

Adults with Chronic Healthcare Needs: Results of Cognitive Testing

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Introduction

This report summarizes the findings from three rounds of testing designed to evaluate questions concerning adults with chronic healthcare needs (ACHCN). These questions were developed by an expert panel at the NIH CRC/RMD (National Institutes of Health Clinical Research Center/Rehabilitation Medicine Department). The panel developed these questions with the broad objective of improving the surveillance and monitoring of health care and related service need and use among people with chronic conditions and/or disabilities at the population level (NIH 2013). The panel defined this population as:

Adults with [1] ongoing physical, cognitive, or mental health conditions or difficulties functioning who [2] need health or related support services of a type or amount beyond that needed by adults of the same sex and similar age (NIH 2013).

The panel recorded its specific purpose as follows:

“to develop a screening instrument intended for use in health surveys and designed to provide the health services research community with the capacities to: a) identify working age adults with chronic health care needs in a consistent manner (prevalence estimation); b) estimate the prevalence, type and level of health care needs in this population (needs assessment), and c) by planning for the inclusion of the screener in more extensive surveys, provide further estimates of key diagnostic, process or outcome measures (access, quality, coordination, cost, health, specific health conditions, functional limitations, etc.) among adults with chronic health care needs in the future” (NIH 2013, p.4.)

RMD approached NCHS/QDRL for its assistance with cognitive testing of competing question formulations and approaches in seven major domains, including: medical care, mental health, prescription medications, therapies, DME and assistive technology, disability, and chronic conditions which (described more fully in table 1). The initial questions (typically 3 in each domain) were drawn from the panel’s own deliberations, the Children with Special Health Care Needs screener (MCHB), the Adults with Special Healthcare needs screener (CAHMI), the ACS-6 disability screener (ACS Disability Subcommittee) and numerous other sources related to the measurement of disability, chronic health or mental health conditions in the adult population. The questions originally delivered to QDRL are listed in table 1 side by side with the finalized versions. As will be detailed in this report, the work between RMD and QDRL was iterative, including meetings and correspondence in between rounds of data collection. In this way, the content and structure of the questions was sequentially altered with the goals of increased clarity and accuracy of responses at each stage.

Table 1. ACHCN domains, constructs and questions

| Domain | Construct | Original Questions | Revised questions ¹ |
|----------------------------|---|---|--|
| 1: Medical care | Visits to medical professionals | <p>A. Do you need or use medical care, mental health, or other health services on a regular basis? (Y/N)</p> <p>B. Do you need or use medical care or other health services more than people your age? (Y/N)</p> <p>C. Other than your annual check-up, do you need or use medical care or other health services on a regular basis? (Y/N)</p> | <p>Do you see medical doctors about your health often? Please do not include an annual check-up in your response. (Y/N)</p> <p>If no: Are you often unable to see a medical doctor when you need to?</p> |
| 2: Mental health | Treatment for mental health, substance abuse and emotional issues | <p>A. Do you need or get treatment or counseling for any kind of mental health, substance abuse, or emotional problem? (Y/N)</p> <p>B. Do you need or use mental health treatment or support such as prescription medications or counseling services on a regular basis? (Y/N)</p> <p>C. Do you need or get treatment or counseling for any kind of mental health, substance abuse, or emotional problem? (Y/N)</p> | <p>Do you use mental health treatment or support such as counseling or substance abuse services?</p> <p>If no: Do you need mental health treatment or support that you do not receive?</p> |
| 3: Prescription medication | Medications used on an ongoing or regular basis | <p>A. Because of a physical, medical, or mental health condition that has a significant effect on your health, do you regularly need or use prescription medications? (Y/N)</p> <p>B. Do you currently need or take prescription medicine (other than vitamins or birth control pills)? (Y/N)</p> | <p>Do you use prescription medicine regularly (other than vitamins or birth control pills)?</p> <p>If no: Do you regularly need prescription medicine that you do not receive?</p> |
| 4: Therapies | Medical therapies | <p>A. Do you need or get special therapy? (For example:</p> | <p>Do you use medical or other therapies often?</p> |

Table 1. ACHCN domains, constructs and questions

| | | | |
|---|---|---|---|
| | (construed broadly) used on an ongoing / regular basis | <p>physical, occupational, speech or respiratory therapy) (Y/N)</p> <p>B. Do you need or use rehabilitative, medical, or complementary/alternative therapies on a regular basis? (Y/N)</p> <p>C. Do you need or use medical or other therapies such as dialysis, physical therapy, or acupuncture on a periodic or regular basis? (Y/N)</p> | <p>(alternative) Do you often use medical or other therapies such as dialysis, physical therapy, or therapy to manage or reduce pain?</p> <p>If no: Do you often need medical or other therapies that you do not receive?</p> |
| 5: Medical equipment and assistive technology | Items such as canes, walkers, medication pumps and hearing aids | <p>A. Do you have an ongoing need for or use of medical equipment or assistive devices such as prostheses, mobility aids, or medication pumps? (Y/N)</p> <p>B. Do you have an ongoing need for or use of medical equipment or assistive devices such as walking aids, communication devices, or breathing aids? (Y/N)</p> | <p>Do you use medical equipment or assistive devices often?</p> <p>If no: Do you need medical equipment or assistive devices that you do not have?</p> |
| 6: Disability | Physical and mental functional limitations | <p>A. Do you have difficulty doing or need assistance to do day-to-day activities? (For example: work, go to school, do housework, socialize, cook, do paperwork) (Y/N)</p> <p>B. ACS-6 questions</p> | ACS-6 questions |
| 7: Chronic conditions | One or more chronic conditions | <p>A. Follow-up questions in each domain</p> <p>B. Do you have ANY serious medical, mental health, or other health condition that has lasted or is expected to last for at least 12 months?</p> | Do you have ANY medical, mental health, or other health condition that has lasted or is expected to last for at least 12 months? (Y/N) |

Table 1. ACHCN domains, constructs and questions

| | | | |
|--|--|---|--|
| | | If yes: Do you have two or more of these serious, ongoing health conditions?" (Y/N) | |
|--|--|---|--|

¹ Final instrument is presented in the appendix

The following report is organized into four sections. Following this initial introduction, Section Two discusses the methods used in the question evaluation study, including the sample selection, sample characteristics, and interviewing procedure. Section Two also summarizes the cognitive interviewing methodology and describes how data analysis was conducted. Section Three provides a summary overview of the findings. Section Four presents a detailed question-by-question review of the findings. The final version of the instrument (as tested in Round Three) is presented in Appendix A.

Methods

Cognitive Interviewing: The aim of a cognitive interviewing study is to investigate how well survey questions perform when asked of respondents, that is, if respondents understand the questions according to their intended design and if they can provide accurate answers based on that intent. As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves a survey’s scientific goals. Findings of a cognitive interviewing project typically lead to recommendations for improving a survey question. Alternatively, results can be used in post-survey analysis to assist in data interpretation.

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

As a qualitative method, the sample selection for a cognitive interviewing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute that is relevant to the type of questions being examined. When studying questions designed to identify persons with chronic conditions, for example, the sample would likely consist of respondents with previously identified chronic conditions and, to discover potential causes of false positive or false negative reporting, some respondents with no known chronic condition. Because of the small sample size, not all social and demographic groups are

represented. Analysis of cognitive interviews does not produce generalizable findings in a statistical sense, but rather, provides an explicit understanding of response processes including patterns of interpretation.

As is normally the case for analyses of qualitative data, the general process for analyzing cognitive interview data involves synthesis and reduction—beginning with a large amount of textual data and ending with conclusions that are meaningful and serve the ultimate purpose of the study. For analysis of cognitive interviews, reduction and synthesis can be conceptualized within five incremental steps—conducting interviews, producing summaries, comparing across respondents, comparing across subgroups of respondents, and reaching conclusions. With each incremental step, a data reduction product is created (Miller, Willson, Chepp and Padilla, 2014). The steps consist of: 1) Conducting interviews to produce interview text; 2) Synthesizing interview text into summaries to produce detailed summaries; 3) Comparing summaries across respondents; 4) Comparing identified themes across subgroups; and 5) Making conclusions. Although these steps are described separately and in a linear fashion, in practice they are iterative; varying levels of analysis typically occur throughout the qualitative research process.

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. In detailing a question’s performance, it is possible to understand the ways in which a question is interpreted by various groups of respondents, the processes that respondents utilize to formulate a response as well as any difficulties that respondents might experience when attempting to answer the question. 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.

Sample: A team of researchers from the National Center for Health Statistic’s Questionnaire Design Research Laboratory interviewed a total of 56 individuals over three rounds of testing. In each of the first two rounds, 20 respondents were interviewed and in the final round 16 respondents were interviewed. The research team recruited a purposive sample of adults aged >18, both with and without (self-identified) chronic conditions or disabilities. Respondents were recruited through newspaper advertisements, flyers, and by contacting previous respondents who met the criteria of this study. A screening process was employed over the telephone to determine the caller’s eligibility for participation. Because questions focused primarily on respondents’ health and health care utilization, particular effort was made to recruit individuals with a variety of health conditions. Additional respondent demographics for the full sample are shown in Table 2.

Table 2: Demographic profile of respondents

| Race | | Age | |
|-------------|----|-------------|----|
| Black | 28 | 18 - 29 | 15 |
| White | 18 | 30 - 49 | 17 |
| Asian | 3 | 50 - 64 | 24 |
| Multiple | 6 | 65 and Over | 0 |

| Race | | Age | |
|--------------|--|-------------------|----|
| Hispanic | | 3 | |
| Non-Hispanic | | 53 | |
| Ethnicity | | Education | |
| | | No HS diploma | 2 |
| | | HS diploma or GED | 8 |
| | | Some college | 20 |
| | | College Degree | 15 |
| Gender | | Graduate Degree | |
| Female | | 30 | 10 |
| Male | | 26 | |

Interviewing Procedures: During the interviews, retrospective, intensive verbal probing was used to collect response process data. First, respondents were administered all of the survey questions, and then interviewers returned to each question and probed retrospectively. Probes included such things as: “Why did you answer the way that you did?” “How did you arrive at your response?” “Can you tell me more about that?” “Can you clarify what you mean?” Video and audio recordings and written notes of interview summaries were used to conduct data analysis. All interviews were conducted face-to-face in the Questionnaire Design Research Laboratory. Interviews typically lasted 60 minutes and respondents were given \$40 once the interview was complete.

Data Analysis: Analysis of interviews was performed in the manner described in the above description of cognitive interviewing methodology. After each interview was conducted, summary notes were written for each question. Summary notes included the way in which a respondent interpreted and processed individual questions, what experiences or perceptions the respondent included as they formulated their answer, and any response difficulties experienced by the respondent. After all interviews and summaries were completed, interviews were compared to identify common patterns of interpretation and response difficulties for each question.

A data entry and analysis software application (Q-Notes) was used to conduct analysis. Q-Notes, developed by the QDRL, ensures systematic and transparent analysis across all cognitive interviews as well as provides an audit trail depicting the way in which findings are generated from the raw interview data.

