

## **Summary of Cognitive Tests of ATUS Eldercare Module**

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## I. Purpose

The American Time Use Survey (ATUS) is a nationally-representative monthly sample survey of households that measures how Americans spend their time. In the summer of 2009, the ATUS Eldercare Working Group began developing a set of summary questions about eldercare which would be administered following the time diary. In support of this effort, the Working Group held a series of caregiver focus groups to refine their understanding of the concept of *eldercare* and the activities it typically includes. The Group then developed a draft set of eldercare questions.

This report summarizes the results of a cognitive test of the eldercare module. The primary objective of this study was to evaluate how well the new questions capture the information sought, to explore participants' understanding of the questions, and to identify problems of question wording or particular concepts. The questionnaire was tested for clarity, comprehension, length, potential sensitivity, and the flow through the instrument.

## II. Methodology

### Participants

Two members of the Working Group conducted 26 cognitive interviews in two rounds (the first phase consisted of 17 interviews; the second phase consisted of 9 interviews). Participants were recruited from local care-provider organizations and a general-population database maintained by the Office of Survey Methods Research (OSMR)<sup>1</sup>. Altogether, eighteen of the participants had provided eldercare within the last three months, four had provided eldercare in the past (but not in the 3-month reference period), and four persons had no prior eldercare experience.

### Procedure

Most of the test sessions in the first phase of testing were conducted in the OSMR laboratory from March 16 – April 1, 2010. At the start of each session, the researcher explained the study's purpose and procedures, and obtained informed consent from the participant. The ATUS time diary and eldercare module questions were administered over the phone; all responses were recorded on paper by the researcher (calling from an adjacent room). Following the ATUS interview, the researcher returned to the testing room and asked participants general debriefing questions about the survey and retrospective probes on the new questions of interest. Most debriefing sessions were recorded in digital audio files. Nine of the test sessions conducted during phase 2 were done over the phone. Test sessions lasted approximately 45 minutes on average, and participants were paid \$40 upon completion of the study. (Two participants were BLS employees and received no compensation, nine of the test sessions were done over the phone and not eligible for compensation.)

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<sup>1</sup> The authors thank Stella Godbolt (OSMR) for her assistance with project recruitment.

### III. Phase 1 Results

The key findings from the first phase of testing are summarized below. These results are based on the mock ATUS interviews and debriefing sessions. With experimental, lab-based research, it is sometimes difficult to pick up the full range of target behaviors, and to get enough sample to answer the target questions about themselves. This is the main reason we conducted targeted recruiting from known care-giver organizations- to ensure that we could get sufficient coverage of the concepts. We were successful at bringing in a relatively diverse set of care providers (e.g., see Table 1, Appendix A). Certain groups were under-represented in the first round of testing - e.g., persons caring for someone living in a nursing home or other facility, persons living with the care recipient - so additional investigation of these populations was done in a second phase of testing to determine if there were unique issues related to their interpretation of, or reaction to, the eldercare questions.

#### Introductory Paragraph

*The next set of questions are about times you may have recently spent assisting or caring for an adult who needed help because of a condition related to aging. For example, as people grow older, it sometimes becomes difficult for them to perform various activities without help-such as grooming, driving, managing the household, taking medication or other common activities.*

Fourteen of the 17 participants in the first round said that they thought this introductory paragraph was clear and effective.

- Three of those people spontaneously mentioned that the examples provided in the text were helpful (e.g., “*they evoke the full spectrum of care-giving activities that I have had to do in my life. I really like this!*”).
- Two people said that they felt that the paragraph was too long and had “*an awful lot of things jammed in there,*” and another commented that there were other reasons (than aging) for providing care - particularly disease and injury.

#### *“Condition Related to Aging”*

Respondents generally understood this phrase as intended. They reported thinking of various ailments that are related to aging, including: Alzheimer’s, diabetes, diminished eye-sight and mobility, becoming weaker, getting older and losing independence/needing assistance, forgetfulness/senior moments, geriatric care, etc. Several people pointed out that these conditions may arise before one gets ‘old,’ due to early onset or accident.

Two participants had a fairly strong, negative reaction to the use of this phrase (though both conceptually understood it).

- “You’re going to miss a lot of people if you restrict this question only to ‘aging.’ There are a large number of rather young people who have severe, chronic illnesses. Three-fourths of my Well-Spouse Group care for someone under the age of 65. Couldn’t you just ask about care provided due to severe illness, injury, or disability?”
- “To exclude everything but age will give a false estimate. The media focuses on Alzheimer’s and ‘elderly’ issue - and the other things are ignored. It annoys me.”

