

RESULTS OF THE COGNITIVE INTERVIEWING STUDY TO EXAMINE PROPOSED QUESTIONS OF THE MODEL DISABILITY SURVEY

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This report presents findings from an evaluation of proposed questions for the World Health Organization’s (WHO) Model Disability Survey (MDS). These questions focus on four areas pertaining to disability: Capacity, Functioning, Broad Environment, and Use of Assistive Devices. This study is a collaborative effort between the Center for Questionnaire Design and Evaluation Research (CQDER) at the National Center for Health Statistics and the Institute for Social Research (ISR) at the University of Michigan.

This study builds upon previous MDS testing studies and was designed to address specific questions raised in those tests. The decision to conduct this study was agreed upon by WHO, NCHS and ISR; this study was designed by NCHS and ISR with input from WHO. The primary purpose of this evaluation is to determine whether proposed questions capture intended constructs as well as to identify response process difficulty. The study also sets out to determine whether section ordering impacts question interpretation, and, if so, the optimal sequence of sections.

Findings indicate that a majority of questions do not perform as intended. For many domains, the construct captured by the capacity and functioning questions significantly overlap, with most respondents interpreting both types of questions as asking about “in-the-skin” abilities. As a result, many respondents provided the exact response to both questions and often complained of repetitiveness. Even instances where respondents provided different answers, the basis for their responses were the same. There were some cases in which the questions performed as intended (i.e. respondents based their answer to the capacity question on “in-the-skin” abilities and their answer to the functioning question on abilities within an environmental context), but this was not the norm. There were also cases where respondents’ interpretations of the functioning questions were entirely out-of-scope, and their responses captured neither functioning nor capacity.

Question performance, however, is improved when environment and functioning questions follow health condition questions. Without the context of health, respondents are less likely to understand these questions as asking about disability-related issues and, as a result, are more likely to form out-of-scope interpretations. The authors of this report believe that the questionnaire requires redesign in fundamental ways in order to obtain the intended information.

This report first presents the methods by which the study was conducted followed by a summary of findings. Detailed findings for individual questions are then presented.

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METHODS

The question evaluation method employed in this study is cognitive interviewing methodology. An overview of the method is next provided followed by details specific to this study.

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 studies provide in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves the scientific goal. Findings of a cognitive interviewing project typically lead to recommendations for improving a survey question, or results can be used in post-survey analysis to assist in data interpretation.

Traditionally, cognitive 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 open-ended follow-up questions that reveal what respondents were thinking and their rationale for that specific response. In this regard, cognitive interviews unfold within a narrative format. 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.

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 disabilities, for example, the sample would likely consist of respondents with a previously known disability and, to discover potential causes of false positive responses, some respondents with no known disability. Because of the small sample size, not all social and demographic groups are represented. Analysis of cognitive interviews does not produce generalizable findings in a statistical sense, but rather, provides an explicit understanding of response processes including patterns of interpretation.

As is 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 resulting in 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. A description of each of these steps and the resulting reduction product is presented below:

- 1) Conducting interviews to produce interview text: collecting narratives from respondents that reveal how each respondent made sense of and went about answering a survey question,
- 2) Synthesizing interview text to produce detailed summaries: detailing how and why each respondent interpreted the question as well as how they formulated their answers, including events or experiences considered as well as any difficulties answering the question,
- 3) Comparing summaries across respondents to produce thematic schema: identifying and mapping common themes that detail phenomena captured and the process of formulating a response,
- 4) Comparing identified themes across subgroups to produce an advanced schema: identifying ways in which different types of respondents may process questions differently depending on their differing experiences and socio-cultural backgrounds,
- 5) Making conclusions to produce study results: determining and explaining the performance of a question as it functions within the context of respondents' various experiences and socio-cultural locations.

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. (For more, see Miller, et. al. 2014.)

WHO MDS Cognitive Interviewing Study

The analytic purpose of this study is threefold: 1) to identify the constructs captured by each question as well as any response difficulty 2) to examine whether the functioning and capacity questions within the same domain capture different constructs, and 3) to examine whether section ordering, specifically the placement of health condition questions prior to the functioning section, impacts respondent interpretation of those functioning questions. To study ordering effects, two versions of the questionnaire with different sequencing were created. The ordering of those versions is presented below:

Version A

Broad Environment
Assistive Devices/Aides
Functioning
Health Conditions
Capacity

Version B

Health Conditions
Capacity
Assistive Devices/Aides
Broad Environment
Functioning

Because of the length of the questionnaire, not all questions proposed for the MDS could be examined. Therefore, to study differences between capacity and functioning questions, both types of questions for each selected domain were included. For example, both capacity and functioning questions for the depression domain were selected. The domains in this study include walking 100 yards, self-care, depression, shortness of breath, pain, cognition, household tasks, and community participation.

Sixty-one face-to-face cognitive interviews were conducted in the Questionnaire Design Research Laboratory at the National Center for Health Statistics and The Institute for Social Research at the

University of Michigan. Thirty-one respondents were asked Version A, and 29 respondents were asked Version B. Prior to the interview, respondents completed a demographic sheet as well as a consent for audio or video-recording the interview. Once completed, the interviewer described the purpose of the study and how the interview would take place. Interviews lasted one hour, and respondents received \$40 in compensation. During the interview, respondents were asked a survey item and were then asked to explain their answer. The types of follow-up questions asked by interviewers depended on respondents' interpretation of the questions as well as their health status and physical abilities. Typical follow-up questions included, "How so?" and "Why do you say that?"

Respondents. The demographic breakdown of respondents appears in Table 1 below. Respondents were recruited through newspaper advertisements and flyers. A screening process was employed over the telephone to determine callers' eligibility for participation. Because questions focused primarily on respondents' abilities and physical conditions, particular effort was made to recruit individuals with a variety of health conditions. Table 2 provides the disability status breakdown of respondents by questionnaire version. Note that these are not self-report disability statuses, but are derived from the respondents' answers to various MDS questions, as explained in Appendix A.

Table 1: Demographic summary of respondents

	<u>Version A</u>	<u>Version B</u>		<u>Version A</u>	<u>Version B</u>
Gender			Education		
Female	13	12	HS diploma	6	5
Male	18	16	Some college	7	7
Transgender		1	Coll. Degree	8	9
			Grad. Degree	10	8
Age					
18 - 29	3	3			
30 - 49	5	4			
50 - 64	12	9			
65 and Over	11	13			

Table 2: Distribution of Respondents by Disability Statuses

	<u>No Disability</u>	<u>Only Physical Disability</u>	<u>Only Mental Disability</u>	<u>Physical and Mental Disability</u>
Version A	5	8	3	7
Version B	5	7	4	12

Method of analysis. Analysis of interviews was performed in the manner described in the previous description of cognitive interviewing methodology. After an interview was conducted, transcripts or summary notes were written for each question. Summary notes included the way in which respondents interpreted and processed individual questions, experiences or perceptions respondents included as they formulated their answer, and any response difficulties experienced. Transcripts were created from audio and video-recordings of interviews, which also ensured the accuracy of summaries and soundness of study conclusions.

After all interviews and summaries were completed, interviews were compared to identify common patterns of interpretation and response difficulties for each question. Themes of the capacity questions were then compared to themes of the functioning question in the same domain. For example, themes identified in the depression capacity question were compared to themes identified in the depression functioning question. This analysis indicated whether the two types of questions capture the same phenomena. Additionally, individual respondents' answers to both capacity and functioning questions within the same domain were examined for inconsistencies—for example, if a respondent answered 'extreme problem' walking a 100 yards to the functioning question, but then reported having 'no difficulty' walking when asked the capacity question. Each case of inconsistency was investigated to determine why the respondent would answer a particular way to one of the questions but differently to the other question.

To examine potential ordering effects, themes identified in a specific question were compared to the same question in the other version. For example, themes identified in the Version A pain functioning question were compared to themes identified in the Version B pain functioning question.

A data entry and analysis software application (Q-Notes) was used to conduct analysis. Q-Notes, developed by the NCHS, allows for a systematic 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.

Because of time limitations, not all questions were asked of all respondents. Additionally, some of the narrative explanations were less complete than others. Findings of this study are based on complete narratives; incomplete cases were excluded.

SUMMARY OF FINDINGS

Analysis of cognitive interviews produced four over-arching themes pertaining to lack of validity and respondent burden. Those themes are 1) construct repetition across functioning and capacity questions, 2) overly complex response process for environment questions, 3) problematic interpretations of the word 'accessible,' and 4) problematic question interpretations due to questionnaire ordering. These overarching themes are discussed below; question-specific findings are presented in the following section.

Functioning/Capacity Construct Repetition

For many domains, the construct captured by the capacity and functioning questions significantly overlap. Although questions are worded differently, respondents often interpreted the two types of questions as the same and based their answers on the same phenomena. Thus, their answers to the two questions were similar. As an example, the table below illustrates the cross-tabulation of responses to the self-care capacity and functioning questions; in all but one of the cases, respondents provided precisely equal responses to both questions.

Table 3: Self-Care Capacity by Functioning

Functioning: How much of a problem is being cleaned and dressed?	Capacity: Do you have difficulty with self-care, such as washing all over or dressing?				
		No Difficulty	Some	A Lot	Cannot Do
	0 No Problem	22	1		
	1		3		
	2		2		
	3				
4 Extreme			1		

Consistent responses do not necessarily indicate that the questions measure the same construct, but this can be determined with examination of the reasons respondents gave for their answers. Analysis of this data confirms that, indeed, respondents considered the same phenomena when answering both questions: their physical ability to dress themselves and to perform personal hygiene activities. Not surprisingly, respondents also perceived the questions as repetitive, with many noting the redundancy and referring to their previous answer.

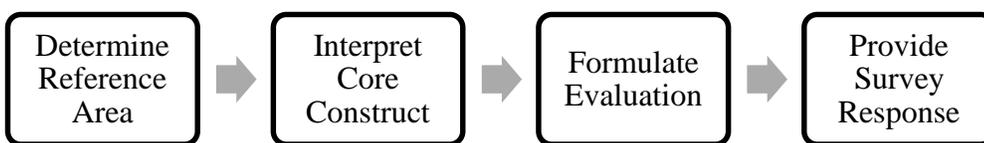
For the most part, respondents interpreted both types of questions to be asking about “in-the-skin” abilities; answers were not typically based on performance or functioning within an environmental context. For example, when asked about pain, respondents were more likely to consider the intensity and frequency of their pain, not the impact of that pain on their daily lives. This pattern, however, varied somewhat when respondents were asked capacity questions prior to functioning questions (i.e., Version B). More specifically, when asked after the frequency and intensity capacity questions, more respondents interpreted the functioning question to be about the impact of their pain on their life. Since they were previously asked about intensity and frequency, it is not surprising that respondents would be less likely to interpret this question as asking about those constructs.

Overly Complex Response Process for Environment Questions

Much more than the capacity and functioning questions, the environment section is highlighted by respondent confusion over key terms and, more generally, how questions should be interpreted. This was particularly true for respondents with no physical disability. As a result, interpretations of questions varied dramatically across respondents.

A breakdown of the question response process illustrates the degree of complexity and respondent burden produced by the environment questions. It also reveals the level of interpretative variation and potential lack of comparability for resulting survey data. Because they are similarly structured, the response process for all environment questions followed a basic pattern. This response process is illustrated in Figure 1 below:

Figure 1: Overall Response Process Environment Questions



To answer each environment question, respondents were first required to identify the specific reference area—the geographic boundary within which to limit their consideration. For example, in the question “How easy or hard does your natural environment of the place you usually live—its temperature, terrain, and climate—make it for you to do the things you need or want to do?” the reference area is “place you usually live.” However, the ways in which respondents defined this area varied. For example, in his interpretation of the phrase “place you usually live,” one respondent surmised that the question was referring to his interior living space and formulated his answer thinking only of his home. Other respondents believed the question was referring to their apartment building or their neighborhood. Still others considered the question to be about their city or the geographical region of the country where they live.

After determining the reference area, respondents were then required to interpret the main component of the question—the core construct. In this same question, for example, the core construct is the “natural environment.” Again, respondents’ conceptualizations of the core construct varied and typically depended on the specific perceived reference area. For example, some respondents considered regional weather patterns while others considered the temperature of their home. Still others considered the presence or absence of hills, while others considered only the built (and not natural) environment.

Finally, after interpreting the various dimensions of the questions, respondents were then required to formulate their response: an evaluation of the core construct within the reference area. In the natural environment question, for example, respondents were asked to determine whether or not their natural environment made their lives easy or hard—in other words, whether it satisfied their needs and wants. As in the interpretation process, respondents varied in the ways they went about making these judgements. For example, in the “natural environment” question, some respondents judged their environment on whether it helped or hindered their physical movement, while others based their answer on whether or not they believed it was convenient. Still others based their answer on whether the environment impacts their health.

In a few cases respondents also considered a reference person—determining whether the question was about themselves or others. For instance, in the question asking “...how easy or hard does the transportation you use make it for you to do the things you need or want to do?, some respondents answered for themselves, while other respondents considered the experiences of hypothetical people (as in, “someone who is disabled might have a hard time on the metro”) or people they knew (as in, “my brother says he doesn’t have a hard time using the bus”).

Interpretive Variation of Term “Accessible”

Respondents understood the term “accessible” as two distinct concepts: convenience and physical accessibility. Respondents who applied the former interpretation considered whether the particular subject of the question was easy to get to, easy to use, or easy to obtain. For example, in response to the environment question about healthcare facilities (“...how easy or hard does your healthcare facility make it for you to do the things you need or want to do?”), one respondent explained that she was thinking about the accessibility of her doctor’s office in that it is close to her subway line. On the other hand, respondents who applied the latter interpretation considered whether the subject in question could be physically entered, physically traveled to or physically used by those with disabilities. In most cases, these respondents understood “accessible” to mean that it had modifications or was ADA¹-compliant.

¹ The Americans with Disabilities Act (ADA) is a federal law that mandates that certain public buildings have modifications that enable persons with disabilities to use the facilities.

For instance, another respondent answering the healthcare facility question determined that his medical complex was “accessible” because ramps and elevators were available for people in wheelchairs. Interpreting the term “accessible” to mean ADA compliant *was not* limited to those respondents who were categorized as “physically disabled;” non-disabled respondents employed this interpretation as well.

Importantly, respondents did not always carry the same interpretation of “accessibility” from one question to the next. For example, in the question about healthcare facilities one respondent considered the accessible parking and entrance ramps at her doctor’s office, but considered the convenience of attending family gatherings when answering the social participation question. A few respondents, in fact, shifted their interpretation of “accessibility” within a single question: at least two respondents considered ADA compliancy for half of the items on the showcard for Question AA3 and AA4 (“...do you use any of these mobility or self-care aids?” and “...do you need any of these mobility or self-care aids?”, respectively) but considered convenience for the other half of the items. Again, this pattern of switching interpretations of “accessible” between questions was observed in both disabled and non-disabled respondents.

Ordering Effects: Cross-Questionnaire Differences

As indicated on Page 3 of this report, two versions of the questionnaire were developed to investigate ordering effects. The ordering of those versions is presented below:

Version A

Broad Environment
Assistive Devices/Aides
Functioning
Health Conditions
Capacity

Version B

Health Conditions
Capacity
Assistive Devices/Aides
Broad Environment
Functioning

Version A places the health condition questions toward the end of the questionnaire so that the environment, assistive devices and functioning questions are asked without a context of health. Conversely, Version B places the health condition questions at the beginnings so that all of the questions are framed by a health context.

Cross-version comparisons indicate that many MDS questions are impacted by framing effects. That is, the way in which respondents interpreted and processed questions was influenced by section ordering. When framed by the context of health, respondents’ interpretations are less varied and are more closely aligned with the questions’ intent. This is especially true for the environment and assistive device section. Without the context of health, respondents were less likely to understand the questions as asking about disability-related issues and, as a result, were more likely to form out-of-scope interpretations. For example, the household task functioning question was sometimes interpreted as “do you like to do housework?”

As previously described, some of the functioning questions appeared to be impacted by placement of those questions in relation to the capacity questions: When respondents are first asked the capacity questions, they are less likely to interpret the functioning questions as asking about capacity and more

likely to base their answer on impact or performance. Thus, when the functioning section follows the capacity section (Version B), there is less redundancy.

Summary Conclusions and Recommendations

These findings indicate that this questionnaire would produce survey data of questionable validity as well as generate undue amounts of respondent burden. For many of the disability domains, the functioning and capacity questions capture identical phenomena and are perceived as repetitive by respondents. Performance, however, is improved when environment and functioning questions follow health condition questions. Without the context of health, respondents are less likely to understand these questions as asking about disability-related issues and, as a result, are more likely to form out-of-scope interpretations.

Given these findings, it is believed that the questionnaire requires redesign in fundamental ways in order to obtain the intended information. Focus of a redesign should concentrate on ordering and content.

Ordering: Many questions require framing by health context to operate as intended and, as such, sets of questions cannot validly operate as separate modules. The following order is recommended:

- I. Health Conditions
- II. Assistive Devices
- III. By Domain (e.g. walking, seeing, hearing)
 - a. Capacity
 - b. Functioning
- IV. Environment

Content: Question content must be similarly relevant to all potential respondents. Environmental barriers, assistive devices and modifications such as entrance ramps and hand bars, are not equally relevant to disabled and non-disabled respondents. As such, questions pertaining to these subjects can be easily misinterpreted. Question design strategies, such as framing, can reduce interpretive error. Items that cannot be written so they are similarly understood by all respondents should be omitted.

QUESTION BY QUESTION REVIEW

This section presents findings for individual questions. Capacity and Functioning questions are first presented, followed by Environment and Assistive Devices.

CAPACITY/FUNCTIONING

WALKING 100 YARDS

Capacity:
 Do you have difficulty walking 100 yards on level ground, that would be about the length of one football field or one city block [if uses aid: without the use of your aid]?

No Difficulty
 Some Difficulty
 A lot of Difficulty
 Cannot Do at All

Functioning:
 Using show card X, how much of a problem is walking a short distance such as a 100m for you?

No Problem				Extreme Problem
0	1	2	3	4

Summary of Findings: The tables below present respondents’ answers to both the capacity and functioning walking questions. Table 4 presents responses from Version A—the version in which respondents first received the environment section followed by the functioning questions and then the capacity questions. Table 5 presents those from Version B—the version in which respondents first received the health conditions section followed by the capacity questions and then the functioning questions.

Table 4: Version A Walking Capacity by Functioning

Functioning: How much of a problem...	Capacity: Do you have difficulty....			
	No Difficulty	Some	A lot	Cannot Do
0 No Problem	12	3	2	
1	1			
2		4		
3			2	
4 Extreme				1

Table 5: Version B Walking Capacity by Functioning

Functioning: How much of a problem...	Capacity: Do you have difficulty....			
	No Difficulty	Some	A lot	Cannot Do
0 No Problem	15	2	1	
1		2		1
2		2		
3		1	2	
4 Extreme			1	1

For the most part, there was little difference between the functioning and capacity questions in that both questions captured “in-the-skin” abilities with little account of the physical environment. With only a few exceptions, respondents considered walking on a flat surface in formulating their answers. As a result, the questions were seen as repetitive, with multiple respondents noting the previous question and referring to their prior answer when explaining their response (e.g. “as I told you before...”). The cases of exception included several respondents, who when answering the functioning question, considered getting out of the house (e.g. going shopping), walking across a crowded room or climbing the stairs. Another exception included an out-of-scope interpretation in which a respondent surmised that living in a dangerous neighborhood could pose a problem walking 100 yards.

Although most respondents considered walking on a flat surface for both questions, those in the sample who use canes tended not to consider the assistive device when answering the capacity question, but did so when answering the functioning question. This explains the few off-diagonal cases in which respondents reported ‘some’ or ‘a lot’ of difficulty walking while at the same time answering ‘no problem’ to the functioning question.

