

Colorectal Cancer Services



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ISBN 1-903766-99-0

First published March 2002

Further details on the process by which the Board is achieving its objectives can be found in the comprehensive Clinical Standards Board for Scotland (CSBS) *Quality Assurance & Accreditation Manual* (August 2000).

Copies of the *Clinical Standards for Colorectal Cancer* are also available from CSBS.

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Copies of this report and of the reports on each Trust/Island NHS Board area, and other CSBS documents, are available on the CSBS website or in print format from CSBS.

Information contained in this report has been supplied by Trusts, or taken from current Trust sources, unless otherwise stated, and is believed to be reliable on publication.

www.clinicalstandards.org

Clinical Standards Board for Scotland
National Overview

Colorectal Cancer Services

Introduction and Acknowledgements

The remit of the Clinical Standards Board for Scotland (CSBS) is to develop and run a national system of quality assurance and accreditation of clinical services, with the aim of promoting public confidence in NHSScotland.

For each project, the Board establishes a project group to:

- develop and consult on the standards and self-assessment framework;
- oversee the process of external peer review;
- report findings to the Board.

The Colorectal Cancer Project Group was established in January 2000 under the chairmanship of Professor Robert Steele, Professor of Surgical Oncology, Tayside University Hospitals NHS Trust. Membership of the Group is given in Appendix 1.

The CSBS *Clinical Standards for Colorectal Cancer* were developed by this group and published in January 2001 following extensive consultation. Copies of the standards are available on request from the Board or on the CSBS website (www.clinicalstandards.org).

Peer review visits to all NHS Board areas in Scotland were conducted during January – November 2001 to assess performance against the standards. Local reports on each visit to Trusts/Island NHS Boards, including a detailed assessment of performance against each standard, have been published and are available on the CSBS website.

This report presents a national overview of colorectal cancer services in Scotland, reporting on performance across Scotland against the standards and including examples of local initiatives relevant to them.

The CSBS gratefully acknowledges the work of the Colorectal Cancer Project Group for its oversight of the project, from its inception to the publication of this report. In addition, the contribution made by every member of the peer review teams was crucial to the success of the visit programme.

The Board wishes to record its thanks to all the staff who contributed to the peer review visits: in particular, the liaison co-ordinators, local review facilitators and lead clinicians in Trusts/Island NHS Boards who were responsible for preparing staff locally for peer review visits and for the compilation of comprehensive self-assessment material prior to visits.

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Introduction

Cancer affects everyone's lives – the 25,000 people who are diagnosed with the disease every year in Scotland, the families and friends of cancer patients and the many health professionals and others involved in the care of patients with cancer. Over the past 50 years the incidence of cancer has risen steadily and colorectal, or bowel cancer, is no exception. On average about 3,500 cases are diagnosed each year and it is the second most common cause of cancer death in Scotland. Survival rates are dependent on the stage the cancer has reached at the time of diagnosis and most cancers have already spread beyond the bowel by the time they are confirmed. Patients who are diagnosed with colorectal cancer have a 45% chance of being alive after five years.

Like cervical cancer, trials have shown that it is possible to detect colorectal cancer at a pre-cancerous stage using a simple screening technique and that deaths from the disease can then be reduced by up to 20%. The NHS is currently funding a UK pilot to assess the feasibility of introducing population based-screening for colorectal cancer and three sites in Scotland are involved. This has already increased the number of cases referred for diagnosis and treatment.

Tackling cancer is one of the NHSScotland priorities, together with heart disease and mental health. The three most common cancers are lung, breast and colorectal, or bowel, cancer. Exploring each aspect of the patient journey from the point of diagnosis for people diagnosed with any of these three cancers, together with a fourth, ovarian cancer, formed one of the first projects tackled by the CSBS. This report sets out the findings of the Board's review of colorectal cancer services across Scotland and it is underpinned by the separate publication of local reports for every NHS Trust/Island NHS Board providing these services in Scotland.

The first step of the process was to develop a series of key standards against which to monitor performance and this was undertaken by a project group which included representatives of all the healthcare professions involved in the treatment of colorectal cancer as well as members of the public with personal experience of the service. Full membership details are given in Appendix 1. From January to November 2001 each acute NHS Trust and Island NHS Board was visited by a team of healthcare professionals and members of the public to assess colorectal cancer services against the standards. This review has provided a unique opportunity to capture a Scotland-wide 'snapshot' of these services which can be used as a baseline against which to inform, support and measure continued improvement in the quality of these services.

Summary of Findings

Several important themes have been identified which apply to cancer services generally, others more specifically to colorectal cancer. All these are explored in detail in the section of this report describing performance against the standards, and a summary of the key findings relating to colorectal cancer is given below:

1. Care of Patients

- Patients with colorectal cancer often undergo quite extensive treatment, which may include a colostomy, and it is important that all members of the team caring for such patients prepare patients for their treatment and involve them in decisions about their options. All review teams commented on the commitment, enthusiasm and professional approach of the staff involved in the care of colorectal cancer patients, and their families and friends. The role of the specialist nurse was found to be particularly important as a link for the patient between the different health professional team members and as a source of information and support. The review teams found that most Trusts had such nurses in place.

2. Referral

- In general, robust referral arrangements are in place across the country from primary care and screening services to hospital services. However, these are often informal between primary and secondary care, and it is important to develop and disseminate protocols that specify local arrangements to ensure the right patients are referred to the right place without unnecessary delay. It is also important that once in 'the system', referral between hospital departments is clearly defined, again to avoid delays in the journey of care and inappropriate investigations. This is particularly important for patients admitted with emergency bowel obstructions, as can be the case with colorectal cancer.

3. Investigation and Diagnosis

- Much effort has been made to introduce 'one-stop' clinics run by multi-disciplinary teams. These aim to carry out all the necessary investigations during one clinic visit, to support rapid diagnosis and to reduce the anxiety caused by waiting for the outcome of tests. However, in the centres that could monitor this, it was clear that waiting times for investigative procedures are unacceptably long and are currently rising. This is partly because patients suffering from a range of gastro-intestinal conditions all need access to the

same procedures and team, and partly due to the pressure on certain services such as imaging and pathology. Although the data collection and analysis systems in many Trusts were inadequate review teams reported that the information gathered during visits indicated that all Trusts were using the appropriate diagnostic investigations.

4. Multidisciplinary Approach

- All Trusts recognised the value of a multidisciplinary approach to decision-making and treatment-planning. Patients were central to this process and encouraged to participate in decisions about their care and their options. However, the multidisciplinary teams were not clearly defined in about half the Trusts visited and only limited written information on discussion and decisions was recorded. In most Trusts where this standard was not met, this was due to certain aspects of the service such, as oncology, being provided by a visiting specialist from another hospital. It was recognised that organising truly multidisciplinary services presents real challenges in some areas as staff can be working on several geographically remote sites, and may also cover more than one Trust. Further, certain services, most notably pathology and imaging, are under extreme pressure and many Trusts are carrying long-term vacancies. Palliative care services were valued by all Trusts and by those using the service and, in general, are available across Scotland, although often not involved in multidisciplinary meetings at an early stage. It was also noted that specialised pharmacy input is a valuable resource that should be core to the team. Trusts are urged to consider ways of using their resources more effectively to ensure that all patients have access to multidisciplinary teams, and to ensure that a Trust-wide approach is taken to this. Finally, at the time of the visits, most Trusts were not participating in Managed Clinical Networks although this is now being addressed through the implementation of *Cancer in Scotland*.

5. Treatment

- It has been difficult to assess Trust performance against the treatment standards, particularly where these involved waiting times, as there were inadequate data collection and analysis systems in place in most Trusts. Where data were available, the delay between diagnosis and treatment was unacceptably long, as was the waiting time between surgery and start of adjuvant chemotherapy, and the booking of radiotherapy and start of radiotherapy treatment.

Of particular concern were the lack of protocols in place for preoperative assessment and the lack of evidence that the necessary preoperative preparations were made. In most cases the surgical techniques appeared to be satisfactory but again many Trusts were unable to provide data to demonstrate this.

6. Chemotherapy

- Most hospitals visited that prescribe chemotherapy had protocols in place and these were made available for review teams during visits. The staff providing chemotherapy services were aware of these protocols and in many places these were under review with expert input from pharmacists with a special interest in chemotherapy as they did not all cover toxic side-effects. The review teams found that there were a number of information leaflets available about chemotherapy and the nursing staff were well trained and provided information and support for patients. Hospitals that did not prescribe chemotherapy but may have to admit patients in their area who were suffering from side-effects did not always have the necessary protocols in place although it was reported that they had good access to the prescribing units for advice.

Chemotherapy services are very stretched in some areas of the country, mainly due to the number of patients in the system and to a shortage of oncologists. In these areas services are sometimes offered outwith the 'normal working hours' of 9-5 which is not in line with recognised guidelines as not all support services are available out-of-hours. Trusts were aware of this and assured the review teams that operating additional services did not compromise patient safety. There was also some concern that in the absence of an oncologist, other medical staff who may not have had the necessary training, were prescribing chemotherapy. While the services provided do strive to meet the highest standards, all staff working in this field should attend accredited training.

7. Radiotherapy

- Radiotherapy may be used to treat cancer (generally before or after surgery) and in some cases it is used as an alternative to surgery or to relieve symptoms of advanced disease. Before a patient receives radiotherapy, calculations must be made about the radiation dose and type, the area to be treated and the distribution of the dose. Treatment is prescribed by clinical oncologists, but others are involved in making the calculations, giving treatment and maintaining the machines.

Modern radiotherapy uses machines called linear accelerators (LinAcs) which deliver high energy X-rays and electrons to kill tumour cells. At present there are not enough LinAcs in Scotland to meet patient demand within reasonable timescales and much of the equipment in use is old and subject to frequent breakdowns. This has been recognised and a national plan is now in place to address this. Some areas also have problems in recruiting key staff including clinical oncologists. These two factors, together with a need to improve care planning, have led to delays in treatment which are unacceptably long at all sites.

8. Communication and Information

- All Trusts had written information about colorectal cancer available and several had developed local leaflets with additional information about the services provided within their Trusts. The visits could not assess the degree and success with which this information reached patients and their families. One issue that arose on several visits was the limited access to private areas where sensitive issues could be discussed. Trusts are urged to address this, as such consultations are recognised as an important element of the patient journey of care. It was also noted that while some staff had attended communication skills training, these courses were not generally attended by senior medical staff who are responsible for discussing sensitive or bad news with patients and their families.

Review teams reported that most patients had good access to stoma nurses who could advise them and support them on a long-term basis before, during and after their treatment.

9. Discharge

- Much effort is directed to discharge planning and management but a lot of work is still needed to make sure that patients, their families and the clinicians responsible for ongoing care have the information they need before, during and at the time of discharge. In some Trusts it was reported that there is a delay between discharge and receipt of the full discharge summary and joint meetings are required between primary and secondary care to address this.

10. Data

- One of the main problems faced throughout the review was the lack of 'evidence' to support the measurement of performance against standards. Much audit activity is underway, mainly at the level of individual healthcare professionals. Even where core data are collected, there was limited awareness amongst those treating patients about what was collected, by whom and how to access this information to monitor their performance against standards.

The information systems which currently support patient care cannot provide the information which is essential to monitor performance against standards of care. This needs to be rectified if NHSScotland is to be able to monitor standards and improve the quality of care. This was particularly noticeable when outcome measures such as survival were reviewed, as without knowing the outcome of current investigations and treatment, it is not possible to identify if and how these can be improved.

Conclusion

Colorectal cancer is common in Scotland and much work is underway to raise awareness about the disease, to try and prevent it and to encourage people with symptoms to attend their GP as early as possible. Once referred, it is important that patients are diagnosed as quickly as possible as early detection of the disease is closely linked with survival. Waiting times at every stage of the colorectal cancer journey are unacceptably long and there is an urgent need to review this at a local and national level.

The staff providing these services are committed and highly professional and are willing to consider changes in services that should lead to an improvement in the quality of clinical care. To achieve the necessary changes, Trusts urgently require to collect information that will monitor performance and provide evidence of the current situation, so that they can identify priority areas locally, and at regional level.

Key Recommendations

People with Colorectal Cancer

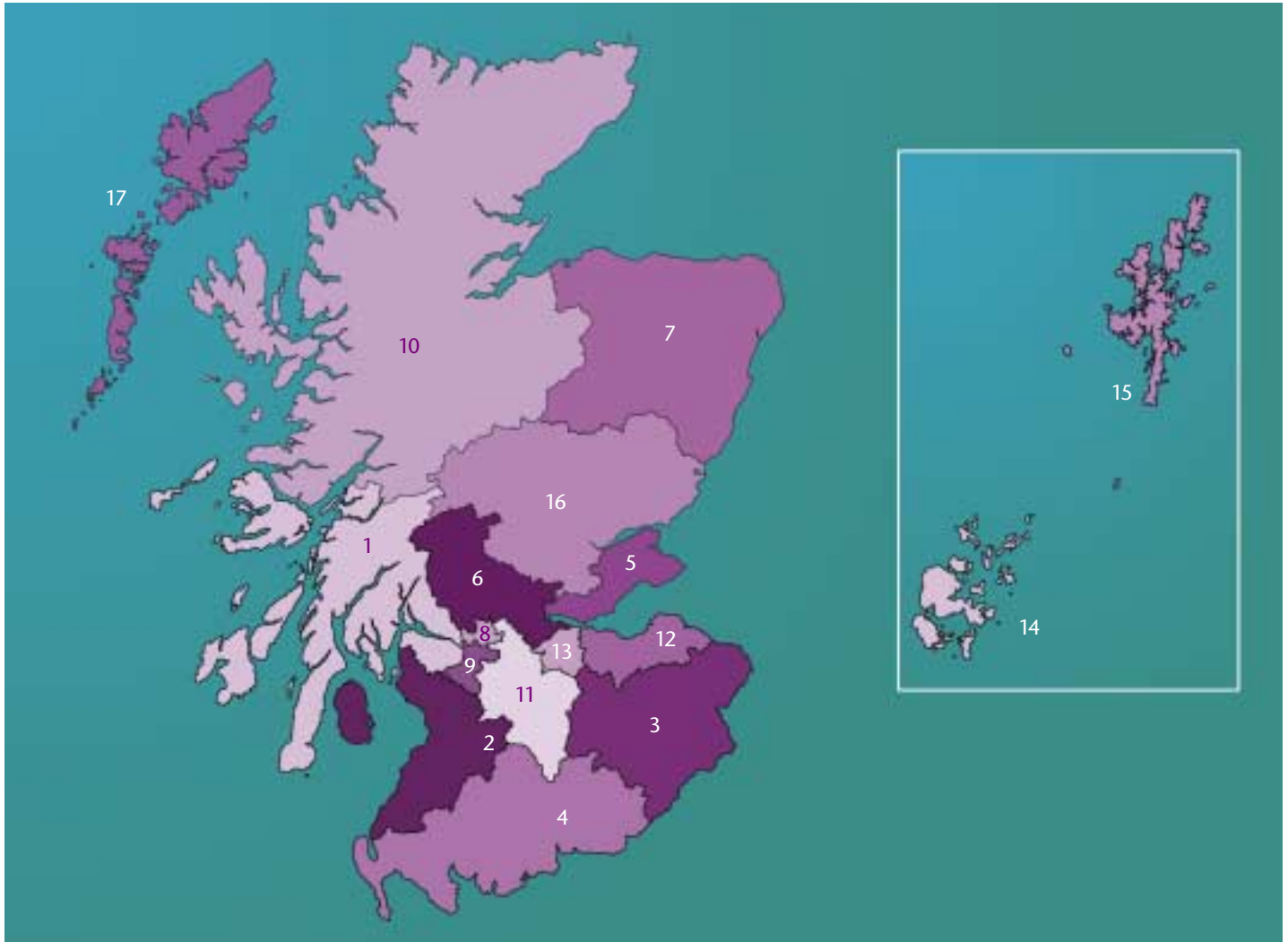
- Patients should have access to a specialist care nurse.
- Referral protocols should be in place, both between primary and acute care and within the hospital.
- There is good evidence that multidisciplinary team working improves the quality of care. All Trusts should ensure these teams are established and that there is a Trust-wide approach to multidisciplinary working.
- Protocols for the prescription and administration of chemotherapy should be in place. These should include the management of side effects.
- All staff involved in prescribing and administering chemotherapy should have accredited training.
- Healthcare professionals working with cancer patients should have training in communication skills.
- Clinical information systems that support the monitoring of performance should be in place at every Trust. National data sets and definitions should be used.

