

2014 National Study of Long Term-Care Providers:

Results of cognitive interviews conducted July—September, 2013

Paul Scanlon, PhD

Questionnaire Design Research Laboratory

National Center for Health Statistics

Centers for Disease Control and Prevention

1. Introduction

This report summarizes the findings from a research project designed to evaluate the 2014 National Study of Long-Term Care Providers (2014 NSLTCP). The NSLTCP is designed to capture information on providers and users of long term care services and supports, focusing on Residential Care Communities (RCCs) and Adult Day Service Centers (ADSCs). Residential Care Communities provide long-term supports and services to individuals who cannot live independently, but generally do not require the skilled level of care provided by a nursing home. Adult Day Service Centers, on the other hand, provide social and health services for the elderly and younger disabled individuals who need supervised care outside the home during the day. This evaluation is based on 20 cognitive interviews conducted at RCCs and ADSCs throughout the Washington, DC and Baltimore, MD metropolitan area by the National Center for Health Statistics's Questionnaire Design Research Laboratory (QDRL). Cognitive interviewing is a qualitative question evaluation method used to evaluate the validity of survey questions (Willis 2005; Miller 2011). The main goals of the project were to: 1) assess respondents' interpretation of the survey questions, 2) identify any potential question response problems that could lead to response error in the survey data, and 3) identify any usability issues with the self-administered paper questionnaire. The following report summarizes the cognitive interviewing methodology and describes how data analysis was conducted. An overview of the findings is then presented, followed by a question-by-question review of the findings.

2. Methodology

Sampling and Respondent Characteristics

Testing took place in July, August and September of 2013, and included a total of 26 interviews across two rounds of data collection. The cognitive interview respondents were RCC or ADSC directors, which is the population the NSLTCP aims to survey.

Respondents were selected using a purposive sample. The goal of a purposive sample is *not* to obtain a statistically representative sample. Instead, the goal is to arrive at a complete understanding of the patterns of interpretation that are elicited by each item in the survey. This is achieved by targeting respondents who help us explore relevant issues that emerge in the course of data collection. In order to participate in the evaluation, each respondent had to be employed as a director of a residential care community or adult day service center. Respondents were recruited through a targeted campaign based on telephone and online directories. Potential respondents were identified and sent an advance letter explaining the NSLTCP cognitive interviewing project and alerting them to the fact that NCHS would be calling in an attempt to schedule an interview. The QDRL then called the potential respondents and scheduled interviews with RCC and ADSC directors who were willing to participate. During this recruitment call, respondents were screened over the telephone in order to confirm that they met the criteria for inclusion.

Table 1: Respondent Characteristics

| | Total | Percentage |
|---------------------|--------------|-------------------|
| <u>First Round</u> | | |
| RCC Director | 10 | 50% |
| ADSC Director | 10 | 50% |
| <u>Second Round</u> | | |
| RCC Director | 3 | 50% |
| ADSC Director | 3 | 50% |

All interviews were conducted off-site and not at the NCHS lab. They all took place at the respondent’s workplace, usually in the director’s office. Prior to beginning the interview, respondents filled out paperwork agreeing to be audio-taped. The interviewer then explained **the purpose of the NSLTCP**, described the study, and told respondents the manner in which the interview would be conducted. Interviews were designed to last 60 minutes. A \$100 token of appreciation was given to respondents at the conclusion of the interview.

Data Collection

Cognitive interviewing, as a qualitative methodology, offers the ability to understand the interpretive process respondents go through in order complete the **NSLTCP**. It is a method that allows the researcher to uncover respondents’ interpretations of items on the form and note where response error may have occurred. The National Study of Long-Term Care Providers RCC and ADSC questionnaires are designed as self-administered paper instruments. The respondents sat at a table (usually their desks) to take the survey, while the interviewer sat next to them to observe their actions for the usability component of this study. As the respondent proceeded through the questionnaire, the interviewer asked concurrent or retrospective follow-up questions (i.e., probes) designed to reveal respondents’ interpretation of each item and any problems they had in arriving at an understanding and/or providing

an answer. The interviewer also noted any difficulties – either observed by the interviewer or reported by the respondent – with questionnaire layout and format.

This cognitive interviewing study consisted of two rounds of data collection. The first round included 20 cognitive interviews and focused on question interpretations and questionnaire usability. Two versions of the RCC and ADSC questionnaires—Versions 1 and 2—were used during this round. After an initial seven interviews (see Table 2), NCHS’ Long Term Care Statistics Branch consulted with the QDRL to make minor changes to Version 1 that focused on the presentation of skip instructions. The remaining seven interviews in the first round used Version 2.

Table 2: Questionnaire Version Use by Round and Facility Type

| | <u>Version 1</u> | <u>Version 2</u> | <u>Version 3</u> | <u>Total</u> |
|---------------------|------------------|------------------|------------------|--------------|
| <u>First Round</u> | | | | |
| RCC Sample | 5 | 5 | 0 | 10 |
| ADSC Sample | 2 | 8 | 0 | 10 |
| <u>Second Round</u> | | | | |
| RCC Sample | 0 | 0 | 3 | 3 |
| ADSC Sample | 0 | 0 | 3 | 3 |
| <u>Total</u> | 7 | 13 | 6 | 26 |

Please note that below, in the question-by-question analysis section, the image presented alongside each question comes from Version 1. Version 1 of both the RCC and ADSC questionnaires are presented in whole in Appendices A and B, respectively; while Version 2 of both the RCC and ADSC questionnaires are presented in Appendices C and D, respectively.

Version 2 of the questionnaire was substantially modified following the first round of cognitive interviews by the Long Term Care Statistics Branch, in consultation with the QDRL. These modifications resulted in Version 3 of both the RCC and ADSC questions, which was used during the second round of cognitive interviews. These questionnaires are presented in Appendices E and F. The second round of cognitive interviews included six cognitive interviews in all, three with a RCC director and three with an ADSC director. This round focused on question interpretations and questionnaire timing, and was run in a slightly different way than the first round. These respondents were given the questionnaire and asked to complete it without consulting the cognitive interviewer. They were then timed, section-by-section (in order to determine the total time burden of the two NSLTCP questionnaires, information that is necessary for OMB clearance). Following the “time trial,” the cognitive interview proceeded using retrospective probing. The results of this time trail were communicated in a separate memo to the Long Term Care Statistics Branch, included below as Appendix G.

Method of Analysis

Data analysis proceeded according to the grounded theory approach (see Glaser and Strauss 1967), which does not aim to test existing hypotheses, but instead generates explanations of how respondents

complete the survey questionnaire and understand its questions. The process of analysis is a constant comparison of data in several steps. The first step occurs within the interview as the interviewer attempts to understand how one respondent has come to understand and answer each item on the questionnaire. Response error is identified in this stage of analysis. This level of analysis is illustrated through the use of respondent examples and quotes in the results section. The examples are designed to give readers a sample of how individual respondents understood and answered a question.

The second step in analysis occurs once the interview is over, and is a systematic comparison across *all* interviews. This level of comparative analysis reveals patterns in the way respondents complete the survey and understand the questions. It also identifies common difficulties with question interpretation and explanations for response error. This level of analysis is demonstrated not so much with specific examples, but with a discussion of the general patterns of interpretation that occur across multiple respondents.

The third level of analysis explores whether various patterns of interpretation (and response error) are more likely among certain groups of respondents, such as RCC directors versus ADSC directors.

The next section discusses results of the study in two parts. The first part begins with a discussion of overall findings from across the questionnaire. These themes are not explanations of how one question in particular functions, but rather, the themes identify patterns of interpretation that are prevalent throughout the instrument and among multiple questions. The second part is a detailed question-by-question account of how respondents interpreted specific items.

3. Results

General Findings

A number of general patterns of usability and interpretation emerged across the questionnaire from the cognitive interviewing data. The two major usability patterns were 1) confusion over the skip instructions, and 2) when and how respondents decided to leave answers or to answer using the numeral "0." While most patterns of interpretation were question-specific, one general pattern of response emerged, wherein respondents tended to guess or estimate counts.

Confusion over Skip Instructions: Simply stated, the respondents were far more likely to ignore the skip instructions presented following the survey questions and continue on than they were to follow the instructions. While this pattern could be observed in other places in the questionnaires (the questions on specialized dementia care starting with Question RCC15, and Question RCC29/ADSC25 on the use of a standardized tool to screen for cognitive impairment), it was particularly noticeable in the first seven questions of the RCC questionnaire and the first three questions of the ADSC questionnaire. In an effort to address this, the skip instructions were highlighted in red and moved to a more prominent position in Versions 2 and 3 of the questionnaires.

While this did change the respondents' behaviors to some degree, it appears that the larger issue has to do with the sheer number of skip (as well as other question) instructions. In general, it appeared as

those the respondents saw so many skip instructions, that they simply stopped paying attention to them. For example, this skip issue was much less prominent in the ADSC sample--whose questionnaire only had a total of four skips—as compared to the RCC sample whose questionnaire had 14 skip instructions.

Blanks and Zeroes

Across both samples and all three versions of the questionnaires, respondents repeatedly did not follow the instructions (usually found in question text or table headers) to enter “0” when the answer to a particular sub-question was in fact “nothing.” Instead, respondents tended to leave blanks instead of entering 0s, or more commonly, enter some 0s but leave other boxes blank. For instance the table below shows how three RCC respondents filled out the race question (Question RCC25)¹. If a respondent wrote in “0,” that will be noted in the table as a “0” in the cell. If a respondent wrote nothing and left it blank, that will be noted in the table as “BLANK”

Table 3: Three Example Respondents’ Answers for Question RCC25

| | <u>Example 1</u> | <u>Example 2</u> | <u>Example 3</u> |
|--|------------------|------------------|------------------|
| Hispanic or Latino | 25 | 3 | BLANK |
| American Indian or Alaska Native | BLANK | 0 | BLANK |
| Asian | BLANK | 1 | 41 |
| Black | 37 | 56 | 5 |
| Native Hawaiian or Other Pacific Islander | 0 | 0 | 0 |
| White | 38 | 40 | 54 |
| Two or more races | 0 | 0 | BLANK |
| Some other category... | BLANK | 0 | BLANK |
| Not reported | BLANK | BLANK | BLANK |
| Total | 8 | 30 | 37 |

This appears to be a random distribution of 0s and blanks. When probed, the respondents always indicated that the blanks meant 0. (In most cases the respondents then attempted to go fill in the 0s, but the cognitive interviewers stopped them in order to preserve the original response data.) What is interesting is that this blanks-for-0s phenomenon only occurred in table questions (such as the staff profile questions, Questions RCC23/ADSC18) or in “multiple-blank” questions such as the race one in the example above (again, Questions RCC25 and ADSC20). No respondent ever left one of the stand-alone open-answer questions (such as Questions RCC31 and ADSC27, on the use of wheeled mobility aids) blank.

What appears to be happening is that respondents are using the “0s” to help them keep track of their calculations and their place in the question. For instance, considering the first example in Table 3, the

¹ The data in this table comes from three RCC respondents in the first round of cognitive interviews. In order to preserve confidentiality, all of these respondent’s RCC populations have been normalized to total 100. So, if a respondent originally entered 5 in the “Hispanic or Latino, of any race” category, and had a total population of 25, in this example 20 (or $5/25 \times 100$) would be entered in the Hispanic or Latino cell.

respondent may have put a 0 in the middle of two present categories as a sort of place holder, as she was figuring out the number of white residents. Across all three examples above, the respondents did not fill in anything in the last category or categories. By the time they reached “not reported” or “some other category,” they had already reached their total population and did not need to spend any more time on this question. This calculation/place-holder logic would explain why no stand-alone questions were ever left blank, as the respondents had only one box to consider at a time.

Estimation of Counts

One last general response trend to mention is the way many respondents actually arrived at their answer in the counts and percentages questions. All the cognitive interview respondents were given information on what data the survey would ask for during both the recruitment and reminder phone calls. They were told they would be asked about their staff characteristics, the demographic characteristics of their residents or participants, and (in the case of the ADSC sample only) their finances.

During the interviews themselves, however, the respondents did not always consult this information to answer the questions—particularly in the age distribution and the finance questions (Questions RCC27/ADSC22 and ADSC8, respectively). Instead, they would estimate based on their memory and knowledge of the center’s population and finances, or (in the age case) they would scan the roster and quickly group respondents based on what age they thought they were.

Question-by-Question Analysis

Please note that throughout this report, questions will be introduced with the full acronym of their questionnaire (i.e. Question RCC1). Subsequent references to the question will be shortened using “R” for the Residential Care Community questionnaire (i.e. Question R1), and “A” for the Adult Day Service Center questionnaire (i.e. Question A1). The Version 2 question text and layout will be shown with the questions in this section (as well as in Appendices B and D). Versions 1 and 3 of the RCC and ADSC questionnaires can be found in Appendices A, C, D, and F respectively.

Questions RCC 1, and ADSC 1

1. Is this residential care community currently licensed, registered, listed, certified, or otherwise regulated by the state?

Yes
 No

IF YOU ANSWERED NO, SKIP TO PAGE 10, BOX A

1. Please indicate whether or not this adult day services center is ...

MARK YES OR NO IN EACH ROW

| | Yes | No |
|--|--------------------------|--------------------------|
| g. Licensed or certified by the State specifically to provide Adult day services | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Authorized or otherwise set up to participate in Medicaid | <input type="checkbox"/> | <input type="checkbox"/> |

IF YOU ANSWERED NO TO 1a OR 1b, SKIP TO PAGE 10, BOX A.

Reference Period

The respondents all appeared to either note the word “currently” in Question RCC1, or assume it in Question ADSC1, and answered about their facilities current state of affairs.

Core Question Interpretation

There was no observable variation in the interpretation of these questions across the respondents. Qs R1 and the first sub-question in A1 ask whether or not a facility is regulated by the state (or in the case of respondents in the District of Columbia, by the local government) via licensure, listing, or certification. Respondents across both types of facilities understood the question to be asking about a process of certification and annual recertification. A number of respondents also mentioned that a part of this process was random or infrequent inspection by the state authorities.

Usability and Response Difficulties

There was only one observable navigation issue with this set of questions, where one ADSC respondent wrote in “yes” instead of checking the box. The respondent indicated that she simple jumped in and didn’t read the instructions. As all respondents answered “Yes” to Q R1 and both part of Q A1, no respondents needed to follow the skip pattern.

Question RCC 2

2. At this residential care community, what is the number of licensed, registered, or certified **residential care beds**? Include both occupied and unoccupied beds.

Number of beds None

IF YOU ANSWERED NONE, SKIP TO PAGE 10, BOX A

Reference Period

The respondents all carried the previous reference period forward and answered about the current state of their facility.

