

**Cognitive Interview Evaluation of the
2010 National Health Interview Survey
Supplement on Cancer Screenings & Survivorship:**
Results of interviews conducted October – December, 2008

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1. Introduction

This report documents cognitive testing results on the 2010 cancer supplement of the National Health Interview Survey (NHIS). The supplement is sponsored by the National Cancer Institute, National Institutes of Health. Testing took place in two rounds between October and December, 2008.

Cancer screening and survivorship questions are located in the sample adult section of the NHIS. The questions tested focused primarily on vitamin use, smoking, experiences with surviving cancer, and cancer screening tests, such as the PSA test, pap test, mammography, spiral CT scan and chest x-ray, and colorectal screenings (including sigmoidoscopy, colonoscopy, CT colonography, and fecal occult blood test).

The majority of this report presents a question-by-question analysis of the survey questions. Emphasis is placed on exploring interpretive patterns and understanding the construct being measured by the survey questions. The discussion of these questions includes descriptions of how respondents interpreted question intent and explanations of why and how respondents interpreted the questions the way they did. Analysis is included for most questions, however, some items were unable to be fully examined due to sample size, questionnaire length (there are approximately 120 questions) and/or limited time. For example, when respondents reported never having used snuff or chewing tobacco¹, they skipped out of related follow-up questions. In other instances, time constraints prevented a thorough evaluation of a given question. When response error was not apparent, follow-up probing was minimally conducted in order to conserve time for other questions. In these cases, firm conclusions are not possible, as the absence of error may be more apparent than real and interpretations may be inconsistent.

¹ Questions on snuff and chewing tobacco were added in the second round of testing upon request by the sponsors. However, because the use of snuff or chewing tobacco could not be incorporated into the recruitment protocol, respondents in the sample had never used either product.

Because testing took place in two rounds, analysis of the original question is presented first, followed by a rationale for question modification and, where appropriate, results of the second round of testing on the revised questions.²

The next section briefly describes the qualitative methodology of cognitive interviewing, including the procedure for sampling interview respondents, the data collection method, and analysis plan. The third section of the report presents a summary of general findings, followed by a more detailed question-by-question analysis.

2. Methodology

Sampling and Respondent Demographics

Testing took place in the National Center for Health Statistics (NCHS) Questionnaire Design Research Laboratory (QDRL). We conducted a total of 39 interviews, 24 in the first round and 15 in the second. Respondents were selected with a purposive sample in mind. The goal of a purpose sample is *not* to obtain a statistically representative sample. Instead, respondents are chosen according to characteristics that would screen them into or out of certain questions. Emphasis is on coverage of the survey questions and topics, *not* the survey population.

In order to test the pap test and HPV questions, we recruited younger women. However, we also recruited respondents over the age of 40 in order to test questions on cancer screenings that are age-specific, such as breast cancer screening, colorectal cancer screening, and the PSA test for men. Callers who reported having had some form of cancer at any point in their life were also asked to participate in the study. Finally, demographic diversity among respondents was also sought, especially in regard to socioeconomic status. The demographic breakdown of respondents appears in Table 1.

A newspaper advertisement in a free commuter newspaper did a good job of identifying the type of respondents we needed, and all respondents were recruited this way. Prior to participation, respondents were screened over the telephone in order to identify key demographics such as age, educational attainment, and income level. Information about their vitamin D usage, smoking behavior, experience with various cancer screening tests and whether or not they ever had cancer was also collected.

At the time of the interview, respondents filled out paperwork whereby they agreed to the interview being video- and audio-taped. The interviewer then explained the purpose of NCHS, described the survey, and told respondents the manner in which the interview would be conducted. After these introductory remarks, interviewers began by administering the survey questions. Once the survey responses were obtained, the interviewer elicited respondent narratives about their knowledge of and experience with the topics covered in the survey questions. This was followed by question-specific probes designed to reveal respondents' interpretation of the question and the ease with which they chose a response category. Through

² The first version of the full instrument tested in round 1 provides the framework for the question-by-question analysis. The second version tested in round 2 is in Appendix A.

the comparison of respondents' survey responses to both their narrative and follow-up probing, interviewers were able to ascertain whether or not and why a response error had occurred. Interviews were designed to last 60 minutes and a \$40 token of appreciation was given to respondents at the conclusion of the interview.

Table 1: Demographic summary of respondents in total and for each round of testing

	<u>Round 1</u> (n=24)	<u>Round 2</u> (n=15)	<u>Total (%)</u> (N=39)
<u>Respondent Age</u>			
Under 40	9	2	11 (28%)
40 and Over	15	13	28 (72%)
<u>Cancer Survivor</u>			
Yes	7	3	10 (26%)
No	17	12	29 (74%)
<u>Gender</u>			
Female	16	11	27 (69%)
Male	8	4	12 (31%)
<u>Race/Ethnicity</u>			
NH-White	8	2	10 (26%)
NH-Black	16	13	29 (74%)
Hispanic	0	0	0 (0%)
<u>Education</u>			
HS or less	4	8	12 (31%)
More than HS	20	7	27 (69%)
<u>Income</u>			
Under 20,000	6	9	15 (38%)
20,000 & Over	15	6	21 (54%)
Don't Know	3	0	3 (8%)

Data Collection

Cognitive interviewing, as a qualitative methodology, offers the ability to understand the interpretive process behind answers to survey questions. Different types of cognitive interviewing techniques exist. Respondent narrative and intensive follow-up verbal probing were the primary methods used for data collection. With these techniques, interviewers administer the survey question, obtain an answer, then probe the respondent for information relevant to their responses. Follow-up probes are typically initiated when contradictory information is given by the respondent, as this may indicate points of confusion and misinterpretation. Probes are also useful for exploring pre-identified areas of concern in the instrument. On the other hand, respondent narrative allows for the exploration of unanticipated problems by producing rich and detailed information on how respondents answered the question, what they were thinking when answering, and how they interpreted the meaning of the question.

Shedding light on the question-response process, data from narratives and probes allow the analyst to determine which stage in the process of answering a survey question – comprehension, retrieval, judgment, or response – the respondent had difficulty with, if any. The appropriateness of response categories can be evaluated with this procedure, as can the ability of participants to draw upon their own experiences and knowledge to answer the questions effectively. Because the intensive interviewing method provides extensive detail on the question-response process, not only does it allow the interviewer to identify *which* questions and/or response categories are problematic, it also shows *why and how* questions are problematic, leading to informed strategies for improving question design and minimizing response error.

Method of Analysis

Data analysis proceeded according to the grounded theory approach which does *not* aim to test existing hypotheses, but instead generates explanations of interpretive and response error patterns that are closely tied to the empirical data. The process of analysis is a constant comparison of data in three distinct steps. The first step occurs within the interview as the interviewer attempts to understand how one respondent has come to understand, process and then answer a survey question. Basic response errors can be identified by comparing respondents' answers to the survey questions to the narrative they provide during the interview. When logical contradictions are evident between the narrative and the survey answer, the interviewer explores why these contradictions occurred.

The second step in analysis occurs once the interview is over, and is a systematic comparison *across* all interviews. This level of comparative analysis reveals *patterns* in the way people answer survey questions. At this level, it's possible to identify the construct that's being captured by the survey question and illustrate the substantive meaning behind the survey statistic.

The final phase of analysis is a comparison of patterns across sub-groups, identifying whether particular *groups* of respondents interpret or process a question differently from other groups. At this level of analysis, that is, identifying patterned differences among subgroups, we begin to understand where potential for bias would occur in survey estimates.

3. Results

Analysis Highlights

Questions asking about causality

Questions that ask respondents to provide a reason for their behavior have been found to be problematic.³ Many factors play a role in determining behavior, and frequently people do not have an understanding of why they behave certain ways. Questions that ask respondents for reasons why they have NOT engaged in some behavior add an extra (and significant) layer of difficulty. Questions posed in the negative add to the cognitive burden, and causal questions in the negative assume that respondents actually have specific reasons for not doing something (and that they went through a conscious decision making process).

This instrument contains several questions that ask respondents why they did not follow doctor recommendations or receive certain cancer screening tests. Two different question formats for obtaining this information were tested, but neither were met with much success. The first format was asked in an open-ended manner, whereby interviewers chose the response category based on the respondent's answer. The second format (which was emphasized in round 2) eliminated the open-ended format and broke each response category into a separate yes/no question.⁴

Three problems shared by these questions were the double negatives they posed and, depending on the format, the fact that it was too difficult to code open-ended responses or that the stem question was not retained in memory as questioning progressed. However, in addition to the complexity of the cognitive task, a larger underlying issue may relate to the very nature of asking people why they do not do or have not done something. The assumption in asking this type of question is that people go through an active decision making process to NOT do something. Sometimes this is true, but often it is not. When it's not true, the survey question becomes difficult to answer, even when a "never thought about it" option is offered. Even though this may be the correct answer, respondents are reluctant to choose it precisely because the question assumes they made a conscious decision. Conversely, some respondents satisfice and choose options that aren't really accurate in order to provide an acceptable answer – an answer that they didn't have to begin with.

Questions for people "in the middle" of implicitly dichotomous groups

Sometimes survey questions make assumptions about groups of people answering the question. For example, a question might assume a respondent is either male or female. While this might seem to be a reasonable assumption, many other dichotomous groupings are overly simplified and make incorrect assumptions about people and their experiences. The result is that the survey question is difficult to answer for certain groups of people, yielding data with low validity and reliability and survey estimates that are biased.

³ See cognitive testing report on complementary and alternative medicine in Q-Bank (Willson, S. 2006. Cognitive Interviewing Evaluation of the 2007 Complementary and Alternative Medicine Module for the National Health Interview Survey, Round 2)

⁴ See questions 3 and 4 in the PSA section for an example of each format.

Such was the case with several topics in this instrument. Specifically, the sections on vitamin use, smoking, and cancer implicitly categorized people in ways that were inaccurate for some respondents. Respondents who didn't fall neatly into the dichotomy assumed by the questions had varying degrees of difficulty providing accurate answers. This was true to the extent that the questions made inaccurate assumptions about their experiences.

For example, several problems were found with the questions on vitamins, including recall issues and telescoping, estimation/judgment difficulties and unintended interpretations. That is, some respondents would provide false positive responses by including vitamin use that fell outside of the 12 month reference period. Additionally, some had trouble estimating how many months or how many days per month they took vitamins. Finally, some were inclined to give false negative responses to whether they took vitamins in the last 12 months because they interpreted the question as asking about regular usage. These errors were not random. Every respondent who was an irregular or sporadic user of vitamins made at least one error of this type.

A similar pattern was found for the questions on smoking. Problems found in these questions related to either estimation difficulties or interpretation inconsistencies. Some respondents could not accurately say how many cigarettes they smoked per day and others interpreted the question on whether they smoked 100 cigarettes in their entire life as asking if they are smokers or non-smokers. The pattern was identical to the one found in the vitamin section. In other words, this type of error was not random, but was more likely among respondents who were not regular smokers (e.g., "social smokers", those in the process of quitting, or those who smoked for very brief periods) than those who either didn't smoke at all or who smoked regularly and frequently.

Finally, some of the cancer-related questions demonstrated this pattern as well. The main problems here were definitional. Interpretation of key terms, such as malignancy, varied. Several respondents weren't sure of the definition. Similarly, some respondents were confused by the response options offered in the question asking them what treatment they received. For example, one respondent didn't know exactly what counted as chemotherapy. She was taking pills to manage a brain tumor, but didn't know if this was a form of chemotherapy. In every case, the respondents who struggled in this manner were those whose experiences didn't fall neatly into either having or not having cancer. Some respondents were diagnosed with and treated for what they called a "precancerous" condition. They were told by doctors that what they had wasn't cancer, but that there was cell growth that would become cancer if not treated, such as dysplasia. Not knowing if dysplasia falls under the definition of malignancy made it difficult for them to know how to answer the question.

The next section is a question-by-question analysis of the entire instrument. It provides detailed results for each item tested as well as findings related to the above discussion.

Question-By-Question Analysis

Diet

[Ask all]

1. During the PAST 12 MONTHS, did you take any MULTI-vitamins, such as One-A-Day, Theragran, or Centrum, etc?

*Read if necessary: There are a number of vitamin and mineral combinations now available. The ways in which nutrients can be combined into pill form is almost infinite. Any combination of 3 or more vitamins and minerals should be included in the MULTI-vitamin category. Combinations labeled as "stress" or "antioxidant" supplements are common and should be included as MULTI-vitamins. Do NOT include combinations of herbal or botanical substances, or combinations of just 2 nutrients (e.g., calcium with vitamin D, etc.) in this question.

