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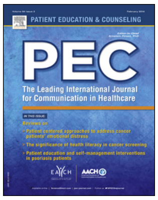

# Knowledge and values for cancer screening decisions: Results from a national survey

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ABSTRACT

*Background:* Guidelines recommend shared decision making (SDM) for cancer screening decisions. SDM requires providers to ensure that patients are informed about screening issues and to support decisions that are concordant with patient values. We evaluated decision-quality factors for breast, colorectal, and prostate cancer screening decisions.
*Methods:* We conducted a national, population-based Internet survey of adults aged 40+ to characterize perceptions about about cancer screening, the importance of information sources, cancer screening knowledge, values and preferences for screening, and the most influential drivers of decisions.
*Results:* Among 1452 participants who completed the survey, the mean age was 60, and 94% were insured. Most participants reported feeling well informed about cancer screening, though only 21% reported feeling extremely well informed. Most participants correctly answered about 50% of the knowledge questions, with the majority markedly overestimating lifetime risk of cancer diagnoses and mortality. Participants rated health care providers as the most important source of information.
*Conclusion:* Although respondents considered themselves well informed about cancer they performed poorly on knowledge questions. This discordance suggests the potential for poor-quality decision making.
*Practice implications:* To improve the quality of decision making, providers need training to utilize decision support tools and time to carry out SDM.

## 1. Background

Cancer screening decisions are considered preference sensitive because there are multiple options, including that of no testing, and the decisions involve important tradeoffs between benefits and harms. We previously found, based on data from a 2007 national survey, that cancer screening decisions consistently failed to meet criteria for being informed [1]. However, in more recent years, professional guidelines have highlighted the importance of ensuring that patients have sufficient information to make informed decisions about cancer screening, including PSA testing for men [2], mammography [3], and colorectal cancer testing for those aged >75 years [4]. The United States Preventive Services Task Force (USPSTF) Workgroup on shared decision making encouraged "informed and joint decisions" for cancer screening [5]. This expectation requires providers to help patients access and process key information. Moreover, cancer-screening decisions are complex and ought to reflect the personal values and preferences of an informed patient [6,7]. These aspects of decision quality are arguably more important than metrics that simply track whether a patient underwent screening [8,9]. We conducted a national Internet survey to evaluate more recently cited decision factors for cancer screening, including individuals' perceptions of being knowledgeable about cancer screening; their rating of the importance of various information sources; their cancer screening knowledge; their values and preferences for screening; and

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perceptions of the most influential drivers of their decision making.

## 2. Methods

### 2.1. Subjects

The survey methodology has been previously described [10]. Briefly, Knowledge Networks (knowledgenetworks.com) surveyed adults aged 40 and older between November 2 and December 13, 2011. Knowledge Networks samples households from its Knowledge Panel, a probability-based web panel designed to be representative of adults in the United States. The sample was designed to be a cross-section of adults in the United States with an oversampling of adults in Washington State. The New England IRB exempted this study from review.

The Knowledge Networks Internet panel differs from other Internet panels in several respects. First, households are recruited through both random-digit dialing and address-based sampling—which enables the panel to include households served only by cell phones or lacking telephone service. Second, the panel is based on a probability sampling of recruited households, and not comprised of volunteers. Third, while data are collected via the Internet, a computer or Internet service are provided to households lacking those resources [11,12].

Screener questions identified respondents who had experienced or discussed with a medical provider one of ten medical decisions (screening for colorectal cancer, breast cancer [mammogram] or prostate cancer [PSA test]); starting medication for hypertension, high cholesterol, depression; or undergoing surgical interventions for arthritis of the knee, arthritis of the hip, cataracts, or frequent low back pain within the past 2 years. We then surveyed these eligible subjects about their interactions with health care providers. Respondents who reported engaging in more than two medical decisions were assigned to complete survey modules on just two topics using a probability selection that gave less common medical decisions a higher probability of selection. Non-responders (those not completing screener questions) received automated email reminders on day three of the field period and periodically until the end of the survey period (December 13, 2011). In this analysis, we report on eligible participants who completed at least one cancer-screening module.

### 2.2. Measures

#### 2.2.1. Cohort characteristics

We assessed demographic characteristics, including age, gender, race, income, marital status, and education. Participants rated their health status, reported whether they currently had health insurance, and whether they considered themselves to be at low, average, or high risk for the specific cancer in question. We also asked participants to rate their perceptions of how well informed they felt about each cancer screening testing using a 0–10 scale, with 0 being “not informed at all” and 10 being “extremely well informed”.

#### 2.2.2. Decision making

We used survey items, based on the DECISIONS study, to question respondents about their preferred sources of information about cancer screening decisions, their knowledge of key information, and the relative importance assigned to values and preferences relevant to the decisions [13–16].

#### 2.2.3. Sources of information

Participants rated the importance of information obtained from their health care providers, their friends and family, and the media, respectively, for making cancer-screening decisions on a 0–10 scale (with 0 being “not at all important” and 10 being “extremely important”). Participants also indicated whether they (or a designee) had used the Internet to search for information about the screening decision and, if so, similarly rated the importance of Internet-derived information.

#### 2.2.4. Cancer-specific knowledge

Each cancer-screening module included 4 to 5 knowledge questions specific to screening for that malignancy, including lifetime incidence and mortality risks and test characteristics. Responses were open-ended, and we credited participants with being correct if the answer was within 10 percentage points of the true value. Given the differing number of questions in each module, we reported the number of correct responses and whether a participant correctly answered 0 versus 1 or more questions.

#### 2.2.5. Values, preferences, and factors influencing decision-making

Participants rated the importance of various goals and concerns (values) surrounding cancer screening using a 0–10 scale (with 0 being “not at all important” and 10 being “extremely important”). They were also queried about their perception of personal cancer risk with the question “do you believe yourself to be at high risk, average risk, or low risk of getting [specific cancer type] cancer?” All subjects were asked about the importance of early detection and knowing whether they have a cancer. Participants completing the breast and prostate modules were also asked about the importance of having peace of mind from a normal result, avoiding false alarms, and avoiding dealing with a cancer that could be harmless. Participants completing the colon cancer modules were asked about the importance of choosing a test that did not require annual testing, avoiding handling stool, and avoiding endoscopy. Finally, participants were asked whether the health care provider’s recommendation, the participant's personal preference, family or friends' preference, or something else played the biggest role in decision-making. For each source of information, participants were asked how important they felt each source of information was using a 0–10 scale, with 0 being “not at all important” and 10 being “extremely important”.

### 2.3. Analyses

We weighted survey results to reflect selected demographic and geographic characteristics of the U.S. population, as reported in the most recent Census Bureau data [17] as well as to adjust for differential probabilities of selection into the survey modules and non-response. Analyses were performed using IBM SPSS V21.0 with the IBM SPSS Complex Samples 20 module applied to account for the complex design.

For each module, we estimated sample means (standard errors), medians (interquartile ranges), and proportions with 95% confidence intervals to describe participant characteristics, information sources, cancer-specific knowledge, and goals and concerns. For descriptive statistics, we also collapsed the 11-point response scales into three categories (0–7, 8–10) because the data were highly skewed and these categories captured much of the underlying variation.

We used adjusted ANOVA and chi-square analyses, respectively, to compare means of continuous variables and proportions of categorical variables across the four decision groups (CRC screening results were reported separately for each gender). We reported global $p$-values for the four-group comparisons. We

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