Core Question Interpretation

There was little variation in the interpretation of this question, and most of the RCC respondents were able to answer this question immediately. Upon probing, one respondent noted that this information was salient as they just filled out their recertification paperwork the week prior to the interview. Another respondent noted she knew the number because they just had a bed open up, and this was one of the rare times where their number of available beds did not match their number of occupied beds. All in all, respondents appeared to act on a familiarity heuristic to answer this question.

However, one respondent was unsure at first whether or not to include the independent living beds that were also located (physically) in the same facility as her residential care community beds. She re-read the instructions at the top of the page and decided that she should not count the independent living beds.

Usability and Response Difficulties

No navigation issues were apparent with Question RCC2. One respondent (who was given Version 1 of the questionnaire) only had three licensed beds at his facility. He saw the skip and went to Box A on the last page of the questionnaire. He was then instructed to continue with the survey even though he would have been ineligible in the production run.

Questions RCC 3, and RCC 3a

3. Does this residential care community **only** serve adults with an intellectual disability or a developmental disability?

Yes
 No

IF YOU ANSWERED YES, SKIP TO PAGE 10, BOX A

3a. Does this residential care community **only** serve adults with severe mental illness? Please do not include Alzheimer's disease or other dementias.

Yes
 No

IF YOU ANSWERED YES, SKIP TO PAGE 10, BOX A

Reference Period

The respondents all carried the previous reference period forward and answered about the current state of their facility.

Core Question Interpretation

The variation in the respondents' interpretations of these questions centered on the specific diagnoses they considered. In Question RCC3, two decision points appeared to direct respondents' answers: if and

how they understood the terms “intellectual disability” and “developmental disability,” and whether or not they considered dementia to be either an intellectual or developmental disability. For the first decision point, a majority of the respondents expressed either discomfort or confusion regarding the terms intellectual and developmental disability. For instance, one respondent interpreted “intellectual” disability to be the same as a “mental” disability:

I’m thinking about mental disabilities. Are those the same as intellectual? But we do more than just that. We do physical disability too, we do mental, developmental...we do it all.

Another respondent who answered “yes,” explained her answer by saying that all of her respondents suffered from “mental disabilities.” When asked to explain, she said:

For example, two [of the residents] are just really old, and their family couldn’t take care of them anymore. When you get old, you start forgetting things.

Another respondent believed that a developmental disability was anything affecting one’s social skills, and indicated that all of his respondents had social issues. This respondent had never heard of the term “intellectual disability,” but thought it sounded derogatory.

The second decision point had to do with whether or not a respondent would consider Alzheimer’s disease and other dementias to be intellectual or developmental disabilities. For instance, one respondent explained why she answered “yes” by explicitly talking about dementia:

I feel as though dementia could be an intellectual disability. I know that these [intellectual] problems don’t necessarily pre-date the dementia. There are a lot of people who live here who were professors and really smart, but now that they have it [they experience intellectual issues].

While more respondents considered dementia to be either an intellectual or developmental disability, there were some respondents who didn’t. When explaining why she answered “no,” another respondent said:

Well, I have I don’t know what...I have adults with dementia. Yes? Is that a yes answer? I don’t think it’s developmental; it’s more of an old age development. I would be stuck with that, I don’t know what to put. They have a disability, but not a developmental disability. That’s just an old age development. So I guess it’s no.

Upon further probing, this respondent indicated that she did think that dementia was maybe an intellectual disability, but that it certainly was not a developmental one. She said that if the question just asked about intellectual disabilities, she probably would have answered “yes” instead of “no.”

In Q R3a, no confusion over whether or not to count dementia existed, as the question explicitly excluded it. However, there was some variation in the specific diagnoses the respondents considered to be a “severe mental illness.” Of the nine respondents who were probed about what diagnoses they

were thinking about, eight said schizophrenia or multiple personality disorder, three mentioned bi-polar disorder, and two noted general psychosis. Two other respondents did not know what to consider for severe mental illness if Alzheimer's and dementia were explicitly excluded. For instance, one of these respondents explained her "no" answer by saying:

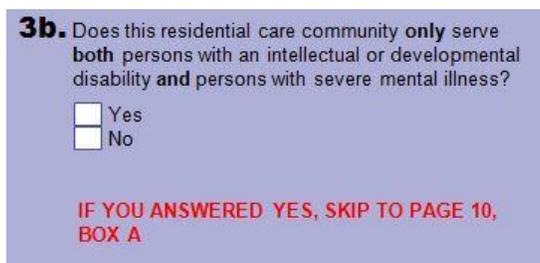
No, I have somebody with Alzheimer's but it said not to include that. So I don't know.

Additionally, all respondents across both questions correctly understood the instruction "only," and did not respond "yes" to the survey questions if they served residents who did not have either intellectual/developmental disabilities or severe mental illnesses, respectively.

Usability and Response Difficulties

There were numerous navigation issues with these two questions. In particular, although four respondents answered "yes" to Q R3, and one other respondent answered "yes" to Q R3a, only one of these five individuals followed the skip pattern directing them to the ineligibility statement in Box A on the last page of the questionnaire, and instead continued on to the next sequential question (either Q R3a or QR3b). Two iterations of these skip instructions were tested throughout the cognitive interviewing project. Version 1 of the questionnaire (seen in Appendix 1a) put the skip instructions next to the answer categories, whereas Versions 2 and 3 of the questionnaire (seen above and in Appendix 1b and 1c) put the skip instructions below the answer categories and emphasized the instructions in red. The one person to follow the instructions was given Version 2 of the questionnaire.

Question RCC 3b



3b. Does this residential care community **only** serve **both** persons with an intellectual or developmental disability **and** persons with severe mental illness?

Yes
 No

IF YOU ANSWERED YES, SKIP TO PAGE 10, BOX A

Reference Period

The respondents all carried the previous reference period forward and answered about the current state of their facility.

Core Question Interpretation

This question appeared to confuse most of the respondents. The two major sources of this confusion was the phrase, "...only serve both persons with..." and the fact that question seemed to ask the same thing as the previous two questions. For example, one respondent said:

What do you mean by most persons? I guess no, because we don't serve people who are mentally ill. Is that what you mean?

Others noted the redundant nature of the question:

It seems like it's repetitive. It just seemed to go up a notch [from the last two questions]. It just added more of the mental.

These points of confusion did not cause much observable variation in how the respondents interpreted and answered the question though. Overall, the respondents reasoned that if they did not say no to both Q R3 and Q R3a, they could not say "yes" to Q R3b. For instance, one respondent reasoned that:

I was thinking, the way I understand it, is that this is a condition in my policy, which it is not. My policy is that they have to be over 60 years old. I specialize in dementia, but I have many who don't have that.

Usability and Response Difficulties

Given the unclear wording and purpose of the question noted above, eight out of ten respondents receiving either Version 1 or 2 of the questionnaire had to re-read this question at least once. This question was eliminated from Version 3 of the questionnaire.

In addition to the confusion over the wording, this question also presented similar issues with navigation as noted above for Questions R3 and R3a. Two respondents answered "yes" to this question, and only one (who received Version 2 of the questionnaire) saw and followed the skip.

Question RCC 4

4. Does this residential care community provide or arrange for any of the following personnel to be on-site 24 hours a day, 7 days a week to meet any resident needs that may arise?

MARK YES OR NO IN EACH ROW

| | Yes | No |
|---|--------------------------|--------------------------|
| a. Personal care aide | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Registered Nurse (RN) or Licensed Practical Nurse (LPN)? | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Director or Assistant Director | <input type="checkbox"/> | <input type="checkbox"/> |

IF YOU ANSWERED NO to 4a, 4b, AND 4c, SKIP TO BOX **A ON PAGE 10. OTHERWISE CONTINUE.**

Reference Period

The respondents all carried the previous reference period forward and answered about the current state of their facility.

Core Question Interpretation

There was a slight amount of variation in the respondents' interpretations of this question, entirely centered upon the term "on-site." Most respondents understood this term to mean on the physical premises of the RCC's property. For instance, one director explained his thinking:

Well I have an assistant director, who helps me out with [his side business, which is unrelated to the RCC]. He's not necessarily here during the day, but I usual am. And he sleeps here. So there's someone on the property at all times. Either in this house or out back in the workshop.

Others applied an even tighter interpretation, understanding on-site to be in the RCC itself, not just on the property:

Well, I [the director] live here. Downstairs, I have an apartment. So that's on-site. There are also assistants who are around at all times. They don't live here, but there's always one on the night shift. But if anything happens in the evening, I come up!

However, a few respondents applied a broader definition of "on-site," understanding it to mean "always available" or "on-call." For instance, one director at a small facility in Maryland noted:

My house is four doors down the street. So I'm saying yes [to on-site]. I can be here in a minute.

Another director, this one of a small facility outside of Baltimore, explained her answer that all three types of personnel were on-site 24/7 by saying:

There might be someone physically here. People take shifts. But the nurse and I are always just a phone call away.

While the large majority of respondents used the more restrictive interpretations of "on-site," but there is a small potential for false positives due to this broader interpretation.

Usability and Response Difficulties

No respondents answered "no" to all three sub-questions, so there was no opportunity to observe whether the skip instructions preformed. However, all the respondents were observed reading the skip instructions and continuing after they determined that they did not apply.

Questions RCC 5, and RCC 5a

5. Does this residential care community offer help with activities of daily living or ADLs, such as help with bathing, either directly or arranged through an outside vendor?

Yes
 No

IF YOU ANSWERED YES, SKIP QUESTION 6

5a. Does this residential care community offer assistance with the administration of medications, give reminders, or provide central storage of medications?

Yes
 No

IF YOU ANSWERED NO, SKIP TO PAGE 10, BOX A

Reference Period

There was a small amount of variation in how the respondents perceived the reference period in Question RCC5. While most respondents appeared to follow the trend noted in the previous questions where they simply answered about the current state of their facility, two respondents mentioned actual or theoretical events in their facility's past. Both of these respondents expressed some confusion over the term ADL, as discussed below.

This variation was not observed in Question RCC5a, with all the respondents appearing to answer only about the current state of their facility.

Core Question Interpretation

There was a small amount of variation in the respondents' interpretations of Q R5. Almost all the respondents had either heard of activities of daily living or the acronym ADLs. A number of respondents noted that anyone in the field should know the acronym, for instance a director from a DC-area facility stated:

Anyone involved in healthcare should know what ADLs are—bathing, dressing, and so forth.

However, two respondents did note some confusion over the term. One respondent explained what she was thinking when answering the question said:

It's like going to the park or playing bingo. We've have bingo nights in the past, and sometimes we let them go to the park.

The other respondent who expressed confusion over the term explained that:

“Activities” sounds like fieldtrips or something like that. We don’t do that. Maybe we thought about something like that when we opened, but we don’t do that.

The two respondents who did not seem to use the standard definition of ADLs were the same ones whose reference periods extended into the past, as noted above. This is consistent with the expected cognitive process, as the respondents continued to search back through their history until they found something that matched their interpretation of the term “activities of daily living.”

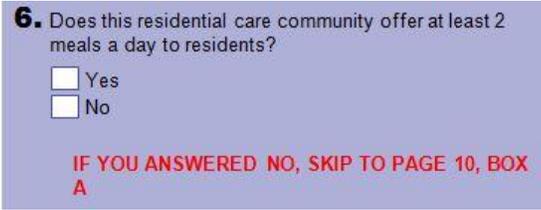
There was almost no variation in the interpretation of Q R5a (to which 8 respondents answered, though only 2 should have following skip logic). One respondent (who did answer “no” to Q R5) noted that all of his residents self-medicate. Upon retrospective probing this respondent did note that he provided central storage of the medication, thus his answer was a false negative. All of the other respondents noted that they offered some assistance—in the form of storage, reminders, or administration—and answered “yes.”

Usability and Response Difficulties

Through Versions 1 and 2 of the questionnaire, only 2 respondents of the 8 who answered “yes” to Q R5 followed the skip pattern directly to Question RCC6. The form of this question was changed substantially in Version 3 of the questionnaire, where Qs R5 and R5a were combined. All the respondents who received Version 3 appeared to read the skip pattern and continued on properly.

The one respondent who answered “no” to Q R5a did not correctly follow the skip to Box A on page 10, and instead continued with the survey.

Question RCC 6



6. Does this residential care community offer at least 2 meals a day to residents?

Yes

No

IF YOU ANSWERED NO, SKIP TO PAGE 10, BOX A

Reference Period

There was no variation in the reference period across the sample, with all respondents considering the current state of their facility.

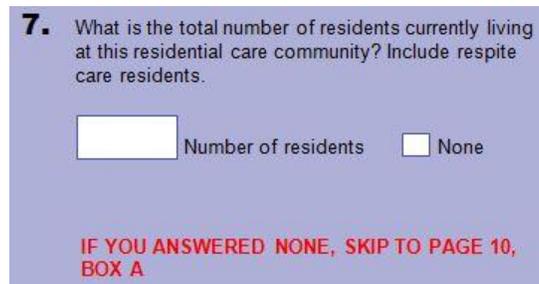
Core Question Interpretation

Likewise, there was no variation in the respondents’ interpretations to Question RCC6. All of the respondents thought about the number of prepared meals they provided their residents. The core construct of “meal” included only full meals, and not between-meal snacks.

Usability and Response Difficulties

All respondents answered “yes” to Q R6, so there was no opportunity to observe whether the skip instructions worked in this particular case.

Question RCC 7



7. What is the total number of residents currently living at this residential care community? Include respite care residents.

Number of residents None

IF YOU ANSWERED NONE, SKIP TO PAGE 10, BOX A

Reference Period

There was no variation in the reference period surrounding Question RCC7, with all the respondents considering the current state of their facility. One respondent seemed to question what the word “currently” actually meant in terms of question—thinking that it could range from the current state on the day of the interview to the average number across a time period such as the current year. In the end, this respondent applied the same pattern as the other respondents and recorded the number of residents on the day of the interview.

Core Question Interpretation

The respondents understood the core construct of “residents currently living at this RCC” to mean the number of currently occupied beds. Generally, the respondents appeared to answer this question through a heuristic, immediately knowing what their occupancy was at the moment. When asked how they knew the numbers so quickly, respondents indicated that many of the state forms they are required to fill out periodically ask a similar question. The number is also highly salient because they need to know it when ordering supplies such as food.

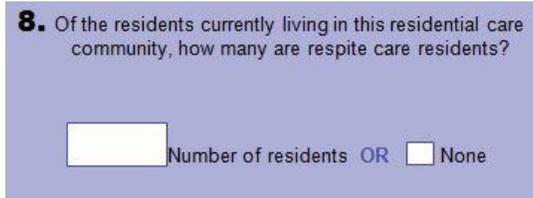
While most of the respondents knew this number off the top of their heads, a few of the larger RCCs’ directors had to consult their roster or their computer system to verify them. These respondents appeared to think in terms of *percent occupancy* instead of *number of residents*.

