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Impact of information about risks and benefits of cancer screening on intended participation

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ABSTRACT

Background: Providing comprehensive information about the risks and benefits of cancer screening is ethically necessary, but information about risks may decrease participation. This study explored the impact of information on intended participation using a randomised factorial design.

Methods: We conducted a mail survey of 2333 adults living in Geneva, Switzerland. Each participant was given one randomly chosen version of a scenario that described a hypothetical cancer screening test, and was asked whether he or she would accept to undergo screening. The versions varied in terms of the amount of information about risks and benefits.

Results: Respondents who received information about risks associated with screening were more likely to refuse participation (odds ratio 2.6 (95% confidence interval (CI) 2.0–3.5)) than those who received minimal information. In contrast, information about benefits had no impact on intended participation (odds ratio 1.0 (95% CI 0.8–1.2)). The impact of information about risks was significantly stronger in women than in men, in respondents who were in poorer health, who have had a doctor visit in the past 6 months, those who have had a cancer screening test in the past 3 years, and those who reported a high desire for autonomy in medical decisions.

Conclusions: Informing potential participants about the risks of screening may reduce participation rates. Enhanced information about the benefits of screening does not counterbalance this effect.

1. Introduction

How to best inform the general public about cancer screening tests is a contentious issue. To reduce cancer-specific mortality at the population level, mass screening programs aim to achieve high participation rates, and to boost participation the value of screening tests is often presented in a favourable light. On the other hand, ethical principles of informed consent require that every prospective participant be fully aware of the advantages and risks of screening. To some prospective

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participants, risks may outweigh the individual benefits, and they may decline to undergo screening. Consequently it has been proposed that screening programs ought to maximise informed choice, instead of maximising participation.[1–3]

The impact of comprehensive information on participation in cancer screening is only partly understood. In a systematic review, Jepson noted that 'It is not clear [...] whether the provision of information about risks and benefits increased or decreased the uptake of screening'.[4] Other reviews have concluded likewise.[3,5] Studies of real-life screening decisions are constrained by the necessity to provide correct information to all participants, and hence typically examine only different means of delivering the same information (e.g. booklets versus videos), more rarely the effects of enhanced information compared with usual practice. For instance, one study compared a standard information leaflet about screening for cervical cancer to a more detailed booklet that addressed risks, benefits and uncertainties of screening; fewer women in the enhanced intervention group expressed the intent to have the test (79% versus 88%, $P = 0.039$).[6] However, most women are repeatedly invited to attend cervical cancer screening in their lives, and it is difficult to disentangle the effect of new information from pre-existing knowledge and attitudes.

Studies of hypothetical decisions afford greater flexibility. The downside of such studies is the uncertain validity of their findings for real-life decisions. For example, screening for prostate cancer is controversial and is not routinely recommended. Two previous studies explored the impact of more detailed information on the intent to undergo screening for prostate cancer: the earlier study found a negative impact of information,[7] whereas the more recent study found no effect.[8] Another study explored the acceptability of a hypothetical screening test for pancreatic cancer,[9] comparing minimal information to a condition where pancreatic cancer was correctly described as incurable; 60% among the uninformed agreed to have the screening, versus 14% of the informed group. Since a screening test devoid of potential benefit should not be proposed at all, participants who received no information may have taken the existence of a clinical benefit for granted.[10] Therefore available evidence suggests that comprehensive information may reduce attendance in cancer screening when compared to usual information, but this reduction may be small in realistic situations.

A difficulty in understanding how people react to information stems from the fact that in most studies 'more information' means 'more information about risks and side-effects.' To date, separate and joint effects of information about risks and benefits have not been explored in studies of cancer screening. In particular, it is not known if any possible dissuasive effect of information about risks can be compensated by information about benefits of cancer screening.

