

# **PSA Test Decision Making: Results from Cognitive Testing: Round 2 August 30, 2006**

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This document presents results from the second round of cognitive interviews with draft items on doctor discussions about PSA testing and decision making. We conducted cognitive interviews with nine male respondents between August 11<sup>th</sup> and August 17<sup>th</sup>, 2006.

Unlike the first round of testing conducted in July, we revised the draft items and test interview protocol throughout the second round, based on observations during the interviews and subsequent discussions with NCI. For each of the items tested, this report shows the wording of the item at the start of testing as well as how it was revised by the end of testing. For reference purposes, response frequencies for the different versions of the items are listed in text boxes followed by question-specific findings. Attachment A contains the final cognitive interview protocol.

This document 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.

## **Summary Demographics**

We conducted cognitive interviews with nine volunteer male respondents. For the first round of testing, we recruited all nine volunteers through a database of community contacts that Westat maintains. In order to meet the criteria for the second round of testing, we needed to utilize additional sources for recruiting. In addition to using the database, we also posted an online notice on Craig's List, put up flyers in Montgomery Works buildings, and recruited family and friends of Westat employees.

All volunteers met the following screening criteria:

- Did not work either full or part-time at the NCI or Westat;
- Were 50 years or older;
- Had not had a diagnosis of prostate cancer in the past;
- Were familiar with the PSA test; and
- Reported having talked with their doctor about the PSA test.

Unlike Round 1, we also instituted a quota system to ensure that at least five of our participants reported having talked with their doctor about the PSA test before they had the PSA test. Additionally, we no longer excluded men who had been diagnosed with an enlarged prostate or BPH in the past, as NCI decided this issue will be handled analytically in studies using the PSA decision-making items. Additionally, 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 in Round 2. As can be seen from the table, six of the respondents were married or living with a partner, five were white, three were African-American, and one respondent was Asian. The age of the respondents ranged from 50 to 76. Although not shown in the table, all of the respondents reported having health insurance.

Table 1. Demographic Profile of the Nine Respondents (Round 2)

Race	Age	Education	Marital status
Asian	65	Graduate school	Married
White	76	Graduate school	Married
White	73	College graduate	Married
African-American	68	College graduate	Married
White	66	Some college	Married
White	60	College graduate	Single
African-American	50	12 <sup>th</sup> grade	Divorced
White	56	Graduate school	Divorced
African-American	53	12 <sup>th</sup> grade	Living with partner

## Overall Findings

In this round, the following were identified as general results:

Early question wordings on some items related to issues such as “cancers that may not harm you” and “cons of the PSA test” alarmed one or two participants and raised questions for others.

Small changes made throughout the testing period steadily improved question flow and respondent understanding and reduced off-topic questions from respondents.

In contrast to Round 1 testing, respondents consistently focused on conversations with their doctors rather than things they learned from other sources (e.g., health fairs).

Recruiting respondents for this round was more time consuming than the first round because of the more stringent criteria.

Across both rounds of testing and 18 interviews, none of the respondents reported discussing cons of the PSA test related to risks for unnecessary treatment with a doctor before having the test.

## 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.

*Discussion of clinical issue or nature of decision*

Initial versions tested (For Round 2, we began by testing two different versions of question 1)

1. Has there ever been a time when you talked with a doctor about the PSA test BEFORE you had the test?  
Yes (n=1)  
No (n=0)
1. Did you ever talk about the PSA test with a doctor before having the test?  
Yes (n=1)  
No (n=0)

Final version tested

1. Have you ever had a PSA test?  
  
Yes (n=7): Before you had the PSA test, did you and a doctor talk about the test?  
Yes (n=5)  
No (n=1)  
DON'T KNOW/DON'T REMEMBER (n=1)  
  
No (n=0): Did you and a doctor talk about the PSA test?  
Yes  
No – **END SURVEY**

Regardless of the version tested, most respondents said they were responding with regards to their first PSA test. One respondent seemed to report a conversation for a subsequent test – a test he had after he began to have prostate-related problems, when the test gained importance to him.

