

Public perceptions of communicating information about bowel cancer screening

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Abstract

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Objectives The National Health Service has recently begun the introduction of a Bowel Cancer Screening Programme (BCSP), offering biennial screening to men and women aged 60–69 years. This study aimed to explore public perceptions regarding the communication of information designed to facilitate informed choice in relation to this new screening programme.

Methods Fourteen single sex focus groups were conducted in England with 86 individuals aged 60–69 years. Focus groups were conducted either with individuals who had participated in the pilot phase of the BCSP, or with members of the public living outside the pilot areas.

Results The majority of participants expressed positive attitudes towards bowel cancer screening, identifying items highlighting the benefits of the programme as important for others to know. Whilst some believed it was appropriate for information regarding the potentially negative aspects of the programme to be communicated at the outset, others expressed concerns about the generation of anxiety and potential for decreased participation. A number of participants questioned the concept of informed choice, arguing that once in place, a screening programme should be vigorously promoted.

Conclusions There is some variation in the type of information favoured by those eligible for bowel cancer screening. This may present challenges for the provision of information aiming to facilitate informed choice in the BCSP. Flexible approaches to information provision that recognize the perceptions of patients may be required.

Background

The National Health Service Bowel Cancer Screening Programme (BCSP) is currently being rolled out in England. Screening invitations and Faecal Occult Blood testing (FOBT) kits are being sent out directly from the programme centres. Since there is no initial contact between screening participants and health professionals, the quality of information provided by the programme is of particular importance. Written information about the programme is provided at two points during the screening process. First, all eligible participants are sent an initial information leaflet detailing the benefits and risks of the screening process along with their FOBT kit. Second, participants with an abnormal FOBT result are sent an information leaflet detailing the benefits and risks of the colonoscopy investigation, along with their results letter and an appointment with a specialist nurse to discuss the procedure.

There has been some debate in recent years with regard to the type of information provided to individuals eligible for screening. Screening programmes in the UK have traditionally been promoted as a beneficial service that should be taken up by all who are eligible. However, amidst ethical concerns about this approach¹ and criticisms of patient information for failing to adequately cover the possible risks of screening,² a shift towards the facilitation of informed choice has occurred. The provision of information regarding both the risks and benefits of screening to participants is now advised by both the General Medical Council³ and National Screening Committee.⁴

However, the provision of balanced information to facilitate informed choice amongst those eligible for screening is potentially problematic. Of particular concern for screening policy makers has been the possibility of decreased uptake following the provision of information including the risks of screening.⁵ Moreover, the extent to which the provision of balanced information actually enables informed choices to be made remains unclear.⁶ Evidence suggests that screening participants tend to be overly

positive about the efficacy of screening tests^{7,8} whilst downplaying or ignoring the associated limitations.⁹ However, direct examinations of public perceptions of the information resources provided to those eligible for screening are rare.

Guidelines for the production of patient information advise that patient involvement is an essential step in the process.^{10,11} This report describes the findings from six focus groups conducted with individuals who had participated in the pilot phase of the BCSP and eight focus groups conducted with members of the public living outside the pilot areas. The study aims were to explore the perceptions of these individuals with regard to the communication of information designed to promote informed choice in the BCSP. The findings informed the development of evidence-based information leaflets for use by participants in the BCSP (<http://www.cancerscreening.nhs.uk>).

Methods

Following ethics approval from Southampton and South West Hampshire Multi-centre Research Ethics Committee, 14 single sex focus groups were conducted with 86 individuals (see Table 1). Of these, 42 were female, with the remaining 44 male. All participants were 60–69 years of age (the target age group for the BCSP). All participants were white British with the exception of two male participants of Asian origin and one female participant of European origin.

Focus group methodology was deemed appropriate for use in the current study as group processes can help people to explore their views and generate questions in ways that they may find more difficult in a face-to-face situation.¹² Cancer screening programmes have been available to women in the UK for a number of years, whereas the BCSP is the first opportunity for men to participate in cancer screening. Therefore, focus groups were conducted on a single sex basis to eliminate any possible bias in the discussions that may have been caused by the women's increased levels of experience with screening.

