



**Clinical Standards ~ March 2008**

**Management of bowel cancer services**

NHS Quality Improvement Scotland is committed to equality and diversity. We have assessed this area of work for likely impact on the six equality groups defined by age, disability, gender, race, religion/belief and sexual orientation. An equality and diversity impact assessment report has been published along with these standards and is available online or in hardcopy upon request.

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First published March 2008

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## Contents

<b>1</b>	<b>Introduction</b>	<b>2</b>
<b>2</b>	<b>Development of the clinical standards for management of bowel cancer services</b>	<b>3</b>
<b>3</b>	<b>Clinical standards for management of bowel cancer services</b>	<b>5</b>
	Standard 1 Referral process	6
	Standard 2 Multidisciplinary working	7
	Standard 3 Audit	10
	Standard 4 Waiting times	11
	Standard 5 Preoperative preparations/investigations	13
	Standard 6 Therapeutic management	20
	Standard 7 Postoperative management	22
	Standard 8 Outcomes	25
<b>4</b>	<b>References</b>	<b>27</b>
<b>5</b>	<b>Appendices</b>	<b>31</b>
	Appendix 1 About NHS Quality Improvement Scotland	32
	Appendix 2 NHS Quality Improvement Scotland standards development methodology	33
	Appendix 3 Membership of the clinical standards for management of bowel cancer services working group	35
	Appendix 4 Glossary	36

## 1 Introduction

Cancer services are provided by a wide range of individuals and organisations (statutory and voluntary), throughout Scotland: from primary care, through secondary care and tertiary hospitals, regional centres such as the Beatson Oncology Centre, Glasgow and local hospices/specialist palliative care units. Cancer treatment and care are highly dependent on other core NHS services, such as diagnostics and imaging, and, therefore, cannot be planned or managed in isolation. The role and importance of others in the delivery of cancer care and the provision of cancer services should also be noted, for example community pharmacists and dentists.

In July 2001, the then Scottish Executive Health Department (SEHD), now the Scottish Government Health Directorates (SGHD), published its cancer strategy, *Cancer in Scotland: Action for Change*<sup>1</sup>. This document sets the context in which NHSScotland should plan activity to improve the services for people across Scotland. The commitment of the then SEHD to tackle cancer in Scotland was emphasised by the new resources that accompanied the cancer strategy, and were allocated specifically to improve cancer services. These funds were distributed through Regional Cancer Advisory Groups (RCAGs), supported by Regional Cancer Networks. Each Regional Cancer Network reports to the Scottish Cancer Group (SCG) via its RCAG.

### Objective

In May 2004, *Cancer in Scotland: Sustaining Change*<sup>2</sup> was published by the SEHD to highlight progress made since the original strategy was published in 2001, and to identify new challenges facing the service. To support NHSScotland in the continuous improvement of cancer services, NHS Quality Improvement Scotland (NHS QIS) agreed to revise and update the four tumour specific cancer standards: breast, colorectal (bowel), lung and gynaecological (ovarian) cancer, first developed in 2001.

## **2 Development of the clinical standards for management of bowel cancer services**

In 2001, the Clinical Standards Board for Scotland (CSBS, one of the organisations drawn together to form NHS QIS) produced standards for breast, colorectal, gynaecological (ovarian) and lung cancer. Peer review visits, to assess performance against the four cancer standards, were carried out throughout Scotland during 2001. Findings from these reviews were published by CSBS in 2002, in the form of local NHS board reports and a national overview.

The standards for core cancer services draw together common elements of service provision covered by the original standards, and these have been developed in light of developments in the service. Subsequently, revisions of the four original tumour specific cancer standards began later in 2006, with the clinical standards for bowel cancer services forming part of this work.

The revision of clinical standards for management of bowel cancer services has been the responsibility of NHS QIS, taking into account advice from SGHD and in consultation with NHS organisations.

Under the direction of the core cancer services working group established by NHS QIS, a clinical adviser was appointed to oversee the revision of the bowel cancer standards. A small working group was then convened to re-examine the evidence base on which the 2001 bowel cancer standards were developed, and to revise the standards in light of changes in current best practice and clinical advancements.

### **Evidence base**

During the revision of the clinical standards for management of bowel cancer services, the working group considered a wide range of evidence, which is fully referenced in Chapter 4 (References).

The following standards and national overview formed the core evidence reviewed by the project group.

- **Clinical standards: colorectal cancer**<sup>3</sup>
- **Local reports: colorectal cancer services**<sup>4</sup>
- **National overview: colorectal cancer services**<sup>5</sup>
- **National Standards: Clinical Governance and Risk Management: Achieving Safe, Effective, Patient-Focused Care and Services**<sup>6</sup>
- **Draft core standards for cancer services**<sup>7</sup>

**Relevance to standards development:** A review of these documents determined the scope of the clinical standards, to establish equity of care and the best possible condition management for patients, no matter where they live. The group considered how these standards should be applied at an operational level, and ensured that duplication would not occur across the above standards.

- **NHS HDL (2007) 21: Strengthening the role of managed clinical networks**<sup>8</sup>
- **Quality assurance frameworks for north of Scotland cancer network (NOSCAN)<sup>9</sup>, south east Scotland cancer network (SCAN)<sup>10</sup> and west of Scotland cancer network (WOSCAN)<sup>11</sup>**

**Relevance to standards development:** The frameworks provide quality assurance measures for all staff involved in the delivery of care in cancer services and are tailored on a regional basis. The frameworks for the three regional cancer networks were reviewed to prevent duplication within the standards.

