Cognitive Interview Evaluation of the 2015 NHIS Cancer Control Supplement

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Introduction

This report documents findings from a cognitive interviewing study done by the Questionnaire Design Research Laboratory (QDRL) to examine questions for the 2015 NHIS (National Health Interview Survey) Cancer Control Supplement. The supplement is sponsored by the National Cancer Institute. Testing took place at the National Center for Health Statistic (NCHS) between April and June, 2014.

The questions cognitively tested focused largely on general health, risk behaviors, cancer screenings, and medical tests. Topics include physical activity, sun protection/indoor tanning, breast cancer, cervical cancer, lung cancer, prostate cancer, colorectal cancer, genetic testing for cancer risk, family history of breast cancer/ovarian cancer and non-cigarette tobacco use.

Methods

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 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves (or fails) the scientific goal. Findings from a cognitive interviewing project typically lead to recommendations for improving a survey question, or results can be used in post-survey analysis to assist in data interpretation.

Traditionally, cognitive testing is performed by conducting in-depth, semi-structured interviews with a small sample of approximately twenty to forty respondents. The typical interview structure consists of respondents first answering the evaluated question and then answering a series of follow-up probe questions that reveal what respondents were thinking when they answered the question and their rationale for their specific response. In this regard, cognitive interviews unfold within a narrative format and are often personal and, in comparison to traditional survey interviews, are unique to each respondent. Through this semi-structured design, various types of question-response problems, such as interpretive errors or recall accuracy, are uncovered—problems that often go unnoticed in traditional survey interviews. By asking respondents to provide textual verification and the process by which they formulated their answer, elusive errors are revealed.

As a qualitative method, the sample selection for a cognitive testing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute that is relevant to the type of questions being examined. When studying questions designed to identify persons with disabilities, for example, the test sample would

likely consist of respondents with a previously known disability and, to discover potential causes of false positive or false negative reporting, some respondents with no known disability. Because of the small sample size, not all social and demographic groups are represented. Analysis of cognitive interviews does not produce generalizable findings in a statistical sense, but rather, provides an explicit exploration of response processes including patterns of interpretation which could lead to response error.

Analysis of cognitive interviews can be conducted from transcribed interviews or, as is often the case, from interviewer notes. The texts of the interviews (either transcribed materials or interviewer notes) are collated by question so that comparisons can be made systematically across all respondents. Several levels of analysis can typically be performed. First, distinct occurrences in which respondents experience difficulty or confusion while answering are identified. Additionally, specific instances or patterns of error are also noted and, most importantly, the particular causes of those errors are identified. In addition to response errors, analysis of cognitive interviews can be conducted to reveal patterns of question interpretation. By comparing each respondent's interpretation to a particular question, patterns can be identified and then examined for consistency and degree of variation among respondents. This type of interpretive analysis does not necessarily illustrate overt response errors, but rather provides deeper insight into the substance or the actual meaning that constitutes the survey data.

NHIS Cancer Control Supplement Cognitive Interviewing Study

The QDRL conducted a total of 40 interviews in two rounds of testing. Round 1 included 21 respondents 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 and Craig's List. Recruitment was guided by the topics included in the survey questions. Therefore, emphasis was placed on people who had used tanning devices, had genetic counseling for cancer risk, had PSA tests or CT scans, or who had mammograms that included follow-up procedures. Additionally, a separate advertisement targeted people who have ever used tobacco products such as e-cigarettes, cigars, pipes, hookahs, cigarillos, bidis, chewing tobacco, snuff, snus, or dissolvable tobacco. Beyond those criteria demographic diversity was sought to the degree possible, and the following tables summarize the demographic composition of the sample, by each round of testing. There were more Black respondents (26) than either White (13) or Asian (1), and only one respondent identified as Hispanic. There was a distribution of ages, but most respondents were between 50 and 64 (this was largely a function of screening into the sample people who had PSA tests or mammograms). There were more females than males (24 to 16, respectively) but there was a wide dispersion around education. The sample consisted of respondents with high school degrees up to and including those with PhDs.

Sample Summary n = 40 (R1: n = 21; R2: n = 19)

Race	Round 1	Round 2
Black	14	12
White	7	6
Asian	0	1

Hispanic	Round 1	Round 2
Hispanic	1	0
Non-Hispanic	20	19

Age	Round 1	Round 2
18 - 29	2	2
30 - 49	5	5
50 - 64	12	10
65 and Over	2	2

Gender	Round 1	Round 2
Female	12	12
Male	9	7

Education	Round 1	Round 2
HS diploma or GED	9	5
College Degree	4	10
Master's Degree	2	4
Professional or Doctorate	6	0

Method of analysis:

Analysis of the interviews included a three stage process involving data reduction and theory building (i.e. drawing conclusions). A data entry and analysis software application (Q-Notes) was used to conduct analysis. Q-Notes, developed by the QDRL, ensures systematic and transparent analysis across all cognitive interviews as well as provides an audit trail depicting the way in which findings are generated from the raw interview data. Without such an analysis, conclusions presented in cognitive interview reports can, without the reader's knowledge, consist of anecdotal reports derived from one or two standout interviews or the general impressions of interviewers. Instead, quotes from individual interviews are presented and used as examples of the themes that have been developed by examining all data points.

To conduct the cognitive interview analysis, original interview text from every interview was first summarized into detailed interview 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 systematically across interviews, identifying interpretive patterns (including patterns of response errors) across interviews. Findings from this second level of analysis depict the phenomena captured by each question and allows for the assessment of construct validity. Finally, a third level of analysis was conducted across subgroups of people to determine whether patterns tended to vary by group.

Summary of Key Findings

1. Respondents' Lack of Knowledge

Many people have very little knowledge about their conditions, medical procedures and treatments. Therefore, questions that go into detail about these topics can be problematic.

Some of the questions tested fell into this category, particularly the cancer screening questions. Many of these questions are intended to capture the prevalence of certain tests being used to detect cancer before a person has any symptoms. However, respondents rarely were able to differentiate between procedures conducted as a routine cancer screening verses procedures conducted to diagnose a condition associated with a troublesome symptom. Rather than provide an answer of "don't know", respondents would answer on the basis of what they DID know. They may have known that they had a particular test, such as a pap test, but they did not always know why. As a result, when they answered "yes" (to, say, having had a pap test), it simply meant that they had such a test done, but not necessarily for the reasons asked about in the question. In other words, they did not always associate these procedures and tests with cancer screenings and, in fact, completely missed the point that the questions were about cancer screening at all.

This highlights the idea that questions about medical tests are made more complicated when causality is introduced into the question. If respondents know very little about the tests and treatment that they receive, they cannot be expected to (accurately) answer questions about why they had these procedures, other than in very general terms. Follow-up procedures to mammograms is another good example. Respondents knew when they had to have follow-up procedures, but they often did not know why. In other words, they knew they were required to have additional tests because of some problem in general, but they did not always know the specific concern. Furthermore, in many cases respondents were thinking of the tests they received to assist the doctor in arriving at a diagnosis of a problem. But respondents often did not know specifically what conditions a test will find or what the physician was looking for or attempting to rule out.

In addition, the wording of some questions further complicated the question-response process by containing language that implied multiple concepts. Questions about CT scans, for example, asked if the respondent ever had a CT scan to *check* or *screen* for lung cancer. Respondents who had a CT scan done to diagnose symptoms were not thinking of screening procedures and answered affirmatively because their symptoms had been *checked* with a CT scan.

2. What Constitutes a "Discussion" with a Clinician?

A number of the questions tested ask about discussions respondents have with their health care provider, as well as any outcome of those discussions. For example, question 57 reads, "Have you even discussed getting a CT scan of your chest area to check or screen for lung cancer with your doctor or other health professional?" In speaking with respondents, it became evident that a "discussion" can mean different things. One prominent interpretation of the concept of a discussion is the notion that there is a relatively equal "back-and-forth" between two conversants. Furthermore, some respondents understood the questions about discussions (or about conversations, advice, or recommendations, depending on the wording of the question) as something where the patient has a choice in the matter. In other words, some of the questions assume that health care providers present the situation and its options to patients who then decide how to proceed or which options to pursue.

However, respondents indicated that do not always experience this type of interaction with their doctors or other health care providers. They don't think about the interaction as a discussion designed to inform them of their options, so they answer "no" to these types of questions. Respondents often understood these questions as asking about an equal back-and-forth conversation but perceive their own experience as simply being told what to do by the physician. For example, questions asking what tests or screenings a physician recommended did not perform well because they confused respondents.