Table 1 Composition of focus groups

Focus group	Sex	No. of participants	Screening pilot results
Pilot 1	Female	7	4 Negative FOBt 3 Positive FOBt + colonoscopy
Pilot 2	Female	5	5 Positive FOBt + colonoscopy
Pilot 3	Male	8	3 Negative FOBt 5 Positive FOBt + colonoscopy
Pilot 4	Female	6	1 Negative FOBt 5 Positive FOBt + colonoscopy
Pilot 5	Male	6	2 Negative FOBt 4 Positive FOBt + colonoscopy
Pilot 6	Male	6	6 Positive FOBt + colonoscopy
Non-pilot 1	Male	8	–
Non-pilot 2	Female	7	–
Non-pilot 3	Male	7	–
Non-pilot 4	Female	7	–
Non-pilot 5	Female	4	–
Non-pilot 6	Male	5	–
Non-pilot 7	Female	6	–
Non-pilot 8	Male	4	–

Six of the focus groups were conducted in June 2005 with individuals who had participated in the pilot phase of the BCSP (pilot focus groups, PFG). A total of 358 invitations to participate were sent to a random sample of screening participants from the Coventry and Rugby areas, stratified by screening result. The invitations were sent from the Director of the screening pilot. Seventy-four (21%) individuals consented to take part, of whom 38 were available on the planned dates of the focus groups, and attended the groups. Four of these PFG focus groups contained individuals with a range of screening results (see Table 1). The other two groups contained only participants who had undergone the colonoscopy procedure as part of the pilot programme, in order to elicit additional views on a planned information leaflet specifically about the colonoscopy procedure. Eight further focus groups were conducted in December 2005 with individuals aged 60–69 who had not participated in the pilot

phase of the BCSP (non-pilot focus groups, NPFG). NPFG individuals were randomly selected from the practice registers of four general practices in different geographical areas. The selected practices were in both rural and urban areas, and served populations of mixed socio-demographic status. A total of 1200 Invitations were sent to non-pilot individuals from their General Practitioner. Two hundred and sixty-seven (22%) consented to take part, of whom 48 were available on the planned dates of the focus groups, and actually attended the groups.

Prior to attending the focus groups, PFG participants were sent the original information leaflet that had been sent to participants in the BCSP pilot, 'Information about the English Bowel Cancer Screening Pilot'. This was a short leaflet (a double-sided sheet of A4 folded into a 10 cm by 21 cm leaflet) designed by the screening team. The primary aim of this leaflet was to provide invitees with basic information about the screening pilot scheme (see Table 2). Data from this first set of focus groups was used to inform the development of revised information materials for use in the BCSP. NPFG participants were sent a draft version of the revised materials for the BCSP, 'Bowel Screening – The Facts', prior to their attendance. This leaflet was fully evidence based and was designed to promote informed choice by providing complete information on the possible risks, benefits and consequences of participation, as recommended by government policy,¹³ patient advocacy groups¹⁴ and professional groups.^{3,4} Therefore, the revised leaflet was much longer than the screening pilot version, containing detailed information such as a diagram of the digestive system, full information on the colonoscopy procedure including complication rates, and bowel cancer survival rates. The revised leaflet was A5 format and 19 pages long (see Table 2). All participants were asked to read the materials, and were told that the discussion would focus on their views of the content and format of the information.

The groups were facilitated by an experienced qualitative researcher (LR), and lasted

Table 2 Content of information leaflets (title and topic headings)**PFG****'Information about the English bowel cancer screening pilot'**

Bowel cancer – the facts
 Why screen for bowel cancer?
 What is bowel cancer and how does it happen?
 The screening test
 Why a pilot study?
 The screening process explained
 What symptoms should I look out for?
 What happens if my result is abnormal?
 If I am diagnosed as having bowel cancer what happens?
 If I took part in the last screening round should I take part again?

