of interventions to improve outcomes and patient experience. Local commissioners need to know how the stage and mode of presentation differs from the national average.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 6

- b. Encouraging earlier diagnosis of bowel cancer: over 98% of people survive for at least five years if diagnosed at stage one, compared to 7% at stage four. Achieving earlier diagnosis will require improvements in participation in screening by harnessing the ability of GPs to promote increased uptake of the National Bowel Cancer Screening Programme (NBCSP), a lower threshold for referral for investigating patients with colorectal symptoms and expanding and making better use of diagnostic capacity. This may require the establishment of specific diagnostic services for patients presenting with bowel symptoms including straight to test.
- c. Reducing unwarranted variation in diagnosis & treatment: commissioners should use the clinical advice outlined in this document to contract high quality services for colorectal cancer. They should identify where providers are not currently compliant and reduce unjustifiable variations in quality and outcomes. For example, commissioners should assure all patients requiring an emergency operation (including for the complications following elective surgery) have a procedure supervised by a specialist colorectal surgeon.
- d. Delivering improvements in the patient experience: a positive experience of treatment and care for patients with bowel cancer is related to ease of access to Clinical Nurse Specialists (CNS). Commissioners need to ensure contracts stipulate adequate levels of CNS support for patients throughout their treatment pathway and during follow-up. Appropriate information and support should be available to patients and carers throughout the pathway. Services must be commissioned to ensure equitable access to care for people living with and beyond bowel cancer aligned with the National Cancer Survivorship Initiative.

## 3. Population needs

#### 3.1 National and local context

This national clinical advice for commissioning of colorectal cancer services sets out the key evidence based priorities for commissioning high quality, patient-centred services for people wherever they live. This evidence based approach will ensure the best value interventions. An effective bowel cancer service depends on local services working seamlessly with specialist services that are commissioned directly by NHSE.

The document covers services for diagnosis of suspected bowel cancer and staging and treatment for confirmed cancer. Separate specialist service specifications for radiotherapy and chemotherapy are being reviewed by NHSE but should not conflict with any of the recommendations in this service specification.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway			-	
Issue/approval date: November 2017	Next review date	e: May 2019		Page 7

#### 3.2 The burden of bowel cancer

Bowel cancer is the second most common cause of cancer mortality for men and women in England. There were 41,300 new cases (55.2% male) in 2014. In 2011 59% of males and 58% of females survived five years. There were 290,000 patients alive following treatment for bowel cancer in 2015.

Survival is dependent on stage at diagnosis. In England, patients diagnosed with a Dukes A. colorectal cancer had a 5-year relative survival rate of 98%. The rates for Dukes B, C and D are 85%, 63% and 7.5%. If the stage at diagnosis was unknown the relative survival rate was 18%. Survival is also related to route to diagnosis. The one-year survival for patients diagnosed through all routes is 76%. Patients diagnosed through emergency presentation (24% of cases) have a one-year survival rate of 49%.

The cost of treating the earliest stages of bowel cancer is lower than for later stages of presentation. 37% of people identified with bowel cancer through the NBCSP are diagnosed as Dukes A cancers, compared with 6% of patients presenting with as an emergency. There is also a variation in the proportion of patients presenting with symptoms with respect to deprivation. 9.6% of the most affluent quintile down to 7.4% in the most deprived quintile are diagnosed with a Dukes A cancer.

Commissioning local services to match the performance that is currently achieved by the best in England should be expected to deliver significant improvements in patient experience and outcome. The national emphasis should be on reducing variation in early diagnosis, a patient priority, which should deliver best value.

## 4. Evidence needs

#### 4.1 Evidence base

The clinical advice outlined in this document draws its evidence and rationale from a range of documents, including:

- Achieving World Class Cancer Outcomes: A strategy for England 2015-20
- Cancer Research UK
- NHS atlas of variation
- NCIN and NCRAS publications
- Office for National Statistics
- NICE guidance
- Association of Coloproctology of GB & I (ACPGBI) guidelines 2007 and 2017
- National Bowel Cancer Audit (NBOCA)
- National Cancer Peer Review Programme Manual of Cancer Services: Colorectal measures
- Cancer reform strategy 2007

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019	Pag	e 8

- Improving outcomes: A strategy for cancer 2011
- British Society of Gastroenterology (BSG) guidelines
- PHE publications

## 4.2 Why improving early diagnosis and increasing participation in screening is a priority

Survival from colorectal cancer is dependent on the stage of presentation. Patients presenting early Dukes' A (Stage 1) cancers represent only 15% of those diagnosed in England in 2014 and had a 98% 5 year survival. Late stage Dukes' C (Stage 3) and Dukes' D (Stage 4) had 63% and 7.5% 5 year survival respectively. It should be noted that Unknown stage represented 18% of new diagnoses and had a lower % year survival than Dukes C at 17%. Unknown stage should reduce as more radiological staging data is effectively collected. In addition to lower survival rates there are increased costs for treatment of late stage colorectal cancer including chemotherapy, radiotherapy, liver and/or lung resection. Treatment of late stage disease is also associated with more complications and side effects including bowel, bladder and sexual dysfunction along with body image issues.

Bowel cancers detected by the national bowel cancer screening programme have a higher percentage of earlier diagnosis, 42% of cancers are diagnosed as polyp and Dukes' A cancers (Stage 1). There is a similar proportion of Dukes' B and C diagnosed as for symptomatic patients but only 8% diagnosed as Dukes' D.

## 4.3 Why reducing unwarranted variation in diagnosis and

#### treatment is a priority

Sharing information about variation helps to drive improvements in health care. High quality data are required so that unwarranted and expected variation may be differentiated.

Examples may be found in the NHS atlas of variation in healthcare for 2015. Map 13 presents data for the percentage of patients diagnosed with bowel cancer of in Stage 1 and 2 (early diagnosis) in 2013 by Clinical Commissioning Group (CCG). Early diagnosis varied between 13.5% for the CCG with the lowest rate to a highest rate at 54.4%. Map 98 presents the data for planned access to adult critical care following emergency excision colorectal surgery by CCG 2013/14. Planned access varied between 0% for the CCGs with the lowest rate to a highest rate of 96.6%.

For patients with bowel cancer variation in other components of the patient pathway also need to be addressed for example, patient satisfaction, access to CNS, permanent stoma rates, access to laparoscopic surgery and organ sparing trans-anal surgery for early rectal cancer, neoadjuvant therapy, age and access to treatment.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 9

## 5. Scope of the bowel cancer service

### 5.1 Aims and objectives of service

The aim of a bowel cancer service should be to:

- Prevent people from dying from bowel cancer, best achieved by early diagnosis. Where this is not possible, extend their lives.
- Maintain the quality of life for people diagnosed with bowel cancer
- Deliver access to the best available treatments for all patients.
- Treat people safely and protect them from avoidable harm
- Help patients recover from bowel cancer related illness and side effects of treatment
- Deliver a positive experience of treatment and care for patients and carers CNS support

#### 5.2 Service description and care pathway

This clinical advice includes all parts of the bowel cancer pathway with the exception of primary prevention, the delivery of awareness programmes and the provision of end of life care.

