

Cognitive Evaluation of the 2015-2016 National Center for Health Statistics' Research and Development Survey

PAUL SCANLON, PhD
Collaborating Center for Questionnaire Design and Evaluation Research
National Center for Health Statistics
Centers for Disease Control and Prevention

This report presents the results of the cognitive evaluation of the 2015-2016 NCHS Research and Development Survey (RANDS) conducted by NCHS' Division of Research and Methodology (DRM). RANDS was a two-round web survey designed as a vehicle for methodology research that primarily uses National Health Interview Survey (NHIS) questions in an effort to 1) explore how web panels may be used to eventually supplement NCHS' address-based sample surveys, and 2) refine the use of targeted embedded probes to expand the findings from cognitive interviewing projects to a wider sample. In order to conduct this research, NCHS contracted the Gallup Organization (Gallup) to conduct two rounds of a survey using their recruited panel, known as the Gallup Panel. In the first round of RANDS, conducted in the fall of 2015, the questionnaire only included existing NHIS questions. The second round of RANDS, conducted in the early spring of 2016, included a set of 21 targeted, embedded, cognitive probes alongside the NHIS questions.¹

This cognitive testing project evaluated the proposed RANDS questionnaire across three rounds of testing. The first round of testing was interviewer-administered, and examined the proposed RANDS Round 1 questionnaire (see Appendix A). The second round of testing used the same questionnaire, but was self-administered with respondents answering the survey questions on Gallup's web survey interface. The third round of testing examined the proposed RANDS Round 2 questionnaire (see Appendix B), and included 21 targeted, embedded probes (designed using the cognitive findings from the first two rounds of testing by NCHS' Collaborating Center for Questionnaire Design and Evaluation Research).

Targeted, embedded probes are close-ended cognitive probe questions that may be included in survey questionnaires directly following the questions under evaluation. This type of standardized probing has been used previously in field test environments, such as when evaluating the Washington Group on Disability Statistics' Extended Set on Functioning's anxiety questions.² However, this methodology has not been used widely in web surveys. Instead, most probing on web surveys uses open-ended questions that attempt to gather data similar to what is collected from face-to-face cognitive interviews. In other words, most online cognitive probing is used to replace or supplement cognitive interviewing³. Targeted, embedded probes on the other hand, are used not to replace cognitive interviewing. Rather, they are designed to expand the findings from cognitive interviews from a purposive, non-statistical sample to a wider population through the use of a statistical survey sample. In short, if designed correctly and administered to a statistical sample, targeted embedded probes allow researchers to determine the extent of the patterns of interpretation found during cognitive interviews across a population, and to then examine whether certain patterns of interpretation are more common in certain sub-groups of that population.

In the case of the RANDS, obtaining a statistical sample from a commercial vendor's panel is difficult given the low overall response rate to surveys administered to panel members. When considering representativeness, one must not only take into account the response rate to the specific survey, but also the initial response rate to the instrument used to construct the panel. In the case of the Gallup panel, panel members are primarily recruited via Gallup's daily RDD tracking poll—so any final response rate must take this into account

This report describes the cognitive interviewing methodology used in this questionnaire evaluation and presents a detailed question-by-question analysis of the RANDS questionnaires. Unlike most Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) evaluation reports, no overall findings are presented for the questionnaire as a whole, as the RANDS is (with the exception of the targeted, embedded probes) simply a sub-set of NHIS questions. Instead of questionnaire-level

¹ See Scanlon 2016

² See Maitland et al 2013; and Loeb 2016

³ See for instance Murphy, Keating, and Edgar 2013; Fowler et al 2015; and Meitinger and Behr 2016

overall findings, “section” level findings are presented in the question-by-question analysis for some of the NHIS sections that comprise the RANDS questionnaire.

METHODS

Cognitive Interviewing Methodology and the Question Response Process

Cognitive interviewing is a qualitative method whose purpose is to evaluate survey questionnaires, and determine which constructs the questionnaires’ items capture. The primary benefit of cognitive interviewing over non-qualitative evaluation methods is that it provides rich, contextual data into how respondents interpret questions, apply their lived experiences to their responses, and formulate responses to survey items based on those interpretations and experiences.⁴ Thus, cognitive interviewing data allows researchers and survey designers to understand whether or not a question is capturing the specific social constructs they originally wanted, and gives insight into what design changes are needed to advance the survey’s overall goals. Additionally, the documented findings of cognitive interviews provide data end users the context needed to more fully understand the quantitative trends that emerge from survey data.

The underlying theory that directs the conduct of cognitive interviews is that of the question response process. Individuals typically interpret survey questions through a four-step process: They first comprehend the underlying construct, then recall the information needed, judge their answer, and finally map their answer onto one of the available response categories,⁵ as visualized here in Figure 1.

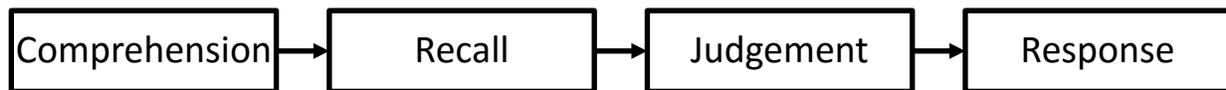


Figure 1: The Basic Question-Response Process Model

In reality, these four stages of response are not always in the exact order shown in the basic model, and oftentimes respondents either jump around (by, for instance, considering the response categories before judging what they should or should not report on the survey) or repeat steps (if they decided to try and recall new information after they’re judged what they should or should not report on the survey). Additionally, some respondents skip steps in the model, and provide a response to the question that does not necessarily take all the constructs and information provided in the question text or instructions into account (oftentimes simply basing their answer on a personal characteristic, or perceived personal characteristic, such as health status). Nonetheless, the overall goal of cognitive interviewing is to uncover the specific ways respondents perform each of these four steps.

Cognitive interviews are typically administered as one-on-one, in-depth, semi-structured qualitative interviews. Respondents are first asked survey items, and then probed about their answers and the thought processes behind them. While some cognitive interviewing relies on “think aloud” prompts, which ask respondents to speak through their thought processes as they are answering the survey, this project instead uses targeted probes that attempt to ascertain exactly which constructs the respondents are considering, and how they are judging and formulating their response. This semi-structured design uncovers not only these constructs, but also question response problems that often are unseen in a survey environment—including interpretive errors and recall inaccuracy. By asking respondents to provide

⁴ Willis 2004, Miller et al 2015

⁵ Tourangeau 1984

textual verification of their responses, and about the processes by which they formulated their answers, these elusive errors are revealed.

Typical cognitive interviewing projects use purposive samples, including respondents that have specific characteristics—such as race, education, or occupation—that are assumed to be relevant to the questions being evaluated. When studying questions related to inclusive education, for instance, the sample would likely consist of both parents who have school-aged children with disabilities and have parents who have school-aged children with no disabilities, allowing for the discovery of both false positive and false negative answers. Because of the limited sample size, not all demographic or occupational groups will be covered in the sample, and the analysis of cognitive interviewing does not provide generalizable findings in a statistical sense.

As a qualitative method, the analysis of cognitive interviewing data involves the iterative synthesis and reduction of the findings—beginning with a large amount of textual data (the raw transcripts and notes from the interviews themselves), and ending with cognitive schemata and conclusions that serve the overall purpose of the study. The analysis of cognitive interviewing can be conceptualized in five incremental stages: conducting the interviews, producing interview summaries, comparing data across respondents, comparing data across sub-groups of respondents, and drawing conclusions. As each step is completed, data are reduced such that meaningful content is systematically extracted to produce a summary that details a question’s performance. It is the ultimate goal of a cognitive interviewing study to produce this conceptual understanding, and it is through data reduction that this type of understanding is possible. This end analytic product is often best understood as a cognitive schema, examples of which are presented throughout this report and illustrated in a standard format. As shown in a prototypical cognitive schema below in Figure 2, the phenomenon or construct under consideration is shown on the left-hand side of the figure, and the various pathways respondents use to understand or judge this phenomenon branch off to the right. Each of these rectangles represent the different patterns of interpretation or judgement, depending on the individual schema, that respondents within the cognitive interviewing sample used when responding to a question. Occasionally, the actual survey answers that each of these patterns of interpretation produced across the sample are also show, and are represented by ovals to the far right-hand side of the figure.

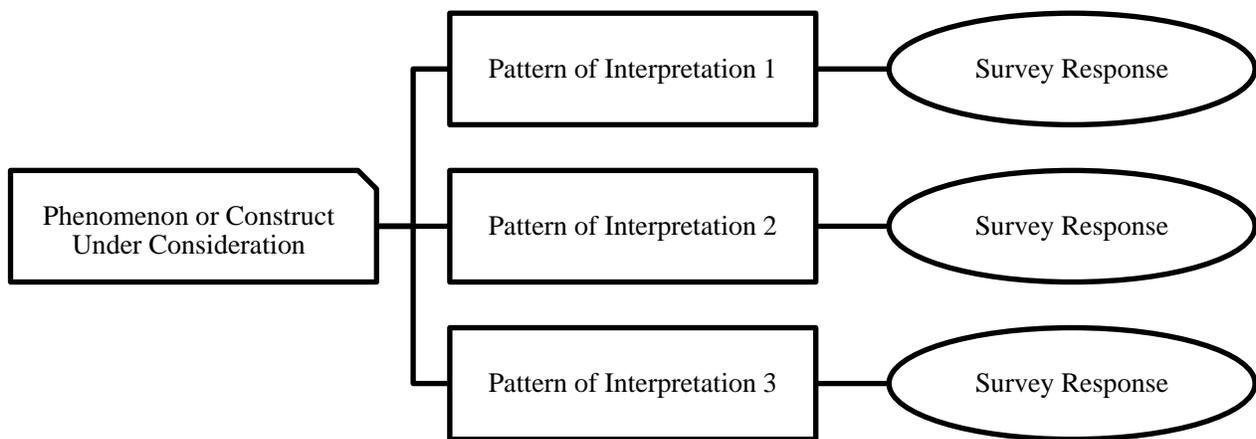


Figure 2: Prototypical Cognitive Schema Used Throughout This Report

Sampling and Respondent Characteristics

For the evaluation of the RANDS, a purposive sample of 35 respondents was recruited to participate in cognitive interviews across three rounds of testing. The sample was purposively recruited in an effort to produce a diverse sample across a number of characteristics, including gender, age, race, educational attainment, and health insurance status. Respondents were recruited through a variety of media, including newspaper and online advertisements. Table 1 below breaks down the sample by round of testing and respondent gender, while Table 2 breaks down the sample by round and respondent race, while Table 3 shows round by respondent age:

Table 1: Sample by Testing Round and Respondent Gender

	Male	Female	Total
Round 1	9	10	19
Round 2	3	8	11
Round 3	1	4	5
Total	13	22	35

Table 2: Sample by Testing Round and Respondent Race

	Black	White	Total
Round 1	8	11	19
Round 2	0	11	11
Round 3	2	3	5
Total	10	25	35

Table 3: Sample by Testing Round and Respondent Age

	Younger than 35	35 to 50	Older than 50	Total
Round 1	4	7	8	19
Round 2	4	2	5	11
Round 3	2	2	1	5
Total	10	11	14	35

Most of the 35 interviews were conducted in NCHS' Questionnaire Design Research Laboratory in Hyattsville, MD, though a few respondents who could only participate outside of business hours or who were unable to gain admittance to the NCHS facility (due to citizenship status) were interviewed outside the lab. These interviews were held in a public space, such as a coffee shop, which was agreed to by both the interviewer and the respondent. In either case, interviews were limited to 60 minutes in length. Respondents in Rounds 1 and 3 were read the RANDS questions and probed verbally; respondents in Round 2 read the questionnaire on Gallup's web survey interface while the CCQDER interviewer observed and asked follow-up probes. In Rounds 1 and 3, probes were administered concurrently alongside the survey questions, allowing the interviewers to get the respondents' immediate impressions and interpretations of the questions. In Round 2, probes were administered retrospectively, which allowed the CCQDER researchers to measure the uninterrupted time it took for a respondent to complete the questionnaire.

QUESTION-BY-QUESTION ANALYSIS

Please note that throughout the question-by-question analysis, the questions are identified by either their NHIS question name, or in the case of non-NHIS questions by either the prefix “NEW” or “PROBE” depending on whether a question is a potential NHIS question (that NCHS’ Division of Health Interview Statistics asked DRM to include on the questionnaire for the purpose of conducting a preliminary evaluation) or a targeted embedded probe, respectively. Furthermore, the questions below are presented in the order used in the RANDS Round 2 questionnaire that was fielded by Gallup (see Appendix B). The order of the NHIS questions in both Round 1 and Round 2 follow the same order as they exist on the production NHIS; this sequence was maintained in order to minimize any differences due to the context and ordering effects between the NHIS and the RANDS.

As noted above, the questionnaire was tested in two modes—interviewer administered and self-administered web formats. Clear mode differences did emerge in a few cases (see for instance the Health Insurance section below), and these are discussed throughout. When mode differences are not mentioned in the sections below, this indicates that clear differences did not emerge in the cognitive testing, and should not be understood to indicate that no differences exist at all. Because the focus of these cognitive interviews was not on the usability of the instrument, there are additional mode differences that may exist that were not captured by the methodology used in this project.

General Health Status Section

- PHSTAT** Would you say your health in general is excellent, very good, good, fair, or poor?
1. Excellent
 2. Very Good
 3. Good
 4. Fair
 5. Poor

This question was administered in all three rounds of testing. Respondents largely approached this question by considering their health conditions and behaviors, and then attempting to judge their overall health by either comparing themselves to a hypothetical “healthy person” or by comparing their current health status to their health status in the past.

Constructs Captured

Respondents considered a wide range of health indicators while answering this question. These ranged from behaviors such as their diet, exercise, and healthcare-seeking habits, to the diagnosis and symptoms of chronic and acute medical conditions. Seven major constructs emerged from the cognitive interviews as indicators of the respondents’ overall health:

- Diet and nutrition habits, including the type and amounts of food consumed
- The amount and frequency of physical activity

- Whether or not, and how much, a respondent smoked or drank alcohol
- The presence or absence of chronic and acute health conditions and diseases
- How often a respondent visited a healthcare provider
- The amount and frequency of pain or fatigue
- Conversations about the respondent’s health with their healthcare providers

In most cases, respondents considered more than one of these indicators as they attempted to judge where their personal health status should be placed on the “Excellent” to “Poor” scale.

Scale Judgement

After determining their general health status with some combination of the seven indicators bulleted above, respondents judged their health status’ position on the “Excellent” to “Poor” scale using three patterns of judgement, which are depicted in Figure 3:

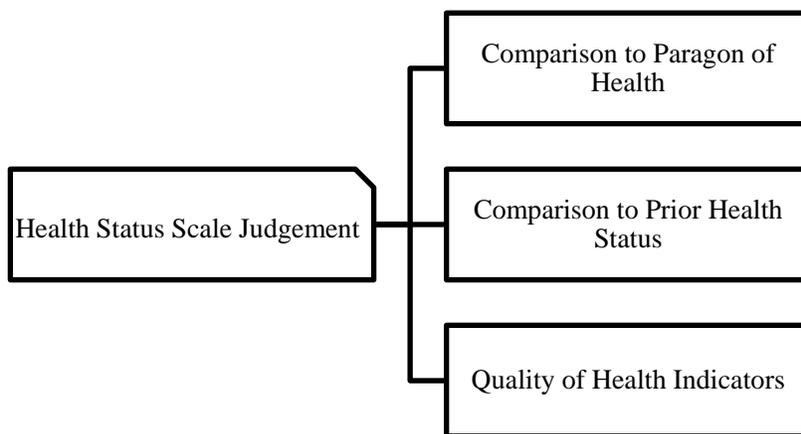


Figure 3: Cognitive Schema Showing Judgement of Health Status in PHSTAT

Comparison to Paragon of Health

Most respondents in the cognitive interviewing sample determined their position on the health scale by either comparing their own health behaviors and conditions to either some hypothetical healthy person, or to their recollection of their previous health status. For example, one respondent who compared herself to a hypothetical paragon of health explained her “very good” response by saying:

I was trying to think of overall health, like the last time I went to the doctor’s, did I have any problems? Even though the last time I went to the doctor’s I didn’t have problems, I put ‘very good’ instead of ‘excellent’ because I feel like there’s room for improvement.

So even though she didn’t have any health problems, and she had previously noted that she eats well and exercises, she thinks that she *could* be healthier, so she couldn’t respond using the higher answer category.

Comparison to Prior Health Status

In addition to comparing themselves against a hypothetical health status, some respondents compared their current health behaviors and conditions to those in their past, and thereby thinking about how their

health status had changed either for the better or for the worse. For instance, one respondent who answered “good” explained that although he has relatively good health habits—saying that, “I’m pretty active, I eat reasonably well. I know what you’re supposed to eat.”—he wouldn’t answer either “very good” or “excellent” because he has an eight-hour-a-day job, and sits for most of the workday. This respondent had just graduated college, and was thinking about how much more he has to sit (and how much less actively he is) now that he holds a full-time job. When asked how he would have rated his health a year earlier when he was not sitting for most of the day, this respondent indicated that he would have choose either “very good” or “excellent.”

Quality of Health Indicators

In addition to those who clearly compared their current health indicators to either a paragon of health or to their prior feelings of health, others simply judged the overall quality of their health behaviors and profile. For example, one respondent who answered “fair” explained his response by saying that “I do have medical issues—the hypertension, the diabetes, I have a spinal cord injury.” Although upon further probing he noted that he actually had been a lot worse off previously, he reported that when he was considering his answer, he was just thinking about the number of issues he was dealing with at the moment. Another respondent who answered “fair” explained that she was only basing her answer on the fact that she weighed too much and wanted to lose weight before her wedding. This respondent noted that she worked out three to four times a week, and has never had any serious chronic or acute medical conditions, but she limited her response to the idea that she wanted to weigh less.

- PROBE1** Why did you answer that way? Because of...
1. My diet and nutrition
 2. My exercise habits
 3. My unhealthy behaviors such as smoking or drinking habits
 4. My health problems or conditions
 5. The amount of times I seek health care
 6. The amount of pain or fatigue that I have
 7. My conversations with my doctor

This question was designed as a content probe targeting PHSTAT, which respondents received directly before this probe. The seven discrete answer categories come directly from the various indicators that the respondents used to determine their health status in the previous question. This question was only administered in the final round of cognitive testing.

Respondents were able to clearly match up their interpretations in PHSTAT with the answer categories in PROBE1, and no additional categories emerged from probing. In an effort to reduce social desirability bias in the question, the phrase “...unhealthy behaviors such as...” was dropped from the third answer category during testing and for the final web survey instrument.

Food Security Section

The first three NHIS questions in this section (FSRUNOUT, FSLAST, and FSBALANC) use a frequency scale as their answer categories, while the final four NHIS questions (FSSKIP, FSLESS, FSHUNGRY, and FSWEIGHT) use the binary yes/no. The preamble to this section is as follows:

These next questions are about whether you were always able to afford the food you needed in the last 30 days.

First, you are going to see several statements that people have made about their food situation. For these statements, please indicate whether the statement was often true, sometimes true, or never true for you in the last 30 days.

- FSRUNOUT** I worried whether my food would run out before I got money to buy more.
1. Often true
 2. Sometimes true
 3. Never true

This question was administered to all respondents across the three rounds of testing. Respondents all appeared to understand the phrase "...food would run out..." to mean that they would have no more food at all until they received more money. On the other hand, multiple patterns of judgement emerged in relation to how the respondents decided how frequently they "worried" if their food would run out.

Overall, four major patterns of judgment emerged from the cognitive interviews that show how respondents came to their decisions about the frequency of worry: considering how often they actually ran out of food, limiting their consideration to their financial situation, considering their level or worry or anxiety about food security, or considering how often they had to employ coping mechanisms (such as food rationing) to ensure they did not run out of food. Figure 4 illustrates these four pathways below:

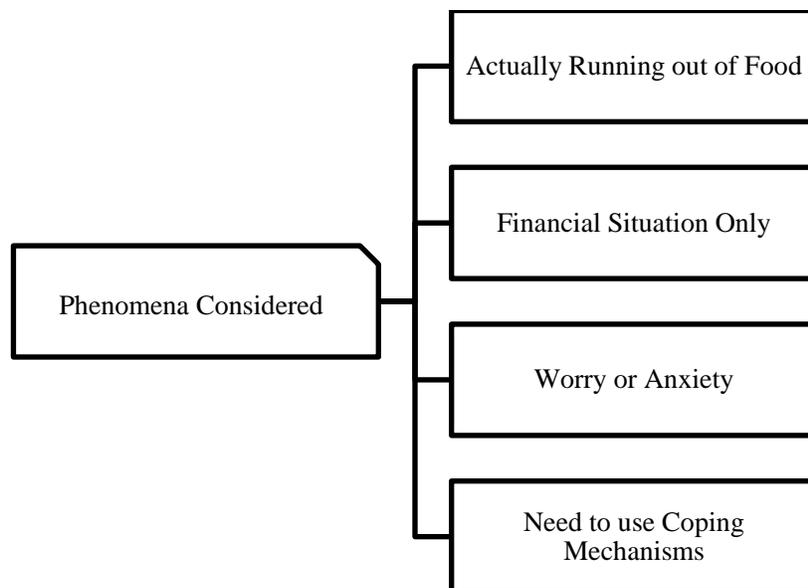


Figure 4: Cognitive Schema for FSRUNOUT

Running out of Food and Financial Situation

In the first two of these patterns, respondents basically consider a binary—whether or not they actually ran out of food, or whether or not their financial situations were dire enough that they would ever have to go without. For instance, one respondent who answered “never true” explained that she understood the whole food security set of questions as asking about food problems “because of needing money.” She went on to explain that she answered “never” (and “no” in the final four food security questions detailed below) because she had money. Likewise, another respondent who answered “never true” explained that she grocery shops every two weeks on the average, and she plans around that schedule: “I try to plan for those two weeks based on my pay day...and it [her food] usually doesn’t run out by then.” Nearly all the respondents who used these patterns of judgment answered FSRUNOUT “never true.”

Worry or Anxiety

Respondents who used the other two patterns of judgement—worry or anxiety, or the necessity of using coping mechanisms—explicitly considered frequency. For instance, one respondent who answered “sometimes true” explained that she was frequently worried about letting food go to waste (such as fruit rotting), and that she tried to avoid higher food costs by trying to eat everything she bought before it went bad. Upon probing, this respondent revealed that she never actually lacked food, but rather that she sometimes worried about the amount of food she wasted. Another respondent who answered “never true” explained that although he sometimes altered his consumption habits to make food last, he was not actually worried about not having enough to eat: “I wasn’t worried that my food would run out because of money, but I wanted to cut some foods to lose weight and be more active.”

Need to Use Coping Mechanism

Other respondents considered the frequency with which they had to employ coping mechanisms to ensure their food did not run out. While not explicitly mentioning “worry,” these respondents thought about ways they could alter their habits to make sure their food lasted. For instance, one respondent who answered “often true” explained how he had to make his supplemental nutrition assistance (which he called “food stamps”) last each month:

What they give us, I’m appreciative of it, but it’s really not enough. It’s really not. It’s four weeks in a month...they give \$160 for a single person, that’s like maybe a week’s work, especially with the food prices going up, and this just to eat. If you want to eat healthy, you can just forget it.

This respondent went on to talk about his coping mechanisms: never buying fresh fruit and vegetables, trying to only eat one meal a day, and going to a food bank as often as possible.

- FSLAST** The food I bought just didn’t last, and I didn’t have money to get more.
1. Often true
 2. Sometimes true
 3. Never true

This question was administered to all respondents across the three rounds of cognitive testing. The interpretive patterns seen in FSLAST are very similar to those seen in the previous question, FSRUNOUT. The one major difference in how respondents answered these questions was that the

“Worry or Anxiety” pattern of judgment—where a respondent considered how frequently they had to worry about their food situation—was not found in FSLAST.

Similar to what was observed in the last question, most respondents in the cognitive interviewing sample that answered “never true” used the binary patterns of judgment (thinking about actually running out of food and only considering their financial situation) when answering the question. Respondents who answered either “sometimes true” or “never true” tended to consider the frequency they had to apply coping mechanisms to ensure they *did not* run out of food. Thus, most of the respondents who answered either “sometimes” or “often true” were not answering about actually running out of food, but about their levels of effort to ensure that their food *did* last until they could get more. For example, one respondent who answered “sometimes true” explained that he has shifted his food-buying habits to match his decreased budget and higher food costs, saying he buys “Oodles of Noodles instead of steak.” However, upon further probing, he said that he never actually ran out of food.

- FSBALANC** I couldn’t afford to eat balanced meals.
1. Often true
 2. Sometimes true
 3. Never true

All respondents across the three rounds of cognitive testing received this question. The cognitive interviews revealed that the response process for FSBALANC was very complex, and required most respondents to make three separate decisions before deciding how to answer the question. The overall response process is visualized in Figure 5, and each step is then detailed below:

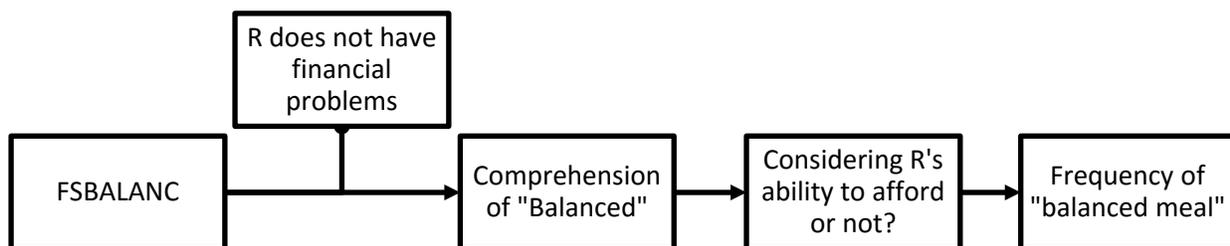


Figure 5: Response Process with Three Decision Points for Question FSBALANC

Response Based Only on Financial Situation

As seen in the previous two food security questions (FSRUNOUT and FSLAST), a portion of the respondents appeared to answer the question without going through the full response process detailed above in Figure 1. These respondents did not include any definition of “balanced meal” or consideration of the frequency they did not eat balanced meals into the response, they simply understood the question to be asking about whether they were financially well-off or not. For example, one respondent who answered “never true” to all the food security questions explained:

The governing clause is money. I have enough money, so it was kind of global [across all the food security questions]. I listened to each question, but my response was global. I’m fortunate—I haven’t been threatened by money in the last 30 days.

This respondent has money, and therefore did not have to consider the details of the individual food security questions. Likewise, another respondent said she understood this question to be about “needing money,” and responded “never true” because she always has enough money for food.