The second core construct in this question, “respite care residents,” is considered in more length below in Question RCC8. Suffice to say here that there was only minor variation in the interpretation of respite care, and that the respondents did include any respite care residents in their responses to Q R7.

Usability and Response Difficulties

There were no usability or response difficulties observed in this question.

Question RCC 8



8. Of the residents currently living in this residential care community, how many are respite care residents?

Number of residents OR None

Reference Period

The respondents, understanding Question RCC8 to be a follow up to Q R7, carried the reference period forward. All responded about the current state of their facility.

Core Question Interpretation

As noted above, the core construct in Q R8 is shared with the previous question (Q R7), and respondents used the same interpretation of “respite care residents” in both instances. While “respite care” appears to be a salient and commonly-understood term across RCC directors, there was a very small amount of variation in how the respondents defined it. Most respondents explained that it was a temporary living situation designed to allow an individual’s primary caregiver a break. For instance, one director explained:

Respite care are people on a temporary stay...it’s a contract you have with a client based on the need of that client.

A few other directors noted that respite care also functioned as a sort of marketing tool, where potential residents could see if they liked the facility on a “trial basis.” For example, another director noted:

It could be a few days; it could be a few weeks. People come here to give their families a break, or to see if they like the place.

Usability and Response Difficulties

Only one respondent had respite care respondents at the time of the interview. Others noted that they did not have any currently, but had accepted them previously. Of the rest, only two respondents checked the “none” box, with the rest writing in “0” or “none” (in two cases) in the blank.

Question ADSC 2

2. Based on a typical week, what is the approximate average daily attendance at this center at this location?

Average daily attendance of participants

None

IF YOU ANSWERED NONE, SKIP TO PAGE 10, BOX A

Reference Period

There is no clear reference period indicated in Question ADSC2, which asks respondents to report on a “typical week.” Though some respondents said they were thinking through the last few months before the interview to calculate an average, in practice, the vast majority of respondents primarily considered only the week of the interview.

Core Question Interpretation

The respondents widely understood the core construct of “average daily attendance” to mean the number of participants they have on any given day. While there was not much variation on the interpretation of the construct itself, there was some variation in how the respondents interpreted and came to an “average” as noted above.

Nearly all respondents noted that there was day-to-day variation in their participation numbers. Some participants were scheduled to be at the ADSC every day, while others were only slated to be there two or three times a week. Additionally, most of the directors indicated that they knew their daily ceiling of participation, but that there was always some percentage of no-shows.

With all of this potential variation, one might expect that the respondents would take extra time on this question. However, most respondents were able to immediately supply an answer to Q A2. When probed, most respondents explained that they were just doing a quick “guestimate,” and that they could take the time to think through a more nuanced answer if they thought it was necessary. Given this, the potential for false answers (in this case, over- or under-counts) is high.

Usability and Response Difficulties

There were no usability or response difficulties observed. Given the purposive sample for the cognitive interviews, all respondents had more than 1 participant in their ADSC. Therefore, no respondents were observed using the “none” box or following the skip pattern.

Question ADSC 3

3. What is the total number of participants currently enrolled at this center at this location?

Number of participants

None →

IF YOU ANSWERED NONE, SKIP TO PAGE 10, BOX A

Reference Period

All the respondents followed the reference period instruction in the question text and answered Question ADSC3 about the current state of their facility on the day of the interview.

Core Question Interpretation

Respondents understood this question as asking them the total number of people on their active roster. While the core construct in Q A3 is similar to that of Q A2 (total enrolment versus daily attendance, respectively), respondents did not employ the same heuristic in this question as they did in the last one. Here, instead of estimating, most respondents consulted their roster in order to provide a firm and accurate number.

Usability and Response Difficulties

There were no usability or response difficulties observed in Q A3. Like with Q A2, given the purposive sample, no respondents used the “none” box. Therefore no respondents applied the skip pattern.

Question ADSC 4

4. What is the maximum number of participants allowed at this adult day services center at this location? This may be called the allowable daily capacity and is usually determined by law or by fire code, but may also be a program decision.

Maximum number of participants allowed

Reference Period

While there was no explicit reference period given in the question text, all the respondents carried the previous one forward to this question, and answered about the current state of their facility.

Core Question Interpretation

There were two major interpretations of the core construct in Question ADSC4. Most respondents noted that their maximum capacity was set by company policy or staffing levels. For instance, one director noted:

110. This is corporate policy, but we never reach that number.

A few other respondents noted that their capacity was only constrained by the fire code, and that they could staff up if necessary. For example, one director in Maryland noted that their attendance was down in the last few months, so they had to cut staff. However, since they could physically handle more participants, if their participation increased again, they would re-hire those workers.

While this number was normally quite salient for the respondents, a couple did have to look it up. One respondent, who interpreted the number to mean the fire code capacity, actually went to look at the building occupancy sign to determine her answer.

Usability and Response Difficulties

There were no usability or response difficulties observed in Q A4.

Questions RCC 9, and ADSC 5

9. What is the type of ownership of this residential care community?

MARK ONLY ONE ANSWER

Private, nonprofit

Private, for profit

Publicly traded company or limited liability company (LLC)

Government—federal, state, county, or local government

5. What is the type of ownership of this adult day services center?

MARK ONLY ONE ANSWER

Private, nonprofit

Private, for profit

Publicly traded company or limited liability company (LLC)

Government—federal, state, county, or local government

Reference Period

All the respondents answered about the current state of their facility. A couple of respondents noted that ownership of the facility had changed in the past few years, but they still answered about the ownership at the time of the interview.

Core Question Interpretation

The interpretation of the core construct—“ownership”—was quite straight-forward. All the respondents understood Questions R9 and A5 to be asking about who owns the RCC or ADSC, and what form that ownership takes.

Usability and Response Difficulties

There was some apparent difficulty surrounding Qs R9 and A5s' answer categories. Some respondents, worked at an LLC (based on follow-up questions or observation), but answered "Private, for profit." Others indicated that they did not know if they were an LLC or even what an LLC was.

There are two issues contributing to these response difficulties. First, there is some (conceptual, at least) overlap between the "Private, for profit" and the "Publicly traded company...LLC" answer categories. As such, the answer categories make this a quasi-double-barreled question—asking about both public/private status and corporate structure.

Second, most of the respondents in the cognitive interviewing sample were not the businesses' owners, but rather just hired directors. This was especially true in the ADSC sample. While these directors may be somewhat familiar with the corporate structure of their facilities and the company/companies behind them, it appears as though a number may not familiar enough to answer this question correctly. It should be noted that the respondents who were both directors AND owners had no problems answering this question.

Questions RCC 10 and ADSC 6

10. Is this residential care community owned by a person, group, or organization that owns or manages **two or more residential care communities**?

Yes
 No

6. Is this center owned by a person, group, or organization that owns or manages **two or more adult day services centers**? This may include a corporate chain.

Yes
 No

Reference Period

Respondents carried the previous question's reference period forward to Questions RCC10 and ADSC 6, and answered about the ownership on the day of the interview.

Core Question Interpretation

Again, as seen above in Qs R9 and A5, there was no noticeable variation in the interpretation around the core construct of ownership. There was some variation in how the respondents approached this question depending on whether they received the RCC or the ADSC form.

As shown above, these two questions are actually slightly different across the two questionnaires, with the ADSC question including the instruction that, "This may include a corporate chain." The RCC question does not include this language, and a number of RCC directors (who worked at facilities owned by corporations) expressed confusion over how to answer. This confusion contributed to two divergent patterns of interpretation surrounding corporate ownership. Some corporate respondents answered

“yes” to Q R10, explaining that their corporation owned more than one facility. For example, one director noted:

It’s a national corporation; they own quite a few in this area too.

However, another respondent (who is the director of a facility in the same corporate chain as the previous example’s respondent) said “no,” explaining that:

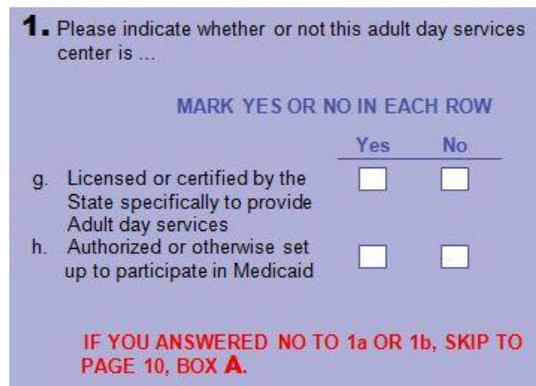
Well, I don’t know. I think I’ll have to say no because a person or a group doesn’t own it. A corporation does. I’m going to write corporation [in the questionnaire’s margin].

This divergence was not present across the ADSC sample, where the respondents received the extra instruction quoted above.

Usability and Response Difficulties

Besides the confusion over corporations in the RCC sample explained above, there were no other usability or response difficulties observed in Qs R10 and A6.

Question ADSC 1



1. Please indicate whether or not this adult day services center is ...

MARK YES OR NO IN EACH ROW

| | Yes | No |
|--|--------------------------|--------------------------|
| g. Licensed or certified by the State specifically to provide Adult day services | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Authorized or otherwise set up to participate in Medicaid | <input type="checkbox"/> | <input type="checkbox"/> |

IF YOU ANSWERED NO TO 1a OR 1b, SKIP TO PAGE 10, BOX A.

Reference Period

Though there is no explicit reference period given, the respondents all answered about the current state of their facility at the time of the interview.

Core Question Interpretation

There are two different, but related, constructs in Question ADSC 1—each presented in its own sub-question.

Licensed by State: Respondents noted that they were considering the annual re-certification process that they must go through to retain their operating license. The ADSC sample included facilities in the states of Maryland and Virginia, and the District of Columbia. While respondents across these

jurisdictions mentioned some different requirements by each of these three states, the process they were considering appeared to be quite comparable.

In addition to the state-level requirements, some respondents explained that there were county-level re-certification requirements. In these cases, the respondents appeared to be thinking about both sets of requirements interchangeably.

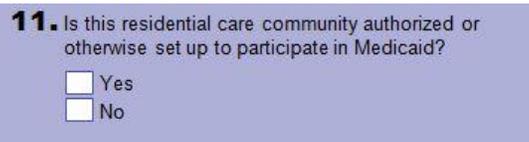
Authorized for Medicaid: Respondents understood sub-question A1a to be asking about the federal correlate of the previous sub-question about state licensure. Again, there was no variation in the interpretation of this construct, as all the respondents noted that there was a federal certification process with the Centers for Medicaid and Medicare Services. Most respondents noted that they only did this once, when the center was opened originally.

Those respondents who were not in their current positions when their center was certified for Medicaid based their answers on the fact that they were able to accept Medicaid money and participants, and therefore reasoned that they must be authorized to participate in the program.

Usability and Response Difficulties

All of the respondents answered “yes” to both sub-Questions A1a and A1b and continued on to Q A2. Thus, there was no opportunity to observe whether or not the skip pattern preformed correctly.

Question RCC 11



11. Is this residential care community authorized or otherwise set up to participate in Medicaid?

Yes

No

Reference Period

The respondents carried forward the reference period from Q R10, and answered Question RCC 11 about the current state of their facility at the time of the interview.

Core Question Interpretation

The interpretation of the core construct here—authorization to participate in Medicaid—emerged somewhat differently than it did for the ADSC sample in sub-Question A1b above. Whereas many of the ADSC directors answered “yes” to their Medicaid question if they believed they were *able to accept* Medicaid participants, most of the RCC respondents considered only if they *currently had* any residents who received Medicaid benefits. For example, one respondent explained her “no” answer by saying:

I am, but I don’t have any [right now]...I’m authorized, but all my people are on private right now. So how should I answer that?...I filled out the paperwork and said that I was

willing to take the subsidy, but I don't need to because of the waiting list. I never bothered. But if someone here is running out of money I won't send them away. So this is another hard one, I don't know how to answer it.

In the end, she decided that since she was not actively taking Medicaid money, the correct response was "no." Other respondents who answered "yes" noted that they believed they were taking Medicaid money from their residents, but did not remember filling out the paperwork.

A few respondents did interpret the question to be simply asking about their authorization to take Medicaid residents, regardless of whether or not they currently had any. For example, one respondent noted that while she did not have any residents who were paying with Medicaid money at the moment, she had enrolled the facility in the "Auxiliary Grant Program," which was a local program that used Medicaid funding. As a result, this respondent answered "yes" to Q R11.

Usability and Response Difficulties

The first, narrow interpretation of this question—whether or not a facility is currently taking Medicaid money—has a high potential for false negative responses. There were no usability issues observed in Q R11.

Questions RCC 12 and ADSC 7

12. During the last 30 days, how many of this residential care community's residents had some or all of their long-term care services paid by Medicaid?

Number of residents OR None

7. During the last 30 days, how many of this center's participants had some or all of their long-term care services paid by Medicaid?

Number of participants

Reference Period

Respondents generally reported followed the proscribed reference period—"the last 30 days." However, in practice they were thinking about their current situation, on the day of the interview. Many respondents consulted their rosters to answer this question. Since these rosters included only the enrolled population on the day of the interview, any RCC residents or ADSC participants who were no longer enrolled at the time of the interview (but were enrolled during the stated reference period) were not considered.

Core Question Interpretation

Like with the previous questions about Medicaid, there was again divergence between the ADSC and the RCC samples' interpretations of Questions RCC12 and ADSC7. In this case, most of the RCC respondents only considered the funds they received for this question: any Medicaid funding a resident might receive for some outside-the-RCC activity did not factor into the respondent's answer.

On the other hand, many of the ADSC directors attempted to include this outside funding into their answers. For instance, one respondent started to go through her roster to try and figure out what other Medicaid funding her participants might receive. In the end, however, this respondent (as well as all the others who tried to approach the question this way) decided that they did not know enough about the outside funding and only answered about the funds coming into the ADSC.

While both of these interpretations came to the same end point—with only the funding going to the facility in question being considered in Qs R12 and A7—the divergent process is important. Under the second pattern of interpretation, if an ADSC director did have enough information about his or her participants' outside funding; there is a possibility that they would include that information in their response.

Usability and Response Difficulties

While no usability difficulties or response errors were observed, the potential inherent in the second pattern of interpretation (as discussed above) might lead to response errors in general, and over-estimates in particular.

