Cognitive Testing of Cervical and Lung Cancer Screening Questions

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1. Introduction

The Division of Cancer Prevention and Control (DCPC), National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Centers for Disease Control and Prevention (CDC) monitors trends in cervical and lung cancer screening in part to achieve Healthy People 2020 health objectives. This report details a study done by the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER), National Center for Health Statistics (NCHS) on survey items aimed at measuring cervical and lung cancer screening procedures. The CCQDER conducted cognitive testing on similar items in 2014 as part of preparation for the 2015 National Health Interview Survey (NHIS) Cancer Supplement. That study identified several problems with question wording. Examples included whether respondents were able to understand the difference between a screening and diagnostic test, and whether they were able to accurately report screening with newer technology, such as human Papillomavirus (HPV) screening tests for cervical cancer and lung cancer screening using low-dose computed tomography.[1] The findings from that study suggested that additional cognitive testing was needed to further improve the measurement of constructs in the cervical and lung cancer screening questions.

2. Methodology

The current study was a cognitive interview evaluation of five cervical cancer screening questions, including questions about Pap tests and HPV tests and eight lung cancer screening questions, including x-rays and CT scans. The aim of cognitive interviewing is to investigate how well survey questions perform when asked of respondents, that is, if respondents understand the questions according to their intended design and if they can provide accurate answers based on that intent. As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents interpret a question, choose to consider relevant aspects of their lives, and formulate a response based on that consideration. Cognitive interviewing provides in-depth understanding of the ways in which a question operates as well as the construct(s) that it captures. Findings from a cognitive interviewing project are beneficial in two ways. First, they can guide recommendations for designing a question that captures the targeted construct. Second, cognitive interview results can be used in post-survey analysis to assist in interpretation of statistical estimates.[2]

[1] For the full report, see Willson, S. (2014). Cognitive Interview Evaluation of the 2015 NHIS Cancer Control Supplement. National Center for Health Statistics. Hyattsville, MD. Accessed at http://wwwn.cdc.gov/QBank/Report.aspx?1136

[2] For a complete discussion of the methodology, see Miller, K., Willson, S., Chepp, V., and Padilla, J. (2014). *Cognitive Interviewing Methodology*. Hoboken, NJ: John Wiley & Sons.

Sampling and Respondent Demographics

The CCQDER conducted a total of 40 interviews in two rounds of testing. Round 1 included 21 interviews and Round 2 included 19. Interviews were held in the lab at NCHS and lasted no longer than one hour. Respondents were recruited through newspaper advertisements in multiple outlets. Sample selection was purposive and guided by the topics included in the survey questions. Therefore, emphasis was placed on recruiting people aged 55 and over who had received x-rays or CT scans and some women under 55 who had received Pap tests. Beyond those criteria, demographic diversity was sought to the degree possible. Table 1 summarizes the demographic composition of the sample in total and by each round of testing. Overall, there were more females than males (22 to 18, respectively). There were more Black respondents (31) than White (7), and two respondents identified as multiracial.[3] Ten respondents had a high school diploma or less and 30 had more than a high school education.

Table 1: Summary of key respondent demographics by round and in total

	Round 1 (n = 21)		**Round 2 (n = 19)**		**Total (n = 40)**	
	Number	Percent	Number	Percent	Number	Percent
Gender						
Male	9	43%	9	47%	18	45%
Female	12	57%	10	53%	22	55%
Race						
Non-Hispanic Black	17	81%	14	74%	31	77%
Non-Hispanic White	2	9.5%	5	26%	7	18%
Multi-Racial	2	9.5%	0	0%	2	5%
Education						
High School or Less	9	43%	1	5%	10	25%
More than High School	12	57%	18	95%	30	75%

Data Collection

The cognitive interviews were face-to-face, in-depth, and semi-structured. The format consisted of interviewers first administering the questions as they were designed for the actual survey context and obtaining an answer from the respondent. In the second part of the interview, the interviewer asked respondents follow-up probes to elicit what respondents were thinking when they answered the question and the rationale for their specific response. In this regard, data unfolded as narrative stories which revealed both errors in responses and the constructs being measured by the questions.

Method of Analysis

Analysis of the interviews included a simultaneous process of data reduction and theory building (i.e. drawing conclusions). A data entry and analysis software application (Q-Notes) was used to store data and conduct analysis. Q-Notes ensured systematic and transparent analysis across all cognitive interviews and provides an audit trail depicting the way in which findings were generated from the raw interview data. Without such an analysis, conclusions presented in a cognitive interview report risk relying on anecdotal reports derived from one or two standout interviews or the general impressions of

[3] No respondents identified as Hispanic.

interviewers. Instead, this report uses quotes from individual interviews to illustrate the themes that were developed by examining all data points.

In conducting the cognitive interview analysis, original interview text from every interview was first summarized into notes. Summary notes specified the way in which individual respondents answered every survey question, including each respondent's interpretation of questions and key terms, activities and experiences considered by respondents, and any response difficulties and errors. Next, analysis was conducted across interviews, identifying interpretive patterns (including patterns of response error) common to each question. Findings from this second level of analysis depict the phenomena captured by the questions and allows for the assessment of construct validity.