Early in the testing process, one respondent was confused about the question's objective – specifically, whether who initiated the conversation was an important consideration in his answer. Based on his confusion and subsequent suggestion, we revised the item after two interviews into the current two-part item. After this change, respondents had no difficulty answering the two-part item.

When asked about topics the talk with their doctor covered, respondents reported that they discussed possible symptoms of prostate problems, acceptable ranges

of PSA test results and how to interpret those results, and demographic-related reasons for screening for prostate cancer.

Recommendation: No further change.

*Discussion of uncertainty*

Initial version tested

2. Has a doctor ever told you that some experts recommend the PSA test and others do not?  
Yes (n=0)  
No (n=1)  
DON'T KNOW (n=0)

Final version tested

2. Has a doctor ever told you that some doctors recommend the PSA test and others do not?  
Yes (n=0)  
No (n=7)  
DON'T KNOW (n=1)

Seven of the 9 respondents reported “No” and two weren’t sure – one because he didn’t remember, and the other because he was uncertain whether to include a discussion with a urologist concerning questions about interpreting PSA test results. The latter respondent eventually selected “no” as his response because the urologist talked about test results, not about whether or not to have the test.

We revised the wording from “experts” to “doctors” after the first interview when a respondent seemed to completely misinterpret the question. He thought the question was asking about “why his doctor ordered the test” rather than “whether the doctor mentioned competing opinions about the test.” After the revised wording, this problem never recurred.

Respondents interpreted “doctor” as including their primary care physicians and their urologists. When explicitly asked, one respondent indicated that he did not include lectures or health fairs where doctors talked about the PSA test in his response.

Recommendation: No further change.

*Discussion of uncertainty*

Initial version tested

3. Has a doctor ever told you that experts are not sure if finding prostate cancer early using the PSA test actually saves lives?  
Yes (n=0)  
No (n=1)  
DON'T KNOW (n=1)

Final version tested

3. Has a doctor ever told you that no one is sure if using the PSA test actually saves lives?  
Yes (n=2)  
No (n=5)  
DON'T KNOW (n=0)

Most respondents answered “no” because their doctors never discussed the test’s properties with them. Two respondents answered “yes.” One said the test was not a “sure thing” and the other described the test as a “tool among tools.”

This item was revised after the first two interviews in order to reduce the length of the question and to eliminate the use of the word “experts”. One of the respondents had asked the interviewer to repeat the item, and the original version of the item was cumbersome to administer. Once the item was revised the interviewers did not have to read the item more than once.

Recommendation: No further change.

*Discussion of pros and cons of alternatives*

Initial version tested

4. Has a doctor ever talked with you about the pluses and minuses of the PSA test?  
Yes (n=0)  
No (n=2)  
DON'T KNOW (n=0)

Final version tested

4. Has a doctor ever talked with you about both the pros and cons of the PSA test?  
Yes (n=0)  
No (n=7)  
DON'T KNOW (n=0)

At the start of Round 2, respondents seemed to focus on the pros of the test, and we were concerned the question could be double-barreled (i.e., measuring two different dimensions within the same item.) Therefore, we added the word “both” after the second interview.

Most respondents were unfamiliar with possible cons of the test. Some speculated that cons might be physical side effects of the test itself, negative physical reactions after the test, or unnecessary worry from an inaccurately positive result.

No one articulated cons related to the nature of the cancer detected by the test.

Early on, we also shifted from “pluses and minuses” to “pros and cons” because one respondent said the former terms were too mathematical.

Even with these revisions, the question seems too broad. For example, one respondent initially answered “no” at question 4 and subsequently answered “yes” to parts of Question 5. With followup, he thought he should have answered “yes” at Question 4. The breadth of the question seemed to confuse him.

Recommendation: Consider eliminating Question 4 because the most important topics are covered in Question 5 below.