### Q1

*Since the 1<sup>st</sup> of [fill month=3 months ago], have you provided any such care or assistance? It doesn’t matter WHERE you provided the care—at your home, at their home or at a care facility—but please exclude financial assistance and help you provided as part of your paid job.*

#### General Observations:

This question posed some difficulties, both for interviewers and respondents. First, the question was somewhat awkward to administer as intended. Several participants attempted to answer immediately following the question stem – before the interviewer could read the exclusions in the second sentence. Several other participants failed to hear (or recall) the question stem, and seemed instead to focus on the second sentence; the interviewer had to repeat the question for these participants.

Second, several participants misunderstood the phrase ‘*exclude financial assistance.*’ During debriefing they said that they interpreted this to mean that we did not want them to include activities such as bill paying, depositing checks, and other financial management assistance they provided their elderly caregiving recipients. One suggested that we explicitly add such activities to the examples provided in the introductory paragraph (e.g., *helping with personal finances*).

Third, perhaps because it was the last thing people heard, several participants focused unnecessarily (and mistakenly) on the exclusion “*as part of your paid job.*” In response to Q1, for example, one person said, “My paid job? What was that –can you repeat the question?” Another reported the care giving she did as part of her work as a home health aide, and said during debriefing that she thought the question had asked her to include such reports.

Fourth, as later revealed in Q2a, one person misinterpreted this question to mean care or assistance to any family member, regardless of age or condition. The debriefing revealed that she understood “an adult with a condition related to aging” as it was intended, (e.g., “geriatric care”), but was not thinking specifically about care provided for an adult with a condition related to aging when she answered this question.

## Noteworthy Reports:

Despite the aforementioned problems, Q1 (in combination with the introductory paragraph) ultimately was fairly effective in identifying individuals who had provided care in the last 3 months for a person because of a condition related to aging. The majority of our study participants had clear-cut care-giving situations, as noted earlier, but here are several noteworthy responses to this question:

- A 68 year old male respondent who cares for his wife (age 66) with severe Multiple Sclerosis in the home answered 'No' to Q1. Despite the fact that his care-giving responsibilities have increased as his wife aged and her condition worsened, he (correctly) did not view her condition as one related to aging.
- A 65 year old female participant lives in a co-op apartment complex with elderly neighbors. She reported providing care to four of her neighbors – mostly in the form of social companionship (“going and visiting with them, making sure they’re not too isolated”).
- A 63 year old respondent had a husband who was diagnosed with a neurological disorder similar to Alzheimer’s when he was in his 50s. She said that she would have reported “No” to Q1 because his condition “wasn’t related to aging –it was just bad luck.”

## “Providing Care or Assistance”

Respondents were asked what providing care or assistance means to them. Most people reported that it meant helping someone do things they aren’t able to do themselves, making sure they’re ok, giving medication, providing proper meals, grooming, driving them to a doctor, running errands for them, etc. Four people reported that talking and listening to people and providing companionship were providing care or assistance.

## Q1a

*How often did you provide this care? Daily, a few times a week, a few times a month, once a month or one time since the 1<sup>st</sup> of December?*

Most people did not evince a problem with this question, and during debriefing said that it was clear and easy to answer. However,

- One participant reported *a few times a week* during the ATUS interview, but said during debriefing that this question was somewhat difficult to answer because she cares for two people with differing needs and schedules. Her recipients have other care providers, too, so the amount and frequency of care she provides varies depending on their availability/need, as well as the recipients’ health.
- One participant said that he ‘*bristled*’ at the response options because he provided care five days a week (i.e., not *daily* and not *a few times a week*) and felt that the gap between these response options was too large.

## Q2.

*Since the 1<sup>st</sup> of [month=3 months ago], how many people have you provided this care to?*

No substantive problems were identified with this question.

## Q2a

*Who did you give this care to? (If Q2 > 1 and the R lists only one person, ask "Who else?")*

No substantive problems were identified with this question. Participants did not have difficulty identifying the relationship of their care recipient(s). About half of the respondents cared for their mother or father, several cared for a spouse, and the rest reported caring for a family friend or neighbor. [Interestingly, two participants identified their recipient as a "surrogate/adopted" father or mother. With the current choice options, these cases would be counted as "friend" or "other non-relative, specify".]

The answers to this question – and the related respondent debriefings – suggest that respondents do not feel they have to be related to or live with their care recipient in order to provide care. We interviewed only one long-distance care provider, but she at least was adamant that this should be counted as care. *"I was still very much involved in his life – calling doctors and administrators several times a week. I basically had a part-time job managing his affairs when he was in the nursing home."* Given that this is a single case, however, additional tests with this population would be warranted if time/resources allow.

