

# BMJ Open Reasons for non-participation in the Northern Ireland Bowel Cancer Screening Programme: a qualitative study

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## ABSTRACT

**Objectives:** To identify the reasons why some people do not participate in bowel cancer screening so that steps can be taken to improve informed decision-making.

**Design:** Qualitative study, using focus groups with thematic analysis of data to identify, analyse and report patterns. Transcripts were repeatedly read and inductively coded using a phenomenological perspective, and organised into key themes.

**Setting:** Belfast and Armagh, two areas of Northern Ireland with relatively low uptake of bowel cancer screening.

**Participants:** Ten women and 18 men in three single-gender focus groups (two male and one female), each with 9–10 participants. Study participants were recruited by convenience sampling from the general public and were eligible for, but had not taken part in, the Northern Ireland Bowel Cancer Screening Programme.

**Results:** Key themes identified were fear of cancer; the test procedure; social norms; past experience of cancer and screening; lack of knowledge or understanding about bowel cancer screening; and resulting behaviour towards the test. Fear about receiving bad news and reluctance to conduct the test themselves were reactions that participants seemed willing to overcome after taking part in open discussion about the test.

**Conclusions:** We identified barriers to participation in bowel cancer screening and used these insights to develop new materials to support delivery of the programme. Some of the issues raised have been identified in other UK settings, suggesting that knowledge about barriers, and strategies to improve uptake, may be generalisable.

## INTRODUCTION

The Northern Ireland Bowel Cancer Screening Programme (NIBCSP) was launched in 2010 to reduce mortality from bowel cancer by detecting early-stage

## Strengths and limitations of this study

- This qualitative study revealed common and consistent barriers to participating in bowel cancer screening, including fear, reluctance to take a stool sample and the perception that taking part was not the social norm.
- The study findings were used in practice to inform production of an explanatory online video for the public that addressed common misconceptions about bowel cancer screening.
- Including people who had undertaken screening would have allowed study of enabling factors.
- We had limited information about the sociodemographic characteristics of study participants.

colorectal cancers to facilitate early treatment. A guaiac faecal occult blood test kit is posted to all men and women aged 60–74 years, completed at home by application of three stool samples to the card and returned to a laboratory by post. Detection of blood may indicate bowel cancer and the person is referred for examination of the bowel, usually by colonoscopy. The screening programme is coordinated and quality-assured by the Public Health Agency (PHA), which is the public arms-length body with responsibility for improving public health and reducing health inequalities in Northern Ireland.

The NIBCSP has the lowest uptake of Northern Ireland's regional population screening programmes at 53.2%. Participation is lower among men (51% in fourth quarter of 2012–2013) and in specific areas (46% in Belfast Health and Social Care Trust and 47.8% in Southern Health and Social Care Trust). In contrast, 81% of 65-year-old men offered abdominal aortic aneurysm screening participate.<sup>1</sup>

Barriers to bowel cancer screening uptake have been studied outside the UK and in the

UK during pilot and roll-out phases of the English national bowel cancer screening programme by qualitative and quantitative methods.<sup>2-4</sup> More recently, a large focus group study of reasons for uptake and non-uptake of the now-established English programme in South Yorkshire and London provided valuable insights into barriers to participation.<sup>5</sup> Palmer *et al*<sup>5</sup> reported that interaction with faeces was regarded as taboo, the non-healthcare setting was unsettling, and feeling well led to a perception that the test was of low relevance. Themes that were common to several reports were fear and disgust, with some gender differences reported.<sup>2 6</sup>

An informed decision is “one where a reasoned choice is made by a reasonable individual using relevant information about the advantages and disadvantages of all the possible courses of action, in accord with the individual’s beliefs.”<sup>7</sup> Promoting informed choice is regarded as an autonomy-respecting approach to cancer screening that recognises that there are risks, benefits and uncertainties related to participating in screening that individuals may weigh differently depending on their values and their capacities to benefit from screening.<sup>8</sup> People with lower levels of education may have greater difficulty reaching informed decisions about participation in bowel cancer screening.<sup>9</sup>

The aim of our study was to understand reasons for non-uptake so that steps can be taken to facilitate informed decision-making. We used a qualitative approach to elicit and explore bowel screening-related beliefs, attitudes and knowledge of individuals who did not participate in the NIBCSP.