Chapter 1

Setting the Scene

- **NHSScotland Regional Breakdown and Index of Visits**
- **The CSBS Approach to Assessment**
- **An Introduction to Cancer**
- **Colorectal Cancer**
- **The CSBS Standards and Your Care**
- **Frequently Asked Questions and Useful Contacts**
















1 Setting the Scene





















1.1 NHSScotland Regional Breakdown and Index of Visits

1	Argyll & Clyde	10	Highland
2	Ayrshire & Arran	11	Lanarkshire
3	Borders	12	Lothian
4	Dumfries & Galloway	13	Lothian (West)
5	Fife	14	Orkney
6	Forth Valley	15	Shetland
7	Grampian	16	Tayside
8	Greater Glasgow (North)	17	Western Isles
9	Greater Glasgow (South)		






















The following hospitals were reviewed during January – November 2001. Local reports (for each area), containing findings of each individual peer review visit and assessments against the standards, are available on the CSBS website (www.clinicalstandards.org) or in print format from CSBS.

Local Report Area:  Estimated Population  Area (square km)  Population (per square km)	Hospitals Reviewed
1. Argyll & Clyde  423,500  7,531  56	Inverclyde Royal Hospital, Greenock Lorn & Islands District General Hospital, Oban Royal Alexandra Hospital, Paisley Vale of Leven District General Hospital, Alexandria
2. Ayrshire & Arran  373,400  3,338  112	Ayr Hospital Crosshouse Hospital, Kilmarnock
3. Borders  106,900  4,734  23	Borders General Hospital, Melrose
4. Dumfries & Galloway  145,800  6,439  23	Dumfries & Galloway Royal Infirmary

Local Report Area	Hospitals Reviewed
<p>5. Fife</p> <p> 350,400</p> <p> 1,323</p> <p> 265</p>	<p>Queen Margaret Hospital, Dunfermline</p> <p>Victoria Hospital, Kirkcaldy</p>
<p>6. Forth Valley</p> <p> 278,000</p> <p> 2,652</p> <p> 105</p>	<p>Falkirk & District Royal Infirmary</p> <p>Stirling Royal Infirmary</p>
<p>7. Grampian</p> <p> 523,400</p> <p> 8,742</p> <p> 60</p>	<p>Aberdeen Royal Infirmary</p> <p>Dr Gray's Hospital, Elgin</p>
<p>8. Glasgow (North)</p> <p> 557,520</p> <p> 372*</p> <p> **</p>	<p>Gartnavel General Hospital, Glasgow</p> <p>Glasgow Royal Infirmary</p> <p>Stobhill Hospital, Glasgow</p> <p>Western Infirmary, Glasgow</p>
<p>9. Glasgow (South)</p> <p> 346,880</p> <p> 186*</p> <p> **</p>	<p>Southern General Hospital, Glasgow</p> <p>Victoria Infirmary, Glasgow</p>
<p>10. Highland</p> <p> 208,600</p> <p> 25,784</p> <p> 8</p>	<p>Belford Hospital, Fort William</p> <p>Caithness General Hospital, Wick</p> <p>Raigmore Hospital, Inverness</p>

* Estimated figure supplied by NHS Greater Glasgow.

** Figure unavailable.

Local Report Area	Hospitals Reviewed
<p>11. Lanarkshire</p> <p> 562,000</p> <p> 2,189</p> <p> 257</p>	<p>Hairmyres Hospital, East Kilbride</p> <p>Monklands Hospital, Airdrie</p> <p>Wishaw General Hospital</p>
<p>12. Lothian</p> <p> 628,920</p> <p> 1,296</p> <p> 485</p>	<p>Royal Infirmary of Edinburgh</p> <p>Western General Hospital, Edinburgh</p>
<p>13. Lothian (West)</p> <p> 154,680</p> <p> 425</p> <p> 364</p>	<p>St John's Hospital, Livingston</p>
<p>14. Orkney</p> <p> 19,480</p> <p> 992</p> <p> 20</p>	<p>Balfour Hospital, Kirkwall</p>
<p>15. Shetland</p> <p> 22,440</p> <p> 1,438</p> <p> 16</p>	<p>Gilbert Bain Hospital, Lerwick</p>
<p>16. Tayside</p> <p> 385,500</p> <p> 7,558</p> <p> 51</p>	<p>Ninewells Hospital, Dundee</p> <p>Perth Royal Infirmary</p>
<p>17. Western Isles</p> <p> 27,180</p> <p> 3,134</p> <p> 9</p>	<p>Western Isles Hospital, Stornoway</p>

1.2 The CSBS Approach to Assessment

The CSBS has developed a methodology which draws upon other quality assurance models to enable it, in partnership with healthcare professionals and members of the public, to both develop standards for clinical services and assess performance across NHSScotland against these standards.

The Board's approach is outlined in its *Quality Assurance & Accreditation Manual* (issued August 2000). Further information and definitions of the terms used in the standards and in the assessment of performance are contained in Appendix 2.

Assessment Categories

Each review team reported its assessment of performance **at the time of the visit** using the categories detailed below:

- **'Met'**: applied when the evidence, either quantitative or qualitative, demonstrated that the standard and/or criterion is being met. When the assessment was based on qualitative information, the review team confirmed this information with Trust staff during the visit.
- **'Not met'**: applied when the evidence, either quantitative or qualitative did not demonstrate that the standard and/or criterion is being met.
- **'Not met (insufficient evidence)'**: applied when no evidence was submitted to the review team, or where the evidence supplied was insufficient to allow an assessment to be made.
- **'Not assessable'**: applied when the criterion had been written in such a way that it was not possible to measure performance in a consistent and meaningful way.
- **'Not applicable'**: applied when a standard and/or criterion did not apply to the hospital being reviewed, usually because the relevant aspect of this service is not provided on that site.



1.3 Introduction to Cancer

In the past, the leading cause of death in the UK was heart attack and other cardiovascular diseases. Deaths from heart disease are now falling and over the last two years, cancer has become the main cause of death in this country accounting for 27% of total deaths in men and 23% in women. Cancer is largely a disease of the elderly with two-thirds of cases diagnosed in people over the age of 65; as the population is generally living longer, these figures are likely to rise. Over 26,000 people in Scotland are diagnosed with cancer each year and in 1999, over 14,000 Scots died from the disease.

Basic Facts about Cancer

The body is made up of many types of cells. Normally cells grow, divide, and produce more cells to keep the body healthy and functioning properly. Sometimes, however, the process fails and cells keep dividing when new cells are not needed. A cancer consists of abnormal cells that increase in number without control or order and then invade and destroy body tissue. The extra cells then form a mass which is called a growth or tumour. Tumours can be benign or malignant and malignant tumours are known as cancer as they have the potential not only to invade and destroy the tissue surrounding the growth but also to produce secondary growths elsewhere in the body.

In Summary

- Cancer is the uncontrolled and disordered growth of cells within a specific organ or tissue type.
- Most cancers (although not all) begin in a single site such as the breast or lung.
- If left untreated, cancers grow steadily often by invading surrounding areas.
- They often also produce secondary or further growths (metastases) and this is the aspect of cancer that is most difficult to treat.

Diagnosis, Assessment and Treatment

Cancer is usually diagnosed through one of two routes. The general practitioner (GP), or a hospital consultant, who thinks that symptoms are suspicious of cancer, may refer the patient to a specialist for investigation for cancer; alternatively, investigation for cancer may follow provisional identification in a screening programme. Both these routes lead to full assessment, diagnosis and treatment if required. Cancer may also present symptomatically as an emergency.

Much of the specific assessment, diagnosis and treatment of cancer takes place in the acute hospital setting (secondary care) although co-ordinated and effective communication between primary and acute care is essential both at the stage of referral and at discharge.

The treatment for each patient is approached on an individual basis; however, there are usually three specific components of treatment of cancer: chemotherapy, radiotherapy, and/or surgery. The order or combination of these will vary according to tumour, stage of disease, or if the patient is involved in a clinical trial.

Communication with patients and their family and friends is also recognised as a core element of care, and information on every aspect of the cancer journey should be available and provided in a range of ways (unless the patient makes it clear they do not want this). This applies not only among patients, so that they have the choice to participate in treatment decisions, but also among the care staff. Good communication is supported by patient-centred record-keeping of assessments of the quality of the patient's life as well as the treatment and progress of their disease.

1.4 Colorectal Cancer

Colorectal cancer is a common disease and on average, 3,500 new cases are diagnosed each year in Scotland. About 1,750 people die from the disease each year and it is the second most common cause of cancer death in Scotland. Survival rates are dependent on the stage the cancer has reached at the time of diagnosis and most cancers have already spread beyond the bowel when they are confirmed. At this stage only about 45% of patients are alive five years after diagnosis.

Colorectal cancer is also known as bowel cancer. The large bowel is the last part of the digestive system where faeces are formed. It has two parts: initially the colon, that leads to rectum which then leads to the outside of the body through the anus. This disease often starts as a polyp on the inside wall of any part of the large bowel. Polyps are like small spots or cherries on stalks and not all of them are pre-cancerous. There is good evidence that the removal of polyps that are found to be pre-cancerous reduces the risk of developing colorectal cancer.

Symptoms and Diagnosis

The most common symptoms of bowel cancer are a change of bowel habit, most commonly increased frequency and/or looser stools persistent for at least six weeks, and rectal bleeding. However these symptoms are fairly non-specific and are also found in other bowel disorders and digestive conditions. The current advice to GPs is to consider early referral of patients to hospital for investigation if they detect clinical abnormalities, such as abdominal tenderness, or if a rectal lesion is present. New and persistent symptoms in a patient of over 45 years or in a younger patient in a genetically high-risk group also warrant referral for investigation. If these criteria do not apply then the patient should be reviewed after four weeks.

A complete colonoscopy is the most reliable test for colorectal cancer and can detect 95% of tumours. This procedure involves passing a long, flexible tube (a colonoscope) with a tiny camera on the end into the large bowel through the anus. The camera allows the doctor to see any tumours or polyps, from which either a sample can be taken, or they can be removed completely. An alternative approach is to use sigmoidoscopy and a double contrast barium enema (DCBE). The sigmoidoscope is shorter and narrower than the colonoscope and allows visual inspection of the rectum and about 75% of colonic lesions. The DCBE detects between 85-95% of colorectal cancers.

Any samples taken are assessed by the pathologist and if colorectal cancer is diagnosed, there will then be an initial assessment of the stage of the disease using imaging techniques such as X-rays, CT scans and ultrasound. Once this full assessment has been made, the treatment options can then be discussed with the patient.

Treatment

When elective surgery is considered, the surgeon will usually discuss with the patient the possibility that the operation could be potentially curative or that it might only provide relief of distressing symptoms. Surgical practice is to remove the tumour with a margin of normal bowel and to remove the supporting tissue and lymph nodes. Biopsies are taken to allow histological assessment of the extent of tumour spread. The extent of the surgery is dependent on the position of the tumour and on whether it has spread, and in some cases it will be necessary to form a colostomy as normal bowel function will not be possible.

Sometimes emergency surgery is necessary if colorectal cancer presents as bowel obstruction, profuse bleeding or bowel perforation. In such instances, the priority is to optimise the general condition of the patient prior to the operation and then carry out an initial operation to resolve the immediate problem. Further assessment may be made at this stage about the treatment of the cancer.

Once the results of the surgery and pathology are available, it is important that these are reviewed by the multi-professional team in order to make decisions about the options for treatment which can then be discussed with the patient and their family.



Chemotherapy is considered as an aid to potentially curative surgery for colorectal cancer and also provides palliation or relief from certain symptoms. Radiotherapy is an aid for rectal cancer and the benefit may be pre- operative or postoperative. Again, radiotherapy may also provide useful palliation in certain cases.

Support and Information

Patients with colorectal cancer, and their families and carers, should find that throughout their journey of care there is the provision of information over time, to allow them to come to terms with the diagnosis, and to be involved in decisions about treatment to the extent they wish. Healthcare professionals caring for patients with cancer recognise that it is not only a physical illness and they can provide constructive support at every stage.

Screening

Research suggests a possible reduction in the number of deaths from colorectal cancer of up to 20%, primarily by reducing emergency presentations and increasing early diagnosis. The NHS is currently funding a UK pilot to assess the feasibility of providing population screening for colorectal cancer and once the results of this pilot are evaluated, a decision will be made about whether to introduce a national screening programme.

1.5 The CSBS Standards and Your Care

CSBS Standards and Questions You Might Want to Ask

The colorectal cancer standards have been summarised and are shown below in blue. Each standard is followed by relevant questions you might want to ask about your care.

Referral guidelines are in place between primary and acute care.

- Why are you referring me?
- Who are you referring me to?

Patients who need urgent treatment get a hospital appointment within two weeks.

- How quickly will I be seen?

Patients are told about the type of test they are getting and why, when they will receive the results, and whom, they will receive them from.

- What tests will I get and what are they for?
- How many will I need?
- Who will give me the results and when?

Referrals are made to the appropriate cancer specialist and multidisciplinary team.

- Is the doctor I will be seeing a cancer specialist?
- Will that doctor have all my test results?

Those discussing the diagnoses and other sensitive issues with patients are trained in communication skills.

- Will the doctor understand my concerns and give me time to ask questions?
- Will a specialist nurse be there to speak to me?

GPs are informed, without undue delay, about a patient's diagnosis, prognosis, proposed treatment and what the patient has been told.

- Who will tell my GP about the results of my tests and the treatment that is planned?
- How quickly will this happen?

Arrangements are in place for the supply of equipment and drugs in the community as well as in hospital.

- Who will arrange for any drugs or equipment I may need when I leave hospital?
- What do I do if I need help overnight or at the weekend?

Waiting times for investigation and treatment are monitored and reduced wherever possible.

- When will my treatment start?
- What will the treatment be like and how long will it take?
- Will there be side-effects and what can I do about them?

Surgery is performed by a specialist or sub-specialist for those cancers where evidence shows this improves the result.

- Is my surgeon a specialist in my type of cancer?

Chemotherapy is prescribed by a medical or clinical oncologist and its administration is supervised by trained staff.

- Is the doctor prescribing my chemotherapy an expert in this field?
- Who will give me my chemotherapy and will they have the right training?

All treatment and care plans are discussed by a multidisciplinary team which includes cancer nurses and all the main consultants.

- Will my treatment be discussed by all the staff involved in my care? Does this team include cancer nurses as well as doctors?

There are formal interdepartmental referral arrangements in place and full records are available to all the staff involved in a patient's care. Wherever possible, integrated care pathways are developed.

- If I have to go to more than one clinic or hospital, will they know about my diagnosis and treatment?

Good supportive care is available throughout treatment and patients know how to get help including from sources outside the NHS.

- Who should I contact if I am worried about my diagnosis, treatment or prognosis?
- What help is available for my family?
- What patient support groups are there in my area?

There are formal arrangements in place for the provision of palliative care and the management of symptoms.

- Who will help me deal with symptoms like pain and tiredness during my treatment?

Patients and their families have good practical and emotional support when they need it.

- Who can I talk to about how I am feeling?
- What support is available for my family?



1.6 Frequently Asked Questions and Useful Contacts

Q. Can I do anything to prevent myself from getting cancer?

A. The cause of many cancers is not known although there is increasing evidence that certain factors do raise the risk of developing cancer. The European Union has developed a 10 point code designed to reduce your risk of getting cancer and this is detailed below:

- Stop smoking.
- Limit alcohol consumption.
- Cover up in the sun.
- Be breast aware.
- Attend screening invitations.
- Eat at least five portions of fruit and vegetables daily.
- Take regular exercise.
- Check for unusual lumps.
- Follow health and safety instructions on substances which may cause cancer.
- Consult a GP if you have continual problems such as persistent cough or a change in bowel or urinary habits.

Q. If I have had cancer are my children more at risk?

A. Very few cancers have a strong enough genetic component to put your children at high risk of developing the disease (less than 5%). The most common cancers where there is evidence of family histories are breast, colorectal and ovarian cancer and if you are concerned about your family history, you should discuss this with your doctor who can refer you to a specialist clinic if necessary.

