



**Institutional Review Board Information**

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## I Co-Investigators and Affiliations

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## II Background

### Purpose

The HRS is designed to provide a uniquely rich, longitudinal data set for the community of scientific and policy researchers who study the health, economics and demography of aging. Since its inception in 1990, the design and execution of a series of nationally representative surveys has involved researchers in the fields of economics, sociology, psychology, demography, medicine and public health.

### Survey Design

The HRS is a national longitudinal study based on core biennial interviews of nearly 20,000 individuals representing the US population over age 50. Hispanics and African-Americans were over-sampled. Every six years, the HRS enrolls a new birth cohort in order to maintain a steady-state representation of the over 50 US population. Baseline interviews with existing birth cohorts were conducted in 1992, 1993, 1998, 2004, 2010, and 2016. Participants are followed through the life course with biennial surveys and supplemental data collections. Data are de-identified and made publicly available at no charge to users.

HRS covers a wide range of topics, including: Health conditions and physical functioning; Income, assets and net worth, and pensions; Employment status and job history; Family structure and transfers of time and money; Health insurance, health care utilization and spending; Psychosocial traits, states, and experiences; Attitudes, preferences, expectations and subjective probabilities; Cognitive performance-based testing; Physical performance-based testing; Demographic characteristics; Housing; access to services and services use (community and nursing home); Retirement plans and perspectives; pension plans; End-of-life changes

in health and distribution of assets reported by next-of-kin; Biological data, including venous blood, dried blood spot and salivary and venous blood DNA samples. HRS also collects supplemental data - typically, in the off-years. Some examples of supplemental studies are: Human Capital Mail Survey (HUMS), Consumption and Activities Mail Survey (CAMS), Diabetes Mail Survey, VA Mail Survey, Life History Mail Survey, Healthy Cognitive Aging Project (HCAP). HRS has partnered in the past with Duke University to conduct the Aging, Demographics and Memory Study (ADAMS) which gathered data from in-home assessments of dementia on a subset of the HRS sample.

#### Data Availability

A simple registration process on line will allow interested researchers to download HRS public use data files, at no charge. Available files, detailed on the website, include early and final release datasets, cross wave files, imputation files and researcher contributions.

HRS, through support from the Social Security Administration, also provides access to a cleaned and ready-to-use version of the public data, known as the RAND-HRS Data. RAND-HRS Data are available as a single file which includes the public use data from all waves of the HRS, or separate files for each wave of data. RAND-HRS Data are distributed in SAS, STATA, and SPSS formats, with accompanying documentation. These files are maintained at RAND, and made available for download via the HRS website.

Sensitive health data are made available through an access agreement. These data are derived from survey responses, as well as physical measures and biospecimen collection.

HRS provides a rich set of restricted access data, which multiply analytical opportunities. Restricted access datasets include linkages with Social Security earnings and benefits records, employer provided pension plans, Medicare records, National Death Index records, and sensitive participant information such as detailed occupation and industry data and detailed geographical files. These files are restricted due to concerns for participant confidentiality. Eligible researchers may apply for use of these data by following procedures outlined on the website <http://hrsonline.isr.umich.edu/rda>

#### Data Support

On-line support to data users is available on the HRS website. See Documentation Products at <http://hrsonline.isr.umich.edu/meta/index.html> or email your data question to [HRSQuest@isr.umich.edu](mailto:HRSQuest@isr.umich.edu)

### III Restricted Data

In order to protect the confidentiality of its respondents, the HRS limits access to certain types of data to users who meet rigorous qualifications guaranteeing the protection of the data. Secure data enclaves at the University of Michigan and elsewhere help to broaden access to these restricted data to users who might not otherwise qualify.

Restricted data are derived from many different sources including respondent interview data, administrative linkages with Social Security or Medicare records, employer surveys, and detailed cause of death records from the National Death Index.

Access to these files is limited to researchers who apply for use and meet eligibility requirements. Due to their sensitive nature and the resulting increased risk to participant confidentiality, these files may not be distributed to the general public. Additionally, some restrictions regarding merger of these data apply.

