# A review of bowel cancer services

## An early diagnosis

Key messages / Prepared for the Auditor General for Scotland

March 2005

AUDIT SCOTLAND

# Key messages

## Why do these services matter?

**1.** Bowel (colorectal) cancer is the third most common cancer in Scotland, with around 3,500 cases diagnosed each year. It is the second most common cause of cancer deaths. The incidence of bowel cancer in Scotland is substantially higher than in England and Wales, and survival rates are consistently lower than in other western European countries (Exhibit 1) but have improved markedly in the last five years.

**2.** The number of cases is expected to continue to rise over the next ten years. This increase in demand will place real pressures on bowel cancer services, as will increased activity arising from the planned introduction of national bowel screening in 2006.

## The study

**3.** Audit Scotland has reviewed the management of bowel cancer services on behalf of the Auditor General. We visited services in each mainland NHS board area in Scotland (26 hospitals), collected management information and clinical activity data, and conducted interviews with staff to identify areas of good practice and review performance against clinical standards and national waiting times targets.

**4.** We also commissioned independent research involving in-depth interviews with patients to gather their views on the experience of bowel cancer services.

**5.** The main findings and recommendations from our review are outlined in this summary report which accompanies the main report.

**6.** We undertook our fieldwork during the period of health service reorganisation when NHS trusts were still in existence in some parts of Scotland. Our recommendations are aimed at the new unified NHS boards which are now in place.

## The future direction for bowel cancer services in Scotland is clear but more emphasis is needed on securing better value from existing resources

**7.** The *Scottish Cancer Plan*[1] and the *Bowel Cancer Framework*[2] provide a clear direction for cancer services, but the absence of specific improvement measures makes it difficult to judge progress.

**8.** Scotland's three managed clinical networks for bowel cancer have made good progress in auditing clinical practice and promoting high quality care. But they need to do more to support improvements in waiting times and make best use of resources. Their work, and that of the three regional cancer networks, has so far focused largely on the new funds available under the cancer plan, these represent only a small fraction of overall spending on cancer services. The real challenge will come in redesigning existing services (including reallocating existing resources) which equate to over 90% of total cancer spend in Scotland, rather than relying on additional funding.

**9.** The national bowel cancer framework group, is well placed to take forward these issues. It is currently preparing detailed strategies to address priority areas such as endoscopic capacity, workforce planning, and training.

## Variation in practice by GPs is contributing to delays in referral….

**10.** The early identification and referral of patients suspected of having bowel cancer is essential for high quality care. But it is not straightforward. The most common symptoms – change in bowel habit, rectal bleeding, abdominal pain and those associated with anaemia, such as pallor and tiredness – are non-specific, occur frequently in the general population, and have a wide variety of causes.

**11.** Because of this, national referral guidelines have been prepared to help GPs identify those patients who should be referred to hospital for specialist diagnostic tests, but GPs do not always follow these guidelines. A third of the patients we interviewed reported major delays before referral to hospital. It would be wrong to generalise too widely from these findings, especially as the presentation of gastrointestinal symptoms in general practice is often vague, but they are consistent with earlier research. Taken together it shows that the way in which some patients are managed in the community could be improved.

**12.** The non-specific symptoms of bowel cancer mean that it is important that formal referral arrangements are in place, but fewer than half of acute divisions had agreed these with primary care. This can lead to inconsistent referral information, making it difficult to identify the most appropriate diagnostic tests for individual patients, or initial referrals being directed to non-specialist staff. Both can lead to delays in diagnosis.

