

Public Knowledge of Benefits of Breast and Prostate Cancer Screening in Europe

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Making informed decisions about breast and prostate cancer screening requires knowledge of its benefits. However, country-specific information on public knowledge of the benefits of screening is lacking. Face-to-face computer-assisted personal interviews were conducted with 10228 persons selected by a representative quota method in nine European countries (Austria, France, Germany, Italy, the Netherlands, Poland, Russia, Spain, and the United Kingdom) to assess perceptions of cancer-specific mortality reduction associated with mammography and prostate-specific antigen (PSA) screening. Participants were also queried on the extent to which they consulted 14 different sources of health information. Correlation coefficients between frequency of use of particular sources and the accuracy of estimates of screening benefit were calculated. Ninety-two percent of women overestimated the mortality reduction from mammography screening by at least one order of magnitude or reported that they did not know. Eighty-nine percent of men overestimated the benefits of PSA screening by a similar extent or did not know. Women and men aged 50–69 years, and thus targeted by screening programs, were not substantially better informed about the benefits of mammography and PSA screening, respectively, than men and women overall. Frequent consulting of physicians ($r = .07$, 95% confidence interval [CI] = 0.05 to 0.09) and health pamphlets ($r = .06$, 95% CI = 0.04 to 0.08) tended to increase rather than reduce overestimation. The vast majority of citizens in nine European countries systematically overestimate the benefits of mammography and PSA screening. In the countries investigated, physicians and other information sources appear to have little impact on improving citizens' perceptions of these benefits.

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Women and men in countries with modern health systems are confronted with the question of whether to participate in screening for breast cancer and prostate cancer. Yet, because screening can also lead to harms such as overtreatment, they need to understand the potential benefits of these screening programs before they can make informed decisions about participating. Ideally, physicians, health pamphlets, and other information sources should assist in clarifying the actual size of benefits.

Screening for breast cancer with mammography is widely encouraged by governmental programs in both the European Union (EU) and the United States under the assumption that the screening programs save lives. In the case of breast cancer, an analysis of randomized trials with some 247 000 women aged 40–74 years showed that for every 1000 women who participated in screening, 3.9 diagnosed

with breast cancer died, compared with 5.0 among those who did not participate (1). The follow-up time ranged between 5.8 and 20.2 years. Thus, the absolute risk reduction was on the order of one in 1000 (2). The authors of a recent review of six trials involving half a million women estimated the absolute risk reduction to be approximately one in 2000 (3). Note that this benefit relates to fewer breast cancer deaths; no reduction in mortality from all cancers or other causes was found. Whether the potential of screening to reduce breast cancer mortality outweighs the harms of overdiagnosis and overtreatment is still under discussion (3–6).

Screening for prostate cancer with prostate-specific antigen (PSA) tests, although often encouraged by physicians and health information pamphlets, is not part of governmental screening programs and is recommended by few medical organizations.

The evidence for any benefit of screening is limited. The U.S. Preventive Services Task Force (7) reviewed the available studies and concluded that it was unclear whether increased detection of prostate cancer from screening would reduce mortality and morbidity, and a nested case-control study concluded that it did not (8). A European randomized trial reported a prostate cancer-specific mortality reduction of about one in 1400 after 9 years (9), but a randomized trial in the United States found no reduction after 7 or 10 years (10). Thus, the best estimate seems to be a reduction of death from prostate cancer of zero or one for every 1000 men screened, and the evidence is insufficient to determine whether the benefits outweigh the harms, such as incontinence through overtreatment of nonprogressive cancers (7–10).

This study addresses two main questions: 1) Do women and men have realistic knowledge about the benefits of mammography and PSA screening, respectively? and 2) What information sources do they rely on? Here, we also addressed a related question: Does the frequency of consulting a given source improve understanding of benefits? To our knowledge, this is the first European survey of women's and men's perceptions of the benefits of mammography and PSA screening, and the information sources that they rely on, with representative samples of the general population.

We conducted a survey of the public's knowledge of the benefits of screening in

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eight countries of the EU and the European part of Russia. The eight EU countries include about 75% of people in the 27 EU countries and have a total population of about 500 million. The European part of Russia has a population of about 106 million out of a total of 143 million Russians. The percentage of women who have had mammography is 57 in Germany, 78 in France, 76 in Austria, 85 in the Netherlands, 66 in Italy, 75 in the United Kingdom, 52 in Spain, 47 in Poland (for women aged 45–54 years), and 19 in Russia (11,12). PSA screening programs do not exist in the nine countries, apart from a regional state-funded program in Tyrol, Austria. National health systems are predominantly financed by taxes in the United Kingdom, Italy, and Poland and by contributions to social health insurance in Austria, France, Germany, and the Netherlands.