The next section summarizes key findings and is followed by a detailed analysis of each question.

3. Results

Summary of Key Findings

Respondent Knowledge

Respondents demonstrated varying levels of knowledge about their state of health and the health care they have received. Levels of knowledge ranged from very little, to partial, to fairly complete; however, most respondents fell in the little to partial range. For example, respondents were not always familiar with the different types of tests they received. Specifically, they did not always know or remember the names of medicals test they had, nor did they always know or remember the purpose of tests they have had.

When respondents were presented with survey questions about cervical and lung cancer screening procedures, their lack of knowledge had an impact on the question-response process. When respondents had little knowledge about the tests they had, they were not likely to report 'don't know' as their answer. Most respondents instead tended to use whatever knowledge they had to choose from among the response options provided to them. Sometimes they chose correctly but sometimes response error occurred.

A common strategy respondents used when they had incomplete knowledge was to choose a response category that best represented the fact that they did not know the answer. For example, 'no' was sometimes chosen as a way to express 'don't know.' Question 2 on HPV screening and question 7 on chest x-rays are examples of where this occurred (see the question-by-question analysis for more details). Another strategy was to choose a response that seemed most likely or reasonably logical in the absence of actual knowledge. For example, in question 7 the categories 'to check for lung cancer' and 'some other reason' were both chosen by respondents who did not know the specific purpose of the x-rays they had. Respondents who reported not knowing the specific purpose of the tests often assumed that checking for lung cancer was included because it seemed reasonable that checking for lung cancer would be included in a chest x-ray. On the other hand, 'some other reason' was sometimes chosen instead, with the assumption that a reason did exist, even if it was unknown by the respondent.

In fact, it was very common that respondents remembered the name of a test they had, but did not know its specific purpose. This was especially true for Pap tests, x-rays, and CT scans (respondents were

generally less familiar with the HPV test). Many respondents knew they had these tests done, but did not know or were uncertain about why.

Additionally, respondents with partial knowledge of procedures had a propensity to confuse different types of tests, particularly if they experienced more than one. For example, Pap tests were confused with tests for HPV as well as other reproductive health procedures (such as pelvic exams), and x-rays and MRIs were confused with CT scans. This made it difficult for respondents to provide accurate answers to the questions.

Respondent Confusion about Question Intent

Aside from knowledge issues, it was not clear to respondents what construct some of the questions were fundamentally aiming to measure. Questions 11, 12, and 13 are good examples (see the question-by-question analysis for details on each). These questions ask for details about CT scans done to check or screen for lung cancer. Respondents interpreted the questions several ways. One pattern of interpretation was to understand the questions as essentially about the test or procedure – such as the CT scan – *irrespective of the purpose*. A second pattern was to understand the questions as being primarily about cancer screening, *irrespective of the procedure*. Many respondents did not make the connection between the two; that is, they did not interpret the question as asking about a specific procedure done for a specific purpose.

Question-by-Question Analysis

1. The following questions are about women's health. Have you EVER HAD had a Pap smear test?
(Read if necessary: A Pap smear 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.)

Answer	R1 & R2
Yes	22
NO	0

This question did not change between rounds and all female respondents answered 'yes'. Respondents correctly understood the question as asking if they had a Pap test at any time in their life. Therefore, respondents who had annual or biannual Pap tests, respondents who had not had Pap tests in over 20 years, and one respondent who had only two Pap tests in her lifetime, all answered 'yes' to this question. The Pap was an extremely common test, such that every woman in the sample reported having had at least one. However, not all respondents connected it to cancer screening. The details of this finding are discussed next.

Overall, the Pap test was familiar to respondents and they were able to report whether or not they have had one. In evidence of this fact, consider that the question includes a definition of Pap tests for interviewers to read if necessary when respondents are not sure what the test is. No respondents needed the definition to be read. All women in the sample recognized the term "Pap smear test". Some respondents also knew that the test was specifically for cancer screening. For example, when asked to define the test, one respondent said, "Pap test is for cells, to find out if you have cancer cells. They look for some kind of cancer cells. That's why they give them, as far as I know."

However, even though respondents heard of the Pap test and knew whether or not they ever had one, there was considerable variation in the extent to which respondents understood the purpose of the test. All respondents understood that a Pap test was in some way related to reproductive health, but many were uncertain about the exact purpose of the test. In many ways this was emblematic of the fact that many respondents lacked knowledge of their health and health care delivery in general. As one respondent explained, "She [the doctor] can do stuff, and she'll be saying [what she's doing], but when you're lying there and you're getting something done to your body…you hear and you don't hear. You hear, but you don't really let it sink in, what you're hearing." Some respondents knew the Pap was a screening for cervical cancer, but others thought it was for uterine cancer. One respondent said, "I believe it's for cancer cells for the uterus."

Other purposes were stated as well. Respondents thought the Pap test was used to identify infections or blockages, STD testing, or a routine test done during pregnancy. Moreover, respondents sometimes believed it was a multi-purpose test, explaining that it was used for both cancer screening and other reasons. One respondent said, "I just want to have the Pap smear around a year for general type things." Another respondent said, "[It's used] to check for any cancer cells, to check for any type of yeast infections, bladder infection, if you have any irritation of your uterine area."

