

Original Investigation

How Patient Centered Are Medical Decisions? Results of a National Survey

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IMPORTANCE Informing and involving patients in their medical decisions is increasingly becoming a standard for good medical care, particularly for primary care physicians.

OBJECTIVE To learn how patients describe the decision-making process for 10 common medical decisions, including 6 that are most often made in primary care.

DESIGN A survey of a national sample of adults 40 years or older who in the preceding 2 years had either experienced or discussed with a health care provider 1 or more of 10 decisions: medication for hypertension, elevated cholesterol, or depression; screening for breast, prostate, or colon cancer; knee or hip replacement for osteoarthritis, or surgery for cataract or low back pain.

SETTING Adults living in households in the United States in 2011.

PARTICIPANTS A national sample of adults drawn from a probability sample-based web panel developed by Knowledge Networks.

MAIN OUTCOMES AND MEASURES Patients' perceptions of the extent to which the pros and cons were discussed with their health care providers, whether the patients were told they had a choice, and whether the patients were asked for their input.

RESULTS Responses were obtained from 2718 patients, with a response rate of 58.3%. Respondents reported much more discussion of the pros than the cons of all tests or treatments; discussions about the surgical procedures tended to be more balanced than those about medications to reduce cardiac risks and cancer screening. Most patients (60%-78%) said they were asked for input for all but 3 decisions: medications for hypertension and elevated cholesterol and having mammograms (37.3%-42.7%). Overall, the reported decision-making processes were most patient centered for back or knee replacement surgery and least for breast and prostate cancer screening.

CONCLUSIONS AND RELEVANCE Discussions about these common tests, medications, and procedures as reported by patients do not reflect a high level of shared decision making, particularly for 5 decisions most often made in primary care.

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In 1982, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research decried the extent to which medical decisions were being made in a paternalistic way, with physicians essentially controlling the decision making. The commission took the position that ethical medicine required that patients be provided with the information they needed to form their own opinions about what should be done, and their voices should be well reflected in the resulting decisions.¹

In the late 1990s, Braddock and associates^{2,3} studied tape recordings of physicians and patients making decisions and reported that patients were not consistently informed or involved when decisions were made. The University of Michigan's DECISIONS survey of patients who had made medical decisions in 2005 through 2007 similarly reported that patients making common medical decisions routinely were poorly informed and that discussions with health care providers were heavily weighted in the direction of their taking medications and having screening tests.⁴⁻⁶ A survey of Medicare patients who had prostate cancer surgery or coronary artery stenting in 2008 reported similar results.⁷

In the last decade, the idea of informing and involving patients in their decisions has begun to take root, at least in policy circles. The American Medical Association⁸ has endorsed shared decision making as a key component of quality medical care when there are options, and the idea has been particularly promoted for primary care as part of the emerging vision of a patient-centered medical home.^{9,10}

In this study, a cross section of US adults 40 years or older was asked in a 2011 survey to indicate whether they reported making 1 of 10 medical decisions and to describe their interactions with health care providers concerning those decisions. The answers provide an updated picture of medical decision making in the United States in 2011 and how it differs by which decision is being made. The results also provide an opportunity to compare the processes for decisions typically made in a primary care setting with those usually made in a specialty setting.

Methods

This study is based on an analysis of data from a survey of adults 40 years and older fielded by Knowledge Networks (Government of British Columbia, Canada). The protocols were approved by the New England institutional review board.

Sample

Knowledge Networks drew a probability sample of individuals 40 years or older from its Knowledge Panel, a probability-based web panel designed to be representative of adults living in households in the United States. This panel is distinctive from most other online panels in at least 3 ways. First, it is based on a sample recruited through both random-digit dialing and address-based sampling. Address-based sampling enables the inclusion of households that are served only by cell phones or have no telephone service. Second, because the panel is based on a probability sampling of households and recruited to be

part of the panel, it differs from those that are formed based on volunteers. Third, although data are collected via the Internet, selected people who do not have computers or Internet service are provided with both so they can be included in the panel, helping to make it more broadly representative.^{11,12}

The sampling proceeded in 2 steps. First, respondents answered questions to identify those who in the preceding 2 years had screening tests for colorectal, breast, or prostate cancer; had started or stopped medication for hypertension, high cholesterol, or depression; had knee or hip replacement for osteoarthritis or surgery for cataracts or low back pain; or had discussions with a health care provider about doing any of these things. Those who had made 1 or more of these decisions were then asked a series of questions about their interactions with health care providers. To limit respondent burden, when a respondent reported facing more than 2 decisions, a probability selection, at a rate inversely related to their prevalence, was made of 2 decisions to address in the survey. Thus, the respondents constitute a probability sample of members of the Knowledge Panel who are 40 years or older and reported making at least 1 of the 10 target decisions in the preceding 2 years. The answers about the decision-making processes describe a probability sample of each type of decision made in the United States with adults 40 years or older in 2010 through 2011.