For completeness, it encompasses:

- Screening
- Investigation, referral and diagnosis
- Treatment
- Patient experience
- Follow up
- Recovery and rehabilitation
- Palliative care

The service will be delivered by multidisciplinary specialist teams, working closely with primary and palliative care teams.

## 6. Essential clinical advice for commissioning

• The service should be commissioned with best clinical practice referring to NICE Quality Standard for Bowel Cancer, ACPGBI guidelines and Achieving World Class Cancer Outcomes: A strategy for England 2015-20.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 10

## 6.1 **Presentation**

#### 6.1.1 Primary care

- Referral of patients who fulfil the referral criteria for 'red flag' symptoms of colorectal cancer outlined in NICE guideline NG12 should be referred using the regionally agreed two-week wait referral pro-forma. The form ensures all referrals are sent to a designated Trust diagnostic service.
- For patients who do not have rectal bleeding but who have unexplained symptoms and do not meet the criteria for a suspected cancer pathway referral outlined in the NICE guidelines (NG12), the faecal immunochemical test (FIT) should be available to guide referral, in line with DG30.
- Patients should be referred when high risk symptoms are present for three weeks before referral is made, in line with the advice given by Public Health England awareness campaigns
- Two week wait referral to be completed within 24 hours of a patient being seen in primary care.
- All symptomatic patients who do not fulfil the two week wait criteria, should be considered for referral to a consultant colorectal surgeon or gastroenterologist using the routine referral point (18 week pathway) or using available straight to test services.
- Patients without 'red flag' symptoms for colorectal cancer should be referred using the Choose and Book service. GPs must attach the referral letter to the Choose and Book documentation.
- All patients with new onset colorectal symptoms over 40 years of age should be considered for referral for further investigation.

#### 6.1.2 Internal referrals

- Referral should be made to colorectal multidisciplinary team (MDT), via the MDT coordinator, within a working day of a diagnosis of colorectal cancer by investigations or clinicians outside of the colorectal MDT.
- The colorectal MDT, via the MDT co-ordinator, should be urgently informed of any unexpected colorectal cancer diagnoses as a result of investigations by clinicians outside the MDT. This should be included within the operational policies of the MDT and diagnostic services (including endoscopy, pathology and radiology). Such referrals should occur within a working day.

#### 6.1.3 Screening

- Patients with cancer or polyps requiring surgical resection identified at a screening centre should be referred to the colorectal MDT local to the patient for treatment on 62 day pathway.
- GPs should promote screening and respond to information from the NBCSP with respect to their patients who have had a positive stool test but do not

proceed with a colonoscopy or CT pneumocolon, and those patients who do not return a completed stool testing kit

#### 6.1.4 Emergency presentation

• Patients presenting as an emergency should have surgery under the care of a consultant colorectal surgeon who is a member of a colorectal MDT. This applies within and out of normal working hours. This may require innovations such as collaboration between Trusts to provide on-call rotas or reconfiguration of services.

#### 6.1.5 Secondary to tertiary referrals

- Referrals from outside the Cancer Alliance and secondary to tertiary referrals should be routed using appropriate referral standard operating procedures from the referring MDT to the colorectal MDT.
- There should be clear pathways for neo adjuvant treatment, early rectal cancer, liver, lung and multi-visceral resections and Hyperthermic Intraperitoneal Chemotherapy (HIPEC).

### 6.2 Diagnosis

#### 6.2.1 Referral processing

- Diagnosis and assessment of all patients referred from primary care on a twoweek wait pathway with a possible diagnosis of colorectal cancer will be carried out by a named diagnostic service in each Trust.
- On receipt of a two week wait referral (based on the NICE 2ww criteria), patients to have an appointment for an outpatient consultation or test within 14 days of referral.
- Patients who do not attend their appointment must be offered a second appointment within 14 days, with the referring clinician informed that they failed to attend the first appointment.

#### 6.2.2 Diagnostic Lead

- Each Trust should have a colorectal diagnostic service with a named lead clinician.
- The named lead is responsible for the process by which patients access appropriate diagnostic tests, to deliver a definitive diagnosis.
- The named lead is responsible for providing a decision point at their Trust for prioritising appointments for all patients referred for investigation of large bowel symptoms. This could be facilitated by the triaged straight to test model.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 12

#### 6.2.3 Diagnostic service (Straight to test)

- Patients should be referred by a GP to a Colorectal 'Diagnostic Service'
- A Diagnostic Service is a designated referral centre, which will triage referrals and assign the most appropriate diagnostic test that will be booked directly with the patient.
- It should be noted that barium enema is not considered to be an appropriate first diagnostic test.
- The key principles of a Diagnostic Service, include:
  - **a.** Referral received to a designated referral centre ideally using a standardised pro-forma (designed in conjunction with Local Clinical Commissioning Groups (CCGs). Referrals sent to dedicated fax or NHS.net email address or to a Choose and Book telephone consultation clinic (for triage). It is recommended that fax referrals are phased out.
  - **b.** Once received, referrals have clinically supervised triage, for example by a trained specialist nurse. Patients may be consulted by telephone to check clinical fitness and the indication according to local policy (building on existing local experience) agreed with local CCGs to one of the following:
    - Colonoscopy (+ OGD if the patient presents with Iron-deficiency anaemia)
    - Flexible Sigmoidoscopy (for investigation of rectal bleeding without anaemia)
    - CT Colonography
    - Out-patient consultation
  - **c.** Patients with investigations that do not reveal cancer, but have a symptomatic condition manageable in primary care should be sent back to the referring GP with a full report of the investigation results including histopathology, and with advice on self-care and primary care medical management. If symptoms persist, patients should be referred via '18 week' pathway to an appropriate outpatient clinic.
  - **d.** Patients diagnosed with adenomatous polyps should be entered into surveillance managed at the acute trust level in accordance with the BSG guidelines.
  - e. Patients diagnosed with cancer should go straight to staging, be seen by a CNS and referred to the Colorectal MDT.
  - **f.** Patients diagnosed with Inflammatory bowel disease (IBD) should be referred to the IBD MDT for further management.

#### 6.2.4 Information

- GPs will be notified of new patients diagnosed with cancer the next working day after the patient has been informed.
- The GP will be informed within 24 hours of the MDT decision, following discussion with the patient in the presence of a CNS and core member of the

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 13

MDT. This will require an establishment of colorectal CNSs to cover a 52 week service.

#### 6.2.5 Investigation protocol for primary colorectal cancer

- The preferred method for making the initial diagnosis of a large bowel primary cancer is by colonoscopy
- Complete examination of the large bowel by either total colonoscopy or CT pneumocolon should be performed before treatment.
- All endoscopy units recognised for colorectal cancer diagnosis should be Joint Advisory Group on GI endoscopy (JAG) accredited.
- All patients with a colorectal primary should have a contrast-enhanced CT of chest, abdomen and pelvis to stage the disease.
- In addition, when not contra-indicated, rectal cancers require local staging by MRI. Transrectal ultrasound may also be used as an additional modality in early rectal cancer.
- Radiology reporting standards must comply with the recommendations from the British Society of Gastrointestinal and Abdominal Radiology and the Royal College of Radiologists. A proforma report of the radiology with CT and MRI should be provided.
- Blood investigations should include haemoglobin, electrolytes, creatinine, liver function test and pre-operative carcinoembryonic antigen (CEA) level.
- Biopsy providing histological proof of malignancy is required in most cases of colorectal cancers treated electively.

