Women's Understanding of the Mammography Screening Debate

Steven Woloshin, MD, MS; Lisa M. Schwartz, MD, MS; Stephanie J. Byram, MS, PhD; Harold C. Sox, MD; Baruch Fischhoff, PhD; H. Gilbert Welch, MD, MPH

Background: The fractious public debate over mammography screening recommendations for women aged 40 to 49 years has received extensive attention in medical journals and in the press.

Objective: To learn how women interpret the mammography screening debate.

Methods: We mailed a survey to a random sample of American women 18 years and older, oversampling women of screening age (40-70 years). Sixty-six percent of women completed the survey (n=503).

Main Outcome Measures: The main outcome measures were women's reactions to the debate, their suggestion for the starting age for mammography screening, and their understanding of the source of the debate.

Results: Almost all women (95%) said that they had paid some attention to the recent discussion about mammography screening. Only 24% said the discussion had improved their understanding of mammography, while 50% reported being upset by the public disagreement among screening experts. Women's beliefs about mammography differed from those articulated by experts in the debate. Eighty-three percent believed that mammography had proven benefit for women aged 40 to 49 years, and 38% believed that benefit was proven for women younger than 40 years. Most women suggested that mammography screening should begin before age 40 years, while only 5% suggested a first mammogram should be performed at 50 years or older. In response to an open-ended question about why mammography has been controversial, 15% cited concerns about the potential harms of radiation and another 12% cited questions about efficacy. Nearly half (49%), however, identified costs as the major source of debate (eg, "Health maintenance organizations [HMOs] don't want to pay for mammography").

Conclusions: Most women paid attention to the recent debate about routine mammography screening for women aged 40 to 49 years, but many believed the debate was about money rather than the question of benefit. Policy makers issuing recommendations about implementation of large-scale mammography screening services need to consider how to effectively disseminate their message.

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From the Veterans Affairs Outcomes Group, Department of Veterans Affairs Medical Center, White River Junction, Vt (Drs Woloshin, Schwartz, and Welch); Center for the Evaluative Clinical Sciences, Dartmouth Medical School, Hanover, NH (Drs Woloshin, Schwartz, Sox, and Welch); Norris Cotton Cancer Center and Department of Medicine, Dartmouth Hitchcock Medical Center, Lebanon, NH; and Department of Social and Decision Sciences, Carnegie-Mellon University, Pittsburgh, Pa (Drs Byram and Fischhoff).

THE RECENT attempt by the US government to make recommendations about mammography screening for women aged 40 to 49 years has led to confusing and often vitriolic debate. Questions about the scientific evidence for mammography for women in this age group led the National Institutes of Health (NIH) Consensus Development Conference panel of medical experts and consumer representatives to conclude initially that women should "decide for themselves."[1] Many advocates of mammography reacted with shock, characterizing the conclusion as "disappointing" and "tantamount to a death sentence."[2] Under great political pressure, the National Cancer Institute's Advisory Board reversed the NIH panel's initial conclusion and recommended mammography screening for younger women.[3]

The fractious debate among experts over mammography screening recommendations for women aged 40 to 49 years has received extensive attention in medical journals[4,5] and the popular press.[2] Because it is well known that the public may interpret the scientific process differently than medical experts,[6] how women understood the debate may have important implications for those advocating evidence-based screening policies. Did women pay attention to the debate? What did they think was the underlying source of the debate? What was their reaction to the public disagreement among screening experts? When did women think they should begin having mammograms? To answer these questions, we conducted a national survey of American women.

SUBJECTS AND METHODS

DESIGN AND SAMPLE

We randomly selected women from a commercially maintained sample frame (National Decision Systems [NDS], Atlanta, Ga) that was compiled from telephone directories and administrative records (eg, driver's license applications, voter registries, real estate purchases). This sample was restricted to women living in households with telephones. Approximately 80% of total US households were represented in this restricted sample frame. We used a stratified random sampling strategy to oversample women of screening age (ie, aged 40-70 years) and women of low income. Specifically, we selected women from the NDS frame within the following categories: age (18-39 years, 40-49 years, 50-69 years, and 70 years and older), estimated income (census tract income above or below 2 times the 1992 poverty threshold for a family of four[7]), and area of residence.

