

# Scottish Needs Assessment Programme



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## Colorectal Cancer

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OFFICE FOR PUBLIC HEALTH IN SCOTLAND  
1 LILYBANK GARDENS  
GLASGOW G12 8RZ  
Tel - 0141 330 5607  
Fax - 0141 330 3687

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## **Colorectal Cancer**

**Dr Boyd Moir**

**formerly Scottish Office Department of Health  
Honorary Clinical Senior Lecturer  
Department of Public Health  
University of Glasgow**

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**Office for Public Health in Scotland  
1 Lilybank Gardens  
Glasgow G12 8RZ  
Tel: 0141 330 5607  
Fax: 0141 330 3687**

## **INTRODUCTORY NOTE**

With the publication in the last couple of years of several reports relating to colorectal cancer, SNAP agreed that a full needs assessment on the topic would not be appropriate. Instead the author was asked to provide a concise summary of current evidence for those involved in planning colorectal cancer services.

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Jack Arrundale, Scottish Cancer Intelligence Unit, Information & Statistics Division

David Brewster, Director of Cancer Registration, Information & Statistics Division

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Veronica Harris, Scottish Cancer Intelligence Unit, Information & Statistics Division

Duncan Jodrell, Senior Lecturer in Clinical Oncology, University of Edinburgh

Gillian Knowles, Marie Curie Cancer Care Centre, Fairmile, Edinburgh

Margaret Kenicer, Consultant in Public Health, Tayside Health Board

Julian Little, Professor of Epidemiology, University of Aberdeen

Colin McArdle, Professor of Surgery, University of Edinburgh

Lesley Macdonald, Director of Public Health, Fife Health Board

Malcolm McWhirter, Director of Public Health, Forth Valley Health Board

Dorothy Moir, Director of Public Health, Lanarkshire Health Board

Liz Porterfield, Health Gain Division, NHS Management Executive

Elizabeth Russell, Professor of Public Health, University of Aberdeen

Bob Steele, Professor of Surgery, University of Dundee

Paul Stroner, Scottish Cancer Therapy Network, Information & Statistics Division

Catherine Thomson, Scottish Cancer Intelligence Unit, Information & Statistics Division

George Venters, Consultant in Public Health, Lanarkshire Health Board

Andrew Walker, Health Economist, Greater Glasgow Health Board

Jan Warner, Director of Central Co-ordinating Unit, Scottish Screening Programme

Norman Waugh, Acting Director of Public Health, Grampian Health Board

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**Please note: the tables and charts in Appendix 1 and 2 are only available in paper format at the moment – please contact the SNAP office if you require these.**

## **EXECUTIVE SUMMARY**

Colorectal cancer is the third most commonly diagnosed cancer in Scotland and caused 1750 deaths in 1996. The risk of colorectal cancer increases substantially with age with the median age at diagnosis being approximately 72 years. The most statistically significant factors for survival after the diagnosis of colorectal cancer (whether death is peri-operative or within five years) are - stage of cancer at presentation, elective or emergency presentation, and the age of the individual; deprivation appears to be a smaller but consistent factor.

There are major recent changes in the patterns of NHS provision for colorectal cancer. The rise in day case procedures show the 1995 figure is 1302% of the 1989 figure, with chemotherapy responsible for most of the increase. Recently the number of inpatient admissions is falling. In the future, services for colorectal cancer will be developed via managed clinical networks and there will be participation in collaborative prospective data collection of an agreed core minimum data set for clinical audit analyses.

Review of preventive factors concluded that there is convincing information that diets high in vegetables reduce the risk of colorectal cancer and that increased amounts of red meat or alcohol in diet increase risk, however, the issues about optimal dietary composition for reduced risk are not fully identified. Also data consistently show a lower risk of colon cancer associated with higher levels of physical activity, and in non-smokers. Epidemiological data and observational studies demonstrate lower colorectal cancer rates associated with some lifestyles, but the effectiveness of health promotion in bringing these about is difficult to establish. Data about drug therapies is not yet strong enough to recommend their use for primary prevention.

Research on which NHS pilots of population screening is based, suggests a possible population reduction of mortality from colorectal cancer of the order of 20% may be achievable. The decision about whether or not a national colorectal cancer population screening programme should be rolled out will depend on the evaluation of the demonstration projects. A quarter of new cases of colorectal cancer occur in people with a family history of the disease and some of these cancers are caused by known inherited predisposition genes which give rise to very high lifetime risks of developing colorectal cancer. Some prevention resources should focus on such people, as evidence suggests that regular colonoscopic screening of people at increased risk of hereditary forms of colorectal cancer can reduce mortality significantly.

The importance of information and truth in communication with the cancer patient has been increasingly emphasised. Slightly different emphases are probably required in different cultural settings, but generally benefits come from greater disclosure of information to the patient (unless this is clearly not wanted). In patients with colorectal cancer there should be strong suspicion that there are associated psychological problems and brief tests should assess the level of distress. Early identification of psychosocial needs of the patient, and the needs of the patients' families and carers, allows most effective action. The minimum core data set for colorectal cancer should include information about communication, psychological and quality of life issues.

Because the preceding symptoms are so non-specific, patients defer seeking medical assessment until they require to be referred as emergencies and such urgent presentations are associated with increased morbidity and mortality. Reducing the proportion of cases presenting as emergencies is thus highly desirable, however for patients who present for elective surgery, there is no evidence that earlier referral in itself will change the stage of cancer at diagnosis. Increasing referrals would increase cancers diagnosed before emergency presentation, but there are two disadvantages: there would be an increase in the numbers of people referred who have either no obvious organic disease or a minor condition, and these people will be made anxious by being sent to an out-patient clinic and have diagnostic investigations which are invasive and unpleasant and also risk of injury to the bowel.

Standards of good practice for diagnostic techniques should include guidance designed to increase acceptability to patients as this may increase patient willingness to present early for investigation. Only a small number of patients presenting as emergencies (major haemorrhage or perforation) require early operation. The majority of patients are likely to benefit from initial resuscitation and stabilisation, with subsequent appraisal and operation by senior experienced staff. Full pre-operative assessment of whether a patient has metastatic disease may involve additional costs in extra tests but will define more precisely those suitable for adjuvant therapy. Full post-operative staging also will allow a clearer appraisal of the clinical outcomes of treatment. Better communication between the hospital and general practitioners is required.

Guidelines in both Scotland and England recommend that chemotherapy should be considered for all patients presenting with the Dukes C colorectal cancer and those with Dukes B disease should be entered into trials as there is considerable uncertainty about which drug combination, dosage and method of administration is optimal.

In Scotland 37% of colorectal cancers are rectal and the clinical guideline proposes that radiotherapy may be offered either pre-operatively or post-operatively for rectal cancers. Pre-operative radiotherapy is preferred for fixed or tethered tumors where the objective is to down-stage the disease prior to surgery. Post-operative radiotherapy is recommended for patients if pathological and surgical reports for the individual patient suggest high risk of recurrent disease. Localised radiotherapy may give an extension of symptom-free survival as well as the relief of distressing and unpleasant symptoms from cancer. The effectiveness of radical radiotherapy as a primary treatment for rectal cancer has not been established in randomised trials, however, patients who are medically unfit for surgery or who refuse surgery can have radiotherapy.

During follow-up of patients procedures are recommended to detect recurrent disease, metachronous tumours or metastatic disease at a stage where treatment may improve the prognosis, in terms of cure, or provide appropriate alleviation of disease process; however, there is little evidence on which to base these recommendations. The other objective of follow-up is to focus further effort on symptom relief and to improve the patient's quality of life. These 'quality-of-life' benefits are likely to be at least as important to patients as gains in survival.

The primary care team should be involved, not only in early referral of patients to hospital services and following patients' discharge from hospital, but also in

continuing and supportive roles for patients with cancer and their informal carers in terms of general assessment of patient needs, continuity of care, support and rehabilitation, and the role of drawing on specialist services when necessary to cope with any special needs of the patient. Macmillan and Marie Curie nurses can bring specialist and holistic benefits to patients with cancer in community and hospice settings and hospital-based clinical nurse specialists caring for patients with colorectal cancer can have a range of effective specialist roles.

