



National Institute on Aging

Publicly Available Databases for Aging-Related Secondary Analyses in the Behavioral and Social Sciences

The databases included in this document have been supported entirely or in part by the National Institute on Aging

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National Institutes of Health
National Institute on Aging
Behavioral and Social Research Program

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DATASETS AVAILABLE

Dataset Name:	The Adelaide Longitudinal Study of Ageing (ALSA)
Sponsoring Organization:	National Institute on Aging (for first four waves)
Principal Investigator:	George C. Myers (deceased) Gary R. Andrews
Data Collection Organization:	Centre for Ageing Studies Flinders University of South Australia

Purpose:

The general purpose of this research is to gain further understanding of how social, biomedical, psychological, and environmental factors are associated with age-related changes in the health and well-being of persons aged 70 years and older. Emphasis is given to the effects of social and economic factors on morbidity, disability, acute and long-term care service use, and mortality. The aim is to analyze the complex relationships between individual and social factors and changes in health status, health care needs and service utilization dimensions.

Description:

The sample for this Australian study was randomly generated from within the Adelaide Statistical Division using the State Electoral Database as the sampling frame. This database provided name, gender, date of birth, postal and residential address. The sample was stratified by gender and the age groups 70-74, 75-79, 80-84, and 85 and over. Both community- and institution-dwelling individuals were included in the list of specified persons. An additional component was that spouses aged 65 and over of specified persons also were invited to participate, as were other household members aged 70 years and over.

The initial baseline data collection for ALSA began in September 1992 and was completed in March 1993. In the first wave, personal interviews were carried out for 2,087 participants, including 566 couples (that is, persons 70 years of age and over and their spouse, if 65 and over). Clinical assessments were obtained for 1,620 of the participants. After an interval of one year from the initial interview, respondents were re-contacted by telephone.

The third wave of the study began in September 1994. This phase was a complete re-assessment, with face-to-face interviews, clinical assessments, self-completed questionnaires, and other clinical and laboratory studies again carried out. A total of 1,679 interviews were carried out at Wave 3, and 1,423 clinical assessments were conducted.

Data collection for the fourth wave began in November 1995 and was completed by the end of February 1996. 1,504 interviews were completed. A fifth wave of telephone interviews was conducted during February 1998, resulting in 1,171 completed interviews. The sixth wave of the study began in October 2000. This phase was a complete re-assessment, with face-to-face interviews, clinical assessments, self-completed questionnaires, and other clinical studies again carried out.

A seventh wave, including complete re-assessment, with face-to-face interviews, clinical assessments, self-completed questionnaires, and other clinical and laboratory studies, was completed in 2003. Additional information was collected at this wave on major transitions occurring in the lives of participants in the preceding 2 years, and the outcomes and coping mechanisms associated with these.

In addition to the primary data collection from respondents, ancillary data collection has been ongoing since the initiation of the study. Data have been collected from secondary providers, including Domiciliary Care and Rehabilitation Services, Meals on Wheels, and the Royal District Nursing Society. Lists of ALSA

participants are compared biannually with the agencies' lists to determine the prevalence and incidence of receipt of services from these organizations.

Another source of information has been the collection of data from the participants' General Practitioners. Each respondent's personal and medical practitioner gives a rating of overall health status, history of services received and current services provided. Current morbidity, medication use, and referrals to specialists also are recorded.

Study Design:

ALSA has been designed to have common instrumentation with US studies. The study collects data from a random, stratified sample of the 70 years and older persons living in the metropolitan area of Adelaide, South Australia. The entire population of older persons living in Adelaide is represented, since both community- and institution- dwelling residents are included.

Data Availability:

All of the above datasets are progressively being archived at ICPSR.

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Dataset Name:	Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Karlene Ball (University of Alabama-Birmingham), Michael Marsiske (University of Florida), John Morris (Hebrew Rehabilitation Center for Aged, Boston), George Rebok (Johns Hopkins University), Sharon Tennstedt (New England Research Institutes), Frederick Unverzagt (Indiana University), and Sherry Willis (Pennsylvania State University)
Data Collection Organization:	University of Alabama-Birmingham, Wayne State University, University of Florida, Hebrew Rehabilitation Center for Aged in Boston, Johns Hopkins University, Indiana University, Pennsylvania State University, and New England Research Institutes (data coordinating center).

Purpose:

The long-term goals of the ACTIVE (Advanced Cognitive Training for Independent and Vital Elderly) study are:

- To test the effectiveness and durability of three distinct cognitive interventions (memory, inductive reasoning, speed of processing) in improving the performance of a diverse sample of older adults on basic measures of cognition.
- To investigate if training in specific cognitive abilities could improve or maintain the cognitively demanding daily living skills (e.g., food preparation, driving, medication use, financial management) of a diverse sample of older adults.
- To investigate the impact of intervention effects on everyday mobility, health-related quality of life and health service utilization.

Description:

ACTIVE was a randomized controlled trial of cognitive interventions designed to maintain functional independence in elders by improving basic mental abilities. Several features made ACTIVE unique in the field of cognitive interventions: (a) use of a multi-site, randomized, controlled, single-blind design; (b) intervention on a large, diverse sample; (c) use of common multi-site intervention protocols, (d) primary outcomes focused on long-term, cognitively demanding functioning as measured by performance-based tests of daily activities; and (e) an intent-to-treat analytical approach. The clinical trial ended with the second annual post-test in January 2002. Subsequently a third annual post-test was completed in December 2003.

Target Population:

The area population and recruitment strategies at the six field sites provided a study sample varying in racial, ethnic, gender, socioeconomic, and cognitive characteristics. Recruitment started in March 1998, and ended in January 2000 with 2,832 enrolled in the trial and 2,802 included in the analytical sample. The sample was 73% White, 26% African-American, and 1% other races. Women comprised 76% of the sample. The average age was 73.6 years, and participants had an average of 13.5 years of education. Male participants have slightly more education (14.4 years) than did women (13.2 years) ($p < .001$). More than a third (36%) of the respondents were married, with women being much more likely to be not married than men. Participants were living independently and were independent in functioning, with the majority (84%) reporting their health as good or better. IADL and ADL data also suggested that the participants were independent and vital. However, at the same time, many of the participants had chronic diseases: arthritis (57%), diabetes (13%), osteoporosis (18%), hypertension (51%), and hypercholesterolemia (45%).

Data Collection:

Measurements consisted of baseline tests, immediate post-test (following the intervention), and two annual post-tests. At baseline, data were collected by telephone for eligibility screening, followed by three in-person assessment sessions, including two individual sessions and one group session, and a self-administered questionnaire. At post-tests, data were collected in-person in one individual session and one group session as well as by self-administered questionnaire.

There were four major categories of measures: proximal outcomes (measures of cognitive abilities that were direct targets of training), primary outcomes (measures of everyday functioning, both self-report and performance), secondary outcomes (measures of health, mobility, quality of life, and service utilization), and covariates (chronic disease, physical characteristics, depressive symptoms, cognitive impairment, psychosocial variables, and demographics).

Study Design:

Phase I of ACTIVE was a randomized controlled, single-blind trial utilizing a four-group design, including three treatment arms and a no-contact control group. Each treatment arm consisted of a 10-session intervention for one of three cognitive abilities – memory, reasoning, and speed of processing. Testers were blind to participant treatment assignment. The design allowed for testing of both social contact effects (via the contact control group) and retest effects (via the no-contact control group) on outcomes. Booster training was provided in each treatment arm to a 60% random subsample prior to first annual post-test. (Results of Phase I were described in Ball et al., “Effects of Cognitive Training Interventions with Older Adults,” *Journal of the American Medical Association*, Vol. 288, November 13, 2002.)

Phase II of ACTIVE started in July, 2003 as a followup study focused on measuring the long-term impact of training effects on cognitive function and cognitively demanding everyday activities. The followup consisted of one assessment to include the Phase I post-test battery. This was completed in late 2004. The aims of Phase II were:

- To determine whether the cognitive interventions (as initial treatment or as a consequence of booster training) have long-term protective effects on functional outcomes.
- To document any delayed transfer of the cognitive training effects to secondary outcomes. For example, what are the effects of cognitive training on health service utilization, on health-related quality of life, and on mobility?
- To identify individual factors that affect response to intervention, including chronic disease(s), sensory impairments, depressive symptoms, physical characteristics, and sociodemographic and psychosocial characteristics.

Data Availability:

The Phase I clinical trial dataset was sent to NACDA in 2005 to be archived for public use.

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Dataset Name:	Aging, Status, and the Sense of Control (ASOC)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	John Mirowsky
Data Collection Organization:	Survey Research Laboratory, University of Illinois

Purpose:

Broad Objective: The ASOC study aims to describe and explain the relationship between age and changes in the sense of control over one's life.

Specific Aims:

Four preliminary cross-sectional surveys (two Illinois, two U.S.) show the average sense of control declines in successively older age groups beginning in late middle age. The current study will measure changes in the sense of control over two follow-up periods, correlate the changes with age, and test hypotheses about the form and components of the association. The main hypotheses are (I) over a period of time, the sense of control declines by an amount that increases with age; (II) the change in sense of control reflects an underlying change in biosocial function, which accelerates with age; (III) higher social status slows the decline in the sense of control, possibly by preserving biosocial function; and (IV) changes in biosocial function and in the sense of control have deviation-amplifying reciprocal effects that accelerate age-dependent changes in the sense of control.

Objectives:

To find out why the sense of control drops precipitously in old age; to identify aspects of personal history that may reduce or delay the old-age decline in sense of control; to test Rodin's hypothesis that physical impairment and the sense of control may have deviation-amplifying reciprocal effects that contribute to a precipitous decline in both that can be slowed or delayed by responsibilities and activities.

Study Design:

This was a three-wave panel survey with fixed three year intervals and repeated assessments of the same variables. Interviews were conducted in 1994-5, 1997-9, and 2000-1

Questionnaire Topics:

Physical Health:

Subjective health; activities of daily living; height and weight; health conditions; expected personal longevity.

Health Behavior:

Exercise; smoking; diet; alcohol use.

Use of Medical Services:

Medical insurance coverage; prescription drug use.

Work Status:

Current employment status; title of current job or occupation & job description; types of work, tasks, or activities; description of work or daily activity and interactions; supervisory status; management position and level; work history.

Sense of Control:

Extent of agreement or disagreement with planning and responsibility versus luck and bad breaks; sense of victimhood versus control.

Social Support and Participation:

Have someone to turn to for support and understanding; frequency of visiting friends or neighbors; doing volunteer work, participating in neighborhood or community service.

Personal and Household Demographics:

Household adults by age group; 18-59, children by age group; relationship of children to adults; marital status; mother still alive, father still alive; childbearing history; birthplace and date; age when came to US, race; native language.

Marital and Family Relations:

Intention of marrying (remarrying) some day; happiness with current relationship; degree of influence in major household decisions; fraction of household tasks one does and evaluation of share; spouse/partner's employment status and education.

Socioeconomic Status:

Father's and mother's education; own education; recent economic difficulty; past economic difficulty; own home versus rent; income.

History of Adversity:

Crime victim; natural disaster victim; unemployment; lack of money for necessities; parental divorce or death..

Future Plans:

Continuing Analysis

Data Availability:

The first two waves of data are available at ICPSR

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Dataset Name:	Alameda County Health and Ways of Living Study 1965, 1974, 1994, 1995 Panel
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	George A. Kaplan

Purpose:

This long-term population-based prospective study of residents in Alameda County, California investigates social and behavioral risk factors for morbidity, mortality, functioning and health. Data have been collected in 1965, 1974, 1983, 1994, 1995, and 1999. With the aging of this cohort, data are becoming increasingly valuable for examining the life-long cumulative effects of social and behavioral factors on a well-characterized population.

Description:

These data constitute four waves of a survey designed to study the influence of health practices and social relationships on the physical and mental health of a typical sample of the population. The first wave “Health And Ways of Living Study, 1965 Panel” (Alameda County, California, ICPSR Study No. 6688) collected information for 6,928 respondents (including approximately 500 women aged 65 years and older) on chronic health conditions, health behaviors, social involvements, and psychological characteristics. The 1974 questionnaire was sent to 6,246 living subjects who had responded in 1965, and were able to be located. A total of 4,864 individuals responded in 1974. The third wave provides a follow-up of 2,729 original 1965 and 1974 respondents and examines health behaviors such as alcohol consumption and smoking habits, along with social activities. Also included is information on health conditions such as diabetes, osteoporosis, hormone replacement, and mental illness. Another central topic investigated is activities of daily living (including self-care such as dressing, eating, and shopping), along with use of free time and level of involvement in social, recreational, religious, and environmental groups. The fourth wave is a follow-up to the 1994 panel, and contains 2,569 cases. This wave examines changes in functional abilities such as self-care activities, employment, involvement in community activities, visiting friends/family, and use of free time since 1994.

Study Design:

A prospective study of the respondents to the 1965 survey, which consisted of a stratified random sample of Alameda County households with non-institutionalized residents aged 21 or older, or aged 16-21 and older if married. Questions were asked on marital and life satisfaction, parenting, physical activities, employment, health status, and childhood experiences. Demographic information on age, race, height, weight, education, income, and religion was also collected. Included with this dataset is a separate file (part 2) containing mortality data.

Future Plans:

Information from the 1998 follow-up will be archived in 2005.

Data Availability:

Archived at NACDA as ICPSR Study No. 6838.

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Dataset Name:	Assessment of Doctor-Elderly Patient Encounters (ADEPT)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Mary Ann Cook
Data Collection Organization:	JVC Radiology and Medical Analysis, LLC

Purpose:

The primary aim of the research is the further development of ADEPT (Assessment of Doctor-Elderly Patient Transactions), an instrument for assessing doctor-elderly patient interactions. Through a collaborative effort with experts in doctor-elderly patient interaction who participated in the development of ADEPT, a database of approximately 500 audio and video tapes of doctors interacting with their elderly patients was established for testing ADEPT and for access by medical educators and researchers.

Description:

The database consists of 435 audio and video tapes of visits of patients age 65 and older (n=46) to their primary physician. About one-quarter (103) of the interactions have a companion present at the visit. Data available on each tape include reason for visit, physician characteristics (age, race, gender), patient characteristics (age, race, gender), companion characteristics (age, race, gender), and length of doctor-patient relationship.

Study Design:

Visits of patients 65 and older to their primary physician were videotaped at four sites: an academic medical center in the Midwest, an academic medical center in the Southwest, a suburban managed care medical group, and an urban group of physicians in independent practice. Repeat visits between the same doctor and patient were taped for 19 patients resulting in 48 tapes of multiple visits. Patients were recruited in the waiting room for a convenience sample. Before the visit, patients provided demographic data and completed a global satisfaction form. Following the visit, patients completed the SF-36, and the ABIM for patient satisfaction. Two weeks following the visit, patients were contacted by telephone and asked about their understanding, compliance and their utilization of health services over the past year. At twelve months, patients were contacted by telephone for administration of the SF-36, the global satisfaction form, and the utilization of health services survey.

Future Plans:

The video tapes will be used in medical education and research

Data Availability:

Archived at the Saint Louis University School of Medicine Library. Researchers and medical educators interested in using the tapes should contact Mary Ann Cook (see below).

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Dataset Name:	Census Microdata Samples Project (also known as The Status of Older Persons in UNECE Countries)
Sponsoring Organization:	United Nations Population Fund National Institute on Aging Economic Commission for Europe
Principal Investigator:	Nikolai Botev
Data Collection Organization:	Population Activities Unit, UNECE, Geneva

Purpose:

The main objectives of the project are: (1) to assemble a set of cross-nationally comparable microdata samples from the population and housing censuses of selected countries in Europe and North America; and (2) to use these samples to study the social and economic conditions of older persons. The samples based on the 1990 round of censuses were designed to allow research on a wide range of issues related to aging, as well as on other social phenomena. A common set of nomenclatures and classifications, derived on the basis of a study of census data comparability in Europe and North America, were adopted as standards for re-coding and harmonization. The processing of the datasets, which included drawing of the samples (when requested by the National Statistical Offices), cleaning (where necessary), and harmonization, was performed by the Population Activities Unit (PAU) of the United Nations Economic Commission for Europe (UNECE).

Description and Study Design:

The recommendations regarding the design and size of the samples drawn from the 1990 round of censuses envisaged: (1) drawing individual-based samples of about one million persons; (2) progressive oversampling with age in order to ensure sufficient representation of various categories of older people; and (3) retaining information on all persons co-residing in the sampled individual's dwelling unit. Most countries have drawn their samples in accordance with these principles. Some countries (specifically Estonia, Finland, Latvia and Lithuania) adhered to earlier recommendations and sampled only the population over age 50 (Estonia, Latvia and Lithuania provided the entire population over age 50, while Finland sampled it with progressive over-sampling). Several countries provided samples that had not been drawn specially for this project, and cover the entire population without over-sampling.

Being census-based samples, these datasets lack most of the detailed information found in specialized surveys. They have, however, several important advantages compared to other data sources: (1) because of the high sampling density, they cover various small groups of older people, information on whom is not commonly available in other sources; (2) these samples contain as much geographic detail as possible under each country's confidentiality requirements; (3) they include more extensive information on housing conditions than many other data sources; and (4) they provide information for a number of countries whose data were not accessible until recently.

Data Availability:

The data collection includes datasets from fifteen countries. The datasets for the nine countries which have signed the standard data release agreement are available through NACDA/ICPSR. According to the rules governing the release of these datasets, they should be used only for the purpose of social and/or behavioral science research. Users are required to sign a Pledge of Confidentiality, stipulating that those who attempt to disseminate copies of the data (in whole or in part) for purposes other than scientific research, or to identify individual respondents, may be subject to prosecution under the applicable laws. Six countries requested that data access be subject to special conditions -- these usually involve obtaining permission from the National Statistical Office (NSO) for the use of the data, and require that a letter requesting this permission together with a description of the proposed research be sent to the NSO. The table in Annex 1 summarizes the status of data acquisition, processing, and access conditions for the participating countries. Annex 2 provides details on the sample sizes and densities for the datasets constructed in accordance with the PAU's recommended sampling strategy, and include oversampling with age.

Future Plans:

PAU is collaborating with the Minnesota Population Center (MPC) and several European institutions on a project to anonymise, integrate, and make accessible for research use microdata samples based on multiple rounds of censuses in several European countries. In addition to the censuses of the 1990-round, this project will cover also the 2000, as well as earlier rounds. The samples created under the new project will be better intergrated/harmonized and documented compared to PAU's samples from the 1990 census round. In order to ensure adequate resources for the new and more ambitious project, funding is being sought from the European Commission within the 6th Framework Programme for Research. The following 13 countries have so far indicated that they will be participating in the new project: Austria, Belarus, Bulgaria, Czech Republic, France, Germany, Hungary, The Netherlands, Portugal, Romania, Slovenia and Spain. All these countries, with the exception of the Netherlands, have already signed the standard data access protocol. More countries are expected to join at a later stage.

Table 1: PAU Census Microdata Project (1990 round of censuses)
Status of Data Acquisition and Processing for the Participating Countries

Countries (in alphabetical order)	Sampling		Data Release	
	Design ¹	Sample drawn by	Data Distributor	Access Conditions ³
Bulgaria	yes	PAU	ICPSR/NACDA	General
Canada	no	1991 PUMFs ²	Statistics Canada	Limited
Czech Republic	yes	PAU	ICPSR/NACDA	General
Estonia	partially	NSO	ICPSR/NACDA	General
Finland	partially	NSO	ICPSR/NACDA	General
Hungary	yes	NSO	Hungarian Central Statistical Office	Limited
Italy	no	1991 IStat 1% sample ²	IStat	Limited
Latvia	partially	NSO	ICPSR/NACDA	General
Lithuania	partially	NSO	ICPSR/NACDA	General
Romania	yes	NSO	ICPSR/NACDA	General
Russia	no	5% GOSKOMSTAT sample	GOSCOMSTAT	Limited
Switzerland	yes	NSO	Swiss Federal Statistical Office	Limited
Turkey	no	1990 SIS 5% sample ²	ICPSR/NACDA	General
UK	no	1991 SAR ²	to be announced	Limited
USA	no	1990 PUMS ²	ICPSR/NACDA ⁴	General

¹ Indicates whether a sample corresponds to the final version of PAU's recommended sampling strategy. 'Yes' signifies that it does. 'Partially' signifies that the sample has been drawn in accordance with an earlier version of the PAU's recommendations, i.e. it covers only the population over age 50 and the persons residing with them (Estonia, Latvia, and Lithuania have provided the entire population over age 50, while Finland has sampled it with progressive oversampling). 'No' indicates that the sample provided has not been drawn specially for this project, and most often covers the entire population without any oversampling.

² Identifies the general purpose sample submitted as part of a country's participation in the project.

³ Identifies the conditions governing the release of a country's microdata sample. 'General' signifies that a country has signed the project's standard data release arrangement. So far 9 countries have signed the standard arrangement. Hungary and Switzerland (marked as 'limited') require a clearance to be obtained from their national statistical offices for the use of microdata, however the documents signed between the PAU and these countries include clauses stipulating that, in general, all scholars interested in social research will be granted access. Russia (also marked as 'limited') requested that certain provisions for archiving the

microdata samples be removed from its data release arrangement. In the case of the UK, the PAU has an agreement with several British scholars to facilitate access to the 1991 SAR through collaborative arrangements.

⁴ Because of its wide user base, 1990 PUMS was not recoded. Instead, PAU offers mapping modules, which recode the PUMS variables into the project's classifications, nomenclatures and coding schemes.

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Dataset Name:	The Charleston Heart Study
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Paul J. Nietert
Data Collection Organization:	Medical University of South Carolina

Purpose:

Originally, the purpose of the Charleston Heart Study as stated in the original 1958 NIH application, was “to attempt to establish a causal relationship between atherosclerosis and the incidence of thrombotic complications in cerebral and coronary arteries. This will be done by explaining the paradoxical difference in the Negro and White races.”

Description:

The Charleston Heart Study (CHS) is a cohort study of 2,283 subjects (1,394 whites, 889 blacks) in which risk factors of coronary disease have been examined for the past 43 years. The CHS began enrolling a random selection of community residents who in 1960 were 35 years of age and older – including men and women, black and white. A unique feature of this cohort is the fact that 102 high socio-economic status (SES) black men were purposefully included. The primary hypothesis of the original study was to investigate racial differences in the manifestation and risk factors for coronary disease. Over the ensuing 40+ years, a variety of outcome measurements were incorporated into the re-examination of the participants, including psychosocial, behavioral, aging and functional measures.

The table below indicates the vital status of the CHS study participants through 12-31-2000

Group	Dead	Presumed Alive*	Total
White men	539 (82.5%)	114 (17.5%)	653 (100%)
White women	500 (67.5%)	241 (32.5%)	741 (100%)
Black men	281 (84.4%)	52 (25.6%)	333 (100%)
High SES black men	59 (57.8%)	43 (42.2%)	102 (100%)
Black women	343 (75.6%)	111 (24.5%)	454 (100%)
Total	1,722 (75.4%)	561 (24.6%)	2,283 (100%)

* Subjects who have not been definitively linked to a death in the National Death Index are presumed for this purpose to be alive.

Objective:

The primary objective was to examine risk factors for heart disease, focusing specifically on whether risk factors are quantitatively similar between whites and blacks.

Study Design:

Prospective cohort study

Data Collection:

Subjects were initially interviewed and examined in 1960 and 1963. Subsequent interviews and examinations took place during the following time periods: 1974-1975, 1984-1985, 1987-1989, and 1990-1991. A search of the National Death Index was completed through the year 2000, matching individuals with date and cause of death.

Future Plans:

Future plans include more permanent archiving of the original data forms, augmentation of the data with additional data, such as inpatient admissions and emergency room visits, Medicare data, nursing home data, and further National Death Index searches. Future studies will examine associations between subject characteristics and end-of-life healthcare costs.

Questionnaire Topics:

Questionnaires have covered many subject areas throughout the years. During the most recent questionnaire (1990-1991), the following topics were examined: general health, smoking, functional disability, physical disability, cardiovascular health, sexual dysfunction, cognitive disability, depression, coffee consumption, medication history, medical history, nutrition, and body image. In addition, serum samples and blood pressure measurements were taken, and a physical exam was performed by a physician.

Data Availability:

Datasets are stored in the National Archive of Computerized Data on Aging (NACDA) in the Inter-university Consortium for Political and Social Research (ICPSR) at the University of Michigan.

Agencies/Organizations Consulted:

National Archive of Computerized Data on Aging within the Inter-university Consortium for Political and Social Research at the University of Michigan, and the National Death Index within the National Center for Health Statistics

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Dataset Name:	Chinese Longitudinal Healthy Longevity Survey (CLHLS)
Sponsoring Organization:	National Institute on Aging; United Nations Fund for Population Activities (UNFPA) and China National Foundation for Social Sciences joined NIA to co-sponsor the expanded survey in 2002
Principal Investigator:	Zeng Yi, Principal Investigator; James W. Vaupel, Program Project Director
Data Collection Organization:	Peking University Center for Healthy Aging and Family Studies (CHAFS), China National Research Center on Aging (CNRCA)

Purpose:

Goal is a better understanding of the determinants of healthy longevity of human beings.

Description of Project and Dataset:

Project will collect extensive data on a much larger population of oldest-old than has previously been studied. Demographic and statistical methods will be used to analyze data in the longitudinal surveys. Research goal: to determine which factors, out of a large set of social, behavioral, biological, and environmental risk factors play an important role in healthy longevity. The large population size, the focus on healthy longevity (rather than on a specific disease or disorder), the simultaneous consideration of various risk factors, and the use of analytical strategies based on demographic concepts make this an innovative demographic data collection and research project.

Objectives:

The objectives of the project are: (1) Collect intensive individual interview data including health, disability, demographic, family, socio-economic, and behavioral risk-factors for mortality and healthy longevity (2) Follow the people in the study to ascertain if they die and if so at what age, from what cause, and health/disability status before death; (3) Collect and organize data on the social, economic, health and environmental conditions of the communities in which the respondents live; (4) Analyze the data collected to estimate the social, behavioral, and environmental risk-factors as determinants of healthy longevity and oldest-old mortality; and (5) Compare the findings with results from other studies of large populations at advanced ages.

Study Design:

The baseline survey was conducted in 1998 and the follow-up survey with replacement of deceased elders were conducted in 2000 and 2002, in randomly selected counties and cities of the 22 provinces. The survey areas covered 985 million persons, 85 percent of the total population in China. An interview and a basic health examination were performed at the interviewee's home.

The survey tried to interview all centenarians who voluntarily agreed to participate in the study in the randomly selected countries (about half the total) and cities of the 22 provinces. For each centenarian, one near-by octogenarian (aged 80-89) and one near-by nonagenarian (aged 90-99) of pre-designated age and sex was interviewed. "Near-by" is loosely defined – it could be in the same village or street if available, or in the same town or in the same county or city. The predefined age and sex that are used to identify approximately equal numbers of male and female nonagenarians and octogenarians are randomly determined, based on code numbers of the centenarians. The idea was to have comparable numbers of male and female octogenarians and nonagenarians at each age from 80 to 99.

Among the total number of 31,283 interviews to the oldest-old aged 80+ in the three waves in 1998, 2000, and 2002, 8,170; 10,457; and 12,656 interviews were conducted with centenarians, nonagenarians, and octogenarians, respectively. In addition, questionnaires of those interviewees who died after the 1998 survey were admitted to one of their close family members.

With a supplementary award from NIA and matching support from UNFPA and Chinese resources, the 2002 wave of our survey has been expanded from covering ages 80+ to ages 65+ through adding a new sub-sample of 4,894 interviewees aged 65-79, with a total sample size of 16,057 elders plus those who were interviewed in the previous wave(s) but died before the 2002 survey.

With support from the Taiwan Academy Sinica and Mainland China Social Sciences Academy, we have also added a sub-sample of 4,478 adult children (aged 35-65) of the elderly interviewees aged 65-110 in seven provinces in eastern coast areas among the 22 provinces of our healthy longevity survey. The main idea is to make a comparative study of intergenerational relationships in the context of rapid aging and healthy longevity between Mainland China and Taiwan. The total sample size of our 2002 survey is therefore 20,535 persons aged 35 --100+.

Questionnaire Topics:

The questionnaire data collected include family structure, living arrangements and proximity to children, activities of daily living (ADL), the capacity of physical performance, self-rated health, self-evaluation on life satisfaction, cognitive function, chronic disease, medical care, social activities, diet, smoking and drinking, psychological characteristics, economic resources, caregivers and family support etc. Relevant demographic, socio-economic, and environmental data on the sampled counties and cities were also collected.

Information about the health status obtained from the oldest-old who were interviewed in the previous wave but died before the current survey was collected by interviewing a close family member. Information before dying consists of cause of death, chronic diseases, ADL before dying, how many times of hospitalization or being bedridden from the last interview to death, whether bedridden before death, length of disability and suffering before death, etc.

Future Plans:

Conduct in-depth data analysis and make the data available to international research community. We also hope to continue the longitudinal survey and research including new follow-up waves in 2005 and 2008.

Data Availability:

The 1998 baseline and 2000 follow-up healthy longevity survey data is now being distributed internationally by the Peking University Center for Healthy Aging and Family Studies (<http://www.pku.edu.cn/academic/population/center/index.htm>) and the program project at Duke University (<http://www.pubpol.duke.edu/centers/ppa/>). The data processing and preliminary analysis of the 2002 follow-up survey are underway and the data sets of 2002 wave will be distributed internationally in October 2004.