Several respondents conflated the Pap test with other OB/GYN procedures, such as pelvic exams, uterine scraping, and other vaginal or uterine exams. For example, one said it was required prior to starting Depo-Provera birth control. Another women had fibroids as teenager and went to the doctor after having a miscarriage. She believed the doctor performed a Pap test to determine the problems with her pregnancy.

In sum, many respondents did not know the exact purpose of a Pap test. However, they were able to answer this question without response error because all were familiar with the test (at least the test name) and knew that they had received one.

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2. An HPV test is sometimes given with the Pap test for cervical cancer screening. Did you have an HPV test with your most recent Pap for cervical cancer screening?

Answer	**R1 & R2**
Yes, I had an HPV test with the Pap test	9
Yes, I had an HPV test but not with the Pap test	2
No	10
Don't Know	1

This question did not change between rounds. Answers to this question were not given with a high level of confidence among most respondents. Respondents were confused by the response options, were not confident in their knowledge of HPV or were unaware of the details of their medical tests. Each of these patterns is discussed next.

The first difficulty with this question was the response categories. Many respondents answered before hearing all of the answer choices. This was in part because respondents initially interpreted this as a

simple "yes" or "no" question. Additionally, once the interviewer read the response options, respondents were still confused. Several respondents needed the question repeated or reported confusion in understanding the answer choices. This confusion sometimes resulted in respondents not thinking about their most recent Pap. Instead, respondents understood the question categories as allowing them to select not only if they had an HPV test with their most recent Pap, but also if they had an HPV test at *any* prior (not most recent) Pap *or* as a separate procedure from the Pap.

Second, many respondents had insufficient knowledge about HPV in general. During follow-up probing interviewers asked respondents to describe their understandings of HPV. Respondents were uncertain of what the procedure itself involved and they were uncertain about the purpose of the test. Ideas about what the HPV test involved ranged from a blood test, to a part of the Pap test, to a separate swab given during a Pap test. Several respondents said that the HPV test involved snipping or clipping a part of the vagina, "womb," or cervix. Others, however, had even less knowledge. For example, one respondent who was not sure what the HPV test is said, "I don't even know what the HPV is."

Respondents also demonstrated confusion regarding the purpose of the HPV test. For example, one women said, "It's human Pappolo-something virus, that's why you do the Pap smear I guess, to catch the virus." She further explained that she thought the Pap test was to test for HPV. "I'm pretty sure, I mean it's got all the same letters, the same 'Pap' in it." This respondent was conflating the "Pap" in Papillomavirus with the "Pap" in Pap test. Several respondents associated the HPV test with cancer screening. Others said it was a test for a virus or bacteria that related to cancer. For example, one respondent explained, "I've heard a lot in the past 2-3 years about HPV and I still haven't got a full understanding of it. But it's a bacteria as far as cancer…I think that's what it is. Or they test you for it. It's just a test that they run for cancer somewhere down there."

Many respondents talked about associating HPV with sexually transmitted diseases and believing the test was primarily for teenagers. For example, one woman said she felt "weird" taking this test, saying she had asked her doctor, "Why do I have to take this? I thought you only take it at your teenage years. But they said no, even though you're not a teenager anymore, you still have to take it." This group of respondents seemed to confuse an HPV vaccination in young adults with the HPV test in women. One respondent explained "They say it's good to have to protect your daughters by having them tested and vaccinated. Again, to help prevent cancer cells." Another respondent similarly said she didn't have an HPV test because, "I always thought it was for teenage girls."

Finally, respondents did not always have the requisite knowledge about their own health care delivery to answer this question confidently. Many respondents did not know or could not recall this information. Several respondents were unsure if they had ever had an HPV test at all, much less if it was at their last Pap verses some other time. One respondent answered 'don't know,' but this was not the common choice among uncertain respondents. Most respondents chose a response option based on their best guess.

None of the respondents who answered "no" reported specifically knowing that they never had an HPV test. Instead, some respondents used 'no' as a proxy for 'don't know' or 'not sure.' For example one woman said 'no' to having an HPV test because "I'm thinking that I don't know if I've had it." She went on to say, "When the speculum is doing what it's doing and they're swabbing, I don't know if one swab is this, they're checking for HPV…I can't say. And then blood is being drawn. They draw for a million and one vials of blood and you don't know exactly what is being tested for sometimes."

Respondents who answered 'Yes, I had an HPV tests but not with the Pap test' did so for a variety of reasons. Some had clear memories of their most recent Pap test and said either their doctor recommend the HPV test or they, themselves, requested it. Other respondents who had HPV tests in the past but not at their most recent Pap incorrectly answered 'Yes, I had an HPV test with the Pap test.' This was in part because of confusion about whether or not they had an HPV test and in part because they did not register the "most recent" part of the question. For example one woman initially answered 'Yes, I had an HPV test with the Pap test,' but during probing she wondered if it was a separate procedure. She explained "I thought that it was part of the Pap, but then now that I'm thinking that it's an additional test, that wouldn't have been part of the HPV test…it was separate, I think." It was impossible to know which answer was correct because the respondent herself did not know the correct answer.

In sum, many respondents were unclear as to the purpose of this test and, unlike the Pap test, they were often uncertain whether or when they had an HPV test.

