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Do Men Receive Information Required for Shared Decision Making About PSA Testing? Results from a National Survey

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Abstract

Most professional organizations, including the American College of Physicians and U.S. Preventive Services Task Force, emphasize that screening for prostate cancer with the prostate-specific antigen (PSA) test should only occur after a detailed discussion between the health-care provider and patient about the known risks and potential benefits of the test. In fact, guidelines strongly advise health-care providers to involve patients, particularly those at elevated risk of prostate cancer, in a “shared decision making” (SDM) process about PSA testing. We analyzed data from the National Cancer Institute’s Health Information National Trends Survey 2011–2012—a nationally representative, cross-sectional survey—to examine the extent to which health professionals provided men with information critical to SDM prior to PSA testing, including (1) that patients had a choice about whether or not to undergo PSA testing, (2) that not all doctors recommend PSA testing, and (3) that no one is sure if PSA testing saves lives. Over half (55 %) of men between the ages of 50 and 74 reported ever having had a PSA test. However, only 10 % of men, regardless of screening status, reported receiving all three pieces of information: 55 % reported being informed that they could choose whether or not to undergo testing, 22 % reported being informed that some doctors recommend PSA testing and others do not, and 14 % reported being informed that no one is sure if PSA testing actually saves lives. Black men and men with lower levels of education were less likely to be provided this information. There is a need to improve patient-provider communication about the uncertainties associated with the PSA test. Interventions directed at patients, providers, and practice settings should be considered.

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Keywords

Shared decision making; PSA testing; Prostate cancer screening; Uncertainty; Patient-provider communication

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Introduction

Prostate cancer is the second most frequently diagnosed cancer and a leading cause of cancer mortality among men in the USA [1]. The American Cancer Society estimates that, in 2014, about 233,000 men will be diagnosed and 29,480 men will die from the disease [1]. When detected at an early stage, prostate cancer is often curable. Screening for prostate cancer with the prostate-specific antigen (PSA) test, however, is controversial [2]. Evidence from randomized controlled trials is mixed regarding the benefits of screening with the PSA test [3]. Results from the European Randomized Study of Screening for Prostate Cancer (ERSPC) showed an increase in cancer incidence with screening (relative ratio (RR) 1.57, 95 % confidence interval (95 % CI) 1.51–1.62) and an improvement in the risk of prostate cancer-specific mortality after 13 years (RR 0.79, 95 % CI 0.69–0.91) [4]. In contrast, results from the U.S. Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial demonstrated an increase in cancer incidence in the screening group (RR 1.12, 95 % CI 1.07–1.17) but *no* significant prostate cancer-specific mortality benefit with screening after 13 years (RR 1.09, 95 % CI 0.87–1.36) [5].

This lack of screening benefit may be attributed to several reasons, including a high rate of screening among the controls [5] and the fact that clinically localized prostate cancer is slow growing and most men with prostate cancer will die of other causes [6]. As such, PSA testing frequently identifies cancers that may never become clinically relevant. Additionally, PSA testing may, in fact, do harm, including the potential for unnecessary test-induced anxiety and stress, false-positive and false-negative results, excess diagnostic evaluation, and ultimately, over-treatment (e.g., surgery or radiation therapy) and treatment side effects (e.g., erectile dysfunction, urinary incontinence, and radiation side effects) [6].

For many years, professional organizations differed in their clinical guidelines for the use of PSA tests for screening [2]. More recently, however, organizations have begun to openly recommend discussion of the benefits and harms of PSA testing [7–9]. Indeed, most professional organizations, including the American Cancer Society (ACS) [10], American Urological Association (AUA) [7], American College of Physicians (ACP) [8], and U.S. Preventive Services Task Force (USPSTF) [11], emphasize that PSA testing should *not* occur before a detailed discussion between the health-care provider and patient about the known risks and potential benefits of the test. Guidelines strongly advise health-care providers to involve patients, particularly those at elevated risk of prostate cancer, in a “shared decision making” (SDM) process about PSA testing. SDM may be achieved through a discussion between a patient and provider, whereby the provider informs the patient about what is known about the PSA test—including its associated risks, benefits, limitations, alternatives, and uncertainties. The patient, in turn, considers his preferences and values and

makes a decision that is informed, consistent with his values, and supported by the provider [12, 13].

