

A review of bowel cancer services

An early diagnosis

Prepared for the Auditor General for Scotland

March 2005



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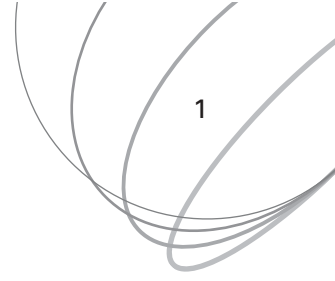
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Contents



Summary **Page 2**

Background
The study
Key findings
Page 3

Part 1. Introduction **Page 4**

What is bowel cancer?
Page 4

Population bowel screening
Page 8

Part 2. Where are we going with bowel cancer services in Scotland? **Page 9**

Has the Health Department set a
clear agenda for bowel cancer
services in Scotland?
Page 9

How effective have networks been
in improving the quality of services
and delivering value for money?
Page 11

Part 3. Referral and diagnosis **Page 15**

Identifying and referring patients
Page 15

Choice of diagnostic method
Page 18

Making best use of existing
diagnostic resources
Page 19

Part 4. Quality of care and treatment **Page 22**

Coordination of care, communication
and support for patients
Page 22

The quality of clinical management of
bowel cancer patients
Page 28

Patient care before surgery
Page 28

Patient care during and after surgery
Page 33

Clinical audit and follow-up
Page 34

Part 5. Waiting times performance **Page 38**

How likely is it that the Health
Department's 2005 '2-month' waiting
times target will be met?
Page 38

Waiting times from GP referral to
initial contact with a hospital clinician
Page 41

Waiting time for diagnosis
Page 43

Waiting time to surgery or other
treatment
Page 44

Part 6. The agenda for the future **Page 45**

The challenge ahead
Page 45

Improving management at primary
care
Page 45

Making efficient use of resources
Page 46

Getting the right staff, with the right
skills in the right place
Page 48

Improving management information
Page 50

Glossary **Page 52**

Appendix 1
Expert advisory group
Page 57

Appendix 2
Bowel cancer clinical compliance with
bowel preparation standard 9f (1-3)
Page 58

Appendix 3
Bowel cancer clinical compliance with
standard 10 (1-2) margin clarity
Page 59

Appendix 4
Bowel cancer clinical compliance with
standard 11c (1-3) anastomotic
dehiscence after surgery
Page 60

Summary



High quality bowel cancer care needs good partnership working between GPs and specialist services, effective communication and coordination, and efficient use of diagnostic resources.

Background

1. Tackling cancer is one of NHSScotland's priorities, together with heart disease and mental health.
2. Cancer affects almost everyone at some point in their life, not just the people who are diagnosed with the disease every year in Scotland, but their families and friends, and the many health professionals and others involved in their care.
3. Colorectal cancer (sometimes known as large bowel cancer) is the third most common cancer in Scotland, with on average about 3,500 cases diagnosed each year. It is the second most common cause of cancer deaths in Scotland. Over the past 50 years its incidence has risen and is predicted to continue to grow for the next ten years.²

The study

4. In carrying out this study on bowel cancer services we:
 - reviewed how health bodies are implementing the *Cancer in Scotland* strategy
 - evaluated the impact of the 'new' cancer monies
 - considered how effectively regional cancer networks and bowel cancer managed clinical networks (MCNs) are helping to improve patient care
 - examined how bowel cancer services in Scotland are performing against clinical standards and national waiting times targets
 - commissioned independent in-depth qualitative research on the experiences of bowel cancer patients
 - audited the current capacity and performance of colonoscopy and other diagnostic tests. This exercise was to help regional cancer networks, and the Scottish Bowel Cancer Framework Group in their planning for implementation of a national bowel cancer screening programme.
5. The review took account of the 2002 Clinical Standards Board for Scotland (CSBS) national overview of colorectal cancer services, and provides a measure of the progress that has been made since then in improving bowel cancer services.

Key findings

6. Our main findings are outlined below and are developed further in the main body of the report:
 - The future direction for bowel cancer services in Scotland is clear but more emphasis is needed on securing better value from existing resources ([see Part 2](#)).
 - Variation in practice by GPs is contributing to delays in referral ([see Part 3](#))....
 - ...and better use can be made of existing diagnostic resources ([see Part 3](#)).
 - Most bowel cancer patients in Scotland receive high quality, well coordinated care ([see Part 4](#))....
 - ...but many patients are waiting too long for diagnosis and treatment. It is unlikely that the target of all patients starting treatment within two months for all urgent referrals will be met by the end of 2005 ([see Part 5](#)).
 - Big challenges lie ahead, but opportunities exist to deliver major improvements in performance ([see Part 6](#)).

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

2 *Cancer Scenarios: An aid to planning cancer services in Scotland* (03: Colorectal Cancer), Scottish Executive, Edinburgh, 2001.

Part 1. Introduction



What is bowel cancer?

7. Bowel (colorectal) cancer is cancer of the colon or rectum. Around 65% of bowel cancers occur within the colon and around 35% in the rectum, or the section where the rectum and the colon join.

8. Bowel cancer develops when cells in the colon undergo a series of changes in some of the genes that control how the cell divides and survives. As a result, the cell divides uncontrollably to form a clump of cells. Initially, these cell changes often produce a pre-cancerous polyp (a clump of abnormal cells the size of a pea on the end of a stalk of normal cells) called an adenoma. Only about five per cent of polyps progress to become life-threatening cancers.

9. The polyp enlarges very slowly, typically over around ten years, to between 1cm and about 5cm in diameter. The abnormal cells invade the stalk of the polyp first, then the underlying tissue of the colon to which the stalk is attached. This

invasion indicates that cancer has developed. The risk of invasive cancer increases once the polyp diameter has exceeded 1cm. Polyps can be either sessile or pedunculated.

10. About 30% of bowel cancers arise from flat lesions. This particularly occurs with cancers of the proximal (right-sided) colon and caecum ([Exhibit 1](#)).

11. If the cancer is not removed quickly, cancerous cells can break off from the tumour and move through veins or lymph vessels to form tumour growths (called metastases or secondaries) elsewhere, particularly in lymph glands or in the liver. Once this has happened, the cure rate falls sharply.

Symptoms of bowel cancer

12. The most common symptoms of bowel cancer include change in bowel habit, rectal bleeding, abdominal pain and those associated with anaemia, such as pallor and tiredness. The non-specific symptoms make assessing an

individual's risk difficult. They also mean that patients may be referred to a wide range of hospital specialities.

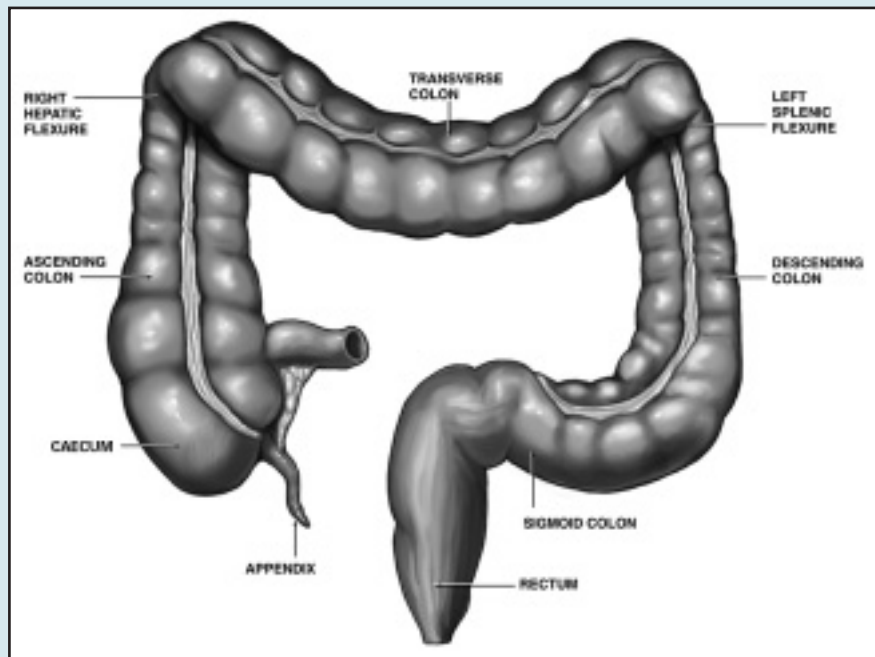
Diagnosis and treatment

13. In cases of suspected bowel cancer, there are two main types of investigation: endoscopy (flexible sigmoidoscopy or colonoscopy) and imaging (barium enema, computed tomography (CT) and CT colonography). Each method has specific advantages and disadvantages that make it more or less appropriate for particular patients.

14. Endoscopy: The main instruments used in endoscopic examination of the large bowel are either a colonoscope or a flexible sigmoidoscope. A colonoscope is a long, thin, flexible tube with a tiny video camera and a light at the end. By adjusting the controls it can be guided in any direction to look at the inside of the colon. It can be used to view the whole of the large bowel. A flexible sigmoidoscope is a long thin flexible tube which contains a

Exhibit 1

Illustration of the anatomy of the large bowel (the colon and the rectum)



Source: Copyright 2005 Nucleus Medical Art, Inc. All rights reserved. www.nucleusinc.com

tiny video camera. Because it is shorter than a colonoscope it can only reach the rectum, sigmoid and descending colon as far as the splenic flexure. For some patients, sedation will be required for either a colonoscopy or flexible sigmoidoscopy.

15. Using an endoscope to view the bowel has the advantage of permitting biopsy and histopathological assessment of any suspicious lesion and removal of polyps. Colonoscopy involves little risk when carried out as a diagnostic procedure by experienced operators. It is, though, associated with a higher risk than flexible sigmoidoscopy or barium enema. The overall procedure-related mortality is approximately 1 in 5,000. The majority of adverse effects occur when polyps are removed during therapeutic colonoscopies rather than during diagnostic colonoscopies.³

16. Imaging: Barium enema is well established in the NHS. It is safe, widely available, and there is no need for sedation. CT colonography (also known as 'virtual colonoscopy') is a relatively new technology.⁴ Patients with abnormal findings may require a subsequent colonoscopy to biopsy or remove suspicious lesions.

17. Ultrasound and CT scans are used to investigate the disease further, usually for staging the cancer rather than for diagnosis. Staging is the process of determining the size, site and spread of the disease. Magnetic Resonance Imaging (MRI) is used for the staging of rectal and more advanced colon cancers. Imaging tests are safe but not entirely risk-free. Barium enema and CT colonography carry a lifetime additional risk of cancer per examination of between one in 10,000 and one in 100,000.⁵

18. Positron emission tomography (PET) imaging (often used in combination with CT scans⁶) has in recent years established itself as a tool for restaging recurrent disease before further surgery.⁷ This technology is not widely used in Scotland as at present there is only one PET scanner in the country which is located in Aberdeen, although a national procurement programme is now underway.

19. Following the investigations described above, a definitive diagnosis is made. For patients with a diagnosis of bowel cancer, there are a number of treatment options:

- **Surgery:** For most patients, surgery is the first-line treatment. The surgeon will remove the portion of the colon or rectum containing the cancer, together with a healthy margin of tissue either side of the tumour and the

³ *Endoscopic perforation of the colon: Lessons from a 10-year study*, Monte L, Anderson M D, Tousif M, Pasha T M, Leighton J A. *Am J Gastroenterology* 2000; Vol 95: 12 3418-3422.

⁴ CT colonography practice in the UK: a national survey, Burling D, Halligan S, Taylor SA, et al. *Clin Radiol* 2004; 59:39-43

⁵ *X-rays. How safe are they?* NRPB, 2001.

⁶ *PET/CT in Oncology: Integration into Clinical Management of Lymphoma, Melanoma, and Gastrointestinal Malignancies*, Schoder H, Larson M L, Yeung H, *The Journal of Nuclear Medicine*. Vol 45, No 1, (Suppl) January 2004.

⁷ PET imaging in assessing gastrointestinal tumors, Hustinx R, *Radiol Clin N Am* 42 (2004) 1123-1139.

surrounding lymph nodes to help reduce the chances of the disease spreading or recurring. For patients with rectal cancer, the use of total mesorectal excision (TME) is now routine practice for cancer in the middle or lower two-thirds of the rectum. The mesorectum is a fatty tissue directly adjacent to the rectum that contains blood vessels and lymph nodes. When rectal cancers recur, it is often in these lymph nodes. TME surgery (removal of the mesorectum) therefore leads to a very low risk that cancer will recur in this part of the bowel.

- **Chemotherapy and radiotherapy:** Chemotherapy and radiotherapy are used for patients with both early and advanced cancers. Chemotherapy can be given as tablets, a weekly injection, an infusion or continuously through a pump after surgery. Radiotherapy is used more commonly to treat cancer of the rectum and can be given prior to or following surgery. Prior to surgery radiotherapy can be used to down-stage the tumour. In cases of advanced bowel cancer, chemotherapy and radiotherapy are given to shrink the cancer, slow the rate of growth and control any symptoms.

Bowel cancer – the third most common cancer in Scotland

20. Bowel cancer is the third most common cancer in Scotland for both men and women, with on average about 3,500 bowel cancer cases diagnosed each year. It is the second most common cause of cancer death in Scotland. Over the past 50 years its incidence has risen.

21. It has been estimated that the incidence of bowel cancer will continue to increase over the next ten years, with the total number of cases set to rise from 3,390 in 1995-96 to 4,467 in 2011-15.⁸ This projected increase will place a significant demand on bowel cancer services.

22. Bowel cancer can develop in men and women of any age but it tends to be a disease of late middle age or older. In the UK, about 75% of cases occur in people over the age of 55 (Exhibit 2).

23. Although the exact cause of bowel cancer is unknown, there are several factors that make people more at risk:

- In the UK, 5-10% of all people diagnosed with bowel cancer have a family history of the disease. Often if there is a family history the disease appears at an earlier age – under 45.
- People who have an inflammatory bowel disease (IBD), such as Crohn's disease or ulcerative colitis, tend to be more at risk. The duration and extent of IBD is an important indicator of heightened risk.

- Those who have had a polyp removed in the past may be at an increased risk.
- Diets high in fat and low in vegetables, combined with an inactive lifestyle, can increase the risk of developing the disease.
- Long-term smoking; it has been estimated that one in five colorectal cancers in the USA might be attributed to tobacco use.

International comparisons of incidence and survival

24. A number of powerful studies have shown substantial variations in survival from bowel cancer. These show Scotland in an intermediate group for bowel cancer survival (along with England, Wales, and Denmark), with higher survival rates than East European countries, but consistently lower survival rates than other Western European Countries⁹ (Exhibit 3).

25. It has been argued that these international variations can in part be explained by the fact that patients in Scotland tend to have more advanced disease before they contact the health service,^{10, 11} but the availability and quality of clinical services are also important.

26. International comparisons do need to be treated with some caution. Scotland's cancer registry is recognised as one of the best in the world. The level of completeness of Scottish data gives high levels of confidence that published figures present a true position of Scotland's

8 *Cancer in Scotland: Sustaining Change – Cancer Incidence Projections for Scotland (2001-2020) An Aid to Planning Cancer Services*, Scottish Executive 2004.

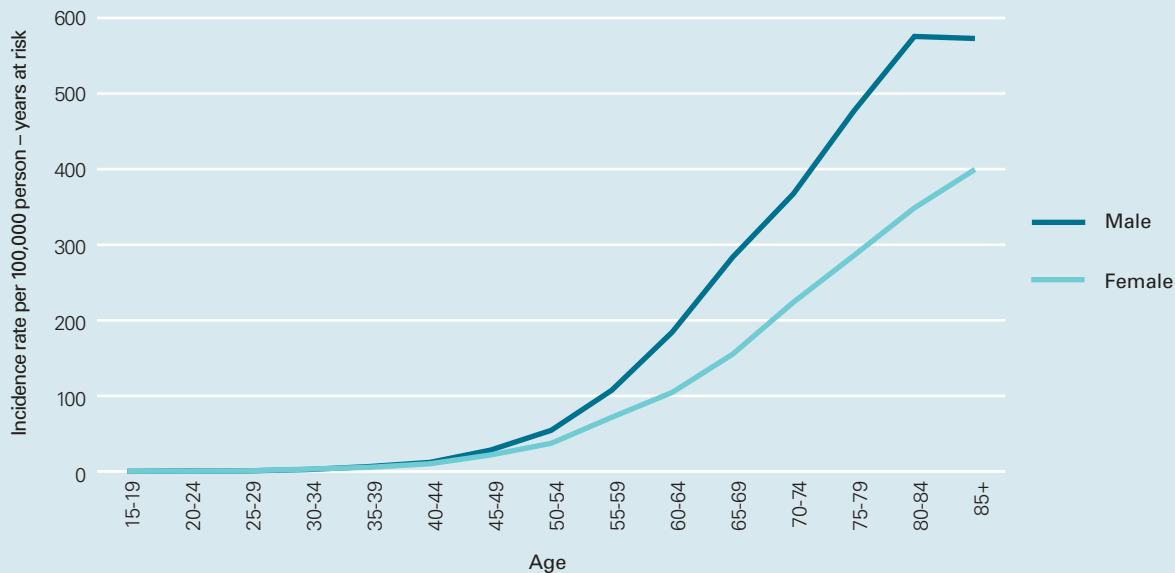
9 *Clinical Outcome Indicators*, Clinical Outcomes Working Group, December 2000.

10 *Understanding variations in survival for colorectal cancer in Europe: a EURO CARE high-resolution study*, Gatta G, Capocaccia R, Sant M, Bell CMJ, Coebergh JWW, Damhuis RAM, Faivre J, Martinez-Garcia C, Pawlega J, Ponz de Leon M, Pottier D, Raverdy N, Williams EMI, and Berrino F (2000), *Gut*; 47: 533-538.

11 *Are differences in stage at presentation a credible explanation for reported differences in the survival of patients with colorectal cancer in Europe?* Woodman C, et al, *Br J Cancer*, 2001. 85(6): 787-790.

Exhibit 2

Incidence of bowel cancer by age and gender, 1997–2001

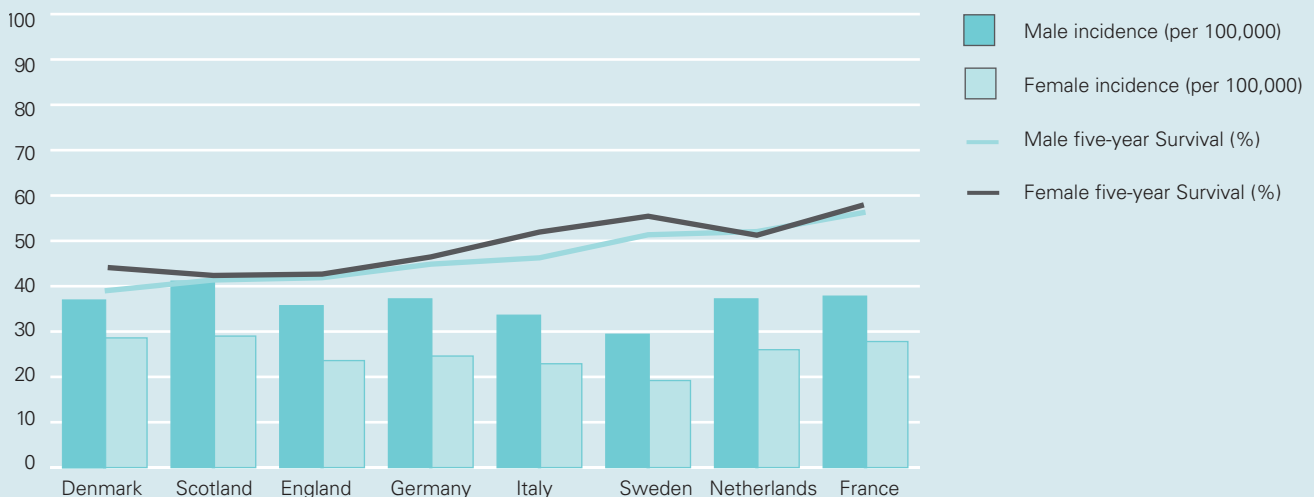


Source: Scottish Cancer Registry, Information Services Division (ISD), October 2004

Exhibit 3

Incidence (1995) and survival rates (1987-89) for bowel cancer: international comparisons¹²

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



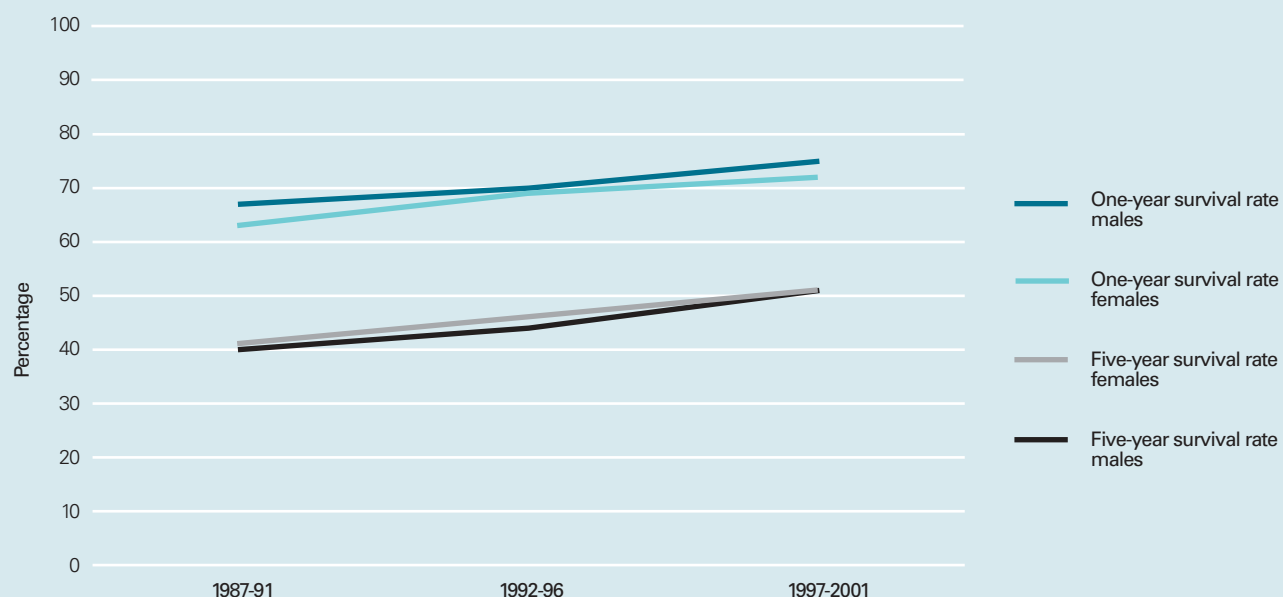
Source: Clinical Outcome Indicators, Clinical Outcomes Working Group, (CRAG) December 2000

¹² Note: incidence rates for colorectal cancer in England also include Wales. Wales is not included in the English survival rate statistics.

Exhibit 4

Relative survival at one and five years for bowel cancer 1987-89 to 1997-2001¹³

There is an upward trend in survival at both one and five years.