## 6.3 Multidisciplinary Team (MDT)

#### 6.3.1 Membership

All members will have a specialised interest in colorectal cancer, with one member taking managerial responsibility for the service as a whole (the Lead Clinician).

Core team should include:

- At least two colorectal surgeons are required, to comply with National Peer Review. The team, however, should have enough Colorectal surgeons to run a colorectal rota for the management of colorectal emergencies, including complications following elective surgery.
- Clinical oncologist with responsibility for radiotherapy for rectal carcinoma.
- Medical oncologist with responsibility for chemotherapy.
- Radiologist with an interest in colorectal imaging and intervention.
- Specialist Gastrointestinal Histopathologist.
- Colonoscopist with expert skills in any of the following disciplines: surgeon, physician or specialist nurse.
- A gastroenterologist.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 14

- At least two Colorectal Clinical Nurse Specialists (CNS) to provide cover for the smaller units. Larger departments will require more.
- Anaesthetist with an interest in the perioperative management of patient with colorectal cancer (including pre-operative assessment).
- MDT Co-ordinator.
- An NHS-employed member of the core or extended team should be nominated as having specific responsibility for users' issues and information for patients and carers.
- At least one of the clinical core members, with direct clinical contact, should have completed the training necessary to enable them to practice at level 2 for the psychological support of cancer patients and carers.
- One of the core MDT members should be nominated as being responsible for the integration of service improvement.
- One of the core MDT members should be nominated as being responsible for the recruitment of patients into clinical trials.
- For medically qualified core members of the MDT, the cover should be provided by a consultant in the same specialty.

The extended team should include:

- Psychologist/liaison Psychiatrist.
- Liver surgeon who is a member of a liver resection MDT.
- Thoracic Surgeon who has a practice in lung resection for metastases, and is a member of a Lung MDT.
- A member of the palliative care MDT (doctor or nurse).
- An expert in insertion of Colorectal stents.
- Consultant in elderly care.
- Dietitian.
- Urologist.
- Gynaecologist.
- Clinical geneticist/genetics counsellor.
- Social Worker.
- Clinical trials co-ordinator or research nurse.
- Bowel Cancer Screening Nurse.
- Stoma care CNS.
- Physiotherapist/Occupational Therapist.

#### 6.3.2 Clinical Nurse Specialist (CNS)

- At least one core nurse member who has completed, is enrolled in, or undertaking, a programme of study in their specialist area of nursing practice, which has been accredited for at least 20 level III Credit Accumulation Transfer (CAT) points.
- A CNS who has completed, is enrolled in or undertaking courses in communication skills and holistic needs assessment which is accredited for CAT points.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 15

- The workload of the CNSs should be reviewed by the Trust and shared with the Cancer Alliance annually to ensure the needs of patients can be met.
- The importance of CNSs with patient care and patient experience should be recognised by Trusts by providing designated administrative support for CNSs.
- There should be an adequate establishment of CNSs to allow for cover arrangements for annual leave and study leave.
- There should be sufficient CNS staffing to support seamless transition of the patient along the different steps of the pathway: diagnosis, peri-operative, adjuvant therapy, living with and beyond, and palliative care.

#### 6.3.3 Attendance

- Attendance of individual core members at the MDT meeting should be 66% with core member or cover attendance achieving 95%.
- For medically qualified core members of the MDT, the cover should be provided by a consultant in the same specialty.
- Written attendance records should be collected for audit.
- All core members with direct patient contact should have attended advanced communications skills training.

#### 6.3.4 Workload

- The core surgical members of the MDT should, as a group, discuss a minimum of 60 new colorectal cancer cases per year (average for two years).
- Core surgical members of the MDT should undertake at least 30 colorectal resections per year. Procedures counted should include elective, emergency, and palliative cases, joint procedures and surgery for benign conditions (average over two years).

#### 6.3.5 Information

- For every patient, MDTs must record a clinical stage at diagnosis based on the radiological findings and a post-operative pathological stage (for patients having an operation).
- Monthly data must be submitted to the cancer registries ( cancer outcomes and services data, COSD) and annually to NBOCA within published timelines.
- The MDT must comply with peer review standards, which are to be viewed as minimum standards.
- All MDTs must submit data to the National Cancer Registration Service and relevant audits.
- Comprehensive and accurate data submission should be considered a key part of a high quality service and failure to comply should result in contractual sanctions
- After a patient is given a diagnosis of cancer, the patient's GP is informed of the diagnosis by the end of the following working day.

• To facilitate staging data there is a need for the adoption of a radiology minimum data set and implementation of radiology proforma reporting.

#### 6.3.6 Meeting

- MDT meetings to be held weekly, with a quorum of core members for at least 95% of the meetings.
- The care of all patients with colorectal cancer should be formally reviewed by the MDT.
- The MDT is expected to comply with national cancer targets.
- An operational policy outlining that all new cancer patients will be reviewed by the MDT.
- The MDT may choose to have a separate pre-operative/diagnostic meeting and post-operative/therapeutic meeting. The membership of this meeting is to be named and agreed by the Lead Clinician of the MDT.
- Core team members meet at least on an annual basis to discuss, review, agree and update the operational policies.
- Feedback should be given to CCGs on the appropriateness and/or timeliness of GP referrals. The feedback should include the stage and route of presentation.
- The MDT operational policy should include a policy for identifying the named CNS for each individual patient, which is recorded in the patient's case notes.
- As MDTs become larger due to hospital mergers and reconfiguration, 'virtual MDT' innovations should be considered for approving and monitoring the treatment plans of patients on the 'pathway' and with no issues requiring discussion by the team.

#### 6.3.7 Onward referral from the diagnostic and assessment service

- The consultant clinician managing the patients' diagnosis is responsible for making an onward referral following the MDT decision.
- Patients with non-malignant disease diagnosed as part of the MDT process remain the responsibility of the referring clinician, most commonly by GP.
- There is a requirement for rapid and efficient communication systems for liaison and cross-referral between all levels of service, including primary care, psychologists, cancer genetic specialists, social workers and palliative care.
- Joint clinics involving different disciplines, to enable a patient to be seen and discussed by two or more of the team members together, may improve patient care. At all times there should be close liaison between all members of the team.

#### 6.3.8 Teenage and Young Adult Pathways (TYA)

• TYA MDTs are responsible for overseeing the care of young adults with cancer

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 17

- The TYA MDT may provide care jointly with local colorectal MDTs for patients aged 13 to 24 years of age, based on locally-agreed guidelines.
- The treatment plan of all cases should be jointly agreed by the respective Colorectal MDT and TYA MDT according to the relevant clinical guidelines.