Comprehension of “Balanced Meals”

The first decision that most respondents had to make was on their definition of the term “balanced meal.” Overall, while respondents did not agree on any one definition of a balanced meal, most of the constructs they considered appear to be in-scope and related to a healthy meal that provides a good base of nutrition. For instance, one respondent explained that she was thinking that “balanced meals, in my eyes, means you have a vegetable, a starch, and a meat. I always have those three things.” Another respondent noted that a “nutritionally balanced [meal] means having fewer processed foods and eating veggies and fruit.” Across the three rounds of cognitive interviewing, the following interpretations of “balanced meal” emerged:

- A meal that includes all the major food groups, i.e. from the “food pyramid”
- A meal that includes a protein or meat, a starch, and vegetables
- A meal that generally includes a variety of foods
- A meal that includes “nutritious” or “healthy” foods
- A meal that is low in fat, sodium, sugars, or other nutrients that are perceived as “unhealthy”
- A meal that does not include artificial or processed foods, or that includes items such as fresh fruits, vegetables, or meat
- A meal that is cooked at home, and not purchased pre-made at a store or restaurant

Most respondents chose a single one of these constructs as their definition of “balanced meal,” and then continued along the response process illustrated above in Figure 5.

Consideration of Ability to Afford or Not

The next decision most respondents made while answering FSRUNOUT was whether or not the question was asking either about their ability to afford balanced meals or about their propensity to actually eat balanced meals. In short, respondents had to decide if the question stem they were responding to was “I couldn’t afford to eat balanced meals,” or “I didn’t eat balanced meals.”

For those respondents who have difficulty affording their food, there is not much difference between these two statements—whether they are explicitly considering affordability or not, they are not able to always have balanced meals. However, the second of these interpretations—only considering whether or not the respondent had balanced meals without thinking about affordability—has the potential to lead to response errors for those respondents who can *always afford* balanced meals, but for one reason or another do not *always have* balanced meals. For example, one respondent who answered “sometimes true” explained his answer by talking about how he has to eat take-out meals that are full of fat most nights during the week because his job at a commercial real estate firm often keeps him at work late: “Well I don’t have access to balanced meals...I usually get Asian through Seamless [an online meal delivery service] for dinner, and the vegetables aren’t fresh and they’re drenched in sauce.” Likewise, another respondent who answered “often true” noted that “I kind of eat vegetables, but I should eat more.” He went on to explain that he did not eat a lot of fresh vegetables (which was how he defined a “balanced meal”) because he did not cook for himself a lot at home, but rather tended to eat out a lot.

Upon further probing, he noted that he did this because he was busy, not because he could not afford the ingredients.

Frequency Judgement

Respondents finally had to judge the frequency they could afford balanced meals (or, in some cases, the frequency they ate balanced meals). However, this was not as simple as assigning their habits to one of the three answer categories. Respondents first had to decide what counted as “always” being able to afford/have balanced meals. Most respondents limited their frequency judgement to how often they were able to afford or have a balanced meal *at dinner*. However, other respondents based their frequency judgment on whether or not they were able to afford or have a balanced meal *at every meal*, while just a couple of respondents based their frequency on how often they were able to afford or have a single balanced meal a day, regardless of the specific meal.

- PROBE2** When answering the last question, how did you define “balanced meal?”
1. A meal with all the major food groups
 2. A meal that includes a starch, a vegetable, and a protein
 3. A meal without a lot of fat, salt, or sugar
 4. A homemade or home-cooked meal
 5. A meal that does not include processed ingredients

This question was designed as a construct probe targeting FSBALANC, which respondents received directly before this probe. The five discrete answer categories come directly from the patterns of interpretation respondents used to define the phrase “balanced meal,” as listed above in the analysis of FSBALANC. This question was only administered in the final round of cognitive testing. No additional categories emerged from this analysis.

- FSSKIP** In the last 30 days, did you ever cut the size of your meals or skip meals because there wasn’t enough money for food?
1. Yes
 2. No

FSSKIP is the first of the final four questions in the food security section, which use a binary yes/no response option scheme as compared to the three-point frequency scheme used in the first three food security questions. All respondents across the three rounds of cognitive testing received this question.

By and large, the respondents understood this question to be asking about skipping meals because of money. As seen in the previous food security questions, a number of respondents who have higher incomes simply answered “no” immediately as they did not ever have food security issues related to money.

However, most respondents did not use this heuristic pathway, and instead considered whether or not they ever skipped meals or cut the size of their meals because of money. For example, one respondent who answered “yes” explained that she will sometimes skip meals to ensure that her children never have to: “Sometimes I will go without to make sure the kids have what they need. And I’ll go hungry.” Another respondent who answered “yes” was specifically thinking about the need to cut the size of his meals at the end of the month when his supplemental nutrition benefits have run out and before he gets more assistance.

A number of respondents who answered “no” indicated that they did occasionally skip meals or cut down the size of their meals, but not because of money. For instance, one respondent noted that she had started a diet in the last month, but because she was doing this for health and not financial reasons, she answered no. Likewise, another respondent noted that he frequently cuts the size of his meals, but this was in order to lose weight, and not because of money: “I do watch what I eat, so actually I do those things, but it isn’t because of money...I did eat less than I thought I should, because of self-image, not because of money.”

- FSLESS** In the last 30 days, did you ever eat less than you felt you should because there wasn’t enough money for food?
1. Yes
 2. No

All respondents received FSLESS across the three rounds of cognitive testing. This question shows a very similar pattern of response as seen in the previous question, FSSKIP. While some respondents heuristically answered “no” because they never have financial issues, most respondents considered whether or not they ever ate less food than they were used to or wanted because of money.

In contrast to FSSKIP, however, a few respondents who answered “yes” were thinking about *saving* money by eating less, not necessarily being required to eat less because of money. For example, one respondent who answered “yes” explained that he would eat at cheaper restaurants at lunch (such as McDonalds instead of Chipotle) in order to save money. Upon further probing, this respondent said that he was never actually worried about running out of money to buy food, but rather that he felt like he should save money on food when he could.

- FSHUNGRY** In the last 30 days, were you ever hungry, but didn’t eat because there wasn’t enough money for food?
1. Yes
 2. No

All respondents across the three rounds of cognitive interviewing received this question. The core construct of FSHUNGRY—going hungry because the respondent did not have enough money to buy food—was universally understood as the most severe across all the food security questions. With the exception of those who (as in the previous questions) simply answered “no” because they had no financial

issues, nearly all respondents based their answer on whether or not they had gone hungry because they could not afford to eat.

One respondent did use an alternative (and potentially out-of-scope) interpretation, indicating that he had an issue with his credit card a few weeks prior to the interview, and therefore had to change his eating habits: “For a couple of days I had a problem with my credit card, so I was unable to get what [food] I wanted. I had to wait for it to clear up.” Upon probing, this respondent revealed that the problem with the card was not due to his financial or debt situation, but was a security measure implemented by the credit card company. Furthermore, he did not go without food for these few days, he simply was not able to buy the usual amount of food that he was used to.

- FSWEIGHT** In the last 30 days, did you lose weight because there wasn’t enough money for food?
1. Yes
 2. No

All respondents received FSWEIGHT across the three rounds of cognitive testing. Respondents followed the same general pattern of response seen throughout the other binary-response food security questions, with nearly all the respondents basing their answers on whether or not they had lost weight because they could not afford food. None of the respondents based their answer on weight loss due to choice, and instead only “counted” weight loss due to financial issues. For instance, one respondent who answered “no” said, “well I’ve lost weight—I have my wedding coming up, so we’re both trying to eat better and less. But not because I couldn’t afford it.”

- PROBE3** Do you do any of the following things?
1. Give your share of food to a family member so they get more to eat
 2. Skip meals in order to make your food last
 3. Keep to a strict budget when buying food
 4. Plan out your meals to avoid running out of food
 5. Add fillers like pasta or bread to stretch food
 6. Save money by not splurging on unnecessary foods
 7. Only buy store-brand or generic foods to save money

This question was designed as a content probe targeting the full food security section, and was written to examine the various coping strategies that respondents use to modify their food security situations. The seven discrete answer categories come directly from the various coping mechanisms respondents explained that they used to head off any of the food security problems asked about throughout the section. For instance, a respondent who only buys cheap, processed food (instead of more nutritious fresh food) may answer all the food security questions using the negative categories (“never true” or “no,” depending on the question). This probe was constructed to see if a targeted, embedded probe could capture these coping mechanisms as another measure of food security after the respondents had already answered a full slate of questions about their food situation.

This question was only administered in the final round of cognitive testing. No additional categories emerged from this evaluation. In an effort to ensure comparability across the entire food security section, the reference period “In the last 30 days...” was added to the question text for the final web survey instrument.

Healthcare Utilization Section

- FHCDV2W** During the last 2 weeks, did you see a doctor or other health care professional at a doctor’s office, a clinic, an emergency room, or some other place?
1. Yes
 2. No

All respondents across the three rounds of cognitive testing received this question. Respondents universally understood that FHCDV2W was asking about healthcare visits in the past two weeks. Some slight variation emerged across the sample in regards to who the respondents “counted” as a doctor—with most thinking about all physicians and mid-level health care professionals (i.e. nurses, physicians’ assistants, and physical therapists). However, a couple of respondents did not include dentists, and only considered them after explicit probing.

The reference period of “2 weeks” given in the question text appeared to frame the question well, with many respondents explicitly rejecting visits that occurred outside the past two weeks during probing.

- PHCDVN2W** How many times did you visit a doctor or other health care professional during the last 2 weeks?

Sixteen respondents across the full three rounds of cognitive interviewing answered yes to the previous question (FHCDV2W) and went on to receive this one. All respondents carried their definitions of the phrase “doctor or other health care professional” forward from the last question into PHCDVN2W.

- F10DVYR** During the past 12 months, did you receive care from doctors or other health care professionals 10 or more times? Do not include telephone calls.
1. Yes
 2. No

All respondents across the three rounds of cognitive testing received F10DVYR, and most respondents continued to carry their interpretation of the phrase “doctor or other health care professionals” forward

from FHCDV2W. While most respondents limited their interpretations to healthcare visits to physicians' offices or hospitals, a few did include visits to dentists and providers such as physical therapists or acupuncturists. Furthermore, a number of respondents initially limited their counts to either their Primary Care Physician (PCP) or their most salient doctor (for example, one respondent initially limited his consideration to just his infectious disease doctor, who he had to visit quite often).

Across the sample, there were two major pathways respondents took when approaching the recall and judgement phases of this question, as depicted below in Figure 6:

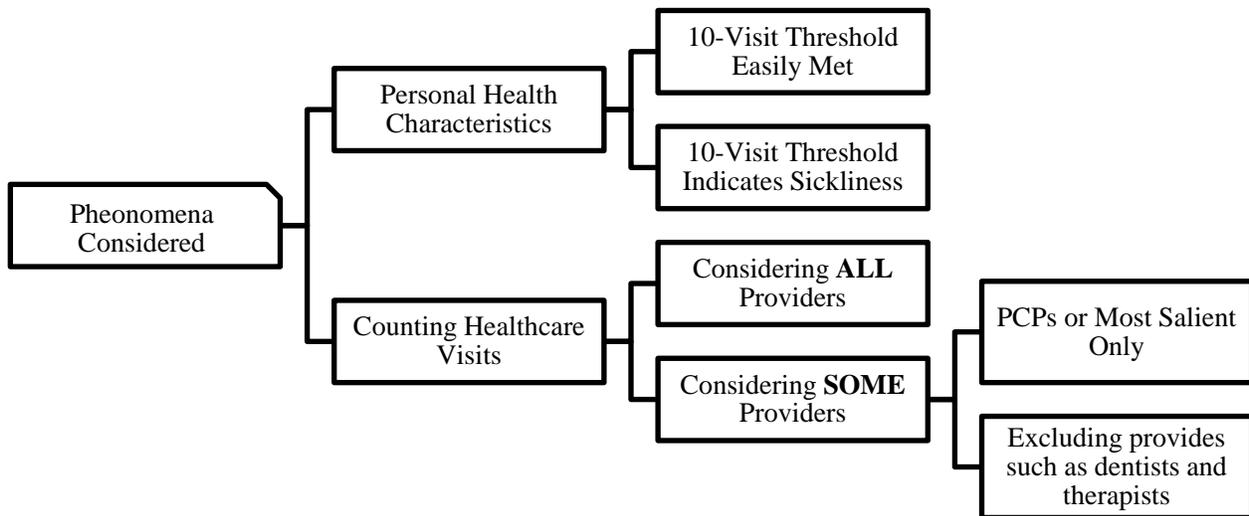


Figure 6: Cognitive Schema for F10DVYR

Personal Health Characteristics

While most respondents attempted to recall and count the number of visits to doctors or healthcare professionals (which depended on their interpretation of that phrase), two separate interpretations emerged where respondents simply based their answers on personal health characteristics. Some respondents who frequented their healthcare providers (and thus certainly met the 10-visit threshold) simply answered “yes” without counting. These respondents tended to have a number of chronic health conditions or had a major medical issue in the past year. For instance, one respondent who answered “yes” explained that she had severely hurt her back about a year ago, and had been going to the physical therapist multiple times a week for the past few months. This respondent did not provide a count of visits, but rather immediately answered “yes” believing that her current healthcare usage was well over the 10-visit threshold.

Another group of respondents simply judged that only someone who was unwell or sickly would meet the 10-visit threshold. Since they did not perceive themselves as unwell, they immediately answered “no.” This heuristic led to a few clear response errors across the sample, as upon probing, some respondents ended up determining that they did in fact visit their doctors more than 10 times in the past year. For example, one respondent answered “no” and noted during probing that someone like her mom (who has a number of chronic conditions) would be the type of person to answer yes. However, when asked to list all the visits she had in the past 12 months, she came up with about 12 visits (including her PCP, OB/GYN, dentist, a specialist, and a couple of visits to the dermatologist).

Counting Healthcare Visits

Another group of respondents answered this question by attempting to count all of their doctors' visits in the last year. While most respondents appeared to include all types of doctors, others restricted their answers to specific types of doctors. A few respondents only counted either their primary care physicians or the physician who is most salient to their health. For instance, one respondent who had overcome cancer in the previous year limited her answer to her visits to the oncologist—and answered “no,” since she did not see her 10 times in the previous 12 months.

Other respondents considered a wider range of doctors, but did not include providers such as dentists or therapists. For example, one woman who answered “no” counted 8 visits over the last year. Upon probing, she revealed that she had not included dentists into her count—but that had she counted the two visits to the dentist she had in the previous year, she would have answered “yes,”

Health Insurance Section

There are a few important mode differences between the health insurance questions on the RANDS and those on the NHIS' Family Health Insurance section. While mode differences are inherent in the comparison between RANDS and NHIS, they have a higher potential of impacting interpretation in questions with long lists of answer categories—particularly where a number of those answer categories are confusing to, or unknown by, the respondents. Where possible given the data, mode differences are described below.

The cognitive findings reported here largely match the reported findings from the previous evaluation of the NHIS Family Health Insurance section in 2014⁶.

FHICOV The next few questions are about health insurance, including health insurance obtained through employment or purchased directly, as well as government programs like Medicare and Medicaid that provide Medical care or help pay medical bills.

Are you covered by any kind of health insurance or some other kind of health care plan?

1. Yes
2. No
9. Don't know

All respondents across the three rounds of cognitive testing received this question, which was overwhelmingly understood as asking whether or not the respondent had health insurance or healthcare coverage.

However, a few respondents appeared to get confused by the long “inclusion” statement in the section's introductory text (“...including health insurance obtained through employment...or help pay medical bills.”). This confusion led directly to one case of response error, where a respondent who answered FHICOV “no” explained during probing that she had Medicaid, but answered no because “I'm not

⁶ Scanlon 2014

employed.” While on its face this inclusion statement is clear, it appears as though some respondents did not read the full statement, or simply skimmed it. In the case that led to a response error noted above, the respondent noted that she saw the phrase “through employment” in the inclusion statement and therefore decided that the question was asking specifically about insurance obtained through an employer.

Respondents appeared to understand that the reference period for this question was their current state of coverage. For instance, one respondent who noted that she would be eligible to join her mother’s health insurance plan in a few months, but was not covered by it, correctly answered this question “no.”

HIKIND Do you have any of the following kinds of health insurance or health care coverage? Include those plans that pay for only one type of service, such as nursing home care, accidents, or dental care. Exclude private plans that only provide extra cash while hospitalized.

1. Private Health Insurance
2. Medicare
3. Medi-Gap
4. Medicaid
5. SCHIP (CHIP/Children’s Health Insurance Program)
6. Military health care (TRICARE/VA/CHAMP-VA)
7. Indian Health Service
8. State-sponsored health plan
9. Other government program
10. Single service plan (e.g. dental, vision, prescriptions)

The 32 respondents who answered “yes” to the gateway question, FHICOV, received HIKIND. This included 9 respondents in the self-report usability testing round, and 23 respondents in the two interviewer-administered rounds. While respondents universally understood this question to be asking about the type of health insurance they had, there was a clear mode effect in how respondents interpreted HIKIND. Furthermore, many respondents had difficulty mapping their responses onto the answer categories: In most cases the 10 answer categories were not relevant to the respondents’ experiences and did not align with how they classified their healthcare coverage.

Comprehension of “Kinds of Health Insurance”

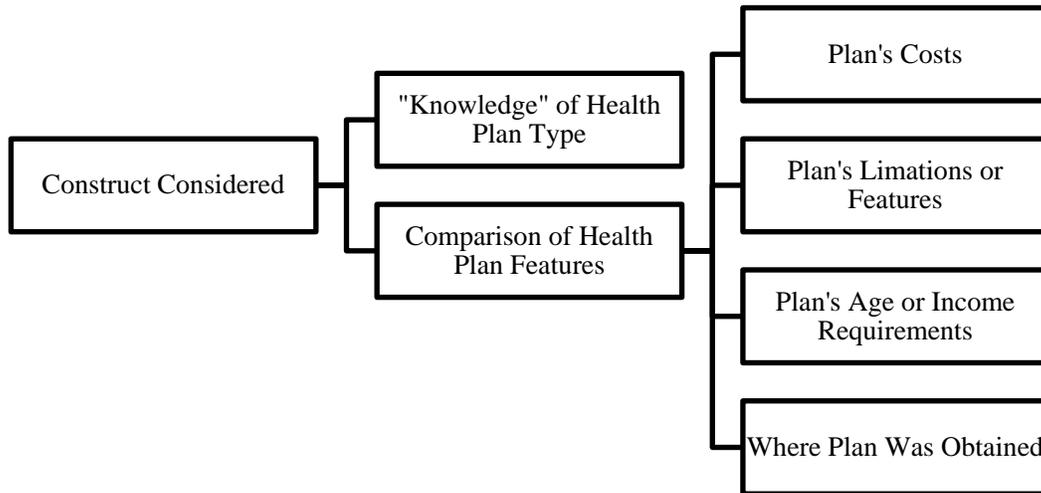


Figure 7: Cognitive Schema for HIKIND

As previous work on this NHIS question has shown⁷, respondents do not have consistent interpretations of HIKIND’s answer categories. In fact, terms such as “private health insurance,” “state-sponsored health plan,” and “single service plan” confuse respondents. Respondents used two basic pathways while interpreting the various types of health insurance: a simplified, knowledge-based pathway and a more complex, comparative pathway. Figure 7 above illustrates the patterns respondents used while interpreting this key construct.

Knowledge-Based Pathway

In the knowledge-based pathway, respondents reported simply “knowing” what type of health insurance they had. This was most common among respondents who had either Medicare or Medicaid. When asked to explain their response, these respondents would simply say that they knew they had one of these programs, usually because they remember the enrollment process. Of course, in a few cases, this pathway led to response error. For example, one respondent in the first round of cognitive testing who answered “yes” to Medicare revealed that he actually had Medicaid (and not Medicare) upon extensive probing.

Comparative Pathway

Most respondents across the three rounds of cognitive testing used the comparative pathway instead of the simplistic heuristic. In this pathway, respondents considered aspects of the types of insurance and made either a positive comparison (i.e. “I have feature X as a part of my health insurance, and these other plans do not.”) or a negative comparison (i.e. “I do not have feature X as part of my health insurance plan, and these others do.”). The features that respondents used in this comparative exercise included things such as the plan’s cost, age requirements, plan limitations, and (most frequently) where they obtained the plan. For instance, one respondent who answered both “private health insurance” and “other government program” determined that she had private insurance because she pays a premium. She went on to try and determine if her plan also qualified as a “state-sponsored” or “other government program” saying:

⁷ See Scanlon (2014), pages 11-15

I guess I think maybe a state-sponsored or other government program because I had to do it through the marketplace, because my job doesn't give me insurance...I feel like its ["private" or "other government"] because it's like a government program that gives me private insurance, because I get the reimbursement from the government to cover [the payment].

This respondent's explanation also illustrates the source of many respondents' confusion while answering HIKIND—the types of insurance given as answer categories are not highly salient. Rather than think about health insurance in terms of the types given in the question, respondents tend to think about the reason they have access to the plan—*where* or *how* they received their coverage (i.e. from the government, from work, purchased their self, etc.). For example, one respondent in the final round of cognitive testing who answered “private” explained that “I have [name of plan] through my work. They pay most and I pay \$100 a month. So, is that private?” This respondent ended up answering “private” because he did not believe that anything else on the list made sense. Figure 8 illustrates the ways that respondents thought about their access to health insurance across the three rounds of cognitive testing. Overall, respondents understood that their health insurance came from one of three places: from their employer, from the fact that they belonged to a special group, or something that they (or a family member) obtained for themselves. Within each of these three general points of access, respondents thought about specific places or ways they obtained their health insurance. For example, within the general “Employer” category, respondents mentioned getting their insurance from a private business, from a government job, or from a parent or partner’s job.

**Respondent's
access to
health
insurance
plan**

Employer

Private Business

Government Job

Parent/Partner's Job

**Membership in a
Special Group**

Older than 65 Years Old

Disability

Low Income

**Obtained for
Self**

Healthcare.gov

Bought directly for him or herself

Figure 8: Ways that Respondents Thought about Accessing their Health Insurance in HIKIND

Given the idea that the method of access is more salient to respondents than the typology provided in the question, it becomes clear that the list of answer categories given in HIKIND are not necessarily exclusive—and thus potentially confusing. The best examples of this deal with the “state-sponsored health plan” and the “other government program” options—both of which indicate a place from which insurance is obtained. As respondents focus their interpretations on *where* they get their health insurance from, many “double-counted” their insurance as private/Medicare/Medicaid *and* either “state-sponsored” or “other government program.” For instance, a respondent in the usability round of testing answered both “Medicaid” and “state-sponsored” as she said she got her Medicaid coverage through the District of Columbia government. Similarly, a respondent in the first round of testing answered both “private” and

“other government program,” noting that she was on her mother’s health insurance plan that she got through her job with the federal government.

Response Process Differences Across Modes

In addition to the variation in how respondents interpreted and judged their response to the 10 answer categories in HIKIND, the overall response process differed between respondents who answered the self-report and the interviewer-administered versions of this question. The self-report version of this question (used in the fielded version of the RANDS, which was only conducted online) is shown below in Figure 9.

The screenshot shows a web survey interface. At the top, it says 'GALLUP Panel™ helping people be heard'. Below that, the survey title is 'CDC/NCHS HEALTH RESEARCH SURVEY'. The main question is: 'Do you have any of the following kinds of health insurance or health care coverage? Include those plans that pay for only one type of service, such as nursing home care, accidents, or dental care. Exclude private plans that only provide extra cash while hospitalized.'

The question is followed by ten categories, each with a 'Yes' and 'No' radio button:

- Private Health Insurance
- Medicare
- Medi-Gap
- Medicaid
- SCHIP (CHIP/Children's Health Insurance Program)
- Military health care (TRICARE/VA/CHAMP-VA)
- Indian Health Service
- State-sponsored health plan
- Other government program
- Single service plan (e.g., dental, vision, prescriptions)

A green 'NEXT' button is located at the bottom right of the form.

Figure 9: Screenshot of Self-Report Version of HIKIND from Gallup Web Survey (Note that on the web instrument these are all presented on one page—they are shown in two columns here in order to save space.)

The self-report version of the question presents the respondent with the full list of ten answer categories at once, with radio buttons used to indicate whether or not the respondent had that type of insurance. Importantly, the respondents *see* all ten types of health insurance at once, on one page. They can, in other words, interpret all 10 types *before* they provide an answer. On the other hand, the interviewer-administered version of the question (which is used in the NHIS), functions as ten *separate* questions with the respondent being asked whether or not they have each health insurance type individually. In this format, respondents provide a yes/no answer to each of the 10 types without knowing what other types (that may better reflect their health insurance) have yet to be asked about. This contrast in administrative styles impacted how the respondents processed and answered the question: respondents who answered the self-administered version in the usability round of testing appeared to think about HIKIND as a single question with 10 answer categories; whereas respondents who answered the interviewer-administered

version approached HIKIND as 10 separate, but similar, questions. These two response pathways are illustrated below in Figures 10 and 11:

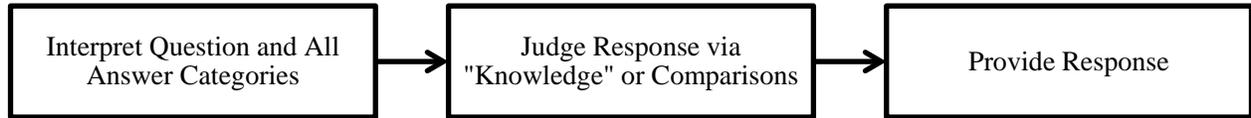


Figure 10: Self-Response Pathway for HIKIND

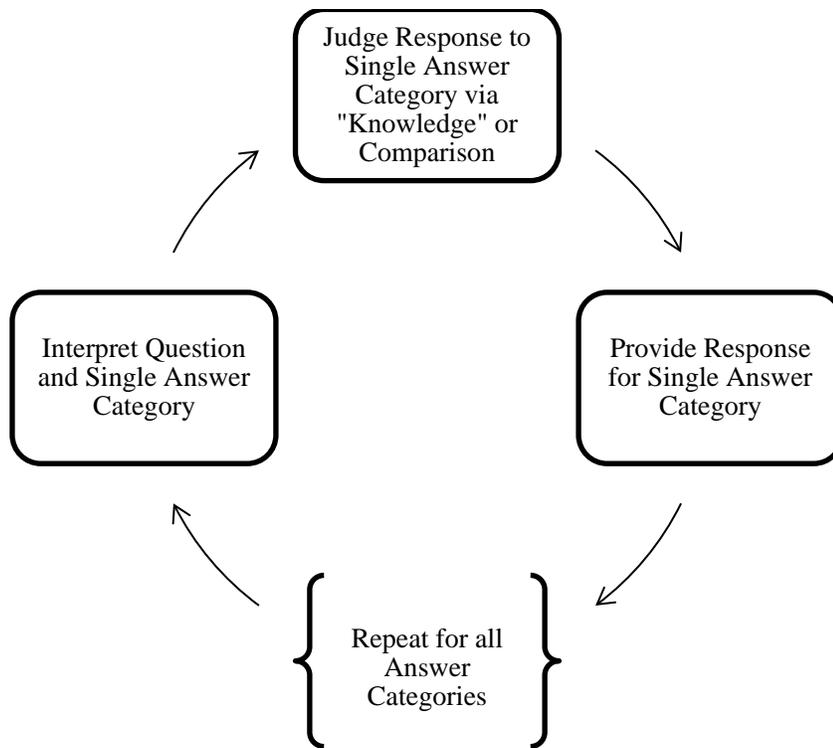


Figure 11: Interviewer-Administered Response Pathway for HIKIND

Analysis of the cognitive interviews shows that the differences between the self-report and the interviewer-administered versions of HIKIND led to different interpretations and levels of cognitive burden. By considering and interpreting all 10 of the answer categories together, the self-respondents were more prone to go back and revise their answer and thought about the various types of insurance in relation to one another. For example, one self-respondent who ended up answering “Medicaid” and “other government program” originally clicked on “Medicare” and “single-service plan.” However, after reading through all of the options, she asked, “Wait, which one is for the elderly?” After thinking more about it, she switched Medicare to Medicaid, and realized that her Medicaid included dental care. She thus de-selected “Single service plan.”