The Survey Instrument

The survey instrument was largely based on a 2007 survey conducted by the University of Michigan (the DECISIONS survey)⁴⁻⁶ and a subsequent survey of Medicare surgical patients.⁷ The focus of this study is on 4 questions designed to characterize the extent to which the health care provider informed and involved patients when a decision was made.

Two questions asked how thorough the discussion was for having or not having the test, medication, or operation:

1. How much did you and the health care provider(s) discuss the reasons you might want _____? (a lot, some, a little, or not at all)
2. How much did you and the health care provider(s) discuss the reasons you might not want _____? (a lot, some, a little, or not at all)

Two other questions asked whether the health care provider received input from the patient about what should be done:

1. Did the health care provider(s) explain that you could choose whether or not to have _____? (yes/no)
2. Did the health care provider(s) ask you whether or not you wanted to have _____? (yes/no)

Following the model of shared decision making laid out by Charles et al¹³ and Sepucha et al,¹⁴ we scored the answers such that the more complete the discussion of the pros and cons, and the more patients were informed that they had a choice and were asked for input, the more shared was the decision and the better (more patient centered) was the decision-making process.

Data Collection

Sample panel members received an e-mail request to participate in the survey on November 2, 2011. Automated e-mail

reminders to nonresponders were sent on day 3 of the field period, and additional customized e-mail reminders to nonrespondents were sent periodically until data collection was completed on December 13, 2011.

Statistical Analysis

Data were weighted to adjust for nonresponse so that those responding to the initial screening questions matched the age, race, sex, and other characteristics of the total population 40 years and older, as estimated from the most recent Current Population Survey conducted by the US Bureau of the Census.¹⁵ The responses about the individual decisions were also weighted to adjust for different probabilities of selection related to the number of decisions they reported making. Thus, the answers of respondents who said they had made 4 decisions were weighted by a factor of 2 to adjust for the fact that only half of the decisions they made are reflected in the data, whereas we have data on all decisions made by respondents who made only 1 or 2 decisions.

Analyses are primarily cross-tabulations by decision type. Items with 4 response options (none, a little, some, and a lot) were consolidated into 2 (none or a little and some or a lot) to facilitate presentation. To summarize results, we created a decision process score by assigning 1 point each for discussing the reasons for a test or treatment “a lot” or “some,” talking about the reasons not to have a test or treatment “a lot” or “some,” explaining that there was a choice to be made (yes), and asking for the patient’s input (yes), producing a score that ranged from 0 to 4.⁷

To examine how much health care providers were tailoring their interactions to individual patients, we compared the interactions concerning decisions to have cancer screening across patient age groups. We analyzed interactions concerning medication for hypertension and elevated cholesterol by whether the patient reported a history that indicated an elevated risk of heart disease (diagnosis of heart disease, previous heart attack, previous coronary artery bypass, angioplasty, or diagnosis of diabetes). We hypothesized there would

be more shared decision making when there was a lower absolute benefit. The specific hypotheses were as follows:

1. Since there is more evidence of benefit for those 50 to 69 years old, there should be more shared decision making for cancer screening when patients are younger than 50 years or 70 years or older.¹⁶⁻²⁰
2. There should be more shared decision making for medication for hypertension and elevated cholesterol when the patient does not have a history indicating an elevated risk of heart disease.²¹⁻²⁴

All analyses were done using the IBM SPSS Complex Samples Module, version 20 (SPSS, Inc). Within Complex Samples, we used the Crosstab module to estimate the confidence intervals for cross-tabulations adjusted for the different probabilities of selection. Tests comparing the Decision Process Score means used the General Linear Modeling module within Complex Samples. All these analyses also considered the geographic stratification within the original sample design.