Q. Can I ask for a second opinion from another cancer specialist?

A. It is perfectly reasonable for patients with cancer, who have several options for the treatment of their disease, to seek a second opinion. Your GP will be able to help you arrange this. A list of organisations that can provide further advice is also provided in this report.

Q. Do all chemotherapy drugs have bad side-effects?

A. A lot of progress has been made in improving the drugs used to treat cancer and there are now over 50 anti-cancer drugs that can be used in various combinations. Each drug has different side-effects which should be discussed with you by the doctor and nurses who give you the treatment. If you want to ask more about this before you agree to treatment, information on these drugs is readily available. Not all chemotherapy causes sickness and hair loss, and there are now several drugs available that can control side-effects very effectively.

Q. Is it true that clinical trials are good for you?

A. Clinical trials are good for you for two reasons: first they ensure that you receive the highest possible standards of care, and second your treatment will be fully documented and the results analysed. They also allow you to make a contribution to improving health services by being part of the evidence that is used to determine the best way to treat diseases. Your permission will always be sought and you will not be entered into a trial without your knowledge and consent. If you do not want to enter a trial this will not affect your treatment. You should always be given full information about any study or trial you are asked to consider and there is usually a specially trained nurse available to discuss this with you and to answer your questions.

Useful Contacts

The following organisations can provide information and support about all aspects of cancer. GPs and healthcare teams treating cancer can also provide you with information about local support groups.

At certain times the telephone lines may be very busy and callers are encouraged to keep trying.

1. Cancer BACUP

2nd Floor
30 Bell Street
GLASGOW
G1 1LG

Tel: 0141 553 1553
www.cancerbacup.org.uk

2. Macmillan Cancer Relief (includes Cancerlink)

9 Castle Terrace
EDINBURGH
EH1 2DP

Tel: 0131 229 3276
www.macmillan.org.uk

3. Tak Tent Cancer Support

Flat 5
30 Shelley Court
Gartnavel Complex
GLASGOW
G12 0YN

Tel: 0141 211 0122
www.taktent.org.uk

4. Cancer Research UK

Federation House
222 Queensferry Road
EDINBURGH
EH4 2BN

Tel: 0131 343 1344
www.cancerresearchuk.org

5. Health Education Board for Scotland

Woodburn House
Canaan Lane
EDINBURGH
EH10 4SG

Tel: 0131 536 5500
www.hebs.scot.nhs.uk

Colorectal Cancer

6. Colon Cancer Concern

9 Rickett Street
LONDON
SW6 1RU

Tel: 020 7381 4711
Fax: 020 7381 5752
www.coloncancer.org.uk/help.htm

7. Beating Bowel Cancer

39 Crown Road
St Margarets
Twickenham
MIDDLESEX
TW1 3EJ

Tel: 020 8892 5266
Fax: 020 8892 1008
www.beatingbowelcancer.org



Chapter 2

National Performance Against the Standards

2 National Performance Against the Standards

The findings across Scotland in terms of performance against the standards are presented in this chapter. A number of examples of innovative local solutions and areas of good practice are described in boxes throughout the text. These examples are not exhaustive – indeed, individual review teams highlighted many innovative examples of good practice across Scotland. It is often the case that the example cited also exists in another location.

It should be noted that a total of 33 hospitals were reviewed to assess performance against the standards. This national overview summarises 28 local reports as Trust wide reports were submitted by four of the Trusts visited and these incorporate all hospital sites within that Trust. This is reflected in the findings by providing information on the number of instances where the criteria were met, based on the denominator of the 28 reports (referred to in the text as hospitals).

Information, Data Collection and Audit

Data collection and regular audit and review of the results facilitate effective healthcare as outcomes can be monitored and, where necessary, improvements made in the quality of treatment and care.

During review visits it was apparent that the methods used for data collection, audit and dissemination of information vary considerably between and within Trusts, Island NHS Boards and hospitals. A key challenge for NHSScotland is to develop systems that support the monitoring of clinical practice, and to disseminate the results of this monitoring. A further challenge is to develop common definitions and analyses so that performance can be compared within and between organisations.

There is clearly a commitment to, and an awareness of, the importance and value of data collection and audit, but too often this is taken forward by enthusiastic individuals without the necessary support when a Trust-wide approach is required.

Although Trusts tried hard to meet the requests for information about services, what was provided was often incomplete. This explains some of the gaps in information provided throughout the reports, and where information was not available to support a response, this has been assessed as ‘Not met (insufficient evidence)’.

More worryingly, it suggests that the organisations responsible for cancer services, and the clinicians working within them, are not in a position to routinely monitor or account for those services, nor can they give patients information on, for example, the length of time they can expect to wait between different stages of treatment. It is not possible for a service to know its effectiveness in the delivery of care without such information. Not only are data systems poor, but also, they do not allow information about different parts of the overall process to be connected.

A national cancer registration scheme has been in operation in Scotland for the last 30 years and the SIGN core data sets are well-established. The Board has already set standards and targets and has provided self-assessment tools which will allow monitoring of performance against these. There is now an urgent need to improve the methods and systems used to collect and analyse information and this should be taken forward at national and local levels.

2.1 Standard 1: Referral Process

Standard Statement

Primary and secondary care collaborate to achieve appropriate referral for patients suspected of having cancer.

Essential Criteria

1. Formal arrangements jointly agreed between GPs and specialists working within the multidisciplinary team for the suspected cancer are in place. These specify which patients are to be referred and to whom.

This criterion was met in 11 hospitals.

2. Formal arrangements jointly agreed between hospital departments and specialists working within the multidisciplinary team for the suspected cancer are in place. These specify which patients are to be referred and to whom.

This criterion was met in seven hospitals.

Strengths

- The majority of Trusts were able to demonstrate that they had good informal relationships with primary care, and effective informal interdepartmental communication.
- In those Trusts where formal arrangements were in place for referral from primary to secondary care, there was evidence of collaboration between primary and secondary care in the development of these arrangements.
- Trusts with evidence of formal arrangements for interdepartmental referral were able to demonstrate that these arrangements were jointly agreed between hospital departments and specialists working within the multidisciplinary team.

Challenges

- A significant proportion of Trusts were unable to produce evidence of formal written information for primary care which indicated which patients with colorectal symptoms are to be referred, and to whom.
- The majority of Trusts did not produce formal written information for interdepartmental referral which indicated which patients with suspected colorectal cancer are to be referred, and to whom.
- It was the perception of a number of Trust representatives that current referral pathways could be streamlined to improve the efficiency of the referral process.

Recommendations

- Although there is evidence that in some cases informal referral pathways are effective, Trusts should be encouraged to formalise these arrangements to increase the efficiency of referrals. This was felt to be particularly valuable in the case of new members of staff who would not be aware of current informal arrangements.
- It is important that there is joint agreement both between primary and secondary care and among hospital departments in the development of these referral arrangements.
- Feedback from primary care representatives suggested that they would welcome clearer guidance from secondary care about indications for referral of suspected colorectal cancer patients and details of to whom they should refer patients.
- The establishment of the Electronic Clinical Communications Implementation (ECCI) programme has the potential to formalise referral arrangements between primary and secondary care.

Examples of local initiatives**Dumfries & Galloway**

Surgeons and GPs in Dumfries & Galloway have met to draw up a Colorectal Clinic Referral Form. This form identifies whether the referral is urgent or not, the duration of symptoms and contains a checklist of symptoms and family history. This draft document will be finalised following the upcoming SIGN Guideline: Colorectal Cancer review meeting.

Lanarkshire

A fast-track service for rectal bleeding is in place at Wishaw General Hospital, in the form of a 'one-stop' clinic. Information leaflets giving criteria for referral to this service have been distributed to GPs. Patients are sent information leaflets on bowel preparation in advance of their clinic appointment, enabling them to have all their investigations, including colonoscopy, performed on the day of clinic. A valuable service is provided in streamlining referral, and reducing delay and patient anxiety.

Examples of local initiatives

North Glasgow

The Integrated Colorectal Cancer Service Guideline has been developed in conjunction with primary and secondary care representatives within NHS Greater Glasgow. There has been encouraging feedback on this guideline from GPs in the Stobhill Hospital, Glasgow, catchment area and it has had a positive effect on the volume and appropriateness of colorectal cancer referrals.

Western Isles

A system which allows GPs to directly book outpatient clinic appointments is currently being piloted as part of the Electronic Clinical Communications Implementation (ECCI) programme at the Western Isles Hospital, Stornoway.

2.2 Standard 2: Multidisciplinary Working

Standard Statement 2(a)

There is a lead consultant for colorectal cancer services.

Essential Criterion

1. Named lead consultant with responsibility for co-ordinating a multidisciplinary system of working.

This criterion was met in 27 hospitals.

Desirable Criterion

2. Managed Clinical Network.

This criterion was not met in any Trust as fully functioning Managed Clinical Networks were not in place.

Strengths

- The majority of Trusts were able to identify a lead consultant for colorectal cancer services.
- Informal networks were in place in a number of Trusts and there was evidence of collaborative working practices both between hospital sites and between Trusts.
- The development of informal networks was particularly strong in remote and rural areas which rely on other Trusts for the provision of key aspects of their service.

Challenges

- In Trusts with more than one hospital site, not all staff were aware that there was one named lead consultant with overall responsibility for co-ordinating a multidisciplinary system of working across the whole Trust, particularly if this individual was not based at the same hospital site.
- The audit function of the Managed Clinical Network was established in a number of Trusts. However, other functions were largely not operational at the time of the visit.

Recommendations

- There should be clear identification of the lead consultant with overall responsibility for colorectal cancer services within the Trust.
- Trusts should encourage and support the development of Managed Clinical Networks for colorectal cancer.

Standard 2: Multidisciplinary Working

Standard Statement 2(b)

Each patient is aware of the named clinician responsible for any given part of their journey.

Essential Criterion

1. Cancer patients are told the name of the clinician responsible for their care at each stage of the patient journey.

This criterion was met in all 28 hospitals.

Strengths

- All patients were aware of the named clinician responsible for their care at any given part of their journey.
- In smaller Trust sites, where the colorectal cancer service is often consultant led, patients are particularly aware of the clinician responsible for their care due to the close-knit nature of the healthcare communities involved.

Challenge

- As all Trusts meet the essential criterion, there are no major challenges in terms of performance against this standard.

Recommendation

- Patients should be provided with both oral and written information detailing the name of the clinician responsible for their care, as patients report difficulties in retaining oral information unless it is backed up in writing.

Standard Statement 2(c)

All patients with colorectal cancer have access to a named cancer nurse with experience and knowledge of their cancer.

Essential Criteria

1. Patients have access to a named cancer nurse with expertise in colorectal cancer.

This criterion was met in 21 hospitals.

2. In cancer centres, patients have access to a specialist cancer nurse.

This criterion was met in three out of five cancer centres.

3. There are locally agreed standards of care covering all aspects of cancer nursing practice and clear communication pathways between professionals.

This criterion was met in seven hospitals.

4. Clear links between hospital-based nursing services and those in the community and palliative care services.

This criterion was met in all 28 hospitals.

Desirable Criterion

5. In non-cancer centres patients have access to a specialist cancer nurse for colorectal cancer.

This criterion was met in 15 out of 23 non-cancer centres.

Strengths

- In the majority of Trusts all colorectal cancer patients have access to a named cancer nurse with experience and knowledge of their cancer.
- The colorectal cancer nurse specialists play a significant role in the care of colorectal cancer patients, providing advice and support throughout their journey of care, and are often the crucial communication link between different members of the multidisciplinary team.
- An important part of the role of the colorectal nurse is educational, in terms of providing training to other nursing staff involved in the care of colorectal cancer patients.
- A number of Trusts were able to illustrate how the palliative care service is well integrated into the colorectal cancer patient's journey of care.
- Specialist posts are emerging to facilitate the seamless discharge of patients from secondary to primary care. Hospital discharge co-ordinator roles were identified in some hospital sites, and it was evident that these had a positive effect on the quality of discharge information and planning.

Strength

- In smaller Trusts the caseload of colorectal cancer patients was often insufficient to warrant a tumour-site-specific specialist nurse. In such cases colorectal cancer patients had access to a general oncology or Macmillan nurse with knowledge of all cancers, and this was considered to be appropriate for the local situation.

Challenges

- In a small number of Trusts, colorectal cancer patients do not have access to a nurse with experience and knowledge of their cancer.
- In some Trusts, where there is a designated colorectal cancer nurse, all colorectal cancer patients do not have access to this service due to a number of factors. These include the geographical distances between Trust sites and the large caseload of colorectal cancer patients treated within the Trust.
- A widespread challenge was that of cover for the colorectal nurse specialist in their absence.
- Only a small number of Trusts were able to provide evidence of locally agreed standards of care covering all aspects of cancer nursing practice. Where these were in place staff confirmed that they were used in the management of patient care. In most other cases standards of nursing care generic to all conditions are in place.

Recommendations

- All patients with colorectal cancer should have access to a named nurse with knowledge and experience of colorectal cancer.
- Arrangements should be in place to ensure that cover is available for the colorectal nurse specialists in their absence.

Examples of local initiatives

North Glasgow

Comprehensive cancer nursing standards are in place at all three hospital sites within North Glasgow University Hospitals NHS Trust. These standards cover all aspects of cancer nursing practice, and there is evidence that these are used in the management of patient care.

Examples of local initiatives

South Glasgow

The colorectal nurse specialist at the Southern General Hospital, Glasgow, plays an important role in providing information and continuing support to patients with colorectal cancer at all stages in their journey of care. The nurse specialist is present when patients are told they have cancer, and then takes the patient to a private room for further discussion. The colorectal nurse specialist also obtains the patient's pathology results and co-ordinates further diagnostic investigations and clinic appointments. This creates an individualised service, where patients receive sensitive information from someone they are familiar with, at a crucial stage in their illness. The review team was very impressed with the colorectal nursing database, which collects an extensive range of patient information. These include details of investigations, communications with the patient, management, follow up arrangements, records of multidisciplinary meetings and nursing notes.

Tayside

Colorectal specialist nurses and other nursing staff who provide a service for patients with colorectal cancer are well qualified. The colorectal specialist nurses play a major role in co-ordinating multidisciplinary working and it is obvious that they are greatly valued by medical staff. A clinical nurse specialist database module is used by the colorectal specialist nurses in Ninewells Hospital, Dundee, to record patient contact, nursing care and audit practice.

Standard 2: Multidisciplinary Working

Standard Statement 2(d)

The management of patients with cancer is multidisciplinary.

Essential Criteria

- 1. Multidisciplinary management protocols are in place for patients with cancer, covering systems for referral (including medical and radiation oncology and palliative care services), investigation, treatment and follow-up.**

This criterion was met in 14 hospitals.

2. Local agreement and awareness of the membership of the colorectal cancer multidisciplinary team. The minimum membership of the team for colorectal cancer is: surgeon, oncologist, pathologist and specialist nurse as a core for regular meetings with a radiologist and colonoscopist who can be co-opted when necessary.

This criterion was met in 12 hospitals.

3. A documented system for the working and decision-making process of the multidisciplinary team.

This criterion was met in 14 hospitals.

4. Cancer centres have a weekly clinical conference.

This criterion was met in three out of five cancer centres.

Desirable Criterion

5. Evidence of specialisation in colorectal cancer within oncology, radiology and pathology services.

This criterion was met in 13 hospitals.

Strengths

- All Trusts recognised the benefits of collectively discussing the management of colorectal cancer patients in a multidisciplinary forum, and most were making steps towards achieving this.
- A number of Trusts had well-established multidisciplinary team meetings where representation of all essential specialties was achieved.
- For those Trusts where multidisciplinary management protocols for patients with cancer were in place, these were comprehensive, and there was evidence to suggest that they were used in the management of patient care.
- In some Trusts, the caseload of colorectal cancer patients was often insufficient to warrant specialisation in oncology, radiology and pathology services. In such cases colorectal cancer patients had access to generalists with knowledge of all cancers, and this was considered to be appropriate for the local situation.

Challenges

- Only half the Trusts had clearly defined multidisciplinary colorectal cancer teams that meet on a regular basis and which have developed local protocols for the management of colorectal cancer.
- The systematic documentation and dissemination of decisions made during the multidisciplinary team meeting was not taking place in some Trusts. In a number of Trusts, patient casenotes were the only method used to document decisions made by the multidisciplinary team. This was not considered to be a completely satisfactory mechanism to ensure that all individuals involved in the care of colorectal patients were made aware of treatment decisions.
- The majority of Trusts that were unable to meet this standard did so because of the remote nature of specific elements of the colorectal service, in particular, the oncology and pathology services.
- Trusts reported difficulties with finding an appropriate time for all essential members of the team to meet, although this has been overcome in certain areas through the use of teleconferencing.