Yes

No

FINDINGS: All respondents were tested on this question. In round 2 there was a minor wording change in the "read if necessary" option, changing the combination from "3 or more..." to "4 or more vitamins & minerals". Because this statement was read to only one respondent (no one else requested clarification upon hearing the question), it had no discernable effect on interpretation or response error. Also, the "etc." at the end of the question was rarely read by interviewers because of its awkwardness.

In all there were issues for 7 respondents. In round 1, two respondents demonstrated possible error by telescoping. That is, vitamin use outside of the 12 month timeframe was included in their answers. These two respondents were erratic users of vitamins and had difficulty remembering whether or not the last time they took vitamins was in the past 12 months. On the other hand, a periodic user may have committed a false negative error because she couldn't remember if the last time she took a multivitamin was 11 or 12 months ago. She says, "Nope. [PAUSE] No, not...no. Well, yeah, I did but I quit because I wasn't taking it with food and it made me nauseous. At the very...like, probably 11 or 12 months ago." Another erratic user wasn't sure if she should include the b-complex vitamin she takes. The interviewer read the "read if necessary" instruction, but this didn't clear it up for her so she decided to answer yes. She commented that it "seems like they're asking about regular usage, even if for only 1 month." Conversely, another respondent who literally took one multivitamin pill in the past year (just prior to getting blood work done) interpreted the question literally and answered yes. Clearly, respondents can interpret this as a question asking about literal behavior OR about general patterns of vitamin use. This was most problematic for sporadic users of vitamins.

Finally, one respondent drinks vitamin water, but didn't include that in his answer. However, it's not unreasonable to think that other people would choose to include such a drink, particularly if they ingest it specifically for the vitamins it contains. For this respondent, the vitamins in the water were an afterthought, so he didn't see himself as taking vitamins. Another respondent drinks "ensure" but similarly didn't include that in her answer because she saw this question as being about pills.

2. During the PAST 12 MONTHS, did you take any calcium supplements or pills? [fill1: Do NOT include any calcium in the MULTI-vitamins you told me about.]

*Read if necessary: Include Tums. Do NOT include milk or calcium-fortified orange juice.

Yes

No

FINDINGS: This question was tested on all respondents and did not change between rounds. Issues were identified in 9 interviews.

First, there was some confusion over what should be included in an answer, but this wasn't always expressed up front. As a result, the "read if necessary" instruction was rarely invoked. When the instruction *was* read, it helped. For example, one respondent drinks fortified OJ specifically for the calcium and asked if that counted. The interviewer read the instruction and the respondent then answered 'no.' However, another respondent takes a pill with calcium and D and answered yes, even though she wasn't sure to include it. During administration she never asked for clarification, so the instruction wasn't read to her. Another person takes Tums and answered no in error because, again, she never sought clarification. Another respondent who didn't seek clarification answered 'yes' to the question because she was thinking of the ensure that she drinks daily. (Note that she did not include ensure in her answer to taking a multivitamin, but does include it here. It never became obvious how or why she made this distinction.)

Two respondents had difficulty with the word "or". One person said, "What do you mean? I know when you said 'calcium', but when you said 'pills' – what kind of pills did you mean?" Another respondent said, "Yes, because Centrum is a pill." They did not interpret the question as asking about only calcium, but rather as being about a calcium supplement *and* any other kind of pill.

Finally, two respondents had issues with the reference period because they were not regular users. One respondent has taken vitamins, but he's taken all different kinds at various different times and isn't very serious about it. He knows he took calcium at some point, but couldn't remember when. He answered yes simply because he knows for sure that he did take the supplement at some point in time. Another answered 'no' thinking it was a year ago she took calcium, but then thought it may have been more like 6 months ago. She stopped taking it because it didn't give her the extra energy she thought it would. As with the previous question, this one was especially problematic for irregular users of vitamins.

3. During the PAST 12 MONTHS, did you take any vitamin D supplements or pills? [fill1: Do NOT include calcium supplements that contain vitamin D or MULTI-vitamins you told me about.]

*Read if necessary: Do NOT include vitamin D fortified milk or other foods such as cereals and bread.

Yes

No [go to next section]

FINDINGS: This question was tested on all respondents and did not change between rounds. Issues were identified in 7 interviews.

As with the previous question, there was some confusion over what should be included and irregular users struggled with the reference period. One person said "supplements don't necessarily have to be pills, right?" Some included pills they reported in Q2. Several respondents took a pill with both calcium and vitamin D and it was confusing about whether they should report that again. The fill helped define that but wasn't consistently administered by the interviewers. A CAPI instrument would solve that problem.

3a. Thinking about the past 12 months, in how many of those MONTHS did you take vitamin D supplements?

_____ number of months

FINDINGS: This question was tested on 11 respondents and did not change between rounds. Issues were identified in 6 interviews.

Estimation errors arose for irregular users. For example, one person answered “at least 8 months” but then during probing states that she should have said the past 11 months and didn’t know why she first answered 8. Another respondent answered 3 months, but it was completely unclear why she gave this answer because during probing it was apparent she hadn’t taken vitamin D for a long time. Another person’s estimate was less erratic, but still inaccurate. He answered 6 months to the survey question, but during probing said he’s taken it since January (i.e., 8 months).

Two other people incorrectly filtered into this question because they included food in their previous answers. (One was not asked the next question because of this error.)

3b. Now, thinking only about that month, on how many DAYS during that month did you take vitamin D supplements? / Now, thinking only about those months, on how many DAYS PER MONTH did you usually take vitamin D supplements?

_____ days per month

FINDINGS: This question was tested on 10 respondents and did not change between rounds. Issues were identified in 4 interviews.

Estimation problems occurred for 3 respondents, and as in previous questions, some estimates were more reasonable than others. Irregular users simply don’t know and, therefore, have to estimate. One respondent said, “Probably like 3 to 4. I know I didn’t take it everyday.” Some try to take it everyday and forget, and this is when it’s impossible to know.

One respondent seemed a little confused about the unit of analysis. She answered “At least once a day,” giving her answer in terms of days, not months.

3c. On the DAY(S) you took vitamin D supplements, was the amount you took usually less than 800 international units (IU), or 800 international units or more?

< 800 IU

>= 800 IU

FINDINGS: This question was tested on 7 respondents and was deleted in round 2. Issues were identified in 4 of the interviews in round 1. All issues were related to knowledge of the respondent. Three respondents gave answers that were complete guesses. For example, one respondent answered less than 800 because her D pill is smaller than her E pill which is 400 IU’s, “so it’ probably less than 400.” One person gave a more reasonable estimate saying that there are “maybe 250 IU’s” in each chewable tablet. She’s heard you can overdo it on vitamins, so she doesn’t take high doses. Someone else with the same concerns chose less than 800 assuming that she would have picked the option on the shelf that had the lower dosage.

Tobacco

[Ask All]

1. Have you smoked at least 100 cigarettes in your ENTIRE LIFE?

Yes

No [go to next section]

FINDINGS: This question was tested on all respondents and did not change between rounds. Respondents tended to fall into either a “smoker” or “non-smoker” category. This made the question easy to answer because it required no calculation or judgment.

Only one issue arose for a respondent who smokes, but only very occasionally. This was a college student who has smoked at parties but doesn’t consider herself a smoker and doesn’t even smoke at every party she attends. Overall she figured the number of cigarettes she’s smoked does add up to 100, but she didn’t like answering ‘yes’ to the question. She thought the question was trying to distinguish between smokers and non-smokers and she would definitely put herself in the non-smoker category. In the end, however, there was no response error because she answered the question literally.

1a. Thinking back over the years you have smoked regularly, about how many cigarettes did you usually smoke each day?

_____ (number per day)

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

Respondents who smoked regularly made this calculation based on how many packs a day they smoked. This was a reasonably easy calculation for them to make (“About a half a pack, so 10.” “About a pack a day. Twenty.”)

However, for the irregular smokers, the question makes the false assumption that they smoked regularly. As a result, one respondent who never smoked for any length of time or with any particular pattern had a difficult time answering and said, “Maybe about 2.” Another reason this was so difficult for her to answer is because she was a teen when she tried smoking, which was a while ago and lasted for only a couple months.

Another issue is related to the meaning of this question vs. the next. Some respondents understood both questions to be asking the same thing and gave the same answer. (Upon hearing 1b they would reply, “That’s the same as the first!” or “Isn’t that what you just asked?”) However, other respondents saw them as different. In these cases, this question (1a) was seen as asking about their “usual” pattern or how much they smoked “most of the time.” As one respondent answered, “I average about 10 a day.” The next question (1b) was interpreted as asking about how much they smoked at their peak or how much they smoke on their heaviest days. One respondent said, “That’s a bad day – when you’re going through some mental stuff.” For another respondent it was, “About 15 when I was out drinking.”

In sum there was an even split in interpretations: 11 respondents understood 1a and 1b as asking the same thing and 11 respondents saw them as different. The intent of the questions should be more clearly communicated.

1b. What is the average number of cigarettes that you smoked daily during the longest period that you smoked?

_____ (number per day)

FINDINGS: This question was tested on 22 respondents and did not change between rounds. See discussion in question 1a above.

2. Do you NOW smoke cigarettes every day, some days or not at all?

Every day [go to next section]

Some days [go to next section]

Not at all

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

Most respondents had no trouble with this question. However, problems did arise for respondents who were trying to quit smoking. One respondent didn't understand the response options and answered "some days, not at all" because there are days now where he doesn't smoke. On the other hand, another respondent who hadn't smoked at all in the past several days answered "everyday" because she has not yet successfully quit. The problem is in the definition of "NOW". How far back does one go? This is not an issue for smokers or non-smokers, but can be problematic for those in the process of quitting.

Similarly, another respondent who smokes infrequently and doesn't see herself as a smoker felt as though choosing "some days" (which she did choose) would put her in the category of smoker and she was uncomfortable with that. She said that smoking 15 cigarettes a month is very different from smoking a couple times a month as she does.

3. Thinking back to when you stopped smoking completely, did you use ANY of the following PRODUCTS:

a. A nicotine gum?

Yes

No

FINDINGS: This question was tested on 12 respondents and did not change between rounds. No issues or errors were observed.

b. A nicotine patch?

Yes

No

FINDINGS: This question was tested on 12 respondents and did not change between rounds. No issues or errors were observed.

c. Any of these other nicotine products---nasal spray, inhaler, or lozenge?

Yes

No

FINDINGS: This question was tested on 12 respondents and did not change between rounds. Only one error was observed in round 2 for a respondent who wasn't sure if the pill she was taking counted as a lozenge. In the end there was no response error because she decided it was not a lozenge.

d. A prescription pill called Chantix or Varenicline?

Yes

No

FINDINGS: This question was tested on 12 respondents and did not change between rounds. No issues or errors were observed.

e. A prescription pill other than Chantix or vareniclene, such as Zyban, Bupropion, or Wellbutrin?

Yes

No

FINDINGS: This question was tested on 12 respondents and did not change between rounds. No issues or errors were observed.

ee. A website or on-line resource?

Yes

No

FINDINGS: This question was tested on 4 respondents and was added in the second round. In the first round, one respondent errantly included a website in his answer to f (telephone line). No issues or errors were observed in round 2.

f. A telephone help line or quit line?

Yes

No

FINDINGS: This question was tested on 12 respondents and did not change between rounds. No issues or errors were observed.

g. A stop smoking clinic, class, support group, or one-on-one counseling?

Yes

No

FINDINGS: This question was tested on 12 respondents and did not change between rounds. This question proved to be vague, as respondents included all kinds of experiences in their answer. Four respondents included things like websites, telephone lines, friends, and a hypnosis session in a Las Vegas hotel with 500 other people. In some cases (e.g., the telephone line) the aid was reported twice (here and in a previous question).

4. Do you now use snuff or chewing tobacco...[READ CATEGORIES]

Everyday

Some days

Not at all [go to next section]

FINDINGS: This question was tested on 15 respondents and was new in round 2. No problems were identified, but no one used either product, so the next two questions couldn't be tested.

5. During the past 30 days, what brand of snuff did you use most often?

Don't use snuff

BEECH-NUT
CAMEL SNUS
COPE
COPENHAGEN
COUGAR
GRIZZLY
HAWKEN
HUSKY
KAYAK
KODIAK
LEVI GARRETT
LONGHORN
MARLBORO SNUS
RED MAN
RED SEAL
ROOSTER
SILVER CREEK
SKOAL
TAYLOR'S PRIDE
TIMBER WOLF

Brand not on LIST _____

6. During the past 30 days, what brand of chewing tobacco did you use most often?

Don't use chewing tobacco

BEECH-NUT
CAMEL SNUS
COPE
COPENHAGEN
COUGAR
GRIZZLY
HAWKEN
HUSKY
KAYAK
KODIAK
LEVI GARRETT
LONGHORN
MARLBORO SNUS
RED MAN
RED SEAL
ROOSTER
SILVER CREEK
SKOAL
TAYLOR'S PRIDE
TIMBER WOLF

Brand not on LIST _____

Lung Cancer Screening

[Ask men and women 40 and over]

1. A lung cancer spiral or helical CT scan (or CAT scan) is a new screening test for lung cancer. During the test, you are asked to hold your breath and you are moved through a donut-shaped X-ray machine as you lie on your back.