Studies that document the kinds of conversations men are having with their health-care providers about PSA testing are limited, and few studies use nationally representative data based on patients' reports (vs. providers') of screening discussions. Most publications in this area report on data collected before 2008 [14–24]; however, it was in 2008 that the USPSTF first advised that health-care providers should not order the PSA test without first discussing with the patient the potential but uncertain benefits and the known harms of PSA testing [25]. The few studies using data collected after 2008 reveal that conversations about PSA testing between patients and providers remain far from optimal [26, 27]. example, in a cross-sectional analysis of data from the 2010 National Health Interview Survey, nearly two thirds (64 %) of men aged 50 to 74 years reported that they had not had a discussion with their provider about the advantages, disadvantages, or uncertain balance of benefits and harms of PSA testing [26].

Understanding the extent to which men are engaged in SDM is important in order to gauge progress toward the Healthy People 2020 goal of increasing the proportion of men who have discussed the advantages and disadvantages of PSA testing with their health-care provider [28]. As a core element of “patient-centered care” and “evidenced-based medicine” [29], it is vital that SDM—particularly for screening tests that have uncertain efficacy—be monitored and encouraged.

To meet this need, we describe the national prevalence of men's engagement in critical components of SDM about PSA testing. Specifically, our goals were as follows: (1) to examine the extent to which health professionals provided men with information critical to SDM prior to PSA screening, including (a) that patients had a choice about whether or not to undergo PSA testing, (b) that not all doctors recommend PSA testing, and (c) that no one is sure if PSA testing saves lives; and (2) to identify characteristics of men who are more or less likely to receive this information. Understanding the characteristics of men who are not engaged by providers in SDM is critical for targeting interventions to high priority audiences and the dissemination of interventions to increase SDM practice.

Methods

Data and Participants

Data for this study were obtained from the National Cancer Institute (NCI)'s Health Information National Trends Survey (HINTS) 4 Cycle 1. HINTS is a nationally representative cross-sectional mail-based survey of noninstitutionalized adults in the USA. HINTS collects data on health communication and health services use, including information about attitudes, behaviors, and communication in health care. Data were collected between October 2011 and February 2012.

The present analyses were restricted to male respondents between the ages of 50 and 74 without a prior prostate cancer diagnosis, as this is the population for whom most screening guidelines recommended SDM about PSA testing at the time of data collection [2]. Details

of the survey design, methodology, and development of HINTS survey items are described elsewhere [30].

Measures

Shared Decision Making—In this study, we assess whether patients were provided with information critical for SDM [12], including whether they were offered the option to undergo or forego PSA testing and whether information about the controversial nature of PSA testing was provided. Respondents were asked, has a doctor or other health-care professional ever told you that: (1) “you could choose whether or not to have the PSA test?,” (2) “some doctors recommend the PSA test and others do not?,” and (3) “no one is sure if using the PSA test actually saves lives?” Response options for all three items were “yes,” “no,” and “not sure.”

PSA Testing—Respondents were asked: “Have you ever had a PSA test?” Response options included “yes,” “no,” and “not sure.”

Covariates—Sociodemographic and health-related factors shown in prior studies to be associated with SDM [26, 27] were also assessed which are as follows: age, race and ethnicity, marital status, household income, education, health insurance status, presence of regular source of health care, urban vs. rural residence, and family history of cancer.

Statistical Analysis

Descriptive analyses were performed to examine the distribution of sociodemographic characteristics within the sample and responses to our three SDM questions. To account for the complex survey sampling design of the HINTS, all statistical analyses were conducted in SAS-callable SUDAAN using appropriate survey weighting procedures to calculate accurate population-level estimates and confidence intervals for the US adult population. Three separate weighted multivariable logistic regression models assessed associations between participant characteristics and SDM measures. Frequencies and chi-square tests comparing SDM across PSA testing status were calculated.

Results

Sample Characteristics

From a total of 1552 men in HINTS 4 Cycle 1, 811 (52 %) met the eligibility criteria (ages 50–74 with no prior history of prostate cancer). In the weighted sample, the majority of men (55 %) were 50–59 years old. Three quarters (75 %) were non-Hispanic White, 74 % were married or living as married, 65 % had household incomes of less than \$75,000, and 37 % had a college degree or higher. Most had health insurance and a regular source of health care (87 and 75 %, respectively). Nearly two thirds (62 %) reported having a family history of cancer. Sample characteristics are summarized in Table 1.

