INSTITUTE FOR SOCIAL RESEARCH • SURVEY RESEARCH CENTER
HEALTH AND RETIREMENT STUDY
UNIVERSITY OF MICHIGAN

Institutional Review Board Information

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I Co-Investigators and Affiliations

David R. Weir, Director, University of Michigan
Kenneth M. Langa, Associate Director, University of Michigan
Helen G. Levy, Associate Director, University of Michigan
Mary Beth Ofstedal, Associate Director, University of Michigan
Charlie Brown, University of Michigan
Eileen Crimmins, University of Southern California
Jessica Faul, University of Michigan
Michael D. Hurd, RAND
Richard Jones, Brown University
Sharon L. R. Kardia, University of Michigan
Kathleen McGarry, University of California, Los Angeles
Jennifer Manly, Columbia University
Olivia S. Mitchell, University of Pennsylvania
Jacqui Smith, University of Michigan
Robert Wallace, University of Iowa

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 with multidisciplinary

content spanning 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 approximately 20,000 individuals representing the US population over age 50. Baseline interviews with existing birth cohorts have been conducted in 1992, 1993, 1998, 2004, 2010, and 2016 with oversampling of Hispanics and African-Americans. Every six years, the HRS enrolls a new birth cohort in order to maintain a steady-state representation of the US population over age 50. Participants are followed through the life course with the core 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. Data are distributed in SAS, STATA, and SPSS formats, with accompanying documentation.

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. These files are maintained at RAND, and made available for download via the HRS website, and are considered HRS public-use data.

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.

In addition, HRS provides a rich set of restricted access data, which include linkages with Social Security earnings and benefits records, employer provided pension plans, Medicare and Medicaid 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: https://hrs.isr.umich.edu/data-products/restricted-data

Data Support

On-line support to data users is available on the HRS website. See Documentation Products at https://hrs.isr.umich.edu/documentation or submit data questions by emailing HRSQuestions@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. Regarding vulnerable populations, HRS does not include participants under the age of 18; some participants may be cognitively impaired and in these cases a proxy informant is sought; HRS does not follow subjects into prison or detention facilities and does not intentionally include pregnant women. The HRS subject population contains the demographic groups in proportions listed in the inclusion table below.

Inclusion Table

	Ethnic Categories						
	Not Hispanic or Latino		Hispanic or Latino		Unknown Ethnicity		
Racial Categories	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**TOTAL**
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 carrying out the aims of 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' private information.

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 login 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: https://hrs.isr.umich.edu/data-products/restricted-data

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

Risks

The HRS is an 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, for willing participants, HRS includes height, weight, blood pressure, grip strength, air flow, timed walk, tandem walk, as well as saliva samples for genotyping, venous blood draws for Hemoglobin A1c, cholesterol, C-reactive protein, and future unspecified uses, allowing a wide variety of assays to be performed and remaining specimens to be stored indefinitely in repository. The ADAMS sub-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, 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. A written acknowledgement of consent to participate in blood draw at the time of the draw was added in 2018.

Mail & Internet Surveys
Consent is inferred by completion and return of questionnaires. Participants are reminded of the voluntary nature of participation at the beginning of each survey.

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.