

UnderStandingAmericaStudy

UAS 634: CAREGIVER SURVEY



Survey author(s): Marco Angrisani

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1 INTRODUCTION

This UAS panel survey, titled "UAS 634: Caregiver Survey", asks respondents who are caregivers (as indicated in UAS 641) about how they are feeling and doing. UAS respondents who are eligible and decide to participate may be asked to participate in a project over a one-year period to understand even more about the impacts of caregiving on their life. 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 indicated they are a caregiver in UAS 641.

As such, this survey was made available to 2473 UAS participants. Of those 2473 participants, 2337 completed the survey and are counted as respondents. Of those who are not counted as respondents, 73 started the survey without completing and 63 did not start the survey. The overall response rate was 94.5%.

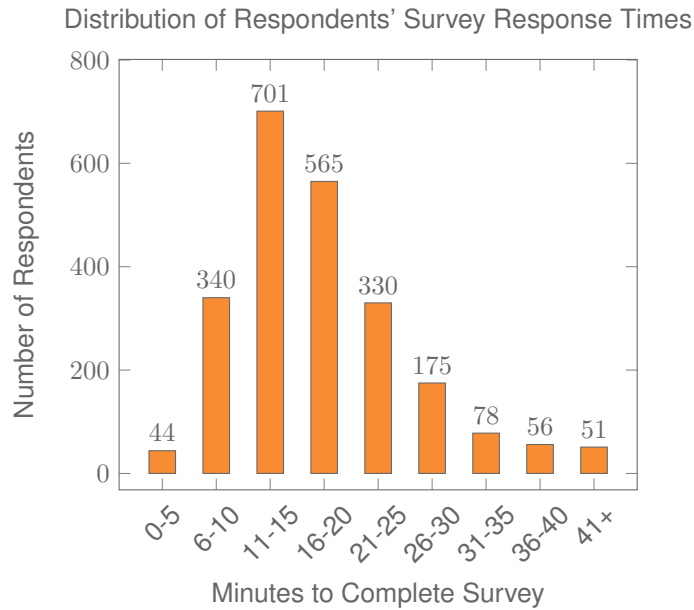
Note: We are unable to provide sample weights for a small number of UAS members (see the Sample and weighting section below for details). If they completed the survey, these members are included in the data set with a weight of zero, but accounted for in the computation of total sample size and survey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

The detailed survey response rate is as follows:

UAS634 - Response Overview	
Size of selected sample	2473
Completed the survey	2337
Started but did not complete the survey	73
Did not start the survey	63
Response rate	94.5%

2.2 Timings

The survey took respondents an average of 18 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.

3 STANDARD VARIABLES

Each Understanding America Study data set 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. These variables are based on the questions asked quarterly in the My Household survey after the application of a cleaning process (<https://uasdata.usc.edu/page/Data+Cleaning+Process>). They are the following:

- **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 `jemuashhidi/emi`. For the primary respondent this identifier is 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 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).
- **uashhid.current**: the current household identifier of the respondent. Uniquely identifies the household a UAS panel member belongs to in a given survey INDEPENDENT of the exact composition of the household in terms of who else in the household are UAS members. Missing (.n) for respondents who are in a single-UAS member household. Available on request in data sets prior to September 3, 2025.
- **survhhid**: uniquely identifies the household a UAS panel member belongs to in a given survey DEPENDENT on the exact composition of the household in terms of who else in the household are UAS members. Is set to missing (.n) if no other household members are UAS panel members at the time of the survey. 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
35. MSG 2025/02
36. MSG 2025/09

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 DEMOGRAPHICS

Every UAS survey data set also includes demographic variables, which provide background information about the respondent and their 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 demographic variables are based on the questions taken from the My Household survey after the application of the cleaning process.

The following variables are available in survey data sets after October 8, 2025:

- **sex**: indicates the sex of the respondent as assigned at birth. Is set to gender if the respondent has not filled out My Household after October 8, 2025.
- **genderid**: indicates the current gender of the respondent. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025. Available in data sets after October 8, 2025.
- **dateofbirth_year**: indicates the year of birth of the respondent.
- **age**: indicates 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. Is set to missing (".") if the respondent was not born in the U.S.
- **countryborn**: indicates the country in which the respondent was born. Is set to missing (".") if the respondent was born in the U.S.
- **state reside**: indicates 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**: indicates the marital status of the respondent.
- **livewithpartner**: indicates whether the respondent lives with a partner.
- **education**: indicates the highest level of education attained by the respondent.
- **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 hisplatinio, so an individual may identify as Hispanic or Latino, and also as a member of one or more racial groups.
- **race**: indicates the race the respondent identifies with most (if mixed). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hisplatinio**: indicates whether the respondent identifies him or herself as being Hispanic or Latino. This variable is asked separately from race.
- **mena**: indicates whether the respondent identifies as being of Middle Eastern or North African ancestry. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **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.
- **workemployer**: indicates whether the respondent works for an employer. Is set to missing (".e") if no answer for laborstatus was given by the respondent. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **workself**: indicates whether the respondent is self-employed. Is set to missing (".e") if no answer for laborstatus was given by the respondent. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **homemaker**: indicates whether the respondent is a homemaker. Is set to missing (".e") if no answer for laborstatus was given by the respondent. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **student**: indicates whether the respondent is a student. Is set to missing (".e") if no answer for laborstatus was given by the respondent. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **notworking**: indicates whether the respondent is not working and not looking for work. Is set to missing (".e") if no answer for laborstatus was given by the respondent. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **If_other**: indicates whether the respondent has another 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).
- **hourswork**: indicates the number of hours the respondent works per week. Is set to missing (.) if the respondent is not currently working or currently on sick or other leave.
- **hhincome**: indicates 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. Based on the hhmemberin variables if the respondent has not filled out My Household after October 8, 2025. Based on hhcomp_total if the respondent has filled out My Household after October 8, 2025.
- **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. Based on

the hhmemberin variables if the respondent has not filled out My Household after October 8, 2025. Based on hhcomp_total if the respondent has filled out My Household after October 8, 2025.

