

Adult Questions on the Health Interview Survey – Results of Cognitive Testing Interviews Conducted April-May 2003

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Overview and Methodology

This report describes findings from a round of cognitive testing on health limitations and health behaviors in the adult section of the Health Interview Survey. Research results were based on 18 interviews conducted by all staff members of the Cognitive Methods Staff of the National Center for Health Statistics in the Questionnaire Design and Research Laboratory (QDRL).

Qualitative methodologies attempt to improve the understanding of experiences through rich, detailed description. Qualitative research allows the uncovering of participant's feelings and experiences with minimal direction from researchers (Crabtree & Miller, 1992; Denzin & Lincoln, 2000). Data emerges from informant interactions, where the investigator is the primary data collection and analysis instrument (Strauss & Corbin, 1990). Qualitative research involves a limited number of informants and attempts to uncover "lived experience" (Crabtree & Miller, 1992). The goal of qualitative research in the context of cognitive testing is not to generalize findings to an entire population but to gain greater understanding of a given questionnaire.

Interpretation of human experiences is the ultimate goal of qualitative research (Josselson and Lieblich, 1995). Interpretivism is the underlying epistemological paradigm guiding this qualitative research and posits that human action is inherently meaningful (Kaplan & Maxwell, 1994; Schwandt, 2000). Interpretivism focuses on the complexity of humans trying to make sense of their situation as it evolves (Kaplan & Maxwell, 1994). Situational context is critical to interpretive analysis (Josselson and Lieblich, 1995). People try to make sense of phenomena by assigning meanings to them; interpretivism posits that knowledge of social reality is gained through social constructions like meanings (Orlikowski & Baroudi, 1991).

Interpretive understanding is a process used by a researcher to gain information about the meaning of an action by inquiring into the actors' definitions of the situation and their motivations for an action or question response (Schwandt, 2000). What a participant says as well as what is left unsaid may be interpreted on multiple levels, by the participant who knows and understands the context and also by the researcher who may be able to connect with themes from other interviews as well as social situations or constructs of which the participant may be unaware. A semi-structure protocol like the one used in this research project allows both the researcher and the researched to weave a coherent narrative out of authentic language from which to construct meanings from reported actions and events; it allows for both the structure of asking specific questions in a specific order as per the questionnaire design with the flexibility of probing in-depth on question interpretation and response formulation. QDRL staff did prescript probes within

the questionnaire to ensure data quantity and comparability; however, emergent probing also was used to gain more information on how the participant chose an answer as well as a better understanding of his or her situation. For the interview, participants were asked each scripted question and were then asked to explain their answer. Typical follow-up questions included, “How so?” and “Why do you say that?” If a participant’s response seemed vague or unclear, the interviewer asked: “Can you give an example to describe what you are talking about?” or “Can you tell me more about that?”

The culminating text from the interview related how participants understood or interpreted each question and also outlined the types of experiences and behaviors participants considered in providing an answer. After an interview was conducted, the researchers wrote up detailed field notes and reflected on the experience of data collection. Videotapes were also reviewed during analysis. Other experts’ opinions and thoughts were solicited in order to incorporate multiple viewpoints.

A variety of techniques are available to assist the qualitative researcher in making sense of findings (Strauss & Corbin, 1990). The immersion/crystallization technique of data analysis was used to keep the researcher as close to the data as possible (Miles & Huberman, 1994; Borkan, 1999). This technique allows the data to speak to the researcher, as the data is reviewed repeatedly and allowed to ‘settle’ in the researcher’s mind. By being close to the data, the researcher was more easily able to identify patterns and discrepancies throughout the data.

This qualitative study was based on emergent design, a technique wherein data collection and analysis occur simultaneously (Strauss & Corbin, 1998; Patton, 1990) and the constant comparative method (Lincoln and Guba, 1985; Strauss and Corbin, 1990; Creswell, 1998). Distinct occurrences in which participants misunderstood terms or expressed difficulty or confusion while answering were noted. Then the following interpretive patterns were examined: 1) participants’ interpretations of key words, 2) the types of behaviors that participants counted as positive responses to particular questions, and 3) the degree of variation among participants’ interpretations.

To analyze the interpretive aspects of question response, the constant comparative method, a standard method for analyzing qualitative data (Lincoln and Guba, 1985; Strauss and Corbin, 1990; Creswell, 1998), was employed. By comparing across all cases, individual response errors were categorized according to a participant’s particular interpretation of a question. From these response error categories, interpretive aspects (e.g. the consistency and degree of variation) of each question were examined.

Strauss and Corbin (1998, page 3) define coding as “the analytic processes through which data are fractured, conceptualized, and integrated.” Coding was the major part of the data analysis process (Crabtree & Miller, 1992; Miles & Huberman, 1994; Strauss and Corbin, 1998). Codes were not mutually exclusive, so one question could have multiple response errors coded.

The primary objective of the cognitive interviews was to identify potential errors that could affect the accuracy of responses to these questions. For example, evidence might emerge in cognitive interviews that the participant misunderstood certain terms, had difficulty remembering the requested information, had experiences that could not be accurately captured in the question format, and so on. Whenever such problems were observed, participants' verbal reports were analyzed in an attempt to identify whether the problems were most likely attributable to characteristics of the question. In many cases, this analysis points to specific concepts, terms, or response formats of questions that might benefit from revision or further development.

Participant Demographics

All participants but one had participated in previous cognitive interviewing projects at the QDRL. Participants were paid \$30 for the interview. Seven participants were female; eleven were male. Ages ranged from 22 to 84. The median and mode participant age was 48. Eight participants had never been married. Seven were married; two were divorced, and one participant was separated. Nine participants reported their race as Black. Eight reported their race as White, and one person considered herself to be American Indian and Black. Four participants reported having a college degree; eight had some college; five had completed high school, and one had not completed high school. Ten participants were employed, while eight were not. Half of the participants reported an income of less than \$20,000, and the remaining eight reported incomes above \$30,000.

Interviews were conducted face-to-face in the QDRL, and the NHIS portion of the interview usually lasted about thirty minutes. The questions covered in each interview varied depending upon the participant's health conditions and behaviors; while a few questions have sparse data, overall question coverage was sufficient for response error coding. A battery of wealth and income questions was administered after the NHIS questions and will be discussed in a future report.

Interviewers began the interview by administering informed consent forms and then read the following to the participant:

Good morning,

Karen may have told you that we will be testing one of our forms which is used to collect demographic information as well as general health questions for the National Health Interview Survey. This survey is carried out in person at the homes of people all across the country. For the general health questions, please answer the questions as you would if you were home. We are interested in your answers, but also how you go about making them. I'd like to ask you to think aloud as you answer each question and tell me everything that comes to your mind in answering the question. I may also ask you questions about the questions.

*Please tell me if there are words you don't understand,
or if the question doesn't make sense to you,
or if you could interpret it two ways,*

*or if it seems out of order,
or if the answer you are looking for is not provided.
The more you can tell us, the more useful it will be to us as we try to develop better
questions. Okay? Do you have any questions before we start?*

Findings

This section discusses the results of the data analysis question by question, focusing on response errors; some questions have suggestions for possible revisions to reduce identified response errors.