Have you EVER had a spiral CT scan?

Yes

No [go to question 2]

FINDINGS: This question was tested on 30 respondents and had minor wording changes between rounds.

Round 2 read “A lung cancer spiral or helical CT scan (or CAT scan) is a new screening test. During the test, you are asked to hold your breath and you are moved through a donut-shaped X-ray machine as you lie on your back.” The change was meant to de-emphasize the focus on lung cancer because respondents sometimes struggled with knowing what test they’ve had as well as what the purpose of the test was. Specifically, they weren’t sure whether the purpose of the test was central to what the question was asking, and even if they were sure, they might not have known the purpose of the test to begin with.

In round 1, difficulties were found in 7 interviews. Four respondents weren’t sure what tests they’ve had or if those tests matched the one asked about in question 1. One respondent answers, “I had a CT scan. Now I don’t know the difference between a spiral...” Another with similar questions said, “I’ve had CT scans, but I don’t know about spiral donut shaped ones.” Additionally, three respondents reported having the test, but either didn’t know why they had it or said the test wasn’t to check for lung cancer. One respondent said, “Yes, but it wasn’t for lung cancer.” Another person said he had this test but “it was an abdominal scan with respect to my bladder cancer.” He reported yes to the question because the scan also picked up part of his lungs. Similarly, another person said, “If it’s for the lungs the answer would be no. But I did have a CT scan for another part of the body related to cancer.” He offered this information because he wasn’t sure exactly what the question was getting at (i.e., the actual test or the purpose of the test) and, therefore, didn’t know whether to answer yes or no. He ultimately answered ‘no’.

The change in round 2 still produced some confusion. The question was tested on 13 respondents and 5 problems were observed that were similar to the first round. One respondent had to think about her answer. When asked what she was thinking, she replied, “The word ‘spiral’ I’m not sure about. But I’ve certainly had a CT scan.” However, three others weren’t sure of the tests they received, but answered yes to the question because the procedure sounded familiar. Another person reported yes to the question because he received a full body scan (which would, of course, include the lungs) after being hit by a car last year.

For some respondents the problem is simply an issue of knowledge. They either don’t know what tests they’ve had or don’t know what the purpose of the test was. In these cases, question wording isn’t the solution because the basic problem is that it’s asking people something they don’t know.

1a. When was your most recent spiral CT scan?

_____ (month/day/year)

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

The central problem with this question relates to recall. Three respondents could only recall the year in which they’d had the test. The rest could narrow it down to the year and month (although 2 had to be prompted to remember the month) and no one could give the day. It’s typical that respondents cannot remember the exact day of any given test, especially the further back in time the test occurred.

2. Have you ever had a chest x-ray to test for lung cancer?

Yes

No [go to next section]

FINDINGS: This question was tested on 29 respondents and changed between rounds. In round 2 the question read, “During the past 12 months, have you had a chest x-ray?” The wording change was

prompted by issues similar to the ones that arose in question 1. Respondents didn't (or couldn't) always know the reason for the test. And sometimes they assumed the reason didn't matter as long as the test captured an image of the lungs.

This question was tested on 16 people in round 1, eight of which had issues. Four respondents knew they had the test and knew that it wasn't to check for cancer, but answered yes anyway. One respondent said, "Yes. Let me answer that different. I had a chest x-ray. I don't think they were looking for lung cancer." Another respondent answered yes, but during probing said, "I had a chest x-ray, but I'm not sure if it was for lung cancer. I think I had pneumonia. Yes...not for lung cancer, but I had a chest x-ray. They could have been checking for lung cancer. I mean, I'm quite sure if they looked at my lungs you might as well say yes. I would go with yes. I mean, if you would see it, I'm sure you would tell me." Several people shared this logic. That is, regardless of why the test was originally ordered, if lung cancer was present the doctor would see it and react to it.

Additionally, four respondents didn't know why they had the test. Sometimes it was simply part of a routine checkup and they weren't sure why the doctor ordered it – especially if the respondent wasn't having any symptoms. For example, one respondent answered yes, but during probing revealed that her internist does what she calls "routine chest x-rays" but she doesn't know what the doctor is looking for.

Because of these issues, the question was changed in round 2 to delete "...to test for lung cancer" from the original question and add a follow-up. The new sequence read, "During the past 12 months have you had a chest x-ray?" If yes: "Was the purpose of this x-ray to check for lung cancer?"

The new question was tested on 13 respondents. Issues were observed in 3 interviews. Overall, the format in round 2 produced less confusion than the wording in round 1.

One respondent had recall issues and telescoped. She received the test in relation to a job she applied for in Jan 2007, but didn't remember the date until she was probed. Two other respondents answered no, but had to think about it in relation to the mammograms they receive. One said, "No...because I think that's different from a mammogram." Another also answered no, reasoning that a mammogram is "not that deep" [to see the lungs] and that there are "no pictures of the lungs" that are produced from the mammogram.

While no response error was demonstrated in the last two examples, they show that respondents can't necessarily answer these question easily and often have to think through the logic of how to answer. A seemingly simple survey question can be a non-trivial cognitive task.

2a. When was your most recent chest x-ray?

_____ (month/day/year)

FINDINGS: This question was tested on 15 respondents and did not change between rounds.

14 respondents had recall issues in trying to answer this question. Three had outright memory error (that is, when probed they remember a different date from the one initially reported). Two others could only report to the year, one could remember only the year and season (only upon probing) and eight could narrow the date down to the month at best.

Pap/HPV

[Ask all women]

1. Have you EVER HAD a Pap smear or Pap test? * Read if necessary: A Pap smear or Pap test is a routine test for women in which the doctor examines the cervix, takes a cell sample from the cervix with a small stick or brush, and sends it to the lab.

Yes

No [go to question 10]

FINDINGS: This question was tested on 27 respondents and did not change between rounds. The question was generally well understood by respondents who had no trouble answering. Many women have a regular routine of getting paps, but even those who didn't ("It's been a while...about 2 years I guess.") were still familiar with the procedure.

However, two respondents did have difficulty with this question because they weren't familiar with the procedure. One respondent's first reply was, "I don't even know what that is." This prompted the interviewer to read the definition, but it didn't clarify anything for the respondent. She answered 'no' to the question, assuming that she'd know if she ever had the procedure. However, the next respondent demonstrates that this is not necessarily true. She answered no, but thought about changing her answer to yes upon hearing question 10 ("What is the most important reason you never had the pap?") because this caused her to think more about it. She said, "I feel like I have, but then don't know why I don't know that." She went on to describe a GYN visit she had in order to receive birth control and it sounded like a routine visit that would include a pap, so she likely has had the test.

It is noteworthy that both respondents were in their 20's.

2. At what age did you have your first pap test? (Females 18-30 ONLY)

_____ age in years

FINDINGS: This question was tested on 11 respondents (one by mistake) and did not change between rounds.

Most respondents could remember their age because having the test corresponded to specific events in their life (e.g., going to college for the first time; experiencing abdominal pain). However, one respondent had difficulty remembering ("Can we go for early 20's?") and another wasn't sure because there was a time when she was having many tests run due to some trouble she was having, and couldn't remember if the pap test was part of that sequence or not.

3. When did you have your MOST RECENT Pap test?

_____ (month/day/year)

FINDINGS: This question was tested on 26 respondents and did not change between rounds.

Memory issues were demonstrated in 20 cases. As with other questions asking about the date of specific tests, some respondents could only remember the year, some could narrow it down to the month, and some couldn't provide any date without follow-up probing during the interview.

4. Did you get the results of your MOST RECENT Pap test?

Yes

No

Only notified if there was a problem

FINDINGS: This question was tested on 26 respondents and did not change between rounds.

This question was not a problem for most respondents. Many said they received their results through the mail, but just as many received them verbally.

Only one problem occurred in relation to the response options. One respondent answered 'yes', but during probing explained that if something were wrong, they would contact her. The last option was the best choice, but in her mind the answer was yes because not hearing anything conveyed a clear message about her test results.

5. Have you had a Pap test in the LAST 3 YEARS where the results were NOT normal?

Yes

No [go to question 11]

FINDINGS: This question was tested on 26 respondents and did not change between rounds.

Problems were detected in 5 interviews. One respondent telescoped and included results she received more than 3 years ago.

In 2 cases the definition of "not normal" was up for debate. For example, one respondent who was diagnosed with HPV has paps that always come back positive for the virus – for her this has become normal. Another respondent said she had a test that was not conclusive – it was not "not normal", they just didn't take an adequate sample of cells and wanted her to complete another test.

Another respondent was tripped up by the double negative. Initially confused, she answered "they were normal" to the survey question. No response error resulted, but it did cause some confusion for the respondent.

Finally, one respondent found this to be a double barreled question. Her reaction to the question was, "No, 'cause I didn't have one." It's been longer than 3 years since she had her last pap. In this case, 'no' meant that she hasn't had a pap at all in the last 3 years.

6. Because of these results, was it recommended that you have more follow-up exams or tests?

Yes

No [go to question 9]

FINDINGS: This question was tested on 11 respondents and did not change between rounds.

Three issues were found. In two cases, respondents answered for treatment they received as a result of the abnormal pap (prescription medication & cryo therapy), not for any additional tests. These are probably false positives. Another respondent failed to report blood work that was ordered following the abnormal pap. In her mind the question was asking if additional paps were taken.

7. Did you follow the recommendation to have more follow-up exams or tests?

Yes [go to question 9]

No

FINDINGS: This question was tested on 10 respondents (should be 11, but one was skipped out by mistake) and did not change between rounds.

The only 2 problems detected were with the 2 respondents who were thinking of treatments, not tests, in the previous question.

8. What is the most important reason that you DID NOT follow the recommendation to have more follow-up exams or tests?

No reason/never thought about it

Put it off/didn't get around to it

Too expensive/no insurance/cost

Too painful, unpleasant, or embarrassing

Had hysterectomy

Don't have doctor

Fear

Other

[go to question 11]

FINDINGS: This question was tested on 1 respondent and was changed between rounds. Round 2 used a yes/no format for each reason.

The categories didn't fit well for the respondent tested in round 1. Her answer was, "I didn't think it was serious." It was hard for the interviewer to decide which option was closest to this response. This was generally a problem with this type of question. Administration is difficult because it's often difficult to match what the respondent says to the response options.

ROUND 2 QUESTION:

8. Are any of the following statements reasons why you DID NOT follow the recommendation to have more follow-up exams or tests? Please answer yes or no to each.

8a. No reason, I never thought about it

Yes

No

8b. I was too busy

Yes

No

8c. It's too expensive

Yes

No

8d. It's too painful, unpleasant, or embarrassing

Yes

No

8e. I've had a hysterectomy

Yes

No
8f. I don't have a doctor

Yes

No

8g. I was afraid

Yes

No

8h. Other _____

FINDINGS: This question was unable to be tested – all respondent skipped because they followed recommendations.

9. Because of these follow-up exams or tests did you have surgery or other treatment?

Yes [go to question 12]

No [go to question 12]

FINDINGS: This question was tested on 9 respondents and did not change between rounds.

Issues were identified in only 2 interviews. Both respondents had been thinking about treatment, even though the previous questions were about further tests. As a result, they were a bit confused by being asked what was, in their minds, the same question. One respondent asked, "When you say 'treatment' do you mean some type of antibiotic or something like that?" However, no response error resulted and they answered yes to this question.

10. What is the most important reason you have [Fill1: NEVER had a Pap test/NOT had a Pap test in the LAST 3 YEARS]?

No reason/never thought about it

Didn't need it/didn't know I needed this type of test

Doctor didn't order it/didn't say I needed it

Haven't had any problems

Put it off/didn't get around to it

Too expensive/no insurance/cost

Too painful, unpleasant, or embarrassing

Had hysterectomy

Don't have doctor

Had an HPV DNA test

Had HPV vaccine

Other

FINDINGS: This question was tested on 2 respondents and was changed between rounds.

This question caused one respondent to go back and change her answer to question 1 because it made her realize she actually did receive a pap test.