From August to October 1997, we mailed a survey (plus a $2 bill as an incentive) to the 800 women who were selected. To maximize the response rate, we mailed reminder letters to nonrespondents after 2 weeks, sent a second copy of the questionnaire after 4 weeks, and attempted to call those who had still not responded after 6 weeks.

Of the 800 women selected, 33 were ineligible for the study (21 were deceased and 12 were men), leaving a possible respondent pool of 767. Of these women, 55 could not be contacted because of incorrect addresses (eg, the survey was returned by the post office as undeliverable or with no forwarding address), 2 could not participate because they did not speak English, and 207 did not return questionnaires. Thus, 503 (66%) of 767 returned completed questionnaires.

SURVEY

A 13-page survey was developed as part of a larger project funded by the US Department of Defense's Breast Cancer Research Program to enhance informed decision making about mammography. The survey was pilot tested with female veterans served by the White River Junction Veterans Affairs Medical Center residing in Vermont, New Hampshire, or western Massachusetts. The domains covered by the final survey included women's reaction to the mammography screening debate, perceptions of personal risk for breast cancer, and attitudes and beliefs about the benefit and downstream consequences of mammography screening.

This article reports results that are relevant to the recent debate about mammography screening. Women were asked if they followed the recent mammography screening debate, how the debate affected their understanding of relevant issues, and how they reacted to the public disagreement among screening experts. Women were also asked the age at which they thought the average woman should have her first mammogram. Other questions related to women's perceived access to information about mammography and ability to use such information in deciding whether to undergo screening. Finally, respondents were asked to identify the source of the debate. We used an open-ended question ("Why do you think there has been controversy about mammography?") to assess beliefs in the least directive or biasing way.

ANALYSIS

Since we sampled women based on age, income, and geographic region, we calculated sample weights for the 800 selected women to reflect the actual age, income, and regional distribution of women in the United States using data from the 1990 US Census.[7,8] We then further adjusted the sample distributions to the population distributions that were reported by the 1990 US Census, creating balance weights.[9] We created 2 sets of balance weights: one that further adjusted for demographic information (ie, age and sex distribution of US women 18 years and older) and one that further adjusted for socioeconomic status (ie, total household income and educational attainment). Both sets of weights yielded results that were almost identical to those of the crude data. For simplicity we therefore present the crude (ie, unweighted) data in the text. Based on our sample size ($n=503$), we estimated that in 95 cases out of 100, responses from the entire US population of women 18 years and older would be within approximately ±4 to ±6 percentage points of the results presented.[10]

Three hundred seventy-four women (74% of respondents) provided an answer to the open-ended question about the source of the controversy about mammography. Compared with the 129 women who did not provide an answer, the 374 responders were younger (mean age, 51 vs 57 years; $P=.03$), but they had nearly identical perceptions about the benefit of mammography at various ages. Two of the authors (S.W. and L.M.S.) independently coded these responses into the following 6 categories: (1) uncertainty about the benefit or age to have a mammogram, (2) disagreement among experts in general (eg, a generic statement that experts tend to disagree), (3) accuracy of mammography (eg, false negatives, false positives), (4) concerns about radiation exposure, (5) financial costs of screening, and (6) irrelevant comments that did not answer the posed question. Interrater agreement was "almost perfect"[11] ($\kappa=0.82$). We resolved disagreements by consensus to yield the final list of comment codes for analysis.

One hundred thirty-eight of these 374 women wrote only irrelevant comments (eg, "I don't know," "I think all women should have mammograms and PAP [Papanicolaou] tests," and "most people don't think it will happen to them . . . doesn't seem like too much of a threat"). Because they did not address the question, these women were excluded from the analysis.

The remaining 236 women (47% of respondents) gave a total of 309 relevant answers to this question. We calculated the proportion of these women with a comment in each response category (ie, the number of women in the response category divided by the 236 women who gave at least one relevant answer). Individuals with multiple mentions of the same code were counted only once. Weighted analyses accounting for item nonresponse to this question yielded virtually identical results to unweighted analyses. For simplicity we therefore present only crude results. All analyses were done using STATA statistical software (STATA Corp, College Station, Tex).