To clarify these issues, we conducted a general population study based on a hypothetical screening scenario which described a blood test to detect an unnamed cancer. Participants were randomly allocated to one of 3 levels of information about benefits, and to one of 3 levels of information about risks. To make the hypothetical screening test as realistic as possible, the risks and benefits were patterned after those reported for mammography screening for breast cancer. We sought to examine to what extent information about risks and benefits influenced the intention to participate in a 'new' screening test in a general population sample, unencumbered by previous knowledge and preconceptions.

2. Methods

2.1. Study design and sample

We conducted a general population survey among residents of the canton Geneva (Switzerland), aged 30–60 years, which included a scenario that described a cancer screening test (Box 1). The scenario was explicitly presented as being invented. The screening test consisted of a blood test conducted on an annual basis among adults of both sexes aged 30 years or more, so that it would apply to all potential respondents. The type of cancer was not specified, but it was described as common, with excellent chances of survival if detected and treated early. We used numbers inspired by breast cancer and mammography screening (10% chance of getting the cancer during one's lifetime, 25% reduction in cancer-specific mortality attributable to screening, positive predictive value of the screening test of 20%).[11] Participants were asked whether they would agree to undergo the screening test on the basis of the information provided. The type and amount of information varied between versions of the questionnaire: all versions included minimal information about the test, to which was added information about the benefits of the screening test (none, survival benefit, or survival benefit and reassurance) and about the associated risks (none, false positive results, false positive and false negative results). The two 3-level experimental factors (information about benefits and risks) were combined in a factorial design, yielding 9 versions of the scenario. In each scenario, information about benefits came first, and information about risks second. Each participant was assigned at random to one version of the questionnaire. To randomise the participants, we attributed a computer generated random number to each individual, sorted them by this random number, and allocated the first ninth to version 1 of the questionnaire, the second ninth to version 2, etc. The study was approved by the Research ethics committee in epidemiology and public health, Institute of social and preventive medicine, Geneva, Switzerland.

Box 1. Screening test scenario. Only the text set in sans-serif type was included.

Minimal information (included in all versions):

Here is a scenario that describes a cancer screening test. This scenario was **invented**. Please read it attentively, **imagine that you are really in the situation that it describes**, and answer the questions below.

During a routine visit, your doctor tells you about a new cancer screening test. This cancer is frequent, as it affects one person out of 10 during their lifetime. If it is detected early and treated by chemotherapy and radiotherapy, the chances of survival are excellent. The screening requires

a blood sample to be drawn once per year, from the age of 30 years.

Information about survival benefits:

If you have the blood test done each ear, in case you have the cancer, it will be detected earlier and your chances of survival will be improved. The screening test decreases the mortality due to this disease by 25%. This means that of 100 persons who would have died from this cancer, the screening test will save 25.

Information about reassurance:

Furthermore, if you do this screening test each year and it is negative, you will be reassured about your health, and so will be your close ones. You will have the feeling of taking good care of your health.

Information about false positive tests:

However the screening test is not perfect. Sometimes the test is positive when the person does not have the cancer. Among **1000** persons who have the test, **50** on average have a positive test, and among these, **10** have the cancer, for the **40** other persons the test result is wrong. To know who really has cancer, all those with a positive test must do additional examinations (blood tests, tissue samples). The persons who do not have the cancer will have had all these tests for nothing.

Information about false negatives:

More rarely, the screening test can be negative in someone who in fact has the cancer. Of **1000** persons who have a negative test, **2** have an undetected cancer, and are therefore mistakenly reassured.

On the basis of this information I would do this screening test.

Yes

No

2.2. Study variables

The main independent variables were the two experimental factors, information about benefits and information about risks. The outcome variable was the respondent's decision to accept or refuse the screening test.

