Title
Discussing uncertainty and risk in primary care: recommendations of a multi-disciplinary panel regarding communication around prostate cancer screening.

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Authors
Wilkes, Michael
Srinivasan, Malathi
Cole, Galen
et al.

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BACKGROUND: Shared decision making improves value-concordant decision-making around prostate cancer screening (PrCS). Yet, PrCS discussions remain complex, challenging and often emotional for physicians and average-risk men.

OBJECTIVE: In July 2011, the Centers for Disease Control and Prevention convened a multidisciplinary expert panel to identify priorities for funding agencies and development groups to promote evidence-based, value-concordant decisions between men at average risk for prostate cancer and their physicians.

DESIGN: Two-day multidisciplinary expert panel in Atlanta, Georgia, with structured discussions and formal consensus processes.

PARTICIPANTS: Sixteen panelists represented diverse specialties (primary care, medical oncology, urology), disciplines (sociology, communication, medical education, clinical epidemiology) and market sectors (patient advocacy groups, Federal funding agencies, guideline-development organizations).

MAIN MEASURES: Panelists used guiding interactional and evaluation models to identify and rate strategies that might improve PrCS discussions and decisions for physicians, patients and health systems/society. Efficacy was defined as the likelihood of each strategy to impact outcomes. Effort was defined as the relative amount of effort to develop, implement and sustain the strategy. Each strategy was rated (1–7 scale; 7 = maximum) using group process software (ThinkTank™). For each group, intervention strategies were grouped as financial/regulatory, educational, communication or attitudinal levers. For each strategy, barriers were identified.

KEY RESULTS: Highly ranked strategies to improve value-concordant shared decision-making (SDM) included: changing outpatient clinic visit reimbursement to reward SDM; development of evidence-based, technology-assisted, point-of-service tools for physicians and patients; reframing confusing prostate cancer screening messages; providing pre-visit decision support interventions; utilizing electronic health records to promote benchmarking/best practices; providing additional training for physicians around value-concordant decision-making; and using re-accreditation to promote training.

CONCLUSIONS: Conference outcomes present an expert consensus of strategies likely to improve value-concordant prostate cancer screening decisions. In addition, the methodology used to obtain agreement provides a model of successful collaboration around this and future controversial cancer screening issues, which may be of interest to funding agencies, educators and policy makers.

KEY WORDS: prostate cancer screening; men’s health; shared decision-making; communication; funding priorities; risk.

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BACKGROUND
How can screening for life-threatening diseases be harmful?
While many screening tests have improved the quantity and quality of a person’s life through early detection of life-threatening or life-altering diseases, other tests have failed to deliver. These tests may fail to deliver because they are inaccurate, poorly performing, have unavailable treatments, high costs, treatment complications or health providers who are unaware of the screening controversies. Prostate cancer screening with the prostate-specific antigen (PSA) blood test epitomizes this controversy. Prostate cancer accounts for about 29,000 cancer deaths annually in the US, yet millions of men may have undetected prostate cancer—the vast majority of whom will remain asymptomatic throughout their life.¹-⁴ At the population level, prostate cancer treatment has only a marginal mortality benefit. PSA as a screening test has reasonable sensitivity to detect aggressive prostate cancers (91%), but cannot distinguish between low-
and high-risk prostate cancers. This results in substantial overdiagnosis (with attendant treatment complications of impotence, incontinence and surgical mortality) of men who would have remained asymptomatic.1–4

For controversial conditions such as prostate cancer screening (PrCS), the medical encounter needs to focus on discussion and education to help patients reach value-concordant decisions.5–11 Value-concordant decision-making can be enhanced using shared decision-making8 techniques to clarify issues. In SDM, medical knowledge (risks, harms and benefits of diagnosis and treatment) is cogently and clearly contextualized through the lens of patient’s values and preferences to elicit a preferred clinical pathway.

