

U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy

# DATA USER'S GUIDE FOR THE PUBLIC USE FILE OF THE SURVEY OF LONG-TERM CARE AWARENESS AND PLANNING



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In particular, DALTCP addresses policies concerning: nursing home and communitybased services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared under contract #HHSP233201500039I between HHS's ASPE/DALTCP and Research Triangle Institute. For additional information about this subject, you can visit the DALTCP home page at https://aspe.hhs.gov/office-disability-aging-and-long-term-care-policy-daltcp or contact the ASPE Project Officer, John Drabek, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201; John.Drabek@hhs.gov.

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# ACRONYMS

The following acronyms are mentioned in this report and/or appendices.

ASPE	Office of the Assistant Secretary for Planning and Evaluation
BMI	Body Mass Index
HIV HPV	Human Immunodeficiency Virus Human Papillomavirus
LTC	Long-Term Care
RV	Recreational Vehicle

# **1. INTRODUCTION**

#### 1.1. Study Purpose and Survey Overview

With the aging of the population, the demand and need for long-term care (LTC) is certain to grow, and with it public and private expenditures. Unlike medical care, where insurance is common, few people have private LTC insurance, and Medicare does not cover LTC. Many older adults pay for LTC out of their income and personal savings until they are poor enough to qualify for Medicaid, a means-tested welfare program. Others, to avoid exhausting their financial resources and relying on Medicaid, depend on unpaid family support or go without needed services.

To help inform federal policy on LTC financing and service delivery, the *Survey of Long-Term Care Awareness and Planning*, sponsored by Office of the Assistant Secretary for Planning and Evaluation (ASPE)/U.S. Department of Health and Human Services, collected new national data on Americans' awareness and attitudes towards LTC and how people plan for retirement. More specifically, the main goals of the survey were: (1) to understand consumer attitudes, knowledge, and experiences with LTC, how people plan for the risk of needing LTC, and people's preferences among public policies on LTC financing; and (2) to examine consumer preferences for specific features of individual LTC insurance policies (e.g., benefit levels, length of coverage, and sponsorship).

In brief, information about LTC and retirement planning was obtained from a large sample of individuals 40-70 years of age who were part of an ongoing Internet panel maintained by GfK Custom Research, LLC. A survey instrument was developed by RTI International in consultation with ASPE and a Technical Expert Panel of experts on LTC, LTC insurance, and survey methodology. Part of the survey was a discrete choice experiment (DCE) or conjoint analysis designed to elicit respondent preferences on specific features of LTC insurance. The survey was cognitively assessed and revised based on the results of the testing. GfK Custom Research, LLC, administered the survey; RTI analyzed the survey and produced this public use file and user guide. RTI's Institutional Review Board approved the overall study protocol on September 10, 2013. Data were collected in August-September 2014.

**Appendix A** is the full instrument for the Survey of Long-Term Care Awareness and Planning and **Appendix B** is the code book for the public use file, which contains every variable name, its label, and unweighted and weighted frequencies.

#### 1.2. Sample Design

The sample focused on the 40-70 age group because most private LTC insurance purchases occur at this age, and this group is most likely to be planning their future LTC use (LifePlans, 2017). Younger age groups are less likely to be knowledgeable about LTC, and older age groups are unlikely to be able to afford insurance policies and have high disability rates that preclude them from purchasing policies.

The sample for the survey consisted of 24,878 noninstitutionalized adults aged 40-70, which was a census of all people in this age category who participated in KnowledgePanel®, an Internet panel maintained by GfK. A total of 15,298 persons responded to the survey, yielding a 61.5% response rate. Thirty cases were excluded because they answered fewer than one-third of the substantive survey questions. These 30 cases do not appear in either completed screener or completed survey numbers.

KnowledgePanel®, developed and maintained by GfK Custom Research, is a probability-based online research panel. Panel members are recruited using residential addresses that cover approximately 97% of United States households; individuals are not allowed to simply volunteer for the panel, they must be chosen to participate. Recruited households that do not have an Internet connection receive a free computer and Internet service. KnowledgePanel® consists of about 55,000 adult members (ages 18 and older) and includes persons living in cell phone-only households. The Hispanic population is also represented in KnowledgePanel® with members recruited in both English and Spanish.

For all new panel members, demographic information such as sex, age, race/ethnicity, income, education, and for Latino members, language proficiency is collected in an online "profile" survey. This information is used to determine eligibility for specific studies and eliminates the need for gathering basic demographic information on each panel survey. After this survey is completed, the panel member is regarded as active and ready to be sampled for other surveys.

Steps are taken to ensure that panel members are not overburdened with survey requests. The primary sampling rule is to assign no more than one survey per week to members. This level of survey frequency helps to keep panelists engaged as part of the panel. On average, members of KnowledgePanel participate in about two surveys a month. This frequency is closer to four per month for panel members with characteristics that may be in higher demand.