Table 1. Demographic Characteristics of Sample (Crude and Weighted)

Characteristic	Crude % (n = 503)	Weighted %	1990 Census, %*
Age, y			
18-39	24	47	46
40-49	31	17	16
50-69	34	24	24
≥70	11	13	14
Race			
White	90	79	78
African American	2	10	11
Hispanic	3	7	7
Other	4	4	4
Household income, $			
<10 000	5	4	13
10 000-24 999	18	17	24
25 000-49 999	31	31	33
50 000-99 999	36	35	22
≥100 000	9	13	8
Highest level of education			
<High school graduate	7	9	25
High school degree	55	50	53
College degree	29	33	17
Postgraduate degree	9	8	5
Census region			
Northeast	15	22	21
Midwest	23	22	24
South	32	29	35
West	30	27	20

**The distributions for women 18 and older from the 1990 US Census[8] are presented for comparisons.*

RESULTS

DEMOGRAPHIC CHARACTERISTICS

Respondents were from all 50 states and the District of Columbia, with ages ranging from 18 to 97 years; one quarter were aged 18 to 39 years (n=121), about one third were aged 40 to 49 years (n=154), one third were aged 50 to 69 years (n=173), and the remaining 11% (n=55) were 70 years or older (**Table 1**). Ninety percent described themselves as white, 3% as Hispanic, and 2% as African American. About half reported a total annual household income of less than $50 000; 5% reported income of less than $10 000, and 9% reported income of $100 000 or more. Almost all reported at least a high school education. Seventy-six percent of the respondents reported having had at least one mammogram, and 5% reported a personal history of breast cancer. Although minority women and women at the lowest socioeconomic level were underrepresented compared with national data,[12] our sample represented a broad spectrum of age, education, and income.

REACTION TO DEBATE

Almost all women (95%) said they paid at least some attention to the recent discussion about screening mammography, while 42% paid a lot of attention (**Table 2**). Most women reported that the debate did not change their understanding of the issues related to mammography. Although half said they were upset by the public clash of screening experts, only 13% reported lacking confidence in the recommendations of such experts.

Table 2. Women's Reaction to Mammography Screening Debate and Beliefs About Mammograms (n = 503)*

Questionnaire Item	% of Respondents: Crude	% of Respondents: Weighted†
Reaction to Debate		
How closely have you followed this debate?		
I have paid no attention	5	10
I have paid a little attention	53	51
I have paid a lot of attention	42	39
How has the debate affected how you understand the issues?		
I am more confused	14	9
No change in my understanding	62	68
I am less confused	24	23
Agree that "I am upset when national expert groups disagree about mammograms."	50	47
Agree that "I have confidence in the recommendations of national expert groups."	51	52
Access to Information About Mammography		
Agree that "I can find the information I need to decide whether to have a mammogram."	79	77
Agree that "My personal doctor is the main source of information I need to decide about mammograms."	62	61
If you have discussed mammograms with your doctor, who brought up the issue of mammography?		
My doctor brought up mammograms	63	57
I brought up mammograms	19	23
I never discussed mammograms with my doctor	18	20
Confidence in Ability to Decide		
Agree that "If I had all the relevant information, I would know how to use it when making a decision about having a mammogram."	79	82
Perception Benefit of Mammography		
"Medical studies have proven that some groups of women benefit from mamograms. For which age groups of women is this true?"		
18-39 y	38	41
40-49 y	83	85
50-74 y	82	82
≥75 y	47	47

**For all percentages, the 95% confidence intervals ranged from ±4 to ±6 percentage points. All questions about agreement used a 5-point Likert scale ("strongly agree," "agree," "neither agree nor disagree," "disagree," or "strongly disagree"). The proportion agreeing consists of those who responded "strongly agree" or "agree."*

†Weighted results reflect the actual age and race distribution of women in the United States based on 1990 US Census data. An alternate set of weights, reflecting the population distribution of income and education, yielded almost identical results.

ACCESS TO INFORMATION ABOUT MAMMOGRAPHY

Experts on all sides of the mammography debate agree that women should have access to relevant information about the benefits and risks of mammography in a com-

prehensible and usable form.[1] Three quarters of the women felt that they could find the information they needed to make a decision about mammography. Most women identified their personal physician as the main source of this information, and about three quarters of women had, in fact, discussed mammography with their doctor. Among these women, 63% indicated that the physician had raised the issue. Women not only felt that they had access to information, but 79% said they could use it to decide whether to have a mammogram. Only 5% doubted their ability to use such information.