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Dataset Name:	The Cross-National Equivalent Files 1980-2002 (BHPS-GSOEP-PSID-SLID)
Sponsoring Organizations:	National Institute on Aging
Principal Investigator:	Richard V. Burkhauser
Data Collection Organization:	The Department of Policy Analysis and Management, Cornell University

Purpose:

The Cross-National Equivalent File 1980-2002 was created to increase the accessibility and use of panel data among cross-national researchers and to assist current Cross-National Equivalent File users in the creation of comparably defined cross-national variables. It provides a set of constructed variables (for example, pre- and post-government household income) that are not immediately available on either of the two surveys. The data permit researchers to track yearly changes in the health and economic well-being of older people relative to younger people in Great Britain, Canada, the United States and Germany from 1980 to the present.

Description and Study Design:

The Cross-National Equivalent File 1980-2002 is developed and administered by the Department of Policy Analysis and Management, Cornell University. It uses subsets of the original British Household Panel Study (BHPS), the Canadian Survey of Labour and Income Dynamics (SLID), the Panel Study of Income Dynamics (PSID) and the English Language Public Use Version of the German Socio-Economic Panel (GSOEP).

The most recent release of the Equivalent File includes 20 years of PSID data from 1980 to 1997, 1999, and 2001. These data come from over 57,000 individuals living in approximately 8,000 households. Not all members of the sample provided an interview in each of the 20 years. The number of respondents in any particular year range from over 18,900 in 1980 to over 20,400 in 2001. Included in the data is any individual who was in the survey for at least one year between 1980 and 2001.

The first nineteen waves of the GSOEP (1984-2002) are also included in the Equivalent File. The nineteen-year sample includes over 30,000 individuals living in approximately 7,000 households in Germany. As with the PSID, there are both respondents and non-respondents in each year.

The CNEF data also include eleven waves of data from the BHPS (1991-2001) and nine waves of data from the SLID (1993-2001). The BHPS data include information on more than 21,000 individuals living in approximately 12,000 households. The SLID data include information on more than 80,000 individuals living in approximately 32,000 households. The Canadian SLID data are not distributed on the CD but are available to CNEF registered researchers through special arrangements with Statistics Canada.

Data Availability:

Those who request the data will receive:

The current Cross-National Equivalent File 1980-2002, which includes BHPS data from 1991-2001, PSID data from 1980 to 1997, 1991, and 2001, and GSOEP data from 1984 to 2002. These data are available in SAS-Windows *.SD2, SAS Transport *.V5X, SPSS-Windows *.SAV, SPSS Transport *.POR, Stata 4.0, and ASCII formats.

Dictionary files that include the variable names, labels, and positions, as well as value labels and formats.

A codebook that describes the methods used to create each variable in each country, the algorithm for its creation based on the original PSID and GSOEP survey variable names, and descriptive statistics for each variable in Adobe Acrobat format.

An explanatory paper that discusses the construction of comparable variables, supplies a list of supporting publications and working papers, and provides an example of how to use the data file for analyses. This paper is available in Adobe Acrobat format.

Included on the CD-ROM with the Cornell University User Package for the current Cross-National Equivalent File 1980-2002 is the English User Package for the GSOEP 1984-2002.

The BHPS and GSOEP data are available to researchers who sign agreements to protect the confidentiality of the data. CNEF-BHPS users must register with the UK Data Archive, the administrator of the BHPS, at www.data-archive.ac.uk/usingData/register/index.asp. Researchers wishing to use the GSOEP must sign a contract with the Deutsches Institut für Wirtschaftsforschung (DIW). Registration information is available www.diw.de/english/sop/faq.

For users who have already signed a contract with either the UK Data Archive or the DIW and have received earlier releases of these data, the charge for the CD-ROM is \$30. Contact Cornell University directly at the address below.

For new users, the dissemination of the current Cross-National Equivalent File 1980-2002 is a two-step process. First it is necessary to sign a contract with the UK Data Archive to use the BHPS or with the DIW to use the GSOEP. After the contract is signed, contact Cornell to receive the data. The charge for the CD-ROM is \$125.

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Dataset Name:	Cross-Sectional and Longitudinal Aging Study
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Baruch Modan (Deceased) Haim Hazan (Co-PI since 1998)
Data Collection Organization:	The Chaim Sheba Medical Center, Sackler School of Medicine, Tel-Aviv University The Herczeg Institute on Aging, Tel Aviv University (since 2000)

Purpose:

The Cross-Sectional and Longitudinal Aging Study is designed to provide a cross-sectional description of health, mental, and social status of the oldest-old segment of the elderly population in Israel, and to serve as a baseline for a multiple-stage research program.

Description:

National Random Stratified Sample

In 1989, a random stratified sample of elderly subjects was selected from the National Population Register (NPR), a complete listing of the Israeli population maintained by the Ministry of the Interior. The NPR is updated on a routine basis with births, deaths, and in and out migration, and corrected by linkage with census data. The study sample consisted of Jewish subjects aged 75+, alive and living in Israel on January 1, 1989, selected randomly from the NPR, stratified by age (five 5-year age groups: 75-79, 80-84, 85-89, 90-94, 95+), sex, and place of birth (Israel, Asia-Africa, Europe-America). One hundred subjects were randomly selected in each of the 30 strata. However, there were less than 100 individuals of each sex aged 95+ born in Israel, so all were selected for the sample. The total group included 2,891 individuals living both in the community and in institutions. Because very few of the 95+ group were located, this age group was eliminated from analysis. A total of 1,820 (76%) of the 75-94 age group were interviewed during 1989-1992.

In the course of tracing the interviewees, those individuals found to have died prior to the point of entry into the study, but not recorded as such (i.e. deaths or emigrations before 1/1/89, late recordings, errors) were considered as "erroneously" selected and were replaced by the next individual from the same population cell. Having anticipated such problems, double the number of cases for each cell was drawn.

Kibbutz Residents Sample

The kibbutz is a social and economic unit based on equality among members, common property and work, collaborative consumption, and democracy in decision making. While in 1961 only 2.5% of the kibbutz population was over age 65, today 10% are beyond this age. There are 250 kibbutzim in Israel, and their population constitutes about 3% of the country's total population. Both economic security and social (network) security exemplify the kibbutz group.

The elderly residents of the kibbutz are comprised of two groups, kibbutz members and elderly parents of members; about 40% of the elderly kibbutz residents fall into the latter category. All kibbutz residents in the country aged 85+, both members and parents, were selected for interviewing, of whom 80.4% (n=652) were interviewed. A matched sample aged 75-84 was selected, and 85.9% (n=674) were successfully interviewed.

Interview

The original interview took approximately two hours to administer, and collected extensive information concerning the socio-demographic, physical, health, functioning, life events (including Holocaust), depression, mental status, and social network characteristics of the sample. The questionnaire used for kibbutz residents in the follow-up interview is identical to that utilized in the national random sample.

Prospective Study:

The longitudinal follow-up is designed to correlate baseline socio-demographic, health, and functional status with three subsequent outcome variables: mortality, selected morbidity, and institutionalization. The original members of the study were located and they or their survivors were re-interviewed three to five years after the original interview. The questionnaire utilized was identical to the baseline questionnaire with some minor exceptions. Some questions considered sensitive (e.g. Holocaust experience, family deaths) and/or redundant (e.g. work history) were eliminated from the second round. An additional cognitive exam (Folstein) and a 24-hour dietary recall interview were added.

The Herczeg Institute on Aging, Tel Aviv University, have continued and led the third stage of the CALAS which investigated the old-old survivors of the original sample during 2001-2002. This stage included a combined research design of quantitative and qualitative data.

Data Availability:

Mortality data for both the national and kibbutz samples are available for analysis as a result of the linkage to the NPR file updated as of June 2000. The fieldwork for first follow up was completed as of September 1994 and for the second follow up as of December 2002. The data file of the three phases of the study is ready for analysis.

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Dataset Name:	Early Indicators of Later Work Levels, Disease, and Death (EI)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Robert W. Fogel
Data Collection Organization:	Center for Population Economics (CPE), the University of Chicago, Chicago, IL Center for Population Economics (Field Office) Vienna, VA

Purpose:

The purpose of EI is to advance the study of life-cycle interactions of biomedical and socioeconomic factors in the aging process. To that end, the EI project has assembled a variety of large datasets covering the life histories of approximately 39,616 white males who served in the Union Army (UA), and of about 6,000 African-American veterans from 51 randomly selected United States Colored Troops companies (USCT). In addition, a sample consisting of 70,000 men examined for service in the Union Army between September 1864 and April 1865 has been assembled. These records will be useful for life-cycle comparisons of rejects and those accepted for service.

Description:

A sample of 331 companies was randomly drawn from the records in the National Archives, containing 39,616 men in the Union Army. Their military records were linked to pension and medical records that detailed the soldiers' health status and socioeconomic and family characteristics. Each soldier was searched for in the US decennial census for the years in which they were most likely to be found alive (1850, -60, -80, 1900, -10). These records comprise the UA. The UA is restricted to white volunteer infantry regiments, with draftees entering those regiments in the final two years of the war. The USCT was collected similarly to the UA and linked to the same pension, medical, and census records.

Types of Data:

The 39,616 UA men have been linked to three main data sources, with each individual identified by a unique identification number. The 70,000 potential recruits who make up the sample of men examined for service were linked only to the census records described below.

Military Data: The military service and wartime medical histories of the UA and USCT men were collected from the Union Army and United States Colored Troops military service records, carded medical records, and other wartime documents.

Pension Data: Wherever possible, the UA and USCT samples have been linked to pension records, including surgeon's certificates. About 70% of men in the Union Army sample have a pension. These records provide the bulk of the socioeconomic and demographic information on these men from the late 1800s through the early 1900s, including family structure and employment information. In addition, the surgeon's certificates provide rich medical histories, with an average of 5 examinations per linked recruit for the UA, and about 2.5 exams per USCT recruit.

Census Data: Both early and late-age familial and socioeconomic information is collected from the manuscript schedules of the federal censuses of 1850, 1860, 1870 (incomplete), 1880, 1900, and 1910.

Data Availability and Future Plans:

Military Data: Cleaned military data for 35,570 recruits from the UA is publicly available through the Inter-University Consortium for Political and Social Research (ICPSR), with the remaining recruits to become available by summer 2006. The dataset consists of complete military, pension, and medical records for recruits from 303 companies from the original UA sample. Release of information on recruits from the remaining 30 companies of the USCT is planned for summer 2006.

Census Data: Cleaned census data for 22,347 recruits from the UA is publicly available through ICPSR and the CPE website extraction system at www.cpe.uchicago.edu. This dataset consists of all available census records for the Censuses of 1850 through 1910. Census data for the remaining linked soldiers in the UA and USCT will be available in summer 2006 from the same sources. About 60% of white soldiers are linked to any census. About 18% of black soldiers are linked to any census.

Surgeon's Certificates Data: A coded version of the surgeon's certificates data for the original UA sample has been publicly released, including specific and total disability ratings. Surgeon's data for the USCT will be released via the CPE website in August 2006.

Men Examined for Service: The examination records for a sample of men examined for service and the census-linked sub-sample of these men will be available from the CPE website in August 2006.

Supporting Datasets: Ecological and environmental variables specifying additional information about the individuals in the UA and USCT samples are also available from such sources as Regimental Histories, Social Statistics of Cities and General Statistics of Cities from 1880 to 1916, and U.S. Federal Censuses of Mortality from 1850 to 1880.

All of the above datasets are publicly available from ICPSR. In addition, copies on CD-ROM may be obtained from the CPE, which also maintains an interactive Internet Data Archive and Documentation Library, which can be accessed at <http://www.cpe.uchicago.edu>.

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Dataset Name:	English Longitudinal Study of Ageing (ELSA)
Sponsoring Organization:	National Institute on Aging (main sponsor) Also the following UK agencies: Department of Health Department of Social Security Department of Transport, Local Government and the Regions Department for Education and Skills Department for Culture, Media and Sport, HM Treasury Office for National Statistics
Principal Investigator:	Professor Sir Michael Marmot
Data Collection Organization:	University College London Department of Epidemiology and Public Health Institute for Fiscal Studies National Centre for Social Research University of Cambridge Department of Psychiatry University of Cambridge Department of Public Health and Primary Care University of Nottingham School of Economics

Purpose:

This is a study of aging and quality of life among older people that explores the dynamic relationships between health and functioning, social networks and participation, and economic position as people plan for, move into and progress beyond retirement.

Description:

The English Longitudinal Study of Ageing (ELSA) was launched as an interdisciplinary consortium in November 2000 and fieldwork for Wave 1 was carried out in 2002-2003. ELSA's data collection effort has been closely modeled on the HRS in the US, with the crucial addition of biological markers and direct assessments of physical impairments. The first wave of ELSA involved face-to-face interviews with respondents aged 50+ drawn from three years of the Health Survey for England. A sample of around 12,000 respondents aged 50+ were interviewed at Wave 1. The Wave 1 questionnaire topics included health and disability, inter-family transfers and family structure, social participation and networks, detailed economic circumstances, and retirement. Wave 2 fieldwork began in June this year. This wave involves a face-to-face interview and a separate nurse visit. The interview repeats topics that were covered in Wave 1 along with new questions about quality of health care, literacy and household consumption. In the nurse visit, the nurse measures the respondent's blood pressure and lung function, takes anthropometric measurements, asks for a sample of blood and saliva, and asks the respondent to carry out some tests of balance and muscle strength.

Objectives:

- Construct three waves of accessible and well-documented panel data,
- Provide these data in a convenient and timely fashion to the scientific and policy research community,
- Describe health trajectories, disability and healthy life expectancy in a representative sample of the English population aged 50+,
- Examine the relationship between economic position and health,
- Investigate the determinants of economic position in older age,
- Describe the timing of retirement and post-retirement labor market activity,
- Understand the relationships between social support, household structure and the transfer of assets.

Study Design:

ELSA used three years (1998, 1999 and 2001) of the existing cross-sectional Health Survey for England (HSE) as a sampling frame to set up a longitudinal survey of a representative sample of the English population aged 50 or more. A total of 12,100 face-to-face CAPI interviews were carried out in respondents' homes in Wave 1. These respondents are currently being interviewed again for Wave 2 using a similar CAPI interview. At this wave, the respondents also have a nurse visit in which biomedical data is collected. Another new aspect of Wave 2 is the 'Exit Interview'. This is an interview carried out with proxy informants to collect data about respondents who have died since Wave 1. This interview includes questions about the respondents' physical and psychological health, the care and support they received, their memory and mood in the last year of their life, and details of what has happened to their finances after their death. At the end of Wave 2 we will also be conducting interviews with respondents who have moved into residential institutions.

Questionnaire Topics:Wave 1 and 2:

General health, disability and physical function, cognitive function, psychological health, health behaviors; Employment, income, assets, consumption, transfers; Social support and participation, family structure, quality of life; Expectations concerning lifespan, future work and future wealth.

New to Wave 2:

Quality of health care received; literacy; household consumption; caring and voluntary work.

Links with Administrative Data:

We are in the process of linking (or facilitating the linkage of) the ELSA data to mortality statistics, a cancer register, NHS hospital episodes data, National Insurance contributions, benefits and tax credit records.

Future Plans:

The intention is to conduct interviews every two years, and to have a nurse visit every four years. We are currently developing Wave 3 for 2006, during which we plan to conduct a separate interview to collect life history information. In this interview respondents will be asked about aspects of their health, relationships, migration, work, housing, and education from their birth onwards.

Data Availability:

The data from ELSA Wave 1 has been submitted to the University of Essex Data Archive (Economic and Social Data Service (ESDS) and is publicly available through their website: <http://www.esds.ac.uk/aandp/access/introduction.asp>. The ESDS will be able to provide all users with support and the documentation needed to use the data most effectively. In addition, ESDS will be forming an agreement with all users of the dataset to ensure that the data is being used appropriately. We anticipate that much of the data will be available for public access without needing permission from the study team, however if researchers want to use more sensitive data (e.g., geographical classificatory variables and DNA) greater restrictions may apply.

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Dataset Name:	Epidemiology of Chronic Disease in the Oldest Old
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Dorothy Rice
Data Collection Organization:	Kaiser Permanente Medical Care Group (KPMCP) Division of Research, Northern California

Purpose:

In response to growing concerns about the potential impact of chronic disease among the elderly, the National Institute on Aging funded a large-scale study in 1988 to examine trends over time in chronic diseases among the elderly with a focus on the 'oldest old' (over age 80). A particular focus of the study was on whether the elderly were living longer with chronic diseases and what that increased longevity might mean for health services utilization. This study was conducted at the Northern California Kaiser Permanente Medical Care Program's Division of Research from 1988-1995. The data are now offered for use by non-Kaiser investigators through a brief application process.

Description:

The intent of sample selection was to create from existing records two 3,000-person cohorts of KPMCP members' aged 65 and over. These cohorts were followed for 9 years each through existing medical records and computerized hospitalization tapes. Mortality ascertainment was done by matching the sample data with state Vital Statistics data. Mortality data was collected for an additional 3 years for each cohort, for a total follow-up time of 12 years. The initial sample was drawn from the KPMCP active membership lists for the years 1971 and 1980. The sample was restricted to members that had a Multiphasic Health Checkup examination (MHC) within 7 years of the baseline date. The sample was stratified to attain equal numbers of observations (1,000 in each) in three sex-age cells for each cohort: 65-69, 70-79, and 80+. The selection was restricted to MHC takers. The first cohort has 2,877 participants with follow-up starting from 1971, and the second has 3,113 participants followed from 1980. Overall, 3,006 women and 2,984 men were included. There are 282 people who are in both cohorts.

Data Collection:

The main data collection effort was focused on medical chart review. The purpose of the chart review was to collect data for a nine-year period about clinical diagnoses of chronic diseases and outpatient health services utilization. Standard data collection forms were developed, pilot tested and used for this purpose, they are included in the documentation. Diagnostic criteria were collected for all cardiovascular diseases, and selected cancers (breast, colon, uterine, cervical). Data on hypertension and diabetes were collected using a standardized protocol (see Diagnostic Criteria - Form D) in the absence of a clinical diagnosis. Data on presence or absence of functional limitations in those with dementia were collected from the medical chart. Nursing home admissions and discharge dates were recorded when present in the chart.

Mortality data was obtained from two sources: (a) Form I in the chart review forms recorded the date, location and causes of death (ICD or E codes) when present in the chart, and (b) the sample was matched with Vital Statistics data which provided the same data. Form I also included a review for the presence of 4 specific conditions in the one month prior to death (pneumonia/influenza, urinary tract infection, decubitus ulcer, septicemia from other sources). For each of these conditions, it was recorded whether septicemia was present. The reviewer also recorded whether an autopsy was performed. Prevalence of chronic diseases was ascertained by conducting a retrospective chart review for a four-year period before the baseline year of 1971 or 1980. Diagnostic criteria were not obtained for prevalent cases, only the clinical diagnosis was obtained.

Health Services Utilization

Outpatient health services utilization for nine years was collected on a quarterly basis for clinic visits and for selected labs and procedures. The clinic types were: emergency, gynecology, home health, medicine,

nursing home, orthopedic, physical therapy, surgery and other. The labs and procedures included: chemistry, hematology, urinalysis, bacteriology, chest x-ray, GI x-ray, ultrasound, CT/MRI, mammogram, resting ECG, treadmill ECG, echocardiograms, nuclear scans, outpatient breast biopsy, cystoscopy, and cataract surgery. Inpatient utilization includes all hospitalizations, procedures done during a hospital stay, length of stay, admitting/discharge diagnosis. These data were taken from existing data tapes routinely maintained by KPMCP from 1971 on.

Data Availability:

These datasets have been documented extensively and are available on CD-ROM from Dr. Haan at the University of Michigan, Epidemiology.

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Dataset Name:	Established Populations for Epidemiologic Studies of the Elderly (EPESE)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	James O. Taylor, Robert B. Wallace, Lisa Berkman, and Dan G. Blazer
Data Collection Organization:	East Boston Neighborhood Health Center, University of Iowa Yale University Duke University.

Purpose:

The objective of the EPESE data collection was to describe the prevalence and incidence of disability and other chronic conditions in addition to predictors of mortality, hospitalization, and placement in long-term care facilities.

Description:

The EPESE project consisted of baseline and annual follow-up surveys on approximately 14,000 persons conducted in four geographically-defined communities: East Boston, Massachusetts; Iowa and Washington counties, Iowa; New Haven, Connecticut (started in 1982-1983); and a five-county-wide region in north-central North Carolina (started in 1986). Half of the participants in the North Carolina EPESE are African-American. The baseline data cover demographic characteristics (age, sex, race, height, weight, income, education, marital status, number of children, employment, and religion); social and physical functioning; chronic conditions; related health problems; health habits; self-reported use of dental, hospital, and nursing home services. More detailed descriptions of the Iowa and North Carolina surveys follow in this document ("Iowa 65+ Rural Health Study" and "PHSE Ten-Year Follow-up of North Carolina EPESE").

Data Availability:

Data from the baseline and the first 6 years of follow-up are available through the National Archive of Computerized Data on Aging, located within the Inter-university Consortium for Political and Social Research (ICPSR) at the University of Michigan. The information is identified as ICPSR #9915. Information from death certificates obtained for deaths occurring in the first 6 years of follow-up is also available.

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Dataset Name:	German Socio-Economic Panel (GSOEP)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Richard V. Burkhauser
Data Collection Organization:	The Department of Policy Analysis and Management, Cornell University

Purpose: The German Socio-Economic Panel (GSOEP) is the only nationally representative panel study of households and individuals in the Federal Republic of Germany. Its purpose is to provide a dynamic record of the socioeconomic characteristics of Germans, including those living in the reunified eastern states formerly known as the German Democratic Republic. These data permit researchers to track yearly changes in the health and economic well-being of older people relative to younger people in Germany from 1984 to the present.

Description and Study Design:

The GSOEP is developed and administered by the German Institute for Economic Research (DIW) in Berlin. The English Language Public Use Version of the GSOEP is distributed and administered by the Department of Policy Analysis and Management, Cornell University.

In addition to standard demographic information, the GSOEP questionnaire also contains objective measures - use of time, use of earnings, income, benefit payments, health, etc. - and subjective measures - level of satisfaction with various aspects of life, hopes and fears, political involvement, etc. - of the German population.

The first wave, collected in 1984 in the western states of Germany, contains 5,921 households in two randomly sampled sub-groups: 1) German Sub-Sample: people in private households where the head of household was not of Turkish, Greek, Yugoslavian, Spanish, or Italian nationality; 2) Foreign Sub-Sample: people in private households where the head of household was of Turkish, Greek, Yugoslavian, Spanish, or Italian nationality. In each year since 1984, the GSOEP has attempted to re-interview original sample members unless they leave the country. A major expansion of the GSOEP was necessitated by German reunification. In June 1990, the GSOEP fielded a first wave of the eastern states of Germany. This sub-sample includes individuals in private households where the head of household was a citizen of the German Democratic Republic. The first wave contains 2,179 households. In 1994 and 1995, the GSOEP added a sample of immigrants to the western states of Germany who arrived after 1984. The first wave contains 522 households. In 1998 a new "refreshment" sample of 1,067 households was selected from the population of private households. Finally, in 2000 a sample was drawn using essentially similar selection rules as the original German sub-sample and the 1998 refreshment sample with some modifications. The 2000 sample includes 6,052 households.

Data Availability:

The first nineteen waves of the GSOEP data, including the first thirteen waves of individuals living in the eastern states of Germany, and the first nine waves of the immigrant data. All data contain English variable and value labels that are translations of the original information provided by the German Institute for Economic Research (DIW). These data are available in SAS-Windows *.SD2, SAS Transport *.V5X, SPSS-Windows *.SAV, SPSS Transport *.POR, Stata 4.0, and ASCII formats.

Dictionary files that include the variable names, labels, and positions, as well as value labels and formats.

Adobe Acrobat version of The GSOEP Study: Desktop Companion To The German Socio-Economic Panel (GSOEP), edited by John Haisken-DeNew and Joachim Frick.

English translations of all questionnaires, from 1984 through 2002, in HTML format.

The first 41 working papers in the Cross-National Studies in Aging Program Project Working Paper Series and Aging Studies Program Paper Series in Adobe Acrobat formats.

Included on the CD-ROM with the English User Package for the GSOEP 1984-2002 is the Cross-National Equivalent File 1980-2002.

For users who have already signed a contract with the DIW and have received earlier releases of these data, registered users receive updated data for a nominal fee of \$30. Contact Cornell University at the address below.

For new users, the dissemination of the GSOEP public-use file is a two-step process. It is first necessary to sign a contract with the original producer of the data, the DIW. After the contract is signed, contact Cornell to receive the data. The charge for the CD-ROM is \$125. Contact the DIW and Cornell at the addresses below.

Contacts:

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Dataset Name:	Health and Retirement Study (HRS)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Robert J. Willis
Data Collection Organization:	Institute for Social Research, University of Michigan

Purpose:

The HRS is designed to provide a uniquely rich, nationally representative longitudinal dataset for the community of scientific and policy researchers who study the health, economics, demography, sociology, and psychology of aging. The fact that data from all these domains are collected in the same survey creates opportunities for new types of interdisciplinary research. In addition, the HRS provides researchers with the capacity to study the effects of expected and unexpected changes in policy, the economy or the society in a timely way, taking advantage of the many “natural experiments” that occur over time. For example, what is the effect of the stock market decline after 2001 on savings and retirement decisions?

The objectives of the study are to:

- Explain the antecedents and consequences of retirement
- Examine the relationship between health, income, and wealth over time
- Examine life cycle patterns of wealth accumulation and consumption
- Monitor work disability
- Provide a rich source of interdisciplinary data, including linkages with administrative data
- Examine how the mix and distribution of economic, family and program resources affect key outcomes, including retirement, dissaving, health declines and institutionalization

Study Design:

The design has these characteristics:

- National panel study
- Initial sample of over 12,600 persons in 7,600 households
- Current total sample of over 22,000 persons in 13,100 households
- Oversamples of Hispanics, Blacks and Florida residents
- Baseline: in-home, face-to-face in 1992 for the 1931-41 birth cohort (and their spouses, if married, regardless of age); in 1998 for 1924-1930 (CODA: Children of the Depression Age) and 1942-47 (War Babies) birth cohorts; in 2004 for 1948-53 (Early Boomers) cohort
- Follow-ups by telephone every second year, with proxy interviews after death. Beginning in 2006, half the sample will have enhanced face-to-face follow-ups that will include the collection of physical measures and biomarkers

HRS provides a research data base that can simultaneously support continuous cross-sectional descriptions of the US population over the age of fifty-five, longitudinal studies of a given cohort over a substantial period of time (up to 18 years by 2010 for the original HRS cohort, following them from age 51-61 to age 69-79) and research on cross-cohort trends. By 2010 the HRS will be able to support cross-cohort comparisons of trajectories of health, labor supply, or wealth accumulation for persons who entered their 50s in 1992, 1998 and 2004.

Questionnaire Topics:

Health and cognitive conditions and status, including physical measures
Retirement plans and perspectives
Psycho-social well-being
Attitudes, preferences, expectations, and subjective probabilities
Family structure and transfers
Employment status and job history
Job demands and requirements

Disability
Demographic background
Housing
Income and net worth
Health insurance and pension plans
Experimental modules

Links with Administrative Data:

Employer Pension Plans
National Death Index
Social Security Administration earnings and (projected) benefits data; W-2 self-employment data
Medicare and Medicaid files

Study of Assets and Health Dynamics among the Oldest Old (AHEAD):

AHEAD is a national panel study with an initial sample of 7,447 respondents aged 70+ (and their spouses, if married, regardless of age). There is a supplemental sample of respondents aged 80+ from the Medicare Master Enrollment File. Wave 1 data collection was completed in 1994 and Wave 2 in 1996. Since 1998, AHEAD respondents have been contacted as part of a joint data collection effort with the HRS.

AHEAD provides detailed coverage of the joint dynamics among health (physical, cognitive, and functional), dementia, economic and family resources, and care arrangements. The AHEAD study provides data on the interplay of resources and late life health transitions, including: the cost of illness borne by the family; differences in how resources are used to offset cognitive, physical, and functional losses; the effectiveness of various care arrangements in preserving function and delaying institutionalization; the extent to which transfers from kin buffer the assets of older persons and slow transitions to late life impoverishment; and the extent and mechanisms for dissaving and Medicaid spend down.

Aging, Demographics, and Memory Study (ADAMS):

One component of the data system is the use of the HRS survey as a sampling frame to support targeted sub-studies. HRS has been used as a sampling frame for the Aging, Demographics and Memory Study (ADAMS) supplement on dementia. This supplement to the HRS conducts a field assessment of a sample of about 930 HRS panel members aged 75+ to clinically assess their dementia status and dementia severity. In combination with multiple waves of HRS data on cognitive performance, functional status, medical history, and socioeconomic measures, a probability function of dementia will be estimated for HRS participants. The addition of this imputed dementia status to the ongoing panel will provide a unique resource for the study of the costs of dementia to the individual and his family. In Yr. 17-22, there is a plan to convert the ADAMS sample into a dementia incidence study, exploiting the highly detailed baseline information collected previously.

The HRS is also used as a sampling frame for mail surveys on other special topics including consumption and time use, prescription drug use and the impact of Medicare Part D, parents' human capital investments in children, and diabetes management by self-reported diabetics; and for a number of experimental topics using Internet interviewing. Because a lot is known about HRS respondents, the HRS provides an efficient frame from which to draw probability samples of relatively rare groups such as the cognitively impaired or diabetics. In addition, research using results from a sub-study can make use of all the information collected in the HRS from waves prior to the sub-study to deal with issues involving initial conditions and selectivity and also automatically provides prospective follow-up information in the core longitudinal survey.

Comparable International Data:

One aspect of the HRS data system, which is not formally part of the HRS project, is the emergence of a set of longitudinal studies of aging in other countries which have been consciously designed to produce data as comparable as possible to that collected by the HRS. These studies include English Longitudinal Study of Ageing (ELSA), Survey of Health, Ageing and Retirement in Europe (SHARE), in eleven countries in Europe, and Mexican Health and Aging Study (MHAS). Israel is planning to enter SHARE, and South Korea

is planning to launch a longitudinal study of aging as well. The HRS has actively collaborated with all of these studies, providing both scientific and technical help.

