



The value of personalized risk information: a qualitative study of the perceptions of prostate cancer patients

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10 **The value of personalized risk information: a qualitative study of the perceptions of**
11 **prostate cancer patients**
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Abstract

Objective. To explore prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Design. A qualitative study was conducted using focus groups. Semi-structured interviews explored participants' experiences with using risk information, and their perceptions of the potential value of precise, personalized, risk information produced by clinical prediction models (CPMs).

Participants. English-speaking patients, ages 54-82, diagnosed with prostate cancer within the past 3 years, residing in rural and non-rural geographic locations in Maine (USA), and attending local prostate cancer patient support groups.

Setting. Six focus groups were conducted with 27 patients; separate groups were held for patients with low, medium, and high-risk disease defined by National Comprehensive Cancer Network guidelines.

Results. Participants most commonly reported receiving risk information that was imprecise rather than precise, qualitative rather than quantitative, indirect rather than direct, and focused on biomarker values rather than clinical outcomes. Some participants felt that personalized risk information could be valuable in helping them make better informed decisions, but most expressed skepticism about its value. Most participants favored decision-making strategies that were heuristic-based and intuitive rather than risk-based and deliberative, and perceived other forms of evidence—emotions, recommendations of trusted physicians, personal narratives—as more reliable and valuable in treatment decisions.

Conclusions. Prostate cancer patients have little experience using personalized risk information, favor heuristic- over risk-based decision making strategies, and perceive personalized risk

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3 information as less valuable than other types of evidence. Patients' preferred approaches to
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5 decision-making and their perceptions of the relative value of different types of evidence are
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7 potential barriers to the clinical use of personalized risk information. Overcoming these barriers
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9 will require providing patients with greater exposure to risk information, environmental
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11 resources for deliberative decision making, and education about the nature and value of
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13 personalized risk information.
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Article Summary

Article Focus

- Personalized risk information is an increasingly common, important form of evidence in the treatment of prostate cancer and numerous other medical conditions, but little is known about the extent to which patients use and value such information.
- This study explored prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Key Messages

- Prostate cancer patients have little experience using personalized risk information in clinical decisions, and the risk information they commonly receive is imprecise, qualitative, and indirect.
- Many prostate cancer patients favor decision-making strategies that are heuristic-based and intuitive rather than risk-based and deliberative, and perceive personalized risk information as having little value in clinical decision making
- Effective application of personalized risk information to clinical decisions will require increasing patients' exposure to this information, creating environmental conditions that favor greater deliberation in decision making, and providing patients with education about its nature and value relative to other types of evidence

Strengths and Limitations

- The study provides empirical evidence on the value of personalized risk information from the patient perspective, and identifies previously unexamined barriers to effective use of this information.

- The study sample was relatively small and homogeneous, and qualitative methods cannot definitively establish the prevalence, causes, or effects of the patients' experiences and perceptions.

For peer review only

Introduction

Personalized, or individualized, risk information—information about the probability of future health outcomes for individual patients¹—is an increasingly common and important form of clinical evidence. In recent years, burgeoning efforts to develop clinical prediction models (CPMs)—statistical algorithms that utilize characteristics of the patient, disease, and treatment to estimate individualized probabilities of health outcomes²—have increased the supply of personalized risk information. Meanwhile, a growing emphasis on the ideals of personalized health care, patient-centered outcomes research, and informed and shared decision making have heightened clinical demand for this information.³⁻⁸ Personalized risk information advances each of these important health care ideals, enabling decision making based on the expected outcomes of individuals rather than groups, on prognostic estimates rather than diagnostic categories,⁹ and on patient values and preferences.² Emerging evidence supports this vision; a recent Cochrane review concluded that personalized risk information promotes informed patient decision making in cancer screening.¹⁰

Nevertheless, the clinical value of personalized risk information is limited by several barriers, including the conceptually abstract nature of risk information,¹¹⁻¹⁴ psychological biases, and well-documented deficits in numeracy that impede its comprehension by both patients and health professionals.¹⁵⁻²² Correspondingly, several studies have shown that patients' understanding of personalized risk estimates produced by CPMs is poor.²¹⁻²⁹ A deeper problem, however, is that precise, quantitative risk information may not be what patients really want or need. Zikmund-Fisher has argued that such information is not always informative, and “simpler, less precise representations” of risk are often more useful to patients.³⁰ In a similar vein, Reyna has

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3 contended that people prefer to construe risk in qualitative terms representing its “gist” meaning,
4 rather than in precise, quantitative terms representing its “verbatim” details.³¹ Gigerenzer has
5 gone further to challenge the conception of rationality underlying efforts to apply risk
6 information to decision making. Extending an argument put forth by the economist Simon in the
7 1950s,³² he emphasizes that rationality is “bounded” by limitations in the cognitive and
8 environmental resources available to decision makers. Consequently, in real world decisions
9 people do not “optimize”—i.e., they do not calculate and weigh probabilities and values in an
10 exhaustive computational search for the best option. Instead, they use heuristics—“fast and
11 frugal” rules of thumb that facilitate adaptive decisions.
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27 These insights raise fundamental questions about the usefulness of precise, quantitative risk
28 information in health care. Is such information really needed and desired by patients? Do
29 patients—as opposed to health professionals—perceive personalized risk information as
30 valuable, and how might their perceptions influence the success of efforts to use CPMs in
31 clinical practice?
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41 The aim of the current research was to explore these questions, focusing on personalized risk
42 information in the treatment of prostate cancer—the most common and 2nd most common male
43 cancer in the US and worldwide, respectively, and the 2nd and 6th leading cause of male cancer
44 deaths.³³⁻³⁵ Approximately 80% of newly diagnosed prostate cancer patients have clinically-
45 localized disease for which there are multiple treatment options—surgery, radiation therapy,
46 conservative treatment (active surveillance)—each with differing potential benefits and harms.³⁴
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55 The same is true for the treatment of more advanced, higher-risk disease. Prostate cancer has
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3 thus become a primary focus of predictive modeling activities, resulting in the development of
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5 over 100 CPMs³⁶⁻⁴² and growing efforts to disseminate and apply these models in clinical
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8 practice.⁴¹⁻⁴⁶
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12 Little is known, however, about prostate cancer patients' perspectives on the value of CPMs and
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14 the information they produce. To this end, the current study explored prostate cancer patients'
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16 experiences with using risk information in treatment decisions, and their perceptions of the value
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18 of precise, personalized risk information produced by CPMs. The ultimate goal was to generate
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20 insights that might inform efforts to use CPMs to promote personalized, informed decision
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22 making in the treatment of prostate cancer and other conditions.
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29 **Methods**

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32 **Study design, participants, and data collection.** This qualitative study employed focus groups,
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34 a useful methodology for exploring people's perceptions, beliefs, and attitudes.^{47,48} From
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36 September 2010–February 2011, 7 focus groups were conducted with 27 prostate cancer patients
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38 in the state of Maine (3-6 patients/group). Participants were members of the Maine Coalition to
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40 Fight Prostate Cancer (MCFPC), a patient advocacy organization that administers 10 support
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42 groups throughout the entire state. Eligible participants were English-speaking prostate cancer
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44 survivors within 3 years of initial diagnosis. A purposive recruiting strategy was employed to
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46 select patients with varying treatment experiences and prognoses. To achieve sufficient within-
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48 group homogeneity to encourage open discussion,⁴⁹ participants were stratified into 3 groups
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50 (**Table 1**) according to their risk for recurrent disease (Low, Medium, High), as defined by U.S.
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52 National Comprehensive Cancer Network guidelines.⁵⁰ A total of 2 Low Risk, 3 Medium Risk,
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3 and 2 High Risk focus groups were conducted at MCFPC support group sites in 3 rural and non-
4 rural towns and cities (Brunswick, Lewiston, Portland). Participants received \$50 compensation.
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7 Sessions lasted approximately 2 hours, were audiorecorded with prior consent of participants,
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10 and transcribed verbatim by a professional transcription service.
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15 **Interview content.** Groups were led by PH and either a professional moderator or another study
16 investigator (TK). Interviews were semi-structured and followed a moderator guide consisting
17 of open-ended questions and close-ended probes designed to elicit patients' past experiences
18 with risk information, preferences for personalized risk information, and attitudes towards
19 CPMs. Interviews utilized visual aids consisting of screenshots of web-based CPMs for several
20 different prostate cancer outcomes (e.g., risk of cancer recurrence, cancer-free survival, death)
21 produced by the Cleveland Clinic (http://www.lerner.ccf.org/qhs/risk_calculator/index.php)⁴²
22 and Memorial Sloan-Kettering Cancer Center (<http://www.mskcc.org/mskcc/html/10088.cfm>).⁵¹
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24 During the course of the study, minor revisions were made in the interview guide to clarify
25 emergent themes.
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41 **Data analysis.** In-depth analysis and line-by-line software-assisted coding of anonymized
42 interview transcripts was conducted using the program NVivo (Version 8; QSR International).
43 First, three investigators (PH, MN, BR) developed a preliminary conceptual schema and
44 codebook by independently reading 3 transcripts, categorizing participants' verbatim statements
45 according to thematic content, and organizing emergent themes—consistent with a “grounded
46 theory” approach to the data.^{52,53} Preliminary codebooks were reviewed by the team and areas of
47 disagreement were resolved through further discussion. A single working codebook was then
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3 produced, which two investigators (MN, BR) used to code the remaining transcripts, employing
4 a “constant comparative” method to compare new data, concepts, and themes with ones
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6 previously identified.^{52,54} The research team held periodic meetings to discuss coding decisions,
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8 identify new themes, and resolve areas of disagreement. Finally, two investigators (PH, NH)
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10 conducted a secondary review of all coded text to organize dominant themes.
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14 15 16 17 18 **Results**

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20 Characteristics of participants are in **Table 2**. The primary interview domains consisted of
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22 participants’ 1) past experiences with risk communication, and 2) perceptions of the value of
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24 personalized risk information produced by CPMs.
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29 30 **Past experiences with risk communication**

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32 Within these broad domains several dominant themes emerged; the first was the broad spectrum
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34 of risk communication experiences and practices reported by participants.
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39 ***Absence of explicit risk communication.*** At one end of the spectrum were a small number of
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41 participants who reported having never received risk information of any kind during the decision
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43 making process:
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46 *I wasn’t actually told about the numbers. I just went by what they were saying. I guess—*
47 *they knew what the numbers were, what the odds were for me, and I went with that and*
48 *yeah, I would’ve wanted to know what the numbers were. [Medium-Risk Participant]*
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51 For these few participants treatment risks were implicitly understood rather than explicitly
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53 communicated:
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56 *I think the conversation that I had with my urologist was we each knew all of those*
57 *possibilities. It was kind of like a given, and our conversation was based on the fact that*
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we each knew those facts, so they weren't really mentioned specifically. It was just, you've got it, here are your options to deal with it because you want to deal with it because it could be fatal, it could spread. [Low-Risk Participant]

Quantitative risk communication. At the other end of the spectrum were just two participants, among all groups, who reported receiving precise, detailed, quantitative risk information. One low-risk and one medium-risk participant each recalled being shown a “histogram” and other visual aids detailing different risk levels for different treatment outcomes, broken down by demographic characteristics. Neither participant, however, recalled their risk estimates.

More commonly, quantitative risk information was communicated in imprecise terms. For example, several participants recalled being provided with “average” risk estimates applicable to patient subpopulations—e.g., stratified by cancer stage—while several others reported receiving a range rather than point estimate of risk.

Categorical risk communication. The more commonly reported mode of risk communication, was categorical and non-quantitative. A low-risk participant noted: “*he didn't say anything about the likelihood of spreading, but, you know, just, what he told me on the phone it was a low, that it was low.*” Other participants recalled the use of similarly broad categories—e.g., “good,” “most likely,” “very remote,” “high,” “very likely.”

Indirect risk communication: the biomarker heuristic. The most commonly reported mode of risk communication by far, however, was indirect, through the use of biomarker information—primarily prostate specific antigen (PSA) values or Gleason scores. Illustrative quotations from men at different levels of risk for disease recurrence are in **Table 3**. For participants in all

groups, biomarker values served as an anchor point that helped them understand the magnitude of their risk and provided a basis for decision making; as one medium-risk participant related, referring to his PSA values: “when you don’t have any guidelines to go by, you gotta have some idea where that is, whether it’s a four or six or ten or whatever.” The use of biomarkers was a heuristic strategy that obviated the need to deal directly with outcome probabilities *per se*:

INTERVIEWER: So they gave you a sense of what those numbers meant ... a four means you have an X percent chance of—

PATIENT 3: No, they didn’t.

INTERVIEWER: But they just said—it was good—versus bad, right?

PATIENT 3: Yeah.

PATIENT 2: That’s what I got out of it when I was told I had—the PSA was 9 I think and my Gleason was 7—and like everybody else, you know, you’re just completely naïve about it, but, by explaining then, telling me that, well, the 9, you better do something about it, you know—I mean, it’s not a necessity, but they didn’t recommend not doing anything about it all ... So those numbers I think ... kind of helps you towards whichever goal you wanna go to. [High-Risk Participant]

I really, you know, I read the books ... And, I’m sure they had all sorts of graphs and stuff like that. But I’ve got to admit when I looked at my Gleason scores, this is gonna sound, you know it’s all irrelevant. You know, my Gleason score is this. Stage 4. [High-Risk Participant]

PATIENT 3: Well I think—if they’re telling me my Gleason scale was under 4, I wouldn’t have done anything.

PATIENT 1: Yeah, that’s what I would do.

PATIENT 3: But when they said 6, that’s when Dr. X said it’s time to really think about it. But with me, I was upset for a little while, but once I made up my mind to do something, then I wasn’t. The whole thing is wondering what you’re gonna do and once you make up your mind—Yeah, then that’s it. [Medium-Risk Participants]

The usefulness of biomarker values appeared to stem from their apparently “hard,” tangible nature, and their straightforward connection to a defined course of action:

PATIENT: My decision was based upon what we had for biopsies and stuff like that.

INTERVIEWER: Okay. Alright.

PATIENT: Not look, you know, a lot of people get hit crossing the street. And, but that doesn’t really—that’s irrelevant to me... but, based upon the information that I had, you know, hard information, I felt very comfortable.

PATIENT 1: All that they’ve been giving me are the scores for my PSA ... My doctor said, when your numbers double in four month spread, he said, we need to do something

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about it ... he says, and I'll nip and tuck it just as soon as it gets up there, and my last time it was aggressive. It went from 0.12 to 5.5 in four months, and so, he encouraged me, and he told me what he was going to do ...

INTERVIEWER: Okay.

PATIENT 2: They give you all kinds of information. And he'll tell you, you know, specifically we're talking about this spread, and this is where you are, and this is what we think ... I totally felt like I was just as much in control of my life as he was. And it gave me, it gave me a lot of courage toward it. I had a bad two days when I found out about it. I haven't had a bad day since. [High-Risk Participants]

The influence of biomarker information contrasted with participants' lack of understanding of its precise meaning:

I really wasn't sure, and to this day, I don't know what the heck a Gleason score is. I'm not certain exactly what the PSA score is and what that is supposed to indicate, but I do know I had several PSA tests, and they started at 17, and there were several in 13, 14 and then a couple with 9 and 10, and then I had one that was 7. [High-Risk Participant]

Perceptions of the value of personalized risk information

Patients' perceptions of the potential value of personalized risk information produced by CPMs, spanned a broad range.

Enabling informed decision making. On the one hand, participants acknowledged several potential benefits related to the ideal of informed decision making. Some participants noted that personalized risk information could help clarify tradeoffs involved with alternative treatment options:

You take a look at that and say the statistics say, wow, you know, I'm not anywhere near as good if I do that over there. I think it would help you with your decision. [High-Risk Participant]

Patient empowerment *vis a vis* their physicians was another perceived value of personalized risk information:

So this is like a whole new concept where, you know, we're empowered, each of us is empowered with making the decision, and that's, like, you think about it and that's pretty unique and wonderful rather than to have a doctor...you know, the doctor can make a mistake, too ... So, like, the doctor is not the god. [Low-Risk Participant]

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Participants believed that such empowerment was necessary because of inherent biases of treating physicians:

I can see this being used to help people make a decision as to what course of treatment they should seek versus what side effect they can live with. Now, if you go to X and ask them what their percentage of incontinence is ... they're gonna give you a skewed number because they don't want to make that million-dollar piece of equipment look bad. [High-Risk Participant]

Some participants—particularly those who had chosen active treatment (surgery, radiation therapy) over active surveillance or watchful waiting—felt that personalized risk information produced by CPMs might have changed their treatment decisions:

PATIENT 2: I mean, if you could plug in these numbers to see what the prediction would be based on what my diagnosis numbers were doing the various procedures, I, I probably would have looked at all those—and that may have strongly influenced me to do something other than what I did ... in my case I think if I had a predictor like this which showed me the same result with watchful waiting or robot or radiation, I would, I would think real strongly about watchful waiting. [Medium-Risk Participant]

Even if personalized risk information did not influence patients' actual decisions, furthermore, many valued such information as a means of simply being informed:

INTERVIEWER: Imagining that these kinds of tools were available when you were going through decision making, do you think this kind of information would have changed the decisions that you actually made about your own treatment?

MULTIPLE PATIENTS (in unison): No.

INTERVIEWER: Then what good is it?

PATIENT 4: Like D. said, it's just a tool for you to go by, you know.

PATIENT 5: Any information you can get adds to your knowledge of where you're gonna go with your treatment. [Medium-Risk Participants]

Skepticism about the value of personalized risk information. Most participants, however, expressed skepticism about the value of personalized risk information. A primary source was the fundamental uncertainty inherent to all risk estimates. Several participants specifically

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3 mentioned the uncertainty involved in applying probability estimates to the realm of single
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5 events experienced by individuals¹⁴:
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10 *You know, I don't care how much information you have, or how much the odds are, it can*
11 *be thrown a monkey wrench. The Patriots are a good example. [Laughter] I mean, you*
12 *looked at all the stats and it said they were gonna win. That ain't how it turned out!*
13 *[Medium-Risk Participant]*
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16 *You don't know which percentage you're going to be in. I mean ... the five-year number*
17 *is 95%. Five percent of the people, their cancer's going to spread. So—I mean, it's a very*
18 *high chance you won't spread, but you could be in the five percent. [Medium-Risk*
19 *Participant]*
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21 Another source of skepticism related to the reliability of statistical models and risk evidence
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23 itself. Several participants raised questions about the “*authenticity*” of CPMs, the qualifications
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25 and experience of CPM producers, and that the novel nature of CPMs. They also felt that
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27 different researchers and models should be “close to giving you the same type of prediction,” and
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29 that conflicting estimates would lower their trust in CPMs. These concerns reflected “epistemic
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31 uncertainty” or the consciousness of what has been termed “ambiguity”—limitations in the
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33 reliability, credibility, or adequacy of risk information.¹⁴
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40 Participants' uncertainties were manifest in skepticism about the value and influence of
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42 personalized risk information in decision making. Participants reported that at the most, they
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44 would use CPMs as a “second opinion” or “adjunct” that would augment—but not take
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46 precedence over—other types of evidence. As a medium-risk participant stated, “*I would*
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48 *consider the numbers very important, but it wouldn't drive the whole decision process.*”
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Participants viewed their own decision making processes as intuitive and based on non-statistical forms of evidence. Emotions were one prominent form, manifesting use of the “*affect heuristic*” in decision making^{55,56}:

I wouldn't choose from that. Well certainly if it were me, I would review what are the side effects of each, and the one thing that hasn't been touched on, and you may not be able to, is the emotional part of the decision. The statistics for most people probably wouldn't be more than 50% of the decision-making process. [Medium-Risk Participant]

For most participants the recommendations of trusted physicians constituted the primary form of evidence, manifesting reliance on what Wegwarth and Gigerenzer have termed the “*trust-the-doctor*”⁵⁷ heuristic:

... I'm a person who, who really respects and honors education ... doctors work damn hard to get a degree and become a medical professional. I have to respect them and their decisions. [High-Risk Participant]

Personal narrative was another form of evidence that took precedence over statistical evidence.⁵⁸⁻

⁶⁰ As one participant articulated: “*To me, you know, we can listen to the statistics from the physicians but it's also nice to hear from the patients and maybe even the wives.*” Reliance on this “*narrative heuristic*” reflected a greater trust in information from the direct experiences of identifiable persons than from anonymous, population-based statistical information:

So I think there's two ways to look at it. I'm not sure, you know, perhaps how does this 67% get generated? Is it based on just numbers or is it also based on doctors and nurses who have actually face-to-faced and worked, you know, and stuff. [Low-Risk Participant]

Trust is experience-based. The experience happens here with people who are vouching and people who have had the experience ... It doesn't happen in a marketplace. [Medium-Risk Participant]

Risk information vs. other types of evidence. More fundamentally, most participants did not accord privileged status to personalized risk information, but instead viewed it as merely one of several types of evidence—all with equal legitimacy and weight in the decision-making process:

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I think anything that you get anywhere is a guide ... Doesn't matter whether it comes from your doctor, the Internet—support group, or anything. Even prayer is a guide. And you got to take that information that you can get, as much as you can get, and make the best decision for you and your family.

