# Men's reactions to disclosed and undisclosed opportunistic PSA screening for prostate cancer

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creening for prostate cancer by prostate-specific antigen (PSA) testing is contentious. 1-5 In a recent systematic review, the US Preventive Services Taskforce concluded:

We are unable to determine the net benefit of screening because we cannot establish the presence and, if present, the magnitude of benefit from screening. We can establish the presence of potential harms. Whether screening would result in benefit, and whether that benefit would outweigh the attendant harms, is unknown.<sup>5</sup>

All protagonists in the public controversy agree that men should make an "informed decision" about whether or not to undergo PSA screening, <sup>1,4</sup> and, hence, need to be fully apprised of the arguments for and against it.<sup>6-9</sup>

It appears that men participate in PSA screening without their full knowledge. Diefenbach et al<sup>10</sup> surveyed 369 Californian men for whom there was corroborated evidence of their having had a PSA test in the previous 2 weeks. Only 26.6% recalled being informed at the time of testing that a PSA test was being ordered. Federman et al<sup>11</sup> reported that 31% of a sample of 173 men who had had PSA screening 3 months earlier were unaware that a PSA test had been ordered. An Australian study revealed that 38% of men who had had a screening test for prostate cancer during the previous 5 years could not recall their doctor discussing the pros and cons of screening. A further 39% recalled 5 or fewer minutes dedicated to such a discussion. 12 While these studies may be affected by recall bias, they suggest that the pros and cons of PSA screening are not adequately discussed with men.

As general practitioners order PSA tests "opportunistically" when requesting other pathology tests, <sup>13</sup> it has been argued that patient autonomy is undermined by such an approach, while GPs are increasing the

### **ABSTRACT**

**Objective:** To assess the degree to which men considered it appropriate for general practitioners to order prostate-specific antigen (PSA) testing if the testing was either "disclosed" or "undisclosed" to the patient.

Design: Telephone-administered survey conducted in June to October 2000.

**Participants:** 514 men aged 50–70 years, identified by random selection of households from the Sydney Electronic White Pages phone directory.

**Methods:** We developed two hypothetical scenarios. Each scenario described a GP ordering a PSA test for a male patient at the same time as other pathology tests were ordered. In Scenario 1, the GP's intention to order a PSA test was disclosed to the patient ("disclosed"). In Scenario 2, the GP did not tell the patient a PSA test was being ordered ("undisclosed"). For each scenario, men reported the degree to which they perceived screening to be "appropriate". We also recorded demographic characteristics, health status and health locus of control, and administered a 14-question knowledge test about prostate cancer and PSA screening.

**Results:** Over 90% of men stated that "disclosed" PSA screening was either "appropriate" or "very appropriate". Significantly fewer (44.9%) rated "undisclosed" screening as appropriate/very appropriate (P < 0.001). While the skewed distribution of responses to Scenario 1 precluded multivariate analysis to determine predictors, men rejecting "undisclosed" PSA screening (Scenario 2) were more likely to be younger (adjusted odds ratio [AOR], 0.97; 95% CI, 0.94–1.00; P = 0.03); to have better knowledge of the issues (AOR, 1.01; 95% CI, 1.00–1.03; P = 0.02); and to be single (AOR, 0.62; 95% CI, 0.41–0.94; P = 0.02).

**Conclusions:** Many men consider that inclusion of PSA screening within a battery of pathology tests without disclosure to the patient is unacceptable. Educating men about the pros and cons of screening may alter their support of opportunistic screening and thus enhance community expectations of "informed participation".

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medicolegal risk to themselves.<sup>1-4</sup> As men's views on PSA screening are relatively unknown, we designed a community survey to explore the appropriateness of screening from their perspective.

### **METHODS**

### **Participants**

This study was part of a larger study in which we recruited participants by random selection of households from the Electronic White Pages phone directory. As reported elsewhere in detail, <sup>14,15</sup> we recruited a representative sample of men aged 50–70 years living in Sydney. Men who had a history of prostate cancer or who were not fluent in English were excluded.