Overall Findings

Health status: Respondents’ perception of their health status was a primary influence on how they responded to questions. For example, respondents who perceive themselves as healthy, tended to base their answers on this perception. This tendency most often resulted in appropriate responses. For example, a “healthy” respondent might be expected to answer “no” to the question on health care usage. Respondents with chronic conditions also tended to answer, as expected, on the basis of their health condition (s). However, this tendency to short-cut the response process could potentially lead to response error when respondents do not attend to the specifics of a question. For example, a respondent

who had had multiple recent bouts with cancer as well as several other incidents of needing care, answered “no” to the question on health care usage because he considers himself “healthy” since he is currently free of cancer.

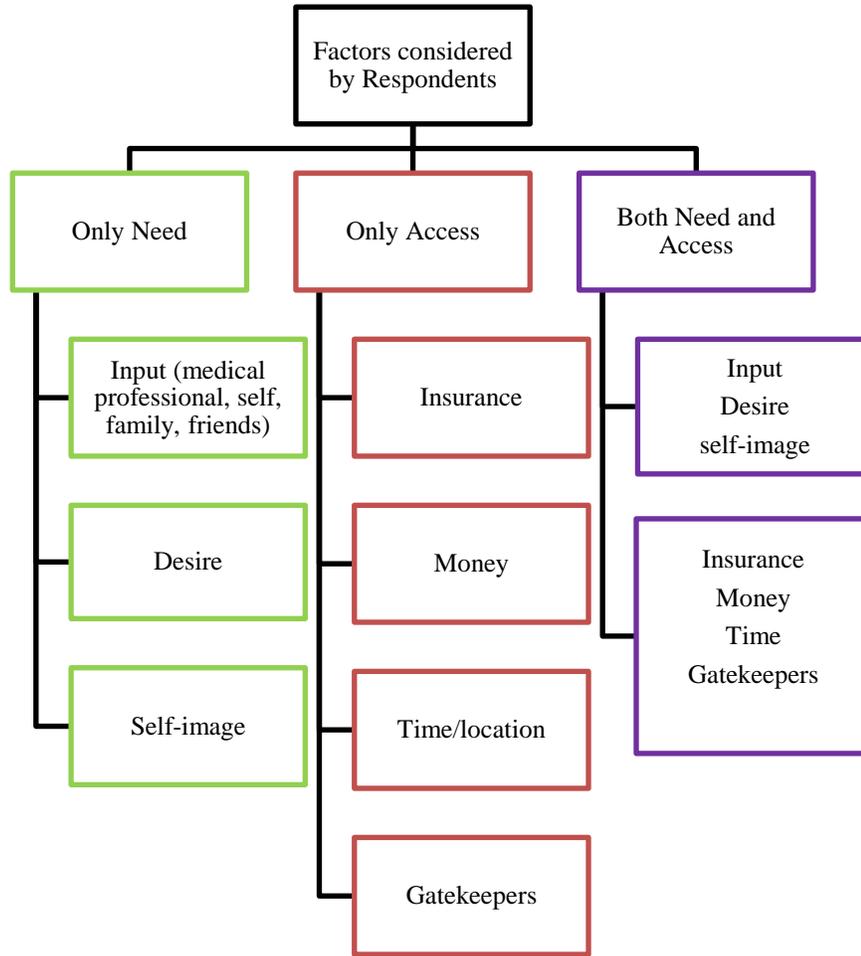
Respondents most often answered based on the condition or conditions that had the most impact on their lives. At times, this led respondents to forget about medications or treatments that did not pertain to their primary condition. For example, a respondent who has depression answered most questions based on her self-concept as “a person with depression.” For this reason, she answered “no” when asked if she had multiple chronic conditions. She was thinking only of the depression and not of her other, less severe, conditions. This pattern was particularly prevalent in Domain 3 (prescription medication). When respondents were asked the number of medications they take, they frequently answered based on medications they take for their primary condition and did not include medications taken for lesser conditions.

Need: A primary goal of the ACHCN survey is to identify both *need* and *use* of health care related to chronic conditions and/or disabilities. While capturing *use* proved to be fairly straightforward, *need* appeared to be a significantly more complex. General issues related to capturing need are described below while specifics of how *need* functioned within individual domains are addressed in the question by question review (Section Four).

Two ways of assessing need were tested. In Round One, within each domain a single question was used to assess both *use* and *need*. For example, respondents were asked, “Do you need or use medical care, mental health, or other health services on a regular basis? (Y/N)” Therefore, respondents were expected to answer “yes” to this question based on both use of medical care AND need of medical care making this a purposefully double-barreled question (based upon the precedent set in the CSHCN screener). However, respondents tended to ignore the *need* aspect of these questions and answered entirely based on *use*. This is likely due to the fact that *use* is easier to assess while *need* is a more complex phenomenon (described below).

In Rounds Two and Three, unmet need (as opposed to need in general) was assessed separately with follow-up questions (rather than within questions also asking about use). For example, in the medical care domain, respondents who answered “no” to the primary question on *use* of medical care, were asked a follow-up question on *need*: “Do you often need care from medical doctors that you do not receive?” Asking two questions rather than one improved respondents’ ability to focus on *need* as separate from *use*.

Figure 1. Response schema for follow-up questions on need



Need appeared to be defined individually within the context of each respondent’s social and medical milieu. Figure 1 visually depicts the response schema associated with questions attempting to assess *need*. In order to formulate answers to these questions, respondents made judgments about their need for care, their access to care or both need and access. Respondents’ assessments of need and access were highly personal, and there was little consistency in how these assessments lead respondents to answer the questions on need.

Judgment of Need: Respondents assessed their healthcare needs by considering both informational inputs, their desire to act on that information and/or their self-image.

Information: Respondents considered one of three sources of information: medical professionals, family or friends, and self-perception. For the most part, respondents relied on the expertise of medical professionals in their assessment of need. If a respondent was told by a medical doctor that they should have a specific test or treatment for a condition, this became significant information in their assessment. For example, one respondent felt she needed a hearing aid because she had been told by an ENT that a hearing aid would help with her hearing loss. For

some respondents need could *only* be determined by a medical professional, and this could be of concern for respondents who lack access to medical care.

Some respondents relied on friends and family to let them know if they needed treatment. While this pattern of relying on input from friends and family was most prevalent in the mental health domain, it was also seen in other domains such as prescription medications (Domain 3). Some respondents noted that depending on family or friends assessments could be unreliable.

Finally, some respondents relied on self-assessment when judging their need for care. Respondents considered symptoms, such as ongoing pain, as cues they might need medical attention. Similarly, respondents who felt “healthy” did not feel the need for care. This pattern was most prevalent in the domains of health care and medical therapy.

Desire: Respondents also considered their desire to act on these informational inputs when assessing their need. Respondents’ desire for treatment was based on convenience, trust in the medical system or concern about side effects. Respondents may think of services as unneeded when they believe treatment will prove inconvenient to them. Other respondents expressed outright distrust of medical professionals and thus do not feel their services are needed. Finally, a few respondents felt that they might need treatment but did not want to deal with the side effects, such as pain.

Self-image: For a few respondents, self-image was significant in informing their assessment of their need for care. Beliefs that equate need for care with stigmatized social statuses (such as being handicapped, being a senior citizen, not being “the kind of persons that needs mental health treatment”) may affect how respondents interpret their needs for care.

Judgment of Access: As depicted in the schema (fig. 1), access to care was also a significant factor for respondents. Determination of *access* to care was also highly personal. Most respondents thought of their ability to cover the cost of services when determining access. Other respondents also included lack of time, difficulty scheduling, location and doctors as barriers to receiving treatment. In considering their ability to cover the cost of treatment many respondents thought of their insurance status. Most respondents with insurance explained that they could get whatever care they wanted because they “have insurance” or “insurance would pay for it.” Similarly, respondents without insurance generally felt they lacked access to care, although a few believed that if they truly needed care, they would find a way to access it.

Time and location were also themes related to how respondents conceptualized access. Time mattered both with regard to delays caused by provider’s schedules, and in some instances, the respondents’ own time constraints. Geographic distance from the provider’s location was also a factor for some respondents.

Finally, a few respondents described how doctors control their access to care. These respondents wanted treatments that their doctors would not authorize.

Response Formulation: Respondents used their assessments of *need* and/or *access* to formulate their responses to the follow-up questions on *need*. Most respondents considered both need and access, though sometimes in inconsistent ways from one respondent to the next.

However, quite a few respondents based their responses solely on *need* without considering *access*. All respondents who determined that they had no need for care answered “no” regardless of their access to care. Additionally, several (n=7) respondents who felt they had a need answered “yes” regardless of access.

Finally, a few respondents (n=5) based their responses to the need questions solely on *access*. For example, several respondents without insurance answered “yes” due to their lack of insurance without considering a specific need.

Partial need: Since questions on unmet *need* were only asked of respondents who answered “no” to the primary questions within each domain, instances of partial unmet need were not captured. This was the intent of the questions as determined during meetings with NIH and QDRL staff. Several respondents answered “yes” to the primary question within a domain based on treatment they were receiving but then also described additional treatment they were not able to get, as intended. This pattern of partial access was particularly prevalent in the domains of mental health and medical therapy.

Summary of questions on unmet needs: The concept of need, or unmet need, is complex and answers to questions in this area will likely be based on a variety of subjective and contextual information. Parsing the unmet need questions from those focused upon service use appears to have improved the performance of the latter, but it remains unclear whether the final round of questions on unmet need performed as intended. It is, at present, difficult to predict what the answers to these questions will produce in the aggregate, and whether such an aggregation would accurately reflect an objective standard of unmet medical needs. Further qualitative study of the roles that such factors as trust in the medical system, convenience of care or self-image play in how respondents conceptualize or answer questions about their unmet needs could be helpful. Field testing in populations with known unmet needs might also provide further information about the performance of these measures as written.

Service Use: Questions on service use were revised throughout the various rounds of testing. In Round One, service use was asked in conjunction with need. When asking respondents about both *need* and *use*, they answered based on use alone. In subsequent rounds of testing, when questions focused solely on *use*, respondents also answered based on *use* alone. For example, asking “Do you need or use medical care, mental health, or other health services on a regular basis?” captured use as did asking, “Do you see medical doctors about your health often? Please do not include an annual check-up in your response.” Questions in other domains were revised to best capture use. Testing often determined whether to use examples in the question. For example, in the medical equipment domain, testing determined that respondents were able to answer the question, “Do you use medical equipment or assistive devices often?” and that examples were not necessary, and could, in fact, be confusing to respondents. Throughout testing, other revisions were made to specific wording and time references to better capture *use*.

Chronic conditions: One of the goals of testing was to determine whether it was necessary to address the presence of chronic conditions as follow up question within each domain or whether chronic conditions could be measured via a single question. Testing in Round One included both multiple follow up questions within each domain as well as a separate domain to assess chronic conditions. Based on the results of Round One, subsequent rounds of testing dropped the domain specific follow up questions as it was determined that a chronic conditions could be accurately captured with a single set of questions. Results of individual question are detailed in the following section.

Relationship of disability to chronic condition

Table 4. Disability (ACS-6) and chronic condition (Domain 7)

| Disability | Chronic Condition | |
|------------|-------------------|----|
| | yes | no |
| yes | 23 | 8 |
| no | 7 | 18 |

As can be seen in Table 4, there is a relationship between disability status and chronic condition although they are not always correlated. Disability was captured by the ACS-6 in all three rounds of testing. Chronic condition was captured by questions 7.1.1/7.1.1a and 7.1.2. Respondents who indicated that they have both a disability and a chronic condition often cite disabilities stemming from their chronic condition. For example, one respondent answered “yes” to several of the disability questions based on symptoms that he has due to scleroderma. While he does work, he can’t do any heavy lifting. Additionally, stiffness in his joints caused by the disease mean that he has trouble putting on pants and socks and, therefore, answered “yes” to the ACS-6 question on dressing and bathing.