## 6.4 Patient notification within outpatient clinic

#### 6.4.1 Diagnosis and treatment options

- Clinic appointments to explain the diagnosis and treatment plan should occur as soon as possible after the MDT meeting.
- It is recommended that the patient is informed that they can bring someone to support them at the clinic appointment.
- The patient should be given the diagnosis by a consultant or appropriately trained team member in the presence of the CNS.
- The cancer diagnosis should be communicated in language the patient can clearly understand and if translation services are needed, these must be provided by a health advocate. Ideally, a family member should not be used for translation when a diagnosis of cancer is given.
- Treatment options should be discussed with the patient. The recommendations of the MDT should be explained with the alternatives discussed before patient makes a decision, including the potential benefits and risk of these treatments, including the effect on bowel function.
- The patient should be offered a written record of the consultation (copy of correspondence to GP).
- The patient should be advised where they can access support and information about bowel cancer.
- The core members of the team communicating a cancer diagnosis should be trained in advanced communication skills.
- Patients should be offered a review by their GP in line with primary care guidelines.

#### 6.4.2 Nursing input

- Patients should be supported by a colorectal CNS who is the designated 'key worker'. Evidence from the Cancer Patient Experience Survey shows that access to a CNS has a positive effect on many aspects of a patient's experience. The support should continue throughout the follow-up period by telephone and in the clinic.
- All patients should receive a Holistic Needs Assessment prior to and at the end of treatment, in line with the National Cancer Survivorship Initiative recommendations.
- Where a patient agrees to complete the Holistic Needs Assessment, there should always be a subsequent follow-up to address any concerns that have

been raised. A relevant plan should be recorded and action taken to help meet these individual needs, for example through referrals and signposting to relevant local and national support services including cancer support centres, psychotherapy, specialist clinics and charity online forums and help lines.

- Providers should make time for these services to be delivered. In particular, time should be given by the CNS for questions, counselling and support, backed up by written information and patients should be given time and support to reflect on their treatment options before having to make a decision. Emotional support should be available to the patient at any stage in their pathway of care.
- The type of written information provided should be documented within the patient's notes.
- Patients who may require a stoma should be seen before surgery by a stoma nurse or CNS trained in stoma therapy. The nurse should site the stoma and provide the patient with written and verbal information. The nurse should be available to assist and advise the patient pre and post-operatively in managing the stoma, including referring to local community services and stoma nurses.

#### 6.4.3 Patient information

- All patients should be offered clear and comprehensive information on:
  - Nature of the disease.
  - Diagnostic procedures being undertaken.
  - Treatment options available.
  - Likely outcomes of treatment in terms of benefits, risks and side effects.
  - o Contact Details for Coordinator of Specialist Team.
  - Sources of psychological and peer support.
  - o Information on benefits available.
  - Contact details for their CNS.
  - Information on support groups available and other types of support that are available.
- Information should be available in languages other than English, and can be provided in other accessible formats, including multimedia.
- Patients should be offered a copy of the clinic letter from the consultation when the diagnosis and treatment plan were explained as a permanent record. It should be recorded in the patient's notes if this offer has been accepted or declined.

#### 6.4.4 Primary treatment

- Patients with a diagnosis of colorectal cancer should have their cases discussed before treatment at an MDT meeting where the treatment plan should be formulated. The discussion may include use of neo-adjuvant therapy and entry into clinical trials where appropriate.
- Cancers detected by national screening programme should be referred back to the patient's local MDT, with treatment performed at that Trust where possible, rather than by the Trust providing the screening service.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019	Page 1	19

#### 6.4.5 Pre-operative treatment for rectal cancer

- Radiotherapy and chemotherapy should be only given after discussion by MDT and under direction of clinical and medical oncologists who are core members of the MDT, working within facilities complying to national guidelines. Multiple discussions at the MDT may be needed for complex cases that require multiple modalities of treatment.
- A referral to a specialist centre for early or advanced pelvic surgery should be considered if this is not available at the local centre
- Radiotherapy is not usually indicated if there is a small risk of recurrence (T1 or T2, N0 disease) or if death is likely before local recurrence would cause symptoms.
- Radiotherapy reduces the risk of local recurrence by 30 40% with a marginal effect on survival.
- Short-course radiotherapy may be indicated for T3 disease where the CRM is clear.
- Pre-operative long-course chemoradiotherapy should be considered in cases of T3 or T4 disease, where the potential circumferential resection margin (CRM) is threatened and where there is radiological evidence of mesorectal lymph node involvement, extramural venous invasion (EMVI) or sphincter involvement. The aim of treatment would be to reduce tumour bulk to allow a curative R0 resection.
- Patients with high rectal cancers should be considered for neo-adjuvant chemotherapy prior to surgery. A short-course of radiotherapy or chemoradiotherapy may also be considered appropriate after the chemotherapy prior to surgery.
- When patients are transferred to a cancer centre for neo-adjuvant treatment they should be provided with a named CNS (key worker) for that element of their treatment pathway by the centre and provided with information on the risks and benefits of treatment.
- The use of advanced radiotherapy techniques such as IMRT/VMAT is encouraged.
- Entry into clinical trials such as those evaluating novel drugs and different sequencing of treatment should be encouraged.
- Patients with rectal cancer who have had chemoradiotherapy should have a repeat CT and MRI pelvis scan 6-10 weeks post-surgery. These should be reviewed at the MDT and a decision made about appropriate treatment.
- Patients who may have had a complete clinical response (cCR) to treatment (estimate 20-25%), may be considered by the MDT for a close follow up policy with surgery in reserve.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 20

#### 6.4.6 Surgery for colorectal cancer

- Surgical management should comply with current Association of Coloproctology of Great Britain and Ireland (ACPGBI) guidelines and current NICE recommendations for colorectal cancer.
- Laparoscopic surgery should only be performed by surgeons who have been appropriately trained and are maintaining their skills and continuing to audit outcomes.
- Surgery should be carried out at hospitals recognised for providing colorectal surgery.
- Major and complex major colorectal surgery should only be performed in hospitals with Level 3 ITU provision.
- Colorectal surgery should only be performed in hospitals with CT scanning available 24 hours a day/7 days a week with on-site interventional radiology provision.
- A formal Enhanced Recovery Programme should be provided for all patients undergoing elective colorectal surgery. This is best facilitated by Trusts providing designated wards or areas of wards, and specialist nurses.
- Pre-operative assessment including cardiopulmonary exercise testing (CPET/CPEX) should be available at all Trusts providing colorectal surgery.
- Surgical teams should be supported by anaesthetists with a special interest in colorectal surgery, expert in the use of thoracic epidural anaesthesia.
- Consideration should be made for specialist low rectal cancer services. Where abdomino-perineal excision for low rectal cancer is required, surgical members of MDT should demonstrate adequate training, including attendance at the national LOREC course.
- If plastic surgery reconstruction is needed, it should be performed in conjunction with a plastic surgeon with an interest in perineal reconstructive surgery.
- For patients undergoing resection surgery for primary rectal cancer, less than 25% should have abdominoperineal excision of rectum (APER). If a distal clearance of at least 1cm can be achieved, a low rectal cancer should be considered for anterior resection.
- Where tumour invades an area of the genitourinary tract in the male, the decision for surgery should be supported by a consultant urologist with appropriate expertise and surgery carried out with their support. Surgery can be carried out in hospitals where this expertise exists.
- Where tumour invades an area of the genitourinary tract in the female, the decision for surgery should be supported by a consultant gynaecologist and/ or consultant urologist with appropriate expertise and surgery carried out with their support. Surgery can be carried out in hospitals where this expertise exists.
- Surgery for recurrent pelvic disease including sacrectomy should be carried out by a surgical team specialising in this type of surgery. Pelvic exenteration should be carried out by a full surgical team in a centre providing vascular, colorectal, urological, gynaecological, spinal, plastic and reconstructive surgery.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 21

