

Slow on the uptake?

Encouraging male participation in the NHS Bowel Cancer Screening Programme



David Wilkins

Men's Health Forum



About the Men's Health Forum

The Men's Health Forum (MHF) is the only independent national organisation campaigning for better health for men and boys. We are a registered charity and a Strategic Partner of the Department of Health. Our vision is a future in which all boys and men in England and Wales have an equal opportunity to attain the highest possible level of health and well-being.

We work to achieve this through:

- Policy development, research and lobbying
- Supporting other organisations and services to engage more effectively with boys and men on health issues
- Leading the annual National Men's Health Week
- Publishing the award-winning range of mini manual health booklets for men
- Running the unique "consumer" website for men: www.malehealth.co.uk.
- Working with MPs and government
- Developing innovative and imaginative best practice projects
- Training service providers and others
- Collaborating with the widest possible range of interested organisations and individuals.

Our work focuses particularly on those groups of men with the worst health and we are striving to ensure that we take account of the diversity of men and their needs.

Although our concentration is on male health, we are committed to the principle of achieving better health for both sexes. We recognise particularly that the health of men and women is often interconnected. We do not advocate improving male health at the expense of female health, nor do we argue in favour of diverting health resources from women to men.

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Executive Summary

Male health is poorer than it need be

Men have worse outcomes than women for many of the most serious health conditions.

These outcomes are believed to be associated with men's less effective use of services, lower levels of health knowledge and poorer self-efficacy. It is also believed that cultural preconceptions about "masculine" behaviour may inhibit male health-seeking. Progress over the past ten years has been very good compared with preceding decades but, as the recently published Public Health White Paper, *Healthy People, Health Lives*, observes (in relation to international comparisons of disease incidence): "...there is significant potential for further improving male life expectancy".

Men and the prevention of illness

Historically, men have tended to be less interested in preventive health measures (for example, men are markedly less likely to attend weight loss services and smoking cessation services). Until very recently, it was not possible to observe whether men were also less likely to take part in health screening programmes because the way that the science had developed had meant that the major universal national screening programmes (breast and cervical screening) were only applicable to women. The National Chlamydia Screening Programme, which relies largely on opportunistic engagement with young people, is open to both sexes and commendably, has made significant efforts to encourage male participation. It has had some measurable success in doing so, but its broad general focus remains on women.

The NHS Bowel Cancer Screening Programme (NHSBCSP), which began in 2006 and now covers the whole of England, therefore provided the first opportunity for all men within a particular qualifying demographic to participate by personal invitation in a national screening programme. Perhaps predictably, male uptake within the programme has been lower than female uptake. Since the inception of the programme, 51% of men have taken up the offer of screening compared to 56.6% of women.

This is an important issue for two reasons. First, because of the obvious need (and statutory obligation) for the NHS to achieve equitable use of services wherever possible. Second, because men are much more likely than women to develop and die from bowel cancer; incidence and mortality rates for bowel cancer more than half as high again in men.

Objectives of the MHF Bowel Cancer Project

The Men's Health Forum Bowel Cancer Project (henceforward "the project") commenced in 2007. It was originally intended to end in 2010 but the end date was subsequently re-scheduled to March, 2011. The project was funded by the Department of Health. The objectives of the project were:

- To understand why men appear less willing than women to participate in the NHSBCSP.
- To recommend actions which might encourage men more seriously to consider participating in the NHSBCSP and thus potentially increase male uptake and close the gap in uptake between men and women.
- To add to the more general knowledge-base about "what works" in encouraging and enabling better male health.

Structure of the MHF Bowel Cancer Project

The project had four phases:

Phase 1

(July 2007 – March 2008)

A scoping review of the literature in relation to male uptake of bowel cancer screening. The review took particular account of the qualitative research conducted as part of the pilot programmes for the NHSBCSP and examined some of the obstacles from a specifically male point of view. It also considered men's knowledge and attitudes in relation to cancer more generally.

Phase 2

(March 2008 – February 2009)

The knowledge gained in Phase 1 was used to develop the content for a series of discussion groups with randomly selected men in the target age group for the NHSBCSP. These discussion groups sought to explore in detail the key obstacles for men, and invited participants to make their own suggestions for encouraging greater engagement of men with the NHSBCSP.

Phase 3

(February 2009 – January 2010)

Phase 3 used the knowledge and ideas generated in Phase 2 to develop a questionnaire. The questionnaire was used to conduct a postal survey of randomly selected men and women in the target age group. The objective of the postal survey was to help narrow down the ideas generated so far to a series of workable recommendations validated by the consultation process.

Phase 4

(January 2010 – March 2011)

The draft recommendations were reported to a seminar of NHSBCSP professionals, academics with an interest in bowel cancer screening, and other people working in the field. The seminar considered the recommendations in the context of the debate about other screening initiatives for men. The publication of the present report forms the final element of Phase 4.

Project Outcomes

Phase 1 confirmed that men tend to be less likely to participate in bowel cancer screening in most countries that have programmes. This suggests that there is something consistently "male" about not taking part (although the size of the gap in uptake between men and women varies from one country to another). A number of theoretical explanations emerged for this pattern of lower male participation. Among others, these explanations included: men's disengagement from health improvement programmes in general; the possibility that men may be more likely to deny their vulnerability to disease; the possibility that men may have a more pessimistic view of cancer prevention; and the fact that women are, for historical reasons, more familiar with screening programmes.

The discussion groups in **Phase 2** suggested that fatalistic attitudes and fear of a positive diagnosis were deterrent factors for some men – although not, perhaps, to the extent that might have been expected. Some men also felt that the messy, “unsavoury” nature of the process would put them off taking part. Participants also identified a barrier which we had not entirely foreseen – the idea that if one feels fit and well, then the offer of screening might not seem relevant. There was also some cynicism about health professionals, which seemed potentially to contribute to the barriers to service use for some men. There was widespread belief that women were “better at” health than men, and that that was related to women’s greater familiarity with preventive services. Many married men identified their wives as the greatest influence on whether or not they took action when they were experiencing health problems.

The **Phase 3** postal survey generated 579 returns from men and 122 returns from women – a response rate of 33%. The inclusion of women enabled us to make comparisons and to look for differences between the sexes that might help us to home in on some of the most important factors for men. We were looking both for factors that might be inhibiting male participation and might be capable of change; and to identify those elements of the programme that might actively be encouraging male participation and which could be enhanced.

The key issues to emerge from the postal survey were that both men and women give great weight to the opinion of their GP when making decisions about their health, and would welcome greater involvement of GPs in the NHSBCSP. Married men were likely to identify their wives as almost as important an influence as their GP, while women identified a much wider range of influences on their health decision-making. Both sexes favoured gender-specific information materials and tended to express a preference for simplified information and memorable slogans. Men were noticeably less likely than women to be deterred by the practical and psychological problems associated with the screening process.

In **Phase 4** of the programme we presented the findings from both the discussion groups and the postal survey to a seminar of around 40 experts. We also invited this group to discuss our recommendations in the broader context of thinking about men’s engagement with other screening opportunities – particularly elective PSA testing for prostate cancer and the development of the NHS Abdominal Aortic Aneurysm Screening Programme, which began its gradual national roll out in 2009, and which targets only men.

Recommendations

The evidence from the project supports the identification of six general principles which can be used to inform the style and content of communication materials associated with the NHSBCSP. It also supports two specific recommendations. The general principles are given first below, followed by the two recommendations:

General principles

1. Make sure that the practical elements of the FOBt are properly understood by men.
Men are more likely than women to see the test as simple to do, and less likely to feel the psychological constraints that deter some people. It may be that the message about practicality could be brought to the forefront of information.
2. Both men and women value information materials that are written specifically with the sex of the recipient in mind.

3. Both sexes prefer short, simple and memorable forms of expression in information materials. We note however, that this preference is not entirely straightforward to achieve. Ethical and medico-legal considerations and the unavoidable need to deliver technical information limit the extent to which the information can be “streamlined”. At the same time, we believe it should be perfectly possible to find an informal and constructive “tone of voice” and succinct, memorable forms of words that stress (for example) the benefits of detecting cancer early or the importance of not making a snap decision to throw the kit away.
4. The inclination in men simply to “deny” health concerns, either through inertia or unacknowledged fear, is not perhaps as commonplace as some people believe. Nevertheless, it is an important factor in some cases and is recognised by many men as a “male characteristic”. It is important to find ways of taking this underlying issue into account when developing communication materials for men.
5. For some men who feel fit and well, it may seem that the FOBt is either not relevant or that somehow there is “more to lose” by taking it (because it might find something wrong). Similarly, some men may react to the inclusion of information about the symptoms of bowel cancer in the NHSBCSP materials, by assuming that they do not need to take part in the programme (because they have no current symptoms). It might be useful to counter these beliefs in information material directed at men.
6. It is crucial to avoid falling back on a “default”, stereotyped view of men when considering how to frame health messages in a “male-sensitive” way (for example by routinely using sports-related imagery). These kinds of “male” approaches will not appeal to all men and indeed, may not appeal to a majority. This is of course, not to say that such approaches have no value at all. It remains important to communicate with men “as they are”.

Recommendations

1. The importance of GPs and other primary care staff

The issue that came up time and again in different forms during our research was the high value placed on the GP and primary care staff in informing personal decision-making in health matters. The advice and encouragement of GPs and primary care staff is important to both sexes but appears to be even more so to men. We recommend the development of interventions in which the patient’s GP is involved in the invitation to participate in the NHSBCSP. We recommend that such interventions involve direct contact between the patient and his local surgery. Ideally, this would incorporate the option of face-to-face contact if that was what the patient wished but a signed letter would be another option. There may be other alternatives.

This approach does have its problems. For obvious reasons of informed choice, GPs and other primary care staff cannot simply “tell” men to take the FOBt, either in the letter of invitation or during a consultation. Furthermore primary care services are often limited for time and resources. It would be necessary to develop an approach that was consistent, could be delivered quickly, and was based on the notion of helping people to decide for themselves. We believe that it is possible to do this.

2. The importance of spouses and partners in men's decision-making

There seems no doubt that, for men who have a spouse or partner, that person is likely to be very influential in their decision-making around health. The idea of seeking to influence men's health-related behaviour via their spouse or partner is however, fraught with problems. Unlike the problems associated with Recommendation 1 above, these problems are ideological rather than practical. We would not want to endorse or reinforce the notion that women somehow have de facto responsibility for the health of their husband or partner. Quite apart from the assumption that this involves about the role of women within relationships, this notion also seems to undermine the idea of enabling men to take greater responsibility for their own health. At the same time, involvement with the health needs of one's partner is a commonly understood feature of many people's long-term relationships (albeit that the balance of that engagement seems more often weighted in one direction than the other).

Our solution is to propose a way forward based on encouraging men simply to discuss their decision-making about the FOBt with anyone with whom they feel comfortable. Our evidence suggests, that the person to whom most men would naturally turn is their wife or partner. Others however, might choose another relative, or a friend (obviously, for men who have no partner, those are the options available anyway). Equally a man might seek a conversation with his GP (or other primary care staff), which brings us back Recommendation 1 above.

We would like to see the development of interventions in which men are encouraged – or perhaps, overtly advised – not to make a decision about the FOBt until they have spoken to a trusted relative, friend or health professional (e.g. GP, practice nurse or a pharmacist). This could be achieved very simply by the use of a variety of media, nationally or locally and/or by an insert of some kind in the NHSBCSP information pack. Generalising the approach in this way would limit the extent to which we were directly giving responsibility to women. It would also mean that we were less likely to disadvantage men who do not have a partner.

1: Background and general introduction

Men have poorer health outcomes

By almost all measures of physical health, men have poorer outcomes than women. The most obvious indicator of this is that men do not live as long. Male life expectancy at birth in the UK is currently 78, female life expectancy is 82.¹ Gender is not the only influence on longevity but the gap between men and women is a consistent factor across socio-economic levels – and indeed, is somewhat larger at lower levels, suggesting that men experience a steeper “social gradient” of health than women (see table below):

Deprivation tenth (least – most deprived groups)	1	2	3	4	5	6	7	8	9	10
Female life expectancy	82.4	81.9	81.9	81.2	80.7	80.2	79.7	79.2	78.8	77.5
Male life expectancy	78.7	78	77.7	76.9	76.3	75.6	74.6	73.9	73.1	71.5
Difference (male – female)	-3.7	-3.9	-4.2	-4.3	-4.4	-4.8	-5.1	-5.3	-5.7	-6.0

Data from 2001 Census

Life expectancy is blunt mechanism for understanding health differences between population groups but has the advantage of being easily understood. There is, of course, no single explanation for this gap between the sexes. Men have a greater likelihood of dying from a very wide range of causes at an earlier age. The two most important factors however, are cancers and diseases of the circulatory system. The mortality rate for circulatory disease in men is 221 per 100,000 population compared with 142 per 100,00 for women,² and men are 60% more likely to develop, and 70% more likely to die from, the 13 most common cancers that are not specific to one sex or the other.³ Men are also markedly more likely to die from a number of other causes, some of which often occur at a young age. These causes include accidents, suicide, and deaths associated with drug or alcohol misuse.

The reasons for men's poorer outcomes

The argument is sometimes advanced that the difference in life expectancy between men and women is biologically inevitable. In other words, that the gender gap is linked to inherent, fixed differences between the sexes. In fact, the scientific consensus tends to be that although such genetically pre-determined differences may exist, they are, at most, only partly responsible for the discrepancies in morbidity and mortality rates.⁴ This can be evidenced at a fairly simple level by making comparisons between countries. The gap in life expectancy between men and women varies widely across Europe with distinct differences, even between neighbouring countries; in Sweden for example, the gap between the sexes is four years, in Finland it is almost seven.⁵

Biology alone cannot explain the extent of such variations. This means we need to look beyond disease and seek explanations in differences in health knowledge, attitudes and behaviours, which do of course vary greatly between nations. In many countries, many of the “lifestyle” risks associated with poorer health are more commonly seen in men.⁶ For example, in the UK, men are more likely to be overweight or obese (66% of men compared with 57% of women⁷); more likely to drink alcohol to excess (31% of men drink in excess of the recommended safe level compared to 20% of women⁸); and more likely to have a poorer diet and a poorer understanding of nutrition.⁹ Men also remain more likely to smoke than women, albeit by a much smaller margin than in the past (22% of men compared with 20% of women¹⁰). Although men are more likely to be physically active than women, only 40% are active at the level recommended for maintaining good cardiovascular health.¹¹ Men also tend to be poorer users of services; for example men are 20% less likely to use primary care services than women.¹²

In short, non-biological factors, particularly attitudinal and behavioural factors, are extremely important determinants of male morbidity and mortality. Since these non-biological factors are not fixed - that is to say, they are capable of change in response to external intervention – it is consequently safe to conclude that large numbers of men are dying earlier than they need.

