UnderStandingAmericaStudy

UAS 667: CAREGIVER QUARTERLY SURVEY



Survey author(s): Marco Angrisani Fielded February 10, 2025 - June 20, 2025

Contents

1	Introduction 1.1 Topics 1.2 Experiments 1.3 Citation	
2	Survey Response And Data2.1Sample selection and response rate2.2Timings2.3Sample & Weighting	
3	Standard Variables	6
4	Background Demographics	11
5	Missing Data Conventions	15
6	Routing Syntax	16
7	Survey with Routing caregiver	17 19 25 26 28 29 31

1 INTRODUCTION

This UAS panel survey, titled "UAS 667: Caregiver Quarterly Survey", asks about respondents' interactions with doctors and other providers, and also about how they are doing and how they feel they are perceived. This survey is no longer in the field.

1.1 Topics

This survey contains questions (among others) on the following topics: Health, Social Networks, Subjective Well-being. A complete survey topic categorization for the UAS can be found here.

1.2 Experiments

This survey did not include any experiments. A complete survey experiment categorization for the UAS can be found here.

1.3 Citation

Each publication, press release or other document that cites results from this survey must include an acknowledgment of UAS as the data source and a disclaimer such as, 'The project described in this paper relies on data from survey(s) administered by the Understanding America Study, which is maintained by the Center for Economic and Social Research (CESR) at the University of Southern California. The content of this paper is solely the responsibility of the authors and does not necessarily represent the official views of USC or UAS.' For any questions or more information about the UAS, contact Tania Gutsche, Project and Panel Manager, Center for Economic and Social Research, University of Southern California, at tgutsche@usc.edu.

2 SURVEY RESPONSE AND DATA

2.1 Sample selection and response rate

The sample selection for this survey was:

All active respondents who reported being informal caregivers in UAS634.

As such, this survey was made available to 2197 UAS participants. Of those 2197 participants, 2072 completed the survey and are counted as respondents. Of those who are not counted as respondents, 10 started the survey without completing and 115 did not start the survey. The overall response rate was 94.31%.

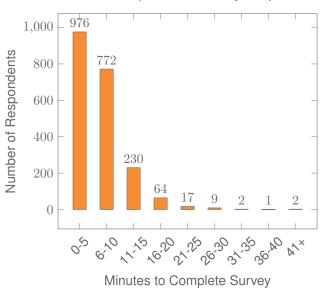
Note: We are unable to provide sample weights for a small number of UAS members (see the Sample and weighting section below for details). If they completed the survey, these members are included in the data set with a weight of zero, but accounted for in the computation of total sample size and survey response rate.%.

The detailed survey response rate is as follows:

UAS667 - Response Overview			
Size of selected sample	2197		
Completed the survey	2072		
Started but did not complete the survey	10		
Did not start the survey	115		
Response rate	94.31%		

2.2 Timings

The survey took respondents an average of 7 minutes, and the full distribution of survey response times is available in the figure below. Times per question are available upon request.



Distribution of Respondents' Survey Response Times

2.3 Sample & Weighting

Sample weights for this survey are computed following the general UAS Weighting Procedure. Specifically, we use a two-step process where we first compute base weights, which correct for unequal probabilities of sampling UAS members, and then generate final, post-stratification weights, which align the sample to the reference population along certain socio-economic dimensions. These are gender (male/female), race and ethnicity (White/Black/Other/Hispanic/Native American), age (18-39/40-49/50/59/60+), education (High school or less/Some college/Bachelor or more), Census regions (Northeast/Midwest//West, excl. CA/CA, excl. LAC, LAC). Benchmark distributions for these variables are derived from the 6 most recent available Current Population Survey (CPS) Basic Monthly Survey with respect to the survey's completion date. The reference population considered for the weights is the U.S. population of adults age 18 and older.

This survey dataset may contain respondents with a weight of zero. These respondents belong to a small group of UAS members for whom sample weights cannot be computed due to non-probability recruitment for special projects. Hence, while they are accounted for in the total number of survey respondents, they do not contribute to any statistics using sample weights. More information is available from the UAS Weighting Procedure. Please contact UAS staff with any questions.

3 STANDARD VARIABLES

Each Understanding America Study data contains a series of standard variables, consisting of individual, household and sample identifiers, language indicator, time stamps and a rating by the respondent of how much he or she liked the survey:

- uasid: the identifier of the respondent. This identifier is assigned to a respondent at recruitment and stays with the respondent throughout each and every survey he/she participates in. When analyzing data from multiple surveys, the 'uasid' can be used to merge data sets.
- **uashhid**: the household identifier of the respondent. Every member is assigned a household identifier, stored in the variable 'uashhid'. For the primary respondent this identifier equals his or her 'uasid'. All other eligible members of the primary respondent's household (everyone who is 18 or older in the household) who become UAS respondents receive the 'uasid' of the primary respondent as their household identifier. The identifier 'uashhid' remains constant over time for all respondents. Thus it is always possible to find the original UAS household of an UAS panel member (even after they, for example, have moved out to form another household).
- survhhid: uniquely identifies the household a UAS panel member belongs to in a given survey. For instance, if the primary respondent and his/her spouse are both UAS members at the time of a given survey, they both receive the same 'survhhid' identifier for that survey. If they subsequently split, they receive two different 'survhhid' in subsequent surveys. They, however, always share the same 'uashhid'. The identifier 'survhhid' is set to missing (.) if no other household members are UAS panel members at the time of the survey. Since individuals can answer the same survey at different points in time (which can be relatively far apart if the survey is kept in the field for a prolonged time), it may be possible that, within the same data set, household members have different 'survhhid' reflecting different household compositions at the time they answered the survey. For instance, suppose that the primary respondent and his/her spouse are both UAS members. If the primary respondent answers the survey when he/she is living with the spouse, but the spouse answers the survey when the couple has split, they receive different 'survhhid'. Hence, the variable 'survhhid' identifies household membership of UAS panel members, at the time the respondent answers the survey. Note: in the My Household survey 'survhhid' is set to unknown (.u) for respondents who last participated in the My Household survey prior to January 21, 2015.
- **uasmembers**: is the number of other household members who are also UAS panel members at the time of the survey. Since individuals can answer the same survey at different points in time (which can be relatively far apart is the survey is kept in the field for a prolonged time), it may be possible that, within the same data set, the primary respondent of a household has a value of '0', whereas the second UAS household respondent has a value of '1'. Therefore 'uasmembers' should be interpreted as the