The causes commonly cited for difficulty walking include: fatigue, pain, a problem with legs or feet, and lack of fitness. Some physically active respondents explained their answer (‘no difficulty’/‘no problem’) as being able to walk or run even longer than 100 yard distances.

The most problematic component of the functioning question involved conceptualization of 100 yards. Without examples, some respondents indicated that they could not envision the distance. Because the capacity question provides examples, respondents experienced no difficulty forming a response. For example, one respondent had trouble conceptualizing 100 yards when first asked the functioning question, but when asked the capacity question, she easily answered explaining that she used to run up and down the field to see her son play football. Even when asked Version B of the questionnaire, where the capacity question is asked first, a full third of respondents were still unable to conceptualize 100 yards when asked the functioning question.

In sum, the walking questions performed the same in that the vast majority of respondents considered walking on a flat surface. In only a few cases, when answering the functioning question, respondents considered activities occurring within a particular environment (i.e. ‘walking up steps,’ ‘going out of the home,’ ‘being in a dangerous neighborhood’). When respondents considered the use of an assistive device, they tended to do so for the functioning question. The ordering of the sections did not appear to impact interpretation.

SELF-CARE

Capacity:				
Do you have difficulty with self-care, such as washing all over or dressing?				
No Difficulty				
Some Difficulty				
A lot of Difficulty				
Cannot Do at All				
Functioning:				
How much of a problem is being cleaned and dressed?				
No Problem				Extreme Problem
0	1	2	3	4

Summary of Findings: The tables below present respondents’ answers to both the capacity and functioning self-care questions. Table 6 presents respondents’ answers from Version A—the version in which respondents first received the environment section followed by the functioning and then capacity questions. Table 7 presents respondents’ answers from Version B—the version in which respondents first received the health conditions section followed by the capacity and then functioning questions.

Table 6: Version A Self-Care Capacity by Functioning

Functioning: How much of a problem...?	Capacity: Do you have difficulty....				
		No Difficulty	Some	A Lot	Cannot Do
	0 No Problem	20	3		1
	1	2	2		
	2				
	3	1			
	4 Extreme Problem				

Table 7: Version B Self-Care Capacity by Functioning

Functioning: How much of a problem...?	Capacity: Do you have difficulty....				
		No Difficulty	Some	A Lot	Cannot Do
	0 No Problem	22	1		
	1		3		
	2		2		
	3				
	4 Extreme Problem			1	

In terms of the activities considered, there was little difference between the functioning and capacity questions: every respondent across both sub-samples considered personal hygiene and physically dressing themselves. A few respondents also considered ancillary constructs—specifically housecleaning and clothing care (e.g., ironing and laundry), although this was always done in concert with either hygiene or dressing. As in the walking domain, virtually all respondents perceived the capacity and functioning questions to be identical, with multiple respondents commenting about the repetitiveness. This duplication is observed in the primarily consistent responses shown in the tables above, although Version B shows more consistency than Version A.

Although all respondents considered the same self-care activities, there was variation in regards to how they went about formulating answers. Specifically, some respondents assessed their physical ability with the use of assistive devices, while others did not. Some respondents also incorporated environmental context into their formulation, for example, considering the length of time needed to clean or dress along with their desire to interact with others. Regardless of the response process used, many (but not all) respondents were consistent when formulating their answers to the two questions. That is, respondents tended to employ the same interpretive pattern when answering the functioning question as they did the capacity question. For example, one respondent explicitly accounted for the modifications made to his house when answering both questions. When explaining his ‘no difficulty’ answer to the capacity question, he stated:

Can I put on shirts, undergarments, shoes? The answer is yes. I dressed myself today; I showered today. We have made adjustment in our home for me to do things safely. Our bathroom is equipped with grab bars. I have a plastic shower seat that I use. So we’ve made adjustment as needed for me to take care of myself.

This respondent used the same reasoning while answering ‘no problem’ to the functioning question, adding that his Velcro shoes help him get dressed.

While most respondents similarly approached and provided equal answers to the two questions, there was some variation to this pattern. This is observed in the off-diagonal cases shown in Tables 6 and 7. For example, the respondent who answered ‘0-no problem’ to the functioning question but ‘cannot do’ to the capacity question, considered the help of others when answering the functioning question but did not for the capacity question. On the other hand, the respondent who answered ‘3’ to the functioning question but ‘no difficulty’ to the capacity question, took into account help from his wife when answering the capacity question but did not for the functioning question.

In sum, the two self-care questions performed similarly in that all respondents considered their hygiene and dressing abilities, although respondents did vary on whether or not they accounted for assistive devices and environmental context. With a few exceptions, when respondents did consider these factors, they tended to do so for both questions. There was little evidence to suggest that the ordering of the sections impacted these patterns.

PAIN

Capacity: In the past 3 months, how often did you have pain? Would you say... Never Some Days Most Days Everyday				
Thinking about the last time you had pain, how much pain did you have? Would you say... A little A lot Somewhere in between				
Functioning: Using the scale on show card X, how much of a problem is having pain for you?				
No Problem 0	1	2	3	Extreme Problem 4

Summary of Findings: Two survey questions used together serve as the capacity measure for pain. The rationale for the use of two questions instead of one question is to simplify the cognitive processes required by respondents to construct an answer. Unlike the other domains, pain is a particularly complex and elusive phenomenon with a myriad of aspects (e.g. characterizations of pain, variability, the role of medication, pain threshold and interference with daily activities). Breaking the measure into two critical dimensions—pain frequency and pain intensity—allows the respondent to focus on specific aspects, thereby improving their ability to provide responses that accurately reflect their pain experience. The response process is also simplified by stipulating a time frame and a specific episode to consider.

In analyzing the resulting survey data, responses from the two questions would be combined to form a summary score that places respondents on a continuum reflecting a broader portrayal of pain. Respondents, for example, reporting ‘a lot’ of pain ‘every day’ would be characterized as having severe pain while, at the other end of the continuum, those experiencing ‘little’ pain on ‘some days’ would be characterized as having minor pain. For this report, the generated continuum variable consists of 5 categories² where respondents reporting ‘never’ are assigned the value=0 (no pain) and those with ‘a lot’ of pain ‘everyday’ are assigned the value=4 (extreme pain). Table 8 illustrates how individual cells were assigned.

² Five categories were used specifically for this study so that a one-to-one comparison could be made with the functioning question. The Washington Group does not stipulate that five categories should be used.

Table 8: Continuum categories for the pain summary score

Thinking about the last time you had pain, how much pain did you have?	In the past 3 months, how often did you have pain?				
		Never	Some Days	Most Days	Every Day
	(Skipped)	Continuum=0			
	A Little		Continuum=1	Continuum=2	Continuum=2
	In Between		Continuum=2	Continuum=3	Continuum=3
A Lot		Continuum=3	Continuum=4	Continuum=4	

The tables below show how cognitive interview respondents answered the frequency and intensity capacity questions. Table 9a presents respondents' answers from Version A, the version in which respondents first received the environment section followed by the functioning section and then the capacity section. Table 9b presents the combined continuum score for Version A. Table 10a presents respondents' answers from Version B, the version in which respondents first received the health conditions section followed by the capacity section and then the functioning section. Table 10b presents the combined score for Version B.

Table 9a: Frequency by Intensity: Version A

Thinking about the last time you had pain, how much pain did you have?	In the past 3 months, how often did you have pain?				
		Never	Some	Most	Every
	(Skipped)	7			
	A Little		5	3	1
	Between		2	2	1
A Lot		2	2	1	

Table 9b: Continuum Pain Score: Version A

0	7
1	5
2	6
3	5
4	3

Table 10a: Frequency by Intensity: Version B

Thinking about the last time you had pain, how much pain did you have?	In the past 3 months, how often did you have pain?				
		Never	Some	Most	Every
	(Skipped)	3			
	A Little		7	2	3
	Between		4	1	3
A Lot		1	2	1	

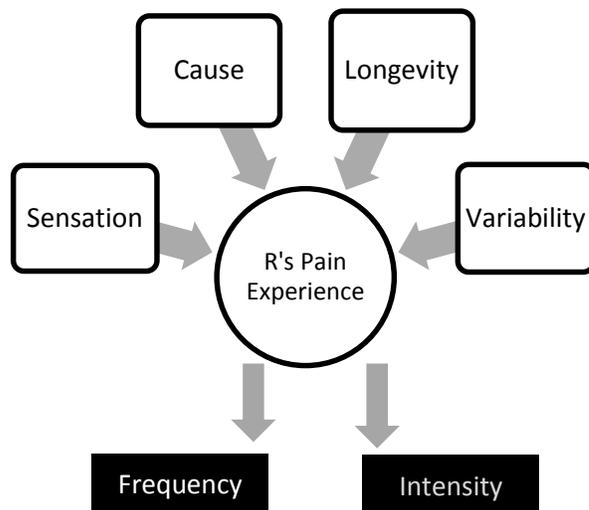
Table 10b: Continuum Pain Score: Version B

0	3
1	7
2	9
3	5
4	3

To formulate answers to the pain frequency and intensity questions, respondents first conceptualized what experiences or episodes to count as pain. To make this determination, respondents considered

cause, the specific feeling sensation, the variability, and the longevity of the pain-causing condition. Figure 2 below illustrates this response pattern.

Figure 2: Question Response Process for Pain Frequency and Intensity



Once determined, respondents then assessed the frequency and intensity of these experiences. For example, when formulating her answer to the frequency question, one respondent spoke aloud:

Back pain primarily. Also I have acid reflux. Both would be discomfort, and the back would be more painful than the acid reflux. The acid reflux would be sharper pain because of the way it come up on you. Some days. I would say at least 3 to 4 days a week. Every other day.

Similarly, when formulating his response to the intensity question, one respondent stated:

A little. The back. Lower back pain related to standing or walking too much. It's not intense pain. It's not unbearable. It's a pain that I know that would go away if I rest or lie down or lay in a comfortable chair.... I know it's going to go away. If it lasts too long I'll do something about it but that hasn't happened.

Importantly, regardless of order (whether or not respondents received Version A or Version B), this response pattern did not vary; the capacity questions performed similarly across all respondents in terms of cause and characteristics considered.

Respondents' answers to the functioning question were based on one of three specific themes: 1) the intensity or frequency of their pain (i.e. the constructs asked in the capacity questions), 2) the degree to which pain impacts their ability to participate in various activities, and 3) the degree to which they are able to accept or cope with pain. In a couple cases, respondents were uncertain as to what the question was asking and on what basis they should formulate their answer. The chart below summarizes the three separate patterns of interpretation. The interpretive themes provide the basis for respondents' answers and represent the construct captured by the question.

Figure 3: Interpretive patterns of the pain functioning question

Capacity	Performance	Acceptance
<ul style="list-style-type: none">• Respondent bases answer on the intensity or frequency of pain.• Respondent does not consider activities impacted by pain.	<ul style="list-style-type: none">• Respondent bases answer on the type and amount of activities impacted by pain.	<ul style="list-style-type: none">• Respondent bases answer on their perceived ability to accept or cope with pain.• Respondent does not consider the amount or frequency of pain.• Respondent does not consider impact on activities.

Approximately, half of all respondents interpreted the question as they did the capacity questions, considering only the frequency and/or intensity of their pain. They did not consider the impact of that pain on their ability to perform various activities. For example, explaining why she answered ‘4-extreme,’ one respondent considered only the frequency of her pain: “I hurt all the time. I wake up in pain. I hurt sitting at work. I hurt now. I’m never without pain.” Another respondent explained his answer (‘3’) based on intensity: “It could be worse, but it’s very painful.”

Approximately a third of all respondents considered the impact of pain on their ability to perform various daily activities. The types of activities considered varied across respondents, ranging from basic actions (e.g. walking) to more specific activities (e.g. visiting friends). Importantly, respondents did not consistently define or consider every impacted activity as being ‘a problem.’ For example, some respondents with extreme pain reported ‘no problem’ or having only a small problem because they are able to do essential activities—though they are no longer able to participate in activities that they once enjoyed (e.g. biking and going for walks). Because respondents held different considerations about activities, respondents reporting the same answer did not always have comparable experiences. For example, one respondent reported ‘1’ because pain makes it difficult for him to walk, while another respondent reported ‘1’ because he sometimes foregoes exercising at the gym.

The remaining respondents based their answer on their perceived ability to cope with pain—regardless of whether or not they experience ongoing or regular episodes of pain. In a few cases, respondents who reported having no pain also reported having an ‘extreme problem’ (4). For example, one respondent explained, “Well I don’t have pain. When a pain occurs it’s an extreme problem a number 4.... It’s not a part of my life but it’s a part of my fears.” Another respondent who also answered ‘extreme’ explained that she hates pain so much that she often takes “Alka-Seltzer” to avoid a potential stomach ache. On the other hand, respondents who saw themselves as having a “high pain threshold” or who are able to “put mind over matter” reported having no or little problem with pain. In a more extreme case, one respondent who experiences debilitating pain and whose activities are seriously limited reported ‘no problem’ because she has learned to accept it as part of her life:

I just think that pain is a part of living - just accept it....Is it a problem? No. If I could choose, I would choose no pain.... I could choose to stop the pain [by choosing] to stop living. But I don't choose to stop living. I think that living is pain for me right now, so it's no problem.

While section ordering did not appear to impact the ways in which respondents interpreted the two capacity questions, it does appear to influence respondents' interpretation of the functioning question: respondents were more likely to interpret the functioning question as asking about performance when the question came after the intensity and frequency questions. Table 11 shows the breakdown of interpretive patterns for both versions of the questionnaire.

Table 11: Interpretative patterns of the pain functioning question

	Version A	Version B
Capacity	50% (13)	37% (10)
Performance	26% (7)	40% (11)
Acceptance	23% (6)	22% (6)
Total	26	27

While half of the respondents interpreted the functioning question as asking about the frequency or intensity of their pain in Version A, only 37% did so in Version B. In Version B, where the frequency and intensity questions were previously asked, more respondents (40%) interpreted the functioning question as asking about the impact of pain. This finding is not surprising given that it would seem illogical to be asked the same question twice. Nevertheless, it is important to note that even when it was previously asked, more than one-third of respondents still interpreted the functioning question as they did the capacity questions, that is, as asking about frequency and/or intensity. The sequence of sections does not appear to influence whether or not respondents interpret the question as asking about acceptance or their ability to cope.

Comparing respondents' answers to the capacity and functioning questions provides a more in-depth understanding of the relationship between the questions. Table 12a and 12b show the cross tabulation of the two measures as well as individual respondents' interpretation of the functioning question. Each letter within the cells represents one respondent; the particular letter indicates that respondent's interpretation of the functioning question. (C represents capacity, P represents performance, and A represents acceptance). Table 12a presents responses from Version A; Table 12b presents Version B.

Table 12a: Version A: Capacity by functioning

Functioning: How much of a problem is having pain for you?	Capacity Pain Score:				
	0	1	2	3	4
0	C		P		
1	P P A	C C	C A	C	
2		C	A	C C	C
3			C	P	C
4	A	A		C	P

C = Capacity interpretative pattern
P = Performance interpretative pattern
A = Acceptance and ability to cope interpretive pattern

Table 12b: Version B: Capacity by functioning

Functioning: How much of a problem is having pain for you?	Capacity Pain Score:				
	0	1	2	3	4
0	C C	P P P	P A		A A
1		C C P A	C A P		
2				P	
3				C P	
4			P	C P	

As can be observed by comparing the two versions, respondents' answers to the functioning and capacity questions are more consistent in Version B, where the capacity questions precede the functioning questions. In all but two cases, respondents' answers consistently align: those reporting more pain tended to report having more of a problem. The two cases that do not align (those reporting extreme pain '4' but no problem '0') interpreted the functioning question as asking about their acceptance or ability to cope with pain; although in extreme pain and unable to participate in numerous activities, they have accepted pain as a fundamental part of their life and so reported 'no problem.' Responses to Version A do not consistently align. The two most inconsistent cases (those reporting no pain but major problem), as in Version B, interpreted the functioning question as asking about their acceptance or ability to cope.

Of note, the functioning question, when interpreted as a capacity question, performs differently depending on the version. Since respondents interpreted both questions similarly, one would expect corresponding responses to both questions. This is true for Version B respondents, but it is not the case for Version A respondents whose reports were widely discrepant (e.g., the respondent with a pain summary score of '3' and '1' for the functioning question). Examination of these specific Version A cases revealed that respondents did not consistently include episodes of pain for both questions as they did in Version B. For example, one respondent considered only pain in his hip when answering the functioning question, but when asked the capacity question he remembered problems with kidney stones. This is likely due to the fact that the capacity question asks respondents to consider the past three months. Since Version A respondents were not first asked this more detailed question, they were not focusing on all episodes of pain.

In sum, for both versions of the questionnaire, there is considerable overlap between the functioning and capacity questions. That is, respondents base their answer to the functioning question not on performance but instead on pain intensity and frequency—although the capacity questions appear to

capture a more accurate account of respondents' pain. Question ordering does not impact the capacity questions. However, in Version B, where health conditions provide a context, the functioning question captures more (but not all) cases of performance. Perhaps most problematic, regardless of order, some respondents interpret the functioning question as asking about their ability to accept or to cope with pain regardless of whether or not they actually experience pain.

SHORTNESS OF BREATH

Capacity: How much difficulty do you have with shortness of breath because of your health? No Difficulty Some Difficulty A lot of Difficulty Cannot Do at All
Functioning: Using show card X, how much of a problem do you have with shortness of health? No Problem 0 1 2 3 4 Extreme Problem

Summary of Findings: The tables below present respondents' answers to both the capacity and functioning shortness of breath questions. Table 13 presents responses from Version A—the version in which respondents first received the environment section followed by the functioning questions and then the capacity questions. Table 14 presents those from Version B—the version in which respondents first received the health conditions section followed by the capacity questions and then the functioning questions.

Table 13: Version A Shortness of Breath Capacity by Functioning

Functioning: How much of a problem...?	Capacity: Do you have difficulty....			
	No Difficulty	Some	A Lot	Cannot Do
Missing				
0 No Problem	10	3		
1	3	7		
2		2		
3		1	1	
4 Extreme Problem				

Table 14: Version B Shortness of Breath Capacity by Functioning

Functioning: How much of a problem...?	Capacity: Do you have difficulty....			
	No Difficulty	Some	A Lot	Cannot Do
Missing				
0 No Problem	17	2		
1	1	4		
2		3		
3		1		
4 Extreme Problem			1	

In terms of the activities considered, there was little difference between the functioning and capacity questions: the vast majority of respondents considered the physical act of breathing for both questions. This explains the near exact responses in the tables above. In describing their answers, many

respondents described “being winded,” “needing to catch my breath,” “gasping” or “struggling for air.” Often respondents described their ability to breathe within the context of performing other activities. Activities considered by respondents include: exercise, walking, climbing stairs and running errands. It is unclear whether the two questions captured capacity, functioning or some combination: Respondents spoke of breathing difficulty in the context of other activities, but those other activities rarely included performance within the environmental context of their lives. For example, one respondent explained: “I’m thinking [of] walking short distances, and I’m out of breath.”

The degree of physical effort in other activities varied across respondents, sometimes impacting responses. For example, some respondents based their answer on their ability to breathe after vigorous exercise, while others based their answer on difficulty breathing after mild exercise. In a few cases, respondents themselves answered the two questions thinking of different levels of activity. For example, one respondent answered “1- problem” to the functioning question because he was thinking of breathing after running up many flights of stairs, but then answered “no difficulty” to the capacity question because he was thinking of breathing without exercise. It is also important to note that a few respondents indicated that they do not have a problem with breathing because they do not engage in activities that would cause such a problem. For example, when asked how much of a problem he has with breathing, one elderly respondent stated, “Very little. I don’t do anything strenuous. Walk a little bit. Pace myself.”