It is also worth noting that respondents' answers to Q2a revealed for the first time that some misunderstood Q1. For example, as noted earlier, one participant who worked as a paid health aide initially reported providing care for three individuals in Q2, but Q2a revealed that one of those recipients was through her paid job. Another respondent reported providing care for three individuals in Q2, but in Q2a reported that two of those (incorrectly identified) recipients were her teenage daughter and niece.

## Q2b

*[Starting with your [fill first person listed in Q2a]], what was his/her age on [fill month=3 months ago] 1<sup>st</sup>?*

No substantive problems with this question. The average age of the care recipient was 78 years old.

### Q2c and Q2c1

*How long have you provided care to him/her? / How many years?*

In general, this question/these questions worked as intended and most respondents provided an answer with little difficulty. The participants were able to easily determine the length of time that they have been providing care. During debriefing it was discovered that many based their answer on a memorable life event – such as a stroke, or when the recipient moved into their home. Twelve of the thirteen participants who provided care said that they had done so for *more than one year* (with a range of 1 – 11 years).

- One participant indicated that this question was somewhat difficult because she knew each of her care recipients as friends prior to providing them care, per se. “*As they get older, they might need more specific help, and looking back early on it can be hard to disentangle what was help that was needed, and more me just being their friend.*”

### Q3

*Did you provide any care or assistance yesterday?*

No substantive problems with this question. Seven of the 13 respondents who said that they provided care in the last 3 months reported that they provided care ‘yesterday,’ as well.

### Q3a

*At which times or during which activities did you provide that care or assistance yesterday?*

This question generally worked as intended. Most respondents who were asked this question were able to go back and identify their care-giving activities.

It is worth noting that some respondents failed to report activities during the diary but mentioned them in response to this summary question. For example, in response to Q3a one respondent said she gave medication to her husband while she was grooming. Her original reported grooming time from the diary was 20 minutes. During the summary question, she said that about five minutes of that time was spent giving medication. Another participant initially had reported in her diary that she was “*in the waiting room at the hospital,*” and hadn’t indicated that she’d done any eldercare at all throughout the day. In response to Q3a, she said that her grandfather had arrived at some point in the afternoon and that she had helped him down to the cafeteria (because he is in a wheelchair) and assisted him with picking out food and eating it. The production ATUS diary would be able to accommodate such changes. Since this

may be a common occurrence, specific instructions should be given to interviewers to break out target activities like those identified in these two examples.

The only negative reaction to Q3a came from one participant who seemed confused and irritated with this question. He asked: "*How is this different from the diary? Didn't I just answer this?*" This respondent had broken out 8 to 10 activities in his diary report that he felt were pretty clearly care-giving activities (e.g., *giving her a bath, giving her medication*). The researcher conducting the session was not sure how to proceed – specific interviewer instructions will be required for this question.

#### Commonly Reported Activities:

The most common activity that respondents reported as *providing care or assistance yesterday* was preparing meals, and all of the respondents who lived with their care recipient identified this activity. One respondent who cared for her neighbor reported the times that she was visiting/talking with her neighbor as providing care or assistance. One respondent whose care recipient seemed to be in need of more help than the other care recipients reported all the activities that involved Hank, his care recipient, as providing care or assistance. Such activities involved watching TV and typing a letter to DC caregivers, in addition to preparing meals and giving him medication. In the follow up questions, he said that activities such as watching TV with Hank are providing care because he is keeping him company. Of the two respondents whose care recipients had home health aide visits on the diary day, both respondents identified the times when they were talking with the home health aide as providing care or assistance.

#### Q3b

*Sometimes people provide care or assistance while doing other activities. During which of the times or activities you just reported was providing care or assistance your main activity?*

Of the seven people who reported providing care yesterday, five had trouble with this question. One person actually thought the question was insulting since he said that everything he did was first and foremost providing care for his recipient. Others reported not understanding what was being asked, felt it was repetitive, or that it was difficult to answer because it was hard to divide up the activities when they were providing care.

One participant said that the relationship between the care giver and recipient will have an effect on how one views this question. He had a very strained relationship, so everything seemed like eldercare, with the exception of taking his grandfather to baseball games (which the grandfather enjoyed). From this participant's perspective, 'providing care' is equated with providing assistance that's necessary, not simply for enjoyment/optional.

Two other participants were able to provide specific times for *main* activities, but they did not differ from the initial diary reports – all of the care activities were *main* activities. During debriefing, one person said that he intentionally did not report 'normal household activities' – like laundry, grocery



shopping, etc. – as providing care or assistance because “*these are things that just have to be done; I don’t punch a clock, I just do them.*”

#### IV. Phase 1 Summary

In summary, the results of this study were encouraging. The bulk of the ATUS Eldercare module questions worked well in our cognitive test session. Participants generally liked the introductory paragraph and found the examples helpful. The initial screener question (Q1) was effective, despite posing some difficulties for both interviewers and respondents; we offer two alternative recommendations for revising this question, below. Q1a – which asks *how often did you provide this care?* – worked well for those who care for only one person, but may need to be revised to accommodate those who provide care to multiple recipients. Respondents had very little difficulty answering questions Q2 – Q3a (i.e., *How many people have you provided care to? – During which times/activities were you providing care yesterday?*), but Q3b (*During which of the times or activities you just reported was providing care or assistance your main activity?*) proved to be problematic for respondents, who found the question conceptually difficult and seemingly repetitive.