#### **1.3. Data Collection Instrument**

The full instrument for the Survey of Long-Term Care Awareness and Planning is included in *Appendix A*. The questionnaire was developed by drawing on questions from earlier surveys, including the Health and Retirement Study, America's Health Insurance Plan's Buyer/Non-Buyer Survey, MetLife's Long-Term Care IQ Survey, Lake

Research Partners and American Viewpoint's survey of California voters, the Own Your Future survey, and the Hawaii Long-Term Care Commission survey of Hawaii residents. The survey domains developed for this survey are summarized in **Table 1**.

TABLE 1. Domains of Survey of Long-Term Care Awareness and Planning				
Domain	Topic Areas			
Risk of Needing LTC	Questions concerning health condition, activities of daily living, and expectations of future LTC needs			
Psychological Characteristics, Knowledge, Skills, and Experience	Questions concerning willingness to take risks, family history of use of LTC, and general knowledge of LTC and associated costs			
Beliefs and Concerns About LTC	Questions concerning home ownership, willingness to modify home and make lifestyle and financial changes to support LTC needs, concerns about future disability, and beliefs about who is responsible for LTC, including paying for it			
Retirement and LTC Planning	Questions concerning current employment status, savings for retirement, retirement planning, and family discussions about LTC			
Information Gathering and Decision Making About Insurance	Questions concerning health, LTC insurance and disability insurance coverage, and knowledge of LTC insurance costs			
Core Demographic and Socioeconomic Information	GfK provided already collected sociodemographic information on its Internet panel members. Questions concerning family size and current household assets and income were included to ensure the most up-to-date information.			
Comparing Insurance Policies with a Combination of Features	Questions concerning the preferences of respondents in side-by- side comparisons of LTC insurance policies with varying features (DCE)			

## 1.4. Data Collection

Although the survey was designed by RTI in collaboration with ASPE, the survey was fielded by GfK, Inc. The survey was administered online by computer from August 8, 2014, to September 21, 2014.

Once assigned to the survey, Internet panel members received a notification email letting them know there was a new survey available for them to take. This e-mail notification contained a link that connected them to the survey questionnaire. After 3 days, automatic e-mail reminders were sent to nonresponding panel members in the sample.

GfK operates a modest incentive program to encourage participation and create member loyalty. For surveys, such as this one, requiring 16 or more survey minutes, survey participation is rewarded with a variety of incentives (e.g., small cash awards, gift prizes, sweepstakes opportunities). For this survey, respondents were rewarded for their participation with 10,000 "KP points" (equivalent to about \$10) that can be exchanged for merchandise and other prizes.

The introductory computer screen contained basic information about the study and the informed consent language. Respondents were asked to acknowledge that they had read the introduction and consent to participate in the study prior to completing the questionnaire. The introduction to the survey explained the study and how the data would be kept confidential:

Your name and e-mail address will never be linked to your answers. We will treat your answers as private to the extent permissible by law. You may also choose not to answer any questions.

Respondents self-administered the questionnaire in the privacy of their own home or location of their choice. Although the survey questions are not overly sensitive, some respondents may consider the information to be private. Respondents could refuse to answer any question that they were not comfortable answering.

After data collection was complete, the final data file was generated following strict quality control procedures at GfK, review by multiple supervisors, and random checking on a case level to ensure proper merging and formatting. GfK de-identified and encrypted the data before final delivery to RTI.

#### **1.5.** Analytic Variables Created to Perform Statistical Analyses

In addition to the variables directly taken from the survey, RTI created several analytic variables from the survey to simplify the analyses, which are listed below. In most of these variables, respondents to the survey were given a choice of strongly agree, agree, neither agree nor disagree, disagree, and strongly disagree. For these analytic variables, we recoded these variables to 1 = Agree (strongly agree or agree), 2 = Neutral (neither agree nor disagree), 3 = Disagree (disagree and strongly disagree), or binary variables, 1 = Agree and 0 = Neutral or Disagree.

- Willing to take chances that family or friends will help pay for LTC. (B2\_a)
- Willing to take chances that government will help pay for LTC. (B2\_b)
- Willing to make major modification to home if disabled. (C5\_a)
- Willing to use the value of home to pay for LTC if disabled. (C5\_b)
- Willing to hire an aide to help with personal care if disabled. (C5\_c)
- Willing to rely on spouse or family to provide care if disabled. (C5\_d)
- Willing to attend an adult day care program if disabled. (C5\_e)
- Willing to family or friend move in to provide care if disabled. (C5\_f)