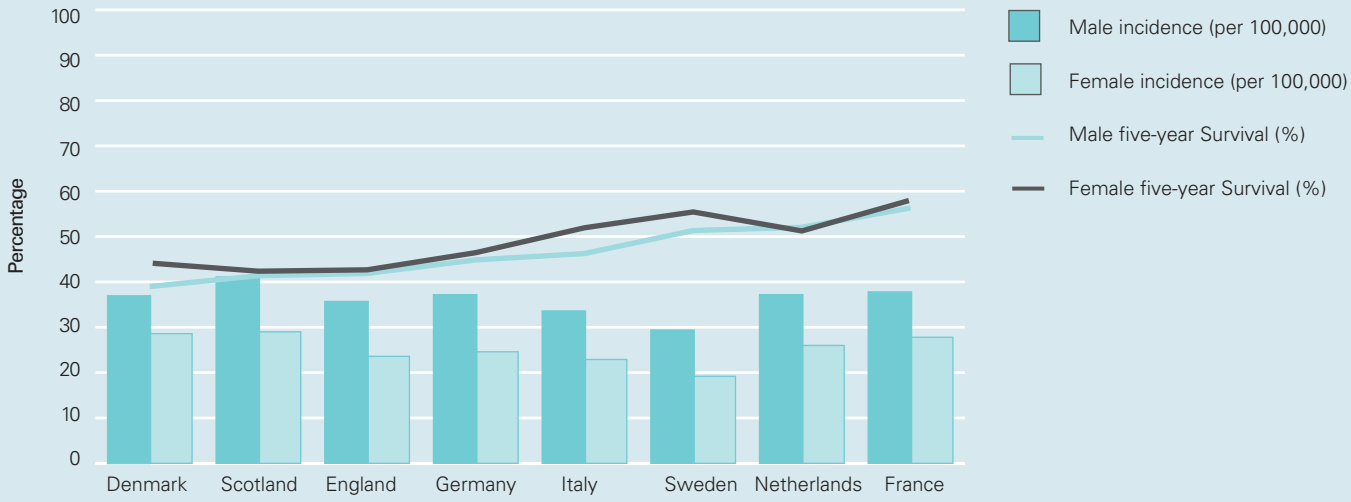
**13.** Although guidelines and protocols are useful, securing effective implementation is a greater challenge. Better identification and referral of suspected bowel cancer cases depends critically upon a partnership approach between hospital-based specialists and local GPs.

1 *Cancer in Scotland: Action for change*, SEHD (2001), Edinburgh: The Scottish Executive.
2 Bowel Cancer Framework for Scotland, SEHD (2004), Edinburgh: The Scottish Executive.

## Exhibit 1

Incidence (1995) and survival rates (1987-89) for bowel cancer: international comparisons[3]

Scotland has a higher incidence and lower survival rate for bowel cancer than most other Western European countries.




**Source:** Clinical Outcome Indicators, Clinical Outcomes Working Group, (CRAG) December 2000

### … and better use can be made of existing diagnostic resources

**14.** The choice of diagnostic method can also be complicated, and needs to take account of the patient's symptoms, age, family history and other risk factors, together with the relative benefits, risks and costs of the diagnostic methods themselves. This is important to diagnose patients accurately, reduce waiting times and make best use of finite resources.

**15.** Clinicians in Scotland have already begun to develop risk-based diagnostic models, building on the research which has taken place in this area in England.[4] The bowel cancer framework group is actively considering how this work can be rolled-out across Scotland so that diagnostic tests (colonoscopy, flexible sigmoidoscopy and barium enema) are effectively targeted and value for money achieved.

**16.** In spite of this only 5 out of 26 hospitals providing bowel cancer services in Scotland (19%) use risk-based diagnostic pathways to guide the choice of diagnostic method, although the rest are working currently to introduce them.

**17.** Some hospitals offer colonoscopy as the main diagnostic test for most patients, regardless of their symptoms. This offers poor value for money, and is unlikely to be the best approach for all patients.

### Most bowel cancer patients in Scotland receive high quality, well coordinated care….

**18.** Multi-disciplinary teams, which discuss and agree care plans for patients, are in place and working effectively at almost every hospital in Scotland providing bowel cancer services. Good progress has been made in developing information for patients, and in training staff in effective communication.

**19.** Patients generally feel that communication is honest and clear, and that they are included in decisions about their treatment. They particularly value the contribution that specialist nurses make in coordinating care and offering support to them and their families. However, there is a need to ensure that specialist nurses' relatively expensive skills are used to best effect, and the Scottish Executive Health Department (SEHD) needs to issue clearer guidance on their role to ensure this.