Shared Decision Making

Table 1 presents the distribution of responses to items assessing elements of SDM. In the weighted sample, 55 % reported that their doctor had ever told them they could choose

whether or not to have the PSA test, 22 % reported that a provider or other health-care professional had ever told them that some doctors recommend the PSA test and others do not, and 14 % reported that their doctor or other health-care professional had ever told them that no one is sure if using the PSA test actually saves lives. Only 10 % of men in the sample reported having discussions with their provider that included all three SDM elements.

Factors Associated with Elements of Shared Decision Making

Table 2 presents factors associated with SDM elements. Age, race/ethnicity, and education were significantly associated with men's reports of having been provided with an option to choose whether or not to have the PSA test. Specifically, younger men were less likely to report that they had been presented with the option to undergo or forego PSA testing compared with those ages 70–74 (ages 50–59: odds ratio (OR) 0.26, 95 % CI 0.10–0.62; ages 60–69: OR 0.36, 95 % CI 0.14–0.93). Non-Hispanic Black men were less likely to report that options had been presented to them (OR 0.42, 95 % CI 0.18–0.98), compared with non-Hispanic White men. Compared to those with higher levels of education, men with lower levels of education were less likely to have discussed PSA test options with providers (high school diploma/GED: OR 0.42, 95 % CI 0.18–0.98; some college: OR 0.50, 95 % CI 0.26–0.95).

Few sociodemographic or health-related factors were associated with men's reports of having been informed that doctors disagree about recommending the PSA test. However, men who had attended some college were less likely to have engaged in this element of SDM (OR 0.50, 95 % CI 0.28–0.89) than were those who had a college degree or higher level of education.

Higher levels of education were also associated with reports of being informed that no one is sure if using the PSA test actually saves lives. Men with some college education were less likely to report that they had received this information from providers (OR 0.43, 95 % CI 0.20–0.95), compared with those who had a college education or more. Additionally, non-Hispanic Black men were less likely to report being informed of this information (OR 0.22, 95 % CI 0.05–0.93) than were non-Hispanic White men.

Shared Decision Making Elements by PSA Testing Status

Receipt of information about options and uncertainties regarding prostate cancer screening by PSA testing status is presented in Fig. 1. All associations were statistically significant at $p < 0.05$, indicating that men who had undergone a PSA test were more likely to report engaging in elements of SDM. Among men who reported having a PSA test (55 %), 81 % reported that their doctor discussed that one could choose to undergo screening or not, 33 % reported that they had been informed that not all doctors agree about recommending PSA testing, and 24 % reported that they had been told that no one is sure that using PSA testing saves lives.

Among those with no prior PSA testing, 72 % reported no SDM communications with their health-care provider. Only 25 % of men who had never undergone PSA testing reported being told that they could choose whether or not to have the PSA test, and only 9 % reported

having been told that doctors disagree about recommending PSA testing. Only 2 % reported having received information that it is uncertain whether PSA testing saves lives.

Discussion

Clinical recommendations from major professional organizations stress the importance of SDM about PSA testing, emphasizing that health-care providers need to educate patients about the risks and uncertainties of screening and help them make individualized, informed, and value-consistent decisions. This study used a nationally representative survey to assess men's reports of having received information needed for SDM about PSA testing. Specifically, we assessed three essential elements of SDM including whether patients were provided the option to undergo or forgo the test and whether they were informed about its controversial nature due to expert disagreement and unclear mortality benefits.

Most respondents who had a PSA test reported that their doctor did give them a choice about whether or not to have the test. However, only about a third of respondents who had a PSA test reported being informed that not all doctors recommend the PSA test, and only one fifth of respondents said they were informed that no one is sure if using the PSA test actually saves lives. These findings are consistent with prior studies that show suboptimal communication and SDM between patients and providers with regard to PSA testing [14–24, 26, 27]. That providers are not discussing these uncertainties before ordering the PSA test for their patients is problematic given the potential harms and controversies associated with the procedure [31–34].