PERCEIVED BENEFIT OF MAMMOGRAPHY

Women's beliefs about the proven benefit of mammography diverged from what has been published in the medical literature. Thirty-eight percent believed that mammography had proven benefit for women younger than 40 years, and 83% believed benefit was proven for women aged 40 to 49 years. Similarly, high proportions of respondents believed that scientific evidence supported mammography for women aged 40 to 49 years and for women aged 50 to 59.

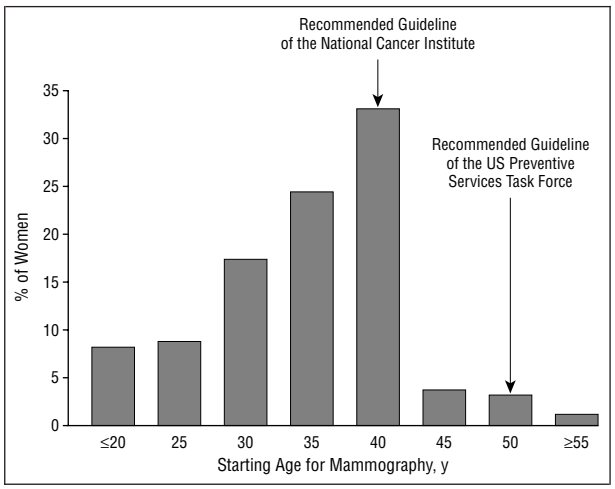

Figure 1. *Distribution of respondents' suggested starting ages for first mammogram (8% of respondents gave answers that were not multiples of 5 years; these responses were included in the next highest 5-year category [eg, 37 years was rounded to 40 years]). Women were asked: "At what age do you think the average woman should have her first mammogram? __ years old."*

While experts have debated whether mammography screening should begin at age 40 or 50 years, **Figure 1** shows that most women thought the first mammogram should be done before age 40 years. Half suggested that a first mammogram should be performed at 35 years or younger, while only 4% suggested beginning screening at 50 years or older.

WHY IS THERE DEBATE ABOUT MAMMOGRAMS?

Figure 2 shows the proportion of women citing each source of controversy in their response to the open-ended question "there has been some discussion about whether all women should have routine mammograms . . . why do you think there is controversy about this issue?" Twenty-seven percent simply asserted that controversy existed because, in general, experts or studies often disagree; these respondents, however, did not specify the substance of the disagreement (eg, "research is not always 100% correct . . . look at two studies and see opposite results," "scientists always disagree about everything"). Fifteen percent said the controversy was about the potentially harmful effects of radiation associated with mammography. Fourteen percent thought the controversy was about the accuracy of mammograms, typically citing concerns about accuracy in general, with a small proportion specifically citing false-negative or false-positive results (only 1% mentioned downstream consequences of false-positive results, eg, "unnecessary biopsies").

Only 12% of women thought the controversy was specifically about the scientific evidence regarding the benefit of mammography screening, either in general or at specific ages. Few (<1%) explicitly stated that the debate was about the efficacy of mammography screening in reducing breast cancer mortality for women aged 40 to 49 years.

In contrast, nearly half of women (49%) believed that the mammography controversy was really about money. Many made general statements suggesting that the controversy was about the financial cost of mammography,