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

Answer	**R1 & R2**
Part of routine exam	13
Because of a problem	2
Other Reason	1

This question did not change between rounds. The majority of respondents said they got Pap tests as part of routine exams. For these respondents, the question was straightforward. Most respondents said they had been getting exams since their teens or twenties. Some respondents reported getting Pap tests from their primary care physicians, others went to OB-GYNs. However, 'routine exam' had different meanings. Most respondents said they got exams regularly, with "regularly" ranging from every six months to every two years. For example, one respondent was participating in a study in which she received Pap and STD tests every six months. She considered these exams "routine" because they were part of the study protocol – which is different from being "routine" from a primary health care perspective.

Aside from the idea of "routine" being interpreted different ways, the last two response options did not function as mutually exclusive. Specifically, 'some other reason' may capture a test being done to detect a problem. Two respondents answered the test was 'because of a problem' and one answered 'some other reason'. The two respondents who answered 'because of a problem' described their experiences. One respondent said that she had a routine exam Pap where they found a problem; her HPV test came back not normal. As a result she had a follow-up test where they scrapped her uterus and then had to get more frequent Pap tests for the next year. The other respondent who said she went because of a problem reported having pain when urinating, during intercourse, and when sitting for long periods of time. She was referred to a specialist GYN who found fibroids on her ovaries, said she had a shrunken uterus, and recommended a hysterectomy. However, the woman who said she went for some 'other reason' reported an experience similar to the previous two respondents. During probing she explained that she went to the doctor because she was having discharge, itching, spotting, and odor. When asked why she chose 'other reason' over 'because of a problem,' she said, "That's a problem and a reason." This suggests she understood those two categories as having similar meaning. Although it was unclear

exactly why she elected to answer 'other reason,' it is clear that the categories did not differentiate reasons in the intended manner.

Generally, respondents seemed to understand this question. Most respondents thought of routine Pap tests, even if "routine" had inconsistent meanings among respondents. Three respondents reported their most recent test was either 'because of a problem' or 'other reason'. However, there was not much difference in why respondents picked 'problem' instead of 'reason', so these categories may not accurately capture different experiences.

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

Answer	R1 & R2
Yes, Pap test not normal	0
Yes, HPV test not normal	0
Yes, both not normal	3
No	19

This question did not change between rounds. When the answer to this question was 'no', which it was for most respondents, it was not a difficult question to answer. Respondents reported knowing this either because they received paper or electronic test results that said "negative" or because they did not receive a call from a doctor telling them the results were positive. Additionally, several respondents were probed if they had *ever* had an abnormal test. Respondents seemed to correctly consider the time period; several said they had past tests with abnormal results, but not in the last three years, so they answered 'no' to the question.

On the other hand, when the answer was something other than 'no', the question was more difficult. Several respondents reported confusion with the answer categories. For example one respondent said, "Both were normal. What category is that?" The phrasing that combined "yes" with "not normal" confused respondents, as it could be interpreted as a double negative. This can place an unnecessary burden on respondents.

Many respondents needed the question repeated or reported confusion. In some cases confusion was due to combining two tests into one question. In other cases it was due to respondents not fully understanding the nature of their health care delivery (i.e., the tests and procedures performed on them) or their health conditions. For example, one respondent who was unclear about each test answered 'both were not normal' because she thought the HPV test was part of the Pap test. In her mind having an HPV test that was abnormal automatically made the Pap test abnormal. She explained she had an abnormal HPV test that led to a follow-up Pap. On probing her confusion and uncertainty became apparent. She said, "It was the HPV part that was not normal. Well, you know, I guess they just…I don't know if they lump it together and just say your whole thing is not normal. I guess that's what they do, I'm not even sure now. I'm assuming it's together – it's during the Pap test. But they're doing the HPV at that time, so if the Pap test is not normal, then it's not normal because of both things I'd assume." Another respondent who was also unclear about the difference between the tests indicated that she actually had HPV and that her Pap tests were abnormal as a result. She said that when her test came back abnormal she had to have her cervix clipped to get it tested for HPV. Her confusion arose over the tests themselves – particularly whether the HPV test and the colposcopy were the same test or different.

Another women interpreted the question as asking about the health of her reproductive system *in general*, and disregarded the part of the question asking about the Pap and HPV tests specifically. She had seen the doctor because of a problem with discharge, itching, and spotting, but both the HPV and Pap tests showed negative results: "They couldn't find nothing…they said everything came back negative." Despite being told that the tests were negative, she answered 'both were not normal' because she knew she had a problem. She explained, "For me, it wasn't normal 'cause when you having some kind of discharge and spotting, something is going wrong. To me, something is going wrong down there."

Respondents with normal test results had little difficulty with this question. However, the question did not perform as well among respondents who had an abnormal Pap, HPV, or pelvic exam in the past three years. The response categories did not accurately distinguish which of the tests were abnormal. Moreover, the categories were, themselves, confusing in the context of a yes/no question. The question was most difficult for respondents who did not have full knowledge of the difference between HPV and Pap test results. While three women reported abnormal results on both test, this was response error – not all of these tests actually were abnormal.

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5. What is the most important reason you have NOT had a Pap or HPV test?