#### Overview of Restricted Access Files

- Social Security data linkage includes income and benefit data
- Medicare data linkage includes information on health care costs, use of services and diagnosis
- National Death Index linkage includes death information such as detailed cause and month/year of death
- Pension detail data include information from coded employer-provided summary plan descriptions
- Industry/Occupation data include participant provided information on occupation and industry details

- Geographical detail data include participant-provided information on state/country of birth and current residence, as well as state, county, ZIPcode and Tract/BNA of the interview site
- Date of Interview data provide day, month and year of participant interview
- Race/Ethnicity data include participant provided race and ethnicity at the time of their enrollment

## IV Sensitive Health Data Products

The Health and Retirement Study strives to provide high quality data without compromising respondent confidentiality. Since respondent health data records contain particularly sensitive information, such data products are released to researchers who qualify for access only through a supplemental registration system. Below, we briefly describe available datasets.

### Biomarker Data

Biomarkers refer to the general range of physiological, metabolic, biochemical, endocrine and genetic measures that can be obtained in living organisms. The term is most commonly used to refer to one-time biochemical or hematological measures made on blood or other available bodily fluids. For many of these measures, there is a normal range, and values outside of this range can serve as an indicator of disease or as an early sign of potential disease.

The Biomarker Data consists of information derived from two types of biological samples obtained in the HRS (in 2006, 2008, 2010, and 2012) to date: blood and saliva. HRS began collecting these samples in 2006 as part of the enhanced face-to-face (EFTF) interview (see below). Saliva is used for DNA extraction, and blood is used to measure a range of other biomarkers. While there are a variety of methods for collecting blood specimens, the HRS has utilized the dried blood spot (DBS) in which participants agree to have their fingers pricked and have spots of blood dripped onto cards. The 2006 and 2008, DBS samples have been assayed for 5 biomarkers: a) Total cholesterol, b) HDL cholesterol, indicators of lipid levels, c) Glycosylated hemoglobin (HbA1c) – an indicator of glycemic control over the past 2-3 months, d) C-reactive protein (CRP), a general marker of systemic inflammation, and e) Cystatin C, an indicator of kidney functioning.

### Telomere Data

The Telomere Data includes average telomere length data from 5808 HRS respondents who consented and provided a saliva sample during the 2008 interview wave. Assays were performed by Telome Health (Telomere Diagnostics, <http://www.telomehealth.com/>). Average telomere length was assayed using quantitative PCR (qPCR) by comparing telomere sequence copy number in each patient's sample (T) to a single-copy gene copy number (S). The resulting T/S ratio is proportional to mean telomere length.

### HRS-dbGaP Cross-Reference File

The HRS-dbGaP Cross-Reference File links HHID/PN (the unique HRS identifier) to the identifier assigned to HRS genetic data stored in the dbGaP system. The genotype data and a limited set of phenotype measures have been deposited in the NIH GWAS repository ([dbGaP](#)). Researchers wishing to use the HRS genetic data must first apply to dbGaP for access to the genotyped data. The process to request access to any dbGaP study is done via the dbGaP authorized access system.

Once access to dbGaP has been granted, researchers who wish to link to HRS phenotype measures not in dbGaP may apply for access to the HRS-dbGaP Cross-Reference File by submitting a Sensitive Data Access Use Agreement.

### HRS Candidate Gene Longevity File

The data package for the HRS Candidate Gene Longevity File contains the data for the phenotypic category Longevity. Information about the genes and specific SNPs to include in this data release were compiled with input from an expert panel. This is not a complete list of genes and SNPs potentially associated with longevity; it is merely a selection of the most biologically promising candidate genes

### **HRS Candidate Gene Cognition and Behavior File**

The data package for the HRS Candidate Gene Cognition and Behavior File contains the data for the phenotypic categories of Cognition and Behavior. Information about the genes and specific SNPs to include in this data release were compiled with input from an expert panel. This is not a complete list of genes and SNPs potentially associated with these phenotype categories; it is merely a selection of the most biologically promising candidate genes.

