Guidance on Cancer Services

Improving Outcomes in Colorectal Cancer

Manual Update 3c, September 2003

DRAFT FOR 2ND CONSULTATION
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Note on the update format

This edition of Improving Outcomes in Colorectal Cancer is an updated version of the Manual published by the Department of Health in 1997. This Manual covers cancers of the colon and rectum (bowel) as before, plus an additional section on anal cancer. The Background section is intended as a general introduction to colorectal cancer, for people who are not experts in the area; it is not based on a formal systematic review.

Material in the Evidence section of each topic area is derived from two different types of source: systematic reviews of research evidence carried out by the NHS Centre for Reviews and Dissemination, and information from audit and other sources which describe the current situation in the NHS.

The reviews of research evidence are designed to provide and evaluate information on the effectiveness of specific interventions. The summaries in this document do not include references; these are given in the full Review of Research Evidence which is published with this update, or in the Review of Research Evidence published with the previous edition of this guidance, which is available on the Department of Health website.¹ Evidence from the reviews is graded A (derived from randomised controlled trials - RCTs), B (observational studies) and C (professional consensus). These are broad categories and the quality of evidence within each category varies widely. Thus it should not be assumed that RCT evidence (grade A) is always more reliable than evidence from observational studies (grade B). More detailed information on the reliability of evidence is given in the Review of Research Evidence.

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Evidence. Information from sources which are not included in either Review of Research Evidence is referenced in this document.

Arabella Melville, writer.

Foreword

When the editorial group responsible for this update first met, there was discussion about the durability of the recommendations made in the original COG Guidance, published in November 1997. How well did they stand up to scrutiny six years later? The view within the editorial group was that much of the content remains valid, although updating was needed in a few important areas where new evidence had become available.

A great deal had been done to take forward the agenda set out in 1997. Nevertheless, there was concern about the unevenness of implementation of those recommendations. The first national Peer Review of cancer services in 2001/2, together with the results of similar exercises around the country, suggested that progress in improving services for patients with colorectal cancer was not as far advanced in some places as it was in breast cancer services. It was therefore felt to be important to use the opportunity provided by this Update to give fresh impetus to the task.

The updating process has therefore concentrated on three main tasks. The first was to breathe new life into dialogue about services for managing bowel cancer by highlighting key issues and enhancing and clarifying the original text. In refocusing attention on this topic, it was felt to be important to emphasise that implementing the Colorectal Guidance was not a ‘done deal’. Whilst much has been achieved, much remains to be done. The expansion of the role of Cancer Networks over recent years provides an opportunity to re-examine these issues.
The second aim was to examine developments in research evidence and refine the text accordingly. The most exciting area has been the management of rectal cancer. Advances have occurred on all fronts: diagnosis, staging, surgery, evaluation of surgery, and radiotherapy. Despite the difficulties of mounting large-scale surgical trials, this has been achieved in rectal cancer, and results were available in time for this Update.

The third change was expansion of the scope of the guidance, with the inclusion in this edition of anal cancer. The coverage of rarer cancers has become our usual practice in recent reports. This makes sense because the rarer cancers do not usually present as separate entities, but tend to fall within the conventional structure of clinical services for more common conditions.

The implementation of population screening for colorectal cancer in older people has not been included within this Guidance, as responsibility for this lies with other national bodies. However, implementation of screening will inevitably impact on services required for symptomatic patients, which are covered by this Update. We welcome national moves to co-ordinate initiatives for this disease group. All share the aim of improving outcomes for people with bowel cancer. The recommendations in this Guidance are consistent with such an approach.

I am particularly grateful to Professor Bob Steele from Ninewells Hospital and Medical School at Dundee for his chairmanship of the editorial board for this Update. He also played an important role in the production of the 1997 Guidance when he worked in Nottingham, supporting the evidence review team at the University of York.

Professor Bob Haward
Chairman, National Cancer Guidance Group.

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Key Recommendations

- Action should be taken to improve recognition of potential symptoms of colorectal cancer in primary care and in the community. Efficient systems should be set up to ensure that patients who may have colorectal cancer are rapidly referred for endoscopy.

- There is an urgent need for substantial expansion of lower GI endoscopy services. Access to both flexible sigmoidoscopy and colonoscopy should be improved and the focus of diagnostic effort should move from barium enema to endoscopy. (Note - This will be crucial for screening services when they are introduced.)

- Cancer Networks and Trusts should review the composition and function of colorectal cancer multi-disciplinary teams (MDTs) and make sure that each MDT has a co-ordinator. They should:
  - Establish systems within Trusts to ensure that all patients with suspected or newly diagnosed colorectal cancer are promptly referred to, and managed by, a colorectal cancer MDT.
  - Review operational links with hepatobiliary (HPB) services and the relevant clinical teams to ensure that patients with potentially resectable liver metastases are referred to specialist MDTs for assessment.
  - Identify specialist MDTs which will manage patients with anal cancer.

- Emergency patients (particularly those with intestinal obstruction) should be managed by colorectal cancer MDTs. This may require the development of emergency teams and transfers of patients between neighbouring hospitals.

- Patients with rectal cancer should be managed by teams trained in all aspects of total meso-rectal excision (TME), including pre- and post-operative assessment, surgical technique, and the role of clinical oncology.

- All aspects of patient-centred care should be re-assessed. Trusts should improve the provision of appropriately trained staff and resources, so that all patients
receive all the information they want at all stages of the patient pathway and have ongoing support from a Clinical Nurse Specialist who is encouraged to play an active part in MDT discussion.
Background

The size of the problem: incidence, mortality and survival rates

Colorectal (large bowel) cancer is the second most common cancer after lung cancer, in terms of both incidence and mortality, in England and Wales. Although prostate cancer is more common in men and breast cancer more common in women, colorectal cancer affects both sexes. Each year, over 30,000 new cases of colorectal cancer are diagnosed, and colorectal cancer is registered as the underlying cause of death in about half this number (Table 1).

Table 1a. Incidence and mortality rates, colorectal cancers, England

<table>
<thead>
<tr>
<th>Cancer site</th>
<th>ICD 10 code</th>
<th>No of registrations</th>
<th>Incidence: crude rate per 100,000 1999</th>
<th>No of deaths</th>
<th>Mortality: crude rate per 100,000 2000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>1999</td>
<td>Men Women</td>
<td>Men Women</td>
<td>Men Women</td>
</tr>
<tr>
<td>Colon</td>
<td>C18</td>
<td>8,822</td>
<td>9,013</td>
<td>35.9</td>
<td>35.8</td>
</tr>
<tr>
<td>Rectum</td>
<td>C19 &amp; C20</td>
<td>6,009</td>
<td>3,970</td>
<td>24.5</td>
<td>16.8</td>
</tr>
<tr>
<td>Anus</td>
<td>C21</td>
<td>255</td>
<td>382</td>
<td>1.0</td>
<td>1.5</td>
</tr>
</tbody>
</table>

Table 1b. Incidence and mortality rates, colorectal cancer, Wales

<table>
<thead>
<tr>
<th>Cancer site</th>
<th>ICD 10 code</th>
<th>No of registrations</th>
<th>Incidence: crude rate per 100,000 2000</th>
<th>No of deaths</th>
<th>Mortality: crude rate per 100,000 2000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>2000</td>
<td>Men Women</td>
<td>Men Women</td>
<td>Men Women</td>
</tr>
<tr>
<td>Colon</td>
<td>C18</td>
<td>652</td>
<td>597</td>
<td>45.1</td>
<td>39.8</td>
</tr>
<tr>
<td>Rectum</td>
<td>C19 &amp; C20</td>
<td>449</td>
<td>273</td>
<td>32.0</td>
<td>18.2</td>
</tr>
</tbody>
</table>

3 Source: data on ONS website (www.statistics.gov.uk).
4 Source: Welsh Cancer Intelligence & Surveillance Unit, data provided on request, November 2002
The incidence of colorectal cancer is gradually increasing. One reason for this is the ageing of the population: as with most forms of cancer, the probability of developing colorectal cancer rises sharply with age. In young people, the risk is very low (except in a small minority with hereditary forms of the disease); between the ages of 45 and 55, the incidence is about 25 per 100,000. Among those aged 75 and above, however, the rate is more than ten times this: over 300 per 100,000 per year. The median age of patients at diagnosis is over 70 years.\(^5\) But population ageing is not the only reason for the overall rise. There has been a gradual increase in age-specific incidence, particularly among men between 65 and 84; and age-specific incidence rates vary across Britain; both of which suggest that lifestyle or environmental factors also contribute. These issues are discussed later in this section, under risk factors.

Survival rates (relative to age-matched groups without colorectal cancer) are now around 45% at five years after diagnosis; beyond five years, relative survival rates decline only slightly: most of those who live this long are cured. Survival rates in the UK have been rising steadily over the past three decades, but substantial international differences (Table 2) suggest that in the early 1990’s (the most recent period for which comparative data are available) there was considerable scope for improvement.

Table 2. Survival rates after diagnosis of colorectal cancer (ICD-9 153-154)\(^6\)

<table>
<thead>
<tr>
<th>Country</th>
<th>Age-standardised relative survival (%), one year after 1990-1994 diagnosis (95% confidence interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Colon</td>
</tr>
<tr>
<td></td>
<td>Men</td>
</tr>
</tbody>
</table>

\(^5\) Incidence figures in Quinn 2001 (op. cit.) show that the median age at diagnosis is 70-74 years.

Both one-year and five-year survival rates were poorer in Wales than in England or Scotland, and poorer in all parts of the UK than in Europe as a whole. Scandinavia, the Netherlands, France, Germany, Italy and Switzerland all reported significantly better outcomes for colon or rectal cancer, and generally both; these differences between countries were similar to those found in previous studies (Eurocare and Eurocare II) of survival rates among patients diagnosed in the 1980s.\(^7\) \(^8\) In Europe generally, the poorest outcomes were found in countries such as Poland, Estonia, Slovakia and Slovenia, which were part of the former Soviet bloc.

The contrast between other Western European countries and Britain (particularly Wales) was greater for colon cancer than for rectal cancer. People with colon cancer tend to develop non-specific symptoms and may present, eventually, as emergency cases with advanced disease. Most colorectal cancer emergencies (about 85%) are due to colon, not rectal, cancer; the prognosis for these patients is often very poor.

European evidence supports the view that the problem in the UK has mainly been due to late diagnosis of colon cancer, leading to high emergency rates. A detailed study of survival variations, using data on samples of patients with colorectal cancer from 11 European cancer registries, was carried out after Eurocare II.\(^9\) Most of the differences in long-term survival between countries were shown to result from


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differences in death-rates in the first six months after diagnosis. Death-rates were highest in places where patients were most likely to be treated as emergencies.

Further investigation revealed that in countries where patients survived longer, a higher proportion had early-stage tumours and patients were more likely to undergo elective surgery. It is clear that the major determinant of survival is disease stage, and that it is possible to achieve earlier diagnosis of colorectal cancer (and thus higher survival rates) across whole populations. High case-survival rates in European countries other than Britain are widely believed to be associated with greater use of opportunistic screening, but no research assessing the veracity of this belief has been identified.

Socio-economic and cultural differences between countries could also play a part. There is an obvious association between patterns of affluence and survival, which can be seen both between European countries and within Britain. The reasons for this are not clear.

Within England, colorectal cancer survival rates vary significantly between health authorities. An analysis of outcomes among patients with colon cancer diagnosed between 1993 and 1995 showed that the national five-year survival rate was 43%, but there was a marked north-south gradient. In northern areas, relative survival rates were 40% or below, whereas in the south, health authority mean rates were around 46%. There were large variations within the conurbations of London and the West Midlands, but overall survival rates in these areas were close to the national average. Outcomes were worst in north-east England (Tyneside, Northumberland and Tees), with five-year survival rates of 30% or lower, and in East London and the City, where only 25% survived for five years. By contrast, Surrey, Hampshire, Dorset and Brent achieved 51% survival rates.


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Characteristics of colorectal cancer

The large intestine, or bowel, has two main sections, the colon and the rectum. About two thirds of tumours develop in the colon and the remainder in the rectum (Figure 1). Colon cancer is equally common in men and women, but rectal cancer is more common in men.

Most tumours are adenocarcinomas which evolve from polyps – small outgrowths in the bowel wall – which may be present for ten years or more before malignancy develops. The disease usually progresses quite slowly. Nevertheless, a substantial proportion of patients – between a third and half in most Trusts – are admitted as emergencies; overall, about 20% arrive through Accident and Emergency departments. Most of these patients have had clear-cut symptoms for some weeks, and often months, before admission.

Diagnosis

Colorectal tumours can usually be seen directly, through an endoscope (colonoscope or sigmoidoscope). A colonoscope allows the inner surface of the whole large bowel to be seen, whilst a flexible sigmoidoscope can reach deep enough into the bowel to detect about 60% of tumours (Figure 1). These instruments can also be used to remove polyps or take samples of tissue for biopsy. Colorectal cancer can also be detected by barium enema.

Figure 1. The large intestine or bowel, and limits of endoscopic access.
Diagnosis is therefore fairly straightforward – at least, in theory. The main problems are in deciding whether a particular individual should undergo investigation in the first place, and then, getting rapid access to appropriate investigations. Deficiencies both in appropriate referral and in access to diagnostic facilities in some NHS hospitals, are reflected in delays in diagnosis. In 1999/2000, over a third of patients with colorectal cancer waited more than three months after consulting their GPs with symptoms before getting their first hospital appointment.\textsuperscript{11}

The most common presenting symptoms and signs of cancer or large polyps are rectal bleeding, persisting change in bowel habit, and anaemia; more advanced tumours are likely to cause weight loss, nausea and anorexia, and abdominal pain. The early symptoms may not be severe and are often not clear-cut, they are common in the general population and can have a variety of other causes. In some patients, symptoms do not become apparent until the cancer is far advanced.

Although the diagnosis is most easily and reliably established by flexible sigmoidoscopy or colonoscopy, barium enema (alone or in association with rigid sigmoidoscopy) is frequently used in NHS hospitals. Computed tomography (CT) or magnetic resonance (MR) imaging is necessary to assess the extent of the tumour.

Patients survive, on average, for three years after diagnosis, but survival times vary widely. The prognosis and type and effectiveness of treatment depend largely on the degree to which the cancer has spread. Spread is often described in terms of Dukes’ stage (Table 3).

**Table 3: Colorectal cancer staging**

<table>
<thead>
<tr>
<th>Dukes’ Stage (modified)</th>
<th>Definition</th>
<th>Approximate frequency at diagnosis</th>
<th>5-year survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Cancer localised within the bowel wall</td>
<td>11%</td>
<td>83%</td>
</tr>
<tr>
<td>B</td>
<td>Cancer penetrating the bowel wall</td>
<td>35%</td>
<td>64%</td>
</tr>
<tr>
<td>C</td>
<td>Cancer in lymph nodes</td>
<td>26%</td>
<td>38%</td>
</tr>
<tr>
<td>D</td>
<td>Distant metastases (most often in the liver)</td>
<td>29%</td>
<td>3%</td>
</tr>
</tbody>
</table>

The more precise TNM classification, based on the depth of tumour invasion (T), lymph node involvement (N) and metastatic spread (M), is slowly superseding Dukes’ system.

In England and Wales as a whole, approximately 55% of patients present with advanced colorectal cancer (Dukes’ stage C or D) – that is, cancer which has spread to the lymph nodes, metastased to other organs, or is so locally invasive that surgery to remove the primary tumour alone is unlikely to be sufficient for cure.  

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12 Frequency and survival statistics based on data from 777 patients derived from St Vincent’s Hospital colorectal cancer database, Dublin. (Mulcahy, 1997, personal communication.) Note that stage frequency and survival figures vary widely between published series from different centres.

13 Figures from NICE Technology Appraisal Guidance no.33, March 2002.
Treatment

Colorectal cancer

Surgery to remove the primary tumour is the principal first-line treatment for approximately 80% of patients, after which about 40% will remain disease-free in the long term. In 20-30% of cases, the disease is too far advanced at initial presentation for any attempt at curative intervention; many of these patients die within a few months.

Surgical skill is crucial to outcomes, and there is evidence of wide variation between the survival rates of patients operated on by individual surgeons. Evidence showing large differences between surgeons in the outcomes they achieve was reviewed for the earlier edition of this guidance. A more recent study suggests that such variations may persist.14

Metastatic disease usually develops first in the liver. 20-25% of patients have clinically detectable liver metastases at the time of the initial diagnosis and a further 40-50% of patients develop liver metastases within three years of primary surgery.15 When the metastatic deposits are confined to a limited area of the liver, expert surgery offers the possibility of long-term cancer-free survival. About 8% of patients are potential candidates for liver resection, which can be life-saving in about 35% of these cases.16

Chemotherapy is given as an adjuvant to surgery to a minority of patients, usually those whose tumour has spread to lymph nodes (Dukes’ stage C), for whom the benefit of chemotherapy has been most clearly demonstrated. Adjuvant radiotherapy can be used to treat rectal cancer; again, a minority of patients receive it. Surgery,

chemotherapy, or radiotherapy may also be used as part of palliative treatment for patients with advanced disease. In the Northern and Yorkshire region in 1999, 27% of patients who underwent surgery for colorectal cancer also received chemotherapy. 12% received radiotherapy in addition to surgery; almost all of these patients had rectal cancer.¹⁷

**Anal cancer: treatment**

Anal cancer is a relatively rare disease (Table 1). The most common form of anal cancer, squamous cell carcinoma, is fundamentally different from other cancers of the colon or rectum. It can usually be successfully treated with concurrent radiotherapy and chemotherapy. Surgery may be used if medical treatment fails.

**Populations at increased risk of colorectal cancer**

Around 5% of patients who develop colorectal cancer suffer from genetic syndromes associated with exceptionally high risk. The two main syndromes, FAP (also known as familial polyposis) and HNPCC, cause colorectal cancer in relatively young people, and those affected require regular monitoring. In general, the risk is greater for people with a family history of the disease, even when no specific genetic syndrome is found (Figure 2).

**Figure 2.**¹⁸

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¹⁸ Diagram constructed by Prof T Bishop and A Melville for the 1997 edition of this guidance, using figures calculated by Bishop from unpublished data from St John; see research evidence for 1997 edition for further details.
Ulcerative colitis is also associated with increased risk of colorectal cancer and the risk rises with the duration of the condition. Patients who have had ulcerative colitis for ten years or more face two to eight times the usual level of risk for their age. Such patients account for fewer than 1% of cases of colorectal cancer.\footnote{Hardy RG, Meltzer SJ, Jankowski JA. Molecular basis for risk factors. In Kerr DJ, Young AM, Richard Hobbs FD, \textit{ABC of colorectal cancer}. London: BMJ Books, 2001.} However, around 75% of patients have neither a clear family history nor any condition known to predispose them to developing colorectal cancer.

