

Communication about colorectal cancer screening in Britain: public preferences for an expert recommendation

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BACKGROUND: Informed decision-making approaches to cancer screening emphasise the importance of decisions being determined by individuals' own values and preferences. However, advice from a trusted source may also contribute to autonomous decision-making. This study examined preferences regarding a recommendation from the NHS and information provision in the context of colorectal cancer (CRC) screening.

METHODS: In face-to-face interviews, a population-based sample of adults across Britain ($n = 1964$; age 50–80 years) indicated their preference between: (1) a strong recommendation to participate in CRC screening, (2) a recommendation alongside advice to make an individual decision, and (3) no recommendation but advice to make an individual decision. Other measures included trust in the NHS and preferences for information on benefits and risks.

RESULTS: Most respondents (84%) preferred a recommendation (47% strong recommendation, 37% recommendation plus individual decision-making advice), but the majority also wanted full information on risks (77%) and benefits (78%). Men were more in favour of a recommendation than women (86% vs 81%). Trust in the NHS was high overall, but the minority who expressed low trust were less likely to want a recommendation.

CONCLUSION: Most British adults want full information on risks and benefits of screening but they also want a recommendation from an authoritative source. An 'expert' view may be an important part of autonomous health decision-making.

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Historically, the emphasis in public health research on cancer screening has been on maximising uptake. However, actively encouraging participation can sit uncomfortably with the contemporary emphasis on promoting informed choice in health decision-making (Raffle, 2001; Jepson *et al*, 2005). In some countries, shared decision-making can take place in a primary care consultation before screening (Miles A. *et al*, 2004; Zapka and Lemon, 2004; Price *et al*, 2010; Zapka *et al*, 2011), but in the UK, which has an organised programme of cancer screening (NHS, 2012), information is mailed out with screening invitations, and the decision about whether to participate must be made by the individual. Although there is some variation between the breast, cervical and bowel screening programmes, and between the nations of the UK, in general the programmes encourage people to use the information provided to weigh up the pros and cons of screening.

Does informed choice necessarily exclude an expert (provider) recommendation? A recent framework on screening communication identified three approaches (Entwistle *et al*, 2008). As well as the two extremes: 'be screened' (a clear recommendation) and 'analyse and

choose' (the individual should weigh up risks and benefits and make their own decision), an intermediate position was identified, termed 'consider an offer', which provides a recommendation but encourages people to consider the trustworthiness of the source (Entwistle *et al*, 2008). This recognises both participation and non-participation as legitimate decisions and is potentially compatible with trying to maximise informed uptake while respecting personal autonomy. It is similar to the libertarian paternalist perspective that provides a default recommendation along with information allowing the individual to decline the default (Wheeler *et al*, 2011). As long as the source is clear, the individual should be able to evaluate the trustworthiness of both the recommendation and the information. A recommendation from a trusted source allows individuals to engage in 'intellectual outsourcing' (Appiah, 2005), consistent with the notion of 'bounded rationality' (Simon, 1957), rather than having to evaluate all the information themselves.

Little is known about public preferences for having an expert/provider recommendation to take part in screening, although the limited evidence available suggests it may be valued (Østerlie *et al*, 2008; Woodrow *et al*, 2008). This could be particularly true for individuals who lack the numeracy skills to evaluate statistical detail about risks and benefits of participation (Reyna *et al*, 2009; Peters, 2012). Lower socioeconomic status (SES) groups in the US report less confidence in their ability to deal with statistical information (Smith *et al*, 2010a). In addition, an Australian study

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carried out in a population with low levels of education found that a decision aid (DA) designed to promote autonomous decision-making about colorectal cancer (CRC) screening increased informed decision making by 22% but reduced uptake by 16% (Smith *et al*, 2010b).

In this study, we assessed public preferences for a recommendation in the context of the National Health Service (NHS) Colorectal (Bowel) Cancer Screening Programme in the UK asking respondents to express a preference between: (i) a strong recommendation to take part in faecal occult blood testing, (ii) a recommendation plus advice to make an individual choice, or (iii) no recommendation but advice to make an individual decision. We also assessed trust in the NHS and desire for information on risks and benefits. We hypothesised that preference for a recommendation would be associated with higher trust, lower desire for information about risks and benefits and lower SES.