I am now going to ask about your general health and the effects of any physical, mental, or emotional health problems. Please answer these questions as you would as if you were talking to me at your home, because that's where this survey generally takes place.

FHS.070 Because of a physical, mental, or emotional problem, do you need the help of other persons with PERSONAL CARE NEEDS, such as eating, bathing, dressing, or getting around inside this home?

- | | |
|----------------|-----------|
| (1) Yes | (FHS.090) |
| (2) No | (FHS.150) |
| (7) Refused | (FHS.150) |
| (9) Don't Know | (FHS.150) |

Responses to this question showed participants were having conceptual problems answering this question. Participants interpreted “need” and “personal care needs” differently. Unclear concepts in the question resulted in a broad array of interpretations.

A few people struggled with when help was required as opposed to convenient. One respondent answered no to this question and then said that it was great when his wife brought him items; for him, help was useful, but not absolutely necessary. People might not want to admit needing help. Those who routinely receive help may answer no because they do not conceptualize it as a need.

The interpretation of what constituted a personal care need led to variations in responses. One man answered yes, then revealed in further probing that he needed help preparing food; preparing food is probably not a personal care need the question was meant to capture. People do not know the next question asks about another type of need.

FHS.090 Do you need the help of other persons with?

- (1) Yes (FHS.150)
- (2) No (FHS.150)
- (7) Don't know (FHS.150)
- (9) Refused (FHS.150)

Bathing or showering?
Dressing?
Eating?
Getting in or out of bed or chairs?
Using the toilet, including getting to the toilet?
Getting around inside the home?

Only two participants were asked this question. One was incorrectly skipped here because he reported needed help preparing food. There is insufficient data to report findings on this question. It is worth noting that the participant who was correctly routed to this question gave conditional “yes, if...” and “sometimes” answers. Including a sometimes category may be helpful to participants.

FHS.150 Because of a physical, mental, or emotional problem, do {you} need the help of other persons in handling ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

- (1) Yes (FHS.170)
- (2) No (FHS.170)
- (7) Refused (FHS.170)
- (9) Don't Know (FHS.170)

Conceptual problems were found relating to different interpretations of routine needs, also the fact that people might not have routine needs as defined by the question, such as going to the gym and going to the doctor for those with limitations. One respondent emphatically stated he did not NEED help. He said he tried to be self-sufficient; for people with limitations, there may be a loss of face in answering yes to this question.

As noted earlier, people also tended to overlap routine needs and personal care needs. One woman said her routine needs and her personal care needs were the same.

Another respondent answered no, but he later reported not being able to manage his money, which does seem like a routine need. Another respondent answered no, although he does rely on services like “Metro Access” to take him places. He defined this as needing help from a service and not other people, so respondents may answer conditionally. However, another respondent with similar circumstances answered yes. One respondent who used a crutch stated no, but he said that his no was a conditional

response under normal circumstances; for example, he could not go to the store in the snow.

The response options seem inadequate, as a few participants wanted to answer sometimes. One respondent reported needing to answer yes to some of the range of example activities in the question and no to others. Another answered no “at the moment”; however, her condition causes her to be fatigued at times, when she is unable to attend to her routine needs.

FHS.170 Does a physical, mental, or emotional problem NOW keep you from working at a job or business?

- (1) Yes (FHS.190)
- (2) No (FHS.190)
- (7) Refused (FHS.190)
- (9) Don't know (FHS.190)

Some respondents had a difficult time distinguishing whether they could work versus if they were easily able to work. One man mentioned he could get by working part-time, but he was limited in how well he could do the work. Another man who answered yes mentioned in the follow-up probing that he could work if it was absolutely necessary; he would have to choose a job that didn't involve long periods of walking or sitting, and working would be difficult for him; however, he's not totally incapable of working.

FHS.190 Are you limited in the kind or amount of work you can do because of a physical, mental or emotional problem?

- (1) Yes (FHS.210)
- (2) No (FHS.210)
- (7) Refused (FHS.210)
- (9) Don't know (FHS.210)

This question seemed repetitive to respondents as well as interviewers. It also seemed like people who answered yes to FHS.170 should have skipped this question, as limitations for something seem pointless if someone can not do the something in the first place. Maybe there should have been a skip that I missed in the instrument?

FHS.210 Because of a health problem, do you have difficulty walking without using any special equipment?

- (1) Yes (FHS.230)
- (2) No (FHS.230)
- (7) Refused (FHS.230)
- (9) Don't know (FHS.230)

Response options did not adequately capture participants' experiences. Three had difficulty walking without a device sometimes; one person simply did not answer yes or no, while the other two debated and chose yes.

FHS.230 Are you LIMITED IN ANY WAY because of difficulty remembering or because you experience periods of confusion?

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

The most common conceptual difficulty noted here refers to the fact that respondents considered both age-related problems in addition to problems caused by physical, mental, and emotional problems. Remembering as a concept seemed to be consistently understood, but five people qualified their answers by attributing their memory loss to getting older. Some older people answered 'yes, because I'm aging', while others answered 'no, although I am getting older and forgetting things more'. Two respondents answered yes because one had forgotten a Bible verse and the other had written out a check for the wrong month; this probably is not what the question is meant to capture. Another respondent, who had similar occasional forgetfulness, viewed this as an Alzheimer's question and responded no. People are answering this question in an inconsistent manner. Generally speaking, people with physical, mental, and emotional problems were able to clearly state whether they had no, one, or both memory loss and confusion.

FHS.250 Are you LIMITED IN ANY WAY in any activities because of physical, mental or emotional problems?

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

This question seemed repetitive, and both respondents and interviewees were not sure how it was different from the other limitations questions. Because of this, a few respondents answered while thinking holistically about their lives, as though we could not possibly be asking yet another question about their limitations. When probed about their limitations, they changed their answer. Another man came up with another, minor limitation to discuss during this question, as he felt like he had already told the interviewer all about his other limitations. Participants seemed to interpret this question in a way to give new or different information to the interviewer. There is no time frame associated with this question. One respondent answered no when he had reported activity-limiting conditions; he was answering based "on this moment".

The conceptual issue here was due to how vague and open the question was; this leads the participant to come up with their own interpretations of what the question asked. For example, some people answered for when their limitation was controlled by medication, while others answered for what their state would be without medication. Clearly, people whose conditions are controlled will be less limited if they answer with their medications in mind. This may result in less comparable survey data.

FHS.350 *Only ask this question if the participant stated they had a limitation.*

Flashcard F2

What conditions or health problems cause your limitations? Please select all that apply.

