Data Sources on Older Americans 2009

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FEDERAL
INTERAGENCY
FORUM ON
AGING
RELATED
STATISTICS

Federal Interagency Forum on Aging-Related Statistics

DATA SOURCES ON OLDER AMERICANS 2009

Data Sources on Older Americans (DSOA) highlights the contents of government-sponsored surveys and products containing statistical information about the older population. All Federal agencies are invited to contribute to this report and participate in the Forum. Starting in 2009, DSOA includes some non-federal data sources. More information about the Forum can be found at http://www.agingstats.gov.

Questions about the *Data Sources on Older Americans* may be directed to the Federal Interagency Forum on Aging-Related Statistics, National Center for Health Statistics, 3311 Toledo Road, Room 6321, Hyattsville, MD. 20782, phone: 301–458–4460, or e-mail: agingforum@cdc.gov.

Note to the User

Data Sources on Older Americans 2009 highlights the aging-related products currently available from member agencies of the Federal Interagency Forum on Aging-Related Statistics (Forum) as well as other Federal agencies. Some data bases or surveys could be listed under more than one agency. Federal agencies often jointly develop data, but produce reports that reflect differing agency missions. For example, the Current Population Survey (CPS) is sponsored by the Bureau of Labor Statistics (BLS), and fielded by the U.S. Census Bureau. Reports based on CPS data and issued by the two agencies differ. BLS reports focus on employment and labor force topics, while U.S. Census Bureau reports focus on living arrangements, money, income, and poverty topics.

Questions about particular data sources or products should be directed to the agency contact specified. For more information on *Data Sources on Older Americans,* contact the Federal Interagency Forum on Aging-Related Statistics, National Center for Health Statistics, 3311 Toledo Road, Room 6321, Hyattsville, MD 20782, phone: 301–458–4460, or e-mail: agingforum@cdc.gov. Copies are also available on the Forum's website at http://www.agingstats.gov.

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	Institutionalized Population in Universe[2]	Subject Domains[4]					Special Elements[5]	Page No.
		Population	Economics	Health Status	Health Risks and Behavior	Health Care		
Department of Commerce								1
U.S. Census Bureau								1
American Community Survey (ACS)	2006+	x					a, f, l	1
Decennial Census (Census)	x	x					a, f, l	4
International Data Base (IDB)		x						8
Longitudinal Employer-Household Dynamics (LEHD)		x	x				f	9
National Longitudinal Mortality Study (NLMS)		x		x	x		d, f, g, h, l	12
Population Projections		x					f	14
Survey of Income and Program Participation (SIPP)		x	x	x		x	d	16
Department of Health and Human Services								19
Administration on Aging								19
Census 2000 Special Tabulation on Aging (STA)	x	x	x				d, f, l, n	19
Agency for Healthcare Research and Quality								21
Healthcare Cost and Utilization Project (HCUP)	x		x	x		x	a, f, g, h	21
Medical Expenditure Panel Survey (MEPS)	1996 only	x	x	x	x	x	a, c, d, f, g, h, i, j, k, m, n	25
Centers for Disease Control and Prevention								27
National Center for Chronic Disease Prevention and Health Promotion								27
Behavior Risk Factor Surveillance Systems Data Files (BRFSS)		x		x	x	x	f, j	27
National Center for Health Statistics								30
Longitudinal Studies of Aging (LSOAs)				x	x	x	h, j, n	30
Health Data Interactive (HDI)	x			x	x	x	a, f, k, n	33
National Ambulatory Medical Care Survey (NAMCS)				x		x	c	34
National Death Index (NDI)	x	x		x				36
National Health and Nutrition Examination Survey (NHANES)				x	x		a, b, e, h	38

NOTES: [1]Surveys may not have collected the information listed above every year. [2]Indicates the institutionalized population is included in the universe at baseline. [3]institutionalized persons that have ambulatory visits are included in NHAMCS. [4]Subject domains refer to broad subject areas that a data source can address. These domains have been used in other Forum publications (i.e., Older Americans: Key Indicators of Well-being). [5]Special elements include a data focus or a survey characteristic in a particular data source.

SPECIAL ELEMENTS:[a]mental health, [b]physical exams (refer to in-person, clinical exams that may include medical and laboratory tests), [c]collection of data on drug cost and use, or alcohol use, [d]income/assets, [e]biological samples collected, [f]some state level estimates possible, [g] medicare and/or medicaid, [h]chronic conditions, [i]caregiving, [j]longitudinal data, [k]access to care, [l]housing, [m]social security, [n]disability.

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National Health and Nutrition Examination Survey—Epidemiologic Followup Study (NHEFS)				x	x			41
National Health Interview Survey (NHIS)				x	x	x	a, d, f, g, h, k, n	43
National Home and Hospice Care Survey (NHHCS)	x			x		x	n	45
National Hospital Ambulatory Medical Care Survey (NHAMCS)	x[3]			x		x		47
National Hospital Discharge Survey (NHDS)				x		x		49
National Mortality Followback Survey (NMFS)	x				x	x	k, n	51
National Survey of Ambulatory Surgery (NSAS)						x		53
National Nursing Home Survey (NNHS)	x			x		x	n	55
National Vital Statistics System (Vital Statistics)	x	x		x			f	57
Centers for Medicare & Medicaid Services								59
Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Surveys)	x					x	a, f, g, k	59
Medicaid (Claims and Enrollment) Data	x					x	f, g, h, i, j	61
Medicare (Fee-for-Service (FFS) Claims, Part D Events, and Parts A/B/C/D Enrollment) Data	x					x	f, g, h, i, j	64
Medicare Chronic Condition Warehouse (CCW)	x			x		x	a, f, g, h, i, j	67
Medicare Current Beneficiary Survey (MCBS)	x			x	x	x	a, d, g, h, i, j, k, l, n	69
Medicare Health Outcomes Survey (HOS)	x			x		x	a, f, g, h, j, n	71
Medicare Health Outcomes Survey-Modified (HOS-M)	x			x			a, f, g, n	73
Minimum Data Set (MDS)	x			x		x	a, f, g, h, i, j, n	75
Outcome and Assessment Information Set (OASIS)				x		x	a, f, g, h, i, j, n	77
National Institutes of Health								78
National Cancer Institute								78

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		Population	Economics	Health Status	Health Risks and Behavior	Health Care		
Surveillance, Epidemiology, and End Results (SEER)	x	x	x	x		x	f	78
National Institute on Aging								81
The Aging, Demographics and Memory Study (ADAMS)		x		x	x		a, b, c, d, e, h, i, l, m, n	81
Health and Retirement Study (HRS) and Assets and Health Dynamics of the Oldest Old (AHEAD)		x	x	x	x		a, c, d, e, g, h, i, m, n	83
National Long Term Care Survey (NLTCS)	x	x		x		x	d, e, g, j, l, n	85
National Social Life, Health, and Aging Project (NSHAP)		x		x	x	x	a, e, i, j, n	88
National Survey of Midlife Development in the United Sates: MIDUS 1 (1995–1996) and MIDUS 2 (2004–2005)		x		x	x		a, b, c, d, e, h, j	90
New Immigrant Survey (NIS)		x	x	x	x	x	d, h, l	92
Panel Study of Income Dynamics (PSID)		x	x				d, f, g, j, l, m	95
Wisconsin Longitudinal Study (WLS)		x	x	x	x		a, d, e, h, j, l,	97
Substance Abuse and Mental Health Services Administration								100
Client/Patient Sample Survey (CPSS)	x	x	x	x	x	x	a, g, h, k, n	100
Drug Abuse Warning Network (DAWN)	x	x		x	x	x	a, k	102
National Survey on Drug Use and Health (NSDUH)		x	x	x	x	x	a, c, d, f, g, h, k, n	104
National Survey of Substance Abuse Treatment Services (N-SSATS)	x					x	a, c, f, g, j, k	107
National Survey of Mental Health Treatment Facilities (NSMHTF)	x	x	x			x	a, f, g, h, j, k, n	109
Treatment Episode Data Set (TEDS)	x				x	x	c, f, g, k	111
Department of Housing and Urban Development								113
Office of Policy Develoment and Research								113
American Housing Survey (AHS)			x				j, l	113
Department of Labor								115
Bureau of Labor Statistics								115
American Time Use Survey (ATUS)		x	x	x	x		d, f, i	115