Additional variables included the respondent's age, sex, nationality, education level (elementary school and vocational training versus high school, technical schools, and university), household income level ($\leqslant$4000 Swiss francs per month versus more than 4000, which corresponds roughly to the official threshold for poverty), health status (excellent or very good versus good, fair or poor), doctor visit for a health problem in the past 6 months, whether the respondent was confronted with medical decisions in the past 6 months (none versus any), and whether the respondent had had a cancer screening test in the past 3 years (based on a list that included screening for breast cancer, cervical cancer, prostate cancer, colorectal cancer, skin cancer). We also measured 3 attitude scales: a scale of cons of cancer screening (5 items), based on Rakowski's scale[12,13] in which we replaced 'mammography screening' by 'cancer screening', and scales of information-seeking about health care in general (8 items) and autonomy in medical decision making.[14] The original autonomy scale includes six general statements and nine items derived from clinical vignettes; we only used the former in this analysis because the other nine items appeared to form a separate factor. Items of all three scales were assessed on a 5-point Likert scale, from 'totally agree' to 'totally disagree.' All three scales had good internal consistency coefficients (cons of screening 0.79, information-seeking 0.78, autonomy preference 0.78) and all were uni-dimensional in factor analysis. We computed a global score for each scale, anchored by 0 and 100. Following an exploratory analysis we dichotomised each scale to facilitate the presentation of results.

2.3. Data collection

The mailing was conducted in 2005 by a private survey firm which owned regularly updated lists of residents, with their age, sex and address. Diplomatic staff and illegal migrants were not included in the database. The firm selected the initial sample and performed the randomisation following our instructions (age limits 30–60, same number of women and men). The survey package contained a cover letter, a numbered questionnaire, and a stamped return envelope. Returns were mailed to the investigators. Up to two reminders were sent to non-responders.

2.4. Power and statistical analysis

To detect a difference in screening refusal rates of 7.5% with power 90% and type 1 error of 5%, we needed about 700 observations per group (17.5% versus 25%: $N = 630$, and 25% versus 32.5%: $N = 760$). As each experimental variable had three levels, 2100 observations were needed. We selected 4670 persons, so that a response rate of 45% would yield the required sample size.

We obtained the percentage of refusals of the screening test in each of the nine experimental conditions. We compared the marginal proportions using chi-square tests, and adjusted the experimental variables for each other in a logistic regression model where refusal was the dependent variable. Based on the initial analysis, we dichotomised the experimental variables as minimal information versus any information on risks or benefits for subgroup analyses. This improved the power of these analyses and simplified the presentation of results. To see if the effect of information differed significantly between subgroups, we used logistic regression models where the dependent variable was refusal of screening, and independent variables were the amount of information about risks or benefits (dichotomised), the group identifier, and an interaction term. For example to see if information about risks influenced men and women differently, the model included as predictors sex (men = 0, women = 1), risk information (none = 0, any = 1), and the sex * information interaction (information given to women = 1, else = 0). In this case a statistically significant interaction term would suggest that the effect of information differed by sex.

To verify the credibility of decisions based on the hypothetical scenario, we examined associations between respondent characteristics and refusal of the screening test, at first using cross-tabulation and chi-square tests. Then we constructed a multivariate model predictive of refusal of the test

using all statistically significant respondent characteristics and the experimental conditions (information about risks and benefits). To assess the adequacy and discrimination of the logistic regression models, we used the Hosmer–Lemeshow test and the area under the receiver operating characteristic curve.

3. Results

3.1. Participant characteristics

Initially 4670 individuals were contacted; 2371 sent back a filled questionnaire, but 16 were eliminated because the respondent was outside the target age range, and 22 had a missing answer to the question about participation in the screening test. This left 2333 (50.0%) respondents.

Participants were evenly split between men and women, among age groups (mean age 42.3, standard deviation (SD) 8.3), and by education level (Table 1). Swiss nationals were in majority, as were respondents with a monthly household income of 4000 Swiss francs or more. Slightly less than half described their health status as excellent or very good, nearly two thirds had had a doctor visit in the past 6 months, and about half had faced at least one medical decision in the past 6 months. Sixty percent had had at least one cancer screening test in the past 3 years. Seventy-five percent had a favourable attitude towards cancer screening, as evidenced by a score of cons below the midpoint of 50 (mean 44.5, SD 23.7). The desire for information scale was skewed towards high values; about half of the respondents had a score of 93 or more (mean 89.9, SD 11.0). The scores for desire for autonomy in decision making were lower (mean 60.8, SD 20.6).