Questions ADSC 8

8. Of this center's revenue from paid participant fees, about what percentage comes from each of the following sources? Your combined entries for operating and non-operating revenue should add up to 100%. Enter "0" for any sources that do not apply.

| | |
|--|------------------------------------|
| <u>Operating revenue</u> | |
| a. Medicaid (including Medicaid managed care programs) | <input type="text"/> % |
| b. Medicare | <input type="text"/> % |
| i. Managed care organizations for persons who are dually eligible for Medicare and Medicaid | <input type="text"/> % |
| j. Veteran's Administration | <input type="text"/> % |
| k. Older Americans Act funding (including USDA Child and Adult Care Food Program, the National Family Caregivers Support Program, and the Home and Community Care Block Grant) | <input type="text"/> % |
| <u>Non-operating revenue</u> | |
| l. Other government (state, city, county funds) | <input type="text"/> % |
| g. Out-of-pocket payment by the participant or family | <input type="text"/> % |
| h. Private insurance | <input type="text"/> % |
| ii. Charitable donations | <input type="text"/> % |
| j. Grants | <input type="text"/> % |
| k. Fundraising contributions | <input type="text"/> % |
| l. Other source | <input type="text"/> % |
| TOTAL | <input type="text" value="100"/> % |

Reference Period

All of the respondents interpreted the question as asking about the current financial situation of their facility, and reported on their most up-to-date numbers. As discussed below, some respondents actually consulted their books to answer this question, while other respondents simply guessed. In the former case, the actual reference period might vary depending on the vintage of the data the

respondent consulted. For instance, if the respondent looked at a financial spreadsheet from the first of the month, the vintage of their data would change depending on when in the month they answered the survey.

Core Question Interpretation

By and large, there was very little variation in how the respondents understood the various types of funding presented in Question ADSC8. Many of the funding sources in this question are included on the various state and local accreditation forms the respondents already fill out on a regular basis. Three areas of confusion did emerge, however.

First, a number of respondents did not know what the difference between “operating” and “non-operating” revenue meant. In QA8, items a—h are found under the former heading, while Items i—l are found under the latter heading. When probed to see how they conceptualized the difference between these two types of funding, responses varied from “money we get from participants versus other sources,” to “money we use to pay for services on one hand, money we use to pay for staff on the other.” Most respondents simply said that they did not know and that they had ignored the headings and focused on the line items instead.

The second area of confusion is perhaps related to this distinction between “operating” and “non-operating” revenue, and deals with how respondents would allocate money between items f and j (“Other government...funds” and “grants,” respectively). Across the ADSC respondents, seven respondents allocated money to Item f, whereas only two allocated money to Item j. In each of these seven cases, the respondents described this money as state or local grants. When asked why they allocated the money to f, instead of Item j, the respondents were not able to describe the difference between these two types of funding. For example, one ADSC director said:

Yeah, I’m not really sure. I mean, we get grants from the state and we just got one from the county, so it’s government money. I guess I just saw this one first [Item f], but it would work here too [Item j]

The fact that respondents appeared to not differentiate between these two items is at least somewhat a result of their inability to differentiate between the operating and non-operating categories, and the fact that more respondents allocated to Item f than to Item j could be as much of an order effect as it is an actual description of the center’s financial situation.

A third, and relatively minor, source of confusion in the comprehension of QA8’s items was the Medicare option. A number of respondents questioned this category, noting that they were unaware that Medicare money was available for adult day care services.

Across all the items in QA8, two patterns of recall and judgment emerged. Directors of larger establishments tended to consult their records when answering the question—either by looking it up on a computer or by calling their business manager. On the other hand, directors of smaller ADSCs tended to simply think through the question, or perhaps consult their roster. This latter pattern of recall and

judgment clearly has potential for some response error. For example, one respondent who did not consult her books or her business manager unknowingly allocated her funding in such a way that her total was 101%, not 100%. In another case, a respondent realized that he was 5% short of 100%, and simply added the extra percent funding to the Personal Insurance category, saying “It probably goes here.”

Usability and Response Difficulties

The respondents were not alerted ahead of time that they would be asked about their funding sources. As such, and especially for those respondents who did not rely on guesswork to answer the question, this question took most respondents a few minutes to complete.

Questions RCC 13 and ADSC 9

13. Is this residential care community part of a continuing care retirement community?

- Yes
 No

9. A continuing care retirement community is a community that offers multiple levels of care such as independent living, residential care and skilled nursing care, and provides residents the opportunity to remain in the same community as their needs change. Is this adult day services center part of a continuing care retirement community?

- Yes
 No

Reference Period

All respondents answered the question about the current state of their facility on the day of the interview.

Core Question Interpretation

It is important to note that in the ADSC version of this question, a continuing care retirement community (or CCRC) was explicitly defined in the question text as “a community that offers multiple levels of care such as independent living, residential care, and skilled nursing care, and provides residents the opportunity to remain in the same community as their needs change.” The RCC version of this question did not provide a definition of a CCRC. Nonetheless, the core construct of “continuing care retirement community” was interpreted in two different ways across both the RCC and the ADSC samples.

The first pattern of interpretation that emerged was to consider this set definition of a CCRC or, in the RCC sample’s case, to consider a similar construct as this definition. These respondents focused on the idea of a “campus,” where residents or participants would move from one level of care to another depending on their needs while staying in the same general geographic location. Some of these respondents compared and contrasted their facility to others they knew to be in a CCRC. For instance, one RCC director noted that while they also offered independent living apartments in the same building as her RCC, she did not think that they had enough levels of care to count as a CCRC. However, she

noted that there were other facilities in her organization’s corporate structure that were set up as CCRCs.

The second pattern of interpretation is looser, and has a high potential for false negative and (especially) false positive responses to the survey question. Generally speaking, these respondents either do not know what a CCRC is (in the RCC case where there was no definition provided) or did not pay attention to or comprehend the definition of a CCRC (in the ADSC case). By either not sticking to or knowing the definition of a CCRC, these respondents used other clues to interpret this question—often by considering one or more of the words “continuing,” “care,” “retirement,” and “community.” For instance, one ADSC director explained her “yes” answer by saying that she thought “continuing care” was related to “supportive care,” which she said was an industry term that means providing alternatives to nursing homes and helps individuals “stay in their community.” A RCC director likewise focused on the word “community,” explaining her “yes” answer by saying that her facility helps people from becoming lonely.

Usability and Response Difficulties

There were no usability difficulties observed. As mentioned above, the second pattern of interpretation of “continuing care retirement community” can lead to response errors, and four respondents (two in each sample) gave false positive answers.

Questions RCC 14 and ADSC 10

14. What is the total number of years this residential care community has been operating as a residential care community at this location?

- Less than 1 year
- 1 to 4 years
- 5 to 9 years
- 10 to 19 years
- 20 or more years

10. What is the total number of years this center has been operating as an adult day services center at this location?

- Less than 1 year
- 1 to 4 years
- 5 to 9 years
- 10 to 19 years
- 20 or more years

Reference Period

Questions RCC14 and ADSC10 asked the respondents to determine how long their facilities have operated at their current location—a time frame that was obviously was not the same for all the respondents. As explained below, the respondents’ interpretations of “current location” were not steady, however, leading to even more variation than expected in the reference period across the sample.

Core Question Interpretation

There were two patterns of interpretation around the core construct of “current location.” Most respondents considered only the time their facility has been located at the same physical address as where the cognitive interview was conducted. For instance, one ADSC director explained his “10-19

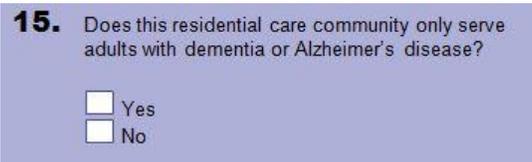
years” answer by saying that their current building was built 15 years ago, which was when they moved in. A few respondents who employed this interpretation not only considered only their current-as-of-the-day-of-the-interview address, but ownership as well. One ADSC director noted that he bought the company and facility in 2009. He explained that even though the facility was an ADSC before that, and that he had kept the old name, he only answered “1-4 years” because of the ownership issue.

The other interpretation focused only on the ownership, and did not consider the physical location of their facility. These respondents either ignored or did not comprehend the “...at this location?” phrase at the end of the question texts. For instance, one RCC respondent answered that she had been running the facility for 16 years. She later explained that the facility’s current building was only 9 years old.

Usability and Response Difficulties

There were no usability issues observed during the administration of either Q R14 or A10. Only one explicit response error was observed. A respondent appeared to miscalculate his answer to Q R14—he said they had been in their current location since 2002, but answered using the “5-9 years” answer category.

Question RCC 15



15. Does this residential care community only serve adults with dementia or Alzheimer's disease?

Yes

No

Please note that the skip instructions following this question changed between Version 1 and Version 2, and between Version 2 and Version 3 of the RCC questionnaire. Additionally, this question appears as Q RCC16 in the third version. All three questionnaires are presented in the appendices to this report.

Reference Period

All the respondents considered the state of their facility on the day of the interview.

Core Question Interpretation

There was very little variation between the respondents’ interpretations of Q R15. All but one respondent considered their facility roster and whether or not all of their residents had some form of dementia. Of the 13 RCC respondents, only three answered yes to this question.

One respondent who answered “no” to Q R15 appeared to understand the question to ask whether or not she *would* only take residents with some form of dementia, not whether or not she *did*. She explained:

I'm authorized to do this, and right now everyone has dementia. But I've had people without [it] before, and I'll do it again, so I'll have to say no...Because it's not my policy that I only take dementia. It just so happens that those people need it [long term care] the most.

So, even though at the moment of the interview all of her residents did indeed have dementia of some kind, she answered "no" interpreting the question to ask about policy, not about practice.

Usability and Response Difficulties

There were a number of usability issues observed for Q R15 (as well as the rest of the R15 series, including Questions RCC 15a, b, c, and d). Specifically, respondents did not follow the skip patterns, particularly those found in Version 1 of the RCC questionnaire.

As noted above, only three respondents answered "yes" to Q R15 (though there was at least one false negative). The table below crosses the responses with the questionnaire versions.

Table 4: Responses to Q R15 by Questionnaire Version

| | <u>Yes</u> | <u>No</u> |
|------------------|------------|-----------|
| Version 1 | 2 | 3 |
| Version 2 | 0 | 5 |
| Version 3 | 1 | 2 |

Version 1 of the RCC questionnaire presents skip patterns following each response, in blue lettering, with an arrow leading to the instruction. All three respondents answering "no" to Q R15 in Version 1 ignored the skip instructions and continued on to Q R15a.

Version 2 of the RCC questionnaire did not present any skip instructions.

Version 3 of the RCC questionnaire presented the skip instruction at the end of the question (again, in this version's case, Q R16). The instruction was emphasized in red lettering. Both of the respondents who answered no this question in Version 3 correctly followed the skip. Likewise, the respondent who answered "yes" in this version continued on correctly.

Questions RCC 15a, 15b, 15c, and 15d

15a. Does this residential care community have specially trained staff for residents with dementia or Alzheimer's disease?

Yes
 No

15b. Does this residential care community have a distinct unit, wing, or floor that is designated as a dementia or Alzheimer's Special Care Unit?

Yes
 No

15c. How many licensed beds are in the dementia or Alzheimer's Special Care Unit?

Number of beds OR N/A

15d. Does this dementia or Alzheimer's Special Care Unit have

No Special Care Unit

MARK YES OR NO IN EACH ROW

| | Yes | No |
|--|--------------------------|--------------------------|
| a. Higher staff-to-resident ratios compared to other units? | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Specially trained staff for residents with dementia or Alzheimer's disease? | <input type="checkbox"/> | <input type="checkbox"/> |

Reference Period

Respondents carried over their reference period from the previous question, and continued to consider the state of their facility on the day of the interview.

Core Question Interpretation

Across these four sub-questions, there was very little observable variation in how the respondents interpreted the various core constructs of "training," "distinct dementia wings or units," "licensed dementia beds," and "staff ratios." The variation that did emerge tended to be directly related to the skip pattern response errors noted above, with ineligible populations answering questions that did not relate to their situation.

Those respondents who correctly screened into sub-Question RCC15a all interpreted "training" to be state- or locally-required specialized training on Alzheimer's or dementia care. These respondents all noted that this was an annual training, and is based on (and teaches them about) current research and standards of care. On the other hand, those respondents who did not correctly follow the skip pattern in Q R15 or did not have skip pattern (in the case of Version 2), interpreted training in a slightly broader sense. These respondents still focused on the training they received about Alzheimer's and dementia care, though they were not thinking specifically of state- or locally-required courses. Instead, they mentioned online training and semi-regular seminars in which they could opt to participate. Please note that this sub-question was not included in the Version 3 RCC questionnaire.

There was even less variation in the respondents' interpretations of sub-Question RCC15b, even between those respondents who correctly screened into the question (those respondents who said they

did *not* only serve residents with dementia) and those who incorrectly screened into the question (those who did say they only served residents with dementia, but ignored the skip pattern in Q R15). All the respondents thought about a separate area of their facility—be it a wing, a section, or an entire floor—reserved solely for patients with dementia. The one complication was observed in Version 1 of the questionnaire with a respondent who should have skipped this sub-question because her whole facility was reserved for dementia residents. She noted her confusion, saying: “I’m not sure what to put, the whole building is for dementia care.” After looking back over the questions for a few seconds, this respondent noticed the skip instructions that she had previously overlooked and proceeded on to Question RCC16.

Again, with sub-Question RCC15c (16 b in Version 3 of the RCC questionnaire), the variation in the respondents’ interpretation was directly tied to the issues with skip patterns. Most respondents, noting in the previous sub-question that they had no distinct wing or floor for dementia patients, wrote “0” or checked the “N/A” box to answer Q R15c. However, two respondents instead wrote the total number of beds their facility had—reading this question the same as they had Q R2. Upon probing, all of these respondents explained that they had not read the question carefully, and did not see the “Alzheimer’s special care unit” limitation.

Most respondents either answered “no” to both items in sub-Question RCC15d, or checked the “N/A” box that was introduced in Version 2. The respondents all understood the question to be asking about staff in a specialized care unit. The only respondents to answer in the affirmative to this question were the directors of dementia-specific facilities, who should have skipped this question altogether. In these two cases, the respondents were answering about their entire staff, and not just the staff of a specialized unit within their RCC. Please note that this sub-question was not included in Version 3 of the RCC questionnaire.

Usability and Response Difficulties

As noted throughout the previous section, there were numerous usability difficulties surrounding the skip patterns in the sub-Question 15 series. The skip patterns presented in Version 3 of the form, which were presented below the questions and emphasized in red, worked and did not lead to any incorrect skips.

