



Institutional Review Board Information

Principal Investigator: Weir, David R.
 Sponsor: NIA U01 AG009740
 Dates: 9/20/90 – 12/31/29
 Website: <http://hrsonline.isr.umich.edu/>

UM Health Sciences/Behavioral Sciences IRB Protocols:
 Core Data Collection protocols: HUM00061128; HUM00246459
 Associated protocols: HUM00056464, HUM00002562, HUM00074501, HUM00079949,
 HUM00080925, HUM00085942, HUM00099822, HUM00103072, HUM00106904, HUM00122335,
 HUM00162561; HUM00168761; HUM00196577; REP00000046

I	Co-Investigators and Affiliations.....	1
II	Background.....	2
	Purpose.....	2
	Survey Design.....	2
	Data Availability.....	2
	Data Support.....	3
III	Human Subjects Review Specific Information.....	3
	Subject Population.....	3
	Inclusion Table.....	3
	Confidentiality Measures.....	3
	Risks.....	4
	Consent Statements.....	4
	Respondent Payments.....	5

I Co-Investigators and Affiliations

- | | |
|--|---|
| David R. Weir, Co-Director, University of Michigan | Richard Jones, Brown University |
| Kenneth M. Langa, Co-Director, University of Michigan | Sharon L. R. Kardia, University of Michigan |
| Jessica Faul, Associate Director, University of Michigan | Lindsay Kobayashi, University of Michigan |
| Jennifer Ailshire, University of Southern California | Kathleen McGarry, University of California, Los Angeles |
| Helen G. Levy, University of Michigan | Jennifer Manly, Columbia University |
| Michael D. Hurd, RAND | Jacqui Smith, University of Michigan |
| Jody Schimmel Hyde, Mathematica | Bharat Thyagarajan, University of Minnesota |
| Jack Iwashyna, Johns Hopkins University | Brady West, University of Michigan |

II Background

Purpose

The Health and Retirement Study (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, 2016, and 2022, 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; and 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 (LHMS), and 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 online registration process 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

Online 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 more than 44,000 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; and 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

	Hispanic			Not Hispanic			Unknown			All
	Male	Female	Unknown	Male	Female	Unknown	Male	Female	Unknown	N
Race Categories										
American Indian/ Alaska Native	79	72	0	119	153	0	2	3	0	428
Asian	13	12	0	217	291	0	1	1	0	535
Black	72	114	0	3214	4682	0	27	27	0	8136
Native Hawaiian/ Other Pacific	5	10	0	16	26	0	0	0	0	57
White	1499	2057	0	12424	15262	0	101	110	0	31453
More than one race	26	38	0	269	345	0	1	1	0	680
Unknown	628	680	0	167	153	0	564	524	10	2726
All	2322	2983	0	16426	20912	0	696	666	10	44015

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 Institutes 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 aimed at preventing reidentification 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, and 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.