The costs of palliative care specific to colorectal cancer would be very difficult to estimate as much of it is within general palliative care and it is often integrated into primary care; special provision is patchy. In England a needs assessment review of palliative and terminal care proposed extending and refocusing resources; in Scotland changes of this type may develop in relation to managed clinical networks for the care of patients with cancer.

## PREFACE

Key milestones were set in 1996 by Management Executive letters<sup>1,2</sup> providing guidance to facilitate plans to be drawn up for each of the principal cancer sites and in the "Priorities and Planning Guidance for the NHS in Scotland 1997/98"<sup>3</sup> it was made clear the high priority to be given to services directed at the prevention and treatment of cancer in general and of lung, breast and colorectal cancer in particular. The need for services to be commissioned on the basis of the available evidence was stated clearly by the Scottish Cancer Co-ordinating and Advisory Committee (SCCAC) report to the Chief Medical Officer in 1996 on the Commissioning of Cancer Services in Scotland<sup>1</sup>. The distribution in 1997 of the Scottish Intercollegiate Guideline Network/Scottish Cancer Therapy Network (SCTN) publication "A National Clinical Guideline for Colorectal Cancer"<sup>4</sup> was timely. This clinical guideline, and the associated fuller Resource Document<sup>5</sup> from the SCTN Focus Group "Guidelines on Best Current Practice for Colorectal Cancer", should have saved considerable duplication of effort in identifying best NHS practice.

When the Chief Scientist Office reviewed SCTN, the opportunity was taken to reassess the provision of the various structures and work programmes in place for cancer services under SCCAC. It was agreed that efforts might be better concentrated if they were focused in a single structure, with leadership and direction provided by a Lead Clinician for Cancer Services in Scotland. In the Spring of 1998 Dr Harry Burns was appointed to this post; the Scottish Cancer Group was established, which replaced SCCAC and the Priority Areas Cancer Team. SCTN was funded for a further 3 years but with a revised focus - on prospective clinical audit (as well as clinical trials) - and reporting to the Management Executive's Cancer Executive Group. This new structure will help to move cancer care forward, not only through clinical guidelines and SCTN, but also through facilitating Managed Clinical Networks<sup>6</sup> for patients with cancer. Managed Clinical Networks are one of the key principles recommended in the Acute Services Review Report 1998<sup>7</sup>. As a starting point within cancer services, well established arrangements for childhood cancer and haematological cancers have shown many of the attributes of multi-disciplinary working in an interactive manner that should provide a sound foundation for Managed Clinical Network development. The most recent Priorities and Planning Guidance for the NHS in Scotland<sup>8</sup> continues to show the importance to be attached to optimum care for patients with cancer and that colorectal cancer is one of the cancers identified as a high priority.



## **1 INTRODUCTION**

In accordance with the brief given, the aim of this SNAP Report is to provide a short, accessible guide for NHS planners and managers of services about the implications of recent reports and guidelines for colorectal cancer. This report also identifies other recent key publications should the reader wish further information about particular issues pertinent to improving the management of patients with colorectal cancer and planning services in Scotland.

Health needs assessment reviews usually identify pointers for health economic evaluation. This type of perspective for colorectal cancer was covered in a commissioned review by the Department of Health<sup>9</sup>, and locally in the more recent Resource Document<sup>5</sup> written by the Scottish Cancer Therapy Network (SCTN) Focus Group on Colorectal Cancer to underpin the Scottish Intercollegiate Guideline Network (SIGN)/SCTN Clinical Guideline on Best Current Practice for Colorectal Cancer<sup>4</sup>. New patterns of health service care are emerging for patients with colorectal cancer which would make further economic estimates speculative if based on currently available national data. This SNAP report will, therefore, mainly concentrate on issues of effectiveness and where particular areas of care have been given new or increasing prominence. The following text summarises a number of recent conclusions and recommendations and provides comments about the likely impact of some of them.

## 2 NATURAL HISTORY AND EPIDEMIOLOGY

**Natural History:** Colorectal cancer is the result of the unrestrained growth of mucosal cells lining the inner surface of the bowel which then progresses into the development of protuberant, and then proliferative, outgrowths of mucosal cells called adenomas. These can regress, or progress into carcinomas in which cell growth escapes normal controlling mechanisms and malignant cells invade neighbouring tissues or detach and disseminate as metastatic spread. On the basis of considerable indirect evidence<sup>10</sup> there appear to be two distinct processes which lead to this malignancy; the production of the adenoma, and then the transformation of the adenoma into an invasive tumour. Each of these processes may be influenced by genetic factors and other circumstances which modify the local environment of these mucosal cells. In general, the development of colorectal cancers takes many years, thus in theory there should be time for effective intervention. Unfortunately, the presenting symptoms of colorectal cancer - blood on, or mixed with, stools; change of bowel habit; anaemia; weight loss; nausea and anorexia; abdominal pain - are often not well defined and may be due to other causes.

### Epidemiology

**Incidence and Risk:** Colorectal cancer is the third most common form of cancer among both men and women in Scotland. In 1996, colorectal cancer accounted for 13.8% of newly diagnosed malignancies (excluding non-melanoma skin cancer) - in males 14.5% and in females 13.1%. It is the second most common cause of death from all cancers among men and the third most common cause of deaths from cancer among women. In 1996, there were 3,486 new cases of colorectal cancer and 1,750 deaths. The lifetime risk of developing colorectal cancer is 4.6% for men and 3.2% for women. The risk of colorectal cancer increases substantially with age. Colorectal cancer is rare under 45 years of age with the median age at diagnosis being approximately 72 years. However, 28% of colorectal cancer is diagnosed among people under 65. **Appendix 1, Table 1.**

The incidence of colorectal cancer rose by about 4.5% in females and 7% in males during the decade 1981-90<sup>11</sup>. However, the most recent publication of Cancer Registration Statistics in Scotland<sup>12</sup> (Sections 3.5-3.7) show more complex trends as in the decade 1986-95 while the incidence in females rose by 4.8%, there has been a larger increase of 23.2% in males. While about 75% of new cases of colorectal cancer occur in people with no known predisposing factors for the disease, 5-6% of these cancers are caused by known inherited predisposition genes which give rise to very high lifetime risk of developing colorectal cancer. These genes include familial adenomatous polyposis (FAP) and heredity non-polyposis colorectal cancer (HNPCC). A further 15 to 20% of cases may be caused by other inherited predisposition genes which give rise to some increased familial risk<sup>13</sup>. Additionally, patients with long-standing inflammatory bowel disease are at increased risk of colorectal cancer.

The incidence of colorectal cancer is higher in Scotland than in England and Wales, and within Scotland there are significant differences in distribution. This regional pattern of incidence was detected in the 1980s with higher than the national average in males in Grampian, Greater Glasgow and Highland and in females in the Borders, Grampian, Highland and Tayside, while significantly lower rates in males

are recorded in Argyll & Clyde, Forth Valley and Lanarkshire, and in females in Lanarkshire and the Western Isles<sup>14</sup> and this regional pattern of slight variation is maintained in the Cancer Registration Statistics published in 1998<sup>12</sup>.

Both sexes showed substantial differences in incidence by deprivation score in the data published for 1981-90<sup>11</sup> where the age standardised incidence rates for the least deprived were 61.3 in males and 47.1 in females, in contrast to the most deprived, in whom the rates were 55.1 and 39.1, respectively. However, the most recently published<sup>12</sup> cancer registration statistics for Scotland (1986-95) show no clear trend for the incidence of colorectal cancer across deprivation categories.

Despite a certain amount of investigation by the Scottish Cancer Intelligence Unit<sup>15</sup> no reasons have been identified for the greater increase in incidence rate in males or the apparent recent change to lose the association between incidence and deprivation.

**Survival:** Apart from lower 1 year survivals in the oldest group, there are surprisingly small reductions in 1, 3, and 5 year survivals with increasing age<sup>16</sup>. The overall 5 year relative survival rate in Scotland improved from 33% in 1968-72 to 44% by 1988-92.