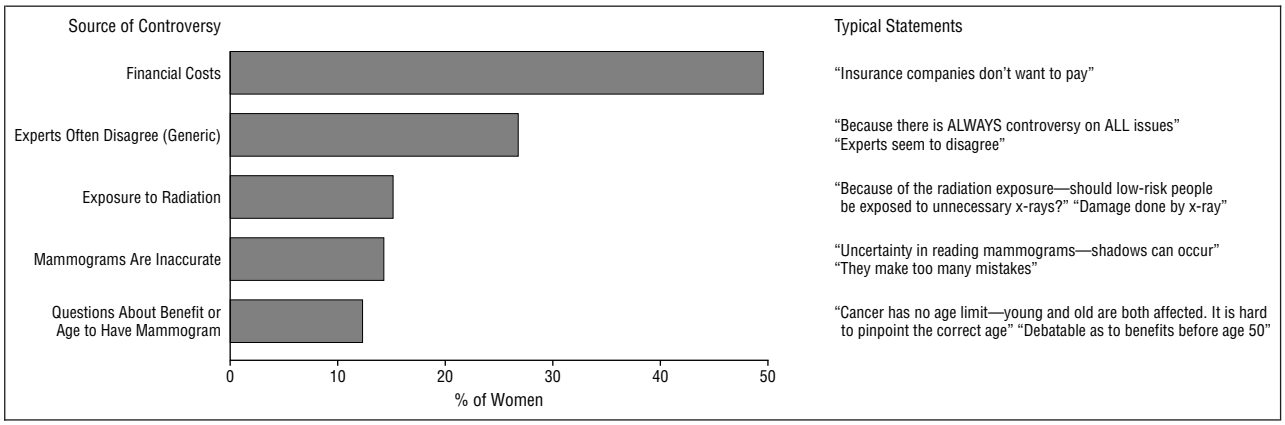

Figure 2. *Categorization of responses to an open-ended question about the source of the recent debate about mammography screening ("Why do you think there has been controversy about mammography?"). Percentages do not add to 100% because some women mentioned more than one category. For these percentages, the 95% confidence intervals ranged from ±4 to ±8 percentage points.*

Table 3. Personal Characteristics, Reactions to Mammography Screening Debate, and Beliefs About Mammograms for Women Who Paid a Lot of Attention to the Debate Compared With Those Who Paid Little or No Attention*

	Paid No or Little Attention (n = 288)	Paid a Lot of Attention (n = 210)
Median age, y	46	51
Breast Cancer Risk		
Prior history of breast cancer, % responding "yes"	2	9
First-degree relative with breast cancer, % responding "yes"	9	17
Had a prior mammogram, % responding "yes"	67	89
"In thinking about all the things that can affect your health, how big of a threat is breast cancer to your health?" %		
Very big or big	17	33
Medium	32	40
Small	45	25
Not a threat	6	2
Reaction to Debate		
"How has the debate affected how you understand the issues?" %		
I am more confused	15	12
No change in my understanding	68	54
I am less confused	17	34
Access to Information About Mammography		
Agree that "I can find the information I need to decide whether to have a mammogram." %	76	84
Confidence in Ability to Decide		
Agree that "If I had all the relevant information, I would know how to use it when making a decision about having a mammogram." %	74	84
Perception of Benefit		
Median ideal age to start mammography, y	35	35
Believe that mammograms have proven benefit for women in the following age groups, %		
18-39 y	35	42
40-49 y	82	87
50-74 y	80	85
≥75 y	44	51
Source of Debate		
Money	46	53
Question of benefit	14	10

**For all percentages, the 95% confidence intervals ranged from ±4 to ±6 percentage points. Results presented are unweighted; both weighting schemes yielded essentially identical results. All questions about agreement used a 5-point Likert scale ("strongly agree," "agree," "neither agree nor disagree," "disagree," or "strongly disagree"). The proportion agreeing consists of those who responded "strongly agree" or "agree."*

such as "the cost to the insurance company." About one third of the comments about costs explicitly asserted that insurers did not want to pay for mammography screening in order to save money (eg, "because of the cost of the procedure, insurance companies want to reduce the number of mammograms that are done," "HMOs are interested in paying the least money. If they considered early detection more profitable, they would be for early mammograms.").

FOLLOWED DEBATE CLOSELY

As shown in **Table 3**, women who followed the debate most closely were more likely to feel that breast cancer was a bigger threat to their health (73% who paid a lot of attention vs 49% who paid little or no attention reported that breast cancer was a "very big," "big," or "medium" threat to their overall health), more likely to report a family history of breast cancer (17% vs 9% reported a first-degree relative with breast cancer), and more likely to have had at least one prior mammogram (89% vs 67% with a prior mammogram). While women who paid more attention were more likely to be of screening age (85% who paid a lot of attention were between ages 40 and 70 years vs 69% who paid little or no attention), all other demographic information was quite similar among those women who followed the debate closely and those who did not.

Women who followed the debate most closely reported feeling less confused about the issues, had greater access to information, and felt more confident in their ability to make a decision about mammography than women who did not pay as much attention. Despite these differences, women who paid a lot of attention were just as likely to believe that mammography had proven benefit for younger women (including those younger than 40 years), and almost all of these women (92%) thought the ideal starting age for mammography was 40 years or younger. Consistent with these findings, few of these women (10%) cited questions of benefit as the source of controversy. Many women who followed the debate closely (53%) felt it was really about money.

COMMENT

Because breast cancer is such an important issue for many women, it is not surprising that most paid attention to the recent debate about mammography screening. This interest was reflected in both the high response rate to our survey and the frequency with which respondents answered the open-ended question. Despite the attention paid to the debate, few women recognized that it was about whether mammography screening reduces breast cancer mortality for women aged 40 to 49 years. In fact, most thought mammography had proven benefit for women in this age group.