In addition to these respondents, there were also respondents who considered their ability to breathe without thinking of another activity. For example, some respondents spoke about difficulty breathing because of a health condition such as asthma, a heart condition or COPD. One respondent explained that when her acid reflux “flares up” she has difficulty breathing because of the pain. Additionally, some respondents described difficulty breathing because of poor health habits, for example smoking and being overweight or out of shape. Finally, a few other respondents explained that they sometimes have difficulty breathing, not because of their own health, but because of poor air quality caused by allergens, pollution or second-hand smoke.

There was some variation to this pattern: In Version A, four respondents did not base their answer on their ability to breathe, but rather on the amount of lethargy or tiredness that they feel. For example, one person explained that their medication makes them feel tired; another respondent explained that the overcast weather makes them feel sluggish. Interestingly, this interpretation was applied to both the capacity and functioning questions; three respondents interpreted the capacity question as being about lethargy, while one interpreted the functioning question this way. No respondent interpreted both questions to be about their energy level; that is, each interpreted one question about energy and the other about breathing. There were no respondents in Version B who interpreted either question as asking about energy level.

DEPRESSION

Capacity: How often do you feel depressed? Would you say... Never Some Days Most Days Everyday				
Thinking about the last time you felt depressed, how depressed did you feel? Would you say... A little A lot Somewhere in between				
Functioning: Using the scale on show card X, how much of a problem do you have with feeling sad, low or depressed?				
No Problem 0	1	2	3	Extreme Problem 4

Summary of Findings: Like the capacity measure for pain, two survey questions used together serve as the capacity measure for depression. Using two instead of one question simplifies the cognitive processes required by respondents to construct answers. Breaking the measure into two critical dimensions—frequency and intensity—allows the respondent to focus on specific dimensions. In analyzing resulting survey data, responses from the two questions would be combined so that respondents can be placed on a depression continuum. Like the pain measure, respondents reporting ‘a lot’ of depression ‘everyday’ would be characterized as having more severe depression while, at the other end of the continuum, those experiencing a ‘little’ depression on ‘some days’ would be characterized as having less serious depression. For this report, the generated continuum variable consists of 5 categories³ where respondents reporting ‘never’ are assigned the value=0 (no pain) and those with ‘a lot’ of pain ‘everyday’ are assigned the value=4 (extreme pain). Table 15 illustrates how individual cells were assigned.

³ Five categories were used specifically for this study so that a one-to-one comparison could be made with the functioning question. The Washington Group does not stipulate that five categories should be used.

Table 15: Continuum categories for the pain summary score

Thinking about the last time you felt depressed, how depressed did you feel?	In the past 3 months, how often did you feel depressed?				
		Never	Some Days	Most Days	Every Day
	(Skipped)	Continuum=0			
	A Little		Continuum=1	Continuum=2	Continuum=2
	In Between		Continuum=2	Continuum=3	Continuum=3
A Lot		Continuum=3	Continuum=4	Continuum=4	

The tables below present respondents' answers to the frequency and intensity capacity questions. Table 16a presents responses from Version A, and Table 16b presents the corresponding combined continuum score. Tables 17a and 17b present data for Version B.

Table 16a: Frequency by Intensity: Version A

Thinking about the last time you felt depressed, how depressed did you feel?	In the past 3 months, how often did you feel depressed?				
		Never	Some	Most	Every
	(Skipped)	4			
	A Little		10		
	Between		2	1	1
A Lot		6	1		

Table 16b Continuum Depression Score: Version A

0	4
1	10
2	2
3	8
4	1

Table 17a: Frequency by Intensity: Version B

Thinking about the last time you felt depressed, how depressed did you feel?	In the past 3 months, how often did you feel depressed?				
		Never	Some	Most	Every
	(Skipped)	9			
	A Little		6	2	
	Between		2	4	1
A Lot		2	1	1	

Table 17b: Continuum Depression Score: Version B

0	9
1	6
2	4
3	7
4	2

In forming their answer to the frequency question, respondents exclusively considered the regularity of 'feeling sad' episodes. Many respondents conceptualized this, as well as the intensity question, as a mental health question and so reported episodes of sadness related to such a condition. While some respondents were not officially diagnosed with depression, some suspected that they might have the

condition and included those occurrences. A few other respondents interpreted ‘feeling depressed’ more broadly, stating that they did not have a mental health condition, but that they felt depressed because of 1) job loss, 2) illness, or 3) family problems; respondents included these types of context-related (as opposed to health based) depression because the feelings were still within their interpretation of ‘feeling depressed.’ In a few cases, respondents reported having feelings of depression but also explained that this was normal and that everyone has these feelings. Respondents formulated their answer to the intensity question by considering whether they are able to ‘shake off the feelings’ by getting their mind on other things or the degree to which their daily lives are hindered by the feelings.

In regard to the functioning question, the basis of respondents’ answers were not always clear. A few respondents waived when answering the functioning question (e.g. “it could be a 2 or a 3”), indicating that the question is a more difficult one to answer. Instead of describing the regularity or magnitude of episodes, as they did for the capacity questions, respondents often spoke about the reason for their feelings (e.g. job loss, financial problems) which provided little insight into the reasoning for their response choice. In some cases, respondents’ answers appeared to be more reflective of their situation than their actual feelings. For example, one respondent, when explaining his answer, described the difficulty getting his fiancé, who is in China and is pregnant, a visa:

And at this point I’m really not sure what to do about it. At this point they keep telling us that I need to have a co-sponsor because my income is not taxable. And it can’t be used as an affidavit of support for her. So she’s sad and that makes me sad. So I’m kind of stuck in this place right now... 4 [extreme problem].

When discernable, however, the vast majority of respondents’ answers were based on the frequency of their feelings (“Nobody is happy all the time.”) or, in fewer cases, the intensity of their feelings (“I just feel bummed out a little bit. Not suicidal or anything.”) There were a few respondents, however, who based their answers on the impact of depression on their lives. These respondents were clinically diagnosed with severe depression or bipolar disorder. For example, one person described having difficulty getting out of bed; another respondent described difficulty coping with mood swings.

For the most part, respondents perceived the capacity and functioning questions to be repetitive. This is observed in the fairly consistent responses across the two questions shown in the tables below; all but 5 of the 52 cases exactly aligned or were off by only one cell.

Table 18a: Version A: Capacity by functioning

Functioning: How much of a problem do you have with feeling sad, low or depressed?	Capacity Depression Score:				
	0	1	2	3	4
0	4	1			
1	1	6			
2		3		4	1
3		1	1	3	

Table 18b: Version B: Capacity by functioning

Functioning: How much of a problem do you have with feeling sad, low or depressed?	Capacity Depression Score:				
	0	1	2	3	4
0	8	1			
1		3		1	
2	1	1	2	3	1
3			1	1	1

	4				1	
--	---	--	--	--	---	--

	4			1	1	
--	---	--	--	---	---	--

Examination of individual cases across the questions reveal that respondents tended to consider the same phenomena for both questions whether it be a diagnosed or suspected mental health condition or feelings of depression caused by job loss, illness, or family problems. This pattern was true for both versions of the questionnaire. For example, one respondent explained that a problem with his knees was the reason he answered ‘some days’ to the capacity question: “My knee is not getting better. It is sad and frustrating. I can’t run; [my] knee restricts me.” When explaining his response to the functioning question (‘2’), he also cited his knee pain: "Mostly knee pain—it distracts me. [I] can’t take long trips. [It’s] frustrating to plan things around the knee.” Similarly, another respondent cited his unemployment and his wife’s disability when explaining his response to the capacity question (“Sometimes you have things to be depressed about-like trying to get a job, my wife’s disability, or not having enough company”) as well as the functioning question (“Looking for jobs and not getting them. 80% of handicapped people can’t get jobs. My wife has been a wheel chair and is now in a hospital bed.”).

In sum, the functioning and capacity questions often appeared to capture the same phenomena: the frequency and intensity of episodes of sadness due to several causes, including a mental health condition. The basis of respondents’ answers to the functioning question, however, was not always clear, and there is evidence to suggest that it is more difficult for respondents to formulate an answer to this question. The ordering of sections appears to make no difference in the interpretation of either question.

COGNITION

Capacity: Do you have difficulty remembering or concentrating? Would you say... No Difficulty Some Difficulty A lot of Difficulty Cannot Do at All												
Functioning: Using the scale on show card X, how much of a problem is remembering to do the important things in your day to day life?												
<table border="0"> <tr> <td>No Problem</td> <td></td> <td></td> <td></td> <td></td> <td>Extreme Problem</td> </tr> <tr> <td>0</td> <td>1</td> <td>2</td> <td>3</td> <td></td> <td>4</td> </tr> </table>	No Problem					Extreme Problem	0	1	2	3		4
No Problem					Extreme Problem							
0	1	2	3		4							

Summary of Findings: The tables below present respondents’ answers to both the capacity and functioning cognition questions. Table 19 provides responses to Version A—the version in which respondents first received the environment section followed by the functioning questions and then the capacity questions. Table 20 provides responses from Version B—the version in which respondents first received the health conditions section followed by the capacity questions and then the functioning questions.

Table 19: Version A: Capacity by Functioning

Functioning: How much of a problem...	Capacity: Do you have difficulty....			
	No Difficulty	Some	A lot	Cannot Do
0 No Problem	2	6		
1	2	5	1	
2		2	1	
3				
4 Extreme	1			

Table 20. Version B Capacity by Functioning

Functioning: How much of a problem...	Capacity: Do you have difficulty....			
	No Difficulty	Some	A lot	Cannot Do
0 No Problem	12	6		
1	1	2		
2		1		
3	1	1	1	
4 Extreme		2	1	

Respondents generally provided consistent answers to the two cognition questions—with functioning asking about remembering important things, and capacity asking about memory and concentration—indicating that they interpreted them as similar, if not congruent, questions. Indeed, the two questions captured very similar sets of constructs. These ranged from remembering obligations to remembering basic household tasks to remembering names and conversations. Although the capacity question asks

about both memory and concentration, the functioning question asks only about remembering, many respondents considered only memory across both questions.

There are a few exceptions to this pattern. For instance, across both Tables 19 and 20 above, the four respondents who answered ‘some difficulty’ to the capacity question and ‘no problem’ to the functioning question considered different constructs across the two questions. The question text in the capacity question asks about both memory and concentration, and these respondents focused on their ability to concentrate or remember. For instance, one respondent who received the Version B questionnaire explained her ‘some difficulty’ answer by saying:

Remembering I have some difficulty. Concentrating I can do...Concentrating is really focusing and paying sharp attention so I get something done or do remember. Remembering is... remembering names if I concentrate I can remember them better. Just doing things without thinking... Or I can say what on earth did I do on Sunday and then it comes back. I think that’s just my stage in life...

The functioning question, on the other hand asks about problems “remembering the important things in your life.” After considering just her abilities in the capacity question, this respondent answered ‘no problem’ to the functioning question, explaining that she had no problem remembering to do the things she felt were important, such as sending emails and remembering to go to her and her husband’s appointments.

This difference is noticeable in other cases as well. For example, the respondent in Table 20 who answered ‘1’ on the problem scale, but ‘no difficulty’ to the capacity question explained that he was thinking about once forgetting to lock his house (which led to a burglary) when answering the functioning question. However, he understood the capacity question to be asking whether or not he had a *health-related* memory or concentrating issue. As he did not, he answered using the negative answer category.

HOUSEHOLD TASKS

Capacity:				
How much difficulty do you have doing household tasks because of your health? Would you say...				
No Difficulty				
Some Difficulty				
A lot of Difficulty				
Cannot Do at All				
Functioning:				
Using the scale on show card X, how much of a problem do you have with getting your household tasks done?				
No Problem				Extreme Problem
0	1	2	3	4

Summary of Findings: The tables below present respondents' answers to both the capacity and functioning household task questions.⁴ Table 21 provides responses to Version A—the version in which respondents first received the environment section followed by the functioning questions and then the capacity questions. Table 22 provides responses from Version B—the version in which respondents first received the health conditions section followed by the capacity questions and then the functioning questions.

Table 21: Version A: Household Capacity by Household Functioning

Functioning: How much of a problem...	Capacity: Do you have difficulty....			
	No Difficulty	Some	A lot	Cannot Do
0 No Problem	10	1		1
1	1	4		1
2	1	2		
3	1	1	1	
4 Extreme				

Table 22: Version B: Household Capacity by Household Functioning

Functioning: How much of a problem...	Capacity: Do you have difficulty....			
	No Difficulty	Some	A lot	Cannot Do
0 No Problem	11	6	1	
1	1	2		
2		1	1	
3	1	2	2	
4 Extreme		2		1

⁴ Unlike other capacity questions in this questionnaire, the capacity household task question is not a Washington Group question.

As seen in both tables, many respondents provided consistent answers to the two questions. Indeed, many respondents saw the two questions as being repetitive and referred to their previous answer when responding to second the question.

For both versions of the questionnaire, respondents conceptualized ‘household tasks’ for the capacity as well as the functioning question similarly. Those tasks included: cooking, cleaning, laundry, house repairs and lawn work. All of these tasks involved physical movement; no one considered intellectual tasks such as paying bills. In explaining their answers, many respondents indicated that either a physical or mental disability impacted their ability to perform household tasks (e.g., being unable to mop a floor because of arthritis or because of severe depression). However, some respondents cited non-health related reasons, including laziness, not liking to do housework, and being too busy. For example, one respondent who answered ‘3’ to the functioning question explained, “It has to hit a breaking point for me to just do it [the cleaning, laundry, vacuuming].... I don’t mind it that much. I just don’t enjoy doing it!” In two cases, respondents surmised that someone may have a problem doing household tasks if they did not have cleaning supplies. Although non-health related causes were cited in both the capacity and functioning questions, this occurred much more often in the functioning question.

Question ordering appears to impact the cause of difficulty reported by respondents. While one-third of respondents receiving Version B (with the health condition section framing the context) cited non-disability reasons, a full two-thirds of respondents cited non-disability reasons when asked Version A. While many respondents considered the same cause for the functioning and capacity questions, others did not. That is, some respondents’ answers were based on the presence of a disability for one question, but answered the other thinking of their laziness or dislike for housework. This pattern accounts for many of the inconsistent responses.

The final reason for inconsistent responses pertains to the use of an aide. In Version B, all three respondents who had an aide did not include the help of their aide when answering the capacity question, but did include the help of their aide when answering the functioning question. For example, one woman who reported having some difficulty cleaning because she has difficulty bending and is afraid of falling, stated that she had ‘no problem’ with household tasks because “I am blessed with friends and neighbors.” In Version A, there was only one respondent who required the help of an aide for household tasks. For both questions, the respondent considered this help: she answered ‘no difficulty’ to the capacity question and ‘no problem’ to the functioning question.

In sum, there is considerable overlap between the capacity and functioning questions. Respondents’ answers to both questions are based on their understanding of ‘household task’ and the reason as to why they do not do the task. The ordering of sections appears to have some impact; in Version A of the questionnaire, respondents were much more likely to consider non-disability causes. In regard to whether or not respondents considered the help of an aide, only 4 respondents in the entire study required the use of such help. Therefore, it is difficult to make definitive conclusions. However, in Version B of the questionnaire all respondents correctly considered the help of an aide; this was not true for Version A of the questionnaire.

COMMUNITY PARTICIPATION

Capacity:				
Because of your health, how much difficulty do you have with joining community activities? Would you say...				
No Difficulty				
Some Difficulty				
A lot of Difficulty				
Cannot Do at All				
Functioning:				
Using the scale on show card X, much of a problem do you have with joining community activities, such as festivities, religious or other activities?				
No Problem				Extreme Problem
0	1	2	3	4

Summary of Findings: By and large, respondents understood the community capacity question and the community functioning question as identical.⁵ Tables 23 and 24 show the respondents' survey responses for each of the two questions, for the Version A and Version B questionnaire, respectively.

Table 23: Version A: Capacity by Functioning

Functioning: How much of a problem...?	Capacity: Do you have difficulty....			
	No Difficulty	Some	A Lot	Cannot Do
0 No Problem	11	4	2	
1	3	3	1	
2		2		
3		3		
4 Extreme Problem				

Table 24: Version B: Capacity by Functioning

Functioning: How much of a problem...?	Capacity: Do you have difficulty....			
	No Difficulty	Some	A Lot	Cannot Do
0 No Problem	9	2	1	
1	1	3		
2	2	1	2	
3			1	
4 Extreme Problem				

More than any of the other capacity/functioning questions, respondents expressed outright confusion. Many asked for the question to be repeated or stated that they could not provide an answer because they did not understand what the question was asking. This was true for disabled and non-disabled

⁵ Unlike other capacity questions in this questionnaire, the capacity community participation question is not a Washington Group question.

respondents. For example, one respondent stated that she has a lot of difficulty participating because of her depression, but she was not sure if the question was asking about mental health conditions.

As a result, there were numerous interpretations of both the capacity and functioning questions. Interpretations centered along four themes: 1) respondents’ actual participation in community activities, 2) their ability to participate given a disability, 3) their ability to participate given other, non-health related restrictions such as not having enough time or money, not knowing where to go or what activities are available, and 4) their desire or level of motivation to participate in the activities. A few respondents focused on the example and answered solely on their dislike for religion or church. For example, one women, explaining her response (‘4 - extreme problem’) stated, “I think they’re boring. I do 4. I tell my boyfriend I’m going to Catholic Church for the grape juice and the wafer.”

Respondents did not always interpret the two questions similarly, and this accounts for the variation in responses across the two questions. One respondent, for example, answered ‘no problem’ to the functioning question because he does indeed attend church and participate in the Knights of Columbus. However, he also answered ‘some difficulty’ to the capacity questions because he has some hearing loss which makes interacting with others more difficult.

The types of community activities that respondents considered was relatively broad and did not vary across the two questions or the two versions. The table below illustrates the various activities considered for both capacity and functioning questions in Version A and Version B.

Table 25: Constructs Present in Capacity/Functioning, Version A/Version B

	Present in Functioning Question		Present in Capacity Question	
	Version A	Version B	Version A	Version B
Active in Neighborhood/Town	●	●	●	●
Arts Events	●	●	●	●
Civil Organization	●	●	●	●
Community Center	●	●		●
Dances	●	●		●
Farmers Market		●		●
Festivals	●	●	●	●
Hang out with Friends			●	●
Horse Race	●			
Politics	●		●	●
Religious Organization	●	●	●	●
Volunteering	●	●	●	●

In sum, these two questions raised the most confusion among respondents, causing many interpretations across respondents and across versions. Ordering of the sections did not appear to impact the question response process.

BROAD ENVIROMENT

All questions in the Broad Environment (BE) section use the following answer categories, which were presented to the respondents on a show card:

1. Very Easy
- 2.
- 3.
- 4.
5. Very Hard
6. Does Not Apply

Each of the question analyses detailed below includes a description and discussion of the range of interpretations of both the core construct (i.e. the subject matter of the question) and the judgment of the “needs stem” (the “need or want to do...” phrase found in all of the Broad Environment questions). Following this, each question write-up also includes a disability analysis and a cross-questionnaire analysis. The former will explore the variation in how the question functioned across the various respondent disability classifications detailed in Appendix A. The latter will explore the differences between how the question performed in Version A (where the BE questions were unframed by any other section) and in Version B (where the BE questions were framed by the Health Condition and Capacity Sections). Additionally, reference *areas* and reference *people* are discussed when appropriate.

Question BE1: Using the scale on show card X, how easy or hard does your health care facility make it for you to do the things you need or want to do?