The eight respondents who indicated that they had a disability but no chronic condition tended to be people who have difficulty hearing or seeing due to circumstances not related to a chronic condition. These respondents do not see their disability as a “condition.” One respondent said of his congenital hearing loss, “It’s not a condition. It’s just who I am.”

Those respondents who indicated that they had a condition but not a disability did not experience any functional limitations due to their condition. For example, several respondents with diabetes answered “no” to all of the disability questions.

Those who indicated that they neither had a chronic condition nor a disability described themselves as “healthy.”

Preamble: Respondents in Round One were read the following preamble:

The next questions are about any kind of health problems or conditions that may affect your well-being, daily activities or health on a regular basis. These conditions may affect the kind or amount of medical care, mental health or other health services you need or use.

The preamble was not read to respondents in Rounds Two or Three. There is no evidence that the preamble served to focus respondents responses on health and health care. Narrative responses were similar in scope across all rounds of testing. Because these questions were asked in isolation, and not within the context of a larger survey, we cannot say whether or not a preamble would be necessary to focus respondents on this topic if they were asked after questions focused on a different topic.

Framing: In Round One, within each domain, several versions of each question were tested. Therefore, respondents received at least two questions within each domain. These were split into two separate sets of questions (Version 1 and Version 2) each of which covered all seven domains. The order of the domains remained the same in each version of the instruments. However, in order to mitigate framing effects, the order of the questions was switched between versions. Occasionally, respondents noted that certain questions seemed the same as a question that they had already answered. For example, one respondent was asked this version of the Domain 2 question in the first question set:

Do you currently need or take prescription medicine (other than vitamins or birth control pills)?

In the second question set, the respondent was asked:

Because of a physical, medical, or mental health condition that has a significant effect on your health, do you regularly need or use prescription medications, supplements or over-the-counter medications?

Upon hearing this second version, the respondent asked, “Didn’t you already ask me that?”

However, since the sets were switched in each version of the instrument and most of the questions differed from each other sufficiently, minimal framing effects were seen.

In Rounds Two and Three, respondents were asked only one version of a question within each domain (although the sample was still spit for some domains where alternative versions of questions continued to be tested in rounds two and three). Again, occasional framing effects were seen when respondents answered questions based on the question they had just answered in the previous domain. For example, this happened at least once in Domain 3 (prescription medication) when respondents answered based on medication they took for mental health conditions. These respondents were still thinking about the question they had just answered on mental health treatment (Domain 2). While this did occur within other domains as well, in general, there were minimal framing effects.

Question by Question Review

For the purposes of this report, questions are identified with a three number system. The first number represents the domain; the second number represents the round and the third number represents the version. For example, Question 2.2.1 represents the question in Domain 2 (mental health), round two, version one.

Domain One: Medical Care

Questions in this domain seek to capture respondents who receive frequent medical care from health professionals that is not covered in the other domains.

Across all rounds, respondents with ongoing conditions were more likely to answer “yes” regardless of how often they needed medical care, while respondents who required treatment for acute conditions often did not consider these when answering the question because they were considered temporary.

The most variation in interpretation between the three rounds was due to slight revisions to the terms used in the questions. Round one uses the phrase “regular basis” as a time reference whereas rounds two and three use the word “often.” Rounds one and three use the phrase “annual check-up,” while round two uses “routine check-up.”

1.1.1 Do you need or use medical care, mental health, or other health services on a regular basis? (Y/N)

This question was asked of 10 respondents in round one. The use of the embedded list in the question confused at least one respondent who indicated that she would answer “yes” for “medical care” but who ultimately answered “no” because she doesn’t use “mental or other health services.”

Interpretation: Respondents uniformly interpreted this question as asking about treatment they receive from medical professionals for physical and mental health conditions. Respondents who answered “yes” generally answered based on their receipt of services from medical professionals to monitor and treat a variety of health conditions such as bipolar, rheumatoid arthritis and scleroderma. Several respondents included regular check-ups when formulating their answers. Respondents who answered “no” don’t go to the doctor often either because they are “healthy” or because they lack insurance and can’t pay for care.

“Regular basis”: There was no consistent interpretation of the phrase “regular basis.” Interpretations of this phrase varied from every day to yearly. Two respondents interpreted the phrase to mean, “Scheduled” and “ongoing” regardless of frequency.

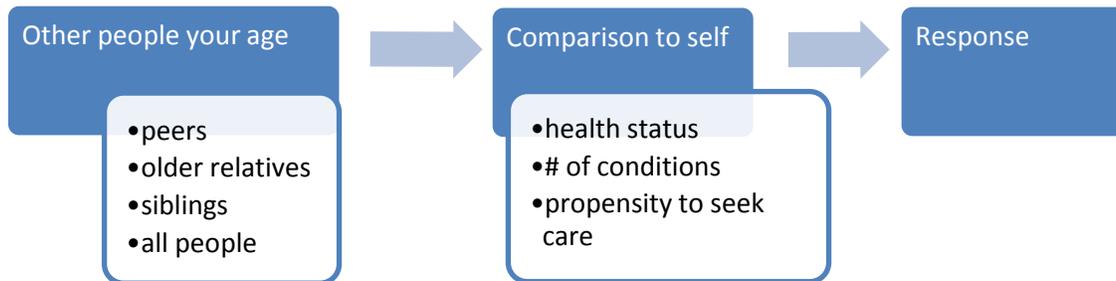
Need: Several respondents did not attend to the part of the question that asked about “need.” For example, one respondent answered “no” despite the fact that she has been unable to continue her treatment for ADD due to lack of insurance. Another respondent also answered “no” because she does not currently use medical care. This respondent said, “I’ve been feeling dizzy. I should have that checked out, but I can’t justify the expense.” Both of these respondents answered based on their current use of health care rather than on their need for health care.

1.1.2 Do you need or use medical care or other health services more than people your age? (Y/N)

This question was asked of 20 respondents in round one. Although it aims to capture a similar construct to that of 1.1.1, this question imposes a greater cognitive burden on respondents. Several respondents stated up front that this was a difficult question to answer. As one respondent put it, “It’s hard to judge

because I don't know the statistics." Another respondent said, "I don't know the statistics on healthy Americans, so I don't really know." However, despite their uncertainty, both respondents answered "no" rather than "don't know."

Figure 2 Comparing self to others response process



As seen in the diagram (Fig.2), in order to formulate a response to this question, respondents first had to identify the group "other people your age." Although some respondents thought of their peers or all people their age, other respondents thought about older relatives or all people in general. Therefore, there was no consistency on the group that respondents used to form their comparison.

Next, respondents had to consider what they know about how much their target group uses "medical care or other health services." Respondents demonstrated that they did not have direct or precise knowledge of this utilization. Therefore, to approximate utilization, respondents considered one or more related aspects such as health status, number of health conditions, and propensity to seek care. Then in order to make the comparison, respondents also had to access what they know about themselves in relation to these aspects. Since there was no way for respondents to make a direct comparison of health care utilization and because it was cognitively easier, more often than not, respondents made a comparison using a single one of these aspects.

Thus, respondents often justified their responses by describing the target group's health status as "unhealthy" and their health status as "healthy" in comparison. For example, one respondent who answered "no" said, "I count my blessings. I still have my health compared to others." Respondents also compared number (or severity) of conditions. For example, one respondent explained that she answered "no" because:

A lot of my peers have diabetes and other conditions. I don't have any of that; I just have COPD.

Similarly, another respondent answered "no" because she "only" has diabetes. The determination of severity was subjective and, therefore, individual to each respondent.

On the other hand, several respondents justified their “yes” answers by providing a list of the numerous conditions that require them to go to the doctor. These respondents did not explicitly consider the health of others but, rather, answered based on the implicit assumption that they use medical care more often than others due to their many health problems.

Finally, a few respondents compared how likely they are to seek care to how likely those in their target group are to seek care. Sometimes this was a negative characterization as in the case of a respondent who answered “no” and described how other people “take advantage” of unnecessary care. Other times this was seen as a positive as in the case of another respondent who said “yes,” saying, “I take advantage of whatever is available to help me.”

1.1.3 Other than your annual check-up, do you need or use medical care or other health services on a regular basis? (Y/N)

This question was asked to 10 respondents in Round One. Two respondents asked for clarification of the scope of the question. One asked, “Are you talking about going to a doctor or getting acupuncture, getting medication or going to a therapist or whatever?”

Interpretation: Respondents answered this question based on a variety of healthcare services that they utilize. Respondents who answered “yes” thought of regular, ongoing appointments they have to see health care providers to treat (often multiple) healthcare conditions. These conditions included mental health conditions such as depression and anxiety and physical conditions such as diabetes and fibromyalgia. Respondents who answered “no” don’t go to the doctor often either because they are “healthy” or because they lack insurance and can’t pay for care. Therefore, despite potential need, respondents answered based on their health care usage.

“Annual check-up”: There was some variation in how respondents interpreted the term “annual check-up.” Most respondents considered this to be a routine, yearly visit to their primary care doctor. Other respondents interpreted this to be any regularly scheduled visit to check or monitor an ongoing condition such as blood glucose checks for patients with diabetes. Finally, one respondent thought an *annual check-up* meant *any* visit to a primary care doctor.

While the question asks respondents to exclude annual check-ups, not all respondents did so. Several respondents considered all of their healthcare utilization including check-ups when formulating their answers. One respondent thought about her annual check-up with her primary care physician as well as her gynecologist in addition to regular check-ups with the neurologist. This respondent answered “yes,” saying, “I really just lump it all together.”

“Regular basis”: This question asks respondents to consider the health care services they receive on a “regular basis.” Respondents interpreted this in two ways. Some respondents answered based on whether they receive regularly scheduled care. For example, a respondent who gets his blood glucose checked every 3 months answered “yes” because his appointments are scheduled at predictable three month intervals. Other respondents answered based on frequency rather than regularity. For example,

one respondent sees her psychiatrist every 6 months but answered “no” because she felt the appointments were too infrequent to include even though they are scheduled in advance at regular intervals.

Need: None of the respondents attended to the part of the question that asked about “need.” For example, one respondent answered “no” but stated that he needed care for both a torn ligament and a possibly infected tooth. Since he does not have insurance, he cannot afford to seek care for these conditions.

1.2.1 Do you use care from medical doctors often? Please do not include routine check-ups in your response.

This question was asked to 20 respondents in Round Two. Five respondents had difficulty answering this question because they found it confusing. In particular, these respondents were confused by the phrase “use care” and by the time word “often”. After several repetitions of the question, all respondents were able to provide an answer.

Interpretation: In answering this question, respondents considered how often they go to the doctor. Unlike respondents who answered questions in round 1 (1.1.1 and 1.1.3), no respondents who answered this question included mental health treatment in their response. Those who answered “yes” described seeing a doctor for a variety of conditions such as sleep apnea, back pain, diabetes and skin problems. While those who answered “no” considered themselves “healthy,” they also described a general reluctance to go to the doctor. For example, one respondent answered “no” despite a variety of fairly recent health issues (including bladder cancer and a hernia) because he “only goes to the doctor when he’s sick.”