From English data published<sup>17</sup> in 1997 it is seen clearly that survival is very dependent on pathological stage (Dukes modified) of the colorectal cancer:

Stage	Definition	% of diagnosis	%5-year survival
A	Localised within bowel wall	11	83
B	Penetrates bowel wall	35	64
C	Spread to lymph nodes	26	38
D	Distant metastases	29	3

The fuller related resource documents published<sup>18</sup> in England in 1997 provided consolidated information that patients whose colorectal cancer presents as an emergency have higher post-operative mortality and poorer survival than patients who present for elective assessment and treatment. Patients who present as emergencies also tend to have more extensive disease, and are usually older. From recent data sets these reports drew from within England, it was shown that about a third of patients with colon cancer and a tenth of those with rectal cancer present as emergencies; there was an increased risk of peri-operative death after emergency presentation (odds ratios were 3.5 for colon cancer and 13.3 for rectal cancer). Preliminary analyses<sup>15</sup> of Scottish clinical audit data of colorectal cancer diagnosed in 1993 showed similar comparative survivals for the cancer stage at diagnosis. The Scottish data also showed slightly higher presentation rates categorised as emergency presentations than were recorded in England. However, the increase in the peri-operative death rate after emergency presentation was not quite as high as in England. Nevertheless, in Scotland, for colon cancer the odds ratio was more than doubled if there was emergency presentation and for rectal cancer there was more than a four-fold increase in the odds ratio for peri-operative death.

A publication in 1996 of local clinical outcomes data<sup>19</sup> does show some apparent regional variations in survival. However, this publication explains that this type

of data should only be regarded as the basis for further appraisal, as survival variation is a consequence of several factors: variations in stage at presentation, access to endoscopy, the nature of surgery (elective or emergency), operative mortality rates and completeness of registration. A recent local study<sup>20</sup> demonstrates that people from more socially deprived post-code areas in Tayside are more likely to present with more advanced colorectal cancer, suggesting that they delay longer in coming to health care facilities and inevitably, therefore, will have poorer prognoses. A more comprehensive recent review of deprivation and health in Scotland<sup>21</sup> included large bowel cancer diagnosed during 1988-92 and showed that the trend to deprivation was associated with a consistent trend to poorer survival rates throughout 1 to 5 years after diagnosis.

The most statistically significant factors for survival after the diagnosis of colorectal cancer (whether death is peri-operative or within five years) are - stage of cancer at presentation, elective or emergency presentation, and the age of the individual; deprivation appears to be a smaller but consistent factor. These analyses confirm the desirability of the early diagnosis, elective surgery and further treatment.

**Hospital Activity:** A recently published study<sup>22</sup> from the South Thames Region over the 5 year period 1989-93 showed that, while the incidence of colorectal cancer registration and number of patients treated remained constant, ordinary hospital admissions for this condition increased by 41% but day case admissions increased 640%. The main increases were due to chemotherapy treatments while most of the remainder was due to assessments by sigmoidoscopy or colonoscopy. In Scotland, while there are increases in the incidence of colorectal cancer, advances in diagnostic and therapeutic procedures have resulted also in large changes in hospital based activity. From the recent data from the Information and Statistics Division of the NHS in Scotland, provided for this SNAP Report (**Appendix 1 - Tables 2,3,4 and Figures 5 and 6**), it is seen that there is an equivalent increase in Scotland in day care procedures during the same 5 year period (1989-95) with the 1993 figure being 474% of the 1989 figure. However, in Scotland, this rise in day case procedures continues even more sharply so that the 1995 figure for day case procedures is 1302% of the 1989 figure (chemotherapy, as in the study in England, is again responsible for most of the increase) and recently the number of inpatient admissions is falling. Clearly there are major recent changes in the patterns of NHS provision for colorectal cancer.

Analyses of data<sup>15</sup> from the audit of colorectal cancer in Scotland on retrospective information (there is also a component of prospective data) for 1993 help to resolve some uncertainties, describe recent patterns of care and their outcomes, and provide some relevant baseline information. However, there is local information that feedback of prospective clinical audit data about avoidable adverse events and pathology results can lead to a reduction in adverse outcomes<sup>23</sup>. For the future it has been decided<sup>9</sup> that for colorectal cancer (also for three other frequently occurring cancers), via managed clinical networks, there will be participation in collaborative prospective data collection of an agreed core minimum data set for clinical audit analyses. Such analyses will also be able to draw data from the Scottish Open Cancer Registration and Tumour Enumeration System (SOCRATES)<sup>24</sup> which uses information from hospital discharges, radiotherapy/oncology records, pathology records and deaths from the General Register Office (Scotland). These analyses should identify NHS targets for

particular actions to improve survival, and eventually quality of life, of patients with colorectal cancer.

**Appendix 2** of this SNAP Report provides further epidemiological data about colorectal cancer of relevance to Health Boards, and allows comparison among them and with whole Scotland data.

### 3 PREVENTION

In 1997 a large comprehensive monograph "Food, Nutrition and the Prevention of Cancer - a Global Perspective"<sup>25</sup> reinforced many existing recommendations of current health promotion themes which also have benefits in reducing colorectal cancer. This review concluded that there is convincing information that diets high in vegetables (not fruit) reduce the risk of colorectal cancer and that increased amounts of red meat or alcohol in diet increase risk. There was less consistent evidence that increased dietary fibre, or starch or carotenoids may have a beneficial effect and that there may be adverse effects from increased dietary sugar, total fat, saturated animal fat, processed meat, heavily cooked meat, or eggs. These conclusions of international experts were based on a systematic review of a large number of cohort and case/control studies, and they also took account of the biomedical plausibility of the epidemiological results.

Since then the large, high-quality Nurses' Health Study reported<sup>26</sup> not only that dietary fibre had no effect on the risk of colorectal cancer and adenoma in women but even demonstrated that increased fibre from vegetable origin was associated with an increase in colorectal cancer in American women - it also cited a smaller recent cohort study in men as being unable to demonstrate that increased dietary fibre reduced risk for colorectal cancer. A separate recent publication from the Nurses' Health Study reported<sup>27</sup> that folate intake from diet (vegetables and fruit are the prime source of dietary folate) or dietary supplements was associated with a decreased risk for colorectal cancer in American women. These recent results from America illustrate the difficulty of interpreting the transcultural observations suggesting substantial benefits of high dietary vegetable intake in reducing the risk of colorectal cancer (by as much as 50%)<sup>23</sup>. Thus, the issues about optimal dietary composition for reduced risk are not fully identified. Additionally, there are further issues about the extent to which it is possible to succeed in changing the dietary habits of UK populations and in 1998 the Economic and Social Research Council published a monograph<sup>28</sup> of its directed programme of research on this important topic.

Epidemiological data consistently show a lower risk of colon cancer associated with higher levels of physical activity<sup>29</sup>, although there are weaker adverse associations from high body mass or patterns of more frequent eating so it remains unclear which of these factors might be causal. Epidemiological data also show a consistent small benefit in reduced risk of colon cancer associated with sections of populations who do not smoke.

In the Resource Document<sup>5</sup> by the SCTN Focus Group on Colorectal Cancer, estimates of the attributable risks of colorectal cancer suggested that healthy eating could reduce colorectal cancer incidence by up to 50%, regular exercise could reduce incidence by up to 25%, and eradicating tobacco smoking could reduce incidence by up to 10%. While the epidemiological data and observational studies demonstrate strong support for substantial reductions in colorectal cancer rates as a result of lifestyle changes, the effectiveness of health promotion in bringing these about is difficult to establish.