Finally, it is important also to remember that, in addition to the differences in health outcome between the sexes, there are also very significant differences between groups of men. Much of this latter is explained by socio-economic factors. English male life expectancy varies greatly by region, from its highest at 84.4 years in the London Borough of Kensington & Chelsea to its lowest, in Blackpool, at 73.7 years.¹³ Even within Kensington & Chelsea however, male life expectancy varies by seven years from the poorest parts of the borough to the wealthiest.¹⁴ There is an argument therefore that in seeking to close gaps in health outcome between men and women, we should, wherever possible, simultaneously be seeking to close gaps between the poorest men and the most well off. That these objectives are closely linked is evidenced by Table 1 above, which suggests that actions specifically intended to improve male health will also have a valuable impact on reducing the “social gradient” in health inequalities.

Tackling men’s poorer outcomes

As we have seen, men’s poorer health outcomes occur across a wide range of health concerns. These poorer outcomes are associated with less effective use of services, lower levels of health knowledge, poorer self-efficacy, and cultural preconceptions which may inhibit health-seeking behaviour. Progress over the past ten years has been very good compared with preceding decades but, as the recently published Public Health White Paper, *Healthy People, Health Lives*, observes (in relation to international comparisons of disease incidence): “... there is significant potential for further improving male life expectancy”.¹⁵

The evidence base about “what works” in male health remains in a state of development although it is much improved in recent years. One of the key lessons is that, because the problem is multi-factorial, it is important not to look for universal solutions. If there is to be progress, it will come by examining each disease, each service and each health behaviour and asking, in each case, a simple question: “Are there are factors capable of change that may lead to better outcomes for men?”

The answer is often “yes”. Moreover, and surprisingly often, the changes that can make a difference turn out to be simple and inexpensive ones. There is also some confidence now in some general principles that can be usefully be applied. This often gives a starting point. The difficulty is always in the detail and it is important fully to understand the context and the particular factors in the particular case. That has been the objective of the project described in this report.

Finally, we should remind ourselves that these issues of gender differences are not just important for the obvious professional reasons or in order to ensure the most effective use of public funds. There are now legislative imperatives to close gaps in use of services and gaps in health outcome. Details of the legislative position are given in the box below.

The Equality Duty

The Equality Act 2006 prohibited sex discrimination in the exercise of public functions. It also placed a duty on public authorities, including the NHS, to promote equality of opportunity between men and women (the “Gender Equality Duty”, or GED). The intention of the Act was that public bodies should seek to achieve equality of outcome between men and women using public services, wherever that was possible. Similar duties already existed in respect of people of different racial origins and disabled people.

The Equality Act 2010 brought together all the existing provisions of previous legislation in one unified *Equality Duty*. This new overall duty includes additional responsibilities in relation to age, sexuality and religious belief but otherwise has precisely the same effect as its predecessor in relation to gender equality. These additional duties will also contribute to addressing the diverse needs of men and boys.

Further information is available from the Government Equalities Office.

2: Introduction to the Men's Health Forum Bowel Cancer Project

The NHS National Bowel Cancer Screening Programme

In July 2006, the first invitations were sent out for the NHS Bowel Cancer Screening Programme (NHSBCSP) for England. Initially the programme was available only in certain parts of the country but it is now fully operational nationwide. It currently offers screening every two years to all men and women aged between 60 and 69, but is in the process of being extended to all people aged between 70 and 74. The programme will achieve full national coverage for this upper age group within the next couple of years. Although not routinely included in the programme, people aged above the higher age limit can request a screening kit by calling the NHSBCSP's national helpline number.

The screening test used in the NHSBCSP and the range of possible outcomes in individual cases are described very briefly in the section below, followed by a section which gives a summary overview of the operational structure of the programme. This information is offered by way of background and in order to give readers a sense of the value of the programme both to individuals and to the NHS. The amount of detail is however kept to a minimum since most readers are likely already to be familiar with the test and with the management structure of the NHSBCSP.

Readers who require further information are advised to visit the web pages of the NHSBCSP at: www.cancerscreening.nhs.uk/bowel/index.html

The screening process

The NHSBCSP uses the faecal occult blood test (FOBt) delivered via a self-administered home-testing kit. Each person in the qualifying age group receives an initial letter explaining that s/he will shortly be invited to take part in the programme and enclosing a booklet *Bowel Cancer Screening – The Facts*. Around a week later s/he receive by post a kit that enables him or her to collect a tiny sample from each of three separate bowel movements. These samples, each smeared on to a specially prepared card, are returned in a post-paid envelope to one of the five regional NHSBCSP hub laboratories. At the laboratory the samples are subject to a chemical process which detects the presence of minute quantities of blood in the stool. Blood in the stool is an "occult" (hidden) symptom that might indicate early stage bowel cancer. The FOBt is capable of detecting this symptom, in many cases, long before the person taking the test would have become aware of it.

Blood in the stool does not in itself indicate that the person taking the test has developed bowel cancer, but it does make it advisable that he or she should have further, more detailed, tests. Occult blood is detected in around 2 tests in every hundred. People whose test shows this result are invited to attend a screening centre for further investigations. In most cases this means a colonoscopy.

During a colonoscopy, the patient is sedated and a thin flexible tube with a tiny camera at one end is inserted into the back passage and used to examine the lining of the large bowel. Of those people who require colonoscopy following the FOBt, around half will be found to have no problems, and will require no further investigation or treatment. Of those remaining, most (four out of every five) will be found to have polyps in the bowel. Polyps are not cancer but it is important to have them removed as they can become cancerous in time. Polyps can almost always be removed on sight during the colonoscopy and the procedure is usually painless. Those polyps that are removed are checked for cancerous cells.

The remaining patients (10% of those who required colonoscopy, roughly 0.2% of those who initially took the FOBt) will be found to have bowel cancer. In many cases however, these cancers will have been identified at an earlier stage than otherwise would have been the case. Because the FOBt results in early detection, the patient's cancer can receive treatment more quickly. Research suggests that the risk of death from bowel cancer in the population as a whole can be reduced by around 16% where a regular screening programme of this kind is used.

For the sake of completeness it should be added that about 4% of people completing the FOBt receive an unclear result the first time their sample is processed. An unclear result is when a suggestion of blood is detected in the samples, but not enough to meet the definition of an abnormal result. These people are invited to submit a second (and sometimes a third) test, and in the majority of cases the re-test shows no traces of blood.

Operational structure of the NHSBCSP

The NHSBCSP is delivered by a national network of "programme hubs" and "screening centres".

Programme hubs

There are five programme hubs located regionally around the country:

- Midlands and North West (Rugby)
- Southern (Guildford)
- London
- North East (Gateshead)
- Eastern (Nottingham)

Each hub provides a centralised administrative and support service on behalf of the network of screening centres in its area. The number of screening centres linked to each hub varies from six (London) to seventeen (Southern).

Programme hubs are responsible for:

- Maintaining the database of people eligible to take part in the screening programme
- Sending out the information letters and screening kits
- Dealing with enquiries from individuals taking the test
- Processing the returned samples
- Notifying people of their individual result
- Issuing appointments for further tests at a local screening centre when an individual's FOBt gives an abnormal result.

Screening centres

The defining aspect of a screening centre is that it provides the necessary facilities, and has achieved the necessary staffing and performance standards to carry out colonoscopies within the requirements of the NHSBCSP. The physical facilities of a screening centre are typically located on the site of a major hospital, although a single named screening centre may operate on more than one site. In many cases screening centres serve geographical areas that are co-terminus with a group of NHS trusts. In some cases however, for geographical or administrative reasons, some trusts have contracts with more than one screening centre.

Screening centres also provide screening nurse clinics, which are the first point of contact with a healthcare professional when someone receives an abnormal FOBt result. The screening nurse clinic is used to discuss the colonoscopy procedure, and assess the patient's fitness for it.

The MHF's interest in the NHSBCSP

The introduction of the NHSBCSP was preceded by a lengthy pilot screening programme which took place in two "rounds" during 2001 – 2003, and 2003 – 2005. The pilot programmes involved offering FOBt screening to all patients aged between 50 and 69 registered with all GP practices in Tayside, Grampian & Fife (the "Scottish pilot"), and Coventry & Warwickshire (the "English pilot"). Both rounds of the pilot programme were evaluated in considerable detail and a lengthy evaluation report into each was published in July 2003¹⁶ and February 2006,¹⁷ respectively. The first report dealt with both the Scottish and English pilots together, the second report with the English pilot only. The combined population (English and Scottish pilots) in the target age group in the first round was half a million people. The population in the target age group in the second round (English pilot only) was 128,000 people.

During both rounds of the pilot programmes, men were significantly less likely than women to take part at all stages of the process. The most basic measure of participation was the proportion of people completing the FOBt and returning stool samples for analysis. During the first round, 52% of men returned samples compared with 61% of women.¹⁸ During the second round, 48% of men returned samples compared with 56% of women.¹⁹ If proportions of men taking up the offer of screening had equalled those of women, then around 10,000 more men would have been screened in the first round and over 5,000 men in the second round.

These discrepancies between men and women in terms of uptake in the two rounds of the pilot programmes are of crucial importance and establish the MHF's interest in the future development of the NHSBCSP. The detection rate for bowel cancer in men submitting a FOBt for analysis was 1.95 per 1000 in the first round (in the English pilot) and 1.4 per 1000 in the second round. If we return to the theoretical numbers of men who would have been screened had the same proportion of men as women participated, it can be observed that 20 more men in the first round would have had their bowel cancer diagnosed, and seven more men in the second round.

The MHF was concerned that there was a risk that the gender imbalance in uptake in the two pilot programmes would be repeated across the whole target population once the programme was rolled out nationwide. Precise figures are very difficult to calculate because of the several variable factors but if that had happened, 250 – 350 cancers in men would have gone undetected in each two year cycle of the NHSBCSP. This is not to mention of course, the missed diagnoses of polyps and adenoma, which are greatly more common and which, as we have seen, are in many cases predictors of cancer in the future.

We have seen that men have poorer outcomes than women over a wide range of health conditions. Cancer is a prime example of this – and bowel cancer no exception. Men are more than one and a half times as likely to develop and die from bowel cancer²⁰ and have poorer five-year survival rates (51% v 53%).²¹ We have seen that these poorer outcomes may reflect both greater lifestyle risks in men and/or men's lower levels of engagement at all levels of provision. Remedial action needs to be taken at whatever level the lack of engagement occurs. Taking action in this way acknowledges that these gender differences in health outcome and engagement with services are an inequality which may stem from the way services are planned, organised and delivered.

The MHF has consistently argued for health policy that takes account of men's particular needs and sensibilities. In recent years we have demonstrated in large-scale projects that services designed specifically for men and "marketed" appropriately can reverse the pattern of lower male than female participation. Examples of MHF projects that have been successful in encouraging male participation include the Men and Chlamydia Project of 2004,²² and the "Workfit" project of 2005,²³ a weight loss programme aimed at BT employees nationwide which used an online system for delivering information and collecting data.

The MHF took the view that the differential uptake between men and women evident in the pilot programmes could be reduced by appropriate action – and that ultimately it should be the target to eliminate the differential altogether. That it was appropriate to try to do this was endorsed in several places by the authors of the evaluation reports from both rounds of the pilot programme. A typical observation is this one from the evaluation of the second round:

*... there will be a need to develop tailored [information] materials for individuals in low-uptake groups.*²⁴

Finally, it should be added that the discrepancy in uptake between the sexes has continued into the NHSBCSP proper. Since the rollout of the programme began, 51% of men have taken up the offer of screening compared to 56.6% of women. Encouragingly, this gap is smaller than that in the pilot programmes but it remains significant. As we have seen, men are at greater risk of developing bowel cancer, so it is essential that they we ensure they are not disadvantaged within the national programme. Men's greater risk of bowel cancer is reflected in positivity rates within the NHSBCSP to date; 2.05% of men test positive for faecal occult blood compared to 1.57% of women.

Project funding

The core funding for the MHF Bowel Cancer Project was provided by the Department of Health under the Section 64 General Scheme of Grants (Section 64 of the Health Services and Public Health Act 1968). This scheme allows the Department of Health to make grants to voluntary organisations in England for activities which support the Department's policy priorities. During the lifetime of the project, additional funding was secured from Roche Products Ltd and NHS Cancer Screening Programmes. The former was added to the general project budget. The latter grant was specifically made to support the postal survey in Phase 3.

3: Structure of the MHF Bowel Cancer Project

The Men's Health Forum Bowel Cancer Project (henceforward "the project") commenced in 2007. It was originally intended to end in 2010 but the end date was subsequently re-scheduled to March, 2011.

The project was managed by the MHF and much of the work was undertaken in-house, although the delivery of the focus groups and the administration of the postal survey in Phases 2 and 3 respectively, were contracted out to a market research firm specialising in health and public sector research.

An Expert Advisory Group was established at the outset of the project. This group met several times over the lifetime of the project and was kept informed of progress throughout. This group also reviewed the various interim reports produced during the project. The MHF acknowledges the support of the Expert Advisory Group with great gratitude. The advice and support given by the individual members was of enormous value and it is true to say that some elements of the work would not have been possible without their expertise. Membership of the Expert Advisory Group is given at Appendix 1.

Three objectives were set for the project:

- To understand why men appear less willing than women to participate in the NHSBCSP.
- To recommend actions which might encourage men more seriously to consider participating in the NHSBCSP and thus potentially increase male uptake and close the gap in uptake between men and women.
- To add to the more general knowledge base about "what works" in encouraging and enabling better male health.

In order to understand the content and development of the project, it is particularly important to understand the second of these three objectives. The purpose of the research was not to find ways of "marketing" uptake of the FOBt to men. It was to find ways of encouraging men to participate fully in the personal decision-making process. The expectation was that this would lead to more men making a properly informed decision to participate on their own account.

The project was organised in four phases. Each of these phases is reported on separately in the four chapters which follow:

Phase 1

(July 2007 – March 2008)

A scoping review of the literature in relation to male uptake of bowel cancer screening. The review took particular account of the qualitative research conducted as part of the pilot programmes for the NHSBCSP and examined some of the obstacles from a specifically male point of view. It also considered men's knowledge and attitudes in relation to cancer more generally.

Phase 2

(March 2008 – February 2009)

The knowledge gained in Phase 1 was used to develop the content for a series of discussion groups with randomly selected men in the target age group for the NHSBCSP. These discussion groups sought to explore in detail the key obstacles for men, and invited participants to make their own suggestions for encouraging greater engagement of men with the NHSBCSP.

Phase 3

(February 2009 – January 2010)

Phase 3 used the knowledge and ideas generated in Phase 2 to develop a questionnaire. The questionnaire was used to conduct a postal survey of randomly selected men and women in the target age group. The objective of the postal survey was to help narrow down the ideas generated so far to a series of workable recommendations validated by the consultation process.