“Use care”: While most respondents interpreted the phrase “use care from medical doctors” to mean *go to the doctor*, several respondents were confused by this phrase. One respondent said:

I don't understand that question. Use care? What kind of care? I got to the doctor and I see him, but... do I use care in going to the doctor? Do I take care in going?

This respondent ultimately answered “yes” and described a particular routine that she follows prior to going to the doctor. Thus, this respondent answered on the basis of the *care* she takes in preparing for her doctor’s appointments.

Another respondent was confused by the term *care*. This respondent was not sure if she should include her regular, frequent visits to the doctor to check on her ongoing conditions. She saw these as different from “treatment” visits. This respondent answered “no” because she decided that these visits to check on ongoing conditions would be considered “routine check-ups” which were explicitly excluded by the question.

“Routine check-ups”: Most respondents interpreted the phrase “routine-check-ups” to be yearly appointments with their primary care doctor, ob-gyn or dentist. However, some respondents took this to mean regularly scheduled appointments to check on ongoing conditions. For this reason, some

respondents who regularly go to the doctor to check the status of an ongoing condition answered “no” while others answered “yes.” For example, one respondent goes to the doctor every 6 weeks to check on his diabetes, gout, hypertension and allergies. This respondent answered “no” to the question because he considered these visits to be “routine check-ups” which are specifically excluded. In contrast, another respondent who sees her doctor once a month to “check-on” her bad knees, asthma, high blood pressure and medication, answered “yes” because she considers “routine check-ups” to mean a yearly visit to the primary care doctor rather than regularly scheduled visits to monitor health conditions.

“Often”: Three respondents were not sure what was meant by the frequency reference “often”. One respondent asked, “What is *often*? Is there a number? Like more than once a year?” Another respondent said, “I see a doctor for maintenance. Is that often? I don’t know if it’s often.”

Other respondents had various interpretations of often. Respondents who answered “yes” saw their doctors anywhere from once a week to every six months. For some, often implied regularity. As one respondent who answered “yes” explained:

[often means] you use it often enough that it can be put on your schedule. When I think of often, it can be with frequency, but I also consider often as an expectation that you’re going to be seeing this person on a more than one or two time basis. That you’re going to develop a relationship with them through your medical needs...it’s an ongoing condition.

Respondents who answered “no” generally concurred with this interpretation. Many of these respondents stated that they answered “no” (whether or not they had seen a doctor for multiple acute health issues recently) because they did not have an ongoing condition that required regular visits to the doctor. For example, one respondent answered “no” even though he had been to the doctor multiple times in the previous months for a torn ligament and tonsillitis. Like other respondents who answered “no,” this respondent said, “I only go to the doctor when I have a problem.” Therefore, “no” respondents prioritized regularity rather than frequency.

1.3.1 Do you see medical doctors about your health often? Please do not include an annual check-up in your response.

This question was asked to 16 respondents in Round Three and all were able to answer without hesitation. Similar to previous questions in this domain (health care), respondents answered this question based on their visits to the doctor. Respondents who answered “yes” described seeing the doctor for a variety of conditions such as high blood pressure, asthma, allergies and diabetes. Respondents who answered “no” don’t go to the doctor often either because they “only go when there’s a problem” or because they lack insurance and can’t pay for care.

“Annual check-up”: Using the term “annual check-up” seemed to cause less confusion than “routine check-ups” which was used in question 1.2.1. Respondents who went to the doctor frequently for routine monitoring of ongoing conditions answered “yes” and did not confuse this with their yearly physical. However, one respondents did not initially attend to the part of the question that asks respondents to exclude annual check-ups. She answered “yes” based on her annual physical but changed her answer to “no” during probing.

“Often”: Respondents who answered “yes” cited medical visits that occurred as frequently as once a week and as infrequently as every six months. There is some indication that for those who pay out of pocket for doctor’s visits (i.e. don’t have insurance) *often* can be less frequent than for those whose visits are covered by insurance. For example, the respondent who answered “yes” because she goes to the clinic every 6 months is homeless and has to pay a co-pay at the clinic. Similarly, another respondent answered “yes” because he had been to the doctor 4 times in the last year. This respondent indicated that he would only go to the doctor if it was really necessary and only after seriously considering the cost. Therefore, for these respondents, 2 or 4 times a year seems *often* because they would rather not go at all due to the cost.

1.2.1a/1.3.1a Do you often need care from medical doctors that you do not receive?

This question was asked as a follow-up question to respondents in Rounds Two and Three who answered “no” to the primary question on health care utilization.

Interpretation: As described in Section Two, respondents answered based on perception of need for care and/or access to care.

Perception of need: Respondents judged their need for care from medical doctors based on informational inputs, desire and self-image (or a combination of these). Respondents relied on professionals and their own symptoms as sources of information. For example, one respondent determined that she has a need for care because she was told by an ENT several years ago that she has hearing loss. Several other respondents determined that they have a need for care because of symptoms of pain (eg gallbladder, knee or back pain). Desire and self-image were also factors in determining need. One respondent determined that he doesn’t have any need based in part on his desire to avoid going to the doctor. This respondent said, “I don’t like doctors, so I don’t need to go very often.”

Two respondents judged that they had no need based on lack of specific symptoms or diagnoses, but these respondents also noted that they would see a doctor if they had access (insurance). One of these respondents said:

I think it would be good to go to the doctor more than I do. I would go if I had insurance. It’s too expensive.

Access to care: In assessing their access to care, respondents thought about ability to pay and difficulty scheduling appointments. Most respondents cited their insurance status as evidence of their ability (or lack of ability) to pay. Other respondents described difficulty they have scheduling appointments, often due to lack of time. One respondent explained that he has access because, “I’m capable of scheduling an appointment.”

Judgement: When formulating their responses to this question on need for care from medical doctors, most respondents considered both their perception of need and access. For example, one respondent who answered “no” gave the explanation:

If I see something wrong, I’d go [to the doctor to] see what it was. I have insurance so that’s no problem.

Similarly, respondents who said “yes” considered both their perceived need for care from medical doctors (need) and their lack of access (often lack of insurance).

At least one respondent answered based solely on access. This respondent, who has been unable to get a test for significant vision difficulties, answered “no” because he has insurance. However, his insurance does not cover the test that he has been told he needs.

A single respondent answered “yes” based only on need. This respondent described her severe knee and back pain and said:

I choose ‘yes’ because I’ve been putting it off and I know like it’s probably something that they have that I have not found out about that could help my knee and my back...

In answering, this respondent did not consider her access to care (she has insurance and intends to make an appointment).

Domain Two: Mental Health

Questions in this domain seek to capture respondents who use mental health or substance abuse services or support.

The most variation in interpretation between the three rounds was due to slight revisions to the terms used in the questions. For instance, the one question in Round One that did not include the term “substance abuse” failed to capture at least one respondent who receives substance abuse services. The inclusion of the frequency references “regular basis” and “often” was left out in round three because they were not uniformly interpreted by respondents and, in some cases, caused confusion.

2.1.1 Do you need or get treatment or counseling for any kind of mental health, substance abuse, or emotional problem? (Y/N)

This question was asked of 20 respondents in Round One. One respondent, who initially hesitated, answered “no” after asking for the question to be repeated during probing.

Interpretation: Respondents generally interpreted the question to be asking about seeing mental health providers such as psychiatrists or therapists or attending support groups such as Narcotics Anonymous (NA) or Alcoholics Anonymous (AA). Respondents discussed treatment for depression, anxiety, medication management, substance abuse, PTSD and marital difficulty. Several who answered “yes” got counseling to help cope with difficult chronic physical health conditions such as HIV, autoimmune disorders, and rheumatoid arthritis.

“Counseling”: Two respondents had unique interpretations of the question involving the word “counseling.” For one respondent, counseling indicates situations where one would get feedback from other people, along the lines of counseling groups. Even though she sees a psychiatrist, she answered “no” to the question based on the fact that she does not attend a *counseling group*. Another answered “yes” based on the fact that she sees a psychiatrist, but because she only sees him for medication

management and not therapy, she would have answered “no” to this question if it had asked about *counseling* alone and not “treatment” as well.

Need: Respondents did not attend to the part of the question asking about need. For example, one respondent who answered “no” described a need for mental health treatment, explaining that she would like to attend counseling groups but cannot due to scheduling difficulties.

2.1.2 Do you need or use mental health treatment or support such as prescription medications or counseling services on a regular basis? (Y/N)

This question was asked of 10 respondents in Round One. None of these respondents had difficulty answering the question.

Interpretation: Respondents generally interpreted this question to include seeing providers such as psychiatrists or therapists for things like medication management, anxiety, ADD, and depression. The absence of “substance use” in the question caused one respondent getting help through NA and AA to answer “no” to this question, where he had previously answered “yes” to question 2.1.1 which specifically named substance abuse as a type of mental health problem. Following up on the first question (2.1.1), this respondent said, “I get a lot of advice in N.A.” In contrast, he explained his answer of “no” to this question saying, “I don’t go to no counseling.” Therefore, this respondent did not consider N.A. or A.A. to be included in the scope of the question.

“Prescription medications”: One person who answered “no” had trouble with both “prescription medications” and “counseling services” being listed in the same question. The respondent felt that the part about prescriptions applied to her, but the counseling part did not since she receives only medication management and not counseling from her psychiatrist. Some respondents latched onto the words “prescription medications” and feature those in their interpretations. For example, one person answered “yes” solely on the basis of using “a lot of prescription medicines,” including some for mental health, although she does see a psychiatrist as well.

“Regular basis”: Respondents who answered “yes” took medicine or received treatment as often as every day and as infrequently as every few months. Only two respondents specifically addressed how they interpreted the phrase “regular basis.” One respondent considered it to be “every day” and therefore answered “no” but says she would have answered “yes” in the absence of that phrase. Another considered it to be more than once every three months. This respondent answered “yes” because he sees his counselor about once a month.

Need: Respondents generally did not attend to the part of the question asking about “need.” For example, one person who answered “no” noted that she has needs for prescriptions for her ADD but cannot get a refill because she no longer has insurance.

2.1.3 Do you need or use mental health treatment or support such as prescription medications, counseling, or substance abuse services on a regular basis? (Y/N)

This question was asked of 10 respondents in Round One, and all respondents were able to provide a ready response.

Interpretation: Most respondents interpreted this question to include seeing psychiatrists and therapists, going through rehab, or attending support groups such as NA/AA or Overeaters Anonymous. They interpreted treatment as a range of things including depression, substance abuse, anxiety, ADHD, PTSD, and medication management. One person answered “yes” to the question based on seeing a therapist but did not consider her visits to a psychiatrist because those visits are just for medication management.

“Regular basis”: Among those who mentioned frequency or timing of treatment, there was no consistent interpretation of “regular basis.” For example, one person answered “yes” to the question even though she sees a psychiatrist once a year for medication management. (She later clarified that it has been 10 years since she was seeing the provider “regularly.”) Two respondents attend support groups (AA/NA and Overeaters Anonymous) groups three times a week.

“Need”: Respondents did not attend to the part of the question asking about “need.” For example, one respondent answered “no” to the question and expressed that it might have been helpful to get some counseling to help deal with mild depression due to unemployment and financial hardship.