[Medium-Risk Participant]

Oh, no. I don't—I don't think it's bullshit, but I do think it is just one of the factors that you would use to make a decision. I agree with the man. But I think that, you know that there's more than just emotion too. I think there's, you know, statistical data and information, there is emotional consideration, there is life—your spouse's circumstance too. [Medium-Risk Participant]

The need for simplicity. Participants expressed an overarching perception that risk information was not only potentially unimportant but detrimental in introducing complexity—another major source of uncertainty¹⁴ that could obscure the pertinent issues in decision making:

It can cloud the issue for an untrained person. Confuse the situation. Maybe more information than you really need to make a good decision. And you get so bogged with all the information that you lose sight of the forest. [Medium-Risk Participant]

But the die was cast and I made my choice. I was going to go with it, and I had that much faith. And the robotic surgery and how really, really, really good it is as opposed to the other types of surgery ... I had that much faith in my choice. And sometimes I don't want to say, gee, I don't want the issues to get clouded by the numbers, but I felt comfortable in what I was doing. [Medium-Risk Participant]

Yet this perception of personalized risk information as obscuring rather than aiding decisions, along with patients' reported reliance on various heuristics (biomarker, affect, white-coat, narrative) reflected a more fundamental need for simplicity in information and the decision-making process. As one participant reported, “*I think sometimes you can have too much information.*”

For many patients the need for simplicity was ultimately manifest in the choice of active prostate cancer treatment (i.e., surgery, radiation therapy): “*... what's simpler than if you have cancer here, what's simpler than taking it out?*” This cognitive strategy exemplified the use of another

simplifying heuristic: a conceptual equation of the cancer diagnosis itself with the necessity of active treatment:

PATIENT 2: There was no watchful waiting for me ... Whether he told me that or not, I just—

INTERVIEWER: There was no option.

PATIENT 2: —no.

PATIENT 1: I, I had the same. I didn't—that wasn't a decision. [Medium-Risk Participants]

And, and you know, when I got those numbers of, you know, the, the biopsies and what not ... I wanted to be done with it ... I wanted it gone ... Let's just rip it out, throw it in the trash can over there in the corner and be done with it. [Medium-Risk Participant]

This “cancer heuristic” not only led many patients to perceive no real choice options, but diminished their interest in personalized risk information:

I, I didn't know these types of models existed. I don't know if I would have used them or not—I might have. Again, I, it was so obvious to take the prostate out, you know—get rid of the problem, but I didn't really care what the percentages were. [Medium-Risk Participant]

PATIENT 1: I had to obviously make a decision, but it was very, for me it was such an easy decision.

PATIENT 3: Yeah.

PATIENT 2: A no-brainer.

PATIENT 1: That may have been naïve, but, I guess, I don't know, it just seemed so logical. So I didn't even think twice about—I didn't even think once about weighing options or risks or ... I never wanted to get into a discussion with my doctor about all that stuff, because it just wasn't, wasn't necessary. [Medium-Risk Participants]

Discussion

Our study provides new insights on an important but understudied issue in the use of CPMs to advance personalized health care: the value of personalized risk information from the patient perspective. The study first demonstrates that such information has significant potential value, since the risk information patients currently receive is typically imprecise rather than precise, qualitative rather than quantitative, indirect (biomarker-based) rather than direct (outcomes-

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3 based), diagnostic rather than prognostic. To our knowledge, the current study provides the first
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5 empirical documentation of these phenomena in prostate cancer care; however, they are not
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7 unique to this disease. Indirect risk communication through biomarker values, for example,
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9 occurs in the treatment of common conditions such as hypercholesterolemia and hypertension,⁹
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11 and heuristics are employed in numerous types of decisions.^{61,62} What the current study newly
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13 brings to light, however, is the critical role of patient values in reinforcing these processes.
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15 Although some prostate cancer patients in our study perceived personalized risk information as
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17 valuable, most viewed other types of evidence as more influential and expressed preferences for
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19 intuitive, heuristic-based rather than deliberative, risk-based approaches to decision making.
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27 These findings should be interpreted cautiously given several study limitations. The sample was
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29 relatively small and homogeneous, and many participants had already made treatment decisions.
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31 The study assessed patient perceptions rather than behaviors, and used qualitative methods, a
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33 powerful approach for ascertaining the nature and breadth—but not the prevalence, causes, and
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35 effects—of people's beliefs and attitudes. Further research using larger, more diverse samples
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37 and quantitative methods is thus needed. Nevertheless, the validity of our findings is supported
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39 by their consistency with mounting evidence that precise, quantitative risk information is not
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41 always what patients need or want.^{30,31} Our findings extend this evidence and have important
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43 implications for potential users of CPMs because they identify patient perceptions of the value of
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45 personalized risk information as an important barrier to the use of CPMs, and suggest potential
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47 modifiable reasons for these perceptions.
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3 The most straightforward reason is lack of exposure to personalized risk information; most study
4 participants reported having never received such information, and its value was thus simply
5 beyond their imagination. This problem might be addressed by exposing patients to what
6 they've been missing; as Steve Jobs famously quipped, "People don't know what they want until
7 you show it to them."⁶³ Yet our study suggests that even if patients were provided with
8 personalized risk information, they may not want it. Study participants expressed an overarching
9 desire for simplicity in information and decision-making approach, manifested in preferences for
10 heuristic- rather than risk-based decision making. This desire for simplicity is common,^{30,64-66}
11 and reflects fundamental limitations in human cognitive capacities (e.g., memory, literacy,
12 numeracy) and available environmental resources (e.g., time, decision support)^{32,67,68} that
13 constrain people's ability to engage in effortful deliberation in decision making, and instead
14 promote intuitive, heuristic-based decision making based on factors other than "estimations of
15 probabilities, gains, costs, and the like."⁶¹ Intuitive and deliberative decision-making approaches
16 each have advantages and disadvantages;⁶⁹ however, if the goal is to increase the perceived value
17 and clinical use of personalized risk information, then the limitations that reduce people's
18 capacity for deliberation must somehow be overcome.

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43 Another factor limiting the perceived value and use of personalized risk information among
44 study participants was a perception that such information is less reliable than non-quantitative
45 evidence. This perception raises a need that has not been addressed in efforts to apply risk
46 information to patient care: to increase patients' *epistemological understanding*—i.e., their
47 comprehension of the nature of risk knowledge and the strengths and weaknesses of the evidence
48 at hand. Our study illustrates the two-fold challenge patients face in using personalized risk
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3 information: they must weigh not only the magnitude of competing probabilities but the value of
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5 competing types of evidence, each with their own strengths and weaknesses. Personalized risk
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7 information represents the strongest form of evidence from the expert perspective; nevertheless,
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9 its clinical value is diminished by uncertainties arising from methodological problems in risk
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11 modeling^{70,71} and the limited applicability of risk estimates to single events experienced by
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13 individuals.⁷² On the other hand, non-quantitative forms of evidence (e.g., “gut feelings,”⁷³
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15 physician recommendations, personal anecdotes) provide a means of mitigating irreducible
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17 uncertainties of risk estimates and are thus valuable from the lay perspective; however, such
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19 evidence is susceptible to numerous biases. Exactly how patients should weight these different
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21 types of evidence is a critical question for future research, but at the very least this task requires
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23 an understanding of their strengths and weaknesses. The lack of such understanding among
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25 study participants suggests that epistemological education should be a primary focus of efforts to
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27 apply personalized risk information to patient care.
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36 Our study thus identifies several requisite tasks for enhancing the value and use of personalized
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38 risk information: 1) increasing patients' exposure to personalized risk information, 2) providing
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40 resources to support deliberative decision making, and 3) providing epistemological education on
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42 the nature of medical knowledge and evidence. The first task has been a primary focus of CPM
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44 proponents; however, more work is needed to effectively disseminate and implement CPMs in
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46 clinical practice. The second task has only begun to be addressed, but promising approaches
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48 include the delivery of personalized risk information through patient-centered decision support
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50 interventions (DeSIs) such as decision aids,^{74,75} and the use of risk communication strategies
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52 such as visual representations to improve the evaluability of risk estimates.^{30,31,76-83} A more
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3 challenging task is to provide the environmental resources—e.g., clinical time, processes, and
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5 incentives—needed for deliberative and collaborative decision making.⁷⁴ The final task, the
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7 provision of epistemological education, is a new frontier that has yet to be explored but calls for
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9 efforts to expand the content of risk information communicated to patients—whether through
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11 DeSIs or larger-scale educational efforts delivered through other channels. It remains for further
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13 research to address these challenges, and to determine how best to help patients translate
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15 personalized risk information into better informed health care decisions.
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36 All authors had full access to all of the data (including statistical reports and tables) in the study
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38 and take responsibility for the integrity of the data and the accuracy of the data analysis. The
39
40 study was approved by the Maine Medical Center Institutional Review Board (IRB#3805X), and
41
42 granted a waiver of informed consent.
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48 All authors have completed the Unified Competing Interest form at
49
50 www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and
51
52 declare that (1) PH, MN, BR, NH, TK, MD, and MH have no relationships with companies that
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54 might have an interest in the submitted work in the previous 3 years; (2) spouses, partners, or
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3 children of PH, MN, BR, NH, TK, MD, and MH have no financial relationships that may be
4 relevant to the submitted work; and (3) PH, MN, BR, NH, TK, MD, and MH have no non-
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7 financial interests that may be relevant to the submitted work.
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47 participate in this study.
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44 **Contributorship Statement**

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46 PH designed the study, obtained funding, conducted interviews and data analysis, drafted the
47 manuscript, and edited the manuscript for important content.
48
49

50 MN, BR, and NH conducted data analysis and edited the manuscript for important content.
51

52 TK assisted in the design of the study, conducted interviews, and edited the manuscript for
53 important content.
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3 CG edited the manuscript for important content.
4

5 MD edited the manuscript for important content.
6
7

8 MH assisted in the design of the study and edited the manuscript for important content.
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11 12 **Data sharing statement**

13 Data sharing: no additional data available; consent for data sharing was not obtained from study
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15 participants.
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References

Table 1. Focus group categories

- Low-risk group: Early-stage, clinically localized disease (Gleason Score ≤ 6 , Stage T1C-T2A, PSA <10)
- Medium-risk group: Intermediate-stage, clinically localized disease (Gleason Score 7, Stage T2B-T2C, PSA 10-20)
- High-risk group: patients with advanced, treatment-refractory, or recurrent disease (Gleason Score 8-10, Stage T3-T4, PSA >20)

Table 2. Characteristics of focus group participants

	<u>N</u>	<u>%</u>
Age		
50-59	6	21%
60-69	18	62%
70-79	4	14%
≥ 80	1	3%
Risk Group		
Low	7	24%
Med	15	52%
High	7	24%
Race		
White/Caucasian	29	100%
Other	0	0%
Education		
High school or less	6	21%
Some college	4	14%
College graduate	10	34%
Post graduate	9	31%
Location		
Brunswick	9	31%
Lewiston	9	31%
Portland	11	38%

Table 3. The biomarker heuristic: illustrative quotes

I was told that with the Gleason score of 9 that that's frightening ... That's extremely aggressive is what this one doctor said, and at the next place that doctor said it's kind of scary, he says, but it can be taken care of. [High-Risk Participant]

*INTERVIEWER: And what was your understanding of what the Gleason score meant?
PATIENT: A high number is, you know -- the top number is, you know, if that's higher than your bottom number, you've got problems. [High-Risk Participant]*

... he gave me the lab report itself and he showed me these different things and he says this here's the Gleason score. The Gleason is this three over four. He said if it had been four over three, you know, we would have been more concerned. He said this shows it's an active cancer but it's not an aggressive cancer and he said so we've got some time to wait. We don't have a lot of time to wait. He said we don't have to worry about going into surgery in the next three weeks or something. [Medium-Risk Participant]

The way they explained to me was that if it's under a four Gleason it's probably not gonna do much. If it's around a six it's kind of getting up there. If it gets up around and eight then it's real aggressive, you gotta do something fast. [Medium-Risk Participant]

My primary care physician, one of the things that she told me which made me feel good was, S, hey, it's low grade, low risk, stage 1. This is not going to get you, S. Something else is going to. [Low-Risk Participant]

My understanding is that, well, as I stated I'm going in for another biopsy in January. At this time I've met the criteria for active surveillance for the past year, and that's where I'm at at this time. In other words, the criteria for PSA testing and whether they've gone up or down in testing. [Low-Risk Participant]

References

1. Edwards A, Hood K, Matthews E, et al. The effectiveness of one-to-one risk communication interventions in health care: a systematic review. *Med Decis Making*. Jul-Sep 2000;20(3):290-297.
2. Steyerberg EW. *Clinical Prediction Models: a Practical Approach to Development, Validation, and Updating*. New York: Springer; 2010.
3. Personalized Health Care: Pioneers, Partnerships, Progress. 2008. <http://www.hhs.gov/myhealthcare/>. Accessed March 12, 2013.
4. Briss P, Rimer B, Reilley B, et al. Promoting informed decisions about cancer screening in communities and healthcare systems. *Am J Prev Med*. Jan 2004;26(1):67-80.
5. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns*. Mar 2006;60(3):301-312.
6. Edwards A, Unigwe S, Elwyn G, Hood K. Effects of communicating individual risks in screening programmes: Cochrane systematic review. *BMJ*. Sep 27 2003;327(7417):703-709.
7. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. *The New England journal of medicine*. Mar 1 2012;366(9):780-781.
8. Elwyn G, Frosch D, Thomson R, et al. Shared Decision Making: A Model for Clinical Practice. *J Gen Intern Med*. May 23 2012;27(10):1361-1367.
9. Vickers AJ, Basch E, Kattan MW. Against diagnosis. *Annals of internal medicine*. Aug 5 2008;149(3):200-203.
10. Edwards AG, Naik G, Ahmed H, et al. Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database Syst Rev*. 2013;2:CD001865.
11. Gillies D. *Philosophical Theories of Probability*. London: Routledge; 2000.
12. Hacking I. *The Taming of Chance*. Cambridge: Cambridge University Press; 1990.
13. Han PK. Conceptual, Methodological, and Ethical Problems in Communicating Uncertainty in Clinical Evidence. *Med Care Res Rev*. Nov 6 2012.
14. Han PK, Klein WM, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Medical decision making : an international journal of the Society for Medical Decision Making*. Nov 2011;31(6):828-838.
15. Brewer NT, Richman AR, Defrank JT, Reyna VF, Carey LA. Improving communication of breast cancer recurrence risk. *Breast cancer research and treatment*. Jun 2012;133(2):553-561.
16. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. *Med Decis Making*. Jan-Feb 2001;21(1):37-44.
17. Sheridan SL, Pignone M. Numeracy and the medical student's ability to interpret data. *Eff Clin Pract*. Jan-Feb 2002;5(1):35-40.
18. Schwartz LM, Woloshin S, Black WC, Welch HG. The role of numeracy in understanding the benefit of screening mammography. *Ann Intern Med*. Dec 1 1997;127(11):966-972.
19. Wegwarth O, Schwartz LM, Woloshin S, Gaissmaier W, Gigerenzer G. Do physicians understand cancer screening statistics? A national survey of primary care physicians in the United States. *Annals of Internal Medicine*. Mar 6 2012;156(5):340-349.

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20. Reyna VF, Nelson WL, Han PK, Dieckmann NF. How numeracy influences risk comprehension and medical decision making. *Psychol Bull.* Nov 2009;135(6):943-973.
21. Han PK, Klein WM, Lehman TC, Massett H, Lee SC, Freedman AN. Laypersons' responses to the communication of uncertainty regarding cancer risk estimates. *Med Decis Making.* May-Jun 2009;29(3):391-403.
22. Han PK, Lehman TC, Massett H, Lee SJ, Klein WM, Freedman AN. Conceptual problems in laypersons' understanding of individualized cancer risk: a qualitative study. *Health Expect.* Mar 2009;12(1):4-17.
23. Ravdin PM, Siminoff LA, Davis GJ, et al. Computer program to assist in making decisions about adjuvant therapy for women with early breast cancer. *J Clin Oncol.* Feb 15 2001;19(4):980-991.
24. Peele PB, Siminoff LA, Xu Y, Ravdin PM. Decreased use of adjuvant breast cancer therapy in a randomized controlled trial of a decision aid with individualized risk information. *Med Decis Making.* May-Jun 2005;25(3):301-307.
25. Siminoff LA, Gordon NH, Silverman P, Budd T, Ravdin PM. A decision aid to assist in adjuvant therapy choices for breast cancer. *Psychooncology.* Nov 2006;15(11):1001-1013.
26. Belkora JK, Rugo HS, Moore DH, Hutton DW, Chen DF, Esserman LJ. Oncologist use of the Adjuvant! model for risk communication: a pilot study examining patient knowledge of 10-year prognosis. *BMC Cancer.* 2009;9:127.
27. Hutton DW, Belkora JK, Shachter RD, Moore DH. Are patients getting the "gist" in risk communication? Patient understanding of prognosis in breast cancer treatment. *J Cancer Educ.* 2009;24(3):194-199.
28. Lipkus IM, Peters E, Kimmick G, Liotcheva V, Marcom P. Breast cancer patients' treatment expectations after exposure to the decision aid program adjuvant online: the influence of numeracy. *Med Decis Making.* Jul-Aug;30(4):464-473.
29. Zikmund-Fisher BJ, Fagerlin A, Ubel PA. Improving understanding of adjuvant therapy options by using simpler risk graphics. *Cancer.* Dec 15 2008;113(12):3382-3390.
30. Zikmund-Fisher BJ. The Right Tool Is What They Need, Not What We Have: A Taxonomy of Appropriate Levels of Precision in Patient Risk Communication. *Med Care Res Rev.* Nov 1 2012.
31. Reyna VF. A theory of medical decision making and health: fuzzy trace theory. *Med Decis Making.* Nov-Dec 2008;28(6):850-865.
32. Simon H. *Models of Man, Social and Rational: Mathematical Essays on Rational Human Behavior in a Social Setting.* New York: Wiley; 1957.
33. Cancer Research UK. Prostate Cancer Statistics. 2013; <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/>. Accessed April 4, 2013, 2013.
34. Rothenberg BM, Marbella A, Belinson SE, et al. Future Research Needs for Comparative Effectiveness of Treatments of Localized Prostate Cancer: Identification of Future Research Needs from Comparative Effectiveness Review No. 13. Rockville (MD)2010.
35. National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Stat Facts Sheets: Prostate. 2013; <http://seer.cancer.gov/statfacts/html/prost.html>. Accessed April 4, 2013, 2013.
36. Cooperberg MR. Prostate cancer risk assessment: choosing the sharpest tool in the shed. *Cancer.* Dec 1 2008;113(11):3062-3066.