Future Plans:

During Years 17-22 of the HRS, the plan is to continue with core data collection on the steady-state design with biennial longitudinal data collection, including the addition of a new cohort in 2010; to continue the aims of the ADAMS supplement on dementia; to add the collection of biological samples, including DNA, physical performance measures and psychosocial content; and to continue the use of mail surveys on special topics, including continued longitudinal measurement of consumption and time use for about half of the sample, as a low-cost complement to the core data collection.

Data Availability:

All publicly available data may be downloaded after registration from <http://hrsonline.isr.umich.edu>. Early Release data files are typically available within three months of the end of each data collection, with the Final Release following at 24 months after the close of data collection activities. Files linked with administrative data are released only as restricted data through an application process, as outlined on the HRS website.

Bibliography:

The HRS bibliography of nearly a thousand publications is on-line at http://hrsonline.isr.umich.edu/papers/sho_papers.php?hfyle=bib_all. To search for a specific publication or topic in the bibliography, click on the link for the [Dynamic Bibliography](#) or go to <http://hrsweb.isr.umich.edu/biblio/index.html>.

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Dataset Name:	Human Mortality Database
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	John R. Wilmoth
Data Collection Organization:	University of California, Berkeley

Purpose:

The Human Mortality Database is being created to provide detailed mortality and population data to researchers, students, journalists, policy analysts, and others interested in the history of human longevity. The main goal of the database is to document the longevity revolution of the modern era and to facilitate research into its causes and consequences.

Description:

As of May 2004, it contains data for 20 countries. For each country, the database includes calculated death rates and life tables by age, time, and sex, along with all of the raw data (vital statistics, census counts, population estimates) used in computing these quantities. Data are presented in a variety of formats with regard to age groups and time periods. The project is a collaborative effort involving researchers at the department of demography of the University of California in Berkeley (USA) and at the Max Planck Institute for Demographic Research in Rostock (Germany). It replaces an earlier NIA-funded project, known as the Berkeley Mortality Database (see www.demog.berkeley.edu/wilmoth/mortality).

Objectives:

We seek to provide open, international access to historical and contemporary data on human mortality. The database will promote both policy analysis and basic scientific research by providing access both to calculated death rates and life tables and to all relevant raw data.

Future Plans:

We plan to add several more countries to the collection over the next few years. We are also developing an interactive web interface to give more options to database users.

Data Availability:

All data is freely available over the internet at www.mortality.org and www.humanmortality.de. Users are required only to complete a brief registration form before gaining access to the database.

Bibliography:

Users will be requested to submit information about publications using data from the database.

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Dataset Name:	Indonesian Family Life Survey (IFLS)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	John Strauss
Data Collection Organization:	RAND/UGM

Purpose:

The Indonesia Family Life Survey (IFLS) will support scientific research on issues related to understanding the social, economic, demographic and health transitions that are taking place in the context of a rapidly changing low-income country. The first wave of IFLS was fielded in 1993 and collected information on over 30,000 individuals living in 7,200 households. The sample covers 321 communities in 13 provinces in Indonesia and is representative of about 83% of the population. These households were revisited in 1997 (IFLS2) and again in 2000 (IFLS3). A 25% sub-sample of households was re-interviewed in 1998 (IFLS2+). The survey is ideally suited for research on topics related to important dynamic aging processes such as the transition from self-sufficiency to dependency, the decline from robust health to frailty, labor force and earning dynamics, wealth accumulation and decumulation, living arrangements and intergenerational transfers.

Description:

IFLS is an on-going multi-level longitudinal survey that collects extensive information on socio-economic and demographic characteristics of respondents. Special attention is paid to the measurement of health, including the collection of biomarker data. In addition to comprehensive life history data on education, work, migration, marriage and child bearing, the survey collects very detailed information on economic status of individuals and households. This includes consumption, earnings, non-labor income and wealth. Recognizing that families and households are not synonymous, links with non co-resident family members are spelled out in conjunction with information on borrowing and transfers. Information is gathered on participation in community activities and in public assistance programs. Measurement of health is a major focus of the survey. In addition to detailed information about use of private and public health services along with insurance status, respondents provide a self-reported assessment of health status. Moreover, a nurse or doctor visits every household and conducts a physical health assessment of each respondent. This includes measurement of anthropometry, blood pressure, lung capacity, a mobility test and level of hemoglobin in the blood. Dry blood spots have also been collected.

In each wave of IFLS, the individual and household surveys are complemented by an extremely comprehensive community and facility survey. This survey involves interviews with local leaders regarding services available in the community, visits to multiple private and public health service providers and visits to multiple schools in every community. Detailed information on the local economy and prices of goods and services are also collected. These data may be matched with the individual and household -level data.

Considerable attention has been placed on minimizing attrition in IFLS. In each re-survey, about 95% of households have been re-contacted. Around 10-15% of respondents have moved from the location in which they were interviewed in the previous wave. In addition, individuals who "split-off" from the original households have been followed. They have added around 1,000 households to the sample in 1997 and about 3,000 households in 2000.

Objectives:

IFLS is designed to support analyses of such aging-related topics as:

- the timing of the transition into frailty;
- the relationship among income, wealth, education, and family support networks and health status;
- the timing of transitions out of the labor force and co-incident events associated with those transitions;

- links between income, education, family support networks, health and labor market outcomes; and
- the effects of changes in social safety nets on welfare of the elderly and their adult children.

Study Design and Future Plans:

1993 (baseline): In-home, face-to-face interview with household head, spouse and sample of their children and sample of other adult household members.
 1997: Follow-up all households, all 1993 "main" respondents and all 1993 household members born before 1967.
 1998: Follow-up of 25% sub-sample (not funded by NIA) Interview selected household members (1993) and all household members (1997 & 1998).
 2000: Follow-up all households, all 1993 "main" respondents, all 1993 household members born before 1967, sample of other 1993 household members.
 2006: Next follow-up planned.

Sample Sizes

1993: 7,200 households; 22,000 individual interviews
 1997: 7,500 households; 33,000 individual interviews
 1998: 2,000 households; 10,000 individual interviews
 2000: 10,400 households; 37,000 individual interviews

Questionnaire Topics:

Consumption	Tobacco consumption
Knowledge of health care providers	Acute Morbidity
Labor earnings and work histories	Ability to perform ADL's
Household and individual assets	Self-treatment
Education and migration history	Health service utilization
Marriage and pregnancy histories	Health Insurance
Links with non co-resident kin	Height, weight, waist/hip, hemoglobin
Transfers and borrowing	Lung capacity, blood pressure, mobility
Household decision-making	Dry blood spots
Community support network	Nurses' assessment of health status

Agencies involved in implementing the survey:

MSU, RAND, UCLA
 University of Gadjah Mada, University of Indonesia
 Indonesian Ministries of Economic Planning, Education, Family Planning and Health
 Input from experts at European, Indonesian, international and U.S. institutions

Contact:

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Dataset Name:	International Database on Aging (IDBA)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Victoria Velkoff, IPC
Data Collection Organization:	US Census Bureau, International Programs Center (IPC)

Purpose:

In response to the need for reliable and internationally comparable statistics on population aging, the National Institute on Aging (NIA) and the International Programs Center (IPC), US Census Bureau, have created a computerized data base which provides detailed demographic and socioeconomic information about the older population in the United States and other countries, both industrialized and developing. The intent of this effort is twofold: to promote a better understanding of the aging process in disparate societies, and to afford researchers and policymakers in the US a better opportunity to gain insights and formulate responses to demands generated by an aging American population.

Description:

The International Data Base on Aging (IDBA) is a subset of a larger International Data Base (IDB) that is maintained and updated by the IPC. The IDB contains the IPC's population projections for all countries of the world, as well as information for as many as 51 demographic and socioeconomic variables for each country. The initial IDB design included virtually no statistics for elderly age groups; as was common until recent years, the elderly typically were aggregated into a broad open-ended age group (e.g., 60 or 65 years old and over). The primary goal of the IDBA is to expand the age coverage of the IDB by assembling census, survey, administrative, and population-projection data for 5-year age groups up to the oldest available grouping.

The detailed IDBA statistics include not only numbers of people in each age cohort, but also their marital status, labor force participation and occupation, mortality rates, and related characteristics. Another goal of the IDBA is to broaden the temporal coverage of statistics on the older population; data for 1950 to the present are included, with population projections running through the year 2050. Information about cohorts over time allows researchers to go beyond mere cross-sectional comparisons to analyses of the same age cohorts in different countries.

Data base contents have been reviewed for internal consistency and international comparability. Source documentation accompanies all information, and additional notation of conceptual definitions and/or data irregularities is provided where necessary. The initial geographic coverage of 31 countries was expanded to 42 in 1989, to 85 in 1994, and to 101 countries in 1996, and currently covers all 227 countries of the world.

Contact:

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Dataset Name:	Iowa 65+ Rural Health Study
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Robert B. Wallace
Data Collection Organization:	University of Iowa College of Medicine

Purpose:

Identify a wide range of risk factors for disease, disability and death among older persons;
 Better understand the natural history of health and disease problems in older persons;
 Identify potential areas of intervention;
 Enhance disease prevention and health promotion in older persons;
 Contribute to health and health services policy (in order to improve the delivery of public health and clinical services to older persons); and
 Improve methodological approaches to the population and clinical study of older persons.

Description:

This cohort was founded in 1981 as a sister study to the Established Populations for Epidemiologic Study of the Elderly (EPESE). It complements the findings of the three other EPESE sites (East Boston, MA; New Haven, CT; and north-central North Carolina) and has common items and methods in many domains. The target population was all persons 65 years and older in two rural counties in east central Iowa: Iowa and Washington counties. In 1981 a census of older persons in the target area was conducted by the investigators, creating an ascertainment list having 99% of the persons identified in the previous year by the US Decennial Census. The baseline survey was conducted between December 1991 and August 1992. Overall, 3,763 persons, or 80% of the target population were interviewed. The population is virtually entirely Caucasian. Subsequently, personal follow-up surveys were conducted 3, 6, and 10 years after the baseline survey. Telephone surveys were conducted 1, 2, 4, 5, and 7 years after the baseline survey.

Data collected from respondents was nearly all from structured questionnaires. At follow-up #6, there were a series of physical function performance tests, the so-called NIA-MacArthur Battery, and blood was drawn for biochemical tests and potentially other determinations. In addition, some datasets were linked to the EPESE dataset under appropriate restrictions, including Iowa state driving records and clinical diagnoses and medical care utilization from the Centers for Medicare and Medicaid Services.

Questionnaire Topics

- | | |
|---|---|
| Demographics | Major health conditions |
| Health care utilization | Hearing and vision |
| Weight and height | Elements of nutrition |
| Sleep problems | Depressive and anxiety symptoms |
| Alcohol and tobacco use | Cognitive performance and dementia screening measures |
| Incontinence | Social networks and support |
| Life satisfaction index | Medication use |
| Worries | Dental problems |
| Activities of daily living | Life events |
| Satisfaction with medical care | Automobile driving habits |
| Brief economic status | Blood pressure |
| Multiple measures of physical and disability status | |

Future Plans:

Data collection was completed in 1992 although continued linking with various indirect data sources may continue under appropriate restrictions. Active analysis is continuing.

Data Availability:

The dataset has been shared with several investigative teams under special arrangement with the Principal Investigator. Early surveys are available from ICPSR. A small storage of blood is available for exploratory analyses.

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Dataset Name:	Longitudinal Employer Household Dynamics (LEHD)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	John Abowd, John Haltiwanger Julia Lane, and Jeremy Wu
Data Collection Organization:	US Census Bureau

Purpose:

The mission of LEHD is to combine federal and state administrative data on employers and employees with core Census Bureau censuses and surveys to improve the quality and understanding of survey products, and to conduct or facilitate research on emerging social and economic policy issues. Of particular importance is the development of a data infrastructure of integrated household and firm datasets that relate employers to their employees and vice-versa. This data infrastructure facilitates longitudinal research applications in both the household/individual and firm/establishment dimensions. The specific research is targeted at filling an important gap in the available data on older workers by providing information on the demand side of the labor market.

Description:

These datasets comprise Title 13 protected data from the Current Population Surveys, Surveys of Income and Program Participation, Surveys of Program Dynamics, American Community Surveys, the Business Register and Economic Censuses and Surveys. We have built employer-employee data relations based on universe state records from twenty-five states: California, Colorado, Delaware, Florida, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Maryland, Minnesota, Missouri, Montana, New Jersey, New Mexico, North Carolina, Oklahoma, Oregon, Pennsylvania, Texas, Virginia, Washington, West Virginia, and Wisconsin. Ten more states are in the process of joining the partnership. LEHD's second method of developing employer-employee data relations through the use of federal tax data has been completed.

LEHD has achieved its objective by:

- Producing summary tables on accessions, separation, job creation, destruction and earnings by age and sex of worker – by industry and geographic area. These tables are available for twenty states and on the website at <http://lehd.dsd.census.gov>.
- Providing state-level micro data to approved researchers at Census facilities. The data files consist of longitudinal datasets on all firms in each participating state (quarterly data, 1991- 2003), with information on age, sex, turnover, and skill level of the workforce as well as standard information on employment, payroll, sales and location.
- Creating new public use files that are derived from the integration of the Survey of Income and Program Participation with detailed earnings histories. A first version of the inference valid synthetic data files has been made available to SSA, CBO and Census, and is being validated.
- Creating new data products (summary tables and enhanced public use data files) by linking worker information to the Business Register that is enhanced by detailed and universal firm pension and benefit information from the 5500 file. This file provides information on whether firms cover employees on a plethora of pension plans, including profit-sharing, 401(k), 403(b)s, IRA's, and defined contribution plans. This work is reported as LEHD Technical Paper No. TP-2003-05, "Describing the Form 4400-Business Register Match."

New data products include: Current Population Survey (1973-1999) enhanced by detailed information on pension plans offered by previous and current employers, the firm take-up rate, and financial characteristics of the firm; Survey of Income and Program Participation (1984, 1990-1993, 1996) enhanced by detailed information on pension plans offered by previous and current employers, the firm take-up rate, and financial characteristics of the firm; and summary information on pension plan coverage by firm type and workforce characteristics from the Business Register.

Data Availability:

Research conducted on the LEHD data and other products developed under this proposal at the Census Bureau takes place under a set of rules and limitations that are considerably more constraining than those prevailing in typical research environments. Successful peer-reviewed proposals to carry out research using the LEHD data must be approved by the Census Bureau, which will confirm that:

- the Bureau would benefit from the proposed research (a requirement for granting access to Title 13 protected data);
- the proposed research is feasible using the LEHD data;
- the variables and cases requested can be supplied; and
- appropriate resources exist to undertake the analysis.

If state data are requested, the successful peer-reviewed proposals must also be approved by the participating state. If federal tax data are requested, the successful peer-reviewed proposals must also be approved by the Internal Revenue Service. Researchers using the LEHD data will be required to obtain Special Sworn Status from the Census Bureau and be subject to the same legal penalties as regular Census Bureau employees for disclosure of confidential information.

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Dataset Name:	Longitudinal Studies of Aging (LSOAs)
Sponsoring Organization:	National Center for Health Statistics (NCHS) National Institute on Aging (NIA)
Principal Investigator:	Julie Dawson Weeks (NHCS)
Data Collection Organization:	U.S. Census Bureau National Opinion Research Center at the University of Chicago

Purpose:

The LSOAs, a collaborative project of NCHS and NIA, is a family of surveys designed to measure changes in health status, health-related behaviors, health care, and the causes and consequences of these changes within and across two cohorts of elderly Americans. The surveys also provide a mechanism for monitoring the impact of proposed changes in Medicare and Medicaid and the accelerating shift toward managed care on the health status of the elderly and their patterns of health care utilization.

Description:

Supplement on Aging (SOA)

This survey was conducted as part of the 1984 National Health Interview Survey (NHIS). The SOA was based on a probability sample of 16,148 persons 55 years of age and older living in the community. Interviews for the SOA were conducted in person by the U.S. Census Bureau. The following topics were covered in the interview:

- Housing characteristics
- Family structure and living arrangements
- Relationships and social contracts
- Use of community services
- Occupation and retirement (income sources)
- Health conditions and impairments
- Functional status, assistance with basic activities
- Utilization of health services, nursing home stays
- Health opinions

Longitudinal Study of Aging

The 1984 SOA served as the baseline for the LSOA, which followed all persons who were 70 years of age and over in 1984 through three follow-up waves, conducted in 1986, 1988 and 1990. All follow-up interviews were conducted over the telephone by interviewers from the U.S. Census Bureau. The major focus of the follow-up interviews was on functional status and changes that had occurred between interviews. Information was also collected on housing and living arrangements, contact with children, utilization of health services and nursing home stays, health insurance coverage, and income. The interview data are augmented by linkage to the Centers for Medicare and Medicaid Services' Medicare enrollment and utilization records, the National Death Index, and multiple cause-of-death records. Second

Second Supplement on Aging

The Second Supplement on Aging (SOA II) was conducted as part of the 1994 NHIS. Interviews for the SOA II were conducted during a follow-up visit with NHIS respondents between October 1994 and March 1996. The SOA II sample is comprised of 9,447 persons who had participated in the 1994 NHIS and had turned 70 years of age by the time of the SOA II interview. The SOA II serves as a comparison cohort to the 1984 SOA, and most of the questions from the SOA were repeated in the SOA II. Topics new to the SOA II include:

- Use of assistive devices and medical implants
- Health conditions and impairments
- Health behaviors
- Transportation
- Functional status, assistance with basic activities, unmet needs (expanded)

Utilization of health services, nursing home stays (expanded)

Second Longitudinal Study of Aging

The SOA II serves as the baseline for the Second Longitudinal Study of Aging (LSOA II). Data collection for the first follow-up wave of the LSOA II was conducted between May 1997 and March 1998. The second follow-up wave of interviewing was fielded in June 1999 and was completed in July 2000. A third follow-up is not scheduled to occur. Many of the questions included in the SOA II are repeated in the follow-up interviews. In addition, the follow up questionnaires include items on cognitive functioning, income and assets, family and childhood health, and more extensive health insurance information.

Data Availability:

SOA

Data from the full SOA sample of persons 55 years of age and older is available on CD-ROM: Series 10, No. 16H (issued July 2001). This CD-ROM also includes data obtained during the 1984 NHIS interview and all related documentation. The study is fully documented in Vital and Health Statistics, Series 1 Number 18.

LSOA

The complete set of data from all four interview waves and corresponding documentation is available on CD-ROM: The Longitudinal Study of Aging, 1984-1990, No. 1 (issued September 1993). The study is fully documented in three Vital and Health Statistics monographs: Series 1, Numbers 18, 21 and 28.

SOA II

The SOA II is available on CD-ROM: The Second Supplement on Aging, 1994, Version 2, No. 1 (issued September 1998).

LSOA II

The complete set of LSOA II data is available on four CD-ROMs: a) LSOA II, 1994-1998, Wave 2 Survivor File, Version SF 1.2 (issued June 2002); b) LSOA II, 1994-1998, Wave 2 Decedent File, Version DF 1.2 (issued August 2002); c) LSOA II, 1994-2000, Wave 3 Survivor File, Version SF 2.2 (issued November 2002); and d) LSOA II, 1994-2000, Wave 3 Decedent File, Version DF 2.2 (issued December 2002).

To request copies of the LSOA CD-ROMs mentioned above, email nchsquery@cdc.gov or telephone (301) 458-INFO. The ROMs are also available from NIA by contacting Julie Dawson Weeks at NHCS or emailing lsoa@cdc.gov. Members of ICPSR at the University of Michigan (see appendix) may obtain the data free of charge through ICPSR.

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Dataset Name:	Longitudinal Study of Generations
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Vern L. Bengston
Data Collection Organization:	University of Southern California, Andrus Gerontology Center

Purpose:

The Longitudinal Study of Generations (LSOG) investigates the effects of recent socio-historical change on family interactions and the aging of successive family generations. The goal is to examine (1) how the structure, functions, and consequences of intergenerational relationships may have changed across recent decades, and (2) how intergenerational relationships influence well-being in the context of life-course transitions. The focus of data collection is on inter-generational dynamics over a period of rapid changes in American society, in terms of the well-being of individual family members in three- and four-generation families.

Description:

This study began collecting data in 1971 with 2,044 adult members of some 300 three- (and later four-) generation families. Since 1985, data have been collected every three years. The great-grandchildren have been added to the study as they turn age 16. With data over 30 years it will be possible to realize the first fully-elaborated generation-sequential design, comparing sets of parents and adult-children at the same age across different historical periods.

Objectives:

(1) To track life-course trajectories of family intergenerational solidarity and conflict over three decades of adulthood, and across successive generations of family members; (2) To identify how intergenerational solidarity, and conflict influence the well-being of family members throughout the adult life course and across successive generations; (3) To chart the effects of socio-historical change on families, intergenerational relationships, and individual life-course development during the past three decades; (4) To examine women’s roles and relationships in multigenerational families over 30 years of rapid change in the social trajectories of women’s lives. These data can extend understanding of the complex interplay among macro-social change, family functioning, and individual well-being over the adult life-course and across successive generations.

Study Design:

The original respondents (in 1971) were identified from a random selection of 840,000 members of the major HMO in southern California at the time. This resulted in a study sample of grandparents, middle-aged parents, and young adult grandchildren (aged 16 and over), and their spouses. These individuals have provided responses at three-year intervals since 1985. In addition, beginning in 1991, the great-grandchildren were added to the longitudinal study when they turned 16. Response rates by survey wave are available from the PI.

Questionnaire Topics:

The study investigates: (1) six dimensions of solidarity (associational solidarity, affectual solidarity, structural solidarity, functional solidarity, normative solidarity, consensual solidarity); (2) family conflict; (3) four types of well-being (psychological well-being, physical well-being, social well-being, and socioeconomic well-being); (4) life events as well as structured life course transitions; and (5) individual manifestations of social change.

Future Plans:

To collect Wave-8 data in 2004 and Wave-9 data in 2007.

Data Availability:

Survey data from Wave-1 through Wave-5 are archived at the Murray Research Center at Radcliffe College.
See “Contacts”

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Dataset Name:	Longitudinal Study of Mexican-American Elderly Health (The Hispanic EPESE)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Kyriakos S. Markides
Data Collection Organization:	University of Texas Medical Branch, Galveston

Purpose:

This is a longitudinal study of over 3,000 Mexican-Americans aged 65 or over living in five southwestern states. The objective is to describe the physical and mental health of the study group and link them to key social variables (e.g., social support, health behavior, acculturation, migration).

Description:

The Hispanic EPESE was funded in 1992 as part of a special initiative of the National Institute on Aging. There was a recognition at that time that while important epidemiological data on elderly Non-Hispanic Whites and African Americans had become available through the EPESE studies begun in the 1980's in East Boston, New Haven, North Carolina, and rural Iowa, comparable data were not available for the Hispanic elderly. A study focusing on the Mexican-American population of the Southwestern United States was proposed.

The main impetus behind the application was that the basic information on the health of the Mexican-American elderly was simply not available. Much of the existing knowledge in that area was based on data from the Hispanic Health and Nutrition Examination Survey (HHANES) conducted in 1982-4. The HHANES covered Mexican-Americans in the Southwest, Cuban Americans in Dade County, Florida, and Puerto-Ricans in the greater New York City area. Unfortunately, the study was limited to persons under 75 years of age and the number of elderly in this study was too small to provide stable estimates of their health status. In addition, the HHANES did not include instruments measuring the physical functioning of subjects. Other available knowledge in the area was also limited in that it had been based on a number of small, regional studies.

In addition to providing basic data on the population's health and health care needs, a guiding principle behind the Hispanic EPESE was that the socioeconomic and health characteristics of Mexican-Americans, including the elderly, were different from those of non-Hispanic white Americans, African-Americans, and other major ethnic groups. Knowledge on whether certain risk factors for mortality and morbidity operate differently in Mexican-Americans was not available. For example, it was not clear whether obesity, physical exercise, social support, and other variables had the same influence on health outcomes in Mexican-American as in other groups.

Objectives:

The primary purpose of the study was to provide estimates of the "prevalence of key physical health conditions, mental health opportunities, and functional impairments in older Mexican-Americans and compare this prevalence with that in other populations." In addition, the intent was to investigate predictors and correlates of these health outcomes cross-sectionally. A two-year follow-up was requested in order to examine predictors of mortality, changes in health outcomes, institutionalization and other changes in living arrangements, and changes in life situations and quality of life.

Study Design:

With this background in mind, the Hispanic EPESE was launched during 1993-4 when the baseline data were collected. To the extent possible, the study was modeled after the existing EPESE studies, especially the Duke EPESE, which included a large sample of African-Americans. Unlike the other EPESE studies that

were restricted to small geographic areas, the Hispanic EPESE aimed at obtaining a representative sample of community-dwelling Mexican-American elderly residing in the five Southwestern states of Texas, New Mexico, Arizona, Colorado, and California. Approximately 85% of Mexican-American elderly reside in these states and data were obtained that are generalizable to roughly 500,000 older people. The final sample of 3,050 subjects at baseline is comparable to those of the other EPESE studies and is sufficiently large to provide stable estimates of most health characteristics of interest.

Interviewers screened a total of 175 households within each sampling unit. This screening (and the interviewing) was completed in two phases. One hundred households were screened during the first phase. The incidence of eligible respondents from these initial 30,000 screened households determined the size of phase two. They attempted to interview eligible respondents as they were identified. Up to four eligible adults were interviewed within each household. Any household with five or more eligible adults was considered a group home and was not eligible. For phase one, interviewers began by making contacts at the first 100 housing units they had listed. They only went beyond this point as needed, to replace households where screening could not be completed. The same procedure was followed with the second phase for up to an additional seventy-five contacts (households screened).

Questionnaire Topics:

Ethnic algorithm	IADLs/ADLs
Living arrangements	Blood pressures
Social support and family contacts	Stressors/life events
Employment history	Health locus of control
Acculturation	Religion and social involvement
Global health rating	Self-esteem (Baseline)
Medical conditions	Performance-oriented mobility assessment
CES-D	Height/Weight
Cognition	Health care services utilization
Health behaviors	Income/financial strain
Medications	Insurance coverage

Availability and Future Plans:

Waves I to IV (1993-1994, 1995-1996, 1998-1999, 2000-2001) are available at the National Archive of Computerized Data on Aging (NACDA). Also available through NACDA is the "Resource Book of the Hispanic Established Populations for the Epidemiologic Studies of the Elderly" which offers a thorough review of the data and its applications.

Data collection for Wave V (6/2004-1/2006) is complete. Re-interviews (10-11 years later) were held with 1,171 of the original 3,050 subjects and 902 new subjects were added. All subjects are age 75 or older. Hemoglobin A1_c test kits were provided to subjects who self-reported diabetes. Approximately 270 of the kits were returned for analyses. Wave V data are being validated and reviewed. A tentative timeline for the archiving of Wave 5 data is November 2006. Wave VI interviewing and data collection is scheduled to begin in Fall 2006.

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Dataset Name:	Los Angeles Family and Neighborhood Survey (L.A.FANS)
Sponsoring Organization:	NICHD, NIA, NIEHS, NIH/OBSSR, Los Angeles County, First 5 LA – the Los Angeles County Children and Families First Commission, DHHS/OASPE, Russell Sage Foundation, Keck Foundation
Principal Investigators:	Anne R. Pebley Narayan Sastry
Data Collection Organization:	Research Triangle Institute (RTI)

Purpose:

The NIA-sponsored component of the Los Angeles Family and Neighborhood Survey (L.A.FANS) will collect, document, and place in the public domain an important new resource for investigating the social and economic determinants of adult health and race and ethnic disparities in adult health as part of Wave 2 of L.A.FANS (L.A.FANS-2). Specifically, we will re-interview adult respondents from Wave 1 of the L.A.FANS (L.A.FANS-1) and collect extensive social, economic, and health data, as well as information on the physical and social environments in which they live and work. These data will allow researchers to examine a wide range of hypotheses about contextual effects on adult health and health-related behaviors using multilevel statistical models.

Description and Study Design:

This study is part of L.A.FANS-2. L.A.FANS was originally designed to study the effects of neighborhoods on children’s wellbeing and residential selection. However, its unique design and sample population provide an important opportunity to investigate major questions in adult health disparities.

L.A.FANS-1 interviewed 2,548 randomly selected adult (RSA) respondents aged 18 to 94 years living in 65 neighborhoods in Los Angeles County. The RSA is a primary respondent in the survey and will be followed over time. Among households that completed the Wave 1 roster, the response rate for sampled and eligible RSA respondents was 85 percent. Sample weights that adjust for the sample design and non-response are available on the public use data.

L.A.FANS is based on a multistage clustered sampling design. First, census tracts in Los Angeles County were divided into three strata based on the percent of the tract’s population in poverty in 1997. The three strata are: very poor (those in the top 10 percent of the poverty distribution), poor (tracts in the next 30 percent of the poverty distribution), and non-poor (tracts in the bottom 60 percent of the distribution). To achieve an oversample of poor and very poor tracts, 20 tracts were sampled in the poor and very poor strata. An additional 25 tracts were sampled in the non-poor stratum, for a total of 65 tracts. In the second stage, census blocks were sampled within each tract and all dwelling units were listed in sampled blocks. In the third stage, households were sampled within each block and screened. Approximately 40-50 households were interviewed in each census tract, for a total sample size of 3,100 households.