- Willing to move-in with children or family/friends to receive care if disabled. (C5\_g)
- Willing to hire a live-in paid caregiver if disabled. (C5\_h)
- Willing to move into an assisted living residence if disabled. (C5\_i)
- Willing to move into a nursing home if disabled. (C5\_d)
- Concerned about using up savings or income to pay for LTC. (C6\_a)
- Concerned about becoming poor due to LTC expense. (C6\_b)
- Concerned about losing independence. (C6\_c)
- Concerned about being unable to depend on family/friend to take care of you. (C6\_d)
- Concerned about being a burden to family. (C6\_e)
- Concerned about being unable to afford high quality care. (C6\_f)
- Concerned about losing control over LTC. (C6\_g)
- It is responsibility of individual to save and pay for their own LTC. (C7\_a)
- It is responsibility of children/family to provide unpaid LTC. (C7\_b)
- If family can't pay for LTC, relatives should help pay. (C7\_c)
- It is responsibility of government to help pay for LTC for all American. (C7\_d)
- Government should promote the purchase of private LTC insurance through lower taxes for people who buy policies. (C8\_a)
- Government should allow people to purchase LTC with tax-deferred funds. (C8\_b)
- Government should require that all people purchase a basic private LTC insurance policy. (C8\_c)
- Government should pay the cost of care after private LTC insurance benefits run out. (C8\_d)

- Government should offer a public LTC insurance program people can voluntarily join. (C8\_e)
- Government should establish a public LTC insurance program that people are required to join. (C8\_f)
- Everyone should have LTC insurance, and a mandatory, public program is the only way to accomplish that. (G7\_a)
- Everyone should have LTC insurance, but private companies should provide the insurance. (G7\_b)
- Requiring people to buy LTC is OK, as long as the price is not too high. (G7\_c)
- Knowing that I have some LTC insurance will give me peace of mind. (G7\_d)

Other variables that were recoded to simplify analysis included the following:

- Any child living within 10 miles (CHLDNEAR). If there is any child living within 10 miles, than CHLDNEAR = YES, otherwise NO.
- Education (PPEDUCAT: 4-level education) Levels: Less than high school, high school, some college, bachelor's degree or higher.
- Any activities of daily living limitations (ADL\_BIN) 1 = YES, 0 = NO.
- Experience with any LTC (LTCEXP: if respondent answered yes to at least two of the five questions (B7, B8, B9\_a, B9\_b, and B9\_c), then LTCEXP = 1; if not, LTCEXP = 0).
- Knowledge of LTC (LTCKNOW: if at least three of the four questions were answered correctly (B10CORRECT = 1, B11CORRECT = 1, B12 = 2, and B13 = 2), then LTCKNOW = 1; if not = 0).
- Total number of concerns regarding LTC (CONCERNCT: sum of variable C6\_a-C6\_g).
- Retirement planner (RETPLNR: RETPLNR = 1 if the respondent answered "yes" to at least five of the ten questions (D5\_a D5\_j) or four of the eight questions (D6\_a D6\_h); (RETPLNR = missing if the respondent's answers were all missing for the above 18 questions).
- LTC planner (LTCPLNR: LTCPLNR = 1 if at least two of the following conditions are true: C1 in (1, 2), D7\_a = 1, D7\_b = 1, D7\_c = 1)).

#### **1.6. Discrete Choice Experiment**

#### 1.6.1. What Are Discrete Choice Experiments?

DCEs are a quantitative technique for obtaining preferences for a good or service that can be used in the absence of revealed preference data (i.e., actual purchasing behavior) to estimate what people will choose given a choice (Mangham et al., 2009). The method involves asking individuals to state their preferences for hypothetical alternative scenarios. The DCE method is used widely to understand respondents' choice behavior in situations such marketing, transportation economics, environmental economics, and health care (Orme, 2010).

The basic premise of DCEs is that products or services can be characterized by a series of well-defined features or "attributes." A particular strength of DCE compared to other stated preference survey methods is that by having survey participants select among concrete alternatives, the reality of opportunity costs and choice constraints is formally imposed on respondents, as they are when people are actually faced with making a purchase choice. Respondents must be willing to "give up" some features of one alternative to select another and vice versa. In contrast, general or open-ended questions are typically not constrained and may elicit unrealistic estimates of preferences for features or participation.

The theoretical underpinnings of DCEs are based on random utility theory, first developed proposed by Thurstone (1927) and expanded by McFadden (1986). Random Utility Theory posits that a latent construct, known as "utility," exists in a person's head that represents their preferences (Louviere, Flynn, & Carson, 2011). Utility cannot be observed by researchers, which is why it is termed "latent," but a DCE can be used by the researcher to infer the person's utility and therefore his or her preferences (Louviere, Flynn, & Carson, 2011). Specifically, DCEs can be used to estimate the relative preferences that respondents have over the different features of an individual product (e.g., for LTC insurance, such features as length of coverage, daily benefit amount, or whether medical underwriting is required).