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Consumer Expenditure Survey (CE)		x	x			x	l	117
Current Population Survey (CPS)		x	x		x		d, f, n	119
National Longitudinal Surveys (NLS)		x	x	x	x	x	j	121
Department of Veterans Affairs								125
National Survey of Veterans (NSV)				x		x	d	125
VHA Survey of Veteran Enrollees' Health and Reliance Upon VA (SoE)		x	x	x	x	x	c, d	126
Veteran Population Model (VetPop)		x					f	128
Federal Reserve System, Board of Governors								129
Survey of Consumer Finances (SCF)			x				d	129
Office of Management and Budget								131
FedStats		x	x	x	x	x	f	131
Social Security Administration								133
New Beneficiary Data System (NBDS)			x				d, m, n	133
OASDI Microdata File, 2001			x				d, f, m, n	134
OASDI Microdata File, 2004			x				d, f, m, n	135
SSI Microdata File			x				d, f, m, n	136
Access to Tabulations and Statistics on Programs Created by the Social Security Act			x					137
International Data Sources								138
English Longitudinal Study of Ageing (ELSA)		x	x	x	x	x	a, b, d, e, h, i, j, l, n	138
Survey of Health, Ageing and Retirement in Europe (SHARE)		x	x	x	x		a, d, h, i, j, l, m, n	140
WHO Statistical Information System (WHOSIS)		x	x	x	x	x		143

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Department of Commerce
U.S. Census Bureau

American Community Survey (ACS)

Sponsor(s): U.S. Census Bureau

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The American Community Survey (ACS) is a nationwide survey designed to provide communities with a fresh look at how they are changing. It will replace the long form in the 2010 Census. The ACS collects information from persons in U.S. households and group quarters similar to the data collected on the Census 2000 long form: such as income, educational attainment, place of birth, disability status, home value, veteran status, and other important data. In addition to producing annual and multiyear characteristics of the population and housing, the survey also collects information for small areas such as blocks, groups, and population subgroups.

Survey Universe / Coverage / Census: A national sample of about 3 million addresses in every county, American Indian and Alaska Native area, and Hawaiian Home Land in the United States, and in Puerto Rico living in housing units and group quarters.

Sample or Research Design: The ACS is a large continuous demographic survey. Single-year estimates are available every year for geographies with populations of 65,000 or more and three-year estimates are available for geographies with population of 20,000 or more. The American Community Survey plans to release five-year estimates for all geographies by the end of 2010 and refresh these estimates every year thereafter.

The ACS sample uses a two-stage stratified annual sample of approximately 838,000 housing units designed to measure socioeconomic and demographic characteristics of housing units and their occupants. The ACS samples housing units from the Census Bureau's Master Address File (MAF). The first stage of sampling involves dividing the United States into primary sampling units (PSUs)—most of which comprise a metropolitan area, a large county, or a group of smaller counties. Every PSU falls within the boundary of a single State. The PSUs are then grouped into strata on the basis of independent information, that is, information obtained from the decennial census or other sources. The strata are constructed so that they are as homogeneous as possible with respect to social and economic characteristics that are considered important by ACS data users.

A pair of PSUs was selected from each stratum. The probability of selection for each PSU in the stratum is proportional to its estimated population. In the second stage of sampling, a sample of housing units within the sample PSUs is drawn. Ultimate sampling units (USUs) are housing units. The USUs sampled in the second stage consist of housing units that are systematically sorted lists of addresses of housing units drawn from the MAF.

The sample for group quarters facilities included such places as college residence halls, residential treatment centers, skilled nursing facilities, group homes, military barracks, correctional facilities, workers' dormitories, and facilities for people experiencing homelessness. Each group quarters facilities is classified according to its group quarters type. All group quarters samples are selected during the main sampling phase. The sample is selected by state, not county, as is done with the housing unit sample. Some locations that were classified in Census 2000 as specific group quarters types are not included in ACS data collection operations. These are domestic violence shelters, soup kitchens, regularly scheduled mobile food vans, targeted non-sheltered outdoor locations, crews of commercial maritime vessels, natural disaster shelters, and dangerous encampments. There are several reasons for their exclusion, depending on the group quarters type, including concerns about privacy and the operational feasibility of repeating interviews for a continuing survey rather than once a decade for a census. Nevertheless, ACS estimates for the total population are controlled to be consistent with the intercensal population estimates. The exclusion of these group quarters types may result in a small bias in some ACS estimates.

Unit(s) of Analysis: Person-level analysis.

Mode of Data Collection: Paper and pencil questionnaire format. Computer Assisted Telephone Interviewing (CATI) and Computer Assisted Personal Interviewing (CAPI) modes are used to follow-up with non-responding households.

Topics/Keywords: Social characteristics, housing, income, National and small area estimates

Data Years: 1996 to present

Linked Data: n/a

Reports: http://www.census.gov/acs/www/

Background / History: n/a

Future Plans: The first 5-year estimates, based on ACS data collected from 2005 through 2009, will be released in 2010.

Bibliography: PowerPoint presentations covering several topics on the ACS are also available through the Census Bureau's Public-Use Presentation Library, which is a collection of downloadable PowerPoint presentations, including slides and speaker notes, designed to inform data users about our various products and services. The web address for the Public-Use Presentation Library is: http://www.census.gov/mso/www/pres_lib/index2.html#ACS.

American Community Survey (ACS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: **http://www.census.gov/acs/www/index.html and http://www.census.gov/acs/www/Products/PUMS/***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Since the American Community Survey reached full implementation in January 2005, data availability is on a program schedule. Similar to the Census website, the ACS website has various tools for accessing survey data and data products: http://www.census.gov/acs/www/index.html. Data tools include the fact sheets, data profiles, multiyear profiles, selected population profiles, and various maps. Public-Use Microdata files from the ACS show the full range of responses made on individual questionnaires. All identifying information is removed to ensure confidentiality. The records selected are a sample of those households and group quarters that received the questionnaire. The questionnaire included questions on age, sex, tenure, income, education, language spoken at home, journey to work, occupation, condominium status, shelter costs, vehicles available, and other subjects. Also, the full range of population and housing information collected in the ACS is available on the Public-Use Microdata website for the ACS located at: http://www.census.gov/acs/www/Products/PUMS/.

Contact: n/a

Email: cmo.acs@census.gov

Phone: 800–923–8282

Website: http://www.census.gov/acs/www/index.html

Decennial Census (Census)

Sponsor(s): U.S. Census Bureau

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The U.S. decennial census serves two main purposes: (1) to apportion the 435 seats in the U.S. House of Representatives among the 50 States—the U.S. Constitution, Article I, Section 2, apportionment of representatives among the States, for the House of Representatives, must be carried out every 10 years (decennially); and (2) to enumerate the resident population. For Census 2000, data on sex, race, Hispanic origin, age, and tenure were collected from 100 percent of the enumerated population. More detailed information, such as income, education, housing, occupation, and industry, was collected from a representative sample of the population.