Most major professional societies have endorsed SDM for decisions around prostate cancer screening for average-risk men aged 55–75 years old.2,3,12–15 In 2010, the American Cancer Society updated its PrCS recommendations to include an informed decision-making/SDM discussion about screening with the PSA test for all men who had a longer than 10-year life expectancy.15 Until recently, the US Preventive Services Task Force (USPSTF) considered the evidence insufficient to recommend for or against prostate cancer screening in this age range, but they encouraged shared decision-making.3 In 2011, the USPSTF recommended against routine PrCS for average-risk men of all ages.3,16

Yet, balanced discussions between clinicians and patients about disease screening remain problematic.17 Objective disease screening discussions are colored by over 50 years of public health efforts that convey “do not delay” messages for cancer screening.18 Overall, the public has an enthusiasm for health screening. This enthusiasm for cancer screening persists even when they understand the risks of false-positive results-identifying “abnormalities” that have a dubious impact on health but may result in a cascade of costly and often aggressive medical interventions.19 At the same time, physicians often worry about liability issues that might arise from missed diagnosis resulting from a decision not to screen.20,21 Primary care physicians have limited time for complex medical discussions, have limited training in effective SDM techniques6,8,22 and are often not up to date on the latest evidence. Additionally, tension exists between specialists who see patients with advanced disease (and therefore push for aggressive screening) and primary care/population health groups who see the myriad of complications from over-diagnosis.

As such, public and private agencies are seeking methods to help patients make complex medical decisions that go beyond providing written material or engaging in brief discussions. Typically, health messages fail for a variety of reasons: the type of message delivered5,23–26; method of delivery; lack of message reinforcement; lack of access to recommended care; non-acceptance on the part of the individual; and inappropriate education level. Similarly, expert consensus groups have identified strategies (Fig. 1) to effectively empower patients facing value-sensitive decisions—utilizing SDM, tailoring messages to match cultural background, connecting messages to patient values, assessing readiness to change, targeting messaging to individuals or entities that influence decision-making by the patient (e.g., spouse), utilizing direct patient stories and using decision support interventions.23–27 New methods are intended to engage, challenge and motivate patients to make value-concordant health choices, but are not commonly used in clinical practice.10,22,28–32

These uncertainties prompted the Centers for Disease Control and Prevention (CDC) to convene a consensus panel to help prioritize communication strategies—to assist patients and physicians in communicating more effectively around prostate cancer screening (PrCS), including PrCS risks, benefits and value preferences. Panel recommendations were intended to help the CDC, public health community and medical communities set priorities for prostate cancer communication methods and in other areas. Here, we describe the process for the panel, main results, implications for PrCS and other health communication.

METHODS

The Multidisciplinary Expert Panel

The CDC convened an expert panel around PrCS communication on June 13–14, 2011, in Atlanta, Georgia. The diverse panel was assembled with experts from across the health care spectrum relevant to PrCS, including individuals with expertise in primary care, oncology, urology, epidemiology, medical education, journalism, health communication and patient advocacy. Participants also included authors of the USPSTF prostate cancer screening evidence report/guidelines and experts from the CDC’s Division of Cancer Prevention and Control (invited panelists listed in Acknowledgements).

Methods

Prior to the in-person meeting, panelists were assigned to one of three groups (health care provider, patient, health system) based on their background. Groups met by conference call 1–2 times prior to the in-person meeting to share their prostate cancer screening research and experiences and to discuss the literature in their assigned area.

Panelists were asked to accept the PrCS recommendations by the USPSTF 2008 rather than engage in debate around the value of population-based PrCS. Specifically, at the time of the panel, USPSTF 2008 guidelines concluded the evidence was insufficient to assess the balance and harms of PrCS in men younger than 75 years old, with a recommendation for SDM to determine individualized screening decisions.2
Early in the meeting, three didactic sessions of 60 min each reviewed the state of the science around prostate cancer screening communication. The first focused on clinician-patient communication, the second focused on patient-directed communication (helping patients make more informed and value-concordant screening decisions) and the third focused on health systems (e.g., system change, electronic health records, reminder systems and social networking). Following each session, panelists discussed methods to improve communication around PrCSC focused on the target groups (providers, patients and health systems) with attention to target audiences, specific messaging, health literacy, media and communication channels and program evaluation.

