

# American Urological Association and Society for Medical Decision Making Conference Proceedings: QUALITY IMPROVEMENT SUMMIT 2016: SHARED DECISION MAKING AND PROSTATE CANCER SCREENING

## **WORKGROUP:**

Danil V. Makarov, MD, MHS, Co-Chair  
Margaret Holmes-Rovner, PhD  
David R. Rovner, MD  
Timothy Averch, MD  
Michael J. Barry, MD  
Kristin Chrouser, MD, MPH  
William F. Gee, MD, FACS  
Kate Goodrich, MD, MHS  
Mike Haynes  
Murray Krahn, MD, MSc, FRCPC  
Christopher Saigal, MD, MPH

Harold C. Sox, MD, MACP  
Dawn Stacey, RN, PhD  
Christopher Tessler, MD  
Robert L. Waterhouse, Jr., MD, MBA  
Angela Fagerlin, PhD, Co-Chair

## **STAFF:**

Heddy Hubbard, PhD, MPH, RN, FAAN  
Suzanne Pope, MBA  
Jennifer Bertsch  
Virginia Vachon (Medical Writer)



American  
Urological  
Association

Education & Research, Inc.

## ABSTRACT

---

**Purpose:** The Quality Improvement Summit of the American Urological Association is a regularly occurring meeting to provide education and promote dialogue around issues of quality improvement and patient safety. Nearly all prostate cancer screening guidelines recommend shared decision making (SDM) strategies when deciding whether prostate specific antigen (PSA) testing is right for a specific patient. This summit, put on in partnership with the Society for Medical Decision Making, focuses on techniques to identify and understand patient values surrounding prostate cancer screening and treatment and to promote incorporation of SDM into prostate cancer screening discussions.

**Materials and Methods:** Information presented at the Quality Improvement Summit was provided by physicians and leading experts in the field of SDM. The open forum of this summit encouraged contributions from participants surrounding their personal experiences with SDM and their thoughts on the tools presented during the day.

**Results:** SDM supports collaboration between physician and patient in situations where there are multiple, preference-sensitive options.

**Conclusions:** Practitioners should include formal SDM procedures surrounding PSA testing in their practices to ensure that testing is in accordance with patient values and desired outcomes. Tools and strategies like those reviewed in this Quality Improvement Summit are invaluable for alleviating potential burden on providers, ensuring communication, and improving quality of care.

## INTRODUCTION

---

On April 2, 2016, the American Urological Association (AUA), in collaboration with the Society for Medical Decision Making (SMDM), a transdisciplinary organization focused on improving health outcomes through the advancement of proactive systematic approaches to clinical decision making and policy formation in healthcare, held a Quality Improvement Summit on prostate specific antigen (PSA) testing and shared decision making (SDM) at AUA headquarters in Linthicum, Maryland. This partnership reflects the commitment of the AUA to educating its members about the most recent research-based methods for implementing SDM (as seen through its educational materials, such as its SDM white paper, Early Detection of Prostate Cancer Guideline statement, and Early Detection of Prostate Cancer policy statement) as well as SMDM's commitment to partnering with clinical organizations to achieve the same goals.<sup>1-4</sup> As a quality improvement initiative, the AUA and SMDM seek to educate providers and promote SDM to improve quality of care. To further this goal, the AUA-SMDM Quality Improvement Summit brought together experts in SDM, urologists, primary care physicians, and patients.

PSA screening is widely recognized as a preference-sensitive decision.<sup>1</sup> The decision involves a trade-off between an expected increase in life expectancy and a potential decline in quality of life.<sup>5</sup> Heijnsdijk et al.<sup>6</sup> demonstrated that summary measures of detriment or benefit are highly reliant upon patient-specific values and influence patient perceptions of outcomes. Helping the patient identify his own values surrounding treatment outcomes, both positive and negative, is critical for ensuring that patients make optimal treatment decisions. SDM is the process of patients and providers working collaboratively to make the optimal decision for any given patients.

Since most recent PSA testing guidelines recommend the use of SDM, the Quality Improvement Summit addressed PSA-based screening for prostate cancer and how

its use should be aligned with individual patients' preferences.<sup>7</sup>

The day's discussion was organized into eight sections, each of which supported discussion of SDM as it relates to PSA. Four of the sections included two presentations covering SDM-focused research and its clinical implementation. National Football League (NFL) Hall of Fame Member and prostate cancer survivor Mike Haynes of the *Know Your Stats* campaign presented the patient perspective on PSA screening and SDM. Participants also participated in two "breakout" role-playing sessions emphasizing important SDM strategies. Each presentation was followed by very engaged discussion between the speakers and audience.

Presentations and discussions throughout the day emphasized that true SDM is different from a "discussion with a patient." SDM research demonstrates that clinicians' perceptions of effective communication may be at odds with those of their patients, who may be unable to absorb well-intentioned, yet highly technical information.<sup>8</sup> The speakers presented data supporting the use of decision aids, decision coaches, and other strategies to improve patient knowledge and prime patients for active involvement in their own treatment decisions, which is important for facilitating integration of SDM into practices. Suggested practices summarized here are based on expert opinion supported by academic research.