- (1) Vision/problem seeing
- (2) Hearing problem
- (3) Arthritis/rheumatism
- (4) Back or neck problem
- (5) Fracture, bone/joint injury
- (6) Other injury
- (7) Heart problem
- (8) Stroke problem
- (9) Hypertension/high blood pressure
- (10) Diabetes
- (11) Lung/breathing problem (e.g., asthma and emphysema)
- (12) Cancer
- (13) Birth defect
- (14) Mental retardation
- (15) Other developmental problem (e.g. cerebral palsy)
- (16) Senility
- (17) Depression/anxiety/emotional problem
- (18) Weight problem
- (19) Missing limbs (fingers, toes or digits), amputee
- (20) Kidney, bladder or renal problems
- (21) Circulation problems (including blood clots)
- (22) Benign tumors, cysts
- (23) Fibromyalgia, lupus
- (24) Osteoporosis, tendinitis
- (25) Epilepsy, seizures
- (26) Multiple Sclerosis (MS), Muscular Dystrophy (MD)
- (27) Polio(myelitis), paralysis, para/quadruplegia
- (28) Parkinson's disease, other tremors
- (29) Other nerve damage, including carpal tunnel syndrome

- (30) Hernia
- (31) Ulcer
- (32) Varicose veins, hemorrhoids
- (33) Thyroid problems, Grave's disease, gout
- (34) Knee problems (not arthritis (03), not joint injury(05))
- (35) Migraine headaches (not just headaches)
- (36) Other impairment/problem (Specify one) _____
- (37) Other impairment/problem (Specify one) _____
- (97) Refused
- (99) Don't know/not sure

Conceptual difficulties stemmed from a number of problems. Seven respondents went through this list and identified every problem they had whether it limited them or not; one even listed problems that he suspected but had not been diagnosed by a health care professional. Many people do not seem to connect this question with the limitations they have just discussed in the rest of this series.

The issue of causation emerged as problematic during cognitive testing. Many laypeople simply are not sure what caused their limitations. This is a knowledge issue. Interviewers often suspected people were speculating on what caused their limitations, and emergent probing confirmed those suspicions. Others listed manifestations of their condition (i.e., post-polio syndrome) because its actual cause was not included in the list.

The major response option problem was caused by respondents tending to select the first item on the long list which was in any way related to their limitation. Respondents also had to deliberate and decide whether to write in their specific condition as other or to choose something on the list that was similar. For example, one woman chose 3 because her disease is in that family; then she considered 23, as it was very similar to her disease; finally she decided to choose other and write in her specific disease. Respondents in survey situations who are not being asked emergent probes about their responses may choose the first reasonable option to avoid reading the entire list.

Another response option problem was one encountered by a bipolar man, who had to select two different categories to represent his single diagnosis. Another older man raised the issue of including prostate problems on the list, as it is problematic for many older men and can cause limitations.

Embarrassment on the part of one respondent with emotional problems indicated social desirability bias may limit the number of respondents in a survey situation who select this response. Others who selected weight problem did so in a self-deprecating way, which is an indication of social desirability bias.

FHS.500
or poor?

Would you say {your} health in general is excellent, very good, good, fair,

- | | |
|----------------|----------------|
| (1) Excellent | (Next section) |
| (2) Very good | (Next section) |
| (3) Good | (Next section) |
| (4) Fair | (Next section) |
| (5) Poor | (Next section) |
| (7) Refused | (Next section) |
| (9) Don't Know | (Next section) |

Several factors contributed to the conceptual problems found during cognitive testing of this question. Some respondents did use situational factors in choosing their response while others did not. For example, one woman did not include her pregnancy-related health limitations.

Two participants provided interesting comparisons of incomparable data. One man who had cancer in remission, cataracts, brain occlusions, prostate problems, and congestive heart failure said his health was good. Another respondent who was fairly healthy and had no limitations at all said his health was good, also. The word “good” was used to describe two very different states of health here.

Respondents also differed on whether they rated their health higher when their conditions were controlled by medication or if they downgraded their health because they had the condition in the first place. People with limitations also discounted them when answering this question. One man said he was in excellent health; he decided on this answer because other than being paraplegic, other aspects of his health were excellent.

Many times their answers seemed to depend on who they were comparing themselves to, which in part seemed to be due to this question’s placement right after the physical limitations section. People sometimes compared themselves to those who could not get around or take care of themselves; others compared themselves to those their own age or those with similar health situations. This also results in incomparable data.

Questionnaire problems stem from this health status question following the series of limitations questions. Many people responded that having excellent or very good health meant being able to do their daily activities or not needing to visit the doctor every week. The effect of this may be to put the idea of limitations in participants’ consciousness when it might not be otherwise.

A few respondents reported not wanting to complain or whine about their health and so choose perhaps categories implying higher functioning than the responses to previous question would indicate applied. One respondent said he “didn’t cry to people” about his health.

HEALTH BEHAVIORS

Part A - Tobacco

These next questions are about cigarette smoking.

AHB.010 Have you smoked at least 100 cigarettes in your ENTIRE LIFE?

- (1) Yes (AHB.020)
- (2) No (AHB.090)
- (7) Refused (AHB.090)
- (9) Don't know (AHB.090)

This question seemed to work well.

AHB.020 How old were you when you FIRST started to smoke fairly regularly?

- * Enter '6' if less than 6 years old.
- * Enter '95' if 95 years old or older.

- (6-94) 6-94 years of age
- (95) 95 years or older
- (96) Never smoked regularly
- (97) Refused
- (99) Don't know

Recall problems were caused by people being unable to pinpoint how old they were, though most respondents were able to give an age range of about two years. Generally, respondents needed some time to talk through what was happening in their lives at that time to map a specific age or range to answer the question.

Each of five respondents who were asked a probe about what smoking fairly regularly meant thought of that phrase a different way. Their thoughts ranged from smoking more than one cigarette a day to smoking the most you had ever smoked to being addicted. This results in incomparable data and burdened respondents.

AHB.030 Do you NOW smoke cigarettes every day, some days or not at all?

- | | |
|----------------|-----------|
| (1) Every day | (AHB.050) |
| (2) Some days | (AHB.060) |
| (3) Not at all | (AHB.040) |
| (7) Refused | (AHB.060) |
| (9) Don't know | (AHB.060) |

There was no category that matched the experience of two respondents. One smoked more than some days but less than every day, which is what she would choose if she had to choose an option. The other woman answered not at all but identified herself as a social, infrequent smoker; she had not quit smoking completely but certainly smoked less than on some days. Expanding the response option categories will more accurately reflect all the possible smoking patterns.

AHB.040 How long has it been since you quit smoking cigarettes?

*** Enter '95' for 95 years old or older.**

- | Number: | Time Period: |
|-----------------|----------------|
| (1-94) 1-94 | (1) Days |
| (95) 95+ | (2) Weeks |
| (97) Refused | (3) Months |
| (99) Don't know | (4) Years |
| | (7) Refused |
| | (9) Don't know |

Social smokers had a very difficult time answering this question; this was where they wound up in the skip patterns, but the question assumes respondents have quit. Two respondents were unable to answer, as they had still smoked occasionally and had not quit smoking.

Recommendation:

In order to reduce confusion in the field, perhaps occasional smokers could be skipped out of this question.

