

# Evaluation of UK Colorectal Cancer Screening Pilot

## Report Supplement

The UK CRC Screening Pilot Evaluation Team

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## Foreword

This Supplementary Report contains further detailed information on methods and results for some components of our Final Report, Evaluation of the CRC Screening Pilot. It is intended to be used as a reference. We have included several of our survey instruments, a journal paper based on our work, and detailed methods and results material.

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# **Supplement S1 – Psychosocial Survey Questionnaire (Chapter 2 in Final Report)**



## UK Colorectal Cancer Screening Pilot



### **What do you think about bowel cancer screening?**

This booklet is part of a study funded by the Department of Health to evaluate the bowel cancer screening pilot. The main aim of this evaluation is to see how people got on with the bowel cancer screening test, establish what they think about doing the test, and to gain an understanding of what people think about bowel cancer.

This booklet also contains questions about how people feel when they receive a positive bowel cancer screening test result (blood being found in the bowel motions) and about the experience of attending for a colonoscopy examination. This project is being undertaken in collaboration with the Universities of Edinburgh, Essex, and Warwick.

Within the last 12 months you were sent a bowel cancer screening test by either the Scottish or English bowel screening centres and you were also invited to attend for a colonoscopy, this is why we are sending you this booklet. It is very important that we hear your views about the bowel cancer screening test and about colonoscopy. We would appreciate it if you could spare a little time to answer the questions in this booklet.

All the information you provide is confidential and your answers in the booklet will not be personally identified. Please **DO NOT** write your name anywhere on the booklet. When you have answered all the questions, please put the booklet in the FREEPOST envelope provided. You do not have to put a stamp on this envelope. If we do not hear from you within a couple of weeks you will be sent a reminder questionnaire. If you do not complete the questionnaire after being sent this reminder you will not be contacted again.

If you do not want to complete this booklet please return it blank in the FREEPOST envelope, and you will not be sent a reminder or be contacted about this study again. This would help us with our costs.

Thank you very much for your help.

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**Section 1**

You were recently asked to do a bowel cancer screening test. At some point after you did this test you were told that there was a problem with your bowel motions – that is *small amounts of blood were found in them by the test*.

Below is a list of possible causes of the problem with your bowel motions. Please indicate how much you agree or disagree that they were causes of the problem by ticking ✓ the appropriate box. These questions are about your positive BOWEL CANCER SCREENING TEST RESULT not your colonoscopy result.

Possible Causes of the problem with your bowel motions (blood being found in them by the bowel cancer screening test).	Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
Stress/worry						
Heredity (runs in my family)						
Germ/ virus						
Altered immunity						
Chance/bad luck						
Poor medical care in my past						
Pollution in the environment						
Ageing						
My mental attitude e.g. thinking about life negatively						
Family problems/worries						
Overwork						
Smoking						
Alcohol						
My emotional state e.g. feeling down, lonely, anxious, empty						
Accident or injury						
My personality						
Diet/eating habits						
Lack of exercise						
My own behaviour						

Please list in rank-order the three most important factors that you now believe caused the problem with your bowel motions (small amounts of blood being found in them by the bowel cancer screening test). You may use any of the items from the box or you may have additional ideas of your own.

1. \_\_\_\_\_ 2. \_\_\_\_\_ 3. \_\_\_\_\_

It is also very important that we understand your views and feelings about the *problem with you bowel motions* (small amounts of blood being found in them by the bowel cancer screening test). Could you please indicate how much you agree or disagree with each of the statements below by placing a tick in the box ✓ that best reflects your views.

How do you feel about the problem with your bowel motions?	Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
I don't understand the problem with my bowel motions.						
Having this problem with my bowel motions makes me feel anxious.						
The problem with my bowel motions will last a long time.						
The problem with my bowel motions makes me feel angry.						
I expect the problem with my bowel motions to last the rest of my life.						
I get depressed when I think about the problem with my bowel motions.						
The problem with my bowel motions has major consequences on my life.						
The problem with my bowel motions doesn't make any sense to me.						
The problem with my bowel motions strongly affects the way others see me.						
There is nothing that can help the problem with my bowel motions.						
The problem with my bowel motions causes difficulties for those who are close to me.						
There is a lot I can do to control my symptoms.						
The negative effects of the problem with my bowel motions can be prevented (avoided) by my treatment.						
The course of the problem with my bowel motions depends on me.						
There is very little that can be done to improve the problem with my bowel motions.						
I have the power to influence the problem with my bowel motions.						

<b>How do you feel about the problem with your bowel motions?</b>	<b>Disagree very strongly</b>	<b>Disagree strongly</b>	<b>Disagree</b>	<b>Agree</b>	<b>Agree strongly</b>	<b>Agree very strongly</b>
The problem with my bowel motions makes me feel afraid.						
The problem with my bowel motions will improve in time.						
My actions will have no affect on the outcome of the problem with my bowel motions.						
My treatment will be effective in curing the problem with my bowel motions.						
What I do can determine whether the problem with my bowel motions gets better or worse.						
Treatment can control the problem with my bowel motions.						
The problem with my bowel motions has serious financial consequences.						
The symptoms of the problem with my bowel motions are puzzling to me.						
The problem with my bowel motions is a mystery to me.						
The problem with my bowel motions will last a short time.						
The problem with my bowel motions does not have much effect on my life.						
I have a clear picture or understanding of the problem with my bowel motions.						
The problem with my bowel motions is serious.						
When I think about the problem with my bowel motions I get upset.						
The problem with my bowel motions will pass quickly.						
The problem with my bowel motions does not worry me.						
The problem with my bowel motions is likely to be permanent rather than temporary.						
Nothing I do will affect the problem with my bowel motions.						

Listed below are a number of symptoms that you may or may not have experienced since you were told that you had a problem with your *bowel motions* (small amounts of blood being found in them by the bowel cancer screening test). Please indicate by ticking  the box **YES** or **NO** whether you have experienced any of these symptoms since this result.

<b>I have experienced this symptom since being told small amounts of blood were found in my bowel motion by the bowel cancer screening test.</b>	<b>Yes</b>	<b>No</b>
Pain		
Nausea		
Weight loss		
Upset stomach		
Bleeding		
Loss of appetite		
Discomfort when passing bowel motion		
Painful wind/gas		
Constipation		
Diarrhoea		

<b>Do you believe that these symptoms are related to small amounts of blood being found in your bowel motion?</b>	<b>Yes</b>	<b>No</b>
Pain		
Nausea		
Weight loss		
Upset stomach		
Bleeding		
Loss of appetite		
Discomfort when passing bowel motion		
Painful wind/gas		
Constipation		
Diarrhoea		

**Section 2**

The next set of statements are concerned with how you have reacted since you were told that there was a problem with your *bowel motions* (small amounts of blood being found in them by the bowel cancer screening test). When answering these questions please think of the time since your **BOWEL CANCER SCREENING TEST** result, rather than the time since your colonoscopy examination.

Since being told that there was a problem with my bowel motions (small amounts of blood being found in them by the bowel cancer screening test)...

**...I have talked to someone about how I have been feeling.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have tried to keep my feelings to myself.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have expressed anger to the person(s) who caused the problem**

Not used	Used somewhat	Used quite a bit	Used a great deal
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Since being told that there was a problem with my bowel motions (small amounts of blood being found in them by the bowel cancer screening test)...

**...I have let my feelings out somehow.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have gone on as if nothing has happened.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have done something which I didn't think would work out, but at least I was doing something.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------



**...I have made light of the situation/I refused to get too serious about it.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have stood my ground and fought for what I wanted.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have been smoking more/less than I used to.**

Quite a bit more than I used to	A little bit more than I used to	The same as I used to	A little bit less than I used to	Quite a bit less than I used to
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**...I have tried not to act too hastily or follow my first hunch (reaction)**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have tried to forget the whole thing.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have tried to look on the bright side of things.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have gone along with fate/sometimes I just have bad luck.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have kept others from knowing how bad things were.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have tried not to burn my bridges, but leave things open somewhat.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have tried to get the person responsible to change his/her mind.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have been smoking more than I used to.**

Agree very strongly	Agree strongly	Neither agree nor disagree	Disagree strongly	Disagree very strongly
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**Since being told that there was a problem with my bowel motions (small amounts of blood being found in them by the bowel cancer screening test)...**

**...I have been eating less fibre than I used to.**

Agree very strongly	Agree strongly	Neither agree nor disagree	Disagree strongly	Disagree very strongly
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**...I haven't let it get to me/refused to think about it too much.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have tried to keep my feelings from interfering with other things too much.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have hoped that a miracle would happen.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have thought about how a person I admire would handle the situation and have used that as a model to help me.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have spoken to someone to find out more about the situation.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have made a plan of action and followed it.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have found new faith**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have asked a relative or friend I respected for advice.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have been taking more/less mild exercise (minimal effort) than I used to.**

Quite a bit more than I used to	A little bit more than I used to	The same as I used to	A little bit less than I used to	Quite a bit less than I used to
---------------------------------	----------------------------------	-----------------------	----------------------------------	---------------------------------

**...I have accepted sympathy and understanding from someone.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have come up with a couple of different solutions to the problem.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have criticised/lectured myself.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have apologised or did something to make up.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**Since being told that there was a problem with my bowel motions (small amounts of blood being found in them by the bowel cancer screening test)...**

**...I have been taking more mild exercise (minimal effort) than I used to.**

Agree very strongly	Agree strongly	Neither agree nor disagree	Disagree strongly	Disagree very strongly
---------------------	----------------	----------------------------	-------------------	------------------------

**...I have made a promise to myself that things would be different next time.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have rediscovered what is important in life**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have wished that the situation would go away or somehow be over with.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have been taking more/less strenuous exercise (heart beats rapidly) than I used to.**

Quite a bit more than I used to	A little bit more than I used to	The same as I used to	A little bit less than I used to	Quite a bit less than I used to
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**...I have fantasised about how things might turn out.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have tried to make myself feel better by eating, drinking, smoking, using drugs etc.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have avoided being with people in general.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have refused to believe that it has happened.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have taken it out on other people.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have slept more than usual.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have been eating more/less fibre than I used to.**

Quite a bit more than I used to	A little bit more than I used to	The same as I used to	A little bit less than I used to	Quite a bit less than I used to
---------------------------------	----------------------------------	-----------------------	----------------------------------	---------------------------------

**...I have spoken to someone who could do something concrete about the problem.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**Since being told that there was a problem with my bowel motions (small amounts of blood being found in them by the bowel cancer screening test)...**

**...I have been taking more strenuous exercise (heart beats rapidly) than I used to.**

Agree very strongly	Agree strongly	Neither agree nor disagree	Disagree strongly	Disagree very strongly
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**...I have just concentrated on what I had to do next – the next step.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have been eating less fatty food than I used to.**

Agree very strongly	Agree strongly	Neither agree nor disagree	Disagree strongly	Disagree very strongly
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**...I have changed something so things would turn out all right.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have drawn on my past experiences, I was in a similar position before.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have got professional help.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have changed or grown as a person in a good way.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have come out of the experience better than when I went in.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have been taking more moderate exercise (not exhausting) than I used to.**

Agree very strongly	Agree strongly	Neither agree nor disagree	Disagree strongly	Disagree very strongly
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**...I have realised that I brought the problem on myself.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have prayed.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have changed something about myself.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have been inspired to do something creative.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**...I have known what needed to be done so I double my efforts to make things work.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**Since being told that there was a problem with my bowel motions (small amounts of blood being found in them by the bowel cancer screening test)...**

**...I have been eating more/less fatty food than I used to.**

Quite a bit more than I used to	A little bit more than I used to	The same as I used to	A little bit less than I used to	Quite a bit less than I used to
---------------------------------	----------------------------------	-----------------------	----------------------------------	---------------------------------

**...I have gone over in my mind what I would say or do.**

Not used	Used somewhat	Used quite a bit	Used a great deal
----------	---------------	------------------	-------------------

**...I have been taking more/less moderate exercise (not exhausting) than I used to.**

Quite a bit more than I used to	A little bit more than I used to	The same as I used to	A little bit less than I used to	Quite a bit less than I used to
---------------------------------	----------------------------------	-----------------------	----------------------------------	---------------------------------

**...I have done something very risky.**

Not used	Used somewhat	Used quite a bit	Used a great deal
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**Since you were told that you had a problem with your bowel motions (small amounts of blood being found in them by the bowel cancer screening test) have you made any changes to your lifestyle to try and reduce your risk of developing bowel cancer? *Please write in the space provided below.***

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**Section 3**

**The questions in the next section are about your COLONOSCOPY EXAMINATION.**

**Recently you were asked to attend the hospital for a COLONOSCOPY EXAMINATION. The following questions are concerned with your views about your experience of the COLONOSCOPY EXAMINATION at the hospital.**

**Before you went to the hospital for your colonoscopy examination, did you discuss the result of your bowel cancer screening test with a nurse from the screening centre?**

Yes

No

**Before you went to the hospital for your colonoscopy examination, did you receive a leaflet explaining what traces of blood the bowel motion meant?**

Yes

No

**If you did receive a leaflet explaining what traces of blood in the bowel motions meant, did you read it?**

Yes

No

**Did you obtain information from any other source about what traces of blood in the bowel motions meant, before you went into hospital for your colonoscopy examination?**

Yes

No

**If you did, please specify in the space below where you obtained this information.**

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**Before you attended for your recent colonoscopy examination at the hospital, did a nurse at the screening clinic explain to you what was involved in the colonoscopy examination?**

Yes

No

**Before you attended for your recent colonoscopy examination at the hospital, did your GP explain to you what was involved in the colonoscopy examination?**

Yes

No

**Did you obtain information from any other source about what was involved in a colonoscopy examination, before you went into hospital for your colonoscopy examination?**

Yes

No

**If you did, please specify in the space below where you obtained this information.**

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**Before you attended for your recent colonoscopy examination at the hospital, did you receive a leaflet explaining what was involved in the colonoscopy examination?**

Yes

No

**If you did, please specify in the space below where you obtained this leaflet.**

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If you did receive a leaflet explaining what was involved in the colonoscopy examination before you attended for your recent colonoscopy examination, did you read it?

Yes

No

**How important was your visit to the hospital for colonoscopy to you?**

Extremely important	Very important	Quite important	Neutral	Quite unimportant	Very unimportant	Extremely unimportant
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**NOW...Please think about what you DID NOT want to happen during your hospital visit for colonoscopy.**

**To what extent did these UNDESIRABLE things happen?**

	<i>Extremely</i>	Very	Quite	Neutral	<i>Quite</i>	Very	Extremely	
Not at all								Very much so

Please write in the space provided what these UNDESIRABLE things were (if there were any)

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**NOW...Please think about what you DID want to happen during your visit to the hospital for colonoscopy.**

**To what extent did these DESIRABLE things happen?**

	<i>Extremely</i>	Very	Quite	Neutral	<i>Quite</i>	Very	Extremely	
Not at all								Very much so

Please write in the space provided what these DESIRABLE things were (if there were any)

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**When you went to the hospital for colonoscopy were you confident that you could handle (emotionally) what was happening, no matter how it worked out?**

Extremely confident	Very confident	Quite confident	Neutral	Quite unconfident	Very unconfident	Extremely unconfident
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**How responsible are YOU for what happened during your visit to the hospital for colonoscopy?**

Extremely responsible	Very responsible	Quite responsible	Neutral	Quite unresponsible	Very unresponsible	Extremely unresponsible
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**When you went to the hospital for colonoscopy, how confident were you that you would be able to make things go the way you wanted then to during your examination?**

Extremely confident	Very confident	Quite confident	Neutral	Quite unconfident	Very unconfident	Extremely unconfident
---------------------	----------------	-----------------	---------	-------------------	------------------	-----------------------

**How responsible is SOMEBODY ELSE for what happened during your visit to the hospital for colonoscopy?**

Extremely responsible	Very responsible	Quite responsible	Neutral	Quite unresponsible	Very unresponsible	Extremely unresponsible
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**When you went to the hospital for colonoscopy, how did things work out in terms of how you thought they would?**

Exactly as I expected	Very much as I expected	A little as I expected	Neutral	A little unlike I expected	Very unlike I expected	Exactly unlike I expected
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Please state how strongly you agree/disagree with the following statements.

**Before I attended for my recent colonoscopy examination at the hospital, I felt that I had as much information as I wanted about what my positive bowel cancer screening test result meant.**

Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
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**Before I attended for my recent colonoscopy examination at the hospital, I felt that I had as much information as I wanted about the procedure.**

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
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**Section 4**

The statements in the following section are about bowel cancer and how you feel about doing a bowel cancer screening test, **NOT** a *colonoscopy examination*. Please tick ✓ the box that best reflects how you feel. Please respond to each statement even if you think some of them sound the same.

**If I am invited to do a bowel cancer screening test in the future, I could easily do it if I wanted to.**

Extremely likely	Very likely	Quite likely	Quite unlikely	Very unlikely	Extremely unlikely
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**I am certain that if I were to develop bowel cancer it would limit *my* social life.**

Extremely uncertain	Very uncertain	Quite uncertain	Quite certain	Very certain	Extremely certain
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**How much control do *you* have over whether *you* do a bowel cancer screening test in the future, if you are invited to do one?**

Complete control	A lot of control	A little control	Not much control	Very little control	No control
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**Do you think it is easy or difficult for *you* to do a bowel cancer screening test in the future, if you are invited to do one?**

Extremely easy	Very easy	Quite easy	Quite difficult	Very difficult	Extremely difficult
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**How strongly would you characterise your desire to do a bowel cancer screening test in the future?**

No desire	Very weak desire	Weak desire	Moderate desire	Strong desire	Very strong desire
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**If somebody develops bowel cancer it is likely that *his or her* financial security would be at risk.**

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
--------------------	---------------	----------------	--------------	-------------	------------------

**If somebody develops bowel cancer, it can almost certainly cause *his or her* death.**

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
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**I desire to do a bowel cancer screening test in the future.**

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
--------------------	---------------	----------------	--------------	-------------	------------------

**If I am invited to do a bowel cancer screening test in the future, I intend to do it.**

Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
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**If I am invited to do a bowel cancer screening test in the future, I will try to do the test.**

Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
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**I am certain that if somebody develops bowel cancer it would damage important relationships in his or her life.**

Extremely certain	Very certain	Quite certain	Quite uncertain	Very uncertain	Extremely uncertain
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**If I develop bowel cancer it is likely that my financial security would be at risk.**

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
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**In comparison to other people my age my chances of developing bowel cancer are...**

Extremely low	Very low	Quite low	Quite high	Very high	Extremely high
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**Doing a bowel cancer screening test in the future is something that I desire to do.**

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
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**I am certain that if I were to develop bowel cancer it would damage important relationships in my life.**

Extremely uncertain	Very uncertain	Quite uncertain	Quite certain	Very certain	Extremely certain
---------------------	----------------	-----------------	---------------	--------------	-------------------

**I think that my chances of developing bowel cancer are...**

Extremely high	Very high	Quite high	Quite low	Very low	Extremely low
----------------	-----------	------------	-----------	----------	---------------

**If you are invited to do a bowel cancer screening test in the future, how likely is it that you would do the test?**

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
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**I feel personally at risk of developing bowel cancer.**

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
---------------------	----------------	-------	----------	-------------------	------------------------

**If I am invited to do a bowel cancer screening test in the future, I am certain that I could do it.**

Extremely uncertain	Very uncertain	Quite uncertain	Quite certain	Very certain	Extremely certain
---------------------	----------------	-----------------	---------------	--------------	-------------------



Please state how likely **EACH** of the factors listed below is to stop **YOU** from doing a bowel cancer screening test if **YOU** were asked to do one in the future, by placing a tick ✓ in the appropriate box across from **EACH** factor.

	Extremely likely to stop me	Very likely to stop me	Quite likely to stop me	Quite unlikely to stop me	Very unlikely to stop me	Extremely unlikely to stop me
Constipation						
Physical disability						
Visual impairment						
Irregular bowel movements						
Diarrhoea						
Current treatment for bowel cancer						
Other bowel disease (Crohn's disease, Irritable bowel syndrome)						
Other illness						
Lack of time						
No where to store the test						

If **somebody** develops bowel cancer it is likely that **he or she** will have to stop living their life the way **they** want to.

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
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How likely do you think it is that **you** would have to stop living your life the way that you want to, if **you** develop bowel cancer?

Extremely likely	Very likely	Quite likely	Quite unlikely	Very unlikely	Extremely unlikely
------------------	-------------	--------------	----------------	---------------	--------------------

If **you** are asked to do a bowel cancer screening test in the future, to what extent are **you** capable of doing it.

Extremely capable	Very capable	Quite capable	Quite incapable	Very incapable	Extremely incapable
-------------------	--------------	---------------	-----------------	----------------	---------------------

If **somebody** develops bowel cancer, they would experience a lot of physical sickness.

Extremely certain	Very certain	Quite certain	Quite uncertain	Very uncertain	Extremely uncertain
-------------------	--------------	---------------	-----------------	----------------	---------------------

I think that **my** chances of developing bowel cancer are very low.

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
---------------------	----------------	-------	----------	-------------------	------------------------

If you were invited to do a bowel cancer screening test in the future how *likely* do you think EACH of the following is to happen? Please tick ✓ the most appropriate box.

Doing a bowel cancer screening test in the future...	Extremely likely to happen	Very likely to happen	Quite likely to happen	Quite unlikely to happen	Very unlikely to happen	Extremely unlikely to happen
... would reduce <i>my</i> chances of dying from bowel cancer.						
... would help find any abnormalities <i>I</i> may have before they become cancerous.						
... would increase <i>my</i> chances of getting treatment earlier.						
... would help <i>me</i> avoid having to have drastic treatment if <i>I</i> had bowel cancer <i>I</i> didn't know about.						
... would put <i>my</i> mind at rest about bowel cancer.						
... would reduce any worries <i>I</i> might have about getting bowel cancer.						
... would increase <i>my</i> confidence about not getting bowel cancer.						
... would reduce any worries <i>I</i> might have about having any 'non-cancerous' abnormalities.						

**How likely do you think it is that *you* will develop bowel cancer?**

Extremely likely	Very likely	Quite likely	Quite unlikely	Very unlikely	Extremely unlikely
------------------	-------------	--------------	----------------	---------------	--------------------

**If *I* were invited to do a bowel cancer screening test in the future, *I* would feel very confident in *my* ability to do it.**

Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
------------------------	-------------------	----------	-------	----------------	---------------------

**If *I* am invited to do a bowel cancer screening test in the future, *I* believe that *I* would be able to do it.**

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
---------------------	----------------	-------	----------	-------------------	------------------------

***I* am certain that if *somebody* develops bowel cancer, it would limit *his or her* social life.**

Extremely uncertain	Very uncertain	Quite uncertain	Quite certain	Very certain	Extremely certain
---------------------	----------------	-----------------	---------------	--------------	-------------------

**If *somebody* develops bowel cancer, they would experience a lot of physical pain.**

Extremely certain	Very certain	Quite certain	Quite uncertain	Very uncertain	Extremely uncertain
-------------------	--------------	---------------	-----------------	----------------	---------------------

**How likely is it that you will die if you develop bowel cancer?**

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
--------------------	---------------	----------------	--------------	-------------	------------------

**If I am invited to do a bowel cancer screening test in the future, I would be willing to do it.**

Extremely unwilling	Very unwilling	Quite unwilling	Quite willing	Very willing	Extremely willing
---------------------	----------------	-----------------	---------------	--------------	-------------------

**If I develop bowel cancer I am certain that I would experience a lot of physical pain.**

Extremely certain	Very certain	Quite certain	Quite uncertain	Very uncertain	Extremely uncertain
-------------------	--------------	---------------	-----------------	----------------	---------------------

**If I am invited to do a bowel cancer screening test in the future, it would be entirely up to me whether I did it or not.**

Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
------------------------	-------------------	----------	-------	----------------	---------------------

**If you were invited to do a bowel cancer screening test in the future how would each of the following things make you feel? Please tick ✓ the box that best reflects how you feel.**

Doing a bowel cancer screening test in the future...	Extremely good	Very good	Quite good	Quite bad	Very bad	Extremely bad
...to reduce <u>my</u> chances of dying from bowel cancer is...						
...to find any abnormalities <u>I</u> may have before they become cancerous is...						
...to increase <u>my</u> chances of getting treatment earlier is...						
...to help <u>me</u> avoid having to have drastic treatment if <u>I</u> had bowel cancer <u>I</u> didn't know about is...						
...to put <u>my</u> mind at rest about bowel cancer is...						
...to reduce any worries <u>I</u> may have about getting bowel cancer is...						
...to increase <u>my</u> confidence about not getting bowel cancer is...						
...to reduce any worries <u>I</u> might have about having any 'non-cancerous' abnormalities is...						

**What proportion of people who will develop bowel cancer will die from this disease?**

None	Very few people	A few people	Quite a few people	Most people	Everyone
------	-----------------	--------------	--------------------	-------------	----------

**I am at less risk of developing bowel cancer than other people my age.**

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
---------------------	----------------	-------	----------	-------------------	------------------------

**If I develop bowel cancer I am certain that I would experience a lot of physical sickness.**

Extremely uncertain	Very uncertain	Quite uncertain	Quite certain	Very certain	Extremely certain
---------------------	----------------	-----------------	---------------	--------------	-------------------

**How likely do you think it is that somebody who develops bowel cancer would die from this disease?**

Extremely likely	Very likely	Quite likely	Quite unlikely	Very unlikely	Extremely unlikely
------------------	-------------	--------------	----------------	---------------	--------------------

If **I** develop bowel cancer, it could almost certainly cause **my** death.

Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
------------------------	-------------------	----------	-------	----------------	---------------------

If you were invited to do a bowel cancer screening test in the future, how **important** would it be to you if each of the following things were to happen? Please tick  the box that best reflects how you feel.

Doing a bowel cancer screening test in the future...	Extremely important to me	Very important to me	Quite important to me	Quite unimportant to me	Very unimportant to me	Extremely unimportant to me
...to reduce <b>my</b> chances of dying from bowel cancer is...						
...to help find any abnormalities <b>I</b> may have before they become cancerous is...						
...to increase <b>my</b> chances of getting treatment earlier is...						
...to help <b>me</b> avoid having to have drastic treatment if <b>I</b> had bowel cancer <b>I</b> didn't know about is...						
...to put <b>my</b> mind at rest about bowel cancer is...						
...to reduce any worries <b>I</b> may have about getting bowel cancer is...						
...to increase <b>my</b> confidence about not getting bowel cancer is...						
...to reduce any worries <b>I</b> might have about having any 'non-cancerous' abnormalities is...						

What do **YOU** think about doing a bowel cancer screening test in the future? Please place a tick  in the most appropriate box

For me, doing a bowel cancer screening test in the future is...

Extremely wise	Very wise	Quite wise	Quite foolish	Very foolish	Extremely foolish
----------------	-----------	------------	---------------	--------------	-------------------

For me, doing a bowel cancer screening test in the future is...

Extremely unimportant	Very unimportant	Quite unimportant	Quite important	Very important	Extremely important
-----------------------	------------------	-------------------	-----------------	----------------	---------------------

For me, doing a bowel cancer screening test in the future is...

Extremely satisfying	Very satisfying	Quite satisfying	Quite dissatisfying	Very dissatisfying	Extremely dissatisfying
----------------------	-----------------	------------------	---------------------	--------------------	-------------------------

**For me, doing a bowel cancer screening test in the future is...**

Extremely unpleasant	Very unpleasant	Quite unpleasant	Quite pleasant	Very pleasant	Extremely pleasant
----------------------	-----------------	------------------	----------------	---------------	--------------------

**For me, doing a bowel cancer screening test in the future is...**

Extremely worthwhile	Very worthwhile	Quite worthwhile	Quite worthless	Very worthless	Extremely worthless
----------------------	-----------------	------------------	-----------------	----------------	---------------------

**For me, doing a bowel cancer screening test in the future is...**

Extremely unnecessary	Very unnecessary	Quite unnecessary	Quite necessary	Very necessary	Extremely necessary
-----------------------	------------------	-------------------	-----------------	----------------	---------------------

**For me, doing a bowel cancer screening test in the future is...**

Extremely good	Very good	Quite good	Quite bad	Very bad	Extremely bad
----------------	-----------	------------	-----------	----------	---------------

**For me, doing a bowel cancer screening test in the future is...**

Extremely useless	Very useless	Quite useless	Quite useful	Very useful	Extremely useful
-------------------	--------------	---------------	--------------	-------------	------------------

**Section 5**

The questions in the following section are about how you have been feeling in the past week. Please read each statement and tick ✓ the box that comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

**I feel tense or 'wound up'.**

Most of the time	A lot of the time	Time to time, occasionally	Not at all
------------------	-------------------	----------------------------	------------

**I still enjoy the things I used to.**

Definitely as much	Not quite as much	Only a little	Hardly at all
--------------------	-------------------	---------------	---------------

**I get a sort of frightened feeling as if something awful is about to happen.**

Very definitely and quite badly	Yes, but not too badly	A little but it doesn't worry me	Not at all
---------------------------------	------------------------	----------------------------------	------------

**I can laugh and see the funny side of things.**

As much as I always could	Not quite so much now	Definitely not so much now	Not at all
---------------------------	-----------------------	----------------------------	------------

**Worrying thoughts go through my mind.**

A great deal of the time	A lot of the time	From time to time, but not too often	Only occasionally
--------------------------	-------------------	--------------------------------------	-------------------

**I feel cheerful.**

Not at all	Not often	Sometimes	Most of the time
------------	-----------	-----------	------------------

**I can sit easy and feel relaxed.**

Definitely	Usually	Not often	Not at all
------------	---------	-----------	------------

**I feel as if I am slowed down.**

Nearly all the time	Very often	Sometimes	Not at all
---------------------	------------	-----------	------------

**I get a sort of frightened feeling like butterflies in the stomach.**

Not at all	Occasionally	Quite often	Very often
------------	--------------	-------------	------------

**I have lost interest in my appearance.**

Definitely	I don't take so much care as I should	I may not take quite as much care	I take as much care as ever
------------	---------------------------------------	-----------------------------------	-----------------------------

**I feel restless as if I have to be on the move.**

Very much indeed	Quite a lot	Not very much	Not at all
------------------	-------------	---------------	------------

**I look forward with enjoyment to things.**

As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
-----------------------	----------------------------	--------------------------------	---------------

**I get sudden feelings of panic.**

Very often indeed	Quite often	Not very often	Not at all
-------------------	-------------	----------------	------------

**I can enjoy a good book or radio or TV programme.**

Often	Sometimes	Not often	Very seldom
-------	-----------	-----------	-------------

**Section 6**

This section is made up of statements *other people* have made about doing a bowel cancer screening test. We would like to know what you think. Please tick ✓ the box that best reflects **YOUR** views.

If you were invited to do a bowel cancer screening test in the future, how *likely* do you think it is that each of the following things would happen? Please tick ✓ the box that best reflects how you feel.

Doing a bowel cancer screening test in the future...	Extremely likely to happen	Very likely to happen	Quite likely to happen	Quite unlikely to happen	Very unlikely to happen	Extremely unlikely to happen
...would be an invasion of <i>my</i> privacy.						
...would be embarrassing.						
...would lead to unpleasant treatment if abnormalities were present.						
...would be disgusting.						
...would be unhygienic.						
...would lead to <i>me</i> having to go to hospital if abnormalities were present.						
...would lead to blood being found in <i>my</i> bowel motion if abnormalities were present.						

**If you were invited to do a bowel cancer screening test in the future...**

...how confident are *you* that *you* could deal (emotionally) with feeling that *your* privacy is being invaded by doing the bowel cancer screening test?

Extremely confident	Very confident	Quite confident	Quite unconfident	Very unconfident	Extremely unconfident
---------------------	----------------	-----------------	-------------------	------------------	-----------------------

...how confident are *you* that *you* could deal (emotionally) with feeling embarrassed by doing the bowel cancer screening test?

Extremely unconfident	Very unconfident	Quite unconfident	Quite confident	Very confident	Extremely confident
-----------------------	------------------	-------------------	-----------------	----------------	---------------------

...how confident are you that you could deal (emotionally) with the possibility of having unpleasant treatment *after* doing the bowel cancer screening test, if abnormalities were present?

Extremely confident	Very confident	Quite confident	Quite unconfident	Very unconfident	Extremely unconfident
---------------------	----------------	-----------------	-------------------	------------------	-----------------------

... how confident are you that you could deal (emotionally) with feeling disgusted by doing the bowel cancer screening test?

Extremely unconfident	Very unconfident	Quite unconfident	Quite confident	Very confident	Extremely confident
-----------------------	------------------	-------------------	-----------------	----------------	---------------------

**If you were invited to do a bowel cancer screening test in the future...**

...how confident are you that you could deal (emotionally) with the unhygienic aspects of doing the bowel cancer screening test?