### **KEYNOTE SPEAKER**

Harold C. Sox, MD, MACP, Patient-Centered Outcomes Research Institute and Active Emeritus Professor of Medicine at Geisel School of Medicine at Dartmouth

Prostate cancer screening guidelines issued by a range of organizations (e.g., American Cancer Society, American College of Physicians, American Urological Association) over the past five years recommend some form of SDM between patients and providers.<sup>8</sup> The single exception is the 2012 guideline issued by the United States Preventive Services Task Force (USPSTF) that recommended against PSA testing because "Reduction in prostate cancer mortality is at most very small;

harms of screening and treatment are common and often persistent,” and concluded with “moderate certainty that benefits of screening do not outweigh harms.”<sup>9</sup> When reviewing this statement by the USPSTF, the question emerges, “how did the Task Force weigh the benefits against harms?” The Task Force used an analytical framework in which the frequency and severity of harms was *subjectively* judged against the frequency and magnitude of benefit. While this approach can be a practical way to review treatment options with individual patients, on a population level this type of comparison is complicated by the fact that the units of harm (e.g., death from prostate cancer or frequency of urinary incontinence) are not equivalent to those of benefit (e.g., relief from worry about cancer, extended longevity). In an effort to better judge the benefits of PSA testing against its potential risks, Heijnsdijk et al.<sup>6</sup> used a single metric (quality-adjusted life years [QALYs]) to measure both harms and benefits. QALYs are equivalent to years in perfect health. This strategy enabled calculation of net benefit (benefits minus harm), thereby avoiding the “apples and oranges” problem faced by the Task Force.

Quality-adjusted life expectancy is the product of multiplying the number of years in a health state by the patient’s utility of being in that health state, such as years spent doing yearly PSA testing or years of urinary incontinence. When calculating gain or loss in QALYs for 1,000 men who undergo PSA testing, the range is broad, and gains can be as high as +93 QALYS or losses as low as -24 QALYS.<sup>6</sup> This range speaks to the individual nature of gains or losses in QALYs; an individual’s net gain or loss is predicated on his clinical outcome and his perception of that outcome. The measures of a patient’s utility include the standard reference gamble, the time-tradeoff, or a mark on a linear scale. Utilities are measured on a scale bounded by zero (the worst possible outcome) and 1.0 (the best possible outcome). Patients’ utilities for a health state typically differ as shown in a study of patients with angina.<sup>10</sup>

Measuring net benefit of screening is not only helpful for making individual decisions. It can also be used to formulate a general recommendation about PSA screening. If everyone in a screening population gained QALYs, everyone should be

screened. If everyone lost QALYs, no one should be screened. However, the net benefit of screening varied in the Heijnsdijk study from gains to losses.<sup>6</sup> This result strongly implies that SDM is the optimal recommendation for the PSA screening decision where some may gain and some may lose QALYs; thus, the patients should have a strong role in the decision making process.

One audience member commented that the concepts involved in measuring the quality of life in a health state can be very difficult for patients to understand and suggested that the analytical framework laid out in the USPSTF colorectal cancer screening guidelines,<sup>11</sup> which included SDM and population-based utility measures, might serve as a model for the PSA screening recommendations as well. Other challenges to risk communication in clinical practice include patient literacy and numeracy, and understanding of the concept of risk itself. Finally, audience members questioned the use of this type of analysis for a blood test rather than for the decision to perform a subsequent diagnostic biopsy, which may involve greater risk and be more suitable for a SDM approach.

## **SHARED DECISION MAKING AND DECISION AIDS**

---

Margaret Holmes-Rovner, Professor Emerita, Health Services Research, Michigan State University, Past President, Society of Medical Decision Making; and Michael J. Barry, MD, Informed Medical Decision Foundation and Massachusetts General Hospital, Past President, Society of Medical Decision Making.

Dr. Holmes-Rover reviewed findings from a recent study with Dr. Fagerlin of over 252 encounters between urologists and patients following a positive biopsy of early-stage prostate cancer (Gleason scores of 6 and 7).<sup>12</sup> The average encounter was 23 minutes, and each encounter was scored using the informed decision making scoring system (IDM).<sup>13</sup> The following aspects of the encounter were graded: 1) Patient's role in decision making, 2) Impact of the decision on the patient's daily life (e.g., context of decision), 3) Nature of the decision or clinical issue, 4) Treatment

choices, 5) Risks and benefits surrounding alternatives, 6) Uncertainties regarding alternatives, 7) Physician assessment of the patient's understanding, 8) Physician assessment of the patient's desire for input from trusted others, and 9) Physician solicitation and exploration of the patient's preference.

Overall, physicians did very well naming choices, outlining *some* risks, and explaining that the decision itself need not be rushed. However, physician checking of understanding was usually brief and limited to the phrase "do you have any questions?" Though this is "checking," the patient reaction is almost always to say "no." Finally, although physicians usually refer to preferences, in one third of transcripts preferences remain unexplored beyond the recognition that patient preferences exist. Surgeons also have preferences; of particular importance is the finding that the recommendation of the physician surrounding surgery has a significant impact on the percentage of patients who would consider surgery as a treatment option. This reflects the leadership role physicians take in these conversations and highlights the need for physicians themselves to jointly consider patients' particular values when counseling them.