Source: Scottish Cancer Registry, ISD, August 2004

performance.^{14,15,16} However, there are several other European countries which have less well developed registries and relatively low levels of cancer registration. These countries may be over-estimating their survival rates, as the relatively small proportion of patients for whom data is available may not be representative of all cancer patients.

27. While Scotland still lags behind its European neighbours, bowel cancer survival rates for both one year (up from 67% to 75% for men and from 63% to 72% for women) and five year-survival (up from 44% to 51% for men and 41% to 51% for women) are improving,¹⁷ and Scotland's most recent statistics show a marked improvement in survival (Exhibit 4).

Population bowel screening

28. A pilot project to establish the effectiveness of Faecal Occult Blood Testing (FOBT) in screening for bowel cancer started in Tayside, Grampian and Fife in Scotland in March 2000 and the West Midlands in England in September 2000. The evaluation showed that screening enabled patients with cancer to be identified earlier.

29. It is estimated that in the long term 150 deaths per year could be prevented in Scotland by introducing population screening for bowel cancer.¹⁸ In comparison, the current breast and cervical cancer screening programmes prevent 40 and 26 deaths per year respectively.

30. The Scottish Executive Health Department (SEHD) has announced that the screening programme will be rolled out across Scotland. The SEHD has convened a bowel cancer framework group which will work with it and regional cancer networks on implementation.

31. The roll-out of bowel cancer screening, combined with the increased incidence of bowel cancer over the next decade, will present a significant challenge for bowel cancer services. But ultimately screening may also prevent some cancers developing by removing polyps which might later have become cancerous.

¹³ Cases diagnosed 1999-2001 do not have five years' follow-up.

¹⁴ *Registration of colorectal cancer in Scotland: an assessment of data accuracy based on review of medical records*, Brewster D, Muir C, Crichton J, Public Health 1995; 109: 285-92.

¹⁵ *Completeness of case ascertainment in a Scottish Regional Cancer Registry for the year 1992*, Brewster D, Crichton J, Harvey JC, Dawson G, Public Health 1997; 111: 339-343.

¹⁶ *Reliability of cancer registration data in Scotland, 1997*, Brewster DH, Stockton D, Harvey J, Mackay M, Eur J Cancer 2002; 38: 414-417.

¹⁷ Scottish Cancer Registry, ISD, August 2004.

¹⁸ *Cancer Scenarios: an aid to planning cancer services in Scotland in the next decade* (03 Colorectal Cancer), Scottish Executive Health Department (SEHD) (2001) Edinburgh: The Scottish Executive.

Part 2. Where are we going with bowel cancer services in Scotland?

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

Scotland's 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 Scottish Cancer Plan, but the real challenge will come in redesigning existing services.

Has the Health Department set a clear agenda for bowel cancer services in Scotland?

32. Tackling cancer is one of NHSScotland's three clinical priorities. But the *Cancer in Scotland* strategy (sometimes called the Scottish Cancer Plan),¹⁹ published in 2001, acknowledged that more could and must be done to reduce cancer's impact. The strategy was designed to:

- help modernise cancer services
- meet waiting times commitments
- deliver Clinical Standards Board Scotland (CSBS) requirements
- provide patients with high quality facilities, care and support.

33. To back up the strategy the Scottish Executive committed:

- an additional £25 million annually ring-fenced until at least the end of 2005-06 ([Exhibit 5 overleaf](#)).

- £33 million for modernising radiotherapy equipment
- £87 million to build a new West of Scotland Cancer Centre
- £1 million annual equivalent for the cancer services improvement programme (CSIP).

34. These funding streams, which are commonly known as the 'new cancer monies' represent significant public investment in cancer services. They cover all cancer types, not just bowel cancer. At the same time, many other improvements in bowel cancer services have also taken place; for example, the development of bowel cancer clinical nurse specialists (CNS), and developments in surgical practice.

35. The SEHD published a *Bowel Cancer Framework for Scotland*²⁰ in 2004 as the starting point for developing a national strategy for bowel cancer services.

19 *Cancer in Scotland: Action for Change*, SEHD (2001), Edinburgh: The Scottish Executive.

20 *Bowel Cancer Framework for Scotland*, SEHD (2004), Edinburgh: The Scottish Executive.

Exhibit 5

Cancer in Scotland: 'new monies' 2001/02 – 2003/04

	2001-02	2002-03	2003-04
Access to diagnosis and treatment	£3,880,000	£7,123,000	£7,007,000
Improving treatment and care	£2,240,500	£7,847,500	£7,685,830
Palliative care	£1,023,000	£1,909,000	£2,372,000
Staff and technology	£2,669,000	£2,858,700	£2,993,700
Making it Happen	£990,000	£3,232,000	£2,549,000
West of Scotland Cancer Centre (Beatson)		£2,000,000	£2,000,000
Scottish Cancer Research Network		£500,000	£500,000
Central implementation costs	£100,000	£200,000	£200,000
Total	£10,902,500	£25,670,200	£25,307,530

Source: Cancer in Scotland: Action for Change Annual Report 2003

More needs to be done in measuring the impact of these strategies

36. *Cancer in Scotland* sets a clear strategic direction for services based on high-quality research,²¹ but it lacks specific targets for improvement or measures to assess the impact and effectiveness of service changes. There are only six measurable targets within the document, and these derive from earlier national policy documents such as *Our National Health* (2000). The bowel cancer framework also concentrates on process (policy and service reviews, research and evaluation) rather than impact and outcomes. Both documents could usefully include measures against which to routinely assess how cancer services are improving and the impact of new investment and changes to services.

For example:

- survival rates
- waiting times
- equity of access to care
- patient satisfaction.

Efficiency and value-for-money

37. More emphasis is needed on securing better value for money within the *Cancer in Scotland* strategy. The document neither considers the balance of resources committed to preventing, detecting and treating cancer, nor does it detail how to achieve value for money in future policies and investments. These are both important requirements of World Health Organisation (WHO) guidelines on National Cancer Control Programmes.^{22,23} Considering these factors when developing future

strategies for cancer services in Scotland would provide an opportunity for the health department to link future plans with two important strands of government policy:

- the 'Wanless' agenda,²⁴ which anticipates a shift of resources from treatment to prevention as a central strand of improving NHS performance over the coming decades
- the 'Efficient Government' agenda which sets challenging targets for cost savings and efficiency improvements across all public services, including the NHS.²⁵

21 *Cancer Scenarios: an aid to planning cancer services in Scotland in the next decade*, SEHD, (2001), Edinburgh: The Scottish Executive

22 *National Cancer Control Programmes: Policies and Managerial Guidelines*, (1st edition), Geneva, WHO, 1995.

23 *National Cancer Control Programmes: policies and managerial guidelines* (2nd edition), Geneva, WHO, 2002.

24 *Securing our Future Health*, Wanless Report: Final Report 2002.

25 *Building a Better Scotland*, Efficient Government – Securing Efficiency, Effectiveness and Productivity, Scottish Executive, Edinburgh, 2004.

The type and scale of service changes that are required

38. The *Bowel Cancer Framework* is not explicit about the scale of change that is required, for example, it does not specify extra endoscopy equipment requirements and additional staffing numbers. The document also lacks clarity on whether the required change will be achieved by further investment, redeploying existing resources, or a combination of both. The SEHD intended the strategy to set the agenda rather than to act as an operational plan for delivering service change. Detailed strategies are now required to address priority areas such as endoscopic capacity, workforce planning and training. It is planned that the national bowel cancer framework group, together with representatives from Scotland's three regional cancer networks will further develop the framework in this way during 2005.

39. Given the long-term nature of the objectives set out in *Cancer in Scotland*, sufficient time is needed for its progress to be assessed. The health department has put in place clear mechanisms for public reporting on delivery of the *Cancer in Scotland* strategy. There are six-monthly progress reports, two annual reports (2002 and 2003) have been published and in 2004 *Sustaining Change* set out the next steps for cancer services in Scotland. This monitoring and reporting, although welcome, is weakened by the absence of specific improvement measures within the initial strategy.

Recommendations:

The health department should:

- set clear and specific measures against which progress in improving cancer services can be assessed and reported (for example, survival, waiting times, patient satisfaction)
- analyse the balance of resources committed to preventing, detecting and treating cancer
- set out how improvements in value for money for cancer services are to be achieved.

How effective have networks been in improving the quality of services and delivering value for money?

Regional Cancer Advisory Groups are working well in delivering the *Cancer in Scotland* strategy

40. The Scottish Cancer Group oversees implementation of *Cancer in Scotland*. It is closely linked to three Regional Cancer Advisory Groups (RCAGs)²⁶ which provide advice to their local NHS boards and cancer services. The three RCAGs are:

- North of Scotland (NOSCAN) – Tayside, Highland, Grampian, Orkney, Shetland and Western Isles NHS Boards.
- South East Scotland (SCAN) – Fife, Borders, Dumfries & Galloway and Lothian NHS boards.
- West of Scotland (WOSCAN) – Argyll & Clyde, Ayrshire & Arran, Forth Valley, Lanarkshire and Glasgow NHS Boards.

41. The RCAGs have an important role in shaping and delivering service change, and are designed to act as a bridge between the SEHD and NHS boards.

42. They are delivering their core role of implementing the *Cancer in Scotland* strategy and have developed robust arrangements in relation to:

- monitoring how the regional action plans are being delivered
- reporting publicly via websites and annual reports
- accounting for the new cancer monies with six-monthly monitoring reports.

43. There is evidence that they used the new cancer monies allocated to them to relieve immediate service gaps and pressure points. We found:

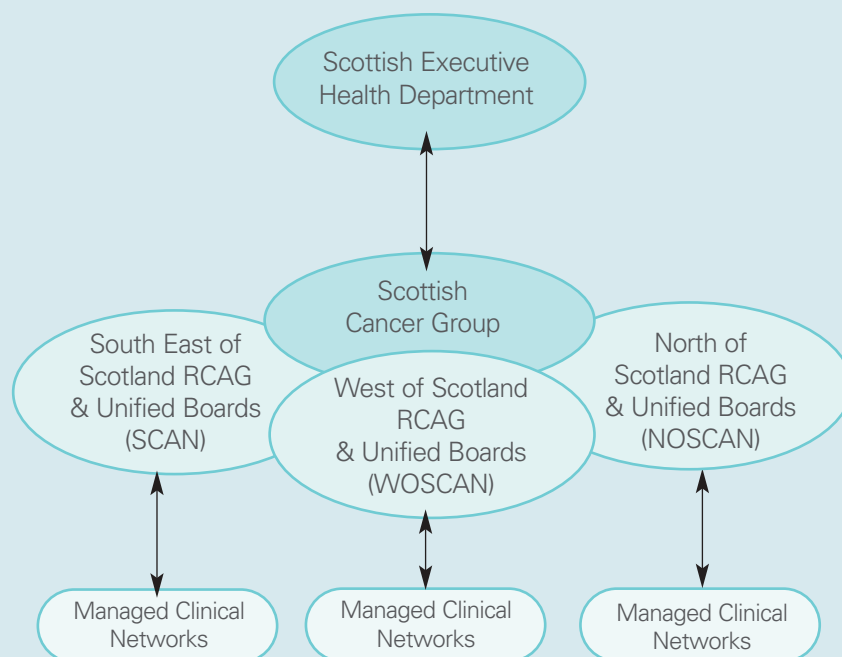
- an emphasis on investments that were likely to provide a direct and immediate impact on patient care
- clear links between how they used the new monies and improvements recommended by the CSBS in 2001
- strong local clinical support for investment decisions.

Bowel cancer MCN arrangements are working well to address issues of quality and clinical practice

44. Managed Clinical Networks (MCNs) are linked groups of health professionals and organisations from the community (GPs and others), general hospitals and specialist centres. These groups work together to ensure that high quality, clinically effective services are provided

Exhibit 6

The relationship between RCAGs, SEHD, health boards and MCNs



Source: Modified version of NHS HDL(2001)71, Annex 2

equitably.²⁷ MCNs report to their local RCAG. They are seen by the Scottish Executive (SE) as the 'cornerstone of the new planning process for cancer services' and the main vehicle for the redesign of services, particularly for bowel and lung cancer services²⁸ (Exhibit 6).

45. MCNs were expected to redesign bowel cancer services by April 2002 to improve patients' experiences of care and delivering waiting times and CSBS standards.²⁹ Bowel cancer MCNs were in place in the West and East of Scotland by 2002 but took longer to introduce in the North of Scotland, where the MCN only became fully operational in 2004.

46. The three bowel cancer MCNs have progressed at different paces and with different emphases. All have made good progress in addressing clinical issues by:

- sharing and discussing clinical audit data
- promoting consistent practice to address issues of equity
- maintaining and improving clinical standards
- developing high-quality patient information.
- accreditation by NHS Quality Improvement Scotland (NHS QIS)
- the circulation of staff between primary and secondary care
- value for money.

47. The West of Scotland (WOSCAN) bowel cancer MCN has been particularly successful in addressing equity of access to services and consistency of clinical practice. For example, it has developed a standardised follow-up protocol for the whole of the West of Scotland, and produced a network-wide standardised and evidence-based patient information pack.

48. But there are three areas where the MCNs do not comply with guidance from the health department. These are:

49. NHS QIS is currently in the process of accrediting Scotland's three regional cancer networks and it is anticipated that, if successful, they will be given a role in quality assuring the work of the tumour-specific MCNs in their own area.

50. Although the MCNs have not yet addressed the issue of the circulation of staff between primary and secondary care, it is not clear what value circulation of staff in this way would add to bowel cancer services.

51. Value for money is dealt with later in the report (See parts 3 and 6).

27 MEL (1999)10 *Introduction of Managed Clinical Networks within the NHS in Scotland*.

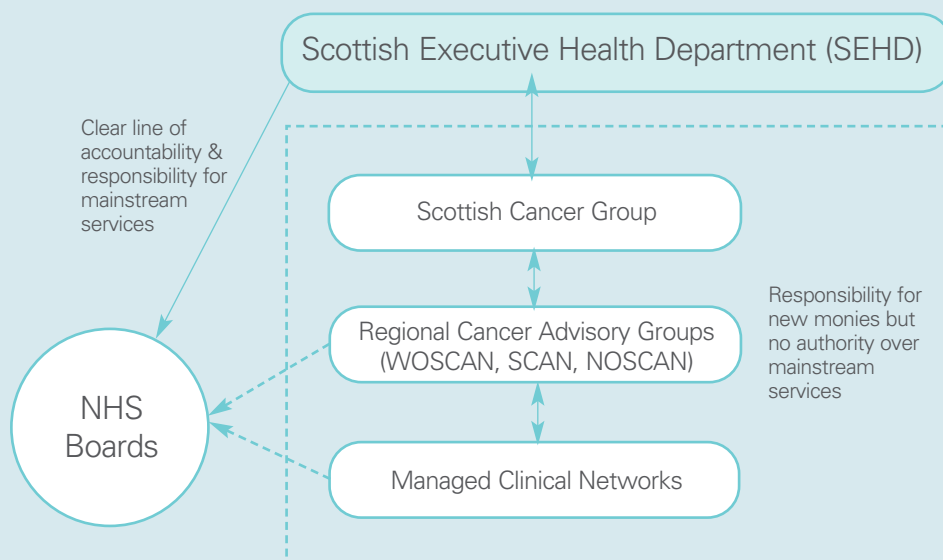
28 *Cancer in Scotland: Action for Change*, chapter 9, SEHD (2001), Edinburgh, Scottish Executive.

29 (HDL(2001)71), *Cancer in Scotland: Action for Change*, RCAG.

Exhibit 7

The contrasting management and accountability models of mainstream service arrangement and RCAGs/MCNs

There are inherent tensions between traditional lines of accountability and the influencing model of network working.



Source: Audit Scotland 2005

A better understanding of the cost and performance of existing cancer services is needed

52. Financial monitoring of *Cancer in Scotland* focuses almost entirely on the new cancer monies with little reference to spending on staff and equipment tied up in existing cancer services. But the new cancer monies reflect only a small fraction of overall spending on cancer services. Although the health department is currently unable to identify what proportion of total NHS Scotland costs is dedicated to cancer services,³⁰ estimates by ISD indicate that £460 million was spent on cancer care in 2003/04, making the £25 million of new monies equate to 5.4% of total cancer spend.

53. Better cost and performance information is needed to manage the services and identify expenditure on treatment, detection, and prevention.³¹ This information would also help the department to assess whether the 'Efficient Government'

agenda is being delivered in cancer care.³² Capturing meaningful information which links expenditure with activity and ultimately outcomes of cancer services in this way is, however, not easy as many services provided by NHSScotland (radiology, endoscopy, pathology, outpatients clinics) are not cancer specific.

Delivering mainstream service change through network working will be a major challenge

54. The challenge of improving bowel cancer services needs to be considered in the wider context of modernising the NHS in Scotland. The Scottish Parliament has in recent years increased NHS spending, including additional funding for cancer services. However, the future agenda for modernising the NHS in Scotland depends increasingly on securing more efficient and effective services (including reallocating existing resources) rather than relying on additional funding.^{33,34,35}

55. The RCAGs and MCNs have made good progress in using new money to build capacity and improve service quality, and in promoting high-quality clinical practice. Work has also begun on more strategic service shifts. There is little evidence yet, of significant progress in securing the efficient use of mainstream NHS resources dedicated to bowel cancer care and improving value for money.

56. The SEHD will face a major challenge in delivering significant mainstream change to services through the network arrangements. There are inherent tensions between the two different models of management and accountability of NHS boards and RCAGs/MCNs. NHS boards have a direct line management relationship with the health department, whereas their relationships with the RCAGs and MCNs are based on negotiation and influence. Networks have no direct responsibility or authority over the

30 *The Cost of Cancer Care in Scotland 2002*, B M J Graham, ISD Cancer Information Group, 2 September 2003 (Final Version).

31 *Securing our Future Health*, Wanless Report: Final Report 2002.

32 *Building a Better Scotland*, Efficient Government – Securing Efficiency, Effectiveness and Productivity, Scottish Executive, Edinburgh, 2004.

33 *Ibid*

34 *The Politics of Health Divergence*, Scott L Greer, The Constitution Unit, University College London. Institute of Public Policy Research (IPPR) Seminar, 16 September 2004, Edinburgh.

35 *The Barnett Formula*, Robert Twigger, Economic Policy and Statistics Division, House of Commons Library, Research Paper 98/8, 12 January 1998.

use that is made of the mainstream cancer services. Yet, it is only through redesigning existing mainstream cancer services, which account for around 95% of cancer services in Scotland, that efficient patient-centred services will be achieved ([Exhibit 7, page 13](#)).

Recommendation:

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 a more sophisticated (programme-based) understanding of current spend across all aspects of cancer provision (tumour types, prevention, detection and treatment), and use this as the basis for future decisions on how to allocate resources
- develop formal measures for reporting on the cost and performance of current cancer services.

Part 3. Referral and diagnosis

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. Fewer than half of health boards had agreed formal referral arrangements 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.

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. In spite of this, only 5 out of 26 hospitals (19%) providing bowel cancer services in Scotland use risk-based diagnostic pathways to guide the choice of diagnostic method, although all others are working to introduce them. Some hospitals offer colonoscopy as the main diagnostic test for almost all patients, regardless of their symptoms. This is not cost effective.

Identifying and referring patients

Why GP referral guidelines are important

57. Promptly identifying and referring patients suspected to have bowel cancer is essential if they are to benefit from high quality care. But it is not a straightforward process because the most common

symptoms are non-specific, occur relatively frequently in the general population, and have a wide variety of causes. This can lead to problems with diagnosis, and referral to a wide range of hospital specialties. Also, a GP will see on average only one new case a year ([Exhibit 8 overleaf](#)).

58. Most of the delays between the onset of symptoms and the start of treatment for bowel cancer occur outside of hospital (either before the patient visits his/her GP, or whilst under the care of the GP).³⁶ This highlights the importance of educating the public about symptoms which may indicate bowel cancer.

59. The SEHD and the Association of Coloproctology have prepared national evidence-based referral guidelines for suspected cancer.^{37,38} These help GPs identify patients who should be referred to hospital for specialist diagnostic tests. The referral guidelines recommend that GPs carry

³⁶ *Delay in diagnosis and treatment of symptomatic colorectal cancer*, Holliday, H W and Hardcastle J D (1979), *Lancet* 1, 309-311.

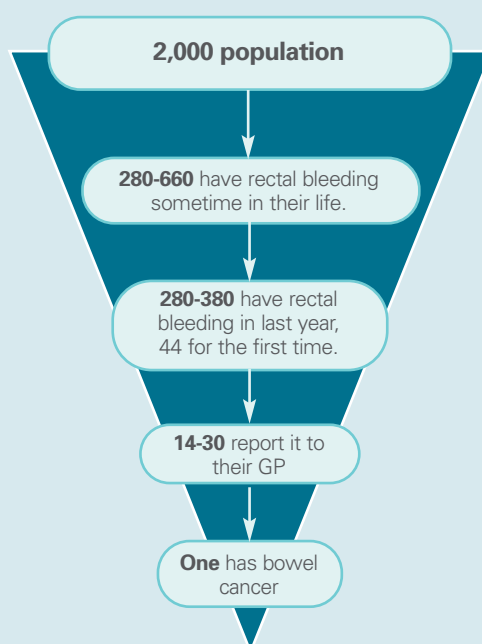
³⁷ *Scottish Referral Guidelines for Suspected Cancer* (NHS HDL (2002) 45), SEHD, 2002.

³⁸ *Guidelines for the Management of Colorectal Cancer* (2001), The Association of Coloproctology of Great Britain and Ireland. London, 2001.

Exhibit 8

Incidence of rectal bleeding in the community and in primary care

The figures have been adjusted to an approximate GP list size of 2,000 patients.



Source: Diagnosis of colorectal cancer in primary care: the evidence base for guidelines. William Hamilton and Deborah Sharp. Family Practice, 2004, Vol. 21, No. 1, 99-106

out a clinical examination of the rectum and abdomen for patients with symptoms of bowel cancer.

60. Earlier research in this area has raised concern about the extent to which GPs undertake these examinations.³⁹ Evidence shows that patients who are not given a rectal or abdominal examination at their first medical consultation experience considerably more delays in being referred for a specialist opinion.⁴⁰ We found that some GPs fail to undertake rectal or abdominal examinations. A third of patients interviewed reported major delays at their GP practice before referral to hospital for diagnosis for this reason. 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 it does show that the way some patients are managed in the community could be improved.

Quotes from patients:

"The first two years, at GP level, I wasn't aware I had colorectal cancer. I kept presenting with this bleeding. He said 'Oh, don't worry about it. It's only haemorrhoids... If it's not bothering you, just let them...' However, I did have other symptoms. I work for the manufacturing industry and I have to have a yearly medical, and the yearly medical said I had anaemia. I was also very lethargic and I reported that to the GP but they never seemed to link it at all. Why didn't they pick up that there was something wrong... instead of this damned two years?"

(Respondent 7)

"That is what he actually said: 'The longer it goes on, the less likely it is to be anything serious.' This is a qualified GP."