Because all female respondents said "yes" to Q1. No respondents were asked this question. Therefore, this question could not be cognitively tested.

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6. The next set of questions are about tests of your chest area. These questions ask about chest x-rays and CT scans, but not mammograms. In the last 12 months, did you have a chest x-ray?

Answer	R1	R2
Yes	11	14
No	9	4

This question did not change between round 1 and round 2. Respondents who answered 'yes' to the question did so for primarily two reasons, diagnosis of symptoms or monitoring of a chronic condition (other than lung cancer). Of the 25 who answered 'yes', 15 had a chest x-ray in the last 12 months because they were experiencing symptoms for which they were seeking a diagnosis. Another seven respondents had regular chest x-rays in order to monitor a chronic conditions (such as TB, COPD or a heart condition). One person had a chest x-ray because he was part of a clinical NIH study. Only two respondents said they had a chest x-ray as a screening tool for cancer. In both cases, the screening was initiated by the respondents, not their physician. Both respondents had relatives who recently died of lung cancer. This prompted them to worry about their chances of developing the disease. As one respondent said, "I know lung cancer isn't catching, but I lost my nephew and he had a spot on his lungs and it ended up being lung cancer and it spread through his brain and he passed away. After that I was kind of nervous…I just figured I'd get it checked out."

However, some respondents were either confused about the type of test they had or were uncertain about how long ago they had it. In both instances, response error was possible. For example, four cases of

response error were found, all of which were due to one of these two difficulties, which are discussed next.

Some respondents were confused by the question because they were not certain whether the test they had was an x-ray or something else. This was especially true when respondents had more than one type of test. Three respondents talked about having multiple tests, and assumed that chest x-rays were included in the battery of procedures they experienced. Many times probing confirmed that a chest x-ray had, indeed, been included in the list of procedures. But in at least in one of these cases, probing revealed that a chest x-ray likely had not occurred and that the answer was a false positive. For example, upon hearing the question, the respondent asked, "Is having a chest x-ray the same as a CT scan?" The interviewer instructed the respondent to answer the best he could. He chose 'yes.' However, after discussing his situation during probing (he went to his physician for a breathing problem), he decided that "I had the CAT Scan. I never had the lung x-ray."

Other respondents had difficulty with the timeframe, which led to reporting errors. All were false positive errors – respondents reported that they had a chest x-ray within the last 12 months when probing revealed they had not. Three of these cases were due to respondents not initially remembering when the test occurred. It was only during the follow-up discussion that they were able to recall the test had taken place longer than 12 months ago. In one other case, the respondent simply ignored the timeframe. He knew that the test occurred outside the 12 month timeframe but included it anyway.

R1: 7. Were any of the chest x-rays you had in the last 12 months done to check for lung cancer, rather than for some other reason?

Answer	R1
Yes, to check for lung cancer	4
No, for some other reason	7

In the next section there is a question similarly worded to this one; it relates to CT scans. It reads, "Were any of the CT or CAT scans done to check or screen for lung cancer, rather than for some other reason?" In round 1 it was found that the clause 'rather than for some other reason' had the potential to confuse respondents, who sometimes thought the question was asking about the 'other reason'. Changes that were made to the CT scan question (question 10 in round 1; question 9 in round 2) were made in parallel to this question. Aside from the confusing clause, other patterns of interpretation were similar in both versions of the question. All patterns are discussed next, under the round 2 question. A total of 25 respondents were asked this question across both rounds.

R2: 7. Were any of the chest x-rays you had in the last 12 months done to check or screen for lung cancer or were they done for some other reason?

Answer	R2
To check for lung cancer	6
For some other reason	8

Often times, respondents did not know why a test was performed. Their lack of knowledge was often discovered only during follow-up probing, not during survey question administration. Instead of answering 'don't know,' they chose a response, but the same response was not chosen by all uncertain respondents. Some chose 'to check for lung cancer' while others chose 'for some other reason.' As a result, the two response options do not meaningfully differentiate between respondents' experiences. In other words, they do not perform as mutually exclusive categories. For example, one respondent answered 'for some other reason,' but only *assumed* that they were checking for multiple things, including lung cancer. He said, "I have a tendency to not ask doctors what they're doing." Another person chose the same answer and said, "I think other things all together. Again, like I said, I'm not a doctor. I just went and got the x-rays done." Another person with the same response pattern said, "I don't know if they did the x-ray for cancer or not. They didn't mention it to me." However, another person with a similar lack of knowledge chose 'to check for lung cancer' reasoning that, "I would think if they do the chest x-ray, that they are checking for lung cancer." But when asked if a clinician told him it was to check for lung cancer, the respondent said, "Not directly." The respondent just assumed it was.

Another source of confusion occurred when respondents believed chest x-rays were done to check for multiple diseases or conditions, which may have included but were not limited to lung cancer. A couple respondents initially answered "both" when the question was read to them. Some respondents chose 'check for lung cancer' if this was one of the conditions being looked for, even if it wasn't the only – or primary – concern. One person who answered 'check for lung cancer' initially explained, "The main reason for the x-ray was really to see if the emphysema had set in more." However, in describing his experience more fully, added that, "[It] was sort of a fishing expedition. I think my doctor was wondering if there could be something cancerous as well as other things going on." Another person gave a similar explanation for her answer. "The first one [x-ray] was checking for asthma and the second was checking for cancer, because I had a constant cough that wasn't ceasing." The interviewer asked if the x-rays were for asthma or lung cancer. The respondent said, "She [the doctor] does both, because she knows I'm around people that smoke a lot. And with the chronic cough, she wants to make sure that my lungs are clear." A total of five respondents had this pattern of interpretation and response.