\footnotetext{\textcopyright 2001 Royal College of General Practitioners. All rights reserved.}
Prevention, Surveillance and Screening (Cancers of the colon or rectum)

There are reasons to believe that many deaths from colorectal cancer could be prevented. The various strands of the argument are given below; each suggests a different form of intervention, but all are complementary.

- Associations between a range of aspects of lifestyle and colorectal cancer are strong and age-standardised incidence rates vary widely between populations, from fewer than two per 100,000 in parts of India and Africa to 55 per 100,000 among men in New Zealand. Overall, colorectal cancer rates are four times as high in more affluent (developed) countries than in less developed countries. This suggests that lifestyle and socio-economic circumstances have a major effect on risk. Although the effectiveness of lifestyle interventions for the reduction of colorectal cancer has not yet been demonstrated in randomised trials, the type of lifestyle that is associated with relatively low rates of colorectal cancer (see below) is known to be generally beneficial for health.

- Polyps can be seen and removed by endoscopy before they become malignant. This means that screening really can prevent this form of cancer.

- Some polyps and early tumours bleed, so their presence can be detected by alert patients, by testing the faeces for blood, or by adequate investigation of iron-deficiency anaemia.

- The disease tends to develop and spread slowly. Resection of early disease usually eliminates it completely, so appropriate action in response to early symptoms can prevent further spread.

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These features of colorectal cancer suggest that educational and screening initiatives, designed both to reduce the incidence of the disease and to increase the probability of early diagnosis, could prevent a substantial proportion of deaths.

**Lifestyle**

It has been suggested that about three quarters of cases of colorectal cancer may be associated with lifestyle and are therefore theoretically avoidable.\(^{21}\) It is not always clear whether the lifestyle factors identified below act independently on risk, since some are associated with each other (e.g. high consumption of processed meat, low consumption of vegetables, and smoking) and with obesity, which is also linked with higher rates of colorectal cancer.

Lower risk has been convincingly linked with the following aspects of lifestyle:

- **Infrequent consumption of meat.** A meta-analysis of prospective observational studies found that an increase of 100g of meat eaten each day was associated with a significant 12-17% increase in risk of colorectal cancer. Processed meat (including sausage, ham, bacon and burgers) was linked with substantially greater risk: each 25g consumed per day increased risk by 49%.\(^{22}\)

- **Matching calorie consumption to need.** It has been widely believed that dietary fat increases risk, because fat accounts for a much higher proportion of overall calorie intake in Western countries with high incidence levels than in low-risk populations. However, detailed analysis of epidemiological evidence shows that the overall proportion of fat in the diet is not significant; what matters is total calorie intake and body mass index. Leaner people are less likely to develop colorectal cancer. There is a consistent – albeit weak – association between

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dietary cholesterol and colorectal cancer, which may be a marker for specific foods such as red meat and eggs.²³

- An active lifestyle. Most studies show an inverse relationship between risk of colon cancer and physical activity; moderately demanding exercise, such as regular brisk walking, can reduce risk by 40 to 50%.²⁴ Active people are also less likely to become obese or to have high waist-to-hip ratios, both of which are associated with higher rates of colorectal cancer.²⁵,²⁶

- Not smoking. Long-term heavy smokers have two to three times the risk of developing colorectal adenoma, but it may be three or four decades before clinical colorectal cancer becomes apparent. It has been estimated that up to 20% of colorectal cancers in the US could be due to smoking.²⁷ The weak association that has been observed between alcohol consumption and colorectal cancer could be due to confounding with smoking, since studies that demonstrated this did not control for smoking, which was not believed to be relevant to colorectal cancer.²⁸

- Frequent consumption of vegetables and possibly, fruit.²⁹ The evidence on this seems somewhat inconsistent; most studies show significantly higher risk in


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people who rarely eat vegetables but others do not. However, if energy-dense foods are replaced with low-calorie vegetable dishes, this will tend to reduce total energy intake, thus reducing risk.

- A high-fibre diet. A well-controlled prospective multi-centre European study (EPIC) which followed 519,978 people over 1,939,011 person-years, found that the quantity of fibre in the diet was inversely related to the incidence of colorectal cancer. Incidence rates in the 20% of participants who consumed the most fibre (32g per day) were about 40% lower than in the 20% who consumed the least (13g per day) (adjusted relative risk, 0.58). A second recent study, of 45,000 older women in the US, found no such protective effect; however, over 80% of these women would have fallen into the lowest fibre intake group of the EPIC study, so this cannot be regarded as evidence against the possible protective effects of a high fibre diet. One study of patients with histories of adenomas and high dietary calcium intake, reported increased adenoma formation in those who took supplements of fibre (ispaghula husk).

**Nutritional supplements and medication**

Long-term use of particular nutritional supplements and specific types of drugs has been linked with reduced incidence of colorectal cancer. These include:

- Vitamin supplements containing folic acid. The Nurses’ Health Study found that folic acid in green vegetables was associated with a modest reduction in risk of

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colon cancer, but the effect of supplementation was much greater and increased over time. After 15 years, the incidence of colon cancer in those who regularly took folic acid was less than one quarter of that among those who did not (15 versus 68 new cases per 10,000 women, 55 to 69 years old). Other studies have also shown inverse associations between folate intake and colon cancer.  

- Selenium. Low selenium intake (reflected in low serum selenium levels) is associated with higher rates of colon cancer. An RCT assessing the effectiveness of 200µg selenium daily in patients with a history of skin cancer found that the total number of cancer deaths was halved by just 4.5 years of selenium supplementation (29 cancer deaths in the treatment group, compared with 57 in controls; relative risk 0.50, 95% CI 0.31 to 0.80); the incidence rates for colorectal, lung and prostate cancers all fell.

- Calcium. Epidemiological data and three published RCTs suggest that calcium supplementation can reduce the risk of adenoma formation in patients with histories of polyps. The benefit (over a period of three years) seems to be fairly small but calcium supplements do not produce any significant adverse effects.

- Regular use of non-steroidal anti-inflammatory drugs (NSAIDs), notably aspirin, seems to reduce the risk of colorectal cancer. Three recent prospective randomised trials have shown that aspirin reduces the frequency of new colorectal

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polyps in high-risk groups.\textsuperscript{38} Epidemiological studies have found about 30\% fewer cases of colorectal cancer among regular users of aspirin, and the NSAID sulindac has been shown to reduce the size and number of polyps in people with familial polyposis.\textsuperscript{39}

- Hormone replacement therapy appears to offer protection to women, particularly from colon cancer; five to ten years’ use halves the risk.\textsuperscript{40} However, this benefit is balanced by an increased risk of breast cancer and coronary heart disease.

\textit{Screening and polyp removal}

Most colorectal cancers result from malignant changes in polyps (adenomas) that developed at least a decade earlier. Polyps can be seen and removed during endoscopic examination of the bowel; 90\% of adenomas can be seen and removed during colonoscopy and about 70\% during flexible sigmoidoscopy, which is a quicker and generally less difficult procedure and therefore more appropriate for people who are not at especially high risk of colorectal cancer. Sigmoidoscopy has been shown to be an effective method of reducing cancers of the rectum and proximal (descending and sigmoid) colon. Initial results have now been published from a multi-centre MRC trial of screening with flexible sigmoidoscopy of people aged 55-65, followed by colonoscopy in those considered to be at high risk. Cancers were found in 0.3\% of those screened, 74\% of which were Dukes’ stage A or B, and adenomas were detected in 12\%. The authors conclude that this screening regimen is acceptable, feasible and safe.\textsuperscript{41}

\textsuperscript{38} Dyer O. Aspirin could be used to prevent cancer (News). \textit{BMJ} 2003, 326:565.

\textsuperscript{39} Information from the US National Cancer Institute website (www.cancer.gov/cancerinfo/pdq/prevention/colorectal/healthprofessional/)

\textsuperscript{40} Boyle, 2002, op. cit.

\textsuperscript{41} UK Flexible Sigmoidoscopy Screening Trial Investigators. Single flexible sigmoidoscopy screening to prevent colorectal cancer: baseline findings of a UK multicentre randomised trial. \textit{Lancet} 2002;359:1291-300.
Both cancers and large polyps (adenomas) may bleed; the quantity may be too small to be visible in the stools but it can often be detected by more sensitive tests for faecal occult blood (FOB). This is the rationale for screening by faecal occult blood testing, followed by endoscopy (flexible sigmoidoscopy or colonoscopy) if the result is positive. Meta-analysis of four randomised controlled trials has shown that screening by faecal occult blood testing reduced the risk of death from colorectal cancer by 16% overall, and by 23% (RR 0.77, 95% CI 0.57 to 0.89) in those who were actually screened.42

Although population screening in older age-groups is now known to be effective, screening is not thought generally appropriate for people in younger age-groups (under 50 years), among whom the risk of colorectal cancer is low. It is anticipated that some form of screening will be introduced in the NHS.

**Anal Cancer: causes and risk factors**

The most common cause of anal cancer appears to be sexually transmitted infection with the human papillovirus (HPV) – the virus which is also thought to be responsible for cervical cancer.43 Known risk factors include immunosuppression, usually due to HIV infection or immunosuppressive drugs; taking the receptive role in unprotected anal intercourse; and longstanding problems in the anal area, such as fistulas (abnormal openings). Smoking also increases risk, with a particularly strong relationship between the number of cigarettes smoked and the risk of anal cancer among pre-menopausal women.44

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For most people, the risk of anal cancer is low (Table 1). Members of groups in which the prevalence is greater, such as gay men, can reduce their risk by not smoking and refusing unprotected anal intercourse.

**Department of Health initiative on colorectal cancer**

In November 2002, the Secretary of State for Health announced a new initiative to reduce deaths from colorectal cancer. This will include the introduction of a national screening programme and improvements in services for symptomatic patients. The Department of Health has recently begun work on expanding and modernising endoscopy services to support this strategy.
1. Patient-centred Care

It is anticipated that the NICE guidance on supportive and palliative care for patients with cancer will be published in 2004. This guidance is intended to complement site-specific guidance, giving detailed and specific recommendations on many of the issues introduced in this section as they apply to cancer care generally, with supporting evidence. It will cover the following topic areas:

- Co-ordination of care
- Face-to-face communication
- Information
- Psychological support services
- Specialist palliative care services
- General palliative care services
- Social support services
- Rehabilitation services
- Complementary therapy services
- Spiritual support services
- Carer and bereavement support services
- User involvement.

A. Recommendations

Clear information

Clear, accurate and accessible information is important, for people at high risk of colorectal cancer and patients with cancer, and to their carers. Cancer Networks and Trusts should provide information in appropriate formats for patients and carers about diagnostic tests and about the nature and treatment of their colorectal cancer. This should include details of further sources of information and support. Relevant
information should be offered to patients at the time when it is likely to be most helpful: before the first hospital appointment for initial diagnostic procedures; when the diagnosis is discussed with the patient; when decisions are being made about further investigation or treatment; and before any particular form of treatment begins..

There should be systems for rapid and efficient communication between primary and secondary care, to ensure that GPs receive crucial information as quickly as possible.

Clinicians should give patients all the information they want and encourage them to become involved in decision-making to the degree that they wish; and they should specifically ask each patient if there is anything else he or she wants to know. Information offered should include information about the disease, diagnostic procedures, treatment options and their effects (including potential adverse effects) and as far as possible, a realistic assessment of predicted outcome. After primary treatment, patients should be offered a candid assessment of the success of the treatment. Copies of letters to GPs should be given to patients.

Those who give this information should be sensitive to the patient’s concerns, preconceptions, preferences and reactions. They should be aware that patients may need time to absorb all the relevant information and that they are likely to have additional questions after the consultation. They should ensure that patients know where they can find information and support between hospital appointments. Clinical staff should ask patients how much information they want about specific aspects of their disease and management at any particular time, and always give patients’ views precedence over those of their relatives or carers.

Patients should have access to individual support and guidance from a member of the specialist colorectal team when required. They should also be given information about sources of social support and practical help, such as local support groups and disability and benefits helplines; again, this should be provided both orally and in writing. Information should be provided in appropriate formats.
All members of the team whose roles involve face-to-face interaction with patients share responsibility for ensuring that their patients understand what is happening to them and about any forms of intervention that are being considered. Clinical Nurse Specialists have particularly important roles in checking that patients do receive all the information that they want, that they understand the information they have been given, and that they receive answers to any additional questions they may have.

Members of the colorectal cancer team - including senior clinicians who break the news to patients that they have cancer - should have training in communication skills. They need to be aware that patients often find it difficult to take in information given during the “bad news” consultation. Patients should be given adequate time to reflect and get answers to their questions before decisions are made about treatment. Consideration should be given to tape-recording consultations (with the patient’s consent) and offering the tape to patients to take home.

**Psychosocial support and continuity of care**

Patients should have access to psychosocial support from a Clinical Nurse Specialist who has had specific training in counselling patients with colorectal cancer and who can offer continuity of care. Patients and their carers should be given a contact telephone number for this nurse so that they can talk to her or him if they have problems or concerns after discharge from hospital.

The condition may be embarrassing and distressing for patients, with taboos about body function and anxiety about continence and odour compounding fears about cancer. Around one fifth of patients are aged over 80 and this group, in particular, are likely to need practical help (particularly from Clinical Nurse Specialists, other allied health professionals, and community care services) with coping with the consequences of their disease.

Psychosocial support is also important for carers looking after patients with advanced colorectal cancer at home. The primary and palliative care teams have particularly
important roles in ensuring that the needs of both patients and carers are identified and met.

**Patients with stomas**

Patients who may require stomas - whether temporary or permanent - should be counselled before surgery by a Clinical Nurse Specialist (either a colorectal cancer CNS who has expertise in stoma care, or a stoma specialist) on the position and implications of a stoma. After surgery, the same nurse should be available to assist patients in managing the stoma and to advise for as long as required on physical, social, sexual and emotional problems associated with the stoma. If they wish, patients who are expected to require, or have received, stomas, should be introduced to others who have stomas and given contact details for appropriate support groups.

**B. Anticipated Benefits**

Information is highly valued. Most people with cancer want to understand what is happening to them and want to know about their prognosis; and there is considerable research evidence showing that better informed patients tend to suffer less anxiety and look after themselves better. Patients particularly value sensitive communication of the cancer diagnosis, which, for most, has an intense emotional impact.
C. Evidence

Patient-centred care in the NHS

A national survey of patients’ experience, which included 15,891 patients with colorectal cancer, revealed considerable scope for improvement in services.\textsuperscript{45} Although almost all patients were told of their diagnosis in person by a hospital doctor, only 27% were then given written information about their condition or the treatment they might receive.

Most patients (83%) said they understood the diagnosis but 28% did not understand the purpose of tests and 35% did not understand explanations about different types of treatment. This level of information provision and understanding is lower than that reported by patients with breast cancer. At the time of first treatment, however, 95% of patients found the doctors’ explanations very or fairly easy to understand; just 2% reported that no explanation was given.

Explanations given by nurses at some Trusts were not so clear. 35% of nurses’ answers to patients’ questions at the worst Trusts were not understood all or most of the time. This suggests deficiencies in nurses’ training in communication at these Trusts, which could reflect a lack of suitably trained Clinical Nurse Specialists (see below); 42% of patients did not know the name of the nurse in overall charge of their care. There were also problems with information about possible side effects of treatment: 40% of patients reported that these had not been adequately explained.

There was wide variability between Trusts in patients’ sense that they were treated with respect and dignity. At the best performing Trust, 6% reported deficiencies in this aspect of care, compared with 38% of patients at the worst. 38% of patients at the worst performing Trust reported that staff talked about them as though they were

not there. A similar proportion (34%) felt that hospital staff did not do all they could to help with their pain; at the best, this figure was 7%.

After their first treatment, 19% of patients overall reported that hospital staff had not spent enough time talking to them about what would happen to them after they left hospital. Only 56% said they had been given written information and 51% were told of support or self-help groups.

A study by the Commission for Health Improvement/Audit Commission provides further information on patient-centred care in NHS hospitals in 2000/2001. This reports that 28% of Trusts visited did not have a clinical nurse specialist for colorectal cancer and that 40% of clinical nurse specialists felt that they were not able to give sufficient time to patients with colorectal cancer. Less than 40% of Trusts had assessed patients’ views of the services they provided, and 90% of lead consultants had had no specific training in breaking bad news to patients.

Psychosocial support

Colorectal surgery can adversely affect several aspects of well-being in the weeks after treatment. After discharge from hospital, patients report problems with mobility, bowel function, fatigue, pain, nutrition, anxiety and the wound. (B: See evidence review for 1997 edition of this document.)

Patients with stomas

A review of cross-sectional studies comparing patients with stomas and those without suggested that stomas are associated with impaired social and sexual functioning. Emotional problems including depression and loneliness were found to be significantly more prevalent among patients with stomas, affecting as many as half in some studies. Body image problems were found in two-thirds of patients with stomas, again significantly more often than in patients without. Patients with stomas were also more likely to report worsening relationships with partners, decreased
ability to work and greater limitations on social activities. (B: See evidence review for 1997 edition of this document.)

D. Measurement

Structure

- Providers should be able to demonstrate that appropriate and adequate oral and written information about colorectal cancer in general and the patient’s own situation and options is given to every patient.

- Providers should be able to demonstrate that services designed to meet the psychosocial needs of patients are available.

Process

- There should be evidence that patients receive oral and written information and support from suitably trained staff, and are informed about other reliable sources of information and support.

- Training for consultants in communication, breaking bad news, discussing prognosis and end of life issues.

Outcome

- Surveys of patients should be carried out by providers to assess the adequacy of each component of patient-centred care.
E. Resource Implications

Resources may be required to allow sufficient staff time for provision of psychosocial, practical and educational support for patients, and for training in communication skills for medical and surgical staff.

Resources are also required to fund training and employment of adequate numbers of clinical nurse specialists.
2. Access to Appropriate Services

A. Recommendations

Improving access to appropriate services is crucial to reducing colorectal cancer mortality, and should be given priority by all levels of the service – primary care, hospital Trusts, and Cancer Networks. Delays in diagnosis can be reduced by streamlining referral systems and improving access to endoscopy. The introduction of a national colorectal cancer screening programme, to which the Department of Health is now committed, will require that improvements have been achieved in these aspects of the service. A specific strategy for the expansion and modernisation of endoscopy services is being developed.