### Interviews

One of 10 trained interviewers from a non-profit market research company (the Hunter Valley Research Foundation) established contact with each household to identify eligible participants and obtain their consent. Once consent was obtained, the interviewer proceeded to administer our computer-assisted telephone interview (CATI). Interviewers first elicited health information (current smoking, previous heart attack/stroke, self-reported health status). Answers to specific questions were used to derive a score (between 1 and 6) on a health locus of control scale<sup>16</sup> (a

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# 1 Selected characteristics of participants (n = 514) (figures represent number [%] of men, except where otherwise specified)

except where otherwis	e specified)
Self-reported health status <sup>20</sup>	
Excellent	98 (19.1%)
Good	283 (55.1%)
Fair	107 (20.8%)
Poor	26 (5.1%)
Current smoker	
Yes	82 (16.0%)
Previous heart attack or stroke	
Yes	44 (8.6%)
Control preferences scale (for PSA screening decisions) <sup>16</sup>	
Passive	117 (22.8%)
Shared/collaborative	222 (43.2%)
Active	173 (33.7%)
Unsure	2 (0.4%)
Knowledge about prostate cancer and PSA screening*	
Mean (SD)	29% (16.3%)
Median	29%
(interquartile range)	(14%–36%)
Health locus of control scale <sup>21</sup>	22
Mean (SD)	3.3 (0.93)
Median (interquartile range)	3.3 (2.7-4.0)

PSA = prostate-specific antigen. \* Based on answers to 14 questions, converted to a score out of 100. <sup>14</sup>

higher score indicating a greater tendency to attribute health status to chance or "luck") and a rating on a control preferences scale (a measure of whether an individual prefers a "passive", "collaborative" or "active" role in medical decision making). Each participant was then presented with two scenarios relating to PSA screening (see below). Participants were also asked 14 questions (in a combination of "true/false" and multiple choice formats) that assessed their knowledge about aspects of prostate cancer (eg, efficacy of PSA screening, risk factors for prostate cancer, treatment side effects). Demographic details (eg, marital status, country of birth, education level, occupation) were elicited at the end of the interview. Interviews were completed between June and October 2000.

A random sample of about 10% of each interviewer's telephone calls (53 calls in total) was monitored throughout the interview process to ensure that interviewers adhered to the wording on the CATI screen.

### **Scenarios**

After being given a description of the PSA test to ensure they understood its purpose and how it was performed, participants were presented with two hypothetical scenarios relating to opportunistic PSA screening. The first scenario described a GP ordering a PSA test along with other blood pathology tests after disclosing the intention to include the PSA test:

Scenario 1 ("disclosed" opportunistic PSA screening):

Mr A is a man in his early 60s. He sees a GP to check his blood pressure before going on a holiday. He is fit and well. He has no symptoms to suggest he has prostate cancer. While he is there, the doctor orders some blood tests. Mr A does not ask the doctor about PSA tests. However, the doctor suggests to Mr A that, "along with the other blood tests, we may as well have your PSA level measured to check your prostate".

In response to this scenario, men indicated how appropriate they thought it would be for the doctor to order a PSA test ("very inappropriate", "inappropriate", "appropriate" or "very appropriate").

Our second scenario also described a GP ordering a PSA test, but the GP did not disclose to the patient that the test was being ordered:

Scenario 2 ('undisclosed' opportunistic PSA screening):

Now imagine that the doctor did not ask Mr A if he wanted a PSA test. So the doctor has gone ahead and ordered a PSA test along with the other blood tests without telling Mr A.

As for Scenario 1, men were asked to rate the GP's behaviour on the same four-point scale of appropriateness.

