

*This vision does not represent government policy but provides useful insight into how bowel cancer services might develop over the next 5 years*

**Annex A**

## **Bowel Cancer 2015**

### **Summary - Improving Outcomes for Bowel Cancer Patients**

More patients will be undergoing relatively simple tests to exclude a diagnosis of bowel cancer (eg flexible sigmoidoscopy). The profile of patients presenting with bowel cancer will have changed with:

- A higher proportion of early stage disease (largely due to screening)
- A lower proportion of emergency admissions (screening and rapid access services)
- More elderly patients, due to demographic changes and hence more co-morbidity

Survival rates will have improved:

1970 - 27% 5 year survival

2000 - 50% 5 year survival

2015 - At least 60% 5 year survival with reduced mortality

Mortality will have fallen, and morbidity will be lower, with more rapid recovery from surgery and less patients requiring aggressive systemic therapy because of downstaging. Inpatient bed usage will have reduced due to the Enhanced Recovery Programme (ERP) and there will be a reduction in the permanent stoma rate. There will be more effective leadership at the service level and less regional variation in services. The views and experiences of patients will be taken into account in improving and rationalising services. Functional outcomes will be measured using PROMs. The role of community based services will have been clearly defined to aid survivorship, and patient information on care and support will be of the highest quality and widely available in a variety of formats.

There will be equity for all bowel cancer patients with significant improvements in the quality and quantity of available data to drive quality improvements in services, choice and outcomes.

### **1. Introduction**

Significant progress has been made on cancer services and outcomes since the publication of the Calman-Hine report in 1995, with the NHS Cancer Plan (2000) and the Cancer Reform Strategy (CRS - 2007) contributing to this progress. Cancer mortality has fallen, survival rates are improving for many cancers and patients' experience of their care has improved.

Despite the considerable progress, survival rates in England for many cancers are currently lower than in many comparable countries. The Coalition Government wants to tackle this, and to focus on improvement in quality and outcomes for cancer patients.

The Coalition Government therefore asked Professor Sir Mike Richards to review the CRS to ensure that we have the right strategy, subject to the 2010 Spending Review, to deliver improved survival rates. The aims of the review of the CRS are to:

- align cancer strategy with the White Paper, *Equity and excellence: Liberating the NHS*
- set the direction for the next 5 years, taking account of progress since the CRS was published in December 2007
- show how outcomes can be improved despite the difficult financial position

As part of the review process, the Bowel Cancer Advisory Group (BCAG) met on Thursday 7<sup>th</sup> October 2010 to update their original vision for bowel cancer services in 2012 which was produced for the CRS in 2007.

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## **2. Background**

Bowel cancer is the third most frequently diagnosed cancer worldwide, accounting for more than 1 million cases and 600,000 deaths every year<sup>1</sup>. In England in 2007, 30,727 people were diagnosed with colorectal cancer and 12,841 people died from it. 5-year survival rates for colorectal cancer are 50.9% in men and 52.6% in women. Survival is strongly related to stage at diagnosis, with survival rates of 90% for localised cases<sup>2</sup>.

## **3. Bowel cancer services in 2012 – a vision**

### **Preventing cancer**

#### Lifestyle

Local and national programmes on reducing obesity (through improved diet and increasing exercise) and reducing alcohol intake are unlikely to have had a major impact on reducing bowel cancer incidence by 2015.

#### Family history

There will be a greater awareness of the family history of bowel cancer, with much greater access to information about the risks. People who are worried about bowel cancer in their families will have access to a range of services which use computerised algorithms to assess levels of current and future risk. These services could be provided in a variety of virtual and physical settings. There will be better assessment and recording of family history in bowel cancer patients, so that they can inform other family members of levels of risk. GPs will be more aware and pro-active about their patients' family history of the disease and other high risk conditions (eg FAP), and will appropriately refer more patients for genetic counselling and assessment. Surveillance of defined high risk groups will be managed through the NHS Bowel Cancer Screening Programme.

### **Diagnosing Cancer Earlier**

#### Screening

The NHS Bowel Cancer Screening Programme will be routinely inviting men and women aged 60 to 75 to complete a Faecal Occult Blood (FOB) test every two years. Men and women aged over 75 will be able to request a kit every two years. The programme will have converted to more accurate and easier to use immunochemical FOB tests following successful pilots, leading to increased uptake of screening. Screening uptake will also be increased across all groups by local and national awareness raising initiatives and the normalisation of bowel screening across the population. Consideration will also have been given to incentivising GPs to discuss bowel screening with non-attenders.

National roll out of once only flexible sigmoidoscopy for men and women aged around 55 will be underway based on successful pilots, supported by an expanded endoscopy workforce and an effective IT system. Accreditation of endoscopy units will be embedded in the system

Evidence for the efficacy of CT colonography will have grown, and will have been factored into both screening and symptomatic services where appropriate. Publication of 1-year survival data will help to monitor the impact of screening and improvements in survival across all groups, including older people.