The pattern of choices made by a respondent provides the data for the statistical model of behavior, which can be analyzed using standard discrete choice econometric techniques (e.g., Train, 2009). With DCE data, a binary model is estimated in which the dependent variable (the selected alternative) is regressed against the various alternative insurance plan characteristics. The parameter estimates in the choice models indicate the relative importance to respondents of different features of LTC insurance. Although we cannot use the model to predict any one person's choice behavior, on average, the statistical choice shares from DCE data and a logit functional form have been shown to closely approximate observed behavior (Train, 2009). The individual characteristics of a respondent (e.g., 50-year-old White female) are the same for all of the alternatives considered for a given respondent, so parameter estimates for these individual characteristics (e.g., age and race) "cancel out" and are not estimable in discrete choice models. However, all additional choice models can be estimated in

which respondent characteristics are interacted with an "opt-out" binary indicator term for choosing no LTC insurance plan, as in Allaire, Brown, & Wiener (2016). Such information can help identify which features are most desired by which types of respondents.

Another common application of DCE data is to scale the relative preference weights in monetary-equivalent estimates of benefit or "willingness to pay." In economics terminology, these estimates do not necessarily represent what an individual is actually "willing" to pay, but rather reflects the total economic value or utility from consumption that is received. This is a standard measure of social welfare and benefit which is widely used in economic evaluation.

DCEs, however, do have several limitations. First, although data collection for DCEs can be straightforward, designing the questionnaire and data analysis can be challenging. Readers are encouraged to look at the International Society for Pharmaceutical Outcomes Research guidelines for experimental design (Reed-Johnson et al., 2013) statistical analysis (Hauber et al., 2014). Second, DCE estimates are best thought of as long-run potential estimates of demand and represent a generous high upper bound on the policies people would actually purchase. Finally, there may be possible bias in the sample produced by GfK because only those with Internet access and facility with a computer would be able to answer questions in our DCE. Despite these limitations, DCE behavior has generally agreed with real-world behavior over the long term. Notable examples exist in diabetes care, health risk reduction, and Human Papillomavirus (HPV) vaccination (Brown et al., 2014; Salampessy et al., 2015; Telser & Zweifel, 2007).

#### 1.6.2. Long-Term Care Discrete Choice Experiment

The objective of the survey was to understand respondents' preferences about LTC insurance to better understand what factors are more and less important to them. Therefore, we developed a series of paired comparisons of alternative LTC insurance plans. Respondents were asked to compare two hypothetical LTC insurance options (including price) and select which they prefer or choose "neither."

The DCE included in this survey contains seven attributes: (1) a daily benefit; (2) the benefit period; (3) the deductible period; (4) health requirements; (5) type of insurer; (6) monthly premium cost; and (7) voluntary or mandatory enrollment. The specific attributes and their levels used in the DCE are presented in **Table 2**. An example scenario from the LTC DCE is presented in **Figure 1**. We asked each respondent to answer two series of questions: the first set contained five sets of comparisons of LTCI products, and the second contained three sets of comparisons of LTC insurance products. The two sets differed on the number of attributes listed within each comparison. The first set included the first six attributes, while the second set included those six plus whether the enrollment was within a mandatory or voluntary system.

TABLE 2. LTC Insurance Attributes Included in the DCE						
Attribute or Question	Description	Levels				
Daily Benefit	How much the policy pays per day toward your LTC costs	\$300, \$175, \$100, \$50 per day				
Benefit Period	How long the policy provides benefits for	Lifetime, 5 years, 3 years, 1 year				
Deductible Period	When you first become disabled, how long before the insurance company will pay for services	None, 1 month, 3 months, 6 months				
Health Requirements	Whether the plan requires a medical exam and a doctor's signature for purchase	None; Healthy and not disabled				
Type of Insurer	The sponsor or seller of the insurance plan	Private company; Federal Government				
Monthly Premium Cost	The amount you pay each month to maintain coverage	\$30, \$100, \$225, \$400 per month				
Type of Enrollment (DCE2 question only)	Whether purchase of the insurance plan shown was required by law	Voluntary: No one must buy insurance; Universal plan: Everyone must buy this policy				

#### FIGURE 1. An Example of Choice Situation Presented in the Survey of Long-Term Care Awareness and Planning

#### Choice #1

Suppose that you were offered a choice today to enroll in the following two long-term care insurance policies.

	INSUREANCE POLICY FEATURE		POLICY A		POLICY B	
	Daily Benefit		\$300 / day		\$50 / day	
	Benefit Period		5 years		3 years	
	Deductible Period	riod None			6 months	
	Health Requirements		None		Healthy and	
					not disabled	
	Type of Insurer		Private company		Private company	
	Monthly Premium Cost		\$400 / month		\$30 / month	
G4a. Which policy, if any, would you choose if these were [] Policy A they only options available? [] Policy B [] Neither of these policies.						