This research suggests that an additional layer of diagnosis must include diagnosing what a patient wants from treatment.<sup>14</sup> A central aspect of SDM that distinguishes it as a process is the presentation of options and choices rather than simply permitting the patient to contribute at junctures where there is a "toss up." This process capitalizes on a skill set distinct<sup>15</sup> from those required to present a patient with a diagnosis and requires multiple rounds of two-way communication. One example provided by the speaker from a recent publication on SDM is "This is a really hard decision because we aren't sure what will happen if you choose option x; let me show you how I think about this, and you can tell me whether it fits with what's important to you."<sup>16</sup> Though development of the skill set is an investment on the part of the physician, it ensures that patients are truly informed and that the decisions they make are consistent with the outcomes they want, thereby increasing patient satisfaction and, therefore, loyalty and decreasing malpractice claims.

While the audience agreed that SDM holds tremendous potential for improving quality of outcomes, several participants reiterated the belief that the average duration of a SDM meeting is well over an hour, even in well-educated patient populations.<sup>8</sup> Participants expressed a desire for feedback on how to incorporate SDM into their workflow and expressed interest in patients' ratings of SDM within their practices, noting that this type of tool can be an important mechanism for evaluating performance and a motivator for physician adoption of better SDM communication strategies.

Dr. Barry presented case studies highlighting the disconnect between patient preferences and physicians' perceptions of those preferences. Patients can be woefully uninformed about treatment outcomes. In one study, fewer than half of patients who had undergone hip or knee arthroplasty were able to answer questions surrounding the likelihood of particular surgical outcomes, including reduction of pain and how long before most patients return to normal activity.<sup>17</sup> Patient preferences can be used to differentiate between clinically equivalent treatments in early stage breast cancer. Patients ranked outcomes of mastectomy versus lumpectomy with radiation, such as loss of breast and natural appearance without clothes, very differently than did physicians.<sup>18</sup> This pattern, common among a number of different disease treatments, highlights that without incorporation of patient values, there can be no SDM.

Finally, Dr. Barry discussed the remarkable regional variation in PSA testing to illustrate that while some variation is an indicator of harmful inconsistencies in *physician preferences* and can be addressed with guidelines, variation in practice that results from patient preference should not be treated the same way. By including SDM in the physician-patient conversation, physicians can avoid variation that stems from poor decision quality. Importantly, data comparing patient knowledge of reasons for the procedure, risks, benefits, and alternate options among patients receiving radical prostatectomy versus coronary stenting for stable

angina demonstrated overall that urologists were leaders in these measures of SDM.<sup>17</sup>

Decision aids are important for identifying options, describing risk, and clarifying patient values. Over 115 randomized trials that include over 35,000 patients show better quality of decisions, increased knowledge, more accurate risk perceptions, lower decisional conflict, and fewer undecided patients when decision aids are used.<sup>8</sup> In a study on the use of decision aids in PSA testing, the men who were undecided on PSA testing generally decided not to be tested following exposure to a decision aid, whereas the choices of those men who were either for or against testing changed very little.<sup>19</sup> An important aspect of this trial, especially in light of the USPSTF guidelines, is that many men who are aware of the evidence still choose to be screened.

The International Patient Decision Aids Standards Collaboration has developed quality criteria for the development and evaluation of decision aids. They suggest that, at a minimum, decision aids include a description of the health condition, *explicit* statement of the choice at hand, identification of eligibility criteria, description of the benefits and harms of each option (in a way that patients can understand), help with patients' values clarification, and identification of the date on which the document was last updated and any funding sources.<sup>20</sup>

Audience members remarked that decision aids should be made by a not-for-profit agency, regularly updated, and freely available. This resource might be forthcoming due to provisions in the Affordable Care Act Section 3506.<sup>21</sup> In fact, the State of Washington has just started certifying decision aids, and the National Quality Forum is developing criteria for certifying decision aids.<sup>22,23</sup> Currently, the Ottawa Hospital Research Institute leads and posts the Cochrane Review of patient decision aids, and additionally they have a database of decision aids rated using the International Patient Decision Aid Standards.<sup>24</sup>

## VALUES CLARIFICATION

---

Murray Krahn, MD, MSc, FRCPC, Director, Toronto Health Economics and Technology Assessment Collaborative, Past President, Society of Medical Decision Making; and Christopher Saigal, MD, MPH, University of California, Los Angeles

Dr. Krahn reflected on the role of patient preferences in prostate cancer screening from the perspective of a decision analyst. SDM and decision analysis share a common underlying conceptual framework: thinking about choices and chances and outcomes. PSA screening is a “preference-sensitive decision” because the comparatively small population-level gain in life expectancy is associated with a small loss in quality-adjusted life expectancy. Thus, how the patients value outcomes determines whether or not screening is desirable.<sup>5</sup> Decisions in preference-sensitive care involve making trade-offs when there are competing risks and benefits, the evidence for one treatment over another is weak, or the preference outcomes vary (as is the case in prostate cancer screening).<sup>25</sup> Dr. Krahn emphasized that during guideline development, committee members are often focused on meta-analyses, randomized trials, and systematic review. Studies that focus on patient preferences or studies that integrate preferences into decision models are less often reviewed in the development of guidelines.

Because PSA fits the definition of a preference-sensitive decision, it is important to develop a measure of utility in the context of PSA testing. The Patient-Oriented Prostate Utility Scale (PORPUS)<sup>26</sup> is a ten-item measure that includes pain, energy, support from family and friends, communication with a physician, emotional well-being, frequency of leaking, sexual function, sexual drive and interest, and bowel problems. When patients who have actually experienced these outcomes are asked for their preferences, differences across sexual, urinary, and bowel dysfunction are much smaller than is reported in the literature as a whole.<sup>26</sup> Together, these studies support SDM to elucidate patient values and utilities when deciding on PSA testing

and/or treatment options.