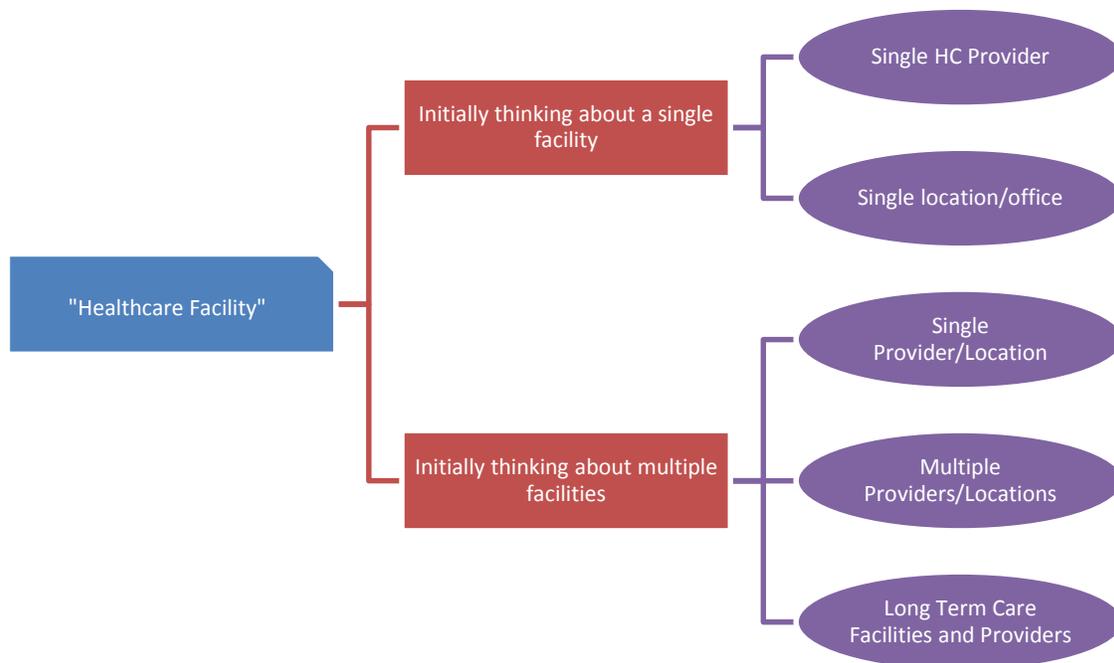
Summary of Findings: Question BE1 was problematic for several reasons: respondents not only expressed a lot of confusion (particularly over the term “health care facility”), but also interpreted both the core construct and the phrase “need or want to do” in a wide variety of ways. Overall, nearly half of the sample indicated in that they did not understand the question or requested clarification. Respondents interpreted “health care facility” in four separate ways—by thinking about a single facility, multiple facilities, their healthcare providers, or long-term care arrangements. Additionally, respondents based their judgment of the healthcare facilities’ satisfaction of their needs or wants on either convenience (such as travel time or ability to schedule an appointment quickly) or, less frequently, on physical accessibility to the facilities.

Core Construct Interpretations: The interpretation of the core construct of “health care facility,” varied across the respondents. The response schema showing the various patterns of interpretation] respondents used to arrive at their conception of a “health care facility” is shown below in Figure 2. Many respondents immediately considered either their healthcare provider (instead of a location or facility) or a single healthcare facility location. For instance, one respondent who answered “1 very easy” to Q BE1 thought of her healthcare provider and explained, “I was thinking about Kaiser as the big...not just the facility I go to. The whole [thing]” Another respondent (who also answered “1 very easy), who illustrates the “single location” pattern of interpretation, simply said, “I’m thinking about the VA hospital.” A number of the respondents in the ISR sample followed this pattern, thinking about the university hospital as their “health care facility.” Other respondents expressed (often times explicitly) confusion over which healthcare facility they should be answering about. For example, one respondent who received Version A explained that she was not sure what he was supposed to be thinking about:

Are you talking about a doctor's office? My hospital? Facility...what's the facility? I go to various doctor's offices...I have no idea what you want from me.

Eventually, these respondents chose one of three patterns of interpretation: they focused on a single location, they answered based on some combination of multiple health care locations and providers, or they considered the care they received in their place of residence because of long-term care needs. For instance, the woman quoted above ended up thinking about both her hospital and her doctor's office, and answered with a "4" response, explaining that she could not always get an appointment quickly, she would prefer more magazines in the waiting area, and that it sometimes requires multiple calls to get her prescriptions renewed. Additionally, a few respondents were unable to decide on a pattern of interpretation and simply indicated that they could not answer the question because they did not understand what it was asking about.

Figure 4: Cognitive Schema of the Interpretation of Question BE1



Judgment of the Needs Stem: After determining what healthcare facility (or provider) they were considering, respondents moved on to interpret “needs and wants.” In this question (as well as all the other Broad Environment questions), respondents typically did not distinguish between necessity (“needs”) and desire (“wants”). Generally, respondents understood the needs stem to mean healthcare services, such as check-ups, medical treatments, and prescription refills. One woman did not think of the help her healthcare facility gave her, but rather how her health insurance company either aided or prevented her from getting the care she needed:

Because it's like the things I need to do I get a note of what I need to do. But when it comes down to actually helping me do these things all you get is a piece of paper. Say for example, with my insurance I was covered through everything. Once I fell injured myself and my teeth, they switched me over to a different insurance that doesn't cover me fully...It's like I didn't give you the right to do that.

Those respondents who interpreted the needs stem as health care services largely based their responses on the ideas of accessibility, availability of services, and hassle. This included parking availability, elevator access, physical proximity to their place of residence, transportation difficulties in getting to the facility, amount of paperwork, and insurance transparency.

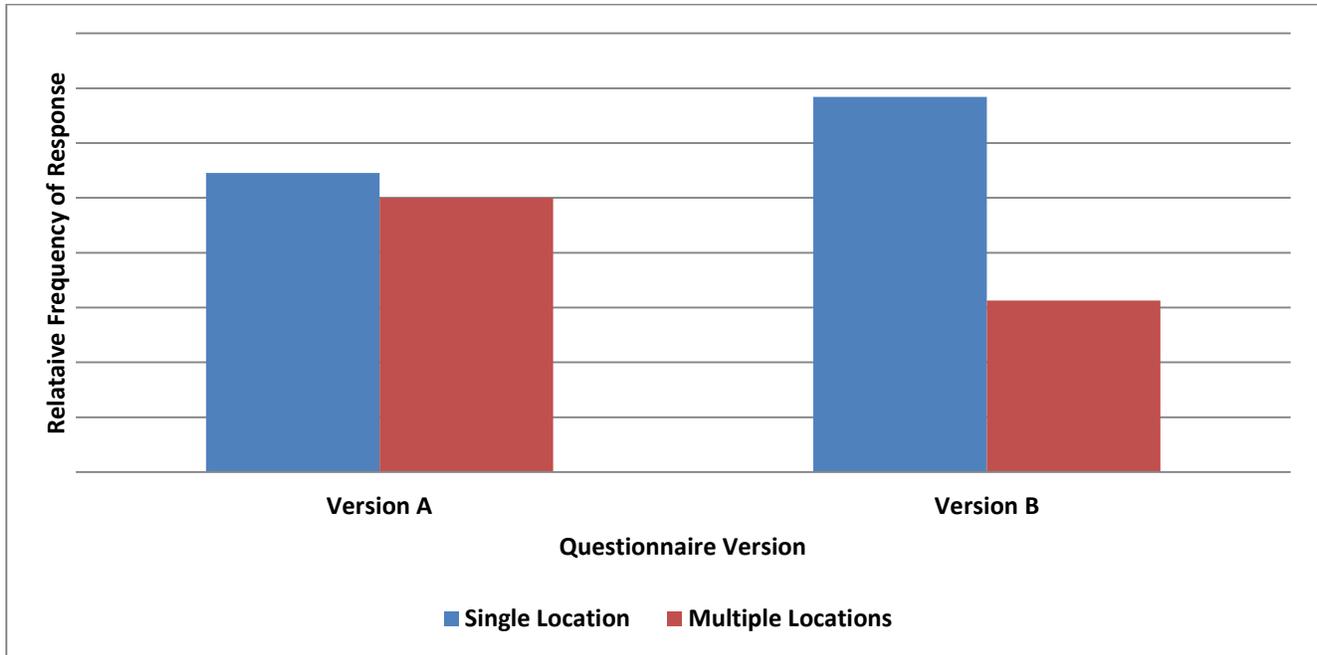
A few respondents viewed this construct to be unrelated to the actual health care services. For instance, a female respondent said that she desired “reading material and a television” at her facility, but did not mention her facility’s ability to provide medical services.

Disability Analysis: Across both versions of the survey, the disabled population was more likely to answer Q BE1 using a negative answer category than the non-disabled population. In particular, the respondents categorized as “physically disabled” (again, see Appendix A) were more likely to report difficulty with their health care facility, independent of the questionnaire version. There is no major difference between the physically disabled or not physically disabled respondents in how they interpret “health care facilities” (though there is a difference between the versions, as explained below). Additionally, there appears to be no correspondence between disability status and whether or not respondents expressed difficulty with the question. However, a difference did emerge as the respondents moved to the judgment phase. Those respondents who were coded as physically disabled were more likely to base their judgment on physical accessibility criterion--such as handicapped parking availability. Respondents who were not coded as physically disabled mainly considered convenience—such as scheduling, transportation, and physical proximity with relation to their residence—when judging their survey response.

Cross-Questionnaire Analysis: While the actual survey responses across the two versions appear similar, as noted above, this question does not consistently capture any one interpretation of “health care facility.” Across both questionnaire versions, some respondents were not able to provide an answer because they were unable to generate a construct for “health care facility;” in other cases respondents gave a middle-of-the-road response due to the same reasoning. In particular, more respondents in Version A (the version without the framing) struggled in determining a definition for “health care facility” than those in Version B. In fact, 17 out of the 31 Version A respondents verbally expressed confusion compared to only 8 out of 29 Version B respondents. The fact that so many more Version A respondents expressed confusion over this question—the very first question they received—as compared to the Version B respondents indicates that ordering and framing effects do indeed matter for the broad environment questions.

Respondents from Version A interpreted “health care facility” using both the single and multiple location pathways. However Version B respondents were much more likely to only use the singular location pathway, as seen in Chart 1 below:

Chart 1: Questionnaire Version by Response Pathway for Question BE1



As noted above, respondents who were coded as “physically disabled” were more likely to consider physical accessibility during the judgment phase than everyone else in the sample. However, this trend displayed a strong framing effect. The physically disabled respondents who received Version B (which, again, framed the environment questions with both the Health Condition and Capacity sections) tended to focus *exclusively* on physical accessibility, while in Version A (where the environment questions were unframed) they tended to think about physical accessibility *in addition* to things such as scheduling convenience and bus routes.

Overall, Question BE1 captured a wide variety of interpretations of “health care facility,” and to a lesser extent, interpretations of the phrase “wants and needs.” This diversity was slightly greater in Version A than Version B—as can be seen across the core construct in Chart 1 above. There were some interpretive differences between respondents with and without physical disabilities, and these differences were affected by framing.

Question BE2: Using the scale on show card X, how easy or hard does the places you socialize and engage in community activities make it for you to do the things you want or need to do?

Summary of Findings: Both the core construct of “places you socialize and engage in community activities” and the needs stem “things you want or need to do” were interpreted inconsistently by the respondents. Respondents considered both places *and* activities when answering this question, and were more likely to think about whether or not that place or activity was convenient to get to than they were to consider whether or not that place had any accessibility features. This was true not only for respondents who were not physically disabled, but also for those respondents who were physically disabled. Furthermore, a strong framing effect was detected. Respondents who received the unframed

Version A of the questionnaire were much more likely to consider whether both the convenience and the physical accessibility of a place or activity met their needs; whereas those respondents who received the framed Version B of the questionnaire were much more focused in their judgment, largely considering only the convenience of a place.

Core Construct Interpretations: The largest amount of variation emerged from the interpretation of the core construct—the places where socialization and community engagement occurred. Table 25 below shows the range of interpretations of the core construct across both questionnaire versions:

Table 26: Question BE2 Core Construct Interpretations

	<i>Version A</i>	<i>Version B</i>
<i>Arts Events</i>	●	
<i>Family Events</i>	●	●
<i>Library</i>	●	●
<i>Movie Theatre</i>	●	
<i>Neighborhood</i>	●	●
<i>Recreation or Community Center</i>	●	●
<i>Place of Worship</i>		●
<i>Restaurant</i>	●	●
<i>Senior Center</i>	●	●
<i>Store</i>	●	●
<i>Work</i>	●	
<i>Volunteering</i>		●
<i>Unspecified “Going Out”</i>	●	●

Some respondents even considered the construct to simply mean “going out.” For instance, one woman was just thinking about getting out of her house and going to the grocery store as her “social engagement.” Overall, the respondents appeared to largely be considering places they enjoyed being—whether or not it was a place that they “socialized or engaged in community activities” in any sort of formalized way. In this way, the question that the respondents appeared to be actually answering was:

How easy or hard do the places you enjoy going make it for you to do the things you need or want to do?

Judgment of the Needs Stem: Further variation emerged around the respondents’ interpretation of the needs stem, which they interpreted in two ways: the convenience or ease of getting to the place and its physical access. One group of respondents based their response primarily on the place of interest’s physical location and how easy or hard it was for them to get there via their available forms of transportation. For example, one respondent who employed this pattern said, “And again, I have a vehicle that I’m able to drive myself.” Another respondent explained:

I’m close to the metro also...I can walk basically downtown. I can walk to the Giant...and everything is convenient for me there...It’s easier to walk than to take the bus—[I have to] wait like half an hour!

The other group of respondents considered the physical accessibility of the place. An example of this would be a respondent (who answered “3”) who claimed that “... it’s an accessible building with

elevators. It's just that if I get in late it's hard to get in because they lock the doors." Likewise, another respondent who answered "3" was thinking about distances she had to walk and whether or not she has to climb stairs:

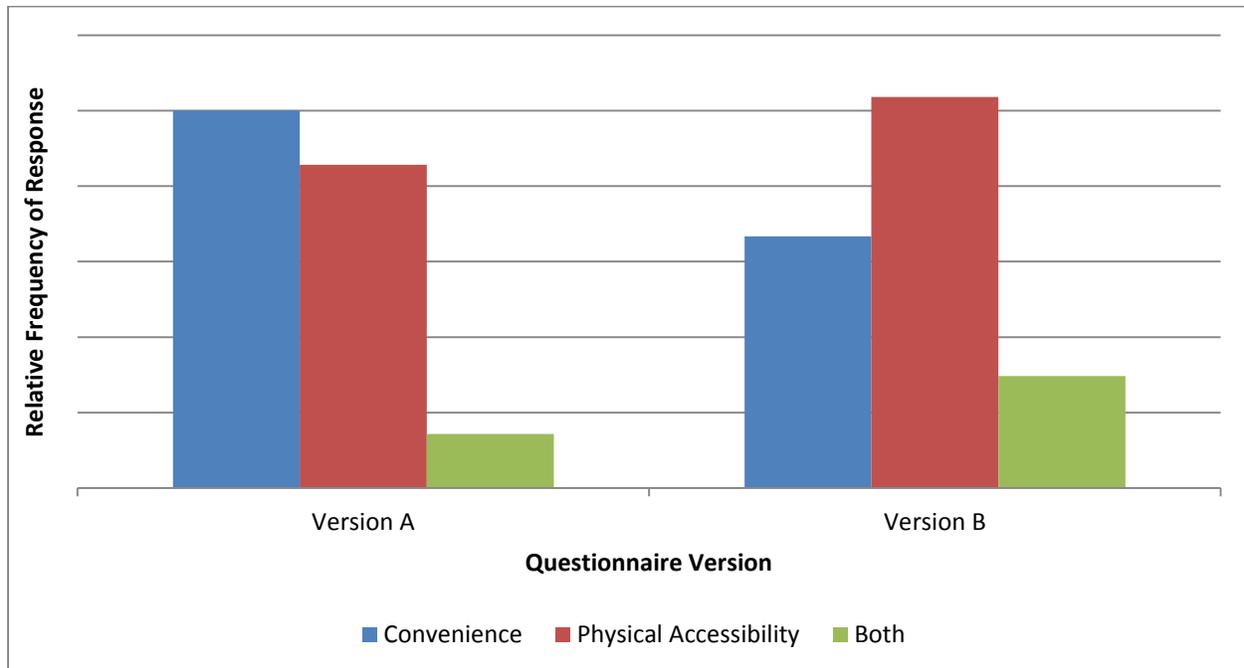
About three. Often it's hard to find close parking and there are stairs and distances [to walk] as it was here when I parked. Like your facility here. I had to park in the parking garage and then walk down three flights of stairs.

The respondents did not always think about these patterns independently. For instance, a physically disabled respondent explained her response by talking about how her community provided her with assistive transportation from her home to the point of interest as well as how these places provided her with "... ramps and handicapped buttons," indicating that these two interpretations are not mutually exclusive and that a third pattern of judgment—a mix of the two other patterns—exists as well. Clearly an individual's interpretation of the needs stem will be at least partially dependent on their previous interpretation of the core construct "place." For instance, a respondent who went to and was thinking about a parade in their community they attended organized by the larger community might not consider handicapped doors and ramps. Conversely, a respondent who was considering a building that was used as a meeting spot for some activity might consider the building's characteristics in its response.

Disability Analysis: Across both versions of the survey, physically disabled respondents were once again more likely to provide unfavorable responses to the survey question. However, there was no distinguishable difference in how they interpreted either the core construct or the needs stem from the non-physically disabled respondents.

Cross-Questionnaire Analysis: Unlike some of the other broad environmental questions, the number of interpretations of the core construct did not diverge much across the two questionnaire versions—both versions captured a similar number of interpretations of "places to socialize and engage in community," as seen in Table 5 above. A noticeable difference did emerge between the two questionnaire versions in the judgment step when the respondents interpreted accessibility. As seen in Chart 2 below, in Version A the respondents tended to use both interpretations of accessibility evenly. However, In Version B, the respondents were much more likely to interpret accessibility as physical accessibility, and tended to think less about the ease of places they were socializing.

Chart 2: Questionnaire Version by Interpretation of "Accessibility" for Question BE2



Therefore, the same general framing effect observed previously in Q BE1 continues here in Q BE2: the framing provided by the Health Status and Capacity Sections of the MDS focus the respondents' interpretations and judgments while responding to the environment questions.

Question BE3: Using the scale on show card X, how easy or hard does the shops, banks and post office in your neighborhood make it for you to do the things you need and want to do?

Summary of Findings: The overall response to Question BE3 was mixed. There was very little variation which core constructs the respondents considered—with most respondents thinking just about the specific locations given in the question text (shops, banks, and post offices). However, respondents again did not agree on what the phrase “need or want to do” referred to, nor did they all think the same range of geographies when considering their answer. While there was not much variation between how physically disabled and non-physically disabled respondents answered Q BE3, there were differences between how respondents who received the unframed Version A of the questionnaire responded to the question in comparison to those who received Version B. In fact, much of the interpretive variation that emerged from this question appears to be due to the fact that Version A respondents did not have enough context with which to focus their responses.