Phase 4

(January 2010 – March 2011)

The draft recommendations were reported to a seminar of NHSBCSP professionals, academics with an interest in bowel cancer screening, and other people working in the field. The seminar considered the recommendations in the context of the debate about other screening initiatives for men. The present report forms the final element of Phase 4.

4: Phase 1 – scoping review of the literature

Introduction

Phase 1 of the project involved searching the relevant literature in order to establish what was already known about men and bowel cancer screening in particular, and male attitudes and knowledge in relation to cancer more generally. The findings from this process were discussed with the Expert Advisory Group, preparatory to developing the work of the project in more detail.

The rest of this chapter is a précised version of the paper that was presented to the Expert Advisory Group in January 2008. It should be noted that, as the FOBt has become more widely used as a basis for screening programmes, there has been a significant increase in research both in the UK and internationally. Because our paper was written during 2007 however, this more recent research is not included.

Background

The obvious starting point for any analysis of men's attitudes to bowel cancer and bowel cancer screening is the evaluation reports from the first two pilot rounds of the NHSBCSP in 2001 – 2003, and 2003 – 2005. For the purposes of this chapter, the more important evaluation report is certainly that of the first round. This is because that report included the findings of two pieces of qualitative research, jointly described in the evaluation report as the "psychosocial survey". The psychosocial survey consisted of:

- Over 2000 questionnaires completed by a randomly selected group of people eligible to participate in the screening programme. The survey group comprised a mix of people who had proceeded to different stages of the screening process, including, in some cases, an ultimate diagnosis of cancer. It also included "non-responders" – people who had failed to take up the offer of screening in the first place.
- Four focus groups (36 people in total) conducted with men and women eligible to participate in the pilot programme. The focus groups considered three aspects of bowel cancer screening: awareness and understanding of bowel cancer; perceptions of bowel cancer; and acceptability of the FOBt.

It should be said at the outset that neither of the evaluations set out specifically to examine gender as a factor in uptake rates. However, many of the findings (including the findings of the psychosocial survey) are broken down by gender in the evaluation reports. As a consequence these reports do contain a lot of relevant and useful information in relation to the differences between men and women.

Statistical observations

As we saw in Chapter 2, men were significantly less likely than women to take up the offer of a FOBt in both rounds of the pilot project even though both sexes received precisely the same information, invitation letter and so on. This difference in uptake varied according to age, social class and ethnic origin but the pattern of lower male uptake was consistent within all those sub-groups. During the first round of the pilot, 52% of men returned samples compared with 61% of women; during the second round 48% of men returned samples compared with 56% of women.

This discrepancy between men and women is not limited to the UK. Several European countries, the USA, Australia and Japan have either already introduced regional FOB testing or have conducted large-scale trials. Examples of differences in uptake between men and women include: Burgundy region of France - 58% uptake in women, 53% uptake in men (approximately 35,000 people p.a. over 11 years);²⁵ Catalonia region of Spain – 21% uptake in women, 19% uptake in men (approx 130,000 people over two rounds);²⁶ various regions of Italy – 50% uptake in women, 44% uptake in men (approximately 830,000 people in one year);²⁷ Higher total uptake by women has also been reported in Hawaii²⁸ and Israel,²⁹ in both cases among ethnically diverse populations. This consistency between different nationalities suggests that there is something “inherently male” about the decision not to participate. At the same time, the significant variation by degree in different countries suggests that any such inherent differences may be moderated by local cultural factors.

Interestingly, in the USA where FOB testing programmes have been aimed, by and large, at self-selected groups (i.e. volunteers, or programmes which require the service user to take the initiative), proportions of men and women have been much closer. In some cases indeed, a higher proportion of men than women have participated in programmes (or taken an FOBt as part of an individual consultation).³⁰ The large-scale Minnesota Cancer Control Study³¹ which is sometimes compared with the NHSBCSP pilots is one such. For the reason given in the first sentence of this paragraph however, these US programmes are not directly comparable to the NHSBCSP and may reflect the greater economic power of men, or men’s greater access via employer-sponsored programmes in the US.

The damaging effect for men of this discrepancy between the sexes is self-evident but it becomes even more disadvantageous once the incidence rates for bowel cancer are taken into account. As we also saw in Chapter 2, men are much more likely than women to develop bowel cancer at all ages within the age range of the NHSBCSP. As would be expected, this meant that diagnosis rates in the NHSBCSP pilot programmes were higher in men. 1.95 cases of bowel cancer were detected per thousand men in the first round compared to 0.84 cases per thousand women;³¹ and 1.4 cases per thousand men were detected in the second round compared to 0.53 cases per thousand women.³²

These differences in diagnosis rates (which are also repeated internationally in varying degree) are in themselves, a convincing argument for concentrated action to increase participation by men in the NHSBCSP. It can be seen that greater numbers of men taking part in the programme will result in a disproportionately greater improvement in the detection rate for bowel cancer overall.

The psychosocial survey in round 1

For some of the measures considered in the psychosocial survey there was no significant difference between men and women. Examples of such areas included; “perceived susceptibility to bowel cancer” and “perceived efficacy of the FOBt in reducing the risk of developing bowel cancer”. Indeed, the proportion believing that the opportunity to take the FOBt was a valuable one, did not fall below 88% for either sex, even among those who chose not to participate in the programme. That there was a high degree of unanimity between men and women on this point, makes the gender differences in uptake even more interesting.

The most notable of those differences is perhaps that men scored significantly higher than women on all measures of the “perceived severity” of bowel cancer – for example: 60.5% of men believed that bowel cancer would cause serious physical pain (compared with 56% of women); 47.6% of men believed that bowel cancer would damage important relationships in their lives (compared with 40.2% of women); and 71.9% of men believed that a diagnosis of bowel cancer was likely to be terminal (compared with 66% of women).³⁴ In other words, men’s views of bowel cancer tends more towards the pessimistic. The evaluation report draws particular attention to the possibility that this increased perception of severity in men “may be important in explaining demographic differences in uptake”.³⁵

It is not at all clear why men should take this view. It can be observed however that, since perceived severity is, at least theoretically, an argument in favour of participation, there is a possibility that men’s lower participation rates represent a form of “denial”. This conclusion is tacitly acknowledged (in reference to both sexes) by the report’s authors who observe in an elegant phrase, that “non-uptake may be an avoidant response to a threat of a positive result”.³⁶ It should perhaps be observed too that, in one sense, a greater fear of bowel cancer among men of this age is not by any means irrational since, as we have seen, such men are actually much more likely than women of the same age to develop the disease.

The psychosocial survey also revealed that there are some obstacles to participation that are more common in women than men. In particular, women are significantly more likely than men to report barriers of practical difficulty in respect of the FOBt (physical disability, visual impairment) and – perhaps more surprisingly – more likely to report psychological difficulty (i.e. that the test is “disgusting” or “embarrassing”).

Having made these observations however, we should remember that just because a higher proportion of men than women regard the likely consequences of diagnosis with bowel cancer as “severe” does not mean that large numbers of women do not feel the same way. Likewise, although women are more likely than men to find the process of the FOBt “embarrassing” and/or “disgusting”, a significant minority of men also had these reactions.

It is particularly noticeable that there is a very marked difference in the embarrassment and disgust measures between people who decided to participate in the programme and those who decided not to. 50% of people who found the idea of the FOBt embarrassing and 36% who found the idea disgusting failed to participate. Only 19% and 12% who had these reactions managed to overcome them and participate anyway. The differences in uptake associated with these indicators were much more marked than they were for those associated with “perceived severity”.

In other words, although “perceived severity” was a good deal more common for both sexes than “disgusting” or “embarrassing” reactions, it was less likely to be associated with deciding not to take the FOBt. This suggests that although it appears ostensibly to be more of a “female” problem, some thought given to minimising the sense of disgust or embarrassment could also play an important part in encouraging male participation in the NHSBCSP.

The findings from the NHSBCSP focus groups suggested that awareness of bowel cancer among both men and women in the target age group is high³⁷ and generally seen as having severe consequences. The paper observes that the privacy and convenience of the process is regarded as enhancing the appeal of the FOBt process. It further notes that participants regarded it as positive that the FOBt:

...does not involve interaction with clinic staff and highly technical medical equipment.

The paper concludes that emphasising the element of personal control in the FOBt may be important in enhancing motivation to participate. Presented slightly differently, this may, in fact, be seen as a particular advantage by men, since other research has suggested that the easier and more streamlined a process is, the more likely men are to use it.

Interestingly, the tendency for men to use all kinds of health services less frequently and less effectively than women is so widely recognised that is familiar to the general public as well as to health professionals. Participants in the focus groups were able to predict quite correctly, that men would be less likely to participate in bowel cancer screening than women.

*I think it's the men you've got to be concerned about*³⁸

Two potential reasons were advanced by focus group participants for why this might turn out to be the case. The first was that men are less concerned than women with the idea of disease prevention, and the second that women are already familiar with the idea of mass screening programmes – and therefore find the idea of taking part less threatening.

Pessimism and “denial”

The psychosocial survey suggested that, while a majority of both men and women feel that the consequences of diagnosis with bowel cancer are likely to be very serious, men are rather more likely than women to perceive the potential outcomes in more negative ways.

Some aspects of men’s help-seeking behaviour in relation to health are fairly well established and have some bearing here. Men are known to be less likely to report symptoms in general, regardless of whether those symptoms necessitate seeking medical help.³⁹ Men are also believed to have a lower sense of themselves as potentially vulnerable to illness; to use an academic phrase, men tend to have “less well developed health cognitions than women”.⁴⁰ This is believed to happen for a variety of cultural reasons ranging from a prevailing greater medicalisation of women’s health to the socialisation of boys and men as “stoical” in the face of discomfort of all kinds (not just in the face of illness and injury).

This background makes it entirely predictable that men would exhibit less interest in health screening than women. In fact, at the most basic level, this may be all the explanation that is needed for men’s lower participation in the NHSBCSP. This background does not in itself however, account for men’s more negative perceptions of a diagnosis of bowel cancer.

Indeed, one might have expected women to be the more negative about the longer term consequences of bowel cancer since it has been established in numerous studies that women have a greater tendency towards anxiety.⁴¹ The question is whether there is any connection between this more negative view in men, and men's greater likelihood of not participating in the NHSBCSP.

Many studies have demonstrated an association between an optimistic outlook and better health, regardless of whether health is measured by self reported health status⁴² or by disease incidence.⁴³ There is less evidence about the connection between pessimism and poorer health, although fatalism and the belief that health is not within one's power to control (not quite the same thing as pessimism of course) have been shown to be associated with lower uptake of health services.⁴⁴ The dispositional tendency to optimism and pessimism however, is believed to be equally distributed in both sexes.⁴⁵ It may be therefore, that simple "pessimism" is not in fact, the most precise way to characterise the group of attitudes more common in men identified in the NHSBCSP evaluation.

There are two potential interconnected explanations that take us beyond pessimism. Both of these possibilities merit further exploration and may prove important in developing effective communication with men.

The first is that it may be men's very disengagement from health issues that makes them more negative about the consequences of a diagnosis of bowel cancer. In other words, it is possible that women's greater willingness to think about and to discuss health matters has simply given them a more rounded knowledge of the subject. A diagnosis of bowel cancer is bound to be extremely serious – but it is not by any means a death sentence. It may be that men are less likely than women to have understood this crucial point.

The second is that there may be an under-recognition of the extent to which men experience fear in relation to their health concerns. As we have seen, men may feel compelled for cultural reasons to keep their health worries to themselves and to "soldier on regardless", perhaps especially in their role as family breadwinner. This may lead to increased anxiety and ultimately to a form of "denial" in which a man feels he would "rather not know". Although this issue is not widely addressed in the literature, a recent paper has highlighted the "profound influence" that fear of diagnosis (in relation to prostate cancer) has on men's use of health services.⁴⁶ A meta-analysis of 32 papers looking at help-seeking behaviour published in 2005 also drew attention to the particular need to "reduce fears associated with consultations for cancer, especially for men."⁴⁷ A study of over 2000 male American car industry workers which monitored intention to screen for bowel cancer over three years found that "those men who had fear and worry about being diagnosed [with bowel cancer]" were those most likely to stick with their decision not to screen.⁴⁸

The decision not to screen because of anxiety about the potential outcome could be construed as a form of risk-taking – a gamble that one does not have cancer or polyps. A substantial body of research confirms men's greater propensity to take risks.⁴⁹ Established measures of risk-taking are exceedingly complex and the field is a specialised one. Outcomes vary according to such factors as social context; age; degree of risk involved; the way the risk is presented; the potential benefits of the risk-taking and so on. Nevertheless an important meta-analysis which examined 150 studies confirmed a consistent pattern of higher levels of risk-taking among men regardless of the theoretical model applied and regardless of the nature of the risk taking examined.⁵⁰

The authors concluded that:

... our results clearly support the idea that male participants are more likely to take risks than female participants.

Because the gap between the sexes was not consistent across all areas of risk, the authors stopped short of confirming the conclusion of previous researchers that risk-taking may be a particular attribute of male psychology. They did however draw an important “new” conclusion about the differences between men and women that may be of particular relevance for our present concern:

... there is an apparent lack of discernment on the part of men and boys. In one of our analyses we showed that males took more risks even when it was clear that it was a bad idea to take a risk... [this] suggests that men and boys would tend to encounter failure or other negative consequences more often than women and girls.

This combination of private fear (highlighted earlier in this section) and men’s greater general willingness to gamble may well be a contributing factor to men’s less effective use of screening and preventive services.

Disgust and Embarrassment

As we have seen, in the UK pilots, 50% of people who decided not to use their testing kit found the idea of doing so “embarrassing” and 36% found the idea of doing so “disgusting”. By contrast only 19% of people who actually used the kit found the process embarrassing and only 12% found it disgusting. Women were rather more likely than men to experience feelings of disgust and embarrassment but the marked difference between the proportions who chose to take part and those who chose not to do so suggests that disgust and embarrassment were important factors in discouraging both men and women from taking an FOBt.

There has been a surprising amount of work in the field of psychology aimed at developing a fuller understanding of the idea of disgust. Only the most basic summary can be given here but those who wish to know more are directed to the work of the experimental psychologist Paul Rozin and colleagues (in particular their essay on disgust in the *Handbook of Emotions*)⁵¹ and to *The Anatomy of Disgust* by William Ian Miller.⁵² This summary draws largely on these two sources (plus two or three other papers by Rozin and colleagues).

The importance of disgust in human behaviour was first addressed by Darwin in the nineteenth century, specifically in relation to human adaptation and evolution. Darwin hypothesised that the feeling of disgust and its associated instinctive physical manifestations arose from the need – which is crucial to survival – to recognise and reject contaminated food. This principle has been accepted as a starting point by all the subsequent theorists but the complexity of disgust reactions still confounds full explanation.