- **hhcomp_male_0_3**: indicates the number of male children ages 0 through 4 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_female_0_3**: indicates the number of female children ages 0 through 4 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_other_0_3**: indicates the number of other-gendered children ages 0 through 4 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_male_4_12**: indicates the number of male children ages 5 through 12 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_female_4_12**: indicates the number of female children ages 5 through 12 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_other_4_12**: indicates the number of other-gendered children ages 5 through 12 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_male_13_17**: indicates the number of male children ages 13 through 17 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_female_13_17**: indicates the number of female children ages 13 through 17 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_other_13_17**: indicates the number of other-gendered children ages 13 through 17 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.

- **hhcomp_male_18_64**: indicates the number of male adults ages 18 through 64 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_female_18_64**: indicates the number of female adults ages 18 through 64 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_other_18_64**: indicates the number of other-gendered adults ages 18 through 64 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_male_65plus**: indicates the number of male adults ages 65 or older who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_female_65plus**: indicates the number of female adults ages 65 or older who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_other_65plus**: indicates the number of other-gendered adults ages 65 or older who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_total_18_64**: indicates the total number of adults 18 through 64 who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_total_65plus**: indicates the total number of adults 65 or older who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_total_adults**: indicates the total number of adults who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **hhcomp_total_children**: indicates the total number of children who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.

- **hhcomp_total**: indicates the total number of people who are living in the respondent's household right now (even if they only live with the respondent part-time or temporarily). Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **parent_guardian_a**: indicates whether the respondent is the parent or guardian of one or more children ages 0 to 4. Is set to missing (".a") if hhcomp_total_children is not greater than 0. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **parent_guardian_b**: indicates whether the respondent is the parent or guardian of one or more children ages 5 to 12. Is set to missing (".a") if hhcomp_total_children is not greater than 0. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.
- **parent_guardian_c**: indicates whether the respondent is the parent or guardian of one or more children ages 13 to 17. Is set to missing (".a") if hhcomp_total_children is not greater than 0. Is set to missing (".v") if the respondent has not filled out My Household after October 8, 2025.

The following variables were provided up until October 8, 2025. Several remain available in data sets created after October 8, 2025 on request.

- **gender**: indicates the gender of the respondent. Available in data sets before October 9, 2025.
- **countryborn_other**: indicates the country of birth if that country is not on the drop down list of countries shown to the respondent'.
- **hisplatinogroup**: indicates which Hispanic or Latino group a respondent identifies him or herself with. Is set to missing (".") if the respondent does not identify him or herself as being Hispanic or Latino. Available in data sets after October 8, 2025 on request.
- **employmenttype**: indicates the employment type of the respondent (employed by the government, by a private company, a nonprofit organization, or self-employed). Is set to missing (".") if the respondent is not currently working or currently on sick or other leave. Available in data sets before October 9, 2025.
- **workfullpart**: indicates whether the respondent works full or part-time. Is set to missing (".") if the respondent is not currently working or currently on sick or other leave. Available in data sets before October 9, 2025.
- **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. Available in data sets before October 9, 2025. Available in data sets after October 8, 2025 on request.

- **hhmembergen_#**: indicates the gender of the household member as reported by the respondent. Available in data sets before October 9, 2025. Available in data sets after October 8, 2025 on request.
- **hhmemberage_#**: indicates the age of the household member. The age is derived from the month and year of birth of the household member as reported by the respondent. Available in data sets before October 9, 2025. Available in data sets after October 8, 2025 on request.
- **hhmemberrel_#**: indicates the relationship of the respondent to the household member as reported by the respondent. Available in data sets before October 9, 2025. Available in data sets after October 8, 2025 on request.
- **hhmemberuasid_#**: indicates the 'uasid' of the 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`. Available in data sets before October 9, 2025. Available in data sets after October 8, 2025 on request.

Lastly, 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 variable 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 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.

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

Start of section **Caregiver**

c.intro (Section Caregiver)

In a recent survey, you told us that you are currently 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. We are interested in how people in the U.S. provide care for a family member or close friend and how caregivers are faring during these times.

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

IF 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

Fill code of question FL_ca003 executed

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

End of section **Caregiver**

Start of section **Relationship**

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

IF not(41 IN b001) THEN

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

b002 (paid to caregive in section Relationship)

Are you paid to provide care to (^a003/the care recipient)?

1 Yes

2 No

3 Other, please specify:

b002_other (other paid to care in section Relationship)

STRING

END OF GROUP

END OF IF

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+

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 Relationship)
STRING

END OF GROUP

End of section **Relationship**

Start of section **Conditions**

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:

c001.other (other insurance coverage care recipient in section Conditions)
STRING

END OF GROUP

IF c001 = RESPONSE AND c001 != 10 AND c001 != 11 THEN

c002 (insurance cover home health services in section Conditions)
Does(any of) their insurance cover home health services, such as home health aids or skilled nursing care?
1 Yes
2 No
3 I don't know

END OF IF

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

IF c003 > 1 THEN

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

c004.minutes (minutes to get to home of care recipient in section Conditions)
How long does it usually take to get to the home of (^a003/the care recipient)?
RANGE 0..59

c004.hours (hours to get to home of care recipient in section Conditions)
RANGE 0..24

END OF GROUP

END OF IF

End of section **Conditions**

Start of section **Tasks**

d_intro (Section Tasks)

Next, we would like to ask how 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 **Intensity**

e001 (how long helping in section Intensity)
How long have you been helping (^a003/the care recipient)?
1 A year or more
2 Less than a year

IF e001 = 1 THEN

e001_years (years helping care recipient in section Intensity)
For how many years?
1 1 year
2 2 years
3 3 years
4 4 years
5 5 years
6 6 years
7 7 years
8 8 years
9 9 years
10 10 years

11 11 years
12 12 years
13 13 years
14 14 years
15 15 years
16 16 years
17 17 years
18 18 years
19 19 years
20 20 years or more

ELSE

e001.months (months helping care recipient in section Intensity)

For how many months?

1 1 month
2 2 months
3 3 months
4 4 months
5 5 months
6 6 months
7 7 months
8 8 months
9 9 months
10 10 months
11 11 months
12 12 months

END OF IF

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 e002 = 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

e004 (needs care recipient met in section Intensity)

Do you think that all the needs of (^a003/the care recipient) are adequately met?