To promote maximum participation and prioritization of ideas by all panelists, we provided each panelist with a laptop computer loaded with “ThinkTank” (GroupSystems, 2011) software. The software allows continuous input of anonymous comments during ongoing discussions and allows all panelists an equal opportunity to express their opinions, preventing individuals from dominating the conversation.

After each session, panelists identified the greatest opportunities to improve decision-making around prostate cancer screening communication. Individuals entered their ideas into ThinkTank™, and ideas were anonymously projected on a screen for group discussion. Responses were edited and condensed by the facilitator and group, after which each panelist anonymously rated each response on a 7 point scale (1–7, 1 = minimum, 7 = maximum) for on two domains: (1) effectiveness: likelihood that appropriate implementation of the communication strategy would lead to meaningful improvement in PrCSC decision-making and (2) feasibility/effort: the effort required to successfully implement each strategy.

Responses and ratings were displayed for group discussion, and agreement was achieved for major strategies. Panelists listed barriers to each strategy and methods needed to overcome them. We reviewed models of cancer communication, and based on participant discussion, utilized that discussion to develop an interactional model of elements that might influence patient–physician decision-making around PrCSC.

Using ThinkTank software, we grouped PrCSC strategies into three areas: those intended for providers, patients and health care systems/public health. We then divided the strategies into five content areas: (1) education/knowledge, (2) financial/regulatory, (3) beliefs/attitudes, (4) messaging and (5) communication/decision-making. For each action, the group discussed benefits and barriers.

RESULTS

Model Development

Based on panelist discussion, we developed a model of elements that influenced patient and physician decision-making. The model suggests that patient decisions occur after they have been informed (via physician, health system, decision support interventions, etc.) and have clarified their preferences, values and risk tolerance.

In the model, we only considered influences on the patient–physician interaction, including the knowledge, experience, biases and health literacy of the patient and the physician. Patient decisions were felt to be influenced by their willingness to participate in decision-making, trust of the clinician and the source of information, the value they placed on health, the opinion and experiences of family/friends, time and access issues, and competing interests (e.g., financial). Physician advice and decision-making might also be influenced by extreme exemplar cases, limited time to engage in discussions, exposure to opinion leaders/CME and institutional policies including quality assurance metrics and competing interests (e.g., patient co-morbidities, professional duties). During physician and patient interaction, we assumed that decision-making would involve explanation of content, contextualization of risk-reward, elicitation of values and screening recommendations.

As we further developed the model, we considered contextual elements that influenced the patient-physician interaction, nested in a larger societal and health system context (Fig. 1; expanded Appendix 1). In this model, some patient and physician elements are influenced by context, while others are intrinsic to the individual. Patients interact directly with and are partially influenced by their society and health system. Physicians interacted with and were partially influenced by their health system(s) and societal factors. Finally, society and the health system interact to set the tone, funding and expectations for improved care. The intersection of all of these forces is the point of decision-making.

Participants acknowledged the complexities in making sound, personalized health care decisions around cancer screening—especially prostate cancer. Participants also identified a large number of activities that could improve communication and decision-making.

Physicians. The group identified many barriers to optimal shared decision-making (SDM), but the two judged most important were (1) a shortage of physician time and (2) physician skill at engaging in such
discussions. The group identified several communication interventions that might improve these shortcomings. Traditional attempts to provide patients with information or empowerment tools utilized brochures and printed messages. Technology-assisted learning now opens opportunities to tailor messages to individual patients, allows interactions between groups of people and collects information from patients that can better inform the health care team.

Based on group ranking regarding strategies to address physician communication issues (Table 1), interventions felt most likely to be effective were (1) changing reimbursement for physicians to promote them spending more time in doctor–patient communication, (2) motivating patients to influence their doctors to engage in SDM, (3) teaching SDM skills in continuing medical education, residency and medical school and (4) requiring SDM discussions as a quality standard in caring for patients between the ages of 50 and 75. Interventions that the group felt would require the most effort included (1) providing patients with tools that allowed them to prepare for their meeting with the physician, (2) providing doctors with tools to assist in discussions with men and (3) providing specific observed feedback to physicians on their counseling and SDM skills.