## METHOD

The PHA commissioned Perceptive Insight, a market research company that is accredited under the Interviewer Quality Control Scheme (<http://iqcs.org>), to facilitate the focus groups. Research ethics approval for this study was not required because no Health and Social Care (HSC) patient information or HSC premises were used. A UK National Research Authority decision tree for this project explaining this decision is shown (see online supplementary methods 1). Participants gave informed consent after being informed of the purpose of the study, that their comments would be confidential and that no identifying information would be published. No identifying information was passed from Perceptive Insight to the PHA. The study is reported with reference to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guideline to improve the quality and transparency of reporting of qualitative studies.<sup>10</sup>

## Recruitment

Purposive recruitment was undertaken by networking, snowballing and on-street recruitment using an eligibility questionnaire. Recruitment was in Belfast and Armagh, representing Belfast and Southern Health and Social

Care Trusts, respectively because these areas have lowest uptake. Inclusion criteria were:

- ▶ Age 60–71 (The NIBCSP target age group at the time of the study).
- ▶ Had not had bowel disease or surgery that would make them ineligible for the NIBCSP.
- ▶ Had not had colonoscopy in previous year and not on an alternative surveillance programme.
- ▶ Had not participated in the NIBCSP.
- ▶ Had not attended a focus group in the past 2 years.
- ▶ Had not been recently bereaved due to cancer.

## Focus groups

Three groups were convened in March 2014: two with male participants and one with female participants, because uptake is lower among men (table 1). All participants were white, spoke English and were from Northern Ireland. All had received but not completed a bowel cancer screening kit except for one focus group participant who had recently entered the eligible age range and had not yet received a test kit. Each focus group was facilitated by one of a team of three female researchers with extensive experience of conducting focus groups. Researchers had no contact with participants prior to the focus groups. Focus groups were held in hotel conference rooms, lasted 90 min and had 9–10 participants. A topic guide shaped discussions (see online supplementary methods 2).

## Analysis

Audio recordings of the sessions were made, reviewed and transcribed verbatim by Perceptive Insight. Transcripts were not shown to participants. Informal results were reported to PHA by Perceptive Insight. Thematic analysis using a six-step process<sup>12</sup> was undertaken independently by two authors (DTB and CT). This is a method for identifying, analysing and reporting patterns within qualitative data. Themes were derived inductively from the data with no pre-existing coding frame from a phenomenological perspective whereby data were analysed from the perspective of the individual.<sup>13</sup> Codes were collated into potential themes, which were reviewed and refined to ensure consistency with the data. Discussions were held to compare and combine analyses, with a high level of agreement. NVivo qualitative data analysis software (QSR International Pty Ltd. V.10, 2012), was used to facilitate data analysis.

**Table 1** Characteristics of focus groups

| Focus Group | Gender | Location | Participants (n) | Social grade range* |
|-------------|--------|----------|------------------|---------------------|
| 1           | Male   | Belfast  | 9                | B–E                 |
| 2           | Male   | Armagh   | 9                | C1–E                |
| 3           | Female | Belfast  | 10               | B–E                 |

\*Social Grade based on National Readership Survey definitions.<sup>11</sup>

## RESULTS

Six key themes were developed from analysis of data.

### Theme 1: Fear of cancer

Fear was one of the major sentiments expressed. Participants described anxiety, shock and fear provoked by different aspects of screening. Receipt of the test kit for the first time commonly provoked shock, particularly among females.

It was a shock, I wasn't expecting it and you get it as soon as you're sixty. Like now I'm sixty they expect me to get everything. [Female, FG3]

This response appeared related to the idea of suddenly being considered 'old'.