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37. Shariat SF, Karakiewicz PI, Roehrborn CG, Kattan MW. An updated catalog of prostate cancer predictive tools. *Cancer*. Dec 1 2008;113(11):3075-3099.
38. Lughezzani G, Briganti A, Karakiewicz PI, et al. Predictive and Prognostic Models in Radical Prostatectomy Candidates: A Critical Analysis of the Literature. *Eur Urol*. Aug 6 2010;58(5):687-700.
39. Cowen ME, Halasyamani LK, Kattan MW. Predicting life expectancy in men with clinically localized prostate cancer. *J Urol*. Jan 2006;175(1):99-103.
40. Eastham JA, Scardino PT, Kattan MW. Predicting an optimal outcome after radical prostatectomy: the trifecta nomogram. *The Journal of urology*. Jun 2008;179(6):2207-2210; discussion 2210-2201.
41. Ross RW, Kantoff PW. Predicting outcomes in prostate cancer: how many more nomograms do we need? *J Clin Oncol*. Aug 20 2007;25(24):3563-3564.
42. Lerner Research Institute, Cleveland Clinic. Risk Calculators. 2010; http://www.lerner.ccf.org/qhs/risk_calculator/index.php. Accessed November 12, 2010.
43. Touijer K, Scardino PT. Nomograms for staging, prognosis, and predicting treatment outcomes. *Cancer*. Jul 1 2009;115(13 Suppl):3107-3111.
44. Cegala DJ, Post DM, McClure L. The effects of patient communication skills training on the discourse of older patients during a primary care interview. *J Am Geriatr Soc*. Nov 2001;49(11):1505-1511.
45. nomogram.org. Prostate Cancer. 2010; http://nomogram.org/Prostate/pros_calc.php. Accessed November 12, 2010.
46. Hoffman A, Montgomery R, Aubry W, Tunis SR. How best to engage patients, doctors, and other stakeholders in designing comparative effectiveness studies. *Health Aff (Millwood)*. Oct 2010;29(10):1834-1841.
47. Sofaer S. Qualitative methods: what are they and why use them? *Health Serv Res*. Dec 1999;34(5 Pt 2):1101-1118.
48. Kitzinger J. Qualitative research. Introducing focus groups. *BMJ*. Jul 29 1995;311(7000):299-302.
49. Morgan D. *Focus Groups in Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1998.
50. National Comprehensive Cancer Network. NCCN Practice Guidelines for Prostate Cancer. . 2010;Version 1: 2010. <http://www.nccn.org>. Accessed December 16, 2012.
51. Memorial-Sloan Kettering Center. Prostate Cancer Nomograms: a Tool for Doctors & Patients. . 2010; <http://www.mskcc.org/mskcc/html/10088.cfm>. Accessed November 12, 2010.
52. Strauss AL, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd ed. Thousand Oaks, CA: Sage; 1998.
53. Ryan GW, & Bernard, H. R. Data management and analysis methods. In: N. K. Denzin, Lincoln YS, eds. *Collecting and Interpreting Qualitative Materials*. Thousand Oaks, CA: Sage; 2003:259-309.
54. Glaser BG. The Constant Comparative Method of Qualitative Analysis. *Social Problems*. 1965;12(4):436-445.
55. Slovic P, Finucane M, Peters E, MacGregor DG. The affect heuristic. In: Gilovich T, Griffin D, Kahneman D, eds. *Heuristics and Biases: the Psychology of Intuitive Judgment*. Cambridge: Cambridge University Press; 2002:397-420.

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56. Slovic P, Peters E, Finucane ML, Macgregor DG. Affect, risk, and decision making. *Health Psychol.* Jul 2005;24(4 Suppl):S35-40.
57. Wegwarth O, Gigerenzer G. Trust-your-doctor: a simple heuristic in need of a proper social environment. In: Hertwig R, Hoffrage U, eds. *Simple Heuristics in a Social World*. New York: Oxford University Press; 2013:67-102.
58. Winterbottom A, Bekker HL, Conner M, Mooney A. Does narrative information bias individual's decision making? A systematic review. *Soc Sci Med.* Dec 2008;67(12):2079-2088.
59. deWit JBF, Das E, Vet R. What works best: objective statistics or a personal testimonial? An assessment of the persuasive effects of different types of message evidence on risk perception. *Health Psychol.* 2008;27(1):110-115.
60. Shaffer VA, Zikmund-Fisher BJ. All stories are not alike: a purpose-, content-, and valence-based taxonomy of patient narratives in decision AIDS. *Med Decis Making.* Jan 2013;33(1):4-13.
61. Gigerenzer G, Selten R. *Bounded Rationality*. Cambridge: MIT Press; 2002.
62. Tversky A, Kahneman D. Judgment under uncertainty: heuristics and biases. *Science.* 1974;185(4157):1124-1131.
63. Isaacson W. *Steve Jobs*. New York: Simon and Schuster; 2011.
64. Peters E, Dieckmann N, Dixon A, Hibbard JH, Mertz CK. Less is more in presenting quality information to consumers. *Med Care Res Rev.* Apr 2007;64(2):169-190.
65. Iyengar SS, Kamenica E. Choice proliferation, simplicity seeking, and asset allocation. *Journal of Public Economics.* 2010;94(7):530-539.
66. Iyengar SS, Lepper MR. When choice is demotivating: Can one desire too much of a good thing? *Journal of Personality and Social Psychology.* 2000;79:995-1006.
67. Legare F, Ratte S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient education and counseling.* Dec 2008;73(3):526-535.
68. Lin GA, Aaronson DS, Knight SJ, Carroll PR, Dudley RA. Patient decision aids for prostate cancer treatment: a systematic review of the literature. *CA Cancer J Clin.* Nov-Dec 2009;59(6):379-390.
69. de Vries M, Fagerlin A, Witteman HO, Scherer LD. Combining deliberation and intuition in patient decision support. *Patient Educ Couns.* May 2013;91(2):154-160.
70. Spiegelhalter DJ, Riesch H. Don't know, can't know: embracing deeper uncertainties when analysing risks. *Philos Transact A Math Phys Eng Sci.* Dec 13 2011;369(1956):4730-4750.
71. Bilcke J, Beutels P, Brisson M, Jit M. Accounting for methodological, structural, and parameter uncertainty in decision-analytic models: a practical guide. *Med Decis Making.* Jul-Aug 2011;31(4):675-692.
72. Han PK. Conceptual, methodological, and ethical problems in communicating uncertainty in clinical evidence. *Med Care Res Rev.* Feb 2013;70(1 Suppl):14S-36S.
73. Gigerenzer G. *Gut Feelings: the Intelligence of the Unconscious*. New York: Penguin Books; 2007.
74. Elwyn G, Frosch D, Volandes AE, Edwards A, Montori VM. Investing in deliberation: a definition and classification of decision support interventions for people facing difficult health decisions. *Med Decis Making.* Nov-Dec;30(6):701-711.

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75. Stacey D, Bennett CL, Barry MJ, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane database of systematic reviews*. 2011(10):CD001431.
76. Lipkus IM. Numeric, verbal, and visual formats of conveying health risks: suggested best practices and future recommendations. *Med Decis Making*. Sep-Oct 2007;27(5):696-713.
77. Visschers VH, Meertens RM, Passchier WW, de Vries NN. Probability information in risk communication: a review of the research literature. *Risk Anal*. Feb 2009;29(2):267-287.
78. Galesic M, Garcia-Retamero R, Gigerenzer G. Using icon arrays to communicate medical risks: overcoming low numeracy. *Health Psychol*. Mar 2009;28(2):210-216.
79. Garcia-Retamero R, Galesic M. Who profits from visual aids: overcoming challenges in people's understanding of risks [corrected]. *Soc Sci Med*. Apr 2010;70(7):1019-1025.
80. Dolan JG, Qian F, Veazie PJ. How well do commonly used data presentation formats support comparative effectiveness evaluations? *Med Decis Making*. Nov-Dec 2012;32(6):840-850.
81. Akl EA, Oxman AD, Herrin J, et al. Using alternative statistical formats for presenting risks and risk reductions. *Cochrane Database Syst Rev*. 2011(3):CD006776.
82. Gigerenzer G, Gaissmaier W, Kurz-Milcke E, Schwartz LM, Woloshin S. Helping doctors and patients make sense of health statistics. *Psychological Science in the Public Interest*. 2007;8:53-96.
83. Spiegelhalter D, Pearson M, Short I. Visualizing uncertainty about the future. *Science*. Sep 9 2011;333(6048):1393-1400.



The value of personalized risk information: a qualitative study of the perceptions of prostate cancer patients

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8 **The value of personalized risk information: a qualitative study of the perceptions of**
9 **prostate cancer patients**
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Abstract

Objective. To explore prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Design. A qualitative study was conducted using focus groups. Semi-structured interviews explored participants' experiences with using risk information, and their perceptions of the potential value of personalized risk information produced by clinical prediction models (CPMs).

Participants. English-speaking patients, ages 54-82, diagnosed with prostate cancer within the past 3 years, residing in rural and non-rural geographic locations in Maine (USA), and attending prostate cancer patient support groups.

Setting. Six focus groups were conducted with 27 patients; separate groups were held for patients with low, medium, and high-risk disease defined by National Comprehensive Cancer Network guidelines.

Results. Several participants reported receiving risk information that was imprecise rather than precise, qualitative rather than quantitative, indirect rather than direct, and focused on biomarker values rather than clinical outcomes. Some participants felt that personalized risk information could be valuable in helping them make better informed decisions, but expressed skepticism about its value. Many participants favored decision-making strategies that were heuristic-based and intuitive rather than risk-based and deliberative, and perceived other forms of evidence—emotions, recommendations of trusted physicians, personal narratives—as more reliable and valuable in treatment decisions.

Conclusions. Prostate cancer patients appear to have little experience using personalized risk information, may favor heuristic- over risk-based decision making strategies, and may perceive personalized risk information as less valuable than other types of evidence. These decision-

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3 making approaches and perceptions represent potential barriers to the clinical use of personalized
4 risk information. Overcoming these barriers will require providing patients with greater
5 exposure to risk information, education about the nature and value of personalized risk
6 information, and training in deliberative decision-making strategies. More research is needed to
7 confirm these findings and address these needs.
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Article Summary

Article Focus

- Personalized risk information is an increasingly common, important form of evidence in the treatment of prostate cancer and numerous other medical conditions, but little is known about the extent to which patients use and value such information.
- This study explored prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Key Messages

- Prostate cancer patients appear to have little experience using personalized risk information in clinical decisions, and the risk information they commonly receive is imprecise, qualitative, and indirect.
- At least some prostate cancer patients favor decision-making strategies that are heuristic-based and intuitive rather than risk-based and deliberative, and perceive personalized risk information as having less value than other forms of evidence.
- Effective application of personalized risk information to clinical decisions will require increasing patients' exposure to this information, creating environmental conditions that favor greater deliberation in decision making, and providing patients with education about its nature and value relative to other types of evidence.

Strengths and Limitations

- The study provides empirical evidence on the value of personalized risk information from the patient perspective, and identifies previously unexamined barriers to effective use of this information.

- The study sample was relatively small, geographically limited, and racially and ethnically homogeneous.
- Qualitative methods cannot definitively establish the prevalence, causes, or effects of patients' experiences and perceptions. Further research using quantitative methods is needed to confirm the study's findings.

For peer review only

Introduction

Personalized, or individualized, risk information—information about the probability of future health outcomes for individual patients¹—is an increasingly common and important form of clinical evidence. In recent years, burgeoning efforts to develop clinical prediction models (CPMs)—statistical algorithms that utilize characteristics of the patient, disease, and treatment to estimate individualized probabilities of health outcomes²—have increased the supply of personalized risk information. Meanwhile, a growing emphasis on the ideals of personalized health care, patient-centered outcomes research, and informed and shared decision making have heightened clinical demand for this information.³⁻⁸ Personalized risk information advances each of these important health care ideals, enabling decision making based on the expected outcomes of individuals rather than groups, on prognostic estimates rather than diagnostic categories,⁹ and on patient values and preferences.² Emerging evidence supports this vision; a recent Cochrane review concluded that personalized risk information promotes informed patient decision making in cancer screening.¹⁰

Nevertheless, the clinical value of personalized risk information is limited by several barriers, including the conceptually abstract nature of risk information,¹¹⁻¹⁴ psychological biases, and well-documented deficits in numeracy that impede its comprehension by both patients and health professionals.¹⁵⁻²² Correspondingly, several studies have shown that patients' understanding of personalized risk estimates produced by CPMs is poor.²¹⁻²⁹ A deeper problem, however, is that precise, quantitative risk information may not be what patients really want or need. Zikmund-Fisher has argued that such information is not always informative, and “simpler, less precise representations” of risk are often more useful to patients.³⁰ In a similar vein, Reyna has

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3 contended that people prefer to construe risk in qualitative terms representing its “gist” meaning,
4 rather than in precise, quantitative terms representing its “verbatim” details.³¹ Gigerenzer has
5 gone further to challenge the conception of rationality underlying efforts to apply risk
6 information to decision making. Extending an argument put forth by the economist Simon in the
7 1950s,³² he emphasizes that rationality is “bounded” by limitations in the cognitive and
8 environmental resources available to decision makers. Consequently, in real world decisions
9 people do not “optimize”—i.e., they do not calculate and weigh probabilities and values in an
10 exhaustive computational search for the best option. Instead, they use heuristics—“fast and
11 frugal” rules of thumb that facilitate adaptive decisions.
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27 These insights raise fundamental questions about the usefulness of precise, quantitative risk
28 information in health care. Is such information really needed and desired by patients? Do
29 patients—as opposed to health professionals—perceive personalized risk information as
30 valuable, and how might their perceptions influence the success of efforts to use CPMs in
31 clinical practice?
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41 The aim of the current research was to explore these questions, focusing on personalized risk
42 information in the treatment of prostate cancer—the most common and 2nd most common male
43 cancer in the US and worldwide, respectively, and the 2nd and 6th leading cause of male cancer
44 deaths.³³⁻³⁵ Approximately 80% of newly diagnosed prostate cancer patients have clinically-
45 localized disease for which there are multiple treatment options—surgery, radiation therapy,
46 conservative treatment (active surveillance)—each with differing potential benefits and harms.³⁴
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55 The same is true for the treatment of more advanced, higher-risk disease. Prostate cancer has
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3 thus become a primary focus of predictive modeling activities, resulting in the development of
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5 over 100 CPMs³⁶⁻⁴² and growing efforts to disseminate and apply these models in clinical
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8 practice.⁴¹⁻⁴⁶
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12 Little is known, however, about prostate cancer patients' perspectives on the value of CPMs and
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14 the information they produce. To this end, the current study explored prostate cancer patients'
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16 experiences with using risk information in treatment decisions, and their perceptions of the value
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18 of precise, personalized risk information produced by CPMs. The ultimate goal was to generate
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20 insights that might inform efforts to use CPMs to promote personalized, informed decision
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22 making in the treatment of prostate cancer and other conditions.
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29 **Methods**

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32 **Study design, participants, and data collection.** This qualitative study employed focus groups,
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34 a useful methodology for exploring people's perceptions, beliefs, and attitudes.^{47,48} From
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36 September 2010–February 2011, 7 focus groups were conducted with 27 prostate cancer patients
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38 in the state of Maine (3-6 patients/group). Participants were members of the Maine Coalition to
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40 Fight Prostate Cancer (MCFPC), a patient advocacy organization that administers 9 statewide
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42 support groups. Eligible participants were recruited by MCFPC and consisted of English-
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44 speaking prostate cancer survivors within 3 years of initial diagnosis. Purposive recruitment
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46 soliciting participation of men at various disease stages was conducted to obtain a study sample
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48 with diverse treatment experiences and prognoses; no volunteers were excluded. To achieve
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50 sufficient within-group homogeneity to encourage open discussion,⁴⁹ participants were stratified
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52 into 3 groups (**Table 1**) according to their risk for recurrent disease (Low, Medium, High), as
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3 defined by U.S. National Comprehensive Cancer Network guidelines.⁵⁰ A total of 2 Low Risk, 3
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5 Medium Risk, and 2 High Risk focus groups were conducted at MCFPC support group sites in 3
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7 rural and non-rural towns and cities (Brunswick, Lewiston, Portland). Participants received \$50
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9 compensation. Sessions lasted approximately 2 hours, were audiorecorded with prior consent of
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11 participants, and transcribed verbatim by a professional transcription service.
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17 **Interview content.** Groups were led by PH and either a professional moderator or another study
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19 investigator (TK). Interviews were semi-structured and followed a moderator guide consisting
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21 of open-ended questions and close-ended probes designed to elicit patients' past experiences
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23 with risk information, preferences for personalized risk information, and attitudes towards
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25 CPMs. To illustrate how CPMs work and what types of information they provide, participants
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27 were briefly shown visual aids consisting of screenshots of web-based CPMs (**Appendix A**) for
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29 several different prostate cancer outcomes (e.g., risk of cancer recurrence, cancer-free survival,
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31 death) produced by the Cleveland Clinic
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33 (http://www.lerner.ccf.org/qhs/risk_calculator/index.php)⁴² and Memorial Sloan-Kettering
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35 Cancer Center (<http://www.mskcc.org/mskcc/html/10088.cfm>).⁵¹ During the course of the study,
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theory” approach to the data.^{52,53} Preliminary codebooks were reviewed by the team and areas of disagreement were resolved through further discussion. A single working codebook was then produced, which two investigators (MN, BR) used to code the remaining transcripts, employing a “constant comparative” method to compare new data, concepts, and themes with ones previously identified.^{52,54} The research team held periodic meetings to discuss coding decisions, identify new themes, and resolve areas of disagreement. Finally, two investigators (PH, NH) conducted a secondary review of all coded text to organize dominant themes. An outline of identified themes is in **Appendix B**. The current analysis focused on participants’ perceptions of the value of personalized risk information; analyses of other themes will be reported separately.

Results

Characteristics of participants are in **Table 2**. The primary interview domains consisted of participants’ 1) past experiences with risk communication, and 2) perceptions of the value of personalized risk information produced by CPMs.

1. Past experiences with risk communication

Within these two broad domains several dominant themes emerged; the first was the broad spectrum of risk communication experiences and practices reported by participants.

Absence of explicit risk communication. At one end of the spectrum were a small number of participants who reported having never received risk information of any kind during the decision making process:

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I wasn't actually told about the numbers. I just went by what they were saying. I guess—they knew what the numbers were, what the odds were for me, and I went with that and yeah, I would've wanted to know what the numbers were. [Medium-Risk Participant]

For these few participants treatment risks were implicitly understood rather than explicitly communicated:

I think the conversation that I had with my urologist was we each knew all of those possibilities. It was kind of like a given, and our conversation was based on the fact that we each knew those facts, so they weren't really mentioned specifically. It was just, you've got it, here are your options to deal with it because you want to deal with it because it could be fatal, it could spread. [Low-Risk Participant]

Quantitative risk communication. At the other end of the spectrum were just two participants, among all groups, who reported receiving precise, detailed, quantitative risk information. One low-risk and one medium-risk participant each recalled being shown a “histogram” and other visual aids detailing different risk levels for different treatment outcomes, broken down by demographic characteristics. Neither participant, however, recalled their risk estimates.

More commonly, quantitative risk information was communicated in imprecise terms. For example, several participants recalled being provided with “average” risk estimates applicable to patient subpopulations—e.g., stratified by cancer stage—while several others reported receiving a range rather than point estimate of risk.

Categorical risk communication. The more commonly reported mode of risk communication was categorical and non-quantitative. A low-risk participant noted: “*he didn't say anything about the likelihood of spreading, but, you know, just, what he told me on the phone it was a low, that it was low.*” Other participants recalled the use of similarly broad categories—e.g., “good,” “most likely,” “very remote,” “high,” “very likely.”

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Indirect risk communication: the biomarker heuristic. The most commonly reported mode of risk communication by far, however, was indirect, through the use of biomarker information—primarily prostate specific antigen (PSA) values or Gleason scores (**Table 3**). Participants in all groups described using biomarker values *in lieu* of probability estimates to understand the magnitude of their risk:

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I really, you know, I read the books ... And, I'm sure they had all sorts of graphs and stuff like that. But I've got to admit when I looked at my Gleason scores, this is gonna sound, you know it's all irrelevant. [High-Risk Participant]

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This “biomarker heuristic”—which has not been previously described as such, to our knowledge—functioned as a shorthand rubric or guide to treatment decisions. As one medium-risk participant articulated, referring to his PSA values: “*when you don't have any guidelines to go by, you gotta have some idea where that is, whether it's a four or six or ten or whatever.*”

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The use of biomarkers was a heuristic strategy that obviated the need to deal directly with outcome probabilities *per se*:

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INTERVIEWER: So they gave you a sense of what those numbers meant ... a four means you have an X percent chance of—

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PATIENT 3: No, they didn't.

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INTERVIEWER: But they just said—it was good—versus bad, right?

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PATIENT 3: Yeah.