- **Cancer Scenarios: An aid to planning cancer services in Scotland in the next decade**<sup>12</sup>
- **Cancer in Scotland: Action for Change**<sup>1</sup>
- **Cancer in Scotland: Sustaining Change**<sup>2</sup>
- **Cancer waiting times: National delivery plan**<sup>13</sup>

**Relevance to standards development:** These documents guide operating divisions and clinicians to implement the measures necessary to improve cancer services. Awareness of the recognised processes across NHSScotland is important when developing standards. These documents helped the working group to develop a practical tool for supporting continuous quality improvement, taking into account how services are delivered and monitored. Further guidance to support the introduction of Cancer in Scotland: Action for Change is available in two Health Department Letters, HDL(2001)54<sup>14</sup> and HDL(2001)71<sup>15</sup>.

### **Standards development**

To take forward the revision of the standards, NHS QIS appointed a working group to review the evidence and use it to inform the revision of the clinical standards. The group was chaired by Professor Bob Steele, Professor of Surgical Oncology, NHS Tayside. Full membership of the group can be found in Appendix 3.

### **Consultation**

Following publication of the Draft Clinical Standards for Management of Bowel Cancer<sup>16</sup> in September 2007, consultation was undertaken. During this period professional groups, health service staff, voluntary organisations and individuals were given the opportunity to influence the development of the standards.

### **Finalising the standards**

Following consultation each written comment and all feedback on the draft standards were used by the working group to produce final standards.

### **3 Clinical standards for management of bowel cancer services**

**Standard 1 Referral process**

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**Standard 2 Multidisciplinary working**

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**Standard 3 Audit**

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**Standard 4 Waiting times**

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**Standard 5 Preoperative preparations/investigations**

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**Standard 6 Therapeutic management**

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**Standard 7 Postoperative management**

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**Standard 8 Outcomes**

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## Standard 1: Referral process

### Standard Statement 1a

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

#### Rationale

Prompt referral from general practitioner (GP) or hospital doctor to a bowel cancer specialist is indicated where bowel cancer is suspected.

References: 17, 18, 19, 20

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#### Essential Criteria

- 1a.1 Formal arrangements jointly agreed between GPs and specialists working within the multidisciplinary team (MDT) for the referral of patients with suspected bowel cancer are in place. These specify which patients are to be referred and to whom.
- 1a.2 Formal arrangements jointly agreed between hospital departments and specialists working within the MDT for the referral of patients with suspected bowel cancer are in place. These specify which patients are to be referred and to whom.

## Standard 2: Multidisciplinary working

### Standard Statement 2a

All patients with bowel cancer are offered access to a cancer clinical nurse specialist.

#### Rationale

Cancer clinical nurse specialists are an integral part of the MDT and work in partnership with patients and carers to plan, deliver and evaluate individualised care focused on facilitating health and enhancing wellbeing.

Reference: 20

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#### Essential Criteria

- 2a.1 All patients have access to a cancer clinical nurse specialist (CNS).
- 2a.2 There are locally agreed standards of care covering all aspects of cancer nursing practice.
- 2a.3 Arrangements are in place to ensure that cover is available for the CNS in their absence.

#### Desirable Criterion

- 2a.4 All patients have access to a cancer clinical nurse with expertise in bowel cancer.

## Standard 2: Multidisciplinary working

### Standard Statement 2b

The management of patients with bowel cancer is multidisciplinary.

#### Rationale

Patients with cancer have complex needs, which cannot be addressed by a single specialty.

References: 8, 17, 20

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#### Essential Criteria

- 2b.1 There is a named lead consultant for bowel cancer services within each provider unit, with responsibility for co-ordinating a multidisciplinary system of working.
- 2b.2 For each provider unit there is local agreement and awareness of the membership of the bowel cancer MDT. The minimum membership of the team for bowel cancer is:
- audit representative
  - cancer clinical nurse specialist
  - clerical support
  - colorectal surgeon
  - designated co-ordinator
  - oncologist
  - pathologist, and
  - radiologist.
- With access to:
- a clinical nurse specialist with expertise in stoma care
  - a colonoscopist who can be co-opted when necessary, and
  - palliative care services.
- 2b.3 The working and decision-making process of the MDT is documented.
- 2b.4 There is a weekly MDT meeting at which all patients are discussed.
- 2b.5 All patients for rectal cancer resection are reviewed at the MDT meeting preoperatively, unless clinical circumstances dictate otherwise.

#### Desirable Criteria

- 2b.6 There is a named lead consultant working within the regional managed clinical network (MCN) for bowel cancer.

### 3 *Clinical standards*

- 2b.7 There is evidence of specialisation in bowel cancer within oncology, pathology, radiology and surgical services.
- 2b.8 There is evidence of specialisation in rectal cancer within surgical services.
- 2b.9 There are systems in place to ensure cover is provided for every discipline at the MDT weekly meeting to enable continuity of care for all patients.

## **Standard 3: Audit**

### **Standard Statement 3a**

Prospective clinical audit of bowel cancer services is carried out using nationally agreed datasets.