## **V Off Year Surveys**

The HRS produces supplemental data on a variety of topics by conducting off-year surveys that enhance, expand or otherwise complement the HRS Core data collection. By design, HRS reflects the many analytical and policy interests in various disciplines. HRS off year survey data products provide increased opportunities for data analysis.

These data products are distributed from the HRS via the webpage for public access data <https://ssl.isr.umich.edu/hrs/>. Some of the files require additional procedures due to their sensitive nature and the resulting increased risk to participant confidentiality.

### **Consumption and Activities Mail Survey (CAMS)**

Begun in 2001, and repeated on the same households biennially, CAMS is the first large-scale national longitudinal study of consumption. It collects data on household expenditures in over twenty categories of spending that cover nearly all of consumption, and on the use of time across more than thirty activities. The sample is a random sample of about forty percent of HRS households.

### **Human Capital Investment Mail Survey (HUMS)**

The 2001 HUMS collected important information designed to facilitate research in a number of areas including parental investment in the human capital of their children, the allocation of parental resources across their offspring, and the effect of educational expenditures on mid-life savings of parents. The current release contains questions about high school attendance, college attendance, and the proportion of college expenses (tuition, food, housing) paid for by the parent of the child.

### **Diabetes Study**

HRS conducted a Diabetes Study in 2003, designed to collect self-reported questionnaire data on aspects of treatment and self-management of diabetes, and to collect a clinical biomarker of glucose control: glycosylated hemoglobin, or HbA1c. The survey questions were drawn from several sources, including validated instruments from the Michigan Diabetes Research and Training Center. Blood spot assays for HbA1c were performed by Flexsite Diagnostics, Inc. Both data collections were done through mail surveys.

### **Health Care and Nutrition Study (HCNS)**

The 2013 HRS Health Care and Nutrition Mail Study contains questions about health care access, food purchases, food consumption and nutrition (including vitamins and other supplements). In November 2013, questionnaires were mailed to a subsample of 12,418 HRS respondents. The sample for the 2013 HCNS consists of all living HRS respondents who were not included in the 2013 Consumption and Activities Mail Survey (CAMS). The field period for the 2013 HCNS was late November 2013 through early May 2014. The data file for the HCNS contains data for 8073 respondents.

### **Health and Well-Being Study (HWB)**

The HRS 2009 Health and Well-Being Study (HWB) is the third wave of a multi-wave mail survey designed to track changes in prescription drug utilization and enrollment in Medicare Part D, the prescription drug benefit administered by Medicare. The baseline wave, administered in 2005, was intended to capture prescription drug use, coverage, and satisfaction prior to the implementation of Medicare Part D, as well as awareness of the new drug benefit and available subsidies. The second wave, administered in 2007, was

designed to capture similar information post-implementation. This wave continues to assess Medicare Part D utilization and satisfaction as well as prescription drug usage and expenditures. In addition, new content on experienced well-being was included as a pilot.

A total of 5,333 respondents returned questionnaires or completed a telephone interview, for a response rate of 75% (among eligible cases). The Health and Retirement Study strives to provide high quality data without compromising respondent confidentiality. Since respondent health data records contain particularly sensitive information, such data products are released to researchers who qualify for access only through a supplemental registration system.

### **HRS Prescription Drug Study (PDS)**

The HRS Prescription Drug Study is a two-wave mail survey designed to track changes in prescription drug utilization during the phase in of Medicare Part D, the prescription drug benefit. The baseline wave was intended to capture prescription drug use, coverage, and satisfaction prior to the implementation of Medicare Part D, as well as awareness of the new drug benefit and the subsidies available for it.

### **Veterans Mail Survey**

The 2013 HRS Veterans Mail Survey contains questions about veterans' health care and experiences in the military. In June 2013, questionnaires were mailed to a subsample of 3,811 HRS respondents. The subsample consisted of respondents who answered "Yes" to the question "Have you ever served in the active military?" in any wave of the HRS study. The field period for the 2013 Veterans Study was June 2013 through the end of October 2013. The data file contains data for 1,871 respondents.