Question 54 about doctor-recommended cervical cancer screening is one example. It reads, "The last time you were told you should be tested for cervical cancer, what test did your doctor or other health professional recommend?" Several women specifically said that their doctor does not inform them of the tests being done or their purpose. As one respondent put it, "They just do what they do." The concept of a doctor recommending a test that the respondent then accepts or rejects was simply not applicable to the way some respondents experience health care delivery or doctor/patient relationships. Respondents sometimes answered the questions based on whether they actually did have the test, not whether the doctor ever recommended it to them. Essentially, then, the questions are measuring a construct different from the one intended.

Other examples of this phenomenon were evident in questions asking respondents if a doctor ever talked with them about advantages and disadvantages of certain tests. For example, question 46 asks, "Did a doctor ever talk to you about the advantages of mammograms?" When such discussions do not exist, the questions were interpreted as asking respondents if they, personally, believe there are advantages or disadvantages to specific tests.

The next section includes analysis of each individual question. It serves as the foundation for the themes discussed here, as readers will see examples of the themes across multiples questions and sections.

Question by Question Analysis

This section details findings of individual questions, including the phenomena captured by the question, response errors identified, and response process bias (i.e. patterns or themes found within one group of respondents). Frequencies are also included for response options respondents chose when answering the survey question. Groups of questions are partitioned into sections by topic, with a summary included for some sections, as appropriate and dictated by findings for the section.

Because there were 98 questions to test in a one-hour cognitive interview, every question could not be explored to the same extent. Probing was prioritized based on pre-determined areas identified by the sponsors and by any emergent respondent difficulties. Not all questions were thoroughly tested, but findings are presented to the extent that they existed.

SECTION 1: PHYSICAL ACTIVITY

The study sample consisted of respondents who reported living in either urban or suburban settings. No one reported living in a rural setting. As such, this series of questions tends to capture one of two constructs. Respondents were thinking either that the questions were about walking for exercise or leisure OR that they were about walking for the practical purpose of getting around, such as to work or running errands.

Additionally, a few questions caused some respondents to think about themselves and their own behavior patterns and other respondents to think about people in general – what this report refers to as the "generalized other". For example, the concept of a place being within "walking distance" was interpreted as either directly related to whether or not the respondent actually makes the walk, whether or not the respondent is inclined to make the walk regardless of ability, OR as whether it's theoretically possible for *anyone* to do so. These different interpretations have implications for question design based on whether the aim of the questions is to capture respondent behavior or the characteristics of the environment in which the respondent lives.

1. Would you call where you live rural? (that is, in the country)

Answer	R1	R2
No	21	19

Respondents described where they live as either urban (in the city) or suburban. No one described where they live as rural. Conceptualizations of "rural" were fairly consistent. Respondents would describe it as "further out in the farmland", "in the country", "The woods. Trees. Not too many stores, like a little country setting area", or "in the middle of nowhere."

Further, the intent of the question was more accurately conveyed to respondents when the parenthetical phrase was read. Therefore, it would be more straightforward for the interviewer if the parentheses were removed. This would make it clear that the phrase 'that is, in the country" should be read to the respondent.

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2. How often are there people walking within sight of your home? Would you say:

Answer	R1	R2
Every day	11	10
Throughout the day	10	9

The first two response options were the only ones chosen by respondents. However, not much distinction was made between these two options – there were interpreted essentially the same way and could, therefore, probably be collapsed into one category. Some respondents gave the answer 'everyday' but when asked to explain, would say that people are walking "throughout" the day. For example, one respondent said people walk by his house "every day, 24 hours a day". Another said there is a "steady flow of traffic" and another said she sees people "all day walking around."

Conversely, some respondents would answer 'throughout the day' to the question even if they were not around to actually witness this activity. One respondent said that he's not sure if people are walking during the middle of the day but answered 'throughout the day' assuming that they are. Others took a different approach and interpreted the question more literally, thinking only of when they, the respondent, actually see people walking. For example, one respondent thought only of people walking before or after work because he's not home otherwise.

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3. How far away from your home is the nearest road, path or trail where you can walk? 0. At my home/ Zero distance _____Number of feet/miles/meters/kilometers away?

Examples of Answers
"less than a mile"
1.5 blocks
1/4 mile
1/8 of a mile
10 feet
100 ft

100 yards
10ft
2 miles
20 yards
4-5 feet
5 blocks
50 feet
at my home
Couple of blocks
half mile

Answers were given in a variety of metrics and respondents could benefit from more guidance on how to answer. Additionally, the question incorporates two different concepts and respondents tended to focus on either one or the other. The common pattern was for respondents to think about either a road or sidewalk for the practicality of getting around or to think about parks or walking trails for leisure or exercise.

A couple respondents heard the two concepts and asked for clarification: "Like a sidewalk? Or a trail? What do you mean by that?" It seems advisable to narrow the intent of the question to one or the other of these concepts. If both concepts are to be measured, it might be more productive to create two questions, one for each concept.

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4. How often does the weather make you less likely to walk? (If needed state " We mean any kind of bad weather that makes you less likely to walk, such as hot, cold, rainy, snowy, and windy) Would you say:

Answer	R1	R2
A little of the time	7	5
Always	3	2
Most of the time	2	2
Never	3	2
Some of the time	6	8

Interpretations of this question fell into one of two patterns. First, respondents thought either of walking for practical reasons, such as running errands, or they thought about walking for exercise or leisure. Second, they contemplated whether rain or snow (no one mentioned heat) would keep them from these activities (errands or exercise). The proportion of respondents thinking of one interpretation or the other was about even.

If the question was understood as relating to exercise, and the respondent did not walk for exercise, it was a double-barreled question – one that makes the assumption that walking for exercise occurs. One respondent's first reply was "I personally don't walk for exercise." When asked how he decided to answer 'some of the time', he said his wife walks for exercise and he was "looking at it from her perspective."

5. For each of the following, tell me whether it is true or not true: Where you live there are roads, paths or trails where you can walk

Answer	R1	R2
Not true	3	2
True	18	17

As with question 3, some respondents focus on roads and sidewalks while others think about trails and parks and the difference was a fairly even split. Additionally, several respondents' interpretations shifted between this question and question 3. It was not clear why respondents would think of trails in the previous question and roads in this one (or vice versa). It could be as simple as assuming that the same question wouldn't be asked twice, so the second question (question 5) must be referring to something different.

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6. For each of the following, tell me whether it is true or not true: Where you live there are shops, stores, or markets within walking distance

Answer	R1	R2
Not true	4	1
True	17	18

The main interpretive issue with this question – and this series of questions – is with the term 'walking distance'. One respondent asked "What is walking distance?" Another stated "I CAN walk there but I wouldn't walk there." In other words, some respondents simply do not think about walking to shop, even if it may literally be possible to do so. This illustrates the possibility that the question can be about a respondent's behavior and inclinations OR it can be about the physical environment. Respondents who recognized this distinction had difficulty with the question.

Other respondents did not see these two possible interpretations. They either based their answers on what they literally do OR on what is literally possible – but did not recognize both possibilities for question meaning.

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7. For each of the following, tell me whether it is true or not true: Where you live) There are bus or transit stops within walking distance of where I live.

Answer	R1	R2
Not true	2	2
True	19	17

Most respondents were thinking about bus stops (particularly those who live in the suburbs) or Metro rail. Beyond that the question was not extensively tested and the discussion for question 6 applies here. That is, the concept of walking distance can be interpreted as related to what the respondent does/can do or as related to what other people might do, given the physical environment.

8. For each of the following, tell me whether it is true or not true: (Where you live) There are places like movies, libraries, or churches within walking distance

Answer	R1	R2
Not true	4	3
True	17	16

Respondents generally limited their interpretations to the examples given and did not mention other types of places. However, the same issue with walking distance that was found in question 6 applies here, that is, they answered either based on what they literally do or on what is theoretically possible for some people.

9. For each of the following, tell me whether it is true or not true: (Where you live) There are places to walk near where you live that help you relax, clear your mind, and reduce stress

Answer	R1	R2
Not true	2	3
True	19	16

Respondents had fairly consistent interpretations of this question in that they thought of places such as parks (that was the most common), shopping, church, movies, and gyms. Also, this question did not invoke considerations of what might be possible for other people, the way questions with the term 'walking distance' did. The latter expression may be more suggestive of an actual behavior that one engages in whereas this wording may be more reflective of the physical environment. But it was impossible to discern this for certain from the respondents' explanations.

10. For each of the following, tell me whether it is true or not true: (Where you live) Most of the streets have sidewalks

Answer	R1	R2
Not true	1	1
True	20	18

This question was not extensively probed. But it was found that respondents understood the concept of sidewalks and knew whether their street (and the streets near them) had any. Moreover, respondents tended to answer in the affirmative even if sidewalks were present on one side of the street but not the other.