Table 1 – Characteristics of participants (*N* = 2333).

Characteristic		*N* (%)
Sex	Men	1060 (45.4)
	Women	1273 (54.6)
Age	30–39 years	781 (33.5)
	40–49 years	748 (32.1)
	50–60 years	804 (34.5)
Nationality	Swiss	1655 (70.9)
	Other	678 (29.1)
Education	Basic	986 (42.9)
	High school or more	1315 (57.1)
Monthly household income	Up to 4000	486 (22.0)
	More than 4000	1722 (78.0)
Health status	Excellent or very good	1040 (45.1)
	Good, fair or poor	1264 (54.9)
Doctor visit in past 6 months	Yes	1482 (64.4)
	No	821 (35.6)
Medical decision in past 6 months	Yes	1183 (51.8)
	No	1102 (48.2)
Had a screening test in past 3 years	Yes	1402 (60.1)
	No	931 (39.9)
Attitude towards screening	Positive (cons $\leqslant$ 50)	1741 (74.8)
	Negative (cons > 50)	587 (25.2)
Desire for information	Higher ($\leqslant$93)	1208 (52.4)
	Lower (>93)	1097 (47.6)
Desire for autonomy in decisions	Higher ($\leqslant$80)	507 (21.8)
	Lower (>80)	1818 (78.2)

3.2. Effect of information

Among participants, 382 (16.4%) stated that based on the available information, they would not do the cancer screening test. This proportion varied according to the information provided (Table 2). The proportion of respondents who declined the test was greater when more information was given about the risks associated with the test. In contrast, the amount of information about the benefits of screening had little impact on the respondents' decision. In a logistic regression analysis which included the two types of information as covariates (Table 3), providing information about false positive tests increased the odds of refusing the test 2.4-fold, and providing information about false positive and false negative tests increased the odds 2.9-fold. The odds ratio of rejecting the test remained unchanged – at 1.0 – regardless of the type of information about benefits. This model discriminated moderately between respondents who accepted and who refused the screening test (area under receiver operating characteristic curve 0.61, 95% confidence interval (CI) 0.58–0.64), but the Hosmer–Lemeshow test was non-significant ($P = 0.15$), indicating a good fit between predicted and observed probabilities. Further adjustment for other patient characteristics did not change the associations between information and the odds of refusing screening (Table 3).

3.3. Subgroup comparisons

We examined the effects of providing information about risks and about benefits on the decision to refuse the screening test in various subgroups of respondents (Table 4). Because the amount of information did not appear to be important, and to simplify the presentation of the results, we dichotomised the variables as 'minimal' versus 'any'. The overall odds ratio for information about risks was 2.6 and the effect of information about benefits was 1.0. The impact of information about risks on the decision was significantly stronger in women than in men, in respondents who were in poorer health, who had had a doctor visit in the past 6 months, those who had had a cancer screening test in the past 3 years, and those who reported a high desire for autonomy in medical decisions. Providing information about benefits had no discernible effect in most subgroups, except in relation to income: this information reduced refusals of the screening test among the poorer respondents, but increased refusals among the more affluent.

3.4. Respondent characteristics associated with refusals

Other variables than information about risks and benefits may influence screening behaviour. We found that refusals were more common among men, respondents with limited

Table 2 – Proportion of participants who refused a hypothetical cancer screening test, by amount and type of information provided.

		Information about benefits		
		Minimal	Survival benefit	Survival benefit and reassurance
Information about risks	Minimal	11.6% (29/250)	5.3% (15/285)	10.0% (26/260)
	False positive tests	16.1% (41/254)	21.7% (58/267)	18.8% (53/282)
	False positive and false negative tests	22.3% (55/247)	23.2% (53/228)	20.0% (52/260)

Table 3 – Refusal of a hypothetical cancer screening test according to information provided.