Disgust is the only emotion which is known to provoke a specific physiological state (nausea). It is marked in humans by the sense of defilement that accompanies the experience of disgust and which often lasts longer than the experience itself. It is also considered notable that humans often have only to think of something disgusting in order to experience a physical reaction.

Disgust is known furthermore, to have “magical” properties; substances which are not in themselves disgusting at all but which happen to look or feel like disgusting substances are capable of provoking a disgust reaction in many people. Similarly, many people are revolted by the idea of touching something that is not disgusting in itself but which has previously been in contact with something perceived as disgusting. Comparable non-human reactions are much less complex; animals demonstrate a rejection of contaminated food that mirrors the perceived origin of disgust in humans but there is no known animal equivalent to disgust in any other circumstances.

There is agreement that many of the things that elicit disgust are universal. In addition to bad food, the accepted universal elicitors of disgust centre on bodily waste and unpleasant bodily odours. Clearly this is highly relevant for the FOBt which requires people to come into closer contact with their own faeces than would normally be the case. This can be seen as an action that involves overcoming not just a cultural taboo but also a powerful emotion and an instinctive physical response (the cultural taboo, of course, having arisen from the emotion/instinct in the first place).

Rozin and colleagues found women to be more likely than men to experience disgust reactions across six of their seven disgust-eliciting domains. As we have already noted, this finding was mirrored in the findings of the NHSBCSP evaluation. This does not detract from the need to address disgust in men however, since disgust is an important inhibiting factor for both sexes.

Embarrassment is not just a different emotion from disgust, it is a different kind of emotion. Disgust is generally accepted to be a “basic” or “primary” emotion (that is to say one which is “hard wired” or genetically given). By contrast, the capacity for embarrassment is believed to develop during childhood and to require cognitive abilities for its elicitation (specifically it requires the “evaluation of one’s behaviour from another’s perspective”).⁵³ It is therefore a “self-conscious emotion”.⁵⁴

The psychological literature offers no precise definition of embarrassment. It was believed for a long time that embarrassment is simply a mild form of shame, associated with the individual’s recognition that he or she has failed to meet a personal standard. This view has been disputed in more recent theory however, not least because embarrassment is widely recognised as often being elicited by praise as well as by attention drawn to a failure.^{55 56}

From our present point of view, perhaps the most important point to emerge from the literature is that there is a significant agreement that for embarrassment to occur, the embarrassed person must be exposed in some way. Exposure is a shared feature, for example, both of embarrassment caused by being seen in a negative light and embarrassment caused by being seen in a positive light (or simply by being seen at all, since embarrassment can occur as a result of being looked at by other people even when in an entirely neutral situation).⁵⁷

More evidence for the idea that exposure is a crucial characteristic of an embarrassing experience is that embarrassment has been shown to be a significantly more acute when it occurs in front of strangers rather than friends and family members (when the sense of exposure is reduced). The exposure theory is also borne out by experimental studies which have found that only 2% of people report having felt embarrassed when alone. The overall conclusion has been is that embarrassment is “almost universally a public phenomenon”.⁵⁸

The FOBt of course, is undertaken (in the great majority of cases) by people who are alone and unobserved. This suggests that they are very unlikely to experience “embarrassment” in the form described above. Indeed, some participants in the focus groups referred specifically highlighted the lack of embarrassment as one of the positive aspects of the FOBt:

... it saves embarrassment.

Not [embarrassing] in your home I wouldn't have thought.

The NHSBCSP evaluation questionnaire specifically asked whether people taking the FOBt were “embarrassed” to do so. Obviously the 50% of respondents who said “yes” to this question were describing a real response that they had actually experienced but they may perhaps have latched on to the word “embarrassed” as the nearest equivalent to some other more intangible feeling of awkwardness or unease associated with the breaking of a taboo. In this sense, “embarrassment” might be just an additional way of describing “disgust” – or even anxiety about the risk of the test resulting in a diagnosis of bowel cancer.

Alternatively it is possible to speculate about ways in which people might feel “genuine” embarrassment even though they are not being observed when they take the FOBt. One possibility is that the sense of “exposure” is somehow vested in the stool sample itself which is of course, submitted for view by a stranger (especially as, as we have already seen, most people will believe that their faeces are an aspect of themselves that is “disgusting”). A second – linked – explanation might be that the posting off of the stool sample compromises people’s sense of personal privacy; “failure to maintain privacy” is one of the recognised causes of embarrassment.⁵⁹ Indeed, 34% of non-responders in the NHSBCSP evaluation saw the FOBt as an “invasion of privacy”. A third – perhaps less likely - possibility is that the embarrassment comes from other people in the household simply knowing that the person concerned is taking the FOBt. Because this draws attention to that person’s bodily functions it might create a feeling of exposure and loss of privacy even though the person is not actually observed at the point of taking the FOBt (although, as we have seen, embarrassment is much less likely to be experienced in the company of relatives and friends).

There is incidentally, relatively little reference to gender differences in the literature related to embarrassment. This may be because few gender differences have emerged. Indeed one series of studies decided to stop including gender in reported analysis for this very reason.⁶⁰

There is a small common denominator between disgust and embarrassment that may be worth noting. One of the ways in which some people are believed to cope with the experience of disgust is by joking about it – a behaviour that is more common in men than women.⁶¹ Embarrassment is also known to have a relationship with humour. Embarrassing incidents often amuse bystanders and provide the material for funny stories told by the embarrassed person.^{62 63} There is furthermore some evidence that a tendency to joke about health issues may be a particular characteristic of men, although it is not clear whether this is helpful or merely a means of avoiding serious engagement with the issue.⁶⁴

Summary of Phase 1, and implications for Phase 2

Discussion of the scoping review of the literature that made up Phase 1 of the project suggested the following questions for Phase 2:

- Do men feel “fatalistic” about cancer (“it’s not worth taking up screening because it won’t make any difference anyway – if cancer is going to get you it will”)?
- Do men have a less sophisticated understanding of cancer than women?
- If so, does that predispose them to a more negative perception of the disease?
- Are men fearful of cancer but restricted by their “masculinity” from saying so?
- If so, is “fear of finding out” likely to influence their decision about whether or not to screen?
- Do men feel more willing than women to “gamble” that they will not develop cancer?
- Is there a feeling that “I’m well at the moment, so there seems no point in taking a test that might reveal that I’m ill”?
- How disgusting is the process of the FOBt?
- What parts of the FOBt are the most disgusting and why?
- How can the sense of disgust be overcome?
- What, precisely, is it about the FOBt process that is embarrassing?
- How can this embarrassment be overcome?
- Is humour an appropriate mechanism to help men deal with disgust and embarrassment?
- Do men and women have different levels of knowledge about cancer?
- Do men and women have different perceptions of cancer risk?
- Do men and women have different attitudes to the value of cancer screening?
- If there are differences, to what extent do these influence the likelihood of men and women participating in bowel cancer screening?
- Is lack of prior knowledge of screening processes a factor in lower participation rates in men?

5: Phase 2 – discussion groups

Introduction

The purpose of Phase 2 was to take the broad ideas that had emerged from the scoping review of the literature in Phase 1 and use them to inform the subject matter for a series of discussions with men in the target age group.

This element of the project was commissioned from a market research agency specialising in social research, and with good experience of working with for the public and charitable sectors. The research process was devised by the MHF in conjunction with the agency and with guidance from the Expert Advisory Group.

Process

Ten group discussions were held during January and February 2009. Each discussion group consisted of around ten participants. All discussion group members were men in the age group eligible for participation in the NHSBCSP. Discussion group members were recruited using an “on-street” method; market research staff approached men in the street and, having established that they met the age condition, invited them to attend a discussion group at a local venue in a few days time. Recruiters were instructed to ensure that they invited a men from a range of different backgrounds. As an incentive, men who agreed to take part in the discussion groups were paid £25.00 for their time and given free copies of MHF publications. In order to make sure that we also heard the views of particular groups of men who might not be picked up by the on-street process (e.g. disabled men), the social research agency also conducted 12 telephone interviews with individual men in under-represented groups.

The discussion groups were held in two parts of the country: the West Midlands (Coventry and Wolverhampton) and the South West (Bristol, Bath and Salisbury). These two areas were chosen specifically because, at that time, the NHSBCSP was well-established in the West Midlands but had not yet been rolled out to the chosen area of the South West.

It was anticipated therefore that the random recruitment process in the West Midlands, was likely to produce a good number of men who had already been invited to take part in the NHSBCSP. Some of these men would have decided to complete the FOBt, some of them would have decided not to do so (inevitably, there were also likely to be some men who had not yet received their first invitation and were unfamiliar with the screening programme).

In the South West, the expectation was that most of the discussion group participants would not have received an invitation to take part in the NHSBCSP (unless they happened to have previously lived in another part of the country). It was probable that some – perhaps even most - of them would not even be aware that the programme existed.

Four of the ten discussion groups were held in the West Midlands, the other six in the South West. In order to capture a range of opinion and reaction relating to personal experience, three different formats were used for the discussion groups. These formats were tailored to the different background circumstances in the two areas. The detailed formats for the discussion groups are included at Appendix 2 but for convenience the key points are summarised in Table 2 opposite:

Format	Number of groups and location	Local circumstances	Content
Format 1	3 in South West 1 in West Midlands	NHSBCSP not established locally NHSBCSP established locally	<p>Your attitudes to health</p> <p>Male attitudes to health</p> <p>Fatalism and male health</p> <p>Fear/denial and male health</p> <p>Stoicism and male health</p> <p>Introduction to NHSBCSP</p> <ul style="list-style-type: none"> • Would you/did you take part? • How are the issues above relevant to the NHSBCSP? • What might inhibit male participation in the NHSBCSP? • What might encourage male participation in the NHSBCSP?
Format 2a	3 in South West	NHSBCSP not established locally	<p>Introduction to NHSBCSP</p> <p>Distribution of a sample test kit to each participant</p> <p>Discussion of immediate reactions to test kits</p> <p>Fatalism, fear and denial and male health</p> <p>What might inhibit male participation in NHSBCSP?</p> <p>What might encourage male participation in NHSBCSP?</p>
Format 2b	3 in West Midlands	NHSBCSP established locally	<p>What was your reaction to your invitation to participate in NHSBCSP?</p> <p>How did you decide whether or not to participate?</p> <p>What did you find off-putting about the process?</p> <p>Fatalism, fear and denial and male health</p> <p>What might inhibit male participation in NHSBCSP?</p> <p>What might encourage male participation in NHSBCSP?</p> <p><i>NB Those men who had not yet been invited to take part in the NHSBCSP were asked to think about the questions having heard the experiences of the other men present.</i></p>

All participants in the discussion groups were given information about bowel cancer symptoms and advice about how to find further help, just in case participation in the groups had raised personal anxieties or made them aware of symptoms in their own case.

Outcomes from the discussion groups

General attitudes to health

Most men felt they had reasonably good health knowledge particularly in relation to diet and exercise. There was some consensus that health is bound to deteriorate as one gets older and that “aches and pains” and some chronic illness are inevitable. There was also a feeling that “we all end up on some form of tablet”. Although some participants described personal experiences in which they had ignored symptoms, the broad consensus was that it is important to act on symptoms early, and most participants said that is what they did.

There was a significant degree of dissatisfaction with GP services. This centred around the feeling that the service does not allow enough time to explore symptoms properly. This was believed to result in GPs resorting too soon to prescribing:

...they have their pen in hand for a prescription before you tell them what's wrong.

The view was also expressed by some that GPs should use consultations to move beyond the immediate reason given by the patient, in order to find out if there were more things he was worried about. Some participants also thought that GPs had too great a tendency to regard symptoms as an inevitable by-product of increasing age:

Some doctors just say “well you're getting old . . . ”

They should look into it more – we are entitled to same level of care as someone 30 years younger.

Fatalism

In general participants felt that the fatalistic view of health was an old-fashioned one, partly because of advances in medicine and partly because it is now so widely known that many of the determining factors are within one's own control. There was however, a minority view from some participants that some elements of personal health are genetically predetermined, and therefore completely beyond our control, or pre-ordained in some other, vaguer, way:

We are all born with cancer

I've always believed that if my time is up, it's up. If your name is on the list, you could be next.

Most however, felt that there was much that one could do to maintain one's health, and that appropriate positive actions could help stave off the risk of poor health.

Fear and denial

Similarly, the groups tended to take the view that to be afraid of the possibility of bad news was a mistake:

...to ignore [symptoms] through fear is foolish.

There was however, rather more acknowledgement of fear as a problem than there was of fatalism:

I always put it off, but then it does not go away, and you ought to go.

There was particularly a feeling that men are more likely to ignore symptoms initially:

You just ignore it, think it is nothing

My wife says "it took you 6 months to go to the docs. Why didn't you go straight away?"

This was thought to be a particularly "male" characteristic:

That's men – we don't need to go to the doctor!

Stoicism

There was a fairly strong feeling among many participants that the idea of stoicism in response to illness was "old-fashioned":

It's a generation thing that happens less now.

The discussion of stoicism did however provoke comments from some participants in relation to "macho" attitudes among some men which attach value to ignoring illness:

You were regarded as a "softy" by your colleagues if you moaned about your aches and pains.

Perceived differences between men and women in relation to health

There was a widely held view that women tend to be better at dealing with their personal health than men. Various manifestations of this were cited and various explanations offered. Women were believed to be more "in tune" with their bodies; more comfortable with using health services - particularly screening programmes; and more likely to seek help with symptoms in good time. Interestingly some participants also felt that women were more likely to "soldier on" in the face of illness – but only after having understood their problems and sought help. The familiarity of women with screening programmes for female conditions was felt to be a particularly important reason underlying their higher uptake of bowel cancer screening.

Women were also perceived to discuss health issues much more commonly with women friends. It was noticeable that many men in the discussion groups said that they were unable to comment on the health attitudes of their male friends because they simply never discussed the issue with them.

Influences on health behaviours

Wives and other family members were identified as key influencers of health behaviours – particularly around diet and in their role of encouraging men to visit their GP:

I'd rather face the doctor than the wife, so I go!

My wife said to me, "if it's there, it's there – so go and do something about it!"

Other influences mentioned were friends and their health experiences (it being more common in later years to have friends who have health problems), and the media.

Attitudes to the NHSBCSP

As would be predicted by the evaluation of the pilot programmes, in-principle support for the idea of the screening programme was virtually universal throughout the discussion groups. Only a couple of participants overtly expressed negative views about the idea. Perhaps surprisingly, these were both men who had lost loved ones to bowel cancer:

I've not got much faith in it... (man who had lost his wife to bowel cancer).

I have an open mind about it... (man who had lost a close relative to bowel cancer).