(Wife of Respondent 10)

Are GPs and hospitals working well together to improve referral?

61. National bowel cancer referral guidelines, which specify which patients are to be referred, and to whom, should be used to develop and agree formal referral arrangements between local GPs and hospital-based specialists. For GPs, however, responding to a large number of condition-specific protocols can be a significant burden. This means that protocols between specialist hospital services and GPs need to be supported by good liaison and communication. Writing and agreeing local protocols is relatively easy, securing effective implementation and compliance is a greater challenge.

62. There is some evidence that where jointly agreed protocols are in place GPs will be better at identifying suspected bowel cancer. This in turn leads to speedy referral to the appropriate hospital specialists with clear benefits for patients (Good practice example 1, quote by respondent 9).

³⁹ Delay in diagnosis and treatment of symptomatic colorectal cancer, Holliday, H W and Hardcastle J D (1979), Lancet 1, 309-311.

⁴⁰ Delay in the diagnosis of colorectal cancer, MacArthur, C and Smith, A, Journal of the Royal College of General Practitioners, 1983, 33, 159-61.

Good practice example 1

Primary/secondary care interface/triage – Borders Colon Service

Objective

The objective of the Borders Colon Service is to streamline clinical activity by having a single referral point, in the form of a clinical coordinator for all patients requiring colonic investigation. Depending upon presenting symptoms, medical history, or the suspicion of colorectal cancer, patients are then triaged to radiology, colonoscopy, or for a surgical opinion. There is an agreed referral protocol with local GP practices.

Why was this needed?

Prior to this service, patients attending their GP with colonic symptoms were referred for investigation and assessment by multiple routes. The period of time until diagnosis was unnecessarily extended by multiple referrals with trips back to the GP in between. There were also often multiple referrals (eg, referrals by GP for both barium enema and colonoscopy) which increased waiting lists unnecessarily and often led to unnecessary clinic visits and tests. All disciplines functioned independently and were not necessarily aware when a diagnosis has been reached.

What are the benefits of the new service?

- The waiting time for urgent barium enema appointments has dropped from 3-4 weeks to nine working days, and the yearly volume of barium enemas has also reduced.
- Urgent colonoscopy waiting times have reduced from 8-10 weeks to approximately two weeks.
- The number of inappropriate barium enemas performed as a precautionary stopgap until a colonoscopy appointment could be booked has dramatically reduced.
- Most patients only have one test performed and are diagnosed more quickly.

63. The non-specific nature of bowel cancer symptoms means that patients with symptoms are often initially referred to gastroenterology departments. Therefore it is important that other hospital departments and bowel cancer specialists also agree formal arrangements so that the appropriate onward referral of patients runs smoothly.⁴¹

Patient quotes:

"I went to my GP and said to him that I'd had some rectal bleeding. He couldn't find anything but he said 'I think I'll send you in to the consultant' ... He just said 'Well as it's unexplained and it's rectal it's got to be investigated, one way or another'. You don't know whether it's going to get worse!"

(Respondent 9)

64. Since the 2002 CSBS review of bowel cancer services in Scotland limited progress has been made in the agreement of referral protocols between GPs and hospital services. Less than half of the acute hospital

divisions in Scotland have agreed referral guidelines and protocols with GPs (Exhibit 9 overleaf).

65. Even where referral protocols are in place, most hospitals reported poor compliance in the use of standard referral forms. This leads to inadequate referral data, making it difficult to identify the most appropriate diagnostic test(s) for individual patients, and can lead to delays in diagnosis. The need for progress in this area has been recognised by the three RCAGs.

66. There are practical resource issues which are acting as constraints on progress in this area. Developing and agreeing referral protocols takes time and carries an opportunity cost. Many specialist services have, over recent years, been working hard to ensure that their multi-disciplinary working arrangements are effectively organised. This has left little space for developmental work with primary care.

67. The health department plans to make the referral process more efficient by introducing electronic referral systems between GPs and hospital services. Technological changes of this kind can help improve performance, but they need to be complemented by local work with GPs and hospital specialists. This is particularly challenging in large urban areas and geographically widespread areas.

68. These technological changes also present the opportunity for improved information on referral and diagnosis to be captured at a national level.

69. Identifying those GP practices where improvement is necessary will be a challenge for NHS boards. GP diagnostic and referral performance is not routinely monitored and this will not change under the new General Medical Services (GMS) Contract. Of the 146 quality indicators within the new contract only two relate to cancer, and neither of these concern

Exhibit 9

Proportion of acute divisions which have agreed referral guidelines with primary care

Limited progress has been made in this area since the earlier CSBS reviews.

	2002	2004
Formal arrangements are in place for the referral of suspected bowel cancer patients, jointly agreed between GPs and specialists working within the bowel cancer multidisciplinary team.	39%	46%

Source: Audit Scotland fieldwork 2004

the speed or quality of diagnosis and referral of suspected cancer patients. Given that GPs are likely on average to see only one new bowel cancer case per year, it would be inappropriate for specific information on this condition to be routinely monitored. Instead, ongoing dialogue between specialist bowel cancer services and primary care colleagues should provide a means for addressing poor compliance with local referral guidelines. Any significant failures of performance should be resolved through local primary care governance arrangements.

Recommendations:

- The national bowel cancer framework group should review existing GP referral guidelines and work with health boards in raising awareness of risk factors with GPs.
- All NHS boards should agree local referral protocols between GPs and specialist bowel cancer services.

Choice of diagnostic method

70. The Scottish Intercollegiate Guidelines Network (SIGN) guideline on managing bowel cancer identifies three methods which are effective in the primary diagnosis of bowel cancer, but it does not specify which should be the investigation of choice.

71. The most recent review of the evidence suggests that flexible sigmoidoscopy is the most appropriate initial investigation for the majority of patients with symptoms that suggest possible lesions in the left (descending or distal) colon, sigmoid or rectum.⁴² This is because it is relatively quick, virtually risk-free and because there is evidence to suggest that for patients who present with symptoms alone (usually rectal bleeding, changed bowel habit or pain), further investigation after a negative flexible sigmoidoscopy is rarely necessary. Ongoing research to further strengthen the evidence base in this area would be of value.

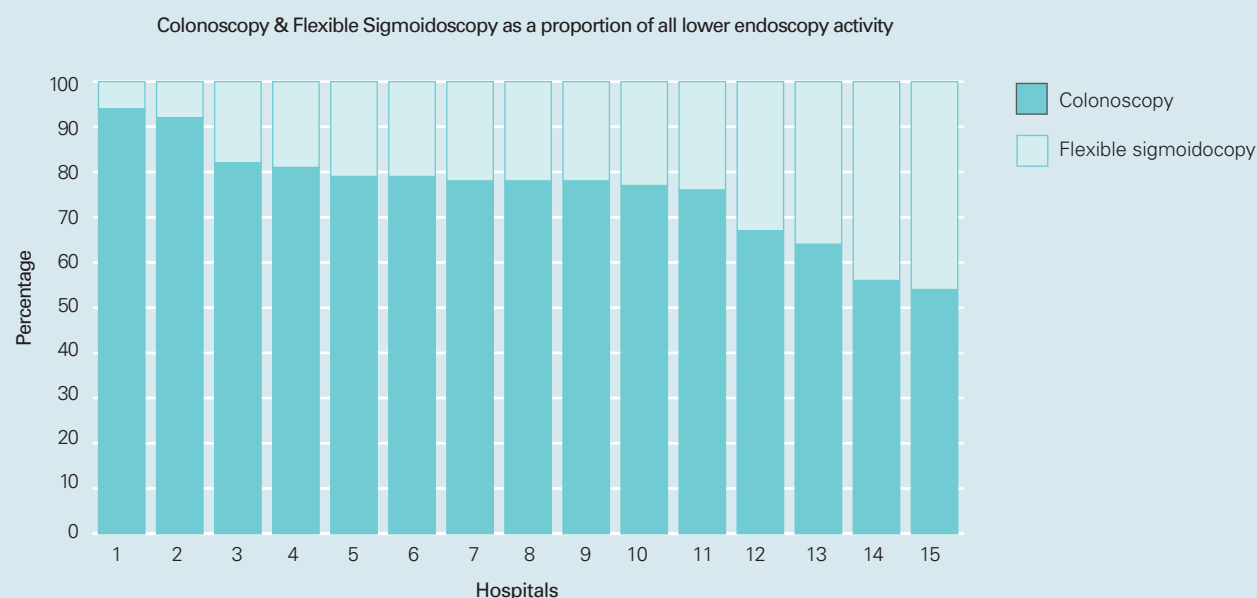
72. Diagnostic colonoscopy is usually appropriate for patients with right-sided symptoms, except for those with palpable masses, for whom imaging (barium enema or CT) is likely to be more suitable. If a complete colonoscopy is not achieved and clinical doubt remains, imaging is necessary. When patients present with iron deficiency anaemia, investigation should continue until the cause is found.

Value for money in diagnostic testing

73. As well as having varied clinical risk, the time and resources required to carry out each test vary enormously. The average time to conduct a colonoscopy in Scotland is between 30 and 45 minutes, over twice as long as an average flexible sigmoidoscopy (15 minutes).

Exhibit 10

Variation in colonoscopy and flexible sigmoidoscopy activity



Source: Audit Scotland fieldwork 2004

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

75. Data collected from several sites across Scotland show a considerable range in colonoscopies and flexible sigmoidoscopies undertaken as a proportion of all lower endoscopy procedures: from 94% colonoscopy and 6% flexible sigmoidoscopy to 54% colonoscopy and 46% flexible sigmoidoscopy ([Exhibit 10](#)). Given that over 35,000 lower gastrointestinal endoscopies were carried out in 2003/04,⁴³ a change in the balance of lower endoscopy procedures undertaken would have significant implications for throughput and the efficient use of resources.

Making best use of existing diagnostic resources

76. There are long waiting times for routine diagnostic tests at many sites in Scotland, but there is a developing body of evidence which shows that targeting the most expensive and time-consuming diagnostic tests towards those patients with the higher risk symptoms can lead to significant efficiencies in the use of resources and reduced waiting times.^{44,45} Clinicians in Scotland have already begun to develop risk-based diagnostic models, building on the research which has taken place in England in this area ([Exhibit 11](#) and [Good practice example 2 overleaf](#)). The Bowel Cancer Framework Group is currently 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.

How common are risk-based diagnostic models in Scotland?

77. Currently less than one in five bowel cancer services in Scotland have risk-based diagnostic pathways in place, although the rest are working to develop and introduce them. In the meantime, individual clinical preference is often the most important factor in determining which diagnostic tests patients receive, rather than their symptoms or other risk factors such as age or infirmity. This means that some patients are being exposed to unnecessary risk and the NHS is not delivering value for money resources. Availability of staff and equipment also skew clinical practice, with clinicians often opting for those tests with the shortest waits; for example, where there are long waits for colonoscopy, clinicians may shift to flexible sigmoidoscopy and barium enema.

⁴³ Scottish Cancer Registry, ISD.

⁴⁴ M R Thompson, I Heath, B G Ellis, E T Swarbrick, L Faulds Wood, W S Atkin. Identifying and managing patients at low risk of bowel cancer in general practice. *BMJ*: 2003. 327; 263-265.

⁴⁵ The diagnostic value of the common symptom combinations of bowel cancer in a surgical clinic. M R Thompson, A Senapati, S Dodds, 2004 (awaiting publication).

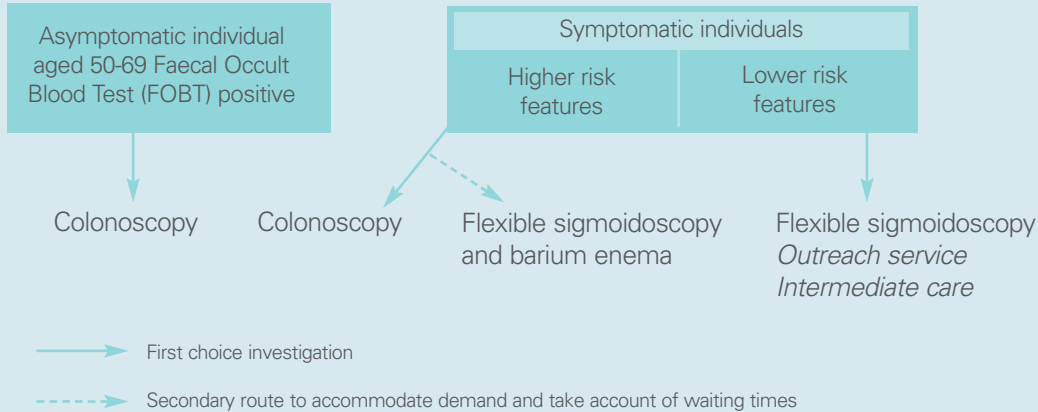
Exhibit 11

Risk-based strategy for investigation of suspected bowel cancer patients in secondary and intermediate care

Patients can be stratified towards appropriate diagnostic test depending upon risk.

Colorectal cancer screening

Symptomatic service



Source: A pragmatic and risk-based strategy for managing patients with rectal bleeding and associated symptoms (Draft 2). Terry O'Kelly (paper presented to Bowel Cancer Framework Group, 7 January 2005)

Good practice example 2

Gartnavel Hospital, NHS Glasgow (North)

Surgeons at Gartnavel General Hospital have published a randomised trial⁴⁶ that shows that patients with large bowel cancer symptoms referred by GPs should go directly to an appropriately staffed direct-access large bowel investigation unit. The Clinical Nurse Specialist in bowel cancer vets and triages all referrals into one of three treatment pathways:

- Direct access colonoscopy, flexible sigmoidoscopy or barium enema
- Nurse-led clinic
- Consultant-led clinic.

The benefits of this approach are that:

- Most patients are able to have their investigations completed at one hospital visit.
- Consultant time can be directed towards those patients with more complex symptoms who are likely to benefit from it
- Waiting times have reduced by 10-14 weeks.

As the cost per patient in the consultant-led group was almost £105 more than the direct-access large bowel investigation unit, this approach has the potential to deliver savings.

46 MacKenzie S, Norrie J, Vella M, Drummond I, Walker A, Molloy R, Galloway D.J., O'Dwyer P.J. Investigation of large bowel symptoms. British Journal of Surgery 2003; 90, no. 8: 941-947(7).

How good is colonoscopy practice in Scotland?

78. Colonoscopy is likely to remain as an important diagnostic test for suspected bowel cancer patients for the foreseeable future. It is important therefore that high quality colonoscopy services are available in Scotland.

79. Recent publications⁴⁷ have acknowledged that current endoscopic practice across the United Kingdom is variable and there are concerns that within Scotland current practice does not conform to the standards set out in Scottish Intercollegiate Guidelines Network (SIGN) and British Society of Gastroenterology (BSG) guidelines.⁴⁸ If risk-based diagnostic models are more commonly adopted, fewer colonoscopies are likely to be needed. This could help rationalise colonoscopy within properly trained specialist teams.

80. In England, £8.2 million has been made available through the National Cancer Plan to fund endoscopy training over the years 2003-06. This has funded three national training centres and seven regional endoscopy training centres.

81. In Scotland, the issue of training for endoscopists to address capacity and quality-related issues has been recognised by the SEHD within the *Bowel Cancer Framework for Scotland*.⁴⁹ The bowel cancer framework group will be considering the overall quality of colonoscopy, initial training and regular refresher courses, peer review and continuous audit of standards during 2005.

82. We found strong evidence that the availability of qualified staff is a significant constraint on the utilisation of existing endoscopy resources in Scotland (see Part 5). If Scotland is not to lag behind England in terms of endoscopic capacity and practice, it is vital that endoscopic training is given prominence, and funding is made available.

Recommendations:

- NHS QIS and SIGN should incorporate guidance on risk-based model(s) for diagnosing suspected bowel cancer patients when reviewing existing clinical standards for colorectal cancer.
- NHS QIS should develop quality indicators for endoscopic practice.

The health department should:

- determine how endoscopy training in Scotland will be supported
- introduce an accreditation programme for endoscopy practitioners (current and future).

47 Palmer K, Morris A I. A snapshot of colonoscopy practice in England: stimulus for improvement. *Gut* 2004;53:163-165.

48 Bowles C J A, Leicester R, Romaya C, et al. A prospective study of colonoscopy practice in the UK today: are we adequately prepared for national colorectal cancer screening tomorrow? *Gut* 2004;53:277-83.

49 Scottish Executive Health Department (2004). *Bowel Cancer Framework for Scotland* (p.13). Edinburgh: The Scottish Executive.

Part 4. Quality of care and treatment



Multi-disciplinary teams (MDTs) are working effectively at almost every hospital in Scotland that provides bowel cancer services. Good progress has been made in developing information for patients, and in training staff in effective communication.

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 clinical nurse specialists (CNS) make in coordinating care and offering support to patients and their families. However, national guidance on their role is needed to ensure their expertise is directed to best effect.

Most hospitals comply with clinical standards. But, a small number of standards have not kept pace with

clinical practice and are in need of 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.

Coordination of care, communication and support for patients

Bowel cancer MDTs in Scotland

83. Good cancer care requires the collaboration of professionals from different disciplines.⁵⁰ This principle is reflected in:

- *Cancer in Scotland*⁵¹
- Clinical Standards Board for Scotland (CSBS) (now NHS Quality Improvement Scotland, (NHS QIS)) clinical standards⁵²
- Scottish Intercollegiate Guidelines Network (SIGN) national clinical guidelines on the management of bowel cancer.⁵³

Bowel cancer MDTs in Scotland – an improving position

84. In 2001, the CSBS national overview of bowel cancer services in Scotland reported that all trusts in Scotland recognised the value of a multi-disciplinary approach to making decisions and planning how they treat patients:⁵⁴ However, at that time only half of the trusts had clearly defined bowel cancer MDTs which met on a regular basis and had developed local protocols for the management of bowel cancer.

85. In 2001, the majority of trusts that were unable to meet the standard failed to do so for one or more of the following reasons:

- because specific elements of the bowel cancer service, such as the oncology and/or pathology services, were not provided on-site
- difficulties with finding an appropriate time for all of the

⁵⁰ Department of Health and Welsh Office. A policy framework for commissioning cancer service. A report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales. Calman-Hine report. London, UK: Department of Health, 1995.

⁵¹ Cancer in Scotland: Action for Change – 05. Improving Cancer Treatment and Care, SEHD 2001.

⁵² CSBS, Clinical Standards, Colorectal Cancer (Standard Statement 2 – Multi-disciplinary Working), CSBS, January 2001.

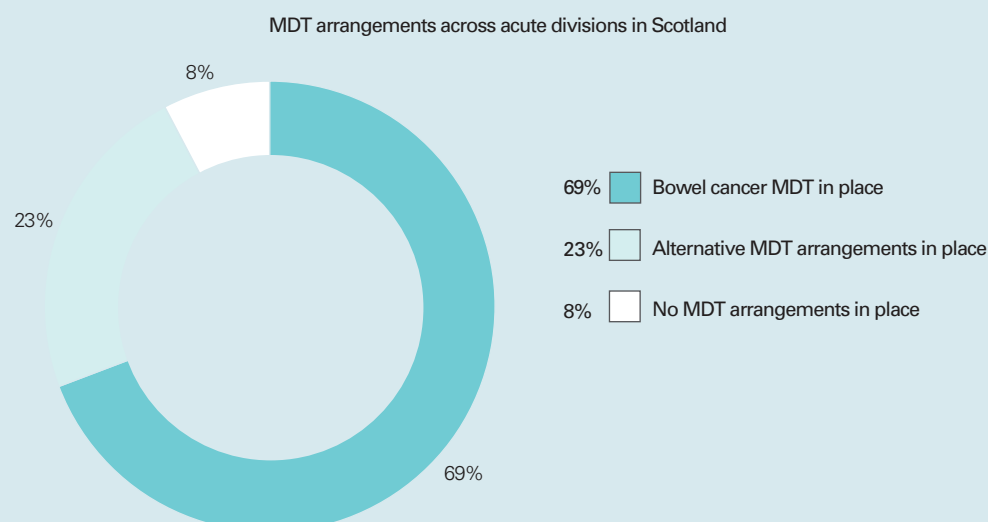
⁵³ Scottish Intercollegiate Guidelines Network, 67: Management of Colorectal Cancer. A national clinical guideline. SIGN, March 2003.

⁵⁴ *National Overview: Colorectal Cancer Services*. CSBS, March 2002.

Exhibit 12

Multi-disciplinary care planning arrangements for bowel cancer patients – 2004

Good progress is being made across NHSScotland in implementing MDT planning for bowel cancer patients.



Source: Audit Scotland fieldwork 2004

essential members of the team to meet (although this was being overcome in some areas through the use of teleconferencing)

- staff vacancies.

86. In 2002, only 43% of bowel cancer services had MDT arrangements in place. Since then, there has been a 26% increase in MDT planning for bowel cancer in NHSScotland (Exhibit 12).

How well are MDTs working?

87. The CSBS standard sets out the minimum 'core' membership for a bowel cancer MDT. It is:

- surgeon
- oncologist
- pathologist
- specialist nurse
- a radiologist and colonoscopist co-opted when necessary.⁵⁵

88. The core membership of a bowel cancer MDT attends 'almost always' or 'frequently' at over 90% of the sites in Scotland which have an operational MDT in place (Exhibit 13 overleaf) (ie, 9 out of the 13 acute divisions). At most sites the MDT was clearly seen as the focal point for all major care planning and review decisions. At several sites the MDT was central to the whole bowel cancer service and served as a forum for assuring clinical audit data, reviewing overall service quality and identifying improvements.

89. Patients recognise and value the importance of multi-disciplinary care planning:

Patient quote

"What difference do you think it makes, that they get together to look at the scans?"

(Researcher)

"I'm more confident. Now I feel, by them all working as a team, if one of them misses... It actually was spelled out to me, coz I talked about this teamwork, and they said 'If one of us has a concern, then we'll bring all the others in'."

(Respondent 7)

"How well do clinicians and oncologists communicate together?"

(Researcher)

"Well I would say 100% because, as I've said, they work as a team. In this particular hospital, it is all a team. It's not just the oncologist. It's the surgeon, the radiologist and everything."

