

**Cognitive Interview Evaluation of the
2008 National Health Interview Survey
Supplement on Immunizations & Cancer Screenings:**
Results of interviews conducted June - August, 2007

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1. Introduction

This report documents cognitive testing results on the 2008 immunization & cancer screening supplement of the National Health Interview Survey (NHIS). The supplement is sponsored by the National Cancer Institute, National Institutes of Health and the National Center for Immunization and Respiratory Disease, Centers for Disease Control and Prevention. Testing took place in two rounds between June and August of 2007.

Immunization and cancer screening questions will be located in both the sample adult section of the NHIS and the sample child section. Testing focused primarily on vaccines, including HPV, shingles, tetanus, and Hepatitis A and B, and on cancer screenings, including pap test, mammography, fecal occult blood test, and colonoscopy/sigmoidoscopy. The sample child section (administered by proxy to the sample adult) included only questions on the HPV vaccine.

The majority of this report presents a question-by-question analysis of the survey questions. Emphasis is placed on items that have the potential to generate response error, that is, they may not capture the information they were designed to measure. The discussion of these questions includes descriptions of how respondents interpreted question intent and explanations of why and how questions presented problems for respondents. Comments are included for most questions, however, some items were unable to be tested. For example, when respondents reported never having received the HPV vaccine, they skipped out of related follow-up questions.

Because testing took place in two rounds, analysis of the original question is presented first, followed by a rationale for question modification and, where appropriate, results of the second round of testing on the revised questions.¹ Because the HPV vaccine is new, sponsors submitted

¹ The first version of the full instrument tested in round 1 can be found in Appendix A. This instrument contains 4 different versions of the HPV questions that were tested in that round. The second version tested in round 2 is in Appendix B. It includes 2 different versions of the HPV questions (version 1 & version 3 from round 1).

several versions of survey questions to be tested. We used the first round of testing to identify the set of questions that worked best, then further tested only those questions in round 2.

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

2. Methodology

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

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

Sampling and Respondent Demographics

Testing took place in the National Center for Health Statistics (NCHS) Questionnaire Design Research Laboratory (QDRL). We conducted a total of 20 interviews, 9 in the first round and 11 in the second. Respondents were selected with a purposive sample in mind. The goal of a purpose sample is *not* to obtain a statistically representative sample. Instead, respondents are chosen according to characteristics that would screen them into or out of the questions. Emphasis is on coverage of the survey questions and topics not the survey population.

In order to adequately test the HPV questions, we were interested in young women between 18 and 26 and women with daughters between the ages of 8 and 26. If a caller reported having

received the HPV vaccine for either themselves or their daughter, they were recruited for the study.

We also recruited some respondents over the age of 40 in order to test questions on cancer screenings that are age-specific. Demographic diversity among respondents was also sought, especially in regard to socioeconomic status. The demographic breakdown of respondents appears in Table 1.

A newspaper advertisement in the Washington Post (for round 1) and in the Express, a free commuter newspaper (for round 2), did a good job of identifying the respondents we needed and most respondents were recruited this way. However, a couple respondents were drawn from the QDRL database of respondents who have participated in previous studies. Prior to participation, respondents were screened over the telephone in order to identify key demographics such as age, educational attainment, and income level, as well as the extent and nature of their cancer screenings.

At the time of the interview, respondents filled out paperwork whereby they agreed to the interview being video- and audio-taped. The interviewer then explained the purpose of NCHS, described the survey, and told respondents the manner in which the interview would be conducted. After these introductory remarks, interviewers began by administering the survey questions. Once the survey responses were obtained, the interviewer elicited respondent narratives about their knowledge of and experience with various cancer screenings and HPV (both the virus itself and the vaccine). This was followed by question-specific probes designed to reveal respondents' interpretation of the question and the ease with which they chose a response category. Through the comparison of respondents' survey responses to both their narrative and follow-up probing, interviewers were able to ascertain whether or not and why a response error had occurred. Interviews were designed to last 60 minutes and a \$40 token of appreciation was given to respondents.

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

	<u>Round 1</u> (n=9)	<u>Round 2</u> (n=11)	<u>Total (%)</u> (N=20)
<u>Has Daughter in Age Range</u>			
Yes	4	6	10 (50%)
No	5	5	10 (50%)
<u>Respondent Age</u>			
Under 30	4	4	8 (40%)
30-39 years	0	3	3 (15%)
40 and Over	5	4	9 (45%)
<u>Race/Ethnicity</u>			
NH-White	1	4	5 (25%)
NH-Black	8	6	14 (70%)
Hispanic	0	1	1 (5%)
<u>Education</u>			
HS or less	3	3	6 (30%)
More than HS	6	8	14 (70%)
<u>Income</u>			
Under 20,000	2	3	5 (25%)
20,000 & Over	5	8	13 (65%)
Don't Know	1	0	1 (5%)
Lives w/ Parent	1	0	1 (5%)

3. Results

Summary of Findings

a. HPV Question Interpretations

Two general points may be made regarding respondent understandings of HPV, both the virus and the vaccine. First, respondents' knowledge of the topic was generally very limited and second, understandings of the disease varied among respondents.

Limited Knowledge: Most respondents had very little knowledge of what HPV was, even if they were familiar with the term. A lack of adequate knowledge didn't negatively impact the ability of respondents to answer fact-based HPV questions, largely because the (final) questions provided enough information and context for respondents to be able to identify the topic. For example, the first HPV vaccine question tested in round 1, "Have you ever heard of a vaccine or shot to prevent cervical cancer?" produced confusion and response error (especially – but not exclusively – among respondents who didn't understand HPV to be related to cervical cancer). The second question in round 2 provided more information and, consequently, less error. It read,

“A vaccine to prevent human papillomavirus or HPV infection is available and is called the cervical cancer vaccine or HPV shot. Before today, have you ever heard of the cervical cancer vaccine or HPV shot?”

This question does a better job at providing context about what's being asked. Thus, even respondents with little knowledge of the topic were able to answer the question.

Varied Understandings: When respondents understood the term HPV, they saw it as a type of cancer *or* as a sexually transmitted disease. A couple respondents who were more familiar with HPV (because they were either diagnosed with HPV or had worked with women's health issues) understood it to be both sexually transmitted and a cancer risk. However, most respondents saw the virus as one or the other: a cancer or a sexually transmitted disease (STD). As a result, some respondents didn't make the connection between the virus and the vaccine. Many respondents had heard of both, but several had heard of one and not the other.

Understanding HPV as either a cancer or an STD produced few problems and little response error. The more troubling pattern relates to age. Several respondents linked the virus to particular age groups. If respondents were older, the vaccine and virus weren't understood as something they had to worry about – these were seen as young women's issues. When age factored prominently into respondents' understandings of HPV, it influenced the way they understood and answered the questions. Some who understood this to be a young woman's issue were confused by HPV questions directed at them. For reasons having nothing to do with question wording, they interpreted the HPV vaccine questions in the sample child section differently from similar questions in the adult section. They would say they'd heard of the vaccine when answering for their daughter, then say they hadn't heard of it when answering for themselves. In sum, if their understanding of HPV incorporated an age component, respondents who had heard of the vaccine would say they had not, because they knew the vaccine was for

younger women. In essence they interpreted the question as asking “Have you ever heard of a vaccine or shot to prevent cervical cancer and HPV infection *for older women?*”

b. Longer Questions Were Often Better Questions

Respondents’ lack of knowledge was not limited to HPV. Respondents were often unfamiliar with medical terms describing medical procedures, tests or vaccines, even those that might be considered common. On the other hand, sometimes the name of the procedure was familiar, but respondents didn’t have a full understanding of what it was. For this reason, including a definition or description of the procedure in the question helped, even though it made it longer.

Conventional wisdom suggests that longer questions are always more problematic than shorter ones; however, there are exceptions to that rule, and this may be one of them. Many respondents were unfamiliar with the terms fecal occult blood test, and sigmoidoscopy/proctoscopy. In these cases, questions that defined the procedures helped respondents understand what the question was asking. The same was true for some vaccines. Respondents who were unfamiliar with Shingles and Hepatitis A were able to answer the questions because of the background information the items provided.

Other topics considered more commonplace could also benefit from questions that include a brief description. It may be taken for granted that respondents are familiar with hysterectomy, pap smear, tetanus, and Hepatitis B, but cognitive testing showed this to be a mistaken assumption. The actual terms may be more familiar than some, but respondents were still unclear about what they meant. For example, most women were familiar with the words pap smear and hysterectomy, but didn’t have full or accurate understandings of them. The question-by-question analysis reviews the variety of definitions women gave for these terms, and shows that sometimes these misunderstandings led to response error. The same is true for the tetanus shot and Hepatitis B. Respondents had heard these terms before, but were unclear about their purpose and often confused the different vaccines. This made answering the questions difficult. Respondents already have incomplete and sketchy knowledge of their vaccine history; adding confusion over which vaccine the question is asking about only serves to degrade data quality further.

Almost all of these questions do provide a brief definition for the interviewer to read if necessary. However, in no case during cognitive testing did respondents ask for clarification or even express confusion when answering the survey questions. As a result, interviewers were never prompted to actually read the definition to the subject. This pattern is common – respondents rarely ask for clarification. Therefore, it is strongly advised that “read if necessary” definitions be incorporated into the questions themselves.

c. Problems with Attitude Questions

Attitude questions were present in two sections of the instrument, the adult HPV section and the mammogram section. Respondents had some difficulties in both sections, but the mammogram questions were most problematic.

HPV: The attitude questions in the adult HPV section were phrased as “Do you think...?” (See questions QA07_E13 through QA07_E15A in the question-by-question analysis.) It was mentioned earlier that even though many respondents have little knowledge of HPV, this had minimal impact on their ability to answer fact-based questions on the topic. However, the same pattern did not hold true for the HPV attitude questions. Respondents who knew little about HPV did not feel comfortable answering knowledge questions about it. Even though the questions asked them what they *thought* to be true, respondents were reluctant to answer, and sometimes didn’t. Many didn’t want to give a wrong answer, some had no idea at all, and others had some information but didn’t necessarily believe it themselves and, therefore, wouldn’t report it.

In the end, respondents didn’t seem to understand that they could speculate if they didn’t know or weren’t sure. Short of pulling the questions from the survey altogether, it would be worthwhile to add a short introduction informing respondents that they aren’t expected to know all the answers and that it’s perfectly acceptable to speculate.

Mammogram: The mammogram attitude questions were very difficult for respondents to answer, chiefly because the intent of the questions wasn’t obvious to them. However, the shift from fact-based to attitude questions, along with the shift from yes/no questions to agree/disagree statements, probably helped add to the confusion. As a result, there were a variety of different interpretations of the questions, resulting in incomparable answers and low construct validity.

The respondents were confused about whether the questions were asking about their own opinion or about someone else’s. Some respondents reported what they thought medical experts believed, but others reported what they, themselves, believed.

A second interpretation problem relates to what kind of recommendations the items referred to. Some respondents understood the first two attitude questions to be asking whether medical experts suggest getting mammograms at all, while others thought that *any* inconsistent message about mammogram was being asked about. For example, some respondents agreed with the statement not because they thought medical experts have different views about getting a mammogram, but because they thought medical experts have differing views about *how often* women should get one. Others with the same notion would disagree with the statement because they thought it was asking simply whether women should have mammograms.

Finally, some respondents answered the questions based on personal experience, while others gave more generalized beliefs that were detached from their actual experience or behavior. For example, several respondents agreed with the statement that “there are so many different recommendations about mammography, it’s hard to know which ones to follow.” Yet their narratives show that they personally had very clear ideas about the value of and frequency with which one should have a mammogram. In reality, it’s not difficult at all for them to know which recommendations to follow. The opinions measured by these items didn’t always line up with personal beliefs or actual behavior. Some respondents’ answers reflect their acknowledgement that *some women* (not themselves) might be confused about different recommendations.

Because these questions performed so poorly, sponsors re-thought the underlying constructs and replaced them with the following:

1. Have you ever read or been given conflicting information about whether you should get a mammogram? [If yes ask...]
2. Did this conflicting information cause you to delay or not get a mammogram in the past year?

To the extent that the second question asks respondents to assess causality for their behavior (a notoriously difficult task because people often do not know why they behave the way they do), it might still pose some challenges to validity. However, these questions are likely an improvement over the original ones tested.

Question-By-Question Analysis

Parental Consent for HPV Vaccine:

QA07_I65 Have you ever heard of a vaccine or shot to prevent cervical cancer?

NEW

YES	1	} [GO TO QA07_I67]
NO	2	
REFUSED	-7	
DON'T KNOW	-8	

Round 1 Results: This section was tested on 4 respondents (others with no daughters skipped out). Two of the four respondents demonstrated false negative response error.

One respondent did not understand the vaccine to be associated with cervical cancer. She saw it as an STD and, therefore, didn't make the connection until she heard the follow-up questions. Upon hearing those questions, she changed her answer to this question from no to yes.

The second respondent answered "no" in error because she also didn't initially understand the first question to be asking about HPV. This became clearer to her when she heard question QA07_I67 that uses the expression "HPV" and briefly describes what it is. Still, this respondent's main concern was in giving her daughter too many vaccines in general; she felt as though she doesn't know enough about the HPV vaccine to allow her daughter to receive it. She did not talk about this as an issue related to sexual activity, but rather as an issue related to the wisdom of administering vaccines to children.

Recommendation: Some people will know exactly what this question means (one respondent answered "That's the HPV or Gardasil shot"). However, many respondents probably need this first question to be more descriptive. Some people will have heard of this vaccine, but won't know enough about it to understand the intent of a question that doesn't give enough information about the topic. See more on this topic in the adult HPV section.

NEW QUESTION IN ROUND 2:

QA07_I65 A vaccine to prevent human papillomavirus or HPV infection is available and is called the cervical cancer vaccine or HPV shot. Before today, have you ever heard of the cervical cancer vaccine or HPV shot?

Round 2 Results: This section was tested on 8 respondents (others with no daughters skipped out). The question was modified to give respondents a better sense of the topic and what the question was asking. A false negative was found for one respondent.

Two respondents were fairly well informed about HPV (one because she had been diagnosed with HPV and the other because she works in international women’s health) and had no trouble answering the question. Five respondents who had very limited knowledge of HPV were still able to answer the question.

However, response error was detected for 1 respondent with little knowledge. She answered “no” to the question even though she admitted during probing that she has, in fact, heard of HPV, cervical cancer and the vaccine for it. She answered “no” because she doesn’t know anything about these topics. So even though she’s heard these terms she doesn’t feel comfortable answering questions about them. This pattern continues in the adult section, where she will not answer knowledge questions about HPV.

Round 2 Recommendation: This question was an improvement over the one tested in round 1 to the extent that it gave more information about the topic and produced less response error. This is extremely helpful for respondents with little knowledge about HPV. However, there remains the possibility that, even when a respondent understands the question, she will respond in error if she makes the assumption that to answer these questions she must possess some basic knowledge of the topic. This may be an untrue assumption, but it’s not an unreasonable one. Perhaps a brief preamble to the section (indicating that respondents need not have extensive knowledge of the topic) might encourage more people to respond.

QA07_I66 Did {DAUGHTER} ever receive the HPV vaccine or HPV shots?

NEW

YES	1	} [GO TO PN QA07_I67]
NO.....	2	
REFUSED	-7	
DON'T KNOW	-8	

Round 1 Results: No response error detected. Respondents gave answers that demonstrated they had a basic understanding of what the HPV shot was. One person’s daughter was actually scheduled to get the shot the following week, and the other said her pediatrician suggested putting it off since her daughter is only 10 (and not, therefore, sexually active) and her insurance doesn’t pay for it yet.

Recommendation: None. Continue to test as-is.

Round 2 Results: This question was tested on 7 respondents (1 skipped out, 3 had no daughters). No interpretation problems or response error was detected.

Round 2 Recommendation: None.

QA07_E66a Did {DAUGHTER} receive all three doses of the HPV vaccine?

YES	1	} [GO TO NEXT SECTION]
NO.....	2	
REFUSED	-7	
DON'T KNOW	-8	

Round 1 Results: Not tested; all respondents skipped out.

Recommendation: None. Continue to test as-is.

Round 2 Results: This question was tested on only 2 respondents (other skipped out). No response error was obvious, but a lack of knowledge does give cause for concern.

One respondent said her daughter received all three shots, and seemed very confident in her answer. However, she indicated that the time in between shots is about 1 ½ weeks. Her daughter received the first shot in April and by August (the time of the interview) she had completed all three shots. If the time in between shots is longer, it would not be possible for her daughter to have completed all shots. This leaves one to wonder if the respondent misreported the vaccine type or misreported the month of the initial shot. The former would result in response error for the previous question.

Round 2 Recommendation: Since there's no way to know what the respondent misreported (the date of first shot or the type of vaccine itself), it's difficult to pinpoint a remedy. One cannot ask a respondent for information they simply don't have.

QA07_I67 {HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26.} If {DAUGHTER}'s doctor recommended the HPV vaccine, would you have her get it?

