A Community Jury on PSA Screening: what do well-informed men want the government to do about prostate cancer screening?

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-004682
Article Type:	Research
Date Submitted by the Author:	13-Dec-2013
Complete List of Authors:	Rychetnik, Lucie; University of Sydney, School of Public Health Doust, Jenny; Bond University, Faculty of Health Sciences and Medicine Thomas, Rae; Bond University, Faculty of Health Sciences and Medicine Gardiner, Robert; University of Queensland, Centre for Clinical Research MacKenzie, Geraldine; Bond university, Faculty of Law Glasziou, Paul; Bond University, Faculty of Health Sciences and Medicine
Primary Subject Heading:	Public health
Secondary Subject Heading:	Qualitative research, Urology
Keywords:	PUBLIC HEALTH, QUALITATIVE RESEARCH, Prostate disease < UROLOGY

A Community Jury on PSA Screening: *what do well-informed men want the government to do about prostate cancer screening?*

Authors

Lucie Rychetnik [1]
Jenny Doust [2]
Rae Thomas [2]
Robert Gardiner [3]
Geraldine MacKenzie [4]
Paul Glasziou [2]

[1] School of Public Health, University of Sydney, NSW, Australia
[2] Centre for Research in Evidence-Based Practice (CREBP), Faculty of Health Sciences and Medicine, Bond University, Queensland, Australia
[3] Centre for Clinical Research, University of Queensland & Department of Urology, Royal Brisbane & Women's Hospital, Queensland, Australia
[4] Faculty of Law, Bond University, Queensland, Australia

Words: 3687

Abstract

Background

PSA screening is controversial. It may improve survival but also leads to harms, particularly the diagnosis and treatment of cancers that would not otherwise have become clinically apparent. Cancer screening policies and advice about programs should take account of public values and concerns.

Objectives

To determine the priorities, values and concerns of men aged 50-70 who were 'fully informed' about the benefits and harms of PSA screening. To empirically examine the value of a community jury process in eliciting public values on PSA screening.

Method

A community jury was convened to consider PSA screening benefits and harms, and whether government campaigns on PSA screening should be conducted. A qualitative analysis was conducted of the jury deliberations, which were audio recorded and transcribed. A survey determined the impact of the jury process on participants' individual testing decisions compared with a control group.

Results

The jury concluded governments should not invest in programs focused on PSA screening directed at the public because the PSA test did not offer sufficient reassurance or benefit and would raise unnecessary alarm. They recommended an alternative program to support GPs to provide patients with better quality and more consistent information about PSA screening.

After the jury, participants were less likely to get tested in the future compared to the controls, but around half said they would still consider doing so.

Conclusions

The jury's unanimous verdict about government programs was notable in the light of their divergent views on whether or not they would be screened themselves in the future. Community juries provide valuable insights into the priorities and concerns of men weighing up the benefits and harms of PSA screening. It will be important to assess the degree to which the findings of community juries on cancer screening are repeatable and generalisable to other settings.

Strengths of the study

- First published study of a community jury on the topic of PSA screening
- Provides in-depth analysis of informed men's priorities and values regarding PSA testing
- Establishes the value of the community jury as a deliberative method for engaging the public in debates about cancer screening to elicit their informed views on policy questions

Limitations of the study

- The broader generalisability of the views and conclusions of this jury has not yet been tested

A Community Jury on PSA Screening: *what do well-informed men want the government to do about prostate cancer screening?*

Introduction

The benefits and harms of PSA screening have been debated for several decades. Based on current evidence, it is possible that screening improves survival but it also leads to harms, particularly the diagnosis and treatment of cancers that would not otherwise have become clinically apparent.[1-3] It was hoped that two large randomised controlled mass population trials with survival as the primary end-point would provide a conclusive answer to the benefits and harms of screening, but the US PLCO trial found no benefit[4], possibly because a large proportion of men in the control arm were screened, and the European ERSPC trial showed a small reduction in prostate cancer mortality (1 life saved for every 1055 men screened) though no reduction in all-cause mortality.[5] Individual centres in the European trial with longer follow-up have shown conflicting results.[6 7]

This equivocal evidence has led to disparate recommendations about PSA screening. The National Screening Committee in the UK and the United States Preventative Task Force have advised against routine PSA testing for asymptomatic men.[8 9] The American Urological Association recommends routine PSA screening for men between the ages of 55 to 69.[10 11] The 2013 Prostate World Congress Melbourne Consensus Statement on Prostate Cancer Testing did not recommend routine screening, but recommended that well-informed healthy men aged 50 to 69 be counselled about the positive and negative aspects of PSA testing and the ability of PSA testing 'to reduce their risk of metastases and prostate cancer specific mortality'.[12]

Because of increasing recognition of the potential harms from screening, information about screening programs has shifted from emphasising screening uptake to ensuring potential participants are provided with adequate information to make an informed choice about whether or not to be screened.[13-15] This, however, requires understanding of complex issues, such as disease specific mortality, avoidance of metastatic disease, and latent cancers that are indolent in nature. The complexity is further compounded by the uncertainties regarding the estimates of screening outcomes. Moreover, the concept of potential harm from an early detection of cancer runs counter to messages men are likely to have previously heard regarding the benefits of early detection. Men with a family history of prostate cancer are particularly likely to have concerns about the benefits and harms from screening.

While offering evidence-based information is ethically imperative,[16] the complexities of PSA screening make this difficult to achieve within the context of the average clinical consultation and can be burdensome for both patients and clinicians.[17] Indeed some patients prefer to be advised what to do rather than considering detailed information about benefits and harms.[13 18] All recommendations on PSA testing emphasise the provision of information and shared decision making. We conducted a community jury process[19-21] to determine the priorities, values and concerns regarding PSA screening among men aged 50-70 who are ‘fully informed’ about the reasons for and against screening. The jury members were asked to deliberate evidence presented by experts on PSA screening and invited to formulate recommendations on potential government actions. A survey using a randomised control design was incorporated to also determine the impact of the jury process on participants’ knowledge and individual testing intentions.[22] The research project was approved by the Bond University Human Research Ethics Committee (R01570) and the protocol registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12612001079831).

Method

Recruitment and selection

The study participants were recruited through unpaid news articles, one paid advertisement in a local paper, two radio interviews and two presentations by the jury facilitator (RT) at Rotary Club community groups. Men were eligible to participate in the study if they were aged between 50 and 70, had no personal history of prostate cancer and were willing to attend an information session on Friday night and community jury sessions on Saturday and Sunday. Participants attending the information session were randomly allocated to either the jury (n=12) or a control group (n=15) by selecting a folded piece of paper from a container. Both were provided with two Facts Sheets about PSA screening.[23 24] The jury members were given additional summarised information to take home,[25-27] which was subsequently discussed as part of the jury process.

Questions for deliberation by the community jury

At the start of the community jury process, the participants were invited to consider two questions about potential government actions regarding PSA screening (Box 1), with the aim of finalising a group response to these questions at the end of the second day. The term government 'campaigns' was purposefully left open so that the jury could deliberate among themselves on what types of government action would or would not be appropriate. The second question asked about an invitation program, as this had been identified by men's health advocacy groups as a way of matching services offered to women.

Box 1: Questions posed to the jury about potential government action

- *Should government campaigns be provided (on PSA screening) and if so, what information should be included in those campaigns?*
- *What do you as a group of men think about a government organised invitation program for testing for prostate cancer?*

Community jury process

The community jury was conducted on the 6-7 April 2013 at Bond University, Queensland, Australia. The jury process was informed by a previous jury conducted in 2007 to examine women's views on mammography screening (protocol details provided by the authors via personal communication).[21] Day one focused on interrogating the expert evidence and day two on jury deliberations. On the first day of the PSA screening jury, the participants heard presentations from the following experts:

- Prof Jim Dickinson, University of Calgary (visiting scholar at Bond University at the time of the jury) who provided information about the prostate, prostate cancer and the methods used to diagnose and treat prostate cancer;
- Prof Robert (Frank) Gardiner, Professor of Urology, University of Queensland who presented information in support of selective screening of informed men and additional information on prostate cancer diagnosis, prognosis and treatment and
- Prof Paul Glasziou, Director, Research Centre for Evidence-based Practice, Bond University who presented on why he did not recommend screening.

The three expert sessions ran for approximately 40 minutes each, followed by questions from the jury. Each session was followed by a facilitated discussion to elicit the men's reflections and responses to the information presented. Any further questions arising from the facilitated discussions were noted and addressed on day two.

At the start of day two, the jury again reflected on the issues raised from day one and identify any final questions for the experts, which were answered via a speakerphone. The jury then deliberated without a facilitator present on the two questions about potential government action on PSA screening (Box 1). Finally the jury's conclusions and recommendations were recorded in a facilitated (LR) feedback session at the end of day two.

Data collection and analysis

The complete community jury process was audio-recorded and transcribed, including the experts' presentations and Q&A sessions, all participant deliberations (facilitated and un-facilitated) and the final compilation of the jury's response and recommendations about government action on PSA screening. The jury's recommendations were compiled onto a flipchart and each point was reviewed and corrected as required by the participants to ensure that the summary of the jury's verdict accurately represented the group's deliberations and conclusions. In addition, two researchers (LR and GM) observed the jury process to compile field notes and provide feedback to the primary facilitator on group process and participant interactions.

The qualitative findings were derived from an analysis of the full transcripts of the jury process. The text was analysed in a multi-stage process comprising detailed descriptive and conceptual coding followed by the preparation of analytical synthesis memos[28] on topics such as reasons for attending jury, important concerns about PSA testing, areas of consensus, areas of divergence and factors influencing personal decisions. Findings on the jury process were also derived from the transcripts, plus from the observational field notes and all researchers' reflections documented in post-jury memos and email exchanges. The validity, relevance and interpretation of the findings were reviewed in research team discussions.

The jury participants completed two written surveys; one before the jury (Friday evening) and one immediately after the jury (Sunday lunchtime). The control group also completed the first survey on Friday and the second one by mail. The first survey collected demographic data and included questions on previous PSA tests and intention of getting tested for prostate cancer in the future if they had no symptoms (scale 0 ‘not at all’ to 10 ‘absolutely’). It also included questions on sources of information about prostate cancer testing (checklist of options) and how informed the men perceived themselves to be about the benefits and harms of prostate cancer testing (scale 0 ‘not at all’ to 4 ‘very’). The second survey re-examined the men’s perceptions of how informed they considered themselves and their intention of having PSA screening in the future if they had no symptoms (analysed by linear regression and ANOVA).

Results

Description of study participants

Of the twelve men randomised to the community jury, one withdrew prior to Saturday and another was unwell and did not return on Sunday. Thus eleven men contributed to the discussions on day one, and ten men contributed to the final jury verdict. All eleven participants completed the pre- and -post jury questionnaire.

Demographics, PSA screening information sources and prior testing

The eleven jury participants were aged between 53 and 68 years (*mean* age = 61, *SD* = 5.04). Two participants had postgraduate qualifications (18%), three were university or technical college graduates (27%), four had some university or technical college experience (37%) and two had a high school education or less (18%). Prior to the jury, the men reported obtaining information from a variety of sources; GPs were the mostly common source of information (nominated by 8 men), followed by family and friends (nominated by 5), the internet and media (nominated by 4 men each) (Table 1). Ten men on the jury reported having previously had a blood test for prostate cancer. Of these, two had been tested once (18%), three had been tested twice (27%), the remaining five had each been tested on three, six, seven, eight and twelve occasions respectively (9% each).

Reasons for attending the jury

The men said they agreed to participate primarily to learn more about prostate cancer and PSA testing. Several noted they wanted to become more aware and informed about their health, that men generally were not very good at this, and they had decided to change their previous *'she'll be right'* attitude. *'I guess having reached the age of 60, realising that we're not all bulletproof...'*. Group discussions also identified the role of wives and doctors in encouraging a more preventive approach to health care. A majority of the men said the jury was an opportunity to learn about a topic on which they knew very little, heard conflicting messages and reports on what to do, or had *'snippets of information each way'* for and against testing. One man revealed he was undergoing regular monitoring of his PSA levels by an urologist after his first PSA test had been ordered by a GP without his knowledge when he had attended for a cholesterol check. One other man said he'd had prior urological symptoms but had been cleared of significant disease. Several participants reported the experiences of family and/or friends with prostate cancer that resulted in variable outcomes, including a number of premature deaths.

Core values related to PSA screening

The men discussed their own and others' experiences of PSA testing and compared the evidence presented at the jury to the information and advice they received from GPs and other doctors. In their reflections, they particularly noted how much of the evidence presented by the experts was unfamiliar and surprising for them; particularly the likelihood of a raised PSA result, the uncertainty about what raised PSA levels mean, and the high prevalence of prostate cancer with no clinical significance. The issues that men identified as important information but unexpected or surprising are summarised in Box 2.