NPFG**'Bowel screening – the facts'**

What is the aim of this leaflet?
 What is the purpose of bowel screening?
 What is the NHS Bowel Screening Programme?
 Is bowel screening important?
 What does the bowel do?
 What is bowel cancer?
 Who is at risk of developing bowel cancer?
 How does the screening test work?
 How is the screening (FOB) test carried out?
 When do I get my results and what do they mean?
 What is a colonoscopy?
 Do I have to have a colonoscopy if I have a positive FOB result?
 How reliable is bowel screening?
 What are the symptoms of bowel cancer?
 What if I need treatment for bowel cancer?
 What happens to my sample once it has been tested?
 Summary
 More information and support

approximately one and a half hours. Support was provided during the focus groups by a second researcher (CW). Central topics discussed by PFG participants were (i) how the decision to participate was made, (ii) understanding of screening results and (iii) attitudes and information needs with regard to the information provided by the pilot programme. The discussion of NPFG participants focused on views on the information presented in the draft leaflet, including any sections deemed to be important, irrelevant, alarming, upsetting or confusing. A general discussion of different sections of the leaflet was also used to elicit participant's comprehension of the information.

The focus group discussions were audio recorded and transcribed verbatim. Transcriptions were checked against the original tapes for accuracy and corrected by LR. The corrected transcripts were imported into HyperResearch software for qualitative data analysis and coded within a framework developed by LR, CW and EW. The coding scheme for the PFG data comprised 43 codes which spanned participants' experience of the initial screening process and, where relevant, follow-up examinations; understanding of results; general attitudes towards screening and communication issues. The NPFG data were subjected to coding under a simplified scheme (23 codes) which covered participants' perceptions and understanding of the draft screening leaflet, attitudes towards screening and communication issues. Coded data were analysed for anticipated and emergent themes, including searches for disconfirming evidence (i.e. evidence which contradicts expectations and assumptions about findings). Examples of anticipated themes included positive attitudes towards screening and the need for a pro-active approach to health. Emergent themes included factors liable to discourage participation in screening and negative views of informed decision making about participation in screening. No disconfirming evidence was found.

Focus group data were analysed across groups within the two main categories (PFG and NPFG). Findings were thematically consistent despite geographical, gender and screening result differences, and varying degrees of intensity of opinion which were attributable to individual (personality) differences. The researchers considered that data saturation had been achieved.

Findings

The overall findings are described below in terms of the main themes that emerged. Following each quote is a descriptor to indicate the gender of the participant, a research number to indicate which focus group they took part in and an indication of their pilot screening result (if applicable). Where possible, PFG and NPFG

findings are described together, since the themes that emerged were often consistent across the two sets of groups.

General perceptions of screening and information provision

The vast majority of both PFG and NPFPG participants held extremely positive views regarding bowel cancer screening. Many PFG participants had viewed the opportunity to be screened as a privilege, and reported taking up the offer of bowel screening without hesitation. Factors identified by PFG participants that had motivated their decision to participate included information relating to the incidence and mortality of bowel cancer, the benefit of early detection, the ease of use of the FOB test and experiences of other screening programmes.

Well I am so positive about the test ... I want it done again, but I don't want to wait for 4 years. (man, PFG 3, positive FOBt + colonoscopy)

I cannot understand anybody not jumping at the chance at the first opportunity and three years later when it comes again, jumping at every opportunity to be screened. (man, PFG 5, negative FOBt)

A small minority of PFG participants expressed negative attitudes towards participation in bowel screening, due to the high levels of anxiety that participation had caused them, or the risks associated with colonoscopy. Additionally, a number of individuals reported that they had initially been fearful of participation but had been persuaded to attend through the influence of others.

I remember the first invitation, I threw it out...I just thought it was – I didn't want to know about it. I more or less got frightened and thought what I don't know won't bother me. Then I spoke to a few people and they said if you go early you've got more of a chance. I phoned up and got another one sent. (woman, PFG2, positive FOBt + colonoscopy)

When PFG participants identified a number of key messages they felt should be emphasized to potential screening participants, the factors identified were almost exclusively

related to information which was perceived to be positive or as having the potential to increase screening uptake. These factors included the ease of use of the FOBt in privacy at home, the symptomless nature of bowel cancer and the high level of support provided by the programme. Similarly, when NPFPG participants were asked which pieces of information they felt should be emphasized in order for individuals to make an informed choice with regard to their participation, overwhelmingly, positive aspects of the screening process were identified, with risky or unpleasant aspects seldom raised.