ROUND 2 QUESTIONS:

10. Are any of the following statements reasons why you have [Fill1: NEVER had a Pap test/NOT had a Pap test in the LAST 3 YEARS]? Please answer yes or no to each.

10a. No reason; I never thought about it

Yes

No

10b. I didn't know I needed this type of test

Yes

No

10c. My Doctor didn't order it or say I needed it

Yes

No

10d. I haven't had any problems

Yes

No

10e. I was too busy

Yes

No

10f. It's too expensive

Yes

No

10g. It's too painful, unpleasant, or embarrassing

Yes

No

10h. I've had a hysterectomy

Yes

No

10i. I don't have a doctor

Yes

No

10j. I've had an HPV DNA test

Yes

No

10k. I've had the HPV vaccine

Yes

No

10l. Other _____

FINDINGS: This question was unable to be tested in round 2 (all skipped out).

11. When, if ever, did you last get a reminder from a doctor or other health professional to have a Pap test?

A year ago or less

1-2 years ago

2-3 years ago

3-5 years ago

More than 5 years ago

Never

My doctor recommended that I don't get this test anymore

FINDINGS: This question was tested on 16 respondents and was not changed between rounds.

Two main issues are associated with this question, the response options and the saliency of getting a reminder. Problems were identified in 6 interviews.

For three respondents, getting a reminder from the doctor isn't important to them and has no bearing on whether or not they schedule a pap. One person said, "I don't know...1 to 3 years I guess. I know myself when I need to get one. Yearly. I know this." Someone else comments, "It's always been my own initiative. I don't remember ever getting one." Another person doesn't need a direct reminder, but uses her prescription refill as the cue to schedule her next appointment. She explained, "When I need a prescription I go back." Two chose 'never', the appropriate category, but one respondent who figured she got reminders but doesn't remember them had a difficult time choosing an option.

One respondent had outright response error because she was thinking of the reminders she gets from her dentist when she answered. She does not get them from her GYN.

Finally, the response options were difficult to administer. There were too many and reading them was awkward – respondents often wouldn't listen to all the options. One respondent chose 'more than 5 years' ago when probing later revealed the better answer was 'never.' However, she initially didn't let the interviewer finish reading the options and, therefore, didn't hear that 'never' was an option. The number of response categories should be reduced.

12. Have you had a hysterectomy? A hysterectomy is when the uterus or womb is removed, not just having your tubes tied to prevent pregnancy.

Yes

No

FINDINGS: This question was tested on 27 respondents and was changed between rounds. In round 2 the definition was placed before the question to improve the flow. In round 1 it was awkward to ask a question of the respondent and then proceed to read a definition rather than wait for an answer. No issues arose in round 2.

13. Have you EVER had BOTH ovaries removed, either as part of a hysterectomy or as one or more separate surgeries?

Yes

No [go to question 14]

FINDINGS: This question was tested on 27 respondents and was not changed between rounds. No issues were identified.

13a. How old were you when you had BOTH of your ovaries removed?

_____ age in years

FINDINGS: This question was tested on 2 respondents and was not changed between rounds. There were no recall difficulties, but one respondent remembered only the year in which it was done and wouldn't do the math to determine how old she was at the time. It was left to the interviewer to calculate age.

14. Have you ever heard of HPV? HPV stands for human papillomavirus (pap-uh-LOW-muh-vi-rus).

Yes

No

FINDINGS: This question was tested on 27 respondents and was not changed between rounds.

Respondents who had heard of HPV reported seeing it on commercials, in the newspaper, in class (one was a med student), or in the doctor's office (via literature or posters). One respondent was diagnosed with HPV and that was when she first heard of it.

One error was identified, which relates to the definition of "heard of." One respondent answered 'no' to the question, but said she had seen the acronym but never the full term. She didn't know what it was and only remembers seeing it on a poster at her clinic. She answered 'no' because she knew so little about it, it didn't seem appropriate to answer 'yes'.

15. Do you think HPV can cause cervical cancer?

Yes

No

FINDINGS: This question was tested on 24 respondents and was changed between rounds. In round 2 "To the best of your knowledge" was added to match the form of question 16. Past testing had shown that respondents with little knowledge about HPV were reluctant to express an opinion. "To the best of your knowledge" was meant to convey the idea that it's fine for them to speculate.

In this testing respondents were willing to speculate, even when they had little knowledge about HPV. However, answers tended to be either 'yes' or 'don't know' (only one person answered 'no'). Most who were unsure answered 'yes'. It's impossible to know for certain, but one hypothesis is that if the question is being asked, then it must be true. As one respondent said, "I would assume."

This indicates that there is likely to be little variation in survey responses (most answers are likely to be 'yes') AND that 'don't know' in this case should be treated differently than in most analyses of survey data.

16. To the best of your knowledge, do you think you can get HPV through sexual contact?

Yes

No

FINDINGS: This question was tested on 24 respondents and was not changed between rounds.

Similar issues emerged. Only one respondent answered 'no'. All others answered 'yes' and a few (3) said

'don't know'. As with the previous question, the lack of variation in answers draws into question the utility of this item.

17. A vaccine to prevent HPV infection is available and is called the HPV shot, cervical cancer vaccine, or GARDASIL®. Before this survey, have you ever heard of the HPV shot or cervical cancer vaccine?

Yes

No

FINDINGS: This question was tested on 24 respondents and was not changed between rounds. No issues or errors were identified. Respondents who said they heard of it could give some explanation about what they heard.

18. Have you ever received the HPV shot or cervical cancer vaccine?

Yes

No [go to question 21]

FINDINGS: This question was tested on 21 respondents and was not changed between rounds. No issues or errors were identified.

19. How many HPV shots did you receive?

1

2

3

More than 3

FINDINGS: This question was tested on 5 respondents and was not changed between rounds.

In round 1, one respondent admitted that she couldn't remember the number of shots she received, so answered only 1. This is likely response error because she was confident that she received the proper dosage as she always follows doctors orders.

20. Have you finished the series of HPV shots that was recommended by your doctor?

Yes

No

[go to next section]

FINDINGS: This question was tested on 4 respondents and was changed in round 2 to read "Have you finished the series of 3 HPV shots?"

One respondent in round 1 said yes (even though she reported getting only 1 shot). However, the wording change in round 2 was unable to be tested. All skipped out.

21. Would you be interested in getting the HPV vaccine?

Yes [go to next section]

No [go to question 22]

FINDINGS: This question was tested on 18 respondents and was not changed between rounds.

The hypothetical nature of this question caused difficulty for some respondents. Five had trouble because their answer was conditional on information they don't have or on factors that might change. One person said, "I gotta figure out what it is first. I don't take nothing I don't know what it is." Another person said, "It depends on where the shot is", and someone else said she would need to know more about the risks. One respondent shows her confusion by saying, "Yes, but it's too expensive, so I wouldn't", which is essentially an answer of 'yes' AND 'no'.

A hypothetical question typically invokes the need for respondents to have specific information that must be accounted for before they can answer yes or no. As a result, 'don't know' responses may be high for this question at best. At worst, it's impossible to know exactly what a response of 'yes' or 'no' means. Meaning varies from person to person to the extent that different parameters or conditions are set up around the question. One person may take factors into account that are ignored by another person. Essentially, then, respondents end up answering different questions in their own minds. As a result, question validity and reliability are low. The survey format may not be the best one for hypothetical questions.

22. What is the MAIN reason you would NOT want to get the vaccine?

Does not need vaccine

Not sexually active

Too expensive

Too old for vaccine

Doctor didn't recommend it

Worried about safety of vaccine

Don't know where to get vaccine

My spouse/family member is against it

Don't know enough about vaccine

Already have HPV

Other

FINDINGS: This question was tested on 7 respondents and was changed between rounds. In round 2 it was written in a yes/no format.

In round 1, five respondents found it difficult to choose an answer. The answers they gave didn't exactly fit the responses and it was too cumbersome to read all the options. As a result, it was decided to test the yes/no format.

ROUND 2 QUESTION:

22. Are any of the following statements reasons why you are not interested in getting the vaccine? Please answer yes or no to each.

22a. I don't need it

Yes

No
22b. I'm not sexually active
Yes
No
22c. The vaccine is too expensive
Yes
No
22d. I'm too old to get the vaccine
Yes
No
22e. My doctor didn't recommend it
Yes
No
22f. I'm worried about the safety of the vaccine
Yes
No
22g. I don't know enough about the vaccine
Yes
No

FINDINGS: This question was tested on 5 respondents in round 2. Problems were found with 3 and all were due to the cognitive task of this format.

Respondents who had trouble either couldn't keep the stem question in mind and/or had problems with the double negative. Others would agree with statements that would not have been mentioned by them otherwise, that is, they would satisfice as long as the premise of the statement was reasonable.

For example, to "my doctor didn't recommend it", one respondent answered "No, he didn't." The double negative was difficult for her to work with. One respondent answered 'no' to I'm not sexually active, but later says that she IS sexually active. Clearly the double negative was a problem. In a similar fashion, another respondent answered 'no' to "I'm not sexually active". She had to think about it for a minute and said that she IS sexually active. Not only did the double negative confuse her, she's answering a different question. Her answer of 'no' means that she's sexually active, it has nothing to do with getting or not getting the vaccine. Similarly, another person answered yes to that question because she is NOT sexually active – it does NOT mean this is a reason why she wouldn't get the vaccine. Another respondent answered 'don't know' to "The vaccine is too expensive", saying "I don't know what it costs so I can't answer." It was easy for respondents to lose sight of the stem question and answer each sub-question as though it were a stand-alone question.

Another respondent, who knew nothing about HPV or the vaccine shifted her interpretations in order to make more sense of the questions. She answered 'no' to "my doctor didn't recommend it", saying, "If you need it, you don't need his recommendation." She went on to explain that she would not let this be the criteria for receiving ANY treatment. For her this was not a question about the HPV vaccine, it was a question about how she approaches her health care in general. Another respondent took a different path in questions that asked something about which she knew so little. She simply agreed with the statements. For example, to "I don't need it" she said "that's true." In earlier narrative it was clear she had thought so little about this topic that the questions forced a reality that wasn't there. She didn't know what HPV was and didn't know about the vaccine. In her words, "If it happens to you, you think about it. If it doesn't,

you don't."

See analysis highlight for more on this topic.

22aa. Which of these is the MAIN reason you are not interested in getting the vaccine?" [Choose from options picked in 22a-g.]

FINDINGS: This question was tested on 5 respondents and was new in round 2.

Interestingly, no issues were found with this question. The option respondents chose here was a decent representation of why they wouldn't get the vaccine (3 said 'don't know enough' and 2 said worried about safety). This is because the previous series of questions was not, in their minds, linked to this question, even though it's structurally designed to be.

Breast Cancer Screening

[Ask women 40 and over]

1. Have you EVER HAD a mammogram? *Read if necessary. A mammogram is an x-ray taken only of the breast by a machine that presses against the breast.

Yes

No [go to question 8]

FINDINGS: This question was tested on 17 respondents and did not change between rounds.

No issues were apparent with this question. All women seemed to be familiar with the test and know whether or not they had one.

1a. When did you have your MOST RECENT mammogram?

_____ (month/day/year)

FINDINGS: This question was tested on 17 respondents and did not change between rounds.

Recall issues were the same here as they were for other questions that ask about dates of tests or procedures. Recalling month is the best most respondents can do (only 2 could come up with a day), and even then it's usually an estimate. Some respondents can only provide a year.

2. After your MOST RECENT mammogram, was it recommended that you have more tests? *Read if necessary: More tests may include another mammogram, a sonogram or ultrasound, an MRI, a biopsy, or something else to check for problems in your breasts.

Yes

No [go to question 9]

FINDINGS: This question was tested on 17 respondents and did not change between rounds.

No issues were apparent with this question. However, note that the 'read if necessary' instruction was

never read – no one asked for clarification.

3. Did you follow the recommendation to have more tests?

Yes [go to question 5]

No

FINDINGS: This question was tested on 6 respondents and did not change between rounds.

No issues were found. Examples of further tests included sonograms, another mammogram, and breast MRI.

4. What is the most important reason why you DID NOT follow the recommendation to have more tests?

No reason/never thought about it

Put it off/Didn't get around to it

Too expensive/no insurance/cost

Too painful, unpleasant or embarrassing

I'm too young

Don't have doctor

Fear

Other

FINDINGS: This question was not tested in round 1. All skipped out. It was changed in round 2 to the yes/no format

ROUND 2 QUESTION:

4. Are any of the following statements reasons why you DID NOT follow the recommendation to have more tests? Please answer yes or no to each.