### **Internet Survey**

Six waves of data have been collected from a sub-sample of the Health and Retirement Study (HRS) Internet-based survey developed jointly by the HRS, Survey Research Center (SRC) Institute for Social Research (ISR) at the University of Michigan, and the RAND Corporation.

The 2013 HRS Internet Survey covered numerous topics including economics (e.g., annuities, expectations), residential history, siblings, cognition and health on approximately 5,813 HRS respondents. The 2011 Internet Survey covered numerous topics including health, cognition, well-being, economics (income, assets, expectations, and consumption), and retirement. Completed interviews were obtained from 4,590 HRS respondents.

The 2009 Internet Survey collected information on a number of topical areas including: health (physical and mental, health behaviors); psychosocial items; economics (income, assets, expectations, and consumption); and retirement. Completed interviews were obtained from 4,433 HRS respondents.

The 2007 Internet Survey collected information on a number of topical areas, including Internet/computers, health and emotional problems, Social Security, numeracy items, psychosocial items, household composition, expectations, questions about housing/checking accounts, and stocks and prescription drug usage and insurance. Completed interviews were obtained from 2,665 HRS respondents.

The 2006 Internet Survey contained several different topical areas, including Internet and computers, health and emotional problems, Social Security, numeracy items, psychosocial items, expectations, questions about housing, checking accounts, stocks, prescription drug usage, and insurance. Completed interviews were obtained from 1,352 HRS respondents.

The 2003 Internet Survey contained several different topical areas including Internet/computers, health problem, disability and work limitations, numeracy items, psychosocial items, expectations, and questions about housing/checking accounts, and stocks. Many of the questions were taken from the HRS survey, the National Health Interview Survey (NHIS) and from the Current Population Survey (CPS). Completed interviews were obtained from 2,197 HRS respondents.

### **Disability Vignette Survey (DVS)**

The Disability Vignette Study (DVS) includes a short sequence of questions about the respondents' own health and disability status, followed by a set of anchoring vignettes. The vignettes provide short descriptions of people in different states of health, which respondents are asked to rate on the same dimensions and scales as they rated their own health. Comparison of respondents' ratings of their own health and their vignette ratings allows researchers to evaluate whether respondents exhibit different response styles. Two versions of the DVS questionnaire (A and B) were administered to assess question ordering and gender effects.

### **Aging, Demographics, and Memory Study (ADAMS)**

The University of Michigan collaborated with Duke University, via subcontract to Duke where Duke University collaborators conducted clinical assessments of dementia and cognitive impairment. IRB approval was gained at each Duke and UM. This national study provides data from a single standardized diagnostic protocol on many aspects of dementia including: antecedents, prevalence, outcomes, costs of care, caregiver time and burden, and cognitive impairment, not demented (CIND).

#### **ADAMS Sample**

The 856 individuals, 70 years of age or older, from all over the country are a subsample from the ongoing participants in the Health and Retirement Study (HRS). These respondents received extensive clinical and neuropsychological assessments in their homes by a team of professionals. These clinical assessments were used to determine whether an individual had dementia, or a less significant level of cognitive impairment (cognitive impairment, not demented [CIND]). In addition, the sub-type of dementia (e.g., Alzheimer's disease or vascular dementia) was determined.

#### **ADAMS Links to the HRS Data**

The ADAMS data come directly from people who have been participating in the HRS and who are surveyed every two years. The available longitudinal data that can be linked to the ADAMS data include: demographics, health, health care utilization, informal care, economic resources and family involvement.

#### **ADAMS Data Availability**

The ADAMS data are currently available after completing the permission protocol we use for researchers using our Sensitive Data. This is not as rigorous as our requirements for using our restricted data, but involves a more thorough registration process than accessing our public use data.

Additional ADAMS information can be found at <http://hrsonline.isr.umich.edu/adams>

### **Healthy Cognitive Aging Project (HCAP)**

Funded through competitive supplement, HRS now conducts cognitive assessments of a subset of participants. HCAP aims to conduct a new population study of dementia of 3000 persons aged 65 and older from the HRS sample as well as an informant nominated by the HCAP-eligible HRS respondent. HCAP will allow analysis of trends by comparison with the HRS ADAMS study of over ten years ago, and international comparisons with other studies using similar protocols. This will support new research on the causes and consequences of dementia, the most burdensome of all age-related diseases.