METHODS

Data were collected as part of a population-based survey carried out by TNS Research International in July 2011. The omnibus survey included questions from a range of contributors on a variety of non-health-related issues. A description of the survey, including questions and response scales, is provided in the supplementary material. The sample included 2067 men and women, aged 50–80 years, living in Great Britain. The majority of people in this age group would either have been invited for CRC screening or be approaching the age of their first invitation (faecal occult blood is offered between 60 and 69 years in England, between 50 and 74 in Scotland and between 60 and 71 in Wales) (NHS, 2011; NHS Cancer Screening Programmes, 2011; NHS Wales, 2011).

Data were collected using home-based, computer-assisted personal interviewing; a methodology commonly used in similar studies (e.g., Robb *et al*, 2009; Beeken *et al*, 2011), in which questions are administered as an interview, and the interviewer enters responses directly into a laptop computer. Where response options are long or complicated, the interviewee is able to look at the screen in order to choose a response. Random location sampling was used to select sample points from the 2001 Census small-area statistics and the postcode address file, stratified by Government Office Region and social grade. At each location, quotas were set for age, gender, children in the home and working status.

Measures

Preferences for level of provider recommendation Informed by previous work, including that of Entwistle *et al* (2008), three options were designed to vary in the level of explicit recommendation accompanying the screening invitation. The question wording was as follows: 'Now I would like you to think about if you were being invited to take part in bowel cancer screening as part of the NHS screening programme. In the information you receive from the NHS, would you prefer: (i) no recommendation—it's up to you to decide whether to do the test or not, (ii) a statement that the NHS thinks you should do the test, but that it's up to you to decide, (iii) a strong recommendation from the NHS to do the test.'

Desire for information Respondents reported how much information on benefits of screening they wanted, on a scale from 1 ('no information') to 10 ('all the information currently available'). The same question was asked on risks. Due to the skewed distribution, responses were recoded into 1–5 ('low'); 6–8 ('medium'); and 9–10 ('high').

Trust in the NHS Respondents were asked to indicate their agreement (on 5-point Likert scales) to two questions adapted from the *Health Information National Trends Survey* (U.S. National Institutes of Health, 2011). The text said: 'Most screening tests have potential risks as well as benefits. How much do you agree or disagree with the following statements: (i) I trust the NHS to decide whether a screening test is worth having; (ii) If the NHS is offering me a screening test, it must be safe'. Responses were recoded into 'agree/strongly agree'; 'neither agree nor disagree'; and 'disagree/strongly disagree'.

Sociodemographic factors We recorded gender, age, country of residence, social grade (as a marker of SES) and marital status. Social grade was based on occupation (or previous occupation if receiving an occupational/private pension), using a classification frequently applied in market research: AB (high or intermediate managerial, administrative or professional occupations); C1 (supervisory, clerical or junior managerial, administrative or professional occupations); C2 (skilled manual workers); and DE (semi-skilled or unskilled manual workers, state pensioners or causal/lowest grade workers and those reliant on state benefits). People who were not working were classified according to the chief wage earner in the household.

All questions were pre-tested for clarity and ease of response using cognitive interviewing techniques ($n = 10$), and the wording was adjusted where necessary.

Analysis

After descriptive analyses, we used ordinal logistic regression to explore associations between level of screening recommendation preference and (i) trust in the NHS, (ii) desire for information on risks and benefits, and (iii) social grade. Analyses were adjusted for other demographic factors. The outcome variable was ordered into (1) no recommendation, (2) consider a recommendation, and (3) a strong recommendation. Adjusted odds ratios (ORs) and 95% confidence intervals (CI) are presented, with a significance level of $P < 0.01$. Analyses were carried out using SPSS 19.0 (IBM, Chicago, IL, USA).