The data were collected as part of the European Consumer Study 2007 conducted between September and December 2006 by the Gesellschaft für Konsumforschung (GfK)-Nürnberg Group (13). Participants within each country were selected according to a quota method based on the official statistics concerning five variables: region, size of household, sex, profession, and age (14). The population in each country was first segmented into subgroups based on these five criteria, and within each subgroup, subjects were sampled in proportion to their distribution in the entire country. Initial contacts were made by telephone; the interviews were conducted in the participants' homes. Consistent with earlier representative quota sampling surveys conducted by the GfK Group, across all countries, about 60% of initial phone contacts resulted in a complete interview; in the remaining cases, sampling was continued until the quotas were met. Across all countries, the age distribution of participants was as follows: 14–19 years (8.4%), 20–29 years (16.6%), 30–39 years (18.0%), 40–49 years (18.4%), 50–59 years (15.2%), 60–69 years (11.8%), and 70 years and older (11.5%). The total number of interviews was 10228, with 2054 in Germany and 2019 in Russia (the countries with the largest populations); 1005 in France, 1042 in the United Kingdom, 1007 in Italy, 1019 in Poland, and 1024 in Spain; and 501 in Austria and 557 in the Netherlands (the two countries with the smallest populations). Participants were questioned in face-to-face personal inter-

views with computer assistance, except in Russia, where for security reasons, interviewers used paper and pencil. Using personal interviews avoided some of the problems of telephone interview methods, such as excluding poorer households without telephones and hence introducing a bias in comparisons between countries.

As a measure of the perceived benefit of mammography screening, we focused on cancer-specific mortality reduction because this is the endpoint typically communicated to the public (as opposed to total mortality reduction, for example). Women were questioned as follows: “1,000 women age 40 and older from the general population participate every 2 years in screening for breast cancer with mammography. After 10 years, the benefit is measured. Please estimate how many fewer women die from breast cancer in the group who participate in screening compared to women who do not participate in screening.” The response alternatives were 0, 1, 10, 50, 100, 200 (out of 1000), and “I don't know.” For the perceived benefit of PSA screening, men were questioned similarly: “1,000 men age 50 and older from the general population participate every 2 years in screening for prostate cancer with PSA tests. After 10 years, the benefit is measured. Please estimate how many fewer men die from prostate cancer in the group who participate in screening compared to men who do not participate in screening.” The response alternatives were the same as those used for breast cancer screening.

To measure the frequency of information sources used, we asked participants how often they used each of 14 sources that were divided into four categories as follows: family and/or friends (considered both a source and a category), experts (general practitioner and pharmacist), general media (television, popular magazines, daily newspapers, and radio), and health-specific sources (pamphlets by health organizations, reference books, health insurance, Internet, consumer counseling, patient counseling, and self-help organizations). The response alternatives were never, rarely, sometimes, frequently, and don't know.

We calculated the proportion of best estimates of screening benefits for all countries, all age groups, and for the group of citizens aged 50–60 years who are targeted by the screening campaigns. The proportion of participants reporting use of sources

CONTEXT AND CAVEATS

Prior knowledge

Given the harms that can ensue from cancer screening procedures, people's decisions as to whether to undergo cancer screening should be based on a realistic knowledge of its benefits.

Study design

Face-to-face-interviews were conducted among a representative sample of men and women in nine European countries, who were asked to choose among estimates of the number of fewer cancer-specific deaths (per 1000 individuals screened) by prostate-specific antigen and mammography screening, respectively. Participants were also queried as to their sources of medical information.

Contribution

This study found dramatic (by an order of magnitude or more) overestimation of the benefits (absolute cancer-specific mortality reduction) of mammography and prostate-specific antigen testing in the vast majority of women and men, respectively, in all countries surveyed. Frequent consultation of sources of medical information (including physicians) was not associated with more realistic knowledge of the benefits of screening.

Implications

A basis for informed decisions by people about participation in screening for breast and prostate cancer is largely nonexistent in Europe, suggesting inadequacies in the information made available to the public.