The historical view of cancer aetiology has been of long latency between initiation and clinical cancer and, therefore, health promotion may only bring benefits many years after maintained changes in lifestyle. However, smoking cessation has been shown now to produce declines in risk of lung and bladder cancer after a few years

and weight loss and hormone replacement therapy have been shown to change the risk of breast cancer within 10 years (the former beneficial, the latter slightly adverse). Epidemiological studies<sup>30</sup> of the effect of hormone replacement therapy on the risk of colorectal cancer and adenoma show it to be reduced to about two thirds by current use, but that this benefit disappeared within 5 years of discontinuing hormone use. Epidemiological and clinical studies<sup>31,32</sup> of aspirin and non-steroidal anti-inflammatory drugs also show consistently low risk for users, both male and female, of colorectal neoplasia, and the earlier detection of clinical lesions as a result of drug induced gastrointestinal bleeding does not seem to explain the protective effect of these drugs. The effect of these types of analgesics also appears to be become apparent comparatively quickly, perhaps through early disruption of the adenoma to cancer sequence. There are issues also about how long the protective effect of such drugs might last after they are discontinued.

The issues about these commonly used drug therapies are not only that there may be benefits to be gained - although we are unclear about the best agent, doses, timing and duration of action and the evidence is not yet strong enough to recommend their use for primary prevention - but also that there may be benefit to be gained from late preventive action from prudent lifestyle measures<sup>33</sup>. If health promotion is effective then there may be potentially large gains both in terms of health and NHS resource savings, and a report<sup>54</sup> in 1998 from the Committee on Medical Aspects of Food and Nutrition Policy concluded "that higher intakes of vegetables, lower red meat and processed meat consumption and diets rich in dietary fibre would reduce the risk of colorectal cancer". Similar advice has been published in Scotland in broader nutritional contexts<sup>35,36</sup>. Prospective epidemiological studies continue in these important areas but definitive evidence seems unlikely to emerge soon, meanwhile some policy advice runs ahead of evidence but in prudent directions.

## 4 CASE IDENTIFICATION

### Population screening

In 1998 the UK National Screening Committee concluded<sup>37</sup> that there was sufficient evidence of the effectiveness of population screening to recommend two pilot projects, screening populations of approximately a million for colorectal cancer. In Scotland the demonstration project of this screening will cover the populations of Grampian, Tayside and Fife Health Boards targeting people aged 50 to 69. The primary test will be the faecal occult blood test, without dietary restriction and without rehydration of the test sample. Follow-up for people with strong positive tests will be by colonoscopy, slight positives will be re-tested with dietary restrictions and a further faecal occult blood test. Where a complete colonoscopy is not possible, flexible sigmoidoscopy plus double contrast barium enema will be used for further investigation. The published research on which this NHS pilot of population screening is based, suggests a possible population reduction of mortality from colorectal cancer of the order of 20% may be achievable, but there are also the objectives of assessing the acceptability and limitations of the screening programme and the identification of possible adverse effects. The decision about whether or not a national colorectal cancer population screening programme should be rolled out will depend on the evaluation of the demonstration projects.

There may also be the opportunity to research the possible effects of more sensitive or specific tests for faecal occult blood or, in the future, the possible extension of screening to an older age group. A further research study is assessing the feasibility, acceptability, and possible benefits of screening for colorectal cancer by a once only flexible sigmoidoscopy of individuals aged 55 - the component of this multi-centre study based in Glasgow has now screened 3,000 individuals by this method. Further large scale screening activities for colorectal cancer are proceeding in the USA and parts of Europe, particularly France and Scandinavia.

### Screening in high risk groups

***Hereditary Risk:*** Rather than screen the whole population in a given age range, secondary prevention may focus on people with a family history of the disease; there is now a broad consensus to support increased surveillance in such groups.

In 1998, following consultation on a draft report<sup>38</sup>, there was the publication of an amended report<sup>13</sup> on Cancer Genetic Services in Scotland with the provision of additional funding for such services. Colorectal cancer was recognised as one of the main cancers with important genetic elements.

About 25% of these cancers occur in people who have a family history of colorectal cancer. About 2-5% of these cases are caused by known inherited predisposition genes which give rise to very high lifetime risks of developing colorectal cancer. These genes include familial adenomatous polyposis (FAP) and heredity non-polyposis colorectal cancer (HNPCC). A further 15-20% of cases may be caused by other inherited predisposition, which gives rise to some increased familial risk.

FAP is a very rare inherited condition which occurs in about 1 in 10,000 births, and is estimated to account for less than 0.5 % of all cases of colorectal cancer but all are almost certain to develop cancer by their 40s. The type of colorectal cancer



caused by FAP is distinctive and screening for this mutation already takes place in Scotland.

HNPCC is estimated to account for about 5% of new cases of colorectal cancer each year. The average age of diagnosis is 45 and this disease is characterised by more rapid development colorectal cancer, and the risk of new primary tumours occurring is also high. Estimates of the lifetime risks of colorectal cancer to carriers of HNPCC genetic mutations vary from 50 - 80%, with a higher risk in males than females. The prevalence of HNPCC in the population is unknown since there have not been any general population estimates of prevalence. However, assuming<sup>39</sup> that 2% of cases are caused by HNPCC and that the lifetime risk to carriers of these genes is 60%, then the number of HNPCC carriers in the population is about 1.7 per 1,000. This implies that there are around 8,800 carriers of the HNPCC genes in the Scottish population.

Some 15-20% of colorectal cancers may be caused by inherited genes, which are more common than HNPCC but which have a much lower lifetime penetrance. A number of studies have found that the relative risk to individuals with a first degree relative with colorectal cancer is about twice the general population risk. The relative risk is higher if there are two first degree relatives with colorectal cancer or if cancer was diagnosed in a relative under the age of 50. It is possible that shared environmental or lifestyle factors may account for some of this observed familial risk. However, it is likely that inherited predisposition genes account for much of the increased relative risk.

The evidence suggests that regular colonoscopic screening of people at increased risk of hereditary forms of colorectal cancer can reduce mortality significantly. Patients aged between 25 and 65 who are considered to be at medium risk of colorectal cancer would be offered colonoscopic screening every 5 years, while patients considered to be at high risk would be screened every 2 years. This age group is proposed because the evidence suggests that genetically determined cancer occurs more frequently at a younger age.

Family history may not provide a very effective means of targeting carriers of HNPCC genes. An estimate in the recent report<sup>13</sup> is that only 25% of HNPCC carriers in the age range 25-65 would be included within the genetic services screening programme. An alternative approach to identify HNPCC carriers<sup>39</sup> proposes genetic assessment being carried out on all people under the age of 55 who are diagnosed with colorectal cancer. Those people who have genetic instability in their tumour would be offered a blood test to screen for HNPCC genetic mutations. Asymptomatic relatives of patients who are found to be carriers of these mutations would also be offered a genetic blood test to determine whether they are carriers of the mutations and, if positive, would be offered regular colonoscopic screening. As development work for this alternative approach, a prospective study is being carried out from the Medical Research Council Human Genetics Unit with funding from the Cancer Research Campaign and the Chief Scientist Office.

***Disease Associated Risk:*** Patients with ulcerative colitis or Crohn's disease are at increased risk of colorectal cancer. The respective prevalence of these diseases are estimated as 160 and 50 per 100,000 (approximately 10,000 people in Scotland) by the British Society of Gastroenterology which recommends their surveillance, particularly for those with the disease for 8 - 10 years.

## **Symptomatic Presentation in Primary Care**

The SIGN/SCTN Clinical Guidelines<sup>4</sup> urge pharmacists and GPs to refer patients for specialist assessment as soon as relevant persistent or recurrent symptoms appear. Subsequently similar guidance was given in the Effective Health Care review of "The management of colorectal cancer"<sup>40</sup> and the Department of Health guidance for general practitioners and primary care teams on "Improving outcomes in colorectal cancer"<sup>17</sup>. Unfortunately, the symptoms of the disease are non-specific (change in bowel habit or rectal bleeding) and one recent UK study estimated a yield of 8% colorectal cancers from patients referred for the investigation of relevant bowel symptoms. (This yield of colorectal cancer is similar to the yield of breast cancer from referral for specialist assessment of breast problems.) Local clinical audit studies of colorectal cancer in 1990-2 show there are comparatively long delays in referral from primary care to hospital specialists (mean 38 days) and further delay (mean 22 days) before assessment provides a definitive diagnosis. However, usually the largest component of delay in diagnosis occurs between the onset of initial symptoms and presentation of these in primary care - perhaps 6 months to a year.