#### **HCAP Sample**

The sampling design is a simple random sample of one-half of HRS respondents aged 65 and older (born 1951 and earlier). This is accomplished by taking half of single-person households and one individual chosen at random within all coupled households. For a variety of reasons, including the desirability of using a spouse to complete an informant report on the subject, we determined not to take more than one person per household. The entire HRS sample has been sorted in this way, but only individuals aged 65 or older, or turning 65 in 2016 are eligible for this assessment.



HACP Links to the HRS Data

The main HCAP respondent is pulled directly from HRS respondents who complete a 2016 Core interview (regular or living proxy interview) and who have been surveyed every two years as part of the HRS. The data collected as part of HCAP can then be linked to the longitudinal HRS data, including: demographics, health and cognition, health care utilization, informal care, economic resources, family involvement, and the psychosocial questionnaires.

HCAP Data Availability

All data collected in the HRS administration of HCAP will be made available to the research community, as the ADAMS data have been, including sampling weights. Genetic risk scores will be created for all HRS respondents who have provided genetic samples, including HCAP participants, through dbGaP and through our own restricted data mechanisms.

**VII Human Subjects Review Specific Information**

**Subject Population**

The HRS subject population is a randomly selected national sample of almost 38,000 persons born in 1959 or earlier and their spouses. HRS subject population does not include participants under the age of 18, some participants may be cognitively impaired and in these cases a proxy informant is sought, does not follow subjects into prison or detention facilities, and does not intentionally consist of pregnant women. The HRS subject population contains the demographic groups in proportions listed in the Inclusion Enrollment Report.

**Inclusion Enrollment Report**

<b>PART A. TOTAL ENROLLMENT REPORT: Number of Subjects Enrolled to Date (Cumulative) by Ethnicity and Race</b>				
<b>Ethnic Category</b>	<b>Sex/Gender</b>			
	<b>Females</b>	<b>Males</b>	<b>Unknown or Not Reported</b>	<b>Total</b>
Hispanic or Latino	2,398	1,838		4,236 **
Not Hispanic or Latino	18,431	14,364		32,795
Unknown (individuals not reporting ethnicity)	360	421		781
<b>Ethnic Category: Total of All Subjects*</b>	<b>21,189</b>	<b>16,623</b>		<b>37,812 *</b>
<b>Racial Categories</b>				
American Indian/Alaska Native	206	163		369
Asian	244	181		425
Native Hawaiian or Other Pacific Islander	25	15		40
Black or African American	3,957	2,643		6,600
White	15,854	12,756		28,610
More Than One Race	191	139		330
Unknown or Not Reported	712	726		1,438
<b>Racial Categories: Total of All Subjects*</b>	<b>21,189</b>	<b>16,623</b>		<b>37,812 *</b>



<b>PART B. HISPANIC ENROLLMENT REPORT: Number of Hispanics or Latinos Enrolled to Date (Cumulative)</b>				
<b>Racial Categories</b>	<b>Females</b>	<b>Males</b>	<b>Unknown or Not Reported</b>	<b>Total</b>
American Indian or Alaska Native	63	53		116
Asian	14	12		26
Native Hawaiian or Other Pacific Islander	7	2		9
Black or African American	98	63		161
White	1,801	1,332		3,133
More Than One Race	23	11		24
Unknown or Not Reported	392	365		757
<b>Racial Categories: Total of Hispanics or Latinos**</b>	<b>2,398</b>	<b>1,838</b>		<b>4,236 **</b>

### Confidentiality Measures

Names, addresses, and contact information are maintained in a separate control file for future contact purposes. This identifying information is necessary to maintain due to the longitudinal nature of the study. This information is only provided to Survey Research Center staff and our collaborators when it is necessary to perform their duties with respect to the Health and Retirement Study – e.g., interviewing, sample reconciliation, mailing of respondent reports, etc. Other access is not permitted as this information is strictly controlled within the Survey Research Center. These data are stored electronically on a secure network server and only authorized personnel can access them. In addition, all ISR personnel and affiliates must sign an ISR Pledge of Confidentiality, which explicitly prohibits disclosure of study participants.