Perceptions of information regarding potentially negative aspects of screening

Nature of the FOB test

Many NPFPG participants felt that the description of the FOBt testing in the leaflet, which suggested that some people may find the procedure unpleasant or embarrassing, was excessively negative. Several individuals suggested that this information might prompt potential participants to experience the testing procedure in a way they might not otherwise have done.

You read it and you say 'Oh blimey. It is going to be unpleasant, embarrassing and unpleasant. I am not going to do that' and that can be as far as they get in the leaflet. (man, NPFPG 6)

Whilst a few PFG participants reported that they had found carrying out the FOBt to be unpleasant, the majority took a light-hearted or pragmatic view of the experience.

It is a messy business isn't it? – so we made a joke out of it, we made light of it all and we put my little grandson's potty in the bathroom. And we called it playing pooh-sticks! (woman, PFG2, positive FOBt + colonoscopy)

Bowel preparation for the colonoscopy procedure

Many PFG participants agreed that the bowel preparation for colonoscopy had been a particularly unpleasant and distressing experience. A number felt that it was inadvisable to be too

explicit about the nature of this procedure since this might cause distress or even decrease participation.

I: Do you wish somebody had told you what it was going to be like?

P: No. I might not have gone through with it! That was, by far, the worst part of the whole procedure, the day before. (man, PFG5, positive FOBt + colonoscopy)

I mean you can give too much information here. As I say we're going through a traumatic time because we've just failed a bowel screening test ... we know we've got a camera to be inserted which none of us look forward to no matter how positively we approached it ... and we know we've got to clean out our insides ... I think it's enough to be told that that's what you'll have to do without elaborating. (woman, PFG2, positive FOBt + colonoscopy)

Conversely, several individuals stated that they would like to have all available information about the screening process at the outset:

I think sometimes it's individual people. Some people do these things and want to know as little as possible. Other people do these things and want to know absolutely everything. I'm inclined to want to know absolutely everything so the more information the better. (woman, NCFG 2)

Colonoscopy risk

A considerable number of participants held particularly strong views with regard to the way information about the possible risks associated with colonoscopy should be communicated. The revised leaflet explained there is about a 1 in 150 chance of excessive bleeding and about a 1 in 1500 chance of a perforation of the bowel occurring following colonoscopy, and that in extremely rare cases colonoscopy may result in death, with current evidence suggesting that this may only occur 1 in 10 000 cases. A majority of both PFG and NCFG participants reported that they found this type of risk information to be alarming, and many felt that providing this information at the outset had the potential to create anxiety and reduce participation. Many participants felt that this information should either be presented in less detail, should be provided

at a later stage of the process only to participants who were offered a colonoscopy, or omitted altogether.

I think something ought to be said but a compromise would be to say 'as with all surgery there are risks associated and these will be explained to you by the nurse when you discuss the possibility of a colonoscopy' or whatever it is. I think there ought to be some mention but maybe not in too much detail. (man, NCFG 1)

I think it might be better at the second stage, if blood is detected and if you have to go for a colonoscopy, then I think one wants as much information as possible, but at that very first stage, I am not so sure. (man, PFG3, positive FOBt + colonoscopy)

There was something at the back here about colonoscopy... I mean that's a long way down the line from what we're being actively invited to participate in. So really they only need so much information. You start to give people too much and you suffer. (woman, PFG1, negative FOBt)

I actually highlighted that and said that, definitely, all that should be out. (man, NCFG 1)

A few participants in both PFG and NCFG groups reported that they did not find colonoscopy risk information to be alarming, with some indicating that they wished to have all information regarding the programme at the stage of having to decide whether to undergo FOBt screening.