RESULTS

Sample characteristics

Respondents ($n = 103$) who did not answer the question on recommendation preference were excluded from the analyses, leaving a sample of 1964 (see Table 1a). Respondents were predominantly white (96%), with the proportions from England, Scotland and Wales matching the population sizes of the three countries (84, 11, and 5%, respectively). There was a balanced distribution by age and gender. More respondents were in the lowest social grade (DE = 37%) than the others (AB = 20%, C1 = 23%, C2 = 20%), partly due to state pensioners being included in this group. Most respondents were married or living as married (62%).

Information, trust and recommendations

The majority of respondents (84%) preferred a recommendation to take part in the CRC screening programme rather than being expected to make the decision entirely themselves. Most (47%) preferred to receive a strong recommendation from the NHS to take part in CRC screening, 37% preferred to consider a recommendation to do the test and only 16% preferred not to have an explicit recommendation (see Table 1a).

Overall, respondents reported high levels of trust in the NHS, both in terms of being able to 'decide whether a screening test is worth having' (79%) and believing that a test offered by the NHS

Table 1a Socio-demographic predictors of recommendation-level preferences

	No recommendation	Consider a recommendation	A strong recommendation	Multivariate ordinal logistic regression for choosing a higher level of recommendation (n = 1877) OR (95% CI)
	n (%)			
All (n = 1964)	323 (16.4)	723 (36.8)	918 (46.7)	
Gender				
Female (n = 1021)	189 (18.5)	389 (38.1)	443 (43.3)	Reference
Male (n = 943)	134 (14.2)	334 (35.4)	475 (50.4)	1.25 (1.09-1.42)**
Age, years				
50-59 (n = 669)	102 (15.2)	262 (39.2)	305 (45.6)	Reference
60-69 (n = 657)	102 (15.5)	242 (36.8)	313 (47.6)	1.03 (0.88-1.21)
70-80 (n = 638)	119 (18.7)	219 (34.3)	300 (47.0)	0.94 (0.80-1.10)
Country				
England (n = 1645)	278 (16.9)	634 (38.5)	733 (44.6)	Reference
Scotland (n = 213)	31 (14.6)	57 (26.8)	125 (58.7)	1.63 (1.31-2.07)***
Wales (n = 106)	14 (13.2)	32 (30.2)	60 (56.6)	1.43 (1.06-1.95)*
Social grade				
AB (high; n = 402)	60 (14.9)	164 (40.8)	178 (44.3)	Reference
C1 (n = 462)	76 (16.5)	167 (36.1)	219 (47.4)	1.11 (0.92-1.34)
C2 (n = 399)	52 (13.0)	144 (36.1)	203 (50.9)	1.16 (0.95-1.41)
DE (low; n = 701)	135 (19.3)	248 (35.4)	318 (45.4)	1.03 (0.87-1.25)
Marital status				
Married (n = 1217)	175 (14.4)	452 (37.1)	590 (48.5)	Reference
Single (n = 178)	36 (20.2)	78 (43.8)	64 (36.0)	0.74 (0.60-0.93)**
Widowed/divorced/separated (n = 569)	112 (19.7)	193 (33.9)	264 (46.4)	0.96 (0.83-1.12)

Abbreviations: CI = confidence interval; OR = odds ratio adjusted for all measures in Tables 1a and 1b. * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$. Percentages may not add up to 100% due to rounding. Percentages are not adjusted. Total *ns* may vary due to missing data.

'must be safe' (76%). Only 9% and 10%, respectively, disagreed with these two statements. However, high trust did not preclude an equally strong desire to be fully informed, with nearly 4 in 5 respondents wanting to receive full information (selecting 9 or 10 on the scale of 1-10) on benefits (78%) and risks (77%) of screening.

Low desire for information on benefits and risks (1-5 on the response scale) was associated with lower social grade (benefits: $X^2(3) = 20.5$, $P < 0.001$; risks: $X^2(3) = 8.5$, $P = 0.04$), although overall desire for information was high across groups. In the lowest social grade (DE), 9% of people had low desire for information on benefits, compared with 3% of people in the highest grade (AB). The equivalent figures for low desire for information on risks were 10% (DE) and 5% (AB). Living in Scotland rather than the other two countries was also associated with lower desire for information (benefits: $X^2(2) = 16.0$, $P < 0.001$; risks: $X^2(2) = 8.5$, $P = 0.02$).