When discussion turned to the reality of participation however, a string of objections emerged. These views identified various barriers to participation. In some cases these barriers could be seen as reflecting some of the hypothesised ideas about denial and fatalism. There was overt recognition in some cases, that some of these objections were irrational:

If it ain't broke, don't fix it.

I didn't want to find anything else. (man who had COPD and prostate problems who had decided not to complete the FOBt)

Fear is the key, not the screening, but the subsequent procedures and "the big C".

Men bury their heads in the sand. If I don't know about it, I can't worry about it.

I would do it but there'd be fear. Its only natural – you'd be relieved as well.

In other cases, the barriers were to do with the practicalities of the FOBt and reflected the findings in earlier research about disgust and embarrassment:

Did you say three samples? I can see some people doing the first one and saying "bugger this for a laugh".

They might do it one day and think I'm not messing around with that again and they'd throw it in the bin.

... messy, well its unpleasant.

... a very unsavoury thing to do so I didn't participate. I didn't fancy the preparation part of handling the poo. It was the process that put me off...

If the test could be performed via a blood test or MRI scan, I would have done the test.

There was also a feeling that the FOBt was only relevant if one already had symptoms:

I don't have the symptoms, so I won't take part.

If I had any symptoms then I would have done it, despite knowing that you should not wait for the symptoms.

Most people would be more inclined to do it if they felt something was wrong. Why should Mr Normal who feels perfectly fit do it?

Some identified barriers that looked beyond the FOBt stage:

If positive I'd be scared. "Can I look after family? Will I go downhill rapidly?" Not fear of dying, fear of way of dying.

... and the potential invasive treatment of getting a positive result [put me off].

Finally, some objections were phrased as scepticism about the whether the process was worth the effort – for example that if the FOBt was positive, one would then just end up on a long waiting list for a the next stage, or "[They will say] 'Oh, we'll just try pills'".

NHSBCSP materials

There was broad consensus that more could be done to encourage men to take part in the NHSBCSP. Many of the suggestions however, were founded on the assumption that the materials were intended simply to promote uptake, rather than to enable people to make an informed decision about whether to take part or not.

There was a positive reaction from some, to the clarity and readability of the materials but other participants felt they were too "clinical". There was some debate about the logic of including materials that described potential symptoms of bowel cancer; some participants argued that this was not necessary and could even be counter-productive, given that the NHSBCSP is aimed at everyone, whether they have symptoms or not. Some participants felt that non-responders should be pro-actively followed up with subsequent letters stressing the risks in not taking the FOBt or that they should receive personal phone calls from their GP surgery.

Most important findings from the discussion groups

The discussion groups generated a range of useful information and ideas. Those that were felt to have particular strength because of the frequency with which they occurred or because of the importance that the groups attached to them, were:

- The very important role of a man's wife or partner in encouraging – indeed, persuading – him to take action over his health.
- Men are aware that more screening programmes are available to women and that women value those screening programmes. The belief was that there must be lessons to be learned from the success of those programmes in engaging with women.
- Among those reluctant to participate, fear and fatalism were not the only barriers. The belief that, if one is fit and apparently in good health then it is not necessary to look for problems, may be a key barrier.
- Disgust and embarrassment are a problem for some men.

6: Phase 3 – postal survey

Introduction

The findings from the discussion groups described in the previous chapter were used to design a postal questionnaire. The content of the questionnaire was developed during the spring of 2009, in partnership with the same market research agency that had worked on the discussion groups. Academic support was provided throughout this planning stage by Prof. Sarah Payne and Paul Hewitson, members of the Expert Advisory Group, whose help and advice we acknowledge with gratitude.

In September 2009, the questionnaire was sent to 2,200 randomly selected men and women aged between 60 and 74 and living in all regions of England and Wales (names and addresses purchased from the electoral roll). In addition to the self-completion questionnaire, each respondent was sent a letter outlining the reasons for the research and encouraging their participation. A helpline number was given in the letter for those people who wanted to know more about the survey or who might need help to complete the survey form. After two weeks a second mail-out, consisting of a reminder letter and another copy of the questionnaire, was sent to those who had not responded to the first mail-out.

The target number for responses was 500 male respondents and 100 female respondents. In the event, completed questionnaires were received from 579 men and 122 women. A further 20 people did not give their sex and these people were excluded from the analysis of the results. The response rate was 33%, which is creditable for this type of survey. The complete questionnaire is at Appendix 3.

Introduction to the findings

The survey form was organised in five sections:

1. Your general health
2. Your attitudes to health
3. About bowel cancer screening
4. Encouraging people to consider screening
5. About you

During analysis of the findings, we concentrated on those areas of the results where there were noticeable differences between men and women. In order to make the present report as readable as possible, we do not always describe the findings in the same order that the questions appeared in the questionnaire. Findings are discussed instead in relation to the most common themes that emerged.

It should also be noted at the outset that differences between men and women were less marked overall than we might have expected. That does not mean however, that there were not some interesting differences between the sexes on some specific and important issues. The rest of this chapter will concentrate on these differences.

We do not discuss the “non-gender” aspects of the findings in detail but the strongest marker of differences in attitude between respondents may have been self-reported health status, with people in poorer health appearing more likely to have negative attitudes (people in poorer health were less likely to have participated in the NHSBCSP when they had the chance for example, and more likely to say they would not participate in future). Another important factor may be marriage, with married people appearing more likely to have positive views about health in general and screening in particular.

The most crucial point to note at the outset is that – predictably – the survey elicited a much better response from people who already had a more positive attitude to bowel cancer screening. This is very clearly evidenced by the fact that, of those 55% of our respondents who had already received an invitation to participate in the NHSBCSP, 88% had taken it up (with virtually equal percentages among men and women). This is of course, significantly greater than the percentage uptake in the population as a whole.

This means that the survey is inevitably restricted in its capacity to help explain non-participation in general. By extension therefore, it is also restricted in its capacity to explain why men may be less likely to participate than women, and why some men are less likely to participate than others. This is rather disappointing but is entirely consistent with the experience of other researchers in the field and certainly does not mean that there is no useful guidance to be had from the findings.

Findings relevant to gender differences

Reasons for not taking up the invitation to participate in the NHSBCSP

As we have seen, only 12% of those respondents who had previously received an NHSBCSP invitation had declined to take up the opportunity of screening. In numerical terms this was 48 people, of whom 39 were men. Of that group, there were some differences between men and women (although the number of women is extremely small). The most common choices among the six named reasons for not taking part were that the test was “too unpleasant” (10 men, one woman) and “Didn’t want to find out I had cancer” (7 men, no women).

The most common choice overall however, was the “other” category, which was chosen by 13 men. Almost all those who took this option chose to give additional information in the text box provided. The most common reason for having chosen “other” (8 of the 11 men) was that the respondent was currently undergoing, or had recently undergone, clinical tests for bowel problems (e.g. colonoscopy).

Attitudes to health in general

A series of statements had been formulated, based on the the discussion group findings, which appeared to characterise some of the potentially “male” attitudes to general health. Respondents were asked to agree or disagree with these statements using a four point Likert scale (“agree”, “strongly agree”, “disagree”, “strongly disagree”). The statements were phrased in both negative and positive terms to avoid any implied “correct answers”.

It is possible to see a pattern of gender differences in people’s response to this series of statements. For the purposes of the results given in the following paragraphs “agree”, and “strongly agree” are combined, as are “disagree” and “strongly disagree”.

Men are more likely to agree that older people are “bound to have poorer health” (61% of men, 50% of women) and, by a narrower margin, to agree that “when you are older, you get so many aches and pains anyway that you don’t worry about new ones” (65% of men, 61% of women). A third of both men and women incidentally, agree that “when you are older doctors give you the impression that you can expect to have poor health and there isn’t very much they can do about it”. This is consistent with views expressed by some in the discussion groups.

Men were less likely to agree that “I always go to see my GP as soon as possible if I have symptoms that worry me” (86% of women, 80% of men) and more likely to agree that “I tend to put off going to see my GP even when I have symptoms that worry me” (29% of men, 26% of women). Men are more likely to agree that “I would rather not know if something was seriously wrong with me” (22% of men, 14% of women) and more likely to feel that “if you are fit and well, it’s a gamble going to see the doctor as they might find something wrong with you” (24% of men, 20% of women). These differences are consistent with each other but are perhaps, in some cases, smaller than might have been expected.

Men were more likely to report that “I never feel frightened when I have an appointment about my health (68% of men, 52% of women). This finding was the reverse of what might have been predicted both by suggestions made in previous research papers and by our own discussion groups - especially so, given the large extent of the difference. If this finding were repeated, perhaps in more sophisticated research, which concentrated specifically on gender differences in anxiety in relation to use of health services, it would call into question one of the more commonly accepted explanations for men’s poorer use of services.

A large majority of both men and women believe that “women are more relaxed about health screening than men”, although men are less likely to think this than women (72% of men, 86% of women). Similarly, and by an even larger majority, both sexes think that “men need more encouragement than women before they will do anything about their health” (82% of men, 90% of women). It should be noted however, that these two questions were asked in general terms rather than individual terms - they did not say, for example, “I think I am less relaxed about health screening than the women that I know”. Observations later in this report suggest an inconsistency between questions phrased about the respondent himself and those phrased as being about “other people”.

Broadly then, although a majority of both sexes feel there is a degree of inevitability about poorer health in older age, this tendency is more common in men. Men are also more likely to be among the minority of both sexes who attempt to “deny” health problems. Both men and women commonly subscribe to the notion that men take less good care of their health than women, although women are rather more likely to think this of men, than men are to think it of themselves.

Attitudes to the FOBt

As we have seen, around half of our respondents had direct experience of having used the FOBt (55% had been invited to take part in the NHSBCSP and 88% of those had done so). For the benefit of those respondents who had never seen an testing kit, the questionnaire gave a brief description of the testing process. This description is at the beginning of Section 3, About bowel cancer screening.

There was a marked trend among men to be more likely to regard the testing process as straightforward (either from personal experience or from the description). Male respondents were more likely to agree that the test is “easy” (65% of men, 52% of women); “simple” (74% of men, 67% of women); and to agree that “I can’t see any difficulties with it” (75% of men, 69% of women).

Albeit by smaller margins, men were also less likely to see the test as actively problematic. They were less likely find it “unpleasant” (23% of men, 27% of women); “messy” (26% of men, 31% of women); or “embarrassing” (8% of men, 12% of women). Men were also less likely to feel that “it’s not very nice having to keep the samples in the house for three days” (15% of men, 18% of women); less likely to be concerned about other people in the house knowing they were taking part in the NHSBCSP (10% of men, 12% of women); and less likely to feel uncomfortable about putting the completed test kit into the post (8% of men, 13% of women).

Across the range of attitudes to the testing process therefore, there was a clear tendency for men to feel more positive about those aspects that could be seen as positive, and to feel less negative about those that could be seen as negative. These findings suggest that men have the potential to be more receptive than women to the FOBt, and that, overall, the explanation for their greater unwillingness to participate in the NHSBCSP lies somewhere other than the process of the test itself.

Factors influencing attitudes to health

For both men and women, the single most significant influence was the respondent’s GP – although, interestingly, the figure was higher for men than women; 90% of men, compared with 81% women, agreed that their GP is an influence. Results were also high for other primary care staff, and also differed by gender (83% of men and 77% of women).

The only other influence that was higher for men than women was “spouse or partner”, which for men came very close to the GP. 86% of men regarded their partner as an influence, compared with 74% of women (although it should be noted that this figure includes all respondents, not just those who were married or living with a partner).

The range of influences on attitudes to health was much wider for women with all other options scoring more highly for women than men as follows: “newspaper or magazine articles” (60% of women v 44% of men); “posters, leaflets and advertising by the NHS” (72% v 63%); “T.V. programmes (68% v 53%); “other family members” (68% v 62%); “friends” (53% v 37%); “radio programmes” (45% v 37%); “pharmacist” (56% v 52%); and the internet (31% v 28%).

On the whole then, men in this age group seem rather less open than women to a range influences on their attitudes to health, preferring to give greater value to two particular influencers; their spouse or partner, and primary care staff - most especially their GP. Of course, this does not mean that there are no other influences of note for men – several others were regarded as being important by more than half the male respondents. There was however a considerable gap between the two leading influences for men and the influence in third place (NHS media campaigns). This was not true for female respondents whose influences were both more wide ranging and more closely clustered. The internet incidentally, was the least popular with both sexes by some margin, a finding which probably reflects the age of the survey group.

What people like and don't like in health campaigns

Survey respondents were asked to rate each of a series of approaches commonly used to encourage people to take steps to improve their health. The most immediate result to observe might be that a huge majority of both sexes like “information that is as simple as possible” (96% of both sexes). A significant majority also preferred “instructions about what to do and what not to do”, although this is rather more popular with women than men (81% of women, 75% of men). Somewhat inconsistently, a majority of both sexes also likes “lots of detailed information about health”, although this is notably less popular with men (55% of men, 63% of women).

Some other choices were also extremely popular, particularly “information especially for my age group” (97% of women, 92% of men) and “information especially for men or women” (91% of men, 93% of women). The availability of helplines was also very popular with both sexes, although somewhat less so with men (84% of men, 91% of women).

In terms of the “style” of information presentation, humour is very popular with both sexes (81% of men, 84% of women), as are “slogans that I can remember”, although this is less so for men (84% of women, 73% of men). “Real life stories about people’s health” were also liked by a majority of all respondents but with a very significant difference in the level of popularity between the sexes (82% of women, 58% of men). “Information that appeals to the emotions” was also less popular with men and was liked by only a minority (54% of women, 45% of men). Endorsement of the information by a “famous person” showed a similar pattern (52% of women, 39% of men).

The questionnaire also offered the option for respondents to reject all the options and say that “I don’t like any kind of information about staying healthy”. This option was chosen by 14 respondents of whom 13 were men. A range of personal reasons was given for doing this, of which the most common was, in broad summary, that “I prefer to make up my own mind”.

The questionnaire also included a list of suggestions for ways of encouraging men to consider participating in bowel cancer screening. These suggestions were based on ideas generated by the discussion groups. Questionnaire respondents were asked to identify up to three of the suggestions on the list first, as “approaches that might work best for you” and second as approaches that “might work best for men in your community”. The list of choices was as follows:

- Messages on local radio
- Advertising and articles in local newspapers
- Endorsement by a local celebrity
- Advertising at local sporting events
- Endorsement by a local sporting personality
- Information distributed in pubs and other social settings
- Information distributed at work
- Information distributed in shops and other commercial premises
- Encouragement from your GP or other health professional
- Encouragement from the NHS directed at the wider population
- A video that could be watched online or given to people on DVD
- An opportunity to ask questions directly to experts

The first, and perhaps most important thing to observe, is that there is considerable difference between men's preferences in respect of themselves, and men's (and women's) ideas of what "men in the local community" might like. This suggests that some elements in the popular perception of men and their attitude to health may be inaccurate. The proviso to this point however, is that – as we have seen – men who declined to take the FOBt were under-represented in the survey group. It is therefore not impossible that people's perceptions of what "men in the local community" might like are more accurate in describing that particular group (i.e. the non-respondents).