In addition, several people expressed concern that the focus of our questions was too narrow – that we’d miss important care-giving activities that were not specifically and/or solely related to a condition related to aging. Two participants in this study cared for “senior” (i.e., over 65 years old) spouses, but they did not view their spouse’s conditions as being related to *aging*, per se (one had been diagnosed with MS in her 50s, and the other had been afflicted with a neurological disorder in his late 50s).

#### V. Phase 1 Recommendations

##### Q1.

##### Recommendation 1:

Reword the introductory paragraph and Q1 so that the exclusionary language in Q1 comes before the question stem, and repeat explicit reference to ‘condition related to aging’ in stem, as follows:

**The next set of questions are about times you may have recently spent assisting or caring for an adult who needed help because of a condition related to aging. For example, as people grow older, it sometimes becomes difficult for them to perform various activities without help – such as grooming, driving, managing the household, taking medication or other common activities. Care may be provided in your home, their home, or at a care facility.**

**Q1: Not including financial assistance or help you provided as part of your paid job, since the 1<sup>st</sup> of [fill=three months ago], have you provided any care or assistance for an adult who needed help because of a condition related to aging?**

- No (Exit Eldercare Questions)
- Yes (Go to Q2)

Recommendation 2:

Keep the same introductory paragraph as above, but split Q1 into two parts – with an initial screener question that contains no exclusions, and a follow-up question that asks about paid work. Delete the financial assistance exclusion from this question altogether; add it as an on-screen interviewer note and cover in interviewer training.

**Q1: Since the 1<sup>st</sup> of [fill=three months ago], have you provided any care or assistance for an adult who needed help because of a condition related to aging?**

- No (Exit Eldercare Questions)
- Yes (Go to Q1\_pw)

**Q1\_pw: Was that care provided as part of your paid job, or something else?**

- No (Go to Q1a)
- Yes (Exit Eldercare Questions)

**Q1a.**

Recommendation 1:

Add an interview instruction that, in the event that the respondent volunteers that he/she cares for multiple individuals, the respondent should answer this question based on the recipient for which he/she provides the most care.

Recommendation 2:

Re-order Q1a and Q2 so that the interviewer knows how many care recipients the respondent has prior to asking about frequency of care. If there are multiple recipients, ask frequency question for each one separately.

**Q1a: Since the 1<sup>st</sup> of [fill month=3 months ago], how many people have you provided this care to? \_\_**  
[GOTO Q2]

**Q2: [If Multiple Recipients] Okay, let's take them one at a time. How often did you provide this care to the first person? Daily, a few times a week, a few times a month, once a month or one time since the 1<sup>st</sup> of December?**

- Daily



- A few times a week → (If multiple recipients, repeat Q2 for each one; else, Go to Q2a)
- A few times a month
- Once a month
- One time → (If multiple recipients, repeat Q2 for each; else if only 1 recipient, Exit Eldercare Questions)

### Q2a - Q3.

#### Recommendation:

Do not change these questions

### Q3a.

#### Recommendation:

Provide some interviewer instructions about how to assist respondents who have difficulty recalling the activities they reported in the diary.

### Q3b.

#### Recommendation:

Drop this question.

## VI. Phase 2 Results

The key findings from the second phase of testing are summarized below. Based on the recommendations from the first phase of testing, the introduction and first question were reworded for more clarity and to test the inclusion of a specific age cutoff, and question 3b was dropped. The second phase tested the revised version and focused on additional investigation of persons providing care to someone living in their home or in a nursing home to determine if there were unique issues related to their interpretation of, or reaction to, the eldercare questions.

#### Introductory Paragraph

*The next set of questions are about times you may have recently spent assisting or caring for an adult age 65 or older who needed help because of a condition related to aging. For example, as people grow older, it sometimes becomes difficult for them to perform various activities without help – such as grooming, driving, managing the household, taking medication or other common activities. Care may be provided in your home, their home, or at a care facility.*

Seven of the nine participants in the second round thought that the introductory paragraph was clear and effective. Two participants thought the introduction was too long. However, all of the participants thought the examples were helpful.