Survey Universe / Coverage / Census: U.S. resident population.

Sample or Research Design: Census 2000 was the last count of the U.S. population collected by the Census Bureau. The Census Bureau's primary method of data collection is to mail out questionnaires using the Local Update of Census Addresses (LUCA) program and by using enumerators. Enumerators are Census Bureau staff that travel door-to-door gathering data by canvassing roads and streets looking for living quarters. For Census 2000, as in several previous censuses, two forms were used—a short form and a long form. The short form was sent to every household, and the long form, containing the seven 100 percent questions plus the sample questions, was sent to only a limited number of households—about one in every six homes. The extended census form collects information on social, housing, economic, and financial characteristics. The national final response rate for Census 2000 was 67 percent. This exceeded the projected response rate of 61 percent and was better than the 65 percent response rate from the 1990 census.

Every person and housing unit in the United States was asked basic demographic and housing questions (for example, race, age, and relationship to householder). A sample of these people and housing units was asked more detailed questions about items, such as income, occupation, and housing costs. The sampling unit for Census 2000 was the housing unit, including all occupants. There were four different housing unit sampling rates: 1-in-8, 1-in-6, 1-in-4, and 1-in-2 (designed for an overall average of about 1-in-6). The Census Bureau assigned these varying rates based on precensus occupied housing unit estimates of various geographic and statistical entities, such as incorporated places and interim census tracts. For people living in group quarters (GQ) or enumerated at long form eligible sites (shelters and soup kitchens), the sampling unit was the person and the sampling rate was 1-in-6.

Postcensal Population Estimates: These are estimates made for the years following a census, before the next census has been taken. National postcensal population estimates are derived by updating the resident population enumerated in the decennial census using a component of population change approach. The following formula is used to update the decennial census counts: decennial census enumerated resident population:

+ births to U.S. resident women

– deaths to U.S. residents

+ net international migration (includes the movement of U.S. Armed Forces between the United States and overseas).

Intercensal Population Estimates: The further from the census year on which the postcensal estimates are based, the less accurate are the postcensal estimates. With the completion of the decennial census at the end of the decade, intercensal estimates for the preceding decade are prepared to replace the postcensal estimates. Intercensal population estimates take into account the census of population at the beginning and end of the decade. Thus intercensal estimates are more accurate than postcensal estimates because they correct for the "error of closure" or difference between the estimated population at the end of the decade and the census count for that date.

Unit(s) of Analysis: Person-level data analysis.

Mode of Data Collection: One of two different survey forms was used to enumerate the U.S. population: (1) A short form with seven basic questions, (2) a long form including all questions from the short form and additional demographic and housing questions. On average, one in every six households received the long form.

Topics / Keywords: Population and housing characteristics, National, State, and local levels of geography, postcensal population estimates, components of change, intercensal population estimates, error of closure.

Data Years: Every 10 years (e.g., 1980, 1990, 2000)

Linked Data: See description of National Longitudinal Mortality Data (NLMS).

Reports: For reports, see http://www.census.gov/main/www/cen2000.html.

SUMMARY TAPE FILES.

Summary File 1 (SF 1) contains 286 detailed tables focusing on age, sex, households, families, and housing units. These tables provide in-depth figures by race and Hispanic origin; some tables are repeated for each of nine race/Latino groups. Counts also are provided for over 40 American Indian and Alaska Native tribes and for groups within race categories. The race categories include 18 Asian groups and 12 Native Hawaiian and Other Pacific Islander groups. Counts of persons of Hispanic origin by country of origin (28 groups) are also shown.

Summary File 1 presents data for the United States, the 50 States, and the District of Columbia in a hierarchical sequence down to the block level for many tabulations, but only to the census tract level for others. Summaries are included for other geographic areas such as ZIP Code Tabulation Areas (ZCTAs) and Congressional districts.

Geographic coverage for Puerto Rico is comparable to the 50 States. Data are presented in a hierarchical sequence down to the block level for many tabulations, but only to the census tract level for others. Geographic areas include barrios, barrios-pueblo, subbarrios, places, census tracts, block groups, and blocks. Summaries also are included for other geographic areas such as ZCTAs.

Summary File 2 (SF 2) contains 47 detailed tables focusing on age, sex, households, families, and occupied housing units for the total population. These tables are repeated for 249 detailed population groups based on the following criteria:

No tables are available for geographic areas having a population of less than 100.

Tables are repeated only for the race groups, American Indian and Alaska Native tribes, and Hispanic or Latino groups having a population of 100 or more within the geographic area.

For a complete list of the 249 population groups, see Appendix H of the SF 2 Technical Documentation (PDF).

Summary File 3 consists of 813 detailed tables of Census 2000 social, economic, and housing characteristics compiled from the sample of approximately 19 million housing units (about 1 in 6 households) that received the Census 2000 long-form questionnaire. Fifty-one tables are repeated for nine major race and Hispanic or Latino groups: White alone; Black or African American alone; American Indian and Alaska Native alone; Asian alone; Native Hawaiian and

Other Pacific Islander alone; Some other race alone; Two or more races; Hispanic or Latino; and White alone, not Hispanic or Latino.

Summary File 3 presents data for the United States, the 50 States, the District of Columbia, and Puerto Rico in a hierarchical sequence down to the block group for many tabulations, but only to the census tract levels for others. Summaries are included for other geographic areas such as Zip Code Tabulation Areas (ZCTAsTM) and Congressional districts (106th Congress).

Summary File 4 (SF4) contains the sample data, which is the information compiled from the questions asked of a sample of all people and housing units.

The sample data are presented in 213 population tables (matrices) and 110 housing tables, identified with "PCT" and "HCT," respectively. Each table is iterated for 336 population groups: the total population, 132 race groups, 78 American Indian and Alaska Native tribe categories (reflecting 39 individual tribes), 39 Hispanic or Latino groups, and 86 ancestry groups.

SF 4 is released as individual files for each of the 50 States, the District of Columbia, and Puerto Rico; and for the United States. The tables (matrices) are identical for all files, but the geographic coverage differs. Data are provided down to the census tract level.

Background / History: n/a

Future Plans: The next decennial census will be conducted in 2010. Reengineering of the 2010 census includes replacing the long form with the American Community Survey (ACS). The ACS is a nationwide survey designed to provide communities a fresh look at how they are changing. It is intended to eliminate the need for the long form in the 2010 Census. The ACS collects information from U.S. households and group quarters similar to what was collected on the Census 2000 long form, such as income, commute time to work, home value, veteran status, and other important data. As with the official U.S. census, information about individuals will remain confidential.

Bibliography: n/a

Decennial Census (Census)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: **http://www.census.gov/population/www/cen2000/briefs/index.html***
- X *Data available for free upon order from agency. Order from: **http://www.census.gov/***
- ☐ *Application process required to obtain some data files*
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Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
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Additional Information:

Data from Census 2000 and previous census surveys can be obtained primarily through various tools used on the Census website (http://www.census.gov/main/www/cen2000.html). Census 2000 is the first census for which the internet site listed above is the primary means of disseminating the data. In addition to formatted tables, the Census Bureau website has maps and data sets available for downloading (file transfer protocol (ftp)), printing, viewing, and manipulating. Special reports and briefs on Census data that provide background information, explain how data was analyzed, and differences between 1990 and 2000 data, can be obtained through the following website: http://www.census.gov/population/www/cen2000/briefs/index.html.

