



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, 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

III Human Subjects Review Specific Information

Subject Population

The HRS subject population is a randomly selected national sample of almost 43,500 persons born in 1965 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 Table

Racial Categories	Ethnic Categories						TOTAL
	Not Hispanic or Latino		Hispanic or Latino		Unknown Ethnicity		
	Female	Male	Female	Male	Female	Male	
American Indian/Alaska Native	148	116	75	76	3	2	420
Asian	319	247	20	17	0	1	604
Native Hawaiian or Other Pacific Islander	22	16	9	4	0	0	51
Black or African American	4,631	3,270	125	88	25	29	8,168
White	15,302	12,662	2,370	1,910	111	105	32,460
More Than One Race	198	165	34	14	0	0	411
Unknown	84	69	404	372	210	225	1,364
Total	20,704	16,545	3,037	2,481	349	362	43,478

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/>

The HRS holds a Federal Certificate of Confidentiality granted by the National Institutes of 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, observational 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, finger-prick blood draws for Hemoglobin A1c, cholesterol, C-reactive protein, and future unspecified uses, and whole blood draws allowing a wide variety of assays to be performed and remaining specimens to be stored indefinitely in repository. The ADAMS project also collected 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. The HCAP project also relies on sensitive data.

Consent Statements

Prior to each interview, participants are provided with a written informed consent information document. At the start of each interview, all respondents are read a confidentiality statement, and give oral consent by agreeing to do the interview. In addition to the provision of an informed consent information document and verbal consent to participate, HRS utilizes the following consent procedures:

Request for Social Security Administration Linkage

Written authorization is required of the respondent to obtain Social Security Administration data. The authorization was developed with Social Security Administration.

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

Since 2006 face-to-face interviews may include the collection of biomarkers and physical measures, 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.

ADAMS

Duke University 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 provides participants with a token of appreciation for 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, an additional payment is provided upon receipt of the returned questionnaire.