Recommendations

- Trusts should ensure that all colorectal cancer patients are discussed at each stage in their journey of care by the relevant specialties within a multidisciplinary forum.
- Formal protocols for colorectal cancer patients should be developed with the collaboration of all specialties involved in the management of colorectal cancer.
- Documentation of the working and decision making of the multidisciplinary team should be systematically carried out and disseminated to all healthcare professionals involved in the management of colorectal cancer.

Examples of local initiatives

Ayrshire & Arran

Trust-wide multidisciplinary team meetings have been established at Ayrshire & Arran Acute Hospitals NHS Trust through the use of information technology. Videoconferencing facilities are utilised to enable staff at both hospital sites to collectively discuss patients with cancer and make joint decisions about their treatment.

Dumfries & Galloway

A system of ensuring that patients with colorectal cancer are discussed at the multidisciplinary meeting and included in colorectal audit has been developed at Dumfries & Galloway Royal Infirmary. All patients with suspected colorectal cancer are registered with the Clinical Audit Department on visualisation of a tumour in out-patients or the endoscopy theatre, and by pathology when a carcinoma is confirmed. Patients are then put on a list for discussion at the multidisciplinary meeting. This enables most patients to be discussed preoperatively and all patients are discussed postoperatively.

Lothian

Multidisciplinary team meetings are well established at the Western General Hospital, Edinburgh. Weekly meetings are held to collectively discuss the management plans for all colorectal cancer patients. Information is entered directly onto the colorectal cancer database during this meeting. This facilitates data collection and enables an instant record of decision-making to be made, and disseminated to all healthcare professionals involved in the care of colorectal cancer patients.

Tayside

A Tayside Gastrointestinal Focus Group has been established with multidisciplinary membership, including representation from primary care, specialist nursing and audit. This group has produced the Tayside Gastrointestinal Cancer Network Integrated Colorectal Cancer Service document and is a forum for the development of an integrated service for colorectal cancer. Audit reports of the colorectal service are provided to the group enabling review of practice.

2.3 Standard 3: Education and Training

Standard Statement

All health professionals in cancer services undertake cancer specific professional education and development including the principles and philosophy of palliative care.

Essential Criteria

1. Doctors, nurses and professions allied to medicine working in multidisciplinary teams have accredited specialist education and training in cancer.

This criterion was met in 20 hospitals.

2. All health professionals involved with cancer services undertake communications skills training.

This criterion was not met in any hospital for all staff.

3. There is evidence of regular discussion of work practice at a local level within the multi-professional team.

This criterion was met in 21 hospitals.

4. There is a multidisciplinary rolling programme of palliative care education for all staff involved in cancer care covering the physical, emotional, social and spiritual aspects of palliative care.

This criterion was met in 16 hospitals.

5. At least one member of a multidisciplinary team has undertaken an accredited course in palliative care.

This criterion was met in 25 hospitals.

Strengths

- The majority of Trusts were able to provide evidence that cancer specific education is available to health professionals in cancer services.
- There is considerable personal investment from Trust personnel to undertake cancer specific education and development.
- In-house training packages have been developed in a number of Trusts as a means of disseminating information to other healthcare professionals.

Challenges

- Communication skills training is not routinely available to all healthcare professionals, and, in particular, to senior medical staff. It is noted that communications skills training is now a component of undergraduate medical education.
- Although there are some excellent examples of palliative care education programmes, these were found to be directed towards nursing staff, and there appeared to be a lack of palliative care education for all healthcare professionals in cancer services.
- Work commitments and financial constraints were cited as major barriers to training, particularly among nursing staff.
- In remote Trusts, travelling distances and the associated costs were cited as further barriers to training.

Recommendations

- Arrangements should be in place to ensure that all healthcare professionals involved in cancer services have access to palliative care and communication skills training as an integral component of cancer specific education and development.
- Trusts should explore the use of information technology (IT) to enhance the training opportunities available to healthcare professionals.
- An evaluation of training needs should be carried out to find out the training requirements of Trust personnel.

Examples of local initiatives

Argyll & Clyde

A three-monthly forum for cancer nurses is held in Argyll & Clyde Acute Hospitals NHS Trust. The specialist oncology nursing team has established this group to share good practice and explore all aspects of oncology nursing and palliative care. The forum is open to all hospital and community nursing staff with an interest in oncology and palliative care.

Lothian

There is a commitment to training and education in cancer at Lothian University Hospitals NHS Trust. The contribution made by medical staff to regional and national educational events in colorectal cancer is commended. Furthermore, a wide range of courses in oncology and palliative care are made available to nursing staff, and there is considerable personal investment by staff to further their knowledge in oncology and palliative care.

West Lothian

There is a commitment to specialist training in cancer at West Lothian Healthcare NHS Trust. A West Lothian Cancer Care Education Forum has been established, which holds four multidisciplinary cancer care education sessions annually. In addition, the Lead Colorectal Cancer Consultant has developed a programme of education specific to colorectal cancer.

2.4 Standard 4: Communication and Information Sharing

Standard Statement

Patients are fully informed of different options for treatment and involved in decision making to the extent they wish.

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.

This criterion was met in all 28 hospitals.

2. Written information leaflets (including information about local support groups) are available for all patients (including those with disabilities and those requiring translation services).

This criterion was met in all 28 hospitals.

3. The breaking of bad news is handled in a sensitive manner.

This criterion was met in all 28 hospitals.

4. Private areas are available in clinics and wards for communicating information.

This criterion was met in 23 hospitals.

Strengths

- All Trusts were able to provide some evidence that colorectal cancer patients received information regarding their illness, and were involved in decision-making.
- Where available, the colorectal nurse specialist played a significant role in reinforcing the information provided to patients by the consultant, and acted as a continuous source of support and information.
- A range of nationally produced and locally developed written information on colorectal cancer was available to patients in all Trusts.
- All Trusts provided oral assurances that mechanisms were in place to minimise the traumatic effect of delivering bad news.

Challenge

- Access to private areas for the purpose of communicating sensitive information was limited or not available in some Trusts.

Recommendations

- Although private areas were available in most Trusts for the purpose of communicating information, these areas were not always solely used for this purpose. Trusts should ensure that dedicated space is made available for communicating sensitive information.
- National information leaflets on colorectal cancer were not always readily available to patients, as the distribution of these leaflets is sometimes limited and patients are required to request their own copy from the specific organisation. Trusts should explore ways to ensure that written information is readily available to patients.

Examples of local initiatives**Dumfries & Galloway**

Dumfries & Galloway Royal Infirmary is in the process of developing a colorectal cancer website to provide patients with online access to information about colorectal cancer, and details of the Dumfries & Galloway Royal Infirmary colorectal cancer service.

Forth Valley

The patient-held guide to chemotherapy in colon and rectal cancer is commended. All colorectal cancer patients who receive chemotherapy are given a copy of this guide. A patient satisfaction survey of this guide has been carried out, and revision of the guide is planned in response to the survey.

North Glasgow

A comprehensive protocol for the breaking of bad news has been developed in North Glasgow University Hospitals NHS Trust. This includes practical advice on preparing patients to receive bad news, assessment of patient knowledge, finding out how much a patient wants to know, sharing information and how to respond to patients' statements and emotions.

Tayside

There are high-quality, locally produced patient information leaflets on a range of topics relevant to colorectal cancer patients, such as diet, investigations, high dependency unit and chemotherapy in use. These have been produced according to a Trust policy, and are evaluated by patients before final production. Leaflets are reviewed annually to ensure that the information they contain is not out of date.

2.5 Standard 5: Audit

Standard Statement

Prospective clinical audit is an integral part of cancer services.

Essential Criteria

1. Continuous collection of SIGN Colorectal Cancer Core Data Set to facilitate audit.

This criterion was met in 24 hospitals.

2. Participation in the Scottish Cancer Therapy Network (SCTN) national data quality assurance programme.

This criterion was met in 26 hospitals.

Desirable Criteria

3. One, two, and five year survival rate is audited.

This criterion was met in 13 hospitals.

4. Regular reporting of casemix and outcome.

This criterion was met in 13 hospitals.

Strengths

- All Trusts recognised the value of clinical audit as a tool to support service evaluation and some have established data collection systems in place.
- The majority of Trusts have commenced collection of the SIGN Colorectal Cancer Core Data Set, and have demonstrated a willingness to participate in the Scottish Cancer Therapy Network Quality Assurance Programme.

Challenges

- Several Trusts were unable to provide accurate data to support those aspects of the colorectal cancer service that can be measured by clinical audit.
- Although the majority of Trusts were collecting the SIGN Colorectal Cancer Core Data Set as part of their existing data systems, these have not always incorporated all the data items included in this data set.
- Resource constraints are cited as a major barrier to effective clinical audit. Clinicians report that they do not have the time, support staff or the systems in place to support data collection activity.
- The majority of Trusts are not auditing long-term survival rates.
- A number of Trusts do not have systems in place to ensure that the regular reporting of casemix and outcome takes place.

Recommendations

- All Trusts should ensure collection of the SIGN Colorectal Cancer Core Data Set, including long-term survival rates, and provide regular reporting of casemix and outcome.
- Trusts should actively participate in national data quality assurance programmes to allow meaningful comparisons to be made across colorectal cancer services.
- Trusts should ensure the sustainable provision of staff to support clinical audit and data collection activity.

Example of a local initiative**Tayside**

A dedicated cancer audit team began prospective audit of colorectal cancer on 1 July 1999. The SIGN Colorectal Cancer Core Data Set together with local items is collected and held on a database. There is also a supplementary module allowing colorectal specialist nurses to collect data relating to their own practice. Database queries have been written to automatically provide information for the CSBS Clinical Standards for Colorectal Cancer. Regular reporting of this data to clinicians enables discussion and review of practice.

2.6 Standard 6: Clinical Trials

Standard Statement

Those involved in delivering cancer services are to try to increase the participation of patients in well-designed, ethical clinical trials.

Essential Criteria

1. Recording of patients offered a clinical trial.

This criterion was met in 21 hospitals.

2. Percentage of patients entering clinical trials is recorded.

Where data were provided to assess this criterion, it was met in 20 hospitals.

3. Informed consent.

This criterion was met in 25 hospitals.

4. Functioning Ethics Committee.

This criterion was met in 25 hospitals.

Strengths

- All Trusts had access to a functioning Ethics Committee, and could provide evidence that informed consent is obtained from all patients prior to participation in clinical trials.
- The majority of Trusts maintain a record of those patients who are offered entry into clinical trials, and also the percentage of patients entered into clinical trials.

Challenges

- Overall the percentage of colorectal cancer patients who are being entered into clinical trials is small.
- Geographical difficulties are cited as the main barrier to patient entry into clinical trials for patients from remote and rural areas.

Recommendations

- Trusts should explore the opportunities to maximise patient entry into clinical trials. However, it is noted that there is a general lack of availability of clinical trials in colorectal cancer.
- Initiatives should be introduced at a national level to increase patient entry into clinical trials.

Examples of local initiatives

Grampian

The review team commends the commitment to clinical trials at Grampian University Hospitals NHS Trust. The Trust has an excellent record of patient entry into clinical trials, which are co-ordinated by the cancer centre at Aberdeen Royal Infirmary.

Lanarkshire

An impressive level of entry of colorectal cancer patients into clinical trials was found in Hairmyres Hospital, East Kilbride. All patients, apart from those who are 'Dukes Stage A', are considered for suitable clinical trials.

2.7 Standard 7: Assessment and Care Planning

Standard Statement

All patients with cancer have their complex needs assessed, documented and acted upon.

Essential Criteria

1. Each patient has an individual documented care plan.

This criterion was met in all 28 hospitals.

2. The individual care plan assesses and documents the most distressing problems as identified by the patient; whether physical, emotional, social or spiritual.

This criterion was met in all 28 hospitals.

3. The most distressing problems are documented in patient notes.

This criterion was met in all 28 hospitals.

4. There is a clear record of what the patient has been told.

This criterion was met in all 28 hospitals.

5. There is evidence of regular review of problems and actions.

This criterion was met in all 28 hospitals.

6. All patients have a written record given to them on discharge documenting medication and detailing: what the medication is, when it was prescribed, why it was prescribed, frequency of administration, dose and formulation.

This criterion was met in three hospitals.

7. Continuity of care for patients with specific palliative care needs is ensured by the appropriate communication of those needs from secondary to primary care.

This criterion was met in 26 hospitals.

8. Continuity of care for patients with ongoing palliative needs is ensured by the appropriate communication of those needs between GPs and 'out-of-hours' co-operatives.

This criterion was met in 16 hospitals.

Desirable Criteria

9. Integrated records.

This criterion was met in one hospital.

10. Social work advice from a designated social worker with a special interest in palliative care.**This criterion was met in 12 hospitals.****Strengths**

- All Trusts were able to demonstrate that individualised care plans were in use for patients with colorectal cancer.
- All Trusts provided oral assurances that all important events during a patient's hospital stay, including what they had been told, are documented in the patient's record.
- The majority of Trusts were able to illustrate that continuity of care is achieved for patients with specific palliative care needs through effective communication between secondary and primary care staff.

Challenges

- Primary healthcare representatives in a number of Trusts expressed their dissatisfaction with the quality of information received at the time of patient discharge.
- The majority of Trusts did not provide comprehensive discharge documentation to patients on discharge.
- Integrated records were not in use for colorectal cancer patients in the majority of Trusts.

Recommendations

- Trusts should revise their immediate discharge documentation to include all the recommended components, and ensure that patients receive their own copy of the immediate discharge document.
- Trusts should ensure that record keeping is complete, and that all those involved in patient care have access to patient records.

Examples of local initiatives**Borders**

The 'Bordoc' out-of-hours General Practitioner service is in place to ensure that continuity of care for patients with specialist palliative care needs is achieved. An information sheet for all patients with continuing palliative care needs is completed on discharge; a copy of which is logged with the 'Bordoc' service.

North Glasgow

It is evident that there is a real commitment to patient audit at Stobhill General Hospital, Glasgow. A number of patient focussed audits have been carried out including, a documentation audit, an audit of spiritual needs, a wound care audit and a survey of patient satisfaction.

2.8 Standard 8: Waiting Times

Standard Statement 8(a)

The time between diagnosis and first definitive treatment is within essential limits.

Essential Criterion

1. Time between diagnosis and first definitive treatment is not more than four weeks.

Where data were provided to assess this criterion, it was not met in any hospitals.

Standard Statement 8(b)

The time between radiotherapy booking and start of radiotherapy is within essential limits.

Essential Criterion

1. Time between radiotherapy booking and start of radiotherapy is not more than four weeks.

Where data were provided to assess this criterion, it was not met in any hospitals.

Standard Statement 8(c)

The time between surgery and start of adjuvant chemotherapy is within essential limits.

Essential Criterion

1. Time between surgery and start of adjuvant chemotherapy is not more than eight weeks.

Where data were provided to assess this criterion, it was met in two hospitals.

Strength

- Waiting times are an issue across Scotland and all Trusts showed an awareness of this. Some have already taken steps to address this at a local level.

Challenges

- Where data were available, the waiting times exceeded the essential criterion in the standard statement.
- A number of Trusts were unable to produce audit data to measure these standards.

Recommendations

- Measures to reduce waiting times should be introduced urgently, at both local and national levels.
- Trusts should ensure that waiting times are recorded as part of data collection activity.

2.9 Standard 9: Preoperative Preparations/Investigations

Standard Statement 9(a)

Rectal cancer is assessed by digital examination and rigid sigmoidoscopy, and fixity and distance from anal verge recorded.

Essential Criterion

1. All patients are assessed.

Where data were provided to assess this criterion, it was met in three hospitals.

Strength

- The majority of Trusts were unable to provide audit data to indicate that all patients receive a full preoperative assessment. However, following interviews with staff during the review process, review teams confirmed that patients were appropriately assessed preoperatively.

Challenge

- A number of Trusts were unable to produce audit data to measure this standard, and it was noted that these data items were not previously included as part of the SIGN Colorectal Cancer Core Data Set. The data set has been revised, and the majority of Trusts now collect the required information.