### Statistical analysis

For each scenario, we compared characteristics of men who indicated testing was "very inappropriate" or "inappropriate" with those who indicated it was "very appropriate" or "appropriate". Wilcoxon signed rank tests were applied to conduct within-group comparisons of men's responses to each of the scenarios. Multivariate analyses were conducted to determine significant and independent predictors of negative reactions ("very inappropriate" or "inappropriate") to each scenario. Variables univariately associated with outcomes at the P < 0.25 level were selected for entry into multivariate

models.<sup>17</sup> Analyses were conducted using SPSS software.<sup>18</sup>

With respect to sample size, we had estimated that we would need to contact 7000 households in order to yield 500 interviews. A sample size of 500 was sufficient to estimate proportions so that 95% CIs for these estimates did not exceed  $\pm 5\%$  of the true value. This sample size also was sufficient to conduct subgroup comparisons of responses between men on categorical predictor variables with a power of 0.80 and an alpha level of 0.05.

### Ethics approval

Our study was approved by the Central Sydney Area Health Service Ethics Review Committee.

### **RESULTS**

As reported in detail elsewhere, <sup>14,15</sup> we identified 585 potential respondents. Of these, 521 consented to take part (raw response fraction, 89.1%). Of these, seven were found to have had a previous diagnosis of prostate cancer and their responses were excluded. This left a final sample size of 514 respondents.

Selected characteristics of the participants are shown in Box 1. The age distribution of the sample was not statistically different from that of the population of men defining the sampling frame. <sup>14</sup> The majority of men were married or living as

### 2 Participant responses to two scenarios describing a general practitioner opportunistically ordering a PSA screening test

### Scenario 1 ("disclosed" opportunistic PSA screening)

Very inappropriate	5 (1.0%)
Inappropriate	16 (3.1%)
Appropriate	197 (38.3%)
Very appropriate	289 (56.2%)
Don't know/can't say	7 (1.4%)

### Scenario 2 ("undisclosed" opportunistic PSA screening)

<b>5</b> .	
Very inappropriate	107 (20.8%)
Inappropriate	166 (32.3%)
Appropriate	171 (33.3%)
Very appropriate	60 (11.7%)
Don't know/can't say	10 (1.9%)

PSA = prostate-specific antigen.

## 3 Significant and independent predictors of the response that opportunistic ordering by GPs of "undisclosed" PSA screening tests is "inappropriate" or "very inappropriate" (Scenario 2)\*

	Proportion of men responding "inappropriate" or "very inappropriate"	Adjusted odds ratio (95% CI)	P
Marital status			
Married/living as married ( $n = 377$ )	51.2%	0.62 (0.41–0.94)	0.02
Single ( <i>n</i> = 126)	62.3%	1.00	
Age <sup>†</sup>		0.97 (0.94–1.00)	0.03
50–54 (n = 173)	59.0%	1.67 (1.01–2.82)	
55–59 (n = 133)	55.6%	1.57 (0.92–2.70)	
60–64 (n = 104)	51.0%	1.22 (0.70–2.16)	
65–70 (n = 93)	46.2%	1.00	
Knowledge about prostate cancer and PSA screening (14-item measure) <sup>†14</sup>		1.01 (1.00–1.03)	0.02
50% correct (n = 432)	52.1%	1.84 (1.08–3.14)	
> 50% correct (n = 71)	66.2%	1.00	

GP = general practitioner. PSA = prostate-specific antigen.  $\star$  11 (2.1%) respondents were excluded from the analysis because of missing or "don't know" responses. † Modelled as continuous.

married (n = 385; 74.9%), were currently employed (n = 361; 70.2%), and usually spoke English at home (n = 448; 87.2%). Just over a third held a university qualification (n = 192; 37.4%).

With respect to men's preferences for decisional control regarding PSA screening, 173 (33.7%) preferred an "active" role, while 117 (22.8%) preferred a "passive" role. Men answered, on average, 29% of the 14 knowledge questions correctly.

## Scenario-based assessment of men's reactions to "disclosed" or "undisclosed" PSA screening

Men's reactions to the two scenarios are shown in Box 2. In response to Scenario 1, over 90% (n = 486; 94.6%) of men stated that it was either "appropriate" or "very appropriate" for the GP to include PSA screening among other serological tests. In response to Scenario 2, in which the intention to include a PSA test was not disclosed, fewer than half the respondents (n = 231; 44.9%) considered this approach "appropriate" or "very appropriate". The difference in responses to the two scenarios was statistically significant (P < 0.001).