NEW

YES 1 [GO TO QA07_I69]
NO 2
DON'T KNOW -7
REFUSED -8

Round 1 Results: No response error detected. However, note that this was a bit awkward for one respondent who had already decided to get the vaccine for her daughter and had it scheduled for next week. In this situation, the question makes the assumption that if a parent has not gotten the shot for her child, she doesn't intend to.

Recommendation: Because the question was simply awkward and didn't produce actual response error, no suggestions are indicated at this time.

Round 2 Results: This question was tested on 7 respondents. Three had difficulty due to the age of their daughter.

Two respondents with daughters in their early 20's said the decision would be up to the child. As one respondent said, "I would strongly encourage her to, but because she's 21 I can't make her. I would pay for it." Since the NHIS sample child section asks only about children under 18 years old, this is not a problem. However, one respondent had the same difficulty answering for her 16-year-old daughter, saying, "That would be her choice. I would let her know about it and it would be up to her...how she feels."

Round 2 Recommendation: To avoid the problem discussed above, the last clause could be softened to allow parents to acknowledge input from their child, especially teenagers. It could be changed to something like "...would you want her to get it?"

QA07_I68 What is the MAIN reason you would NOT want {DAUGHTER} to get the vaccine?

NEW

DOES NOT NEED VACCINE 1 [GO TO NEXT SECTION]
NOT SEXUALLY ACTIVE 2 [GO TO NEXT SECTION]

TOO EXPENSIVE	3	[GO TO QA07_I70]
TOO YOUNG	4	}
DOCTOR DIDN'T RECOMMEND IT	5	
WORRIED ABOUT SAFETY OF VACCINE	6	
DON'T KNOW WHERE TO GET VACCINE	7	
MY SPOUSE/FAMILY MEMBER IS AGAINST IT	8	
SECTION]		
DON'T KNOW ENOUGH ABOUT VACCINE	9	
OTHER.....	10	
REFUSED	-7	}
DON'T KNOW	-8	

[GO TO NEXT

Round 1 Results: This question may not be getting the “main” reason. It was administered as an open-ended question, with the interviewer coding the response. Two respondents received the question.

Both respondents were able to provide an answer, but it didn't reflect their most important reason. The first subject answered #6 (worried about safety) but her narrative suggested that the main reason is that her daughter is too young and is, therefore, not sexually active.

A similar discrepancy occurred with the second respondent who initially answer #9 (don't know enough about vaccine). Probing suggested that she's actually worried about the safety of the vaccine because it's so new – she said kids already receive so many vaccines she's cautious about rushing into another one...“if it [*cervical cancer*] doesn't run in your family, should you jump on it?” The interviewer code of #9 isn't exactly inappropriate, but it's hard to say if #6 wouldn't be better.

Recommendation: Keep question as-is for now, and continue testing. Need more data.

Round 2 Results: This question was tested on only 1 respondent. Fitting her answer into a response option was not straightforward. Her actual response was, “Because there is the stipulation of age. There seems something wrong with that picture.” It didn't make sense to the respondent that a vaccine of this nature is offered only to girls and young women. If it protects against cancer then all women should be able to get it. The interviewer chose option 9 (don't know enough about vaccine), but that doesn't capture the essence of what the respondent was communicating.

Round 2 Recommendation: None. Asking respondents “why” questions in a close-ended format is necessarily fraught with problems. Response options that aren't inductively created – and that are designed to capture a complex phenomenon – rarely adequately reflect the reality of many people's situation.

QA07_I69 The cost of the vaccine may be about \$360-500. Would you have {DAUGHTER} get the vaccine if you had to pay this amount?

NEW

YES	1	[GO TO NEXT SECTION]
NO.....	2	[GO TO QA07_I70]
REFUSED	-7	[GO TO NEXT SECTION]
DON'T KNOW	-8	[GO TO NEXT SECTION]

Round 1 Results: Two respondents were tested and both had problems.

One respondent answered “no” because she assumed the question was asking if she could pay this amount in one lump sum – she can’t. But if she could work out a payment schedule with the doctor, she would be willing to pay up to \$500.

The question was too hypothetical for the second respondent and elicited a hypothetical response (“it depends”). Her daughter is 10 and not sexually active – therefore she can wait until her insurance provider covers the cost. But if her daughter were a teenager she would get it now regardless if it were covered or not. So the decision to pay depends on the age and sexual activity of her daughter.

Recommendation: Continue to test as-is. Need more data on patterns of interpretation.

Round 2 Results: This question was tested on 6 respondents. One had enough difficulty that she couldn’t provide an answer, saying “it depends...if she needs it then yes, if she doesn’t, then no.” The respondent had no knowledge of the conditions under which women should receive this vaccine so she couldn’t answer the question.

Round 2 Recommendation: This question is very hypothetical and has the potential to produce very unreliable estimates. Consider dropping it.

QA07_I70 If {DAUGHTER} could get the vaccine free or at a much lower cost, would you have her get it?

NEW

YES 1
NO 2
REFUSED -7
DON'T KNOW -8

Round 1 Results: Only tested on one person.

Recommendation: None. Continue to test as-is.

Round 2 Results: Only tested on one person.

Round 2 Recommendation: None.

FOBT

QA07_B30 A stool blood test, also known as a Fecal Occult Blood Test, is a test to check for colon cancer. It is done at home using a set of 2 or 3 cards to determine whether the stool contains blood. Have you ever done a stool blood test using a home kit?

Alternative Wording: A stool blood test or fecal blood test is a test done at home to check for colon cancer. You use a stick or brush to obtain one or more stool samples, and return the samples to the doctor’s office or laboratory. Have you ever done a stool blood test using a home kit?

AF22

YES 1
NO 2 [GO TO QA07_B33]
REFUSED -7 [GO TO QA07_B33]

DON'T KNOW -8 [GO TO QA07_B33]

Round 1 Results: This section was tested on 5 respondents (others were under 40). One respondent may have had response error. She answered no to the question, but probing revealed that she did have this test 2 years ago in 2005. She was part of an NIH study for a mosquito vaccine. Twice a day for three days she used a stick to put a stool sample in what she described as a little pill case. She didn't know why they were checking her stool, just that it was part of the study protocol.

Other respondents had no trouble with this question. Even when they weren't sure of the expression "fecal occult blood test," the rest of the description got the point across. The alternate wording didn't seem to make a difference one way or the other. The description of the test is probably adequate enough that the use of "cards" vs. "stick/brush" has no impact on respondent interpretation of the question.

Recommendation: No changes suggested at this time. Collect more data using either version of the question.

ROUND 2 QUESTION WORDING:

QA07_B30 The following questions are about the blood stool or occult blood test, a test to determine whether you have blood in your stool or bowel movement. The blood stool test can be done at home using a kit. You use a stick or brush to obtain a small amount of stool at home and send it back to the doctor or lab. Have you EVER HAD a blood stool test, using a HOME test kit?

Round 2 Results: This question tested on 9 respondents (2 skipped because of age). No response error or difficulties were detected. Respondents were not always familiar with the terms "blood stool or occult blood test" but the question was descriptive enough to allow them to answer.

Round 2 Recommendation: None. Question performs well.

QA07_B31 When did you have your most recent stool blood test using a home kit to check for colon cancer?

AF24

A YEAR AGO OR LESS1
MORE THAN 1 YEAR AGO UP TO
2 YEARS AGO2
MORE THAN 2 YEARS AGO UP TO
5 YEARS AGO3
MORE THAN 5 YEARS AGO4
REFUSED -7
DON'T KNOW -8

Round 1 Results: Question not tested – respondents skipped out.

Recommendation: None.

Round 2 Results: Question tested on only 2 respondents. There were some recall issues, but the large response options were able to absorb the imprecision. For example, one respondent answered, "I would estimate it's been more than 5 years...maybe more than 7 years."

Round 2 Recommendation: None.

QA07_B35 What was the main reason you had your most recent stool blood test using a home kit?
Was it...

NEW

- PART OF A ROUTINE EXAM.....1
- BECAUSE OF A PROBLEM, OR2
- SOME OTHER REASON.....3
- REFUSED -7
- DON'T KNOW -8

Round 1 Results: Question not tested – respondents skipped out.

Recommendation: None.

Round 2 Results: Question dropped in round 2.

NEW QUESTION TESTED IN ROUND 2:

QA07_B35 [if most recent screening exam 1 year ago or less, read:]

Was your most recent HOME blood stool test recommended by a doctor or other health professional?

[else if *never* had a FOBT or last test more than 1 year ago, read:]

In the PAST 12 MONTHS, has a doctor or other health professional RECOMMENDED that you have a HOME blood stool test?

Round 2 Results: This question tested on 6 respondents. One had an interpretation problem and likely response error with the word “recommend.” She had the test done as a “routine check-up” 4 or 5 years ago and answered “no” to the question. She said the results were normal and her doctor hasn’t suggested it since. Clearly her doctor recommended it the first time, but because it was not motivated by the suspicion of a problem, she did not define it as a “recommendation.”

Round 2 Recommendation: Interpretation problems with the word “recommend” are apparent throughout future sections of the instrument. Different, more descriptive language should be substituted for the word recommend. The new language depends upon the intent of the question and on how sponsors operationalize “recommend.”

Colonoscopy/ Sigmoidoscopy

QA07_B33 A sigmoidoscopy and a colonoscopy are both tests that examine the bowel by inserting a tube in the rectum. The difference is that during a sigmoidoscopy, you are awake and can drive yourself home after the test; however, during a colonoscopy, you may feel sleepy and you need someone to drive you home. Have you ever had a colonoscopy?

NEW

- YES 1
- NO 2 [GO TO PN QA07_B36]
- REFUSED-7 [GO TO PN QA07_B36]
- DON'T KNOW-8 [GO TO PN QA07_B36]

Round 1 Results: This section was tested on 5 respondents (other skipped out based on age). No problems detected. Respondents who didn’t know exactly what a colonoscopy/sigmoidoscopy was were able to answer the question anyway because of the explanation provided.

Recommendation: No change for round 2.

QUESTION TESTED IN ROUND 2:

QA07_B33 Have you EVER HAD a sigmoidoscopy, colonoscopy, or proctoscopy? These are exams in which a health care professional inserts a tube into the rectum to look for signs of cancer or other problems.

Round 2 Results: Sponsors changed this question in round 2 for reasons unrelated to lab testing. This question was tested on 9 respondents (2 skipped due to age). No problems were detected. Respondents were more familiar with the term colonoscopy than the other two, but were still able to answer the question because it provided an adequate description of the procedures.

Round 2 Recommendation: None. The question works no better or worse with the addition of the word proctoscopy.

QA07_B34 When did you have your most recent colonoscopy to check for colon cancer?

NEW

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 5 YEARS AGO2
- MORE THAN 5 UP TO 10 YEARS AGO3
- MORE THAN 10 YEARS AGO4
- REFUSED -7
- DON'T KNOW -8

Round 1 Results: Not tested – no one had a colonoscopy.

Recommendation: None.

QUESTION TESTED IN ROUND 2:

QA07_B34 When did you have your MOST RECENT exam?

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 5 YEARS AGO2
- MORE THAN 5 UP TO 10 YEARS AGO3
- MORE THAN 10 YEARS AGO4
- REFUSED -7
- DON'T KNOW -8

Round 2 Results: Sponsors changed this question in round 2 for reasons unrelated to lab testing. This question was tested on only 2 respondents. Both had colonoscopies, neither had trouble remembering when.

Round 2 Recommendation: None.

NEW QUESTION IN ROUND 2:

QA07_B33 For a SIGMOIDOSCOPY, a flexible tube is inserted into the rectum to look for problems. A COLONOSCOPY is SIMILAR, but uses a longer tube, and you are usually given medication through a needle in your arm to make you sleepy, and told to have someone else drive you home. A PROCTOSCOPY is an older exam that used a rigid tube. Was this MOST RECENT exam a sigmoidoscopy, colonoscopy, proctoscopy or something else?

Round 2 Results: Sponsors added this question in round 2 for reasons unrelated to lab testing. Two people were tested; neither had a problem identifying a colonoscopy as the test they had.

Round 2 Recommendation: None. The change in question wording seemed to have no effect on question understanding.

QA07_B32 What was the main reason you had your most recent colonoscopy? Was it...

NEW

PART OF A ROUTINE EXAM.....1
BECAUSE OF A PROBLEM, OR2
SOME OTHER REASON.....3
REFUSED -7
DON'T KNOW -8

Round 1 Results: Not tested – no one had a colonoscopy.

Recommendation: None.

QUESTION TESTED IN ROUND 2:

QA07_B32 What was the MAIN reason you had this exam - was it part of a routine exam, because of a problem, or some other reason?

PART OF A ROUTINE EXAM.....1
BECAUSE OF A PROBLEM, OR2
SOME OTHER REASON.....3
REFUSED -7
DON'T KNOW -8

Round 2 Results: Sponsors changed this question in round 2 for reasons unrelated to lab testing. This question was tested on only 2 respondents. Neither had trouble answering.

Round 2 Recommendation: None. The change in wording seemed to make no difference.

QA07_B36 Have you ever had a sigmoidoscopy?

NEW

YES 1
NO 2 [GO TO PN QA07_B39]
REFUSED-7 [GO TO PN QA07_B39]
DON'T KNOW-8 [GO TO PN QA07_B39]

Round 1 Results: Respondents were not overly familiar with the term “sigmoidoscopy,” but the description in the previous question was sufficient enough to allow them to generally understand the question. In other words, they know whether or not they’ve had a test involving their rectum. No errors were detected.

Recommendation: None.

Round 2: QUESTION DELETED FOR REASONS UNRELATED TO LAB TESTING.

QA07_B37

NEW

When did you have your most recent sigmoidoscopy to check for colon cancer?

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 5 YEARS AGO2
- MORE THAN 5 UP TO 10 YEARS AGO3
- MORE THAN 10 YEARS AGO4
- REFUSED -7
- DON'T KNOW -8

Round 1 Results: Only tested on one person (no one else had a sigmoidoscopy). No problems detected.

Recommendation: None.

Round 2: QUESTION DELETED FOR REASONS UNRELATED TO LAB TESTING.

QA07_B38

NEW

What was the main reason you had your most recent sigmoidoscopy? Was it...

- PART OF A ROUTINE EXAM.....1
- BECAUSE OF A PROBLEM, OR2
- SOME OTHER REASON.....3
- REFUSED -7
- DON'T KNOW -8

Round 1 Results: Only one person tested. She easily chose a response option, but it wasn't clear it was the best choice. Because she has HIV her doctor said she's at a higher risk of cancer, so she gets this screening more than what's usual. She chose "some other reason" but other categories seem appropriate too.

Recommendation: Continue testing as-is. Need more data if possible.

Round 2: QUESTION DELETED FOR REASONS UNRELATED TO LAB TESTING.

QA07_B39

NEW

In the past 5 years, has a doctor recommended that you have a sigmoidoscopy, colonoscopy or stool blood test?

- YES1
- NO.....2
- DID NOT GO TO DOCTOR IN PAST 12 MONTHS 92
- REFUSED -7
- DON'T KNOW -8

Round 1 Results: No problems detected.

Recommendation: None.

QUESTION TESTED IN ROUND 2:

QA07_B39

[if most recent screening exam 10 year ago or less, read:]

Was your most recent test recommended by a doctor or other health professional?

[Else if never had a test or last test more than 10 years ago, read:]

In the PAST 12 MONTHS, has a doctor or other health professional RECOMMENDED that you have a sigmoidoscopy or colonoscopy?

- YES 1
- NO 2
- DID NOT SEE DOCTOR IN THE PAST 12 M.....3
- REFUSED -7
- DON'T KNOW -8

Round 2 Results: This question was tested on 6 respondents. No response error or interpretation difficulty was detected. This is interesting, given that the word “recommend” confused people in every other section. It’s difficult to say why; perhaps because this is not typically a test people schedule on their own, as they can with a pap test or mammogram.

Round 2 Recommendation: None. However, if changes are made to similarly worded questions, the same changes should be made to this question as well.

Hysterectomy

QA07_E5

Have you had a hysterectomy?

[IF NEEDED, SAY: "A hysterectomy is when the uterus or womb is removed, not just having your tubes tied to prevent pregnancy."]

- YES1
- NO2
- REFUSED -7
- DON'T KNOW -8

Round 1 Results: Tested on all 9 respondents. Most respondents didn’t know exactly what a hysterectomy was, but did have a general idea. One person said “it’s the removal of the uterus...I think. It’s major.” One person thought it was getting your tubes tied. Two other respondents thought it was the removal of the ovaries. But all associated it with not being able to have children, so no response error was detected. The definition didn’t help, because no one asked for clarification.

Recommendation: None for round 2.

Round 2 Results: This question was moved to follow the pap smear section rather than precede it as in the first round. This movement had no discernable effect on question interpretation. All 11 respondents were tested on the question, which remained unchanged from round 1.