Public-Use Microdata Area (PUMA) is a geographic entity for which the U.S. Census Bureau provides specially selected extracts of raw data from a small sample of long-form census records that are screened to protect confidentiality. The extract files are referred to as public use microdata samples (PUMS). Public use microdata areas, which must have a minimum census population of 100,000 and cannot cross a State line, receive a 5-percent sample of the long form records; these records are presented in State files. These PUMAs are aggregated into super-PUMAs, which must have a minimum census population of 400,000 and receive a 1-percent sample in a national file. PUMAs and super-PUMAs are mutually exclusive, that is, they use different records to create each sample. Data users can use these files to create their own statistical tabulations and data summaries.

Specific microdata samples available on CD-ROM/DVD can be obtained through the census catalog available on the U.S. Census Bureau's home page (http://www.census.gov/).

Postcensal and intercensal population estimates can be obtained through the following website: http://www.census.gov/popest/estimates.html

Contact: n/a

Email: pio@census.gov

Phone: 301–763–3691

Website: http://www.census.gov/main/www/cen2000.html

International Data Base (IDB)

Sponsor(s): National Institute on Aging, USAID, OGAC, U.S. Census Bureau, other U.S. Government agencies

Data Collection Agency: U.S. Census Bureau, Population Division, International Programs Center

Purpose / Primary Goals: The International Data Base (IDB) is a computerized source of demographic statistics for 227 countries and areas of the world. The IDB was created in the U.S. Census Bureau's International Programs Center (IPC) in response to the information requirements of organizations that sponsor IPC's research efforts. The IDB provides quick access to demographic measures for individual countries or selected groups of countries of the world. The IDB contains IPC's estimates and projections, with information dating back as far as 1950 and as far ahead as 2050. The major types of data available in the IDB include:

- Population by age and sex
- Vital rates, infant mortality, and life tables
- Fertility and child survivorship
- Migration

Data characteristics:

- Temporal: Selected years, 1950–present, projected demographic data to 2050.
- Spatial: 227 countries and areas.
- Resolution: National population, with selected data by age and sex.

Survey Universe / Coverage / Census: See: http://www.census.gov/ipc/www/idb/estandproj.php

Sample or Research Design: See: http://www.census.gov/ipc/www/idb/estandproj.php

Unit(s) of Analysis: Countries

Mode of Data Collection: n/a

Topics / Keywords: International data; Demographic statistics

Data Years: Selected years, 1950–present, projected to 2050

Linked Data: n/a

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

International Data Base (IDB)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

X User-specified online data query or table generation possible. Website: http://www.census.gov/ipc/www/idb/

X Some or all public-use files downloadable free from website

☐ Data available for free upon order from agency.

☐ Application process required to obtain some data files

☐ Payment required for the preparation/supply of data

Data Access to Non Public-Use data (i.e., data with confidential information)

☐ Application process required to obtain data files

☐ Use of Research Data Center required for access to restricted-use data

☐ Payment required for the preparation / supply of data

Additional Information:

Contact: U. S. Census Bureau or Information Resources and Dissemination Branch Call Center
E-mail: n/a
Phone: 1–866–758–1060
Website: http://www.census.gov/ipc/www/idb/

Longitudinal Employer-Household Dynamics (LEHD)

Sponsor(s): National Institute on Aging, U.S. Census Bureau, National Science Foundation

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The mission of LEHD is to link Federal and State administrative data on employers and employees with core Census Bureau data sources, including 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 worker, job, 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.

These datasets comprise Title 13 protected data from the Current Population Surveys, Surveys of Income and Program Participation, American Community Surveys, the Business Register, and Economic Censuses and Surveys. We have built employer-employee data relations based on universe State Unemployment Insurance wage records and Quarterly Census of Employment and Wages from all but a few states. 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 47 States and on the website at http://lehd.did.census.gov. Additional web-based analytical tools are also available on the website.
- Providing State-level micro data to approved researchers at Census Bureau facilities. The data files consist of longitudinal datasets on all firms in each participating State (quarterly data, 1991-current), 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 Social Security Administration (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)s, 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 (1973–2003) 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, 1990–93, 1996, 2001, 2004) 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.

Survey Universe / Coverage / Census: n/a

Sample or Research Design: n/a

Unit(s) of Analysis: n/a

Mode of Data Collection: n/a

Topics / Keywords: Older workers; Local Employment Dynamics; LEHD; integrated data

Data Years: 1991-Present

Linked Data: Title 13 and 26 protected data from the state Unemployment Insurance Wage Records, Quarterly Census of Earnings and Wages, Statistical Administrative Records System, Social Security Numident, Current Population Surveys, Surveys of Income and Program Participation, American Housing Survey, American Community Surveys, the Business Register, and Decennial and Economic Censuses and Surveys with federal tax data.

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Longitudinal Employer-Household Dynamics (LEHD)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

*X User-specified online data query or table generation possible. Website: **http://lehd.did.census.gov***

*X Some or all public-use files downloadable free from website: **http://lehd.did.census.gov***

☐ Data available for free upon order from agency.

*X Application process required to obtain some data files from: Free by contacting **virtualrdc@cornell.edu***

☐ Payment required for the preparation/supply of data

Data Access to Non Public-Use data (i.e., data with confidential information)

*X Application process required to obtain data files: **http://www.ces.census.gov***

☐ Use of Research Data Center required for access to restricted-use data

☐ Payment required for the preparation / supply of data

Additional Information:

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.

Contact: Jeremy Wu
E-mail: Jeremy.s.wu@census.gov
Phone: 301–763–5290
Website: http://lehd.did.census.gov

National Longitudinal Mortality Study (NLMS)

Sponsor(s): National Heart, Lung, and Blood Institute; National Cancer Institute; National Institute on Aging; National Center for Health Statistics; U.S. Census Bureau

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: To study the effects of demographic and socioeconomic characteristics on differentials in U.S. mortality rates.

Survey Universe / Coverage / Census: Sample drawn from Census surveys, matched to death certificates

Sample or Research Design: The NLMS currently consists of Annual Social and Economic Supplements, which cover the period from March 1973 to March 2002, Current Population Surveys for February 1978, April 1980, August 1980, December 1980, and September 1985, and one 1980 Census cohort, 26 cohorts in all. Important variables available for analyses are standard demographic and socio-economic variables such as, education, income, and employment as well as information collected from death certificates, including cause of death.

Data Limitations: The NLMS is based on specific survey months of the Current Population Survey, the Annual Social and Economic Supplement, and a subset of the 1980 Census. These are one-time data collection processes with no subsequent data collection. Therefore, one limitation of NLMS data is that they provide a one-time only baseline measurement of subjects in a long-term follow-up situation. Another limitation of these data is that, although the CPS and census instruments do provide extensive data collection capabilities in specific subject matter areas, desirable general or specific health information is not collected, and smoking status is available on only a limited number of records.

Unit(s) of Analysis: Individual and spouse data available.

Mode of Data Collection: Mortality information is obtained from death certificates available for deceased persons through the National Center for Health Statistics.

Topics / Keywords: Mortality rates and Demographic and socioeconomic characteristics

Data Years: 1973–2006. Samples drawn from each Census survey were matched to and are current with a 2006 match of death certificates.

Linked Data: Medicare Claims data. SEER. Geocoding match underway.