number of household and UAS panel members at the time the respondent answers the survey. Note: in the My Household survey 'uasmembers' is set to unknown (.u) for respondents who last participated in the My Household survey prior to January 21, 2015.

- sampleframe: indicates the sampling frame from which the household of the respondent was recruited. All UAS recruitment is done through address based sampling (ABS) in which samples are acquired based on postal records. Currently, the variable 'sampleframe' takes on four values reflecting four distinct sample frames used by the UAS over the year (in future data sets the number of sample frames used for recruitment may increase if additional specific populations are targeted in future recruitment batches):
 - 1. U.S. National Territory: recruited through ABS within the entire U.S.
 - 2. Areas high concentration Nat Ame: recruited through ABS in areas with a high concentration of Native Americans in the zip-code. Within these batches, individuals who are not Native Americans are not invited to join the UAS.
 - 3. Los Angeles County: recruited through ABS within Los Angeles County.
 - 4. California: recruited through ABS within California.

Note: prior to March 6, 2024 this variable was called sampletype and had the following value labels for the above list in UAS data sets:

- 1. Nationally Representative Sample: recruited through ABS within the entire U.S.
- Native Americans: recruited through ABS in areas with a high concentration of Native Americans. Within these batches, individuals who are not Native Americans are not invited to join the UAS.
- 3. LA County: recruited through ABS within Los Angeles County.
- 4. California: recruited through ABS within California.
- **batch**: indicates the batch from which the respondent was recruited. Currently, this variable takes the following values (in future data sets the number of batches may increase as new recruitment batches are added to the UAS):
 - 1. ASDE 2014/01
 - 2. ASDE 2014/01
 - 3. ASDE 2014/01
 - 4. Public records 2015/05
 - 5. MSG 2015/07
 - 6. MSG 2016/01
 - 7. MSG 2016/01
 - 8. MSG 2016/01
 - 9. MSG 2016/02

- 10. MSG 2016/03
- 11. MSG 2016/04
- 12. MSG 2016/05
- 13. MSG 2016/08
- 14. MSG 2017/03
- 15. MSG 2017/11
- 16. MSG 2018/02
- 17. MSG 2018/08
- 18. MSG 2019/04
- 19. MSG 2019/05
- 20. MSG 2019/11
- 21. MSG 2020/08
- 22. MSG 2020/10
- 23. MSG 2021/02
- 24. MSG 2021/08
- 25. MSG 2021/08
- 26. MSG 2022/02
- 27. MSG 2022/02
- 28. MSG 2022/08
- 29. MSG 2022/11
- 30. MSG 2022/11
- 31. MSG 2023/01
- 32. MSG 2023/06
- 33. MSG 2023/09
- 34. MSG 2023/10
- 35. MSG 2025/02

Note: prior to March 6, 2024 this variable had the following value labels for the above list in UAS data sets:

- 1. ASDE 2014/01 Nat.Rep.
- 2. ASDE 2014/01 Native Am.
- 3. ASDE 2014/11 Native Am.
- 4. LA County 2015/05 List Sample
- 5. MSG 2015/07 Nat.Rep.
- 6. MSG 2016/01 Nat.Rep. Batch 2

- 7. MSG 2016/01 Nat.Rep. Batch 3
- 8. MSG 2016/01 Nat.Rep. Batch 4
- 9. MSG 2016/02 Nat.Rep. Batch 5
- 10. MSG 2016/03 Nat.Rep. Batch 6
- 11. MSG 2016/04 Nat.Rep. Batch 7
- 12. MSG 2016/05 Nat.Rep. Batch 8
- 13. MSG 2016/08 LA County Batch 2
- 14. MSG 2017/03 LA County Batch 3
- 15. MSG 2017/11 California Batch 1
- 16. MSG 2018/02 California Batch 2
- 17. MSG 2018/08 Nat.Rep. Batch 9
- 18. MSG 2019/04 LA County Batch 4
- 19. MSG 2019/05 LA County Batch 5
- 20. MSG 2019/11 Nat. Rep. Batch 10
- 21. MSG 2020/08 Nat. Rep. Batch 11
- 22. MSG 2020/10 Nat. Rep. Batch 12
- 23. MSG 2021/02 Nat. Rep. Batch 13
- 24. MSG 2021/08 Nat. Rep. Batch 15
- 25. MSG 2021/08 Nat. Rep. Batch 16
- 26. MSG 2022/02 Nat. Rep. Batch 17 (priority)
- 27. MSG 2022/02 Nat. Rep. Batch 17 (regular)
- 28. MSG 2022/08 Nat. Rep. Batch 18
- 29. MSG 2022/11 LA County Batch 6
- 30. MSG 2022/11 Nat. Rep. Batch 20
- 31. MSG 2023/01 Nat. Rep. Batch 21
- 32. MSG 2023/06 Nat. Rep. Batch 22
- 33. MSG 2023-09 Native Am. Batch 3
- 34. MSG 2023-10 Nat. Rep. Batch 23
- primary_respondent: indicates if the respondent was the first person within the household (i.e. to become a member or whether s/he was added as a subsequent member. A household in this regard is broadly defined as anyone living together with the primary respondent. That is, a household comprises individuals who live together, e.g. as part of a family relationship (like a spouse/child/parent) or in context of some other relationship (like a roommate or tenant).