1 Yes

2 No

3 I don't know

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

e005.intro (Section Intensity)

Have you made any of the following changes to **schooling or work** due to your caregiving responsibilities?

SUBGROUP OF QUESTIONS

e005a (I stopped working in section Intensity)

I stopped working

1 Yes

2 No

e005b (I dropped out of school in section Intensity)

I dropped out of school

1 Yes

2 No

e005c (I cut down on hours of work/schooling in section Intensity)

I cut down on hours of work/schooling

1 Yes

2 No

END OF SUBGROUP

END OF GROUP

IF e005a = 1 OR e005b = 1 OR e005c = 1 THEN

e006 (changes caused financial strain in section Intensity)

Have any of these changes caused financial strain?

1 Yes

2 No

END OF IF

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

e006b (how many hours miss from work or school because of caregiving responsibilities in section Intensity)

During the past seven days, how many hours did you miss from work or school because of your caregiving responsibilities?

RANGE 0..168

e006b.dk (dk how many hours miss from work or school because of caregiving responsibilities in section Intensity)

OR

1 Not applicable; I'm not working or in school

e006b.script (Section Intensity)

Please enter the number of hours or check the "Not applicable; I'm not working or in school" box.

END OF GROUP

e006c (how much caregiving responsibilities affect your ability to get things done in section Intensity)

During the past seven days, how much did your caregiving responsibilities affect your ability to get things done at work, at school, or at home?

Consider whether your caregiving responsibilities limited the amount of work you could accomplish, the number of tasks you could complete, and how thoroughly you could complete your tasks. Please select a number on the scale below, where 0 indicates **no negative impact** and 10 **the highest negative impact** on your productivity.

0 0 No impact

1 1

2 2

3 3

4 4

5 5

6 6

7 7
8 8
9 9
10 10 Highest impact

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

e007_intro (Section Intensity)

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

SUBGROUP OF QUESTIONS

e007a (Missed doctor appointments in section Intensity)

Missed doctor appointments

- 1 Yes
- 2 No

e007b (Reduced or stopped exercising in section Intensity)

Reduced or stopped exercising

- 1 Yes
- 2 No

e007c (Reduced or stopped eating healthy meals in section Intensity)

Reduced or stopped eating healthy meals

- 1 Yes
- 2 No

e007d (Reduced or stopped doing things you enjoyed in section Intensity)

Reduced or stopped doing things you enjoyed

- 1 Yes
- 2 No

e007e (Reduced or stopped spending time with friends in section Intensity)

Reduced or stopped spending time with friends

- 1 Yes
- 2 No

e007f (Reduced or stopped spending time with family in section Intensity)

Reduced or stopped spending time with family

- 1 Yes
- 2 No

e007g (Reduced or stopped spending time with spouse or romantic partner in section Intensity)

Reduced or stopped spending time with spouse or romantic partner

- 1 Yes
- 2 No

e007h (Other changes in section Intensity)

Other changes, please specify:

- 1 Yes
- 2 No

END OF SUBGROUP

e007h.other (specify other changes in section Intensity)

Other changes

STRING

END OF GROUP

End of section **Intensity**

Start of section **Wellbeing**

f_intro (Section Wellbeing)

Next, we would like to know your feelings about helping (^a003/the care recipient).

f001 (don't have enough time for yourself in section Wellbeing)

How often do 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 Wellbeing)

How often do 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

f003 (how often feel angry around care recipient in section Wellbeing)

How often do you feel angry when you are around (^a003/the care recipient)?

- 1 Never
- 2 Rarely

- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

f004 (caregiving responsibilities affect relationship with family members or friends in negative way in section Wellbeing)

How often do you feel that your caregiving responsibilities affect your relationship with family members or friends in a negative way?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

f005 (feel strained around care recipient in section Wellbeing)

How often do you feel strained when you are around (^a003/the care recipient)?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

f006 (health has suffered because of caregiving responsibilities in section Wellbeing)

How often do you feel that your health has suffered because of your caregiving responsibilities?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

f007 (not have enough privacy in section Wellbeing)

How often do you feel that you don't have as much privacy as you would like because of (^a003/the care recipient)?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

f008 (feel social life has suffered in section Wellbeing)

How often do you feel that your social life has suffered because of your caregiving responsibilities?

- 1 Never
- 2 Rarely

- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

f009 (lost control of life since started helping care recipient in section Wellbeing)
How often do you feel that you have lost control of your life since you started helping (^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 do you feel uncertain about what to do about (^a003/the care recipient)?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

f011 (feel should be doing more for care recipient in section Wellbeing)
How often do you feel you should be doing more for (^a003/the care recipient)?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

f012 (feel could be doing better job for care recipient in section Wellbeing)
How often do you feel you could be doing a better job in caring for (^a003/the care recipient)?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Quite frequently
- 5 Nearly always

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

f013_intro (Section Wellbeing)

Next, we have a few questions about your experience helping (^a003/the care recipient). For each statement, please mark whether this describes your situation not so much, somewhat, or very much.

SUBGROUP OF QUESTIONS

f013 (Helping care recipient has made more confident about abilities in section Wellbeing)

Helping (^a003/the care recipient) has made you more confident about your abilities

- 1 Not so much
- 2 Somewhat
- 3 Very much

f014 (Helping care recipient has taught to deal with difficult situations in section Wellbeing)

Helping (^a003/the care recipient) has taught you to deal with difficult situations

- 1 Not so much
- 2 Somewhat
- 3 Very much

f015 (Helping care recipient has brought closer to them in section Wellbeing)

Helping (^a003/the care recipient) has brought you closer to them

- 1 Not so much
- 2 Somewhat
- 3 Very much

f016 (Helping care recipient gives satisfaction that they are well cared for in section Wellbeing)

Helping (^a003/the care recipient) gives you satisfaction that they are well cared for

- 1 Not so much
- 2 Somewhat
- 3 Very much

END OF SUBGROUP

END OF GROUP

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 use the following strategies when you are experiencing stress. 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