Limitations

The influence of the public's overestimation of screening benefits on actual participation in screening was not addressed in this study, and the work was restricted to European countries.

From the Editors

of health information was calculated for all countries, all age groups, and all of the 14 sources. Correlation coefficients between frequency of use of particular sources of health information and estimates of screening benefits were calculated. For mammography screening, overestimation of benefit was defined as the difference between the estimated benefit (expressed in X out of 1000 women) and one out of 1000. For instance, if the estimate was 50 in 1000, the

overestimation was 49 in 1000. A positive correlation means the higher the reported frequency of use, the larger the overestimation. For PSA screening, the same procedure was used except that estimates of 0 were not scored as underestimation, but 0 and 1 in 1000 were considered equally accurate. The correlations between overestimation and frequency of use of particular sources did not include participants who answered the question concerning the benefit of screening with “don’t know” (Table 1 shows the frequency of these responses).

Among all participants, only 1.5% of women (range across different countries: 0.8%–2.9%) chose the best estimate for reduction in mortality due to breast cancer screening, that is, one woman for every 1000 screened (Table 1). Four times as many women answered that the benefit was zero, and 92.1% overestimated the benefit by at least one order of magnitude or answered that they did not know; this proportion was higher (95.9%) in the eight EU countries due to the large proportion of no-benefit estimates in Russia. The greatest overestimation was observed in France, the Netherlands, and the United Kingdom, where more than 40% of the women answered that the reduction in mortality was 100 or 200 women per 1000 screened; in the United Kingdom, almost 27% chose the highest figure. These three countries also had high participation rates in mammography screening. In Russia, where the availability of mammography equipment is limited (15), the percentage of women who exhibited overestimation or did not know was the lowest of the countries surveyed, 82%.

Some of the women included in our study were younger than women targeted by screening programs and may have had

little motivation to inform themselves about screening. However, in every country, the percentage of women who gave the best estimate was lower among those aged 50–69 years and thus targeted by screening programs than among women younger than 50 years, and in every country but Russia, the proportion of 50- to 69-year-old women giving the best estimate was smaller than in all other age groups.

In all countries surveyed, only 10.7% of men made reasonable estimates of the benefits of prostate cancer screening (ie, deaths from prostate cancer prevented for every 1000 men screened were less than or equal to one, Table 2); 89.3% overestimated or answered that they did not know. Like their female counterparts, more than 40% of the French men estimated that screening would save 100 or 200 men from dying from prostate cancer per 1000 screened. Men in Austria, the Netherlands, Spain, and the United Kingdom made similar overestimates. As observed for women, the percentage of Russian men who overestimated the benefits or did not know was the lowest among the nine countries surveyed, 77%.

Similar to what was observed in women, the distribution of estimates made by men between the ages of 50 and 69 years was not more accurate than what was observed overall. The percentage of men who estimated zero and one life saved decreased from 8.3% and 2.4%, respectively, in all age groups to 7.3% and 1.9%, respectively, among men aged 50–69 years.

Most (59%) women reported using one or more sources frequently, compared with 47% of men (data not shown). In every country, older citizens searched for more information than younger ones (data not shown).

Within the general categories of health information sources, family and friends,

experts, general media, and health-specific sources, the correlations between the frequencies of use of two sources were consistently high (correlation coefficients >.5), whereas the correlations between sources from different categories were consistently lower (data not shown). The sources of health-related information reported most often were family and/or friends, followed in descending order by experts (general practitioner and pharmacist), general media (television was the most reported source in this category), and health-specific sources (among all participants, the seven sources in this category were the least used among the 14 sources).

Individual trends according to country were observed with respect to sources of health information (Table 3). In Poland and Russia, family and/or friends were by far the most often reported source of information. In Austria, France, Germany, Italy, and Spain, the general practitioner was the primary source of information, and, except for family and friends, little use was made of other sources in these countries. The Netherlands had the most even distribution of reported information sources. In the United Kingdom, the frequency of reported consultation of most sources of information was generally low. For only two sources did British citizens report higher than average frequencies.