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<sup>1</sup> WHO. Cancer, fact sheet 297. Geneva: World Health Organisation, 2009

<sup>2</sup> Cancer Research UK. By stage at diagnosis. London: Cancer Research UK, 2009

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### Public Awareness

The increased national and local focus on the public and professional awareness of bowel cancer will have resulted in significant improvements in outcomes for patients. Awareness of the signs and symptoms of bowel cancer will be much more widespread amongst the public, particularly amongst high risk and hard to reach groups following targeted interventions. There will be a better understanding of what works for public awareness programmes using the Cancer Awareness Measure, and the general issue of bowels and their function will be more talked about in society. There will be more shared learning, information provision and sharing of best practice amongst GPs and other primary care providers.

### **Ensuring better treatment**

#### Access and referral

Patients and their primary care teams will have access to risk-assessment computerised algorithms in a variety of virtual and physical settings, leading to more appropriate referral to secondary care. GPs will have direct access to flexible sigmoidoscopy to discount cancer in those patients who do not fit urgent referral criteria, particularly for rectal bleeding and/or change in bowel habit where flexible sigmoidoscopy with abdominal examination and check haemoglobin has been shown to be a safe as first line diagnostic test<sup>3</sup>. This would provide savings from more expensive colonoscopy (only 30% of patients would need to go on to colonoscopy). Multi-Disciplinary Teams (MDTs) will feedback to GPs on appropriateness of referrals.

Early diagnosis will mean less patients reporting as emergencies. To massively reduce delays in diagnosis there will be regular audit (root cause analysis) at MDT of 'opportunities missed' for diagnosing cancer earlier (due to patient, referrer or diagnostics, or all or some of these), followed by action planning to deal with reasons for delayed diagnosis, and then further audit.

#### Diagnosis and staging

Colonoscopy, CT, and MRI will continue to be the major diagnostic and staging modalities, although the ratios of usage of each may alter. These may be supplemented with tumour markers. For example, baseline CEA should be standard at the time of diagnosis. The number of barium enemas will have reduced considerably and only used for those patients where other imaging techniques are inappropriate. New contrast agents for MRI (currently on trial) may improve detection of lymph nodes. Colonoscopic ultrasound will be used to detect depth of invasion of colonic tumours (especially where therapeutic colonoscopy may be an option). CT colonography will be more advanced. The use of colonoscopy in the frail elderly will decrease and be superseded by CT colonography and by minimal prep CT to reduce patient discomfort and the risks associated with full mechanical bowel preparation.

The Royal College of Radiologists will have developed a pro forma on MRI to drive up the quality of data recording. Pro forma based reporting will be linked to pathology, leading to better engagement of radiologists in reporting and measurement.

### Treatment

#### *Surgery*

Multi-Disciplinary Teams (MDTs) will continue to be the norm for providing high quality bowel cancer services, and clinical pathways will have been implemented (eg North Tyneside).

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<sup>3</sup> *Predictive value of common symptom combinations in diagnosing colorectal cancer*:MR Thompson et al.; British Journal of Surgery: 2007; **94**, 1260-1265

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Surgery will remain the mainstay of treatment for most patients with bowel cancer, but the type of surgery will have changed:

- Patients with curable small volume disease will be treated by therapeutic colonoscopy (eg endoscopic resection of colon lesions)
- Laparoscopic surgery will be the norm at least for elective surgery for colon cancer, driven by patient choice
- The pilot training programme on extra levator abdominoperineal excision (ELAPE) technique to improve the care of low rectal cancer patients will have been completed and rolled out if successful
- Novel techniques (eg transanal excisional microsurgery - TEMS) will be available in major centres for highly selected groups of patients
- Enhanced Recovery Programmes will be implemented routinely
- Colonic stenting will have become routine practice as a bridge to surgery for patients presenting with obstruction. Emergency surgery at night will have reduced considerably
- Surgery for metastatic liver disease will have increased
- Quality of rectal surgery will continue to improve (based on a multidisciplinary approach to assessment of patients), and will include advances in selection of patients for abdominoperineal (AP) resection and in surgical techniques for APs to reduce risk of local recurrence
- Rigorous quality assurance of surgery will be the norm, based on pathology assessments. Pathology services will also be quality assured

#### *Radiotherapy*

Short course preoperative radiotherapy will be delivered to selected groups of patients based on a level of risk of local recurrence assessed by the MDT. New approaches to improve accuracy of radiotherapy (eg Image-Guided Radiotherapy) will be underway. Improvements in technical radiotherapy will be applied to rectal cancer. Patients with advanced local rectal cancer will receive long course neoadjuvant radiochemotherapy. The treatment of anal cancer and lower rectal cancer will have become more specialised.

Quality outcome measures will have been agreed that include both effectiveness of treatment in curing the cancer and a measure of bowel functional outcome. The latter may become part of a Patient Reported Outcome Measure (PROM). Another outcomes measure could be local recurrence rates for rectal cancer.

#### *Chemotherapy / Novel treatments*

The current shift from intravenous 5FU to oral capecitabine will be maintained.

