

# UnderStandingAmericaStudy

UAS 330: CAREGIVER SURVEY



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## 1 INTRODUCTION

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This survey, titled "UAS 330: Caregiver Survey", asks how you are feeling and if you provide care for a family member or friend. This survey is no longer in the field. This survey was funded out of a U01 Toward a Next Generation of Health Administrative Supplement.

### 1.1 Topics

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This survey contains questions (among others) on the following topics: Family, Health, Covid-19. A complete survey topic categorization for the UAS can be found [here](#).

### 1.2 Experiments

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This survey includes experiment(s) of the following type(s): Auxiliary Randomization. Please refer to explanatory comments in the Routing section for detailed information. A complete survey experiment categorization for the UAS can be found [here](#).

### 1.3 Citation

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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](mailto:tgutsche@usc.edu).

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## 2 SURVEY RESPONSE AND DATA

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### 2.1 Sample selection and response rate

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The sample selection for this survey was:

All active respondents.

As such, this survey was made available to 9010 UAS participants. Of those 9010 participants, 6975 completed the survey and are counted as respondents. Of those who are not counted as respondents, 34 started the survey without completing and 2001 did not start the survey. The overall response rate was 77.41%.

Note: We are unable to provide sample weights for a small number of UAS members (see the Sample 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.%.

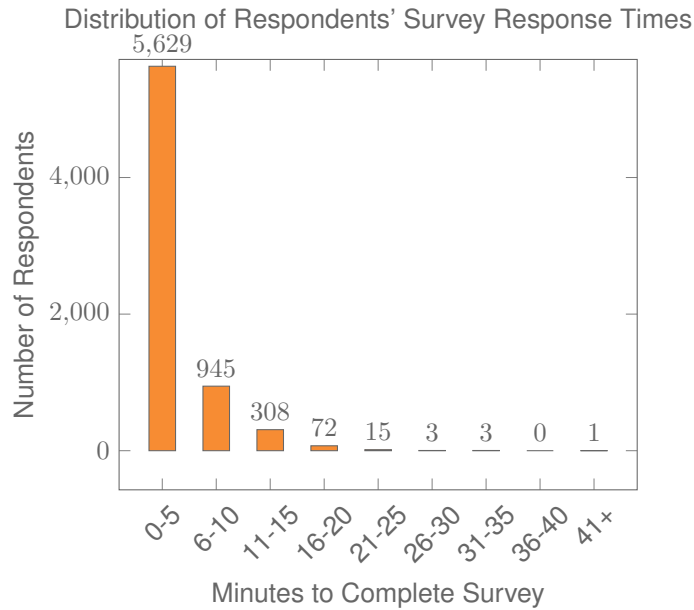
The detailed survey response rate is as follows:

UAS330 - Response Overview	
Size of selected sample	9010
Completed the survey	6975
Started but did not complete the survey	34
Did not start the survey	2001
Response rate	77.41%

### 2.2 Timings

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The survey took respondents an average of 3 minutes, and the full distribution of survey response times is available in the figure below. Times per question are available upon request.



### 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.

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### 3 STANDARD VARIABLES

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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.
  2. 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

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.

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## 4 BACKGROUND DEMOGRAPHICS

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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’.
- **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.
- **hisplativo**: 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 hisplativo, 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.
- **disabled**: indicates whether the respondent has a disability.
- **If\_other**: specifies other labor force status.
- **laborstatus**: 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, If\_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.
- **hhmembervnumber**: 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 'hhmembervnumber' 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.

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## 5 MISSING DATA CONVENTIONS

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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 single-response 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.

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## 6 ROUTING SYNTAX

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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.



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## 7 SURVEY WITH ROUTING

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### **mainintro** (Section Stress)

This survey asks how you are feeling and if you provide care for a family member or friend.

Start of section **Stress**

### GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

#### **st.intro** (Section Stress)

We would like to know how you have been feeling recently.