Frequent consulting of sources was not associated with an increase in understanding of the benefits of screening, but instead was often associated with overestimation. For the women in Austria, France, Germany, Poland, Russia, Spain, and the United Kingdom, there was no single source of information whose frequent use was associated with more accurate understanding of the benefits. By contrast, German women

Table 1. Estimated reduction of breast cancer mortality through regular participation in mammography screening (women only)*

Reduction out of 1000	Percentage of responders									
	Mean	Germany	France	Austria	The Netherlands	Italy	United Kingdom	Spain	Poland	Russia
None	6.4	1.4	0.8	2.4	0.7	5.3	2.0	3.9	4.2	16.1
1	1.5	0.8	1.3	2.9	1.4	1.3	1.9	2.7	0.8	1.7
10	11.7	12.8	15.7	11.0	10.7	10.6	10.3	6.9	9.7	12.4
50	18.9	21.3	21.7	22.1	22.6	17.4	13.9	11.7	20.5	20.1
100	15.0	16.8	21.5	20.8	22.5	13.9	17.0	11.3	14.8	10.8
200	15.2	13.7	23.7	11.0	20.1	15.2	26.9	15.7	17.1	6.8
Don't know	31.4	33.1	15.3	29.8	22.1	36.3	28.0	48.0	32.9	32.1

* Question: How many fewer women die from breast cancer in the group who participate in screening, compared to women who do not participate in screening? Mean across all nine countries is weighted by sample size.

Table 2. Estimated reduction of prostate cancer mortality through regular participation in prostate-specific antigen screening (men only)*

Reduction out of 1000	Percentage of responders									
	Mean	Germany	France	Austria	The Netherlands	Italy	United Kingdom	Spain	Poland	Russia
None	8.3	3.8	1.6	4.1	3.0	5.7	0.5	9.3	5.0	20.3
1	2.4	2.3	2.7	3.5	2.2	1.8	0.9	4.3	0.7	2.9
10	14.4	17.7	16.9	24.4	11.5	11.9	15.9	17.0	13.9	10.7
50	19.3	23.0	21.6	27.1	20.2	18.5	17.3	25.1	17.9	15.0
100	14.0	17.2	21.1	20.8	20.3	9.2	15.6	18.8	14.5	7.3
200	11.8	9.7	20.2	14.2	14.2	12.2	19.5	17.9	11.3	3.4
Don't know	29.8	26.3	15.9	5.9	28.5	40.6	30.2	7.6	36.7	40.4

* Question: How many fewer men die from prostate cancer in the group who participate in screening, compared to men who do not participate in screening?
 Mean across all nine countries is weighted by sample size.

who more often consulted leaflets and pamphlets from medical organizations (41% of Germans use this source; Table 3) tended to overestimate the benefit of mammography screening ($r = .15$, 95% confidence interval [CI] = 0.07 to 0.23), as did French women ($r = .12$, 95% CI = 0.04 to 0.29). The German women who more often consulted a general practitioner ($r = .10$, 95% CI = 0.02 to 0.18) or a pharmacist ($r = .11$, 95% CI = 0.03 to 0.19) for health information also had less accurate understanding of benefits.

The only sources associated with improved knowledge of the benefits of breast cancer screening were consumer counseling in the Netherlands ($r = -.18$, 95% CI = -0.35 to -0.01) and in Italy ($r = -.17$, 95% CI = -0.27 to -0.07) and patient counseling ($r = -.16$, 95% CI = -0.26 to -0.06) and self-help groups ($r = -.12$, 95% CI = -0.22 to -0.02) in Italy alone.

The results for PSA screening confirmed the general conclusion that consultation of sources of medical information is not associated with knowledge of the benefits of screening. For men in Austria, Germany, the Netherlands, Russia, and Spain, there was no single source whose frequent use was associated with better understanding of benefits. Information from health insurances was associated with less overestimation in France ($r = -.11$, 95% CI = -0.20 to -0.02), Poland ($r = -.13$, 95% CI = -0.25 to -0.01), and Italy ($r = -.18$, 95% CI = -0.29 to -0.08), and information from radio with less overestimation in the United Kingdom ($r = -.11$, 95% CI = -0.21 to -0.01).

For both mammography and PSA screening, there was no single country in which frequent consulting of general practitioners and health pamphlets improved understanding of benefits. The overall

effect across all nine countries was a slight positive correlation between overestimation and frequency of consultation for general practitioners ($r = .07$, 95% CI = 0.05 to 0.09) and health pamphlets ($r = .06$, 95% CI = 0.04 to 0.08).