Reports: n/a

Background / History: The National Longitudinal Mortality Study (NLMS) consists of a database developed for the purpose of studying the effects of demographic and socio-economic characteristics on differentials in U.S. mortality rates. The NLMS is a unique research database in that it is based on a random sample of the non-institutionalized population of the United States. It consists of U.S. Census Bureau data from Current Population Surveys, Annual Social and Economic Supplements and a subset of the 1980 Census combined with death certificate information to identify mortality status and cause of death. The study currently consists of approximately 3.0 million records with over 250,000 identified mortality cases.

Future Plans: n/a

Bibliography: http://www.census.gov/nlms/bibliography.html

National Longitudinal Mortality Study (NLMS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- X *Application process required to obtain some data files from: Norman Johnson at norman.j.johnson@census.gov*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- X *Use of Research Data Center required for access to restricted-use data. Website: http://www.ces.census.gov/*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

An NLMS public-use file is available to interested researchers upon request through NLMS-Census Bureau principal investigator, Norm Johnson. Due to the confidential nature of the NLMS Title 13 data, the NLMS Public-use file consists of a restricted set of NLMS variables.

Research access to the entire NLMS database may be arranged through the principal investigators of the NLMS sponsoring agencies. Research topics of interest should fall within the general health interests of the agency. Principal investigators sponsor research through a quick-turnaround approval process established by the NLMS Steering Committee. The committee determines the priority of all NLMS research. Committee approved projects are assigned to an NLMS statistician who works directly with the researcher as a statistical consultant and as the interface to the NLMS database. Results are delivered to researchers on a, short-turnaround, flow basis through the most convenient means available in either electronic or hard copy format.

Researchers may also be interested in gaining access to a file containing the same information as the NLMS public-use file but which also includes geographical information. This file is available through the Census Bureau's Research Data Centers. For complete information on the use of the Census Bureau's Research Data Centers go to the Center for Economic Studies Census Bureau's website: http://www.ces.census.gov/.

A researcher may work directly with an NLMS statistician on-site at the Census Bureau by becoming a Special Sworn Census Bureau employee. A person interested in this option must first gain research sponsorship of a project through an NLMS sponsoring agency according to the NLMS Steering Committee approval process and then apply for Special Sworn status through Norm Johnson, Census Bureau NLMS Principal Investigator.

Contact: Norman J. Johnson
E-mail: norman.j.johnson@census.gov
Phone: 301–763–4270
Website: http://www.census.gov/nlms/

Population Projections

Sponsor(s): U.S. Census Bureau, Population Projections Branch

Data Collection Agency: U.S. Census Bureau

Survey Universe / Coverage / Census: U.S. Resident Population

Purpose / Primary Goals: Information about the possible future race/origin/age/sex composition of the United States.

Sample or Research Design: The 2008 National Population Projections for the United States use Census 2000 as their base population and were created using the cohort-component method, which uses assumptions about the components of population change (births, deaths, and net international migration). They are based on Census 2000 results, official post-census estimates, vital statistics data from the National Center for Health Statistics, and historical data on immigration.

The fertility level for the U.S. as a whole is assumed to remain under the replacement level throughout the projection period, rising slightly but ultimately declining to a level just below its 2000 value. The rise in the overall total fertility rate is influenced by the current high level of fertility for Hispanics, and their growing share of the population. The decline is due primarily to the projected decline in Hispanic fertility. The projected total fertility rate in 2010 is 2.06, and it is projected to fall to 2.03 by 2050. Mortality is assumed to continue to decline over time. By 2050, life expectancy at birth is assumed to increase to 80.9 for men and 85.3 for women. Net international migration is assumed to increase over the projection period, though not at the rates observed in the 1990's, increasing from 1.3 million per year in 2010 to just over 2.0 million in 2050.

Race and Hispanic origin: Projections are produced by race and Hispanic origin (defined according to the Office of Management and Budget 1997 guidelines). For each of five racial categories (White, Black, American Indian and Alaska Native, Asian, and Native Hawaiian and Other Pacific Islander) the population that would give that response alone and the number that would give it alone or in combination with other races are projected.

For a more detailed discussion of the cohort-component method and the assumptions about the components of population change, see the Population Projections website listed below.

Unit(s) of Analysis: Person-level data analysis

Mode of Data Collection: n/a

Topics / Keywords: Fertility, Immigration/emigration, Life expectancy, Mortality and Race and Hispanic origin

Data Years: 2000–2050

Linked Data: n/a

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Population Projections

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: http://www.census.gov/population/www/projections/2008projections.html*
- *X Some or all public-use files downloadable free from website: http://www.census.gov/population/www/projections/2008projections.html*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Population Projections Branch

E-mail: n/a

Phone: 301–763–2428

Website: http://www.census.gov/population/www/projections/index.html

Survey of Income and Program Participation (SIPP)

Sponsor(s): U.S. Census Bureau

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: To collect source and amount of income, labor force information, program participation and eligibility data, and general demographic characteristics to measure the effectiveness of existing Federal, State, and local programs; to estimate future costs and coverage for government programs, such as food stamps; and to provide improved statistics on the distribution of income in the country. SIPP also offers detailed information on cash and noncash income on a sub-annual basis in addition to collecting data on taxes, assets, liabilities, and participation in government transfer programs.

Survey Universe / Coverage / Census: U.S. civilian noninstitutionalized population

Sample or Research Design: This is a longitudinal survey—a continuous series of national panels.

The SIPP sample is a multistage-stratified sample of the U.S. civilian noninstitutionalized population with sample sizes ranging from approximately 14,000 to 45,000 interviewed households per panel. The duration of each panel ranges from 2½ years to 4 years.

The Census Bureau over sampled the low-income population for the 1996, 2001, 2004, and 2008 Panels using decennial census information. Housing units within each PSU were split into high- and low-poverty strata. If the housing unit received the Census long form that included income questions, the unit's poverty status was determined directly; for other housing units, poverty status was assumed on the basis of responses to Census short-form items predictive of poverty rates.

Unit(s) of Analysis: All household members 15 years old and over are interviewed by self-response; proxy response is permitted when household members are not available for interviewing.

Mode of Data Collection: Most interviews conducted through 1991 were in the form of personal visits. In 1992, SIPP switched to maximum telephone interviewing to reduce costs. Wave 1, 2, and 6 interviews were still conducted in person, but other interviews were conducted by telephone to the extent possible.

With the 2004 and 2008 Panels personal interviews were required for the first interview and maximizing of phone interviews was suggested for subsequent waves. Telephone interviews and personal visits are carried out by the same interviewer interacting with the same respondents. Interviewers typically make phone calls from their homes. For security and confidentiality reasons, they are not allowed to use cellular or cordless telephones in the interviews. If a standard telephone is not available, the interviews must be conducted face-to-face. Repeated unavailability of a respondent by telephone may also require an in-person visit to the listed address.

Topics / Keywords: Income, labor force participation, program participation eligibility.

Data Years: 1983–2009 (to date)

Linked Data: The Census SIPPs are linked to the IRS wage records and 1040SEs and 1040 Tips. These exist for each year from 1982 to most recent year lagged one year. The Social Security earnings are from IRS forms and owned by IRS. They are the employer reported wages and salaries and self-employed reported income subject to taxation by Social Security up to the maximum subject to tax. They exist for each year from 1951 to most recent year lagged one year.

SSA benefit records contain information on Medicare Part A, Part B, and Part D low income subsidy and Medicaid subsidies of Medicare Part B (QMB, SLMB, QI).