Reactions were mixed to the inclusion of a specific age cut-off. One respondent said that she felt that the cut-off helped draw a distinction between eldercare and caring for younger, disabled family members (the intended purpose of the age inclusion), but most respondents thought that 65 was an arbitrary – and too young – cut-off, and preferred that it be dropped from the introductory paragraph and Q1.

### Q1

*Not including financial assistance or help you provided as part of your paid job, since the 1<sup>st</sup> of [fill=three months ago], have you provided any care or assistance for an adult age 65 or older who needed help because of a condition related to aging?*

The revision to question 1 seemed to address the problems of the original question found during the phase 1 testing. The question was less awkward to read for interviewers, and seemed to be clear to respondents as compared to the original version. Two people with

- Two respondents whose spouses had Parkinson's disease did not think that Parkinson's was a condition related to aging.

### Q1a through Q3

No unique problems were found with the remaining questions during the second phase of testing.

## **VII. Conclusion**

The overall results of the study were encouraging. After additional testing of the revised questions, the ATUS Eldercare module questions worked well in our cognitive test session. However, the test underscored the need to have clear interviewer training guidelines and/or on-screen instructions about what constitutes care or assistance (e.g., is companionship *care*?), how to record frequency of care for multiple recipients, and the proper procedures for referring back to the diary to identify care activities or times. We also found that the inclusion of a specific age cut-off was problematic for a number of respondents. Although many said that “65” was a familiar benchmark, few felt that it was necessary or appropriate for questions dealing with eldercare. Because we collect information about care-recipients' ages, too, researchers can subset their analyses by age without a specific age reference in the question itself. We therefore recommend dropping that from the module.

Finally, the eldercare module took a reasonable amount of time to administer. For those who had not provided any care within the last three months, it took an average of 30 seconds to complete the module. For those who provided care within the past 3 months, but not yesterday, the questions took about 90 seconds to administer. When respondents reported care yesterday, the average administration took less than 5 minutes (the longest took 8 minutes).

## Appendix A

**Table 1. Test Participant Care-Giving Profiles**

Participant #	Caregiver Status	Frequency of Care	Provide Care Yesterday?
1	Provides care to “adopted father” (77) who lives in the household. “Adopted father” needs intensive care and is unable to do many things on his own. Has a home health aide who helps out. Care recipient is able to be left alone for a few hours, but respondent feels he can’t be left alone for a whole day without help.	Daily	Yes
2	Provides care to mother (83) who had a stroke in 2002. Mother lives with respondent and also has a home health aide.	Daily	Yes
3	Provides care to spouse (75) who had bypass operation in 2005. Care recipient is independent, but needs reminding to take medication and cannot prepare meals. Providing meals is care now because ever since his surgery, she obsesses over making sure he is eating correctly (makes everything from scratch, etc).	Daily	Yes
4	Provides care to father (72), and two of father’s friends (both 60). Care recipients are getting older and need help with preparing meals and driving them to places.	Daily	Yes
5	Provides care to neighbor (95) who is deaf and has osteoporosis. She checks up on him twice a day. Once a month she provides care to her friend’s father (80) who has cancer.	Daily	Yes
6	Provides care to “surrogate mother” (92) who is “fiercely independent”, but helps her take her medication, cook dinner, and take her shopping. Care recipient is living in nursing facility currently. She does not count the times she visits her in the nursing facility as care, more as doing her a favor.	A few times a week (when she provided the care)	No
7	Assists mother (96) with medications, listening to her, preparing meals, helping out with household (e.g., gardening)	A few times a week	No
8	Provides care for girlfriend’s mother (83) who had a stroke 7 years ago and a friend of the family (79) – cooking, taking them out shopping, movies, doctor’s appointments, giving medication.	A few times a month	No

Table 1, continued.

Participant #	Caregiver Status	Frequency of Care	Provide Care Yesterday?
9	Father-in-law (80) lives with respondent for three months out of the year (lives with other family rest of year). Father-in-law needs help driving, help with diet and exercise.	Daily (when providing care)	No
10	Husband (77) who had Alzheimer's since 1999 died in February. Helped husband with daily needs such as dressing, eating, and taking medication.	Daily (when husband was alive)	No
11	Not a care provider	N/A	N/A
12	No care provided during reference period, but extensive experience caring for both his grandfather (70s, dementia) and father (50s, Alzheimer's).	None now; daily when provided care	No
13	Father (68) has cancer -R helps with feeding etc.; grandfather (92) had strokes, incapacitated/in wheelchair -R assists periodically. (R also is employed as home health aide.)	Few times a week	Yes
14	Provides social stimulation, companionship, and light assistance for several elderly people (80s) in her building.	Few times a month	No
15	Provided care for her husband for seven years while he was dying of progressive neurological disorder similar to Alzheimer's. Part of that time he was living in house; then he moved into a nursing home in Canada. He died in December 2009, just before reference period started.	None now; daily when provided care in home; a few days a week when in facility	No
16	Not a care provider	N/A	N/A
17	Wife has had MS since 1996 (since she was in her mid-50s). R provides 24-hour care on the weekends; during the week he has help from 9AM - 5PM.	Daily	Yes
18	Not a care provider	N/A	N/A
19	Provided care to mother-in-law (90) before she went to live in assisted living. Sister now provides majority of care. Visits MIL occasionally but not in the three month reference period.	Daily (when providing care)	No
20	Provides care to father (89) who has Alzheimer's.	Daily	Yes
21	Wife (63) has Parkinson's which he didn't think was related to aging. However, provides care to mother and stepfather.	Several times a week	Yes
22	Not a care provider.	N/A	N/A
23	Provides care to mother and father. Father cannot drive himself anymore and mother is diabetic and requires insulin shots.	Daily	Yes
24	Care provider to spouse.	Daily	Yes