Box 2 Information identified by the men as important but unexpected or surprising

- Prevalence of prostate cancer among older men (higher than expected)
- Progression of many prostate cancers (slower than expected)
- That prostate cancers may not have any clinical / health implications (unexpected)
- Scale of PSA test levels and thus what it means to have 'raised' PSA levels (scale greater than expected)
- Degree of uncertainty about correlations between PSA test results and risk of cancer (higher than expected, some unaware of benign hyperplasia or other causes of raised PSA levels)
- Treatment side-effects such as impotence and incontinence (higher than expected)
- Notion of PSA testing as a matter of individual choice, rather than indicated by evidence or the 'right' thing to do (unexpected)

Overall the group concluded that given the uncertain evidence and divergent opinions about screening, PSA testing was an individual choice for which they needed to take personal responsibility. For some in the group, the idea that it was acceptable to chose not to have a PSA test - even if offered or advised to have one - was a revelation as they had previously interpreted such a choice as avoidance or as being 'slack' about their health: *'I was of the opinion when I came in that every man over 60 should be screened as a matter of fact, but now I think I've changed my ideas, that it's a personal decision'* The group also concluded that the poor quality or lack of information provided by GPs did not currently support men in making informed decisions. Thus one of the most discussed concerns among the participants was the variable and inconsistent advice provided by their GPs; as well as the inadequate or conflicting information and messages about PSA testing from different doctors, media campaigns and other sources. The points reflecting general group consensus during deliberations are summarised in Box 3, while some differences in opinion are summarised in Box 4.

The men were generally concerned that GPs were not following the guidelines of their College[26], and that it depended on which GP they went to as to whether or not they were advised to have a PSA test, and what (if any) information was provided when a test was ordered. For example, the jury shared experiences of their doctors requesting PSA tests without informing the patient, for example at a time when another blood test was also requested. For one participant this experience resulted in significant personal regret and ongoing anxiety associated with continued monitoring *'If only I hadn't gone for the cholesterol test in 2007'*. Conversely, another man had been refused a PSA test even though he specifically asked for it and he changed his doctor as a result. The group also shared their own and others experiences of inconsistency in how different doctors interpret PSA test results (e.g. what degree of elevated PSA levels were perceived to be ok or expected); and how urologists varied in what they recommended once PSA levels were found to be raised (eg biopsy versus no biopsy, surgery or monitoring). The men also worried about the lack of standardisation of testing procedures e.g. whether or not men were advised to abstain from sexual activity before testing.

In addition to the core concerns about the available information and advice, the men were also concerned about the relationship between PSA testing and anxiety and depression. On deliberating the evidence many concluded that the apparent uncertainties in the science of PSA testing primarily mean that a raised PSA test result (or subsequent diagnosis of prostate cancer) was a source of significant anxiety without offering any valuable information on how to act: *'all they're going to say is yeah, you've got it. You're going to worry for the next 15* *years, is it bigger, is it smaller, am I going to get tested again?'*.

After deliberating the evidence most of the jury concluded that having a PSA test was a genuinely difficult and personal choice. As a result, several of the men expressed concerns about the active promotion of PSA testing by some doctors and through public campaigns and charities such as 'Movember'.[29] This was considered by some to be deceptive in the light of current uncertainty about what PSA results mean, the lack of available technologies to differentiate aggressive versus indolent cancers, and the lack of satisfactory/safe treatment options for prostate cancer. The jury's discussions focused on the importance of not harming men through unnecessary investigations and treatments, including those for whom the cancer will never progress, or for whom other conditions would kill them first. Several in the group agreed that for many of their peers other emerging health problems, including cardiovascular disease, diabetes, or mental health were more important concerns than prostate cancer.

Box 3: Points of general consensus

In general the men on the jury agreed on the following issues and points:

- Need for better and more standardised information; particularly more about the limitations, pros and cons of PSA testing. The group particularly liked a figure based on available trial data that reported the number of men harmed (side effects of treatment and associated psychological effects) and the 1 potential life saved per 1000 men screened.
- Need for GPs to advise men of why PSA testing is not recommended by their guidelines
- Importance of men taking responsibility and being able to make their own informed personal decisions about testing
- Need for GPs to provide information about what it means to have a raised PSA test: *'if she'd talked to me just briefly about these things in terms of the imprecise nature of the whole screening process, I would have been a lot better off and felt a lot less stressed on leaving that day.'*
- Valuing the availability of the test for those who want it
- Valuing the time to ask questions and discuss issues with experts
- Obtaining information from an independent source, with no financial or other vested interests
- Not promoting PSA testing to the general population given the current uncertain status of the evidence and likelihood of findings of latent cancers if you look for them
- Avoiding unnecessary anxiety among their family, friends and the community associated with promoting PSA testing when considering the uncertainty of the PSA test and not knowing how to interpret the results
- Directing funds from screening towards generating better diagnostic tests, predictors to distinguish aggressive vs indolent cancers and safer treatment options
- Importance of not wasting government funds on doing wasteful testing, importance of considering costs and benefits of government funded programs, not focusing on something if it isn't sufficiently important as a health concern or risk *'In most people it isn't an issue, why make it an issue'*
- Important to prioritise those things that are more likely to impact on men's health
- Perception that government sponsored information sent directly to public is often thrown out or ignored (gave example of colorectal cancer screening material)

Box 4: Some differences of opinion

The men on the jury expressed some differences of opinion on the following points:

- Personal decisions on whether or not it is better to have the test
  '..is there a test for lung cancer, heart disease, colon cancer, dementia, diabetes? I'd be getting tested for all those long before I'd get a bloody prostate test'

- The importance of impotence and incontinence against the risk of death
  P1 'I would have thought longevity at 70 was more important than sexual activity.'
  P2 'Oh it depends'
  P3 'Probably a lot of men..'
  P2 'Horses for courses, I think'
  P1 'I'm just saying, who would die over sex?'

- Whether or not (degree to which) men in general will want all of the information provided to the community jury – but group agreed the information should be available for those who do want it

- Whether or not they want doctors to advise / tell them what to do, or whether it is up to each man to make their own decision

- Whether or not it had been a good idea for them to ask the expert presenters what their personal decisions were about PSA testing. Most said they wanted to know, one man said the responses swayed his own view too much and he would have preferred not to know (The group asked the presenters whether or not they had had a PSA test: one had, two hadn't)

Community jury verdict on community-level questions

The jury's responses to the community-level questions (Box 1) on potential government action on PSA screening for prostate cancer were as follows (final day, n = 10):

- Recommended against any government campaigns aimed at the public on the topic of PSA screening. This included a recommendation against any organised invitation program for prostate cancer screening. (unanimous)

- Proposed instead a campaign targeting general practitioners (GPs) to assist GPs to provide better quality and more consistent information to their patients about PSA testing for prostate cancer. The men particularly wanted GPs to provide to patients information on: the unreliable nature of the PSA test, prevalence of raised PSA levels in older men, prevalence of prostate cancer relative to risk of death, screening outcomes (rates/1000 men screened), treatment side-effects (rates). (unanimous)

- Proposed that facts about PSA screening for prostate cancer, including that it is not currently recommended in Australian GP practice guidelines and an explanation of why, could be provided directly to the public if it was included as part of a broader 'men's health' information program or website. The latter was preferred to identifying PSA screening as a targeted priority issue. (unanimous)

Jury's rationale for final verdict

The jury's primary concern was that any public campaign focused on PSA testing for prostate cancer had potential to cause anxiety and alarm among the majority of men who did not need to be concerned about prostate cancer. Other reasons given by the jury for why they believed a government campaign on PSA screening was not warranted were nominated as follows:

- Contradictory nature of the current status of the science
- Unreliable nature of the PSA test
- Low incidence of mortality from prostate cancer
- High cost of such a campaign
- Funds required are more likely to be better used on research into the diagnosis and treatment of prostate cancer

‘*We don’t want the government to invite us or our mates to come along and get tested. We don’t want that to happen because we don’t want our mates to worry. We don’t want people to make a fuss, we don’t want our government to waste our money.’*

Individual-level PSA testing decisions

After the jury the men considered themselves better informed about the benefits and harms of prostate cancer testing compared with prior to the jury (F = 14.34, p = .004) (Table 2). This improvement was significantly greater than in the control group (F = 7.3, p=.01). Following the jury, the men also decreased their intention to be screened for prostate cancer in future compared with their intentions prior to the jury (F = 8.83, p = .014) (Table 2). The jury also scored 4.3 points lower on the post-jury intention to test scale than the controls (p=0.001) (Table 3). At the end of the jury, five men reported they were ‘not at all’ likely to get tested in the future if they had no symptoms, whereas six would consider it – and of these, four were more likely than not to do so (i.e. scored $\geq$5 on scale 0 to 10) (Table 4).

Discussion

Government policies must take account of public values and concerns. Deliberative methods such as community juries are well suited to support evidence-informed public engagement on screening policies and programs.[19] In this study, a group of men aged between 50 and 70, after deliberating on the benefits and harms of PSA screening, concluded that governments should not invest in any organised programs focused on PSA screening that were directed at the public. They determined that the PSA test did not offer sufficient reassurance or benefit to warrant a public campaign, and that such an approach would raise unnecessary alarm about prostate cancer. The jury did however want men to continue to have access to the test and to be able to make an informed choice about whether or not to be screened. They recommended an alternative government program aimed at supporting GPs to provide patients with better quality and more consistent information about the benefits and harms of PSA screening.

The jury's verdict on public campaigns was not anticipated by the research team; rather we expected that if anything, the jury may identify a need for a public education campaign on PSA screening. The jury overwhelmingly reported being previously unaware of the relative benefits and harms of screening, and their preference for obtaining such information from their doctor. The option of a government program targeting GPs was nominated by the jury themselves, reflecting their primary concern about the lack of information provided by their doctors and their shared experiences of inconsistent PSA screening advice. The findings indicate the facilitation process had been open and non-directive.

The jury's unanimous verdict about government programs was notable in the light of the men's divergent views on whether or not they would get tested again in future themselves if they had no symptoms. The findings support other literature indicating community juries delineate and rise above individual decisions to consider higher order questions about the common good.[30] This study provides valuable insights into the concerns and priorities with regard to PSA testing among men aged 50-70; both as individuals and as citizens invited to weigh community benefits and harms. It will be important however to repeat the process with other juries to assess the repeatability and generalisability of the findings to other parts of Australia. Similarly, it will be relevant to assess the potential impact of varying aspects of the community jury process, such as the method of recruiting participants or of presenting evidence. It will also be valuable to compare the effectiveness of eliciting public values about cancer screening using other deliberative methods.[31]

The recent Australian NHMRC draft *Information for Health Practitioners: Prostate Specific Antigen (PSA) Testing for Prostate Cancer in Asymptomatic Men*[32] provides guidance on communicating the evidence on the benefits and harms of PSA screening to asymptomatic men. It will be imperative to identify effective mechanisms to facilitate implementation of this guidance within Australian general practice. It will be also important to better align and even regulate the messages about PSA testing that are promoted in media campaigns by prostate cancer charities and other non-government organisations and special interest groups so that more consistent information and advice is presented.

Table 1: Reported sources of information on testing for prostate cancer prior to jury

	N = 11	%
General Practitioner	8	73
Family and friends	5	46
Internet	4	36
The media	4	36
Other (urologist/surgeon)	2	18
Other (hospital seminar)	1	9
Never looked for information	2	18

NB: Men could endorse more than 1 category

Table 2: Reported changes compare pre-post jury measures: perception of how well informed and how likely to test for prostate cancer

Comparison of Continuous Variables at Pre- and Post-assessment (N = 11)

	Pre-assessment		Post-assessment			
	Mean	*SD*	*Mean*	*SD*	*F*	*p*
Informed about harms and benefits	2.0	1.2	3.6	0.5	14.34	0.004
Likely to test for Prostate Cancer	7.3	3.5	3.5	4.1	8.83	0.014

Table 3: Future intention to test for prostate cancer comparing jury to controls

Predicting Future Intention to Test for Prostate Cancer *

	B	*SE B*	CI Lower	CI Upper	*p*
Constant	-0.11	1.51	-3.25	3.03	0.944
Pre-assessment intention to test score	0.72	0.16	0.38	1.06	0.000
How many times tested previously	0.66	0.19	0.26	1.06	0.003
Group membership (jury/control)	-4.31	1.09	-6.58	-2.04	0.001

Note. N=25. CI= confidence interval.

* Because it was anticipated men who had been tested for prostate cancer previously would be more likely to continue with this course of action, group differences in intention to be tested for prostate cancer in the future were examined using linear regression, adjusting for baseline future intention to test, the number of times a man had a PSA test at baseline, and his group membership.

Table 4: Intention to be screened in future after jury process

Value: how likely to be tested if no symptoms (0 = 'not at all'; 5 = 'maybe'; 10 = 'absolutely')	Frequency	%
0	5	46
4	2	18
5	1	9
8	1	9
10	2	18
Total	11	100

Acknowledgements

This project was supported by a Screening and Test Evaluation Program (STEP) grant (#633033) from the National Health and Medical Research Council (NHMRC), a NHMRC Project Grant (#1023791), and the Bond University Vice Chancellor's Research Grant Scheme.