	Refused cancer screening test (%)	Odds ratio for refusing test, adjusted for information about risks and benefits	Odds ratio adjusted for information about risks and benefits and other relevant patient characteristics[a]
Information about risks	($P < 0.001$)	($P < 0.001$)	($P < 0.001$)
Minimal	8.8	1.0	1.0
False positive tests	18.9	2.4 (1.8–3.3)	2.5 (1.8–3.4)
False positive and false negative tests	21.8	2.9 (2.1–3.9)	3.0 (2.2–4.2)
Information about benefits	($P = 0.97$)	($P = 0.98$)	($P = 1.00$)
Minimal	16.6	1.0	1.0
Survival	16.2	1.0 (0.8–1.3)	1.0 (0.7–1.3)
Survival and reassurance	16.3	1.0 (0.7–1.3)	1.0 (0.7–1.3)

[a] Health status, medical decision in past 6 months, screening test in past 3 years, attitude toward screening, desire for information, desire for autonomy (multivariate model in Table 5).

education, those with a low income, those in excellent or very good health, those who had not seen a doctor nor made a medical decision in the past 6 months, those who had not had any screening test in the past 3 years, and those who had negative attitudes towards screening, a lower desire for information, and a higher desire for autonomy in medical decisions (Table 5). In multivariate analysis, the socio-demographical variables became non-significant, contrary to variables that measured health, health service use, past screening experience, and attitudes. This adjustment did not alter the effects of the experimental variables, i.e. the type of information provided about the screening test. The final model (Tables 3 and 5, last columns) fitted the data well (Hosmer–Lemeshow test, $P = 0.57$) and discriminated adequately between those who accepted and those who refused the hypothetical screening test (area under receiver operating characteristic curve 0.74, 95% CI 0.71–0.76).

4. Discussion

4.1. *Overview*

In this study, information about the risks of cancer screening increased the odds of refusing the test more than twofold, whereas detailed information about benefits had no impact on the probability of refusal. This result indicates that respecting the principles of informed consent comes at a cost: refusals of screening may increase if people receive comprehensive and balanced information. Importantly, the negative impact on participation was not counterbalanced by a more detailed description of the benefits of screening.

The difference that we observed was less pronounced than the difference reported in a previous study that used a hypothetical screening test for pancreatic cancer,[9] probably because the description of risks and benefits was more realistic in our study. However, the effect of information about risks was stronger than what would be anticipated based on studies of real-life screening decisions.[3] Possibly, this is because the effect of information is easier to detect when the topic is new to the respondent, as was the case of our scenario. In real-life situations, most respondents already have an opinion about the screening test under consideration, and the effect of newly provided information materials may be attenuated. Since the public is usually positively predisposed towards screening[10] and overestimates its survival benefits,[15–17] perhaps due to biased content of media sources,[18,19] it may take more than a single exposure to additional information to modify attitudes and intentions. In our study, the screening test was hypothetical, which avoided the influence of any preconceptions on the results.

The effect of information of either positive or negative type was generally consistent across subgroups of respondents, particularly across strata of age, nationality, education, recent involvement in medical decisions, attitude towards screening, and desire for information in medical decisions. This supports the general applicability of our findings. However, the negative effect of information about risks was stronger in women, people in good health, those who had had a

Table 4 – Effects of information about risks and about benefits on the decision to refuse a hypothetical cancer screening test, by respondent characteristic.