#### **Rationale**

Clinical audit is a continuing process that helps to identify clinically important variations in practice and encourages examination of the reasons for these. It identifies the changes required to effect improvements. It is, therefore, integral to the process of implementing guidelines and standards.

References: 21, 22

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#### **Essential Criteria**

- 3a.1 There is a system in place for the continuous collection of the nationally agreed bowel cancer core datasets, to facilitate audit. This data is submitted to MCNs for comparative audit reporting and feedback.
- 3a.2 There is annual reporting of case-mix and outcome including 1, 2, and 5-year survival rate.
- 3a.3 There is a minimum of 90% case ascertainment against cancer registry data.

## Standard 4: Waiting times

### Standard Statement 4a

The time between urgent referral and first treatment is not more than 62 days.

#### Rationale

This is a measure of the system's ability to supply timely care.

References: 19, 23

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#### Essential Criteria

- 4a.1 In at least 95% of patients, and in accordance with SGHD guidelines, the maximum wait from urgent referral to treatment is 62 days.
- 4a.2 In a minimum of 95% of patients, the maximum wait from notification of a positive screening test to treatment is 62 days.
- 4a.3 In accordance with SGHD guidelines, there is a protocol in place to record the reason why waiting time targets are not met.

#### Desirable Criterion

- 4a.4 All patients with bowel cancer receive equitable treatment and are treated within 62 days, from referral to first treatment, regardless of urgency of referral.

## **Standard 4: Waiting times**

### **Standard Statement 4b**

The time between surgery and start of adjuvant chemotherapy is minimised.

#### **Rationale**

There is evidence that adjuvant chemotherapy increases cure rates for patients with high-risk (stage III) bowel cancer.

References: 24, 25, 26

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#### **Essential Criterion**

- 4b.1 In a minimum of 95% of patients who receive adjuvant chemotherapy, the time between surgery and start of adjuvant chemotherapy is not more than 56 days.

## Standard 5: Preoperative preparations/investigations

### Standard Statement 5a

Assessment procedures are in place for all patients with rectal cancer being considered for elective treatment.

#### Rationale

Rectal examination and cross-sectional imaging is necessary to assess operability and need for preoperative radiotherapy.

References: 20, 27, 28, 29, 30

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#### Essential Criterion

- 5a.1 Patients being considered for elective treatment are assessed by digital rectal examination (DRE) and either computed tomography (CT) scanning or magnetic resonance imaging (MRI) scanning of the primary tumour.

#### Desirable Criteria

- 5a.2 MRI is used for the local staging of the tumour.
- 5a.3 Trans-rectal ultrasound (TRUS) is available for the assessment of early stage disease.

## **Standard 5: Preoperative preparations/investigations**

### **Standard Statement 5b**

The rectum and whole colon is visualised perioperatively in patients undergoing treatment with curative intent.

#### **Rationale**

These investigations are undertaken to avoid missing synchronous tumours and to remove synchronous adenomas.

Reference: 20

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#### **Essential Criterion**

- 5b.1 The rectum and whole colon is visualised by colonoscopy or CT colonography preoperatively (or when this is not possible because of the nature of the tumour, within 12 months of resection) in 95% of patients undergoing treatment with curative intent.

### **Standard Statement 5c**

Perioperative tumour staging is performed with appropriate imaging in all patients undergoing surgery for bowel cancer.

#### **Rationale**

Accurate staging is necessary to detect metastatic disease, guide treatment and avoid inappropriate surgery.

Reference: 31

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#### **Essential Criterion**

- 5c.1 A CT scan of the chest, abdomen and pelvis is performed preoperatively (or postoperatively where preoperative scanning is not possible because of emergency presentation) in 90% of patients undergoing surgery for bowel cancer.

## **Standard 5: Preoperative preparations/investigations**

### **Standard Statement 5d**

Arrangements are in place to facilitate the effective assessment of all patients who require stoma care.

#### **Rationale**

Access to a clinical nurse specialist with expertise in stoma care increases patient satisfaction and optimal independent functioning.

Reference: 20

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#### **Essential Criteria**

- 5d.1 All elective patients who require a stoma are assessed preoperatively by a CNS with expertise in stoma care.
- 5d.2 All elective patients have their stoma site marked preoperatively.

#### **Desirable Criterion**

- 5d.3 Emergency patients who require a stoma are assessed preoperatively by a healthcare professional with expertise in stoma siting.

**Standard Statement 5e**

Patients have preoperative DVT prophylaxis and antibiotic prophylaxis unless contra-indicated.

**Rationale**

Preoperative preparation is necessary to minimise complications.

Reference: 20

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**Essential Criteria**

- 5e.1 All patients receive DVT prophylaxis.
- 5e.2 All patients receive antibiotic prophylaxis.

## **Standard 5: Preoperative preparations/investigations**

### **Standard Statement 5f**

There is access to stenting facilities for the palliation of obstructing bowel cancer.

#### **Rationale**

There is evidence to show that stenting is an effective minimally invasive technique for relieving large bowel obstruction.

Reference: 20

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#### **Essential Criterion**

5f.1 There are facilities in place to allow the stenting of obstructing bowel cancers.

### **Standard Statement 5g**

Bowel cancer genetic counselling is available.

#### **Rationale**

There is evidence to show that a proportion of bowel cancers are genetically determined.