Author contributions

LR led the preparation and subsequent revisions of the manuscript, contributed to the study design, and led the analysis and interpretation of the qualitative data. JD and PG led the conception and design of the study, contributed to the interpretation of the data and made substantial revisions to the manuscript. RT contributed to the study design, led the analysis and interpretation of the quantitative data, and made substantial revisions to the manuscript. RG and GM contributed to the study design and interpretation of the data, and made significant revisions to the manuscript.

Data Sharing Statement

In addition to the qualitative analysis reported in this paper, a survey using a randomised control design was incorporated to determine the impact of the jury process on participants' knowledge and individual testing intentions. This paper includes the pre-jury and immediate post-jury findings on the men's self reported knowledge of PSA testing and future intentions to screen.

Additional quantitative findings from this survey and the results of a 3 month follow-up measuring knowledge of PSA testing and intention to screen in future have been reported elsewhere (under review) and cited as reference 22.

Competing Interests

None

References

1. Chou R, Croswell JM, Dana T, Bougatsos C, Blazina I, Fu R, et al. Screening for Prostate Cancer: A Review of the Evidence for the U.S. Preventive Services Task Force. *Ann. Intern. Med.* 2011;155 (11):762-71.
2. Djulbegovic M, Beyth RJ, Neuberger MM, Stoffs TL, Vieweg J, Djulbegovic B, et al. Screening for prostate cancer: systematic review and meta-analysis of randomised controlled trials. *Br. Med. J.* 2010;341.
3. Ilic D, Neuberger MM, Djulbegovic M, Dahm P. Screening for prostate cancer. *Cochrane Database Syst. Rev.* 2013(1).
4. Andriole GL, Crawford ED, Grubb RL, 3rd, Buys SS, Chia D, Church TR, et al. Prostate cancer screening in the randomized Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial: mortality results after 13 years of follow-up. *J. Natl. Cancer Inst.* 2012;104(2):125-32.
5. Schröder FH, Hugosson J, Roobol MJ, Tammela TLJ, Ciatto S, Nelen V, et al. Prostate-Cancer Mortality at 11 Years of Follow-up. *N. Engl. J. Med.* 2012;366(11):981-90.
6. Hugosson J, Carlsson S, Aus G, Bergdahl S, Khatami A, Lodding P, et al. Mortality results from the Göteborg randomised population-based prostate-cancer screening trial. *The Lancet Oncology* 2010;11(8):725-32.
7. Sandblom G, Varenhorst E, Rosell J, Löfman O, Carlsson P. Randomised prostate cancer screening trial: 20 year follow-up. *BMJ* 2011;342.
8. Mackie A, UK National Screening Committee. Screening for Prostate Cancer Review against programme appraisal criteria for the UK National Screening Committee (UK NSC). London: National Health Service, June 2010.
9. Moyer VA. Screening for Prostate Cancer: U.S. Preventive Services Task Force Recommendation Statement. *Ann. Intern. Med.* 2012;157(2):120-34.
10. American Urological Association. Early Detection of Prostate Cancer: AUA Guideline, 2013.
11. Mitka M. Group now advises against routine psa screening. *JAMA* 2013;309(22):2316-16.
12. The Melbourne Consensus Statement on Prostate Cancer Testing. . A consensus view on the early detection of prostate cancer, led by experts at the Prostate Cancer World Congress, Melbourne, 7-10th August 2013. http://www.prostatecancerresearch.org.au/new-apcr/wp-content/uploads/The-Melbourne-Consensus-Statement-on-PSA-Testing.pdf.
13. Entwistle VA, Carter SM, Trevena L, Flitcroft K, Irwig L, McCaffery K, et al. Communicating about screening. *Br. Med. J.* 2008;337(7673):3.
14. Irwig L, Glasziou P. Informed consent for screening by community sampling. *Eff. Clin. Pract.* 2000;3(1):47-50.
15. Stefanek ME. Uninformed Compliance or Informed Choice? A Needed Shift in Our Approach to Cancer Screening. *J. Natl. Cancer Inst.* 2011;103(24):1821-26.
16. Shaw D, Elger B. Evidence-based persuasion: an ethical imperative. *JAMA* 2013;309(16):1689-90.
17. Woolf SH, Krist A. The liability of giving patients a choice: shared decision making and prostate cancer. *Am. Fam. Physician* 2005;71(10):1871-2.
18. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making - A national study of public preferences. *J. Gen. Intern. Med.* 2005;20(6):531-35.
19. Rychetnik L, Carter SM, Abelson J, Thornton H, Barratt A, Entwistle VA, et al. Enhancing Citizen Engagement in Cancer Screening Through Deliberative

Democracy. *J. Natl. Cancer Inst.* 2013;105(6):380-86.

20. Hawkes N. Women “jurors” are asked how to present risk-benefit ratio of breast cancer screening. *BMJ* 2012;345.
21. Paul C, Nicholls R, Priest P, McGee R. Making policy decisions about population screening for breast cancer: The role of citizens' deliberation. *Health Policy* 2008;85(3):314-20.
22. Thomas R, Glasziou P, Rychetnik L, Mackenzie G, Gardiner F, Doust J. What is the Immediate and Short-term Impact of a Community Jury on Men’s Attitudes to Prostate Cancer Screening? *Under review* 2013.
23. Andrology Australia. Factsheet: PSA Testing. https://www.andrologyaustralia.org/wp-content/uploads/Factsheet_PSA-Test.pdf: Monash Institute of Medical Research, Victoria, Australia May 2013.
24. Cancer Council Australia. Early Detection Factsheets: Prostate Cancer. http://www.cancer.org.au/about-cancer/early-detection/early-detection-factsheets/prostate-cancer.html, February 2013.
25. Ilic D, Neuberger MM, Djulbegovic M, Dahm P. Screening for prostate cancer (Review - Plain Language Summary). *Cochrane Database Syst. Rev.* 2013(1).
26. Royal Australian College of General Practitioners. Guidelines for preventive activities in general practice (The Red Book) *Chapter 9.8 (Prostate Cancer)*. 8th ed. South Melbourne, Victoria: The Royal Australian College of General Practitioners, 2012.
27. Urological Society of Australia and New Zealand. PSATesting Policy (Executive Summary). http://www.usanz.org.au/uploads/29168/ufiles/USANZ_2009_PSA_Testing_Policy_Final1.pdf, 2009.
28. Charmaz K. *Constructing grounded theory : a practical guide through qualitative analysis*. London: SAGE Publications, 2006.
29. Movember Australia. About Movember http://au.movember.com/about/ (accessed 30 July 2013).
30. Elwood P, Longley M. My health: Whose responsibility? A jury decides. *J. Epidemiol. Community Health* 2010;64(9):761-64.
31. Agency for Healthcare Research and Quality. The AHRQ Community Forum Deliberative Methods Demonstration *Effective Health Care Program*. http://www.effectivehealthcare.ahrq.gov/ehc/assets/File/Demonstration-Methods-Deliberative-130213.pdf, 2013.
32. NHMRC. Public consultation on the draft Prostate Specific Antigen (PSA) Testing for Prostate Cancer in Asymptomatic Men: Information for Health Practitioners http://consultations.nhmrc.gov.au/public_consultations/prostate_cancer (accessed 31 July 2013), 2013.

BMJ Open

A Community Jury on PSA Screening: what do well-informed men want the government to do about prostate cancer screening- a qualitative analysis

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-004682.R1
Article Type:	Research
Date Submitted by the Author:	23-Mar-2014
Complete List of Authors:	Rychetnik, Lucie; University of Notre Dame Australia, School of Medicine Sydney Doust, Jenny; Bond University, Faculty of Health Sciences and Medicine Thomas, Rae; Bond University, Faculty of Health Sciences and Medicine Gardiner, Robert; University of Queensland, Centre for Clinical Research MacKenzie, Geraldine; Bond university, Faculty of Law Glasziou, Paul; Bond University, Faculty of Health Sciences and Medicine
Primary Subject Heading:	Public health
Secondary Subject Heading:	Qualitative research, Urology
Keywords:	PUBLIC HEALTH, QUALITATIVE RESEARCH, Prostate disease < UROLOGY

A Community Jury on PSA Screening: what do well-informed men want the government to do about prostate cancer screening- a qualitative analysis

Authors

Lucie Rychetnik [1]
Jenny Doust [2]
Rae Thomas [2]
Robert Gardiner [3]
Geraldine MacKenzie [4]
Paul Glasziou [2]

[1] School of Medicine Sydney, University of Notre Dame Australia, and School of Public Health, University of Sydney, NSW, Australia
[2] Centre for Research in Evidence-Based Practice (CREBP), Faculty of Health Sciences and Medicine, Bond University, Queensland, Australia
[3] Centre for Clinical Research, University of Queensland & Department of Urology, Royal Brisbane & Women's Hospital, Queensland, Australia
[4] Faculty of Law, Bond University, Queensland, Australia

Words: 3687

Abstract

Objectives Cancer screening policies and programs should take account of public values and concerns. This study sought to determine the priorities, values and concerns of men who were 'fully informed' about the benefits and harms of PSA screening; and empirically examine the value of a community jury in eliciting public values on PSA screening.

Setting Community jury was convened on the Gold Coast, Queensland (Australia) to consider PSA screening benefits and harms, and whether government campaigns on PSA screening should be conducted.

Participants 27 men (volunteers) aged 50-70 with no personal history of prostate cancer and willing to attend jury 6-7 April 2013: 12 were randomly allocated to jury (11 attended).

Outcome measures A qualitative analysis was conducted of the jury deliberations (audio recorded and transcribed) to elicit the jury's views and recommendations. A survey determined the impact of the jury process on participants' individual testing decisions compared with control group.

Results The jury concluded governments should not invest in programs focused on PSA screening directed at the public because the PSA test did not offer sufficient reassurance or benefit and could raise unnecessary alarm. It recommended an alternative program to support GPs to provide patients with better quality and more consistent information about PSA screening. After the jury, participants were less likely to be tested in the future compared with the controls, but around half said they would still consider doing so.

Conclusions The jury's unanimous verdict about government programs was notable in the

light of their divergent views on whether or not they would be screened themselves in the future. Community juries provide valuable insights into the priorities and concerns of men weighing up the benefits and harms of PSA screening. It will be important to assess the degree to which the findings are generalisable to other settings.

Strengths of the study

- First published study of a community jury on the topic of PSA screening
- Provides in-depth analysis of informed men's priorities and values regarding PSA testing
- Establishes the value of the community jury as a deliberative method for engaging the public in debates about cancer screening to elicit their informed views on policy questions

Limitations of the study

- The broader generalisability of the views and conclusions of this jury has not yet been tested

A Community Jury on PSA Screening: *what do well-informed men want the government to do about prostate cancer screening?*

Introduction

The benefits and harms of PSA screening have been debated for several decades. Based on current evidence, it is possible that screening improves survival but also leads to harms, particularly the diagnosis and treatment of cancers that would not otherwise become clinically apparent.[1-3] It was hoped that two large randomised controlled mass population trials with survival as the primary end-point would provide a conclusive answer to the benefits and harms of screening, but the US PLCO trial found no benefit[4], possibly because a large proportion of men in the control arm were screened, and the European ERSPC trial showed a small reduction in prostate cancer mortality (1 life saved for every 1055 men screened) though no reduction in all-cause mortality.[5]

This equivocal evidence has led to disparate recommendations about PSA screening. The National Screening Committee in the UK and the United States Preventative Task Force have advised against routine PSA testing for asymptomatic men.[6 7] The American Urological Association recommends routine PSA screening for men between the ages of 55 to 69.[8 9] The 2013 Prostate World Congress Melbourne Consensus Statement on Prostate Cancer Testing did not recommend routine screening, but recommended that well-informed healthy men aged 50 to 69 be counselled about the positive and negative aspects of PSA testing and the ability of PSA testing 'to reduce their risk of metastases and prostate cancer specific mortality'.[10]

Because of increasing recognition of the potential harms from screening, information about screening programs has shifted from emphasising screening uptake to ensuring potential participants are provided with adequate information to make an informed choice about whether or not to be screened.[11-13] This, however, requires understanding of complex issues, such as disease specific mortality, avoidance of metastatic disease, and latent cancers that are indolent in nature. The complexity is further compounded by the uncertainties regarding the estimates of screening outcomes. Moreover, the concept of potential harm from an early detection of cancer runs counter to messages men may have previously heard regarding the benefits of early detection. Men with a family history of prostate cancer are particularly likely to have concerns about the benefits and harms from screening.

While offering evidence-based information is ethically imperative,[14] the complexities of PSA screening make this difficult to achieve within the context of the average clinical consultation and can be burdensome for both patients and clinicians.[15] Indeed some patients prefer to be advised what to do rather than considering detailed information about benefits and harms.[11 16] All recommendations on PSA testing emphasise the provision of information and shared decision making. We conducted a community jury process[17-19] to determine the priorities, values and concerns regarding PSA screening among men aged 50-70 who we ‘fully informed’ about the reasons for and against screening. The jury members were asked to deliberate evidence presented by experts on PSA screening and invited to formulate recommendations on potential government actions. A survey using a randomised control design was incorporated to also determine the impact of the jury process on participants’ knowledge and individual testing intentions.[20] The research project was approved by the Bond University Human Research Ethics Committee (R01570) and the protocol registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12612001079831).

