

PSA Test Decision Making: Results from Cognitive Testing: Round 1 July 26, 2006

This memorandum reports results from the first round of cognitive interviews with draft items on doctor discussions about PSA testing and PSA test decision making. We conducted cognitive interviews with nine male respondents between July 17th and July 21st, 2006. This memorandum is organized in three sections. The first section, Summary Demographics, presents background information about the nine volunteer cognitive interview respondents. The second section, Overall Findings, presents general findings observed across the interviews. The third section, Question-Specific Findings, presents more detailed findings that pertain to individual draft questions. For reference purposes, we present the question and response frequencies in text boxes followed by question-specific findings. We revised the protocol somewhat after the second interview based on discussions with NCI following the first two interviews. Attachment A contains the final cognitive interview protocol. The results presented here are largely descriptive. However, some findings lead us to make recommendations, suggest rewordings, and/or identify things for NCI to think about. We used headings to highlight these various recommendations or issues to consider.

Summary Demographics

We conducted cognitive interviews with nine volunteer male respondents. We recruited the volunteers through a database that Westat maintains and through community contacts. All volunteers met the following three screening criteria:

- Did not work either full or part-time at the FDA, NIH, NCI, or Westat;
- Current age of 50 years or older; and
- Had not had a diagnosis of prostate cancer in the past.

Additionally, towards the end of Round 1 we added additional screening criteria. We ensured that the final interviews were conducted with men who had heard of the PSA test and had not been diagnosed with an enlarged prostate or BPH in the past. We did not screen out men who experienced problematic prostate symptoms such as frequent urination, as this symptom is not uncommon among this population. Within all the screening constraints, volunteers were recruited to reflect a range of ages (over 50 years), ethnicities, and education levels.

Table 1 shows basic demographic characteristics for the nine respondents. As can be seen from the table, almost all of the respondents were married. Four of the respondents were white, 3 of the respondents were African-American, and 2 of the respondents were Asian. The age of the respondents ranged from 50 to 73. Although not shown in the table, all of the respondents reported having health insurance.

Table 1. Demographic Profile of the Nine Respondents

Race	Age	Education	Marital status	Discussed PSA with doctor?
White	70	College Graduate	Married	Yes
African American	73	College Graduate	Married	Yes
African American	55	High School Graduate	Married	No
White	68	Some College	Married	Yes
White	64	Some College	Married	Yes
African American	56	Some College	Married	Yes
Asian	66	Some post-graduate work	Married	Yes
Asian	50	College Graduate	Divorced/Widowed	No
White	64	Some College	Married	Yes

Overall Findings

We identified three sets of overall findings related to:
 question interpretation;
 question redundancy; and
 respondent screening.

Question Interpretation

- “Talked about” is interpreted quite broadly. From respondents’ perspectives, “talked about” includes a range of conversation types and topics. Many of the conversations respondents described were not detailed “discussions.” If NCI is interested in capturing pre-PSA test decision making or information exchange, then a more specific term or some defining context might help. The following is one suggestion for question structure and flow that probably requires refinement:

Q1. Did you ever have a PSA test?

Q2. Before that test, did your doctor explain to you what the PSA test is?

Q3. What issues or topics did that explanation cover?

(Selected list of pros and cons presented here)

Something to think about: Does this suggested question structure presume a proactive doctor? If so, is that presumption desirable?

- After two interviews, we substituted the term “doctor” for the term “health care professional.” “Doctor” worked fine and helped respondents focus on doctor-patient interactions.
- The full question series aggravated one respondent because in his mind, no one would say “no” to having a PSA test, and the questions seemed to suggest otherwise.

- Respondents reported family involvement in decisions about the PSA test. Typically this involvement did not include family members talking with respondents' doctors. Rather, the involvement tended to be focused on urging the respondent to get the PSA test and pointing out the benefits associated with the test.

Question Redundancy

- The two respondents who said “no” in response to question 1 did not see subsequent items as redundant or annoying. They viewed the items as an educational tool. This led to surprising interpretations for some items. For example, one of these respondents answered “definitely” at question 5 because from now on he definitely wants to be involved in decisions regarding the PSA test. It seems likely to us that respondents will make similar unintended interpretations under standard survey conditions because conversational norms lead respondents to expect new questions rather than overlapping questions that interviewers could infer the answers to.

