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1.0 Introduction

1.1 Foreword

Following successful evaluation of the UK colorectal cancer screening pilot a Scottish Bowel Screening Programme rolled out across Scotland between June 2007 and December 2009.

All men and women between the ages of 50 – 74 are being invited to participate in the programme through completion of a faecal occult blood test at home every two years. The Community Health Index (CHI) is the key patient identifier throughout the screening episode.

A Scottish Bowel Screening Centre has been established at Kings Cross Hospital in Dundee consisting of the call-recall office, helpline and laboratory. More than 800,000 people are being issued with home test kits every year and individuals are being screened once every two years. The central laboratory carries out the tests on the home test kits and the centre refers positive screening test results via the Bowel Screening IT System (BoSS) directly to the relevant local colorectal service for further investigations.

This Scottish Bowel Screening Manual brings together the experience of both the UK colorectal cancer screening pilot and the Scottish Bowel Screening Programme to help health professionals. It sets out the background to the programme, the programme specification, more information about the Bowel Screening Centre along with identifying roles and responsibilities. The manual will help ensure that NHS Boards operate to a common set of protocols and procedures.

The Manual will be published on the Bowel Screening website at http://www.bowelscreening.scot.nhs.uk/ and will continue to be developed over time based on the evidence, experiences and feedback from health professionals involved in the national programme.
I hope you find this manual helpful.

Professor Bob Steele
Lead Clinician
Scottish Bowel Screening Programme
2.0 Background

2.1 Evidence and Results from the Pilot (2000 – 2007)

The incidence of colorectal cancer is high in Scotland; it is the third most common malignancy experienced in the male and female populations and is second only to lung cancer as a cause of cancer death in the combined male and female population.

The most recently published figures\(^1\) state that 3.4% of men (1 in 30) and 2.3% of women (1 in 44) in Scotland will develop colorectal cancer by the age of 74.

For men, the risk of getting colorectal cancer over the age of 50 is 1 in 18 (5.5%) and, for women, the equivalent risk is 1 in 22 (4.5%)\(^1\).

There have been three randomised controlled trials (RCT) undertaken which provide the evidence base for screening with guaiac-based faecal occult blood tests (FOBt) for colorectal cancer from England \(^2\), Denmark \(^3\) and the US \(^4\). In summary, the evidence from RCTs and a Cochrane Review\(^5\) indicate a decrease of 16% mortality from colorectal cancer in the screened populations.

Appendix I provides a comparison of the cancer registrations, complete to the 31st December 2006, by Dukes' Staging, of those NHS Boards piloting bowel cancer screening in 50-69 year olds and those NHS Boards not piloting screening. The charts highlight an increase of approximately 10% in the registration of early stage cancers (Dukes 'A') in the Boards piloting screening in the first year following screening implementation.

\(^1\) www.isdscotland.org/cancer_information
\(^2\) Hardcastle JD, Chamberlain JO, Robinson MHE, Moss SM, Amar SS, Balfour TW et al. Randomised controlled trial of faecal occult blood screening for colorectal cancer. Lancet 1996; 348; 1472-1477
\(^3\) Kronborg O, Fenger C, Olsen J, Jorgensen OD, Sondgaard  O. Randomised study of screening for colorectal cancer with faecal occult blood test. Lancet 1996; 348; 1467-1471
In the *Cancer Scenarios* document\(^6\) it is estimated that once the programme is established, 150 deaths per year would be prevented, in comparison to the breast screening programme which prevents 40 deaths per year, and the cervical screening programme which prevents 60 cases per year and 26 deaths. It has been calculated that screening using FOBt costs about £5,900 per life year saved, which is well below the threshold most European countries are willing to pay, and therefore is a cost effective intervention\(^7\) & \(^8\).

*The Council of the European Union - Proposal for a Council Recommendation on Cancer Screening*, stated that colorectal screening tests which fulfil the requirements of the recommendation include faecal occult blood screening for colorectal cancer in men and women age 50-74 (*The Council of the European Union - Proposal for a Council Recommendation on Cancer Screening, Brussels, 25 November 2003, 15026/03*).

### 2.2 UK National Screening Committee

Following a review of the evidence from the three RCTs and other published work, the UK National Screening Committee (NSC) recommended to Health Ministers that screening for colorectal cancer should be piloted to assess the feasibility, acceptability and practicality of a national programme for the general population.

Requests for bids to undertake the pilot work were made in Scotland\(^9\) and England. Following evaluation of the bids, a consortium of Grampian, Tayside and Fife Health Boards was successful in Scotland, and Coventry and Warwickshire Health Authorities in England.

A matched cohort study comparing eligible age and sex matched individuals in the pilot areas and in the areas in Scotland not, at that time, being offered screening has demonstrated a 27% decrease in colorectal cancer mortality for those who participated.

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\(^9\) NHS MEL(1998)62. *Screening for Colorectal Cancer*
in the screening process. This is in keeping with the findings of the previous randomised studies.

2.3 UK Pilot

The colorectal cancer screening pilot in Scotland commenced in April 2000 in Tayside, Grampian and Fife. All men and women registered with a GP in these three areas aged between 50-69 years were invited to participate.

The final invitations for the first screening round of the colorectal cancer screening pilot were sent out in October 2002; follow-up investigations were completed by March 2003. Following the Options and Implications Report\textsuperscript{10} to the then Scottish Executive Health Department (SEHD) in early 2002, funding was provided through National Services Division (NSD) for a second screening round of the pilot to gather further information.

A comprehensive evaluation of the first round of the pilot has been undertaken to assess the feasibility of rolling screening out in a national programme. The Evaluation Group’s report was published in Spring 2003\textsuperscript{11} and the evaluation noted that “the UK Pilot has demonstrated that key parameters of test and programme performance observed in randomised studies of FOBt screening can be repeated in population based pilot programmes”. A summary of the results of the first round have also been published.\textsuperscript{12}

The second screening round of the pilot commenced in December 2002, which provided additional information to assist in planning for roll out. The third round of the pilot commenced in May 2005 and was completed in May 2007 in Tayside, Grampian and Fife. Appendix 3 provides the Key Performance Indicators for rounds 1, 2 and 3. Three rounds of the Scottish Arm of the pilot have also been published.\textsuperscript{13}

\textsuperscript{10} Implications and Options Colorectal Cancer Screening, National Services Division, Common Services Agency. February 2002

\textsuperscript{11} The UK CRC Screening Pilot Evaluation Team (2003) Evaluation of UK Colorectal Cancer Screening Pilot – Final Report


\textsuperscript{13} Steele RJC, McClements PL, Libby G et al. (2008) Results from the first three rounds of the Scottish demonstration pilot of FOBT screening for colorectal cancer. Gut 2009 58: 530-535 originally published online November 26, 2008 doi: 10.1136/gut.2008.162883
A recent matched cohort study comparing eligible age and sex matched individuals in the pilot areas and in the areas in Scotland not, at that time, being offered screening has demonstrated a 27% decrease in colorectal cancer mortality for those who participated in the screening process. This is in keeping with the findings of the previous randomised studies.

See link to Dukes’ Staging Comparison figure:

Appendix 1 Dukes’ Staging.doc
3. Programme Specification

3.1 Aim and Policy

The aim of the Scottish Bowel Screening Programme is to reduce the overall mortality from colorectal cancer in the population by at least 16%. This would be achieved by inviting the target population (men and women between 50 – 74 years) to complete a faecal occult blood test at home every 2 years.

On 3rd February 2006, a Health Department Letter was circulated to NHS Boards.

3.2 Programme Scope

The Bowel Screening Programme invites all men and women between the ages of 50 – 74 years with a CHI number to participate. Eligible people not readily accessible through their CHI address (e.g. travelling people, people in long stay NHS care) will be able to participate following national and local protocols. Arrangements are in place for individuals who transfer in or out of Scotland. For example letters will issue (to the known/CHI address) from the Scottish Bowel Screening Centre to those who commence the screening pathway in Scotland and subsequently transfer out of Scotland. Those who transfer into Scotland and have a CHI number will be called to participate in the Programme.

All individuals are sent a guaiac-based FOBt in the first instance. If the overall result is positive, the individual is referred to hospital for assessment and offered a colonoscopy, if appropriate. Robust plans for referral and safe guarding procedures have been agreed and implemented.

The National Screening Co-ordinator based within NHS Scotland Screening Programmes, National Services Division (NSD), NHS National Services Scotland (NSS), is responsible for co-ordinating and monitoring the screening programme. However, the screening programme is integrated with existing colorectal services to ensure equity for all patients.

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1 HDL (2006)3 Bowel Cancer Screening Programme
The NHS Boards are responsible for ensuring the quality and performance of care for the patients within their Board area who are referred for further investigation and treatment, and also for encouraging uptake in their local population.

3.3 Estimated Target Population and Projected Numbers

Target Population

Background
During the pilot the target population included all men and women between the ages of 50 – 69 years.

As stated previously, The Council of the European Union - Proposal for a Council Recommendation on Cancer Screening stated that screening tests which fulfil the requirements of the recommendation include initial FOBt screening for colorectal cancer in men and women age 50-74\(^2\). Taking this into consideration, the then Scottish Government Scottish Bowel Cancer Framework Group recommended that the national programme should extend the age range to 50-74.

Projected Numbers\(^3\)
The table below provides the projected target population for Scotland. Due to the ageing population, this increases substantially by 2016.

Projections for 50 – 74 years

<table>
<thead>
<tr>
<th>Year</th>
<th>2010</th>
<th>2015</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>715,157</td>
<td>770,723</td>
<td>811,500</td>
</tr>
<tr>
<td>Females</td>
<td>776,387</td>
<td>840,143</td>
<td>893,300</td>
</tr>
<tr>
<td>Total</td>
<td>1,491,544</td>
<td>1,610,866</td>
<td>1,704,800</td>
</tr>
</tbody>
</table>

Taking into consideration the projected numbers, and the biennial nature of the programme, it can be estimated that the programme would need to invite approximately 805,433 individuals in 2015 rising to 852,400 by 2020.


3.4 Colorectal Service

The screening programme is integrated with existing colorectal service within NHS Boards. Any participant with an overall positive screening test result is referred into the existing care pathway for patients with colorectal symptoms. The screening programme is viewed as an additional urgent high risk referral route and not as a separate service. The only exception to this will be that all referrals from the screening programme should be referred for colonoscopy in the first instance. Referral to colonoscopy should be agreed within local protocols that ensure that the quality standards and waiting time targets are met.\(^4\)

See Bowel Screening Flowchart – Figure 1.

In order to reduce anxiety, encourage participation and compliance, and minimise the risks of colonoscopy, all individuals who have a positive screening test are offered pre-colonoscopy assessment by a suitably qualified health care professional. This assessment can be completed in existing pre-assessment clinics if available. Ideally the nurses undertaking the assessment should be part of the endoscopy or colorectal cancer team and have undergone appropriate training. However, alternative arrangements may be made, e.g. telephone interview, or assessment by GPs. The reason for the pre-assessment is that these individuals will not have had any contact with health care professionals at this stage (unless they have visited their GP) and will require further advice, reassurance and explanation of the risks as well as the benefits of colonoscopy and identification of any co-morbidity. Informed consent will also be obtained for colonoscopy.

Following assessment, if the participant is a suitable candidate for colonoscopy, they will be provided with an appointment for colonoscopy. If the colonoscopy is incomplete, then either a repeat colonoscopy will be offered or a referral for a double contrast barium enema or CT colonography (when available) will be provided.

The result of the colonoscopy should be provided to the patient and also copied to their GP Practice.

Following colonoscopy, individuals will be managed appropriately depending on the result.

Colorectal services in NHS Boards will require to quality assure (QA) the service that is provided and this should be integral with existing QA procedures and must meet the programme’s nationally set clinical standards (*NHS Quality Improvement Scotland (NHS QIS) Bowel Screening Standards* were published on 6 March 2007 and can be accessed at [www.nhshealthquality.org](http://www.nhshealthquality.org))
Pre-assessment to assess fitness for colonoscopy

Did Not Attend

Attend pre-assessment clinic to assess fitness for colonoscopy

Send another appointment

Did Not Attend

Unfit for colonoscopy

Fit for colonoscopy

Refer for colonoscopy

Colonoscopy undertaken

Inform GP & Clinician

Refer to clinician for assessment

Unfit for colonoscopy

Inform GP & Clinician

Refer to clinician for assessment

Unfit for colonoscopy

Inform GP & GP

Inform participant & GP

Unfit for colonoscopy

Inform participant & GP

Refer to appropriate speciality

Colonscopy undertaken

Refer for surgery / oncology

Inform participant & GP

Colonoscopy complete

Patient declines to proceed. GP informed

Colonscopy complete

GP informed

Cancer suspected

Other pathology

Follow-up SIGN guidelines

Pathology

Other pathology

Adenoma

Cancer suspected

Negative

Negative

Barium Enema / CT Colonography performed

Barium Enema / CT Colonography incomplete

Other Pathology

Refer to clinician

Refer for surgical assessment

Refer to appropriate speciality

Refer to clinician

Return to list to be invited in 2 years

NHS BOARD
4. Bowel Screening Centre

4.1 Call-recall

Background:
The Scottish Bowel Screening Centre, consisting of the call-recall office, helpline and laboratory has been established in Kings Cross Hospital in NHS Tayside in Dundee.

Process:

- The Chief Executives of all NHS Boards in Scotland agreed a national plan for roll out (see Appendix 2).
- All NHS Boards participating in the Programme by December 2009
- The Community Health Index (CHI) is the key participant identifier throughout the screening episode.
- Prior Notification Lists (PNLs) are not currently issued to GPs (based on feedback from the pilot).
- Individuals are invited to participate in bowel screening at some point over the two-year round of screening. In most instances this call date is an individual’s birthday either in Year 1 or Year 2. Their recall date is calculated 2 years from initial invitation date.
- Anyone turning 50 will be called immediately.
- The number of invitations to each NHS Board area will be pre-determined by the number in the target population requiring invitation over a 2 year period.
- The Centre will provide a helpline facility for individuals to contact with enquiries about the screening programme and process. The helpline (Freephone 0800 0121 833) is available Monday – Friday 8 a.m. – 5 p.m.
- The helpline is staffed by trained staff with good communication skills. They are not health care professionals.
- Helpline advice is restricted to relevant screening information. Individuals with enquiries about symptoms or with other health related enquiries are referred back to their General Practitioner.
- Individuals returning a screening test are sent a result within two weeks of receipt of the test by the Centre\(^1\). The Centre refers

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\(^1\) NHS Quality Improvement Scotland Bowel Screening Programme Clinical Standards – Standard 3c.1
positive screening test results via the Bowel Screening System (BoSS) directly onto SCI Gateway to the relevant local colorectal service for further investigations.

- The Centre will send screening test positive result information to Primary Care at the same time.
- Data will be provided to Information Services Division (ISD) by the Centre and NHS Boards.

### 4.2 Centre Procedures and Protocols

There are Standing Operating Procedures (SOPs) and Protocols in place to administer the programme within the Centre and these are quality assured.

An effective system of document control for operational procedures has been identified and is central to the quality management system of the Centre. This ensures that each document is:

1. approved for use by authorising personnel prior to use,
2. uniquely identified with the identification to include the date of issue, the revision version, the total number of pages and the authorising signatories,
3. legible, readily identifiable and retrievable,
4. regularly reviewed and updated as required, and
5. contained in a readily accessible master list that identifies its current revision status and distribution, the purpose of which is to prevent the use of an invalid or obsolete document.

These SOPs are reviewed annually or when new procedures or changes are introduced. All staff will be involved in creating and reviewing the SOPs to give ownership and improve adherence.

Daily audit checks will be carried out by staff within the Centre to ensure the quality of all correspondence and issue of results.

### 4.3 Overview of Bowel Screening System (BoSS)

An IT System for the National Bowel Screening Centre has been developed and is made up of two main components – call-recall and laboratory.
BoSS tracks the participant journey from pre-notification through to the point at which they receive a result. No subsequent clinical information is held within BoSS.

**Call-recall**
BoSS calls all eligible participants from CHI based on the following selection criteria:-

- must be aged between 50 and 74,
- CHI record must have an Area of Residence

Eligible participants are downloaded from CHI and allocated a call-recall date within the next 2 years (see section 4.1).

BoSS also ensures that participants are called before their 75th birthday.

For those who meet the eligibility criteria, new CHI registrations prompt an immediate bowel screening invitation.

When a participant is called, they will be sent a pre-notification letter followed by an invitation letter which includes the FOB test kit. If they do not reply within 6 weeks, BoSS issues a reminder letter.

A participant is considered to be a non responder if no response is received within 6 months of invitation.

Recall date will always be reset to 2 years from first invitation.
Call-recall User Interface
This module allows users in the Centre to view a participant’s screening details and can also carry out the following functions:-

- add an Exclusion Status to halt a participant’s screening cycle,
- issue a replacement kit, and
- change a recall date (e.g. where compliance has expired).

Book-In
This module allows nominated laboratory users to book-in and sort kits received in the laboratory.

Screening
This module enables certain laboratory users to enter kit results for both kit types (Faecal Occult Blood Test (FOBT) and the Faecal Immunochemical Test (FIT)).

Security Management
This module allows the Atos Help Desk to add/remove/edit users of BoSS.

Organisation Management
This module holds information on all institutions and referral organisations.

Login/Logoff Launch pad
This module allows the user to log on to BoSS and shows the applications to which they have access.

Materials Management
This module allows both call-recall and laboratory users to record lot numbers for both kits and reagents.

System Administration
This module allows the senior laboratory staff to deal with all queries and view interactive reports.
QA/QC Management
This module allows laboratory staff to create Quality Control (QC) batches and record test results for QC kits. Quality Assessment kits can also be created in batches of 1 and results input.

Screen on Demand
This module allows call-recall staff to call participants and tie them to an institution for the duration of a screening cycle.

Call-recall & Laboratory Reports
A range of core reports are available on a daily basis for both the call-recall and laboratory modules.

BoSS Rule Book
This module details all business rules related to BoSS. This information will be available in an electronic format.

SCI Gateway
When a person has a positive screening test result, a referral is automatically sent to their NHS Board via SCI Gateway.

How will BoSS report positive referrals to SCI Gateway?

The Bowel Screening System (BoSS) refers participants with a positive bowel screening result to their local NHS Board via SCI Gateway.
See SCI gateway flowchart at Annex A.

Each record in BoSS holds details of the participant’s NHS Board of residence.

When a positive screening test result is recorded for a participant, BoSS sends out a “positive” letter to both the participant and their GP (if they have one).

It is the NHS Board’s responsibility to provide an appropriate contact telephone number. Any changes to this number must be alerted to the Bowel Screening Centre to ensure participants are provided with a valid contact telephone number and can be supported through the screening pathway.
These letters are sent out in the post.

BoSS also sends a pre-populated message to the participant’s local NHS Board via SCI Gateway. A copy of the SCI Gateway referral is at Annex B.

Each NHS Board has provided a “receiving” address in SCI Gateway which is included in the BoSS application. BoSS therefore automatically knows which NHS Board should receive the SCI Gateway message.

Each NHS Boards has arranged for authorised personnel to have access to the SCI Gateway address specified. These staff are responsible for checking SCI Gateway daily to check if any referrals have been received from BoSS.

The authorised personnel pick up the BoSS messages and make appointments for the participants accordingly. If a referral is received and it needs to be forwarded to another NHS Board, this can be done using SCI Gateway (see SCI Gateway flowchart). It is the responsibility of each NHS Board to action received referrals promptly.
How BoSS will report positive referrals to SCI Gateway

Process

1. NHS Boards all inform NSD of the address that they wish to use to receive referrals from BoSS
2. BoSS application records an address for each NHS Board
3. When a positive result is input, BoSS automatically sends out a result letter to the participant and their GP (if they have one)
4. BoSS then automatically sends a pre-populated message to the designated address in SCI Gateway
5. Message can be viewed by Health Board staff with appropriate user permissions
6. Referral can then be directed to the appropriate hospital/health care professional by authorised personnel
7. Contact is then made with the patient by the appropriate hospital/health care professional
Annex B

REFERRAL LETTER
MEDICAL IN CONFIDENCE

<table>
<thead>
<tr>
<th>Date Referral Created</th>
<th>12-Feb-2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date Referral Submitted</td>
<td>13-Feb-2011</td>
</tr>
</tbody>
</table>

REFERRAL TO

Scottish Bowel Screening Programme Local Coordinator

Consultant / receiving practitioner and/or specialty clinic

Any Hospital
2 Any Street
Any Place
Any Town
Any Where
X99 9XX

Hospital and hospital address
Hospital unit no.
X999H
Email address
-

Urgency of referral
Urgent - Suspected Cancer
High Risk of Bowel Cancer

UCPN
134000000006D

PATIENT DETAILS

Surname
SURNAME
Forename(s)
FORENAME
Title
-
Sex
Female
Date of birth
10-Feb-1961
CHI no.
9999999999

Patient’s address
75 ANY STREET
ANY TOWN
ANY PLACE
ANY WHERE
X99 9XX
Contact number(s)
-

REGISTERED GP DETAILS

Name
GP NAME1
GP code
X9999
Practice name
PRACTICE NAME1
Practice code
X99999

Practice address
ADDRESS LINE 1
ADDRESS LINE 1
ADDRESS LINE 1
X99 9XX
Contact number(s)
-

REFERRING HCP DETAILS

Organisation Name
Scottish Bowel Screening Programme
Organisation address
Scottish Bowel Screening Centre
Kings Cross
Clepington Road
Dundee
DD3 8AE
Contact No.
01382 425677
4.4 Escalation Procedures for the Scottish Bowel Screening Centre

Introduction

Any screening programme has the potential for significant adverse incidents. It is important to audit incidents with the aim of minimising risk. In this way improvements in practice can be identified and disseminated to a wider group. There is also potential for an incident to occur at any stage in the screening process and for complaints/issues about the service to become high profile.

NHS Quality Improvement Scotland (NHS QIS) now known as Healthcare Improvement Scotland has developed Bowel Screening standards covering six key areas:-

- general
- call-recall
- the screening process
- the laboratory process
- pre-colonoscopy assessment
- colonoscopy and histopathology

As the bowel screening programme is the responsibility of both the local NHS Boards and the Scottish Bowel Screening Centre (SBoSC) based in Dundee separate escalation procedures have been developed for the SBoSC and for NHS Boards. NHS Tayside is responsible for delivery of efficient call-recall, screening and laboratory processes within the SBoSC.

A Scottish Bowel Screening Programme Governance Strategy has been developed setting out the key roles, responsibilities and relationships for the programme and providing a strategic framework for the development of clinical governance. It is essential that management of the risks relating to the Bowel Screening Programme are set within the context of this Governance Strategy and the organisations' (SBoSC/NHS Tayside) system of governance and risk management.

The methodology for ascribing levels of risk should be consistent with local proactive risk assessment, risk management and
incident reporting processes already in place. Identifying the likelihood of most events occurring can be subjective and based upon the knowledge and expertise of those involved. Evidence and statistics may however be available regarding the recurrence of certain events and this information can help anticipate and plan.

- **Annex A** sets out the escalation framework for the Scottish Bowel Screening Centre.
- Scottish Bowel Screening Centre Escalation Flowchart attached at **Annex B**
- Categorisation of Risks - Example - **Annex C**

**NATIONAL SERVICES DIVISION**

October 2012
ANNEX A

SCOTTISH BOWEL SCREENING PROGRAMME
Escalation Procedures for the Scottish Bowel Screening Centre

1. Any member of staff in the Scottish Bowel Screening Centre who becomes aware of a suspected problem should follow the agreed escalation procedures.

2. The Scottish Bowel Screening Centre Manager and Clinical Services Manager should be advised of all suspected problems. The Bowel Screening Lead Clinician should also be advised of problems where appropriate (see below)

GREEN

3. If local investigation concludes that the problem will only have minimal impact and the risk assessment is Green, the Bowel Screening Centre Manager and the Clinical Services Manager should be advised and effective countermeasures should be put in place to resolve the issue satisfactorily.

AMBER

4. If a fairly significant problem is identified (and the risk assessment is Amber) but there is no cessation in service provision then the SBoSC Manager and the Clinical Services Manager should be advised and planned action initiated to resolve the problem. The Bowel Screening Lead Clinician should be advised of the problem and the action taken and outcome.

4.1 If the action successfully resolves the problem a report should be provided to National Services Division (NSD). The SBoSC and NSD should continue to monitor for recurrence. Formal feedback should be provided to NSD and reported as part of the six monthly NSD/NHS Tayside performance reviews.

If the action does not resolve the problem then it should be treated as having a significant impact and the risk assessment should be escalated to Red.
5. A major/catastrophic problem is defined as the Scottish Bowel Screening Centre being unable to meet service provision and/or mandatory Healthcare Improvement Scotland Bowel Screening standards to such an extent that cessation of the service for an extended period of time is likely or necessary. In these circumstances the Clinical Services Manager, on behalf of NHS Tayside, should provide a detailed report to NSD immediately on the extent of the problem and including potential solutions.