Far and away the most popular choice when respondents chose what they themselves would find beneficial in encouraging their participation was "encouragement from your GP or other health professional" which was chosen by 88% of male respondents (and 89% of female respondents). The next most popular choice was "encouragement from the NHS directed at the wider population" (58% of men, 63% of women)

These two most popular choices were followed – some way behind – by "an opportunity to ask questions directly to experts" (35% of men, 39% of women) and "advertising and articles in local newspapers", although this latter was rather less popular with men than women (32% of men, 44% of women). "Information distributed at work" was endorsed by 13% of male respondents, which is exactly half of the proportion of respondents who were in work, and for whom this option would be relevant (69% of male respondents to the survey described themselves as retired).

None of the choices that might be seen as more relevant to "male culture" was particularly popular with men and all such options recorded very low levels of support. "Advertising at local sporting venues" was endorsed by only 3% of male respondents for example, and similarly low percentages were recorded for "endorsement by a local sporting personality" (4%) and "information distributed in pubs and other social settings" (5%).

When participants were asked about "men in your local community" however, these "male culture" options were very much more popular. 15% of men and 30% of women for example thought that "advertising at local sporting venues" was a good idea. Likewise, 21% of men and 22% of women thought that "information distributed in pubs and other social settings" would be worthwhile.

The increase in support for these kinds of options was mirrored by a fall in support for action within the NHS, which people thought less likely to work for other people than it would for themselves. Only 70% of women thought that encouragement from a GP would work for men in their community for example (against – as we have seen - 88% of men who favoured that option when thinking about themselves as individuals).

In short then, it seems to be that both sexes favour health information that is memorable, simple and directive. In terms of translating advice, information and opportunity into action, women appear open to a significantly wider range of influences than men, who rely much more heavily on two particular sources – surgery staff and their wife or partner.

In line with these general observations, it appears that both men and women would be most influenced to consider bowel cancer screening by guidance from their GP. Additionally, posters, leaflets and advertising from the NHS are also considered influential. Most other potential communication mechanisms have much lower levels of support (with the possible exception of the workplace as a means of distribution – although this option is not strongly relevant for this particular target group).

Finally, both men's and women's perceptions of men and "what men think" may differ considerably from what men actually say they think.

Summary of findings from Phase 3

We should perhaps begin this section by re-stating that a very significant majority of respondents (over 90% of both sexes) said they would favour information written differentially for men and women. There were a number of findings from the postal survey that are particularly helpful in thinking about male-specific approaches.

In terms of general attitudes to health, there is a degree of fatalism among both sexes that older age inevitably means poorer health but the tendency towards this belief is rather more common in men. Similarly, while only a minority of people incline to "denial" of health problems, men are rather more likely than women to exhibit this attitude. On the positive side, men showed a marked tendency to regard the process of using the FOB testing kit more positively than women. They were more likely to think of the practicalities as easy, and somewhat less likely to experience negative psychological responses (such as embarrassment and disgust). This is potentially very useful in thinking about how to engage with men and suggests that the explanations for men's lower participation rates may not be strongly linked to problems with the FOBt itself.

Influences on behaviour also varied by sex. Both sexes regard their GP as the single greatest influence but, for men, this degree of influence is almost matched by that of their spouse or partner. This was a distinct gender difference, with women noticeably less likely to highlight their spouse or partner as an important influence (although a majority still do so). These two influences – GP/primary care staff and spouse/partner – were of much more importance for men than any others. Women acknowledged a wider range of influences, several others of which were also strong. A sizeable majority of both men and women subscribe to the notion that men take less good care of their health than women (although women are rather more likely to think this of than men are to think it of themselves).

The characteristics that people like to see in health information campaigns emerged strongly, with little difference between the sexes. People like simplicity, clear guidance, memorable phrasing and – to a slightly lesser extent but still popular – the use of humour. People also value helplines. In addition to gender-specific information, both sexes were also very strongly in favour of age-specific information. Men are significantly less likely than women to be impressed by additional "sales techniques" such as appeals to the emotions, and "real life" stories.

In terms of the mode of delivery for health information, encouragement from the GP was very clearly the most popular choice for both sexes with around 90% support. The other approach regarded as likely to be effective was generalised encouragement by the NHS. Use of local media such as local press and radio, was popular only with a minority, and less popular with men than women. There was potentially some support for health information delivered in the workplace but it is difficult to be certain because the majority of respondents were retired (for this reason, this finding is not particularly relevant to the project anyway).

Approaches suggested in the focus groups as particularly likely to work with men were comprehensively rejected. Endorsements by sporting personalities and sports clubs received extremely low levels of support, and neither sex was at all positive about the distribution of health information in pubs and other social settings. Furthermore, both women and men

significantly over-estimated (by comparison with actual responses from men in the survey), the advantages of these kinds of “male-specific” approach. This suggests that stereotyping of men’s interests and lifestyles is a potential pitfall. Having said that, we should remind ourselves perhaps, that men who declined the FOBt were under-represented in our survey. These men may well prefer some of these approaches.

We should note that the rejection of these particular male-specific approaches does not mean that successful male-specific approaches do not exist. The questionnaire findings suggest that there are indeed some key emphases that could be made that would make the NHSBCSP more appealing to men, and that these emphases are different from those that would be made for women. We attempt to identify these emphases in the next chapter.

7: Phase 4 – recommendations for action

The expert seminar

On January 26th, 2011, the findings and interim recommendations from the project were presented to an invited audience of 45 people which included senior cancer prevention specialists from the public and voluntary sectors. Academics, NHSBCSP staff and other health professionals were also present, including people working at a local level to encourage participation in the NHSBCSP. All but one of the project's own Expert Advisory Group were also in attendance. The seminar, which took place at the King's Fund in London, was structured to encourage participation and debate. It was the first event of its kind convened specifically to explore the particular needs of men in relation to bowel cancer screening.

The audience debated the findings and recommendations of the project to that point. The starting point for the debate was to consider what is known about men's engagement screening programmes in general. As well as hearing about the MHF project, there were presentations about the new national screening programme for abdominal aortic aneurysms (which only targets men) and about how best to help male patients decide whether take the PSA test for prostate cancer. There was also a presentation describing a recent research project which had measured increases in participation in the NHSBCSP associated with two particular trial interventions, a procedural leaflet and a letter of endorsement from the patient's GP. Additionally, the audience heard about another MHF project, commissioned from the Centre for Men's Health at Leeds Metropolitan University, which has been exploring "what works" in relation to health communication with men.

The event was extremely valuable to the development of our thinking about the relevance of the project both to the needs of the NHSBCSP and to the needs of men invited to screen. There was confirmation from the audience that the problems we had been seeking to address in the project were still current. It emerged during the event that there was interest in this issue beyond the national strategic level. Some individual PCTs had made local attempts to address the problem of lower male uptake of screening and the insights of colleagues involved with this work were extremely helpful towards the development of this final report.

The project's particular emphasis on developing a more sophisticated understanding of men's attitudes was warmly welcomed. There was a strong view from the audience that uptake was not as high as it might be for either sex, and that there was significant scope for increasing engagement with the NHSBCSP by exploring different forms of communication.

There was good consensus that the draft recommendations of the MHF project were feasible, and capable of bringing about an improvement in men's engagement with the NHSBCSP. Much of the debate concentrated on the practical and structural aspects of the recommendations and how they might be implemented, either via the NHSBCSP itself or by NHS organisations seeking to support screening at the local level. Some of the ideas and suggestions that emerged are incorporated into the discussion in the section below.

A list of attendees at the event is given at Appendix 4.

Introduction to the recommendations

The recommendations of the project are few in number, pleasingly straightforward and potentially inexpensive. We are confident that they are supported by the evidence and have strong potential to improve men's engagement with the NHSBCSP. The specific recommendations are discussed in detail below, preceded by some general principles associated with style and content to be taken into account when putting them into practice.

In reading the recommendations, it is important to remember the second of the two objectives of the project given in Chapter 2. That is, that we were seeking to "recommend actions which might encourage men more seriously to consider participating in the NHSBCSP and thus potentially increase male uptake and close the gap in uptake between men and women."

In other words, although the problem we are attempting to address is that men are less likely than women to return a completed test kit, we were not looking simply for ways "sell" the FOBt to men. Instead we were trying to understand how best to help men to engage with the NHSBCSP and the personal decision-making that that entails. The expectation is that if we can help men to engage with the process in a fully informed way, then we increase the likelihood that more men will decide for themselves to take the opportunity of screening when it is offered.

General principles associated with style and content

1. Make sure that the practical elements of the FOBt are properly understood by men.
Our research suggests that men are more likely than women to see the test as simple to do, and less likely to feel the psychological constraints that deter some people. It may be that this message about practicality could be brought to the forefront of information.
2. Our research indicates that both men and women would value information materials that are written specifically with the sex of the recipient in mind. It seems probable that such an approach has the potential to encourage both sexes to participate more fully in the NHSBCSP, although in this case, we are concerned only with identifying the principle in respect of men.
3. Similarly, both sexes expressed a preference for short, simple and memorable forms of expression in information materials. This preference is not however, entirely straightforward to achieve. The style and content of the letters and leaflets presently in use is, to a significant extent, dictated by ethical and medico-legal considerations. Furthermore, some technical information does not lend itself to simplification beyond a certain point. It is also proper that individuals should be given enough information to make a fully considered decision.

It is therefore not appropriate to develop a "clunk click, every trip" style slogan that focuses solely on encouraging people to use the FOB testing kit when it arrives. At the same time, it should be perfectly possible to find an informal and constructive "tone of voice" and succinct, memorable forms of words that stress (for example) the importance of not making an immediate decision to throw the kit away or the benefits of detecting cancer early.

4. Our research suggests that the inclination in men simply to “deny” health concerns, either through inertia or unacknowledged fear, is not perhaps as commonplace as some people believe. Nevertheless, it did emerge as an important factor in some cases and is recognised by many men as a “male characteristic”. It is important to find ways of taking this underlying issue into account when developing communication materials for men.
5. Some men in the discussion groups identified a potential reason for declining the invitation to take the FOBt, that we had not identified in the literature review. This was that, if one feels fit and well, then it may seem that the FOBt is either not relevant or that somehow there is “more to lose” by taking it (because it might find something wrong). The postal survey suggested that this belief might be somewhat more common in men. Similarly, some men suggested that by describing the symptoms of bowel cancer, the NHSBCSP information might actually make it less likely that some people would choose to take part (i.e. if the recipient does not have symptoms, then the FOBt appears less relevant). It might be useful to counter these beliefs in information material directed at men.
6. It is crucial to avoid falling back on a “default”, stereotyped view of men when considering how to frame health messages in a “male-sensitive” way. This is not to say that messages exploiting men’s interest in (for example) football have no value at all. Likewise, it remains important to communicate with men “as they are and where they are”. These approaches have been shown in the past to work very well with some groups of men and in some circumstances. The point to remember is that they will not appeal to all men and indeed, may not appeal to a majority.

Recommendations

There are only two substantive recommendations:

1. The importance of GPs and other primary care staff

The issue that came up time and again in different forms during our research was the high value placed on the GP and primary care staff in informing personal decision-making in health matters. It seems probable that this factor is perhaps of particular importance to this age group (although we did not address this specific point in the research). The advice and encouragement of GPs and primary care staff is important to both sexes but appears to be even more so to men.

We therefore recommend the development of interventions – informed by the principles outlined above - in which the patient’s GP is involved in the invitation to participate in the NHSBCSP. Additionally, we think that there may be particular value in interventions in which the GP is seen to endorse the idea of informed engagement with the programme. We recommend that such interventions involve direct contact between the patient and his local surgery. Ideally, this would incorporate the option of face-to-face contact if that was what the patient wished but a signed letter would be another option. There may be other alternatives.

This approach does have its problems. For obvious reasons, GPs and other primary care staff cannot simply advise men to take the FOBt, either in the letter of invitation or during a consultation. Furthermore primary care services are often limited for time and resources. It would be necessary to develop an approach that was consistent, could be delivered quickly, and was based on the notion of helping people to decide for themselves. We believe that it is possible to do this.

2. The importance of spouses and partners in men's decision-making

There seems no doubt that, for men who have a spouse or partner, that person is likely to be very influential in their decision-making around health. Other MHF research has often uncovered this same finding, although not through such a formal process. The idea of seeking to influence men's health-related behaviour via their spouse or partner is however, fraught with problems. Unlike the problems associated with Recommendation 1 above, these problems are ideological rather than practical.

The MHF has debated this issue internally on several occasions and has always concluded that we would not want to endorse or reinforce the notion that women somehow have de facto responsibility for the health of their husband or partner. Quite apart from the assumption that this involves about the role of women within relationships, this notion also seems to undermine one of the central objectives of the MHF – to enable men to take greater responsibility for their own health.

At the same time, it seems that involvement with the health needs of one's partner is a commonly understood feature of many people's long-term relationships, albeit that the balance of that engagement seems more often weighted in one direction than the other.

Our solution is to propose a way forward based on encouraging men simply to discuss their decision-making about the FOBt with anyone they feel comfortable with. Our evidence suggests, that the person to whom most men would naturally turn is their wife or partner. Others might choose another relative, or a friend. Obviously, for men who have no partner, those are the options available anyway. Equally a man might seek a conversation with his GP (or other primary care staff), which brings us back to the other potential mechanism for increasing men's involvement discussed at Recommendation 1 above.

We would like to see the development of interventions in which men are encouraged – or perhaps, overtly advised – not to make a decision about the FOBt until they have spoken to a trusted relative, friend or health professional (e.g. GP, practice nurse or a pharmacist). This could be achieved very simply by the use of a variety of media, nationally or locally and/or by an insert of some kind in the NHSBCSP information pack.

Generalising the approach in this way would limit the extent to which we were directly giving responsibility to women. It would also mean that we were less likely to disadvantage men who do not have a partner. If it were targeted at the whole community rather than just men (perhaps with some gender-specific content), a generalised approach of this kind could, in our view, potentially help both men and women with the decision-making process and hence improve informed uptake by both sexes.