25	Provided care to spouse (no terminal illness or dementia).	Daily	No
26	Provides care to husband who has Parkinson's.	Daily	Yes

## Appendix B

### ATUS Eldercare Questions

#### Cognitive Interview Protocol

Instructions to CATI interviewers or programmer notes are in ALL CAPS (for future reference when the items are deployed).

*Cognitive interviewer questions and notes in italics:*

*Please note that the cognitive interviewing questions are suggested probes and may not be asked exactly as shown and extemporaneous follow-up probes will be used for unclear answers from respondents.*

*Since the ATUS is a telephone interview, the diary portion of the ATUS and the eldercare questions will be administered via telephone. The debriefing questions will be administered in person.*

Eldercare questions will be asked after the ATUS diary. (ATUS questionnaire is available at [/www.bls.gov/tus/tuquestionnaire.pdf](http://www.bls.gov/tus/tuquestionnaire.pdf).)

#### Participant Recruitment

- 4/5 Eldercare Provider Population, 1/5 General Population
- Number of cognitive interviews – 40
- During recruitment call, collect the following information (to see if sample is diverse):
  - Age
  - Race
  - Earnings
  - Education
  - From eldercare providers, ask type of limitation/condition care recipient has as well as recipient's age



- **Beginning of Cognitive Interview**

Introduction to respondent:

1. *Explanation of tasks*
  - a. *topic: go through a diary of what you did yesterday and then ask a few summary questions*
  - b. *evaluate questions, not you*
  - c. *need to know how people like you answer the questions, what you think when you hear certain terms and phrases, and how easy or difficult the question is*
  - d. *no wrong answer*
  - e. *ask a question, then ask follow-up questions after to determine how you arrived at an answer*
  - f. *for the follow-up questions, think back to your thoughts as you originally answered the question*
2. *General issues*
  - a. *confidentiality*
  - b. *voluntary*
  - c. *permission to tape*
  - d. *consent form*
3. *I'll leave now and call you on the phone. I'll have you on the speaker phone and there might be another person with me taking notes.*

## *Administer Diary*

### **S1: Introduction**

We will go ahead and start the interview now.

1. We are conducting a survey for the Bureau of Labor Statistics on how people in America spend their time. This information will help law makers understand how people divide their time between work, family and other demands in our fast-paced society.

### **S2: Household Roster**

1. What are the names (just the first) of all the persons living in your household? Please start with your name. I have you as [FILL NAME].
2. What is the name of the next person?
3. How is [FNAME]'s related to you?
4. Is anyone else living there now?

person ID	First name	Sex	Relationship	Age
1				
2				
3				
4				
5				
6				
7				

### S3: Time-use Diary

1. Now I'd like to find out how you spent your time yesterday, [yesterday's day & date], from **4 am yesterday morning to 4 am this morning**. I'll need to know where you were and who else was with you. If an activity is too personal, there's no need to mention it.
  
2. So let's begin. Yesterday, [previous weekday] at **4:00 AM**, what were you doing? What did you do next?  
IF PERSON MENTIONS THAT HE/SHE WAS DOING TWO OR MORE THINGS AT ONCE, ASK WHAT WAS THE MAIN ACTIVITY.
  
3. How long did you spend [ACTIVITY]?
  
4. ASK FOR ALL ACTIVITIES, EXCEPT:
  - SLEEPING (1),
  - GROOMING (2),
  - "PERSONAL" ACTIVITIES, AND
  - DK/REFUSAL.
  - WORK ACTIVITIESWho was with you? / Who accompanied you?
  