Method

Community juries provide an opportunity to examine what 'mini-publics' would conclude if well-informed and supported to deliberate on a given topic.[21] While various kinds of deliberative methods exist, we adopted the community jury method as this has been successfully applied in other settings to consider questions on breast cancer screening.[18 19]

Recruitment and selection

The study participants were recruited through unpaid news articles, one paid advertisement in a local paper, two radio interviews and two presentations by the jury facilitator (RT) at Rotary Club community groups. Men were eligible to participate in the study if they were aged between 50 and 70, had no personal history of prostate cancer and were willing to attend an information session on Friday night and community jury sessions on Saturday and Sunday. We sought to recruit twelve participants to the jury: thirty-one men were recruited, four withdrew prior to the Friday information night, and all of those who attended the information session chose to participate in the study randomisation. The twenty seven participants attending the information session were randomly allocated to either the jury (n=12) or a control group (n=15) by selecting a folded piece of paper from a container. Members of both groups were provided with two Facts Sheets about PSA screening.[22 23] The jury members were given additional summarised information to take home,[24-26] subsequently discussed as part of the jury process.

Questions for deliberation by the community jury

At the start of the community jury process, the participants were invited to consider two questions about potential government actions regarding PSA screening (Box 1), with the aim of finalising a group response to these questions at the end of the second day. The terms government 'campaigns' and 'organised invitation program' were purposefully left open so that the jury members could deliberate among themselves on what types of government action would or would not be appropriate. The second question about an invitation program was asked because this had been identified by men's health advocacy groups as a way of matching breast cancer screening services offered to women.

Box 1: Questions posed to the jury about potential government action

- *Should government campaigns be provided (on PSA screening) and if so, what information should be included in those campaigns?*
- *What do you as a group of men think about a government organised invitation program for testing for prostate cancer?*

Community jury process

The community jury was conducted on the 6-7 April 2013 at Bond University, Queensland, Australia. The jury process was informed by a previous jury conducted in 2007 to examine women's views on mammography screening (protocol details provided by the authors via personal communication).[19] Day one focused on interrogating the expert evidence and day two on jury deliberations. On the first day of the PSA screening jury, the participants heard presentations from the following experts:

- Prof Jim Dickinson, University of Calgary (visiting scholar at Bond University at the time of the jury) who provided information about the prostate, prostate cancer and the methods used to diagnose and treat prostate cancer;
- Prof Robert (Frank) Gardiner, Professor of Urology, University of Queensland who presented information in support of selective screening of informed men and additional information on prostate cancer diagnosis, prognosis and treatment (author 4); and
- Prof Paul Glasziou, Director, Research Centre for Evidence-based Practice, Bond University who presented on why he did not recommend screening (author 6).

The three expert sessions ran for approximately 40 minutes each, followed by questions from the jury. Each session was followed by a facilitated discussion to elicit the men's reflections and responses to the information presented. Any further questions arising from the facilitated discussions were noted and addressed on day two. Expert witnesses RG and PG were introduced to the jury as members of the research team. Other than to present evidence and answer the jury's questions, the expert witnesses did not attend any of the jury deliberations.

At the start of day two, the jury again reflected on the issues raised from day one and identify any final questions for the experts, which were answered via a speakerphone. The jury then deliberated without a facilitator present on the two questions about potential government action on PSA screening (Box 1). Finally the jury's conclusions and recommendations were recorded in a facilitated (LR) feedback session at the end of day two.

Data collection and analysis

The complete community jury process was audio-recorded and transcribed, including the experts' presentations and Q&A sessions, all participant deliberations (facilitated and un-facilitated) and the final compilation of the jury's response and recommendations about government action on PSA screening. The jury's recommendations were compiled onto a flipchart and each point was reviewed and corrected as required by the participants to ensure that the summary of the jury's verdict accurately represented the group's deliberations and conclusions. In addition, two researchers (LR and GM) observed the jury process to compile field notes and provide feedback to the primary facilitator on group process and participant interactions.

The qualitative findings were derived from an analysis of the full transcripts of the jury process. The text was analysed in a multi-stage process comprising detailed descriptive and conceptual coding followed by the preparation of analytical synthesis memos[27] on topics such as reasons for attending jury, important concerns about PSA testing, areas of consensus, areas of divergence and factors influencing personal decisions. Findings on the jury process were also derived from the transcripts, plus from the observational field notes and all researchers' reflections documented in post-jury memos and email exchanges. The validity, relevance and interpretation of the findings were reviewed in research team discussions. The qualitative findings are summarised under 'reasons for attending the jury', 'core values related to PSA screening', and Boxes 2, 3 and 4. The jury's recommendations and rationale for their final verdict are summarised in the section 'community jury verdict on community-level questions'.

The jury participants completed two written surveys; one before the jury (Friday evening) and one immediately after the jury (Sunday lunchtime). The control group also completed the first survey on Friday and the second one by mail. The first survey collected demographic data and included questions on previous PSA tests and intention of getting tested for prostate cancer in the future if they had no symptoms (scale 0 'not at all' to 10 'absolutely'). It also included questions on sources of information about prostate cancer testing (checklist of options) and how informed the men perceived themselves to be about the benefits and harms of prostate cancer testing (scale 0 'not at all' to 4 'very'). The second survey re-examined the men's perceptions of how informed they considered themselves and their intention of having PSA screening in the future if they had no symptoms (analysed by linear regression[28] and repeated measures ANOVA).

Results

Description of study participants

Of the twelve men randomised to the community jury, one withdrew prior to Saturday and another was unwell and did not return on Sunday. Thus eleven men contributed to the discussions on day one, and ten men contributed to the final jury verdict. All eleven participants completed the pre- and -post jury questionnaire.

Demographics, PSA screening information sources and prior testing

The eleven jury participants were aged between 53 and 68 years (*mean* age = 61, *SD* = 5.04). Two participants had postgraduate qualifications (18%), three were university or technical college graduates (27%), four had some university or technical college experience (37%) and two had a high school education or less (18%). Prior to the jury, the men reported obtaining information from a variety of sources; GPs were the mostly common source of information (nominated by 8 men), followed by family and friends (nominated by 5), the internet and media (nominated by 4 men each) (Table 1). Ten men on the jury reported having previously had a blood test for prostate cancer. Of these, two had been tested once (18%), three had been tested twice (27%), the remaining five had each been tested on three, six, seven, eight and twelve occasions respectively (9% each).

Reasons for attending the jury

The men said they agreed to participate primarily to learn more about prostate cancer and PSA testing. Several noted they wanted to become more aware and informed about their health, that men generally were not very good at this, and they had decided to change their previous *'she'll be right'* attitude. '*I guess having reached the age of 60, realising that we're not all bulletproof...'*. Group discussions also identified the role of wives and doctors in encouraging a more preventive approach to health care. A majority of the men said the jury was an opportunity to learn about a topic on which they knew very little, heard conflicting messages and reports on what to do, or had *'snippets of information each way'* for and against testing. One man revealed he was undergoing regular monitoring of his PSA levels by an urologist after his first PSA test had been ordered by a GP without his knowledge when he had attended for a cholesterol check. One other man said he'd had prior urological symptoms but had been cleared of significant disease. Several participants reported the experiences of family and/or friends with prostate cancer that resulted in variable outcomes, including a number of premature deaths.

Core values related to PSA screening

The men discussed their own and others' experiences of PSA testing and compared the evidence presented at the jury to the information and advice they received from GPs and other doctors. In their reflections, they particularly noted how much of the evidence presented by the experts was unfamiliar and surprising for them; particularly the likelihood of a raised PSA result, the uncertainty about what raised PSA levels mean, and the high prevalence of prostate cancer with no clinical significance. The issues that men identified as important information but unexpected or surprising are summarised in Box 2.

Box 2 Information identified by the men as important but unexpected or surprising

- Prevalence of prostate cancer among older men (higher than expected)
- Progression of many prostate cancers (slower than expected)
- That prostate cancers may not have any clinical / health implications (unexpected)
- Scale of PSA test levels and thus what it means to have 'raised' PSA levels (scale greater than expected)
- Degree of uncertainty about correlations between PSA test results and risk of cancer (higher than expected, some unaware of benign hyperplasia or other causes of raised PSA levels)
- Treatment side-effects such as impotence and incontinence (higher than expected)
- Notion of PSA testing as a matter of individual choice, rather than indicated by evidence or the 'right' thing to do (unexpected)

Overall the group concluded that given the uncertain evidence and divergent opinions about screening, PSA testing was an individual choice for which they needed to take personal responsibility. For some in the group, the idea that it was acceptable to chose not to have a PSA test - even if offered or advised to have one - was a revelation as they had previously interpreted such a choice as avoidance or as being ‘slack’ about their health: *‘I was of the opinion when I came in that every man over 60 should be screened as a matter of fact, but now I think I’ve changed my ideas, that it’s a personal decision’* The group also concluded that the poor quality or lack of information provided by GPs did not currently support men in making informed decisions. Thus one of the most discussed concerns among the participants was the variable and inconsistent advice provided by their GPs; as well as the inadequate or conflicting information and messages about PSA testing from different doctors, media campaigns and other sources. The points reflecting general group consensus during deliberations are summarised in Box 3, while some differences in opinion are summarised in Box 4.

The men were generally concerned that GPs were not following the guidelines of their College[25], and that it depended on which GP they went to as to whether or not they were advised to have a PSA test, and what (if any) information was provided when a test was ordered. For example, the jury shared experiences of their doctors requesting PSA tests without informing the patient, for example at a time when another blood test was also requested. For one participant this experience resulted in significant personal regret and ongoing anxiety associated with continued monitoring *‘If only I hadn’t gone for the cholesterol test in 2007’*. Conversely, another man had been refused a PSA test even though he specifically asked for it and he changed his doctor as a result. The group also shared their own and others’ experiences of inconsistency in how different doctors interpret PSA test results (e.g. what degree of elevated PSA levels were perceived to be ok or expected); and how urologists varied in what they recommended once PSA levels were found to be raised (eg biopsy versus no biopsy, surgery or monitoring). The men also worried about the lack of standardisation of testing procedures e.g. whether or not men were advised to abstain from sexual activity before testing.

In addition to the core concerns about the available information and advice, the men were also concerned about the relationship between PSA testing and anxiety and depression. On deliberating the evidence many concluded that the apparent uncertainties in the science of PSA testing primarily mean that a raised PSA test result (or subsequent diagnosis of prostate cancer) was a source of significant anxiety without offering any valuable information on how to act: *'all they're going to say is yeah, you've got it. You're going to worry for the next 15 years, is it bigger, is it smaller, am I going to get tested again?'*.

After deliberating the evidence most of the jury concluded that having a PSA test was a genuinely difficult and personal choice. As a result, several of the men expressed concerns about the active promotion of PSA testing by some doctors and through public campaigns and charities such as 'Movember'.[29] This was considered by some to be deceptive in the light of current uncertainty about what PSA results mean, the lack of available technologies to differentiate aggressive versus indolent cancers, and the lack of satisfactory/safe treatment options for prostate cancer. The jury's discussions focused on the importance of not harming men through unnecessary investigations and treatments, including those for whom the cancer will never progress, or for whom other conditions would kill them first. Several in the group agreed that for many of their peers other emerging health problems, including cardiovascular disease, diabetes, or mental health were more important concerns than prostate cancer.

Box 3: Points of general consensus

In general the men on the jury agreed on the following issues and points:

- Need for better and more standardised information; particularly more about the limitations, pros and cons of PSA testing. The group particularly liked a figure based on available trial data that reported the number of men harmed (side effects of treatment and associated psychological effects) and the 1 potential life saved per 1000 men screened.
- Need for GPs to advise men of why PSA testing is not recommended by their guidelines
- Importance of men taking responsibility and being able to make their own informed personal decisions about testing
- Need for GPs to provide information about what it means to have a raised PSA test: *'if she'd talked to me just briefly about these things in terms of the imprecise nature of the whole screening process, I would have been a lot better off and felt a lot less stressed on leaving that day.'*
- Valuing the availability of the test for those who want it
- Valuing the time to ask questions and discuss issues with experts
- Obtaining information from an independent source, with no financial or other vested interests
- Not promoting PSA testing to the general population given the current uncertain status of the evidence and likelihood of findings of latent cancers if you look for them
- Avoiding unnecessary anxiety among their family, friends and the community associated with promoting PSA testing when considering the uncertainty of the PSA test and not knowing how to interpret the results
- Directing funds from screening towards generating better diagnostic tests, predictors to distinguish aggressive vs indolent cancers and safer treatment options
- Importance of not wasting government funds on doing wasteful testing, importance of considering costs and benefits of government funded programs, not focusing on something if it isn't sufficiently important as a health concern or risk *'In most people it isn't an issue, why make it an issue'*
- Important to prioritise those things that are more likely to impact on men's health
- Perception that government sponsored information sent directly to public is often thrown out or ignored (gave example of colorectal cancer screening material)

Box 4: Some differences of opinion

The men on the jury expressed some differences of opinion on the following points:

- Personal decisions on whether or not it is better to have the test
  '..is there a test for lung cancer, heart disease, colon cancer, dementia, diabetes? I'd be getting tested for all those long before I'd get a bloody prostate test'

- The importance of impotence and incontinence against the risk of death
  P1 'I would have thought longevity at 70 was more important than sexual activity.'
  P2 'Oh it depends'
  P3 'Probably a lot of men..'
  P2 'Horses for courses, I think'
  P1 'I'm just saying, who would die over sex?'