Reference: 20

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#### **Essential Criteria**

- 5g.1 Patients with a family history of bowel cancer and individuals with a family history of bowel cancer have access to a clinical genetics service that can estimate the genetic risk of bowel cancer and recommend surveillance strategies.
- 5g.2 A family history is taken from all patients with bowel cancer.

## Standard 6: Therapeutic management

### Standard Statement 6a

Within the MDT, all patients are considered for adjuvant or palliative chemotherapy/radiotherapy. In addition, patients with metastatic disease are considered for surgical treatment.

#### Rationale

Patients with rectal tumours that involve or threaten the mesorectal fascia on preoperative imaging may benefit from preoperative radiotherapy (with or without concurrent chemotherapy), and those with involved circumferential margins (CRM) postoperatively should have pelvic radiotherapy (usually with concurrent chemotherapy) if preoperative treatment has not been given.

Those with node positive tumours and/or T4 disease who are physically and psychosocially fit may benefit from adjuvant chemotherapy.

There is evidence that chemotherapy for metastatic bowel cancer will improve survival and quality of life, and palliative radiotherapy may also improve symptoms. In addition, there is evidence that surgical treatment of metastatic liver or lung disease may prolong survival in appropriately selected patients.

Reference: 20

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#### Essential Criteria

- 6a.1 All rectal cancer patients with a tumour or lymph node(s) threatening or involving the CRM on preoperative imaging receive preoperative radiotherapy (with or without concurrent chemotherapy).
- 6a.2 All patients with histologically involved CRM, after resection for rectal cancer, receive postoperative radiotherapy (with or without concurrent chemotherapy) unless there is a documented contra-indication.
- 6a.3 Patients with liver or lung metastases are considered for surgical treatment (including ablative) of their metastases.
- 6a.4 The reason why patients with node positive tumours and/or T4 disease do not receive adjuvant therapy is recorded.
- 6a.5 Patients with inoperable disease are considered for palliative treatment.

### **Standard Statement 6b**

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

#### **Rationale**

This is a measure of the quality of both preoperative assessment and resection.

Reference: 20

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#### **Essential Criteria**

- 6b.1 All distal resection margins are free of tumour.
- 6b.2 Inpatients undergoing primary resection (ie without preoperative radiotherapy or chemoradiation) for rectal cancer, a minimum of 90% of CRM are free of tumour.

## **Standard 7: Postoperative management**

### **Standard Statement 7a**

Arrangements are in place for all patients undergoing bowel cancer surgery to access appropriate postoperative services.

#### **Rationale**

Patients undergoing bowel cancer surgery often benefit from a High Dependency Unit (HDU) and may require admission to an Intensive Therapy Unit (ITU).

Patients requiring a stoma benefit from professional support.

Reference: 32

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#### **Essential Criteria**

- 7a.1 All provider units have access to a High Dependency Unit (HDU).
- 7a.2 All provider units have access to an Intensive Therapy Unit (ITU).
- 7a.3 All elective patients who require a stoma are assessed postoperatively by a CNS with expertise in stoma care.

### **Standard Statement 7b**

All pathology reports on bowel cancer resection specimens are constructed in a format clearly corresponding to the relevant national dataset (RCPath, NCDDP) with easily identifiable data items.

#### **Rationale**

This is essential to allow meaningful case-mix analysis, treatment planning and quality assurance.

References: 20, 33

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#### **Essential Criteria**

- 7b.1 Pathology reports on resection specimens (as produced on the laboratory information system) are in the form of a list of macroscopic and microscopic data items in accordance with nationally agreed core datasets and guidelines.
- 7b.2 The mean number of lymph nodes examined for resection specimens is at least 12.

#### **Desirable Criterion**

- 7b.3 Pathology reporting permits individual data items to be electronically recorded and searchable.

## **Standard 7: Postoperative management**

### **Standard Statement 7c**

Anastomotic dehiscence (which is of clinical significance) after bowel cancer surgery is within acceptable limits.

#### **Rationale**

Anastomotic dehiscence is a major cause of morbidity and a measure of the quality of surgical care.

Reference: 20

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#### **Essential Criteria**

- 7c.1 Anastomotic dehiscence is not more than 5% after colonic anastomosis.
- 7c.2 Anastomotic dehiscence is not more than 10% after rectal anastomosis.
- 7c.3 Anastomotic dehiscence is not more than 20% after anterior resection with total mesorectal excision.

## **Standard 8: Outcomes**

### **Standard Statement 8a**

Operative mortality for bowel cancer surgery and mortality resulting from chemotherapy and radiotherapy is within acceptable limits.

#### **Rationale**

Treatment-related mortality is a marker of the quality of the whole service provided by the MDT.

Reference: 20

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#### **Essential Criterion**

8a.1 Treatment-related mortality is not more than 5%.

## **Standard 8: Outcomes**

### **Standard Statement 8b**

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

#### **Rationale**

Permanent stoma rate can be used as a guide to the quality of cancer surgery.

Reference: 20

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#### **Essential Criterion**

8b.1 Permanent stoma rate is not more than 40% in patients with rectal tumours.

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## **5 Appendices**

**Appendix 1 About NHS Quality Improvement Scotland**

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**Appendix 2 NHS Quality Improvement Scotland standards development methodology**

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**Appendix 3 Membership of the clinical standards for management of bowel cancer working group**

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**Appendix 4 Glossary**

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## Appendix 1: About NHS Quality Improvement Scotland

NHS Quality Improvement Scotland (NHS QIS) was set up by the Scottish Parliament in 2003 to take the lead in improving the quality of care and treatment delivered by NHSScotland.