Cancer Networks should review referral systems and ensure that all those who are likely to refer patients with colorectal cancer, particularly GPs, geriatricians and haematologists, are aware of local referral guidelines. A referral proforma for suspected colorectal cancer should be developed by the Network and distributed to GPs and Trusts throughout the Network. Each Trust should have a central system (either a computer link or a fax/telephone number) specifically for rapid and efficient referral of patients with possible or suspected colorectal cancer to a designated diagnostic service managed by the colorectal cancer MDT. Such patients should not be referred initially either to individual clinicians or to radiology services for barium enema.
Urgent referral guidelines

The Department of Health has published the following criteria for referral within two weeks. These are currently being revised and new guidelines are scheduled for publication in 2005.

Criteria for urgent referral

<table>
<thead>
<tr>
<th>Sign, symptom or combination</th>
<th>Age threshold</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rectal bleeding WITH a change in bowel habit to looser stools and/or increased frequency of defecation, persistent for six weeks.</td>
<td>All ages</td>
</tr>
<tr>
<td>A definite palpable right-sided abdominal mass</td>
<td>All ages</td>
</tr>
<tr>
<td>A definite palpable rectal (not pelvic) mass</td>
<td>All ages</td>
</tr>
<tr>
<td>Rectal bleeding persistently WITHOUT anal symptoms*</td>
<td>Over 60 years†</td>
</tr>
<tr>
<td>Change of bowel habit to looser stools and/or increased frequency of defecation, WITHOUT rectal bleeding and persistent for six weeks.</td>
<td>Over 60 years†</td>
</tr>
<tr>
<td>Iron deficiency anaemia without an obvious cause (Hb &lt; 11g/dl in men or &lt; 10g/dl in postmenopausal women).</td>
<td>no age criterion</td>
</tr>
</tbody>
</table>

* Anal symptoms include soreness, discomfort, itching, lumps, prolapse and pain.
† 60 years is considered to be a maximum age threshold. Local cancer networks may elect to set a lower age threshold (e.g. 55 years or 50 years).

80-85% of patients with bowel cancer have these symptoms at the time of diagnosis, but only about one third of patients come through the fast-track route. When these symptom and sign combinations occur for the first time in any patient, he or she should be referred to a colorectal cancer MDT as an urgent case under the two week standard.

46 Available on the Department of Health website (www.doh.gov.uk/cancer)
Patients with the following symptoms and no abdominal or rectal mass are at low risk of cancer:

- Rectal bleeding with anal symptoms.
- Change in bowel habit to decreased frequency of defecation and harder stools.
- Abdominal pain without clear evidence of intestinal obstruction.

**Prompt recognition of warning signs and symptoms, and appropriate action**

GPs should refer patients with signs or symptoms that might be due to colorectal cancer for initial investigation using colonoscopy or flexible sigmoidoscopy. Colonoscopy (or flexible sigmoidoscopy plus barium enema, if patients find colonoscopy unacceptable) should be used when symptoms suggest possible cancer of the right or transverse colon. Because colorectal cancer is both relatively common and curable if treated early, it is important that the possibility of cancer should be considered early in the diagnostic process, particularly by GPs, but also by geriatricians, haematologists, and others who may see these patients.

Symptoms other than those in the list above, which should also prompt referral for endoscopy, include faecal incontinence, a sense of incomplete defaecation, and passing mucus via the rectum. The threshold for referral for investigation should be reduced if other members of the patient’s family have had a diagnosis of colorectal cancer.

Patients with iron-deficiency anaemia (apart from menstruating women) should be referred for colonoscopy, not barium enema (see Topic 4). People over the age of 50 with rectal bleeding of recent onset or other suspicious symptoms should have rectal examination and flexible sigmoidoscopy or colonoscopy; their symptoms should not be attributed to haemorrhoids until the possibility of colorectal cancer or adenomatous polyps has been excluded. GPs should be alert to the possibility that colorectal cancer can co-exist with haemorrhoids. It is important that investigations for bowel symptoms or anaemia should continue until the cause is found.

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GPs and practice nurses should take opportunities to discuss bowel problems with patients who, because of their age, lifestyle or family history might be at risk of developing colorectal cancer, and should explain to such patients how they might reduce their level of risk. They should describe the symptoms of colorectal cancer and emphasise its curability when treated early. Primary care staff should routinely offer lifestyle guidance, encouraging and assisting patients to give up smoking, take regular exercise, minimise their consumption of processed meat, eat more vegetables and lose weight; this will tend to reduce the risk of a wide range of diseases including colorectal cancer (see Background: Prevention, Surveillance and Screening).

GPs should not refer patients with suspected colorectal cancer to a specific clinician (as opposed to a diagnostic clinic) who is not a core member of a colorectal cancer multi-disciplinary team (see Topic 3, Multi-disciplinary Teams).

**Access to endoscopy**

Endoscopy services throughout England and Wales need to be expanded and improved; this should be recognised as an urgent priority by all Networks and Trusts. The NHS Modernisation Agency’s endoscopy programme has demonstrated scope for service improvement through streamlining care. This approach should be extended to all endoscopy services in England and Wales. It is also clear that greater endoscopy capacity is required for diagnosis and management of symptomatic disease, and will be essential when screening programmes are implemented. High quality training programmes need to be established to meet this demand.

All patients with symptoms that could be due to colorectal cancer, particularly rectal bleeding or a recently-established change to looser and/or more frequent motions, should have rapid access to colonoscopy or flexible sigmoidoscopy and any further procedures that may be necessary to reach a diagnosis. Networks will need to

47 In this document, endoscopy refers to any method used to examine the inside of the bowel. Colonoscopy and sigmoidoscopy are forms of endoscopy which allow examination of the whole bowel and the lower part of it, respectively (Figure 1, p.9).
monitor waiting time to endoscopy, in order to achieve the target of two months from urgent referral by a GP to treatment, which will become national policy in 2005. It is unlikely that this target can be achieved unless colonoscopy waiting times are less than four weeks.

Trusts should consider establishing open-access (possibly qualified by criteria such as the patient’s age) endoscopy clinics;\textsuperscript{48} these may be led by any appropriately trained individuals, including specialist nurses and GPs. All those who carry out endoscopy should be able to demonstrate that they have adequate training and should audit their results. Endoscopy staff should use check-lists to ensure that each patient’s history and endoscopy findings are accurately recorded.

Networks should develop guidelines for further investigation of patients with symptoms when the cause is not apparent from flexible sigmoidoscopy or barium enema. Adherence to these guidelines should be audited.

**Patients with non-specific symptoms**

The most common non-specific symptoms of colorectal cancer - for example, tiredness - are due to iron-deficiency anaemia caused by undetected blood loss, particularly in older men or post-menopausal women; patients with bowel polyps or cancer may have no other symptoms. Trusts should agree specific local guidelines which ensure that such patients are referred promptly to the endoscopy service.

**Emergency admissions**

Patients who present as emergencies with large bowel obstruction or other symptoms likely to be caused by colorectal cancer should be assessed and managed by members of a colorectal cancer MDT. If no such MDT is available at the hospital to which patients are initially admitted, transfer to a neighbouring hospital which has

\textsuperscript{48} Open access should be taken to mean direct referral by GPs, rather than through consultants or other indirect routes.
emergency access to an appropriate MDT, should be considered. This applies to patients admitted at night or during weekends, as well as those who are admitted during normal working hours.

Inevitably, a small proportion of patients who present as emergencies – particularly those with peritonitis – will not, receive care initially through the colorectal cancer MDT. The management of such patients should be passed to the appropriate MDT following diagnosis. A policy should be agreed by each Trust which links the colorectal cancer MDT with this form of triage system.

GPs and others who may deal with such patients should be given information on which local hospitals offer emergency treatment for colorectal cancer, so that they can make the initial referral to the appropriate hospital.

**High risk groups**

Cancer Networks should develop guidelines on the nature and frequency of surveillance for people at high risk of developing colorectal cancer. This should be based on the British Society of Gastroenterology and the Association of Coloproctology of Great Britain and Ireland (BSG/ACPGBI), which can be found on the BSG website (www.bsg.org.uk). The recommendations below are derived mainly from this guidance.

Several disease groups are associated with increased risk, of which the largest are patients who have had colorectal cancer, those found to have multiple or large (≥ 1 cm) adenomatous polyps, and patients with longstanding colitis. Regular colonoscopy is recommended for people in all these groups, but the frequency with which this should be carried out depends on the particular condition.

About 10% of patients have an inherited predisposition for colorectal cancer. Specific identifiable gene mutations (notably FAP and HNPCC) confer exceptionally
high risk – probably about a 60% lifetime risk of developing colorectal cancer.\textsuperscript{49} Members of families known to carry such mutations, and people with more than two first degree relatives with colorectal cancer, should be referred to clinical geneticists for genetic screening. All those with high-risk genetic syndromes require frequent surveillance from a younger age; those who have familial polyposis (associated with a 1 in 2.5 risk of death from colorectal cancer) are likely to require surgery to remove the colon and lifetime surveillance of any residual rectal stump.

People with two first degree relatives with colorectal cancer, or one first degree relative whose colorectal cancer is diagnosed before the age of 45, have a lifetime risk of death from colorectal cancer of 1 in 6 or 1 in 10 respectively. The BSG/ACPGBI guidelines suggest that people who meet these criteria should be referred for colonoscopy at 35-40 years of age, or as soon thereafter as the risk is recognised.

Colonoscopy, flexible sigmoidoscopy and barium enema can be uncomfortable and embarrassing to the patient and involve some risk (Topic 4: \textit{Primary Diagnosis}). Patients should be informed about these disadvantages, which must be balanced against potential benefits.

Appropriate systems should be established for inviting individuals in high risk groups for surveillance. Clinicians who carry out these tests should have appropriate training and should be able to refer patients to genetic counselling services.

\section*{B. Anticipated Benefits}

Reducing the threshold for action on symptoms of colorectal cancer, reducing diagnostic delay by improving referral systems and enhancing access to appropriate investigations, and developing systems for screening high-risk individuals, would all


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increase the probability of early diagnosis and thus, of successful treatment. These changes could also reduce the number of patients who present as emergencies, since most have symptoms for weeks or months before admission.

Late diagnosis appears to be the main reason for relatively poor survival rates among patients with colorectal cancer in England and Wales. Improving awareness of symptoms and the importance of adequate investigation, and expanding access to appropriate forms of endoscopy must, therefore, be crucial components of any strategy to improve outcomes.

C. Evidence

Urgent referrals and the two-week guidelines

Some GPs seem to be over-cautious about classifying referrals as urgent, and some do not follow national guidelines correctly. This could have serious consequences since diagnosis and treatment is delayed when patients with cancer are not referred as urgent cases. The CHI/Audit Commission investigation of cancer services in 2000/2001 reported that 18% of patients found to have colorectal cancer were referred as “not urgent”, when adherence to national guidelines should have led to urgent referral. This study also found that at least half of those who are referred as urgent cases do not fit national guideline criteria.

Studies of the impact of the two-week referral guidelines show wide variations in different hospitals, but the outcomes are generally not clear because the few published studies are neither well designed nor adequately reported. In some hospitals it appears that the establishment of services to deal with patients referred under the two-week guidelines have meant that all patients – including those who are not referred as

urgent – are now being seen more quickly. For example, one service reported that the time from referral to diagnosis was 11 days for fast-track referrals and 35 days for other non-emergency referrals. The average wait for all elective patients dropped from 38 days in the run-up to the introduction of the two-week service to 17 days thereafter. In contrast, waiting times in a Welsh hospital increased from nine to 16 weeks for patients with colorectal cancer who were not referred through the fast-track service.(B)

One large study (2,181 patients) describes the experience of a one-stop clinic run by a specialist multi-disciplinary colorectal cancer team. Flexible sigmoidoscopy was used for patients over the age of 45. This service achieved a median waiting time of nine days and median time to treatment of 24 days. Over three-quarters of patients with cancer were referred via this clinic; 8% of the patients seen in the clinic had cancer. In 62% of cases, the tumour stage was Dukes’ A or B; by contrast, only 22% of patients referred by other routes had Dukes’ stage A or B tumours: most of these were stage C.(B)

About 12% of patients referred through fast-track services described in the evidence review were found to have cancer. It is not clear whether these clinics accept referrals under all the criteria in the two-week guidelines; some hospitals have a different referral pathway for patients with anaemia.

**Delays in diagnosis**

There is considerable evidence in the research literature of delays, often lasting a year or more, between the onset of symptoms of colorectal cancer and diagnosis. This is principally due to patient delay in reporting symptoms, and to a lesser extent, GP and hospital delay. There is no clear relationship between length of delay and stage of cancer or outcome, but the situation is confounded by the fact that more advanced tumours (for which the outcome of treatment is poor) produce more obvious and alarming symptoms, so tend to be investigated relatively quickly.(B) Some GP and hospital delay is due to inadequate investigation of symptoms, misdiagnosis, and false
negative results of diagnostic tests. (B: See evidence review for 1997 edition of this document.)

Waiting times in the NHS

A national survey of NHS patients carried out in 1999/2000 (just before the publication of two-week referral guidelines for colorectal cancer) found that 34% of patients with colorectal cancer had had an appointment with a hospital doctor within two weeks of visiting their GP with symptoms. However, a substantial proportion – 37% – had to wait over three months for their first hospital appointment. 13% waited seven or more months. 39% of women and 35% of men reported that their condition had deteriorated while they waited for a hospital appointment.

Delays associated with inadequate assessment of iron-deficiency anaemia can be particularly long. This is an issue of concern because anaemia may be the only symptom of colon cancer, but the majority of patients with anaemia of unknown cause are not referred for investigations that would reliably reveal the presence of colon cancer. The potential importance of this is illustrated by a study of post-menopausal women or men with documented iron-deficiency anaemia, which found that 25% of those in which the cause was identified within one year, had bowel cancer. A quarter of cases were not diagnosed for over a year; two of these patients had had negative barium enemas. Only 35% of the study group of 431 patients had any


54 Ibid.
investigation of the lower gastro-intestinal (GI) tract; 56% of those with histories of GI complaints were offered no GI investigation at all.\(^{55}\)

**Open-access endoscopy in the UK**

There is a wide range of open-access endoscopy services across the UK and cancer incidence rates vary widely across these services. One report described an evening clinic which picked up an unusually high proportion of cases: 25 cancers in 179 self-referred patients and 91 cancers in 648 patients referred by GPs – a 14% cancer rate in both groups. Another evening clinic reported highly positive feedback from patients and GPs but a much lower cancer incidence rate (2.4%). A potentially crucial difference between these is that the former was advertised in the context of a public awareness campaign conducted by a cancer charity, and patients had direct access to the clinic via a telephone help-line provided by the charity. This seems to have been particularly effective for getting men to get their symptoms investigated.\(^{b}\)

Most open-access endoscopy clinics offer flexible sigmoidoscopy. The yield of cancers and polyps detected varies between clinics, according to the particular patient population investigated.

The largest study identified (2,701 cases) was of an open-access colonoscopy service established in 1996.\(^{56}\) Waiting time averaged 44 days in the last year of the audit. Overall, 4% of patients had cancer and 10% had polyps. Change in bowel habit (particularly development of diarrhoea) in patients over the age of 45 was especially likely to signify cancer or polyps: of 348 patients with unexplained diarrhoea, 10% had cancer and 10% polyps. Among 69 patients referred to the same hospital for

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\(^{55}\) Logan E, personal communication, 2003.

\(^{56}\) Paul Cann, personal communication, 2003.
investigation of anaemia, 28% had a malignant condition, of whom six (8.7%) had bowel cancer.\textsuperscript{57}

Despite the availability of the open-access colonoscopy service, fewer than half of all referrals for suspected colorectal cancer came by that route – probably because of GPs’ misapprehension that direct referral to a consultant leads to faster diagnosis.

Another direct-access colonoscopy service reported an 8% incidence of colorectal cancer among 100 patients. Few details were given in this report.

Two services were described in one Trust, one led by doctors, the other by nurses. The doctor-led service reported a 13.2% cancer rate and a trend towards identification of cancer at an earlier stage (25% stage A in 1997-8, compared with 10% in 1993). Fewer cancers (1.6%) were detected among patients referred to the nurse-led flexible sigmoidoscopy clinic for investigation of rectal bleeding.

Similarly low cancer rates (2%) were reported in another nurse-led sigmoidoscopy clinic. However, when this service became available, the waiting time for routine outpatient clinics fell from 16 weeks to eight.\textsuperscript{B}

\textit{Improving access to hospital-based services: information based on experience in the Cancer Services Collaborative}

Improvements in the referral process between GPs and bowel clinics have been described by several Trusts. In East Berkshire, referral criteria were agreed by relevant clinical leads/consultants. Establishment of a standard referral proforma and a central fax point to deal with initial referrals led to a steady rise in the number of referrals received in this way.\textsuperscript{58}

\begin{flushleft}
\textsuperscript{57} Greenaway JR, Cann PA. Investigation of iron deficiency anaemia (IDA) in adults. \textit{MD thesis, 2001; publication status to be checked}

\textsuperscript{58} Cancer Services Collaborative, case study BwC 2.2.
\end{flushleft}
Referral systems in Aintree, Liverpool, were re-designed with the help of the NHS Cancer Services Collaborative. Now, all referrals go to a co-ordinator who agrees a clinic appointment time with the patient, sends information about the test and an appropriate bowel preparation product to the patient, and liaises with the GP. The co-ordinator ensures that patients are sent to the right clinic and that feedback is given to those who require it. One in nine patients referred through this system were found to have cancer.

**Emergency admission**

About a fifth of patients who undergo surgery for colorectal cancer are admitted as emergencies; the average GP is likely to encounter one such patient every three years. The Trent/Wales audit found that the mortality rate in this group was four times higher than among those who underwent elective surgery (21.7% for emergency/urgent surgery, versus 5.5% for scheduled/elective procedures; see also Topic 5, *Surgery*). Patients who present as emergencies are likely to have experienced symptoms (most often change in bowel habit, abdominal pain and vomiting) for about three weeks; in up to a quarter of cases, symptoms may be present for three months before admission. (B)

Although there is no reliable research evidence to indicate how emergency rates could be reduced, comparisons between parts of Europe show that higher emergency admission rates and poorer survival rates are both typical of places where colon cancer is diagnosed at a later stage.

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59 This case-study was reported at the Colorectal Cancer Conference of the Cancer Services Collaborative, March 2002; information derived from the NHS Modernisation Agency website (www.modernnhs.nhs.uk). The project managers, Julie Cunningham and Kathy Collins, can be contacted on 0151 529 3899.


**High risk groups** *(See 1997 evidence review)*

About 15-20% of colorectal cancers occur in people with one or more first degree relatives who have also had colorectal cancer. These people are twice as likely to develop colorectal cancer as the general population in the same age-group.

Individuals with a family history are more likely to develop the disease at an early age, especially if cancer was diagnosed in their relative(s) before the age of 55. The degree of risk, relative to individuals with no family history of the disease, varies with the age of the individual (Figure 2, Background).