- **hardware**: indicates whether the respondent ever received hardware or not. Note: this variable should not be used to determine whether a respondent received hardware at a given point in time and/or whether s/he used the hardware to participate in a survey. Rather, it indicates whether hardware was ever provided:
 - 1. None
 - 2. Tablet (includes Internet)
- **language**: the language in which the survey was conducted. This variable takes a value of 1 for English and a value of 2 for Spanish.
- **start_date (start_year, start_month, start_day, start_hour, start_min, start_sec)**: indicates the time at which the respondent started the survey.
- end_date (end_year, end_month, end_day, end_hour, end_min, end_sec): indicates the time at which the respondent completed the survey.
- **cs_001**: indicates how interesting the respondent found the survey.

4 BACKGROUND DEMOGRAPHICS

Every UAS survey data set includes demographic variables, which provide background information about the respondent and his/her household. Demographic information such as age, ethnicity, education, marital status, work status, state of residence, family structure is elicited every quarter through the "My Household" survey. The demographic variables provided with each survey are taken from the most recent 'MyHousehold' survey answered by the respondent. If at the time of a survey, the information in "My Household" is more than three months old, a respondent is required to check and update his or her information before being able to take the survey.

The following variables are available in each survey data set:

- gender: the gender of the respondent.
- **dateofbirth_year**: the year of birth of the respondent.
- age: the age of the respondent at the start of the survey.
- **agerange**: if the respondent's age cannot be calculate due to missing information, 'agerange' indicates the approximate age. Should a value for both the 'age' and 'agerange' be present, then 'age' takes precedence over 'agerange'.
- o citizenus: indicates whether the respondent is a U.S. citizen.
- **bornus**: indicates whether the respondent was born in the U.S.
- **stateborn**: indicates the state in which the respondent was born. This is set to missing (.) if the respondent was not born in the U.S.
- **countryborn**: indicates the country in which the respondent was born. This is set to missing (.) if the respondent was born in the U.S.
- countryborn_other: indicates the country of birth if that country is not on the drop down list of countries shown to the respondent'.
- **statereside**: the state in which the respondent is living.
- immigration_status: indicates whether the respondent is an immigrant. It takes one of the following values: 0 Non-immigrant, 1 First generation immigrant (immigrant who migrated to the U.S), 2 Second generation immigrant (U.S.-born children of at least one foreign-born parent), 3 Third generation immigrant (U.S.-born children of at least one U.S.-born parent, where at least one grandparent is foreign-born), or 4 Unknown immigrant status.
- maritalstatus: the marital status of the respondent.
- livewithpartner: indicates whether the respondent lives with a partner.

- education: the highest level of education attained by the respondent.
- hisplatino: indicates whether the respondent identifies him or herself as being Hispanic or Latino. This variable is asked separately from race.
- hisplatinogroup: indicates which Hispanic or Latino group a respondent identifies him or herself with. This is set to missing (.) if the respondent does not identify him or herself as being Hispanic or Latino.
- white: indicates whether the respondent identifies him or herself as white (Caucasian).
- **black**: indicates whether the respondent identifies him or herself as black (African-American).
- **nativeamer**: indicates whether the respondent identifies him or herself as Native American (American Indian or Alaska Native).
- **asian**: indicates whether the respondent identifies him or herself as Asian (Asian-American).
- pacific: indicates whether the respondent identifies him or herself as Native Hawaiian or Other Pacific Islander.
- **race**: indicates the race of the respondent as singular (e.g., '1 White' or '2 Black') or as mixed (in case the respondent identifies with two or more races). The value '6 Mixed' that the respondent answered 'Yes' to at least two of the single race categories. This variable is generated based on the values of the different race variables (white, black, nativeamer, asian, pacific). This composite measure is not conditional on hisplatino, so an individual may identify as Hispanic or Latino, and also as a member of one or more racial groups.
- working: indicates whether the respondent is working for pay.
- **sick_leave**: indicates whether the respondent is not working because sick or on leave.
- **unemp_layoff**: indicates whether the respondent is unemployed or on lay off.
- unemp_look: indicates whether the respondent is unemployed and looking for a job.
- retired: indicates whether the respondent is retired.
- o disabled: indicates whether the respondent has a disability.
- If_other: specifies other labor force status.
- Iaborstatus: indicates the labor force status of the respondent as singular (e.g., '1 Working for pay' or '2 On sick or other leave') or as mixed (in case the respondent selects two or more labor statuses). The value '8 Mixed' indicates that the respondent answered 'Yes' to at least two of the single labor force status variables. This variable is generated based on the values of the different labor status variables (working, sick_leave, unempl_layoff, unempl_look, retired, disabled, lf_other).

- **employmenttype**: indicates the employment type of the respondent (employed by the government, by a private company, a nonprofit organization, or self-employed). This is set to missing (.) if the respondent is not currently working or currently on sick or other leave.
- **workfullpart**: indicates whether the respondent works full or part-time. This is set to missing (.) if the respondent is not currently working or currently on sick or other leave.
- **hourswork**: indicates the number of hours the respondent works per week. This is set to missing (.) if the respondent is not currently working or currently on sick or other leave.
- hhincome: is the total combined income of all members of the respondent's household (living in their household) during the past 12 months.
- **anyhhmember**: indicates whether there were any members in the respondent's household at the time he/she answered the survey as reported by the respondent.
- **hhmembernumber**: indicates the number of household members in the respondent's household at the time of the survey as reported by the respondent. It may be that 'anyhhmember' is 'Yes', but 'hhmembernumber' is missing if the respondent did not provide the number of household members at the time of the survey.
- hhmemberin_#: indicates whether a household member is currently in the household as reported by the respondent. Household members are never removed from the stored household roster and their information is always included in survey data sets. The order of the roster is the same order in which household members were specified by the respondent in the 'MyHousehold' survey. The order is identified by the suffix _# (e.g., _1 indicates the first household member, _2 the second household member, etc.).