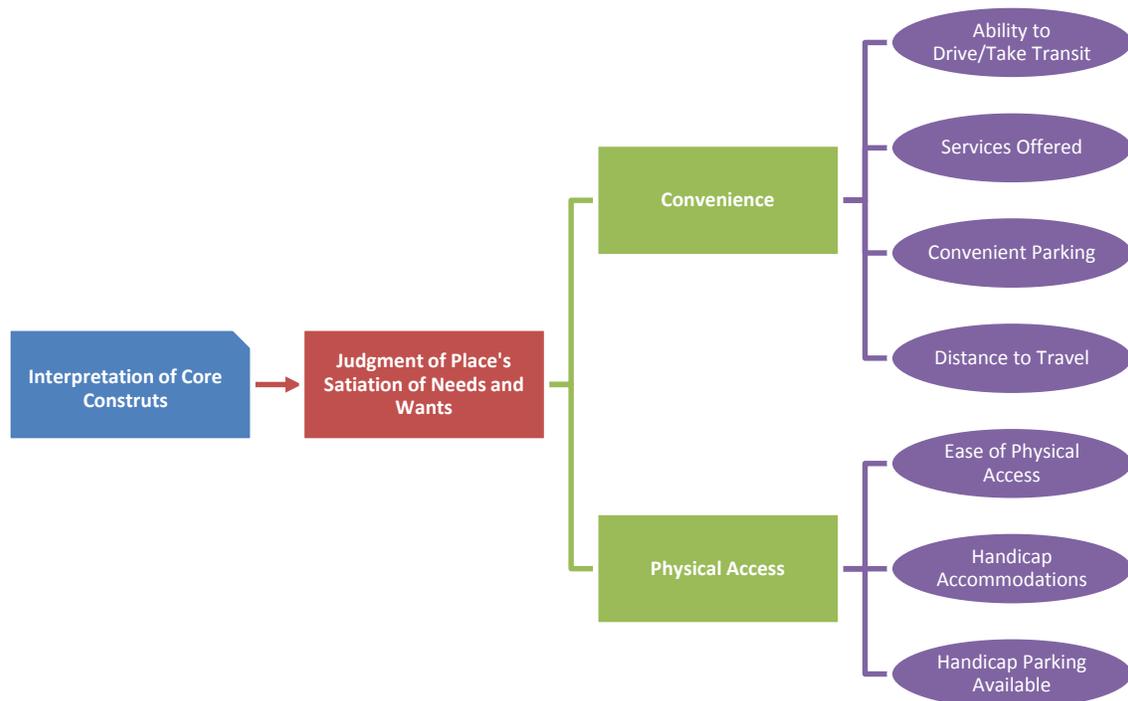
Reference Area: Most respondents interpreted “neighborhood” in a similar way. As noted above in the Summary of Findings Section, the range of interpretations for the reference area extended from a respondent’s living area to their neighborhood to their region. In Q BE3, most respondents were thinking about their town—probably as a result of the question text including “post office.” Since most towns have one (or just a few) post offices, respondents likely associate a place such as a post office

with a town level of geography. However, some respondents deviated from this town level of geography, with a number focusing on their metropolitan region as a whole. The questionnaire versions differed on this point, which will be discussed further below. Suffice to say here that both the range of interpretations of “neighborhood,” as well as how far afield the respondents considered, was greater in Version A than in Version B.

Core Construct Interpretations: There was very little variation in the interpretation of the core constructs “shops, banks, and post office.” As might be expected, most respondents thought about post offices—certainly due in large part to the fact that it was the last example the respondents heard in the question text. In addition to the three specific places cited in the text, respondents also considered grocery stores, movie theatres, and transit stops. Overall, the respondents appeared to understand the question as asking about “physical locations of commerce or services outside the home.” In fact, one respondent explicitly excluded shopping she does online at home, saying: “No I don’t do any shopping. Everything is [online].”

Judgment of the Needs Stem: While the interpretations of the core constructs did not vary much across the sample, a large amount of variation emerged from how respondents judged their “needs and wants.” As can be seen in the visualization of the response schema below, after respondents interpreted the core constructs, they then judged those places on either their convenience or their physical accessibility.

Figure 5: Cognitive Schema of the Judgment of Question BE3



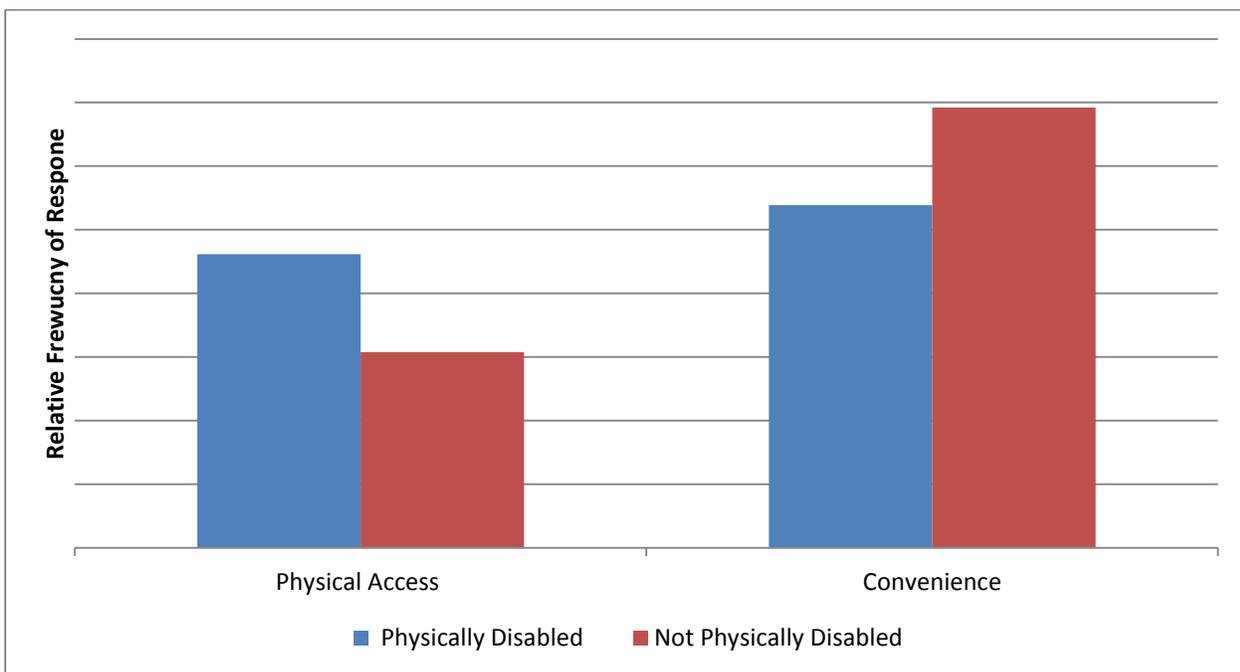
Respondents tended to consider either a place’s convenience or its physical access, but not both of these pathways together. This process is in opposition to how the respondents approached the judgment step in the previous question, Q BE2, where a number of respondents considered *both* physical accessibility *and* convenience. However, within both of these two pathways, respondents tended to consider more than one aspect of either convenience or physical access. For instance, one respondent considered

convenience, and explained that he had access to a number of services within a short distance, and that he was able to use transit to get to them:

I work at George Mason University and a lot of the things I need to do or want to do are right on campus... They have transportation on campus and to the metro center. And it's very close to a shopping center...

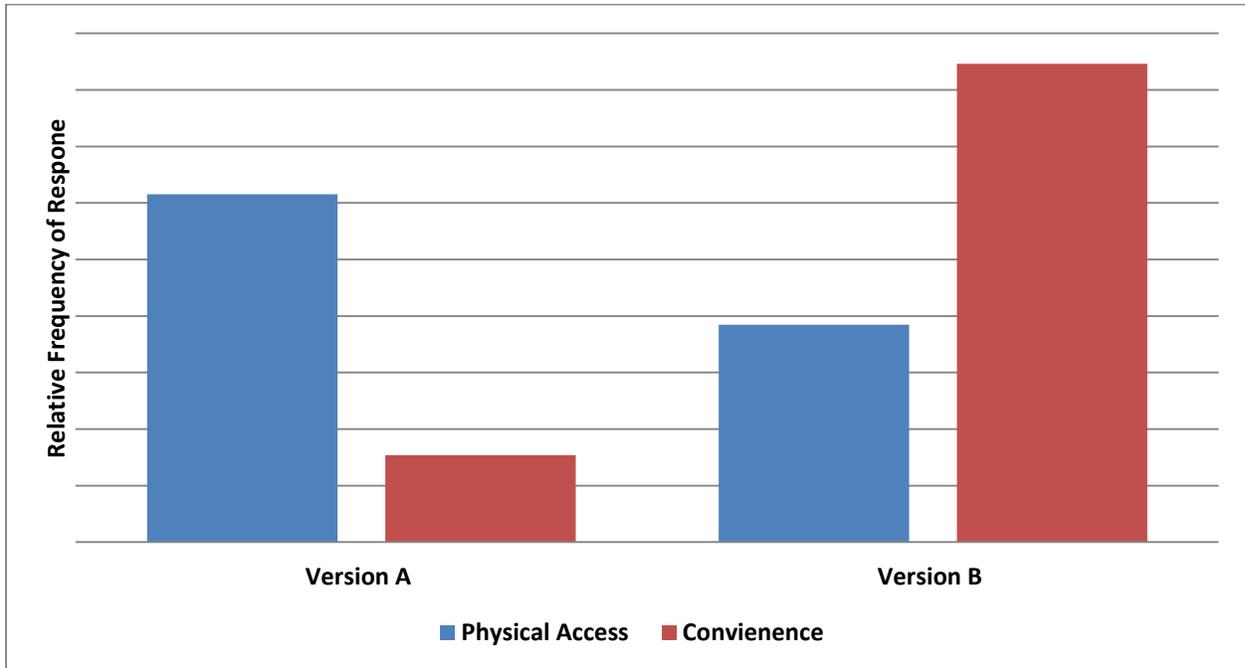
Disability Analysis: Only a slight difference emerged during the disability analysis: respondents who were classified as having a physical disability split their judgements relatively evenly between the consideration of physical accessibility and convenience. However, as seen below in Chart 3, respondents without a physical disability were much more likely to base their judgment on convenience than on physical accessibility.

Chart 3: Patterns of Judgment by Disability Status for Question BE3



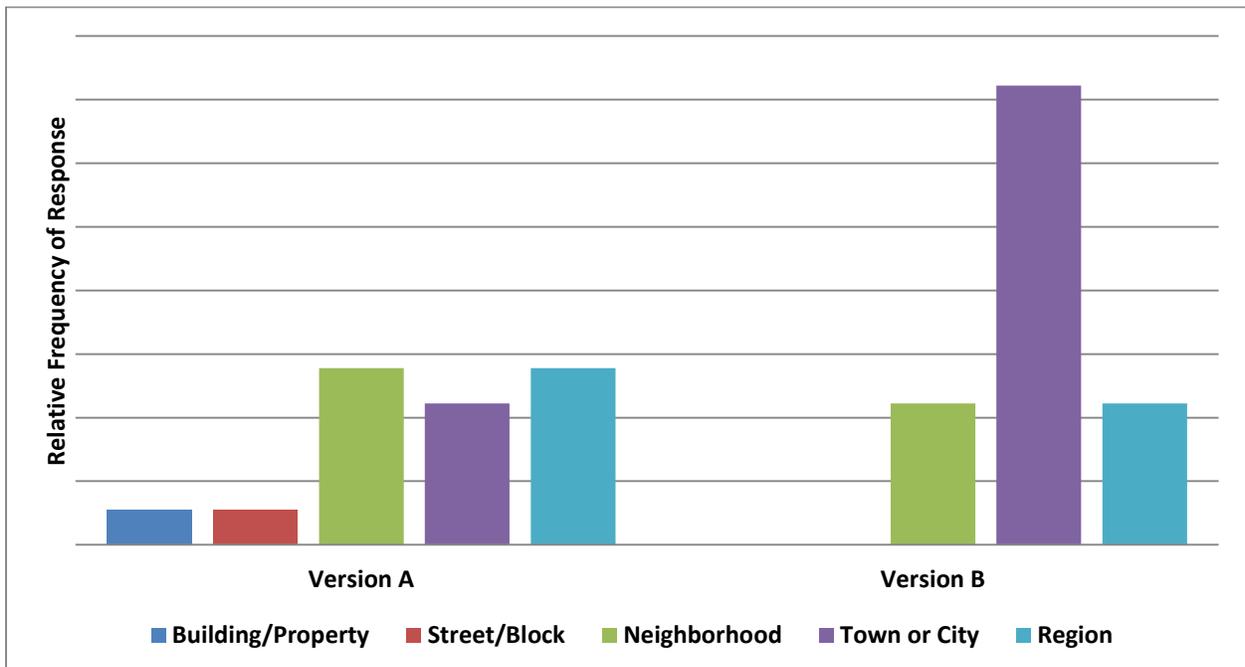
Cross-Questionnaire Analysis: Two major differences emerged across the questionnaire versions. First, as mentioned above in the disability analysis of Q BE3, there was a significant difference in how the respondents who received Version A of the questionnaire judged the needs stem over those respondents who received Version B.

Chart 4: Pattern of Judgment by Questionnaire Version for Question BE3



As can be seen above in Chart 4, the patterns of interpretation between the two versions were nearly opposite—with Version A respondents much more likely to consider whether or the physical access of a place met their needs and wants, while Version B respondents were similarly more likely to think about whether or not a place was convenient.

Chart 5: Questionnaire Version by Reference Area for Question BE3



In addition to how the respondents judged the needs stem, there was also a noticeable difference in the reference area the respondents used to frame both their interpretation of the core construct and the

judgment of their “needs and wants.” Chart 5 above shows the relative frequency of the various reference areas the respondents used for each questionnaire version. It is again clear that the un-framed Version A produces more cognitive variation than does the framed Version B. While most respondents who received Version A were thinking about either their neighborhood, the town they live in, or the metropolitan region, a few others considered things like the street they live on or their house or property. For instance, one Version A respondent was thinking about the hill she lives on:

...I live on the bottom of the hill on [a street in DC], so I usually have to walk up the hill. When my legs aren't feeling bad it's fine...I don't have to go too far.

Nearly all the Version B respondents, on the other hand, referenced their town when conceptualizing Q BE3.

Question BE4: Using the scale on show card X, how easy or hard does the transportation you use make it for you to do the things you need or want to do?

Summary of Findings: The respondents neither answered, nor understood, Question BE4 consistently. This inconsistency, at its core, stems from the complexity of the response process the respondents must navigate when answering this question. In the respondents' eyes, this question was asking about the more holistic act of *getting around*. Thus, most respondents did not simply consider whether or not their mode of transportation met their needs and wants, but rather thought about how easy or difficult it was to not only use their mode of transportation, but also to get to and from their car, bus, or subway. As was the case in the previous Broad Environment questions greater differences in interpretation between the respondents who received different questionnaire Versions than there were between physically disabled and non-physically disabled respondents.

Core Construct Interpretations: The respondents largely interpreted “transportation” in two ways: They considered their personal vehicles (cars and bikes) and/or public transportation, such as the buses or the subway. Additionally, nearly all the respondents considered more than one mode of transportation. For instance, one respondent said:

Very easy. Because if I'm not able to drive, I can call a friend. The city has this call-a-bus [service, through the county government]. Call a cab, when I purchase a book of [cab] tickets, I pay \$10 and get \$20 worth...I can get around.

Another respondent listed all the ways she gets around:

Bus, the train, the MetroAccess, and the little vans. [I take] the bus daily; train daily; MetroAccess two or three times a week. If I could afford it, I would use it more...They run 24/7.

In general, respondents appeared to consider this question to be asking: “how easy or hard is it for you to travel or get around?” In understanding the question this way, respondents by and large were not thinking about how the individual pieces of the transportation system satiate their needs or wants. Rather, they “rated” how well the overall transportation system works; considering, for example, how long they have to wait for buses or trains.

Reference Area: As Q BE4 is specifically about transportation, many of respondents across both questionnaire versions were thinking about wide areas—usually their town or region. However, this varied some based on what form of transportation the respondents considered. Specifically, those who considered public transportation—buses and the metro—sometimes based their answer on the ease or difficulty of getting to that mode. In these cases, the respondents based their answer on a more local area—usually the streets or neighborhood they had to traverse to get to the bus or subway stop. This interpretation was not universal, however: Some other respondents who considered their use of the subway thought about the overall system and whether or not it met their needs and wants.

Reference Person: Unlike previous questions in the Broad Environment series, in Q BE4 respondents did not all interpret the phrase “you use” in the question text to simply be referring to themselves. While most respondents did consider “you” to mean the physical self, a few respondents interpreted it to mean “you” in a general, third-person sense not distinctly tied to the respondent’s own experiences. For instance, one respondent (who had no disabilities) considered (and answered based on) how people *with* disabilities might interact with the transportation infrastructure:

I give it a 2 as well... they have those lifts now for people in some of the busses and you lift a wheelchair up. And then they have the curb things in the street. A lot of the buses have the lifts for people...[but] I don’t see it in every mode of transportation. A lady in my neighborhood needed it. They didn’t have anything for people who were handicapped. Or people who couldn’t see. They need something to accommodate people.

Another respondent was thinking even more generally. While claiming that he drove everywhere, he answered the question with a response of “3,” based on his assessment of the public transportation system although he did not personally use it.

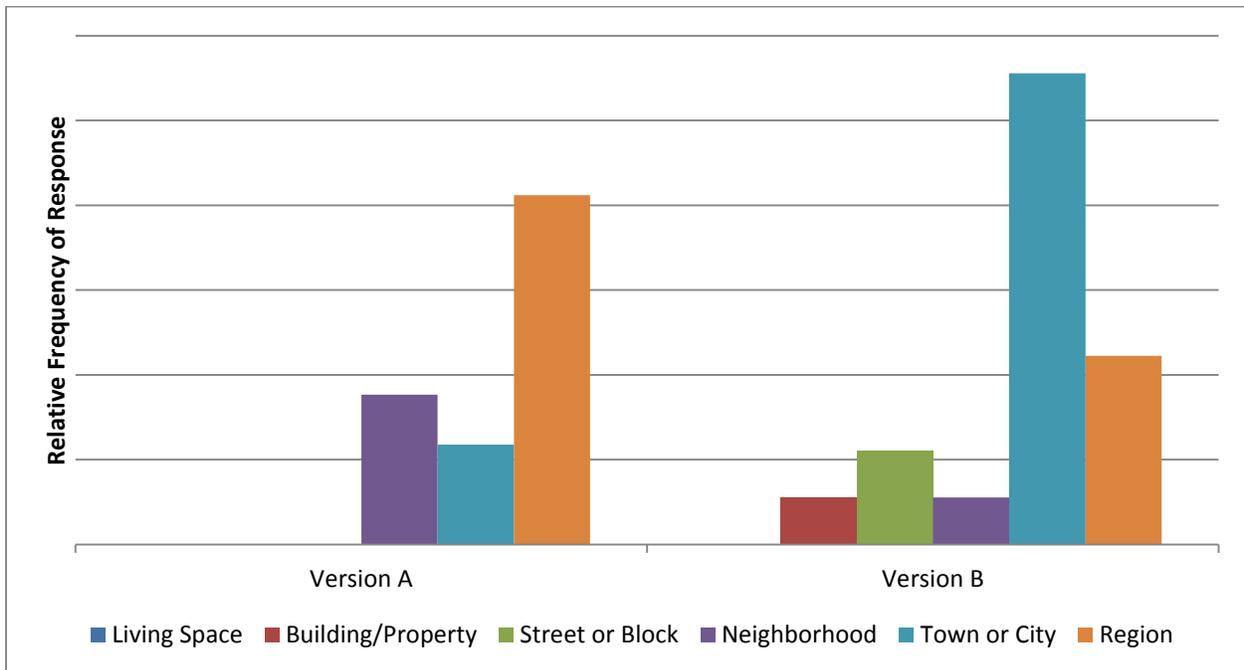
Judgment of the Needs Stem: While respondents continued to consider whether their physical accessibility or convenience needs and wants were met in a similar way as the previous Broad Environment questions, their judgment in Q BE4 was more complex as respondents tended to consider multiple “phases” of transportation. In particular, a number of respondents considered and judged both their trips to and from their primary mode of transportation (i.e. the walk to and from a bus stop) *and* the use of their primary mode of transportation (i.e. the bus ride itself).

As the respondents *independently* judged these various aspects of the use of transportation, their judgments occasionally conflicted. In these cases, respondents weighed these aspects and then *reported* on the one that was more salient to them at the time of the interview. For example, one woman who answered “4” explained that she was thinking about her bus rides to go shopping. She indicated that she had to walk up and down very steep hills to get to the bus stop, which was difficult in any sort of weather. However, she also noted that the bus ride itself was very easy, and that she was usually given one of the priority seats at the front of the bus. So while this respondent considered both “phases” of her transportation, in the end she reported on her judgment of the walk to and from the bus stop, not on the bus ride itself.