Other respondents chose a different path and answered 'some other reason' if lung cancer was being looked for but wasn't the only or primary reason. For example, one respondent explained that he chose the answer of 'some other reason' because he understood the question as asking "if it was *only* for cancer screening." Another person with the same rationale stated, "I think they were checking for other reasons also. I don't think that they primarily were looking for lung cancer. I was having some problems with my chest, so I think they were looking for everything." Similarly, another person said, "He [the doctor] was checking to make sure I didn't have pneumonia but wanted to cover all the bases…he wanted to check everything, thorough." When asked why he did not choose 'to check for lung cancer' he said, "Because I wasn't 100% sure. I didn't initially go in for a lung cancer check – lung cancer screening – that wasn't the initial onset. When you say 'lung cancer', you're being specific." Altogether, eight respondents demonstrated this pattern.

In sum, the question was interpreted as asking whether the x-ray was done to check *exclusively and only* for lung cancer or it was interpreted as asking whether the x-ray was done to check for lung cancer *along with other conditions*. Moreover, there was no consistent pattern to the judgment process respondents demonstrated in choosing a response option. Respondents with similar interpretations and experiences chose different response options.

8. The following questions are about CT scans, also called CAT scans. During this test, you are lying down and moved through a donut shaped x-ray machine while holding your breath. Have you EVER HAD a CT or CAT scan?

Answer	R1	R2
Yes	16	17
No	3	2

This question did not change between rounds. Many respondents knew whether or not they ever had a CT scan. Of the 33 who answered 'yes' to this question, 23 demonstrated no confusion, difficulty or obvious response error. This was evident in the descriptions they gave of the procedure. Examples include:

> *You lay on this machine and it goes through. When it gets to where it needs to get, it stops and you're supposed to hold your breath and don't move. And you hear this clicking noise…and they're watching you from another room and talking to you through speakers.*
>
> *You lay down on a table. Lie still and at various times hold my breath when instructed.*
>
> *You lay down and go into a circle thing and they have you in for 45 minutes. They give you ear plugs because the noise was too loud in the machine.*
>
> *It's not a terrible machine. And it's fast. You lie flat with the area that they are aiming at well exposed, and they wheel you into this thing and it makes a certain amount of clatter and it whirs around and then it's over and you're wheeled back out.*

Other respondents, however, were not entirely certain of the procedures they have had, including whether what they had was a CT scan. As a result, some were possibly aided by the preamble definition because it resonated with their experience. One person answered 'yes' and explained, "I just remember lying on a bed. And it was very uncomfortable because I think I'm claustrophobic. And they put me in there and I had to stay still and they were taking images of my brain." She was not certain of the procedure, but answered 'yes' because the description matched her experience.

However, despite the preamble describing the procedure, some respondents remained confused. For example, one respondent continued to ask questions before deciding to answer 'yes'. He asked, "Do they do one when they do a colon test? Do they do it only for Blacks?" In his experience he was not lying down, so he may not have had a CT scan. He decided to answer 'yes' anyway because he associated a CT scan with a check of his colon (he may have been thinking of a colonoscopy). Another respondent who was unsure of the test decided not to provide an answer. She explained, "I remember lying down and going through a machine…the isolation of it all." She also remembered a beeping sound. Even though her description matches the procedure for a CT scan, she was not certain enough to provide an answer. Another respondent answered 'no' but his description suggests he may have had a CT scan. He said he was lying down and moved into a "tube," and remembered wearing ear plugs. When asked why he said no, he explained, "No, [because I was] not holding my breath." Another person also answered 'no' because "I don't remember the details." Even though she did remember the technicians suggesting that she wear ear plugs due to the sounds and beeps in the machine, this memory was not enough evidence for her to answer 'yes'.

In some cases the source of respondents' confusion came from mixing up different kinds of tests and procedures, despite the introductory definition. Some respondents confused a CT scan with an MRI. One respondent who answered 'yes' described the CT Scan as a machine "moving" or "revolving" around him. He may have been describing an MRI. Another person said he had both an MRI and a CT scan. When asked to describe the difference, he said, "I think it was like the same machine, but the MRI was closed in. The other ones were open. The MRI you go into a tube no bigger than yourself, but the [CT] scan, those are the big round ones." And a third respondent said that there is no difference between an MRI and a CT scan – they are "synonyms." Other respondents confused CT scans with x-rays. One person who answered 'yes' to this question describes a procedure that sounded more like an x-ray than a CT scan. When asked to describe the procedure, she said, "You come in, disrobe, put a hospital gown on. You go into a room and they put you up against a machine and run about four or five different chest x-rays and they either send you or the doctor the results." Given this description, the interviewer asked what the difference is between x-rays and a CT scan. The respondent said, "There really isn't a difference."