Appendix 1: Membership of the Expert Advisory Group

TJ Day

Co-ordinator: Informed Choice

NHS Cancer Screening Programmes (Sheffield)

Tim Elliott;

Team Leader: Cancer Screening and Male Cancers

Cancer Policy Team, Department of Health

Paul Hewitson

Research Fellow

Department of Primary Health Care, University of Oxford

Prof. Sarah Payne

School for Policy Studies, Bristol University

Stephen Sibbald

Director of Operations

Men's Health Forum

Steve Smith

Head of Biochemistry

Midlands and North West Hub,

National Bowel Cancer Screening Programme

Prof. David Weller

General Practice Section, Division of Community

Health Sciences, University of Edinburgh

David Wilkins

Policy and Projects Officer

Men's Health Forum

Appendix 2: Topic guides

Topic guides for the discussion groups in Phase 2 of the research

Four groups were held using Format 1, which looked at male health behaviours and attitudes. Formats 2A and 2B both included a more focused discussion on the process of the NHSBCSP. Guide 2A was used in the South West, where the NHSBCSP had not yet been rolled out. All participants in these groups were given an FOBt kit to examine and discuss. Guide 2B was used in the West Midlands, where participants were likely to have already been invited to participate in the NHSBCSP. In this case, participants were asked to reflect on their responses when they had received the kit through the post.

Discussion Groups using Format 1

1. Introduction and welcome

- Introduce self and thank respondents for coming
- Housekeeping – fire exits, location of toilets, length of group
- Intro to mruk research
- Research on behalf of MHF
- Research commissioned by Dept. of Health (i.e. is important)
- Confidentiality – MRS Code of Conduct
- Explain aims and objectives of the group – To explore attitudes and behaviour towards health-related issues.
- Please give opinions freely but only one person speaking at a time
- Recording for analysis purposes
- Group to introduce themselves

2. General issues and warm up

- To what extent do you think people consider their health on a day-to-day basis? Why?
- How seriously do you take your health? Why?
- Do you take active steps to stay healthy?
- What about if you are ill, or have symptoms of an illness? How do you react? Why?
- Do you seek help/medical advice? Why?
- How do you think people make sense of illness? Why react this way?

3. Fatalism

- IF MENTIONED PREVIOUSLY: Some of you suggested that you do not worry about your health, because you have little control over whether you get ill or not.
- IF NOT MENTIONED PREVIOUSLY: Research suggests that some people believe that their health is predetermined, and your actions make little or no difference.
- Do you agree with this? Do you believe this or know of other men that believe this?
- Why do you think you/other men think this way about health?
- How do you think this affects your/other people's behaviour?
- Do you think this way of thinking is specific to men? Do you think women behave in a similar manner?
- IF A DIFFERENCE IS MENTIONED: Why do you think men are more likely / less likely to think like this?
- Do you think certain illnesses or diseases are more likely to attract this type of thinking? If so which? Why?
- IF NOT MENTIONED PREVIOUSLY: Do you think cancer is more likely to attract this type of thinking? Why?

4. Fear and Denial

- IF MENTIONED PREVIOUSLY: Some of you suggested that some people are afraid of facing up to illness and disease, even if they don't admit it, and this could lead to ignoring symptoms or not taking up opportunities for health checks like screening programmes
- IF NOT MENTIONED PREVIOUSLY: Research suggests that some people are afraid of facing up to illness and disease, even if they don't admit it, and this could lead to ignoring symptoms.
- Do you agree with this? Do you recognise this in your own behaviour or the behaviour of others?
- Why do you think you/other men think this way about illness and disease?
- How do you think this affects your/other people's behaviour?
- Do you think this way of thinking is specific to men? Do you think women behave in a similar manner?
- IF A DIFFERENCE IS MENTIONED: Why do you think men are more likely / less likely to think like this?
- Do you think certain illnesses or diseases are more likely to attract this type of thinking? If so which? Why?
- IF NOT MENTIONED PREVIOUSLY: Do you think cancer is more likely to attract this type of thinking? Why?

5. Stoicism

- IF MENTIONED PREVIOUSLY: Some of you suggested that some people “soldier on” regardless of how ill they are, or the symptoms they are showing.
- IF NOT MENTIONED PREVIOUSLY: Research suggests that some people “soldier on” regardless of how ill they are, or the symptoms they are showing.
- Do you agree with this? Do you recognise this in your own behaviour or the behaviour of others?
- Why do you think you/other men think this way about illness and disease?
- How do you think this affects your/other people’s behaviour?
- Do you think this way of thinking is specific to men? Do you think women behave in a similar manner?
- IF A DIFFERENCE IS MENTIONED: Why do you think men are more likely to think like this?
- Do you think certain illnesses or diseases are more likely to attract this type of thinking? If so which? Why?
- IF NOT MENTIONED PREVIOUSLY: Do you think cancer is more likely to attract this type of thinking? Why?

6. NHSBCSP

- Brief outline of NHSBCSP and the processes involved. Explain that men are less likely to participate.
- What are your initial feelings towards the screening process?
- Would you take part? Why would you/wouldn’t you?
- What elements of the process would put you off participating? Why?
- What role do you think the issues we discussed earlier play in preventing men from participating in bowel cancer screening?
- What do you think prevents men the most, from participating? Why?
- Do you think there are any other issues that prevent men from participating? Why?
- What information would you like to have to help you make a decision about whether to participate?
- Imagine you worked for the NHS and it was your job to increase the number of men that participate in the screening process
- What would you do?
- What information would you distribute?
- How would you circulate the information?
- How would you try to overcome some of the obstacles we have discussed?

7. Summary

- Summary of key issues
- Any other comments?
- Hand out patient information leaflets in case taking part has raised any anxieties

Thank and close

Discussion Groups using Format 2A

1. Introduction and welcome

- Introduce self and thank respondents for coming
- Housekeeping – fire exits, location of toilets, length of group
- Intro to mruk research
- Research on behalf of MHF
- Research commissioned by Dept. of Health (i.e. is important)
- Confidentiality – MRS Code of Conduct
- Explain aims and objectives of the group – to explore attitudes and behaviour towards health-related issues.
- Please give opinions freely but only one person speaking at a time
- Recording for analysis purposes
- Group to introduce themselves

2. Attitudes towards the FOBt process

- Explanation of the FOBt process. Hand out kits, explain how they work.
- What are your initial feelings towards the screening process?
- Would you take part? Why would you/wouldn't you?
- What elements of the process would put you off participating? Why?
- How do you think you'd feel if you got this information?

3. Fatalism, fear and denial

- How useful do you think this kind of screening test is? Why?
- Is screening for diseases and illnesses, such as cancer, important to do?
- EXPLANATION: Explain that fewer men take part, and that fatalism, fear and denial are important factors in their decision making. Explain what is meant fatalism, fear and denial.
- IF MENTIONED PREVIOUSLY: Some of you mentioned similar ideas to these earlier.
- Do you agree with this? Do you recognise this in your own behaviour or the behaviour of others?

- Why do you think you/other men think this way about illness and disease?
- How do you think this affects your/other people's behaviour?
- Do you think this way of thinking is specific to men? Do you think women behave in a similar manner?
- IF A DIFFERENCE IS MENTIONED: Why do you think men are more likely / less likely to think like this?
- How important do you think these issues would be when deciding whether to take part in the screening process or not? Why?

4. Other responses

- How do you think the issues we have discussed affect men's decision about the FOBt?
- What do you think prevents men the most, from participating? Why?
- Do you think this way of thinking is specific to men? Do you think women behave in a similar manner?
- IF A DIFFERENCE IS MENTIONED: Why do you think men are more likely to think like this?

5. NHSBCSP

- Do you think there are any other issues that prevent men from participating? Why?
- What information would you like to have to help you make a decision about whether to participate?
- Imagine you worked for the NHS and it was your job to increase the number of men that participate in the screening process
- What would you do?
- What information would you distribute?
- How would you circulate the information?
- How would you try to overcome some of the obstacles we have discussed?

6. Summary

- Summary of key issues
- Any other comments?
- Hand out patient information leaflets in case taking part has raised any anxieties

Thank and close.

Discussion Groups using Format 2B

1. Introduction and welcome

- Introduce self and thank respondents for coming
- Housekeeping – fire exits, location of toilets, length of group
- Intro to mruk research
- Research on behalf of MHF
- Research commissioned by Dept. of Health (i.e. is important)
- Confidentiality – MRS Code of Conduct
- Explain aims and objectives of the group – to explore attitudes and behaviour towards health-related issues.
- Please give opinions freely but only one person speaking at a time
- Recording for analysis purposes
- Group to introduce themselves

2. Attitudes towards the FOBt process

- How did you think you feel when you first received the information?
- What were your initial feelings towards the screening process?
- How did the prospect of doing it make you feel?
- How did you make the decision whether to take part or not? What factors did you consider?
- Did you take part? Why did you/didn't you? **STRESS THAT PEOPLE DON'T HAVE TO SAY WHETHER THEY TOOK PART OR NOT**
- What elements of the process put you off participating? Why?

3. Fatalism, fear and denial

- How useful do you think this kind of screening test is? Why?
- Is screening for diseases and illnesses, such as cancer, important to do?
- What reasons do you think prevent men from participating in tests such as these?
- **IF MENTION FATALISM, FEAR OR DENIAL:** You mentioned fatalism, fear and denial (use language similar to that used by respondents)
- Do many of you recognise these views in your own behaviour or the behaviour of others?
- Why do you think you/other men think this way about illness and disease?
- How do you think this affects your/other people's behaviour?
- Do you think this way of thinking is specific to men? Do you think women behave in a similar manner?
- **IF A DIFFERENCE IS MENTIONED:** Why do you think men are more likely / less likely to think like this?

- How important were these issues when deciding whether to take part or not? Why?
- EXPLANATION: Explain that fewer men take part, and that fatalism, fear and denial are important factors in their decision making. Explain what is meant fatalism, fear and denial.

4. Other responses

- Were there any other issues that you considered when deciding whether to take part? Why?
- How important were these issues when deciding whether to take part or not? Why?
- How do you think the issues we have discussed affect men's decision about the FOBt?
- What do you think prevents men the most, from participating? Why?
- Do you think this way of thinking is specific to men? Do you think women behave in a similar manner?
- IF A DIFFERENCE IS MENTIONED: Why do you think men are more likely / less likely to think like this?

5. NHSBCSP

- What information would you like to have to help you make a decision about whether to participate?
- Did you feel there was any information or support you were lacking when making your decision?
- Imagine you worked for the NHS and it was your job to increase the number of men that participate in the screening process
- What would you do?
- What information would you distribute?
- How would you circulate the information?
- How would you try to overcome some of the obstacles we have discussed today?

6. Summary

- Summary of key issues
- Any other comments?
- Hand out patient information leaflets in case taking part has raised any anxieties.

Thank and close

Appendix 3: Postal survey questionnaire



Name
Add1
Add2
Add3
Add4
Add5
Add6
Add7

September 2009

Dear Name

The NHS National Bowel Cancer Screening Programme Survey of public attitudes

The Men's Health Forum, a national charity, has been asked by the Department of Health to survey people's attitudes to the NHS National Bowel Cancer Screening Programme. The survey is being conducted by Cello mruk research, an independent market research organisation

By the end of this year, all adults aged 60 – 69 will be invited to take part in bowel cancer screening every two years. The screening programme is already available in most parts of the country but there are a small number of areas that it has not yet reached. From next year, the programme will gradually be extended to include people up to age 75. Screening takes place at home and is self-administered (i.e. people taking the initial screening test do not need to see a doctor or nurse). More information about the screening process is given in the enclosed survey form.

This survey will help us to understand why men in particular have seemed less willing to take up the offer of screening so far. The survey is being sent to both men and women because we want to know the views of both sexes.

Your answers will help us improve the way the NHS Bowel Cancer Screening Programme is organised so that more people consider taking part in screening. That will help us to detect more cancers at an early stage when treatment is more likely to be successful.

You can help by completing the enclosed questionnaire and returning it within the next 7 days using the enclosed Freepost envelope (you won't need a stamp). All the answers you give will remain confidential. Only the overall findings from the survey will be passed on. No-one from the NHS or the Men's Health Forum will see your individual response.

There are instructions as you read through the survey but if you have any questions, need any help filling in the form or require a large print version, please call the Cello mruk research helpline on Freephone 0800 073 2607. If you want to know more about the reasons for the survey you can telephone Men's Health Forum on (01963) 362047. Please note that this survey is only intended for people aged between 60 and 74. Please do not complete this form unless you are in this age group.

I very much hope that you will take part and would like to thank you in advance for your help with this important research.

Yours sincerely,

David Wilkins, Head of Policy, Men's Health Forum

SECTION 1: GENERAL HEALTH**Q1 How would you describe your health in general?**

Please tick (✓) one box only

Very good
Good
Fair
Poor
Very poor

☐ ☐ ☐ ☐ ☐

Office Use (1)

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2

3

4

5

Q2 Have you ever been diagnosed with bowel cancer?

Please tick (✓) one box only

Yes
No

☐ ☐

Office Use (2)

1

2

Q3 Have you ever been invited to take part in the NHS Bowel Cancer Screening Programme?

Please tick (✓) one box only

Yes
No
Don't know/not sure

☐ GO TO Q4
☐ GO TO Q6
☐ GO TO Q6

Office Use (3)

1

2

3

Q4 Did you decide to complete the home screening test?

Please tick (✓) one box only

Yes
No

☐ GO TO Q6
☐ GO TO Q5

Office Use (4)

1

2

Q5 Why did you decide not to take part?

Please tick (✓) all that apply

Didn't understand what I had to do
Decided it wasn't necessary
Didn't have enough time
Thought the test was too complicated
Thought the test was too unpleasant
Didn't want to find out that I might have cancer
Other (Please tick and write in below)

☐ ☐ ☐ ☐ ☐ ☐ ☐

Office Use (5)

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SECTION 3: ABOUT BOWEL CANCER SCREENING

The NHS Bowel Cancer Screening Programme involves sending a home testing kit to every person in the country aged 60 – 69 every two years. The test itself requires people to take very small samples of three separate bowel motions and wipe them onto special cards. The cards are then sent off to a laboratory to see if the samples contain tiny traces of blood. These traces of blood usually cannot be seen with the naked eye. This kind of blood in the bowel motion can be an early indicator of cancer.

The results of the test come back by post within two weeks. If the laboratory finds blood in the sample, that does not mean that the person has bowel cancer (nine out of ten findings of blood are not cancer). A finding of blood does however, lead to the offer of a hospital appointment for a further, more detailed, examination.

Q8 Does the home testing kit sound like something you would be willing to do (or willing to do again if you have already done it before)?