Questions RCC 16 and ADSC 11

| 16. For each of the following services, please indicate whether the service is... | | | | |
|---|--|--|--|--|
| | Provided ONLY by staff at this facility | Provided ONLY by outside vendors through arrangement. <i>Select this category if community staff arrange for an outside service vendor to provide this service. Please do not select if community staff only provide referrals.</i> | Provided by BOTH staff at this facility AND outside vendors. | Service NOT provided <i>Select this category if the service is not provided or if community staff only provide referrals</i> |
| a. Routine and emergency dental services by a licensed dentist | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Hospice services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Social work services—provided by licensed social workers or persons with a bachelor's or master's degree in social work, and include an array of services such as psychosocial assessment, individual or group counseling, and referral services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Any case management services—generally a process of assessment, planning, and facilitation of options and services for an individual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Mental health services—target residents' mental, emotional, psychological, or psychiatric well-being and include diagnosing, describing, evaluating, and treating mental conditions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Any therapeutic services—physical, occupational, or speech | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Pharmacy services—including filling of and delivery of prescriptions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Podiatry services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Skilled nursing services—must be performed by a RN or LPN and are medical in nature | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Transportation services for medical or dental appointments | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. Transportation services for social and recreational activities, or shopping | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

11. For each of the following services, please indicate whether the service is...

| | Provided ONLY by staff at this center | Provided ONLY by outside vendors through arrangement. <i>Select this category if center staff make arrangements for an outside service vendor to provide this service.</i> <i>Please do not select if center staff only provide referrals</i> | Provided by BOTH staff at this center AND outside vendors. | Service NOT provided <i>Select this category if the service is not provided or if center staff only provide referrals</i> |
|---|--|--|--|---|
| a. Routine and emergency dental services by a licensed dentist | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Hospice services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Social work services—provided by licensed social workers or persons with a bachelor's or master's degree in social work, and include an array of services such as psychosocial assessment, individual or group counseling, and referral services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Any case management services—generally a process of assessment, planning, and facilitation of options and services for an individual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Mental health services—target residents' mental, emotional, psychological, or psychiatric well-being and include diagnosing, describing, evaluating, and treating mental conditions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Any therapeutic services—physical, occupational, or speech | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Pharmacy services—including filling of and delivery of prescriptions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Podiatry services | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Skilled nursing services—must be performed by a RN or LPN and are medical in nature | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Transportation services for medical or dental appointments | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. Transportation services for social and recreational activities, or shopping | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. Daily round trip transportation services to/from this center | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Reference Period

All respondents considered the services their facilities offered on the day of the interview.

Core Question Interpretation

Across the sub-questions in Question RCC16 and Question ADSC11 (R18 and A14 on Version 3 of the two questionnaires), the respondents concurrently considered two dimensions—the scope of the services, and where that service was offered. These two dimensions correspond to the rows and the columns in the table, respectively. The greatest amount of variation in interpretation occurred in the first dimension, particularly in items c and d (social work and case management services), and items j, k and l (transportation services, please note that item l is only found on the ADSC questionnaire).

In the first case, a number of respondents noted that they considered social work and case management services to be equivalent. In most cases, when probed, they were able to distinguish them—often times using language from the question text (i.e. “licensed” and “counseling” versus “assessment”). However,

most respondents' immediate reactions were to combine these constructs. This conflation is probably due to the fact that most facilities—both RCCs and ADSCs—have outside social workers come in and perform both case management and traditional social work functions.

The transportation items also caused some confusion, leading to variation in the respondents' interpretations of the various categories. This was less of an issue in the RCC cases, though a couple of respondents did initially answer item j (transportation for medical appointments) in the affirmative, and then changed their answer when they came to item k. These two respondents both explained that they were thinking about more social activities, but then saw the next category and realized that medical and social activities were to be separated.

This issue of separating the various types of transportation was more noticeable in the ADSC questionnaire, where three sub-types of transportation were presented instead of the two in the RCC questionnaire. In particular, the most salient type of transportation services to the ADSC directors appeared to be the daily round trip to and from the facility—which was presented last in item l. A number of ADSC respondents answered in the affirmative to either items j or k before they saw item l, and went back to revise their responses to the previous transportation items. However, at least three ADSC respondents did not go back and revise their affirmative answers to items j or k. Upon probing, these respondents noted that they did not provide medical or social transportation, but that they had been thinking of daily round trip. The placement of the most salient form of transportation after less salient forms increases the probability of response errors, particularly false positives.

Besides the respondents' comprehensions of the various sub-questions in Q R16 and A11, the answer categories (or column headers, given the tabular form of this set of questions) also caused a small amount of variation. Generally, the respondents across both samples understood the columns to be asking whether or not they had staff members provide the service or whether or not they had non-staff members come in to the facility to provide the service. Across the whole cognitive interviewing sample, two respondents understood the answer categories to be asking about the physical location of the service—either in the facility or outside the facility.

One other area of confusion related to the answer categories was largely limited to the transportation items (again, items j and k in the RCC form and items j, k and l in the ADSC form). A number of respondents were unsure of where to place transportation provided by family members of either the residents or the participants. In most cases, these respondents eventually decided that family members counted as “outside vendors,” and therefore answered using the “Only outside vendors” or “Both” categories, depending on whether or not the facility also provided that particular service.

Please note that in Version 3 of both the RCC and the ADSC questionnaire, the case management item (item d in the previous versions) was dropped.

Usability and Response Difficulties

Besides the ordering and salience issues noted above with the transportation items, there were no usability or response difficulties observed.

Questions RCC 17 and ADSC 12

17. For about how many of the current residents does this residential care community manage, supervise, or store medications; administer medications; or provide assistance with self-administration of medications?

Number of residents OR None

12. For about how many of the currently enrolled participants does this center manage, supervise, or store medications; administer medications; or provide assistance with self-administration of medications?

Number of participants OR None

Reference Period

The respondents all considered their current rosters on the day of the interview.

Core Question Interpretation

Three patterns of interpretation emerged across both the RCC and ADSC samples for Questions RCC17 and ADSC12. The first and most common pattern was for respondents to consider all the various constructs in a *union*—thus considering the total number of residents or participants for whom the facility 1) manages/supervises/and stores medication, 2) administers medication, OR 3) provides assistance with self-administration of medication. In other words, these respondents considered all of these various constructs separately and combined the residents or participants who fell in these categories when determining their response.

The second pattern of interpretation was only used by two respondents—one from each of the RCC and ADSC samples. In this case, they considered the *intersection* of these concepts, and only counted residents or participants for whom they provided all of these various services. In the RCC case, this respondent ended up answering “0,” because although the facility helped manage and administer the medication, they did not have any residents who self-administered their own medication.

This leads into the third pattern of interpretation, which was for the respondent to consider only one of the five possible constructs (management, supervision, storage, administration, self-administration) presented in the question text. By far, the most common form of this pattern was for respondents to focus on the self-administration construct. This led to at least three false negatives (i.e. reports of “0”) and at least one under-count. For example, one RCC director provided an answer of “0.” When asked to explain, she said:

Well, we don't allow any of our residents to self-administer. That's a county and state rule, and we follow it. Plus, most of our patients have memory issues, so they wouldn't be able to self-administer even if they were allowed.

Follow up probing revealed that this director was not thinking at all about the other four possible constructs, and instead thought the question was simply asking about the number of residents who self-administer their medication.

Usability and Response Difficulties

There were no usability issues observed. As explained above, this question can function as a quintuple-barreled question, which increases the probably of response errors—particular undercounts.

Questions RCC 18 and ADSC 13

18. As a part of the admission process, does this residential care community screen residents for **depression** with a standardized tool or scale?

- Yes
 No

13. As a part of the admission process, does this center screen participants for **depression** with a standardized tool or scale?

- Yes
 No

Reference Period

The respondents were all thinking about their current admission procedures as of the day of the cognitive interview.

Core Question Interpretation

The respondents almost all understood this question as clearly asking not whether they used *any* screener or standardized tool during the admissions process, but one that specifically measured depression. Given this frame, two patterns of interpretation emerged. Most respondents thought only about scales or tools they themselves [the RCC or ADSC staff] used. For instance, a many ADSC directors noted that they used standardized scales during the admissions process—they specifically mentioned the “BIMMS” and the “MiniMental” tools. They all noted that these scales did not include elements about depression, and therefore answered the question in the negative.

While most respondents answered Questions RCC18 and ADSC13 thinking only about facility staff-administered tools, a number of directors—particularly RCC ones—considered the data they received from outside physicians during the admissions process. These respondents noted that they received health information about their prospective residents or participants from the patients’ doctors, and that this information typically included mental health diagnoses such as depression. A few of the respondents who considered this information from outside doctors answered Qs R18 and A13 in the affirmative. For example, one RCC director explained her “yes” answer by saying: “Well, we go to their doctors. They [the doctors] screen them with some tool and then tell us.”

On the other hand, the majority of respondents who considered the outside sources of depression information did not? believe that it counted towards Qs R18 and A13, since the facility did not administer the tool or scale directly. For instance, and other RCC director explained her “no” answer using the same logic as seen in the previous example:

We actually receive this information from their doctor when they are admitted. Their doctor or [healthcare] practitioner fills out a form and gives it to us. And obviously, we know who is on anti-depressants.

Given that respondents used the same logic to explain opposite answers using this pattern of interpretation, the possibility for response errors exists for Qs R18 and A13.

Usability and Response Difficulties

There were no usability difficulties observed. As noted above, the second pattern of interpretation of the core construct has a high potential for response errors.

Questions RCC 19 and ADSC 14

19. Please indicate whether or not this residential care community offers **disease-specific programs** for residents with the following conditions.

These programs may include one or more of the following services—education, physical activity, diet/nutrition, medication management, or weight management.

MARK YES OR NO IN EACH ROW

| | Yes | No |
|--|--------------------------|--------------------------|
| a. Alzheimer's disease and other dementias | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Cardiovascular disease (e.g., heart disease, stroke, high blood pressure) | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Depression | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Diabetes | <input type="checkbox"/> | <input type="checkbox"/> |

14. Please indicate whether or not this adult day service center offers **disease-specific programs** for participants with the following conditions.

These programs may include one or more of the following services—education, physical activity, diet/nutrition, medication management, or weight management.

MARK YES OR NO IN EACH ROW

| | Yes | No |
|--|--------------------------|--------------------------|
| a. Alzheimer's disease and other dementias | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Cardiovascular disease (e.g., heart disease, stroke, high blood pressure) | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Depression | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Diabetes | <input type="checkbox"/> | <input type="checkbox"/> |

Reference Period

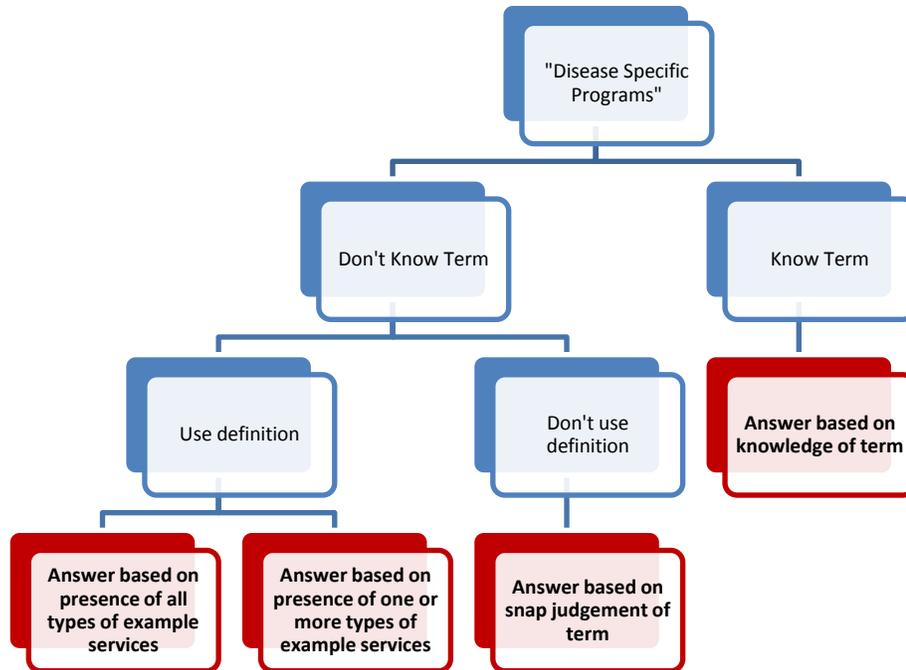
The respondents largely considered their current service offerings at the time of the interview, though due to the confusion over the core construct, explained below, a few respondents considered events or services they offered in the past. These retrospective considerations tended to be framed by specific residents or participants who were no longer at the facility, and ranged from a few months to two years in the past.

Core Question Interpretation

The term “disease specific programs,” as well as its accompanying definition, confused most of the respondents, and led to a large amount of variation in how they interpreted Questions RCC19 and

ADSC14. Two major decision points emerged from this question, each leading to multiple patterns of interpretation. The schema that emerged from the responses to these questions is shown below:

Figure 1: Cognitive Schema for Questions RCC19 and ADSC14



The first decision point that respondents came to was how to approach the term “disease specific programs,” which was bolded in the question text. The simplest decision here was whether or not the respondent actually knew this term, with a vast majority of respondents indicating that they did not. Those few respondents who did know the term simply answered the question based on their knowledge of the term. These respondents tended to interpret the term to mean an initiative or set (and often named or branded and advertised) program—a specialty in dementia care, for instance.

For the majority of respondents who did not know the term “disease specific programs,” they next decided to either answer the question immediately based on a snap judgment of the term itself, or proceed to the definition provided in the second paragraph of the question text. About half of the respondents who did not know the term followed each of these two paths.

In this first case, the respondents did not proceed to the definition and instead attempted to use their initial judgment of the term to answer the question. Because the term was bolded, and because the questionnaire up to this point had presented a number of industry-standard terminology (viz. “continuing care retirement community,” “respite care,” “case management services”), these respondents may have felt some sort of social desirability pressure to “know” this term even if they did not, and answer based on what they could immediately understand given the phrasing of the question. For instance, on ADSC director who answered “no” to all the various diseases explained her response by saying:

A disease specific program should have a strict protocol; there is a specific protocol or pathway to follow. We don't have such a thing.

However, when probed, she explained that they gave special, close supervision to the dementia patients. However, they aren't in a separate ward or area, so she did not think that this counted as a disease specific program. Likewise, she said the facility provides special diets to diabetes and heart disease patients, but that she didn't count those either. She went on to explain:

It says disease specific programs. And to me, that means that there is some kind of pathway, some written out plan. Where it says that every patient will get their blood checked every morning...whereas our nurses just [use] their better judgment on nutritional evaluation, on who needs their blood sugar checked.

Even though this respondent admitted that she did not know this term, and had not heard it as an industry standard, she interpreted it to mean something very strict and standardized—similar to how she knew the previously-presented industry standard terms were to be interpreted.