Of the thousands of potentially different possible pairings that could be constructed and shown in the DCE, we used best DCE practices from the literature to select a statistically efficient design. First, we created 500 unique choice situations for the first five questions, each of was broken into 100 blocks of five choice situations. Next, each respondent was randomly assign a block of choice situations. Then, within that block, the questions were randomly ordered. Finally, the A/B choices were randomly ordered between left and right sides of the screen. This process was then repeated for the second set of questions. By designing the process in this way, we minimized the burden on respondents by asking a small, efficient set of questions which include sufficient variety in plan features to enable interactions with respondent characteristics, are orthogonal (the comparisons are sufficiently uncorrelated to be statistically efficient and minimize standard errors in the estimation), have minimal overlap (few plan features are the same across the two alternatives, ensuring that each question provides new information).

## 1.7. Publicly Available Research Using the Survey

Publicly available research using the Survey of Long-Term Care Awareness and Planning includes the following:

- Allaire, B.T., Brown, D.S., & Wiener, J.M. (2016). Who wants long-term care insurance? A stated preference survey of attitudes, beliefs, and characteristics. *Inquiry*, 53, 1-8.
- Brown, D., Allaire, B., & Wiener, J.M. (2016). Choosing long-term care insurance policies: What do people want? Report to the Office of the Assistant Secretary for Planning and Evaluation. Report to the Office of the Assistant Secretary for Planning and Evaluation. Washington, DC: U.S. Department of Health and Human Services. Available at <u>https://aspe.hhs.gov/basic-report/choosing-long-term-care-insurance-policies-what-dopeople-want</u>.
- Greene, A.M., Thach, N.T., Wiener, J.M. & Khatutsky, G. (2016). *Long-term services and supports: What are the concerns and what are people willing to do?* Report to the Office of the Assistant Secretary for Planning and Evaluation. Washington, DC: U.S. Department of Health and Human Services. Available at <u>https://aspe.hhs.gov/basic-report/long-term-</u> services-and-supports-what-are-concerns-and-what-are-people-willing-do.
- Khatutsky, G., Wiener, J.M., Greene, A.M., & Thach, N.T. (2017). Experience, knowledge, and concerns about long-term services and supports: Implications for financing reform. *Journal of Aging and Social Policy*, 29(1), 51-69.
- Khatutsky, G., Wiener, J.M., Thach, N., & Greene, A.M. (2016). *What do people know about long-term services and supports?* Report to the Office of the Assistant Secretary for Planning and Evaluation. Washington, DC: U.S. Department of Health and Human Services. Available at <u>https://aspe.hhs.gov/basic-report/what-do-people-know-about-long-term-</u> <u>services-and-supports</u>.
- Wiener, J.M., Khatutsky, G., Greene, A.M., Thach, T., Allaire. B., & Brown, D. (2015). Long-term care awareness and planning: What do Americans want? Presented at an Office of the Assistant Secretary for Planning and Evaluation Policy Forum. Washington, DC: U.S. Department of Health and Human Services. Available at <a href="https://aspe.hhs.gov/report/long-term-care-awareness-and-planning-what-do-americans-want">https://aspe.hhs.gov/report/long-term-care-awareness-and-planning-what-do-americans-want</a>.
- Wiener, J.M., Khatutsky, G., Thach, N., & Greene, A.M. (2016). Which way for long-term services and supports financing reform? Report to the Office of the Assistant Secretary for Planning and Evaluation. Washington, DC: U.S. Department of Health and Human Services. Available at: <u>https://aspe.hhs.gov/basic-report/which-way-long-term-services-and-supportsfinancing-reform</u>.

Wiener, J.M., Khatutsky, G., Thach, N., Greene, A.M. & Allaire, B., Brown, D., Lamont, H., Marton, W., & Shipley, S. (2015). Findings from the survey of long-term care awareness and planning research brief. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at <u>https://aspe.hhs.gov/basic-report/findings-survey-long-term-care-awareness-and-planningresearch-brief</u>.

# 2. DATA PROCESSING AND DISCLOSURE ANALYSIS

## 2.1. Weighting and Variance Estimation Procedures

GfK used data from the 2013 March supplement of the Current Population Survey to weight the respondents to represent the noninstitutionalized population of the United States age 40-70 years. Respondents were weighted using the following variables: sex, age, race/ethnicity, census region, metropolitan status, education, and household income.