The genetic syndromes FAP and HNPCC account for about 5% of colorectal cancers. People with FAP develop hundreds of polyps; by the age of 40, most will have colon cancer unless they have had surgery to remove the colon. People with HNPCC also develop colorectal cancer at an early age but it is less often preceded by the growth of multiple polyps. Genetic testing can be helpful for identifying gene carriers; about 80% of these families have higher than normal frequency of polyps. (B)

People with inflammatory bowel disease, including Crohn’s disease and ulcerative colitis, account for fewer than 1% of new cases of colorectal cancer. The risk increases with the duration of the disease.

There are no research studies showing the reduction in risk of death from colorectal cancer associated with surveillance of people at high risk, but extrapolation from studies of population screening (see Background) suggests that some form of regular surveillance is likely to be highly effective.
D. Measurement

Structure

• Referral guidelines and referral pro-formas for patients with signs or symptoms suggestive of colorectal cancer.

• Availability of adequate rapid-access endoscopy services.

• Systems for stabilisation of patients with intestinal obstruction and rapid transfer of emergency patients, when necessary, to hospitals where they can be assessed by a specialist colorectal cancer MDT.

• Access to testing for early detection of colorectal cancer for those at high risk, with reminder systems and quality control programmes.

• A genetic assessment and surveillance service.

• Protocols for screening high risk individuals.

Process

• Audit of use by GPs of access routes to diagnosis of colorectal cancer, and audit of timescales from initial referral to first treatment.

• Audit of proportion of non-menstruating adult patients with iron-deficiency anaemia of unknown cause, as defined in two-week referral guidelines, who are referred for investigation.

• Audit of time-lag between GP consultation with bowel symptoms that could be due to colorectal cancer, and appropriate endoscopy.

• Audit of time from first hospital appointment to definitive diagnosis

• Audit of effects of GP referral guidelines

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• Provider compliance with surveillance protocols.

• Proportion of patients invited for surveillance who take up the offer.

• Proportion of patients with colorectal cancer presenting as emergencies.

• Evidence that all patients found to have colorectal cancer are referred to the colorectal cancer MDT.

**Outcome**

• Stage of cancer at diagnosis.

**E. Resource Implications**

Surveillance of members of high-risk groups, as proposed in BSG/ACPGBI Guidelines, is not likely to change dramatically the number of colonoscopies performed annually, but rather ensure that colonoscopy is offered to the correct groups of patients and that resources are not wasted.

Resources will be required for the establishment of colorectal assessment and genetic counselling and surveillance services.
3. Multi-disciplinary Teams

A. Recommendations

The management of all patients with colorectal cancer should be the responsibility of colorectal cancer multi-disciplinary teams (MDTs). Any patient under the care of a clinician who is not a core member of such an MDT should be promptly referred to an appropriate team when colorectal cancer is suspected. Cancer Networks should make specific arrangements to ensure rapid access to a member of a specialist colorectal cancer MDT for all patients admitted as emergencies to any hospital, at any time. (See Topic 5, Surgery and Pathology, for discussion of emergency cases.) Guidelines should be agreed by all Trusts within each Cancer Network to ensure prompt and efficient referral of every patient suspected or found to have colorectal cancer to a colorectal cancer MDT, and the implementation of these guidelines should be audited.

Colorectal cancer MDTs in General Hospitals should take responsibility for all patients with cancer of the colon or rectum. Cancer Networks should agree specialisation criteria for members of these teams.

Where Trusts already have colorectal cancer MDTs, their composition, mode of operation and functions should be reviewed and refined in line with the recommendations in this section. If more than one colorectal cancer MDT works in a single Trust, all should work to a single protocol. Teams should be merged if they deal with small numbers of patients (fewer than 60 new cases per year) or if core members such as radiologists or oncologists cannot attend meetings regularly. Small hospitals within a single Trust should consider merging their teams.

Colorectal cancer MDTs should refer patients with anal cancer to designated teams with expertise in the management of this condition; these teams will work in a limited number of Cancer Centres (see Anal cancer, below). Patients who might benefit from
Resection of liver metastases should also be referred to specialised MDTs, which may in practice be those which have been previously established to provide surgery for patients with pancreatic cancer,\textsuperscript{62} except where separate specialist liver resection teams have been established.

Colorectal cancer MDTs should consist of a core team of members who have particular interest and expertise in this area and who will make a commitment to attend a majority of MDT meetings, and associates who are members of an extended team. The extended team should consist of designated individuals who should be available to work with core MDT members when their expertise is required. Where shortage of staff time creates problems with regular MDT attendance, Trusts should examine individual members’ commitments and seek to streamline administrative processes to increase efficiency, using methods developed by the Cancer Services Collaborative.\textsuperscript{63}

At any one time, a named member of the team should be the principal clinician to whom the patient relates, e.g. the surgeon in the early stages of the disease, the oncologist during adjuvant treatment, and oncologist or palliative care physician at later stages. It is important that such arrangements should be explicit and properly understood by patients and their GPs, who should be given information about the members of the team involved in their management.

The core team should be responsible for planning care in a seamless way so that each patient receives prompt and appropriate care throughout the process of diagnosis and treatment, including the period when palliation may be needed, until the patient is released from follow-up or dies. One member of this team (either a Clinical Nurse Specialist or the team co-ordinator) must have a system for tracking all patients.

\textsuperscript{62} This type of team is defined in \textit{Improving Outcomes in Upper Gastro-intestinal Cancers}, available on the Department of Health website (www.doh.gov.uk/cancer/pdfs/manualuppergimay02.pdf).

\textsuperscript{63} www.nhs.uk/npat
throughout their illness, including those who are referred to linked MDTs (for example for liver resection) and bringing them back to the core team.

The colorectal cancer MDT

A colorectal cancer MDT in a relatively small DGH, serving a population of 200,000, could expect to deal with about 120 new patients per year, and would include two or three surgeons. Larger centres may be able to form teams with more specialised members, such as hepato-biliary surgeons.

The core team should include the following members:

- At least two specialist surgeons who have been trained in, and maintain a special interest in, techniques relevant to colorectal cancer, and who can demonstrate a high level of skill in this area. Each surgeon in the MDT should carry out a minimum of 20 colorectal resections with curative intent per annum. Sub-specialisation should be specifically encouraged among surgeons who treat patients with rectal cancer.

- Oncologist. Whenever elective surgery is considered for patients with rectal cancer, clinical oncologists should be involved in discussion about each patient before surgery is scheduled. In view of the current shortage of clinical oncologists in the NHS, teleconferencing may be appropriate to enable this discussion to be held. A medical oncologist may also be included in the MDT if available.

- Diagnostic radiologist with gastrointestinal expertise.

- Histopathologist.

- Skilled colonoscopist of any discipline (surgeon, physician, or specialist nurse). See Topic 4, *Primary diagnosis and pre-operative evaluation*, for criteria for assessing skill in colonoscopy and recommendations on training.

- Clinical Nurse Specialists (CNS). In many respects, the role of CNSs for colorectal cancer is similar to that of breast care nurses. A CNS should be
available to provide support, assistance, information and advice to every patient. He/she should have specific expertise in colorectal cancer and in addition, should be trained in communication skills and counselling. These nurses should ensure that patients’ non-clinical needs – for example, for information and support – are met (see Topic 1, Patient-centred care).

- Palliative care specialist (doctor or nurse), who should work with palliative care services in the community.

- Clinical trials co-ordinator or research nurse.

- Meeting co-ordinator, who should take responsibility for organising MDT meetings (see below). The co-ordinator should have the authority to ensure that extended team members such as social workers and psychologists are available when required. The co-ordinator should also be responsible for feedback about patients referred to more specialised teams, and the return of such patients to the local colorectal cancer MDT.

- Team secretary who will provide clerical support for the MDT, recording all decisions made by the team and communicating appropriate information promptly to all those (such as GPs) who may require it. In smaller teams, the co-ordinator may take the role of team secretary.

MDTs should maintain close contact with other professionals who are actively involved in supporting the patient or carrying out the treatment strategy decided by the core team (the extended team). Extended teams should include the following members:

- Gastroenterologist

- Liver surgeon who is a member of a liver resection MDT and can advise the colorectal cancer MDT.

- Thoracic surgeon with expertise in lung resection.
• Interventional radiologist with expertise in insertion of lower intestinal stents.

• GPs/primary care teams

• Dietitian

• Liaison psychiatrist/clinical psychologist

• Social worker

• Clinical geneticist/genetics counsellor

• Other allied health professionals

Selected individuals from the extended team may be included in the core team.

Each network should ensure that nominated individuals are available to fill each role in every extended team and should carry out regular audits to check that they do, in fact, fulfil the function of that role when required. Trusts may pool resources so that individuals with specific expertise work with more than one colorectal cancer team. Teams based in cancer units must work closely with colleagues in the associated cancer centre.

**Anal cancer MDTs**

Particular colorectal cancer MDTs, based in cancer centres with radiotherapy facilities, should be designated as specialist anal cancer MDTs which will provide treatment for patients with anal cancer (See Topic 8, Anal Cancer). These teams will be called “anal cancer MDTs” in the text below. It is not envisaged that these should be teams which deal only with anal cancer, nor are they expected to have meetings separately from their parent colorectal cancer MDTs; rather, this term is intended to describe the function of designated MDTs which have the range of expertise necessary for the management of anal cancer.
Cancer Networks and radiotherapy centres should work together to determine where patients with anal cancer should be treated. Clear referral systems should be established within each Network to ensure that responsibility for the management of every patient with anal cancer is passed to the appropriate MDT when the initial diagnosis is made.

Anal cancer MDTs should include the same range of disciplines as other colorectal cancer MDTs (see The Colorectal Cancer MDT, above, for details of core and extended teams), but the members should also have specific expertise in the management of anal cancer. In addition, each anal cancer MDT requires access to plastic surgery and should have links with a gynaecological oncologist with expertise in vulval cancer. At least one, and preferably two, members of the anal cancer MDT should specialise in surgery for anal cancer.

Within each designated radiotherapy facility, responsibility for the treatment of patients with anal cancer should be taken by no more than two clinical oncologists, who should have specialist knowledge of chemo-radiotherapy and be core members of the anal cancer MDT.

Liver resection MDTs

Each network should identify or establish a specialised MDT which has the expertise and facilities to provide surgery for patients with liver metastases in a centre which serves a population of at least two million. This may be a hepato-biliary and pancreatic MDT which carries out both liver resection and surgery for pancreatic cancer. Where two or three smaller networks co-operate to create a joint team, there should be explicit arrangements for referral between networks.

Referral to a specialist liver resection MDT, for an opinion about the feasibility of resection, should be considered for patients in relatively good general health who have undergone curative resection for a primary colorectal tumour or who have a resectable primary tumour and who are believed, on the basis of imaging, to have resectable liver metastases; decisions about liver resection should be made by the
HBP team. Cancer Networks should agree criteria specifying which patients should be referred to HBP teams and produce formal referral protocols for them; other patients should not normally be referred to this team.

The membership of the liver resection MDT should normally be the same as the hepato-biliary and pancreatic cancer MDT which is responsible for pancreatic resection,\textsuperscript{64} except where a specialist liver resection team with expertise in cancer treatment is available.

**Organisation of MDT meetings**

Meetings should be arranged weekly in sessional time by the team co-ordinator. The co-ordinator should work with other members of the MDT to ensure that all the following patients are identified for discussion at the meeting, and that copies of their case notes, along with diagnostic, staging, and pathology information, are available for consideration at the meeting:

- Every new patient with a diagnosis of colorectal cancer. The MDT co-ordinator should work with pathologists, radiologists and endoscopists to ensure that all new cases are identified.

- All patients who have undergone resection with curative intent and histopathological information is available.

- All patients with newly identified recurrent or metastatic disease.

- Patients who have been referred back for management by their local colorectal cancer MDT after referral to a specialist MDT.

- Any other patients whose management is thought by any member of the MDT to require discussion.

\textsuperscript{64} See www.doh.gov.uk/cancer/pdfs/manualuppergimay02.pdf.

**DRAFT FOR 2\textsuperscript{ND} CONSULTATION**
All information necessary for effective team functioning and clinical decision-making should be available at each meeting. Team members should be adequately prepared for the meeting, so that they can discuss each case without delay; such preparation and attendance at meetings should be recognised as important clinical commitments and time should be allocated accordingly.

Each MDT should have adequate systems for recording decisions made at meetings and ensuring that appropriate action is taken to carry out these decisions. Information and decisions about individual patients should be recorded on an appropriate pro-forma; ideally, this should be available on a laptop computer so that it can be used during MDT meetings. The meeting co-ordinator should keep a record of attendance by individual MDT members.

The MDT should discuss the histopathological features of each excised specimen after surgery, in order both to monitor the quality of surgery and to decide whether the patient might benefit from further treatment. Photographs of the margin of the specimen can be helpful to inform this debate. Patients with rectal cancer for whom elective surgery is planned should be discussed by the MDT before surgery; a clinical oncologist should be involved in this discussion.

The lead clinician, working with the meeting support staff, should take responsibility for ensuring that treatment plans and other decisions relevant to specific patients are sent to their GPs as quickly as possible.

Audit, clinical trials, and other issues of relevance to the Trust or Cancer Network should also be discussed at MDT meetings. Networks and Trusts should ensure that adequate resources and support – in terms of investment, expertise and time – are provided for audit, and MDT lead clinicians should provide feedback about such requirements to those who have responsibility for managing clinical audit.

There should be an operational policy meeting at least once a year at which the colorectal cancer team discusses and reviews its policies. This meeting should be organised around an open agenda to which all members of the team may contribute.
Achieving consistency within Cancer Networks

Network-wide guidelines should be agreed, with joint protocols for clinical management, referral and audit. There should be adequately supported network-wide audit, not only of clinical issues and outcomes, but also of the activity of individual surgeons and of patients’ and carers’ experience of the service. Cancer Networks should organise meetings between colorectal cancer MDTs at least biannually, at which information derived from audit is used to identify and reduce variations within the Network.

How the team functions

Each MDT should have an administrative head, usually the Lead Clinician, who should work closely with the co-ordinator. Teams should, however, seek to achieve pluralistic or distributed leadership for decision-making, and a democratic ethos should be encouraged. It is important that all clinical members of the MDT, including specialist nurses, should play active parts in discussing treatment plans, since each can offer a distinctive and valuable perspective. The participation of clinical nurse specialists should be regarded as essential to effective team function. MDTs should consider taking specific training in effective team-work.

B. Anticipated Benefits

The most important benefits of team working are improved co-ordination of care and the opportunity to consider each case from a variety of perspectives. Patients managed by a team are more likely to be offered a range of types of treatment at appropriate times and to receive seamless care through all stages of the disease. When MDTs function well, they offer a supportive environment where individual members can share their concerns. MDT meetings also provide opportunities for surgeons to receive feedback from histopathologists and other team members on the results of their work. This can lead to marked improvements in surgical technique.
Treatment by MDTs which treat relatively large numbers of patients, rather than by individual surgeons who may only deal with a few, can be expected to produce substantial benefits for patients. There is accumulating evidence that hospitals that treat more than 20 new patients with rectal cancer per annum – the minimum number that would be treated by MDTs working in accordance with the recommendations in this section – achieve better outcomes. Their patients are less likely to receive permanent colostomies, suffer fewer post-operative complications, have lower local recurrence rates and are more likely to become long-term survivors. Concentration of surgery in the hands of fewer, more specialised surgeons, working in the context of MDTs, can be expected to produce similar benefits.

C. Evidence

A recent report, based on site visits carried out by the Commission for Health Improvement and the Audit Commission in winter 2000/2001,\(^6^5\) shows that multidisciplinary team working is less well developed in colorectal cancer care than in breast cancer care. Of twelve Trusts which reported that they had colorectal cancer MDTs, half held weekly patient-planning meetings and a third held meetings fortnightly; the other two met monthly or less. It seems that the other six Trusts did not hold regular colorectal MDT meetings at which patient management was planned.

In Trusts that did have colorectal cancer MDTs, surgeons who were not members nevertheless carried out operations. A third of lead consultants reported problems dissuading colleagues from occasional practice. In one Trust, for example, four out of eight surgeons who carried out operations for colorectal cancer attended MDT meetings; in a second, only one of the two main colorectal cancer surgeons attended MDT meetings and the patients treated by the second surgeon (about a quarter of the

\(^6^5\) Commission for Health Improvement and the Audit Commission, National Service Framework Assessments No.1 – NHS Cancer Care in England and Wales.
total) were not discussed by the MDT. 40% of lead consultants, working in 21 Trusts, said there were surgeons in their Trust who regularly carried out operations for colorectal cancer but did not attend MDT meetings.

Patients who underwent emergency surgery by anyone other than a designated specialist working in an MDT were unlikely to be referred on to a specialist for subsequent management.

Fewer than 20% of MDTs had administrative support for meetings, and in those Trusts where regular MDT meetings were held, only 56% kept minutes. Most MDT meetings were held outside normal working hours, often during lunch time.

Research evidence on MDT function in cancer care is mainly based on experience with breast care MDTs. This is summarised in *Improving outcomes in breast cancer: Update of the COG guidance manual* (2002), which can be found on the NICE website.66

The NHS Cancer Services Collaborative offers information based on practical experience of improving the effectiveness of colorectal cancer MDTs. The following reforms have emerged as helpful:

- Improve organisation of MDT meetings (the role of the co-ordinator is crucial to this – see below).

- Review the timing of meetings by discussion with all members, including visiting oncologists and radiologists, to allow all members to attend.

- Streamline referral systems. For example, the MDT registration form can be designed to double as an oncology referral letter.

- Develop a clear and efficient structure for the meeting and work to a defined agenda.
Better organisation of meetings leads to more efficient use of time and allows more patients to be discussed. It also results in more patients being managed in accordance with guidelines.

The NHS Modernisation website\(^{67}\) includes a description of the role of the co-ordinator of the colorectal cancer MDT at the Royal Hants County Hospital; it is clearly designed to maximise the efficiency and effectiveness of the MDT. The co-ordinator supports the MDT by ensuring that it has the information it needs to make decisions efficiently at meetings, and that its decisions are recorded and acted upon. She is in touch with all members of the MDT, acting as the focal point for information, collecting information from a variety of sources and making sure it is available when and where it will be required. She identifies patients who should be discussed at each MDT meeting and ensures that their notes and films are available; she prepares the minutes, records decisions in patients’ notes, checks that appropriate action is taken, writes referral letters, and passes information to patients and GPs. She maintains the Cancer Outcomes Database, tracks requests for endoscopy and imaging and their results, and acts as the contact point for audit.