Recommendations

- Trusts should ensure that all colorectal cancer patients receive a full preoperative assessment.
- Trusts should ensure that an accurate record of all preoperative assessments received by colorectal cancer patients is maintained.

Standard Statement 9(b)

The rectum and whole colon is visualised preoperatively using a combination of barium enema and sigmoidoscopy (rigid or flexible) or colonoscopy or CT colonoscopy (colonography).

Essential Criterion

1. The rectum and whole colon is visualised preoperatively in a minimum of 70% of patients.

Where data were provided to assess this criterion, it was met in 12 hospitals.

Strength

- The percentage of colorectal cancer patients who have the rectum and whole colon visualised preoperatively meets the essential criterion in many Trusts.

Challenges

- Not all Trusts were able to produce audit data to measure this standard.
- Some Trusts were not carrying out preoperative visualisation of the rectum and whole colon in all appropriate colorectal cancer cases.

Recommendations

- Trusts should ensure that all appropriate colorectal cancer patients receive preoperative visualisation of the rectum and whole colon.
- Trusts should ensure that an accurate record of all preoperative assessments received by colorectal cancer patients is maintained.

Standard 9: Preoperative Preparations/Investigations**Standard Statement 9(c)**

A chest X-ray or chest CT scan is always performed preoperatively.

Essential Criterion**1. Chest X-ray or chest CT scan is performed preoperatively for all patients.**

Where data were provided to assess this criterion, it was met in three hospitals.

Challenges

- The majority of Trusts were unable to produce audit data to measure this standard, although it was the perception of most Trusts that all patients receive a preoperative chest X-ray or chest CT scan.
- Documentation to enable measurement of this standard was often incomplete.

Recommendations

- Trusts should ensure that all patients receive a preoperative chest X-ray or chest CT scan.
- Trusts should ensure that an accurate record of all preoperative investigations received by colorectal cancer patients is maintained.

Standard 9: Preoperative Preparations/Investigations

Standard Statement 9(d)

The abdomen is imaged preoperatively by ultrasound or CT or MRI or intraoperatively by ultrasound wherever possible.

Essential Criterion

1. The abdomen is imaged preoperatively by ultrasound or CT or MRI or intraoperatively by ultrasound in a minimum of 80% of patients.

Where data were provided to assess this criterion, it was met in nine hospitals.

Challenges

- A number of Trusts were unable to produce audit data to measure this standard.
- Some Trusts were not always carrying out preoperative or intraoperative abdominal imaging in all appropriate colorectal cancer patients.

Recommendations

- Trusts should ensure that all appropriate patients receive preoperative or intraoperative abdominal imaging.
- Trusts should ensure that an accurate record of all preoperative investigations received by colorectal cancer patients is maintained.

Standard Statement 9(e)

All patients likely to require a stoma have access to a stoma clinical nurse specialist.

Essential Criteria

1. All patients likely to require a stoma have access to a stoma nurse specialist.

This criterion was met in 25 hospitals.

2. All patients likely to require a stoma are assessed preoperatively by a stoma clinical nurse specialist.

This criterion was met in 19 hospitals.

3. A minimum of 80% of patients have their stoma site marked preoperatively.

Where data were provided to assess this criterion, it was met in 10 hospitals.

4. The stoma clinical nurse specialist is able to supply a range of products.

This criterion was met in all 28 hospitals.

Strengths

- In the majority of Trusts, all colorectal cancer patients likely to require a stoma have access to a stoma clinical nurse specialist.
- The majority of Trusts appeared to prepare patients satisfactorily for stomas.
- The stoma clinical nurse specialists play a significant role in the care of stoma patients, providing advice and support throughout their journey of care.

Challenges

- In a minority of Trusts, not all stoma patients have access to a stoma clinical nurse specialist.
- Although Trusts were confident that the stoma clinical nurse specialist carried out preoperative assessment and stoma siting in all patients who are expected to require a stoma, there was often an absence of audit data to support this.
- A widespread challenge was the provision of cover for the stoma nurse specialists in their absence.

Recommendations

- Trusts should ensure that all patients who are expected to receive a stoma have access to a stoma nurse specialist.
- Trusts should ensure that accurate data collection is maintained to evaluate the service offered to stoma patients.

Examples of local initiatives

Fife

A specialist nurse is in place at Queen Margaret Hospital, Dunfermline, to provide support and advice to colorectal cancer patients who are experiencing sexual difficulties following their treatment. If requested, patients with sexual problems can be referred to this specialist service.

Shetland

In Shetland, the Consultant Colorectal Surgeon identified a deficiency in the service offered to stoma patients and initiated a patient questionnaire which resulted in the introduction of the Stoma Resource Nurse Service.

Standard 9: Preoperative Preparations/Investigations

Standard Statement 9(f)

Patients have preoperative bowel preparation, DVT prophylaxis and antibiotic prophylaxis, wherever possible.

Essential Criteria

1. A minimum of 80% of patients have bowel preparation.

Where data were provided to assess this criterion, it was met in 11 hospitals.

2. A minimum of 70% patients have DVT prophylaxis.

Where data were provided to assess this criterion, it was met in 19 hospitals.

3. All patients have antibiotic prophylaxis.

Where data were provided to assess this criterion, it was met in seven hospitals.

Strengths

- The majority of Trusts were able to provide evidence that the percentage of patients who receive DVT prophylaxis was within essential limits.
- It was the perception of most Trusts that all appropriate patients receive preoperative bowel preparation.

Challenge

- Although most Trusts were confident that all patients received DVT and antibiotic prophylaxis, there was often an absence of audit data to support this.

Recommendations

- Trusts should ensure that all colorectal patients receive antibiotic and DVT prophylaxis, and bowel preparation, in accordance with best practice recommendations.
- Trusts should ensure that an accurate record of bowel preparation, DVT and antibiotic prophylaxis received by colorectal cancer patients is maintained.

2.10 Standard 10: Surgical Management

Standard Statement

The distal margins (for all tumours) and circumferential margins (for rectal tumours) are free of tumour.

Essential Criteria

1. All distal resection margins (for all tumours) are clear.

Where data were provided to assess this criterion, it was met in seven hospitals.

2. A minimum of 70% of circumferential margins (for rectal tumours) are clear.

Where data were provided to assess this criterion, it was met in 18 hospitals.

Strength

- The rate of circumferential tumour clearance for rectal cancer is satisfactory in the majority of Trusts.

Challenges

- Some Trusts provided audit data that indicated that a very small percentage of distal resection margins for all tumours were not clear.
- A number of Trusts were unable to produce audit data to measure this standard.

Recommendations

- Trusts should ensure that distal resection margins for all tumours are clear.
- Trusts should ensure that audit data on resection margins are included in the core data set.
- In the rare event where a distal resection margin is found not to be clear the reasons for this should be fully explored.

2.11 Standard 11: Postoperative Management

Standard Statement 11(a)

Units dealing with colorectal cancer to have access to an onsite high dependency unit (HDU) and access to an appropriate intensive therapy unit (ITU).

Essential Criterion

1. All units to have appropriate access to both high dependency unit and intensive therapy unit.

This criterion was met in 23 hospitals.

Strength

- The majority of hospitals have access to onsite HDU and appropriate access to ITU.

Challenges

- A minority of hospitals do not have access to an onsite HDU, or appropriate access to ITU facilities.
- A number of Trusts highlight problems with accessing HDU facilities for colorectal cancer patients as a result of the demand for beds and inadequate staffing of high dependency facilities.

Recommendations

- All hospitals that undertake colorectal cancer surgery should have onsite access to a HDU and appropriate access to an ITU.
- High dependency facilities should be adequately staffed, and the number of allocated beds should be appropriate to the high dependency caseload of the hospital.

Examples of local initiatives

South Glasgow

There is a good working relationship between the staff managing the HDU and those managing the ITU at the Victoria Infirmary, Glasgow. Ready access to these facilities is reported and both areas have made provision for the comfort of relatives of patients in the HDU and ITU.

West Lothian

An innovative pager system is in place within the HDU/ITU at St John's Hospital, Livingston. The system enables the relatives of critically ill patients to leave the unit, and be immediately contacted by pager in the event of an emergency.

Standard 11: Postoperative Management

Standard Statement 11(b)

All pathology reports conform to a required standard.

Essential Criterion

1. The Joint National Guidelines Minimum Data Set Colorectal Cancer Histopathology report is completed in all resected cases.

This criterion was met in 20 hospitals.

Strength

- In the majority of Trusts it is routine practice for the above report to be completed for all resected cases.

Challenge

- Not all Trusts complete the required histopathology data set for all resected cases. Those Trusts which do not meet this standard cite staff shortages as the reason for this.

Recommendation

- Trusts should make arrangements to ensure that the Joint National Guidelines Minimum Data Set Colorectal Cancer Histopathology report is completed for all resected cases.

Example of a local initiative

Tayside

A high-quality pathology service was found to be in place. There is specialisation in colorectal cancer and participation in research and audit. Routine collection of the required histopathology dataset through use of an electronic reporting system is commendable.

Standard 11: Postoperative Management

Standard Statement 11(c)

Anastomotic dehiscence (which is of clinical significance) after colorectal cancer surgery is within essential limits.

Essential Criteria

1. Anastomotic dehiscence is not more than 5% after colonic anastomosis.

Where data were provided to assess this criterion, it was met in 19 hospitals.

2. Anastomotic dehiscence is not more than 10% after rectal anastomosis.

Where data were provided to assess this criterion, it was met in 17 hospitals.

3. Anastomotic dehiscence is not more than 20% after anterior resection with total mesorectal excision for rectal cancer.

Where data were provided to assess this criterion, it was met in 16 hospitals.

Strength

- Where data were available, the anastomotic dehiscence rate following colorectal cancer surgery was within essential limits.

Challenge

- Some Trusts were unable to produce audit data to measure this standard.

Recommendations

- Trusts should ensure that the audit of surgical outcomes includes data on dehiscence rates.
- In the rare event where the anastomotic dehiscence rate exceeds the essential maximum limit the reasons for this should be fully explored.

Standard 11: Postoperative Management

Standard Statement 11(d)

All patients are considered and discussed within the multidisciplinary team, for adjuvant or palliative chemotherapy/radiotherapy, or for surgical treatment of metastatic disease.

Essential Criteria

1. All patients are discussed by the multidisciplinary team.

This criterion was met in 14 hospitals.

2. All patients with histologically involved circumferential margins, after resection for rectal cancer, receive postoperative radiotherapy unless there is a documented contra-indication.

Where data were provided to assess this criterion, it was met in 12 hospitals.

3. A minimum of 15% of patients undergoing curative resection receive adjuvant chemotherapy.

Where data were provided to assess this criterion, it was met in 14 hospitals.

4. If chemotherapy is not considered appropriate the reason is recorded in the patient's notes.

This criterion was met in 26 hospitals.

5. Patients with liver or lung metastases are considered for surgical treatment of their metastases.

This criterion was met in 26 hospitals.

Strength

- Those Trusts with established multidisciplinary team meetings used these as a forum to discuss the postoperative management of colorectal cancer patients.

Challenge

- Not all colorectal cancer patients are collectively discussed by the multidisciplinary team to ensure appropriate postoperative treatment.

Recommendation

- The postoperative management of colorectal cancer patients should be collectively discussed by the multidisciplinary team.

2.12 Standard 12: Chemotherapy

Standard Statement

Chemotherapy is prescribed, dispensed, administered and supervised in a safe and effective manner.

Essential Criteria

1. Chemotherapy to conform to Joint Council for Clinical Oncology (JCCO) (1994) guidelines, this includes the following:

2. Cancer chemotherapy is carried out in designated in-patient or out-patient facilities which are properly equipped for the purpose.

This criterion was met in 18 hospitals.

3. Cancer chemotherapy regimes are prescribed on the basis of a protocol in regular use in the department.

This criterion was met in 17 hospitals.

4. Protocols are known and readily available to any staff involved in the delivery of chemotherapy.

This criterion was met in 16 hospitals.

5. Protocols contain an account of toxic effects of the drugs used and recommendations for their management.

This criterion was met in 15 hospitals.

6. Chemotherapy is initiated by an accredited clinician using protocols jointly agreed between members of the multi-disciplinary team.

This criterion was met in 19 hospitals.

7. Chemotherapy is dispensed by trained and experienced practitioners working with suitable equipment in an appropriate environment.

This criterion was met in 21 hospitals.

8. Chemotherapy is administered by trained and experienced practitioners.

This criterion was met in 20 hospitals.

9. Departments administering cancer chemotherapy are to have access to education and training courses for all healthcare professionals administering chemotherapy.

This criterion was met in 21 hospitals.

Strength

- The majority of Trusts in which chemotherapy is prescribed and administered ensured that it is prepared and delivered in designated facilities by appropriately trained personnel.

Challenges

- Only half of the Trusts are adhering to all components of the Joint Council for Clinical Oncology guidelines.
- Not all Trusts have readily available protocols for prescribing chemotherapy and dealing with toxic effects.

Recommendations

- Trusts should ensure that all aspects of chemotherapy prescription, delivery and administration conform to Joint Council for Clinical Oncology guidelines.
- Trusts should ensure that appropriate protocols for colorectal cancer chemotherapy are developed, and are readily available to all staff involved in the administration of chemotherapy.

Examples of local initiatives

Highland

There are plans to establish an electronic prescribing system for chemotherapy between the cancer centre at Raigmore Hospital, Inverness, and the peripheral sites at Belford Hospital, Fort William, and Caithness General Hospital, Wick. This will facilitate the prescription of chemotherapy, which is carried out by the consultant oncologist who is based at the cancer centre.

Lothian

The chemotherapy department's ISO9000 accreditation at the Western General Hospital, Edinburgh, is commendable. A high level of quality assurance is ensured, through six-monthly auditing of all systems involved in the delivery of chemotherapy.

Orkney

The hospital-based Macmillan nurse has developed a training package which enables local staff to develop skills in chemotherapy administration. This model of disseminating information to meet local training needs is commended, and there is recognition of the financial and time constraints faced by local staff who wish to travel to mainland sites for training and educational purposes.

2.13 Standard 13: Outcomes

Standard Statement 13(a)

Operative mortality for elective colorectal cancer surgery and mortality resulting from chemotherapy and radiotherapy is within essential limits.

Essential Criterion

1. Treatment related mortality is not more than 5%.

Where data were provided to assess this criterion, it was met in seven hospitals.

Strength

- The operative mortality rates for the majority of Trusts, where data were available to measure this standard, were within essential limits.

Challenge

- Many Trusts were unable to provide the audit data necessary to measure this standard.

Recommendation

- Comprehensive prospective collection of the SIGN Colorectal Cancer Core Data Set is essential.

Standard Statement 13(b)

Permanent stoma rate after rectal cancer surgery is within essential limits.

Essential Criterion

1. Permanent stoma rate is not more than 40% in patients with rectal tumours.

Where data were provided to assess this criterion, it was met in 10 hospitals.

Strength

- In Trusts where data were available to measure this standard, the permanent stoma rate for colorectal cancer patients was within essential limits.

Challenges

- Many Trusts, which were able to provide data to measure this standard, had a permanent stoma rate which exceeded the essential criterion.
- A number of Trusts were unable to provide the audit data necessary to measure this standard.

Recommendations

- In those Trusts where the permanent stoma rate exceeds the essential maximum limit the reasons for this should be fully explored.
- Comprehensive prospective collection of the SIGN Colorectal Cancer Core Data Set is essential.

Standard 13: Outcomes

Standard Statement 13(c)

Local recurrence after rectal cancer surgery with or without radiotherapy is within essential limits.

Essential Criterion

1. The local recurrence rate is not more than 15%.

This criterion was not met in any of the hospitals.

Strength

- Although no Trust had mature enough data to enable assessment of this standard, most recognised the importance of collecting data on local recurrence rates.

Challenge

- Although some Trusts had started collecting data on local recurrence rates, the volume of data, and the time period over which this data had been collected, were insufficient to enable a meaningful measurement of local recurrence rates to be made at this stage.

Recommendation

- Local recurrence rates are an important outcome measure that should be audited by all Trusts as part of the SIGN Colorectal Cancer Core Data Set.

2.14 Standard 14: Symptom Management

Standard Statement

Care is provided in accordance with relevant SIGN guidelines, or where these do not exist, in accordance with good practice guidelines which are evidence-based.

Essential Criteria

1. Persistent poorly controlled problems are discussed with, or referred to, the specialist palliative care team.

This criterion was met in 17 hospitals.