There was notable variation in respondents’ understandings of what a hysterectomy is. Some thought it’s when a woman has her ovaries removed, others thought it was the uterus. Some understood only that *something* is removed or that it involves the removal of *all* female parts. Two respondents thought the purpose was important – that a hysterectomy is done for health reasons, not as a birth control method – and two simply suggested that it’s a procedure that leaves a woman unable to have children (“being

barren...not fruitful"). As one respondent sums up, "It's taking out something inside because you have a problem. An ovary or something? I don't know."

Having experience with a hysterectomy didn't necessarily translate into a respondent having a solid definition of the procedure. One respondent said, "In my instance it was the removal of the uterus, cervix, fallopian tubes – actually I don't know if they're there...but they did remove my ovaries."

These unstable understandings sometimes meant respondents weren't exactly confident in their answers. One respondent answered "no" originally, but upon probing said, "I pretty sure I haven't had one."

Round 2 Recommendation: A hysterectomy is clearly not a well understood procedure. Yet because it's not a completely foreign word, no respondent asked for clarification when answering the survey question. As a result, interviewers were never prompted to read the "if needed" definition. Sponsors are strongly advised to incorporate that definition into the question itself. Respondents need the definition for clarification, but it's highly unlikely they're hearing it under the current format.

Pap smear

QA07_E5

AD4

Have you ever had a Pap test to check for cervical cancer?

[IF NEEDED, SAY: "Sometimes, a woman has a routine pelvic exam, she also has a Pap smear to test for cancer of the cervix. A doctor takes a cell sample from the cervix with a small stick or brush and sends it to the lab."]

YES	1	
NO	2	[GO TO PN QA07_E8]
REFUSED	-7	[GO TO QA07_E9]
DON'T KNOW	-8	[GO TO QA07_E9]

Round 1 Results: This section tested on all 9 respondents. This question had non-trivial interpretation problems. Several respondents did not link the pap test to a check for cervical cancer. In at least one case this produced response error. This respondent answered "no" when she has, in fact, had pap tests. She said she's only had a "regular pap" and "I don't think I was checked for cervical cancer. I just know I had a regular pap smear. I don't think she [the doctor] did anything more. If she did, I didn't know about it." This subject did not understand that the pap is a test for cervical cancer.

Several other respondents answered yes, but also weren't thinking about the pap as a check for cancer. They said they had paps during their pregnancies when the doctor wanted to check for a potential problem with the pregnancy. There was no response error, because it was evident they've received paps during non-pregnancy check-ups, but the larger point is that their understanding of pap tests is flawed. This impacts the way they answer questions about paps.

Another respondent specifically asked if this was the same thing as a pap smear. This prompted the interviewer to read the definition, but the respondent was still confused.

Recommendations: It might be worthwhile to incorporate a brief definition into the question. Then again, it still might not solve the problem. Some women seem to be confusing a pelvic exam with a pap smear, but even that's a bit unclear. Could continue testing as-is to collect more data.

QUESTION TESTED IN ROUND 2:

QA07_E5 Have you EVER HAD a Pap smear or Pap test?

[IF NEEDED, SAY: "A Pap smear is a routine test for women in which the doctor examines the cervix, takes a cell sample from the cervix with a small stick or brush, and sends it to the lab."]

YES	1	
NO	2	[GO TO PN QA07_E8]
REFUSED	-7	[GO TO QA07_E9]
DON'T KNOW	-8	[GO TO QA07_E9]

Round 2 Results: This question was changed for reasons unrelated to lab testing, except for the addition of the term “pap smear”. It was tested on all 11 respondents. No problems emerged in the second round. All respondents talked about the pap as something they get during a yearly visit to the doctor or GYN, and all used the expression pap smear (not pap test) when discussing their experience.

Round 2 Recommendation: None. It’s likely that the addition of the term “pap smear” added clarity to the question.

QA07_E6 How many Pap tests have you had in the last 6 years?

AD5

_____ # of PAPS		
NONE	0	[GO TO PN QA07_E8]
REFUSED	-7	
DON'T KNOW	-8	

Round 1 Results: There were several problems with this question. First, because of the interpretation problems discussed in the previous question, several respondents included procedures they understood as pap tests when they probably weren’t. These were procedures they had done during pregnancies because of specific concerns about the pregnancy.

Second, it was evident that respondents didn’t always answer this on the basis of an actual memory. Instead, their answers were based on the opinion they had of how often they *think* they should be getting a pap test. For example, one subject said, “maybe 5...I get it once a year.” It was a typical response for respondents to say they get pap tests once a year, therefore the answer must be 5 or 6. When pressed, they often could not recall their last test. One respondent admitted she probably doesn’t go every 12 months, but maybe every 15 months because she might not make the appointment right away.

Unlike other sorts of screening tests, these respondents knew exactly how often they should be getting a pap test (once a year), and answered this question based on that knowledge – not because they were trying to side step the question, but probably because routine doctor visits are not typically encoded into memory. So to answer the survey question, they relied on what they *intend* to do, not what they *actually* do.

Recommendations: It may not be possible to reliably get this information. More data may help inform a solution. Could consider adding “your best estimate is fine” because that works well for the mammogram question – and that’s how women are answering here anyway.

QUESTION TESTED IN ROUND 2:

QA07_E6 How many Pap smears or Pap tests have you had in the LAST 6 YEARS?

Round 2 Results: Since all respondents reported having had a pap test, all 11 were tested on this question.

Five respondents provided answers that were based on their conception of the recommended pap schedule, and said “about once a year.” One woman didn’t answer from her experience at all, but understood the question as asking how often a woman (in general) should go. She answered, “you get one every year...it depends.” When asked what it depends on, she said it depends on your health problems – if you have them you may have to go more regularly. When pressed about what *she* actually does, she answered “about 6...once a year.”

Three respondents answered based on the month they try to go each year. Two had variable patterns (due to health issues requiring more frequent paps) and had to give estimates.

Round 2 Recommendation: Women use a variety of methods to answer this question, none of which produce an exact number (which is likely impossible anyway because these kinds of doctor visits aren't typically encoded into memory – there was one exception. One young respondent had only just started yearly GYN check-ups and clearly remembered her first pap test.). Sponsors and analysts should understand that this number is only an estimate.

QA07_E7 How long ago did you have your most recent Pap test?

AD6

A YEAR AGO OR LESS	1	[GO TO QA07_E9
MORE THAN 1 UP TO 2 YEARS AGO	2	[GO TO QA07_E9
MORE THAN 2 UP TO 3 YEARS AGO	3	[GO TO QA07_E9
MORE THAN 3 UP TO 5 YEARS AGO	4	[GOTO QA07_E8]
MORE THAN 5 YEARS AGO	5	[GOTO QA07_E8]
REFUSED	-7	[GO TO QA07_E9]
DON'T KNOW	-8	[GO TO QA07_E9]

Round 1 Results: Data from this question show the same problems as the previous question: it seems to be capturing respondents’ notions of when they *should* get a pap test, not when they actually do. It’s not getting at memory as much as beliefs. One respondents illustrates this point well. She answered, “within the past year...I don’t remember the month.” When asked, she couldn’t even remember the season, she simply relies on getting her reminder card in the mail. “I’m good about going. I just can’t tell you when I was there.”

Recommendations: It may not be possible to reliably get this information. More data may help inform a solution.

QUESTION TESTED IN ROUND 2:

QA07_E7 When did you have your MOST RECENT Pap smear or Pap test?

Round 2 Results: Sponsors changed this question for reasons unrelated to lab testing. The wording change seemed to have no effect on respondent interpretation. No problems emerged in the second round. All respondents recalled either the month or season of their last pap.

Round 2 Recommendation: None.

QA07_E8

What is the ONE most important reason why you have {NEVER had a Pap test/NOT had a Pap test in the last 3 years}?

AD10

NO REASON/NEVER THOUGHT ABOUT IT	1
DIDN'T KNOW I NEEDED THIS TYPE OF TEST	2
DOCTOR DIDN'T TELL ME I NEEDED IT	3
HAVEN'T HAD ANY PROBLEMS.....	4
PUT IT OFF/LAZINESS	5
TOO EXPENSIVE/NO INSURANCE/COST	6
TOO PAINFUL, UNPLEASANT, OR EMBARRASSING.....	7
HYSTERECTOMY	8
DON'T HAVE A DOCTOR	9
HAD HPV VACCINE	10
HAD HPV DNA TEST	11
OTHER.....	91
REFUSED	-7
DON'T KNOW	-8

Round 1 Results: Tested on 3 respondents. It was difficult to answer for 2 of them. The best answer for them would be #1 (no reason), but that's not how they answered the question. This was something that never crossed their mind, so they had no specific reason. However, The question is structured in a way that suggests a more meaningful reply is expected. When respondents don't have a meaningful reply (because they've never thought about it), they're not sure how to answer. This makes it hard for the interviewer to code because the respondent doesn't come right out and say, "no reason; never thought about it."

Recommendations: Continue to collect data, if possible.

Round 2 Results: Not tested – all respondents have had a pap test.

Round 2 Recommendation: None.

QA07_E9

In the past 3 years, has a doctor recommended that you have a Pap test?

AD11

YES	1
NO.....	2
REFUSED	-7
DON'T KNOW	-8

Round 1 Results: This presented problems and possible false negatives for several respondents. Because they had a very clear idea of how often they should get a pap test, the doctor doesn't need to recommend they have one. One person answered yes, not because her doctor recommended it, but because she believes she should be going once a year for her annual check-up. This might be a false positive.

Still another respondent answered yes because she believes her doctor ordered a pap test during her pregnancy in order to investigate a "strange discharge" she was having. Some respondents are clearly unsure of the purpose of pap test, or even exactly what a pap test is. This pattern of interpretation is likely to inflate survey estimates of paps.

Recommendations: More data are needed to understand how respondents experience and conceptualize pap tests.

QUESTION TESTED IN ROUND 2:

QA07_E09 [if most recent Pap test 3 years ago or less, read:]

Was your most recent Pap smear or Pap test recommended by a doctor or other health professional?

[Else if never had a Pap test or last test more than 3 years ago, read:]

In the PAST 12 MONTHS, has a doctor or other health professional RECOMMENDED that you have a Pap smear or Pap test?

- YES 1
- NO 2
- DID NOT SEE DOCTOR IN THE PAST 12 M.....3
- REFUSED-7
- DON'T KNOW-8

Round 2 Results: Sponsors changed this question for reasons unrelated to lab testing. All 11 respondents were tested on this question. Ten had interpretation issues and response comparability problems.

The word “recommend” is open to many different interpretations and makes for very inconsistent answers among respondents. To some respondents, “recommend” means that it’s not the patient’s choice or decision, but the doctor’s. Others saw it as something that happens outside of the usual yearly check-up routine, some associated it with a health problem and the need for additional testing, and others thought of it as the *first time* a doctor told them they should start having pap tests. One respondent associated it exclusively with the referral slip she needs in order to see her GYN.

One respondent sums the difficulties up nicely, saying “That’s a good question. It’s a routine part of my healthcare. Once a year I go to the GYN and have a gynecological exam, which includes a pap test.” She ultimately answered yes. Another respondent with the same interpretation explains her hesitation in answering yes: “It’s just part of my annual exam...[the question] makes it sound like they’re recommending that specifically...like they think there’s a problem.”

Yet others with the same understanding answered “no” to the question: “No, it was just time for me to get one.” “No, regular.” “No, it’s just out of habit” to get a pap. In sum, not only was there variation in understandings of the word “recommendation,” respondents with the same definition would answer the question differently – some would say yes, some would say no.

Round 2 Recommendations: Survey responses are not comparable among respondents, meaning that survey estimates have low validity (i.e., are measuring many different constructs). The word “recommendation” needs to be dropped in favor of a word that more clearly communicates the intent of the question. In other words, “recommend” is a complex concept that cannot be directly measured and needs to be fully operationalized.

QA07_E10 When do you expect to have your next Pap test?

NEW

- A YEAR OR LESS FROM NOW 1
- 1-3 YEARS FROM NOW 2
- 3-5 YEARS FROM NOW 3
- MORE THAN 5 YEARS FROM NOW 4
- WHEN DOCTOR RECOMMENDS IT 5
- NEVER, HAD HPV DNA TEST 6
- NEVER, HAD HPV VACCINE..... 7

NEVER, OTHER REASON..... 8
 REFUSED-7
 DON'T KNOW-8

Round 1 Results: Not sure how useful this question is. It's unwittingly measuring the same construct as the other questions – expectations and beliefs about how often women should get pap tests.

Recommendations: None.

Round 2 Results: Respondents didn't have trouble answering this question. (Note that the word pap smear was added to question in round 2 to match changes made in other questions.) Most understood that they should have a pap once a year, and gave an answer that was a year out from the month of their last pap.

Round 2 Recommendation: None.

QA07_E10 Have you ever had a Pap test where the results were NOT normal?

AD8

YES 1
 NO..... 2
 DON'T KNOW-7
 REFUSED -8

Round 1 Results: This was a problem for only one woman who was thinking of when her doctor checked for a potential pregnancy complication, and it's not clear that this was a pap test at all. She produced a false positive response.

Recommendations: None.

Round 2 Results: No problems detected in this round. (Note that the word pap smear was added to question in round 2 to match changes made in other questions.)

Round 2 Recommendation: None.

VERSON 1 HPV QUESTIONS

HPV Awareness

QA07_E11 Have you ever heard of HPV? HPV stands for Human Papillomavirus.

NEW

YES 1
 NO..... 2
 REFUSED-7
 DON'T KNOW-8 } **[GO TO PN QA07_E16]**

Round 1 Results: Tested on 3 respondents. No problems detected. Respondents who have heard of HPV generally don't know much about it – and realize they don't. Because respondents are unclear about this condition, having both "HPV" and "Human Papillomavirus" in the question helped them understand what the question was about.

Recommendation: None.

Round 2 Results: This question tested on 5 respondents. Three were familiar with the topic, two because they work in women’s health and one because she has HPV. One was not very familiar with the virus but could answer the question anyway. However, another respondent who was familiar with the vaccine did not make the connection between it and the virus and answered “no” to this question.

Round 2 Recommendation: None.

QA07_E12 Where did you hear about HPV? [CODE ALL THAT APPLY]

NEW

HEALTH CARE PROVIDER/CLINIC	1
FAMILY OR FRIENDS	2
TV ADVERTISEMENT	3
TV NEWS.....	4
TV SHOW	5
NEWSPAPER OR MAGAZINE	6
INTERNET	7
SCHOOL	8
OTHER.....	9
REFUSED	-7
DON'T KNOW	-8

Round 1 Results: Tested on 2 respondents (one had never heard of HPV and skipped out). No problems or response errors detected.

Recommendation: None.

Round 2: Question dropped for reasons unrelated to lab testing.

QA07_E13 Do you think HPV can cause cervical cancer?

NEW

YES	1
NO.....	2
DON'T KNOW	-7
REFUSED	-8

Round 1 Results: There were some difficulties with this question. Both respondents understood their limitations and couldn’t speculate on whether or not HPV causes cancer. Both answered don’t know. What’s interesting is that one respondent said, “I personally don’t know, but they say it can.” She had heard something about it, but wasn’t convinced herself, so answered “don’t know.” This question may be difficult for respondents who feel unsure about their knowledge of HPV and their knowledge of cervical cancer – which may be many respondents. It is likely to elicit many “don’t know” responses.

Recommendation: None. Need more data.

Round 2 Results: This question tested on 4 respondents (one skipped who had never heard of HPV).

It was difficult for one respondent who understood this as something different than what was asked in relation to her daughter in the sample child section. Overall, she didn’t understand HPV as something that older women have to worry about so this line of questioning confused her. She sees this as an issue affecting her 15-year-old daughter, not herself. Her answer of “no” essentially means that HPV is a concern for young women, not for her.

Round 2 Recommendation: This set of “do you think” questions is difficult for people who don’t know much about the topic and don’t understand that it’s acceptable to speculate when answering. An introduction that conveys the message that it’s okay to speculate might help.

QA07_E14 Do you think you can get HPV through sexual contact?

NEW

YES 1
NO..... 2
DON'T KNOW-7
REFUSED-8

Round 1 Results: This question functioned in a manner similar to the previous. One respondent gave a response of “don’t know.” Her actual answer was “probably...maybe.”

Recommendation: None. Need more data.

Round 2 Results: This question tested on 4 respondents. The same person who had difficulty in the previous question had trouble here too. There was a clear disconnect between her understanding of HPV vis-à-vis her daughter and herself. She answers ‘no’ to this question, but when talking about HPV in relation to her daughter, she clearly sees it as an STD issue, describing how she talked to her daughter about sexual activity and using condoms.

Round 2 Recommendation: None, aside from the previous.

QA07_E15 Do you think HPV causes AIDS?

NEW

YES 1
NO..... 2
DON'T KNOW-7
REFUSED-8

Round 1 Results: Both respondents seemed more willing and confident to answer this question, largely because they know something about AIDS. They answered this question based on their knowledge of AIDS, not on their knowledge of HPV. Both answered ‘no.’