5.1 NSD and the Bowel Screening Governance Committee will consider the detailed report and agree actions to be taken. NSD will also inform the Scottish Government Health Directorates of the problem and the agreed action plan.

5.2 The agreed action plan is implemented by the Scottish Bowel Screening Centre and NSD will monitor and report to the Scottish Government Health Directorates and the Bowel Screening Governance Group.

5.3 If the action plan resolves the problem a report should be provided to National Services Division (NSD). The SBoSC and NSD should continue to monitor for recurrence. Formal feedback should be provided to NSD and also reported as part of the six monthly NSD/NHS Tayside performance management reviews.

5.4 If the Action Plan does not resolve the problem then NSD and the Scottish Government Health Directorates will consider further action and whether a full independent external investigation/peer review is instigated.

NATIONAL SERVICES DIVISION
October 2012
Escalation Procedures for the Scottish Bowel Screening Centre

Resolved

**Risk Assessment is Green**
Incident or Variance occurs. Effective countermeasures put in place and issue is resolved.

Centre Manager & Clinical Services Manager discuss and no further action required.

Not resolved or

**Risk Assessment is Amber**
Incident or Variance occurs and requires a prolonged countermeasure but is resolvable.

Centre Manager & Clinical Services Manager discuss.
- Inform NSD
- Continue to monitor
- No further action required.

Not resolved or

**Risk Assessment is Red**
Incident or Variance occurs and a countermeasure is not possible.

Centre Manager & Clinical Services Manager discuss and no resolution is identified.
- Advise NSD of inability for local resolution
- Continue to monitor
- Further action to be identified by NSD and NHS Tayside.
## SCOTTISH BOWEL SCREENING PROGRAMME
### Escalation Procedures for the Scottish Bowel Screening Centre

#### Categorisation of Risks - Example

<table>
<thead>
<tr>
<th>Description</th>
<th>Strategic</th>
<th>People</th>
<th>Financial</th>
<th>Operational</th>
<th>Clinical</th>
<th>IM &amp; T</th>
<th>External</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GREEN</strong></td>
<td>Minimal impact on the Programme Scope</td>
<td>Minimal disruption to staff/very minor delay in recruiting staff. Minor H &amp; S incident/minor staff complaint/short-term vacancy.</td>
<td>No Financial impact</td>
<td>Minimal impact – no service disruption/no adverse publicity.</td>
<td>No obvious clinical harm or injury to participant.</td>
<td>IT unavailable or slow response for a few minutes.</td>
<td>Minimal impact on services or operations.</td>
</tr>
<tr>
<td><strong>AMBER</strong></td>
<td>Minor/ Moderate impact/change to Programme scope.</td>
<td>H &amp; S incident with some harm/staff unrest/key post vacant/unable to recruit skilled staff to key roles for extended period.</td>
<td>Damage/loss of equipment or supplies and/or increase in costs of staffing, supplies or services &gt;£1000 - &lt;£2500</td>
<td>Minor impact on service provision/some public embarrassment/some objectives partially achievable/local adverse publicity</td>
<td>Extensive injury/harm/medical intervention required.</td>
<td>IT down or slow for between 2 hours – 5 days/poor information impacting on decision making, causing wrong decision to be taken impacting on the operation/loss of data.</td>
<td>Impact requiring change to services to comply with new legislation or directions. SBoSC not in line with some SEHD policies/national protocol or direction.</td>
</tr>
<tr>
<td><strong>RED</strong></td>
<td>Major/ Complete change impacting on the original fundamental programme scope</td>
<td>Severe H &amp; S incident/industrial action/sustained loss of key groups of staff/death causing termination of operations.</td>
<td>Damage/loss of equipment or supplies and/or increase in costs of staffing, supplies or services &gt;£2500</td>
<td>Significant impact on service provision/unable to function or carry out programme obligations/highly damaging national or international publicity.</td>
<td>Major harm/death</td>
<td>IT down or slow for 1 working week/huge loss of data causing termination of services/decision based on corrupted information threaten Programme future.</td>
<td>Significant and costly change to comply with legislation and directions. Programme unable to continue operations.</td>
</tr>
</tbody>
</table>
4.5 Laboratory

Background:
The single Scottish Laboratory is based within the Scottish Bowel Screening Centre at Kings Cross, Dundee. The Laboratory aspects for roll out of the Scottish Bowel Screening Programme were well established during the three pilot screening rounds [2000-2007]. Faecal Immunochemical Test (FIT) kits are used as second line testing in the Programme if equivocal results are found with the initial guaiac-based Faecal Occult Blood Test (FOBT)\(^1\). Potential improvements to the screening algorithm continue to be actively investigated.

Accreditation & Quality Assurance:

- Accreditation of the consultant-led Laboratory was achieved after assessment by Clinical Pathology Accreditation (UK) Ltd under ISO 15189 based standards in November 2008. Re-accreditation is applied for bi-annually and is granted subject to maintaining standards: a surveillance visit is conducted every two years between major assessments and this was done in February 2011. The Laboratory continues to have no non-compliances.
- Laboratory procedures comply with Health and Safety Codes of Practice and the Quality Policy of the Department of Blood Sciences, NHS Tayside.
- Comprehensive quality assurance techniques are conducted as described in the relevant standard operating procedures.
- Internal Quality Control is performed at a rate of 2.00% of the workload [+- 0.10%]. The quality control challenges are designed to be indistinguishable from the kits submitted by participants.
- The Laboratory participates in the Yorkshire EQAS, an external quality assessment scheme registered with CPA (UK) Ltd.
- The overall outcome performance of the Programme and the work of each individual Screener are monitored on a monthly basis using the percentages of positive, weak positive and negative FOBT and positive and negative FIT.

\(^1\)Bowel Screening Programme – Proposal to Programme Board – Introduction of Faecal Immunochemical Tests
• The Quality Manager for Blood Sciences, NHS Tayside, annually conducts all audit activities required for compliance with the standards laid down by CPA (UK) Ltd.
• The Laboratory is measured against the Standards for the Bowel Screening Programme published by NHS Quality Improvement Scotland (QIS) and meets all of these.

Process:
• Test kits are received each morning, then booked-in and sorted by date order: the number of unlabelled kits is documented.
• All problems are passed to senior Laboratory staff for immediate resolution.
• Testing of FOBT and FIT is performed following standard operating procedures by trained Screening staff supervised at all times by senior staff.
• 95% of all tests are completed within 5 working days of receipt.
• Following testing, the result entered into the BoSS system which automatically generates a result letter for issue the following working day.
The following flowchart shows the two-tier reflex FOBT/FIT screening algorithm.

**Note:**
- FOBT – guaiac-based faecal occult blood test
- FOBT positive – 5 or 6 windows positive
- WP – FOBT weak positive – 1-4 windows positive
- FIT – faecal immunochemical test
5. NHS National Services

5.1 Commissioning Arrangements

Background:
National Services Division (NSD), NHS National Services Scotland, commissions the central elements of the programme. Funding is provided to NSD under the top-slicing arrangements (for most recent top-slicing estimates please contact NSD).

Process:
The central elements include:
- Scottish Bowel Screening Centre,
- centre staff,
- bowel screening call-recall system (development & maintenance),
- test kits, and
- equipment.

A Service Agreement (SA) between NSD and NHS Tayside is in place for the overall management of the Centre.

The SA details what is required of NHS Tayside and the reporting structure to NSD.

Meetings will be held twice a year to discuss funding and management issues.

5.2 Information Services (ISD), NHS National Services Scotland

ISD has responsibility for producing agreed Scottish Bowel Screening reports against the Key Performance Indicators (KPIs) for the bowel screening programme both at national and NHS Board level.

Please refer to National Minimum Dataset for definitions and indication on what data are collected and collated (nationally or locally) as part of the programme.
5.3 Monitoring and Evaluation

National Services Division (NSD), NHS National Services Scotland (NSS) is responsible for implementing the national rollout in conjunction with NHS Boards. On completion of rollout, NSD will continue to monitor the effectiveness of the programme.

The role of Information Services (ISD) is to collate and analyse data and produce statistics for use in monitoring and evaluation of the programme. ISD also has a role in reporting and publishing national data and will analyse the data from the Centre, NHS Board data returns and the colorectal cancer minimum dataset on a regular basis to produce the KPIs for the programme. There will also be the ongoing monitoring of the Healthcare Improvement Scotland standards for the screening programme.

NHS Boards will collate additional data on their screened patients which will be generated, collated and analysed locally to assist the NHS Board coordinators in their role of local performance monitoring.

See Chapter 6 – Collection of minimum dataset and download of data to ISD.

Reports

The new Bowel Screening IT system (BoSS) produces reports relating to both call-recall and laboratory statistics. These reports will be viewable via Mobius, which is an external system that allows users to view reports online. There are 3 main viewers of BoSS reports

- Screening Centre
- ISD (restricted to certain reports)
- Practitioner Services Division (PSD) – only undelivered mail reports.
Notes:
1. Figures extrapolated from first round pilot data
2. 100,000 target population = all males and females 50-74 years
3. Figures based on 60% uptake and 2.1% positivity
4. Not all individuals who have a positive FOBt test progress to colonoscopy as it may be inappropriate or may be refused
5. Colonoscopy and Barium Enema – small number of patients who were not referred, DNAs etc
6. No neoplasia includes Diverticular Disease, IBD, etc
7. BSG guidelines used for follow up of adenomas
8. Surgery includes invasive cancers and surgery for adenomas/benign disease
### 5.4 National Minimum Dataset

<table>
<thead>
<tr>
<th>Column Name</th>
<th>Standard / KPI</th>
<th>Definition</th>
<th>Response</th>
<th>Format</th>
<th>Field Length</th>
<th>Codes and Expected Values</th>
<th>Validation</th>
</tr>
</thead>
<tbody>
<tr>
<td>HBIDENT</td>
<td>Health Board identifier/code</td>
<td>Character</td>
<td>Character</td>
<td>1</td>
<td>See appendix (iii).</td>
<td>Must be completed.</td>
<td></td>
</tr>
<tr>
<td>CHINUM</td>
<td>Unique Community Health Index number</td>
<td>CHI</td>
<td>Characters</td>
<td>10</td>
<td>All 10 digits must be entered even if this includes a leading zero</td>
<td>Must be completed. Check against DOB and SEX.</td>
<td></td>
</tr>
<tr>
<td>PATSNAME</td>
<td>Patient’s surname</td>
<td>Name</td>
<td>Characters</td>
<td>35</td>
<td>e.g. Smith</td>
<td>Free text, NO COMMAS.</td>
<td></td>
</tr>
<tr>
<td>PATFNAME</td>
<td>Patient’s forename</td>
<td>Name</td>
<td>Characters</td>
<td>35</td>
<td>e.g. John</td>
<td>Free text, NO COMMAS.</td>
<td></td>
</tr>
<tr>
<td>DOB</td>
<td>Person Birth Date</td>
<td>Date</td>
<td>CCYY-MM-DD</td>
<td>10</td>
<td>e.g. 1952-04-07</td>
<td>Date validation (DD 1-31, MM 1-12, CCYY 19**) and must be prior to all other dates.Check against CHINUM.</td>
<td></td>
</tr>
<tr>
<td>PATPCODE</td>
<td>Full postcode</td>
<td>Postcode</td>
<td>LL(N)N NLL</td>
<td>8</td>
<td>e.g. FK13 6JR, G2 1AF</td>
<td>Must be completed against CHINUM.</td>
<td></td>
</tr>
<tr>
<td>SEX</td>
<td>Person Sex (at birth)</td>
<td>M/F</td>
<td>Characters</td>
<td>1</td>
<td>0 - Not Known, 1 - Male, 2 - Female, 9 - Not specified</td>
<td>Must be completed and checked against CHINUM. 2nd last digit should be odd if male and even (including 0) if female.</td>
<td></td>
</tr>
<tr>
<td>SCRERESDAT</td>
<td>QIS 6a.1 Date of notification of a screening result. This is the ‘Date Referral Submitted’ for the investigation of a positive screening test, located near the top left hand corner of the SCI Gateway referral below ‘Date Referral Created’. See Appendix (vi).</td>
<td>Date</td>
<td>CCYY-MM-DD</td>
<td>10</td>
<td>e.g. 2008-08-12</td>
<td>Must be completed, date validation (DD 1-31, MM 1-12, CCYY 20**) and must be prior to, or equal to, first available colonoscopy date offered. N/A or Not known are not accepted.</td>
<td></td>
</tr>
<tr>
<td>PRECOLAS</td>
<td>QIS 5a Pre-colonoscopy assessment offered?</td>
<td>Y/N</td>
<td>Characters</td>
<td>2</td>
<td>00 - No, 01 – Yes, 02 – Refused, 99 - Not known</td>
<td>If left blank all subsequent entries must be blank.</td>
<td></td>
</tr>
<tr>
<td>Date Precol</td>
<td>KPI</td>
<td>Date of pre-colonoscopy assessment</td>
<td>Date</td>
<td>CCYY-MM-DD</td>
<td>10</td>
<td>e.g. 2008-08-13</td>
<td>Date validation (DD 1-31, MM 1-12, CCYY 20**) and must equal to or after SCRERESDAT and equal to or prior to DATECOLOFF.PRECOLAS must be 01(Yes).</td>
</tr>
<tr>
<td>------------</td>
<td>-----</td>
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<td>------</td>
<td>------------</td>
<td>----</td>
<td>----------------</td>
<td>----------------------------------------------------------------</td>
</tr>
<tr>
<td>Furthass</td>
<td>QIS</td>
<td>Further opportunity for pre-colonoscopy assessment offered?</td>
<td>Y/N</td>
<td>Characters</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 - Not known</td>
<td>N/A is not accepted.</td>
</tr>
<tr>
<td>Coloffered</td>
<td>QIS</td>
<td>Has a date for colonoscopy been offered at pre-assessment?</td>
<td>Y/N</td>
<td>Characters</td>
<td>2</td>
<td>00 - No, 01 – Yes, 02 – Refused, 99 - Not known</td>
<td>If PRECOLAS = 01(Yes) then this must be completed. If PRECOLAS = 00 (No) then this must be blank. N/A is not accepted.</td>
</tr>
<tr>
<td>Datecoloff</td>
<td>QIS</td>
<td>First available colonoscopy date offered</td>
<td>Date</td>
<td>CCYY-MM-DD</td>
<td>10</td>
<td>e.g. 2008-08-14</td>
<td>Date validation(DD 1-31, MM 1-12, CCYY 20**). If COLOFFERED = 01(Yes) then this must be completed. Must be after or equal to DATEPRECOL and/or after SCRERESDAT.</td>
</tr>
<tr>
<td>Colperf</td>
<td>KPI</td>
<td>Colonoscopy performed?</td>
<td>Y/N</td>
<td>Characters</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 - Not known</td>
<td>N/A is not accepted.</td>
</tr>
<tr>
<td>Datecolperf</td>
<td>QIS</td>
<td>Date colonoscopy performed</td>
<td>Date</td>
<td>CCYY-MM-DD</td>
<td>10</td>
<td>e.g. 2008-08-15</td>
<td>Date validation(DD 1-31, MM 1-12, CCYY 20**). If COLPERF = 01(Yes) then this must be completed. If COLPERF = 00(No), 99(Not known) then this must be left blank. Must be equal to or after DATEPRECOL and SCRERESDAT.</td>
</tr>
<tr>
<td>Colreason</td>
<td>New KPI</td>
<td>Reason for not having a colonoscopy</td>
<td>Code</td>
<td>Characters</td>
<td>2</td>
<td>01- Under surveillance, 02- Clinical decision, 03-Declined, 04-Patient died, 05 – DNA, 00- No reason given.</td>
<td>If COLPERF = 00(No) then this must be completed.</td>
</tr>
<tr>
<td>Variable</td>
<td>QIS</td>
<td>Description</td>
<td>Type</td>
<td>Characters</td>
<td>Validation</td>
<td>Notes</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-----</td>
<td>-------------</td>
<td>------</td>
<td>------------</td>
<td>------------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>COLCOMP</td>
<td>QIS 6b</td>
<td>Colonoscopy completed? Examination is complete when the colonoscopist considers that the entire length of the bowel has been visualised.</td>
<td>Y/N</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 – Not known</td>
<td>If COLPERF = 01(Yes) then this must be completed. If COLPERF = 00(No) or 99 (Not known) then this must be left blank. N/A is not accepted.</td>
<td></td>
</tr>
<tr>
<td>BARENCTC</td>
<td>QIS 6c.5</td>
<td>Has a Barium enema, computed tomography (CT) colonography, other radiological examination or a second colonoscopy completed (when the first was incomplete)?</td>
<td>Y/N</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 – Not known</td>
<td>If COLCOMP = 00(No) then this must be completed. N/A is not accepted.</td>
<td></td>
</tr>
<tr>
<td>BARECTALT</td>
<td>QIS 6c.1</td>
<td>If BARENCTC = 00(No) then was an alternative date for any of these procedures offered?</td>
<td>Y/N</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 – Not known</td>
<td>If BARENCTC = 00(No) then this must be completed. N/A is not accepted.</td>
<td></td>
</tr>
<tr>
<td>BARCTDAT</td>
<td>QIS 6c.1</td>
<td>If barium enema, computed tomography colonography or other radiological examination completed, date performed?</td>
<td>Date</td>
<td>CCYY-MM-DD</td>
<td>008-08-16</td>
<td>Date validation (DD 1-31, MM 1-12, CCYY 20**). If BARENCTC = 01(Yes) then this must be completed. Must be equal to or after DATECOLPERF, DATECOLOFF, DATEPRECOL and SCRERESDAT.</td>
<td></td>
</tr>
<tr>
<td>CANCER</td>
<td>KPI 8, 19, 22, 23</td>
<td>Invasive Cancer detected?* (defined as invasive cancer arising from the colon and rectum including polyp cancers which should normally be coded T1N0M0)</td>
<td>Y/N</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 – Not known</td>
<td>If COLPERF = 01(Yes) or BARENCTC = 01(Yes) then this must be completed. N/A is not accepted.</td>
<td></td>
</tr>
<tr>
<td>ICD-10</td>
<td>KPI 24, 25, 26</td>
<td>ICD-10 classification of neoplasm</td>
<td>Code</td>
<td>5</td>
<td>C18, C18.0, C18.1, C18.2, C18.3, C18.4, C18.5, C18.6, C18.7, C18.8, C18.9, C19, C20</td>
<td>If CANCER = 01(Yes) then this must be completed. If CANCER = 00(No) then this must be left blank.</td>
<td></td>
</tr>
<tr>
<td>TNM-T</td>
<td>KPI 9 - 14</td>
<td>Tumour classification (after surgery)</td>
<td>T</td>
<td>4</td>
<td>pTX, pT0, pT1, pT2, pT3, pT4,pT4A, pT4B, TX, T0, T1, T2, T3, T4, 99 - Not known</td>
<td>CANCER must = 01(Yes) and must be a valid value from National Data Definitions (if pathology).</td>
<td></td>
</tr>
<tr>
<td>TNM-N</td>
<td>KPI</td>
<td>Nodal classification (after surgery)</td>
<td>N</td>
<td>Characters</td>
<td>3</td>
<td>pNX, pN0, pN1, pN2, NX, N0, N1, N2, 99 - Not known</td>
<td>CANCER must = 01(Yes) and must be a valid value from National Data Definitions ¹(if pathology).</td>
</tr>
<tr>
<td>TNM-M</td>
<td>KPI</td>
<td>Metastases classification (after surgery). If there is enough clinical information then record as M0 or M1.</td>
<td>M</td>
<td>Characters</td>
<td>3</td>
<td>pMX, MX, M0, M1, 99 - Not known</td>
<td>CANCER must = 01(Yes) and must be a valid value from National Data Definitions ¹.</td>
</tr>
<tr>
<td>DUKES</td>
<td>KPI</td>
<td>TNM derived Dukes’ stage</td>
<td>Stage</td>
<td>Characters</td>
<td>3</td>
<td>01=A, 02=B, 03A=C1, 03B=C2, 04=D, 96=Not applicable, 99=Not known</td>
<td>CANCER must = 01(Yes) and must be a valid code from National Data Definitions ¹. 03 is not accepted.</td>
</tr>
<tr>
<td>POLYP</td>
<td>KPI</td>
<td>Polyps detected?</td>
<td>Y/N</td>
<td>Characters</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 - Not known</td>
<td>If COLPERF = 01(Yes) or BARENCTC = 01(Yes) then this must be completed. N/A is not accepted.</td>
</tr>
<tr>
<td>ADENOMA</td>
<td>KPI</td>
<td>Adenoma detected? (must have histological diagnosis)</td>
<td>Y/N</td>
<td>Characters</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 - Not known</td>
<td>If COLPERF = 01(Yes) or BARENCTC = 01(Yes) then this must be completed. N/A is not accepted.</td>
</tr>
<tr>
<td>ADENNO</td>
<td>KPI</td>
<td>This is a count for the number of adenomas submitted for pathological examination</td>
<td>Number/X</td>
<td>Numeric or Character</td>
<td>3</td>
<td>Numerical value, X - Not assessable, 99 - Not known</td>
<td>If ADENOMA = 01(Yes) then this must be completed. N/A is not accepted.</td>
</tr>
<tr>
<td>ADENSIZE</td>
<td>KPI</td>
<td>The maximum dimension in mm of the largest adenoma submitted for pathological examination</td>
<td>Max size (mm) /X</td>
<td>Numeric or Character</td>
<td>3</td>
<td>Numerical value, X - Not assessable, 99 - Not known</td>
<td>If ADENNO is a number then this must be completed.</td>
</tr>
<tr>
<td>POLYPCA</td>
<td>KPI</td>
<td>Polyp cancer detected?</td>
<td>Y/N</td>
<td>Characters</td>
<td>2</td>
<td>00 - No, 01 – Yes 99 - Not known</td>
<td>If COLPERF = 01(Yes) or BARENCTC = 01(Yes) then this must be completed. N/A is not accepted.</td>
</tr>
<tr>
<td>POLYPECT</td>
<td>QIS</td>
<td>Polypectomy performed at colonoscopy?</td>
<td>Y/N</td>
<td>Characters</td>
<td>2</td>
<td>00 - No, 01 – Yes, 99 - Not known</td>
<td>If COLPERF = 01(Yes) then this must be completed.</td>
</tr>
<tr>
<td>COMPLICP</td>
<td>KPI 7</td>
<td>The most serious complication arising directly from the colonoscopy requiring admission.</td>
<td>Description</td>
<td>Characters</td>
<td>00 - None, 01 - Perforation: A Pneumatic, B Mechanical, C Therapeutic, 02 - Bleeding, 03 - Pain, 04 - Sedation related, 05 - Post polypectomy, 06 - Death, 96 - Not applicable, 98 - Other, 99 - Not known</td>
<td>Must be a valid code from National Data Definitions 2.</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>------</td>
<td>--------------------------------------------------------------------------------</td>
<td>-------------</td>
<td>-----------</td>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>MORT</td>
<td></td>
<td>Has the patient died? (not necessarily of colorectal cancer)</td>
<td>Y/N</td>
<td>Characters</td>
<td>00 - No, 01 - Yes, 99 - Not known</td>
<td>*must have histological confirmation 1 NCDDP Colorectal Cancer Pathology Data Standards August 2007 2 NCDDP Colorectal Cancer Clinical Data Standards February 2008</td>
<td></td>
</tr>
</tbody>
</table>
5.5 Key Performance Indicators

1. Overall uptake of screening
2. Overall uptake of screening by Scottish Index of Multiple Deprivation (SIMD) 2009
3. Positive screening test result rate

Note: The 31 day and 62 day waiting time targets for screened patients are now reported by the Cancer Waiting Times Team


KPI 4 is included here for reference only

4. Time from screening test result date to date colonoscopy performed
5. Percentage of people with a positive screening test result going on to have a colonoscopy performed
6. Colonoscopy completion rate
7. Percentage of colonoscopic complications
8. Crude cancer detection rate
9. Percentage of people with screen detected cancers that are Dukes' Stage A
10. Percentage of people with screen detected cancers that are Dukes' Stage B
11. Percentage of people with screen detected cancers that are Dukes' Stage C1
12. Percentage of people with screen detected cancers that are Dukes' Stage C2
13. Percentage of people with screen detected cancers that are Dukes' Stage D
14. Percentage of people with screen detected cancer that are Dukes' stage Not known
15. Percentage of people with screen detected cancers that are Not staged
16. Percentage of people with screen detected cancers that are staged
17. Polyp cancer detection rate
18. Percentage of polyp cancers
19. Overall adenoma detection rate
20. High risk adenoma detection rate
21. Positive Predictive Value of current screening test to cancer
22. Positive Predictive Value of all adenomas where adenoma is the most serious diagnosis
23. Positive Predictive Value of current screening test to high risk adenoma
24. Positive Predictive Value of current screening test to high risk adenoma or cancer
25. Positive Predictive Value of current screening test to any adenoma or cancer diagnosis
26. Percentage of people with screen detected cancers that are malignant neoplasms of the colon (ICD-10 C18)
27. Percentage of people with screen detected cancers that are malignant neoplasms of the rectosigmoid junction (ICD-10 C19)
28. Percentage of people with screen detected cancers that are malignant neoplasms of the rectum (ICD-10 C20)

KPIs from Rounds 1, 2 and 3 of the pilot are attached at Appendix 3.
6. NHS Boards

There should be a designated consultant in public health medicine (CPHM) or registered specialist in public health identified as the bowel screening coordinator for each NHS Board. There should also be a designated lead clinician for each NHS Board area.