“Patients do not necessarily know their values surrounding specific outcomes,” said Dr. Saigal, who then discussed measurement of patient values. Values clarification is designed to help patients understand their values surrounding a newly presented health decision. Currently there are no “gold standards” for elucidating patient values.<sup>27</sup> Values clarification can pose a challenging cognitive load for patients and create an emotional burden as patients sort through how they feel about sometimes disturbing possible future side effects. Time trade-off is one method that asks patients to “trade off” years of life against a bad outcome. However, many patients simply do not have the emotional strength nor the abstract ability to engage in this research method. Rating scales can be difficult because patients tend to use the ends of the scale more than the middle, leading to systematic bias.<sup>28</sup> Accordingly, values clarification exercises have been found to have significant biases when ranking what is important to patients in terms of health outcomes.<sup>29</sup>

Alternatively, conjoint analysis, a mode of measuring values from consumer marketing, may serve as a valuable tool in the prostate cancer arena.<sup>30</sup> Importantly, non-clinical attributes, such as distance to travel for care, can be incorporated.<sup>31</sup> Conjoint analysis has a lower emotional and cognitive burden than other methods and is used to predict consumer behaviors (imagine PSA testing as a product with different outcomes). Conjoint analysis has been shown to outperform time trade-off in terms of variance in stated preferences and has a superior predictive validity regarding preferences for novel health states.<sup>30</sup> In addition, this type of analysis can lend insights into the motivations behind patient decisions. For example, men expressed that seeking treatment for prostate cancer made them feel like they were “taking action.” For others, this action took the form of “saying no” to the surgeon or actively electing surgery.

One challenging aspect of conjoint analysis is the balance between making it short and making it precise. Typically patients who used conjoint analysis found the tool

satisfactory and experienced less decisional conflict than when given a pamphlet alone. Coupled with the comparative performance of the test, these aspects of conjoint analysis make it a viable approach for use in the clinic alongside preference assessment and treatment guidelines.

## DECISION COACHING

---

Kristin Chrouser, MD, MPH, Minneapolis Veterans Administration Medical Center; and Dawn Stacey, RN, PhD, University Research Chair in Knowledge Translation to Patients, School of Nursing, University of Ottawa

To introduce the idea of decision coaching, Drs. Chrouser and Stacey guided the summit participants and audience members through a role-playing exercise. Each group had participants take on the roles of clinician or provider, patient, patient's partner, and decision coach. The patient was a 69-year-old white man, newly diagnosed with Gleason score 4+3=7 prostate cancer with PSA = 10ng/mL. He has a few genitourinary symptoms and uses medication for mild erectile dysfunction. Participants were asked to role-play and coach the patient through a discussion of treatment options.

Following the activity, participants were asked about their recommendations. Though recommendations by providers are appropriate in many cases, the role of the *decision coach* is unique in that he or she does not and should not offer suggestions. Decision coaches can be "navigators" employed by the hospital, nurses, or other support staff trained in the concept of SDM.<sup>32</sup> In the case of prostate cancer, decision coaches can serve as a valuable tool to help the patient to digest the information he has been given and process conflicting opinions or advice. Decision coaching can be done over the phone or face-to-face.<sup>33</sup>

Though audience members agree that patients often need help navigating options,

many physicians feel that it is *their* role to guide patients to the appropriate treatment. Though practitioners are busy, many do not like the idea of ancillary care taking over communication with patients. The point was made, however, that although the physician knows more about care, other healthcare professionals, including community health workers or decision coaches, are often better able to *communicate* with patients.<sup>34</sup> Indeed, in studies evaluating patient decision aids with lower-literacy patients, gains in participation and knowledge were higher than among average patients.<sup>35</sup>

Dr. Stacey built upon the group activity and presented evidence surrounding healthcare decision coaching. Though physicians may make recommendations for their patients with the intention of helping a patient make a decision, they may inadvertently be erecting a barrier to SDM by reinforcing a power imbalance.<sup>36</sup> In order to participate in SDM, patients must be aware of their own personal values and preferences as recommendations may preempt any discussion about what those values may be. In order to participate, patients must have a perceived influence on a decision-making encounter by having permission to participate, confidence in their own knowledge, and self-efficacy in using their SDM skills.<sup>37</sup> When asked how the process of SDM can be improved, many patients identified nurses as being helpful in explaining the information, providing support by listening, and serving as facilitators by providing doctors with preferences.

Decision coaches are trained healthcare professionals who are non-directive and provide support that aims to develop patient skills surrounding thinking about options, preparing patients to discuss decisions during clinician consultation, and implementing decisions if appropriate.<sup>33</sup> The decision coach can clarify the decision, point out options to be considered, review the reasons to choose the option or benefits, and note the benefits and potential disadvantages of each option. Approaches decision coaches can use to clarify values include asking patients which benefits are most important, which harms are most important to avoid, and rating

the importance on a scale from least important to most important. Throughout the process, coaching must be tailored to patients' needs.<sup>38</sup>

Though the use of third-party decision coaches can be associated with increased resources (e.g., time to train and overhead) and can raise issues of triangulation or confusion in terms of reimbursement and liability, it can relieve demands on the clinician and become an integrated part of care.<sup>34</sup> A systematic review measured the advantages of using decision coaches and found a similar increase in knowledge to that associated with the use of decision aids.<sup>39</sup> However, the increase in values clarification achieved with decision coaches can be especially important in settings where patients are in need of additional guidance.