2. Locally agreed policies for pain management based on SIGN Guideline for Control of Pain in Cancer Patients.

This criterion was met in 15 hospitals.

3. Locally agreed policy on the management of symptoms in particular, but not exclusively, for: agitation/confusion, anorexia, breathlessness, constipation, fatigue, insomnia, lymphoedema, nausea/vomiting, oral care.

This criterion was met in four hospitals.

Strengths

- The majority of Trusts were able to demonstrate that patients with persistent, poorly controlled symptoms, are referred to the palliative care team for management of these symptoms.
- Over half the Trusts had locally agreed policies for pain management based on the SIGN Guideline for the Control of Pain in Cancer Patients.

Challenge

- The majority of Trusts do not have established policies for the management of other palliative care symptoms.

Recommendations

- Trusts should ensure that policies are in place for the management of all palliative care symptoms.
- Trusts should ensure that palliative care services are involved in the care of patients with cancer from an early stage in their treatment, and throughout their journey of care as required.

Examples of local initiatives

Borders

Staff at the Borders General Hospital, Melrose, were able to demonstrate that the palliative care service is well integrated into the cancer patient's journey. A website has been developed which provides information and support to patients and staff on palliative care issues. Funds have also been secured for the development of a Managed Clinical Network for palliative care.

Forth Valley

Palliative care is well integrated into the colorectal cancer service provided by Falkirk & District Royal Infirmary and Stirling Royal Infirmary. There is a specialist palliative care team at each hospital, and strong links between these teams, hospital staff, and staff in the community. Palliative care staff visit the wards on a regular basis and are involved at an early stage in the management of patients with palliative care problems.

North Glasgow

The specialist palliative care service is well developed and integrated into the care of cancer patients at Stobhill Hospital, Glasgow. The palliative care consultant attends the weekly multidisciplinary team meeting where the management plans of colorectal cancer patients are discussed. There is a 24-hour telephone advice service provided by the local hospice, and there are comprehensive policies on pain control and the management of other palliative care symptoms.

South Glasgow

An integrated care pathway for cancer pain has been piloted within South Glasgow University Hospitals NHS Trust, and will be distributed throughout the Trust once it has been approved.

2.15 Standard 15: Drugs

Standard Statement

Prescribed essential drugs are obtainable when required (including 'out-of-hours' for patients at home).

Essential Criteria

1. A list of essential drugs (including those required for syringe drivers) is agreed in each Health Board Area. These drugs are available at all times, especially out-of-hours, from designated pharmacy source(s).

This criterion was met in 21 hospitals.

2. There are locally agreed guidelines on the use of syringe drivers and drugs used with syringe drivers.

This criterion was met in 26 hospitals.

3. This arrangement includes pharmacy advice from a specialist pharmacist with particular interest in palliative care.

This criterion was met in 22 hospitals.

4. These arrangements are known to palliative care staff, primary healthcare teams (GPs, district nurses) and on-call co-operatives/ doctors.

This criterion was met in 19 hospitals.

Strength

- Most Trusts have systems in place to ensure that essential drugs are available at all times, and that guidelines on the use of syringe drivers are available.

Challenges

- Access to pharmacy advice from a specialist pharmacist in palliative care is limited.
- Arrangements for the supply of essential drugs, and advice on palliative care drugs are not always made known to those staff who provide palliative care in the community.

Recommendation

- Trusts should ensure that drugs and syringe drivers are available at all times, and that palliative care staff, GPs, district nurses and on-call co-operative doctors are aware of the arrangements for essential drugs and who to access for advice about these drugs.

Examples of local initiatives

Argyll & Clyde

The 'Model Scheme for Palliative Care' has been set up in Argyll & Clyde Acute Hospitals NHS Trust to ensure that essential drugs are available at all times. The system identifies particular pharmacies in the area that hold supplies of essential drugs, and there are five pharmacists who have received training to provide specialist information and advice on the pharmaceutical aspects of palliative care.

Fife

The Fife Network of Palliative Care Pharmacists has been established to ensure that palliative care medication can be accessed at all times in the area covered by the NHS Board. Nine pharmacies in the locality are designated to hold stocks of an agreed list of essential drugs at all times and to provide advice on palliative care issues. There is evidence that information about this service is effectively disseminated to community staff through the distribution of information leaflets and the running of educational sessions to raise awareness.

2.16 Standard 16: Equipment

Standard Statement

All patients receiving palliative care have timely delivery of equipment essential to their needs.

Essential Criteria

1. There is an effective and efficient system to ensure the supply of equipment (including syringe drivers) and training in the use of this equipment.

This criterion was met in 24 hospitals.

2. There is a database established for the whereabouts of essential equipment.

This criterion was met in 22 hospitals.

3. There is a clear designated authority for management of the equipment store.

This criterion was met in 23 hospitals.

4. Equipment is labeled with a telephone number for quick uplift of items.

This criterion was met in 20 hospitals.

5. Basic equipment is delivered to the patient within 24 hours, seven days a week.

This criterion was met in 11 hospitals.

6. Arrangements are in place to ensure that syringe driver use can be established 24 hours a day, seven days a week.

This criterion was met in 26 hospitals.

7. Syringe drivers in the community are supplied by Primary Care Trusts and are maintained annually.

This criterion was met in 25 hospitals.

8. There is a rolling programme for replacement of syringe drivers resulting in the provision of one single type of driver in each Health Board area.

This criterion was met in eight hospitals.

Desirable Criteria

9. Health Boards and Trusts work with Local Authorities to set up a joint equipment service where this does not already exist.

This criterion was met in 23 hospitals.

Strengths

- The majority of Trusts have systems in place to ensure the efficient supply of palliative care equipment, and training in the use of this equipment.
- The majority of Trusts have arrangements in place to guarantee that syringe driver use can be established at all times, and that these syringe drivers are maintained annually.
- Most NHS Boards are working towards establishing joint equipment stores with Local Authorities.

Challenges

- The majority of Trusts do not have systems in place to ensure that basic equipment is delivered to patients within 24 hours, seven days a week.
- Only a small proportion of Trusts have a replacement programme for syringe drivers resulting in the provision of one single type of syringe driver in each NHS Board.

Recommendations

- NHS Boards and Trusts should work together to ensure that arrangements are in place to enable basic equipment to be delivered to the patient within 24 hours, seven days a week.
- Syringe driver replacement programmes should be established to ensure that one type of syringe driver is in use in each area covered by the NHS Board.

2.17 Standard 17: Discharge

Standard Statement

Effective discharge planning begins on or shortly after admission and is a continual process. Communication and transfer of information among healthcare professionals is essential to a seamless process.

Essential Criteria

1. Discharge is planned and all relevant information communicated at the appropriate time to the patient and to those involved in continued provision of care.

This criterion was met in 20 hospitals.

2. A hand held discharge document is provided.

This criterion was met in 25 hospitals.

3. A full discharge summary is sent to the patient's GP.

This criterion was met in 27 hospitals.

Strengths

- Primary healthcare representatives from all Trusts confirmed that they receive full discharge summaries for all colorectal patients.
- Immediate discharge summaries are provided to GPs for colorectal patients in the majority of Trusts.

Challenges

- Primary healthcare representatives in a number of Trusts expressed their dissatisfaction with the quality of information received at the time of patient discharge.
- Patients do not routinely receive a personal copy of their immediate discharge information as they are instructed to deliver this to their GP.
- Primary healthcare reported that there are often delays between patient's discharge and receipt of the full discharge summary.

Recommendations

- Trusts should ensure that all patients receive a personal copy of their immediate discharge information.
- Trusts should be aware of the time taken for GPs to receive a full discharge summary and ensure that where possible this is kept to a minimum.

Examples of local initiatives

Grampian

Grampian University Hospitals NHS Trust has exemplary patient discharge documentation. Information is written in a patient-friendly and easy-to-read format. This discharge information contains comprehensive medication details. It also has sections for further appointments, any home visits that have been arranged, information leaflets received, equipment that has been taken home, with contact details for problems of return of equipment, and any special instructions.

Highland

The seamless discharge of patients is achieved by the close-knit nature of the hospital and primary care communities within Highland NHS Board. Community and palliative care staff become involved in discharge planning for patients with complex needs at an early stage in their journey of care. There are also plans to introduce an electronic discharge document which will further facilitate discharge planning in the future.

Lanarkshire

The seamless discharge of colorectal cancer patients from secondary to primary care is enhanced by the role of the hospital discharge liaison co-ordinators. The Macmillan liaison nurse also plays an important role in ensuring continuity of care between primary and secondary care. Community staff are often informed of patients' impending discharge prior to the event.

Chapter 3

Conclusions

This national overview, and the accompanying local reports, set out the performance of NHSScotland as a whole, and of each Trust/Island NHS Board, against the colorectal cancer standards published by the Board in 2001.

A number of general themes have emerged and these apply to all cancers. First, without exception, each review team was struck by the commitment, dedication and hard work of staff involved in providing cancer care, frequently under considerable pressure. The services provided are responsive to patient needs and a number of innovative service developments were observed during visits. Of particular note was the multidisciplinary approach which is used in most Trusts to assess and plan treatment for cancer patients. All Trusts were enthusiastic about working together internally and across Trusts to provide rapid and 'seamless' access to care, and the next challenge is to establish regional cancer networks to support and strengthen joint working.

Second, members of the public have been involved at every stage of each cancer project. This has provided a valuable perspective on the work of project groups in setting standards and on review visits, and has also given members of the public the chance to contribute to all aspects of the review process, rather than simply to read a report prepared without their input.

Third, action is needed to improve and support clinical data systems and audit. At present these vary considerably, both between Trusts/Island NHS Boards, and between individual sites within a single Trust. Frequently, systems are developed locally by enthusiasts without the necessary support and, as a result, many Trusts were unable to provide basic monitoring information about their performance against standards. In particular, Trusts face considerable challenges in monitoring waiting times throughout the patient journey, and it is important that this is addressed at a national level as well as locally.

Fourth, there is evidence that, although time-consuming for all concerned, the standards, self-assessment and review processes have already been a focus for change and improvement. In particular, the self-assessment element of the process is being used as a tool locally to monitor progress, and in many sites its completion has brought staff together to discuss service delivery. The Board's work has re-focused the agenda in many Trusts and revived the enthusiasm to work together to achieve changes and improvements. No one believes major changes can be achieved immediately but already small steps have been taken. Teams are meeting where before this was not happening. Protocols are being

developed and shared with all those involved in care, primary and secondary. Change is occurring not only in sites visited – review team members are taking back new ideas to use in their practice as well. Additional funds provided through the Scottish Cancer Group have attracted bids to address problems identified during the Board’s visits. The patient movement is growing and new posts for Patient Involvement Officers are being advertised.

This report, and the local reports on each Trust/Island NHS Board, together with the examples of good practice they contain, are designed to support and encourage the process of continual improvement in services. The findings of this report will be presented to the Scottish Cancer Group in support of the work under way on the implementation of the Scottish Cancer Plan.

The Board looks to each Trust/Island NHS Board, guided by its Clinical Governance Committee, to ensure that, in close collaboration with the staff responsible for providing the service, practice is reviewed in the light of the report’s findings and recommendations and appropriate action taken. Considerable momentum has built up and it is important to use this enthusiasm to take forward the work of strengthening and improving cancer services.

Under the arrangements established in September 2001, each NHS Board is responsible for the performance of its local NHS services. NHS Boards are accountable to the Scottish Executive Health Department who will use the reports, and local responses to them, to monitor local and national performance. The public, both locally and nationally, also have an important role to play in ensuring that changes are made.

The Board reserves the right to revisit a Trust/Island NHS Board where it considers there are serious issues that need further external monitoring and report. The Board intends periodically to review and raise its standards, in the light of the latest evidence about best practice and the performance of the service, and to conduct further national reviews so as to encourage continuing quality improvement.

Appendices

Colorectal Cancer Project Group

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The Board member working with the Colorectal Cancer Project Group was

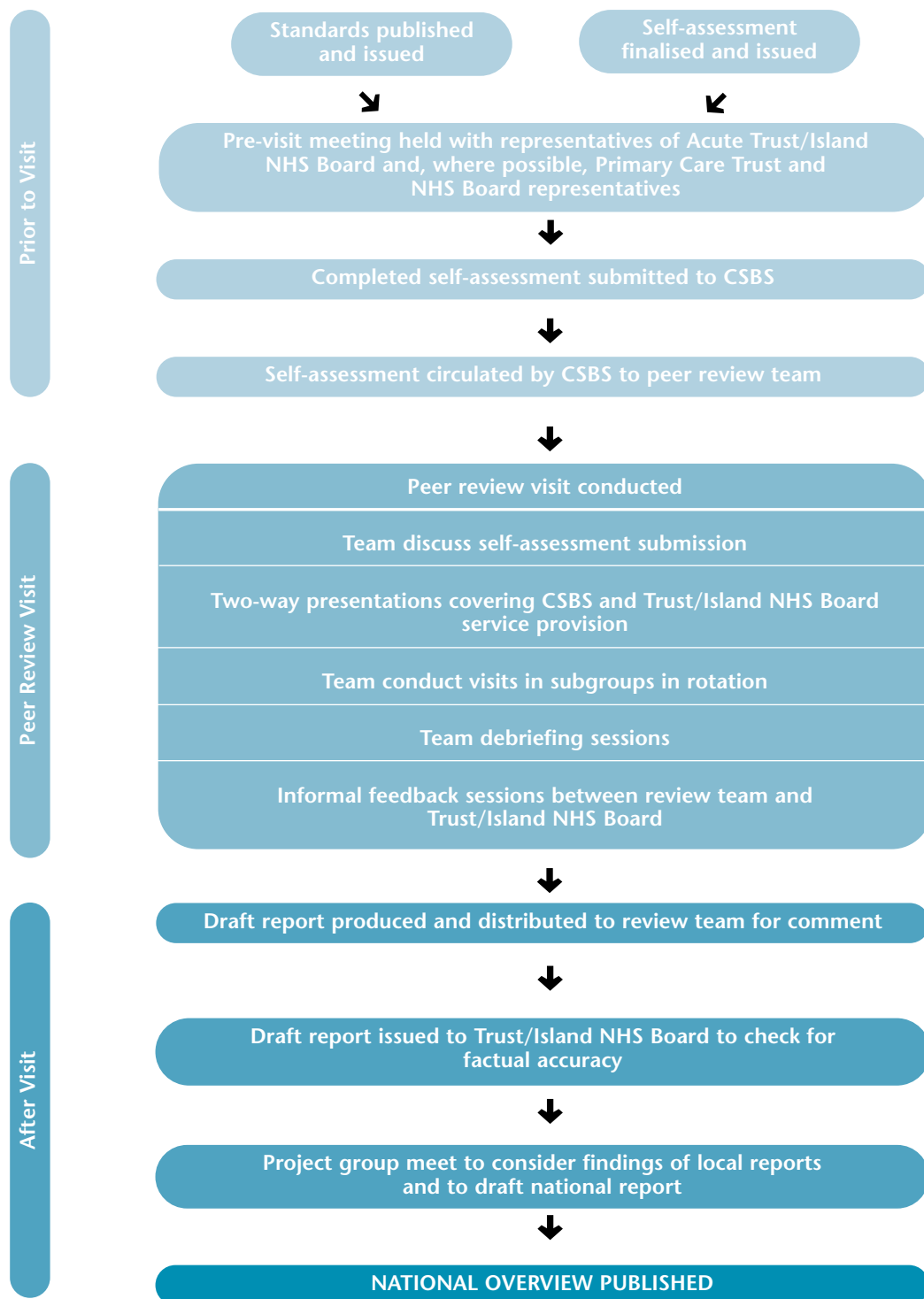
Mrs Philippa Grant.

Ms Frances Smith (Director of Nursing & Quality), **Ms Nanisa Feilden** (Project Officer) and **Ms Angela Bayly** (Project Officer) from the Clinical Standards Board for Scotland, provided support.

Appendix 2

Quality Assurance and Accreditation: the Approach Used in this Review

The CSBS accreditation process is outlined in the flow chart:



Standards

All standards set by the Board comprise a standard statement and related criteria.

Standard Statement

Describes the agreed performance for the specific area, determined by those who are involved in the delivery/receipt of the service.

Criteria

State exactly what must be done for the standard to be reached.