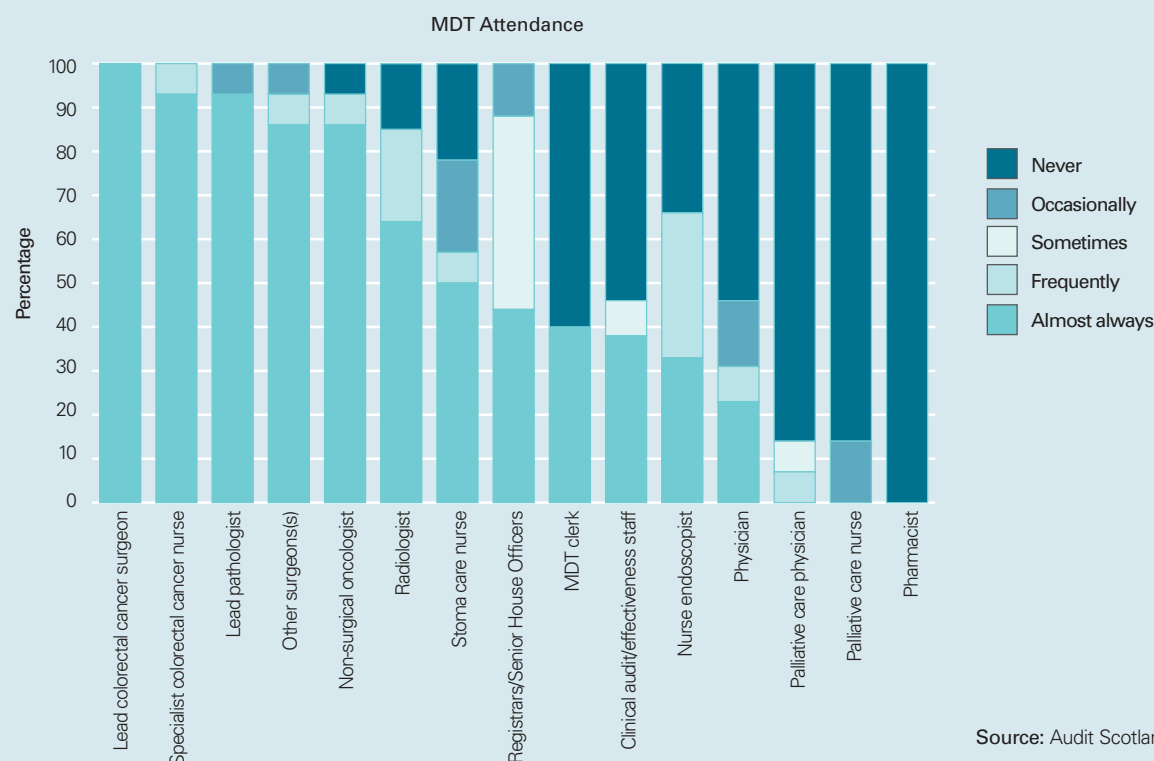
(Respondent 7)

90. There are areas where MDT working can be strengthened:

- Radiology shortages across NHSScotland affect the ability of radiologists to participate fully in bowel cancer specific MDT meetings, with radiologists attending 'almost always' at just over 60% of sites.

Exhibit 13

Frequency of attendance at bowel cancer MDTs by professional discipline



- Clinical audit staff attend 'almost always' at just over a third of MDT meetings.
- MDT coordinators are only in place at 40% of sites despite the guidance that they be appointed on the basis that better organisation of meetings leads to more efficient use of time and allows more patients to be discussed. It also results in more patients being managed in accordance with guidelines. The absence of dedicated administrative support for MDTs means that at many sites clinical nurse specialists (CNS) or consultant surgeons were forced to spend time ensuring that agendas were prepared, patients' records collected: a questionable use of their valuable time.⁵⁷

Recommendation:

- Regional Cancer Advisory Groups should ensure that all acute divisions are compliant with the CSBS standard for bowel cancer MDTs.

Pathology: at the centre of the MDT

91. Pathology is the diagnosis and management of disease through the processing and examination of cells and tissue. It has a major role in multidisciplinary management of bowel cancer services.

92. After surgery, pathological examination of the resection specimen helps determine prognosis and decide treatment. For this reason, the pathologist is a key member of the core multidisciplinary bowel cancer team and often leads the discussions at MDT meetings.

93. The specialty is, however, facing particular problems in staffing and resources. This has been acknowledged by the health department in commissioning the Scottish Pathology Action Group Report⁵⁸ and the Recruitment, Training and Retention of Medical Laboratory Scientific Officers (Biomedical Scientists) report.⁵⁹

94. We found no evidence that staff shortages were affecting the speed of pathology reporting for bowel cancer services. This may, however, mask difficulties in other non-cancer pathology services.

Bowel cancer clinical nurse specialists (CNS)

95. The role of bowel cancer CNS has developed since the early 1980s when it emerged as a distinct area building on stoma care, palliative care and other related disciplines. The role is now recognised as an important aspect of patient care.

⁵⁶ Cancer Services Collaborative 'Improvement Partnership'. Multidisciplinary Team Resource Guide [monograph online]. London: NHS Modernisation Agency, 2004.

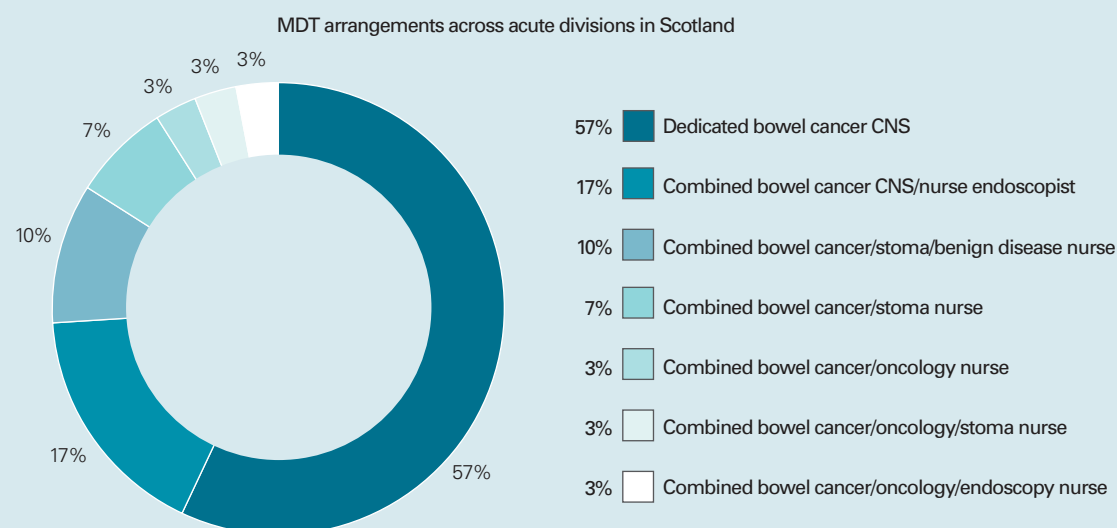
⁵⁷ Kelly MJ, National Cancer Service Collaborative colorectal cancer workshop, (2002) Birmingham (minutes).

⁵⁸ Scottish Pathology Action Group SEHD Unpublished Data.

⁵⁹ The Recruitment, Training and Retention of Medical Laboratory Scientific Officers, (2001) SMASAC.

Exhibit 14

Bowel cancer clinical nurse specialists roles



Source: Audit Scotland fieldwork 2004

96. Bowel cancer CNS play an important role in coordinating the care of patients and providing reassurance through what can be a complex and worrying series of encounters with the health service.

97. Bowel cancer CNS are now recognised as central to bowel cancer services. At many sites doctors had been instrumental in securing funding to create and fill these posts, demonstrating the value that surgical and medical staff place on this role. At the time of our fieldwork, all NHS boards in Scotland had at least one bowel cancer CNS in post, and they were in place at almost every hospital site in Scotland that provides bowel cancer services.

98. A significant minority of bowel cancer patients will require a temporary or permanent stoma. For them, access to a stoma CNS is vitally important. These specialist nurses provide pre and post-operative support and care to bowel cancer patients and are important members of the care team.

99. Patients reported varying levels and types of contact with bowel nurse specialists. They were reported to work very well with surgeons at the time of initial diagnosis, and before and after surgery. As well as emotional support and guidance, they provided patients and their carers with detailed information about treatment and prognosis, and acted as an ongoing point of contact. In a number of cases they also recommended sources of further information, for example, on the internet, and sometimes provided emotional support to other family members. This information enabled patients to feel more in control of their lives.

100. At some sites, they played an important role in co-ordinating treatment and care by liaising between the other professionals in the multi-disciplinary care team; for example, finding out test results, arranging appointments and helping to minimise delays in care.

Patient quotes:

"She is the bowel cancer specialist nurse who works with the clinician under who I am being treated. And she is my link. If I want to talk to the oncologist, she is the person I would chat to first about whether I need a clinic appointment or whether I would do it over the phone. She supports people going through the clinic... she is very much the support person who helps you get a handle on what is going on for you."

(Respondent 3)

"She has 20 years' experience. Seven years colon rectal. Great help to the coordination. To make it streamlined."

(Respondent 10)

Bowel cancer CNS roles

101. Although clinical standards require that all patients with bowel cancer have access to a named cancer nurse with expertise in bowel cancer,⁶⁰ there is no national guidance on how this specialist role should be organised; for example, how many CNS might be required per hospital,

what qualifications they should hold and what their role might entail. There is little reliable information that would permit estimates to be made of how many CNS in cancer are needed, where and for what purpose.⁶¹ This has led to a wide variety of approaches being adopted to meeting that particular clinical standard (Exhibit 14, previous page). CNS are a valuable, highly-skilled resource and it is important that their expertise is directed where it can bring best effect so that value for money is achieved.

102. In general this diversity reflects the conscious decision by local bowel cancer services to develop the local bowel cancer CNS role to meet local needs and circumstances in a cost-effective way. For example, where the volume of bowel cancer patients does not justify a dedicated bowel cancer role it is common for the bowel cancer CNS role to be combined with other cancer or gastrointestinal related activities.

103. However, there was evidence that where the bowel cancer CNS role is split with another aspect of patient care, the joint role was perceived by some patients to be negatively affecting the quality of care (See quote by respondent 8). The tension between developing the bowel cancer CNS role cost-effectively whilst at the same time meeting the needs of all patients clearly needs careful management.

Patient quote:

"She didn't come to me. I assumed it was because I wasn't going through chemotherapy... My husband says I should have (seen the nurse specialist). He said he feels somebody should have spoken to me before and after."

(Respondent 8)

104. A number of workforce planning actions are included within the recently published Framework for Nursing People with Cancer in Scotland⁶² so that a consistent approach to the CNS role can be introduced throughout the country. This will allow sufficient flexibility for local service needs to be met while at the same time providing assurance that value for money is achieved. As part of that process the health department should consider how cost-effective split bowel cancer CNS roles can be introduced without compromising the needs of all patients. It should also clarify the respective roles of specialist and generalist nurses in the planning and delivery of care (Good practice example 3).

Recommendation:

The health department should consider issuing guidance on good practice in relation to:

- the role of the bowel cancer CNS, so that their expertise is directed to best effect
- coordination of the dual CNS role to avoid compromising patient care.

The importance of providing good communication and information to bowel cancer patients

105. Information and communication directly affect the patient's experience of NHS services. The Scottish Cancer Plan⁶³ made a commitment that patients and their carers must be:

- involved as equal partners in decisions about their care and treatment, and
- provided with the information they need, when they need it.

106. The CSBS Clinical Standards for Colorectal Cancer⁶⁴ also require services to provide patients with information, and to communicate sensitively with patients and their families.⁶⁵

107. In 2001, the CSBS found that all trusts had written information about bowel cancer and several had developed local leaflets with additional information about the services provided within their trusts. At that time, while some staff had attended communication skills training, these courses were not generally attended by senior medical staff: the very people who are often responsible for discussing sensitive or bad news with patients and their families.

61 SEHD (2004). Nursing People with Cancer in Scotland. A Framework. Edinburgh: The Scottish Executive.

62 Ibid.

63 SEHD (2001). Cancer in Scotland: Action for Change (p. 28). Edinburgh: The Scottish Executive.

64 CSBS Standard Statement 4 (Communication and Information Sharing). Essential Criteria 2. Written information leaflets (including information about local support groups) are available for all patients (including those with disabilities and those requiring translation services).

65 CSBS Standard Statement 4 (Communication and Information Sharing). Essential Criteria 1. Patients with cancer receive information about their illness at all stages. The treatment options are discussed and decisions taken in partnership with the patient. Essential Criteria 3. The breaking of bad news is handled in a sensitive manner.

Good practice example 3

A strategic approach to the development of the clinical nurse specialist role

Ayrshire & Arran has a clear and well thought through strategy for the development of CNS across a range of specialties. The overall approach reflects good practice in a number of ways, as it is:

- *Seamless* – clear links have been made between CNS and primary care so that there is good coordination and communication.
- *Based on shared learning* – approaches to knowledge transfer between specialist and generalist nurses, many of whom will care for patients with cancer, are well thought through.
- *Sustainable* – the acute division has carefully considered how to develop new services and devised effective strategies to integrate them into their mainstream services once specific funding ends.
- *Linked to the MDT* – CNS are key members of the MDT and are well supported by the team.
- *Inclusive* – supervision and support for CNS staff is well developed, recognising that this can at times be an isolating role.

Good practice example 4

West of Scotland Cancer Network (WOSCAN) evidence-based patient information

In 2003/04, WOSCAN undertook a large scale project to generate a flexible, evidence-based information pack which could be used by professionals across the Network when sharing information with bowel cancer patients. It could also be used by patients to keep records and as a document in which they could record questions or queries they might wish to ask the professionals who were providing their care. The material has been organised and presented so that it can be used flexibly in response to the particular needs of individual patients, and can also be added to as patients' information needs change over time.

The process of developing the material reflected many aspects of good practice, as it was:

- *Patient-centred* – research took place with past and current patients to identify what they would like to have known/know.
- *Network-wide* – all of the patient information currently in use across the WOSCAN area was gathered, from which the best was selected.
- *Evidence-based* – teams of patients and professionals graded material according to evidence-based criteria (research, patients' views).
- *Inclusive* – plans are in place for versions of the information to be developed for patients who are deaf, blind, or for whom English is not their first language.
- *Based on the principles of continuous improvement* – the process includes patient and professional evaluation after six months and a re-audit of the materials after two years.

Information

108. In 2004, all sites had either developed their own information for patients or were using appropriate material prepared by specialist charities such as Colon Cancer Concern, Cancer BACUP or Macmillan Cancer Relief. In WOSCAN, Grampian, and Tayside extensive research had taken place with patients and their families to determine the types of information which they found to be of greatest value at the different stages of diagnosis and treatment ([Good practice example 4, page 27](#)).

Communication

109. Peoples' responses and expectations vary enormously in terms of how much information they want, and when. This makes it difficult to specify hard and fast rules on how to communicate with patients and their families.

110. Clinicians' communication regarding diagnoses and treatment options was generally regarded as very good. In particular, clinicians' frankness, honesty and willingness to share medical information ([See patients' communication quotes below](#)).

Patients' communication and information 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)

"I have a great relationship with my surgeon and oncologist, you know? Not just that (cancer). We talk about other things. He's checking 'How are you getting on?' and discussing my

last scan. I have a slight surgical hernia now and we discuss that, but we discuss other little things; you know, things that we might have a laugh over. A passing conversation. I think that's more personal."

(Respondent 7)

Patients' choice quotes:

"So she (the anaesthetist) talked through that and I opted for the epidural because it sounded a better way of coming through surgery afterwards and would reduce the amount of pain control I would have to have in the high dependency unit."

(Respondent 3)

"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)

111. Clearly, these findings reflect in part the continuing commitment shown to developing staff skills in this important area of service quality. However, as in the earlier CSBS findings, there is continuing evidence of some senior clinicians failing to engage in training and development opportunities concerned with ensuring effective communication with patients.

Recommendation:

- NHS boards should consider issuing formal guidance on communication training for senior clinicians.

The quality of clinical management of bowel cancer patients

The overall position

112. There are clear clinical standards in place for the treatment of patients with bowel cancer⁶⁶ which set out the quality of clinical service that patients should receive. They are complemented by clinical guidelines for the management of bowel cancer.⁶⁷ We found that most hospitals comply with clinical standards but:

- a small number of pre-operative standards have not kept pace with clinical practice and are in need of updating, and
- 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 ([Exhibit 15](#)).

Patient care before surgery

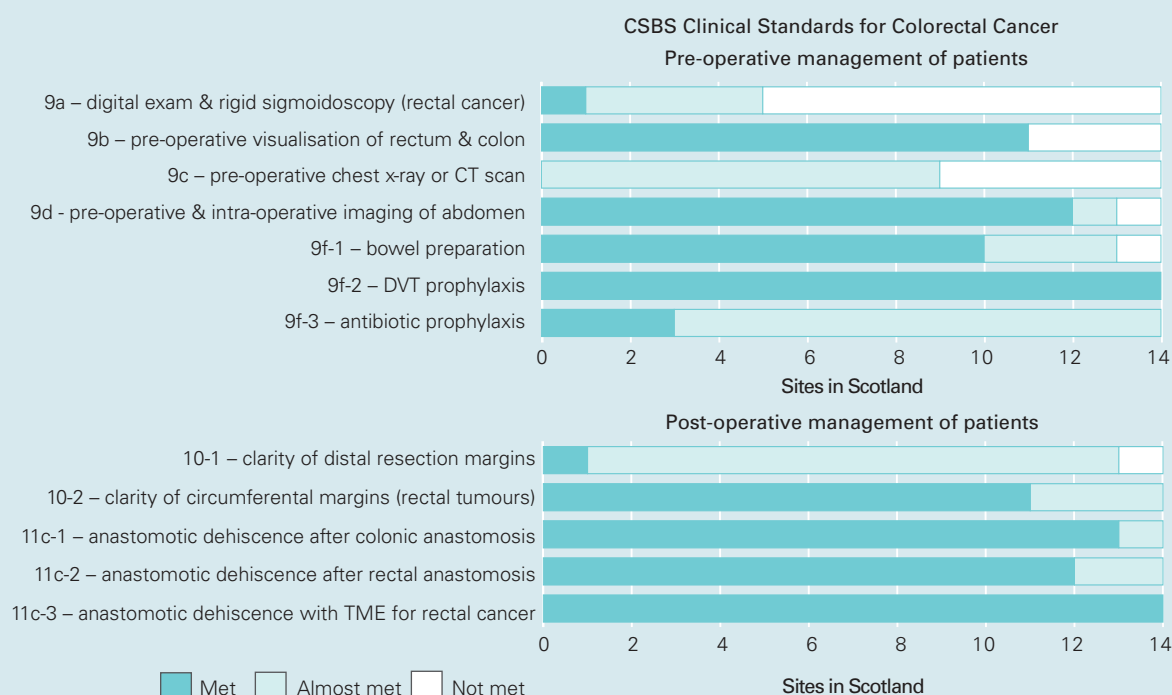
113. Pre-operative diagnostic tests and investigations are essential for all patients if the extent of the cancer is to be fully assessed and the decision about the approach to treatment made. Prior to surgery taking place preparations are also required, for example, to ensure that antibiotics are administered properly to reduce the risk of infection, and measures are taken to reduce the prospect of the patient suffering from deep vein thrombosis (DVT) after the operation. These requirements are all reflected in the CSBS preoperative preparations/investigations clinical standards for colorectal cancer.

66 CSBS. Clinical Standards. Colorectal Cancer, January 2001.

67 Management of Colorectal Cancer. A national clinical guideline (67), SIGN, 2003.

Exhibit 15

Bowel cancer compliance with clinical standards across NHSScotland (2002)



Source: NOSCAN, SCAN, WOSCAN

114. We found that:

- only one of the seven essential criteria for the management of patient care before surgery (9f-2) was fully met at all sites
- one of the seven essential criteria (9f-3) was either fully or almost met at all sites
- two of the seven essential criteria (9d and 9f-1) were either fully or almost met at all but one site
- three (9a, 9b and 9c) were unmet at more than one site across NHSScotland.

Standard 9a: All rectal cancer patients are assessed by digital examination and rigid sigmoidoscopy

115. For patients with rectal cancer a rectal examination is needed to assess whether surgery is possible and if so whether preoperative radiotherapy is required. The clinical standard suggests that a rigid sigmoidoscope should be used as part of this process. A rigid

sigmoidoscope is a lighted tube which allows the health professional to look into the rectum and a portion of the lower large intestine (ie, the sigmoid colon). It can be used to take a sample of tissue (a biopsy) from the sigmoid colon.

116. Three sites in Scotland met the standard. However, at all sites except one over half of patients receive either or both of these diagnostic investigations ([Exhibit 16 overleaf](#)). The most reasonable explanations for the apparent poor performance is a combination of the following:

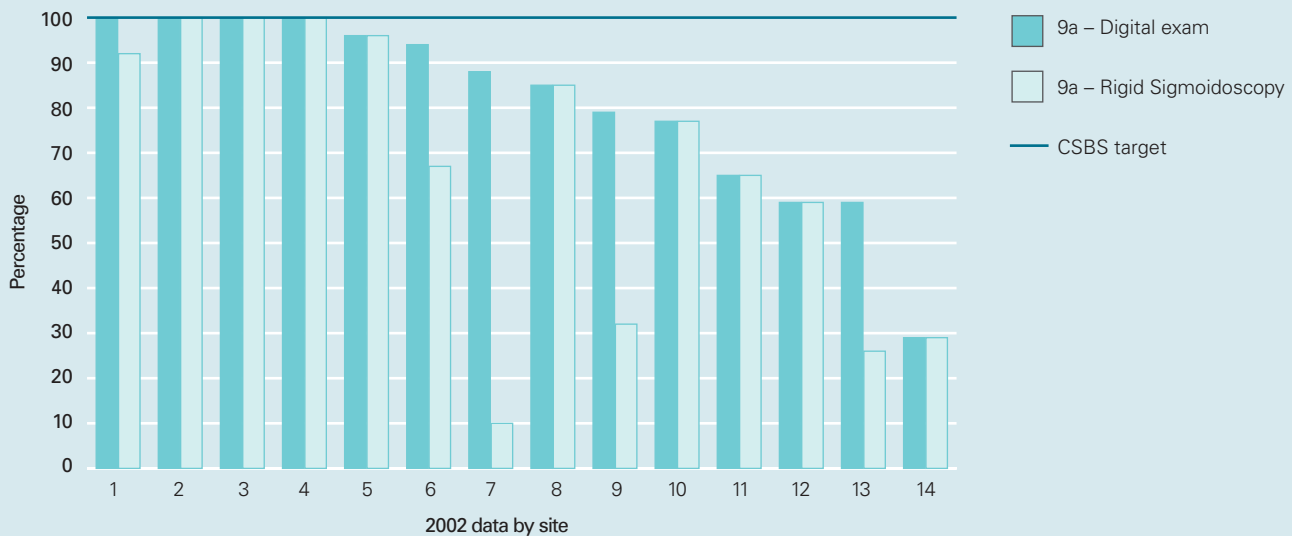
- the use of rigid sigmoidoscopy has, at several sites, been largely overtaken by flexible sigmoidoscopy, a change in clinical practice which is not recognised in the clinical standard
- at other sites, clinicians are failing to record in patients' case notes that these tests have taken place. This failure of documentation means that they are not able to demonstrate whether or not they are complying with the standard.

Recommendations:

- NHS QIS should review this clinical standard to ensure that it more accurately reflects desired clinical practice, consistent with development in clinical management, in this area.
- Bowel cancer MCNs should reinforce to clinicians the need for accurate recording of all diagnostic tests and preparations that have taken place and audit improvements in compliance in this area.
- Bowel cancer lead clinicians within acute divisions should consider how best to deliver integrated record keeping for diagnostic testing and staging of bowel cancer patients.