L.A.FANS-1 interviews were conducted in person using computer-assisted personal interviewing (CAPI) survey techniques, in English and Spanish. The adult interview collected extensive social, economic, demographic, and health information on the respondent, including: educational history, social background (parents’ birth places and occupations, family composition and place of residence in childhood, birthplace and date, immigration status and history), marriage and relationship history, fertility and adoption history, observed and self-reported race/ethnicity, occupation and work history, public program participation history, health insurance history, health care utilization, health status measures (e.g., general health status, childhood health status, diagnosed chronic conditions, weight and height, work limitations), health behaviors, residential history and reasons for neighborhood selection, income of individual family members, detailed assets information, attitudes about health behaviors, perceptions of the neighborhood, interactions with neighbors, and involvement in local activities.

Wherever possible, L.A.FANS-1 used well-tested questions or sections from national surveys, such as the Health and Retirement Study (HRS), Panel Study of Income Dynamics (PSID), National Longitudinal Surveys (NLS), and National Health Interview Survey (NHIS), and other urban surveys, such as the Project on Human Development in Chicago Neighborhoods, to facilitate comparisons. L.A.FANS-1 survey began in April 2000 and was completed at the end of 2001. Fieldwork for L.A.FANS-2 is planned for 2006-2007.

L.A.FANS-2 will significantly enhance the utility of the L.A.FANS data for studies of adult health disparities by:

1. Replicating *self-reported* health measures from L.A.FANS-1 and collecting new self-reports on treatment, health behaviors, functional limitations, quality and quantity of sleep, anxiety, health status “vignettes,” and changes in health status since the first interview;
2. Collecting physiological markers of disease and health status, including diabetes, hypertension, obesity, lung function, immune function, and cardiovascular disease;
3. Expanding the data collected on adults’ work conditions, stressful experiences, and social ties.

Future Plans:

The L.A.FANS-2 is planned for 2006-2007. It will: (1) recontact and reinterview panel RSA respondents, whether or not they have moved since Wave 1, and (2) interview a new sample of adult respondents in each sampled neighborhood who have moved into the neighborhood since Wave 1. Thus, L.A.FANS-2 combines the advantages of a panel study with those of a representative cross-sectional study of respondents in sampled neighborhoods.

Data Availability:

Public use data from L.A.FANS-1 are available for downloading at www.lasurvey.rand.org. Researchers can also apply for a restricted use version of the L.A.FANS-1 data that contain considerable contextual and geographically-referenced information. Application procedures are described at www.lasurvey.rand.org/policyver1.htm. New data from L.A.FANS-2 will be released shortly after fieldwork is completed, with information on the release plans available on the L.A.FANS website.

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Dataset Name:	The Luxembourg Income Study (LIS)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Timothy M. Smeeding
Data Collection Organization:	Luxembourg Income Study,

Purpose and Description:

Since its beginning in 1983, the LIS has grown into a cooperative research project with a membership that includes countries in Europe, North America, and Australia. The database now contains information for 29 countries for one or more years. Negotiations are in the process of adding data from additional countries, including Korea, Japan and New Zealand. The LIS databank has a total of over 130 datasets covering the period 1968 to 2001. During 2004, we continue to work to complete a fifth wave of data for the late 1990s and 2000.

Objectives:

- Test the feasibility for creating a database containing social and economic data collected in household surveys from different countries;
- Provide a method which allows researchers to use the data under restrictions required by the countries providing the data;
- Create a system that allows research requests to be received from and returned to users at remote locations; and
- Promote comparative research on the social and economic status of various populations and subgroups in different countries.

Data Availability:

The dataset is accessed globally via electronic mail networks (see chart on next page). Extensive documentation concerning technical aspects of the survey data and the social institutions of income provision in member countries is also available to users.

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LIS DATABASE LIST: Country and Year¹

Country	Code ²	Historical Datasets	Wave I around 1980	Wave II around 1985	Wave III around 1990	Wave IV around 1995	Wave V around 2000
Australia	AS	•	1981	1985	1989	1994	•
Austria	AT	•	•	1987	•	1994/1995/1997	2000 ⁵
Belgium	BE	•	•	1985	1988/1992	1997	•
Canada	CA	1971/1975	1981	1987	1991	1994/1997/1998	2000
Czech Republic	CZ	•	•	•	1992	1996	•
Denmark	DK	•	•	1987	1992	1995/1997	•
Estonia	EE	•	•	•	•	•	2000
Finland	FI	•	•	1987	1991	1995	2000
France ³	FR	•	1979/1981	1984A/1984B	1989	1994	•
Germany ⁴	GE	1973/1978	1981	1983/1984	1989	1994	2000
Hungary	HU	•	•	•	1991	1994	1999
Ireland	IE	•	•	1987	•	1994/1995/1996	•
Israel	IL	•	1979	1986	1992	1997	2001
Italy	IT	•	•	1986/1987	1989/1991	1993/1995	1998/2000
Luxembourg	LX	•	•	1985	1991	1994/1997	2000
Mexico	MX	•	•	1984	1989/1992	1994/1996/1998	2000
Netherlands	NL	•	•	1983/1986* /1987	1991	1994	1999
Norway	NW	•	1979	1986	1991	1995	2000
Poland	PL	•	•	1986	1992	1995	1999
R.O.C.-Taiwan	TW	•	1981	1986	1991	1995/1997	2000
Romania	RO	•	•	•	•	1995/1997	•
Russia	RL	•	•	•	1992	1995	2000
Slovak Republic	SK	•	•	•	1992	1996	•
Slovenia	SI	•	•	•	•	1997	1999
Spain	SP	•	1980	•	1990	•	•
Sweden	SW	1967/1975	1981	1987	1992	1995	2000
Switzerland	CH	•	1982	•	1992	•	2000 ⁵
United Kingdom	UK	1969/1974	1979	1986	1991	1994/1995	1999
United States	US	1969/1974	1979	1986	1991	1994/1997 State file: 1995-7	2000

¹Year given is reference year, not necessarily the year that the data were collected.

²Codes are the LIS database country abbreviations.

³France has an income survey (1979, 1984) and a budget survey (1984, 1989, 1994).

⁴Germany has three different databases: an income and expenditure survey (1973, 1978, 1983); a transfer income survey (1981); and three cross-sections from the Socio-Economic Panel Study (GSOEP) (1984, 1989, 1994, 2000)

⁵Anticipated that this will be available during 2005.

Dataset Name:	The Second Malaysian Family Life Survey (MFLS-2)
Sponsoring Organization:	National Institute on Aging National Institute of Child Health and Human Development
Principal Investigator:	Julie DaVanzo
Data Collection Organization:	RAND and the National Population and Family Development Board (NPFDB) of Malaysia

Purpose:

The second round of the Malaysian Family Life Survey (MFLS-2) is a follow-up of the 1976-1977 Malaysian Family Life Survey (MFLS-1). As in MFLS-1, the MFLS-2 covers both the respondents' and spouses' marriage, fertility, employment, education and migration histories as well as extensive information on the household economy. The MFLS-2 contains a supplementary sample of persons age 50 or older. The data permit analysis of intergenerational transfers to the elderly and their covariates; the living arrangements of the elderly; the health of the elderly; labor supply, occupation and retirement status of the elderly; and their migration patterns. This supplement fills the gap left by many standard sources of demographic and economic information about Third World populations, such as fertility surveys and labor force surveys, which effectively exclude the elderly.

Description:

Field work for MFLS-2 began in Aug. 1988 and was completed in Jan. 1989. The survey was fielded in four samples:

The Panel Sample - Women who were the primary respondents to the First Malaysian Family Life Survey (MFLS-1), who at that time (1976) were ever-married women aged 50 or younger. There are 926 Panel households in MFLS-2, a follow-up rate of 72%.

The Children Sample - Children aged 18 or older in 1988 of the women interviewed as primary respondents for MFLS-1; i.e. adult children of the women eligible for the MFLS-2 Panel sample. There were interviews with one child, selected at random, inside the Panel household and two children, selected at random, living elsewhere in Peninsular Malaysia. There are 1,136 respondents in the Children sample.

The New Sample - A sample of households with a woman aged 18-49 (regardless of her marital status) or an ever-married woman under age 18. There are 2,184 respondents in MFLS-2 New Sample.

The Senior Sample - Selected households with a person age 50 or over. There are 1,357 respondents in the Senior Sample.

Data Availability:

Information about how to obtain is available at <http://www.rand.org/labor/FLS/MFLS/index.html#order>.

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Dataset Name:	Matlab Health and Socioeconomic Survey (MHSS)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	M. Omar Rahman
Data Collection Organization:	RAND, The Harvard School of Public Health, The University of Pennsylvania, and The International Centre for Diarrhoeal Disease Research, Bangladesh

Purpose:

The ultimate goal of the survey effort is to enter into the public domain a new and unique microlevel dataset for research on aging. In particular, these new data will support in-depth analyses -- not possible with existing survey data -- on interrelated topics having to do with life-cycle investments in the physical, economic, and social well-being of the elderly. These topics include the effect of socioeconomic and behavioral factors on adult survival, health status, and health care utilization; the linkages among elderly well-being, kin characteristics and intergeneration of resource flows, and the impact of community services and infrastructure on adult health and other human capital acquisition.

Description:

This study addresses these concerns by means of a major family and community survey conducted in 1996 in Matlab, a region of rural Bangladesh in which there is an ongoing prospective Demographic Surveillance System (DSS). For a detailed description of the Matlab surveillance population, please refer to J. Menken and J.F. Phillips, 1990 "Population Change in a Rural Area of Bangladesh, 1967-87," *Annals of the American Academy of Political and Social Science*, 510:87-101. Further information about Matlab can be obtained from the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDRDB) (<http://www.icddrb.org/>).

Study Design:

It is important to note that the MHSS actually consists of four distinct and separate surveys that have different samples and serve different analytic objectives. These component surveys are:

The Main Survey consisting of household- and individual-level information on 4,364 households clustered in 2,687 baris, an approximately one-third random sample of the total number of baris in the Surveillance area. This component is likely to be the one that is most useful to the widest group of analysts. The Main data contains an additional 174 households clustered in 94 other baris that fell outside the prescribed sampling scheme and which should be dropped from analyses. Thus, the total number of households found in the Main sample data are 4,538.

The Determinants of Natural Fertility Survey (DNFS), a specialized survey consisting of household- and individual-level information on a particular follow-up group of 1,790 households out of the 2,441 women who were originally interviewed about their health and pregnancy status in the mid 1970s. The available data on 1,806 DNFS women in these 1,790 households represents approximately an 80% sample of the surviving 2,273 DNFS women.

The Outmigrant Survey, another specialized survey consisting of household- and individual-specific information on 552 outmigrants who had left the households of the primary sample between 1982 and the date of the MHSS and had not returned to their original households or baris. This represents approximately an 8% sample of outmigrants who had left since 1982.

The Community/Provider Survey consists of information on community infrastructure and services on the 141 constituent villages of the primary sample respondents and detailed data on 254 health/family planning providers, and 100 educational facilities potentially serving (in the opportunity set of) the primary sample

households in the MHSS. This constitutes a near census of schools and health and family planning clinics serving the study population and a sample of individual health/family planning providers.

Questionnaire Topics:

Household Questionnaire Topics:

Consumption	Labor earnings
Household and individual assets	Borrowing and lending histories
Agricultural and nonagricultural income	Transfers and remittances
Economic shocks	Marriage histories
Education and training histories	Employment histories
Migration histories and residential change	Pregnancy histories
Non co-residential kin	Children ever born
Life styles and habits	Ability to perform ADL's
Acute morbidity	Chronic morbidity and disability
Self-treatment	Outpatient health services utilization
Impatient health services utilization	Living arrangements history
Social support networks	Other transfers

Directly Observed Objective Measurements:

Anthropometrics
Physical performance measures
Cognitive testing

Community Questionnaire Topics:

Quality indicators of schools in risk set of households
Quality indicators of health providers in risk set of households
Village Characteristics

Data Availability:

The MHSS data and documentation have been sent to ICPSR for inclusion in their public NACDA holdings. Once the MHSS has been entered into the data archive at ICPSR, all documentation concerning the MHSS (codebooks, etc.) will be available in PDF format from ICPSR. The MHSS data are available in a sub-file format in which subsections of the survey questionnaire are stored in separate data files. Each sample described above (Main, DNFS, Outmigrant, and Community/Provider) has its own set of data subfiles. Questions about the MHSS survey should be directed to mhss-supp@rand.org.

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Dataset Name:	Mexican Health and Aging Study
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Beth J. Soldo
Data Collection Organization:	Mexican National Institute of Statistics, Geography and Informatics (Instituto Nacional de Estadística, Geografía e Informática, INEGI)

Purpose:

The overall goal of the MHAS is to locate research on Mexico’s unique health dynamics in a broad socioeconomic context. The specific aims of the project are to:

- *examine* the aging processes and its disease and disability burden in a large representative panel of older Mexicans;
- *evaluate* the effects of individual behaviors, early life circumstances, migration and economic history, community characteristics, and family transfer systems on multiple health outcomes;
- *compare* the health dynamics of older Mexicans with comparably aged Mexican-born migrants in the U.S. and second generation Mexican-American using similar data collected by the HRS and the NHANES III to assess the durability of the migrant health advantage;
- *assess* the health of all components of the population from which migrants are selectively recruited: Mexican-born migrants living in the US, migrants who returned to Mexico after various length stays in the U.S., internal migrants, and older Mexicans who have aged-in-place; and,
- *consider* the ways in which intergenerational transfer systems affect old-age health dynamics in a country where migration is commonplace and remittances may repay prior investments or insure against uncertainty in old age.

Description:

MHAS is nationally representative of the 13 million Mexicans born prior to 1951; inferences can be drawn at the national and urban/rural levels. The six Mexican states which are home to 40% of all migrants to the U.S. were over-sampled at a rate of 1.7:1.

Study Design:

A total of 11,000 households with at least one person aged 50 or older were selected for the baseline study in 2001, based on the Mexican National Employment Survey 2000. Spouse/partners of eligible respondents were interviewed also, even if the spouse was born after 1950. Completed interviews were obtained in 9,862 households, for a total of 15,186 individual interviews.

All interviews were face-to-face, with average duration of 82 minutes. A direct interview (on the Basic questionnaire) was sought, and Proxy interviews were obtained when poor health or temporary absence precluded a direct interview.

The study was designed to ensure comparability with the U.S. Health and Retirement Study in many domains.

Future Plans:

Follow-up interviews are being conducted with surviving respondents in the Spring-Summer 2003; next-of-kin interviews are conducted for those deceased.

Respondent files will be linked to Mexican GIS data summarizing community amenities and socio-economic profiles and the location of nearby health facilities.

Questionnaire Topics:

HEALTH MEASURES: self-reports of conditions, symptoms, functional status, hygienic behaviors (e.g., smoking & drinking history), use/source/costs of health care services, depression, pain, reading and cognitive performance;

BACKGROUND: Childhood health and living conditions, education, ability to read/write and count, migration history, marital history;
FAMILY: rosters of all children (including deceased children); for each, demographic attributes, summary indicators of childhood and current health, education, current work status, migration. Parent and sibling migration experiences;
TRANSFERS: financial and time help given to and received by respondent from children, indexed to specific child; time and financial help to parent;
ECONOMIC: sources and amounts of income, including wages, pensions, and government subsidies; type and value of assets. All amount variables are bracketed in case of non-response.
HOUSING ENVIRONMENT: type, location, building materials, other indicators of quality, and ownership of consumer durables;
ANTHROPOMETRIC: for a 20% sub-sample, measured weight, height; waist, hip, and calf circumference; knee height, and timed one-leg stands.

Data Availability:

Data from the study are public use. The 2001 baseline data and documentation can already be downloaded from the project website, www.pop.upenn.edu/mhas.

Agencies/Organizations Consulted:

University of Michigan Institute for Social Research (ISR)
Mexican National Institute of Public Health (INSP)
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Dataset Name:	National Long Term Care Survey (NLTC)
Sponsoring Organization:	1982: Assistant Secretary for Planning & Evaluation/Health Care Financing Administration 1984: Health Care Financing Administration/National Center for Health Services Research 1989: National Institute on Aging/Duke University/Assistant Secretary for Planning & Evaluation 1994: National Institute on Aging/Duke University/Assistant Secretary for Planning & Evaluation 1999: National Institute on Aging/Duke University/Assistant Secretary for Planning & Evaluation 2004: National Institute on Aging/Duke University/Assistant Secretary for Planning & Evaluation
Principal Investigator:	Kenneth G. Manton
Data Collection Organization:	US Census Bureau

Purpose:

The 1982, 1984, 1989, 1994, 1999, and 2004 National Long Term Care Surveys (NLTC) are surveys of the entire Medicare enrolled aged population with a particular emphasis on the aged who are functionally impaired. The samples drawn from aged Medicare beneficiary enrollment files are nationally representative of both community and institutional residents. As sample persons are followed through the Medicare record system, virtually 100% of cases can be longitudinally tracked so that declines, as well as increases, in disability may be identified as well as exact dates of death. NLTC sample persons are followed until death and are permanently and continuously linked to the Medicare record system from which they are drawn. Linkage to the Medicare Part A and B service use records extends from 1982 to 2004, so that detailed Medicare expenditures and types of service use may be studied. Medicare file updates are received on an annual basis. Through the careful application of methods to reduce non-sampling error, the surveys provide nationally representative data on:

- The prevalence and patterns of functional limitations, both physical and cognitive;
- Longitudinal and cohort patterns of change in functional limitation and mortality over 22 years;
- Medical conditions and recent medical problems;
- Health care services used;
- The kind and amount of formal and informal services received by impaired individuals and how it is paid for;
- Demographic and economic characteristics like age, race, sex, marital status, education, and income and assets;
- Out-of-pocket expenditures for health care services and other sources of payment;
- Housing and neighborhood characteristics.

Description and Study Design:

The NLTC was designed to measure the point prevalence of chronic (90 days or more) disability in the US elderly Medicare enrolled population and changes (both improvement and incidence) in chronic disability (and institutionalization) over time. In addition, it measures the relation of such changes to health status (self report and Medicare file diagnosis) vital states and to detailed records of Medicare service use and costs.

The 1982 NLTC sample was randomly drawn from Medicare administrative files. Over 35,000 persons over age 65 who were Medicare eligible and alive on April 1, 1982, were drawn. A two-stage procedure identified chronically disabled persons for household interviews. This identified 6,393 persons with at least one chronic (duration of 90 days or more) impairment in seven Instrumental Activities of Daily Living (IADL) or nine Activities of Daily Living (ADL). Since residence was confirmed in the screening,

institutional residents can be separated from the nondisabled community residents who reported no ADL or IADL impairments. Chronically disabled community residents were interviewed at home to assess health, functioning, social, economic, and other factors. No institutional interviews were conducted in 1982.

The 1984 NLTCs had a complete longitudinal design with an institutional component. All persons surviving to 1984 who, in 1982 either reported chronic disability or were in institutions, were re-interviewed in 1984 with either a detailed community or institutional questionnaire. Consequently, not only disabled survivors were tracked, but also previously disabled survivors who had become nondisabled. In addition, community residents screened in 1982, and who were not chronically disabled, were re-screened with the same instrument in 1984 to determine disability incidence. A new sample who became age 65 between the 1982 and 1984 surveys and who survived to 1984 was drawn from Medicare files and screened. The 1984 sample provides estimates of two-year disability and mortality rates for a longitudinally followed population and representative cross-sectional prevalence estimates of disability and institutional residence of the total 1984 US elderly Medicare enrolled population 65 and over. The Next-of-Kin survey was conducted along with this wave.

The 1989 NLTCs was designed to estimate disability and institutionalization rates for the 1982-1984 and 1984-1989 periods. Persons in either 1982 (or 1984) who were institutionalized, or who received a detailed community survey and survived to 1989, were re-interviewed – either in the community or in an institution. An “aged-in” sample who became 65 between 1984 and 1989 and survived to 1989 were selected and screened for disability. All non-disabled persons over age 75 (in 1989) from the 1984 sample were automatically screened in 1989. The Informal Caregiver survey was conducted with this wave.

The 1994 NLTCs was designed to precisely estimate disability and institutionalization rates for the 1982-1994 period. Persons in either the 1982, 1984, or 1989 surveys who received a detailed interview in the community or an institution and survived to 1994 were re-interviewed, wherever they might reside. An aged-in sample who became 65 between 1989 and 1994 and survived to 1994 were selected and screened for disability. Furthermore, in 1994, a supplementary group of community interviews were conducted with nondisabled persons (the healthy supplement). This group will be followed like all other detailed interview persons in subsequent years. Further, a group age 95+ (N = 540) were also drawn in 1994 and screened for disability. This supplemental sample greatly increases the precision associated with estimates of the extremely aged.

The 1999 NLTCs was designed to precisely estimate disability and institutionalization rates for the 1982-1999 period. In 1999, NLTCs employed, for the first time, Computer Assisted Personal Interviewing (CAPI). Persons in either the 1982, 1984, 1989, or 1994 surveys who received a detailed interview (in the community or in an institution) and survived to 1999 were reinterviewed if they resided in the US. An “aged-in” sample who became 65 between 1994 and 1999 and survived to 1999 were selected and screened for disability. A supplementary group were selected for detailed interviews as part of the “healthy subsample.” This group, some of whom were interviewed in 1994, will be followed like other detailed interview groups in future survey years. Also, a group of persons age 95+ (N = 600) were selected in 1999, enabling precise estimates of the extreme aged population. The Informal Caregiver and the Next-of-Kin surveys were conducted with this wave.

The 2004 NLTCs was designed to precisely estimate disability and institutionalization rates for the 1982-2004 period. In 2004, NLTCs again employed CAPI. Persons in either the 1982, 1984, 1989, 1994, or 1999 surveys who received a detailed interview (in the community or in an institution) and survived to 2004 were reinterviewed if they resided in the US. An “aged-in” sample that became 65 between 1999 and 2004 and survived to 2004 were selected and screened for disability. A supplementary group was selected for detailed interviews as part of the “healthy subsample.” This healthy subsample, some of whom were interviewed in 1994 and 1999, will be followed like other detailed interview groups in future survey years. Also, a group of persons aged 95+ (N = 1584) were selected in 2004, enabling precise estimates of the extreme aged population. A subset of this 95+ age group were assigned to the healthy subsample in order to provide detailed information on those persons who are nondisabled and over the age of 95. The Informal Caregiver survey was conducted with this wave.

In each of the six surveys, large samples (N~20,000) of the oldest-old population (i.e., those 85 and over) are obtained. The survey data (i.e., detailed community and institutional interviews; screening surveys of nondisabled persons) were linked to Medicare service use files for the years 1982 to 2004. The linkage to Medicare enrollment files between 1982 and 2004 was 100%, i.e., there was complete follow-up of all cases (including survey non-respondents) for Medicare eligibility (and for most years, detailed Part A and B use), mortality, and date of death. Medicare mortality records (and dates of death) are available for 1982 to 2005.

In the new 1982, 1984, 1989, 1994, 1999, and 2004 NLTCS file linked to Medicare service use and cost data 1982 to 2004, a number of ancillary analytic variables and special longitudinal weights were appended to aid the investigator in dealing with the complex cross temporal studies of the survey. This will become increasingly important as, with the 1999 file, meaningful cohort analyses can be conducted. Medicare benefit changes can be correlated with period changes in disability and health. The number of deaths (i.e., about 32,000 from 1982 to 2005) is large enough that detailed mortality analyses can be done. Over the 22 years spanned by the six surveys, a total of 49,242 distinct individuals were followed from and linked to Medicare records. The 1994 survey file was added to the public use linked file during 1996. The 1999 survey's public use file is available for the Center for Demographic Studies. The 2004 survey's public use file is anticipated to be released in 2006.

Data Availability:

The Beta-1 version of the 2004 NLTCS, meaning the first issuance of the data for public use, is available. It is a more user-friendly product than the 1999 counterpart. Check <http://nlcs.cds.duke.edu/news.htm> for 2004 data documentation products.

The 1982, 1984, 1989, 1994 and 1999 National Long Term Care Survey Public Use Files are available on CD-ROMs. This CD-ROM may be requested by printing out the data request letter which can be obtained at http://www.cds.duke.edu/pdf/NLTCS_Data_Use_Agreement.pdf. This letter must be notarized. After receipt of your notarized letter, the CD-ROM will be shipped. Detailed information on the application procedure is available from the Center for Demographic Studies' web site: http://www.cds.duke.edu/NLTCS/FAQ_Data.htm#Q1.2.

Continuously linked Medicare data (1982 thru 2004) for the persons in the 1982, 1984, 1989, 1994, and 1999 National Long Term Care Surveys have been placed on CD-ROM. These data are only available from CMS. CMS contact information is provided below. All records have a unique sequence number to link to the National Long Term Care Survey respondents. Documentation for all years has been included on the CD for ease of use. See the Center for Demographic Studies' web site for more information on how to obtain CMS data: <http://www.cms.gov/data/requests/default.asp>.

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Dataset Name:	National Longitudinal Mortality Study (NLMS)
Sponsoring Organization:	National Heart, Lung, and Blood Institute National Cancer Institute National Institute on Aging National Center for Health Statistics
Principal Investigator:	Each sponsor has a PI/Rep on the NLMS Steering Committee, which oversees the operation and research efforts of the NLMS
Data Collection Organization:	U.S. Census Bureau

Purpose:

To study the effect of differences in demographic and socio-economic characteristics on differentials in U.S. mortality rates.

Description:

The NLMS is a longitudinal mortality study consisting of U.S. Census Bureau data from the Current Population Surveys and the 1980 Census. These data are linked to death certificate information to identify mortality status and cause of death. The study has just completed an expansion phase and now contains approximately 2.5 million records with 250,000 identified mortality cases.

Study Design:

The study consists of 26 Current Population Survey (CPS) cohorts and one 1980 Census Bureau cohort with mortality information obtained from death certificates through administrative record linkage techniques for deceased persons covering the time interval, 1979 to 1998. All information collected by these instruments is available for analyses. The Current Population Surveys are March Supplements selected from the time period from March 1973 to March 1998.

Mortality information is obtained through record linkage to the National Death Index, a file of death certificate information on all deaths in the United States, maintained by the NCHS. Upon request, information from any available source may be linked to NLMS records. The NLMS routinely links geographical and demographic information from Census Bureau surveys and censuses to the NLMS database. NLMS is in the process of linking Medicare information to NLMS records. The Census Bureau and CMS have approved the linkage protocol and data acquisition is currently underway. Incorporation of CMS data into the NLMS is expected to take approximately one year to complete.

Future Plans:

The plan for the NLMS is to link information on mortality to the NLMS every two years. This effort would also include expanding the NLMS population base by incorporating new March Supplement Current Population Survey data into the study as they become available.

Data Availability:

A public use dataset is available from NLMS-Census Bureau contacts. Due to the confidential nature of the data used in the NLMS, the public use dataset consists of a reduced number of CPS cohorts with a fixed followup period of five years. NIA does not make the data available directly. Research access to the entire NLMS database can be obtained through first contacting the NIA program contact named below. Interested investigators should email the NIA contact and send in a one page prospectus of the proposed project. NIA will approve projects based on their relevance to the NIA Behavioral and Social Research (BSR) Program's Areas of Emphasis (see <http://www.nia.nih.gov/research/extramural/behavior/emphasis.htm>).

Approved projects are then assigned to NLMS statisticians at the Census Bureau who work directly with the researcher to interface with the database. Investigators receive the reference manual for the full database and information on previous analyses that the database has been used for. A Census Bureau programmer will conduct the specific analyses required by the investigator. A modified version of the public use data files is available also through the Census restricted Data Centers. However, since the database is quite complex, many investigators have found that the most efficient way to access it is through the Census programmers.

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Sponsoring Organization:	National Longitudinal Survey: 1990 Resurvey of Older Males (NLS-Older Males)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Herbert Parnes
Data Collection Organization:	The NLS are sponsored by the Bureau of Labor Statistics (BLS) of the U.S. Department of Labor. The National Longitudinal Surveys program is housed within the Office of Employment and Unemployment Statistics at BLS.

Purpose:

This project has made available to gerontological researchers a rich longitudinal data bank spanning a quarter of a century in the lives of a representative national sample of men who were 69-84 years of age when last interviewed in 1990.

Description:

The original sample of 5,020 men, first interviewed in 1966, was re-interviewed periodically until 1983 under a contract with the US Department of Labor. The study provided a detailed longitudinal record of their labor market activity, health, financial status, family structure, and attitudes toward and experience in retirement. The NIA grant made possible a re-interview in 1990 with the surviving men and the widows (or other next-of-kin) of the decedents. Interviews were obtained with 2,092 surviving men, with 1,341 widows, and, in the absence of a widow, with 865 other relatives of decedents--an astonishing 86 percent of the original number of sample cases.

The merging of the 1990 data (including death certificate information for the decedents) brings into being an unprecedented longitudinal data bank that allows the current state of physical and psychological well-being and the socioeconomic status of the men to be explored in the light of their earlier records. The fact that blacks were over-represented in the original sample in a ratio of about three or four to one means that there is a sufficient number of surviving black men (about 500) for statistically reliable interracial comparisons (the oversample of Blacks is 19.3%). As a bonus, there is current information on labor market activity, income, and assets for a sample of about 1,350 widows, 90 percent of whom are between 60 and 89 years of age. This information can be linked to earlier data on the women's health and work activity that was reported by their late husbands.

Due to the original sample selection, other NLS cohorts contain wives and daughters of the older men. These other surveys also hold a wealth of detailed information on aging and retirement issues., especially on income transfers.

The sample size for each interview year is in the following table:

YEAR	TOTAL	YEAR	TOTAL
1966	5020	1976	3487
1967	4744	1978	3219
1968	4648	1980	3001
1969	4381	1981	2832
1971	4175	1983	2633
1973	3951	1990	20921
1975	3732		

1 Interviews were completed during 1990 with 2,092 surviving members of the original sample and with 1,341 widows and 865 next-of-kin of deceased respondents.