2.2.1/2.3.1 Do you use mental health treatment or support such as counseling or substance abuse services?

This question was asked of 25 respondents in Rounds Two and Three. Respondents did not have difficulty answering the question.

Interpretation: As in Round One, interpretations of this question were based on going to detox or group counseling or seeing providers such as psychiatrists, therapists, and counselors to manage and treat conditions. Respondents considered mental health conditions to include things such as depression, anxiety, PTSD, substance abuse, schizoaffective disorder, and medication management. Similar to what was found in Round One, one respondent uses counseling to help cope with difficult health conditions, in this case fibromyalgia.

One respondent who answered “no” interpreted it to be asking if he used drugs to deal with the stress of personal problems. In addition, possible response error occurred with one respondent who answered “yes” because she was in counseling/therapy for about three to four months earlier this year but is not currently seeing anyone.

Timeframe: Frequency of seeing providers varied from “as needed” to once a month to every two weeks, with every two weeks being the most common.

2.2.2 Do you use mental health treatment or support such as counseling or substance abuse services often?

This question was asked of 11 respondents in Round Two. Two respondents had difficulty answering “yes” or “no” based on the presence of the word “often.” They were not sure how to define “often” and were, therefore, not sure how to answer.

Interpretation: Similar to other versions, respondents interpreted the question to include seeing psychiatrists, counselors, and therapists for a range of issues including PTSD, bipolar, depression, anxiety, and schizoaffective disorder. As with other questions, one respondent who answered “yes” gets mental health treatment to help cope with a health problem, in this case vision problems.

Often: Respondents did not have a consistent interpretation of what was meant by “often.” Similar to other versions—both those that used the phrase “regular basis” or did not include a time word at all—respondents mentioned a range of frequencies from every two months to every week when they mentioned frequency of treatment.

2.2.1a/2.3.1a/2.2.2a Do you (often) need mental health treatment or support that you do not receive?

This question was asked as a follow-up question to respondents in Rounds Two and Three who answered “no” to the primary question on mental health care. In Round Two, the modifier “often” was included, but was dropped in Round Three.

Interpretation: As described in Section Two, respondents answered based on their perception of their need for mental health treatment and/or their access to mental health treatment.

Perception of need: Respondents judged their need for mental health treatment based on informational inputs, desire and self-image (or a combination of these). Respondents relied on professionals, friends and family and their own symptoms as sources of information. For example, one respondent determined that he has a need for mental health treatment because he has recurring anxiety that affects his ability to get things done. Another respondent determined that he does not have a need for mental health treatment saying, “My doctor never told me I need that kind of thing.” Some respondents felt they could rely on friends and family to advise them about when or whether to seek mental health treatment while one respondent noted that friends and family are not always reliable.

Desire and self-image were also factors in determining need. Several respondents indicated that they did not want to seek treatment but wondered if they would benefit from it. One respondent determined that she doesn’t have any need based in part because she sees herself as “not the kind of person who needs mental health treatment.”

Access to care: In assessing their access to mental health treatment, respondents thought about ability to pay, difficulty scheduling appointments and convenience. Most respondents cited their insurance status as evidence of their ability (or lack of ability) to pay. Other respondents described the inconvenience of treatment. One respondent explained that he she was told by her doctor to check into an inpatient substance abuse program, but she described the inconvenience of being away from her husband for a full month. Based on the inconvenience (access), this respondent answered “no.”

Judgement: When formulating their responses to this question on need for mental health treatment, most respondents considered both their perception of need and access. For example, one respondent who answered “no” gave the explanation:

*I have the ability and resources to seek counselling if I need it. I have insurance. I have money.
But I don't feel depressed.*

Similarly, respondents who said “yes” thought about conditions that they would like to seek mental health treatment for (need) and their lack of access (often lack of insurance). For example, one respondent feels depressed (need) but doesn’t have insurance (access) and doesn’t know where to go for treatment (access). However, some respondents, such as the one described above, considered only need or only access when formulating their responses.

Domain 3: Prescription Medications

3.1.1 Do you currently need or take prescription medicine (other than vitamins or birth control pills)? (Y/N)

This question was asked to all 20 respondents in Round One of the survey. One respondent initially thought this question only referred to mental health prescriptions because it directly followed the questions about mental health. Initially he said, “No, and put a question mark next to that question, it’s a little confusing.” After the follow up question in which he was asked if he took medication because of any medical, mental health, other health condition he expressed confusion and the question was repeated. In probing he explained:

The reason I hesitated, I’m not taking anything for the mental health, but I am [taking other medication] ... I didn’t know if it [the question] was addressing the mental health issue still, because it came right after that [the mental health question]. I’m putting in it categories or boxes...I do that in my life, I definitely separate the mental from the physical.

Interpretation: Respondents uniformly interpreted this question to be about medications prescribed by a doctor that they currently take. All of the respondents who answered “yes” reported medication(s) they needed to manage a chronic condition. For example, several respondents reported taking blood pressure medication, insulin or diabetes pills, while others discussed use of anti-depressants, pain medication and other medicines. This question explicitly asked respondents not to include vitamins or birth control in their response. None of the respondents considered birth control in their responses and most respondents did not include vitamins. The exception was a respondent who said she was not sure if she should include vitamin D, because she took this upon a doctor’s recommendation due to deficiency. However, this respondent took other prescription medication as well, so would answer affirmatively regardless of her use of vitamin D. No respondents who *only* took vitamins or birth control answered “yes.” Likewise, no respondents who took *only* over the counter drugs responded affirmatively.

As Needed: Most respondents answered the question based on drugs taken regularly rather than “as needed.” Two respondents said they had a prescription medication that they used periodically and another did not think about an inhaler she uses as needed. One of these respondents said he took Cialis “as needed” but answered “yes” because of other prescription medications that he uses regularly. However, when he answered “yes” he said he was not thinking of Cialis.

Need: This question captured respondents who currently used prescription medication, but did not capture unmet need. Only respondents who reported that they took prescription medication answered

this question affirmatively. For example, one respondent said he needed medication but did not receive it answered “no” to this question.

3.1.2 Because of a physical, medical, or mental health condition that has a significant effect on your health, do you regularly need or use prescription medications? (Y/N)

This question was asked to the 10 respondents who were given version one of the survey in Round One.

Interpretation: Most respondents gave the same answers to 3.1.2 as they did in 3.1.1 and reported the same interpretation of the question. They described medication they used regularly for chronic conditions.

As needed drugs: As with question 3.1.1 other respondents who took medication “as needed” such as Cialis or an inhaler did not include these in their answers, but answered “yes” due to other medication that they took more “regularly.” The inclusion of the word “regularly” seemed to reinforce respondents’ tendency to not include “as needed” medication, so those who initially hesitated on how to answer were swayed into answering “no.” However there were two instances where respondents changed their answers from “yes” to “no” related to their use of “as needed” medications. One respondent who said “no” reported using insulin because he had diabetes that was assessed by a doctor every 3 months. He said he did not take medication regularly. Likewise, the respondent who took ADD medication when she felt “I really need it” said “no.” Both of these respondents seemed to be thinking about their medication as “as needed” and therefore different from “regularly” used.

Need: The woman described in question 3.1.2 who had a limited number of ADD pills that she took occasionally answered “no” because she did not use the pills regularly. She responded to the question as though it were asking solely about use not need. No other respondents said they “needed” medication that they didn’t get.

3.1.2a How many prescription medications do you use for these conditions?" (Numeric response)

When respondents said “yes” they use prescription medication (3.1.2), they were asked 3.1.2a as a follow-up.

Interpretation: Respondents uniformly understood this as asking about the number of prescription medications they use. Six of the ten respondents reported taking medication. Respondents who took fewer medications had an easier time recalling the number accurately than did those who used more medications. One respondent who took eleven medications referred to a list of medication that she reported regularly using to help her remember when to take which medications.

As needed: As with the other questions, respondents who took over the counter medication or prescription medication “as needed” (inhaler or Cialis) did not include them in the count.

3.1.3 Because of a physical, medical, or mental health condition that has a significant effect on your health, do you regularly need or use prescription medications, supplements or over-the-counter medications? (Y/N)

This question was asked of ten respondents in Round One.

Interpretation: Despite the question asking respondents to include “supplements “ and “over the counter medication” respondents only focused on prescription medications when formulating their answers. Several respondents answered “no” to the question despite taking supplements, such as ginkgo or vitamin D, on a daily basis. Respondents who take supplements and who answered “yes,” indicated that they answered based on their use of prescription medications rather than on their use of supplements. One respondent did not understand the difference between prescription and over the counter medication saying, “I gotta have a prescription to get it from over the counter.”

“regularly”: Respondents understood “regularly” to mean at regularly scheduled intervals as opposed to “as needed.” Therefore, respondents did not include over the counter pain or allergy medications because these are used “as needed.” For example, one respondent explained why he didn’t include his allergy medication:

I don't take that all the time. I don't take anything day-to-day to get me through my day.

Need. As with respondents who answered question 3.1.1, respondents answered this question based on use of medication not need of it. Two respondents reported there were vitamins or supplements they needed but did not receive because they were not covered by insurance and were not affordable and neither included them in this category.

3.1.3a How many medications do you use for these conditions?" (Numeric response)

When respondents answered “yes” to question 3.1.3, they were asked this follow-up question. In total, seven of the ten respondents in Round One, were ask how many medications they used.

Interpretation: This question performed the same as 3.1.2a in that respondents understood this as a question pertaining to prescription medication. However, two respondents who used insulin did not include it in their medication count, while a third respondent did include it. One of the respondents who did not include insulin among her medications, used an insulin pump and described it in a later question about medical equipment.

As seen with question 3.1.2a, respondents taking fewer medications or who took medications for fewer conditions had an easier time recalling the exact number. Respondents who took more medications generally either forgot some of them or needed a reference cue.

Multiple Chronic Conditions. Respondents with multiple chronic conditions frequently focused only on medications for what they considered their primary condition or conditions. For example, one respondent took about 10 medications, but only included the five pain medications that she takes for fibromyalgia in her initial count; she did not mention several serious medications including insulin, diabetes pills, and high blood pressure medication. Another man included medications he used for diabetes, high blood pressure and cholesterol when first asked, but on probing added a prescription allergy medication.

As Needed. As with the other questions related to prescription medicine, respondents did not include medication that they took “as needed” in their responses regardless if it was prescription of over the counter.

3.2.1/3.3.1 Do you use prescription medicine regularly (other than vitamins or birth control pills)?

In Rounds Two (n=20) and Three (n=16), all respondents were administered this question.

Interpretation: All but one of the respondents answered based on their current use of prescription medications. A single respondent answered based on past use of prescription medication. This respondent, who took blood pressure medicine in the past, answered “yes” although he stopped taking it a year ago because he no longer needed it. No respondents included over the counter medication, vitamins, or birth control in their initial responses and no respondents said “yes” if they needed prescriptions that they didn’t receive.

Some medications, including specific vitamins and aspirin are available both with and without a prescription. Respondents who received aspirin from a pharmacy counted it as prescription medication whereas those who purchased it without a prescription did not. This was the case even if a doctor had specifically told the respondent to use aspirin. Some respondents who took prescribed vitamins viewed them as separate from the vitamins they were told not to include because they were not over the counter vitamins. For example one respondent said, “The doctor also prescribed vitamins for me, I don’t know if that’s considered a prescription or not.” However, all of the respondents who took aspirin or prescription vitamins took other prescription medications as well. Therefore, the inclusion of aspirin or vitamins would not have changed their responses from “yes” to “no.”