In the past 30 days, how often have you been bothered by any of the following problems:

#### SUBGROUP OF QUESTIONS

##### **st001** (Feeling nervous, anxious, or on edge in section Stress)

Feeling nervous, anxious, or on edge

- 1 Not at all
- 2 Several days
- 3 More than half the days
- 4 Nearly every day

##### **st002** (Not being able to stop or control worrying in section Stress)

Not being able to stop or control worrying

- 1 Not at all
- 2 Several days
- 3 More than half the days
- 4 Nearly every day

##### **st003** (Feeling down, depressed, or hopeless in section Stress)

Feeling down, depressed, or hopeless

- 1 Not at all
- 2 Several days
- 3 More than half the days
- 4 Nearly every day

##### **st004** (Little interest or pleasure in doing things in section Stress)

Little interest or pleasure in doing things

- 1 Not at all
- 2 Several days
- 3 More than half the days

| 4 Nearly every day

END OF SUBGROUP

END OF GROUP

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

**st\_intro2** (Section Stress)

In the past 30 days, how often have you felt:

SUBGROUP OF QUESTIONS

**st005** (unable to control the important things in life in section Stress)

That you were unable to control the important things in your life?

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Fairly often
- 5 Very often

**st006** (confident about ability to handle personal problems in section Stress)

Confident about your ability to handle personal problems?

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Fairly often
- 5 Very often

**st007** (things were going your way in section Stress)

That things were going your way?

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Fairly often
- 5 Very often

**st008** (difficulties were piling up so high could not overcome them in section Stress)

Difficulties were piling up so high that you could not overcome them?

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Fairly often

| 5 Very often

END OF SUBGROUP

END OF GROUP

End of section **Stress**

Start of section **Loneliness**

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

**In\_intro** (Section Loneliness)

In the past 30 days, how often have you felt:

SUBGROUP OF QUESTIONS

**In001** (Lack of companionship in section Loneliness)

Lack of companionship

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Fairly often
- 5 Very often

**In002** (Alone in section Loneliness)

Alone

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Fairly often
- 5 Very often

**In003** (Left out in section Loneliness)

Left out

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Fairly often
- 5 Very often

**In004** (Isolated from others in section Loneliness)

Isolated from others

- 1 Never
- 2 Almost never

- 3 Sometimes
- 4 Fairly often
- 5 Very often

END OF SUBGROUP

END OF GROUP

End of section **Loneliness**

Start of section **Caregiving**

**ca\_intro** (Section Caregiving)

We are interested in how Americans provide care for a family member or close friend, and how caregivers are faring during these times.

**ca001** (spend any time assisting a family member or close friend in section Caregiving)

In the past 30 days, did you spend any time assisting a family member or close friend (e.g. parent, grandparent, wife, husband, adult or minor child with special needs, other family member, neighbor or close friend) with basic personal activities because they are unable to handle them without help?

By that we mean daily activities such as dressing, eating, bathing, paying bills, managing medication, food preparation, grocery shopping, doctor visits, emotional support, driving, and other types of personal assistance.

- 1 Yes
- 2 No

**IF ca001 = 1 THEN**

**ca002** (who caregiving for in section Caregiving)

Who is the family member or close friend you are caregiving for?

If you provide care to more than one person, please indicate the person who requires the most time and energy from you as a caregiver.

- 1 Spouse/ partner
- 2 Parent
- 3 Son or daughter
- 4 Son or daughter-in-law
- 5 Grandparent
- 6 Grandchild
- 7 Sibling
- 8 Other relative
- 9 Friend/ companion, roommate
- 10 I am employed as a paid caregiver

**IF ca002 != 10 THEN**

**ca003** (paid to caregive in section Caregiving)

Are you paid to provide care to that family member or close friend?

1 Yes

2 No

**END OF IF**

**GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN**

**ca004** (which conditions or disabilities in section Caregiving)

Which of the following conditions or disabilities, if any, apply to the person you are helping to care for? 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

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 Other (please write in):

13 None

**ca004.other** (other which conditions or disabilities in section Caregiving)

STRING

**END OF GROUP**

**GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN**

**ca005.intro** (Section Caregiving)

Does that family member or close friend need help with any of the following activities?