	Information about risks		Information about benefits	
	OR (95% CI)[a]	P-value[b]	OR (95% CI)[a]	P-value[b]
Overall	2.6 (2.0–3.5)		1.0 (0.8–1.2)	
Sex		0.017		0.64
Men	1.9 (1.3–2.8)		1.0 (0.7–1.4)	
Women	3.8 (2.5–5.9)		0.9 (0.7–1.3)	
Age		0.44		0.12
30–39	2.0 (1.3–3.3)		0.8 (0.5–1.2)	
40–49	3.0 (1.9–4.7)		1.4 (0.9–2.1)	
50–60	3.1 (1.8–5.2)		0.8 (0.5–1.2)	
Nationality		0.80		0.64
Swiss	2.6 (1.9–3.6)		1.0 (0.8–1.4)	
Other	2.8 (1.8–4.8)		0.9 (0.6–1.4)	
Education		0.89		0.87
Basic	2.8 (1.8–4.3)		1.1 (0.8–1.5)	
High school or more	2.5 (1.7–3.6)		0.9 (0.7–1.3)	
Monthly household income		0.13		0.004
Up to 4000	1.8 (1.1–3.1)		0.6 (0.4–0.9)	
More than 4000	3.1 (2.2–4.3)		1.3 (1.0–1.7)	
Health status		0.008		0.27
Excellent or very good	1.9 (1.4–2.8)		1.1 (0.8–1.6)	
Good, fair or poor	4.3 (2.7–6.9)		0.9 (0.6–1.2)	
Doctor visit in past 6 months				
Yes	3.5 (2.4–5.3)	0.038	1.0 (0.7–1.4)	0.76
No	1.9 (1.3–2.9)		1.0 (0.7–1.4)	
Medical decision in past 6 months		0.062		0.51
Yes	3.8 (2.3–6.1)		0.9 (0.6–1.3)	
No	2.1 (1.5–3.0)		1.1 (0.8–1.5)	
Had a screening test in past 3 years		<0.001		0.071
Yes	4.9 (3.0–7.9)		1.3 (0.9–1.8)	
No	1.7 (1.2–2.4)		0.8 (0.6–1.1)	
Attitude toward screening		0.42		0.20
Positive (cons $\leqslant$ 50)	2.3 (1.5–3.5)		0.8 (0.6–1.2)	
Negative (cons > 50)	2.9 (2.0–4.3)		1.1 (0.8–1.5)	
Desire for information		0.42		0.87
Higher ($\leqslant$93)	2.3 (1.6–3.5)		1.0 (0.7–1.4)	
Lower (>93)	2.9 (2.0–4.3)		1.0 (0.7–1.4)	
Desire for autonomy in decisions		0.043		0.52
Higher ($\leqslant$80)	4.4 (2.5–7.7)		0.8 (0.5–1.3)	
Lower (>80)	2.2 (1.6–3.1)		1.0 (0.8–1.4)	

[a] Odds ratio (95% confidence interval).
[b] P-value for difference between strata, based on an interaction test from logistic regression model.

cancer screening test in the past, those who had a recent doctor visit, and those who had a higher desire for autonomy in medical decisions. Interestingly, these are the groups that may have the greatest familiarity with screening in real life. Possibly, these groups had *a priori* particularly favourable opinions of screening, so that the description of risks made the greatest impact. Ironically, one of the respondents spontaneously wrote on her questionnaire 'I'm happy that this is not the case for mammography screening', when in fact we used mammography screening data as a basis for the scenario. Future studies of screening behaviour should examine the interplay between pre-existing information or beliefs and new concordant or discordant information.

As for the impact of information about benefits of screening, it differed only according to income: the effect was favourable among poorer respondents but negative among

Table 5 – Odds ratios of refusing a hypothetical cancer screening test according to participant characteristics.