## **THE PATIENT PERSPECTIVE**

---

Mike Haynes, Urology Care Foundation *Know Your Stats* Campaign and National Football League (NFL) Hall of Fame Member

While working for the NFL, Mr. Haynes discovered he had prostate cancer during a 2008 screening conducted by the AUA's Urology Care Foundation and supported by the NFL Player Care Foundation. Mr. Haynes shared with the audience his own experience with prostate cancer screening and treatment as well as his experience as a spokesperson and educator. He described his experiences discussing prostate cancer with other men, many of whom are unaware of the significance of family histories or the elevated risk associated with being African American. In sharing his personal story, Mr. Haynes brought forth a sense of urgency surrounding the importance of PSA testing and its potential to save lives.

An audience member raised the concern that while Mr. Haynes' story is compelling, there is no advocacy for patients who did not get the PSA test and are fine or for those patients who have suffered poor outcomes needlessly as the result of a preference-discordant use of PSA screening. Audience members emphasized the

importance of promoting appropriate health care as well as fitness when discussing men's health.

## COMMUNICATIONS

---

Angela Fagerlin, PhD, Professor and Chair, Department of Population Health Sciences, University of Utah, Research Scientist, VA Salt Lake City Center for Informatics Decision Enhancement and Surveillance (IDEAS), President-Elect, Society of Medical Decision Making; and Robert L. Waterhouse, Jr., MD, MBA, Carolina Urology Partners, PLLC

Dr. Fagerlin reinforced the importance of communication in preference-sensitive decisions. Care must be taken to ensure a patient understands the benefits and risks of screening, and how the information can be used when deciding upon screening. Though patients are often comfortable asking questions and discussing preferences, it is rare that patients will disagree with a physician. In one study, only two percent of patients reported that they would ever disagree with their physicians.<sup>40</sup> In some cases, interest of the patient and the skill set of the physician can be obstacles to SDM. In the case of prostate cancer, patients can have difficulty talking about impotence, incontinence, and treatment options. In many cases, a lack of knowledge is an obstacle, but literacy and numeracy can also be considerations. The average American reads at a 7<sup>th</sup> or 8<sup>th</sup> grade level; implicit in this is that there are many people reading below that level. Illiterate people need not have low IQ or poor social functioning; hence illiteracy can be frequently hidden from healthcare providers. While decision aids can be helpful for this population, many decision aids are written at a 9<sup>th</sup> or 10<sup>th</sup> grade (or higher) level, making them inaccessible to the very people who would benefit from them the most. Numeracy can be a significant barrier to SDM because many patients do not understand measures of risk.<sup>41</sup> In fact, approximately 20 percent of college-educated adults could not identify whether a one or ten percent risk of getting prostate cancer is a larger risk.<sup>42</sup> The use of graphs

and figures, especially icons of people, to illustrate risk can increase patient understanding.<sup>43</sup>

When eliciting patient preference, it is important to ask focused, open-ended questions. Asking the patient to repeat what he understood can ensure that the communication was effective, that the patient understands the key information correctly, and the physician understands the patient's values that lead to this decision. Finally, ending the conversation by talking about the next steps can reinforce that a decision not to get screened this time does not eliminate the chance to be screened next year, should the patient change his mind.

Dr. Waterhouse discussed how cultural identity and leadership styles can shape how physicians communicate with patients. In discussions with patients, the physician is the leader, highlighting the responsibility and the need for higher degrees of cultural awareness. Understanding and adjusting to one's cultural self-identity is important for effective interactions with others. Additionally, patient cultural identity can inform trust or mistrust of physicians and can determine how patients react to certain leadership styles. Dr. Waterhouse encouraged participants to build an understanding of "yourself and your own tendencies, and how you interact with others." He went on to explain that cultural self-identity includes both cultural and universal dimensions.<sup>44</sup> Even within our own country, cultures vary greatly. The way in which people see their own culture based on these types of dimensions impacts the ways in which they communicate. Differences in perceptions can stem from individual versus family priorities, openness to risk, and acceptance of hierarchy.<sup>45</sup> These cultural differences impact the ways in which people perceive even the same approach to SDM by a single practitioner.

Being mindful of patient health literacy and communicating with the most effective style is important. Assumptions can sabotage efforts to determine health priorities. While empathy is useful for putting yourself in someone's *position*, it is very difficult to place yourself in someone's *perception*. For example, cultural memory of

physicians can play into current interactions: the assumption that African Americans have more aggressive disease can shape treatment recommendations.<sup>46</sup> Inherent biases of both patients and physicians can lead to poorer communication, increased trepidation for both physician and patient, and, therefore, treatments that are not consistent with a patient's values. African American men, for example, have less access overall to treatment: African American men are 33 percent less likely to have surgery than Caucasians with a similar grade of disease.<sup>47</sup> Finally, inability to identify with the physician is also a factor in patient willingness to openly discuss healthcare values.<sup>48</sup>