Those respondents, who did go on to consult the definition, approached this definition in two ways. Similar to what was observed previously with the medication assistance question (Qs R17 and A12), some respondents took the definition to require the *intersection* of all the examples given. Thus, an activity was only a disease specific program if it included education, physical activity, diet/nutrition, medication management, *and* weight management. Others understood the definition to simply require the *union* of the services—therefore a disease specific program includes *one or more* examples of education, physical activity, etc. For example of the first pattern, one RCC director noted that they did not offer any disease specific programs for dementia. When asked to explain why, she said:

Education. Education for whom? For the [dementia] patients? In almost all of our cases, that wouldn't make any sense.

Even though she went on to explain that they did provide many other services for their dementia patients, she felt as though she could not count it as a disease specific program because they were missing the education element.

On the other hand, an ADSC director explained why he answered “yes” for a diabetes specific program, by saying:

We do not offer disease specific programs for Alzheimer's, for cardiovascular disease, for depression. Now, for diabetes...again, I'd have to ask what you mean by that. We do administer insulin. We do have a registered dietitian. So we do modify diets for diabetics. Is that a program or not? Is that a disease specific program or not? It seems like it is according to this list [the definition statement].

In this case, the respondent understood the list to be examples and not requirements of a disease specific program, and was able to answer in the affirmative.

Usability and Response Difficulties

There were no usability difficulties observed in these questions. Given the large amount of variation in interpretation of what constitutes a “disease specific program,” the probably for response errors is quite high for this question—particularly false negatives, given the “or” statement in the definition. In addition to response errors, the confusion over this term leads to the respondents spending a disproportionate amount of time on this question.

Questions RCC 20 and ADSC 15

20. Does this residential care community review residents' life history, abilities, and interests when developing programs and activities?

- Yes
 No

15. On a regular basis, does this center create daily schedules based on each participant's life history, abilities, and interests?

- Yes
 No

Reference Period

The respondents were all thinking about their current policies at the time of the cognitive interview.

Core Question Interpretation

There was only a slight amount of variation observed with this question. Most respondents understood this question to be asking about whether or not they asked their residents' and participants' families and the participants themselves about their interests and abilities when creating schedules and activities. A number of RCC respondents mentioned their formal “care plans” or “service plans” when explaining their responses, though most people understood the question in a general and non-formalized sense.

The slight variation was largely confined to the ADSC directors. A few of these respondents understood the question to be asking whether or not they created *individual* schedules for each of their participants, and therefore answered Question ADSC15 “no.” Upon probing, all of these respondents explained that they did take the general interests and abilities of the participants into account when making the center-wide schedule, they simply did not create a different schedule for each participant. This pattern of interpretation will potentially lead to false negative answers.

Usability and Response Difficulties

There were no usability or response difficulties observed in these questions.

Questions RCC 21 and ADSC 16

21. On a regular basis, does this residential care community seek input from residents and their families into how the resident's room is decorated?

- Yes
 No

16. On a regular basis, does this center seek input from participants and their families into what personal care services are received by the participant?

- Yes
 No

Reference Period

The respondents all carried over the reference period from the previous question, and continued to answer about the current practice at the time of the interview. For practical purposes, the RCC directors' reference period was based on the last time they had an admission to their facility, while the ADSC directors were thinking about their annual reviews with their participants families and caretakers.

Core Question Interpretation

While Questions RCC21 and ADSC16 ask about different core constructs—room decoration and personal care, respectively—both were approached by the respondents in very similar ways. In the RCC case, the respondents were thinking about the process of bringing in a new resident to their facility, and how they facilitate that transition. All the RCC directors responded “yes” to Q R21, and most noted a very informal process for this consultation. Typically, they explained that they would have the family bring in mementos or other objects from the resident's previous house that would make the transition smoother for the new resident.

In the ADSC case, the respondents were thinking primarily of non-medical care, which they review with the participants' families or caretakers at annual status meetings. Specifically, the respondents mentioned the types of foods the participants liked to eat, and any new activities the families thought that they could incorporate into the center's schedule. Additionally, two respondents mentioned regular out-reach to the participants themselves—both through group meetings or “client councils” that were designed to provide a formal link between the participants and the center's management.

Usability and Response Difficulties

There were no usability or response difficulties observed in these questions.

Questions RCC 22 and ADSC 17

22. On a regular basis, does this residential care community give residents choices for each of the following?

MARK YES OR NO IN EACH ROW

| | Yes | No |
|---------------------|--------------------------|--------------------------|
| a. Meal times | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Where they eat | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Meal types/menus | <input type="checkbox"/> | <input type="checkbox"/> |

17. On a regular basis, does this center give participants choices for each of the following?

MARK YES OR NO IN EACH ROW

| | Yes | No |
|---------------------|--------------------------|--------------------------|
| a. Meal times | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Where they eat | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Meal types/menus | <input type="checkbox"/> | <input type="checkbox"/> |

Reference Period

The respondents were all considering their current policies at the time of the cognitive interview when answering Questions RCC22 and ADSC17.

Core Question Interpretation

Across the three core constructs in Qs R22 and A17—meal times, meal locations, and meal types/menus—there was almost no variation in interpretation across the two samples for the first two. Both RCC and ADSC directors thought about meal times as when they offered food to the residents or participants and whether or not they were required to eat at a specified time. Most directors answered “yes” to this question, indicating that while most meal times were set, there was flexibility if a resident or participant had need.

Similarly, there was no variation in how the directors understood the sub-question about meal locations, again considering where the food was served and whether or not their residents or participants could choose an alternative location. Again, those respondent who answered yes to this sub-question noted that meals were generally taken in set, common areas, but that there was flexibility based on the need or desires of the participants.

There were two distinct interpretations of the meal type/menu sub-question, however. When considering whether or not they offered flexibility in the composition of the meals some respondent considered only dietary restrictions, others considered dietary preference, while others considered both. Most respondents considered dietary restrictions—either alone or with dietary preference. For instance, when one ADSC respondent explained her “yes” answer to the type/menu sub-question by saying:

We have some clients who are vegetarian or who are diabetic, or who don't eat pork...so dietary restrictions, not just for health reason, but for religious reasons or whatever.

This was the common interpretation of dietary restrictions—respondents were thinking about both health restrictions (vegetarianism, low-sodium diets, etc) and religious restrictions (*kashrut* or “kosher” rules, *halal* and *haram* restrictions, etc).

Other respondents thought about dietary preference, such as which foods a resident or participant liked or did not like. The respondents commonly understood this to mean choices on a menu—such as offering two different main dishes.

Usability and Response Difficulties

There were no usability or response difficulties observed in these questions.

Questions RCC 23 and ADSC 18

23. For each category of staff listed below, please indicate the number of staff that currently work at this residential care community full-time and part-time. Please include:

- both full-time and part-time residential care community employees (an individual is considered a community employee if the community is required to issue a Form W-2 on their behalf), and
- other individuals or organization staff under contract with and working at this residential care community full-time and part-time.

| Current Residential Care Community Staff | | Number of Full-Time Staff If none, enter "0" | Number of Part-Time Staff If none, enter "0" |
|--|--|---|---|
| a. RNs | Residential care community employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |
| b. LPNs/licensed vocational nurses (LVNs) | Residential care community employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |
| c. Certified nursing assistants, nursing assistants, home health aides, home care aides, personal care aides, personal care assistants, and medication technicians or medication aides | Residential care community employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |
| d. Social workers—licensed social workers or persons with a bachelor's or master's degree in social work | Residential care community employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |
| e. Activities directors or activities staff | Residential care community employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |

18. For each category of staff listed below, please indicate the number of staff that currently work at this adult day services center full-time and part-time. Please include:

- both full-time and part-time center employees (an individual is considered a center employee if the center is required to issue a Form W-2 on their behalf), and
- other individuals or organization staff under contract with and working at this center full-time and part-time.

Please report either the number of full-time and part-time staff OR the number of full-time equivalent (FTE) staff, but not both, for the center employee category and the contract staff category. If this center does not have any staff for a specific category, enter "0" under the number of full-time and part-time staff.

| Current Center Staff | | Number of Full-Time Staff If none, enter "0" | Number of Part-Time Staff If none, enter "0" |
|--|--------------------|---|---|
| a. RNs | Center employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |
| b. LPNs/licensed vocational nurses (LVNs) | Center employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |
| c. Certified nursing assistants, nursing assistants, home health aides, home care aides, personal care aides, personal care assistants, and medication technicians or medication aides | Center employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |
| d. Social workers—licensed social workers or persons with a bachelor's or master's degree in social work | Center employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |
| e. Activities directors or activities staff | Center employee(s) | <input type="text"/> | <input type="text"/> |
| | Contract staff | <input type="text"/> | <input type="text"/> |

Reference Period

The respondents were considering their staff profile at the time of the cognitive interview.

Core Question Interpretation

There are three major classes of constructs the respondents had to consider across Questions RCC23 and ADSC18: Staff roles, staff schedules, and staff contracts. The first set of constructs—the roles, including RNs, LPNs, CNAs, social workers, and activity directors—are presented as the primary row headers. The second set of constructs—staff schedules—are presented in the questions as the column headers; while the third set—staff contracts—are the secondary row headers.

There was very little confusion or variation across the staff role constructs. Each of the five types of employees appeared to be common and salient terms. The one point of confusion appeared to be that the list of employee types was not exhaustive—for example, a number of directors wondered where they would be placed. While most of these directors simply excluded themselves from the profile, one placed themselves in the “activities directors” category and another two placed themselves in one of the nursing categories (based on their professional certification).

There was a slight amount more confusion and variation in interpretation in the second set of constructs. Primarily, respondents were unsure at first what to count as full- and part-time work, as no standard was given in the instructions. Given this lack of direction, the respondents simply applied a heuristic to these common terms and were quickly able to categorize their staff. However, upon probing (and as evidenced in the following questions, Questions RCC24a and RCC24b and ADSC 19a and ADSC19b), there was little consistency across the respondents as to what specific work schedule counted as either part- or full-time.

The largest amount of confusion was observed surrounding the third set of constructs. While the terms RCC/ADSC employees and “contract staff” appeared to be common and salient, upon probing there again was not a standard definition across the samples. For instance, one RCC director counted a RN who worked at the facility daily to be a contract employee. When asked why, the respondent explained: “Because I [the owner and director of the RCC] signed a contract with her, and she has agreed to it.” When asked whether she paid this employee via a 1099 type of arraignment [the IRS form used for contract work], she said no, this employee received a W-4 [the IRS form used for employee withholding, which is not used for contract work].

So, one pattern of interpretation surrounding the construct “contract staff” was whether or not they signed a contract, or were contractually required to show up to work. However, other respondents understood the difference between community/center staff and contract staff to be based on their tax obligations (as outlined in the question text). This first pattern of interpretation therefore increases the potential for response errors (particular over-counts of contract workers, and the subsequent under-count of community/center staff).

Usability and Response Difficulties

There were a number of usability and response difficulties observed across Qs R23 and A18. First and foremost, most respondents were observed *not* reading the instructions, or only partially reading the instructions. While there may be many reasons for this, one key thing to point out is that the questions’ instructions and definitions are located in four distinct areas—1) the immediate question text; 2) the bullet points underneath the question text; 3) within the row headers; and 4) within the column headers. Since completing a staff profile is something that the respondents already have to do during their annual recertifications, and in other state and local forms and surveys, they are probably less likely to read special instructions and try to figure out the answers without reading them.

Following from the respondents’ tendencies to not read or follow the specialized instructions, most respondents did not consistently enter “0” as requested in the categories where they had no staff. When the respondents did enter “0”s into the boxes, it seemed to be as a way of calculating their answers or keeping track of where they were on the form. Upon probing, all of the respondents noted that their blanks meant “0,” and were not missed answers.

Questions RCC 24a, RCC 24b, ADSC 19a, and ADSC 19b

Please indicate how many hours you consider to be part time and full time. Enter your answer in in the box to the right of the statement.

24a. Part-time staff can work a maximum of _____ hours per week.

24b. Full-time staff must work a minimum of _____ hours per week.

Please indicate how many hours you consider to be part-time and full-time. Enter your answer in the box to the right of the statement.

19a. Part-time staff can work a maximum of _____ hours per week.

19b. Full-time staff must work a minimum of _____ hours per week.

Reference Period

The respondents carried over their reference period from the previous question, and continued to answer about their current staffing.

Core Question Interpretation

The interpretations of the two constructs here—part-time work and full-time work—were consistent across both samples, as a heuristic division between people who work some of the time versus people who work all of the time. What was not consistent, as noted above, were the respondents' actual answers to the two sub-questions. The respondents all understood Questions RCC24a and ADSC19a to be asking about the ceiling of part-time work. However, a few respondents carried this interpretation over to Questions RCC24b and ADSC19b, and instead attempted to determine the maximum amount of time a full-time staff member might work.

Usability and Response Difficulties

Besides the above-noted difficulty where some respondents did not see the switch from “maximum” in sub-question a to “minimum” in sub-question b, there was a noticeable usability issue dealing with the presentation of these two questions. Specifically, the questions are formatted with both a line in the question and a box following the question. Because this was the only question on either questionnaire to use this format (with the question being a statement instead of an actual question), there was a large amount of confusion over what to do with the extra blank space. Some respondents simply wrote the answer twice—once in the blank and another time in the box. However, some respondents thought that the box represented a separate question. One RCC respondent who wrote “16” on the line and “4” in the box thought that he should put the time “the staff actually worked” in the box and the maximum on the line. One ADSC respondent thought that it represented the end points of a range, and wrote “10” on the line and “39” in the box, indicating that a part-time staff member worked anywhere between 10 and 39 hours a week.

Questions RCC 25 and ADSC 20

25. Of the residents currently living in this residential care community, how many are in each of the following categories? Count each resident only once. Enter "0" for any categories with no residents.

| | NUMBER OF RESIDENTS |
|---|----------------------|
| a. Hispanic or Latino, of any race | <input type="text"/> |
| b. American Indian or Alaska Native, not Hispanic or Latino | <input type="text"/> |
| c. Asian, not Hispanic or Latino | <input type="text"/> |
| d. Black, not Hispanic or Latino | <input type="text"/> |
| e. Native Hawaiian or Other Pacific Islander, not Hispanic or Latino | <input type="text"/> |
| f. White, not Hispanic or Latino | <input type="text"/> |
| g. Two or more races, not Hispanic or Latino | <input type="text"/> |
| h. Some other category reported in this residential care community's system | <input type="text"/> |
| i. Not reported (race and ethnicity unknown) | <input type="text"/> |
| TOTAL | <input type="text"/> |

NOTE: Total should be the same as provided in Question 7.