Audit data from a Cancer Centre in Wales show that the proportion of patients referred to specialist oncologists increased from below 60% to 100% with the institution of regular MDT meetings. (B)

**Surgical specialisation and patient throughput**

There is now a substantial body of research assessing the effects on outcomes in colorectal cancer of surgical specialisation and patient throughput (both the number of cases treated per surgeon and per hospital). The evidence review carried out to support this guidance includes six systematic reviews and 32 primary studies, none of which had been published at the time of the first edition of this guidance (1997).

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\(^{66}\) www.nice.org.uk  
\(^{67}\) www.nhs.uk/npat
As a general rule, the more complex the operation, the greater the surgical skill required; such skill is acquired and developed through specialised training and experience and maintained by regular practice. It is not, therefore, surprising that in surgical oncology as a whole, the benefits of higher volume practice and greater specialisation would be particularly apparent in outcomes for types of cancer for which surgery is more challenging. And this is indeed the pattern with colorectal cancer. Surgery for rectal cancer, which is more difficult to do well, shows volume and specialisation effects more clearly than surgery for colon cancer.

None of the reviews which contribute to the evidence on this issue included more than five primary studies of colorectal cancer. Nevertheless, they are consistent in finding evidence that for rectal cancer at least, higher patient volumes and greater specialisation among surgeons were associated with better outcomes – lower surgical complication rates, decreased local recurrence, lower colostomy rates, and improved survival. One review concluded that outcomes in rectal cancer were related more to the surgeon’s technique than to the number of patients treated; another commented that later studies found a greater difference between specialist surgeons than earlier. However, neither of these were good quality reviews.

Most of the primary studies report more recent data, and as such, are likely to be more relevant to current practice.

In rectal cancer, 11 of 13 studies assessing surgical specialisation reported that more specialised surgeons achieved better outcomes. All six studies of specialisation showed significant effects on one or more of the following measures of outcome: survival rates (up to five years); quality of surgery (assessed by anastomotic leak rates or tumour-free excision margins); and local recurrence rates. The volume evidence was less consistent, with two out of four studies showing significantly higher survival rates among patients treated by higher-volume surgeons. Of the two studies which showed no effect of surgeon volume, one, using data from 1984-6, reported very high variability between surgeons; the other used a “high volume” cut-off of just three procedures per year. The latter study did, however, find lower recurrence and
mortality rates for surgeons with more specialist experience. Indeed, all seven studies that used recurrence rates as an outcome measure for rectal surgery found significant benefits of either higher volume practice or surgical specialisation. (B)

There is less evidence for colon cancer, although some studies reported on patients with colorectal cancer, the majority of whom would have had cancer of the colon. However, once again, the advantages of surgery by specialists are reflected in consistently higher survival rates. (B)

Studies of hospital throughput show the same general pattern of results. One study examined liver resection for metastatic colorectal cancer and found a highly significant association between higher throughput and 30-day survival rates. Higher hospital volumes and treatment in more specialised units are associated with generally better outcomes – including lower complication rates, shorter in-patient times and better survival rates – in rectal cancer, but the effect is less clear for colon cancer. (B)

A recent large, high-quality study found that colostomy and mortality rates in patients with rectal cancer (tumour stage I-III) were significantly linked with hospital volumes. The absolute rates of both stoma formation and two-year mortality were 7% higher in hospitals that carried out fewer than seven operations per year on this group of patients, compared with those which carried out more than 20. (B)

**D. Measurement**

**Structure**

- A system for identification of all patients with newly-diagnosed or recurrent colorectal cancer and assembly of all information relevant to these patients which may be required to inform discussion by the MDT.

- Appropriate pro-forma for recording information and MDT decisions about individual patients.
• Arrangements for MDT meetings in normal working hours.

• Meeting co-ordinator and secretarial resources to support MDT meetings.

• Systems to ensure that all patients with colorectal cancer who receive initial treatment by anyone other than an MDT member are promptly referred to the MDT.

• Presence of specialist team members with adequate training and dedicated sessions.

• Systems to ensure that patients are promptly referred to an anal cancer MDT

• Designation of members of colorectal cancer MDTs to form anal cancer MDTs in specified cancer centres.

• Designated liver resection MDTs.

Process

• Minutes and attendance records of formal MDT meetings.

• Evidence in minutes of meetings that the management of every patient with newly diagnosed or newly recurrent colorectal cancer is discussed at an MDT meeting.

• Use of pro-forma to record decisions about individual patients.

• Evidence of discussion of all patients found to have liver or lung metastases, and referral of such patients for further management by appropriate specialists.

• Evidence in minutes that resection margins of all excised specimens are discussed at MDT meetings.

• Evidence that clinical nurse specialists contribute to discussion at MDT meetings.
- Details of patients who undergo resection by any surgeon who is not an MDT member, and reasons for this.

- Delay between surgery and initiation of chemotherapy.

- Number of new patients treated annually by each MDT.

- Number of resections carried out annually by each surgeon in the MDT.

**Outcome**

- 30 day, 3 and 5 year relative survival rates, adjusted by age and stage at diagnosis, for each surgeon and for the MDT.

- Audit of variations in outcomes and use of adjuvant therapy within the network.

**E. Resource Implications**

Where recommendations made in the previous edition of this guidance have not been fully implemented, additional investment will be required to support the activities of colorectal cancer MDTs and liver resection MDTs, which are likely to deal with larger numbers of patients.

Increasing both the proportion of patients managed by specialists and the range of activities carried out by specialists will produce pressure for increasing the number of key members of staff. These changes and their resource consequences will have to be assessed locally.

Adequate funding is essential for audit, data collection, and employment of data managers.
4. Primary Diagnosis and Pre-operative Evaluation

A. Recommendations

Improving diagnostic services for patients who could have colorectal cancer should be recognised as a priority by Cancer Networks and Trusts. Networks should carry out an urgent review of services for diagnostic endoscopy of the lower intestinal tract.

Within each Cancer Network, MDTs should agree a series of local clinical guidelines for diagnostic investigations for colorectal cancer, the use of which should be audited throughout the Network. These should deal with establishing the initial diagnosis, pre-operative assessment, assessment of emergency cases, and follow-up procedures.

Initial investigation of suspected colon cancer or polyp

Colonoscopy is the most sensitive method for investigating suspected colon cancer and removing pre-malignant polyps, and it can be used for most groups of patients, including those who are frail. Rapid access to colonoscopy should be facilitated by increased provision of services and streamlined referral systems (see Access to Appropriate Services, Topic 1). Where colonoscopy services are so limited that diagnosis of colorectal cancer is delayed or methods other than colonoscopy are routinely used to investigate suspected colon cancer, Trusts should review the pattern of endoscopy clinic activity (see Topic 9, Follow-up), to ensure rapid access to colonoscopy for patient groups who are most likely to have colon cancer (in particular, those who meet national criteria for two-week referral).

Those who carry out colonoscopy need a high level of skill which can only be achieved by extensive experience and regular practice. Trusts should therefore
concentrate colonoscopy services so that those who carry out this procedure do at least one list per week (normally six cases) or 250 per annum. The performance of all those who carry out colonoscopy should be audited, and those whose completion rates fall below 90% (excluding patients with obstruction or failed bowel preparation) should have further training.

Flexible sigmoidoscopy has the advantages of being quicker and more readily available than colonoscopy, and patients may not require sedation. However, it only permits visualisation of part of the colon and will miss many colon tumours. It may, nevertheless, be appropriate for particularly frail patients, for initial investigation of people under the age of 50 with fresh rectal bleeding, and for investigation of patients who are suspected to have tumours in the left (descending) colon. Cancer Networks should develop protocols defining further investigation when a diagnosis cannot be established by flexible sigmoidoscopy.

Barium enema is not the preferred diagnostic method for patients with suspected colorectal cancer, and its use is expected to decline as colonoscopy services improve. Trusts should move from rigid to flexible sigmoidoscopy in association with barium enema for patients who refuse colonoscopy or colonoscopy is considered inappropriate, and where rapid access to colonoscopy is not currently feasible.

Assessment of CT colonography in clinical trials should be encouraged; such a trial, funded by the Health Technology Assessment Programme, will begin in late 2003. The evidence on the effectiveness of CT colonography is not at present sufficient for it to be recommended for routine use.

*Emergency patients*

To inspect the whole colon, the operator must get the tip of the colonoscope all the way to the caecum, where the large bowel ends; this is known as completion.
CT scanning should be used to assess patients with suspected intestinal obstruction, unless the patient has a condition such as peritonitis which would make post-operative CT more appropriate.

Investigation of suspected rectal cancer

Patients with symptoms which could be due to rectal cancer should be offered flexible sigmoidoscopy, in order that a tissue diagnosis may be obtained. Patients with invasive rectal tumours for whom surgery is being considered should have MRI scans before treatment begins, to identify the boundaries of the tumour and lymph node involvement, and thus inform management.

Particular MDTs should be identified which have, and can further develop, expertise in the management of early rectal tumours. Patients with T1 tumours, who might benefit from local excision, should be referred to these teams. Transrectal ultrasound (TRUS) should be available to assess such tumours.69

Further assessment, imaging and identification of metastatic disease

Patients should undergo pre-operative abdomino-pelvic CT scanning to assess tumour stage and metastatic spread, unless this information would have no influence on management – for example, if the patient is receiving palliative treatment only. CT scanning may be done after emergency surgery if not possible beforehand.

Ultrasound (US) imaging of the liver may be used to check for metastatic disease, but it should be recognised that negative findings may not be reliable. If the patient is in good general health and external US reveals either no evidence of metastatic disease or only limited metastatic deposits, CT imaging or intra-operative US is necessary to determine what further treatment might be appropriate. CT imaging of the liver is especially important for patients who appear to have Dukes’ B or C tumours who are

69 TRUS is widely used in urology and this technology should therefore be available in most Trusts, at least in principle. However, a specialised attachment is required for assessment of rectal tumours.
fit enough for liver resection; when a patient appears to have limited liver metastases, his or her management should be discussed with the liver resection MDT.

Co-ordination of patient journeys

Trusts should establish pre-booking systems so that dates for further diagnostic investigations and initial treatment can be agreed with patients when they are informed of the diagnosis. Diagnostic tests should be scheduled so as to minimise the number of hospital appointments required for each patient.

Patients should be given information about their disease, tests and treatment options as soon as the diagnosis is confirmed. They should have the support of a clinical nurse specialist at this time and should be given his or her telephone number so they can call if they have any questions or other problems. (See Topic 1, Patient-centred care.)

B. Anticipated Benefits

Rapid and accurate diagnosis is essential in colorectal cancer, both so that the disease can be treated at an early stage, and to reduce the risk of patients presenting as emergencies. Improved access to endoscopy will reduce waiting times for patients and improve the accuracy of diagnosis. There will be fewer false negative results if the percentage of complete colonoscopies is increased, and good colonoscopy technique will minimise the complication rate.

More precise assessment - especially of liver metastases - would result in more appropriate treatment and allow more accurate reporting of case-mix data. Ultrasound is useful in the first instance to identify patients with metastatic disease, but additional pre- or peri-operative imaging methods are important for appropriate selection of patients who might benefit from further treatment such as liver resection.
C. Evidence

Diagnosis of colorectal cancer in NHS hospitals

The 1999/2000 survey of NHS cancer patients\textsuperscript{70} found that just over half of those with colorectal cancer were given the diagnosis during their first hospital appointment but 22\% had to wait for another two weeks or more; 4\% waited for over three months. For almost a third of patients (32\%), the delay between first hospital appointment and first treatment was over three months. Those referred under the two-week urgent referral guidelines may wait up to six weeks for diagnostic colonoscopy. The diagnostic test reported by the largest proportion of patients was some form of scan (41\%). 60\% of patients did not recall having any form of endoscopy. 23\% had barium enemas. This report does not say what proportion of patients had more than one form of diagnostic investigation.

A case study reported by the Cancer Services Collaborative describes how the co-ordination of patients’ journeys from referral to treatment was improved at the Leicester Royal Infirmary.\textsuperscript{71}

Endoscopy services

Hospital episode statistics show that the use of both colonoscopy and flexible sigmoidoscopy has been rising each year since 1995/6. In 2000/1, the last year for which data are available, there were 154,000 colonoscopies in England and 134,000 day-case flexible sigmoidoscopies. A typical Trust carried out between 500 and 1,000 colonoscopies and 400-800 flexible sigmoidoscopies per annum.\textsuperscript{72}


\textsuperscript{71} Cancer Service Collaborative Service Improvement Guide, Case study BwC 4.1. Contact Kim Brett, Radiology Department, 0116 258 5155.

\textsuperscript{72} Figures quoted in The NHS Colorectal Cancer Programme, Department of Health, 2003.
A survey of 164 endoscopy units in the UK (published in 1999) revealed that the median population size served was 250,000, and that the median number of colonoscopies performed was 150/100,000 people (375 per 250,000) per year. 70% of units reported that they could not create an additional weekly endoscopy session, usually because of lack of nursing support (81% of units), shortage of endoscopists (72%) and the lack of theatre time (51%) (See research evidence for Topic 2, Access to Appropriate Services).(B)

**Endoscopists**

Traditionally, endoscopy clinics have been run by consultant gastroenterologists and endoscopy has been carried out by hospital doctors. However, there is accumulating evidence that both flexible sigmoidoscopy and diagnostic colonoscopy can be carried out safely by appropriately trained nurses or GPs. Complication rates for both diagnostic methods can be found in the evidence review for the 1997 edition of this document.73

A survey of prevalence of, and attitudes to, endoscopy carried out by nurses in the UK, found that nurses carried out endoscopy in 43% of the 176 units from which responses were obtained. Respondents – medical directors of endoscopy units – generally appeared unhappy about nurses conducting colonoscopy, particularly therapeutic colonoscopy. (See research evidence for Topic 2, Access to Appropriate Services).(B)

A randomised controlled trial comparing flexible sigmoidoscopy results achieved by doctors and nurses showed equally good outcomes for both groups.(A) Similar outcomes were also demonstrated in a non-randomised controlled trial in which either nurses and doctors carried out diagnostic colonoscopy. Uncontrolled studies of endoscopy also report that nurses are able to achieve excellent results: a completion rate of 94% (documented by video) in one study of colonoscopy, and a 93% success

73 See Department of Health website.
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rate for flexible sigmoidoscopy in another. No complications were reported in any of these studies. (B)

A survey of 27 NHS primary care endoscopy providers, of which 21 provided lower gastro-intestinal endoscopy, found that GPs could perform endoscopy safely. Complication rates for 12,260 investigations were well below those reported in the literature from secondary care settings. Average waiting times were 1.2 weeks for urgent cases and 3.4 weeks for routine referrals. (B)

Case-control studies from the US, comparing colonoscopy carried out by family practitioners with colonoscopy by gastroenterology or general surgery services, found that the only significant difference between these groups was a higher rate of cancer diagnosis in the family practice group. (B) Two uncontrolled, retrospective studies of diagnostic/therapeutic colonoscopy undertaken by a rural family physician showed completion rates of over 90% in sedated patients but only 35% of patients who had not received sedation. There was one major complication in 751 examinations in one of these studies. (B)

Accuracy of alternative diagnostic strategies

A review of studies of the accuracy of double contrast barium enema and colonoscopy found that colonoscopy is more sensitive than barium enema and offers the option of therapeutic intervention (polypectomy). Colonoscopy is therefore a more useful diagnostic method for patients with symptoms that could be due to colorectal polyps or cancer. A large retrospective study from a large UK teaching hospital came to similar conclusions. (B) However, the skill of the operator is crucial to the effectiveness of any diagnostic method used; and reliable diagnosis of colon cancer by colonoscopy requires a high completion rate, which can only be achieved by a skilled colonoscopist.

Most published case series report colonoscopy completion rates of over 90%; in contrast, data from the Trent/Wales audit suggested that completion rates in the NHS were as low as 50%. A considerably higher figure – 75% – was reported in an audit
carried out by BSG in 1994. Nevertheless, this is still well below the level that is generally considered acceptable.

Achieving high colonoscopy completion rates

A large retrospective study from Sweden found that endoscopists who carried out colonoscopy more often were significantly more likely to achieve a complete examination. There was a clear correlation between completion rates and the number of examinations performed in a 90 day period among endoscopists who carried out fewer than 29 procedures (about two per week), but there was no improvement above this level. The total number of colonoscopies carried out by the endoscopist was also important, with continued improvement over the first 200 cases.

An audit in a UK hospital focused on completion rates for individual endoscopists over a 17 month period. Two consultants achieved rates of 96% and 98%, but completion rates for two assistants, who carried out 143 and 65 colonoscopies, were poorer: 77% and 80%, respectively. The authors suggested that this was due to pressure of work in the first case, and inadequate numbers carried out in the second; the assistants’ workload was adjusted and at re-audit, their completion rates had risen to 93%.

Another UK audit, carried out in a combined DGH and specialist endoscopy unit, reported on colonoscopy completion rates by specialist endoscopists, gastroenterology consultants, colorectal surgeons, specialist registrars, and a nurse practitioner. Patients with very inadequate bowel preparation or impassable tumours were excluded. The overall completion rate was 93%, with little difference between disciplines: the range was from 89% (surgeons) to 98% (specialist endoscopists). This was a prospective study which lasted for two months; health care professionals knew their performance was being audited.

Liver imaging

Studies of the diagnostic accuracy of pre-operative liver imaging suggest that overall, CT is slightly better than US. But there have been few direct comparisons between US and CT in this situation, and the studies that were identified have serious methodological flaws. Other studies give figures for sensitivity and specificity but the research methods and patient populations differ; consequently, figures derived from these studies vary widely.

In general, abdominal US offers high levels of specificity but relatively poor sensitivity (42-75% in different studies; accuracy around 90%) in other words, when lesions are identified as metastases, they are likely to be malignant. However, a substantial proportion of patients with negative US scans – possibly more than half of those who appear to be free of metastatic disease – do in fact have tumour in the liver. Two studies report sensitivity figures for contrast-enhanced CT of 93-94%, but a small study (n=44) (the focus of which was the potential role of PET scanning) reported a much lower figure for the sensitivity of CT: just 37.5%. (B)

Intra-operative US (IOUS) seems to be significantly more sensitive than abdominal US, and to offer high overall levels of accuracy in detecting liver metastases. One study reported that both laparoscopic US and IOUS were more accurate than CT. (B)

Imaging for local staging of rectal cancer

CT versus MRI

The evidence reviewed suggests that MRI is better than CT for locally staging primary rectal cancer, but it is not entirely consistent. There is wide variability between results reported in different studies and considerable overlap between the results obtained with each form of imaging.