Objectives:

- Examine the progression of disability from middle to old age
- Examine male mortality in the pre- and post-retirement years
- Examine patterns of economic adjustment to widowhood in old age
- Examine the adequacy of post-retirement medical care benefits
- Examine the extent of interest in and ability to work among aged males
- Examine the extent and character of labor market activity among aged males
- Examine the adjustment to retirement
- Examine the quality of life of the elderly
- Examine changes in economic well-being in the retirement years

Data Availability:

The merged data and documentation for the Older Men are publicly available to the research community via download from www.nlsinfo.org.

Contact:

NLS User Services

Center for Human Resource Research

The Ohio State University

921 Chatham Lane, Suite 100

Columbus, OH 43221-2418

Phone: (614) 442-7366

Fax: (614) 442-7329

Email: usersvc@postoffice.chrr.ohio-state.edu

NLS Homepage: <http://www.bls.gov/nls/>; NLS Bibliography: <http://www.nlsbibliography.org/>

Dataset Name:	National Nursing Home Survey Followup (NNHSF)
Sponsoring Organization:	National Institute on Aging
Project Officers:	Jennifer Madans, National Center for Health Statistics
Data Collection Organization:	National Center for Health Statistics, DHHS/APSE

Purpose:

The primary purpose of the NNHSF is to provide data on the flow of persons in and out of long-term care facilities and hospitals.

Description:

The National Nursing Home Survey Followup (NNHSF) is a longitudinal study which follows the cohort of current residents and discharged residents sampled from the 1985 National Nursing Home Survey (NNHS). The NNHSF builds on the data collected in the 1985 NNHS by providing longitudinal information on nursing home and hospital utilization. The study was conducted in three waves. Wave I of the NNHSF was conducted from August through December 1987. Wave II of the NNHSF was conducted from July through November 1988, approximately 12 months after the completion of Wave I. Wave III, the final wave of the study, began in January 1990 and ended in April 1990. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) collaborated with NCHS and NIA in conducting Wave III of the NNHSF.

The 1985 NNHS collected a variety of information about long-term care facilities and their residents. Data were collected on a sample of patients who were current residents at the time of contact with the facility as well as a sample of discharges that occurred 12 months prior to the facility contact. There were 5,243 current residents and 6,023 discharges. For the current residents, detailed information was collected regarding dependence in activities of daily living, functional impairments, diagnoses, the receipt of services, cognitive and emotional status, charges, source of payments, history of nursing home use and a number of other topics of considerable prognostic significance. For the discharged residents, detailed information was obtained regarding diagnoses and services, source of payments, nursing home and hospital use prior to the sampled nursing home stay, hospitalization during the sample stay, and nursing home re-admissions subsequent to the sample stay. To supplement the current and discharged resident components, the 1985 NNHS included a new component - the Next-of-Kin (NOK). The NOK, using a Computer Assisted Telephone Interviewing (CATI) system, was designed to collect information about current and former nursing home residents that is not generally available from patient records or other sources in the nursing home.

The NNHSF obtains additional information on a portion of the residents for whom a Current Resident Questionnaire (CRQ) or a Discharged Resident Questionnaire (DRQ) was completed. The Wave I followup cohort is comprised of two types of cases. All cases with a completed NOK interview who were not known to be deceased as of the NOK are included. Cases that were eligible for the NOK but did not result in a completed interview were also included in Wave I. Interviews were completed for 6,001 subjects. At the time of contact, 1,998 subjects were found to be deceased. The NNHSF Wave II obtained additional information on those surviving subjects for whom a Wave I interview had been completed. In addition, interviews were attempted for Wave I subjects for whom no interview attempt was made through interviewer error at the time of Wave I but who were not known to be deceased. Wave II interviews were completed for 3,868 subjects. At the time of contact, 723 subjects were found to be deceased.

Information on the vital status of the subject (alive/deceased) at the time of the Wave II interview and the response status of the Wave II questionnaire (completed/not completed) was used to identify subjects eligible for a Wave III interview. A total of 3,160 subjects for whom some information was obtained during Wave II and who were alive at the time of the interview were initially identified as potentially eligible for Wave III, and 3,121 subjects were finally eligible.

In September 1994, the National Nursing Home Survey Followup Mortality Public Use Data Tape was released, covering the years 1984-1990. It contains the multiple cause-of-death information for 6,507 subjects from the NNHSF found to be deceased after linking and matching of files with the National Death Index. Information on the mortality tape includes the date of death, region of occurrence and residence, etc. All NNHSF tapes include a patient identification number common across files to allow linkage among them.

Data Availability:

Public Use data tapes for each wave and the mortality tape are available through the National Technical Information Office (NTIS), NACDA and the ICPSCR at the University of Michigan (see Appendix). The 1985 survey tape includes eight files: the facility questionnaire, nursing staff questionnaire, current resident questionnaire, discharged resident questionnaire, expense questionnaire, nursing staff sampling list, current resident sampling list, discharged resident sampling list. The next-of-kin questionnaire is available on a separate tape.

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Dataset Name:	The National Survey of Families and Households Reinterview (NSFH-Reinterview)
Sponsoring Organization:	National Institute on Aging National Institute of Child Health and Human Development
Principal Investigator:	Larry L. Bumpass
Data Collection Organization:	The University of Wisconsin Survey Center

Description:

The National Survey of Families and Households, conducted during 1987 and 1988, is a national sample survey that covers a wide variety of issues on American family life. The first wave interviewed 13,017 respondents, including a main cross-section sample of 9,643 persons aged 19 and over plus an oversample of minorities and households containing single-parent families, stepfamilies, recently married couples, and cohabiting couples. In each household, a randomly selected adult was interviewed. In addition, a shorter, self-administered questionnaire was filled out by the spouse or cohabiting partner of the primary respondent. Interviews averaged about 100 minutes, although interview length varied considerably with the complexity of the respondent's family history. Topics covered included detailed household composition, family background, adult family transitions, couple interactions, parent-child interactions, education and work, economic and psychological well-being, and family attitudes. The original sample was re-interviewed in 1992-93, five years after the original interview. The third wave of interviews was conducted 2001-2003 and the data and documentation are freely available on the NSFH website.

Objectives:

- Gather life history information for the period since the prior interview, including marriages, marital dissolutions, births, work experience, and other transitions
- Measure health and well-being in a variety of domains
- Measure family processes, including parenting and spousal relationships
- Examine interhousehold exchanges with older parents and adult children, caregiving, and social support
- Examine current labor force involvement, income sources, assets and debt

Study Design:

Baseline, 1987-88; Follow-up, 1992-94:

Personal interview of all surviving members of the original sample via face-to-face personal interview. Personal interview with the current spouse or cohabiting partner almost identical to the interview with the main respondent. Personal interview with the original spouse or partner of the primary respondent in cases where the relationship has ended. Telephone interview with "focal children" who were originally 13-18, and were ages 18-23 at survey. Short telephone interview with "focal children" who were originally age 5-12, and were ages 10-17 at survey. Short proxy interviews with a surviving spouse or other relative in cases where the original respondent has died or is too ill to interview. A telephone interview with a randomly selected parent of the main respondent.

Follow-up 2001-03:

Telephone interviews with: Surviving members of the original respondents who had a "focal child" age 5 or over at the first interview. The first interview spouse/partner of these original respondents, whether or not the couple was still together. The "focal children" who were in the household and ages 5-18 at the first interview and ages 18-33 at wave 3—most of whom were interviewed at wave 2. All other original respondents age 45 or older in 2000, and their first interview spouse/partner.

Oversamples: Blacks, 9.2%; Mexican-Americans, 2.4%; Puerto Ricans, 0.7%

Data Availability:

The dataset is freely available by FTP. Extensive information about the content and availability of the data can be found at: <http://www.ssc.wisc.edu/nsfh/home.htm>. Contact: NSFHHELP@SSC.WISC.EDU for further information.

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Web Site: <http://www.ssc.wisc.edu/nsfh/home.htm>

Dataset Name:	The National Survey of the Japanese Elderly
Sponsoring Organization:	National Institute on Aging Japanese Ministry of Health, Labor and Welfare Longevity Foundation
Principal Investigator:	Jersey Liang
Data Collection Organization:	Central Research Services Co., Tokyo Japan

Purpose:

The National Survey of The Japanese Elderly (NSJE) was designed to create a panel data set for use in cross-cultural analyses of aging, health, and well-being between the U.S. and Japan. The questionnaires were designed to be partially comparable to many surveys of the aged. These included Americans' Changing Lives, 1984 National Health Interview Survey Supplement on Aging, Health and Retirement Survey (HRS), the Asset and Health Dynamics Among the Oldest Old (AHEAD), and Well-Being Among the Aged: Personal Control and Self-Esteem (WBA).

Description:

The NSJE was based on a national sample of 2,200 noninstitutionalized elderly aged 60+ in Japan. This cohort has been interviewed once every 3 years since 1987. To ensure that our database is representative of the 60+ population, the 1987 cohort was subsequently supplemented by including those between 60 and 62 in 1990 and 1996. In 1999, a new cohort of Japanese adults 70+ was added to the surviving members of previous cohorts to form a database of 3,990 respondents 63+, of which some 3,000 were 70+. Currently a 6-wave longitudinal database (1987, 1990, 1993, 1996, 1999, & 2002) is in place, with wave 7 beginning in 2006.

Questionnaire Topics:

- Demographics (age, sex, marital status, education, employment)
- Social Integration (interpersonal contacts, social supports)
- Health Limitations on daily life and activities
- Health Conditions
- Health Status (ratings of present health)
- Level of physical activity
- Subjective Well-Being and Mental Health Status (life satisfaction, morale),
- Psychological Indicators (life events, locus of control, self-esteem)
- Financial situation (financial status)
- Memory (measures of cognitive functioning)
- Interviewer observations (assessments of respondents).

Data Availability:

Data from the first two waves of the *National Survey of the Japanese Elderly* are currently in the public domain and can be obtained from the National Archive of Computerized Data on Aging (URL: www.icpsr.umich.edu/NACDA). Wave 3 data were submitted for public use in 2004 and should be available soon. Additional data are being prepared for future public release.

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Dataset Name:	National Survey of Midlife Development in the United States: MIDUS 1, 1995-1996; and MIDUS 2, 2003-2008
Sponsoring Organization:	The John D. and Catherine T. MacArthur Foundation; National Institute on Aging
Principal Investigator:	Orville G. Brim (MIDUS 1); Carol D. Ryff (MIDUS 2)
Data Collection Organization:	University of Wisconsin Survey Center

Purpose:

The National Survey of Midlife Development in the United States (MIDUS) is a collaborative, interdisciplinary investigation of patterns, predictors, and consequences of midlife development in the areas of physical health, psychological well-being, and social responsibility. Respondents were drawn from a nationally representative random-digit-dial sample of non-institutionalized, English-speaking adults, aged 25-74, selected from working telephone banks in the coterminous United States. Those queried participated in an initial telephone interview and responded to a mail questionnaire.

The second National Survey of Midlife Development in the United States (MIDUS 2) carries forward MIDUS 1. It returns to the original sample, plus enlisting a new sample of African Americans. The second study will also expand the focus by incorporating detailed neurophysiological assessments on a large subsample in three geographic regions.

Description:

Main Sample: Contains responses from the main survey of 4,242 respondents. Respondents were asked to provide extensive information on their physical and mental health throughout their adult lives, and to assess the ways in which their lifestyles, including relationships and work-related demands, contributed to the conditions experienced. Those queried were asked to describe their histories of physical ailments, including heart-related conditions and cancer, as well as the treatment and/or lifestyle changes they went through as a result. A series of questions addressed alcohol, tobacco, and illegal drug use, and focused on history of use, regularity of use, attempts to quit, and how the use of those substances affected respondents' physical and mental well-being. Additional questions addressed respondents' sense of control over their health, their awareness of changes in their medical conditions, commitment to regular exercise and a healthy diet, experience with menopause, the decision-making process used to deal with health concerns, experiences with nontraditional remedies or therapies, and history of attending support groups. Respondents were asked to compare their overall well-being with that of their peers and to describe social, physical, and emotional characteristics typical of adults in their 20s, 40s, and 60s. Information on the work histories of respondents and their significant others was also elicited, with items covering the nature of their occupations, work-related physical and emotional demands, and how their personal health had correlated to their jobs. An additional series of questions focusing on childhood queried respondents regarding the presence/absence of their parents, religion, rules/punishments, love/affection, physical/verbal abuse, and the quality of their relationships with their parents and siblings.

Siblings and Twins: The Survey also contains similar data from a survey of 951 respondents, each of whom was a sibling of a respondent in the main survey. Siblings participated in the same assessments as the respondents. The Survey also contains twins data, from a separate national survey unrelated to the main MIDUS survey. From this separate national survey, a total of 1,996 twins agreed to participate. The Twins respondents were given the same assessments as the Main and Siblings samples. Additionally, the Twins sample was asked a series of questions about their birth, shared physical characteristics, childhood and adult relationships with their twin, whether they were dressed alike as children, and whether others experienced difficulty identifying them correctly.

Study Design:

Telephone interview and self-administered mail questionnaire.

Future Plans:

An NIA-funded project is currently carrying out a return to respondents in MIDUS 1 for a second wave of data collection. The primary aim is to collect a second wave of data, approximately 9-10 years later, on the core MIDUS 1 Main sample, Twins, and Siblings. At T2, respondents will be 34 to 85 years of age, thus providing unique opportunities to investigate, in a population sample, longitudinal change in behavioral, psychosocial, and experiential factors hypothesized to influence unfolding profiles of positive health and well-being, on the one hand, and disability, morbidity, and mortality, on the other. Data collection largely repeats T1 assessments (45 minute phone interview, 100 page self-administered questionnaire) plus additions in select areas (e.g., cognitive functioning, optimism and coping, life events, caregiving).

In addition, MIDUS 2 is using diary techniques to assess daily stressors in a subsample of respondents; conducting cognitive testing through telephone interviews; collecting biological data on a subsample of respondents, including baseline biomarkers as well as laboratory challenge studies, with assessments of salivary cortisol, blood pressure, and heart rate variability; and collecting EEG measures to focus on the central circuitry of emotion, related to affect and depression.

Data Availability:

MIDUS I data are available via the Inter-university Consortium for Political and Social Research (ICPSR) website: <http://www.icpsr.umich.edu>.

Additional information about MIDUS 1, the principal investigators, and related research can be found at <http://midmac.med.harvard.edu>.

Additional information about MIDUS 2 can be found at: <http://midus.wisc.edu>.

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Dataset Name:	National Survey of Self-Care and Aging: Baseline and Follow-up
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Gordon H. DeFrieze
Data Collection Organization:	Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill

Purpose:

This follow-up to the “National Survey of Self-Care and Aging: Baseline, 1990-1991” (archived at NACDA as ICPSR Study No. 6718) was conducted in 1994 to continue examination of the health status and self-care practices of individuals aged 65 or older who were interviewed at baseline during 1991.

Description:

NIA funded a seven-year cooperative agreement with UNCCCH to conduct a two-wave survey of over 3,000 persons 65 and older, with 1000 respondents being 85+. The purpose of this survey was to collect data on older people’s functional status, their use of three types of self- care practices, and clinical, social and behavioral antecedents and consequences of different patterns of self-care. These data were linked to Medicare/Medicaid health utilization records. Funding for this study is officially over, but with archiving of the data, this represents a rich resource for those interested in self-care and aging research. Data from this follow-up has been linked with the baseline data (ICPSR Study No. 6718) using the variable ARCHIVID.

Study Design:

The stratified random sample of non-institutionalized Medicare beneficiaries 65 years of age and older in 1990 was drawn from 50 primary sampling units (PSUs), 38 urban and 12 rural. Stratification was by gender and three age groups (65-74, 75-84, 85 or older).

Part 1: Telephone interviews were conducted with individuals who were interviewed at baseline. A proxy was interviewed if the subject was too ill or cognitively unable to respond. Included were questions about the type and extent of self-care behaviors for activities of daily living, management of chronic conditions (through self-care activities, equipment use, and environmental modifications), and medical self-care for acute conditions, along with questions regarding change in health status since baseline, health service utilization, nursing home visits, and sociodemographic/economic status.

Part 2: For subjects who had been institutionalized since baseline, interviews were conducted with proxies. Information was gathered regarding demographic status, living arrangements prior to institutionalization, and reasons for institutionalization.

Part 3: For subjects who had died since baseline, information was again gathered through interviews with proxies. Questions covered nursing home admissions and date and place of death. Part 4 consists of data from interviews conducted at baseline (ICPSR 6718) merged with interviews conducted at this follow-up.

Data Availability:

Archived at NACDA as ICPSR Study No. 2592.

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Dataset Name:	New Beneficiary Survey (NBS) and New Beneficiary Follow-up (NBF)
Sponsoring Organizations:	National Institute on Aging Social Security Administration Health Care Financing Administration Assistant Secretary for Planning and Evaluation Office of the Assistant Secretary for Health Agency for Health Care Policy and Research
Principal Investigator:	Howard M. Iams, Social Security Administration
Data Collection Organization:	Social Security Administration

Purpose:

The New Beneficiary Data System (NBDS), developed over the past decade, is an increasingly important source of information on the changing circumstances of aged and disabled beneficiaries. Based initially on a survey of new beneficiaries conducted in 1982, the dataset was subsequently enhanced with information from administrative records, and in 1991, through follow-up interviews with survivors from the original survey. The result is a longitudinal data file - a rich source of information on these cohorts of aged and disabled persons during the first decade after they began receiving benefits.

Description:

The Initial Data Base: The NBS

The New Beneficiary Survey (NBS) was conducted in late 1982 with a sample representing nearly 2 million persons who had begun receiving Social Security benefits during a 12-month period in 1980-81. Interviews were completed with three types of beneficiaries: 9,103 retired workers, 5,172 disabled workers, and 2,417 wife or widow beneficiaries. (These sample numbers are slightly lower than the numbers previously reported in some publications. During the course of analysis, several hundred respondents were found to have received Social Security benefits prior to 1980-81. These respondents are excluded here and in later stages of the NBDS). In addition, interviews were obtained from 1,444 persons aged 65 or older who were covered by Medicare but were not receiving Social Security payments because of high earnings. The NBS interviews covered a wide range of topics, including demographic characteristics, marital and childbearing history, employment history, current income and assets, and health. Selected data were also gathered from spouses and added from administrative records.

The New Beneficiary Follow-Up

Designed to meet a growing need for longitudinal data on the dynamics of disability and aging, follow-up interviews were conducted throughout 1991 with surviving respondents from the NBS. By the time of the 1991 survey, four-fifths of the original respondents were still alive. Interviews were completed with 87% of these survivors - 3,428 of the original retired-worker men, 2,811 retired-worker women, and 1,754 wife or widow beneficiaries. By 1991, almost all of these persons were in their early- to mid-seventies.

Survival Rates

Preliminary data reveal that 24 percent of the original respondents had died by the time of the NBF. The wife or widow beneficiaries had the highest survival rate (84.3%), followed by the Medicare-only and retired-worker groups (78.9% and 78.1%, respectively). Although disabled-worker beneficiaries were the youngest group, they had experienced the highest mortality, with only 69 percent surviving.

Links with Administrative Data

Since the 1982 survey, selected information on the NBS respondents has been compiled periodically from Social Security, Supplemental Security Income (SSI), and Medicare records. These administrative data -- which can be linked to the earlier survey data -- make it possible to analyze changes in respondents' covered

earnings, cash benefits, and health expenditures. The SSA annual administrative earnings extend from 1951 through 1999. SSA benefits, SSI benefits, and mortality status refer most recently to Dec. 2001.

Questionnaire Topics:

The NBF questionnaire was designed with an emphasis on measuring changes over time. It updated the profile of economic circumstances obtained in the NBS, and added or expanded sections on health, family contacts, and post-retirement employment. The interviews also explored major changes in life circumstances that might underlie changes in economic status (for example, death of a spouse, an episode of hospitalization, or a change in residence). In addition, disabled-worker beneficiaries were asked about their efforts to return to work experiences with rehabilitation services, and knowledge of SSA work incentive provisions.

Data Availability:

The 1982 NBS and the 1991 NBF data are publicly available through NACDA. The NBS and NBF are also available from the Social Security Administration at a cost of \$150. The NBF data can be linked to the public use NBS and administrative files.

The New Beneficiary Data System as described, the 1982 New Beneficiary Survey, the 1991 New Beneficiary Follow-up and Administrative record data are available on the Internet location for the Social Security Administration. The Address is: <http://www.socialsecurity.gov/policy/docs/datasets/nbds.html>.

Bibliography:

First findings from the NBS, with emphasis on the recent follow-up survey, have been presented in a series of brief statistical reports published by the Social Security Administration. The initial set - Notes 1 through 5 - was published in the fall 1993 Social Security Bulletin. The first report provided an overview of the NBS data files, describing the original sample, the 1991 survivors, and the kind of information available in the NBS. Notes 2 through 5 focused on persons in the disabled-worker cohort, describing their death rates, recovery rates, health and functional status, work attempts, and marital status. The next set of reports - Notes 6 through 11 - was published in the spring 1994 Bulletin. This set focuses on the cohort of aged beneficiaries in the NBS who first received Social Security benefits on the basis of old age in mid-1980-81. These notes examine the surviving aged cohort in 1991 in terms of their health and functional status, marital status, employment experience and earnings, income sources, changes in pensions, and their feelings of "well-being".

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Dataset Name:	New Immigrant Survey (NIS)
Sponsoring Organizations:	National Institute on Aging National Institute of Child Health and Human Development Office of Behavioral and Social Science Research National Science Foundation US Citizenship and Immigration Services Assistant Secretary for Planning and Evaluation Pew Charitable Trusts
Principal Investigator:	James P. Smith, RAND Guillermina Jasso, New York University Douglas S. Massey, Princeton University Mark R Rosenzweig, Yale University
Data Collection Organization:	NORC (first round)

Purpose:

Immigration has a major impact on American society—it accounts for one-third of US population growth, and the US takes in more immigrants than all other countries combined. In perhaps no other area of public policy is there such a large gap between information needs and existing data. Immigration processes and immigration policy continue to be the subject of much political and scientific debate. What are the contributions and costs of immigrants to the economy? What is the relationship between legal and illegal immigration? What is known about the origins of legal immigrants, how many return to their home countries, and what factors affect their assimilation? The main objective is to provide a public use database on new legal immigrants to the US that can address scientific and policy questions about migration behavior and the impacts of migration. The aims of the study are:

- To assess the differences that occur within immigrant lifestyles pre- and post-immigration, how social networks of families serve as support, and family reunification;
- To evaluate employment situations prior to immigration, i.e., occupation, income, and social assimilation;
- To evaluate the assimilation of immigrants into US society;
- To examine the schooling of immigrants;
- To compare NIS survey instruments with comparable instruments used in major US longitudinal surveys;
- To examine the transition from temporary to permanent citizenship; and
- To compare the health and wellbeing of immigrants with native citizens.

Description:

The NIS is a multi-cohort prospective-retrospective panel of new legal immigrants to the US. It was designed following specific recommendations from the National Research Council and other scientific panels, which have long advocated the creation of a longitudinal study of immigrants to overcome the limitations of government statistics and extant databases with information on the foreign-born. A survey pilot project, the NIS-P, was carried out in 1996 to inform the fielding and design of the full NIS. Baseline interviews were ultimately conducted with 1,127 adult immigrants. Sample members were interviewed at baseline, six months and twelve months, with half of the sample also interviewed at three months.

The first full cohort, NIS-2003, is based on a nationally representative sample of the electronic administrative records compiled for new immigrants by the US government. NIS-2003 sampled immigrants in the period May-November 2003. The geographic sampling design takes advantage of the natural clustering of immigrants. It includes all top 85 Metropolitan Statistical Areas (MSAs) and all top 38 counties, plus a random sample of other MSAs and counties. Interviews were conducted in respondents' preferred languages. The baseline was multi-modal: 60% of adult interviews were administered by telephone; 40% were in-person. The baseline round was in the field from June 2003 to June 2004, and includes in the Adult Sample 8,573 respondents, 4,336 spouses, and 1,072 children aged 8-12.

Questionnaire Topics:

Several modules of the NIS were designed to replicate sections of the continuing surveys of the US population that provide a natural comparison group. Other modules and questions are unique to the NIS.

Health: Self-reports of conditions, symptoms, functional status, smoking and drinking history, use/source/costs of health care services, depression, pain.

Background: Childhood history and living conditions, education, migration history, marital history, military history, fertility history, language skills, employment history in the US and foreign countries, social networks, religion.

Family: Rosters of all children; for each, demographic attributes, education, current work status, migration, marital status and children; for some, summary indicators of childhood and current health, language ability.

Transfers: Financial assistance given/received to/from respondent from/to relatives, friends, employer.

Economic: Sources and amounts of income, including wages, pensions, and government subsidies; type, value of assets and debts.

Housing environment: Type, ownership of consumer durables.

Data Availability:

Public-release data from the NIS-2003 baseline and the NIS-P are housed at the Princeton Office of Population Research Data Archive, accessible via the project website: <http://nis.princeton.edu>
Users must complete a short registration process the first time they access the data.

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Dataset Name:	Nihon University Japanese Longitudinal Study of Aging (NUJLSOA)
Sponsoring Organizations:	National Institute on Aging Nihon University
Principal Investigator:	Yasuhiko Saito
Data Collection Organization:	Central Research Services Inc. (CRS)

Purpose:

NUJLSOA is designed to provide data representative of the total older Japanese population, comparable to that collected in the US and other countries. When the initial questionnaire was designed, the format of questions was made comparable to the format of the (US) Longitudinal Study of Aging II (LSOAI). The LSOAs (Longitudinal Studies of Aging) is a family of surveys designed to measure changes in health status, health-related behaviors, and the causes and consequences of these changes within and across two cohorts of elderly Americans.

NUJLSOA was also devised to be comparable to the Asset and Health Dynamics Among the Oldest Old (AHEAD, a pre-1924 birth cohort) sample of the Health and Retirement Study (HRS), which has now been merged with the HRS.

Study Design:

The sample was selected using a multistage stratified sampling method which went through prefectures, regions and municipalities to select 340 primary sampling units. The sample of individuals was selected for the most part by using the National Residents Registry System, considered to be universal and accurate because it is a legal requirement to report any move to local authorities within two weeks. From each of the 340 areas, 6-11 persons aged 65-74 were selected and 8-12 persons aged 75+ were sampled. The population 75+ was oversampled by a factor of 2. Weights have been developed for respondents to the first wave of the survey to reflect sampling probabilities. Weights for the second wave are under development. With these weights, the sample should be representative of the 65+ Japanese population.

In Fall 1999, 4,997 respondents aged 65+ were interviewed, 74.6 percent of the initial target. Twelve percent of responses were provided by proxies, because of physical or mental health problems. The second wave of data was collected in November 2001. The third wave was collected in November 2003.

Questionnaire Topics:

Family structure, and living arrangements
Subjects' parents/Spouse's parents/Children
Socioeconomic status
Intergenerational exchange
Health behaviors
Chronic conditions
Physical functioning
Activities of daily living
Instrumental activities of daily living
Functioning in the community
Mental health depression measures
Vision and hearing
Dental health
Health care utilization
Other service utilization

Data Availability:

A CD is available which includes the codebook and data files for the first wave of the national sample. The second wave of data will be released in 2006. Instructions for obtaining the data can be found at <http://www.usc.edu/dept/gero/CBPH/nujlsa>.

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Dataset Name:	Panel Study of Income Dynamics (PSID)
Sponsoring Organizations:	National Institute on Aging National Science Foundation Department of Health and Human Services/ APSE United States Department of Agriculture
Principal Investigator:	Frank Stafford
Data Collection Organization:	University of Michigan, Institute for Social Research

Purpose:

The Panel Study of Income Dynamics, begun in 1968, provides a wide variety of information about families and individuals, as well as some information about the locations in which sample families reside. The central foci of the data are economic and demographic, with substantial detail on income sources and amounts, employment, family composition changes, childbirth and marriage histories, and residential location. Content of a more sociological or psychological nature is also included in some waves of the study.

Description:

Over the life of the PSID, the National Institute on Aging has funded supplements on wealth, health, parental health and long term care, and the financial impact of illness. The NIA has also funded health and housing supplements to the PSID database in order to identify and predict situations of dependent care among individuals aged 55 and above and to model retirement and residential mobility. Global health questions were asked in years prior to 1999. Starting in 1999, much greater detail on specific health conditions and health care expenses is included. In 2001, a question series about 30-day emotional distress was added. In 2003, the two stem questions from the Composite International Diagnostic Interview were added to assess symptoms of 12-month major depression. PSID household wealth measures are included in the 1984, 1989, 1994 and 1999-2003 waves. Savings measures are incorporated in 1989, 1994 and 1999-2003. The 1999 wave contains extensive questions on pensions of the Head and Wife, and a special NIA-sponsored data collection of Head's and Wife's employer pension plans is currently being analyzed. The 2001-2003 waves added a supplement on philanthropic giving and volunteering. A question series on internet and computer use was added in 2003.

In 1996, the PSID began a special compilation of all persons ever in PSID families who were known to have died – information for more than 4,000 individuals through the 1997 wave, including death dates. Cause of death information from the National Death Index (NDI) will be added to the file. The resulting dataset will be released under confidential contract. For each wave from 1999 on, the PSID will update this file with newly discovered deaths and match these new cases to the NDI for cause of death. Because of its panel nature, the PSID is unique in having such a sizeable number of deceased individuals, yielding adequate power for analysis of the relative contributions of various factors to mortality hazards. This project will further the understanding of mortality and morbidity processes by providing dates and causes of death information in a well-established long-term longitudinal dataset that also contains information on generational links and socioeconomic and health conditions of individuals over time. These data will allow researchers to analyze the causal linkages among these measures. Moreover, with the availability of environmental measures in the PSID, such as the social and family history variables and GIS-linked environmental data, researchers will be able to investigate the impact of environmental factors on long-term health and eventual mortality. These kinds of studies will inform the persistent question of the relative power of different factors shaping health and mortality.