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 **Social**

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

h_intro (Section Social)

Next, we have some questions regarding your relationship with (^a003/the care recipient). Please check the answer that best shows how you feel about each statement:

SUBGROUP OF QUESTIONS

h001 (How much do they really understand the way you feel about things in section Social)

How much do they really understand the way you feel about things

- 1 Not at all
- 2 A little
- 3 Some
- 4 A lot

h003 (How much can you open up to them if you need to talk about your worries in section Social)

How much can you open up to them if you need to talk about your worries

- 1 Not at all
- 2 A little
- 3 Some
- 4 A lot

h004 (How often do they make too many demands on you in section Social)

How often do they make too many demands on you

- 1 Not at all
- 2 A little
- 3 Some
- 4 A lot

h007 (How much do they get on your nerves in section Social)

How much do they get on your nerves

- 1 Not at all
- 2 A little
- 3 Some
- 4 A lot

END OF SUBGROUP

END OF GROUP

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

h005.intro (Section Social)

Next, we have some questions about your close family members and friends (not including (^a003/the care recipient)). Please check the answer that best shows how you feel about each statement:

SUBGROUP OF QUESTIONS

h008 (close family members and friends how much do they really understand the way you feel about things in section Social)

How much do they really understand the way you feel about things

- 1 Not at all
- 2 A little
- 3 Some
- 4 A lot

h010 (close family members and friends how much can you open up to them if you need to talk about your worries in section Social)

How much can you open up to them if you need to talk about your worries

- 1 Not at all
- 2 A little
- 3 Some
- 4 A lot

h011 (close family members and friends how often do they make too many demands on you in section Social)

How often do they make too many demands on you

- 1 Not at all
- 2 A little
- 3 Some
- 4 A lot

h014 (close family members and friends how much do they get on your nerves in section Social)

How much do they get on your nerves

- 1 Not at all
- 2 A little
- 3 Some
- 4 A lot

END OF SUBGROUP

END OF GROUP

h022 (choice in taking on caregiving responsibility for care recipient in section Social)

Do you feel you had a choice in taking on the caregiving responsibility for (the care recipient)?

- 1 Yes
- 2 No

IF h022 = 2 THEN

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

h022a (why no choice to provide caregiving to care recipient in section Social)

What was the main reason you had no choice?

- 1 (^a003/the care recipient) expected me to provide care
- 2 Others, including family members, expected me to provide care
- 3 There is no one else available to provide care
- 4 Financial reasons/ can't afford to pay someone to provide care.
- 5 Other reason, please specify:

h022a_other (other why no choice to provide caregiving to care recipient in section Social)

STRING

END OF GROUP

END OF IF

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

h023_intro (Section Social)

Think of those who need help with basic personal activities because they are unable to handle them by themselves. How do you think the help should be shared between these groups? Give a percentage (from 0% to 100%) for each group, making sure the total adds up to 100%.

SUBGROUP OF QUESTIONS

h023a (shared with government in section Social)

Government

STRING

h023b (shared with private companies/for-profit in section Social)

Private companies/for-profit

STRING

h023c (shared with non-profit/charities/religious organizations in section Social)

Non-profit/charities/religious organizations

STRING

h023d (shared with family/relatives/friends in section Social)

Family/relatives/friends

STRING

h023_total (Total in section Social)

Total

NUMBER (NO DECIMALS ALLOWED)

END OF SUBGROUP

h023_script (Total in section Social)

Please make sure the total equals 100%. Please enter a whole number percentage for each group. Please enter a percentage for each group.

END OF GROUP

End of section **Social**

Start of section **History**

IF a002 > 1 THEN

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

i001_dummy (who is also care recipient in section History)

You indicated that you currently provide care to more than one person. Besides (^a003/the care recipient) (the one who requires the most time and energy from you as a caregiver), what is your relationship to the other person(s) you provide care for?

This is someone (parent, grandparent, wife, husband, child, another family member, neighbor, or close friend) you spend time assisting with basic personal activities because they are unable to 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).

Please select all that apply.

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:

i001_relative (other relative who also is care recipient in section History)
STRING

i001_other (other who also care recipient in section History)
STRING

END OF GROUP

END OF IF

i002 (in past provide care to anyone else than the person(s) currently providing care for in section History)
In the past, did you provide care to anyone else than the person(s) you are currently pro-

viding care for that you no longer provide care for?

1 Yes

2 No

IF i002 = 1 THEN

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

i003_dummy (who is past care recipient in section History)

What is your relationship to the person(s) you provided care for in the past. Please select all that apply.

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 was employed as a paid caregiver
- 42 Other, please specify:

i003_relative (other relative who past care recipient in section History)
STRING

i003_other (other who past care recipient in section History)
STRING

END OF GROUP

END OF IF

i004 (percent chance will provide care, next 5 years, for family member or close friend in section History)

Looking ahead to the next 5 years, what are the chances that you will spend any time assisting a family member or close friend, **including** the individual(s) you have already mentioned, with basic personal activities because they will be 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. 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).

Use the slider below to indicate the percent chance that you will provide care, sometime in the next 5 years, for a family member or close friend.

RANGE 0..100

End of section **History**

Start of section **Uasclear**

alir := /* Preload if the respondent is part of the UAS ALIR project (see <https://uasdata.usc.edu> for details). */

IF alir = 2 THEN

cl_intro (Section Uasclear)

We are about to launch a new study for caregivers called UAS-Caregiving Lifecourse Experiences Assessed in Real-time (UAS-CLEAR). This study, supported by the National Institute of Health, will help researchers understand how people who provide care for a family member or close friend are faring. For this goal, the study will use data from surveys and fitness tracking devices.

Please answer the following questions about the type of phone you have to find out if you are eligible to participate.