*Discussion of pros and cons of alternatives*

Initial version tested

5. Has a doctor ever told you that... (REPEAT EACH TIME)	Yes	No	DON'T KNOW/ NOT SURE
a. The PSA test cannot always tell whether someone has prostate cancer or not?	(n=1)	(n=0)	(n=0)
b. Many types of prostate cancer are not harmful, even without treatment?	(n=0)	(n=1)	(n=0)
<i>(first revision of item b)</i> <i>Some types of prostate cancer are harmless?</i>	(n=)	(n=2)	(n=1)
c. The results of the PSA test cannot tell if a man has a harmful type of prostate cancer, or one that will not cause him harm even without treatment?	(n=0)	(n=1)	(n=0)
<i>(first revision of item c)</i> <i>The results of the PSA test cannot tell if a man has a harmful or harmless type of prostate cancer?</i>	(n=1)	(n=2)	(n=0)
d. Treating ANY type of prostate cancer can lead to serious side effects, such as problems with urination or having sex?	(n=0)	(n=2)	(n=0)

Final version tested

5. Has a doctor ever told you that... (REPEAT EACH TIME)	Yes	No	DON'T KNOW/ NOT SURE
a. The PSA test is not always accurate?	(n=5)	(n=2)	(n=1)
b. Some types of prostate cancer are slow-growing and therefore not likely to harm you?	(n=1)	(n=3)	(n=1)
c. The results of the PSA test cannot tell if a man has a slow-growing or fast-growing prostate cancer?	(n=0)	(n=4)	(n=1)
d. Treating any type of prostate cancer can lead to serious side effects, such as problems with urination or having sex?	(n=3)	(n=4)	(n=0)

In general, this set of items worked much better in Round 2. Respondents focused on conversations with their doctors and they didn't mention pros and cons that were off-topic. They generally understood that the goal of these questions was to determine whether they talked with their doctors about the various topics listed. This is an improvement from the Round 1 testing where several respondents interpreted these items as educational or informational in nature.

Item 5a. We revised this item after the first interview to decrease its length. Once the item was revised, we also tested two different wording choices: “not always accurate” and “wrong.” There was no clear preference among respondents between these alternative wordings. “Wrong” may be more easily understood by some respondents, but “not always accurate” seemed to capture the item intent more effectively because respondents saw it as linked to measurement.

Recommendation: No further revision

Item 5b. The wording of this item changed throughout testing and several different versions were tested. Use of the word “harm” created anxiety for many respondents. The language was too strong. The idea of cancer that is “not likely to harm you” was surprising to respondents, even for at least one respondent who stated “If you are 80 years old and you have a slow-growing cancer, there is no reason to fool with it. You are probably going to outlive the cancer in your lifetime.”

Shifting the wording from “cancers that are harmless” to “slow-growing” enhanced understanding, but some respondents were still troubled or bothered by the phrase “not likely to harm you.”

Recommendation: Revise wording for item 5b to “Some types of prostate cancer are slow-growing and need no treatment.” This revision eliminates the use of the problematic word “harm”, but has not been tested.

Item 5c. This item also evolved throughout testing with different versions being tested. Because of the changes, there is no constant test of respondent preference. Respondents understood the difference between the concepts of “slow growing” and “fast growing” cancers and could report whether they talked about it with their doctor.

Recommendation: Eliminate all references to “harm” and revise item 5c to “The results of the PSA test cannot tell the difference between slow-growing and fast-growing prostate cancer.” This revision is based on suggestions from respondents, but has not been tested.

Item 5d. No problems identified. This item was altered slightly to de-emphasize the word “any”.

Recommendation: No further revision.



*Exploration of Patient Preference*

6. Has a doctor ever asked you whether or not *you wanted* to have the PSA test?  
Yes (n=2)  
No (n=7)

No problems identified.

Recommendation: No revision

*Involvement*

7. Have you been involved *as much as you wanted* in deciding whether to have a PSA test?  
Definitely (n=8)  
Somewhat (n=0)  
Not at all (n=1)

Respondents reported being involved as much as they wanted to be. Eight of nine appropriately selected “definitely.” The ninth misinterpreted the question and selected “not at all,” reporting how involved he actually was rather than how involved he wanted to be. We think this misinterpretation was due to anxiety built up through the interview.

Recommendation: Consider dropping this item if no variance is anticipated.