As an example, if the first household member is in the household at the time of the survey, 'hhmemberin_1' is set to '1 HH Member 1 is in the HH'; if he/she has moved out, 'hhmemberin_1' is set to '0 HH member 1 is no longer in the HH'. Since information of other household members (stored in the variables listed below) is always included in survey data sets, information about 'hhmemberin_1' is available whether this person is still in the household or has moved out.

- hhmembergen_#: indicates the gender of another household member as reported by the respondent.
- **hhmemberage**_#: indicates the age of another household member. The age is derived from the month and year of birth of the household member as reported by the respondent.
- hhmemberrel_#: indicates the relationship of the respondent to the other household member as reported by the respondent.

- hhmemberuasid_#: is the 'uasid' of the other household member if this person is also a UAS panel member. It is set to missing (.) if this person is not a UAS panel member at the time of the survey. Since this identifier is directly reported by the respondent (chosen from a preloaded list), it may differ from the actual (correct) 'uasid' of the UAS member it refers to because of reporting error. Also, this variable should not be used to identify UAS members in a given household at the time of the survey. This is because the variables 'hhmemberuasid_#' are taken from the most recent 'My Household' and changes in household composition involving UAS members may have occurred between the time of the respondent answered 'My Household' and the time the respondent answers the survey. To follow UAS members of a given household, it is advised to use the identifiers 'uashhid' and 'survhhid'.
- **lastmyhh_date**: the date on which the demographics variables were collected through the 'My Household' survey.

In addition, data sets created after May 8, 2025 include an urbanicity variable. It is based on panel members' current census tract of residence and the 2010 Rural-Urban Commuting Area (RUCA) codes released by the US Department of Agriculture's Economic Research Service. To preserve confidentiality, the UAS collapses the 10 primary RUCA codes to 4 levels: Metropolitan, Micropolitan, Small/Rural, and Unknown. The Metropolitan level corresponds to primary RUCA codes 1-3, the Micropolitan level corresponds to RUCA codes 4-6, and the Small/Rural UAS classification corresponds to RUCA codes 7-10.

For detailed information and definitions of the 10 primary RUCA codes, please visit the USDA ERS Rural-Urban Commuting Area Codes site. Surveys conducted completely prior to May 8, 2025 will have an urbanicity data set available on request.

5 MISSING DATA CONVENTIONS

Data files provide so-called clean data, that is, answers given to questions that are not applicable anymore at survey completion (for example because a respondent went back in the survey and skipped over a previously answered question) are treated as if the questions were never asked. In the data files all questions that were asked, but not answered by the respondent are marked with (.e). All questions never seen by the respondent (or any dirty data) are marked with (.a). The latter may mean that a respondent did not view the question because s/he skipped over it; or alternatively that s/he never reached that question due to a break off. If a respondent did not complete a survey, the variables representing survey end date and time are marked with (.c). Household member variables are marked with (.m) if the respondent has less household members (e.g. if the number of household members is 2, any variables for household member 3 and up are marked with (.m).

UAS provides data in STATA and CSV format. Stata data sets come with include variable labels that are not available in the CSV files. Value labels are provided for singleresponse answer option. In STATA these labels will include the labels 'Not asked' and 'Not answered' for (.a) and (.e), and will show in tabulations such as 'tab q1, missing'. For multiple-response questions a binary variable is created for each answer option indicating whether the option was selected or not. A summary variable is also provided in string format reflecting which options were selected and in which order. For example, if a question asked about favorite animals with options cat, dog, and horse, then if a respondent selected horse and then cat, the binary variables for horse and cat will be set to yes, while the overall variable would have a string value of '3-1'. If no answer was given, all binary variables and the summary variable will be marked with '.e'.

Questions that are asked multiple times are often implemented as so-called array questions. Supposing the name of such question was Q1 and it was asked in 6 different instances, your data set would contain the variables $Q1_1_$ to $Q1_6_$. To illustrate, if a survey asked the names of all children, then child_1_ would contain the name of the first child the respondent named and so on.

More information about the UAS data in general can be found on the UAS Data Pages web site.

6 ROUTING SYNTAX

The survey with routing presented in the next section includes all of the questions that make up this survey, the question answers when choices were provided, and the question routing. The routing includes descriptions of when questions are grouped, conditional logic that determines when questions are presented to the respondent, randomization of questions and answers, and fills of answers from one question to another.

If you are unfamiliar with conditional logic statements, they are typically formatted so that *if* the respondent fulfills some condition (e.g. they have a cellphone or a checking account), *then* they are presented with some other question or the value of some variable is changed. If the respondent does not fulfill the condition (e.g. they are not a cellphone adopter or they do not have a checking account), something *else* happens such as skipping the next question or changing the variable to some other value. Some of the logic involved in the randomization of questions or answers being presented to the respondent is quite complex, and in these instances there is documentation to clarify the process being represented by the routing.

Because logic syntax standards vary, here is a brief introduction to our syntax standards. The syntax used in the conditional statements is as follows: '=' is equal to, '<' is less than, '>' is greater than, and '!=' is used for does not equal. When a variable is set to some number N, the statement looks like 'variable := N'.