We achieve our objectives through five key functions that link together:

- providing clear advice and guidance on effective clinical practice
- setting clinical and non-clinical standards of care
- reviewing and monitoring the performance of NHS services
- supporting NHS staff in improving services, and
- promoting patient safety and implementation of clinical governance.

We deliver our commitments to the public and to NHSScotland by following an approach that is:

- **independent** – we reach our own conclusions and report on what we find
- **open and transparent** – we explain what we do, how and why we do it, and what we find, using language and formats that are easy to understand and to access
- **sensitive and professional** – we recognise needs, beliefs and opinions and respect and encourage diversity.

Our work is:

- **partnership-focused** – we work with patients and the public, NHSScotland and many organisations to improve the quality of care and avoid duplication
- **evidence-based** – we base our conclusions and recommendations on the best evidence available as indicated in Chapter 2 (Development of the clinical standards for management of bowel cancer services : evidence base).
- **quality-driven** – we make sure our own work is monitored and evaluated, internally and externally.

## Appendix 2: NHS Quality Improvement Scotland standards development methodology

### Basic principles

A major part of our remit is to develop and run a national system of quality assurance of clinical services. Working in partnership with healthcare professionals and members of the public, we set standards for clinical services, assess performance throughout NHSScotland against these standards, and publish the findings. The standards are based on the patient's journey as he or she moves through different parts of the health service. A wide range of conditions and services have already been addressed, including asthma services for children and young people and bowel screening programme.

In fulfilling our responsibility to develop and run a system of quality assurance, we take account of the principles set out in Fair for All<sup>34</sup> and Partnership for Care<sup>35</sup>, to ensure that 'our health services recognise and respond sensitively to the individual needs, background and circumstances of people's lives'.

We will ensure that consideration of equality and diversity issues feature prominently in the design, development and delivery of all our functions and policies.

The standards are developed in accordance with the commitments of the National Health Service Reform (Scotland) Act 2004<sup>36</sup> which state that 'individual patients receive the service they need in the way most appropriate to their personal circumstances and all policy and service developments are shown not to disadvantage any of the people they serve'.

### Process

For each set of standards we develop, we appoint a group representing a range of stakeholders, including healthcare professionals and members of the public, to:

- oversee the development of, and consultation on, the standards and self-assessment framework, and
- recommend an external peer review process.

The way in which standards are developed is a key element of the quality assurance process. Project groups working on our behalf are expected to:

- adopt an open and inclusive process involving members of the public, voluntary organisations and healthcare professionals
- work within NHS QIS policies and procedures, and
- test the measurability of draft standards by undertaking pilot reviews.

The standards are clear and measurable, based on appropriate evidence, and written to take into account other recognised standards and clinical guidelines. The standards are:

- written in simple language and available in a variety of formats
- focused on clinical issues and include non-clinical factors that impact on the quality of care
- developed by healthcare professionals and members of the public, and consulted on widely
- regularly reviewed and revised to make sure they remain relevant and up to date, and
- achievable but stretching.

### Format of standards and definition of terminology

All our standards follow the same format.

- Each standard has a **title**, which summarises the area on which that standard focuses.
- This is followed by the **standard statement**, which explains the level of performance to be achieved.
- The **rationale** section provides the reasons why the standard is considered to be important.
- The standard statement is expanded in the section headed **criteria**, which states exactly what must be achieved for the standard to be reached. Criteria are **essential**, in that it is expected that they will be met wherever a service is provided. Other criteria are **desirable**, in that 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. The criteria are numbered for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority.

### Clinical governance and risk management standards

Every patient using healthcare services should expect these to be safe and effective. The NHS QIS standards for clinical governance and risk management<sup>6</sup> will ensure NHS boards can provide assurance that clinical governance and risk management arrangements are in place, and are supporting the delivery of safe, effective, patient-focused care and services.

These standards underpin all care and services delivered by NHSScotland and provide the context within which NHS QIS service and condition-specific standards apply. They should be read in conjunction with all our standards.

The clinical governance and risk management standards are available on request from NHS QIS or can be downloaded from the website ([www.nhshealthquality.org](http://www.nhshealthquality.org)).

### Assessment of performance against the standards

The framework for the NHS QIS review process is as follows.

- Once the current cancer standards have been finalised, these will link into the accreditation of regional managed clinical networks for cancer.
- With the need for a cohesive and comprehensive approach to continual improvement based on these standards, the subsequent measurement, and assessment and reporting of the standards from a local, regional and nationwide perspective will be adopted, with support provided by Information Services Division, NHS National Services Scotland.
- Ongoing monitoring of the standards will be a function of the networks with NHS QIS intervening if there were concerns regarding data. Occasional visits may be undertaken by NHS QIS on a regional basis to test the system.

Our processes are subject to internal and external evaluation, to help improve the quality assurance system.

### Revision of the standards

NHS QIS standards are considered for revision and updating every 3 years. If a revision of a set of standards is undertaken the original standards will be withdrawn and the revised standards would be considered for further updating every 3 years thereafter. Please check the status of these standards with the Standards Development Unit if they are past the 3 years revision date.