4a. No reason; I never thought about it

Yes

No

4b. I was too busy

Yes

No

4c. It's too expensive

Yes

No

4d. It's too painful, unpleasant or embarrassing

Yes

No

4e. I'm too young

Yes

No

4f. I don't have doctor

Yes

No

4g. I'm afraid

Yes

No
4h. Other _____

FINDINGS: This question was not tested in round 1. All skipped out.

5. As a result of these additional tests after your [fill1: mammogram/mammograms] were you diagnosed with cancer?

Yes

No [go to question 7]

FINDINGS: This question was tested on 6 respondents. It did not change between rounds. No issues or error were detected.

6. How was your breast cancer found?

Found by myself by accident

Found by myself during a self breast examination

Found by my spouse or partner

Found by a physician during routine breast exam

Found by a mammogram

Found by Magnetic Resonance Imaging (MRI)

Other – specify

FINDINGS: This question was not tested. All skipped out. It did not change between rounds.

7. Have you EVER HAD a biopsy to test or remove a lump in your breast that was found NOT to be cancer?

*Read if necessary: A biopsy is the removal of a sample of tissue to see whether cancer cells are present.

Yes [go to question 9]

No [go to question 9]

Lump removed was cancerous [go to question 9]

FINDINGS: This question was tested on 6 respondents. It did not change between rounds. No issues or error were detected.

8. What is the most important reason why you have [fill1: NEVER had a mammogram/NOT had a mammogram in the PAST 2 YEARS]?

No reason/never thought about it

Didn't need it/didn't know I needed this type of test

Doctor didn't order it/didn't say I needed it

Haven't had any problems

Put it off/Didn't get around to it

Too expensive/no insurance/cost

Too painful, unpleasant or embarrassing

I'm too young

Don't have doctor

Other

FINDINGS: This question was not tested in round 1. All skipped out. It changed in round 2 to the yes/no

format.

ROUND 2 QUESTION:

8. Are any of the following statements reasons why you have [fill1: NEVER had a mammogram/NOT had a mammogram in the PAST 2 YEARS]? Please answer yes or no to each.

8a. No reason; I never thought about it

Yes

No

8b. I didn't know I needed this type of test

Yes

No

8c. My doctor didn't order it or say I needed it

Yes

No

8d. I haven't had any problems

Yes

No

8e. I was too busy

Yes

No

8f. It was too expensive

Yes

No

8g. It's too painful, unpleasant or embarrassing

Yes

No

8h. I'm too young

Yes

No

8i. I don't have a doctor

Yes

No

8j. Other _____

FINDINGS: This question was not tested in round 2. All skipped out.

9. A breast MRI, or magnetic resonance image, shows what is inside the breast, like a mammogram, but does not require squeezing the breast. Before getting a breast MRI, you are given a dye through a needle in the arm. During the test, your lie on your stomach and the bed moves into a tunnel-shaped machine.

Have you EVER HAD a breast MRI?

Yes

No [go to next section]

FINDINGS: This question was tested on 16 respondents. It did not change between rounds.

Only one reported having had this test, but another respondent wasn't sure. She answered 'no' but said it may have been the follow-up procedure that was done because the film from her regular mammogram wasn't clear. Most respondents were unfamiliar with this test.

9a. When did you have your MOST RECENT breast MRI?

_____ (month/day/year)

FINDINGS: This question was tested on 1 respondent. It did not change between rounds.

The respondent could only remember the year (saying it was "about 2 years ago").

10. What was the MAIN reason you had this breast MRI?

Follow-up of an abnormal mammogram

Because of a breast problem

My healthcare provider told me I was high-risk

Family history of breast cancer

Part of a routine exam

I requested it

FINDINGS: This question was tested on 1 respondent. It changed in round 2 because the options were too lengthy and difficult to administer.

ROUND 2 QUESTION:

10. What was the MAIN reason you had this breast MRI? Was it part of a routine exam, because of a problem, or some other reason?

FINDINGS: This question was tested on 1 respondent, and the options were still hard to code. The respondent changed her answer from 'some other reason' to 'because of a problem' during probing. The respondent couldn't explain why she initially chose 'some other reason,' but it's likely because the reason she had in her mind wasn't on the list. Upon talking about the question in depth she was able to choose a more fitting option.

PSA

[Ask Men 40 and over]

1. Have you ever had a PSA test?

Yes

No [go to question 3]

FINDINGS: This question was tested on 12 respondents and was changed between rounds.

Eights respondents were tested in round 1, and three didn't know what a PSA test was. As one respondent said, "What does that PSA stand for? Post something? I can't answer because I'm not sure what it is." A short definition was added for the second round.

ROUND 2 QUESTION:

1. A PSA test is a blood test to detect prostate cancer. It is also called a prostate-specific antigen test. Have you ever had a PSA test?

Yes

No [go to question 4]

FINDINGS: This question was tested on 4 respondents. The definition helped, but one person was not sure if he'd had this test because many tests have been done as part of a study he's involved with.

1a. When did you have your most recent PSA test?

_____ (month/day/year)

FINDINGS: This question was tested on 5 respondents. It did not change between rounds.

As with other questions about test/procedure dates, recall was an issue here. A month and year was the best all could do, and four of those were estimates.

2. What was the MAIN reason you had this PSA test - was it part of a routine exam, because of a problem, or some other reason?

Part of a routine exam [go to question 5]

Because of a problem [go to question 5]

Other reason [go to question 5]

FINDINGS: This question was tested on 5 respondents. It did not change between rounds.

The options didn't fit well for three respondents. For 2 this was because they've had prostate cancer and the question seems to assume you haven't. In other words, is it part of a "routine" exam if you've had cancer? Both respondents gave this answer, even though they get the test done twice a year. For them this is routine, but it is NOT routine for most people.

3. What is the MAIN reason you have not had a PSA test?

I haven't had time for it

My doctor advised me not to have it

I can't afford it

I've read or heard conflicting recommendations about it

I don't think it would help me

I don't know enough about it

FINDINGS: This question was tested on 1 respondent (it should have been two, but was skipped by mistake). It was deleted in round 2.

For this respondent the categories didn't fit well. He said, "Maybe I was too scared. I'm being honest. It depends after you explain it and let know what it was. I know that after 40 men are supposed to get checked for prostate – especially black men." The interviewer did know which option to pick.

4. Are any of the following statements reasons why you have not had a PSA test?

a. I haven't had time for it

Yes

No

b. My doctor advised me not to have it

Yes

No

c. I can't afford it

Yes

No

d. I've read or heard conflicting recommendations about it

Yes

No

e. I don't think it would help me

Yes

No

f. I don't know enough about it

Yes

No

FINDINGS: This question was tested on 5 respondents. It did not change between rounds.

Much like other questions of this nature, one respondent lost sight of the stem question and answered the sub-questions as stand-alone questions. Another respondent tended to agree with statements that he wouldn't have suggested himself. Another respondent felt as though the questions didn't really apply. He is poor, lives in a shelter, and gets his health care from the local ER. When he sees a doctor it's for a specific and usually serious problem or symptom he's having. There are never any discussions about preventative or routine care. He answered 'yes' to many of these questions, but they didn't really apply – he doesn't think about this type of health care and it's not part of his personal experience.

5. [Before you had the PSA test] did a doctor EVER talk with you about the advantages and disadvantages of [it] / the PSA test?

Yes

No

FINDINGS: This question was tested on 5 respondents and changed in round 2.

This was split into 2 questions in round 2 because respondents didn't think of both advantages and disadvantages but still answered 'yes' to the question.

ROUND 2 QUESTIONS:

5. [Before you had the PSA test] did a doctor EVER talk with you about the advantages of [it] / the PSA test?

Yes

No

5a . [Before you had the PSA test] did a doctor EVER talk with you about the disadvantages of [it] / the PSA test?

Yes
No

FINDINGS: This question was tested on 1 respondent in round 2 (3 were skipped by mistake). The one person who was tested is poor, lives in a shelter, and gets his health care from the local ER. When he sees a doctor it's for a specific and usually serious problem or symptom he's having. There are never any discussion about preventative or routine care. There was no response error here, but the question assumes respondents receive preventative care.

6. {{Before you had the PSA test}} did a doctor EVER tell you that some doctors recommend {{it}} / the PSA test and others do not?

Yes [go to next section]

No [go to next section]

FINDINGS: This question was tested on 5 respondents and changed in round 2. One person had an interpretation issue. He was thinking of variations in *when* (at what age) the doctor recommends the test, not *whether* the doctor recommends it.

ROUND 2 QUESTION:

6. {Before you had the PSA test} did a doctor ever tell you that experts disagree about whether men should have PSA tests?

Yes

No

FINDINGS: This question was tested on 1 respondent in round 2 (3 were skipped by mistake). The one person who was tested is poor, lives in a shelter, and gets his health care from the local ER. When he sees a doctor it's for a specific and usually serious problem or symptom he's having. There are never any discussion about preventative or routine care. There was no response error here, but the question assumes respondents receive preventative care.

Colorectal Cancer Screening

[Ask men and women 40 and over]

1. Sigmoidoscopy and colonoscopy are exams in which a doctor inserts a tube into the rectum to look for polyps or cancer. For a sigmoidoscopy, the doctor checks only part of the colon and you are fully awake. For a colonoscopy, the doctor checks the entire colon, and you are given medication through a needle in your arm to make you sleepy, and told to have someone drive you home.

*If needed: A polyp is a small growth that develops on the inside of the colon or rectum

*If needed: Before these tests, you are asked to take a medication that causes diarrhea

Have you EVER HAD a sigmoidoscopy?

Yes

No

FINDINGS: This question was tested on 29 respondents and did not change between rounds.

Issues were detected in 5 interviews and had to do with confusion over the test. Respondents were sometimes uncertain about the exact test they had, even if they knew generally that it was to check for

colorectal problems. Respondents were more like to have heard of and be familiar with the colonoscopy than the sigmoidoscopy. For example, one respondent answered 'yes' claiming he's "had all the tests" and has to have "the colon thing" every 5 years now that he's 69. He described his colonoscopy in detail, but it's less clear that he's had the sigmoidoscopy. Similarly, another respondent may have given a false positive because everything he described having was consistent with a colonoscopy, not sigmoidoscopy.

2. Recall that a colonoscopy is similar to a sigmoidoscopy but the doctor checks the entire colon, and you are given medication through a needle in your arm to make you sleepy, and told to have someone drive you home.

Have you ever had a colonoscopy?

Yes

No

FINDINGS: This question was tested on 29 respondents. In round 2 this was shortened to "Have you ever had a colonoscopy?"

Only 2 respondents seemed to demonstrate any confusion over the colonoscopy test. These respondents were, in general, confused over the exact tests they received, so any further definitions wouldn't help. Sometimes people don't know, but answer yes or no anyway.

3. Virtual colonoscopy, also known as CT colonography, is a new type of test that looks for polyps or cancer in the colon. The day before the test, you take laxatives to clean out your colon. During the test, your colon is filled with air and you are moved through a donut-shaped X-ray machine as you lie on your back and then on your stomach. You do not need medication to make you sleepy during this test.

*If needed: This test is not the same as a colonoscopy or a sigmoidoscopy.

*If needed: A polyp is a small growth that develops on the inside of the colon or rectum

Before today, HAD YOU EVER HEARD of virtual colonoscopy or CT colonography?

Yes

No

FINDINGS: This question was tested on 16 respondents in round 1. The wording was slightly modified in round 2 to try to clarify the procedure and differentiate it from a regular colonoscopy. 2 false positives were likely in round 1 due to confusion over the two procedures and respondents thinking they were the same thing or confusing one with the other.

ROUND 2 QUESTION:

3. CT colonography is a new type of test that looks for cancer in the colon. During the test, your colon is filled with air and you are moved through a donut-shaped X-ray machine as you lie on your back and then stomach. Unlike regular colonoscopies, you do not need medication to make you sleepy during this test, but you DO take laxatives to clean out your colon.

*if needed: This is also called virtual colonoscopy

*if needed: This is not same as colonoscopy or sigmoidoscopy

Before today, HAD YOU EVER HEARD of CT colonography?

Yes

No

FINDINGS: This question was tested on 13 respondents in round 2.

One respondent wasn't sure about the test but answered yes anyway. Even though she didn't know exactly what the procedure was she said, "it probably deals with the same thing" as the other two tests and that "everyone's had them these days."

4. Have you EVER HAD a virtual colonoscopy or CT colonography?

Yes

No [go to question 6]

FINDINGS: This question was tested on 29 respondents. It did not change between rounds.

It was unclear if error occurred for 2 respondents who answered 'yes'. One person said he had both a colonoscopy and virtual colonoscopy in 1998, but the virtual version probably wasn't available back then. Similarly another respondent's description of the procedure didn't quite match up to the description in the question. Some people simply don't have the knowledge necessary to answer these questions accurately.