NHS Boards also provide resources to investigate all participants with a positive screening test result where appropriate. Local NHS Board planning and funding arrangements also take account of the following:

- health professionals required for pre-assessment
- additional workload on diagnostic services
- additional workload on surgery and oncology

NHS Boards have responsibility:

1. to provide support and publicity to encourage uptake (see Chapter 7 for more information),
2. to develop protocols for travellers and homeless people and those in long stay institutions,
3. to establish receiving arrangements for SCI Gateway referrals from BoSS,
4. for pre-assessment for colonoscopy (see Appendix 4),
5. for colonoscopy (see Appendix 5),
6. for collection of minimum dataset for all bowel screening referrals,
7. for submission of data to Information Services NHS National Services Scotland (ISD), and
8. for production of annual reports on the performance of bowel screening in their area.

NHS Boards are required to ensure the quality and performance of care for the patients within their Board area who are referred for further investigation and treatment. Any patient with an overall positive screening test result will be referred into the existing care pathway for patients with bowel symptoms. From April 2010 the 62-day urgent cancer waiting time target was extended to include screened positive patients and all patients referred urgently with a suspicion of cancer. The screening programme should therefore be viewed as an additional urgent referral route and not as a
separate service. Waiting time data definitions can be accessed on the ISD website at [New Cancer Waiting Times Targets](#).

### 6.1 Support and Publicity to Encourage Uptake

Effective communication channels and a clear strategy are at the centre of this bowel screening programme to ensure full integration and support from partners and service providers. The main focus of the communications strategy is to raise awareness of the importance of the screening programme in the early detection of bowel cancer. Key target groups in raising awareness of the bowel screening programme are health professionals, partners and the general public. (See Chapter 7)

The communication strategy outlines why we should communicate with the key target groups, what information is appropriate to give, and how and when we communicate with these groups. Monitoring our communication outputs is also to be considered, to ensure we are communicating effectively.

NHS Health Scotland provides a portfolio of communications material and will continue to monitor and evaluate the content of this material. NHS Health Scotland will also brief local coordinators on the aims and objectives of the campaign.

NHS Boards are responsible for ensuring:

- increasing knowledge with clinicians both in primary and secondary care,
- identifying local priority groups and targeting them accordingly,
- identifying local opportunities to increase uptake and promotion of campaign material and information, and
- providing information about follow-up tests and treatment.

(See Chapter 7 – Communication Strategy)
NHS Boards have a responsibility to develop protocols for:

- Travellers/homeless people, and
- Those in long stay institutions.

(See Chapter 8 for more information)

6.2 Referral of Screening Test Positive Individuals

The Bowel Screening call-recall System (BoSS) refers participants with a positive bowel screening result to their local NHS Board via SCI Gateway. When a positive screening test result is recorded for a participant, BoSS sends out a “positive” letter to both the participant and their GP (if they have one). These letters are sent by post.

BoSS also sends a pre-populated message to the participant’s local NHS Board via SCI Gateway to a pre-determined “receiving” address in SCI Gateway.

Individual NHS Boards are responsible for arranging for authorised personnel to have access to the SCI Gateway address specified, and responsibility for ensuring that the SCI Gateway address is checked daily to pick up any referrals received from BoSS.

The authorised personnel can then pick up the BoSS messages and make appointments for the participants accordingly.

If a referral has been received and needs to be forwarded to another NHS Board, this can be done using SCI Gateway (see SCI Gateway flowchart at Chapter 5).

6.3 Pre-assessment for colonoscopy

In order to reduce anxiety, encourage participation and compliance and minimise the risks of colonoscopy all individuals who have a positive screening test result should be offered a pre-colonoscopy assessment by a suitably qualified health care professional.
Managing referrals

Once notification of an individual with a positive result is received by the NHS Board, the NHS Board must ensure that there is a robust pathway to capture and manage referrals.

SCI Gateway must, without exception, be checked every morning Monday – Friday for new referrals from the Bowel Screening Programme. Individuals referred by the Scottish Bowel Programme should be managed, from an administrative perspective, as urgent referrals for colonoscopy. NHS Board protocols should be in place to ensure that pre-assessment and colonoscopy appointments are allocated in a timely manner. Protocols should contain role specific guidance to outline explicitly the responsibilities of colleagues and teams contributing to the management of individuals referred by the Screening Programme. There must be more than one individual responsible for accessing and actioning the referrals.

Reports will be produced for each meeting of the NHS Board’s Bowel Screening Group / monthly outlining the number of referrals received from the Screening Centre during the reporting period, describing individuals’ progress along their investigative pathway and the actions taken to address any delays. This will ensure that all individuals complete a pathway.

There is evidence that the time interval between receiving a positive screening test result and assessment for colonoscopy can result in significant anxiety. HIS Standard 5, Pre-colonoscopy Assessment, states that this time should be within 14 days for at least 80% of individuals and also that there are arrangements to identify all individuals who do not participate in pre-colonoscopy assessment and offer them a further opportunity to do so.

Health Care Professionals templates and guidance

It is suggested that in all cases a single assessment pro-forma is used to pre-assess patients for colonoscopy (see Appendix 4). The assessment crib sheet and assessment criteria could also be used to assist in undertaking the pre-assessment (see Appendix 4).

1 31-day target from date decision to treat to first cancer treatment.
62-day target from receipt of an urgent referral with a suspicion of cancer to first cancer treatment.
Non-responders and un-contactables

If a screening participant does not respond, is un-contactable or does not attend for pre-assessment a reminder should be sent approximately two weeks later, a copy being sent to their GP. This is in recognition that screening participants have had no contact with a health care professional up until the point of pre-assessment. If there is no response to the reminder within approximately two weeks the NHS Board will write to the participant and GP advising that if the participant reconsiders within a six month period the NHS Board can be contacted to undertake the pre-assessment.

If the individual reconsiders or has symptoms they can be referred by their GP through the normal symptomatic service route.

At this stage the screening participant is returned to the National Bowel Screening Programme and will be invited to participate in two years time if not over the age of 75.

Information pathway for patients

There is evidence that providing information about tests and investigations reduces anxiety and encourages participation (see *NHS QIS Standard 5 – Pre-colonoscopy assessment*). NHS Boards may wish to enclose information about colonoscopy (example – Appendix 5) with the letter of contact to the individual. This might include an explanation of the process of colonoscopy, the possible risks and outcomes, and is known to reduce anxiety in individuals awaiting further investigation.

NHS Boards will wish to consider the timing of issue of certain elements of information. The under noted is a suggested pathway.

Notification of positive result:

- Issue letter of notification of positive result (Bowel Screening Centre)
- Clinic appointment letter for pre-assessment (either face to face or telephone appointment dependant on NHS Board) and information about colonoscopy.
At face to face pre-assessment appointment (if the decision is to proceed to colonoscopy).

- Consent form (example – Appendix 5), contact card, next of kin form, bowel prep instructions, day surgery leaflet, diabetic information leaflet (if required), anticoagulation information leaflet (if required) and follow up arrangements.
- Colonoscopy appointment letter.

Following telephone pre-assessment appointment (if the decision is to proceed to colonoscopy):

- Consent form, contact card, next of kin form, bowel prep instructions, day surgery leaflet, diabetic information leaflet (if required), anticoagulation information leaflet (if required) and follow up arrangements.
- Colonoscopy appointment letter.

Following colonoscopy:

- Colonoscopy report.
- Recovery advice.

**Clinical assessment/fitness for colonoscopy**

The pre-assessment is an essential step to assess health fitness for the procedure. Some individuals may be assessed as high risk for colonoscopy and certain precautions need to be taken to minimise risk during the procedure. Other individuals may be deemed high risk for a screening colonoscopy due to significant co-morbid disease. The assessment criterion (Appendix 4) outlines some of the conditions for consideration. Consideration should be given to the specific follow up of patients where a known risk factor has been identified in the pre-assessment or during the screening colonoscopy procedure. NHS Boards are advised to have protocols in place for dealing with individuals on anticoagulants or who have diabetes and for bowel cleansing/preparation which comply with British Society of Gastroenterology guidance.

If from a telephone assessment there are potential risks/complications a face to face pre-assessment should be offered. If past history/medication has not been requested from the
GP or is difficult to obtain Clinicians responsible may consider best practice to obtain past history from GPs. NHS Boards should have a designated person(s) who makes the final decision on a person’s fitness to safely proceed the referral and participants should be seen by this person. The decision and the reasons should be clearly recorded and written communication should be given to the participant and their GP. The participant should be involved throughout the process and clear explanations and information should be given to assist the patient to make an informed choice.

In cases where the individual has decided not to progress with a colonoscopy, however reconsiders, they can be referred by their GP for colonoscopy through the normal symptomatic service route if thought appropriate.

Consent difficulties

See section 8.2.1; procedure for dealing with individuals with physical incapacity or consent difficulties.

Bowel Preparation

There is no national protocol for bowel preparation and its issue. NHS Boards to have local protocols in place.

Exclusions from screening colonoscopy

Individuals who are excluded from having a screening colonoscopy are:

- individuals who have had surgery in the past to remove their entire colon and rectum (Note that individuals who have formation of Ileo Anal pouch should continue to be invited for bowel screening and screened endoscopically as there is a continued risk of bowel cancer developing in the pouch),
- individuals who have had a complete colonoscopy in the previous 12 months,
- individuals who have had a myocardial infarct in the past 3 months (colonoscopy can be delayed to minimise risk), and
- any individual who is experiencing any acute or severe inflammatory process at the time such as ulcerative colitis, Crohn’s disease or acute diverticulitis.
6.4 Colonoscopy

6.4.1 See NHS Quality Improvement Scotland (NHS QIS) now known as Healthcare Improvement Scotland (HIS) Bowel Screening Clinical Standards (published February 2007).

There is evidence that waiting for colonoscopy creates anxiety (see HIS Standard 6, Colonoscopy and Histopathology). In at least 95% of cases the interval between the notification of the positive screening test result to the NHS Board and the date offered for colonoscopy should be within 31 days. The health care professional with responsibility for pre-assessment should endeavour to ensure that any clinical induced delays or patient choice delays are kept to a minimum.

6.4.2 Incomplete colonoscopy

Failure to complete colonoscopy may result in significant neoplasia being missed. A date for a barium enema or a computed tomography (CT) colonography should be offered within 31 days of an incomplete colonoscopy (see HIS Standard 6 c – A completion investigation of the entire large bowel is carried out after incomplete colonoscopy).

6.4.3 Colonoscopy findings

In order to minimise a participant’s anxieties, the findings of colonoscopy should be discussed following the procedure. To ensure a seamless pathway of care between secondary and primary care, delays in written communication should be kept to a minimum.

The findings of the colonoscopy should be discussed with the participant as soon as the participant is awake enough to be receptive to this. Ideally this should be followed up with a discussion with the person responsible for collecting the individual if the participant permits. Individuals should be told verbally what the next stage is e.g. no follow-up, barium enema or awaiting biopsy results.
6.5 Pathology

Background:

Cancer resections and polyps/biopsies will be sent to pathology. In the pilot, the workload on pathology was substantial.

Process:

NHS Boards will ensure quality of pathology is delivered and maintained to meet national bowel screening standards published by NHS QIS.

A National QA Pathology process has been established under the umbrella of the Scottish Pathology Network.

1. Pathologists reporting screening specimens are required to participate in the EQA slide circulation. The slide circulation is organised across the UK. This commenced in Spring 2010.

2. Reports on cancers and polypoid cancers issued in the programme will be formulated in accordance with UK guidelines (Royal College of Pathologists [www.rcpath.org](http://www.rcpath.org)). The specific bowel screening publication ‘Reporting Lesions in the NHS Bowel Cancer Screening Programme’ available from [www.cancerscreening.nhs.uk/bowel/publications/index.html](http://www.cancerscreening.nhs.uk/bowel/publications/index.html).

3. Experience from the pilot programme and early screening rounds has shown that about 15% of new cancers are early stage “polyp cancers” (a cancer focus in a lesion removed as a polyp and potentially cured at the time of endoscopic removal). This is well recognised as a difficult diagnostic area. The governance group of the bowel screening programme has recommended that a referral/review system is instituted. The attached Standard Operating Procedure details the operation of the system. Any polypoid cancer or suspected polypoid cancer (or any case in which there is diagnostic difficulty in this area) should be sent to Anne Park, Department of Pathology, Ninewells Hospital, Dundee DD1 9SY. Each case will be seen by two of a panel of three pathologists and a report issued to the referring department. A referral form is included with the SOP. The paperwork will also be published on the Scottish
Pathology Network (SPAN) website  
www.pathologyscotland.org.

4. Tumour staging is an important determinant of outcome and a surrogate of successful screening. Staging is a multidisciplinary activity and final stage for each patient will be documented at the colorectal MDT. Radiology and pathology data are particularly important in this regard. A Staging Protocol has been developed for the Bowel Screening Programme and is available at Appendix 7.

6.6 Radiology

Background:

Following an incomplete colonoscopy, a referral for a double contrast barium enema or a computed tomography (CT) colonography is made.

Process:

Radiology appointment will be offered.

NHS Boards will ensure quality of radiological procedure is delivered and maintained to meet national bowel screening standards published by HIS.

6.7 Collection of minimum dataset for all bowel screening referrals

A minimum dataset has been developed to monitor and evaluate the Bowel Screening Programme. NHS Boards are responsible for collection of this minimum dataset for all individuals with a positive screening test result. This information should then be submitted to colleagues at Information Services (ISD) Scotland Services within six months of a positive test result.

6.8 Submission of data to Information Services NHS National Services Scotland (ISD)

Non-clinical information is provided by BoSS (the Bowel Screening IT system) and clinical information is provided by the individual
NHS Boards. The 14 NHS Boards may use different software packages to generate the data file and, to accommodate this, a specification of the data items to be collected and the format required has been developed.

6.8.1 BoSS

Non-clinical data should be in csv format (comma separated value), in the correct order with the column headings as per the minimum dataset BoSS specification.

6.8.2 NHS Boards

The clinical data should be in csv format (comma separated value), in the correct order with column headings as per the minimum dataset NHS Board specification (see Chapter 5.4).

6.8.3 Submission of information to ISD

Bowel Screening Information from BoSS and the Health Boards – Submitting the Minimum Dataset – Instructions. The most up-to-date version (v.6) has been circulated to NHS Boards and is also available on request.
6.9 Escalation Procedures

Any screening programme has the potential for significant adverse incidents. It is important to audit incidents with the aim of minimising risk. In this way improvements in practice can be identified and disseminated to a wider group. There is also potential for an incident to occur at any stage in the screening process and for complaints/issues about the service to become high profile.

NHS Quality Improvement Scotland (NHS QIS) now known as Healthcare Improvement Scotland (HIS) has developed Bowel Screening standards covering six key areas:-

- general
- call-recall
- the screening process
- the laboratory process
- pre-colonoscopy assessment
- colonoscopy and histopathology

As the bowel screening programme is the responsibility of both the local NHS Boards and the Scottish Bowel Screening Centre (SBoSC) based in Dundee separate escalation procedures have been developed for the SBoSC and for NHS Boards.

NHS Board responsibilities are set out below:-

- provide support and publicity to encourage uptake.
- develop protocols for travellers and homeless people and those in long stay institutions,
- establish receiving arrangements for SCI Gateway referrals from BoSS
- pre-assessment for colonoscopy
- colonoscopy
- collection of a minimum dataset for all bowel screening referrals
- download data to Information Services NHS National Services Scotland (ISD) and
- production of annual reports on the performance of bowel screening in their area.
The following covers escalation procedures within these areas.

A Scottish Bowel Screening Programme Governance Strategy has been developed setting out the key roles, responsibilities and relationships for the programme and providing a strategic framework for the development of clinical governance. It is essential that management of risks relating to the Bowel Screening Programme are set within the context of this Governance Strategy and individual NHS Boards’ systems of governance and risk management.

The methodology for ascribing levels of risk should be consistent with local proactive risk assessment, risk management and incident reporting processes already in place. Identifying the likelihood of most events occurring can be subjective and based upon the knowledge and expertise of those involved. Evidence and statistics may however be available regarding the recurrence of certain events and this information can help anticipate and plan.

Annex A sets out the escalation framework for NHS Boards.
Annex B includes an escalation flowchart for NHS Boards
Annex C – Categorisation of Risks - example

NATIONAL SERVICES DIVISION
October 2012
ANNEX A
SCOTTISH BOWEL SCREENING PROGRAMME
Escalation Procedures for NHS Boards

1. Any healthcare professional involved in the Scottish Bowel Screening programme who becomes aware of a suspected problem should follow their agreed local NHS Board clinical governance procedures and the Bowel Screening Programme escalation procedures.

GREEN

2. If local investigation concludes that the problem will only have minimal impact and the risk assessment is Green, local governance procedures should be followed and the local Service Manager advised to ensure that effective countermeasures are put in place to resolve the issue satisfactorily.

AMBER

3. If a fairly significant problem is identified (and the risk assessment is Amber) but there is no cessation in service provision then the local Service Manager, the NHS Board Lead Bowel Screening Clinician and the NHS Board Screening Coordinator should be advised and planned action initiated to resolve the problem. The Programme Manager, Scottish Bowel Screening National Services Division (NSD) should also be advised of the problem and the action taken and outcome.

3.1 If the action successfully resolves the problem a report should be provided to NSD. The NHS Board should continue to monitor for recurrence.

3.2 If the action does not resolve the problem then it should be treated as having a significant impact and the risk assessment should be escalated to Red.
RED

4. A major/catastrophic problem is defined for example as the NHS Board being unable to meet service provision or the occurrence of a significant clinical incident. It also includes the cessation of services that will impact on screening participants e.g. cancellation of colonoscopy sessions or loss of key staff for an extended period of time is likely or necessary and can not be resolved locally and there is the potential for adverse publicity. In these circumstances the NHS Board Chief Executive, NHS Board Screening Co-ordinator, the local NHS Board Lead Bowel Screening Clinician and NSD should be alerted immediately on the extent of the problem by the relevant local Service Manager. A detailed report should be forwarded to NSD on the extent of the problem and including potential solutions.

4.1 Depending on the nature of the incident NSD in discussion with local Screening Co-ordinator, Managers and Lead Clinician will agree actions to be taken. NSD will also inform the Scottish Government Health Directorate (SGHD) of the problem and the agreed action plan. The Bowel Screening Governance Committee will also receive a detailed report in due course.

4.2 The agreed action plan is implemented by the NHS Board and NSD will monitor and report to the SGHD and the Bowel Screening Governance Group.

4.3 If the action plan resolves the problem a report should be provided to NSD. The NHS Board and NSD should continue to monitor for recurrence.

4.4 If the Action Plan does not resolve problem then NSD and SGHD will consider further action and whether a full independent external investigation/peer review is instigated.

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ANNEX B
SCOTTISH BOWEL SCREENING PROGRAMME
Escalation Procedures for NHS Boards

Resolved

**Risk Assessment is Green**
Incident or Variance occurs. Effective countermeasures put in place and issue is resolved.

Local Governance procedures to be followed and local Service Manager advised.
- Countermeasures put in place to resolve
- continue to monitor
- no further action required.

Not resolved or

**Risk Assessment is Amber**
Incident or Variance occurs and requires a prolonged countermeasure but is resolvable.

Local Service Manager, Lead NHS Board Bowel Screening Clinician and NHS Board Screening Co-ordinator discuss
- Inform Programme Manager, Bowel Screening, NSD
- Continue to monitor
- no further action required.

Not resolved or

**Risk Assessment is Red**
Incident or Variance occurs and a countermeasure is not possible.

Lead Bowel Screening Clinician and NHS Board Screening Co-ordinator discuss and no resolution is identified and/or could have significant impact on Programme.
- Advise Chief Executive
- Advise National Screening Co-ordinator, NSD
- Continue to monitor
- Further action to be identified by NSD and NHS Board.
## ANNEX C

### SCOTTISH BOWEL SCREENING PROGRAMME Escalation Procedures for the NHS Boards

#### Categorisation of Risks - Example

<table>
<thead>
<tr>
<th>Description</th>
<th>Strategic</th>
<th>People</th>
<th>Operational</th>
<th>Clinical</th>
<th>External</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GREEN</strong></td>
<td>Minimal impact on the Programme Scope</td>
<td>Minimal disruption to staff/very minor delay in recruiting staff. Minor H &amp; S incident/minor staff complaint/short-term vacancy.</td>
<td>Minimal impact – no service disruption/no adverse publicity.</td>
<td>No obvious clinical harm or injury to participant.</td>
<td>Minimal impact on services or operations.</td>
</tr>
<tr>
<td><strong>AMBER</strong></td>
<td>Minor/ Moderate impact/change to Programme scope.</td>
<td>H &amp; S incident with some harm/staff unrest/key post vacant/ unable to recruit skilled staff to key roles for extended period.</td>
<td>Minor impact on service provision due to capacity issues/some public embarrassment/some objectives partially achievable/local adverse publicity.</td>
<td>Injury/harm/ medical intervention required e.g. screening referral dealt with inappropriately</td>
<td>Impact requiring change to services to comply with new legislation or directions.</td>
</tr>
<tr>
<td><strong>RED</strong></td>
<td>Major/ Complete change impacting on the original fundamental programme scope</td>
<td>Severe H &amp; S incident/industrial action/sustained loss of key groups of staff/ causing termination of operations.</td>
<td>Significant impact on service provision/unable to function or carry out programme obligations/ highly damaging national or international publicity.</td>
<td>Major clinical complication e.g. as a result of colonoscopy resulting in significant harm/injury to a screening participant.</td>
<td>Significant and costly change to comply with legislation and directions.</td>
</tr>
</tbody>
</table>
6.8 Annual Reports on the performance of bowel screening in their area

ISD Scotland will provide annual key performance indicators (KPIs) nationally and to all individual NHS Boards (see Appendix 3 and Chapter 5 – NHS National Services).

Annual Reports have been published each year since 2009. All annual reports including the latest Programme KPI report (which was released in August 2012) are available at:

http://www.isdscotland.org/Health-Topics/Cancer/Bowel-Screening/
7. Communications

7.1 2010 – Going forward

Effective communication and a clear strategy are at the centre of the Scottish Bowel Screening Programme in order to ensure the programme is fully integrated in the health system, there is support from partners and service providers, and the uptake and impact of the programme can be maximised.

At the outset of the development of the national programme a Communications and Coverage Group was established. This set out a national communications strategy identifying the aims and objectives of the work needed to be undertaken to inform, communicate and publicise. The main focus of the strategy was to identify, implement and evaluate methods for raising awareness of the Scottish Bowel Screening Programme as it is rolled out across Scotland between 2007 - 2011.

A suite of campaign materials was developed and as each NHS Board launched the bowel screening programme in its area, these materials were used to support local awareness.

The development of materials and the communications strategy is informed by research undertaken to understand how people might engage with the programme and be encouraged to take the test.

NHS Health Scotland chair a National Screening Communications & Information Group (NSCIG) which meets quarterly to oversee and advise communications activities relating to all screening programmes in Scotland, including a standing item on Bowel Screening.

There is also a national communications group under the auspices of The Scottish Government’s Detect Cancer Early programme which oversees the development of the various strands of the DCE public awareness campaigns. In 2013 DCE will launch the Bowel Cancer element of the DCE programme, with a focus on screening. Strategic links will be made between the NSCIG and the DCE communications group to ensure communications activity for Bowel Screening and DCE are dovetailed appropriately.
7.2 COMMUNICATION GOAL AND OBJECTIVES

Aim
The aim of the national communications strategy from the outset was to support activities undertaken by local NHS Health Boards to raise awareness of and maximise the uptake of the Scottish Bowel Screening Programme in Scotland during roll-out.

Now the roll-out is complete, the key objectives continue to be to:
- Increase awareness of bowel cancer in the Scottish population
- Identify audience and key stakeholders to ensure partnership working
- Provide targeted information on bowel screening, including the benefits and the risks, to support informed choice
- Promote the importance of early detection through screening
- Provide information on how easy it is to complete the test
- Support and integrate equality and diversity issues
- Develop/adapt and make available a wide range of communications resources and activities for reaching target groups and engaging partners
- Take account of evaluation and research work previously undertaken
- Evaluate and keep under review the effectiveness of efforts to raise awareness.

Main Key Message of communications activities:
The main key message remains:
- Bowel screening reduces deaths from bowel cancer

Supporting Key Messages
Beyond the central message, supporting key messages include:
- All men and women between the ages of 50 and 74 are being invited by post for bowel screening every two years
- The test is easy to do
- Early detection could save your life
- Bowel cancer is a common cancer
- Men have a 50% higher risk than women
- It is important to take the test every two years, even if you have had a negative result in the past
- You can call the National Bowel Screening Service Helpline (0800 0121 833) for more information about completing the test.
• Know the symptoms of bowel cancer, and if you have any concerns, seek consultation with your doctor as soon as possible.