	Univariate analysis		Multivariate analysis	
	OR (95% CI)[a]	*P*-value	OR (95% CI)[a]	*P*-value
Men (versus women)	1.4 (1.1–1.7)	0.006	Not retained	
Age (versus 30–39 years)		0.08	Not retained	
40–49 years	1.3 (1.0–1.7)			
50–60 years	1.0 (0.7–1.3)			
Swiss nationality (versus other)	1.1 (0.9–1.4)	0.33	Not retained	
Basic education (versus high school or more)	1.4 (1.1–1.7)	0.008	Not retained	
Low monthly household income (⩽4000 Francs versus >4000)	1.3 (1.0–1.7)	0.044	Not retained	
Excellent or very good health status (versus good, fair or poor)	1.4 (1.1–1.8)	0.002	1.4 (1.1–1.8)	0.003
No doctor visit in past 6 months (versus one or more)	1.7 (1.4–2.2)	<0.001	Not retained	
No medical decision in past 6 months (versus one or more)	1.8 (1.4–2.2)	<0.001	1.5 (1.2–1.9)	0.001
No cancer screening test in past 3 years (versus one or more)	2.0 (1.6–2.5)	<0.001	1.5 (1.2–1.9)	0.001
Negative attitude toward screening (cons >50 versus ⩽50)	3.7 (3.0–4.7)	<0.001	3.4 (2.6–4.4)	<0.001
Lower desire for information (score ⩽93 versus >93)	1.3 (1.1–1.7)	0.008	1.4 (1.1–1.7)	0.011
Higher desire for autonomy in decisions (score ⩽ 80 versus >80)	1.7 (1.4–2.2)	<0.001	2.2 (1.7–2.9)	<0.001

[a] Odds ratio (95% confidence interval).

the wealthier respondents. We have no plausible explanation for this finding other than type 1 error.

Information about risks of screening was not the only predictor of non-participation in screening. We found that very good health, lack of involvement in medical decisions, non-participation in screening in the past 3 years, low desire for information, high desire for autonomy and mostly negative attitudes towards screening were all related to non-participation. This indicates that propensity to participate in screening is influenced by various psychological and behavioural variables, and not only by the information provided about the screening test.

4.2. *Strengths and limitations*

The strengths of this study include its randomised design, the large sample size, and the population-based sampling frame. The main limitation is the hypothetical nature of the decision that we observed: one cannot be sure that people would react to real-life situations as they have when faced with a written scenario. However, the vignette method is considered trustworthy when the situation that is depicted is familiar to the respondent;[20] its validity has been firmly established in some contexts,[21] and it repeatedly yields results that are consistent with theory.[9,22,23] Furthermore, the risk factors for accepting the hypothetical screening test (Table 5) are remarkably similar to risk factors for having undergone at least one actual cancer screening test in the past 3 years.[24] This suggests that the vignettes elicited plausible reactions from participants, consistent with actual screening practice.

Furthermore, we did not explore any framing effects for the provided information.[25] We presented the risk and benefit information related to accepting the screening test, not to declining the test; we presented risks as frequencies in a cohort of 1000 persons, not as 'one in X' or as percentages; we presented benefits first and risks second, not the opposite. Any of these choices may have influenced the proportions of respondents who declined the hypothetical screening test. However, it is less likely that framing effects would influence the differences between scenario, since framing was identical for all nine versions.

A further limitation is the 50% participation rate, which may cause selection bias. Because of this we put little trust in the absolute proportions of participants or non-participants estimated in this study. However, we are more confident about the validity of between-group comparisons, because selection bias could cause such associations only through unlikely and convoluted mechanisms. Also, we did not examine the effect of tailoring information to each person's preferences, since not everyone wants to know all facts related to a medical decision.[26,27] This made sense as we were interested in information provided in public campaigns, where individualisation is impractical if not impossible. A final limitation is that we used the model of breast cancer screening in constructing the vignettes. Other types of cancer screening tests will differ in their effectiveness and in their risks. Whether the impact of information would be similar in other situations is impossible to predict.

5. Conclusion

This study confirms that public campaigns for cancer screening cannot maximise both participation and information. Comprehensive information about the risks of screening may double or triple the likelihood that people will decline the test, and insisting on the benefits of screening is unlikely to remedy this undesirable effect. Some would argue that the necessity of informed consent outweighs any negative consequences, but others may not value informed consent higher than public health effectiveness.[28] Resolving this dilemma will require a debate involving all stakeholders.

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Conflict of interest statement

Agathe Charvet-Bérard was employed at the Geneva Foundation for Breast Cancer Screening from 2006 to 2009; the Foundation had no role in this study. T.V.P., S.C. and L.S. have no conflict of interest related to this study.

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