Some criteria are **essential** as it is expected that they will be met wherever a service is provided. Others are **desirable/aspirational** in that they will promote continuous quality improvement as they are being met in some parts of the service and demonstrate levels of quality which other providers of a similar service should strive to achieve.

Self-Assessment

Each set of clinical standards has an accompanying self-assessment framework developed by the CSBS. This framework gives guidance about the type of evidence required to demonstrate performance against the standards. It is completed and submitted to CSBS prior to a peer review visit, together with extensive additional documentation. The evidence obtained from this self-assessment exercise comprises the main source of written evidence considered by each peer review team.

Peer Review

Peer review is the process by which a multidisciplinary review team, including members of the public, carries out a hospital review to validate the quantitative data submitted through the self-assessment. This is done by gathering qualitative information through both discussions with staff in clinical areas, and observation.

During each review, the review team was guided by a clinician as team leader to ensure a multidisciplinary consensual assessment was reached. At the conclusion of the review, the review team provided feedback to the Trust/Island NHS Board giving a broad overview of its assessment, which was based on the written self-assessment, and evidence obtained during the review visit.

To enhance the consistency of the process, a CSBS manager and a project officer accompanied each visit, both of whom provided the secretariat and developmental support for the project group during the standard-setting phase of the project.

The schedule for a colorectal cancer external peer review visit included:

- initial meeting with key personnel responsible for the service under review;
- dialogue with clinicians, audit staff and managers based on the written evidence;
- scrutiny of documentation;
- interviews with staff members;
- regular team briefings throughout the day to assess progress and to compile the local report; and
- feedback to the Trust/Island NHS Board representatives on conclusion of the visit.

In addition, the CSBS review team met with local health council and patient representatives, GPs and representatives from the area NHS Board.

The review team for each peer review visit comprised different people. Although this presents challenges in achieving consistency of process, it promotes sharing of good practice and ensures that each review team assesses the performance of a hospital against the standards, not by comparing one hospital with another.

In order to determine whether a particular criterion is 'met' or 'not met', each review team requires to identify evidence on a variety of levels. For example, to demonstrate that a particular issue is addressed in a local protocol, evidence is sought during the peer review process as follows:

- description of the issue and how it should be managed in a local written protocol (submitted as part of the self-assessment);
- confirmation of awareness of the location and content of the protocol through staff interviews;
- evidence of a process in place for the protocol to be regularly updated; and
- collection of data through an integrated care pathway/audit sheet, leading to provision of collated audit data confirming compliance with the local protocol.

Until a legal interpretation of the Data Protection Act is made as to whether patient records can be accessed for purposes other than managing patient care, CSBS review teams are not scrutinising individual patient records. Therefore, in cases where it is stated that information is recorded in individual patient casenotes, and during the visit staff interviews corroborate the claim, an assessment of 'met' will be made.

The responsibility of CSBS is to report whether the services provided by NHSScotland – nationally and locally – meet agreed standards, but not to review individual cases or the work of individual healthcare professionals. In achieving this aim, variations in practice (and potential quality) within a service will be encountered. Where such variation exists between hospitals (eg between hospitals within a Trust/Island NHS Board), this will be stated; treatment variations will also be reported but will not identify patients or healthcare professionals.

Reports

A local written report was drafted at the time of each visit by CSBS. The draft report was then circulated to the review team for comment, and to the Trust/Island NHS Board concerned to allow a check for factual accuracy.

On conclusion of the peer review programme, the project group reconvened to study the findings and examine trends in order to draw conclusions and make recommendations to the CSBS.

Appendix 3

Co-ordinating Cancer Care

The pathways of care for cancer are complex, often poorly co-ordinated and can be confusing.

There is no single pathway through the system and patients may move between the different stages described in the table below. The lists under each heading illustrate the wide range of services and professionals involved in cancer care.

Stage	Initial Contact and Referral	Diagnosis and Options for Treatment
What might happen	<ul style="list-style-type: none"> • discussion of symptoms causing concern • routine screening tests • examination in A&E 	<ul style="list-style-type: none"> • tests: <ul style="list-style-type: none"> - scans, CT, MRI - X-ray - endoscopy - pathology (eg biopsy) - blood tests - sample of cells (FNA) • information and advice • discussion of options
Where	<ul style="list-style-type: none"> • GP surgery • screening service • A&E unit • home – may receive information/advice by post, Internet or phone from voluntary or NHS organisations 	<ul style="list-style-type: none"> • hospital • GP surgery • home – information/advice from voluntary or NHS organisation
Who may be involved	<ul style="list-style-type: none"> • GP • practice nurse • screening service staff, radiographer, nurse, doctor • A&E staff 	<ul style="list-style-type: none"> • oncologist • surgeon • physician • specialist nurse • radiographer • radiologist • pathologist • GP

Treatment and Care	Palliative and Terminal Care	Monitoring and Follow-up
<ul style="list-style-type: none"> • radiotherapy • chemotherapy • surgery • counselling/psychological support • information 	<ul style="list-style-type: none"> • palliative treatment (eg non curative drug or radiotherapy treatment) • therapy (eg physiotherapy) • counselling/psychological support 	<ul style="list-style-type: none"> • tests (scans, X-ray, pathology) • check up
<ul style="list-style-type: none"> • hospital • home • clinics • GP surgery 	<ul style="list-style-type: none"> • hospital • home • hospice • private hospital/nursing home 	<ul style="list-style-type: none"> • GP surgery • home • hospital out-patient clinic
<ul style="list-style-type: none"> • oncologist (clinical or medical) • surgeon • specialist nurse • other health professionals (eg physiotherapist, dietician) • GP • palliative care nurse • palliative care doctor • social worker • psychologist or counsellor 	<ul style="list-style-type: none"> • palliative care nurse • palliative care doctor • social worker • community nurse • psychologist or counsellor • other health professionals (eg physiotherapist, dietician) • GP • radiotherapist • radiographer 	<ul style="list-style-type: none"> • GP • surgeon • physician • oncologist • specialist nurse • pathologist • radiographer • radiologist

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Glossary of Terms

A&E	Accident and Emergency Department.
accreditation	A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.
acute sector	Hospital-based health services which are provided on an in-patient or out-patient basis.
adjuvant	A substance that, when added to a medicine (or treatment), speeds or improves its action which aids another, such as an auxiliary remedy.
adjuvant chemotherapy	The use of chemotherapy after initial treatment by surgery and/or radiotherapy. The aim of adjuvant therapy is to destroy any cancer that has spread.
adjuvant radiotherapy	The use of radiotherapy in association with treatment by surgery.
adjuvant therapy	Treatment given in addition to the primary therapy or a secondary remedy assisting the action of another.
anal sphincter	The muscle around the anus, essential for faecal continence.
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. Separation of the layers of an anastomosis.
antibiotic	A chemical substance produced by a microorganism which has the capacity, in dilute solutions, to inhibit the growth of or to kill other microorganisms. Antibiotics that are sufficiently nontoxic to the host are used as chemotherapeutic agents in the treatment of infectious diseases of man, animals and plants.
antibiotic prophylaxis	The administration of antibiotics to reduce the prospect of infection.

anus	The opening at the lower end of the colon, through which faeces are discharged.
assessment	The process of measuring the quality of an activity, service or organisation.
audit	Systematic review of the procedures used for diagnosis, care, treatment, and rehabilitation, examining how associated resources are used and investigating the effect care has on the outcome and quality of life for the patient.
barium enema	Technique for examination of the bowel. Procedure in which the colon is filled with an opaque fluid (barium) so that an X-ray can be taken to see what is in the colon.
BASO	British Association of Surgical Oncologists.
benign	Non-cancerous, used to refer to tumours which grow slowly in one place and which, once removed by surgery, tend not to recur.
biopsy	The removal of a small piece of tissue from an organ or part of the body for histological analysis, microscopic study, or pathologic evaluation. It is an important means of diagnosing cancer from examination of a fragment of the tumour.
bowel	Another name for the intestine, both large and small.
bowel preparation	Measures taken to ensure that the bowel is empty of faeces.
caecum	Beginning or proximal portion of the colon; located on the lower right side of the abdomen, where the small intestine empties into it.
cancer	The name given to a group of diseases that can occur in any organ of the body, and also blood, which involve abnormal or uncontrolled growth of cells.
cancer centres	Cancer services are based in cancer centres. Such centres provide the entire spectrum of cancer care – both on-site and to associated cancer units.
care plan	A document which details the care and treatment that a patient/user receives and identifies who delivers the care and treatment.

carer	A person who looks after family, partners or friends in need of help because they are ill, frail, or have a disability. The care they provide is unpaid.
case record	Patient's notes; documentation of care.
CAT scan	Computerised axial tomography. See computerised tomography.
CDS	See core data set.
cells	The individual units from which tissues of the body are formed. All living organisms are composed of one or more cells.
chemotherapy	Systemic therapy with medications that reach every cell in the body.
clinical conference	Includes doctors/nurses/professions allied to medicine and other different specialties contributing to discussions on how to manage patients or diseases.
clinical effectiveness programme	The extent to which specific clinical interventions, when deployed, do what they are intended to do, ie maintain and improve health, securing the greatest possible health gain from the available resources. This is assessed through clinical effectiveness programmes.
clinical governance	A framework through which NHS organisations are accountable for both continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.
clinical oncologist	A doctor who specialises in the use of radiotherapy but who may also use chemotherapy.
Clinical Resource and Audit Group	The lead body within the Scottish Executive Health Department promoting clinical effectiveness in Scotland. The main committee, together with its subcommittees provides advice to the Health Department, acts as a national forum to support and facilitate the implementation of the clinical effectiveness agenda and funds a number of clinical effectiveness programmes and projects. Abbreviated as CRAG. Website address: www.show.scot.nhs.uk/crag/

clinical service	Service provided by health care professionals.
Clinical Standards Board for Scotland	The Clinical Standards Board for Scotland is a statutory body, established as a special Health Board in April 1999. Its role, in line with the Scottish Executive's commitment to quality, openness and public accountability, is to promote public confidence that the services provided by the NHS are safe and that they meet nationally agreed standards, and to demonstrate that, within the resources available, the NHS is delivering the highest possible standards of care. Abbreviated as CSBS.
clinical trial	Research study conducted with patients, usually to evaluate a new treatment or drug. Each trial is designed to answer scientific questions and to find better ways to treat individuals with a specific disease.
colectomy	Surgery to remove all or part 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). See also margins of resection.
colleges	In the UK medical world the term colleges, as for example in "The Royal College of...", refers to bodies which usually combine an educational standards and examination role with promotion of professional standards.
colon	Also called the large intestine. This structure has six major divisions: caecum, ascending colon, transverse colon, descending colon, sigmoid colon and rectum. The total length is approximately five feet in the adult and it is responsible for forming, storing and expelling waste matter.
colonography	A CT of the abdomen and pelvis that focuses on the colon using intravenous contrast medium and rectal insufflation.
colonoscopist	A person who examines patients using colonoscopy.
colonoscopy	Examination of the interior of the bowel using a long, flexible, instrument (a colonoscope) inserted through the anus. A colonoscope is capable of reaching to the upper end of the large bowel (colon) and can be used to diagnose diseases of the large intestine.

colostomy	An opening created by a surgeon into the colon from the outside of the body; provides a new path for waste material to leave the body after part of the colon has been removed. The colostomy may be temporary, eventually being closed after weeks or months to restore continuity; or permanent, usually when the rectum or lower colon has been removed. An appliance is usually worn over the colostomy opening (stoma) to prevent soiling of clothes.
combined modality	Use of different treatments (surgery, chemotherapy, radiotherapy).
computerised tomography	An X-ray imaging technique used in diagnosis and radiation treatment planning. This can reveal many soft tissue structures not shown by conventional radiography.
contra-indication	Any condition, past or present, which makes a particular line of treatment unsuitable or undesirable.
co-operative	A system of working where the establishment is owned and run jointly by its members.
core data set	A minimum set of information related to a specific medical condition – includes demographic, clinical management and outcome data.
CPA	Clinical Pathology Accreditation.
CPC	Clinico Pathological Conference.
CRAG	See Clinical Resource and Audit Group.
criterion/criteria	Criterion is the term used for the singular. We have one criterion, and several criteria. Criteria provide the more detailed and practical information on how to achieve a standard and can be described as structure, process and outcome criteria.
CSBS	See Clinical Standards Board for Scotland.
CT	See computerised tomography.
curative resection	Operation in which the surgeon believes that all cancer-containing tissue has been removed.
cytology	The study of cells under the microscope.
cytotoxic	Type of substance toxic to cells; refers to drugs used in chemotherapy to kill or slow down the reproduction of cancer cells.

cytotoxic drugs	Chemicals that are directly toxic to cells, preventing their reproduction or growth. Cytotoxic agents can, as a side effect, damage healthy, noncancerous tissues or organs which have a high proportion of actively dividing cells, for example, bone marrow, hair follicles. These side effects limit the amount and frequency of drug administration.
data set	A list of required and specific information relating to a specific disease.
data source	The source of evidence to demonstrate whether a standard or criterion is being met.
desirable (criterion/criteria)	Good practice that is being achieved in some parts of the service and demonstrates levels of quality to which other providers of a similar service should strive.
DGH	District General Hospital (non-teaching hospital).
diagnosis	Identification of an illness or health problem by means of its signs and symptoms. This involves ruling out other illnesses and causal factors for the symptoms.
digital rectal exam	Used to detect rectal cancer. The doctor inserts a lubricated, gloved finger into the rectum and feels for abnormal areas.
discharge	A discharge marks the end of an episode of care. Types of discharge include in-patient discharge, day-case discharge, day-patient discharge, out-patient discharge and PAM discharge.
distal	Term that indicates direction or location in the colon. Distal colon is closer to the rectum. Proximal colon is closer to the caecum.
double-contrast barium enema	DCBE. Technique (see barium enema) in which the bowel is filled with air or gas between the introduction of barium and radiographic imaging. This allows accurate visualisation of the inner surface of the bowel.
Dukes' Stage	Category of tumour defined by internationally agreed criteria. Stages defined by Dukes range from Stage A, which is cancer limited to the bowel wall, to Stage C, where the cancer has spread to nearby lymph nodes. Stage D has been added to this system to include cancers with metastatic spread. See also staging.

DVT prophylaxis	Measures taken to reduce the prospect of the patient suffering from deep vein thrombosis after an operation.
efficacy	Strength, effectiveness. The ability of a drug to control or cure an illness. Efficacy should be distinguished from activity, which is limited to a drug's immediate effects on the microbe triggering the disease.
elective	Subject to the choice or decision of the patient or physician, applied to procedures that are advantageous to the patient but not urgent.
eligible	A patient is eligible for treatment if the benefits of that treatment outweigh the risks.
essential (criterion/criteria)	A criterion that should be met wherever a service is provided.
evaluation	The study of the performance of a service (or element of treatment and care) with the aim of identifying successful and problem areas of activity.
evidence-based	The process of systematically finding, appraising, and using current research findings as the basis for clinical decisions.
excision biopsy	Surgical biopsy that removes entire lesion.
extent of disease	This is measured in stages. See staging.
formal arrangement	Agreement in the form of a written document, forming local strategy/documentation.
gastroenterologist	A physician with additional training in digestive diseases.
generic standards	Standards that apply to most, if not all, clinical services.
GP	General Practitioner.
guidelines	Systematically developed statements which assist in decision-making about appropriate health care for specific clinical conditions.
HDL	See Health Department Letter.
HDU	High Dependency Unit.
Health Council	Each NHS Board area has a Health Council, an organisation whose aim is to promote public consultation and participation in health-related matters.

Health Department Letter	Health Department Letter (formerly known as Management Executive Letters – MELs), formal communications from the Scottish Executive Health Department to NHSScotland.
healthcare professional	A person qualified in a health discipline.
histological diagnosis	Study of what is under the microscope; the most minute branch of anatomic study; the information in a pathology report.
histological grade	The degree of similarity of the cancer cells to normal cells when examined under the microscope.
histopathology	The science concerned with the study of microscopic changes in diseased tissues.
ICP	See integrated care pathway.
imaging	The production of images of organs or tissues using radiological procedures, particularly using scanning techniques.
in situ	A cancer that is “in place”: is non-invasive: has not spread beyond the initial structure.
Information and Statistics Division	The Information and Statistics Division is part of the National Health Service in Scotland, Common Services Agency. Health service activity, manpower and finance data are collected, validated, interpreted and disseminated by the division. This data is received from NHS Boards, NHS Trusts and general practices. Abbreviated as ISD. Website address: www.shaw.nhs.uk/isd/index.htm
informed consent	The principle by which a patient/user is informed about the nature, purpose and likely effects of any treatment proposed before being asked to consent to accepting it.
in-patient	A person who is admitted to hospital for observation, examination or treatment.
integrated records	Complete medical notes relating to a patient and including information from every treatment service which they have used.