### Patients' quotes:

*"She said I have some good news and some bad and she drew where it was, why it could not be saved at all because it was right on the edge. There was a specialist rectal nurse there. Excellent.*

*(Respondent 10)*

*"How did that make you feel: to have a choice?"*

*(Researcher)*

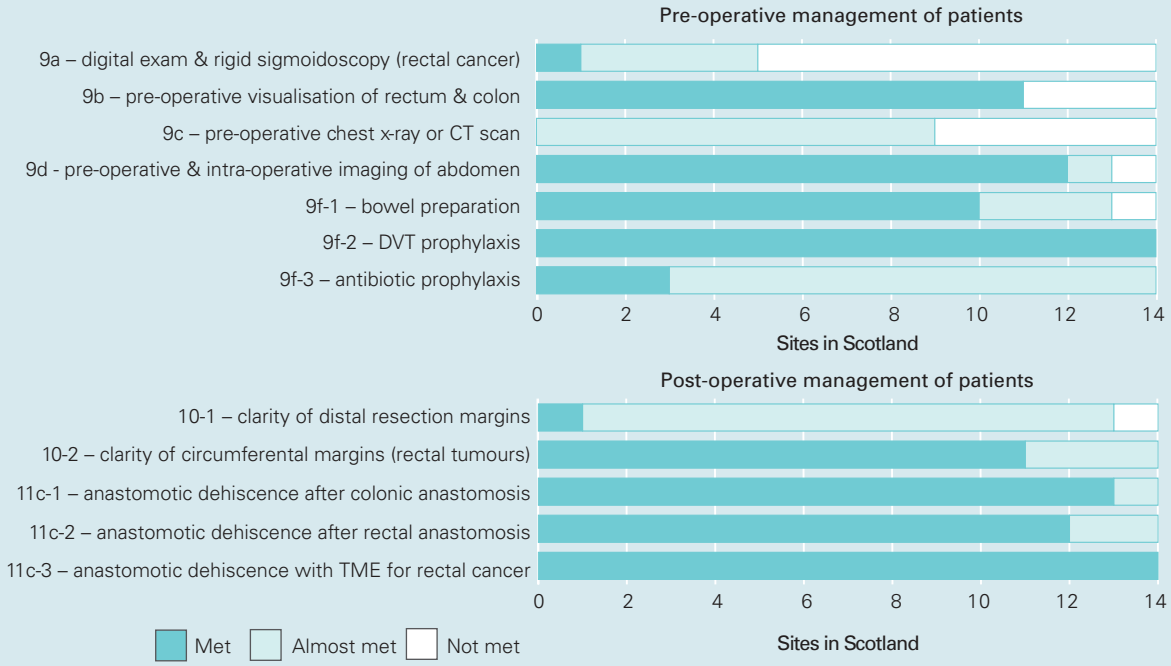
*"I was surprised but pleased they didn't just do unto me. I felt I had got some say in what was going on."*

*(Respondent 3)*

3 Note: incidence rates for colorectal cancer in England also include Wales. Wales is not included in the English survival rate statistics.
4 The diagnostic value of the common sympton combinations of bowel cancer in a surgical clinic, M R Thompson, A Senapati, S Dodds. 2004 (awaiting publication).

# Exhibit 2

Bowel cancer compliance with clinical standards across NHSScotland




**Source:** NOSCAN, SCAN, WOSCAN

**20.** There are clear clinical standards for the treatment of patients with bowel cancer, and most hospitals comply with those standards (Exhibit 2). A small number of the standards have not kept pace with clinical practice and need updating. Clinicians at some hospitals need to record more accurately the care that patients are receiving if they are to demonstrate that standards are being met.

**21.** There is good evidence that patients with rectal cancer who are operated on by a specialist surgeon do better, and performance is improving. Across Scotland, almost 90% of patients with rectal cancer were operated on by a specialist in 2003, and no hospital fell below 75%.

**… but many patients are waiting too long for diagnosis and treatment. Whilst performance is improving, if current trends continue it is unlikely that the target of all patients starting treatment within 2 months from urgent referral will be met by the end of 2005**

**22.** *Our National Health*[5] pledged that by 2005 the maximum wait from urgent referral to treatment for all cancers will be two months.

**23.** This target, presents a major challenge for bowel cancer services. In the third quarter of 2004 only six in ten patients in Scotland started treatment within the two-month target period (Exhibit 3, page 4). Almost 70% of patients with bowel cancer were not given an urgent referral by their GP.

**24.** Bowel cancer patients pass through three stages of care:

- GP referral to initial contact with a hospital clinician.
- Initial contact with a hospital clinician to definitive diagnosis.
- Definitive diagnosis to the start of treatment.