20. Of the participants currently enrolled at this center, how many are in each of the following categories? Count each participant only once. Enter "0" for any categories with no participants.

| | NUMBER OF PARTICIPANTS |
|--|------------------------|
| a. Hispanic or Latino, of any race | <input type="text"/> |
| b. American Indian or Alaska Native, not Hispanic or Latino | <input type="text"/> |
| c. Asian, not Hispanic or Latino | <input type="text"/> |
| d. Black, not Hispanic or Latino | <input type="text"/> |
| e. Native Hawaiian or Other Pacific Islander, not Hispanic or Latino | <input type="text"/> |
| f. White, not Hispanic or Latino | <input type="text"/> |
| g. Two or more races, not Hispanic or Latino | <input type="text"/> |
| h. Some other category reported in this center's system | <input type="text"/> |
| i. Not reported (race and ethnicity unknown) | <input type="text"/> |
| TOTAL | <input type="text"/> |

NOTE: Total should be the same as provided in Question 3.

Reference Period

All of the respondents were considering the current registered populations of their long term care facilities at the time of the interview.

Core Question Interpretation

There was very little variation across the nine race categories. Most respondents simply used a heuristics to assign their residents or participants to the various race or ethnicity categories. For example, when asked to explain why she knew she had 3 black residents, one RCC director answered, "Because I can count them." When then asked how she knew these three residents were indeed "black," the respondent answered, "well, I guess that's just what they are. I mean, I can look across the room and see black and white and Asian residents and staff."

The complex nature of proxy race reporting on surveys is dealt with extensively in the literature², but suffice to say here that there appeared to be three major ways the respondents "knew" the race of their

² See for instance Harris, D. R. (2002). "In the Eye of the Beholder: Observed Race and Observer Characteristics." University of Michigan Population Studies Center Research Report 02-522; Saperstein, A. (2006). "Double-checking the Race Box: Examining Inconsistency between Survey measures of Observed and Self-Reported Race." *Social Forces* 85 (1): 57-74.

residents or participants: based on phenotypes (as in the example above), based on self-report (usually on entrance forms or from physicians at the time of admittance), and based on language. In an example of this latter way, a director of an ADSC that largely served Asian participants differentiated his few black and white participants not by skin color, but rather by their native language. In fact, he wanted to further differentiate the Asian population, saying that most of his participants were Mandarin speakers, but that he had two Korean-speaking participants too.

The two categories that elicited the most confusion and comments were Categories g and h (“Two or more races...” and “Some other category...” respectively). A number of respondents explained that did not know how they were supposed to know whether their residents or participants fit into these categories instead of the more traditional race categories seen in Categories a-f.

Usability and Response Difficulties

There were no noticeable response difficulties in Questions RCC25 or ADSC20, with the exception of two people adding their boxes wrong and arriving at a number that did not match either Q R7 or A5. In both cases, the respondents noticed the reminder text following the question, and realized their mistake.

In terms of usability, most respondents continued to follow the pattern noted above in Q R23/A18, and only wrote in “0s” to help them calculate their answers. This was particularly noticeable in this question, as very few respondents had any responses outside of the traditional race/ethnicity categories found in sub-items a-f. Within those six categories, the respondents did tend to write in the “0” to indicate that no residents or participants at their facility were of that race/ethnicity. However, in the later sub-items (after the respondents had already calculated a total equal to Q R7/A5), the respondents tended to write in nothing, leaving the box blank. In every case upon probing, the respondents confirmed that the blank meant “0.”

Questions RCC 26 and ADSC 21

26. Of the residents currently living in this residential care community, how many are in each of the following categories? Enter “0” for any categories with no residents.

| | NUMBER OF RESIDENTS |
|-----------|----------------------|
| a. Male | <input type="text"/> |
| b. Female | <input type="text"/> |
| TOTAL | <input type="text"/> |

NOTE: Total should be the same as provided in Question 7.

21. Of the participants currently enrolled at this center, how many are in each of the following categories? Enter “0” for any categories with no participants.

| | NUMBER OF PARTICIPANTS |
|-----------|------------------------|
| a. Male | <input type="text"/> |
| b. Female | <input type="text"/> |
| TOTAL | <input type="text"/> |

NOTE: Total should be the same as provided in Question 3.

Reference Period

All of the respondents continued to consider their facilities' total enrollments at the time of the interview.

Core Question Interpretation

The respondents understood this question to be asking about the sex distributions of their residents or participants. There was no variation in their interpretations of this question.

Usability and Response Difficulties

There were no usability or response difficulties observed in the administration of Questions RCC26 or ADSC21.

Questions RCC 27 and ADSC 22

27. Of the residents currently living in this residential care community, how many are in each of the following age categories? Enter "0" for any categories with no residents.

| | NUMBER OF RESIDENTS |
|------------------------|----------------------|
| a. 17 years or younger | <input type="text"/> |
| b. 18-44 years | <input type="text"/> |
| c. 45-54 years | <input type="text"/> |
| d. 55-64 years | <input type="text"/> |
| e. 65-74 years | <input type="text"/> |
| f. 75-84 years | <input type="text"/> |
| g. 85 years or older | <input type="text"/> |
| TOTAL | <input type="text"/> |

NOTE: Total should be the same as provided in Question 7.

22. Of the participants currently enrolled at this center, how many are in each of the following age categories? Enter "0" for any categories with no participants.

| | NUMBER OF PARTICIPANTS |
|------------------------|------------------------|
| a. 17 years or younger | <input type="text"/> |
| b. 18-44 years | <input type="text"/> |
| c. 45-54 years | <input type="text"/> |
| d. 55-64 years | <input type="text"/> |
| e. 65-74 years | <input type="text"/> |
| f. 75-84 years | <input type="text"/> |
| g. 85 years or older | <input type="text"/> |
| TOTAL | <input type="text"/> |

NOTE: Total should be the same as provided in Question 3.

Reference Period

Again, all of the respondents continued to consider their facilities' total enrollments at the time of the interview.

Core Question Interpretation

The respondents all understood this question to be asking about the age distribution of the facility, based on their residents' and participants' ages on the day of the interview. There was no variation in their interpretations of Questions RCC27 or ADSC22.

Usability and Response Difficulties

There a few usability difficulties noted during the administration of this question. First and foremost, the data this question requests is not as easy to report as it may seem. Over half the respondents across both the RCC and ADSC samples did not have their residents' or participants' ages attached to their rosters, and had to answer the question going resident-by-resident down the list and grouping them according to the age categories given. This was less of an issue for the large or corporate centers who had computerized databases they could query.

Adding to this reporting difficulty was the age categories themselves. While the first two (17 and under; 18—44 years, respectively) were not difficult for the respondents (due to their relatively infrequency, and thus high salience); a number of respondents had difficulty with the categories as they were set up. These respondents appeared to want to use 0-9 decades (i.e. 50—59 years; 60—69 years; etc.) and a number had to go back and change their answers when they realized they had misclassified some of their residents or participants. A few directors noted that their annual reports to the state included similar age data, but used the 0—9 decades instead of the 5—4 decades presented in the questionnaire.

While, as noted above, a few respondents did catch their mistakes in misclassifying their respondents into the questionnaire's age categories, this format (and the resulting confusion) might have led to other non-observed response errors. These errors could lead to both over- and underestimates, depending on the misclassification.

Question ADSC 23

23. Of the participants currently enrolled at this center, how many live in each of the following places? Enter "0" for any categories with no participants.

| | NUMBER OF PARTICIPANTS |
|---|------------------------|
| a. An assisted living or similar residential care community (e.g., adult care or personal care residence) | <input type="text"/> |
| b. A private residence (house or apartment) | <input type="text"/> |
| c. A nursing home or other institutional setting | <input type="text"/> |
| d. Some other place | <input type="text"/> |
| TOTAL | <input type="text"/> |

NOTE: Total should be the same as provided in Question 3.

Reference Period

The respondents again considered their ADSC's currently enrolled participants at the time of the interview when answering Question ADSC23.

Core Question Interpretation

The respondents all understood this question to ask about where their participants lived. There was no variation around this core construct, with the directors all considering the places where their participants slept outside the ADSC.

On the other hand, there was a great deal of variation in across the four answer categories—Sub-items a—d. This variation stemmed specifically from where the respondents classified their participants who lived in “group homes.” Across the sample, these group homes were described as facilities that provide room, board, and basic care, and appeared to be distinguished from Residential Care Facilities by their level of care and programming. While the respondents all had consistent definitions of group homes, they did not classify these facilities consistently across the answer categories. Across the ADSC sample, the respondents placed these group homes in all the four answer categories except for the “nursing home or other institutional setting” one (Sub-item c). Most respondents put group homes into the first two answer categories (“assisted living or similar residential care community” and “private residence,” respectively).

Usability and Response Difficulties

Besides the clear variation noted above surrounding “group homes,” and the initial confusion that the respondents expressed when not seeing a group home category, there were no usability or response difficulties observed in the administration of Q A23.

Questions RCC 28 and ADSC 24

28. Of the residents currently living in this residential care community, about how many have been diagnosed with each of the following conditions?

NUMBER OF RESIDENTS

| | |
|---|----------------------|
| a. Alzheimer's disease or other dementias | <input type="text"/> |
| b. Intellectual/developmental disability | <input type="text"/> |
| c. Severe mental illness | <input type="text"/> |
| d. Depression | <input type="text"/> |

24. Of the participants currently enrolled at this center, about how many have been diagnosed with each of the following conditions?

NUMBER OF PARTICIPANTS

| | |
|---|----------------------|
| a. Alzheimer's disease or other dementias | <input type="text"/> |
| b. Intellectual/developmental disability | <input type="text"/> |
| c. Severe mental illness | <input type="text"/> |
| d. Depression | <input type="text"/> |

Reference Period

The respondents continued to consider their currently enrolled population at the time of the cognitive interview.

Core Question Interpretation

The respondents all understood this question to ask about the presence of the four diseases presented in Sub-Items 1—d across their current population of residents or participants. There was likewise no variation noted within the respondents' interpretations of these four diseases. The variation noted above in Q R3, where the respondents were unsure whether or not to include Alzheimer's disease and dementia as an "intellectual or developmental disability" was not present here in Question RCC28 or ADSC 24 as "Alzheimer's disease or other dementias" was implicitly separated from "intellectual/developmental disability" as it was presented as a distinct answer category.

There was variation in how the respondents (within both the RCC and ADSC samples) determined the number of residents or participants in each disease category. Most respondents only included the *diagnosed* number of residents or participants in each category. However, other respondents included the *observed* number of residents or participants in each category—that is people they suspected to have a particular condition based on their behavior or medication, and not on a formal diagnosis from a doctor as noted in their medical records. This pattern was particularly noticeable in the ADSC sample (where they have less total interaction with the participants than an RCC director has with her or his residents; and where they might not need to handle all of a participant's medications), and in the "depression" answer category (Sub-Item d).

Usability and Response Difficulties

There were no usability or response difficulties observed in Questions R28 or A24.

Questions RCC 29 and ADSC 25

29. Before or upon admission, does this residential care community use a standardized tool to conduct a formal assessment of its residents to identify anyone with a cognitive impairment?

Yes
 No

25. Before or upon admission, does this center use a standardized tool to conduct a formal assessment of its participants to identify anyone with a cognitive impairment?

Yes
 No

Please note that this question was removed from Version 3 of both the RCC and the ADSC questionnaires, and the findings presented below are limited to the 20 respondents who received Versions 1 or 2 of the two questionnaires.

Reference Period

The directors were all thinking of their facility's current policy at the time of the interview.

Core Question Interpretation

As seen above in Qs R18 and A13, which asks about the use of a standardized tool screening for depression, two major patterns of interpretation emerged around the phrase "using a standardized tool to conduct a formal assessment:" 1) administration by the facility's staff and 2) administration by an outsider, usually a physician. However, while in these previous questions the respondents were more likely to not consider assessments performed by doctors as counting towards a "yes" answer, in the case of Questions RCC29 and ADSC25, the trend is reversed.

Here, most respondents who answered "yes" to the survey question were thinking of a tool or scale administered by a physician or other doctor before admittance to the facility. In a few cases, the respondents were thinking both of this outside assessment combined with a less formal entrance interview that their staff conducts during the admission process.

Usability and Response Difficulties

Given that the relative frequency of the two patterns of interpretation flipped between this question and the previous one asking about a standardized tool or scale, the potential for response errors in either both Qs R18/A13 and R29/A25 is high. For instance, one ADSC respondent who explained her "no" answer to the depression scale question by saying that she got that information from a doctor, went on to explain her "yes" answer to the cognitive impairment scale question by (again) saying that she got the information from a doctor. When asked to explain her deviation, she responded:

Oh, I guess I don't know. That's just what I was thinking when I saw each of those questions. You're right, it doesn't make sense!

Besides this high potential for response error, no other usability or response difficulties were observed during the administration of this question.

Questions RCC 29a and ADSC 25a

29a. Based on this assessment, about how many of the residents currently ~~living in this residential care community have~~ been identified as having a cognitive impairment?

Number of residents OR N/A

25a. Based on this assessment, about how many of the participants currently enrolled at this center have been identified as having a cognitive impairment?

Number of participants OR N/A

Please note that this question was removed from Version 3 of both the RCC and the ADSC questionnaires, and the findings presented below are limited to the 20 respondents who received Versions 1 or 2 of the two questionnaires.

Reference Period

All the respondents who skipped into Questions RCC29a and ADSC25a carried their previous reference period over and continued to answer about their facility's current population on the day of the cognitive interview.

Core Question Interpretation

Three patterns of interpretation emerged around the respondents' understanding of the core construct of "cognitive impairment." The first, and most dominant pattern, was to equate cognitive impairment with Alzheimer's disease and dementia. For example, one ADSC director said that "there is 100% overlap between dementia and [cognitive impairment]."

The second most common pattern of interpretation was to consider the residents' and participants' actions, and not any specific diagnosis. Some respondents, for example, noted their participants' ability to problem-solve or do specific tasks such as reading. Others understood it to be related to the amount of care they had to provide. For instance, a RCC director explained that the 5 residents she considered cognitively impaired, "are not capable of being by themselves," and had to be observed constantly.

A third pattern, related to the other two, focused on normality. The respondents who employed this pattern explicitly described individuals with cognitive impairment as being outside-of-normal in one way or another. For instance, a RCC director explained the construct by saying that individuals with cognitive impairment have "less than full cognition." Likewise, an ADSC director explained that cognitive impairment was "something that prevents you from functioning normally. You know, people are sick, or they get older."

Usability and Response Difficulties

In Version 1 of both the RCC and ADSC questionnaires, respondents were instructed to skip Qs R29a and A25a if they answered “no” to Q R29/A25. None of the respondents who were supposed to skip Q R29a/A25a did, and the skip instruction was removed in Version 2 of the questionnaires. In its place, a “N/A” box was added next to the answer box in Q R29a/A25a. Of the two people who received Version 2 of the questionnaire and reported no participants with cognitive impairment (both were ADSC directors), both simply wrote in “0” and ignored the checkbox.