AHB.050 On the average, how many cigarettes do you now smoke a day?

*** Enter '1' if less than 1 cigarette.**

*** Enter '95' if 95 or more cigarettes.**

(1-94) 1-94 cigarettes (AHB.080)

(95) 95+ cigarettes (AHB.080)

(97) Refused (AHB.080)

(99) Don't know (AHB.080)

This question seemed to work well. One respondent with variable smoking patterns had some difficulty estimating how many cigarettes he smoked in a day.

AHB.060 On how many of the PAST 30 DAYS did you smoke a cigarette?

*** Enter '0' for none.**

(0) None (AHB.080)

(1-30) Days (AHB.070)

(97) Refused (AHB.070)

(99) Don't know (AHB.070)

Only two respondents answered this question, so there is not enough data to adequately evaluate it. However, one reported estimation difficulty.

AHB.070 On the average, when you smoked during the PAST 30 DAYS, about how many cigarettes did you smoke a day?

*** Enter '1' if less than 1.**

*** Enter '95' if 95 or more cigarettes.**

(1-94) 1-94 cigarettes (AHB.080)

(95) 95+ cigarettes (AHB.080)

(97) Refused (AHB.080)

(99) Don't know (AHB.080)

There is insufficient data to report findings on these two questions. Only two participants answered them. One was able to come up with an estimate for both questions, but the other was unable to answer the question. She smoked two packs in the past 30 days and could not generate an estimate. Thus, the potential for knowledge and recall-related difficulties exists.

AHB.080 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
- (7) Refused
- (9) Don't know

This question seemed to work well for the five people who answered it.

Part B - Physical Activity

The next questions are about physical activities that you may do in your LEISURE time. (Read only if they ask exercise, sports, physically active hobbies...)

AHB.090 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?

*** Read if necessary:** How many times per day, per week, per month, or per year do you do these activities?

Times per:	Time period:
(0) Never (AHB.110)	Day, Week, Month, Year
(1-995) 1-995	
(996) Unable to do this type of activity (AHB.110)	
(997) Refused (AHB.110)	
(999) Don't know (AHB.110)	

Conceptual difficulties were caused by the lack of a time frame in the question, different interpretations of the concepts of leisure time and vigorous activities, and answering for all kinds of exercise. The lack of a time period led to estimation problems. It increased the respondent's cognitive burden when trying to answer the question. One man had been sick for 3 months and was unsure if he should answer with his current low activity or his previous higher activity level. Two respondents who reported being confused by a lack of time frame were probed about what time frame they were considering; one answered the past 30 days, while the other answered now or presently. Another man based his answer on his activity last week, which was not a typical week for him.

Leisure time had different meanings for different participants. Retired people often thought of all their time as leisure time. Other people said they used leisure time to do nothing at all; thus, some people may not report their exercise, as they do not consider down time to be a time for exercise. If this is meant to solely capture non-work exercise, perhaps saying 'non-work' physical activities might be subject to less interpretive difficulties. A man employed part-time said he does not differentiate between being active at work versus at home.

Vigorous activity also had different meanings for the participants. A woman with many health problems reported that doing anything was vigorous for her. Another man missed the vigorous part of the question and said that he was thinking about being outside when it was warm and he was sweating. People had different opinions on whether walking was a vigorous activity or not. A man with post-polio mentioned his answer was based on daily living activities (getting himself in and out of the bathtub) rather than voluntary leisure time vigorous activities. However, another man with one leg who had trouble getting around did not include the extra effort his disability caused him in getting

around. Another man answered that he thought sex was a vigorous activity and based his answer accordingly!

Respondents often answered this question using their entire exercise repertoire. Participants wanted to include all their exercise and did not realize that other questions would be following up on non-vigorous activities. People seemed very eager to tell the interviewer each and every physical activity they performed regularly or irregularly. As mentioned above, people with disabilities and non-active people may think back in time for something, anything relevant to report. Social desirability bias may contribute to this. One woman said she felt guilty about answering never to this question.

The question is overly complex. During probing after answers that seemed out of place, people routinely reporting not hearing different parts of the question. For example, one woman did not hear the word 'vigorous' in the question. She said the question was confusing and contained too much information.

Knowledge and recall difficulties were also stemmed from the lack of a time frame in the question. Also, participants reported giving their best guess about how often they exercised. As stated earlier, physical activity can vary by health status, motivation, and other commitments.

AHB.100 About how long do you do these vigorous leisure-time physical activities each time?

Number:	Time period:
____(1-995) 1-995	(1) Minutes
(997) Refused (AHB.110)	(2) Hours
(999) Don't know (AHB.110)	

The conceptual difficulties were caused by people who were asked this question because they answered yes to the previous question. One woman who got this only exercised four or five times a year; the man with post-polio answered based on how long it took him to get ready in the morning.

This appears to be difficult for people to estimate. Most people prefaced their answer with about or gave a time frame, like 15 to 20 minutes in their answer.

The same social desirability bias discussed above affected this question also. People seemed to want to extend their time, even when they acknowledged their routine varied.

AHB.110 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?

* **Read if necessary:** How many times per day, per week, per month, or per year do you do these activities?

* **Read if necessary:** This question is asking about physical activities (exercise, sports, physically active hobbies) that you may do in your leisure time.

Times per:	Time period:
(0) Never (AHB.130)	Day, Week, Month, Year
(1-995) 1-995	
(996) Unable to do this type of activity (AHB.130)	
(997) Refused (AHB.130)	
(999) Don't know (AHB.130)	

The issue of leisure time discussed in AHB.090 also caused conceptual difficulties here. One physically disabled man initially counted walking up steps, but then discounted that activity, as he viewed it as work and not leisure. He did not count his physical therapy either, as that was not activity done in his leisure time.

Also, people repeated information that they had already given to the vigorous activity question, resulting in an overestimate for AHB.090 and more interview time to improve the accuracy of the answer.

Another type of conceptual difficulty is that participants had wildly different ideas of what light or moderate exercise was. One woman counted lying in the bathtub, possibly because she does a little sweating there. Another woman said she gardens, which is strenuous but would not report that in the question, which she perceived as not asking about activities of daily living, although a man with post-polio did report activities of daily living like vacuuming, which is very strenuous for him. One person reported opportunistic exercise as opposed to regular, planned physical activity, while most people did not report opportunistic exercise. One woman reported doing laundry and taking care of her children as light to moderate activity.

A new complexity issue was found when a participant reported not hearing the 10 minutes in the question. One man counted running for a minute or two to get to his bus in the mornings on the way to work. Another man reported lifting objects for work. He might not have heard the leisure time portion of the question. Someone else reported cleaning that he does for his job. A woman specifically stated she missed the concept of leisure time because it was buried in the question.

The same social desirability issues apply to this question also. The man reporting opportunistic exercise and the woman reporting her child care may have done so because they wanted to give the impression of being healthy.

AHB.120 About how long do you do these light or moderate leisure-time physical activities each time?