7.3 COMMUNICATION ROLES

A number of partners play a specific role in delivering communications for this programme.

NHS Health Scotland:
• Developed communications strategy and supported annual roll-out of communications campaign with and for NHS Scotland Health Boards
• Creates, develops, provides and distributes communications materials
• Undertakes ongoing monitoring and evaluation of content and updating of information materials
• Provides support to the national programme and NHSScotland Health Boards on communication activities
• Identifies national opportunities for raising awareness of the programme through national events and media
• Chairs the National Screening Communications & Information Advisory Group.

National Services Division:
• Provides expertise on updating of information materials
• Provides funding for national information materials
• Informs and directs national communications needs.

Scottish Government:
• Provides funding to fund national communications activities
• Provides support and leadership in terms of Ministerial support for awareness raising.

Individual NHSScotland Health Boards:
• Undertakes local publicity to raise awareness of the programmes, identifying local opportunities to promote the programme and encourage uptake
• Increase knowledge of the programme amongst clinicians in primary and secondary care
• Identifies local priority groups to target and raise awareness
• Provides information about follow-up tests and treatment.
National Bowel Screening Centre for Scotland, NHS Tayside, Dundee:
- Manages calls to the Scottish Bowel Screening Helpline (0800 0121 833)
- Provides intelligence and expertise on the information needs of those contacting the centre in order to inform the development of materials and communication messages.

NHS 24 / Helpline:
To ensure that calls to NHS 24 Helpline are dealt with efficiently, the NHS Helpline will provide:
- Information on the Scottish Bowel Screening Service, its eligible groups, the procedure for being involved and signposts to the specific Scottish Bowel Screening Helpline where appropriate
- Support in accessing translations and alternative formats of campaign material
- Information on signs and symptoms and route for referral to GP if caller has concerns
- General information and literature on bowel cancer and signpost to the Bowel Cancer UK helpline (0800 840 35 40) for more detailed information on bowel cancer.

Partners in the voluntary sector:
- Work in partnership with all interested parties in order to maximise national uptake of the Scottish Bowel Screening Programme
- Help to publicise and promote the Scottish Bowel Screening Programme and its key messages
- Provides information and literature on bowel cancer via the Bowel Cancer Advisory Service
- Provides feedback and input for current and future Bowel Screening information, literature and material.
7.4 COMMUNICATIONS ACTIVITIES AND RESOURCES

7.4.1 Reaching the target audience

The Scottish Bowel Screening Campaign has two main target groups, public and professional.

The general public eligible for the programme are:
- men between the ages of 50-74 years
- women between the ages of 50-74 years

This includes specific sub-groups which evidence suggests are experiencing differential uptake:
- deprived communities
- ethnic minority communities
- people with disabilities
- travellers and homeless people

The professional groups include key health professionals and key staff in the community/voluntary sector – working in or providing information about the screening programme

The communications strategy was developed to support the successful delivery of the programme and implementation of the roll-out included the need for information materials.

7.4.2 Sources of information to support uptake and raise awareness:

A suite of materials and resources have been developed for the national programme and can be used locally and across Scotland.

The use of branding helps people to identify with a service, its place, its authenticity and its purpose. The national programme now has an established brand so that there is a consistent a look and feel which runs across all resources. In line with the Scottish Government’s brand guidelines, all materials also carry the Healthier Scotland logo.
• **Posters**
  Awareness raising posters for the public and for use by professionals in surgeries, hospitals and community settings.

• **General information leaflet**
  Translations of all public information leaflets and booklets are available online to download as PDF in 9 key languages as well as English:
  - Urdu
  - Bengali
  - Hindi
  - Spanish
  - French
  - Polish
  - Russian
  - Lithuanian
  - Chinese [Traditional]

  We are happy to consider requests for translations in other alternative languages and formats. Please contact the NHS Health Scotland Publications team at [http://www.alternative.formats@health.scot.nhs.uk](http://www.alternative.formats@health.scot.nhs.uk) or telephone 0131 536 5500.

• **Support materials**
  Information materials are provided with the invitation letter and test kit when this is sent out to those eligible for the programme. This includes: *Bowel Screening: Your Questions Answered*, a leaflet aimed to introduce the screening programme and the test itself; and two *Step by step instruction* leaflets for the initial FOBt Test and for the repeat FiT test.

  See accessing resources below to get hold of on-line or hard copies.

• **DVD**
  A DVD has been developed to assist healthcare professionals to deliver key information about the programme and help explain the bowel screening test. It promotes informed uptake by providing a clear and practical guide on how to perform the screening test.

  This DVD can be used in a variety of settings, including community groups and in one-to-one patient consultations. It has subtitles and voiceover options in:
Communications

- English
- British Sign Language (BSL)
- Polish
- Urdu
- Sylheti
- Punjabi
- Chinese (Cantonese with traditional Chinese subtitles)

It is available as a DVD or can be viewed online and can be downloaded from: http://www.healthscotland.com/topics/health/screening/bowel.aspx, the Bowel Screening Programme website at: http://www.bowelscreening.scot.nhs.uk/index.php/bsdvd as well as on YouTube at: http://www.youtube.com/user/NHSHealthScotland and on http://www.signtube.com

All of the materials above are available for NHSScotland Health Boards to use and supplies can be requested from local Health Promotion departments and NHS Health Scotland. See section on accessing resources below.

- Easy-Read Version
In 2012, NHS Health Scotland & NSD supported Bowel Cancer UK to produce a Bowel Cancer & Screening resource for people with learning disabilities and their carers. A link to this resource, entitled ‘Good Bowel Health: A Resource for people with learning disabilities’ will be available at: www.nhsinform.co.uk/screening from September 2012.

The resource demonstrates:
- What is involved in the bowel screening process
- Why good bowel health is essential
- Why recognising the symptoms of bowel cancer is so crucial
- How important the bowel cancer screening programme is.

- Website
A dedicated Scottish Bowel Screening Programme website was created for those seeking more information about the programme. This is hosted by NHSScotland National Services Scotland: http://www.bowelscreening.scot.nhs.uk
In 2012, a new screening zone was developed by NHS Health Scotland in partnership with NHS 24. This screening zone, aimed at members of the public, is available at www.nhsinform.co.uk/screening and has a dedicated section on bowel screening.

- **Helpline**
  There is also a National Bowel Screening Freephone Helpline (0800 0121 833) which is run by the Scottish Bowel Screening Centre in Dundee. The staff here are able to answer queries from the public and give more information about how to complete the test and help them to re-order a test kit.

7.5 THE NATIONAL PROGRAMME AND LOCAL NHS BOARDS WORKING TOGETHER

What the national programme can do to support NHS Health Boards

In order to ensure the messages delivered are as effective and consistent as possible, it’s important to build upon the communications work undertaken to date and brand awareness established.

Support and advice on communications activities can be obtained from NHS Health Scotland which manages the national communications strategy and delivers national communications for the Programme. The Communications team can be reached on 0131 536 5500.

Materials and artwork are also available as detailed in the sections below.

What does the national programme need from NHS Health Boards?

The national programme needs information from NHS Health Boards in order to inform key national stakeholders, co-ordinate activities and consider any implications or opportunities for the programme across Scotland.

The national programme and Health Boards can really benefit from shared learning and information. When undertaking local activities the national programme communications team would want to be notified of:
• Local planned, proactive marketing and/or media relations work
• Local reactive media relations and the nature of the enquiry/ies from the media
And would ask that they are
• Passed on any marketing/media/advertising/partnership opportunities brought to local boards which the board is not able to undertake but the national programme might be able to consider.

7.5.1 NHSScotland Boards and communications activities

There are many communications activities which can be, and are being, undertaken by NHSScotland Health Boards.

The national programme works to support local delivery and this local awareness raising. Communications activities which have been undertaken by Health Boards on a local level include:
  • Local radio advertising and interviews
  • Local media relations and press partnerships
  • Inserts in NHS payslips
  • Engagement and partnership with local community and voluntary groups
  • Road shows and stalls at local events (football matches, Agriculture shows)
  • Convenience and Outdoor advertising
  • Distributing a locally produced DVD

The national programme continues to provide support in terms of branding, materials and advice and ideas. Images, artwork files and logos are available on a disc for use on locally produced materials and these can be obtained from the communications team on – 0131 536 5500.

• Print Advertising - the local press
Local papers talk to the reader on a personal level, and it is also an effective medium at imparting detailed information. Local papers also have a tendency to be more receptive to carrying editorial pieces.

There are well over 300 local Scottish newspapers. Local newspapers are very well read among some of the deprived groups identified. Local newspapers
also have a longer ‘shelf’ life than daily papers, as they are usually only printed once a week.

Many area Health Boards through their Communication departments and/or Health Promotion departments have taken out local advertising and continue to consider this option for raising awareness.

- **Media Relations**

As many health professionals know, media coverage of health issues can help to inform the public and encourage action such as going for screening or contacting the health service.

Many area Health Boards through their Communication departments have undertaken activity to raise awareness of the bowel screening programme through local media coverage. This has included issuing press releases and undertaking interview on the launch of the bowel screening programme in their local area; releasing local statistics on the uptake of the programme; realising local statistics on the incidence of bowel cancer; stories featuring individuals who have benefited from screening, and so on.

Using statistics, cases studies and resources including the Bowel Screening leaflet, posters and the Bowel Screening website, Health Boards can continue to raise awareness of the programme through local print, radio, TV and on-line media.

Bowel Cancer Awareness month (established by Bowel Cancer UK) is **April**. This affords a useful ‘hook’ every year for driving attention to the programme and how those eligible can look after their health.

For photocalls, pull-up/pop-up advertising banners are available on loan from the national programme 0131 275 6757.

- **Radio Advertising**

Local radio is a trusted source of information and, similar to local press, can have a community focus. Radio, by comparison to other media, can be more intimate with radio listening often being a more individual experience between station and listener.
Local radio can be local commercial radio stations; local/regional opt-outs of BBC Radio Scotland such as BBC Radio Borders or BBC Radio Highland; and community radio (very local stations, often staffed by volunteers and operating right at the heart of communities).

Those eligible for the programme will be listeners or AM, FM or DAB station output. Each station is able to supply information on their audience reach – how many listeners, the age/gender etc. breakdown of their listenership. Targeting advertising at the right group of listeners can be very effective.

- **Ambient /convenience advertising**
  Other forms of advertising include posters at bus stops, washroom panels, branded credit card size information cards, beer mats, panels and/or screens at football/sporting grounds and so on.

A previous bowel cancer campaign by BCAP found that washroom panels and beer mats worked well in raising awareness amongst the older males in a C2DE demographic particularly.

Such advertising opportunities can be taken up locally by Health Boards and national branding can be used for this with consent from the national programme.

- **Online advertising**
  With campaigns where there is a lot of information to communicate or the subject matter is fairly complex, people often want to seek further information/research in their own time.

The Bowel Screening Programme website is easy for the public to access if and when they use search engines to search for ‘bowel screening Scotland’, ‘bowel screening’ or ‘bowel cancer Scotland’. A simple message is to ‘google’ bowel screening and follow the link to the Scottish Bowel Screening Programme.

In exploring opportunities to raise awareness locally it is worth considering online and/or the online sites of local media, companies and organisations. For example, if undertaking advertising on a local radio station there may also be an opportunity through the stations website too as a package, or say through advertising with a local football club.
• **Roadshows**
Roadshows can be a very effective form of field marketing. Having stands/stalls/displays/mobile advertising units at community days, fetes/fairs, shopping centres, festivals, agricultural markets, sporting events, etc. where those eligible for screening and their loved ones might attend can be a very good way of raising awareness. Leaflets, showing the DVD on a screen, having people to ask questions of at the event can help people to become more familiar with the programme and its benefits so that they recognise the invitation to participate when they receive it in the post.

• **TV**
Television can be a very effective way to raise general awareness of a programme or service across the population.

The 50-74 age group does include lots of TV viewers. Picking the right timing and programmes to advertise around could reach those eligible for the programme and their loved ones and friends.

National television advertising is not being undertaken by the programme at this stage while the full national programme is bedding in. However, it is possible to advertise locally and during 2009 NHS Greater Glasgow and Clyde advertised across the West of Scotland transmitter areas through STV using a campaign developed using the national programme brand.

### 7.6 ACCESSING RESOURCES

#### 7.6.1 For healthcare professionals:

The *Bowel Screening Information Pack for Healthcare Professionals* is available at: [http://www.healthscotland.com/documents/2065.aspx](http://www.healthscotland.com/documents/2065.aspx). This resource folder for healthcare professionals contains pages on: taking part in the Bowel Screening Programme; the FOBt test; the screening pathway; the National Bowel Screening Centre; what NHS Boards need to know and general information on bowel cancer in Scotland. Hard copies can be obtained from your local health promotion department or from [http://nhs.healthscotland-publications@nhs.net](http://nhs.healthscotland-publications@nhs.net)

The Information Sheet on *Bowel Cancer in Scotland* is part of the *Bowel Screening Information Pack for Healthcare Professionals* and is also available...


### 7.6.2 For those eligible for the screening programme:


The **Bowel Screening: Your Questions Answered** booklet which explains the programme and why it’s important to take part is available at: [http://www.healthscotland.com/documents/2064.aspx](http://www.healthscotland.com/documents/2064.aspx) or in hard copy from:
http://www.nhs.healthscotland-publications.nhs.net. The booklet is produced in English and nine other languages.


### 7.6.3 Marketing materials for use with the public:


Three posters to raise awareness of the bowel screening programme in Scotland are available to download at: [http://www.healthscotland.com/documents/2066.aspx](http://www.healthscotland.com/documents/2066.aspx) or in hard copy from: nhs.healthscotland-publications@nhs.net.
8. Protocols

8.1 Clinical Protocols

Background:

Clinical protocols will be locally developed and should closely link with existing colorectal pathways. The exception to this is the pre-assessment for participants with a positive screening test result.

A flowchart of the process can be found at the end of this section.

Process:

8.1.1 Pre-assessment
The Centre will issue positive results to patients and copy to the GP Practice but pre-assessment appointments will be the responsibility of the NHS Board.

Each participant with a positive screening test result will be pre-assessed prior to being offered a colonoscopy.

Chapter 6 (NHS Boards) sets out best practice protocol for pre-assessment.

8.1.2 Colonoscopy

Background:

Colonoscopy is the first investigation offered following a positive screening test result.

Process:

Following pre-assessment, if appropriate, a colonoscopy appointment is offered at the time of pre-assessment.

NHS Boards will ensure quality of colonoscopy is delivered and maintained to meet national bowel screening standards published by HIS.
See Chapter 6 (NHS Boards) for more information.

8.1.3 Radiology

Background:

Following an incomplete colonoscopy, a referral for a double contrast barium enema or a computed tomography (CT) colonography is made.

Process:

Radiology appointment will be offered.

NHS Boards will ensure quality of radiological procedure is delivered and maintained to meet national bowel screening standards published by HIS.

8.1.4 Pathology

Background:

Cancer resections and polyps/biopsies will be sent to pathology. In the pilot, the workload on pathology was substantial.

Process:

NHS Boards will ensure quality of pathology is delivered and maintained to meet national bowel screening standards published by NHS QIS.

See Chapter 6 (NHS Boards) for more information.

8.1.5 Screening Flowcharts:
SCREENING CENTRE

Call target population 50-74 from CHI

Send first invitation

Test kit NOT returned within 6 weeks

Send reminder letter

No response

Return to list to be invited in 2 years

Test kit returned

Negative result

Overall positive result

Referral to NHS Board

NHS BOARD COLORECTAL SERVICE

Repeat testing required

Positive result

Referral to NHS Board

Negative result

Replacement test kit sent

Replacement kit requested

Send Reminder Letter

No Response

GP & Participant informed

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8.2 Other Eligible Groups Protocols

- Individuals with physical incapacity and individuals with consent difficulties
- Individuals in long stay institutions
- Individuals in Prisons
- Individuals in the Armed Forces
- People who do not wish to be screened
- Travellers and Homeless people

8.2.1 Procedure for dealing with individuals with physical incapacity or consent difficulties.

Physical incapacity
Individuals with all levels of physical ability will be invited by the bowel screening programme. It is important to note that although FOBt sampling may easily be carried out by a carer the next step for positive patients is an invasive procedure. The participant must be fully informed of the consequences of a positive FOBt result and the possible further investigation.

Consent difficulties
The Adults with Incapacity (Scotland) Act 2000 is an Act of the Scottish Parliament that makes provision for the property, financial affairs and personal welfare of adults who are incapable by reason of mental disorder or inability to communicate. The law of Scotland generally presumes that adults (those aged 16 or over) are legally capable of making personal decisions for themselves and managing their own affairs. That presumption can be overturned in relation to particular matters or decisions on evidence of impaired capacity.

The Adults with Incapacity (Scotland) Act 2000 sets out the framework for regulating intervention in the affairs of adults who have (or may have) impaired capacity, in the circumstances covered by the Act. A revised Code of Practice for Part 5 of the Act was issued in 2008 (CEL 11 2008) and was circulated to NHS Board Chief Executives in March 2008. This circular set out the 5 general principles of the Act namely (1) benefit, (2) minimum necessary intervention, (3) take account of the wishes of the adult, (4) consultation with relevant others and (5) encourages the adult to exercise residual capacity.
The Act allows for an intervention but an intervention is only permitted where the adult lacks capacity in relation to the subject matter of the intervention. It is necessary to consider whether the adult lacks capacity in relation to the relevant matter each time a decision or action fails to be taken. The Act also sets out that carers and relatives will have valuable information about the patient’s present and past wishes and feelings but care should be taken not to let them simply answer for the adult, or put words into his or her mouth.

Meaning of treatment – Under subsection 47(4) of the Act, ‘medical treatment’ includes any procedure or treatment designed to safeguard or promote physical or mental health. Screening is classed as treatment for the purposes of the Act.

General Authority to treat – Authority to do what is reasonable in the circumstances in relation to medical treatment is set out in section 47 of the Act.

Process

An individual’s primary health care provider (this may or may not be a General Practitioner) should be involved to consider what, if any, intervention is required in individual cases. They will be able to assess the situation based on the individual’s past and present medical history and consider the best way forward in terms of the Act.

Good practice would also be to provide health care messages about the signs and symptoms to look out for as set out in the Scottish Bowel Screening: Your Questions Answered Leaflet.

8.2.2 Protocol for People in Long Stay Institutions and Prisons
(This protocol is only applicable for those who are in care or serving sentences for over 6 months)

Medical Dictionary Definition for Long-Term Care Facility

A facility that provides rehabilitation, restorative, and / or ongoing skilled nursing care to patients or residents in need of assistance with activities of daily living. Long-term care facilities include
Background
There may be individuals in long stay institutions that are within the eligible age range. However, careful assessment by health care professionals (HCP) responsible for their care will be essential.

Process:

- NHS Boards should develop protocols to ensure that those in long stay institutions within their area who are eligible to participate can be informed about the programme. The precise mechanism will need to be determined through locally developed protocols.

- NHS Boards will be required to ensure that key HCPs are contacted in each institution within their NHS Board area so that those eligible to be invited to participate in the programme can be identified to the Centre.

- Using the Bowel Screening Call-Recall (BoSS) call on demand module the Centre will issue all invitation packs and result letters to the participants identified HCP.

- For individuals with positive screening test results pre-assessment for colonoscopy should be arranged between the HCPs in the institution and the local NHS Board.

- Following pre-assessment the individuals should be referred to the local hospital for further investigations. Normal procedures for hospital admission will be carried out.

- On closure of this screening cycle the BoSS record will revert to the demographic details held on CHI and will no longer be attached to the BoSS call on demand. The next recall invitation will go to the address held on CHI and will only reach the participant if they have returned to their home address. So recall of the institution will have to restart every two years or when the HCP provides information directly to the Helpline.
The Centre procedure for calling the identified various institutions will follow the same principle for each as follows:

- Procure a list of HCPs responsible as identified by their NHS Board
- Contact these HCPs to ask for:
  - The named HCP to send the invitation packs and results c/o
  - The CHI numbers of eligible individuals who can make informed choice as regards taking part in bowel screening
- The Centre will contact each named institution every two years to request CHI numbers of eligible individuals.

The institution may contact the Centre to ask on behalf of an individual that they be invited for screening. This is in the same way that any non responder who has already been invited contacts the Helpline to request to be screened.

Standard Operating Procedures and flow plans will ensure that once trained all Helpline staff can add participants to this module when they are contacted by a HCP.

This process is the expected pathway.

8.2.3 Protocol for People in the Armed Forces

Background

Service Personnel should request bowel screening via their Service Medical Centre, and the Ministry of Defence should either arrange or commission screening on their behalf.

Work, being led by Scottish Government Health Directorates in partnership with the MoD, is currently underway to issue all forces personnel in Scotland Community Health Index (CHI) numbers by the end of 2012. Forces personnel will then be invited for Bowel Screening using the usual call-recall mechanism.
Process
Information will be provided once a protocol has been agreed.

8.2.4 Protocol for People who do not wish to be screened - Informed dissent

Background and Process
Those who advise that they do not wish to participate in the Programme and sign a “disclaimer” letter to that effect are excluded (see Appendix 8, Letter ID 13). This is currently part of the programme.

A small number of the population strongly object to being invited and refuse from the outset of their conversation with Helpline staff, to receive any further correspondence. It is important that the person wishing to withdraw from the screening programme understands the implications of his or her decision and also understands that he or she can be returned to call/recall at any time on request. The SBSC Helpline Officer will make every effort to obtain written evidence of the informed nature of a person’s decision.

If the decision is communicated by telephone and the person is unwilling or unable to confirm the decision in writing, it is advisable to ask a supervisor to witness the call so that at least two members of staff can independently confirm and document the ceasing instruction. The caller will also be asked to confirm that their GP can be notified of their decision so that they can be provided with support and advice.
8.2.5 Protocol for Travellers and Homeless People

Background
Travellers and homeless people may not have a fixed address in Scotland or be registered with an NHS Scotland GP practice but will be included in bowel screening as long as they have a CHI number.

Process
Minimum expected from NHS Boards

- All NHS Boards should develop protocols to ensure that travellers and homeless people within their area are informed about the programme. The precise mechanism will need to be determined through locally developed protocols – an example of an NHS Board protocol is attached at Appendix 6
- NHS Boards should liaise with housing offices, libraries and community pharmacies and encourage them to display posters
- It is necessary that the individual keeps their details up to date with the GP Practice and / or the Centre for follow-up and recall. The participant will be invited following normal procedure.
- Travellers on static sites are usually registered with a GP and have a postal address therefore will be called using the usual call-recall mechanism.

This process is the expected pathway.

Optional for NHS Boards
- NHS Boards may choose to identify Health Care Professionals (HCP) to raise awareness, provide support and education in travelling and homeless groups. The HCP should encourage registration with a GP and to participate in screening.
- NHS Boards can request that a group of eligible travellers or homeless be added to Bowel Screening Call-Recall System (BoSS) call on demand module. This will allow a HCP to identify participants to the Centre under an allocated name for example ‘Meadowfield Travellers Site’ or ‘Oldtown Homeless Practise’. HCPs will provide an active CHI number
to the Centre. The Centre will call all those identified who are eligible for screening.

Once allocated under this heading the participant invitation packs will be issued on the following day c/o the named HCP. The named HCP will then be responsible for issuing and supporting these individuals through the process. Individuals will return their test kits directly to the Centre in the freepost envelope as per the normal practice. Results will be issued c/o the HCP.

On closure of this screening cycle the BoSS record will revert to the demographic details held on CHI and will no longer be attached to the BoSS call on demand module. The process will be repeated every 2 years or when the HCP provides information directly to the Helpline.

The above can also be used for travellers or homeless requesting bowel screening through Keep Well Nurses.

**8.2.6 Cross Border Protocol**

A protocol has been developed for ensuring that those residents living in the border region between Scotland and England can access the appropriate screening programme. This protocol was developed in partnership with the Scottish Bowel Screening Centre, NHS Borders and NHS Dumfries and Galloway and is consistent with other cancer screening programme protocols. It is the agreed protocol between Scotland and England ensuring that residents are invited to either the Scottish or English Bowel Screening Programme as appropriate. The protocol can be accessed at Appendix9.
8.3 Safe Guarding Protocol

Background:
Safe Guarding in a screening programme means that at any point of the screening pathway it is possible to identify what stage each individual is at within their screening episode. It also identifies if an individual defaulted at any point. It ensures that the screening programme can be adequately monitored and that there is an identified end point of screening for all individuals.

Process:
Call-Recall
- Only participants with a valid CHI record and an Area of Residence (AOR) will be invited
- Individuals not listed on CHI must contact a GP Practice to register on CHI.
- All eligible participants with a CHI number but who are not registered with a GP Practice will still be invited. The onus is on an individual to ensure that demographic information is kept up-to-date
- All eligible individuals with a CHI number but no Area of Residence will not be invited. This is to ensure a point of referral.