**Patients.** Panelists more easily reached consensus about interventions to improve cancer communication for patients than for providers (Table 2). The group recommended development of a trusted website (information source) that could serve as a one-stop home for high-quality information and decision support interventions on cancer screening. Such a site could use current quality assessment guidelines to consider which decision support interventions to include/credential. Within the group, there were divisions between the views of specialists and primary care providers about the appropriateness of information related to screening and treatment from a population perspective. Given that the disagreements are unlikely to be resolved, such a website would need to be evidence-based and peer-reviewed; it should avoid being all things to everyone. Participants acknowledged differences between social groups in addressing issues of related to cancer and health screening.

Based on the ranking, the most effective strategies to improve patient PrCS decision-making include: (1) making reliable and accurate educational tools publicly available and (2) empowering patients to have direct conversations with the physicians. Participants also felt men should be engaged outside of the doctor–patient encounter to learn: (1) the importance of making medical decisions in the face of uncertainty; (2) that they can choose various levels of involvement with their doctor, from no involvement to complete involvement; (3) information about the medical condition (prostate cancer) and the decision that needs to be made (to screen or not).

The participants felt the most effective cancer communication intervention directed at patients would be to move some education about PrCS away from the doctor–patient encounter to learning programs, including group meetings led by non-physician health educators. Patient small-group meetings focused on health education have been quite effective in helping patients manage their chronic illnesses. Such meetings could play an important role in preparing patients to interact with their physicians, answer common questions and thus reduce time needed for doctor–patient discussions.

They also suggested a pre-visit phone call to get patients thinking about these issues as well as framing PrCS discussions as attempts to keep them healthy, not just to look for cancer.

![Figure 1](https://example.com/figure1.png)

**Figure 1.** Two-part model of elements influencing medical decisions around complex medical decisions.
Table 1. Improving Physician Behaviors Around Prostate Cancer Screening Discussions

| Average rank for effectiveness in achieving behavioral change (1–7, 7=maximum) | Theme | Item | Barriers to change related to each item | Average rank for effort to achieve change (1–7, 7=maximum) |
|---|---|---|---|---|
| 6.9 | Financial and regulation | Change reimbursement to incentivize doctor–patient communication | • If you don’t pay you won’t get it done  
• Will cost system money to increase time for clinicians | 3.3 |
| 6.9 | Communication and messaging | Have consumers apply pressure to physicians to engage in SDM | • Will require process to inform/motivate patients  
• Will need to have advocacy groups take on this agenda  
• Notable expenses for such campaign | 5.4 |
| 6.9 | Education and knowledge | Teach shared decision-making skills (with good and poor examples) in continuing medical, residency and medical school education | • Teaching skills is for more difficult than teaching knowledge and will require models, practice, and feedback | 4.8 |
| 6.9 | Financial and regulation | Implement SDM and cancer screening communication as quality standard (e.g., pay for performance) and adjust reimbursement | • May obtain minimal performance, with just checkboxes EMR measures  
• Regulation is “easy” for EMR capable systems—developing the standard of care is difficult | 3.3 |
| 6.7 | Financial and regulation | Do not allow PSA test ordering until there is documentation of SDM in the EMR | • Will require that each EMR be set up to disallow ordering until documentation is provided | 5.8 |
| 6.4 | Communication and messaging | Provide clinicians with interactive tools to allow men to visualize risks and benefits and aid in their understanding (e.g., smart phone apps) | • Will need development, funding and regular updating.  
• Will need to be done by CDC or other credible source | 6.2 |
| 6.3 | Financial and regulation | Benchmark PSA testing by providing data on other provider’s PSA testing rates | • Could be done within & between group practices | 4.6 |
| 6.2 | Communication and messaging | Provide clear and simple messages that providers can use with their patients | • Such messages need to be in a central repository or database and be easily accessible. | 5.8 |
| 5.9 | Communication and messaging | Provide table of effective preventive strategies based on the expected benefit to the patient so that patients and providers can allocate their time appropriately | • Needs to be produced by credible source  
• Needs to be disseminated  
• Needs to be simple and understandable to both patients and providers | 5.9 |
| 5.9 | Communication and messaging | Convey in messaging that groups are “making money” from testing decisions | • Will be politically difficult  
• Will create inter-professional discord | 5.6 |
| 5.5 | Education and knowledge | Provide direct observational feedback to clinician on their counseling and shared decision-making skills | • Will need to be done by outside advocacy groups  
• Easier to do in medical school and residency  
• No real mechanism to do this in practice  
• Could more easily be done by health care systems (such as VA or Kaiser) where such resources and motivation exists | 6.2 |
| 5.4 | Education and knowledge | Provide guidelines on when to use SDM and when to use more directed decision-making | • Such education is difficult to disseminate and is best done in training programs not in CME environments | 5.8 |
| 5.0 | Financial and regulation | Use accreditation lever (mandatory testing or module completion for recertification) | • Will require broad buy-in from multiple constituencies | 4.1 |
| 4.4 | Financial and regulation | Work with professional organizations to promote awareness and skill building | • This would need to involve many professional and advocacy groups | 4.2 |
| 4.3 | Financial and regulation | Prevent ordering of PSA test unless it is linked to patient SDM signed note (using HIV as a model) | • Requires both system approval and programming of the EMR | 3.5 |
| 4.0 | Communication and messaging | Re-label “prostate cancer” to another name that better captures the varied nature of abnormal cells | • At best will be a slow evolution and there are powerful forces who will continue to push for it to be considered “cancer” | 3.3 |
| 3.9 | Behavior | Provide data to providers on patients (or percentage of patients) who don’t opt in to PSA testing so they know that not everyone is selecting “testing” | • Will require each health care system or laboratory to compile this data separate  
• If you do this nationally it may not have as much meaning to any given provider or patient | 5.9 |
| 3.6 | Behavior | Measure quality of care in the doctor–patient encounter and provide bonus when SDM is done well (may be more related to physician than patient) | Would have cost implications to physicians and health care systems | 2.0 |