Delays after presentation in primary care may result in slight disease progression but more clearly it prolongs the period of patient anxiety about their diagnosis. Because the preceding symptoms are so non-specific, patients defer seeking medical assessment until they require to be referred as emergencies and such urgent presentations are associated with morbidity and mortality and (if presenting with advanced disease) may not be amenable to effective therapy. Current efforts, (not only from NHS resources but also from general cancer charities and specific ones such as Colon Cancer Concern) e.g. National Bowel Cancer Week, are being directed to make the general public, and the primary care professions, more aware of the need to present for expert assessment if there are symptoms which might be due to bowel cancer.

## 5 PATIENT-CENTRED CARE

### Health related quality of life: Communication: Psychosocial issues

Both clinical guidelines for colorectal cancer issued to the NHS in 1997, the SIGN/SCTN publication in Scotland<sup>4</sup> - particularly the Resource Document<sup>5</sup> - and, slightly later, the Guidance on Improving Outcomes in England<sup>18</sup> placed major emphasis on the overlapping key themes of Patient-centred care: Health related quality of life: Communication: Psychosocial issues. The Scottish guidance gave more cover to a review of health related quality of life issues which were pertinent to patients with colorectal cancer and this provided the basis for its central recommendation that “treatment and support should add to quality of life as well as prolonging it”.

Both guidance documents emphasised the importance of communication - in providing truthful, accurate information to patients over a period of time as they come to terms with the diagnosis and treatment, in discussing treatment options with patients whenever this is possible, and in allowing patients the opportunity to be involved in decision-making to the extent that they wish. There was evidence that many patients feel they are not given sufficient information and that they value accurate information, although it was also identified that this was most appreciated by patients with a reasonable prognosis and treatment options. Most patients wished to hear bad news from a hospital based specialist and some would not wish to hear this from others on a recurring basis. There was also agreement that it was important to provide staff with training in communication and counselling skills so that they could provide better psychological support to patients. The importance of information and truth in communication with the cancer patient has been emphasised in an extensive recent monograph on this topic<sup>36</sup> which shows that slightly different emphases are probably required in different cultural settings, but that generally benefits come from greater disclosure of information to the patient (unless this is clearly not wanted).

Both guidance documents also emphasised the general importance of psychological aspects of all stages of the diagnosis, assessment, and management of cancer patients. The Scottish clinical guideline documents for colorectal cancer<sup>4,5</sup> covered more general psychological issues such as the need for high initial suspicion of a psychological problem, the use of appropriate brief tests to assess the level of distress, and the availability of appropriate psychosocial expertise; and these were set in the context of earlier general guidance about primary care roles for patients with cancer<sup>42</sup>. The initial English clinical guidance documents<sup>18</sup> placed particular emphasis on the special needs for counselling patients who would require a stoma, and for the need for this type of support prior to, and after, surgery but the later brief guidance<sup>17</sup> for primary care stressed the importance of communication in more numerous contexts.

The English guidance<sup>18,17</sup> gave greater prominence to the issue of patient-centred care than was readily apparent in the Scottish guideline<sup>4,5</sup>. Despite many recommendations in the Scottish guideline about psychosocial issues, it was disappointing that the associated pilot edition of the minimum core data set for colorectal cancer did not include provision to collect information about communication, psychological and quality of life issues. However, it seems probable that as progress is made with the recommendations of the Acute Services Review becoming applied to cancer care, these additional areas (which patients

value as contributing to the quality of their life with cancer and its treatments) will have appropriate clinical audit data collected and analyses made, but this will require additional resources. A thoughtful expert review has advised against trying to combine statistical analyses focused on survival with assessments of quality of life and has recommended a strategic approach to cover these areas<sup>43</sup>.

The main probable benefit of early diagnosis is that it may allow disease management to be planned, thus avoiding presentations such as colonic obstruction which requires emergency surgery. Avoidance of urgent presentations improves the prognosis since the mortality rate following emergency surgery is much higher than that with elective surgery. Reducing the proportion of cases presenting as emergencies (currently approximately 25%) is thus highly desirable. However for patients who present for elective surgery, there is no definitive evidence that earlier referral in itself will change the stage of cancer at diagnosis. While this may appear counter-intuitive, it is probable that colorectal cancers are slow growing and may be present in the bowel for several years before they are diagnosed with current techniques.

Increasing referrals would increase cancers diagnosed before emergency presentation, but there are two disadvantages: there would be an increase in the numbers referred who have either a minor condition or no obvious organic disease, and these people will be made anxious by being sent to an out-patient clinic and have diagnostic investigations which are invasive and unpleasant and also carry a risk of injury to the bowel.

## 6 EFFECTIVE SERVICES: THE MULTI-DISCIPLINARY TEAM

**Primary Care:** The early advice in England<sup>18</sup> made the topics of “access to services” and the “multi-disciplinary team” central to the guidance. More adequate prominence of the crucial and continuing roles of primary care were included in a later guidance publication<sup>17</sup> providing general practitioners and primary care teams with information about improving outcomes in colorectal cancer.

In Scotland, slightly earlier appropriate advice<sup>42</sup> had been issued about the role of primary and palliative care services in relation to all patients with cancer. This report<sup>42</sup> provides much broader and more appropriate guidance about the primary care team continuing and supportive roles for patients with cancer and their informal carers in terms of:- the key roles for general assessment of patient needs, continuity of care, support and rehabilitation, and (from the maintained link with patient/carer) the role of drawing on specialist services when necessary to cope with any special needs of the patient. The subsequent clinical guidelines about colorectal cancer in Scotland<sup>4</sup>, therefore, concentrated mainly on the role of general practitioners in the appropriate early referral of patients to hospital services and, briefly, on their support roles following patients' discharge from hospital.

**Diagnostic Services:** Access to diagnostic services was dealt with in guidance in England<sup>18,17</sup> in terms of logistics and technical effectiveness of the range of procedures. In Scotland<sup>4,5</sup>, the guidance covered mainly technical effectiveness. These aspects will not be repeated here, but it seems worth commenting about the issues relating to patients' perceptions and acceptance of the diagnostic procedures, since adverse perceptions will contribute to patients' delays in presenting for diagnosis.

Barium enema followed by radiography, although generally recognised to be an embarrassing investigation, is less invasive than endoscopy. Nevertheless, the pain and discomfort of the former has been reported as similar to that experienced during colonoscopy<sup>44</sup>. Serious complications occur, such as perforations - 1:10,000 or even death 1:50,000<sup>1</sup>. Average diagnostic sensitivity has been estimated as 95%<sup>19</sup>. The costs are intermediate between those of sigmoidoscopy and colonoscopy.

Sigmoidoscopy examines only the lower 30-40 cm of the bowel (depending on the experience of the operator) and is likely, therefore, to miss about 30% of colon cancers and this diagnostic inefficiency has quality of life implications. It is also perceived as an embarrassing and painful procedure. One study of a group of patients attending for flexible sigmoidoscopy<sup>45</sup> found 31% of the patients reported pain, 42% discomfort, but generally most patients experienced less pain than they expected; pain levels increased significantly with age, and 27% reported moderate to extreme embarrassment. \_

Colonoscopy has the advantage of usually being able to assess the whole of the colon, allowing biopsy and histopathological diagnosis of suspicious lesions, and will permit the removal of polypoid lesions during the procedure (10-20% of procedures may not reach the caecum). However, not only is it an embarrassing and uncomfortable procedure, it has a serious complication rate which is not negligible - perforation 1:600, haemorrhage 1:3,600, and death 1:5,000<sup>9</sup>. While guidelines of good practice have been set for colonoscopy by the British Gastroenterology

Society (1991)<sup>46</sup>, they do not cover all issues relating to patient acceptability, although important issues such as adequate sedation and monitoring are included.