I'd rather know risks and everything. It doesn't bother me ... I can't see any point in hiding facts from anybody. I know that it might affect some people but ... they're going to need it anyway if there are problems ... so what's point in pretending? (woman, NCFG 7)

You don't like to think that you're ever going to reach that stage but they've got to inform you of the possible consequences, you know. You'd be led down a blind alley almost wouldn't you? (woman, PFG2, positive FOBt + colonoscopy)

Perceptions of length and complexity of information

A number of NCFG participants expressed concerns relating to the format of the information provided to them (19 pages, A5). Some felt that people may be discouraged from reading

the leaflet due to its length and the detailed nature of the medical information it contained, and that this in turn could lead to a reduction in participation.

I don't know how you make it much shorter but it's the user friendliness to people who honestly would never read anything unless they were forced. (man, NPGF 6)

Desire to promote FOBt screening

A number of NPGF participants raised issues with regard to the provision of balanced information to promote informed choice. Some felt there was an inherent contradiction in establishing a screening programme and then not actively encouraging participation. Others felt that providing balanced information rather than encouragement was misguided or naïve, especially in light of the time, effort and resources spent on planning and implementation. Several participants felt very strongly about this point and became irritated when discussing the lack of guidance contained within the materials. These individuals often felt that the programme should be strongly promoted.

You've got a choice as to whether you actually do this or whether you don't but then the choice wouldn't be there if you didn't think it was valid or necessary. (woman, NPGF 2)

It actually makes me very cross, all this sensitivity about what you are doing. People in the end of the day, whatever you say in here, they can throw it in the bin or do what they want. You are not making them do it. But I think you could surely be encouraging people to follow a sensible course. (man, NPGF 6)

Similarly, a number of individuals in these groups were concerned that the tone of the leaflet seemed overly negative and that this might have an effect on uptake of screening. Some felt that the positive aspects of the programme ought to be emphasized in the leaflet in order to balance out alarming sections:

I found that it was written in a way that would frighten people and I am not sure whether that's the intention is it, to frighten people? (man, NPGF 3)

There's so many negative things here that it just makes you feel fear and we don't want to feel fear ... I'd just like it to have a more positive tone. We're not talking about dying here. The leaflet is about not dying and I think it should adopt that attitude. (woman, NPGF 5)

Discussion

The current study found extremely positive perceptions of screening for bowel cancer amongst focus group participants. In terms of perceptions of information regarding screening, participants almost exclusively identified items highlighting the benefits of the programme as important for others to know. There were a variety of responses to information regarding the potentially negative aspects of the programme, such as the risks associated with colonoscopy. Whilst some individuals believed it was appropriate for this information to be communicated to screening participants at the outset, others expressed concerns about the generation of anxiety and the consequent potential for decreased participation. These individuals suggested that this information should either be disclosed at a later stage, covered in less detail or omitted altogether. They did not seem concerned that by postponing information about colonoscopy, individuals could end up in the situation of having a positive FOBt result and then not wishing to proceed with colonoscopy, and possibly wishing they had never been tested. Some concerns were also expressed regarding the perceived negative tone of the leaflets and the high volume of information provided. A number of individuals took issue with the concept of providing explicit information regarding both the risks and benefits of screening rather than providing encouragement to attend.

The study utilizes qualitative methodology to provide insight into the public's perceptions of information regarding screening for bowel cancer. A limitation of the study is the likely bias in favour of positive perceptions of the BCSP inherent in individuals who have participated in the screening pilot, and to a lesser degree, indi-

viduals from the general population attending the focus groups. Similarly, the majority of focus group participants appeared to be highly motivated with regard to their health. Further work is also required in order to ascertain the perceptions of individuals declining screening. Nonetheless, individuals who attend screening make up the majority of those who are invited (59% of those invited to participate returned FOBt kits in the first phase of the pilot programme in England¹⁵). Therefore, the perceptions of these individuals are of considerable importance. A further limitation is the low level of participation by individuals from ethnic minority backgrounds (only three individuals from ethnic minority backgrounds participated in the focus groups). Individuals from different backgrounds may have held different perceptions regarding information about the screening programme, and further work with these groups is required. No formal data was collected regarding education or literacy levels of participants, which may also have provided further understanding of findings. The possibility of social desirability responding¹⁶ must also be acknowledged given the apparent link between the researchers and the BCSP. However, every effort was made by the researchers to minimize this, and the range of views expressed by participants would suggest it was not an important issue in this study.