**25.** We analysed where delays for patients tend to occur. For most patients the shortest wait is from first clinical contact in hospital to diagnosis; the longest wait is for treatment to start after diagnosis. Much work needs to be done to streamline the process through which care is provided to reduce delays. The introduction of pre-booking of diagnostic tests should lead to improvements in waiting times performance.

**26.** In England all urgent bowel cancer referrals should be seen within two weeks. There are no Scottish targets for the time from GP referral to first clinical contact. We found that only 45% of patients are seen within two weeks and 14% of patients wait longer than two months.

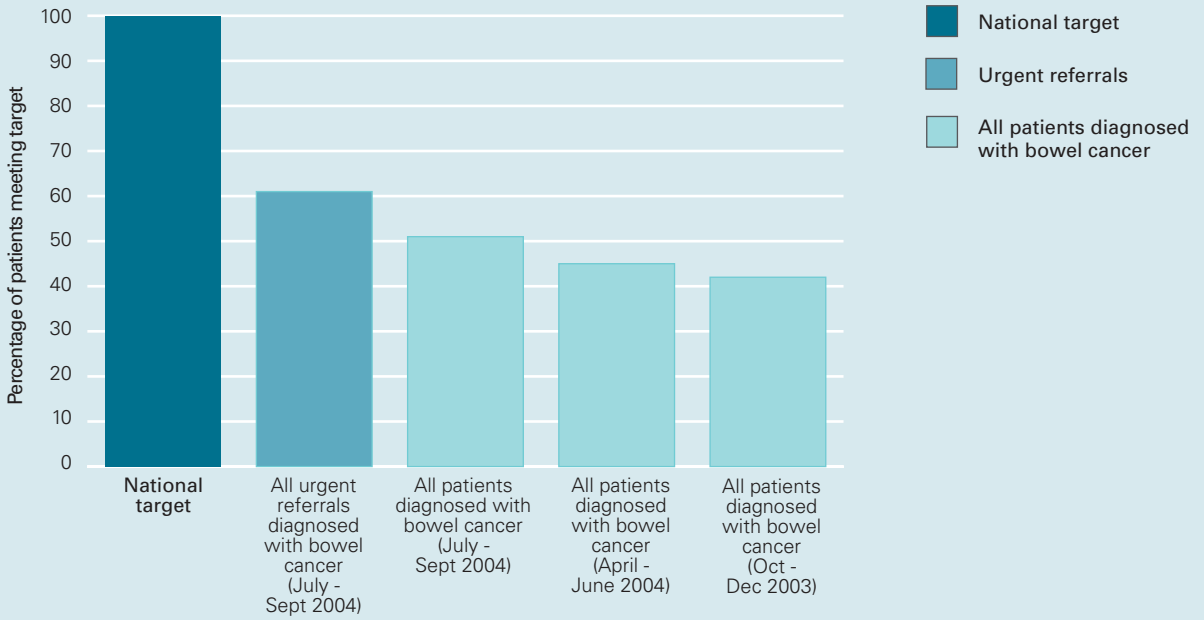
**27.** The reasons for these delays include:

- the continued reliance on paper-based referral systems

5 *Our National Health, a plan for action, a plan for change: The* Scottish Executive, December 2000.

## Exhibit 3

**Performance against the national target, that by 2005 the maximum wait from urgent referral to treatment for all cancer will be two months (Oct – Dec 2003 to July – Sept 2004)**




**Source:** Colorectal Cancer Waiting Times Quarterly Report January 2005 (Compiled by ISD on behalf of the Regional Cancer Networks)/Audit Scotland fieldwork 2004

- 'named' referrals to individual consultants
- unclear referral information from GPs.
- the impact of the New Deal for junior doctors

**28.** Once patients have been seen by the clinical team, diagnosis is relatively fast. More than half receive a diagnosis within a week, and almost 75% within a month.

**29.** The CSBS standard for the time between diagnosis and first definitive treatment is that this should be no more than four weeks (CSBS Standard 8a). Only six in ten patients currently start treatment within four weeks.

**30.** Two of the most common reasons for delays are:

- routine staging delays (eg, waiting times for CT and MRI scans) or referrals for further investigation prior to surgery
- lack of facilities (including theatre and staff).

### Big challenges lie ahead, but opportunities exist to deliver major improvements in performance

**31.** Big challenges lie ahead in meeting the 2005 waiting times target for the diagnosis and treatment of urgent bowel cancer patients, and implementing national bowel screening so that it does not slow up diagnosis and treatment for symptomatic patients.

