# HEALTH AND RETIREMENT STUDY 2016 Harmonized Cognitive Assessment Protocol (HCAP)

Release Version: Final, Version 1.0 Release Date: February 2023

Data Description and Usage

To the researcher: This dataset is intended for exclusive use by you under the terms specified in the HRS Sensitive Data Access Use Agreement. If there are any questions about its use, please contact the HRS Help Desk (hrsquestions@umich.edu).

Please cite HRS-HCAP as the data source in any publications or research based upon these data, and provide a copy of any publications to the HRS. The following citation should be included in any research reports, papers, or publications based on these data:

In text: "The Health and Retirement Study (grant number U01 AG009740) and the Harmonized Cognitive Assessment Protocol (grant number U01 AG058499) are sponsored by the National Institute on Aging and conducted by the University of Michigan."

In references: "Langa, KM, Ryan, LH, McCammon, RJ, Jones, RN, Manly, JJ, Levine, DA, Sonnega, A., Farron, M., & Weir, DR. (2020). The Health and Retirement Study Harmonized Cognitive Assessment Protocol Project: Study design and methods. Neuroepidemiology, 54, 64 - 74. doi: 10.1159/000503004." Available at: [https://pubmed.ncbi.nlm.nih.gov/31563909/].

"Weir DR, Langa KM, Ryan LH. 2016 Harmonized Cognitive Assessment Protocol (HCAP): Study Protocol Summary." Available at: [http://hrsonline.isr.umich.edu/index.php?p=shoavail&iyear=ZU].

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# Data Description and Usage

### 1. Introduction

The Harmonized Cognitive Assessment Protocol (HCAP) 2016 was funded as a competing revision to the Health and Retirement Study (HRS) (U01AG009740). Data collection was conducted by the Institute for Social Research, Survey Research Center, at the University of Michigan.

By receiving the data files, you agree to use them for research and statistical purposes only and to make no effort to identify respondents. In addition, you agree to send the HRS a copy of any publications you produce based on the data. See <a href="Obtaining the Data">Obtaining the Data</a> (at the end of this document) for additional details.

### 1A. Study Overview and Purpose

The Harmonized Cognitive Assessment Protocol (HCAP) was developed by the Health and Retirement Study (HRS) for two primary purposes. The first was to update the previous ADAMS study with a new protocol that was less expensive and could be administered to a much larger sample with less stratification, providing a better basis for follow-up studies of incidence (Weir, 20111). The second was to provide a flexible basis for international comparisons with other longitudinal studies, and in particular the HRS family of studies. The HCAP collects a carefully selected set of established and validated cognitive and neuropsychological assessments and informant reports to better characterize cognitive function in older adults. The protocol was designed to harmonize well with prior studies, including the Rush University Memory and Aging Project (Bennett, et al, 2012), the 10/66 studies that rely primarily on the Community Screening Interview for Dementia (CSI-D; Prince, et al, 2011), and the previous HRS dementia study known as ADAMS (Langa, et al, 2005). Versions of HCAP are being conducted in Mexico, India, England, Ireland, Northern Ireland, Chile, China, and South Africa.

To facilitate the use of the data in international comparisons the HRS has for this final release worked with the Gateway to Global Aging team to harmonize variable naming, constructed variables, and imputations so that the data will be easily used with data products created by Gateway from HCAP studies in other countries (web link??). We thank Sandy Chien, Alden Gross, Jinkook Lee, and Erik Meijer for their valuable assistance. As the HCAP data become fully harmonized the studies will be able to make comparable classifications to discriminate Normal, Cognitive Impairment, and Dementia status. The HRS can provide assistance with interviewer training and protocol implementation to studies interested in using HCAP.