- Laparoscopic surgery should be delivered, as a minimum, in line with Peer Review guidelines. All patients who fulfil agreed criteria should be offered laparoscopic surgery as a treatment option.
- All core surgical members of the MDT should have appropriate training in laparoscopic colorectal surgery. In MDTs where this is not the case, where there is no contra-indication for laparoscopic surgery, the patient must be referred to another member of the MDT with the appropriate skills.
- If there is no contra-indication for laparoscopic surgery, but the MDT has no core surgical member available to provide laparoscopic surgery, the patient must be referred to another MDT where this procedure can be performed within cancer waiting times.
- Commissioners should agree benchmark rates for surgical outcomes, informed by audits.

#### 6.4.7 Emergency surgery

- Surgery for patients presenting as an emergency, including surgery to manage the complications of elective surgery, should be conducted by specialist colorectal surgeons. Patients should not be managed for emergency major colorectal interventions by generalists.
- Colonic stenting should be offered to treat patients presenting with bowel obstruction.
- There should be a 7 day service for emergency colonic stenting. Cancer Alliances should assure their regions provide access for patients to emergency colonic stenting.
- After emergency surgery, all post-operative colorectal patients must be admitted to an ITU/HDU bed. In some cases, patients will need admission to ITU/HDU for pre-operative optimisation.
- If initial life-saving surgery is not performed by a core member of the colorectal cancer MDT (for example, a member of the IBD MDT), the patient should be referred to a core member of the colorectal cancer MDT. The case should be discussed at the next colorectal MDT meeting for review and subsequent management. The patient should also be referred to the colorectal specialist nurse (and stoma nurse if required).
- All patients treated as an emergency, should be discussed at the next available MDT meeting to plan further management.

#### 6.4.8 Staging and reporting

- Colorectal cancer should be reported and staged according to the Royal College of Pathologists' (RCPath) national dataset for colorectal cancer (3rd edition).
- Use of the RCPath reporting proforma is advised. If this is not possible, pathology reports should include, as a minimum, all the information that would be present in the completed proforma.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 22

- TNM and Dukes' staging are required. Dukes' staging is not applicable if there is no residual tumour after neoadjuvant therapy.
- In line with NICE guidance (DG27), all colorectal cancer patients should be tested for molecular features of Lynch syndrome, at diagnosis of colorectal cancer. Adherence to this guidance should be regularly audited and patients should be informed of the result and possible implications.
- Patients identified with suspected Lynch syndrome and Familial Adenomatous Polyposis (FAP) should be discussed at the MDT meeting and referred to appropriate genetic counselling services.

#### 6.4.9 Histopathology outcome measures

- Facilities should be available for the storage of histology slides for a minimum of ten years and tissue blocks for specimens indefinitely.
- Pathology labs must have appropriate external accreditation.
- Pathologists must participate in appropriate external quality assurance (EQA) schemes.
- A designated specialist gastrointestinal pathologist should attend colorectal cancer MDT meetings and be available for discussion of the patient's treatment plan.
- All colorectal histology for patients with bowel cancer must be discussed at the MDT meeting.
- Pathology services should complete the Royal College of Pathologists dataset in reporting. TNM8
- Reporting pathologists should provide information that allows the quality of surgery to be assessed, e.g. quality of the mesorectal excision margin, involvement of the circumferential margin, and number of lymph nodes retrieved (although the latter also reflects other factors).
- Each pathologist should retrieve an average of at least 12 lymph nodes from colorectal cancer resection specimens.
- Adherence to the RCPath dataset should be audited.
- Pathology reports are enhanced by the inclusion of photographs of the specimen with inked margins.
- Turnaround times should be based on the RCPath key performance indicators, i.e., 80% of cases should be reported within seven days and 90% within ten days.
- All appropriate molecular diagnostic and/or genomic tests should be undertaken in order to determine a patient's eligibility for targeted cancer medicines.
- Data to be provided to the Cancer Registry.

#### 6.4.10 Post-operative adjuvant treatment (Chemotherapy)

• At the post surgery MDT discussion, the indications for chemotherapy should be discussed for all patients, including a discussion regarding their medical fitness. WHO performance status must be recorded.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019	Р	age 23

- The mismatch repair (MMR) status should be determined to see if a patient could have microsatellite instability (MSI-H). This would influence whether chemotherapy is given and the choice of chemotherapy used. It would also help determine which patients should be referred for genetic counselling.
- If clinical or pathological staging of colorectal tumours reveals a high risk Dukes B (stage II) cancer, then adjuvant chemotherapy should be recommended if the patient is fit for treatment. High risk features may include emergency presentation, T4, EMVI, less than 12 lymph nodes harvested and poorly differentiated tumours.
- If clinical or pathological staging of colorectal tumours reveals node positive disease (Dukes C, stage III), adjuvant chemotherapy should be recommended if the patient is fit for treatment.
- The risks and benefits of treatment must be clearly discussed with the patient.
- Chemotherapy should be delivered as close to the patient's home as possible.
- No patient should be travelling to medical oncology centres for standard chemotherapy.
- All patients should be start treatment within 6-10 and a maximum of 12 weeks from the operation.
- Every chemotherapy patient should have a named CNS (key worker) for this element of their pathway. The CNS should be a member of the oncology team. This will require an establishment of oncology CNSs to cover a 52 week service provided by the cancer centre.
- Chemotherapy should be administered in accordance with regionally-agreed clinical guidelines. The choice of chemotherapy should be based on up-to-date research.
- Entry into appropriate clinical trials is encouraged.
- Following treatment, the medical oncology team must provide (electronic) end of treatment summaries including individualised care plans, in line with National Cancer Survivorship Initiative (NCSI), with an accessible record of treatment for local units, GPs and patients.
- A process should be in place to enable rapid admission to a specialist centre for any patient having complications of chemotherapy. The management of chemotherapy complications presenting as an emergency should be provided by specialist oncologists via the acute oncology service.
- Written information must be provided, including on who to contact and how if complications or other problems are experienced following treatment.
- All patients should be provided with appropriate information to enable (where appropriate) self-management of side-effects, or access to community-based services and allied health professionals for assistance in managing side-effects or the late effects of treatment. Online forums provide useful sources of peer support and patient experience.