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

q_phone (phone in section Uasclear)

Which of the following mobile phones do you currently own or have for personal use? (The phone must be in working condition and have a cell plan or be WiFi-enabled)

I own or have for personal use:

- 1 An Android smartphone
- 2 An Apple iPhone
- 3 Another type of internet-connected phone, please specify:
- 4 A mobile phone that can only make calls or send text messages
- 5 No working mobile phone of any kind

q_phone.other (other phone in section Uasclear)

STRING

END OF GROUP

IF q_phone IN (3,4,5) THEN

earlyexit (Section Uasclear)

Thank you for answering these questions. You do not qualify to join this study. The project requires participants to have an Android or Apple phone in good working condition with specific phone plans that will work with a UAS phone app. We very much appreciate your participation in the UAS, and we will contact you again when there are more UAS surveys to be completed.

havephone := '2'

ELSE

havephone := '1'

END OF IF

IF havephone = 1 THEN

q_phoneplan (phone plan in section Uasclear)

Which of the following types of cell phone plan do you have on your phone?

- 1 A contract for phone and data with a carrier such as Verizon, TMobile, Sprint, AT&T, etc. in which you are billed for the use of the phone on a monthly basis
- 2 Pay-as-you-go plan, where you purchase a number of minutes in advance that are used up as you use the phone, and replenished as needed
- 3 Pre-paid plan, where the cell phone comes with a pre-paid number of minutes. When those minutes are used up, you can buy more, or you can stop using the phone
- 4 I am not sure what kind of plan I have for my mobile phone

IF q_phoneplan IN (2,3,4) THEN

earlyexit (Section Uasclear)

Thank you for answering these questions. You do not qualify to join this study. The project requires participants to have an Android or Apple phone in good working condition with specific phone plans that will work with a UAS phone app. We very much appreciate your participation in the UAS, and we will contact you again when there are more UAS surveys to be completed.

haveplan := '2'

ELSE

haveplan := '1'

END OF IF

END OF IF

IF havephone = 1 AND haveplan = 1 THEN

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

cl.intro2 (Section Uasclear)

Great! You qualify to participate in UAS-CLEAR. We now describe what the study involves. After learning more about the study, if you are interested in participating, you can let us know below and we will follow up with you if you are selected to participate.

One more thing before we move on:

q_sw0 (currently use fitness tracking device in section Uasclear)

Do you currently use a fitness tracking device such as an Apple Watch, Samsung Watch, Fitbit, Google Watch, Garmin, Oura, etc.?

- 1 Yes
- 2 No

END OF GROUP

IF q_sw0 = 1 THEN

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

q_sw1 (fitness tracker you use in section Uasclear)

Which fitness tracker(s) do you use? If you have more than one device, please list the one that you consider your primary device and wear the most often.

- 1 Apple Watch
- 2 Samsung fitness tracker or smartwatch
- 3 Fitbit
- 4 Google fitness tracker or smartwatch
- 5 Garmin fitness tracker or smartwatch
- 6 Oura ring
- 7 Other, please specify:

q_sw1_other (other which fitness tracker(s) currently use in section Uasclear)

STRING

END OF GROUP

IF q_sw1 IN (1,2,3,4) THEN

IF q_sw1 = 1 THEN

havedevice := '1'

ELSEIF q_sw1 = 2 THEN

havedevice := '2'

ELSEIF q_sw1 = 3 THEN

havedevice := '3'

ELSEIF q_sw1 = 4 THEN

havedevice := '4'

END OF IF

ELSE

havedevice := '5'

END OF IF

ELSE

havedevice := '5'

END OF IF

IF havedevice IN (1,2,3,4) THEN

Fill code of question FLFitbitApple executed

compatible_device (Section Uasclear)

Congratulations! You have a compatible fitness tracking device and you can use it for this study. We ask that you participate for at least **one year** starting when you connect your personal (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google

tracker/smartwatch) with the study. After the year is over, you may continue to participate as long as the study continues and you remain enrolled in the UAS.

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

procedures_nonalir (Section Uasclear) **STUDY PROCEDURES**

Participants' Selection: We will randomly select 1,000 interested UAS members to participate in this study. To ensure everyone is fairly represented, we are looking for people across the country of all ages, health, and economic backgrounds.

Enrollment: If you are selected to participate, you will connect your personal (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) to the study. This should take about 5 minutes, and the UAS help desk will be available to provide assistance if you need it.

IF have device IN (1,2,4) THEN

activities_nonalir_apple (Section Uasclear) **Study activities:**

If you are selected to participate: We will ask you to install the UAS phone app called "Zemi" (instructions about how to do that will be provided). We will ask you to use the Zemi app in order to enroll and connect your (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) to the study. This should take about 5 minutes. We will send you instructions for doing this and the UAS help desk will be available if you need assistance. Once you are enrolled, we will ask you to wear your (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) on your wrist at all times, including when you are sleeping. You can take it off for charging, special occasions, or other reasons- just please wear it as much as possible. You will earn up to **\$5 per month** for wearing the (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) and keeping it synced with your phone or tablet. We will ask you to complete a short survey **every three months**, for which you will be paid **\$3 per survey**. Within the first four months of your participation, we will ask you to answer a short survey through your smartphone **five times a day for one week**. We will call this the **"week assessment"**. To do this, you will use the Zemi app. You will earn **\$2 for each short survey you complete**.

ELSE

activities_nonalir_fitbit (Section Uasclear) **Study activities:**

If you are selected to participate: We will ask you to use the UAS study pages to enroll and connect your personal Fitbit to this study (instructions about how to do that will be provided). Once you are enrolled, we will ask you to wear your Fitbit on your wrist at all times, including when you are sleeping. You can take it off for charging, special occasions, or other reasons- -just please wear it as much as possible. You will earn up to \$5 per month for wearing the Fitbit and keeping it synced with your phone or tablet. We will ask you to complete a short survey **every three months**, for which you will be paid **\$3 per survey**. Within the first four months of your participation, we will ask you to answer a short survey through your smartphone **five times a day for one week**. We will call this the **"week assessment."** To do this, you will use the Zemi app. You will earn **\$2 for each short survey you complete**.

END OF IF

END OF GROUP

keyinfo3_nonalir (Section Uasclear)

Communication: During the study, we will send you notifications and reminders to wear and sync your (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) through your UAS study pages or via email.