However, considering all of the answer categories together comes at a price of cognitive burden, and many self-respondents expressed confusion. For example, another self-respondent who answered “Private Health Insurance,” “Medicare,” and “Medicaid” revealed upon probing that she only has Medicaid. She explained her answers say, “Oh that was just so confusing for me...I get Obamacare, I have [name of plan]. So, I guess I don’t know what to answer about that.” Likewise, by considering all of the answer categories at once, a few respondents “gave up” once they found the answer category that was most salient and ignored the rest. For instance, one respondent who only answered “private health insurance” noted upon probing that she paid for her dental coverage separately, but stopped paying attention to the answer categories once she had determined that her main health insurance was private: “Once I saw what my answer was, I kind of just assumed that nothing else would have fit...and the list was just way too much. At some point, I tuned out [the other options] because mine was already mentioned.”

On the other hand, almost none of the respondents who received the interviewer-administered version expressed confusion or frustration. So, although they were answering 10 individual questions in comparison to one, because they only had to think about a single concept at a time, their overall cognitive burden appeared to be much less than the self-response group.

However, the interviewer-administered respondents were much less likely to go back and change any incorrect answers than the self-respondents were. A number of these respondents, for example, reported that they had private health insurance, but then also noted that they had Medicaid. Upon probing, each of these respondents revealed that they answered private because their Medicaid was administered by a private company (e.g. Kaiser Permanente), but none insisted that they change their original “private health insurance” response to “no.”

- PROBE4** Which of the following best describes how you get your health insurance?
1. It’s given to all people older than 65
 2. It’s obtained through an employer
 3. It’s through one of my parent’s or guardian’s employers
 4. It’s provided by the government to people who have difficulty affording health insurance
 5. It’s obtained through healthcare.gov or one of the state health insurance marketplaces
 6. It’s obtained through a government job

As described above, the way the respondents had access to their health insurance was much more salient than they type of health insurance they had. As such, PROBE4 was designed as a way of collecting this information so that it could be used to verify the respondents’ responses to HIKIND. The six discrete answer categories come directly from schema respondents used to describe their health insurance, shown above in Figure 8. This probe question is similar to an existing NHIS question—PLNWRK (question FHI.210_01.000 on the 2015 NHIS Family questionnaire) that is currently asked only of respondents who report having private health insurance.⁸ This question was only administered in the final round of cognitive testing.

⁸ NHIS questionnaire are available at: <http://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm>

All the respondents in the final round of cognitive testing received this question, and were largely able to match up their situations with the response categories. One respondent who was still on her parent's health insurance plan noted that there was no option for this (the original version of the probe only included five answer categories, and did not have an option for parent or guardian's employers), and ended up answering "through an employer" and "through a government job" as her parents worked for the federal government. Due to this, "through one of my parent's or guardian's employers" was added as an answer category for the remainder of the cognitive testing and was included in the final instrument.

- PLNMGD** Do you have any of the following kinds of health insurance or health care coverage? Include those plans that pay for only one type of service, such as nursing home care, accidents, or dental care. Exclude private plans that only provide extra cash while hospitalized.
1. HMO (Health Maintenance Organization)
 2. IPA (Individual Practice Plan)
 3. PPO (Preferred Provider Organization)
 4. POS (Point of Service)
 5. Fee-for-Service
 6. Indemnity
 9. Don't know

Of the 32 respondents who received HIKIND across the three rounds of cognitive testing, 17 reported having private health insurance and went on to receive PLNMGD, MGCHMD, PCPREQ, PROBE5, and PROBE6. Of these 17, three were from the self-report usability round, while 14 were from one of the two interviewer-administered rounds.

As seen in previous testing⁹, most respondents thought about the features of PPOs and HMOs when answering PLNMGD, and arrived at their answer by comparing and contrasting their plan's features with what they understood PPOs and HMOs to typically offer. (It is important to note that unless they *knew* they had one of the other types of insurance, respondents tended to ignore all the answer categories besides HMOs or PPOs.) Respondents had similar understanding about the features and drawbacks of HMOs and PPOs across the sample: they typically thought of PPOs as providing lots choices and providers, but costing a lot; while they believed that HMOs have more restrictions and fewer choices, but lower costs. Most respondents therefore applied the response schema shown below in Figure 12, where they compared their own plan's cost, amount of choice they had in regards to their providers, and the number of physical locations to a hypothetical PPO or HMO.

⁹ See Scanlon (2014), pages 35-37

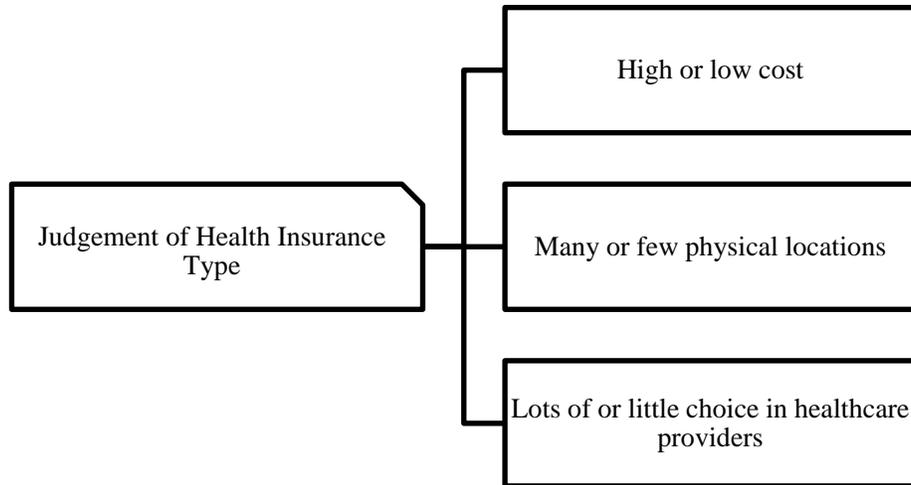


Figure 12: Cognitive Schema Showing Judgement of Type of Health Plan in PLNMGD

Some respondents did not use this comparative pathway and answered this question heuristically—simply knowing what type of private insurance plan they had without having to go through the comparative exercise. Relatedly, a few respondents actually pulled out their health insurance cards and reported what was printed on them (during an actual NHIS interview, respondents are asked to consult their cards or other health insurance documentation).

Beyond those using the comparative or heuristic pathways described above, a few respondents were not familiar with any of the types of private health insurance given in the answer categories—including HMOs or PPOs. One of these respondents actually answered “don’t know,” while the others attempted to guess or reason out an answer. For example, one respondent who answered “fee-for-service” explained his answer by saying:

Those are difficult terms, I’ll answer the question and say fee-for-service. The answer in my head was Blue Cross, and so I tried to match Blue Cross to one of your seven terms. I did the best I could! ...I feel like it’s fee-for service: I show up and then I almost always have to pay sometime, and it’s a total mystery as to what portion I pay. I don’t think I’ve ever gone and it’s free, and I also don’t think I’ve ever gone and paid the whole bill.

Upon further probing, this respondent noted that while he had seen the term HMO before in the news, he did not know what it or a PPO meant, and nobody had ever described his insurance as either one to him before.

- MGCHMD** Under your private plan, can you choose any doctor or must you choose one from a specific group or list of doctors?
1. Choose any doctor
 2. Choose from a group or list
 9. Don't know

As noted in the previous examination of this question¹⁰, respondents do not have consistent interpretations of the phrases “any doctor” or “choose from a group or list” across the cognitive interviewing sample. Respondents used three major patterns of interpretation when deciding the level of choice their plan provided: they could choose *any doctor at all*, they could choose any doctor at all but it was *cheaper to choose from a list*, or they had to (or should) choose doctors *within their plan’s network*. The latter two of these patterns of interpretation led to respondents answering both “choose any doctor” and “choose from a group or list.” The survey responses that each of these three patterns of interpretation produced is shown below in Figure 13, with the survey responses depicted using ovals and the patterns depicted using rectangles:

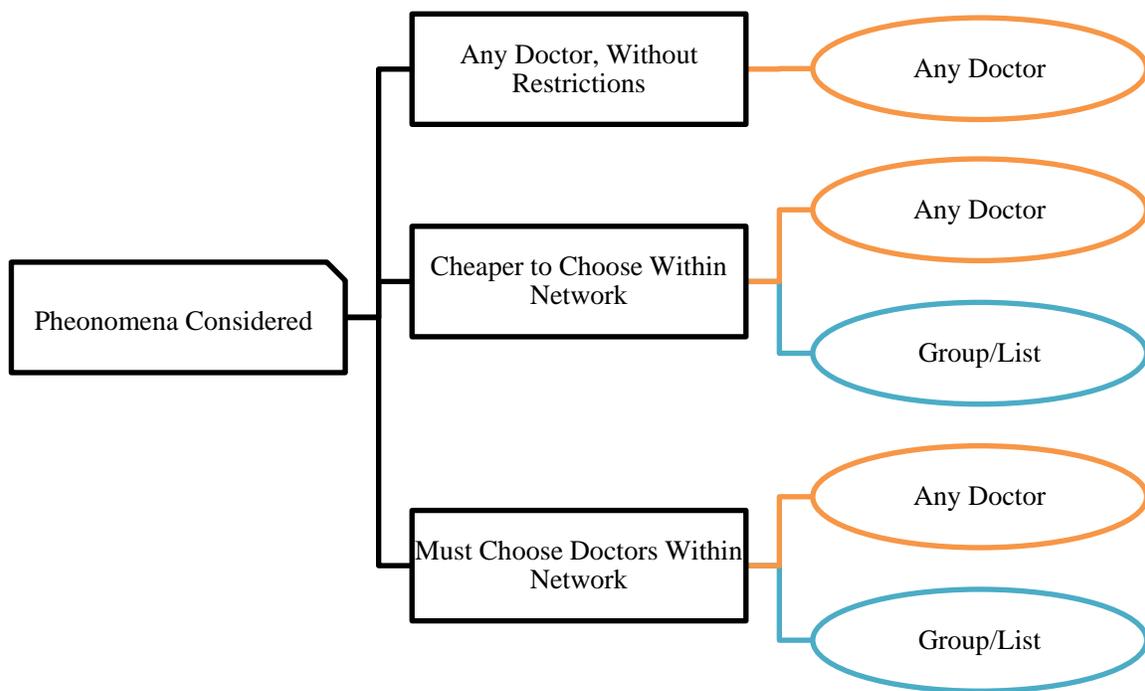


Figure 13: Cognitive Schema, and Associated Survey Responses, for MGCHMD

As seen above, those respondents who were thinking about their ability to choose any doctor at all without restrictions all answered using the “choose any doctor” response option (the orange ovals in Figure 13). Many of these respondents explained that while they could pick any doctor they wished, they might have to pay more if they do so. For example, one first round respondent who answered “choose any doctor” explained his answer by saying, “I can choose any doctor I want. They don’t have to be on a list.” These respondents were simply thinking about their personal ability to go to any doctor at all, and did not focus their attention on the cost of doing so. Upon probing, most of these respondents explained that they would have to pay more if they went to a provider outside of their plan, however, they based their original answer on their simple ability to go to any doctor. In this way, these respondents more or

¹⁰ See Scanlon (2014), page 38

less understood the question as asking, “Does your plan restrict you from seeing any doctor or not?” All the respondents who employed this pattern of interpretation answered the previous question, PLNMGD, by saying they had either PPOs or Fee-for-Service plans—which do give plan holders greater flexibility in their choice of providers as compared to HMOs or other managed care plans.

Another set of respondents explicitly considered the cost ramifications of their choice. Specifically, these respondents—most of whom answered PPO in the previous question, PLNMGD—all noted that while they could go to any doctor at all, it was cheaper to stay within their plan’s network. However, as seen in Figure 13 above, the respondents who interpreted the question this way answered either “any doctor” (again, the orange ovals) *or* “group/list” (the blue ovals). Thus, two respondents who thought about the exact same thing while responding to the question, could answer the question in completely different ways. For example, one respondent in the first round of testing who answered “choose from a group or list” explained that there was a cost benefit to staying in the network: “I could go outside the network, but it costs more.” The fact that there was a cost savings to staying in the network meant that she was restricted to a list of providers in practice. However, another respondent in the same round answered “choose any doctor” while thinking about the same thing: “We *can* choose any doctor, but the costs are different.” She went on to say that while she did her best to keep her care within the network, there were no real restrictions to her choosing an outside provider.

Finally, a third group of respondents thought about the fact that they were absolutely restricted in their choice of medical provider to those doctors within their plan’s network. However, even these respondents—who largely reporting having HMOs in the previous question—did not provide consistent answers to MGCHMD. Most respondents who used this pattern of interpretation answered “choose from a group or list,” as for example a respondent from the final round of testing who explained that his expenses were only reimbursed if he “stuck to the plan” and saw a doctor from within his HMO’s list. However, a few respondents did answer “choose any doctor,” largely thinking about their ability to choose any doctor *from within the network* or their ability to *switch doctors whenever they wanted*. For instance, one respondent who had a national HMO explained that he could theoretically pick any doctor from within that plan regardless of geography:

You do have a choice. It’s not like this is the list of doctors here [in the local area], and then...I couldn’t choose a doctor from outside my area. I’m not limited to just within my area.

This respondent noted that there while he was officially “assigned” to an HMO location by his house, he could visit any other location and still be covered.

- PCPREQ** Does this plan require you to have a primary care doctor who approves all your care?
1. Yes
 2. No
 9. Don’t know

This question has been reworded since the previous examination of the health insurance questions, and the 17 respondents who received PCPREQ across the three rounds of cognitive testing all had a relative consistent interpretation of the question. Respondents understood this question as asking whether or not they were required to get a referral from a PCP prior to seeing any sort of specialist, and this very simple schema is shown below in Figure 14:

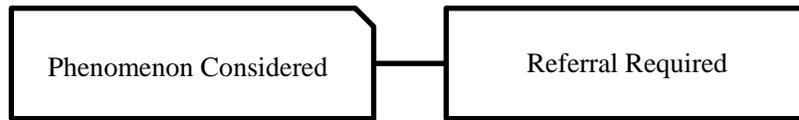


Figure 14: Cognitive Schema for PCPREQ

It is important to note that respondents restricted their interpretations of PCPREQ to whether or not they were *required* to get a referral from a PCP, and did not base their responses on whether or not they felt like *having* a PCP was a good idea or whether or not their insurance company *suggested* that they use a PCP. For instance, one respondent who answered “no” said that “They [his insurance company] request that, but I’ve never abided by that!” Upon further probing, he confirmed that he was able to go to a specialist without first consulting his PCP.

Some respondents explained that they felt like getting the referral from their PCP was a perfunctory step since they were always approved. However, these respondents still based their answer on whether or not this step was a requirement to get their care approved and paid for. For example, one respondent who answered “yes” noted that whenever she wanted to go see a specialist, her PCP always wrote her a referral and usually did so very quickly, and sometimes even did over the phone. She said that she had never had a request denied, but based her answer on the fact that she still had to go through this step, as minor as it may seem.

- PROBE5** How knowledgeable are you about the features of your health insurance plan?
1. Not at all knowledgeable
 2. A little knowledgeable
 3. Somewhat knowledgeable
 4. Very knowledgeable

- PROBE6** How confident are you about your answers to the health insurance questions?
1. Not at all confident
 2. A Little
 3. Somewhere in between a little and a lot
 4. Very confident

PROBE5 and PROBE6 were designed to probe the respondents’ attitudes towards their responses to the previous set of health insurance questions (regardless of whether or not they skipped into the sub-set of questions about private health insurance) in an effort to allow for a nuanced analysis of the missing data in this section. All five respondents in the third round of cognitive testing received these questions. They interpreted PROBE5 based on either the amount of experience they had with their health insurance plan or the amount they had read about (or researched) their plan. However, they based their responses to PROBE6 *only* on their experience with their plan. For example, one respondent who answered “Somewhat knowledgeable” to PROBE5 and “A Little” to PROBE6 noted that she had “done her homework” when choosing her plan, but that “some of these things—like an HMO or the other one, a PPO—I never remember which is which.” She explained that she feels like she knows her benefits well,

but that a lot of the specific terminology surrounding health insurance confused her and she could not be entirely confident in her answers.

Work Status Section

WRKCOR The next questions are about the work you do.

Which of the following were you doing last week?

1. Working for pay at a job or business
2. With a job or business but not at work
3. Looking for work
4. Working, but not for pay, at a family-owned job or business
5. Not working at a job or business and not looking for work

All respondents across the three rounds of cognitive testing received this question. Overall, WRKCOR was understood to be asking, “are you currently working”, and very few individuals who were employed expressed any confusion. Many non-workers, however, expressed some confusion over which category they should report. For instance, one respondent answered “working...at a family-owned job” because she is a stay-at-home parent, and did not see any other options that fit her situation. Other respondents noted that they were confused whether or not “looking for work” had to be an active process. For example, one respondent who eventually answered “Looking for work” struggled, explained that she was not actively sending resumes out to potential employers, but if she happened upon a job opening, she might apply.

WHYNOWK2 What is the main reason you did not work last week?

1. Taking care of house or family
2. Going to school
3. Retired
4. On a planned vacation from work
5. On family or maternity leave
6. Temporarily unable to work for health reasons
7. Have job or contract and off-season
8. On layoff
9. Disabled
10. Other

Twelve respondents across the three rounds of testing did not answer “working for pay at a job or business” to WRKCOR, and received WHYNOWK2. They universally understood this question to be asking about the specific reason or reasons why they did not have a for-pay at the time of the interview.

While this question was not probed extensively, a difference between those who answered “temporarily unable to work for health reasons” and “disabled” emerged. Respondents understood the ninth answer category to be “On disability,” which was the typical phrase used to indicate enrollment in the SSDI program. In doing so, they limited their interpretation of this answer category to actually receiving disability benefits from the government (specifically Social Security Disability Insurance, or SSDI), and used the sixth answer category (“Temporarily unable...”) if they were injured or disabled, but did not receive any SSDI benefits.

Chronic Conditions Section

Respondents typically used one of three patterns of interpretation when answering the general (or “gateway”) chronic condition questions that asked whether or not they had ever been told they had one condition or another. These general patterns are illustrated in the schema below in Figure 15, with the survey responses they tend to elicit. In general, respondents either thought about 1) the condition itself, 2) the symptoms, or perceived symptoms, associated with the condition, or 3) their overall general health.

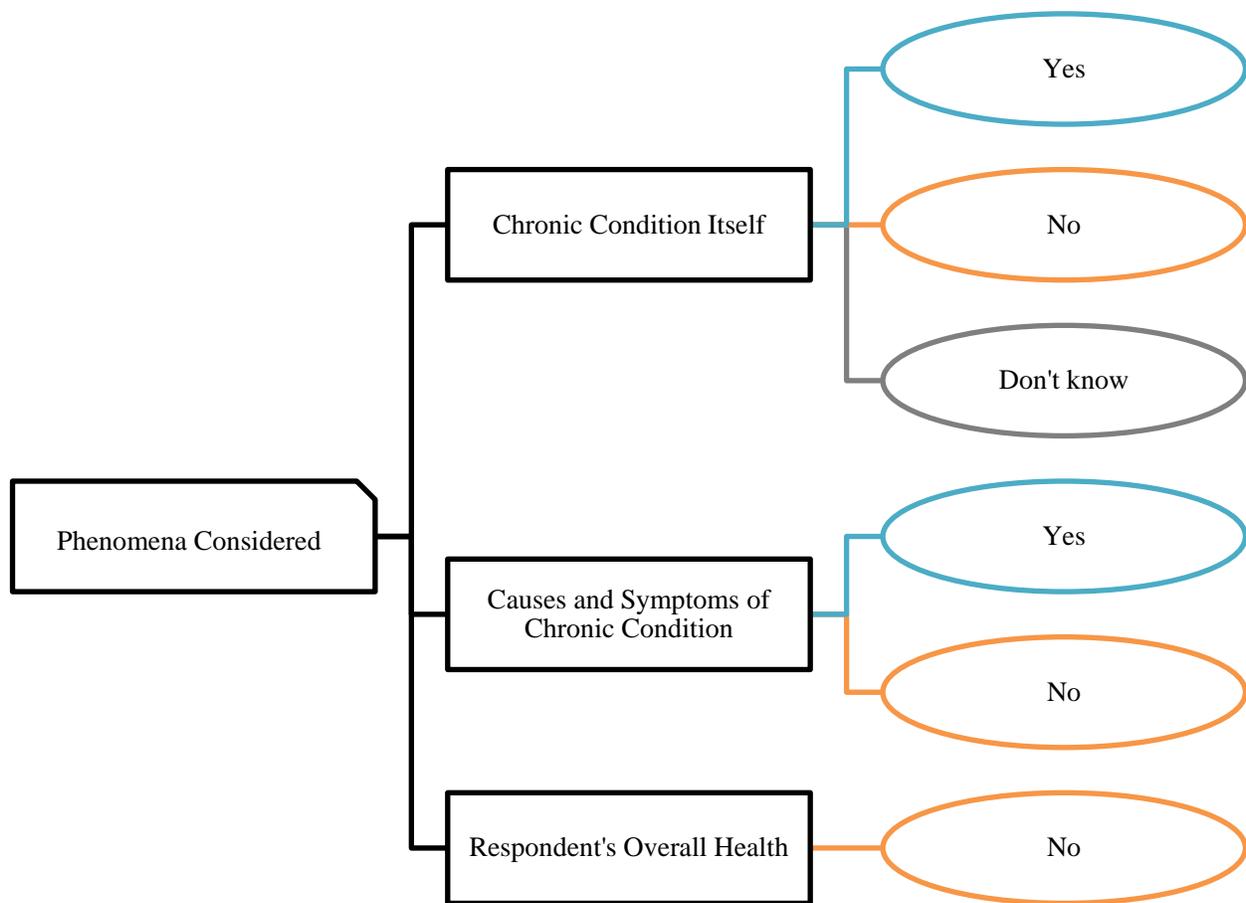


Figure 15: General Cognitive Schema, and Associated Survey Responses, for Chronic Condition Questions

Respondents who considered the chronic condition itself tended to focus on whether or not they remembered their doctor explicitly telling them that they had the condition under question. While some respondents who answered “no” explicitly know they had not been diagnosed with the chronic condition, others answered “no” because they had never *heard* of the condition—using the logic that if indeed they did have the condition, they would have some knowledge about it. Respondents who answered “don’t know” either did not remember if they had been diagnosed one way or the other, or (more commonly) did not recognize the chronic condition but could not be sure that they did not have it.

Other respondents tended to consider the causes of, or symptoms associated with, the chronic condition, instead of the condition itself. Respondents associated symptoms with conditions either because they were explicated in the question text (as in HYPEV, see below) or based on what they understood about the condition. In some cases, this led to interpretive errors. For instance, while many respondents thought that the emphysema and COPD questions (EPHEV and COPDEV, respectively) related to pulmonary diseases, a few respondents understood the word “pulmonary” to mean *heart*-related, and not *lung*-related.

Finally, other respondents used a heuristic pathway to answer the chronic conditions gateway questions. These respondents reasoned that since they were in generally good overall health, and did not have any long-term health issues, they did not have any of the conditions. In this way, they skipped over the comprehension or recall phases of the response pathway and instead immediately answered the question. All of the individuals who responded using this pattern answered the questions “no.”

Please note that an evaluation of a similar set of NHIS and proposed NHIS questions about diabetes was conducted recently by NCHS. The findings described below for DIBEV, DIBPRE1, DIBAGE, PROBE9, INSLN, and DIBPILL are largely congruent with the previous findings¹¹.

HYPEV The next series of question will ask you about certain medical conditions.

Have you ever been told by a doctor or other health professional that you had hypertension, also called high blood pressure?

1. Yes
2. No
9. Don't know

All respondents across the three rounds of cognitive testing received HYPEV, which functions as a gateway question for the follow-up hypertension questions (HYPMDEV2 and HYPMED2). Figure 16 below shows the two patterns of interpretation that respondents used while answering this question:

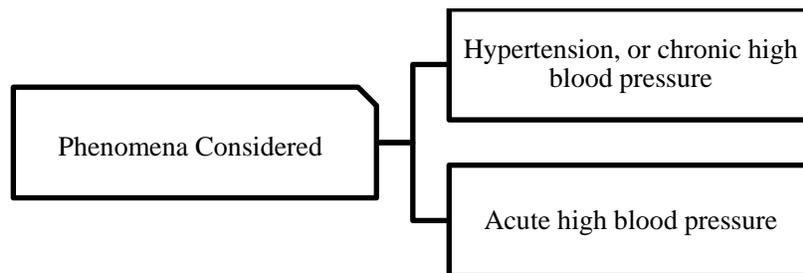


Figure 16: Cognitive Schema for HYPEV

While most respondents understood this question to be asking whether or not they had been diagnosed with the chronic condition known as “hypertension,” a few respondents did not limit their comprehension to the chronic condition and instead thought about acute bouts of high blood pressure.