**SUBGROUP OF QUESTIONS**

**ca005a** (Getting across a room in section Caregiving)

Getting across a room

1 Yes

2 No

**ca005b** (Bathing in section Caregiving)

Bathing

1 Yes

2 No

**ca005c** (Eating in section Caregiving)

Eating

1 Yes

2 No

**ca005d** ( Getting in and out of bed in section Caregiving)

Getting in and out of bed

1 Yes

2 No

**ca005e** (Using the toilet in section Caregiving)

Using the toilet

1 Yes

2 No

**ca005f** (Preparing a hot meal in section Caregiving)

Preparing a hot meal

1 Yes

2 No

**ca005g** (Shopping for grocery and other necessities in section Caregiving)

Shopping for grocery and other necessities

1 Yes

2 No

**ca005h** (Making phone calls in section Caregiving)

Making phone calls

1 Yes

2 No

**ca005i** (Taking medication in section Caregiving)

Taking medication

1 Yes

2 No

**ca005j** (Paying bills and keep tracking of expenses in section Caregiving)

Paying bills and keep tracking of expenses

1 Yes

2 No

**ca005k** (Managing money in section Caregiving)

Managing money

1 Yes

2 No

END OF SUBGROUP

END OF GROUP

IF ca005a = 1 OR ca005b = 1 OR ca005c = 1 OR ca005d = 1 OR ca005e = 1  
OR ca005f = 1 OR ca005g = 1 OR ca005h = 1 OR ca005i = 1 OR ca005j = 1 OR ca005k  
= 1 THEN

IF ca005a = 1 THEN

ca006\_order(1) := 1

END OF IF

IF ca005b = 1 THEN

ca006\_order(2) := 2

END OF IF

IF ca005c = 1 THEN

ca006\_order(3) := 3

END OF IF

IF ca005d = 1 THEN

ca006\_order(4) := 4

END OF IF

IF ca005e = 1 THEN

ca006\_order(5) := 5

END OF IF

IF ca005f = 1 THEN

ca006\_order(6) := 6

END OF IF

IF ca005g = 1 THEN

ca006\_order(7) := 7

END OF IF

IF ca005h = 1 THEN

ca006\_order(8) := 8

END OF IF

IF ca005i = 1 THEN

| ca006\_order(9) := 9

END OF IF

IF ca005j = 1 THEN

| ca006\_order(10) := 10

END OF IF

IF ca005k = 1 THEN

| ca006\_order(11) := 11

END OF IF

ca006\_order(12) := 12

**ca006** (which activities assist with in section Caregiving)

Which of these activities do you assist that family member or close friend with? Please check all that apply.

- 1 Getting across a room
- 2 Bathing
- 3 Eating
- 4 Getting in and out of bed
- 5 Using the toilet
- 6 Preparing a hot meal
- 7 Shopping for grocery and other necessities
- 8 Making phone calls
- 9 Taking medication
- 10 Paying bills and keep tracking of expenses
- 11 Managing money
- 12 None of the above

END OF IF

**ca007** (where living person giving care for in section Caregiving)

Where does the family member or close friend for whom you are a caregiver live?

- 1 With me
- 2 With another family member
- 3 By themselves
- 4 In a nursing home
- 5 Other

**ca008** (who is caregiving in section Caregiving)

Are you the only person assisting that family member or close friend or is somebody else providing care?



- 1 I am the only caregiver
- 2 I do most of the caregiving activities, but somebody else provides care occasionally
- 3 I equally share caregiving activities with somebody else
- 4 Somebody else does most of the caregiving activities, but I provide care occasionally

**ca009** (how long care given in section Caregiving)

For how long have you been providing care to that family member or close friend?

- 1 I have been providing care for more than a year
- 2 I have been providing care for less than a year

**IF ca009 = 1 THEN**

**ca009\_years** (years how long care given in section Caregiving)

For how many years have you been providing care to that family member or close friend?

RANGE 1..120

**ELSEIF ca009 = 2 THEN**

**ca009\_months** (months how long care given in section Caregiving)

For how many months have you been providing care to that family member or close friend?