Screening

- Recruiting low education respondents who had heard of the PSA test was very difficult. None of the Round 1 respondents had less than high school education. One respondent had a high school diploma and that was the lowest education level we were able to recruit, given the desire to interview men who had heard about the PSA Test.
- A few of the respondents were particularly health conscious – perhaps more so than the general population. At least two respondents were diabetic, one had an enlarged prostate, and others mentioned potential prostate symptoms (e.g., frequent urination).
- At least one respondent reported misinformation about prostate cancer (e.g., prostate cancer is the second leading cause of cancer deaths among men). The accuracy of his questionnaire responses seemed unaffected by his misinformation.
- We will continue to screen in Round 2 for obvious prostate symptoms such as enlarged prostate. Should we screen for more subtle potential symptoms of prostate issues (e.g., frequent urination)?

Question Specific Findings

The following questions are about discussions doctors may have with their patients about the PSA test that is used to look for prostate cancer.

1. *Discussion of clinical issue or nature of decision*

Have you and a doctor ever talked about the PSA test?

Yes (n=7)

No (n=2)

Everyone understood question 1 and had no trouble answering it. However, when probed, it was clear that “talked” was interpreted broadly. It included asking doctors for approval, giving permission to doctors to order the PSA test, and discussing PSA test results. Respondents reported that the talk they had with their doctor was part of a routine conversation about blood workups or blood test results. In these conversations, discussions about the PSA test were generally not very salient because most respondents had negative results. In other words, the PSA test was not highlighted for specific followup conversation by the doctor or by our respondents.

Notably, when conversations did occur focusing on decision making for the PSA test, respondents had already made the decision that they wanted the test and doctors simply approved their requests. For example one respondent saw a film about awareness of prostate cancer especially among African-American men. This led him to initiate a conversation with his doctor about getting the test.

2. *Discussion of uncertainty*

Has a doctor ever mentioned to you that experts have different opinions about the PSA test?

Yes (n=4)

No (n=5)

When respondents were even aware there were different opinions about the PSA test, the opinion they focused on was whether to do the PSA test or a rectal exam. Several respondents felt there was a controversy about which test was more accurate. The following are a few things that were mentioned:

- The PSA test is a “prescreening” for the rectal exam,
- The two tests were interchangeable, and
- The PSA test is an alternative test for men who refuse to have a rectal exam.

No one mentioned disagreements among experts about whether or not to get the PSA test. For example, one respondent said, “The PSA is a standard accepted by everyone. There are no differing opinions among experts.”

When probed, one respondent indicated he was aware that prostate cancer can be a slowly-progressing cancer that may not need treatment. Like the other respondents, this respondent saw the PSA as a standard test, accepted by everyone.

In follow-up conversations during the interviews, respondents mentioned a variety of information sources about the PSA test, not just their doctors. Examples of information sources respondents mentioned included MSNBC, the Internet and conversations with peers. We tried to focus the interview on conversations with doctors. However, since few respondents had prolonged conversations with their doctors, we think they broadened the scope of their responses at question 2 to other information sources.

Suggested rewording: Did your doctor tell you that some experts recommend using the PSA test to look for prostate cancer and some experts do not recommend the test to look for prostate cancer?

3. <i>Discussion of pros and cons of alternatives</i>			
Which of the following topics about PSA tests have you ever talked about with a doctor?			
Have you talked about::			
	Yes	No	DON'T KNOW/ NOT SURE
the PSA test's effects on your peace of mind?	(n=1)	(n=8)	<input type="checkbox"/>
the PSA test's chances for giving wrong results?	(n=4)	(n=5)	<input type="checkbox"/>
the PSA test's ability to find prostate cancer early?	(n=5)	(n=4)	<input type="checkbox"/>
the PSA test's chances for finding prostate cancers that might never bother you?	(n=3)	(n=6)	<input type="checkbox"/>
the PSA test's importance to your family?	(n=5)	(n=4)	<input type="checkbox"/>
the possibility that treating prostate cancer could lead to serious side effects such as problems with urination or having sex?	(n=4)	(n=5)	<input type="checkbox"/>
NONE OF THESE			

Respondents over-reported discussions of pros and cons. They seemed to be reporting their experiences and their knowledge about the PSA test. They did not seem to focus on topics covered in conversations with their doctors.

We are not sure what is causing the lack of focus on conversations with their doctors and the consequent over-reporting. We have identified a few hypotheses based on respondents' comments and responses.