# Independent predictors of men's reactions to "disclosed" or "undisclosed" PSA screening

The skewed distribution of responses to Scenario 1 precluded multivariate analysis.

However, it was possible to undertake this analysis for Scenario 2. Three respondent characteristics were significant and independent predictors of negative reactions to "undisclosed" PSA screening: younger age (adjusted odds ratio [AOR], 0.97; 95% CI, 0.94–1.00; P=0.03); greater knowledge about prostate cancer and PSA screening (AOR, 1.01; 95% CI, 1.00–1.03; P=0.02); and being unmarried (AOR=0.62; 95% CI, 0.41–0.94; P=0.02) (Box 3). Variables that were not predictive included men's preferences for involvement in PSA screening decisions, health locus of control, and self-reported health status.

### **DISCUSSION**

To our knowledge, our study is the first to compare men's views about "disclosed" and "undisclosed" PSA screening. An overwhelming majority endorsed "disclosed" PSA screening if a GP elected to initiate its inclusion among a battery of serological tests. Ransohoff et al have speculated that GPs are positively reinforced for ordering tests that may potentially diagnose asymptomatic cancer, 23 irrespective of the risks involved in such testing. "Undisclosed" inclusion of PSA screening within a battery of tests was significantly more likely to be rejected by the respondents, although nearly half remained convinced of its appropriateness. It would seem that a sizeable proportion of men respect GPs for taking the

initiative, regardless of the extent to which GPs give them sufficient information to make an "informed decision". Younger men were significantly less likely to endorse such an approach, suggesting that older men may be more willing to acquiesce to "paternalistic" GP behaviour and may be more accepting of it.<sup>24,25</sup> Older men may also feel more vulnerable about prostate cancer. Men exhibiting more accurate knowledge about prostate cancer and the pros and cons of its early detection were less likely to endorse Scenario 2. "Undisclosed" screening may be less acceptable to men the more aware they become of the scientific uncertainty about the efficacy of PSA screening and the potential adverse consequences of screening.

As decision aids foster patient empowerment as well as improve knowledge, 14,26 their wider use might change men's views about "disclosure" more generally. On the other hand, some level of support for opportunistic screening may persist, even with more transparent discussions between GPs and patients of the pros and cons of screening. While some have conceptualised the decision whether to undergo PSA screening as a "toss-up" between a possible extended life and possible harms of screening, 27 some men may always place greater weight on improved life expectancy. While we tried to ensure that our knowledge test assessed men's knowledge of both the pros and cons of PSA screening, we accept that there is no 'gold standard" for such measures and others may seek to emphasise different aspects.

The high response rate and random selection of participants from the community are strengths of our study. However, as the sample was recruited from an urban area, the findings may not be generaliseable to all Australian men. While order effects within our CATIs may also have biased our results, the shift in men's views from Scenario 1 to Scenario 2 was substantial, suggesting our findings were not produced by artefacts in study design.

In future research, we recommend that scenarios could be posed in which GPs are depicted as either informing or not informing men of the pros and cons of PSA screening. Other scenarios could elicit views about various methods to assist men to make an informed choice, including consent forms, mandatory disclosure (as required for HIV testing) or "cooling-off" periods (during which patients are advised to take time to think over their decision). Educating men about the pros and cons of screening may alter their support of opportunistic screen-

#### RESEARCH

ing and thus enhance community expectations of the "informed participation" recommended by health authorities.

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### **COMPETING INTERESTS**

None identified.

