

## The Pittsburgh Regional Caregiver Survey Detailed Survey Methods

### Overview and sponsorship

The *Pittsburgh Regional Caregivers Survey* involved telephone interviews with more than 1,000 informal caregivers in the seven-county Pittsburgh Metropolitan Statistical Area, primarily in Allegheny County. It was sponsored by the Stern Family Foundation and the Emily Kelly Roseburgh Memorial Fund of The Pittsburgh Foundation. The survey was conducted by the University Center for Social & Urban Research (UCSUR) at the University of Pittsburgh in collaboration with the Health Policy Institute (also at the University of Pittsburgh).

### Target population

The target population was unpaid, informal caregivers (most were family members) of adults age 50 and older residing in Allegheny (Pittsburgh, PA), Armstrong, Butler, Beaver, Fayette, Washington and Westmoreland counties (all in PA and adjacent to Allegheny County). Caregivers could be of any age, and there were no requirements that the respondent be the “primary caregiver,” or the person who provides the most care to the care recipient.

### Caregiver definition

“Caregiver” was defined by the following screener section:

*Many people need different kinds of help as they get older, or when they have a serious or long-term illness or disability. Most often the people who provide this help or care are family members, partners, or good friends. They are called family caregivers, using the term “family” broadly.*

*Family caregivers provide different kinds of help. It can be help with personal care such as bathing, dressing, or moving from bed to chair. It can be help with household tasks such as managing finances, making appointments, or providing transportation. It can also be help with medical/nursing tasks like managing medications, operating equipment like oxygen tanks or suctioning tubes, or giving injections.*

*This survey is about these different kinds of care. It is considered unpaid care, even if the family caregiver is reimbursed by the ill person or others for transportation costs and other expenses.*

***Are you or anyone in your household currently providing unpaid care to a relative, partner, or friend age 50 years or older to help them take care of themselves because of a chronic illness or disability? This may include helping with personal needs, household chores, or medical / nursing tasks. It might also be managing a person's finances or arranging for outside services. This adult need not live with you.***

***1. YES***

***2. NO (NOT A CAREGIVER – not eligible)***

*Beyond emotional support and companionship, caregiving may include many different types of specific help.*

***Do you currently help with PERSONAL CARE TASKS, such as bathing, dressing, grooming, eating, moving from bed to chair, or going to the toilet?***

1. YES

2. NO

***Do you currently help with HOUSEHOLD TASKS, such as shopping, managing personal finances, arranging for outside services, or providing transportation?***

1. YES

2. NO

***Do you currently help with MEDICAL OR NURSING TASKS, such as managing medications, changing dressing on wounds, or monitoring equipment like oxygen tanks?***

1. YES

2. NO

***Must say YES TO AT LEAST ONE OF THE THREE FOLLOW-UP QUESTIONS ABOVE TO QUALIFY.***

#### Field operations

Data were collected between February 14 and July 10, 2017 using computer-assisted telephone interviewing (CATI) by trained UCSUR interviewers. Interviewers were monitored continuously for quality control by field supervisors. Up to 20 attempts were made on different days at varying times of the day on each phone number before classifying the sample point as a non-contact. The survey took an average of 60 minutes to complete and was approved by the Institutional Review Board of the University of Pittsburgh. Participants were paid \$15 for completing the survey.

#### Survey instrument

The survey covered a variety of topics including care recipient (CR) and caregiver (CG) profiles; CR disability / needs for care; kinds of help provided by CG's; caregiver support networks (informal and paid); CG formal support / training; Impacts of caregiving on the CG (physical, financial, emotional, social); CG physical and mental health; Impacts of caregiving on work / employment; CG out-of-pocket expenses; Caregiving following hospitalization (preparation; inclusion); CG interaction with the long-term services and supports (LTSS) system; and CG attitudes towards potential caregiver support policies.

Full question wording and topline frequencies for all survey items is available in a separate PDF file on this website. There are additional PDF files that present breakouts of all survey frequencies by CR age, CG age, CG education level, CG income, CG-CR gender, hours per week spent caregiving, CG-CR relationship, and CR Alzheimer's Dementia status.

#### Sample design

A mix of probability and non-probability sampling methods was used to capture a broad range of caregivers while remaining within budget and time constraints. Methods included probability sampling via random digit dialing (RDD) of both landline and cellular phones with screening for caregivers; and random sampling from listed landline household samples targeting middle-aged and older adults. Non-probability methods included recruitment from the UCSUR Research registry, a pre-recruited panel; and volunteer call-in samples generated using recruitment flyers through local service providers.

The RDD and listed household samples were purchased from Survey Sampling International, Inc. (SSI). The UCSUR research registry has been built over the last five years by recruiting participants of (primarily) telephone surveys conducted by the Center, many of which were RDD or probability-based listed household sample studies. Participants have also been recruited to the registry through advertisements on the website, flyers, and through cross-listings with other University of Pittsburgh research registries. The volunteer sample recruitment through local service providers was facilitated by prior collaborations with those providers, many of whom also provided input to the survey design.