### Appendix 3: Membership of the clinical standards for management of bowel cancer services working group

Name	Title	NHS board area/ organisation
Professor Bob Steele (Chair)	Professor of Surgical Oncology	NHS Tayside
Mr John Anderson	Consultant Colorectal Surgeon	NHS Greater Glasgow and Clyde
Professor Frank Carey	Clinical Leader in Pathology	NHS Tayside
Dr Paul Cormie	Macmillan Lead GP, Cancer and Palliative Care	NHS Borders
Mr Jim Docherty	Consultant Colorectal Surgeon	NHS Highland
Ms Gillian Knowles	Colorectal Cancer Clinical Nurse Specialist	NHS Lothian
Mrs Linnet McGeever	Lead Macmillan Colorectal Clinical Nurse Specialist	NHS Forth Valley
Mr John Milne	Lead Pharmacist, Oncology Services	NHS Lanarkshire
Ms Peigi Muir	South East Scotland Cancer Network (SCAN) Colorectal Audit Facilitator	NHS Lothian
Dr Leslie Samuel	Macmillan Consultant Oncologist	NHS Grampian
Mr Tim Searles	Chief Executive	Bowel Cancer Prevention Scotland
Dr Steven Yule	Consultant Radiologist	NHS Grampian

Support from NHS QIS was provided by the Standards Development Unit: Mrs Anne Coote (Project Administrator), Ms Hilary Davison (Head of Standards Development Unit), Ms Clare Echlin (Senior Project Officer) and Miss Ali McAllister (Project Officer).

## Appendix 4: Glossary

<b>abdomen</b>	The portion of the body which lies between the chest and the pelvis.
<b>ablative</b>	Taking away or removing.
<b>acute care</b>	Refers either to a pattern of healthcare in which a patient is treated for an acute (immediate and severe) episode of illness, or to the subsequent treatment of injuries related to an accident or other trauma, or care during recovery from surgery. Acute care is usually given in a hospital by specialised personnel using complex and sophisticated technical equipment and materials, and is often necessary for only a short time.
<b>adenoma</b>	An area of the lining of the bowel (mucosa) which is made up of abnormally growing cells. This process is benign but in a small number of cases it may lead to development of a cancer that can spread through the bowel and to other parts of the body.
<b>adjuvant chemotherapy</b>	The use of chemotherapy in addition to surgery and/or radiotherapy. The aim of adjuvant therapy is to destroy any cancer that has spread.
<b>anastomosis</b>	An artificial connection, created by surgery, between two tubular organs or parts, especially between two 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.
<b>anastomotic dehiscence</b>	Bursting open or splitting of the surgical connection between two sections of intestine.
<b>anterior resection</b>	Surgical removal of part of the rectum with a primary anastomosis formed. See anastomosis.
<b>antibiotic prophylaxis</b>	The administration of antibiotics to reduce the prospect of infection.
<b>ascites</b>	Accumulation of fluid in the abdominal cavity.
<b>audit</b>	The measuring and evaluation of care against best practice with a view to improving current practice and care delivery.
<b>bowel</b>	A tube-like structure which runs from the stomach to the anus. It allows digestion of food and the discharge of waste products.
<b>cancer</b>	The name given to a group of diseases that can occur in any organ of the body, and in blood, and which involve abnormal uncontrolled growth of cells.
<b>cancer centres</b>	Cancer services are based in cancer centres. Such centres provide the entire spectrum of cancer care - both on-site and to associated cancer units.
<b>cancer nurse specialist (CNS)</b>	Registered nurses with a high level of experience in cancer patient care. Most cancer nurse specialists are based in cancer treatment units and can offer specialist care and information about cancer and different treatment types, as well as advice and support to cancer patients and their families.
<b>case-mix</b>	Population of patients with different prognostic factors.
<b>chemotherapy</b>	The use of drugs that kill cancer cells, or prevent or slow their growth.
<b>circumferential margins (CRM)</b>	Margins of the tissue surrounding a cancer after it has been removed.

<b>clinical governance</b>	<p>Ensures that patients receive the highest quality of care possible, putting each patient at the centre of his or her care. This is achieved by making certain that those providing services work in an environment that supports them and places the safety and quality of care at the top of the organisation's agenda.</p> <p>Management of clinical risk at an organisational level is an important aspect of clinical governance. Clinical risk management recognises that risk can arise at many points in a patient's journey, and that aspects of how organisations are managed can systematically influence the degree of risk.</p>
<b>clinical nurse specialist</b>	A clinical nurse specialist is a registered nursing professional who has acquired additional knowledge, skills and experience, together with a professionally and/or academically accredited post-registration qualification (if available) in a clinical specialty. They practice at an advanced level and may have sole responsibility for a care episode or defined client/group.
<b>Clinical Standards Board for Scotland (CSBS)</b>	The Clinical Standards Board for Scotland was a statutory body, established as a Special Health Board in April 1999. Its role was to develop and run a system of quality control of clinical services designed to promote public confidence that the services provided by the NHS met nationally agreed standards, and to demonstrate that, within the resources available, the NHS was delivering the highest possible standards of care. On 1 January 2003, CSBS was merged, along with four other clinical effectiveness bodies, to form NHS Quality Improvement Scotland (NHS QIS).
<b>colon</b>	Part of the bowel. Also called the large intestine or large bowel. This structure has five major divisions: caecum, ascending colon, transverse colon, descending colon, and sigmoid colon. The colon is responsible for forming, storing and expelling waste matter into the rectum.
<b>colonic anastomosis</b>	A procedure in which a part of the colon is removed and the two remaining ends are rejoined.
<b>colonic stenting</b>	The insertion of a cylindrical, expandable metal mesh into a narrowed segment of bowel to relieve obstruction.
<b>colonoscopy</b>	Examination of the interior of the large 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 bowel.
<b>computed tomography (CT)</b>	An X-ray imaging technique used in diagnosis that can reveal many soft tissue structures not shown by conventional radiography. A computer is used to assimilate multiple X-ray images into a two-dimensional and/or three-dimensional cross-sectional image.
<b>contraindication</b>	Any factor in a patient's condition that makes it unwise to pursue a certain line of treatment. For example, an attack of pneumonia in a patient would be a strong contraindication to using a general anaesthetic.
<b>cross-sectional imaging</b>	The term used to cover different techniques (currently MRI, computed tomography and ultrasound) which produces cross-sectional images of the body. Modern equipment can also produce 3D images.
<b>curative</b>	Having properties which cure. Something which overcomes disease and promote recovery.