- Whether or not (degree to which) men in general will want all of the information provided to the community jury – but group agreed the information should be available for those who do want it

- Whether or not they want doctors to advise / tell them what to do, or whether it is up to each man to make their own decision

- Whether or not it had been a good idea for them to ask the expert presenters what their personal decisions were about PSA testing. Most said they wanted to know, one man said the responses swayed his own view too much and he would have preferred not to know (The group asked the presenters whether or not they had had a PSA test: one had, two hadn't)

Community jury verdict on community-level questions

The jury's responses to the community-level questions (Box 1) on potential government action on PSA screening for prostate cancer were as follows (final day, n = 10):

- Recommended against any government campaigns aimed at the public on the topic of PSA screening. This included a recommendation against any organised invitation program for prostate cancer screening. (unanimous)

- Proposed instead a campaign targeting general practitioners (GPs) to assist GPs to provide better quality and more consistent information to their patients about PSA testing for prostate cancer. The men particularly wanted GPs to provide to patients information on: the unreliable nature of the PSA test, prevalence of raised PSA levels in older men, prevalence of prostate cancer relative to risk of death, screening outcomes (rates/1000 men screened), treatment side-effects (rates). (unanimous)

- Proposed that facts about PSA screening for prostate cancer, including that it is not currently recommended in Australian GP practice guidelines and an explanation of why, could be provided directly to the public if it was included as part of a broader 'men's health' information program or website. The latter was preferred to identifying PSA screening as a targeted priority issue. (unanimous)

Jury's rationale for final verdict

The jury's primary concern was that any public campaign focused on PSA testing for prostate cancer had potential to cause anxiety and alarm among the majority of men who did not need to be concerned about prostate cancer. Other reasons given by the jury for why they believed a government campaign on PSA screening was not warranted were nominated as follows:

- Contradictory nature of the current status of the science

- Unreliable nature of the PSA test
- Low incidence of mortality from prostate cancer
- High cost of such a campaign
- Funds required are more likely to be better used on research into the diagnosis and treatment of prostate cancer

'*We don't want the government to invite us or our mates to come along and get tested. We don't want that to happen because we don't want our mates to worry. We don't want people to make a fuss, we don't want our government to waste our money.'*

Individual-level PSA testing decisions

After the jury the men considered themselves better informed about the benefits and harms of prostate cancer testing compared with prior to the jury ($F = 14.34$, $p = .004$) (Table 2). This improvement was significantly greater than in the control group (F = 7.3, p=.01). Following the jury, the men also decreased their intention to be screened for prostate cancer in future compared with their intentions prior to the jury ($F = 8.83$, $p = .014$) (Table 2). The jury also scored 4.3 points lower on the post-jury intention to test scale than the controls (p=0.001) (Table 3). At the end of the jury, five men reported they were 'not at all' likely to get tested in the future if they had no symptoms, whereas six would consider it – and of these, four were more likely than not to do so (i.e. scored $\geq$5 on scale 0 to 10) (Table 4).

Discussion

Government policies must take account of public values and concerns. Deliberative methods such as community juries are well suited to support evidence-informed public engagement on screening policies and programs.[17] In this study, a group of men aged between 50 and 70, after deliberating on the benefits and harms of PSA screening, concluded that governments should not invest in any organised programs focused on PSA screening that were directed at the public. They determined that the PSA test did not offer sufficient reassurance or benefit to warrant a public campaign, and that such an approach would raise unnecessary alarm about prostate cancer. The jury did however want men to continue to have access to the test and to be able to make an informed choice about whether or not to be screened. They recommended an alternative government program aimed at supporting GPs to provide patients with better quality and more consistent information about the benefits and harms of PSA screening.

The jury's verdict on public campaigns was not anticipated by the research team; rather we expected that if anything, the jury may identify a need for a public education campaign on PSA screening. The jury overwhelmingly reported being previously unaware of the relative benefits and harms of screening, and their preference for obtaining such information from their doctor. The option of a government program targeting GPs was nominated by the jury themselves, reflecting their primary concern about the lack of information provided by their doctors and their shared experiences of inconsistent PSA screening advice. The findings indicate the facilitation process had been open and non-directive.

Community juries are not intended to be representative of the wider population in the statistical sense; rather they offer valuable insights on the informed views and conclusions of a 'mini-public'.[21] This study provides valuable insights into the concerns and priorities with regard to PSA testing among men aged 50-70; both as individuals interested in PSA testing, and as citizens invited to weigh community benefits and harms. The jury's unanimous verdict about government programs was notable in the light of the men's divergent views on whether or not they would get tested again in future themselves if they had no symptoms. These findings support other literature indicating community juries delineate and rise above individual decisions to consider higher order questions about the common good.[30] While the men’s personal interest in PSA testing did not appear to hinder their willingness and ability to consider more broadly its relative value for their community, other kinds of public may have reached different conclusions. For example, a majority of the jury had been previously tested, and while the proportion of Australian men who have ever had a PSA test is unknown, approximately 20% of Australian men aged 45 to 74 years had screening PSA tests between 2010-2011.[31] In other countries such as the US the participation in PSA testing is relatively high; around 50% among men aged 60-74.[32] The impact of these differences on the deliberation and conclusions of a jury on PSA testing is currently unknown.

It will be important therefore to repeat the deliberative process with other juries, both to examine the views of different publics, and to assess the generalisability of the findings to other parts of Australia and other countries with different information and services. Similarly, it will be relevant to assess the potential impact on jury deliberations or conclusions of varying aspects of the community jury process, such as the method of recruiting participants or of presenting evidence. Different publics could include men of different ages; a mixed group of men aged 50-70 and partners or other family members (particularly as the men noted the influence of partners on their health behaviours); or a random sample from the electoral roll - although these methods are still affected by respondents’ level of interest. Other forms of evidence could include the personal stories of men affected by prostate cancer and/or the side-effects of treatment, or those without a diagnosis but whose PSA level is being monitored. Finally, it will also be valuable to compare the effectiveness of eliciting public values about cancer screening using other deliberative methods.[33]

The recent Australian NHMRC *Information for Health Practitioners: Prostate Specific Antigen (PSA) Testing for Prostate Cancer in Asymptomatic Men[34]* provides guidance on communicating the evidence on the benefits and harms of PSA screening to asymptomatic men. It will be imperative to identify effective mechanisms to facilitate implementation of this guidance within Australian general practice. It will be also important to better align and even regulate the messages about PSA testing that are promoted in media campaigns by prostate cancer charities and other non-government organisations and special interest groups so that more consistent information and advice is presented.

Table 1: Reported sources of information on testing for prostate cancer prior to jury

	N = 11	%
General Practitioner	8	73
Family and friends	5	46
Internet	4	36
The media	4	36
Other (urologist/surgeon)	2	18
Other (hospital seminar)	1	9
Never looked for information	2	18

NB: Men could endorse more than 1 category

Table 2: Reported changes compare pre-post jury measures: perception of how well informed and how likely to test for prostate cancer

Comparison of Continuous Variables at Pre- and Post-assessment (N = 11)

	Pre-assessment		Post-assessment			
	Mean	*SD*	*Mean*	*SD*	*F*	*p*
Informed about harms and benefits	2.0	1.2	3.6	0.5	14.34	0.004
Likely to test for Prostate Cancer	7.3	3.5	3.5	4.1	8.83	0.014

Table 3: Future intention to test for prostate cancer comparing jury to controls

Predicting Future Intention to Test for Prostate Cancer *

	B	*SE B*	CI Lower	CI Upper	*p*
Constant	-0.11	1.51	-3.25	3.03	0.944
Pre-assessment intention to test score	0.72	0.16	0.38	1.06	0.000
How many times tested previously	0.66	0.19	0.26	1.06	0.003
Group membership (jury/control)	-4.31	1.09	-6.58	-2.04	0.001

Note. N=25. CI= confidence interval.

* Because it was anticipated men who had been tested for prostate cancer previously would be more likely to continue with this course of action, group differences in intention to be tested for prostate cancer in the future were examined using linear regression, adjusting for baseline future intention to test, the number of times a man had a PSA test at baseline, and his group membership.

Table 4: Intention to be screened in future after jury process

Value: how likely to be tested if no symptoms (0 = 'not at all'; 5 = 'maybe'; 10 = 'absolutely')	Frequency	%
0	5	46
4	2	18
5	1	9
8	1	9
10	2	18
Total	11	100

Acknowledgements

This project was supported by a Screening and Test Evaluation Program (STEP) grant (#633033) from the National Health and Medical Research Council (NHMRC), a NHMRC Project Grant (#1023791), and the Bond University Vice Chancellor's Research Grant Scheme.

Funding

This work was supported by the Bond University Vice Chancellor's Research Grant Scheme

Author contributions

LR led the preparation and subsequent revisions of the manuscript, contributed to the study design, and led the analysis and interpretation of the qualitative data. JD and PG led the conception and design of the study, contributed to the interpretation of the data and made substantial revisions to the manuscript. RT contributed to the study design, led the analysis and interpretation of the quantitative data, and made substantial revisions to the manuscript. RG and GM contributed to the study design and interpretation of the data, and made significant revisions to the manuscript.

Competing Interests

None

Data Sharing Statement

In addition to the qualitative analysis reported in this paper, a survey using a randomised control design was incorporated to determine the impact of the jury process on participants' knowledge and individual testing intentions. This paper includes the pre-jury and immediate post-jury findings on the men's self reported knowledge of PSA testing and future intentions to screen.

Additional quantitative findings from this survey and the results of a 3 month follow-up measuring knowledge of PSA testing and intention to screen in future have been reported elsewhere (under review) and cited as reference 20.

References

1. Chou R, Croswell JM, Dana T, et al. Screening for Prostate Cancer: A Review of the Evidence for the U.S. Preventive Services Task Force. Annals of Internal Medicine 2011;**155** (11):762-71
2. Djulbegovic M, Beyth RJ, Neuberger MM, et al. Screening for prostate cancer: systematic review and meta-analysis of randomised controlled trials. British Medical Journal 2010;**341** doi: c4543
10.1136/bmj.c4543[published Online First: Epub Date]|.
3. Ilic D, Neuberger MM, Djulbegovic M, et al. Screening for prostate cancer. Cochrane Database of Systematic Reviews 2013(1) doi: Cd004720
10.1002/14651858.CD004720.pub3[published Online First: Epub Date]|.
4. Andriole GL, Crawford ED, Grubb RL, 3rd, et al. Prostate cancer screening in the randomized Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial: mortality results after 13 years of follow-up. J Natl Cancer Inst 2012;**104**(2):125-32
5. Schröder FH, Hugosson J, Roobol MJ, et al. Prostate-Cancer Mortality at 11 Years of Follow-up. New England Journal of Medicine 2012;**366**(11):981-90 doi: doi:10.1056/NEJMoa1113135[published Online First: Epub Date]|.
6. Mackie A, UK National Screening Committee. Screening for Prostate Cancer Review against programme appraisal criteria for the UK National Screening Committee (UK NSC). London: National Health Service, June 2010.
7. Moyer VA. Screening for Prostate Cancer: U.S. Preventive Services Task Force Recommendation Statement. Annals of Internal Medicine 2012;**157**(2):120-34 doi: 10.1059/0003-4819-157-2-201207170-00459[published Online First: Epub Date]|.
8. American Urological Association. Early Detection of Prostate Cancer: AUA Guideline. 2013; (7 June 2013). http://www.auanet.org/education/guidelines/prostate-cancer-detection.cfm.
9. Mitka M. Group now advises against routine psa screening. JAMA 2013;**309**(22):2316-16 doi: 10.1001/jama.2013.6922[published Online First: Epub Date]|.
10. The Melbourne Consensus Statement on Prostate Cancer Testing. . A consensus view on the early detection of prostate cancer, led by experts at the Prostate Cancer World Congress, Melbourne, 7-10th August 2013. http://www.prostatecancerresearch.org.au/new-apcr/wp-content/uploads/The-Melbourne-Consensus-Statement-on-PSA-Testing.pdf.
11. Entwistle VA, Carter SM, Trevena L, et al. Communicating about screening. British Medical Journal 2008;**337**(7673):3 doi: a1591[published Online First: Epub Date]|.
12. Irwig L, Glasziou P. Informed consent for screening by community sampling. Eff Clin Pract 2000;**3**(1):47-50
13. Stefanek ME. Uninformed Compliance or Informed Choice? A Needed Shift in Our Approach to Cancer Screening. Journal of the National Cancer Institute 2011;**103**(24):1821-26 doi: 10.1093/jnci/djr474[published Online First: Epub Date]|.
14. Shaw D, Elger B. Evidence-based persuasion: an ethical imperative. JAMA 2013;**309**(16):1689-90 doi: 10.1001/jama.2013.2179[published Online First: Epub Date]|.
15. Woolf SH, Krist A. The liability of giving patients a choice: shared decision making and prostate cancer. Am Fam Physician 2005;**71**(10):1871-2
16. Levinson W, Kao A, Kuby A, et al. Not all patients want to participate in decision making - A national study of public preferences. J Gen Intern Med 2005;**20**(6):531-35 doi: DOI 10.1111/j.1525-1497.2005.0088.x[published Online First: Epub Date]|.
17. Rychetnik L, Carter SM, Abelson J, et al. Enhancing Citizen Engagement in Cancer Screening Through Deliberative Democracy. Journal of the National Cancer Institute 2013;**105**(6):380-86