Mismatches in power distance, formal versus informal communication style, and masculine versus feminine behavior further compound communication challenges.<sup>49-51</sup> Decision coaches can be very helpful for serving as cultural translators when educating patients about their options. Between the diagnosis and a follow-up meeting to discuss options, communication with a support staff member who is more culturally accessible to the patient can promote high-quality outcomes. There are cultural challenges at both the individual provider and national healthcare level that impact communication for SDM. However, potential improvements may be achieved through thoughtful consideration of setting, self, and patient, with focus on empathy. Audience members commented that residents are not getting the communication skills training of watching faculty interact with patients. It was noted that few residents have never had the experience delivering bad news, a state that puts them at a disadvantage for assessing cultural gaps.<sup>52</sup>

## **DOING SHARED DECISION MAKING IN PRACTICE: PSA SCREENING**

---

David R. Rovner, MD, Professor Emeritus, College of Human Medicine, Michigan State University

When making medical decisions, the question of how likely something is to occur if

one is treated must be balanced against what happens as a result of various modalities of treatment. PSA screening and prostate cancer treatment is a preference-sensitive decision, and the outcome occurs not to the physician but to the patient. In order to make an informed decision, patients must be able to put their own utilities on outcomes. To do that, they must be apprised of the risks and benefits, and physicians must determine whether patients really understand.

In a role-playing exercise, participants were provided with scenarios (including patient information, what the physician knows about the patient, and what the partner or wife might want) and asked to help the patient come to a decision about PSA testing.

Overall, participants voiced that it is difficult to gauge the right amount of communication around the consequences of an abnormal PSA. Participants agreed that a good first step is to communicate with the patient to get a sense of how he feels about preventative care and screening. One urologist commented that he rarely gets the chance to talk about PSA with patients because the test is generally done by the primary care physician before the patient is referred. In some cases, the primary care physician is unaware of the implications of testing. One urologist says to patients, “if you would be uncomfortable knowing you have cancer and not treating it, screening may not be for you.” Participants agreed that use of an evidence-based decision aid does not necessarily add time to the visit.

During discussion, participants revisited the idea that SDM surrounding PSA testing may provide needlessly complicated information since so few patients end up undergoing biopsy. Though the potential benefits of SDM in the detection and treatment of prostate cancer seem a more high-yield area in which to engage in an SDM approach, screening still presents the risk of over-diagnosis and over-treatment of prostate cancer. Given the current data on the downstream consequences of PSA screening, physicians “owe it to the patient” to offer to describe the potential outcomes.

## FEDERAL GOVERNMENT PERSPECTIVE

---

Kate Goodrich, MD, MHS, Director, Centers for Medicare & Medicaid Services Center for Clinical Standards and Quality

Dr. Goodrich presented information on how SDM has been integrated into certain national coverage determinations. The government defines SDM as sharing as much information as a patient wants to hear around a particular test or technology with an emphasis on the patient's preferences. Generally, coverage decisions are made locally; however, a request made by an outside party can begin the process of national coverage determination. Medicare Improvements for Patients & Providers Act (MIPPA) legislation passed in 2008 allowed the national coverage determination process to be applied to preventive services if screening is “reasonable and necessary,” and recommended with a grade A or B by the USPSTF.<sup>53</sup> In response to the 2011 National Lung Screening Trial, USPSTF gave a grade B to screening in 2013 for a subset of patients.<sup>54</sup> Among a few other criteria, coverage determination for screening requires SDM. Because there is such a narrow window of evidence of benefit (and two other trials that were negative), CMS requires the use of a published, evidence-based decision aid.<sup>55</sup> The decision aid is designed to result in a more accurate perception of risk; aids are often pictorial and provide evidence about options along with pros and cons of those options.<sup>1</sup>

Dr. Goodrich emphasized that CMS did *not* propose a penalty for PSA testing, but when developing quality measures around safety, had elected to include appropriate PSA testing as a measure that urologists could choose to report under the new Quality Payment Program. Depending on the physician's performance on the metric, reimbursement could be impacted. Push back from AUA and others prompted suspension of the measure until USPSTF is finished revisiting deliberations on their PSA testing recommendations. Should the recommendation remain unchanged, coverage decisions can continue to be made at the local level,

unless an outside party requests national coverage. At this point, a public process to propose a coverage determination will begin, but by law, the USPSTF recommendations must be followed.

## **CONCLUSIONS AND NEXT STEPS**

---

Timothy Averch, MD, AUA Quality Improvement and Patient Safety Committee Vice Chair and University of Pittsburgh Medical Center

The day's event concluded with the AUA's quality leaders reflecting upon the communication strategies covered during the talks and how data and practical concerns can converge in SDM. AUA quality leaders underscored the importance of SDM for complex medical decisions. Aspects of SDM include good and culturally aware communication skills, the use of a third party, such as a decision coach, when prudent. However, the Quality leadership also emphasized that this is a rapidly evolving field. As SDM becomes tied to payment models and quality measures the strategies and considerations outlined in this meeting will represent the cutting edge of physician-patient communication.