The PSID has collected some basic health information over most waves. The measures apply to both the Head and Wife, irrespective of age. Coverage of the full age range, which has been in place since the 1999 wave, allows a life course perspective for researchers. The measures include health limitations in work and everyday life. In 2001, a question series on 30-day non-specific emotional distress was added. Questions assessing the symptoms of major depression over the past 12 months were included in 2003. Available online is a report assessing the quality of health data in the PSID and providing comparative analyses with

NHIS, "[Analysis of the Quality of the Health Data in the PSID](#)":

http://www.isr.umich.edu/src/psid/q_inc_data/report_on_health_qsv2.pdf. This assessment revealed a high degree of comparability between PSID and NHIS in the prevalence estimates of a range of health conditions and health behaviors.

A planned separate release concerns data on pension plans. Basic pension information and the name of the employer of the Head and Wife were collected in the 1999 wave, and the named employers were contacted in 2000 for copies of Summary Plan Descriptions (SPD) of employee pensions. From this the PSID will use the individual characteristics of Head and Wife to impute pension wealth under different retirement assumptions and include these estimates on a public release Internet file. Because of the long earnings histories available in the PSID, estimates of Social Security wealth could be constructed without resorting to confidential Social Security earnings records.

Study Design:

Reporting unit is the family: single person living alone or sharing a household with other non-relatives; group of people related by blood, marriage, or adoption; unmarried couple living together in what appears to be a fairly permanent arrangement. Respondent is usually the family Head, who is usually the major adult male earner. Interviews conducted annually from 1968 through 1997. Biennial interviewing began in 1999. Event history calendar methodology added in 2001 to facilitate recall of employment spells. Oversample of Blacks (30%). Waves 1990 through 1995 included a 20% Hispanic oversample; within the Hispanic oversample, Cubans and Puerto Ricans were oversampled relative to Mexicans.

Data Availability:

Main data files, that is, cross-year individual files and annual family files, are updated with each subsequent wave of data. Other special public-release files include the 1968-1980 Retrospective Occupation-Industry Files; the 1985 Ego-Alter File; the 1968-1985 Relationship File; the 1988 Time and Money Transfers File; the 1985-2001 Childbirth and Adoption History File; the 1985-2001 Marriage History File; the 2001 Parent Identification File; two 1990 Health Supplement Files; the 1991 Parent Health Supplement file; the 1993 Health Care Burden File; the 1984, 1989, 1994, 1999 and 2001 Wealth Supplement Files, which provide details on the level of various types of assets; and the 1994-2001 Hours of Work and Wage Files.

Restricted files include the Geocode Match File with information for 1968 through 2001, the 1968-2001 Death File, and the 1991 Medicare Claims File.

The Internet provides access to main release and archive files. All data from 1994 through 2001 are available as public release files; prior waves can be obtained in archive versions. No data were collected in 1998 or 2000 or 2002, as the study was moved to a two-year periodicity. The special files with weights for families are also available on the website.

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Dataset Name:	PHSE Ten-Year Follow-up of the North Carolina EPESE
Sponsoring Organizations:	National Institute on Aging
Principal Investigator:	Dan G. Blazer
Data Collection Organization:	Duke University Medical Center

Purpose:

To perform a ten-year, fourth in-person follow-up of the North Carolina EPESE cohort originally interviewed in 1986/87. The purpose of this follow-up study is to obtain information on four primary outcome variables (cognitive status, depression, functional status, and mortality) and four primary independent variables (social support, social class, social location, and chronic illness).

By using data from the fourth in-person interviews across the ten years of follow-up, investigators will be able to characterize trajectories of the major dependent variables and their relationships to the independent variables over time, which will provide valuable information about change and stability as well as heterogeneity in the dynamics of change. The major goal is to examine the relationships between social factors and chronic disease on the one hand and health outcomes on the other.

Description:

The Piedmont Health Survey of the Elderly is one of four Established Populations for Epidemiologic Studies of the Elderly (EPESE), and complements the other three sites providing a population which is both urban and rural and contains approximately equal numbers of black and white participants across a broad socioeconomic base. The Duke site was originally funded by the National Institute on Aging, Epidemiology, Demography and Biometry Program (NIA/EDBP) to complete seven waves of data collection (three in-person and four telephone interviews) in order to examine the health of a sample of 4,162 elderly persons, their use of health services, and factors that influence their health and use of health services. The study was planned to provide data for researchers, policy makers and clinicians.

A Resource Data Book detailing results from the baseline survey has been distributed to medical school libraries and schools of public health around the country. Sixty-eight publications have resulted from this study to-date and an additional 90 analyses are under way. The Duke site has benefited from the planning process, which involved investigators from all of the EPESE sites plus the NIA/EDBP staff, in the development of questions and physical performance measures to be examined, to which Duke investigators have added questions reflecting their interests, and questions especially relevant to the Duke sample.

Objectives:

- To develop a ten-year, fourth in-person follow-up of the Piedmont Health Survey of the Elderly (Established Populations for Epidemiological Studies of the Elderly/Duke). See Cornoni-Huntley, J., Blazer, D.G., Everett, D.F., Brock, D.B. & Farmer, M.E. (eds.) 1990.
- To attempt interviews with approximately 2,060 subjects (or proxy responders) estimated to be available for interview from the original cohort of 4,162 subjects.
- To obtain information on the primary outcome variables (cognitive status, depression, functional status, and mortality) and the primary independent variables (social support, social class, social location, and chronic illness) through a series of questions identical to questions administered during the first three in-person interviews.
- To obtain information on medication use, health behaviors, life changes and stress, weight and height, and blood pressure by using methods identical to those utilized during the first three in-person interviews.
- To test a series of hypotheses which consider longitudinal trajectories of these variables based in part on the view that functional status, cognitive status and depression are interrelated through time. These variables also predict mortality.

Study Design:

A ten-year, in-person follow-up of a cohort of 4,162 persons 65 and older initially interviewed in 1986/87 and followed annually for six years thereafter.

A random stratified household sample with an over-sampling of blacks.

Questionnaire Topics:

Demographics	Alcohol Use	Independence
Health Conditions	Cognition	Personal Mastery
Health Service Utilization	Activities of Daily Living	Social Support
Hearing and Vision	Incontinence	Social Interaction
Weight and Height	Smoking	Religion
Nutrition	Life Satisfaction	Self Esteem
Sleep	Medications	Economic Status
Depression	Life Changes	Blood Pressure

National Death Index files have been searched and death certificates obtained for the members of this study. Sample members have been matched with HCFA Medicare Part A files to obtain information on hospitalizations, and will be matched on HCFA Medicare Part B (outpatient) files.

Future Plans:

There are no plans for additional waves of the Piedmont Health Survey of the Elderly. The ten-year follow-up interviews were completed in December 1997.

Data Availability:

As mentioned above, results from the first seven waves of data collection from the Piedmont Health Survey of the Elderly have resulted in a Resource Data Book and some 75+ publications in refereed journals. Data from the first wave of the survey is in the public domain and can be obtained from National Archive of Computerized Data on ging (NACDA) at <http://www.icpsr.umich.edu/NACDA/archive.html> or from the National Archives, Center for Electronic Records (<http://www.nara.gov/nara/electronic/>) in Washington, DC.

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Dataset Name:	Precursors of Premature Disease and Death
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Michael J. Klag
Data Collection Organization:	Johns Hopkins University School of Medicine (The Precursors Study)

Purpose:

This study was established in 1946 to identify precursors of premature cardiovascular disease and hypertension. The purpose of the study has broadened, however, as the cohort has aged.

Description:

This is a long-term prospective study, begun in 1946, of 1,337 former Johns Hopkins University medical students enrolled in graduating classes 1948 to 1964. Participants were an average of 22 years of age at entry and have been followed to an average age of 69 years. Data are collected through annual questionnaires, supplemented with phone calls and substudies. Self-reports of diseases and risk factors have been validated. Funded continuously for fifteen years.

Objectives:

Specific Aim I:

To continue a detailed description of the onset of disease and death in a standardized fashion in an ongoing cohort.

Specific Aim II:

To determine risk of disease (especially CVD) and death associated with alcohol intake, physical inactivity and other factors over the life course from young adulthood (mean age 22 years) to old age (mean age 72 years) at end of grant period.

Specific Aim III:

To determine the relation of psychological, social, and health behavioral factors and disease assessed at multiple times from youth to middle age to onset of mild functional difficulty and use of compensatory responses to preserve physical function. In addition, the relationship of use of compensatory mechanisms to the subsequent trajectory of decline in physical function will be determined.

Specific Aim IV:

To examine determinants of end-of-life planning, attitudes toward aggressive medical care, and end-of-life care that is consistent with previously expressed wishes of the study participants.

Study Design:

Prospective longitudinal cohort study with detailed information at baseline (1947-1964) during medical school and annual follow-up for events and exposures through annual questionnaires.

Questionnaire Topics:

Every year from 1988 to 2003, anywhere from 2 to 6 questionnaires have been administered, in categories such as the following, that repeat periodically:

- | | |
|---------------------------------|----------------------------|
| Morbidity | Supplemental Illness |
| Health Behavior | Family and Career |
| Retirement | Job Satisfaction |
| Blood Pressure and Weight | Medications |
| Work Environment | Social Network |
| Diabetes | Osteoarthritis |
| Health Locus of Control | Preventive Health Services |
| General Health | Functional Limitations |
| Memory Functioning | Smoking |
| Religious Beliefs and Practices | |
| Links with Administrative Data: | |

National Death Index searches for all nonrespondents.

Data Availability:

Collaborations have been established with investigators at a number of institutions. Annual questionnaire data for 1988 through 2003 will be archived at NACDA.

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Dataset Name:	1990 Public Use Microdata Sample for the Older Population (PUMS-O)
Sponsoring Organization:	Administration on Aging US Census Bureau
Data Collection Organization:	US Census Bureau

Purpose:

Public Use Microdata Samples (PUMS) and Public Use Microdata Samples on the Older Population (PUMS-O) are available on tape and as a custom produced CD-ROM. These allow investigators to design their own tabulations and look at relationships among variables not shown in the standard products offered by the Census Bureau.

Description:

Public-use microdata samples are computer data files that contain the edited responses from a sample of individual households. The records contain no identifying information, and only large geographic areas (with a minimum population of 100,000) are identified to protect the confidentiality of respondents.

A public-use microdata sample focusing on the older population (PUMS-O) was created from the 1990 census. This sample consists of 3 percent of households with at least one member aged 60 or older. Although, the highest age presented is age 90, this allows analysis of data on the very old for most states with a reasonable degree of reliability. Since data for all members in households containing a person 60 years and over will be on the file, users will be able to analyze patterns such as living arrangements and sources of household income from which older members may benefit. Additionally, users will be able to augment the PUMS-O sample with a PUMS file. The Census Bureau has issued two "regular" PUMS files for the entire population. One PUMS file will contain 1 percent of all households; the other PUMS file will contain 5 percent of all households. Both files have most sample data items, and differ only in geographical composition. The 1-percent file contains geographic areas that reflect metropolitan vs. non-metropolitan areas. The 5-percent file shows counties or groups of counties as well as large sub-county areas such as places of 100,000 or more.

The geography on the 5-percent PUMS file matches that of the PUMS-O file. Since data for different households are present on the two files, users can merge the PUMS-O file with the 5-percent PUMS to construct an 8-percent sample. However, weighted averages must be constructed for any estimates created because each sample yields state-level estimates. Thus, it is possible to analyze substate areas even for the very old. In states where the geographic areas identified on the PUMS-O and the 5-percent PUMS are coterminous with State Planning and Service Areas (used by service providers in relation to the Older Americans Act), the Planning and Service Areas are identified.

*Information collected from all households**

Population	Housing
Household relationship	Description of building
Sex	Number of rooms in unit
Race	House/apartment owned or rented
Age	Business or medical office on property
Marital status	Value or monthly rent
Spanish/Hispanic origin	Meals included in rent

*Information collected from a sample of households**

Population	Housing
Social characteristics	Year moved into residence
Place of birth, citizenship, year of entry	Number of bedrooms
Education - enrollment and attainment	Complete plumbing and kitchen facilities

Ancestry	Telephone
Migration (residence 5 years ago)	Autos, light trucks and vans available
Language spoken at home and ability to speak English	House heating fuel
Veteran status	Source of water and method of sewage disposal
Work disability	Year structure built
Mobility and self-care limitations	Condominium status
Fertility (children ever born)	Farm residence
Shelter costs, including utilities	Mortgage and loans
Economic characteristics	Real estate taxes and insurance
Employment and unemployment, year last worked	
Place of work and means of transportation to work	
Work experience, income, and sources of income in 1989	
Occupation, industry, and class of worker	

* Persons in group quarters, including institutions, are asked population items only.

Data Availability:

PUMS and PUMS-O files are released on computer tape and CD-ROM. Information on these files is available from Customer Services at the Bureau of the Census at (301) 457-4100. These files can be obtained through ICPSR at the University of Michigan (see Appendix).

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Dataset Name:	Religion, Aging, and Health Survey
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Neal Krause
Data Collection Organization:	Harris Interactive, New York

Purpose:

The purpose of this study is to assess the relationship between multiple dimensions of religion, psychological well-being, and self-rated health in late life. In the process, an emphasis is placed on assessing whether the relationships among religion, health, and well-being differ significantly for older whites and older African Americans.

Description:

The data for this cross-sectional study come from a nationwide survey of older whites and older African Americans. The study population is defined as all household residents who were either white or black, noninstitutionalized, English-speaking, and at least 66 years of age. Geographically, the study population was restricted to the coterminous United States (i.e., residents of Alaska and Hawaii were excluded). Finally, the study was restricted to people who were currently practicing Christians, individuals who were Christians in the past but no longer practice any religion, and people who were not affiliated with any faith at any point in their lifetime. Individuals practicing a religion other than Christianity (e.g., Jews or Muslims) were excluded because it would be difficult to devise a set of religion measures that are suitable for persons of all faiths.

The sampling frame consisted of eligible persons contained in the Centers for Medicare and Medicaid Services (CMS). A five-step procedure was used to draw the sample. First, once each year researchers at CMS draw a 5 percent sample of names from their master file with a simple random sampling procedure. The sampled names include individuals who were 65 years of age or older. However, by the time the field period for the study began, subjects in the 5 percent file were at least 66 years of age. This is why the study population was defined above as all persons 66 years of age and older. In the second step of the sampling procedure, the 5 percent file was split into two subfiles - one contained older whites and the other contained older blacks. Each file was sorted by county, and then by zip code within each county. Then in the third step, an nth interval was calculated for each file based on the total number of eligible records. Following a random start, 75 nth selections were made in each subfile. In the fourth step of the sampling strategy, primary sampling units (PSUs) were formed by selecting approximately 25 names above and 25 names below each case identified in step three. Finally, in the last step, sampled persons from each PSU were recruited for an interview with the goal of obtaining approximately 10 cases per PSU.

Interviewing began in March 2001 and concluded in August 2001. The data collection was performed by Harris Interactive (formerly Louis Harris and Associates). All interviews were conducted face-to-face in the homes of the study participants. A total of 1,500 interviews were completed. Older blacks were oversampled so that sufficient statistical power would be available to fully explore race differences in religion. Consequently, the final sample was comprised of 748 elderly whites and 752 older blacks. The overall response rate for the study was 62 percent.

Future Plans:

NIA has provided funding for three additional waves of interviews with the older adults who participated in the Wave 1 survey.

Questionnaire Topics:

Based on extensive qualitative research, closed-ended survey items were developed to assess approximately fourteen dimensions of religion. Among the dimensions of religion are formal activities and involvement in the church, social support in the church, religious music, prayer, religious coping, God-mediated control, religious meaning, forgiveness, religious doubt, and religious commitment. Questions were also included to assess self-rated health, depressive symptoms, self-esteem, life satisfaction, optimism, and death anxiety.

Data Availability:

The Wave 1 and Wave 2 data have been sent to the University of Michigan's ICPSR for processing and archiving.

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Dataset Name:	Resources for Enhancing Alzheimer's Caregiver Health (REACH)
Sponsoring Organization:	National Institute on Aging National Institute of Nursing Research
Principal Investigator:	Richard Schulz
Data Collection Organization:	Reach Coordinating Center, University of Pittsburgh

Purpose:

This initiative will carry out social and behavioral research on interventions designed to enhance family caregiving for Alzheimer's disease and related disorders (ADRD). It will examine the feasibility and outcomes of different intervention approaches rather than provide definitive information on the one best intervention strategy for enhancing dementia-specific family caregiving.

Description:

Resources for Enhancing Alzheimer's Caregiver Health (REACH) is an initiative that was established in 1995 by the National Institutes of Health. Six research sites have been funded through cooperative agreements with the National Institute on Aging and the National Institute of Nursing Research. The projects focus on characterizing and testing the most promising home and community based interventions for enhancing family caregiving, particularly with minority families. A unique feature is the examination of AD burdens and interventions in three ethnic groups (Caucasians, Hispanics, and African Americans).

Objectives:

The study goals shared by all the REACH sites include:

- (1) the design of theory-driven caregiving interventions to test hypotheses about intervention processes and their effect on family caregivers;
- (2) the specification of intervention components to understand the pathways through which interventions actually produce desired outcomes and to examine the effectiveness of a variety of psychosocial, behavioral, and technological interventions to strengthen family members' capacities to care for individuals with ADRD;
- (3) the development of standardized outcome measures to assess the impact of comparable strategies on caregivers and their care recipients; and
- (4) the creation of a common database to help compare the effectiveness of different interventions across the range of identified populations.

Study Design:

The five general types of REACH interventions are:

- (1) Individual Information and Support strategies that increase caregivers' understanding of dementia and their particular caregiving situation;
- (2) Group Support and Family Systems efforts that provide caregivers with multiple forms of social support;
- (3) Psychoeducational and Skill-Based Training approaches that teach caregivers coping and behavioral management strategies;
- (4) Home-Based Environmental interventions that modify the home environment's effect on the care recipient and support the caregiver; and
- (5) Enhanced Technology Systems such as home-centered computer/telephone networks that are designed to reduce caregiver distress and isolation.

Caregiver/care recipient dyads are entered into the study using standardized eligibility criteria. The dyads are randomized at each intervention site using site-specific procedures. Standardized assessment batteries are administered at baseline, 6, 12, and 18 months.

Reach II: REACH II was funded in 2001 to test a single multi-component intervention among family caregivers of persons with Alzheimer's disease or related disorders. Built upon the findings of REACH, the overall objectives of REACH II are to:

- 1) identify and reduce modifiable risk factors among diverse family caregivers of patients with ADRD;

- 2) enhance the quality of care of the care recipients; and
- 3) enhance the well-being of the caregivers.

Recruitment for REACH II was completed in January 2004 with 642 participants entering the study across 5 participating sites.

Questionnaire Topics:

Demographics	Caregiver medications
Care recipient physical health	Care recipient medications
Care recipient physical impairment	Caregiver depression
Care recipient behavior	Caregiver mental health/wellbeing
Care recipient cognition	Caregiver social support
Caregiver burden	Caregiver religiosity
Caregiver physical health	Caregiver social activities
Cost	Service utilization

Links with HCFA Medicare data are possible with both caregivers and care-recipients.

Future Plans:

All sites have completed data collection for all follow-up time points (6-month, 12-month, 18-months), with the last site finishing in December 2001. The Coordinating Center continues to undertake all data management and the archiving of the multi-site core data for the project, along with appropriate documentation.

Reach II: Follow-up data (6-months) were collected, with the last follow-ups done in July 2004. The data have been prepared for analysis and archiving.

Data Availability:

In a cooperative agreement with the Inter-University Consortium for Political and Social Research (ICPSR), at the University of Michigan, the REACH baseline data have been archived and are available to the public at that site. All 6-month, 12-month, and 18-month data are archived and available at <http://www.icpsr.umich.edu/NACDA>.

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Dataset Name:	Seattle Longitudinal Study (SLS) of Adult Cognitive Development
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	K. Warner Schaie
Data Collection Organization:	Pennsylvania State University

Purpose:

The general purpose of this study is to examine the changes in intelligence and various abilities throughout adulthood. The data provide a normative base to determine the ages of detectable decrements in ability and the magnitudes of the decrements. The study also seeks to examine patterns of generational differences and age-related differences and to determine the effects of educational intervention on intellectual decline.

Description:

This ongoing, longitudinal-sequential study of adult-cognitive development, which began in 1956, focuses on individual differences in age-related changes and differences across cohorts.

Study Design:

This study is a mixed cross-sectional, longitudinal, and time-lag design. Included are family studies of cognitive similarity, prospective studies of early signs of dementia via psychological and genetic markers, as well as the investigation of personality and demographic variables that affect cognitive change in adults from young adulthood to advanced old age.

Questionnaire Topics:

Health Behavior Questionnaire, Behavioral Rigidity Questionnaire, Family Environment Questionnaires, Life Complexity Inventory, CES-D Depression Questionnaire, Cognitive and Neuropsychology batteries.

Links with Administrative Data:

Group Health Cooperative of Puget Sound Medical Records and Pharmacy Records.

Data Availability:

Information on this project including many downloadable documents and other items of interest to researchers is now available. The URL is <http://geron.psu.edu/sls>. Data sets, with identifiers removed, from the first four cycles of the study (1956, 1963, 1970, and 1977) are available on this site to qualified researchers.

Agencies/Organizations Consulted or Involved in Project Development:

Group Health Cooperative of Puget Sound; University of Washington Alzheimer Center.

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Dataset Name:	Social Environment and Biomarkers of Aging Study (SEBAS)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Noreen Goldman, Maxine Weinstein
Data Collection Organization:	Center for Population and Health Survey Research Bureau of Health Promotion Ministry of Health, Taiwan

Description:

The Social Environment and Biomarkers of Aging Study (SEBAS) provides information regarding the health and well-being of older persons in Taiwan. Taiwan has undergone rapid demographic, social, and economic changes, becoming a highly urbanized and industrial society with a growing population of persons age 65 or older. SEBAS explores the relationship between life challenges and mental and physical health, the impact of social environment on the health and well-being of the elderly, and biological markers of health and stress. The study collected self-reports of physical, psychological, and social well-being, plus extensive clinical data based on medical examinations and laboratory analyses. Examination of health outcomes included chronic illnesses, functional status, psychological well-being, and cognitive function. Questions regarding life challenges focused on perceived stress, economic difficulties, security and safety, and the consequences of a major earthquake. Biological markers were used to identify cardiovascular risk factors, metabolic process measures, immune-system activity, the hypothalamic-pituitary adrenal axis, and sympathetic nervous system activity.

Objectives:

- To collect biological markers of risk factors for disease and chronic illness, particularly those associated with exposure to challenge
- To elaborate the relationship between life challenge and health
- To explore how the social environment affects the relationship between exposure to challenge and health

Study Design:

- Interview of random sub-sample of participants from 27 PSUs from the 1999 Survey of Health and Living Status of the Middle Aged and Elderly in Taiwan.
- Face-to-face interview with participant.
- Hospital visit and collection of blood and urine specimens.

Data Availability:

Data are available through the ICPSR at <http://webapp.icpsr.umich.edu/cocoon/ICPSR-STUDY/03792.xml>

Future Plans:

A second round of data collection will take place in 2006.

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Dataset Name:	Survey of Health, Ageing and Retirement in Europe (SHARE)	
Sponsoring Organization:	European Commission National Institute on Aging Office Federal de l'Education et de la Science (OFES) Switzerland Austrian Science Funds Belgian Science Policy Administration	
Principal Investigator:	Professor Axel Boersch-Supan	
Data Collection Organization:	Infas (GE) TNS Demoscopia (ES) Intervjubolaget (SE) Kapa Research (GR) MIS Trend (AT) Liege University (BE)	TNS NIPO (NL) SFI (DK) DOXA (IT) INSEE (FR) Antwerp University (BE)

Purpose:

The longitudinal Survey of Health, Ageing and Retirement in Europe (SHARE) collects interdisciplinary data on European citizens over the age of 50. SHARE is designed after the US Health and Retirement Study (HRS) and the English Longitudinal Study of Ageing (ELSA). Comparability with these surveys is one of the core targets. The current SHARE project aims at several preparatory surveys in a selected number of European countries, culminating in a main prototype survey of about 22,000 households in 11 countries.

Description:

The main aim of SHARE, an EU-sponsored project, is to create a pan-European interdisciplinary panel data set covering persons aged 50 and over. The project brings together many disciplines, including demography, economics, epidemiology, psychology, sociology and statistics. Scientists from some 15 countries have worked on feasibility studies, experiments, and instrument development, culminating in a survey of about 22,000 individuals. The multidisciplinary nature of the data provides new insights into the complex interactions between economic, health, psychological and social factors determining the quality of life of the elderly.

SHARE started in January 2002. An international, interdisciplinary team prepared the study. After several multi-country pilots, the first wave was collected in 2004.

The oldest-old in the SHARE sample are underrepresented as compared to HRS and ELSA. The NIA support allows an extension with longer and specialized interviewer training geared at the oldest old; permits longer field times and more frequent contact attempts; allows for split interviews at two points in time; and a set of experimental anchoring vignettes.

Eleven countries ranging from Scandinavia (Sweden, Denmark), Western and Central Europe (France, Belgium, The Netherlands, Germany, Switzerland, Austria) to the Mediterranean (Spain, Italy, Greece) are currently participants. The survey will follow a common set-up across all countries with the goal of collecting data that are strictly comparable to allow cross-country research.

Study Design:

In most participating countries there were registers of individuals that permitted stratification by age. Where these registers were administered at a regional level (Germany and The Netherlands), a two or multi-stage design was needed in which regions were sampled first and then individuals selected within regions. In the two Nordic countries (Denmark and Sweden), samples were drawn from national population registers, a relatively simple and efficient design. In France and Spain, access to population registers came through the co-operation of the national statistical office, while in other countries no co-operation was possible. In three countries (Austria, Greece and Switzerland), telephone directories were used as sampling frames, which

required the pre-screening of eligible participants. Thus, the sampling designs vary from simple random selection of households to rather complicated multi-stage designs. These differences are reflected in the design weights and in efficiency.

Although the actual fieldwork in SHARE was carried out by a different agency for each country, the programming of the individual instruments was done centrally. The data were collected using a computer assisted personal interviewing (CAPI) program, supplemented by a self-completion paper and pencil questionnaire. A total of 22,000 face-to-face CAPI-interviews were carried out in respondents' homes.

Questionnaire Topics:

Demographics: marital status, country of birth, education, and occupation and details about parents last occupation, health status, and frequency of contact.

Physical Health: self-reported general health, longstanding illness or disability, eyesight and hearing, difficulties with a range of (instrumental) activities of daily living.

Grip Strength: physical measurement recording the respondent's maximum handgrip strength.

Walking Speed: time it takes for the respondent to walk a certain distance.

Behavioral Risks: smoking, alcohol use, and physical activities.

Cognitive Function: subjective and objective measures of 4 aspects of cognitive functioning. 1

Mental Health: how respondents view their lives and emotional problems.

Health Care: recent doctor visits, hospital stays, level of health insurance.

Employment and Pensions: current work activities, work income, pensions.

Children: information about the respondents' children.

Social Support: help respondents might receive from family and others.

Financial Transfers: any regular financial transfers and payments the respondent(s) may have given or received from non-household members, including inheritances.

Housing: current housing situation, including the size and quality of the accommodation value of their property, mortgages or rent payments.

Household Income: summary of the household income from various sources.

Consumption: household expenditures, e.g. on food, fuel, electricity, and telephone.

Assets: financial and non-financial assets and income from these assets.

Expectations: level of certainty about the future; how risk is valued.

Future Plans:

The intention is to conduct interviews every two years. Wave 2 is being developed for 2006. Current plans are to augment the questions by a life-history, to extend the range of health measures (e.g., puff test, obesity test with measured rather than reported body mass index) and the range of vignette domains).

Data Availability:

The data from SHARE Wave 1 will be available for all scientific users from the SHARE website www.share-project.org. Users will be required to complete a brief registration form and certify their scientific origin before gaining access to the database.

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Dataset Name:	Trends in Health and Aging
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	James Lubitz
Data Collection Organization:	National Center for Health Statistics

Purpose:

The major purpose of the project is to provide up-to-date information on the trends in behaviors, health status, socio-economic status, health care utilization, health care insurance, and cost of care for the older population of the United States. Trends in Health and Aging is a web-based system at <http://www.cdc.gov/nchs/agingact.htm> intended for use by policy and program analysts, researchers, and the general public. Trends in Health and Aging contains information from NCHS surveys and other data systems in a format easily accessible to users. It draws upon the considerable statistical resources of NCHS and other Federal agencies to provide current and historical information on health and well-being of the elderly population in the United States.

Description:

In Trends in Health and Aging, trend data on the elderly population in the United States are organized under eight general topic areas: demography (or population composition), vital statistics, health status and well-being, functional status and disability, risk factors and health behavior, health care utilization, health care expenditures and insurance, and injuries. Care is taken to make sure that the data are comparable across years.

The target population is persons 65 years of age and older, but many of the tables also contain data on 45-64 year olds for comparison purposes and to represent the “baby boomer” generation. Open-age intervals (50 and 65 years and over) can be seen both in a crude and age-adjusted form. The 2000 standard residential population of the United States is typically used to age adjust the data.

The data are aggregated in interactive tables developed with user-friendly software. Thus, the data can be presented in the form of charts and maps by the exact variables needed, and extracted in standard formats. Each table displays the selected measure(s) by sex, age interval, and race or Hispanic origin, for as many years as the data from the particular system are available. Where possible, the tables present the information by state. Metadata accompanying each table provide important information on 1) data sources, 2) statistical methods used to get the information, and 3) references to corresponding publications and supporting Internet sites. The data on the website are continually updated and expanded based on the current expansion plan, the availability of new data, and users’ suggestions.