11. For each of the following, tell me whether it is true or not true: (Where you live) Traffic makes it unsafe to walk

Answer	R1	R2
Not true	13	15
True	8	4

Most respondents conceptualized pedestrian safety in this question as having sidewalks, traffic lights and cross walk signals. One issue arose regarding of whom the respondent was thinking. For example, some respondents indicated that the traffic where they live doesn't make it unsafe for them personally (because they can adequately navigate through the environment), but it might be unsafe for children. In thinking this way, instead of answering 'not true' they would answer 'true' (thinking not of themselves but of children). This is another example of the difference between thinking of self vs. other, and this interpretive distinction came up again in the next questions.

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12. For each of the following, tell me whether it is true or not true: (Where you live) Crime makes it unsafe to walk

Answer	R1	R2
Not true	18	14
True	3	5

Again, the question is unsafe for whom? A couple respondents said they do not feel unsafe walking (for example, late at night) in their neighborhood but that another person might or a woman might. Other respondents were thinking about this question in one of two ways. They thought it as asking about the characterization of crime in their neighborhood (that is, whether the neighborhood has a reputation for being unsafe) or about what they do to mitigate their potential for becoming a victim – such as not going out late at night.

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13. For each of the following, tell me whether it is true or not true: (Where you live) Dogs or other animals make it dangerous to walk

Answer	R1	R2
Not true	20	17
True	1	2

Almost all respondents focused on the example given in the question and were thinking about dogs, not other animals. So when they answered true or not true, it was in regard to whether the dogs in their neighborhood are controlled and on a leash. It also came up again that while the respondent doesn't feel it's dangerous, big dogs could scare children – so he answered 'true'.

SECTION 2: TOBACCO

In this section, similar questions were asked for different tobacco products and similar patterns were found regardless of the product being asked about. For example, questions asking "Do you now use [X] every day, some days or not at all?" did not perform well for people who used the product intermittently. When respondents used the product only on special occasions, spontaneously with their friends, or did not usually buy the product for themselves, they would choose to answer 'not at all' even when they specifically indicated that they would, indeed, use the product again. They chose 'not at all' because they did not see it as part of their regular or habitual behavior.

14. The next question is about electronic cigarettes or e-cigarettes. You may also know them as vape-pens, hookah-pens, e-hookahs, or e-vaporizers. Some look like cigarettes and others look like pens or small pipes. These are battery-powered, usually contain liquid nicotine, and produce vapor instead of smoke. Have you EVER used e-cigarettes EVEN ONE TIME?

Answer	R1	R2
Yes	7	6
No	14	13

Respondents generally understood what e-cigarettes are, so there were no response errors (false positive or false negative). Respondents who reported never using e-cigarettes were asked whether or not they knew what these were. Almost all said they knew what e-cigarettes were, and mentioned seeing other people use them, seeing them advertised, or seeing them in stores. Only one respondent did not know what an e-cigarette was ("I don't smoke. I don't have the slightest idea what you're talking about.").

Among those who had ever used e-cigarettes, the question was understood by different types of users. Thirteen respondents reported ever having used e-cigarettes, eight because they were trying to quit smoking (none reported it as a successful strategy and so did not continue using e-cigarettes). Three respondents tried e-cigarettes as an experiment but weren't impressed enough with them to continue. One person uses e-cigarettes socially, but not very often and only when offered by others. Only one respondent reported being a regular user of e-cigarettes. The question did capture all these different experiences.

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15. Do you now use e-cigarettes every day, some days, or not at all?

Answer	R1	R2
Not at all	6	5
Everyday	0	1

This question, and others worded like it, presented some difficulties for respondents, especially those who use the product in an irregular or intermittent fashion. One respondent uses e-cigarettes, but only socially when the opportunity presents itself. This respondent answered 'not at all' because she hasn't bought an e-cigarette in 3 months. However, she made clear the fact that she intends to use them again, she just has no idea when the occasion may arise – which is why she said 'not at all'. This pattern occurred in questions 18 and 21 as well.

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16. Have you EVER smoked a regular cigar, cigarillo, or little filtered cigar EVEN ONE TIME? Some common cigar brands include Black & Milds, Swisher Sweets, Cheyenne and Macanudo.

Answer	R1	R2
Yes	13	11
No	8	8

The first thing that was awkward about this question is the manner in which it is supposed to be read to the respondent. It requires the interviewer to ask a question and then continue to talk, which is confusing to the respondent as well as being mildly rude. Many respondents actually answered before

hearing the second sentence. Additionally, there was no evidence that hearing the brand names helped the respondents in any way and, in one case, may have served to introduce unnecessary confusion. One person said, "If you're specifically asking me about those brands, I'd say no." The interviewer read the question again without the brand names and the respondent answered "yes, cigar". The best option may be to delete the last sentence from the question and use it as a "read if necessary" if the interviewers need it.

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17. Have you smoked at least 50 regular cigars, cigarillos, or little filtered cigars in your entire life?

Answer	R1	R2
Yes	6	4
No	7	7

When probed, most people indicated that they knew what these products were. However, the question may capture false positive responses for smokers who use a variety of products including those that might not be listed in the question. For example, one person answered yes because he was thinking about his smoking *in general*. He answered "yes, because I smoked for 3 years" but clarified that he smoked *cigars* only 3 or 4 times in that timeframe.

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18. Do you now smoke regular cigars, cigarillos, or little filtered cigars every day, some days, or not at all?

Answer	R1	R2
Not at all	10	8
Some days	3	3

This question has issues similar to question 15, the question for e-cigarettes. That is, it might not do a good job at capturing people who use the product intermittently, with no predictable pattern or who don't see themselves as having this as a habit. For example, one respondent smokes cigars on occasion. The last time he smoked was two weeks ago and he probably will again, should the opportunity present itself. But he answered 'not at all', explaining that this is not something he normally does, doesn't buy cigars, and has no specific plan for when this will occur again. However, he knows it WILL occur. Another respondent gave the same response with a similar rationale. The last time she bought a cigarillo was two months ago and the last time she smoked one was one month ago, so she doesn't see it as part of her regular behavior.

Others used similar reasoning, but chose 'some days' instead. When asked why, one person said "Once in a while, really. Not every day. Not sometimes. Just on occasion. Like a birthday or special events." The 'not at all' category captured non-regular users more than the 'some days' category did.

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19. On how many of the PAST 30 DAYS have you smoked a regular cigar, cigarillo, or little filtered cigar? (open-ended)

This question posed fewer problems than the previous question to the extent that respondents could more easily supply an answer. This may be because it asks respondents to report on behavior rather than to assess their behavior or habits and then pick a category that doesn't quite fit their assessment.

20. Have you EVER smoked a regular pipe, water pipe, hookah filled with tobacco or bidi (bee-dee) EVEN ONE TIME?

Answer	R1	R2
Yes	7	11
No	14	8

Respondents had different understandings of these products, particularly hookahs. Some were thinking the question was related to marijuana use. Specifically, false positive responses occurred among respondents who smoke marijuana. Moreover, this interpretation may not be limited to those who actually use marijuana. One respondent answered 'no' to the question but said, "You know, they aren't smoking no tobacco in those things", referring to hookahs. Because some people were thinking about marijuana being smoked in hookahs, this question captures not only the people it intended to (i.e., those who smoke tobacco in hookahs) but also some people it did not.

21. Do you now smoke regular pipes, water pipes, hookahs filled with tobacco or bidis (bee-dees) every day, some days, or not at all?

Answer	R1	R2
Not at all	5	9
Some days	2	2

This question shares a pattern with similar questions, such as question 15 and 18 (e-cigarettes and cigars). If respondents do it very infrequently, don't plan for it, or don't buy the product, they tend to say 'not at all'. A good example here was one respondent who spends about one week every two months in Florida (where she used to live full time). When she is in Florida, she does hookah fairly often with her friends. But when she's in this area she never does, so she answered 'not at all' thinking of her time here. This is another good example of how respondents assess their habits when deciding how to answer the question rather than report on actual behavior.

22. Smokeless tobacco products are placed in the mouth or nose and can include chewing tobacco, snuff, dip, snus (snoose), or dissolvable tobacco. Have you EVER used smokeless tobacco products EVEN ONE TIME?

Answer	R1	R2
Yes	3	5
No	18	14

Most respondents knew generally what these some of these products are, but not necessarily all of them. Some respondents had never heard of snuff or snus. On the other hand, chewing tobacco was universally known and helped ground the meaning of the question when other products were unfamiliar. Respondents who had used any of the products answered without expressing confusion. We found only one case of false positive response error. This respondent included the gum he was using for smoking cessation.