Recommendation: None.

Round 2: Question deleted for reasons unrelated to lab testing.

QA07_E15A Do you think HPV can go away on its own without treatment?

NEW

YES 1
NO..... 2
DON'T KNOW-7
REFUSED-8

Round 1 Results: One respondent answered “don’t know” to all these questions because she felt she had no basis on which to speculate. The other respondent answered “no” because she reasoned that

“anything left untreated will not go away...not even a yeast infection.” The premise of this question was familiar enough to her (i.e., do conditions heal themselves?) that she was able to use the logic of something she knew to extrapolate to something she didn’t.

Recommendation: None. Need more data.

Round 2 Results: This question was tested on 4 respondents. All could answer the question and only one was a little reserved about giving an answer she wasn’t sure about saying, “I don’t think so...I could be wrong.”

Round 2 Recommendation: This set of “do you think” questions is difficult for people who don’t know much about the topic and don’t understand that it’s acceptable to speculate when answering. An introduction that conveys the message that it’s okay to speculate might help.

[Females 18-27]

HPV Vaccine

QA07_E16 Have you ever heard of a vaccine or shot to prevent cervical cancer?

NEW	
YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

} [GO TO PN QA07_E18]

Round 1 Results: Their knowledge is sketchy, but respondents were able to answer the question. Probing revealed no specific problems with this question.

Recommendation: None.

Round 2 Results: This question was tested on 5 respondents. One demonstrated response error because she understood these questions different for herself and her daughter. She has heard of the vaccine, which she got for her daughter. However, here she answers “No...not yet.” This is because she doesn’t see HPV as a concern for older women. She was not thinking of HPV in general or in the abstract, but was answering the question in relation to herself. Her answer means, no, she’s not heard of an HPV vaccine for 49-year-old women.

Round 2 Recommendation: It’s plausible that women will produce response error on many of these questions when they understand HPV and the vaccine as something that relates to only young women. It might be necessary to address this issue either in the questions themselves or in an introduction to these questions.

QA07_E17 Have you ever received the HPV vaccine or HPV shots?

NEW	
YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

} [GO TO PN QA07_E18]

Round 1 Results: One respondent tested. No problems detected.

Recommendation: None.

QUESTION TESTED IN ROUND 2:

QA07_E17 Have you ever received the cervical cancer vaccine or HPV shot?

Round 2 Results: This question tested on 4 respondents. None demonstrated any difficulties.

Round 2 Recommendation: None.

QA07_E17a Did you receive all three doses of the HPV vaccine?

YES	1	} [GO TO QA07_E22]
NO	2	
REFUSED	-7	
DON'T KNOW	-8	

Round 1 Results: Not tested.

Recommendation: None.

QUESTION TESTED IN ROUND 2 WAS OPEN-ENDED

Round 2 Results: This question was tested on only one respondent. No problems emerged.

Round 2 Recommendation: None.

QA07_E18 {HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26.} Would you be interested in getting the vaccine?

NEW

YES	1	[GO TO PN QA07_E20]
NO	2	
REFUSED	-7	
DON'T KNOW	-8	

Round 1 Results: All respondents answered yes, but it was purely an abstract idea to them. Because they had very little knowledge of the topic (HPV and cervical cancer – many don't even realize the pap is a cervical cancer screening, that's how little they know about cervical cancer) they were thinking about protecting their health *in general*, and vaccines *in general* seem to do that. As one respondent said, "it seems like something important."

Recommendation: Not sure that this question is measuring anything useful, or intended. Need more data.

Round 2 Results: This question tested on 4 respondents. Two had difficulty.

One respondent said, "Not for myself – that's for young women." Another respondent who knew very little about the vaccine said, "I'm not sure" and couldn't answer yes or no, even though she said she would get it for her daughter. Both respondents understood HPV differently for themselves vs. their daughters.

Round 2 Recommendation: It's plausible that women will produce response error on many of these items when they understand HPV for themselves vs. young women. It might be necessary to address this issue either in the questions themselves or in an introduction to these questions.

QA07_E19 What is the MAIN reason you would NOT want to get the vaccine?

NEW

DOES NOT NEED VACCINE	1	[GO TO PN QA07_E22]
NOT SEXUALLY ACTIVE	2	[GO TO PN QA07_E22]
TOO EXPENSIVE	3	[GO TO QA07_E21]
TOO OLD FOR VACCINE	4	} [GO TO PN QA07_E22]
DOCTOR DIDN'T RECOMMEND IT	5	
WORRIED ABOUT SAFETY OF VACCINE	6	
DON'T KNOW WHERE TO GET VACCINE	7	
MY SPOUSE/FAMILY MEMBER IS AGAINST IT	8	
DON'T KNOW ENOUGH ABOUT VACCINE	9	
OTHER.....	10	
REFUSED	-7	
DON'T KNOW	-8	

Round 1 Results: Not tested.

Recommendation: None.

Round 2 Results: This question was tested on 4 respondents. One was difficult to code because she spent some time trying to reason through her answer. She said, "I don't have a cervix and I'm too old...now that I think about it, I'd say age because I still get paps." The interviewer ended up coding #4 (too old for vaccine). The other respondent said, "because I have HPV." The interviewer coded "other."

Round 2 Recommendation: A category should be added for women with HPV. Aside from that, it will take some work on the part of the interviewer to be able to code a response – respondents will often not produce clean answers that easily fit into a category. Moreover, because this is a topic to which they haven't given much thought, they will not always have ready-made reasons available to pluck from memory. As a result, respondents have to construct a reason on-the-spot, increasing both the burden and administration time of this question.

QA07_E20. The cost of the vaccine may be about \$360-500. Would you get the HPV vaccine if you had to pay this amount?

NEW

YES	1	[GO TO PN QA07_E22]
NO.....	2	[GO TO QA07_E21]
REFUSED	-7	[GO TO PN QA07_E22]
DON'T KNOW	-8	[GO TO PN QA07_E22]

Round 1 Results: There were some problems with this question. It was too hypothetical for one respondent who said, "I don't know...it depends." She went on to describe different scenarios under which she would and would not pay for the vaccine. Another respondent answered "no" but probing revealed that she would pay for it if she could do so over time. She could NOT afford to do so in one lump sum. She interpreted the question as asking whether she could pay that amount in one installment.

Recommendation: This question may need to be made more concrete.

Round 2 Results: Question not tested – all respondents skipped out.

Round 2 Recommendation: None.

QA07_E21

If you could get the HPV vaccine free or at a much lower cost, would you get it?

NEW

YES	1
NO.....	2
REFUSED	-7
DON'T KNOW	-8

Round 1 Results: One subject tested. No problems detected.

Recommendation: None.

Round 2 Results: Question not tested – all respondents skipped out.

Round 2 Recommendation: None.

VERSION 2 HPV QUESTIONS

QHPV1

A vaccine to prevent the human papillomavirus or HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL®. (Have you/has she) ever had the HPV vaccination?

YES	1
NO.....	2
DOCTOR REFUSED WHEN ASKED.....	3
REFUSED	-7
DON'T KNOW/NOT SURE	-8

Round 1 Results: version 2 not tested – this question is the same in version 3.

Recommendation: None.

Round 2 Results: Not tested.

Round 2 Recommendation: None.

(ISD)Q04

How many HPV shots did you receive?

_____ # of shots	
All shots.....	96 [skip out]
REFUSED	-7 [skip out]
DON'T KNOW	-8 [skip out]

Round 1 Results: version 2 not tested – this question is the same as version 3.

Recommendation: None.

Round 2 Results: Not tested.

Round 2 Recommendation: None.

VERSION 3 HPV QUESTIONS

[Adults 18-49]

QHPV1 A vaccine to prevent the human papillomavirus or HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL®. (Have you/has she) ever had the HPV vaccination?

YES 1
NO 2
DOCTOR REFUSED WHEN ASKED3
REFUSED-7
DON'T KNOW/NOT SURE-8

Round 1 Results: Version 3 tested on 2 respondents. No problems detected.

Recommendation: none.

Round 2 Results: This version was tested on 6 respondents. One subject couldn't answer because she simply wasn't sure if she'd heard of it or not – although she did report hearing about it for her daughter. Another respondent produced response error because she was confused by the age factor as well. She asked, "Can you get it if you're over 26?" (this respondent was 29) and answered "no" to the question. However, during probing she said if it could protect her or save her life she would definitely want to get it.

Round 2 Recommendation: The age factor continues to confuse some respondents who are aware that the vaccine has been approved/recommended for younger women but not older ones. It might be necessary to address this issue either in the questions themselves or in an introduction to these questions.

(ISD)Q04 How many HPV shots did you receive?

___ Number of shots
All shots96 [skip out]
REFUSED-7 [skip out]
DON'T KNOW-8 [skip out]

Round 1 Results: Not tested – both respondents skipped out.

Recommendation: None.

Round 2 Results: This question not tested – all skipped out.

Round 2 Recommendation: None.

[Females 65 and Under (NCI) or Males and Females 18-49 (CDC)]

HPV Awareness

QA07_E11 Have you ever heard of HPV? HPV stands for Human Papillomavirus.

NEW

YES 1
NO 2 }
}

REFUSED-7 [GO TO PN QA07_E16]
 DON'T KNOW-8

Round 1 Results: No problems detected. Both answered “yes” and their narrative validates this response.

Recommendation: None.

Round 2 Results: This question was tested on 6 respondents. Only one had trouble answering and never said yes or no conclusively. Because she didn’t know much about HPV, she didn’t feel comfortable answering questions about it. She said, “I didn’t know about it until I heard about it on the TV ads. I heard of cervical cancer, but didn’t know it was a virus you could get.” Clearly the respondent absorbed some information from the ads, but didn’t feel confident enough about the topic to answer the survey questions.

Round 2 Recommendation: This is the same problem seen in other HPV questions. It’s difficult for people who don’t know much about the topic and don’t understand that it’s acceptable to speculate when answering. An introduction that conveys the message that it’s okay to speculate might help.

QA07_E12 Where did you hear about HPV? [CODE ALL THAT APPLY]

NEW

HEALTH CARE PROVIDER/CLINIC 1
 FAMILY OR FRIENDS 2
 TV ADVERTISEMENT 3
 TV NEWS..... 4
 TV SHOW 5
 NEWSPAPER OR MAGAZINE 6
 INTERNET 7
 SCHOOL 8
 OTHER..... 9
 REFUSED-7
 DON'T KNOW-8

Round 1 Results: No problems detected, but note that one respondent wanted clarification: “where I first heard of it?” The interviewer re-read the question and she answered with no trouble.

Recommendation: None.

Round 2: Question deleted for reasons unrelated to lab testing.

QA07_E13 Do you think HPV can cause cervical cancer?

NEW

YES 1
 NO..... 2
 DON'T KNOW-7
 REFUSED-8

Round 1 Results: Both respondents had heard of HPV and it’s link to cervical cancer. As a result, they were able to answer this question. Both said “yes” and their narrative validates this response.

Recommendation: None.

Round 2 Results: This question was tested on 6 respondents. Two could not provide answers because they didn't know much about HPV and didn't realize it was acceptable to speculate. One person said, "I'm not sure because I don't know anything about it."

Round 2 Recommendation: This is the same problem seen in other HPV questions. It's difficult for people who don't know much about the topic and don't understand that it's acceptable to speculate when answering. An introduction that conveys the message that it's okay to speculate might help.

QA07_E14 Do you think you can get HPV through sexual contact?

NEW

YES 1
NO 2
DON'T KNOW -7
REFUSED -8

Round 1 Results: Because both respondents made a clear link between HPV and cervical cancer, they were less confident in answering this question about sexual contact. As a result, one answered "don't know." The other answered "yes" as a guess. She literally said, "I would assume so. I never really thought about it." During probing she says, "I suppose if I thought about it, it makes sense that it would be through sexual contact."

Clearly, when respondents have little-to-no knowledge of a topic about which they've given little thought, they are uncomfortable answering knowledge questions about it. These question come across to them as a quiz and it seems as though they are at least a little embarrassed by their lack of knowledge.

Recommendation: None. Need more data.

Round 2 Results: This question was tested on 6 respondents. Two could not provide answers because they didn't know much about HPV and didn't realize it was acceptable to speculate. One person said, "I've heard that you can, but I don't know." This respondent could have provided an answer of yes, but because she wasn't convinced of that answer herself, she chose not to answer at all.

Round 2 Recommendation: This is the same problem seen in other HPV questions. It's difficult for people who don't know much about the topic and don't understand that it's acceptable to speculate when answering. An introduction that conveys the message that it's okay to speculate might help.

QA07_E15 Do you think HPV causes AIDS?

NEW

YES 1
NO 2
DON'T KNOW -7
REFUSED -8

Round 1 Results: This question was easier to answer because both respondents knew something about AIDS and provided an answer on that basis. As one respondents said, "only the AIDS virus causes AIDS."

Recommendation: None.

Round 2: This question was deleted for reasons unrelated to lab testing.

QA07_E15A Do you think HPV can go away on its own without treatment?

NEW

YES 1
NO 2
DON'T KNOW-7
REFUSED-8

Round 1 Results: Both respondents could answer this, but they were not thinking of HPV per se, they were thinking about the nature of viruses or vaccines in general. One person said, “if it could go away on its own, there wouldn’t be a vaccine for it.” The other admitted her response was a guess and her reasoning was that the virus might lie dormant for a while, but that one you get a virus you always have it.

They were able to speculate about HPV because they took what they knew about viruses or vaccines and applied it to this question.

Recommendation: None.

Round 2 Results: This question was tested on 6 respondents. Four had issues. One subject answered no, but followed that up with “I just don’t know”. Another person changed her answer 3 times before settling on ‘yes’, and 2 respondents couldn’t answer at all because they didn’t know enough about HPV.

Round 2 Recommendation: This is the same problem seen in other HPV questions. It’s difficult for people who don’t know much about the topic and don’t understand that it’s acceptable to speculate when answering. An introduction that conveys the message that it’s okay to speculate might help.

VERSION 4 HPV QUESTIONS

(ISD)Q01 The human papillomavirus is a common virus known to cause genital warts and some cancers, such as cervical cancer in women. Before today, have you ever heard of the Human Papillomavirus or HPV? This is not HIV.

YES 1
NO 2
REFUSED-7
DON'T KNOW-8

Round 1 Results: Three respondents were tested on version 4. None had trouble answering this question. Two didn’t seem to make the connection between the virus and the vaccine, but that didn’t impair their ability to answer questions about the two. No one confused HPV with HIV in any of the questions in any version of this instrument.

Recommendation: Because the phrase “This is not HIV” comes *after* the respondents is asked a question AND because no one seemed to confuse HPV with HIV, try simply dropping that last sentence from the question. Otherwise, this question works well.

Round 2 Results: THIS VERSION NOT TESTED IN ROUND 2.

(ISD)Q02 A vaccine to prevent HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL®. Before today, have you heard of the cervical cancer vaccine, HPV shot, or Gardasil? The vaccine was licensed and approved in June 2006.

YES 1
 NO..... 2
 REFUSED-7
 DON'T KNOW-8

Round 1 Results: No problems detected. However, the last sentence never got read because it comes *after* the question is asked of the respondent. Reading the sentence after the respondent answered didn't change any answers – in other words, no one needed it to help clarify anything.

Recommendation: Drop the last sentence. It's awkwardly placed and doesn't add any clarity for the respondent. Otherwise, the question worked well.

Round 2 Results: THIS VERSION NOT TESTED IN ROUND 2.

(ISD)Q03 Have you ever had the HPV vaccination?

YES 1
 NO..... 2 [skip out]
 REFUSED-7 [skip out]
 DON'T KNOW-8 [skip out]

Round 1 Results: One person wasn't sure and had to think about this. She was thinking back to elementary and high school because she remembered getting many vaccines while in school. She admitted she couldn't remember specifically and said that the HPV vaccine could have been combined with one of the shots she received and she didn't know it. She answered "no" to the question because to her knowledge she did not get the vaccine.

The difficulty experienced by this respondent is a function of answering vaccine questions more than it is a function of HPV knowledge. People have very little knowledge of their vaccine history (see the Tetanus and Hepatitis sections), and as a result, their answers to those questions are not reliable.

Recommendation: None – more data are needed.

Round 2 Results: THIS VERSION NOT TESTED IN ROUND 2.

(ISD)Q04 How many HPV shots did you receive?

___ Number of shots
 All shots.....96 [skip out]
 REFUSED-7 [skip out]
 DON'T KNOW-8 [skip out]

Round 1 Results: Not tested – all skipped out.

Recommendation: None.

Round 2 Results: THIS VERSION NOT TESTED IN ROUND 2.

VERSION 5 HPV QUESTIONS

(ISD)Q01 The human papillomavirus is a common virus known to cause genital warts and some cancers, such as cervical cancer in women. Before today, have you ever heard of the Human Papillomavirus or HPV? This is not HIV.