Transfers in
- Individuals who are eligible and provide information on previous bowel screening will have their recall date amended.
- When an eligible individual moves from outside NHS Scotland, they will be issued an immediate call-recall date.

Transfers out
- Individuals who transfer to another NHS Board will continue to have their own recall date and be called within 2 years. If they are in the middle of the screening test pathway this will continue until a result is achieved and the results are then sent to their new address (see below - referral to NHS Boards).
- If an individual transfers out of NHS Scotland in the middle of the screening test pathway an interim or final result letter concluding the screening episode in Scotland will be issued to the last known address and will be copied to the last known General Practitioner data held on the Community Health Index.
People who default the screening test.

- Individuals who default the FOBt screening test pathway will be sent one reminder after their initial invitation. If they do not respond to the reminder they will automatically be put back on the 2 yearly recall.
- Individuals who default the second line FIT screening test pathway will be sent two reminders. If they do not respond to the reminders they will automatically be put back on the 2 yearly recall.
- GP practices will be notified of those people who return a spoiled or out of date screening kit.

Referral to NHS Boards

Background:
All participants with a positive screening test result will be automatically referred to their local NHS Board by SCI Gateway.

Process:
- A participant with a positive screening test result will be referred from the Bowel Screening System (BoSS) via (SCI Gateway) to the participant’s NHS Board.
- This referral will be sent directly to a pre-defined point of contact in the Health Board.
- The referral sent will be via a standard protocol-based referral which will be populated automatically from BoSS.
- The IT system will provide a way of confirming that the referral has reached its destination. The Screening Centre will contact an NHS board by fax where the electronic referral is shown to have failed.
- It is the responsibility of the individual NHS Board to action positive screening test referrals promptly.
- BoSS will recall all individuals 2 years from invitation date.
NHS Boards (HIS Standards)

Background:
When an individual is referred to an NHS Board for assessment and investigation it will be essential that each NHS Board can identify the outcome for each participant with a positive screening test result (see extract from HIS standards below).

Process:
- This will be locally agreed but could follow same mechanism as for symptomatic patients and should take into account NHS QIS Bowel Screening Programme Standards.
- Tracking systems and mechanisms for measuring waiting times for bowel screened participants will require to be developed locally. However, previously established waiting times tracking systems could be used.

Extract from Essential HIS criteria:-

Pre-colonoscopy assessment

- The time between the receipt of a positive screening test result by the NHS Board and the offered appointment date for pre-colonoscopy assessment should be within 14 days for at least 80% of individuals.
- Arrangements should be in place to identify all individuals who do not participate in pre-colonoscopy assessment and they should be offered a further opportunity to do so.
- All individuals with a positive screening test result should be offered a pre-colonoscopy assessment and a full explanation of the process of colonoscopy, the possible risks and the possible outcomes. The opportunity to discuss any concern should be provided at this stage and written information provided.
- Pre-colonoscopy assessment should be carried out by a healthcare professional who has appropriate skills, knowledge and experience and national guidance should be followed to identify those at a higher risk than normal from a colonoscopy.
• Clear and appropriate patient pathways are followed for individual with a positive screening test result who do not proceed to colonoscopy.

• GPs are informed of all individuals with a positive screening test result who do not proceed to colonoscopy.

• At least 80% of individuals who undergo pre-colonoscopy assessment and are deemed fit for colonoscopy are offered a date at the time of assessment.

**Colonoscopy**

• In at least 95% of cases, the interval between the notification of the positive screening test result to the NHS Board and the date offered for colonoscopy is within 31 days.

• In at least 95% of cases, GPs are notified of the results of colonoscopy within seven days.

• A date for a barium enema or a computed tomography (CT) colonography is offered within 31 days of an incomplete colonoscopy.

• The reports for at least 80% of radiological examinations are authorised within seven days of the date of the examination.
9. Healthcare Improvement Scotland Quality Standards

The development of clinical standards for the bowel screening programme is the responsibility of Healthcare Improvement Scotland, taking into account advice from the Scottish Bowel Screening Programme and in consultation with NHS organisations.

HIS established a project group to take this work forward, chaired by Professor Bob Steele. The group first met in February 2006 and considered a number of topics surrounding the bowel screening programme pathway and for this starting point six key areas for clinical standards were identified.

- general
- call-recall
- the screening process
- the laboratory process
- pre-colonoscopy assessment and
- colonoscopy and histopathology

HIS published Bowel Screening Programme Clinical Standards on 6 March 2007 and these can be accessed on the NHS QIS website at:

http://www.nhshealthquality.org/nhsqis/3344.html
10. Governance Strategy

10.1 Introduction

Executive Summary

Governance arrangements and responsibilities for the Scottish Bowel Screening Programme are shared across the NHS in Scotland under the umbrella of the NHSScotland Healthcare Quality Strategy that was published in June 2010. This Governance Strategy aims to ensure that Scottish Bowel Screening participants access a bowel screening pathway that is safe, effective and person centred. To ensure that requires the engagement across national and local systems including the Scottish Bowel Screening Centre (hosted by NHS Tayside) and local NHS Boards who require to deliver the further diagnostic tests to those who screen positive.

In summary

NHS Tayside is responsible for delivering safe, effective and person centred bowel screening through the Scottish Bowel Screening Centre and their local governance arrangements.

All 14 NHS Boards are responsible for the safe, effective and person centred diagnostic testing arrangements for those who test positive through the Bowel Screening Programme.

National Services Division is responsible for facilitating the national performance management and reporting of all aspects of the Programme to ensure the safe, effective and person centred bowel screening pathway. This is delivered through the Bowel Screening Programme groups and structures.

The Healthcare governance sub-group of the Bowel Screening Programme Board advises and reports on the governance of all centrally commissioned and delivered elements of the programme. It also makes recommendations to NHS Board Chief Executives on changes required in the organisation and delivery of locally managed programme services in the light of audit findings.

More detailed information on these Governance structures are set out in this Chapter of the Bowel Screening Manual.
10.1.1 Scottish Bowel Screening Programme

The Scottish Bowel Screening Programme (SBoSP) commenced a phased roll out in mid-2007. All NHS Boards commenced bowel screening by December 2009, and national coverage was achieved by December 2011.

The SBoSP sends an invitation every two years to all men and women registered on the Community Health Index (CHI), between 50-74 years of age. Individuals receive information to explain the programme, an instruction leaflet and a screening test kit. The completed kit is returned to the central laboratory for testing. If an individual has a positive result an electronic referral is made to their NHS Board of residence which is responsible for making arrangements for the individual to be assessed and for any further investigation, usually examination of the bowel by colonoscopy. (See Appendix 1 for a flowchart of the screening process).

National Services Division (NSD) NHS National Services Scotland, has a co-ordinating, commissioning and performance management role in relation to the programme. There is a single screening centre for Scotland hosted by NHS Tayside, based at King’s Cross Hospital, Dundee. This provides the call/recall office, helpline facility and the screening test laboratory. This activity is managed through a Service Agreement (SA) between NSD, on behalf of Scottish Government, and NHS Tayside which sets out the activity, finance and oversight arrangements for the Scottish Bowel Screening Centre.

NHS Boards have a responsibility to contact all individuals referred from the screening centre with a positive screening test, to provide a timeous appointment for pre-assessment and investigation, usually by screening colonoscopy, and thereafter all necessary treatment and care (See Appendix 10 for an organogram showing organisational relationships).

This section of the manual provides an overview of the healthcare governance arrangements required to support the delivery of the SBoSP to the highest standard. This replaces an original Governance Strategy, published in 2006 which offered a strategic
framework for clinical governance from implementation to 2011. It is intended to be a living document and will be subject to ongoing review and revision in light of the impact of implementing the three quality ambitions (Safe, Effective and Person-Centred care) arising from publication of the NHS Scotland Healthcare Quality Strategy in June 2010.

10.1.2 Healthcare Governance and Clinical Quality

Clinical Governance and Risk Management (CGRM) arrangements are core aspects of the management of health services within the NHS. The term ‘Clinical Governance’ was first advised in NHS MEL (1998) 75¹. NHS Scotland published a Healthcare Quality Strategy² in June 2010 and this restated a commitment to deliver high quality healthcare with a particular emphasis on ‘Safe, Effective and Person-Centred’ care.

In common with other national screening programmes the SBoSP has worked, since its inception, to the agreed clinical quality standards³ published by NHS Quality Improvement Scotland (HIS) and in addition reports against a number of Key Performance Indicators (KPIs) collected within every NHS Board in Scotland. The KPIs are collated and analysed by Information Services Division of NSS. The second publication on 31 August 2010⁴ covered every NHS Board in Scotland for the first time, recognising that a number of NHS Boards were only able to provide partial data in light of recent implementation of the programme in their area.

10.2 Purpose of the Governance Strategy

All NHS organisations are required to maintain robust clinical governance and risk management arrangements. The introduction of the concept of Healthcare Quality has extended this responsibility and this strategy seeks to advise an overarching Governance framework which will provide assurance to the public for whom the SBoSP is provided, to the wider NHS in particular the

² [HEALTHCARE QUALITY STRATEGY SGHD 2010](http://www.show.scot.nhs.uk/sehd/mels/1998_75.htm)
³ [BOWEL SCREENING STANDARDS QIS 2007](http://www.show.scot.nhs.uk/sehd/mels/1998_75.htm)
⁴ [BOWEL SCREENING KPIs ISD 2010](http://www.show.scot.nhs.uk/sehd/mels/1998_75.htm)
territorial NHS Boards, and to the clinical teams involved in delivering elements of the programme.

NHS Quality Improvement Scotland was required, under the terms of NHS HDL (1002) 48 to undertake a process of External Quality Assurance of national Screening programmes. This external review is intended to focus on whether the screening programme is delivering care to the level stated in the Clinical Standards for Bowel Screening, but it is recognised that there are a number of other key elements to the programme which sit outside these Standards. Healthcare Improvement Scotland (HIS), which replaced NHS QIS on 1st April 2011, no longer intends to routinely review performance against the published standards; rather a targeted approach will be applied to review services where there is evidence that a review will be helpful. This evidence will include information derived from the concurrent work being taken forward by HIS in relation to the quality of endoscopy services.

10.3 A Governance Strategy for the Scottish Bowel Screening Programme

10.3.1 Components of the Healthcare Governance / Quality Strategy
At a strategic level, there are six components that underpin Healthcare Quality and these in turn are reflected in the three quality ambitions published as part of NHS Scotland commitment to continuous improvement of healthcare services. The six domains are:

- **Person Centred**: Understanding and improving individual care experience, providing sufficient information and supporting individual choice. This also includes consultation and patient involvement and partnership working.
- **Safe**: reducing all harmfull variation in care thus achieving a reduction in the number of events which may lead to harm.
- **Effective**: that the most appropriate technologies and interventions are used to deliver healthcare and that the care that is delivered is subject to an ongoing programme of audit and scrutiny leading to further improvement when issues are identified.

---

5 NHS (HDL) 2001 48 Quality Assurance for Breast and Cervical Screening Programmes
• **Efficient**: the service makes best use of all available resources, eliminating waste and demonstrating best practice in financial performance as well as in use of the workforce involved in delivering the programme.

• **Timely**: that there will be no unnecessary delays in delivering elements of the programme and that all positive results will be acted upon within the agreed timelines as set out in the clinical quality standards.

• **Equitable**: the programme will be able to demonstrate that all who are invited to participate in the programme are supported to do so and that there will be no exclusions based on disability or any other aspect of lifestyle or culture.

### 10.3.2 Responsibilities

NSD / NSS is committed to working in close partnership with NHS Boards, Information Services Division of NSS, Healthcare Improvement Scotland and NHS Health Scotland, to deliver the SBoSP safely, effectively and in a person centred manner, and to consistently achieve optimal outcomes for patients.

The SBoSP requires a number of organisations to work together to ensure the quality of care for each individual participant in the programme at every stage of their journey. It is assumed that all participants in the delivery of SCoSP will be working to the Clinical Standards for Bowel Screening (published by NHS QIS 2007) and will be active participants in Clinical Governance and Risk Management arrangements within their own NHS Board.

This requires all of the groups involved in the programme to understand their role;

• **National Services Division, NHS National Services Scotland**: key responsibility for the coordination of all aspects of the SBoSP, including oversight and support of the Governance arrangements. NSD will be responsible for the management of the service agreement relating to the Scottish Bowel Screening Centre and all other nationally commissioned elements of the programme. This will include the routine capture of information, including staffing, finance and activity, as well as the publication of an annual report now based on the six domains of quality.

• **All territorial NHS Boards**: responsible for the local delivery of clinical services to screening test positive patients, for
seeking assurance that all eligible individuals are offered Bowel screening, and for encouraging them to participate in the programme.

- **Scottish Bowel Screening Centre and NHS Tayside:** responsible for the quality of service in relation to the delivery of the aspects of the SBoSP delegated to the centre in Dundee.

- **Healthcare Improvement Scotland:** responsible for providing external assurance that the SBoSp is being delivered in a manner that achieves published quality and clinical standards.

- **Scottish Government Health Directorates (SGHD), Population Screening Directorate:** responsible for ensuring that policy on national screening is kept up to date and to give formal assurance to Senior Directors and Ministers that the SBoSP is being delivered to the appropriate standard.

### 10.3.3 Healthcare Governance Structure for SBoSP

A Healthcare Governance subgroup of the Bowel Screening Programme Board will be established with responsibility to provide oversight of all aspects of the quality of the delivery of SBoSP.

In particular the group will:

- Oversee the delivery of an effective level of Patient and Public Involvement and monitor the user experience.

- Monitor risk management, including incident reporting; as well as reviewing complaints, compliments and comments from users.

- Review outcomes and benefits arising from the SBoSP, seeking to benchmark performance across NHS Scotland and other equivalent programmes.

- Ensure that programmes of Clinical Effectiveness are appropriate and effective; to include improvements arising from clinical audit, particularly in areas identified as being associated with significant risk,

- Ensure that information governance standards are maintained and are appropriately and effectively addressed within the programme.

- Ensure that research associated with SBoSP is appropriately and effectively controlled in research governance terms,
monitor research literature to ensure the SBoSP is being delivered using best available evidence

- Ensure that the education, training and continuing professional development of centrally employed staff is appropriately and effectively managed;

The SBoSP Healthcare Governance sub-group will:

- Report to the Scottish Bowel Screening Programme Board on the governance of all centrally commissioned and delivered elements of the programme;

- Make recommendations to the NHS Board Chief Executives on changes required in the organisation and delivery of locally managed programme services in the light of audit findings.

10.3.4 Monitoring and Evaluation

Monitoring and evaluation of the SBoSP at individual NHS Board level and nationally will be undertaken by a Monitoring and Evaluation Group supported by NSD and Information Services Division (ISD) of NSS. KPIs for the overall programme will be provided by NHS Boards, collated and analysed by ISD, and results shared with individual NHS Boards prior to publication.

The Monitoring and Evaluation Group will regularly report to the Healthcare Governance subgroup on the relevant aspects of these processes and, by exception, on any issues of concern or requiring further investigation.

10.3.5 Accountability

The formal accountability for the achievement of the delivery of a quality service for the population of an NHS board area lies with the Chief Executive of each NHS Board; and thus they hold the overall responsibility and accountability for the governance of those elements of the SBoSP carried out within their NHS Board by their staff. It is recognised that NHS Boards will usually delegate the leadership of Healthcare Governance arrangements to one of the senior clinical managers of the NHS Board, most often the Medical Director.

To that end it is essential, and an assurance is given, that the Healthcare Governance subgroup will liaise directly with an NHS
Board should an issue of concern be identified. A reciprocal arrangement is sought in that members of the SBoSP Healthcare Governance subgroup are available to support any work being undertaken within an NHS board in relation to any aspect of the SBoSP.

10.4 Specific Areas of Governance Enquiry

10.4.1 Within the programme

The full screening algorithm is set out in appendix 1; however from the individual participant's perspective these key areas require a process of quality assurance:

- **Call / Recall** – that all eligible persons are sent an invitation on a 2 yearly basis
- **Screening Centre and Laboratory** – the testing of screening samples is undertaken in a consistent and reliable manner and that results are communicated timeously, in particular that referral of individuals with a positive test result to their local NHS Boards is robust.
- **Helpline** – that this is able to provide accurate advice in a timely and helpful manner
- **Pre Colonoscopy assessment** – that NHS Boards have a reliable process to contact individuals referred with a positive screening test result to offer a time bound appointment for colonoscopy at a local centre.

10.4.2 Outwith the programme

The following issues are technically beyond the authority of the SBoSP but are integral to the successful delivery of the commitment to both early detection of cancers and to the effective treatment of any screen detected disease.

- **Colonoscopy** – NHS Board monitor the quality of the colonoscopy service offered. In contrast to the English Bowel Screening Programme where there is a separate programme for colonoscopy for screening: NHS Scotland offers colonoscopy within the NHS Boards standard GI service arrangements. The quality assurance of SBoSP requires all colonoscopy providers to report issues and concerns as part of the overall screening programme arrangements. In addition Healthcare Improvement Scotland is progressing
work on the wider assurance of endoscopy, including colonoscopy services through the JAG (Joint Advisory Group on GI Endoscopy).

- **Surgical / Clinical Intervention when a cancer is identified** – that NHS Boards monitor the quality of the surgical, or other interventional care offered following identification of a screen detected cancer. The quality assurance of SBoSP requires all interventional care providers to report issues and concerns as part of the screening programme risk management arrangements. The SBoSP also seeks to monitor the incidence of ‘interval cancers’ as a means of completing the cycle of assurance.

### 10.5 Conclusion

Healthcare Governance is a wide-ranging agenda and in order for it to be implemented appropriately and effectively in respect of Bowel Screening it is essential that all participants maintain awareness with regards to the diversity of activity across NHS Board boundaries. The main stakeholders will have different roles and responsibilities and clinical governance operational plans will need to be tailored to the needs of each to a considerable extent.
Appendix I - Screening Programme Flowchart
Appendix II – Responsibilities and Relationships Organogram
Appendix III - Components of Clinical Governance

1) Consultation and Patient Involvement and Partnership Working
Involving the public and patients in local clinical governance arrangements can serve different purposes. At an individual level, the involvement of patients in decisions about their care increases the effectiveness of their treatment. At the more collective level, public and patient involvement can provide a means for the screening programme to demonstrate accountability to the populations we serve (directly or indirectly), to improve staff-public communication, understanding and relations, and engage the specific expertise that the members of the public have to offer in influencing the planning, delivery and monitoring of the screening programme from the experience-based perspectives of those on the receiving end of care.

The screening programme needs to be able to demonstrate how the public and other stakeholders have been involved in the decision-making processes for service delivery and how relevant information about services is provided to the public with the following aims:

- enhancing accountability,
- working with partner agencies and avoiding duplication,
- sharing information and best practice,
- using appropriate methods of patient and public involvement,
- supporting the public and patients in the PPI process,
- ensuring feedback to the community.

2) Risk Management
It is only through the effective management of risk that we can be assured that the screening programme is doing everything possible to manage to meet the programme’s objectives, and to protect patients, staff, the public and other stakeholders against a plethora of risks. Risk Management has been defined as the culture, processes and structures that are directed towards the effective management of potential opportunities and adverse effect.

Good risk management awareness and practice at all levels is a critical success factor for any organisation. Risk is inherent in every aspect of the screening programme, from call/recall to patients undergoing
colonoscopy. The need is to adopt a systematic and consistent approach to risk management with the following aims:

- enhancing accountability,
- promotion of NSS-wide no-blame culture;
- working with NHS Boards where appropriate to establish complementary approach to risk management;
- ensuring a robust system for critical incident reporting is in place to identify risks and to learn from errors and near misses;
- sharing lessons learned from complaints and good practice;
- creating a strategy for the management of poor performance;
- organising training as appropriate.

3) Clinical Audit
Clinical Audit is conventionally concerned with assessing the quality of care delivered to patients by individuals or organisations. Audit seeks to improve the quality of patient care through a system whereby clinicians examine their practice and compare the results against agreed standards and best practice, modifying their practice where indicated. The Programme Board will promote and support clinical audit within individual professional groups and, where appropriate, multi-disciplinary audits with the aims of:

- increasing Board audit awareness;
- increasing awareness of the benefits of audit and the necessity for the complete audit cycle;
- developing a NSS Audit Strategy;
- creating an Audit Sub-Group;
- implementing a robust system for audit;
- increasing multi-disciplinary involvement in audit;
- improving data quality;
- identifying and accessing any national resources for audit;
- sharing anonymised results from the audits in order that staff can learn from each others experience.

The Clinical Governance subgroup will monitor the appropriate and effective operation of a clinical audit programme.
4) Clinical Effectiveness & Research

Where appropriate, stakeholder organisations will embrace clinical effectiveness as a central characteristic of the services they deliver and/or commission. Effectiveness will underpin planning decisions and service delivery. Professional skills in this area will be supported through programmes of continuing education, training and development. Evidence based practice will be promoted through coordinators, clinical leads, and professional collaboration and meetings.

Wherever possible, SBoSP will use appropriate benchmarking tools, and will identify and/or adopt relevant indices for measuring and monitoring the impact of its services.

SBoSP will ensure that all staff can conveniently access evidence based information and will encourage staff to make maximum use of library services and other systems which enhance the application of evidence based medicine.

SBoSP will ensure that all research carried out or contributed to by its staff is registered and that systems are in place and operating appropriately to ensure that all registered research complies with research governance standards including, where appropriate, research ethics consideration/approval. Aims include:-

- development of a strategic approach to clinical effectiveness;
- ensuring that staff have access to the best available evidence;
- supporting the development of staff skills in literature searching, critical appraisal and change management;
- supporting effective dissemination of evidence-based practice;
- supporting the implementation of national and other sources of guidance, both within provider services and commissioned services, particularly:
  - NHS QIS / SIGN guidelines;
  - Integrated Care Pathways;
• ensuring strategies and policies are in place to assist clinical staff in optimising medicines management, in particular, patient group directions.
• ensuring strategies and policies are in place to monitor the compliance of research activity with research governance standards.

5) Education, Training & Continuing Professional Development
Employers have a statutory responsibility to ensure that all personnel carrying out duties on their behalf are appropriately trained and this responsibility is discharged through the policies and work of their Staff Governance Committees. Where training relates to the clinical work of staff involved in the Bowel Screening Programme, the Clinical Governance subgroup will also have an interest and responsibility. The Clinical Governance SBoSP will invest effort into developing strategies, to attract staff with appropriate knowledge, skills and attitudes, but also to motivate, develop and support them in providing sustainable high quality services to our users. SBoSP stakeholder organisations will be responsible for ensuring that the development of staff is in line with organisational objectives. Delivering a quality service depends on:

• enhancing the skills of existing staff through training and development; and
• developing new groups of staff with the right skills and competencies to meet Programme priorities.

Means of achieving these objectives may include:

• systems to ensure that all staff are appropriately registered with professional bodies.
• CPD through personal development planning;
• Appraisal;
• multi-disciplinary training;
• remedial training;
• PDP planning;
• effecting linkage, where appropriate, with education providers to support personal development needs;
• linking training needs to the strategic business and direction of the organisation;
• leadership development.
SBoSP aims to identify problems with performance at the earliest possible stage to protect both staff and patients. Appraisal and individual development planning processes will underpin policies and procedures. The aim will always be to identify individuals showing signs of difficulties and/or under performance and help these to be addressed before more serious problems arise.

6) **Use of information**
All NHS organisations are held accountable, through Clinical Governance, for continuously improving confidentiality and security procedures in accordance with the Caldicott Report. The Guardian is usually the Medical Director.