As Needed. Respondents with multiple chronic conditions did not generally include medications that were taken “as needed” in their responses. For example one woman who used an inhaler said “no” and respondent who used a pain patch and narcotic pain killers on occasions did not remember them when she thought of her prescription medicines. However, a respondent who took both pills and a cream for rosacea, a skin condition, was unsure whether or not to include it. Ultimately she included the pills but not the cream noting, “I do have like a cream ointment and I don’t think about it but it is a prescription and I have a prescription for antibiotic.” Although she used them periodically, they were designed to be taken regularly. She hesitated explaining it was not for a serious conditions because:

if I don’t use it...my skin might break out...I was unsure if you were talking about like blood pressure or cholesterol, those type of medications [for more serious health-related conditions].

Multiple Chronic Conditions. Respondents initially thought of medications relating to their primary illness first and thought about pills before other medications. A respondent wore a hormone patch all of the time said “no” and a respondent who used nasal spray initially answered only based on drugs relating to her fibromyalgia pain. On the other hand, some respondents did include ointments, one woman who thought about psoriasis as a prevalent condition in her life, discussed her use of cream for psoriasis when first asked about her medication use.

Need. As with the previous versions of questions in this domain, when answering this question, respondents who needed medication that they did not receive did not include them in their responses.

3.2.1a How many different prescription medications (3.3.1a medicines) do you use?

There was a slight change in wording between Rounds Two and Three of the survey. To make the questions more consistent and to make it easier for interviewers to ask these questions, the word “medication” was changed to “medicine.” There did not appear to be any differences in how respondents answered this question based on the wording.

Interpretation: Most respondents understood this as a question about the number of prescription medications they currently take. Respondents did not include vitamins or over the counter medications in their responses unless they had been prescribed by a doctor. However, while some respondents included prescription creams, ointments, prescription shampoo, gels, inhalers, or patches in their answers, others did not include these kinds of items. In general, respondents first thought of pills and then other medication types.

This question was difficult for respondents who took multiple medications for multiple conditions. Respondents focused on the medications they used for what they considered their most serious illnesses and often forgot medications that were used for other conditions. As seen in other versions of this question, in this question, respondents taking fewer prescriptions were better able to recall them.

3.2.1b/3.3.1b Do you regularly need prescription medicine that you do not receive?

This question was asked as a follow-up question to respondents in Rounds Two and Three who answered “no” to the primary question on prescription medicines.

Interpretation: As described in Section Two, respondents answered based on perception of need for care and/or access to care.

Perception of need: Respondents judged their need for prescription medicine based on informational inputs and desire. Respondents relied on information from professionals or friends and family. For example, one respondent determined that she has a need for prescription medicines because these medicines were prescribed by her primary care doctor to treat various conditions such as high blood pressure. Another respondent felt she needed a certain medicine because she had been told by a friend that it might help her hearing loss. Desire was also a factor in respondents’ judgment of need for prescription medicine. One respondent determined that she did not need a prescription saying, “I don’t like to take medicine even when the doctor gives it to me.”

Access to care: In assessing their access to prescription medicine, respondents thought about ability to pay and difficulty getting a prescription. Most respondents cited their insurance status as evidence of their ability (or lack of ability) to pay. Two respondents noted that they could not get the medicine they want because their doctors won’t provide it. One of these respondents who has severe knee pain said she wishes her doctor would give her some pain medicine that is “worth taking.”

Judgement: When formulating their responses to this question on need for prescription medication, most respondents considered both their perception of need and access. For example, one respondent, who answered “yes,” said he sometimes used his friend’s anti-anxiety drug and would like to have a prescription for it (need). However, he lacks insurance (access), so he can’t go to the doctor to get his own prescription.

A single respondent answered “yes” based only on need. This respondent described her severe back pain but also said that she was confident that she could get the medicine that she wants when she goes to the doctor.

Domain 4: Medical Therapies

Domain 4 covers medical therapies such as pain management, acupuncture and physical therapy. Different versions of the question included various examples or no examples at all. Versions also differed in their use of time words. Some versions had no time word while others used “often” or “regular basis” to provide a time reference.

4.1.1 Do you need or get special therapy? (For example: physical, occupational, speech or respiratory therapy)

This question was asked of 19 respondents in Round One, and all were readily able to answer the question.

Interpretation: While not all respondents had a clear understanding of the term “special therapy” or of what was meant by the examples given, almost all were able to provide an appropriate answer. A few respondents who answered “no” based their understanding of the term special therapy on treatment they had received in the past (for example, physical therapy for a car accident), but most had a more vague notion of what special therapy referred to. For example, one respondent who answered “no” thought it might be. “...treatment for more serious physical issues... injuries of some sort that require treatment.” However, even respondents who weren’t quite sure what the terms referred to were able to accurately indicate that they were not receiving such treatment. Respondents who answered “yes” understood the question in terms their own experiences of treatment. These treatments include physical therapy, pain management, and speech therapy.

Less clear were treatments not covered in the examples given in the question. Two respondents decided to include counseling or “mental therapy” in their interpretation of this question. As one respondent put it, “Therapy is therapy.” These respondents answered “yes” to the question based on the inclusion of counseling. In contrast, most respondents who indicated in earlier questions that they received counseling, did not answer “yes” to this question. A third respondent wondered if he should include yoga in his answer while yet another respondent considered whether to include her recent chemotherapy. These two respondents answered “no” because they decided that these were not within the scope of the question.

Timing: Some respondents answered based on treatment they had received in the recent past, treatments they currently receive and on treatments they expect to receive in the near future. Other respondents answered based on treatments they receive periodically or as needed. For example, one respondent who had completed physical therapy for back pain several months prior answered “yes” because she expected to get more physical therapy for the pain in coming months. Even though this respondent was not currently receiving treatment, she considered this treatment ongoing.

Need: Across the board, respondents answered based on their use of therapy rather than on their need for therapy. For example, one respondent who answered “no” described how he previously received physical therapy for a knee injury. He had to discontinue this therapy a few years ago because he became unemployed. This respondent still has knee pain and would seek more physical therapy if he could afford it.

4.1.2 Do you need or use rehabilitative, medical, or complementary/alternative therapies on a regular basis?

This question was asked to 10 respondents in Round One. All of the respondents answered “no” to this question, even those who answered “yes” to question 4.1.1. Several respondents asked for the question to be repeated and expressed uncertainty about what the question was asking.

“Complementary/alternative”: In general, respondents were confused by the term “complementary/alternative.” Several respondents stated that they were not sure what this meant. Other respondents interpreted this term to mean anything from “acupuncture” to “someone who has to go to a therapist often” to “services that are free of charge to help those who are less fortunate.”

4.1.3 Do you need or use medical or other therapies such as dialysis, physical therapy or acupuncture on a periodic or regular basis?

This question was asked to 10 respondents in Round One.

Interpretation: Unlike question 4.1.2 which asks about “complementary/alternative therapies”, this question was easily understood by respondents. Overall, respondents’ patterns of interpretation were similar to those for question 4.1.1. The inclusion of “acupuncture” in the examples did not influence respondents’ answers. Several respondents, both those who answered “yes” and those who answered “no,” indicated that they needed or wanted acupuncture but could not get it because it is not covered by insurance.

“Periodic or regular basis”: Respondents interpreted “regular basis” to mean any therapy treatment that is used often, at regular intervals or on a schedule. For example, one respondent answered “yes” because she goes to the chiropractor every six months and her visits are prescheduled. In contrast, another respondent answered “yes,” noting the use of “periodic” in the question. This respondent does acupuncture sometimes but not often or on a regular basis.

4.2.1/4.3.1 Do you use medical or other therapies often?

This question was asked of 18 respondents in Rounds Two and Three. One respondent was initially unsure of what was meant by “medical therapies” but ultimately decided that it meant things like “physical therapy.”

Interpretation: As seen in Round One, respondents in Rounds Two and Three also demonstrated that while those who receive therapies and those who don’t approach the question differently, all are able to answer accurately. Again, those who don’t receive therapies have a vague understanding of what is meant by the question and those who do receive therapies understand the question in relation to their treatment.

“Medical or other therapies”: This version of the question did not provide examples, and therefore, respondents provided a broad array of possible interpretations of the phrase “medical or other therapies.” These interpretations included physical therapy, ice and dry heat for pain, group therapy, counseling, drug rehabilitation, occupational therapy, spiritual therapy (received at church), acupuncture, meditation and “going to the doctor.” One respondent who has fibromyalgia did not include her regular physical therapy when answering this question because she considers this the primary treatment for her condition. To this respondent, “therapy” is an ancillary treatment. However, response error was not seen in this case because the respondent answered “yes” to the question based on her frequent use of heating pads for pain due to her condition.

“Often”: When asked this version of the question which uses the time word “often,” respondents answered “yes” based on treatment they receive every day, once a month, as needed or “not that often.” In the case of the latter example, the respondent did not attend to the word often at all. Respondents who had completed therapeutic treatment in the past answered “no.”

4.2.2/4.3.2 Do you often use medical or other therapies such as dialysis, physical therapy, or therapy to manage or reduce pain?

This question was asked to 19 respondents in Rounds Two and Three. In this version of the question which provides examples, respondents focused on the specific examples given. Respondents who answered “yes” to this question reported similar treatments for pain management and physical therapy as those who answered “yes” to 4.2.1/4.3.1, in which no examples were provided.

Therapy to manage or reduce pain: Several respondents seemed unsure of what was meant by the phrase “therapy to manage or reduce pain.” Possible interpretations ranged from “pills” to “grief counseling” to “hypnosis” to “ice and wet heat” to “physical therapy for muscle pain.”

Often: Interpretations of “often” for this question were similar to those in question 4.2.1/4.3.1. Respondents answered “yes” based on treatments they received as frequently as twice a week or as infrequently as every six months or “not often.” Respondents who had received therapeutic treatment in the past answered “no.”

4.2.2a/4.3.2a *Do you often need medical or other therapies that you do not receive?*

This question was asked as a follow-up question to respondents in Rounds Two and Three who answered “no” to the primary question on medical therapy.

Interpretation: As described in Section Two, respondents answered based on perception of need for care and/or access to care.

Perception of need: Respondents judged their need for medical therapy based on informational inputs, desire and self-image (or a combination of these). Respondents relied on professionals, friends and family and their own symptoms as sources of information. For example, one respondent determined that he needs some additional therapy because a friend told him he might benefit from post-surgery therapy. Several other respondents determined that they have a need for physical therapy, massage therapy or acupuncture because of symptoms of pain (eg. knee or back pain). Desire and self-image were also factors in determining need. One respondent determined that she doesn’t have any need based in part on her self-image as someone who is “not handicapped.” Another respondent described herself as “stubborn” and preferred to handle her knee pain on her own.

Access to care: In assessing their access to care, respondents thought about ability to pay and convenience. Most respondents cited their insurance status as evidence of their ability (or lack of ability) to pay. Other respondents described the inconvenience of physical therapy appointments. One respondent explained that he doesn’t “have time to go to 3 appointments every week.”