Reports: SIPP publications can be found at www.sipp.census.gov/sipp/pubs.html.

Background / History: n/a

Future Plans: SIPP has been an important source of data reflecting the economic well-being of U.S. households over time. However, the length and breadth of the interviews and the longitudinal household design have resulted in ever-increasing number of refusals to participate. Many steps have been taken to curtail attrition, including monetary incentives, but have not been successful in reducing it to an acceptable level. In addition, the complexity of the instrument, has led to long delays before the data can be understood, documented, and finally, disseminated.

In fiscal year 2007, the Census Bureau began planning and development for re-engineering the SIPP program to provide wealth, income, health insurance, and program participation data for the United States. These plans take advantage of the advances that the Census Bureau has made in acquiring and integrating administrative records with survey data in recent years and in modeling for local area estimates.

This re-engineered program will be a collaborative effort among the traditional SIPP stakeholders, such as the Office of Management and Budget, the Social Security Administration, the Department of Health and Human Services, the Department of Agriculture, the Department of Labor, the Small Business Administration, and the Congressional Budget Office. The focus will be on meeting the information needs of policymakers, these agencies, and the research community.

The main activities of the re-engineering process include: (1) improvements in the collection instrument and processing system; (2) development of an Event History Calendar as part of the collection instrument; (3) use of administrative records data to impute and evaluate survey data; (4) development of survey content and use of reimbursable supplements, through interactions with stakeholders.

Bibliography: n/a

Survey of Income and Program Participation (SIPP)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: http://www.census.gov/sipp/*
- *X Some or all public-use files downloadable free from website: http://www.ces.census.gov/*

- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

For the 1984–93 panels, a Panel of households was introduced each year generally in February. A 4-year Panel was introduced in April 1996. A 2000 Panel was introduced in February 2000 for 2 waves. A 3-year 2001 Panel was introduced in February 2001, and a 4 year 2004 Panel was introduced in February 2004. A 2008 Panel was introduced in September of 2008 and planned for collection until December 2012.

Data collected in SIPP and supporting documentation are available in various forms. They include published estimates based on those data, micro data in several formats, documentation for each of the micro data files, and more general documentation about methodological issues in SIPP. The latter includes the SIPP Quality Profile, a series of working papers distributed by the Census Bureau, articles published in academic journals, and conference proceedings.

All public use micro data files can be obtained on CD-ROM directly from the Census Bureau. SIPP micro data are available online from the SIPP website at http://www.census.gov/sipp/. The Internet site offers two data access tools DataFerrett and the SIPP FTP site, DataFerrett is a system that enables users to access and manipulate large demographic and economic data sets on-line. The SIPP FTP site has data files and documentation for downloading.

Cross-sectional data are presented for various socioeconomic characteristics for a 4-month period. Longitudinal data are presented for a 2½-year or 3-year period. Variables for both data sets include age, race, sex, Hispanic origin, marital status, household/family relationship, educational attainment, work experience, and income. Basic cross-sectional questions are supplemented with topically relevant questions such as employment history, work disability, education, health care, financial assets, retirement accounts, etc.

Contact: n/a

E-mail: hhes.sipp.survey@census.gov

Phone: n/a

Website: http://www.sipp.census.gov/sipp/

Department of Health and Human Services

Administration on Aging

Census 2000 Special Tabulation on Aging (STA)

Sponsor(s): Administration on Aging

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: To provide State and area agencies on aging with detailed small-area data from Census 2000 on the number and characteristics of the over (60+) population.

The Special Tabulation on Aging (STA) is a set of 116 population tables and 69 housing and household tables that were tabulated by the Census Bureau for AoA from the Census 2000 sample ("long form") data. The topics covered in these tabulations include age, sex, race, Hispanic or Latino origin, marital status, income, poverty, disability, and much more. This tabulation provides much more detail on the older population (60+) than is available from other Census sources.

The data are organized by individual tables. Each table includes data for a State (including the District of Columbia and Puerto Rico) and data are shown for a number of geographical levels: United States (50 States +DC), State, Planning and Service Area (PSA—the geographic area served by a single area agency on aging), county, county subdivision in 12 States with a population of 2,500 or more, place with a population of 2,500 or more, census tract, as well as American Indian and Alaska Native areas. Also, the urban and rural components of States and PSAs are shown.

Survey Universe / Coverage / Census: n/a

Sample or Research Design: Census 2000 sample

Unit(s) of Analysis: Persons 60 and over

Mode of Data Collection: Census "long form"

Topics / Keywords: Marital status, income, poverty, disability

Data Years: 2000

Linked Data: n/a

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Census 2000 Special Tabulation on Aging

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: **http://www.aoa.gov/AoARoot/Aging_Statistics/Tab/specialtab.aspx***
- *☐ Some or all public-use files downloadable free from*
- *☐ Data available for free upon order from agency.*
- *☐ Application process required to obtain some data files*
- *☐ Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *☐ Application process required to obtain data files*
- *☐ Use of Research Data Center required for access to restricted-use data*
- *☐ Payment required for the preparation / supply of data*

Additional Information:

The data of the Special Tabulation on Aging along with documentation are available on the AoA website listed above.

Contact: Saadia Greenberg
E-mail: Saadia.Greenberg@aoa.hhs.gov
Phone: 202–357–3554
Website: http://www.aoa.gov/AoARoot/Aging_Statistics/Tab/specialtab.aspx

Agency for Healthcare Research and Quality

Healthcare Cost and Utilization Project (HCUP)

Sponsor(s): Agency for Healthcare Research and Quality, Center for Delivery, Organization, and Markets

Data Collection Agency: A Federal-State-Industry partnership sponsored by the Agency for Healthcare Research and Quality

Purpose / Primary Goals: The Healthcare Cost and Utilization Project (HCUP) is a federally-funded project that builds on the efforts of State data organizations, hospital associations, and private data organizations to create a national resource of health care data. HCUP maintains the largest collection of longitudinal, all-payer hospital care databases in the United States, enabling research on a broad range of health policy issues.

The HCUP is a family of health care databases and related software tools and products. HCUP databases are made possible through voluntary efforts of State data organizations, hospital associations, and private data organizations to create a national information resource of encounter-level health care data. HCUP administrative data includes all payer types (i.e., data on services received by all, regardless of who paid for the service), and goes back to 1988 in some States.

The databases enable research on a broad range of health policy issues, including cost and quality of health services, medical practice patterns, patient safety, access to health care programs, and outcomes of treatments at the national, State, and local market levels.

Because of their large size and scope, HCUP databases enable unique analyses: they include information on specific medical conditions and procedures (including rare events); they are useful in tracking utilization for population subgroups, such as minorities, children, women, and the uninsured; and they can be employed to analyze different geographic levels (national, regional, State, and community) within the United States. To augment the HCUP databases, AHRQ has developed publicly available software tools and Web-based products that can be used by audiences with varying levels of research experience.

HCUP also produces statistics based on the AHRQ Quality Indicators (QIs) that have been applied to the HCUP Nationwide Inpatient Sample (NIS). These statistics provide insight into potential quality of care problems. The AHRQ Quality Indicators are measures of health care quality that make use of readily available hospital inpatient administrative data. The four modules include: Prevention Quality Indicators that identify hospital admissions that evidence suggests could have been avoided, at least in part, through high-quality outpatient care; Inpatient Quality Indicators that reflect quality of care inside hospitals including inpatient mortality for medical conditions and surgical procedures; Patient Safety Indicators that reflect quality of care inside hospitals but focus on potentially avoidable complications and iatrogenic events; and Pediatric Quality Indicators (PDIs) that can be used with hospital inpatient discharge data to provide a perspective on the quality of pediatric healthcare. Specifically, PDIs screen for problems that pediatric patients experience as a result of exposure to the healthcare system and that may be amenable to prevention by changes at the system or provider level.