SBoSP will integrate the policies and controls that govern our use of information in respect of both paper and electronic records, and will ensure that best practice is used to inform all developments in the area, giving particular regard to Caldicott Guardianship, Data Protection and the Freedom of Information Act under the overall heading, *Information Governance*. Information Governance issues will be reported to the Clinical Governance subgroup.
11. Contact Details

National Services Division
Ms Carol Colquhoun
National Screening Co-ordinator
NHS Scotland Screening Programmes
National Services Division
NHS National Services Scotland
Gyle Square, 1 South Gyle Crescent
EDINBURGH EH12 9EB
Email: carol.colquhoun@nhs.net
Tel: 0131 275 6158   Fax: 0131 275 7614

Mrs Janice Birrell
Programme Manager
National Services Division
NHS National Services Scotland
Gyle Square, 1 South Gyle Crescent
EDINBURGH EH12 9EB
Email: janice.birrell@nhs.net
Tel: 0131 275 6609   Fax: 0131 275 7614

Scottish Bowel Screening Programme – Lead Clinician
Professor Robert J.C. Steele
Professor of Surgical Oncology
Department of Surgery and Molecular Oncology
Ninewells Hospital and Medical School
Dundee DD1 9SY
Email: r.j.c.steele@dundee.ac.uk
Tel: 01382 632174   Fax: 01382 496361
Contact Details

**Bowel Screening Centre Manager**
Ms Linda Brownlee  
Scottish Bowel Screening Service Manager  
Scottish Bowel Screening Centre  
Kings Cross  
Clepington Road  
Dundee DD3 8EA  
Email: linda.brownlee@nhs.net  
Tel: 01382 425 678 ext 35678  Fax: 01382 425679

**Head of Bowel Screening Centre Laboratory**
Ms Judith Strachan  
Consultant Biochemist and Head of BSC Laboratory  
Scottish Bowel Screening Centre  
Kings Cross  
Clepington Road  
Dundee DD3 8EA  
Email: judith.strachan@nhs.net  
Tel: 01382 660111 ext 33364 (Ninewells)  
01382 660111 ext 13339 (Perth Royal Infirmary)  
01382 660111 ext 71266 (Scottish Bowel Screening Centre)
Appendix I – Dukes’ Stage Comparisons

CRC Registrations by Dukes’ Staging for Health Boards piloting screening
Males and Females, aged 50-69
Bowel Screening Pilot commenced
April 2000

CRC Registrations by Dukes’ Staging for Health Boards not piloting screening
Males and Females, aged 50-69

*includes data to December 2006
Breakdown of Dukes’ Staging in the Screen-detected Population, Scotland
Males and Females aged 50-69
Date of invite April 2000 to June 2007

<table>
<thead>
<tr>
<th>Dukes’ Stage</th>
<th>2000/01</th>
<th>2001/02</th>
<th>2002/03</th>
<th>2003/04</th>
<th>2004/05</th>
<th>2005/06</th>
<th>2006/07*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not known</td>
<td>3.0</td>
<td>1.6</td>
<td>2.9</td>
<td>9.4</td>
<td>8.6</td>
<td>6.7</td>
<td>5.3</td>
</tr>
<tr>
<td>Dukes’ D</td>
<td>17.6</td>
<td>27.1</td>
<td>18.6</td>
<td>17.8</td>
<td>22.4</td>
<td>32.4</td>
<td>34.2</td>
</tr>
<tr>
<td>Dukes’ C</td>
<td>15.7</td>
<td>27.1</td>
<td>22.9</td>
<td>27.0</td>
<td>32.8</td>
<td>22.9</td>
<td>21.3</td>
</tr>
<tr>
<td>Dukes’ B</td>
<td>57.2</td>
<td>45.7</td>
<td>47.3</td>
<td>34.5</td>
<td>38.1</td>
<td>37.0</td>
<td></td>
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<tr>
<td>Dukes’ A</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
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*includes data to June 2007
Percentage of CRC Registrations by Dukes' Stage for Health Boards not piloting screening
Males and Females aged 50-69

1999/2000

Dukes’ D: 26.4
Dukes’ C: 28.5
Dukes’ B: 13.5
Dukes’ A: 9.9
Dukes’ unknown: 11.9

2000/2001

Dukes’ D: 23.1
Dukes’ C: 27.6
Dukes’ B: 12.6
Dukes’ A: 11.9
Dukes’ unknown: 11.9
### NHS Scotland Bowel Screening Roll Out Plan

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This table shows the roll-out plan for bowel screening across different NHS regions in Scotland, starting from June 2007 and ending in December 2008.
### Key Performance Indicators - Summary May 2008

<table>
<thead>
<tr>
<th>Min Standard</th>
<th>Min Standard</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall uptake of screening</td>
<td>60%</td>
<td>55.0</td>
</tr>
</tbody>
</table>

This relates only to persons successfully completing the FOB testing process. No adjustment is made for kits or initial letters returned by GPO.

<table>
<thead>
<tr>
<th>Min Standard</th>
<th>Min Standard</th>
<th>Min Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall uptake of screening by SIMD deprivation</td>
<td>Least Deprived</td>
<td>62.1</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>58.6</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>53.8</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>47.3</td>
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<tr>
<td></td>
<td>5</td>
<td>41.2</td>
</tr>
</tbody>
</table>

The Scottish Index of Multiple Deprivation (SIMD) has six domains (income, employment, education, housing, health, and geographical access) at datazone level, which have been combined into an overall index.

<table>
<thead>
<tr>
<th>Min Standard</th>
<th>Min Standard</th>
<th>Min Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response rate for first kit sent</td>
<td>&gt;= 50% of those invited</td>
<td>43.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Min Standard</th>
<th>Min Standard</th>
<th>Min Standard</th>
<th>Min Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time btwn appt with specialist nurse and colonoscopy</td>
<td>2 weeks</td>
<td>20.4</td>
<td>25.8</td>
</tr>
<tr>
<td></td>
<td>4 weeks</td>
<td>44.1</td>
<td>61.0</td>
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<td></td>
<td>6 weeks</td>
<td>64.7</td>
<td>77.8</td>
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<td>8 weeks</td>
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<td>20 weeks</td>
<td>96.2</td>
<td>99.3</td>
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</table>

N.B. colonoscopy date taken from nurse report assumed to be first offered colonoscopy date.
<table>
<thead>
<tr>
<th>Min Standard</th>
<th>Target</th>
<th>Complete First Round Data</th>
<th>Complete Second Round Data</th>
<th>Complete Third Round Data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>5 Proportion of people found FOBt positive</strong></td>
<td>To Be Agreed</td>
<td>20.7</td>
<td>19.0</td>
<td>11.6</td>
</tr>
<tr>
<td>(per 1000 screened i.e. with FOBt result available)</td>
<td></td>
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<tr>
<td><strong>6 Crude cancer detection rate for all ages</strong></td>
<td>To Be Agreed</td>
<td>2.1</td>
<td>1.2</td>
<td>0.7</td>
</tr>
<tr>
<td>(This includes polyp cancers)</td>
<td></td>
<td></td>
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<tr>
<td><strong>7 % people with screen detected cancers that are Dukes’ Stage A</strong></td>
<td>To Be Agreed</td>
<td>49.2</td>
<td>40.1</td>
<td>36.3</td>
</tr>
<tr>
<td>(includes polyp cancers)</td>
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<tr>
<td>(must have histological confirmation)</td>
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<tr>
<td><strong>8 % people with screen detected cancers that are Dukes’ Stage B</strong></td>
<td>To Be Agreed</td>
<td>20.3</td>
<td>29.4</td>
<td>21.8</td>
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<td>(must have histological confirmation)</td>
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<tr>
<td><strong>9 % people with screen detected cancers that are Dukes’ Stage C1</strong></td>
<td>To Be Agreed</td>
<td>18.1</td>
<td>20.3</td>
<td>31.5</td>
</tr>
<tr>
<td>(must have histological confirmation)</td>
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<tr>
<td><strong>10 % people with screen detected cancers that are Dukes’ Stage C2</strong></td>
<td>To Be Agreed</td>
<td>2.8</td>
<td>3.0</td>
<td>2.4</td>
</tr>
<tr>
<td>(must have histological confirmation)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>11 % people with screen detected cancers that are Dukes’ Stage D</strong></td>
<td>To Be Agreed</td>
<td>7.1</td>
<td>2.0</td>
<td>0.8</td>
</tr>
<tr>
<td>(must have histological confirmation)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>12 % people with screen detected cancers that are staged.</strong></td>
<td></td>
<td>97.5</td>
<td>94.9</td>
<td>92.7</td>
</tr>
<tr>
<td>(must have histological confirmation)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>13 Overall adenoma detection rate</strong></td>
<td></td>
<td>6.5</td>
<td>5.2</td>
<td>2.6</td>
</tr>
<tr>
<td>(per 1000 screened i.e. with FOBt result available)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>14 Positive Predictive Value of all adenomas where adenoma</strong></td>
<td></td>
<td>36.5</td>
<td>30.3</td>
<td>29.1</td>
</tr>
<tr>
<td>is the most serious diagnosis (%) of people with any risk adenoma out of those FOBt positive</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>15 High risk adenoma detection rate</strong></td>
<td>To Be Agreed</td>
<td>0.8</td>
<td>0.5</td>
<td>0.3</td>
</tr>
<tr>
<td>(per 1000 screened i.e. with FOBt result available)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>16 Percentage of people found to be FOBt positive going on to have colonoscopy performed</strong></td>
<td>To Be Agreed</td>
<td>85.5</td>
<td>89.5</td>
<td>81.3</td>
</tr>
<tr>
<td><strong>17 Rate of colonoscopic complications [requiring admission]</strong></td>
<td>To Be Agreed</td>
<td>0.3</td>
<td>0.4</td>
<td>0.1</td>
</tr>
<tr>
<td>(% of people with admissions for complications out of those who had colonoscopy)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Min Standard</td>
<td>Target</td>
<td>Complete First Round Data</td>
<td>Complete Second Round Data</td>
</tr>
<tr>
<td>---</td>
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<td>---------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>18</td>
<td>Percentage of polyp cancers (% of people with polyp cancers out of all those with cancer)</td>
<td>17.8</td>
<td>15.2</td>
<td>9.7</td>
</tr>
<tr>
<td>19</td>
<td>Polyp cancer detection rate (Rate of polyp cancers per 1000 screened i.e. FOBt result available)</td>
<td>0.38</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>20</td>
<td>Positive Predictive Value of FOBt to cancer (polyp cancers and invasive crc) (% of people with malignant outcome out of those FOBt positive)</td>
<td>12.0</td>
<td>7.0</td>
<td>7.5</td>
</tr>
<tr>
<td>21</td>
<td>Positive Predictive Value of FOBt to high risk adenoma (% of people with high risk adenoma out of those FOBt positive)</td>
<td>4.3</td>
<td>3.1</td>
<td>3.1</td>
</tr>
<tr>
<td>22</td>
<td>Positive Predictive Value of FOBt to high risk adenoma or cancer (polyp cancers and invasive crc) (% of people with malignant outcome or high risk adenoma out of those FOBt positive)</td>
<td>16.3</td>
<td>10.2</td>
<td>10.6</td>
</tr>
<tr>
<td>23</td>
<td>Positive Predictive Value of FOBt to any adenoma or cancer diagnosis (% of people with malignant outcome or any risk adenoma out of those FOBt positive)</td>
<td>48.4</td>
<td>37.4</td>
<td>36.6</td>
</tr>
<tr>
<td>Assessment criteria</td>
<td>Rationale</td>
<td>Action</td>
<td></td>
<td></td>
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<tr>
<td>------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recent MI</td>
<td>Risk of dysrhythmias following MI. Prepare patient for anticipated outcome that delaying</td>
<td>Risk of increasing or decreasing patient’s blood pressure during colonoscopy. This risk could cause another cardiovascular event.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recent IVA</td>
<td>Risk of dysrhythmias following MI. Prepare patient for anticipated outcome that delaying</td>
<td>The risk of colonoscopy may outweigh the benefits. Discuss with stroke consultant.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Valvular heart disease</td>
<td>Anticoagulants are no longer recommended for the prevention of infective endocarditis in patients with cardiac risk factors. Need to contact the patient's cardiologist to seek advice and to alert them to the fact that warfarin may be required during colonoscopy.</td>
<td>The risk of colonoscopy may outweigh the benefits. Discuss with stroke consultant.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart Valve replacement</td>
<td>Anticoagulants are no longer recommended for the prevention of infective endocarditis in patients with cardiac risk factors. Need to contact the patient's cardiologist to seek advice and to alert them to the fact that warfarin may be required during colonoscopy.</td>
<td>The risk of colonoscopy may outweigh the benefits. Discuss with stroke consultant.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal Defibrillator</td>
<td>Risk of electrical interference when using defibrillator.</td>
<td>Risk of electrical interference when using defibrillator.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pacemaker</td>
<td>Risk of electrical interference when using defibrillator.</td>
<td>Risk of electrical interference when using defibrillator.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hyper tension/high Blood Pressure</td>
<td>Risk of increasing patient’s blood pressure during colonoscopy.</td>
<td>Risk of electrical interference when using defibrillator.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest Pain/Anxia</td>
<td>There is a risk of cardiac ischaemia with the administration of sedation which could result in arrhythmias or MI. Establish frequency of angina attacks. Liaise with relevant cardiologist if appropriate in order to stabilize patient before colonoscopy.</td>
<td>Establish frequency of angina attacks. Liaise with relevant cardiologist if appropriate in order to stabilize patient before colonoscopy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory problems</td>
<td>Risk of respiratory depression during procedure due to effects of sedation. Risk of emergency surgery from bowel perforation during colonoscopy. Underlying condition would put patient at greater risk. Contact with multidisciplinary team associated with the patient’s ongoing medical care. Keep patient informed of progress of enquiry and involve patient in decision making process as to whether to proceed.</td>
<td>Contact with multidisciplinary team associated with the patient’s ongoing medical care. Keep patient informed of progress of enquiry and involve patient in decision making process as to whether to proceed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>Risk of respiratory depression during procedure due to effects of sedation. Risk of emergency surgery from bowel perforation during colonoscopy. Underlying condition would put patient at greater risk. Contact with multidisciplinary team associated with the patient’s ongoing medical care. Keep patient informed of progress of enquiry and involve patient in decision making process as to whether to proceed.</td>
<td>Contact with multidisciplinary team associated with the patient’s ongoing medical care. Keep patient informed of progress of enquiry and involve patient in decision making process as to whether to proceed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>COPD/Bronchitis/Emphysema</td>
<td>Risk of respiratory depression during procedure due to effects of sedation. Risk of emergency surgery from bowel perforation during colonoscopy. Underlying condition would put patient at greater risk. Contact with multidisciplinary team associated with the patient’s ongoing medical care. Keep patient informed of progress of enquiry and involve patient in decision making process as to whether to proceed.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Sleep apnoea</td>
<td>Risk of oxygen/oxygen intercostal muscle during sedation and recovery.</td>
<td>Risk of oxygen/oxygen intercostal muscle during sedation and recovery.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anaemia</td>
<td>One of the commonest forms of anaemia is iron deficiency anaemia. In anaemic patients, prepare patient before colonoscopy.</td>
<td>Anaemic patients may require an additional 1-2 h before colonoscopy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood disorders</td>
<td>Antibiotics are recommended for patients with severe neutropenia and/or underlying infection. Discuss with relevant haematologist.</td>
<td>Antibiotics are recommended for patients with severe neutropenia and/or underlying infection. Discuss with relevant haematologist.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Renal impairment</td>
<td>Risk of fluid and electrolyte imbalance due to bowel prep. Discuss with relevant renal physician. Consider a low volume bowel preparation e.g. Fleet. If on dialysis liaise with the appropriate renal unit.</td>
<td>Discuss with relevant renal physician. Consider a low volume bowel preparation e.g. Fleet. If on dialysis liaise with the appropriate renal unit.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>One of the commonest forms of diabetes is oral hypoglycaemia. In diabetic patients, prepare patient before colonoscopy.</td>
<td>One of the commonest forms of diabetes is oral hypoglycaemia. In diabetic patients, prepare patient before colonoscopy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glaucoma and eye problems</td>
<td>Potential drug interaction if patient already on eye drops for glaucoma. Consult with multidisciplinary team associated with the patient’s ongoing medical care. Alert endoscopy staff to patient’s condition if proceeds to colonoscopy.</td>
<td>Consult with multidisciplinary team associated with the patient’s ongoing medical care. Alert endoscopy staff to patient’s condition if proceeds to colonoscopy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>Risk of emergency GA for surgery for peritonitis/following due to compromised airway from neck arthritis.</td>
<td>Risk of emergency GA for surgery for peritonitis/following due to compromised airway from neck arthritis.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ESRD</td>
<td>Risk of hypoproteinaemia due to reduced carbohydrate intake. Liaise with diabetes liaison nurse. Consider reducing insulin by 30-50% during bowel prep to prevent hypoglycaemia. Maintain carbohydrate intake e.g. fruit juices and high sugar drinks. Ensure early morning appointment for colonoscopy.</td>
<td>Liaise with diabetes liaison nurse. Consider reducing insulin by 30-50% during bowel prep to prevent hypoglycaemia. Maintain carbohydrate intake e.g. fruit juices and high sugar drinks. Ensure early morning appointment for colonoscopy.</td>
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<td>Anaemia and eye problems</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Anticoagulant and antiplatelet therapy</td>
<td>Acute bleeding in patients undergoing colonoscopy on these drugs is a high risk situation. In many cases the risk of thrombosis may be much lower and it may be possible to stop these drugs. However in high risk cases bridging therapy should be considered.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Overactive bladder</td>
<td>Risk of perforation during acute diverticulitis with local sepsis. Patients who complain of marked abdominal pain with local sepsis. Need to undergo prompt investigation and appropriate treatment.</td>
<td>Patients who complain of marked abdominal pain with local sepsis. Need to undergo prompt investigation and appropriate treatment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inflammatory bowel disease</td>
<td>Colonoscopy should only be avoided in an exacerbation of symptoms. Keep patient informed of progress of enquiry and involve patient in decision making process. Alert endoscopy staff to patient’s condition if proceeds to colonoscopy.</td>
<td>Colonoscopy should only be avoided in an exacerbation of symptoms. Keep patient informed of progress of enquiry and involve patient in decision making process. Alert endoscopy staff to patient’s condition if proceeds to colonoscopy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fever</td>
<td>Patients may be sensitive or allergic to drugs that may be administered prior to or during colonoscopy. E.g. A particular bowel cleansing agent, benzodiazepines or opiate analgesics. Determine whether patient has any known allergies or sensitivities. Arrange for alternative bowel prep if appropriate. Alert endoscopy unit.</td>
<td>Patients may be sensitive or allergic to drugs that may be administered prior to or during colonoscopy. E.g. A particular bowel cleansing agent, benzodiazepines or opiate analgesics. Determine whether patient has any known allergies or sensitivities. Arrange for alternative bowel prep if appropriate. Alert endoscopy unit.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug interactions</td>
<td>Patients may be on medication which may interacts with sedation and analgesia. Check British national Formulary for drug interactions with analgesia and sedatives.</td>
<td>Patients may be on medication which may interacts with sedation and analgesia. Check British national Formulary for drug interactions with analgesia and sedatives.</td>
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<td></td>
</tr>
<tr>
<td>Steroids</td>
<td>The increased mirror stress caused by colonoscopy may require an increased dose of steroids. Increased risk of infection due to immuno-compromised. Advise that steroids must continue to be taken. Ensure that the endoscopist is aware that the patient is on steroids and that they can assess the situation during colonoscopy and anticoagulation/steroid related additional doses. May need antibiotic prophylaxis.</td>
<td>The increased mirror stress caused by colonoscopy may require an increased dose of steroids. Increased risk of infection due to immuno-compromised. Advise that steroids must continue to be taken. Ensure that the endoscopist is aware that the patient is on steroids and that they can assess the situation during colonoscopy and anticoagulation/steroid related additional doses. May need antibiotic prophylaxis.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Herbal remedies</td>
<td>Some herbal remedies may increase the risk of bleeding during polypectomy, or cause adverse drug reactions due to sedation. Determine if patients are taking any herbal remedies providing advice re discontinuing relevant products prior to colonoscopy.</td>
<td></td>
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<tr>
<td>CJD/vCJD</td>
<td>The infecting agent in vCJD cannot be removed or destroyed by conventional sterilisation or decontamination methods. Patient need to be asked at pre-assessment “Have you ever been notified that you are at increased risk of CJD/vCJD for public health purposes”. If the answer is yes need to seek advice from consultant gastroenterologist/surgeon.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility issues/interpreter/religious and cultural needs</td>
<td>Arrangements may have to be made. Document and ensure necessary arrangements can be made.</td>
<td></td>
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</tbody>
</table>

| NB                      | Keep patient informed of progress of enquiry and involve patient in decision making process and alert endoscopy staff when required. |

|------------------------------------|------------------------------------------------------------------|

### Pre Colonoscopy Assessment Crib Sheet

<table>
<thead>
<tr>
<th>✓</th>
<th>Checklist</th>
<th>Suggested</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ensure correct patient</td>
<td>Please confirm your name, DOB and address</td>
</tr>
<tr>
<td></td>
<td>If on the telephone confirm the time of call is still suitable and ensure privacy during the call. Calls must not be continued if the participant is driving.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If the patient does not answer the telephone call further attempts should be made during the allocated assessment time and using all available telephone numbers.</td>
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<tr>
<td></td>
<td>Messages should not be left on answer machines without prior consent.</td>
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<tr>
<td></td>
<td>When a patient does not attend the pre assessment clinic or cannot be contacted then 1 further appointment will be allocated. If they fail to attend a second appointment then a letter will be sent to the patient and the GP confirming their non attendance, the patient will also receive a leaflet detailing the signs and symptoms of bowel cancer.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>It is important to ensure the patient is capable of answering all of the questions and consenting. If you get the sense they are not, information / advice should be sought from the patient and their GP.</td>
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<tr>
<td></td>
<td>If the patient is unable to speak for themselves and has asked another person to give information on their behalf you must ensure that the participant is present. The name of the person speaking and their relationship to the patient should be documented. If the patient is not present another assessment time should be arranged.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Acknowledge feelings of anxiety.</td>
<td>Are you aware that you have had a positive result/have you received a letter from the Bowel Screening Centre?</td>
</tr>
<tr>
<td></td>
<td>Explain briefly the many reasons for blood being present in the stool.</td>
<td>The test that you did for us showed that there is evidence of small amounts of blood in the stool. Are you aware of this?</td>
</tr>
</tbody>
</table>
There are lots of simple explanations for having blood in the stool:

- Bleeding from the back of the nose or the mouth
- Inflammation in the stomach or in the bowel
- Haemorrhoids or tears at the back passage
- The reason we use this test is that you may have polyps in the bowel that you are unaware of and we know that if these polyps are left untreated in some cases they can develop into cancer.
- In some cases we also may find a cancer which you may be unaware of because you do not have any symptoms. These cancers are likely to be in the early stages because they have been picked up by the screening process.

We use the test that you did simply to identify people for the next test / investigation – colonoscopy.

Provide stats and facts relevant to your Health Board. On average only about *% of people with a positive result have cancer, etc.

<table>
<thead>
<tr>
<th>Checklist</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Assess for knowledge level and give a brief overview of colonoscopy and the preparation.</td>
<td>Did you read the colonoscopy information leaflet we sent to you? Do you have any questions or concerns? Because you will have sedation for this procedure do you have someone to collect you and stay with you for at least 24 hours? Your bowel has to be really clean so that we can get good views of the lining of the bowel. You will need to take special medicine the day before that will clean out your bowel. The preparation we use is called Klean Prep or alternative It comes in 4 sachets and each sachet has to be made with a litre of water, so that means that you need to drink 4 litres the</td>
</tr>
<tr>
<td>Checklist</td>
<td>Suggested</td>
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<td>--------------------------------------------------------------------------</td>
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</tr>
<tr>
<td></td>
<td>day before. Stress the importance of completing all 4 litres. Discuss the</td>
</tr>
<tr>
<td></td>
<td>importance of a liquid diet when starting the prep. Provide reassurance</td>
</tr>
<tr>
<td></td>
<td>that they will receive written information through the post.</td>
</tr>
<tr>
<td>Assess current state of health.</td>
<td>Complete the assessment form.</td>
</tr>
<tr>
<td></td>
<td>Explain the rational for the assessment i.e. risks of sedation and</td>
</tr>
<tr>
<td></td>
<td>colonoscopy and complete assessment form. This is more than a tick box</td>
</tr>
<tr>
<td></td>
<td>exercise and each answer should be explored thoroughly. Provide</td>
</tr>
<tr>
<td></td>
<td>information if necessary about medication and insulin.</td>
</tr>
<tr>
<td>Assess for recent colonoscopy.</td>
<td>Have you had a colonoscopy before? If so when and where. You should</td>
</tr>
<tr>
<td></td>
<td>check the result to ensure complete colonoscopy with good views.</td>
</tr>
</tbody>
</table>

Decide at this point if colonoscopy referral is to be made

| Explain to the patient.                                                  | **No colonoscopy referral**                                               |
|                                                                          | Your medical condition suggests to me that the risk of colonoscopy might  |
|                                                                          | be higher for you I would like to discuss it with your consultant to see  |
|                                                                          | get their opinion. I will telephone you to let you know what is          |
|                                                                          | happening. It may be because that it would be safer for you not to have  |
|                                                                          | a colonoscopy due to the fact that the vast majority of people will not  |
|                                                                          | have a cancer. I will keep your GP Practice informed of the outcome.     |
|                                                                          | If you experience symptoms you should report to your GP Practice and this|
|                                                                          | can be reviewed.                                                         |

<p>| Colonscopy referral                                                      | Negotiate appropriate date and time.                                     |
|                                                                          | Let them know that they will receive the appointment and all other      |
|                                                                          | information by post. Or ask them to phone the Bowel Screening           |
|                                                                          | Administrator to make an appointment.                                   |
|                                                                          | Confirmation of the appointment and information will then be            |</p>
<table>
<thead>
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<tr>
<td></td>
<td>sent out by post. Stress the importance that if they cannot attend the colonoscopy appointment for any reason they must contact the department (colonoscopy is a very valuable resource) Provide a contact number if they have any further queries or questions.</td>
</tr>
<tr>
<td>Explain the main events on the day of colonoscopy.</td>
<td>Where the department is. Approximate length of time in department. Further assessment by endoscopy nursing staff. Purpose of sedation and analgesia (conscious sedation) not completely knocked out. Communication of results i.e. verbally and written.</td>
</tr>
<tr>
<td>Discuss possible outcome including possibility of incomplete test.</td>
<td>Normal Polyps. Discuss the implications of this and having then excised. Other benign bowel conditions. Cancer. Reassure that if this is likely to be the case there is a good chance that this might be in the early stages.</td>
</tr>
<tr>
<td>Check gaps in knowledge.</td>
<td>Any other questions?</td>
</tr>
<tr>
<td>Check that they are happy to proceed.</td>
<td>Yes/no</td>
</tr>
<tr>
<td>Ensure they have a contact number.</td>
<td></td>
</tr>
<tr>
<td>Thanks for attention and close interview.</td>
<td></td>
</tr>
<tr>
<td>Marry up with the endoscopy admission sheet as per local protocol.</td>
<td>Important issues about risk and consent will be covered again before the colonoscopy by the endoscopy staff as per local protocol.</td>
</tr>
</tbody>
</table>
Pre Assessment for Colonoscopy

It is important to ensure that the person is capable of answering all of the questions and consenting.