Extremely confident	Very confident	Quite confident	Quite unconfident	Very unconfident	Extremely unconfident
---------------------	----------------	-----------------	-------------------	------------------	-----------------------

...how confident are you that you could deal (emotionally) with the possibility of having to go to hospital *after* doing the bowel cancer screening test, if abnormalities were present?

Extremely unconfident	Very unconfident	Quite unconfident	Quite confident	Very confident	Extremely confident
-----------------------	------------------	-------------------	-----------------	----------------	---------------------

...how confident are you that you could deal (emotionally) with the possibility of blood being found in your bowel motion by the bowel cancer screening test, if abnormalities were present?

Extremely confident	Very confident	Quite confident	Quite unconfident	Very unconfident	Extremely unconfident
---------------------	----------------	-----------------	-------------------	------------------	-----------------------

How does the thought of developing bowel cancer make you feel?

**The thought of developing bowel cancer makes me feel...**

Extremely angry	Very angry	Moderately angry	A little angry	Not at all angry
-----------------	------------	------------------	----------------	------------------

**The thought of developing bowel cancer makes me feel...**

Not at all annoyed	A little annoyed	Moderately annoyed	Very annoyed	Extremely annoyed
--------------------	------------------	--------------------	--------------	-------------------

**The thought of developing bowel cancer makes me feel...**

Extremely anxious	Very anxious	Moderately anxious	A little anxious	Not at all anxious
-------------------	--------------	--------------------	------------------	--------------------

**The thought of developing bowel cancer makes me feel...**

Not at all frightened	A little frightened	Moderately frightened	Very frightened	Extremely frightened
-----------------------	---------------------	-----------------------	-----------------	----------------------

**The thought of developing bowel cancer makes me feel...**

Extremely worried	Very worried	Moderately worried	A little worried	Not at all worried
-------------------	--------------	--------------------	------------------	--------------------

**The thought of developing bowel cancer makes me feel...**

Not at all scared	A little scared	Moderately scared	Very scared	Extremely scared
-------------------	-----------------	-------------------	-------------	------------------

**The thought of developing bowel cancer makes me feel...**

Extremely humiliated	Very humiliated	Moderately humiliated	A little humiliated	Not at all humiliated
----------------------	-----------------	-----------------------	---------------------	-----------------------

If you were invited to do a bowel cancer screening test in the future how would each of the following things make you *feel* if they were to happen? Please tick ✓ the box that best reflects how you feel.

Doing a bowel cancer screening test in the future...	Extremely good	Very good	Quite good	Quite bad	Very bad	Extremely bad
...feeling that <i>my</i> privacy was being invaded would be...						
...being embarrassed would be...						
...the possibility of having to have unpleasant treatment if abnormalities were present would be...						
...being disgusted would be...						
...it being unhygienic would be...						
...having to go to hospital if abnormalities were present would be...						
... having blood being found in <i>my</i> bowel motion if abnormalities were present would be...						

How does the thought of *NOT developing* bowel cancer make *you* feel?

The thought of *NOT* developing bowel cancer makes me feel....

Extremely satisfied	Very satisfied	Moderately satisfied	A little satisfied	Not at all satisfied
---------------------	----------------	----------------------	--------------------	----------------------

The thought of *NOT* developing bowel cancer makes me feel....

Not at all glad	A little glad	Moderately glad	Very glad	Extremely glad
-----------------	---------------	-----------------	-----------	----------------

The thought of *NOT* developing bowel cancer makes me feel....

Extremely happy	Very happy	Moderately happy	A little happy	Not at all happy
-----------------	------------	------------------	----------------	------------------

The thought of *NOT* developing bowel cancer makes me feel....

Not at all pleased	A little pleased	Moderately pleased	Very pleased	Extremely pleased
--------------------	------------------	--------------------	--------------	-------------------

The thought of *NOT* developing bowel cancer makes me feel....

Extremely excited	Very excited	Moderately excited	A little excited	Not at all excited
-------------------	--------------	--------------------	------------------	--------------------

The thought of *NOT* developing bowel cancer makes me feel....

Not at all delighted	A little delighted	Moderately delighted	Very delighted	Extremely delighted
----------------------	--------------------	----------------------	----------------	---------------------

If you were to do a bowel cancer screening test in the future how *important* would it be to you if each of the following things were to happen? Please tick ✓ the box that best reflects how you feel.



Doing a bowel cancer screening test in the future...	Extremely important to me	Very important to me	Quite important to me	Quite unimportant to me	Very unimportant to me	Extremely unimportant to me
...feeling that <i>my</i> privacy was being invaded would be...						
...being embarrassed would be...						
...the possibility of having to have unpleasant treatment if abnormalities were present would be...						
...being disgusted would be...						
...it being unhygienic would be...						
...having to go to hospital if abnormalities were present would be...						
... having blood being found in <i>my</i> bowel motion if abnormalities were present would be...						

**Do you agree or disagree with the following statements?**

	Very strongly agree	Strongly agree	<i>Agree</i>	Disagree	Strongly disagree	Very strongly disagree
I prefer not to think about bowel cancer						
I avoid reading about bowel cancer						
I avoid watching TV programmes about bowel cancer						
I avoid listening to radio programmes about bowel cancer						
I don't want to know anymore about bowel cancer						

**Section 7**

**It is also very important for us to understand how people who are important to you feel about *you* doing a bowel cancer screening test in the future. Please answer all of the following questions by ticking ✓ the box that best reflects your views.**

**How likely are the following people to want you to do a bowel cancer screening test in the future?**

Your...	Extremely likely	Very likely	Quite likely	Quite unlikely	Very unlikely	Extremely unlikely
...partner						
...children						
...doctor						
...friends						

**Most people who are important to me would approve of me doing a bowel cancer screening test in the future.**

Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
------------------------	-------------------	----------	-------	----------------	---------------------

**Most people who are important to me think that I should do a bowel cancer screening test in the future.**

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
---------------------	----------------	-------	----------	-------------------	------------------------

**Most people who are important to me would support me doing a bowel cancer screening test in the future.**

Disagree very strongly	Disagree strongly	Disagree	Agree	Agree strongly	Agree very strongly
------------------------	-------------------	----------	-------	----------------	---------------------

**Most people who are important to me would think it is a good idea for me to do a bowel cancer screening test in the future.**

Agree very strongly	Agree strongly	Agree	Disagree	Disagree strongly	Disagree very strongly
---------------------	----------------	-------	----------	-------------------	------------------------

**How likely are you to do what the following people think you should do?**

Your...	Extremely likely	Very likely	Quite likely	Quite unlikely	Very unlikely	Extremely unlikely
...partner						
...children						
...doctor						
...friends						

**Section 8**

A number of statements which people have used to describe themselves are given below. Read each statement and then tick  the box to indicate how you feel *right now*, that is *at the moment*. There are no right or wrong answers. Do not spend too long on any one statement but give the answer which seems to describe your feelings best.

<i>Right now...</i>	Not at all	Somewhat	Moderately so	Very much so
...I feel calm				
...I feel secure				
...I feel tense				
...I feel strained				
...I feel furious				
...I feel upset				
...I am presently worrying over possible misfortunes				
...I feel satisfied				
...I feel frightened				
...I feel comfortable				
...I feel irate				
...I feel nervous				
...I am jittery				
...I feel indecisive				
...I feel enraged				
...I feel content				

...I feel mad at the world				
...I feel confused				
...I feel steady				
...I feel pleasant				
...I feel at ease				
...I am worried				
...I feel frustrated				
...I feel self-confident				
...I am relaxed				
...I feel angry				

**Section 9**      **The questions in the following sections are about you. Some are about the type of person you think you yourself are, and others are about diet and exercise. Please answer all of these questions and remember that this questionnaire is completely confidential and your answers will not be personally**

**Here are a number of characteristics that may or may not apply to you. Please tick ✓ the box that best reflects how you feel about each statement.**

**I see myself as someone who does a thorough job.**

Disagree strongly	Disagree a little	Neither agree nor disagree	Agree a little	Agree strongly
-------------------	-------------------	----------------------------	----------------	----------------

**I see myself as someone who can be somewhat careless.**

Agree strongly	Agree a little	Neither agree nor disagree	Disagree a little	Disagree strongly
----------------	----------------	----------------------------	-------------------	-------------------

**I see myself as someone who is a reliable worker.**

Disagree strongly	Disagree a little	Neither agree nor disagree	Agree a little	Agree strongly
-------------------	-------------------	----------------------------	----------------	----------------

**I see myself as someone who tends to be disorganised.**

Agree strongly	Agree a little	Neither agree nor disagree	Disagree a little	Disagree strongly
----------------	----------------	----------------------------	-------------------	-------------------

**I see myself as someone who tends to be lazy.**

Disagree strongly	Disagree a little	Neither agree nor disagree	Agree a little	Agree strongly
-------------------	-------------------	----------------------------	----------------	----------------

**I see myself as someone who perseveres until the task is finished.**

Agree strongly	Agree a little	Neither agree nor disagree	Disagree a little	Disagree strongly
----------------	----------------	----------------------------	-------------------	-------------------

**I see myself as someone who does things efficiently.**

Disagree strongly	Disagree a little	Neither agree nor disagree	Agree a little	Agree strongly
-------------------	-------------------	----------------------------	----------------	----------------

**I see myself as someone who makes plans and follows through with them.**

Agree strongly	Agree a little	Neither agree nor disagree	Disagree a little	Disagree strongly
----------------	----------------	----------------------------	-------------------	-------------------

**I see myself as someone who is easily distracted.**

Disagree strongly	Disagree a little	Neither agree nor disagree	Agree a little	Agree strongly
-------------------	-------------------	----------------------------	----------------	----------------

**The following questions are about your dietary habits.**

<b>About how many times <u>A WEEK</u> do you have a bowl of breakfast cereal?</b>				
<b>What kind do you have the most often? (choose 1 type only, if possible)</b>				
<b>Cereal Type</b>	<b>Less than 1 a week</b>	<b>1-2 a week</b>	<b>3-5 a week</b>	<b>6+ a week</b>
<b>Sugar Type:</b> For example, Frosties, Coco Pops, Ricicles				
<b>Rice/Corn Type:</b> For example, Corn Flakes, Rice Krispies, Special K				
<b>Porridge/Ready Brek</b>				
<b>Wheat Type:</b> For example, Shredded Wheat, Fruit 'n Fibre, Weetabix				
<b>Muesli Type:</b> For example, Alpen, Jordans				
<b>Bran Type:</b> For example, All-Bran, Sultana Bran				

<b>How many pieces of bread (including rolls, ciabatta, pitta, naan, chapatis etc) do you eat on <u>A USUAL DAY</u>?</b>				
<b>Are they usually made with white, brown, or wholemeal flour? (choose 1 only, if possible)</b>				
<b>Bread made with</b>	<b>Less than 1 a day</b>	<b>1-2 a day</b>	<b>3-4 a day</b>	<b>5 or more a day</b>
White flour				
Brown or granary flour				
Wholemeal flour				

<b>About how many times <u>A WEEK</u> do you eat a serving of each of the following foods? (Tick <input type="checkbox"/> a box for each type of food listed)</b>				
<b>Food</b>	<b>Less than 1 a week</b>	<b>1-2 a week</b>	<b>3-5 a week</b>	<b>6+ a week</b>
Pasta or rice				
Potatoes				
Peas				
Beans (baked, tinned, dried) or lentils				
Other vegetables (any type)				
Fruit (fresh, canned or frozen)				

About how many times <u>A WEEK</u> do you eat a serving of each of the following foods? (Tick <input type="checkbox"/> a box for each type of food listed)				
Food	Less than 1 a week	1-2 a week	3-5 a week	6+ a week
Cheese (except <i>cottage</i> )				
Beefburgers or sausages				
Beef, pork, lamb/mutton, goat (or nuts, if vegetarian)				
Bacon, meat pies, processed meat				

About how many times <u>A WEEK</u> do you eat a serving of each of the following foods? (Tick <input type="checkbox"/> a box for each type of food listed)				
Food	Less than 1 a week	1-2 a week	3-5 a week	6+ a week
Chicken or turkey				
Fish ( <b>NOT</b> fried)				
<b>Any fried food:</b> For example, chips, fish, cooked breakfast, samosas				
Cakes, pastries, pies, puddings				
Biscuits, chocolate, crisps				

How much milk do you yourself use in <u>A DAY</u> for drinking or in cereal, tea or coffee?				
What kind of milk do you usually use? (choose only 1, if possible)				
Milk	Less than a quarter pint	About a quarter pint	About half a pint	1 pint or more
Full Fat				
Semi Skimmed				
Skimmed				

How many pats or rounded teaspoons of margarine, butter or other spread do you usually use in <u>A DAY</u> on bread, toast, potatoes or vegetables?	
	Number of pats
<b>Butter/Margarine:</b> Flora, Vitalite, Sunflower types, Krona etc.	
<b>Low fat spread:</b> Gold/Lowest, Outline, Shape, Flora Extra Light, Olivo, etc	

What sort of fat do you use? (choose one on each line)	Butter, solid fat, ghee, lard, dripping.	Hard/soft margarine, dairy blends, half fat butter	Polyunsaturated sunflower oil, margarine, low fat spread	Pure Vegetable oil (e.g. olive, peanut, sunflower)	No fat used
On bread & vegetables.					
For frying.					
For baking or cooking.					

The questions that follow are about physical exercise.

Considering a 7-day period (a week), how many times on average do you do the following kinds of exercise (for more than 15 minutes at any one time) during your free time?

For example if you play squash three times a week for 1 hour at each time, write the number '3' on the line across from the 'strenuous exercise' option. If you go for a 15-minute swim twice a week, please write the number '2' on the line across from the 'moderate exercise' option. If you practice yoga for 1 hour five times a week, please write the number '5' on the line across from the 'minimal' exercise option. If you take no strenuous, moderate or mild exercise for more than 15 minutes at any one time during a typical 7-day period please write '0' on each line.

Please write the **NUMBER** on each line.

**Times Per Week**

**A) Strenuous exercise – heart beats rapidly**

(i.e. running, jogging, hockey, soccer, squash, basketball, judo/karate, roller skating/blading, vigorous swimming, vigorous long distance bicycling)

\_\_\_\_\_

**B) Moderate exercise – not exhausting**

(i.e. fast walking, tennis, easy bicycling, volleyball, badminton, easy swimming, dancing)

\_\_\_\_\_

**C) Mild exercise – minimal effort**

(i.e. yoga, fishing from river bank, bowling, golf, easy walking)

\_\_\_\_\_

Considering a 7-day period (a week), during your **leisure-time** how often do you engage in any regular activity long enough to work up a sweat (heart beats rapidly)?

- Often
- Sometimes
- Never/rarely

Are you a smoker?

- I used to smoke in the past, but no longer do so.
- Yes I am a smoker.
- No I am not a smoker.

Please write your height in either feet/inches or metres/centimetres in the space provided.

*Feet/Inches*                      *or*                      *Metres/Centimetres*

\_\_\_\_\_

Please write your weight as accurately as you can in either stones/pounds or kilograms, in the space provided.

*Stones/pounds*    *Kilograms*

\_\_\_\_\_

Do you know anyone personally (family/friends) who has had bowel cancer?

- Yes
- No

Have any members of your family (blood relatives, NOT relatives by marriage) had bowel cancer?

- Yes
- No

Please answer the next question ONLY if you are female.

If you are taking (or have taken in the past) the oral contraceptive pill, please state in the space provided how many years in total you have taken it for.

Years  
\_\_\_\_\_

Section 10

The following questions are about your background. All your answers will be treated with the strictest

What is your gender?  Female  Male

What is your age? (Please tick  $\checkmark$  relevant box)

- 50 to 54  55 to 59  60 to 64  
 65 to 69  70+

What is your marital status? (Please tick  $\checkmark$  one box)

- Married  Living with partner  
 Single  Widowed  
 Have a partner but do not live with them  Separated or divorced

What is your employment status (Please tick  $\checkmark$  one box)

- Working full-time (over 30 hours per week)  Unemployed  
 Working part-time (up to 30 hours per week)  Full-time student  
 On a government scheme  Looking after a home/family  
 Not working or seeking work for other reasons  I am retired/on sick benefit

Which of the following do you hold? (Please tick  $\checkmark$  all of which apply)

<input type="checkbox"/> Higher Degree (Master, PhD)
<input type="checkbox"/> First Degree or other degree level qualification
<input type="checkbox"/> Higher National Certificate or Diploma
<input type="checkbox"/> Teaching qualification
<input type="checkbox"/> Nursing or other medical qualification
<input type="checkbox"/> Ordinary National Certificate or Diploma
<input type="checkbox"/> City & Guilds advanced craft
<input type="checkbox"/> GCE/GCSE A or A/AS Levels (or school leavers certificate) or Scottish Higher
<input type="checkbox"/> GCE O-Level, GCSE grades A to C, SCE Standard grades 1 to 3, SCE ordinary grades A to C, CSE grade 1
<input type="checkbox"/> Royal Society of Arts
<input type="checkbox"/> Any other professional, vocational or foreign qualification
<input type="checkbox"/> None of these

At what age did you finish your formal education? (Write number in the box)

Years  
\_\_\_\_\_

**What is your average monthly income (after tax)? (Tick  $\surd$  one box)**

<input type="checkbox"/> £0 to £499
<input type="checkbox"/> £500 to £799
<input type="checkbox"/> £800 to £1099
<input type="checkbox"/> £1100 to £1599
<input type="checkbox"/> £1600 to £1799
<input type="checkbox"/> £1800 to £1999
<input type="checkbox"/> £2000 to £2499
<input type="checkbox"/> £ 2500 and over

**What is your households average monthly income (after tax)? (Tick one box)**

<input type="checkbox"/> £0 to £499
<input type="checkbox"/> £500 to £799
<input type="checkbox"/> £800 to £1099
<input type="checkbox"/> £1100 to £1599
<input type="checkbox"/> £1600 to £1799
<input type="checkbox"/> £1800 to £1999
<input type="checkbox"/> £2000 to £2499
<input type="checkbox"/> £ 2500 and over

**What is your ethnic group? Choose one section from A to E and then tick  $\surd$  the appropriate box to indicate your cultural background.**

**A. Black or Black British**

- Caribbean
- African
- Any other (please write in)

\_\_\_\_\_

**B. Mixed**

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other (please write in)

\_\_\_\_\_

**C. Asian or Asian British**

- Indian
- Pakistani
- Bangladeshi
- Any other (please write in)

\_\_\_\_\_

**D. White/Caucasian**

- British
- Scottish
- Irish
- Any other (please write in)

\_\_\_\_\_

**E. Chinese or other ethnic group**

- Chinese
- Any other (please write in)

\_\_\_\_\_

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Finally, now that you have had the opportunity to participate in the pilot of the bowel cancer screening programme, do you think that this type of screening test should be offered regularly to all men and women your age? (Please tick  $\surd$  one box)

- Yes, I think this type of screening test should be offered regularly to all men and women my age.**
- No, I do not think that this type of screening test should be offered regularly to all men and women my age.**



# **Supplement S2 Paper on Focus Group Studies (Chapter 2 in Final Report)**

## **“Do it yourself” screening to reduce mortality from colorectal cancer by completion of a Faecal Occult Blood Test (FOBT): Findings from focus group discussion.**

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Keywords: Colorectal/bowel cancer, faecal occult blood testing (FOBT), feasibility, acceptability.

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*Abstract*

### **Objective**

A pilot study of the feasibility and acceptability of screening for colorectal cancer by faecal occult blood testing (FOBT) is underway in the UK. The pilot differs from existing NHS cancer screening programmes in two important respects: First, it would target both men and women and second, the FOBT is a home test kit requiring self-collection of faecal samples to be posted to a laboratory. The present study aimed to examine psychological issues that might influence FOBT acceptability and uptake.

### **Methods**

Given the novelty of this type of screening test it is important to conduct an initial exploration of psychological issues using focus group methodology. Four focus groups were conducted and 36 men and women participated.

### **Findings**

Participants were aware of colorectal cancer and viewed it as having psychosocially severe consequences, principally as a result of friends’ or relatives’ experience. Diet, heredity and pollution, but not exercise were suggested by the groups as factors enhancing risk of the disease. That the screening test could be completed at home was viewed as enhancing perceived behavioural control and privacy. The groups’ identified a number of possible barriers to completion including concerns about hygiene and storage and fears of a positive result.

### **Conclusions**

A home test kit is likely to be welcomed as a means of screening for colorectal cancer. Motivation may be enhanced by messages relating to avoiding the psychosocial consequences of the disease and emphasizing positive aspects of personal control.

Colorectal cancer is a major threat to public health in the UK with over 34,000 new cases diagnosed every year (Garvican, 1998). Moreover, it is the second most common cause of death from cancer in the UK (Office for National Statistics, 1998). Colorectal cancer develops in the large bowel (comprised of the colon and the rectum), the last part of the digestive system where stool is formed. Although the prognosis for colorectal cancer is poor with a relative survival rate at five years of 37% (Austoker, 1994) this is related to the fact that very often symptoms do not present until the cancer has metastasised. Survival rates are much higher at around 82-87 per cent when colorectal cancer is detected at an early, asymptomatic stage (Hart, Wicks, & Mayberry, 1995). As such screening for early stage colorectal cancer is one important way of trying to reduce morbidity and the mortality rate from this disease. There are two main methods of screening for colorectal cancer, sigmoidoscopy and faecal occult blood testing (FOBT). The factors associated with interest in and uptake of sigmoidoscopy

have been discussed elsewhere (Sutton, Wardle, Taylor, McCaffery, Williamson, Edwards, Cuzick, Hart, Northover, & Atkin, 2000; Wardle, Sutton, Williamson, Taylor, McCaffery, Cuzick, Hart, & Atkins, 2000). The FOBt is based on the principle that cancers bleed into the bowel and that this blood can be identified. The blood that the test detects is not visible to the naked eye and requires chemical analysis in a laboratory. Completing the FOBt requires the individual to collect small samples of their own faecal matter on three separate occasions within 14 days, place the samples on a specially designed card and post it to the screening centre for analysis. The FOBt has both preventive and early detective functions, since it may detect blood caused by polyps which, if left untreated, could become cancerous. Three randomised controlled trials have demonstrated that population screening of people over 50 years of age for blood in the faeces can reduce the mortality rate from colorectal cancer by between 15 and 33% (Hardcastle, Chamberlain, Robinson, Moss, et al., 1996; Kronborg, Fenger, Olsen, Jorgensen, & Sondergaard, 1996; Mandel, Bond, Church, Snover et al., 1993).

Population screening for colorectal cancer is under consideration in the U.K. The Department of Health and the Scottish Executive have funded a two-year pilot of FOBt screening amongst men and women aged 50-69 years. The objectives of the pilot include an assessment of the effectiveness, feasibility and public acceptability of the FOBt. Whilst national screening programmes have been established in the UK for the prevention of cervical and detection of breast cancer, the proposed programme addresses not only a different cancer, with possible low public salience (cf. Williamson & Wardle, 2002), but also differs because it includes both men and women and utilises a self-completion home-test kit. An essential part of the evaluation of the FOBt pilot screening programme trial in the UK is to look beyond the health gains demonstrated in the randomised trials of the FOBt procedure and to investigate whether the establishment of a national screening programme is feasible. As high levels of participation are critical to the success of any cancer screening programme one particularly important measure of feasibility will be the potential rate of uptake achievable. Evidence from controlled trials suggests that initial uptake may vary between 25.5% (Mant, Fuller, Northover, et al. 1992) and 77% (Cuckle, Wald, & Butler, 1986). There is also evidence of sociodemographic variability in uptake. Studies have generally reported that uptake is lower amongst men than women (Faivre, Arveux, Milan, Durand, Lamour, & Bedenne, 1991; Herbert et al, 1995; King, Fairbrother, Thompson, & Morris, 1994; Mant et al, 1992), and higher amongst people from high socio-economic groups (Brown, Potosky, Thompson & Kessler, 1990; Farrands, Hardcastle, Chamberlain, & Moss, 1984). Consequently one important component of the evaluation is an assessment of the social and psychological factors that may influence the acceptability of FOBt screening.

### **The Present Study**

The present study forms part of the evaluation of the screening pilot. The study utilised focus group methodology to conduct initial explorations of peoples beliefs and views about colorectal cancer and the acceptability of FOBt screening in the U.K. Focus group discussion (Basch, 1987; Kitzinger, 1995; Morgan, 1996) was considered particularly appropriate in the present context as participants were not familiar with FOBt screening, and could be shown the home tests kits and allowed to react to them freely during the discussions. In a similar study in the U.S. Weitzman, Zapka, Estabrook, & Goins, (2001) utilised focus group discussions to explore awareness of colorectal cancer, patterns of perceived risk for colorectal cancer, barriers and facilitators to screening and experiences and intentions with regard to FOBt screening. They reported that knowledge about the prevalence of colorectal cancer and its contribution to the mortality burden of the US was low, and that there was poor understanding of women's risk. Additionally, participants tended to inaccurately perceive family risk as the single most important determinant of risk, and that their personal risk was lower than average if they had not experienced symptoms of colorectal problems. Weitzman and colleagues also reported that some of the participants perceived FOBt screening as messy and as such found the procedure unacceptable. Fear of cancer being found was also perceived as a barrier to acceptance.

### *Method*

#### **Participants**

Thirty-six people, 25 men and 11 women, participated in four focus groups. Three of the groups were gender mixed, one group comprised males only. Two groups were conducted with established lunch club groups, one was conducted with a group of Rotary club members and the fourth group was conducted with employees of a large manufacturing plant. The participants ranged in age from 35 to 75 years and the majority (N = 22) were still working: 14 people were retired. All of the participants were white<sup>1</sup>. The majority of participants were age eligible for inclusion in the FOBt screening pilot. None of the focus group participants had at that point, been invited to participate in the colorectal/bowel cancer screening pilot. One man had previously completed a FOBt, however this was on the recommendation of a GP following the presentation of symptoms.

#### **Procedure**

Details of the colorectal (bowel) cancer screening pilot and the evaluation of the pilot were provided to all groups in advance of any discussions and any individual who felt that they could not participate was given the

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<sup>1</sup> Further research has been commissioned by the Department of Health to evaluate pilot acceptability in ethnic minority populations and is ongoing.

opportunity to opt out. All individuals invited to take part in the focus groups agreed to participate. The discussions were guided by a moderator (IOS) and were audio-recorded with the permission of the participants. The moderator used questions broadly structured around the components of the theory of planned behaviour (Ajzen, 1988), the health belief model (Becker, 1974; Janz & Becker, 1984) and protection motivation theory (Rippetoe & Rogers, 1987; Rogers, 1975) to facilitate the discussions.

Each session commenced with the moderator stimulating a discussion about colorectal cancer. The group participants were asked if they had heard about colorectal cancer, how prevalent the disease was and what symptoms were associated with it. The next phase of discussion focused on peoples understanding of screening in general and what types of screening they were familiar with. Following on from this the participants were introduced to the idea of FOBt screening for bowel cancer, and they were quizzed about any experiences they had with FOBt screening. After FOBt screening was explained a FOBt kit was presented to the groups and an explanation of how to complete the test kit was provided. At this point the groups were asked for reactions to the test kit. In the final phase of the discussions the groups were asked how they felt about FOBt screening having seen the test kit, how important it would be to themselves to do it, how other people might feel about them doing the test kit, and what the potential benefits and barriers of completing the test kit were.

### **Analysis**

The audio-recorded discussions were transcribed verbatim and supplemented by information from brief notes made by the moderator during the discussions. The transcripts were reviewed and the data was categorised according to three broad topic areas: awareness and understanding of colorectal/bowel cancer, perceptions of colorectal/bowel cancer and acceptability of colorectal/bowel cancer screening. Themes relevant to the socio-cognitive models of health behaviour used to guide the questioning were identified and interpreted, and are supported by quotations from the transcripts.

#### *Results*

### **Awareness of colorectal/bowel cancer**

#### **General Understanding**

The majority of participants acknowledged that colorectal cancer was very common with most people knowing someone who had suffered from the disease. For several participants awareness was associated with knowing that colostomy was one outcome for people who had the disease:

*“Cancer of the colon...which involves colostomies...”*

*“I’ve had a neighbour who’s had it...she’s had a colostomy.”*

Some of the older participants suggested that the reason why colorectal cancer was apparently so common now was because cancer was stigmatised in the past:

*“But...going back years ago...there was none of this about cancer and so forth...”*

*“Years ago the subject wasn’t openly discussed...people still died with cancer but it wasn’t discussed like it is today. I don’t think it was quite so rife in those days as it is now but I think one of the reasons why is that we didn’t hear a lot about it...cause it wasn’t openly discussed.”*

One female participant commented that colorectal cancer was probably more common amongst men, and there was general agreement that the over 50s were most at risk of developing the disease.

#### **Symptomatology**

When asked what early symptoms were associated with colorectal cancer most people responded accurately that changes in bowel habit including diarrhoea, constipation, and pain were typically associated with the disease:

*“...I should think diarrhoea and bleeding in the stools”.*

Several participants suggested that blood loss was a symptom of early stage colorectal cancer, however no one clarified that this blood loss was occult.

#### **Causation**

With regard to the causes of colorectal cancer people were unanimous that a bad diet was the most significant factor. Participants habitually responded:

*“...diet...wrong food...junk food...fatty stuff.”*

The most specific comments about the role of diet came in the form of questions from two men who were aware of the results of some scientific research that implicated a protective role for high fibre diets:

*“So what does it mean for theories about roughage or a high fibre diet in relation to bowel cancer?”*

*“...what’s the latest ideas about bran in relation to colorectal cancer? There were some surveys and there was a hypothesis...bacterial products could damage the colon and bran could sort these out.”*

There was also some discussion regarding the role of genes. Several participants were sure that colorectal cancer was familial:

*“...I would have thought that bowel cancer was hereditary”.*

In one of the focus groups some participants were suspicious about the potential causes of colorectal cancer as well as cancer in general. One woman suggested that prescribed drugs and the long-term side effects of taking antibiotics may be cause for concern:

*“...people are given more drugs for illnesses...you don’t basically know what drugs you’ve been given and what side effects there could be...”*

Additionally, several other participants who were concerned about the role of diet in the causation of colorectal cancer suggested that this may be a reflection of modern food production technology, for example:

*“We don’t know what chemicals are put in the food.”*

*“I was going to say...insecticides...in the old days...you didn’t seem to hear of cancer so much as what you do now because things were grown properly in the fields.”*

Others felt that the level of environmental pollution in the atmosphere could be a factor:

*“You also don’t know what you’re breathing in”.*

*“Probably the biggest cause nowadays...what you breath in when you walk along the road...with the cars”.*

Perhaps notably, whilst diet, heredity and environmental pollution were suggested as causes, exercise or level of physical activity did not feature in the groups’ discussions.