To be honest I was angry, it was telling me I was old. [Female, FG3]

All of a sudden just because of your age you get this thing 'you may have cancer'. [Male, FG2]

However, several people acknowledged that they were reaching the age that they could be affected.

You're coming up to the age and you're afraid. [Female, FG3]

Some participants thought that waiting on results would be an anxious time, and many people described fear about receiving bad news.

It's kind of scary and it's all leading up to the result. [Male, FG1]

Some individuals worried about being called in for investigations, though others did state that a positive screening test did not mean a cancer diagnosis.

Well you would nearly have a heart attack if you opened the letter and you need to come back in. [Female, FG3]

It'll be no different from breast screening, you sometimes get a call back and it's not a problem. [Female, FG3]

Fear was mentioned frequently in the male groups, several of whom commented that men were less likely to see doctors or take part in screening than women. However, some statements suggested that the men recognise the importance of screening.

[W]omen are nearly religious about going and getting checked for cancer [Male, FG1]

It used to be that men wouldn't have went to the doctor unless they were really dying... but now with much more access to media people are clued in and know of the importance of early intervention and therefore screening is so important. [Male, FG1]

Many individuals seemed inhibited from acting by their fear. Avoidance of thinking about cancer, and a preference for 'not knowing' were expressed several times. However, this was balanced by numerous statements in favour of knowing.

The treatment as well, it might be invasive and your whole life might change. Hospitalised, chemo. If it happens, it happens and I'll deal with it then. Don't want to pre-empt it. [Male, FG1]

I would rather have the result than not have it. [Female, FG3]

While there was much fear expressed about receiving a diagnosis of cancer, there was none expressed about the possibility of having a cancer undiagnosed due to not taking the test. Rather, some of the participants acknowledged that a rational understanding of the benefits of bowel screening competed with an intuitive reluctance to take part.

You should want to know, but don't. [Male, FG1]

If it was my son I would be cross at him telling him to do it and that it's important, I'd catch his poo for him but I won't do it myself. It doesn't make any sense. [Female, FG3]

Some people believed that a negative test result would be reassuring. Many male (but no female) participants advocated using fear as a motivational tool in an advertising campaign to 'shock' individuals, often referring to tobacco campaigns.

There's nothing wrong with scare tactics, they use them for drink-driving and to stop people smoking. [Male, FG1].

### Theme 2: The test procedure

Repugnance at the idea of screening participants having to handle their own faeces was often expressed. Many people described reluctance to collect the samples though this seemed to present a more significant barrier for females.

I didn't like the idea of it, collecting my bits of poo. [Female, FG3]

It's not the kind of thing you want to do. [Male, FG1]

There were mixed views about how difficult the test was to use, though no participants said that they had attempted to complete it. One participant advocated production of a video to explain how to do the test.

I read the thing, if it had have been a relatively straight forward [process] I would have done it the one time but it just looked so complicated. [Male, FG2]

It looks more complicated than it is. [Male, FG1]

One issue with the test that emerged repeatedly was taking samples three times. It seemed that many people might be able to bring themselves to do the test once, but not three times. Others were concerned about leaving a partially completed test kit sitting for several days or having to carry it around with them while away from home.

You have to do it over a number of days then you have to have that sitting about somewhere. [Female, FG3]

Sometimes you don't always be at home, you're maybe at work and are you going to have to carry it about all day with you? [Female, FG3]

Suggestions for making the test more acceptable involved limiting the need for interacting with faeces: using an alternative test; using a test that required only one sample; doing the test in a mobile screening van or doctors' surgery; or being investigated by a healthcare professional.

Why not use a blood sample instead of that. You use a blood sample for everything else. [Male, FG2]

[If my] doctor told me 'My colleague is going to examine you for bowel or prostate cancer' I would tell them to work away [go ahead]. [Male, FG2]

I think it is like as this man says degrading, you would prefer maybe a doctor or nurse than having to do it yourself. [Male, FG2]

Some people thought that the obligation inherent in having an appointment with a healthcare professional would make them more likely to attend.