Check Date of Birth and Address
If on the telephone confirm that the time is still suitable and ensure privacy
Give explanation of positive FOB test result and rational for colonoscopy and ask:
Have you read the colonoscopy information leaflet? YES/NO
Do you have any questions? YES/NO
Do you have a responsible adult to collect you and stay with you for the first 24 hours? YES/NO

Give an overview of:
Colonoscopy procedure YES/NO
Risks and complications YES/NO
Sedation YES/NO
Consent process YES/NO
The prep YES/NO
Explain the rationale for the assessment.

<table>
<thead>
<tr>
<th>Do you have or have ever had any of the following</th>
<th>YES</th>
<th>NO</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CARDIOVASCULAR</strong></td>
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<tr>
<td>MI</td>
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<td>CVA</td>
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<td>Pacemaker</td>
<td></td>
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<tr>
<td>Hypertension/High Blood Pressure</td>
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<td>Chest pain or Angina</td>
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<td><strong>RESPIRATORY</strong></td>
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<td>Respiratory problems</td>
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<td><strong>OTHER RELEVANT CONDITIONS</strong></td>
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<tr>
<td>Epilepsy</td>
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<tr>
<td>Blackout/collapse/fainting/dizzy spells</td>
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<td>Glaucoma or other eye problems</td>
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</table>

Appendix 4: Assessment Form
## Arthritis

## Diabetes

### WARFARIN THERAPY
Do you take Warfarin/Heparin/Aspirin/ Clopidogrel (Plavix)?

### BOWEL DISEASE
Bowel Diseases
Previous colonic surgery?

### OTHER RELEVANT INFO

- Previous abdominal or pelvic surgery
- Are you having other cancer treatments?
- Problems with previous anaesthetic or sedation
- Do you have any other serious illness?
- Do you have any allergies/sensitivities?

Are you taking any other medication, prescription or otherwise at present (steroids)? Please list

- Are you on any medication to help you sleep at night? Please list

- Use herbal remedies

- Have you ever been notified that you are at risk of CJD or vCJD for public health purposes?
- Do you have any mobility issues?
- What is your weight?
- What is your height?
- Do you smoke?
- Weekly alcohol units
- Do you require an interpreter? (this should ideally be established before pre-assessment)
- Do you have any particular religious or cultural needs?
- Do you have any bowel related symptoms at present? If so please state

Any other relevant information

Give contact number

### Nurse Outcome

<table>
<thead>
<tr>
<th>Patient fit for outpatient colonoscopy</th>
<th>Appointment Date &amp; Time</th>
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<td>Not referred for colonoscopy</td>
<td>Reason</td>
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<tr>
<td>Patient needs further outpatient assessment</td>
<td>Date &amp; Time</td>
</tr>
<tr>
<td>Declined colonoscopy</td>
<td>GP informed</td>
</tr>
<tr>
<td>Needs in-patient colonoscopy</td>
<td>Arrangements</td>
</tr>
</tbody>
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Comments
What is a colonoscopy?

You need a colonoscopy because you have recently had a positive result (blood in your bowel motions) through the bowel-screening programme.

A colonoscopy is a test to look at the lining of the colon (large bowel) using a flexible, tube-like telescope called a colonoscope.

This instrument is carefully passed through the rectum (back passage) and round the colon to see if there are any obvious abnormalities that may have been causing the bleeding (this may not have been visible to the naked eye).

Samples (biopsies) of any abnormality seen may also be taken.

What must I do before my colonoscopy?

It is important that your bowel is empty and clean so that we can get a clear view of the lining of the bowel wall. We will, therefore, ask you to take some strong laxatives to clean out the bowel on the day before the test. This will be sent through the post with your appointment letter. It is important that you follow the instructions for the laxatives carefully and take all the medicine to make sure that we get a good view of the lining of your bowel. The laxatives will make you go to the toilet frequently throughout the day with diarrhoea until it eventually runs clear. It is, therefore, wise to stay close to a toilet once you have taken the medicine and avoid travelling or going to work.

What about my other tablets or medicines?

Special advice will be given to you if you are a diabetic or on Warfarin tablets. If you are taking iron pills these will have to be stopped a week before your test. Otherwise take your usual tablets as normal. You will be asked about your tablets at your pre-assessment.

Will I feel anything during the colonoscopy?

You will be given an injection into a small canula (small tube) inserted into a vein to sedate you. It will make you feel sleepy and relaxed, although you may not be completely asleep. The sedation can sometimes stop you remembering the test itself and for a few hours afterwards. During the test air will be put into your bowel so that there is a good view of the lining of the bowel, you may feel some windy type pains like abdominal cramps. You may also get the feeling that you want to go to the toilet, but because the bowel is empty there is no danger of this happening. You may also pass small amounts of wind. Don’t be embarrassed, this is common because we are putting air into your bowel.
The lining of the bowel will be examined and a biopsy - a small piece of tissue – may be taken for examination in the laboratory. It is also possible to remove polyps during the colonoscopy. Polyps are small growths, rather like warts, which will be examined in more detail. Both of these procedures are done painlessly with tiny instruments passed through the flexible telescope.

**What happens after the test?**

You will need about an hour to rest before going home. You may feel a little bloated and may feel some wind pains, but this usually settles quite quickly once you pass wind. You can eat and drink as normal after the test and you may restart any medicines that you have missed. Because you have sedation you must have a responsible adult to take you home and stay with you for 12 hours. You also should not drive or operate machinery, drink alcohol, take sleeping tablets or sign legal documents for the next 24 hours. When you are fully awake the doctor or nurse looking after you will discuss the findings at the test. This may be followed up by a telephone call, or a letter as sometime people cannot remember what was said due to the effects of the sedative. If any biopsies or polyps were removed you may be asked to attend a further outpatient appointment or to discuss the results with your GP.

**Are there any risks or complications?**

Colonoscopy is generally a very safe procedure. However, as it is an invasive procedure, which involves giving a sedative, it carries a small risk of complications. The main risks include:

- Bleeding from the biopsy site or the site where a polyp was removed
- Small tear or damage to the lining of the bowel

It must be stressed that these complications are very rare (about 1 in 1,000 cases). However, in severe cases it may be necessary to carry out an operation to correct the problem.

Other complications include

- A reaction to the sedative medication.
- Disturbance to your heart rate and breathing.
- In a few cases, the colonoscopy is not successfully completed and this may mean another test is required (the nurse or doctor will discuss this with you should this happen).

It is important for us to know about what tablets you are taking. We will also want to know about your past medical history so that we can make special arrangements for you if necessary.

**What happens if I do not want to go ahead with the test?**

The decision to go ahead with the test is entirely yours (you may wish to discuss this with your family). We would, however, encourage people who have blood in their bowel motions to proceed to colonoscopy. Whilst very few people actually have a bowel cancer we have found a larger number of people have polyps or other minor diseases of their bowel. If you felt that you did not want to have a colonoscopy we would write to inform your G.P.
Consent Form
Colonoscopy

I, ..................................................................................................................

of ..................................................................................................................
..................................................................................................................
..................................................................................................................

hereby consent
(or hereby consent to the submission of my child/ward ...........................................)

to the procedure of

Colonoscopy +/- Polypectomy

the purpose of which has been explained to me in the document entitled:

“Colonoscopy - Information for Patients"

I confirm that:
  ▪ I have read the document
  ▪ I have understood the information that has been given to me
  ▪ I understand that I will be given the opportunity to ask questions about the procedure

I also give consent for any necessary biopsies and for photographs or x-rays to be taken.

Signed (Patient/Parent) ................................................................. Date ......................

Name of Patient/Parent .............................................................................
(Block capitals)

Please ensure that you bring this form with you.
You do not have to sign this before you attend if you have further questions you would like answered
Even if you have signed the form you are under no obligation to proceed with the test

To be completed by the Endoscopist

I confirm that the patient received written information about the procedure, including the
risks, and has been given the opportunity to ask any further questions.

Signed ................................................................. Date ......................
Endoscopist/Medical Practitioner
Pre-assessment for colonoscopy

In order to reduce anxiety, encourage participation and compliance and minimise the risks of colonoscopy, all individuals who have a positive screening test result should be offered a pre-colonoscopy assessment by a suitably qualified health care professional.

Managing referrals

Once notification of an individual with a positive result is received by the NHS Board, the NHS Board must ensure there is a robust pathway to capture and manage referrals.

SCI Gateway must, without exception, be checked every morning Monday – Friday for new referrals from the Bowel Screening Programme. Individuals referred by the Scottish Bowel Screening Programme should be managed, from an administrative perspective, as urgent referrals for colonoscopy. NHS Board protocols should be in place to ensure that pre-assessment and colonoscopy appointments are allocated in a timely manner. Protocols should contain role specific guidance to outline explicitly the responsibilities of colleagues and teams contributing to the management of individuals referred by the Screening Programme. There must be more than one individual responsible for accessing and actioning the referrals.

Reports will be produced for each meeting of the NHS Board’s Bowel Screening Group / monthly outlining the number of referrals received from the Screening Centre during the reporting period, describing individuals’ progress along their investigative pathway and the actions taken to address any delays. This will ensure that all individuals complete a pathway.

There is evidence that the time interval between receiving a positive screening test result and assessment for colonoscopy can result in significant anxiety. NHS QIS Standard 5, Pre-colonoscopy Assessment, states that this time should be within 14 days for at least 80% of individuals and also that there are arrangements to identify all individuals who do not participate in pre-colonoscopy assessment and offer them a further opportunity to do so.

Health Care Professionals templates and guidance

It is suggested that in all cases a single assessment pro-forma is used to pre-assess patients for colonoscopy (see appendix 4). The assessment crib sheet and assessment criteria could also be used to assist in undertaking the pre-assessment (see appendix 4).

Non-responders and un-contactables

If a screening participant does not respond, is un-contactable or does not attend for pre-assessment a reminder should be sent approximately two weeks later, a copy being sent to their GP. This is in recognition that screening participants have had no contact with a health care professional up until the point of pre-assessment. If there is no response to

---

1 31-day target from date decision to treat to first cancer treatment.
2 62-day target from receipt of an urgent referral with a suspicion of cancer to first cancer treatment.
the reminder within approximately two weeks the NHS Board will write to the participant and GP advising that if the participant reconsiders within a six month period the NHS Board can be contacted to undertake the pre-assessment.

If the individual reconsiders or has symptoms they can be referred by their GP through the normal symptomatic service route.

At this stage the screening participant is returned to the National Bowel Screening Programme and will be invited to participate in two years time if not over the age of 75.

Information pathway for patients
There is evidence that providing information about tests and investigations reduces anxiety and encourages participation (see NHS QIS Standard 5 – pre-colonoscopy assessment). NHS Boards may wish to enclose information about colonoscopy (example - appendix 5) with the letter of contact to the individual. This might include an explanation of the process of colonoscopy, the possible risks and outcomes, and is known to reduce anxiety in individuals awaiting further investigation.

NHS Boards will wish to consider the timing of issue of certain elements of information. The under noted is a suggested pathway.

Notification of positive result:
- Issue letter of notification of positive result (Bowel Screening Centre).
- Clinic appointment letter for pre-assessment (either face to face or telephone appointment dependant on NHS Board) and information about colonoscopy.

At face to face pre-assessment appointment (if the decision is to proceed to colonoscopy):
- Consent form (example – appendix 5), contact card, next of kin form, bowel prep instructions, day surgery leaflet, diabetic information leaflet (if required), anticoagulation information leaflet (if required) and follow up arrangements.
- Colonoscopy appointment letter.

Following telephone pre-assessment appointment (if the decision is to proceed to colonoscopy):
- Consent form, contact card, next of kin form, bowel prep instructions day surgery leaflet, diabetic information leaflet (if required), anticoagulation information leaflet (if required) and follow up arrangements.
- Colonoscopy appointment letter.

Following colonoscopy:
- Colonoscopy report.
- Recovery advice.

Clinical assessment/fitness for colonoscopy
The pre-assessment is an essential step to assess health fitness for the procedure. Some individuals may be assessed as high risk for colonoscopy and certain precautions need to be taken to minimise risk during the procedure. Other individuals may be deemed high risk for a screening colonoscopy due to significant co-morbid disease. The assessment
criteria (appendix 4) outlines some of the conditions for consideration. Consideration should be given to the specific follow up of patients where a known risk factor has been identified in the pre-assessment or during the screening colonoscopy procedure. NHS Boards are advised to have protocols in place for dealing with individuals on anticoagulants or who have diabetes and for bowel cleansing/preparation which comply with British Society of Gastroenterology guidance.

If from a telephone assessment there are potential risks/complications a face to face pre-assessment should be offered. If past history/medication has not been requested from the GP or is difficult to obtain Clinicians responsible may consider best practice to obtain past history from GPs. NHS Boards should have a designated person(s) who makes the final decision on a person’s fitness to safely proceed the referral and participants should be seen by this person. The decision and the reasons should be clearly recorded and written communication should be given to the participant and their GP. The participant should be involved throughout the process and clear explanations and information should be given to assist the patient in order to make an informed choice.

In cases where the individual has decided not to progress with a colonoscopy, however reconsiders, they can be referred by their GP for colonoscopy through the normal symptomatic service route if thought appropriate.

Consent difficulties
See section 8.2.1; procedure for dealing with individuals with physical incapacity or consent difficulties.

Bowel Preparation
There is no national protocol for bowel preparation and its issue. NHS Boards to have local protocols in place.

Exclusions from screening colonoscopy
Individuals who are excluded from having a screening colonoscopy are:

- individuals who have had surgery in the past to remove their entire colon and rectum. (Note that individuals who have formation of Ileo Anal pouch should continue to be invited for bowel screening and screened endoscopically as there is a continued risk of bowel cancer developing in the pouch.)
- individuals who have had a complete colonoscopy in the previous 12 months,
- individuals who have had a myocardial infarct in the past 3 months (colonoscopy can be delayed to minimise risk), and
- any individual who is experiencing any acute or severe inflammatory process at the time such as ulcerative colitis, Crohn’s disease or acute diverticulitis.
Appendix 7

SCOTTISH BOWEL SCREENING PROGRAMME

STAGING DATA – PROTOCOL

Final 1.1
Scottish Bowel Screening Programme – Staging Data - Protocol

Prof Frank Carey, Lead Pathologist, Scottish Bowel Screening Programme
Prof Bob Steele, Clinical Lead, Scottish Bowel Screening Programme
Ms Paula McClements, Statistician, ISD
Mrs Janice Birrell, Programme Manager National Services Division

Programme Board
Carol Colquhoun, National Screening Co-ordinator

Version history

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<tr>
<td>Prof Frank Carey</td>
<td>Scottish Bowel Screening Lead Pathologist</td>
<td>NHS Tayside</td>
</tr>
<tr>
<td>Dr David Brewster</td>
<td>Director – Scottish Cancer Registry</td>
<td>NHS National Services Scotland</td>
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<tr>
<td>Detect Cancer Early Team</td>
<td>DCE/Policy</td>
<td>Scottish Government Health and Social Care Directorates</td>
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<td>NHS Boards</td>
<td>Lead Bowel Screening Clinicians and Co-ordinators</td>
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1. Background

The Scottish Bowel Screening Programme commenced a phased roll out in June 2007 with all NHS Boards participating in the Programme by December 2009. By December 2011 everyone within the eligible age range in Scotland had been invited to participate in at least one round of bowel screening. Tumour staging is an important determinant of outcome and a surrogate of successful screening. Staging is a multidisciplinary activity and final stage for each patients will be documented at the colorectal MDT. Radiology and pathology data are particularly important in this regard.

The Programme has developed Key Performance Indicators (KPIs) and has reported against these KPIs annually in August 2009, 2010, 2011 and 2012. These are available via the ISD website at [http://www.isdscotland.org/Health-Topics/Cancer/Bowel-Screening/](http://www.isdscotland.org/Health-Topics/Cancer/Bowel-Screening/).

Part of the review of these KPIs is to try to establish the quality and completeness of the data uploaded to ISD through working in partnership with NHS Boards. With this in mind we are keen to follow-up with NHS Boards on reporting and staging of colorectal cancers. In parallel with developing this protocol an audit was undertaken across all NHS Boards participating in screening pathology in early 2012 in order to confirm the data that are collected. The Royal College of Pathologists have an established standard and dataset for reporting cancer (issued in September 2007) and the audit is using these standards (and further standards specified by NHS Healthcare Improvement Scotland) as a benchmark.

The core data items contained within the Royal College of Pathologists Dataset for colorectal cancer\(^1\) includes that TNM stage (5th edition) and Dukes’ stage are core requirements for collection. Scottish Bowel Screening KPI Reports published to date highlight that capturing the cancer stage for screening participants has been challenging for some NHS Boards. As a result an example of good practice was circulated to NHS Board Bowel Screening Co-ordinators however it is apparent from the most recent data upload that the challenge remains with many cancer staging data being recorded as ‘Not stated’ or ‘Not known’. The following document provides a protocol that aims to help NHS Boards ensure that the stage for screen detected cancers is recorded accurately. These staging data are required and necessary in order to demonstrate any change in staging and thus the effectiveness of the programme over time.

2. Detect Cancer Early Programme\(^2\)

The Scottish Government Health and Social Care Directorates (SGHSC) Detect Cancer Early (DCE) Programme launched in early 2012 with the aim of increasing the number of cancers detected at the first stage of the disease by 25 per cent. The DCE Programme has an initial emphasis on breast, colorectal and lung cancer. It is hoped that this will be achieved through a variety of initiatives including maximising informed

---


2. Scottish Government (February 2012) – Detect Cancer Early Briefing Pack – “The earlier we find cancer the easier it is to treat”.
consent to participants in the national bowel screening programme. A six week marketing campaign commenced from 20 February 2012 comprising television, radio, outdoor, digital and field marketing activity, running alongside a public relations programme. There will follow a targeted DCE campaign on the cancers noted above later in the year/into 2013. There will therefore need to a parallel drive to ensure that the recorded stage of cancers detected through the Scottish Bowel Screening programme is accurate and complete.

3. Bowel Screening Information from BoSS and NHS Boards Submitting the Minimum Dataset – v6.0

A guide to uploading data was produced to help NHS Boards upload data to Information Services Division twice a year and, where possible, conforms to National Clinical Dataset Development Programme (NCDDP) standards for dataset items. The minimum dataset populates the programme KPIs which in turn incorporate some of the NHS Quality Improvement Scotland (now Healthcare Improvement Scotland) Bowel Screening Clinical Standards. Both the minimum dataset and associated guide document are regularly reviewed to ensure that any changes to the KPIs are reflected.

4. Multidisciplinary Team

NHS Quality Improvement Scotland (now Healthcare Improvement Scotland) developed standards for the management of core cancer services in March 2008. These standards recognised that patients with cancer have complex needs. As well as clinical, these may include financial, social, spiritual and psychological needs and that these needs will vary throughout the patient journey. Standard 2 focussed on the requirement that all patients with cancer should be managed by a multidisciplinary process including all aspects of treatment and care, including symptom management and end-of-life care.

The NHS QIS essential criteria includes that there are multidisciplinary management protocols covering systems for referral (including to medical, surgical, oncology and palliative care services), investigation, diagnostics, staging for treatment, treatment, follow-up and end-of-life care for patients with cancer.

Key information that directly affects treatment decisions (eg. staging, performance status and co-morbidity) is collected by the MDT. It is crucial that it is the stage recorded at the MDT meeting that is used to populate the Scottish Bowel Screening KPI dataset.

Note: The National Clinical Dataset Development Programme (NCDDP) was established in 2003 and decommissioned on 31st March 2010.

Tables showing the codes and values are set out in this document and an extract is set out below relating to the recording of a cancer diagnosis and staging.

3 NHS Quality Improvement Scotland (February 2007) Clinical Standards – Bowel Screening Programme ISBN 1-84404-452-1

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Sub-code</th>
<th>Sub-value</th>
<th>Explanatory Notes</th>
</tr>
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<tbody>
<tr>
<td>00</td>
<td>TNM Classification pT0</td>
<td>No evidence of primary tumour</td>
<td></td>
<td></td>
</tr>
<tr>
<td>01</td>
<td>TNM Classification pTis</td>
<td>Carcinoma in situ (CIS)(^1)</td>
<td>A</td>
<td>Intra-epithelial</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>B</td>
<td>Intra-mucosal</td>
</tr>
<tr>
<td>02</td>
<td>TNM Classification T1</td>
<td>Tumour invades submucosa.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>03</td>
<td>TNM Classification T2</td>
<td>Tumour invades muscularis propria.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>04</td>
<td>TNM Classification T3</td>
<td>Tumour invades through muscularis propria into subserosa or into perirectal tissue or other non-peritonealised tissue.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>05</td>
<td>TNM Classification T4</td>
<td>Tumour directly invades other organs or structures(^4) and/or perforates visceral peritoneum.</td>
<td>T4A</td>
<td>Invades other organs or structures</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>T4B</td>
<td>Involves visceral peritoneum</td>
</tr>
<tr>
<td>06</td>
<td>TNM Classification TX</td>
<td>Primary tumour cannot be assessed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>99</td>
<td>Not known</td>
<td>Includes ‘not recorded’.</td>
<td></td>
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</table>

\(^1\) Bowel Screening Information from BoSS and the Health Boards Submitting the Minimum Dataset Instructions March 2009 Version 6.0
Further information:

- pTis includes cancer cells confined within the glandular basement membrane (intraepithelial) or lamina propria (intramucosal) with no extension through muscularis mucosae into submucosa.
- UK pathology practice does not allow for stage pTis in colorectal carcinoma staging.

Tumours in this category should be classified as adenomas with high grade dysplasia.

2 Direct invasion in pT4 includes invasion of other segments of the colorectum by way of the serosa, e.g. invasion of sigmoid colon by a carcinoma of the caecum.

Table 2 - TNM Nodal Classification - *Use Value not Code except 99*

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<td>TNM Classification N0</td>
<td>No regional lymph node metastasis.</td>
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<tr>
<td>01</td>
<td>TNM Classification N1</td>
<td>Metastases in 1 to 3 regional lymph nodes.</td>
</tr>
<tr>
<td>02</td>
<td>TNM Classification N2</td>
<td>Metastases in 4 or more regional lymph nodes.</td>
</tr>
<tr>
<td>04</td>
<td>TNM Classification NX</td>
<td>Regional lymph nodes cannot be assessed. Polyp cancers will be in this group unless definitive surgery is performed.</td>
</tr>
<tr>
<td>99</td>
<td>Not known</td>
<td>Includes 'not recorded'.</td>
</tr>
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</table>

All polyp cancers should fall within T1NX category.

Table 3 – TNM Metastases Classification - *Use Value not Code except 99* (this data will not reliably be obtained from pathology. Most metastases are diagnosed solely on radiological examination).