- There are too many topics listed in question 3, so respondents lose track of the question stem. If this hypothesis is correct, we would expect a gradual shift in focus across topics. If NCI is interested, this is a trend we could look for in Round 2 testing by further probing how the respondents are interpreting the question or selecting the response and looking for changes across topics in question 3.
- The psychological tone of some of the topics leads respondents away from thoughts about conversations with their doctors toward other support-type resources or toward general implications that follow from more specific topics they discussed with their doctor. For example, one respondent who reported yes for "importance to your family" said that since his doctor told him the PSA test could help detect cancer, he inferred that his family would be affected by him undergoing the test.
- The question wording may be misunderstood. "Ever talked about with your doctor" may be misconstrued as "ever talked about." For example, one respondent said "yes" to "importance to your family," saying that he tells his brothers to get the PSA test because it is important. When probed, this respondent clarified that he did not talk to his doctor directly about importance to his family.
- Question goals may be misinterpreted. At least four and probably five respondents saw this question as a tool for raising awareness about the PSA test's strengths and weaknesses. This interpretation perhaps leads to over-reporting what respondents are currently interested in or what they now want to discuss with their doctors.

We also found some more specific wording issues listed below.

- "Cancers that might never bother you" was problematic wording. Respondents were not sure whether to focus on physical or physical and emotional impacts of cancer. In addition, some respondents seemed to think of prostate symptoms more broadly. For example, one respondent could imagine having symptoms like frequent urination that would not "bother" him unless he was diagnosed with prostate cancer. For this respondent, "bother" seemed synonymous with "diagnosis of cancer."
- "Possibility that treating prostate cancer could lead to serious side effects" was also problematic. Two respondents misinterpreted this item as asking about side effects from having the PSA test.

- “Urination” and “having sex” were both well understood by all respondents. No one offered alternative wording.

Recommendation: The set of “pros and cons” in question 3 should cover topics doctors are expected to discuss based on the recommended standards. The current list seems to include topics doctors might cover.

4. *Exploration of Patient Preference*

Has a doctor ever asked you whether or not *you wanted* to have the PSA test?

Yes (n=3)

No (n=6)

When asked, respondents noticed distinctions between questions 1 and 4. Respondents understood question 4 as an item about choice and question 1 as an item about conversations.

Among those responding “yes,” two said their doctors asked for their approval to order the PSA test as one of a battery of blood tests. A third respondent reported that his doctor said, “Last year your PSA test came back normal. I think you should have another one. Do you have a problem with that?”

Among those responding “no,” two respondents said they never talked to their doctors at all about the PSA test. Three respondents said the PSA test is part of their routine blood panel and is never pulled out separately for a discussion. Respondents thought that their doctors’ approaches might be due to their histories of negative PSA test results. The last respondent who said “no” indicated that he told his doctor he wanted to get the test.

5. *Involvement Outcome*

Have you been involved *as much as you wanted* in deciding whether to have a PSA test?

Would you say...

Definitely (n=7)

Somewhat (n=1)

Not at all

OTHER RESPONSE (n=1)

The question reads as a Yes/No question, and one respondent felt the three-point scale was awkward.

Something to think about: Will the three-point scale be useful? Is there sufficient variance? Would two options convey nearly as much information without confusing or irritating any respondents?

6. *Recency*

When did you have your most recent discussion with a doctor about the PSA test?

Was it...

- a. A year ago or less? (n=6)
- b. More than 1 year but not more than 2 years? (n=0)
- c. More than 2 years but not more than 5 years? (n=1)
- d. Over 5 years ago? (n=0)
- e. Never had a discussion (n=2)
- f. REFUSED
- g. DON'T KNOW

The respondents who responded “no” at question 1 correctly selected “never had a discussion” at question 6.

One respondent wasn't sure his last conversation about the PSA test should be included in his response for question 6. This R said, “It wasn't really a discussion. He [the doctor] agreed to having the test and the results came out fine. I never spoke to him again about it.”

Something to think about: What is the goal for question 6? In terms of the decision making standard, is having the conversation once sufficient? If so, then recency may be irrelevant.

If it is important to measure recency, notice that what question 6 measures is time passed since respondents' last PSA test or last set of PSA test results.

7. Besides your doctor, has any other health care professional (such as a nurse practitioner) ever talked to you about the PSA test?
- Yes (n=1)
 - No (n=8)

Only one respondent said “yes” to this question. This respondent had attended a seminar on men's health issues provided by Kaiser and run by a urologist. If seminars and other public information forums are not relevant, the item should explicitly exclude them. For example: “Do not include information from seminars, television, or the Internet” could be added to the end of the question stem.