Predictors of recommendation preferences

As shown in Table 1b, respondents who did not trust the NHS were less likely to prefer a recommendation (OR: 0.68, 95% CI: 0.54-0.85, $P = 0.001$). Somewhat paradoxically, those who wanted less information on the benefits of the test were also less likely to want a recommendation (medium information: OR: 0.67, 95% CI: 0.53-0.85, $P = 0.001$; low information: OR: 0.68, 95% CI: 0.47-0.98, $P = 0.04$). Desire for information on risks did not show a consistent association with preference for a recommendation.

Contrary to our prediction, social grade was not associated with recommendation preference. Of the other five socio-demographic and geographic variables (see Table 1a), men were more likely than women to prefer a recommendation (OR: 1.25, 95% CI: 1.09-1.42, $P = 0.001$) and respondents who were single were less likely to prefer a recommendation than the married group (OR: 0.74, 95% CI: 0.60-0.93, $P = 0.008$). Respondents in Scotland and Wales were more likely to prefer a recommendation than those in England (OR: 1.63, 95% CI: 1.31-2.07, $P < 0.001$ and OR: 1.43, 95% CI: 1.06-1.95, $P = 0.02$ for Scotland and Wales, respectively).

DISCUSSION

This study found widespread preference for a recommendation from the NHS to take part in CRC screening, with 84% of respondents wanting either a strong recommendation to participate (47%) or a recommendation alongside individual choice (37%). This is consistent with findings in Norway where women welcomed the 'paternalistic' provision of mammography appointments (Østerlie *et al*, 2008), and qualitative research in the UK showing that people wanted faecal occult blood test information to promote participation strongly (Woodrow *et al*, 2008).

Despite preference for a recommendation, there was also a desire for full information about risks and benefits. A recommendation was seen as an *adjunct* to information, not an alternative, and respondents who preferred a recommendation expressed a desire for *more* information on the benefits of screening. This

Table 1b Predictors of recommendation-level preferences

	No recommendation	Consider a recommendation	A strong recommendation	Multivariate ordinal logistic regression for choosing a higher level of recommendation (n = 1877) OR (95% CI)
	n (%)			
All (n = 1964)	323 (16.4)	723 (36.8)	918 (46.7)	
<i>Desire for information on risks and benefits</i>				
<i>How much information should a screening leaflet have about the benefits?</i>				
9–10 (high; n = 1553)	240 (15.9)	540 (35.8)	727 (48.2)	Reference
6–8 (medium; n = 325)	45 (14.7)	138 (45.1)	123 (40.2)	0.67 (0.53–0.85)**
1–5 (low; n = 112)	25 (24.3)	34 (33.0)	44 (42.7)	0.68 (0.47–0.98)*
<i>How much information should a screening leaflet have about the risks?</i>				
9–10 (high; n = 1528)	244 (16.5)	538 (36.4)	697 (47.1)	Reference
6–8 (medium; n = 301)	36 (12.5)	121 (42.0)	131 (35.5)	1.34 (1.04–1.71)*
1–5 (low; n = 158)	29 (19.7)	49 (33.3)	69 (46.9)	1.29 (0.94–1.77)
<i>Trust in the NHS</i>				
<i>I trust the NHS to decide whether a screening test is worth having.</i>				
Strongly agree/agree (n = 1610)	224 (14.4)	562 (36.2)	766 (49.4)	Reference
Neither agree nor disagree (n = 237)	49 (22.0)	96 (43.0)	78 (35.0)	0.71 (0.59–0.86)**
Strongly disagree/disagree (n = 183)	46 (26.7)	59 (34.3)	67 (39.0)	0.68 (0.54–0.85)**
<i>If the NHS is offering me a test, it must be safe.</i>				
Strongly agree/agree (n = 1542)	224 (15.1)	534 (36.1)	723 (48.8)	Reference
Neither agree nor disagree (n = 281)	54 (20.0)	111 (41.1)	105 (38.9)	0.83 (0.69–0.99)*
Strongly disagree/disagree (n = 203)	42 (21.8)	72 (37.3)	79 (40.9)	0.94 (0.75–1.17)