### **Perceived threat of colorectal cancer**

#### **Physical Severity**

There was general acceptance that colorectal cancer was very dangerous and that it presented a very real threat to mortality:

*“...bowel cancer comes second to the number of deaths – cancer wise- than lung cancer...”*

*“Believe me...you would not want to go through what Michael went through. Believe me you would not want to do it.”*

Moreover, one participant described the physical pain associated with the disease in dramatic terms:

*“...the pain is absolutely excruciating”.*

#### **Psychosocial Severity**

Several participants highlighted the psychosocial severity of colorectal cancer above and beyond the physical implications of the disease. One man was particularly concerned about the severity of the disease in terms of quality of life:

*“...99% of people do not have a clue...they don’t know how their quality of lifestyle is going to be compromised...”*

*“...you suffer from bowel cancer...this is going to be the sort of quality of life you’re going to have.”*

Additionally, treatment outcomes were viewed as particularly challenging:

*“...these colostomy bags are terrible things...they really are awful...”*

*“...the colostomy bag...it really is quite unpleasant...I mean there are quite a lot of people who committed suicide because they can’t cope with it”.*

#### **Perceived Susceptibility**

Most participants acknowledged that they were at risk because of their age. Several participants felt that some people would not accept or recognise their personal vulnerability to colorectal cancer:

*“I’m all right Jack sort of thing...you’ll get a few of them...”*

There was also a suggestion that this perception may be related to the notion of ‘not wanting to tempt fate’:

*“You might get a few who’ll say ‘oh I’m not tempting providence or any thing like that’...I’m all right Jack”*

In contrast some participants felt that people would understand that they were at risk but would simply deny the idea and that this would be especially true of men:

*“I think there would still be an element of...not thinking they can’t get it but just not wanting to know...I do think that...it will be more likely to be men that do that”*

### **Acceptability of FOBt screening.**

#### **General Attitude**

While some of the participants thought the actual FOBt procedure was amusing the majority of participants reacted positively and there was widespread acceptance of the principle, for example:

*“Well I’m pleasantly surprised...I think it’s a wonderful thing.”*

*“It’s a good idea really...”*

One participant was not impressed with the idea of being asked to participate however, and felt that because many people have had to have other medical tests and procedures they would be disinterested in FOBt screening:

*“...we’ve all had tests and investigations and all sorts...then they send out one of these things (FOBt)...I couldn’t be bothered. Do we really want yet another investigation...we’ve had enough.”*

The same participant also felt that being proactive about one’s health (early detection) wasn’t necessarily the best idea. Essentially this man was saying that you should leave well alone:

*“Louise...two days before she died she said to me...‘I just wish I’d been left to just die normally’...”*

While most of the men who participated were positively inclined towards doing the FOBt, there was concern that men in general may find it hard to accept the notion of screening and the FOBt because they have never been targeted by a population screening programme before. This was contrasted with the acceptability of the test to women who because of their participation in cervical and breast cancer screening, are familiar with the idea of screening and therefore more positively inclined towards participating in colorectal cancer screening:

*“I think it’s the men you’ve got to be concerned about.”*

*“...its quite easy to discuss prevention and detection with women. Men...they just carry on with life...I think that is going to be the success of this, its going to rest on that, a guy has got to see some sort of benefit or some sort of reason for him to get involved with this.”*

*“Our wives would take it on board because they’ve probably been involved with breast screening anyway.”*

#### **Perceived Benefits**

Several participants recognised the efficacy of the test in reducing mortality from bowel cancer:

*“You could go on for years and years with it growing and infesting in your bowel...whereas this way...you’ve got the quick result and the quick treatment”.*

*“...if it’s discovered earlier so much the better...”*

There was however some concern amongst participants that screening for colorectal cancer might over burden the already overburdened NHS (and reduce screening efficacy), for example:

*“...the NHS...could they possibly cope with the amount of surgical procedures that might have to be carried out?”*

*“...I was wondering about the logistics of the job and there being enough facilities...you know...to cope with this enormous amount of work.”*

Some participants felt that the general perception of the NHS as being overstretched might make participating unacceptable to some people:

*“...that may be one of the disincentives for people who don’t respond...they see the health service as one long round of cancelled appointments...”*

#### **Perceived Behavioural Control**

Participants’ contrasted the benefits of a home test kit with other types of screening test and considered it convenient:

*“I was thinking about bottles with large pieces of stool in it...it’s much more straightforward.”*

*“It seems like the easiest way of doing it.”*

Similarly, because the FOBt can be done at home and does not require a trip to a GP surgery or hospital clinic the test was perceived as being very convenient:

*“...we’re not subject to the doctor or the hospital.”*

*“I don’t have to go to the hospital, I don’t have to go to the doctor and I can do this...”*

One person from the focus groups felt that because the FOBt was being sent to someone’s home, the individual had more control over the decision to participate in screening or not:

*“The fact that it’s coming into someone’s home...they have got the choice whether they participate or not...”*

Having to complete the FOBt oneself may also be viewed as giving an individual more personal control over the procedure itself:

*“The thing is would you rather do this yourself or would you rather go to the GP and then have to go to a clinic or something? Or get somebody else to do it?”*

The FOBt was also perceived as being less physically invasive than other types of cancer screening techniques, and less invasive than it could be given the location of colorectal cancers:

*“...it has got to be better...than perhaps what...would happen at a clinic with all these skinny silver instruments and things.”*

*“...it’s still the perception of invasion of your body isn’t it? I think this (pointing to the kit) is much better.”*

Being able to complete the FOBt at home was also viewed by several participants as having several psychological advantages, in particular saving on embarrassment:

*“...it saves embarrassment.”*

*“Not (embarrassing) in your home I wouldn’t have thought.”*

In terms of practical barriers to completion of the FOBt several participants highlighted problems individuals with disabilities might have:

*“I’m also concerned about people who are impaired in any form...arthritis...things like that.”*

### **Perceived Costs**

One potential cost of FOBt screening is the requirement for people to handle faecal matter, a task that may provoke feelings of disgust and concerns regarding personal hygiene. When the FOBt kit and procedure was described to the focus groups, most of the participants reported that they did not find the idea disgusting, nor were they unduly concerned about the personal hygiene aspects of handling faecal matter:

*“I wouldn’t worry.”*

*“Well, you wash your hands...as you’re taught to do as a child anyway.”*

One man was shocked when the procedure was described however and found the idea very off putting. Moreover, several participants commented that they would expect the kit and the procedure to put some people off:

*“I don’t think everybody is going to be too happy...”*

*“Some people might find it off putting...”:*

Some participants were concerned about general hygiene while completing the test kit especially in terms of where to store the kit for example:

*“I would be (concerned) because where, I mean obviously you can’t put it in the fridge can you? Where would you put it, in the bathroom cabinet?”*

However several other participants indicated that storage/hygiene while completing the kit was not a ‘big deal’:

*“I don’t actually think the storage is a problem.”*

*“Put it in a fridge bag...put it on top of your bathroom cabinet.”*

It is often suggested that completing a screening test raises anxiety and fear amongst those invited to participate. Some participants agreed that completing the FOBt would make them fearful or anxious of a positive result:

*“It’s a good idea really. But the only thing is that I think it would frighten me to death...because if I find anything else wrong with me lately...”*

*“...that’s (receipt of a positive result) when they panic then.”*

*“...once you’ve done it...I think I’d be absolutely terrified in case the results came back saying you’ve got it.”*

While acknowledging the potential upset caused by receipt of a positive result (albeit a false positive one) one participant indicated that the benefit of finding out that one was cancer free made this cost worthwhile:

*“Oh yes it might upset them...but feel the joy of knowing that its only polyps and not cancer... it might cause a bit of worry at the beginning but if it comes out that its only polyps that would be a joy.”*

## **Discussion**

Focus group methodology was used in the current study to illustrate the FOBt home test kit and to elicit peoples’ understanding and awareness of colorectal (bowel) cancer as well as their feelings regarding completing a kit if it were sent to them in the post.

Since bowel cancer has not yet been the subject of a mass education campaign the success of screening might rely to an extent on the salience of the disease and its perceived prevalence and consequences. The present sample perceived the disease as common and for many participants awareness of the disease was due to personal experience of friends and relatives with the disease. Relatedly, personal experience was of a disease that was described as having extremely unpleasant physical and psychosocial consequences. In particular, colostomy was viewed as a very negative outcome with severe chronic impacts on lifestyle and psychosocial functioning. Avoidance of these outcomes may be key elements of attempts to motivate participation in screening, particularly since colorectal cancer screening has both preventive and early detective functions.

Participants accurately suggested that diarrhoea, constipation, and pain were typical symptoms of colorectal cancer. Blood in the stool was also suggested, however nobody stated that this blood would be occult. Understanding that the FOBt detects blood that is not visible to the naked eye is very important as, those who mistakenly believe that the test detects visible blood may decide not to complete the test if they have not noticed any blood themselves when they have a bowel motion (cf. Weitzman et. al., 2001).

When asked about the causes of colorectal/bowel cancer the most frequent response from most focus group participants was diet and two participants mentioned that a diet high in fibre may be protective, an accurate perception (Willett, Stampfer, Colditz, Rosner et.al., (1990). Several participants also speculated that the environment, modern food technologies and the use of prescription drugs might be related to the development of colorectal/bowel cancer. None of the focus group participants cited lack of exercise or physical activity as factors likely to contribute to disease onset whilst there is evidence for a role of these factors (Giovannucci, Colditz, Stamfer & Willett, 1996). The present data do not permit direct assessment of the relationship between beliefs regarding causation and perceived personal risk, an established predictor of other types of screening uptake (e.g. Vaile, Calnan, Rutter, & Wall, 1993; Orbell & Sheeran, 1993; 1998). Participants in the present groups were prepared to accept that they were vulnerable simply by virtue of their age.

If offered to the general population, colorectal cancer screening by FOBt would be the first programme to utilise a home test kit. A home test kit might be viewed on the one hand as more convenient than a clinic procedure, but might also create concerns regarding test efficacy. Handing responsibility to the patient to complete the test correctly has considerable psychological and social implications, particularly if educationally, physically or socially disadvantaged people are found to have lower completion rates. Participants in the present focus groups welcomed the idea of a ‘do it yourself kit’. Completing the FOBt in one’s own home was perceived by the focus groups’ participants as (a) convenient, permitting control over when and where the behaviour is performed (b) allows completion of the test in total privacy and (c) ensures that participation in screening is less embarrassing in terms of the physical and psychological exposure which might be anticipated at a clinic appointment. Physical invasion is typically associated with screening technology whilst the FOBt was perceived to be non invasive by both male and female participants. The fact that the FOBt was perceived as convenient is noteworthy, as previous research has reported that the inconvenience of appointment times is frequently cited as a barrier to attendance for breast and cervical screening (e.g. Marshall, 1994; Orbell, et al., 1996; Rutter, Calnan, Field, & Caile, 1997). High perceived behavioural control and self-efficacy with regard to completion of FOBt are likely to be important psychological processes affecting both intention to try to complete the test and actual test completion (Ajzen 1988, Rippetoe & Rogers, 1987; Rogers, 1975).

It should be acknowledged that participants in the present focus groups had not actually tried to collect samples of faecal matter and did not comment on perceived behavioural control over doing so, except with regard to those with disabilities such as arthritis. One previous study (Hoogwerf, Hislop, Morrison, Burns, & Sizto, 1990) reported that self-belief regarding one’s ability to take a faecal sample was positively associated with participating in FOBt screening. The present groups did however, discuss the issue of personal hygiene when collecting a sample of faecal matter and a minority of participants found the idea disgusting or off-putting, as did participants in Weitzman et al’s (2001) focus groups. Most participants were more concerned about storing the kit while it was being completed and the implications this would have for general hygiene.



Taken together, the findings obtained here suggest that enhancing perceived behavioural control may have an impact on uptake of colorectal cancer screening. Such efforts might usefully address the convenience, privacy and autonomy with which the test can be completed, the simplicity of the test that has to be done, and perhaps procedural suggestions regarding collection of faecal matter, hygiene, storage or even ways to modify diet to ensure that a sample can be collected.

Negative emotional reactions have been reported as barriers to most types of screening. In terms of the emotional costs of participating in colorectal (bowel) cancer screening the decision to participate was not viewed as something that could cause emotional upset or anxiety. Unlike breast cancer screening, for example, the likelihood of experiencing physical pain or discomfort when doing the FOBt is negligible and it does not involve an interaction with clinic staff and highly technical medical equipment. It is perhaps unsurprising, therefore, that participants did not perceive participation as likely to be particularly stressful. In contrast, several focus group participants perceived the possibility of receiving a positive result, and the time between completing the test and receiving the result, as particularly stressful. An Australian study utilised the Health Belief Model (Becker, 1974; Janz & Becker, 1984) as a conceptual framework, and reported that non-participants perceived that participating in FOBt screening would cause them more worry (Macrae, Hill, St John, Ambikapathy, Garner and the Ballarat General Practice Research Group 1984). This may be especially problematic for any national colorectal (bowel) cancer screening programme given the high false positive rate FOBt screening carries. Although one participant did dismiss any anxiety and worry as a small price to pay for finding out that one was cancer clear, it would be pertinent to develop measures for addressing any such anxiety raised.

There was a perception amongst focus groups participants (both the males and females) that men would be less likely to accept colorectal/bowel cancer screening than women, a suggestion supported by evidence from the trials (Faivre et.al., 1991; Herbert et.al., 1995; King et.al., 1994, Mant et.al., 1992) (despite the fact that most male focus group participants welcomed the FOBt and expressed the desire to participate in the programme). Analysis of the focus group transcripts did not reveal any specific differences in the particular beliefs expressed by men and women, but participants suggested that men may be less prevention-oriented than women and more likely to consider health care only in response to symptoms. The validity of this suggestion remains an issue for further research since to date, published findings relating to screening uptake have been restricted to female samples.

It should be acknowledged that the present findings do not directly assess the views of members of ethnic minorities nor can they be treated as nomothetic. Nonetheless, the present findings indicate a number of specific issues which might be addressed by future, nomothetic research aiming to predict, explain or intervene with regard to participation in screening to reduce mortality from colorectal cancer.

#### **Acknowledgements**

This research forms part of the evaluation of CRC screening pilot in Scotland and England which was commissioned by the Department of Health (DoH R&D 1217132). The evaluation team comprises Professor David Weller, Professor Freda Alexander, Dr Harry Campbell, Mr Malcom Dunlop, Dr John Forbes, Dr Sally Wyke (University of Edinburgh), Professor Ala Szepura (University of Warwick), Professor Sheina Orbell (University of Essex), Dr Aileen Neilson (Lothian Primary Care Trust), & Dr Andrew Walker (Greater Glasgow Health Board). We would like to thank Louise Roberts, Carol Wheatley and Pat Ramsell, from the Colorectal Screening Unit, Rugby, for their assistance in contacting focus group participants.

The views expressed are those of the authors and not necessarily those of the Department of Health.

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**Supplement S3 Questionnaire and Audit  
Form for Primary Care Study (Chapter 5 in  
Final Report)**



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17/06/03

EVALUATION OF PILOTS OF SCREENING FOR COLORECTAL CANCER

Dear Dr

As you know, patients in your practice were recently invited to participate in a pilot screening programme for colorectal cancer, using the faecal occult blood test (FOBT).

In evaluating this pilot, a very important component is the extent to which it impacted on your practice – information is needed on how FOBT screening would affect factors such as workload and organisation in primary care practices. We are also interested in your more general views on FOBT screening.

We would therefore be very grateful if you could spend a few minutes completing the enclosed questionnaire and return it in the reply-paid envelope by **Friday 31<sup>st</sup> August 2001**. Your responses, and those of your colleagues in primary care, will be of critical importance in determining the feasibility of FOBT screening in the UK; they will be treated in absolute confidence.

Your assistance is greatly appreciated. If you have any queries about the questionnaire, please contact either myself or David Weller on the numbers below.

Yours sincerely,

Ms Ruth Jepson & Professor David Weller

Phone:  
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0131 650 2675  
07946 456827

Email:  
[ruth.jepson@ed.ac.uk](mailto:ruth.jepson@ed.ac.uk); [david.weller@ed.ac.uk](mailto:david.weller@ed.ac.uk)



**GENERAL PRACTITIONER  
questionnaire to evaluate the workload impact of  
pilots for colorectal cancer screening**

**SECTION 1. YOUR VIEWS ON WORKLOAD ISSUES RELATED  
TO COLORECTAL CANCER SCREENING**

1. Do you think that a national programme (along similar lines to the pilot your patients have been involved with) would impact substantially on workload in primary care?

Yes

No

Not sure

**If YES, do you think that general practices should be remunerated for this additional workload?**

Yes

No

Not sure

**Comments:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PLEASE RETURN THIS QUESTIONNAIRE IN THE SAE BY: \_\_\_\_\_ / \_\_\_\_\_ /2001**

## **SECTION 2. MEETING BETWEEN SCREENING PILOT TEAM AND PRACTICE**

This meeting was an important opportunity for the screening pilot team to explain the pilot to your practice.

### **2. Did you attend this meeting?**

Yes

No

⇒ *proceed to question 6*

If *YES*,

### **3. How long did the meeting last?**

.....hours .....minutes

### **4. How many staff from the practice attended?**

Total number of staff

Number of GPs

Number of practice nurses

Number of other staff

Can't remember

### **5. What is your impression of how the meeting went, did you find it useful and how could it have gone better?**

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### **6. Would you have liked a meeting after screening was over for feedback?**

Yes

No

### **SECTION 3. PRE-SCREENING CHECKING OF PATIENT LISTS**

You will recall that prior to recruiting patients from your practice, the screening pilot team provided you with lists of patients from the Community Health Index (CHI) and asked if your practice could remove any patients who didn't fulfil the pilots' inclusion criteria.

#### **7. Did your practice devote time to this task?**

Yes

No ⇒ proceed to Section 4

***If YES***

#### **8. Which staff groups were involved (please tick all that apply)?**

GPs Practice managers

Administrative staff Practice nurses

Other

#### **9. Please estimate the amount of time that you personally spent on this process**

0-15mins    15-30mins    30-60mins    1-2 hours    >2hours    don't know

#### **10. Do you think it was a useful/valuable exercise?**

Yes

Don't know

No If NO, please specify why not:

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#### **11. Do you have any comments on how the process could have been improved?**

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## SECTION 4. WORKLOAD IMPACT

We are interested in the amount of **extra** time that you, as a GP, spent on activities which resulted directly from the FOBT screening pilot. We would like you to think of activities that occurred during what you regarded as the *busiest* week of the period that patients from your practice were being invited to take part in the screening pilot. Please estimate the **extra** time you spent on the following activities during this week, and complete the questions below. We are interested in all activities associated with screening, including dealing with patients' information needs, the screening process itself, and any time spent on follow-up investigations.

### 12. How often were you involved in the following activities?

#### Patients' information needs about CRC screening

	Very often	Often	Sometimes	Never
Telephone enquiries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enquiries during normal consultations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consultations specifically for CRC screening enquiries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### a) The screening process

Discussions with your staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paperwork (e.g. copies of result letters)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Queries from pilot unit (e.g. checking of addresses, deaths)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Time spent with patients undergoing further investigations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 13. What percentage of your time in this period do you estimate that you spent on the above activities?

0-1%      1-2%      2-5%      5-10%      10-20%      >20%

### 14. Any other comments on workload impact

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## SECTION 5. NATURE OF THE ENQUIRIES

We would like you to think of the enquiries you received since your patients became involved in the screening project. Which of the following information needs have you responded to?

Information need	Please tick if you responded to this information need		If you have ticked a box, indicate frequency of enquiry		
	<input type="checkbox"/>	→	Very often	Often	Sometimes
Instructions on how to perform the screening test	<input type="checkbox"/>	→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Confusion over information provided by the pilot site	<input type="checkbox"/>	→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advice on whether or not to participate	<input type="checkbox"/>	→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concern/fear arising from a positive result	<input type="checkbox"/>	→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Questions about bowel symptoms, prompted by the screening programme	<input type="checkbox"/>	→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Questions about the risks and benefits of colorectal cancer screening	<input type="checkbox"/>	→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Explanation about next stage e.g. colonoscopy	<input type="checkbox"/>	→	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What other kinds of queries did you receive (if any)?

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## **SECTION 6. ORGANISATIONAL FACTORS**

Although your patients were recruited directly by the screening pilot centre, good communication and co-ordination between the centre, the endoscopy unit and your practice is essential in order for screening to be successful.

### **15. How satisfied were you with the INFORMATION provided to you on the following items**

#### **a) The screening pilot (e.g. leaflets, verbal information)**

Very satisfied

Partially satisfied

Dissatisfied

Did not receive any information

Received but did not read the information

#### **b) The outcomes of your patients' involvement in the initial screening (e.g. positive and negative results)**

Very satisfied

Partially satisfied

Dissatisfied

Did not receive any information

#### **c) The outcomes of your patients' involvement in follow-up investigations (e.g. results of colonoscopies)**

Very satisfied

Partially satisfied

Dissatisfied

Did not receive any information

### **16. If you rang the screening pilot centre, how well were your enquiries dealt with?**

Very well

Acceptably

Poorly

Did not ring

**17. Do you have any further comments on the experiences your practice had of the FOBT screening pilot?**

## **SECTION 7. YOUR VIEWS ON COLORECTAL CANCER SCREENING**

**18. Do you consider that a national programme of FOBT screening should be introduced?**

Yes

No

Not sure

Need to wait for pilot results

**Comments:** \_\_\_\_\_  
\_\_\_\_\_

**19. Do you think that the screening project was a valuable and positive experience for your patients?**

Yes

No

Not sure

## **SECTION 8. ABOUT YOU**

**20. Do you work:**

Fulltime

Part-time



<1 day

1-2 days

2-3 days

3-4 days

**21. What is your gender?**

Male

Female

**22. How many years is it since you qualified?**

0-5 years

5-10 years

10-15 years

15-20 years

>20 years

**Date form completed:** \_\_\_\_/\_\_\_\_/2001

*Thank you very much for taking the time to complete this questionnaire. Please could you now return it to the evaluation team in the pre-paid reply envelope.*

*Ruth Jepson and David Weller  
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*Fax: +44 (0)131 650 9519*

*For office use only*

*Date entered onto database:*

*Questionnaire (<4 months)*

## Audit sheet for primary care staff - GP Version (Chapter 5)



### GENERAL PRACTITIONER workload impact audit sheet for pilot of colorectal cancer screening

#### The purpose of the audit

Patients in your practice are currently being invited to participate in a pilot programme of screening for colorectal cancer, using the FOBT. An important component of the evaluation of this pilot is a determination of the impact screening has on your practice – that is, how much extra workload does the programme generate for you and your colleagues? We will be asking you to fill in the audit sheet over a period of one week.

#### Filling in the audit

We would be grateful if you could keep this audit form in an accessible place, and fill it in each time you undertake an activity relating to the pilot of colorectal cancer screening. Such activities could include answering enquiries from patients or the pilot screening unit, paperwork, discussions with members of staff, and time spent with patients requiring further investigations. If possible we would ask you to fill in the audit for each activity as *they occur*.

#### Who should fill in this audit?

This audit should just be filled in by **GPs only**. Other audits will be circulated for practice nurses, the practice manager and receptionists.

#### What happens at the end of the audit period?

Please return this form to the Practice Manager.

#### Can I have more information?

If you or your colleagues feel that you are unable to take part in this exercise, or you require clarification over any aspect of this audit, please contact either Ruth Jepson (0131 650 9462), or David Weller (0131 650 2675, 07946 456827), email: [ruth.jepson@ed.ac.uk](mailto:ruth.jepson@ed.ac.uk) or [david.weller@ed.ac.uk](mailto:david.weller@ed.ac.uk)

**Thank you very much for your help - your participation in this exercise will greatly assist in determining the feasibility of widespread screening for FOBT.**

**Please complete this audit over the period:  
Monday to Friday**

#### How many full time equivalents (FTE) are you?

*For example, a GP who works full-time would be 1 FTE, one who works 2 days per week would be 0.4 FTE, and one who works 3 days per week would be 0.6 FTE*







Once again, we thank you for your assistance with this audit. Your responses will be extremely helpful in determining the feasibility of CRC screening using the FOBT.

If you have any further comments about the audit, or the workload impact of CRC screening in your practice, please detail them below.

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**Supplement S4 'Free Text' comments  
from General Practice staff on  
questions related to remuneration,  
patient enquires, workload impact and  
whether a programme should be  
introduced (Chapter 5 in Final Report)**

<b>Country</b>	<b>Staff*</b>	<b>Comments on remuneration</b>
Scotland	GP	Several consultations both before and after colonoscopy. Question of appropriate action for those with negative colonoscopy doesn't seem to have been fully discussed with patients and generated several consultations.
Scotland	GP	Although workload high still a very worthwhile exercise & something we should be doing.
Scotland	GP	Any work generated by GP's needs to be given adequate resources.
Scotland	GP	This individually will not increase workload much the problem is the number of small increases from extra new work and transfer from secondary care all adds up to a lot and extra resources have to be provided for this. We have had no increase in staff budget to allow for staff for * and there is a limit to what we can absorb without extra staff. NO NEW WORK WITHOUT EXTRA RESOURCES.
Scotland	GP	Over the course of the recent study about 5-10 patients specifically phoned or made appointments to discuss study with me, so some GP workload IS involved. Also given that study funding is usually "generous" it is likely in future that there will be less "back-up" and perhaps more GP contacts. General practice is strained at the seams and funding IS needed for additional work.
Scotland	GP	A screening program such as this will impact on workload. I would question the relevance of the word "substantially". Address checking, dealing with patients who prefer to seek a GP opinion, and follow up will all involve extra workload.
Scotland	GP	Needs more resources not more money.
Scotland	GP	Although would not impact on GP time, increase in staff workload and should be remunerated
Scotland	GP	Positive results were dealt with by the screening organisers so GPs did not have to write referral letters or give patients results.
Scotland	GP	Patients like to discuss the explanations given in positive findings and further investigations
Scotland	GP	Huge number of files came in to the practise which need to be checked and filed.
Scotland	GP	Paperwork generated, searching for notes, filing screening letters increased our, and receptionists load and we had to find (non remunerated) then increase in hours. Also patient counselling was an unforeseen problem and we had to increase conversation only for this too.
Scotland	GP	Even if the impact is small there should be remuneration for it.
Scotland	GP	No significant increase in workload (for me). Many patients mentioned they were involved but only those with related bowel problems were concerned enough to "take up my time" I imagine most of the workload increase would have been for filing staff but still a small fraction of our letters.
Scotland	GP	Both extra GP consultation and extra staff time are involved.
Scotland	GP	Nice to be asked if it would affect us. Usually first we know is when patients are sent by 3rd party.
Scotland	GP	Several patients made appointments to discuss findings instead of phoning the advertised helpline.
Scotland	GP	Generated a significant number of consultations for explanation and reassurance.
Scotland	GP	Certainly had to deal with several phone calls and possibly about 12 extra consultations calling for further explanation/reassurance/further investigation.
Scotland	GP	It is all adding to the general workload.
Scotland	GP	Not itself a lot extra, but a drop of the tidal wave being washed into general practice!
Scotland	GP	Screening test has led to an increase in patient anxiety - no matter how well explained, therefore this will create increased GP/patient contact time. Results in either +/- will need explanations.
Scotland	GP	Extra work would largely be administrative - we would need resource for this.

<b>Country</b>	<b>Staff*</b>	<b>Comments on remuneration</b>
Scotland	GP	Great deal of patient contact, especially with waiting times for endoscopy (and surgery where necessary)
Scotland	GP	I think the main impact has been on secondary care but there has been some extra work involved reassurance and, at times, coordinating between different departments.
Scotland	GP	This requires central funding and not item of service - as ever!
Scotland	GP	There is no 'slack' in the system. Either "extra" time must be funded, or some other part of our workload will have to be dropped instead.
Scotland	GP	Main workload is with those who turn out to have bowel tumours but screening means they are picked up earlier so hopefully do better.
Scotland	GP	The work load will relate to positive FOBs that are not associated with colorectal cancer and therefore require further investigation.
Scotland	GP	I think substantially is too strong a word. It would be yet another task for practices which, if added to other extra demands, the total becomes substantial and should be remunerated.
Scotland	GP	If properly supported and rapid assessment input could be minimised.
Scotland	GP	Workload issues have to be balanced against overall benefit (i.e. avoidance of cancer developing)
Scotland	GP	There is now no spare capacity in primary care - at GP/nurse or administrative staff level. All new initiatives must be followed by resource.
Scotland	GP	Too a question - of service funding has its limitations in a context of 'general' underfunding.
Scotland	GP	Many patients have sought advice regarding the screening for colorectal cancer, whether they should participate or not, how reliable the test is, how much reassurance a negative result is, what additional tests might involve, etc..etc.. - This is important and requires time to answer but.. Where do we fit this in to a workload that is now beyond an acceptable level?! More money would allow employment of more practice nurses/GPs to deal with all this or share the burden generally.
Scotland	GP	Use of accommodation and secretarial staff time in organising.
Scotland	GP	Takes up a lot of practice nurse time and resource and also generates follow up appointments.
Scotland	GP	The workload increase is small and mainly admin time, though a few queries by worried patients. However even this small increment should be adequately resourced, otherwise it's the same old story of GP being a 'Dumping Ground'.
Scotland	GP	We are a small practice but there was a lot of mail to be filed for those having tests repeated, and also quite a bit of GP time in chasing up one defaulter with social problems.
Scotland	GP	Given that there is an impact on workload (I'm not sure what equates with "substantial") it would seem appropriate for it to be adequately resourced at ALL levels of involvement.
Scotland	GP	Lot of queries from patients about screening programme and a lot of appointments to discuss outcome of positive FOBs etc..
Scotland	GP	Thus far I have not noticed any substantial increase in workload.
Scotland	GP	I was surprised that it has hardly impacted on the practice workload at all.
Scotland	GP	We had a lot of patients coming fretting about their recall
Scotland	GP	Screening our people not suitable, took us 2 weekend's work.
Scotland	GP	We used funding for administration staff time. Our staff worked flat out and the work involved is extra. Without additional funding what should they give up?
Scotland	GP	But there is almost no history of this ever having happened.
Scotland	GP	I'm not sure how practices could be remunerated: perhaps a small payment for checking pre-screening lists.

<b>Country</b>	<b>Staff*</b>	<b>Comments on remuneration</b>
Scotland	GP	It all depends on additional resource (not just money) so that there is no opportunity cost in addition to the false positive activity.
Scotland	GP	It is an issue of workload rather than money. If we do manage this, what do we take out instead?
Scotland	GP	Dependant on who initials screening process and how much practical work involved for practices. Could be argued that has in general medial services but the screening attracts target payments to run along these lines
Scotland	GP	Significant number of patients have contacted me to discuss their abnormal results DESPITE the help line number.
Scotland	GP	Where from? Health services already underfunded - we need more people working not just money.
Scotland	GP	Despite the fact that this has not impacted SUBSTANTIALLY, there has been an impact and this should be remunerated as it is extra workload.
Scotland	GP	Difficult to quantify. This study seemed to try hard to minimise the GP workload but even the extra paperwork and small queries from patients, often several a day, was noticeable.
Scotland	GP	Consultation time frequently required for explanation of process and results. It can be quite anxiety provoking for some.
Scotland	GP	Largely for the extra administrative time involved filing reports etc.. It is one small piece of a large increase in workload in general practice - our whole workload needs to be addressed and remedied.
Scotland	GP	The copious letters sent to the practice all require filing. The workload for the reception staff is ludicrous in the extreme!
Scotland	PM	The information to be provided has to be accurate and precise. Screening of the lists took a great deal of time within our practice and feel that same reimbursement is appropriate.
Scotland	PM	Remuneration is not always the answer. It implies that staff will be happy to work overtime to get extra jobs done - this is not always the case, nor should it be. A paid person per LHCC to visit practices for screening records would be useful.
Scotland	PM	You will see it took 8 hours to check the list and remuneration for this should be considered.
Scotland	PM	If lists to be checked accurately i.e. GPs/PN check all notes - very time consuming, otherwise very little input in this practice required re result/recall letters.
Scotland	PM	Sometimes this extra workload can not be done during normal work hours, and overtime may be required.
Scotland	PM	The programme did not cause us a substantial amount of extra work. If it was extended to all patients in a certain age group, it might. If funding was offered as an incentive, such as for immunisations and smears, that would be very beneficial.
Scotland	PM	We are at the stage where we cannot take on any additional work. Core service and present practice clinical services are using all our resources fully (support staff).
Scotland	PM	Time was needed for checking list and answering/re-routing questions from patients. Not a lot of time for this pilot.
Scotland	PM	The NON cancer positives would generate obligatory secondary referral for specialised assessment if not fully investigated by the gastero enterologists at the time of screening.
Scotland	PM	All additional studies impact on medical and admin time. We are already working to capacity and in general practice.
Scotland	PM	We felt it appropriate to screen list before being sent out - this took 12 hours of admin time and about 1 hour of GP time - so remuneration would have been appreciated.

<b>Country</b>	<b>Staff*</b>	<b>Comments on remuneration</b>
Scotland	PM	All practices in Dundee have not had a staff review for 10 years and are often understaffed.
Scotland	PN	If screening ran as pilot we would not be involved with samples etc. but if this changed it would impact on time.
Scotland	PN	This involved a lot of clerical time for a very busy understaffed practice.
Scotland	PN	I found some patients who participated in the pilot study i.e. blind, low intelligence or even people needing reassurance and advice or home visits took up time of practice nurse. Therefore if this was ongoing remuneration would be required.
Scotland	PN	I was never involved in the screening. I knew about it, and some patients discussed it with me during consultations for other problems, but that was my total involvement.
Scotland	PN	They have plenty and more work to contend with.
Scotland	PN	Not involved apart from patients asking for advice on how to do test.
Scotland	PN	When remuneration is offered you will always get better cooperation as extra staff can be employed to deal with routine day to day tasks.
Scotland	PN	There appears to have been a lot of false positives, and re arriving patients / advising them re diet pre testing / + helping with their anxiety re long wait before colonoscopy.
Scotland	PN	I have said no from a practice nurse's view.
Scotland	PN	Obviously with screening, positive findings are going to increase but as this is part of our job, not sure payment is justified but then I am not a GP!
Scotland	PN	Input was minimal
Scotland	PN	There has been an impact but not substantial. How it has effected me is that patients on warfarin take some time and a number of visits later to become 'steady'.
England	GP	Drawing from the experience locally - number of consultations increase.
England	GP	This would facilitate the use of extra admin time
England	GP	I would prefer for any extra work to be able to be completely delegated to the consultant or a nurse specialist by giving the patient access to a 24hr helpline, not have any extra work or reimbursement.
England	GP	I feel that earlier detection of Colorectal Cancers would probably reduce Primary Care workload, as these cases would present anyway in a worse condition.
England	GP	Any reason why we should be unpaid clerks, administrators etc for someone else's programme?
England	GP	It would be helpful to receive details of how many patients were found to be ? Colorectal Cancer.
England	GP	Additional workload involves explaining procedures, especially barium enema if ordered. Patients are often unsure of how to collect samples for the screening test.
England	GP	Please send default, DNA or similar comments of patients separately so that they may be filed individually rather than as a list of patients. Copies of list cannot be filed due to confidentiality.
England	GP	It ** a bit work.
England	GP	The colorectal screening has not impacted on my workload - and as a patient who was screened I did not need to see my GP.
England	GP	Well received by patients and quite helpful in assessment of bowel symptoms.
England	GP	Have not personally had to deal with any positive results - & is actually helpful to know screening is negative write "worried well"!
England	GP	Patients were discussion with some regarding the pilot screening and reassurance.
England	GP	Some extra work in putting results into patient record - can this be done electronically as well as in writing. Negative test results must be entered also - if we have to do these m workload increase will be considerable.