Data Collected: The (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) typically collects the following health information, although this may vary with the type of (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) you have: Steps, activity, and exercise Heart rate Breathing rate Sleep Oxygen saturation Electrocardiogram Cardiac Fitness Temperature Skin temperature GPS (only if you consent) Device information like model and charging frequency (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) may be able to collect more health information in the future such as blood pressure or glucose. If you agree to participate, we will also have access to the information data that your (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) may have recorded prior to enrolling in the study.

Compensation: You can earn up to **\$142** if you participate in this study for one year. This includes earning **\$5 per month** for wearing your (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) and syncing the data for **at least 20 days each month**. You will be able to track how many days of data we have received through your UAS study pages. It also includes earning **\$3** for answering a short survey **once every three months** and up to **\$70** for completing your "week assessment."

keyinfo4_nonalir (Section Uasclear)

Withdrawal: If you decide to withdraw from the study at any point, you will still receive

any rewards you earned before withdrawing.

How will your data be kept safe: We take several steps to keep your Study Data confidential. First, only UAS staff will have access to any personally identifiable data. The UAS-CLEAR study team, the funding agency and Biomedical Research Alliance of New York (BRANY) will only have access to DEIDENTIFIED study data that is linked only to your UAS ID number. The BRANY IRB (Institutional Review Board) reviews and monitors research studies to protect the rights and welfare of research participants. When you set up your (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) account, any information (including personal information) you provide on the (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) app will be transmitted to (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) as part of their Terms of Service. However, (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) does not retain personal information, and no personal information will be sent from (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) to the study team. UAS will continue to securely maintain your personal or contact information.

Future Use of Information: After removal of any personally identifiable information, your information could be used for future research studies or distributed to another investigator for future research studies without your consent.

Certificate of Confidentiality: To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. The researchers will use the Certificate to resist any demands for information that would identify you.

keyinfo5_nonalir (Section Uasclear)

Risks or Discomforts: This is a minimal risk study, which means that the risk of experiencing any harm or discomfort in this study is no greater than the risk you would encounter in daily life. Some questions may make you feel uncomfortable or distressed. You can choose to stop the study at any time or skip any question. There are potential privacy and security risks. Your study information could be subject to unauthorized access or your data could be linked to you. We plan to minimize the possibility of a breach of confidentiality by instituting data safeguarding procedures and state of the art encryption.

Benefits: You may or may not receive any benefit from being in this study. You may gain new insight about your activity, fitness, sleep, and overall health through wearing your (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) and viewing your (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) data regularly. If you take part in this study, the results

may help the investigators study how people who provide care for a family member or close friend fare on a daily basis and how their wellbeing may be improved.

Alternatives: An alternative would be to not participate in this study. Whether you participate in this study or not will not impact your participation in other UAS studies.

keyinfo6_nonalir (Section Uasclear)

Voluntary Participation: It is your choice whether to participate. If you choose to participate, you may change your mind and leave the study at any time. If you decide not to participate, or choose to end your participation in this study, you will not be penalized or lose any benefits that you are otherwise entitled to.

Participant Termination: You may be removed from this study without your consent for any of the following reasons: you do not follow the investigator's instructions, at the discretion of the investigator or the sponsor, or the sponsor closes the study. If this happens, the investigator will discuss other options with you.

Contact Information: If you have questions or concerns about this study, you can get in touch with your Study Manager, Tania Gutsche, at tgutsche@usc.edu and (213) 821-1819. If you have any questions about your rights as a research subject or complaints regarding this research study, or you are unable to reach the research staff, you may contact a person independent of the research team at the Biomedical Research Alliance of New York Institutional Review Board at 516-318-6877. Questions, concerns or complaints about research can also be registered with the Biomedical Research Alliance of New York Institutional Review Board at <https://www.branyirb.com/concerns-about-research>.

Thank you so much for being a valued Understanding America Study participant.

If you are interested in UAS-CLEAR, please let us know in the next question.

ELSE

no_compatible_device (Section Uasclear)

For this project, we will provide you with a fitness tracking device (Fitbit Charge 6), which is for you to keep.

We ask that you participate for at least **one year** starting when you connect your study-provided Fitbit with the study. After the year is over, you may continue to participate as long as the study continues and you remain enrolled in UAS.

GROUP OF QUESTIONS PRESENTED ON THE SAME SCREEN

procedures_nonalir_nodevice (Section Uasclear)

STUDY PROCEDURES

Participants' Selection: We will randomly select 1,000 interested UAS members to participate in this study. To ensure everyone is fairly represented, we are looking for people across the country of all ages, health, and economic backgrounds.

Enrollment: If you are selected to participate:UAS staff will contact you to confirm your current mailing address and then mail you a Fitbit.Once you receive your Fitbit, we will ask you to install the Fitbit app on your smartphone or tablet within 1 week.The enrollment guide included in the package will help you set up your Fitbit device and account and enroll in the study. This should take you about 10 minutes and the UAS help desk will be available to provide assistance if you need it.

The Fitbit app is free, and you can remove it whenever you wish to withdraw from the study. You will need to share your location information with the Fitbit app to obtain your time zone. However, we will not collect or use this information for research purposes without your consent.

activities_nonalir_nodevice (Section Uasclear)

Study activities:

If you are selected to participate:Once you are enrolled, we will ask you to wear your Fitbit on your wrist at all times, including when you are sleeping. You can take it off for charging, special occasions, or other reasons- -just please wear it as much as possible. You will earn up to **\$5 per month** for wearing the Fitbit and keeping it synced with your phone or tablet.We will ask you to complete a short survey **every three months**, for which you will be paid **\$3 per survey**.Within the first four months of your participation, we will ask you to answer a short survey through your smartphone **five times a day for one week**. We will call this the **"week assessment."** To do this, you will install and use the UAS phone app called "Zemi" (we will contact you with instructions about how to install and use the Zemi app close to that week). You will earn **\$2 for each short survey you complete**.

END OF GROUP

keyinfo3_nonalir_nodevice (Section Uasclear)

Communication: During the study, we will send you notifications and reminders to wear and sync your Fitbit through your UAS study pages or via email.