4a.. When did you have your MOST RECENT virtual colonoscopy or CT colonography?

_____ (month/day/year)

FINDINGS: This question was tested on 4 respondents and underwent a minor wording change. In round two it read, "When did you have your most recently CT colonography?"

Two respondents could give a month and year, and two could give only the year. No one could remember a day.

5. What was the MAIN reason you had this virtual colonoscopy or CT colonography - was it part of a routine exam, because of a problem, as a follow-up test of an earlier test or screening exam, or some other reason?

Part of a routine exam

Because of a problem

Follow-up test to an earlier test or screening exam

Other reason

FINDINGS: This question was tested on 4 respondents.

A possible error arose in one interview. The respondent chose 'part of routine exam'. At first he said the doctor recommended it because of age. But then he talked about how this test was ordered because the regular colonoscopy failed – the doctor couldn't see as far as he wanted to. This suggests that another option may have been better.

6. During the past 10 years did a doctor tell you that you had a polyp in your colon or rectum?

*If needed: A polyp is a small growth that develops on the inside of the colon or rectum

Yes

No

FINDINGS: This question was tested on 28 respondents. It did not change between rounds.

Three respondents were unsure what a polyp was. Two asked for a definition and the 'if needed' sentence clarified it. Another respondent wasn't sure about the polyp, even after the definition was read. This was because she wasn't sure what her actual diagnosis was.

7. The following questions are about the blood stool or occult blood test, a test to determine whether you have blood in your stool or bowel movement. The blood stool test can be done at home using a kit. You use a stick or brush to obtain a small amount of stool at home and send it back to the doctor or lab.

Have you EVER HAD a blood stool test, using a HOME test kit?

Yes

No [go to question 10]

FINDINGS: This question was tested on 29 respondents. It did not change between rounds.

Most respondents had no trouble answering this question. Only one had a problem recalling if he had this done because he was part of a study where many tests were run. He came back and changed this answer (from no to yes) when he got to question 10, but it's impossible to say which response was correct.

8. Have you had a HOME blood stool test in the LAST 3 YEARS where the results were NOT normal?

Yes

No [go to question 10]

FINDINGS: This question was tested on 19 respondents. It did not change between rounds.

Issues were found similar to those in the pap section. For 3 respondents this was a double barreled question because they had not had this test in the past 3 years. Also, 2 people struggled with the double negative. One person replied, "Not normal? No...they were normal." Another issue was in defining "not normal." One person was thinking that her test was negative and did negative mean "not normal?" Finally, one person responded in error because she was thinking of the results of a different test. The FOBT test came back normal, but because she was still having bleeding she requested a colonoscopy, which showed that she had polyps. It was the colonoscopy that came back abnormal, not the FOBT, but she reports yes because both tests were done in relation to the same problem. The symptom became the unit of analysis, not the test.

9. Because of these results, what additional tests or surgery did you have?

None

Another Fecal Occult Blood Test

Sigmoidoscopy

Colonoscopy

Barium enema

Surgery

FINDINGS: This question was tested on 1 respondent. It did not change between rounds.

This respondent demonstrated error because she was thinking of the problem, not the test. See previous question.

10. Have you EVER been given a HOME blood stool test kit that you did not complete and return to the doctor or laboratory?

Yes

No

FINDINGS: This question was tested on 28 respondents. It did not change between rounds.

Only one problem was detected. One respondent replied, "never had one." The answer was 'no', but the question was double barreled.

11. *(For respondents who had not had colonoscopy in the past 10 years, sigmoidoscopy in the past 5 years, CT colonography in the past 5 years, or FOBT in the last year)*

In the PAST 12 MONTHS, did a doctor or other health professional RECOMMEND that you be tested to look for problems in your colon or rectum?

Yes

No [go to question 14]

FINDINGS: This question was tested on 20 respondents. It did not change between rounds.

Only two issues were found. One respondent said 'no' then 'yes' during probing. Initially she was thinking only of more invasive tests like the colonoscopy, but later realized she should include the FOBT. Another respondent was confused about the purpose of the test. He said, "It's been recommended, but not because of problems. It's been recommended as routine so that if you're between the ages of 50 and 60 you should have a colonoscopy."

12. Did the doctor or other health professional recommend to you any particular tests?

Yes

No [go to question 14]

FINDINGS: This question was tested on 2 respondents. It did not change between rounds.

No issues or problems were found.

13. Which tests to check for colon cancer did the doctor or other health professional recommend to you?
Possible tests include stool blood or fecal occult blood test; sigmoidoscopy; colonoscopy; CT colonography or virtual colonoscopy; or other. [CODE ALL THAT APPLY]

Stool blood test/fecal occult blood test [go to next section]

Sigmoidoscopy [go to next section]

Colonoscopy [got to next section]

CT colonography/virtual colonoscopy [go to next section]

Other [go to next section]

FINDINGS: This question was tested on 2 respondents. It did not change between rounds.

One respondent discussed both sigmoidoscopy and colonoscopy with her doctor, but they decided to do the colonoscopy and that's what she reported. It's unclear whether the question should have captured the sigmoidoscopy as well. The next respondent chose 'other' saying it was "just a physical exam." This doesn't seem to match the question intent either.

14. *(For respondents who had not had colonoscopy in the past 10 years, sigmoidoscopy in the past 5 years, CT colonography in the past 5 years, or FOBT in the last year)*

What is the most important reason you have [fill1: NEVER had any kind of test to look for problems in your colon or rectum // NOT had any kind of test to look for problems in your colon or rectum RECENTLY]?

No reason / never thought about it

Didn't need it / Didn't know I needed this type of test

Doctor didn't order it / didn't say I needed it

Haven't had any problems

Put it off / Didn't get around to it

Too expensive / No insurance/Cost

Too painful, unpleasant, or embarrassing

Had another type of colorectal exam

Don't have doctor

Other

FINDINGS: This question was tested on 10 respondents. It was deleted in round 2 in favor of the yes/no format.

Issues were found in 5 interviews in round 1. All problems manifested in coding difficulties. Respondent's answers didn't match the categories closely enough to make one category the obvious choice. As a result, it took some work on the part of the interviewer (and respondent) to arrive at a satisfactory option. For example, one respondent gave several different answers as the 'main' reason. First she said "there were no abnormalities." Not sure what option to pick, the interviewer read some of the categories to the respondent who chose 'Dr. didn't say I needed it' and added "I guess I'll go with that one." Later during probing she explained that she hasn't had any of these tests because she "just hasn't said anything to the doctor about it." In another case, the respondent replied, "I would say at this point it's avoidance – the old 'if it ain't broke, don't fix it.' Males are not particularly fond of doctors." Again unsure of which category to choose, the interviewer read the options. The respondent chose 'haven't had any problems' but also thought about 'didn't need it.'

These are good illustrations of how difficult it can be to choose a meaningful category in an interview

setting. Part of the problem stems from the format of the question. It's not easy to match respondents' words to preconceived categories. The categories are essentially manufactured reasons which frequently don't neatly fit into people's experiences. But equally important is the task of asking why a respondent hasn't done something. Causal survey questions (i.e., questions that ask respondents for the reasons behind their behavior) in general don't perform well on surveys. Causal questions in the *negative* add an extra burden and are even less likely to carry much validity or reliability.

15. Are any of the following statements reasons why you have [never had any kind of test to look for problems in your colon or rectum//not had any kind of test recently]?

a. I haven't had time for it

Yes

No

b. My doctor didn't order it/say I needed it

Yes

No

c. I didn't think that I needed it/know I needed this type of test

Yes

No

d. I can't afford it/my insurance doesn't cover it

Yes

No

e. Testing is too painful, unpleasant, or embarrassing

Yes

No

f. I don't know enough about it

Yes

No

FINDINGS: This question was tested on 17 respondents and had a minor wording change in round 2 to try to clarify the cognitive task of choosing yes or no. In the second round it read, "Which of the following are reasons why you have [fill1: NEVER had any kind of test to look for problems in your colon or rectum // NOT had any kind of test to look for problems in your colon or rectum RECENTLY]? Please answer yes or no to each." This wording change had no discernable effect on interpretation, as similar problems were found in both rounds.

Complex cognitive task: Problems were identified in at least 7 interviews. The cognitive task of keeping the stem question in mind, assessing causality, and translating the double negative was too difficult for some respondents. For example, after the first question (14a) one respondents said, "What type of test?" In this case and one other, the interviewer didn't finish the series because the difficulty, combined with the repetitiveness of the task seemed too harassing.

Double negative: The double negative caused problems for some respondents. Upon hearing 'my doctor didn't order it', one respondent didn't answer yes or no but instead said, "it hasn't been ordered." Another person said, "He did order it." Two other respondents dealt with the double negative by replying true or false instead of yes/no.

False assumptions: Sometimes the statements carried false assumptions. For one person the doctor

recommended it, but didn't order it. The respondent decided to say 'no' because the doctor didn't literally order it. Also note that the respondent is evaluating this statement independent from the stem question. Similarly another respondent said, "He did order it." Her answer of 'no' means that he did order the test (she hasn't had it yet but plans to) – it is *not* a reason why she hasn't had it. She clearly lost sight of the original stem question.

Forgetting the stem question: As some of the previous examples suggest, respondents often forgot the stem question and evaluated the statements as stand-alone questions. This was obvious in 14d (too expensive/insurance doesn't cover). Two respondents didn't answer because they didn't know if their insurance covered it or because they didn't know how much it costs. For 14e (testing too painful) one respondent said, "I don't know because I never had it. But I have heard people say it doesn't hurt [because they were asleep]". Someone else stated, "I've never had it done, so I can't answer that question." Both are clearly evaluating this statement by itself and not in relation to why they haven't had the test.

Satisficing: Relatedly, in evaluating the individual statements some respondents said 'yes' to statements simply because they made sense, not because they were reason for not getting the tests. For 14e (testing is too painful) one respondent answered 'yes' and said, "I would assume so, so those are things I would consider." Someone else simply said "okay" to this statement. In neither case was this a reason for not getting the test, but because the statement made sense to the respondent, they answered 'yes.'

Causality: Overall, many complex and interrelated problems were demonstrated with this question. While some problems were a function of the format of the question, the fundamental issue lies in the difficulty of asking people to assess and report the reasons for their behavior. In reality, many people do not know why they behave certain ways (or in this case, why they do NOT behave certain ways). Survey questions that ask respondents for information they don't have are destined to fail. Respondents may answer the questions, but the validity and reliability of data will be extremely poor.

14aa. Which of these is the MAIN reason you {NEVER had any kind of test to look for problems in your colon or rectum// NOT had any kind of test to look for problems in your colon or rectum RECENTLY?}? [choose from response options picked in 14a-e.]

FINDINGS: This question was tested on 4 respondents. It was new to round 2.

This question was most problematic for one respondent who couldn't answer because she *does* plan on getting the test. Her doctor recently suggested she get a colonoscopy because she's 49. For her, the question carried a false assumption that because she hasn't had the test yet, she doesn't plan on getting it.

The other three respondents chose an answer fairly easily, despite the difficulties described for the previous series. It seems this question was disassociated from the previous question in the minds of the respondents. This makes sense, considering many lost sight of the stem question in the previous question (which is the common link between that one and this one).

Survivorship

[Ask all]

1.1 Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?

Yes

No [END INTERVIEW]

FINDINGS: This question was tested on all respondents and did not change between rounds.

Three respondents were unsure what exactly counts as cancer. One respondent probably gave a false positive. She has had moles removed on several occasions that she said were “suspicious.” The biopsy showed that they were not cancerous but that they would become so if she ignored them. Her doctor described them as ‘precancerous’ and this description motivated her confusion over how to answer. She didn’t know if precancerous cells would be considered a malignancy. She would have answered ‘no’ if the word malignancy was not in the question. The word ‘malignancy’ confused another respondent who wasn’t sure about its definition. She has a brain tumor that she says is benign. She’s been managing it with medication since 1998, but she’s not sure if the pills would be classified as chemotherapy or not. To her, malignancy is “the aggressive ability to exceed a localized area” so she answered no to this question, but wasn’t sure if she should answer yes – some cancers don’t spread and maybe that’s what she has. Another respondent had similar confusion over precancerous cells that were found from a pap test. She was diagnosed as having dysplasia, but she chose to answer no because she didn’t have cancer, per se.

It seems clear that people with a certain type of experience with cancer aren’t completely clear about the difference between or definition of ‘cancer’ vs. ‘malignancy’. These are people who have been told what they had was ‘precancerous’.