Exhibit 16

Clinical compliance with Standard 9a – all rectal cancer patients are assessed by digital examination and rigid sigmoidoscopy



Source: Audit Scotland fieldwork 2004

Standard 9b: The rectum and whole colon is visualised preoperatively in a minimum of 70% of patients

117. Visualising the rectum and whole colon of patients with bowel cancer before surgery should take place to ensure that no tumours are missed. The 70% visualisation target set within the clinical standards reflects the fact that around 30% of bowel cancer patients present as emergencies and, for these patients visualisation before surgery may not always be possible.

118. This clinical standard was met at all but three sites in Scotland (11 out of 14) ([Exhibit 17](#)).

119. Further investigations are taking place on the reasons for non-compliance at those three sites (for example, resource constraints or exceptionally high levels of emergency admissions) which will be reported to the appropriate bowel cancer MCN. The report will include details of any improvement actions that need to be put in place to secure future compliance with the standard.

Recommendation:

- Bowel cancer MCNs should report back to their RCAG on action taken to secure sustained compliance with the standard.

Standard 9c: Chest X-ray or chest CT scan is performed preoperatively for all patients

120. Patients' chests need to be assessed before surgery to detect whether cancer has spread to the lung. This standard, that all patients receive either a chest X-ray or chest CT scan before surgery, was not met at any site in Scotland ([Exhibit 18 page 32](#)). The vast majority of sites were, however, close to compliance.

121. The most likely explanation for our findings relate to the practical arrangements for reviewing X-rays at many hospitals. It is common for X-rays to be reviewed by the consultant surgeon in charge of the case rather than being formally reported by radiology staff. If no metastatic disease is found X-rays are not always returned to patients' records. When checking patients'

records, clinical audit staff are unable to record an X-ray has taken place. At a practical level this has no negative consequences for patient care. It does though make it difficult for clinicians to demonstrate compliance with the required clinical standard. It is also inconsistent with the Ionising Radiation (Medical Exposure) Regulations 2000 which came into force in January 2001. These specify that a clinical evaluation of the outcome of each medical exposure should be recorded.⁶⁸

122. These findings highlight governance issues which need to be addressed by acute divisions and bowel cancer MCNs.

Exhibit 17

Bowel cancer clinical compliance with Standard 9b – the rectum and whole colon is visualised preoperatively in a minimum of 70% of patients



Source: Audit Scotland fieldwork 2004

Recommendations:

- Clinicians should ensure that a record of all chest imaging is placed in patient notes and that all chest X-ray films are returned to the imaging department for reporting.
- Bowel cancer MCNs should report back to their RCAG on action taken to secure sustained compliance with the standard.

Standard 9d: Abdomen is imaged preoperatively by ultrasound or CT or MRI or intraoperatively by ultrasound in a minimum of 80% of patients

123. This standard is designed to:

- check whether cancer has spread to the liver
- avoid any inappropriate surgery
- check for fluid in the abdominal cavity, kidney enlargement, and
- assess the extent of the primary tumour.

124. The standard was met at 12 out of 14 sites. Of the two non-compliant sites one was very close to the standard (79%). As with standard 9b, the appropriate bowel cancer MCN is reviewing the reason for significant non-compliance at the other site (51%) and will be reporting back to its RCAG on action taken to secure sustained compliance with the standard ([Exhibit 19 overleaf](#)).

Standards 9f (1-3): Bowel preparation

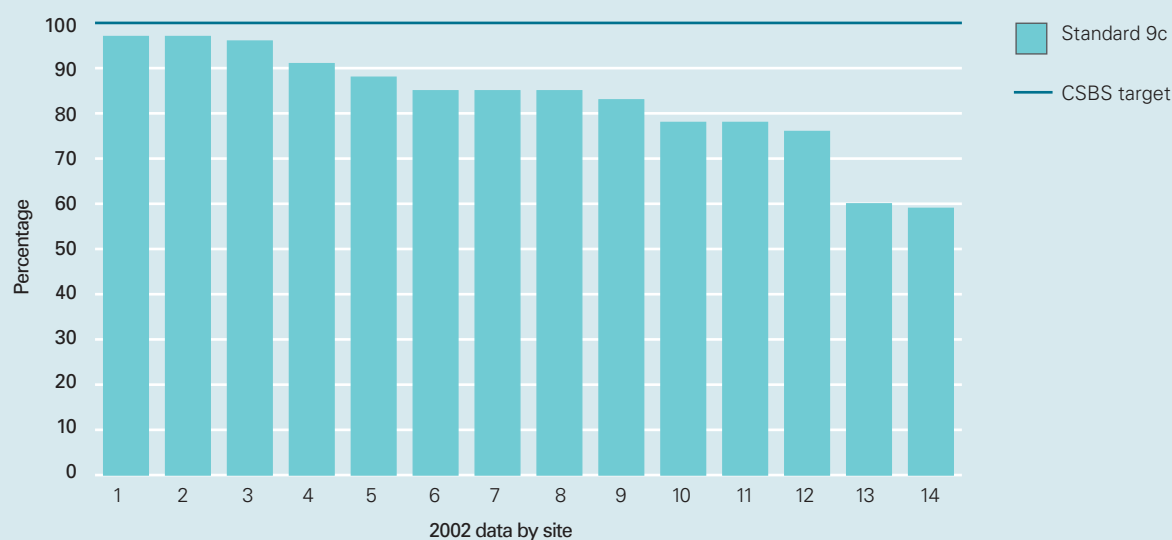
125. The purpose of bowel preparation is to ensure that the bowel is clear of faeces, antibiotics are administered properly to reduce the risk of infection, and measures are taken to reduce the prospect of the patient suffering from deep vein thrombosis after the operation.

126. We found that:

- The target for standard 9f(1), that a minimum of 80% of patients should have bowel preparation, was met at 10 out of 14 sites. All but one of the four non-compliant sites were close to the standard (53%, 72%, and at two sites 73%).
- The target for standard 9f(2), that a minimum of 70% of patients should have DVT prophylaxis, was met at all sites in Scotland.

Exhibit 18

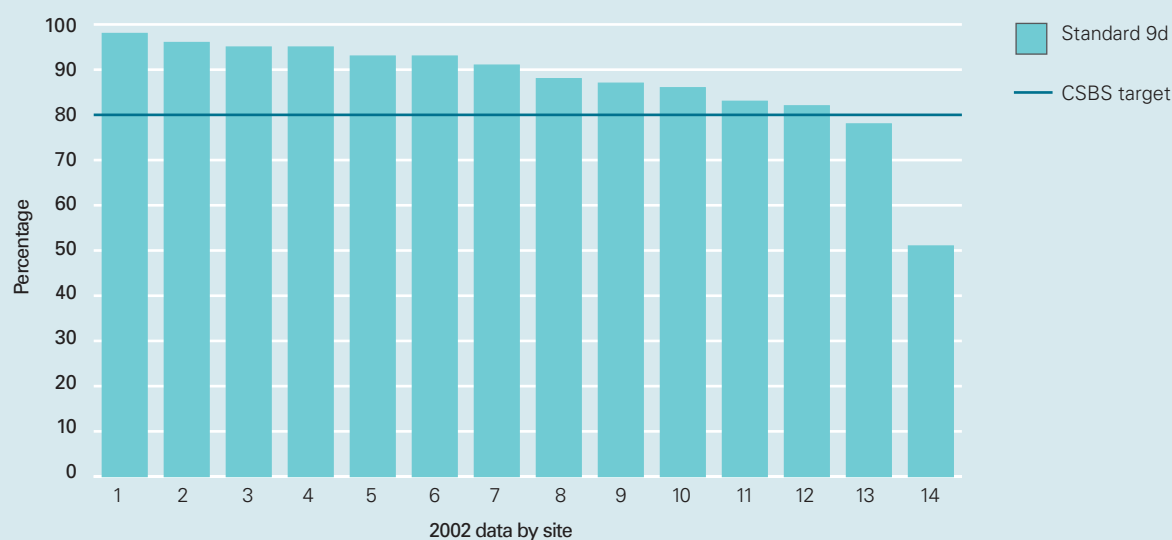
Bowel cancer clinical compliance with Standard 9c – chest X-ray or chest CT scan is performed preoperatively for all patients



Source: Audit Scotland fieldwork 2004

Exhibit 19

Bowel cancer clinical compliance with Standard 9d – abdomen is imaged preoperatively by ultrasound or CT or MRI or intraoperatively by ultrasound in a minimum of 80% of patients



Source: Audit Scotland fieldwork 2004

- The target for standard 9f(3), that all patients are to have antibiotic prophylaxis, was only met at four sites, although this standard remains consistent with recent research.⁶⁹ All the other sites were close to the standard (80-99%) (Appendix 2).

127. The performance in relation to Standard 9f(1) has highlighted an area where the clinical standards has not kept pace with developments in both evidence and clinical practice. There is no compelling evidence that backs up the selection of 80% as a target figure. In fact, current evidence does not support its routine use. The most recent SIGN guideline on the Management of Bowel Cancer⁷⁰ recommends that the decision to use bowel preparation must be individualised according to the patient's needs and the surgeon's experience.

Recommendation

- NHS QIS should update standard 9f(1) to bring it into line with most recent evidence and current clinical practice in consultation with bowel cancer MCNs.

Patient care during and after surgery

128. Performance in this area is very good, with high levels of compliance with clinical standards. All of the five clinical standards were either fully or almost fully met at all sites in NHSScotland. Where the standards were not fully met, all sites were close to the target performance level.

Standards 10 (1-2): Clarity of tumour margin after surgery

129. The aim of surgery for bowel cancer is to remove the primary cancer with a complete outer covering of normal tissue. This outer covering is known as the tumour margin and exists in three dimensions related to the primary cancer, proximal, distal and circumferential (lateral).

130. If surgical resection is feasible and appropriate it is generally accepted that a clear margin should always be achievable unless a small number of specific circumstances exist; for example, if the surgery is a palliative debulking operation.

131. Attaining a cancer-free circumferential margin can be particularly challenging in rectal cancer which is reflected in the 70% target set in the CSBS standard 10(2). It is because of this added technical anatomical difficulty that radiotherapy has a supporting role to surgery in the treatment of rectal cancer.

132. We found that:

- Standard 10(1), that all distal resection margins for all tumours are clear, was met at only two sites. However, at all but one of the remaining sites, performance was at over 90%. At one site, the high levels of 'missing data' made it impossible for definitive judgements about performance to be made. The appropriate bowel cancer MCN is reviewing the pathology data for those patients to provide assurance that appropriately high standards of clinical practice are being achieved.
- Standard 10(2), that a minimum of 70% of circumferential margins (for rectal tumours) are clear, was met at all sites (Appendix 3).

Standards 11c (1-3): Anastomotic dehiscence after surgery

133. After part of the colon or the rectum has been removed during surgery, normal practice is to attempt to join the two ends together again (with the exception of an abdominal perineal excision of rectum where the whole rectum and anal canal has to be removed and the patient therefore has to have a permanent colostomy). A recognised complication of a colonic resection where a join (anastomosis) has been made is dehiscence or breakdown of this anastomosis. This is an important complication as it leads to intra-abdominal infection and has a high mortality rate (in the region of 50%).

134. We found that:

- Standard 11c(1), that anastomotic dehiscence is not more than 5% after colonic anastomosis, was met at all but one site. The non-compliant site is very close to the target figure (6%).
- Standard 11c(2), that anastomotic dehiscence is not more than 10% after rectal anastomosis, was met at all but two sites. The two non-compliant sites were both close to the target figure.
- Standard 11c(3), that anastomotic dehiscence is not more than 20% after anterior resection with TME for rectal cancer, was met at all sites (Appendix 4).

69 Glenny AM, Song F. Antimicrobial prophylaxis in colorectal surgery. Qual Health Care 1999; 8: 132-6.

70 Scottish Intercollegiate Guidelines Network, 67: Management of Colorectal Cancer. A national clinical guideline. SIGN, March 2003.

Recommendation:

- When updating standard 11c(3), NHS QIS should consider setting a more stretching standard for future performance based on current international best practice, in line with its goal of ensuring that targets of achievement are ratcheted up as performance improves.

Surgical sub-specialisation

135. There is good evidence that patients with rectal cancer who are operated on by a specialist surgeon have better outcomes than those who are operated on by a generalist.⁷¹ However, there is no nationally accepted definition of what constitutes a specialist surgeon. For the purposes of our review, we included within our definition of a specialist surgeon someone who:

- has either undergone specialist training
- is on the appropriate register of the Royal College of Surgeons, or
- is working within a bowel cancer service where the lead clinician has adopted a formal policy of only allowing surgeons who have a sub-specialist interest in rectal surgery to operate on patients with rectal cancer.

136. On that basis, there has been a clear improvement in surgical sub-specialisation in this area over the last three years ([Exhibit 20](#)).

137. Improvements in the levels of sub-specialisation were found across Scotland. At every site, at least 75% of patients with rectal cancer were operated on by a surgeon with a sub-specialist interest (range 75%-97%).

Updating of clinical standards and minimum data sets

138. Clinical standards reflect the best knowledge available at the time that they were developed. As soon as they have been approved and published, they run the risk of becoming out-dated as a result of developments in clinical practice. This situation has arisen with a number of the CSBS standards for bowel cancer which now present a potentially misleading negative picture of clinical performance. It would therefore be timely for them to be subject to review.

139. The current clinical standards provide for periodic judgements to be made about the safety with which chemotherapy is prescribed, dispensed, administered and supervised through the NHS QIS inspection process. Existing clinical standards do not, apart from one standard concerning waiting times between surgery and the start of adjuvant chemotherapy, provide for the routine monitoring and reporting of oncology services for those patients for whom oncology is either the main treatment regime or a significant adjunct to surgery or palliative care.

140. For pathology too, although clinical standards are in place concerning compliance with the joint national guidelines minimum data set for colorectal histopathology, the timeliness and quality of pathology reporting is not part of the management information that is captured for the routine performance management of bowel cancer services.

141. When reviewing existing bowel cancer standards there will be value in considering:

- where changes need to be made to reflect changes in current clinical good practice

- how the standards can be developed so that a comprehensive perspective on the quality and timeliness of all aspects of bowel cancer care is best achieved.

142. The results should be clear, measurable and linked to evidence. At the same time as drafting the revised standards, information requirements and current data availability should be considered and addressed.

Recommendation:

- NHS QIS should consider all the issues highlighted above when reviewing the bowel cancer clinical standards.

Clinical audit and follow-up

Clinical audit

143. Good progress has been made in bowel cancer clinical audit since the 2002 CSBS visits with reliable data now available nationally. However:

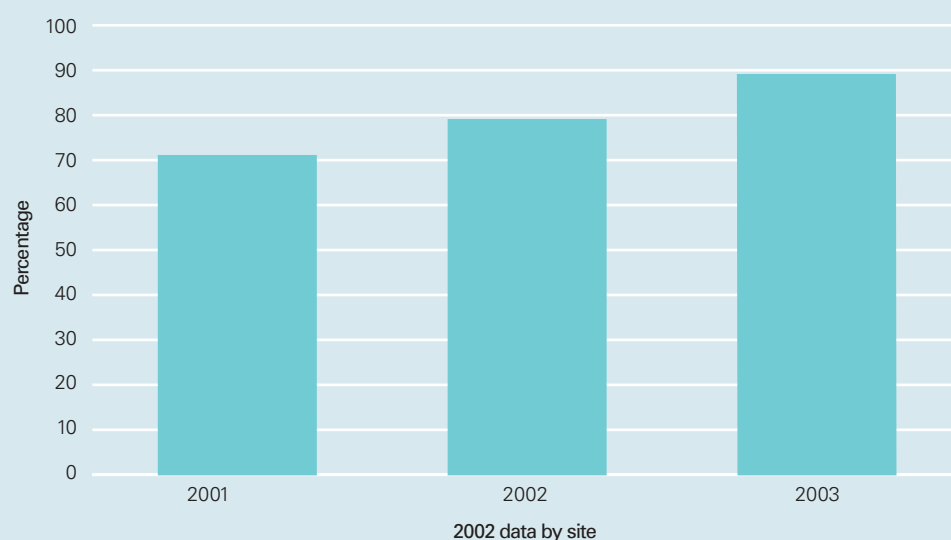
- further work is needed to ensure consistency of data reporting between all three bowel cancer networks
- improvements are needed at some sites in the recording of the care provided to patients on clinical records
- staffing levels are an issue at some sites. There is evidence of a clear linkage between adequate staffing and the extent to which clinical audit can help the service identify improvements needed and measure whether they are being achieved.

71 Martling AL, Holm T, Rutqvist LE, Moran BJ, Heald RJ, Cedemark B. Effect of a surgical training programme on the outcome of rectal cancer in the County of Stockholm. Stockholm Colorectal Cancer Study Group, Basingstoke Bowel; Cancer Research Project. *Lancet* 2000; 359: 93-6.

Exhibit 20

The percentage of patients with rectal cancer in Scotland operated on by a specialist surgeon 2001-03

Surgical sub-specialisation in this area is improving year on year.



Source: Audit Scotland fieldwork

Good practice example 5

Clinical audit

Ayrshire & Arran: combining strong governance and continuous service improvement

There are two ways in which clinical audit in Ayrshire works well. First, as well as coordinating and reporting on national minimum data sets, clinical effectiveness staff assist clinicians and other staff in analysing local data that is then used to develop services. Second, the clinical effectiveness role has been designed so that it is integrated with the routine care of patients.

Continuous service improvement

There are three Lead Cancer Audit Facilitators within the clinical effectiveness department – one covers bowel cancer, gynaecology, upper gastroenterology, and head and neck. Data collection is carried out for local audit and MCN audit, they liaise with QIS and ISD. The MCN dataset is used so they can compare data with other trusts. Regular reports are distributed to the trust, NHS board and SE. In addition, they respond to requests received for specific audit work from the trust and individual consultants, and they support all cancer projects conducted in the trust.

Linking good governance and care planning

The facilitator for the bowel cancer MDT is part of the clinical effectiveness department in Ayrshire & Arran. As part of her role she:

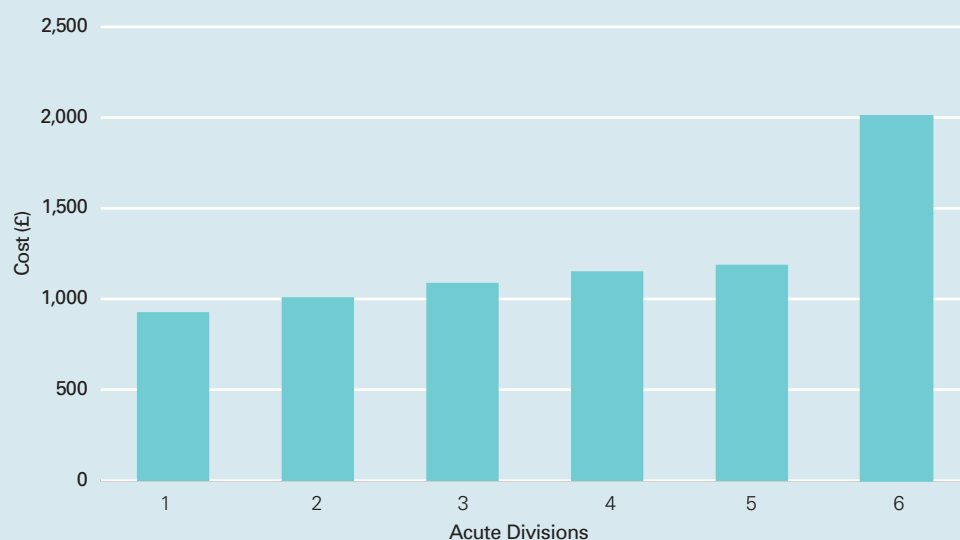
- provides administrative support to the MDT
- organises slides and reports
- takes minutes which are checked for accuracy by the lead clinician, and
- generates letters summarising decisions made at the MDT which are sent to GPs and placed in patients' notes.

This partnership approach with clinicians linking in with the work of the bowel cancer MDT and supporting wider service developments has led to clinical effectiveness being seen as part of, and adding value to, the wider bowel cancer service rather than another burden upon hard-pressed clinical and nursing staff.

Exhibit 21

'Average' patient five-year surveillance costs for bowel cancer patients across NHSScotland

Only six datasets are included, as a common follow-up protocol has only been agreed in the West of Scotland and is being followed by all acute divisions within the WOSCAN network.



Source: Audit Scotland fieldwork 2004

144. The support provided by clinical audit departments to colleagues ranged from full involvement in MDT working and the provision of tailored ad-hoc pieces of data analysis, to basic level compliance with national clinical data returns. The extent to which clinical audit staff were able to add value depended critically upon a number of factors:

- Resources – particularly staff who are not diverted to other non-audit duties.
- Support from clinicians.
- Specialist training.
- Technology.

145. An extended role for clinical audit staff where they are fully involved in organising bowel cancer MDT meetings has begun to evolve at a number of larger acute divisions. For example, Tayside and Ayrshire & Arran. This model ensures that the clinical audit process is fully integrated with the routine management of patient care. (Good practice example 5, page 35).

146. These local new approaches to clinical audit support need to be balanced against the need for regular consistent reporting of national data on bowel cancer clinical performance. To date, national reporting has been co-ordinated in an ad-hoc fashion, relying on the support of the three bowel cancer MCNs. As the national bowel cancer framework develops further a stronger national lead may be required by the health department.

Recommendations:

- Acute divisions should:
 - recognise that clinical audit and information are a central aspect of a quality service and ensure that staff are not diverted to other non-audit duties
 - ensure that IT and audit strategies are integrated wherever possible to maximise opportunities to mechanise data collection and analysis.
- The health department should create a framework for national reporting of bowel cancer clinical audit data under the leadership of clinicians representing each bowel cancer MCN.

Follow-up

147. Patients who have had curative surgery for bowel cancer are followed up for four reasons:

- To detect any spread of the disease to another part of the body in the hope that early detection and treatment will result in improved survival.
- To survey the remaining colon and rectum to detect recurrence and/or other cancer or benign polyps.
- For the psychological support of the patient.
- For audit purposes.

148. The follow-up of bowel cancer patients although useful for reassurance and surveillance is of little clinical value and is labour-intensive and expensive. Follow-up is sometimes perceived as low priority so target dates for surveillance are not always being met when services are under pressure.

149. The Association of Coloproctology⁷² acknowledges the absence of evidence from randomised trials of survival benefits from routine follow-up and cites the most persuasive arguments for routine follow-up as being patient support and audit. It endorses the use of colonoscopic follow-up on the basis that it has been shown to produce a high⁷³ yield of treatable adenomatous polyps and cancers, but recognises the risks to patients of the invasive nature of colonoscopy.

150. The most recent SIGN guideline⁷⁴ recommends follow-up of patients who have undergone curative surgery to facilitate the early detection of spread of the disease in the hope that detecting and treating cancer early will improve chances of survival. It does not specify the frequency or detailed clinical protocol through which follow-up⁷⁵ should take place. Recent research⁷⁶ concluded that, based on available data and current costs, intensive follow-up after curative resection for bowel cancer is economically justified and should be normal practice. Further research is required though to gain a full understanding of the efficacy of specific surveillance tools.