18. Hawkes N. Women “jurors” are asked how to present risk-benefit ratio of breast cancer screening. BMJ (Clinical Research Ed) 2012;**345** doi: 10.1136/bmj.e7886[published Online First: Epub Date]|.
19. Paul C, Nicholls R, Priest P, et al. Making policy decisions about population screening for breast cancer: The role of citizens' deliberation. Health Policy 2008;**85**(3):314-20 doi: DOI 10.1016/j.healthpol.2007.08.007[published Online First: Epub Date]|.
20. Thomas R, Glasziou P, Rychetnik L, et al. What is the Immediate and Long-term Impact of a Community Jury on Men’s Attitudes to Prostate Cancer Screening? Under review 2013
21. Goodin RE, Dryzek JS. Deliberative Impacts: the macro-political uptake of mini-publics. Politics Society 2006;**34**(2):219-44
22. Andrology Australia. Factsheet: PSA Testing. https://www.andrologyaustralia.org/wp-content/uploads/Factsheet_PSA-Test.pdf: Monash Institute of Medical Research, Victoria, Australia May 2013.
23. Cancer Council Australia. Early Detection Factsheets: Prostate Cancer. http://www.cancer.org.au/about-cancer/early-detection/early-detection-factsheets/prostate-cancer.html, February 2013.
24. Ilic D, Neuberger MM, Djulbegovic M, et al. Screening for prostate cancer (Review - Plain Language Summary). Cochrane Database Syst Rev 2013(1) doi: Cd004720 10.1002/14651858.CD004720.pub3[published Online First: Epub Date]|.
25. Royal Australian College of General Practitioners. Guidelines for preventive activities in general practice (The Red Book) Chapter 98 (Prostate Cancer). 8th ed. South Melbourne, Victoria: The Royal Australian College of General Practitioners, 2012.
26. Urological Society of Australia and New Zealand. PSATesting Policy (Executive Summary). http://www.usanz.org.au/uploads/29168/ufiles/USANZ_2009_PSA_Testing_Policy_Final1.pdf, 2009.
27. Charmaz K. *Constructing grounded theory : a practical guide through qualitative analysis*. London: SAGE Publications, 2006.
28. Vickers AJ, Altman DG. Analysing controlled trials with baseline and follow up measurements. BMJ 2001;**323**:1123-24
29. Movember Australia. About Movember http://aumovembercom/about/; (accessed 30 July 2013).
30. Elwood P, Longley M. My health: Whose responsibility? A jury decides. J Epidemiol Community Health 2010;**64**(9):761-64
31. Currow D, Armstrong B. PSA needs order MJA Insight 2011; (25 May 2012). http://www.mjainsight.com.au/view?post=david-currow-bruce-armstrong-psa-needs-order&post_id=6489&cat=comment.
32. Prasad SM, Drazer MW, Huo D, et al. 2008 US preventive services task force recommendations and prostate cancer screening rates. JAMA 2012;**307**(16):1692-94 doi: 10.1001/jama.2012.534[published Online First: Epub Date]|.
33. Agency for Healthcare Research and Quality. The AHRQ Community Forum Deliberative Methods Demonstration Effective Health Care Program. http://www.effectivehealthcare.ahrq.gov/ehc/assets/File/Demonstration-Methods-Deliberative-130213.pdf, 2013.
34. NHMRC. Public consultation on the draft Prostate Specific Antigen (PSA) Testing for Prostate Cancer in Asymptomatic Men: Information for Health Practitioners http://consultations.nhmrc.gov.au/public_consultations/prostate_cancer (accessed 31 July 2013), 2013.

A Community Jury on PSA Screening: *what do well-informed men want the government to do about prostate cancer screening?*

Authors

Lucie Rychetnik [1]
Jenny Doust [2]
Rae Thomas [2]
Robert Gardiner [3]
Geraldine MacKenzie [4]
Paul Glasziou [2]

[1] School of Medicine Sydney, University of Notre Dame Australia, and School of Public Health, University of Sydney, NSW, Australia
[2] Centre for Research in Evidence-Based Practice (CREBP), Faculty of Health Sciences and Medicine, Bond University, Queensland, Australia
[3] Centre for Clinical Research, University of Queensland & Department of Urology, Royal Brisbane & Women's Hospital, Queensland, Australia
[4] Faculty of Law, Bond University, Queensland, Australia

Words: 3687

Abstract

Objectives Cancer screening policies and programs should take account of public values and concerns. This study sought to determine the priorities, values and concerns of men who were 'fully informed' about the benefits and harms of PSA screening; and empirically examine the value of a community jury in eliciting public values on PSA screening.

Setting Community jury was convened on the Gold Coast, Queensland (Australia) to consider PSA screening benefits and harms, and whether government campaigns on PSA screening should be conducted.

Participants 27 men (volunteers) aged 50-70 with no personal history of prostate cancer and willing to attend jury 6-7 April 2013: 12 were randomly allocated to jury (11 attended).

Outcome measures A qualitative analysis was conducted of the jury deliberations (audio recorded and transcribed) to elicit the jury's views and recommendations. A survey determined the impact of the jury process on participants' individual testing decisions compared with control group.

Results The jury concluded governments should not invest in programs focused on PSA screening directed at the public because the PSA test did not offer sufficient reassurance or benefit and could raise unnecessary alarm. It recommended an alternative program to support GPs to provide patients with better quality and more consistent information about PSA screening. After the jury, participants were less likely to be tested in the future compared with the controls, but around half said they would still consider doing so.

Conclusions The jury's unanimous verdict about government programs was notable in the

light of their divergent views on whether or not they would be screened themselves in the future. Community juries provide valuable insights into the priorities and concerns of men weighing up the benefits and harms of PSA screening. It will be important to assess the degree to which the findings are generalisable to other settings.

Strengths of the study

- First published study of a community jury on the topic of PSA screening
- Provides in-depth analysis of informed men's priorities and values regarding PSA testing
- Establishes the value of the community jury as a deliberative method for engaging the public in debates about cancer screening to elicit their informed views on policy questions

Limitations of the study

- The broader generalisability of the views and conclusions of this jury has not yet been tested

A Community Jury on PSA Screening: *what do well-informed men want the government to do about prostate cancer screening?*

Introduction

The benefits and harms of PSA screening have been debated for several decades. Based on current evidence, it is possible that screening improves survival but ~~it~~ also leads to harms, particularly the diagnosis and treatment of cancers that would not otherwise ~~have~~ become clinically apparent.[1-3] It was hoped that two large randomised controlled mass population trials with survival as the primary end-point would provide a conclusive answer to the benefits and harms of screening, but the US PLCO trial found no benefit[4], possibly because a large proportion of men in the control arm were screened, and the European ERSPC trial showed a small reduction in prostate cancer mortality (1 life saved for every 1055 men screened) though no reduction in all-cause mortality.[5]

This equivocal evidence has led to disparate recommendations about PSA screening. The National Screening Committee in the UK and the United States Preventative Task Force have advised against routine PSA testing for asymptomatic men.[6 7] The American Urological Association recommends routine PSA screening for men between the ages of 55 to 69.[8 9] The 2013 Prostate World Congress Melbourne Consensus Statement on Prostate Cancer Testing did not recommend routine screening, but recommended that well-informed healthy men aged 50 to 69 be counselled about the positive and negative aspects of PSA testing and the ability of PSA testing 'to reduce their risk of metastases and prostate cancer specific mortality'.[10]

Because of increasing recognition of the potential harms from screening, information about screening programs has shifted from emphasising screening uptake to ensuring potential participants are provided with adequate information to make an informed choice about whether or not to be screened.[11-13] This, however, requires understanding of complex issues, such as disease specific mortality, avoidance of metastatic disease, and latent cancers that are indolent in nature. The complexity is further compounded by the uncertainties regarding the estimates of screening outcomes. Moreover, the concept of potential harm from an early detection of cancer runs counter to messages men may ~~are likely to~~ have previously heard regarding the benefits of early detection. Men with a family history of prostate cancer are particularly likely to have concerns about the benefits and harms from screening.

While offering evidence-based information is ethically imperative,[14] the complexities of PSA screening make this difficult to achieve within the context of the average clinical consultation and can be burdensome for both patients and clinicians.[15] Indeed some patients prefer to be advised what to do rather than considering detailed information about benefits and harms.[11 16] All recommendations on PSA testing emphasise the provision of information and shared decision making. We conducted a community jury process[17-19] to determine the priorities, values and concerns regarding PSA screening among men aged 50-70 who we~~are~~ ‘fully informed’ about the reasons for and against screening. The jury members were asked to deliberate evidence presented by experts on PSA screening and invited to formulate recommendations on potential government actions. A survey using a randomised control design was incorporated to also determine the impact of the jury process on participants’ knowledge and individual testing intentions.[20] The research project was approved by the Bond University Human Research Ethics Committee (R01570) and the protocol registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12612001079831).

Method

Community juries provide an opportunity to examine what ‘mini-publics’ would conclude if well-informed and supported to deliberate on a given topic.[21] While various kinds of deliberative methods exist, we adopted the community jury method as this has been successfully applied in other settings to consider questions on breast cancer screening.[18 19]

Recruitment and selection

The study participants were recruited through unpaid news articles, one paid advertisement in a local paper, two radio interviews and two presentations by the jury facilitator (RT) at Rotary Club community groups. Men were eligible to participate in the study if they were aged between 50 and 70, had no personal history of prostate cancer and were willing to attend an information session on Friday night and community jury sessions on Saturday and Sunday. We sought to recruit twelve participants to the jury: thirty-one men were recruited, four withdrew prior to the Friday information night, and all of those who attended the information session chose to participate in the study randomisation. The twenty seven participants attending the information session were randomly allocated to either the jury (n=12) or a control group (n=15) by selecting a folded piece of paper from a container. Members of both groups were provided with two Facts Sheets about PSA screening.[22 23] The jury members were given additional summarised information to take home,[24-26] ~~which was~~ subsequently discussed as part of the jury process.

Questions for deliberation by the community jury

At the start of the community jury process, the participants were invited to consider two questions about potential government actions regarding PSA screening (Box 1), with the aim of finalising a group response to these questions at the end of the second day. The terms government ‘campaigns’ and ‘organised invitation program’ were purposefully left open so that the jury members could deliberate among themselves on what types of government action would or would not be appropriate. The second question about an invitation program was asked because this had been identified by men's health advocacy groups as a way of matching breast cancer screening services offered to women.

Box 1: Questions posed to the jury about potential government action

- *Should government campaigns be provided (on PSA screening) and if so, what information should be included in those campaigns?*
- *What do you as a group of men think about a government organised invitation program for testing for prostate cancer?*

Community jury process

The community jury was conducted on the 6-7 April 2013 at Bond University, Queensland, Australia. The jury process was informed by a previous jury conducted in 2007 to examine women's views on mammography screening (protocol details provided by the authors via personal communication).[19] Day one focused on interrogating the expert evidence and day two on jury deliberations. On the first day of the PSA screening jury, the participants heard presentations from the following experts:

- Prof Jim Dickinson, University of Calgary (visiting scholar at Bond University at the time of the jury) who provided information about the prostate, prostate cancer and the methods used to diagnose and treat prostate cancer;
- Prof Robert (Frank) Gardiner, Professor of Urology, University of Queensland who presented information in support of selective screening of informed men and additional information on prostate cancer diagnosis, prognosis and treatment (author 4); and
- Prof Paul Glasziou, Director, Research Centre for Evidence-based Practice, Bond University who presented on why he did not recommend screening (author 6).

The three expert sessions ran for approximately 40 minutes each, followed by questions from the jury. Each session was followed by a facilitated discussion to elicit the men's reflections and responses to the information presented. Any further questions arising from the facilitated discussions were noted and addressed on day two. Expert witnesses RG and PG were introduced to the jury as members of the research team. Other than to present evidence and answer the jury's questions, the expert witnesses did not attend any of the jury deliberations.

At the start of day two, the jury again reflected on the issues raised from day one and identify any final questions for the experts, which were answered via a speakerphone. The jury then deliberated without a facilitator present on the two questions about potential government action on PSA screening (Box 1). Finally the jury's conclusions and recommendations were recorded in a facilitated (LR) feedback session at the end of day two.