The findings were most consistent on identification of tumour-positive lymph nodes; both primary studies and a systematic review concluded that MRI was more effective than CT in this respect, although it appears that a substantial proportion of involved
lymph nodes are likely to be missed with either method. The primary studies reviewed showed that MRI, using a body coil or endorectal coil, was superior to CT for correctly staging rectal cancer. For the assessment of lymph nodes, MRI with the body phased coil was superior. 

**Transrectal ultrasound**

Transrectal ultrasound is used to distinguish between lesions confined to superficial layers of the rectum (which may be benign) and those that invade the muscle wall. This information is important for decision-making about the extent of surgery. Primary studies reported varying levels of accuracy for this discrimination, from 76% to 100%. There were some variations according to the type of equipment used, but it is not clear whether any of these is superior to the others: the apparent differences could reflect differences between studies in patient populations and methods used. 

A systematic review compared the accuracy of one particular type of transrectal ultrasound, endoscopic ultrasonography (EUS), with that of CT and MRI. The authors concluded that EUS had the highest sensitivity, specificity and accuracy for assessing tumour penetration into the muscle of the bowel wall. Pooled sensitivity, specificity and accuracy figures for EUS were 78%, 93% and 87%, respectively. 

**D. Measurement**

**Structure**

- Availability of colonoscopy service with fully trained staff and sufficient capacity to provide prompt diagnostic services for patients with suspected colon cancer.

- Availability of rapid-access flexible sigmoidoscopy.

- Access to transrectal ultrasound.
Process

- Audit of delay between initial referral and appropriate endoscopy.

- Audit of the number of colonoscopies carried out per year by each individual who carries out this procedure, and their completion rate.

- Proportion of patients who undergo CT scanning.

- Audit of delay between initial diagnosis and CT scan of patients with operable disease.

- Audit of delay between initial diagnosis and MRI scan of patients with locally advanced rectal cancer.

- Use of appropriate imaging procedures for detection of early metastatic disease.

- A system for auditing the quality of diagnostic procedures which links outcomes with training.

Outcome

- Complications of diagnostic procedures such as perforations.

E. Resource Implications

Implementation of these recommendations on diagnosis will lead to a substantial increase in the use of colonoscopy and possibly also of flexible sigmoidoscopy, and reduced use of barium enema and rigid sigmoidoscopy. The cost impact of this change cannot be estimated precisely because of uncertainty in the figures available for use in the economic analysis.

Colonoscopy is the most expensive of these methods. However, it is also the only method by which cancer can be reliably diagnosed or excluded (or other pathology...
identified as the cause of bowel symptoms) without further investigation. If every patient with suspected colorectal cancer is initially referred for colonoscopy, it is estimated that the total cost of additional colonoscopies would be £24.4m. This cost would be substantially offset by reduction in the use of barium enemas.

If every patient is initially referred for flexible sigmoidoscopy, the estimated cost is higher, at £38m, because some would require additional investigations (barium enema or colonoscopy). A mixed system, with 80% flexible sigmoidoscopies and 20% colonoscopies, would cost £35.3m.

These figures are based on total costs over the lifetime of the equipment used. In reality, a large initial investment would be required for a move towards increased use of endoscopy, for equipment, staff training and facilities. The costs would then decline over a number of years.

Better access to imaging (CT and MRI) is required; an initiative designed to improve access to CT scanning is now underway.
5. Surgery and Histopathology

Surgery with curative intent aims to remove the whole tumour; if it succeeds, the patient may be rendered free from cancer. When curative surgery is not possible, patients may benefit from stenting to relieve obstruction, or from palliative surgery.

A. Recommendations

High quality surgery is crucial to patients’ survival. Surgery should be undertaken by specialist colorectal cancer surgeons who are members of colorectal cancer MDTs and who can demonstrate low tumour involvement at the margins of the excised specimens, low rates of surgical complications, and high survival rates among their patients.

Surgeons should assess the liver during surgery. If primary surgery is potentially curative but metastases are suspected or discovered in a limited area of the liver, imaging (not biopsy) should be used to judge whether these might also be resectable. Further action based on these findings (such as offering chemotherapy or referral to a specialist liver resection team) should be discussed by the MDT.

Every MDT which treats patients with rectal cancer should undergo training in total mesorectal excision (TME); all members of the core team should be involved. Since TME is the technique most likely to achieve clear surgical margins of cancers of the middle and lower third of the rectum, it should be available for all patients with rectal cancer for whom it is appropriate.

Surgeons should aim to preserve the nerves and plexuses on which sexual potency and bladder function depend, as far as this can be achieved without compromising tumour excision.
Each Cancer Network should agree evidence-based guidelines dealing with antibiotic use, prophylaxis for deep vein thrombosis and bowel preparation before surgery. Adherence to these guidelines should be audited.

Surgical performance should be discussed in MDT meetings, using histopathology reports and audit of short- and long-term outcomes of surgery. The margins of excised tissue should be checked by a histopathologist to ascertain whether they contain cancer. Avoidable adverse effects of surgery such as leaking anastomoses and local recurrence should be audited and should be used to identify surgeons who require further training.

Time and facilities must be made available for continuing training for MDT members in techniques such as TME, which lead to better outcomes for patients.

Current NICE guidance recommends that open resection should be used in preference to laparoscopic surgery. This guidance is due to be reviewed in August 2003.75

**Management of emergencies**

Appropriate management of patients admitted as emergencies demands a high level of expertise and facilities. If these are not available, the mortality rate in this group can be very high. Cancer Networks should therefore develop and agree specific guidelines for the management of these patients, including those who present out of normal working hours. These should state that any patient admitted as an emergency with intra-luminal obstruction or other signs or symptoms of colorectal cancer should, like patients coming through standard routes, be managed by a colorectal cancer MDT. The guidelines should specify holding procedures to stabilise patients without surgery until they can be seen by MDT members, except where the patient’s condition is such that delaying surgery would increase the risk of death.


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It may be necessary to extend colorectal cancer teams across organisational boundaries to allow emergency patients to be managed in this way. Procedures should be developed for transferring patients to neighbouring hospitals when the admitting hospital does not have a colorectal cancer MDT to deal with emergencies. (See Topic 2, Access to Appropriate Services.)

Facilities and services should be established to provide stenting for patients with intestinal obstruction, particularly those with serious co-morbidity, so that emergency surgery may be avoided. Cancer Networks should assemble teams with appropriate expertise and sufficient capacity to stent about 15 people per million population per annum. The decision to use a stent should be made by a colorectal cancer MDT and stenting for patients with intestinal obstruction should be carried out within 48 hours of admission. Stents should be inserted only by appropriately trained individuals (usually interventional radiologists, ideally working with endoscopists).

Patients with rectal cancer rarely present as emergencies.

**Histopathology**

After surgery carried out with curative intent, the histopathologist should assess the overall quality of the resection specimen and report on this at the next MDT meeting. Photographs of the specimen should be available at the meeting. Circumferential margin involvement of excised rectal tumours should be specifically discussed, and the team should audit each surgeon’s performance in terms of this measure.

The histopathologist should search for as many lymph nodes as possible in the excised specimen (particularly when the tumour appears to be Dukes’ stage B), and the number found should be audited. In patients with colon cancer who are treated with curative intent, twelve or more nodes should normally be examined; if the median number is consistently below twelve, the surgeon and the pathologist should discuss their techniques. Time and facilities should be available for additional training for histopathologists in the assessment of colorectal cancer specimens.
Pathologists should complete the Royal College of Pathologists’ Minimum Dataset for colorectal cancer and bring this, along with photographs of the excised specimen, to be discussed at the first available colorectal team meeting. The dataset should include information on the size, stage, type, grade and appearance of the tumour, depth of invasion, number of lymph nodes excised and number affected, and tumour involvement at surgical margins, including circumferential plane involvement or clearance in rectal cancer. These data should also be communicated to the local cancer registry.

Stoma

Surgeons should aim, wherever possible, to conserve the anal sphincter. If any patient is likely to be given a stoma, whether temporary or permanent, its nature and implications should be carefully explained to the patient and his/her carers and its position discussed before surgery. Patients who receive temporary colostomies should be given a planned date for closure prior to discharge after initial surgery. This date may be scheduled to follow adjuvant chemotherapy.

B. Anticipated Benefits

Typically, at least 10% of patients with colorectal cancer who undergo emergency surgery for intestinal obstruction will die. Improved systems for managing these patients is likely to reduce peri-operative death-rates. Stents may be used to relieve intestinal obstruction so that emergency surgery can be avoided, and may prevent peri-operative death in patients with high levels of co-morbidity. Intestinal stenting could theoretically reduce the overall death-rate by 4%, and its cost is likely to be balanced by reduced intensive care costs.

Good surgery – in particular, TME for patients with rectal cancer – is associated with reduced local recurrence and improved long term survival. Accurate and detailed histopathology reporting can lead to improvements in the quality of surgery through
feedback to surgeons on the results they achieve, and provides better information on which decisions on adjuvant therapy may be based. Increasing the number of lymph nodes examined in the surgical specimen will improve the accuracy of staging and will tend to increase long-term survival rates, particularly in patients with colon cancer; there is no consensus on the precise number of nodes that need to be examined, but it is clear from the research evidence that it should be in double figures.

Antibiotic prophylaxis reduces post-operative mortality and infections and reduces length of stay. Thrombo-prophylaxis reduces the risk of deep vein thrombosis and associated morbidity and costs. A reduced rate of stoma formation is likely to improve quality of life for individual patients and reduce long-term costs to the NHS. (See evidence review for 1997 edition of this guidance.)

C. Evidence

Surgical skill, technique and quality of surgery

There is evidence of wide variability in outcomes achieved by individual surgeons, with large differences in both peri-operative and long-term survival rates. For example, rates of anastomotic dehiscence (breakdown of the surgical re-connection of the bowel) have been found to vary from 0% to 43% between surgeons.

Lymph nodes

The removal and identification of lymph nodes containing tumour can be crucial to survival for two reasons. First, tumour left behind in lymph nodes after surgery can precipitate local recurrence. Second, decision-making on the need for adjuvant therapy depends on the stage of the cancer. Chemotherapy is not normally appropriate for patients with Dukes’ stage B (node-negative) tumours (Topic 7), but offers proven benefits for those with stage C tumours – that is, those whose cancer
has spread to neighbouring lymph nodes. It is not clear, however, how many lymph
nodes need to be removed and checked before surgeons and histopathologists can be
confident that all that contain tumour have been identified.

Three variables contribute to the yield of lymph nodes: the aggressiveness of surgery;
the diligence of the pathologist in searching the specimen; and the anatomy of the
patient and tumour. And there are costs to be balanced against potential benefits of a
higher node harvest. More precise surgery and pathological techniques demand more
time and effort. In theory, more aggressive surgery to remove more lymph nodes
might have adverse effects, but the evidence reviewed did not show this.

The research evidence shows that when more nodes are examined, tumours are
significantly more likely to be classified as node-positive (Dukes’ stage C).
Conversely, when few nodes are examined, there is a substantial risk of under-
staging. (B)

The survival rate among patients whose tumours are classified as node-negative
(Dukes’ B) on the basis of the examination of a relatively small number of lymph
nodes (the criterion varies between studies, from 6 to 16, with a mode of 14) is
consistently poorer than that of comparable patients whose tumour was staged on the
basis of more nodes. In studies which compared outcomes in these groups, patients in
the former group fared as badly as those classified as Dukes’ C. In studies which
reported recurrence and survival rates, both outcomes were significantly poorer
among patients classified as node-negative when fewer lymph nodes were examined.
In one such study, 43% of patients staged as T3 N0 (Dukes’ B) after examination of
≤9 nodes had local recurrences and 30% survived, compared with 10% local
recurrence and 71% survival rates in similarly staged patients when 10 or more nodes
had been assessed.
A study carried out using cancer registry data from 1988-1991 reports that 14% of patients treated in the UK had 12 or more nodes examined: 10% in the Thames region, 15% in the Mersey region.76

**Local recurrence after surgery for rectal cancer**

Local recurrence is a serious problem after surgery for rectal cancer, with reported rates varying from less than 10% to over 40%. Recurrence usually leads to death after a prolonged period of severe pain and distressing symptoms. Complete excision of the tumour, with surgical margins free from cancer cells, is associated in observational studies with one-tenth of the recurrence rate and one-third of the death-rate found when there is involvement of the margin. (B: See evidence review for 1997 edition of this document.)

Total mesorectal excision (TME) is associated with about half the rate of local recurrence, compared with conventional surgery for cancer in the lower two thirds of the rectum. Long-term survival rates are significantly higher after TME.(B) Outcomes - particularly the incidence of surgical complications - improve with increasing experience of the technique. The differences in outcomes between TME and conventional surgery are so great that a randomised controlled trial directly comparing the effectiveness of these different surgical approaches would be unethical. TME is also less likely to damage sexual function in men.(B)

In some regions of England, colorectal cancer MDTs have now been trained in TME; this training is believed to pay for itself by reducing morbidity after surgery.(C) In other parts of Europe where long-term survival rates are generally better than in the UK (including Norway, Sweden and the Netherlands), all surgeons who carry out elective surgery for rectal cancer have been trained in TME by the English team which developed this technique. The majority of surgeons who carry out operations

for rectal cancer in the NHS have not had such training, although TME is now standard practice among specialist rectal surgeons.

**Laparoscopic surgery**

The evidence on laparoscopic surgery has been reviewed for NICE. This shows that laparoscopic surgery leads to consistently better short-term outcomes than open surgery, but effects on long-term survival rates are not yet known and there is concern that this technique has important drawbacks, such as limited opportunity for tumour staging. RCTs currently in progress, in particular the MRC CLASICC trial, are expected to clarify the situation.

**Emergency surgery**

About a third of colon cancer patients and a tenth of rectal cancer patients are admitted as emergencies. The peri-operative mortality rate of emergency surgery is many times higher than that of elective surgery (Topic 2). This appears to be due mainly to the poor physical status of patients at admission. After taking into account 30 day mortality, emergency admission does not appear to be an independent predictor of longer term survival. (B: See evidence review for 1997 edition of this document.)

**Colorectal stents**

A systematic review of published data on the efficacy and safety of stenting in colorectal obstruction identified 29 case series describing 598 attempted stent insertions. 97% of the patients had cancer. The review reported clinical success in 88% of cases and effective palliation in 90%. Adverse effects included a 1% mortality rate, 10% stent migration rate and 10% stent re-obstruction rate. 56% of stent insertions were palliative, 44% pre-operative. The authors concluded that

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Ibid.
colorectal stents offer good palliation and are safe and effective as a “bridge to surgery”. Use of a stent can avoid the need for a stoma.

Eighteen additional published case-series, each reporting at least 20 procedures, confirm these conclusions. These show that expanding metal stents usually remain effective for more than a year, and in many cases, provide palliation until death. Stenting can also provide temporary relief of acute obstruction in patients for whom resection might be appropriate, so that elective colorectal surgery, with tumour staging and adequate surgical preparation, can be planned. (B)

About thirty hospitals in the UK use colorectal stents regularly. Most of these offer stenting only for palliation of intestinal obstruction; very few currently provide stenting before surgery. It is believed that the reasons for this are lack of experience with the technique and difficulty in obtaining funding.

**Histopathology**

Local recurrence of rectal cancer is associated with tumour involvement in the surgical margins, and accurate staging requires information on lymph node status. Many histopathologists fail to examine and report on all relevant margins and lymph nodes. (B: See evidence review for 1997 edition of this document.)

**Preparation for Surgery**

Antibiotic prophylaxis, usually given at the time of anaesthesia for colorectal surgery, significantly reduces the risk of wound and other infections. (A: See evidence review for 1997 edition of this document.) CEPOD data indicates that routine procedures for appropriate management may be neglected in emergency cases. For example, 28% of these patients received no antibiotic prophylaxis before or during surgery. (B: See evidence review for 1997 edition of this document.)
Stoma

The type of operation surgeons choose to carry out is an important determinant of stoma rates. Data from the Trent/Wales Audit (carried out in the early 1990’s) shows that 47% of patients with rectal cancer were given a stoma after surgery. By contrast, some specialist units report stoma rates as low as 10%. Stomas reduce quality of life and are costly to maintain. There is no evidence that removal of bowel wall tissue more than 2cm below (distal to) a tumour in the lower third of the rectum confers any survival advantage, but it may affect the need for permanent stoma formation. (B: See evidence review for 1997 edition of this document.)

D. Measurement

Structure

- An efficient system of data collection, audit and feedback for individual surgeons and teams.

- Availability of stenting for patients with acute intestinal obstruction.

Process

- Audit of radial margin involvement of rectal tumours excised by each surgeon.

- Proportion of “curative” resections of rectal cancers with involved surgical margins

- Use of suitably detailed proforma for histopathology data; this should be based on the ACPGBI national colorectal cancer data set, to which all teams should contribute.
• The proportion of histopathology reports which give the degree of involvement of surgical margins, including circumferential margins, the number of lymph nodes examined and the number involved.

• Positive circumferential margin rate for each surgeon; this should be audited and should be consistently below 20% for the MDT (except where patients have had a long course of pre-operative radiotherapy).

• Number of lymph nodes examined in surgical specimens from patients treated with curative intent. The median number should not fall below twelve in patients with Dukes’ B or C colon cancer.

• Regular reviews of histopathology at team meetings to ensure that standards are met both for histopathology reports and for surgery.

• Presence and use of evidence-based protocols for bowel preparation, antibiotic prophylaxis and thromboprophylaxis.

Outcome

• Case-mix adjusted perioperative mortality; infection, anastomotic leak, and local recurrence rates.

• Rate of permanent stoma formation

• Proportion of emergency patients treated by members of the specialist colorectal cancer team

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E. Resource Implications

Some colorectal cancer MDTs will require additional training to enable them to provide total mesorectal excision for patients with rectal cancer. Although TME takes longer to carry out and may therefore be more costly initially, the reduction in local recurrence can be expected to reduce longer-term costs of treatment.

Other recommendations in this section are not expected to require significant additional resources, except where recommendations made in the previous edition of this guidance have yet to be fully implemented.
6. Radiotherapy in Primary Disease

A. Recommendations

Each Cancer Network should develop evidence-based policy on radiotherapy for rectal cancer, which should be agreed and implemented by all radiotherapy units and colorectal cancer MDTs in the Network. This may specify either routine pre-operative radiotherapy or selective post-operative radiotherapy, as in the MRC CR07 trial; results from this trial, which are expected to become available in 2006, will show how the outcomes of these regimens differ. Radiotherapy is not likely to be appropriate for patients with primary colon cancer.