The statistical weight variable is called "WEIGHT" on this data set. The weight variable is used to calculated weighted frequencies and other estimates. For example, below is the SAS code and output for the weighted frequency distribution of self-reported number of chronic conditions:

```
proc freq data=in.dhhs ltc puf;
 tables A2 CCOND;
 weight WEIGHT;
    run:
                      Chronic condition count 0-6: composite variable
                                   for A2_a-A2_f
                                                 Cumulative
                                                            Cumulative
                A2 CCOND
                         Frequency
                                       Percent
                                                  Frequency
                                                               Percent
                          10028
4024
1040
                     0
                                        65.55
                                                   10028
                                                                  65.55
                                                      14052
15092
                     1
                                          26.30
                                                                   91.86
                                          6.80
                                                                  98.65
                     2
                     3
                               175
                                          1.14
                                                      15267
                                                                  99.80
                                24
                                                      15291
                                           0.16
                     4
                                                                   99.95
                     5
                                 3
                                           0.02
                                                       15294
                                                                   99.97
                                           0.03
                                                       15298
                                                                  100.00
                     6
                                 4
```

Below is an example of logistic regression, using the weight variable, that studies the effect of gender (PPGENDE, 1 = male, 2 = female) on one's willingness to attend an adult day care program several days a week if he or she became disabled (C5\_e\_BIN, 0 = not willing, 1 = willing).

```
proc logistic data=in.dhhs_ltc_puf DESCENDING;
  class ppagecat ppgender ppethm;
  model C5_E_BIN=ppgender;
  weight WEIGHT;
run;
  The LOGISTIC Procedure
  Model Information
```

Data Set IN.DHHS LTC PUF Response Variable C5 e bin If you became disabled, how willing would you be to do the following: attend an adult day care program several days a week? Such programs provide help with personal care, as well as meals and recreational activities (recoded to 2 levels). Number of Response Levels 2 Weight Variable weight Post-Stratification weight Model binary logit Optimization Technique Fisher's scoring Number of Observations Read 15298 Number of Observations Used 15276 Sum of Weights Read 15297.99 Sum of Weights Used 15268.07 Response Profile Ordered Total Total Value C5 e bin Frequency Weight 1 Very Willing/Somewhat Willing 10498 10090.171 2 Not Too Willing/Not At All Willing 4778 5177.901 Missing . . Probability modeled is C5 e bin='Very Willing/Somewhat Willing'. NOTE: 22 observations were deleted due to missing values for the response or explanatory variables. NOTE: 1 response level was deleted due to missing or invalid values for its explanatory, frequency, or weight variables. Class Level Information Design Class Value Variables PPGENDER Female 1 Male -1 The LOGISTIC Procedure Model Convergence Status Convergence criterion (GCONV=1E-8) satisfied. Model Fit Statistics Intercept Intercept and Criterion Only Covariates AIC 19559.132 19541.791 SC 19566.766 19557.059 -2 Log L 19557.132 19537.791 Testing Global Null Hypothesis: BETA=0 Test Chi-Square DF Pr > ChiSq

```
Likelihood Ratio 19.3409 1 <.0001
 Score 19.3495 1 <.0001
 Wald 19.3375 1 <.0001
 Type 3 Analysis of Effects
 Wald
 Effect DF Chi-Square Pr > ChiSq
 PPGENDER 1 19.3375 <.0001
 Analysis of Maximum Likelihood Estimates
 Standard Wald
Parameter DF Estimate Error Chi-Square Pr > ChiSq
Intercept 1 0.6646 0.0171 1508.5710 <.0001
PPGENDER Female 1 0.0752 0.0171 19.3375 <.0001
 Odds Ratio Estimates
 Point 95% Wald
 Effect Estimate Confidence Limits
 PPGENDER Female vs Male 1.162 1.087 1.243
```

In this example, we can conclude that females are 16% (Odds Ratio = 1.162, p-value <0.0001) more willing than males to attend an adult day care program several days a week if they became disabled.

#### 2.2. Protections Against Individual Disclosure

To respect the privacy of survey respondents, it is important to ensure that respondents are not identifiable. To inform our data disclosure procedures, we reviewed Health Insurance Portability and Accountability Act of 1996 requirements and other privacy regulations. We have also reviewed the requirements for archiving data on the National Archive of Computerized Data on Aging website. To protect the identity of individuals, our data disclosure activities include the following:

#### 2.2.1. Remove State of Residence and Some Other Variables

Personally identifiable information variables--data that directly identify an individual such as personal names, addresses, and other unique identifiers--do not appear on the data file. Other identifiable variables such as weight and height pose risk because of extreme values, so they were removed but the variable Body Mass Index (PPH1BMI) is retained.

Geographic variables are important researchers to analyze area differences but they also pose disclosure risk because when crossed with other respondent characteristics it may be possible to identify the respondent. On our data file, the crosstabulation of state and other identifying characteristic such as age, race, or sex has some cells with three or fewer respondents. Thus, state was removed from public use data. However, the four-level (PPREG4) and nine-level regional (PPREG9) variables remain on the file.