We also found that respondents who were Black, younger, and had lower levels of education were less likely to receive information required for SDM about PSA testing. These findings suggest a need for additional research to understand disparities in reports of SDM among these groups. It is possible that racial differences in SDM are partially a product of patients' views and preferences; for example, African Americans may be more likely than Whites to prefer that health-care providers make certain health-care decisions for them [35]. However, health-care providers' interpersonal biases might also contribute to the observed racial differences in SDM [36], with health-care providers engaging African American patients in decision making to a lesser extent than White patients [37]. Patient barriers to SDM such as limited health literacy, low self-efficacy, and language barriers may further contribute to racial disparities in reports of SDM [38]. Finally, it is also possible that the present findings reflect an awareness among health-care providers that African Americans have an increased risk of prostate cancer and, as such, may realize the added benefit from earlier screening and detection. These men should be informed of both the known harms and potential benefits of screening at an earlier age and SDM should proceed with an understanding that there are no comparative data to demonstrate that men at higher than average risk for prostate cancer will benefit more from screening when compared to those at average risk. Improved provider communication regarding PSA testing with minority patients may lead to more accurate perceptions of risks and benefits, more value-consistent choices, and potentially, better outcomes.

Studies have revealed some of the reasons for suboptimal patient-provider communication about the complexities of PSA testing. For example, lack of time is the most frequently reported barrier by health-care providers [22, 23, 39]. Many health-care providers believe that involving patients in a well-rounded discussion of the trade-offs inherent in PSA testing is impractical, particularly in the context of an annual visit where there are severe time constraints and competing demands [23, 24]. However, evidence from three systematic reviews (on interventions to implement SDM, and impact of decision aids on processes of care and patient outcomes) indicates that there is no systematic increase in consultation length when SDM is implemented or decision aids are employed [40–42]. Other common reasons reported by health-care providers for not discussing PSA testing include forgetfulness, patient health literacy, language barriers, fear of liability, and the belief that such a discussion would not influence whether patients order the test [23, 24, 39, 43, 44]. The latter reason is particularly concerning, given that studies of prostate cancer screening decision aids have consistently shown that enhanced patient knowledge is associated with decreased patient interest in screening [40, 45].

While time constraints and other barriers may limit opportunities to discuss PSA testing, several factors may motivate health-care providers to screen their patients. In particular, prior research points to the importance of health-care providers' beliefs in the general efficacy of screening and of PSA testing specifically, as well as their concerns that prostate cancer often presents asymptotically [22]. Research suggests that there may be a general belief among primary care providers that screening should be part of routine care. One recent study found that primary care physicians could be divided into two screening-related practice patterns [46]: "routine" and "nonroutine" screeners. Routine screeners were providers who recommended regular PSA testing beginning around age 50 for asymptomatic men with no known risk factors and at least a 10-year life expectancy. Routine screeners were frequently unable to accurately describe the recommendations of any medical organization, were unaware of the controversy about PSA testing, and believed that population-based screening was a universally supported standard of care [46]. A more recent national study of 3914 primary care physicians found that many (60 %) physicians are "routine" screeners, while 27 % are variable and 13 % are consistent "nonscreeners" [47]. This investigation also revealed that routine screeners were less likely to be familiar with the guidelines about PSA testing and to report any effect of guidelines on their clinical practice compared with variable and consistent nonscreeners.

Implications

Our results suggest a need for strategies to increase SDM about PSA testing in clinical practice. Marshaling resources to improve SDM may require raising awareness among health-care providers about the controversies surrounding the PSA test. This may be accomplished through the distribution of educational materials (e.g., clinical practice guidelines) and the implementation of educational seminars for health-care providers. Helping providers understand the benefits of SDM in the clinical process and for patient-centered outcomes is also critical, as is providing providers with opportunities for skills training in SDM (e.g., training modules on risk communication, discussing scientific uncertainty with patients, eliciting patient preferences and values, and using decision aids

during encounters) [48, 49]. Training programs may be as simple as giving providers background reading and slide sets for self-teaching or as robust as offering online and video-based tutorials designed to help providers develop skills in providing decision support. Such training may increase providers' interest in SDM, enhance their self-efficacy, and teach providers the skills needed to facilitate SDM.