Trends in Health and Aging contains FAQ, First Visit, Instructions, and other pages to help visitors and a Contact Us feature for user feedback. Each message posted is sent directly to the Trends in Health and Aging mailbox and answered in a timely manner.

Future Plans:

A usability study is being conducted to improve the functionality of the site. Users will be able to access the tables more quickly. All indicators are updated as soon a new data become available. New topics planned to be added include:

- Incontinence
- HIV/AIDS
- All cause mortality
- High cholesterol
- Hypertension
- Obesity
- Special equipment use

Currently, the Spanish version of the Data Warehouse is being developed. This version will contain the text of web-pages, explanatory messages and the names of the variables and the character values in Spanish.

On the basis of Trends in Health and Aging, a pilot package of teaching modules is being developed. The teaching modules are intended for university settings, as well as professionals working in health and human service organizations, who might use the data in such activities as planning, evaluating programs, writing proposals, etc.

Data Availability:

All tables in Trends in Health and Aging are available for viewing and/or downloading from the website. The data can be accessed online or downloaded to users' machine. The tables and other material are also distributed on annual CD-ROMs.

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Dataset Name:	The Wechsler Adult Intelligence Scale Archives (NIA-WAIS) on Aging and Multiple Cognitive Abilities
Sponsoring Organization:	National Institute on Aging
Principal Investigator(s):	John J. McArdle, John L. Horn, and Fumiaki Hamagami (archivist)
Data Collection Organization:	Department of Psychology, University of Virginia

Purpose:

The broad purpose of the research is to evaluate a variety of theoretical propositions about the dynamic of growth and change over age in cognitive abilities. A variety of existing data collected in other studies have been organized. Added to this collection are new longitudinal data. A new method for analyzing these data was developed. From 1980 to 1998, test protocols and demographic information about the Wechsler Adult Intelligence Scale (WAIS) were collected. A database has been formed which accumulates the data from over 100 independent research studies and over 40,000 individual persons from cross-sectional, longitudinal, and family research. During the past four years of this project, additional data has been added using a strategically selected set of adults who had been tested before on a wider battery of ability measures, including three-wave longitudinal retest data on the National Growth and Change Study (NGCS) sample, and a seventh-wave of longitudinal data on the smaller Bradway-McArdle Longitudinal Study sample.

Description:

The Wechsler Adult Intelligence Scale (WAIS) has been widely used in psychological research and clinical applications. Results from WAIS studies on age differences and age changes define much of what is believed to be known about adult intellectual development. However, due to variations in data collection and data analysis methods, the substantive conclusions that can be drawn from the WAIS literature are often clouded and sometimes contradictory.

In 1980, Jack McArdle and John L. Horn started an NIA-sponsored project to collect raw score information on the WAIS. This research was initially motivated by three issues: (1) The meta-analysis summary of research studies of the WAIS showed that many important age related results were inconsistent. (2) The techniques of meta-analysis made several untested assumptions. (3) There was a possibility that new methods of linear structural modeling using raw data, an approach termed a “mega-analysis,” could be used to bring together previously inconsistent results.

A variety of new statistical methods have made it clear how the raw data from different studies can be effectively combined and reliably used as a collective. Many of these newer techniques were initially developed as statistical solutions to problems of “missing data,” “selection bias,” “factorial invariance,” “test bias,” or “multilevel analyses.” In general, all these new statistical methods focus on the convergence or linkages among the variables or participants from seemingly different studies, or parts of studies. It seemed likely that more could be accomplished if all raw data from separate studies are evaluated for comparability and then used together. In the approach termed “mega-analysis,” the degree to which the raw data from different data collections can be combined is raised as a statistical question.

Study Design:

To initiate this kind of research synthesis the PIs wrote letters to about 100 researchers, made in-person visits to about 20 laboratories and researchers, and basically requested copies of any available WAIS data. These requests were successful largely due to the cooperative nature of the scientists, and a large archive of available WAIS data (N>40,000 cross-sectional, N>5,000 longitudinal; N>3,000 relatives) was created. The large collection is described below.

These WAIS data include demographic information on (a) age at testing, (b) date of testing, (c) gender, (d) ethnicity, (e) educational level, (f) individual codes for repeated testing, (g) family codes for relatives, and (h) WAIS testing form. Information on most of the sub-scales of the WAIS were coded and stored, including: Information, Comprehension, Similarities, Arithmetic, Digit Span, Vocabulary, Digit Symbol Substitution, Picture Completion, Block Design, Picture Arrangement, and Object Assembly.

During the last several years, a maximally informative set of new intellectual abilities data under the heading of the National Growth and Change Study (NGCS) has been collected. These new data were collected on N>500 persons from all over the USA to fill in notable age-related gaps in the available life-span archive. In all recent data collections multiple measures were included on the Woodcock-Johnson Revised (WJ-R) tests of intellectual abilities. Also included is a 30 minute demographic questionnaire based on questions about “Successful Aging” in the areas of (a) educational status, (b) health status, and (c) social status, and participants also completed the (d) 16PF Personality Inventory, and (e) each session ended with an open-ended questionnaire designed to obtain quantitative information about their self-reported mental activities and changes and qualitative information about relevant life experiences.

Currently Archived Data:

A brief listing of the current collection of NIA-WAIS data (in Table 1) illustrates how a large amount of individual information about multiple intelligences (N>40,000) can be accumulated by combining the information from many different studies.

The WAIS data from fifteen large sets of longitudinal data (N>5,000) that have already been archived are summarized in Table 2. These data come from entirely different sources but have some comparable sets of ability measures. More detailed descriptions of these longitudinal data are described in the longitudinal codebooks and research publications (see below).

WAIS data have been collected and organized from twelve large samples of family relationships data (N>3,000), and nine large studies with cross-cultural WAIS data (N>3,800). These WAIS data were collected in as much detail as possible, including copies of the item-level raw data (N>4,500) and the additional archiving of any other measurement scales used. Longitudinal WISC data on adolescents and children from the same studies (N>2,500) was also collected. Any researcher can apply to use subsets or combinations of these restricted data sets.

Table 1: Summary of Cross-sectional Data Archived in the NIA-WAIS Databank

BROAD DATABASE CATEGORY	SIZE (N)
Assorted Healthy Adults	5,463
High School & College Students	5,942
WAIS-R (1980) Standardization	1,880
Wechsler Bellevue Form I	1,330
WISC-R (1973) Standardization	1,998
Assorted Relative Groupings	3,180
Longitudinal & Retest Data	1,018
Australian Longitudinal Data	1,780
Mixed Longitudinal & Relative Data	699
WISC Longitudinal Data	528
Puerto Rican Standardization	1,320
South African English Standardization	1,596
South African Afrikan Standardization	1,121
Japanese Standardization	620
Korean Standardization	442

Mentally Impaired (WB I)	5,101
Mentally Impaired (WAIS)	3,530
Physically Impaired	1,650
Social Deviants	938
Drug & Alcohol Problems	813
Total Useable WAIS Protocols	40,877

Table 2: Current Longitudinal Data Archived in the NIA-WAIS Databank (Total N > 5,000)

Study –Yr	Source	Location	Linkage	Total N	Age Range	WAIS Forms
BGL-71	Bayley	Berkeley, CA	Longit(6) Families	53	16-36	WB-I, WAIS
MAL-84	Weinberg & Scarr	Minnesota, MN	Longit(2) Ado Families	222	16-46	WAIS(4)
GSL-81	Eichorn, et al	SF Bay Area, CA	Longit(2) Families	156	18-40	WB-I, WAIS
BML-84	Bradway & McArdle	SF Bay Area, CA	Longit(3)	110	28-58	WAIS, WAIS+
BVL-63	Berkowitz & Green	Rochester, NY	Longit(2)	197	50-70	WB-I
HBL-74	Rudinger & Thomae	Bonn, Germany	Longit(5)	100	59-75	HAWIE
DAL-80	Botwinick & Siegler	Duke, NC	Longit(11)	267	60-90	WAIS
NTL-72	Jarvik et al	New York, NY	Longit(4) Twins	268	60-90	WB-I(6)
BVL-72	Reimanis & Green	Rochester, NY	Longit(2)	187	62-80	WAIS
NEL-71	Granick & Birren	Philadelphia, PA	Longit(3)	47	70-87	WAIS
HCF-76	DeFries, et al	Honolulu, HI	Biological Families	416	16-64	WAIS
TAF-79	Horn, et al	Austin, TX	Adoption Families	647	25-54	WAIS
MHL-76	Elias, et al	Orono, MN	Longit(4)	1,226	17-83	WAIS+
HML-77	Albert	Boston, MA	Longit(2)	229	30-80	Wechsler Memory +
SWL-99	Peterson, et al	Stockholm, Sweden	Longit(7) Twin	1,023	44-95	WAIS (3)

Future Plans:

This is an ongoing NIA-supported research project and the data are updated frequently. The current research is designed to carry out age-sensitive multivariate dynamic analyses of the data already collected. These WAIS data continue to be used in a variety of novel structural and dynamic analyses, and most of these analyses include more than one of these WAIS datasets (see bibliography).

Data Availability:

The NIA-WAIS data archive website is currently under construction as a node of the UVA website (<http://kiptron.psyc.virginia.edu>) and plans are to add additional links to other relevant websites, including NACDA. Comments on this website are welcome.

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Dataset Name:	Wisconsin Longitudinal Study (WLS)
Sponsoring Organization:	National Institute on Aging
Principal Investigator(s):	Robert M. Hauser
Data Collection Organization:	Center for Demography of Health and Aging, University of Wisconsin-Madison

Purpose:

The Wisconsin Longitudinal Study (WLS) is the first of the large, longitudinal studies of American adolescents, and it thus provides the first large-scale opportunity to study the life course from late adolescence through the mid-50s in the context of an extensive and long-running record of ability, aspiration, and achievement. The WLS cohort of men and women, mainly born in 1939, precedes by about a decade the bulk of the baby boom generation that continues to tax social institutions and resources at each stage of life. For this reason, the study can provide early indications of trends and problems that will become important as the larger group passes into the retirement years. This adds to the value of the study in obtaining basic information about the life course as such, independent of the cohort's vanguard position with respect to the baby boom.

Description:

The WLS is a long-term study of a one-third random sample (N = 10,317) of men and women who graduated from Wisconsin high schools in 1957 and of their randomly selected brothers and sisters. Survey data were collected from the graduates or their parents in 1957, 1964, 1975, and 1992/93 and from a selected sibling in 1977 and 1993/94. Data from new surveys of graduates, siblings, and their spouses and widows were added in 2005. WLS data provide a comprehensive record of social background, youthful aspirations, schooling, military service, family formation, labor market experiences, and social participation of the original respondents. Beginning in 1992-94, there are extensive, self-reported data on health and retirement. Survey data from earlier years have been supplemented by mental ability tests (of graduates and their siblings), measures of school performance, and characteristics of communities of residence, schools and colleges, employers, and industries. Social background measures include earnings histories of parents from Wisconsin state tax records. In 1977 the study design was expanded with the collection of parallel interview data for a highly stratified subsample of 2000 siblings of the primary respondents.

Given the population from which it is drawn, the WLS sample is not representative of all strata of society. All members of the primary sample—and 93% of their siblings—graduated from high school, as compared to an estimated 75% of Wisconsin youth in the late 1950s. There are only a handful of African American, Hispanic, or Asian persons in the sample.

The WLS sample does otherwise appear to be broadly representative of white, non-Hispanic American men and women who have completed at least a high school education. Of all Americans aged 50 to 54 in 1990 and 1991, approximately 66 percent are non-Hispanic white persons who completed at least 12 years of schooling. Age variation occurs in repeated observations, rather than in cross-section.

In the 1992/93 follow-up the graduates were 53 or 54 years old when interviewed. In all, 8493 of the 9741 surviving members of the original sample were interviewed. In 1993/94 randomly selected siblings of the high school graduates were interviewed.

In addition to the survey data, college characteristics, company characteristics, and female job histories have been developed. Multiple cause of death data from NDI-Plus have been linked for graduates and siblings, and links are now being created for parents of the graduates and siblings.

Data Availability:

The 2004 WLS graduate data version 11.0 were released in 2005, a preliminary release of data gathered from the original graduate respondents. WLS documentation and data are accessible from <http://dpls.dacc.wisc.edu/wls/index.html>. Data resources include on-line codebooks, details of variable construction, error and update reports, telephone survey flow charts, mail survey instruments, publication lists, and tools for locating variables and finding relevant publications. The study description, cumulative bibliography, and documentation may be downloaded without restriction. Data may be downloaded through a web browser or anonymous FTP after registration and agreement with a simple licensing policy. Data are downloadable in SAS, SPSS, and STATA formats and in modular form for users with limited disk space.

Previous editions of the WLS data and documentation are archived at ICPSR (#6163). Past rounds of WLS data have been updated. A list and description of the changes can be found at http://www.ssc.wisc.edu/wlsresearch/data/updates/change_notice/chnt_023.htm

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DATASETS TO BE ARCHIVED IN THE FUTURE

Dataset Name:	NIA Collaborative Studies on Dementia Special Care Units
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Douglas Holmes
Data Collection Organization:	National Alzheimer Center

Purpose:

1. To coordinate the analyses of cross-site data collected during the 10-site collaborative studies.
2. To conduct meta-analyses of emergent data, as a means to determining whether the effort, as a totality, had an appreciable impact on nursing home residents with dementing illness.
3. To prepare all cross-site, common-core data for archiving.

Description:

This was a 10-site collaborative effort begun in 1991. The National Evaluation of Special Care Units (PI: Leon) represents the largest sample of nursing homes for evaluating SCU/non-SCU features and their effects (data from nearly 1,500 SCU facilities was collected). A follow-up Trends in Special Care Survey examined the status of special care in 1995-1996 in over 3,000 nursing homes. A common database was developed to characterize SCUs and their outcomes on residents, family and staff. Coordinating Center PI: Holmes and Site PIs: Evans; Grant; Holmes; Kutner; Lawton; Leon; Lindeman; Montgomery; Morris; Sloane).

Objectives:

The aim of the collaborative studies was to evaluate the possible impacts of special dementia care upon nursing home residents suffering from dementing illness.

Links with Administrative Data:

Many of the sites collected administrative data as part of their respective projects. Statistical techniques for addressing data reflecting different units of measurement (e.g., residents, v. units, v. nursing home, v. nursing homes in a state) were explored, selected, and adapted.

Future Plans:

To publish the meta analyses, and to archiving of data. In addition, a special edition of Research and Practice in Alzheimer's Disease; this edition deals exclusively with findings relating to special dementia care.

Data Availability:

The data are not archived as yet. However, meta-analyses are ongoing; they are being conducted by meta-analysts at Columbia University. There are plans to archive all data by December 2003.

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Dataset Name:	Origins of Variance in the Old-Old: Octogenarian Twins (The OCTO Twin Study)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Gerald E. McClearn
Data Collection Organization:	Institute of Gerontology, University College of Health Sciences, Jönköping, Sweden.

Purpose:

The overall aim is to estimate the relative contributions of environmental and genetic influences to variability in late life in age-related variables of health, physical and cognitive functioning, interpersonal relations, personal control, life satisfaction and mental health. By using a genetically informative sample, the genetic and environmental bases of individual differences in late life health and functioning are addressed.

Description:

Participants are drawn from the entire population of intact, like-sexed pairs of twins 80 years and older in the Swedish Twin Registry. The first wave involved 351 pairs (149 identical and 202 same-sex fraternal). The second, third, fourth, and fifth waves involved 235, 144, 86, and 43 pairs, respectively. Participation rates were somewhat higher than original projections due to lower non-response and mortality rates than expected.

Study Design:

The twin pairs were followed longitudinally at 2-year intervals, using 5 measurements. In-person testing was conducted by registered nurses using a broad-based biobehavioral battery. The biomedical portion included a battery of tests designed to assess general health status with a focus on measures sensitive to age changes which might serve as useful biomarkers of aging. The cognitive battery included domains of crystallized and fluid intelligence, memory, spatial ability, perceptual speed, problem solving, and verbal ability.

Topics in Dataset:

Health and functional capacity
Cognitive functioning
Personality and personal control
Psychological well-being
Interpersonal functioning

Links with Administrative Data:

Swedish Census Statistics

Future Plans:

Longitudinal follow-ups of survivors, record keeping of death certificates, medical and dental records. Autopsy of individuals with dementia.

Data Availability:

Primary data analysis of this project will continue at least through 2005. Archiving after that time will conform to the rules and regulations of the Swedish Data Inspection Authority and the Swedish Twin Registry. Requests for collaboration on data analyses are considered on individual bases.

Agencies/Organizations Involved in Project Development:

National Institute on Aging
The Pennsylvania State University
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Dataset Name:	Swedish Adoption/Twin Study of Aging (SATSA)
Sponsoring Organization:	National Institute on Aging Swedish Social Research Council
Principal Investigator:	Nancy L. Pedersen
Data Collection Organization:	Karolinska Institutet, Sweden

Purpose:

SATSA is a longitudinal program of gerontological genetics designed to address issues of the relative importance of genetic and environmental influences on biobehavioral aging.

Description:

The Swedish Adoption/Twin Study of Aging (SATSA) is a longitudinal program of research in gerontological genetics to study individual differences in behavioral and functional capabilities of aging human beings. The SATSA sample of twins separated early in life and matched twins reared together was identified from the Swedish Twin Registry, which includes nearly 70,000 pairs of twins born in Sweden between 1886 and 1990.

Four longitudinal waves of questionnaires (personality, health, environment) were conducted at three-year intervals. Four waves of in-person testing of cognition and health-related measures were conducted at rolling 3-year intervals. Questionnaires were also given to the participants just prior to the in person testing. There are raw data sets for each of the data collection occasions, as well as SAS datasets that have measures, such as factor or scale scores, computed from the raw data. SATSA started in 1984 and is ongoing. There are 2020 individuals with information from the questionnaire and 820 individuals with cognitive and in-person testing data. A fifth wave of in person testing was completed in December, 2001, and a sixth wave of in person testing was recently started. A fifth questionnaire was mailed in June, 2004, nearly 20 years after the first Q.

Questionnaire Topics:

Personality, childhood environment, current environment, working environment, health and health related behaviors, life events, social support. In person testing includes: General and specific cognitive abilities (13 cognitive tests and reaction time), MMSE, spirometry, blood pressure, functional abilities and measured ADL, nutritional status, clinical chemical profiles (lipids and lipoproteins), metal assays, MAO, H.pylori status.

Links with Administrative Data:

Swedish National Cancer Registry, Swedish Cause of Death Registry, Swedish Inpatient Discharge Registry, regular updates (monthly) with national population registry for current address and status.

Future Plans:

Data are still being collected during the sixth wave of in-person testing. Data set management is being coordinated with OCTO-Twin and the Study of Dementia in Swedish Twins.

Data Availability:

The data are in the process of being archived. Copies of the data are currently available at NIA and can also be obtained by submitting a written request to the PI. No information that can be manipulated to identify specific individuals will be provided.

Bibliography:

Over 190 publications (see website for the Swedish Twin Registry, below)

Contact:

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Dataset Name:	Victoria Longitudinal Study
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Roger A. Dixon

Purpose:

The Victoria Longitudinal Study (VLS), which began in 1987, examines changes in cognitive functioning in late life. It was originally designed specifically to evaluate the magnitude and direction of normal aging-related changes, as well as individual differences in several aspects of cognitive aging (especially memory). These emphases continue, but they have been supplemented by new initiatives to examine a wide range of correlates and precursors of differential cognitive change in late life. These correlates include factors from such domains as health conditions, health beliefs, biological vitality, and social activities and integration. As the samples age, new research is exploring transitions from normal cognitive aging to cognitive impairment and dementia.

Study Design:

Three independent samples of adults (initially ranging in age from 55 to 85 years; each initially numbering about 500 participants) are followed at three-year intervals. The samples derive from the three successive decades of the VLS. Sample 1 (from the 1980s) has now been tested on six occasions, and Sample 2 (from the 1990s) has been tested on four occasions. Sample 3 (from the 2000s) is being tested for the second occasion. A broad range of measures are employed pertaining to health and medications, cognition and memory, metacognition, memory compensation, personality and affect, leisure and social activities, and sensory and physical status. Patterns of change, individual differences in change, and predictors of differential change have been examined.

Questionnaire Topics:

Metamemory, Personal Health History, Functional Health, Personality, Well-being, Demographic Background, Lifestyle/Activities, and Memory Compensation.

Future Plans:

New second-wave data from Sample 3 are being collected. Scoring and data entry for Wave 4 of Sample 2 and other recent waves continue. New studies of mild cognitive impairment have been developed, and one report is under review at a major journal. New studies of the role of social engagement on cognitive status and “buffering” cognitive decline have also been implemented, and one report is presently under review. Finally, the potential role of non-steroidal anti-inflammatory drugs as a buffer of normal cognitive decline is being explored, with promising results to be presented at a 2006 conference.

Data Availability:

The data are not archived. An initial partial dataset will be archived with funding from the next competing renewal. The PI has collaborated extensively with other investigators interested in using these data, and has provided data and measures to numerous researchers. Collaborative “cross-cultural” studies have been completed (e.g., with Sweden) and are being planned for a broader range of countries. VLS data sharing, as part of a larger NIH proposal, is planned and presently under review.

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DATASETS AVAILABLE THROUGH PRINCIPAL INVESTIGATOR

Dataset Name:	The UNC Alumni Heart Study
Sponsoring Organization:	NHLBI, NCI, NIA and the MacArthur Foundation
Principal Investigator:	Ilene C. Siegler
Data Collection Organization:	Behavioral Medicine Research Center at Duke University

Purpose:

This study was originally designed to test the hypothesis that hostility measured in adolescence predicts coronary disease in midlife. The study also provides the opportunity to study normal aging in a cohort of early baby boomers (born 1946-1949) and their spouses. A total of 6,340 persons have joined the UNCAHS.

Description:

The project began with MMPI taken in 1964-1966 on 7,008 persons enrolled at UNC 1964-1966. In 1986, 5,000 persons were located and enrolled. A small longitudinal pre-test sample (n=300) was developed. In 1992, 1,100 spouses of participants were enrolled. Data are collected by mailed questionnaires. The 10th questionnaire (2004-05) also has a Web-based response option.

Objectives:

To understand personality, health and disease in adulthood.

Study Design:

Prospective/retrospective – limited repeated measures at unequal intervals.

Questionnaire Topics:

- BASELINE RISK INDICATORS FOR CORONARY HEART DISEASE (CHD) (Q1)
- NEO Personality Inventory, HOSTILITY, LIPIDS (Q2)
- SOCIAL FACTORS (Q3)
- WOMEN'S HEALTH ON MAMMOGRAPHY AND MEDICAL HISTORY (WQ1)
- ITEMS FOR NEW NEO FACET SCALES FOR AGREEABLENESS AND CONSCIENTIOUSNESS (Q4)
- ENROLLED SPOUSES WITH BRIEF (Q1-Q4)
- WEIGHT & EXERCISE (Q5)
- NUTRIENT INTAKE AND DEPRESSION (Q6) HRT USE FOR WOMEN (WQ2)
- RE-MEASURE OF ADULT PERSONALITY WITH NEO-PI-R [NEO Personality Inventory Revised] (Q7)
- UPDATE OF MEDICAL HISTORY (Q8) AND UPDATE MENOPAUSAL STATUS (WQ3)
- UPDATE OF CHD RISK INDICATORS, HOSTILITY, SES, AND WELL-BEING (Q9)
- UPDATE ON MENOPAUSAL STATUS AND RESPONSE TO WHI FINDINGS ON HRT (W4)
- UPDATE ON HEALTH STATUS, FAMILY HISTORY OF DISEASE (Q10)

Future Plans:

Monitor changing risk profiles, morbidity and mortality and study normal aging.

Data Availability:

This is an ongoing study. Respondents have been promised complete confidentiality. The data are not archived. Investigators may access the data via collaboration, but the data may not be removed from the laboratory.

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Dataset Name:	Epidemiology of Aging and Physical Functioning
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Ira B. Tager
Data Collection Organization:	University of California –Berkeley, School of Public Health

Purpose:

This longitudinal study was undertaken to address: 1) the relationships between self-reported physical activity, directly measured aerobic capacity and lung function and tests of physical performance on self-reported physical functioning in the elderly; 2) the role of social factors in the maintenance of self-reported physical functioning in the elderly and in the modification of the underlying factors of physical activity, aerobic capacity and performance on objective tests of function.

Description:

A community based sample of 2,092 persons aged 55 years and older was recruited in Sonoma, CA—a city with a large number of retired persons. The cohort was followed for four surveys approximately 18 months apart.

Objective:

The overall objective is to unravel the complex relationships between the physiological factors that affect the ability to perform leisure time physical activity (aerobic capacity, lung function, muscle strength, balance) and the social factors that influence the ability to engage in leisure time physical activity and levels of functional capacity in the elderly. Over the last several years, an additional objective has been added: the application of methods of causal statistical inference (e.g., use of marginal structural models, and structural nested failure-time models) to explore the complex relationships that constitute the hypothesized “disablement process”.

Study Design:

A community census was conducted to recruit a representative sample of persons age 55 years and older in the city of Sonoma, CA. Between May 1993, and December 1994, 2,092 subjects were recruited and the cohort was observed for a baseline evaluation and three subsequent surveys approximately 18 months apart. At each evaluation the following occurred: 1) a detailed home evaluation with questionnaire, measures of functional performance, vision and anthropometrics; and 2) a laboratory evaluation that included ECG, blood pressure, treadmill exercise testing with real-time gas analysis, spirometry, bioelectric impedance and stereoscopic vision. All cohort members’ vital status is tracked on an ongoing basis. Several special sub-studies were conducted: measures of isokinetic muscle function; DEXA measurements to generate study-specific equations for conversion of bioelectric impedance to lean body mass and fat mass.

Data Collection:

Data are obtained from: 1) in-person and telephone-administered questionnaires; 2) objective measurements of functional performance transcribed to forms; 3) directly from computer data files for treadmill exercise testing and lung function data. All data are entered into SAS data bases that contain range and logic checks. At entry, 10% of records are double data entered. After data entry, all data are evaluated for values that are out of range or are inconsistent, based on content rather than on the format of the questionnaires or instrumentation output. All changes to data are documented with signatures and/or specific computer programs. Primary data sets are never changed once they have been “closed”. All secondary data sets created for specific analyses are retained.

Future Plans:

Four surveys have been completed. No further field work is planned except for continued observation of the vital status of the cohort. The emphasis now is on data analysis and the publication of papers.

Questionnaire Topics:

General medical health (symptoms and diagnoses and procedures), general self-reported health assessments, leisure time physical activity (current and past), physical functioning, social environment (living arrangements, hobbies, etc.), medications; cognitive function, smoking, second hand tobacco smoke exposure, alcohol use.

Data Availability:

Currently not available, specific requests to the PI will be considered.

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Dataset Name:	Hypertension, Aging, and Intellectual Functioning
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Merrill F. Elias
Data Collection Organization:	University of Maine

Purpose:

To assess the relationships between hypertension and performance on the Wechsler Adult Intelligence Scale.

Objectives:

- 1) To examine interactions between age cohort membership and hypertension with respect to performance on the Wechsler Adult Intelligence Scale (WAIS).
- 2) To determine relationships among hypertension, education, occupational status, sex, mood state, and longitudinal decline in WAIS test performance over time.

Study Design:

Longitudinal, Cross Sectional and Cross-Sequential

Questionnaires:

- 1) Wechsler Adult Intelligence Scale
- 2) Cornell Medical Index
- 3) State-Trait Anxiety Inventory
- 4) Zung Depression Scales

Future Plans:

This project ended on July 1, 2000. Data analysis is continuing.

Data Availability:

The data are not publicly archived, but are available through collaboration with the Principal Investigator and his colleagues. After approval of the project in concept, investigators should be prepared to submit a brief proposal (6 pages single spaced) which will be evaluated for scientific quality using criteria established for NIH review. The research must also meet NIH guidelines for the protection of human subjects, use of minorities, women and children in research and be approved by the applicants' Institutional Review Board as well as the University of Maine. Researchers submitting proposals must be prepared to support the costs of the research. Investigators should be prepared to establish their scientific credentials and to support the fact that their background and training is commensurate with the research proposed. Contact with the Principal Investigator is advisable before submitting a formal proposal. Studies dealing with the relationship of mood state or social psychological variables to longitudinal change in WAIS Test performance are strongly encouraged, as are studies dealing with methodological and quantitative issues in longitudinal data analysis, e.g., creative uses of dynamic structural equation modeling or survival analysis.

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Dataset Name:	Odense Archive of Population Data on Aging
Sponsoring Organization:	National Institute on Aging Danish Research Council
Principal Investigator:	James W. Vaupel (Program Director) James R. Carey, James W. Curtsinger, Anatoli I. Yashin, Kenneth G. Manton, Thomas E. Johnson, Niels Holm, Kaare Christensen, Vaino Kannisto, A. Roger Thatcher, Hans Lundstrom, Axel Skyttthe and Kirill Andreev
Data Collection Organization:	Duke University, University of Southern Denmark, University of California Davis, University of Minnesota, University of Colorado at Boulder

Purpose:

The Odense Archive of Population Data on Aging includes several databases of relevance to studies of oldest-old mortality.

Description:

The Odense Archive of Population Data on Aging currently consists of the following six databases:

Kannisto-Thatcher Oldest-Old Database consists of population counts and death counts by single year of age, by year of birth, and by calendar year for males and females in 28 developed countries (not including the United States), mostly since 1950, at ages 80 and above.

Lundstrom Database for Sweden consists of population counts and death counts by single year of age, by year of birth, and by calendar year for males and females in Sweden since 1861, for ages 51 and above.

Andreev-Skyttthe Database for Denmark is similar, except it starts at age 0 and year 1870.