YES 1
NO 2
REFUSED -7
DON'T KNOW -8

Round 1 Results: Version 5 was tested on one subject. She had no trouble with this question – she answered “yes” and her narrative validates this response.

Recommendation: The last sentence is probably unnecessary (see other versions) and could be dropped. Otherwise, the question is fine.

Round 2 Results: THIS VERSION NOT TESTED IN ROUND 2.

QHPV1 A vaccine to prevent the human papillomavirus or HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL[®]. (Have you/has she) ever had the HPV vaccination?

YES 1
NO 2
DOCTOR REFUSED WHEN ASKED 3
REFUSED -7
DON'T KNOW/NOT SURE -8

Round 1 Results: No problem detected. Not difficult for the respondent to answer.

Recommendation: None.

Round 2 Results: THIS VERSION NOT TESTED IN ROUND 2.

Mammography

QA07_E22 Have you ever had a mammogram?

AD14

[IF NEEDED, SAY: "A mammogram is an x-ray taken of each breast separately by a machine that flattens or squeezes each breast."]

YES 1
NO 2
[READ DEFINITION, IF STILL NO, GO TO PN QA07_E25]
REFUSED -7 **[GO TO PN QA07_E26]**
DON'T KNOW -8 **[GO TO PN QA07_E26]**

Round 1 Results: This section tested on 6 respondents (one was under 30 but in the screener said she had a mammogram because of family history so we tested her on these questions).

All but one respondent answered this question without difficulty. The respondent who had trouble was confused over the term “mammography” and needed the definition read to her. She was inclined to equate mammography with a clinical breast exam, but the definition made it clear to her because she knew it did not involve an x-ray. She ended up reporting “no,” which was the appropriate answer. However, it subsequent questions about mammograms, she reverts to her original understanding (thinking the questions were asking about clinical breast exams) and demonstrates response error.

Recommendation: It would make the question a little longer, but consider reading the definition just prior to asking the question. Many less-educated respondents may not be familiar with the term.

Round 2 Results: This question was tested on all 11 respondents. Some were younger than the age range, but we tested for understanding. No one had difficulty answering the question, and no response error was detected.

Round 1 Recommendation: None.

QA07_E23 How many mammograms have you had in the last 6 years? Your best estimate is fine.

AD16

_____ MAMMOGRAMS [HR: 0-99]
 NONE0 [GO TO QA07_E25]
 REFUSED -7
 DON'T KNOW -8

Round 1 Results: No problems detected. Respondents seemed to be reporting based on actual experience rather than notions of what their schedule *should* be, as they did for pap tests. This may be because recommendations for frequency of mammograms isn't as well understood as those for pap tests.

Recommendation: None. In fact, consider adding “your best estimate is fine” to the pap test question as well – because that’s what the question is getting anyway.

Round 2 Results: This question was tested on 6 respondents. Five hadn't had a mammogram, mostly due to age.

The estimates that women gave tended to be based on a schedule they had in mind about how often they should get a mammogram. Their answers were not exact. For example, one respondent answered 6, but she said her first mammogram was when she was 45, which was only 4 years ago. If that's true – and it's impossible to say if it is – then this answer cannot be right. It suggests she's answering based on how often she *thinks* she is supposed to be getting a mammogram. She was not thinking of actual exams she's had and adding them up to arrive at an answer. Other respondents came right out and admitted they were estimating, giving answers such as: “Maybe 3”, “probably 4”, “I'd say maybe 3...kinda every 2 years I try to go.”

Round 2 Recommendation: None. This question is fine as long as sponsors realize they're getting estimates, not true values.

QA07_E24 How long ago did you have your most recent mammogram?

AD17

A YEAR AGO OR LESS1
 MORE THAN 1 UP TO 2 YEARS AGO2
 MORE THAN 2 UP TO 3 YEARS AGO3

MORE THAN 3 UP TO 5 YEARS AGO	4
MORE THAN 5 YEARS AGO	5
REFUSED	-7 [GO TO PN QA07_E26]
DON'T KNOW	-8 [GO TO PN QA07_E26]

Round 1 Results: No problems detected. Respondents seemed to be reporting based on actual experience rather than notions of what their schedule *should* be.

Recommendation: None.

QUESTION TESTED IN ROUND 2:

QA07_E24 When did you have your MOST RECENT mammogram?

Round 2 Results: Sponsors changed this question for reasons unrelated to lab testing. It was tested on 6 respondents, and the wording change made no difference in interpretation. There were no problems with this question, and most were able to recall the month and year of their last mammogram.

Round 2 Recommendation: None.

QA07_E25 In the past 2 years, has a doctor recommended that you have a mammogram?

AD26

YES	1
NO	2
REFUSED	-7
DON'T KNOW	-8

Round 1 Results: This question captured different constructs for different respondents. Of the 5 respondents tested, 2 had interpretation issues with the word “recommend” and demonstrated false negatives as a result. They both answered “no” to the question because they already know how often they should get a mammogram. They don’t need their doctor to tell them to do it. As one respondent said, her doctor already knows she gets mammograms regularly and just tells her “make sure you go and get it” when she gets her yearly check-up. To her this is not a recommendation. A recommendation is when the doctor tells someone who wouldn’t otherwise plan to get a mammogram, to go and get one.

Recommendation: This is a complicated, but potentially troublesome, pattern in the interpretation of “recommendation,” and has implications beyond mammograms. More data on understandings of the term recommendation would help inform solutions to this problem.

Round 2 Results: This question was dropped from round 2 in favor of the next questions.

QUESTION TESTED IN ROUND 2:

QA07_E24a What was the MAIN reason you had this mammogram -- was it part of a routine exam, because of a problem, or some other reason?

PART OF A ROUTINE EXAM.....	1
BECAUSE OF A PROBLEM, OR.....	2
SOME OTHER REASON.....	3
REFUSED	-7
DON'T KNOW	-8

Round 2 Results: This question was tested on 6 respondents. One showed potential response error. She answered “some other reason,” but said that she got the mammogram because she felt her breasts

had changed size following her pregnancy and that the nipples were asymmetrical. She was concerned and wanted a mammogram to check things out. Her doctor supported this decision. Response option 2 is probably the better answer, however, it's likely she didn't pick it because she didn't know for sure whether there was a problem.

Round 2 Recommendation: Response option 3 may confuse some people. If there's any nuance at all to why they got a mammogram, they may choose this option over the first two. Limit the categories to the first two. Have an other-specify category available, but don't offer it in the reading of the question.

QA07_E25

[if most recent mammogram test 2 years ago or less, read:]

Was your most recent mammogram recommended by a doctor or other health professional?

[Else if never had a mammogram or last test more than 3 years ago, read:]

In the PAST 12 MONTHS, has a doctor or other health professional RECOMMENDED that you have a mammogram?

- YES 1
- NO 2
- DID NOT SEE DOCTOR IN THE PAST 12 M.....3
- REFUSED-7
- DON'T KNOW-8

Round 2 Results: This question was tested on 6 respondents. Four had difficulty, which in every case stemmed from the word "recommend."

The problem with this question is identical to its counterpart in the pap section. The word "recommend" is highly problematic. It's interpreted a variety of ways and people answer differently even when they share definitions. For example, one respondent replied, "As part of a routine exam...I guess yes," while another answered no, saying she knows how often she needs to go and doesn't need a recommendation by her doctor. The construct validity and reliability on this question is very low – it's not measuring the same concept for everyone. In other words, answers of yes don't all mean the same thing.

Round 2 Recommendation: Sponsors need to operationalize the word "recommend". It's empirically demonstrated to be a complex concept that cannot be directly measured. Once the definition has been explicated, a more concrete word can be substituted in these questions.

QA07_E26

Please tell me if you agree or disagree with the following statements:

Medical experts have differing views about whether women should have mammograms. Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED-7
- DON'T KNOW-8

Round 1 Results: These attitude questions were very problematic. Many respondents needed the questions read more than once. Respondents simply did not understand the intent of these questions.

The shift from fact-based to attitude questions along with the shift in sentence structure (i.e. statement vs. question) probably contributed to this problem, though it's difficult to empirically document that. However, there were interpretation issues above-and-beyond those structural issues.

One respondent answered this question in relation to the views of other women, not the views of "medical experts." Another respondent did focus on the "medical expert," but said her doctor gives her the option of whether or not she wants one (note, too, that she was thinking of a clinical breast exam, NOT a mammography), so this question must mean that any given doctor can go either way on this.

Respondents also answered in contradictory ways from one attitude question to the next (agreeing in one, only to disagree with the same notion in the second), further demonstrating that they did not fully understand the questions.

Recommendation: Drop this question and use E29 which seemed to be the least confusing. Continue to test E29 in the second round.

Round 2 Results: This question was tested on 11 respondents. It was difficult for many to answer, several needed the question repeated, and a variety of interpretations were demonstrated.

Some respondents understood the question to be asking about whether medical experts think women should have mammograms at all, while others interpreted the question as asking whether recommendations for mammogram frequency were consistent.

Most respondents understood "medical experts" to mean doctors, but at least one respondent had a broader definition. She included insurance companies and policy makers in her understanding.

Some women answered the question based on their opinion, not on the opinion of medical experts. One respondent said, "Having a mammogram is very important to detect breast cancer." Another said, "I feel all women should have one because you never really know what's happening with your breasts."

Round 2 Recommendation: This question needs to be adequately operationalized and communicated in a more straightforward manner. The agree/disagree format is probably not the best method.

QA07_E27 There are conflicting recommendations from medical experts about whether women should have mammograms. Do you...

Strongly Agree	1
Somewhat Agree.....	2
Somewhat disagree	3
Strongly disagree	4
No opinion	5
REFUSED	-7
DON'T KNOW	-8

Round 1 Results: This question was just as problematic as the previous. One person answered, "I agree that you should have them." Another subject said, "every woman needs a mammogram. You don't know whether it runs in your family." And still another respondent was thinking of two women she knew who both had breast cancer but received very different treatments – so she answered agree because doctors prescribe different treatment for the same disease. She was not answering about mammograms, but about breast cancer.

Recommendation: Drop this question and use E29 which seemed to be the least confusing. Continue to test E29 in the second round.

Round 2 Results: This question was tested on 11 respondents and had the same problems as the previous question.

Round 2 Recommendation: This question needs to be adequately operationalized and communicated in a more straightforward way to the respondents. The agree/disagree format is probably not the best method.

QA07_E28 There are so many different recommendations about mammography, it's hard to know which ones to follow. Do you...

Strongly Agree	1
Somewhat Agree.....	2
Somewhat disagree	3
Strongly disagree	4
No opinion	5
REFUSED	-7
DON'T KNOW	-8

Round 1 Results: This question was less problematic, but still presented some difficulty. Contradictory answers were still given, and the question had to be read more than once.

Recommendation: Drop this question and use E29 which seemed to be the least confusing. Continue to test E29 in the second round.

Round 2 Results: This question tested on 11 respondents. Similar difficulties arose here as for the others.

Five respondents answered "agree," yet all but one had a mammogram schedule they follow. This represents a clear disconnect between women answering in general terms for these questions and their own beliefs, their doctors' beliefs, and their experience. One woman who agreed with the statement said, "Everything changes on a daily basis. One day it's this, the next day it's something else," yet she expressed no confusion, personally, about mammograms. She's got a 2 year schedule that she's on and her doctor goes along with it. The opinion that this question is measuring doesn't always line up with respondents' personal beliefs or actual behavior.

Round 2 Recommendation: This question needs to be adequately operationalized and communicated in a more straightforward way to the respondents. The agree/disagree format is probably not the best method.

QA07_E29 I feel confused about contradictory recommendations I have read or heard about having a mammogram. Do you...

Strongly Agree	1
Somewhat Agree.....	2
Somewhat disagree	3
Strongly disagree	4
No opinion	5
REFUSED	-7
DON'T KNOW	-8

Round 1 Results: No major problems were detected with this question, probably due to the fact that the question is oriented to what *they* feel and doesn't ask them about what doctors or other women think (which they can't really know).

Recommendation: Continue testing this question.

Round 2 Results: This question was tested on 11 respondents. Most did better with this one because they were able to say whether or not they feel confused about recommendations for mammograms. However, response error was detected for one respondent. She answered strongly agree when her explanation suggests the opposite is true. She gets a mammogram every 2 years for the past 10 years and will "stay with what I've been doing. It's been working." The language and structure of the question probably confused her.

Round 2 Recommendation: This question needs to be adequately operationalized and communicated in a more straightforward way to the respondents. The agree/disagree format is probably not the best method.

Hormone Replacement Therapy

QA07_E26 Are you currently taking hormone replacement therapy or HRT for menopause?

AD28

[IF NEEDED, SAY: "This is a pill, patch or treatment that gives women more of the female hormone, estrogen."]

YES	1	} [GO TO QA07_E28]
NO	2	
REFUSED	-7	
DON'T KNOW	-8	

Round 1 Results: This section tested on 5 respondents (others skipped out for age). No response error was detected on this question. However, interpretation problems might be present. One respondent reported that she has *never* been on HRT, but went on to describe a situation about 3 years ago when she was having hot flashes and was prescribed a weekly patch to control the symptoms. She's 49 and her menstruation is becoming irregular, yet she doesn't see her self as going through menopause.

Recommendation: This would need further testing, but it's not unreasonable to think that many women will be under-informed about menopause symptoms and treatment and, therefore, not understand what hormone replacement therapy is. It might be worthwhile to incorporate the definition into the question and test further.

Round 2 Results: This question was tested on 4 respondents (others skipped due to age). No response error or interpretation problems were evident.

Round 2 Recommendation: None in addition to that suggested in the first round.

QA07_E27 Some women go on and off hormone replacement therapy. How long have you taken HRT altogether?

NEW

[IF NEEDED, SAY: "Please total all the time you have taken HRT."]

A YEAR AGO OR LESS	1
MORE THAN 1 UP TO 2 YEARS	2
MORE THAN 2 UP TO 4 YEARS	3
MORE THAN 4 UP TO 8 YEARS	4
MORE THAN 8 YEARS AGO	5
REFUSED	-7

Round 1 Results: Not tested.

Recommendation: None.

Round 2 Results: This question tested on only one subject. No problems evident.

Round 2 Recommendation: None.

SHINGLES

Q01. Shingles is an outbreak of a rash or blisters on the skin that may be associated with severe pain. The pain is generally on one side of the body or face. Shingles is caused by the chicken pox virus. A vaccine for shingles has been available since May 2006. Have you ever had the Zoster or Shingles vaccine, also called Zostavax®?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

Round 1 Results: This question tested on 3 people. No problems detected. One respondent initially heard the word “shingles” and thought it had to do with restless leg syndrome, but realized it didn’t upon hearing the rest of the question. Another respondent was familiar with it because her partner had it.

Recommendation: Despite the length of this question, no immediate problems surfaced.

Round 2 Results: This question was tested on 5 respondents. No response error or interpretation problems were apparent. Respondents had heard of shingles, but not the vaccine.

Round 2 Recommendation: None. The question is long, but because respondents knew little-to-nothing about the topic, the explanation was necessary.

TD/TDAP

Q01. Have you received a tetanus shot in the past 10 years?

- 1 Yes
- 2 No [SKIP BEYOND Q03]
- 7 Refused [SKIP BEYOND Q03]
- 9 Don't know [SKIP BEYOND Q03]

Round 1 Results: This section tested on all 9 respondents. Many respondents have very little knowledge of the vaccines they have received. In this question 4 respondents were clearly making guesses as to whether they received the tetanus shot. Even when they know they’ve had vaccines, the don’t remember (or never knew) which ones.

Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don’t know.

Round 2 Results: This section tested on 11 respondents. Some were not confident about their answers, and arrived at them by deduction rather than by actual memory. For example, one respondent answered yes, not because she specifically remembered getting the shot, but because she thinks it was

“definitely a requirement for school.” Another woman answered yes, explaining “I must have hurt myself” but she couldn’t specifically recall the injury.

Another person answered “don’t know” then changed her answer to a timid “no” upon hearing the Hepatitis B question. She was confused over the shots she’s had, and answered “unless it’s a requirement for school, I don’t think so.”

Round 2 Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don’t know.

Q02. Was your most recent tetanus shot given in 2005 or later?

- | | | |
|---|------------|----------------------|
| 1 | Yes | [SKIP TO CHECKPOINT] |
| 2 | No | [SKIP BEYOND Q03] |
| 7 | Refused | [SKIP TO CHECKPOINT] |
| 9 | Don’t know | [SKIP BEYOND Q03] |

Round 1 Results: One person was confused by the wording “2005 or later” and ended up reporting the date. The other respondents who had trouble simply couldn’t remember and came up with a very rough estimate.

Recommendation: Try to simplify the wording.

Round 2 Results: This question tested on 8 respondents. Three found it difficult to remember when they received the shot. After hearing the question, one person said, “Yeah, around there.” Another answered, “I don’t know. I think so...I think it was 2005.” But later she said it was about 5 years ago. She basically had no idea.

Round 2 Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don’t know.