Finally, a fourth respondent wasn’t explicitly told he has cancer (“No, not in those words”), but he’s not convinced the doctors have explained the situation to him in full. Because he doesn’t know exactly what his problem is, he’s worried it might be cancer and is currently seeking a third opinion.

1. In general, would you say your quality of life is:.....

1 Excellent

2 Very good

3 Good

4 Fair

5 Poor

FINDINGS: This question was tested on 22 respondents and did not change between rounds. However, the series up through question 9 was asked only of cancer survivors in round 1. In round 2 this set of questions was asked of everyone just prior to the questions on cancer. Because of time limitations, not all respondents were directly probed on this set of questions. Since the majority of these are essentially attitude questions, no response error was found.

People answered this question on the basis of several different criteria, including physical health, life problems, career success, and spiritual wellbeing.

Five respondents thought of physical health when answering this question. A couple cancer survivors

considered the fact that they are still alive. One respondent fighting cancer thought about answering poor but decided on fair. He said, "I wanted to say the worst one, but I'm not in the grave yet." In contrast, another cancer survivor answered 'very good' because "I'm still alive. I'm still functioning. All my parts are working so that is very good." However, this interpretation wasn't just among cancer survivors. For example, one respondent who never had cancer answered 'excellent' because "I'm healthy. I'm living. I'm still here." A couple others said they were thinking about general health when answering this question.

Other respondents thought of life problems overall when answering this question. One person answered 'good' because she has "ups and downs." Another person was thinking of his marital problems, legal problems and job problems. One respondent was homeless, and another was thinking of her financial situation and how she is able to deal with life on the whole.

Some respondents thought specifically of career success. One respondent answer 'fair' because he has two degrees and is still only working part time. A second respondent answered 'very good'. Even though she admitted that she's "stumbled" and "made some bad decisions", on the whole she is pleased with the goals she has set and achieved for herself. Another respondent took the opposite view. She was recently laid off from her job and described it as the best thing that could have happened because it was killing her. She answered 'excellent' as a result.

Finally, a couple respondent thought of spirituality. One person answered 'good' because he's active in his church and generally had a positive person as a result. Sometimes he isn't able to get the things that he wants, but he's thankful for what he has. Another respondent said a few years ago the answer would have been 'poor' but now it's 'very good' because she's invited Christ into her life. Similar to the previous respondent, she said that God makes her more content with what she has. Things aren't perfect (that's why she didn't answer 'excellent'), but she's in a much better place than she used to be.

2. In general, how would you rate your physical health:....

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

Respondents thought of a variety of dimensions in regard to physical health. This included fitness level, ability to complete daily activities, the absence or presence of illness, or some combination of these.

Six people used fitness level to rate their physical health. One respondent said 'excellent' because "I now have time to do more exercise...which I'm doing." Another respondent factored two variables into her assessment. She answered 'very good' because she has no illness. However, she didn't choose 'excellent' because she's "overweight and out of shape."

Four respondents thought of their ability to complete daily activities. For example, one respondent answered 'good' because she can still do things like put her clothes and shoes on, but didn't choose a better option because she can't pull her arm back all the way and can't vacuum because of her masectomy.

Finally, five respondents based their answer on the presence or absence of illness. For example, one person answered 'excellent' and said, "I feel good. There's nothing wrong." Another respondent chose 'very good' instead of 'excellent', saying "I'm not sick, but there's always room for improvement."

However, one person was thinking of her spiritual health, which seems very different from the question intent. Additionally, another respondent couldn't answer because he was thinking of his pain, which varies from day-to-day. He wouldn't 'average out' the pain overall because that would be a misrepresentation of how he experiences it – some days are very bad and some are okay.

3. In general, how would you rate your mental health, including your mood and your ability to think?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

Most respondents answered this question based on at least one of the abilities mentioned in the question. They based their assessment on their cognitive abilities, sadness (or happiness), or the absence of mental illness. However, one person was thinking of her spiritual health.

Four respondents were thinking of their cognitive abilities when answering this question. One person answered 'very good' because he said, "I'm kinda sharp. I don't talk much, but I observe things." Another person said he chose 'good' because "I don't get enough sleep all the time. Sometimes I need to get more sleep and that has a lot to do with my mental faculties."

Other people thought of their mood. One respondent said 'excellent' because she's happy about being able to spend more time with her family lately. A cancer survivor said only 'good' because he has some sadness over thinking about his future and the likelihood that cancer may be a part of that.

A couple respondents thought about mental illness in general. One person answered 'very good' because she's never had a problem with "mental stability" and another answered 'excellent' because she's never had any problems with her "mental health."

While most respondents seemed to tap into either, mental health, mood or cognitive abilities, one person couldn't provide an answer because it was double barreled for him. He said, "Those are two different questions you got there. Your mood and your ability to think are two different things." His mood is very down at times because he doesn't have a good job, but his ability to think is 'excellent'.

4. In general, how would you rate your satisfaction with your social activities and relationships?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

Respondents answered on the basis of family relationships/dating/romance, friends & social networks, or relationships with coworkers.

Often, respondents thought of their family (or dating) relationships when answering this question. For example, one respondent thought of his relationship with his wife. His prostate cancer means he “can’t be a husband” anymore so he answered ‘poor’. Two respondents chose ‘excellent,’ one because her relationship with her family has been good lately and another because he and his girlfriend are getting along very well.

Other respondents thought about relationships with friends, not family. One respondent is going through a divorce but answered ‘good.’ This is because he was thinking more about his ability to get along with people and make friends than the trouble he has with his wife. He said, “I get along with people; people get along with me.” Another respondent thought about her friends when she answered ‘good’. She thought even though she has friends, it could be better because she doesn’t get to spend as much time with them as she would like. She’s not working right now and can’t afford to join them when they go places. She didn’t answer less than ‘good’ because some things are free (so she can join them) and she’s good at meeting new people. Another respondent had the same interpretation, but wasn’t sure whether to answer ‘fair’ or ‘poor’ because social activities cost money and he doesn’t have a job. He specifically said he interpreted this question as asking about “going out and interacting with people in social settings.” Another respondent answered ‘good’ because he has “good friendships”. When he’s feeling down he always has someone he can call. Someone else was unhappy about the fact that she doesn’t have friends and answered ‘fair’.

Finally, another respondent was thinking about the tension she has with co-workers. She answered ‘good’, saying that her relationship with them was “all right.” (She would not go into details.)

5. In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

This was similar to the previous question in that respondents were thinking of family, jobs, friends, neighborhood involvement, and social activities when answering this question.

However, it was double barreled and caused difficulty for some respondents and some didn’t understand the question altogether. One person couldn’t answer and said, “I don’t understand that question. What do you mean ‘carry out’? How do you go about your roles...?” Another respondent could answer only by saying, “Not a factor.” To him the question wasn’t applicable because he doesn’t have a large network of family or friends and his work doesn’t involve much interaction with people. This question was long and confusing and not very different from the previous one in the minds of many respondents. Not much information would be lost by dropping it.

6. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

- 1 Completely
- 2 Mostly
- 3 Moderately
- 4 A little
- 5 Not at all

FINDINGS: This question was asked of 22 respondents and did not change between rounds.

Respondents were generally thinking about either walking specifically or their ability to complete daily activities.

One person answered ‘a little’ because his artificial hip can make it hard to “get around”. It gives him a good deal of pain. He also has asthma, which adds to the difficulty. Another person also answered ‘a little’ because she’s had radiation therapy (for breast cancer) that affected her lungs. This makes it hard to go up and down stairs or to walk long distances. Another person said ‘moderately’ because he walks every day, but is bothered by a degenerative disc in his neck when doing so. He’s in physical therapy for it and takes medication (steroids & percocet) to minimize its effects. Another person answered ‘completely’ saying, “I can walk around and move” – this has never been a problem for him.

Some people didn’t think specifically about walking. One respondent answered ‘not at all’ because he can’t carry anything. He said “I don’t even carry a packback.” Another person said it takes no effort to do the things listed in the question. She doesn’t have to strain or push herself to do any of those things – they come “very naturally” so she answered ‘completely.’ One person answered ‘completely’ because he “does this stuff all the time.” He helps out around the house cleaning up, vacuuming, going to the store, etc. He said he also exercises.

7. In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Often
- 5 Always

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

Most people were thinking about everyday problems or personal relationships and answered based on how depressed or anxious/stressed they were about these things. However, assessments vary. Some respondents would answer ‘never’ because the problems they deal with are normal, while others would report how these problems made them feel, regardless of whether they were normal (that is, part of life). Two cancer survivors factored their experience with cancer into their response, and how they worry or are depressed about it.

Some people assessed their personality in general, and didn’t think about specific factors or events that

make them anxious, depressed or irritable. For example, one person described herself as being in a bad mood “a lot” and answered ‘sometimes’ because she can be irritable. Another person answered ‘rarely’ even though she sees herself as an anxious or impatient person. She answered ‘rarely’ because she’s “almost never depressed.” Similarly, another respondent answered ‘never’ because “I don’t be depressed – I keep my head up.” He said he’s “always doing something.”

Respondents who thought of specific events brought up a variety of factors. Some discussed everyday problems including things like having to deal with traffic frustrations (which makes them irritable). Another person chose ‘sometimes’ because she had unexpected company (this happens frequently) and this has come to irritate her. One respondent thought of how parenting sometimes stresses her out, but she answered ‘never’ because she accepts it as part of life. Another respondent also thought of parenting challenges but chose ‘rarely’ over ‘never’ because she has a 12 year old and “we have our ups and downs.”

Other people thought about various financial challenges. Some talked about managing their money as the economy grows worse. One respondent was anxious about losing more money and how he’s irritable about having to deal more frequently with financial institutions as he changes his long-term financial planning. Another person brought up paying bill as a source of irritation. Still another respondent answered ‘often’ because he’s concerned about finding a job. He said this makes him feel “sad or depressed.”

One cancer survivor answered ‘sometimes’ because his relationship with his wife has suffered as a result of his prostate surgery. Another cancer survivor also answered ‘sometimes’ because he’s worried or sad about the possibility that cancer may come back.

8. (In the past 7 days) How would you rate your fatigue on average?

- 1 None
- 2 Mild
- 3 Moderate
- 4 Severe
- 5 Very severe

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

Respondents thought of different factors when answering this question. Many interpreted ‘fatigue’ as feeling tired, run down or sleepy. For example, one respondent answered ‘mild’ because she feels “tired” sometimes. In a similar manner, another respondent answered ‘mild’ because to say ‘none’ “would be lie”. She said everyone gets tired once in a while, but it’s not a problem for her. Another respondent said being fatigued is when you “feel like you’ve been hit by a truck.” She answered ‘none’ because she used to feel this way from her job but doesn’t since being laid off. Another person answered ‘mild’ because by the end of the day she’s tired from the energy she has to put in at work all day. One respondent has a physical job lifting boxes and answered ‘mild’ because to say none “would be a lie.” He chose mild because he doesn’t have any chronic problems. Another person answered ‘moderate’ because she’s been waking up in the middle of the night lately, someone else said ‘none’ because he’s been sleeping well, and one person answered ‘mild’ because he has no problem getting to sleep but can get tired from strenuous exercise.

Some respondents thought of physical health when answering this question. For example, one respondent answered ‘moderate’ because the muscle relaxer he takes for back pain makes him tired. One

person answered 'mild' because he's been feeling sick to his stomach lately.

9. (In the past 7 days) How would you rate your pain on average? Use a scale of 0-10 with 0 being no pain and 10 being the worst imaginable pain.

FINDINGS: This question was tested on 22 respondents and did not change between rounds.

One respondent made her judgment based on an appropriate or expected level of pain, for example based on age. She answered 'zero' but this didn't mean she has no pain. She said she was "thinking of pain at my age – I'm 53." She said she has "aches and pains" but they are age-specific. She has some arthritis in her hands but said "It's not limiting me." This is different from other respondents who would give a number (albeit a low number) when they had minor pain that could be deemed "normal", such as headaches and menstrual cramps.

All respondents included physical pain in their assessment. One cancer survivor answered 5 because she sometimes gets a sharp pain in her back and neck but she's getting used to it and it was much worse right after her mastectomy than it is now.

A couple respondents answered 1 (or 2) for pain they described as being minor. One person gave that response because of some muscle soreness he was having after doing some gardening, two people thought of headaches they had last week, and another thought of a skin irritation she had after running one day. Similarly, another respondent answered 2 from menstrual cramps.

However, one respondent also thought of emotional pain and couldn't give a single answer because that was much higher than her physical pain. Another person couldn't answer because he couldn't average out his pain. It varies from day-to-day and to average it out would be a misrepresentation of how he experiences it.