Data Collected: The Fitbit typically collects the following health information:Steps, activity, and exerciseHeart rateBreathing rateSleepOxygen saturationElectrocardiogramCardiac FitnessTemperatureSkin temperatureGPS (only if you consent)Device information like model and charging frequencyFitbit may be able to collect more health information in the future such as blood pressure or glucose**Compensation:** You can

earn up to **\$302** if you participate in this study for one year. This includes earning **\$5 per month** for wearing your study-provided Fitbit for **at least 20 days each month**. You will be able to track how many days of data we have received through your UAS study pages. It also includes earning **\$3** for answering a short survey **once every three months** and up to **\$70** for completing your "week assessment." Finally, it includes the **\$160** value of the study-provided Fitbit, which is yours to keep.

keyinfo4_nonalir_nodevice (Section Uasclear)

Withdrawal: If you decide to withdraw from the study at any point, you will still receive any rewards you earned before withdrawing.

How will your data be kept safe: We take several steps to keep your Study Data confidential. First, only UAS staff will have access to any personally identifiable data. The UAS-CLEAR study team, the funding agency and Biomedical Research Alliance of New York (BRANY) will only have access to DEIDENTIFIED study data that is linked only to your UAS ID number. The BRANY IRB (Institutional Review Board) reviews and monitors research studies to protect the rights and welfare of research participants. When you set up your Fitbit account, any information (including personal information) you provide on the Fitbit app will be transmitted to Fitbit as part of their Terms of Service. However, Fitbit does not retain personal information, and no personal information will be sent from Fitbit to the study team. UAS will continue to securely maintain your personal or contact information.

Future Use of Information: After removal of any personally identifiable information, your information could be used for future research studies or distributed to another investigator for future research studies without your consent.

Certificate of Confidentiality: To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. The researchers will use the Certificate to resist any demands for information that would identify you.

keyinfo5_nonalir_nodevice (Section Uasclear)

Risks or Discomforts: This is a minimal risk study, which means that the risk of experiencing any harm or discomfort in this study is no greater than the risk you would encounter in daily life. Some questions may make you feel uncomfortable or distressed. You can choose to stop the study at any time or skip any question. There are potential privacy and security risks. Your study information could be subject to unauthorized access or your data could be linked to you. We plan to minimize the possibility of a breach of confidentiality by instituting data safeguarding procedures and state of the art encryption.

Benefits: You may or may not receive any benefit from being in this study.

You may gain new insight about your activity, fitness, sleep, and overall health through wearing your Fitbit and viewing your Fitbit data regularly. If you take part in this study, the results may help the investigators study how people who provide care for a family member or close friend fare on a daily basis and how their wellbeing may be improved.

Alternatives: An alternative would be to not participate in this study. Whether you participate in this study or not will not impact your participation in other UAS studies.

keyinfo6_nonalir_nodevice (Section Uasclear)

Voluntary Participation: It is your choice whether to participate. If you choose to participate, you may change your mind and leave the study at any time. If you decide not to participate, or choose to end your participation in this study, you will not be penalized or lose any benefits that you are otherwise entitled to.

Participant Termination: You may be removed from this study without your consent for any of the following reasons: you do not follow the investigator's instructions, at the discretion of the investigator or the sponsor, or the sponsor closes the study. If this happens, the investigator will discuss other options with you.

Contact Information: If you have questions or concerns about this study, you can get in touch with your Study Manager, Tania Gutsche, at tgutsche@usc.edu and (213) 821-1819. If you have any questions about your rights as a research subject or complaints regarding this research study, or you are unable to reach the research staff, you may contact a person independent of the research team at the Biomedical Research Alliance of New York Institutional Review Board at 516-318-6877. Questions, concerns or complaints about research can also be registered with the Biomedical Research Alliance of New York Institutional Review Board at <https://www.branyirb.com/concerns-about-research>.

Thank you so much for being a valued Understanding America Study participant.

If you are interested in UAS-CLEAR, please let us know in the next question.

END OF IF

consent (consent in section Uasclear)

Do you wish to be considered to participate in UAS-CLEAR?

1 Yes, I consent to be considered to participate in UAS-CLEAR

2 No, I do not consent to be considered to participate in UAS-CLEAR.

IF consent = 1 THEN

consent.yes (Section Uasclear)

Thanks! We will follow up with you if you are selected to participate.

```

IF havedevice IN (1,2,3,4) THEN
  consent_gps (consent GPS in section Uasclear)
  (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch) col-
  lects health information and GPS information. If you are selected to par-
  ticipate in UAS-CLEAR, do you give the Understanding America Study per-
  mission to use the GPS information collected by the (Apple Watch/Samsung
  tracker/smartwatch/Fitbit/Google tracker/smartwatch)?
  1 Yes, I give the UAS permission to use the GPS information collected by (Apple
  Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch)
  2 No, I do not give the UAS permission to use the GPS information collected by
  (Apple Watch/Samsung tracker/smartwatch/Fitbit/Google tracker/smartwatch)
ELSE
  consent_gps_noddevice (consent GPS no device in section Uasclear)
  Fitbit collects health information and GPS information. If you are selected to partici-
  pate in UAS-CLEAR, do you give the Understanding America Study permission to
  use the GPS information collected by the Fitbit?
  1 Yes, I give the UAS permission to use the GPS information collected by Fitbit
  2 No, I do not give the UAS permission to use the GPS information collected by Fitbit

  consent_gps := consent_gps_noddevice
END OF IF
ELSEIF consent = 2 THEN
  whyrefused (why refused in section Uasclear)
  Please let us know why you are not interested in participating in this project.
  STRING
END OF IF
ELSE
  reward := '6'
END OF IF
ELSE
  cl.intro.alir (Section Uasclear)
  We are about to launch a new study for caregivers called UAS_Caregiving_Lifecourse
  Experiences_Assessed_in_Real-time (UAS-CLEAR). This study, supported by the National
  Institute of Health, will help researchers understand how people who provide care for
  a family member or close friend are faring. For this goal, the study will use data from
  surveys and Fitbit watches. As a valued participant in the America Life in Realtime
  (ALiR) project, you are automatically eligible to participate in UAS-CLEAR.

  The duration of the UAS-CLEAR study is one year, during which we ask you to
  keep wearing your Fitbit as you are already doing for the ALiR project and answer
  additional surveys.