Data collection and analysis

The complete community jury process was audio-recorded and transcribed, including the experts' presentations and Q&A sessions, all participant deliberations (facilitated and un-facilitated) and the final compilation of the jury's response and recommendations about government action on PSA screening. The jury's recommendations were compiled onto a flipchart and each point was reviewed and corrected as required by the participants to ensure that the summary of the jury's verdict accurately represented the group's deliberations and conclusions. In addition, two researchers (LR and GM) observed the jury process to compile field notes and provide feedback to the primary facilitator on group process and participant interactions.

The qualitative findings were derived from an analysis of the full transcripts of the jury process. The text was analysed in a multi-stage process comprising detailed descriptive and conceptual coding followed by the preparation of analytical synthesis memos[27] on topics such as reasons for attending jury, important concerns about PSA testing, areas of consensus, areas of divergence and factors influencing personal decisions. Findings on the jury process were also derived from the transcripts, plus from the observational field notes and all researchers' reflections documented in post-jury memos and email exchanges. The validity, relevance and interpretation of the findings were reviewed in research team discussions. The qualitative findings are summarised under 'reasons for attending the jury', 'core values related to PSA screening', and Boxes 2, 3 and 4. The jury's recommendations and rationale for their final verdict are summarised in the section 'community jury verdict on community-level questions'.

The jury participants completed two written surveys; one before the jury (Friday evening) and one immediately after the jury (Sunday lunchtime). The control group also completed the first survey on Friday and the second one by mail. The first survey collected demographic data and included questions on previous PSA tests and intention of getting tested for prostate cancer in the future if they had no symptoms (scale 0 'not at all' to 10 'absolutely'). It also included questions on sources of information about prostate cancer testing (checklist of options) and how informed the men perceived themselves to be about the benefits and harms of prostate cancer testing (scale 0 'not at all' to 4 'very'). The second survey re-examined the men's perceptions of how informed they considered themselves and their intention of having PSA screening in the future if they had no symptoms (analysed by linear regression[28] and repeated measures ANOVA).

Results

Description of study participants

Of the twelve men randomised to the community jury, one withdrew prior to Saturday and another was unwell and did not return on Sunday. Thus eleven men contributed to the discussions on day one, and ten men contributed to the final jury verdict. All eleven participants completed the pre- and -post jury questionnaire.

Demographics, PSA screening information sources and prior testing

The eleven jury participants were aged between 53 and 68 years (*mean* age = 61, *SD* = 5.04). Two participants had postgraduate qualifications (18%), three were university or technical college graduates (27%), four had some university or technical college experience (37%) and two had a high school education or less (18%). Prior to the jury, the men reported obtaining information from a variety of sources; GPs were the mostly common source of information (nominated by 8 men), followed by family and friends (nominated by 5), the internet and media (nominated by 4 men each) (Table 1). Ten men on the jury reported having previously had a blood test for prostate cancer. Of these, two had been tested once (18%), three had been tested twice (27%), the remaining five had each been tested on three, six, seven, eight and twelve occasions respectively (9% each).

Reasons for attending the jury

The men said they agreed to participate primarily to learn more about prostate cancer and PSA testing. Several noted they wanted to become more aware and informed about their health, that men generally were not very good at this, and they had decided to change their previous *'she'll be right'* attitude. '*I guess having reached the age of 60, realising that we're not all bulletproof...'*. Group discussions also identified the role of wives and doctors in encouraging a more preventive approach to health care. A majority of the men said the jury was an opportunity to learn about a topic on which they knew very little, heard conflicting messages and reports on what to do, or had *'snippets of information each way'* for and against testing. One man revealed he was undergoing regular monitoring of his PSA levels by an urologist after his first PSA test had been ordered by a GP without his knowledge when he had attended for a cholesterol check. One other man said he'd had prior urological symptoms but had been cleared of significant disease. Several participants reported the experiences of family and/or friends with prostate cancer that resulted in variable outcomes, including a number of premature deaths.

Core values related to PSA screening

The men discussed their own and others' experiences of PSA testing and compared the evidence presented at the jury to the information and advice they received from GPs and other doctors. In their reflections, they particularly noted how much of the evidence presented by the experts was unfamiliar and surprising for them; particularly the likelihood of a raised PSA result, the uncertainty about what raised PSA levels mean, and the high prevalence of prostate cancer with no clinical significance. The issues that men identified as important information but unexpected or surprising are summarised in Box 2.

Box 2 Information identified by the men as important but unexpected or surprising

- Prevalence of prostate cancer among older men (higher than expected)
- Progression of many prostate cancers (slower than expected)
- That prostate cancers may not have any clinical / health implications (unexpected)
- Scale of PSA test levels and thus what it means to have 'raised' PSA levels (scale greater than expected)
- Degree of uncertainty about correlations between PSA test results and risk of cancer (higher than expected, some unaware of benign hyperplasia or other causes of raised PSA levels)
- Treatment side-effects such as impotence and incontinence (higher than expected)
- Notion of PSA testing as a matter of individual choice, rather than indicated by evidence or the 'right' thing to do (unexpected)

Overall the group concluded that given the uncertain evidence and divergent opinions about screening, PSA testing was an individual choice for which they needed to take personal responsibility. For some in the group, the idea that it was acceptable to chose not to have a PSA test - even if offered or advised to have one - was a revelation as they had previously interpreted such a choice as avoidance or as being 'slack' about their health: *'I was of the opinion when I came in that every man over 60 should be screened as a matter of fact, but now I think I've changed my ideas, that it's a personal decision'* The group also concluded that the poor quality or lack of information provided by GPs did not currently support men in making informed decisions. Thus one of the most discussed concerns among the participants was the variable and inconsistent advice provided by their GPs; as well as the inadequate or conflicting information and messages about PSA testing from different doctors, media campaigns and other sources. The points reflecting general group consensus during deliberations are summarised in Box 3, while some differences in opinion are summarised in Box 4.

The men were generally concerned that GPs were not following the guidelines of their College[25], and that it depended on which GP they went to as to whether or not they were advised to have a PSA test, and what (if any) information was provided when a test was ordered. For example, the jury shared experiences of their doctors requesting PSA tests without informing the patient, for example at a time when another blood test was also requested. For one participant this experience resulted in significant personal regret and ongoing anxiety associated with continued monitoring *'If only I hadn't gone for the cholesterol test in 2007'*. Conversely, another man had been refused a PSA test even though he specifically asked for it and he changed his doctor as a result. The group also shared their own and others' experiences of inconsistency in how different doctors interpret PSA test results (e.g. what degree of elevated PSA levels were perceived to be ok or expected); and how urologists varied in what they recommended once PSA levels were found to be raised (eg biopsy versus no biopsy, surgery or monitoring). The men also worried about the lack of standardisation of testing procedures e.g. whether or not men were advised to abstain from sexual activity before testing.

In addition to the core concerns about the available information and advice, the men were also concerned about the relationship between PSA testing and anxiety and depression. On deliberating the evidence many concluded that the apparent uncertainties in the science of PSA testing primarily mean that a raised PSA test result (or subsequent diagnosis of prostate cancer) was a source of significant anxiety without offering any valuable information on how to act: *'all they're going to say is yeah, you've got it. You're going to worry for the next 15 years, is it bigger, is it smaller, am I going to get tested again?'.*

After deliberating the evidence most of the jury concluded that having a PSA test was a genuinely difficult and personal choice. As a result, several of the men expressed concerns about the active promotion of PSA testing by some doctors and through public campaigns and charities such as 'Movember'.[29] This was considered by some to be deceptive in the light of current uncertainty about what PSA results mean, the lack of available technologies to differentiate aggressive versus indolent cancers, and the lack of satisfactory/safe treatment options for prostate cancer. The jury's discussions focused on the importance of not harming men through unnecessary investigations and treatments, including those for whom the cancer will never progress, or for whom other conditions would kill them first. Several in the group agreed that for many of their peers other emerging health problems, including cardiovascular disease, diabetes, or mental health were more important concerns than prostate cancer.

Box 3: Points of general consensus

In general the men on the jury agreed on the following issues and points:

- Need for better and more standardised information; particularly more about the limitations, pros and cons of PSA testing. The group particularly liked a figure based on available trial data that reported the number of men harmed (side effects of treatment and associated psychological effects) and the 1 potential life saved per 1000 men screened.
- Need for GPs to advise men of why PSA testing is not recommended by their guidelines
- Importance of men taking responsibility and being able to make their own informed personal decisions about testing
- Need for GPs to provide information about what it means to have a raised PSA test: *'if she'd talked to me just briefly about these things in terms of the imprecise nature of the whole screening process, I would have been a lot better off and felt a lot less stressed on leaving that day.'*
- Valuing the availability of the test for those who want it
- Valuing the time to ask questions and discuss issues with experts
- Obtaining information from an independent source, with no financial or other vested interests
- Not promoting PSA testing to the general population given the current uncertain status of the evidence and likelihood of findings of latent cancers if you look for them
- Avoiding unnecessary anxiety among their family, friends and the community associated with promoting PSA testing when considering the uncertainty of the PSA test and not knowing how to interpret the results
- Directing funds from screening towards generating better diagnostic tests, predictors to distinguish aggressive vs indolent cancers and safer treatment options
- Importance of not wasting government funds on doing wasteful testing, importance of considering costs and benefits of government funded programs, not focusing on something if it isn't sufficiently important as a health concern or risk *'In most people it isn't an issue, why make it an issue'*
- Important to prioritise those things that are more likely to impact on men's health
- Perception that government sponsored information sent directly to public is often thrown out or ignored (gave example of colorectal cancer screening material)

Box 4: Some differences of opinion

The men on the jury expressed some differences of opinion on the following points:

- Personal decisions on whether or not it is better to have the test
  '..is there a test for lung cancer, heart disease, colon cancer, dementia, diabetes? I'd be getting tested for all those long before I'd get a bloody prostate test'

- The importance of impotence and incontinence against the risk of death
  P1 'I would have thought longevity at 70 was more important than sexual activity.'
  P2 'Oh it depends'
  P3 'Probably a lot of men..'
  P2 'Horses for courses, I think'
  P1 'I'm just saying, who would die over sex?'

- Whether or not (degree to which) men in general will want all of the information provided to the community jury – but group agreed the information should be available for those who do want it

- Whether or not they want doctors to advise / tell them what to do, or whether it is up to each man to make their own decision

- Whether or not it had been a good idea for them to ask the expert presenters what their personal decisions were about PSA testing. Most said they wanted to know, one man said the responses swayed his own view too much and he would have preferred not to know (The group asked the presenters whether or not they had had a PSA test: one had, two hadn't)

Community jury verdict on community-level questions

The jury's responses to the community-level questions (Box 1) on potential government action on PSA screening for prostate cancer were as follows (final day, n = 10):

- Recommended against any government campaigns aimed at the public on the topic of PSA screening. This included a recommendation against any organised invitation program for prostate cancer screening. (unanimous)

- Proposed instead a campaign targeting general practitioners (GPs) to assist GPs to provide better quality and more consistent information to their patients about PSA testing for prostate cancer. The men particularly wanted GPs to provide to patients information on: the unreliable nature of the PSA test, prevalence of raised PSA levels in older men, prevalence of prostate cancer relative to risk of death, screening outcomes (rates/1000 men screened), treatment side-effects (rates). (unanimous)

- Proposed that facts about PSA screening for prostate cancer, including that it is not currently recommended in Australian GP practice guidelines and an explanation of why, could be provided directly to the public if it was included as part of a broader 'men's health' information program or website. The latter was preferred to identifying PSA screening as a targeted priority issue. (unanimous)

Jury's rationale for final verdict

The jury's primary concern was that any public campaign focused on PSA testing for prostate cancer had potential to cause anxiety and alarm among the majority of men who did not need to be concerned about prostate cancer. Other reasons given by the jury for why they believed a government campaign on PSA screening was not warranted were nominated as follows:

- Contradictory nature of the current status of the science

- Unreliable nature of the PSA test
- Low incidence of mortality from prostate cancer
- High cost of such a campaign
- Funds required are more likely to be better used on research into the diagnosis and treatment of prostate cancer

'*We don't want the government to invite us or our mates to come along and get tested. We don't want that to happen because we don't want our mates to worry. We don't want people to make a fuss, we don't want our government to waste our money.'*

Individual-level PSA testing decisions

After the jury the men considered themselves better informed about the benefits and harms of prostate cancer testing compared with prior to the jury (F = 14.34, p = .004) (Table 2). This improvement was significantly greater than in the control group (F = 7.3, p=.01). Following the jury, the men also decreased their intention to be screened for prostate cancer in future compared with their intentions prior to the jury (F = 8.83, p = .014) (Table 2). The jury also scored 4.3 points lower on the post-jury intention to test scale than the controls (p=0.001) (Table 3). At the end of the jury, five men reported they were 'not at all' likely to get tested in the future if they had no symptoms, whereas six would consider it – and of these, four were more likely than not to do so (i.e. scored ≥5 on scale 0 to 10) (Table 4).