Survey Universe / Coverage / Census: All-payer community hospitals in the U.S.

Sample or Research Design: The Nationwide Inpatient Sample (NIS) is a database of hospital inpatient stays. Researchers and policymakers use the NIS to identify, track, and analyze national trends in health care utilization, access, charges, quality, and outcomes. It is the largest all-payer inpatient care database in the United States containing data from approximately 8 million hospital stays per year. The sampling frame for the NIS is a sample of hospitals that comprises approximately 90 percent of all hospital discharges in the United States. The number of States in the NIS has grown from 8 in the first year to 40 currently. NIS is the only national hospital database with charge information on all patients, regardless of payer, including persons covered by Medicare, Medicaid, private insurance, and the uninsured. Its large sample size enables analyses of rare conditions, such as congenital anomalies; uncommon treatments, such as organ transplantation; and special patient populations, such as children.

The Kids' Inpatient Database (KID) is a nationwide sample of pediatric inpatient discharges and was specifically designed to permit researchers to study a broad range of conditions and procedures related to child health issues. The 2006 KID contains data drawn from 38 State Inpatient Databases and includes 2-3 million hospital discharges for children 0 to 20 years of age. The sample of pediatric discharges comes from between 2,500 to 4,000 U.S. community hospitals (defined as short-term, non-Federal, general and specialty hospitals, excluding hospital units of other institutions). The KID's large sample size enables analyses of both common and rare conditions such as congenital anomalies, uncommon treatments, and organ transplantation. The data includes charge information on all patients, including children covered by Medicaid, private insurance, and the uninsured.

The State Inpatient Databases (SID) contain the universe of inpatient discharge abstracts from participating States. The data are transformed into a uniform format to facilitate multi-State comparisons and analyses. Together, the SID encompasses about 90 percent of all U.S. community hospital discharges. Some States include discharges from specialty facilities, such as acute psychiatric hospitals. The SID contain a core set of clinical and non-clinical information on all patients, regardless of payer, including persons covered by Medicare, Medicaid, private insurance, and the uninsured. In addition to the core set of uniform data elements common to all SID, some include other elements, such as the patient's race.

The State Ambulatory Surgery Databases (SASD) contain data from ambulatory care encounters from hospital-affiliated and sometimes freestanding ambulatory surgery sites. The SASD databases capture surgeries performed on the same day in which patients are admitted and discharged. The data represent ambulatory surgery encounters in non-inpatient health care settings such as ambulatory surgery centers, freestanding clinics, and hospital outpatient departments from States selected by AHRQ.

The Nationwide Emergency Department Sample (NEDS) is a unique and powerful database that yields national estimates of emergency department (ED) visits. The NEDS was created to enable analyses of emergency department (ED) utilization patterns and support public health professionals, administrators, policymakers, and clinicians in their decision-making regarding this critical source of care. The NEDS was constructed using records from both the HCUP State Emergency Department Databases (SEDD) and the State Inpatient Databases (SID). The SEDD capture information on ED visits that do not result in an admission (i.e. treat-and-release visits and transfers to another hospital). The SID contain information on patients initially seen in the emergency room and then admitted to the same hospital. The NEDS contains almost 26 million (unweighted) records for ED visits for over 950 hospitals and approximates a 20-percent stratified sample of U.S. hospital-based EDs. The NEDS contains clinical and resource use information included in a typical discharge abstract, with safeguards to protect the privacy of individual patients, physicians, and hospitals (as required by data sources). The NEDS can be weighted to produce national estimates. The NEDS excludes data elements that could directly or indirectly identify individuals, hospitals, or states. Purchase of the NEDS beginning in 2006 is open to all users who sign a Data Use Agreement.

The State Emergency Department Databases (SEDD) contain data from hospital-affiliated emergency departments for visits that do not result in hospitalizations. The SEDD are designed to allow analyses of such emergency department-related concerns such as patient flow, access to care, and practice variations in emergency department care settings.

Unit(s) of Analysis: NIS: hospital inpatient stays; KID: pediatric inpatient discharges; SID: inpatient discharges; SASD: ambulatory care encounters; SEDD: hospital-affiliated emergency department visits; NEDS: emergency department visits from the SID that resulted in an admission and the emergency visits from the SEDD that did not result in admission.

Mode of Data Collection:Administrative records

Topics / Keywords: Health statistics, Health care utilization, Health care access, Health care charges, Quality of care, Health care outcomes, Health insurance, Illnesses, Organ transplantation, Hospital inpatient stays, Inpatient discharges, Pediatric inpatient discharges, Ambulatory care, Emergency room visits

Data Years: NIS (starting in 1988), KID (starting in 1997), NEDS (starting in 2006), SID (starting in 1995), SASD (starting in 1997), SEDD (starting in 1999)

Linked Data: NIS includes hospital identifiers that permit linkages to the American Hospital Association's database and county identifiers that permit linkages to the Area Resource File.

Reports: HCUP Methods Series features a broad array of methodological information on the HCUP databases and software tools. Reports in the HCUP Methods Series (http://www.hcup-us.ahrq.gov/reports/methods.jsp) are listed in chronological order.

HCUP Database Reports are specific to the design and use of the HCUP databases.

- Nationwide Inpatient Sample (NIS) reports
- Kids' Inpatient Database (KID) reports
- Nationwide Emergency Department Sample (NEDS) reports
- State Inpatient Databases (SID) reports
- State Ambulatory Surgery Databases (SASD) reports
- State Emergency Department Databases (SEDD) reports

New Findings and Publications based on HCUP data are available within the HCUP section of the AHRQ website (http://www.AHRQ.gov/data/). Publications are listed by author. Information includes title, publication, data, and sometimes access to an abstract. A comprehensive list of AHRQ publications is also available on the AHRQ website (http://www.ahrq.gov/).

HCUP Statistical Briefs present simple, descriptive statistics on a variety of specific, focused topics. Statistical Briefs (http://www.hcup-us.ahrq.gov/reports/statbriefs.jsp) are listed in chronological order.

HCUP Highlights illustrate key findings from the HCUP databases.

- Economic and Health Costs of Diabetes
- Evaluation Report
- The Value of Hospital Discharge Data

Background / History: http://www.hcup-us.ahrq.gov/

Future Plans: n/a

Bibliography: http://www.hcup-us.ahrq.gov/reports.jsp

Healthcare Cost and Utilization Project (HCUP)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: **http://hcupnet.ahrq.gov***
- *☐ Some or all public-use files downloadable free from website*
- *☐ Data available for free upon order from agency. Order from website*
- *X Application process required to obtain some data files*
- *X Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *☐ Application process required to obtain data files*
- *☐ Use of Research Data Center required for access to restricted-use data*
- *☐ Payment required for the preparation / supply of data*

Additional Information:

Contact: HCUP User Support at: http://www.hcup-us.ahrq.gov/techassist.jsp
Email: hcup@ahrq.gov
Phone: 1–866–290-HCUP
Website: http://www.ahrq.gov/data/hcup/

Medical Expenditure Panel Survey (MEPS)

Sponsor(s): Agency for Healthcare Research and Quality, National Center for Health Statistics

Data Collection Agency: Westat, U.S. Census Bureau

Purpose / Primary Goals: The MEPS is conducted to provide nationally representative estimates of health care use, health care expenditures, sources of payment, health insurance coverage and health status for the U.S. civilian noninstitutionalized population. The MEPS comprise three component surveys: the Household Component (HC), the Medical Provider Component (MPC), and the Insurance Component (IC). The Household Component is the core survey and it forms the basis for the MPC sample. Together these surveys yield comprehensive data that provide national estimates of the level and distribution of health care use and expenditures, support health services research, and can be used to inform health care policy. The MEPS was initiated in 1996 and is a continuous ongoing survey. MEPS predecessor surveys were conducted in 1987 and 1977.