In this survey of more than 10000 people in nine European countries, 92% of women and 89% of men overestimated the benefits of mammography and PSA screening, respectively, by an order of magnitude or more, or stated that they did not know what the benefits were. This percentage was the lowest in Russia, with 82% for women and 77% for men. Consulting general practitioners, health pamphlets, and other information sources generally did not increase accurate knowledge of benefits; the only major exception was information from health insurances about PSA screening.

Our use of a numerical response scale with particular categories (0, 1, 10, 50, 100,

Table 3. Percentage of participants reporting that they use specific sources of health information sometimes or frequently*

Source	Mean†	Germany	France	Austria	The Netherlands	Italy	United Kingdom	Spain	Poland	Russia
Family/friends	62	65	60	61	50	62	53	47	67	69‡
General practitioner	59	68	69	68	50	79‡	53	72	43	44
Pharmacist	54	56	62	59	54	70‡	49	66	49	43
Television	43	45	57‡	43	51	38	35	32	42	42
Popular magazines	26	36	39‡	33	33	20	22	21	30	18
Daily newspaper	25	29	38‡	38	30	19	25	24	25	20
Radio	23	20	36‡	34	28	12	22	21	30	23
Leaflets and pamphlets by health organizations	21	41‡	36	23	30	13	14	17	12	14
Reference books about health topics	20	20	23	23	27‡	15	25	15	15	22
Health insurance company	17	19	27	20	44	3	9	54‡	21	4
Internet (eg, health portals)	15	17	21	17	42‡	11	26	16	14	7
Consumer counseling	6	3	8	4	20‡	4	3	9	4	6
Patient counseling	6	2	3	3	20‡	6	5	8	9	5
Self-help organizations	4	3	5	2	8‡	2	4	6	3	4

* Response alternatives were never, rarely, sometimes, frequently, and don't know.

† Mean across all nine countries was weighted by sample size.

‡ Highest value for each source.

200) may have influenced participants' estimates and may have contributed to the large amount of overestimation observed. However, we have indirect evidence that an open response format might not reduce the degree of overestimation. At the time of this study (December 2006), we conducted an independent survey with a different polling institute (TNS Emnid) in Germany and with a new representative sample of 1018 citizens, in which we included the question: "Early detection with mammography reduces the risk of dying from breast cancer by 25%. Assume that 1,000 women aged 40 and older participate regularly in screening. How many fewer would die of breast cancer?" No response categories were used. The proportion of correct answers was equally low, and overestimation was even larger, with a median estimate of 500 lives saved for every 1000 women screened by mammography (16).

This study did not assess perceived harms and economic costs, or whether the degree of overestimation of benefit translates into higher participation in screening. An association between overestimation and participation has been demonstrated in other studies, although this association was not observed for African American women (17,18). We also do not know whether the results are generalizable to other countries. Domenighetti et al. (19) found similar overestimation of mammography in telephone interviews conducted with women in Switzerland and the United States and also reported overestimation for women in the United Kingdom and Italy, but we are not aware of any surveys of the perceived benefit of PSA tests that were conducted simultaneously in different countries. Nor are we aware of any representative nationwide survey of the perceived quantitative benefit of mammography or PSA screening in the United States. A study with 145 American women with above-average education reported an average perceived breast cancer-specific mortality reduction of 60 in 1000 (20), and a study of 207 women attending general internal medicine clinics in Wisconsin reported that 76% overestimated the relative risk reduction (21).

We do not know why women and men overestimate the benefits of screening, but the results in Table 3 may indicate potential reasons. After family and friends, whose information might actually derive from the other sources in Table 3, the most frequently mentioned sources were general practitioner

and pharmacist. Studies on physicians' lack of knowledge about the benefits of screening and conflicts of interest support the possibility that these professionals contribute to overestimation (6,16,22). The observation that health-specific sources rarely improve understanding of screening (except for health insurance in several countries) also implicates these sources as a further potential cause, a hypothesis that is consistent with the findings that few pamphlets, letters of invitation, and Web sites explain the size of the benefit. If they do, the explanation is almost always in terms of a relative risk reduction rather than in the more transparent form of an absolute risk reduction (16).

In conclusion, this study documents that information about the benefits of mammography and PSA screening has not reached the general public in nine European countries, including the age group targeted by screening programs. Knowing the benefit of a treatment is a necessary condition for informed consent and rational decision making. At present, however, the available information sources are not designed to communicate benefits clearly. As a consequence, preconditions for informed decisions about participation in screening are largely nonexistent in Europe.

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