It is important to note that even though some respondents were somewhat confused about the tests they have had, this did not always lead to response error. However, in four cases it did (one false positive, two false negatives and one left blank).

R1: 9. Were any of the CT or CAT scans you had done of your chest area?

Answer	**R1**
Yes	8
No	3
Several areas of upper body region	5

This question was asked only in round 1. Respondents interpreted "chest area" different ways. Some respondents interpreted the question as asking whether *only* their chest was targeted in the procedure. For example, one respondent who chose 'no' explained his answer by saying, "Because I only had that one time when I was younger for the lower back" after a car accident. Another respondent answered 'yes' because the doctor was monitoring a heart condition (a "first degree AV block").

However, some respondents experienced the CT scan as a full body scan. Those who thought of the procedure as covering their whole body ended up providing different answers. Two respondents answered 'yes', reasoning that even though they thought it was a full body scan, the chest is included in the full body. Another respondent answered 'no' because the scan wasn't exclusive to the chest. He said, "They scanned the whole body. There's no way you can get around it. When the whole body goes in, it's from the brain all the way down to the tips of your toes." Another person spontaneously answered "full body scan." He had a difficult time knowing which option to choose, so the interviewer marked 'several areas of the upper body region'.

Finally, the category 'several areas of the upper body region' was problematic when only one area of the upper body was scanned. Two respondents who had their heads scanned chose 'several areas of the upper body region'. But in reality, it was not 'several areas' it was only their head. Others who had their head scanned answered 'no'.

Because of the difficulties with interpreting "chest area" and with the response categories, this question was eliminated and not included in round 2.

R1: 10. The next questions are only about CT or CAT scans to check or screen for lung cancer. Do not include any CT or CAT scans of your chest area that were NOT done to check or screen for lung cancer. Were any of the CT or CAT scans done to check or screen for lung cancer, rather than for some other reason?

Answer	R1
Yes, to check or screen for lung cancer	6
No, for some other reason	6

This question was modified between rounds. Because it was long and convoluted, it had the potential to confuse respondents, who sometimes were not sure what the question was asking. For example, during probing one respondent said, "I didn't understand the question. I thought it was asking me, 'Did they test for something other than cancer.'"

Moreover, findings in round 1 show that some respondents did not have full understanding of the different procedures they had. Additionally, even when they were certain they had the procedure, they may not have known why they had it. These patterns occurred in round 2 as well, and are discussed next.

R2: 9. The next questions are about CT or CAT scans to check or screen for lung cancer. Were any of the CT or CAT scans done to check or screen for lung cancer or were they done for some other reason?

Answer	R2
To check or screen for lung cancer	7
For some other reason	9

The primary pattern in this question (in both rounds) is that respondents did not always know the reason why they had the test done. Despite this, they would choose from among the response categories rather than answer 'don't know'. Twenty eight respondents answered this question and the response distribution was about evenly split; 13 answered 'lung cancer' and 15 chose 'some other reason'. However, those answers meant different things to different respondents. For example, some chose 'some other reason' when they did not know the reason. During probing one respondent said, "I don't know what the reason is." Of her doctor she said, "Whatever she thinks I should do, that's what I do…a lot of times I really don't want to know because it might me something bad that she's telling me." Another person said, "I don't know. I don't think it was for the lungs." Another person said, "I'm not a doctor, so I don't know the different types of scans [meaning reasons] they do." And someone else explained, "They didn't tell me specifically what they were looking for, but they were going to run tests for this, tests for that, so on, and so on…So I was fine with it. I wasn't asking questions. Go ahead and do what you have to do." Each of these respondents answered 'for some other reason' as a proxy for 'I

don't know'. They assumed that, presumably, there was a reason, even if they did not know what that reason was.

On the other hand, some respondents who were uncertain why they had the CT scan decided to answer 'to check or screen for lung cancer.' When asked about his answer, one respondent explained, "I said that because it was either that or something else, but I really meant what I said when I said I think it was a fishing expedition." When asked why he chose 'to check or screen for lung cancer', he said, "I don't know. I do think he [the doctor] thought that cancer could well be the reason that I'm losing weight." The respondent did not know this for sure – he was assuming. Another respondent said, "They never told me. They said it was okay and that was good news. When they bring me a lot of good news, I don't question. I don't go looking for trouble." During question administration one respondent said, "I'm not sure if it was scanning for lung cancer. I had breathing problems." When the interviewer asked how she would answer the question she said, "It was probably to screen for lung cancer – it was by a pulmonologist." Respondents who were not sure about the reason for the test sometimes chose this answer because it seemed logical that cancer screening would be done.

The question was more difficult to answer when respondents believed that the test was performed for more than one reason. Upon hearing the question, one respondent said, "Both actually." She could not provide an answer and left it blank. She said, "Maybe it should say 'primary for lung cancer'." Another respondent also gave the answer, "It was both." When asked which answer he would choose, he went with 'some other reason'. Another respondent who initially answered outside of the response categories said, "Lung cancer and respiratory system." When asked if he was told that the procedure was to test for lung cancer he replied, "Not directly." He just assumed that the doctor would check for lung cancer because the respondent had chest congestion.