151. As part of the audit we examined local policies in relation to follow-up and found significant variations in practice. Using unit cost estimates for surveillance of bowel cancer⁷⁶ we have calculated how the cost of the different practices varies, as shown in [Exhibit 21](#). For an 'average' patient, five-year surveillance costs range from £580 - £2,001. Linked with the surveillance costs are the resource demands that the various practices place on NHSScotland.

152. There are also cost and effectiveness issues associated with who undertakes follow-up. For those patients for whom follow-up is purely psychological, it could be argued that using a CNS rather than physicians or surgeons to undertake follow-up provides opportunities to reduce the cost of follow-up. Nurse-led follow-up is beginning to be adopted in several sites in Scotland. Further research is

required on the cost and efficiency of nurse-led follow-up. Research into patient preferences in this area would also be of value, as would research into other options such as GP-led follow-up.

Patient quote:

"It's a whole team work. It's team effort looking after you. I'm seeing somebody nearly every six weeks. I know when my scans are this year and next. I know when all my appointments at the oncologist's and surgeon's are, right up to a year ahead. It's all ordered. I know that if there was a little problem, they'd sort it straight away. Now I don't worry. I know my dates, everything. It puts me a lot more at ease."

(Respondent 7)

Recommendations:

- NHS QIS should consider issuing guidance on the appropriateness and cost-effectiveness of different follow-up models/regimes.
- The health department should consider commissioning research on the cost and efficiency of nurse-led follow-up, including patient preferences in this area.

72 Association of Coloproctology of Great Britain and Ireland. Guidelines for the management of colorectal cancer. London: Association of Coloproctology of Great Britain and Ireland, 2001.

73 An adenoma is a benign tumour.

74 Management of Colorectal Cancer. A national clinical guideline (67). SIGN, March 2003.

75 Renehan AG, O'Dwyer ST, Wynes DK (2004) Cost-effectiveness analysis of intensive versus conventional follow-up after curative resection for colorectal cancer. British Medical Journal, 328, 81-4.

76 Sources of costs are taken from the Renehan et al. research cited earlier, and are based on estimates including direct, indirect and overhead costs based on 2002 prices. Sources of cost estimates are from Department of Health reference costs, Gilbert et al., multicentre aneurysm screening study and their in-house financial department.

Part 5. Waiting times performance

Many patients are waiting too long for diagnosis and treatment. Based on current trends it is unlikely that the target of all patients starting treatment within two months for all urgent referrals will be met by the end of 2005.

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. 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.

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 in such a way that it does not slow up diagnosis and treatment for non-screened patients.

How likely is it that the Health Department's 2005 'two-month' waiting times target will be met?

153. *Cancer in Scotland* recognises the importance that patients place upon waiting times and the anxiety that waiting for diagnosis and treatment can create. *Our National Health*⁷⁷ pledged that by 2005 the maximum wait from urgent referral to treatment for all cancers will be two months.

154. At the time of the 2001 CSBS national overview report on Colorectal Cancer Services 'it [was] difficult to assess Trust performance against treatment standards, particularly where those involved waiting times, as there were inadequate data collection and analysis systems in place in most Trusts'.⁷⁸ Since that time, good progress has been made and national data is now routinely available.

155. Slow and uneven progress is being made in improving overall waiting times ([Exhibit 22](#)).

156. The most recent data which distinguishes between urgent and non-urgent referrals does though show improved performance in this area, with six in ten of all patients referred urgents by their GP starting treatment within the two-month target period. If current trends continue the 2005 two-month target will not be met. ([Exhibit 23](#)).

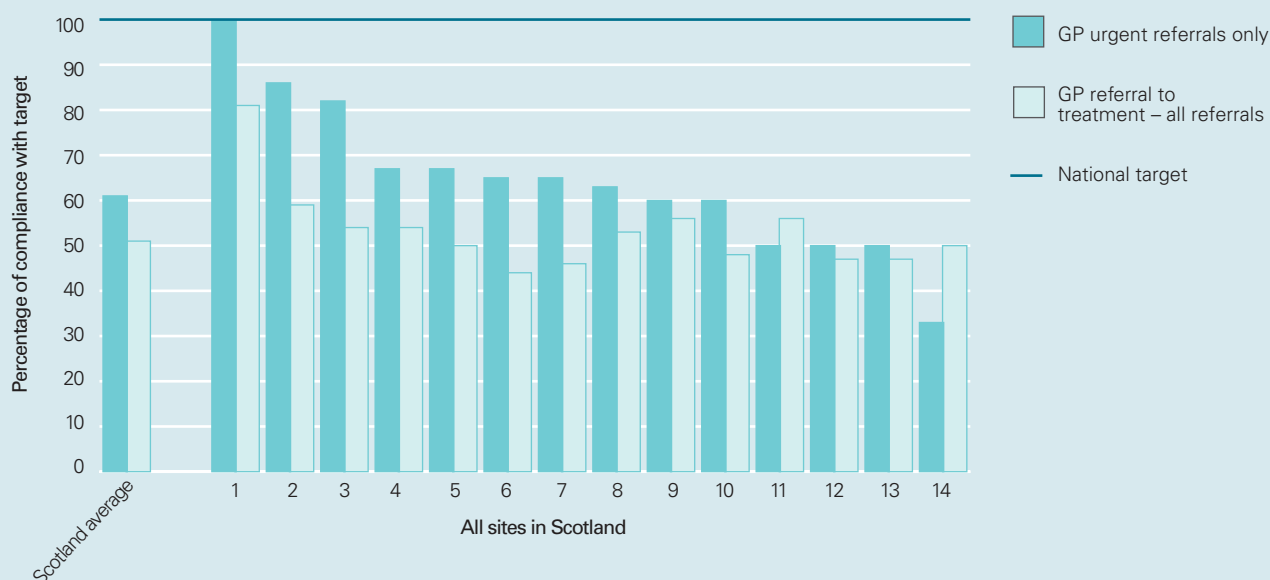
157. Waiting list initiatives monies have been used at many sites across Scotland to shorten waiting times for diagnosis and treatment. Their use has focused on catching 'long-waiters' who would otherwise breach existing waiting times guarantees. But it is clear that the gap between current performance and the 2005 bowel cancer waiting times target is so great that expanding the use of waiting list initiatives monies for bowel cancer services will not be affordable and sustainable in the future. A different approach will need to be taken.

77 SEHD (2001). *Our National Health: A plan for action, a plan for change*. Edinburgh: SE.

78 CSBS. *National Overview: Colorectal Cancer Services* (p7). CSBS, March 2002.

Exhibit 22

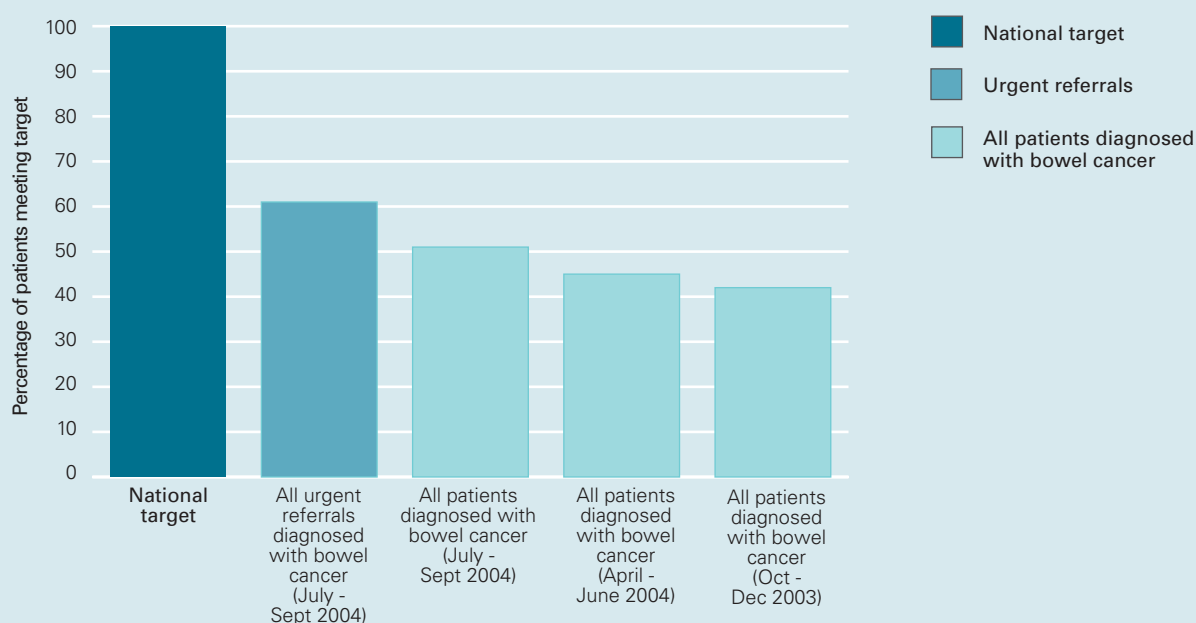
Illustrates the percentage of bowel cancer patients in Scotland seen within the two-month 2005 'urgent referral' waiting times target (July – September 2004)



Source: NOSCAN, SCAN and WOSCAN

Exhibit 23

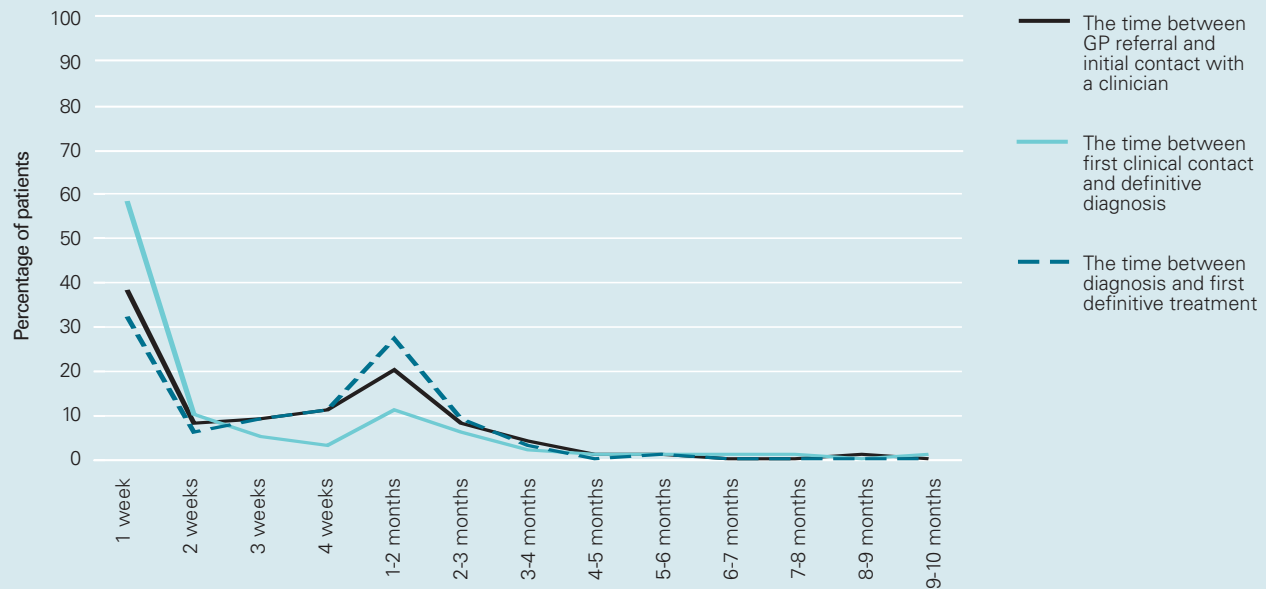
Performance against the national target, that by 2005 the maximum wait from urgent referral to treatment for all cancer will be two months (October – December 2003 to July – September 2004)



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

Exhibit 24

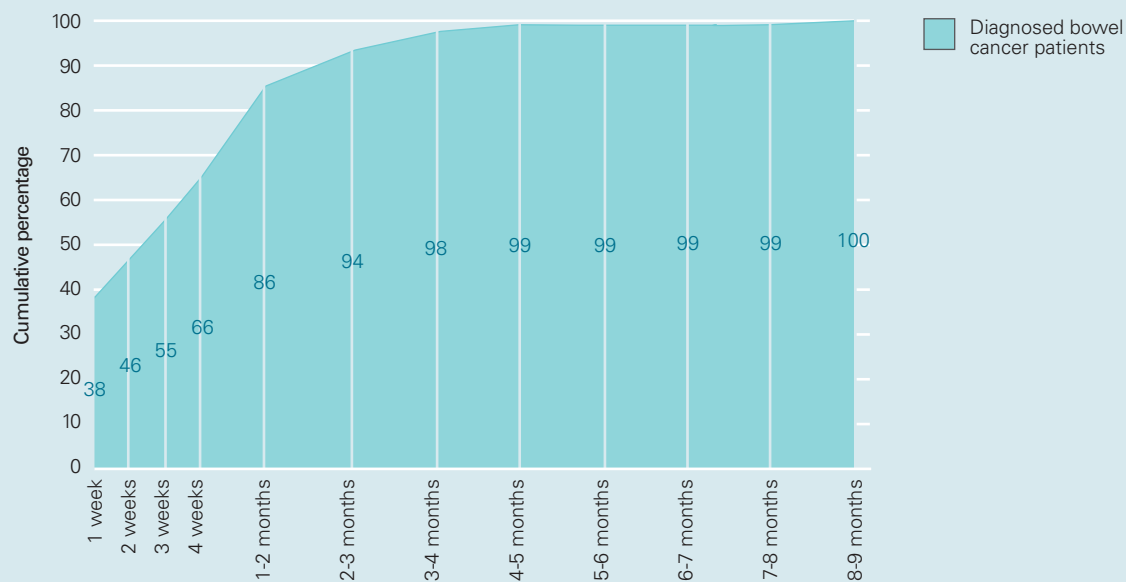
Average waiting times for the three main stages of the bowel cancer patient journey across Scotland (October – December 2003)



Source: NOSCAN, SCAN and WOSCAN

Exhibit 25

Bowel cancer waiting times from GP referral to first clinical contact at hospital across Scotland (October – December 2003)



Source: Audit Scotland fieldwork 2004

Are there specific bottlenecks that need to be tackled?

158. We analysed detailed waiting times information on the three main stages of the bowel cancer patient journey (GP referral to initial contact with a hospital clinician; initial contact with hospital clinician to diagnosis; and, diagnosis to first treatment) to identify whether any specific bottlenecks exist within bowel cancer services ([Exhibit 24](#)).

159. The data shows a striking uniformity in waiting times performance at each stage of the patient journey for all patients diagnosed with bowel cancer. For the vast majority of patients time from first clinical contact to diagnosis is the shortest stage of their journey, with time from diagnosis to treatment the longest. This is at least partly because the data includes emergency patients. As around 35-40% of all bowel cancer patients are treated as emergencies,⁹ this at least in part explains the relatively good performance in seeing, diagnosing and treating so many patients in the first week of care.

The challenge of defining urgency for suspected bowel cancer patients

160. The health department has been working with the Information Services Division and Regional Cancer networks to agree a definition of urgency which can be used across NHSScotland. As a result, accurate data on the speed of diagnosis and treatment of 'urgent' referrals may now begin to be captured.

161. The risk of stratifying patients in this way is that it may lead to a two-tier service, with 'urgent' cases being seen rapidly but significant numbers of 'non-urgent' patients (who may have cancer) waiting unacceptable

periods of time. In England it was found that the introduction of the 'two-week rule' ('that all urgent cancer referrals be seen within two-weeks') led to longer waits for non-urgent referrals. Unfortunately, a significant proportion of non-urgent patients were actually suffering from cancer.

162. The definition of urgency which has been adopted is that those patients whose referral is marked as urgent by their GP will be classified as urgent referrals. There are sometimes difficulties in securing agreement between GPs and hospital specialists on whether specific patients are 'urgent'. Hospital specialists have in the past sometimes 'adjusted' the urgency of referral either upwards (from 'non-urgent' to 'urgent') or downwards (from 'urgent' to 'non-urgent') based on their own assessment of risk and urgency.

163. Stratifying patients into urgent and non-urgent groups should not compromise the care of patients if tackled effectively.

164. In order to address concerns about the potential creation of a two-tier system by introducing specific waiting times for urgent referrals, the health department intends to report waiting times for both urgent referrals and all other patients diagnosed with bowel cancer.

Recommendations:

- The bowel cancer framework group should issue guidance on referral and triage arrangements/handling of referrals and allocating priority in secondary care.
- The health department should audit the implementation of national guidance on urgency of referral for bowel cancer. This

would allow relative waiting times to be measured based on urgency of referral (urgent and non-urgent), together with the relative proportion of patients diagnosed through each referral route.

Waiting times from GP referral to initial contact with a hospital clinician

165. If the 2005 waiting times target is to be met every stage of the patient journey must proceed in a timely fashion. For the stage from GP referral to initial contact with a hospital clinician we did not find that to be the case ([Exhibit 25](#)):

- Only 46% of patients across Scotland are seen within two weeks (207 patients).
- Only 66% of patients are seen within a month (304 patients).
- 20% waited between four and eight weeks (96 patients).
- 14% of patients (63 patients) waited longer than two months.

166. It is possible that real waiting times may be longer than this, since between 35% and 40% of bowel cancer patients are admitted as emergencies. As these patients will be seen straight away, it might be more realistic to assess waiting times for elective care by discounting the patients who are seen in week one.

167. 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.

Good practice example 6

Single medical/surgical waiting list for diagnostic interventions – Grampian University Hospitals Trust (GUHT)

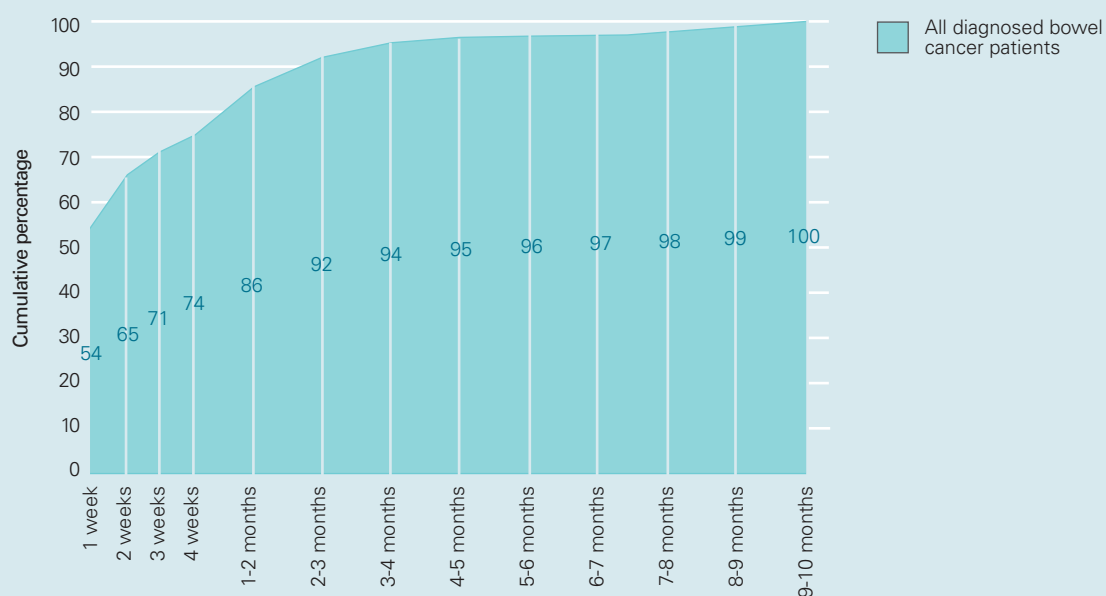
The Trust Endoscopy Group has persuaded physicians and surgeons to agree to introduce a common list for investigations and follow-up of upper and lower GI conditions between GI physicians and surgeons. Mechanisms to achieve this are currently being put in place.

The benefits of such an approach are:

- variations in waiting times are reduced as they are not determined by the activity of individual clinicians
- the anxiety which patients experience while waiting for diagnosis is minimised.

Exhibit 26

Bowel cancer waiting times from first clinical contact to definitive diagnosis across Scotland (October – December 2003)



Source: Audit Scotland fieldwork 2004

Good practice example 7

NHS Glasgow (South)

Referral process

South Glasgow has developed a risk-based protocol in collaboration with primary care for all patients referred with bowel cancer symptoms. GPs now refer direct to one central point. All referrals are triaged and referred for the appropriate investigation, sometimes without the need to see a clinician. This began in 2002 and is being phased in across all GP practices in South Glasgow.

The trust records details of patient demographics, symptoms and outcomes on a database. This allows the trust to adapt its risk-based protocol based on evidence and caseload experience.

168. The reasons for these waiting times are complex and include:

- the continued reliance upon paper-based referral systems which creates a 'paper-chase' and significant delays
- 'named' referrals to individual consultants, which creates delays when that consultant is unavailable for reasons such as annual leave or sickness absence
- unclear referral information from GPs, which leads to potentially urgent referrals being treated as either 'soon' or 'routine' with a consequent delay in access
- the impact of the 'New Deal' for junior doctors which has reduced the time junior doctors are able to spend working with consultants at outpatient clinics where many initial medical/surgical consultations take place.

169. There is some evidence that waiting times for gastrointestinal physicians are significantly longer than those for bowel cancer surgeons.

170. If the 2005 waiting times target is to be met then performance will need to improve significantly.

The number of bowel cancer patients seen by hospital clinicians is a small proportion of total patients with colorectal symptoms. Only around one in ten suspected bowel cancer patients is actually suffering from the disease, so improving bowel cancer waiting times performance will have major implications for all gastrointestinal services.

171. Each of the three cancer networks needs to identify the specific service changes that are needed (at each site) to deliver the required step-change in performance. Scotland's three bowel cancer MCNs have been tasked with identifying their key targets for improvement actions. This bottom-up approach to identify service improvement is more likely to achieve ownership and secure change. Some work has already begun in improving performance in this area ([Exhibit 11, page 20 and Good practice example 6](#)).

Recommendation:

- The three regional cancer networks' improvement plans should be used to inform the further development of the *Bowel Cancer Framework*.