#### 6.4.11 Post-operative adjuvant treatment for rectal cancer (radiotherapy)

• Following the post-operative discussion at the MDT, patients with positive resection margins for rectal cancer should be considered for post-operative long-course radiotherapy (with or without concurrent chemotherapy) if they did

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 24

not receive neoadjuvant radiotherapy. However, this should be rarely needed. The aim of the MDT is to manage patients with chemotherapy, pre-operative (chemo)radiotherapy and surgery to prevent a R1+ resection and the need for post-operative chemoradiotherapy.

#### 6.4.12 Rehabilitation and management of late effects

- Rehabilitation services should be aligned with the National Cancer Action Team (NCAT) rehabilitation pathway for colorectal cancer.
- All patients must have access to appropriately skilled allied health professionals (including stoma nurses, occupational therapists, physiotherapists, psychologists and dietitians) to support their individual needs throughout the cancer pathway.
- Specialist rehabilitation services should be available for patients with the consequences of treatment (such as fatigue or pain) or late-effects (for example sexual function, bladder/bowel issues) with no time limit on access. An example would be a CNS-led clinic on regaining bowel control. There should be clear referral guidelines from MDTs to these services.
- Standardised screening tools and outcome measures (where available and appropriate) should be used.
- Standardised rehabilitation information should be provided.

#### 6.4.13 Living with and beyond cancer

- Survivorship is about ensuring those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible. All patients should receive 'Recovery Package' interventions, which comprise:
  - Holistic needs assessments (HNA) and plan of care should be conducted firstly around diagnosis, then at end of treatment, whenever the patient's needs change or at any other time at the patient's request.
  - Treatment summary to be completed at end of primary treatment and shared with the GP and patient improved communication between cancer services and primary care.
  - Sources of information for patients and their families.
  - Cancer Care Review (CCR) states that a GP should review a patient within 6 months of a new cancer diagnosis (Quality and Outcome Framework, 2002).
  - Health and Wellbeing events: All patients should be provided with appropriate health and wellbeing information to enable selfmanagement of side-effects or access to community-based services and allied health professionals for assistance with managing any sideeffects or late effects of treatment. This would also include advice about access to schemes that support people to undertake physical activity, healthy weight management and vocational rehabilitation support etc.
- The combination of these interventions above will help enable better outcomes for cancer survivors, through creating a shared understanding between patient

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 25

and professionals about the issues important to the patient, what they can expect during recovery, and identifying any needs to be addressed.

#### 6.5 Clinical review and surveillance

#### 6.5.1 Stratified follow-up

- Cancer Alliances should promote the development of plans by Trusts to implement stratified and remote or self-care follow-up along the lines of the National Cancer Survivorship Initiative (NCSI). Those patients with good social support and minimal long term effects of their treatment should be suitable for self-managed follow-up. Patients with stomas, bowel function, and other late effects of treatment (surgical or chemotherapy) may initially need planned hospital follow-up or in the community by trained staff. The frequency of follow up investigations delivered either remotely or in secondary care will depend upon the risk of recurrence and should be intended to pick up recurrence before symptoms develop. A system must be developed for rapid re-entry of patients to the specialist cancer service as required.
- Stratified follow-up involves reduction of routine appointments from the pathway. Routine surveillance tests will still be completed as outlined below. The results will be reviewed by appropriately qualified or trained staff and the patient and GP informed of the results. This information may trigger a recall of the patient back to specialist services as required.
- Patients should be offered a 1:1 appointment with the CNS at the end of primary treatment to explain how stratified follow up works and to ensure the patient knows how to contact the service if there are any concerns or symptoms in between surveillance testing. (This could be done in the same session as the end of treatment HNA).
- There should be a policy for follow-up of HPCC and FAP. The frequency of surveillance colonoscopy for these groups of patients should be in line with British Society of Gastroenterology surveillance guidelines. Ideally there should be a single clinical lead to oversee service delivery for the surveillance of these patients and ensure referral pathways are followed.

#### 6.5.2 Minimum follow-up schedule

- Colorectal cancer follow-up is the shared responsibility of the specialist team, primary care and the patient. A minimum follow-up schedule should be agreed. It should include at least 2 CT scans of the chest, abdomen and pelvis and a colonoscopy within the first three years after surgery. A completion colonoscopy should be performed as soon as practicably possible in those patients who had an incomplete examination before surgery. Teams may choose to supplement this with regular CEA tests, which may continue for five years post-treatment.
- After 5 years, patients may have further surveillance colonoscopies and if not, should be encouraged to join the national screening program.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 26

- Tests should be delivered irrespective of whether a patient is seen in the clinic.
- The follow-up schedule may be conducted in the form of telephone clinics or virtual clinics in place of conventional clinical visits for patients.

#### 6.5.3 Surveillance

- Patients who contact any member of the colorectal specialist team with worrying symptoms will be seen by the appropriate team within two weeks and if necessary, the case will be discussed at the MDT meeting.
- All patients following initial treatment for colorectal cancer, will be given information about self-care and surveillance. A list of symptoms that could be a cause for concern and a contact number for the Colorectal CNS will be given as part of the information pack developed by Trusts.
- GPs and patients should also be given information on symptoms which may indicate recurrence.

#### 6.5.4 Discharge

- Discharge should follow local policies devised by the Trusts and CCGs.
- A treatment summary should be sent to the GP and patient within 6 weeks of discharge following primary treatment - surgery, chemotherapy or radiotherapy. The National Cancer Survivorship Initiative treatment summary template should be utilised. This template is available on Somerset and Infoflex systems. Follow up after surgery should focus on post-operative issues, promoting and sustaining recovery (including early detection and management of late effects), future planning, and stoma management. Patients' emotional and practical needs should be assessed, using an HNA undertaken by a CNS to identify specific needs, and appropriate care has or needs to be provided.

#### 6.6 Management of advanced and recurrent disease

#### 6.6.1 Systemic chemotherapy for potentially operable disease

- Patients identified with locally advanced or with potentially curable metastatic disease, should be discussed at the MDT meeting, with appropriate input from Hepatobiliary (HPB) and Thoracic Surgery and considered for neoadjuvant chemotherapy as a prelude to surgical treatment. These patients require restaging following neoadjuvant treatment and further review by the MDTs before progressing to surgical treatment.
- Prior to chemotherapy the pathological sample should be used to determine the genetic status of the tumour (RAS/BRAF). This will be used to guide the

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 27

oncologist as to whether a patient may benefit from an EGFR inhibitor such as cetuximab or panitumumab.

- As well as a conventional CT scan and possibly a liver MRI scan, a PET scan may be considered appropriate in these cases before surgery.
- Timing (pre- or post-surgery) and type of chemotherapy should be individualised based on MDT review and options discussed with patient, in accordance with national waiting times.
- Colorectal MDTs should refer all patients with liver and/or lung metastases to designated MDTs.
- Patients with metastatic disease of uncertain curability should also be restaged after chemotherapy and reviewed by the MDT at the end of treatment. Some of these patients may enter the curative pathway.
- Patients with metastatic disease with a treatment plan to have chemotherapy should have a baseline CT scan of thorax, abdomen and pelvis performed within six weeks of the start of their chemotherapy regime.
- There must be written protocols for the management of complications and toxicities.
- Chemotherapy should be provided as close as possible to the patient's home.
- Chemotherapy should be given by specially trained nursing staff, ideally within a designated day case chemotherapy unit, with close supervision by Oncologists. There should be expert pharmacy and 24 hour laboratory support.
- Each patient receiving chemotherapy should be given a contact number for a chemotherapy CNS.
- Patients receiving chemotherapy should have access to a specialist acute oncology team, on a 24-hour basis.
- All Trusts admitting emergency patients, should have established and specialist acute oncology team and an electronic flagging system for chemotherapy patients within A&E.
- Patients should be encouraged to participate in nationally and locally coordinated trials.