I don't look at it the same as a smear test or breast screening, you're just used to going for those and you get your letter regularly and just go for the appointment. You feel you have to go for the appointment. [Female, FG3]

Many people suggested that if the test involved interaction with, or endorsement by, their general practitioner (GP) they would be more likely to participate.

I have mine in the bedroom, because if my GP says do it then I will do it. [Male, FG2].

### Theme 3: Social norms

Several participants said that they found the idea of the bowel cancer test embarrassing.

Well it is a bit of a taboo subject, your bowel movements. [Male, FG2]

It's more embarrassing than a smear or a mammogram. [Female, FG3]

Some had spoken to others who had taken the test and felt encouraged to participate.

My friend did it and got back the all clear so she's put me in the mind to do it, but her husband won't do it either, and she says to me you need to do it but I'd already threw it in the bin. I will reorder it. [Female, FG3]

Males suggested that information campaigns should include a celebrity endorsement by someone who had been affected by bowel cancer.

I think if you got more personalities to come forward then they desensitise it or there's a stigma to it [Male, FG2]

In all groups, most participants said that they would take the test after they had discussed their concerns.

I think that we're able to sit here and discuss is an encouragement, through the post I think it's easy to put aside [Male, FG1]

I will definitely do it. Everyone sitting talking about, and we all have the same fears and the same reasons of not doing it. [Female, FG3].

### Theme 4: Past experience of cancer and screening

Most participants knew people who had cancer. Their anecdotes often focused on the side effects and futility of treatment.

A lot of the time it's too late anyway, I've seen what chemo does to someone and that person was going to get 5 years at the most. [Female, FG3]

The principle that early treatment was more successful was understood by many people.

[I]f you get it at an early stage you're more likely to recover. [Male, FG1]

Other screening tests seemed more acceptable to the participants. Some men had already undergone screening for abdominal aortic aneurysm. All females had undergone screening for breast cancer and some also for cervical cancer.

### Theme 5: Lack of knowledge or understanding about bowel cancer screening

Almost all participants were surprised when the test kit arrived and most did not know who had sent it, but a minority knew people who had taken the test already.

When I got that I didn't have a clue where it even came from. [Female, FG3]

Many found the test kit difficult to distinguish from junk mail and private advertising.

I have been getting several other private companies for screening under the pretence of trying to look official when it is really a scam. [Male, FG2]



They sent me the stuff out and all about the bowel test but I didn't do it, it's like that hidden hearing thing you think you're going to end up paying for it. [Female, FG3]

Many people believed samples had to be taken on consecutive days (they have up to 10 days to collect three samples). Several people said that they did not complete the test because they felt well.

I read the symptoms and just thought I don't have any of them. [Male, FG1]

Many participants were surprised at how common bowel cancer is, and several suggested that this information should be used to increase participation in the programme.

### Theme 6: Resulting behaviour towards the test

Participants described a clear pattern of behaviour: The test kits were set aside for a period of time, possibly with an intention to complete it at a later stage, and either kept indefinitely or eventually put in the bin.

I put it somewhere and thought I'll deal with that another time. [Female, FG3]

Opened it up had a look at it and just put it in the corner and thought I'll do it in a while. [Male, FG1].