Q03. There are currently two types of tetanus shots available today. One is the Td or tetanus-diphtheria vaccine and the other is called Tdap or Adacel™. They are similar except the Tdap shot also includes a pertussis or whooping cough vaccine. Thinking back to your most recent tetanus shot, did the doctor tell you the vaccine included the pertussis or whooping cough vaccine? The shot is often called Tdap or ADACEL™.

- | | |
|---|--------------------------------|
| 1 | Yes – included pertussis |
| 2 | No – did not include pertussis |
| 3 | Doctor did not say |
| 7 | Refused |
| 9 | Don’t know |

Round 1 Results: Tested on 3 respondents. They had no idea and couldn’t answer the question.

Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don’t know.

Round 2 Results: This question was tested on 7 respondents. Three demonstrated difficulty and response error.

One respondent wasn’t sure, saying she’d never heard about the different type of shots. She answered “no” because she thinks the doctor would have told her if he was giving her something out of the ordinary.

Another person chose “don’t know” saying, “I would never know the difference between the two.” She never remembers the doctor telling her anything, and she received so many shots before traveling to Africa last year she admits she can’t remember them all. Another respondent also chose “no – did not include pertussis”. She answered, “They didn’t tell me a thing. They just came at me.” In each case, the best answer would have been option 3, not option 2.

Round 2 Recommendation: Even with the explanation this is a difficult question to answer because respondents simply don’t know. Also, the response options should be read to the respondent so that the distinction between options 2 and 3 doesn’t get lost.

HEPATITIS A

AAU.370 Have you EVER received the hepatitis B vaccine?

READ IF NECESSARY: This is given in three separate doses and has been available since 1991. It is recommended for newborn infants, adolescents, and people such as health care workers, who may be exposed to the hepatitis B virus.

- (1) Yes (AAU.380)
- (2) No (A_ACUT_END)
- (7) Refused (A_ACUT_END)
- (9) Don’t know (A_ACUT_END)

Round 1 Results: This section tested on all 9 respondents. Findings similar to the tetanus section occurred here. Answers are not reliable. Respondents either don’t have this information, or they think they know when they don’t. For example, one respondent answered with confidence that she received not only the Hepatitis B shot, but also A and C. She gave a whole description of how she received the last shot, Hepatitis C in 11th grade. Another respondent gave a similar recount of her vaccine history which involved getting a vaccine for Hepatitis A, B, and C. Another respondent said she got the Hepatitis B shot when she was 2 years old and knows this because she recently saw her shot record. However, if the vaccine wasn’t available until 1991, she couldn’t have received it when she was 2 (which would have been 1989).

These narratives show that even when respondents think they know their vaccine history, they may not.

Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don’t know.

Round 2 Results: This question tested on all 11 respondents. Three respondents had notable difficulty. One respondent couldn’t answer because she didn’t know/couldn’t remember. She used to draw blood back in the ‘80’s and would sometimes stick herself by mistake. Because this was the “pre-AIDS” era there wasn’t the concern there is today, so she’s not sure if she received the Hep B shot after one of these mistakes or not.

Two other respondents had trouble answering, which prompted the interviewer to read the definition. In both cases it allowed the respondent to arrive at a more confident answer. One said, “since it’s been out since 1991 I think I’d say yes.” She changed her mind because her mother would have made sure she got the vaccine. She said it’s like when the Gardasil shot came out and her mother said, “Hey, you can get this.”

Round 2 Recommendation: The definition helped respondents who were having difficulty; however, they still had no specific memory of getting the vaccine and had to deductively arrive at an answer (which may or may not be correct).

AAU.380 Did {you} receive at least 3 doses of the hepatitis B vaccine, or less than 3 doses?

- (1) Received at least 3 doses
- (2) Received less than 3 doses
- (7) Refused
- (9) Don't know

Round 1 Results: A couple respondents were not sure what the word “doses” meant. It was interpreted as the actual injection and as medicine itself, where one shot could contain several different types of vaccines. Another person thought the question was referring to three Hepatitis shots – A, B, and C. She answered yes to the question, thinking she’s had all three vaccines.

Recommendation: It might be better to use the word “shot” instead of doses. Aside from that, many people don’t know this information.

Round 2 Results: This question was tested on 8 respondents. Four had recall issues, or simply didn’t know the information.

One respondent answered “all 3 doses,” but didn’t specifically remember getting 3. She just assumed she did because she does remember going back more than once. To her that means she must have received all 3. One person admitted, “I don’t remember.” She worked in a hospital for a brief stint and said she didn’t keep track of all her shots. Another person answered less than three because she remember getting only 2 and thinks that fulfilled the requirement.

Round 2 Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don’t know or can’t remember.

Q01. The hepatitis A vaccine is given as a two dose series routinely to some children starting at 1 year of age, and to some adults and people who travel outside the United States. Although it can be given as a combination vaccine with hepatitis B, it is different from the hepatitis B shot, and has only been available since 1995. Have you ever received hepatitis A vaccine?

- | | | |
|---|------------|---------------|
| 1 | Yes | |
| 2 | No | [SKIP TO Q03] |
| 7 | Refused | [SKIP TO Q03] |
| 9 | Don't know | [SKIP TO Q03] |

Round 1 Results: Some respondents admitted they were guessing when they said “yes” or “no” or simply answered “don’t know.” One person said, “I’m assuming that if I had the other [Hepatitis B], I must have had it.” They seemed to assume they knew more about Hepatitis B.

Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don’t know.

Round 2 Results: This question tested on all 11 respondents. Most expressed less difficulty with this question than the other vaccine questions because they were less familiar with it and, therefore, more willing to answer no. Only one person said “don’t know” because she wasn’t sure: “I know I got vaccines, I just don’t know what.” All other who weren’t sure simply answered no.

Round 2 Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don’t know.

Q02. How many hepatitis A shots did you receive?

___ (# of hepatitis A shots)

- 3 All shots
- 7 Refused
- 9 Don't know

Round 1 Results: Only tested on 2 people.

Recommendation: None.

Round 2 Results: This question tested on 2 respondents. One said "I think I had 2" but she wasn't 100% sure. The other respondent said she received 1, implying that was all that's necessary.

Round 2 Recommendation: None. Survey questions are probably not the best method for obtaining reliable information on vaccines. Its essentially asking people something they don't know.

Q03. Has a doctor or other health professional ever told you that you had any kind of chronic, or long-term liver condition?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

Round 1 Results: No problems detected with this question. Probing supported survey responses.

Recommendation: None.

Round 2 Results: This question tested on all 11 respondents. No problems were detected.

Round 2 Recommendation: None.

Q07. Have you ever traveled outside of the United States to countries other than Europe, Japan, Australia, New Zealand or Canada, since 1995?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

Round 1 Results: No problems detected, probably because 8 respondents had never traveled outside the U.S. in their life, and the other had traveled recently (to Rome and Brazil).

Recommendation: None.

Round 2 Results: This question tested on all 11 respondents. No problems were detected.

Round 2 Recommendation: None.

Appendix A: Instruments used in Round 1 testing

[Men and Women with Daughter 8+]

Parental Consent for HPV Vaccine

QA07_I65 Have you ever heard of a vaccine or shot to prevent cervical cancer?

NEW

YES	1	} [GO TO QA07_I67]
NO	2	
REFUSED	-7	
DON'T KNOW	-8	

QA07_I66 Did {DAUGHTER} ever receive the HPV vaccine or HPV shots?

NEW

YES	1	} [GO TO PN QA07_I67]
NO	2	
REFUSED	-7	
DON'T KNOW	-8	

QA07_E66a Did {DAUGHTER} receive all three doses of the HPV vaccine?

YES	1	} [GO TO NEXT SECTION]
NO	2	
REFUSED	-7	
DON'T KNOW	-8	

QA07_I67 {HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26.} If {DAUGHTER}'s doctor recommended the HPV vaccine, would you have her get it?

NEW

YES	1	[GO TO QA07_I69]
NO	2	
DON'T KNOW	-7	
REFUSED	-8	

QA07_I68

NEW

What is the MAIN reason you would NOT want {DAUGHTER} to get the vaccine?

- DOES NOT NEED VACCINE 1 [GO TO NEXT SECTION]
 - NOT SEXUALLY ACTIVE 2 [GO TO NEXT SECTION]
 - TOO EXPENSIVE 3 [GO TO QA07_I70]
 - TOO YOUNG 4
 - DOCTOR DIDN'T RECOMMEND IT 5
 - WORRIED ABOUT SAFETY OF VACCINE 6
 - DON'T KNOW WHERE TO GET VACCINE 7
 - MY SPOUSE/FAMILY MEMBER IS AGAINST IT 8
- } [GO TO NEXT SECTION]
- DON'T KNOW ENOUGH ABOUT VACCINE 9
 - OTHER..... 10
 - REFUSED-7
 - DON'T KNOW-8

QA07_I69

NEW

The cost of the vaccine may be about \$360-500. Would you have {DAUGHTER} get the vaccine if you had to pay this amount?

- YES 1 [GO TO NEXT SECTION]
- NO 2 [GO TO QA07_I70]
- REFUSED-7 [GO TO NEXT SECTION]
- DON'T KNOW-8 [GO TO NEXT SECTION]

QA07_I70

NEW

If {DAUGHTER} could get the vaccine free or at a much lower cost, would you have her get it?

- YES 1
- NO 2
- REFUSED-7
- DON'T KNOW-8

[Men and Women age 40+]

FOBT

QA07_B30

A stool blood test, also known as a Fecal Occult Blood Test, is a test to check for colon cancer. It is done at home using a set of 2 or 3 cards to determine whether the stool contains blood. Have you ever done a stool blood test using a home kit?

Alternative Wording: A stool blood test or fecal blood test is a test done at home to check for colon cancer. You use a stick or brush to obtain one or more stool samples, and return the samples to the doctor's office or laboratory. Have you ever done a stool blood test using a home kit?

AF22

- YES 1
- NO-2 [GO TO QA07_B33]
- REFUSED-7 [GO TO QA07_B33]
- DON'T KNOW-8 [GO TO QA07_B33]

QA07_B31 When did you have your most recent stool blood test using a home kit to check for colon cancer?

AF24

- A YEAR AGO OR LESS1
- MORE THAN 1 YEAR AGO UP TO
2 YEARS AGO2
- MORE THAN 2 YEARS AGO UP TO
5 YEARS AGO3
- MORE THAN 5 YEARS AGO4
- REFUSED -7
- DON'T KNOW -8

QA07_B35 What was the main reason you had your most recent stool blood test using a home kit?
Was it...

NEW

- PART OF A ROUTINE EXAM.....1
- BECAUSE OF A PROBLEM, OR2
- SOME OTHER REASON.....3
- REFUSED -7
- DON'T KNOW -8

Colonoscopy
QA07_B33

A sigmoidoscopy and a colonoscopy are both tests that examine the bowel by inserting a tube in the rectum. The difference is that during a sigmoidoscopy, you are awake and can drive yourself home after the test; however, during a colonoscopy, you may feel sleepy and you need someone to drive you home. Have you ever had a colonoscopy?

NEW

- YES 1
- NO 2 **[GO TO PN QA07_B36]**
- REFUSED-7 **[GO TO PN QA07_B36]**
- DON'T KNOW-8 **[GO TO PN QA07_B36]**

QA07_B34 When did you have your most recent colonoscopy to check for colon cancer?

NEW

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 5 YEARS AGO2
- MORE THAN 5 UP TO 10 YEARS AGO3
- MORE THAN 10 YEARS AGO4
- REFUSED -7
- DON'T KNOW -8

QA07_B32 What was the main reason you had your most recent colonoscopy? Was it...

NEW

- PART OF A ROUTINE EXAM.....1
- BECAUSE OF A PROBLEM, OR2
- SOME OTHER REASON.....3
- REFUSED -7
- DON'T KNOW -8

Sigmoidoscopy

QA07_B36

Have you ever had a sigmoidoscopy?

NEW

- YES 1
- NO 2 [GO TO PN QA07_B39]
- REFUSED-7 [GO TO PN QA07_B39]
- DON'T KNOW-8 [GO TO PN QA07_B39]

QA07_B37

When did you have your most recent sigmoidoscopy to check for colon cancer?

NEW

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 5 YEARS AGO2
- MORE THAN 5 UP TO 10 YEARS AGO3
- MORE THAN 10 YEARS AGO4
- REFUSED -7
- DON'T KNOW -8

QA07_B38

What was the main reason you had your most recent sigmoidoscopy? Was it...

NEW

- PART OF A ROUTINE EXAM.....1
- BECAUSE OF A PROBLEM, OR2
- SOME OTHER REASON.....3
- REFUSED -7
- DON'T KNOW -8

QA07_B39

In the past 5 years, has a doctor recommended that you have a sigmoidoscopy, colonoscopy or stool blood test?

NEW

- YES1
- NO2
- DID NOT GO TO DOCTOR IN PAST 12 MONTHS 92
- REFUSED -7
- DON'T KNOW -8

[Females 18+]

Hysterectomy

QA07_E5

Have you had a hysterectomy?

AD12

[IF NEEDED, SAY: "A hysterectomy is when the uterus or womb is removed, not just having your tubes tied to prevent pregnancy."]

- YES1
- NO2
- REFUSED -7
- DON'T KNOW -8

**Pap smear
QA07_E5**

AD4

Have you ever had a Pap test to check for cervical cancer?

[IF NEEDED, SAY: "Sometimes, a woman has a routine pelvic exam, she also has a Pap smear to test for cancer of the cervix. A doctor takes a cell sample from the cervix with a small stick or brush and sends it to the lab."]

- YES1
- NO.....2 **[GO TO PN QA07_E8]**
- REFUSED -7 **[GO TO QA07_E9]**
- DON'T KNOW -8 **[GO TO QA07_E9]**

QA07_E6

AD5

How many Pap tests have you had in the last 6 years?

- _____ # of PAPS
- NONE0 **[GO TO PN QA07_E8]**
- REFUSED -7
- DON'T KNOW -8

QA07_E7

AD6

How long ago did you have your most recent Pap test?

- A YEAR AGO OR LESS1 **[GO TO QA07_E9]**
- MORE THAN 1 UP TO 2 YEARS AGO2 **[GO TO QA07_E9]**
- MORE THAN 2 UP TO 3 YEARS AGO3 **[GO TO QA07_E9]**
- MORE THAN 3 UP TO 5 YEARS AGO4 **[GOTO QA07_E8]**
- MORE THAN 5 YEARS AGO5 **[GOTO QA07_E8]**
- REFUSED -7 **[GO TO QA07_E9]**
- DON'T KNOW -8 **[GO TO QA07_E9]**

QA07_E8

AD10

What is the ONE most important reason why you have {NEVER had a Pap test/NOT had a Pap test in the last 3 years}?

- NO REASON/NEVER THOUGHT ABOUT IT1
- DIDN'T KNOW I NEEDED THIS TYPE OF TEST2
- DOCTOR DIDN'T TELL ME I NEEDED IT3
- HAVEN'T HAD ANY PROBLEMS.....4
- PUT IT OFF/LAZINESS5
- TOO EXPENSIVE/NO INSURANCE/COST6
- TOO PAINFUL, UNPLEASANT,
OR EMBARRASSING.....7
- HYSTERECTOMY8
- DON'T HAVE A DOCTOR9
- HAD HPV VACCINE 10
- HAD HPV DNA TEST 11
- OTHER..... 91
- REFUSED -7
- DON'T KNOW -8

QA07_E9

AD11

In the past 3 years, has a doctor recommended that you have a Pap test?

- YES1
- NO.....2
- REFUSED.....-7
- DON'T KNOW-8

QA07_E10

NEW

When do you expect to have your next Pap test?

- A YEAR OR LESS FROM NOW 1
- 1-3 YEARS FROM NOW 2
- 3-5 YEARS FROM NOW 3
- MORE THAN 5 YEARS FROM NOW 4
- WHEN DOCTOR RECOMMENDS IT 5
- NEVER, HAD HPV DNA TEST 6
- NEVER, HAD HPV VACCINE..... 7
- NEVER, OTHER REASON..... 8
- REFUSED-7
- DON'T KNOW-8

**IF EVER HAD A PAP TEST CONTINUE WITH QA07_E10;
ELSE SKIP TO QA07_E11;**

QA07_E10

AD8

Have you ever had a Pap test where the results were NOT normal?

- YES 1
- NO..... 2
- DON'T KNOW-7
- REFUSED.....-8

HPV VERSION 1

[Females 65 and Under]

HPV Awareness

QA07_E11

NEW

Have you ever heard of HPV? HPV stands for Human Papillomavirus.

- YES 1
- NO..... 2
- REFUSED-7
- DON'T KNOW-8

[GO TO PN QA07_E16]

QA07_E12

NEW

Where did you hear about HPV? [CODE ALL THAT APPLY]

- HEALTH CARE PROVIDER/CLINIC 1
- FAMILY OR FRIENDS 2
- TV ADVERTISEMENT 3
- TV NEWS 4
- TV SHOW 5
- NEWSPAPER OR MAGAZINE 6
- INTERNET 7
- SCHOOL 8
- OTHER 9
- REFUSED -7
- DON'T KNOW -8

QA07_E13

NEW

Do you think HPV can cause cervical cancer?