The RDD frame theoretically provides complete coverage of the target caregiver population. The listed landline frames do not cover caregivers with unlisted phone numbers or those who use only cellular telephones. The research registry and volunteer call-in samples are non-probability methods (even though some of the registry participants were recruited using probability methods), and thus provide unknown coverage of the target population.

#### Sample outcome rates by sample type

The table below presents sample outcomes and basic screening, cooperation, and response rates separately by sample type, and for the total sample. More than 37,000 phone numbers were dialed or processed to generate the 1,008 completed interviews.

	<b>RDD</b>	<b>Listed Landline</b>	<b>Research Registry</b>	<b>Volunteer Call-In</b>	<b>Total</b>
<b>Total sample</b>	15776	16720	4541	257	<b>37294</b>
<b>Completed</b>	126	260	434	188	<b>1008</b>
<b>Screened eligible</b>	191	419	680	197	<b>1487</b>
<b>Screened ineligible</b>	4675	5162	2893	43	<b>12773</b>
<b>Unable to screen</b>	10910	11139	968	17	<b>23034</b>
<b>Screening rate</b>	30.8%	33.4%	78.7%	93.4%	<b>38.2%</b>
<b>Cooperation rate</b>	66.0%	62.1%	63.8%	95.4%	<b>67.8%</b>
<b>Response rate</b>	20.3%	20.7%	50.2%	89.1%	<b>25.9%</b>

The following formulas were used to calculate the rates reported in the table:

Screening rate: (screened eligible + screened ineligible / total sample)

Cooperation rate: (completed / screened eligible)

Response rate: (screening rate X cooperation rate)

The overall screening rate was 38.2%, the cooperation rate was 67.8% among identified eligible caregivers, for an final overall response rate of 25.9%. As would be expected, the screening rates were much higher for the research registry and volunteer call-in samples. The cooperation rate was also much higher for the volunteer sample, but was similar for the registry, listed household, and RDD samples.

Sociodemographic and caregiving context differences by sample type (%)

	<b>RDD</b> (n=126)	<b>Listed Landline</b> (n=260)	<b>Research Registry</b> (n=434)	<b>Volunteer Call-In</b> (n=188)	<b>Total</b> (n=1008)
<b>CG–CR Relationship</b>					
Adult Child	61.1	53.1	52.1	55.9	<b>54.2</b>
Spouse	21.4	29.2	16.6	20.7	<b>21.2</b>
<b>CR age 80 and older</b>	48.2	54.2	54.4	58.5	<b>53.9</b>
<b>CG age 65 and older</b>	21.4	39.9	29.5	30.9	<b>31.4</b>
<b>Female CG</b>	64.3	75.8	71.9	85.1	<b>74.4</b>
<b>CG Race</b>					
Non-Hispanic White	81.7	91.2	73.5	81.4	<b>80.6</b>
Non-Hispanic Black	11.9	5.8	21.4	15.4	<b>15.1</b>
<b>CG Bachelors degree or higher</b>	46.8	40.6	45.9	53.7	<b>46.1</b>
<b>CG income \$50K or higher</b>	45.6	47.7	55.0	46.0	<b>50.5</b>
<b>CG provides care 20 ≥ hours per week</b>	34.9	35.2	20.6	55.9	<b>32.8</b>
<b>CR has Alzheimer’s</b>	18.7	22.4	18.7	40.5	<b>23.7</b>

In general, the different sample types were comparable on sociodemographic variables, with a few notable exceptions. The volunteer sample contained older care recipients, more female caregivers, and more caregivers with at least a Bachelor’s degree. The research registry sample consisted of more non-Hispanic black caregivers, and also more caregivers with incomes of at least \$50,000. The listed landline sample resulted in more caregivers age 65 and older. Lastly, the volunteer call-in sample had much higher rates of caregivers providing at least 20 hours of care per week, and who were caring for a recipient who had Alzheimer’s / Dementia.

Estimation and weighting decisions

The mix of probability and non-probability sampling approaches made decisions about how to combine, weight, and/or calibrate the data quite complex. In addition, there are no existing valid benchmark population data for caregivers in the Pittsburgh MSA. This is the first attempt at a large community-based survey of informal caregivers in the Pittsburgh region. Thus, post-stratification raking adjustments were not seen as an option. There have been population-based surveys of caregivers at the national level that could be used for such adjustments. However, given the unique local demographics (i.e., Pittsburgh has more older adults than other regions), we decided against that approach. Another option would be to use the RDD probability sample to adjust or calibrate the remainder of the sample. However, given that we completed only 126 RDD surveys (much higher than anticipated effort for each complete and cost considerations), we decided that this approach was also not optimal. Thus, we decided to present unweighted data. We do plan on controlling for sample type in all statistical analyses for subsequent peer-reviewed papers using the data. In sum, because the sample was drawn using a mix of probability and non-probability methods, some caution is warranted in drawing conclusions about the entire population of local caregivers.

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