5. Where were you while you were [ACTIVITY]?

#### INTERVIEWER NOTES ON PROBING

- a. Probe for simultaneous activity: What would you say is your MAIN Activity?
  - (1) **If DP can estimate the time for each activity:** Record each activity on its own line in the diary
  - (2) **If DP cannot estimate the time for each activity but reports a MAIN activity:** Record the main activity first followed by a / and then the second activity
  - (3) **If DP cannot identify a MAIN activity:** Record the first activity mentioned followed by a / and then the second activity mentioned

## S4: Eldercare Questions

The next set of questions are about times you may have recently spent assisting or caring for an adult who needed help because of a condition related to aging. For example, as people grow older, it sometimes becomes difficult for them to perform various activities without help—such as grooming, driving, managing the household, taking medication or other common activities.

Q1: Since the 1<sup>st</sup> of [fill month=3 months ago], have you provided any such care or assistance? It doesn't matter WHERE you provided the care—at your home, at their home or at a care facility—but please exclude financial assistance and help you provided as part of your paid job.

- No → (Exit Eldercare Questions)
- Yes → (Go to Q1a)  
→

Q1a: How often did you provide this care? Daily, a few times a week, a few times a month, once a month or one time since the 1<sup>st</sup> of December?

- Daily
  - A few times a week
  - A few times a month
  - Once a month
  - One time → (Exit Eldercare Questions)
- } → (Go to Q2)

Q2: Since the 1<sup>st</sup> of [fill month=3 months ago], how many people have you provided this care to? \_\_  
[GOTO Q2a]

Q2a: Who did you give this care to? (If Q2 > 1 and the R lists only one person, ask "Who else?")

READ IF NECESSARY:

- Mother
  - Father
  - Spouse
  - Partner
  - Brother
  - Sister
  - Other Relative
  - Friend
  - Neighbor
  - Other non-relative, specify \_\_\_\_\_
- [GOTO Q2b]

Q2b: [If more than 1 person from Q2] **Starting with your [fill first person listed in Q2a], what was his/her age on [fill month=3 months ago] 1<sup>st</sup>?**

[If only 1 person from Q2] **What was his/her age on [fill month=3 months ago] 1<sup>st</sup>?**

- Years  
[GOTO Q2c]

Q2b2: **What was your [fill next person listed in Q2a]'s age on [fill month=3 months ago] 1<sup>st</sup>?**

- Years  
[GO TO Q2c]

Q2c: **How long have you provided care to him/her?**

- 0 to 5 months
  - 6 to 11 months
  - 1 year
  - More than one year
- } [If Q2 > 1 and there is at least one care recipient whose age has not been collected then GO TO Q2b2, else GO TO Q3.]  
[GOTO Q2c1]



Q2c1: **How many years?** \_\_\_\_\_

[If Q2 > 1 and there is at least one care recipient whose age has not been collected then GO TO Q2b2, else GO TO Q3.]

Q3: **Did you provide any care or assistance yesterday?**

- No (Exit eldercare questions)
- Yes → (GOTO Q3a)  
→

Q3a. **At which times or during which activities did you provide that care or assistance yesterday?**

Select activities from diary.  
Have all day option.  
(GOTO Q3b)

Q3b. **Sometimes people provide care or assistance while doing other activities. During which of the times or activities you just reported was providing care or assistance your main activity?**

Select activities from diary.

(Exit eldercare questions)

## Debriefing Protocol

Now I'd like to ask some follow-up questions.

The next set of questions are about times you may have recently spent assisting or caring for an adult who needed help because of a condition related to aging. For example, as people grow older, it sometimes becomes difficult for them to perform various activities without help—such as grooming, driving, managing the household, taking medication or other common activities.

Q1: Since the 1<sup>st</sup> of [fill month=3 months ago], have you provided any such care or assistance? It doesn't matter WHERE you provided the care—at your home, at their home or at a care facility—but please exclude financial assistance and help you provided as part of your paid job.

- No → (Exit Eldercare Questions)
  - Yes → (Go to Q1a)
- 

1. *What do you think of when you hear condition related to aging? Or, what does a condition related to aging mean to you?*
2. *Is there another phrase or term that you would use instead of “condition related to aging”?*
3. *Do you think other people will have trouble with this term? If yes, how so?*
4. *What age do you think of when you hear “adult” in this question?*
5. *What sort of care did you think of when you heard this question? What does “provided care or assistance” mean to you?*
6. *Do you think other people would think of this term in the same way?*
7. *What time period did you use? Was it easy or difficult for you to answer this question? How so?*

8. **Do you think a person needs to be living with you for you to say that one is providing care or assistance? Do you think the person needs to be living in his/her own home in order for one to provide care or assistance? Do you think that you have to be the only person providing care to a person in order for you to say that one is providing care or assistance?**[Possibly add vignettes here, instead of or in addition to these questions]

Q1a: **How often did you provide this care?**

- Daily
  - A few times a week
  - A few times a month
  - Once a month
  - One time
- (Exit Eldercare Questions)
- 