With the current level of use of these three investigations, and the probability that their use will expand further, effort should be made to ensure that patients' perceptions and experience are more fully considered in guides of good practice for these procedures. However, because many doctors appear to regard endoscopy as a minor procedure, there are increases in some of these procedures being carried out by more junior medical staff or by clinical nurse specialists. Guidance designed to increase acceptability to patients should be incorporated into standards of good practice for these techniques. The finding that patients anticipated even more discomfort and embarrassment than they suffered from the more invasive procedures suggests that there is scope for patients to have early access to simple, clear, reassuring information about what they are likely to experience during these investigations. Some Hospital Trusts may have suitable information sheets which are sent to patients at an early stage but the practice is not universal.

Most of the diagnostic investigations for colorectal cancer will be followed by a period of waiting for the results. When one of the possible diagnoses is cancer, anxiety is increased by any undue delay. This issue has been well recognised and is now addressed in patients with a possible diagnosis of breast cancer. The same speed to impart the diagnosis within a supportive and counselling environment is less explicitly a part of clinical practice for patients with cancer of the colorectum. This is particularly important for patients who are at high risk of colorectal cancer.

**Surgery and pathology:** SCTN/SIGN guidelines do not make recommendations about the costs and benefits of treatment by specialist surgeons as opposed to general surgeons. Much of the evidence on the benefits of such an approach is suggestive rather than conclusive<sup>40</sup>. However, specialisation may facilitate a more integrated clinical team approach to the management of patients with colorectal cancer and is preferred for some more technically difficult cases. There is evidence from peri-operative mortality monitoring studies that operations undertaken at night, or by junior staff, are likely to be associated with higher complication and mortality rates. Both the SIGN/SCTN Guideline, and the earlier guideline from the Royal College of Surgeons of England, recommend that surgery on these emergency patients should be carried out during daytime hours by experienced surgeons and anaesthetists. Only a small number of patients presenting as emergencies (major haemorrhage or perforation) require early operation. The majority of patients are likely to benefit from initial resuscitation and stabilisation, with subsequent appraisal and operation by senior experienced staff. The recent Acute Services Review Report<sup>7</sup> emphasises the need to aim at quality standards of care and to monitor these by quality assurance mechanisms and clinical audit appraisals.

The SIGN/SCTN guidelines for colorectal cancer make a number of recommendations about surgical technique and multi-disciplinary diagnostic pre-operative appraisal, post-operative staging and joint (surgeon, pathologist) reporting. Most of the recommendations relating to surgical technique will not be disputed. The report advocates the technique of total mesorectal excision for suitable cases of rectal cancer (approximately half of the rectal cancers). Improved operative techniques for "curative" surgery may reduce local recurrence and increase survival rates; for example, the main advocate of total mesorectal excision has demonstrated lower recurrence rates and improved survival at 10 years after surgery. However, this is a contentious issue and comparable recurrence and

survival has been described by some surgeons not practising this technique. One 'order-of-magnitude' estimate is that total mesorectal excision requires approximately a further 30 minutes in theatre and adds two days to length of hospital stay. Also, the likelihood of an anastomatic leak is higher and some surgeons recommend a covering colostomy. Thus, a second operation is required in some of this group, adding to early morbidity and costs.

Full pre-operative assessment of whether a patient has metastatic disease may involve additional costs in extra tests but will define more precisely those suitable for adjuvant therapy. Full post-operative staging also will allow a clearer appraisal of the clinical outcomes of treatment. Variation between surgeons, in terms of 'immediate' outcomes such as post-operative mortality and complication rates, has been demonstrated and attempts to reduce this variability should improve overall performance. The report also makes clear that better communication between the hospital and general practitioners is required. It is not clear to what extent the 'good practices' recommended for surgeons and pathologists are already part of routine clinical work.

**Adjuvant chemotherapy:** Guidelines in both Scotland and England recommend that chemotherapy should be considered for all patients presenting with the Dukes C colorectal cancer and those with Dukes B disease should be entered into trials. Approximately 50% of all colorectal cancers are Dukes C but not all patients are medically fit or willing to undergo chemotherapy. There is evidence that survival can be improved in the Dukes C cancers (particularly colon cancer) but there is considerable uncertainty about which drug combination, dosage and method of administration is optimal. Based on literature reports of stage-specific survival, treating 100 patients by chemotherapy is equivalent to increasing the number surviving to at least three years post-operatively by 17<sup>5</sup>. The SIGN/SCTN Guideline recommends that patients should be entered into clinical trials to address various uncertainties about optimum schedules of chemotherapy. There are low-cost, administratively simple, UK trials which meet the requirements of this recommendation.

**Adjuvant radiotherapy for rectal cancer:** In Scotland, 37% of colorectal cancers are rectal and the SIGN/SCTN guideline proposes that radiotherapy may be offered either pre-operatively or post-operatively for rectal cancers. Pre-operative radiotherapy is preferred for fixed or tethered tumours where the objective is to down-stage the disease prior to surgery. Post-operative radiotherapy is recommended for patients if pathological and surgical reports for the individual patient suggest a high risk of recurrent disease (tumour involvement of lateral margins, regional node spread).

The Resource Document<sup>5</sup> for the SIGN/SCTN clinical guideline estimated that about 400 cases are potentially eligible for pre-operative radiotherapy. However, the true figure will be lower as age constraints, patient fitness and the fact that some patients require emergency surgery at diagnosis will reduce this number. Two pre-operative regimens have been shown to be effective: 2000-2500cGy in 4-5 fractions or 4000cGy in 20 fractions. The disadvantage of the former is that patients have to undergo immediate surgery in order to benefit, so good co-ordination and scheduling are required. With the latter schedule, surgery is delayed for up to six weeks. The larger fractions give rise to more toxicity and may be less suitable for frailer patients.

Numbers eligible for post-operative radiotherapy were more difficult to estimate as patients would not be offered it if they have had either pre-operative radiotherapy or total mesorectal excision, both of which should become more common as a result of the recommendations of the SIGN/SCTN guideline. Post-operative radiotherapy is recommended as 2500-4000cGY in 20 fractions.

Radiotherapy is intended to reduce local recurrence and increase relapse-free survival. Research suggests that survival increases by between 9% (pre-operative) and 14% (post-operative) but these gains have been at the margins of statistical significance in the research trial data. Based on literature reports of stage-specific survival rates, the survival gain is equivalent to about 4 additional people being alive 5 years after treatment per 100 undergoing radiotherapy<sup>2</sup>. As important as improved survival, is the reduction in local recurrence of rectal cancer which can be achieved, as this is usually painful and difficult to treat effectively. Pre- and post-operative radiation of rectal cancers are being assessed in a clinical trial by the Medical Research Council (CR-07) and appropriate patients should be entered in this study.

**Nursing care:** The SIGN/SCTN guideline recommends clinical nurse specialists be available in all centres for the treatment of colorectal cancer. They can perform general roles within a multi-disciplinary team: co-ordinating the response to a patient's needs, offering individualised advice, involving the patient's family and carers, bridging the gap between hospital and primary care. They may have more focused specialist roles.

The benefits of stoma care nurses are widely recognised. Also, there is consensus about the specialist and holistic benefits that Macmillan and Marie Curie nurses can bring to patients with cancer in community and hospice settings. The benefits of clinical nurse specialists in other hospital settings, in the context of colorectal cancer, have not been demonstrated in a randomised trial and, given the emphasis on a multi-disciplinary team, this could be difficult to prove now, however, there is evidence of benefit in the context of breast cancer and other specialities. Clinical nurse specialists caring for patients with colorectal cancer may have effective specialist roles, in the delivery of chemotherapy, in counselling and support, and in undertaking flexible sigmoidoscopy examinations. Clinical nurse specialists have been shown to improve quality of life for patients with breast cancers and there is every likelihood that these forms of specialist nursing would improve colorectal cancer patients' quality of life, a matter of great concern to the individual and their families.

The requirements are dedicated time of an experienced nurse and appropriate training in oncology and counselling courses. Such nurses are not widely available at present, hence many of the costs of implementing this recommendation may require additional funding. However, it is expected that the provision of this additional nursing input would free some medical time and, therefore, it should be cost-effective. It seems probable that an education and training strategy would evolve from the basis of the recent NHS human resource strategy<sup>47</sup>.