23. Have you used smokeless tobacco products at least 20 times in your entire life?

Answer	R1	R2
Yes	1	3
No	2	2

Because this question was asked only of respondents who had ever used any of the products referred to in the previous question, they were thinking of the product for which they answered in question 22. Of the eight respondents who had used these products, most had tried them just once in their life and only one respondent was a regular user (of dip).

24. Do you NOW use smokeless tobacco products every day, some days, or not at all?

Answer	R1	R2
Not at all	3	3
Everyday	0	2

This was not tested on many respondents and those who were asked the question either used products regularly or had tried the product only once in their youth – as a result, these respondents had no difficulty with the response options. The categories "Not at all" and "everyday" fit these types of experiences well.

25. On how many of the PAST 30 DAYS have you used chewing tobacco, snuff, dip, snus, or dissolvable tobacco?

This was not tested on many respondents (only 3) and those who were asked the question had tried the product only once in their youth, so there were no difficulties (such as with recall or judgment) in providing an open-ended answer.

26. During the past 30 days, what brand of smokeless tobacco product did you use MOST OFTEN?

Only one person was filtered into this question (because he was the only regular user of these products). He had no trouble because his brand was here. He uses dip and uses only one brand all the time.

SECTION 3: SUN PROTECTION / INDOOR TANNING

Aside from a few issues arising for individual questions, there were no thematic difficulties that respondents had with this section. Most understood the concepts contained in the questions.

27. DURING THE PAST 12 MONTHS, has a physician or other health care provider talked to you about reducing your exposure to the sun or indoor tanning devices such as sunlamps, sunbeds, or tanning booths to reduce the risk for skin cancer?

Answer	R1	R2
Yes	4	3
No	17	16

Findings for this question fall into the larger theme of the multiple ways in which the concept of "discussion" exists among respondents. In this question, the phrase "talked to you" resulted in two cases of possible response error. One respondent answered "no" to this question but then explained that, while a doctor HAS informed her about the risks of skin cancer associated with sun exposure, it was not in the context of a one-on-one discussion. It was in a group setting at her local senior center. The other respondent answered "no" because she did not remember specifically going to her doctor to discuss that issue in particular, but thinks that the doctor probably did discuss that with her. She understood the question as asking whether she (not the doctor) ever initiated the discussion and that the discussion was specifically focused on this topic rather than being a conversation that may have included other topics as well. Even if these two respondents answered as intended, their interpretations highlight the nebulous nature of the underlying construct, "discussion".

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28. Have you EVER used an indoor tanning device such as a sunlamp, sunbed, or tanning booth? Do NOT include times you have gotten a spray-on tan.

Answer	R1	R2
Yes	5	7
No	16	12

Respondents understood what sunlamps, sunbeds and tanning booths are and, therefore, had no trouble accurately answering whether they had ever used them or not. Only one questionable case arose where the respondent was using "light therapy" as a treatment for psoriasis and answered "yes". His reasoning was that the UV light used for his therapy is the same that is used for tanning.

The administration of the question is awkward to the extent that a question is asked followed by a statement. Many times a respondent answers immediately upon hearing the question and the interviewer must interrupt the respondent in order to read the last sentence. In an act of politeness, the interviewer did not always read the last sentence. This, however, had no discernable effect on their interpretations – respondents were not thinking of spray-on tans to begin with. In fact, many respondents did not even know such a thing existed. The last sentence was essentially unnecessary and could be a 'read if necessary' instruction to assist the interviewer.

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29. DURING THE PAST 12 MONTHS, have you used an indoor tanning device such as a sunlamp, sunbed, or tanning booth?

Answer	R1	R2
Yes	3	2
No	4	5

Like the previous question, respondents understood the question to be asking about indoor tanning. Moreover, no recall issues were detected for the 14 respondents who had ever used indoor tanning; respondents gave answers that were within the 12 month timeframe.

30. DURING THE PAST 12 MONTHS, where did you use an indoor tanning device such as a sunlamp, sunbed, or tanning booth? Please SELECT ALL that apply:

The categories tested in the question in round 1 were confusing to respondents, particularly categories 2 and 4 because they contained similar information (e.g., a gym). This made it difficult to differentiate between the two options. They read as follows:

2. A fitness center such as a gym or health club, recreation center, yoga/Pilates or dance studio
4. A residential common area, such as a gym or lobby of an apartment complex or college dorm

These were changed for round 2 to read:

2. A fitness center such as a gym or health club, recreation center, yoga/Pilates or dance studio
4. A residential common area, such as an apartment complex or college dorm

However, even though respondents were able to choose an appropriate category in round 2, the question was still very cumbersome for interviewers to administer because each response option was very long to read. As a result, sometimes interviewers did not read all the categories in their entirety, particularly when respondents interjected an answer before all the categories had been read. It is reasonable to expect that this pattern will exist during actual survey administration as well.

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31. DURING THE PAST 12 MONTHS, have you had a problem (such as a rash or burn) caused by using an indoor tanning device such as a sunlamp, sunbed, or tanning booth?

In round 1 this question included a 'mark all that apply' option and read:

DURING THE PAST 12 MONTHS, have you had a problem (such as a rash or burn) caused by using an indoor tanning device such as a sunlamp, sunbed, or tanning booth? Do NOT include problems you have experienced from getting a spray-on tan.

**Read if necessary: By "sunburn" we mean even a small part of your skin turns red or hurts for 12 hours or more.*

1. Got a sunburn
2. Got a rash
3. Got a skin infection
4. Experienced another problem
5. I have not had any problems from indoor tanning

This was a difficult question for respondents to process in round 1 because it was long and fairly complicated. Respondents sometimes lost track of what it was asking. It was simplified in the second round to become a yes/no question with a follow-up asking "What problem did you have?" for respondents who answer yes. The flow of the question in round 2 was easier for interviewers to read, however, it was not fully tested because only one respondent filtered into the question. She answered "yes" because she had experienced a burn and "red bumps" after using a tanning booth.

32. How old were you THE FIRST TIME you used an indoor tanning device such as a sunlamp, sunbed, or tanning booth? Do NOT include times you have gotten a spray-on tan.

There could be recall issues with this question, particularly for older respondents who used tanning devices in their youth. For example, one respondent said "maybe 12-15 years ago" and another said "I'm trying to think…early 20's probably." These respondents tended to give age or timeframe ranges rather than a specific number. However, other respondents were able to remember their age because it wasn't that long ago that they used a tanning device, or because they associated the activity with some other event, such as going on vacation.

33. DURING THE PAST 12 MONTHS, have you: used self-applied fake sunless tanning products, also known as self-tanning or fake tanning?

Answer	R1	R2
Yes	3	0
No	18	19

In round one the question was worded the following way:

During the past 12 months have you: Used SELF-APPLIED sunless tanning products, including creams, lotions, sprays, mists, or towelettes, also known as self-tanning or fake tanning?

When asked during probing, most respondents understood the concept of sunless tanning, however, a couple did not realize that was what the question was asking about. Two respondents incorrectly thought it was asking about sunscreen and answered 'yes'. The wording for round 2 was changed to emphasize that the question was asking about sunless tanning. In round two we encountered no response error.

34. Gotten a spray-on or mist tan AT A TANNING SALON or other business?

Answer	R1	R2
Yes	3	1
No	17	18

Respondents understood the concept of a spray-on tan, but in this question the timeframe was unclear because none is specifically stated. For example, one person answered the question based on whether she had EVER gotten a spray-on tan. If the intent of the question is to continue the with the 12 month timeframe of the previous question, this may be missed by some respondents.

SECTION 4: BREAST CANCER

The fact that many people do not understand everything about the health care they receive or the conditions they have played a role in this section. Respondents know that they have had mammograms and they even know that the procedure is for cancer screening. But those who have had follow-up procedures often do not know why. As a result, it was difficult for many respondents to answer these questions correctly because their experiences did not allow them to interpret the questions as intended.

35. Have you ever had a mammogram?

Answer	R1	R2
Yes	10	11
No	1	0

This question was not cognitively tested. It was included as a filter question in order to test the follow-up questions.

36. How much did you pay for this mammogram. Was it NONE, PART, or ALL of the cost?

Answer	R1	R2
None of the cost	9	11
Part of the cost	1	0

Most respondents answered this question without difficulty because they generally knew if they had insurance and whether or not they had to pay any amount for their mammogram. However, in round 1 there was potential confusion because of the complicated nature of insurance and how respondents understand insurance. For example, one respondent erroneously answered 'none of the cost'. She had to pay what her insurance did not cover, but to her the question sounded like it was designed for people with no insurance at all. We added the phrase 'out of pocket' to the question in round 2 to make it consistent with similar questions and to encourage respondents to report any type of payment they had to make. We found no response error in round 2 and no one expressed confusion. The question in round 2 was:

"How much did you pay out of pocket for this mammogram. Was it NONE, PART, or ALL of the cost?"