<b>Country</b>	<b>Staff*</b>	<b>Comments on remuneration</b>
England	GP	only problem is patients coming with positive for FOB's for reassurance - but not too many.
England	GP	patients do still present with worries and anxiety regarding test results.
England	GP	A number of patients have consulted us following positive results and has involved discussion to try and talk things out with possible scenarios.
England	GP	General practice is struggling to cope. Even a small increase in work is very difficult to accommodate. Remuneration allows us to employ extra staff/partners to cope.
England	GP	My personal workload did not appreciably increase within this pilot - but I'm not sure how it affected other staff.
England	GP	Although as you will know the majority view in the recent GP survey was no additional work.
England	GP	Only saw patients with related problems.
England	GP	The workload for the pilot has been noticeable. Patients have made consultation for discussion of the tests & explanation of written material received.
England	GP	A number of patients wanted me to explain what this was all about and asked my opinion on doing the test. It took up time in appointments.
England	GP	Low morale, difficulty finding time, money to cover costs - problem can no longer operate as a charity.
England	GP	Has had a small impact on workload but not substantial in my opinion.
England	GP	Some increased workload but largely administrative - chasing up non-attenders for follow up.
England	GP	We have had a small but steady stream of extra consultations from patients about the process.
England	GP	I have not noticed significantly increased workload but some patients have had longer consultations to discuss it.
England	GP	It is not practical to expect more & more tasks without adequately funding them.
England	GP	Practice nurse time may be needed more than doctor to explain risks/findings etc.
England	GP	Some non-English patients have made appointments specifically to get explanation of test. One phone call from nurse specialist to match patient details.
England	GP	We were adequately informed about this pilot which appears to have been appreciated by our patients. We will be very interested in the outcome.
England	GP	I think that the workload will be indirect in that the other patients referred for Ix or OPA to Gastroenterologists etc will be put back on the work causing them to visit their GP to ask for letters etc to try and bring forward their appointment. This amounts to considerable extra work and hassle. Any screening and further Ix and I4 should not impinge on any way with current NHS work. The screening programme should be completely separate from current NHS resources i.e. new consultants, nurses, secretaries, beds, colonoscopy suite etc. So that other patient care is not affected in any way because of the extra workload generated by the screening.
England	GP	Patients came with queries or to ask if they felt they should do the test or to have "permission" not to do it but not a lot of people.
England	GP	It is a good idea but nursing staff and GP's fully stretched already. Extra "manpower" would be required if we have to initiate tests - however if it is done centrally as a pilot then no payment is necessary.
England	GP	Cynical about whether the HM Government would fund it properly.
England	GP	Extra work created. Worried well - worried diagnosed unwell, time to explain positive findings.
England	GP	Yet again - government screening policy makes more work for no input - staff search on computer & then entering results yet again more work thrown onto GP.

<b>Country</b>	<b>Staff*</b>	<b>Comments on remuneration</b>
England	GP	The whole NHS seems to be suffering from increased demands - often clinically with no explanation or support to do it.
England	GP	None of my patients have been found to be suffering from Carcinoma Conditions. Several patients have told me their results whilst consulting for another reason.
England	GP	Yes increased workload if pilot is performed in primary care sector and can't go ahead unless funding for staff and doctor time available.
England	PM	Our only ongoing extra work, is really, entering positive results on computer.
England	PM	I'm sure GPs will expect remuneration for the time taken.
England	PM	I have written not sure because there was little of my time involved in the process although it may have impacted more on clinical staff in discussions/reassurances with patients etc.
England	PM	All our patients are dealt with directly by St Cross Hospital Rugby and are dealt with very efficiently with no involvement by the practice. We are sent a weekly update on our patients.
England	PM	There is impact, I could not say it was substantial itself, more another task with other extra tasks it did create anxiety.
England	PM	Some impact only. Not a substantial increase in workload.
England	PM	I felt that the overall campaign was fairly easy to administer in General Practice. Once the list of eligible patients were supplied, the only admin work required afterwards was filing away faxed reports into patient notes.
England	PM	Additional staff time.
England	PM	It often appears that additional work moves to primary care without the appropriate resources.
England	PM	Considerable extra work has come our way from many sources in recent months. If we are not remunerated, existing staff have to take on more and more which leads to demotivation and dissatisfaction.
England	PM	Time spent checking details prior to study and further time informing GPs (each sheet was practice based not GP based).
England	PM	Work involved is not as much as anticipated, but still significant. Particularly prior to screening when ensuring communication within practice so that all staff knew what was happening.
England	PM	Extra staff time would be required - administratively.
England	PM	There was no appreciable increase in workload caused by what is a very worthwhile programme
England	PM	Especially as in the practice we have a high Asian population with language problems. Took a lot of time explaining how to do the test correctly - and many worries were sorted when follow ups came.
England	PM	Very little extra work involved at this practice.
England	PM	Staff administrative time to enter on database would be useful.
England	PN	Follow up screening always adds to workload but it may save further discomfort and lives of the patients.
England	PN	Very important screening.
England	PN	Some impact only. Not a substantial increase in workload xxxxxxxx
England	PN	We've got a lot going on, everything seems be pushed our way, from secondary care.
England	PN	Patients anxieties. Need time to discuss issues.
England	PN	The pilot here has not caused us any extra workload, however if a national programme were to include the Practice Nurse then the answers to the above would be yes.
England	PN	If in general the overall opinion is that "yes" is the answer then yes GP practices should be remunerated for this additional work.



<b>Country</b>	<b>Staff*</b>	<b>Comments on remuneration</b>
England	PN	If the screening remains being carried out outside the surgery, paperwork & queries are a minimum to the workload in the practice.
England	PN	Occasionally patients commented that they were taking part & seemed pleased & interested in the project. Did not cause me any inconvenience at all.
England	PN	No additional workload for me personally. I was not fully involved on this occasion directly. Unable to attend meeting prior to testing. Though wanted to be there.
England	PN	Small input from practice nurses.
England	PN	If workload increased dramatically then remuneration may be appropriate.
England	PN	Main impact on clerical staff - it would take time to check through records for pre-checks. Also if results are put on computer - clerical time again. Time means money!
England	PN	A very worthwhile screening programme that would be worth the financial costs.
England	PN	I work at the branch surgery. I have no information about the programme and no involvement other than occasional questions from patients.

<b>Country</b>	<b>Staff</b>	<b>Comments on why they thought PNL/CHI list checking not useful</b>
Scotland	GP	Impractical for GP to remember useful details of huge list supplied, therefore had to check list from memory, many patients had had resent bored, investigating, which I could not remember, told waste of time, I think patients should be asked of to exclude themselves by sending back sheet questionnaire.
Scotland	GP	Number of patients excluded tiny ?worthwhile
Scotland	GP	There is no ease way to check which patients should be sent for and which shouldn't other than checking records.
Scotland	GP	Terminal patients would be known by GPs, other categories would not be affected to the same extent by invitation.
Scotland	GP	Pros and Cons
Scotland	GP	No time to pull all the notes, only screened list on basis of memory.
Scotland	GP	Not really in a large practice, it was hard to take out unsuitable people - not knowing them.
Scotland	GP	Difficult to accurately * patients.
Scotland	GP	Disagree with screening process.
Scotland	GP	The amount of time is not good use of time - we have stopped doing this for break screening - but worded the letter more carefully.
Scotland	GP	List of requested patients does not equal "seen by" list of patients.
Scotland	GP	Time consuming.
Scotland	GP	Simply perusing a list of names to see if any "stood out" is not terribly useful. Ideally patient records should be correlated but this would take too much time.
Scotland	GP	Why do I want to spend half an hour reading notes?
Scotland	GP	Problems - partners don't work to personal link
Scotland	PM	I could only spare time to check for deceased patients. The workload was far too big to check for the other areas.
Scotland	Rec	Patients not found. Didn't believe offer would have caused problem
England	GP	Patients do not always advise us of changes of details, seems little point in cross referencing with data base.
England	GP	Should be better will increase correlation of records over time.
England	GP	I don't think it turned up anything unusual.
England	GP	Identified too few to exclude.
England	PN	However, not much time prior to commencement of pilot.
England	Rec	Don't know anything about it.
England	Rec	Was not involved.
England	Rec	I was not part of the practice at the time of the pilot.

<b>Country</b>	<b>Staff</b>	<b>Comments on how PNL/CHI list checking process could be improved</b>
Scotland	GP	It seemed to go smoothly with very little panic from patients.
Scotland	GP	Very few exclusions were allowed in categories presented - few patients not terminal but not in great health that I would have preferred were excluded from programme.
Scotland	GP	Local hospital should have record of all those who are already under follow up for rectal Ca reducing our workload further in note/record checks.
Scotland	GP	Clearer guidelines meant people who already had colonoscopy in year prior to screening, * already * GI units.
Scotland	GP	Far too short timetable for GPs and practice staff to check large patient lists. This exercise took up a large amount of staff time.
Scotland	GP	Yes. I think it should have been avoided. A simple letter to screened patients inviting them to exclude themselves if appropriate would be better.
Scotland	GP	Screening letter sent to a patient of mine who died years ago. Upset wife naturally.
Scotland	GP	Not feasible to check records - dependant on recognising anyone on patient list of whom I knew and who would be unsuitable.
Scotland	GP	Not involved
Scotland	GP	No complaint at all about the process, but it must be recognised that this is yet another pressure on our and for staff's time.
Scotland	GP	Marked delay between seeing screening nurse and attending colonoscopy causing increased concern in patients.
Scotland	GP	Uses hadn't been generated!
Scotland	GP	Better information earlier!
Scotland	GP	Software such as CMR/read codes to screen out known cancer patients.
Scotland	GP	As an additional task on top of everything else I feel such a task, while important just gets squeezed in - clearly time to complete such a task requires resource to free a GP/nurse/administrator to complete it effectively.
Scotland	GP	Practice audited for patients in age group and exclusion Dx
Scotland	GP	Staff would appreciate being paid for their time.
Scotland	GP	Sorry I only came on board at this practice as a partner and the pilot was up and running.
Scotland	GP	Either someone could come into the practice to renew notes, or send out an 'apologetic' letter to accommodate mistakes.
Scotland	GP	Unfortunately it was done by personnel lists. As we don't work that way some patients on my list I didn't know at all but a colleague knew well. I didn't know how it could be improved though.
Scotland	GP	Satisfactory.
Scotland	PM	More information before sheets sent out to practice.
Scotland	PM	More notice about the task would have resulted in a better records check.
Scotland	PM	The checking of the practice list was quite onerous as it took approx. 8 hours for the computer operator to go through checking all details. This on top of a very busy workload was a bit frustrating.
Scotland	PM	Checking list re patients not meeting criteria was very time consuming. Perhaps this could be incorporated into letter addresses to patient advising them to ignore contents if criteria not met i.e. Listing exclusions. We did not pull every patients notes on list as doctors felt this was too time consuming. GPs scanned list - staff checked *
Scotland	PM	Information relating to an evaluation of the project would have allowed a better decision as to whether it would be beneficial as a national screening programme.
Scotland	PM	GP practices should be remunerated for administrative time.
Scotland	PM	No, this seems the most appropriate way to identify patients to call or exclude from pilot.
Scotland	PM	Personal contact from pilot team re the importance of inclusion/exclusion.
Scotland	PM	Found it relatively unobtrusive/time consuming!

Country	Staff	Comments on how PNL/CHI list checking process could be improved
Scotland	PN	No - wasn't involved.
Scotland	PN	More info given to patients
Scotland	PN	Working from same computer data base.
Scotland	PN	Practice Nurses were not involved.
Scotland	PN	Remuneration for clerical staff involved
Scotland	PN	I, as a nurse was not involved in this.
Scotland	PN	Not really involved in this process
Scotland	PN	Information to all primary care team.
Scotland	Rec	Less letters sent re 'false positives' etc the end result only would have been req'd
Scotland	Rec	Not involved. (No reception staff input).
England	GP	No - no feedback from staff of note
England	GP	I think probably there was no need to do it.
England	GP	If given more notice to check lists. If we had better computer data c read codes etc for bowel problems/operations etc - something we aim to improve.
England	GP	A number of patients that needed to be excluded (colitis, already being investigated) still received screening packs.
England	GP	Asian patients need to be followed by Asian language speaking social workers to be encouraged to comply and also to be explained the
England	GP	Don't send us lists to check, as patient, has complained.
England	GP	More time given or someone supplied to do it.
England	GP	General consensus was that it was very well organised.
England	GP	Ask patients to include/exclude themselves.
England	GP	The development of appropriate disease registers at PLT level.
England	GP	Time consuming.
England	GP	I wasn't a partner at the time it was being initiated and didn't have a "list".
England	GP	All should be invited and it is up to the screening team to exclude those who don't need it (e.g.ca bowel) already undergoing screening.
England	GP	Practice Manager reimbursed for work taken away from her usual busy schedule.
England	PM	More notice would have helped.
England	PM	A search was done in the age range specified and then the patients were checked to make sure they were not under treatment for specified condition. I don't think it could be improved on.
England	PM	Would have liked a longer period for checking as we were not computerised. Hospital could not supply list of patients on regular screening.
England	PM	A specific data clerk for the exercise would have been beneficial.
England	PM	More time.
England	PM	No, I think the process had been well thought out.
England	PM	When dead letters received at Warwickshire Health Authority patients complained when we rang to clarify details. They also said no letter was received by them. ? Frightened or worried about request not fully understanding the letter.
England	PM	Any test results should be sent by e-mail and not faxed if possible.
England	PM	A bit more time to go through list would have been appreciated.
England	PN	As I was not present with the introduction of this pilot scheme, I am not aware of what was involved time wise with the above questions.
England	PN	More time
England	PN	I was not made aware of meetings etc. The first I knew of it was when my patients asked me about it.
England	PN	Practice Nurses could have been included.
England	PN	Why am I filling in this questionnaire.
England	PN	Not involved ? Prior to my arrival.
England	PN	This would have been done by admin staff but only a very short time from lists to invitations, so not done and low staff level at the time.

<b>Country</b>	<b>Staff</b>	<b>Comments on how PNL/CHI list checking process could be improved</b>
England	PN	I would have been involved and eager to help if I had been asked.
England	Rec	We were not involved.
England	Rec	We should have received more information with regard to how the screening was going to be done, If a patient had phoned up with a query, I don't feel I had enough knowledge about any of it, to help them anyway!
England	Rec	Although the explanation on how the test should be done by patients to us was very clear to us some patients seem to have difficulty understanding procedure.
England	Rec	Did not attend this meeting
England	Rec	Checklist was probably sent to main surgery. We are branch surgery.
England	Rec	I wasn't involved in this project at this stage.
England	Rec	More of reception staff should have been asked to attend along with admin staff.
England	Rec	Surgery not directly involved. Patient contact direct with Rugby Hospital.
England	Rec	I'm afraid that I cannot comment on this section, being a receptionist I wasn't involved.
England	Rec	A leaflet in Punjabi would have been useful to give to Asian patients.
England	Rec	Sorry about this but as a receptionist I was not involved in the above.

Country	Staff	Comments on workload
Scotland	GP	Percentage of time is small but is superimposed on an already stretched service. Like many issues which impinge on general practice, the involvement in this project was small, but additional to many other individual small tasks in which we get involved.
Scotland	GP	No major impact on me personally seemed to run very smoothly.
Scotland	GP	The paperwork generated by the screening pilot was EXCESSIVE - will need to be reduced if ongoing screening system.
Scotland	GP	Really very minor impact on workload (so far)
Scotland	GP	Patients presenting bowel symptoms were asked if they had completed the test. Those who had not were persuaded to do so.
Scotland	GP	Absolutely minimal. Some patients wanted to discuss it or tell of results.
Scotland	GP	Mainly in explaining results and further investigations required - allaying anxiety.
Scotland	GP	There was a much greater impact on the clinical staff- filing numerous letters ( - often letters to tell us that someone did not respond)
Scotland	GP	Very little impact on practice. If we had had more positives this would have increased.
Scotland	GP	GP may not have been directly involved all the time but it is additional work for administration staff, checking and 'pulling' notes etc..
Scotland	GP	Just yet another item for GPs to deal with. Roll on retirement, ill health or suicide.
Scotland	GP	Considerable extra work for already hard pressed reception/filing staff.
Scotland	GP	Did not keep record - very difficult to answer.
Scotland	GP	There has been significantly increased workload because of the much larger waiting time in the surgical clinics which must be partly related to this pilot.
Scotland	GP	Main workload was due to anxiety re positive results.
Scotland	GP	Report forms (FOB results) were very user-UNfriendly.
Scotland	GP	Only that this questionnaire would be easier to complete if I'd had it sooner after completion of the screening. (A minor point only - not a real grumble!!)
Scotland	GP	Long waiting time for investigation.
Scotland	GP	Supporting patients waiting for investigation/operation was the main problem.
Scotland	GP	Paperwork and filing delegated to practice staff - should they be surveyed as well - it would be a different (higher) percentage of their time.
Scotland	GP	Quite a lot of anxiety from patients with a positive result.
Scotland	GP	Deciding what to do about numerous letters as an individual patient - made decision to file old centrally, then renew and hopefully file in patient's notes "find"/"completion" letter BUT this is not yet available, therefore advise similar system to breast screening.
Scotland	GP	Whilst a low percentage of time it's just another squeeze on time available.
Scotland	GP	Difficult to quantify amongst the deluge of other mail that needs checking.
Scotland	GP	Main impact on receptionist's filing
Scotland	GP	The highest impact was on administration staff with a large volume of letters to be scanned into records.
Scotland	GP	Very little, perfectly appropriate, useful reminder for health promotions and defaulters from other invests caught up with.
Scotland	GP	Less than I thought it would be.
Scotland	GP	More than indicated from meeting. Lots of patients phoning us for results - particularly polyps.
Scotland	GP	Not significant at all.
Scotland	GP	Minimal impact - to my pleasant surprise
Scotland	GP	Given that the practice is already at 100% capacity, the extra 1-2% is pushing at our capacity limits.
Scotland	GP	Paperwork (copies and letters etc) was HUGE every letter received needs to be filed, notes pulled etc..
Scotland	GP	Helped save time for those patients with vague abdo symptoms.

Country	Staff	Comments on workload
Scotland	GP	Probably only one occasion in each category above.
Scotland	GP	Impact seemed negligible.
Scotland	GP	These questions are impossible to answer without having audited as we went along, so the questions are pointless and any answers would be pointless.
Scotland	PM	No real work caused by patients making enquiries. The idea that GP teams can stop regular work to meet with outside teams to get information is unrealistic. In an ideal world it might work.
Scotland	PM	As mentioned already - too much work involved to check list for "criteria"
Scotland	PM	As practice manager, very little. Most impact was on reception and records work. They reported slight increase in number of calls and filing, but not significant.
Scotland	PM	Minimal if results positive.
Scotland	PM	Most of the time was spent identifying and collating result letters purely out of interest in the pilot and ensuring GPs were aware any positive results before filing more - more a monitor role.
Scotland	PM	Really minimal and seen to be for very good reason - unlike some of the things we are asked to do!
Scotland	PM	Virtually no impact.
Scotland	PM	Don't know!
Scotland	PN	No impact on my workload.
Scotland	PN	Patient's querying letters sent to them. Patients needing further explanation of taking sample.
Scotland	PN	Again, just me of the many extra pilots and projects being asked to do.
Scotland	PN	I was actually on holiday the week the kits were first sent out.
Scotland	PN	Workload was more 'query' led than active - but did take time out of patient consultations.
Scotland	PN	Spent time encouraging patients to complete the screening!
Scotland	PN	Not sure that we got letter re screening and result for patients records. Certainly can think of patient in Feb who received letter of results (neg) but practice got nothing (yet! - May). Relevance of this is that patient anaemic and we were going to do routine FOBs, therefore repeating the process.
Scotland	PN	I had two patients on warfarin who had positive FOBs. One lady reported to me great confusion at the hospital about what to do about warfarin. When to restart etc. and that it was the most painful thing ever experienced. She had to go back and this took a lot of talking through. The other patient had two visits and she took a long time to get back to 'normal' after stopping the warfarin and she awaited results for four weeks which gave her great concern.
Scotland	PN	Minimal impact on workload
Scotland	Rec	Too many letters required filing - end result would have been enough. The GPs could advise anyone through queries as the guide book was clear about the process.
Scotland	Rec	Difficult to judge workload impact. Few queries. Lots of filing. Result sheets did not include GP names.
Scotland	Rec	Only filing some of the letters which came to our practice.
Scotland	Rec	No extra work
Scotland	Rec	Was only really involved with filing reports, didn't create a lot of work.
England	GP	Minimal for me.
England	GP	Unable to give accurate figures - records not kept.
England	GP	Anxiety was generated in patients which led to a number of "explanatory consultations". Some patients were concerned when called back for more tests. Levels of anxiety notably dropped as increasing public awareness/education re pilot. Increased nos patients seen and changes in bowel habit/bleeding more.
England	GP	I suspect that this would increase if the screening process was broadened.
England	GP	Overall - minimal

Country	Staff	Comments on workload
England	GP	Here's the one about the time & the ball of straw!
England	GP	During screening process, seemed to be little impact on workload - patients appear to have coped well with process & gained as much information as they needed re. Follow up for screening unit.
England	GP	Practice staff were involved significantly more than GP's.
England	GP	Obviously there was a workload impact. Despite clear instructions patients came in/rang/enquired/regarding/when and why. Also added correspondence/ filing data collection.
England	GP	Minimal.
England	GP	One patient found to have adenomatous polyps - needed a lot of chasing up to get patient admitted for research as he became symptomatic between screening process and treatment.
England	GP	Made little impact on overall workload and was actually helpful in some instances when a patient presented with bowel symptoms or test for FOB had already been done (saved time).
England	GP	Mainly classification of results and general discussions.
England	GP	Those people who did not or could not do test came into surgery and I had to do the test on 3-4 patients or more.
England	GP	To my surprise, no real impact on workload.
England	GP	Admittedly this was only a relatively small increase in workload but we are having so much else forced on us at present that general practice will soon collapse. All additions to workload is accumulative.
England	GP	Difficult to quantify.
England	GP	Very little.
England	GP	Negligible impact on workload personally.
England	GP	2% workload increase may not seem much but is heavy in relation to increasing amount of workload/NHS initiatives etc.
England	GP	Just another 2%!
England	GP	Impact was minimal, often mentioned as an addition to presenting problem. Occasionally asked why people were recalled.
England	GP	Many patients commented on the FOBT screening test as part of the consultation for an unrelated problem. The discussion may have added 2-3 minutes to the consultation time but the feedback was generally positive.
England	GP	Not overall task.
England	GP	minor only
England	GP	Too long ago to remember.
England	GP	I don't think any of our positives have had any further Ix job. I expect patient concerns and workload will for them.
England	GP	Impact hardly noticeable.
England	GP	No I expected some discussion/calls from patients
England	GP	More on admin staff than GP
England	PM	A few queries came my way but they were few and not enough to significantly increase my workload.
England	PM	More advance warning, so it could be slotted into the practice workload agenda would have been more beneficial to us.
England	PM	Some very anxious patients needed to talk to someone during the screening process.
England	PM	Recall for test information. Increased filing.
England	PM	One receptionist took control - had very little impact on her workload.
England	PM	Usually discussed when came for appointment concerning other matters.
England	PN	There was nothing but a positive reaction about the screening from the patients, some didn't like doing the screening but did it anyway.
England	PN	Most of our enquiries came long before the programme started. Probably needed the



Country	Staff	Comments on workload
		information sooner.
England	PN	some very anxious patients needed to talk to someone during the screening process
England	PN	I was on maternity leave 31/01/01 - 13/08/01
England	PN	Practice manager dealt with all paperwork & queries. Practice nurse spoke to patient who had any worries regarding screening.
England	PN	As a junior practice nurse I had no specific time for screening programme - I had a few general enquiries from staff or patients.
England	PN	No workload impact.
England	PN	Didn't create any significant extra workload for me personally.
England	PN	Very little workload impact to me.
England	PN	Most enquiries were via our interpreter.
England	PN	I only knew about the screening via patients comments and enquiries.
England	PN	All dealt with by Karen Joseph.
England	PN	There was very little impact on my time or other members of staff. I was impressed with the efficient way the screening was run.
England	Rec	Recording recalls in notes for follow-ups and positive results "spoilt" not recorded!
England	Rec	Very little.
England	Rec	As a receptionist, I was never really involved but would like to have been.
England	Rec	I work at the Branch Surgery. The Main Surgery may have done more work regarding the above.
England	Rec	I wasn't involved in this screening exercise in anyway.
England	Rec	I work part time - 3 days per week so depending on the day the screening took place would dictate my involvement.
England	Rec	People generally were not sure whether to send kits here or rugby, this was a very common enquiry, this involved more time on reception with explanations.
England	Rec	This screening started before I commenced employment.
England	Rec	Unable to answer - not involved.
England	Rec	The workload impact as far as I was personally involved was very little.
England	Rec	Had no involvement in this.
England	Rec	Never had any enquiries.
England	Rec	No involvement.

<b>Country</b>	<b>Staff</b>	<b>Comments on patient enquiries</b>
Scotland	GP	Non specific anxiety and "I'd rather not know", "So where did the blood come from?"
Scotland	GP	Questions about late follow up - 1st test positive, 2nd negative, but patients then received 3rd test after interval. This was not explained at time of 2nd negative result - and I had no knowledge of this phase as a GP.
Scotland	GP	Reassurance when asked to provide follow up samples.
Scotland	GP	Queries from patients who had thought that I had referred them but hadn't told them!
Scotland	GP	I was surprised that very few people asked about it. Everyone seemed to accept it and appreciate it.
Scotland	GP	Confusion regarding re-screening by patient.
Scotland	GP	Patients just told us they had been asked to take part in their consultations.
Scotland	GP	Asked to relay result of Biopsies to patient.
Scotland	GP	Some patients felt because they had had THIS "cancer test" they did not require another type or "cancer test" e.g. cystoscopy for haematuria, because their FOB had been negative.
Scotland	GP	Some patients asking if they should perform test when they have had recent investigation or known bowel pathology. Patients asking to be included although out with the age group tested.
Scotland	GP	People out with patient group also heard about test and wanted to participate.
Scotland	GP	One patient had had altered bowel habit, blood and mucous per rectum for approx. 1 year but was too embarrassed to attend. The patient, however, did take part in screening, had a positive result and was given a date for colonoscopy. By this stage, anxiety was extreme, they felt unable to wait for the associated date and I have had to write to explain the situation and expedite colonoscopy. I am not yet aware if this has been successful. I think I spent approx. 30 minutes with this patient during a surgery of 7.5 minute appointment slots!
Scotland	GP	From patients out with the screening age group.
Scotland	GP	"Why have I to wait so long for colonoscopy?"
Scotland	GP	One particularly complex patient was last to follow up because of notes going astray - finally required admission for transfusion.
Scotland	GP	Results of follow up investigations.
Scotland	GP	Mainly enquiries about whether or not to participate or not - and implications of doing so.
Scotland	GP	Many patients were anxious especially because of the long delays.
Scotland	GP	Did anyone really think through what the impact of possibly having dozens of positive FOBs would do to an already overstretched dept? As far as I am aware no extra colorectal surgeons were taken on to deal with patients requiring surgery - subsequently the wait for 'non-urgent' routine appointments for colorectal problems has lengthened exponentially. I suspect, as usual, that some politician has sanctioned this without making sure extra staff and resources were in place. I have had several very angry patients waiting for many weeks longer than they should have.
Scotland	GP	Questions relating to screening of families especially where a blood relative already has Ca Colon.
Scotland	GP	Impact on patients waiting for GI investigations.
Scotland	GP	Concerns re delay in colonoscopy and surgery
Scotland	GP	Patient refused to take part.
Scotland	GP	How good is test? How reassuring is a negative result? Details about colonoscopy - is it done while I'm awake? Etc..
Scotland	GP	Enquiries were infrequent.
Scotland	GP	Relatives of those screened out with age bracket requesting screening. Increased

Country	Staff	Comments on patient enquiries
		awareness of symptoms in relatives (out with screening) results in increased consultations with GP for "check up".
Scotland	GP	Many patients were keen to advise the practice that they had been invited to take part.
Scotland	GP	What to do if the person was on regular aspirin or on warfarin.
Scotland	GP	Comments on "Having done THAT test for you (me??) doctor" Blank look from me "You know - the samples!" Good, well done etc...
Scotland	GP	People expected or accepted that this test was "routine", i.e. not a pilot so may expect this every year or so? Accept that is then clear if cancer!
Scotland	GP	I wrote to Prof Steele about a patient who didn't see the point - his case as he has regular bleeding PR and attends a clinic for his previous large bowel disease.
Scotland	GP	Concerns that younger first degree relatives should also be tested when carcinoma had been detected as a result of screening programs
Scotland	GP	Complaints re: pre colonoscopy preparation!!
Scotland	GP	General re what colonoscopy involves and also is it 100% conclusive?
Scotland	GP	Result requests
Scotland	GP	The process of endoscopy
Scotland	GP	Ensuring that patients scheduled for further investigations and surgery actually received such - in patients phoning because they hadn't heard. Chasing up results especially histology from consultants, after anxious phone calls from patients.
Scotland	GP	"When is it starting?", "Will I be screened?"
Scotland	PN	Diet.
Scotland	PN	We had a lot of telephone calls asking if it was a hoax!!
Scotland	PN	Kits lost down loos! Kits opened incorrectly. Kits lost!
Scotland	PN	One or two patients required re-assuring and more information after being asked to re-submit samples because of inadequate results.
Scotland	PN	Genetic links? Risk to children? Will I die soon?
Scotland	PN	One query from patient who wanted home testing kit explained. Patients indicated that CRC study had prompted or promoted home tests.
Scotland	PN	Unused kits - unable to use them! Patients returned them to practice - ?what will they do with them.
Scotland	PN	Positive comments from patients who participated in the study.
Scotland	PN	Amazingly I have had no queries. The kit seemed to explain adequately.
Scotland	PN	Patients with haemorrhoid wondering if they should participate.
Scotland	Rec	One disabled patient requiring help.
Scotland	Rec	No queries received
Scotland	Rec	Passed to GPs
Scotland	Rec	Patients unsure when they received test pack of what to do with it, maybe not made clear enough for patients & when to do test.
Scotland	Rec	Any queries passed on the phone. No of screening unit.
England	GP	Requests from patients not in age group, to have screen.
England	GP	Why some people had tests and not others - according to age and geographical areas.
England	GP	The administration staff had a few enquiries - the pack the patients received was informative and took them carefully through the procedure.
England	GP	Some patients having heard about the project were anxious that they had not heard from the team and thought they had been overlooked because friends had already received their kit.
England	GP	None. People seem to know about screening via local publicity & accept need for it.
England	GP	Some patients coming in with symptoms when FOB re. How many symptomatic patients did not come to see Dr when FOB reported re (? - false negative)
England	GP	Anything you could possibly think of.