## BIBLIOGRAPHY

---

1. Makarov D, Fagerlin A, Chrouser K. AUA White Paper on Implementation of Shared Decision Making into Urological Practice. American Urological Association Website. 2015. <http://www.auanet.org/education/other-aua-clinical-guidance-documents.cfm>. 1-9-2017.
2. Carter HB, Albertsen PC, Barry MJ, et al. Early detection of prostate cancer: AUA Guideline. *J Urol*. 2013; 190: 419.
3. American Urological Association. Early detection of prostate cancer policy statement. American Urological Association Website. April 2013. <http://www.auanet.org/education/policy-statements/early-detection-of-prostate-cancer.cfm>. 1-11-2017.
4. Urology Care Foundation. Is prostate cancer screening right for me? Urology Care Foundation Website. 2014. <http://www.urologyhealth.org/educational-materials/is-prostate-cancer-screening-right-for-me>. 1-11-2017.
5. Krahn MD, Mahoney JE, Eckman MH, et al. Screening for prostate cancer. A decision analytic view. *JAMA*. 1994; 272: 773.
6. Heijnsdijk EA, Wever EM, Auvinen A, et al. Quality-of-life effects of prostate-specific antigen screening. *N Engl J Med*. 2012; 367: 595.
7. Hoffman R. Screening for prostate cancer. UpToDate® Website. Jul 13 2016. <https://www.uptodate.com/contents/screening-for-prostate-cancer>. 1-9-2017.
8. Stacey D, Legare F, Col NF et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2014; 1: CD001431
9. US Preventive Services Task Force. Final Recommendation Statement, Prostate Cancer: Screening. US Preventive Services Task Force Website. May 2012. <https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/prostate-cancer-screening>. 1-9-2017.
10. Nease RF, Jr., Kneeland T, O'Connor GT, et al. Variation in patient utilities for outcomes of the management of chronic stable angina. Implications for clinical practice guidelines. Ischemic Heart Disease Patient Outcomes Research Team. *JAMA*. 1995; 273: 1185.
11. Whitlock EP, Lin JS, Liles E, et al. Screening for colorectal cancer: a targeted, updated systematic review for the U.S. Preventive Services Task Force. *Ann Intern Med*. 2008; 149: 638.
12. Holmes-Rovner M, Montgomery JS, Rovner DR, et al. Informed Decision Making: Assessment of the Quality of Physician Communication about Prostate Cancer Diagnosis and Treatment. *Med Decis Making*. 2015; 35: 999.
13. Braddock CH, 3rd, Edwards KA, Hasenberg NM, et al. Informed decision making in outpatient practice: time to get back to basics. *JAMA*. 1999; 282: 2313.
14. Mulley AG, Trimble C, Elwyn G. Stop the silent misdiagnosis: patients' preferences matter. *BMJ*. 2012; 345: e6572.

15. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med.* 2012; 27: 1361.
16. Fried TR. Shared Decision Making--Finding the Sweet Spot. *N Engl J Med.* 2016; 374: 104.
17. Fowler FJ, Jr., Gallagher PM, Bynum JP, et al. Decision-making process reported by Medicare patients who had coronary artery stenting or surgery for prostate cancer. *J Gen Intern Med.* 2012; 27: 9116.
18. Sepucha KR, Levin CA, Uzogara EE, et al. Developing instruments to measure the quality of decisions: early results for a set of symptom-driven decisions. *Patient Educ Couns.* 2008; 73: 504.
19. Barry MJ, Wexler RM, Brackett CD, et al. Responses to a Decision Aid on Prostate Cancer Screening in Primary Care Practices. *Am J Prev Med.* 2015; 49: 520.
20. International Patient Decision Aid Standards (IPDAS) Collaboration. Using IPDAS. International Patient Decision Aid Standards (IPDAS) Collaboration Website. Jan 28, 2015. <http://ipdas.ohri.ca/using.html>. 1-9-2017.
21. US Department of Health & Human Services. Read the Law, The Affordable Care Act, Section by Section. US Department of Health & Human Services Website. Aug 28, 2015. <https://www.hhs.gov/healthcare/about-the-law/read-the-law/>. 1-9-2017.
22. Washington State Health Care Authority. Health Care Authority certifies first patient decision aids. Washington State Health Care Authority Website. Aug 22, 2016. <http://www.hca.wa.gov/about-hca/health-care-authority-certifies-first-patient-decision-aids>. 1-9-2017.
23. National Quality Forum. NQF to Develop National Standards, Measurement for Patient Decision Aids. National Quality Forum Website. [http://www.qualityforum.org/Helping\\_Patients\\_Make\\_More\\_Informed\\_Decisions.aspx](http://www.qualityforum.org/Helping_Patients_Make_More_Informed_Decisions.aspx). 1-9-2017.
24. The Ottawa Hospital Research Institute. Patient Decision Aids. The Ottawa Hospital Research Institute Website. Apr 17, 2015. <https://decisionaid.ohri.ca/>. 12-7-2016.
25. O'Connor AM, Wennberg JE, Legare F, et al. Toward the 'tipping point': decision aids and informed patient choice. *Health Aff (Millwood).* 2007; 26: 716.
26. Krahn M, Ritvo P, Irvine J, et al. Construction of the Patient-Oriented Prostate Utility Scale (PORPUS): a multiattribute health state classification system for prostate cancer. *J Clin Epidemiol.* 2000; 53: 9200.
27. Giesler RB, Ashton CM, Brody B, et al. Assessing the performance of utility techniques in the absence of a gold standard. *Med Care.* 1999; 37: 580.
28. Cook KF, Ashton CM, Byrne MM, et al. A psychometric analysis of the measurement level of the rating scale, time trade-off, and standard gamble. *Soc Sci Med.* 2001; 53: 1275.
29. Soucek J, Stacks JR, Brody B, et al. A trial for comparing methods for eliciting treatment preferences from men with advanced prostate cancer: results from the initial visit. *Med Care.* 2000; 38: 1040.