For example, one respondent who answered “yes” explained her answer by saying that she had once run to her doctor’s appointment, and thus her blood pressure was high when they took it at the beginning of the visit. However, upon probing she noted that her doctor was not concerned, did not diagnose her with hypertension, and had never said she had a high reading since then. Likewise, another respondent who answered “yes” reported that his doctor told him that he “borderline” high blood pressure, and because of this he changed his diet and his tests have come back normal since then. During probing, this respondent noted some confusion over whether to answer “yes” or “no,” but decided that since the question asked if he had *ever* been told he had high blood pressure, his borderline diagnosis should count.

Of the six respondents who answered “yes” using the acute high blood pressure pattern of interpretation, only one answered “yes” to the follow-up question (HYPMDEV2) about whether or not they had ever been prescribed medicine for their hypertension. This suggests that the NHIS follow-up questions on hypertension (and the resulting recoding they permit) may work as effective “checks” on respondents’ answers to the overall question.

¹¹ Dunston et al 2016

HYPMDEV2 Has a doctor ever prescribed any medicine for your high blood pressure?

1. Yes
2. No

Fifteen respondents across the three rounds of cognitive testing received this question. Respondents largely understood HYPMDEV2 to be asking whether or not their doctors had ever written them a prescription for blood pressure medicine. However, one respondent based her answer not on the prescription itself, but rather on whether she actually took the medicine. After answering the question “no,” she explained by saying, “They [the doctor’s office] offered me medicine, but I didn’t accept it.” She went on to note that she was able to control her high blood pressure through a change in diet, and had never taken any blood pressure medication.

HYPMED2 Are you now taking any medicine prescribed by a doctor for your high blood pressure?

1. Yes
2. No

The same fifteen respondents who received HYPMDEV2 went on to receive and answer HYPMED2. All fifteen understood this question to be asking whether or not they were currently taking blood pressure medication. They did not appear to limit their interpretations to prescription-only medicines, as two respondents noted that they were taking over-the-counter aspirin for their blood pressure. However, both of these respondents explained that their doctor had told them to take it, which counted as a prescription in their view.

EPHEV Have you ever been told by a doctor or other health professional that you had emphysema?

1. Yes
2. No

Only the 30 respondents in Rounds 1 and 2 received EPHEV. Respondents in Round Three received a newly designed question—NEWLUNG--instead. This question was probed jointly with COPDEV and AASMEV.

Most respondents did not know what distinguished emphysema, COPD, or asthma—they simply knew that they either had never been told they had them, or that these were lung or pulmonary diseases. For instance, one respondent who answered “no” to EPHEV, COPDEV, and AASMEV said, “I know they have to do with respiratory or breathing, but what distinguishes one from another, I do not know.” Similarly, another respondent who answered “no” to all three gateway questions explained that he had heard of all three diseases from television commercials, but besides thinking that they all had to do with breathing, he didn’t know how they were different.

A few respondents did report having been diagnosed with one of these lung conditions, but even in these cases, the respondents were unsure about how the one they had was different than the other two. For example, one respondent who answered “no” to EPHEV and COPDEV, but “yes” to AASMEV explained that she would have remembered being diagnosed with either COPD or emphysema. When asked what she thought these two conditions were, she said, “I’m not sure—more about your lungs I guess.”

A few respondents had total misinterpretations of these conditions, and did not even think about them as lung issues—particularly in EPHEV and COPDEV (asthma being a more common, and thus salient, condition than either emphysema or COPD). For instance, two respondents appeared to confuse emphysema with *eczema*, and explained their “no” answers by saying that they did not have any skin issues. Similarly, a few respondents thought that the word “pulmonary” meant heart-related and not lung-related. These respondents thus considered whether or not they had ever been told by a doctor that they had heart disease or other circulatory issues. For instance, one respondent who answered “yes” to COPDEV referred to the condition as “coronary heart disease,” even after the question had been re-read multiple times. He went on to explain his answer: “in my arteries, yes, because that’s where they had to the by-passes and then the blood clots in my lungs, which is a blood problem too.”

- COPDEV** Have you ever been told by a doctor or other health professional that you had chronic obstructive pulmonary disease, also called COPD?
1. Yes
 2. No

Only the 30 respondents in Rounds 1 and 2 received COPDEV. Respondents in Round Three received a newly designed question—NEWLUNG--instead. This question was probed jointly with COPDEV and AASMEV. Findings for COPDEV are detailed above in EPHEV.

- NEWLUNG** Have you ever been told by a doctor or other medical professional that you have Chronic Obstructive Pulmonary Disease, or COPD, emphysema, or chronic bronchitis?
1. Yes
 2. No
 9. Don’t know

The five respondents in Round Three received NEWLUNG, while the 30 in Rounds 1 and 2 did not. NEWLUNG was designed by CQDER and NHIS staff to replace the existing NHIS questions of EPHEV, COPDEV, and CBRCHYR. In addition to the concern that the question about chronic bronchitis is capturing acute bronchitis (see the analysis of CBRCHYR on p. XX), the apparent difficulty that respondents have differentiating emphysema and COPD (as noted above in the analysis of EPHEV) led NHIS staff to consider a “combination” question that asked about all three of these conditions at once. This question was designed to both frame chronic bronchitis as a serious condition and to reduce overall respondent burden. Analysis of the cognitive interviews of NEWLUNG suggest that it succeeds at both these goals.

Respondents who answered this question “no” followed the same form seen above in EPHEV and COPDEV—they considered whether or not they had any lung problems or if a doctor had ever told them they had one of the listed conditions. However, in contrast to the series of questions asked in Rounds 1 and 2, these respondents only had to respond to one question, instead of three separate questions.

There is also evidence that NEWLUNG frames chronic bronchitis as a serious condition, and separate than acute bouts of bronchitis. For example, one respondent who answered “no” to NEWLUNG explained upon probing that she had been diagnosed with bronchitis in high school, but that it was treated with antibiotics and “cleared up” within a couple of weeks. She decided that this did not count as “chronic bronchitis.”

- PROBE8** Which condition were you told you had?
1. COPD
 2. Emphysema
 3. Chronic Bronchitis
 4. Bronchitis
 5. Something else

PROBE8 was designed as a content probe of NEWLUNG. One of the two goals for the NEWLUNG question was to eliminate non-chronic bronchitis from the estimates currently produced from the NHIS using CBRCHYR. By explicitly asking respondents which conditions they considered when answering NEWLUNG, PROBE8 will permit researchers to quantify this particular measurement error. During the initial design of the probe questions, PROBE7 and PROBE8 were intended to be presented in numerical order. However, upon review the project team realized that PROBE8 would provide valuable framing for PROBE7, and their order was reversed on the final RANDS questionnaire.

This question was only administered to one of the five respondents in Round Three of testing, and no findings are available.

- PROBE7** Thinking about the most recent time you had symptoms of Chronic Obstructive Pulmonary Disease or COPD, emphysema, or chronic bronchitis, how long did the symptoms last?
1. Less than one week
 2. One week to less than one month
 3. One month to less than three months
 4. Three or more months

Like PROBE8, PROBE7 was designed to assess the potential measurement error of the NEWLUNG question, specifically the misinterpretation of chronic bronchitis, by attempting to class the duration of the conditions that respondents considered when answering NEWLUNG.

PROBE7 was only administered to one respondent in the third round of cognitive testing, and no findings are available.

- AASMEV** Have you ever been told by a doctor other health professional that you had asthma?
1. Yes
 2. No
 9. Don't know

All respondents across the three rounds of cognitive testing received AASMEV. In Rounds 1 and 2, AASMEV was probed alongside EPHEV and COPDEV. Findings for AASMEV are detailed above in EPHEV.

- AASTILL** Do you still have asthma?
1. Yes
 2. No

Nine respondents across the three rounds of cognitive testing answered “yes” to AASMEV and went on to receive the asthma follow-up questions starting with AASTILL. Respondents did not approach this question uniformly, and instead appeared to use two patterns of interpretation: either considering asthma to be a life-long condition or thinking about the length of time since they had their last asthma attack.

Respondents who used the former interpretation—that they would *always* have asthma—correspondingly all answered the question “yes.” They emphasized that it did not matter when their last attack was, as they were still at risk of having another. For example, one respondent who answered “yes” explained her answer by saying:

I wouldn't count it out. I haven't had an attack in five years, but I'm sure if someone told me to breathe in a nebulizer, I wouldn't make it reach the top. That's something I've always struggled with. I definitely can tell in my very active life that shortness of breath is there—it just hasn't become an asthma attack or anything like that lately.

The other pattern of interpretation—that you only had asthma if you had experienced an attack recently—led to both “yes” and “no” answers. Additionally, the time threshold that respondents used to judge whether or not they still had asthma was not consistent. For instance, one respondent who answered “no” reported that he had not had an attack for “a couple of years.” However, another respondent who answered “yes” noted that she had her last attack about two years ago, which meant that she still had the condition.

- AASMYR** During the past 12 months have you had an episode of asthma, or an asthma attack?
1. Yes
 2. No

The same nine respondents who received AASTILL went on to receive and answer ASMYR. They all considered only the past 12 months when responding to this question—with the five respondents who answered “no” all mentioning that they had experienced attacks prior to the last year during probing.

Respondents did not limit their responses, however, to serious asthma attacks. Two respondents who answered “yes” noted that they had simply experienced mild symptoms of asthma during the last year, but had not had a full-on attack.

- AASMERYR** During the past 12 months have you had to visit an emergency room or urgent care center because of asthma?
1. Yes
 2. No

The same nine respondents who answered the previous detailed questions on asthma continued on to receive AASMERYR. All respondents were considering only the past 12 months, and were specifically thinking about visiting emergency rooms. None of the nine respondents in the cognitive sample who received AASMERYR reported going to an urgent care center for the asthma attack they reported above in AASMYR.

- DIBEV** [Other than during pregnancy,] have you ever been told by a doctor or other health professional that you have diabetes or sugar diabetes?
1. Yes
 2. No
 3. Borderline
 9. Don't know

All respondents received and answered DIBEV, and they followed the same general patterns of interpretation seen throughout the other gateway chronic condition questions as depicted above in Figure 15.

Diagnosis of Diabetes

Most respondents considered the condition itself, limiting their interpretation to whether or not they remember their doctor ever explicitly telling them that they diabetes. Quite a few respondents explained that they knew about diabetes because they had family members who had it, and thus were aware of the condition and followed up with their physicians about it. For example, one respondent who noted a family history explained her “yes” answer by saying that about five years before she had asked her doctor to test her for it, and he found elevated levels of (hemoglobin) A1C and diagnosed her.

Symptom and Causes of Diabetes

Other respondents limited their consideration to the symptoms of diabetes, instead of thinking about an “official” diagnosis. These respondents were typically thinking about blood sugar levels. For example, one respondent who answered “no” said that “I’ve had blood drawn by doctors before, and have never seen bad sugar levels.” Likewise, another R said that she did not have diabetes because, “I’ve been told that I have low levels of blood sugar, actually...that’s the opposite.” Just a few respondents considered symptoms besides blood sugar levels. For instance, one respondent in the third round who answered “borderline” noted that she was always on the lookout for signs of the disease because “everyone in my family besides my mom has it. Two generations down.” She went on to explain her answer by saying that she has noticed some skin discoloration and bruising on her arms and face, which she associates with prediabetes. Upon probing, she revealed that a doctor has never told her that she has borderline or prediabetes, and that she had not had her blood tested in years—she was simply basing her response on the physical signs that she had observed.

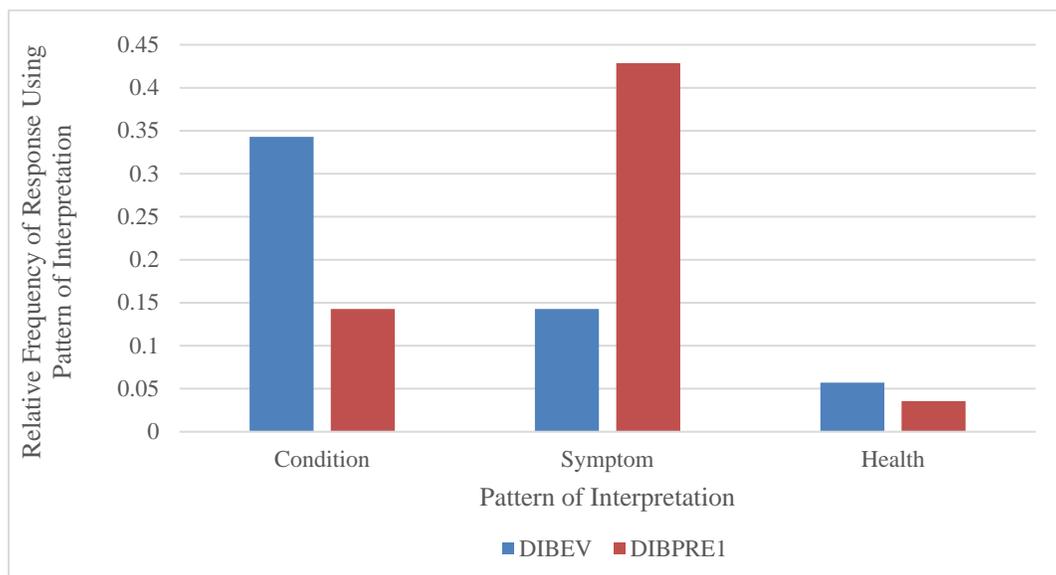
Perception of General Health

Finally, a couple of respondents based their “no” answers on their perception of overall general health. Since they were healthy, these respondents reasoned that they did not have any chronic conditions, including diabetes. For example, one respondent in the first round who answered “no” explained his response by simply saying, “Again, I don’t have any health problems, so it doesn’t relate to me.”

- DIBPRE1** Have you ever been told by a doctor or other health professional that you have any of the following: prediabetes, impaired fasting glucose, impaired glucose tolerance, borderline diabetes, or high blood sugar?
1. Yes
 2. No
 9. Don’t know

Twenty-eight respondents answered DIBEV “no” and went on to receive the follow-up question about prediabetes. While the same three patterns of interpretation emerged in DIBPRE1 as did in DIBEV—thinking about being explicitly told a diagnosis by a doctor, thinking about the symptoms of prediabetes, or simply considering overall health—they did so in different frequencies. In particular, many more respondents considered diabetes’ symptoms and causes when responding to DIPRE1 than did when considering DIBEV, as seen below in Chart 1, which shows the relative frequencies of responses of these 28 respondents who used each of these three patterns of interpretation across the two questions:

Chart 1: Relative Frequencies of Patterns of Interpretations in DIBEV and DIBPRE1 among Respondents Who Answered both Questions



Specifically, most respondents considered blood sugar levels when responding to DIBPRE1 (shown in the “Symptom” set of bars in Chart 1 above) than did when responding to DIBEV. Many respondents reported that they answered “no” to DIBPRE because their levels were “normal,” but answered “no” to DIBEV because they had never been diagnosed. For example, one respondent in the first round of testing who answered “no” explained her answer to DIBPRE by saying that all she ever remembers her doctoring telling her about blood sugar was that “everything is normal.” Likewise, another respondent who answered “no” said she thought this question was asking about high blood glucose, and that she believed hers was tested every year at her checkup. She said she was never told anything about her glucose levels, so she figured that the correct answer was “no.”

It is possible that this increased interpretation based on blood sugar levels as compared to DIBEV is due to the framing provided from DIBPRE1’s question test, which explicitly and repeatedly mentions sugars. In fact, while no respondents mentioned the term “glucose” when explaining their answers to the unframed DIBEV, quite a few did during probing of DIBPRE1.

DIBAGE How old were you when a doctor other health professional first told you that you had diabetes or sugar diabetes?

The five respondents who answered “yes” to DIBEV were administered (or “skipped into”) DIBAGE. All understood this question to be asking about when their diabetes or prediabetes was diagnosed by doctor. Not all of these respondents limited their responses to full diabetes, however. One respondent who answered “28” explained that she was thinking about when she was first diagnosed with prediabetes, and that she was not diagnosed with full diabetes until age 32.

PROBE9 Were you told that you have Type 1 or Type 2 diabetes?

1. Type 1
2. Type 2
3. Another type
9. Don't know

This probe question was taken directly from the National Health and Nutrition Survey (NHANES)'s diabetes section. No respondents in the third round of cognitive testing answered DIBEV "yes;" therefore this question was not administered to any cognitive interviewing respondents and no findings are available. However, a similar question was recently tested for potential inclusion in the NHIS, and some interpretive variation emerged¹².

INSLN Are you now taking insulin?

1. Yes
2. No

The eight respondents who answered either "yes" or "borderline" to DIBEV, or "yes" to DIBPRE1, skipped into INSLN. All respondents understood this question to be asking if they were, at the time of the interview, actively taking insulin.

DIBPILL Are you now taking diabetic pills to lower your blood sugar? These are sometimes called oral agents or oral hypoglycemic agents

1. Yes
2. No

The same eight respondents who skipped into INSLN went on to receive DIBPILL. These respondents all thought about whether or not they were actively, at the time of the interview, taking pills for their diabetes. While some respondents clearly thought about whether or not their pills "lower[ed] blood sugar" and answered accordingly, most just thought about whether or not their doctor had prescribed them *any* pills because of their diabetes. Upon probing, these respondents reported not knowing whether or not the pills were supposed to lower blood sugar or do something else.

¹² See Dunston et al 2016, pages 19-20

- CBRCHYR** Have you ever been told by a doctor or other health professional that you had chronic bronchitis
1. Yes
 2. No

The 30 respondents in Rounds 1 and 2 received CBRCHYR. It was not administered to the respondents in Round Three, but was replaced with the combination question NEWLUNG (analyzed above). Figure 17 illustrates the schema used by respondents when answering CBRCHYR:

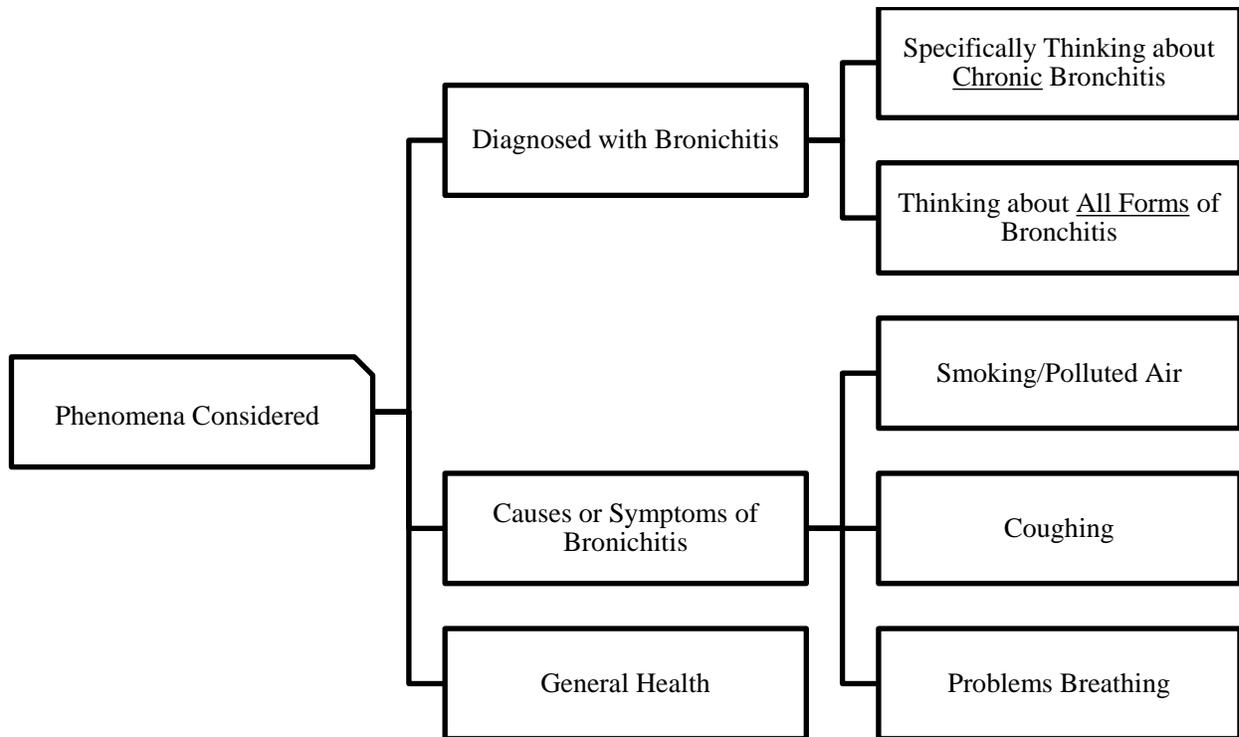


Figure 17: Cognitive Schema for CBRCHYR

Diagnosis of Chronic Bronchitis

While respondents used the same three-pattern response schema seen throughout the other chronic condition questions (see Figure 15), there was noticeable variation in how respondents understood “chronic bronchitis.” In short, while most respondents who used the “condition” pathway thought about chronic bronchitis as a serious and long-term ailment, others appeared to disregard the “chronic” component of the condition and instead based their answers on whether or not they had ever been diagnosed with any bronchitis at all. For example, one respondent who answered “yes” explained that he was diagnosed with bronchitis in 1999, and believed that it was due to his smoking habit. However, he said that it cleared up within a year and upon probing was unclear whether or not he was diagnosed with *chronic* bronchitis, or just acute bronchitis. Likewise, another respondent who answered “yes” said she knows that her doctor told her that she had bronchitis, but “I don’t know what the difference is between bronchitis and chronic bronchitis.” Upon further probing, this respondent revealed that she has an inhaler and uses it when her bronchitis “flares” up.

Causes or Symptoms of Chronic Bronchitis

In addition to the respondents who considered the condition itself, others focused their interpretations on the causes and symptoms they perceived to be associated with bronchitis. For example, one respondent who answered “no” explained that he thought she had an uncle with bronchitis, which she said was “problems with the lungs and breathing.” She went on to say that this uncle was a smoker, and that’s why originally had an upper respiratory infection that led to the bronchitis.

Perception of General Health

As seen throughout the other chronic condition questions, a couple of respondents continued to base their answers not on the condition or symptoms, but rather on their own general (good) health. As seen throughout the chronic conditions section, these respondents all answered the question “no” because they were generally healthy people.

Smoking Section

- SMKEV** Have you smoked at least 100 cigarettes in your entire life?
1. Yes
 2. No
 9. Don’t know

All respondents across the three rounds of cognitive testing receiving SMKEV. They used two basic pathways when answering this question, as illustrated below (with the responses to which each pathway leads) in Figure 18:

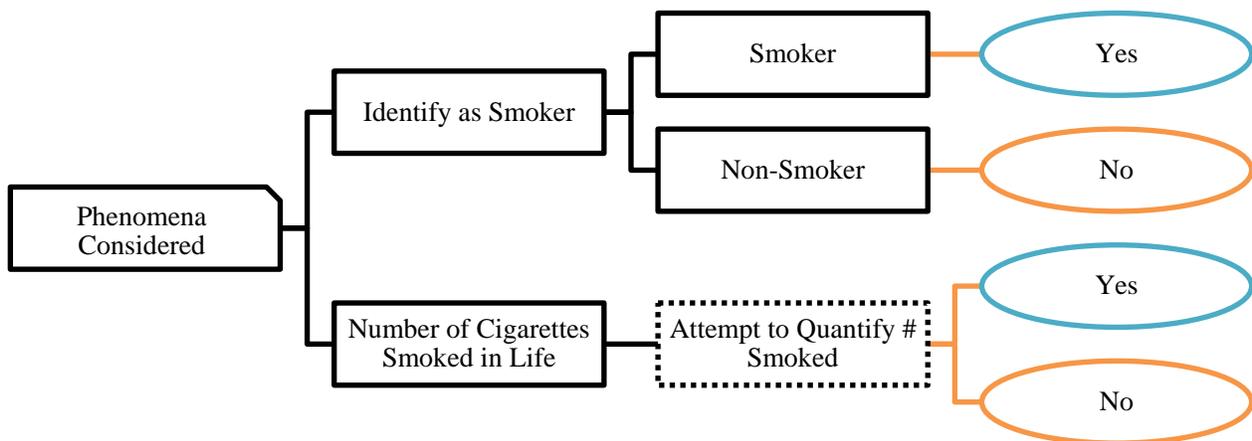


Figure 18: Cognitive Schema, and Associated Survey Responses, for SMKEV

Respondents either heuristically answered the question based on their identity as either smokers or non-smokers, or by considering (and attempting to quantify) the total number of cigarettes they had ever smoked.

Identify as Smoker or Non-Smoker

Most respondents, including all but one who answered SMKEV “yes,” responded based simply on whether they identified as either smokers or non-smokers. Use this pathway, respondents did not attempt to quantify the total number of cigarettes they had ever smoked. Rather, they translated the fact that they considered themselves either smokers or non-smokers into an answer. For example, one respondent who answered “yes” explained her response by simply saying, “I’ve been smoking since I was 16.” Likewise, another respondent who answered “yes” noted that “I’ve been smoking for 40 years...at least ½ a pack a day.” Respondents who answered this way did not necessarily limit their interpretations to just tobacco cigarettes. For instance, one respondent who answered “yes” went on to say, “I like weed!” and explained that he smoked marijuana most days.

Non-smokers also employed this pattern, explaining that their “no” responses were easy because they simply did not smoke. For example, one respondent who answered “no” said “I’ve never smoked, so definitely not 100 [cigarettes].” Similarly, another person who answered “no” simply said, “I’ve never smoked.”

Number of Cigarettes Smoked in Life

Other respondents who answered “no” used a more complete recall and judgement pathway when responding to SMKEV, and attempted to count all the cigarettes they had ever smoked in order to determine whether or not they were under the 100-cigarette threshold. Most of these respondents could recall specific instances of smoking (often described as “trying”) cigarettes. For instance, one respondent in the third round of testing explained that he had smoked exactly three cigarettes in his entire life:

I’ve tried it three times—one in high school, one in college, and one after college.
Always when I was drinking.

This respondent went on to explain that he remembers these events clearly because he got a really bad headache each time.

Only one respondent in the cognitive sample who used the recall and judgement pathway went on to answer SMKEV “yes.” This respondent, in the second, self-administered round, went through the math until she was sure that she had reached 100 cigarettes. She explained her thought process saying:

[There are] 20 cigarettes in a pack, so five packs is 100—I’m sure I’ve smoked more than five packs: I’ve been smoking since I was 22 [years old].