Results

Of the 5682 panel members asked to respond, 3396 (59.8%) answered the questions about which decisions they had discussed with their health care providers. Of those who responded to the initial questions, 2788 reported making 1 or more of the target decisions, and 2718 (97.5%) completed the entire survey. The overall response rate of 58.3% assumes nonrespondents were eligible at the same rate as screening question respondents (American Association for Public Opinion Research, Response Rate 4).²⁵ Of the respondents, 27.2% reported on only 1 decision, while the other 72.8% described 2 decisions.

Table 1 presents some demographic characteristics of those who made each decision. Patients who discussed cataract surgery were much older than those making other decisions, while those who made decisions about mammograms and depres-

Table 1. Selected Characteristics of Those Who Reported Discussing 10 Medical Decisions in a Nationally Representative Survey of US Adults

| Characteristic | Total No. | No. (%) | | | |
|-------------------------|-----------|------------|-------------|---------------------------|---------------------|
| | | Aged >65 y | Male Sex | >4-Year College Education | White, Non-Hispanic |
| Medication | | | | | |
| Blood pressure | 1027 | 435 (42.4) | 507 (49.4) | 228 (22.2) | 711 (69.2) |
| Cholesterol | 822 | 322 (39.2) | 418 (50.9) | 205 (24.9) | 593 (72.1) |
| Depression | 386 | 94 (24.4) | 123 (31.9) | 96 (24.9) | 295 (76.6) |
| Cancer screening | | | | | |
| Colon | 796 | 300 (37.7) | 376 (47.3) | 266 (33.4) | 602 (75.6) |
| Breast ^a | 683 | 196 (28.7) | 0 | 203 (29.7) | 502 (73.5) |
| Prostate ^b | 291 | 124 (42.6) | 291 (100.0) | 101 (34.8) | 226 (77.9) |
| Surgery | | | | | |
| Knee replacement | 166 | 80 (48.2) | 82 (49.4) | 41 (24.6) | 131 (78.9) |
| Hip replacement | 59 | 34 (57.6) | 32 (55.2) | 13 (22.4) | 43 (74.1) |
| Low back | 157 | 64 (40.8) | 76 (48.4) | 27 (17.1) | 121 (77.1) |
| Cataract | 319 | 256 (80.3) | 134 (42.0) | 69 (21.6) | 272 (85.3) |

^a Female-only topic.

^b Male-only topic.

sion medication were younger. Sex was about evenly split (other than for mammography and prostate-specific antigen [PSA] testing), but decisions about depression medications were much more common among women. Those who made decisions about cancer screening were a little more likely than those making other decisions to be college graduates. Ethnic composition was relatively similar across decisions, except that cataract decisions were more common among white respondents.

The Figure shows that for all decisions, patients reported more discussion of the pros than of the cons. For medications, around twice as many participants reported a lot or some dis-

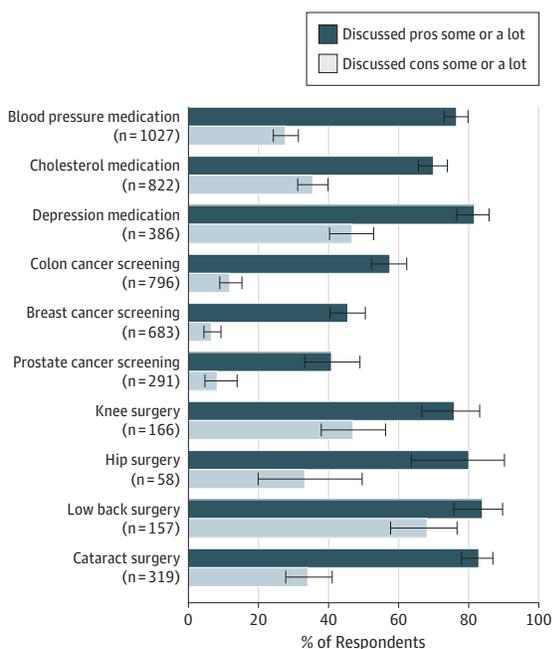
ussion of the pros as those who reported that much conversation of the cons, with not much difference among the medication decisions. For cancer screening, the discussion of cons was almost nonexistent, despite recent concerns raised about the possible downsides of PSA testing and of mammograms.¹⁶⁻²⁰ However, there was less discussion of the pros of testing as well compared with that for medications and for surgery. In particular, the lowest rates of reported discussion of pros in the Figure are for mammograms and PSA testing.