## DISCUSSION

We have described the fears and beliefs of people who do not undergo bowel cancer screening in Northern Ireland. The findings overlap with some previous reports, suggesting that some reactions to the screening programme by its target group are common across the UK, and perhaps more widely.<sup>2 5 6</sup>

Many of the themes identified coincide with common social-cognitive models of health behaviour decision-making including social norms, attitudes and beliefs. Emotions play a critical role in health behaviours and are often neglected in formal models to understand or predict health behaviours.<sup>14 15</sup> Fear was prominent in discussion, especially among men. Bowel cancer screening is the only population cancer screening programme offered to men in Northern Ireland. An intervention that engages with the emotions of the screening-eligible population by using anticipated regret has been trialled in Scotland to increase uptake in bowel screening in Scotland.<sup>16</sup> The use of anticipated regret has been shown to increase organ donor registration.<sup>17</sup> The perception that treatment (particularly chemotherapy) was futile was common in our study and in Palmer *et al.*<sup>5</sup> Over-diagnosis and false-positive diagnosis were not mentioned by participants. In a survey of people invited to flexible sigmoidoscopy screening, fearing cancer increased people's intention to undergo screening, but not uptake, while finding thoughts of cancer

uncomfortable predicted lower uptake.<sup>18</sup> The behaviour of 'delaying uptake, leading to non-uptake',<sup>5</sup> or 'avoidant procrastination'<sup>6</sup> was common in our study. The proposal by male participants of a 'shocking' information campaign could have unintended consequences.<sup>18</sup> Women did not advocate using fear, but discussed the need for bowel cancer incidence and survival rates to be included in information campaigns. A variety of approaches may be necessary to allow for variation in individuals' health information processing style.<sup>19</sup>

Repugnance towards the test procedure might be overcome for some people in future by the use of a faecal immunochemical test (FIT), which requires only one sample.<sup>20 21</sup> A study of FIT testing in Scotland showed that using FIT resulted in greater uptake, particularly in deprived areas.<sup>22</sup>

In our study and in Palmer *et al.*<sup>5</sup> the idea of the test being 'degrading' was expressed in identical terms, and yet a very encouraging aspect of the focus groups was that after discussion many of the participants said that they would now undergo the screening. This supports the existence of a 'tipping point', described by Palmer *et al.*<sup>5</sup> among people who took the test after discussion, leading them to recommend normalisation of open discussion. Endorsement of the programme by GPs was recommended by Palmer *et al.*<sup>5</sup> and our findings also support this.<sup>23</sup> A randomised controlled trial suggested that an electronically signed GP endorsement letter boosted participation by 11%.<sup>23</sup> The Northern Irish participants were particularly supportive of endorsement by public figures, such as sportspeople.

Misconceptions could affect uptake: some people believed that because they did not have symptoms, they did not need to take the test. It was commonly believed that the test should be conducted on three consecutive days. Confusion with junk mail and private 'screening' tests appears unique to our study, perhaps due to lower recognition of Health and Social Care Northern Ireland branding. Some focus group participants proposed an online explanatory video, and we have now produced one to provide information and address misconceptions that were apparent in this study (available online at <http://www.cancerscreening.hscni.net/2188.htm>), and the findings of this study will inform future communications with the public about the NIBCSP. Advance notification letters that alert individuals to an upcoming invitation to screening have been shown to be effective<sup>24</sup> and cost-effective<sup>25</sup> elsewhere, and we have now started a pilot of this practice in the NIBCSP.

Our study was limited by its small size and limited sociodemographic information about participants, including a lack of information about educational attainment. We excluded people who had taken part in the programme, so our report cannot shed light on the factors that motivated them to take the test. The socio-economic status of participants was similar in all groups, preventing us from drawing conclusions about differing levels of educational attainment and other social factors

on motivations. We were unable to explore the effects of other illnesses or symptoms on knowledge, attitudes and beliefs about bowel cancer screening.

We are currently conducting studies of non-participation in Breast and Cervical Cancer Screening Programmes and have included groups of screening attenders in order to explore enabling factors in addition to barriers.

Our study is one of two conducted in the UK since the national bowel cancer screening programmes have been implemented fully as part of routine healthcare. It demonstrates that some barriers to participation, such as fear and repugnance are persistent over time. This information will be valuable in informing policy and public engagement as the UK cancer screening programmes continue to evolve. The study provides specific insights into reasons for non-uptake of the NIBCSP and these findings will be used by the PHA to reduce barriers to uptake and promote informed decision-making.

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