- SMKNOW** How often do you now smoke cigarettes? Every day, some days, or not at all?
1. Every day
 2. Some days
 3. Not at all

Ten respondents answered “yes” to SMKEV and went on to receive and answer SMKNOW. There was clear variation in the response step (see Figure 1) of this question where these respondents had to match their smoking frequency to one of three answer categories: “Every day,” “Some days”, or “Not at all.” All of the respondents who answered “Every day” understood that option to indicate they smoked one or more cigarette each day. However, respondents used two distinct interpretations of “Some days.” Figure 19 below shows these various patterns of response and their associated survey responses:

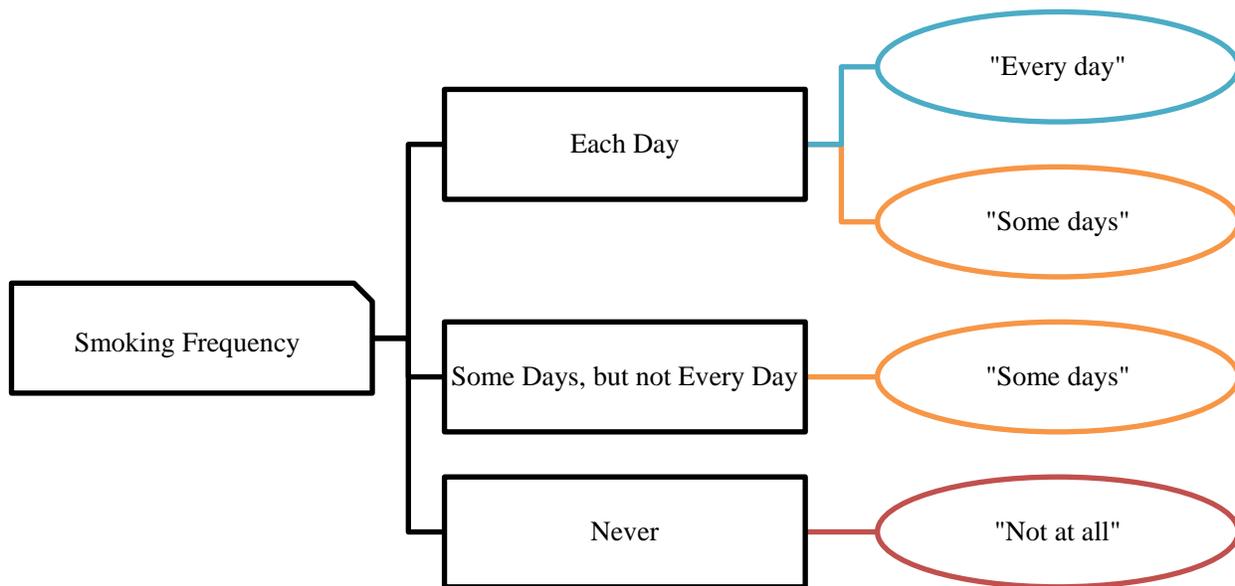


Figure 19: Cognitive Schema, and Associated Survey Responses, Showing How Frequency Mapped onto Answer Categories for SMKNOW

One group of respondents understood “Some days” to be basically the midpoint on the “Every day” to “Not at all” continuum—i.e. they smoked, but not each and every day. For example, one respondent in the third round who answered “Some days” explained that she smokes about two to three times a week, and only when she is feeling stressed, but that most days she does not smoke at all.

However, another group of respondents interpreted “Some days” as meaning “less than I smoked previously.” These respondents all explained that they had cut down their smoking, but upon probing all revealed that they still smoked every day. Similar to what is seen below in ALC12MNO (where respondents are asked about the number of alcoholic drinks they consume), a few respondents appeared to only count days of high amounts of smoking—for instance only counting days where they smoked ½ a pack as “smoking days” for the purpose of this question. For instance, one respondent in the second round who answered “Some days” explained what she was counting by saying:

I’ll put five cigarettes out [every day], but I’ll only smoke two of them unless someone pissed me off! Or when I’m work all day and night... [For example] I only smoked one today so far.

Upon further probing, this respondent revealed that she was only counting the days where she smokes the full complement of five cigarettes that she puts out, which she says is typically the 2 days that she works double shifts at work. The other days, she will still smoke, but simply smokes fewer than five cigarettes.

SMKQTNO How long has it been since you quit smoking cigarettes?

No respondents in the three rounds of cognitive testing received SMKQTNO, as no respondents answered “Not at all” to SMKNOW. Therefore, no findings are available.

CIGQTYR During the past 12 months, have you stopped smoking for more than one day because you were trying to quit smoking?

1. Yes
2. No

The same 10 respondents who received and answered SMKNOW went on to receive CIGQTYR. Respondents all understood the question to be asking whether or not they were *currently* trying to quit smoking. Respondents who had tried to quit previously, but had either given up trying or had resumed smoking prior to the last year all answered the question “no,” indicating that the “past 12 months” reference period given in the question text was effective.

SMKANY Have you ever smoke a cigarette even one time?

1. Yes
2. No

Twenty-five respondents answered SMKEV “no” and skipped into SMKANY. Overall, respondents understood this question to be asking if they had ever smoked even just one cigarette in their life. However, respondents used three different (but nested) patterns of interpretation when comprehending “cigarettes,” as seen below in Figure 20:

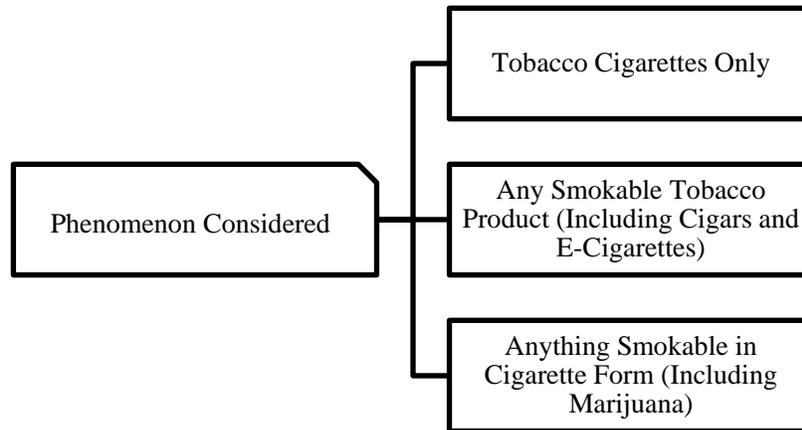


Figure 20: Cognitive Schema for SMKANY

Tobacco Cigarettes Only

Most respondents understood “cigarette” to only mean a traditional tobacco cigarette that one would typically buy in packs of 20. For example, one respondents who answered “yes” explained that he was thinking about a specific time when he was 18 years old and his friend bought a pack of cigarettes from a store for them to try (he noted that he took one puff of a cigarette and then threw it away and has not smoked since then). Others using this pattern of comprehension explicitly excluded non-cigarettes from their interpretations, even if they were tobacco-based. For instance, one person who answered “no” was vehement in her rejection of smoking: “It’s gross—all the women in my family smoked. My mother finally quit [using] smoking cessation programs...both grandmothers died of lung cancer.” However, upon probing, this respondent explained that had previously smoked cigars at weddings and had smoked pot, but that “those aren’t cigarettes” and thus did not count towards this question.

All Smokable Tobacco Products

Other respondents used a wider interpretation of “cigarettes” to include all tobacco products that are smoked (or “vaped”), and included things such as cigars, cigarillos, and e-cigarettes in addition to traditional cigarettes. For example, one respondent who answered “yes” noted that she was thinking about her e-cigarette, and upon probing explained that she had never actually tried a traditional cigarette in her life.

Anything Smokable in Cigarette Form

Finally, a few respondents used an extremely inclusive definition of “cigarette,” and appeared to count all cigarette-shaped items that could be smoked—including items such as clove and marijuana cigarettes. For instance, one respondent who replied “yes” to this question said that he was thinking about how he smokes cloves, pot, and cigars a couple of times a year. Likewise, another respondent who answered “yes” explained that she had never had cigarettes, but had smoked pot occasionally in high school and college.

Because these three patterns of interpretation are nested—tobacco cigarettes are included in all three definitions of cigarettes—and assuming that the intent of this question is to *only* capture traditional cigarette use, the two out-of-scope patterns will only lead to false positive responses, but not false negative ones. When a respondent answers this question “no,” the cognitive interviewing findings suggest that they are certain to have never smoked a single tobacco cigarette.

PROBE10 In the previous questions, what kind of cigarettes were you thinking of?

1. Tobacco cigarettes
2. Cigars
3. Marijuana cigarettes
4. E-cigarettes

PROBE10 was designed as a content probe for the full smoking section (SMKEV, SMKNOW, SMKQTN, CIGQTYR, and SMKANY). As seen above in the analyses of SMKEV and SMKANY, this section captures items beyond traditional tobacco cigarettes. The answer categories in PROBE10 are taken directly from the analyses of SMKEV and SMKANY in an attempt to tease out the potential false positive responses in these two questions.

This question was administered to four respondents in the third round of testing (one respondent was incorrectly skipped out of this question by the interviewer). These individuals all understood PROBE10 to be asking about the types of smokable items they had included in their answers to the previous smoking questions.

Physical Activity Section

The current physical activity section on the NHIS asks a series of five questions to obtain an estimate of adult leisure-time physical activity and to measure progress towards the national Physical Activity Guidelines¹³. These questions ask respondents about how often they do vigorous, moderate, or muscle-strengthening physical activities, and for vigorous and moderate exercise, how long they do those physical activities. Figure 21 shows the progression a respondent takes through this section of the NHIS questionnaire:

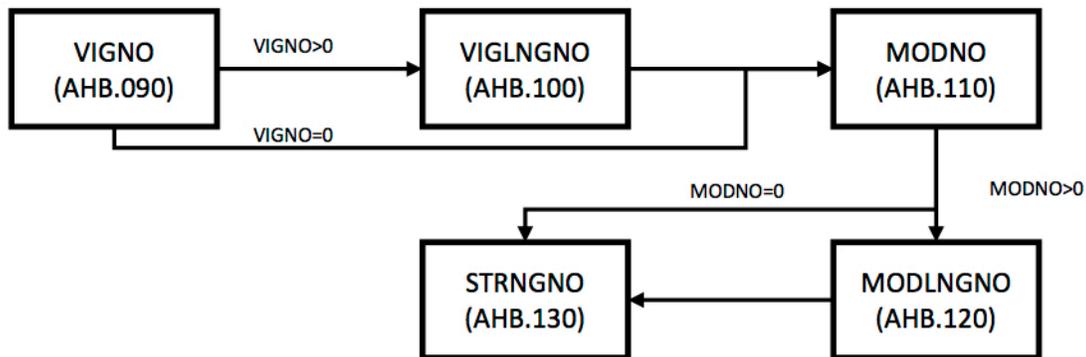


Figure 21: Flowchart of 2016 NHIS Physical Activity Section

¹³ See <http://health.gov/PAGuidelines>

The NHIS is an interviewer-administered survey. Thus, respondents do not know what questions are forthcoming, and must therefore interpret each question based only on their personal experience and the framing provided by earlier items on the questionnaire. In short, an NHIS respondent answering VIGNO (the first question in the series, about vigorous physical activity) does not know they will next be asked questions about moderate and strength-based questions (MODNO and STRNGNO, respectively), and therefore do not know to exclude moderate physical activity when responding to VIGNO. Analysis of the cognitive testing of the physical activity section reveals that this framing effect is important, as respondents do not have consistent understandings of the terms “vigorous physical activities” and “moderate physical activities.” Due to this, a mode effect emerged between the self- and interviewer-administered rounds of cognitive interviewing in regards to how the respondents interpreted to these questions.

A potential new NHIS physical activity question—NEWPHYSACT—was tested in the third round of cognitive interviewing and included on the second web survey. As described below, this question would be used in place of the existing VIGNO/VIGLNGNO and MODNO/MODLNGNO series of questions. In order to eliminate any framing effects the terms “vigorous” and “moderate” provide, this question was administered as the first question in physical activity section in the third round of testing and the second web survey.

Although in the second round of RANDS NEWPHYSACT was administered before the existing NHIS physical activity questions (see Appendix B), in this report the question-by-question analysis order will be modified so that readers can understand the phenomena that VIGNO/VIGLNGNO and MODNO/MODLNGNO capture and that lead to the design on PROBE11, PROBE12, and PROBE13.

VIGNO How often do you do vigorous leisure-time physical activities for at least 10 minutes that cause heavy sweating or large increases in breathing or heart rate?

All respondents received and answered VIGNO and MODNO and understood that the basic premise of both of these questions was that they were being asked how often they do some level of physical activity. These range of activities that respondents considered as either “vigorous” or “light to moderate” broad. Table 4 shows which activities respondents counted as either vigorous or moderate across the entire cognitive sample:

Given that the question texts define vigorous and moderate exercise based on sweat and breathing rate, it is reasonable that respondents would not universally match physical activities to either vigorous or moderate levels of exercise. While a walk uphill for one respondents might cause a lot of sweating (and therefore be counted as vigorous), it might not even register as significant activity for another respondent (and either be counted as light to moderate exercise or not be counted at all). Because the National Physical Activity Guidelines are based on personal effort, this construct variability is actually a feature of this set of questions, not a flaw.

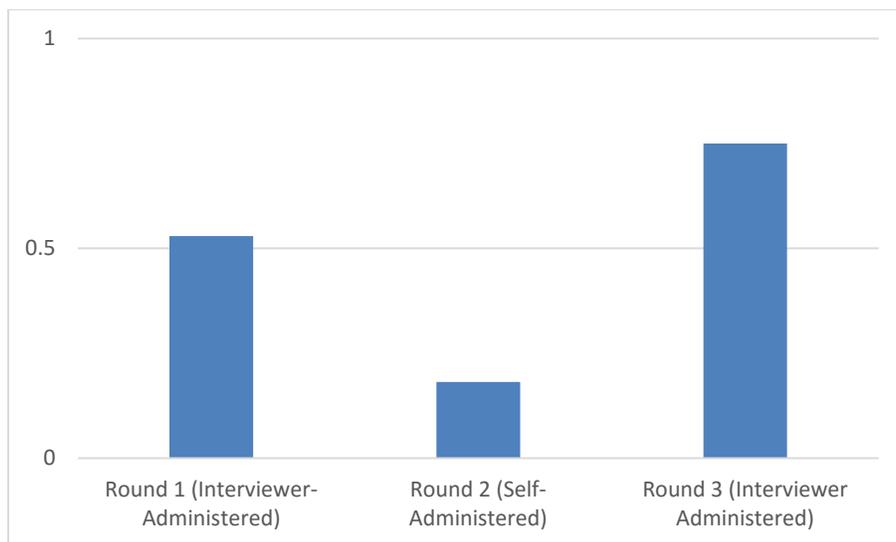
Table 4: Constructs Considered in VIGNO and MODNO

	Vigorous	Light or Moderate
Hiking	•	•
Jogging	•	•
Running	•	•
Sports	•	•
Swimming	•	•
Walking	•	•
Working Out	•	•
Cardio	•	
Cycling	•	
Dancing	•	
Chores		•
Yoga		•

However, one issue that emerged during cognitive interviewing was that many respondents “double-counted” activities as both vigorous and light to moderate. For instance, one respondent in the first round was thinking about jogging three times a week when he answered VIGNO: “Like every three days...I do some jogging around the neighborhood.” However, when he then received MODNO, he also answered “3 times a week” and reported that he was still thinking about jogging: “Yeah, jogging...again, like every three days.” When probed to see whether he considered jogging vigorous or moderate exercise, he said, “Yeah, it’s moderate I guess. I don’t get too sweaty.”

In the interviewer-administered version of this section (Rounds 1 and 3 of the cognitive testing), respondents do not know that “vigorous” physical activity should be differentiated from “moderate.” Chart 2 shows the relative proportions of this “double-counting” phenomenon across the three rounds of cognitive testing:

Chart 2: Relative Proportion of Double Counting Activities across VIGNO and MODNO



It is clear that double-counting is much more prevalent in the interviewer-administered rounds, and less so in the self-administered round. Figure 22 shows how respondents received these questions during the second round of cognitive testing.

The screenshot shows the Gallup Panel interface for the CDC/NCHS Health Research Survey. At the top, the Gallup Panel logo is displayed with the tagline "helping people be heard". Below this, the survey title "CDC/NCHS HEALTH RESEARCH SURVEY" is shown in green. The main content area contains three questions, each with a text input field and a dropdown menu for frequency. The first question asks about vigorous activities, the second about light or moderate activities, and the third about activities designed to strengthen muscles. A green "NEXT" button is located at the bottom of the question section, and a footer note reads "Do not print, store, or copy this page."

Figure 22: Screenshot of Self-Report Version of Physical Activity Section from Gallup Web Survey

By seeing that the vigorous question would be followed by one asking about light or moderate physical activity, respondents were able to tell that they should separate activities into these categories before responding to VIGNO.

VIGLNGNO About how long do you do these vigorous leisure-time physical activities each time?

VIGLNGNO, the duration follow-up question to VIGNO, was only administered in the third round of cognitive testing. This question was not systematically probed, and no cognitive findings are available.

MODNO How often do you do light or moderate leisure-time physical activities for at least 10 minutes that cause only light sweating or a slight to moderate increase in breathing or heart rate?

The cognitive findings for MODNO are described above in the analysis of VIGNO.

MODLNGNO About how long do you do these light or moderate leisure-time physical activities each time?

MODLNGNO, the duration follow-up question to MODNO, was only administered in the third round of cognitive testing. This question was not systematically probed, and no cognitive findings are available.

NEWPHYSACT The next questions are about physical activities (exercise, sports, physically active hobbies...) that you may do in your leisure time.

In the past week, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your breathing rate? This may include sports, exercise, and brisk walking or cycling for recreation or to get to and from places, but should not include housework or physical activity that may be part of your job.

The five respondents in the third round received and answered NEWPHYSACT. This question was included as a potential replacement in the NHIS for the existing multi-question physical activity series of questions including VIGNO, VIGLNGNO, MODNO, MODLNGNO, and STRNGNO (see analyses above), and has been cognitively tested previously, but in Britain¹⁴. As described below in the analyses for VIGNO and MODNO, respondents are not consistent about which activities to count as either vigorous or moderate physical activities. This “single-item” question attempts to unburden respondent from having to make this decision—therefore reducing the likelihood of measurement error.

The five respondents who received this question understood it to be asking about how many days they had completed at least 30 minutes of physical activity in the last week. One respondent, who answered “7” expressed the fact that as she was a smoker, she lost her breath very easily. Thus, she counted the moderate exercise that she got from walking her dog and from walking to and from activities towards her answer. Another respondent, who answered “2,” explained that he was only thinking about the number of days he goes to the gym per week. He said typically he goes four days a week, but he recently had colon

¹⁴ Milton, Bull, and Bauman 2010

cancer and when thinking exclusively about the past week (in opposition to his “normal” routine) he said the correct answer was “2.”

PROBE11 Which of the following types of physical activity, if any, did you include when you
PROBE12 answered the previous question?
PROBE13

1. Running
2. Jogging
3. Walking or hiking for exercise
4. Walking to or from an activity
5. Walking at work
6. Working out with exercise equipment
7. Cycling, swimming, or other aerobic exercises
8. Yoga or stretching
9. Playing sports
10. Housework or yardwork

PROBE11, which is the same question as PROBE12 and PROBE13, was designed to serve as a content probe for all three-major physical activity question sets—NEWPHYSACT, VIGNO/VIGLNGNO, and MODNO/MODLNGNO. Administering the same probe after all three question will allow for a quantitative evaluation of the different constructs the three questions capture. The answer categories for PROBE11, PROBE12, and PROBE13 were drawn directly from the analyses of the first two round of cognitive testing of VIGNO and MODNO. Initially “cycling” and “swimming” were separate answer categories, but following the first two interviews in the third round, they were condensed into a new answer category that read” cycling, swimming, or other aerobic exercises.”

Respondents all understood these probe questions to be asking them which physical activities they had counted towards the previous question, and were able to accurately match their experiences to the answer categories.

STRNGNO How often do you do leisure-time physical activities specifically designed to strengthen your muscles such as lighting weights or doing calisthenics?

All respondents received and answered STRNGNO. This question was universally understood as a specialized version of the previous physical activity frequency questions (VIGNO and MODNO) specifically asking about strength training. Most respondents considered whether or not they ever (and if so, how often) they lifted weights or did other activities that primarily targeted building muscles. Besides lifting, respondents also thought about bodyweight exercises (such as pushups, sit-ups, and squats), physical therapy, and yoga.

Alcohol Section

ALC1YR These next questions are about drinking alcoholic beverages. Included are liquor such as whiskey or gin, beer, wine, wine coolers, and any other type of alcoholic beverage.

In any one year, have you had at least 12 drinks of any type of alcoholic beverage?

1. Yes
2. No
9. Don't know

All respondents received and answered ALC1YR, which is the first question in the alcohol section on the NHIS. Most respondents understood this question to be asking whether or not they had consumed 12 or more alcoholic drinks in the past year (and not the reference period used in the question test, “in any one year”). Although they largely agreed on what the question was asking about, they employed a variety of methods to arrive at their final answers. As shown below in Figure 23, three major patterns of interpretation emerged:

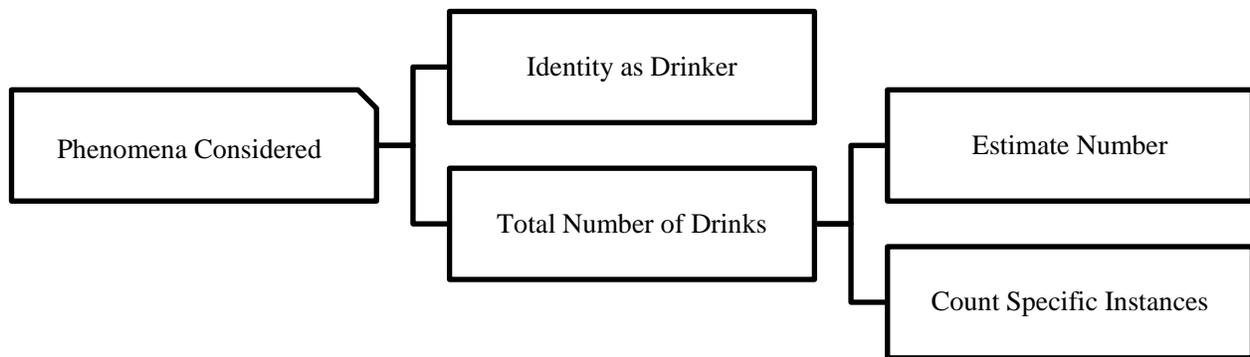


Figure 23: Response Schema for ALC1YR

Identity as a Drinker or Non-Drinker

Most respondents simply based their response on their identity as either a drinker or a non-drinker in a similar process to what was seen above in SMKEV (where respondents based their responses on whether or not they identified as either smokers or not). For instance, one respondent who answered “no” explained that she was religious and therefore wasn’t a drinker: “I don’t drink. I drink for religious observance...but I don’t drink. We have no alcohol in the house—I don’t buy it.”

Respondents who answered “yes” also employed this interpretation. For example, one young respondent explained his response by simply saying, “I’m a teen. Of course, I drink!” Likewise, another respondent noted that drinking is how he socializes: “I’m a very social drinker. So yeah, more than 12.”

Total Number of Drinks

While most respondents in the cognitive sample answered using the identity pattern of interpretation, a number of others attempted to quantify their drinking habits to make sure they were either above or below the 12-drink threshold. They went about this quantifying activity in two ways: estimating based on their

average drinking behavior or counting specific instances and trying to come up with an exact number of drinks they had consumed in the last year.

For example, one respondent who answered “no” used estimation to get at her response, noting that she had only drunk once or twice in the last year, and thus figured that she had not reached the 12-drink threshold. Similarly, another respondent who answered “yes” estimated that he had drunk enough to hit 12 drinks: “In the last 12 months, have you had 12 drinks? I drink pretty much every month—so I figure I’ve had at least one drink a month.”

Others actually thought about specific instances when they drank and tried to come up with a total number of drinks that was either above or below 12. For example, one respondent who answered ALC1YR “no” explained her response by saying that the only times she drank in the last year was when she went to parties, and she could only recall going to two parties and had two glasses of wine at each. Another respondent who answered “yes” determined her answer thinking about the number of drinks she had on her anniversary: “Yes—I drink, especially on our anniversary. I’ve had more than 12 that night!”

Reference Period

While most respondents in the cognitive sample understood ALC1YR to be asking whether or not they had had at least 12 drinks in the past year (and again, not “in any one year” as the question text specifies), a few respondents used other reference periods that correspondingly led to different interpretations. For instance, one respondent who answered “no” explained that she understood the question to be asking if she drank 12 drinks *at a time in the last year*, which she said she never does. Upon deeper probing, this respondent revealed that she had only drunk about four times in the past year, and drank about two drinks each time—so while this interpretation was out-of-scope, it did not produce a response error in this case. Another respondent who used a divergent interpretation understood the question to be asking if she had had 12 drinks *ever*, not just in the past year. When asked to explain how she arrived at her “yes” response, she said: “Scotch. I used to love it!” Following up, it emerged that this respondent had developed Celiac disease in 2012, and she reported that, “I haven’t had a drop since then.” Likewise, another respondent who answered “yes” noted upon probing that “It’s been years since I drank,” and explained that he understood the question to be asking if he had consumed 12 or more drinks *ever*. No respondents in the cognitive sample used the reference period of “in any one year”—i.e. considering any year ever, but only one year.

- ALCLIFE** In your entire life, have you had at least 12 drinks of any type of alcoholic beverage?
1. Yes
 2. No

Eleven respondents answered “no” to ALC1YR and therefore went on to receive ALCLIFE. All 11 understood that this question was asking about whether or not they had consumed at least 12 alcoholic drinks in their entire life. While these 11 respondents’ definitions of “drinks” varied (see a full accounting of the interpretation of the term “drink” below in the summary for ALCAMT starting on page 58), none of the respondents’ particular interpretations of this term in ALCLIFE led to any response errors: respondents who answered “no” all had drunk fewer than 12 “standard” (i.e. 5oz of wine, 1.5oz of liquor, or a 12oz of beer) drinks in their lives, while respondents who answered “yes” all had drunk more than 12 standard drinks. For instance, one respondent who answered “yes” explained that he used to be a regular drinker, and had “easily had more than 12 drinks in a week during some stretches [of his life].”

However, he quit drinking about five years beforehand and so answered ALC1YR “no” (incorrectly, as he used the “last year” reference period to answer the question and ALCLIFE “yes” (correctly, since he had well over 12 drinks in his entire life).

ALC12MNO In the past year, how often did you drink any type of alcoholic beverage?