<b>Country</b>	<b>Staff</b>	<b>Comments on patient enquiries</b>
England	GP	Why can't my friend/relative be included?
England	GP	More queries related to results of colonoscopies.
England	GP	Several female patients wanted to know how to persuade their husbands to undertake the screening test.
England	GP	Patients outside the inclusion age-group asking to be screened.
England	GP	Mainly the above.
England	GP	Why hasn't this happened before, will I get tested again.
England	GP	Where is Coventry?
England	GP	How to speed up follow up appointments.
England	GP	Patients outside age range requesting screening.
England	GP	Questions on how reliable test is many felt "falsely" reassured - ?? May not report change in bowel habit within few months of test as assume all is well.
England	GP	Reason for initial positive result i.e. false positive caused by diet.
England	GP	Only above.
England	GP	Positive findings on colonoscopy - prevent anxieties.
England	GP	Blind patient could not do it.
England	GP	No one ever asked me. Your information pack was extremely helpful and comprehensive.
England	GP	Discussed the results.
England	PN	Bowel preparation - timetables. Reassuring patients on next stage - colonoscopy.
England	PN	Language difficulties appeared to cause most of the problems - practice has mainly Asian patients who were reluctant to phone the advice line number and preferred to come to the surgery with any queries.
England	PN	Why me? Why this age group?
England	PN	If the practice were directly involved - why they were specifically chosen for the test.
England	PN	Any response was positive on patients part. They were keen to do the screening realising the importance of it.
England	PN	Concerns re results, what could it mean? Why haven't I had one (out of age group)
England	PN	None that I can remember.
England	PN	Not queries, but patients appear to be confused about who was doing screening. Some patients thought it was directly from us.
England	PN	Was it too late to send it off - have had a re-think?
England	Rec	I only received queries regarding "How to do" screening test and why they (patients) were contacted. Only patient I spoke to who was worried as there was bowel cancer in the family and thought they were the only one(s) being screened.
England	Rec	Some patients ask where they should send it back to.
England	Rec	People asking when they were going to be called for the screening.
England	Rec	Length of time it would take for results to come back.
England	Rec	Patients registered with our practice but living outside of Warwickshire wanted to be included.
England	Rec	None.
England	Rec	Is this test sent from the hospital or surgery.
England	Rec	Patients were frightened of what it would reveal, so would not take part even after explaining what it would mean to their health.
England	Rec	We only received enquiries from the Screening Project Staff, clarifying addresses with receptionists. Also one or two of our patients called in to say that they were not interested in taking part in the screening project.

Country	Staff	Experience of pilot - comments
Scotland	GP	Generally very good.
Scotland	GP	We found it iniquitous that patients FOB positive on screening had 1x weeks before patient urgently referred with symptoms.
Scotland	GP	It created a great deal of anxiety.
Scotland	GP	Worthwhile experience.
Scotland	GP	Unlike the Breast Screening I received no information on results which were negative on the first test. This should be in the patient's notes.
Scotland	GP	Well organised and did not cause extra GP work.
Scotland	GP	Patients require more reassurance about follow-up procedures and length of follow up required. I.e. yearly FOBs etc
Scotland	GP	Far too much paperwork.
Scotland	GP	It is a pity that we have received no interim figures on what number (%) are called for further investigation, and what % have had neoplasm detected, and at what stage.
Scotland	GP	Main problem in Aberdeen was insufficient resource at hospital end in rapidly following up a positive response. One lady went private in view of the potential delay.
Scotland	GP	Certainly raised awareness and mainly positive discussion about colorectal cancer.
Scotland	GP	I think this must have overloaded an already stretched GI/colorectal service in Aberdeen.
Scotland	GP	Disappointing that the pilot has been suspended because of inadequate provision at secondary care level. Also pilot has had major negative impact on routine referrals to the colorectal service.
Scotland	GP	Too long a wait between positive FOB and colonoscopy.
Scotland	GP	Very worthwhile.
Scotland	GP	Have concerns about follow up and treatment once identified as potentially having a problem. ? Secondary care adequately resourced to deal with this?
Scotland	GP	See Section 14 - at one point this year one of my patients waited 10 months for a 1st appointment with a change in bowel habit.
Scotland	GP	As you are well aware a screening programme requires appropriate resourcing - this is a new activity - and undertaking the programme should not impair on the existing provision of secondary care services.
Scotland	GP	Huge delays in GI service in introducing pilot to this area with an already overloaded and under-resourced GI services. Patients had significant delay from res FOB to colonoscopy.
Scotland	GP	Very useful but should have been properly funded.
Scotland	GP	The time taken for positive screening result to colonoscopy was on occasion too long. Having been told that there was a positive result for this investigation the patients felt that further investigation should of started with no delay!
Scotland	GP	There as a long wait for patients between positive result and colonoscopy and also for those requiring bowel surgery. This caused a LOT of anxiety for patients.
Scotland	GP	All positive
Scotland	GP	Many patients contacted me to discuss positive results, therefore significant anxiety for them and work for me.
Scotland	GP	Our perception was that wait times for bowel investigations got worse during the period of the pilot - therefore symptomatic patients may have suffered.
Scotland	GP	Lots of letters mostly negative results- what do we do with them?
Scotland	GP	Similar recording of patient participation as in breast screening i.e. Small shaker and details of patient, date of screening and result to record permanently in notes would be useful.
Scotland	GP	Would have been useful to know who had negative screening? Have had 5-6

Country	Staff	Experience of pilot - comments
		people since then who have been to me and been anaemic - on asking patients to send FOBx3 - they said "- but I have already done that doctor".
Scotland	GP	Some patients found the length of time to wait for colonoscopy after positive result of screening unacceptable
Scotland	GP	The pilot was very well run.
Scotland	GP	I received a letter pre Polyp excision which seemed to throw the onus of follow up onto the practice. We have no system to cope with follow up.
Scotland	GP	We had one patient who was very distressed having been told as a result of colon** that she had a tumour. The practice was not informed of this until a later date. I felt this was the only area where fault could be found with the pilot but it was a serious
Scotland	GP	How much did it cost the NHS? I would like to know the percentage of people sent for colonoscopy and the percentage of abnormalities, though I am sure all were adequately followed up by yourselves.
Scotland	GP	I think I've filled in 2-3 evaluation questionnaires. ? Duplicated by you? Misaddressed? My mistake? I would be interested to know how many of our patients had pathology.
Scotland	GP	Letter sent out was very poor quality in terms of style, font appearance etc. . 4-6 week wait for tumour removal following positive result is diabolical.
Scotland	GP	A lot of extra letters to read along and courier mail!
Scotland	GP	Results NOT available when partners came to surgeries
Scotland	GP	Very frequent need to repeat test.
Scotland	GP	I have misgivings about asymp* patients receiving investigation before those with symptoms.
Scotland	GP	No problems
Scotland	GP	Far too much paper produced.
Scotland	PM	No flexibility for patients who changed their minds about screening.
Scotland	PM	The screening pilot appears to have been well organised, as apart from the checking of the patient list there has been very little practice involvement.
Scotland	PM	No. Must say I personally feel it was a worthwhile screening programme and should be done nationwide.
Scotland	PM	Only occasional queries received from patients.
Scotland	PM	Perhaps evaluation forms sent out to too many to complete. This in itself is very time-consuming.
Scotland	PM	Poor feedback re conclusions of investigations. Too many loose ends.
Scotland	PM	Seems to have been a very successful well run pilot, most beneficial for our patients with minimal disruption for practice.
Scotland	PM	Pilot nurse/facilitator had a significant positive impact.
Scotland	PM	Lists, results, and packs could have been sent through internal mail, but were posted incurring high postage costs.
Scotland	PM	Doctor would like to have been informed quicker when a definite diagnosis was made. Doctor appreciated your part was done and it was over to NHS. Patient informed doctor of outcome of tests.
Scotland	PN	Excellent idea - if could continue
Scotland	PN	I did not need to be involved in this.
Scotland	PN	As you see from my comments, I had almost nothing to do with this scheme. However, I knew about it and I think its excellent that the screening is done & I sincerely hope it continues professionally & personally.
Scotland	PN	As a practice nurse had very little info given on the pilot programme.
Scotland	PN	Recall letter frightened them.
Scotland	PN	Something I found, which was very much appreciated, was the fact that results came back very promptly.
Scotland	PN	Very little information, and little need for me to be involved.

Country	Staff	Experience of pilot - comments
Scotland	PN	I was asked to give patients information about the screening programme, but I personally was given no information.
Scotland	PN	A worthwhile project. Patients need not approach their GP with an "embarrassing" (to them) problem.
Scotland	PN	I was aware of study through personal channels - not practice and think it is very worthwhile. Apologies for not filling in first questionnaire sent to practice. It sat on our desk but prioritising work meant we did not even have time to fill it in. I am filling this in at home!
Scotland	Rec	Seemed to be a lot of duplication of paperwork. Results came back as numbers which no one seemed to know what they meant.
Scotland	Rec	Pleased with number from practice that took part.
Scotland	Rec	Was actually quite surprised how many people took part. Don't know figures but it appeared to me that a lot of patients had participated.
Scotland	Rec	Unaware of information for receptionists
England	GP	Administration staff noticed increased workload - significant for a short period of time.
England	GP	Some patients concerned when asked to repeat tests - thought they had cancer and not sometimes aware that test "inadequate" etc.
England	GP	Excellent programme, well launched and thought out.
England	GP	As noted earlier.
England	GP	Impinged very little on our daily workload.
England	GP	Gives false reassurance. If positive result lots of people said to me "I can't have cancer as my test was negative".
England	GP	One patient had the test but negative 2nd test, Adv to retest 3/12. Blood tests since o Hb of 9 & FOB x 3 tue (not arranged by me) Tried to a/w team to organise earlier FV but promise of returned calls never materialised. Patient ref via2/52 referral system in the end.
England	GP	Generally positive.
England	GP	I did not have the feeling that I got much involved except for the occasional letter, re. a patient. Not much extra workload.
England	GP	Computerised link for letters and results would improve values to GP's & patients.
England	GP	Not enough knowledge of the system
England	GP	Perhaps Bowel Cancer would have been a better title than Colorectal cancer.
England	GP	Too long a wait for colonoscopy.
England	GP	The feedback from patients.
England	PM	Some staff members had already done the pilot with their own practice so found it useful when asked questions by patients.
England	PM	I thought it seemed well organised. I have had no complaints to me from GP's, patients or staff relating to lack of information or poor communication.
England	PM	Always very helpful.
England	PM	This questionnaire has come too late - memories of meeting very vague as a long time ago.
England	PM	Very satisfied.
England	PM	We were having enquiries (anxious) before we had been briefed i.e. "I saw on the back of a bus."
England	PM	A list of results would have been helpful.
England	PM	Excellent screening campaign.
England	PM	No big impact on surgery. Organisation of screening appeared very good.
England	PM	My feeling from the practice point of view is that it went well, did not involve us in a lot of work & on the whole was well organised.
England	PM	Information on patients caused to do repeat FOB test was initially thought to be useful but also actually amounted to quite a lot of moves, many of whom needed no

<b>Country</b>	<b>Staff</b>	<b>Experience of pilot - comments</b>
		further investigation. Was this info at this stage necessary?
England	PM	An excellent programme, weekly updates very useful.
England	PN	Not involved in, or discussed with.
England	PN	A LIST OF RESULTS WOULD HAVE BEEN HELPFUL
England	PN	I have not personally had any feedback maybe at GP or Practice Manager level.
England	PN	I have not been in port long enough to comment here.
England	PN	Patients were put off by the instructions I.e. having to hold stool with loo paper when it came out. With some people (especially as some have loose motions) I asked them to make a 'hammock' of cling film under seat across the loo - the they could 'perform', collect stool sample easily, drip contents in loo, then throw away cling film. This was far more appealing and several patients (including myself)! Did this method successfully.
England	PN	Please supply information in Asian languages as this was our biggest problem.
England	Rec	Seems to work very well - no complaints from patients.
England	Rec	Did not have anything to do with screening.
England	Rec	Unable to complete the questionnaire as I was not involved in the pilot scheme.
England	Rec	Excellent service.
England	Rec	Apologies for poor response to questionnaire but I haven't been involved in many aspects but patients have been very happy with project.
England	Rec	I rang on a personal basis as a patient with an initial unclear result. My calls were dealt with quickly efficiently & pleasantly - excellent.



Country	Staff	Comments on whether a national programme should be introduced
Scotland	GP	Experience in other countries seems to me to prove the value of this. But we must provide rapid colonoscopy facilities.
Scotland	GP	More worthwhile than Clinical Smears.
Scotland	GP	But must be separately resourced - GPs cannot do the counselling.
Scotland	GP	We cannot get investigations for people and symptoms
Scotland	GP	But has implications for resources to deal with positive results.
Scotland	GP	Insufficient feedback to form an opinion.
Scotland	GP	Too early to tell. Has generated patient anxiety without results yet.
Scotland	GP	Only if enough resource to perform colonoscopy without long delay.
Scotland	GP	If results indicate worthwhile.
Scotland	GP	If pilot adds further weight to satisfactory" screening" criteria AND colonoscopy resources increased.
Scotland	GP	Depends whether staff available to treat - should not have priority over patients with symptomatic Bowel Ca.
Scotland	GP	Not until we have sufficient resources - surgeons, theatres, clinical time etc..
Scotland	GP	Only if fully funded in hospital and primary care.
Scotland	GP	Needs a cost/benefit/workload analysis.
Scotland	GP	Remember - I know the faces, names and families of those who have had successful early colonectomy - the statistics and cost of the exercise are fading more rapidly from my conscious!
Scotland	GP	I also consider that a national health service fit and funded to provide such a service should be introduced while continuing appropriate provision of necessary patient care.
Scotland	GP	AS IMPORTANT as breast/Cx smear screening.
Scotland	GP	And must ensure back up for colonoscopies and colorectal surgery are staffed adequately.
Scotland	GP	Patients seemed quite positive about it. Cancers were picked up.
Scotland	GP	If pilot becomes a national programme then secondary investigation needs more resource to avoid a deteriorating service for symptomatic /early cancer cases.
Scotland	GP	Trying to provide a comprehensive pro-active service in the midst of a clinically underfunded poorly reacting service - makes no sense.
Scotland	GP	Patients who present with symptoms suggestive of possible colorectal cancer are not being seen/investigated efficiently - screening seems likely to make this worse.?!
Scotland	GP	Probably yes, if properly resourced.
Scotland	GP	Needs to be resources for colonoscopy ASAP after positive result - is this happening?
Scotland	GP	Wait for colonoscopy too long after positive test results.
Scotland	GP	System needs all costs to be considered and funded. Primary Care is not an infinite pre-paid resource.
Scotland	GP	If money available that is not needed for other endemic based priorities.
Scotland	GP	Provided results of pilot indicate it to be as beneficial as initially claimed.
Scotland	GP	If pilot results positive, then no obvious administrative reason not to go ahead with programme.
Scotland	GP	Several patients discovered to have occult carcinomas.
Scotland	PN	Prevention is of utmost importance.
Scotland	PN	Any screening programme is beneficial.
Scotland	PN	I think it could be very expensive and cause a lot of distress until FOB testing = FOB pos or neg.
England	GP	Introduce if results good.
England	GP	Surely you would always wait for pilot results.

<b>Country</b>	<b>Staff</b>	<b>Comments on whether a national programme should be introduced</b>
England	GP	We certainly had several "Positive Tumours". Effect on long term benefit?
England	GP	Good idea if cost effective.
England	GP	Only if effective in detecting cancer early and decreasing morbidity/mortality. Is it cost effective?
England	GP	Report in Coventry telegraph last week suggests has been low.
England	GP	It is imperative however that either remuneration for the extra workload is provided or that GP's are not involved at all.
England	GP	It will be many years before any useful information can be relied on.
England	GP	My wife and I were both in the age group to be screened /took part/ and felt the whole process worked extremely well.
England	GP	Indication from overseas studies indicate several asymptomatic patients have lower morbidity and longer survival rates.
England	GP	If it picks up the problems.
England	GP	Would like to see the results of your pilot.
England	GP	2 Colectomies - 1 benign adenom, 1 netastatic already
England	GP	I thought that was what this pilot was intended to determine.
England	GP	The answer to the above is yes - pending results.
England	GP	Seems like a good idea - should go ahead if successful in pilots.
England	GP	Obviously with back up colonoscopy
England	GP	Also not sure.
England	GP	But I suppose it will involve us I.e. GP's
England	GP	Depends on pick up rate, no. of colonoscopies in normal people, patient anxiety etc.
England	GP	Properly financed for GP practice involvement.
England	GP	We already do the test on patients.
England	PN	The screening should be offered to everyone.
England	PN	Need good info pack for healthcare professionals to enable good advice to patients.
England	PN	Option should be given to everyone especially if family history.

**Supplement S5 Formative analysis of  
prospective interviews (Organisation and  
Management) (Chapter7 in Final Report)**

## Formative Analysis

A partial (formative) analysis was conducted following the prospective interviews. Brief summaries of some observations made as part of this formative analysis are presented below with an example of text format in section B.2. The points made in the summaries reflect the largely prospective views and thinking on the Pilot at a time when screening was just beginning to be implemented in each site. The themes presented are not in any order of priority but reflect common issues arising from local stakeholders grouped under the textual analysis schedule headings (see Appendix A Table A.2 column B). We returned to these issues for verification, or otherwise, in the post-experience second round. Much had moved on, of course, and some of the issues raised had been resolved.

The following are some of the (formative) observations which emerged after reading and analysis of the Scottish interview data:

### Internal context:

- *the pilot design started from the premise that there existed a stable network of people respected for their professional interests and ability;*
- *the above assumption led to choice of a confident evolutionary approach to initiating the pilot;*
- *perceived importance of clarity regarding any weaknesses identified in pilot processes – which was seen as the rationale, anyway, for the pilot;*

### Operational management processes and issues:

- *persisting questioning of quality assessment procedures in colonoscopy process;*
- *knock-on implications for symptomatic service not fully apprehended (but perceived to be significant);*
- *histopathology, in spite of need for complex and difficult decisions, had at time of interviews no mechanism or forum for circulation of slides/scanned images for analysis and discussion;*
- *some issues, such as QA, not built into or owned by the health boards whose role is to monitor these; but uniformity of quality expected to be nationally, not locally driven;*

### Strategic management issues:

- *based on assumption of good networks, systems and protocols allowed to develop from (clinical) practice, rather than being management driven;*
- *informal and pragmatic approach to day to day management with less record keeping than English site;*

### Human resources issues:

- *serious anxiety re potential clinical skill resources availability for rollout; already much pressure on existing service;*
- *primary care – implications for workload and systems not yet thought through;*

### Clinician issues and concerns:

- *concerns about clinical protocols, particularly polyp protocols; but lack of good data on effects of different follow up protocols;*
- *patient follow-up issues posing ethical and structural problems – e.g. where screening ends, ascribing clinical responsibility;*

Pilot broad issues:

- *(as other pilots) not all aspects perceived as necessarily replicable at roll-out; evidence of energy and goodwill, but also reflection upon potential within pilot for small-scale inefficiencies;*
- *tension between pilot site and evaluation function.*

The following are some of the (formative) observations which emerged after reading and analysis of the English interview data:

Internal context:

- *strong project management structure in lead trust used to initiate the pilot;*
- *project development and operation formal in style;*
- *the trusts then worked together to plan, to develop and co-ordinate protocols and quality standards;*
- *one of few nurse fundoscopists works in locality and consulted in development of pilot;*
- *strong reliance on experience of breast screening, at Trust and national level;*

Operational Management processes and issues:

- *concerns about protocol overload;*
- *launch delay affected staff morale and retention;*
- *awareness of disappointing early Scottish uptake emphasised importance of public awareness/understanding;*

Strategic management issues:

- *departments with capacity pressures show a keen interest in having their workload monitored– though senior management may enthuse about ‘creative response’ to capacity ‘challenges’, these are areas where symptomatic service could be more affected;*
- *management structure progressively tightened as project initiation phase developed;*

Human resource issues:

- *for rollout, thought not to be enough consultant colonoscopists – potential to broaden their function to supervision, interpretation and trouble-shooting?;*
- *colonoscopists think potential for training nurse colonoscopists, radiographers are already trained to carry out barium enemas – trend is there to invest in;*

Clinician issues and concerns:

- *funding for extra workload involved in follow up care not clearly identified;*
- *necessity of personal contact and full discussion before undergoing colonoscopy strongly advocated;*
- *so, discussion about accessibility of the nurse-led clinic and whether this could affect uptake;*
- *wide clinician interest/concern re acceptability issues and uptake rates in population;*
- *mailing lists checked at general practice level for sensitivity to death/terminal illness/diagnosis;*

Pilot broad issues:

- *fears about potential colonoscopy demands were uppermost when considering national rollout*
- *lesson learned the hard way that IT requirements needed to be built in ab initio;*
- *information system not covering appointment changes, or recording colonoscopy and beyond for individual patients – being logged manually<sup>2</sup>;*

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<sup>2</sup> This issue was first observed in the English site but this report highlights the occurrence of this problem subsequently at the Scottish site, after the first round of interviews were completed.

## TEXTUAL ANALYSIS OF STAKEHOLDER INTERVIEWS – PROSPECTIVE VIEWS (CONDENSED TEXT, ONLY ON 'MANAGEMENT ISSUES' COMPONENT OF INTERVIEWS)

### English Pilot Site

#### *Management issues*

Post-bid acceptance, some of the influence and steer in producing and defining objectives for the pilot came from the site, some from national (and local) screening experience, based particularly in breast screening. Given the self-acknowledged tendency to compartmentalisation in the NHS, this focus on breast screening experience during early discussion was initially, perhaps, a source of mild irritation to some whose professional interests lay more in the colorectal area, but the experience nevertheless proved constructive. National Screening Office (NSO) also believed that they exerted a strong influence on the English site. But when it came to initiation, the site considered that NSO had not had a clear project plan or targets, and at the same time that colorectal cancer was an area of expertise that they considered themselves experienced at, 'We've helped them develop – they hadn't got their act together, basically.'

Nationally, prior experience, however, was seen as instrumental in moving swiftly from the trial research evidence to developing quality standards and parameters based on clinical practice and protocols which 'Applied to colorectal has given us a lot of short cuts ... because we knew what we were doing' (NSO). The protocols to be used were discussed within and among the trusts, and decisions on their adoption came from the executive group and steering group. A practitioner wryly observed, though, that protocols are easier to write than they are to fit individual patients into.

It was recognised that colonoscopy is not done well nationally, the self-reported completion rates quoted at around 50%; the interest on site was in completion, complication and pick-up rates, and frequent reviews. The pilot was seen by some lead clinicians as raising endoscopy standards in the participating trusts; software from the Association of Coloproctology was being used to collect data and inform databases, and the profile of protocols, data collection – and training – was believed to have been raised. Related surgery did not, at time of interview, have explicit quality standards per se, but the audit in terms of surgery would be referred to quality standards e.g. leak rates etc, without as yet setting specific targets. Given the increase in data becoming available, the stated aim was to reflect on practice, and work towards putting in any additional quality standards deemed necessary, in an evolutionary way.

At individual trust level, the integration of national screening standards and data collection within the trust was welcomed for the extra information that would be made available; failures should be picked up at trust level. If, say, a low colonoscopy completion rate were to be identified, then the expectation was that the operator would retrain, or be taken off the pilot; the NSO would remain as quality backup or fail-safe.

For project initiation and implementation, a tightly focused project management approach was considered, particularly by senior managers, to be the most effective way to start. Not all the trusts were accustomed to this way of working, and might well complain that the lead trust was throwing its weight about, again.

*'They usually accuse us of taking over, and leading the whole thing - which is exactly true.'*

**Senior Manager**

It took some time to get the project team on board, to communicate objectives and ensure that team members across the participating trusts understood their responsibilities and what they were expected to contribute.

*'... It wasn't really a team in the sense of people going away and doing pieces of work. It was a hard slog to get people to meet deadlines ... and people didn't come forward with agenda items beforehand.'*

**Manager**

Hindsight suggested more careful team selection and greater clarity in communicating roles, by working with the other trusts involved to convey to them what was required from their representatives on the project team. Senior involvement and ownership, once gained, helped move the project on. Concentrating on initiation, structures, project team and board, reporting arrangements, target dates, information flow, began to bring results. More time to plan became available, though – much more - when it became clear that development of the information system, and therefore of the English launch, would be delayed. The Scots pilot site would go ahead and launch, while its English counterpart had to sit by and polish its protocols. Succinctly summed up as ‘nightmare’. On site there was a loss of momentum and morale. Some staff, particularly the newly hired, left.

*‘One of the difficulties has been the delay, and the problem of keeping the staff on board. Emotionally, psychologically, enthusiasm, all the rest of it, in what’s .. jolly nearly a six-month delay.’*

**Senior Clinician**

One hard lesson learned from this event was that information systems to measure performance should have been designed and developed alongside the design and development of the systems and processes they were to measure, as Scotland had done; so that IT involvement should have been formally incorporated from the very beginning, with a board and tight monitoring. Perhaps another hard-learned lesson was that organisations within the NHS ought to be treated as any other supplier, and no less robustly

*‘NHSIA, we started off too casual with them ..... all going to be really relaxed, and very quick, very fast – we trusted that, and that was a mistake I’ll never make again ... another NHS organisation, another mistake we made – working together, whereas really (we) should have treated them more like we would a supplier. And we didn’t do that.’*

**Manager**

Meantime, Scottish experience showed the importance of a good launch. It was understood down south that Scotland were unable to launch as they had planned, with ministerial attendance etc; this served to underline the fact that media impact and presence may have an important effect on uptake rates. There was continuing interest in, and concern about, what those rates would be in the English pilot, and a resolve to launch as strongly as possible.

There was discussion and differing opinion offered re NHS structural issues which could relate to roll-out. Some argued in favour of big centralised units for efficiency of service delivery, others for small organisations where it just took longer to aggregate sufficient numbers to demonstrate the quality of care. A manager questioned the value of vested organisation-speak and attitudes; another who was newly arrived to the NHS saw NHS structures, and thinking, as antiquated –

*‘It’s got a lot to learn about business and commerce ... so many barriers and hierarchy – you may need to speak to 10 people where one would suffice ...too many cooks – just people building empires.’*

**Manager**

Emphasis was laid on the importance of communications between trusts who were working together, even though surgeons might freely admit that they would rather squeeze another case into tomorrow’s session than spend that time at an off-site meeting. Inter-trust relations were variable, with some in the lead trust acknowledging that they did take over at times, though there was also awareness that inter-trust relations and ownership or involvement were all improved by sharing around the responsibilities and leads with their fellow trusts.

Clinicians in particular showed a keen interest in capacity issues and, therefore, in monitoring workload. Some, particularly those in the other participating trusts, were not sure how much funding was following the work, and had been unable to find out. The point was repeatedly made that the colonoscopy and radiology services were under pressure from the symptomatic service:

*'There may be space in the colonoscopy suite, but no staff available ... (there's) no capacity in the system. We're full. And (it's) very rarely anything but full.'*

**Clinician**

*'.. still a question mark over the funding in terms of, realistically, whether the thing's been costed properly, and how much of our time it will take per case ...'*

**Clinician**

Radiologists described the experience of living in a culture of massive demand and a rising reliance on tests, summed up as 'too many tests, not enough (radiologists) and not enough equipment', to the extent that waiting times were a preoccupation, there were delays in reports, backlogs in tests, particularly ultrasound and MRI. In the lead trust it was felt that there was not enough radiology time for cancer as a whole; that surgeons were being appointed – including colorectal surgeons - without any of the accompanying radiological resource input that should accompany such an appointment. Further training, though, was ongoing. Up to 70% of general ultrasound was said currently to be carried out by sonographers, and 'most' barium enemas by trained radiographers. Efforts were, it seemed, being made to improve the efficiency of systems. On an occasion where several prioritisation options had been offered to a clinical directors' meeting, in spite of 'much hand wringing and dolefulness', no decision had actually been taken. Asked if a forum existed to implement efficiency decisions,

*'Uh, there is one. It's called you scream, you shout, you throw the rattle out of the pram and you threaten to be sick everywhere.'*

**Clinician**

On the other hand, trust management could wax lyrical about 'capacity challenges' while considering that there was 'potential for us to use our capacity in far more creative ways'. But another such, in another trust, warned of

*'people who are overworked, they're running round to chase their tail, they're short-cutting things, they're going to make mistakes.'*

**Senior Manager**

Similarly, clinicians expressed serious concerns about capacity and pressures on the service, some brought up in early discussions about the pilot 'particularly about finance and – money and time, and where it was all coming from.'

It would seem that the climate was one of uncertainty about how the pilot would work out. But one factor in this may be the different stages the pilot sites were at when the interviews were carried out. This one was just starting up, after a protracted delay, while the Scottish site was up and away.

At the very early stage when interviews took place, there was little actual pilot experience to confirm the views given below on the pilot's anticipated knock-on effects on symptomatic services.

General thinking was that some increased pressure might be anticipated on the services running at, or near, full capacity. While the full flow of cases was building up, the trusts that prided themselves on their experience and expertise in handling colorectal cancer believed they could deal with screening investigations in the early weeks, and had been reassured that the situation would be reassessed as necessary. It might be necessary to move symptomatic activity to other lists to accommodate the 2-week



time limit for screening cases. Required colonoscopy completion rates of 85% for screening also meant fewer patients per session.

If the impact proved to be consistent, and capacity needed review, it was considered operationally possible to transfer cases to another trust, but this might create difficulties for clinical management.

The planned nurse-led clinic had been sited in an outlying location, which had caused general concern that people might have difficulty getting there, which might in turn affect uptake. The trust furthest away from this clinic had decided that its trained nurses would offer counselling and advice to anyone turning up in need of same, and monitor whether it would be useful to hold another clinic.

Barium enemas were being fitted in, with relatively low numbers at two trusts, and the third had reduced its waiting lists by holding sessions on Saturdays, and was able to fit in the screening lists.

Fears about potential colonoscopy demands were uppermost when considering national roll-out, as in ‘Another huge swathe who will need scoping ... there aren’t enough consultants in the country!’

Radiologists made the general point about their role in cancer management that their skills were spread very thinly; they reported that radiologists make the ‘vast majority of diagnoses,’ with continuing involvement in management, and ongoing imaging. They were concerned about potentially grossly inadequate resourcing of radiology input relative to colorectal surgeons’ appointments.

Existing data-sets and quality standards would roll out, if working well in the pilot. However, mechanisms would need devising for better prioritisation.

Clearly, costs would be incurred, but a public health clinician’s view was that 60-70% uptake would make it effective and cost-effective to roll out. An alternative view was, ‘Let’s hope the government realise how expensive it is to do this!’ But it was also thought that government seemed keen on ear-marked funding.

### **Scottish pilot site**

#### *Management issues*

Quite a strong impression emerged from the interviews of an able, purposeful and cohesive group of clinicians supported by similarly capable and experienced administrators at a national level. A local GP described the senior people as ‘capable, energetic and enthusiastic’. A public health clinician involved from the outset spoke approvingly of the calibre of clinicians involved, with none on board who might

*‘give you an absolute headache (and) don’t understand the wider perspective of screening and the difference between screening and the symptomatic services.’*

**Clinician**

Those interviewed saw the health service as a relatively small community. The feeling of stability and the network of contact and communications was palpable:

*‘And everybody knows everybody, you know ..’*

**Clinician**

*‘ ... very very quickly there’s a high level of trust and confidence between all the players in the pilot ... we know that because of the things they tell us, and the openness with which they approach us’*

**Scottish Office**

which seemed to have informed its structures and the pragmatic style of its development. The team had chosen to adopt what might be described as a confident, evolutionary approach; the players were prepared to look at, to learn from and change the things that needed changing. They saw this as one of the reasons

for the pilot, and one of their self-allotted tasks was ‘spotting and sorting problems’ and drawing on relevant professional strengths, including their own and others’ experience, to do so.

*‘This is our fourth month (of operation) and the learning curve is exponential ...we just look at it sensibly, and when it’s something X should take a view on, then X takes the view ... we thought – we vaguely knew what we were going to do. Now get on and do it ... cleaning up what needed to be done; a lot of information there – to be taken on board and used.’*

**Manager**

Quite a widely expressed view was that, however long and hard they might have worked out the theory, practice could still throw up the unexpected:

*‘If something is not happening the way we think it ought to, we have to go back over the ground again and say No, we must do this. But we could never have written it all out in the first place anyway.’*

**Manager**

*‘ ... why the pilot has been really good to do, because there are so many issues... that you couldn’t anticipate.’*

**Clinician**

A decision had deliberately been taken to adopt the relaxed and interactive team approach they felt suited the project - and which they believed contrasted with the English way of doing it – but the Scots management style nonetheless, they pointed out, did also contain elements of planning and organisation, (but not too much):

*‘ ... we took .. a much more relaxed approach ... (but) there has to be a project plan, and some target dates and named individuals. But I don’t think ... we have to be project-planned to within an inch of our life!’*

**Senior Manager**

The approach as described above also extended to communications, informal but seemingly effective; so that a manager might have a regular weekly ‘quick catch-up’ with her line manager without the ordered formality of sitting down to a meeting. Phone calls to colleagues might be a first response to a problem picked up. Meetings might be called at short notice for rapid resolution of a problem, rather than waiting for the formal channels.