# 1B. The Sample Interviewed in 2016

HCAP cases includes a pair of interviews, one by the Target Respondent (preselected HRS panel member, age 65+) and one by an Informant (nominated by the Target Respondent). Ideally, both interviews are conducted at the same time

<sup>&</sup>lt;sup>1</sup> David R. Weir, Robert B. Wallace, Kenneth M. Langa, Brenda L. Plassman, Robert S. Wilson, David A. Bennett, Ranjan Duara, David Loewenstein, Mary Ganguli, Mary Sano, "Reducing case ascertainment costs in US population studies of Alzheimer's disease, dementia, and cognitive impairment—Part 1" Alzheimer's & Dementia 7 (2011) 94-109.

with a trained HRS interviewer in the Target Respondent's home. When schedules do not permit, the Informant interview was conducted by telephone.

While the majority of HCAP cases included both a Target Respondent and Informant interviews, there were some instances where a Target did not nominate any potential informants (n=313). There were also a few cases where only an informant interview was conducted (n=149) as the Target Respondent was not well-enough to attempt an interview. The consent and interview protocols and materials were developed with a series of pilot studies. HCAP was administered in both English and Spanish.

The eligible sample consisted of pre-selected HRS Panel respondents, age 65 or older (birth year 1952 or earlier), who completed their 2016 interview before they become eligible for the HCAP study. Of those who were age-eligible and who completed their 2016 Core Interview, those eligible for HCAP were selected via the following process: (1) Randomly select 1/2 of uncoupled Respondents; (2) Randomly select 1 Respondent from each coupled household.

Additional information about the recruitment and interview process is available in the User Guide which can be downloaded from the HRS Website.

### 1C. Interviews

# 1C1. Respondent Interview

The Respondent interview contain questions that were asked of all HCAP respondents and include the following:

- A MMSE
- B TICS
- C Word List Learning & Recall Immediate
- D Retrieval Fluency
- E Letter Cancellation
- F Backward Count
- G 10/66 Respondent
- H Word List Recall Delayed
- I Story Memory Immediate
- J Word List Recognition
- K Constructional Praxis Immediate
- L Symbol-Digit Modalities Test
- M Constructional Praxis Delayed
- N Story Memory Delayed
- O Logical Memory Recognition
- P Number Series
- 0 Raven's
- R Trail Making
- S CES-D Depressive Symptoms
- T Smell Test (Optional)

## 1C2. Informant Interview

The Informant interview contain questions that were asked of all HCAP informants and include the following:

```
A - Informant Demographics
B - Jorm IQCODE
C - Blessed Part 2
D - Activities
E - CSI-D - Cognitive Activities
F - 10/66 - Informant
G - Blessed Part 1
```