Abbreviations: CI = confidence interval; OR = Odds ratio adjusted for all measures in Tables 1a and 1b. * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$. Percentages may not add up to 100% due to rounding. Percentages are not adjusted. Total *ns* may vary between variables due to missing data.

could be seen as paradoxical—people wanting to make their own decisions requiring less information to do so, and further research is needed to understand why this might be. Alternatively, people who want a recommendation might feel that full information, particularly about the benefits, is needed to explain why a recommendation is being made. Whether people who want information always read or understand it is a different issue (Jepson *et al*, 2005); balanced information may be valued in itself, rather than necessarily reflecting an intention to use the information in decision-making. The information leaflet may simply be held in reserve in case of need; as with information leaflets provided with medicines (Jepson *et al*, 2007).

Preference for a recommendation could be interpreted as consistent with the notion of 'intellectual outsourcing' (Appiah, 2005), which recognises that no one can be fully autonomous in all decisions, and in some circumstances, it is appropriate to rely on a trusted other to provide advice rather than engaging with the information personally. Across most areas of life, from finance to plumbing, people recognise that others' expertise is critical, and the key is to find a trusted source. In the UK screening context, trust in the NHS was significantly associated with preference for a recommendation. In this sample, most respondents reported high levels of trust, but the small proportion (9%) with low trust were more likely to want to make a decision without a recommendation. This fits with the emphasis on evaluating the trustworthiness of the source of an offer in the 'consider an offer' approach (Entwistle *et al*, 2008).

Men were more likely than women to prefer a recommendation, and single people were less likely than married people to want a recommendation. Although differences in screening uptake by gender and marital status have been found previously (Seeff *et al*, 2004; van Jaarsveld *et al*, 2006; von Wagner *et al*, 2011), it is not clear how recommendation preferences might interact with approaches to screening communication to affect participation.

Our findings suggest that primary care interactions relating to screening may need to be tailored to the demographic characteristics of the individual patient.

Previous research has shown SES differences in awareness of the purpose of screening or its effects (James *et al*, 2008; Orbell *et al*, 2008; Beeken *et al*, 2011), but the present results, using social grade as a marker of SES, showed no evidence that this translates into differences in recommendation preferences. However, concern remains that evaluating complex information in order to reach an informed decision might be more problematic to those from socially disadvantaged backgrounds (Raffle, 2001), and there remain challenges to achieving informed decision-making across all groups. Even when information materials are specifically designed for low-literacy groups, it can be difficult to facilitate informed decision-making. The DA used by Smith *et al* (2010b) was carefully developed to be clear and easy to read, but only a third of the intervention group made an informed decision about screening, and the mean knowledge score, though higher in the DA arm than the control group, was only 6.5 out of 12. Qualitative work associated with the trial indicated that some participants did not understand the purpose of the DA and others felt overloaded by risk information and statistics (Smith *et al*, 2012). Future work might benefit from more fine-grained analysis of the specific aspects of screening knowledge that are associated with different behavioural outcomes.

Another study found no evidence that DAs reduce participation in CRC screening (Steckelberg *et al*, 2011); however, the mean knowledge score was also around 50% in the DA group, confirming the difficulty of achieving very high knowledge. In our study, there was some evidence that lower SES groups were less likely to want information about the risks and benefits of screening, although overall it should be noted that desire for information was high across all the groups. Given the differential uptake of CRC screening by SES in the UK (von Wagner *et al*,

2011), more research is urgently needed to explore interactions between SES, knowledge acquisition and screening uptake.