<b>dataset</b>	A list of required and specific information relating to a single disease.
<b>deep vein thrombosis (DVT) prophylaxis</b>	Measures taken to reduce the prospect of the formation of blood clots in the deep veins of the legs or pelvis after an operation.
<b>digital rectal examination (DRE)</b>	A digital examination of the lower rectum performed through the anal canal to detect palpable abnormalities in the lower rectum and anal canal. The doctor inserts a lubricated, gloved finger into the rectum and feels for abnormal areas.
<b>distal margins</b>	The distal end of the resected piece of bowel (ie end nearest the anus).
<b>elective</b>	Subject to the choice or decision of the patient or physician, applied to procedures that are advantageous to the patient, but not urgent.
<b>family history</b>	The medical history of immediate blood relatives (mother, father, grandparents and siblings).
<b>genetic counselling</b>	The process by which patients or relatives, at risk of an inherited disorder, are advised of the consequences and nature of the disorder, the probability of developing or transmitting it, and the options open to them in management and family planning in order to prevent, avoid or ameliorate it.
<b>Health Department Letter (HDL)</b>	A formal communication from the former Scottish Executive Health Department (SEHD) to NHSScotland, previously known as a Management Executive Letter – MEL.
<b>high dependency unit (HDU)</b>	An area of a hospital for patients who require more intensive observation and/or nursing than would be expected in a general ward.
<b>Information Services Division (ISD)</b>	Part of NHS National Services Scotland. Health service activity, manpower and finance data are collected, validated, interpreted and distributed by ISD. These data are received from NHS boards and general practices. Website address: <a href="http://www.isdscotland.org">www.isdscotland.org</a>
<b>intensive therapy unit (ITU)</b>	An area of a hospital to which patients are admitted for treatment of actual or impending organ failure that may require technological support.
<b>intraoperative</b>	Patient care procedures performed during the operation that are ancillary to the actual surgery. These include monitoring, fluid therapy, medication, transfusion, anaesthesia, radiography, and laboratory tests.
<b>large bowel obstruction</b>	Blockage of the large bowel preventing the passage of waste matter or gas. If untreated this can result in perforation of the bowel and probable death.
<b>lymph nodes or glands</b>	Small bean-shaped organs located along the lymphatic system. Nodes filter bacteria or cancer cells that are travelling through the body.
<b>macroscopic</b>	Large enough to be visible to the naked eye.
<b>magnetic resonance imaging (MRI)</b>	An imaging technique used to image the internal structures of the body. The technique uses a large magnet to excite and then monitor atoms within cells, and is particularly useful for detecting some cancers and monitoring their progress.
<b>managed clinical network (MCN)</b>	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.
<b>metastases</b>	The spread of tumour cells from one part of the body to another unrelated part of the body by the way of the bloodstream or lymphatics.

<b>morbidity</b>	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.
<b>mortality (rate)</b>	The number of deaths in a given population during a specified period of time.
<b>multidisciplinary</b>	An approach combining the knowledge, skills and expertise of a range of organisations and professionals.
<b>multidisciplinary team</b>	A multiprofessional 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.
<b>NCDDP</b>	National Clinical Dataset Development Programme. Website address: <a href="http://www.clinicaldatasets.scot.nhs.uk">www.clinicaldatasets.scot.nhs.uk</a>
<b>NHS board</b>	There are 21 NHS boards of two types: 14 territorial boards responsible for healthcare in their areas and seven special health boards which offer supporting services nationally.
<b>oncologist</b>	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.
<b>oncology</b>	The study of the biology and physical and chemical features of cancers. Also the study of the cause and treatment of cancers.
<b>outcome</b>	A measure of the effects, beneficial or adverse, which a person experiences as a result of the care, treatments or services they have received.
<b>palliative care</b>	Palliative care is the active total care of patients and their families by a multiprofessional team when the patient's disease is no longer responsive to curative treatment.
<b>palliative resection</b>	Removal of a portion of the bowel to relieve symptoms - but leaving visible disease in the patient.
<b>pathologist</b>	A qualified medical practitioner trained in the study of disease processes.
<b>pathology</b>	The study of disease processes with the aim of understanding their nature and causes. This is achieved by observing samples of fluid and tissues obtained from the living patient by a variety of techniques, or at post mortem.
<b>peer review</b>	Review of a service by those with expertise and experience in that service, either as a provider, user or carer, but who are not involved in its provision in the area under review. In the NHS QIS approach, all members of a review team are equal.
<b>performance status</b>	In medicine (oncology and other fields), performance status is an attempt to quantify cancer patients' general wellbeing. This measure is used to determine whether they can receive chemotherapy, whether dose adjustment is necessary, and as a measure for the required intensity of palliative care.
<b>perioperative</b>	The time period that is preoperative or intraoperative or no more than 30 days postoperative.
<b>permanent stoma</b>	A permanent opening of the bowel to the body surface created by surgery.