Before release, HRS data files are subject to a three-stage iterative process to ensure data confidentiality. In the first stage, before raw data files are created, a disposition list is created of variables to be removed or masked for confidentiality. In the second stage, the remaining variables are tested for any possible identifying content. If problems are found, stage 1 is corrected and repeated. When testing is complete, the data files are subject to final review and approval by the HRS Data Protocol committee.

The HRS distributes its data to the public via a secure website maintained on the premises of ISR. Registration is required of all users who wish to download the data files. After online registration is completed, individual passwords are sent via email, allowing the user to logon to the data distribution area of the website to download data.

With respect to linked data or data deemed to be too sensitive in nature or in conjunction with other survey information, these data are considered restricted and are released only by a rigorous application procedure outlined on our website: <http://hrsonline.isr.umich.edu/rda/>

And, lastly, the HRS holds a Federal Certificate of Confidentiality granted by the National Institute of Mental Health, which gives HRS a shield against being forced to disclose study participants in a court of law.

### Risks

The HRS is a non-invasive social science protocol. The main risk to respondents is possible re-identification. Our stringent procedures are outlined above. HRS collects physical measures and biomarkers. Specifically, HRS includes for willing participants height, weight, blood pressure, grip strength, air flow, timed walk, tandem walk, as well as saliva samples for genotyping, and finger-prick blood draws for Hemoglobin A1c, cholesterol, C-reactive protein, and future unspecified uses. The ADAMS project also collects other health measures, such as (a) medical history, medications, history of cognitive changes, and family history; (b) the

administration of the neuropsychological test battery; (c) a brief physical examination which includes measurements of blood pressure and heart rate, and self-reported height and weight; (d) a standardized neurological examination; and (e) a 5-7 minute standardized video tape segment to cover portions of the mental status and neurological examinations.

### **Consent Statements**

Most of the interviews will be conducted by telephone. Consistent with on-going HRS practice (telephone and some personal interviews) all respondents are read a confidentiality statement when first contacted, and give oral or implied consent by agreeing to do the interview. For each interview (Core, Mail Survey, Internet, or supplemental data collection), participants are provided with a written informed consent information document. In addition to verbal consent to participate and provision of an informed consent information document, HRS utilizes the following consent procedures.

### **Request for Social Security Administration Linkage**

Written consent is required of the respondent to obtain Social Security Administration data. The authorizations were developed with Social Security Administration. Participants are presented (if in person) or mailed (if telephone interview) the form for review and signature.

### **Physical Measures, Saliva, Dried Blood Spot and Venous Blood Collection**

In 2006 during face-to-face interviews, HRS began collecting expanded health information in the areas of physical performance, salivary DNA and dried blood spots for specific and non-specific assays. Written consent forms are used to collect these data.

In 2016, venous blood collection was added to the HRS. There is a verbal consent script regarding willingness to participate and have information shared with partner health professionals for the blood draw.

### **Mail Surveys**

Consent is inferred by completion and return of questionnaires. Each package mailed to a sample household will contain a cover letter describing the purpose of the study and the voluntary nature of participation.

### **ADAMS**

Duke obtained written informed consent typically from the respondent and the informant. In situations where significant cognitive impairment was suspected, a separate signature was sought to document permission to forward a summary of findings to the respondent's personal physician.

The University of Michigan retains all rights to the data, including the stored genetic samples.

### **HCAP**

Written consent is obtained from the participant, the participant's proxy reporter, and an informant.

### **Respondent Payments**

The HRS typically will provide participants with a token of appreciation for their participation. When participants agree to an in-person interview that includes collection of physical measures and biomarkers, payment is slightly higher. This payment is provided at the initial re-contact for longitudinal sample members, and after completion of the interview for newly enrolled participants.

For in-person interviews that include a leave-behind questionnaire – typically a deeper exploration of a substantive area already included in the Core survey (such as disability vignettes), an additional payment is provided upon receipt of the returned questionnaire.