30. Byrne MM, Soucek J, Richardson M, et al. Racial/ethnic differences in preferences for total knee replacement surgery. *J Clin Epidemiol.* 2006; 59: 1078.
31. Shackley P, Slack R, Michaels J. Vascular patients' preferences for local treatment: an application of conjoint analysis. *J Health Serv Res Policy.* 2001; 6: 151.
32. O'Connor AM, Stacey D, Legare F. Coaching to support patients in making decisions. *BMJ.* 2008; 336: 228.
33. Stacey D, Murray MA, Legare F, et al. Decision coaching to support shared decision making: A framework, evidence, and implications for nursing practice, education, and policy. *Worldviews Evid Based Nurs.* 2008; 5: 25.
34. Woolf SH, Chan EC, Harris R, et al. Promoting informed choice: transforming health care to dispense knowledge for decision making. *Ann Intern Med.* 2005; 143: 293.
35. Durand M-A, Carpenter L, Dolan, et al. Do Interventions Designed to Support Shared Decision-Making Reduce Health Inequalities? A Systematic Review and Meta-Analysis. *PLoS One.* 2014; 9: e94670.
36. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns.* 2014; 94: 291.
37. Legare F, Stacey D, Gagnon S, et al. Validating a conceptual model for an inter-professional approach to shared decision making: a mixed methods study. *J Eval Clin Pract.* 2011; 17: 554.
38. The Ottawa Hospital Research Institute. Decision Coaching. Apr 24, 2015. <https://decisionaid.ohri.ca/coaching.html>. 12-7-2016.
39. Stacey D, Kryworuchko J, Bennett C, et al. Decision coaching to prepare patients for making health decisions: A systematic review of decision coaching in trials of patient decision aids. *Med Decis Making.* 2012; 32: E22.
40. Frosch DL, May SG, Rendle KA, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood).* 2012; 31: 1030.
41. Fagerlin A, Rovner D, Stableford S, et al. Patient education materials about the treatment of early-stage prostate cancer: a critical review. *Ann Intern Med.* 2004; 140: 721.
42. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. *Med Decis Making.* 2001; 21: 37.
43. Zikmund-Fisher BJ, Witteman HO, Dickson M, et al. Blocks, ovals, or people? Icon type affects risk perceptions and recall of pictographs. *Med Decis Making.* 2014; 34: 443.
44. Samovar LA, Porter RE, McDaniel ER. *Intercultural communication : a reader.* 13th ed. Boston, Mass.: Wadsworth Cengage Learning; 2012.
45. Hofstede GH. *Cultures and organizations : software of the mind.* Rev. ed. New York: McGraw-Hill; 1997.

46. Moses KA, Paciorek AT, Penson DF, et al. Impact of ethnicity on primary treatment choice and mortality in men with prostate cancer: data from CaPSURE. *J Clin Oncol.* 2010; 28: 1069.
47. Moses KA, Orom H, Brasel A, et al. Racial/ethnic differences in the relative risk of receipt of specific treatment among men with prostate cancer. *Urol Oncol.* 2016; 34: 415.
48. Royal C, Baffoe-Bonnie A, Kittles R, et al. Recruitment experience in the first phase of the African American Hereditary Prostate Cancer (AAHPC) study. *Ann Epidemiol.* 2000; 10: S68.
49. Schoenfelder T. Enhancing patient outcomes by decreasing power distance. Caliper Website. Apr 22, 2014. <https://www.calipercorp.com/enhancing-patient-outcomes/>. 1-10-2017.
50. The Business Communication. The Advantage and disadvantage of formal communication. The Business Communication Website. <http://thebusinesscommunication.com/advantage-and-disadvantage-of-formal-communication/>. 1-10-2017.
51. Leigh E. Men & women communicating in the workplace. The Center for Healthcare Communication. [http://www.communicatingwithpatients.com/articles/male\\_female\\_communication.html](http://www.communicatingwithpatients.com/articles/male_female_communication.html). 1-10-2017.
52. Chesanow N. Delivering 'bad' vs 'serious' news to patients. Medscape website. Jan 27, 2016. [http://www.medscape.com/viewarticle/856955\\_6](http://www.medscape.com/viewarticle/856955_6). 1-11-17.
53. Government Printing Office. Public Law 110-215 Medicare Improvements for Patients and Providers Act of 2008. Government Printing Office Website. Jul 2008. <https://www.gpo.gov/fdsys/pkg/PLAW-110publ275/pdf/PLAW-110publ275.pdf>. 1-9-2017.
54. US Preventive Services Task Force. Final Recommendation Statement, Lung Cancer: Screening. US Preventive Services Task Force Website. Dec 2013. <https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/lung-cancer-screening>. 1-9-2017.
55. Centers for Medicare & Medicaid Services. Decision Memo for Screening for Lung Cancer with Low Dose Computed Tomography (LDCT) (CAG-00439N). Centers for Medicare & Medicaid Services Website. Feb 2015. <https://www.cms.gov/medicare-coverage-database/details/nca-decision-memo.aspx?NCAId=274>. 6-13-2017.