# 1D. Data Updates and Alerts

The 2016 HCAP Final Version 1.0 data contain diagnostic categorizations based on a diagnostic algorithm, sampling weights, imputations and edits to the data to make them better harmonized to other HCAP studies. The HCAP Informant data set includes a new variable INF1RELSCORE. The syntax below generated this score:

```
miss1 = nmiss(INF1CSIDMENTAL rs, INF1ACTIV RS, INF1CSIDMEMORY rs,
INF1CSIDPUT rs, INF1CSIDKEPT rs, INF1CSIDFRDNAME rs, INF1CSIDFAMNAME rs,
INF1CSIDCONVERS rs, INF1CSIDWORDFIND rs, INF1CSIDWORDWRG rs, INF1CSIDPAST rs,
INF1CSIDLASTSEE rs, INF1CSIDLASTDAY rs, INF1CSIDORIENT rs,
INF1CSIDLOSTOUT rs, INF1CSIDLOSTIN rs, INF1CHORES RS, INF1HOBBY RS,
INF1MONEY RS, INF1CHANGE RS, INF1REASON RS);
     miss3 = nmiss(INF1BL2FEED rs, INF1BL2TOILET rs, INF1BL2DRESS rs);
     misstot = (miss3*3) + miss1;
      array a csid{15} INF1CSIDPUT rs INF1CSIDKEPT rs INF1CSIDFRDNAME rs
INF1CSIDFAMNAME rs INF1CSIDCONVERS rs INF1CSIDWORDFIND rs INF1CSIDWORDWRG rs
INF1CSIDPAST rs INF1CSIDLASTSEE rs INF1CSIDLASTDAY rs INF1CSIDORIENT rs
INF1CSIDLOSTOUT_rs INF1CSIDLOSTIN rs INF1CHORES RS INF1CHANGE RS;
      do lcv = 1 to 15;
      if a csid{lcv} eq 1 then a csid{lcv} = .5;
      else if a csid{lcv} eq 2 then a csid{lcv} = 1;
     end;
      if INF1MONEY RS eq 1 then INF1MONEY RS = .5;
     else if INF1MONEY RS eq 2 then INF1MONEY RS = 1;
     if INF1PHYS eq 1 then do;
      INF1CHORES RS = 0;
     INF1BL2FEED rs = 0;
     INF1BL2TOILET rs = 0;
     INF1BL2DRESS rs = 0;
      end;
      if misstot ne 30 then do;
      INF1RELSCORE = (30/(30-misstot))*((sum(INF1ACTIV RS,
INF1CSIDMENTAL rs, INF1CSIDMEMORY rs, INF1CSIDPUT rs, INF1CSIDKEPT rs,
INF1CSIDFRDNAME rs, INF1CSIDFAMNAME rs, INF1CSIDCONVERS rs,
INF1CSIDWORDFIND rs,
      INF1CSIDWORDWRG rs, INF1CSIDPAST rs, INF1CSIDLASTSEE rs,
INF1CSIDLASTDAY rs, INF1CSIDORIENT rs, INF1CSIDLOSTOUT rs, INF1CSIDLOSTIN rs,
INF1CHORES RS, INF1HOBBY RS, INF1MONEY RS, INF1CHANGE RS, INF1REASON RS,
INF1BL2FEED rs, INF1BL2TOILET rs, INF1BL2DRESS rs))-((miss1+miss3)*9));
      end;
```

For more information on the origins of this Score, see https://1066.alzint.org/population based study prevalence.php

Data alerts, new file notifications, and updates concerning the HRS 2016 HCAP Final Release will be placed on the HRS Data Alert web page here.

We recommend that users check this location regularly.

If you have any questions concerning our Final releases, or wish to notify us of errors, please send electronic mail to:

HRS Questions: hrsquestions@umich.edu

### 2. Variable Names and Labels

Variable names closely align with conventions used by the Gateway for Global Aging. Respondent variables begin with the letters "R1" to designate the Respondent wave 1 followed by the specific variable name. Informant variables start with INF1 for informant wave 1, followed by the variable name.

### 3. Data Files

The 2016 HCAP (Final, Version 1.0) data release contains 2 files. The files are listed below along with the name of the file, number of cases (N), and number of variables (NV). The 2016 HCAP data are provided in ASCII format, with fixed-length records. The records in the data files are sorted in order by the primary identifiers. You'll want to use associated SAS, SPSS, or STATA program statements to read the data into the analysis package of your choice.

Prefix	Description	File Name	N	NV
=====	=======================================	=======	====	===
HC	Informant Information	HC16HP_I	3496	294
HC	Respondent Information	HC16HP R	3496	433

The following extensions are used for the 2016 HCAP Final release files:

- .da ASCII data files
- .sas SAS program statements
- .sas7bdat for "ready-to-use" SAS files
- .sps SPSS program statements
- .sav for "ready-to-use" SPSS files
- .do STATA do statements
- .dct STATA dictionary statements
- .dta for "ready-to-use" Stata files
- .txt codebook files

# 4. Primary Identification Variables

Identification variables are stored in character format and are used to link files within and across waves of data.

### 4A. Primary identification variables

Primary identification variables include HHID and PN. The HHID, or Household Identifier, is six digits, and is stable across waves of data collection. The HHID uniquely identifies an original household and any household derived from the original household in subsequent waves of data collection. HHID is

included on each data file in the 2016 HCAP release. Users should note that the HHID and PNs in the Informant File are linked to the HRS-HCAP Respondent. Informants do not have their own unique HHID and PNs.