RANGE 0..12

**END OF IF**

**ca010** (hours per week giving care in section Caregiving)

How many hours per week do you spend assisting that family member or close friend?

RANGE 1..168

#### GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

**ca011\_intro** (Section Caregiving)

Has your work or schooling changed due to your caregiving responsibilities?

#### SUBGROUP OF QUESTIONS

**ca011a** (stopped working in section Caregiving)

I stopped working

- 1 Yes
- 2 No

**ca011b** (changed job in section Caregiving)

I changed job

- 1 Yes
- 2 No

**ca011c** (dropped out of school in section Caregiving)

I dropped out of school

- 1 Yes
- 2 No

**ca011d** (cut down on hours of work/schooling in section Caregiving)  
I cut down on hours of work/schooling

- 1 Yes
- 2 No

**ca011e** (other changes due caregiving in section Caregiving)  
Other changes, please describe:

- 1 Yes
- 2 No

END OF SUBGROUP

**ca011e\_other** (specify other changes due caregiving in section Caregiving)  
STRING

END OF GROUP

IF ca011a = 1 OR ca011b = 1 OR ca011c = 1 OR ca011d = 1 OR ca011e = 1  
THEN

**ca012** (when changes occurred in section Caregiving)

When did your work or schooling change due to caregiving responsibilities? (If more than one change, please indicate the most recent)

- 1 2019 or before
- 2 January 2020
- 3 February 2020
- 4 March 2020
- 5 April 2020
- 6 May 2020
- 7 June 2020
- 8 July 2020
- 9 August 2020
- 10 September 2020
- 11 October 2020
- 12 November 2020
- 13 December 2020

END OF IF

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

**ca013\_intro** (Section Caregiving)

Have you done any of the following due to your caregiving responsibilities?

**SUBGROUP OF QUESTIONS**

**ca013a** (Missed doctor appointments in section Caregiving)

Missed doctor appointments

1 Yes

2 No

**ca013b** (Reduced or stopped exercising in section Caregiving)

Reduced or stopped exercising

1 Yes

2 No

**ca013c** (Reduced or stopped eating healthy meals in section Caregiving)

Reduced or stopped eating healthy meals

1 Yes

2 No

**ca013d** (Reduced or stopped doing things you enjoyed in section Caregiving)

Reduced or stopped doing things you enjoyed

1 Yes

2 No

**END OF SUBGROUP**

**END OF GROUP**

**END OF IF**

End of section **Caregiving**

Start of section **Covid**

**IF ca001 = 1 THEN**

**intro\_covid** (Section Covid)

The following questions help us understand to what extent the COVID-19 pandemic has impacted your life and caregiving responsibilities. Please consider any effects or consequences of the pandemic, including social-distancing guidelines, friends or relatives being infected with COVID, changes to any costs associated with caregiving, and any other impacts of the pandemic.

**cv001** (change in caregiving responsibilities in section Covid)

Because of the COVID-19 pandemic, your caregiving responsibilities have

1 Increased a lot

2 Increased a little

3 Stayed roughly the same

4 Decreased a little

5 Decreased a lot

**cv002** (change in caregiving costs in section Covid)

Due to the pandemic, have the personal financial costs to you that are associated with providing care increased, decreased, or stayed the same? (for example, commuting expenses, outlays for nursing homes or hourly help that you pay for, or any other expenses that you personally incur)

- 1 Increased a lot
- 2 Increased a little
- 3 Stayed roughly the same
- 4 Decreased a little
- 5 Decreased a lot

**cv003** (biggest challenges in section Covid)

We would like to learn more about the biggest challenges that you have experienced when providing care during the pandemic.

If you are willing, please tell us about the biggest things that may have changed in your caregiving efforts before and after COVID, or any challenges you and the person(s) you care for may have faced?