**Follow-up:** The SIGN/SCTN guideline<sup>4</sup> recommends that, if surgery was potentially curative, hospital-based follow-up should consist of examination of rectal anastomoses regularly for 2 to 3 years, possibly regular ultrasound scanning of the liver for 2 to 3 years, and colonoscopy / barium enema X-ray every 3 to 5 years. In addition, Chorion Embryonic Antigen (CEA) assays, monitoring of signs and



symptoms, and provision of supportive information can be carried out either in primary care or in a hospital follow-up setting. However, many surviving patients are elderly and have co-morbidities, hence full adherence to invasive investigations of this regimen will not always be appropriate.

This<sup>4</sup> guideline's main aim in follow-up of patients is to recommend procedures to detect recurrent disease, metachronous tumours or metastatic disease at a stage where treatment may improve the prognosis (in terms of cure) or provide appropriate alleviation of disease process. However, there is little evidence on which to base most of these recommendations and a subsequent review<sup>40</sup> could demonstrate no survival advantage for patients with colorectal cancer using current follow-up procedures. There is a Medical Research Council trial proposed to assess follow-up procedures for colorectal cancer and, if this comes to fruition, this could identify the optimum protocol. In future, new tests, possibly ultrasound monitoring, (preliminary enquiry suggests that the recommendation for ultrasound could have significant resource consequences in some centres and benefits are not clear) may be developed to detect recurrent or advanced disease earlier. This might result in more frequent follow-up use of surgery, clinical oncology and palliative care to allow such therapy to be more effective.

The other objective of follow-up is to focus further effort on symptom relief and to improve the patient's quality of life. There will be the need to be guided by the symptoms which most impair the patient's life and the aims should be to devote appropriate resources to achieve the best holistic outcome. This may require further physical or chemical therapy, or psychosocial support to the patient and their family. Apart from stoma care, psychosocial support appears deployed in a rather patchy manner at present. While further provision of such resources at the initial stages of the patient's illness may increase costs, there is no doubt that psychosocial problems are dealt with most effectively when they are tackled early. Subsequent severe morbidity, which is difficult and expensive to resolve would, therefore, be minimised. These 'quality-of-life' benefits are likely to be as important to patients as survival gains from standard therapeutic measures.

**Palliative care and treatment for advanced disease:** In Scotland, guidance was issued about the broad general issues of palliative care<sup>48,42</sup> before the SIGN/SCTN guideline on colorectal cancer, which therefore dealt only with the narrower focus of treatment for advanced disease. The recommendations on this aspect of colorectal cancer fell under four different headings:- primary radical radiotherapy for inoperable cases of rectal cancer, local palliative radiotherapy, chemotherapy for patients with recurrent or disseminated disease (e.g. liver metastases), and psychosocial support.

The effectiveness of radical radiotherapy as a primary treatment for rectal cancer has not been established in randomised trials, however, patients who are medically unfit for surgery or who refuse surgery can be treated with radiotherapy. The dose will vary according to the circumstances of the patient, but the guideline recommended 4500 - 5500cGy in 20 fractions. There is a Medical Research Council trial of radiotherapy for advanced disease(CR-05) and this should help to identify optimum therapy.

Some metastatic deposits cause adverse symptoms e.g. bone, and radiotherapy can be given as local palliation where this option has not previously been used. It has shown some health status improvement by reducing rates of tumour recurrence

and possibly delaying onset of metastatic disease but this has not been established in a randomised trial. The dose recommended is in the range 3000-5000cGy in up to 6 fractions.

There is debate about the desirability of patients with advanced cancer undergoing chemotherapy treatment. However, the review<sup>5</sup> of studies of patients receiving chemotherapy for advanced colorectal cancer showed a survival benefit of around six months on average. There was also the extension of symptom-free survival as well as the relief of distressing and unpleasant symptoms from cancer in substantial minorities of patients. However, chemotherapy itself does have adverse side-effects and there is the need to guard against adding to the distress of patients who already have poor quality of life. While there is evidence of prolonging good quality of life for many patients with advanced disease, some patients will not wish to be actively managed beyond symptomatic control alone.

The resources required for the palliative care of patients with colorectal cancer are difficult to calculate. Around one-third of patients with colorectal cancer have advanced disease when they are first diagnosed. In addition, up to half of Dukes C cases undergo an operation which is not thought to have been curative by the surgeon. Finally, disease recurrence will occur in some cases with Dukes A and B cancers - in one series in, albeit in 1984, 4% and 13% respectively<sup>49</sup>. Overall, almost 60% of people presenting with colorectal cancer will die within 5 years of diagnosis. Such patients will require the holistic assessments and total provision of palliative care as well as any special therapies particularly effective against colorectal cancer. The costs of palliative care specific to colorectal cancer would be very difficult to estimate, as much of it is within general palliative care, and it is often integrated into primary care; special provision is patchy.

The Department of Health in England commissioned a needs assessment review<sup>50</sup> of palliative and terminal care, which proposed extending and refocusing resources. Additionally, their guidance on improving outcomes in colorectal cancer<sup>18</sup> covered recurrent and advanced disease and palliative care.

The benefits of preventing cancer recurrence and terminal care can be discussed in terms of deaths averted and recurrences avoided but what does this mean in terms of beneficial gain to patients? The survival gain depends on the patient's age and any co-morbidity. Less than 30% of patients are less than age 65 when diagnosed, as colorectal cancer usually occurs late in life. The median age at diagnosis in Scotland is 72, when average life expectancy is of the order of 10 years.

Apart from curing more people diagnosed with colorectal cancer, the main gain in health status from better treatment of this cancer comes from prolonging life of good quality despite the presence of cancer, in minimising recurrent disease, and in alleviating terminal illness. Reasonable health status is achievable, even in patients with terminal disease, and follow-up of patients having standard palliative care found that deterioration of physical health could be confined to the final few months of life, if local recurrence could be prevented. As with other forms of care for elderly patients, great attention should be given to realistic patient life goals and there should be a holistic health care approach to patients living with, and dying from, cancer. Numerous studies of patients with cancer show that most people wish to be told about their diagnosis and the options for treatment; this increased autonomy contributes positively to their life.

## 7 CONCLUDING COMMENTARY

Most of the key issues which may reduce population risk of colorectal cancer are already incorporated in national health promotion advice. However, it could be useful to assess whether local health promotion departments, when carrying out their broad range of activities in promoting better diet, increased exercise, and non-smoking, are linking these to the potential benefit of reducing the risk of colorectal cancer.

The new initiatives to detect colorectal cancer at earlier, more treatable, stages by screening high risk groups and the general population will require rigorous evaluation.

Epidemiological data show that colorectal cancer is not only an important cause of death, but also many patients survive to require increasingly complex packages of care which are being delivered in changing patterns of NHS provision. There is an increasing incidence, particularly in males, and there is a continuing trend to increased survival for patients with colorectal cancer. However, data from centres of excellence in the UK and abroad suggest that optimum application of best current practice can increase survival further.

There is scope to increase efforts at more adequate communication with patients: about diagnostic procedures for colorectal cancer, at the time when the cancer is diagnosed, in discussing the treatment options, and when following-up patients. This would improve the quality of life of patients who live with, and die from, colorectal cancer.

The Clinical Standards Board for Scotland will play a crucial part in the development and application of appropriate clinical standards of care for patients with colorectal cancer. This, allied with the work of the Scottish Cancer Group in establishing managed clinical networks underpinned by quality assurance arrangements for cancer services, including Scotland-wide prospective clinical audit, is designed to ensure that services are continuously monitored and improved for the benefit of patients.