The formatting of the questions and routing are designed to make it easier to interpret what is occurring at any given point in the survey. Question ID is the bold text at the top of a question block, followed by the question text and the answer selections. When a question or variable has associated data, the name links to the appropriate data page, so you can easily get directly to the data. Text color is used to indicate the routing: red is conditional logic, gold is question grouping, green is looping, and orange is used to document randomization and other complex conditional logic processes. The routing is written for a computer to parse rather than a human to read, so when the routing diverges significantly from what is displayed to the respondent, a screenshot of what the respondent saw is included.

The name of the randomization variables are defined in proximity to where they are put into play, and like the question ID the names of the randomization variables can be used to link directly to the associated data page.

7 SURVEY WITH ROUTING

/* Respondents who reported being informal caregivers in UAS634 are invited to this survey and asked if they are still providing informal care. If they are not, they are asked why they are no longer providing care and exit out of the survey (per variable a001).

If the respondent is still providing care, they are asked if anything has changed per variables ch001 to ch007 (including whether the person they are caring for has changed). The updated information is then used in the remainder of the survey to ask about their caregiving experiences. */

Start of section Caregiver

a001 (still spent any time assisting someone in section Caregiver) In a recent survey, you told us that you were assisting someone (parent, grandparent, wife, husband, child, another family member, neighbor, or close friend) with basic personal activities because they cannot handle them without help.

By assisting someone with basic personal activities, we mean daily activities such as dressing, eating, bathing, paying bills, managing medication, food preparation, grocery shopping, doctor visits, emotional support, driving, and other personal assistance. Please **exclude** assistance given to children who are not yet self-sufficient due to their age (for example, too young to dress themselves or unable to prepare a meal).

Is this still the case? Note that this can include a person you mentioned previously or a new person you are helping.

1 Yes 2 No

2110

End of section Caregiver

Start of section Preload

preload_a002 := /* Preloaded a002 answer from UAS637 */ preload_a003 := /* Preloaded a003 answer from UAS637 */ preload_b001 := /* Preloaded b001 answer from UAS637 */

```
IF preload_b001 = EMPTY THEN
preload_b001 := 99
END OF IF
```

preload_b001_other := /* Preloaded b001_other answer from UAS637 */ preload_b001_relative := /* Preloaded a002 answer from b001_relative */ preload_b003 := /* Preloaded b003 answer from UAS637 */ preload_b004 := /* Preloaded b004 answer from UAS637 */

IF preload_b004 = EMPTY THEN preload_b004 := 99 END OF IF

preload_b004_other := /* Preloaded b004_other answer from UAS637 */ preload_b004_none := /* Preloaded b004_none answer from UAS637 */ preload_c001 := /* Preloaded c001 answer from UAS637 */

IF preload_c001 = EMPTY THEN preload_c001 := 99 END OF IF

preload_c001_other := /* Preloaded c001_other answer from UAS637 */ preload_c003 := /* Preloaded c003 answer from UAS637 */

IF preload_c003 = EMPTY THEN preload_c003 := 99 END OF IF

preload_c003_other := /* Preloaded c003_other answer from UAS637 */

End of section Preload

IF a001 = 2 THEN

a004 (when stop assisting someone in section Caregiver) When did you stop assisting someone (parent, grandparent, wife, husband, child, another family member, neighbor, or close friend) with basic personal activities? DATE

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

a005 (main reason why caregiving role has ended in section Caregiver)

Could you please share the main reason why your caregiving role has ended? We understand that this can be a sensitive subject. Remember that your response is entirely voluntary.

1 The person I was caring for has recovered from their illness or limitation(s)

2 The person I was caring for has moved into a care facility (e.g., nursing home, assisted living)

3 The person I was caring for is now provided with professional care services at home

4 The person I was caring for is now assisted by another family member or friend

5 The person I was caring for has passed away 6 Other, please specify:

a005_other (other main reason why caregiving role has ended in section Caregiver)

STRING

END OF GROUP

a003 := preload_a003 b001 := preload_b001 b001_other := preload_b001_other

ELSE

Start of section Change

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

ch_intro (Section Change)

Here is the information about your caregiving situation that you have provided. Please review it and indicate whether this information is still correct. If you indicate that the information needs to be changed, you will be able to do that on the next screens.

SUBGROUP OF QUESTIONS

ch001 (Number of people you spend time assisting correct in section Change) Number of people you spend time assisting: (^preload_a002/Not reported previously) person(s)

1 Correct

2 Change

ch002 (Person you primarily care for correct in section Change) Person you primarily care for: (^preload_a003/No name, nickname, or initials provided)

1 Correct

2 Change

ch003 (Relationship with care recipient correct in section Change) Relationship with (^preload_a003/No name, nickname, or initials provided): (preload who is care recipient())

1 Correct

2 Change

ch004 (Age of care recipient correct in section Change) Age of (^preload_a003/No name, nickname, or initials provided): (^preload_b003/Not reported previously) 1 Correct 2 Change

ch005 (Conditions or disabilities care recipient correct in section Change) Conditions or disabilities of (^preload_a003/No name, nickname, or initials provided): (preload conditions or disabilities care recipient()) 1 Correct

2 Change

ch006 (Types of insurance coverage of care recipient correct in section Change) (^preload_a003/No name, nickname, or initials provided) has the following types of insurance coverage: (preload insurance coverage care recipient())

1 Correct

2 Change

ch007 (Where lives care recipient correct in section Change)

(^preload_a003/No name, nickname, or initials provided) lives: (preload where care recipient lives())

1 Correct

2 Change

END OF SUBGROUP

ch_script (Section Change)

END OF GROUP

IF ch001 = 2 THEN

a002 (how many people spend assisting in section Caregiver)
How many people do you spend time assisting with basic personal activities because
they are unable to handle them without help?
1 1
2 2
3 3
4 4
5 5 or more
ELSE
a002 := preload_a002

END OF IF

IF ch001 = 2 AND a002 > 1 THEN

a003_intro (Section Caregiver)

For the following questions, please think about the person you **primarily** care for, that is the person who requires the most time and energy from you as a caregiver.