The potential benefits and risks of pre-operative radiotherapy (including both short- and long-term effects on bowel and sexual function) should be discussed with all patients with rectal cancer. Those who fulfil the inclusion criteria for the CR07 trial should be encouraged to participate in it. If chemoradiotherapy is used, it should be an established regimen. Pre-operative radiotherapy should normally be given in a short course, using 3- or 4-field techniques to minimise the irradiated volume. Longer courses of pre-operative radiotherapy are appropriate for selected patients with invasive tumours, where shrinking the tumour would facilitate curative resection. Post-operative radiotherapy should be reserved for patients who are judged after surgery to be at high risk of recurrence.

When one radiotherapy centre serves several Trusts, a clinical oncologist may need to provide assessment and advice for patients in one hospital and treat them in another. An experienced oncology nurse should be available to provide help, information and support for all patients, and to ensure that they receive adequate pain relief when required.
The radiotherapy service should conform with guidelines in Quality Assurance in Radiotherapy.79

B. Anticipated Benefits

Pre-operative radiotherapy more than halves the risk of local recurrence and may improve five-year survival rates. However, these benefits are balanced by significant morbidity, so it is essential that those patients who are most likely to benefit should be clearly identified. The results of CRO7 are expected to provide valuable information to aid decision-making on radiotherapy for patients with rectal cancer.

C. Evidence

Meta-analysis of individual patient data in randomised trials comparing radiotherapy plus conventional surgery with surgery alone for rectal cancer, shows that the addition of radiotherapy significantly reduces local recurrence rates. Pre-operative radiotherapy produces a greater proportional reduction in local recurrence than post-operative (57%, compared with 37%). Pre-operative radiotherapy also leads to a significant reduction in mortality rates among patients who receive 30Gy biological equivalent dose (BED) or more. (A)

Modern treatment methods, using megavoltage equipment with a minimum of three fields to deliver radiotherapy to smaller volumes of tissue, reduce the toxicity of treatment. However, even this form of radiotherapy is likely to cause long-term problems with bowel function. Five to nine years after surgery, only 14% of 84 patients who had undergone pre-operative radiotherapy (BED 37.7Gy over 5-7 days, 79 Quality Assurance in Radiotherapy: A quality management system for radiotherapy. Department of Health circular, PL/CMO(94)7, Department of Health, 1994.

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using modern techniques) in the context of a Swedish RCT assessed their bowel movement as excellent, compared with 32% of 87 patients who had had surgery alone. 7% of the irradiated group, but none of the controls, rated their bowel function as bad. Nearly half of those in the irradiated group had to use faecal incontinence pads, compared with 22% in the control group. Other problems, such as urgency of defaecation and loss of skin on the perineum, were also significantly more troublesome in irradiated patients.

Radiotherapy given before TME also reduces local recurrence, from 8.2% to 2.4% (p<0.001), but no reduction in mortality has been shown at a median of two years after surgery. (A) Two RCTs, currently in progress, are expected to throw further light on the issue of whether radiotherapy is worthwhile for patients who undergo TME. In one of these (the Stockholm IV trial), all patients receive TME. The other (the MRC CRO7 trial) compares pre-operative radiotherapy for all patients with selective post-operative radiation for the 15-20% of patients whose excised tissue is found, on histological examination, to have tumour in the resection margins. TME is undertaken at the surgeon’s discretion.

A small RCT (70 patients) found that the addition of chemotherapy (CRT) to long course pre-operative radiotherapy (RT) for non-resectable rectal cancer produced significant reductions in local recurrence, but CRT caused more acute toxicity than RT alone. The numbers surviving after five years were too small for differences between groups to achieve statistical significance.(A) The results of two larger trials are expected shortly.

D. Measurement

Structure

- Availability of radiotherapy and systems for providing pre-operative radiotherapy without significantly delaying surgery.
Process

- Proportion of eligible patients entered into MRC CRO7.

- Proportion of patients with rectal cancer offered pre-operative radiotherapy, in particular those who go on to have curative resection. This should be assessed in the context of local recurrence rates.

Outcome

- Local recurrence rates after curative surgery for rectal cancer

- Radiotherapy-related morbidity – including long-term effects on bowel function, sexual activity, and social life.

- Mortality rates at one and five years.

E. Resource Implications

The recommendations in this section are not expected to have any significant impact on resource use.
7. Adjuvant Chemotherapy

A. Recommendations

Cancer Networks should agree guidelines on the use of adjuvant chemotherapy, which should be revised annually in the light of recent research evidence. Adjuvant therapy should be considered for all patients in reasonable health whose disease is sufficiently advanced that such treatment is likely to be beneficial. Judgements about a patient’s fitness to receive chemotherapy should be made on the basis of performance status and co-morbidity, rather than age.

Systemic chemotherapy should be offered to all patients who, after surgery for Dukes’ stage C or D colon or rectal cancer, are fit enough to tolerate it. The MDT should ensure that adjuvant chemotherapy is scheduled to begin within six weeks of surgery.

The standard treatment has been a course of 5-fluorouracil and folinic acid (FUFA), given intravenously over six months. The results of a number of large trials evaluating the role of current and new chemotherapeutic agents, used singly or in combination, and including some drugs that can be taken by mouth, have been reported since the 2002 NICE appraisal. Further results will be reported in the next two years. The results of these trials are likely to influence the standard of care, particularly in advanced disease. An update of the appraisal guidance on drugs to treat colorectal cancer is expected from NICE in late 2004 or early 2005.

Chemotherapy for patients with metastatic disease (including those for whom liver resection may be appropriate) is discussed in Topic 10, Recurrent and Advanced Disease.

80 See Background for explanation of Dukes’ staging.
The place of chemotherapy in the treatment of patients with Dukes’ stage B cancer must be a matter for discussion between patients and their oncologists. Chemotherapy is not recommended for patients with Dukes’ stage A cancers.

Chemotherapeutic agents require special care in delivery and dealing with adverse effects. There should be written protocols on the management of complications and toxicities. Chemotherapy should be given in a designated area under close supervision by oncologists and chemotherapy nurse specialists, with expert pharmacy and 24 hour laboratory support.

Patients receiving chemotherapy should have access to emergency care, information and advice from oncology trained staff on a 24 hour basis. They and their GPs should be given written information on appropriate action for dealing with side-effects of chemotherapy.

**B. Anticipated Benefits**

The absolute increase in 5-year survival rates achieved by FUFA chemotherapy in patients with Dukes’ C colon cancer is between 4 and 13%. The survival benefit for patients with rectal cancer is believed to be similar, although the evidence is somewhat weaker.

**C. Evidence**

Around 25-30% of patients present with Dukes’ stage C cancers. Meta-analysis of several randomised controlled trials shows that protracted systemic chemotherapy can improve survival in this group of patients, although the precise size of the benefit remains uncertain. (A)
Although some uncertainty remains about agents other than FUFA, it is now clear that treatment for six months is as effective as longer durations of up to a year.\(^{(A)}\)

There are insufficient randomised data to provide clear evidence on the effectiveness of chemotherapy for patients with Dukes’ stage B colorectal cancer. The proportional reduction in recurrence may be similar in stages B and C, but absolute benefits are likely to be less when the mortality rate is lower. \((A: \text{See evidence review for 1997 edition of this document.})\) However, patients whose Dukes’ stage B tumours have adverse features such as vascular invasion, obstruction or poor histological differentiation, have a higher disease-related mortality rate and are therefore more likely to benefit from chemotherapy.

Chemotherapy has not been tested in patients with Dukes’ stage A disease.

**D. Measurement**

**Structure**

- Facilities for provision of chemotherapy under supervised conditions.

**Process**

- Proportion of patients with locally advanced tumours who receive chemotherapy.
- Proportion of patients enrolled in trials of adjuvant chemotherapy.

**E. Resource Implications**

The recommendations in this section are not expected to increase costs above current levels.
8. Anal Cancer

A. Recommendations

Anal cancer is a rare disease and specific expertise is important to optimise outcomes for patients. All patients with anal cancer, including those who have undergone local excision, should therefore be referred to multi-disciplinary anal cancer teams which can provide specialist management. These are described in Topic 3, Multi-disciplinary Teams.

Patients for whom curative treatment is likely to be appropriate should have a CT scan of the abdomen and pelvis or pelvic MRI.

Primary treatment

Concurrent chemo-radiotherapy, using mitomycin C, 5-fluorouracil and radiation, is appropriate for most patients. Other forms of treatment, such as surgical excision, may be considered by anal cancer MDTs, but surgery is usually reserved for salvage.

There are still some areas of uncertainty about optimum treatment, and eligible patients should be encouraged to participate in trials such as the NCRN ACT 2 trial.

Management of relapse

All patients with suspected or confirmed relapse should be discussed by the anal cancer MDT. Those with confirmed locoregional recurrence should undergo cross sectional imaging and treatment options, including salvage surgery, should be considered by the MDT. Palliative radiotherapy, chemotherapy and palliative care should be discussed with patients who have metastatic disease or who are not sufficiently fit to undergo potentially curative treatment.

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B. Anticipated Benefits

Increasing specialisation in the management of anal cancer will enhance the probability that patients receive appropriate treatment. This may include the use of less aggressive approaches for patients with early disease, is likely to improve outcomes for those with more advanced disease, and will facilitate improvements in the management of both acute and late adverse effects. Management by a suitably constituted MDT will ensure that patients receive the support of specialist nurses and psychosocial teams. The concentration of salvage surgery in the hands of specialists will provide a sufficient caseload for surgeons to develop techniques which minimise morbidity.

C. Evidence

Three randomised controlled trials have been performed to evaluate concurrent chemoradiotherapy (CRT) using mitomycin C, 5-flurouracil (5FU) and radiotherapy to treat anal cancer. Two trials, by UKCCCR (n=585) and EORTC (n=110), compared radiotherapy alone with CRT. Both demonstrated a highly statistically significant reduction in locoregional failure, with improvements in colostomy-free survival (EORTC) and reduction in deaths from anal cancer (UKCCCR) with CRT, although neither showed any significant effect on overall survival. The RTOG trial tested the benefit of adding mitomycin C to 5FU and radiotherapy, and also demonstrated statistically significant improvements in colostomy-free and disease-free survival with this regimen.

The current NCRN phase III trial (ACT2) is comparing two CRT schedules (mitomycin C, 5FU, RT versus cisplatin, 5FU, RT) and post-CRT adjuvant
chemotherapy (cisplatin/5FU x2 versus control). The radiotherapy fields used in this trial are designed to improve outcomes and reduce acute toxicity.

D. Measurement

Process

• Evidence that patients are fully informed and involved in the decision making process about treatment.

• Proportion of anal cancer patients treated by primary CRT.

• Proportion of eligible anal cancer patients entered into ACT 2 trial.

Outcome

• Five year local failure and survival rates of patients who undergo potentially curative treatment with information on initial stage, co-morbidity, performance status and other features of case-mix.

• Audit of short term and long term adverse effects of treatment

E. Resource implications

No resource implications specific to these recommendations have been identified. There may be some support costs associated with the formalisation of supra-network anal cancer MDTs. These have not been calculated as the number of patients involved is small.
9. Follow-up

A. Recommendations

All patients who develop recurrent or metastatic disease should be discussed by the colorectal cancer MDT (See Topic 10). This section deals with patients who have had primary treatment and are believed to be tumour-free.

Follow-up for patients treated for anal cancer should be the responsibility of anal cancer MDTs. It is anticipated that the majority of these patients will be followed up by clinical oncologists.

Short-term follow-up

Follow-up in the weeks after surgery for colorectal cancer should focus on post-operative problems, future planning (including the possible use of adjuvant therapy), and stoma management. Nursing and dietetic support should be provided for all patients. Clinical nurse specialists should specifically ask patients how they are coping with everyday life and provide appropriate advice and support, as well as arranging for patients to receive whatever other help they may need.

Patients who did not undergo complete colonoscopy before surgery should be offered colonoscopy within six months of discharge. Similarly, patients who did not have a CT scan of the liver before surgery should have such a scan within six months.

Longer term follow-up

MDTs in each network should agree follow-up guidelines for patients who have undergone curative surgery for colorectal cancer; these should be adopted throughout the network and revised yearly in the light of new research evidence. In view of the continuing uncertainty about the effectiveness of different aspects and forms of
follow-up, networks should actively support the NCRN trial of follow-up strategies (FACS). MDT members at participating Trusts should discuss the possibility of entry into this trial with all patients who meet the inclusion criteria.81

Colonoscopy may be offered at five-yearly intervals to check for new polyps or tumours; it should not normally be carried out more frequently when the patient has a clean (polyp-free) colon,82 but patients with five or more adenomas should be offered more frequent checks. Colonoscopy may not be beneficial for patients with clean colons and life-expectancy of less than fifteen years, since they are very unlikely to develop a new colorectal tumour during this period.

Clinical nurse specialists should check that patients and their carers have their contact details, and that they are aware that they can talk to her or him after discharge from hospital if they are concerned about the disease or its consequences.

Patients and their GPs should be given full information on symptoms which might signify cancer recurrence. They should have rapid access to the colorectal team if they become aware of such symptoms so that treatment can be initiated as quickly as possible. They should be reassured that the risk of recurrence declines rapidly after the first two years after treatment, until by year five, recurrence is very unlikely.

B. Anticipated Benefits

Short-term follow-up is important to identify problems that the patient experiences after surgery so that remedial action may be taken. Colonoscopic examination may detect adenomas or carcinomas which were missed at the time of initial diagnosis and surgery, whilst liver CT can detect treatable metastatic disease. Longer term follow-

81 These are given in the trial protocol. There is no age limit but participants must have completed primary treatment with no evidence of cancer, have no concurrent serious illness, and no inherited syndrome causing colon cancer.

82 In this context, a “clean colon” means no evidence of significant polyps or tumour in the bowel.
up can provide useful information for audit of outcomes and is required in many clinical trials, but it is not clear what aspects of follow-up offer significant benefits for individual patients.

C. Evidence

Short-term follow-up

Post-treatment colonoscopy

In some cases, complete visualisation of the colon is impossible before surgery but it may become possible after the anastomosis has healed. This may be regarded as completion of the initial diagnostic work-up. It is appropriate because individuals who have polyps or tumours are more likely to have polyps or tumours elsewhere in the colon than those who do not. A colonoscopic examination three years after removal of adenomas is as effective for detection of new potentially pathogenic adenomas as colonoscopy one year later. (A: See evidence review for 1997 edition of this document.) Most recurrences develop outside the bowel, in the liver, lung or abdominal cavity, and cannot, therefore, be identified by colonoscopy.

Hospital vs. GP follow-up

One small randomised controlled trial, which included patients who underwent surgery for colorectal cancer, compared immediate discharge to the GP with hospital follow-up over 6 months. GP follow-up was found to be equally satisfactory. Most patients who developed symptoms consulted their GP initially, regardless of the group to which they were allocated. (A: See evidence review for 1997 edition of this document.)

Follow-up in hospital will be compared with primary care-based follow-up in the recently-launched FACS trial. This trial will also assess the effectiveness of serial
CEA measurements and regular imaging (abdominal ultrasound/chest x-ray alternating with CT) over five years. Results are not expected until 2008.

**Longer-term follow-up**

Evidence published since the first edition of this guidance shows that follow-up can increase the probability of long-term survival after surgery for colorectal cancer, at least among patients with Dukes’ stage B/C disease. There have been two recent meta-analyses, both of which used data from the same five RCTs (n=1342), which show that more intensive follow-up is associated with significant improvements in five-year survival rates. Both reported a risk ratio for all-cause mortality of 0.81 (95% CI: 0.70 to 0.94). These results should, however, be interpreted with caution because the trials on which they are based were small, the type of follow-up programmes evaluated varied widely, and there was significant heterogeneity between them. It was not clear what elements of the more intensive follow-up programme were important.

Two additional RCTs investigating follow-up were not included in these meta-analyses. In one of these (discussed in the previous edition of this guidance), CEA levels were monitored and second-look surgery was considered when CEA rose in the intervention group. This trial closed when it was discovered that mortality levels in this group were significantly higher than in control patients.

The second trial varied follow-up strategies according to the risk of recurrence in individual patients. The five-year survival rate among patients who had risk-adapted follow-up was significantly greater than for those in the minimal follow-up group. The authors concluded that follow-up is efficient and cost-effective if patients at higher risk are followed up more intensively than those at lower risk. Patients at greatest risk are those with more advanced tumours at the time of resection – particularly Dukes’ stage C.

The liver is the most common site of recurrence after complete excision of the primary tumour and liver resection can lead to long-term survival in some patients.
There has, therefore, been particular interest in the effectiveness of liver imaging in follow-up. Two RCTs (included in the meta-analyses) found that more frequent liver CT scans resulted in the detection of more asymptomatic metastases, but did not increase the number of curative liver resections. Two further studies of liver CT during follow-up reported accuracy rates of 87%.(B)

Eight proposed or on-going RCTs, designed to answer outstanding questions about the optimum follow-up after curative resection of colorectal cancer, have been identified. In the UK, the NCRN trial of follow-up strategies (FACS) aims to randomise 4890 patients to investigate the value of monitoring CEA (a cancer marker which can be detected in blood) in primary care and intensive hospital follow-up with CT and ultrasound scanning of the liver or abdomen. The detection of metastatic disease suitable for surgical treatment is a key feature of the study.

Follow-up in the NHS

Follow-up practice by 140 consultant colorectal cancer surgeons in England and Wales in 1995 was very variable, ranging from a single routine appointment to regular outpatient appointments for more than ten years. Most surgeons continued routine follow-up for 2-5 years after initial surgery. Surgeons who specialised in gastro-intestinal disorders used colonoscopy significantly more frequently, whilst non-specialists were more likely to use barium enema. Routine imaging to detect asymptomatic liver metastases was relatively unusual; 23% used liver ultrasound and just 4% used liver CT.83(B)

Psychological and other outcomes

Follow-up may have positive or negative psychological outcomes. Positive outcomes include reassurance and support. Negative outcomes include false reassurance,

increased anxiety, fear associated with early detection of an incurable recurrence, morbidity and mortality associated with operations done in response to abnormal test results, and distress caused by false-positive results.

Recurrence of colorectal cancer is usually symptomatic. Around 75% of recurrences produce symptoms between follow-up appointments, even if these are scheduled at three-monthly intervals. There is evidence that reassurance at follow-up consultations can lead some patients to fail to report symptoms promptly when they do occur between appointments. (See evidence review for 1997 edition of this document.)

D. Measurement

Structure

- Access to specialist treatment for recurrent colorectal cancer.

- Evidence that patients and their GPs have an agreed system for short-term follow-up and continuing access to hospital specialists when required.

E. Resource Implications

The recommendations in this section are not expected to have any significant impact on resource use. Studies of costs of follow-up are summarised in the evidence review carried out for this guidance; these show considerable variability and it is not possible to draw any meaningful conclusions from them.
10. Recurrent and Advanced Disease

A. Recommendations

Cancer Networks should agree guidelines for the management of patients with recurrent and advanced disease. These guidelines should specify referral pathways to specialised MDTs for patients who are believed to have metastases confined to part of the liver or lung, for whom curative interventions may be possible.