Questions RCC 30 and ADSC 26

30. Assistance refers to **needing any help or supervision from another person, or use of special equipment**. As a reminder, please provide answers only for the residential care portion of your campus.

Of the residents currently living in this residential care community, about how many now need **any assistance** in each of the following activities?

| | NUMBER OF RESIDENTS | |
|--------------------------------------|----------------------|----------------------------------|
| a. With eating, like cutting up food | <input type="text"/> | OR <input type="checkbox"/> None |
| b. With dressing | <input type="text"/> | OR <input type="checkbox"/> None |
| c. With bathing or showering | <input type="text"/> | OR <input type="checkbox"/> None |
| d. In using the bathroom (toileting) | <input type="text"/> | OR <input type="checkbox"/> None |

26. Assistance refers to **needing any help or supervision from another person, or use of special equipment**. As a reminder, please provide answers only for the adult day services center portion of your campus.

Of the participants currently enrolled at this center, about how many need **any assistance** in each of the following activities?

| | NUMBER OF PARTICIPANTS | |
|--------------------------------------|------------------------|----------------------------------|
| a. With eating, like cutting up food | <input type="text"/> | OR <input type="checkbox"/> None |
| b. With dressing | <input type="text"/> | OR <input type="checkbox"/> None |
| c. With bathing or showering | <input type="text"/> | OR <input type="checkbox"/> None |
| d. In using the bathroom (toileting) | <input type="text"/> | OR <input type="checkbox"/> None |

Reference Period

The respondents were all thinking about their currently-enrolled residents or participants on the day of the cognitive interview.

Core Question Interpretation

Across Questions RCC30 and ADSC26, there are four sub-questions that present separate constructs—aid with eating and drinking, aid with dressing, aid with bathing and showering, and aid with toileting. Within the interpretations of each of these four constructs there were different amounts and dimensions of variation.

Eating and Drinking

Across both the RCC and ADSC sample, there was very little variation in the respondents’ understanding of this sub-question (Sub-question a). By and large, they believed that this question was asking about

the number of residents or participants who needed physical help with eating—ranging from cutting food to assistance grabbing the correct utensils to physically feeding the participant. There was no observable variation across the two samples in terms of this interpretation.

Dressing

There was more variation in the interpretation of this construct. Most respondents understood the question to be asking only about physical help getting dressed. However, a few respondents were thinking about the number of people they needed to help pick out clothes or to remind to get dressed before going out or beginning their day. There was a noticeable difference between how the two samples considered this question. Simply put, it appeared to make more sense to the RCC directors, where dressing is an everyday task. Almost all of the ADSC respondents, on the other hand, noted that they only rarely had to help people get dress—usually because of some accident where soiled clothes had to be removed.

Bathing and Showering

Again, there was deviation between the RCC and ADSC samples, with the ADSC directors expressing more confusion than the RCC directors because showing and bathing were not common events at ADSCs and only happened because of accidents. There were two distinct patterns of interpretation of this construct across both the samples—physical help with bathing and showing, and observation of bathing and showering. Respondents tended to only consider one of these two interpretations. The former pattern tends to produce a smaller answer to the survey question than the latter pattern of interpretation. For example, one RCC director who was thinking only about physical help bathing noted they provided 40%³ of their residents assistance, while another director who was thinking about observation answered 100%, saying, “We watch everybody. We just don’t want anyone to fall.”

Toileting

While there was no major difference observed between the RCC and ADSC samples for this sub-question, a similar set of patterns of interpretation emerged here as the ones noted above with the bathing sub-question. Most respondents were considering only physical help toileting. However, a number of directors instead considered the number of residents or participants they observed using and/or reminded to use the restroom in their answer to this sub-question.

Usability and Response Difficulties

While there were no usability difficulties observed, it should be noted that most respondents across both samples “guestimated” their responses to Qs R30 and A26. While in some cases the directors were able to call their nursing staff to obtain counts, in most cases they simply browsed their roster or applied heuristic rules to their population (i.e. “I would say a little over half of our population needs help toileting, so [given a population of 100] I guess 60.”) to arrive at their survey answers. This, combined

³ Both respondents answered the survey question using whole numbers, and not percentages. They have been changed to percentages here for confidentiality purposes.

with the wide divergence of answers between the two interpretations of physical assistance and observation, leads to a high risk of response errors.

Questions RCC 31 and ADSC 27

31. Of the residents currently living in this residential care community, about how many use a manual, electric, or motorized wheelchair or scooter?

Number of residents

27. Of the participants currently enrolled at this center, about how many use a manual, electric, or motorized wheelchair or scooter?

Number of participants

Reference Period

The respondents all considered their currently-enrolled population on the day of the cognitive interview when answering Questions RCC31 and ADSC27.

Core Question Interpretation

The respondents by and large interpreted this question as asking about the number of respondents who used *scooters*. For example, one ADSC director answered “0.” Upon probing, she explained:

We don’t let them in here actually. We did for a while, and it seemed like everyone was getting them from Medicare or their insurance. But we don’t really have space, so I don’t allow them. They can use wheelchairs instead.

Most respondents similarly appeared to either ignore or (more probably) not see the word “manual” in the question text and instead latched on to the words “electric, or motorized.”

A few respondents did, however, buck this overwhelming trend and combined the total number of both motorized and non-motorized wheeled aids when answering the question. In these cases they were primarily thinking of manual wheelchairs and motorized scooters.

Usability and Response Difficulties

Only one respondent who received Version 1 of the two forms and reported having no participants use wheeled devices used the “None” checkbox—everyone else who reported having no participants simply wrote in “0.” The checkbox was removed in Version 2. There were no blank answers across any of the respondents.

There were no usability issues observed during the administration of these questions. As noted above, there were response difficulties noted, wherein the respondents only considered part of the question text.

Questions RCC 32 and ADSC 28

32. Of the residents currently living in this residential care community, about how many were discharged from an overnight hospital stay in the last 90 days? Exclude trips to the hospital emergency department that did not result in an overnight hospital stay.

Number of residents OR None

28. Of the participants currently enrolled at this center, about how many were discharged from an overnight hospital stay in the last 90 days? Exclude trips to the hospital emergency department that did not result in an overnight hospital stay.

Number of participants OR None

Reference Period

There was some variation in the reference period across the two samples. Some respondents attempted to follow the “last 90 days” instruction, and attempted to combine data across partial months. However, most respondents reported using the last two or three monthly reports they could produce. The effective reference period for Questions RCC32 and ADSC28 ranged from 68 days (two months and a week) to around 100 days (last three monthly reports plus the current month).

Core Question Interpretation

There was very little variation in the interpretation of this question—with the notable exceptions of the cases of response difficulties explained below. Generally, the respondents understood Qs R32 and A28 to be asking about the number of people who stayed overnight in a hospital during their reference period. As explained below, some people did include emergency visits in their estimates, but most did not and only counted non-emergency inpatient visits.

Usability and Response Difficulties

There were a number of response difficulties and errors associated with Qs R32 and A28. As seen in the previous question (R31/A27), a number of respondents did not read or fully comprehend the entire question text—with most of the difficulty stemming from the exclusion statement presented in the last sentence of the text (“Exclude trips...overnight hospital stay”). The most common type of error relating to this exclusion statement was to ignore it. For instance, one ADSC director who answered “1” explained that:

We took [a resident] to the hospital because she fell and we were worried she broke something. We took her to the ER right away, and she was back in a few hours.

A few other respondents ignored other parts of the question text. For example, when explaining what she thought the question was about, a RCC director said: “visits to the hospital that do not require an overnight stay.”

In addition to these response errors, a response difficulty also emerged that was specific to the ADSC sample. While all the centers’ policies state that they should be informed about when a participant goes to the hospital when they are offsite (officially, they are supposed to do a re-admission procedure upon hospital discharge), almost every ADSC director noted that they did not reliably receive this information.

Therefore, some answers from ADSC directors included off-site hospitalizations, while others did not. In either case the directors all assumed that the number they were providing was an undercount.

Questions RCC 33 and ADSC 29

33. Of the residents currently living in this residential care community, about how many were treated in a hospital emergency department in the last 90 days?

Number of residents OR None

29. Of the participants currently enrolled at this center, about how many were treated in a hospital emergency department in the last 90 days?

Number of participants OR None

Reference Period

The respondents all carried over their reference period from the previous question. Therefore, the effective reference period varied from just over 60 days to around 100 days.

Core Question Interpretation

There was no variation in how the respondents interpreted this question. They all believed that it was asking about the number of trips their residents or participants had to the emergency room during their reference period.

Usability and Response Difficulties

The same response difficulty that emerged for the ADSC directors in Q A28 was also present here in Question ADSC29. Given that they did not have reliable information on what happened to their participants off-site, the respondents all assumed that the count they provided for this question was an undercount.

Question ADSC 30

30. In the last 12 months, about how many participants were newly enrolled into this center? Count all participants who were newly enrolled—including participants who later died and participants who are no longer enrolled—regardless of the reason.

Number of participants OR None

Reference Period

The respondents all considered the past 12 months, and not the previous calendar year, when considering Question ADSC30. Respondents tended to consult the previous 12 monthly reports, so the

actual reference period varied from 12 months to 12 months and a few weeks, depending on the date of the cognitive interview.

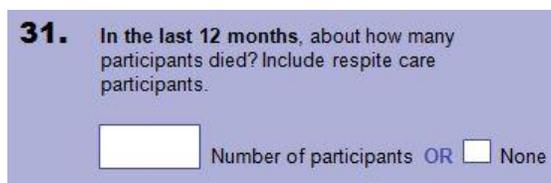
Core Question Interpretation

The respondents all understood Q A30 to ask about the number of enrollees their center gained over the last 12 months. In most cases, the respondents did not appear to even consider the inclusionary statements in the last sentence (about people who died and people who quit the program), as this was separate data in their monthly reports or databases.

Usability and Response Difficulties

There were no usability or response difficulties observed during the administration of this question. Almost all of the respondents consulted either a computer database or printed report when answering this question, while a few called either their nursing or finance departments.

Question ADSC 31



31. In the last 12 months, about how many participants died? Include respite care participants.

Number of participants OR None

Reference Period

The respondents, consulting the same data sources as they did in Q A30, carried over their previous reference period into Question ADSC31.

Core Question Interpretation

Most respondents clearly understood this question to ask about the number of their enrolled participants who died over the reference period. They all again consulted computer databases, reports, or nursing staff to answer this question.

The inclusionary statement “include respite care participants” confused some respondents and correspondingly affected their interpretation of the question as a whole. Two respondents thought the direction meant to include respite care participants *in addition* to the number of deaths. For instance, one director answered “12.” When asked to explain, he noted that three participants had left the center for a residential center and another nine had passed away while enrolled.

Usability and Response Difficulties

Besides the confusion over the inclusionary statement dealing with respite care participants, there were no usability or response difficulties noted in this question.

Question ADSC 32

32. In the last 12 months, about how many participants, including respite care participants, permanently stopped using this adult day services center? Exclude deaths.

Number of participants OR None

Reference Period

The respondents continued to consider the same data sources as they had for the previous two questions, and therefore carried over their various reference periods ranging from 12 months to almost 13 months.

Core Question Interpretation

The respondents all understood this question to mean the number of participants who had left their center for some reason other than death. They gave examples such as the family moving, financial issues, and discharge to hospice care.

Usability and Response Difficulties

There were no usability or response difficulties noted in the administration of this question during the cognitive interviews.

Questions RCC 34 and ADSC 33

34. An Electronic Health Record is a computerized version of the resident's health and personal information used in the management of the resident's health care. Other than for accounting or billing purposes, does this residential care community use Electronic Health Records?

- Yes
 No

33. An Electronic Health Record is a computerized version of the participant's health and personal information used in the management of the participant's health care. Other than for accounting or billing purposes, does this adult day services center use Electronic Health Records?

- Yes
 No

Reference Period

The respondents all considered their current records management system at the time of the cognitive interview when responding to Questions RCC34 and ADSC33.

Core Question Interpretation

Respondents largely understood this question to be asking about a computer system that stores, and allows them and their staff to manage, their residents' and participants' health records. Across the two samples, only four respondents answered "yes" to Question RCC34 or ADSC33. Of these three, one respondent explained that her facility sent out bills using a computer system (but that they did not store patient health records on the computer)—a false positive.

Of the respondents answering "no," one RCC director said she was thinking about doctors' and nurses' notes, and did not count the "patient records" that they do keep on a computer system. When asked what information was in these patient records, she said medication history, care history, and billing. In this case, it appears that the respondent decided that since her records management system included billing details, according to the exclusionary statement at the end of the question text ("Other than for accounting or billing purposes...") she should not count her database as an Electronic Health Record system.

Usability and Response Difficulties

Besides the one case of obvious response error noted above, there were no other usability or response difficulties observed during the administration of this question.

Questions RCC 35 and ADSC 34

35. Does this residential care community's computerized system support **electronic health information exchange** with each of the following providers?

MARK YES OR NO IN EACH ROW

| | Yes | No |
|--------------|--------------------------|--------------------------|
| a. Physician | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Pharmacy | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Hospital | <input type="checkbox"/> | <input type="checkbox"/> |

34. Does this adult day services center's computerized system support **electronic health information exchange** with each of the following providers?

MARK YES OR NO IN EACH ROW

| | Yes | No |
|--------------|--------------------------|--------------------------|
| a. Physician | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Pharmacy | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Hospital | <input type="checkbox"/> | <input type="checkbox"/> |

Reference Period

Respondents continued to think about their current computer and communications systems at the time of the interview when considering Questions RCC35 and ADSC34.

Core Question Interpretation

The traditional way RCCs and ADSCs have communicated confidential medical information with physicians, pharmacies, and hospitals has been via fax. As such, the respondents all understood this question not to be asking whether they used a computerized system to communicate with these medical providers, but rather whether or not they were still faxing medical records and requests to these providers.

However, simply not faxing did not appear to be enough to count as a “yes” for most of the respondents. When probed about the differences between these computerized communications systems and the faxing method, a number of respondents talked about easily accessible, two-way communication. For example, one ADSC director explained what she was thinking by saying:

It’s not just emailing either. It’s like a common server or something that we or the physicians can use and access patient records.

Likewise, another ADSC director explained:

It’s where a hospital can access our records and we wouldn’t have to send their [the participants’] medical records to them [the hospital]. Same thing with the physician and the pharmacy. We wouldn’t need to fax them the records.

This concept of remotely-accessible medical records was central to most of the respondents’ interpretation of the construct surrounding the phrase “electronic health information exchange.” In this way, a few respondents explicitly noted that emailing did not count as electronic health information exchange, as it was not openly accessible by both parties. It appears therefore that the key aspect of this term was not “electronic,” but rather “information exchange.”

Usability and Response Difficulties

There were no usability or response difficulties observed during the administration of Qs R35 or A34.