- YES 1
- NO 2
- DON'T KNOW -7
- REFUSED -8

QA07_E14

NEW

Do you think you can get HPV through sexual contact?

- YES 1
- NO 2
- DON'T KNOW -7
- REFUSED -8

QA07_E15

NEW

Do you think HPV causes AIDS?

- YES 1
- NO 2
- DON'T KNOW -7
- REFUSED -8

QA07_E15A

NEW

Do you think HPV can go away on its own without treatment?

- YES 1
- NO 2
- DON'T KNOW -7
- REFUSED -8

[Females 18-27]

HPV Vaccine

QA07_E16 Have you ever heard of a vaccine or shot to prevent cervical cancer?

NEW

- YES 1
 - NO 2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO PN QA07_E18]**

QA07_E17 Have you ever received the HPV vaccine or HPV shots?

NEW

- YES 1
 - NO 2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO PN QA07_E18]**

QA07_E17a Did you receive all three doses of the HPV vaccine?

- YES 1
 - NO 2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO QA07_E22]**

QA07_E18 {HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26.} Would you be interested in getting the vaccine?

NEW

- YES 1 **[GO TO PN QA07_E20]**
- NO 2
- REFUSED -7
- DON'T KNOW -8

QA07_E19

NEW

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

- DOES NOT NEED VACCINE 1 [GO TO PN QA07_E22]
 - NOT SEXUALLY ACTIVE 2 [GO TO PN QA07_E22]
 - TOO EXPENSIVE 3 [GO TO QA07_E21]
 - TOO OLD FOR VACCINE 4
 - DOCTOR DIDN'T RECOMMEND IT 5
 - WORRIED ABOUT SAFETY OF VACCINE 6
 - DON'T KNOW WHERE TO GET VACCINE 7
 - MY SPOUSE/FAMILY MEMBER IS AGAINST IT 8
 - DON'T KNOW ENOUGH ABOUT VACCINE 9
 - OTHER..... 10
 - REFUSED-7
 - DON'T KNOW-8
- } [GO TO PN QA07_E22]

QA07_E20.

NEW

The cost of the vaccine may be about \$360-500. Would you get the HPV vaccine if you had to pay this amount?

- YES 1 [GO TO PN QA07_E22]
- NO 2 [GO TO QA07_E21]
- REFUSED-7 [GO TO PN QA07_E22]
- DON'T KNOW-8 [GO TO PN QA07_E22]

QA07_E21

NEW

If you could get the HPV vaccine free or at a much lower cost, would you get it?

- YES 1
- NO 2
- REFUSED-7
- DON'T KNOW-8

HPV VERSION 2

QHPV1

A vaccine to prevent the human papillomavirus or HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL®. (Have you/has she) ever had the HPV vaccination?

- YES 1
- NO 2
- DOCTOR REFUSED WHEN ASKED.....3
- REFUSED-7
- DON'T KNOW/NOT SURE-8

(ISD)Q04

How many HPV shots did you receive?

- _____ # of shots
- All shots.....96 [skip out]
- REFUSED-7 [skip out]
- DON'T KNOW -8 [skip out]

HPV VERSION 3

QHPV1 A vaccine to prevent the human papillomavirus or HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL®. (Have you/has she) ever had the HPV vaccination?

- YES 1
- NO 2
- DOCTOR REFUSED WHEN ASKED3
- REFUSED-7
- DON'T KNOW/NOT SURE-8

(ISD)Q04 How many HPV shots did you receive?

- ___ Number of shots
- All shots96 [skip out]
- REFUSED-7 [skip out]
- DON'T KNOW-8 [skip out]

[Females 65 and Under (NCI) or Males and Females 18-49 (CDC)]

HPV Awareness

QA07_E11 Have you ever heard of HPV? HPV stands for Human Papillomavirus.

NEW

- YES 1
 - NO 2
 - REFUSED-7
 - DON'T KNOW-8
- } **[GO TO PN QA07_E16]**

QA07_E12 Where did you hear about HPV? [CODE ALL THAT APPLY]

NEW

- HEALTH CARE PROVIDER/CLINIC 1
- FAMILY OR FRIENDS 2
- TV ADVERTISEMENT 3
- TV NEWS 4
- TV SHOW 5
- NEWSPAPER OR MAGAZINE 6
- INTERNET 7
- SCHOOL 8
- OTHER 9
- REFUSED-7
- DON'T KNOW-8

QA07_E13 Do you think HPV can cause cervical cancer?

NEW

- YES 1
- NO 2
- DON'T KNOW-7
- REFUSED-8

QA07_E14

NEW

Do you think you can get HPV through sexual contact?

YES 1
 NO 2
 DON'T KNOW -7
 REFUSED -8

QA07_E15

NEW

Do you think HPV causes AIDS?

YES 1
 NO 2
 DON'T KNOW -7
 REFUSED -8

QA07_E15A

NEW

Do you think HPV can go away on its own without treatment?

YES 1
 NO 2
 DON'T KNOW -7
 REFUSED -8

HPV VERSION 4

(ISD)Q01 The human papillomavirus is a common virus known to cause genital warts and some cancers, such as cervical cancer in women. Before today, have you ever heard of the Human Papillomavirus or HPV? This is not HIV.

YES 1
 NO 2
 REFUSED -7
 DON'T KNOW -8

(ISD)Q02 A vaccine to prevent HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL®. Before today, have you heard of the cervical cancer vaccine, HPV shot, or Gardasil? The vaccine was licensed and approved in June 2006.

YES 1
 NO 2
 REFUSED -7
 DON'T KNOW -8

(ISD)Q03 Have you ever had the HPV vaccination?

YES 1
 NO 2 [skip out]
 REFUSED -7 [skip out]
 DON'T KNOW -8 [skip out]

(ISD)Q04 How many HPV shots did you receive?

____ Number of shots
All shots.....96 [skip out]
REFUSED -7 [skip out]
DON'T KNOW -8 [skip out]

HPV VERSION 5

(ISD)Q01 The human papillomavirus is a common virus known to cause genital warts and some cancers, such as cervical cancer in women. Before today, have you ever heard of the Human Papillomavirus or HPV? This is not HIV.

YES 1
NO..... 2
REFUSED-7
DON'T KNOW-8

QHPV1 A vaccine to prevent the human papillomavirus or HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL®. (Have you/has she) ever had the HPV vaccination?

YES 1
NO..... 2
DOCTOR REFUSED WHEN ASKED.....3
REFUSED-7
DON'T KNOW/NOT SURE -8

[FEMALES 30+]

Mammography

QA07_E22 Have you ever had a mammogram?

AD14

[IF NEEDED, SAY: "A mammogram is an x-ray taken of each breast separately by a machine that flattens or squeezes each breast."]

YES1
NO.....2
[READ DEFINITION, IF STILL NO, GO TO PN QA07_E25]
REFUSED -7 **[GO TO PN QA07_E26]**
DON'T KNOW -8 **[GO TO PN QA07_E26]**

QA07_E23 How many mammograms have you had in the last 6 years? Your best estimate is fine.

AD16

_____ # of MAMMOGRAMS
NONE0 **[GO TO QA07_E25]**
REFUSED -7
DON'T KNOW -8

QA07_E24 How long ago did you have your most recent mammogram?

AD17

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 2 YEARS AGO2
- MORE THAN 2 UP TO 3 YEARS AGO3
- MORE THAN 3 UP TO 5 YEARS AGO4
- MORE THAN 5 YEARS AGO5
- REFUSED -7 [GO TO PN QA07_E26]
- DON'T KNOW -8 [GO TO PN QA07_E26]

QA07_E25 In the past 2 years, has a doctor recommended that you have a mammogram?

AD26

- YES1
- NO2
- REFUSED -7
- DON'T KNOW -8

QA07_E26 Please tell me if you agree or disagree with the following statements:

Medical experts have differing views about whether women should have mammograms.
Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED -7
- DON'T KNOW -8

QA07_E27 There are conflicting recommendations from medical experts about whether women should have mammograms. Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED -7
- DON'T KNOW -8

QA07_E28 There are so many different recommendations about mammography, it's hard to know which ones to follow. Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED -7
- DON'T KNOW -8

QA07_E29 I feel confused about contradictory recommendations I have read or heard about having
a mammogram. Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED -7
- DON'T KNOW -8

[Next two Questions for Women 40+]

Hormone Replacement Therapy

QA07_E26 Are you currently taking hormone replacement therapy or HRT for menopause?

AD28

[IF NEEDED, SAY: "This is a pill, patch or treatment that gives women more of the female hormone, estrogen."]

- YES1
 - NO2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO QA07_E28]**

QA07_E27 Some women go on and off hormone replacement therapy. How long have you taken HRT altogether?

NEW

[IF NEEDED, SAY: "Please total all the time you have taken HRT."]

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 2 YEARS2
- MORE THAN 2 UP TO 4 YEARS3
- MORE THAN 4 UP TO 8 YEARS4
- MORE THAN 8 YEARS AGO5
- REFUSED -7
- DON'T KNOW -8

SHINGLES

[Males and Females 50+]

Q01. Shingles is an outbreak of a rash or blisters on the skin that may be associated with severe pain. The pain is generally on one side of the body or face. Shingles is caused by the chicken pox virus. A vaccine for shingles has been available since May 2006. Have you ever had the Zoster or Shingles vaccine, also called Zostavax®?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

TD/TDAP

[Men and Women 18+]

Q01. Have you received a tetanus shot in the past 10 years?

- | | | |
|---|------------|-------------------|
| 1 | Yes | |
| 2 | No | [SKIP BEYOND Q03] |
| 7 | Refused | [SKIP BEYOND Q03] |
| 9 | Don't know | [SKIP BEYOND Q03] |

Q02. Was your most recent tetanus shot given in 2005 or later?

- | | | |
|---|------------|----------------------|
| 1 | Yes | [SKIP TO CHECKPOINT] |
| 2 | No | [SKIP BEYOND Q03] |
| 7 | Refused | [SKIP TO CHECKPOINT] |
| 9 | Don't know | [SKIP BEYOND Q03] |

If R's age <65 then ask Q03 Else skip to Hepatitis A

Q03. [PRONOUNCE "Td" TEE DEE (RHYMES WITH "SEE"). PRONOUNCE "Tdap" TEE DAP (RHYMES WITH "CAP").]

There are currently two types of tetanus shots available today. One is the Td or tetanus-diphtheria vaccine and the other is called Tdap or Adacel™. They are similar except the Tdap shot also includes a pertussis or whooping cough vaccine. Thinking back to your most recent tetanus shot, did the doctor tell you the vaccine included the pertussis or whooping cough vaccine? The shot is often called Tdap or ADACEL™.

- | | |
|---|--------------------------------|
| 1 | Yes – included pertussis |
| 2 | No – did not include pertussis |
| 3 | Doctor did not say |
| 7 | Refused |
| 9 | Don't know |

HEPATITIS A

[Men and Women 18+]

AAU.370 Have you EVER received the hepatitis B vaccine?

READ IF NECESSARY: This is given in three separate doses and has been available since 1991. It is recommended for newborn infants, adolescents, and people such as health care workers, who may be exposed to the hepatitis B virus.

- | | |
|----------------|--------------|
| (1) Yes | (AAU.380) |
| (2) No | (A_ACUT_END) |
| (7) Refused | (A_ACUT_END) |
| (9) Don't know | (A_ACUT_END) |

AAU.380 Did {you} receive at least 3 doses of the hepatitis B vaccine, or less than 3 doses?

- (1) Received at least 3 doses
- (2) Received less than 3 doses
- (7) Refused
- (9) Don't know

Q01. The hepatitis A vaccine is given as a two dose series routinely to some children starting at 1 year of age, and to some adults and people who travel outside the United States. Although it can be given as a combination vaccine with hepatitis B, it is different from the hepatitis B shot, and has only been available since 1995. Have you ever received hepatitis A vaccine?

- 1 Yes
- 2 No [SKIP TO Q03]
- 7 Refused [SKIP TO Q03]
- 9 Don't know [SKIP TO Q03]

Q02. How many hepatitis A shots did you receive?

___ (# of hepatitis A shots)

- 3 All shots
- 7 Refused
- 9 Don't know

Q03. Has a doctor or other health professional ever told you that you had any kind of chronic, or long-term liver condition?

Alternative wording: DURING THE PAST 12 MONTHS, have you been told by a doctor or other health professional that you had any kind of liver condition?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

Q07. Have you ever traveled outside of the United States to countries other than Europe, Japan, Australia, New Zealand or Canada, since 1995?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

Appendix B: Instruments used in Round 2 testing

[Women with Daughter 8+]

Parental Consent for HPV Vaccine

QA07_I65 A vaccine to prevent human papillomavirus or HPV infection is available and is called the cervical cancer vaccine or HPV shot. Before today, have you ever heard of the cervical cancer vaccine or HPV shot?

NEW

- YES 1
 - NO 2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO QA07_I67]**

[IF NEEDED SAY: “The brand name of the vaccine is Gardasil or Cervarix.”]

[IF DK OR REFUSE, SAY: “HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26.”]

QA07_I66 Did {DAUGHTER} ever receive the cervical cancer vaccine or HPV shot?

NEW

- YES 1
 - NO 2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO PN QA07_I67]**

[IF DK OR REFUSE, SAY: “HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26.”]

QA07_E66a How many HPV shots did {DAUGHTER} receive?

_____ # of shots

- All shots 96 **[GO TO NEXT SECTION]**
- REFUSED -7 **[GO TO NEXT SECTION]**
- DON'T KNOW 8 **[GO TO NEXT SECTION]**

QA07_I67 {HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26.} If {DAUGHTER}'s doctor recommended the HPV vaccine, would you have her get it?

NEW

- YES 1 **[GO TO QA07_I69]**
- NO 2
- DON'T KNOW -7
- REFUSED -8

QA07_I68

NEW

What is the MAIN reason you would NOT want {DAUGHTER} to get the vaccine?

- DOES NOT NEED VACCINE 1 [GO TO NEXT SECTION]
 - NOT SEXUALLY ACTIVE 2 [GO TO NEXT SECTION]
 - TOO EXPENSIVE 3 [GO TO QA07_I70]
 - TOO YOUNG 4
 - DOCTOR DIDN'T RECOMMEND IT 5
 - WORRIED ABOUT SAFETY OF VACCINE 6
 - DON'T KNOW WHERE TO GET VACCINE 7
 - MY SPOUSE/FAMILY MEMBER IS AGAINST IT 8
- } [GO TO NEXT SECTION]
- DON'T KNOW ENOUGH ABOUT VACCINE 9
 - OTHER..... 10
 - REFUSED-7
 - DON'T KNOW-8

QA07_I69

NEW

The cost of the vaccine may be about \$360-500. Would you have {DAUGHTER} get the vaccine if you had to pay this amount?

- YES 1 [GO TO NEXT SECTION]
- NO 2 [GO TO QA07_I70]
- REFUSED-7 [GO TO NEXT SECTION]
- DON'T KNOW-8 [GO TO NEXT SECTION]

QA07_I70

NEW

If {DAUGHTER} could get the vaccine free or at a much lower cost, would you have her get it?

- YES 1
- NO 2
- REFUSED-7
- DON'T KNOW-8

[Women age 40+]

FOBT

QA07_B30

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

AF22

- YES 1
- NO2 [GO TO QA07_B33]
- REFUSED-7 [GO TO QA07_B33]
- DON'T KNOW-8 [GO TO QA07_B33]

QA07_B31

When did you have your MOST RECENT blood stool test using a kit at home?

AF24

- A YEAR AGO OR LESS1
- MORE THAN 1 YEAR AGO UP TO
2 YEARS AGO2
- MORE THAN 2 YEARS AGO UP TO
5 YEARS AGO3
- MORE THAN 5 YEARS AGO4
- REFUSED-7
- DON'T KNOW-8

QA07_B35

[if most recent screening exam 1 year ago or less, read:]

Was your most recent HOME blood stool test recommended by a doctor or other health professional?

[else if *never* had a FOBT or last test more than 1 year ago, read:]

In the PAST 12 MONTHS, has a doctor or other health professional RECOMMENDED that you have a HOME blood stool test?

NEW

- YES 1
- NO 2
- DID NOT SEE DOCTOR IN THE PAST 12 M.....3
- REFUSED-7
- DON'T KNOW-8

Colonoscopy

QA07_B33

Have you EVER HAD a sigmoidoscopy, colonoscopy, or proctoscopy? These are exams in which a health care professional inserts a tube into the rectum to look for signs of cancer or other problems.

[*Read if necessary. A proctoscopy is an older exam that used a rigid tube.]

*Pronunciation guide: sigmoid-OS-copy, colon-OS-copy, proc-TOS-copy.