Number:	Time period:
(1-995) 1-995	(1) Minutes
(997) Refused	(2) Hours
(999) Don't know (AHB.130)	

The questionnaire problem involved people being routed into this question who had answered taking care of children or activities done at work. This was confusing for the participant and caused them to come up with a random number to answer the question.

One man increased the length of his activity when he answered this question; this may be due to social desirability bias or because his routine was so variable; the time he spent walking was dependent on the weather. People answered with ranges again; the time ranges varied from five to 90 minutes long.

AHB.130 How often do you do leisure-time physical activities specifically designed to STRENGTHEN your muscles such as lifting weights or doing calisthenics? (Include all such activities even if you have mentioned them before.)

*** Read if necessary:** How many times per day, per week, per month, or per year do you do these activities?

*** Read if necessary:** This question is asking about physical activities (exercise, sports, physically active hobbies) that you may do in your leisure time.

Times per:	Time period:
(0) Never	Day, Week, Month, Year
(1-995) 1-995	
(996) Unable to do this type of activity (AHB.140)	
(997) Refused (AHB.140)	
(999) Don't know (AHB.140)	

Hardly anyone was able to correctly define calisthenics. Participants cited using a step machine, physical therapy, exercises to increase heart rate, group aerobic exercise, running, and bicycle riding as examples of calisthenics.

Leisure time again caused some conceptual difficulties.

Lack of a time frame tripped up a man who replied never, because he had not lifted weights in the past year. Another man who was using a 30 day time frame switched

his time frame during this question to his average exercise in the past year. This also could also be because he did not want to answer never; he had been ill for three months and had not exercised while ill.

Some incorrect answers, like a man who reported riding a bicycle, may have been due to the question's complexity. The phrase 'strengthens muscles' may get lost, so participants try to find an exercise behavior they had not reported already.

Part C - Alcohol

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.

AHB.140 In ANY ONE YEAR, have you had at least 12 drinks of any type of alcoholic beverage?

- (1) Yes (AHB.160)
- (2) No (AHB.150)
- (7) Refused (AHB.150)
- (9) Don't know (AHB.150)

This question seemed to work well.

AHB.150 In your ENTIRE LIFE, have you had at least 12 drinks of any type of alcoholic beverage?

- (1) Yes (AHB.160)
- (2) No (AHB.210)
- (7) Refused (AHB.210)
- (9) Don't know (AHB.210)

This question seemed to work well.

AHB.160 In the PAST YEAR, how often did you drink any type of alcoholic beverage?

*** Read if necessary:** How many days per week, per month, or per year did you drink.

- | | |
|----------------------------|----------------|
| Number of days: | Time period: |
| (0) Never (AHB.210) | (0) Never/None |
| (1-365) 1-365 (AHB.170) | (1) Week |
| (997) Refused (AHB.210) | (2) Month |
| (999) Don't know (AHB.210) | (3) Year |

AHB.170 In the PAST YEAR, on those days that you drank alcoholic beverages, on the average, how many drinks did you have?

*** Enter '1' if less than 1 drink.**

*** Enter '95' if 95 or more drinks.**

(1-94) 1-94 drinks

(95) 95 and more

(97) Refused

(99) Don't know

For AHB.160 and AHB.170, coming up with an estimate seemed difficult and took some participants a few minutes. People usually answered in ranges, so field interviewers may have to make rounding decisions for this question.

AHB.180 In the PAST YEAR, on how many DAYS did you have 5 or more drinks of any alcoholic beverage?

*** Read if necessary:** How many days per week, per month, or per year did you have 5 or more drinks in a single day?

Number of days:	Time period:
(0) Never/none	(0) Never/None
(1-365) 1-365 days	(1) Week
(997) Refused	(2) Month
(999) Don't know	(3) Year

This question seemed to work well. Only five people were skipped here, and four of them responded never. The other participant did have some difficulty with his estimation. He ended up estimating how many friends' birthdays and special events happened in the last year, as that was usually when he drank five or more drinks.

AHB.210 On average, how many hours of sleep do you get in a 24-hour period?

_____ (3-24) 3-24 hours

(97) Refused

(99) Don't know

Conceptual difficulties stemmed from some people including naps while others did not. Some respondents also initially replied with the time they spent in bed; upon probing, they stated they were often awake for some of this time.

Knowledge/recall problems are based on how many people estimated their answer. Again, people tended to answer in ranges. One woman's sleep patterns were so variable she averaged her sleep over a month. People can have widely varied amounts of sleep; on weekdays people may sleep less than the on weekends. Some sleep schedules depend on the energy and health of young children. Other people just have erratic sleep schedules. All of these make averaging an amount of sleep difficult. Some people just were not sure how much sleep they got.

AIDS

The next questions are about the test for HIV, (the virus that causes AIDS).

ADS.040

[If the participant has donated blood, read:]

Except for tests you may have had as part of blood donations, have you ever been tested for HIV?

[Else, read:]

Have you ever been tested for HIV?

[endif]

- | | |
|----------------|-----------|
| (1) Yes | (ADS.065) |
| (2) No | (ADS.050) |
| (7) Refused | (ADS.140) |
| (9) Don't know | (ADS.140) |

The same issue caused both of these response errors; a lack of knowledge co-exists with the active versus passive testing concept. A few participants reported not knowing if they had been tested for HIV. For example, one man reported he probably had not been tested for HIV. This relates to the concept of active HIV tests, where someone actively seeks out an HIV test, and passive HIV testing, where a person may assume that he/she has been tested by a regular physician while giving blood for other diagnostic tests. The knowledge part of the problem comes from people not knowing what their physician tests them for and thus not being able to report accurately or confidently if they have been tested. Another man responded that he did not think so, but he could not clearly answer yes or no to the question. He did not have that knowledge.

ADS.050 I am going to show you a list of reasons why some people have not been tested for HIV (the virus that causes AIDS). Which one of these would you say is the MAIN reason why you have not been tested?

Flashcard A11

- (01) It's unlikely you've been exposed to HIV
- (02) You were afraid to find out if you were HIV positive (that you had HIV)
- (03) You didn't want to think about HIV or about being HIV positive
- (04) You were worried your name would be reported to the government if you tested positive
- (05) You didn't know where to get tested
- (06) You don't like needles
- (07) You were afraid of losing job, insurance, housing, friends, family, if people knew you were positive for AIDS infection
- (08) Some other reason (ADS.055)
- (09) No particular reason
- (97) Refused
- (99) Don't Know

Even participants who admitted they had other possible answers to this question chose (01), it's unlikely they've been exposed to HIV. In this interview, an interviewer suspected social desirability bias when a man who discussed answers two and eight in the probing chose one. It may be easier and more socially desirable to report one than to report being afraid or worried.

ADS.055 What was the main reason why you have not been tested?

Main reason:

This question was not tested, as no participants were skipped here.

ADS.065 **Flashcard A12**

I am going to show you a list of reasons why some people have been tested for HIV, (the virus that causes AIDS).

[If the participant has donated blood, read:]

Not including your blood donations, which of these would you say was the MAIN reason for your last HIV test?