Now, I will ask you some questions about your experiences with cancer.

10. What do you think are the chances that your cancer will come back or get worse within the next 10 years? Would you say...

- 1 Very low
- 2 Fairly low
- 3 Moderate
- 4 Fairly high
- 5 Very high

FINDINGS: This question was tested on 10 respondents and did not change between rounds. Because of time limitations, not all respondents were able to be directly probed on this question.

The criteria respondents used to arrive at an answer were based on two different factors. One basis for judgment was on specific facts. For example, people would use past experience with cancer or rely on what their doctor told them about their situation. Some respondents had easily treatable forms of cancer (small tumors with 'clear margins') or aggressive ones that come back ("Mine is a recurrent form of cancer that I'm always managing.").

However, more often, respondents answered the question based on wishful thinking or on maintaining a

positive attitude. One person acknowledged the difference and said, "I'm going to say moderate, but that's as a layman. Their [doctors] opinion is that you need to be active about checking this to make sure it doesn't jump on you again. Moderate could even be an optimistic view. You're asking what I think, right? Logically it would be higher than that. We don't usually face reality, per se."

Another perspective is that this is an impossible question to answer. One person said, "50/50" and that it's completely up to fate. Cancer is unexplainable and unpredictable. Another person said if something's going to happen to her it will – it's all in God's plans.

11. How often do you worry that your cancer may come back or get worse? Would you say...

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Often
- 5 All the time

FINDINGS: This question was tested on 10 respondents and did not change between rounds. Because of time limitations, not all respondents were able to be directly probed on this question.

No one had trouble with this question, but one did make the distinction between thinking about it and worrying about it. One respondent said, "I don't fret about it." He thinks about it every day, but says there is a difference. He just goes on with his life.

On the other hand, another respondent equated thinking about it with worrying about it. One person said, "I do think about it. I don't think about it every week."

12. At any time since you were first diagnosed with cancer, did a doctor or other health professional tell you that your cancer had come back (that is, you had a recurrence)?

- 1 Yes → GO TO question 12B
- 2 No → GO TO question 13
- 3 I don't know/ Not sure → GO TO question 13

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

No issues or errors were found.

12B. IF YES: What was the year of your most recent recurrence?

_____ year

FINDINGS: This question was tested on 3 respondents and did not change between rounds.

No issues or errors were found.

13. In the last 12 months have you received any treatment for your cancer? By treatment, we mean surgery, radiation therapy, chemotherapy, or bone marrow or stem cell transplant. Do not include surgical biopsy, insertion of medication ports, such as a Hickman, or long-term hormonal treatments such as tamoxifen or aromatase inhibitors (e.g. Arimidex or Femara) for breast cancer.

- 1 Yes→ GO TO question 13B
- 2 No→ GO TO question 14
- 3 Don't know

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

In one case, it's unclear if the treatment the respondent reported should be included. He said he's receiving 'BCG therapy' after they removed a tumor – he said this is the new standard for bladder cancer.

Aside from that, the question was long and difficult to administer. People wanted to provide an answer after the question was posed, but then the interviewer proceeds to read a long definition on what to include and not include. Perhaps a hybrid of this question and the alternative one below would suffice: "In the last 12 months have you received either surgery, radiation therapy, chemotherapy, bone marrow transplant or stem cell transplant to treat cancer?"

Alternative: When was the last time you received surgery, radiation therapy, chemotherapy, bone marrow transplant, or stem cell transplant to treat cancer?

13B. Are you currently in active treatment now?

- 1 Yes [go to question 15]
- 2 No [go to question 14]
- 3 I don't know/ Not sure

FINDINGS: This question was tested on 5 respondents and changed between rounds in an effort to make the question more direct. The version in round 2 read, "Are you currently being treated for cancer?"

No issues or problems were detected.

14. To the best of your knowledge, are you now free of cancer (that is, at this time, you don't have cancer in any part of your body)?

- 1 Yes
- 2 No
- 3 I don't know/ Not sure

FINDINGS: This question was tested on 9 respondents and did not change between rounds.

No issues or problems were found.

If you've had more than one cancer diagnosis, please think about your most recent cancer diagnosis for the next few questions.

15. What types of treatment did you receive for this (only or most recent) cancer? Please select all that apply.

- 1 Surgery to remove the tumor
- 2 Radiation
- 3 Chemotherapy
- 4 Hormonal treatments (tamoxifen or aromatase inhibitors)
- 5 Bone marrow or stem cell transplant
- 6 Did not receive treatment [go to question 17]
- 7 Other (specify)

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

Three issues were identified. This question was somewhat confusing for one respondent who wasn't sure what she had as cancer to begin with. She had a precancerous mole removed and said it wasn't "full-blown surgery" and that she thinks they called it "an excision". Another person who wasn't sure she actually had cancer (she said it was precancerous dysplasia) did not report the cryotherapy treatment she received because it didn't seem to fit any of the categories.

Some of the cancer-related questions, such as this one, don't work well for those who were diagnosed with and treated for a precancerous condition. If these respondents should have skipped out of this section, the screening question should be clarified for them. However, if they should filter into these questions, the entire section should be re-evaluated with this group in mind.

Another person initially reported only radiation, but during probing said she also received chemotherapy and surgery. She didn't know why she didn't report those.

16. At the completion of your cancer treatment, did you receive a written summary from your doctor(s) or medical care providers that described or explained the treatment you had received?

- 1 Yes
- 2 No
- 3 I don't know/ Not sure

FINDINGS: This question was tested on 9 respondents and changed between rounds in order to clarify the meaning of 'written summary'.

In round 1 response error was found in 5 interviews. Respondents were not sure what to include in their answer to the question. Two people answered 'yes' because they were thinking of the lab reports. One person included a booklet about bladder cancer. Conversely, another respondent answered 'no' to the question even though she received information about treatment and post-treatment and that this information was written down for her. It was impossible to determine why she didn't initially include this in her answer.

One person answered 'no' to the question because he discusses everything with his doctor first so that after treatment there are no surprises. He didn't think of documents he may have received afterward. He said he's been given the surgical notes and summary of what happened during surgery, but he wasn't

thinking of that when answering the question. What's important to him are the pre-treatment discussions he has with his doctor, not the post-treatment discussions.

To help clarify some of this confusion, in round 2 the question read, "At the end of your cancer treatment(s), did your doctor give you a single written document describing all the treatments you actually received? This would NOT include general pamphlets about cancer treatments or individual lab results."

This was tested on only 2 respondents in round 2. One had difficulty because she wasn't sure what she received from the doctor. "It probably was, but I got a lot of paper." She decided to say 'yes' because she did remember getting a copy of the hospital bill that showed everything she had received and how much it cost.

This question did not perform well – there was lots of error and confusion – regardless of the wording. The most probable reason is that people don't or can't keep track of all the paperwork they receive from doctors and hospitals. They either don't know if they received such a document, or aren't sure about exactly which document the question is asking.

17. Have you EVER received advice from a doctor, nurse, or other healthcare professional about where you should return or who you should see for routine cancer check-ups after completing treatment for cancer?

1 Yes → GO TO question 17B

2 No → GO TO question 18

3 Not sure → GO TO question 18

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

No issues or errors were found, but often the doctor (or group) who administers treatment is the same doctor (or group) who provides follow-up care.

17B. IF YES: Was this information written down, printed on paper, or provided in an electronic format for you?

1 Yes

2 No

3 I don't know/ Not sure

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

Issues were detected in 7 interviews. Because the doctor (or group) who administers treatment is often the same doctor (or group) who provides follow-up care, 2 respondents included appointment cards for their next visit as information that was written down for them.

In 5 other cases the question was understood as asking them to pick one of the options. This didn't cause error, per se, but responses were "all of the above", "printed on paper" or "it was written down".

18. Did you have any public or private health insurance that paid for all or part of your cancer treatment? (Examples of insurance include Medicare, Medicaid, insurance offered through an employer, the military, or a policy you bought on your own)

- 1 Yes
- 2 No
- 3 I don't know/ Not sure

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

No issues or errors were found. The question captured public, private, and military health insurance. However, note that the parenthetical sentence was rarely read by interviewers due to its awkwardness. It proved to be unnecessary anyway.

19. After you were diagnosed with cancer, did your doctor, nurse or other health professional talk with you about how cancer may affect your emotions or your relationships with other people?

- 1 Yes → GO TO question 20
- 2 No → GO TO question 19B
- 3 Don't know/ Not sure

FINDINGS: This question was tested on 10 respondents. The categories changed between rounds.

Seven interviews were conducted in round 1. The question was double barreled for 3 respondents who didn't need this discussion. One respondent specifically said the question made "some assumptions about people's experiences". She said it "implies you're brought into the office" to talk about your diagnosis and treatment. But she didn't know it was cancer until *after* they surgically removed the tumor. She said her answer of 'no' makes it sound like her doctors were negligent, which was not the case.

Two others said 'no' but that they didn't really need this type of discussion anyway. As a result, the categories in round 2 were changed to:

- Yes
- No, but it may have been helpful
- No, and I didn't think it was necessary

This question was tested 3 times in round 2, and one person was confused by the choices. She couldn't answer and lost track of what the question was asking. The interviewer re-read the question and she said, "Just straight no."

19B. Would you have liked it if your doctor had initiated a discussion about these topics with you?

- 1 Yes
- 2 No
- 3 Don't know/ Not sure

FINDINGS: This question was tested on 5 respondents and was deleted in round 2 and incorporated into the categories of question 19.

In round 1, four respondents had issues because the discussion wasn't necessary given their situation. As one respondent explained, he wasn't offended that the doctor never brought it up, but he didn't feel

deprived because he didn't either. This is because his doctor isn't his source of emotional support and he doesn't expect him to be.

20. How satisfied were you, overall, with how well your doctor, nurse, or other health professional, met your emotional and social needs related to your cancer diagnosis and treatment?

- 1 Very satisfied
- 2 Somewhat satisfied
- 3 Not satisfied
- 4 Don't know

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

In three cases the question wasn't applicable to the respondent because they didn't need or want emotional support from their doctor. They still answered the question, but did so thinking of other things. For example, one respondent answered 'very satisfied' because "it was awfully good news" that her cancer was small and the type that doesn't spread. That's what she was satisfied about, NOT the level of emotional support she received from her doctor. Another respondent answered 'very satisfied' because she didn't need it and didn't get it. This was not an evaluation of the level or quality of support.

21. After your cancer was diagnosed, did you receive professional counseling or join a support group to help you cope?

- 1 Yes → GO TO question 22
- 2 No → GO TO question 21B
- 3 I don't know/ Not sure → GO TO question 22

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

Only two issues were detected. One person answer 'no' even though she sees a psychiatrist. She answered no because she doesn't receive real counseling from him, only medication for depression. This may be a false negative. Another respondent included discussions she's had with her surgeon's nurse. The respondent said she's had "one-on-one with a nurse, but not a support group." She was thinking of each appointment she has with her surgeon. The nurse always checks her in (taking her vitals, etc.) and talks with her about how it's going. This is very helpful to the respondent so she included it here. This is likely a false positive.

21B. What was the main reason you did not get professional counseling or join a support group?

- 1 I didn't know these services were available → GO TO question 21c
- 2 I didn't want it → GO TO question 22
- 3 I didn't think I needed it → GO TO question 22
- 4 I couldn't afford it → GO TO question 22
- 5 Some other reason (please specify) → GO TO question 22

FINDINGS: This question was tested on 8 respondents and did not change between rounds.

No issues or errors were detected.

21C. Would you have been interested in receiving professional counseling or joining a support group if you had known about it?

- 1 Yes
- 2 No
- 3 I don't know/Not sure

FINDINGS: Not tested. All skipped out.

For the next few questions, please answer based on all of your experiences since the first time you were diagnosed with cancer.

22. Did you participate in a research study or clinical trial as a part of your cancer treatment?

- 1 Yes
- 2 No
- 3 I don't know/Not sure

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

Only one issue was found – a likely false positive. One respondent said she took a survey that was being handed out at Howard University Center (where she receives treatment). This was not a clinical trial, but it's unclear exactly what it was.

23. Were you EVER denied health insurance or life insurance coverage because of your cancer?

- 1 Yes
- 2 No
- 3 I don't know/Not sure

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

Only one issue arose for one respondent who answered 'no' but said she never tried to get life insurance. She didn't want to go through all that screening only to be turned down. This was double barreled for her.

24. To what degree has cancer caused financial problems for you and your family?

1 A lot

2 Some

3 A little

4 Not at all

5 I don't know/ Not sure

FINDINGS: This question was tested on 10 respondents and did not change between rounds.

No issues or errors were detected.