#### 2.2.2. Top Coding and Bottom Coding of Continuous Variables

Continuous variables with extreme upper or lower tails were top and bottom coded to ensure that respondents in the upper and lower tails cannot be identified. For example, BMI data above 55 and below 16 are top and bottom coded. *Table 3* lists the variables that were top or bottom coded:

TABLE 3. Survey Variables That are Top and Bottom Coded							
Original Recorded Variable Variable		Label	Top/Bottom Code				
PPHHSIZE	PPHHSIZE_r	Household Size	top code to 7 or more				
C3a	C3a_r	About how much do you still owe on your home mortgage?	top code to 99th percentile (520,000 or more)				
C4b	C4b_r	About how much do you currently owe on your home equity line of credit?	top code to 99th percentile (232,000 or more)				
C5a	C5a_r	What is the present value of your primary residence? That is, what would it bring if it was sold today?	top code to 99th percentile (1,500,000 or more)				
D3	D3_r	(Assuming you return to the workforce,) At what age do you plan to stop working for pay?	top code to 90 or older and bottom code to 40 and under				
ppfs0637	ppfs0637_r	Q30: In an average month, what are your total purchases and expenses, excluding your mortgage or rent?	top code to \$8,000 or more, bottom code to \$100 and less.				
pph20029	pph20029_r	Q48: In the past 12 months, how much has your family spent out-of-pocket for medical expenses not covered by insurance?	top code to \$20,000 or more				

#### 2.2.3. Recode Categorical Variables

Variables on education level (PPEDUC) and household type (PPHOUSE) were recoded because of low count in some categories. PPEDUC has a low count for lower grade categories, such as "no formal education" and "1st, 2nd, 3rd, or 4th grade," so those categories were grouped to form "8th grade or lower" category. The variable PPHOUSE has low counts for people who used a boat, RV, or van as their house; this category is combined with category "A mobile home." This recoding is summarized in **Table 4**.

TABLE 4. Recode of Survey Categorical Variables						
Original Variable	Levels	Label	Recoded Variable	Recode		
PPEDUC	No formal education, 1st, 2nd, 3rd, or 4th grade, 5th or 6th grade, 7th or 8th grade, 9th grade, 10th grade, 11th grade, 12th grade NO DIPLOMA, HIGH SCHOOL GRADUATE, Some college, no degree, Associate degree, Bachelor's degree, Master's degree Professional or Doctorate degree	Education (Highest Degree Received)	PPEDUC _r	Combine the first 4 categories to form '8th grade or lower'		
PPHOUSE	A one-family house detached, A one-family house attached, A building with 2 or more apartments, A mobile home, Boat/RV/van etc.	Housing Type	PPHOUSE _r	Combine the last 2 categories to form 'A mobile home, Boat, RV, van, etc.'		

#### 2.2.4. Combined Variables

Some mental health disorder and medical disease diagnoses are either rare or are highly sensitive (such as HIV) and could be used to identify a respondent. To avoid the disclosure risk yet still provide valuable information for researchers, some variables were combined to create new variables. The changes are summarized in **Table 5**.

- A new variable, PPH1SCHB, was created where PPH1SCHB = 1 if a respondent answered "yes" to any of the three mental health conditions: bipolar (PPH1BIPO), Schizoaffective Disorder (PPH1SCHA), and Schizophrenia (PPH1SCPH).
- HIV (PPH1HIV) and cystic fibrosis (PPH1CYSF) were added to an existing variable, PPH1OTHR (been diagnosed with some other medical conditions), that is if PPH1HIV = 1 or PPH1CYSF = 1, then PPH1OTHR = 1.

A group of variables provided information for up to ten children in the household about their age (F2\_AGE\_CHILD1-F2\_AGE\_CHILD10), gender (F2\_GENDER\_CHILD1-F2\_GENDER\_CHILD10), and whether they live within 10 miles of the respondent (F2\_LIVE\_CHILD1-F2\_LIVE\_CHILD10). These identifiable variables not only pose disclosure risk, but also are difficult for researchers to use.

For each of the first ten children, we first decided whether the child is under 18 or is 18 or older, then added them up for each respondent to create the following variables:

- F2\_under18: How many children are under age 18.
- F2\_18older: How many children are age 18 or older.

TABLE 5. Combined Variables					
Combined Variable Label		Original Variable			
PPH1SCHB	Have you been diagnosed with	PPH1BIPO (bipolar) = 1 or PPH1SCHA			
	any of the following medical	(schizoaffective disorder) = 1 or PPH1SCPH			
	conditions? (Bipolar Disorder,	(schizophrenia)=1			
	Schizophrenia, or				
	Schizoaffective Disorder)				
PPH1OTHR	Been diagnosed with some	PPH1HIV (HIV) = 1 or PPH1CYSF (cystic			
	other medical conditions.	fibrosis) = 1			
F2_under18	How many children are under	Count number of children under age 18:			
	age 18	F2_AGE_CHILD1-F2_AGE_CHILD10			
F2_18older	How many children are 18 or	Count number of children 18 or older:			
	older	F2_AGE_CHILD1-F2_AGE_CHILD10			
F2_under18_male	How many sons are under	Count number of male children under 18:			
	age 18	F2_AGE_CHILD1-F2_AGE_CHILD10,			
		F2_GENDER_CHILD1-F2_GENDER_CHILD10			
F2_under18_female	How many daughters are	Count number of female children under 18:			
	under age 18	F2_AGE_CHILD1-F2_AGE_CHILD10,			
		F2_GENDER_CHILD1-F2_GENDER_CHILD10			
F2_18older_male	How many sons are 18 or	Count number of male children 18 or older:			
	older	F2_AGE_CHILD1-F2_AGE_CHILD10,			
		F2_GENDER_CHILD1-F2_GENDER_CHILD10			
F2_18older_female	How many daughters are 18	Count number of female children 18 or older:			
	or older	F2_AGE_CHILD1-F2_AGE_CHILD10,			
		F2_GENDER_CHILD1-F2_GENDER_CHILD10			
F2_LIVE	How many of your children live	F2_LIVE_CHILD1-F2_LIVE_CHILD10			
	within 10 miles of you?				