#### 6.6.2 Surgery for metastatic disease

- Liver surgery to be supervised by a HPB MDT
- Lung surgery to be supervised by a Lung MDT
- Peritoneal surgery and HIPEC to be supervised by a peritoneal MDT at specialised centres
- Recurrent locally advanced rectal cancer surgery should be managed by subspecialist colorectal MDT.

#### 6.6.3 Palliative chemotherapy and radiotherapy

• The aim of palliative treatment is to maintain a patients quality of life (QoL), increase overall survival (OS) and possibly convert an inoperable patient to operable depending on their response.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 28

- Cancer Alliances should develop regional chemotherapy guidelines based on current best practice. Survival may be increased from 6-9 months without treatment to 18-24 months or more with chemotherapy depending on a patients treatment tolerance, biology and response.
- Patients with known metastatic disease who are to commence chemotherapy should have a baseline CT scan of thorax, abdomen and pelvis performed within six weeks of the start of their chemotherapy regime.
- The genetic status of the tumour (RAS/BRAF) should be used to guide the oncologist as to whether a patient may benefit from an EGFR inhibitor. MSI status may identify patients may who benefit from immumotherapies.
- Treatment options for recurrent and advanced colorectal cancer should be clearly explained to the patient. They should be given realistic information about the potential effectiveness and adverse effects.
- Early referral to a supportive palliative care team should be considered for every palliative patient.
- Patients whose symptoms are difficult to control or who have psychosocial problems should be referred to a psycho-oncological team and/or to a supportive care team (Hospital Support Nurse, Social Worker, Macmillan Nurse or Hospice referral).
- Palliative radiotherapy should be considered for any patient with localised symptomatic disease

#### 6.6.4 Other treatments to improve symptom control

- Interventional oncology, surgical bypass stoma, or endoscopic stenting should be considered alongside palliative care services.
- Colorectal stenting should follow regional guidelines.

#### 6.6.5 Specialist palliative care and hospice care

- Referral to palliative care may be undertaken by any member of the colorectal team.
- Patients who will need a palliative care pathway should be identified through the weekly MDT meeting.
- An HNA should be undertaken at the point of referral and previous HNA plans should be provided to the palliative care team.
- The palliative care team will deliver symptom control advice, information, supportive care and referral to specialist services (e.g. home palliative care, Marie Curie care, hospice care).
- All of the hospices should provide a range of services including:
  - o Day care
  - Admission for symptom relief
  - o Terminal care
  - Bereavement counselling
  - Pain clinics
  - Complementary medicine

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date: May 2019			Page 29

- Psychological support
- Help with benefits and social care issues
- Access to local specialist palliative (level 3/4) rehabilitation specialists

#### 6.7 Information / data submission

- Each colorectal MDT must submit data to NBOCA.
- Hospitals performing emergency surgery including for the complications of elective surgery should participate in the National Emergency Laparotomy Audit (NELA).
- MDT co-ordinators should ensure collection of the national cancer minimum dataset (Cancer Outcomes and Services Dataset (COSD)) information and clinical information in real-time and submit this data monthly to the national portal in line with published timescales.
- Services must comply with the collection of the mandatory Cancer Services and Outcomes Dataset (COSD) and SACT (Systemic Anti-Cancer Therapy) dataset. If the service is a provider of radiotherapy it must also comply with the collection the RTDS (Radiotherapy Dataset). The care of patients should be regularly audited locally.

#### 6.8 Research

- Patients should be offered the opportunity to be involved in local, national and international trials relating to treatment of patients with colorectal cancer, irrespective of their stage of cancer or their care setting.
- Opportunities for research should be discussed for all patients at MDT meetings.
- All diagnostic and treatment teams should take opportunities to foster basic and clinical cancer research within the auspices of the medical schools, NHS Trust R&D or NIHR portfolios, for example, the for the establishment of tissue banks.

## 7. Cancer networks and population covered

#### 7.1 Cancer Alliances

• Cancer Alliances including the three National Cancer Vanguards have been formed following the recommendations of the Cancer Taskforce and are the vehicles to ensure that commissioners and providers understand what is required to improve cancers services and to support the implementation of change in the light of local needs. Alliances will to be important in ensuring

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 30

that the population covered have equal access to care and provide the necessary reduction in variation and increase in better more cost effective care. Each Cancer Alliance will need to have an Expert Advisory Group (EAG) made up of clinicians across the Alliance with expertise in the management of Colorectal Cancer.

- The EAG will report to the Cancer Alliance Board. They will be responsible for adapting the National Clinical Advice to develop local referral guidelines, care pathways, standards of care and to share good practice and innovation. They should also collectively implement NICE Improving Outcomes Guidance including the use of new technologies and procedures as appropriate and carry out network and national audits.
- Cancer Alliance Boards and EAGs should include patient and carer representatives.
- Each EAG should agree an up-to-date list of appropriate clinical trials and other well-designed studies for bowel cancer patients and record numbers of patients entered into these studies by each MDT. The emergence of the ability to test for a wide range of molecular abnormalities in tumours for the identification of multiple small sub-groups of patients for single centre clinical trials will mean that the cancer networks will need to take an increasingly proactive role in the promotion of research networks.

#### 7.2 Population covered

- In general, this service covers patients registered with an English General Practitioner within a CCG, resident in the European Union and eligible for treatment in the NHS under reciprocal arrangements. Patients from Scotland, Wales and Northern Ireland are not part of this commissioned service and the Cancer Alliances and Trusts must have separate arrangements in place for these patients.
- The service is accessible to all patients with a suspected (or confirmed) bowel cancer regardless of sex, race, or gender. Providers require staff to attend mandatory training on equality and diversity and the facilities provided must offer appropriate disabled access for patients, family and carers. When required the providers will use translators and printed information available in multiple languages.
- The provider has a duty to co-operate with the commissioner in undertaking Equality Impact Assessments as a requirement of race, gender, sexual orientation, religion and disability equality legislation.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 31

### 7.3 Any acceptance and exclusion criteria

• The role of local and specialist services are described in this document. Additional detail is to be found in relevant specialist commissioning service specifications.

#### 7.4 Interdependencies with other services

• Rapid access to diagnostic services is a key enabler of high quality outcomes, as is sufficient capacity to deliver appropriate treatment.

#### 7.5 Interdependencies with other organisations

High quality cancer intelligence is a key enabler for quality improvement. It is
essential that prompt and accurate data are supplied to NBOCA and the
National Cancer Registration Service (NCRAS), including relevant treatment
datasets for radiotherapy and systemic anti-cancer therapy. NBOCA and
NCRAS will be a key partners in providing information monitoring the delivery
of this service specification, as well as improvements in quality.

Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	: May 2019		Page 32

## 8. Key service outcomes

8 Key Service C	Jutcomes				
Performance indicator	Indicator		Threshold	Method of measurement	Consequence of breach
<ul> <li>Specialist Team</li> </ul>	% of new cancer discussed at MD <sup>-</sup>		100%	National Cancer Peer Review	
	Specialist team h membership	as full	95% quorate, 66% individual attendance	National Cancer Peer Review	
	Proportion of all p indicators met	beer review		National Cancer Peer Review	
	Peer review: Imm	ediate risks		National Cancer Peer Review	
	Peer Review: Ser	ious concerns		National Cancer Peer Review	
	Core MDT members who have direct clinical contact with patients attendance at advanced communications course		100%	National Cancer Peer Review	
	Patients reporting availability of a C		90%	Cancer Patient Experience Survey	
Waiting	TWW referrals se	en in 2 weeks	93% <sup>1</sup>		
times	Patients treated v of two week wait		85% <sup>1</sup>		
	Patients treated v of agreeing treat		96% <sup>1</sup>		
	Patients treated v		96%		
	Patients	Surgery	94% <sup>1</sup>		
	subsequent treatment within 31	Systemic therapy	98% <sup>1</sup>		
	days	Radiotherapy	96% <sup>1</sup>		
	Diagnostic test re working days of r	equest	80% <sup>1</sup>		
-		-	-	cross tumour sites on	an aggregated
basis. However c     Audit	ommissioners may Participation in NI		100%	NBOCA	
- //////	% of expected		10070		
	cases on whom d	ata is collected			

Performan ce Indicator indicator	Thresh	old Method of measurement	Conseque nce of breach
Clinical Advice for the Commissioning of the Whole		ctal Cancer Clinical Expert Gro	quo

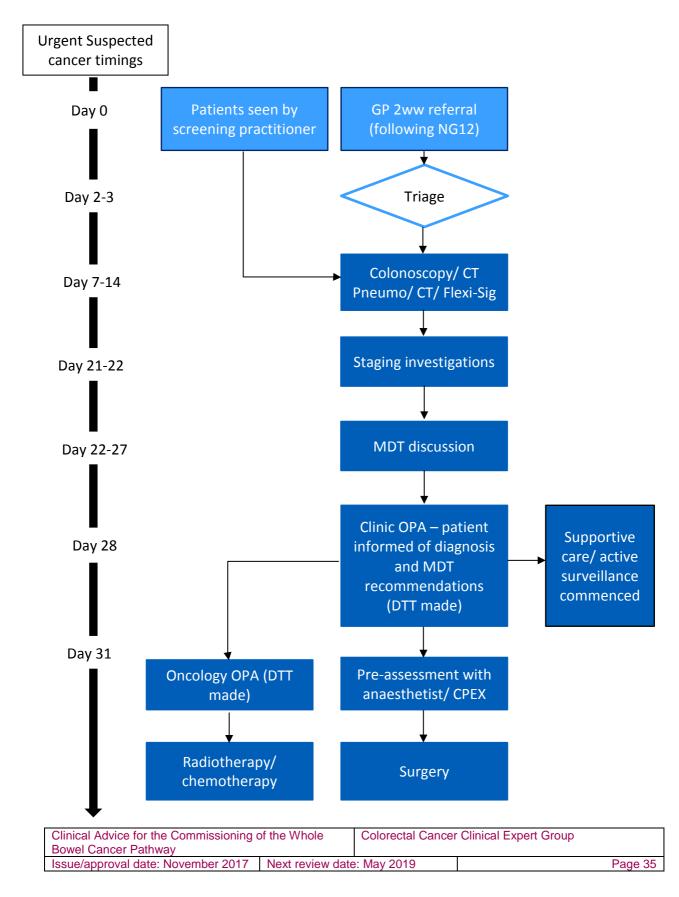
 Bowel Cancer Pathway
 Issue/approval date: November 2017
 Next review date: May 2019
 Page 33

Outcomes	One year survi	val by stad	ae			
	Five year surviv					
	Proportion of p					
	through the em					
	Mortality • Sur and by a		gical 30 I 90 day age, ge and			
		y 30 day	diotherap ) and 90 by age, ge and			
		ther and by a	temic rapy 30 I 90 day age, ge and			
Patient experience		atients reporting being treated ith respect and dignity			Cancer Patient Experience Survey	
	Cancer patient experience survey questions scored		Green		Cancer Patient Experience Survey	
			Red		Cancer Patient Experience Survey	
Trial participatio n	Recruitment int	Recruitment into trials		All trials should be offered to eligible people	NIHR	
Cancer registration	DCO rates, Sta completeness of and RTDS data applicable)	of COSD,	SACT		National Cancer Registration Service	

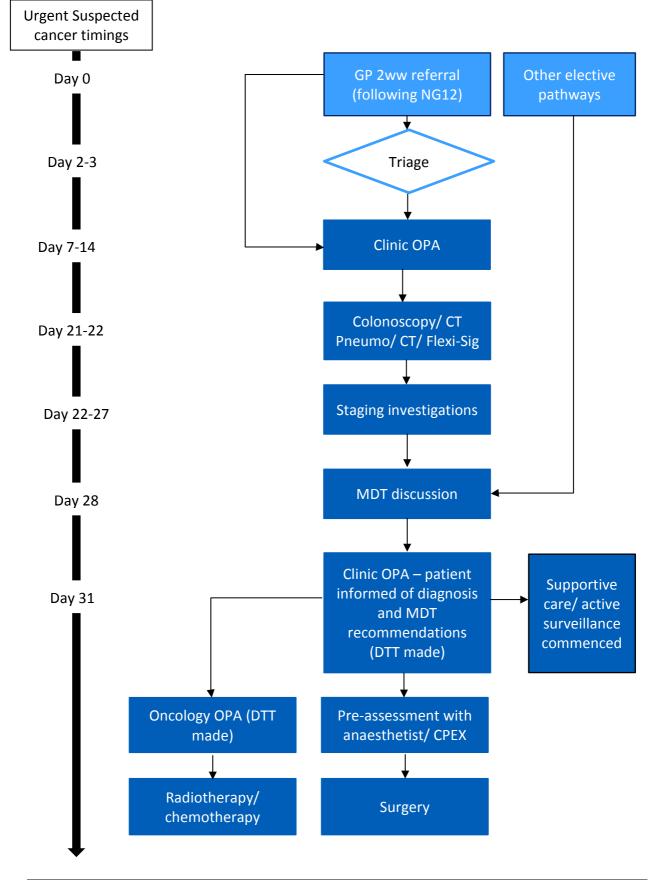
Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 34

## Appendix 1 Pan Vanguard best practice colorectal times pathway

#### **Colorectal Timed Pathway (28 days)**



#### **Colorectal Timed Pathway (31 days)**



Clinical Advice for the Commissioning of the Whole		Colorectal Cancer	Clinical Expert Group	
Bowel Cancer Pathway				
Issue/approval date: November 2017	Next review date	e: May 2019		Page 36