It is important to acknowledge the barriers reported by providers to SDM when designing interventions to increase SDM practice. Considering alternate ways of providing patients with information needed to make informed decisions about PSA testing may surmount barriers such as time limitations. Decision aids, for example, can be used to convey unbiased information about the risks and benefits of screening *prior* to a patient encounter, thus reducing the demands on providers to convey complex information in a brief encounter [15, 50–52]. Decision aids may also allow men to learn about the uncertainties of PSA testing at their own pace and potentially minimize the effects of the power differential [53] in conversations with providers. Team-based approaches to SDM (e.g., decision coaching by nurses) may also help to ameliorate barriers such as time constraints while simultaneously fostering continuity in the decision making process and improving the quality of decision support provided to patients [54–56]. Lastly, organizational-level changes that communicate the importance of SDM should be considered to nudge providers to involve patients in decision making. This may include incorporating reminders and prompts in electronic medical records, making physical space changes to facilitate open discussions with patients, and creating policies and procedures incentivizing providers to practice SDM.

Limitations and Future Directions

Our study had several important limitations. First, we did not measure all aspects of SDM such as patients' understanding of the decision, patients' self-efficacy for decision making, the providers' recommendations regarding screening, or who initiated the discussion. Moreover, we did not assess men's sense of being well informed about PSA testing or their preferences for involvement in SDM about PSA testing. All these limitations point to the need for a more detailed evaluation of the process of SDM.

Another limitation is that we relied on self-reports and were not sure that respondents accurately recalled their discussions with providers [57, 58]; for instance, some respondents who underwent PSA testing may have assumed that the provider presented the option to test and described the uncertainties associated with the test. Also, the questions in this study concerned whether patients had *ever* undergone a PSA test and been informed about various aspects of the test; thus, some of the interactions reported on may have occurred prior to the release of the 2008 USPSTF recommendation. Finally, our study reports on data collected in 2011–2012. Given the recent interest in patient-centered care [59, 60], the extent of SDM may have increased since the time of data collection. Continued research should involve using more recent data and studies that assess additional components of SDM about PSA testing, preferably using more direct measures (e.g., observation of decision making in primary care settings).

Although clinical guidelines strongly recommend that health-care providers engage patients in SDM prior to ordering a PSA test [11], many men do not receive information required for

SDM. Large proportions of patients report that they were not informed about the uncertainties associated with PSA testing, and many patients who have undergone PSA testing report that they were not informed that they had a choice about whether or not to have the test. These findings may reflect providers' limited uptake of clinical guidelines that recommend SDM about PSA-based screening. Additional research is warranted to determine the best ways to involve patients in screening decisions and improve the implementation of SDM by providers.

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Fig. 1.
Weighted prevalence of elements of shared decision making by PSA testing status, Health Information National Trends Survey 4 Cycle 1

Table 1 Sample characteristics (*N*=811), Health Information National Trends Survey 4 Cycle 1

Respondent characteristics	Weighted %	95 % confidence interval
Age		
50–59 years	54.6	53.4–55.8
60–69 years	35.2	34.3–36.1
70–74 years	10.2	9.4–11.0
Race/ethnicity		
Non-Hispanic White	75.3	73.0–77.4
Non-Hispanic Black	9.6	7.0–13.0
Hispanic	9.7	7.4–12.6
Non-Hispanic other	5.4	3.3–8.8
Marital status		
Married, cohabitation	73.9	69.8–77.5
Not married	26.2	22.5–30.2
Household income		
<\$20,000	17.8	14.4–21.9
\$20,001–\$35,000	16.4	13.3–20.1
\$35,001–\$50,000	11.8	9.0–15.5
\$50,001–\$75,000	19.4	15.6–23.9
>\$75,000	34.5	30.4–38.8
Education		
<HS/GED	11.9	9.4–14.9
HS diploma/GED	21.6	18.2–25.4
Some college	29.5	25.7–33.6
College graduate or higher	37.0	33.5–40.6
Insurance		
Yes	86.5	81.0–90.6
No	13.5	9.4–19.0
Regular doctor		
Yes	75.2	71.3–78.8
No	24.8	21.3–28.7
Living in metropolitan areas		
Urban	83.0	79.3–86.1
Rural	17.0	13.9–20.7
Family history of any cancer		
Yes	61.9	56.8–66.7
No	38.1	33.4–43.2
Ever had PSA test(s)		
Yes	55.3	50.3–60.2
No	44.7	39.9–49.7
Has a doctor ever told you that you could choose whether or not to have the PSA test?		