Discussion

Government policies must take account of public values and concerns. Deliberative methods such as community juries are well suited to support evidence-informed public engagement on screening policies and programs.[17] In this study, a group of men aged between 50 and 70, after deliberating on the benefits and harms of PSA screening, concluded that governments should not invest in any organised programs focused on PSA screening that were directed at the public. They determined that the PSA test did not offer sufficient reassurance or benefit to warrant a public campaign, and that such an approach would raise unnecessary alarm about prostate cancer. The jury did however want men to continue to have access to the test and to be able to make an informed choice about whether or not to be screened. They recommended an alternative government program aimed at supporting GPs to provide patients with better quality and more consistent information about the benefits and harms of PSA screening.

The jury's verdict on public campaigns was not anticipated by the research team; rather we expected that if anything, the jury may identify a need for a public education campaign on PSA screening. The jury overwhelmingly reported being previously unaware of the relative benefits and harms of screening, and their preference for obtaining such information from their doctor. The option of a government program targeting GPs was nominated by the jury themselves, reflecting their primary concern about the lack of information provided by their doctors and their shared experiences of inconsistent PSA screening advice. The findings indicate the facilitation process had been open and non-directive.

Community juries are not intended to be representative of the wider population in the statistical sense; rather they offer valuable insights on the informed views and conclusions of a 'mini-public'.[21] This study provides valuable insights into the concerns and priorities with regard to PSA testing among men aged 50-70; both as individuals interested in PSA testing, and as citizens invited to weigh community benefits and harms. The jury's unanimous verdict about government programs was notable in the light of the men's divergent views on whether or not they would get tested again in future themselves if they had no symptoms. These findings support other literature indicating community juries delineate and rise above individual decisions to consider higher order questions about the common good.[30] While the men's personal interest in PSA testing did not appear to hinder their willingness and ability to consider more broadly its relative value for their community, other kinds of public may have reached different conclusions. For example, a majority of the jury had been previously tested, and while the proportion of Australian men who have ever had a PSA test is unknown, approximately 20% of Australian men aged 45 to 74 years had screening PSA tests between 2010-2011.[31] In other countries such as the US the participation in PSA testing is relatively high; around 50% among men aged 60-74.[32] The impact of these differences on the deliberation and conclusions of a jury on PSA testing is currently unknown.

It will be important therefore to repeat the deliberative process with other juries, both to examine the views of different publics, and to assess the ~~repeatability and~~ generalisability of the findings to other parts of Australia and other countries with different information and services. Similarly, it will be relevant to assess the potential impact on jury deliberations or conclusions of varying aspects of the community jury process, such as the method of recruiting participants or of presenting evidence. Different publics could include men of different ages; a mixed group of men aged 50-70 and partners or other family members (particularly as the men noted the influence of partners on their health behaviours); or a random sample from the electoral roll - although these methods are still affected by respondents' level of interest. Other forms of evidence could include the personal stories of men affected by prostate cancer and/or the side-effects of treatment, or those without a diagnosis but whose PSA level is being monitored. Finally, it will also be valuable to compare the effectiveness of eliciting public values about cancer screening using other deliberative methods.[33]

The recent Australian NHMRC *Information for Health Practitioners: Prostate Specific Antigen (PSA) Testing for Prostate Cancer in Asymptomatic Men[34]* provides guidance on communicating the evidence on the benefits and harms of PSA screening to asymptomatic men. It will be imperative to identify effective mechanisms to facilitate implementation of this guidance within Australian general practice. It will be also important to better align and even regulate the messages about PSA testing that are promoted in media campaigns by prostate cancer charities and other non-government organisations and special interest groups so that more consistent information and advice is presented.

Table 1: Reported sources of information on testing for prostate cancer prior to jury

	N = 11	%
General Practitioner	8	73
Family and friends	5	46
Internet	4	36
The media	4	36
Other (urologist/surgeon)	2	18
Other (hospital seminar)	1	9
Never looked for information	2	18

NB: Men could endorse more than 1 category

Table 2: Reported changes compare pre-post jury measures: perception of how well informed and how likely to test for prostate cancer

Comparison of Continuous Variables at Pre- and Post-assessment (N = 11)

	Pre-assessment		Post-assessment			
	Mean	*SD*	*Mean*	*SD*	*F*	*p*
Informed about harms and benefits	2.0	1.2	3.6	0.5	14.34	0.004
Likely to test for Prostate Cancer	7.3	3.5	3.5	4.1	8.83	0.014

Table 3: Future intention to test for prostate cancer comparing jury to controls

Predicting Future Intention to Test for Prostate Cancer *

	B	*SE B*	CI Lower	CI Upper	*p*
Constant	-0.11	1.51	-3.25	3.03	0.944
Pre-assessment intention to test score	0.72	0.16	0.38	1.06	0.000
How many times tested previously	0.66	0.19	0.26	1.06	0.003
Group membership (jury/control)	-4.31	1.09	-6.58	-2.04	0.001

Note. N=25. CI= confidence interval.

* Because it was anticipated men who had been tested for prostate cancer previously would be more likely to continue with this course of action, group differences in intention to be tested for prostate cancer in the future were examined using linear regression, adjusting for baseline future intention to test, the number of times a man had a PSA test at baseline, and his group membership.

Table 4: Intention to be screened in future after jury process

Value: how likely to be tested if no symptoms (0 = 'not at all'; 5 = 'maybe'; 10 = 'absolutely')	Frequency	%
0	5	46
4	2	18
5	1	9
8	1	9
10	2	18
Total	11	100

Acknowledgements

This project was supported by a Screening and Test Evaluation Program (STEP) grant (#633033) from the National Health and Medical Research Council (NHMRC), a NHMRC Project Grant (#1023791), and the Bond University Vice Chancellor's Research Grant Scheme.

Author contributions

LR led the preparation and subsequent revisions of the manuscript, contributed to the study design, and led the analysis and interpretation of the qualitative data. JD and PG led the conception and design of the study, contributed to the interpretation of the data and made substantial revisions to the manuscript. RT contributed to the study design, led the analysis and interpretation of the quantitative data, and made substantial revisions to the manuscript. RG and GM contributed to the study design and interpretation of the data, and made significant revisions to the manuscript.

References

1. Chou R, Croswell JM, Dana T, et al. Screening for Prostate Cancer: A Review of the Evidence for the U.S. Preventive Services Task Force. Annals of Internal Medicine 2011;**155** (11):762-71
2. Djulbegovic M, Beyth RJ, Neuberger MM, et al. Screening for prostate cancer: systematic review and meta-analysis of randomised controlled trials. British Medical Journal 2010;**341** doi: c4543
10.1136/bmj.c4543[published Online First: Epub Date]|.
3. Ilic D, Neuberger MM, Djulbegovic M, et al. Screening for prostate cancer. Cochrane Database of Systematic Reviews 2013(1) doi: Cd004720
10.1002/14651858.CD004720.pub3[published Online First: Epub Date]|.
4. Andriole GL, Crawford ED, Grubb RL, 3rd, et al. Prostate cancer screening in the randomized Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial: mortality results after 13 years of follow-up. J Natl Cancer Inst 2012;**104**(2):125-32
5. Schröder FH, Hugosson J, Roobol MJ, et al. Prostate-Cancer Mortality at 11 Years of Follow-up. New England Journal of Medicine 2012;**366**(11):981-90 doi: doi:10.1056/NEJMoa1113135[published Online First: Epub Date]|.
6. Mackie A, UK National Screening Committee. Screening for Prostate Cancer Review against programme appraisal criteria for the UK National Screening Committee (UK NSC). London: National Health Service, June 2010.
7. Moyer VA. Screening for Prostate Cancer: U.S. Preventive Services Task Force Recommendation Statement. Annals of Internal Medicine 2012;**157**(2):120-34 doi: 10.1059/0003-4819-157-2-201207170-00459[published Online First: Epub Date]|.
8. American Urological Association. Early Detection of Prostate Cancer: AUA Guideline. 2013; (7 June 2013). http://www.auanet.org/education/guidelines/prostate-cancer-detection.cfm.
9. Mitka M. Group now advises against routine psa screening. JAMA 2013;**309**(22):2316-16 doi: 10.1001/jama.2013.6922[published Online First: Epub Date]|.
10. The Melbourne Consensus Statement on Prostate Cancer Testing. . A consensus view on the early detection of prostate cancer, led by experts at the Prostate Cancer World Congress, Melbourne, 7-10th August 2013. http://www.prostatecancerresearch.org.au/new-apcr/wp-content/uploads/The-Melbourne-Consensus-Statement-on-PSA-Testing.pdf.
11. Entwistle VA, Carter SM, Trevena L, et al. Communicating about screening. British Medical Journal 2008;**337**(7673):3 doi: a1591[published Online First: Epub Date]|.
12. Irwig L, Glasziou P. Informed consent for screening by community sampling. Eff Clin Pract 2000;**3**(1):47-50
13. Stefanek ME. Uninformed Compliance or Informed Choice? A Needed Shift in Our Approach to Cancer Screening. Journal of the National Cancer Institute 2011;**103**(24):1821-26 doi: 10.1093/jnci/djr474[published Online First: Epub Date]|.
14. Shaw D, Elger B. Evidence-based persuasion: an ethical imperative. JAMA 2013;**309**(16):1689-90 doi: 10.1001/jama.2013.2179[published Online First: Epub Date]|.
15. Woolf SH, Krist A. The liability of giving patients a choice: shared decision making and prostate cancer. Am Fam Physician 2005;**71**(10):1871-2
16. Levinson W, Kao A, Kuby A, et al. Not all patients want to participate in decision making - A national study of public preferences. J Gen Intern Med 2005;**20**(6):531-35 doi: DOI 10.1111/j.1525-1497.2005.0088.x[published Online First: Epub Date]|.
17. Rychetnik L, Carter SM, Abelson J, et al. Enhancing Citizen Engagement in Cancer Screening Through Deliberative Democracy. Journal of the National Cancer Institute 2013;**105**(6):380-86

18. Hawkes N. Women "jurors" are asked how to present risk-benefit ratio of breast cancer screening. BMJ (Clinical Research Ed) 2012;**345** doi: 10.1136/bmj.e7886[published Online First: Epub Date]|.
19. Paul C, Nicholls R, Priest P, et al. Making policy decisions about population screening for breast cancer: The role of citizens' deliberation. Health Policy 2008;**85**(3):314-20 doi: DOI 10.1016/j.healthpol.2007.08.007[published Online First: Epub Date]|.
20. Thomas R, Glasziou P, Rychetnik L, et al. What is the Immediate and Long-term Impact of a Community Jury on Men's Attitudes to Prostate Cancer Screening? Under review 2013
21. Goodin RE, Dryzek JS. Deliberative Impacts: the macro-political uptake of mini-publics. Politics Society 2006;**34**(2):219-44
22. Andrology Australia. Factsheet: PSA Testing. https://www.andrologyaustralia.org/wp-content/uploads/Factsheet_PSA-Test.pdf: Monash Institute of Medical Research, Victoria, Australia May 2013.
23. Cancer Council Australia. Early Detection Factsheets: Prostate Cancer. http://www.cancer.org.au/about-cancer/early-detection/early-detection-factsheets/prostate-cancer.html, February 2013.
24. Ilic D, Neuberger MM, Djulbegovic M, et al. Screening for prostate cancer (Review - Plain Language Summary). Cochrane Database Syst Rev 2013(1) doi: Cd004720 10.1002/14651858.CD004720.pub3[published Online First: Epub Date]|.
25. Royal Australian College of General Practitioners. Guidelines for preventive activities in general practice (The Red Book) Chapter 98 (Prostate Cancer). 8th ed. South Melbourne, Victoria: The Royal Australian College of General Practitioners, 2012.
26. Urological Society of Australia and New Zealand. PSATesting Policy (Executive Summary). http://www.usanz.org.au/uploads/29168/ufiles/USANZ_2009_PSA_Testing_Policy_Final1.pdf, 2009.
27. Charmaz K. *Constructing grounded theory : a practical guide through qualitative analysis*. London: SAGE Publications, 2006.
28. Vickers AJ, Altman DG. Analysing controlled trials with baseline and follow up measurements. BMJ 2001;**323**:1123-24
29. Movember Australia. About Movember http://aumovembercom/about/; (accessed 30 July 2013).
30. Elwood P, Longley M. My health: Whose responsibility? A jury decides. J Epidemiol Community Health 2010;**64**(9):761-64
31. Currow D, Armstrong B. PSA needs order MJA Insight 2011; (25 May 2012). http://www.mjainsight.com.au/view?post=david-currow-bruce-armstrong-psa-needs-order&post_id=6489&cat=comment.
32. Prasad SM, Drazer MW, Huo D, et al. 2008 US preventive services task force recommendations and prostate cancer screening rates. JAMA 2012;**307**(16):1692-94 doi: 10.1001/jama.2012.534[published Online First: Epub Date]|.
33. Agency for Healthcare Research and Quality. The AHRQ Community Forum Deliberative Methods Demonstration Effective Health Care Program. http://www.effectivehealthcare.ahrq.gov/ehc/assets/File/Demonstration-Methods-Deliberative-130213.pdf, 2013.
34. NHMRC. Public consultation on the draft Prostate Specific Antigen (PSA) Testing for Prostate Cancer in Asymptomatic Men: Information for Health Practitioners http://consultations.nhmrc.gov.au/public_consultations/prostate_cancer (accessed 31 July 2013), 2013.