```

cl_intro_alir2 (Section Uasclear)

We now describe what the study involves and ask you whether you are interested in participating.

procedures_alir (Section Uasclear)

STUDY PROCEDURES

Participants' Selection: We expect about 1,000 UAS members to participate in this study. To ensure everyone is fairly represented, we are looking for people across the country of all ages, health, and economic backgrounds.

Enrollment: If you are interested in participating in this project, you will be automatically enrolled in the UAS-CLEAR study since you are already participating in the ALiR study.

activities_alir (Section Uasclear)

Study activities:

If you are interested in participating: We will ask you to wear your Fitbit on your wrist at all times, including when you are sleeping. You can take it off for charging, special occasions, or other reasons - just please wear it as much as possible. You will earn up to **\$5 per month** for wearing your Fitbit and keeping it synced with your phone or tablet. By wearing your Fitbit, you will contribute data to both ALiR and UAS-CLEAR at once, but will earn the rewards of each study **separately**, a total of up to **\$10 a month**. We will ask you to complete a short survey **every three months**, for which you will be paid **\$3 per survey**. Within the first four months of your participation, we will ask you to answer a short survey through your smartphone six times a day for **one week**. We will call this the **"week assessment."** To do this, you will install and use the UAS phone app called "Zemi" (we will provide you with instructions about how to install and use the Zemi app close to that week). You will earn **\$2 for each short survey you complete**.

keyinfo3_alir (Section Uasclear)

Communication: During the study, we will send you notifications and reminders to wear and sync your Fitbit through your UAS study pages or via email.

Data Collected: The Fitbit typically collects the following health information: Steps, activity, and exercise Heart rate Breathing rate Sleep Oxygen saturation Electrocardiogram Cardiac Fitness Temperature Skin temperature GPS (only if you consent) Device information like model and charging frequency Fitbit may be able to collect more health information in the future such as blood pressure or glucose **Compensation:** You can earn up to **\$142** if you participate in the UAS-CLEAR study for one year. This includes earning **\$5 per month** for wearing your Fitbit for **at least 20 days each month**. You will be able to track how many days of data we have received through your UAS study pages (separately for the ALiR and UAS-CLEAR projects). It also includes earning **\$3** for answering a short survey **once every three months** and up to **\$70** for completing your

"week assessment."

keyinfo4.alir (Section Uasclear)

Withdrawal: If you decide to withdraw from the study at any point, you will still receive any rewards you earned before withdrawing.

How will your data be kept safe: We take several steps to keep your Study Data confidential. First, only UAS staff will have access to any personally identifiable data. The UAS-CLEAR study team, the funding agency and Biomedical Research Alliance of New York (BRANY) will only have access to DEIDENTIFIED study data that is linked only to your UAS ID number. The BRANY IRB (Institutional Review Board) reviews and monitors research studies to protect the rights and welfare of research participants. When you set up your Fitbit account, any information (including personal information) you provide on the Fitbit app will be transmitted to Fitbit as part of their Terms of Service. However, Fitbit does not retain personal information, and no personal information will be sent from Fitbit to the study team. UAS will continue to securely maintain your personal or contact information.

Future Use of Information: After removal of any personally identifiable information, your information could be used for future research studies or distributed to another investigator for future research studies without your consent.

Certificate of Confidentiality: To help us protect your privacy, we have obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. The researchers will use the Certificate to resist any demands for information that would identify you.

keyinfo5.alir (Section Uasclear)

Risks or Discomforts: This is a minimal risk study, which means that the risk of experiencing any harm or discomfort in this study is no greater than the risk you would encounter in daily life. Some questions may make you feel uncomfortable or distressed. You can choose to stop the study at any time or skip any question. There are potential privacy and security risks. Your study information could be subject to unauthorized access or your data could be linked to you. We plan to minimize the possibility of a breach of confidentiality by instituting data safeguarding procedures and state of the art encryption.

Benefits: You may or may not receive any benefit from being in this study. You may gain new insight about your activity, fitness, sleep, and overall health through wearing your Fitbit and viewing your Fitbit data regularly. If you take part in this study, the results may help the investigators study how people who provide care for a family member or close friend fare on a daily basis and how their wellbeing may be improved.

Alternatives: An alternative would be to not participate in this study. Whether you participate in this study or not will not impact your participation in other UAS studies.

keyinfo6.alir (Section Uasclear)

Voluntary Participation: It is your choice whether to participate. If you choose to participate, you may change your mind and leave the study at any time. If you decide not to participate, or choose to end your participation in this study, you will not be penalized or lose any benefits that you are otherwise entitled to.

Participant Termination: You may be removed from this study without your consent for any of the following reasons: you do not follow the investigator's instructions, at the discretion of the investigator or the sponsor, or the sponsor closes the study. If this happens, the investigator will discuss other options with you.

Contact Information: If you have questions or concerns about this study, you can get in touch with your Study Manager, Tania Gutsche, at tgutsche@usc.edu and (213) 821-1819. If you have any questions about your rights as a research subject or complaints regarding this research study, or you are unable to reach the research staff, you may contact a person independent of the research team at the Biomedical Research Alliance of New York Institutional Review Board at 516-318-6877. Questions, concerns or complaints about research can also be registered with the Biomedical Research Alliance of New York Institutional Review Board at <https://www.branyirb.com/concerns-about-research>.

Thank you so much for being a valued Understanding America Study participant.

If you are interested in UAS-CLEAR, please let us know in the next question.

consent (consent in section Uasclear)

Do you wish to be considered to participate in UAS-CLEAR?

1 Yes, I consent to be considered to participate in UAS-CLEAR

2 No, I do not consent to be considered to participate in UAS-CLEAR.

IF consent = 1 THEN

consent_yes (Section Uasclear)

Thanks! We will follow up with you if you are selected to participate.

ELSEIF consent = 2 THEN

whyrefused (why refused in section Uasclear)

Please let us know why you are not interested in participating in this project.

STRING

END OF IF

END OF IF

End of section **Uasclear**

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. */