The study findings add to a body of literature demonstrating the public's optimism about the benefits of mammography screening,¹⁷ cervical screening⁸ and PSA testing.¹⁸ The positive perceptions of screening for bowel cancer frequently remained when participants were provided with information detailing both the risks and benefits of the screening process, and were often expressed in tandem with a desire to reduce anxiety and promote screening by minimizing information concerning the negative aspects of screening. The variability in desire for information relating to the potentially negative aspects of screening in focus group participants has been demonstrated previously. For example, 39% of women in one study reported that they did not wish to receive detailed information on

the limitations of mammography screening,⁹ and in a similar study, significantly more women rated information regarding the benefits of screening mammography as 'very important' than information about the limitations.¹⁹ It has been suggested that individual's positive attitudes regarding screening may be a function of the vigorous manner in which screening has traditionally been promoted.⁷

The attitudes demonstrated by study participants towards the provision of balanced information designed to facilitate informed choice are of some relevance. A number of participants raised concerns about the provision of balanced information, with a few reacting to the lack of encouragement regarding participation contained in the information with irritation. Evidence from the treatment literature has shown that some individuals may not wish to be involved in making decisions regarding their care,²⁰ or may wish to review evidence about treatment options but follow the guidance of health professionals when making decisions.²¹ However, the relevance of this work to participation in cancer screening, where the decision-making process occurs largely in the absence of a health professional, is questionable.²² There is little published work directly examining the patients' preferred level of guidance or encouragement with regard to cancer screening decisions, and more research in this area is clearly needed. The roots of the desire for encouragement observed in the current study appear to be related to the overly positive perceptions of screening held by the majority of participants. It has also been suggested that the reduced input into medical decision making preferred by older individuals may be a cohort effect of growing up in an era of medical paternalism, or a developmental effect where reliance on others for medical decision making increases in older age.^{23,24}

The findings from the current study present a challenge for policy makers and providers of information to those eligible for screening. After years of debate, informed choice now prevails with respect to participation in cancer screening. It is clear that informed choice is an intricate concept, and whilst the provision of balanced

information is by no means sufficient to facilitate informed choice, it appears to be necessary.²² The importance of providing information to allow people to understand the possible risks, benefits and consequences of medical procedures is now embedded in government policy,¹³ and is stressed by professional^{3,4} and patient advocacy groups.¹⁴ It is neither the belief of the authors nor the purpose of this paper to suggest that those eligible for screening should have access to anything less than full and balanced information. However, there appears to be some variation in individuals' perceptions of both the level of detail and the level of encouragement that should be contained in such information. Therefore, an approach to information provision that recognizes the perceptions of these individuals may be required. An educational programme informing the public about informed choice may be necessary to challenge unrealistically positive perceptions of screening and promote understanding of why both the risks and the benefits of screening programmes should be understood. A flexible approach to information provision which recognizes this variation in desire for information may also be necessary. Indeed, one recent approach suggests that all individuals should be provided with a minimum level of information regarding risks and benefits, as well as the option of either following the guidance of an authoritative health body, or accessing more detailed information to assist in making an individual choice.²⁵ Despite years of debate regarding the role of patient autonomy in cancer screening participation, the views of patients themselves have been largely overlooked. Further research is needed to examine the level of guidance and the level of information that is required by those eligible for screening.

Conclusions

There is some variation in the type of information favoured by those eligible for bowel cancer screening, with some preferring to minimize information regarding the negative aspects of screening and others happy to be

provided with all information at the outset. Some screening participants oppose the provision of balanced information to facilitate informed choice, preferring to be provided with encouragement to participate in screening. Further research is needed to accurately establish the level of information and guidance required by those eligible for screening and to capture the views of those who have opted not to be screened.

Practice implications

Approaches to the provision of information to those eligible for screening that recognize the perceptions of patients are required. Educational programmes informing the public about informed choice may be necessary to challenge unrealistically positive perceptions of screening and promote understanding of why both the risks and the benefits of screening programmes should be understood. Similarly, a flexible approach to information provision, which incorporates the option of following the guidance of an authoritative health body, may be warranted.

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