[Else, read:]

Which of these would you say was the MAIN reason for your last HIV test?

- (01) Someone suggested you should be tested
 - (02) You might have been exposed through sex or drug use
 - (03) You might have been exposed through your work or at work
 - (04) You just wanted to find out if you were infected or not
 - (05) For part of a routine medical check-up or for hospitalization or a surgical procedure
 - (06) You were sick or had a medical problem
 - (07) You were pregnant or delivered a baby
 - (08) For health or life insurance coverage
 - (09) For military induction, separation, or military service
 - (10) For immigration
 - (11) For marriage license or to get married
 - (12) You were concerned you could give HIV to someone
 - (13) You wanted medical care or new treatments if you tested positive
- Some other reason Go to ADS.066
- (13) No particular reason
 - (97) Refused
 - (99) Don't know

Conceptual difficulty was caused by response option two assuming knowledge of partner's status. Social desirability bias may have been present when participants chose no particular reason; this is an issue similar to that discussed in ADS.050.

Questionnaire problems were found for HIV+ participants. One of the interviewers interviewed an HIV+ person, who was tested regularly to determine the levels of virus in his blood and his immunological functioning. He was thinking about his first test, when he was diagnosed, not his most recent test. None of the responses really fit the experiences of an HIV+ person.

Inadequate response options are caused by the many possible answers. Over use of no particular reason is a concern. The response options are overly complex and led to use of response 13 rather than response 1, which actually both applied to the participant's situation.

ADS.066 What was the main reason for your last HIV test?

Main reason: _____

One person answered this question. She received her HIV test through an NIH-sponsored research study. This question seemed to work well.

ADS.140 What are your chances of GETTING HIV, (the virus that causes AIDS)?
Would you say high, medium, low, or none?

- (1) High
- (2) Medium
- (3) Low
- (4) None
- (5) Already have HIV or AIDS
- (7) Refused
- (9) Don't know

The conceptual difficulty is caused by the structure of the question, which essentially assumes the respondent is HIV-negative. Although option 5 does exist to handle that case, the question root itself could cause confusion in an interview with someone who is HIV-positive, as happened in an interview done in the QDRL. Also, the possibility exists that people don't have a good idea what puts them at risk for HIV, so this question may not be adequately capturing risk behavior.

A few sexually active respondents chose none; the emergent probing revealed them to be at some risk for infection. Social desirability bias is one explanation for people downgrading their risk.

ADS.150 **Flashcard A14**

Tell me if ANY of these statements is true for YOU. Do NOT tell me WHICH Statement or statements are true for you. Just IF ANY of them are.

- (a) You have hemophilia and have received clotting factor concentrations.
 - (b) You are a man who has had sex with other men, even just one time.
 - (c) You have taken street drugs by needle, even just one time.
 - (d) You have traded sex for money or drugs, even just one time.
 - (e) You have tested positive for HIV, (the virus that causes AIDS).
 - (f) You have had sex (even just one time) with someone who would answer “yes” to any of these statements.
-
- (1) Yes, at least one statement is true
 - (2) No, none of these statements are true
 - (7) Refused
 - (9) Don't know

Response option d is rather ambiguous. What about someone who's traded drugs for sex? Or money for sex? It is unclear if the question is trying to identify sex providers or their clients or both. Response option f assumes substantial knowledge of a partner's risk status.

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Appendix A – Original Questionnaire Used in Testing

I am now going to ask about your general health and the effects of any physical, mental, or emotional health problems. Please answer these questions as you would as if you were talking to me at your home, because that's where this survey generally takes place.

FHS.070 Because of a physical, mental, or emotional problem, do you need the help of other persons with PERSONAL CARE NEEDS, such as eating, bathing, dressing, or getting around inside this home?

- (1) Yes (FHS.090)
- (2) No (FHS.150)
- (7) Refused (FHS.150)
- (9) Don't Know (FHS.150)

FHS.090 Do you need the help of other persons with?

- (1) Yes (FHS.150)
- (2) No (FHS.150)
- (7) Don't know (FHS.150)
- (9) Refused (FHS.150)

Bathing or showering?

Dressing?

Eating?

Getting in or out of bed or chairs?

Using the toilet, including getting to the toilet?

Getting around inside the home?

FHS.150 Because of a physical, mental, or emotional problem, do {you} need the help of other persons in handling ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

- (1) Yes (FHS.170)
- (2) No (FHS.170)
- (7) Refused (FHS.170)
- (9) Don't Know (FHS.170)

FHS.170 Does a physical, mental, or emotional problem NOW keep you from working at a job or business?

- (1) Yes (FHS.190)
- (2) No (FHS.190)
- (7) Refused (FHS.190)
- (9) Don't know (FHS.190)

FHS.190 Are you limited in the kind or amount of work you can do because of a physical, mental or emotional problem?

- (1) Yes (FHS.210)
- (2) No (FHS.210)
- (7) Refused (FHS.210)
- (9) Don't know (FHS.210)

FHS.210 Because of a health problem, do you have difficulty walking without using any special equipment?

- (1) Yes (FHS.230)
- (2) No (FHS.230)
- (7) Refused (FHS.230)
- (9) Don't know (FHS.230)

FHS.230 Are you LIMITED IN ANY WAY because of difficulty remembering or because you experience periods of confusion?

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

FHS.250 Are you LIMITED IN ANY WAY in any activities because of physical, mental or emotional problems?

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

FHS.350 *Only ask this question if the participant stated they had a limitation.*

Flashcard F2

What conditions or health problems cause your limitations? Please select all that apply.

- (1) Vision/problem seeing
- (2) Hearing problem
- (3) Arthritis/rheumatism
- (4) Back or neck problem
- (5) Fracture, bone/joint injury
- (6) Other injury

- (7) Heart problem
- (8) Stroke problem
- (9) Hypertension/high blood pressure
- (10) Diabetes
- (11) Lung/breathing problem (e.g., asthma and emphysema)
- (12) Cancer
- (13) Birth defect
- (14) Mental retardation
- (15) Other developmental problem (e.g. cerebral palsy)
- (16) Senility
- (17) Depression/anxiety/emotional problem
- (18) Weight problem
- (19) Missing limbs (fingers, toes or digits), amputee
- (20) Kidney, bladder or renal problems
- (21) Circulation problems (including blood clots)
- (22) Benign tumors, cysts
- (23) Fibromyalgia, lupus
- (24) Osteoporosis, tendinitis
- (25) Epilepsy, seizures
- (26) Multiple Sclerosis (MS), Muscular Dystrophy (MD)
- (27) Polio(myelitis), paralysis, para/quadruplegia
- (28) Parkinson's disease, other tremors
- (29) Other nerve damage, including carpal tunnel syndrome
- (30) Hernia
- (31) Ulcer
- (32) Varicose veins, hemorrhoids
- (33) Thyroid problems, Grave's disease, gout
- (34) Knee problems (not arthritis (03), not joint injury(05))
- (35) Migraine headaches (not just headaches)
- (36) Other impairment/problem (Specify one)_____
- (37) Other impairment/problem (Specify one)_____
- (97) Refused
- (99) Don't know/not sure

FHS.500
or poor?