Finally, some respondents remained confused about the different tests they had. One respondent had clear response error on this question because during probing it was discovered that he was thinking of the x-rays he had, not the CT scan. (Even for the x-rays they did not tell him it was to screen for lung cancer – which is what he answered. He assumed it was because he didn't know what else the test could be for.) Another respondent answered 'for some other reason' but admitted, "I'm getting mixed up with the scan and the x-ray."

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11. When did you have your MOST RECENT CT or CAT scan of your chest area to check or screen for lung cancer?

Answer	**R1**	**R2**
A year ago or less	3	6
More than 1 year but not more than 2 years	1	0
More than 2 years but not more than 3 years	0	1
More than 3 years but not more than 5 years	1	0
Over 5 years ago	2	7

This question did not change between rounds. For the test about which they were thinking (which was not always a CT scan), most respondents were able to recall how long ago it was done. However, they were not always tending to the clause 'to check or screen for lung cancer' nor were they always thinking

about the CT scan. In other words, some respondents interpreted this as a question essentially about the CT scan (regardless of the reason for it) while others interpreted it as a question essentially about cancer screening (regardless of the test used to screen for it).

Some respondents answered for the test that they believed was for cancer screening (even when it was not a CT scan). For example, one respondent was thinking of the x-rays he had. Another respondent was also thinking of x-rays. Upon probing she said, "CAT scan, no. I only had x-rays." In this case she focused on the test she had for cancer screening.

Other respondents answered for the correct test, but not for the correct reason (i.e., lung cancer screening). For example, one respondent was thinking of the CT scan she had, but it was done after a car accident, not for lung cancer screening.

In sum, respondents did not always connect and keep in mind both aspects of the question – the specific test *and* the specific reason it was performed.

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12. How many CT or CAT scans to check or screen for lung cancer have you had in the LAST 3 YEARS? (Numerical, open-ended.)

This question did not change between rounds. Answers ranged from zero (the most common answer) to 3. However, this question performed similarly to the previous question (see above). Respondents were NOT always tending to the clause 'to check or screen for lung cancer'. For example, one respondent answered 2, but during probing explained that the CT scans he was thinking of were to diagnose shortness of breath and respiratory issues. He did not know if they were specifically for lung cancer.

Other respondents not tending to the clause "to check or screen for lung cancer" would include all the CT scans they had, regardless of why they had them. One respondent answered 2, but only one of those was to check for lung cancer. The other was to diagnose a problem he was having with his back. The same was true for another respondent. She answered 2, but only one was to check for lung cancer. The other was to diagnose headaches and blackouts. She said, "In January I went in the machine that was a scan for the lungs, because I was coughing too much and the cough wasn't going away." But the other was a scan of her head because of the headaches – and it may not have even been a CT scan, it may have been an MRI. Another respondent also said, "I know I've been through twice." When probed, he said one was prior to a heart procedure and the other was to diagnose shortness of breath. Another answered 3, but this included two CT scans and one PET scan, all of which were to monitor the lung cancer he already had. Finally, some respondents were not thinking about CT scans at all. One respondent answered 0, but was thinking of x-rays he received to check for lung cancer, not CT scans.

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13. When do you expect to have your next CT scan of your chest area to check or screen for lung cancer?

Answer	**R1**	**R2**
Less than a year from now	1	2
One year from now	0	1
More than one year from now	0	0

When doctor recommends it	4	7
Never	1	0

This question did not change between rounds. Many respondents never thought about the prospect of a future test prior to hearing this question. As a result, they chose a category that seemed reasonable, which most often was 'when doctor recommends it.' Of the 16 respondents who were asked this question, 11 chose this answer. However, the response meant different things. For example, 'when the doctor recommends it' was sometimes interpreted as something close to 'never'. One respondent said, "I don't see a reason why I should, as long as I feel that my lungs have air capacity and I don't have funny sensations in my chest." The interviewer specifically asked another respondent why 'never' was not the best choice. "I wouldn't say 'never'…because 'never' sounds very final. He [the doctor] might decide there's some reason to do it. But not in the foreseeable future." Similarly, another respondent said, "Only if a doctor would recommend it. I don't really have any symptoms or anything. And I don't smoke." In a similar vein, another respondent said, "She [the doctor] would have to recommend it…if something is not going on [symptoms], then the doctor would have to make that decision." Another person said, "They ain't saying anything about me getting another one. So I don't know whether I should go get another one or what."

For the one person who did choose 'never', it was a personal choice and not linked to a physician's advice. He said, "There are risks with this kind of medical intervention. So I'm not going to seek out a CT scan. Of course, if there's some sort of medical emergency, certainly. But I'm not on a fishing expedition." Another respondent gave the answer of 'when doctor recommends it', but was not really thinking about the doctor. When asked if and when he would get a CT scan again, he said, "Maybe a few years from now. Just precautionary." He explained that this was not a doctor recommendation, it was just what he, himself, thought might happen.

Finally, one respondent was thinking of the wrong test when answering this question. He was thinking of x-rays, not CT scans. In fact, he was thinking of x-rays for *all* the questions because the x-rays were done for cancer screening. In his mind, the questions were about tests done to screen for lung cancer. The screening for lung cancer was the salient construct for him, not the type of test.