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PATIENT 2: That's what I got out of it when I was told I had—the PSA was 9 I think and my Gleason was 7—and like everybody else, you know, you're just completely naïve about it, but, by explaining then, telling me that, well, the 9, you better do something about it, you know—I mean, it's not a necessity, but they didn't recommend not doing anything about it all ... So those numbers I think ... kind of helps you towards whichever goal you wanna go to. [High-Risk Participant]

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The usefulness of biomarker values appeared to stem from their apparently “hard,” tangible nature, and their straightforward connection to a defined course of action:

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PATIENT: My decision was based upon what we had for biopsies and stuff like that.

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INTERVIEWER: Okay. Alright.

PATIENT: Not look, you know, a lot of people get hit crossing the street. And, but that doesn't really—that's irrelevant to me... but, based upon the information that I had, you know, hard information, I felt very comfortable.

The influence of biomarker information contrasted with participants' lack of understanding of its precise meaning:

I really wasn't sure, and to this day, I don't know what the heck a Gleason score is. I'm not certain exactly what the PSA score is and what that is supposed to indicate, but I do know I had several PSA tests, and they started at 17, and there were several in 13, 14 and then a couple with 9 and 10, and then I had one that was 7. [High-Risk Participant]

2. Perceptions of the value of personalized risk information

Patients' perceptions of the potential value of personalized risk information produced by CPMs, spanned a broad range.

Enabling informed decision making. On the one hand, participants acknowledged several potential benefits related to the ideal of informed decision making. Some participants noted that personalized risk information could help clarify tradeoffs involved with alternative treatment options:

You take a look at that and say the statistics say, wow, you know, I'm not anywhere near as good if I do that over there. I think it would help you with your decision. [High-Risk Participant]

Patient empowerment *vis-a-vis* their physicians was another perceived value of personalized risk information:

So this is like a whole new concept where, you know, we're empowered, each of us is empowered with making the decision, and that's, like, you think about it and that's pretty unique and wonderful rather than to have a doctor...you know, the doctor can make a mistake, too ... So, like, the doctor is not the god. [Low-Risk Participant]

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3 Participants believed that such empowerment was necessary because of inherent biases of
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6 treating physicians:

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8 *I can see this being used to help people make a decision as to what course of treatment*
9 *they should seek versus what side effect they can live with. Now, if you go to X and ask*
10 *them what their percentage of incontinence is ... they're gonna give you a skewed*
11 *number because they don't want to make that million-dollar piece of equipment look bad.*
12 *[High-Risk Participant]*
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15 Some participants—particularly those who had chosen active treatment (surgery, radiation
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17 therapy) over active surveillance or watchful waiting—felt that personalized risk information
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19 produced by CPMs might have changed their treatment decisions:

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22 *PATIENT 2: I mean, if you could plug in these numbers to see what the prediction would*
23 *be based on what my diagnosis numbers were doing the various procedures, I, I probably*
24 *would have looked at all those—and that may have strongly influenced me to do*
25 *something other than what I did ... in my case I think if I had a predictor like this which*
26 *showed me the same result with watchful waiting or robot or radiation, I would, I would*
27 *think real strongly about watchful waiting. [Medium-Risk Participant]*
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31 Even if personalized risk information did not influence patients' actual decisions, furthermore,
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33 many valued such information as a means of simply being informed:

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35 *INTERVIEWER: Imagining that these kinds of tools were available when you were going*
36 *through decision making, do you think this kind of information would have changed the*
37 *decisions that you actually made about your own treatment?*

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39 *MULTIPLE PATIENTS (in unison): No.*

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41 *INTERVIEWER: Then what good is it?*

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43 *PATIENT 4: Like D. said, it's just a tool for you to go by, you know.*

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45 *PATIENT 5: Any information you can get adds to your knowledge of where you're*
46 *gonna go with your treatment. [Medium-Risk Participants]*

47 ***Skepticism about the relative value of personalized risk information.*** Most participants,
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49 however, expressed skepticism about the value of personalized risk information. A primary
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51 source was the fundamental uncertainty inherent to all risk estimates. Several participants
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53 specifically mentioned the uncertainty involved in applying probability estimates to the realm of
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55 single events experienced by individuals¹⁴:
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5 *You know, I don't care how much information you have, or how much the odds are, it can*
6 *be thrown a monkey wrench. The Patriots are a good example. [Laughter] I mean, you*
7 *looked at all the stats and it said they were gonna win. That ain't how it turned out!*
8 *[Medium-Risk Participant]*
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11 *You don't know which percentage you're going to be in. I mean ... the five-year number*
12 *is 95%. Five percent of the people, their cancer's going to spread. So—I mean, it's a very*
13 *high chance you won't spread, but you could be in the five percent. [Medium-Risk*
14 *Participant]*
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17 Another source of skepticism related to the reliability of statistical models and risk evidence
18 itself. Several participants raised questions about the “*authenticity*” of CPMs, the qualifications
19 and experience of CPM producers, and the novel nature of CPMs. They also felt that different
20 researchers and models should be “close to giving you the same type of prediction,” and that
21 conflicting estimates would lower their trust in CPMs. These concerns reflected “epistemic
22 uncertainty” or the consciousness of what has been termed “ambiguity”—limitations in the
23 reliability, credibility, or adequacy of risk information.¹⁴
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35 Participants' uncertainties were manifest in skepticism about the value and influence of
36 personalized risk information in decision making. Participants reported that at the most, they
37 would use CPMs as a “second opinion” or “adjunct” that would augment—but not take
38 precedence over—other types of evidence. As a medium-risk participant stated, “*I would*
39 *consider the numbers very important, but it wouldn't drive the whole decision process.*”
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49 ***Risk information vs. other types of evidence.*** More fundamentally, many participants did not
50 accord privileged status to personalized risk information, but instead viewed it as merely one of
51 several types of evidence—with at least equal legitimacy and weight in the decision-making
52 process:
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Oh, no. I don't—I don't think it's bullshit, but I do think it is just one of the factors that you would use to make a decision. I agree with the man. But I think that, you know that there's more than just emotion too. I think there's, you know, statistical data and information, there is emotional consideration, there is life—your spouse's circumstance too. [Medium-Risk Participant]

I think anything that you get anywhere is a guide ... Doesn't matter whether it comes from your doctor, the Internet—support group, or anything. Even prayer is a guide. And you got to take that information that you can get, as much as you can get, and make the best decision for you and your family. [Medium-Risk Participant]

Emotions were one prominent form of non-statistical evidence that participants utilized in decision making, manifesting use of the “affect heuristic”^{55,56}:

I wouldn't choose from that. Well certainly if it were me, I would review what are the side effects of each, and the one thing that hasn't been touched on, and you may not be able to, is the emotional part of the decision. The statistics for most people probably wouldn't be more than 50% of the decision-making process. [Medium-Risk Participant]

For other participants the recommendations of trusted physicians constituted the primary form of evidence, manifesting reliance on what Wegwarth and Gigerenzer have termed the “trust-the-doctor”⁵⁷ heuristic:

... I'm a person who, who really respects and honors education ... doctors work damn hard to get a degree and become a medical professional. I have to respect them and their decisions. [High-Risk Participant]

Personal narrative was another form of evidence that participants prioritized over statistical evidence.⁵⁸⁻⁶⁰ As one participant articulated: “To me, you know, we can listen to the statistics from the physicians but it's also nice to hear from the patients and maybe even the wives.” For some participants the use of narrative evidence appeared to function as a heuristic—a mental shortcut that obviated the need to rely on statistical evidence. Reliance on this “narrative heuristic”—well-described in the literature although not typically characterized as a heuristic—manifested a greater trust in the reported experiences of identifiable individuals than in statistical information:

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Trust is experience-based. The experience happens here with people who are vouching and people who have had the experience ... It doesn't happen in a marketplace. [Medium-Risk Participant]

So I think there's two ways to look at it. I'm not sure, you know, perhaps how does this 67% get generated? Is it based on just numbers or is it also based on doctors and nurses who have actually face-to-faced and worked, you know, and stuff. [Low-Risk Participant]

The need for simplicity. Several participants expressed an overarching perception that risk information was not only potentially unimportant but detrimental in introducing complexity—another major source of uncertainty¹⁴ that could obscure the pertinent issues in decision making:

It can cloud the issue for an untrained person. Confuse the situation. Maybe more information than you really need to make a good decision. And you get so bogged with all the information that you lose sight of the forest. [Medium-Risk Participant]

But the die was cast and I made my choice. I was going to go with it, and I had that much faith. And the robotic surgery and how really, really, really good it is as opposed to the other types of surgery ... I had that much faith in my choice. And sometimes I don't want to say, gee, I don't want the issues to get clouded by the numbers, but I felt comfortable in what I was doing. [Medium-Risk Participant]

Yet this perception of personalized risk information as obscuring rather than aiding decisions, along with patients' reported reliance on various heuristics (biomarker, affect, white-coat, narrative) reflected a more fundamental need for simplicity in information and the decision-making process.

For many patients the need for simplicity was ultimately manifest in the choice of active prostate cancer treatment (i.e., surgery, radiation therapy): "... what's simpler than if you have cancer here, what's simpler than taking it out?" This cognitive strategy exemplified the use of what could be characterized as a simplifying "disease heuristic": a conceptual equation of the mere diagnosis of disease with the necessity of active treatment:

PATIENT 2: There was no watchful waiting for me ... Whether he told me that or not, I just—

INTERVIEWER: *There was no option.*

PATIENT 2: *—no.*

PATIENT 1: *I, I had the same. I didn't—that wasn't a decision. [Medium-Risk Participants]*

And, and you know, when I got those numbers of, you know, the, the biopsies and what not ... I wanted to be done with it ... I wanted it gone ... Let's just rip it out, throw it in the trash can over there in the corner and be done with it. [Medium-Risk Participant]

Although the conceptual equation of disease diagnosis with treatment necessity has been previously recognized,⁹ it has not been characterized as a decision-making heuristic. However, our data suggests that it have a heuristic function—obviating patients' need and desire to attend to outcome probabilities and leading many patients to perceive no real choice options:

I, I didn't know these types of models existed. I don't know if I would have used them or not—I might have. Again, I, it was so obvious to take the prostate out, you know—get rid of the problem, but I didn't really care what the percentages were. [Medium-Risk Participant]

PATIENT 1: *I had to obviously make a decision, but it was very, for me it was such an easy decision.*

PATIENT 3: *Yeah.*

PATIENT 2: *A no-brainer.*

PATIENT 1: *That may have been naïve, but, I guess, I don't know, it just seemed so logical. So I didn't even think twice about—I didn't even think once about weighing options or risks or ... I never wanted to get into a discussion with my doctor about all that stuff, because it just wasn't, wasn't necessary. [Medium-Risk Participants]*

Discussion

Our study provides preliminary insights on an important but understudied issue in the use of CPMs to advance personalized health care: the value of personalized risk information from the patient perspective. The study first demonstrates that such information has significant potential value, since the risk information at least some patients currently receive is typically imprecise rather than precise, qualitative rather than quantitative, indirect (biomarker-based) rather than direct (outcomes-based), diagnostic rather than prognostic. To our knowledge, the current study

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3 provides the first empirical documentation of these phenomena in prostate cancer care; however,
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5 they are not unique to this disease. Indirect risk communication through biomarker values, for
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7 example, occurs in the treatment of common conditions such as hypercholesterolemia and
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9 hypertension,⁹ and heuristics are employed in numerous types of decisions.^{61,62} What the current
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11 study newly brings to light, however, is the critical role of patient values in reinforcing these
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13 processes. Although many prostate cancer patients in our study clearly perceived personalized
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15 risk information as valuable, they viewed other types of evidence as relatively more influential
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17 and expressed preferences for intuitive, heuristic-based rather than deliberative, risk-based
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19 approaches to decision making.
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27 These findings should be interpreted cautiously, however, given several study limitations. The
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29 sample was relatively small, geographically limited, and homogeneous in race and ethnicity.
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31 Many participants had already made treatment decisions, and their negative attitudes towards
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33 personalized risk information may thus have been biased by a motivation to avoid regret or
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35 dissonance over not having used such information. Participants' negative attitudes could also
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37 have been influenced by the particular ways in which the information was represented by the
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39 websites shown in the interviews. It is conceivable that alternative representational methods—
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41 e.g., using visualizations or other patient-centered risk communication strategies aimed at
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43 improving comprehension—may have encouraged more favorable attitudes. This possibility
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45 remains to be explored and is an important focus for future research. Finally, the study assessed
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47 patient perceptions rather than behaviors and used qualitative methods, a powerful approach for
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49 ascertaining the nature and breadth—but not the prevalence, causes, and effects—of people's
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51 beliefs and attitudes. Further quantitative studies using larger, racially and ethnically diverse
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3 samples are thus needed to confirm our preliminary findings. Nevertheless, the validity of these
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5 findings is supported by their consistency with mounting evidence that precise, quantitative risk
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7 information is not always what patients need or want.^{30,31} Our findings have important
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9 implications for potential users of CPMs because they identify patient perceptions of the value of
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11 personalized risk information as a barrier to the use of CPMs, and suggest potential modifiable
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13 reasons for these perceptions.
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20 The most straightforward reason is lack of exposure to personalized risk information; most study
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22 participants reported having never received such information, and its value was thus simply
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24 beyond their imagination. This problem might be addressed by exposing patients to what
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26 they've been missing; as Steve Jobs famously quipped, "People don't know what they want until
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28 you show it to them."⁶³ Yet our study suggests that even if patients were provided with
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30 personalized risk information, they may not always want it. Study participants expressed an
31
32 overarching desire for simplicity in information and decision-making approach, manifested in
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34 preferences for heuristic- rather than risk-based decision making. This desire for simplicity is
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36 common,^{30,64-66} and reflects fundamental limitations in human cognitive capacities (e.g.,
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38 memory, literacy, numeracy) and available environmental resources (e.g., time, decision
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40 support)^{32,67,68} that constrain people's ability to engage in effortful deliberation in decision
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42 making, and instead promote intuitive, heuristic-based decision making based on factors other
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44 than "estimations of probabilities, gains, costs, and the like."⁶¹ Intuitive and deliberative
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46 decision-making approaches each have advantages and disadvantages;⁶⁹ however, if the goal is
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48 to increase the perceived value and clinical use of personalized risk information, then the
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50 limitations that reduce people's capacity for deliberation must somehow be overcome.
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6 Another factor limiting the perceived value and use of personalized risk information among
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8 study participants was a perception that such information is less reliable than non-quantitative
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10 evidence. This perception raises a need that has not been addressed in efforts to apply risk
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12 information to patient care: to increase patients' *epistemological understanding*—i.e., their
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14 comprehension of the nature of risk knowledge and the strengths and weaknesses of the evidence
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16 at hand. Our study illustrates the two-fold challenge patients face in using personalized risk
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18 information: they must weigh not only the magnitude of competing probabilities but the value of
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20 competing types of evidence, each with their own strengths and weaknesses. Personalized risk
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22 information represents the strongest form of evidence from the expert perspective; nevertheless,
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24 its clinical value is diminished by uncertainties arising from methodological problems in risk
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26 modeling^{70,71} and the limited applicability of risk estimates to single events experienced by
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28 individuals.⁷² On the other hand, non-quantitative forms of evidence (e.g., “gut feelings,”⁷³
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30 physician recommendations, personal anecdotes) provide a means of mitigating irreducible
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32 uncertainties of risk estimates and are thus valuable from the lay perspective; however, such
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34 evidence is susceptible to numerous biases. Exactly how patients should weight these different
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36 types of evidence is a critical question for future research, but at the very least this task requires
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38 an understanding of their strengths and weaknesses. The lack of such understanding among
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40 study participants suggests that epistemological education should be a primary focus of efforts to
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42 apply personalized risk information to patient care.
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53 Our study thus identifies several potentially important tasks for enhancing the value and use of
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55 personalized risk information: 1) increasing patients' exposure to personalized risk information,
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3 2) providing resources to support deliberative decision making, and 3) providing epistemological
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5 education on the nature of medical knowledge and evidence. The first task has been a primary
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7 focus of CPM proponents; however, more work is needed to effectively disseminate and
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9 implement CPMs in clinical practice. The second task has only begun to be addressed, but
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11 promising approaches include the delivery of personalized risk information through patient-
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13 centered decision support interventions (DeSIs) such as decision aids,^{74,75} and the use of risk
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15 communication strategies such as visual representations to improve the evaluability of risk
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17 estimates.^{30,31,76-83} A more challenging task is to provide the environmental resources—e.g.,
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19 clinical time, processes, and incentives—needed for deliberative and collaborative decision
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21 making.⁷⁴ The final task, the provision of epistemological education, is a new frontier that has
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23 yet to be explored but calls for efforts to expand the content of risk information communicated to
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25 patients—whether through DeSIs or larger-scale educational efforts delivered through other
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27 channels. It remains for further research to address these challenges, and to determine how best
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29 to help patients translate personalized risk information into better informed health care decisions.
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53 All authors had full access to all of the data (including statistical reports and tables) in the study
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55 and take responsibility for the integrity of the data and the accuracy of the data analysis. The
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3 study was approved by the Maine Medical Center Institutional Review Board (IRB#3805X), and
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5 granted a waiver of informed consent.
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10 All authors have completed the Unified Competing Interest form at
11
12 www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and
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14 declare that (1) PH, MN, BR, NH, TK, CG, MD, and MH have no relationships with companies
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16 that might have an interest in the submitted work in the previous 3 years; (2) spouses, partners,
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18 or children of PH, MN, BR, NH, TK, CG, MD, and MH have no financial relationships that may
19
20 be relevant to the submitted work; and (3) PH, MN, BR, NH, TK, CG, MD, and MH have no
21
22 non-financial interests that may be relevant to the submitted work.
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55 participate in this study.
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Contributorship Statement

PH designed the study, obtained funding, conducted interviews and data analysis, drafted the manuscript, and edited the manuscript for important content.

MN, BR, and NH conducted data analysis and edited the manuscript for important content.

TK assisted in the design of the study, conducted interviews, and edited the manuscript for important content.

CG edited the manuscript for important content.

MD edited the manuscript for important content.

MH assisted in the design of the study and edited the manuscript for important content.

Data sharing statement

Data sharing: no additional data available; consent for data sharing was not obtained from study participants.

References

Table 1. Focus group categories

- Low-risk group: Early-stage, clinically localized disease (Gleason Score ≤ 6 , Stage T1C-T2A, PSA <10)
- Medium-risk group: Intermediate-stage, clinically localized disease (Gleason Score 7, Stage T2B-T2C, PSA 10-20)
- High-risk group: patients with advanced, treatment-refractory, or recurrent disease (Gleason Score 8-10, Stage T3-T4, PSA >20)

Table 2. Characteristics of focus group participants

	<u>N</u>	<u>%</u>
Age		
50-59	6	21%
60-69	18	62%
70-79	4	14%
≥ 80	1	3%
Risk Group		
Low	7	24%
Med	15	52%
High	7	24%
Race		
White/Caucasian	29	100%
Other	0	0%
Education		
High school or less	6	21%
Some college	4	14%
College graduate	10	34%
Post graduate	9	31%
Location		
Brunswick	9	31%
Lewiston	9	31%
Portland	11	38%

Table 3. The biomarker heuristic: illustrative quotes

I was told that with the Gleason score of 9 that that's frightening ... That's extremely aggressive is what this one doctor said, and at the next place that doctor said it's kind of scary, he says, but it can be taken care of. [High-Risk Participant]

*INTERVIEWER: And what was your understanding of what the Gleason score meant?
PATIENT: A high number is, you know -- the top number is, you know, if that's higher than your bottom number, you've got problems. [High-Risk Participant]*

... he gave me the lab report itself and he showed me these different things and he says this here's the Gleason score. The Gleason is this three over four. He said if it had been four over three, you know, we would have been more concerned. He said this shows it's an active cancer but it's not an aggressive cancer and he said so we've got some time to wait. We don't have a lot of time to wait. He said we don't have to worry about going into surgery in the next three weeks or something. [Medium-Risk Participant]

The way they explained to me was that if it's under a four Gleason it's probably not gonna do much. If it's around a six it's kind of getting up there. If it gets up around and eight then it's real aggressive, you gotta do something fast. [Medium-Risk Participant]

Appendix A. Clinical prediction model screenshots used as interview aids

Memorial Sloan-Kettering Cancer Center
 PROSTATE CANCER INFORMATION | MAKING AN APPOINTMENT
 mskcc.org
 PREDICTION TOOLS
 Change Prediction Tool

Prostate Cancer Nomograms: Pre-Treatment

TEXT SIZE [A] [A]

This nomogram can be used to predict what will happen after receiving a primary treatment (e.g. radical prostatectomy, brachytherapy, or external beam radiation therapy). To learn more, visit our [frequently asked questions](#).