Waiting time for diagnosis

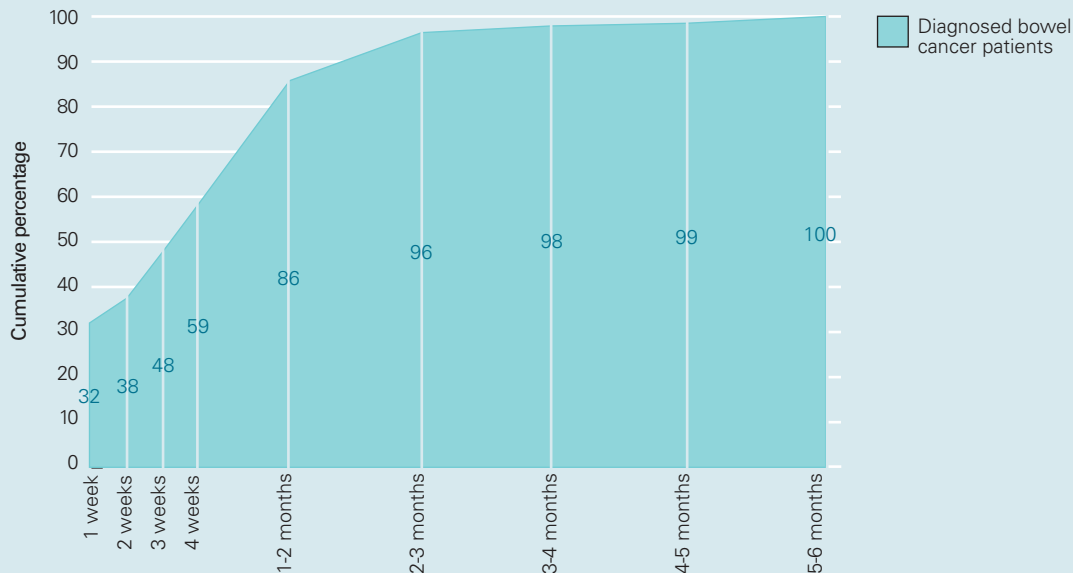
172. If the 2005 waiting times target is to be met, every stage of the patient journey must proceed in a timely fashion, including waiting times from initial clinical contact at hospital to definitive diagnosis.

173. We found that:

- the vast majority of bowel cancer patients (74%) received their diagnosis within four weeks of first contact with a hospital clinician ([Exhibit 26](#)). This reflects the relatively high proportion of bowel cancer patients who are admitted as emergencies
- 35% of patients waited more than two weeks, and

Exhibit 27

Bowel cancer waiting times from definitive diagnosis to first definitive treatment across Scotland (October – December 2003)



Source: Audit Scotland fieldwork 2004

- 26% of patients waited more than a month for diagnosis.

174. The reasons for the diagnostic delays for patients waiting longer than two weeks (177 patients) and more than a month (130 patients) are complex, and include:

- *Capacity issues* – the inability of some endoscopy and radiology services to cope with demand for diagnostic tests because of staff and equipment limitations.
- *Organisational issues* – where the sequential booking of diagnostic tests creates cumulative delays in the process as a series of small delays between tests accumulates into an unacceptably long total wait.
- *Failed or unclear tests* – this necessitates repeat tests which add delays into the process.

175. There is no specific performance target in place for the time taken from initial contact with a hospital clinician to definitive diagnosis. However, using the SEHD

two-month target from referral to first treatment and CSBS waiting times targets for other stages of the bowel cancer patient journey, it is possible to infer a target of two weeks from initial contact to definitive diagnosis.

176. Some work has already begun in improving performance in this area ([Good practice example 7, page 43](#)).

177. It is likely that changes in both administrative/organisational and diagnostic practices – actions which are already taking place at many sites – will lead to significant improvements in performance in this area. These issues are explored further in the final section of the report *The Agenda for the Future*.

Waiting time to surgery or other treatment

178. The CSBS sets a standard that time between diagnosis and first definitive treatment should be no more than four weeks (CSBS Standard 8a). We reviewed whether this standard was being met ([Exhibit 27](#)).

179. There is a significant gap between the standard and current performance, with only six in ten patients starting treatment within a month.

180. Two of the most common reasons for the delays are:

- routine staging delays (eg, waiting times for CT and MR scans for staging cancer) prior to surgery
- lack of facilities, including theatres and staff.

181. Our data does not distinguish between the various treatment regimes (surgery, palliative care, chemotherapy). Further research is required to understand the reasons for these delays and whether there are specific bottlenecks in any of the various treatment routes, either at a national level or within specific geographical areas.

Part 6. The agenda for the future



182. This section of the report considers:

- How improvements in the management of suspected bowel cancer patients might be achieved at primary care.
- How best use can be made of existing diagnostic resources to enable patients to receive speedy diagnoses.
- What actions need to take place to ensure that the right staff, with the right skills, are in place to deliver high quality services.
- Implications for the future management and monitoring of bowel cancer services.

The challenge ahead

183. Much good work is taking place across NHSScotland to improve the quality of care which bowel cancer patients receive by:

- 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 secure more efficient use of resources
- capitalising on the opportunities that new technology brings to streamline and simplify the patient pathway
- developing the nurse endoscopy role to ensure that existing endoscopic resources are used to maximum capacity.

184. But, big challenges lie ahead. Meeting the 2005 waiting times target for the diagnosis and treatment of urgent bowel cancer patients and implementing national bowel screening in such a way that it does not disadvantage symptomatic patients will require a concerted and coordinated agenda of change to be

delivered across all fronts; from primary care through to specialist hospital services and cancer centres.

Improving management at primary care

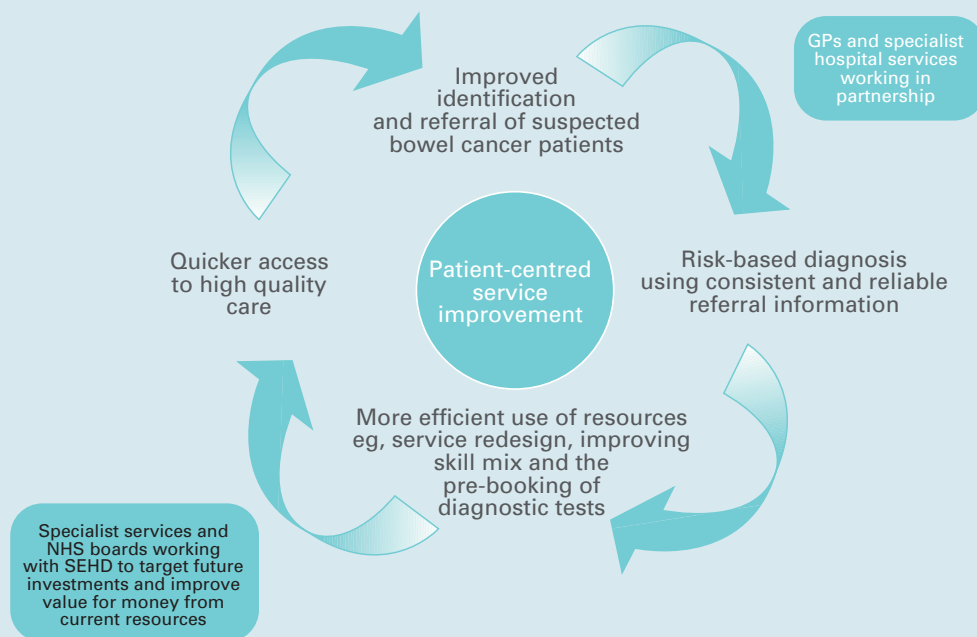
185. As we have shown, promptly identifying and referring patients suspected to be suffering from bowel cancer is not a straightforward process. Although national evidence-based referral guidelines for suspected cancer are in place for GPs it is clear that this is not enough in itself to secure consistent high quality referral.

186. Local referral protocols, which are now in place in most parts of Scotland, can help, but securing effective implementation and compliance is a challenge and depends critically upon a partnership approach being developed between hospital-based specialists and local GPs.

187. Once GPs know which patients to refer and to whom, and they provide accurate information on the patients' symptoms and history to

Exhibit 28

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



Source: Audit Scotland 2005

hospital specialists, those specialists can determine the urgency with which the patient should be seen and ensure that they are given the most appropriate diagnostic tests. This effective partnership can lead to a 'virtuous circle' of change which makes best use of resources, reduces waits and directs care to those in greatest need, and supports continuous improvement (Exhibit 28).

Making efficient use of resources

Shared waiting lists

188. Significant improvements in efficiency can be created by streamlining referral processes and improving the coordination of waiting list management. Traditional patterns of waiting list management for diagnosis, where medical staff hold their own 'individual' lists and where 'named' referrals skew referral patterns, create sub-optimal use of resources, and lead to significant variability of waits within bowel cancer services. For example, where 'named' referrals are the norm, at the same hospital a patient referred to a particular 'named' clinician may wait only 2-4 weeks for a routine outpatient

appointment or colonoscopy and yet a patient with the same symptoms referred to his/her colleague in the same building might experience a wait of 6-9 months for the same test, simply because of the different size of the two individual waiting lists. Increased adoption of joint waiting lists for diagnostic tests will help to address this and should lead to more equitable access to services and more rational use of resources.

Coordinating and pre-booking diagnostic tests

189. At some sites diagnostic tests are not well coordinated between the different parts of the service. Where individual diagnostic tests are booked separately one after another only once the results of the previous test are known, cumulative delays are generated. These can be avoided by the pre-booking of all of the tests that are needed at the same time. This approach, known as 'partial' or 'full booking' not only reduces delays but it can also avoid unnecessary hospital visits. Pre-booking, and the coordination of linked clinics (surgical, medical, radiological) are both beginning to be adopted within Scotland.

190. Much work still needs to be done to improve the basic management of the patient journey, by:

- better coordinating the booking of tests
- redesigning patient pathways, removing unnecessary steps and processes
- capitalising on the opportunities that new technology brings to reduce the reliance on paper-based systems which carry with them inherent delays.

191. Staff from the Cancer Service Improvement Programme (CSIP) within the Centre for Change and Innovation (CCI) have been working with bowel cancer services staff to enable changes of this kind to be achieved and have been successful in redesigning services at several sites across Scotland (Exhibit 29).

Endoscopy capacity

192. Staff and diagnostic equipment in endoscopy are clearly a constraint within bowel cancer services, as is access to CT and MRI scans for

Exhibit 29

A redesigned patient pathway

Maximum 62 days from urgent GP referral to 1st definitive treatment

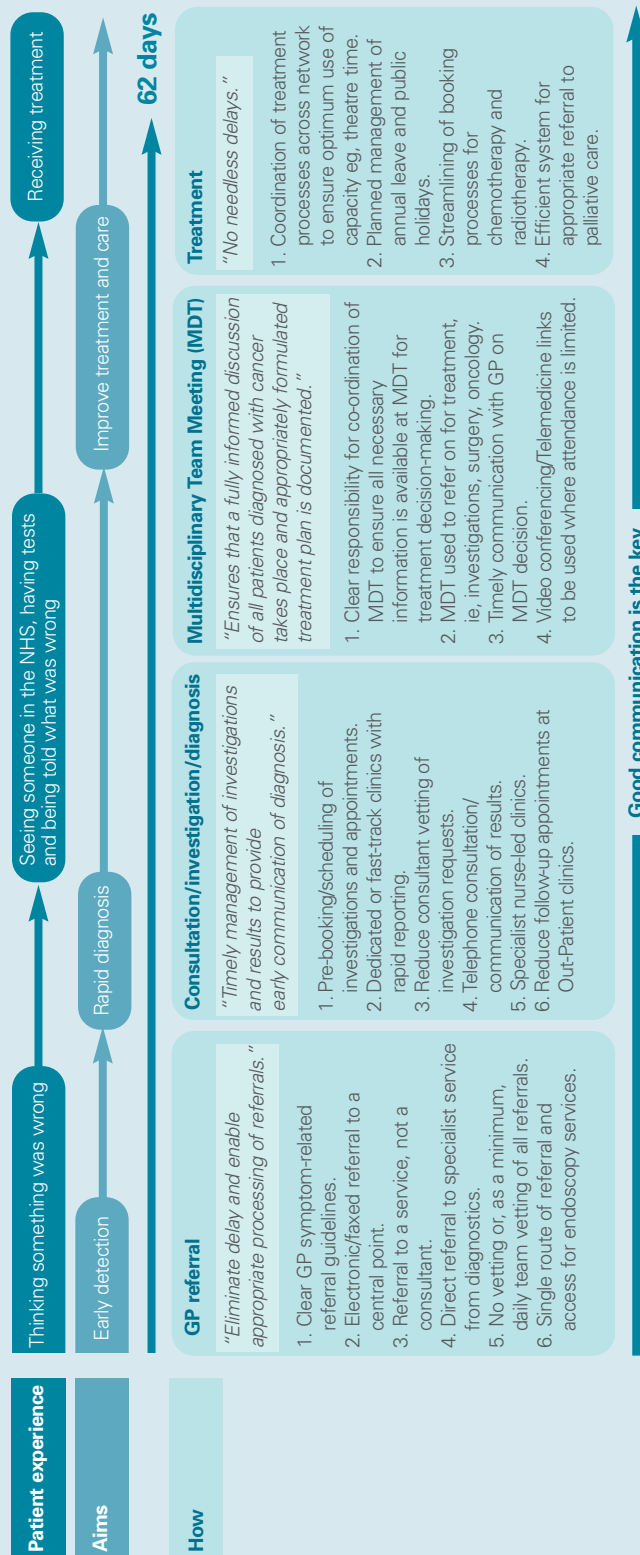
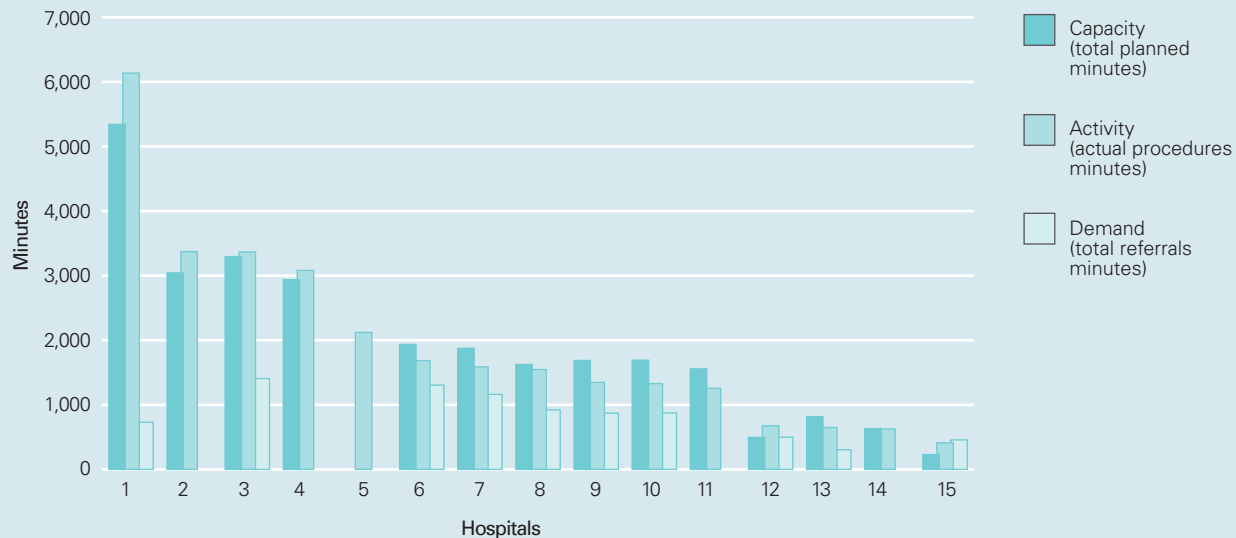


Exhibit 30

Endoscopy demand, capacity and activity across Scotland

At most sites there is a poor match between demand and capacity.



Source: Audit Scotland fieldwork 2004

staging purposes. It seems likely that some additional investment in resources may be required to improve waiting times performance and support the implementation of national bowel cancer screening. There is generally a poor understanding of the use to which existing endoscopy resources are put and the relative efficiency of these services across NHSScotland. We found that:

- at many sites in Scotland the endoscopy resources available are greater than demand
- at only one site that was able to provide us with demand and capacity data, was demand greater than resources available ([Exhibit 30](#)).

193. The reasons for this mismatch between capacity, activity and demand are complex, and include:

- staff holiday, sickness absence
- inflexible skill-mixing
- poor matching of supply (the various diagnostic tests) to shifting patterns of referral, which leads to backlogs being created
- shortages of qualified staff.

We also found wide variation in the extent to which endoscopy resources are fully utilised ([Exhibit 31](#)).

194. Improving the efficiency with which these resources are used will form a key strand of preparing for the implementation of national bowel cancer screening. If all sites across Scotland were able to reduce their did not attend (DNA) rates from the national average to the lower quartile figure, over 1,700 extra lower endoscopies could take place annually.

Getting the right staff, with the right skills, in the right place

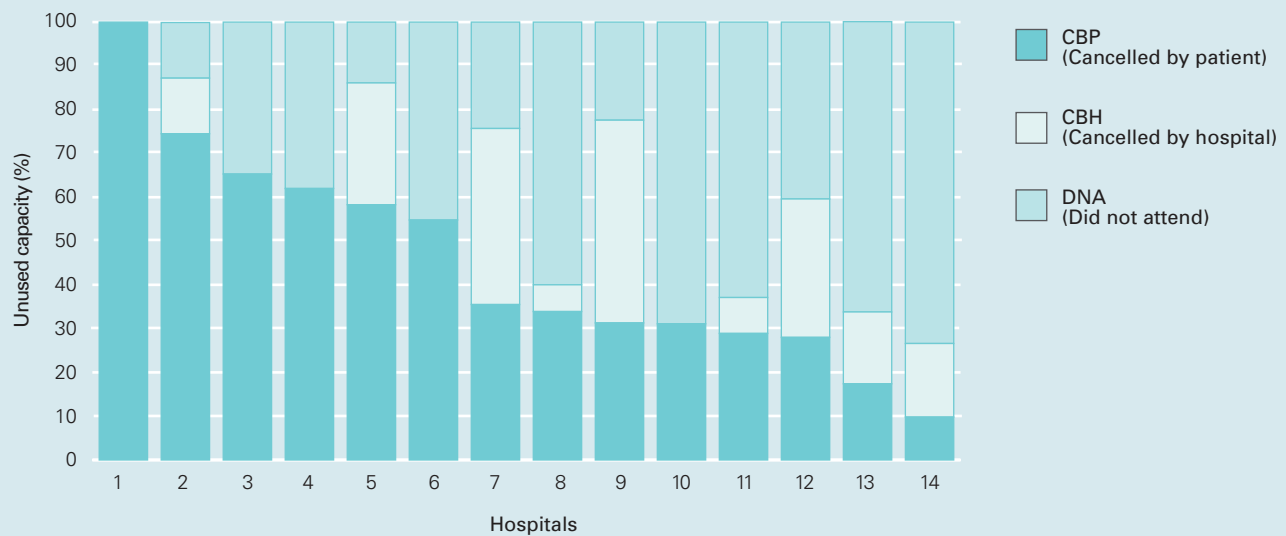
195. We found strong evidence that a more significant restraint on endoscopy activity than equipment or rooms is the availability of qualified staff. This echoes earlier research.⁸⁰ Few endoscopy suites are working to full capacity, ie, operating morning and afternoon sessions five days a week, the limiting factor being staffing constraints ([Exhibit 32](#)).

196. The unused capacity created by staffing constraints is equivalent to 30,000 additional lower gastrointestinal endoscopic procedures annually.

197. Traditionally, endoscopy has been carried out by hospital doctors. There is increasing interest and a growing demand for the appointment of nurse endoscopists in Scotland. These are specially qualified nurses who are competent to undertake flexible sigmoidoscopies, colonoscopies or other endoscopic investigations. The nurse endoscopist role has developed rapidly over the last three years ([Exhibit 33 overleaf](#)).

Exhibit 31

Unused endoscopy capacity across Scotland

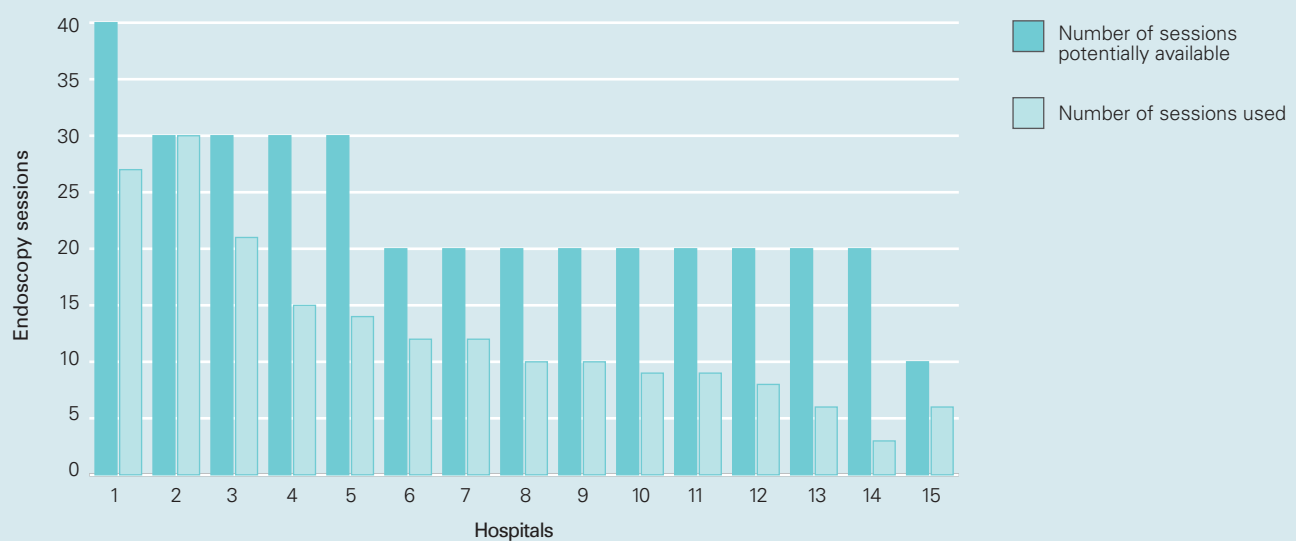


Source: Audit Scotland fieldwork 2004

Exhibit 32

Unused endoscopy sessions

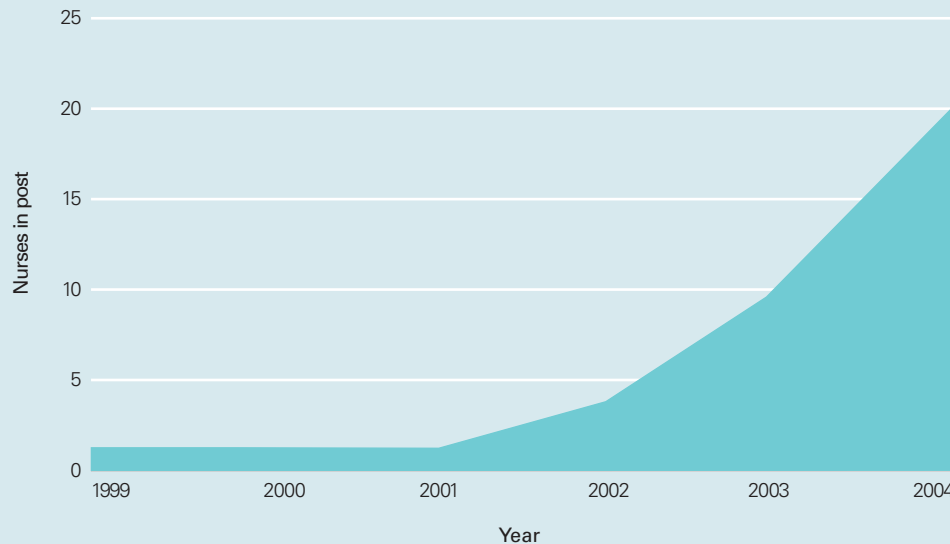
Available endoscopy sessions are not being fully utilised across Scotland



Source: Audit Scotland fieldwork 2004

Exhibit 33

Numbers of lower GI nurse endoscopists in Scotland 1999-2004



Source: Audit Scotland fieldwork 2004

198. There is good evidence that flexible sigmoidoscopy and diagnostic colonoscopy can be carried out safely by appropriately trained nurses and GPs. Levels of satisfaction amongst patients using nurse-led endoscopy clinics are consistently high.^{81,82,83}

199. The further development of the nurse endoscopy role, GP endoscopy and/or other non-medical staff suitably trained and competent in this area would make a significant difference in both increasing the capacity to support bowel cancer screening and reducing 'lost' capacity.