Internal validation	When an assessment of one service or procedure is made by several groups of observers, and their methods and findings carefully checked against each other for consistency, then the conclusions can be described as having undergone internal validation.
intervention	Healthcare action intended to benefit the patient.
invasive	Cancer that can or has spread from its histological original site.
investigation	A medical procedure to assist diagnosis.
irradiated	See radiotherapy.
irradiation	Radiation therapy.
ISD	See Information and Statistics Division.
Island NHS Board	Island NHS Boards do the work of both Boards and Trusts in that they have a strategic and operational role. There are three Island NHS Boards, covering Shetland, Orkney, and the Western Isles.
ITU	Intensive Therapy Unit.
JCCO	Joint Council for Clinical Oncology.
jointly agreed	Where both parties involved (if one is the patient, include the carer with patient's consent) have decided together on a particular course of action/non-action, to benefit of the patient.
lead consultant	Clinician with administrative responsibilities for a specific service.
LHCC	See Local Health Care Co-operative.
LN	Lymph node.
Local Health Care Co-operative	A grouping of general medical practices.
local information pack	Information relevant to a specific service.
lymph	Almost colourless fluid that travels through the lymphatic system, bathing body tissues and carrying cells that help fight infection; operates much like the circulatory system.

lymph nodes or glands	Small bean-shaped organs located along the lymphatic system. Nodes filter bacteria or cancer cells that might travel through the lymphatic system.
lymphoedema	The swelling of an arm, leg or another part of the body which sometimes happens when lymph nodes and vessels in the armpit or groin have been removed or damaged by surgery or radiotherapy, or have been blocked by a tumour.
malignant	Cancerous. Malignant tumours can invade and destroy surrounding tissue and have the capacity to spread.
managed clinical network	A formally organised network of clinicians. The main function is to audit performance on the basis of standards and guidelines, with the aim of improving healthcare across a wide geographic area, or for specific conditions.
margins of resection	Cut edges of the specimen taken out during biopsy; edges of the excision (excised tissue) checked for the presence of tumour cells. If no cancer has reached the edge of the tissue, margins are clean mass.
medical oncologist	A doctor who specialises in the use of chemotherapy.
medication	Drugs prescribed to treat a condition.
MEL	Management Executive Letter (now known as Health Department Letters – HDL), formal communications from the Scottish Executive Health Department to NHSScotland.
metachronous	Describes a colonic polyp that occurs after the original polyp was found.
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, lymph nodes.
metastatic lesions	Cancerous lesion or tumour at another site that has the same cancer cells as the original tumour.

monitoring	The systematic process of collecting information on clinical and non-clinical performance. Monitoring may be intermittent or continuous. It may also be undertaken in relation to specific incidents of concern or to check key performance areas.
morbidity	A diseased condition or state. The incidence of a particular disease or group of diseases in a given population during a specified period of time.
mortality	The number of deaths in a given population during a specified period of time.
MRI	Magnetic resonance imaging. A special imaging technique used to image internal structures of the body, particularly the soft tissues. An MRI image is often superior to a normal X-ray image. It uses the influence of a large magnet to polarize hydrogen atoms in the tissues and then monitors the summation of the spinning energies within living cells. Images are very clear and are particularly good for soft tissue, brain and spinal cord, joints and abdomen. These scans may be used for detecting some cancers or for following their progress.
mucosa	Mucous membrane lining the inside of the colon; a membrane rich in mucous glands.
mucous	A viscous fluid secreted by mucous membranes.
multidisciplinary	A multidisciplinary team is a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition, the scale of the service being provided and geographical/socio-economic factors in the local area.
multidisciplinary system of working	A method of working in a multidisciplinary team with protocols in place for most, if not all, eventualities.
multifocal disease	Occurring in more than one location in an organ of the body, eg the breast.
named cancer nurse	Name of nurse, eg Staff Nurse Smith, ward 7/ Macmillan cancer nurse.

named lead consultant	Named clinician with administrative responsibilities for a specific service, who is thus identified as the lead member of a team caring for a patient.
negative nodes	Lymph nodes showing no signs of cancer.
neoadjuvant chemotherapy	Chemotherapy that is given before the treatment of a primary tumour with the aim of improving the results of surgery or chemotherapy and preventing the development of metastases.
NHS Board	NHS Boards replaced the separate board structures of Health Boards and NHS Trusts. The NHS Boards cover the same geographical area as the old Health Boards. The overall purpose of unified NHS Boards is to ensure the efficient, effective and accountable governance of the local NHS system and to provide strategic leadership and direction for the system as a whole, focusing on agreed outcomes.
NHS priorities	The three national clinical priorities are mental health; coronary heart disease and stroke; and cancer.
NHSScotland	The National Health Service in Scotland.
nodal status	The presence or absence of cancer in lymph nodes draining the area where the primary tumour is found.
non-invasive	In situ cancer that does not spread outside the polyp or colon lining.
nurse	A person who is specially trained to provide services that are essential to or helpful in the promotion, treatment, maintenance, and restoration of health and well being.
oncologist	A doctor who specialises in the treatment of cancer patients. A clinical oncologist, or radiotherapist, specialises in treating cancer with radiation or drugs, and a medical oncologist specialises in treating cancer with drugs.
oncology	The study of the biology and physical and chemical features of cancers. Also the study of the cause and treatment of cancers.
out-of-hours	Between 5pm – 9am Monday to Friday and also weekends (not between 9am – 5pm Monday to Friday).

outcome	The end result of care and treatment and/or rehabilitation. In other words, the change in health, functional ability, symptoms or situation of a person, which can be used to measure the effectiveness of care and treatment, and/or rehabilitation.
out-of-hours co-operative	Arrangement where a group of general practitioners in an area cover for each other out of normal working hours by taking part in an extended rota.
out-patient	A patient reviewed in a hospital but who does not need to be admitted to the hospital.
palliative care	Palliative care is the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment.
PAM	See professions allied to medicine.
pathologic diagnosis	A histological diagnosis, the microscopic assessment of the tumour.
pathological	Relating to or arising from disease.
pathologist	Doctor who identifies diseases by studying cells and tissues under a microscope.
pathology	The study of disease processes with the aim of understanding their nature and causes. This is achieved by observing samples of blood, urine, faeces, and diseased tissue obtained from the living patient or at autopsy, by the use of X-rays, and by many other techniques.
patient	A person who is receiving care or medical treatment (especially in a hospital). A person who is registered with a doctor, dentist, or other healthcare professional, and is treated by him/her when necessary. Sometimes referred to as a user.
patient journey	The pathway through the healthcare system taken by the patient (the person who is receiving treatment), and as viewed by the patient.
PCI	Prophylactic Cranial Irradiation – literally means preventative radiotherapy to the head. With some types of cancer that can spread to the brain, doctors like to give a short course of radiotherapy to the brain. The idea of this is that it kills off any microscopic spread that may already be there.

PCRG	See Primary Care Reference Group.
PCT	Primary Care Trust. See Trust and Primary Care.
peer review	Review of a service by those with expertise and experience in that service, either as a provider, user or carer. In the CSBS method all members of a review team are equal.
peri	Prefix meaning near, around, or enclosing.
perioperative	Within 30 days of surgery.
pharmacist	A qualified professional who understands the nature and effect of medicines and how they may be produced and used to prevent and treat illness, relieve symptoms or assist in the diagnosis of disease. Pharmacists use their expertise for the well-being and safety of users and the public.
physician	A specialist in medicine.
policy	An operational statement of intent in a given situation.
polyp	Small outgrowth of tissue arising from the mucous membrane of the colon.
positive lymph nodes	Lymph nodes that contain cancer cells.
post	Prefix meaning following or after.
pre	Prefix meaning before or preceding.
prescription	Usually a written recipe of treatment.
primary care	The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS. Primary care encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.
Primary Care Reference Group	Established to help the CSBS ensure that the component of care delivered to patients outside hospitals is included in its standards, and to promote the accreditation of general practices. Abbreviated as PCRG.
primary tumour	Original site of the cancer; the first.

procedure	The steps taken to fulfil a policy.
professions allied to medicine	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dieticians, etc. Abbreviated as PAM.
prognosis	An assessment of the expected future course and outcome of a person's disease.
prophylaxis	The prevention of disease; preventive treatment. Intervention to prevent an unwanted outcome.
protocol	A policy or strategy which defines appropriate action. Also covers the adoption, by all staff, of national or local guidelines to meet local requirements in a specified way, resulting in what are known as local protocols.
QA	See quality assurance.
qualitative information	Qualitative data can include personal evidence or statements, samples of documentation or other output, video or sound recordings, objects, and is typically non-numerical.
quality assurance	Improving performance and preventing problems through planned and systematic activities including documentation, training and review. Abbreviated as QA.
Quality Assurance Manual	CSBS document outlining the methods and procedures to be used in setting standards and reviewing services.
quality of life	The overall appraisal of an individual's situation and subjective sense of well-being.
quantitative information	Quantitative information is data presented in numerical form.
radiation	Radiation is energy in the form of waves or particles. See radiation therapy.
radiation therapy	Treatment with high-energy rays from X-rays or other sources to kill or slow cancer cells; can also reduce pain from cancer spread to bone by killing tumour at this site.
radiology	The use of X-rays in the diagnosis, treatment and monitoring of disease.

radiotherapy	The use of radiation, usually X-rays or gamma rays, to kill tumour cells.
randomised	Randomly allocated to one of more than one different choices.
rationale	Scientific/objective reason for taking specific action.
RCGP	Royal College of General Practitioners.
RCN	Royal College of Nursing.
rectum	Area at the end of the colon where faecal matter is stored until it is eliminated.
recurrence	Recurrence is when new cancer cells are detected at the site of the original tumour, following treatment.
referral	The process whereby a patient is transferred from one professional to another, usually for specialist advice.
regime	Treatment programme, eg for drugs, also known as a regimen.
regional oncology centre	A centre providing area-wide cancer services.
resection	Surgical removal of a portion of any part of the body. For example, a section of diseased intestine may be removed and the healthy ends sewn together.
risk factor	A clearly defined occurrence or characteristic that has been associated with the increased rate of a subsequently occurring disease or health problem. Risk factors include aspects of personal behaviour, lifestyle, environmental exposure, or inborn or inherited characteristics, which are known to be associated with the disease.
risk factor stratification	Assessing and grading of risk factors relevant to a patient. See risk factor.
Scottish Executive Health Department	The Scottish Executive Health Department is responsible for health policy and the administration of the National Health Service in Scotland. Abbreviated as SEHD.

Scottish Intercollegiate Guidelines Network	SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland, to sponsor and support the development of evidence-based clinical guidelines for NHSScotland. Where a SIGN guideline exists for a specialty or service for which CSBS is setting standards, it will be referenced. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Secretariat, Royal College of Physicians, 9 Queen Street, Edinburgh EH2 1JQ. Abbreviated as SIGN. Website address: www.sign.ac.uk/
SCTN	Scottish Cancer Therapy Network.
secondary care	Care provided in an acute sector setting. See acute sector.
section	In surgery this is the act of cutting (the cut or division made is also called a section).
SEHD	Scottish Executive Health Department.
self-assessment	Assessment of performance against standards by individual clinical teams and/or Trusts providing the service to which the standards are related.
sentinel lymph node	The sentinel lymph node is the lymph node near a body organ or part of an organ which is thought to be the first that the tissue fluid draining from that organ reaches. So, if there is a cancer in the organ, this lymph node may be the one most likely to contain cancer cells if the cancer has begun to spread. Different techniques for evaluating the sentinel lymph node are currently being assessed.
sigmoidoscopy	Examination of the rectum and sigmoid colon with a sigmoidoscope (an instrument inserted through the anus in order to inspect the interior of the rectum and sigmoid colon). It is used to investigate diarrhoea or rectal bleeding, particularly to detect colitis or cancer of the rectum.
SIGN	See Scottish Intercollegiate Guidelines Network.
SIGN guideline	Scottish Intercollegiate Guidelines Network guideline.
social work	Social work services provide advice and practical help for problems resulting from social circumstances. A social worker is a person who has obtained a professional qualification in social work. A social worker supports vulnerable people and their carers with the aim of enhancing the quality of all aspects of their daily lives.

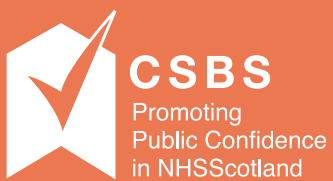
specialist	Person who is an expert in the subject.
staging	Process of describing whether cancer has spread from its original site to another part of the body. Staging involves clinical, surgical and pathology assessments.
standard statement	An overall statement of desired performance.
statutory	Enacted by statute; depending on statute for its authority as a statutory provision. Required by law.
stoma	A surgically created opening into the body from the outside. A stoma, in which the bowel is taken to the outer surface of the abdomen, is invariably necessary when the anal canal is removed and may sometimes be necessary after other surgical interventions for colorectal cancer.
stoma therapist	Healthcare specialist trained to help patients care for, and adjust to, colostomy.
symptom	A reported feeling or observable physical sign of a person's condition that indicates a physical or mental abnormality.
syringe driver	A means of administering pain-killing or chemotherapy drugs under the skin which relieves patients of the need for frequent injections.
systematic	Methodical, according to plan and not casually or at random.
systemic	Involving the whole body.
systemic therapy	Treatment that goes through the system, usually via the blood, and reaches and affects cells all over the body.
team leader	Senior clinician who leads a CSBS review team during its Trust and Island NHS Board visits and plays a key role in drawing together the assessments of all team members.
tertiary centre	A major medical centre providing complex treatments, which receives referrals from both primary and secondary care. Sometimes called a tertiary referral centre.
therapy	A word often used to mean treatment.
TNM classification	TNM classification provides a system for staging the extent of cancer. T refers to the size of the primary tumour. N refers to the involvement of the lymph nodes. M refers to the presence of metastases or distant spread of the disease. See staging.

TNM staging	Tumour, Node, Metastasis. A descriptive method of assessing the spread of cancer. Staging of breast cancer is based on the TNM classification which classifies the size, site and spread of the disease. Therapeutic decisions are formulated in part according to staging. The numbers 1, 2, 3, and 4 are used to denote the stages and each number refers to a possible combination of TNM factors. For example: a Stage 1 breast cancer is defined by the TMN group: T1, N0, M0 which means: T1 – Tumour is 2cm or less in diameter, N0 – No regional lymph node metastasis, M0 – No distant metastasis.
total mesorectal excision (TME)	A technique for surgical removal of rectal cancer which involves meticulous dissection and excision of tissue surrounding the rectum.
treatment plan	Protocol of care which specifies what should be done, when and with what aim.
triple assessment	Clinical, pathological, and radiological assessment.
Trust	A Trust is an NHS organisation responsible for providing a group of healthcare services for the local population. An Acute Hospital Trust provides hospital services. A Primary Care Trust delivers primary care/community health services. Mental health services (both hospital and community based) are now usually provided by Primary Care Trusts.
tumour	A lump or mass of cells which can be either benign or malignant. Also known as a neoplasm.
ultrasound	Test that bounces sound waves off tissues and converts the echoes into pictures.
unified Board	See NHS Board.
WHO	World Health Organisation. A United Nations agency dealing with issues concerning health and disease around the globe.
WTE	Whole Time Equivalent.
X-ray	An imaging technique that uses energy beams of very short wavelengths that can penetrate most substances except heavy metals. This is the most common form of imaging technique used in clinical practice everywhere in the world, with the image captured on photographic film.

Our Commitment

The Board will:

- involve NHS staff, patients and the public in all parts of its work;
- work with and support NHS staff in improving standards;
- assist NHSScotland in delivering the highest quality of NHS care to each patient;
- base its conclusions and recommendations on the best evidence available;
- be open and transparent in all its work through wide circulation of reports written in language that can be understood by all and is jargon free;
- seek to avoid duplication of effort through working closely with other national organisations involved in improving the quality of care within the NHS;
- ensure that its own work is subject to quality assurance and evaluation.



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