37. As a result of your MOST RECENT mammogram, were you informed that your mammogram showed that you have dense breast tissue?

Answer	R1	R2
Yes	5	5
No	5	6

Respondents were often not thinking of their most recent mammogram when they answered this question. Instead, they were thinking of the question as asking simply if they have EVER been told that they have dense breasts. To them, the essence of the question was whether or not they had dense breasts, not what the timeline was for when they were told this. In round 2 the wording was changed to:

"Were you EVER informed that your mammogram showed that you have dense breast tissue?"

This solved the timeframe issue. However, in round 2 difficulties persisted with this question, most of which centered on being able to understand what 'dense breasts' meant. This phenomenon speaks to the larger theme that many people have a certain lack of knowledge about their health and medical histories. For example, one respondent answered 'yes' to this question and explained her answer by saying that she has "a lot of fatty tissue". Another woman said "They saw some cluster or something" and a third

respondent said she was told "we found a little mass". All answered 'yes' to the question. Generally, the tendency of this question may be to produce false positive responses, as respondents often do not know the technical terms for what they have (or had) and do not know if "dense breasts" is a technical term. On the other hand, there were no cases of false negative response error. In other words, the question did capture women who have been told that they have dense breasts.

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38. After your MOST RECENT mammogram, were you advised to have more tests because your breasts are dense?

Answer	R1	R2
Yes	2	5
No	5	0

Similar to the previous question, respondents were often not thinking of their most recent mammogram when they answered this question. Instead, they were thinking of the question as asking simply if they were EVER advised to have more tests. In round 2 the wording was changed to:

"Were you EVER advised to have more tests because your breasts are dense?"

Although this solved the timeframe problem, there are still issues with this question, again related to knowledge. Respondents know whether they had additional tests, and often know what those tests were, but they frequently do not know WHY they had follow-up tests. As a result, they would answer 'yes' to this question if they had more tests, regardless of the reason; that is, they did not limit their responses to having more tests because of dense breasts. Like the previous question, this one is also prone to false positive responses, as four were discovered in testing. Again, this is a function of the lack of knowledge that respondents have about their medical histories and the fact that questions which incorporate a cause-and-effect evaluation to be made on the part of the respondent are complicated and difficult to answer.

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39. What tests were recommended?

Answer	R1
Breast MRI	1
Ultrasound	1

This question was deleted in round 2 because of the finding in similar questions that respondents essentially did not distinguish between a test being recommended and actually having a test.

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40. Which tests did you actually have?

Answer	R1	R2
Breast MRI	1	1
Ultrasound	1	1
Additional mammogram	0	3

While some confusion may exist regarding the tests that they have, it was difficult to specifically identify whether respondents answered this question erroneously. In other words, if a respondent said she had an ultrasound, it was not possible to know if that was the test she actually did have unless she,

herself, expressed doubt. In this study, no one did express doubt. In fact, this question was generally easier for respondents to answer because even if they did not understand *why* they had them, they did know *if* they had follow-up procedures.

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41. After your MOST RECENT mammogram, were you advised to have more tests for another reason?

Answer	R1	R2
No	1	4
Yes	0	1

This question is similar to 38, but was asked of women who said 'no' to that question. It was not extensively tested. In round 2 the timeframe was changed to EVER, and read:

"Were you EVER advised to have more tests for another reason?"

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42. After your MOST RECENT mammogram, were you advised to have more tests?

Answer	R1	R2
Yes	2	2
No	7	4

This question is similar to question 38 but is asked only of respondents who answered "no" to having dense breasts. Only two respondents answered "yes" to the question; one erroneously. She was not thinking of her most recent mammogram. Because she has a "breast nodule" that is monitored every 6 months, she answered "yes". However, upon probing, she indicated that after her last mammogram they did NOT make her get another one. She answered "yes" because they often do make her get more than one.

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43. Why were these tests recommended?

Answer	R1	R2
Because my mammogram was abnormal	1	2
Because of another problem	0	0
Because of another reason	1	1

This question was asked of women who answered "no" to having dense breasts. Even though it requires knowledge on the respondent's part, the categories for this question seem general enough that respondents could answer. In other words, the categories do not require respondents to know the specific medical reason that more tests were advised. However, the question does require some level of knowledge that respondents may not possess. For example, one respondent answered 'another reason' but said that she wasn't really sure if they needed to re-do the mammogram because of dense breasts or because of another reason. In reality, her answer was "don't know" but she chose from the response categories given.

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44. Which tests were recommended?

Answer	Cases
Additional mammogram(s)	1
Ultrasound	1

This question was asked only of women who answered "no" to having dense breasts. It was deleted in round 2 because respondents in round 1 essentially did not distinguish between a test being recommended and actually having a test.

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45. Which tests did you actually have?

Answer	R1	R2
Additional mammogram(s)	1	2
Ultrasound	1	0
Breast MRI	0	1

This is similar to question 40 but is asked only of women who answered "no" to having dense breasts. While some confusion may exist regarding the specific tests that they have had, it was difficult to specifically identify whether there was any error on this. In other words, if a respondent said she had an ultrasound, it was not possible to know if that was the test she actually had unless she, herself, expressed doubt. In this study, no one did express doubt. In fact, this question was generally easier for respondents to answer because they knew whether or not they had follow-up procedures.

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46. Did a doctor EVER talk with you about the advantages of mammograms?

Answer	R1	R2
Yes	9	9
No	1	2

This question (and all questions asking about advantages/disadvantages) does not always capture information that is conveyed by a clinician to a respondent. Sometimes respondents answer the question based on what they, themselves, believe to be true, regardless of how they acquired the opinion. They hear the question as asking "do you think mammograms are beneficial?" They are not thinking of discussions with their health care provider, per se. One respondent who answered 'yes' to the question said, "I usually read that on my own."

Other respondents assume mammograms are beneficial simply because the screenings are part of a routine checkup. Others don't remember the specifics of any discussions, but answer 'yes' because they assume a discussion such as this had occurred.

47. Did a doctor EVER talk with you about the disadvantages of mammograms?

Answer	R1	R2
Yes	3	6
No	7	5

Like the previous question some respondents understand this question as asking whether they personally think mammograms are disadvantageous – not whether a doctor ever talked with them about this. However, this question also functioned in a somewhat different manner from the previous question on advantages because many respondents were perplexed by the premise that there could be disadvantages to begin with. Respondents would say things like, "There's never been anyone who mentioned this. What would the disadvantages be? It's early cancer detection!" Another person echoed this thought, "How can there be disadvantages?" As a result, this question is perceived almost as a "trick question". In fact, one respondent specifically described it as "a tricky question". When asked why, she said it's a "weird" question because "I don't think about it that way" (i.e., that there are disadvantages).

This unusual premise leads some respondents to misunderstand the question altogether and think it is asking about the disadvantages of NOT having a mammogram – so they would erroneously answer 'yes' to the question. For example, one respondent explained, "Yes. Because if you don't have one, they won't know if you have a lump. Like, they could catch it, but if it goes undetected, then they have to cut off a breast." Another 'yes' answer was explained as "other than if it's not treated early, you may require treatment that could've been avoided."

SECTION 5: CERVICAL CANCER

Lack of knowledge among respondents was an issue in this section to a larger extent than it was in the previous section. Many respondents, for example, know that they receive a pap test (usually annually), but, unlike mammogram, they do not know that the test is a screening for cervical cancer. As a result, they were answering the questions based on their own experiences which they did not understand in relation to cancer screening. The premise of the entire section was not understood by some respondents. Again the larger theme emerged where they know that they have had a test, but they do not always know why. Additionally, some respondents did not know what HPV was. Others had heard the term but did not know if they received a test for it. The pattern in these questions is reflective of the doctor-patient paradigm where patients are not aware of what the physician is doing, or why.

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48. Have you ever had a pap smear test?

Answer	R1	R2
Yes	12	12

This question was not cognitively tested. It was included as a filter question in order to test the follow-up questions.

49. 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?

Answer	R1	R2
Yes	6	4
No	3	4

A couple of respondents did not know what the HPV test was ("What is HPV? Sounds like AIDS."). One answered 'don't know' to this question, but the other answered 'no'.

More frequently, respondents were familiar with HPV (the acronym, not necessarily the condition) but did not know if they have received the test. In these cases they would most often answer 'don't know'. For example, one respondent said, "I don't know. I don't think so. I don't think they ever told me that. They just take the pap and tell you it's normal." It was a common theme for respondents to have little specific knowledge about the medical procedures they have.

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50. How much did you pay out of pocket for this Pap or HPV test - Was it NONE, PART, or ALL of the cost?