Data for surgical procedures vary substantially by procedure. While the reported discussion of the downsides of cataract surgery and hip replacement surgery look similar to the medication discussions, those considering knee replacement surgery and back surgery reported considerably more discussion of the potential cons. In fact, the high rate of reported discussion of the possible downsides of back surgery makes that decision stand out as the most balanced of all decisions studied.

Data in Table 2 show the frequency with which patients reported they were told that there was a choice to make and were asked what they wanted. Among the 3 medication decisions, health care providers were less likely to make it clear there was a choice for hypertension medications (66.0%) than for the other 2 decisions. Among the cancer screening decisions, patients considering mammograms were least likely to believe they had a choice (54.4%). With respect to surgery, back and knee replacement stood out as having the highest percentages of patients who were told they had a choice, while those considering cataract surgery (35.8%) were the least likely to report being told they had a choice.

Turning to the other data in Table 2, patients reported that health care providers were least likely to ask for input for decisions about taking medication for hypertension and elevated cholesterol and for having a mammogram (only about 40% for each). They were most likely to ask for patient input for 3 of the 4 surgical decisions (knee replacement, lower back, and cataract) (all ≥70%). The other 4 decisions—colon and prostate cancer screening, medication for depression, and hip replacement surgery—were in between.

Figure. Discussions About Common Tests, Medications, and Procedures as Reported by Patients



Proportion (and 95% CIs) of patients who reported discussing the pros and cons "some" or "a lot" with their health care provider(s) for each topic.

Table 2. Proportion of Patients Who Were Asked What They Wanted and Were Told They Could Choose

| Characteristic | Total No. ^a | Providers Explained Choices | | Providers Asked Patients' Preference | |
|-------------------------|------------------------|-----------------------------|-----------|--------------------------------------|-----------|
| | | No. (%) | 95% CI | No. (%) | 95% CI |
| Medication | | | | | |
| Blood pressure | 1027 | 674 (66.0) | 62.1-69.6 | 378 (37.3) | 33.5-41.2 |
| Cholesterol | 822 | 610 (74.9) | 70.7-78.6 | 347 (42.7) | 38.2-47.3 |
| Depression | 386 | 293 (76.7) | 71.2-81.4 | 251 (66.0) | 59.8-71.7 |
| Cancer screening | | | | | |
| Colon | 796 | 548 (69.0) | 64.0-73.5 | 475 (60.8) | 55.8-65.6 |
| Breast | 683 | 369 (54.4) | 49.3-59.4 | 268 (39.5) | 34.7-44.6 |
| Prostate | 291 | 185 (63.9) | 55.9-71.1 | 173 (60.0) | 52.0-67.5 |
| Surgery | | | | | |
| Knee replacement | 166 | 143 (85.9) | 78.6-90.9 | 118 (72.4) | 63.1-80.2 |
| Hip replacement | 59 | 41 (71.3) | 54.9-83.6 | 35 (60.2) | 42.1-75.8 |
| Low back | 157 | 140 (90.4) | 82.3-95.0 | 122 (78.0) | 68.7-85.1 |
| Cataract | 319 | 114 (35.8) | 29.5-42.7 | 222 (69.9) | 63.3-75.8 |

^a The number for some percentages may vary slightly due to item nonresponse.

Table 3 gives the decision process scores as a way of summarizing the above data from the 4 questions. The lowest (worst) decision process scores are for breast (mean, 1.5) and prostate (mean, 1.7) cancer screening. The decisions about hypertension and cholesterol-lowering medications and screening for colon cancer are next, along with cataract surgery (mean, 2.0-2.2). The best decision processes were reported by those considering low back surgery (mean, 3.2), followed by those considering knee replacement surgery (mean, 2.8) or medication for depression (mean, 2.7).

Table 4 lists the decision process scores for reported interactions concerning cancer screening by age of the respondent. Health care providers may have been slightly ($P = .19$) more active about informing and involving patients considering colon cancer screening if they were 50 years or older than if they were younger. For breast and prostate cancer screening, there were no statistically meaningful differences in the discussions by age.

In **Table 5**, the hypothesis that there would be more shared decision making for patients at lower risk also was not sup-

ported. Decision process scores may be higher for low-risk patients considering hypertension medications ($P = .09$) and tended that way for cholesterol medication decisions ($P = .26$). However, the differences, if any, were small, and the scores for all groups were comparatively low, averaging around 2 of a possible 4 points.