The PN, or Person Number, is three digits, and uniquely identifies a respondent within an original household (HHID). The PN does not change across waves. PN is included on each data file in the 2016 HCAP release.

# 5. Distribution Files and Directory Structure

### 5A. Distribution Files

The distribution files are packaged for download from our Web site in one large .zip file, HC16.zip, which contains six smaller .zip files and this data description document, in .pdf format, HC16dd.pdf.

```
Data files

HC16da.zip - data files.

Program statement files

HC16sas.zip - SAS program statement (.sas) and "ready-=to-use"

file (.sas7bdat).

HC16sps.zip - SPSS program statement (.sps) and "ready-=to-use"

file (.sav).

HC16sta.zip - STATA program statement (.do/.dct) and "ready-=to-use" file (.dta).

Documentation files

HC16cb.zip - codebook.

H16qn.zip - questionnaire.
```

Users will need to unzip the data files, program statement files, and codebook files. The  $\frac{\text{codebook files}}{\text{codebook for each section}}$  are also available on our Web site in an HTML format which provides an index for each section.

### 5B. Directory Structure

While a particular setup is not required for using the 2016 HRS HCAP files, if the following directory structure is used, then no changes to the path name in the data descriptor files is necessary. If you use a different structure, change the directory references in the distribution files.

Directory	Contents
=======================================	=======================================
c:\HC2016\	Files downloaded from <a href="HRS Web site">HRS Web site</a>
c:\HC2016\codebook\	Unzipped files from HC16cb.zip
c:\HC2016\data\	Unzipped files from HC16da.zip
c:\HC2016\sas\	Unzipped files from HC16sas.zip
c:\HC2016\spss\	Unzipped files from HC16sps.zip
c:\HC2016\stata\	Unzipped files from HC16sta.zip
c:\HC2016\qnaire\	Unzipped files from H16qn.zip

### 6. Program Statements

Each data file comes with associated SPSS, SAS, or STATA program statements to read the data. Files containing SPSS statements are named with a .sps extension, those with SAS statements with a .sas extension, and those with STATA statements with .do and .dct extensions. The statement files are named beginning with the same prefix as the corresponding data file. For example, SAS statements in the file HC16I\_R.sas correspond with the HC16I\_R.da data file

# 6A. Using the Files with SAS

To build a SAS file for a particular dataset, two file types must be present for that dataset: SAS program statement files and .da data files. Files with the suffix "da" contain the raw ASCII data for SAS to read.

A SAS system file can be created by the \*.sas file into the SAS Program Editor. If the data file is located in "c:\HC2016\data", you can run the downloaded \*.sas file as is. A SAS system file (\*.sas7bdat) will be saved to directory "c:\HC2016\sas". If the files are not located in the specified directories, you will need to edit the \*.sas file to reflect the proper locations prior to running the file.

# 6B. Using the Files with SPSS

To build an SPSS file for a particular dataset, two file types must be present for that dataset: .sps program statement files and .da data files. Files with the suffix "da" contain the raw data for SPSS to read.

To create an SPSS system file, open the \*.sps file in SPSS as an SPSS Syntax File. If the data file is located in "C:\HC2016\data", you can run the downloaded \*.sps file as is. An SPSS system file (\*.sav) will be saved to directory "C:\HC2016\spss". If the files are not located in the specified directories, you will need to edit the \*.sps file to reflect the proper locations prior to running the file.

### 6C. Using the Files with Stata

To use Stata with a particular dataset, the following three file types must be present for the Stata dataset: .dct files, .do files and .da data files. Files with the suffix "da" contain the raw data for Stata to read. Files with the suffix "dct" are Stata dictionaries used to describe the data. Files with the suffix "do" are short Stata programs ("do files") which you may use to read in the data.

To create a Stata system file, load the .do file into Stata and then submit it. If the \*.dct files are located in "C:\HC2016\stata" and the data file is located in "C:\HC2016\data", you can run the downloaded .do file as is. If the files are not located in these directories, you must edit the \*.do and \*.dct files to reflect the proper path names before you run the files.