For those under 18 or 18 or older, we then added up the children who are male or female and created the following variables:

- F2\_under18\_male: How many sons are under age 18.
- F2\_under18\_female: How many daughters are under age 18.
- F2\_18older\_male: How many sons are age 18 or older.
- F2\_18older\_female: How many daughters are age 18 or older.

We have also combined the ten variables indicating whether a child lived within 10 miles of respondent to create a single variable F2\_LIVE (how many of your children live within 10 miles of you) and then top coded this variable to 5 or more.

# **3. PUBLIC USE FILE**

## 3.1. Public Use File Components

The public use data file has three components:

- 1. Variables from the Survey of Long-Term Care Awareness and Planning. *Appendix A* is the full instrument of the survey.
- 2. Analytic variables previously created for prior analysis, see **Section 1.5** for the list of analytic variables created to perform statistical analysis.
- 3. Variables appended from other GfK surveys. These include variables provide demographic information such as age, sex, race, education, marital status, and geographic location. It also includes variables that asked about respondents' type of investments, financial perspective, medical condition, health information source, opinion on United States health system etc. The GfK variable names are prefixed by "pp."

## 3.2. Access Public Use File

The data set and its format file can be access from <u>https://www.icpsr.umich.edu/icpsrweb/NACDA/studies/36969</u>.

Suppose the user downloaded the data set (dhhs\_ltc\_puf.sas7bdat) and formats file (formats.sas7bcat) and saved them on the computer's C drive. To access data in SAS, simply type the following code:

```
libname in 'c:';
libname library 'c:';
data puf;
  set in.dhhs_ltc_puf;
run;
```

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## DATA USER'S GUIDE FOR THE PUBLIC USE FILE OF THE SURVEY OF LONG-TERM CARE AWARENESS AND PLANNING

## Files Available for This Report

#### MAIN REPORT

- HTML <u>https://aspe.hhs.gov/basic-report/data-users-guide-public-use-file-survey-long-term-care-awareness-and-planning</u>
- PDF <u>https://aspe.hhs.gov/pdf-report/data-users-guide-public-use-file-survey-</u> long-term-care-awareness-and-planning

**APPENDIX A.** Survey of Long-Term Care Awareness and Planning Questionnaire

- HTML <u>https://aspe.hhs.gov/basic-report/data-users-guide-public-use-file-survey-long-term-care-awareness-and-planning-appendix-survey-long-term-care-awareness-and-planning-questionnaire</u>
- PDF <u>https://aspe.hhs.gov/pdf-report/data-users-guide-public-use-file-survey-long-term-care-awareness-and-planning-appendix-survey-long-term-care-awareness-and-planning-questionnaire</u>

**APPENDIX B.** Codebook for Survey of Long-Term Care Awareness and Planning

- HTML <u>https://aspe.hhs.gov/basic-report/data-users-guide-public-use-file-survey-long-term-care-awareness-and-planning-appendix-b-codebook-survey-long-term-care-awareness-and-planning</u>
- PDF <u>https://aspe.hhs.gov/pdf-report/data-users-guide-public-use-file-survey-long-term-care-awareness-and-planning-appendix-b-codebook-survey-long-term-care-awareness-and-planning</u>

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services Office of Disability, Aging and Long-Term Care Policy Room 424E, H.H. Humphrey Building 200 Independence Avenue, S.W. Washington, D.C. 20201 FAX: 202-401-7733

NOTE: All requests must be in writing.

## **RETURN TO:**

Office of Disability, Aging and Long-Term Care Policy (DALTCP) Home <a href="http://aspe.hhs.gov/office-disability-aging-and-long-term-care-policy-daltcp">http://aspe.hhs.gov/office-disability-aging-and-long-term-care-policy-daltcp</a>

Assistant Secretary for Planning and Evaluation (ASPE) Home http://aspe.hhs.gov

U.S. Department of Health and Human Services (HHS) Home http://www.hhs.gov