Strengths and limitations

To our knowledge, this is the first study to ask the public what type of screening recommendation they want or how much information on benefits and risks they would like. The study benefited from a large national sample of adults in Britain, although in line with the population distribution across the UK nations, most respondents were from England (84%). The proportion of non-white respondents reflected population demographics and was therefore too small to allow comparisons by ethnic group. It is well-established that screening participation varies by ethnic group (Moser and Patnick, 2009; CDC, 2012), so further investigation of recommendation preferences in non-white groups should be a priority for future research. By using an omnibus survey that included questions from other organisations on non-health-related topics, we reduced the likelihood that participation would have been biased by factors affecting responses to the questions reported here. The question on preferences for a recommendation was framed within the context of CRC screening and the outcome could be different for other types of cancer screening. In addition, future work would benefit from the development of more comprehensive measures to assess other aspects of the Entwistle *et al* (2008) approach. Finally, we used an occupational indicator of SES, and this might be a reason for the lack of association between SES and recommendation preference.

Policy implications and future research

These results support UK policies that provide full information on potential benefits and risks of screening tests as well as a recommendation from the NHS to attend screening. This approach has recently been adopted in Scotland (NHS, 2011) and fits with current UK government policy to 'empower the greatest number possible from all groups and communities ... to make an *informed choice to participate* in cancer screening' (Department of Health (UK), 2011, our italics). 'Consider an offer' may help reduce the tension between an explicit informed choice approach and an implicit aim to maximise coverage. These findings are particularly timely given the current review of information materials used within the NHS cancer screening programmes (Richards, 2011), although this survey was carried out before the announcement of this and the associated review of mammography provision. 'Consider an offer' provides a way to communicate about cancer screening that reduces the decision-making burden while still promoting autonomous decision-making (Entwistle *et al*, 2008), although further research is needed to establish how best to provide the combination of a recommendation and information on risks and benefits (Perneger *et al*, 2011). Qualitative research might be useful in further understanding the reasons for people's information preferences and the ways in which information provided with a screening invitation is actually used.

In the future, we may want to work towards educating the public, as healthcare users, about the evolving nature of the evidence-base for cancer screening; hence the need for informed decisions based on individual circumstances. For some patients, this may require working through a decision-making process with the primary care physician so that factors such as co-morbidities are discussed before a negotiated 'recommendation' can be reached (Weller *et al*, 2009); an approach that will rely on health professionals in primary care settings being up-to-date with national screening guidelines.

Future research could build on these results with more nuanced questions on information and recommendation preferences that

could address public understanding of the constraints placed on healthcare providers in the extent of recommendation they *can* provide given the imperative of basing advice on the best available evidence. In addition, attitudes to communication about other screening modalities could be explored, particularly in the context of screening tests where the evidence for efficacy is contested, such as prostate-specific antigen testing and, increasingly, mammography (Gomella *et al*, 2011; van Ravesteyn *et al*, 2012), where any kind of 'nudge' to take part could be seen as inappropriate (Ploug *et al*, 2012).

CONCLUSION

Most British adults want full information on risks and benefits of screening but they also want a recommendation from an authoritative source. This supports the 'consider an offer' approach within which an 'expert' view from a trusted source may be an important part of autonomous health decision-making.

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Conflict of interest

The authors declare no conflict of interest.

Disclaimer

We had full access to all data (including statistical reports and tables) in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. There have been no previous publications of this study.

Ethical approval

This study was exempt from ethical approval under the guidelines for the UCL Research Ethics Committee which state that approval is not needed for studies 'involving the use of ... survey procedures ... unless information obtained is recorded in such a manner that human participants can be identified'. The survey was anonymous. TNS Research International abides by the Market Research Society Code of Conduct and data protection legislation.

Reproducible research statement

The questionnaire used in this study is available as supplementary material. The data set will be available to interested researchers after a period of personal use.

Author contributions

CC, AS, CvW, JWar, JWal and DW conceived of the study. CC, VH, CJ, AS, CvW and JWal developed the measures and supervised the fieldwork. CJ, AM, AS, CvW and JWal carried out the analyses and wrote the first draft of the paper. All the authors contributed to the final version of the manuscript.

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