END OF IF

IF ch002 = 2 THEN

a003 (name care recipient in section Caregiver)

Could you provide a name, nickname, or initials for the person you(**primarily**) care for? We will use your chosen name, nickname or initials to refer to this person throughout the rest of the survey. If you prefer not to provide a name, nickname, or initials, you may leave this blank and we will refer to this person as the care recipient.

STRING ELSE

a003 := preload_a003

END OF IF

IF ch003 = 2 THEN GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

b001_dummy (who is care recipient in section Relationship) Who is (**^a003/the care recipient**) to you?

Spouse/partner

1 Husband

2 Wife

- 3 Female romantic partner
- 4 Male romantic partner Parent
- 5 Mother

6 Father

- 7 Stepmother
- 8 Stepfather Parent-in-law
- 9 Mother-in-law
- 10 Father-in-law
- 11 Stepmother-in-law
- 12 Stepfather-in-law Son or daughter (including biological or adopted)

13 Son

14 Daughter

15 Stepson

16 Stepdaughter Son or daughter-in-law

17 Son-in-law

- 18 Daughter-in-law
- 19 Step son-in-law

20 Step daughter-in-law Grandparent

21 Grandfather

22 Grandmother

23 Step-grandfather

24 Step-grandmother Grandchild

25 Grandson

26 Granddaughter

27 Step-grandson

28 Step-granddaughter Sibling

29 Brother

30 Sister

31 Step-brother

32 Step-sister Aunt or Uncle

33 Aunt

34 Uncle Cousin

35 Female cousin

36 Male cousin

37 Other relatives, please specify: Friend/companion, roommate, or neighbor

38 Friend/companion

39 Roommate

40 Neighbor

41 I am employed as a paid caregiver

42 Other, please specify:

b001_relative (other relative who is care recipient in section Relationship) What other relative is (**^a003/the care recipient**) to you? STRING

b001_other (other who is care recipient in section Relationship) What other relationship does (**^a003/the care recipient**) have to you? STRING

END OF GROUP

ELSE

b001 := preload_b001 b001_relative := preload_b001_relative b001_other := preload_b001_other

END OF IF

IF ch004 = 2 THEN

b003 (age care recipient in section Relationship) How old is (**^a003/the care recipient**)? 1 0 -10 years 2 11 to 17 years 3 18 to 29 years 4 30 to 49 years 5 50 to 64 6 65 to 79 7 80 to 89 8 90+ **ELSE** b003 := preload_b003

END OF IF

IF ch005 = 2 THEN GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

b004 (conditions or disabilities care recipient in section Relationship) Which of the following conditions or disabilities, if any, apply to (**^a003**/the care recipient)? Please check all that apply, or write in an answer if it is not in the list below.

1 Alzheimer's disease, other dementia or cognitive impairment, mild cognitive impairment (MCI), or memory problems

2 Cancer 3 Stroke

4 Intellectual or developmental disability

5 Physical disability or injury

6 Mental health or psychiatric disability

7 Diabetes

8 Heart disease

9 Other chronic illness

10 Vision impairment, blindness

11 Other age-related impairments

12 Long-term effects of COVID-19 lasting more than 3 months

13 Frailty

14 Other, please specify:

15 None of the above. Please specify the reason you are assisting the person you provide care for:

b004_other (other conditions or disabilities care recipient in section Relationship)

STRING

b004_none (none conditions or disabilities care recipient in section Relation-

ship) STRING

END OF GROUP

ELSE

b004 := preload_b004 b004_other := preload_b004_other b004_none := preload_b004_none

END OF IF

IF ch006 = 2 THEN

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

c001 (insurance coverage care recipient in section Conditions)

Does (**`a003**/the care recipient) have any of the following types of insurance coverage (please check all that apply):

1 Medicare

- 2 Medicare Advantage
- 3 Medicaid
- 4 Medigap
- 5 Employer-sponsored retiree coverage
- 6 Employer-sponsored health plan
- 7 VA
- 8 COBRA
- 9 Private insurance
- 10 Does not have insurance
- 11 Don't know
- 12 Other, please specify:

 $\textbf{c001_other}$ (other insurance coverage care recipient in section Conditions) STRING

END OF GROUP

ELSE

c001 := preload_c001 c001_other := preload_c001_other

END OF IF

IF ch007 = 2 THEN GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

c003 (where care recipient lives in section Conditions)
Where does (^a003/the care recipient) live?
1 With me

2 With other family members

3 With other non-family members

4 By themselves

5 In a nursing home

6 In an assisted living facility

7 Other, please specify:

c003_other (other where care recipient lives in section Conditions) STRING

END OF GROUP

ELSE

c003 := preload_c003 c003_other := preload_c003_other

END OF IF

End of section **Change**

Start of section Intensity

e002 (regular schedule or not in section Intensity)

Thinking about all the ways you helped (**^a003**/the care recipient) in the last month, did you help on a regular schedule or did it vary? By regular schedule, we mean the same days and times every week.

1 Regular schedule

2 Varying schedule

IF = 002 = 1 THEN

e002a (number of days per week help care recipient in section Intensity) How many days per week did you help (**^a003/the care recipient**)? RANGE 0..7

ELSE

e002b (number of days in last month help care recipient in section Intensity) In the last month, how many days altogether did you help (**^a003**/the care recipient)? RANGE 0..31

END OF IF

e002c (hours help care recipient on days helped in section Intensity) On the days when you helped (**^a003**/the care recipient), about how many hours did you spend helping? RANGE 0..24

e003 (only one assisting care recipient in section Intensity) Are you the only one assisting (**^a003**/the care recipient) or are other people providing care?