Disability Analysis: Very little difference emerged between how respondents who were physically disabled and those who were not answered Question BE4. One small difference that did emerge was within the Judgment of the needs stem step, where it appears that disabled respondents were slightly more likely to judge their needs and wants based on their trips to and from their primary mode of transportation (i.e. walking to and from a car) than did the respondents who were not physically disabled.

Cross-Questionnaire Analysis: The different ranges of reference areas, noted above in the analysis of Question BE3 does not hold up here in Question BE4. The unframed Version A produces a tighter set of reference areas than does the framed Version B, as seen below in Chart 6.

Chart 6: Reference Area by Questionnaire Version for Question BE4



While in this case Version B has a wider range than Version A in terms of interpretation of the reference area, the fact that the un-framed Version A is more likely to produce less “local” interpretations continues. Besides the reference area, no other significant differences between the questionnaire versions emerged.

Question BE5: Using the scale on show card X, how easy or hard does your dwelling (including toilet and all rooms) make it for you to do the things you need or want to do?

Summary of Findings: By and large, physically disabled and non-physically disabled respondents comprehended, judged, and responded to this question in the same ways. While some variation did emerge within how respondents judged whether or not their “dwelling” satiated their needs or wants, the spread of this variation was nearly the same across disabled and non-disabled respondents. On the other hand, the version of the questionnaire that the respondents received did matter: the ways those who received the unframed Version A of the questionnaire judged and responded to Question BE5 were markedly different than those who received the framed Version B.

Core Construct Interpretations: Most respondents understood Q BE5 to be asking about the features of their homes, and only a small amount of variation emerged around how they thought about the core construct of “dwelling.” Typically, the respondents considered only their interior living spaces. In particular, respondents mentioned the bathrooms, kitchens, and bedrooms.

However, some respondents also included their whole building (for those who did not live in a single-family home, such as an apartment building) or their surrounding property (such as their house's lawn). It is important to note that all of the respondents limited their interpretations of "dwelling" to the interior and exterior spaces on their (or their landlord's) property. Nobody for instance considered their neighbor's lawn, the street in front of their home, or any sort of public space while answering this question.

Reference Person: As seen in the previous question, Q BE4, not all the respondents understood the word "you" in the question text to only be referring to them. Simply put, while most interpreted the "you" in the question text to mean themselves, a few respondents understood it to mean some other person—either hypothetical or real. For instance, one respondent thought about her niece who has a leg issue:

It's pretty easy for me. I guess I have to go up the steps...or go down the steps to go to the bathroom in the basement. So my niece came over and her knee is bad so it's difficult for her to go up the steps...I'd give it a 2. Because overall a friend of mine he has a bad leg and I see how he goes up the steps when he has to go to the bathroom.

An important finding to note is that this alternative interpretation of "you" was limited to respondents who received the un-framed Version A. All respondents who received Version B only thought of themselves while answering Question BE5.

Judgment of the Needs Stem: A great deal more variation emerged when the respondents judged how well their dwelling satisfied their needs and wants. Respondents considered one of four separate patterns of judgment:

1. Their ease of physical movement around the dwelling
2. The presence or absence of mobility or self-care accommodations
3. Their perception of the quality and their enjoyment of the dwelling
4. The available of services and features within the dwelling (such as porches or nice kitchens).

The first two of these patterns are relatively self-explanatory. In the first one, respondents thought about their ability to physically navigate around the dwelling, and how their dwelling's layout either helped or hindered their movement. In the second pattern, respondents considered whether or not they had aids or modifications—such as shower seats or grab bars—in their dwelling that helped the move about and do their day-to-day activities.

The third and fourth of these patterns are similar to one another. A respondent judging the dwelling on its quality will consider the dwelling holistically, thinking about aspects that they like or don't like. For example, one respondent who received Version A of the questionnaire explained her answer by saying:

I would say very easy...Well, we've got essentially a three-bedroom house. We have a living room, dining room, library, and almost a full finished basement...3 and a half bath...We essentially have three full floors in the back.. I wouldn't say it's big, but it's very comfortable...It's more that it's laid out well than it's big.

Overall, respondents using the “perception of quality and their enjoyment of the dwelling” pattern of judgment are considering the question: “Do you like this dwelling?”

Respondents who employed the “available of services and features” pattern of judgment did not consider the dwelling holistically, but rather focused on one or a few specific services or activities that the dwelling either provided or did not provide. For instance, one respondent who received Version B was thinking about how she did not like bringing her friends into her home because of tensions within her family, and thus answered the survey question with a “2.” She explained:

Like all the things you need—sleep or eating—you can do at your house. But a lot of other things like social needs—like friends and stuff like that—you can’t do at your house....It’s not a place where I would want to invite my friends over.

In a few cases, respondents appeared to consider two or more of these patterns. For example, one respondent considered both her ability to move throughout the dwelling and the accommodations she had installed:

On that level I have a living room, three rooms, [and] a bathroom. I can’t get a walker through the doorjamb to the bathroom...[And] the tub is a problem. If I get in it I can’t get out. I do have raised toilets. On that level I’m good.

This combination—considering both physical movement and accommodations was common. In fact, nearly all the respondents who considered mobility or self-care accommodations also mentioned movement. However, the inverse is not the case: a number of respondents thought only about movement and did not think about accommodations for their health or physical abilities. For example, one respondent explained her answer by saying, “I was thinking of the restrooms and it’s easy and I live on a rambler so it’s all one floor.”

Disability Analysis: In general, respondents with disabilities did not approach or answer Q BE5 differently than respondents without disabilities.

Chart 7: Survey Response by Disability Status, Q BE5

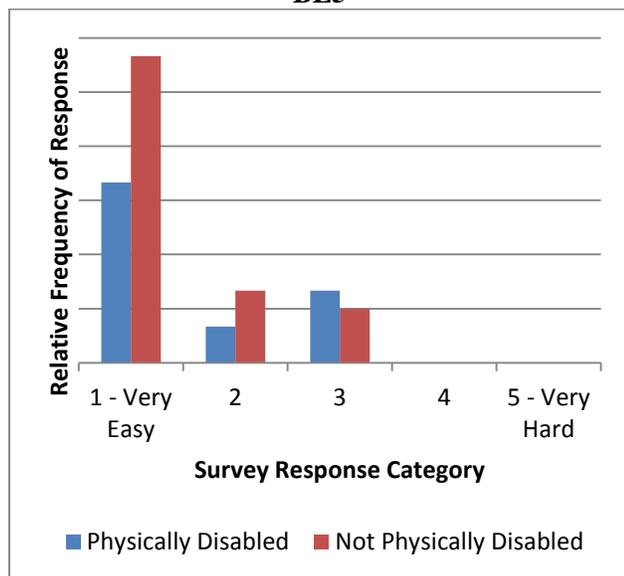


Chart 8: Pattern of Judgment by Disability, Q BE5

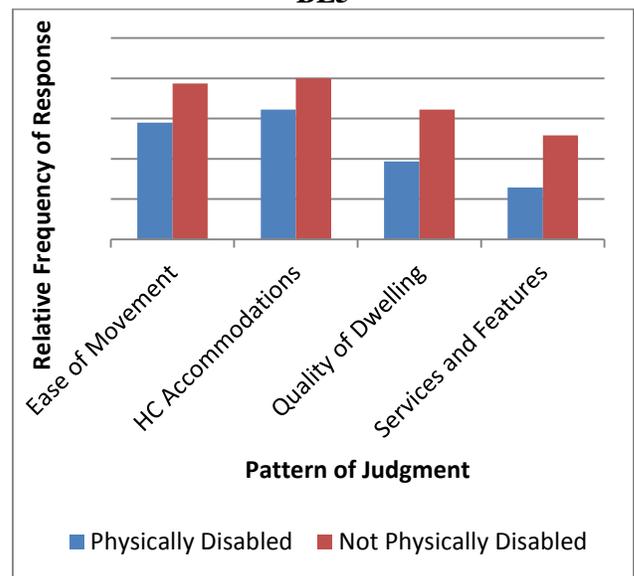


Chart 9: Version by Reference Area, Q BE5

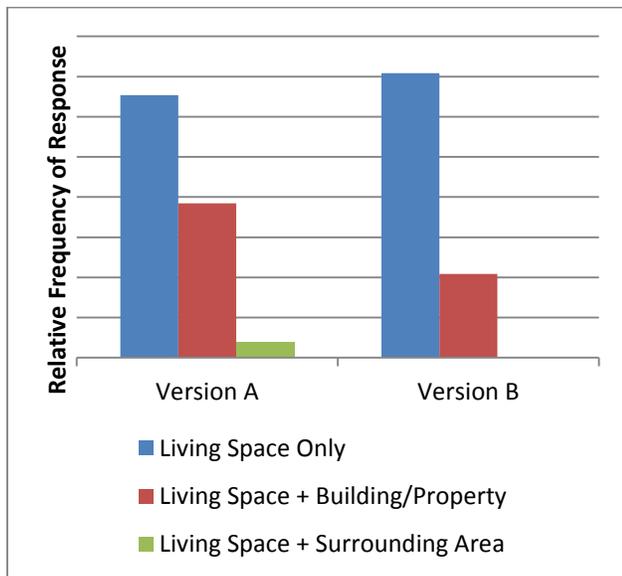
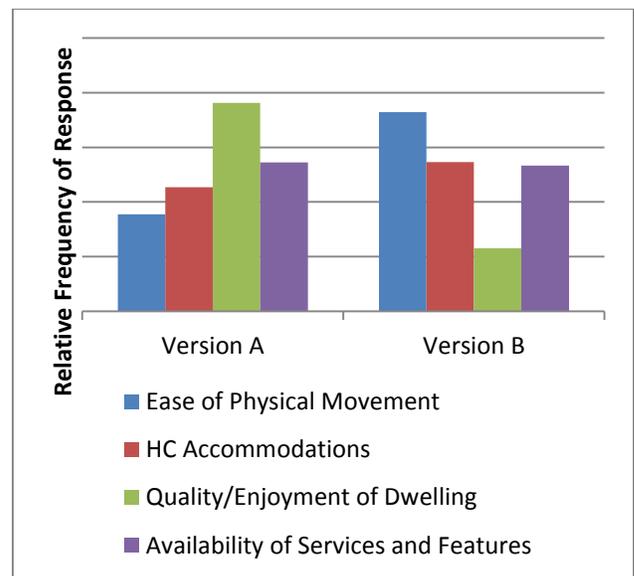


Chart 10: Version by Pattern of Judgment, Q BE5



In terms of survey answers, no respondents across the entire sample answered either “4” or “5 – Very Hard” to this question. Furthermore, as seen above in Chart 7, both the physically disabled and non-physically disabled respondents responded to the question in very similar patterns. Similarly, no major difference emerged between how physically disabled and non-physically disabled respondents judged their dwellings, as can be seen above in Chart 8: both populations applied the four patterns of judgment in comparative proportions—with more respondents in both disability classes considering the presence or absence of handicap accommodations or their ability to move about the space.

Cross-Questionnaire Analysis: Mirroring the patterns seen in the previous Broad Environment questions, the unframed Version A again led to more interpretations based on a wider geographic area under consideration; while the respondents receiving the framed Version B tended to think more about themselves and a limited geographic area. As seen above in both Charts 9 and 10, Version B produced slightly less variation than did Version A. Furthermore, as seen in Chart 9, those respondents who received the framed Version B were more likely to think about their dwelling as only their living space (and not spaces further afield) than were those who received Version A.

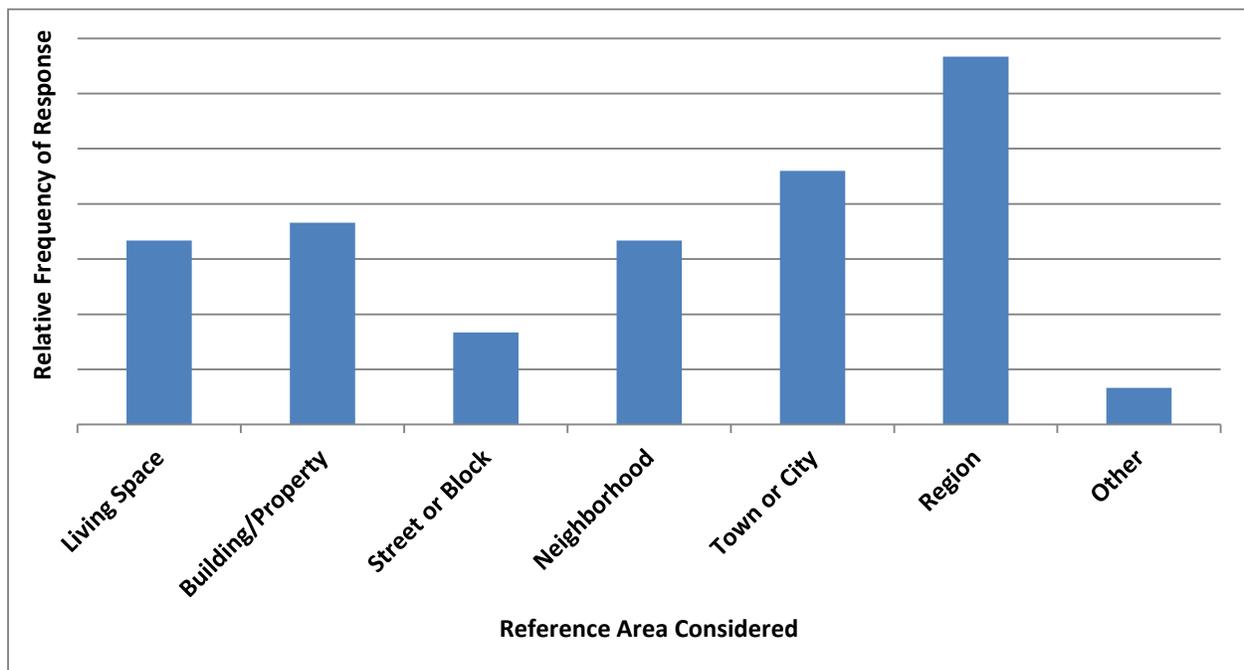
An additional difference between the two versions, mentioned previously, dealt with who the respondents actually answered Q BE5 *about*. When considering this “reference person,” all the respondents from Version B considered only themselves, while a number of respondents who received Version A also (or only) thought about other people.

Question BE6: Using the scale on show card X, how easy or hard does your natural environment of the place you usually live—its temperature, terrain, and climate—make it for you to do the things you need or want to do?

Summary of Findings: Due to its vague wording, complexity, and the resulting large variety of pathways respondents can use to answer it, Question BE6 does not produce consistent responses. The key to this confusion is the interaction between the core construct “natural environment” and the geographic indicator “place you usually live.” Both “place” and “environment” can be (and were) interpreted in multiple ways, and respondents’ interpretation of the latter is dependent on their conceptualization of the former. Thus respondents with similar physical abilities, living in similar situations in the same town answered this question in different ways and arrived at different answers.

Reference Area: Respondents considered a wide range of reference areas while responding to Q BE6. They ranged from the very close-to-self such as living areas and buildings and property, to areas much further afield such as towns and cities and the metropolitan region as a whole:

Chart 11: Relative Frequency of Reference Areas for Question BE6



As seen above in Chart 11, no one interpretation was dominant across the cognitive interviewing sample. This variation is certainly due to the weak framing provided the vague instruction “...the place you usually live.” Given that respondents base their interpretation of survey questions on their individual lived experiences, a term as un-focused as “place you usually live,” will not only produce a large variety of responses *between* respondents, but could also vary for an *individual* respondent based on the salient items and actions in their life at the time of the survey interview.

Core Construct Interpretations: The respondents also interpreted the core construct in Q BE6, “natural environment,” in a wide variety of ways. On the face, the term “natural environment” would seem to evoke *nature*. However, most respondents did not think about only their natural environment (or, as the question text suggests, “temperature, terrain, and climate.”), and a large group of respondents did not think about their natural environment *at all*. Four general patterns of interpretation emerged around the core construct: the built environment of the reference area, climate and temperature of the reference area, the people in the reference area, and the terrain of the reference area. Of these four, the first two patterns of interpretation were by far the most common.

It is important to note, however, that while a respondent might have been thinking about his or her climate and temperature, they were doing so about the reference area determined in the previous stage of response. Thus, if a respondent was thinking about their town or region as the reference area, they tended to think about climate as a natural phenomenon. For example, one respondent thought about the variable climate of the Washington Area:

At least a 2. We do have occasional snow. Have extreme temps...Hills. When I go on my bike ride if I have to go down the hill and then up the hill.. I'll sometimes put my bike on the bus to get up that hill.

However, if a respondent was thinking about his or her living space or building and property (or some other interior reference area), they would think about climate and temperature as an artificial phenomenon—i.e. air conditioning and heating. For instance, one person noted that his building had poor air conditioning during the summer months:

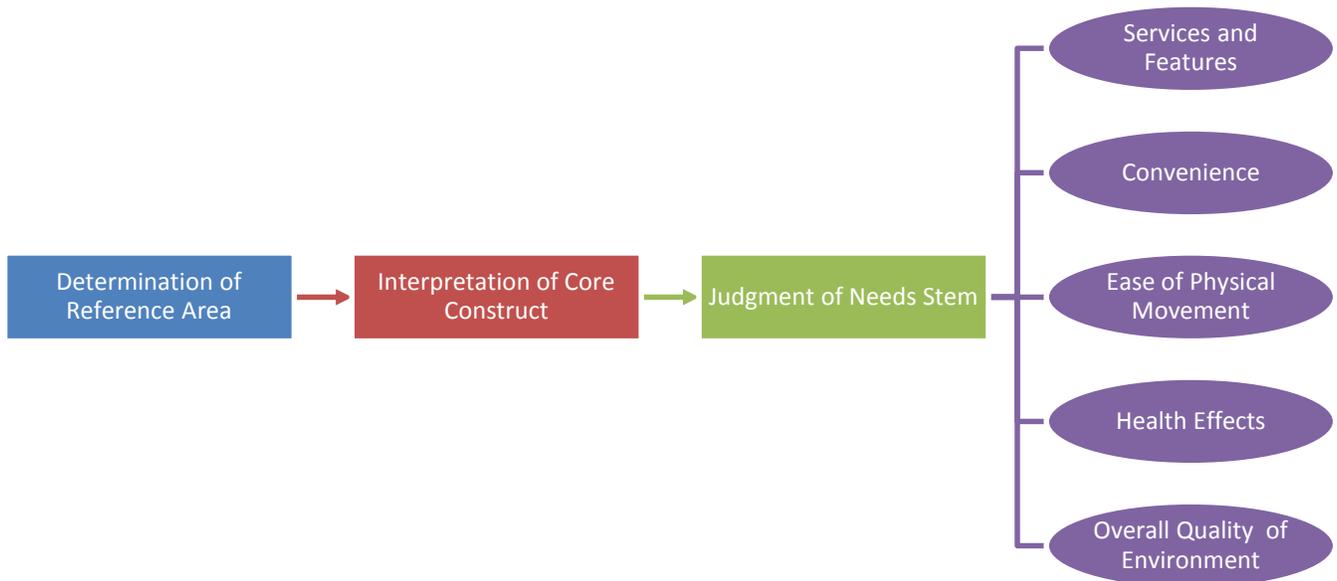
Well the sometimes the AC doesn't work as well as it should. So if it's a hot day it'll be kinda hot. Hotter than I'd like it. So I'd say hmmm 2 if it's too hot for me to sleep. Every summer. AC's just not that great. Like right now 70 80 cools down pretty good. Once it gets to 85-90 can't compete with the heat. Have to get on them about that...

Both of these respondents reported an answer of “2” to the survey question, but clearly interpreted the construct in very different ways. This complex interaction between the respondents' interpretations of the reference area and the core constructs is the major contributor to the high levels of variation seen across the responses to Q BE6.