Chemotherapeutic agents such as oxaliplatin will be more widely used in the adjuvant setting and future trial results will inform whether novel therapies may have found their place (and have been deemed cost effective by NICE) for certain groups of patients. These will have been reappraised, and if proved reliable biomarkers will be used to select subgroups of patients who will benefit. The SCOT trial, randomising patients who have undergone curative resection from colon cancer with an intermediate risk of relapse to 12 or 24 weeks of chemotherapy with Oxaliplatin and Capecitabine will have reported, as will adjuvant studies of Avastin (bevacizumab).

The principle of clinically led decisions regarding giving patients access to cancer treatments, as established with the Cancer Drugs Fund, will have become mainstream practice in the NHS. There will be equity of access for all patients who need treatment regardless of age, race, creed, social class or post code.

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Further information will be available on the use of molecular markers to determine whether or not a given patient is likely to respond to chemotherapy (trial in progress), thus reducing both the health and economic burdens of futile treatments.

#### *Communications with primary care*

MDTs will write simple letters to GPs regarding their patients' treatment and what has been explained to the patient, thus avoiding duplication.

### **Living with and beyond cancer**

#### Information

Information prescriptions based on information pathways will be routinely available to bowel cancer patients as part of their treatment, care and aftercare. Information will be culturally appropriate and available in a variety of formats to suit patient preferences. Easily accessible mechanisms will be in place for patients to access supportive information at all stages of their pathway. Mechanisms will also be in place to enable information to be input and updated by providers as appropriate.

#### Face-to-care communication

All lower GI MDT members will have been trained through the Connected advanced communications skills programme.

#### Clinical Nurse Specialists

The role of the Clinical Nurse Specialist will be vital in providing support to patients. This vital role will be more widely recognised and CNS posts will be protected and will have increased in number.

#### Survivorship

Following treatment, bowel cancer patients will have personalised risk stratification, holistic assessment and care planning. They will be supported to self manage, where appropriate, have access to case management support and/or specialist services, and access to appropriate information including lifestyle advice and physical activity interventions.

There will be improved identification of those patients who have had curative treatment and those who are at high risk of recurrence/metastasis and who would be suitable for further treatment if recurrence/metastasis found. Follow-up with Carcinoembryonic Antigen (CEA) and CT will focus on this group.

#### Patient experience

There will be annual cancer patient experience surveys which the NHS will use to improve the quality of services. Other surveys or PROMs will be undertaken specific issues or groups of patients.

### **Reducing cancer inequalities**

All actions in the National Cancer Equality Initiative (NCEI) report *Reducing cancer inequality: Evidence, progress and making it happen* will have been implemented under the five main themes: data collection, analysis and publication; targeted interventions (eg people's work programme, BME work programme); training, development and research; embedding equality; and evaluation and monitoring. MDTs will routinely record demographic data on their patients.

We will try to better understand the reasons inequalities develop and then determine which of these are within the influence and control of healthcare.

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### **Delivering care in the most appropriate setting**

Transforming inpatient care will have delivered on four priorities: the Enhanced Recovery Programme; day case/23 hour stay where possible; acute oncology; and averting inappropriate emergency admissions.

### **Using information to improve quality and choice**

#### Data collection

There will be national monitoring of key outcomes for lower bowel procedures with clear definitions and reliable methods for capturing them. These will be made available to the public, and will be an essential driver for:

- Quality improvement by providers
- Patient choice
- Stronger commissioning
- Health services research

All clinical teams will be mandated to collect a minimum dataset on all patients. This will enhance the quality of individual patient care and communication between primary, secondary and tertiary care. The complete dataset will also be made available to cancer registries and to national clinical audits (NBOCAP). The data set will also include data on: staging; 1-year survival, incidence, mortality, outcome for patients (including local recurrence) and equality. The audit will include measure for all MDTs, and will be supported by providers. There will be an annual meeting at MDT level to discuss the audit results to help drive up quality and standards. The data will then be sent to Cancer Registries.

The National Cancer Intelligence Network (NCIN) will have grown in size and breadth to provide analysis of health services/population level data, broken down by a variety of issues and groups to inform current and future policy.

### **Service Profile**

#### Community

- *Online assessment of risk of serious illness (based on age/symptoms/family history)*
- *Delivery of some chemotherapy*
- *More home care at end of life*

#### GP Surgery

- *Advice on risk based on family history using computerised algorithms*
- *Triage of patients based on age, symptoms, family history*
- *Simple treatments for piles and fissures*
- *Ongoing support and care*

#### Polyclinic

- *Family history assessment service*
- *Assessment and flexible sigmoidoscopy for symptomatic patients at low risk*
- *Chemotherapy delivery*

#### DGH with a full A&E service\*

- *Assessment of higher risk patients*
- *Diagnostic testing including colonoscopy, CT and MR for symptomatic patients*
- *MDT*
- *Surgery*

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- *Chemotherapy*
- *Screening colonoscopy where JAG accredited*

*Larger DGHs (serving populations over 150,000)*

- *Screening colonoscopy*
- *Satellite radiotherapy services*

*Specialist centres (serving populations over 1.5 million)*

- *TEMS*
- *RT*
- *Complex chemotherapy*

*\* Assumption: bowel surgeons will be essential for the delivery of acute general surgical services*

**Bowel Cancer Advisory Group, December 2010**