PSA: prostate-specific antigen, SDM: shared decision-making, EMR: electronic medical record, VA: Veterans Administration, NNT: number needed to treat, NNH: number needed to hard
Health Care Systems. Not surprisingly, many of the communication approaches recommended for health care systems were complex and costly (Table 3). Participants felt an essential step would be to change reimbursement strategies so that time spent on careful PrCS discussions would be adequately reimbursed. The cost-effectiveness of this strategy would need to be examined, with a likely reduction in low-yield testing, biopsies and surgery. The group also encouraged creative thinking around developing incentives intended to improve physical PrCS communication. Almost all participants endorsed the idea to incentivize documentation of SDM as a regularly monitored quality control measure but recognized the difficulties that would surround implementation.

Participants expressed the concern that health care systems should take responsibility for helping men to understand they have choices in health care as well as giving them the knowledge and tools to make informed decisions. They suggested that celebrities might be more effective at communicating messages than traditional approaches such as mailings or posters in doctor’s offices. They strongly encouraged development of interactive, engaging and customizable eLearning tools that could be used in the office or provided to individuals (apps or web-based decision support interventions).
and that would interface with the electronic health records. For instance, clinicians could then review patient responses on values/preferences for SDM around prostate cancer screening. Doctors could then direct discussion to specific areas of confusion or uncertainty. Most importantly, participants felt these decision support interventions would be most useful to clinicians by allowing them to focus available time on areas that deserved the most attention and also allow quality monitoring of physician–patient communication and decision-making.

**DISCUSSION**

Screening for cancer raises complex issues involving risks and benefits to the patient. The ultimate screening decision
belongs to the patient informed by best evidence, expert judgment and personal values, and acquisition of clear information is of paramount importance. Information aside, cancer screening discussions are often emotional and influenced by personal, professional and societal factors. This expert panel on communication about prostate cancer screening sought to determine methods to both provide high-quality information and help individuals make value-concordant PrCS decisions.

Importantly, our panelists included a variety of stakeholders. Their viewpoints differed, as each group was familiar with a different piece of the prostate cancer screening puzzle. For instance, patient advocates often wanted to protect patients from the harms of testing that were not honestly or openly discussed and from perceived biased viewpoints of specialists. The primary care physicians treated many of the complications of surgery or radiation and did not directly see the benefit of population-level prostate cancer screening. Specialists saw patients who had or were worried about advanced cancer; they strongly believed their procedures saved lives and improved the quality of men’s lives. When our group came to an impasse over a specific perspective, we acknowledged disagreement and moved on to discussion in other areas.