Discussion

These data show that there is still considerable paternalism in medical decision making, and the decisions we studied that are most physician driven are those typically made in a primary care, rather than a surgical, setting.

Decisions about taking medication to modify cardiovascular risks are clearly among those that are most health care provider driven. The discussions are usually slanted toward taking the medication, and only a few of these discussions involved patients by asking them for input. The reported overall process was only slightly, if at all, better for low-risk patients.

Table 3. Overall Decision Process Score (Scale 0-4)^a

| Characteristic ^b | Total No. | Decision Process Score Category, No. (%) | | | Mean (SD) Score |
|-----------------------------|-----------|--|------------|------------|-----------------|
| | | 0-1 | 2 | 3-4 | |
| Medication | | | | | |
| Blood pressure | 993 | 323 (32.5) | 298 (30.0) | 372 (37.5) | 2.1 (1.2) |
| Cholesterol | 795 | 235 (29.6) | 225 (28.3) | 335 (42.1) | 2.2 (1.3) |
| Depression | 371 | 61 (16.4) | 85 (22.9) | 225 (60.6) | 2.7 (1.2) |
| Cancer screening | | | | | |
| Colon | 783 | 273 (34.9) | 197 (25.2) | 313 (40.0) | 2.0 (1.2) |
| Breast | 671 | 349 (52.0) | 180 (26.8) | 142 (21.2) | 1.5 (1.2) |
| Prostate | 287 | 117 (40.8) | 96 (33.4) | 74 (25.8) | 1.7 (1.2) |
| Surgery | | | | | |
| Knee replacement | 163 | 29 (17.8) | 22 (13.5) | 112 (68.7) | 2.8 (1.1) |
| Hip replacement | 57 | 11 (19.3) | 18 (31.6) | 28 (49.1) | 2.5 (1.2) |
| Low back | 152 | 11 (7.2) | 20 (13.2) | 121 (79.6) | 3.2 (1.0) |
| Cataract | 314 | 70 (22.3) | 118 (37.6) | 126 (40.1) | 2.2 (1.0) |

^a Respondents received 1 point for each of the following responses: discussed pros = some or a lot, discussed cons = some or a lot, asked preference = yes, and choices explained = yes.

^b Percentages may not total 100 due to rounding.

Table 4. Decision Process Score for Cancer Screening Decisions by Patient Age

| Age Group, y | Total No. | Decision Process Score Category, No. (%) ^a | | | Mean (SD) Score | Significance Test (f) ^b | P Value |
|----------------------------------|-----------|---|------------|------------|-----------------|--|---------|
| | | 0-1 | 2 | 3-4 | | | |
| Colon cancer screening | | | | | | | |
| <50 | 91 | 39 (43.3) | 25 (27.3) | 27 (29.4) | 1.7 (1.2) | 1.7 | .19 |
| 50-69 | 511 | 172 (33.6) | 134 (26.3) | 205 (40.1) | 2.0 (1.2) | | |
| >70 | 181 | 62 (34.2) | 38 (21.0) | 81 (44.8) | 2.0 (1.3) | | |
| Breast cancer screening | | | | | | | |
| <50 | 193 | 103 (53.3) | 48 (24.8) | 42 (21.9) | 1.5 (1.2) | 0.2 | .84 |
| 50-69 | 357 | 186 (52.0) | 89 (25.0) | 82 (22.9) | 1.5 (1.2) | | |
| >70 | 120 | 61 (50.3) | 42 (35.2) | 17 (14.5) | 1.4 (1.0) | | |
| Prostate cancer screening | | | | | | | |
| <50 | 35 | 17 (47.0) | 6 (18.1) | 12 (34.9) | 1.9 (1.5) | 1.0 | .38 |
| 50-69 | 175 | 72 (41.1) | 67 (38.4) | 36 (20.5) | 1.6 (1.1) | | |
| >70 | 76 | 28 (37.0) | 22 (29.2) | 26 (33.8) | 1.9 (1.1) | | |

^a Percentages may not total 100% due to rounding.

^b One-way analysis of variance for differences in means across age groups.