### **REFERENCES**

- 1 Catalona WJ. Informed consent for prostatespecific antigen screening. *Urology* 2003; 61: 17-19.
- 2 Stricker PD, Eisenger DR. Patient preference and prostate cancer screening. *Med J Aust* 1997; 167: 240-241.
- 3 Talcott JA. What patients should be told before agreeing to a blood test that could change their lives. *Urology* 2000; 61: 7-9.
- 4 Woolf SH, Rothemich SF. Screening for prostate cancer: the roles of science, policy, and opinion in determining what is best for patients. Annu Rev Med 1999; 50: 207-221.
- 5 Harris R, Lohr KN. Screening for prostate cancer: an update of the evidence for the US

- Preventive Services Task Force. Ann Intern Med 2002; 137: 917-929.
- 6 National Cancer Institute, US National Institutes of Health. Prostate cancer: screening and testing. Available at: http://www.nci.nih.gov/cancer\_information/testing (accessed Feb 2005).
- 7 Feightner JW. Screening for prostate cancer. In: The Canadian guide to clinical preventive health care. Canadian Task Force on Preventive Health Care. Available at: http://www.ctf-phc.org/Sections/section10ch067.htm (accessed Feb 2005).
- 8 Canadian Cancer Society. Prostate specific antigen (PSA) test for prostate cancer. 2005. Available at: http://www.ontario.cancer.ca/ccs/internet/standard/0,3182,3543\_10175\_275266\_langld-en,00.html (accessed March 2005).
- 9 UK National Health Service. Prostate cancer risk management. Available at: http://www.cancerscreening.nhs.uk/prostate/index.html (accessed Feb 2005).
- 10 Diefenbach PN, Ganz PA, Pawlow AJ, Guthrie D. Screening by the prostate-specific antigen test: what do the patients know? *J Cancer Educ* 1996; 11: 39-44.
- 11 Federman DG, Goyal S, Kamina A, et al. Informed consent for PSA screening: does it happen? Effect Clin Pract 1999; 2: 152-157.
- 12 Slevin TJ, Donnelly N, Clarkson JP, et al. Prostate cancer testing: behaviour, motivation and attitudes among Western Australian men. *Med J Aust* 1999; 171: 185-188.
- 13 Gattellari M, Young JM, Ward J. GP and patient predictors of PSA screening in Australian general practice. Fam Pract 2003; 10: 27-39.
- 14 Gattellari M, Ward JE. A community-based randomised controlled trial of three different educational resources for men about prostate cancer screening. Patient Educ Counsel 2005. In press.
- 15 Gattellari M, Ward JE. A community study using specified and unspecified scenarios to investigate men's views about PSA screening. Health Expectations 2004; 7: 274-289. Available

- at: http://www.blackwell-synergy.com/links/doi/10.1111/j.1369-7625.2004.00285.x/enhancedabs (accessed Mar 2005).
- 16 Lau RR. Origins of health locus of control beliefs. *J Pers Soc Psychol* 1982; 42: 322-334.
- 17 Hosmer DW, Lemeshow S. Applied logistic regression. Brisbane: John Wiley and Sons, 2001
- 18 SPSS for Windows. Release 12.0. User's guide. Chicago, Ill: SPSS Inc, 2003.
- 19 Ward JE, Hughes AM, Hirst GHL, Winchester L. Men's estimates of prostate cancer risk and self-reported rates of screening. Med J Aust 1997; 167: 250-253.
- 20 Ware J. SF36 health survey: manual and interpretation guide. Boston: The Health Institute, 1993.
- 21 Marshall GN, Collins BE, Crooks VC. A comparison of two multidimensional health locus of control instruments. *J Pers Assess* 1990; 54: 181-190.
- 22 Degner LF, Sloan JA, Venkatesh P. The control preferences scale. Can J Nurs Res 1997; 29: 21-43
- 23 Ransohoff DF, McNaughton Collins M, Fowler FJ. Why is prostate cancer screening so common when the evidence is so uncertain? A system without negative feedback. *Am J Med* 2002; 113: 663-667.
- 24 Guaganoli E, Ward P. Patient participation in decision-making. Soc Sci Med 1998; 3: 329-339.
- 25 Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: a review of published surveys. Behav Med 1998; 24: 81-88.
- 26 Davison BJ, Kirk P, Degner LF, Hassard TH. Information and patient participation in screening for prostate cancer. *Patient Educ Counsel* 1999; 37: 255-263.
- 27 Pauker SG, Kassierer JP. Contentious screening decisions: does choice matter? N Engl J Med 1997; 336: 1243-1244.

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