Judgement: When formulating their responses to this question on need for medical therapy, most respondents considered both their perception of need and access. For example, one respondent answered “yes” because he wants physical therapy for knee pain (need), but he does not have time to get the therapy (access).

Similarly, respondents who said “yes” thought about conditions that they would like to get therapy for (need) and their lack of access (often lack of insurance).

A single respondent answered “yes” based only on need. This respondent said he needed a knee brace for running but also said that he could easily get one.

Domain 5: Medical Equipment

Questions in this domain seek to capture respondents’ use of and need of medical equipment and assistive technology. Different versions of the question provided various examples of medical equipment, or no examples at all. Another difference in versions is seen in the words used to denote timeframe. In Round One “ongoing” is used whereas in Rounds Two and Three “often” is used.

5.1.1 *Do you have an ongoing need for or use of medical equipment or assistive devices such as walking aids, communication devices, or breathing aids? (Y/N)*

This question was asked of 20 respondents in Round One.

Interpretation: Most respondents interpreted this question as asking about their use of medical equipment or assistive devices they use due to various health conditions such as fibromyalgia, vision impairment or multiple sclerosis. Respondents who answered “yes” generally answered based on their use of items such as canes, walkers, or CPAP (Continuous Positive Air Pressure) machines. Respondents who answered “no” generally did so because they are “healthy” and therefore do not need these items. At least one respondent answered “no” because he thought the equipment that he uses (a tool to put socks on), was not as “serious” as the examples listed in the question.

Need: Respondents who answered “yes” to this question were answering based on their use, not their need, of medical equipment or assistive devices. Respondents who answered “no” did not always attend to the need portion of this question. For example, one respondent answered “no” because he did not use a hearing aid; however, he indicated a need for a hearing aid and was expecting to receive one within the next month.

5.1.2 Do you have an ongoing need for or use of medical equipment or assistive devices such as prostheses, mobility aids, or medication pumps? (Y/N)

This question, which includes a different set of examples than question 5.1.1, was asked of 10 respondents in Round One. Several respondents were confused by the examples listed in this version of the question. At least one respondent was confused by the term “prostheses.” This respondent was able to accurately answer “no” to the question. Another respondent was not sure if her cane would qualify since “cane” was not listed as an example; however, the respondent eventually decided to answer “yes” because of her use of a cane. Therefore, even though no response error was evident, there is the potential for difficulty with this question.

Interpretation: As with question 5.1.1, respondents interpreted this question as asking about their use of certain medical equipment or assistive devices. Respondents who answered “yes” based their answer on their *use* of a cane, insulin pump, asthma inhaler, or grabber. Respondents who answered “no” generally did so because they do not currently use a cane, walker, prostheses, breathing apparatus or other unspecified equipment.

“Ongoing”: Respondents had various interpretations of the term “ongoing.” Some respondents who answered “yes” had been using their medical equipment or assistive devices daily for many years. Others who answered “yes” used assistive devices on rare occasions of high physical activity. For example, one respondent answered “yes” because he used a cane once or twice per day on a recent vacation. This respondent never used a cane before or after this vacation.

Need: Respondents who answered “yes” to this question were answering based on their use, not their need, of medical equipment or assistive devices. Respondents who answered “no” indicated that they neither needed nor used such devices.

5.2.1 Do you use medical equipment or assistive devices often? (Y/N)

This question was asked to 9 respondents in Round Two.

Interpretation: Respondents had a fairly uniform interpretation of the phrase “medical equipment or assistive devices.” Most respondents were thinking of mobility devices, audio devices, and blood pressure cuffs. Respondents who answered “yes” thought of their use of a cane, blood pressure cuff, CPAP machine, ergonomic tools, or inhalers. Most respondents who answered “no” viewed themselves as healthy people that are “not physically handicapped.” At least one respondent who owned and used an assistive device answered “no” because he did not think that his device, a magnifying screen and voice-guided computer software, would qualify.

“Often”: The term “often” was interpreted loosely. Respondents who answered “yes” used their equipment or devices as frequently as every day or twice a week and as infrequently as “sometimes.” For example, one respondent who uses her inhaler “sometimes” answered “yes.”

5.2.2 Do you use medical equipment or assistive devices often such as mobility aids, communication devices or medication pumps? (Y/N)

This question was asked to 11 respondents in Round Two. At least one respondent was confused by the examples provided. This respondent asked, “What are those?” after hearing the question.

Interpretation: When answering this question, the majority of respondents were thinking of their current use of devices such as canes, wheel chairs, white canes, hearing aids, etc. One respondent with a vision impairment answered “yes” and was thinking of her white cane, referred to as an “identity cane.” Although she does not need the cane to guide her walking, she uses it to let people know that she has vision impairment. This respondent does not always use the “identity cane” because she does not always want people to know about her condition. Respondents who answered “no” did not identify as having a chronic condition.

Timeframe: Most respondents answered based on their current use of devices and did not address frequency. However, one respondent answered “no” because he does not use his cane on a “regular basis.” This respondent only uses his cane in the house which he did not consider to be frequently enough to qualify.

5.3.1 Do you use medical equipment or assistive devices often?

This question was administered to 16 respondents in Round Three. As seen with previous questions in this domain, respondents answered this question based on their current use of equipment and devices such as canes, knee braces, shoulder braces, etc.

Interpretation: Respondents who answered “yes” answered based on their use of a cane, lymphatic boots, tens machine, knee brace, or shoulder brace. Some of respondents had prescriptions for these devices while others bought the devices without a prescription from a retail store. Respondents who answered “no” did not use devices such as canes, wheel chairs, hearing aids, or shower chairs.

“Often”: Respondents’ interpretation of the word “often” varied. Some respondents who answered “yes” used the equipment once a day while others used the equipment once a month. Some respondents’ use of equipment varied on the weather. One respondent only uses his cane when it is cold outside, because cold weather induces his arthritic pain.

5.2.1a/5.3.1a Do you ever need medical equipment or assistive devices that you do not have? (Y/N)

This question was asked as a follow-up question to respondents in Rounds Two and Three who answered “no” to the primary question on medical equipment.

Interpretation: As described in Section Two, respondents answered based on perception of need for care and/or access to care.

Perception of need: Respondents judged their need for medical equipment based on informational inputs, desire and self-image (or a combination of these). Respondents relied on professionals and their own symptoms as sources of information. For example, one respondent determined that he has a need for a blood pressure monitor because he was told by a doctor that he has high blood pressure. Several other respondents determined that they have a need for equipment because of symptoms of pain (e.g. knee or shoulder pain). Desire was also a factor in determining need. Several respondents had been told to use equipment but didn’t want to use it. For example, one respondent was told by a doctor to use a shoulder brace, but he doesn’t like to wear it. Another respondent was told to use equipment for massaging her muscles, but she prefers to do her own exercises. “I know what I need more than they do,” she said.

Access to care: In assessing their access to care, respondents thought about ability to pay and doctors’ authorizations. Most respondents cited their insurance status as evidence of their ability (or lack of ability) to pay. One respondent described how his doctor was unwilling to write a prescription for a “special sock” that a nurse told him he needs.

Judgement: When formulating their responses to this question on need for medical equipment, most respondents considered both their perception of need and access. For example, the respondent mentioned above answered “yes” because he decided he needs a “special sock” (need) but he was not able to get the sock because he cannot get a prescription for it from his doctor (access).

Several respondents answered “yes” based only on need. For example, the respondent who wants to use a blood pressure machine acknowledged that he has access to the machine at his doctor’s office. Another respondent who wants a cream for pain said that she could probably get it from her doctor.

Domain Six: Disability

In all three rounds, disability was assessed using the ACS-6 set of questions. This short set of questions to measure disability has been previously validated through extensive testing. The ACS-6 covers six domains of functioning: hearing, seeing, cognition, mobility, self-care and independent living (Appendix A). In Round One, a single alternative item was tested. This single item focused on difficulty doing day-

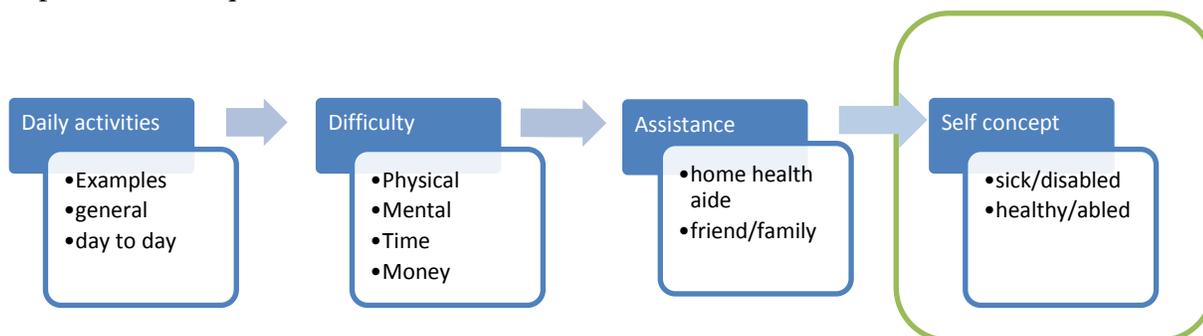
to-day activities rather than specific domains of disability. Since this question was not as effective as the ACS-6 in identifying disability, only the ACS-6 was asked in rounds two and three.

In addition to the ACS-6 the following alternative question was tested in Round One:

6.1.1 Do you have difficulty doing or need assistance to do day-to-day activities? (for example: work, go to school, do housework, socialize, cook, do paperwork)

Most respondents were able to provide an answer to this question without hesitation. However, two respondents struggled to provide a response. One respondent wanted to answer “sometimes” rather than “yes” or “no.” This respondent said she is functional when she’s on her medication for mental health disorders, but when she’s not on her medication, she has trouble doing daily activities due to indecision. Another respondent initially answered “no” because he focused on the word “assistance.” On probing, this respondent changed his answer to “yes” because realized the question also asked about “difficulty.”

Interpretation: This question aimed to capture disability status, as an alternative to the ACS-6 set of questions. However, this question did not consistently do so. Most respondents considered three decision points when answering this question 1) definition of daily activities and 2) type of difficulty or assistance and 3) assistance. A second group also considered self-concept when formulating their responses to this question.



Definition of Daily Activities: The first decision point that respondents considered was their interpretation of “daily activities.” Taking a cue from the examples listed in the question, the majority of respondents understood the question to refer to the tasks of everyday life such as work, chores, errands, and personal care. For instance, one respondent, who answered “no” to the question, considered his daily activities:

Work, getting around...things that require basic motor skills like walking somewhere, driving, going to the store.

Other respondents interpreted the question as a question about general functioning without thinking about specific activities. For example, one respondent explained her answer of “no” saying, “I can take care of myself and do all that needs to be done.”

A third pattern can be seen in respondents who interpreted daily activities as the things they do every day without regard to the examples given. As one respondent said, “If I do it, it’s my daily activity.” Respondents in this category struggled to answer the question because they felt that by definition the things they could do were things that were not difficult for them. As one respondent said, “Most of the things I do because I know I can do them.” These respondents answered “no” to the question because they did not have difficulty or need assistance to do the things they had chosen to do even if, due to their health, there were other activities that they had chosen not to do. Therefore, this self-limiting of activities influenced the way some respondents answered the question.

Type of difficulty: Next, respondents considered the types of difficulties they may have or assistance they might need to accomplish “daily activities.”