1. **How did you come up with your answer?**

2. **Was it easy or difficult for you to answer this question? If so, why?**

Q2: **Since the 1<sup>st</sup> of [fill month=3 months ago], how many people have you provided this care to? \_\_**

[GOTO Q2a]

*Probe if respondent showed signs of confusion or uncertainty – e.g., You seemed to hesitate when we got to that question. Can you tell me a little bit about what you were thinking when you answered this question?*

Q2a: **Who did you give this care to? (If Q2 > 1 and the R lists only one person, ask "Who else?")**

READ IF NECESSARY:

- Mother
- Father
- Spouse
- Partner
- Brother
- Sister
- Other Relative
- Friend
- Neighbor
- Other non-relative, specify \_\_\_\_\_

[GOTO Q2b]

*Probe if respondent showed signs of confusion or uncertainty – e.g., You seemed to hesitate when we got to that question. Can you tell me a little bit about what you were thinking when you answered this question?*

Q2b: [If more than 1 person from Q2] Starting with your [fill first person listed in Q2a], what was his/her age on [fill month=3 months ago] 1<sup>st</sup>?

[If only 1 person from Q2] What was his/her age on [fill month=3 months ago] 1<sup>st</sup>?

- Years  
[GOTO Q2c]

1. *How did you come up with your answer?*
2. *Was it easy or difficult for you to report your [FILL from Q2; Ex: mother's] age? If so, why?*

Q2c: How long have you provided care to him/her?

- 0 to 5 months
  - 6 to 11 months
  - 1 year
  - More than one year
- [If Q2 > 1 and there is at least one care recipient whose age has not been collected then GO TO Q2b2, else GO TO Q3.]  
[GOTO Q2c1]



Q2c1: How many years?     

[If Q2 > 1 and there is at least one care recipient whose age has not been collected then GO TO Q2b2, else GO TO Q3.]

1. *How did you come up with your answer?*
2. *Was it easy or difficult for you to report how long you've been providing care or assistance? If so, why?*

Q3: Did you provide any care or assistance yesterday?

- No (Exit eldercare questions)
- Yes → (GOTO Q3a)



1. *When you thought of yesterday, what time period did you think about? Probe for potential confusion over reference period.*
2. *If providing care or assistance to more than 1 person: Who were you thinking about when you answered this question?*

Q3a. At which times or during which activities did you provide that care or assistance yesterday?



Select activities from diary.

Have all day option.

(GOTO Q3b)

1. *How did you come up with your answers?*
2. *How difficult was this to answer?*
3. *Were there any activities that you were not sure about reporting or not? If so, why?*

**Q3b. Sometimes people provide care or assistance while doing other activities. During which of the times or activities you just reported was providing care or assistance your main activity?**

Select activities from diary.

1. *How did you come up with your answers? What does a “main activity” mean to you?*
2. *How difficult was this to answer?*
3. *Were there any activities that you were not sure about reporting or not? If so, why?*

**Additional probes:**

1. *What age range do you think of when you hear the term “eldercare”?*
  - *Do you think someone that is 50 and receives care would be receiving eldercare?*
2. *What types of activities did you think of when you heard “provided care or assistance because the person needed help...”? Are there activities that you wouldn’t normally think about as providing care or assistance?*

**Ask only for caregivers:**

1. *What types of activities do you think of as “providing care or assistance” that you didn’t already report or do yesterday?*
2. *Are there other activities that you did yesterday that you would include that are not already captured in the time diary? If so, what are those activities?*
3. **ASK IF RESPONDENT LIVES WITH CARE RECIPIENT:**
  - a. *How do you think about the times that the respondent is in the room with you?*
  - b. *Do you think of these times as “providing care”? Why or why not?*
4. *(If the care recipient is a spouse) Did you include any activities as “providing care or assistance” that you have always done for the person?*
  - a. *How do you think about the activities you have always done for your husband/wife (such as doing laundry, cooking)?*
  - b. *Why or why wouldn’t you count those activities as providing care?*
5. *Estimate number of hours for eldercare based on answers given.*
6. *According to your answers, you reported that you spent about XX hours providing care or assistance to an adult with an aging related condition yesterday. Do you think this is an accurate estimate? Why or why not?*

*Ask only for non-caregivers:*

1. **IF RESPONDENT IS MARRIED TO A PERSON OVER THE AGE OF 60, ASK:**
  - *Did you think of your spouse and care you may have provided him/her when answering this questions?*
2. *Have you had any non-work related contact yesterday with an individual who might be considered needing care because of a condition related to aging?*
  - a. *If yes, what type of care does this person need?*
  - b. *What type of contact did you have?*

***That is the end of the interview. Thank you so much!***