Twenty-four respondents answered “yes” to ALC1YR and skipped into ALC12MNO. The response pathway for this question is very complex, and variation emerge across how the respondents approached each step in the question-response process (as depicted above in the Methods Section in Figure 1). The overall response process for ALC12MNO is illustrated in Figure 24:

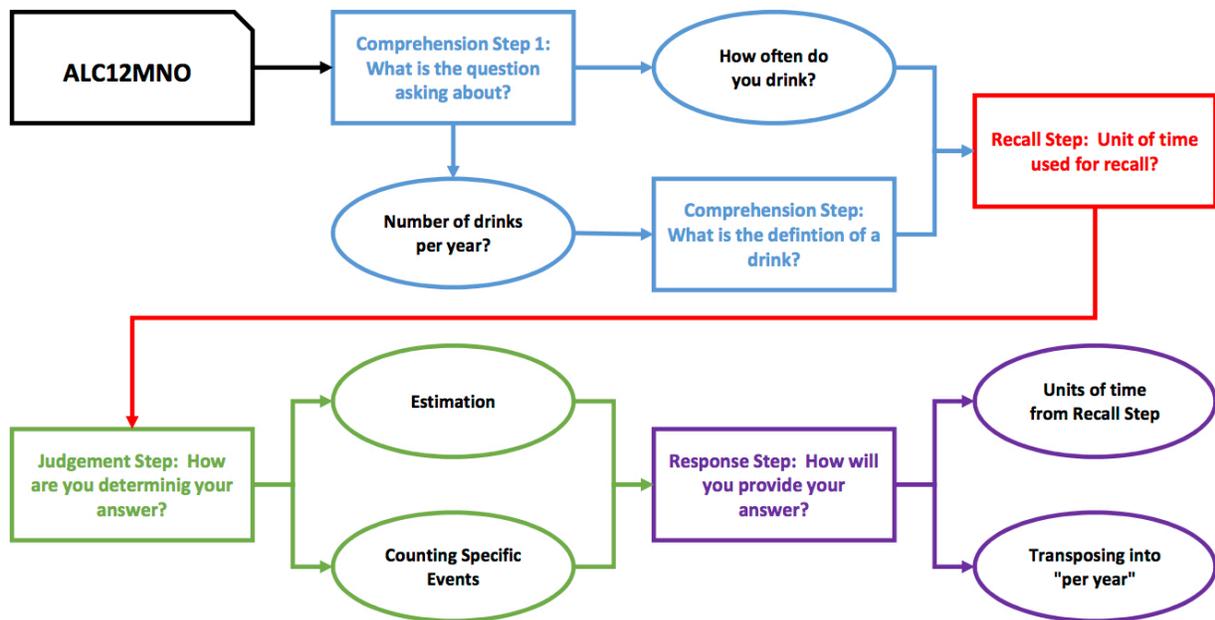


Figure 24: Response Process for ALC12MNO

Comprehension Step (Shapes Outlined in Blue in Figure 24 Above)

Frequency of Drinking

Respondents first had to decide what they thought ALC12MNO to be asking about. Most understood this question to be asking about how often they drank alcohol—that is, *how many times* they drank in the last year. For example, when probed, one respondent in the first round restated the question in her own words, saying, “How much do I drink? Maybe two or three times...I don’t drink much.”

Number of Drinks a Year

However, a few respondents instead understood this question to be asking *how many drinks* they had in the last year. For instance, one respondent in the second round calculated his answer out loud, saying, “It’s less than one a week on average—some weeks I don’t have any at all. Maybe at a party, I’ll have more.” In the end, this respondent estimated that he had about two to three *drinks* a month on average.

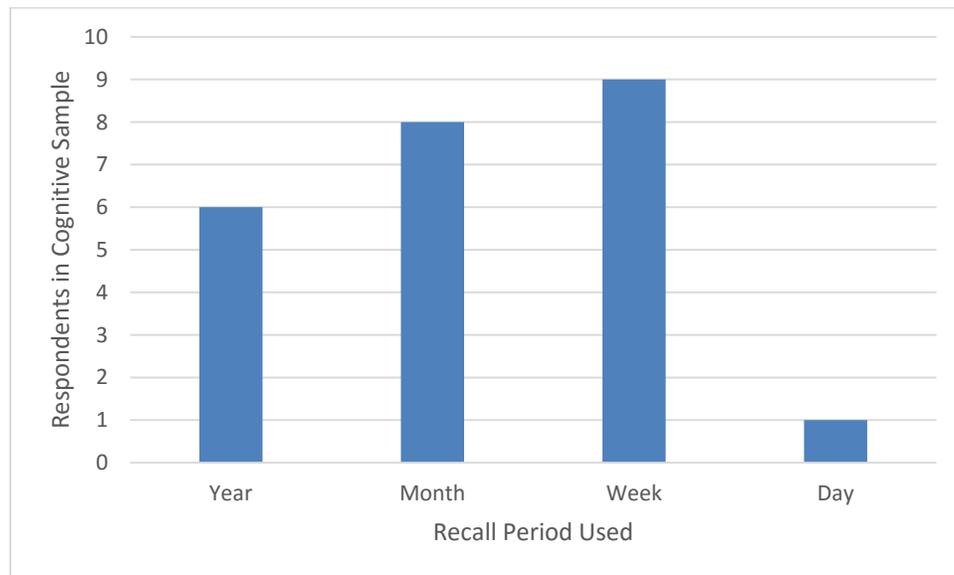
Those respondents who employed this second interpretation of the question also had an extra comprehension step: they had to define what exactly counted as a drink. For instance, the respondent who answered “2-3 per month” from above went on to say that he was thinking about a can of beer as one drink. However, another respondent who considered the number of drinks she had during the past year (and answered “4 drinks per week”) was thinking of glasses of wine she poured herself (since she was underage, and could not drink out a restaurants or bars). Likewise, a third respondents who employed this “drinks per year” pattern of interpretation (and answered “6 drinks per year”) was thinking about mixed drinks that she has at either bars or at friends’ houses—each mixed drink being one alcoholic drink in her mind for the purposes of this question, regardless of its size or alcohol content. (A further discussion of the interpretation of the term “drink” is presented below in the analysis of ALCAMT starting on Page 58)

Recall and Judgement Steps (Shapes Outlined in Red and Green in Figure 24 Above)

While distinct, the recall and judgement steps respondents used to answer ALC12MNO are related: respondents first decided which time period they would use to aid in their recall, and then within that time period quantified the number of times they drank by either counting specific instance or coming up with an estimate based on their normative behavior.

When attempting to recall the number of times (or number of drinks) they drank in the previous year, most respondents did not actually consider the full year. Rather, most thought about a shorter time period and either estimated or counted the number of times they drank (or number of drinks they had) in that timeframe. Chart 3 shows the distribution of the time periods that respondents used across the cognitive sample during the recall phase of response:

Chart 3: Number of Cognitive Respondents Using Each Recall Period for ALC12MNO (n=24)



Within each of these recall periods, respondents then decided how to judge his or her answer. As seen previously in ALC1YR, respondents quantified their response either by counting specific instances of drinking in that period, or by estimating their normative behavior over that period. For instance, one respondent who was thinking about a month recall period judged his answer by estimating, explaining:

For me, it just depends on the occasion. But I know like [on average] monthly—‘cause I didn’t drink every week, I know that! Not every week, but I was think I’d say 2-4 times a month, but for me, it’s hard. So, I’d just put a range down.

In contrast to this, another respondent (who used a week as her recall period) counted the drinks she had in that period: “I guess when you think back you might not be able to remember all the drinks you have in a year. But I remember that I drank 5 last week.”

Response Step (Shapes Outlined in Purple in Figure 24 Above)

In the response step of the ALC12MNO response process, respondents determined how to report the answer they came up with following the recall and judgement phases. On the NHIS (and Rounds 1 and 3 of this cognitive testing project) the response was completely opened-ended, with respondents able to use any unit of frequency they want to answer the question. In the self-report version of this question, respondents were only slightly confined in their answer choices—they were presented with a blank numeric field and then a pull-down menu showing the available units of frequency (times per day, per week, per month, or per year) as seen in the screenshot below in Figure 25:

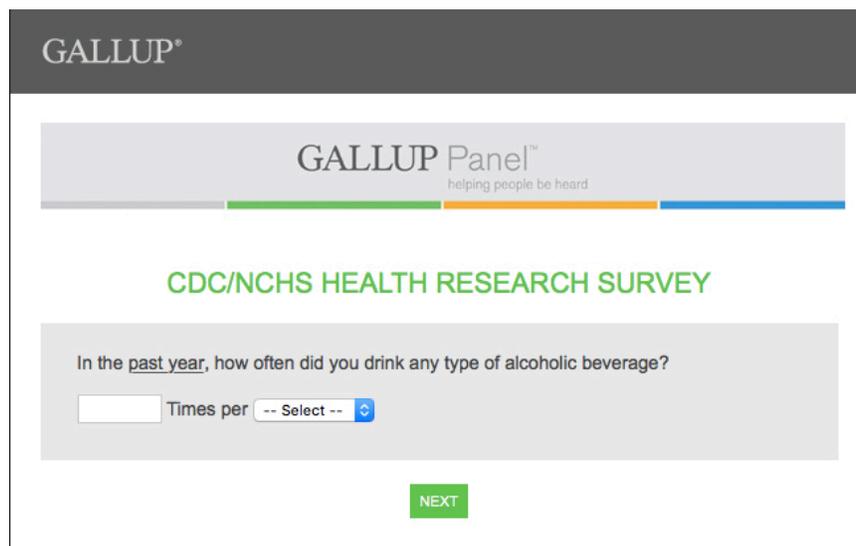


Figure 25: Screenshot of Self-Report Version of ALC12MNO from Gallup Web Survey

Most respondents reported their response in the same units of frequency that they used during the recall and judgement steps. So, for instance, a respondent who estimated her answer based on the number of times she drank in a typical week would then go on and provide a response to ALC12MNO using “per week” as her unit of frequency.

On the other hand, while the question text did not ask the respondents to report their answer in terms of times per year, a number of them believed that was what was being requested, and correspondingly transposed their original response into a “times per year” frequency. Most respondents who did this simply multiplied their response by the number of days, weeks, or months in a year to arrive at their final, reported answer. For example, one respondents who said he drank once a month simply multiplied that by 12 to get a final answer of “12 times a year.” However, other respondents who attempted to transpose their responses did not simply multiple their original response by either 365, 52, or 12. Rather, they multiplied *and then* added or subtracted times (or drinks) in an attempt to make this average better fit their actual drinking habits. For instance, one respondent who answered “50 times a year” explained that she was originally thinking about drinking once a week, but noted that she probably did go a couple of weeks across the year where she did not drink at all, and therefore reported less than “52 times a year.” Likewise, another respondent who was originally thinking that he drinks everyday gave a final response of “200 times a year,” noting that he was sure he didn’t actually drink each and every day. He then went

on to guess a number that was lower than 365 times a year, but higher than every other day (180 times a year).

ALCAMT On those days that you drank alcoholic beverages in the past year, how many drinks did you have on the average?

The twenty-four respondents who received ALC12MNO went on to receive and answer ALCAMT. While in the question text, ALCAMT asks for an average number of drinks the respondent typically consumes in a sitting, not all understood it that way. Additionally, variation over what counted as a “drink” emerged, and respondents used different strategies when deciding what to report as their final answer.

Question Comprehension

Overall, respondents understood this question in a variety of ways, as shown below in Figure 26:

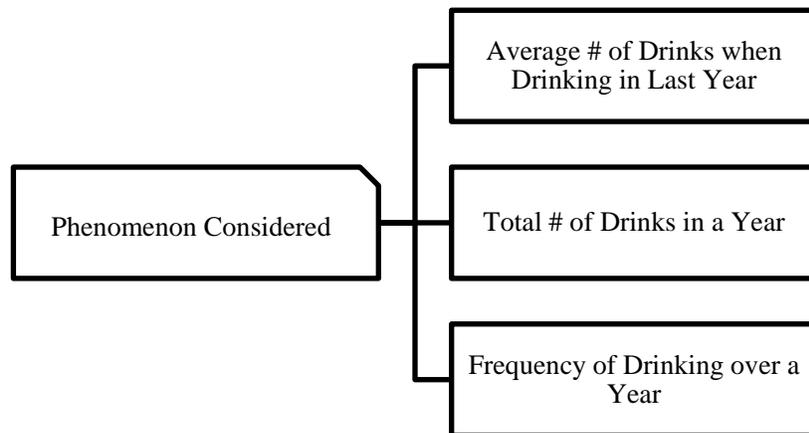


Figure 26: Patterns of Interpretation of ALCAMT

Average Number of Drinks in Year

Most understood ALCAMT as intended by the question text—that they were being asked the average number of drinks they typically had when they drank. For example, one respondent who reported her answer as “1” noted that, “I’ll usually have a single glass of wine” and that this was fairly consistent behavior on her part.

Total Number of Drinks in Year

However, a couple of other interpretations emerged as well from respondents who appeared flustered by the question text. All of the respondents who applied these alternative patterns had less than college levels of educational attainment, and the relatively convoluted question text (“On those days that you drank...how many drinks did you have on the average?”) appeared to confuse them. A couple of respondents thought that the question was asking them the *total number of drinks* they had in the last year. For instance, one respondent who answered “2” explained that he had drunk twice in the year, and “I had only one drink each time—so two total.”

Frequency of Drinking in Year

Other respondents understood this question to be more or less asking the same thing as the previous question (ALC12MNO)—their drinking frequency. One respondent who answered “6 drinks a month” asked for the question to be repeated twice and then said:

How come they don't ask me by the week or the month, instead of by the year? That's too general. Now, if you break it down into a week or month, that's more specific...I'm gonna say maybe six drinks a month. Sometimes in the month it might vary. It's hard to determine for the year. To try and calculate that by the year: it's impractical.

This respondent appeared to be trying to calculate a total number of drinks for the year, but gave up and just gave a drinking frequency instead. Likewise, another respondent (who answered the question “50” started trying to count her total number of drinks, but ended up giving a frequency instead because she found the calculation too difficult:

Six-pack times four [weeks in a month] equals 24...12 months in a year. Wait. 12 months times four Saturdays equals 48. Plus, two for months that have five Saturdays equals 50. So, 50 times a year.

Comprehension and Judgement of “Drinks”

Respondents did not have uniform definitions of a “drink.” In this question, some respondents considered “standard” drinks (such as cans or bottles of beer, or glasses of wine or mixed drinks purchased from a restaurant or bar); others considered “non-standard” drinks (such as drinks poured or prepared at home, or non-standard size servings such as tall-boy cans of beer or entire bottles of liquor), while others considered *both* standard and non-standard servings when judging their answer.

Standard Drink Sizes

Respondents using standard measures (i.e. 5oz of wine, 1.5oz of liquor, or a 12oz of beer) were typically thinking about drinking at bars or restaurants. For example, one respondent who reported drinking “1” drink on average explained that she was thinking of glasses of wine that she gets at restaurants: “One glass probably. Maybe two...Typically I'll order a glass of red or a glass of white wine.” Likewise, another respondent (who answered “1 or 2”) was thinking about how much he typically drinks at a bar when he's watching sports and playing pool with friends on the weekend: “I got some buddies I shoot pool with on Sundays. I may have a beer and a [mixed] drink while I'm down there [at the sports bar].” Besides drinking at restaurants and bars, the other respondents who used standard drink sizes were those thinking of drinking beer—which typically comes in standard-sized bottles or cans. For instance, one person who answered “2” explained “I'll have two beers if I'm going out.” and noted upon probing that he was thinking about bottles of Budweiser.

Non-Standard Drink Sizes

Other respondents thought about “a drink” in less standardized ways. Typically, this emerged as people thought about pouring or mixing their own wine or liquor drinks at home or at friends' houses. These respondents did not consider drinks in terms of the equivalent of one shot of liquor or 5 oz. of wine (the standard serving sizes of each), but rather a discrete glass or serving of an alcoholic drink—regardless of its size or alcohol content. For example, one respondent who answered “2” explained what he was thinking, saying: “I'll split a bottle of wine with my wife on Friday, Saturday, and Sunday. I'll get two glasses of wine from that.” Since a 750ml bottle has about 25oz. of wine, this respondent's “2 glasses” are in reality more than 2 *servings* of wine. Nonetheless, he counted each pour as a single “drink.”

This issue was particularly pronounced when respondents considered liquor and mixed drinks—especially because people noted that they often mix different liquors together, and use different amounts—depending on their mood and supply. One respondent who noted that the number of drinks that he gets out of his weekly half-pint of liquor varies, simply answered “1,” and explained that he was counting the bottle as a single drink.

A few respondents explicitly noted that they were not using a uniform serving size when judging their response because of the difficulty of reporting across different types of alcohols and drinks. One respondent who answered “1 to 2” stated this clearly, saying:

I just count it [a drink] as the glass. So, we had a wedding in December and I had one glass of Champagne. And at our wedding I had like two drinks. But I guess they were different because one was a margarita and the other was a glass of wine. But I was just counting each as “cups.

Response

Once respondents had determined their average number of drinks, they had to decide how to report their answer. In the interviewer-administered Rounds 1 and 3 (and in the NHIS itself), the respondents have the ability to answer whatever they want—including both ranges and single “point estimates.” However, in the self-report Round 2 (and on the production RANDS web survey), the respondents were presented with a blank *numeric-only* field (Figure 27 below), that only accepted numbers between 0 and 99—thus limiting respondents to solitary point estimates, and not allowing ranges.

The screenshot shows a survey interface. At the top, it says "GALLUP Panel™ helping people be heard". Below that, in green text, is "CDC/NCHS HEALTH RESEARCH SURVEY". The main question is: "On those days that you drank alcoholic beverages in the past year, how many drinks did you have on the average?". There is a white text input field below the question. At the bottom center, there is a green button with the word "NEXT" in white capital letters.

Figure 27: Screenshot of Self-Report Version of ALCAMT from Gallup Web Survey

Overall, respondents appeared to primarily judge their average drinks as ranges and then decided to report them as is or as a single estimate. Two strategies emerged in how respondents made (or had no other option in the case of the self-report version) this range-to-estimate translation. Some respondents took the mathematic mean or median of their range and reported that (as a rounded figure if necessary—no respondents in the cognitive sample tried to report anything other than a whole number). For instance, one respondent who answered “2” explained that she thought she typically drank between one and three drinks when she went to bars, and decided to report the number in the middle of that range.

Others reported either the upper or lower limits of their range, explained that they believed it to be more representative of their reality. For example, one respondent in the second round said he typically drank

six to seven beers at a time, but explained that “I’ll say seven. I drink liquor too, but it’s hard to count liquor because I drink it out of the bottle, so I’ll put seven.”

- PROBE14** When answering the previous questions, what did you count as a drink?
1. A can or bottle of beer or malt liquor
 2. A glass of wine or shot of liquor
 3. A bottle of wine or liquor
 4. A drink you purchased from a restaurant or bar
 5. A drink you made or poured for yourself

PROBE14 was designed as a content probe, specifically to look at the patterns of comprehension surrounding the term “drink” as a unit of measurement in ALCAMT. AS described above in the analysis of ALCAMT (and seen prior to that in one of the minor interpretations of ALC12MNO), respondents do not have or use a uniform definition of “a drink.” Some respondents think of drinks in standard serving sizes (i.e. bottles or cans of beer, or drinks prepared in standard sizes at bars or restaurants), while others counted non-standard serving sizes such as home pours of wine or liquor or uncommon sizes of alcoholic drinks (such as 24oz. cans of beer or full bottles of liquor). PROBE14 was designed to quantify how respondents apply these various definitions, and its answer categories come directly from the probing of ALC12MNO, ALCAMT, ALC5UPNO, and BINGE.

This question was administered to all five respondents in Round Three. The first two respondents in this round received the initial version of this question, which had a different question stem and a different set of answer categories than the final version shown above:

When answering the previous questions, which of the following, if any, did you count?

1. The number of cans or bottles of beer or malt liquor, glasses of wine, or shots of liquor
2. The number of bottles of wine or bottles of liquor
3. The number of drinks you purchased from a restaurant or bar
4. The number of drinks you made or poured for yourself

Both respondents who received this version of the question understood it to be asking them to break down their responses to ALCAMT into the four categories. For example, one respondent gave the average number of drinks of each category she would typically consume, and explained her thinking by saying: “At one time I can have 3 shots or 1 bottle of wine, which is unlimited pours. Because it’s my bottle—I am the bottle holder!”

Based on this feedback, the question was altered to emphasize the fact that the respondents were being asked to explain what they counted as “a drink.” The final version was tested on the last three respondents in the third round, and they all understood the question as intended and were able to map their responses to the five answer categories.

ALC5UPNO In the past year, on how many days did you have [4 for female respondents; 5 for male respondents] or more drinks of any alcoholic beverage?

The same 24 respondents who answered ALCAMT also received and answered ALC5UPNO, and all understood the question to be asking them the number of days they had either four (for women) or five (for men) drinks in a single day in the last year. However, variation emerged in both how respondents comprehended “drinks” and how they judged the number of days they consumed alcohol at or above the threshold.

Comprehension of “Drinks”

Just as seen with the previous alcohol questions that have asked about (or caused respondents to think about) drinks as a unit of measurement, there was no uniform understanding of what counted as “a drink.” Respondents generally carried the interpretations they used in ALCAMT (or, in the case the five Round Three respondents, PROBE14) forward into ALC5UPNO. So, for instance, one respondent who thought about a drink as a can of beer in ALCAMT thought about the number of days he had five or more cans of beer in this question. However, carrying forward these interpretations led to clear response errors in some cases. For example, the respondent who counted one half-pint of liquor as “1 drink” in ALCAMT carried this definition forward and answered “0” to ALC5UPNO, since he only drank a *single* half-pint of liquor a day.

A more detailed analysis of the issue surrounding the use of “drinks” as a standard unit of measurement is presented above in the analyses of ALCAMT (page 58) and PROBE14 (page 61).

Judgement of Number of Days

When judging the number of days, they had drunk at or above the four- or five-drink threshold, respondents appeared to use one of three separate patterns of judgement. As seen below in Figure 28 (which also shows the survey responses each pattern of interpretation produced in the ovals to the right), respondents used one of three separate patterns of interpretation when calculating their answer:

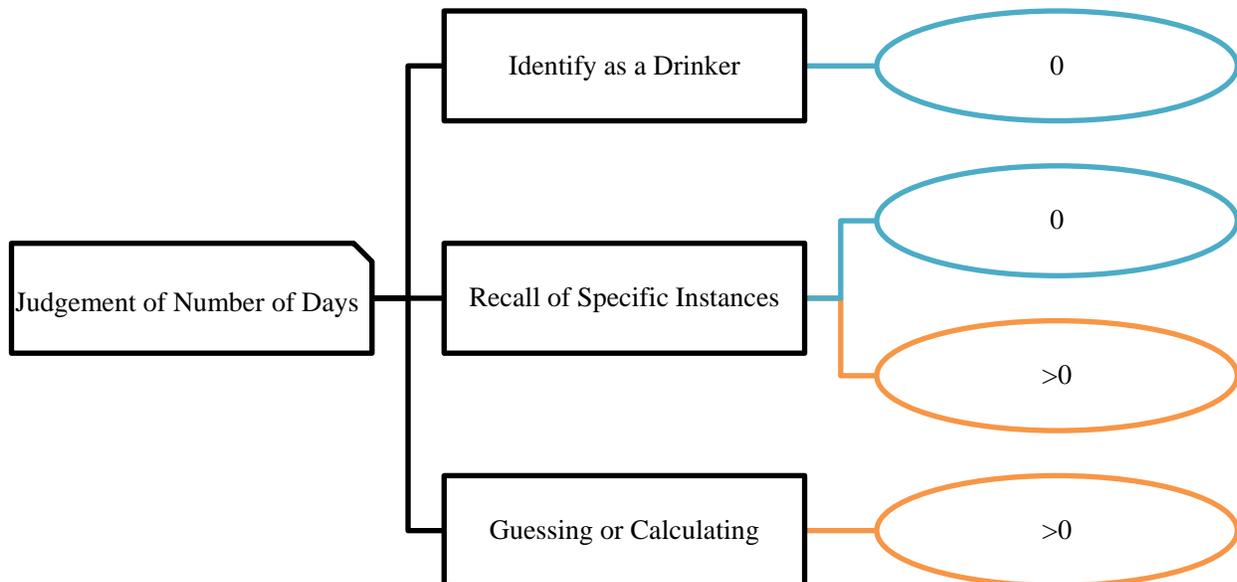


Figure 28: Cognitive Schema, and Associated Survey Responses, for ALC5UPNO

Identify as Drinker or Non-Drinker

Respondents using the first pattern of judgement—thinking about whether or not they identify as a drinker—all answered ALC5UPNO “0.” These respondents basically used a heuristic to answer this question—reasoning that since they were not prone to drinking large amounts of alcohol, they therefore never had more than four or five drinks in a single day. For example, one respondent who used this pattern explained her “0” answer by saying, “That’s [four drinks] too much! That means you’re an alcoholic [if you drink that much].” Since she wasn’t an alcoholic, and only alcoholics drank that much, it stood to reason in her mind that she never hit the four-drink threshold.

Recall of Specific Instances of Binge Drinking

The other two patterns of judgement are similar to what emerged in both ALC12MNO and ALCAMT. Some respondents attempted to recall and count the specific instances when they drank at or above the four- or five-drink threshold. For instance, one respondent who answered “2” said, “Just New Years and Cinco de Mayo,” while another who also answered “2” explained that she only drank that much at the two weddings that she attended in the last year.

Estimate Based on Normal Behavior

Other respondents simply guessed or calculated an estimate based on their normative behavior. For example, one respondent who answered “1” could not think of a specific instance, but instead assumed that it must have happened at some point in the last year:

I’m usually done by then! It’d have to be a special occasion—I’d say once. I can’t say exactly when, but I don’t want to lie...I’m just assuming, because I probably did!

Another respondent answered “48” and explained that she drinks six beers each Saturday, and calculated that since there are four Saturdays in a month, and 12 months in a year, her answer must be “48.”

BINGE Considering all types of alcoholic beverages, during the past 30 days, how many times did you have [4 for female respondents, 5 for male respondents] or more drinks on an occasion?

The same respondents who received ALC5UPNO went on to receive and answer BINGE. This question is intended to be understood as different from the previous question (ALC5UPNO, about the number of days the respondent drank above a sex-based threshold in the past year) in two ways. First, the reference period in BINGE is “the past 30 days,” instead of “the past year” in ALC5UPNO. Second, BINGE asks about the number of drinks consumed on an “occasion,” while ALC5UPNO asks about the number of “days.” In general, respondents understood the first difference and ignored the latter one, in effect understanding the question to be asking, “In the past 30 days, how many times did you drink four/five or more drinks?”