Enter Your Information Clear Calculate

To gather the information required below, download our PDF [worksheet](#).

Primary Treatment Outcome
 To calculate results for a specific primary treatment outcome, select an option from the list below. (Each primary treatment outcome must be selected one at a time, followed by re-clicking the "Calculate" button.)
 Learn more about the below [primary treatment outcomes](#).

- Progression Free Probability after Radical Prostatectomy
- Progression Free Probability with Brachytherapy
- Relapse-Free Probability After External Beam Radiation Therapy

Pre-Treatment PSA
 PSA value from the laboratory report before receiving primary therapy. ng/ml (0.1 to 100)

Current Age
 years old (1 to 100)

Your Results

Learn more about your results below.

Extent of Disease Probability	Probability
Indolent Cancer	7%
Organ Confined Disease	67%
Extracapsular Extension	34%
Seminal Vesicle Invasion	9%
Lymph Node Involvement	3.3%
Primary Treatment Outcome	
Progression Free Probability after Radical Prostatectomy	5 Year 97%
	10 Year 95%

Print These Results

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Prostate Cancer Nomograms: Post-Radical Prostatectomy

TEXT SIZE [A] [A]

This nomogram can be used to predict the probability that a patient's cancer will recur after radical prostatectomy, that is, the probability that at two, five, seven and ten years that the patient's serum PSA level will become detectable and begin to rise steadily. The nomogram should only be used for patients when radical prostatectomy is the sole, primary treatment. To learn more, visit our [frequently asked questions](#).

Enter Your Information Clear Calculate

To gather the information required below, download our PDF [worksheet](#).

Pre-Treatment PSA
 PSA value from the laboratory report before the radical prostatectomy was performed or any other therapy for prostate cancer begun. ng/ml (0.1 to 100)

Age
 years old (20 to 120)

Gleason Grade

Primary Gleason Grade at Surgery
 The primary Gleason grade from the radical prostatectomy pathology report.

Secondary Gleason Grade at Surgery
 The secondary Gleason grade from the radical prostatectomy pathology report.

Your Results

Learn more about your results below.

Progression-Free Probability After Surgery	Probability
2 Year	99%
5 Year	81%
7 Year	72%
10 Year	61%

Print These Results

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Prostate Cancer Nomograms: Hormone Refractory

TEXT SIZE [A] [A]

For patients with advanced, metastatic prostate cancer that has been treated maximally with hormone therapy to control the effects of the male hormone, androgen. The nomogram predicts the survival probability one to two years later. To learn more, visit our [frequently asked questions](#).

Enter Your Information Clear Calculate

To gather the information required below, download our PDF [worksheet](#).

Current Age
 years old (40 to 85)

KPS (Karnofsky Performance Status)
 KPS value, assigned by a physician, nearest to the planned treatment start date or today's date.

Hemoglobin
 HGB value from the laboratory report nearest to the planned treatment start date or today's date. g/dl (6 to 17)

PSA
 PSA value from the laboratory report closest to the planned treatment start date or today's date. ng/ml (0.01 and 8450)

LDH (Lactate Dehydrogenase)
 LDH value from the laboratory report closest to the planned treatment start date or today's date. IU/L (116 to 1955)

ALK (Alkaline Phosphatase)
 ALK value from the laboratory report closest to the planned treatment start date or today's date. IU/L (19 to 3079)

Albumin
 Albumin value from the laboratory report closest to the planned treatment start date or today's date. g/dl (2.6 to 5.2)

Your Results

Learn more about your results below.

Survival Probability	1 Year 97%
	2 Year 82%
Median Survival Months	45

Print These Results

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Prostate Cancer
Predicting Post-Treatment Freedom from Recurrence

Pre-Treatment PSA Level (ng/mL)	20
Clinical Stage	T1c
Year of Surgery	2008
Surgeon Experience (# of prior cases)	50
Primary Gleason Grade (post-op)	3
Secondary Gleason Grade (post-op)	4
Surgical Margins Status	Positive
Extracapsular Extension?	No
Capsular Invasion Type	None
Seminal Vesicle Invasion?	No
Lymph Node Status	Negative
Adjuvant Radiotherapy?	No
Brachytherapy Isotope (If applicable)	I-125
Brachytherapy D90 (Gy) (If applicable)	100

Calculate

	Radical Prostatectomy	Brachytherapy
7-Year Recurrence-Free Percentage ¹	78.1%	51.7%
9-Year Recurrence-Free Percentage ^{2,3}	37.0%	34.4%
10-Year Recurrence-Free (high volume surgeon) Percentage ⁴	39.4%	



Metastatic Prostate Cancer
Overall Survival after Castration

Age (years)	60
KPS (%)	90
Hemoglobin (g/dL)	15
PSA (ng/mL)	0
LDH (U/L)	120
ALK (U/L)	20
Albumin (g/dL)	5.2

Calculate

1-Year Survival Probability

0.97

2-Year Survival Probability

0.80

* Smaletz O, Scher H, Small EJ, Verbel DA, McMillan A, Regan K, Kelly WK, Kattan MW. Nomogram for overall survival of patients with progressive metastatic prostate cancer following castration. J Clin Oncol 2002;20(19):3972-3982.

Appendix B. Theme outline – Focus group study

A. PAST EXPERIENCES WITH RISK COMMUNICATION

1. Extent of communication
 - a. No risk communication
 - b. Detailed communication of individualized, quantitative risk information
 - c. Non-individualized quantitative risk communication
 - d. Imprecise quantitative risk communication
 - e. Categorical risk communication: qualitative categories
 - f. Indirect risk communication: biomarker heuristic
2. Sources of risk information
 - a. Doctor: urologist, radiation oncologist, PCP, other
 - b. Other health professionals: nurse navigators, etc.
 - c. Friends, family
 - d. Internet, books

B. PERCEIVED VALUE OF PERSONALIZED RISK INFORMATION

1. Promote SDM
2. Provide insight into physician thinking
3. Provide second opinion / counter physician bias
4. Confirmatory
5. Facilitate advance care planning
6. Justify decisions

C. PERCEIVED CHALLENGES IN USE OF PERSONALIZED RISK INFORMATION

1. Lack of self-efficacy in understanding risk information
2. Logistic barriers: lack of time
3. Physician bias/self-interest
4. Preference for simplicity
5. Low perceived need for information
 - a. Low preference for information and participation in decision making
 - b. Trust the doctor heuristic
 - c. Cancer heuristic (removal heuristic: “cut it out”): perceived lack of decision
 - d. Reliance on intuitive vs. rational decision-making approaches
6. Distrust of statistical information: “anti-statistics” viewpoint
 - a. Preference for anecdotal/narrative vs. statistical information: “unreality” of numbers vs. narrative information
 - b. Questionable relevance to individual: reference class problem
 - c. Uncertainty: epistemic (ambiguity)
 - i. Imprecision
 - ii. Conflicting data
 - iii. Missing data, multiple/unknown/unaccounted risks
 - iv. Source credibility

- d. Uncertainty: aleatory (randomness)
7. Motivated reasoning: desire for good news/fear of bad news

D. VALUE OF INDIRECT RISK COMMUNICATION (BIOMARKER HEURISTIC)

1. Provide sense of control
2. Communicate the bottom-line/gist
3. Represent “hard information”
4. Facilitate decision resolution
5. Simplify decision making

E. INTERPRETATION OF PERSONALIZED RISK ESTIMATES

1. Understanding of risk estimate: frequency or confidence statement
2. Perceived difficulty

F. COMMUNICATION OF UNCERTAINTY (AMBIGUITY)

1. Preferences for/against
2. Reactions to use of range/confidence interval

References

1. Edwards A, Hood K, Matthews E, et al. The effectiveness of one-to-one risk communication interventions in health care: a systematic review. *Med Decis Making*. Jul-Sep 2000;20(3):290-297.
2. Steyerberg EW. *Clinical Prediction Models: a Practical Approach to Development, Validation, and Updating*. New York: Springer; 2010.
3. Personalized Health Care: Pioneers, Partnerships, Progress. 2008. <http://www.hhs.gov/myhealthcare/>. Accessed March 12, 2013.
4. Briss P, Rimer B, Reilley B, et al. Promoting informed decisions about cancer screening in communities and healthcare systems. *Am J Prev Med*. Jan 2004;26(1):67-80.
5. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns*. Mar 2006;60(3):301-312.
6. Edwards A, Unigwe S, Elwyn G, et al. Effects of communicating individual risks in screening programmes: Cochrane systematic review. *BMJ*. Sep 27 2003;327(7417):703-709.
7. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. *The New England journal of medicine*. Mar 1 2012;366(9):780-781.
8. Elwyn G, Frosch D, Thomson R, et al. Shared Decision Making: A Model for Clinical Practice. *J Gen Intern Med*. May 23 2012;27(10):1361-1367.
9. Vickers AJ, Basch E, Kattan MW. Against diagnosis. *Annals of internal medicine*. Aug 5 2008;149(3):200-203.
10. Edwards AG, Naik G, Ahmed H, et al. Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database Syst Rev*. 2013;2:CD001865.
11. Gillies D. *Philosophical Theories of Probability*. London: Routledge; 2000.
12. Hacking I. *The Taming of Chance*. Cambridge: Cambridge University Press; 1990.
13. Han PK. Conceptual, Methodological, and Ethical Problems in Communicating Uncertainty in Clinical Evidence. *Med Care Res Rev*. Nov 6 2012.
14. Han PK, Klein WM, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Medical decision making : an international journal of the Society for Medical Decision Making*. Nov 2011;31(6):828-838.
15. Brewer NT, Richman AR, Defrank JT, et al. Improving communication of breast cancer recurrence risk. *Breast cancer research and treatment*. Jun 2012;133(2):553-561.
16. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. *Med Decis Making*. Jan-Feb 2001;21(1):37-44.
17. Sheridan SL, Pignone M. Numeracy and the medical student's ability to interpret data. *Eff Clin Pract*. Jan-Feb 2002;5(1):35-40.
18. Schwartz LM, Woloshin S, Black WC, et al. The role of numeracy in understanding the benefit of screening mammography. *Ann Intern Med*. Dec 1 1997;127(11):966-972.
19. Wegwarth O, Schwartz LM, Woloshin S, et al. Do physicians understand cancer screening statistics? A national survey of primary care physicians in the United States. *Annals of Internal Medicine*. Mar 6 2012;156(5):340-349.
20. Reyna VF, Nelson WL, Han PK, et al. How numeracy influences risk comprehension and medical decision making. *Psychol Bull*. Nov 2009;135(6):943-973.

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21. Han PK, Klein WM, Lehman TC, et al. Laypersons' responses to the communication of uncertainty regarding cancer risk estimates. *Med Decis Making*. May-Jun 2009;29(3):391-403.
22. Han PK, Lehman TC, Massett H, et al. Conceptual problems in laypersons' understanding of individualized cancer risk: a qualitative study. *Health Expect*. Mar 2009;12(1):4-17.
23. Ravdin PM, Siminoff LA, Davis GJ, et al. Computer program to assist in making decisions about adjuvant therapy for women with early breast cancer. *J Clin Oncol*. Feb 15 2001;19(4):980-991.
24. Peele PB, Siminoff LA, Xu Y, et al. Decreased use of adjuvant breast cancer therapy in a randomized controlled trial of a decision aid with individualized risk information. *Med Decis Making*. May-Jun 2005;25(3):301-307.
25. Siminoff LA, Gordon NH, Silverman P, et al. A decision aid to assist in adjuvant therapy choices for breast cancer. *Psychooncology*. Nov 2006;15(11):1001-1013.
26. Belkora JK, Rugo HS, Moore DH, et al. Oncologist use of the Adjuvant! model for risk communication: a pilot study examining patient knowledge of 10-year prognosis. *BMC Cancer*. 2009;9:127.
27. Hutton DW, Belkora JK, Shachter RD, et al. Are patients getting the "gist" in risk communication? Patient understanding of prognosis in breast cancer treatment. *J Cancer Educ*. 2009;24(3):194-199.
28. Lipkus IM, Peters E, Kimmick G, et al. Breast cancer patients' treatment expectations after exposure to the decision aid program adjuvant online: the influence of numeracy. *Med Decis Making*. Jul-Aug;30(4):464-473.
29. Zikmund-Fisher BJ, Fagerlin A, Ubel PA. Improving understanding of adjuvant therapy options by using simpler risk graphics. *Cancer*. Dec 15 2008;113(12):3382-3390.
30. Zikmund-Fisher BJ. The Right Tool Is What They Need, Not What We Have: A Taxonomy of Appropriate Levels of Precision in Patient Risk Communication. *Med Care Res Rev*. Nov 1 2012.
31. Reyna VF. A theory of medical decision making and health: fuzzy trace theory. *Med Decis Making*. Nov-Dec 2008;28(6):850-865.
32. Simon H. *Models of Man, Social and Rational: Mathematical Essays on Rational Human Behavior in a Social Setting*. New York: Wiley; 1957.
33. Cancer Research UK. Prostate Cancer Statistics. 2013; <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/>. Accessed April 4, 2013, 2013.
34. Rothenberg BM, Marbella A, Belinson SE, et al. Future Research Needs for Comparative Effectiveness of Treatments of Localized Prostate Cancer: Identification of Future Research Needs from Comparative Effectiveness Review No. 13. Rockville (MD)2010.
35. National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Stat Facts Sheets: Prostate. 2013; <http://seer.cancer.gov/statfacts/html/prost.html>. Accessed April 4, 2013, 2013.
36. Cooperberg MR. Prostate cancer risk assessment: choosing the sharpest tool in the shed. *Cancer*. Dec 1 2008;113(11):3062-3066.
37. Shariat SF, Karakiewicz PI, Roehrborn CG, et al. An updated catalog of prostate cancer predictive tools. *Cancer*. Dec 1 2008;113(11):3075-3099.

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38. Lughezzani G, Briganti A, Karakiewicz PI, et al. Predictive and Prognostic Models in Radical Prostatectomy Candidates: A Critical Analysis of the Literature. *Eur Urol*. Aug 6 2010;58(5):687-700.
39. Cowen ME, Halasyamani LK, Kattan MW. Predicting life expectancy in men with clinically localized prostate cancer. *J Urol*. Jan 2006;175(1):99-103.
40. Eastham JA, Scardino PT, Kattan MW. Predicting an optimal outcome after radical prostatectomy: the trifecta nomogram. *The Journal of urology*. Jun 2008;179(6):2207-2210; discussion 2210-2201.
41. Ross RW, Kantoff PW. Predicting outcomes in prostate cancer: how many more nomograms do we need? *J Clin Oncol*. Aug 20 2007;25(24):3563-3564.
42. Lerner Research Institute, Cleveland Clinic. Risk Calculators. 2010; http://www.lerner.ccf.org/qhs/risk_calculator/index.php. Accessed November 12, 2010.
43. Touijer K, Scardino PT. Nomograms for staging, prognosis, and predicting treatment outcomes. *Cancer*. Jul 1 2009;115(13 Suppl):3107-3111.
44. Cegala DJ, Post DM, McClure L. The effects of patient communication skills training on the discourse of older patients during a primary care interview. *J Am Geriatr Soc*. Nov 2001;49(11):1505-1511.
45. nomogram.org. Prostate Cancer. 2010; http://nomogram.org/Prostate/pros_calc.php. Accessed November 12, 2010.
46. Hoffman A, Montgomery R, Aubry W, et al. How best to engage patients, doctors, and other stakeholders in designing comparative effectiveness studies. *Health Aff (Millwood)*. Oct 2010;29(10):1834-1841.
47. Sofaer S. Qualitative methods: what are they and why use them? *Health Serv Res*. Dec 1999;34(5 Pt 2):1101-1118.
48. Kitzinger J. Qualitative research. Introducing focus groups. *BMJ*. Jul 29 1995;311(7000):299-302.
49. Morgan D. *Focus Groups in Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1998.
50. National Comprehensive Cancer Network. NCCN Practice Guidelines for Prostate Cancer. . 2010;Version 1: 2010. <http://www.nccn.org>. Accessed December 16, 2012.
51. Memorial-Sloan Kettering Center. Prostate Cancer Nomograms: a Tool for Doctors & Patients. . 2010; <http://www.mskcc.org/mskcc/html/10088.cfm>. Accessed November 12, 2010.
52. Strauss AL, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd ed. Thousand Oaks, CA: Sage; 1998.
53. Ryan GW, & Bernard, H. R. Data management and analysis methods. In: N. K. Denzin, Lincoln YS, eds. *Collecting and Interpreting Qualitative Materials*. Thousand Oaks, CA: Sage; 2003:259-309.
54. Glaser BG. The Constant Comparative Method of Qualitative Analysis. *Social Problems*. 1965;12(4):436-445.
55. Slovic P, Finucane M, Peters E, et al. The affect heuristic. In: Gilovich T, Griffin D, Kahneman D, eds. *Heuristics and Biases: the Psychology of Intuitive Judgment*. Cambridge: Cambridge University Press; 2002:397-420.
56. Slovic P, Peters E, Finucane ML, et al. Affect, risk, and decision making. *Health Psychol*. Jul 2005;24(4 Suppl):S35-40.

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57. Wegwarth O, Gigerenzer G. Trust-your-doctor: a simple heuristic in need of a proper social environment. In: Hertwig R, Hoffrage U, eds. *Simple Heuristics in a Social World*. New York: Oxford University Press; 2013:67-102.
58. Winterbottom A, Bekker HL, Conner M, et al. Does narrative information bias individual's decision making? A systematic review. *Soc Sci Med*. Dec 2008;67(12):2079-2088.
59. deWit JBF, Das E, Vet R. What works best: objective statistics or a personal testimonial? An assessment of the persuasive effects of different types of message evidence on risk perception. *Health Psychol*. 2008;27(1):110-115.
60. Shaffer VA, Zikmund-Fisher BJ. All stories are not alike: a purpose-, content-, and valence-based taxonomy of patient narratives in decision AIDS. *Med Decis Making*. Jan 2013;33(1):4-13.
61. Gigerenzer G, Selten R. *Bounded Rationality*. Cambridge: MIT Press; 2002.
62. Tversky A, Kahneman D. Judgment under uncertainty: heuristics and biases. *Science*. 1974;185(4157):1124-1131.
63. Isaacson W. *Steve Jobs*. New York: Simon and Schuster; 2011.
64. Peters E, Dieckmann N, Dixon A, et al. Less is more in presenting quality information to consumers. *Med Care Res Rev*. Apr 2007;64(2):169-190.
65. Iyengar SS, Kamenica E. Choice proliferation, simplicity seeking, and asset allocation. *Journal of Public Economics*. 2010;94(7):530-539.
66. Iyengar SS, Lepper MR. When choice is demotivating: Can one desire too much of a good thing? *Journal of Personality and Social Psychology*. 2000;79:995-1006.
67. Legare F, Ratte S, Gravel K, et al. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient education and counseling*. Dec 2008;73(3):526-535.
68. Lin GA, Aaronson DS, Knight SJ, et al. Patient decision aids for prostate cancer treatment: a systematic review of the literature. *CA Cancer J Clin*. Nov-Dec 2009;59(6):379-390.
69. de Vries M, Fagerlin A, Witteman HO, et al. Combining deliberation and intuition in patient decision support. *Patient Educ Couns*. May 2013;91(2):154-160.
70. Spiegelhalter DJ, Riesch H. Don't know, can't know: embracing deeper uncertainties when analysing risks. *Philos Transact A Math Phys Eng Sci*. Dec 13 2011;369(1956):4730-4750.
71. Bilcke J, Beutels P, Brisson M, et al. Accounting for methodological, structural, and parameter uncertainty in decision-analytic models: a practical guide. *Med Decis Making*. Jul-Aug 2011;31(4):675-692.
72. Han PK. Conceptual, methodological, and ethical problems in communicating uncertainty in clinical evidence. *Med Care Res Rev*. Feb 2013;70(1 Suppl):14S-36S.
73. Gigerenzer G. *Gut Feelings: the Intelligence of the Unconscious*. New York: Penguin Books; 2007.
74. Elwyn G, Frosch D, Volandes AE, et al. Investing in deliberation: a definition and classification of decision support interventions for people facing difficult health decisions. *Med Decis Making*. 2010;30(6):701-711.
75. Stacey D, Bennett CL, Barry MJ, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane database of systematic reviews*. 2011(10):CD001431.