Judgment of Needs Stem: Once the respondents decided which of the four ways they would interpret their “natural environment,” they had to judge whether or not this natural environment satiated their needs and wants. As seen throughout the other Broad Environment questions, multiple patterns of judgment emerged; in Question BE 6 five patterns of judgment emerged. They include whether or not the natural environment had various *services or features* that satiated the respondents needs, whether or not the natural environment was *convenient* for activities or daily life, how the natural environment contributed to the respondent's *ease of movement*, what *health effects* the natural environment had on the respondent, and the judgment of the *overall quality* of the natural environment. The response schema incorporating these various patterns of judgment is illustrated below in Figure 4.

None of these five patterns was dominate across the cognitive interview sample, although “health effects” was employed only by a few respondents. Some respondents considered only one of these patterns of judgment, while others considered two or more. The former was much more common in Version B, while only one respondent in Version A applied only one pattern of judgment to their reasoning.

Figure 6: Cognitive Schema of the Judgment of Question BE6



It is important to stress again that these judgments are based on the respondents’ interpretations of the “natural environment” core construct, which itself was framed by the reference area. At a minimum, given the seven different reference areas, the four interpretations of the construct, and the five patterns of judgment that emerged from the cognitive interviews, there are *at least 140 different response pathways* a respondent could use to arrive at his or her final answer to Question BE6. Such a wide variety of possible responses not only leads to a very low level of construct validity, but also to a high potential for response error.

Disability Analysis: Few differences emerged during analysis between respondents in the different disability categories. At the most basic level, respondents who were not physically disabled tended to answer the question using the “1 – Not Hard” answer category, while physically disabled respondents’ answers varied a slight bit more. However, by and large respondents who were physically disabled did not determine the reference area, interpret the core construct, or judge their needs and wants in a different pattern than did the respondents who were not physically disabled.

Cross-Questionnaire Analysis: The same cross-questionnaire version differences that emerged in the previous Broad Environment questions are present here in Q BE6 as well. First, the respondents had a broader set of reference areas, and were more likely to consider a further afield reference area if they received the un-framed Version A, while they were more likely to think of a geography close to the home if they received Version B. This trend can be seen below in Chart 12:

Chart 12: Questionnaire Version by Reference Area, Q BE6<

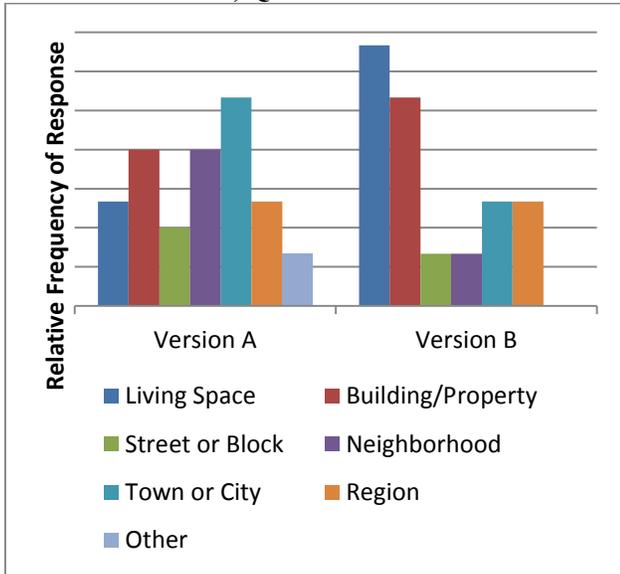
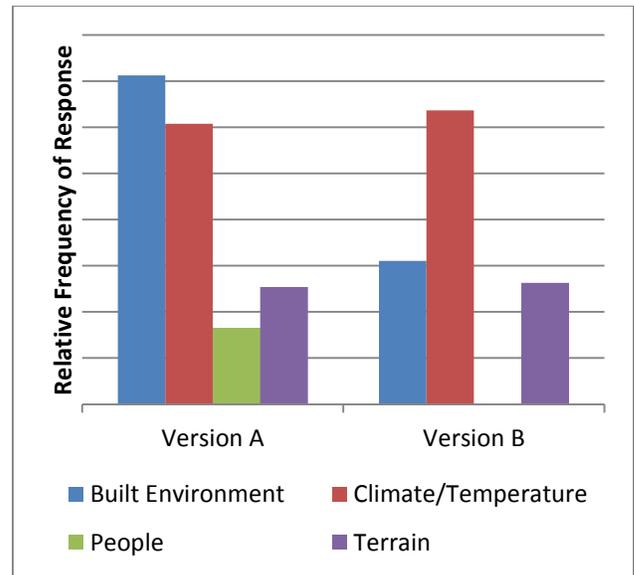


Chart 13: Questionnaire Version by “Natural Environment,” Q BE6



Secondly, the respondents who received the framed Version B continued to show less variation in the interpretation of the core construct. In this case, as can be seen above in Chart 13, the Version A respondents had no one dominant interpretation, while the Version B respondents tended to be thinking about climate and temperature. Additionally, in the judgment phase, the Version B respondents—who had already received questions about Health Conditions and Capacity—were much more likely to judge their environment on its ease of physical movement than the Version A respondents who had no health framing.

Question BE7: Using the scale on show card X, how easy or hard does the lighting, noise, and crowds in your surroundings make it for you to do the things you need or want to do?

Summary of Findings: Question BE7 was interpreted in a much more consistent manner than any of the previous Broad Environment questions. Respondents only considered the three aspects of the core construct ambiance given as examples in the question text—lighting, noise, and crowds. Furthermore, they universally judged these three aspects of ambiance in the same way: lighting as a positive characteristic; noise and crowds as “negative” characteristics. However, the interpretations of the reference area varied widely, and those respondents who received the unframed Version A of the questionnaire again had a wider set of reference areas than did those who received the Version B. Additionally, the plural term “surroundings” made the respondents’ task of determining the reference area even more complex, with some respondents considering (and attempting to respond about) multiple geographic areas.

Reference Area: Like what was seen in Question BE6, Question BE7 explicitly mentions the reference area in the question text. While in the previous question the term “place” was used, this question asks about “surroundings.” The respondents’ attempts at un-packaging this term is the largest source of variation in the overall interpretation of Q BE7. The respondents considered a similar range of locations for the reference area as they did in previous questions—from their living space itself to the building and

property, to their city and the Washington region. However, the framing by the plural term *surroundings* adds additional complexity.

While in previous questions most respondents considered a single reference area, in Q BE7 a significant number thought about multiple reference areas and locations. It appears that the word *surroundings* itself has a dynamic meaning to some respondents.

Most respondents considered surroundings to be a static or singular location—much like what was seen in Q BE6 for the term “place.” For example, one respondent who considered only a single location explained his answer like this:

Environment has nothing to do with noises. It’s because someone in some other apartment is making too much noise. The lighting is neutral you can see in the halls fine.

Others understood the reference area in a more dynamic sense and thought about (and went on to judge) multiple locations. Some of these respondents noted difficulty in providing a response. For instance, one such respondent said:

Let’s see I don’t know you caught me off guard there...I don’t know...In my environment? In my home? My mind went to [the local community college] because I go down there five days a week...We have an active senior program in the gym where it’s anywhere between sixty to seventy people.

Clearly, if a respondent thought about a single reference area, then they would only judge that single location’s ambiance later in the response process. On the other hand, if a respondent considered multiple locations, then he or she would go on to judge each of these location’s ambiance and then combine those judgments in some way to arrive at a survey response.

Core Construct Interpretations: There was very little variation across the sample in the interpretation of the core construct in Q BE7. This construct—ambiance—is explicitly framed in the question text with the phrase “lighting, noise and crowds.” The respondents largely limited their interpretations of ambiance to these three terms, and most considered either two or all three during the judgment phase.

Judgment of the Needs Stem: As noted above, most respondents appeared to think about either two or three of the examples—lighting, noise, or crowds—provided in the question text. For example [emphasis added]:

I live in a **quiet** neighborhood there are only 10 homes on my street. We’re fortunate in my home. Now again do they mean am I in my home? If I go down to the grocery store, then this is actually really hard to answer...If I have to go down to the main roads...I have to go really early in the morning...in the shopping center there’re fools...the **drivers, the crowds:** I just don’t like that

Each of the three aspects of ambiance given in the question text were interpreted across the board as either a positive or a negative aspect. Lighting was generally perceived to be a good thing; respondents frequently used the “adequate lighting,” and explained that the more light the better in their minds. Noise, on the other hand, was generally assumed to be negative, and typically associated with loud neighbors or noisy locations. Finally, crowds were also generally perceived to be negative: Respondents

largely noted how crowds interfered with their needs or desires to perform various actions (like parking or shopping quickly).

While the respondents tended to both think about the various aspects of ambiance similarly, and to consider multiple aspects when judging their surroundings; they typically only *answered* the question based on one of the aspects. Take the example above, for instance. While the respondent considered both noise (“I live in a quiet neighborhood...”) and crowds (“the drivers, the crowds: I just don’t like that”), she based her survey response only on the noise aspect and responded with a “1 – Very Easy.”

Disability Analysis: A few differences in interpretation of Q BE7 by respondents with physical disabilities versus respondents without physical disabilities emerged. As seen below in Chart 14, respondents with physical disabilities were more likely to focus on their living space, property, or the areas nearby (such as the street than were the respondents without physical disabilities.

Chart 14: Disability Status by Reference Area, Q BE7

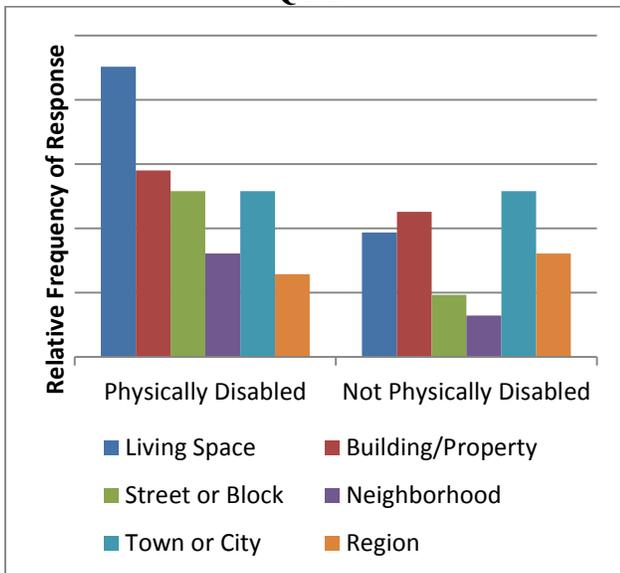
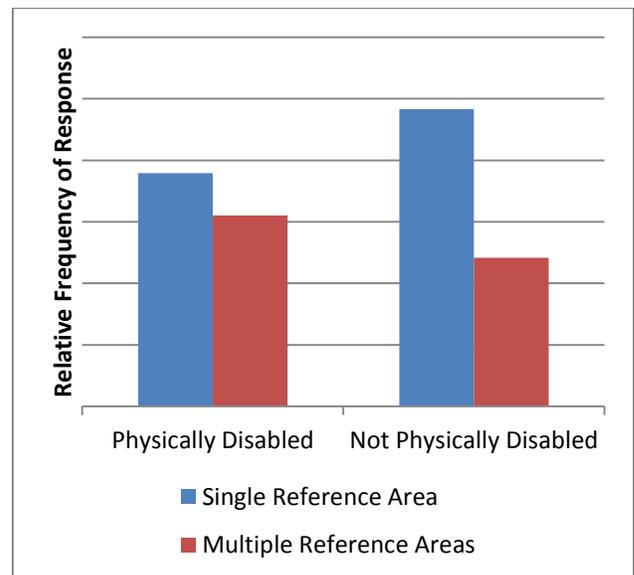


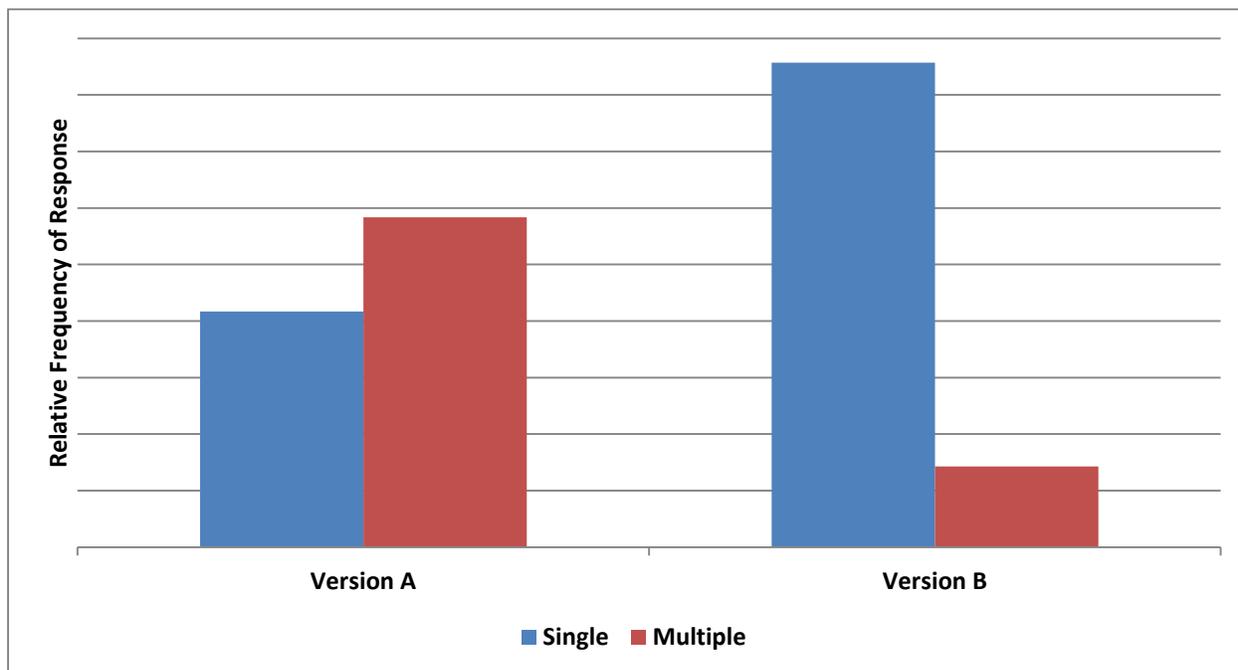
Chart 15: Disability Status by Response Pattern, Q BE7



Furthermore, as seen in Chart 15, respondents without physical disabilities were more likely to consider only a single reference area, while respondents with physical disabilities split between thinking about single or multiple locations. However, beyond these differences in the determination of the reference area, there was not much differentiation between how respondents with physical disabilities and those without interpreted the core construct of ambiance, or judged how it did or did not satiate their needs and wants.

Cross-Questionnaire Analysis: Only one major difference between the questionnaire versions emerged: Respondents who received the framed Version B were much more likely to consider only a single reference area, whereas the respondents who answered the un-framed questionnaire Version A were split between considering a single or considering multiple reference areas:

Chart 16: Questionnaire Version by Response Pattern for Question BE7



This distribution pattern in Chart 16 is very similar to the one seen above in Chart 15—where respondents with physical disabilities were split in their interpretations and respondents without physical disabilities favored a single location. The questionnaire version sub-samples had almost the same number of respondents classified as physically disabled (15 received Version A, while 19 answered Version B, see Appendix A). While further research is necessary, these findings may indicate that the differences seen in Chart 15 and 16 are due to an interaction between cognitive framing and health or disability status.

Given the fact that some of the Assistive Aid/Device Utilization (AA) questions were used in identifying whether or not an individual coded as disabled (see Appendix A), the following questions do not include a disability analysis.

The response categories for all of the Assistive Aid/Device Utilization questions were:

1. Yes
2. No
Don't Know
Refused

Question AA1: Do you have someone to assist you with your day-to-day activities at home or outside, including family and friends?

Summary of Findings: Respondents expressed a substantial amount of confusion when answering Question AA1, particularly what exactly they should count as assistance. This difficulty led to a large amount of variation both in the interpretation of the core construct of “assistance with day-to-day activities,” as well as in the resulting judgment of whether or not they had someone who gave them that assistance.

Core Construct Interpretations: The construct for “assistance with day-to-day activities” held a wide array of interpretations across the cognitive interviewing sample, and its interpretation caused noticeable confusion among the respondents. One respondent summed up her confusion, saying: “I mean everyone needs assistance sometimes.” While in the end they understood the question to be asking about routine tasks such as bathing, laundry, cooking, cleaning, and yard work, most respondents first considered a wider range of less ordinary tasks before deciding that the question was just about routine ones.. However, some respondents continued to consider out-of-the-ordinary tasks for their responses. For example, one respondent said:

Well recently I had to buy a dehumidifier. So the store loaded it and a friend at home helped me get it out of the car.

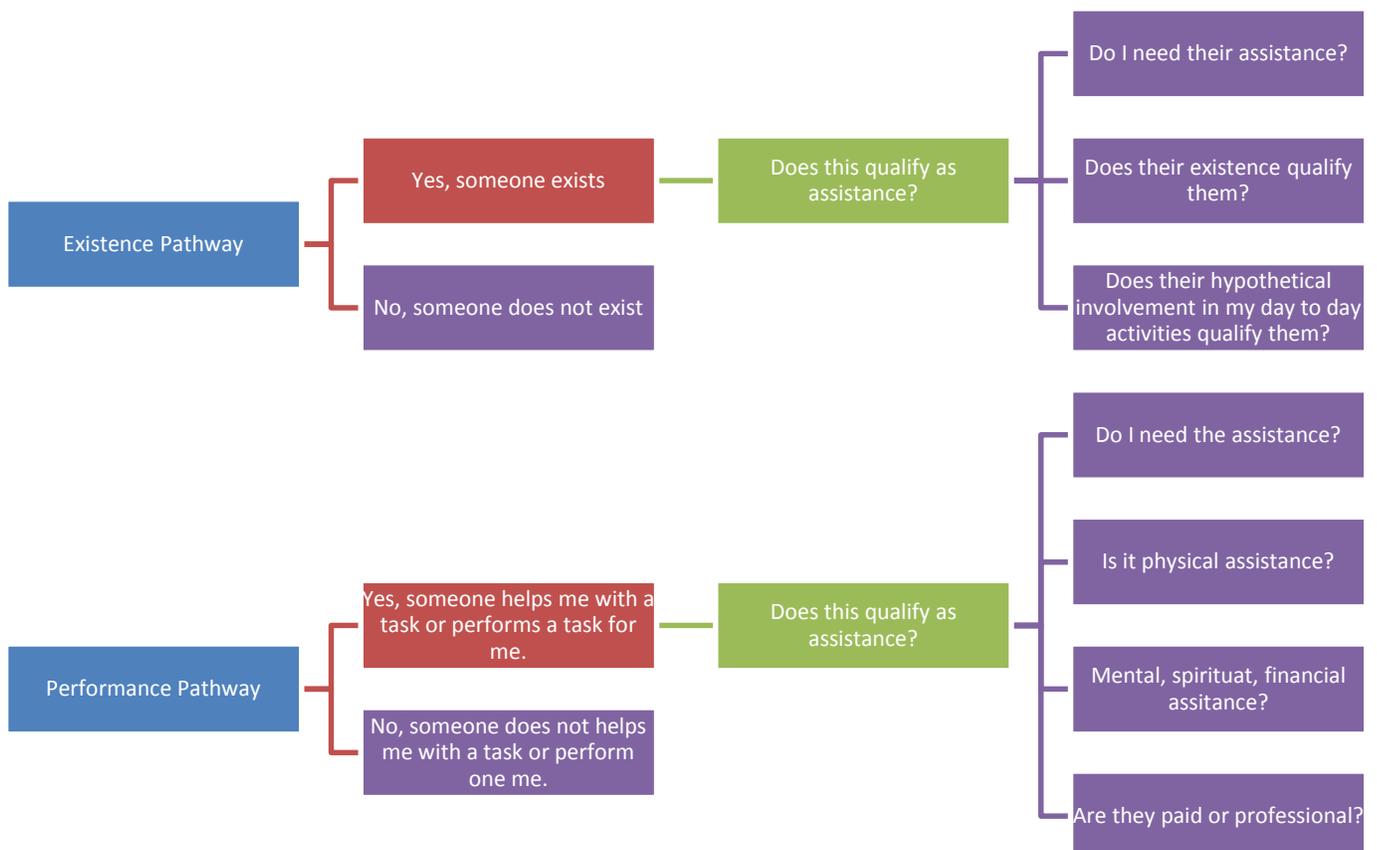
While the respondent recognized that purchasing a dehumidifier was not an ordinary, day-to-day task, she still included it as part of her interpretation. Another respondent noted a time when he needed assistance cutting down a tree. These respondents appeared to comprehend the question as “do you ever need anyone to help you?” focusing on perhaps the most salient instances when they needed assistance, instead of help with their everyday activities.