200. Two critical issues for endoscopy services in Scotland are:

- Determining the approach for training of endoscopists (of any discipline) within Scotland. At present, the only specialist training

currently available is the nurse endoscopist course at Glasgow Caledonian University. This is inadequate in scale to meet current needs, with many staff travelling to England to undertake specialist training of this kind.

- Accreditation and quality assurance for endoscopy services in Scotland.

201. These are both pressing issues which need to be resolved before the national roll-out of bowel cancer screening.

Improving management information

202. A theme throughout the report has been the need to improve the level and quality of routine management information available about the performance of bowel cancer services.

203. This becomes particularly critical at a time when the services faces the twin challenges of the 2005 waiting times target and the major service change of introducing national bowel cancer screening.

204. Although the quality of waiting times data is improving, it is still inadequately sensitive to enable local bowel cancer services to identify the specific changes and improvements that they need to make to their services if they are to successfully meet the 2005 target. There are also challenges associated with the integration of national screening and local service data. This integrated information will be needed to inform service management decisions to ensure that the introduction of national screening does not compromise symptomatic services.

81 Arumugam PJ, Rao GN, West J, et al, the impact of open access flexible sigmoidoscopy: a comparison of two services. J Royal Coll Surg Edinb 2000; 45: 366-8
 82 Basnyat PS, Gomez KF, West J et al, Nurse-led direct access endoscopy clinics: the future? Surg Endosc Ultrason Interv Tech 2002; 16:166-9
 83 Basnyat PS, West J, Davies PS et al, The nurse practitioner endoscopist. Ann R Coll Surg Engl 2000; 82: 331-2.

205. Meeting the waiting times targets and the implementation of national screening will both have significant service implications beyond the confines of bowel cancer services as:

- A significant proportion of patients who screen positive will be suffering from other chronic GI conditions, such as inflammatory bowel disease (IBD) or Crohn's disease, and will require support from GI services.
- The low diagnostic yield from lower GI endoscopic tests means that improving bowel cancer waiting times performance will generate significant additional service activity for general gastroenterology services.

206. The impact of national bowel cancer screening and the 2005 cancer waiting times target on general gastroenterology services will therefore need to be carefully monitored.

Recommendations

The health department should:

- monitor the impact of the introduction of national bowel screening on general gastroenterology services
- commission regular research on patients' experiences of bowel cancer services to assess the impact of current service redesign initiatives.

Glossary

Term	Description
Adenoma (or adenomatous polyp)	A benign epithelial tumour in which the cells form recognisable glandular structures or in which the cells are clearly derived from glandular epithelium.
Adjuvant therapy	Therapy given to assist the action of another treatment such as surgery eg, adjuvant chemotherapy or radiotherapy.
Anaemia	Too few red blood cells in the bloodstream, resulting in insufficient delivery of oxygen to tissues and organs.
Anastomosis	An artificial connection, created by surgery, between two tubular organs or parts, especially between two normally separate parts of the intestine. For example, a junction created by a surgeon between two pieces of bowel which have been cut to remove the intervening section.
Anastomotic dehiscence	Splitting open ie, separation of the layers of an anastomosis.
Anterior resection of rectum	A technique used when cancer of the rectum is 5-12cm from the anus. The operation is usually performed through a vertical cut from above the bone of the pelvis. In most instances the ends are joined together, so that bowel function is normal. In cases where it is not possible to join the ends together, the end of the bowel will then be brought through the abdominal wall and opened as a colostomy.
Antibiotic prophylaxis	The administration of antibiotics to reduce the risk of infection – particularly used in conjunction with surgery where the risk of post-operative infection is high.
Biopsy	The removal of a small piece of tissue from an organ or part of the body for histological analysis, microscopic study, or pathological evaluation. It is an important means of diagnosing cancer from an examination of a fragment of the tumour.
Caecum	Also spelt cecum, it is the first portion of the large bowel, situated in the lower right quadrant of the abdomen. The caecum receives faecal material from the small bowel (ileum) which opens into it. The appendix is attached to the caecum.
Chemotherapy	The treatment of disease by means of chemicals that have a toxic effect on cells used to selectively destroy cancerous tissue. It is seen as an aid to potentially curative surgery for colorectal cancer and also provides palliation or relief from certain symptoms.
Clinical oncologist	A doctor who specialises in the use of radiotherapy but who may also use chemotherapy (see also medical oncologist).
Colectomy	Surgery to remove part or all of the colon. In a partial colectomy, the surgeon removes only the cancerous part of the colon and a small amount of surrounding healthy tissue (called a margin).
Colitis	Inflammation of the colon.
Colonoscopy	Examination of the entire colon and rectum by a long, flexible tube, with a tiny camera on the end, introduced through the anus and guided visual control. It is the most reliable test for colorectal cancer detecting approximately 95% of tumours.
Colostomy	A cut into the bowel to create an artificial opening or "stoma" to the exterior of the abdomen. This opening serves as a substitute anus through which the intestines can eliminate waste products until the bowel can heal or other corrective surgery can be done. The bowel movements fall into a collection pouch.

Term	Description
Crohn's disease	An inflammatory disease of the gastrointestinal tract that seems to have both genetic and environmental causes, not well understood. Common symptoms include recurrent abdominal pains, fever, nausea, vomiting, weight loss and diarrhoea which is occasionally bloody. Complications include gastrointestinal bleeding, fistulas and anal fissures.
CT colonography	Used to examine the colon and rectum, and detect abnormalities such as polyps and cancer. It is less invasive than a conventional colonoscopy. It involves using a CT scanner to produce two- and three-dimensional images of the entire colon and rectum. CT colonography is performed on an empty bowel. Sedation is not usually required. The colon is distended by insufflation with air or carbon dioxide, via a small rectal tube. Antispasmodic agents and/or contrast agents may be administered intravenously before the scan. The CT scan is done with the patient holding his or her breath for approximately 20 seconds in both the supine and prone positions. The images are then manipulated and interpreted by a radiologist.
CT (Computed tomography) scan	A special radiographic technique that uses a computer to assimilate multiple X-ray images into a two dimensional cross-sectional image. This can reveal many soft tissue structures not shown by conventional radiography.
Debulking	To surgically remove as much of the tumour as possible.
Diagnostic pathway	The various tests that a patient may experience as part of the process of confirming their illness.
Digital Rectal Examination (DRE)	A digital (finger) rectal examination checks for abnormalities of organs or other structures in the pelvic and lower abdominal area. During a digital rectal examination, a health professional inserts a lubricated, gloved finger of one hand into the rectum and may use the other hand to press on the lower abdomen or pelvic area.
Distal colon	The distal colon comprises the rectum, the sigmoid and the descending colon.
Double contrast barium enema (DCBE)	A radiographic diagnostic procedure that involves the introduction of barium containing contrast material into the lower gastrointestinal tract via the anus followed by insufflation. X-rays taken after installation of the barium will outline the course and anatomy of the lower GI tract, allowing any tumour to be visualised in detail. DCBE detects about 85-95% of colorectal cancer.
Downstaging	The use of treatment e.g. chemotherapy or radiotherapy to reduce the size of a tumour, prior to another curative treatment, such as surgery.
Dukes' stage	Classification of the pathological stage of colorectal cancer (figures for five year survival at diagnosis of each stage are given in brackets): Stage A – localised within bowel wall (85%); Stage B – penetrates bowel wall (65%); Stage C – spread to lymph nodes (40%); "Stage D" – distant metastases (<5%).
DVT prophylaxis	Measures taken to reduce the prospect of the patient suffering from deep vein thrombosis after an operation.
Endoscope	An expensive and usually highly flexible fiberoptic viewing instrument with capabilities of diagnostic (biopsy) or even therapeutic functions.
Endoscopy	The visual inspection of any cavity of the body by means of an endoscope.

Term	Description
Familial Adenomatous Polyposis Coli (FAP)	A hereditary predisposition to the development of several hundreds or thousands of tubular adenomas throughout the large intestine, usually detectable by sigmoidoscopy before the age of 35. Malignant change can occur in a small amount of the polyps within 12 years of development. FAP accounts for around 1% of all colorectal cancer in the UK.
FOBT (faecal occult blood test) screening	Screening for colorectal cancer using a chemical test that measures the presence of blood.
Gastroenterology	The diagnosis and treatment of diseases and disorders affecting the stomach, intestines and associated organs.
Gastroenterologist	A physician with additional training in digestive diseases.
Hereditary non-polyposis colorectal cancer (HNPCC)	HNPCC is associated with a gene mutation. In those affected, the risk of developing colorectal cancer rises from the age of 20 to 80% by the age of 80 in men. Other cancers occur in carriers of the gene mutation – the risk to females include endometrial and ovarian cancer.
Histopathological diagnosis	Diagnosis made by a pathologist studying cells or tissue at a microscopic level.
Inflammatory Bowel Disease	Inflammatory Bowel Disease (IBD) is an umbrella term referring to two chronic diseases that cause inflammation of the intestines: ulcerative colitis and Crohn's disease. Although they are different diseases, they do have features in common, including the symptoms, but there are important distinctions also.
Insufflation	A medical treatment undertaken by blowing a powder, gas, or vapour into a bodily cavity.
Lesion	An abnormal change involving any tissue or organ due to disease or injury. There are numerous types of lesions with different naming classifications.
Lymph nodes	Small bean-shaped organs located along the lymphatic system. Nodes filter bacteria or cancer cells that might travel through the lymphatic system.
Mesorectum	A fatty tissue directly adjacent to the rectum that contains blood vessels and lymph nodes. For patients with rectal cancer in the middle or lower two-thirds of the rectum, total mesorectal excision (TME) is now routine clinical practice.
Metastasis	Spread of cancer from one part of the body to another.
Metastatic cancer	Cancer that has spread from its original site to other parts of the body; most commonly bone, lung, liver, brain, and lymph nodes.
Linear accelerators (LinAcs)	Modern radiotherapy machines, which deliver high-energy X-rays and electrons to kill tumour cells.
Medical oncologist	A doctor who specialises in the use of chemotherapy.
MRI (magnetic resonance imaging) scan	A special imaging technique used to image internal structures of the body, particularly the soft tissues. Images are very clear and often superior to a normal X-ray image. Scans may be used for detecting some cancers or for following their progress.

Term	Description
Palliative	Treatment provided to alleviate symptoms or reduce the severity of symptoms without curing the underlying disease.
Palpable mass	A tumour that can be felt by hand during a physical examination.
Patient Journey	A technical term used within the NHS to describe the various stages that an individual patient may experience as they progress from referral and diagnosis through to treatment. 'Mapping' the patient journey, i.e. recording the experience that patients go through, is often used to identify how care might be better co-ordinated and treatment speeded up.
Pendunculated polyps	Polyps on "stalks" are described as pendunculated and are the easiest to remove with clipping. They are also less likely to be cancerous compared to polyps which are sessile.
PET (positron emission tomography) scan	Positron emission tomography, also called PET imaging or a PET scan, is a diagnostic examination that involves the acquisition of physiologic images based on the detection of positrons. Positrons are tiny particles emitted from a radioactive substance administered to the patient. The subsequent views of the human body developed by this technique are used to evaluate a variety of diseases.
Polyp	Small outgrowth of tissue arising from the mucous membrane of the colon.
Polypectomy	Surgical removal of a polyp.
Prophylaxis	Treatment that helps to prevent a disease before it occurs e.g. antibiotic prophylaxis to prevent infection.
Radiotherapy	The treatment of disease by ionising radiation. Radiotherapy can be used to treat cancer, usually before or after surgery, and in some cases as an alternative to surgery or to relieve symptoms of advanced disease.
Resection margin	When a tumour is removed, a pathologist checks to make sure the edges of the tissue are free of cancer cells. This indicates whether all of the cancer has been removed. The pathologist also measures how far in from the edge cancer cells do occur. The term "margins" or "resection margins" is used to refer to the distance between the tumour and the edge of the tissue. The margins are measured on all six sides: front and back, top and bottom, left and right. Seeing how close cancer cells are to the edge of the removed tissue helps doctors make the right treatment decisions.
Sessile polyps	Polyps which are ulcerated or flat, or ulcerate into the bowel. An open surgical procedure is often needed to remove these types.
Sigmoidoscopy	A narrower, shorter tube than that used in colonoscopy, which can be flexible or rigid, with a camera on the end that allows visual inspection of approximately 75% of lesions in the rectum and sigmoid colon (the S-shaped part of the colon).
Staging	Process of describing whether cancer has spread from its original site to another part of the body. Staging involves clinical, surgical and pathology assessments. Restaging is a repeat of this process to investigate recurrent disease to establish whether the cancer has progressed since the last staging was carried out (See under Duke's Stage for the different classifications of bowel cancer).

Term	Description
Stoma	A surgically constructed opening in the abdominal wall that permits the passage of waste after a colostomy or ileostomy.
Total mesorectal excision (TME)	A technique for surgical removal of rectal cancer which involves meticulous dissection and excision of tissue surrounding the rectum.
Triage	A method of ranking sick or injured people according to the severity of their sickness or injury in order to ensure that medical and nursing staff facilities are used most efficiently.
Ulcerative colitis	A disease that causes inflammation and sores, called ulcers, in the lining of the large intestine. The most common symptoms are abdominal pain and bloody diarrhoea. The cause of the disease is still unclear.
Ultrasound scan	A type of imaging technique, which uses high-frequency sound waves.

Appendix 1

Expert advisory group

Area	Representative
Cancer Networks	Evelyn Thompson, West of Scotland Cancer Network (WOSCAN) Co-ordinator
Gastroneterology	Dr Perminder Phull, Head of Gastroneterology Service, Grampian University Hospitals Trust Dr John Wilson, Consultant Gastroneterologist, NHS Fife (Chair of SCAN Colorectal Group)
General Practice	Dr Michael Boyle, GP, Linlithgow Group Medical Practice
NHS Quality Improvement Scotland (QIS)	Ms Frances Smith, NHS QIS
Service Management	Elizabeth Preston, Assistant General Manager, Western General Hospital, NHS Lothian
Surgeons	Mr Ian Finlay, Consultant Surgeon, Glasgow Royal Infirmary, NHS Glasgow (past Chair of WoSCAN Colorectal Cancer Managed Clinical Network)
Palliative care	Dr Pamela Levack, Macmillans Consultant in Palliative Medicine, Ninewells Hospital and Roxburghe House, Dundee
Pathologists	Professor Frank Carey, Consultant Pathologist, Ninewells Hospital, Dundee, NHS Tayside
Primary Care	Helen Spratt, Director of Nursing, Highland Primary Care Trust, NHS Highlands
Public Health	Dr Harry Burns, Director of Public Health, Greater Glasgow Health Board, NHS Glasgow
Radiologists	Dr Fat Wui Poon, Consultant Gastrointestinal Radiologist, Glasgow Royal Infirmary, NHS Glasgow
Specialist nurses	Ms Linnet Mcgeever, Colorectal Nurse Specialist, NHS Forth Valley
Voluntary Sector	Dr J Gordon Paterson OBE, Chair of Scottish Cancer Coalition
Scottish Executive Health Department (Observer)	Liz Porterfield, Cancer Services Co-ordinator, Scottish Executive Health Department

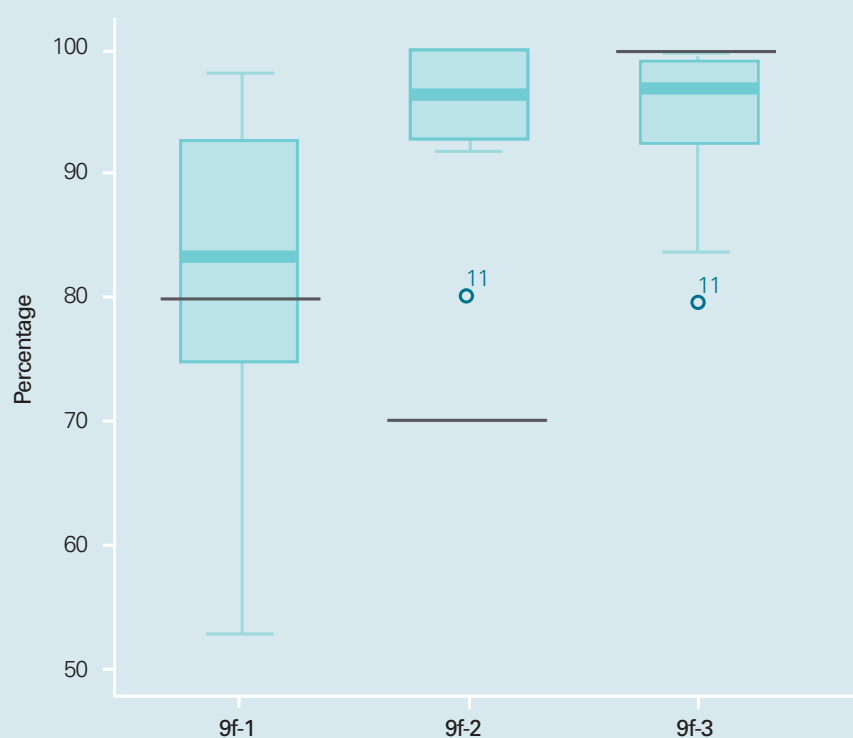
Appendix 2

The black line illustrates the target figure for performance set by the standard. The thick turquoise line shows the median performance across NHSScotland. The boxes show the lower and upper quartile performance limits. The lines extending from the boxes show the minimum and maximum performances. Circles and asterixes are outliers.

Bowel cancer clinical compliance with bowel preparation standards 9f (1-3)

Pre-operative preparations and investigations required for bowel cancer patients:

1. A minimum of 80% of patients should have bowel preparation;
2. A minimum of 70% of patients should have DVT prophylaxis;
3. All patients are to have antibiotic prophylaxis.



Source: Audit Scotland fieldwork 2004

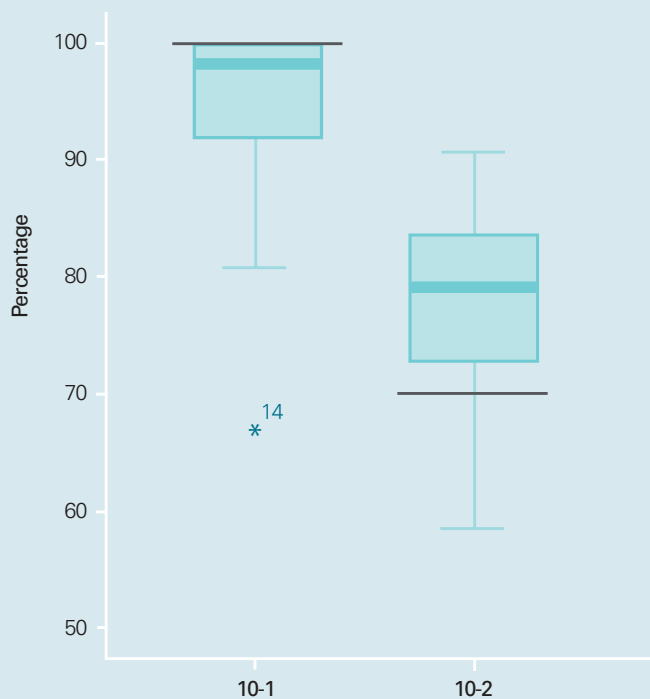
Appendix 3

The black line illustrates the target figure for performance set by the standard. The thick turquoise line shows the median performance across NHSScotland. The boxes show the lower and upper quartile performance limits. The lines extending from the boxes show the minimum and maximum performances. Circles and asterixes are outliers.

Bowel cancer clinical compliance with standard 10 (1-2)

Clarity of tumour margin after surgery:

1. All distal resection margins (for all tumours) are clear;
2. A minimum of 70% of circumferential margins (for rectal tumours) are clear.



Source: Audit Scotland fieldwork 2004

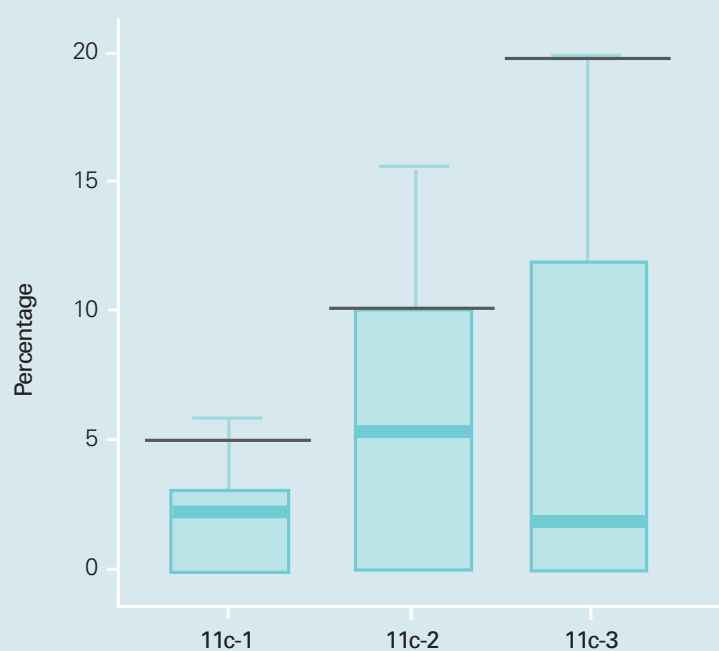
Appendix 4

The black line illustrates the target figure for performance set by the standard. The thick turquoise line shows the median performance across NHSScotland. The boxes show the lower and upper quartile performance limits. The lines extending from the boxes show the minimum and maximum performances. Circles and asterixes are outliers.

Bowel Cancer Clinical Compliance with Standard 11c(1-3)

Anastomotic dehiscence after surgery:

1. Is not more than 5% after colonic anastomosis;
2. Is not more than 10% after rectal anastomosis; and 3. is not more than 20% after anterior resection with TME for rectal cancer.



Source: Audit Scotland fieldwork

A review of bowel cancer services

An early diagnosis



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