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76. Lipkus IM. Numeric, verbal, and visual formats of conveying health risks: suggested best practices and future recommendations. *Med Decis Making*. Sep-Oct 2007;27(5):696-713.
77. Visschers VH, Meertens RM, Passchier WW, et al. Probability information in risk communication: a review of the research literature. *Risk Anal*. Feb 2009;29(2):267-287.
78. Galesic M, Garcia-Retamero R, Gigerenzer G. Using icon arrays to communicate medical risks: overcoming low numeracy. *Health Psychol*. Mar 2009;28(2):210-216.
79. Garcia-Retamero R, Galesic M. Who profits from visual aids: overcoming challenges in people's understanding of risks [corrected]. *Soc Sci Med*. Apr 2010;70(7):1019-1025.
80. Dolan JG, Qian F, Veazie PJ. How well do commonly used data presentation formats support comparative effectiveness evaluations? *Med Decis Making*. Nov-Dec 2012;32(6):840-850.
81. Akl EA, Oxman AD, Herrin J, et al. Using alternative statistical formats for presenting risks and risk reductions. *Cochrane Database Syst Rev*. 2011(3):CD006776.
82. Gigerenzer G, Gaissmaier W, Kurz-Milcke E, et al. Helping doctors and patients make sense of health statistics. *Psychological Science in the Public Interest*. 2007;8:53-96.
83. Spiegelhalter D, Pearson M, Short I. Visualizing uncertainty about the future. *Science*. Sep 9 2011;333(6048):1393-1400.

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12 **The value of personalized risk information: a qualitative study of the perceptions of**
13 **prostate cancer patients**
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Abstract

Objective. To explore prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Design. A qualitative study was conducted using focus groups. Semi-structured interviews explored participants' experiences with using risk information, and their perceptions of the potential value of ~~precise,~~ personalized, risk information produced by clinical prediction models (CPMs).

Participants. English-speaking patients, ages 54-82, diagnosed with prostate cancer within the past 3 years, residing in rural and non-rural geographic locations in Maine (USA), and attending ~~local~~ prostate cancer patient support groups.

Setting. Six focus groups were conducted with 27 patients; separate groups were held for patients with low, medium, and high-risk disease defined by National Comprehensive Cancer Network guidelines.

Results. ~~Several p~~Participants ~~most commonly~~ reported receiving risk information that was imprecise rather than precise, qualitative rather than quantitative, indirect rather than direct, and focused on biomarker values rather than clinical outcomes. Some participants felt that personalized risk information could be valuable in helping them make better informed decisions, but ~~most~~ expressed skepticism about its value. ~~Most~~ Many participants favored decision-making strategies that were heuristic-based and intuitive rather than risk-based and deliberative, and perceived other forms of evidence—emotions, recommendations of trusted physicians, personal narratives—as more reliable and valuable in treatment decisions.

Conclusions. Prostate cancer patients appear to have little experience using personalized risk information, may favor heuristic- over risk-based decision making strategies, and may perceive

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personalized risk information as less valuable than other types of evidence. These decision-making approaches and Patients' preferred decision making approaches to decision making and their perceptions may represent potential barriers to the clinical use of personalized risk information. Overcoming these barriers will require providing patients with greater providing patients with greater exposure to risk information, education about the nature and value of personalized risk information, and training in deliberative decision-making strategies, environmental resources for deliberative decision making, and education about the nature and value of personalized risk information. More research is needed to confirm and address these findings and address these needs.

Article Summary

Article Focus

- Personalized risk information is an increasingly common, important form of evidence in the treatment of prostate cancer and numerous other medical conditions, but little is known about the extent to which patients use and value such information.
- This study explored prostate cancer patients' experiences with risk information and their perceptions of the value of personalized risk information in treatment decisions.

Key Messages

- Prostate cancer patients appear to have little experience using personalized risk information in clinical decisions, and the risk information they commonly receive is imprecise, qualitative, and indirect.
- At least some p~~Many p~~rostate cancer patients may favor decision-making strategies that are heuristic-based and intuitive rather than risk-based and deliberative, and perceive personalized risk information as having little less value in clinical decision making than other forms of evidence.
- Effective application of personalized risk information to clinical decisions will require increasing patients' exposure to this information, creating environmental conditions that favor greater deliberation in decision making, and providing patients with education about its nature and value relative to other types of evidence.

Strengths and Limitations

- The study provides empirical evidence on the value of personalized risk information from the patient perspective, and identifies previously unexamined barriers to effective use of this information.

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- The study sample was relatively small, geographically limited, and racially and ethnically homogeneous.
- Qualitative methods cannot definitively establish the prevalence, causes, or effects of ~~the~~ patients' experiences and perceptions. Further research using quantitative methods is needed to confirm the study's findings.

Introduction

Personalized, or individualized, risk information—information about the probability of future health outcomes for individual patients¹—is an increasingly common and important form of clinical evidence. In recent years, burgeoning efforts to develop clinical prediction models (CPMs)—statistical algorithms that utilize characteristics of the patient, disease, and treatment to estimate individualized probabilities of health outcomes²—have increased the supply of personalized risk information. Meanwhile, a growing emphasis on the ideals of personalized health care, patient-centered outcomes research, and informed and shared decision making have heightened clinical demand for this information.³⁻⁸ Personalized risk information advances each of these important health care ideals, enabling decision making based on the expected outcomes of individuals rather than groups, on prognostic estimates rather than diagnostic categories,⁹ and on patient values and preferences.² Emerging evidence supports this vision; a recent Cochrane review concluded that personalized risk information promotes informed patient decision making in cancer screening.¹⁰

Nevertheless, the clinical value of personalized risk information is limited by several barriers, including the conceptually abstract nature of risk information,¹¹⁻¹⁴ psychological biases, and well-documented deficits in numeracy that impede its comprehension by both patients and health professionals.¹⁵⁻²² Correspondingly, several studies have shown that patients' understanding of personalized risk estimates produced by CPMs is poor.²¹⁻²⁹ A deeper problem, however, is that precise, quantitative risk information may not be what patients really want or need. Zikmund-Fisher has argued that such information is not always informative, and “simpler, less precise representations” of risk are often more useful to patients.³⁰ In a similar vein, Reyna has

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9 contended that people prefer to construe risk in qualitative terms representing its “gist” meaning,
10 rather than in precise, quantitative terms representing its “verbatim” details.³¹ Gigerenzer has
11 gone further to challenge the conception of rationality underlying efforts to apply risk
12 information to decision making. Extending an argument put forth by the economist Simon in the
13 1950s,³² he emphasizes that rationality is “bounded” by limitations in the cognitive and
14 environmental resources available to decision makers. Consequently, in real world decisions
15 people do not “optimize”—i.e., they do not calculate and weigh probabilities and values in an
16 exhaustive computational search for the best option. Instead, they use heuristics—“fast and
17 frugal” rules of thumb that facilitate adaptive decisions.
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28 These insights raise fundamental questions about the usefulness of precise, quantitative risk
29 information in health care. Is such information really needed and desired by patients? Do
30 patients—as opposed to health professionals—perceive personalized risk information as
31 valuable, and how might their perceptions influence the success of efforts to use CPMs in
32 clinical practice?
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39 The aim of the current research was to explore these questions, focusing on personalized risk
40 information in the treatment of prostate cancer—the most common and 2nd most common male
41 cancer in the US and worldwide, respectively, and the 2nd and 6th leading cause of male cancer
42 deaths.³³⁻³⁵ Approximately 80% of newly diagnosed prostate cancer patients have clinically-
43 localized disease for which there are multiple treatment options—surgery, radiation therapy,
44 conservative treatment (active surveillance)—each with differing potential benefits and harms.³⁴
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50 The same is true for the treatment of more advanced, higher-risk disease. Prostate cancer has
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thus become a primary focus of predictive modeling activities, resulting in the development of over 100 CPMs³⁶⁻⁴² and growing efforts to disseminate and apply these models in clinical practice.⁴¹⁻⁴⁶

Little is known, however, about prostate cancer patients' perspectives on the value of CPMs and the information they produce. To this end, the current study explored prostate cancer patients' experiences with using risk information in treatment decisions, and their perceptions of the value of precise, personalized risk information produced by CPMs. The ultimate goal was to generate insights that might inform efforts to use CPMs to promote personalized, informed decision making in the treatment of prostate cancer and other conditions.

Methods

Study design, participants, and data collection. This qualitative study employed focus groups, a useful methodology for exploring people's perceptions, beliefs, and attitudes.^{47,48} From September 2010–February 2011, 7 focus groups were conducted with 27 prostate cancer patients in the state of Maine (3-6 patients/group). Participants were members of the Maine Coalition to Fight Prostate Cancer (MCFPC), a patient advocacy organization that administers 9 statewide support groups throughout the entire state. Eligible participants were recruited by MCFPC and consisted of English-speaking prostate cancer survivors within 3 years of initial diagnosis. Purposive recruitment soliciting participation of men at various disease stages. –A purposive recruiting strategy was employed to select was conducted to obtain a study sample with varying diverse treatment experiences and prognoses; no volunteers were excluded. To achieve sufficient within-group homogeneity to encourage open discussion,⁴⁹ participants were stratified

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9 into 3 groups (**Table 1**) according to their risk for recurrent disease (Low, Medium, High), as
10 defined by U.S. National Comprehensive Cancer Network guidelines.⁵⁰ A total of 2 Low Risk, 3
11 Medium Risk, and 2 High Risk focus groups were conducted at MCFPC support group sites in 3
12 rural and non-rural towns and cities (Brunswick, Lewiston, Portland). Participants received \$50
13 compensation. Sessions lasted approximately 2 hours, were audiorecorded with prior consent of
14 participants, and transcribed verbatim by a professional transcription service.
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22 **Interview content.** Groups were led by PH and either a professional moderator or another study
23 investigator (TK). Interviews were semi-structured and followed a moderator guide consisting
24 of open-ended questions and close-ended probes designed to elicit patients' past experiences
25 with risk information, preferences for personalized risk information, and attitudes towards
26 CPMs. To illustrate how CPMs work and what types of information they provide, participants
27 were interviewed briefly utilizing shown visual aids consisting of screenshots of web-based CPMs
28 (Appendix A) for several different prostate cancer outcomes (e.g., risk of cancer recurrence,
29 cancer-free survival, death) produced by the Cleveland Clinic
30 (http://www.lerner.ccf.org/qhs/risk_calculator/index.php)⁴² and Memorial Sloan-Kettering
31 Cancer Center (<http://www.mskcc.org/mskcc/html/10088.cfm>).⁵¹ During the course of the study,
32 minor revisions were made in the interview guide to clarify emergent themes.
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45 **Data analysis.** In-depth analysis and line-by-line software-assisted coding of anonymized
46 interview transcripts was conducted using the program NVivo (Version 8; QSR International).
47 First, three investigators (PH, MN, BR) developed a preliminary conceptual schema and
48 codebook by independently reading 3 transcripts, categorizing participants' verbatim statements
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according to thematic content, and organizing emergent themes—consistent with a “grounded theory” approach to the data.^{52,53} Preliminary codebooks were reviewed by the team and areas of disagreement were resolved through further discussion. A single working codebook was then produced, which two investigators (MN, BR) used to code the remaining transcripts, employing a “constant comparative” method to compare new data, concepts, and themes with ones previously identified.^{52,54} The research team held periodic meetings to discuss coding decisions, identify new themes, and resolve areas of disagreement. Finally, two investigators (PH, NH) conducted a secondary review of all coded text to organize dominant themes. An outline of identified themes is in Appendix B. The current analysis focused on participants’ perceptions of the value of personalized risk information; analyses of other themes will be reported separately.

Results

Characteristics of participants are in **Table 2**. The primary interview domains consisted of participants’ 1) past experiences with risk communication, and 2) perceptions of the value of personalized risk information produced by CPMs.

1. Past experiences with risk communication

Within these two broad domains several dominant themes emerged; the first was the broad spectrum of risk communication experiences and practices reported by participants.

Absence of explicit risk communication. At one end of the spectrum were a small number of participants who reported having never received risk information of any kind during the decision making process:

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I wasn't actually told about the numbers. I just went by what they were saying. I guess— they knew what the numbers were, what the odds were for me, and I went with that and yeah, I would've wanted to know what the numbers were. [Medium-Risk Participant]

For these few participants treatment risks were implicitly understood rather than explicitly communicated:

I think the conversation that I had with my urologist was we each knew all of those possibilities. It was kind of like a given, and our conversation was based on the fact that we each knew those facts, so they weren't really mentioned specifically. It was just, you've got it, here are your options to deal with it because you want to deal with it because it could be fatal, it could spread. [Low-Risk Participant]

Quantitative risk communication. At the other end of the spectrum were just two participants, among all groups, who reported receiving precise, detailed, quantitative risk information. One low-risk and one medium-risk participant each recalled being shown a “histogram” and other visual aids detailing different risk levels for different treatment outcomes, broken down by demographic characteristics. Neither participant, however, recalled their risk estimates.

More commonly, quantitative risk information was communicated in imprecise terms. For example, several participants recalled being provided with “average” risk estimates applicable to patient subpopulations—e.g., stratified by cancer stage—while several others reported receiving a range rather than point estimate of risk.

Categorical risk communication. The more commonly reported mode of risk communication was categorical and non-quantitative. A low-risk participant noted: “he didn't say anything about the likelihood of spreading, but, you know, just, what he told me on the phone it was a low, that it was low.” Other participants recalled the use of similarly broad categories—e.g., “good,” “most likely,” “very remote,” “high,” “very likely.”

Indirect risk communication: the biomarker heuristic. The most commonly reported mode of risk communication by far, however, was indirect, through the use of biomarker information—primarily prostate specific antigen (PSA) values or Gleason scores—(Illustrative quotations from men at different levels of risk for disease recurrence are in Table 3). For participants in all groups, biomarker described using biomarker values in lieu of probability estimates to understand the magnitude of their risk:

I really, you know, I read the books ... And, I'm sure they had all sorts of graphs and stuff like that. But I've got to admit when I looked at my Gleason scores, this is gonna sound, you know it's all irrelevant. [High-Risk Participant]

This “biomarker heuristic”—which has not been previously described as such, to our knowledge—provided a basis for decision making functioned as a shorthand rubric or guide to treatment decisions. As values served as an anchor point that helped them understand the magnitude of their risk and provided a basis for decision making, as one medium-risk participant related articulated, referring to his PSA values: “when you don't have any guidelines to go by, you gotta have some idea where that is, whether it's a four or six or ten or whatever.” The use of biomarkers was a heuristic strategy that obviated the need to deal directly with outcome probabilities *per se*:

INTERVIEWER: So they gave you a sense of what those numbers meant ... a four means you have an X percent chance of—

PATIENT 3: No, they didn't.

INTERVIEWER: But they just said—it was good—versus bad, right?

PATIENT 3: Yeah.

PATIENT 2: That's what I got out of it when I was told I had—the PSA was 9 I think and my Gleason was 7—and like everybody else, you know, you're just completely naïve about it, but, by explaining then, telling me that, well, the 9, you better do something about it, you know—I mean, it's not a necessity, but they didn't recommend not doing anything about it all ... So those numbers I think ... kind of helps you towards whichever goal you wanna go to. [High-Risk Participant]

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~~PATIENT 3: Well I think if they're telling me my Gleason scale was under 4, I wouldn't have done anything.~~

~~PATIENT 1: Yeah, that's what I would do.~~

~~PATIENT 3: But when they said 6, that's when Dr. X said it's time to really think about it. But with me, I was upset for a little while, but once I made up my mind to do something, then I wasn't. The whole thing is wondering what you're gonna do and once you make up your mind—Yeah, then that's it. [Medium Risk Participants]~~

The usefulness of biomarker values appeared to stem from their apparently “hard,” tangible nature, and their straightforward connection to a defined course of action:

PATIENT: My decision was based upon what we had for biopsies and stuff like that.

INTERVIEWER: Okay. Alright.

PATIENT: Not look, you know, a lot of people get hit crossing the street. And, but that doesn't really—that's irrelevant to me... but, based upon the information that I had, you know, hard information, I felt very comfortable.

~~PATIENT 1: All that they've been giving me are the scores for my PSA... My doctor said, when your numbers double in four month spread, he said, we need to do something about it... he says, and I'll nip and tuck it just as soon as it gets up there, and my last time it was aggressive. It went from 0.12 to 5.5 in four months, and so, he encouraged me, and he told me what he was going to do...~~

~~INTERVIEWER: Okay.~~

~~PATIENT 2: They give you all kinds of information. And he'll tell you, you know, specifically we're talking about this spread, and this is where you are, and this is what we think... I totally felt like I was just as much in control of my life as he was. And it~~

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gave me, it gave me a lot of courage toward it. I had a bad two days when I found out about it. I haven't had a bad day since. [High-Risk Participants]

The influence of biomarker information contrasted with participants' lack of understanding of its precise meaning:

I really wasn't sure, and to this day, I don't know what the heck a Gleason score is. I'm not certain exactly what the PSA score is and what that is supposed to indicate, but I do know I had several PSA tests, and they started at 17, and there were several in 13, 14 and then a couple with 9 and 10, and then I had one that was 7. [High-Risk Participant]

2. Perceptions of the value of personalized risk information

Patients' perceptions of the potential value of personalized risk information produced by CPMs, spanned a broad range.

Enabling informed decision making. On the one hand, participants acknowledged several potential benefits related to the ideal of informed decision making. Some participants noted that personalized risk information could help clarify tradeoffs involved with alternative treatment options:

You take a look at that and say the statistics say, wow, you know, I'm not anywhere near as good if I do that over there. I think it would help you with your decision. [High-Risk Participant]

Patient empowerment *vis-à-vis* their physicians was another perceived value of personalized risk information:

So this is like a whole new concept where, you know, we're empowered, each of us is empowered with making the decision, and that's, like, you think about it and that's pretty unique and wonderful rather than to have a doctor...you know, the doctor can make a mistake, too ... So, like, the doctor is not the god. [Low-Risk Participant]

Participants believed that such empowerment was necessary because of inherent biases of treating physicians:

I can see this being used to help people make a decision as to what course of treatment they should seek versus what side effect they can live with. Now, if you go to X and ask them what their percentage of incontinence is ... they're gonna give you a skewed number because they don't want to make that million-dollar piece of equipment look bad. [High-Risk Participant]

Some participants—particularly those who had chosen active treatment (surgery, radiation therapy) over active surveillance or watchful waiting—felt that personalized risk information produced by CPMs might have changed their treatment decisions:

PATIENT 2: I mean, if you could plug in these numbers to see what the prediction would be based on what my diagnosis numbers were doing the various procedures, I, I probably would have looked at all those—and that may have strongly influenced me to do something other than what I did ... in my case I think if I had a predictor like this which showed me the same result with watchful waiting or robot or radiation, I would, I would think real strongly about watchful waiting. [Medium-Risk Participant]

Even if personalized risk information did not influence patients' actual decisions, furthermore, many valued such information as a means of simply being informed:

INTERVIEWER: Imagining that these kinds of tools were available when you were going through decision making, do you think this kind of information would have changed the decisions that you actually made about your own treatment?

MULTIPLE PATIENTS (in unison): No.

INTERVIEWER: Then what good is it?

PATIENT 4: Like D. said, it's just a tool for you to go by, you know.