“Occasion” is supposed to signify an event that occurs over about two hours—so a single day of drinking could, in theory, contain multiple “occasions.” Respondents *did not* divide their drinking in this manner. For instance, one respondent who noted that she drinks a six-pack of beer each Saturday answered “4.” When asked to explain what she was thinking about, she said, “there are four Saturdays in each month.” Further probing revealed that she did not always drink all six of these beers in a single sitting; however,

since she interpreted “day” and “occasion” to be congruent units of time, her answer did not take this into account.

Respondents used the same patterns of judgement in BINGE that they did in ALC5UPNO (see Figure 28 above). See the analysis of the previous question for more detail.

- PROBE15** Thinking about the typical occasion when you drank [4 for female respondents, 5 for male respondents] or more drinks, what is the average amount of time it took you to consume your drinks?
1. Less than 2 hours
 2. 2 hours to less than 12 hours
 3. 12 hours to less than 24 hours
 4. 24 hours (one day) or more

PROBE15 was designed as a content probe of BINGE, in an effort to better understand and quantify the length of the “occasions” that respondents considered. As noted above in the analysis of BINGE, while the term “occasion” was intended to be interpreted as a period of about two hours, respondents in the cognitive sample did not interpret it this way.

PROBE15 was administered to the five respondents in the third round of cognitive testing. These respondents interpreted the question to be asking about how long the drinking sessions they counted in BINGE lasted on average. For instance, one respondent explained that the question was asking “How long do I usually drink for?” They were all able to map their responds to the four answer categories.

Obesity Section

AHGT_FT How tall are you without shoes?

AWGT_LB How much do you weigh without shoes?

Neither AHGT_FT nor AWGT_LB were probed during the cognitive interviews, and no findings for either question are available.

Access to Healthcare and Utilization Section

AHCDLY_1 There are many reasons people delay getting medical care. Have you delayed getting care for any of the following reasons in the past 12 months?

You couldn't get through on the telephone.

1. Yes
2. No

AHCDLY_2 You couldn't get an appointment soon enough.

1. Yes
2. No

AHCDLY_3 Once you get there, you have to wait too long to see the doctor.

1. Yes
2. No

AHCDLY_4 The clinic or doctor's office wasn't open when you could get there.

1. Yes
2. No

AHCDLY_5 You didn't have transportation

1. Yes
2. No

All respondents across all three rounds of cognitive testing received and answered the five questions in the AHCDLY series, which asks about potential reasons people may have “delayed getting care” in the past year. All five of these questions were probed together, retrospectively after the full series was administered. Respondents all understood that the questions were asking them whether or not they had to delay or put off getting healthcare because of the five potential impediments presented in AHCDLY_1 through AHCDLY_5.

While respondents certainly conceptualized each of the five potential reasons for delay in a variety of ways, consistent variation emerged across all five questions in the set in regards to how the respondents actually judged what counted as “delayed getting care.” For instance, in AHCDLY_1 (asking about difficulty getting in touch with a doctor's office over the phone), one respondent who answered “yes” explained that she thought about how she was put on hold for about 30 minutes. This respondent said that when this happens, she'll usually just hang up and try again until she gets through. However, another respondent who answered “no” was also thinking about being put on hold. He explained that eventually he would get through to the office, so that did not count as delayed care.

This variation was even more pronounced in AHCDLY_3, which asks about having too long a wait at the doctor's office itself. Some respondents answered “yes” only thinking about having to wait so long that they gave up and left. For instance, one respondent who answered “yes” had to wait so long at the emergency room that she simply gave up and went home:

I was just sitting there for five hours! I was miserable—there was no place to lie down, just sit. I just gave up and went home.

Others judged that long (or uncomfortable) delays merited a “yes” response, even if they did not give up did eventually receive care. For example, one respondent who answered “yes” noted, “I had to wait 30 or 40 minutes! They were just running behind schedule.” Further probing revealed that she still saw the doctor that visit.

AHCAFY_1 During the past 12 months, was there any time when you needed any of the following, but didn’t get it because you couldn’t afford it?

Prescription medicines.

1. Yes
2. No

AHCAFY_2 Mental health care or counseling

1. Yes
2. No

AHCAFY_3 Dental care (including checkups)

1. Yes
2. No

AHCAFY_4 Eyeglasses

1. Yes
2. No

AHCAFY_5 To see a specialist

1. Yes
2. No

AHCAFY_6 Follow-up care

1. Yes
2. No

All respondents received and answered the six questions in the AHCAFY series, which were probed together, retrospectively after the entire series was administered. This series of questions was generally understood to be asking about whether or not the respondent had financial issues that prevented them from obtaining care in the six domains under question (prescription medicine, mental healthcare, dental care, eyeglasses, specialist care, and follow-up care). However, significant variation emerged across the entire six-question set about what constituted the ability to afford care. Two major patterns of interpretation emerged, as shown below in Figure 29:

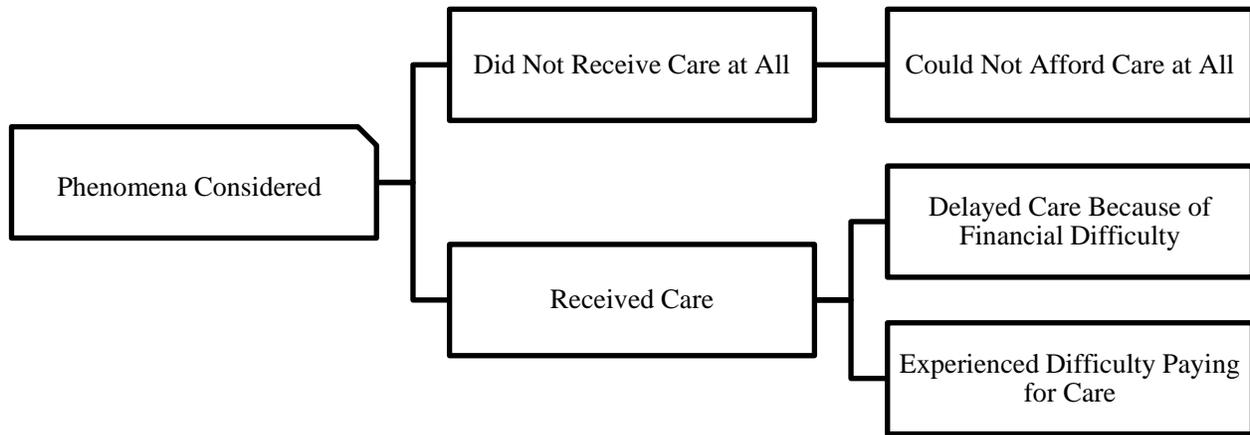


Figure 29: Cognitive Schema for the AHCAFY Series

Most respondents understood the questions to be asking whether or not they could not afford any of the specified care *at all*. For example, one respondent who answered “no” to _1 explained that he had to tap into his emergency fund in order to pay for an expensive medicine that was not covered by his insurance, but since he still got the medicine decided that the best answer was “no.” In a similar way, this same respondent then answered “yes” to the dental care question (AHCDLY_3), saying “I just couldn’t afford that. I had to get the medicine, so I didn’t get to the dentist last year.” Another R answered “yes” to AHCAFY_1 explaining that “My orthopedist proscribed me foot cream, but I didn’t ask for the generic version. So even with insurance, the cream came to \$790. I just decided to not get it.”

However, other respondents based their answers on their perceived difficulties affording the various types of care, regardless of *whether or not they actually got care in the end*. Respondents considering financial difficulties employed two separate patterns of interpretation. The first group considered whether or not financial hardships made the *delay in care*. For example, one respondent who answered “yes” to AHCAFY_1 explained that when she changed insurance companies, she had to change doctors and had to schedule a first-time visit with her new psychiatrist in order to refill a prescription. She had to wait until she had the money to afford both the visit and the prescription, and thus had to delay her refill by a few weeks. Likewise, another respondent who answered “yes” to ACHAFY_3 said, “When I got this job, my insurance didn’t turn over right away. It was time to go to my dentist, but I had to wait until the new insurance kicked in. I already had one visit this year, so I wasn’t too rushed, but I did have to put it off.”

A few other respondents were even broader in their interpretation of affordability, thinking about whether or not they had any financial hardships due to the *need for care*. For instance, one respondent answered AHCAFY_3 “yes,” explaining that “dentures are really expensive, and most of the cost isn’t covered by my insurance.” Upon probing, he noted that he still got the dentures when he needed them, he just had to shift money around and could not splurge on luxuries for a while. Similarly, another respondent answered “yes” to AHCAFY_4 and said, “My glasses were really expensive. Even with insurance, they cost a lot.” Again, upon probing this respondent revealed that she still purchased the glasses, but it cut into her savings to do so.

Health Information Technology Section

HIT1A During the past 12 months, have you ever used computers to do any of the following?

Look up health information on the Internet

1. Yes
2. No

HIT3A Schedule an appointment with a health care provider

1. Yes
2. No

All respondents across all three rounds received HIT1A and HIT3A. These questions were not probed systematically, and no findings are available

Affect Section (K6 Scale)

The six NHIS questions in this section (ACISAD, ACINERV, ACIRSTLS, ACIHOPLS, ACIEFFRT, and ACIWTHLS) together form the “K6” scale, which is a derivation of the longer, 10-item Kessler Psychological Distress Scale (K10). NCHS supported the development of the K6 scale, which was designed to be able to differentiate between respondents with severe mental illnesses and those without severe mental illnesses¹⁵.

Please note that the respondents in Rounds 1 and 3 were all read the preamble (“During the past 30 days, how often did you feel”) for the first question—ACISAD. For the remaining questions in the scale, the preamble was only read if the respondent asked for the question to be repeated or if the interviewer felt that the respondent needed the question to be re-framed. Respondents in the self-administered Round 2, all six items in the scale were presented on one screen, with the preamble at the top (as seen below in Figure 30):

¹⁵ See Kessler et al 2003

During the past 30 days, how often did you feel...

So sad that nothing could cheer you up?

All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

Nervous?

All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

Restless or fidgety?

All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

Hopeless?

All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

That everything was an effort?

All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

Worthless?

All of the time
 Most of the time
 Some of the time
 A little of the time
 None of the time

NEXT

Figure 30: Screenshot of the K6 Scale used in the Self-Administered Round 2

ACISAD During the past 30 days, how often did you feel...

So, sad that nothing could cheer you up?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

All 35 respondents received and answered ACISAD and generally understood the question to be asking them how frequently they felt sad. Variation emerged, however, in how the respondents comprehended the question’s key construct, the term “so sad that nothing could cheer you up.”

Comprehension

Respondents comprehended the term “so sad that nothing could cheer you up” using one of five patterns of interpretation, shown below in Figure 31:

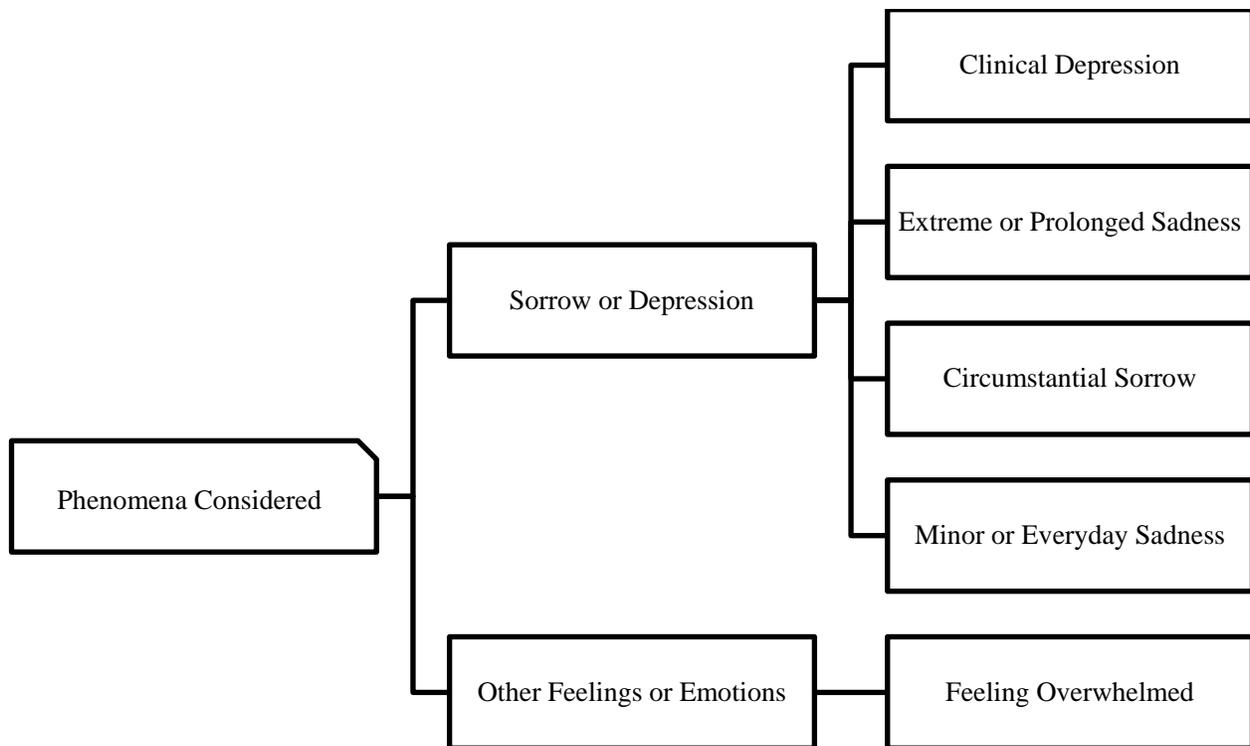


Figure 31: Cognitive Schema for ACISAD

Sorrow or Depression

Most respondents thought about some level of sorrow or depression—ranging from clinically diagnosed depression, through extreme sadness or non-diagnosed depression and circumstantial sorrow, to minor, everyday feelings of sadness.

Respondents who interpreted this key construct as clinical depression strictly considered whether or not they had been diagnosed with depression. In many cases, this was a relatively straightforward decision. For example, one respondent who answered “None of the time” said, “No—a doctors never told me that I’m depressed. So never.” Likewise, another respondent who answered “Some of the time” explained that she has been diagnosed with bipolar disease, and thus is depressed sometimes (and manic other times).

However, other respondents who struggled with this clinical definition of sadness appeared to be caught between what they believed the question to be asking about (clinical depression) and being able to express their lived experiences. For instance, one respondent who eventually decided to answer “None of the time” had a hard time determining if she should include some traumatic circumstances that she had gone through recently:

It’s about someone who is depressed—depressed status. I was really sad, sad for real, when one of my patients passed. Sad for real is different than just saying, “That’s sad”—you know, a throw-away line. I was sad for real. But I guess it isn’t the same as this, so none [of the time].

Other respondents did not limit their interpretations to clinical depression, but instead considered other levels of sadness, ranging from extreme sorrow and (undiagnosed) depression to momentary bouts of everyday sadness. For example, one respondent was thinking about being chronically and extremely sad when she answered “None of the time,” and expressed that she was thinking that her sadness never

reached the point of being, “a depressed state—a debilitating state.” Similarly, another person who answered “None of the time” explained what he was considering by saying, “It’s so sad over a long period of time. Really sad, maybe for a week or longer. It’s not just being sad for a day.”

Quite a few respondents considered extreme bouts of acute sadness—feeling really sad during (or due to) an event, but then getting over it when the event concluded. For instance, one respondents who answered “Some of the time” was thinking about financial issues when answering, and explained, “You’re depressed...it’s some [of the] time, because it depends on the circumstances I’m in at the time. Like not being financially [well-off] the way I want.” This individual went on to explain that when he got paid, this feeling went away. Another respondent who answered “All of the time” expressed a similar understanding, when she noted that she was particularly sad at the moment because of a number of circumstances in her recent life, but that she normally was not this sad:

My boyfriend was killed in September, and my mom is having dialysis now. I’ve not always been a happy person—I’ve had struggles before, but it’s much much harder now.

Other respondents defined “so sad that nothing could cheer you up” as just “being sad,” and not only counted bouts of extreme sadness, but quotidian sadness as well. For example, one respondent who answered “A little of the time” explained his reasoning by saying:

Sometimes you have a bad day, you know? If somebody dropped a million bucks, I’d get cheered up! There’s always something that could cheer me up, but it just usually doesn’t happen like that. So, I have a bad day.

This phenomenon—where some respondents include low-levels of everyday sadness into their answers to questions that, on their face at least, appear to be asking about more severe emotions—is not uncommon. Previous work by NCHS on the Washington Group for Disability Statistics Child Functioning Module also noted this pattern of interpretation¹⁶.

Other Feelings or Emotions

Finally, a few respondents defined this key construct in more holistic terms, and appeared to be considering their general levels of stress and well-being instead of sorrow or depression specifically. For instance, one respondent who answered “Some of the time” was thinking about being overwhelmed by life:

It’s because my kids are out of state, and I’m thinking about them and want to be down with them and see them, but it’s hard for me to get down there. You got the weight of the world on your shoulders—it’s hard.

Another respondent used almost identical language when explaining his “A little of the time” response: “[Thinking about] the pressures of life—they seem to come down of you—the weight of the world. It can overwhelm you sometimes.”

¹⁶ See Massey et al 2014; Massey et al 2015; Scanlon, Miller, and Massey (Forthcoming)

ACINERV During the past 30 days, how often did you feel...

Nervous?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

All respondents received ACINERV. While respondents all understood the question to be asking them how often they were nervous, they did not all interpret the key construct of “nervous” the same way. Overall, three major patterns of interpretation emerged (shown below in Figure 32), all of which were distributed relatively evenly across the cognitive sample.

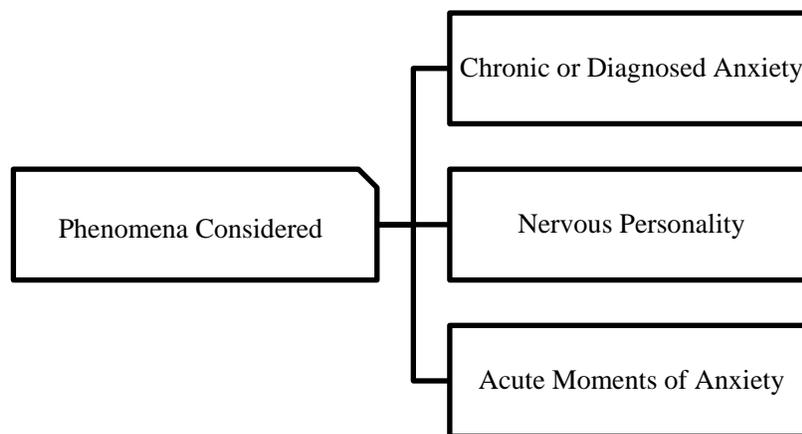


Figure 32: Cognitive Schema for ACINERV

Chronic or Diagnosed Anxiety

Some respondents limited their definition of “nervous” to chronic or diagnosed severe anxiety. These respondents thought about nervousness as a debilitating condition that limits people’s abilities to everyday things. One respondent who employed this pattern and answered “a little” was basing her answer on the fact that she had childhood trauma, and was diagnosed with anxiety and other PTSD symptoms:

They [the symptoms] kinda went away and then reappeared and led to really severe anxiety. But I think slowly over time it’s getting a bit better.

When asked what frequency this anxiety occurred at that led to answer “a little,” she said, “an hour to two hours a day,” noting that this is much less than it was a few years ago.

As was the case with respondents who thought about diagnosed depression in ACISAD, respondents who did not have diagnosed or chronic anxiety, but were defining “nervous” this way in ACINERV, treated the question like a binary “yes” or “no” one. For instance, one respondent who answered “none of the time” understood this answer to be the equivalent of “no” and explained, “I was thinking about panic attacks and severe anxiety—it’s a serious clinical condition and my husband’s been diagnosed. But I haven’t been.”

Nervous Personality

Other respondents conceptualized “nervous” not as a chronic condition *per se*, but rather as a personality trait. These respondents based their answer on whether or not they considered themselves to be a nervous person, and if so, how often it *affected* their social interactions or life. For instance, one respondent who answered “none” explained that she was not thinking of any sort of diagnosed condition when answering, but rather “about someone who is more apprehensive [than most].” She said she wasn’t a very apprehensive person and thus answered “none of the time.”

On the other hand, respondents who did think of themselves as nervous people also had to judge their response and map it to one of the affirmative answer categories. To do this, most considered how prone they were to moments of panic, apprehensiveness, or “the jitters.” For example, one respondent who answered “a little” explained her reasoning by saying:

It’s like a roller coaster and I say [to myself]: “Please don’t let this happen!” Sometimes I’m worried, most of the time I’m not. Like with my husband. He’s really prickly, and sometimes I worry about setting him off.

Another respondent answered “Some of the time” and was thinking about a general sense of unease he gets from world news. This respondent explained that he’s a Muslim, and sometimes he gets really nervous “because of what’s going on around the world—because of my religion.” Likewise, another respondent who answered “Some of the time” was thinking about how he has a constant sense of anxiety, but it only peaks in certain situations, like trying to talk to girls in public.

Acute Moments of Anxiety

Finally, the third pattern of interpretation of “nervous” that emerged was to consider the frequency of nerve-wracking situations, such as job interviews or having to speak publically. The respondents who employed this pattern did not think of themselves as nervous people, but instead saw nervousness as a natural response that happens in stressful situations. For instance, one respondent was thinking about a job interview when she answered “a little,” saying she was considering “just regular, nervous feelings.”

A few respondents even appeared to consider nervousness a good thing in some circumstances: something that that helped them achieve goals. For example, one respondent who answered “a little” was thinking of having to do presentations at work. She said, “It [nervousness] can drive me forward sometimes” and noted that her nerves sometimes helped her focus on a single task.

- PROBE16** Which of the following statements, if any, describes your feelings of nervousness?
1. Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing
 2. These are positive feelings that help me to accomplish goals and be productive
 3. The feelings sometimes interfere with my life, and I wish that I did not have them
 4. I have been told by a medical professional that I have anxiety

PROBE16 was originally designed as a content probe for the anxiety questions on Washington Group on Disability Statistic’s Extended Set on Functioning¹⁷, which include ANX_1 through ANX_3 (documented below, starting on page 84). Throughout the testing of the Extended Set on Functioning, which took place across a variety of countries, four interpretations of the term “anxiety” emerged, as shown below in Figure 33.¹⁸ Three of these interpretations appear to be “in-scope”—capturing a limitation or burden that stems from “anxiety”—and the respondents who employed them understood “anxiety” to be a negative feeling. On the other hand, one of the four patterns conceptualized “anxiety” as a positive force that respondents believed to be helpful in their day-to-day lives. This positive conceptualization represents an “out-of-scope” pattern of interpretation.

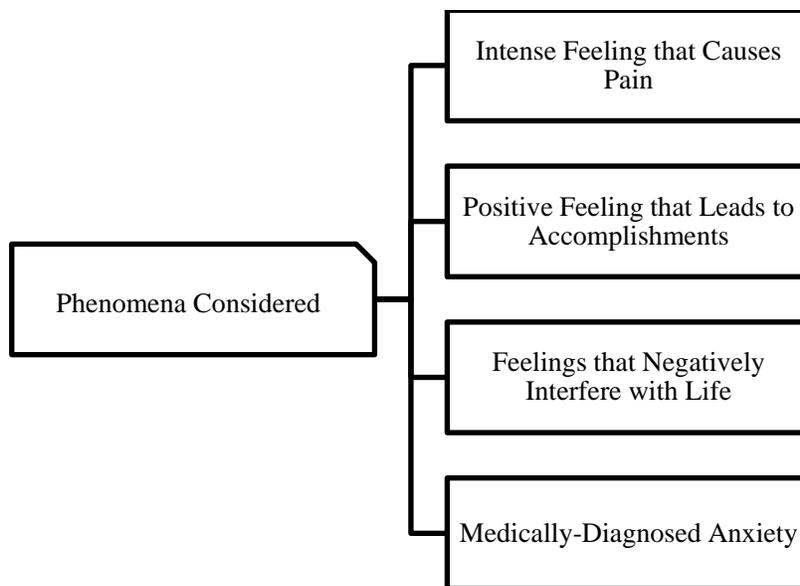


Figure 33: Cognitive Schema for the Anxiety Section that Emerged in Previous Cognitive Testing Projects

While the three in-scope interpretations were most common across the cognitive sample, the out-of-scope “positive” interpretation only emerged in the United States and Canada. However, this absence may have been an artifact of the particular samples drawn for the cognitive interviews. As noted in Maitland et al (2013: 28), PROBE16 was designed as a structured probe that could be embedded in a multi-national field test, in order to obtain a more accurate picture of the distribution of these four interpretative patterns:

¹⁷ Referred to throughout this report as the “Extended Set.” See http://www.cdc.gov/nchs/data/washington_group/wg_extended_question_set_on_functioning.pdf for the questions and Miller et al 2011 and Loeb 2016 for information on the testing and evaluation of the question set.

¹⁸ See <http://www.unescap.org/stat/disability/analysis> for the results of this testing project. The cognitive interviews were conducted in Cambodia, Canada, Kazakhstan, Maldives, Mongolia, Philippines, South Africa, Sri Lanka, and the United States of America.

It is possible, however that this [positive] interpretation did exist in other regions that were not sufficiently detailed in this [cognitive interview] narratives. The field test was used to determine the extent of this pattern and whether it exists in particular subgroups.

Given the extensive analysis that already exists for this particular targeted, embedded probe¹⁹, it was included verbatim on RANDB—not only following the anxiety questions (as PROBE21 below), but alongside the K6 “Nervous” question (ACINERV) as well.

PROBE16 was only administered to respondents in the third round of testing. Respondents did not have any difficulty mapping their experiences with nervousness to the four answer categories. Of the five respondents who received the question, three selected only one category, while the other two selected multiple answers. For instance, one respondent who answered using the 2nd and 4th answer categories explained her answer by saying:

Diagnosed. But in addition, I would actually say that my anxiety makes me feel productive, because I feel keyed up all the time and I get a lot done!

ACIRSTLS During the past 30 days, how often did you feel...

Restless or fidgety?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

All respondents across all three rounds of cognitive testing received ACIRSTLS. Four separate patterns of interpretation emerged across the responses to this question. Figure 34 shows the interpretive schema that emerged from the analysis of ACIRSTLS:

¹⁹ See Maitland and Miller 2010; Maitland et al 2013; Baena and Padilla 2014; and Loeb 2016.