STRING

END OF IF

End of section **Covid**

Start of section **Burden**

IF ca001 = 1 THEN

```
bu_questions := array(1 →"bu001", 2 →"bu002", 3 →"bu003", 4 →"bu004", 5 →"bu005",  
6 →"bu006", 7 →"bu007", 8 →"bu008", 9 →"bu009", 10 →"bu010", 11 →"bu011", 12  
→"bu012", 13 →"bu013", 14 →"bu014", 15 →"bu015", 16 →"bu016", 17 →"bu017", 18  
→"bu018", 19 →"bu019", 20 →"bu020", 21 →"bu021", 22 →"bu022")
```

/\* The question series bu001 to bu022 are presented in random order per variables bu\_order with values:

- 1 My life satisfaction has suffered because of my caregiving (bu001)
- 2 Because of the time I spend caregiving I don't have enough time for myself (bu002)
- 3 My caregiving responsibilities interfere with my family and private life (bu003)
- 4 I feel angry when I am around my care recipient (bu004)
- 5 My caregiving responsibilities interfere with my work life (bu005)

- 6 I feel strained when I am around my care recipient (bu006)
- 7 My health has suffered because of my caregiving (bu007)
- 8 I feel like I have lost control of my life since I began caring for my care recipient (bu008)
- 9 I feel like I could be doing more for my care recipient (bu009)
- 10 I am not getting enough sleep because of my caregiving responsibilities (bu010)
- 11 My caregiving activities require a lot of physical effort (bu011)
- 12 I often feel emotionally exhausted because of my caregiving activities (bu012)
- 13 My financial situation has worsened because of my caregiving responsibilities (bu013)
- 14 I feel trapped by my caregiving responsibilities (bu014)
- 15 Caring for my care recipient is important to me (bu015)
- 16 I enjoy caring for my care recipient (bu016)
- 17 Caring for my care recipient makes me feel good (bu017)
- 18 There is value in what I do every day for my care recipient (bu018)
- 19 My care recipient appreciates my caregiving efforts (bu019)
- 20 I have family and/or friends that make me feel supported in my caregiving responsibilities (bu020)
- 21 I have family and/or friends that can provide respite from my caregiving responsibilities if needed (bu021)
- 22 I am confident I can provide the care that my care recipient needs (bu022)

Answer options for all questions in the series are:

- 1 Strongly disagree
- 2 Disagree
- 3 Neither agree nor disagree
- 4 Agree
- 5 Strongly agree

\*/

IF sizeof(bu\_order) = 0 THEN

```
bu_order := shuffleArray(array(1 →1, 2 →2, 3 →3, 4 →4, 5 →5, 6 →6, 7 →7, 8 →8, 9
→9, 10 →10, 11 →11, 12 →12, 13 →13, 14 →14, 15 →15, 16 →16, 17 →17, 18 →18,
19 →19, 20 →20, 21 →21, 22 →22))
```

END OF IF

#### GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

##### **bu\_intro** (Section Burden)

The following questions ask you about how providing care for that family member or close friend has affected you and your life, if at all.

Please tell us how much you agree or disagree with the following statements.

##### SUBGROUP OF QUESTIONS

```
LOOP FROM 1 TO 7
```

```
/* Question series bu001 to bu022 are presented in random order per variables
bu_order as described above. */
```

```
END OF LOOP
```

END OF SUBGROUP

END OF GROUP

#### GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

##### **bu\_intro2** (Section Burden)

Please tell us how much you agree or disagree with the following statements.

##### SUBGROUP OF QUESTIONS

```
LOOP FROM 8 TO 14
```

```
/* Question series bu001 to bu022 are presented in random order per variables
bu_order as described above. */
```

```
END OF LOOP
```

END OF SUBGROUP

END OF GROUP

## GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

**bu\_intro2** (Section Burden)

Please tell us how much you agree or disagree with the following statements.

### SUBGROUP OF QUESTIONS

LOOP FROM 15 TO 22

/\* Question series bu001 to bu022 are presented in random order per variables  
bu\_order as described above. \*/

END OF LOOP

END OF SUBGROUP

END OF GROUP

END OF IF

End of section **Burden**

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 interview?

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

STRING

IF ca001 = 1 THEN

reward := 7

ELSE

reward := 1

END OF IF

dummy := doPayout(reward)

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. \*/