Answer	R1	R2
None of the cost	11	10
Part of the cost	1	2

This question included the phrase "out of pocket" which seems to capture more accurate information and produce less confusion than when it is left out of the question (see question 36 on mammograms). Response error was not detected here, but this question was not extensively probed.

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51. 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
Because of a problem	2	1
Routine exam	10	10

There were respondents who were not thinking about their most recent pap when they answered this question. Instead, they were thinking about why they have pap tests *in general*. As a result, most answered 'routine exam'. However, this constitutes response error when the last pap test a respondent had was in relation to the diagnosis of a problem, which was the case for two respondents.

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

Answer	R1	R2
No	8	12
Yes, HPV test not normal	1	0
Yes, Pap test not normal	2	0

Most respondents were thinking about the pap test and not HPV. No response error was found and respondents expressed no confusion about the question, so extensive probing was not conducted. Knowing when results from a test are not normal was definitely within the realm of what respondents know and remember about themselves in the past three years.

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53. What is the most important reason you have NEVER had a Pap or HPV test/NOT had a Pap or HPV test in the LAST 5 YEARS?

This question was not cognitively tested. All respondents in the sample had received a pap test in the last 5 years.

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54. The last time you were told you should be tested for cervical cancer, which test did your doctor or other health professional recommend?

Answer	R1	R2
Both tests	3	3
My doctor did not recommend a test to check for cervical cancer	4	3
My doctor left the choice to me	2	1
Pap test	2	3

This question confused respondents in multiple ways. First, it is unclear what 'recommend' means. The word implies a choice on the part of a patient but many respondents do not perceive a choice. In other words, many respondents experience interactions with their doctor as having to follow "doctor's orders". One person said, "She automatically ordered a pap but didn't discuss it with me. They just do what they do." Another said, "She decides and I do. I trust her and she does that."

Second, a pap is a routine yearly procedure for the vast majority of women. And a routine means that the procedure is automatic and not requiring of a conversation. "They probably do check for cervical cancer, but they never discussed that." Another respondent admits "there was no big conversation" about what tests she was getting. A third said, "There was not a lot of discussion to inform me."

Third, respondent don't always associate the pap with a test for cervical cancer screening. For example, one woman chose the response, "my doctor did not recommend…". She explained her answer by saying that the doctor never specifically said anything about cervical cancer, but that she (the respondent) did get the pap. In developing this theme, it was found that respondents often see the test as indicative of other problems, such as using it as a check for sexually transmitted infection, so they often include those experiences in their answers.

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55. When the doctor recommended you have [FILL ANSWER FROM PREVIOUS QUESTION], how often did the doctor say you should be tested?

Answer	R1	R2
Every 3 years	1	0
Every 6 months	1	0
Every year	5	5
Every 5 years	0	2

This question is largely measuring respondents' knowledge and opinion of the generic guidelines for how often a woman should receive a pap test. Less often are they thinking about something their doctor specifically told them.

Additionally, when respondents did think of a specific discussion, some were including follow-up pap procedures for problems they had treated. (For example, one respondent said that after her hysterectomy they checked her to make sure everything went well with the procedure.) This interpretation could be an artifact of the wording which suggests that a doctor recommended the test. If the test is routine – and, therefore, not perceived as a recommendation – then respondents are prompted to think of pap tests that WERE recommended, and those might have been associated with a problem/treatment and not a routine screening.

SECTION 6: LUNG CANCER

Lack of knowledge was prevalent in this section as well as the previous two. For this series of questions, the main concept being asked about from the respondents' perspective was the CT scan itself. They answered these questions in relation to having that test, regardless of the reason. In fact, many times the respondent did not know the reason for having the test. Respondents would report having this test done, but they were not necessarily thinking about it in relation to routine screening for lung cancer.

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56. A CT scan of your chest area is a test during which you are lying down and moved through a donut shaped x-ray machine while holding your breath. It is a new type of test to check or screen for lung cancer. Before today, have you EVER HEARD of a CT scan of your chest area to check or screen for lung cancer?

Answer	R1	R2
Yes	14	14
No	3	1

Most respondents report that they have heard of this test and many times this was because they, themselves, had the procedure. However, the words "check" and "screen" appear to be two different concepts. Probing revealed that many respondents were not thinking of this test in relation to lung cancer screening. Examples of what respondents were thinking include having a "virtual physical", pre-surgery procedures, and diagnosis of a physical symptom that may have not had anything to do with cancer. Some respondents did suspect their doctor may have been checking for lung cancer, but not as a routine screening.

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57. Have you ever discussed getting a CT scan of your chest area to check or screen for lung cancer with your doctor or other health professional?

Answer	R1	R2
Yes	9	10
No	6	4

There are multiple judgments respondents must make about this question before being able to answer it. First, respondents must decide what constitutes a discussion with their health care provider. For example, one respondent said she and her doctor did not discuss the test in terms of whether or not to have one. She said that it was performed without negotiation because it was a way of clearing her for upcoming surgery. This was a common theme throughout these questions. Many people do not perceive being given a choice in having tests done, so there is no "discussion" in this regard.

Second, since there often was no perceived discussion, respondents were thinking about what they actually had and NOT what they talked about. For example, one respondent answered 'no' and explained "I had a scan, but I was standing, not lying down." Another respondent gave a similar reply: "It was a scan but I wasn't moving. It was moving around you." These respondents were answering whether or not they every HAD a CT scan, not whether they ever discussed getting one with their doctor. (Note: this made question 61 – have you ever had a CT scan – seem repetitive to them because in their mind they already answered that question here, in question 57.)

Finally, respondents have to decide what counts as a "screening." Several respondents answered 'yes' because they had the test as a diagnostic procedure for a physical problem they were having. For example, one respondent was having such trouble breathing that she went to the ER. They did a CT scan of her lungs and diagnosed her with pneumonia. Another respondent was having pain in her chest. She said they did a CT scan to check for lung cancer. "They did a gastro check, too, to check my stomach." She also saw a cardiologist. Nothing was ever diagnosed and the pain eventually subsided. A couple other respondents had other forms of cancer (breast and prostate) and said 'yes' to this question because their doctor ordered the CT scan to check that their cancer had not spread.

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58. Did the doctor or other health professional EVER talk with you about the advantages of lung cancer CT screening?

Answer	R1	R2
Yes	6	9
No	3	1

The concept of what constitutes a discussion was present in this question as it was in the others. One respondent answered 'yes' but explains that it was not exactly a discussion because "the doctor just said to do it to check for cancer if you're a smoker." In a similar vein, another person said "Implicitly, yes. I mean, he sent me there without going into depth." For some respondents the fact that a doctor orders a test is proof enough that he or she thinks it's advantageous. However, this is a very different premise from having a discussion in which the doctor explains the advantages/disadvantages in order for the patient to make his or her own decision. Additionally, respondents were not always thinking about having this test for lung cancer screening. They often had the test for diagnostic purposes for any condition and were including these experiences in their answers.

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59. Did the doctor or other health professional EVER talk with you about the disadvantages of lung cancer CT screening?

Answer	R1	R2
Yes	5	5
No	3	5

A couple respondents answered 'yes' to this question even though they had no specific recollection of such a discussion. They just assumed that their doctor would have mentioned this. One person said, "I'm pretty sure he did." Another said, "I'm going to answer yes." When asked what he was thinking, he said that he just assumed it would have been mentioned.

Also, several respondents interpreted the question (and answered it) based on the disadvantages of NOT having the test (a similar interpretation to that found in question 47 on mammograms). And finally, as with previous questions, some respondents were answering based on their experience with the test being used for diagnostic purposes of any condition, not just cancer.

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60. What possible harms did you and the doctor discuss?

Answer	R1	R1
CT scans sometimes find slow-growing cancers that may never have caused problems	2	1
False-alarms because CT scan can find spots that are not lung cancer and do not need treatment	2	1
Follow-up tests that are needed to find out if lung spots are cancer or not may have complications	2	2
Radiation exposure over time	5	3

For respondents who interpreted the previous question as the disadvantages of NOT having the test, this question was odd. As a result, their answers do not reflect what the question is trying to capture. Instead, respondents would simply choose the options that sounded most reasonable to them, devoid of any actual conversation that was had between them and their health care provider. In fact, most respondents did not answer this question in relation to what a health care provider actually told them. For example, one respondent answered, "Pretty much all of that." When asked to explain, she said the doctor did not discuss this, but gave her information pamphlets. Several respondents gave answers based on pamphlets they received from the doctor's office, not based on verbal conversation.

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61. Have you EVER HAD a CT scan of your chest area to check or screen for lung cancer?