*‘If it was a significant issue we’d just pick up the phone, we wouldn’t wait for meetings. And everybody knows everybody, you know ... once we had identified what the problem was, and if it was a significant enough problem, the way I’d expect it to be dealt with is then there would be a quick meeting of the key people who would get together and sit down to discuss it. I don’t think it would wait to the next steering group meeting.’*

**Clinician**

And informal approaches would be used ahead of formal ones, in the hope that this could be enough to head off an incipient problem. Staff had been actively encouraged to raise issues, and ‘we can talk about possible solutions – (but they) may be in your hands’.

Some very hard negotiating could also happen – not too much was relaxed about this encounter as reported. A trust was being challenged to work through its preconceptions and to deliver on its service agreement:

*‘Screening was seen in the past as taking the patient to point of abnormality, not to point of diagnosis. So there was a perception that we would be getting colonoscopy for free - had to get rid of that perception, and test it - if free, you’ll be getting it at our convenience ... no it isn’t like that. Your proposal made it quite clear you’d budgeted for colonoscopy, this is how you saw it*

*happening ... can you deliver? The chief executive said - I never even saw the damn thing! ... from then on it was relatively straightforward.'*

**Scottish Office**

(We discuss further aspects of relations with trusts below.) Formal structures were also employed to monitor delivery on agreements and to ensure feedback – if not volunteered, it could be tracked down and required:

*'We have had to ask two pilot sites why they were failing to meet what they'd said they would deliver – we were disappointed they didn't come and tell us ... took it to Scottish Management Group (who are) producing management performance indicators ... just in case anybody forgets to tell us about the non-functioning endoscopy suite, or that a piece of kit has packed up – there's an opportunity 4 times a year to scoop them up.'*

**Scottish Office**

However, the informal encouragement for people to raise issues could also bear fruit in that 'even people you don't know very well will tell you' about matters causing them anxiety, on occasion rather than those who would have been expected to raise them. Management was then concerned that these issues and 'scenarios that need to be thrashed out, because something's gone wrong with the process' get very thoroughly sorted out at that stage, and weaknesses eliminated – so there would be no nasty surprises for the Scottish Executive, or the 'English arm.' Trust and confidence was expressed in the health service's ability to organise and run this pilot in the way they described - or the alternative would have been 'a much more project-managed approach' ...

In terms of project initiation and implementation<sup>3</sup>, it was clear that there was always a strong clinical lead which shaped the pilot's development, with less trust management input. An 'evolutionary management plan' existed at the outset – and differing views on how much management input this would entail - but protocols were in place for colonoscopy and for pathology from the beginning. Quality was seen as a major issue, particularly in follow-up investigation (and symptomatic colonoscopy).

*'It's been clinically run. We set up the various processes – the lab group, and working parties for all the different clinical aspects of the job, we've drawn up protocols – hasn't been much management input, certainly not trust management input, very little.'*

**Senior Clinician**

National management's view of its input might differ here. Its co-ordinating and development role re quality standards and its understanding of screening issues earned respect in the community. The development of standards was based on practice and derived from clinical trials, though selection and definitions needed further work. The aim was to produce quality standards that would support the process.

*'What we've tried to do is take the principle of having quality standards and being crystal clear about their definition, the way in which they're measured, and setting something that is achievable, and then something that's gold standard. If you like ... the ultimate aim is to see if we can reduce mortality. working from a logical series of events that's happening for each person who's in the pilot, and the stages at which we should be measuring what's happening.'*

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<sup>3</sup> *Note:* The data described and discussed in this section have taken the form of a narrative. The key to the story came in a comment from a senior clinician who was involved in writing the bid, that when submitted it had a number of 'blank areas for further discussion' in it which were expected to be negotiated and filled in. It seems that this did not happen and that the bid was awarded with some funding, but without further discussion of outstanding issues. This may help explain the evolutionary developmental style of working as not just a preferred *modus operandi* but very necessary given that the starting gun for the pilot was fired rather a long way back, before such vital issues as funding for capacity requirements had been fully worked out and agreed. It's at this point that the trajectory begins to seem less like a pilot, rather more a voyage of discovery, with all that may entail.

## Scottish Office

Starting from about 70 suggested standards from professional interest groups, and the danger of getting 'bogged down in their own professional interests,' a framework was devised. Suggested standards were cut back to about half, then to the clinicians 'who came back with something so much more elegant', so no ownership problems there, and they would then revisit with hard data to test and refine, and

*'identify the robust and useful against the misleading and confusing (with the warning that) practitioners will be tested against the standards – the bucket of water comes when you're tested against it. Remember why you're doing it.'*

## Senior Manager

However, a significant structural weakness had been identified by stakeholders in terms of trust management involvement, which was being addressed while the prospective interviews were taking place. Trust management input was observed to be minimal. During the setting up of the pilot, trust financial difficulties and reorganisations, with key clinical appointments not yet made, had meant that trust involvement was not, probably could not be, close. There might have been general support for the pilot, and an interest in the 'glory and publicity' and any attendant funding, but no close attention at senior levels. Clinicians with wide screening experience might feel that

*'In general, trusts (managements) do not have a full appreciation of the complexities of screening programmes.'*

## Clinician

So that when it came to the essential monitoring that must be done in the trusts themselves, there was a clear need for this, but a gap where trust involvement should exist. Evaluators were told that steps were now being taken to meet with trust staff and to 'embed the scheme into the trust structure' in a way that had not been possible before – but might be difficult for the trusts to exhibit 'ownership' now. This will be an important issue to follow up, and particularly in the event of roll-out.

One of the issues said not to be resolved at the time the bid was accepted, was that of specific funding for treating the extra surgical, radiotherapy etc cases which would be screen-identified. This had been consistently raised by clinicians and formed an explicit part of the bid as submitted. It had not been addressed, other than by what was described as a 'nudge, nudge, wink' response, which was not considered by clinicians as constructive or professional. Knock-on implications for symptomatic services, if not picked up as part of the screening programme could, it was thought, result in 'a shambles'. Waiting times for colorectal cancer surgery in Grampian and Tayside were described as already far too long for the symptomatic patients - and might be exacerbated by proposals to deal with the overspend there (a blanket ban on recruitment had been in place as one response). Two scenarios envisaged were:- increased waiting times for everybody for surgery, or fast-tracking screen-detected cancers, thus increasing waiting times for the symptomatic patients and leading to an equally unacceptable two-tier service.

There were further fears for the 'enormous pressure' on the service, that might be increased by accelerated symptomatic waiting lists without the staff to deliver, from clinician-driven surveillance systems duplicating the pilot, and from more referrals from GPs as their (and the public's) awareness increased. Colonoscopy provision was a major issue being discussed at trust level and beyond, with communication planned to the CMOs.

Follow-up protocols had not, it seemed, been finalised at the time of the interviews, and a scarcity of sound comparative data was said to have hampered the development or adoption of generally acceptable protocols. Clinical ethics indicated that a group identified as at intermediate risk because of adenomatous polyps should go into a colonoscopic surveillance programme, rather than back into screening, which could have the potential effect of snowballing demand from that group.

Informed primary care opinion tended to the view that it should be the responsibility of the screening system to establish clear guidance for people emerging from the screening process; to arrange follow-up for all categories of people receiving investigation, and to give a clear understanding of what the long-term follow-up would be. Counselling and information about the importance of polyps and follow-up, and explanation - while unsedated - for people whose colonoscopy was normal, about its meaning and what to do if symptoms or problems developed, was also thought very important; summed up as very tight exit policies, and needing (among other things) a sophisticated call-recall system. Screening programme policies in 'difficult areas' were required by GPs to be explicit, and responsibility taken for them by the programme, with 'unknowns' funded and investigated as a matter of urgency, and not

*'down to individual general practitioners, who are not expert, to make that clinical judgement on behalf of their patients.'*

#### **Clinician**

There was broad awareness, and warning, that of course not all aspects of the pilot would be replicable were there to be roll-out. There was a fairly general feeling that staffing levels in the pilot were on the low side, which was compensated for by particularly high levels of flexibility, commitment and interest that could not be sustained at such a high level *ad infinitum*. So that some spare capacity for down time would have to be built in. On the other hand there would be economies of scale, for example in volume despatch of the test kits which was largely being done by hand (with concern for possible RSI risks). It had been important there to retain control of despatch numbers on a day to day basis as effectively the only 'braking mechanism' in reserve if, for example, the entire system should become inundated with positive test results.

**Supplement S6 Summative analysis  
(Organisation and Management)  
(Chapter 7 in Final Report)**

## **1. Context: approach to planning and implementing Pilot**

One key finding from both prospective and retrospective interviews was that the pilot sites differed in the way in which they were initiated and the way in which their organisation and management structures developed. Although both sites had been dependent on the enthusiasm of local clinicians in bidding for a local pilot, in Scotland the development of the pilot initially remained with the small group of individuals (4 - 5 people) who started the process, whereas in England the Trust Management and hence members of the Trust Board were also involved from the start.

Development of the pilots was inevitably also closely related to the context in which the pilots were set up. Scottish health services are a close knit community, both geographically and professionally. The size of the community lends itself to informal networks and this networking is perceived by many to be an effective mechanism for successful development of services. In contrast, the England pilot had submitted a tender which demonstrated that formal methods of project implementation would be used to implement the Pilot.

Conversely, when it came to the development of the Information System, Scotland was contractually bound to a formal development process, whereas the English site chose an evolutionary approach.

At the start of the Pilot process, staff within the pilot were encouraged to take the approach chosen by the perceived management leaders. Thus, the Scottish pilot managers chose informal management methods and the English pilot site managers followed the formal processes that were common practice within the Trust. Indeed, the English National Screening Office perceived the piloting exercise as an opportunity to assess the methods used by English site Trust Managers. However, partner Trusts within the English pilot did not necessarily share an understanding of these formal management methods and it took time to establish joint ownership of the project.

One feature of the internal context of the Scottish Pilot was the initial lack of involvement of senior Trust managers. This was revealed in many ways, by, for example, little involvement in the original bid, lack of clarity among senior pilot employees about lines of management and appraisal responsibility, lack of knowledge about the pilot by Trust senior managers and assumptions that clinical leaders were doing all that was necessary to progress the pilot. Reporting structures to the Scottish National Screening Office were better developed than reporting structures to the Trust Board. Indeed, senior Trust managers did not perceive a need to become involved as the pilot was seen, at the beginning, as self financing, externally policed and clinician-led. Almost the exact opposite situation pertained at the English site where clear lines of reporting were put in place at the outset and leadership was perceived as a dual partnership between the lead clinician and Trust managers.

Interestingly, over the duration of the Pilot, both sides shifted somewhat towards the opposite approach. Retrospectively, this feature was identified by several interviewees to be due to contact with an alternative perspective. The Managers of the pilot sites were in close, often daily contact, as were the project coordinators in the National Screening Offices. Key individuals from the teams involved emphasised that learning from the other team was one of the advantages of the different approaches. Retrospectively, there was enthusiasm for a more formal system of implementation from most interviewees.

Thus, as the pilots developed Scotland perceived the advantages and necessity to formalise their systems. England meanwhile, having reaped the benefits of a more formal approach, recognised that the constraints of this system produced a rigidity which could be relaxed to progress development of systems.

## 2. Operational management processes (Quality management)

Some of the quality management issues arising from the pilots were not foreseen in the planning stages. In general, many of these issues related to communications between different stakeholders. Many stakeholders referred to the usefulness of the pilots in this respect and many shared the comment that it had been more complicated than they at first supposed. At the outset, the problems of quality assurance were largely perceived to be related to the testing of the kits and the subsequent diagnostic tests. Care was taken to discuss protocols for these two processes in both pilot sites and the importance of documentation and protocols was acknowledged by both senior clinical and scientific managers and their staff. It was only after both pilots had started that the implications of quality assurance for other systems began to be appreciated.

A number of issues continued as matters of debate throughout the length of the pilot, and remain issues that need further discussion at the end of the pilot.

### 2.1 Protocols and joint working practices

Although at the outset of the pilot there were concerns about protocol overload, this proved to be a useful feature of the pilot start up process. With the benefit of hindsight many of those interviewed commented on the usefulness of meetings and the shared approach to developing data sets, pathways and protocols at the outset.

*“There’s been a lot of cross over in quality assurance visits, we use standardised protocols that are the same in each, we use the same information material up to a point.”*

**National Screening Office**

These meetings also helped to cement relationships between key personnel and appeared to enable the perspective of each pilot site to broaden. Inevitably, however, the early incentive for sharing seemed to be lost as the pilots progressed and there was much less awareness of each other towards the end of the pilot. Although high level meetings continued, staff further down the hierarchy were less exposed to the experience at the other sites. This shared experience may have been helpful in reducing the isolation experience by, particularly, the nurses. For any future pilot, setting up speciality specific staff groups, even if by simple communication means such as teleconferencing, could provide a useful method of inter-site learning and identifying common problems. The benefits of this approach were best exemplified by the excellent relationship between the operational managers at the two national screening offices.

### 2.2 Quality Indicators and standards

There was universal agreement that there were too many indicators. However, it was also acknowledged that this was perhaps necessary for piloting, and that at the end of the pilot a consensus would be easier to reach about reduced sets for roll-out. Common standards were agreed at the start of the pilot across both sites.

### 2.3 Laboratory Quality Assurance (QA) processes

#### *a) Quality control*

As there were no existing standards for quality control of large scale FOB testing in the UK context, both pilot sites designed their systems from scratch. FOB testing quality control methods were introduced from the start and the repetitive nature of the task of reading kits was recognised and planned for by both pilot sites, although the process was not simple.

*Everything is a lot more complex than I had expected. I thought the process was so simple, and it’s not..... and just the sheer volume of quality assurance, health and safety, statistical data, required to run the lab.*



**Scottish Pilot Site Staff Member**

An important part of the management of quality in the laboratories was identified as limiting the time spent doing repetitive tasks. In common for the two laboratories was a recognition that enforced limitation of kit reading time was therefore a necessary measure.

Of the two different procedures adopted for kit reading :

- Scotland used double recording (paper and IT) of results, approximately 100 kits per person per shift
- England used double reading of kits but paperless, 50/59 per hour (two people) or 50 per hour one person

There has been some debate within the pilot about the best method of reading kits. England used two readers to assess one kit and the IT system was geared to respond if there was disagreement between the two readers. In Scotland double reading did not take place.

*b) Laboratory Process Measures*

The English pilot site reported that process measures formed an important part of overall quality assurance.

*“ Like how many samples were we getting through, how many were positives, how many were...were queries, you know to.... to get a feel on an ongoing basis as to how the system is working. I'll give you an (example) every now and again a GP will phone up and say everything alright with your serum x's. And you'll say well as far as I'm aware our QC's okay, umm. He said well we're getting a lot of high ones, umm potassium's a good example of this in, particularly this time of the year we occasionally get it. You go, you say okay I'll go and investigate, you investigate, everything in the lab looks alright, and then you start to uncover the fact that well the couriers have changed their rounds, the order in which they pick up samples. And that particular GPs err practise is now being picked up a lot later in the day, and samples are hanging around a lot longer. Umm you know it's the end user is actually being very much more sensitive than anything else that we're doing at picking up changes.”*

**English Pilot Site Staff Member**

During the course of the pilot it would appear that a number of quality control issues, including interpretation of results have arisen. Although it is clear that there has been dialogue between scientists, and between scientists and Alpha who supplied the kits, those with responsibility for day to day management of laboratories would have benefited from more communication between England and Scotland at an operational level. This could be arranged informally but the development of a “learning environment” extending across all managers responsible for aspects of quality assurance and control, would be beneficial.

## 2.4 Colonoscopy services

One of the key quality indicators, the time between a positive FOBt result and colonoscopy was set at 2 weeks, although there was evidence from local services in both England and Scotland that colonoscopy services were under pressure. However, since funding was put into the pilot sites for colonoscopy, it was assumed this would cover the predicted workload. On setting the quality standard for colonoscopy waiting time, however, closer examination of several issues may have suggested caution:

- current capacity and local issues, for example rooms, clinic durations and availability of support staff, at local trusts,
- exact nature of clinic arrangements for additional colonoscopies,
- speed of information flow within the system (this was unknown at the time of standard setting),
- logistical issues of pace of return of FOB test kits.

Other, unexpected events also adversely influenced actual colonoscopy waiting times. These included

- the numbers of polyps disclosed for some patients considerably lengthening time for each examination,

- the amount of paperwork required by the pilot,
- higher than expected prevalence of positive FOBts in some areas,
- absence of some promised clinic slots,
- unexpected sickness of key personnel.

*And I think maybe people are more aware of that now, and are much more honest and upfront about yes colonoscopy waiting lists. But I do think an interesting issue is the quality standards, because it was agreed that there should be a two week time period between a patient seeing the specialist nurse and then having colonoscopy, which is completely unrealistic, and I think that put a lot of pressure on people, and I still hear myself saying that's just a marker revealed in the sand, and it (the two week standard) is still an ideal but in the real world we know that that's not possible*

#### **National Screening Office**

Within the pilots no standard was set for time to receipt of post colonoscopy results. This was partly because it was recognised at the outset that pathology services were under pressure nationally, but also that there was variability within the Pilot itself. In fact there was considerable variation between trusts and in some cases the pilot nurses identified this wait time as an issue for patients. Pilot nurses spent a considerable part of their effort, particularly in Scotland where the information system was less adequate, chasing results and monitoring the flow of paper during this period. In one trust for example it was identified that, for patients who had some pathology at colonoscopy there was a bottleneck between colonoscopy and a letter being despatched to GPs. This is a process that should be investigated as part of the revision of the IT system

## **2.5 Completed colonoscopies**

Some concerns expressed during initial interviews about proof of completion of colonoscopy were not repeated at retrospective interviews. This may be because the confidence of the colonoscopists increased and at the same time other issues, such as data management, absorbed reflective management time. Nevertheless, the question of proof of completed colonoscopy has significant impact on pathology services as well as colonoscopy services and may need further discussion before roll-out. Recent publications have also raised the issue of possible transfer of New variant CJD during colonoscopy. The demand for proof of completion is still an issue for debate at the end of the pilot.

*Well we were contracted to provide high quality colonoscopy with proof of completion, with a discussion under what would be acceptable as proof. And what I'm saying is that that discussion really is ongoing, that there is some variance within the group as to what the right solution is, and it's met problems in terms even of the terminal ileum biopsies, even though that's a gold standard.*

#### **Clinician Conducting Colonoscopies**

Care was taken with the pilots to involve primary care as little as possible. However, if colorectal cancer screening is to be managed and commissioned centrally, it is important that a) mechanisms of negotiation with local commissioners are set up as part of quality management strategy and b) funding of key services such as additional capacity for colonoscopy and radiology does not become hi-jacked by and harnessed to local priorities.

## **2.6 Radiology services**

For radiology it was readily recognised that the standards set for DCBE were those that should have been in place anyway. None of the partner sites identified any difficulties in implementing protocols once the hard slog of writing and negotiating them between partners sites was completed. Neither were problems of protocols anticipated for roll-out

*"I would think so, I mean barium enemas are one of the relatively easier things to audit in radiology. Umm I think most departments have, will probably have, an idea about that".*

## Radiologist from Partner Site

Radiologists' experience in general was that not as many DCBEs were undertaken as anticipated and numbers did not put pressure on the system. The pressure on radiology arose rather from the fact that those patients who presented difficulties to the colonoscopists also presented problems for radiologists. In some cases this led to these cases joining the queues for CTs and thus influencing waiting lists and total cost of screening. It is worthy of reflection that the most difficult cases for colonoscopy and radiology sometimes are those cases which have co-morbidities that may preclude aggressive action if an early stage adenoma were disclosed. This may suggest amendments to the protocol so that a further risk assessment is conducted after a failed colonoscopy and before automatic referral to DCBE. Although a small number these cases will appear as follow up failures, thereby apparently reducing the efficiency of the programme, unless identified in a separate category.

## 2.7 Pathology Services

Although there has been discussion within the pilots of the quality issues related to colonoscopy another key area (pathology services) received less attention. If a full risk assessment were done of the screening programme pathway, pathology services would appear as an important area of influence on programme quality. This arises from a combination of sources and circumstances, viz;

- the impact of the high number of polyps per case,
- an acknowledged shortage of histopathologists,
- intrinsic difficulties of classification (staging) of pathologies of which the service has less experience,
- minimum data sets not yet fully adapted to the pathology that has been found in screening service as opposed to symptomatic service.

All these factors could combine to place future services under severe strain. Indeed, the high number of polyps diagnosed has, in effect, increased the case load of this service by a factor of approximately five times the number of colonoscopies conducted. Pathology services should therefore be scoped as a multiple of the number of colonoscopies.

*It is it's not truly multiple polyp patients, it's not multiple polyposis. It is if you simply consider it as a an English umm expression, but you know I think they're talking in terms of some huge number of polyps, like over 100, before it can be called multiple polyposis, err so we're just dealing with, I've had up to 18, but that'll be a mixture of hyperblastic polyps, tubular adenomas, and tubular vilus adenomas. But it's, you know it's sitting at the microscope, getting that all onto yellow forms as you're dictating the report,.... I'm just waiting for a fall through the ice, that's the problem.*

**Histopathologist**

## 2.8 Work flow and capacity management

A crucial part of the operation management of the pilots was work-flow management. The screening pilots appeared to be sensitive to screening capacity in terms of colonoscopy waiting times within each trust, although this was not an integrated part of the IS system. More difficult to regulate, and therefore manage, was kit return rates. Thus, was particularly acute over festivals and holiday periods. It can be expected that the rate of despatch of kits will be better tuned in the second round of screening as knowledge of response rates on a micro level is acquired. This issue should be recognised as a regular item for process review within the FOBt service and within the information system itself.

*“usually we don't know until umm it happens that day, and say oh why haven't got any, or we've got treble the amount of. Oh that's another thing of umm bank holidays, which this last bank holiday was awful because err we ended up with three lots of three piles of letters on the day we came back, which took us, well Wednesday, Thursday and Friday to clear”*

**Screening Pilot Staff Member**

It would be easy to lay the problem of local delays and the need to stop and start sending out of kits as an issue related solely to the screening pilot. However, evidence from several sources suggests that some local services were suffering from capacity problems completely unrelated to the screening pilots. Undoubtedly, the screening pilots put additional pressure on the system. In service conditions, using quality indicators at a national level alone to monitor local performance would have labelled some localities as a failing screening service. In fact, surgical and radiological services as a whole were struggling. In this situation quality management mechanisms which include a dialogue with local commissioners become crucial. This may result in an effect of screening being to improve quality per se, as illustrated below :

*Stakeholder: I mean from a medical point of view we would see it very positively, and the pilot has provided an opportunity to increase the, and to improve the facility in (one locality in Scotland). And you know perhaps management may think differently, but certainly from a clinical point of view it's a very positive effect, and I think all along I have certainly felt that one of the major major advantages of colorectal cancer screening is it will drive up the quality of diagnostic services.*

*Interviewer: Is it just diagnostic services?*

*Stakeholder: No I think it drives up treatment services as well ..... all I can say is that we tried to improve services for a number of years, and using a number of sort of different strategies, and this has been by far the most successful.*

**Member of Screening Pilot**

## 2.9 Outcome vs Process Measures

The contrast between the needs of the pilot sites and those of the evaluation team was most starkly highlighted in the key measures used during piloting. In general, the evaluation team demanded outcome measures, and initially these measures were perceived as important by both pilot sites and evaluation team. As the pilots progressed to the management of patients, however, emphasis changed quite rapidly to process measures, required to micro-manage quality. This tension was perhaps more marked because the pilots themselves were developmental and outcome measures were initially seen as targets by the pilot teams. In practice, ad hoc control processes led to a proliferation of personal systems as additional records were kept, outside the formal IT system; for example, radiologists as well as laboratory managers identified feedback of some process measures, e.g. failed colonoscopies or failed colonoscopies *and* DCBEs as vital to pro-active day to day management of quality. All reported that they would appreciate short term feedback loops inserted into the information system. This feature was most obvious in Scotland where the Pilot nurses developed their own paper-based systems driven by the need to manage process.

The evaluation team identified systems to ensure all cancers are identified and recorded as essential. The suggestion that under-recording may have taken place indicates that pilot site process measures may be failing to identify patients with no record of a result following investigative procedures.

## 2.10 Assuring quality of datasets

The role of nurses in tracking data proved to be important. Interestingly, the Scottish National Office saw a solution to improving the quality of datasets by extending the role of nurses into data collectors.

*Well I think probably we could utilise the nurses more than we have done, for example in you know the sort of gathering of clinical data, the nurses could play more of a role, particularly if we were using established kind of hospital data collection systems to get clinical data..... And I think we can use, yeah we can use the nurses more to validate clinical data. I think probably, certainly within Scotland our colorectal pilot nurses didn't have any formal training.*

**Scottish National Screening Office**

Although this may not be a cost-effective solution, it does highlight the essential role nurses played in local monitoring of quality issues.

The role of clinicians as well as clerical staff in validating data, was also perceived as vital by managers of the pilots, although it was recognised at both sites that this was a matter of team work.

*And I think that there are some levels of data that clinicians have to be involved in. So I mean, I don't mean that they should go out and collect these data, but they should be actually be involved in the validation process, so that the quality of the data is better.*

**Scottish National Screening Office**

## 2.11 Training and accreditation

At the end of the pilot the Scottish Laboratories spend a considerable amount of time developing the pilot protocols into a case for CPA accreditation. This was held to have been a worthwhile exercise and of benefit in the context of colorectal cancer screening. In particular the experience of both laboratories was that the variability in the returned FOBt kits and the amount of detail required within the laboratory could not have been predicted without a pilot.

One of the positive effects of the pilots has been to raise awareness about the importance of training and accreditation for colonoscopy. Discussion of capacity issues relating to colonoscopists has underscored the lack of organisations able to train and accredit colonoscopists.

*“we couldn't roll out in Scotland unless we had a (colonoscopy) training programme. And things like even for accreditation purposes etc you would really need to bring it north of the border. And I think it's been very beneficial the colonoscopists that have gone down to Saint Mark's for a couple of days, and that just shows that you know there's, we've got a lot of experienced clinicians that they actually find it advantageous to do two day's refresher course. So I would hope that we could facilitate something up here. And I think as well, I think certainly the Scottish Cancer Group, it's been raised there, because it's not just an issue for screening, it's an issue for you know all endoscopy services, so, and that's quite good too, it's kind of had an impact on the symptomatic side as well”*

**Scottish National Screening Office**

## 2.12 Links with local Trusts

Links with local trusts proved to be essential component of quality management. Partially this was because these quality issues crossed pilot/trust boundaries and when problems occurred strong local links proved invaluable.

*“Stakeholder: I think involving trust management more would be something that was, with hindsight (something we) learned, we would have involved the trust management more in managing the actual you know pilot site, or monitoring what was happening there.*

*Interviewer      What has been the side effects of (local trust management) not being involved?*

*Stakeholder: It just sort of tended to be if there were things that weren't working as well as they should have done, trust management didn't know about it until we told them about it. I think if it was rolled out we would want trust management to be more proactive in that, that they would actually be, you know if they were a trust that were hosting a kind of like call recall, within the colorectal cancer screening programme, we would actually expect them to be acting first, and then advising us you know what action they've taken.”*

**Scottish National Screening Office**

Also, although problems often revealed themselves through the quality management framework, once these were unravelled the solutions necessary were systems solutions that needed attention at Trust level.

*“we experienced many difficulties until we got real management engagement in this”*

**Non-Clinical Trust Staff**

### **3: General management issues**

#### **3.1 Commissioning and strategic management of pilots**

An initial assumption was that colorectal cancer screening would be ‘just like breast screening’. But experience showed that the scale and rate of FOB testing made significant difference. Thus, at the end of the Pilot lessons had been learnt but there was a feeling that to roll out to a full recall system would be different.

*I think the organisational logistics of colorectal cancer screening are huge in that the population that has to be invited is different from the other cancer screening programmes that we’ve got established, like breast and cervical, because you’re inviting almost double the population, men and women.*

**Member of Scottish National Screening Office**

The contrasting management styles, formal versus informal, at the two sites has already been discussed. In Scotland the pilot was implemented informally by clinical champions, based on assumption of good networks, systems and protocols allowed to develop from (clinical) practice, rather than being management driven. This had consequences for strategic management at a local level which included the relationships between the pilot and local trusts.

*“when the pilot began to bite insofar as affecting other parts of the service were concerned, and although it’s all right now, (informal management at the outset) lessened people’s predisposition to be helpful I think, because it was seen as being somebody’s creature rather than being umm institutional, if you like.”*

**Non-clinical Trust staff**

Formal project implementation methods were used at the English site. Thus, management structures progressively tightened during the implementation phase but as the pilot matured managers of the English pilot site took over strategic responsibility. The reverse happened in Scotland. The importance of relationships to local management only became apparent as the pilot had to face certain issues. In the retrospective interviews a clear view emerged of the best model for strategic management for Scotland. This model is a hybrid of the two pilot site models since it relies heavily on clinical champions but acknowledges the importance of engagement within the strategic management of the Trust.

*“we’ve got an example now since then of cancer networks being set up which have gone in the other direction, it has been a very strongly set pattern which has been implemented across Scotland with full managerial input at the beginning, but with very very powerful clinical champions and it’s worked better umm in the sense that it’s been a much more organised approach.”*

**Senior Manager in Scotland**

*But I do think for me it’s probably made me realise that maybe using a more formal project management structure would have been a good idea umm. You need to have more local control, and more local management, like trust management.*

**Scottish Screening Office**

#### **3.2 Management of capacity**

Although commissioning of the pilots assumed that capacity issues could be managed, these became a dominant feature of the pilots as colonoscopy rates were higher than planned and waiting lists lengthened.

Throughout the interviews there was a theme, repeated by many stakeholders within the pilot sites themselves, that a major constraint on screening was the issue of capacity in symptomatic services. All pilot site stakeholders had experienced the impact of pressures on colonoscopy services within the pilots; some because they were dealing with anxious patients, others because they were negotiating with local services to find spaces or manage throughput. These issues were summarised by one of the pilot site Clinical Directors thus:

*The problem is nation-wide, and we've talked about it nationally, and we've talked about it at national conferences and steering groups. Endoscopy services all over the country are under immense pressure, and some places are worse than others. And waiting lists for endoscopies, for colonoscopies for instance, can be 6 or 8 months. ...This is for diagnostic ones ....the roll-out sites would have to be selected carefully as being sites that have capacity to do the colonoscopies, and that it would not damage the other service”.*

**Pilot Site Clinical Director**

*And it's not just capacity in terms of space, because you can always be innovative about time, and have evening sessions, and weekend sessions. It's capacity in terms of people to do it, endoscopists and nurses.*

**Pilot Site Clinical Director**

At the outset it was postulated that there would be an impact on radiology services and provision was made, within the framework of piloting, for extra double contrast barium enemas to be performed should colonoscopy be incomplete. In practice the anticipated volume of DCBEs was not reached. However, it was noted that there was still potential for disruption of symptomatic services even with low volumes of DCBEs. In addition, the logistics of failed colonoscopies caused concern as patients would need to undergo two bowel preparations unless co-ordination of services was such that a same day radiology slot could be made available in the event of a failed colonoscopy. In practice, it was observed that the most difficult group of patients for colonoscopy offered the most challenges for other diagnostic tests since these cases were most likely to have pathology such as diverticular disease or significant co-morbidities.

A further point was made about strategic management of capacity by many interviewees from different perspectives. This point is best summarised by the following quote:

*And if you look carefully at the amount of time for instance an endoscopist spends endoscoping, you'll find that there's more gaps between cases than time spent actually endoscoping. And, and it's the same for the nurses there, and you find nurses are doing jobs that could be done by support workers, and doctors and nurses are doing paperwork that could be done by secretaries, and if they were freed from doing those jobs, and this is a system problem, if you looked at the systems in the endoscopy departments you could make those, you could get a lot more work through in the same time by thinking about how you're doing it, you could oil the wheels as it were.*

**Pilot Site Clinical Director**

These observations are a familiar situation in limited resource systems. This can result in highly skilled professionals spending time on routine unskilled tasks such as paper and patient chasing.

Many of the stakeholders in the retrospective interviews also identified the potential strategic importance of the Cancer Networks in supporting colorectal cancer screening. Their role was seen as highly influential, particularly in setting and achieving quality assurance goals. Another key influence that was identified in the retrospective interviews was local ownership of aspirations, targets and standards.