<b>positron emission tomography (PET)</b>	A specialized scintigraphic imaging technique now frequently combined with CT which demonstrates uptake of tracer in areas of high cell metabolism and can help differentiate between benign and malignant masses. It is most frequently used to help stage lung cancer by demonstrating or excluding distant metastases.
<b>postoperative</b>	After a surgical procedure.
<b>preoperative</b>	Before a surgical procedure.
<b>primary care</b>	The conventional first point of contact between a patient and the NHS. This is the care given to patients outside hospitals and is typically, though not always, delivered through general practices. Other providers include dentists, pharmacists, optometrists and ophthalmic medical practitioners. Primary care services are the most frequently used of all services provided by the NHS.
<b>primary tumour</b>	Original site of the cancer. The mass of tumour cells at the original site of abnormal tissue growth.
<b>prognosis</b>	An assessment of the expected future course and outcome of a person's disease.
<b>protocol</b>	Operational instructions which regulate and direct activity. Protocols may be national, or agreed locally to take into account local requirements.
<b>psychosocially</b>	Involving psychological and social characteristics.
<b>R0 (resection)</b>	Where the primary tumour is completely removed during resection.
<b>radiology</b>	The use of imaging in the diagnosis, treatment and monitoring of disease.
<b>radiotherapy</b>	The use of radiation, usually X-rays or gamma rays, to kill tumour cells.
<b>Regional Cancer Advisory Groups (RCAGs)</b>	There are three Regional Cancer Advisory Groups – North, West and South East Scotland, each providing a strategic, advisory and planning focus for their respective locality cancer services and NHS boards.
<b>rectal</b>	Pertaining to the rectum, the distal or lowest portion of the large intestine.
<b>rectal anastomosis</b>	A procedure in which a part of the rectum is removed and the two remaining ends are rejoined.
<b>rectum</b>	The distal or lowest portion of the large intestine.
<b>referral</b>	The process by which a patient is transferred from one professional to another, usually for specialist advice and/or treatment.
<b>resection</b>	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.
<b>review</b>	Examine or assess (something) formally with the possibility or intention of bringing about change if necessary. See peer review.
<b>RCPATH</b>	Royal College of Pathologists.
<b>Scottish Cancer Group (SCG)</b>	Leads and directs the cancer services reconfiguration programme in Scotland. The SCG is a multidisciplinary group which advises Ministers, the Chief Medical Officer and the Scottish Government on the strategic priorities and objectives for the development of cancer services, including service quality, research and audit, clinical trial, and clinical effectiveness. The Group also provides advice on trends in incidence and mortality, scientific advances and on the implementation of nationally agreed initiatives for the delivery of cancer services, programmes of prevention and screening. Website address: <a href="http://www.show.scot.nhs.uk/sehd/cancerinscotland/pages/SCgroupmeetings.htm">www.show.scot.nhs.uk/sehd/cancerinscotland/pages/SCgroupmeetings.htm</a>

<b>Scottish Government Health Directorates (SGHD)</b>	The SGHD is responsible for both NHSScotland and for the development and implementation of health and community care policy. It is also responsible for social work policy and for community care and voluntary issues. Website address: <a href="http://www.show.scot.nhs.uk/sghd">www.show.scot.nhs.uk/sghd</a>
<b>secondary care</b>	Hospital-based (acute) health services which are provided on an inpatient or outpatient basis. See acute care.
<b>stage</b>	The extent to which cancer has spread from its original site to other parts of the body. Usually denoted by a number from Stage 1 (least severe) to Stage 4 (more advanced).
<b>surveillance</b>	The ongoing, systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know.
<b>tertiary care</b>	Specialised consultative care, usually on referral from primary or secondary care personnel, by specialists working in a centre that has personnel and facilities for special investigation and treatment.
<b>threatening</b>	Where preoperative staging of the primary tumour suggests that an R0 resection might not be obtained.
<b>total mesorectal excision</b>	A technique in which the tissue surrounding the rectum, which may contain tumour cells, is removed along with the rectum itself.
<b>trans rectal ultrasound (TRUS)</b>	Used to assess apparently very early rectal cancers. An ultrasound probe is inserted into the rectum, via the anus, to help identify which layers of the rectal wall the cancer has involved.
<b>tumour</b>	An abnormal mass of tissue. A tumour may be either benign (not cancerous) or malignant (cancerous). Also known as a neoplasm.
<b>ultrasound</b>	An imaging test that bounces sound waves off tissues and converts the echoes into pictures.
<b>X-ray</b>	An imaging technique that uses energy beams of penetrating electromagnetic energy. This is the most common imaging technique used in clinical practice everywhere in the world, with the image captured on photographic film or digitally.