PATIENT 5: Any information you can get adds to your knowledge of where you're gonna go with your treatment. [Medium-Risk Participants]

Skepticism about the relative value of personalized risk information. Most participants, however, expressed skepticism about the value of personalized risk information. A primary source was the fundamental uncertainty inherent to all risk estimates. Several participants

specifically mentioned the uncertainty involved in applying probability estimates to the realm of single events experienced by individuals¹⁴:

You know, I don't care how much information you have, or how much the odds are, it can be thrown a monkey wrench. The Patriots are a good example. [Laughter] I mean, you looked at all the stats and it said they were gonna win. That ain't how it turned out!
[Medium-Risk Participant]

You don't know which percentage you're going to be in. I mean ... the five-year number is 95%. Five percent of the people, their cancer's going to spread. So—I mean, it's a very high chance you won't spread, but you could be in the five percent. [Medium-Risk Participant]

Another source of skepticism related to the reliability of statistical models and risk evidence itself. Several participants raised questions about the “authenticity” of CPMs, the qualifications and experience of CPM producers, and ~~that~~ the novel nature of CPMs. They also felt that different researchers and models should be “close to giving you the same type of prediction,” and that conflicting estimates would lower their trust in CPMs. These concerns reflected “epistemic uncertainty” or the consciousness of what has been termed “ambiguity”—limitations in the reliability, credibility, or adequacy of risk information.¹⁴

Participants' uncertainties were manifest in skepticism about the value and influence of personalized risk information in decision making. Participants reported that at the most, they would use CPMs as a “second opinion” or “adjunct” that would augment—but not take precedence over—other types of evidence. As a medium-risk participant stated, “*I would consider the numbers very important, but it wouldn't drive the whole decision process.*”

Risk information vs. other types of evidence. More fundamentally, many participants did not accord privileged status to personalized risk information, but instead viewed it as merely one of

several types of evidence—with at least equal legitimacy and weight in the decision-making

process:

Oh, no. I don't—I don't think it's bullshit, but I do think it is just one of the factors that you would use to make a decision. I agree with the man. But I think that, you know that there's more than just emotion too. I think there's, you know, statistical data and information, there is emotional consideration, there is life—your spouse's circumstance too. [Medium-Risk Participant]

I think anything that you get anywhere is a guide ... Doesn't matter whether it comes from your doctor, the Internet—support group, or anything. Even prayer is a guide. And you got to take that information that you can get, as much as you can get, and make the best decision for you and your family. [Medium-Risk Participant]

Participants viewed their own decision making processes as intuitive and based on non-statistical

forms of evidence. Emotions were one prominent form of non-statistical evidence that

participants utilized in decision making, manifesting use of the “affect heuristic” in decision

making^{55,56}.

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I wouldn't choose from that. Well certainly if it were me, I would review what are the side effects of each, and the one thing that hasn't been touched on, and you may not be able to, is the emotional part of the decision. The statistics for most people probably wouldn't be more than 50% of the decision-making process. [Medium-Risk Participant]

For most other participants the recommendations of trusted physicians constituted the primary

form of evidence, manifesting reliance on what Wegwarth and Gigerenzer have termed the

“trust-the-doctor”⁵⁷ heuristic:

... I'm a person who, who really respects and honors education ... doctors work damn hard to get a degree and become a medical professional. I have to respect them and their decisions. [High-Risk Participant]

Personal narrative was another form of evidence that took precedence participants prioritized

over statistical evidence.⁵⁸⁻⁶⁰ As one participant articulated: “To me, you know, we can listen to

the statistics from the physicians but it's also nice to hear from the patients and maybe even the

wives.” For some participants the use of narrative evidence appeared to function as a heuristic—a mental shortcut that obviated the need to rely on statistical evidence. Reliance on this “narrative heuristic”—well-described in the literature although not typically characterized as a heuristic—manifested a greater trust in the reported experiences of identifiable persons individuals than from than in statistical information—anonymous, population-based statistical information:

Trust is experience-based. The experience happens here with people who are vouching and people who have had the experience ... It doesn't happen in a marketplace.
[Medium-Risk Participant]

So I think there's two ways to look at it. I'm not sure, you know, perhaps how does this 67% get generated? Is it based on just numbers or is it also based on doctors and nurses who have actually face-to-faced and worked, you know, and stuff. [Low-Risk Participant]

~~*Trust is experience based. The experience happens here with people who are vouching and people who have had the experience ... It doesn't happen in a marketplace.*~~
~~[Medium-Risk Participant]~~

Risk information vs. other types of evidence. More fundamentally, most many participants did not accord privileged status to personalized risk information, but instead viewed it as merely one of several types of evidence—all with equal legitimacy and weight in the decision-making process:

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[Medium-Risk Participant]

Oh, no. I don't—I don't think it's bullshit, but I do think it is just one of the factors that you would use to make a decision. I agree with the man. But I think that, you know that there's more than just emotion too. I think there's, you know, statistical data and information, there is emotional consideration, there is life—your spouse's circumstance too. [Medium-Risk Participant]

The need for simplicity. [Participants](#) [Several participants](#) expressed an overarching perception that risk information was not only potentially unimportant but detrimental in introducing complexity—another major source of uncertainty¹⁴ that could obscure the pertinent issues in decision making:

It can cloud the issue for an untrained person. Confuse the situation. Maybe more information than you really need to make a good decision. And you get so bogged with all the information that you lose sight of the forest. [Medium-Risk Participant]

But the die was cast and I made my choice. I was going to go with it, and I had that much faith. And the robotic surgery and how really, really, really good it is as opposed to the other types of surgery ... I had that much faith in my choice. And sometimes I don't want to say, gee, I don't want the issues to get clouded by the numbers, but I felt comfortable in what I was doing. [Medium-Risk Participant]

Yet this perception of personalized risk information as obscuring rather than aiding decisions, along with patients' reported reliance on various heuristics (biomarker, affect, white-coat, narrative) reflected a more fundamental need for simplicity in information and the decision-making process. ~~As one participant reported, "I think sometimes you can have too much information."~~

For many patients the need for simplicity was ultimately manifest in the choice of active prostate cancer treatment (i.e., surgery, radiation therapy): "... what's simpler than if you have cancer here, what's simpler than taking it out?" This cognitive strategy exemplified the use of ~~another simplifying~~ [what could be characterized as a simplifying "cancer disease heuristic"](#): ~~characterized by~~ a conceptual equation of the ~~mere diagnosis of cancer diagnosis itself disease~~ with the necessity of active treatment:

PATIENT 2: There was no watchful waiting for me ... Whether he told me that or not, I just—

INTERVIEWER: There was no option.

PATIENT 2: —no.

PATIENT 1: *I, I had the same. I didn't—that wasn't a decision. [Medium-Risk Participants]*

And, and you know, when I got those numbers of, you know, the, the biopsies and what not ... I wanted to be done with it ... I wanted it gone ... Let's just rip it out, throw it in the trash can over there in the corner and be done with it. [Medium-Risk Participant]

~~Although (This The conceptual equation of disease diagnosis with treatment necessity is a has been previously recognized phenomenon,⁹ this type of categorical thinking it has not been previously described characterized as a decision-making heuristic. However, our data suggests that it have a heuristic function—obviating patients' need and desire to attend to outcome probabilities and suggests that such thinking has the heuristic function of “cancer heuristic” not only leading many patients to perceive no real choice options, but diminishing their interest in personalized risk information:~~

I, I didn't know these types of models existed. I don't know if I would have used them or not—I might have. Again, I, it was so obvious to take the prostate out, you know—get rid of the problem, but I didn't really care what the percentages were. [Medium-Risk Participant]

PATIENT 1: *I had to obviously make a decision, but it was very, for me it was such an easy decision.*

PATIENT 3: *Yeah.*

PATIENT 2: *A no-brainer.*

PATIENT 1: *That may have been naïve, but, I guess, I don't know, it just seemed so logical. So I didn't even think twice about—I didn't even think once about weighing options or risks or ... I never wanted to get into a discussion with my doctor about all that stuff, because it just wasn't, wasn't necessary. [Medium-Risk Participants]*

Discussion

Our study provides ~~new-preliminary~~ insights on an important but understudied issue in the use of CPMs to advance personalized health care: the value of personalized risk information from the patient perspective. The study first demonstrates that such information has significant potential value, since the risk information ~~at least some~~ patients currently receive is typically imprecise

rather than precise, qualitative rather than quantitative, indirect (biomarker-based) rather than direct (outcomes-based), diagnostic rather than prognostic. To our knowledge, the current study provides the first empirical documentation of these phenomena in prostate cancer care; however, they are not unique to this disease. Indirect risk communication through biomarker values, for example, occurs in the treatment of common conditions such as hypercholesterolemia and hypertension,⁹ and heuristics are employed in numerous types of decisions.^{61,62} What the current study newly brings to light, however, is the critical role of patient values in reinforcing these processes. Although many prostate cancer patients in our study clearly perceived personalized risk information as valuable, ~~most~~ they viewed other types of evidence as relatively more influential and expressed preferences for intuitive, heuristic-based rather than deliberative, risk-based approaches to decision making.

These findings should be interpreted cautiously, however, given several study limitations. The sample was relatively small, geographically limited, and homogeneous in race and ethnicity. ~~Many~~ Many participants had already made treatment decisions, and their negative attitudes towards personalized risk information may thus have been biased by a motivation to avoid regret or dissonance over not having used such information. Participants' negative attitudes could also have been influenced by the particular ways in which the information was represented by the websites shown in the interviews. It is conceivable that, though not a focus of the interviews, alternative representational methods—e.g., using visualizations or other patient-centered risk communication strategies aimed at improving comprehension—may have encouraged more favorable attitudes. This possibility remains to be explored and is an important focus for future research. Finally, the study assessed patient perceptions rather than behaviors, and used

qualitative methods, a powerful approach for ascertaining the nature and breadth—but not the prevalence, causes, and effects—of people’s beliefs and attitudes. Further ~~research quantitative studies~~ using larger, racially and ethnically diverse samples ~~and quantitative methods is~~ are thus needed to confirm our preliminary findings. Nevertheless, the validity of ~~our these~~ findings is supported by their consistency with mounting evidence that precise, quantitative risk information is not always what patients need or want.^{30,31} Our findings ~~extend this evidence and~~ have important implications for potential users of CPMs because they identify patient perceptions of the value of personalized risk information as ~~an important~~ barrier to the use of CPMs, and suggest potential modifiable reasons for these perceptions.

The most straightforward reason is lack of exposure to personalized risk information; most study participants reported having never received such information, and its value was thus simply beyond their imagination. This problem might be addressed by exposing patients to what they’ve been missing; as Steve Jobs famously quipped, “People don’t know what they want until you show it to them.”⁶³ Yet our study suggests that even if patients were provided with personalized risk information, they may not always want it. Study participants expressed an overarching desire for simplicity in information and decision-making approach, manifested in preferences for heuristic- rather than risk-based decision making. This desire for simplicity is common,^{30,64-66} and reflects fundamental limitations in human cognitive capacities (e.g., memory, literacy, numeracy) and available environmental resources (e.g., time, decision support)^{32,67,68} that constrain people’s ability to engage in effortful deliberation in decision making, and instead promote intuitive, heuristic-based decision making based on factors other than “estimations of probabilities, gains, costs, and the like.”⁶¹ Intuitive and deliberative

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9 decision-making approaches each have advantages and disadvantages;⁶⁹ however, if the goal is
10 to increase the perceived value and clinical use of personalized risk information, then the
11 limitations that reduce people's capacity for deliberation must somehow be overcome.
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16 Another factor limiting the perceived value and use of personalized risk information among
17 study participants was a perception that such information is less reliable than non-quantitative
18 evidence. This perception raises a need that has not been addressed in efforts to apply risk
19 information to patient care: to increase patients' *epistemological understanding*—i.e., their
20 comprehension of the nature of risk knowledge and the strengths and weaknesses of the evidence
21 at hand. Our study illustrates the two-fold challenge patients face in using personalized risk
22 information: they must weigh not only the magnitude of competing probabilities but the value of
23 competing types of evidence, each with their own strengths and weaknesses. Personalized risk
24 information represents the strongest form of evidence from the expert perspective; nevertheless,
25 its clinical value is diminished by uncertainties arising from methodological problems in risk
26 modeling^{70,71} and the limited applicability of risk estimates to single events experienced by
27 individuals.⁷² On the other hand, non-quantitative forms of evidence (e.g., “gut feelings,”⁷³
28 physician recommendations, personal anecdotes) provide a means of mitigating irreducible
29 uncertainties of risk estimates and are thus valuable from the lay perspective; however, such
30 evidence is susceptible to numerous biases. Exactly how patients should weight these different
31 types of evidence is a critical question for future research, but at the very least this task requires
32 an understanding of their strengths and weaknesses. The lack of such understanding among
33 study participants suggests that epistemological education should be a primary focus of efforts to
34 apply personalized risk information to patient care.
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Our study thus identifies several ~~requisite-potentially important~~ tasks for enhancing the value and use of personalized risk information: 1) increasing patients' exposure to personalized risk information, 2) providing resources to support deliberative decision making, and 3) providing epistemological education on the nature of medical knowledge and evidence. The first task has been a primary focus of CPM proponents; however, more work is needed to effectively disseminate and implement CPMs in clinical practice. The second task has only begun to be addressed, but promising approaches include the delivery of personalized risk information through patient-centered decision support interventions (DeSIs) such as decision aids,^{74,75} and the use of risk communication strategies such as visual representations to improve the evaluability of risk estimates.^{30,31,76-83} A more challenging task is to provide the environmental resources—e.g., clinical time, processes, and incentives—needed for deliberative and collaborative decision making.⁷⁴ The final task, the provision of epistemological education, is a new frontier that has yet to be explored but calls for efforts to expand the content of risk information communicated to patients—whether through DeSIs or larger-scale educational efforts delivered through other channels. It remains for further research to address these challenges, and to determine how best to help patients translate personalized risk information into better informed health care decisions.

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11 All authors had full access to all of the data (including statistical reports and tables) in the study
12 and take responsibility for the integrity of the data and the accuracy of the data analysis. The
13 study was approved by the Maine Medical Center Institutional Review Board (IRB#3805X), and
14 granted a waiver of informed consent.
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20 All authors have completed the Unified Competing Interest form at
21 www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and
22 declare that (1) PH, MN, BR, NH, TK, CG, MD, and MH have no relationships with companies
23 that might have an interest in the submitted work in the previous 3 years; (2) spouses, partners,
24 or children of PH, MN, BR, NH, TK, CG, MD, and MH have no financial relationships that may
25 be relevant to the submitted work; and (3) PH, MN, BR, NH, TK, CG, MD, and MH have no
26 non-financial interests that may be relevant to the submitted work.
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43 party to do any or all of the above.
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Contributorship Statement

PH designed the study, obtained funding, conducted interviews and data analysis, drafted the manuscript, and edited the manuscript for important content.

MN, BR, and NH conducted data analysis and edited the manuscript for important content.

TK assisted in the design of the study, conducted interviews, and edited the manuscript for important content.

CG edited the manuscript for important content.

MD edited the manuscript for important content.

MH assisted in the design of the study and edited the manuscript for important content.

Data sharing statement

Data sharing: no additional data available; consent for data sharing was not obtained from study participants.

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References

Table 1. Focus group categories

- Low-risk group: Early-stage, clinically localized disease (Gleason Score ≤ 6, Stage T1C-T2A, PSA <10)
- Medium-risk group: Intermediate-stage, clinically localized disease (Gleason Score 7, Stage T2B-T2C, PSA 10-20)
- High-risk group: patients with advanced, treatment-refractory, or recurrent disease (Gleason Score 8-10, Stage T3-T4, PSA >20)

Table 2. Characteristics of focus group participants

	<u>N</u>	<u>%</u>
Age		
50-59	6	21%
60-69	18	62%
70-79	4	14%
≥ 80	1	3%
Risk Group		
Low	7	24%
Med	15	52%
High	7	24%
Race		
White/Caucasian	29	100%
Other	0	0%
Education		
High school or less	6	21%
Some college	4	14%
College graduate	10	34%
Post graduate	9	31%
Location		
Brunswick	9	31%
Lewiston	9	31%
Portland	11	38%

Table 3. The biomarker heuristic: illustrative quotes

I was told that with the Gleason score of 9 that that's frightening ... That's extremely aggressive is what this one doctor said, and at the next place that doctor said it's kind of scary, he says, but it can be taken care of. [High-Risk Participant]

INTERVIEWER: And what was your understanding of what the Gleason score meant?

PATIENT: A high number is, you know -- the top number is, you know, if that's higher than your bottom number, you've got problems. [High-Risk Participant]

... he gave me the lab report itself and he showed me these different things and he says this here's the Gleason score. The Gleason is this three over four. He said if it had been four over three, you know, we would have been more concerned. He said this shows it's an active cancer but it's not an aggressive cancer and he said so we've got some time to wait. We don't have a lot of time to wait. He said we don't have to worry about going into surgery in the next three weeks or something. [Medium-Risk Participant]

The way they explained to me was that if it's under a four Gleason it's probably not gonna do much. If it's around a six it's kind of getting up there. If it gets up around and eight then it's real aggressive, you gotta do something fast. [Medium-Risk Participant]

Appendix A. Clinical prediction model screenshots used as interview aids

Memorial Sloan-Kettering Cancer Center
 PROSTATE CANCER INFORMATION | MAKING AN APPOINTMENT
 PREDICTION TOOLS
 Change Prediction Tool

Prostate Cancer Nomograms: Pre-Treatment
 TEXT SIZE [A] [A]

This nomogram can be used to predict what will happen after receiving a primary treatment (e.g. radical prostatectomy, brachytherapy, or external beam radiation therapy). To learn more, visit our [frequently asked questions](#).

Enter Your Information Clear Calculate

To gather the information required below, download our PDF [worksheet](#).

Primary Treatment Outcome
 To calculate results for a specific primary treatment outcome, select an option from the list below. (Each primary treatment outcome must be selected one at a time, followed by re-clicking the "Calculate" button.)
 Learn more about the below [primary treatment outcomes](#).

- Progression Free Probability after Radical Prostatectomy
- Progression Free Probability with Brachytherapy
- Relapse-Free Probability After External Beam Radiation Therapy

Pre-Treatment PSA
 PSA value from the laboratory report before receiving primary therapy: 20 ng/ml (0.1 to 100)

Current Age
 61 years old (1 to 100)

Your Results
 Learn more about your results below.

CURRENT MODEL	HISTORICAL MODEL
Extent of Disease Probability	
Indolent Cancer	7%
Organ Confined Disease	67%
Extracapsular Extension	24%
Seminal Vesicle Invasion	9%
Lymph Node Involvement	13%
Primary Treatment Outcome	
Progression Free 5 Year	97%
Probability After Radical Prostatectomy 10 Year	95%

Print These Results

Memorial Sloan-Kettering Cancer Center
 PROSTATE CANCER INFORMATION | MAKING AN APPOINTMENT
 PREDICTION TOOLS
 Change Prediction Tool

Prostate Cancer Nomograms: Post-Radical Prostatectomy
 TEXT SIZE [A] [A]

This nomogram can be used to predict the probability that a patient's cancer will recur after radical prostatectomy, that is, the probability at two, five, seven and 10 years that the patient's serum PSA level will become detectable and begin to rise steadily. The nomogram should only be used for patients when radical prostatectomy is the sole, primary treatment. To learn more, visit our [frequently asked questions](#).

Enter Your Information Clear Calculate

To gather the information required below, download our PDF [worksheet](#).

Pre-Treatment PSA
 PSA value from the laboratory report before the radical prostatectomy was performed or any other therapy for prostate cancer begun: 30 ng/ml (0.1 to 100)

Age
 61 years old (20 to 120)

Gleason Grade

Primary Gleason Grade at Surgery
 The primary Gleason grade from the radical prostatectomy pathology report: Grade 3

Secondary Gleason Grade at Surgery
 The secondary Gleason grade from the radical prostatectomy pathology report: Grade 4

Your Results
 Learn more about your results below.

CURRENT MODEL	HISTORICAL MODEL
2 Year	99%
5 Year	81%
7 Year	72%
10 Year	61%

Print These Results

Make An Appointment
 Call us to schedule an appointment or contact us online

Memorial Sloan-Kettering Cancer Center
 PROSTATE CANCER INFORMATION | MAKING AN APPOINTMENT
 PREDICTION TOOLS
 Change Prediction Tool

Prostate Cancer Nomograms: Hormone Refractory
 TEXT SIZE [A] [A]

For patients with advanced, metastatic prostate cancer that has been treated maximally with hormone therapy to control the effects of the male hormone, androgen. The nomogram predicts the survival probability one to two years later. To learn more, visit our [frequently asked questions](#).

Enter Your Information Clear Calculate

To gather the information required below, download our PDF [worksheet](#).

Current Age
 60 years old (40 to 85)

KPS (Karnofsky Performance Status)
 KPS value assigned by a physician, nearest to the planned treatment start date or today's date: 90

Hemoglobin
 HGB value from the laboratory report nearest to the planned treatment start date or today's date: 15 g/dl (6 to 17)

PSA
 PSA value from the laboratory report closest to the planned treatment start date or today's date: 0.01 ng/ml (0.01 and 8450)

LDH (Lactate Dehydrogenase)
 LDH value from the laboratory report closest to the planned treatment start date or today's date: 120 IU/L (116 to 1955)

ALP (Alkaline Phosphatase)
 ALP value from the laboratory report closest to the planned treatment start date or today's date: 20 IU/L (19 to 3079)

Albumin
 Albumin value from the laboratory report closest to the planned treatment start date or today's date: 5.2 g/dl (2.6 to 5.2)

Your Results
 Learn more about your results below.