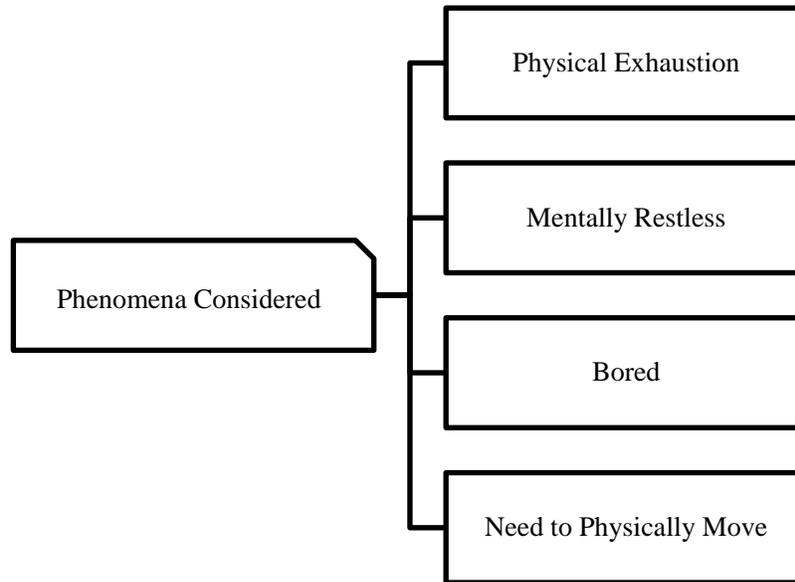


Figure 34: Cognitive Schema for ACIRSTLS

Physical Exhaustion

Most respondents across the three rounds of testing considered physical exhaustion, or being tired, when answering ACIRSTLS, an interpretation that appears to be out-of-scope. Many of these respondents thought about whether or not (and if so, how often) they had sleep problems that affected their day-to-day life. For example, one respondent who answered “Most of the time” noted that she has a lot of difficulty sleeping at night—both falling asleep and staying asleep—which tends to make her very tired during the day. Another respondent who also answered “Most…” said that she typically only gets a few hours of sleep a night because she has so much to do. When asked to explain what she was thinking about when answering this question, she replied:

Not getting any sleep. I’ll go to bed at 2am and get up at 8am…As a wife and mother, I never get a day off!

On the other hand, respondents who believed they got enough sleep answered “None of the time.” For instance, one said this question was asking “about someone who is not rested and who did not get enough sleep.” She went on to explain that she takes vitamins and gets good sleep, so the question does not apply to her.

Mentally Restless

Other respondents thought about being mentally restless—using phrases such as “mind is spinning” and nothing that they were thinking about someone who could not “turn off” or “come down” when they wanted to. Many of these respondents also thought about how this made them physically tired (because, for instance, it prevented them from sleeping). For instance, one respondent who answered “A little of the time” noted that he thought the question was asking about whether he “can’t sleep or am anxious.” He went on to say that “sometimes I can’t sleep. I feel tired [physically], but I come home and I’m just wired.”

Others did not explicitly link this mental restlessness to physical exhaustion, but rather thought about it as an issue unto itself. For example, one person who answered “A little…” explained that when she was

sick recently she was both unable to go out and interact with people like she normally would and was on medication. As a result, she reported that her “mind was spinning” whether or not she was physically tired, and that she could not relax. Likewise, another respondent who answered “A little...” explained that “I analyze and overthink every aspect of my life” and that because of this tendency, she could not get her brain to “turn off.”

Bored

A few respondents simply considered whether or not they were probed about being bored. These individuals thought about their ability to stay in one place—either physically or mentally. For example, one respondent who answered “Some of the time” explained that he did not like being in one place too long, and especially did not like sitting at home by himself: “I have to be out, like with the guys. I just like to move.” Similarly, another person who answered “A little...” noted that “I have to go outside” and that she will sometimes feel “cooped up” at home. This respondent went on to say, however, that this feeling was not really a bad thing, as it makes her go do new things and not just sit at home alone.

Physical Need to Move

Finally, a number of other respondents understood this question to be asking how often they felt like they had to physically move about. Most of these people explained that they were thinking of pacing or physical tics (like shaking their legs) because they were nervous or had too much energy. For example, one respondent who answered “None of the time” explained that she thought the question was asking about whether she needed to move around when she was nervous:

You always have to keep moving. I understand that some people—that’s how they are when they’re nervous, but that’s not how I am when I’m nervous.

Another respondent answered “A little...” and said that he occasionally “gets physical tics” when he is nervous.

PROBE17 Do you consider restlessness and fidgetiness a good thing or a bad thing?

1. Good thing
2. Bad thing
3. Neither good nor bad

PROBE18 How concerned are you about feeling restless or fidgety?

1. Very concerned
2. Somewhat concerned
3. A little concerned
4. Not at all concerned

PROBE17 and PROBE18 were designed to better understand how respondents thought about the terms “restless” and “fidgety.” As noted in the analysis above of ACIRSTLS (and below in the analysis of ACIEFFRT), some respondents did not consider restlessness or fidgeting (or the fact that “everything is an effort” in ACIEFFRT) to be a problem, but rather feelings that helped them accomplish more in life. In an effort to determine the extent of this “positive” interpretation, and whether or not it is limited to specific sub-groups, these two probes were included in the second round of RANDES.

These questions were only administered to respondents in Round Three of cognitive testing. Respondents understood that these two questions were following up on their responses to ACIRSTLS, and they explained their responses to the probes in light of their answers to the main question. For instance, one respondent who answered “Some of the time” in ACIRSTLS chose the “Neither good nor bad” answer in PROBE17. She explained that: “There are positives and negatives to it. I used to be more restless, but it’s just who I am.” This respondent then went on to answer “A little” to PROBE18, and noted that although she answered “Some...” in the main question, she was only a little concerned with her restlessness “...because I am used to it at this point in my life” and she has found ways to cope.

ACIHOPLS During the past 30 days, how often did you feel...

Hopeless?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

All respondents across the three rounds of cognitive testing received ACIHOPLS, which they interpreted in three separate, but closely related ways. These three patterns are show below in Figure 35:

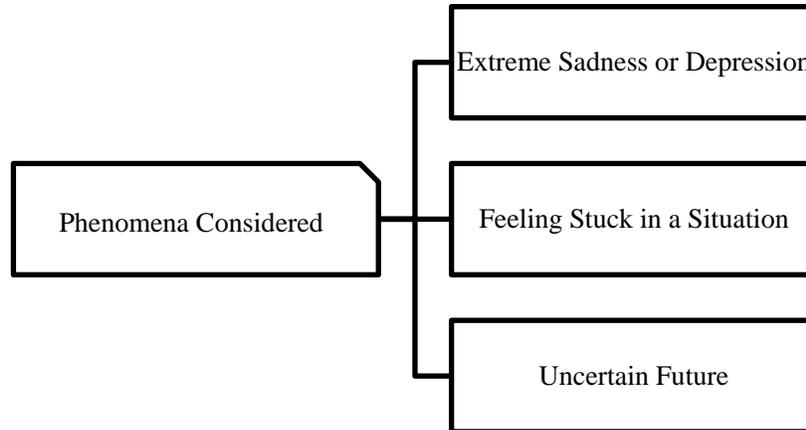


Figure 35: Cognitive Schema for ACIHOPLS

Extreme Sadness or Depression

Some respondents understood this question to be asking about how often they felt extremely sad or depressed—thinking about something more problematic than what was asked about in ACISAD above. These respondents did not consider run-of-the-mill sadness, but instead either 1) very intense feelings of sorrow or depression, or 2) long-running or chronic episodes of sorrow. For example, one respondent who answered “None of the time” said that she was actually contrasting this with the previous question on being sad (ACISAD, which she answered “Some of the time”), saying she was considering whether or not she was “*very sad*,” and went on to say: “Sad is just some sort of phase that you can overcome. Hopeless

is much deeper sadness to me.” Similarly, another person who reported “None…” explained that she was thinking about “hopeless” as feeling very down about yourself and just being generally depressed.

A couple of other respondents focused more on the duration of the feelings than their intensity. For instance, one individual who answered “None…” noted that while he does get sad, it does not tend to persist: “I might get blue, but not hopeless—not long term.” Another respondent who also answered “None…” was thinking about a person’s problems getting to be so bad that they become apathetic: “It means you just give in; you don’t care anymore.”

Feeling Stuck

Related to the interpretation of hopeless as persistent sorrow, some respondents understood ACIHOPLS as asking whether or not they felt stuck or trapped in a bad situation. For example, one person who answered “All of the time” was asked to relate what she was thinking about and mentioned both family problems and issues with her marriage:

I feel hopeless because what people have done to our family in the last year, and I just feel like I’m not a part of the marriage anymore. I just sometimes want to take a break from the world and close my door.

For this respondent, it was not just thinking about a single event, but rather an overwhelming sense that she could not escape the negative aspects of her life. Likewise, another individual who answered “Most of the time” noted that she has felt trapped dealing with all of her family and social obligations:

Since my mom started dialysis, I kind of pick up what she can’t do. It consists of having to go get prescriptions, or going to get groceries, or taking the food out, or washing the dishes…it takes a lot of energy.

Another person who answered “A little of the time” explained that he answers that way because he felt that way just once in a while, saying that he was thinking about when “you’re searching for an answer [to a problem] and it seems like nothing’s there.”

Respondents who answered “None of the time” also employed this pattern. For example, one person who answered “None…” explained that:

Hopeless is when there’s nothing that can be done about a situation—feeling like you’re doing everything and you can’t get results no matter what you do.

Uncertain Future

A number of respondents understood “hopeless” to indicate a fear of, or uncertainty about, the future. For example, one who answered “A little of the time” noted that he has a hard time understanding where his future is leading—he had recently graduated from college and had started a job, but he was distressed that he was not able to see how his future would “come together.” Another respondent answered “None of the time” and noted that he was thinking about whether or not “things seem to be getting so bad that I couldn’t see anything good in the future.” In a similar vein, another person who reported “None…” noted that, “What I think of is someone who really can’t see any future—something bad going on in their life and they can’t see a way out.”

Many of the respondents who used this pattern thought about how financial hardships made their future prospects unclear and stressed them out. For example, when asked to explain why he answered “A little of the time,” one individual said:

Sometimes you're faced with a lot of challenges—like paying the bills—it takes a lot of faith to keep up. Sometimes hopeless[ness] comes because you don't know what the future holds...After paying the last bill, can I afford anything else?

Another respondent who answered “A little...” thought about not knowing if she could afford a class that would help her progress in her career, and thus her future was unsettled: “I need money to take a business class...but I don't think I'll have the money in time.”

ACIEFFRT During the past 30 days, how often did you feel...

That everything was an effort?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

A great deal of variation emerged from the analysis of ACIEFFRT, which all respondents received and answered. In short, respondents understood this question to be asking one of two entirely different, unrelated questions. As result, ACIEFFRT may not produce comparable data across survey respondents. Figure 36 shows these two major interpretations:

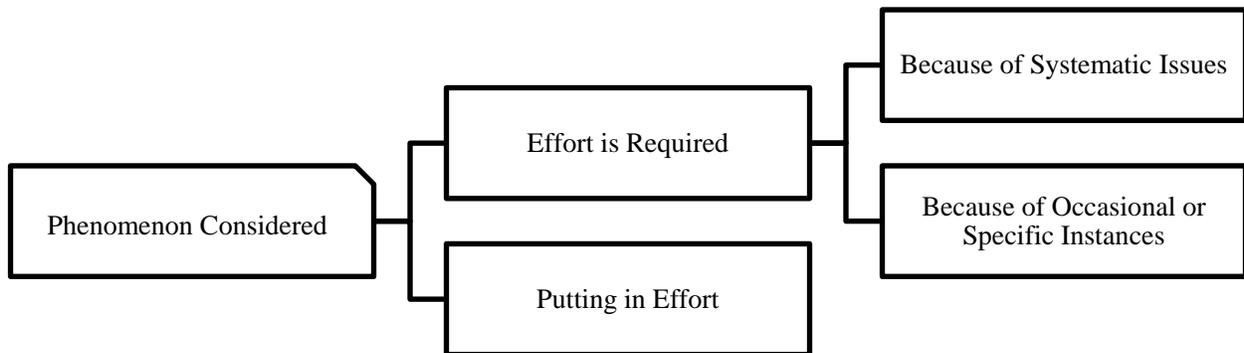


Figure 36: Cognitive Schema for ACIEFFRT

These two interpretations are opposite and incompatible. Respondents who use the first interpretation—that the question is asking them whether or not extra effort is required for one reason or another—consider a more frequent answer category (i.e. “Most of the time” or “All of the time”) to be a negative thing. However, respondents who use the second interpretation—that the question is asking them whether or not they put in an effort—use the more frequent patterns to indicate a positive character trait. These two competing interpretations were each used by about half of the sample.

Effort is Required

About half the respondents in the cognitive interviewing sample interpreted ACIEFFRT as asking them how often they needed to put in an effort to get things done. This interpretation, on the face at least, appears to be a direct reading of the phrase in the question text: "...everything was an effort." Most of these respondents considered whether they had to put in *extra* or *special* effort in order to get through their day-to-day activities, and tended to focus either on 1) systematic issues that would cause them to have to put in more effort (such as a physical disability) or 2) occasional, or very specific, issues that make them spend more energy (such as an uncooperative co-worker).

Most of the respondents who answered this question based on whether or not their day-to-day activities required extra effort thought about whether or not they had (or there were) chronic or systemic problems that would necessitate extra effort. Respondents considered both internal issues (such as disability or illness) or external ones (such as bureaucracy). For example, one respondent who answered "None of the time" was thinking about whether or not she was depressed and would therefore have to spend even more energy than normal to get things accomplished: "Is it too much of an effort to get up and do daily tasks?" She explained her "None..." by saying, "I feel like even when I'm putting in an effort, it's not an effort"—thus indicating that she did not feel burdened when trying to accomplish things. On the other hand, another person answered "Most of the time" explained that his health was a burden on his day-to-day routines:

I think of that as day-to-day things you have to do to maintain your life. And because of my health, that's difficult, so I would say most of the time.

Likewise, a different respondent who answered "A Little of the time" was thinking about how often her health affected her ability to get tasks done: "Depends on the knees and the hands—it's the arthritis...and there's nothing I can do about it."

Other respondents focused less on their chronic health conditions, and more on familial or societal issues that either did or did not burden them. For example, one respondent who answered "Most..." was thinking about the pressures she has because of her large family and her resulting responsibilities. When asked to explain what she was considering when answering, she said:

If I was feeling a little down, and I had to brush my knees off and get back up and do what I needed to do. That could be over basically anything. I'm the eldest that's responsible [in the family]. I guess you could say everyone in my family...looks up to me. I have grown grandchildren, I have five great grandchildren. And I just feel that there's so much to do in life, and if I don't do it, it won't get done.

Another respondent who answered "Some of the time" was thinking about how most things that he has to do requires a lot of paperwork, which is burdensome:

Everything requires so much paperwork, and you can never do anything with just a phone call—you need to document it and back it up, and you sort of can't always trust things to go right when you have to.

Others did not focus on chronic issues, but rather on whether or not they encountered occasional or specific problems that made them put in more effort than normal. These specific issues ranged from getting children to clear their room, to hitting one too many traffic lights on a commute, to dealing with co-workers who did not contribute to projects. For example, one respondent who answered "A little of the time" explained that she was thinking about, "when people are given only a little effort...I have to then decide to step up [and give more effort] or not...Only a little because most people do their jobs." Another person who answered "None of the time" noted that she never really hit too many obstacles—

such as lots of traffic lights or the gas light coming on in her car too frequently—that would throw her off her day-to-day routine.

Putting in Effort

The other half of the respondents in the cognitive sample used a completely different interpretation, and answered ACIEFFRT as if it was asking “How often do you put in effort?” These respondents understood this question to be asking them about whether or not they worked hard and gave tasks “their all,” and overwhelming reported that they understood “effort” to be a positive thing when they were answering the question. For example, one respondent who answered “Most of the time” explained his answer by saying, “I strongly believe that all my handiwork will one day pay off, and I do see progress...I’ve taught myself to believe that everything I do every day is an effort leading to a better life.” Another person who answered “All of the time” said that “My job makes me feel that way: Like I put my all in...I’m giving it 100%, and I’m not slacking.”

A number of these respondents framed their answers by thinking about the fact that they wished they gave *more* effort—thus believing that a more frequent answer on the response scale (i.e. “Most of the time” or “All of the time”) was something to which they aspired. For example, one individual who answered “Some of the time” noted that he wished he put in more effort and that in an ideal world, he would give everything his effort. He explained his “sometimes” by saying that he applied himself to a lot of tasks, but not all of them: “I never like it when a problem defeats me. I’ll usually ask until I find a resolution.”

PROBE19 Would you consider everything being an effort to be a good thing or a bad thing?

1. Good thing
2. Bad thing
3. Neither good nor bad

PROBE20 How concerned are you about feeling as if everything is an effort?

1. Very concerned
2. Somewhat concerned
3. A little concerned
4. Not at all concerned

PROBE19 and PROBE20 are nearly identical to PROBE17 and PROBE18, respectively. Just as with the previous probes for the “restless and fidgety” question (ACIRSTLS), these questions were designed to determine the extent of the seemingly out-of-scope “positive” interpretation (that ACIEFFRT was asking about how frequently a respondent *puts in an effort* as described in the analysis above).

These two questions were again only administered to the respondents the third round of cognitive testing, and appeared to correctly ascertain which pattern they used to answer ACIEFFRT. For instance, one respondent who answered “Some of the time” to ACIEFFRT (and said that she was thinking about how often she applies herself to a task) reported “Good thing” to PROBE19 and “Not at all” to PROBE20, explaining that she thinks that that everything is an effort “means that someone’s trying.” Likewise, another respondent who answered PROBE19 “Good thing” explained that “It’s good to put effort into things...I do most of the time.” This respondent answered ACIEFFRT “Most of the time” and answered PROBE20 “Not at all.”

ACIWTHLS During the past 30 days, how often did you feel...

Worthless?

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

All 35 respondents across the three rounds received ACIWTHLS, and they universally understood the question to be asking whether or not (and how often) they felt like they had no self-worth or value:

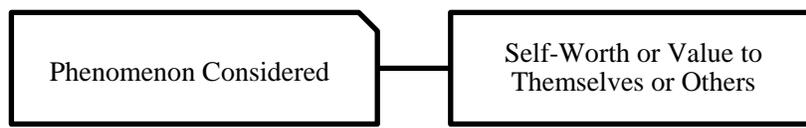


Figure 37: Cognitive Schema for ACIWTHLS

Respondents did not consider whether or not they had high self-esteem, but rather focused their response on what they considered to be a serious problem or lack of self-worth.

Because they set the bar for “worthless” so high, most respondents in the cognitive sample answered “None of the time.” For example, one person in the second round explained her answer by saying, “I’ve always had some worth—I know that about myself” and noting that being worthless means “Not being able to contribute anything.” Another respondent said, “At the end of the day, I have self-worth. Even though I might not be applied in the best way, I have worth.”

A few respondents did judge themselves to meet this bar, and explained their answers by thinking about their value to themselves and others. For instance, one respondent who answered “Most of the time” noted that she was thinking about: “When you don’t feel like you’re worth it—my job and my husband make me feel like that sometimes.”

Internet Use Section

AWEBOFNO How often do you use the Internet?

All respondents across the three rounds received and answered AWEBOFNO. No variation emerged across the way they answered this question, with all the respondents understanding it to be asking about the frequency they use the World Wide Web. Respondents considered internet use both on desktop and laptop computers and smartphones.

Anxiety Section

The three NHIS anxiety questions included in RANDS—ANX_1, ANX_2, and ANX_3—were developed as part of the Washington Group on Disability Statistics Extended Set on Functioning. These questions have been tested extensively²⁰, and the findings from this cognitive testing project match previous findings.

- ANX_1** How often do you feel worried, nervous, or anxious?
1. Daily
 2. Weekly
 3. Monthly
 4. A few times a year
 5. Never

All respondents received ANX_1. Variation did emerge across how respondents interpreted the question, as shown below in Figure 38. All of these patterns are ones that have emerged in previous evaluations of ANX_1 as well.

²⁰ See Massey et al (2016) and Loeb 2016 for more information

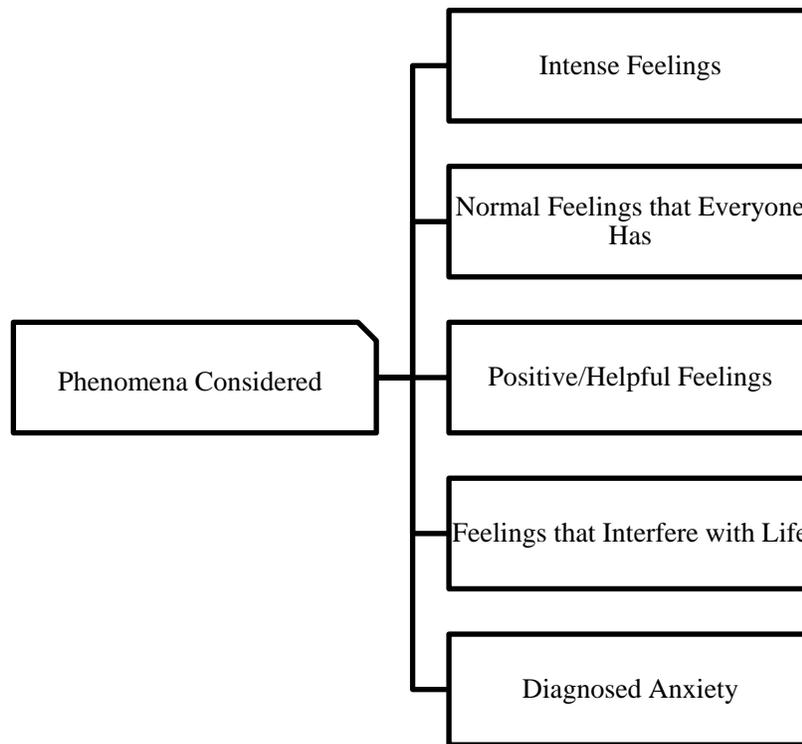


Figure 38: Cognitive Schema for ANX_1

With the exception of those who were thinking about diagnosed anxiety, most respondents considered more than one of the interpretive patterns while answering. Most of these five patterns appear to be in-scope (with the exception of the “Positive/Helpful Feelings” pattern), and this question (alongside the ANX_2 and ANX_3 follow-up questions) should produce reliable data.

Intense Feelings

Respondents who used this pattern thought about whether or not they were ever worried or anxious to the point that they felt physical pain or discomfort. For example, one respondent who answered “Weekly” was thinking about when he tried to talk to girls in public. Thinking specifically of an incident on the train on the way to the interview, he said, “I feel it in my chest—I just can’t do it. That’s always it.”

Normal Feelings

Many respondents thought about normal feelings of nervousness and worry that occur because of every-day or regular events in their life. These people considered things such as public speaking, job interviews, or social functions. For instance, one respondent who answered “A few times a year” noted that she was thinking of the stress she has when she plans parties at her house: “Like, I plan an event, and people don’t get there on time—they don’t call me, they don’t show up right away.”

Positive or Helpful Feelings

As noted above in ACINERV, one out-of-scope interpretation that emerged was when respondents thought about nervousness or anxiety as a positive feeling that helped them achieve their goals. For

example, one respondent in the first round who answered “Daily” was thinking about the nervousness as providing the energy he uses to get up and be productive each day:

To me, my perception of “worries” is that it put me on my feet. It gets me going—I use it to get something done every day.

Feelings that Interfere with Life

Some respondents considered anxiety, worry, and nervousness as feelings that directly impacted or interfered with their lives. Like those who employed the “positive” interpretive pattern described above, these people focused on the outcome of their feelings and not only the sources. For instance, one respondent who answered “Daily” explained the constant calls she has been receiving from debtors and bill collectors since she lost her job a few months ago made her hesitant to ever answer the phone. She went on to note that she was thinking of “...bills I’m not able to pay right away...and they [the bill collectors] keep calling and calling, and make me nervous to answer.”

Diagnosed Anxiety

Finally, a few other respondents based their answer to ANX_1 on whether or not they had ever been diagnosed with anxiety (or in one case, depression) by a medical professional. For example, one respondent who answered “Never” said that he had never been told by a doctor that he has anxiety, and although he noted that he did get nervous or worried upon occasion, “it’s never been enough to go talk [to a doctor] about.” On the other hand, another person answered “A few times a year” and explained that he was thinking of anxiety attacks. He said that he was diagnosed with anxiety about 10 years ago, but through a combination of medication and counseling, he rarely had anxiety attacks anymore and could only think of two instances in the past year.

- ANX_2 Do you take medication for these feelings?
1. Yes
 2. No

All respondents received and answered ANX_2. No variation emerged, and respondents universally understood ANX_2 to be a follow-up to ANX_1 asking about whether they took medication for the worry, nervousness, or anxiety they reported in the first question:



Figure 39: Cognitive Schema for ANX_2

All respondents who reported “Never” in ANX_1 went on to answer “No” in ANX_2. People who answered “Yes” to this question all limited their interpretation to prescriptions, and no respondents appeared to count over-the-counter medicine towards their answer.

- ANX_3** Thinking about the last time you felt worried, nervous, or anxious, how would you describe the level of these feelings? Would you say you felt a little this way, a lot this way, or somewhere in between?
1. A little
 2. A lot
 3. Somewhere between a little and a lot

The 24 respondents across the three rounds who did not answer “None” to ANX_1 and “No” to ANX_2 went on to receive ANX_3. All of these individuals understood this question to be asking about the intensity of the feelings they reported in ANX_1.

Given the wide variety of stressors and situations that respondents considered when making their original frequency judgement in ANX_1, however, no standard judgement of intensity emerged. Each respondent judged the frequency of their feelings based on their own particular lived experience, and took a number of factors into account, including how long the feelings have lasted and whether or not the feelings have been better or worse in the past. As a result, what one respondent may consider to be on the “A Little” level of feelings, another may consider to be either “A lot” or “Somewhere in between...”

- PROBE21** Which of the following statements, if any, describes your feelings?
1. Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing
 2. These are positive feelings that help me to accomplish goals and be productive
 3. The feelings sometimes interfere with my life, and I wish that I did not have them
 4. I have been told by a medical professional that I have anxiety

PROBE21 is nearly identical to PROBE16 (which includes the word “nervousness” in its question text), and its purpose and design is described in detail above.

The five respondents in Round Three received PROBE21, and all were able to map their experiences onto one of the four answer categories. These respondents all recognized the fact that while PROBE21 was worded similarly as PROBE16, the two questions were asking about different phenomena. A number of respondents differentiated their response in PROBE21 (and to the anxiety series of questions) from what they had said before in ACINERV and PROBE16. For example, one respondent who answered “These are positive feelings...” to PROBE16, answered “The feelings sometimes interfere...” here. She explicitly noted that she thought of anxiety as worse than nervousness, and said that when her anxiety peaks—not just her constant worrying, but anxiety—“It can be really intense you know? I can’t do anything, I have to put a hold on my life.”

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