### C.3.3 Models of Service

#### **FOB testing**

Several interviewees mentioned the possibility of developing an industrial scale testing centre for FOB testing. For example, in Scotland, it was hypothesised that one unit could do all FOB testing supported by more local pathology and colonoscopy services.

*Yeah, well certainly for Scotland yes. I mean whether it would be feasible for the whole of the UK, I don't know, but for Scotland I'm quite convinced that it would be feasible to run it from a single unit. And in terms of, one of the things we have learned about screening is that quality control is essential. And it would be much easier to monitor quality from a single centre. So certainly that is my opinion, and certainly the opinion of our biochemists with whom I work closely.*

**Clinical Director of Pilot Site**

#### **Colonoscopy**

In the light of the strain on the capacity of colonoscopy services, many interviewees drew attention to the following two issues, the national shortage of qualified colonoscopists and the limited facilities currently available. Two solutions were proposed. First, there were no dissenters to the concept of increasing training for nurse colonoscopists to further extend skills from flexible sigmoidoscopy, working under the supervision of a surgeon able to intervene in the case of an adverse event. Nurses were enthusiastic about the extended role of nurse colonoscopists, particularly in terms of care pathway and continuity of service.

*"Well you know if you say a couple of nurse endoscopists per network population, and they could probably do a full week's worth of colonoscopy. And I mean I'd have probably the two people covering each Trust over the patch, so that you got a sort of continuous service, and continually maintaining the skills, and bringing the protocols and processes closer together, the quality assurance stuff"*

**Nurse Manager at Local Trust**

However, this would need further investigation before a roll-out of this model. Arising from discussion of facilities, a second idea put forward for Scotland was a mobile colonoscopy service, based either on a mobile colonoscopy "trailer" or mobile colonoscopists using local facilities. The attraction of such a service was perceived to be management of quality based on the development of highly skilled colonoscopists but disadvantages would include the need for teleconferencing facilities, for example, to provide input to local clinical decision making, usually done at multi-disciplinary team meetings (MDTs) within Trusts.

*Now having people centrally placed is good from, and super-specialists and in super-specialist centres, it's good from one point of view, but it's not very good for getting them to MDTs in the periphery, unless you're going to have you know video links, and you know high resolution links, and you can actually look at the slides, and you don't need to be in the same place, you can actually be somewhere else, conferencing facilities. And then you need think about colonoscopists the same could be said with the colonoscopists, why not have peripatetic colonoscopists.*

**Clinical Director of Pilot Site**

#### **Pathology services**

During the interviews a strong argument for a clinically-led screening service was made, based on the quality issues relating to colonoscopy. Again arguments were made for a mobile pathology service. As quality and ownership are closely related this issue was discussed with stakeholders. One view was that clinical leadership could rotate throughout participating Trusts with, for example, a two year tenure but that the suggestion was feasible.

#### **Radiology services**

Within the pilot sites some DCBE services are provided by radiographers who manage examinations and report jointly with radiologist. Although most discussion centred around the possibility of training nurses to perform endoscopy, respondents in the sites also raised the issue of training radiographers in endoscopy.



## 4 Human resource management (HRM) issues

Many of the human resource issues relating to the pilots arose from the capacity issues already discussed in this report. At the heart of these capacity issues are the national shortages of key personnel; estimates by the Royal Colleges are that nationally 400 extra pathologists are needed currently and over 500 radiologists, similarly surgeons from most specialities are also in short supply.

### 4.1 Roles of professional staff

At the start of the pilots, the majority of concerns centred around the perceived shortage of colonoscopists and/or availability of facilities for colonoscopists (where sufficient staff were available). These concerns remained throughout the pilot.

However, as experience grew within the pilots a shift of position of many medical staff occurred towards the idea of other professions easing the burden of shortages in colonoscopists and radiologists, for example

*So I think that it's going to be particularly the role of the GI physician to take on the more complex, the more difficult, the interventional, and the less complex and routine endoscopy should be done not by doctors at all, should be done by nurses.*

#### **Pilot Colonoscopist**

This was a common local perception in the English pilot site since one of the key individuals involved in initiation of the pilot bid was a champion for nurse endoscopy and there was local experience of an extended role for allied healthcare professionals. However, others warned that capacity issues, especially the shortage of colonoscopists, was not so easily solved.

*I think there's going to be need and space for both (nurses and doctors undertaking colonoscopy). But you don't become( )you don't become a skilled endoscopists, particularly at colonoscopy, in a year or two. You know, it's going to take the nurses I would say upwards of 5 years before they acquire the level of skill that is required to perform well within the screening programme.*

#### **Colonoscopist**

The expectation of increased pressure on already stretched colonoscopy services featured in many of the prospective Scottish interviews. The reported need for an increase in both colonoscopists and colonoscopy facilities was clearly reinforced within the pilot sites by lengthening of waiting lists and by a capacity survey undertaken by the Scottish Health Board. The retrospective interviews confirmed the speculation in the prospective interviews.

### 4.2. Support staff

At the outset of the pilots each site specified its own staff and skills complement. In both pilots this was predicated on the delivery of FOBt kits and estimates of the number of positive tests that would require colonoscopy. A minimal number of support staff were specified at clerical level. A key result of this was that, as the administrative burden increased (with information systems and activity monitoring developed), the main responsibility for maintenance of many of these systems was added to the tasks required of individual members of professional staff. This had several important consequences.

For the Scottish pilot, because the computer information system provided support for only half of the total patient pathway a paper system was devised to supplement the gaps and a paper mountain rapidly developed. The clerical staff had neither the skills nor the training to deal with this and the problem was shelved until crisis point was reached. The crisis was partially resolved by an additional PC based information system and consultation with a data specialist. However, a vital component of the information system remained dependent on paper-based systems, co-ordinated by link nurses in the local Trusts where colonoscopy was performed. These essentially clerical tasks were undertaken by nurses in addition to their clinical workload and this led to considerable delays in completing datasets for each patient. The resulting impact on quality assurance was an unresolved issue at the end of the pilot.

For the English site, the centralisation of the nursing staff at the pilot, possible because the geographical distances were much less than in Scotland, allowed a culture of sharing of tasks to develop. This was most obvious for the Helpline. In both sites, however, the sheer volume of data and the task of data entry was seriously under-estimated and at certain times both sites had to devote considerable human resources, often using professional staff to catching up on routine data entry.

The massive data collection exercise involved in the pilot placed a serious administrative burden on clinical staff. This revealed itself in two ways, firstly the amount of incomplete data reported in the data sets and in the retrospective interviews, especially interviews with the nurses who spent a substantial amount of their time chasing paperwork.

*“Umm I think I’ve got it down to a fine art now, where I actually physically take these datasets, when the patients are coming into surgery, to the consultant’s secretary, and then she holds onto them, and then it’s just a case of when I know those patients are in I just keep knocking on the door and saying have they been done. And I do get them done. I think I’ve pretty much got it to the best of my ability really..... But I think we have spent a lot of laborious time checking data on the computer system. And I think that is a waste of nursing time.”*

#### **Screening Pilot Nurse**

This is not a clinical task and there was a consensus across both pilots that the solution was two fold. Firstly, clerical assistance should be given a higher priority for investment, especially at local trusts. Second, IT systems should be specified to minimise duplication of paperwork.

### **4.3 Role of nurses**

The use of nursing staff necessarily differed in the two pilot sites, dictated by geographical considerations. As a consequence the centralised staff in the English site were able to provide support for sick leave and annual leave. In Scotland the screening nurses were very isolated and cover was not immediately available.

Within the English pilot, although the nurses were employed as screening nurses, their role became integrated within the local services to which they were attached. In both pilots the screening nurses provided a vital liaison between the service and the patient, the service and the GPs, and between the screening unit and symptomatic services, particularly local colonoscopy services. As the pilots developed the roles of the nurses at both sites developed into five main components:

- managing clinical aspects of patient pathways through the system;
- managing patient satisfaction at all stages;
- managing data flows through the system;
- liaison and early intervention between Trusts and pilot sites;
- liaison and intervention between services interfacing with the pilots.

The team working aspect of a centralised service was identified as the key to success by the nurses from the English pilot and greatly missed by the nurses in the Scottish Pilot.

*“I mean we work together closely as a team. I think if you did, if we have any problems then we can always go to (screening manager), and she’s always really good at listening and helping you out”*

#### **English Pilot Nurse**

It was acknowledged by several interviewees in Scotland that the English model was effective and, in particular, prevented the isolation experienced by the nurses in Scotland. The main advantages of team working were identified as:

- cover for CPD, sick and maternity leave;

- increased training opportunities;
- sharing of responsibilities, trouble shooting and problem solving;
- better communications within team;
- clearer identity;
- clearer focus for information;
- less isolation.

On the question of whether liaison nurses should belong to local trusts or the screening service, mixed opinions emerged. There were perceived to be advantages of belonging to the local trusts

*“And belongs to that hospital, I think that would be a lot better idea. Because to be fair the way that I run it compared to X or Y is so very different, and it’s only through, okay we started the job equal the same, but each hospital has its own way of doing things.”*

**Pilot Nurse**

But equally there were advantages of belonging to the screening service, mostly experienced by the nurses at the English site. However, it was also observed that there was a strong case to be made for integration of roles, so for example, it was envisaged that Colorectal Specialist Nurses or other cancer nurses might take on the role of screening nurses where it was not feasible to have a centralised system such as that developed at the English pilot.

All the screening pilot nurses talked about the importance of integration into the Cancer Networks on a day to day basis.

*“Yeah, I mean I can see in the future, I mean at the moment we have a specialist colorectal cancer nurse service, and although our screening nurse is sort of part of it, she certainly has a very defined role, and the others don’t get involved with screening. But I can see in the future that you know that say in a big hospital that has you know maybe 4 specialist colorectal nurses, then there could be a certain amount of job sharing there. And I know that’s particularly important at holiday times as well”*

**Clinical Director of a Screening Pilot**

#### 4.4 Training

Both pilots gave serious consideration to training their staff at the outset of piloting. The one notable exception were the pilot nurses in Scotland *“But I do think that the nurses got minimal training, they didn’t actually really get training, they got information about the pilot.”* Naturally, there has been staff turn over and cover for illness, maternity leave etc, throughout the pilot and less thought has been given to induction and training for newly recruited staff. Pilot managers, in most cases recognised this and attempted personal inductions but documentation about the pilot was not always readily available. This is understandable as the pilots were viewed as a one-off project. Consideration should be given to a training pack for each site for the second round of screening, as some staff suffered from the problem of “learning on the hoof”.

**Supplement S7 Summative analysis  
(Information Systems) (Chapter 7 in Final  
Report)**

## 1. Introduction

The results will be presented in two ways. The issues arising from the modified thematic framework will be identified in order. Some general overarching results will then be discussed to complete the analysis (*mapping and interpretation*), and these will be presented as key issues should the colorectal cancer screening programme be extended and rolled out.

## 2. System specification

Process of developing system specification

At the start of piloting for a potential Colorectal Cancer Screening Programme, wide consultation resulted in a National Screening Committee Workbook appraising the evidence for colorectal cancer screening and outlining current consensus on the main features of any potential programme. This workbook, colloquially known as the “Green Book” (Garvican 1998) envisaged that information systems would be PC-based and would provide the dual role of pilot management and also be capable of producing performance statistics.

In more detail the Green Book included some discussion of the scope of information system/s related to colorectal cancer screening programmes: Some of the functions the system would include are shown in **Table S7.3.1**. The Green Book had been developed through a comprehensive consultation process and was an important document in terms of representing a consensus view. What quickly became clear to those developing the piloting was that the Green Book was not a document capable of operationalisation. This point was independently recognised by both Scottish and English Screening Offices and the pilot sites. Nevertheless both offices were also conscious that their experience in breast screening could be used to pilot the colorectal cancer screening information system:

*“ we did, at the start of the development of the colorectal system, involve the breast screening people from the Trust” as “.... there are strengths and weaknesses in the breast screening system that you can learn from..”*

**Senior Manager, English National Screening Office**

And those who were assisting in developing the objectives for the system valued the experience of the breast screening programme compared to the content of the Green Book.

*“...but one of the key people to have around was someone that had been through a similar pilot roll-out and was able to eloquently bring out a large number of issues that nobody would have thought about, certainly not in the Green Book.”*

**IT Consultant**

The value of these early discussions to extend the Green Book underlined the importance of defining the objectives and scope of the information system “...it was only as we got into the practicalities, that it would have been hard to think through theoretically, that we were uncovering issues...” Project Manager, English site. These early discussion, using the Green Book as a foundation and consulting those with piloting experience, were an essential part of the process as recognised in the definition of the functions of an information system (Jayaratna, 1994).

One of the most crucial influences on the development of the IS at this stage was the experience in project management brought to the process by the English Pilot Site Team. Indeed it was recognition of these skills which formed part of the decision to pilot in Coventry and Warwickshire. The English site identified the development of the IS system as pivotal to time-scaling for their Project Management Plan and the local Management Team brought in an IT Consultant (an ex-IT Director of the Trust) to scope and advise on the IS component of the pilot. This Consultant recommended that the most efficient approach to the project would be to use an approach referred to throughout the pilot as Information Modelling. The first two strands of Jayaratna’s description of an information system, viz: *...efficient and effective means of identifying the “real” needs of the users and developing information processing systems for satisfying*

*these needs* were undertaken. In fact, the English pilot site proposed that this exercise was done for the piloting process as a whole. The attraction of this approach was recognised by both National Screening Offices and both pilot sites, and this phase of development of the IS was a joint undertaking. This provided a very efficient means of undertaking this phase as the approach required few meetings but used a process which was universally acceptable and acknowledged to be useful.

### **Information Modelling**

This step introduced by the English Pilot Site, the process of defining users' needs, became known as Information Modelling; the process name assigned by the Consultants Kennedy Carter who were called in to do 12 days work. The Consultants had developed Information Modelling as one of their skills and used the process to build databases as well as produce complete Information Systems. This approach is recognised and well accepted in the IT industry and is used to develop complete systems, which can include database/s, web-based applications and manual systems. It is important to recognise that the Consultants considered that a database can be build directly as the end of the product of Information Modelling process.

*...(we are) providing consultancy in translation based development techniques which means building a model or set of models of a system in a rigorous and precise fashion that will turn into code automatically.....*

**Consultant from Kennedy Carter**

One of the questions arising from the interviews was how far the various individuals and organisations shared the vision of what could be done by Information Modelling. Undoubtedly, the Project Managers at the English Pilot Site knew what they were expecting and could envisage the point at which an Information Model became an Information System.

*It's worth noting that nobody, as far as I know, apart from perhaps the (English Site Consultant) at those meetings was familiar with the information modelling techniques and notations....*

**Consultant from Kennedy Carter**

To others not familiar with the process, it was not evident that they understood the process to be other than identifying key processes and data items. Particularly, in Scotland it was tacitly accepted that SchlumbergerSema would be undertaking the development work since the data used for call and recall was on the centrally commissioned Community Health Index (CHI) system. They were present at the meetings with Kennedy Carter but were operating within the constraints of their quality managed system developments. Thus, the specification understood by the personnel from SchlumbergerSema was from their perception;

*.....we've got the specification, and it was a one line statement. Things like call men and women between the ages of 50 and 69, that was like one process, go and do it. The next process was invite the people for first time kit, then that would be another process.....*

**Software Developer from Scotland**

Thus, although those commissioning Kennedy Carter saw the product of Information modelling as “...it's basically a definition of a problem in information terms, but from an information model point of view rather than a process point of view...” a specification of process was carried away by the Scottish development team.

Jayaratna's definition of IS recognises the need for efficient processes of development. Was the approach adapted by the pilots efficient in IS terms? It was the opinion of all those involved that the 12 days commissioned from Kennedy Carter was worthwhile and that the process was efficiently completed within this period. All those who participated in the information modelling saw it as an essential part of the process and one that must be replicated in more depth if roll-out is recommended.

*It's an aid to a thought process and it very much I think helped us in that. We had it in front of us in a number of meetings. We talked it through and it raised all sorts of issues that needed thinking*

*about both in Scotland and in England and from that point of view I think it was very, very helpful. I think the IA involvement at an early stage from that point of view was useful as (they) were asking all sorts of questions based on the model.*

**IT Consultant**

### **The end point of the screening process**

A crucial issue at this point is where those developing the systems saw the end point of the IS. Involving those from the Breast Screening Programme had proved worthwhile in terms of capturing past experience and modelling process. Thus the information modelling process identified two potential end points within the process 1) after registration of result from returned FOB test, and 2) at the time of colonoscopy<sup>4</sup>. Thus, the end point/s of colorectal screening and the interfaces between the colorectal IS system and the hospital patient administration systems offer the potential for different interpretations, particularly when priorities were being set by outside contractors who had been offered finite resources and a limited specification.

*“The system stopped, er, could be a couple of end points I would say. If the result was negative, say if it was just a one off negative result, then the patient screening process stopped there or if the patient went to what are called the clinical side, where it went to the nurse colonoscopy or surgery etc they could have stopped there, so there’s various end points.*

**IT Consultant, Scottish Site**

The vision in Scotland quickly resolved into a two part system:

*Stakeholder: Okay err we were commissioned to do is call all women and men between the ages of 50 and 69, that they would receive a kit through the post and this kit will be sent out to them. The kit will be tested and sent back into the system, and from there you may be given an appropriate result letter. The result letter may generate another kit, or it may generate what we call a nurse appointment, where you’re sent for further analysis.*

*Interviewer: Okay so the stop point was, as far as the commissioning was concerned, was the point at which the patient was passed over to colonoscopy.*

*Stakeholder: Yes, yes really.*

**IT Consultant, Scottish Site**

In England, by contrast, the IS remained as a more holistic system:

*Certainly we were very keen in England to develop a system if at all possible that really supported the process and that means it's got to take, you know, it's got to do things more efficiently and more effectively than you can do manually and in a way that produces sensible information. Because a lot of this - partly because it was a pilot and partly because it was a clinical process anyway - the clinical information that you are recording and the process information that you are recording on the way - if you record it properly and effectively the bi product of that is that you get good information for all different purposes : for evaluation, for clinical management, for process management.*

**IT Consultant, English Site**

*The clinical process I think with any such systems is the paramount thing because at the end of the day you are dealing with individuals' personal health and obviously in something like colorectal*

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<sup>4</sup> In diagnostic terms the definitive period of diagnosis of colon cancer is not a point but a period of increasing certainty starting with the suspicion of cancer on seeing lesions through the colonoscope to confirmation of the pathology of the tissue sample after histology. Thus, within a screening programme there can be said to be three possible end points, 1) sending out of letter to patient informing that there is no evidence of FOB, and 2) completion of colonoscopy which is classified as No abnormal diagnosis. The third end point blurs for those with suspicious lesions as they move onto a diagnostic phase after a positive colonoscopy, with possibly many diagnostic tests to confirm the diagnosis.

*cancer you have got some things that need very immediate attention if diagnosed. So again, you want your information systems to really flag up where you have got positives and things and in all of the appropriate places so that the appropriate action is taken, the appropriate letters are sent, the appropriate follow-ups and reminders and so on. So I think the clinical side of it is probably more important than the administrative side.*

**IT Consultant, English Site**

Given the different vision it is not difficult to see that, with limited resources, the Scottish system would evolve as an administrative system to get the kits and results to patients and the English system would attempt a more seamless solution.

### **Specification creep**

One key problems, well recognised within the IT industry is “specification creep”. This arises as a client's thinking and perception of the systems under development changes “with every change in desired state and or current state, there may be corresponding changes in the problem definitions and notional systems” (Jayaratna, 1994). This was observed by several people involved in the piloting process, typically:

*We did experience something that is so common to IT projects that it almost goes without saying (it is certainly not specific to this project) - the phenomenon of the 'growing specification'. We started with a simple specification that could easily have been handled by a download from the population database, an Access or similar screening office system, and a lot of administrative support. However, as the development began and users were shown the prototype in progress, the more ideas they had and the more they requested from the system.*

**Screening Office Personnel**

In theory at least, the information modelling phase should have minimised this phenomena. In the event the systems development methodologies adopted in both Scotland and England appeared to keep the specification contained. In one key respect this was not the case resulting in huge forms that were difficult to complete, and this will be discussed further when clinical data sets are considered.

### **Information modelling and quality standards**

All those interviewed regarded the joint development of the two pilot sites as having a strong influence on the quality of discussion and outcome for the definition of standards for colorectal screening. The Green Book did not have as much influence on defining quality standards as reference to other screening programmes and the expertise of the Screening Offices themselves.

*“We drew a lot on the Breast Screening experience and we are happy that we correctly identified quality standards.”*

**National Screening Office Team**

Early in the process, however, a dynamic tension appeared between those who wanted to monitor system quality and clinicians who were interested in the evidence that could be gained from the pilot patients. Thus, on the one hand there was a need to keep a minimum data set for quality purposes but on the other hand not miss vital clinical data.

*“Interviewer: as research clinicians you wanted to collect as much data as you could?  
Stakeholder: Yes, that's partly why the datasets are as big as they are..”*

**Scottish Pilot Site Team Member**

The format of the piloting process allowed an exploration and full discussion of quality standards throughout the lifetime of the pilot, without fixing these ‘in stone’ from the beginning. Staff from both Screening Offices were not satisfied that all the quality standards that were useful had been identified until later in the screening pilots. In addition, some quality standards were slow to emerge from the wealth of data that was collected.



*Well, because of the speed with which we set it up we concentrated on processing patients and collecting data items and producing analysis later. So we had a lot of data sitting there, that we could get hold of, for a while.*

**Scottish Pilot Site Team Member**

The Objects within the Information Model are identified in **Table S7.3.2**. As can be seen from this Table, there are no specific objects relating to the post-screening treatment. However, this is the only phase of the patient pathway in which the results of histopathology of colonoscopy samples can be confirmed. This part of the data set, although vital to the evaluation team in terms of the number of cases detected and a crucial primary outcome measure for both the Pilots and for any potential screening programme, was not revealed by the Information Modelling process. The English pilot site nursing staff who were following processes very carefully noted the absence of this data and developed a paper system. However, the Evaluation Team report of February 2002 noted

*“It is clear that pathology data are not being adequately captured by the screening offices. The situation is much better in the English pilot; here the use of on-going audit of invasive cancer cases is clearly useful. However, we urge both pilots to computerise the results of all pathological analyses of resection samples.”*

**Evaluation Team Report, February 2002**

A useful exercise for the post-piloting period will be a re-convening of the team who originally produced the information model, for one meeting, to capture this learning.

#### **Infra-structure issues**

To understand the differences in the way the systems developed and have been used in the two pilot sites, it is essential to understand the context in which both pilots were developed. The unique features of both systems, and the progress of their development, was strongly related to this context. Indeed, the context produced a marked divergence of aims for the two software development teams, after the information modelling phase, which resulted in significant differences in the installation and the product finally installed at the two pilot sites.

In Scotland the register to be used for the screening programme is held and managed centrally by a large IT Management company, SchlumbergerSema, under contract for NHSE Scotland. This company runs the Community Health Index (CHI) a complete database of persons registered for healthcare in Scotland. The Scottish Screening Office commissioned this company to develop the colorectal cancer screening system.

SchlumbergerSema negotiated a contract with the NHSE that detailed contractual agreement about any software development methods that would be used for commissioned projects. Specifically, the company has an approach which protects against “programming” errors and tests the robustness of the software at each stage of development, and during implementation, and also regulates changes to maintain safe and continued operation. The methods used are robust in terms of documentation of the development, and in their team working methods, so that the development is protected against loss of systems or personnel. As these methods are enforced by contract, new applications such as the colorectal cancer system are governed by contracts.

*“The fact that it was going to be based largely on pre-existing legacy systems they already had meant that a lot of the design was already constrained.”*

**IT Consultant**

Thus, although the methods used are capable of producing software very quickly, the rigidity of the contract means that faster implementation equates with higher cost since more people have to be used to produce the “programmes”. The consequence for the colorectal Pilot, with a limited budget, was that the team from the company were constrained in the software they could produce. In effect, a tacit agreement was reached during discussions that the limits of the *software development* would be to produce a system which was capable of identifying those at risk, issuing invitations and tracking the returned kits, and registering the results of the FOB laboratory test. The time scales for this were explicit:

**In the Scottish site:**

*“Basically the NHS came to SchlumbergerSema and asked for the system to be written in something like a month. We thought it just couldn’t be done within a month. Because that was various techniques and methodologies, and we used the what we call the mainframe experience”.*

*Yeah, basically everything was all geared towards time scales. You know like they wanted to make the call recall done within a month, we gave them it in two. Then they wanted, the NHS in Scotland wanted the clinical servicing done, I really don’t know the time scale, but I knew it was quite short.*

**SchlumbergerSema**

Thus, in Scotland, although the Information Model had been shared, only part of the IS delineated as necessary by the model was developed.

*The big emphasis that we put on was getting the patient selection right. And being able to issue tests and slightly less emphasis on what would happen if the test came back positive and subsequent monitoring reports.*

**Scottish National Screening Office**

This computer-based system was produced very quickly and proved to be robust to failure, exactly how the development method was designed to perform. SchlumbergerSema also provided good support for the system with the software developers in close, sometimes daily contact with the Screening Office Team. The part of the Information System that recorded process and activity after laboratory results were available developed organically and piecemeal as user requirements were identified. The later part of the ad-hoc IS was partly developed by SchlumbergerSema on a PC platform and partly as a paper-based system. The strategy of developing a PC-based system was driven by the nature of the contract with the NHS. At a central commissioning level the NHS had negotiated a contract which secured robust software development.

*Basically we’ve got three sorts of testing phases. We’ve got our grid test, which is your first time you’re working on a problem ..... Then you go through your unit test. Then you go through a systems environment, which is totally discrete from your unit test. And your systems environment usually someone else tests your work and goes through all the tests that you’ve done, then.*

**SchlumbergerSema**

The contract precluded SchlumbergerSema producing the second part of the system, identified as the “clinical system” in the same manner and on the same platform as the “patient call system”.

*The clinical system was developed by another team. And as soon as we had finished the, what I call the call recall system, round about February the clinical system took off.*

For the English site a different approach was adopted. The contract for development of the IS was given to the NHS Information Authority. They were presented with the Information Model and asked to implement this specification. The information model envisaged that a software system could be developed that would support the whole process described in the model, through to completed colonoscopy. The hardware platform on which the software was to be mounted was also considered. Taking an approach, also implicit in the information model of future proofing the development because roll-out might occur, a browser-based system was strongly suggested by the model.

Browser-based systems have the advantage of being platform-independent, i.e. not dependent on the hardware or operating system on which they are implemented. Thus, the system developed could be used in most locations and rolled out with minimum investment. Prospectively, in terms of the pilot site a browser-based system also had the short term advantage that access to the system could be from any remote location. An additional small point was that the graphics of browser-based systems are such that it is much easier to produce a good looking, user-friendly presentation of the system.

The issue of remote location is important as the IT at University Hospitals Coventry and Warwickshire is centrally supported and the hospital policy is to have all software and core hardware (servers) at a central location where back-up power can be provided and security can be maintained at the highest level. Thus, the constraints at the English pilot site suggested that a browser-based system mounted at Walsgrave and secured within NHSNet would be modern, future-proof and capable of extension to other locations, should roll-out be decided upon. On the face of it this was the most appropriate choice for the system and one that had the best long term advantage. Discussions with NHSIA during commissioning by the English National Screening Office also included the short time scale available for the pilot and time-scales similar to those suggested by the Scottish Screening Office formed part of the constraints on the contract. Unlike SchlumbergerSema, this was not seen by NHSIA as a constraint, as they were not contractually bound to the same safety systems. This, therefore allowed freedom of choice in the software development methodology. As the information modelling approach was already a part of the IS development a logical conclusion of this process was a modern IT development technique, known as Rapid Application Development (RAD). This approach may have been attractive because it is fast and includes the user as an intrinsic part of the process<sup>5</sup>. Information modelling can be seen as one of the front ends to this approach, well tested and accepted in the IT industry in the UK (Silagy) indeed the consultants Kennedy Carter would have used a variant of this approach had they continued. Thus, appropriate application software, and an appropriate development methodology, was chosen within the context of the English pilot site, the information model and the potential future of the pilot for England.

*“To be honest, I’m beginning to think they really did know what we wanted, they did understand what we wanted.”*

#### **English Pilot Site Staff Towards the End of The Piloting Process**

##### **Equipment specification**

Part of the process of development of the IS was to scope the peripheral equipment required to support the processes. Thus, large volumes of letters were necessary and communications with patients included various components such as the kits, instruction leaflets, return envelopes etc. Equipment purchase was left to the individual trusts and the two sites chose different systems. Both sites suffered some teething problems but individual purchase specifications suited local circumstances for example, in terms of user support.

Printers were an issue at both sites although for different reasons. In Scotland the letters were often of very poor quality because SchlumbergerSema, who operated large scale printing facilities linked to the CHI system at a site remote to the screening unit, were supplied by the NHS with printers which were very out

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<sup>5</sup> The Pilot Commissioners for the English site requested that we did not interview the IS developers. However, this superstition has been confirmed by those who were observers, managers or users during system development.

of date technology. In fact these dot matrix printers were replaced soon after the start of the pilot. Nevertheless, the Scottish pilot started with a print quality which should have been regarded as unacceptable for any age group, but particularly older people.

In terms of the equipment used to collate the patient communications, collators, bar-coding equipment etc. so much is dependent on local circumstances, expertise and support that the experience of the pilot sites can be of limited assistance to other Trusts. Bar coding the kits was efficient for the English site and the common lesson was that both sites under-estimated the volume of letters and thus under specified the robustness of the equipment. Details of the equipment purchased can be found in the Post Pilot Workbook produced jointly by the Pilot sites and Evaluation Group.

During retrospective interviews many respondents identified that the bar coding system had been an effective method of handling test kits and Commissioners in Scotland were considering installation in Scotland for the second round of screening.

*“The only thing I would say about that is the laboratory, it would be better if we had things like barcodes etc, we don’t have that, and that was that’s the other problem with our mainstream system, we would have to change it to have the capacity to use barcodes.”*

**Scottish National Screening Office**

### **3. Systems evolution after commissioning**

As seen in the last section, the development of the IT systems fulfilled the first of Jayaratna’s criteria for an information system in that “real” user needs were identified efficiently and effectively. Since one key aim of the pilot process was to explore aspects of operationalising the trial findings on colorectal cancer screening, the changes that evolved with use of the IS provided crucial data. It was not an expectation of the commissioners that the systems developed would be suitable for running a national programme;

*Stakeholder: The pilot was only ever set up to, if you like, call those eligible within the relevant populations, once only. It wasn’t set to be a call and recall system. So it was like, it was like a lower level.*

*Interviewer: So there didn’t seem any need at that point to go into sort of what you see as an all-encompassing system.*

*Stakeholder: No because in fairness, it was a pilot and the pilot may have been unsuccessful and to spend millions in terms of procuring an IT system would have been inappropriate.*

**IS Commissioner**

However, the same stakeholder described the tension between an investment which produced a system which performed properly for the pilot and the possibility of the system never being used again. ... *it’s a tricky balance with public money*”. In terms of those developing the IS one of their design criteria, particularly given the scoping of the Information Modelling, was that they should (using Jayaratna’s definition of the function of an IS),

“ensure that the resulting information processing systems continue to satisfy changing user needs by the most efficient means of acquiring, storing, processing, disseminating and presenting information”.

How the system evolved after implementation is therefore as important as how it was commissioned.

Do the systems do what they were designed to do?

One primary objective of both information systems was to provide all the components necessary to identify and despatch FOBt kits and follow-up with information on returned kits, spoiled kits and non-responders, etc. Both systems performed these functions with few hiccups, other than the teething troubles that would normally be expected.

For the English site hardware interface issues were a problem, as communication with the server was slow even when the system held relatively few records. Mounting the software on a web-based platform, remotely accessed by the Rugby site from the server in Coventry, was only partially successful. Although this method was possibly efficient for both Walsgrave IT Support Staff and NHS IA in terms of software development and support, the approach was less satisfactory for the users. Furthermore, NHS IA staff could not necessarily replicate the user's experience remotely. As staff changed and those who had not been directly involved with commissioning took over management of the English and Scottish pilots frustrations with the system were articulated, particularly with the speed of the system in England and the data backlog in Scotland.