<table>
<thead>
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<th>Code</th>
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<th>Explanatory Notes</th>
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<tr>
<td>00</td>
<td>TNM Classification pM0</td>
<td>No distant metastases.</td>
</tr>
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<td>01</td>
<td>TNM Classification pM1</td>
<td>Distant metastases present.</td>
</tr>
<tr>
<td>02</td>
<td>TNM Classification pMX</td>
<td>Presence of distant metastases cannot be assessed.</td>
</tr>
<tr>
<td>99</td>
<td>Not known</td>
<td>Includes 'not recorded'.</td>
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MDT discussion of radiological stage is crucial to get accurate final stage.
Table 4 - Dukes’ Classification

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<th>Code</th>
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<td>Tumour limited to the bowel wall, lymph nodes negative.</td>
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<td>Dukes’ B</td>
<td></td>
<td></td>
<td>Tumour spread beyond muscularis propria, lymph nodes negative.</td>
</tr>
<tr>
<td>03</td>
<td>Dukes’ C</td>
<td>A</td>
<td>C1</td>
<td>Lymph nodes positive but apical node negative.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>B</td>
<td>C2</td>
<td>Apical lymph node involved.</td>
</tr>
<tr>
<td>04</td>
<td>Dukes’ D</td>
<td></td>
<td></td>
<td>Distant metastases</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>99</td>
<td>Not known</td>
<td></td>
<td></td>
<td>Includes ‘not recorded’.</td>
</tr>
</tbody>
</table>

Dukes’ D can not be reliably staged from pathology reports – needs MDT final stage information.
Table 5 - Classification of Colorectal Tumours

<table>
<thead>
<tr>
<th>TMN classification</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>T</strong> Primary tumour</td>
<td></td>
</tr>
<tr>
<td>TX Primary tumour cannot be assessed</td>
<td></td>
</tr>
<tr>
<td>T0 No evidence of primary tumour</td>
<td></td>
</tr>
<tr>
<td>T1 Tumour invades submucosa</td>
<td></td>
</tr>
<tr>
<td>T2 Tumour invades muscularis propria</td>
<td></td>
</tr>
<tr>
<td>T3 Tumour invades through muscularis propria into subserosa or non-peritonealised pericolic or perirectal tissues</td>
<td></td>
</tr>
<tr>
<td>T4 Tumour directly invades other organs (pT4a) and/or involves the visceral peritoneum (pT4b)</td>
<td></td>
</tr>
<tr>
<td><strong>N</strong> Regional lymph nodes</td>
<td></td>
</tr>
<tr>
<td>NX Regional lymph nodes cannot be assessed</td>
<td></td>
</tr>
<tr>
<td>N0 No regional lymph node metastasis</td>
<td></td>
</tr>
<tr>
<td>N1 Metastasis in 1 to 3 regional lymph nodes</td>
<td></td>
</tr>
<tr>
<td>N2 Metastasis in 4 or more regional lymph nodes.</td>
<td></td>
</tr>
<tr>
<td><strong>M</strong> Distant metastasis</td>
<td></td>
</tr>
<tr>
<td>MX Distant metastasis cannot be assessed</td>
<td></td>
</tr>
<tr>
<td>M0 No distant metastasis</td>
<td></td>
</tr>
<tr>
<td>M1 Distant metastasis</td>
<td></td>
</tr>
</tbody>
</table>

5. The Collection of Bowel Screening Staging Data

Arrangements for collecting, collating and uploading Bowel screening data are organised locally by each NHS Board. Different staff are often involved in the process e.g. administrative, nursing, audit (with or without clinical background) etc.

Good practice identified to the Programme emphasises that those entering the staging data for screening participants who are either trained audit or clinical staff results in more complete and accurate staging data being reported for a screening episode.

Again good practice identified that staging data can be captured at the weekly Multidisciplinary team (MDT) meetings.

6. Quality Assurance of Screening Data uploads

The most recent data uploaded in May 2012 confirms that 88.2% of people with a screen detected cancer are staged, as per the Dukes’ Classification (table 8).

Overall for Scotland for the two year period reported 28.3% of the cancer detected were stages as Dukes’ A, 23.1% as Dukes’ B, 21.9% as Dukes’ C1, 2.3% as Dukes’ C2 and 2.1% as Dukes’ D. Additionally 10.5% were staged as ‘Not known’ and 11.8% were ‘Not stated’. Dukes’ stage ‘Not known’ is where the Dukes’ stage has not been pathologically determined. ‘Not stated’ is where the staging data have not yet been supplied.

7. Polyp Cancers

A Polyp Cancer is defined as a cancer that is removed by colonoscopy. In some cases this will be followed by a completion colectomy, in which case accurate lymph node staging can be achieved. However for the purposes of the Scottish Bowel Screening Programme it is recommended that all polyp cancers that are not followed by a colectomy are staged as Dukes’ A, unless there is evidence to the contrary (e.g. from imaging). However it is still important that the Programme is able to distinguish between “polyp” cancers Dukes’ A and “non-polyp” cancers Dukes A. This can be achieved by ensuring that the data field for polyp cancer is populated. Polyp cancers should be coded T1NX.

8. Next Steps/Way Forward

An audit of anonymised NHS Board completed pathology reports is currently concluding and it is planned that this will be reported to the Scottish Bowel Screening Programme in the first instance. The Scottish Bowel Screening Programme Board will report back on this audit to each NHS Board and collectively. The Programme will continue to work in partnership with all NHS Boards to try to drive up the quality and completeness of the data collected for the Programme.

Contacts:-

<table>
<thead>
<tr>
<th>Mrs Janice Birrell</th>
<th>Prof RJC Steele</th>
</tr>
</thead>
<tbody>
<tr>
<td>Programme Manager</td>
<td>Lead Bowel Screening Clinician</td>
</tr>
<tr>
<td>National Services Division</td>
<td>NHS Tayside</td>
</tr>
<tr>
<td>Gyle Square</td>
<td>Surgery and Molecular Oncology</td>
</tr>
<tr>
<td>1 South Gyle Crescent</td>
<td>Ninewells Hospital</td>
</tr>
<tr>
<td>EDINBURGH</td>
<td>University of Dundee</td>
</tr>
<tr>
<td>EH12 9EB</td>
<td>Dundee</td>
</tr>
<tr>
<td></td>
<td>DD1 9SY.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ms Paula McClements</th>
<th>Professor Frank Carey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statistician</td>
<td>Lead Bowel Screening Pathologist</td>
</tr>
<tr>
<td>Cancer Surveillance Team</td>
<td>NHS Tayside</td>
</tr>
<tr>
<td>NHS National Services Scotland</td>
<td>Ninewells Hospital</td>
</tr>
<tr>
<td>Gyle Square</td>
<td>University of Dundee</td>
</tr>
<tr>
<td>1 South Gyle Crescent</td>
<td>DUNDEE</td>
</tr>
<tr>
<td>EDINBURGH</td>
<td>DD1 9SY.</td>
</tr>
</tbody>
</table>
This is your invitation and test kit for bowel screening.

NHS Scotland recommends bowel screening to all people aged between 50 and 74 every two years. The NHS register shows that you are within the age range to do the test.

Screening aims to find cancer of the bowel at an early stage when treatment is simpler and more effective. The screening test looks for hidden blood in the bowel motion. This can be caused by a number of conditions, including bowel cancer. Doing the screening test is a good way of looking after your health. It’s quick and easy and you do it all at home. The result comes back to you within two weeks.

We apologise if this letter comes at an inappropriate time or if you have health or other concerns that prevent you from taking part. You may wish to phone the confidential Helpline on 0800 0121 833 for advice or if you have any other questions.

We will send you a reminder in 6 weeks but you can decide not to do the test. Your decision will not affect any health care you receive from your GP or hospital.

**It’s important that:**
- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as possible once you have all three samples on it.
This is your replacement bowel screening test kit

Please destroy any other old test kits and letters.

Doing the screening test is a good way of looking after your health as early treatment for bowel cancer is simpler and more effective. It’s quick and easy and you do it all at home.

Please read the enclosed leaflets carefully. Remember that you can call the confidential Helpline on 0800 0121 833 if you have any questions.

**It’s important that:**
- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as possible once you have all three samples on it.
No longer issued
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your test result shows tiny traces of blood present in your sample. This is quite common and does not always mean there is a problem. However it is important that you do another test. This has been enclosed for you.

Please read the instruction leaflet carefully. Remember that you can call the confidential Helpline on 0800 0121 833 if you have any questions.

It’s important that:

- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as you have both samples on it.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your result can’t be issued at this time because the laboratory was unable to test the kit for technical reasons. As accurate bowel screening is important we have sent you another kit. Please take the test again and we apologise for any inconvenience.

Please read the instruction leaflet carefully. Remember that you can call the confidential Helpline on 0800 0121 833 if you have any questions.

It’s important that:

- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as you have both samples on it.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your result can’t be issued at this time as it appears that the kit has been returned to the centre and it has not been used.

As accurate bowel screening is important we have sent you another kit. Please take the test again, following the instructions carefully. Remember that you can call the confidential Helpline on 0800 0121 833 if you have any questions about how to do the test.

It’s important that:

- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as you have both samples on it.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your result can’t be issued at this time, because

- the time between the first sample date and testing was too long
- or
- some dates were missing.

As accurate bowel screening is important we have sent you another kit. Please take the test again, following the instructions carefully. Remember that you can call the confidential Helpline on 0800 0121 833 if you have any questions about how to do the test.

**It’s important that:**
- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as you have both samples on it.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your test result can’t be issued at this time as it appears that the kit has been partly completed. Not all the required samples have been applied.

As accurate bowel screening is important we have sent you another kit. Please take the test again, following the instructions carefully. Remember that you can call the confidential Helpline on 0800 121 833 if you have any questions about how to do the test.

It’s important that:
- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as you have both samples on it.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your result can’t be issued at this time as it appears that the bowel motion may not have been applied correctly.

As accurate bowel screening is important we have sent you another kit. Please take the test again, following the instructions carefully. Remember that you can call the confidential Helpline on 0800 0121 833 if you have any questions about how to do the test.

It’s important that:

- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as you have both samples on it.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your test result can’t be issued at this time as your name on the kit has been changed. If you wish to update your details, please contact your GP. Please do not write or change details on the kit. If you do, it will not be tested.

As accurate bowel screening is important we have sent you another kit. Please take the test again, following the instructions carefully. Remember that you can call the confidential Helpline on 0800 0121 833 if you have any questions about how to do the test.

It’s important that:
- You check that this is your date of birth –
- You read the enclosed leaflets carefully.
- You understand why you are doing the test.
- You label your kit. You must use the label at the bottom of this page. Unlabelled kits will not be tested.
- You complete the kit as soon as you can.
- You post your kit as soon as you have both samples on it.
Letter ID 9
Overdue kit body text

No longer in use
REMINDER

You were recently sent an invitation for bowel screening.

If you still have the invitation pack that was recently sent to you, please complete the kit and return it to us as soon as you can.

If you need another kit we will be happy to replace it for you. To order a new kit, please call the Helpline or email us at bowelscreening.tayside@nhs.net quoting the reference number as above.

NHS Scotland offers bowel screening tests to all people aged between 50 and 74 every two years. The NHS register shows that you are within the age range to do the test.

Screening aims to find cancer of the bowel at an early stage when treatment is simpler and more effective. The screening test looks for hidden blood in the bowel motion. This may be caused by a number of conditions, including bowel cancer. Doing the screening test is a good way of looking after your health. It’s quick and easy and you do it all at home. The result comes back to you within 2 weeks.

I apologise if this letter comes at a time when you have health or other concerns that prevent you from taking part.

Remember that you can call the confidential Helpline on 0800 0121 833 if you have any questions.

If you decide not to do the test you don’t need to take any action. Your decision will not affect any health care you receive from your GP or hospital. You will be called for screening again in 2 years time if you are still in the age range.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

No blood was found in your bowel motion. This means that you do not need any further investigations or treatment at the present time. You will be called again for screening within two years.

It’s important to remember that 100% accuracy cannot be guaranteed because not all cancers or polyps bleed all of the time, and the screening test is looking for blood. This means that sometimes a cancer will be missed - the screening test picks up two out of every three existing bowel cancers. Changes can also happen in between one screening test and the next, so it is important that you repeat the screening test every two years and never ignore symptoms.

Symptoms:
- Repeated bleeding from the back passage or blood in your motions.
- A recent change in bowel habit that continues every day for over 6 weeks without going back to normal.
- Looser motions, or alternating loose motions with constipation (constipation alone is less likely to be serious).
- Pains in the stomach that are severe, continual and have started recently, especially after eating.
- You have recently lost weight without trying.
- You have been told that you are anaemic, or look pale and feel tired much of the time.

These symptoms can be caused by a number of conditions including bowel cancer. If you notice any of the above symptoms, make an appointment to see your doctor.
Letter ID 12
Positive result body text

You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your test result shows hidden blood in your bowel motion. There are lots of simple explanations for this, including bleeding gums, inflammation in the stomach, polyps in the bowel, haemorrhoids (piles), or broken skin around the back passage.

A more serious explanation could be that early bowel cancer sometimes bleeds. A colonoscopy is the best way of looking for the cause of bleeding, which in some but not all cases may be due to bowel cancer.

What is a colonoscopy?
- A colonoscopy is an examination of the bowel using a fine flexible tube. The tube is passed into the bowel via the back passage. It is usually done as a hospital outpatient appointment.
- The tube allows a doctor or nurse to inspect the bowel fully.
- If found, ‘polyps’ can be removed without the need for surgery.
- Polyps are small growths of cells on the bowel wall.
- Removal of polyps can give long-term protection from bowel cancer.
- Remember, very few of the people who need a colonoscopy will have bowel cancer.

Your NHS Board will contact you in the next few days to explain the colonoscopy procedure to you. You will also be able to ask any other questions you may have about bowel screening.

If you wish to contact them yourself, the contact details are:
…………………

Your GP has a copy of your test result and will know that a colonoscopy is planned. You will be invited for another bowel screening test within two years.
You recently contacted the Bowel Screening Centre to tell us that you do not want to be part of the Bowel Screening Programme.

In Scotland, we invite all men and women between 50 and 74 years of age to take part in bowel screening every two years. Research shows that regular bowel screening helps to save lives.

I understand that you do not wish to receive any more invitations to take part in the bowel screening programme. We can remove your name from the list of people who are invited. However, written confirmation is needed to ensure there is no misunderstanding. Your GP will be informed of your decision.

Please sign and return the lower part of this letter to confirm your wish to be removed from the Bowel Screening Programme. If you do not send back the completed form, you will be sent another bowel screening test kit within two years.

Remember, if you change your mind you can rejoin the programme at any time. Contact us at the above address or simply send your completed test kit within the valid time period.

If you have any questions, please telephone the confidential Bowel Screening Helpline on 0800 0121 833.

Yours sincerely
Professor Bob Steele

---

To: Scottish Bowel Screening Programme, Kings Cross, Clepington Road, Dundee DD3 8EA.

Please do not send me any more invitations to take part in the Scottish Bowel Screening Programme.

- I assume full responsibility for this decision and confirm that I have read the statement that bowel screening can reduce the risk of death from bowel cancer.
- I understand that I can change my mind at any time, and request a bowel screening test if I wish. I can do this by contacting the Bowel Screening Centre at any time in the future.

My name is:............
My address is:.........
Signature..........................................................Date........................................
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

There was a technical failure during the test process and unfortunately a test result cannot be issued. I apologise for any inconvenience that this has caused you.

This happens on rare occasions, and means that you will be invited for screening again. You will shortly receive a new invitation pack. If you have any questions, please telephone the confidential Helpline on 0800 0121 833.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

We could not issue a result on this test because it appears to have been used incorrectly. We note that this has happened twice.

If you wish to continue with the screening, please contact the confidential Bowel Screening Helpline on 0800 0121 833 to talk through any problems that you may have and to arrange for another test kit to be sent out.

If you do not contact us you will be called for screening again in 2 years time if you are still in the age range.

It is important that you look out for any of these symptoms:

- Repeated bleeding from the back passage or blood in your motions.
- A recent change in bowel habit that continues every day for over 6 weeks without going back to normal.
- Looser motions, or alternating loose motions with constipation (constipation alone is less likely to be serious).
- Pains in the stomach that are severe, continual and have started recently, especially after eating.
- You have recently lost weight without trying.
- You have been told that you are anaemic, or look pale and feel tired much of the time.

These symptoms may be caused by a number of conditions, including bowel cancer. If you notice any of the above symptoms, make an appointment to see your doctor.
You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your test result shows hidden blood in your bowel motion. There are lots of simple explanations for this, including bleeding gums, inflammation in the stomach, polyps in the bowel, haemorrhoids (piles), or broken skin around the back passage.

Another important and more serious explanation could be that early bowel cancer sometimes bleeds. A colonoscopy is the best way of looking for the cause of bleeding, which in some but not all cases may be due to bowel cancer.

**What is a colonoscopy?**
- A colonoscopy is an examination of the bowel using a fine flexible tube. The tube is passed into the bowel via the back passage. It is usually done as a hospital outpatient appointment.
  - The tube allows a doctor or nurse to inspect the bowel fully.
  - If found, ‘polyps’ can be removed without the need for surgery.
  - Polyps are small growths of cells on the bowel wall.
  - Removal of polyps can give long-term protection from bowel cancer.
  - Remember, very few of the people who need a colonoscopy will have bowel cancer.

However, we are unable to refer you to hospital because you have moved out of Scotland.

Please show this letter to your new GP, as it is important that you have a colonoscopy of your bowel.
Dear Doctor,

This patient <CHI, Forename, Surname, Address> returned a bowel screening test kit.
The test was positive and the following information was issued to the patient:

You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your test result shows hidden blood in your bowel motion. There are lots of simple explanations for this, including bleeding gums, inflammation in the stomach, polyps in the bowel, haemorrhoids (piles), or broken skin around the back passage.

Another important and more serious explanation could be that early bowel cancer sometimes bleeds. A colonoscopy is the best way of looking for the cause of bleeding, which in some but not all cases may be due to bowel cancer.

**What is a colonoscopy?**
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- If found, ‘polyps’ can be removed without the need for surgery.
- Polyps are small growths of cells on the bowel wall.
- Removal of polyps can give long-term protection from bowel cancer.
- Remember, very few of the people who need a colonoscopy will have bowel cancer.

Your NHS Board will contact you in the next few days to explain the colonoscopy procedure to you. You will also be able to ask any other questions you may have about bowel screening.

If you wish to contact them yourself, the contact details are: ....................

Your GP has a copy of your test result and will know that a colonoscopy is planned. You will be invited for another bowel screening test within two years.
Dear Doctor,

Your patient <CHI, Forename, Surname, Address> returned a bowel screening test kit.

The result was a second spoiled and the following information was issued to the patient:

You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

We could not issue a result on this test because it appears not to have been used correctly. We note that this has happened twice.

If you wish to continue with the screening, please contact the Bowel Screening Helpline to talk through any problems that you may have arrange for another test kit to be sent out.

If you do not contact us you will be called for screening again in 2 years time if you are still in the age range.

It is important that you look out for any of these symptoms:

- Repeated bleeding from the back passage or blood in your motions.
- A recent change in bowel habit that continues every day for over 6 weeks without going back to normal.
- Looser motions, or alternating loose motions with constipation (constipation alone is less likely to be serious).
- Pains in the stomach that are severe, continual and have started recently, especially after eating.
- You have recently lost weight without trying.
- You have been told that you are anaemic, or look pale and feel tired much of the time.

These symptoms may be caused by a number of conditions, including bowel cancer. If you notice any of the above symptoms, make an appointment to see your doctor.
Letter ID 26
GP Mailer Overdue kit

Letter removed
Dear Doctor,

Your patient <CHI, Forename, Surname, Address> returned a bowel screening test kit.

The result was positive, but they have now moved out of the eligible area. The following information was issued to your patient:

---

You recently sent a completed bowel screening kit for testing. Thank you for taking the time to do the test and returning it to the Bowel Screening Centre.

Your test result shows hidden blood in your bowel motion. There are lots of simple explanations for this, including bleeding gums, inflammation in the stomach, polyps in the bowel, haemorrhoids (piles), or broken skin around the back passage.

Another important and more serious explanation could be that early bowel cancer sometimes bleeds. A colonoscopy is the best way of looking for the cause of bleeding, which in some but not all cases may be due to bowel cancer.

**What is a colonoscopy?**

- A colonoscopy is an examination of the bowel using a fine flexible tube. The tube is passed into the bowel via the back passage. It is usually done as a hospital outpatient appointment.

  - The tube allows a doctor or nurse to inspect the bowel fully.
  - If found, ‘polyps’ can be removed without the need for surgery.
  - Polyps are small growths of cells on the bowel wall.
  - Removal of polyps can give long-term protection from bowel cancer.
  - Remember, very few of the people who need a colonoscopy will have bowel cancer.

However, we are unable to refer you to hospital because you have moved out of Scotland.

Please show this letter to your new GP, as it is important that you have a colonoscopy of your bowel.
Dear Doctor,

Your patient, <CHI, Forename, Surname, Address> was recently invited to take part in the Scottish Bowel Screening Programme.

However, your patient has informed us that he/she has no colon.

We would like to have this confirmed in writing, and would be grateful if you complete this form and return it to us at the above address.

Your patient is aware that we are making this request and has consented to this medical information being shared in order to be correctly excluded from Bowel Screening.

If you have any enquiries in this regard, please contact the Bowel Screening Services Manager on 01382 425678.

Name: ............................................................................................................
CHI: ............................................................................................................
Address: .......................................................................................................
GP practice <Practice Code>: ........................................................................
I confirm that the above patient has no colon and has had a permanent Ileostomy. This patient should be removed from the Bowel Screening Programme.
Or
This patient passes stool via remaining colon and/or rectum and may be eligible to continue in bowel screening.
The details of previous bowel surgery are:
........................................................................................................................
........................................................................................................................
........................................................................................................................

GP Name (please print): ...........................................................

GP Signature: ..............................................................Date.............
A Scottish Bowel Screening Programme invitation letter was returned undelivered from this address.

Bowel screening saves lives. If you wish to participate in the programme, please contact the confidential Helpline on 0800 0121 833, and we will resend your bowel screening test kit. Our specially trained staff will be happy to help you and answer any questions.
Letter ID 31
Wrong kit returned body text

No longer in use
Dear Doctor

Re:

Please note that the above patient registered with this GP practice, has asked to be permanently opted out of bowel screening. This patient received a leaflet explaining the facts of bowel screening and it was also emphasised that:

- In Scotland, all men and women between 50 and 74 years of age are invited to take part in bowel screening every two years.
- Screening trials have shown that regular screening can significantly lower the risk of death from bowel cancer in people in this age group.
- It is possible to be removed from the list of people invited. This involves written confirmation to ensure there is no misunderstanding.
- The GP practice is informed of a decision to permanently opt out.
- A change of mind at any time is accepted by contacting the above address or by returning a kit within the valid time period.

Documentary evidence of your patient's decision will be permanently stored at the Scottish Bowel Screening Centre.

This patient will no longer be invited 2 yearly for bowel screening.

If you have any enquiries please telephone the helpline.
The Scottish Bowel Screening Programme began roll out in June 2007. The Programme is now fully rolled out to all 14 NHS Boards and invites more than 800,000 eligible participants between the age of 50 – 74 every year. The Community Health Index is the key patient identifier throughout the screening episode.

An IT system (BoSS) for the Scottish Bowel Screening Programme was developed made up of two main components – call-recall and laboratory. BoSS tracks the participant journey from invitation through to the point at which a screening test result is issued. No subsequent clinical information is held in BoSS.

BoSS calls all eligible participants from CHI based on the following selection criteria:-

- Must be aged between 50 and 74
- CHI record must have an Area of Residence.

The attached provides a protocol for handling residents living in the border region between Scotland and England. This protocol was developed in partnership with the Scottish Bowel Screening Centre, NHS Borders and NHS Dumfries and Galloway and is consistent with other cancer screening programmes. It is the agreed protocol between Scotland and England ensuring that residents are invited to either the Scottish or English Bowel Screening Programme as appropriate.
### NHS Dumfries and Galloway

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Scottish/BoSS action required</th>
<th>English system action required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person living in Scotland GP in Scotland</td>
<td>BoSS to invite as should have CHI and ‘flagged’ as being resident in an NHS Board in Scotland.</td>
<td>No action</td>
</tr>
<tr>
<td>Person living in Scotland GP in England e.g. Carlisle</td>
<td>BoSS to invite as should have CHI and ‘flagged’ as being resident in an NHS Board in Scotland. Referrals to be made to Dumfries and Galloway as normal. If not suitable participant to discuss with NHSScotland staff.</td>
<td>No action</td>
</tr>
<tr>
<td>Person living in England GP in Scotland</td>
<td>Will not be invited by BoSS to participate in the Scottish Programme as participant not flagged as being resident in an NHS Board in Scotland. These participants have an AoR of “D” (Cumbria) or “E” (Northumbria).</td>
<td>English system should call</td>
</tr>
</tbody>
</table>

### NHS Borders

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Scottish/BOSS* action required</th>
<th>English system action required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person living in Scotland GP in Scotland</td>
<td>BOSS to invite as should have CHI and ‘flagged’ as being resident in Scottish Board.</td>
<td>No action</td>
</tr>
<tr>
<td>Person living in Scotland GP in England (Berwick-on Tweed, Tweedmouth, Wooler)</td>
<td>BOSS to invite as should have CHI and ‘flagged’ as being resident in Scottish Board. Referrals to be made to Borders General Hospital as usual. If not suitable, patient to discuss with BGH staff.</td>
<td>No action</td>
</tr>
<tr>
<td>Person living in England GP in Scotland (Coldstream, Kelso, Duns, Chirnside, Newcastleton)</td>
<td>Will not be invited by BOSS to participate in the Scottish Programme as participant not flagged as being resident in an NHS Board in Scotland. These participants have an AoR of “D” (Cumbria) or “E” (Northumbria).</td>
<td>English system should call</td>
</tr>
</tbody>
</table>

*NB. BOSS is informed by the CHI but will only call based on Board of residence, not GP registration status.*
Appendix I0 – Responsibilities and Relationships Organogram