The Danish Twin Registry consists of individual level data on twin pairs born in Denmark between 1870 and 1930. For each twin pair, date of birth and dates of death (if dead), sex, and zygosity are available.

Carey Database on Medflies consists of daily death counts for large, genetically heterogeneous cohorts of Medflies followed until extinction. About 5 million Medflies are included.

Curtsinger Database on Drosophila consists of similar data but on smaller cohorts of Drosophila that are classified by genotype. About 50,000 Drosophila are included.

Data Availability:

All of the above data are available and will be sent to qualified researchers on request. The investigator responsible for each dataset will review such requests.

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Dataset Name:	The Women's Health and Aging Study (WHAS I, WHAS II, and WHAS III)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Linda Fried
Data Collection Organization:	Center on Aging and Health, Johns Hopkins University Medical Institutions

Purpose:

Increases in life expectancy, the resulting increase in the older population, and the rising costs of long-term care have made age-associated disability and dependency matters of national concern. Disability in old age is often associated with poor quality of life, dependence on formal and informal care providers, substantial medical and long-term care costs and increased risk of other adverse health outcomes. WHAS seeks to define the causes and consequences of disability, with a particular focus on health care and older women because women make up the majority of the older population, represent a larger proportion of the total population at each higher age, report higher rates of physical disability, and spend more years in a disabled state. This study is:

- Examining the natural history of physical disability and frailty
- Identifying the major diseases and conditions responsible for physical disability and frailty
- Evaluating causes of changes in physical function and frailty over time, including both decline and improvement
- Assessing the role of health care utilization, community and informal services in modifying the course and severity of disability and frailty
- Identifying subsets of disabled women at highest risk of progression of disability and frailty; and
- Determining opportunities for secondary and tertiary prevention of frailty and disability

While it is recognized that potentially valuable male-female comparisons are sacrificed by examining women only, and that certain findings on the causes and course of disability in women may not hold true in men, the magnitude of the problem in women and the analytic power gained by studying women only made this a compelling focus, and findings will, in large part, be generalizable to men.

Study Design:

WHAS-I: The study population was obtained by drawing a random sample from the Health Care Financing Administration's Medicare enrollment file for the 32,538 women residing in 12 contiguous Zip Code areas in Baltimore, MD. The sampling frame represented all female Medicare beneficiaries as of September 1, 1992. Over 4,000 women were screened to identify disabled older women living in the community, and 1,002 agreed to participate. After a baseline interview, follow-up in-person interviews were conducted with participants every six months for the next three years, and annual telephone interviews for two years after that. Enrollment and data collection were conducted between 1992 and 2000.

Description:

An extensive home interview ascertained many aspects of physical function and disability, including tasks affected, severity of difficulty, and adaptation to disabilities. Also assessed were: history of physician diagnosis, symptoms and severity of 20+ diseases and conditions, current use of medications, psychological functioning, social support, health-related behaviors, and health care utilization. Impairments assessed included strength, balance, functional reach, visual memory, block construction, and cognitive function. There were performance-based measures of functioning, including chair stands, walking speed, lock and key, buttoning, and phone use. In addition, a nurse administered a standardized protocol at baseline including: blood pressure and heart rate; anthropometry; vision; electrocardiogram; electrocardiogram; musculoskeletal assessment; audiometry; and pulmonary function. These offer objective measurements of severity of disease as well as impairments.

An important component of the investigation is the determination of the causes of the disability experienced by these women. The study is investigating the role of major chronic diseases in causing disability, including coronary heart disease; congestive heart failure; chronic obstructive pulmonary disease; osteoarthritis of hands, hips and knees; rheumatoid arthritis; hip fracture; stroke; intermittent claudication; diabetes; cancer; and Parkinson's Disease. Also considered are frailty, vision and hearing impairment, falls and balance abnormalities, and urinary incontinence. Data from the interviews were supplemented by information abstracted from medical records at hospitals and physicians' offices to verify the presence and severity of specific diseases and conditions. A team of clinicians reviewed each case and decided what conditions caused the limitations of functioning.

A subset of 100 WHAS participants were invited to participate in the Weekly Disability Substudy, a 6-month study aimed at characterizing short-term variability in function and testing the reliability of both self-report and performance indicators of functioning.

WHAS II: Risk Factors for Physical Disability in Aging Women

This study was begun in 1994 to understand the natural history of changes in physical function in nondisabled women and of onset of disability, and the causes of incident disability. This study has a representative sample of 436 initially nondisabled or mildly disabled women 70-79 years of age, sampled from the same sampling frame and catchment area of WHAS-I. Now in the 12th year of the study, important insights have been gained in understanding how limitations in function progress to frailty and physical disability. Sensitive methods have been developed for early detection of changes in function that predict subsequent difficulty. These methods help to identify the factors that put individuals at increased risk of physical disability and to design interventions to delay or prevent disability and prolong independence.

WHAS III: Pathogenesis of Disability in Older Women

This study evaluates the role of potential contributors to the pathogenesis of disability: inflammation, hormones, and micronutrient deficiencies, singly, in combination and in relation to existing diseases, impairments and frailty. These questions are being addressed through analysis of already-collected data from the WHAS I and WHAS II studies, combining data on the one-third most disabled women living in the community (WHAS-I), the 2/3 least disabled women in the community, and an ancillary study which collected blood, analyzed many measures, and stored plasma and serum. WHAS III has the following research aims:

1. to establish population norms and rates of change for pathogenic biomediators and frailty
2. to determine the degree to which these biomarkers explain frailty and disability status
3. to evaluate longitudinally the independent and interactive contributions of pathogenic biomediators to disability, over and above that of disease, and the potential role of frailty as a modifier of these relationships
4. to develop screening nomograms for clinical identification of those at high risk of severe disability and assess potential impact of interventions needed to meaningfully delay such progression
5. to produce a monograph based on WHAS results that describes evidence for a causal pathway to disability and its risk factors.

Data Availability:

Those with scientific interests in analysis of these data are invited to contact lead investigators and to develop an analysis proposal if goals are consistent with data collected.

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DATASETS CURRENTLY UNAVAILABLE

Dataset Name:	Terman Life-Cycle Study, as supplemented
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Howard S. Friedman
Data Collection Organization:	University of California, Riverside

Purpose:

Study of predictors of longevity across the life-span from 1922 (when the participants were children) through the present.

Description of Project and Dataset:

The long-term objective of this project is the achievement of a sophisticated, developmentally-sensitive understanding of the roles played by key behavioral and psychosocial factors in human health and longevity, using the unique seven-decade Terman archive. The primary outcome variables are longevity, cause of death, and old-age well-being.

The Terman Gifted Children Study (later renamed the Terman Life Cycle Study) began in 1921-22 when most of the 1528 participants were in elementary school. Major efforts have been made to follow up on and improve the dataset. Data have been collected/refined on the subjects' social relations, education, personality, habits, careers, families, mental health, life stress, physical activities, physical health, date of death, and cause of death through 2000. Until the project began, the study aimed primarily to describe the life course of gifted individuals. That is, the study was originally focused on addressing such issues as whether bright children were neurotic, introverted, sickly eggheads. (It turned out they were not). As young adults, they were generally healthy and successful. In middle age, they were largely productive citizens, but with none clearly identifiable as a "genius." In short, the focus of previous studies (by others) had been on social and career success. Few predictive studies using the data had been undertaken, with little or no study of health as a function of individual differences. Especially noteworthy is that death certificates have been and are being collected from state agencies, and coded cause of death using a certified nosologist supervised by medical expert, Dr. Criqui, who has expertise in coding death certificates.

Terman's aim was to secure a reasonably random sample of bright California children, and so most public schools in the San Francisco and LA areas in the 1920's were searched for bright children, nominated by their teachers and tested by Terman. The sample was later characterized as a productive, intelligent segment of the 20th century middle-class American men and women. The average birth date was 1910, with a S.D. of four years. Most were pre-adolescent when first studied; those still living are now in their 90's.

Study Design:

Archival prospective cohort design.

Topics (and Names of Surveys, as applicable):

Hundreds of variables and indexes measured and created across seven decades.

Future Plans:

- (1) To further extend, improve, and refine the Terman archival data-base, including collecting and coding death certificates from 1991-2000, so that it will be of greater value for addressing questions in health and aging, thus leveraging the existing investment in this project.
- (2) To analyze the correlates and effects of physical activity at each stage of life, and across time.
- (3) To examine if and how purpose and social connectedness affect successful aging in the very old.
- (4) To study validated archival personality scales within a modern five-factor framework, including their relationship to facets of each factor (assessed by the NEO PI-R) and determine which facets are most related to longevity and cause of death.
- (5) To study healthy aging.

Data Availability:

The new data, including death certificates, will be archived and available, as permitted by law (increasingly restrictive), upon completion of the project at the University of California, Riverside. No data are available for release at this time, but the PI welcomes collaboration under certain circumstances.

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DATASETS UNDER DEVELOPMENT

Dataset Name:	The Longitudinal Study of Aging Danish Twins 1995-1997-1999-2001-2003
Sponsoring Organization:	National Institute on Aging The Danish National Research Council
Principal Investigator:	James W. Vaupel and Kaare Christiansen
Data Collection Organization:	The University of Southern Denmark

Description:

The Longitudinal Study of Aging Danish Twins focuses on elucidating causes of variation in survival, health, diseases, loss of abilities, and cognitive functions among the elderly and the oldest-old. LSADT includes twins aged 70+ in the Danish Twin Registry, hereby creating a longitudinal study in a genetically informative population.

Objective:

- (1) To obtain longitudinal data about health, functioning, cognitive abilities, depression, symptomatology, lifestyle, social factors, quality of life and survival among Danish twins aged 70+.
- (2) To supplement the self-reported assessment of key outcomes such as physical functioning with behavioral measures of physical abilities, comprising strength, agility, speed and pulmonary peak-flow among the participants.
- (3) To obtain DNA samples from the LSADT- participants using cheek swabs or blood spot.
- (4) To study sex differences in determinants of (healthy) life expectancy and the association between health and mortality using demographic and biometrical methods.
- (5) To study genetic and environmental determinants of old-age health, functioning and survival.

Study Design:

The LSADT sample was drawn from the older cohorts of the Danish Twin Registry, which includes all twins born between 1870 and 1910 and all like-sex twin pairs born between 1911 and 1930 in Denmark. LSADT began in 1955 with the assessment of members of like-sex twin pairs born in Denmark prior to 1920 (i.e., at least 75 years old at the beginning of 1995). The surviving members of the initial cohort were followed up every two years in 1997, 1999, and 2001. Additional cohorts were also added at the 1997, 1999, and 2001 assessments and subsequently followed at two-year intervals. Twins born between 1920 and 1923 (i.e., at least 73 years old at the beginning of 1997) were added in 1997; twins born 1924 to 1928 (i.e., at least 70 years old at the beginning of 1999) were added in 1999; and twins born between 1929 and 1930 (i.e., at least 70 years old at the beginning of 2001) were added in 2001. The surviving individuals from the 2001 survey were followed up again in 2003. Thus, LSADT uses a cohort-sequential design. Participation rates among survivors at any given wave ranged from approximately 70-80%. A total of 4,371 individual twins have completed LSADT intake assessment.

Data Availability:

Information about the content and availability of the data can be found at the following website:

<http://www.pubpol.duke.edu/centers/ppa/> and
<http://www.sdu.dk/health/person/?id=kchristensen@health.sdu.dk>

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Dataset Name:	National Social Life, Health, and Aging Project (NSHAP)
Sponsoring Organization:	NIA, NICHD, OBSSR
Principal Investigator:	Linda J. Waite
Data Collection Organization:	National Opinion Research Center (NORC)

Purpose:

Social support and personal relationships, particularly marriage, bolster psychological and physical health as people age. Intimacy constitutes an essential, but poorly understood, aspect of both healthy aging and social life at older ages. The National Social Life, Health, and Aging Project (NSHAP) will examine the role of relationships in healthy aging. This research will provide physicians and public health policy makers with a scientific base of information for advising older people about positive social and intimate relationships, as well as designing health programs to capitalize on and promote these relationships. Such interventions may be important for prolonging independence, relieving anxiety, reducing morbidity, and preventing dysfunction or disease as people age.

The goals of the project include:

- Describing the health of older community-residing Americans. We are specifically interested in distributions of physical health, illness, medication use, cognitive function, emotional well-being, sensory function, health behaviors, and social connectedness.
- Evaluating the relationship between health and older adult interpersonal connections. We will look specifically at the associations between interpersonal relationships and physical illness and disability, mental illness, and medication use and health behaviors.
- Examining the importance of gender and cultural and economic context for older adult health and social connectedness. We are specifically interested in how the experience of aging and its implications for health and functioning differ according to gender, race and ethnicity, social class, education, and religiosity.
- Identification of the biological pathways through which social connectedness affects various aspects of health, such as physical function, illness, sensory function, and health behaviors.
- Describing health behaviors and health care utilization among older adults, and ascertain their perceptions about physician-patient communication and health care services.

Description:

From July 2005 to March 2006, NSHAP interviewed 3,004 men and women ages 57-85, with a 74.5 percent response rate. Face-to-face interviews and biomarker collection took place within respondents' homes. The NSHAP study received full human subjects approval from both the University of Chicago's and the National Opinion Research Center's IRBs.

Questionnaire Topics:

Data collected includes: 1) demographic characteristics; 2) social networks; 3) social and cultural activity; 4) physical and mental health including cognition; 5) well-being; 6) illness; 7) medications and alternative therapies; 8) history of sexual and intimate partnerships; and 9) patient-physician communication. NSHAP also collected important health information in the home, including height, weight, blood pressure, blood spots (glucose, Hemoglobin A1c, CRP, EBV antibodies), saliva (HIV antibodies, sex hormone evaluation), and sensory measures (vision, hearing, taste, touch, smell).

Future Plans:

Several manuscripts using the data from Wave I interviews are currently in progress. The study aims to follow respondents longitudinally every three years, and is now beginning preparations for a second wave of data collection, including interviews and biological measures.

Data Availability:

Primary data analysis of this project will continue at least through 2008. Data will be made publicly available in two phases, beginning in 2007. De-identified questionnaire data will be made available first. Data from some biological measures will be available later, due to the time required to process, code, clean, and prepare laboratory data.

Bibliography:

The conceptual model for the NSHAP study is described in Lindau, Stacy Tessler, Edward O. Laumann, Wendy Levinson, and Linda J. Waite. 2003. "Synthesis of Scientific Disciplines in Pursuit of Health: The Interactive Biopsychosocial Model." *Perspectives in Biology and Medicine* 46(3):S74-S86.

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Dataset Name:	Study on Global Ageing and Adult Health (SAGE)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Ties Boerma [PI], Can Celik, Somnath Chatterji, Paul Kowal, Saba Moussavi, Nirmala Naidoo, Fanny Naville, Agnes Prudhomme, Emese Verdes.
Data Collection Organization:	Data collection by contract in each country. World Health Organization (WHO) collates, cleans and manages data sets.

Purpose:

The WHO Study on Global AGEing and Adult Health (SAGE) used the World Health Survey (WHS) Programme to develop a range of valid, reliable and comparable survey modules and as a baseline round of data collection in 2002/03. SAGE is planned as a study that will generate nationally representative cohorts of about 5,000 respondents aged 50+ years at each of 4-6 sites. These cohorts can then be followed up for a period of 5-10 years. Each site will also include a smaller sample of respondents less than 50 years. The study will address issues of health and health related outcomes, participation in economic activities, risks to health, and coverage of health interventions. Data will be collected on health examinations and performance tests such as anthropometry, grip strength, blood pressure and tests of cognition, vision and mobility, in order to allow adjusting for biases in self-reported health domains, including activities of daily living and instrumental activities of daily living. SAGE will also collect data on biomarkers (for diabetes, anemia, hypercholesterolemia and others) to improve the precision of self-reported health and morbidity.

The specific aims of SAGE are:

- To obtain reliable, valid and comparable data on levels of health on a range of key domains for older adult populations;
- To examine patterns and dynamics of age-related changes in health using longitudinal follow-up of survey respondents, and to investigate socio-economic consequences of these health changes;
- To supplement and cross-validate self-reported measures of health with the anchoring vignette approach to improving comparability of self-reported measures, and through measured performance tests for selected health domains; and,
- To collect health examination and biomarker information to improve reliability of data on morbidity, risk factors and monitor effect of interventions.

Description:

1) The main body of work for this study program is to implement a longitudinal study in between four to six countries to be selected from the following: India, China, Mexico, South Africa, Ghana and the Russian Federation. Additional sites may be brought on board with local resources. The first round of data collection for SAGE is scheduled to occur starting in Sept/Oct 2005.

2) The second activity is to work with 10 International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) field sites to implement either the full survey or an abbreviated short module in a selection of these sites as part of routine demographic surveillance, and to develop new methodologies to measure health and health-related outcomes.

3) The third area of work is with the Study of Health, Ageing and Retirement in Europe (SHARE), which is implementing the health state descriptions and vignettes methodology in 11 countries in Europe. This will improve the empirical understanding of health of older persons in Europe and the

understanding of the cross-national comparability of results from various countries using these methodologies.

Study Design:

Face-to-face administered questionnaire; field cognitive and performance tests; anthropometrics; baseline and follow-up biomarkers (cardiovascular, other), subjective well-being and quality of life (Day Reconstruction Method) in probability samples.

Questionnaire Modules:

<p><u>Household Questionnaire:</u></p> <ul style="list-style-type: none">• Geocoding/GPS Information• Recontact Information• Household Roster• Housing• Household and Family Support Networks and Transfers• Assets and Household Income• Household Expenditure	<p><u>Individual Questionnaire:</u></p> <ul style="list-style-type: none">• Socio-Demographic Characteristics• Work History and Benefits• Health State Descriptions• Risk Factors and Preventive Health Behaviors• Chronic Conditions and Health Services Coverage• Health Care Utilization• Social Capital• Subjective Well-Being and Quality of Life• Impact of HIV/AIDS• Anthropometrics, Performance Tests and Biomarkers *
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*Measured tests include: height, weight, blood pressure, timed walks, grip strength, immediate and delayed verbal recall, digit span (forwards and backwards), verbal fluency, spirometry, near and distant vision tests, Hemoglobin A1c, HgB, total cholesterol, HDL/LDL, triglycerides, HIV.

Data Availability:

The data will be available via the World Health Organization website: <http://www.who.int/whs> or <http://www3.who.int/sage>. Basic tables will be provided for all to use until each country has had a chance to analyze and use the data, after which data sets will be provided as STATA data files. All microdata with accompanying metadata will be made available through a WHO web server. The data collection instruments are currently available.

Contact:

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Dataset Name:	Survey of Health, Ageing and Retirement in Israel (SHARE-Israel)
Sponsoring Organization:	National Institute on Aging National Insurance Institute (Israel) German-Israeli Foundation for Scientific Research and Development
Principal Investigator:	Howard Litwin
Data Collection Organization:	Israel Gerontological Data Center, Hebrew University, through the B.I. Cohen Institute for Public Opinion Research, Tel Aviv University

Purpose:

The longitudinal Survey of Health, Ageing and Retirement in Israel (SHARE-Israel) collects interdisciplinary data on Israelis over the age of 50. SHARE-Israel is designed after the US Health and Retirement Study (HRS) and the Survey of Health, Ageing, and Retirement in Europe (SHARE-Europe). The main aim of SHARE-Europe, an EU-sponsored project, is to create a pan-European interdisciplinary panel data set covering persons aged 50 and over. The project brings together many disciplines, including demography, economics, epidemiology, psychology, sociology and statistics. Scientists from some 15 countries have worked on feasibility studies, experiments, and instrument development, culminating in a survey of about 22,000 individuals. The multidisciplinary nature of the data provides new insights into the complex interactions between economic, health, psychological and social factors determining the quality of life of the elderly.

Comparability with these surveys is one of the core targets of SHARE-Israel. The cultural diversity of the Israeli population provides unique points of reference for international comparison. For example, the country is younger than most Western societies, the majority of the older population is a Jewish cohort of largely immigrant background, and there is an Arab minority of 19 percent. In addition, Israeli society presents a unique set of conditions and characteristics that can yield new insight and understanding regarding the social dynamics of important aspects of population aging. For example, there are the unique life trajectories of many older Israelis. The current elderly cohort in Israel comprises people who experienced significant and multiple dislocations during their lifetimes, because of war, migrations (many impelled) and economic adversity. There is also the increased probability of terrorist acts, a topic that will require increasing attention around the world.

Study Design:

Following HRS and SHARE practice, the target sample for data collection in SHARE-Israel is all persons age 50+ in 1,700 households and their spouses of any age. Toward this end, a multi-stage design was employed combining the probability sampling of statistical areas with the creation of a sampling list within each statistical area using the telephone directory database. In the first stage, a sample of 150 statistical areas was drawn from the 2,300 statistical areas into which Israel is divided. Prior to drawing, the statistical areas were stratified according to social and demographic characteristics based on nationality (Jewish and Arab areas), geographic region, type of community and socio-economic level. The probability of inclusion was proportionate to the number of residents aged 50+ in the statistical area. In the second stage, residential units in each of the selected statistical areas were listed and matched to the national residential telephone directory file (phone coverage in Israel is about 95%). In the final stage, each interviewer received a list of addresses and was instructed to interview all eligible persons.

The generic SHARE questionnaire was adapted and translated into Hebrew, Arabic and Russian. These languages were also incorporated into the Computer Assisted Personal Interview (CAPI) mechanism, with some difficulty, due to their right-to-left direction.

The SHARE-Israel survey was fielded from October 2005 through July 2006. Data were transferred to the Netherlands, according to SHARE protocol

Questionnaire Topics:

The Israeli survey instrument addresses the major areas covered in HRS, and SHARE, but adds two domains not addressed in those surveys: 1) the measure of life-long trauma, including exposure to the Holocaust, and 2) examination of reactions to pension reform, that is, the delay of eligibility for retirement benefits in Israel.

Trauma: Respondents are asked to indicate difficult life events that they have experienced and the degree to which they were affected by them. The 17 events in the list range from war and terror related incidents to personal bereavement and distress. A separate inventory chronicles respondents' exposure to the Holocaust.

Pension Reform: This section addresses awareness of the legislated delay in the age of eligibility for retirement pension in Israel (men to age 67 and women to age 64), perceptions about implications of the change in pension age, information regarding personal plans for employment or retirement in light of the change, and sources of income that will be used to bridge the period between retirement and receipt of the pension, if early retirement is indeed contemplated.

Demographics: marital status, country of birth, education, and occupation and details about parents last occupation, health status, and frequency of contact.

Physical Health: self-reported general health, longstanding illness or disability, eyesight and hearing, difficulties with a range of (instrumental) activities of daily living.

Grip Strength: physical measurement recording the respondent's maximum handgrip strength.

Walking Speed: time it takes for the respondent to walk a certain distance.

Behavioral Risks: smoking, alcohol use, and physical activities.

Cognitive Function: subjective and objective measures of 4 aspects of cognitive functioning. 1

Mental Health: how respondents view their lives and emotional problems.

Health Care: recent doctor visits, hospital stays, level of health insurance.

Employment and Pensions: current work activities, work income, pensions.

Children: information about the respondents' children.

Social Support: help respondents might receive from family and others.

Financial Transfers: any regular financial transfers and payments the respondent(s) may have given or received from non-household members, including inheritances.

Housing: current housing situation, including the size and quality of the accommodation value of their property, mortgages or rent payments.

Household Income: summary of the household income from various sources.

Consumption: household expenditures, e.g. on food, fuel, electricity, and telephone.

Assets: financial and non-financial assets and income from these assets.

Expectations: level of certainty about the future; how risk is valued.

Future Plans:

The intention is to conduct interviews every 2 years. Wave 2 is being developed for 2008.

Data Availability:

The aim is to make the data available for secondary analysis by means of user-friendly public use data files by mid-2007.

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Dataset Name:	The UAB Study of Aging: Mobility Among Older African-Americans and Whites
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	Richard M. Allman
Data Collection Organization:	Center for Aging, University of Alabama at Birmingham

Description:

The UAB Study of Aging is an ongoing prospective, observational, cohort study of 1,000 community-dwelling adults age 65 and older. Recruitment was based on a random sample of Medicare beneficiaries residing in five central Alabama counties, stratified by race, sex, and urban/rural residence. In-home assessments of factors hypothesized to predict mobility were conducted 1999-2001. The sample is 50% African American; 50% male, and 51% rural; mean age = 75. 3 (S.D. = 5). Telephone interviews are obtained every 6 months to define subsequent mobility in terms of life-space (the area in which subjects move) over a three year follow-up period. Confirmation and ascertainment of vital status at 36 months is pending.

Data Collection:

Baseline in-home assessments lasting approximately two hours were conducted between 1999 and 2001 by trained interviewers. Most follow-up interviews are being conducted by telephone. Questionnaires were mailed to subjects' physicians to verify medical diagnoses.

Interviewed	Dates Mo/Yr	Interviewed	Unknown Status	Cumulative Deaths	Cumulative Withdrawals
Baseline	12/99-2/01	1000	0	0	0
6-Month	6/00-9/01	943	37	18	2
12-Month	12/01-3/02	942	16	38	4
18-Month	6/01-9/02	904	34	58	4
24-Month	12/02-3/03	883	29	84	4
30-Month	6/02-9/03	847	31	117	5
36-Month	12/03-3/04	785	66	143	6
Mortality Ascertainment not completed; confirmation pending through National Death Index					
42-Month	6/03-6/04	778	32	185	5
48-Month Telephone	1/04-1/05	734	44	215	7
48-Month In-home	2/04-2/05	624			
54-Month	9/04-8/05	683	61	243	13
60-Month	4/05-2/06	662	61	264	13
66-Month	In progress				

Questionnaire Topics:

Short and intermediate term patterns of mobility change, predictors of mobility, nursing home placement, and mortality will be defined using 1999-2001 in-home assessments as the baseline. Questions relate to hypothesized predictors of mobility limitation and include the following:

Sociodemographic Variables Age Gender	Geriatric Syndromes: Falls Urinary incontinence
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Race/ethnicity	Constipation
Marital status	Poor visual acuity
Education	Hearing impairment
Income	Body mass index
Residence (metro vs. rural)	Poor appetite
Social support	Weight loss
Transportation	Vertigo/dizziness
Diseases	Syncope/fainting
Hypertension	Pain
Myocardial infarction	Neuropsychological Factors
Heart failure	Cognitive status
Stroke	Depression
Fractures	Anxiety
Osteoarthritis/ gout	Fear of falling
Liver disease	Fear of car crashes
Gall bladder disease	Health Behaviors
Kidney failure	Dietary intake
Diabetes	Never exercising
Parkinsons	Polypharmacy
Peripheral neuropathy	Physical Performance
Macular degeneration	Timed walk
Anemia	Timed chair stands
	Timed balance

Data Availability:

After baseline data is merged with all follow-up telephone interview data and three-year vital status information, it will be available on the UAB Center for Aging Website (www.aging.uab.edu). Data will be provided in a raw ASCII or SPSS format with a complete data dictionary.

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Dataset Name:	Vietnam Era Twin Study of Aging (VETSA)
Sponsoring Organization:	National Institute on Aging
Principal Investigator:	William S. Kremen and Michael J. Lyons
Data Collection Organization:	University of California, San Diego; Boston University; Vietnam Era Twin Registry

Purpose:

The VETSA projects form a multi-disciplinary, longitudinal twin study of aging that is currently in its first wave of data collection. Its goals are to determine genetic and environmental influences on successful aging or age-related decline in the following domains: cognitive; brain; personality-psychosocial; and health-medical. The VETSA comprise genetic epidemiology (classical twin design) as well as molecular genetic approaches.

Description:

VETSA twins are randomly selected from the Vietnam Era Twin (VET Registry), a national sample of male-male twin pairs who were in any branch of military service during the Vietnam era (1965-1975). As of March, 2006 we have assessed approximately 450 twin pairs in the primary VETSA project. The goal is to re-test study participants every 5 years. The VETSA has a very narrow wave 1 age range (51-59). This provides a baseline in mid-life prior to many substantial age-related changes, and increased power to detect change within individuals over time.

VETSA assessments in the primary project include: 1) Neurocognitive: IQ and general cognitive ability, executive function, working memory, episodic memory, processing speed, attention/vigilance, cognitive inhibition, and visual-spatial function. 2) Personality-Psychosocial: personality traits, SF-36, family environment, social support, attachment, resiliency, coping styles, life stresses, self-esteem, depression, and activities. 3) Health-Medical: self-report and medical history, standard blood pressure, ankle-arm index, spirometry, visual acuity and contrast sensitivity, audiometry, grip strength, motor speed, and stored blood samples for genotyping and clinical chemistries. The VETSA also has access to previously collected data from prior VET Registry studies. The VET Registry has links to the National Death Index.

The VETSA MRI study has to date imaged over 160 twin pairs from the primary VETSA project. The imaging protocol includes 3D structural MRI, diffusion tensor imaging, and T2*-weighted mapping of the hippocampus. The goal of the VETSA MRI study is to image the same subset of VETSA participants every 5 years in concert with the primary VETSA project.

The VETSA Cortisol study has to date obtained saliva samples for neuroendocrine assays on over 220 twin pairs from the primary VETSA project. Cognitive declines, brain changes, depression, and components of the metabolic syndrome (diabetes, hypertension, central obesity) are all of importance with respect to aging, and all have all been associated with elevated cortisol levels. Five samples per day on two different days at home and 7 in-lab samples are collected in this study. These are being used to determine levels of cortisol, testosterone, and DHEA. The goal is again to collect these samples every 5 years in concert with the primary VETSA project.

Data Availability:

The data for wave 1 are still being collected. Data will not be available until at least 5 years after the completion of data collection for a given wave. After that time, individuals interested in accessing the data will need to contact the principal investigators. Any use of the data will also need to be approved by the VET Registry.

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