Would you say {your} health in general is excellent, very good, good, fair,

- (1) Excellent (Next section)
- (2) Very good (Next section)
- (3) Good (Next section)
- (4) Fair (Next section)
- (5) Poor (Next section)
- (7) Refused (Next section)
- (9) Don't Know (Next section)

HEALTH BEHAVIORS

Part A - Tobacco

These next questions are about cigarette smoking.

AHB.010 Have you smoked at least 100 cigarettes in your ENTIRE LIFE?

- | | |
|----------------|-----------|
| (1) Yes | (AHB.020) |
| (2) No | (AHB.090) |
| (7) Refused | (AHB.090) |
| (9) Don't know | (AHB.090) |

AHB.020 How old were you when you FIRST started to smoke fairly regularly?

- * Enter '6' if less than 6 years old.
- * Enter '95' if 95 years old or older.

- | |
|-----------------------------|
| (6-94) 6-94 years of age |
| (95) 95 years or older |
| (96) Never smoked regularly |
| (97) Refused |
| (99) Don't know |

AHB.030 Do you NOW smoke cigarettes every day, some days or not at all?

- | | |
|----------------|-----------|
| (1) Every day | (AHB.050) |
| (2) Some days | (AHB.060) |
| (3) Not at all | (AHB.040) |
| (7) Refused | (AHB.060) |
| (9) Don't know | (AHB.060) |

AHB.040 How long has it been since you quit smoking cigarettes?

- * Enter '95' for 95 years old or older.

- | Number: | Time Period: |
|-----------------|----------------|
| (1-94) 1-94 | (1) Days |
| (95) 95+ | (2) Weeks |
| (97) Refused | (3) Months |
| (99) Don't know | (4) Years |
| | (7) Refused |
| | (9) Don't know |

ADS.050 I am going to show you a list of reasons why some people have not been tested for HIV (the virus that causes AIDS). Which one of these would you say is the MAIN reason why you have not been tested?

Flashcard A11

- (01) It's unlikely you've been exposed to HIV
- (02) You were afraid to find out if you were HIV positive (that you had HIV)
- (03) You didn't want to think about HIV or about being HIV positive
- (04) You were worried your name would be reported to the government if you tested positive
- (05) You didn't know where to get tested
- (06) You don't like needles
- (08) You were afraid of losing job, insurance, housing, friends, family, if people knew you were positive for AIDS infection
- (08) Some other reason (ADS.055)
- (09) No particular reason
- (97) Refused
- (99) Don't Know

AHB.060 On how many of the PAST 30 DAYS did you smoke a cigarette?

*** Enter '0' for none.**

- (0) None (AHB.080)
- (1-30) Days (AHB.070)
- (97) Refused (AHB.070)
- (99) Don't know (AHB.070)

AHB.070 On the average, when you smoked during the PAST 30 DAYS, about how many cigarettes did you smoke a day?

*** Enter '1' if less than 1.**

*** Enter '95' if 95 or more cigarettes.**

- (1-94) 1-94 cigarettes (AHB.080)
- (95) 95+ cigarettes (AHB.080)
- (97) Refused (AHB.080)
- (99) Don't know (AHB.080)

AHB.080 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
- (7) Refused
- (9) Don't know

Part B - Physical Activity

The next questions are about physical activities that you may do in your LEISURE time. (Read only if they ask exercise, sports, physically active hobbies...)

AHB.090 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?

*** Read if necessary:** How many times per day, per week, per month, or per year do you do these activities?

- | | |
|--|------------------------|
| Times per: | Time period: |
| (0) Never (AHB.110) | Day, Week, Month, Year |
| (1-995) 1-995 | |
| (996) Unable to do this type of activity (AHB.110) | |
| (997) Refused (AHB.110) | |
| (999) Don't know (AHB.110) | |

AHB.100 About how long do you do these vigorous leisure-time physical activities each time?

- | | |
|----------------------------|--------------|
| Number: | Time period: |
| ____(1-995) 1-995 | (1) Minutes |
| (997) Refused (AHB.110) | (2) Hours |
| (999) Don't know (AHB.110) | |

AHB.110 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?

* **Read if necessary:** How many times per day, per week, per month, or per year do you do these activities?

* **Read if necessary:** This question is asking about physical activities (exercise, sports, physically active hobbies) that you may do in your leisure time.

Times per:	Time period:
(0) Never (AHB.130)	Day, Week, Month, Year
(1-995) 1-995	
(996) Unable to do this type of activity (AHB.130)	
(997) Refused (AHB.130)	
(999) Don't know (AHB.130)	

AHB.120 About how long do you do these light or moderate leisure-time physical activities each time?

Number:	Time period:
(1-995) 1-995	(1) Minutes
(997) Refused	(2) Hours
(999) Don't know (AHB.130)	

AHB.130 How often do you do leisure-time physical activities specifically designed to STRENGTHEN your muscles such as lifting weights or doing calisthenics? (Include all such activities even if you have mentioned them before.)

* **Read if necessary:** How many times per day, per week, per month, or per year do you do these activities?

* **Read if necessary:** This question is asking about physical activities (exercise, sports, physically active hobbies) that you may do in your leisure time.

Times per:	Time period:
(0) Never	Day, Week, Month, Year
(1-995) 1-995	
(996) Unable to do this type of activity (AHB.140)	
(997) Refused (AHB.140)	
(999) Don't know (AHB.140)	

Part C - Alcohol

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.

AHB.140 In ANY ONE YEAR, have you had at least 12 drinks of any type of alcoholic beverage?

- (1) Yes (AHB.160)
- (2) No (AHB.150)
- (7) Refused (AHB.150)
- (9) Don't know (AHB.150)

AHB.150 In your ENTIRE LIFE, have you had at least 12 drinks of any type of alcoholic beverage?

- (1) Yes (AHB.160)
- (2) No (AHB.210)
- (7) Refused (AHB.210)
- (9) Don't know (AHB.210)

AHB.160 In the PAST YEAR, how often did you drink any type of alcoholic beverage?

*** Read if necessary:** How many days per week, per month, or per year did you drink.

- | | |
|----------------------------|----------------|
| Number of days: | Time period: |
| (0) Never (AHB.210) | (0) Never/None |
| (1-365) 1-365 (AHB.170) | (1) Week |
| (997) Refused (AHB.210) | (2) Month |
| (999) Don't know (AHB.210) | (3) Year |

AHB.170 In the PAST YEAR, on those days that you drank alcoholic beverages, on the average, how many drinks did you have?

*** Enter '1' if less than 1 drink.**

*** Enter '95' if 95 or more drinks.**

- (1-94) 1-94 drinks
- (95) 95 and more
- (97) Refused
- (99) Don't know

AHB.180 In the PAST YEAR, on how many DAYS did you have 5 or more drinks of any alcoholic beverage?

* **Read if necessary:** How many days per week, per month, or per year did you have 5 or more drinks in a single day?