Answer	R1	R2
Yes	8	10
No	7	4

As mentioned earlier, many respondents essentially answered this question when they answered question 57. One person commented, "We already answered that." (The interviewer administered the question again and she answered "yes".) Those who answered 'yes' were often not thinking of routine lung cancer screening. They were thinking of having the test for the diagnosis of a physical symptom or problem they were having, such as pneumonia, chest pain, trouble breathing, prostate cancer (to see if it spread), bronchitis and asthma.

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

Answer	R1	R2
A year ago or less	4	4
More than 2 but not more than 3 years	0	1
More than 1 year but not more than 2 years	2	3
More than 3 years but not more than 5 years	2	2

Aside from the conceptual issues already discussed (the lack of incorporating the notion of lung cancer screening into their interpretations), no recall issues were found here. Respondents could generally remember when the last test was done – largely because they remembered when they were having symptoms that were serious enough to warrant a CT scan.

63. How many CT scans of your chest area have you had in the LAST 3 YEARS?

Answer	R1	R2
1	3	7
2	1	1
3	2	1

This question performed similar to question 62. Aside from the conceptual issues already discussed (the lack of incorporating the notion of lung cancer screening into their interpretations), no recall issues were found here. Respondents could generally remember how many tests they have had.

64. Who first raised the idea of getting a CT scan of your chest area to check or screen for lung cancer? Was it you, or was it a health care provider?

Answer	R1	R2
Health care provider	7	8
You	0	2

Again, many respondents were not answering this question in the context of cancer screening. Several had gone to the doctor for symptoms they were having, such as pneumonia, chest pain, trouble breathing, bronchitis and asthma. One person said, "I know that I was having trouble breathing…so I asked from a referral to get a CT scan." Some were having follow ups from other forms of cancer (prostate and breast) to check if the cancer had spread.

65. Was your CT scan part of a plan to be checked or screened for lung cancer regularly, even if there is no reason to think you have lung cancer?

Answer	R1	R2
No	4	3
Yes	0	2

This question was confusing for some respondents because many were not answering these series of questions in the context of routine cancer screening. They were thinking about it being used to determine the cause of symptoms they were having that could be related to many different conditions. As a result, the question sometimes had to be repeated and respondents answered 'no' because no further tests were scheduled – they had already been diagnosed.

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66. Before you had a CT scan to check or screen for lung cancer, did a doctor EVER tell you that the best way to prevent lung cancer is to stop smoking if a current smoker (or do not restart if an ex-smoker)?

Answer	R1	R2
Yes	7	8
No	0	2

Because respondents were not following the premise of this series of questions, they essentially heard only the last part of this question and answered whether their doctor even told them to stop smoking. In general, respondents were not thinking about this advice in relation to having had a CT scan for lung cancer.

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67. 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	3	1
When doctor recommends it	5	6
Never	0	2

Again, respondents were not necessarily thinking of cancer screening when answering this question. They were thinking of their experience with the test as a diagnostic tool. For example, one respondent said, "It depends on if anything [a problem] comes up again." Several other respondents expressed this same idea.

SECTION 7: PROSTATE CANCER

The overarching theme for this section relates to what it means to have a discussion with a health care provider. Most respondents do not perceive their relationship with their provider in terms of having a conversation that is give-and-take and which actively involves the patient in the decision-making process. As a result, the questions asking about those conversations functioned more as attitude questions – respondents were not thinking about what information their doctor conveyed to them about the PSA test. They were thinking more about what they, themselves, believe about the PSA test, irrespective of how they formed that opinion.

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68. Have you ever discussed getting a PSA test with your doctor or other health professional?

Answer	R1	R2
Yes	5	5
No	1	0

Respondents answered 'yes' to this question for different reasons. 'Yes' sometimes meant that it was part of a routine physical exam and sometimes it meant that the respondent asked the doctor for the test. When the respondent requested the test, it was either because he had heard of the test and understood it to be something that men should have or because he was having a problem and was seeking diagnosis.

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69. Who first raised the idea of getting a PSA test? Was it you, or your doctor or other health professional?

Answer	R1	R2
You	3	2
Your health care provider	1	2

In round one we found that respondents could have difficulty if the test was part of a routine physical. One respondent did not provide an answer because his perception was that no one made the choice – it was simply part of his yearly check-up. We added the category 'neither' in round 2 to accommodate this interpretation. However, most respondents were able to make a choice.

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70. Did your doctor or other health professional ask how you felt about PSA testing?

Answer	R1	R2
No	6	3
Yes	0	1

Almost all respondents answer 'no' to this question. There was not much description around the fact that respondents had a conversation with their health care provider about whether or not to get the test. Some described it as routine (and, therefore, with little to discuss) or as something they asked for and their doctor readily provided. One respondent, however, was thinking of his treatment for prostate cancer, not the screening test for it.

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71. Have you EVER HAD a PSA test?

Answer	R1	R2
Yes	5	4
No	1	0

No error was found for this question. All respondents understood that this was a check for prostate cancer, but this was likely due to the fact that men who had ever had a PSA test were purposely screened into the sample.

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72. Which of the following best describes the decision to have the PSA test done?

Answer	R1	R2
Your doctor/nurse/ other health professional and you made the decision together	3	3
Your doctor/nurse/ other health professional made the decision	1	0
You made the decision	0	1

The concept of making a decision to get this test did not always resonate with the way respondents thought about it. When the test was understood as part of a routine exam, there is no decision, it's simply standard procedure. For example, one respondent explained, "For many men my age, it's part of a physical exam." One respondent couldn't give an answer as a result of this reasoning, but others with the same rationale chose 'your doctor and you made the decision'.

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73. Which of the following best describes the decision not to have the PSA test done?

This question wasn't tested – all respondents had the PSA test.

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74. Has a doctor or other health professional ever told you that... ...The PSA test is not always accurate?

Answer	R1	R2
Yes	3	2
No	3	2

This series of questions, from 74 to 79, tend to capture respondents' knowledge or opinion of the PSA test, irrespective of where they acquired this knowledge. In other words, respondents consider multiple sources of information when answering these questions, including not just their health care providers but also TV, the Internet, family and friends. One respondent specifically said, "I wasn't told by him, but I've heard it can [lead to serious side effects]." Another person said he tends to hear the good things about the test from his doctor and the bad things from the news and media. Other respondents were thinking about what they knew from the media only. As such, these questions function as attitude questions as much as they are a measure of what kind of information is conveyed from doctor to patient.

Additionally, two respondents were thinking of their experiences of having prostate cancer when answering these questions. They were not thinking about the test that led to their diagnosis.

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75. Has a doctor or other health professional ever told you that... ...Some types of prostate cancer are slow-growing and need no treatment?

Answer	R1	R2
Yes	1	2
No	5	2

Time limits prevented a full exploration of this question, however the same pattern found in question 74 is relevant here.

76. Has a doctor or other health professional ever told you that... ...Prostate cancer usually does not grow or cause health problems in men who have it?

Answer	R1	R2
No	3	1
Yes	0	1

Time limits prevented a full exploration of this question, however the same pattern found in question 74 is relevant here.

77. Has a doctor or other health professional ever told you that... ...Treating any type of prostate cancer can lead to serious side-effects, such as problems with urination or having sex?

Answer	R1	R2
Yes	4	3
No	2	1

Time limits prevented a full exploration of this question, however the same pattern found in question 74 is relevant here.

78. Has a doctor or other health professional ever told you that... ...No one is sure if using the PSA test actually saves lives?

Answer	R1	R2
Yes	1	0
No	5	3

Time limits prevented a full exploration of this question, however the same pattern found in question 74 is relevant here.

79. Has a doctor or other health professional ever told you that... ...The PSA test can help some men avoid death from prostate cancer?

Answer	R1	R2
Yes	3	4
No	3	0

Time limits prevented a full exploration of this question, however the same pattern found in question 74 is relevant here.

SECTION 8: COLORECTAL CANCER

Respondents were predominantly thinking of colonoscopies when answering these questions. They were much less familiar with the FIT test, but some did report having their stool checked for blood. However, as with other sections, respondents were not limiting their answers to routine cancer screening. They also included diagnostic tests for problems they were having checked out.

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80. Have you ever discussed getting a test to check for colon cancer with your doctor or other health professional?

Answer	R1	R2
Yes	10	11
No	4	2

In this question, most respondents were thinking of colonoscopies. Moreover, like the other cancer screening questions, some respondents do not understand the question to be about routine colon cancer

screening, but rather about tests they have had in relation to obtaining a diagnosis for problems they were having. For example, one respondent answered 'yes' because he gets colonoscopies in relation to a chronic GI condition that he has to manage, and another respondent said 'yes' because the procedure was done to diagnose a problem she was having with digestion.