In most cases, the respondents’ references to household tasks and yard work indicate that the instruction “at home or outside” was understood to limit the response one’s home and/or property. In some cases, however, the reference area included a larger area beyond the respondents’ immediate property, including locations such as the grocery store.

Judgment of Use: Beyond the core construct of “assistance,” there was also variation around the phrase “Do you have someone...” While most respondents understood “someone” to be a family member, friend, or paid assistant (such as a nurse or paid laborer), two distinct interpretations of the actually assistance they provided emerged. On one hand, some respondents simply considered the construct to refer to the *existence* of someone. For instance, one respondent claimed, “I have friends to do things with.” Other respondents considered whether or not someone *performed* or assisted with a task. Respondents employing this latter pattern of judgment identified things such as a living assistant that helped the respondent get dressed or laborers contracted to cut the respondent’s lawn. Many respondents struggled with making this choice between the two interpretations. For instance, one respondent attempted to clarify if the question was asking: “Is there someone who exists who could help me or do I call upon someone to help me?”

After respondents selected the pattern of judgment they wished to employ, respondents then determined whether or not this someone existed or assisted them with a task. If the respondent concluded that this someone did not exist or that he or she was not solicited for assistance, they responded “no” to Q AA1. On the other hand, if a respondent believed the contrary to be true, they then made a judgment about whether or not the assistance they received qualified for an affirmative response. The schema illustrated below summarizes this process:

Figure 7: Response Process for Question AA1



Based on the pattern of judgment selected, respondents considered one of the above questions (in purple) when making their final judgment and response to the survey question. For instance, under the existence pathway, a respondent noted that, “[My] two daughters live nearby and they would be available to help me if I need and called upon,” but still responded with a “no” to question. Although he acknowledged that he had family members that could assist him if called upon, he believed that this was not enough for him to respond “yes” to Question AA1 because he didn’t need their help. On the other hand, another respondent who answered “yes” thought that just having a group of friends nearby that she could ask for help qualified. This respondent did not note that she has asked these friends for assistance, but was simply considering whether or that that assistance could *exist*.

Another respondent answered no, but used the performance pathway. In explaining his answer, he said:

No I have friends. There are a couple of girlfriends come by now and then. As far as being there to assist me, [they] sometimes might cook something. [But] I don’t think it qualifies... Assistant would be some... like a home or health aide.

While this respondent identified individuals in his life that assists him with daily tasks such as cooking, he believed this did not qualify him to respond “yes” to the question because he did not need the assistance. Furthermore, he felt that since this person was not paid or a professional it further disqualified him from responding “yes.”

Cross-Questionnaire Analysis: Two major cross-questionnaire differences about how respondents answered Question AA1 emerged. Respondents tended to generate different interpretations for the reference area of their “day-to-day activities” based on which questionnaire version they received. Following the trend noted above throughout the Broad Environment questions, Version B respondents were more likely to consider constructs that were closer (in terms of proximity) to their physical self than were Version A respondents. Specifically, those respondents who answered the framed Version B tended to interpret “outside” to be closer to one’s home than Version A respondents did, including activities such as yard work. On the other hand, Version A respondents frequently referenced grocery shopping, running errands, and out-of-the-ordinary tasks.

Another cross-questionnaire difference emerged during the judgment phase of response. While respondents in both questionnaire versions selected the “Existence” and the “Performance” Pathways (see Figure 5 above) with similar frequency, there were noticeable differences in how they actually applied the various patterns of judgment (the purple boxes in Figure 5) in order to arrive at a “yes” or “no” answer.

For example, respondents in Version A were more likely to simply consider the *existence of someone* as enough of a qualification to respond affirmatively to Question AA1. One Version A respondent, who replied with a “yes,” said, “I have friends I can call on, but sometimes they aren’t available.” Thus, this respondent reports that 1) her friends exist, 2) they could help if she needed it, but 3) they are not always present, and judges that she should answer “yes” to the question. On the other hand, most Version B respondents considered the simple fact that help existed to not be enough of a qualifier. For instance, a female Version B respondent responded “no” to Question AA1, and explained that she has close friends that help her “in the sense of my mental health,” but do not provide her with the level of support she thinks should count for this question. This respondent therefore reported that 1) her friends exist, 2) they provide some social support, but 3) they do not help her physically accomplish tasks, and then

judges that she should answer “no” to Question AA1. The fact that respondents who received the different questionnaires would take a similar set of facts and arrive at different answers indicates that the cognitive framing provided by Version B does indeed affect how respondents approach the survey questions.

Question AA2: Do you take medicines on a regular basis?

Question AA2 was not systematically probed during the cognitive interviews; no findings are available.

Question AA3: Looking at show card X, do you *use* any of these mobility or self-care aids?

Question AA4 Looking at show card X, do you *need* any of these?

The show card displayed the following items:

1	Orthopedic footwear
2	Artificial limb (leg/foot)
3	A cane or walking stick
4	Crutches
5	A wheelchair
6	A walker or a scooter
7	Braces
8	An adapted motor vehicle
9	Extenders or grasping tools
10	Another aid

Summary of Findings: Because Question AA4 was designed as a follow-up to Question AA3, these questions were analyzed, and are presented, together. Their interpretations of the core constructs across the two questions are identical—respondents simply carried their conceptualizations forward from Q AA3 to Q AA4.

Overall, Questions AA3 appeared to capture whether or not respondents *had* any of the devices on the show card, and respondents had relatively tight interpretations of the devices—with a few exceptions discussed below. However, respondents did not consistently judge whether or not they *needed* these devices in Question AA4—with some respondents thinking that only constant reliance on the device qualified as a “need,” while others used a much looser standard and qualified even occasional reliance as a “need.”

Core Construct Interpretations: While the respondents’ interpretations of some of these items were similar, other items caused some confusion. Respondents easily and consistently identified the following items: artificial limbs, cane or walking stick, crutches, wheelchair, and walker or scooter.

Their interpretations of these five items did not vary, probably because these are either very common items (such as a cane or crutches) or self-explanatory (such as an artificial limb). However, their interpretations differed for orthopedic footwear, braces, adapted motor vehicles, extenders and grasping tools, and other aids. The figure below summarizes the interpretations of the items that showed extensive variation:

Figure 8: Interpretation of Selected Items on the Questions AA3 and AA4 Show Card

"Orthopedic Footwear"	"Braces"	"Adapted motor vehicle"	"Extenders or grasping tools"	Other Aids
<ul style="list-style-type: none"> •Footwear such as sneakers •Shoe inserts prescribed by a physician •Shoe inserts bought over-the-counter 	<ul style="list-style-type: none"> •Elastic Joint Brace •Dental Braces •Structure providing back brace •Plastic leg braces 	<ul style="list-style-type: none"> •(Motorized) Wheelchair •Scooter •Car with chair lift •Car with pedal extenders •Car with modified steering wheel •Car modified for "someone without limbs" 	<ul style="list-style-type: none"> •Device used to pick up items •Device used to reach high up •Clippers (for landscaping) •Specialized tool for "someone without limbs" 	<ul style="list-style-type: none"> •Button around neck for emergencies •Bed with grab rails •Velcro Straps •Health-related cushions and neck rolls •Grab handles in bath rooms •Hearing aids

Some respondents simply identified “orthopedic footwear” to be a reference to normal shoes. For instance, a female respondent noted that she used orthopedic footwear, citing her usage of “Easy Spirits” and “Ugg boots.” The term “braces” captured the construct of added support. But the bodily location and the sturdiness of the material varied. One Version A respondent explained that he was thinking about “...dental braces, from the orthodontist.” Respondents that used “other aids” listed their aids as prompted. All of these aids were mobility or health related. One respondent, who suffered a stroke that left one side of his body incapable of performing certain tasks, stated how he used a fair amount of Velcro and installed grab rails in various places of his house to assist with his disability.

The term “Adapted Motor Vehicles” was not consistently understood at all, and a number of respondents indicated that they were confused by the term. Upon probing, most respondents believed it simply referred to a wheelchair or scooter, even though another item on the show card clearly included these devices. A few respondents did comment on this overlap, which seemed to increase their confusion. For example, when asked what he was considering when he said “no” to having (and needing) an adaptive motor vehicle, one respondent said, “It sounds like a wheelchair to me, but you have wheelchair here as number 5. I don’t know.”

Extenders and grasping tools were often mentioned in the context of their assistive abilities. Many respondents characterized them by their ability to assist with tasks, or to make them more convenient. Importantly, they were not always interpreted as a tool related to health or disability. For instance one respondent explained that she did have a grasping tool, but that she didn’t need it because of any sort of chronic issue or disability:

Let me see: I have one of those to reach things up high, like on shelves, instead of getting the stool. It's not because I'm handicapped, it just makes it easier.

Some other respondents explained that these devices were a necessity due to their health. One female respondent, for example, noted that she, "absolutely had to have them [extenders and grasping tools]," thinking about how unsteady she was on her feet and how she had difficulty balancing and reaching at the same time.

Judgment of Use: The pairing of Questions AA3 and AA4 aimed to capture both the respondents' usage of and need for assistive devices. When judging their use and need for these devices, the respondents employed a variety of patterns. These include:

1. Respondents expressed that they used and needed their assistive device(s).
2. Respondents expressed that they used, but did not need, their assistive device(s).
3. Respondents articulated that they possessed but did not use their assistive device(s).
4. Respondents articulated they did not have or use, but needed certain assistive devices.
5. Respondents articulated that they did not use or have, but desired certain assistive devices.

Respondents commonly articulated that they used, but did not need, their assistive device. A fair number of respondents also expressed that they had, but did not use their assistive devices. One such respondent, who answered "yes" in Q AA3 but "no" to needing a cane in Q AA4 explained:

They issued me one. But I don't use it... Sometimes I think it's faster if I'm late if I don't use it... I can walk without it but it is there as an aid.

Other respondents claimed that they only needed to use their aids under certain circumstances, such as the using a walking stick in a rocky area. These respondents did not apply this pattern of judgment uniformly however. While a majority of respondents who indicated that they sometimes came upon situations where they needed their device answered "yes" to the corresponding item in Question AA4, a large number instead answered "no." This latter group believed that in order for them to say "yes" to the need question, they would have to require the device's assistant all or a majority of the time.

Additionally, a few respondents answered Question AA4 not with need in mind, *per se*, but instead by considering their desire. These respondents indicated that having the device would be helpful, but it was not necessary. For instance, one respondent said that she wanted, "... an adapted motor vehicle if some wants to donate one to me."

Cross-Questionnaire Analysis: There were only slight differences between the respondents' interpretations of Questions AA3 and AA4 across the two questionnaire versions. For example, Version A respondents and Version B respondents identified different constructs for "braces". Respondents in Version A understood "braces" to be elastic braces for joints, dental braces, and a structured brace for ones back. On the other hand, Version B respondents had a tighter interpretation of "braces," and uniformly understood the term to be referring to leg braces. These small differences in interpretation could simply be due to the sample; however, and further, targeted research would be necessary to draw meaningful cross-questionnaire conclusions.

Question AA5: Looking at show card X, are there any of these things that make it easier for you to participate in activities outside your home?

Question AA6: Looking at show card X, do you *need* any of these?

The show card displayed the following items:

1. Accessible public buildings open to the public, e.g. shops, cinemas or worship places
2. Accessible public buildings, e.g. city hall or post office
3. Accessible signage and way finding
4. Accessible public toilets
5. Accessible public transportation
6. Accessible roads, paths, and trails.
7. Do not use anything

Summary of Findings: Similar to Questions AA3 and AA4, Question AA5 and its follow-up Question AA6 are presented together. As seen with the previous set of questions, respondents carried their interpretations of the core constructs forward from Q AA5 to Q AA6.

Core Construct Interpretations: A number of the items on Questions AA5 and AA6’s show card confused the respondents, leading to a wide variety of interpretations. Many respondents were unable to draw distinctions between the first two items—accessible public buildings open to the public, and accessible public buildings. Most respondent dealt with this by simply considering them to be the same category. For example, one respondent believed the items were the same, but with rearranged words, noting: “These really seem similar. One says accessible public buildings open to the public and one says accessible public buildings.” Likewise, another respondent explained that she, “. . .kind of want[s] them in the same category.” The phrase “open to the public” did not appear to correlate in the respondents minds to the examples in Item 1 (“shops, cinemas or worship places”) more than they did to the examples given in Item 2 (“city hall or post offices”). This lack of differentiation between the examples muddied the constructs and lowered their validity. A few respondents, for instance, wondered why places of worship were included in the first example alongside commercial establishments, and not included alongside the more civic spaces in the second item.

Much of the other variation in how the respondents interpreted show card’s items related to how they interpreted these core constructs alongside the term “accessible.” Across all of the items, respondents generally identified “accessible” in two ways (similar to what was seen previously in the Broad Environment questions): either meaning *available or convenient* or *specifically designed for someone with disabilities*. So, for instance, some respondents understood “accessible public transportation” (the fifth item on the card) to mean public transportation with handicap modifications such as ramps or special seats, while just as many understood it to mean public transportation that was easy or convenient to get to.

A number of respondents explicitly noted the multiple denotations of the term. For instance, one respondent noted: “So accessible can mean two things: ADA [American Disability Act] compliant or

easy to get to.” Cases like this, where a respondent understood (and eventually judged) both constructs, was not uncommon. This same respondent was unable to give a response, and explained by saying:

Well I mean it again it’s how you define accessible. The first five I interpret as being referring to ADA. But having roads, paths, and trail as opposed to mud.

A few other minor interpretations of “accessible” emerged as well. One respondent understood accessible to mean she could *practically use* a facility. She explained: “[Accessible means] like I’m able to go there...So accessible there [on the card] would be like a gas station or a McDonalds but not a fancy restaurant.” This interpretation of accessible is both spatial and economic—a place would need to be geographically located somewhere the respondent could get to, AND be within her financial means.

Additionally, some respondents expressed their confusion with how the ADA-compliant interpretation of “accessible” related to the core construct under question. For example, one respondent explained his “no” answer to Item 6 by saying:

Accessible roads and paths and trails... I wonder what that means. I’m thinking I’ve never seen an accessible hiking path.

This problematic interaction between the core construct and the term “accessible” was most pronounced in Item 6—“accessible roads, paths, and trails”—and Item 3—“accessible signage and way finding.” By a large, respondents—both those who noted capacity issues elsewhere in the MDS survey and those who did not—had a very difficult time conceptualizing how either a sign or a road could be accessible.

Judgment of Use: Once respondents interpreted the various constructs, they then determined if they did or did not use an item. For those respondents who did not believe that an accessible feature on the show card existed (or that they had access to), they quickly answered “no” to the item. On the other hand, those respondents who indicated that they did indeed have access to an accessible feature then judged whether or not their use and need qualified as either a “yes” or “no” answer for Qs AA5. Respondents judged their answer to Question AA5 using two pathways: whether they actually use the accessible feature, or simply whether the accessible feature exists.

For the first of these pathways, the respondents not only had to know that a feature—such as an accessible public toilet—existed, but that they used it as well. Depending on the respondents’ interpretation of the term “accessible” this judgment was thus about either availability (for those respondents who conceptualized accessible as available or convenient), or need (for those respondents who conceptualized accessible as ADA compliant). This latter interpretation is important. Even if a respondent understood an accessible toilet to be one with (for instance) wide stalls and grab bars, and even if they could physically access such a toilet, they would answer “no” because they did not need the accessible feature. For example, one woman who answered “no” to public transportation noted that she was specifically thinking about the reserved seats at the front of the bus. When asked to explain why she answered “no” to the item, she said, “I would say no because I don’t need them.”

The second of the two pathways is much simpler. These respondents all reported “yes” to the item in question, because they knew that the particular accessible feature existed. For instance, one respondent who answered “yes” to both the first two items explained that she was thinking about ramps and automatic door buttons. She went on to note that she did not necessarily use these features, but that they

were there in case some people did need them. In short, these respondents were answering the question, “Do you see any of these things [on the show card] in your day-to-day life?”

Cross-Questionnaire Analysis: There were again some small differences between how the respondents interpreted Questions AA5 and AA6 between the two versions of the questionnaire. As seen throughout the Assistive Device and Broad Environment sections, respondents who received the unframed Version A were much more likely than those who received the framed Version B to not think about health or disability-related constructs. In this case, the Version A respondents were more likely to conceptualize “accessible” as available or convenience, while most Version B respondents thought about “accessible” in terms of something being modified for individuals with disabilities.

APPENDIX A: DISABILITY STATUS CODING CRITERIA

This report includes analysis based on the disability status of the respondents, following the hypothesis that the disabled and health populations may interpret some questions differently from one another. While respondents were recruited into the cognitive interviewing sample based on the presence or absence of certain pre-existing health conditions, the cognitive interview itself provides extensive data that allows for a more comprehensive, transparent, and consistent classification of respondents' health status. This rich, thick data was used to create and apply a disability classification system for the respondents. The following rules determined the respondents' classification:

Respondents were labeled as having a “physical disability” if any of the following criteria were met:

- If respondents indicated that they use any of the mobility devices on Question AA3 besides option (1) “orthopedic footwear.”
- Respondents indicated impediments with getting out of their home, walking, or self-care; answered 2 or higher on Question(s) F1, F2, or F4.
- Indicated vision loss; responds yes on Question HC1.
- Indicated hearing loss; responds yes on Question HC2.
- Expressed more than “some difficulty” walking or climbing steps; 3 or greater on Question C1.
- Claimed to have “some difficulty” (or greater) with walking 100 meters on level ground; answered 2 or greater on Question C2.
- Indicated “some difficulty” with shortness of breath; answered 2 or greater on Question C9.
- Expressed difficulty in doing household tasks because of health; responded 2 or greater on Question C14.

Respondents were labeled as having a “mental disability” if any of the following qualifications were met:

- Indicated depression or anxiety; responded yes to Question HC12
- Indicated other mental or behavioral disorders on Question HC23
- Has difficulty with self-care due mental ability. Respondents indicated difficulty with in Question C3 or problems with self-care on Question F4 (respondent manuscripts had to be evaluated).
- Indicated depression more frequent than “some days” on Question C10.

Given this classification scheme, the respondents were distributed across the two questionnaires in the following way:

Appendix Table 1: Distribution of Respondents by Disability Statuses

	No Disability	Only Physical Disability	Only Mental Disability	Physical and Mental Disability
Version A	5	8	3	7
Version B	5	7	4	12
Total	10	15	7	19

For the analysis throughout the report, we commonly collapsed these four categories into two: Physically Disability (Only Physical Disability, and Physical and Mental Disability) and No Physical Disability (No Disability and Only Mental Disability). The distribution across the two questionnaire versions of this division is as follows:

Appendix Table 2: Distribution of Respondents by Collapsed Disability Statuses

	Physical Disability	No Physical Disability
Version A	15	8
Version B	19	9
Total	34	16