NEW

- YES 1
- NO 2 [GO TO PN QA07_B36]
- REFUSED-7 [GO TO PN QA07_B36]
- DON'T KNOW-8 [GO TO PN QA07_B36]

QA07_B34

When did you have your MOST RECENT exam?

NEW

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 5 YEARS AGO2
- MORE THAN 5 UP TO 10 YEARS AGO3
- MORE THAN 10 YEARS AGO4
- REFUSED-7
- DON'T KNOW-8

QA07_B33
problems. A

someone
Was this
else?

For a SIGMOIDOSCOPY, a flexible tube is inserted into the rectum to look for COLONOSCOPY is SIMILAR, but uses a longer tube, and you are usually given medication through a needle in your arm to make you sleepy, and told to have else drive you home. A PROCTOSCOPY is an older exam that used a rigid tube. MOST RECENT exam a sigmoidoscopy, colonoscopy, proctoscopy or something

Pronunciation guide: sigmoid-OS-copy, colon-OS-copy, proc-TOS-copy.

- SIGMOIDOSCOPY1
- COLONOSCOPY2
- PROCTOSCOPY3
- SOMETHING ELSE4
- REFUSED -7
- DON'T KNOW -8

QA07_B32

NEW

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

- PART OF A ROUTINE EXAM.....1
- BECAUSE OF A PROBLEM, OR2
- SOME OTHER REASON.....3
- REFUSED -7
- DON'T KNOW -8

QA07_B39

NEW

[if most recent screening exam 10 year ago or less, read:]

Was your most recent test recommended by a doctor or other health professional?

[Else if never had a test or last test more than 10 years ago, read:]

In the PAST 12 MONTHS, has a doctor or other health professional RECOMMENDED that you have a sigmoidoscopy or colonoscopy?

- YES 1
- NO 2
- DID NOT SEE DOCTOR IN THE PAST 12 M.....3
- REFUSED -7
- DON'T KNOW -8

[Women 18+]

Pap smear

QA07_E5

AD4

Have you EVER HAD a Pap smear or Pap test?

[IF NEEDED, SAY: "A Pap smear is a routine test for women in which the doctor examines the cervix, takes a cell sample from the cervix with a small stick or brush, and sends it to the lab."]

- YES1
- NO2 **[GO TO PN QA07_E8]**
- REFUSED -7 **[GO TO QA07_E9]**
- DON'T KNOW -8 **[GO TO QA07_E9]**

QA07_E6

AD5

How many Pap smears or Pap tests have you had in the LAST 6 YEARS?

- _____ # of PAPS
- NONE0 **[GO TO PN QA07_E8]**
- REFUSED -7
- DON'T KNOW -8

QA07_E7

AD6

When did you have your MOST RECENT Pap smear or Pap test?

- A YEAR AGO OR LESS1 **[GO TO QA07_E9]**
- MORE THAN 1 UP TO 2 YEARS AGO2 **[GO TO QA07_E9]**
- MORE THAN 2 UP TO 3 YEARS AGO3 **[GO TO QA07_E9]**
- MORE THAN 3 UP TO 5 YEARS AGO4 **[GOTO QA07_E8]**
- MORE THAN 5 YEARS AGO5 **[GOTO QA07_E8]**
- REFUSED -7 **[GO TO QA07_E9]**
- DON'T KNOW -8 **[GO TO QA07_E9]**

QA07_E8

AD10

What is the most important reason you have [NEVER had a Pap smear or Pap test/NOT had a Pap smear or Pap test in the LAST 3 YEARS]?

- NO REASON/NEVER THOUGHT ABOUT IT1
- DIDN'T KNOW I NEEDED THIS TYPE OF TEST2
- DOCTOR DIDN'T TELL ME I NEEDED IT3
- HAVEN'T HAD ANY PROBLEMS.....4
- PUT IT OFF/LAZINESS5
- TOO EXPENSIVE/NO INSURANCE/COST6
- TOO PAINFUL, UNPLEASANT,
OR EMBARRASSING.....7
- HYSTERECTOMY8
- DON'T HAVE A DOCTOR9
- HAD HPV VACCINE 10
- HAD HPV DNA TEST 11
- OTHER..... 91
- REFUSED -7
- DON'T KNOW -8

QA07_E09

[if most recent Pap test 3 years ago or less, read:]

Was your most recent Pap smear or Pap test recommended by a doctor or other health professional?

[Else if never had a Pap test or last test more than 3 years ago, read:]

In the PAST 12 MONTHS, has a doctor or other health professional RECOMMENDED that you have a Pap smear or Pap test?

NEW

- YES 1
- NO..... 2
- DID NOT SEE DOCTOR IN THE PAST 12 M.....3
- REFUSED-7
- DON'T KNOW-8

QA07_E10

When do you expect to have your next Pap smear or Pap test?

NEW

- A YEAR OR LESS FROM NOW 1
- 1-3 YEARS FROM NOW 2
- 3-5 YEARS FROM NOW 3
- MORE THAN 5 YEARS FROM NOW 4
- WHEN DOCTOR RECOMMENDS IT 5
- NEVER, HAD HPV DNA TEST 6
- NEVER, HAD HPV VACCINE..... 7
- NEVER, OTHER REASON..... 8
- REFUSED-7
- DON'T KNOW-8

**IF EVER HAD A PAP TEST CONTINUE WITH QA07_E10;
ELSE SKIP TO NEXT SECTION, HYSTERECTOMY**

QA07_E10

Have you EVER had a Pap smear or Pap test where the results were NOT normal?

AD8

- YES 1
- NO..... 2
- DON'T KNOW-7
- REFUSED-8

[Females 18+]

Hysterectomy

QA07_E5 Have you had a hysterectomy?

AD12

[IF NEEDED, SAY: "A hysterectomy is when the uterus or womb is removed, not just having your tubes tied to prevent pregnancy."]

- YES1
- NO.....2
- REFUSED-7
- DON'T KNOW-8

HPV VERSION 1

[Females 65 and Under]

HPV Awareness

QA07_E11 Have you ever heard of HPV? HPV stands for Human Papillomavirus.

NEW

- YES 1
 - NO..... 2
 - REFUSED-7
 - DON'T KNOW-8
- } [GO TO PN QA07_E16]**

QA07_E13 Do you think HPV can cause cervical cancer?

NEW

- YES 1
- NO..... 2
- DON'T KNOW-7
- REFUSED-8

QA07_E14 Do you think you can get HPV through sexual contact?

NEW

- YES 1
- NO..... 2
- DON'T KNOW-7
- REFUSED-8

QA07_E15A Do you think HPV can go away on its own without treatment?

NEW

- YES 1
- NO..... 2
- DON'T KNOW-7
- REFUSED-8

[Females 18+]

HPV Vaccine

QA07_E16 Have you ever heard of a vaccine or shot to prevent cervical cancer and HPV infection?

NEW

- YES 1
 - NO 2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO PN QA07_E18]**

[IF NEEDED SAY: "The brand name of the vaccine is Gardasil or Cervarix."]

[IF DK/REFUSE, SAY: "HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26"]

QA07_E17 Have you ever received the cervical cancer vaccine or HPV shot?

NEW

- YES 1
 - NO 2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO PN QA07_E18]**

[IF DK/REFUSE, SAY: "HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26"]

(ISD)Q04 How many HPV shots did you receive?

- _____ # of shots
- All shots 96
- REFUSED -7
- DON'T KNOW -8

QA07_E18 {HPV is a virus that can cause cervical cancer. A vaccine that protects against HPV has been approved for females ages 9 to 26.} Would you be interested in getting the vaccine?

NEW

- YES 1 **[GO TO PN QA07_E20]**
- NO 2
- REFUSED -7
- DON'T KNOW -8

QA07_E19

NEW

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

- DOES NOT NEED VACCINE 1 [GO TO PN QA07_E22]
 - NOT SEXUALLY ACTIVE 2 [GO TO PN QA07_E22]
 - TOO EXPENSIVE 3 [GO TO QA07_E21]
 - TOO OLD FOR VACCINE 4
 - DOCTOR DIDN'T RECOMMEND IT 5
 - WORRIED ABOUT SAFETY OF VACCINE 6
 - DON'T KNOW WHERE TO GET VACCINE 7
 - MY SPOUSE/FAMILY MEMBER IS AGAINST IT 8
 - DON'T KNOW ENOUGH ABOUT VACCINE 9
 - OTHER..... 10
 - REFUSED-7
 - DON'T KNOW-8
- } [GO TO PN QA07_E22]

QA07_E20.

NEW

The cost of the vaccine may be about \$360-500. Would you get the HPV vaccine if you had to pay this amount?

- YES 1 [GO TO PN QA07_E22]
- NO..... 2 [GO TO QA07_E21]
- REFUSED-7 [GO TO PN QA07_E22]
- DON'T KNOW-8 [GO TO PN QA07_E22]

QA07_E21

NEW

If you could get the HPV vaccine free or at a much lower cost, would you get it?

- YES 1
- NO..... 2
- REFUSED-7
- DON'T KNOW-8

HPV VERSION 3

[Women 18-49]

HPV Vaccine

QHPV1

A vaccine to prevent the human papillomavirus or HPV infection is available and is called the cervical cancer vaccine, HPV shot, or GARDASIL®. Have you ever had the HPV vaccination?

- YES 1
- NO 2
- DOCTOR REFUSED WHEN ASKED 3
- NEVER HEARD OF HPV/HPV INFECTION 4
- NEVER HEARD OF HPV SHOT/CERVICAL
CANCER VACCINE/GARDASIL 5
- REFUSED -7
- DON'T KNOW/NOT SURE -8

(ISD)Q04 How many HPV shots did you receive?

- ___Number of shots
- All shots 96
- REFUSED -7
- DON'T KNOW -8

[Women 18-49 (CDC)]

HPV Awareness

QA07_E11

Have you ever heard of HPV? HPV stands for Human Papillomavirus.

NEW

- YES 1
 - NO 2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO PN QA07_E16]**

QA07_E13

Do you think HPV can cause cervical cancer?

NEW

- YES 1
- NO 2
- DON'T KNOW -7
- REFUSED -8

QA07_E14

Do you think you can get HPV through sexual contact?

NEW

YES 1
 NO 2
 DON'T KNOW -7
 REFUSED -8

QA07_E15A

Do you think HPV can go away on its own without treatment?

NEW

YES 1
 NO 2
 DON'T KNOW -7
 REFUSED -8

[FEMALES 30+]

Mammography

QA07_E22

AD14

Have you EVER HAD a mammogram?

machine

[IF NEEDED, SAY: " A mammogram is an x-ray taken only of the breast by a that presses against the breast. "]

YES1
 NO2
[READ DEFINITION, IF STILL NO, GO TO PN QA07_E25]
 REFUSED -7 **[GO TO PN QA07_E26]**
 DON'T KNOW -8 **[GO TO PN QA07_E26]**

QA07_E23

How many mammograms have you had in the LAST 6 YEARS?

AD16

_____ # of MAMMOGRAMS
 NONE0 **[GO TO QA07_E25]**
 REFUSED -7
 DON'T KNOW -8

QA07_E24

When did you have your MOST RECENT mammogram?

AD17

A YEAR AGO OR LESS1
 MORE THAN 1 UP TO 2 YEARS AGO2
 MORE THAN 2 UP TO 3 YEARS AGO3
 MORE THAN 3 UP TO 5 YEARS AGO4
 MORE THAN 5 YEARS AGO5
 REFUSED -7 **[GO TO PN QA07_E26]**
 DON'T KNOW -8 **[GO TO PN QA07_E26]**

QA07_E24a

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

- PART OF A ROUTINE EXAM.....1
- BECAUSE OF A PROBLEM, OR.....2
- SOME OTHER REASON.....3
- REFUSED -7
- DON'T KNOW -8

QA07_E25

[if most recent mammogram test 2 years ago or less, read:]

Was your most recent mammogram recommended by a doctor or other health professional?

[Else if never had a mammogram or last test more than 3 years ago, read:]

In the PAST 12 MONTHS, has a doctor or other health professional RECOMMENDED that you have a mammogram?

NEW

- YES 1
- NO..... 2
- DID NOT SEE DOCTOR IN THE PAST 12 M.....3
- REFUSED -7
- DON'T KNOW -8

QA07_E26

Please tell me if you agree or disagree with the following statements:

Medical experts have differing views about whether women should have mammograms. Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED -7
- DON'T KNOW -8

QA07_E27
should have

There are conflicting recommendations from medical experts about whether women
mammograms. Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED -7
- DON'T KNOW -8

QA07_E28 There are so many different recommendations about mammography, it's hard to know which ones to follow. Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED -7
- DON'T KNOW -8

QA07_E29 I feel confused about contradictory recommendations I have read or heard about having a mammogram. Do you...

- Strongly Agree1
- Somewhat Agree.....2
- Somewhat disagree3
- Strongly disagree4
- No opinion5
- REFUSED -7
- DON'T KNOW -8

[Women 40+]

Hormone Replacement Therapy

QA07_E26 Are you currently taking hormone replacement therapy or HRT for menopause?

AD28

[IF NEEDED, SAY: "This is a pill, patch or treatment that gives women more of the female hormone, estrogen."]

- YES1
 - NO2
 - REFUSED -7
 - DON'T KNOW -8
- } **[GO TO QA07_E28]**

QA07_E27 Some women go on and off hormone replacement therapy. How long have you taken HRT altogether?

NEW

[IF NEEDED, SAY: "Please total all the time you have taken HRT."]

- A YEAR AGO OR LESS1
- MORE THAN 1 UP TO 2 YEARS2
- MORE THAN 2 UP TO 4 YEARS3
- MORE THAN 4 UP TO 8 YEARS4
- MORE THAN 8 YEARS AGO5
- REFUSED -7
- DON'T KNOW -8

SHINGLES

[Women 50+]

Q01. Shingles is an outbreak of a rash or blisters on the skin that may be associated with severe pain. The pain is generally on one side of the body or face. Shingles is caused by the chicken pox virus. A vaccine for shingles has been available since May 2006. Have you ever had the Zoster or Shingles vaccine, also called Zostavax[®]?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

TD/TDAP

[Men and Women 18+]

Q01. Have you received a tetanus shot in the past 10 years?

- 1 Yes
- 2 No [SKIP BEYOND Q03]
- 7 Refused [SKIP BEYOND Q03]
- 9 Don't know [SKIP BEYOND Q03]

Q02. Was your most recent tetanus shot given in 2005 or later?

- 1 Yes [SKIP TO CHECKPOINT]
- 2 No [SKIP BEYOND Q03]
- 7 Refused [SKIP TO CHECKPOINT]
- 9 Don't know [SKIP BEYOND Q03]

If R's age <65 then ask Q03

Else skip to Hepatitis A

Q03. [PRONOUNCE "Td" TEE DEE (RHYMES WITH "SEE"). PRONOUNCE "Tdap" TEE DAP (RHYMES WITH "CAP").]

There are currently two types of tetanus shots available today. One is the Td or tetanus-diphtheria vaccine and the other is called Tdap or Adacel[™]. They are similar except the Tdap shot also includes a pertussis or whooping cough vaccine. Thinking back to your most recent tetanus shot, did the doctor tell you the vaccine included the pertussis or whooping cough vaccine? The shot is often called Tdap or ADACEL[™].

- 1 Yes – included pertussis
- 2 No – did not include pertussis
- 3 Doctor did not say
- 7 Refused
- 9 Don't know

HEPATITIS B & A

[Women 18+]

AAU.370 Have you EVER received the hepatitis B vaccine?

[READ IF NECESSARY: This is given in three separate doses and has been available since 1991. It is recommended for newborn infants, adolescents, and people such as health care workers, who may be exposed to the hepatitis B virus.]

- (1) Yes (AAU.380)
- (2) No (A_ACUT_END)
- (7) Refused (A_ACUT_END)
- (9) Don't know (A_ACUT_END)

AAU.380 Did {you} receive at least 3 doses of the hepatitis B vaccine, or less than 3 doses?

- (1) Received at least 3 doses
- (2) Received less than 3 doses
- (7) Refused
- (9) Don't know

Q01. The hepatitis A vaccine is given as a two dose series routinely to some children starting at 1 year of age, and to some adults and people who travel outside the United States. Although it can be given as a combination vaccine with hepatitis B, it is different from the hepatitis B shot, and has only been available since 1995. Have you ever received hepatitis A vaccine?

- 1 Yes
- 2 No [SKIP TO Q03]
- 7 Refused [SKIP TO Q03]
- 9 Don't know [SKIP TO Q03]

Q02. How many hepatitis A shots did you receive?

___ (# of hepatitis A shots)

- 3 All shots
- 7 Refused
- 9 Don't know

Q03. Has a doctor or other health professional ever told you that you had any kind of chronic, or long-term liver condition?

Alternative wording: DURING THE PAST 12 MONTHS, have you been told by a doctor or other health professional that you had any kind of liver condition?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

Q07. Have you ever traveled outside of the United States to countries other than Europe, Japan, Australia, New Zealand or Canada, since 1995?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know