One reason that few women correctly identified the source of the debate may be that so many women have a strong belief that the benefit of mammography has been scientifically proven. Women did not distinguish between the relatively weak evidence supporting mammography screening for women aged 40 to 49 years[13-15] and the strong evidence for mammography screening for older women.[16] In addition, almost half of women believed that proof of benefit existed for women aged 18 to 39 years, a position not supported by any findings in the scientific literature. Consistent with this finding, more than half believed mammography screening should begin before age 40 years. Patients may have a bias to believe in the efficacy of screening, a predisposition that might lead them to an uncritical acceptance of screening at any age. To make sense of

the debate, women who assumed that mammography has proven benefit must look elsewhere for the source of the controversy.

What did women think the debate was about? Many of their perceptions about the source of the mammography debate are troubling. The NIH consensus panel was explicitly charged to examine the evidence for mammography screening without considering financial costs.[1] Nonetheless, most women thought the debate was about money. In particular, they believed that the arguments against routine mammography were motivated by a desire to control costs (and enhance the profits of payors) rather than by scientific questions about benefit. Despite the concern about the financial motives of those questioning routine mammography for women aged 40 to 49 years, few questioned the financial motives of supporters of mammography screening. Additionally, while most experts report that there is negligible radiation risk with mammography,[1] 13% of women thought concerns about radiation exposure stimulated the debate.

Women's beliefs about mammography may reflect confusion or nonacceptance of guidelines. Many women and perhaps their physicians may be recalling earlier recommendations (ie, those of the American Cancer Society[17] and the National Cancer Institute[18]) to obtain a baseline mammogram between ages 35 and 40 years. Physicians may have trouble explaining why recommendations have shifted in the direction of greater caution when recommending routine mammography for younger women. It is also possible that physicians may not know or have confidence in the current recommendations of national organizations.[19] Alternatively, women or their physicians may not accept current recommendations if they contradict strongly held beliefs.

One possible limitation of our study is the representativeness of our sample. Our sample frame did not include women living in households without a telephone and women who have requested that their name be removed from the NDS database. Even with these restrictions, however, about 80% of households in the country were eligible for sampling. Second, although our sample represents women across a broad range of age, education, and income, minority women and women with the lowest socioeconomic indicators were underrepresented. Thus, whether minority women or women with little formal education reacted differently to the debate is a reasonable question.

A final concern is that there may have been systematic bias in our sample because respondents differed from nonrespondents. Our response rate of 66%, an unusually good rate for a mail survey, lessens this concern. Our findings were the same regardless of how we corrected for differences between our sample and the US population (unweighted or 2 methods of weighting), showing that the beliefs examined did not differ significantly by these characteristics. To the extent that women with the lowest level of educational attainment (eg, did not graduate from high school) were underrepresented, we overrepresented women with the greatest access and ability to interpret information about mammography. If bias was introduced because of our sample's slightly higher than average socioeconomic status, our findings are probably a low estimate of the prevalence of misunderstandings about the benefit of mammography and the reason for the debate.

Our findings may provide 2 important suggestions for future policy makers debating about large-scale implementation of screening services. First, the public may pay attention to such debates. Since our results have shown the difficulty of communicating scientific evidence, those thinking of making public recommendations need to consider how to effectively disseminate their message.[20] Second, the public may misconstrue the debate. For a public already skeptical about managed care,[21] the authors of evidence-based recommendations need to recognize that society may perceive any recommendation other than an unqualified endorsement for a test or treatment as a mechanism for cost containment rather than a conclusion of objective scientific study. Consequently, policy statements should be explicit about how financial costs were considered in making the recommendations and should be especially clear if costs were not considered. These suggestions may be relevant in the ongoing debate about testing for cancer susceptibility genes (eg, *BRCA1*). This debate may be particularly acrimonious given the widespread interest in such tests among the public,[22] powerful financial interests on the part of the biotechnology sector, and the lack of evidence that testing has benefit.

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Corresponding author: Steven Woloshin, MD, MS, Veterans Affairs Outcomes Group (111B), Department of Veterans Affairs Medical Center, North Hartland Road, White River Junction, VT 05009 (e-mail: steven.woloshin@dartmouth.edu).

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