The concept of "having a discussion" with a physician was sometimes missed by respondents. A couple answered 'yes' simply because they had had colonoscopies – they were not thinking of any specific discussion with their doctor. Also, the concept of who initiates the discussion came up again in this question. One respondent answered 'no' because she did not raise the subject herself. "I haven't discussed it. He's discussed it with me." It's likely this respondent should have answered "yes".

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81. The blood stool or occult blood test, or fecal immunochemical or FIT test, are tests to determine whether you have blood in your stool or bowel movement. These tests can be done by the doctor or lab. Has your doctor or other health professional EVER told you about these tests to check for colon cancer?

Answer	R1	R2
Yes	11	9
No	3	5

Most of the respondents were unsure of this test by name, but did know if they ever had a test to check for blood in their stool. Some, however, were unclear about the question in general. This lack of knowledge can lead to error. For example, one respondent answered 'yes' and explained that she had a test where she had to drink a gallon of fluid and they "put her in a twilight sleep" and went into her rectum. This was clearly not the FIT test but more likely a colonoscopy.

In addition to not knowing what the FIT test is, many respondents were answering for procedures they actually had, not ones that they talked about with their doctor. These patterns were common throughout the cancer screening questions.

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82. Did your doctor or other health professional say that these tests are a good way to check for colon cancer?

Answer	R1	R2
Yes	8	8
No	1	0

Many respondents answered 'yes' to this question, but several had no memory of an actual discussion with their health care provider. Instead they answered on the basis of personal opinion (of whether they think colonoscopies are a good way to check for colon cancer) or on the assumption that their doctor must think the tests are good, otherwise the doctor would not have ordered it.

Several respondents were thinking of experiences they had with the diagnosis of a problem they were having, which sometimes had nothing to do with cancer but with other GI issues. And finally, some respondents were thinking only of colonoscopies – not the FIT test – when they answered this question.

83. Did your doctor or other health professional describe the ADVANTAGES of the blood stool or FIT test as an option to check for colon cancer?

Answer	R1	R2
Yes	1	3
No	3	3

See next question for a discussion of findings.

84. Did your doctor or other health professional describe the DISADVANTAGES of the blood stool or FIT test as an option to check for colon cancer?

Answer	R1	R2
Yes	2	3
No	7	6

Respondents who initially focused on colonoscopies in this series of questions continued to do so with questions 83 and 84. Similarly, respondents continued to think of diagnostic experiences, not routine cancer screenings. This question on disadvantages of the FIT test performed similar to other questions asking respondents about disadvantages of a given test – a couple interpreted it as the disadvantages of NOT having the test. This makes sense in light of the fact that many respondents think about diagnostic procedures when answering these questions. If a doctor orders a diagnostic test, it doesn't make sense to think of it as disadvantageous, so respondents interpret the question in a way that makes sense to them and their experiences.

85. How much did you pay for your most recent colonoscopy? Was it all, part, or none of the cost?

Answer	R1	R2
None of the cost	5	7
Part of the cost	4	3

This question was not extensively probed, but it performed similarly to the same question in other sections (questions 36 and 50). The phrase "out of pocket" was added in round 2 because it seemed clearer to respondents.

SECTION 9: GENETIC TESTING

In this section respondents were thinking differently about genetic counseling vs. genetic testing. They were mildly confused about what genetic counseling would entail, despite the introduction defining the concept. However, only two respondents reported ever having genetic counseling.

86. Has a doctor or health professional ever recommended or referred you to get genetic counseling because of your family history of cancer?

Answer	R1	R2
Yes	4	1
No	16	17

Several concepts are embedded in this question and can give rise to a variety of interpretations. The first relates to who actually brings up the topic of genetic counseling and the second relates to how one understands the term "genetic counseling".

One respondent answered 'no' to this question because she, herself, brought it up, not her doctor. This distinction regarding who initiates the discussion was one that was found in other questions that also ask about discussions respondent have with health care providers.

Also, respondents who answered 'yes' were tending to think of tests they had to check for the particular cancer that ran in their family. Because pancreatic cancer ran in one respondent's family, her doctor did a CT scan of her abdomen to see if her pancreas looked normal. Another respondent said he received genetic testing that showed he inherited a recessive, benign "prostate cancer" gene. But he differentiated this from genetic counseling. In other words, respondents were not limiting their answers to conversations about genetic counseling. Another respondent asked her doctor for genetic counseling and "the test came back negative and that was it." She did not recall receiving any actual counseling.

In sum, regardless of the presence or absence of response error, the reasoning demonstrated by these respondents suggests that the concept of genetic counseling is thought of as different from actual testing. Moreover, the concept of testing can involves multiple things such as CT scan or genetic profiling.

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87. Have you ever received genetic counseling for cancer risk?

Answer	R1	R2
Yes	2	0
No	19	18

Respondents thought about this question similar to the way they thought about the previous. The two respondents who answered 'yes' to this question were thinking of tests they actually received. One had a CT scan of her abdomen and the other had genetic testing of his genes to determine his risk for prostate cancer.

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88. Please think about your MOST RECENT genetic counseling session for cancer risk. Which kind of cancer was it for? Breast cancer?

Answer	Cases
No	1

Question was not sufficiently tested – only one respondent answered yes and there was no error (she was tested for pancreatic cancer).

89. Please think about your MOST RECENT genetic counseling session for cancer risk. Which kind of cancer was it for? Ovarian cancer?

Answer	Cases
No	1

Question was not sufficiently tested – only one respondent answered yes and there was no error (she was tested for pancreatic cancer).

90. Please think about your MOST RECENT genetic counseling session for cancer risk. Which kind of cancer was it for? Colon or rectal cancer?

Answer	Cases
No	2

Question was not sufficiently tested – only two respondents answered yes and there was no error (one was tested for pancreatic and the other for prostate cancer).

91. Please think about your MOST RECENT genetic counseling session for cancer risk. Which kind of cancer was it for? Another type of cancer?

Answer	Cases
Yes	2

Question was not sufficiently tested – only two respondents answered yes and there was no error (one was tested for pancreatic and the other for prostate cancer).

92. Please think about your MOST RECENT genetic counseling session for cancer risk. Which kind of cancer was it for? Specify other cancer for which received genetic counseling

Question was not sufficiently tested – only two respondents answered yes and there was no error (one was tested for pancreatic and the other for prostate cancer).

93. Compared to the average {man/woman} your age, would you say that you are more likely to get colon or rectal cancer, less likely, or about as likely?

Answer	R1	R2
About as likely	4	6
Less likely	10	8
More likely to get colon or rectal cancer	3	1

With this set of three questions, respondents made their judgments based on genetics, lifestyle or both. Lifestyle was the most common factor. One respondent exemplifies the rationale respondents used. "I try to eat well. I try to exercise. I just try to do the right things. Drink plenty of fluid…juices…less alcohol." Using a different rationale, one respondent said 'less likely' because "It's not hereditary. It doesn't run in my family."

However, the question can give respondents trouble when they think of and weigh in both factors (genetics and lifestyle). Most who did this arrived at an answer, but one respondent could not. She said, "I don't know. I have a history of cancer, so maybe." But then she said that weight, race, income, insurance, and diet play a role too. So when she takes those factors into account, she thinks her chances are less. Most respondents, however, did not think in complicated ways and were able to answer these three questions.

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94. Compared to the average woman your age, would you say that you are more likely to get breast cancer, less likely, or about as likely?

Answer	R1	R2
About as likely	4	4
Less likely	3	4
More likely to get breast cancer	4	1

Time limits prevented a full exploration of this question. See question 93 for general findings that apply here.

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95. Compared to the average woman your age, would you say that you are more likely to get ovarian cancer, less likely, or about as likely?

Answer	R1	R2
About as likely	4	4
Less likely	4	6
More likely to get ovarian cancer	1	0

Time limits prevented a full exploration of this question. See question 93 for general findings that apply here.

SECTION 10: FAMILY HISTORY

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96. The next few questions are about the number of your second-degree relatives who have been diagnosed with breast or ovarian cancer. How many of your grandparents, aunts, uncles, nieces, nephews, or grandchildren have ever been diagnosed with breast cancer?

Respondents answered this question to the best of their knowledge, even if they didn't know everything about their family medical history. Many would not have known what "second-degree relative" meant without the specific examples given in the actual question. Only one response error was found for one respondent who was thinking of any form of cancer, but most respondents did catch the fact that the questions asked about a specific type of cancer.

97. How many of them were diagnosed with breast cancer before the age of 50?

Only 5 people answered this question, so not much data was collected on it. No issues surfaced regarding interpretation or difficulty – the concept of breast cancer was not confusing.

98. How many of your grandmothers, aunts, nieces, or granddaughters have ever been diagnosed with ovarian cancer?

Time limits prevented a full exploration of this question. See question 96 for general findings that apply here.