Number of days:	Time period:
(0) Never/none	(0) Never/None
(1-365) 1-365 days	(1) Week
(997) Refused	(2) Month
(999) Don't know	(3) Year

AHB.210 On average, how many hours of sleep do you get in a 24-hour period?

_____ (3-24) 3-24 hours
(97) Refused
(99) Don't know

AIDS

The next questions are about the test for HIV, (the virus that causes AIDS).

ADS.040 **[If the participant has donated blood, read:]**

Except for tests you may have had as part of blood donations, have you ever been tested for HIV?

[Else, read:]

Have you ever been tested for HIV?

[endif]

- | | |
|----------------|-----------|
| (1) Yes | (ADS.065) |
| (2) No | (ADS.050) |
| (7) Refused | (ADS.140) |
| (9) Don't know | (ADS.140) |

ADS.050 I am going to show you a list of reasons why some people have not been tested for HIV (the virus that causes AIDS). Which one of these would you say is the MAIN reason why you have not been tested?

Flashcard A11

- (01) It's unlikely you've been exposed to HIV
- (02) You were afraid to find out if you were HIV positive (that you had HIV)
- (03) You didn't want to think about HIV or about being HIV positive
- (04) You were worried your name would be reported to the government if you tested positive
- (05) You didn't know where to get tested

- (06) You don't like needles
- (09) You were afraid of losing job, insurance, housing, friends, family, if people knew you were positive for AIDS infection
- (08) Some other reason (ADS.055)
- (09) No particular reason
- (97) Refused
- (99) Don't Know

ADS.055 What was the main reason why you have not been tested?

Main reason:

ADS.065 **Flashcard A12**

I am going to show you a list of reasons why some people have been tested for HIV, (the virus that causes AIDS).

[If the participant has donated blood, read:]

Not including your blood donations, which of these would you say was the MAIN reason for your last HIV test?

[Else, read:]

Which of these would you say was the MAIN reason for your last HIV test?

- (01) Someone suggested you should be tested
 - (02) You might have been exposed through sex or drug use
 - (03) You might have been exposed through your work or at work
 - (04) You just wanted to find out if you were infected or not
 - (05) For part of a routine medical check-up or for hospitalization or a surgical procedure
 - (06) You were sick or had a medical problem
 - (07) You were pregnant or delivered a baby
 - (08) For health or life insurance coverage
 - (09) For military induction, separation, or military service
 - (10) For immigration
 - (11) For marriage license or to get married
 - (12) You were concerned you could give HIV to someone
 - (13) You wanted medical care or new treatments if you tested positive
- Some other reason Go to ADS.066
- (13) No particular reason
 - (97) Refused
 - (99) Don't know

ADS.066 What was the main reason for your last HIV test?

Main reason:_____

ADS.140 What are your chances of GETTING HIV, (the virus that causes AIDS)?
Would you say high, medium, low, or none?

- (1) High
- (2) Medium
- (3) Low
- (4) None
- (5) Already have HIV or AIDS
- (7) Refused
- (9) Don't know

ADS.150 **Flashcard A14**

Tell me if ANY of these statements is true for YOU. Do NOT tell me WHICH Statement or statements are true for you. Just IF ANY of them are.

- (a) You have hemophilia and have received clotting factor concentrations.
 - (b) You are a man who has had sex with other men, even just one time.
 - (c) You have taken street drugs by needle, even just one time.
 - (d) You have traded sex for money or drugs, even just one time.
 - (e) You have tested positive for HIV, (the virus that causes AIDS).
 - (f) You have had sex (even just one time) with someone who would answer "yes" to any of these statements.
-
- (1) Yes, at least one statement is true
 - (2) No, none of these statements are true
 - (7) Refused
 - (9) Don't know

Flashcard F2

- (1) Vision/problem seeing
- (2) Hearing problem
- (3) Arthritis/rheumatism
- (4) Back or neck problem
- (5) Fracture, bone/joint injury
- (6) Other injury
- (7) Heart problem
- (8) Stroke problem
- (9) Hypertension/high blood pressure
- (10) Diabetes
- (11) Lung/breathing problem (e.g., asthma and emphysema)
- (12) Cancer
- (13) Birth defect
- (14) Mental retardation
- (15) Other developmental problem (e.g. cerebral palsy)
- (16) Senility
- (17) Depression/anxiety/emotional problem
- (18) Weight problem
- (19) Missing limbs (fingers, toes or digits), amputee
- (20) Kidney, bladder or renal problems
- (21) Circulation problems (including blood clots)
- (22) Benign tumors, cysts
- (23) Fibromyalgia, lupus
- (24) Osteoporosis, tendinitis
- (25) Epilepsy, seizures
- (26) Multiple Sclerosis (MS), Muscular Dystrophy (MD)
- (27) Polio(myelitis), paralysis, para/quadruplegia
- (28) Parkinson's disease, other tremors
- (29) Other nerve damage, including carpal tunnel syndrome
- (30) Hernia
- (31) Ulcer
- (32) Varicose veins, hemorrhoids
- (33) Thyroid problems, Grave's disease, gout
- (34) Knee problems (not arthritis (03), not joint injury(05))
- (35) Migraine headaches (not just headaches)
- (36) Other impairment/problem (Specify one) _____
- (37) Other impairment/problem (Specify one) _____
- (97) Refused
- (99) Don't know/not sure

Flashcard A11

- (01) It's unlikely you've been exposed to HIV
- (02) You were afraid to find out if you were HIV positive (that you had HIV)
- (03) You didn't want to think about HIV or about being HIV positive
- (04) You were worried your name would be reported to the government if you tested positive
- (05) You didn't know where to get tested
- (06) You don't like needles
- (10) You were afraid of losing job, insurance, housing, friends, family, if people knew you were positive for AIDS infection
- (08) Some other reason (ADS.055)
- (09) No particular reason
- (97) Refused
- (99) Don't Know

Flashcard A12

- (01) Someone suggested you should be tested
- (02) You might have been exposed through sex or drug use
- (03) You might have been exposed through your work or at work
- (04) You just wanted to find out if you were infected or not
- (05) For part of a routine medical check-up or for hospitalization or a surgical procedure
- (06) You were sick or had a medical problem
- (07) You were pregnant or delivered a baby
- (08) For health or life insurance coverage
- (09) For military induction, separation, or military service
- (10) For immigration
- (11) For marriage license or to get married
- (12) You were concerned you could give HIV to someone
- (13) You wanted medical care or new treatments if you tested positive
- Some other reason Go to ADS.066
- (13) No particular reason
- (97) Refused
- (99) Don't know

Flashcard A14

- (a) You have hemophilia and have received clotting factor concentrations.
- (b) You are a man who has had sex with other men, even just one time.
- (c) You have taken street drugs by needle, even just one time.
- (d) You have traded sex for money or drugs, even just one time.
- (e) You have tested positive for HIV, (the virus that causes AIDS).
- (f) You have had sex (even just one time) with someone who would answer “yes” to any of these statements.