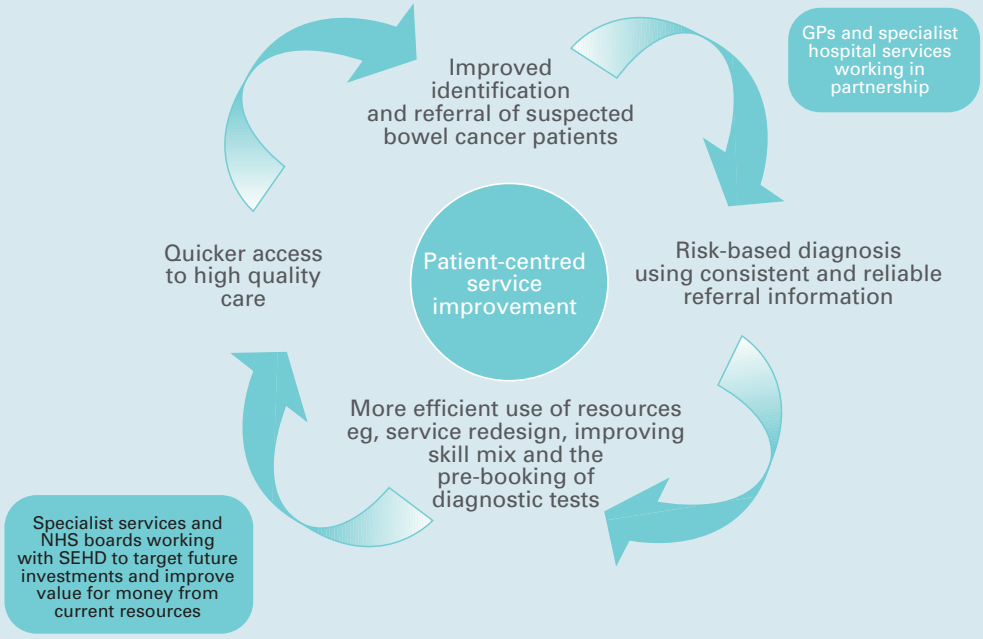
**32.** The agenda for the future should include:

- strengthening the partnership between GPs and specialist services to improve the identification and referral of suspected bowel cancer patients
- implementing risk-based diagnostic models to speed up the diagnostic process and make more efficient use of resources
- streamlining and simplifying the patient pathway and introducing pre-booking of diagnostic tests to reduce delays
- developing the nurse and GP endoscopy role to ensure that existing endoscopic resources are used to maximum capacity. At present few endoscopy suites are working to full capacity, largely because of a lack of qualified staff
- improving the routine management information available on the cost and performance of bowel cancer services, and
- using that information to target investment in the staff, equipment and locations where it will have most effect.

**33.** Delivering this will require coordinated activity within and across the three Regional Cancer Networks with clear leadership from the Health Department. This could lead to a 'virtuous circle' of change which supports continuous improvement in bowel cancer services in Scotland (Exhibit 4, page 5).

## Exhibit 4

The 'virtuous circle' of partnership working and intelligent targeting of existing and new resources




**Source:** Audit Scotland 2005

# Key recommendations

- When preparing future strategies for cancer services in Scotland the Health Department should include:
  - clear and specific measures against which progress in improving cancer services can be assessed and reported (for example, survival, equity of access to care, waiting times, patient satisfaction)
  - a clear statement on how improved value for money is to be achieved.

- The Health Department should:
  - consider how best to deliver improved efficiency and the redesign of existing services within the network-based model of working
  - develop formal measures for reporting on the cost and performance of current cancer services
  - determine how endoscopy training in Scotland will be supported and introduce an accreditation programme for endoscopy practitioners.
- The national bowel framework group should consider reviewing existing GP referral guidelines and work with the health department in raising awareness of risk factors with GPs.

- All NHS boards should agree local referral protocols between GPs and specialist bowel cancer services.
- The bowel cancer framework group should issue guidance on referral and triage arrangements/handling of referrals and allocating priority in secondary care.
- The key improvement actions identified by Scotland's three bowel cancer clinical networks to ensure that the 2005 waiting times target will be met, should be used to inform future development of the bowel cancer framework.

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