Respondent characteristics	Weighted %	95 % confidence interval
Yes	55.4	51.3–59.4
No/not sure	44.6	40.6–48.7
Has a doctor or other health-care professional ever told you that some doctors recommend the PSA test and others do not?		
Yes	22.1	18.2–26.4
No/not sure	77.9	73.6–81.8
Has a doctor or other health-care professional ever told you that no one is sure If using the PSA test actually saves lives?		
Yes	13.9	11.5–16.6
No/not sure	86.1	83.4–88.5

Table 2

Weighted multiple logistic regression of shared decision making outcomes among men 50 to 74 years old,
Health Information National Trends Survey 4 Cycle 1

	Has a doctor ever told you that you could choose whether or not to have the PSA test?	Has a doctor or other health- care professional ever told you that some doctors recommend the PSA test and others do not?	Has a doctor or other health-care professional ever told you that no one is sure if using the PSA test actually saves lives?
	Yes <i>n</i> =587 OR (95 % CI)	Yes <i>n</i> =595 OR (95 % CI)	Yes <i>n</i> =595 OR (95 % CI)
Age			
50–59 years	0.26 (0.10–0.62)	0.58 (0.24–1.41)	0.69 (0.19–2.53)
60–69 years	0.36 (0.14–0.93)	0.77 (0.31–1.91)	1.01 (0.30–3.40)
70–74 years	1.00	1.00	1.00
Race/ethnicity			
Non-Hispanic White	1.00	1.00	1.00
Non-Hispanic Black	0.42 (0.18–0.98)	0.62 (0.20–1.96)	0.22 (0.05–0.93)
Hispanic	0.89 (0.32–2.51)	1.44 (0.57–3.68)	1.13 (0.42–3.06)
Non-Hispanic other	1.19 (0.25–5.75)	–	–
Marital Status			
Married, cohabitation	1.00	1.00	1.00
Not married	0.61 (0.34–1.07)	0.91 (0.38–2.16)	0.99 (0.43–2.28)
Household income			
<\$20,000	0.75 (0.25–2.20)	0.48 (0.12–1.94)	0.32 (0.06–1.85)
\$20,001–\$35,000	1.01 (0.37–2.75)	0.94 (0.36–2.50)	1.85 (0.55–6.30)
\$35,001–\$50,000	0.66 (0.28–1.59)	0.37 (0.12–1.14)	0.51 (0.15–1.75)
\$50,001–\$75,000	1.69 (0.70–4.07)	0.73 (0.31–1.70)	0.78 (0.28–2.17)
>\$75,000	1.00	1.00	1.00
Education			
<HS/GED	0.46 (0.12–1.81)	0.48 (0.09–2.64)	0.77 (0.11–5.38)
HS diploma/GED	0.42 (0.18–0.98)	0.52 (0.20–1.35)	0.38 (0.09–1.56)
Some college	0.50 (0.26–0.95)	0.50 (0.28–0.89)	0.43 (0.20–0.95)
College graduate or higher	1.00	1.00	1.00
Insurance			
Yes	1.00	1.00	1.00
No	0.72 (0.24–2.14)	0.72 (0.21–2.51)	0.38 (0.07–2.10)
Regular doctor			
Yes	1.00	1.00	1.00
No	0.60 (0.29–1.24)	1.19 (0.48–2.96)	1.02 (0.40–2.58)
Living in metropolitan areas			
Urban	1.00	1.00	1.00
Rural	0.56 (0.28–1.11)	0.58 (0.21–1.56)	0.39 (0.12–1.20)
Family history of cancer			

	Has a doctor ever told you that you could choose whether or not to have the PSA test?	Has a doctor or other health-care professional ever told you that some doctors recommend the PSA test and others do not?	Has a doctor or other health-care professional ever told you that no one is sure if using the PSA test actually saves lives?
	Yes <i>n</i>=587	Yes <i>n</i>=595	Yes <i>n</i>=595
	OR (95 % CI)	OR (95 % CI)	OR (95 % CI)
Yes	1.00	1.00	1.00
No	0.82 (0.48–1.41)	0.71 (0.33–1.51)	0.64 (0.27–1.55)