Table 5. Decision Process Score for Blood Pressure and Cholesterol Medication Decisions by Number of Self-reported Heart Disease Risk Factors^a

| Self-reported Heart Disease Risk Factors | Total No. | Decision Process Score Category, No. (%) ^b | | | Mean (SD) Score | Significance Test (t) ^c | P Value |
|--|-----------|---|------------|------------|-----------------|------------------------------------|---------|
| | | 0-1 | 2 | 3-4 | | | |
| Blood pressure medications | | | | | | | |
| None | 613 | 187 (30.5) | 172 (28.1) | 254 (41.4) | 2.2 (1.2) | 1.7 | .09 |
| ≥1 | 366 | 131 (35.8) | 119 (32.6) | 116 (31.6) | 2.0 (1.1) | | |
| Cholesterol medications | | | | | | | |
| None | 515 | 143 (27.8) | 152 (29.5) | 220 (42.8) | 2.3 (1.3) | 1.1 | .26 |
| ≥1 | 266 | 85 (32.0) | 70 (26.2) | 111 (41.8) | 2.2 (1.2) | | |

^a Heart disease risk factors include past diagnosis of coronary artery disease or heart disease; heart attack; heart bypass surgery, angioplasty, or coronary artery stent; or diagnosis of diabetes.

^c Independent samples t test for differences in means across heart disease risk groups.

^b Percentages may not total 100 due to rounding.

Depression medication decisions were better by comparison because patients were more likely to report they were asked for input, and the cons of taking medication were discussed to a greater extent, leading to an overall higher than average decision process score.

Surgical decisions, while varying by procedure, looked more like decisions for depression medication than medications to lower cardiovascular risks. The descriptions of discussions about the pros and cons of back surgery are very close to being balanced. Knee replacement surgery also stands out from the other decisions in similar ways. The overall decision process scores for these 2 decisions are the highest of those studied.

Finally, the US Preventive Services Task Force has concluded that the evidence does not support routine PSA screening.^{19,20} Although mammography for women 50 years or older has not been as controversial as PSA testing, questions have been raised about the net value of screening women younger than 50 years or 70 years or older.¹⁷ Recent studies¹⁶⁻¹⁸ have reported quite modest survival benefits from annual mammography, while concluding that as many as 1 in 5 women treated for breast cancer may have had cancers that would have never presented clinically. Given these findings, we thought we might see more shared decision making concerning these tests. They did not show up in the ways we expected. Almost no discussion of the downsides of cancer screening was reported for any of these tests. Moreover, there was little, if any, relationship between patient age and the decision process scores.

Some potential limitations of these data should be noted. First, patient reports of their interactions with health care providers may be imperfect, although 1 study²⁶ of similar questions found they corresponded well with ratings by an independent observer. Second, despite efforts to be inclusive and weighting to mirror the population, the Knowledge Panel may underrepresent some groups, including those with the least

computer capabilities. Third, although most decisions about cancer screening and hypertension and cholesterol medications take place in primary care, some of them no doubt involved specialists, as did some decisions about medication for depression. Moreover, some of these decisions could have been made primarily with someone other than a physician, such as a nurse practitioner. Finally, it would not be appropriate to conclude that primary care physicians share decisions less often than do specialists. We cannot dissociate the effects of the kind of decision being made from the specialty of the physician. Although surgical decisions looked better than most medication and cancer screening decisions in this particular sample of decisions, decision making around coronary artery stenting was poor in a study of Medicare patients,⁷ and in this study, decision making about depression medications compared favorably with the surgical decisions. Decision making certainly varies by health care provider and by decision.

In conclusion, in 2011, we saw great variation in the extent to which patients reported efforts to inform them about and involve them in 10 common decisions. Although there was variation within decision types, decisions concerning 4 surgical procedures were much more shared than decisions about cancer screening and 2 very common long-term medications for cardiac risk reduction. If shared decision making is to be one defining characteristic of primary care as delivered in medical homes, primary care physicians and other health care providers will need to balance their discussions of pros and cons to a greater degree and ask patients for their input more consistently. Finally, despite the controversies concerning mammograms and PSA tests, primary care physicians and other health care providers are not doing much shared decision making about these tests, nor are they discussing the downsides of screening. However, perhaps the comparatively low rates at which they are discussing the benefits of breast and prostate cancer screening reflect some of the concerns that have been raised.

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Analysis and interpretation of data: All authors.

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Critical revision of the manuscript for important intellectual content: Gerstein, Barry.

Statistical analysis: Fowler, Gerstein.

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