1 I am the only caregiver

2 I do most of the caregiving activities, but other people provide care occasionally 3 I equally share caregiving activities with other people

4 Other people do most of the caregiving activities, but I provide care occasionally

End of section Intensity

Start of section Tasks

d_intro (Section Tasks)

Next, we would like to ask about ways you may have helped (**^a003**/the care recipient) in the last month.

d001 (help with laundry, cleaning, making hot meals in section Tasks) In the last month, did you help (**^a003**/**the care recipient**) with laundry, cleaning, making hot meals, or do these chores for them?

1 Yes

2 No

3 They do not need help with this

d002 (shop for groceries or personal items in section Tasks) In the last month, did you shop with (**^a003/the care recipient**) for groceries or personal items or shop for them?

1 Yes

2 No

3 They do not need help with this

d003 (drive places in section Tasks)

In the last month, did you drive (^a003/the care recipient) places?

1 Yes

2 No

3 They do not need help with this

d004 (help with handling bills or banking in section Tasks)
In the last month, did you help (^a003/the care recipient) with handling bills or banking, or do this for them?
1 Yes

2 No

3 They do not need help with this

d005 (help with personal care such as eating, showering or bathing, dressing or grooming, or using the toilet in section Tasks)

In the last month, did you help (**^a003**/the care recipient) with personal care such as eating, showering or bathing, dressing or grooming, or using the toilet?

1 Yes 2 No 3 They do not need help with this

d006 (help get around, that is, getting in and out of bed, getting around inside home, or leaving home to go outside in section Tasks)

In the last month, did you help (**`a003/the care recipient**) get around, that is, getting in and out of bed, getting around inside their home, or leaving their home to go outside? 1 Yes

2 No

3 They do not need help with this

d007 (help keep track of their medications in section Tasks)

In the last month, did you help (**^a003**/the care recipient) keep track of their medications? By keeping track, we mean making sure they take the correct amount at the right time.

1 Yes

2 No

3 They do not need help with this

d008 (assist with medical equipment in section Tasks)

In the last month, did you assist (**`a003/the care recipient**) with medical equipment (for example, oxygen tanks, injections) or managed medical care (for example, ostomy care, IVs, or blood testing)?

1 Yes

2 No

3 They do not need help with this

d009 (assist with healthcare-related assistance in section Tasks)

In the last month, did you assist (**^a003**/the care recipient) with healthcare-related assistance, including making appointments for them, driving them to appointments, or assisting them with health insurance changes or applications?

1 Yes

2 No

3 They do not need help with this

d010 (provide emotional support in section Tasks)

In the last month, did you provide emotional support to (**^a003**/the care recipient), that is listening to their concerns or being available when they are upset?

1 Yes

2 No

3 They do not need help with this

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

d011 (help other activity in section Tasks)
In the last month, did you help (^a003/the care recipient) with any other activity we haven't mentioned?
1 Yes, please specify:

2 No

d011_other (specify help other activity in section Tasks) STRING

END OF GROUP

d012 (how stressful helping care recipient in section Tasks)
How stressful do you find helping (^a003/the care recipient)?
1 Not at all
2 A little
3 Somewhat
4 Quite a bit
5 A great deal

d013 (how rewarding helping care recipient in section Tasks)
How rewarding do you find helping (^a003/the care recipient)?
1 Not at all
2 A little
3 Somewhat
4 Quite a bit
5 A great deal

End of section Tasks

Start of section Wellbeing

f_intro (Section Wellbeing) Select the response that best describes how you have felt about providing care over the **past month**.

f001 (don't have enough time for yourself in section Wellbeing)
How often did you feel that because of the time you spend with (^a003/the care recipient) you don't have enough time for yourself?
1 Never
2 Rarely
3 Sometimes
4 Quite frequently
5 Nearly always

f002 (feel stressed between caring and other responsibilities in section Wellbe-

ing)

How often did you feel stressed between caring for (**^a003**/the care recipient) and trying to meet other responsibilities (work/family)?

1 Never

2 Rarely

3 Sometimes

4 Quite frequently

5 Nearly always

f005 (feel strained around care recipient in section Wellbeing)

How often did you feel strained when you are around (**^a003**/the care recipient)? 1 Never

2 Rarely

3 Sometimes

4 Quite frequently

5 Nearly always

f010 (feel uncertain what to do about care recipient in section Wellbeing)
How often did you feel uncertain about what to do about (^a003/the care recipient)?
1 Never

2 Rarely

3 Sometimes

4 Quite frequently

5 Nearly always

End of section Wellbeing

Start of section Efficacy

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

se_intro (Section Efficacy) Please indicate the degree to which you agree or disagree with the following statements:

SUBGROUP OF QUESTIONS

se001 (I know where to get the caregiving services I need in section Efficacy) I know where to get the caregiving services I need

1 Strongly disagree

2 Disagree

3 Neither agree nor disagree

4 Agree

5 Strongly agree

se002 (I have people I can turn to when I need help with my problems that

come from caregiving in section Efficacy)

I have people I can turn to when I need help with my problems that come from caregiving

1 Strongly disagree

2 Disagree

3 Neither agree nor disagree

4 Agree

5 Strongly agree

se003 (I feel confident that I can manage future caregiving challenges in section Efficacy)

I feel confident that I can manage future caregiving challenges

1 Strongly disagree

2 Disagree

3 Neither agree nor disagree

4 Agree

5 Strongly agree

END OF SUBGROUP

END OF GROUP

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

co_intro (Section Efficacy)

There are many ways to try to deal with stressful situations. We would like to know how often you used the following strategies when you experienced stress in the **past month**. Don't answer on the basis of whether each strategy seems to work or not, just report how often you do it.