Survival Probability 1 Year	97%
Survival Probability 2 Year	82%
Median Survival Months	45

Print These Results

Make An Appointment
 Call us to schedule an appointment or contact us online
[contact us](#)

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Cleveland Clinic QHS RISK CALCULATOR

Prostate Cancer
Predicting Post-Treatment Freedom from Recurrence

Pre-Treatment PSA Level (ng/mL) 20

Clinical Stage T1c

Year of Surgery 2008

Surgeon Experience (# of prior cases) 50

Primary Gleason Grade (post-op) 3

Secondary Gleason Grade (post-op) 4

Surgical Margins Status Positive

Extracapsular Extension? No

Capsular Invasion Type None

Seminal Vesicle Invasion? No

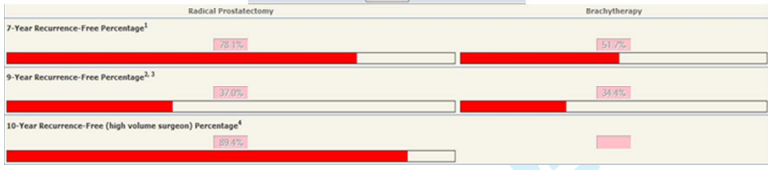
Lymph Node Status Negative

Adjuvant Radiotherapy? No

Brachytherapy Isotope (if applicable) 1125

Brachytherapy D90 (Gy) (if applicable) 100

Calculate



Cleveland Clinic QHS RISK CALCULATOR

Metastatic Prostate Cancer
Overall Survival after Castration

Age (years) 60

KPS (%) 90

Hemoglobin (g/dL) 15

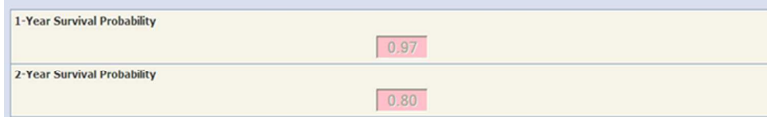
PSA (ng/mL) 0

LDH (U/L) 120

ALK (U/L) 20

Albumin (g/dL) 5.2

Calculate



¹ Smaletz O, Scher H, Small EJ, Verbel DA, McMillan A, Regan K, Kelly WK, Kattan MW. Nomogram for overall survival of patients with progressive metastatic prostate cancer following castration. *J Clin Oncol* 2002;20(19):3972-3982.

Appendix B. Theme outline – Focus group study

A. PAST EXPERIENCES WITH RISK COMMUNICATION

1. Extent of communication
 - a. No risk communication
 - b. Detailed communication of individualized, quantitative risk information
 - c. Non-individualized quantitative risk communication
 - d. Imprecise quantitative risk communication
 - e. Categorical risk communication: qualitative categories
 - f. Indirect risk communication: biomarker heuristic
2. Sources of risk information
 - a. Doctor: urologist, radiation oncologist, PCP, other
 - b. Other health professionals: nurse navigators, etc.
 - c. Friends, family
 - d. Internet, books

B. PERCEIVED VALUE OF PERSONALIZED RISK INFORMATION

1. Promote SDM
2. Provide insight into physician thinking
3. Provide second opinion / counter physician bias
4. Confirmatory
5. Facilitate advance care planning
6. Justify decisions

C. PERCEIVED CHALLENGES IN USE OF PERSONALIZED RISK INFORMATION

1. Lack of self-efficacy in understanding risk information
2. Logistic barriers: lack of time
3. Physician bias/self-interest
4. Preference for simplicity
5. Low perceived need for information
 - a. Low preference for information and participation in decision making
 - b. Trust the doctor heuristic
 - c. Cancer heuristic (removal heuristic: “cut it out”): perceived lack of decision
 - d. Reliance on intuitive vs. rational decision-making approaches
6. Distrust of statistical information: “anti-statistics” viewpoint
 - a. Preference for anecdotal/narrative vs. statistical information: “unreality” of numbers vs. narrative information
 - b. Questionable relevance to individual: reference class problem
 - c. Uncertainty: epistemic (ambiguity)
 - i. Imprecision
 - ii. Conflicting data
 - iii. Missing data, multiple/unknown/unaccounted risks
 - iv. Source credibility

d. Uncertainty: aleatory (randomness)

7. Motivated reasoning: desire for good news/fear of bad news

D. VALUE OF INDIRECT RISK COMMUNICATION (BIOMARKER HEURISTIC)

1. Provide sense of control
2. Communicate the bottom-line/gist
3. Represent “hard information”
4. Facilitate decision resolution
5. Simplify decision making

E. INTERPRETATION OF PERSONALIZED RISK ESTIMATES

1. Understanding of risk estimate: frequency or confidence statement
2. Perceived difficulty

F. COMMUNICATION OF UNCERTAINTY (AMBIGUITY)

1. Preferences for/against
2. Reactions to use of range/confidence interval

References

1. Edwards A, Hood K, Matthews E, et al. The effectiveness of one-to-one risk communication interventions in health care: a systematic review. *Med Decis Making*. Jul-Sep 2000;20(3):290-297.
2. Steyerberg EW. *Clinical Prediction Models: a Practical Approach to Development, Validation, and Updating*. New York: Springer; 2010.
3. Personalized Health Care: Pioneers, Partnerships, Progress. 2008. <http://www.hhs.gov/myhealthcare/>. Accessed March 12, 2013.
4. Briss P, Rimer B, Reilley B, et al. Promoting informed decisions about cancer screening in communities and healthcare systems. *Am J Prev Med*. Jan 2004;26(1):67-80.
5. Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns*. Mar 2006;60(3):301-312.
6. Edwards A, Unigwe S, Elwyn G, Hood K. Effects of communicating individual risks in screening programmes: Cochrane systematic review. *BMJ*. Sep 27 2003;327(7417):703-709.
7. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. *The New England journal of medicine*. Mar 1 2012;366(9):780-781.
8. Elwyn G, Frosch D, Thomson R, et al. Shared Decision Making: A Model for Clinical Practice. *J Gen Intern Med*. May 23 2012;27(10):1361-1367.
9. Vickers AJ, Basch E, Kattan MW. Against diagnosis. *Annals of internal medicine*. Aug 5 2008;149(3):200-203.
10. Edwards AG, Naik G, Ahmed H, et al. Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database Syst Rev*. 2013;2:CD001865.
11. Gillies D. *Philosophical Theories of Probability*. London: Routledge; 2000.
12. Hacking I. *The Taming of Chance*. Cambridge: Cambridge University Press; 1990.
13. Han PK. Conceptual, Methodological, and Ethical Problems in Communicating Uncertainty in Clinical Evidence. *Med Care Res Rev*. Nov 6 2012.
14. Han PK, Klein WM, Arora NK. Varieties of uncertainty in health care: a conceptual taxonomy. *Medical decision making : an international journal of the Society for Medical Decision Making*. Nov 2011;31(6):828-838.
15. Brewer NT, Richman AR, Defrank JT, Reyna VF, Carey LA. Improving communication of breast cancer recurrence risk. *Breast cancer research and treatment*. Jun 2012;133(2):553-561.
16. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. *Med Decis Making*. Jan-Feb 2001;21(1):37-44.
17. Sheridan SL, Pignone M. Numeracy and the medical student's ability to interpret data. *Eff Clin Pract*. Jan-Feb 2002;5(1):35-40.
18. Schwartz LM, Woloshin S, Black WC, Welch HG. The role of numeracy in understanding the benefit of screening mammography. *Ann Intern Med*. Dec 1 1997;127(11):966-972.
19. Wegwarth O, Schwartz LM, Woloshin S, Gaissmaier W, Gigerenzer G. Do physicians understand cancer screening statistics? A national survey of primary care physicians in the United States. *Annals of Internal Medicine*. Mar 6 2012;156(5):340-349.

20. Reyna VF, Nelson WL, Han PK, Dieckmann NF. How numeracy influences risk comprehension and medical decision making. *Psychol Bull.* Nov 2009;135(6):943-973.
21. Han PK, Klein WM, Lehman TC, Massett H, Lee SC, Freedman AN. Laypersons' responses to the communication of uncertainty regarding cancer risk estimates. *Med Decis Making.* May-Jun 2009;29(3):391-403.
22. Han PK, Lehman TC, Massett H, Lee SJ, Klein WM, Freedman AN. Conceptual problems in laypersons' understanding of individualized cancer risk: a qualitative study. *Health Expect.* Mar 2009;12(1):4-17.
23. Ravdin PM, Siminoff LA, Davis GJ, et al. Computer program to assist in making decisions about adjuvant therapy for women with early breast cancer. *J Clin Oncol.* Feb 15 2001;19(4):980-991.
24. Peele PB, Siminoff LA, Xu Y, Ravdin PM. Decreased use of adjuvant breast cancer therapy in a randomized controlled trial of a decision aid with individualized risk information. *Med Decis Making.* May-Jun 2005;25(3):301-307.
25. Siminoff LA, Gordon NH, Silverman P, Budd T, Ravdin PM. A decision aid to assist in adjuvant therapy choices for breast cancer. *Psychooncology.* Nov 2006;15(11):1001-1013.
26. Belkora JK, Rugo HS, Moore DH, Hutton DW, Chen DF, Esserman LJ. Oncologist use of the Adjuvant! model for risk communication: a pilot study examining patient knowledge of 10-year prognosis. *BMC Cancer.* 2009;9:127.
27. Hutton DW, Belkora JK, Shachter RD, Moore DH. Are patients getting the "gist" in risk communication? Patient understanding of prognosis in breast cancer treatment. *J Cancer Educ.* 2009;24(3):194-199.
28. Lipkus IM, Peters E, Kimmick G, Liotcheva V, Marcom P. Breast cancer patients' treatment expectations after exposure to the decision aid program adjuvant online: the influence of numeracy. *Med Decis Making.* Jul-Aug;30(4):464-473.
29. Zikmund-Fisher BJ, Fagerlin A, Ubel PA. Improving understanding of adjuvant therapy options by using simpler risk graphics. *Cancer.* Dec 15 2008;113(12):3382-3390.
30. Zikmund-Fisher BJ. The Right Tool Is What They Need, Not What We Have: A Taxonomy of Appropriate Levels of Precision in Patient Risk Communication. *Med Care Res Rev.* Nov 1 2012.
31. Reyna VF. A theory of medical decision making and health: fuzzy trace theory. *Med Decis Making.* Nov-Dec 2008;28(6):850-865.
32. Simon H. *Models of Man, Social and Rational: Mathematical Essays on Rational Human Behavior in a Social Setting.* New York: Wiley; 1957.
33. Cancer Research UK. Prostate Cancer Statistics. 2013; <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/>. Accessed April 4, 2013, 2013.
34. Rothenberg BM, Marbella A, Belinson SE, et al. Future Research Needs for Comparative Effectiveness of Treatments of Localized Prostate Cancer: Identification of Future Research Needs from Comparative Effectiveness Review No. 13. Rockville (MD)2010.
35. National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Stat Facts Sheets: Prostate. 2013; <http://seer.cancer.gov/statfacts/html/prost.html>. Accessed April 4, 2013, 2013.
36. Cooperberg MR. Prostate cancer risk assessment: choosing the sharpest tool in the shed. *Cancer.* Dec 1 2008;113(11):3062-3066.

37. Shariat SF, Karakiewicz PI, Roehrborn CG, Kattan MW. An updated catalog of prostate cancer predictive tools. *Cancer*. Dec 1 2008;113(11):3075-3099.
38. Lughezzani G, Briganti A, Karakiewicz PI, et al. Predictive and Prognostic Models in Radical Prostatectomy Candidates: A Critical Analysis of the Literature. *Eur Urol*. Aug 6 2010;58(5):687-700.
39. Cowen ME, Halasyamani LK, Kattan MW. Predicting life expectancy in men with clinically localized prostate cancer. *J Urol*. Jan 2006;175(1):99-103.
40. Eastham JA, Scardino PT, Kattan MW. Predicting an optimal outcome after radical prostatectomy: the trifecta nomogram. *The Journal of urology*. Jun 2008;179(6):2207-2210; discussion 2210-2201.
41. Ross RW, Kantoff PW. Predicting outcomes in prostate cancer: how many more nomograms do we need? *J Clin Oncol*. Aug 20 2007;25(24):3563-3564.
42. Lerner Research Institute, Cleveland Clinic. Risk Calculators. 2010; <http://www.lerner.ccf.org/qhs/risk_calculator/index.php>. Accessed November 12, 2010.
43. Touijer K, Scardino PT. Nomograms for staging, prognosis, and predicting treatment outcomes. *Cancer*. Jul 1 2009;115(13 Suppl):3107-3111.
44. Cegala DJ, Post DM, McClure L. The effects of patient communication skills training on the discourse of older patients during a primary care interview. *J Am Geriatr Soc*. Nov 2001;49(11):1505-1511.
45. nomogram.org. Prostate Cancer. 2010; <http://nomogram.org/Prostate/pros_calc.php>. Accessed November 12, 2010.
46. Hoffman A, Montgomery R, Aubry W, Tunis SR. How best to engage patients, doctors, and other stakeholders in designing comparative effectiveness studies. *Health Aff (Millwood)*. Oct 2010;29(10):1834-1841.
47. Sofaer S. Qualitative methods: what are they and why use them? *Health Serv Res*. Dec 1999;34(5 Pt 2):1101-1118.
48. Kitzinger J. Qualitative research. Introducing focus groups. *BMJ*. Jul 29 1995;311(7000):299-302.
49. Morgan D. *Focus Groups in Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1998.
50. National Comprehensive Cancer Network. NCCN Practice Guidelines for Prostate Cancer. . 2010;Version 1: 2010. <http://www.nccn.org>. Accessed December 16, 2012.
51. Memorial-Sloan Kettering Center. Prostate Cancer Nomograms: a Tool for Doctors & Patients. . 2010; <<http://www.mskcc.org/mskcc/html/10088.cfm>>. Accessed November 12, 2010.
52. Strauss AL, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd ed. Thousand Oaks, CA: Sage; 1998.
53. Ryan GW, & Bernard, H. R. Data management and analysis methods. In: N. K. Denzin, Lincoln YS, eds. *Collecting and Interpreting Qualitative Materials*. Thousand Oaks, CA: Sage; 2003:259-309.
54. Glaser BG. The Constant Comparative Method of Qualitative Analysis. *Social Problems*. 1965;12(4):436-445.
55. Slovic P, Finucane M, Peters E, MacGregor DG. The affect heuristic. In: Gilovich T, Griffin D, Kahneman D, eds. *Heuristics and Biases: the Psychology of Intuitive Judgment*. Cambridge: Cambridge University Press; 2002:397-420.

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4
5
6
7
8
9 56. Slovic P, Peters E, Finucane ML, Macgregor DG. Affect, risk, and decision making. *Health Psychol.* Jul 2005;24(4 Suppl):S35-40.
- 10 57. Wegwarth O, Gigerenzer G. Trust-your-doctor: a simple heuristic in need of a proper
11 social environment. In: Hertwig R, Hoffrage U, eds. *Simple Heuristics in a Social World*.
12 New York: Oxford University Press; 2013:67-102.
- 13 58. Winterbottom A, Bekker HL, Conner M, Mooney A. Does narrative information bias
14 individual's decision making? A systematic review. *Soc Sci Med.* Dec 2008;67(12):2079-
15 2088.
- 16 59. deWit JBF, Das E, Vet R. What works best: objective statistics or a personal testimonial?
17 An assessment of the persuasive effects of different types of message evidence on risk
18 perception. *Health Psychol.* 2008;27(1):110-115.
- 19 60. Shaffer VA, Zikmund-Fisher BJ. All stories are not alike: a purpose-, content-, and
20 valence-based taxonomy of patient narratives in decision AIDS. *Med Decis Making.* Jan
21 2013;33(1):4-13.
- 22 61. Gigerenzer G, Selten R. *Bounded Rationality*. Cambridge: MIT Press; 2002.
- 23 62. Tversky A, Kahneman D. Judgment under uncertainty: heuristics and biases. *Science.*
24 1974;185(4157):1124-1131.
- 25 63. Isaacson W. *Steve Jobs*. New York: Simon and Schuster; 2011.
- 26 64. Peters E, Dieckmann N, Dixon A, Hibbard JH, Mertz CK. Less is more in presenting
27 quality information to consumers. *Med Care Res Rev.* Apr 2007;64(2):169-190.
- 28 65. Iyengar SS, Kamenica E. Choice proliferation, simplicity seeking, and asset allocation.
29 *Journal of Public Economics.* 2010;94(7):530-539.
- 30 66. Iyengar SS, Lepper MR. When choice is demotivating: Can one desire too much of a
31 good thing? *Journal of Personality and Social Psychology.* 2000;79:995-1006.
- 32 67. Legare F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared
33 decision-making in clinical practice: update of a systematic review of health
34 professionals' perceptions. *Patient education and counseling.* Dec 2008;73(3):526-535.
- 35 68. Lin GA, Aaronson DS, Knight SJ, Carroll PR, Dudley RA. Patient decision aids for
36 prostate cancer treatment: a systematic review of the literature. *CA Cancer J Clin.* Nov-
37 Dec 2009;59(6):379-390.
- 38 69. de Vries M, Fagerlin A, Witteman HO, Scherer LD. Combining deliberation and intuition
39 in patient decision support. *Patient Educ Couns.* May 2013;91(2):154-160.
- 40 70. Spiegelhalter DJ, Riesch H. Don't know, can't know: embracing deeper uncertainties
41 when analysing risks. *Philos Transact A Math Phys Eng Sci.* Dec 13
42 2011;369(1956):4730-4750.
- 43 71. Bilcke J, Beutels P, Brisson M, Jit M. Accounting for methodological, structural, and
44 parameter uncertainty in decision-analytic models: a practical guide. *Med Decis Making.*
45 Jul-Aug 2011;31(4):675-692.
- 46 72. Han PK. Conceptual, methodological, and ethical problems in communicating
47 uncertainty in clinical evidence. *Med Care Res Rev.* Feb 2013;70(1 Suppl):14S-36S.
- 48 73. Gigerenzer G. *Gut Feelings: the Intelligence of the Unconscious*. New York: Penguin
49 Books; 2007.
- 50 74. Elwyn G, Frosch D, Volandes AE, Edwards A, Montori VM. Investing in deliberation: a
51 definition and classification of decision support interventions for people facing difficult
52 health decisions. *Med Decis Making.* 2010;30(6):701-711.
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55
56
57
58
59
60
75. Stacey D, Bennett CL, Barry MJ, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane database of systematic reviews*. 2011(10):CD001431.
76. Lipkus IM. Numeric, verbal, and visual formats of conveying health risks: suggested best practices and future recommendations. *Med Decis Making*. Sep-Oct 2007;27(5):696-713.
77. Visschers VH, Meertens RM, Passchier WW, de Vries NN. Probability information in risk communication: a review of the research literature. *Risk Anal*. Feb 2009;29(2):267-287.
78. Galesic M, Garcia-Retamero R, Gigerenzer G. Using icon arrays to communicate medical risks: overcoming low numeracy. *Health Psychol*. Mar 2009;28(2):210-216.
79. Garcia-Retamero R, Galesic M. Who profits from visual aids: overcoming challenges in people's understanding of risks [corrected]. *Soc Sci Med*. Apr 2010;70(7):1019-1025.
80. Dolan JG, Qian F, Veazie PJ. How well do commonly used data presentation formats support comparative effectiveness evaluations? *Med Decis Making*. Nov-Dec 2012;32(6):840-850.
81. Akl EA, Oxman AD, Herrin J, et al. Using alternative statistical formats for presenting risks and risk reductions. *Cochrane Database Syst Rev*. 2011(3):CD006776.
82. Gigerenzer G, Gaissmaier W, Kurz-Milcke E, Schwartz LM, Woloshin S. Helping doctors and patients make sense of health statistics. *Psychological Science in the Public Interest*. 2007;8:53-96.
83. Spiegelhalter D, Pearson M, Short I. Visualizing uncertainty about the future. *Science*. Sep 9 2011;333(6048):1393-1400.