### 7. Documentation

### 7A. Masked Variables

In order to protect the confidentiality of respondents, some variables are either masked or not included in public release data sets. In general, respondent names, addresses, days of specific dates, information on

geographical relocation, and similar variables are not included in publicly released files.

# 7B. Other Specify Questions and Open Ends

"Other Specify" and "Open End", or questions that are answered with text (e.g., activity) are included in final data releases. For the Final release, HRS staff reviewed these comments for the following questions:

```
INF1RELOTH_A, INFORMANT RELATIONSHIP TO RESPONDENT: SPECIFIED INF1ACT6A1, ACTIVITIES: OTHER HOME ACTIVITY 1 - SPECIFIED INF1ACT6B1, ACTIVITIES: OTHER HOME ACTIVITY 2 - SPECIFIED INF1ACT6C1, ACTIVITIES: OTHER HOME ACTIVITY 3 - SPECIFIED INF1ACT18A1, ACTIVITIES: OTHER OUTSIDE HOME ACTIVITY 1 - SPECIFIED INF1ACT18B1, ACTIVITIES: OTHER OUTSIDE HOME ACTIVITY 2 - SPECIFIED INF1ACT18C1, ACTIVITIES: OTHER OUTSIDE HOME ACTIVITY 3 - SPECIFIED
```

Responses were grouped into larger categories to protect respondent confidentiality.

### 8. Obtaining the Data

### 8A. Registering and Downloading the Data

HRS data are available for free to researchers and analysts at the <a href="HRS Website">HRS Website</a>. In order to obtain public release data, you must first register at our Web site. Once you have completed the registration process, your username and password will be sent to you via e-mail. Your username and password are required to download any data files.

By registering all users, we are able to document for our sponsors the size and diversity of our user community allowing us to continue to collect these important data. Registered users receive user support, information related to errors in the data, future releases, workshops, and publication lists. The information you provide will not be used for any commercial use, and will not be redistributed to third parties.

### 8B. Conditions of Use

By registering, you agree to the "Conditions of Use" governing access to Health and Retirement public release data. You must agree to:

- not attempt to identify respondents
- not transfer data to third parties except as specified
- not share your username and password
- include specified citations in work based on HRS data
- provide information to us about publications based on HRS data
- report apparent errors in the HRS data or documentation files
- $\bullet$   $\,$  notify us of changes in your contact information

For more information concerning privacy issues and conditions of use, please read our  $\underline{\text{Conditions of Use}}$ .

### 8C. Publications Based on Data

As part of the data registration process, you agree to include specified citations and to inform HRS of any papers, publications, or presentations based on HRS data. Please send a copy of any publications you produce based on HRS data, with a bibliographical reference, if appropriate, to the address below.

Health and Retirement Study Attn: Papers and Publications The Institute for Social Research P.O. Box 1248 Ann Arbor, MI (USA) 48106-1248

Alternately, you may contact us by e-mail at <a href="https://www.nrsquestions@umich.edu">hrsquestions@umich.edu</a> with "Attn: Papers and Publications" in the subject line.

### 9. If You Need to Know More

This document is intended to serve as a brief overview and to provide guidelines to using the 2016 HRS HCAP (Final, Version 1.0) data. If you have questions or concerns that are not adequately covered here or on our Web site, or if you have any comments, please contact us at hrsquestions@umich.edu. We will do our best to provide answers.

### 9A. HRS Internet Site

Health and Retirement Study public release data and additional information about the study are available on the Internet. To access the data and other relevant information, point your Web browser to the HRS Web site.

https://hrs.isr.umich.edu/about

# 9B. Contact Information

If you need to contact us, you may do so by one of the methods listed below:

Internet: Help Desk at our Web site

E-mail: hrsquestions@umich.edu

Postal service:

Health and Retirement Study The Institute for Social Research The University of Michigan P.O. Box 1248 Ann Arbor, MI 48106-1248

FAX: (734) 647-1186