The majority of respondents referenced physical limitations and abilities. For example, one respondent answered “yes” explaining how she has difficulty cooking and doing housework because standing and bending cause her pain. Two respondents also mentioned mental/cognitive factors such as ability to think clearly. Respondents who answered “no” mentioned similar physical and mental limitations. For example, one respondent who said “no” mentioned that he can “think clear enough to pay the bills” and that he “can walk wherever I need to go.”

Respondents also considered external burdens such as time and money when answering this question. For example, one respondent who answered “yes” said, “It takes me a long time and I run out of time. That’s the difficulty.” Another respondent considered the financial barriers that make doing daily activities like grocery shopping difficult. A third respondent noted that lack of transportation causes difficulty for him (with a focus on availability of transit rather than accessibility).

Assistance: Finally, respondents considered whether and what type of assistance they might need. Most respondents considered assistance from friends and family, health care providers and home health aides. For example, one respondent with eye problems was driven to the doctor by his mother. Another respondent has 24-hour nursing care due to his symptoms of Multiple Sclerosis. These respondents responded “yes.”

Self-concept: For a few respondents, self-concept played a role in shaping their responses to this question, in addition to the decision points described above. Two of these respondents described difficulties they have but answered “no” because they see themselves as people who “can do it.” For example, one respondent said she had difficulty doing things around the house due to her torn ligaments but then explained that she answered “no” because:

I can't do everything, but mostly it's manageable. It's not going to be done on time, but it can be done...on my own.

Other respondents answered directly based on self-concept without considering the decision points. These respondents answered “no,” whether they had difficulties or not, and explained that people who answer “yes” to this question would be people who are “disabled” or “someone who can’t take care of himself.” These respondents did not identify with this characterization and therefore, answered “no.”

ACS-6

Are you deaf or do you have serious difficulty hearing? (Y/N)

Are you blind or do you have serious difficulty seeing even when wearing glasses? (Y/N)

Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (Y/N)

Do you have serious difficulty walking or climbing stairs? (Y/N)

Do you have difficulty dressing or bathing? (Y/N)

Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (Y/N)

The ACS-6 was asked to all respondents in all rounds. These six questions target specific physical and cognitive limitations. While there was some correlation between respondents reporting one or more of these disabilities and question 6.1.1, the relationship was complex for some respondents and conditions as can be seen in table 3.

Table 3. comparison of 6.1.1 to ACS-6

| Any “yes” on ACS-6 | Question 6.1.1: difficulty doing daily activities | |
|--------------------|---|----|
| | yes | no |
| yes | 5 | 8 |
| no | 2 | 5 |

The five respondents who answered “yes” to at least one ACS-6 question and 6.1.1 all had serious conditions that severely limited their ability to function within at least one ACS-6 domain. These included both physical (fibromyalgia, scleroderma) and mental conditions (PTSD, severe depression).

For the eight respondents who answered “no” to 6.1.1 but “yes” to one of the ACS-6 questions, question 6.1.1 was much more general. These respondents answered “yes” to 6.1.1 because in general they are able to get things done. The ACS-6 questions ask about very specific domains of functioning, so while these respondents may be able to get things done in general, they have difficulty in one or two specific areas. Most of these respondents indicated a difficulty either climbing stairs or remembering things. However, these difficulties did not impact their ability to “get things done.”

The two respondents who answered “yes” to 6.1.1 but no to the ACS-6 questions were specifically thinking about housework. Their conditions make it difficult for them to do chores around the house.

The ACS-6 does not have a question that specifically addresses difficulty doing household chores while the examples in 6.1.1 include housework. Additionally, both of these respondents noted that they did not answer “yes” to the ACS-6 question on walking or climbing stairs because that question asks about “serious difficulty” rather than “difficulty.” Both respondents felt that a *serious difficulty* would prevent someone from doing the activity altogether whereas a *difficulty* is just “an inconvenience.”

Finally, the five respondents who answered “no” to both questions all considered themselves “healthy” and “fully functional.”

Domain Seven: Chronic Condition

In Round One, two ways of determining chronic condition were assessed. Following questions in each domain, respondents who answered “yes” were asked if their answer was based on a health condition. A second follow-up question asked about duration of the condition. Respondents were also asked a stand-alone question on chronic condition at the end of the survey. Those who answered “yes” to this single item, were then asked if they had more than one chronic condition. Since the single question (with follow-up) captured chronic condition as accurately as the multiple follow-up questions, it was decided to use the single question (with follow-up) in rounds two and three.

7.1.1 Is this because of ANY medical, mental health or other health condition? (Y/N)

In Round One, this question was asked as a follow-up to respondents who answered “yes” to questions in domains concerning medical care, mental health, prescription medication and medical therapies (Domains 1-5). All respondents answered “yes” to this question because they were receiving treatments due to various health conditions. These conditions included fibromyalgia, diabetes, depression, back pain and high blood pressure.

7.1.1a Is this a condition that has lasted or is expected to last for at least 12 months? (Y/N)

In Round One, this question was asked as a follow-up question to respondents who answered “yes” to question 7.1.1. Almost all respondents answered “yes” either because their health condition had already lasted more than 12 months or because their condition was permanent. As one respondent said, “Scleroderma is permanent. It’s going to last my whole life.”

Three respondents answered “no” because they were *hopeful* that their conditions would not last up to 12 months. For example, one respondent believes his diabetes is “up in the air.” This respondent gets his blood tested every three months and says his blood glucose levels are good, he will not have to use insulin any more. Another respondent is in physical therapy for an injury and is hoping that his injury will heal soon.

7.1.2 Do you have ANY (7.1.3 serious) medical, mental health, or other health condition that has lasted or is expected to last for at least 12 months? (Y/N)

This question was asked in all three rounds of testing. In the first round of testing, it was asked in addition to the multiple follow-up questions in each domain (7.1.1 and 7.1.1a). All of the respondents

who answered “yes” to one of the follow-up chronic condition questions, also answered “yes” to this single item question. Therefore, it was decided that only the single question would be asked in rounds two and three since no information was gained by asking about chronic conditions within each domain. Additionally, a variation of the question that added the modifier “serious” was tested in Round One. The addition of this modifier did not change how respondents answered the question, so it was not used in Rounds Two and Three.

Interpretation: Almost all respondents understood this question to be asking about health conditions they may have. Respondents who answered “yes” listed a variety of conditions such as diabetes, torn ligaments, scleroderma, Meniere’s disease and bipolar disorder. However, one respondent answered “yes” based on the counseling he receives although he does not consider himself to have any particular “condition.”

Respondents answered “no” for a variety of reasons: lack of chronic condition, disability that is not considered a “condition” and prospective time orientation. Most respondents answered “no” because they do not currently have a chronic condition and consider themselves “healthy.” For example, one respondent said, “Thank God I don’t have anything like that! I’m healthy!” A few of these respondents answered “no” despite conditions like migraines and dermatitis. Respondents did not consider these conditions to have a *serious* impact on their lives. Some respondents who answered “no” referenced conditions they had had in the past that they had recovered from. For example, one respondent mentioned that he had had childhood asthma, and another respondent said that she had had schizophrenia for 8 years but that it was resolved. Another respondent who had cancer than had been in remission and then reoccurred multiple times hesitated before answering “no.” He said, “Once you have it, it is always in the back of your mind that it’s going to come back somewhere else.”

Respondents who had vision or hearing loss that was not attributable to another chronic condition answered “no.” For example, one respondent had hearing loss in one ear since she was a child, but she does not think of it as “a condition.” Another respondent with hearing loss said, “That’s just life.” This is in contrast to respondents who had vision or hearing loss due to a chronic condition (such as vision loss due to retinitis pigmentosa) as these respondents answered “yes” to this question.

A few respondents answered “no” because they are hopeful that their condition will not last a full 12 months. For example, one respondent with a foot ulcer hoped that it would heal soon. Two of these respondents answered “no” even though their conditions had lasted longer than 12 months. They were thinking prospectively and hoping that their conditions would resolve within the next 12 months.

Finally, three respondents provided false negative answers because they heard the question incorrectly. One respondent answered “no” but then changed his answer to “yes” when he realized that it included mental health. This respondent was diagnosed with bipolar disorder at age nine. Two other respondents answered “no” because they only heard “mental health” when the question was initially read. Both respondents changed their answers to “yes” when the question was repeated in probing. These respondents both had chronic conditions that were not related to mental health. One respondent said, “I heard ‘mental health.’ I was thinking about mental health and that threw me off.”

7.1.2a Do you have two or more of these on-going health conditions? (Y/N)

In all three rounds, this was asked as a follow-up question to respondents who answered “yes” to questions 7.1.2 and 7.1.3. Respondents who answered “yes” discussed the same conditions they did in previous questions. However, one respondent who had been diagnosed with bipolar depression answered “yes” considering “mania” and “depression” to be two different conditions. Those who answered “no” said they only have one condition. For example, one respondent said, “Nope. It’s just the diabetes.”

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ACHCN Instrument (round 3 final)

| | | |
|---|--|---|
| Domain One: Medical care | 1.1) Do you see medical doctors about your health often? Please do not include an annual check-up in your response. 1.1a) If no: Are you often unable to see a medical doctor when you need to? | <input type="checkbox"/> Yes → Go to Question 2 <input type="checkbox"/> No → Go to Question 1.1a |
| Domain Two: Mental health | 2.1) Do you use mental health treatment or support such as counseling or substance abuse services? 2.1a) Do you need mental health treatment or support that you do not receive? | <input type="checkbox"/> Yes → Go to Question 3 <input type="checkbox"/> No → Go to Question 2.1a |
| Domain Three: Prescription medications | 3.1) Do you use prescription medicine regularly (other than vitamins or birth control pills)? 3.1a) How many different prescription medicines do you use? (numeric) 3.1b) Do you regularly need prescription medicine that you do not receive? | <input type="checkbox"/> Yes → Go to Question 3.1a <input type="checkbox"/> No → Go to Question 3.1b |
| Domain Four: Therapies | | |

4.1) Do you use medical or other therapies often?

Yes → Go to Question 5
 No → Go to Question 4.1a

4.1a) Do you often need medical or other therapies that you do not receive?

4.2) Do you often use medical or other therapies such as dialysis, physical therapy, or therapy to manage or reduce pain?

Yes → Go to Question 5
 No → Go to Question 4.2a

4.2a) Do you often need medical or other therapies that you do not receive?

**Domain Five:
DME /
assistive
technology**

5.1 Do you use medical equipment or assistive devices often?

Yes → Go to Question 6
 No → Go to Question 5.1a

5.1a) Do you need medical equipment or assistive devices that you do not have?

**Domain six: ACS-6
Disability**

6.2a Are you deaf or do you have serious difficulty hearing? (Y/N)

6.2b Are you blind or do you have serious difficulty seeing even when wearing glasses? (Y/N)

6.2c Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (Y/N)

6.2d Do you have serious difficulty walking or climbing stairs? (Y/N)

6.2e Do you have difficulty dressing or bathing? (Y/N)

6.2f Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (Y/N)

**Domain
seven:
Chronic
condition
status**

7.1 Do you have ANY medical, mental health, or other health condition that has lasted or is expected to last for at least 12 months? (Y/N)

Yes → Go to Question 7.1a
 No → finish

7.1a Do you have two or more of these on-going health conditions? (Y/N)