SUBGROUP OF QUESTIONS

co001 (I try to see the situation in a more positive light in section Efficacy) I try to see the situation in a more positive light

1 Never

2 Rarely

3 Sometimes

4 Often

5 Almost always

 ${\bf co002}$ (I do something to think about the situation less, such as watching TV, reading, sleeping, or shopping in section Efficacy)

I do something to think about the situation less, such as watching TV, reading, sleeping, or shopping

1 Never

2 Rarely 3 Sometimes 4 Often 5 Almost always co003 (I concentrate my efforts on doing something about the situation I'm in in section Efficacy) I concentrate my efforts on doing something about the situation I'm in 1 Never 2 Rarely 3 Sometimes 4 Often 5 Almost always **co004** (I accept there is nothing I can do in section Efficacy) I accept there is nothing I can do 1 Never 2 Rarely 3 Sometimes 4 Often 5 Almost always

END OF SUBGROUP

END OF GROUP

End of section Efficacy

Start of section Aspects

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

In_intro (Section Aspects) The next questions are about how you feel about different aspects of your life.

During the past month, how often did you feel...

SUBGROUP OF QUESTIONS

In001 (Lack of companionship in section Aspects)Lack of companionship1 Never2 Rarely3 Sometimes4 Often

5 Almost always

In002 (Left out in section Aspects)

Left out

1 Never

2 Rarely

3 Sometimes

4 Often

5 Almost always

In003 (Isolated from others in section Aspects) Isolated from others

1 Never

2 Rarely

3 Sometimes

4 Often

5 Almost always

END OF SUBGROUP

END OF GROUP

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

In004_intro (Section Aspects)

During the **past month**, how often did you experience the following with (**^a003/the** care recipient)?

SUBGROUP OF QUESTIONS

ps001 (You had positive or enjoyable interactions care recipient in section Aspects) You had positive or enjoyable interactions

1 Never

2 Rarely

3 Sometimes

4 Often

5 Almost always

 $\ensuremath{\text{ps002}}$ (You had irritating, hurtful, annoying, or stressful interactions care recipient in section Aspects)

You had irritating, hurtful, annoying, or stressful interactions

1 Never

2 Rarely

3 Sometimes

4 Often

5 Almost always

END OF SUBGROUP

END OF GROUP

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

In004_intro2 (Section Aspects)

During the **past month**, how often did you experience the following with your close family members and friends (not including (**^a003**/the care recipient))?

SUBGROUP OF QUESTIONS

ps003 (You had positive or enjoyable interactions family friends in section Aspects) You had positive or enjoyable interactions

1 Never

2 Rarely

3 Sometimes

4 Often

5 Almost always

ps004 (You had irritating, hurtful, annoying, or stressful interactions family friends in section Aspects)

You had irritating, hurtful, annoying, or stressful interactions

1 Never

2 Rarely

3 Sometimes

4 Often

5 Almost always

END OF SUBGROUP

END OF GROUP

sl001 (sleep quality in section Aspects)
During the past month, my sleep quality was...
1 Poor
2 Fair
3 Good
4 Very good
5 Excellent

sl002 (felt fatigued in section Aspects) During the **past month**, I felt fatigued... 1 Never 2 Rarely 3 Sometimes 4 Almost always

phys_intro (Section Aspects)

Now, we would like to ask about specific activities that you may have engaged in during the past month.

phys001 (moderate physical activity in section Aspects)

How often did you engage in **moderate** physical activity in the **past month**? Examples include leisurely sports such as brisk walking, water aerobics, slow biking, and gardening.

0 Never

1 Less than once per week

2 1-2 times per week

3 3 or more times per week

phys002 (vigorous physical activity in section Aspects)

How often did you engage in **vigorous** physical activity in the **past month**? Examples include competitive sports, running, swimming laps, jumping rope, hiking uphill, and dancing.

0 Never

1 Less than once per week

2 1-2 times per week

3 3 or more times per week

al001 (drink any alcoholic beverages such as beer, wine, or liquor in section Aspects)

Now, we would like to ask about your use of alcohol. When we use the word "drink" in the next questions, we mean either a glass of wine, a can or bottle of beer, or a shot or jigger of liquor, either alone or in a mixed drink.

Did you drink any alcoholic beverages such as beer, wine, or liquor in the **past month**?

1 Yes 2 No

IF al001 = 1 THEN

al002 (how many days per week have alcohol to drink in section Aspects)In the past month, on average, how many days per week did you have any alcohol to drink? For example, beer, wine, or any drink containing liquor.0 None or less than once a week

11

22

3 3 4 4 5 5 6 6 7 7 (Every day)

al003 (how many drinks consume in section Aspects) In the past month, on the days you drank, how many drinks did you consume? RANGE 0..9223372036854775807

END OF IF

End of section Aspects

END OF IF

Start of section Closing

CS_001 (HOW PLEASANT INTERVIEW in section Closing)
Could you tell us how interesting or uninteresting you found the questions in this survey?
1 Very interesting
2 Interesting
3 Neither interesting nor uninteresting
4 Uninteresting
5 Very uninteresting
CS_003 (comments in section Closing)

Do you have any other comments on the survey? Please type these in the box below. (If you have no comments, please click next to complete this survey.) STRING

End of section Closing

/* Please note that although question CS_003 is listed in the routing, the answers are not included in the microdata in the event identifiable information is captured. Cleaned responses are available by request. */