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## 8 REFERENCES

1. The Scottish Office National Health Service in Scotland Management Executive. Scottish Cancer Co-ordinating and Advisory Committee. Commissioning Cancer Services in Scotland: Report to the Chief Medical Officer, SODoH. NHS MEL (1996) 54
2. The Scottish Office National Health Service in Scotland Management Executive. Commissioning Cancer Services in Scotland: Guidance for Purchasers and Providers in Planning the Service Configuration for Cancer Centres and Units. NHS MEL (1996) 83
3. The Scottish Office National Health Service in Scotland Management Executive. Priorities and Planning for the NHS in Scotland 1997-98. NHS MEL (1996) 59
4. Scottish Intercollegiate Guidelines Network. Colorectal Cancer: A National Clinical Guideline recommended for use. Published by Scottish Intercollegiate Guidelines Network 1997. ISBN 1 899893 85 7.
5. Scottish Colorectal Cancer Focus Group. Guidelines on Current Practice for Colorectal Cancer. Scottish Cancer Therapy Network 1997.
6. The Scottish Office National Health Service in Scotland Management Executive. Introduction of Managed Clinical Networks within the NHS in Scotland 1999-2002. NHS MEL (1999) 10
7. The Scottish Office Department of Health. Acute Services Review Report. (1998) The Stationery Office.
8. The Scottish Office National Health Service in Scotland Management Executive. Priorities and Planning for the NHS in Scotland 1999-2002. NHS MEL (1998) 63
9. Mountney L, Sanderson H, Harris J. 'Colorectal Cancer' in 'Health Care Needs Assessment' (volume 1) A Stevens and J Raftery (Eds) (Radcliffe Medical Press, Oxford 1994).
10. Cotton S, Sharp L, Little J. The adenoma-carcinoma sequence and prospects for the prevention of colorectal neoplasia. Critical Reviews in Oncogenesis 1996 7(5&6) 293-342.
11. Sharp L, Black RJ, Harkness EF, Finlayson AR, Muir CS. Cancer Registration Statistics Scotland 1981-1990. Information & Statistics Division, National Health Service in Scotland, 1993.
12. Information & Statistics Division: Scottish Cancer Intelligence Unit. Cancer Registration Statistics Scotland 1986-1995. Edinburgh: ISD, National Health Service in Scotland, 1998.
13. The Scottish Office National Health Service in Scotland Management Executive. Commissioning Cancer Services in Scotland: Cancer Genetics Services in Scotland. NHS MEL (1998) 73.
14. Kemp I, Boyle P, Smans M, Muir C, eds. Atlas of Cancer Incidence in Scotland 1975~1980 Incidence and Epidemiological Perspective. Lyon: International Agency for Research, 1995 (LARC Scientific Publications No. 72).
15. Harris V, Thomson C. Personal communications: Scottish Cancer Intelligence Unit, Information & Statistics Division, National Health Service in Scotland, 1999.
16. Black RJ, Sharp L, Kendrick SW. Trends in Cancer Survival in Scotland 1968-1990. Information & Statistics Division, National Health Service in Scotland, 1993.
17. Department of Health NHS Executive. Guidance to general practitioners and primary care teams. Improving outcomes in colorectal cancer. 1998 Department of Health.

18. Department of Health NHS Executive. Improving outcomes in colorectal cancer: Guidance on Commissioning Cancer Services. 1997 Department of Health, NHS Executive EL(97)66.
19. The Scottish Office National Health Service in Scotland Management Executive. Clinical Outcome Indicators - July 1996. NHS MEL (1996) 18.
20. Ionescu M V, Carey F, Tait IS, Steele R J C. Socio-economic status and stage at presentation of colorectal cancer. *Lancet* 1998 352: 1439.
21. McLaren G, Bain M. Deprivation and health in Scotland: insights from NHS data. Edinburgh: ISD, National Health Service in Scotland, 1998.
22. Pollock A M, Vickers N. Trends in colorectal cancer care in southern England, 1989-93: using HES data to inform cancer services reviews. *J Epidemiol Community Health* 1998 52: 433-438.
23. Consultant Surgeons and Pathologists of the Lothian and Borders Health Boards. Lothian and Borders large bowel cancer project: immediate outcome after surgery. *British Journal of Surgery* 1995 82: 888-890.
24. Information & Statistics Division: Scottish Cancer Intelligence Unit. Annual Report 1996-1997. Edinburgh: ISD, National Health Service in Scotland, 1997.
25. World Cancer Research Fund in association with the American Institute for Cancer Research Food, nutrition and the prevention of cancer: a global perspective. Washington 1997 The American Institute for Cancer Research. ISBN: 1 899533 05 2
26. Fuchs C S *et al.* Dietary fibre and at the risk of colorectal cancer and adenoma in women. *N Eng J Med* 1999 340: 169-176.
27. Giovannucci E *et al.* Multi-vitamin use, folate and colon cancer in women in the nurses' health study. *Ann Intern Med* 1998 129: 517-524.
28. Social and Economic Research Council. The nation's diet: the social science of food choice. Ed. A Murcott 1998 Longman ISBN: 0 582 30285 4.
29. US Surgeon General's Report. Physical activity and health. US Department of Health and Human Sciences. 1996.
30. Grodstein F *et al.* Postmenopausal hormone use and risk for colorectal cancer adenoma. *Ann Intern Med* 1998 128:705-712.
31. IARC Working Group. IARC Handbook of Cancer Prevention. Volume 1. Non-steroidal anti-inflammatory drugs. Lyon. IARC 1997.
32. Sander R S *et al.* Aspirin and Non-steroidal anti-inflammatory agents and risk for colorectal adenomas. *Gastroenterology* 1998 114: 441-447.
33. Hoover R N. Cancer prevention: better late than never? *Ann Intern Med* 1998 128: 771-772.
34. Working Group on Diet and Cancer of the Committee on Medical Aspects of Nutrition. Report on: Nutritional aspects of the development of cancer. 1998 Report on Health and Social Subjects. No. 48. DH: The Stationery Office
35. The Scottish Office National Health Service in Scotland Management Executive. Eating for Health: A Diet Action Plan for Scotland. NHS MEL (1996) 63.
36. The Scottish Office National Health Service in Scotland Management Executive. Towards a Healthier Scotland. NHS MEL (1998) 6.
37. The Scottish Office National Health Service in Scotland Management Executive. Screening for Colorectal Cancer. NHS MEL (1998) 62.
38. The Scottish Office National Health Service in Scotland Management Executive. Commissioning Cancer Services in Scotland: Cancer Genetics Services in Scotland. NHS MEL (1998) 7.
39. Dunlop M. Personal communication. MRC Human Genetics Unit. 1999.
40. Effective health care. The management of colorectal cancer. 1997 Volume 3: Issue 6 The NHS Centre for Reviews and Dissemination.

41. Communication with the cancer patient: information and truth. Eds. A Surbone and M Zwitter. Volume 809 Annals of the New York Academy of Sciences. 1997 ISBN 0 89766 986 x
42. The Scottish Office National Health Service in Scotland Management Executive. Commissioning Cancer Services in Scotland: Primary and Palliative Care Services. NHS MEL (1997) 17.
43. Cox DR, Fitzpatrick A, Fletcher AE, Gore SM, Spiegelhalter DJ, Jones DR. Quality of life assessment: can we keep it simple? *J Royal Stat Soc (Series A)* 1992 155: 353 -392.
44. Steine S. Which hurts most? A comparison of pain rating during double contrast barium enema examination and colonoscopy. *Radiology* 1994 191: 99-101.
45. McCarthy B D, Moskowitz M A. Screening of flexible sigmoidoscopy: patient attitudes and compliance. *J Gen Intern Med* 1993 8: 120-125.
46. British Gastroenterology Society. Recommendations for standards of sedation and patient monitoring during gastrointestinal endoscopy. 1991 32: 327-36.
47. The Scottish Office National Health Service in Scotland Management Executive. Towards a New Way of Working: The Plan for Managing People in the NHS in Scotland. NHS MEL (1998) 33.
48. The Scottish Partnership Agency for Palliative and Cancer Care with the Scottish Office Home and Health Department Clinical Resource and Audit Group: Palliative Cancer Care Guidelines 1994.
49. Phillips R, Hittinger R, Blesovsky L, Fry J, Fielding P. Local recurrence following curative surgery for large bowel cancer: 1 The overall picture. *Br J Surg* 1984 71: 12-16.
50. Higginson I. Palliative and Terminal Care - in Health Care Needs Assessment: Second Series. Eds. A Stevens and J Raferty 1997 Radcliffe Medical Press; Oxford. ISBN 1 85775 199 X.