All patients with recurrent or metastatic disease should be discussed by the colorectal cancer MDT when the recurrence is first discovered. Members of the team should discuss options for treating the disease and palliating symptoms with the patient. Treatment plans should be recorded for each patient and all treatment given should be audited against locally-agreed guidelines.

Any proposed treatments should be clearly explained to patients, who should be given realistic information both about potential effectiveness and adverse effects. Patients should be invited to become actively involved in decision-making about treatment options, but they should be also be given the opportunity to say if this is not what they want. Patients’ carers and families should be kept informed, and information given to family members should not be withheld from the patient (See Topic 1, Patient-centred care).

Specialist palliative care teams should be involved in caring for patients with advanced disease (see Topic 11). Palliative care specialists should be involved in the management of patients throughout their illness, but their contribution is especially important for those who develop symptoms which are difficult to control, or who have psychosocial problems.
Management of patients with localised liver or lung metastases

Patients with metastases confined to limited areas of the liver or lung, and who are sufficiently fit to undergo further treatment after resection of the primary tumour, should be referred to a specialist MDT for an opinion on their management. Any patient for whom resection of liver metastases might be appropriate should be discussed by a specialist liver resection MDT (Topic 3, Multi-disciplinary Teams).

Liver resection teams should work with colorectal cancer teams within each Cancer Network to develop policies on chemotherapy for patients who are to receive liver resection. There should be close liaison between oncologists in colorectal cancer MDTs and the specialist team to which they refer patients with liver metastases. The oncologist from the referring MDT should be invited to join the specialist MDT for meetings at which these patients are to be discussed. Participation in clinical trials evaluating the role of adjuvant chemotherapy in addition to liver resection should be encouraged.

Pre-operative chemotherapy may be appropriate to shrink liver metastases; NICE recommends that the combination of oxaliplatin and FUFA should be considered for patients with metastases confined to the liver, whose disease might become resectable after chemotherapy.84

Interventions to reduce problems associated with advanced colorectal cancer

A variety of interventions, including debulking surgery, stenting, chemotherapy and radiotherapy, may be used to relieve problems caused by locally advanced colorectal cancer. Colorectal cancer MDTs should consider which of these might be appropriate for individual patients.

Palliative surgery and stent insertion

Palliative surgery to reduce tumour bulk and relieve intestinal obstruction can have an important role in the management of patients with advanced colorectal cancer. Stenting should also be available to relieve bowel obstruction, particularly in frail patients and those with significant co-morbidity.

Chemotherapy

Patients with newly-diagnosed recurrent or metastatic disease should have the opportunity to discuss chemotherapy with an oncologist. The oncologist should assess the patient’s suitability for palliative chemotherapy, which should usually be offered to patients with reasonable performance status (normally, those who are capable of getting up and looking after themselves). Initial chemotherapy treatment should be based on either infused FUFA or an oral fluoropyrimidine. Trusts should have the infrastructure available to offer infusional chemotherapy delivered through central venous access catheters.

Palliative chemotherapy is normally given for a period of months, followed by radiological assessment of response. Recent research (MRC CRO6b) suggests that intermittent use of 5FU-based chemotherapy may be as effective as continuous treatment until disease progression. Oncologists should discuss second line chemotherapy with patients whose cancer progresses on first line treatment.

Participation in clinical trials evaluating palliative chemotherapy – for example, the MRC CRO8 (FOCUS) trial of first-line irinotecan and oxaliplatin combination therapies – is strongly encouraged. Clinicians should discuss enrolment in such studies with suitable patients. Further studies are necessary to assess the effectiveness of chemotherapy in older patients, who form the majority of patients with colorectal cancer but who tend to be under-represented in trials.

It is recognised that this is a rapidly developing field, with considerable recent research activity including the evaluation of combination first-line therapy, optimal second-line therapy, sequencing of regimens and evaluation of targeted therapies. This evidence will be considered when current NICE appraisals are reviewed.

**Radiotherapy**

Short courses of radiotherapy (one to five fractions) should be available without delay for patients with metastatic disease in the bones or lungs. Radiotherapy should also be offered to those patients with locally recurrent or advanced rectal cancer and pelvic pain, who have not previously undergone radiotherapy.

**B. Anticipated Benefits**

Surgery for metastases confined to the liver or lung can be curative when carried out by specialists with experience of this type of work. Although such resection is only appropriate for a minority of patients, it can increase five year survival rates from close to zero to over 30%. Pre-operative chemotherapy can produce a similar increase in survival rates in selected patients whose liver metastases are initially too extensive for surgery, by shrinking the tumour so that curative resection becomes possible.

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In advanced or metastatic disease, early chemotherapy can increase survival time, reduce symptoms and improve quality of life; nevertheless, some patients who could benefit do not receive it. Chemotherapy can be particularly effective if it is given before symptoms develop – as they inevitably will if the disease has progressed beyond the point at which curative resection is possible.

Palliative surgery or stenting can relieve symptoms of locally advanced disease in some patients; for those with locally advanced rectal cancer for whom surgery may not be appropriate, radiotherapy can provide valuable palliation and may prolong survival in some patients. Palliative radiotherapy is also effective for pain relief in patients with bone metastases.

C. Evidence

Palliative stents

The evidence on stenting is summarised in Topic 5, Surgery and histopathology. This shows that stents can provide effective and cost-effective palliation of intestinal obstruction in advanced colorectal cancer, obviating the need for a stoma or resection, often until death. They cause relatively few adverse effects.(B)

Surgery for liver and lung metastases

Curative surgery is sometimes possible when metastases are small and localised. There are no good comparative studies but case series reports suggest 5-year survival rates of 30-35% in selected patients. (B: See evidence review for 1997 edition of this document.)

However, few patients can be treated successfully in this way.
Chemotherapy

Meta-analysis of individual patient data from 13 randomised controlled trials (1365 patients) shows that palliative chemotherapy increases median survival time by 3.7 months and reduces the risk of death by 35% (24-44%, 95% CI). This represents an absolute improvement in survival rate of 16% at one year. (A) This analysis did not, however, assess effects of palliative chemotherapy on quality of life.

There have been two recent NICE appraisals of newer chemotherapeutic agents for advanced and metastatic disease. The evidence on which these appraisals were based is summarised on the NICE website.87

Chemotherapy given early in the course of metastatic disease produces better outcomes than chemotherapy given after symptoms have become severe, increasing survival by 3-6 months without increasing adverse effects on quality of life. Response rates are highest with FUFA or 5-FU modulated with another chemotherapeutic agent such as methotrexate. (A)

Radiotherapy

External radiotherapy used alone eases pain in a high proportion of patients with locally advanced rectal cancer. In some patients, tumours have gone into complete remission or regressed sufficiently to permit curative surgery after prolonged fractionated radiotherapy of 45 to 50 Gy.

4-7% of patients develop bone metastases, for which palliative radiotherapy has been shown to be effective. (A: See evidence review for 1997 edition of this document.)

D. Measurement

Structure

- Systems allowing rapid access to the colorectal treatment team for patients who develop symptoms of recurrent disease.

Process

- Audit of treatment planned for each patient, treatment actually given, and delay between the decision to offer treatment and initiation of treatment.

- Audit of outcomes, including symptoms and adverse effects of treatment.

- Protocols to guide symptom assessment and treatment and recording of data on their use.

- Audit of use of palliative treatment.

Outcome

- Results of symptom control audits.

- Surveys of satisfaction with care.

E. Resource Implications

- The use of chemotherapy for advanced and metastatic disease is likely to continue to increase. However, oral chemotherapy may be less expensive than intravenous therapy.

- Surgery for localised metastatic disease is likely to be undertaken more frequently. Such surgery is normally carried out in specialist tertiary centres and additional
resources are likely to be required to allow these centres to expand the volume of surgery carried out. The cost of this expansion has not been calculated.

- Palliative stenting is highly cost-effective and could conserve resources when used instead of palliative surgery.
11. Palliative Care

The NICE guidance on supportive and palliative care for people with cancer\textsuperscript{88} will be published in 2003. It is intended to complement site-specific guidance, giving detailed recommendations on many issues relevant to this section as they apply to cancer care generally, with supporting evidence. The areas it covers are listed on p.24 of this document (Patient-centred care).

A. Recommendations

Most patients with advanced colorectal cancer stay in their own homes and general practitioners and district nurses play crucial roles in their care. Primary care teams should have access to advice from palliative care specialists, who should be involved in the management of all patients with advanced disease. Specialist nurses should remain in contact with patients throughout the course of their disease.

Patients with advanced colorectal cancer may benefit both from treatment of the cancer (Topic 10) and from palliative care. These are overlapping approaches to management.

Pain and symptom control

Control of pain and other symptoms is crucial for patients suffering from advanced colorectal cancer. Palliative care specialists should be members of, and integrated with, colorectal cancer MDTs; their role includes the provision of education and advice for other health professionals – in the community as well as in hospitals – and direct patient management. Specialist pain control is particularly important for

\textsuperscript{88} National Institute for Clinical Excellence. Supportive and palliative care for cancers.
patients with locally recurrent rectal cancer, in whom pain can be very severe and difficult to manage.

The Palliative Care Team

The role of the multidisciplinary supportive and palliative care team is described in the NICE guidance to which reference is made above. The palliative care team should, at a minimum, include a consultant in palliative medicine, a specialist palliative care nurse and a social worker. The team should also have access to other skills including counselling for dying patients and their carers, spiritual guidance, specialist dietary support and advice, and practical support.

Patients and their carers should have access to palliative care on a 24-hour basis, and should have continuity of contact with a named member of the palliative care team. There should be local arrangements to ensure continuing care. Patients should be helped to remain in the place they prefer, whether this is their home, hospital, or hospice, and should, whenever possible, be able to choose where they die.

B. Anticipated Benefits

Provision of effective palliative treatments and adequate pain control, combined with high quality care services, can improve quality of life for people with advanced colorectal cancer. Effective palliative care by well co-ordinated home care teams allows patients to stay at home longer, if this is their preference. This is preferred by most patients and is the least expensive option for the NHS.

C. Evidence

A postal survey of GPs of 213 patients diagnosed with lung or colorectal cancer in a single (former) UK health trust found that 20% of GPs were unwilling to define
patients as needing palliative care, although an unambiguous diagnosis of incurable malignancy had been made by specialist hospital doctors in outpatient consultation letters or discharge summaries. Similar numbers of GPs also expressed dissatisfaction with the promptness (26%), clarity (16%), and adequacy (25%) of information provided by the hospital. The authors identify several mitigating factors, such as GPs’ unfamiliarity with the implications of standard treatments, and the association of GPs’ definition of patients as palliative with poorer prognosis. Nevertheless, they concluded that the findings have implications for patient care in the community, patients’ informed choices, and palliative care research.(B)

D. Measurement

Structure

- Evidence that adequately resourced and staffed palliative care services are available in hospitals, hospices and the community.

- Evidence that specialist pain relief services are available when required.

- Providers should demonstrate clear mechanisms for referral to, and communication between, primary care, community and hospital services involved in the delivery of general and specialist palliative care.

Process

- Written protocols to guide symptom assessment and treatment.

- Proportion of patients referred to specialist palliative care services.

Outcome

- Results of symptom control audits

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• Surveys of patients’ and carers’ satisfaction with care.

E. Resource Implications

Increased resources are required in some areas to create effective multidisciplinary palliative care teams and to monitor outcomes.
Glossary

Abdomino-perineal excision of the rectum (APER, APR)
A surgical procedure for removal of the rectum which involves incisions in both the abdomen and perineum (around the anus) and results in permanent colostomy.

Adenomatous polyp
A tumour which protrudes from the inner surface of the bowel. These tumours are generally benign when small, but may grow and become malignant.

Adjuvant chemotherapy
The use of chemotherapy after initial treatment by surgery and/or radiotherapy. The aim of adjuvant therapy is to destroy any cancer that has spread.

Adjuvant radiotherapy
The use of radiotherapy in association with treatment by surgery. This is used for rectal, rather than colon, cancer, and may be given before or after surgery to reduce the risk of recurrence.

Anal sphincter
The muscle around the anus, essential for faecal continence.

Anastomosis
A junction created by a surgeon between two pieces of bowel which have been cut to remove the intervening section.

Barium enema
Technique for examination of the bowel. Barium sulphate, introduced into the bowel through the anus, is used to coat the inner surface of the colon and rectum so that it can be seen using X-rays.

Biopsy
Removal of a sample of tissue or cells from the body to assist in diagnosis of a disease.

Carcinoembryonic antigen (CEA)
A protein found in the blood which may increase in quantity when a person has colorectal cancer.
Chemotherapy
The use of medications (drugs) that are toxic to cancer cells. These drugs kill the cells, or prevent or slow their growth. The drug most often used in colorectal cancer is 5-fluorouracil, usually with folinic acid.

Circumferential plane involvement
Cancer in tissue surrounding the bowel.

Clinical Oncologist
A doctor who specialises in the use of radiotherapy but who may also use chemotherapy.

Colonoscopist
A person who examines patients using colonoscopy.

Colonoscopy
Examination of the interior of the bowel using a long, flexible instrument - a colonoscope - inserted through the anus (see endoscopy). A colonoscope is capable of reaching to the upper end of the large bowel (colon) and can be used for the removal of polyps.

Continuous portal vein infusion
Delivery of a drug through the portal vein to the liver over an extended period of time.

Crohn’s disease
A chronic bowel condition which is associated with increased risk of colorectal cancer.

CT
Computed tomography. An X-ray imaging technique.

Curative resection
Operation in which the surgeon believes that all cancer-containing tissue has been removed.

Cytology
Examination of cells taken from tissue.

Double-contrast barium enema
Technique (see barium enema) in which the bowel is filled with air or gas between the introduction of barium and radiographic imaging. This allows accurate visualisation of the inner surface of the bowel.
Dukes’ Stage
Refers to the allocation of categories to groupings of tumours defined by internationally agreed criteria. Stages defined by Dukes range from Stage A, which is cancer limited to the bowel wall, to Stage C, where the cancer has spread to nearby lymph nodes. Stage D has been added to this system to include cancers with metastatic spread.

Endoscopy
Examination of the interior of the bowel using a tubular device with a light at the end (colonoscope or sigmoidoscope), inserted through the anus.

Faecal occult blood test
A method of detecting blood in stool.

Familial adenomatous polyposis (FAP)
An inherited condition which leads to the development of huge numbers of colorectal polyps in early adulthood. Individuals who carry the FAP gene are likely to develop colorectal cancer by the age of forty unless preventive action is taken.

Field
In radiotherapy, the area selected for treatment, on which the radiotherapy beam is focused.

Fraction
Radiotherapy is usually given over an extended period. The dose delivered each day is known as a fraction.

Grade (of tumour)
See histological grade.

Hepatic artery
The vessel that delivers oxygen-rich blood to the liver.

HDU
High dependency unit.

Hereditary non-polyposis colorectal cancer (HNPCC)
An inherited condition which predisposes individuals to developing colorectal cancer at an unusually young age.

**Histological grade**
The degree of similarity of the cancer cells to normal cells. Grade is assessed by a pathologist.

**Histology**
Examination of the microscopic structure of tissue by a pathologist.

**Immunotherapy**
The use of interventions intended to stimulate the immune system.

**Inflammatory bowel disease**
Any condition in which the bowel is chronically inflamed, such as Crohn’s Disease or ulcerative colitis.

**Local recurrence**
Return of the cancer in the remaining bowel or nearby pelvic structures.

**Lymph node**
A small collection of tissue along the lymphatic system which acts as a filter. White cells and cancer cells, in particular, collect in lymph nodes. They are found in many parts of the body, including the pelvis and groin. Lymph nodes are also known as glands.

**Margins of excision/resection; surgical margins**
The edges of the tissue removed during surgery.

**Medical oncologist**
A doctor who specialises in the use of chemotherapy.

**Meta-analysis**
A statistical technique used to pool the results from research on a particular issue.

**Metastasis**
The spread of a cancer from the primary site to somewhere else via the bloodstream or the lymphatic system.
Metastatic cancer
Cancer which has spread to a site distant from the original site.

MRI
Magnetic resonance imaging. An imaging technique.

Necrosis
The death of an individual cell or groups of cells in living tissue.

Nodal status
The presence or absence of cancer in lymph nodes draining the area where the primary tumour is found.

Oncologist
A doctor who specialises in treating cancer.

Oncology
The study of the biology and physical and chemical features of cancers. Also the study of the cause and treatment of cancers.

Palliation
The alleviation of symptoms due to the underlying cancer, without prospect of cure.

Perioperative
Within thirty days of surgery.

Plexus
A network of nerves and/or blood vessels.

Polychemotherapy
The use of more than one drug to kill cancer cells.

Polyp
See adenomatous polyp.

Portal vein
The vein which takes blood from the wall of the intestine to the liver.
Prophylaxis
Intervention to prevent an unwanted outcome.

Protocol
A well defined programme of treatment.

Quality of life
The individual's overall appraisal of his/her situation and subjective sense of well-being.

Radiotherapy
The use of radiation, usually X-rays or gamma rays, to kill tumour cells.

Recurrence/disease free survival
The time from the primary treatment of cancer to the first evidence of cancer recurrence.

Sigmoidoscopy
Examination of the interior of the rectum and lower part of the colon (sigmoid) using a tubular instrument - a sigmoidoscope - inserted through the anus (see endoscopy). Sigmoidoscopes may be flexible or rigid; flexible sigmoidoscopes are capable of reaching deeper into the bowel.

Staging
Refers to the allocation of categories (Dukes’ Stage A, B, C, D) to groupings of tumours defined by internationally agreed criteria. Staging helps determine treatment and indicates prognosis.

Stoma
A surgically created opening through which the bowel is taken to the outer surface of the abdomen. A stoma is invariably necessary when the anal canal is removed (see abdomino-perineal excision of the rectum) and may sometimes be necessary after other surgical interventions for colorectal cancer.

Surgical biopsy
Surgery, usually performed during flexible sigmoidoscopy or colonoscopy, to remove a sample of tissue for examination by a pathologist.

Systemic
Involving the whole body.
Total mesorectal excision (TME)
A technique for surgical removal of rectal cancer which involves meticulous dissection and excision of tissue surrounding the rectum.

Ulcerative colitis
A chronic bowel condition which is associated with increased risk of colorectal cancer.

Ultrasound
The use of sound waves to form a picture of internal tissues.

Vascular infiltration
Invasion of veins or lymphatic vessels by carcinoma cells, indicating a propensity for distant spread.