By addressing intervention effectiveness, these recommendations are intended to help providers and others determine the wisdom of particular strategies in pursuit of value-concordant PrCS decision-making. Clearly, potential effectiveness is dependent upon using the right social lever for the right condition—design, engagement strategy and implementation must all be thoroughly considered.

Multi-faceted interventions utilizing social media, health messages and financial incentives may improve PrCS decision-making. For example, coupling public health announcements on tobacco cessation in California with an increase in cigarette sales tax led to significant decreases in cigarette consumption. Policies that regulate salt ingestion are predicted to reduce blood pressure, risks of cardiovascular disease and provide substantial savings.

Similarly, doubling the price of alcohol is projected to reduce alcohol-related and sexually transmitted diseases by 6%. These social policy changes do not address informed decision-making in clinical care but instead use other societal levers to improve day-to-day decisions leading to the adoption of healthy behaviors. The financial impact of these interventions on the lives of patients was enough to make individual reconsider the value of a cigarette or a drink at the time of purchase. As such, panel participants recommended consideration of new financial/regulatory incentives to improve physician-patient communication around prostate cancer screening to supplement emerging decision-support technology. For instance, financial incentives may encourage patients to discuss cancer screening and preventive behaviors with their physicians—and provide the opportunity for physicians to more thoughtfully engage patients around the risks and benefits of specific interventions.

The panelists strongly encouraged more innovative use of new social and interactive media tools to improve both physician and patient decision-making, rather than simply improving knowledge acquisition. Decision support interventions (including for prostate cancer screening) present information in an understandable manner, have been shown to increase knowledge, reduce decisional conflict, clarify values and lead patients to take a more active role in their health care. Decision support interventions have been shown on meta-analysis to reduce PrCS with PSA. However, these patient-focused decision support interventions are infrequently used in clinical practice, often due to lack of awareness of the tools, the additional time taken to utilize the tool or the lack of access to the tool at the point of care. Well-constructed decision support interventions (icon arrays, stadium diagrams, roulette wheels) address the complexity of medical and numerical information, biases and incorporate patient preferences. Our group emphasized that having a trusted central site (such as within AHRQ, AAMC MedPortal or CDC) with vetted programs would help overcome some of the access issues. System redesign might be necessary to help with decision-aid implementation, with additional time/space allocated to have patients (and physicians) review the decision support interventions. Such aids can provide useful customized output to prepare patients for a discussion with their health care provider.

Participants felt that improved physician communication skills should be addressed through educational interventions at all levels—medical school (undergraduate medical education), residency training (graduate medical education) and continuing medical education. Residency programs are increasingly emphasizing patient-oriented outcomes, with attention being paid to enhanced communication skills. Evidence suggests that traditional CME does not effectively improve physician practice-based behaviors or decisions, and CME has tended to ignore assisting clinicians to improve communication skills. Assessment, feedback interventions and recertification examinations offer opportunities to increase clinically meaningful outcomes if they can focus more on clinical behaviors than on factual recall. Panel members also felt that offering providers financial incentives is a tool to facilitate improved decision-making.

Health systems also have an important role to play in improving communications around PrCS, including system and clinic flow changes to systematize screening educational resources, discussions and incentives. Some health care systems have found great success in using reminders to stimulate communication around specific topics (via electronic medical records, emails and social networks). These systems can be expensive, but early reports indicate
they seem to reduce overall costs and improve quality (Kaiser Permanente, personal communication).

In summary, effective communication around prostate cancer screening is essential to match available evidence with patient values and desires. This article provides a background for how such communication might be approached from the perspective of providers, patients, and the health care system. While all of the suggested interventions require resources to develop and evaluate, the lessons learned now will enhance screening communication in the future.

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Corresponding Author: Michael Wilkes, MD, PhD.; University of California, Davis School of Medicine, 1 Shields Avenue, Sacramento, CA, USA (e-mail: mwilkes@ucdavis.edu).

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