*.... in the last few months, we arranged for the IA to come up. Both \*\*\*\*\* and I said, "Look, we're new to this system we've inherited. Why don't we speak to you because you've developed it and we've, you know, we've moved on now and we're doing different things. Can we come down?" And they said, "Well, it would be far easier if we came up." So three of them came up and it's the first time that they've ever seen our system working.*

*Well, they can see so much of it when they get into it, but they have problems getting into it as well sometimes when it's slow. They've got everything on site you see. So when they travelled up here they couldn't believe how slow we were. He says, "Oh, this is daft". I says, "Well now you know how we feel". But having come up and spent the day with us, they saw a lot of our problems and they were, they've been brilliant really. I mean, they are really good. They do all our things quite quickly.*

**English Site Staff Member**

Much of the English system was computer-based although some processes remained paper-based. One test of the system was how easy it was to provide data for the Evaluation Team. For England this was accomplished without too much difficulty, although there were exceptions:

*And they're on paper. And they're in the bottom of the drawer, nicely ordered in my room and when the report came out and then we got that it was something like 18% positive datasets missing I said "Well, I've got 'em sat in my room".*

**English Site Staff Member**

The Scottish Call system appeared to be highly accessible to the staff at the screening centre and apart from problems with the franking equipment and the collator (resolved by Alpha producing new pamphlets) no major problems were encountered within this system. When early modifications to data screens, particularly screens relating to laboratory FOBt results, were requested during the early implementation phase these appear to have been resolved satisfactorily.

Nevertheless the vision in the Information Modelling went far beyond the call system that was developed for the Scottish Pilot. As positive FOBt cases started coming through the Scottish system, paper systems were used to track cases and this data was then entered onto the "clinical system" (the PC based system). The forms which evolved were particularly important for capturing data on colonoscopy.

*Stakeholder: the data comes back from the nurses and is put into the computer. At the moment umm we've been waiting until data sets have been complete to put them on the computer.*

*Interviewer: And you wait for all the bits of paper to assemble from the various sources before you actually put a closed episode, or put it into your computer, then close the episode?*

*Stakeholder: That's right, yeah. And the problem has been that the IT system hasn't been used. You know, we haven't been able to, it hasn't been user friendly.*

**Scottish Site Staff Member**

In fact, although the pilot nurses had identified the need for recording of post FOBt processes for patients, and particularly the need to make sure no patients were lost to follow-up, the systems that evolved were paper-based and were in addition to local clinical systems and records for patients notes. A series of paper forms were developed by various members of the pilot team. These forms were not multi-part forms so where copies were retained this was done by individual clinicians producing a photocopy. With hindsight many stakeholders, particularly in Scotland commented on the length and complexity of the forms that were required by the pilot units.

*...that's how it started off and, I mean, because I as far as I know nobody is what would be considered an expert in designing forms and things. No-one who was involved.*

**Evaluation Team Member**

*And there was no clear system of tracking missing, knowing what was missing. Things were filed and without having been entered (on the computer) etc etc. The actual collection and entry of the data didn't seem to, to me, didn't seem to have been thought through properly; there's a nurse form and a colonoscopy form, and a, and a pathology form, and a surgery form, and another pathology form. They're all generic across all three regions (and these are) single forms but several sheets, far too much data*

**Data Specialist for Scotland**

The Information Model predicted the necessity for the above processes but the contractually restrained commissioning of only the “front-end” call part of the system as identified by the Information Model pre-disposed the evolution away from a fully integrated solution. The pre-disposition of the contractual situation was further encouraged by the Scottish Commissioners placing emphasis on the patient selection and test kit issue process – see Section 3.1.6. It can be argued that had the Information Modelling system recognised this constraint and their own bias at the onset, a solution for good paper-based systems could have been introduced at the start of the pilot.

In the last few months of the Scottish Pilot this situation was rectified to some extent by employment of a Data Collection Specialist who resolved many of the problems, including identifying the most efficient way of dealing with the data backlog and the missing data on the complex forms. With the perfect vision of hindsight this “cure” arguably cost around the same as it would have done to provide a computerised solution to the post FOBt information needs at the start. Prevention rather than cure may have been more cost-effective for the Scottish Screening Pilot and the consequences of failing to remedy this situation are starkly spelt out in the Evaluation Team report of February 2002;

*“We are confident that the data which we have analysed from the English pilot are of high quality....Sadly, we are much less confident for the Scottish data.....”*

**Evaluation Team Report, February 2002**

But do the systems do what they were designed to do? For neither system can the answer be an unequivocal “yes”. However, the English system remains closer to the vision of the information model and offers a complete start to finish system, although colonoscopy forms from remote sites still need to be paper-based, the potential for access to the system through the web-browser is theoretically possible. Using Jayaratna's definition the English system has been efficient at acquiring, processing and disseminating information but the computer-based part of the system has demonstrated irritating slowness both for presentation of data and for searching and data manipulation as more storage was used (due to search routines exploring larger datasets). Thus, although all five criteria have been largely satisfied at an architecture level (although search routines must be improved) at the vital user interface the system is not presenting as satisfactory. In terms of the available data the English site have been able to either download or produce paper-based datasets for all information requested (e.g. for patients who did not have colonoscopy despite a positive FOBt).

The question of whether the Scottish system does what it was designed to do must be answered in two parts. The “call” or mainframe part of the Scottish system fulfils all the five criteria above. Acquisition, storage, processing, dissemination and presentation of the call system have all satisfactorily evolved. However, this was always only half of the system as envisaged by the joint Information Modelling process. The remainder of the IS provided by various paper systems and the PC based “clinical system” has fallen far short of what was required of it and is characterised by missing data, a large backlog, complex forms and poor record systems. The system follows the patient rather than tracking the process *for* the patient to ensure all appropriate activities are undertaken. In terms of risk management the Scottish system remained very exposed for much of the pilot as it was not possible to identify where the screening process had delayed or broken down for an individual. In practice each pilot nurse was taking responsibility for this part of the process and returning all the forms once colonoscopy was finished, leaving pathology results to follow.

This was not perceived to be an IT issue however by many of the stakeholders associated with the Scottish pilot, and the perception of processing of data not being an IS function persisted to a late stage in the pilot evolution.

*And I don't think that was anything to do with the IT system, I think it was more to do with the systems of collecting the clinical data so that it could be input. Or that the procedures for inputting clinical data did not include making sure that the data set was complete before it was input onto the IT system.*

**Scottish National Screening Office**

In terms of Jayaratna's definition the English system, paper systems and software, appear to have “supported operational and control issues” and the “colorectal call system” in Scotland also met this criterion more than adequately. The remaining issues with the “clinical system” in Scotland have been largely resolved as far as catching up on data entry. However, if roll-out is decided upon a repeat of the process undertaken with the initial information modelling may be a worthwhile investment for the Commissioners. During this process, it would also be worthwhile identifying the type of system to be used to support each function, i.e. computer or paper-based system. Serious consideration should also be given to capturing some data on hand-held devices<sup>6</sup> and using direct downloads of files through the NHSNet. The Scottish system must be developed so the “call system” and “clinical system” become fully integrated.

#### **Development of datasets**

Those stakeholders involved with the initial development of the datasets for the pilot were concerned that all the necessary data should be captured and acknowledged that more data was likely to be captured than was necessary. This was revealed in the paper records that were started, as well as data items in the software. For example;

*..... just imagine the little teething troubles or well, we need to do it that way instead of this way, and we need to record, a bit like the Helpline, I just said, we don't need to record every phone call, but we need to record the more lengthy and you know involved ones. You know it's all it's that kind of thing that we're working on at the minute.*

**English Pilot Site Team Member**

*I mean it's partly umm when they started off designing the forms, and it's a case of you know, it happens quite often in sort of research or data collection exercises, people sit down and say right what shall we collect. And it grows and becomes complex and also then the err pathologists and nurses, say what they want to collect, and everyone has their own slight interests.*

**Evaluation Team Member**

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<sup>6</sup> Hand held computers, for example Palm Pilot or Pocket Compaq series, with integral flash cards operating Microsoft CE or compatible software. It will be necessary to adhere to current data protection protocols with regard to patient identity on these devices, for example, following electronic health record (EHR) protocols.

Hindsight allowed reflection on the importance of being able to selectively reduce the datasets during the piloting process. It will be important if screening pilots for other conditions are commissioned to acknowledge the positive nature of this evolutionary approach to development of datasets and make resources available for the datasets to be wider than will be finally necessary.

*With hindsight now we look at the datasets and think oh no they're far too big, we should have had them, refined them down. But at that moment in time I think we had no idea what we wanted to collate, or not that we had no idea, but we wanted to try and get as much information as possible. But I think what we find now is that some of the data items are actually you know, we can do without.*

#### **Scottish National Screening Office**

The piloting process allowed time for the datasets to develop and discussions to take place about what was essential, as opposed to desirable, information for both quality and process monitoring. The initial perception at the start of the pilot was that things were rushed and there was no time for proper discussion. However, over the lifetime of the pilot all stakeholders began to appreciate the evolutionary approach to developing the screening programme. In particular, there was a synergy between the piloting process and national planning for cancer, which was advancing during this period in both England and Scotland. Both were implementing cancer plans; Cancer in Scotland and the NHS Cancer Plan and thus important steps could be taken to incorporate external datasets, including the Royal College of Pathologists Minimum Dataset and Colorectal Core Dataset defined in the SIGN guideline 'Colorectal Cancer - A National Clinical Guideline'.

A primary objective of the screening pilots was to record the number of cases of colorectal cancer identified. The prime outcome for the evaluation is the prevalence of colorectal cancer in the areas covered by the pilot. Nevertheless, one of the most difficult tasks during evaluation was to identify from the data collected (software and paper-based systems) the number of cases and stages of cancer in those screened.

*Interviewer: Give me some examples of that, which are the difficult data issues in your experience (of this pilot)?*

*Stakeholder: Okay, I'll give you, what example shall I give you? I don't know if there is such a thing as completeness. Just say in trying to identify the cancers that were picked up through colonoscopy. You've got various different forms and various different bits of information recorded on them, which would go from the actual results of the colonoscopy, err and then any results of the pathology from the from the colonoscopy, and then surgery and results of pathology from surgery. And the, so there isn't at any one point the answer is yes, this there isn't one field which tells you; yes you've got a cancer. Err so you have to build up a picture of what's happened to somebody through various results of colonoscopy and the pathology.*

*Interviewer: So there's no point at which umm the team as it were signs the patient off as definitely CA colon, or other.*

*Stakeholder: Not within not within the databases no.*

*Interviewer: Right you've got to close the screening, you've got to close the screening down.*

*Stakeholder: Yeah and actually yeah, and know at the end what this person was.*

*Interviewer: And we said it was a complete colonoscopy, we didn't say it was a complete colonoscopy with a confirmed result.*

#### **Conversation with Evaluation Team Member**

The evidence from the interview quoted above and from others at the pilot sites has highlighted the importance of have a rigorous definition of a completed screening episode. The evaluation also highlighted



that the information system must be capable of collating data items into a definition of episode closure, preferably in a single field or report. The Breast Screening Information system has reporting routines which allow this, and similar routines should be developed for the colorectal cancer screening programme before roll-out is contemplated.

### **Compatibility and integration with other systems**

One element of the definition of an IS is that it should “support operational and control issues”. Compatibility within this criterion can be viewed from three aspects. Firstly, the format of data and information from the colorectal systems must be capable of transfer within the programme itself and this has been discussed extensively in previous sections. Secondly, data from systems outside the screening pilot has to be available/suitable for use; and thirdly the programme has to interface with the systems used for routine clinical care, including clinical governance and risk management systems.

### **Data outside system**

Scotland has a natural advantage in terms of management of patient selection and invitation to screening. The CHI system demonstrates the advantages of a centrally maintained registration system and the colorectal cancer screening pilot was able to fully exploit this advantage. Users were able to envisage detailing such as ensuring that a patient doesn't receive a breast screening appointment in the same week as a colorectal test kit. Conversely, it may be that patients actually prefer a single screening episode and an integrated call system could also manage this possibility.

*I would say that every screening programme depends on one common item, no matter what they are, and that is your, in our case our community health index (CHI). And therefore the bit that interacts with that could, the selection bit I believe could be common..... you'd probably work towards a front end umm for the CHI system and call recall system, which had commonality. And also would have the advantage of being able to manage duplicate invitations, so you wouldn't necessarily send an FOBT kit to a woman the same week she was invited for mammography.*

**Scottish Health Commissioner**

However, a colonoscopy clinical IS was in use in some hospitals in the Scottish pilot (Endoscribe) and dual entry on both the pilot forms and Endoscribe added to the colonoscopy workload. The possibility of sharing data between the clinical systems within the whole colorectal system and Endoscribe should be explored and developed.

Neither site identified the potential to use hand-held devices for data capture, although examples of this practice have been available in the NHS for many years and this has been successfully demonstrated with much younger generations of current technologies. As mentioned already, since much of the activity for those with positive FOB tests is remote from the screening unit, the collection of data from nurse clinics and colonoscopy sessions on hand-held devices or laptops with non-volatile backup storage and download capability may be the most efficient solution.

In terms of data directly pertaining to programme outcomes which are held on hospital patient administration systems or GP systems, e.g. histopathology after resection or post colonoscopy adverse incidents, the means of capturing these data needs further discussion.

### **Interface with routine systems**

The national picture is changing so rapidly that strategies must be developed to keep compatibility of colorectal screening datasets under review. This need was recognised during the pilot development but systems were not sufficiently advanced to take advantage of the opportunities.

*To be frank I think the hospital end systems themselves were still fairly, and still are, they are still developing and we are now completely re-looking at everything on the basis of the new national cancer plan and the new national cancer data set which is literally just coming out this year. What the things we are doing with the national cancer .. Yeah. I think what we are struggling with nationally at the moment - this is going off colorectal a little bit is that we were all setting off*

*three or four years ago down a road based on national strategy, information for health, of electronic patient records which were primarily organisation based, so in other words, this organisation would have cross the board systems that supported its clinical processes and within that there would be certain specialist clinical systems that supported specific departments and so on. So for example, you would have results reporting in order entry and electronic prescribing systems across the whole organisation.*

#### **IT Specialist Member of English Pilot**

Neither pilot site had the time or funding to develop links between the routine hospital patient administration systems. In the absence of this interface, the patient became the main source of information, particularly about past history and medication. When asked about possible areas for development should roll-out occur, this was a key topic for many interviewees, for example;

*“...it would also help when the nurses saw patients, to help then decide whether they were fit for colonoscopy or not. Because at the moment we have to take the patient’s word, a lot of the time, for what medication they’re on and what allergies they have and that kind of thing.”*

**National Screening Office**

This interviewee also recognised that the developments of electronic health records, particularly “smart cards” was going to be an important component of this integration, “ *It would be nice if we could have that electronically. It would also be nice to be able to link in*”. Discussion of integration of records underlined a key message for commissioners that the pace of change in information technologies is such that IS should be kept continually under review by an expert advisory group. Several interviewees offered opinions on useful skills to include on this group. In particular, several confirmed the usefulness of the data entry specialist to the Scottish Pilot “..... *but I wish we’d had (data entry expert) right at the very beginning, because I think that would have solved a lot of problems*” and all agreed on the need for advisors from outside the NHS.

One key area of interface with symptomatic services arises within the pathology laboratory. As patients with a positive biopsy at colonoscopy become part of the symptomatic services, so their resection specimens are processed through the normal laboratory systems. Identification of screening patients is through reliance on a stamp appearing on the resection request form. Anecdotally, the pathologists suspected that many forms remained unstamped, either because the stamp wasn’t working or staff were unaware of the necessity to stamp the form or the source of the patient. Thus, in principle, undercounting of the number of positive cases in the screening pilot is a possibility. As a final comment this casual system is a good example of a system which has a high risk of failure because it is not fail-safe and is dependent on too many people appreciating the importance of a seemingly unimportant action in a clinical situation.

*Interviewer: so a slight glitch in the IT system there, the self-inking stamp wasn’t self inking and it seems a bit random as to whether the surgeon will stamp the form or not anyway*

*Stakeholder: No it’s not random, it’s uniformly absent.*

*Interviewer: So in the heat of clinical battle it’s not happening?*

*Stakeholder: It’s not happening.*

**Endoscopy Unit Manager**

#### **User developments and interaction**

One aspect of efficient IS development is the capacity for “providing facilities and a learning environment for users and information systems specialists to improve the effectiveness of their decision models”. The availability of good training, training manuals and user support is crucial to efficient implementation of systems although experiential learning was a perfectly reasonable model to adopt for the pilots. At the

point of implementation of the computer based IS systems both providers offered training for the whole team and the providers in Scotland were extremely accessible for user support. However, although training was provided at the point of implementation of the system from that time on, knowledge was passed from one team member to another and manuals were not available for self-directed learning.

*Interviewer: But NHS IA haven't given you a manual?*

*Stakeholder: Not that I've seen. Might be (another staff member) had one but she would have shown it to me.*

#### **English Pilot Site Staff Member**

The need for written training material was acknowledged but as there were few resources for this activity within the pilot teams, including the national offices, knowledge was lost when staff left and not captured for future employees. For future pilots it may be important to allow sufficient resources for IS providers to produce user friendly documentation and for pilot sites to develop initial drafts of training material for their information systems.

In both pilots mechanisms for adaptation and additions to the system were clear. Both agencies providing the software were flexible about meeting changing user needs once the software was implemented. Both pilots were appreciative of the willingness of SchlumbergerSema and NHS IA to make small modifications at no extra cost and the systems for requests for larger scale modifications, which couldn't be absorbed within routine maintenance, was acceptable and understood by both pilot sites.

### **5. Needs assessment and system specification for potential systems roll-out**

To ensure that all data that related to the lessons for roll-out from the information system's interviews was captured from the pilot an additional round of textual analysis was conducted. In addition to the coding used to collate data for this report, specific searches were undertaken in all available documentation (minutes of meetings, specification documents and interview transcripts) for key words. Key words used included roll-out, future, plans, learning and lessons. The results were matched against the coding for missing topics. There was a high concordance between the text searches and the coding. Of the 30 references from the thirteen interviewees who discussed roll-out, only two issues were not disclosed in the interviews. These two issues both pertained to technical detail about the computer systems. In addition, the topics raised were examined for relevance to the theoretical model used to explore information system issues. The topics raised mapped very closely to the framework/definition proposed by Jayaratna and segments from this definition have been used to structure the learning.

#### **An efficient means of acquiring information – Data collection and definition of endpoints**

There are real issues within the current system in Scotland about continuity across the interfaces between paper-based systems and computer supported systems. The backlog of data has been a problem which has now been solved but the situation which gave rise to the problem is still present and must be systematically approached and resolved. As a result of the initial implementation being constrained to a "call" system, the rest of the information system has developed in a fragmented manner with various computer-based and ad-hoc paper-based systems. The means of identifying when data that should be on the system is missing is labour intensive, not automated, and subject to error.

As the pilots roll out colonoscopy, pathology and radiology data that needs matching and combining with the call/recall dataset will be collected remotely. Components of both the call/recall system and the current clinical system need linkage for both information and data entry. If parts of this system are to be paper-based, audit systems must be in place to ensure no data is lost and hence no patient is lost to follow-up. One crucial component that must be discussed across the whole programme is how an episode will be completed. As the primary outcome is number of cases detected, reports to combine clinical data should be developed as for the Breast Screening system (including where appropriate resection results after surgery) so as to produce a definitive and staged diagnosis. The information modelling process was useful in identifying these components and systems. As local Trusts are recruited to the screening programme,

commissioning protocols should specify the local responsibilities for data entry and quality of data. In return the screening programme should facilitate the easy transfer of remotely acquired and stored data.

An efficient means of storing and processing information” - Hardware and software platform requirements

Several interviewees suggested that the information systems would need re-construction from scratch. However, although neither system has been designed to recall patients, the commissioners should seriously consider “Evolution instead of revolution”(IS Commissioner). The experience of the English pilot site suggests that a browser-based system, secured within NHSNet, is feasible but the experience of the same site with a remote server also proved very time consuming. For those who are using the system for processing, not just downloading or transfer of small datasets, the speed of the system at the English pilot site is frustrating. This was partially the nature of the link with the server and partially a known, but solvable, software problem related to the search routines. It is recommended that the specification for any Trust that is considering mounting Colorectal Screening software on a remote sever should include broadband access to the screening software AND the hospital information system. It would appear that with the addition of a recall facility, increased flexibility in the appointment system and improved archiving and search routines the English software could evolve to meet these objectives.

As experienced with the other screening programmes, the difficulty of differing protocols at each trust should not be underestimated. Theoretically the choice of a browser-based system is appropriate and one that has the best long term advantage. Currently national standards for NHS Net interfaces are being developed and once all trusts operate to these standards this should assist implementation. Nevertheless, if a browser-based system is the choice for roll-out, a phased implementation linked to implementation of the NHS IM & T strategy and capability would be advisable.

For the Scottish system, firstly, a recall facility is needed as, for both pilots, this was not included in the original specification. Bar coding should also be considered for the Scottish system as this has proved useful in the English pilot. For the Scottish pilot the major problem that has arisen is a lack of continuity of systems after completion of the FOB test. The “clinical system” is PC based and the local users are very satisfied with the reporting programme, Business Objects, provided. Should the pilots roll-out, a scoping exercise will be needed to identify whether a mainframe based clinical system, integrated with the call (and recall) system is necessary. The PC system, appears to fulfil user requirements. However, a period of consultation, between software developers, data entry specialists, pilot site managers and Scottish Health Board IT experts, facilitated by independent consultants with experience in development of complex systems would be useful to re-examine strategic objectives, output, reporting processed and local systems requirements. Browser-based systems, as trialed in the English site should also be considered for collection of data currently held on “clinical system”. In terms of hardware, it may be feasible to use custom designed hand-held devices at local colonoscopy centres. This would have the advantage of local ownership of data wherever colonoscopy was provided.

Many issues need resolution before national and local systems can be implemented including:

- Arrangements for data entry onto software systems at site of colonoscopy,
- Browser based radiology and histopathology systems,
- Linkage of data entered for colonoscopy and subsequent diagnostic tests most notably histopathology, to datasets held locally for other purposes e.g. Endoscribe, hospital information systems, minimum pathology and colon cancer datasets etc,
- Protocols for up dating for data copied automatically from other systems,
- Linkage of locally held colonoscopy datasets to main system to reduce data entry workload at Screening Centre and contribute to automatic quality monitoring systems, including monitoring of empty fields,
- Mechanisms for downloading locally entered data, preferably via NHSNet,
- Data security including back-up and encryption of patient data or use of unique identifiers,
- Physical security of devices, including protection from mechanical damage from use in clinical surroundings, protection from loss of data or illegal access or use,
- Improved flexibility of booking systems especially for pre-colonoscopy visit at English site.

There are many initiatives to link cancer data and develop the patient record in both Scotland and England; for example, Scottish Care Information initiative, Tayside has recently received funding to develop a colorectal cancer database and major advances in protocols linked to developing the electronic health record. A scoping exercise of current and proposed initiatives prior to development of colorectal system, and funding of a post specifically to oversee developments in colorectal cancer *including* screening should prevent unnecessary overlap or duplication of effort. All national information systems should include automatic reporting on key outcomes and quality measures, including automatic algorithms for identification and staging of patients with confirmed colon cancer. Serious consideration should also be given to methods of archiving of data and ease of access to archived data. The English site experience was that regular routines for archiving would have improved office efficiency and speed of access to the system.

### **Efficient means of presenting and disseminating information; The user interface**

A most important issue identified by interviewees was that the amount of information collected could be reduced from the wide number of items identified at the start of the pilots. The piloting process allowed identification of several refinements including:

- Simplification of paper-based forms both in quantity and content,
- Improved design of forms,
- Redesign of computer input screens,
- Redesign of reporting screens,
- Appreciation of user-friendliness of Business Objects in building queries for Scottish system.

The dissemination of information held in the colorectal databases is an important issue for the future integration of national information systems. Here integration is the keyword and recommendations about scoping current developments have a particular resonance when considering dissemination of information from the system. The scoping exercise recommended must give due consideration to information outputs to other users, including PCTs, national Cancer Registry and other datasets. A watching brief should be kept on data protection and ethical considerations when developing patient identifiers for the colorectal screening systems.

*Yeah. And that was a very time-consuming thing as well, and that would cut out some of the nurse's time, you know, unnecessary time in trawling through pages and pages of, you know looking for people who hadn't had their colonoscopy and why you know. And did I need to write to them again, people who, you know because sometimes people didn't attend, or cancelled their colonoscopy, but didn't do it through me. They left a message or something, and then it was up to me to find the time within the next few weeks to write to that person, or to phone them, and say why had they cancelled, did they want to book another appointment. Maybe they weren't in, and so you've got to remember to phone them again when you've next got time to do it. Or you write to them and you give them 3 weeks to respond and they don't respond, do we write again, and so on. So it's very difficult to keep track of people, I've found that's enormously time-consuming, and it would have been so helpful to have a database of all the patients referred to me, so that I could click a few buttons and immediately produce a list of all the people that I needed to phone. You know, and I think that wasn't realised as well, was that the nurse does need at least one day free for administrative.*

### **Pilot Nurse**

One key issue identified by pathologists at both sites was that the information systems were not geared to single patients with multiple specimens. Thus, for each specimen all the patient's details had to be re-entered. This was true of both software and paper-based systems. It is essential that this issue is resolved before a second round of screening as it is a potential source of data entry error. As expected, the range of pathology seen in such a big population raised issues of classification, particularly of pathology in the interphase. In practice many pathologists found the minimum dataset did not reflect the range of pathologies disclosed or the additional commentary they wished to give to their findings. Before further IS

development the pathology dataset needs revisiting, preferable by resourcing of a professional conference day.

Supporting operational, control and strategic organisational objectives – Reporting and monitoring of activity

As discussed previously the definition of endpoints for the screening programme is a crucial strategic issue. This topic needs further careful post pilot discussion. In the experience of the Colorectal Cancer Screening Pilot Evaluation Team and other cancer screening programmes, several data items are necessary to identify those cases with cancer. The development of computer algorithms to identify these cases as part of the reporting system would be a worthwhile investment. Similarly, the Scottish system does not present to the user as an integrated, seamless whole. Interviewees made a clear distinction between the two components “clinical” system and the “screening” system. This differentiation has risks, as performance in one component may be perceived to be distinct from performance in the other, a distinction that has already cost the Scottish pilot in terms of data entry and hence quality management.

An end point of the piloting process should be a definitive set of quality standards. This definitive set of standards can then be used as the basis for developing reports from the IS. These standards should also be translated into audit criteria, and software systems designed specifically to output audit reports at pre-defined (but capable of user variation) intervals. Access and rights to specific reports should be part of the Service Level Agreements between Commissioner and all providers, including PCTs.

One key issue identified by the pilots was the difficulty of identifying adverse events, particularly complications following colonoscopy. This problem arises because admissions after colonoscopy may not be to the same Consultant or Trust, especially if the admission is as an emergency. In addition, adverse events reported to GPs are also difficult to capture. All events should, at some point be capable of capture. The major issue is the time-lag between the event and the Screening Programme learning from the event. The problematic nature of capturing this information suggests that other means will be necessary to identify poorly performing colonoscopists. The piloting process has not identified a single, simple means of capturing this data and this must remain an on-going and very important issue for the National Screening Offices. Less crucial but still important is capturing data on post-colonoscopy GP visits.

### **A learning environment**

#### 1) Revisiting information modelling

The piloting exercise and the relatively small funding allocated specifically for IS issues has proved worthwhile in terms of capturing lessons for the future. The information modelling exercise was particularly useful. This would have been undertaken as part of any software development by the company commissioned to undertake the work. The strength of the CRC pilot was that the information modelling was independent of the software development itself. Thus, the model developed was independent of local considerations or software platforms and enabled the specific issues related to the colorectal cancer screening programme to emerge without constraint. In this way the needs of the programme were more (England) or less (Scotland) able to drive the development of the system. Thus in England “we need this for the colorectal cancer screening programme....” took precedence over “you can’t do that because our local system works this way....” and solutions for problems were found despite local constraints. Although unaware of the exact nature of the constraints in the IS contracts in Scotland, a consultant employed to undertake information modelling at the beginning of the project reflected that in his experience in other (non-NHS projects), *“it’s just that you know the way the contracts are put together is they’re almost forced into doing things a certain way. You’re building a solution to a particular problem rather than a solution you can integrate into a bigger system.”*

#### 2) Skills, support and training

The IS providers commissioned for both sites provided initial training for key staff. However, as staff changed there was little continuity of training from the providers of the systems. In particular, system documentation was very ad-hoc and more closely related to technical development issues than user needs. For future IS commissioning, contracts should specify the nature of documentation, on line assistance and

detail required for end-users. Screening sites should consider the advisability of designation of specific IS training responsibility to one member of staff who should also act as main link person to the IS providers.

Neither pilot site had specifically identified personnel responsible for IT within the pilot staff. At National Screening Office level expertise in this area was spread very thin. Yet the whole IS was the backbone of the project and the influence of data collection specialists impacted greatly in Scotland.

*“I mean I actually feel, and I’ve always thought that within screening programmes you need like an IT manager. You know an IT project manager that can see the bigger picture to oversee it, and I think that’s maybe what’s been lacking”*

**National Screening Office**

If further roll-out or second round of screening is funded, serious consideration should be given to supporting an IT officer, with the necessary hardware skills, with dedicated time within the pilots.

### 3) To the future

The pilot has come full circle and the true learning will take place, both from this report, and from a further debriefing and information modelling phase. It is strongly recommended that, building on the lessons from the piloting and evaluation and prior to any further software development, a debriefing exercise be undertaken followed by a refinement of the information model since this will more than repay the investment. This exercise should include agreement on a definitive set of Quality Standards and information needed to calculate quality parameters and should involve any contractors that were involved with the original systems development. As information technology, particularly the development of the electronic patient record, European-wide and national IS protocols and browser-based information systems, is a rapidly changing field the National Screening Office may wish to consider a standing advisory panel on Information Systems. This panel would usefully include independent information systems experts from outside the field of healthcare as well as those with expertise in systems implementation methods.

**Table S7.3.1 Some of the functions of a colorectal cancer screening programme information system envisaged in the Green Book.**

- hold and update registers of men and women aged 50-69 registered with the relevant primary care group (the accuracy of HA databases will be higher for women than for men, because entries have been corrected for other screening programmes);
- generate screening invitations;
- generate barcodes to enable positive sample detection for returned test kits;
- record test results, deferrals or declined invitations, and generate resulting action codes;
- issue a reminder to non-participants;
- generate results letters for participants and inform their GPs;
- book appointments (in conjunction with hospital services) for diagnostic investigation and notify patient;
- record normal investigation findings and histopathology results; this is for recording interval cancers and suspending routine investigations in confirmed CRC patients;
- generate letters to patients on histopathology results, and relevant action codes.
- be able to generate routine statistics on:
  - response to invitation;
  - results of tests;
  - waiting times for investigations;
  - results of investigations
  - and (possibly) interval cancers.

In addition, the system would be:

- both efficient and user-friendly,
- have the capacity to handle a large number of records
- be able to accommodate all the necessary details on programme features listed above.
- readily adaptable to sites beyond the screening pilots in light of possible roll-out of screening after the pilot.



### Table S7.3.2 Objects identified in Information Model

An object can be seen as a high level construct that ties data with the functions that operate on that data. The following objects were identified in the information modelling process. All sub-levels are listed alphabetically and the listing implies no priority

#### Screening subjects:

Ceased client  
Declined Subject  
Positive client  
Issued Test Kit  
Residence  
Screening Batch  
Screening Episode  
Screening Incident  
Screening Subject  
Suspended Client  
Selected Client

#### Further Investigation

Accepted Investigation  
Declined Investigation  
Double Contrast Barium Enema Result  
Early Complication Type Arising During Investigation  
Finding of Investigation  
Flexible Sigmoidoscopy Result  
Investigation  
Investigation Finding Type  
Investigator  
Late Complication Type Arising During Investigation  
Prior Symptom Type for Investigation  
Proposed Investigation

Colorectal Cancer Screening Programme  
(set default values)

#### Colonoscopy

Cancer Result  
Carcinoma  
Clinical Procedure  
Clinical Result

#### General practitioners

General Practitioner  
GP Practice  
Primary Care Unit

Colonoscopy Result  
Colorectal Screening Clinic Appointment  
Complication Type  
Consultant  
Nothing Found  
Positive Client  
Surgery  
Symptom Type

#### Faecal Occult Blood Test Kits

Internal Control Test Kit  
Primary Reading  
Reader  
Reading Session  
Returned Test Kit  
Returned Test Kit From Different Subject  
Returned Test Kit Requiring Further Investigation  
Returned Test Kit Requiring Retest  
Returned Test Kit With Negative Result  
Secondary Reading  
    Slightly Abnormal Returned Test Kit  
    Technically Failed Test Kit  
Test Kit Requiring Reading  
    Test Kit Returned Spoilt  
Unread Returned Test Kit