Please tick (✓) one box only

Yes ☐ No ☐ Not sure ☐

Office Use (54) 1 2 3

Q9 Now you have read a description of the test, which of the following would you use to describe how you feel about the home testing procedure:

Please tick (✓) all that apply

The test is messy	<input type="checkbox"/>	Office Use (55) 1
The test is easy	<input type="checkbox"/>	Office Use (56) 1
The test is unpleasant	<input type="checkbox"/>	Office Use (57) 1
The test is embarrassing	<input type="checkbox"/>	Office Use (58) 1
The test is simple	<input type="checkbox"/>	Office Use (59) 1
The test is complicated	<input type="checkbox"/>	Office Use (60) 1
I don't mind what the test entails. It is worth it for health reasons.	<input type="checkbox"/>	Office Use (61) 1
I wouldn't want to have to do anything that involved getting close to my bowel motions	<input type="checkbox"/>	Office Use (62) 1
I can't see any difficulties with it	<input type="checkbox"/>	Office Use (63) 1
It sounds like it would be physically difficult to do	<input type="checkbox"/>	Office Use (64) 1
My bowel movements are not regular enough	<input type="checkbox"/>	Office Use (65) 1
My bowel movements are too frequent	<input type="checkbox"/>	Office Use (66) 1
It's not very nice having to keep the samples in the house for three days	<input type="checkbox"/>	Office Use (67) 1
I wouldn't mind other people in the house knowing I was doing it	<input type="checkbox"/>	Office Use (68) 1
I would mind other people in the house knowing I was doing it	<input type="checkbox"/>	Office Use (69) 1
I don't like the idea of putting the samples in the post	<input type="checkbox"/>	Office Use (70) 1
The anxiety during the wait for the results to come back puts me off	<input type="checkbox"/>	Office Use (71) 1
I don't like the idea that it might lead to further tests	<input type="checkbox"/>	Office Use (72) 1

SECTION 4: ENCOURAGING PEOPLE TO CONSIDER SCREENING

Q10 How influential are each of the following on your attitude to health (e.g. encourages you to think about healthy eating; keeping fit or doing health checks)?

Please tick (✓) one box for each statement

	No influence at all	Not particularly influential	Fairly influential	Very influential	Office Use
Spouse/partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (73) 1 2 3 4
Other family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (74) 1 2 3 4
Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (75) 1 2 3 4
Newspaper or magazine articles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (76) 1 2 3 4
Posters, leaflets and advertising by the NHS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (77) 1 2 3 4
TV programmes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (78) 1 2 3 4
Radio programmes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (79) 1 2 3 4
The internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (80) 1 2 3 4
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (81) 1 2 3 4
Practice nurse or other surgery staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (82) 1 2 3 4
Pharmacist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (83) 1 2 3 4
Other (Please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (84) 1 2 3 4
Other (Please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (85) (86)
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (87) 1 2 3 4
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Office Use (88) (89)

There is lots of information about how to stay healthy these days on TV, radio, newspapers, posters and leaflets.

Q11a What do you like and what don't you like when you see/hear this type of information? (if you don't like any information, please tick that box)

Please tick (✓) one box for each statement

	Dislike a lot	Dislike	Like	Like a lot	Office Use	
Facts and statistics about health	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (70)	
Real life stories about people's health	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (71)	
Instructions about what to do and what not to do	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (72)	
Lots of detailed information	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (73)	
Information that is as simple as possible	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (74)	
Humour	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (75)	
Slogans that I can remember	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (76)	
Information that appeals to the emotions	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (77)	
Information especially for my age group	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (78)	
Information especially for men or women	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (79)	
Inclusion of helpline numbers	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (80)	
The involvement of a famous person	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1 2 3 4 (81)	
I don't like any kind of information about staying healthy	<input type="checkbox"/> 1	PLEASE GO TO Q11B				1 (82)

IF YOU HAVE INDICATED THAT YOU 'DON'T LIKE ANY KIND OF INFORMATION ABOUT STAYING HEALTHY', PLEASE ANSWER QUESTION 11B, OTHERWISE PROCEED TO QUESTION 11C.

Q11b Please explain why you don't like any kind of information about staying healthy?

Please write in below

Office Use

(83) (84)

(85) (86)

(87) (88)

The table below lists various ways in which people could be given additional information about the NHS Bowel Cancer Screening Programme encouraging them to think about taking part.

Q11c Which of the following approaches might work best for you? Please select a maximum of three responses
Please tick (✓) no more than 3 boxes

	Office Use
Messages on local radio	<input type="checkbox"/> 1 (89)
Advertising and articles in local newspapers	<input type="checkbox"/> 1 (90)
Endorsement by a local celebrity	<input type="checkbox"/> 1 (91)
Advertising at local sporting events	<input type="checkbox"/> 1 (92)
Endorsement by a local sporting personality	<input type="checkbox"/> 1 (93)
Information distributed in pubs and other social settings	<input type="checkbox"/> 1 (94)
Information distributed at work	<input type="checkbox"/> 1 (95)
Information distributed in shops and other commercial premises	<input type="checkbox"/> 1 (96)
Encouragement from your GP or other health professional	<input type="checkbox"/> 1 (97)
Encouragement from the NHS directed at the wider population	<input type="checkbox"/> 1 (98)
A video that could be watched online or given to people on DVD	<input type="checkbox"/> 1 (99)
An opportunity to ask questions directly to experts	<input type="checkbox"/> 1 (100)

As we said at the beginning, this survey is particularly about encouraging men to consider taking part in the NHS Bowel Cancer Screening Programme. The list below is the same as the previous question

Q12 Which of the following approaches might work best for men in your community? Please select a maximum of three responses.

Please tick (✓) no more than 3 boxes

	Office Use
Messages on local radio	<input type="checkbox"/> 1 (101)
Advertising and articles in local newspapers	<input type="checkbox"/> 1 (102)
Endorsement by a local celebrity	<input type="checkbox"/> 1 (103)
Advertising at local sporting events	<input type="checkbox"/> 1 (104)
Endorsement by a local sporting personality	<input type="checkbox"/> 1 (105)
Information distributed in pubs and other social settings	<input type="checkbox"/> 1 (106)
Information distributed at work	<input type="checkbox"/> 1 (107)
Information distributed in shops and other commercial premises	<input type="checkbox"/> 1 (108)
Encouragement from your GP or other health professional	<input type="checkbox"/> 1 (109)
Encouragement from the NHS directed at the wider population	<input type="checkbox"/> 1 (110)
A video that could be watched online or given to people on DVD	<input type="checkbox"/> 1 (111)
An opportunity to ask questions directly to experts	<input type="checkbox"/> 1 (112)
Please add any ideas or comments of your own in the box below:	
	(113) (114)
	(115) (116)

SECTION 5: About You

Q13 How old are you?

Please tick (✓) one box only

	Office Use (117) (118)
60	<input type="checkbox"/>
61	<input type="checkbox"/>
62	<input type="checkbox"/>
63	<input type="checkbox"/>
64	<input type="checkbox"/>
65	<input type="checkbox"/>
66	<input type="checkbox"/>
67	<input type="checkbox"/>
68	<input type="checkbox"/>
69	<input type="checkbox"/>
70	<input type="checkbox"/>
71	<input type="checkbox"/>
72	<input type="checkbox"/>
73	<input type="checkbox"/>
74	<input type="checkbox"/>
Between 60 and 74 but would prefer not to say	<input type="checkbox"/>

Q14 Are you male or female?

Please tick (✓) one box only

Male ☐Female ☐

Q15 What is your marital status?

Please tick (✓) one box only

Married/living with partner ☐Separated/divorced ☐Widowed ☐Single ☐

Q16 What is your current employment status?

Please tick (✓) one box only

	Office Use (120) (121)
Retired	<input type="checkbox"/>
Employed (including self-employed): 35 hours or more p.w.	<input type="checkbox"/>
Employed (including self-employed): Fewer than 35 hours p.w.	<input type="checkbox"/>
Unemployed and looking for work	<input type="checkbox"/>
Unemployed because of disability or long term sickness	<input type="checkbox"/>
Looking after family/home	<input type="checkbox"/>
Other	<input type="checkbox"/>

Q17 Thinking about your last or current main occupation, please tick which box best describes the sort of work you do (if you are not working now, please tick a box to show what you did in your last job)?

Please tick (✓) one box only

	Office Use (122) (123)
Modern professional occupations such as: teacher - nurse - physiotherapist - social worker - welfare officer - artist - musician - police officer (sergeant or above) - software designer	<input type="checkbox"/>
Clerical and intermediate occupations such as: secretary - personal assistant - clerical worker - office clerk - call centre agent - nursing auxiliary - nursery nurse	<input type="checkbox"/>
Senior managers or administrators (usually responsible for planning, organising and co-ordinating work and for finance) such as: finance manager - chief executive	<input type="checkbox"/>
Technical and craft occupations such as: motor mechanic - fitter - inspector - plumber - printer - tool maker - electrician - gardener - train driver	<input type="checkbox"/>
Semi-routine manual and service occupations such as: postal worker - machine operative - security guard - caretaker - farm worker - catering assistant - receptionist - sales assistant	<input type="checkbox"/>
Routine manual and service occupations such as: HGV driver - van driver - cleaner - porter - packer - sewing machinist - messenger - labourer - waiter / waitress - bar staff	<input type="checkbox"/>
Middle or junior managers such as: office manager - retail manager - bank manager - restaurant manager - warehouse manager - publican	<input type="checkbox"/>
Traditional professional occupations such as: accountant - solicitor - medical practitioner - scientist - civil / mechanical engineer	<input type="checkbox"/>
Looking after family/home	<input type="checkbox"/>
I did not work	<input type="checkbox"/>

Q18 How would you describe yourself?

Please tick (✓) one box only

		Office Use	
		(124)	(125)
White			
British	<input type="checkbox"/>	0	1
Irish	<input type="checkbox"/>	0	2
Any other White background (please tick and write in)	<input type="checkbox"/>	0	3
	(126) (127)		
Mixed			
White & Black Caribbean	<input type="checkbox"/>	0	4
White & Black African	<input type="checkbox"/>	0	5
White & Asian	<input type="checkbox"/>	0	6
Any other mixed background (please tick and write in)	<input type="checkbox"/>	0	7
	(128) (129)		
Asian or Asian British			
Indian	<input type="checkbox"/>	0	8
Pakistani	<input type="checkbox"/>	0	9
Bangladeshi	<input type="checkbox"/>	5	0
Chinese	<input type="checkbox"/>	1	1
Any other Asian background (please tick and write in)	<input type="checkbox"/>	1	2
	(130) (131)		
Black or Black British			
Caribbean	<input type="checkbox"/>	1	3
African	<input type="checkbox"/>	1	4
Any other Black background (please tick and write in)	<input type="checkbox"/>	1	5
	(132) (133)		
Other			
Other (please tick and write in)	<input type="checkbox"/>	1	6
	(134) (135)		
Prefer not to say	<input type="checkbox"/>	1	7

Thank you very much. Your responses will help us improve communication within the NHS National Bowel Cancer Screening Programme.

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Appendix 4: Registered attendees at the Expert Seminar held at the King's Fund on January 26th 2011

Peter Baker [Event Chair]

CEO

Men's Health Forum

Bryan Jones [Speaker]

Policy and Campaigns Manager

The Prostate Cancer Charity

Mike Harris [Speaker]

Communications Lead

NHS Abdominal Aortic Aneurysm Screening Programme

Dr Steve Robertson [Speaker]

Reader in Men's Health

Centre for Men's Health,
Leeds Metropolitan University

Mark Robinson [Speaker]

Research Officer

Centre for Men's Health,
Leeds Metropolitan University

Paul Hewitson [Speaker]

Research Fellow

Department of Primary Health Care,
Oxford University

David Wilkins [Speaker]

Policy and Projects Officer

Men's Health Forum

Stephen Sibbald

Director of Operations

Men's Health Forum

Steve Smith

Biochemistry Head

University Hospitals Coventry
and Warwickshire NHS Trust

Tim Elliott

Team Leader

Cancer Screening and Male Cancers,
Cancer Policy Team, Department of Health

Dr Christian von Wagner

Research Associate

University College London

Dr Gemma Vart

Research Associate

University College London

Jane Allberry

Deputy Director

Cancer Services, End of Life Care and
Dermatology, Department of Health

Caroline Pundyke

Health Promotion and Outreach Officer

Bowel Cancer UK

Gail Curry

Health Promotion and Outreach Officer

Bowel Cancer UK

Prof David Weller

*Head, School of Clinical Sciences
and Community Health*

University of Edinburgh

Lilian Wiles

Head of Patient Services

Beating Bowel Cancer

Gwen Kaplan

Cancer Awareness Roadshow Team Leader

Cancer Research UK

Gillian Kilgour

Cancer Awareness Nurse Team Leader

Cancer Research UK

Martin Powell

Cancer Awareness Roadshow Nurse

Cancer Research UK

Audrey Howarth

*Health Improvement Practitioner,
Bowel Cancer Screening*

NHS Bolton

Mark Flanagan

Chief Executive
Beating Bowel Cancer

Julie Tucker

Health Improvement Practitioner
Breast and Bowel Cancer Screening,
Queen Elizabeth Hospital Gateshead

Bob Hulme

Men's Health Coordinator
Directorate of Public Health,
NHS North Lincolnshire

Prof Sarah Payne

Professor in Health Policy and Gender
School for Policy Studies, University of Bristol

Glen Poole

Chair
The Men's Network, Brighton & Hove

Maya Monteiro

Health Professionals Programme Manager
World Cancer Research Fund

Anneliese Levy

Information Officer
Prostate Cancer Charity

Dr Claire Knight

Health Information Officer
Cancer Research UK

Helen Jessop

Screening Promotion Officer
Screening Division, Public Health Wales

Dafydd Snelling

Screening Promotion Officer
Screening Division, Public Health Wales

Harbhajan Singh

Lead Member
Greenwich LINK Project

Innocent Muza

*Health Improvement Specialist,
Health Inequalities*
NHS-Luton

Patricia Johnson

Senior Biomedical Scientist/Section Leader
Bowel Screening Centre,
Queen Elizabeth Hospital Gateshead

Sharon McCreadle

Senior Team Leader
Bowel Screening Hub,
Queen Elizabeth Hospital Gateshead

Joy Ward

Admin Team Leader
Bowel Screening Hub,
Queen Elizabeth Hospital Gateshead

Farid Akhtar

Screening Outreach Worker
NHS National Cancer Screening Programme,
Camden PCT

Dominic Rai

Partner
"Men Talking"

Richard Dunning

Partner
"Men Talking"

Anita Ralli

Policy & Public Affairs Officer
Beating Bowel Cancer

Rachel Korboe

Screening Officer / Data Analyst
NHS Barnet, Enfield and Haringey

Davinia Springer

Cancer Screening Facilitator
Public Health, NHS Greenwich

Nafeesah Mian

Cancer Service Improvement Facilitator
North Central London Cancer
Commissioning Network

Yinka Ebo

Senior Health Information Officer
Cancer Research UK

TJ Day

Co-ordinator, Informed Choice
National Cancer Screening Programmes

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The MHF's mission, vision, values and beliefs statement can be read in full at www.menshealthforum.org.uk

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