The 1996 MEPS also included a nationally representative sample of nursing homes and persons who were nursing home residents at any time during 1996. Details on the Nursing Home Component (NHC) are provided on the MEPS website.

Survey Universe / Coverage / Census: U.S. civilian noninstitutionalized population (MEPS HC).

Sample or Research Design: The MEPS Household Component (HC) sample is drawn from respondents to the National Health Interview Survey (NHIS) conducted by the National Center for Health Statistics (NCHS). The MEPS HC uses an overlapping panel design in which data are collected through a series of five rounds of interviews over a 2½ -year period. This series of data collection rounds is launched each subsequent year on a new sample of households to provide two overlapping panels of survey data for current annual estimates of health care expenditures and other key estimates. Each annual sample size is about 15,000 households; the sample size of persons age 65 and over is approximately 4,000 (for the 2001 MEPS and in subsequent years).

A number of quality-related enhancements were made to the MEPS beginning in 2000, including the fielding of an annual self-administered questionnaire (SAQ). This questionnaire contains items on patient satisfaction and accountability measures from the Consumer Assessment of Healthcare Providers and Systems (CAHPS®; previously known as the Consumer Assessment of Health Plans), the SF-12 physical and mental health assessment tool, EQ-5D EuroQol 5 dimensions with visual scale (2000-03), and several attitude items. Starting in 2004 the K-6 Kessler mental health distress scale and the PH2 two-item depression scale were added to the SAQ.

The MEPS Insurance Component (IC) is an annual panel survey that collects data on health insurance plans obtained through employers, unions, and other sources of private health insurance. Information on premiums, deductible and co-payment provisions, and distributions of premiums and costs across payers are obtained. The MEPS IC supports estimation at the national and State levels.

The primary purpose of the Medical Provider Component (MPC) is to collect detailed charge and payment data from hospitals, physicians, home health care providers, and pharmacies to supplement/replace information received from MEPS HC respondents to aid in the estimation of health care expenses.

Unit(s) of Analysis: HC: person-level, family-level, event-level, insurance unit-level; IC: establishment-level.

Mode of Data Collection: HC: computer-assisted personal interview (CAPI); IC: telephone interview, mail questionnaire, telephone followup for nonrespondents; MPC: telephone interview and mailed survey materials.

Data Years: Ongoing since 1996, predecessor surveys conducted in 1977 and 1987

Linked Data: For approved Data Center projects MEPS data can be linked to secondary data files at the state, county, and Zip Code level, including linkage to the Area Resources File. For 1987 and 1996 analytic files marginal tax rates are available. For 1996–99 linked HC-IC data are available. Researchers with approved Data Center projects can also supply their own data to be merged with AHRQ MEPS data.

A file containing a cross-walk to link each MEPS panel to the previous year's National Health Interview Survey Public Use File is available upon request from AHRQ.

Reports: For copies of data products and reports, see the MEPS website. Selected MEPS data products are available from the AHRQ Publications Clearinghouse, phone: 1–800–358–9295; outside the United States: 703–437––2078; TDD for the hearing impaired, toll free: 888–586–6340. Address: P.O. Box 8547, Silver Spring, MD 20907.

Background / History: http://www.meps.ahrq.gov/mepsweb/about_meps/survey_back.jsp

Future Plans: Ongoing longitudinal data collection and dissemination will continue

Bibliography: http://www.meps.ahrq.gov/mepsweb/data_stats/publications.jsp

Medical Expenditure Panel Survey (MEPS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website:* ***http://www.meps.ahrq.gov/mepsweb/data_stats/meps_query.jsp***
- *X Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency. Order from*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- *X Use of Research Data Center required for access to restricted-use data. Website:* ***http://www.meps.ahrq.gov/mepsweb/data_stats/onsite_datacenter.jsp***
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

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Website: http://www.meps.ahrq.gov/mepsweb

Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion

Behavioral Risk Factor Surveillance System (BRFSS)

Sponsor(s): Centers for Disease Control and Prevention (CDC)

Data Collection Agency: State-based systems

Purpose / Primary Goals: The Behavioral Risk Factor Surveillance System (BRFSS) is designed to collect State-specific general population data on behaviors that are related to the leading causes of morbidity and mortality. States use BRFSS data to identify emerging health problems, establish and track health objectives, and develop and evaluate public health policies and programs. Because comparable methods are used from State to State and from year to year, States can compare risk factor prevalence with other States and monitor the effects of interventions over time. Also, the use of consistent methods in a large group of States permits the assessment of geographic patterns of risk factor prevalence. BRFSS data also can be used to examine smaller geographic areas within States. For example, CDC has analyzed BRFSS data starting in 2002 for many metropolitan and micropolitan statistical areas, and some counties within those areas for a project called Selected Metropolitan/Micropolitan Area Risk Trends (SMART) BRFSS. States and local health departments rely on data from the BRFSS to:

- Determine high-priority health issues and identify populations at highest risk for illness, disability, and death by analyzing data according to respondents' age, sex, education, income, and race/ethnicity.
- Develop strategic plan and targeted prevention activities and programs.
- Examine trends in behaviors over time to monitor the effectiveness of public health programs and progress in meeting prevention goals, such as Healthy People 2010 Objectives.
- Support community policies and programs that promote health and prevent disease—for example, by educating the public, the health community, and policymakers about disease prevention.

Survey Universe / Coverage / Census: State-based general adult (18 years or older) population; data collected each month throughout the calendar year in all 50 States, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam, with assistance from CDC

Sample or Research Design: The BRFSS questionnaire comprises of core questions and optional modules. There are three types of core questions. Fixed core questions are asked every year. Rotating core questions are asked every other year. Emerging core questions typically focus on "late-breaking" health issues. These questions are evaluated at the end of a survey year to determine if they are valuable. If the coordinators decide to keep the questions, they are added to the fixed core, rotating core, or optional modules, whichever is most appropriate. All states must ask all core questions. The optional modules are standardized questions that are supported by the CDC that cover additional health topics or are more detailed questions on a health topic included in the core. Each year states must choose which optional modules they will use based on the data needs of their state.

Unit(s) of Analysis: State-level

Mode of Data Collection: Telephone interview

Topics / Keywords: Health behaviors, Health conditions, Health objectives, Health problems (emerging), Longitudinal data, Morbidity (leading causes of), Mortality (leading causes of), Quality improvement and Risk factors

Data Years: Yearly since 1984

Linked Data: n/a

Reports: Surveillance summaries and other relevant reports and information can be accessed at http://www.cdc.gov/brfss/pubs/index.htm.

Background / History: By the early 1980s, scientific research clearly showed that personal health behaviors played a major role in premature morbidity and mortality. Although national estimates of health risk behaviors among U.S. adult populations had been periodically obtained through surveys conducted by the National Center for Health Statistics (NCHS), these data were not available on a state-specific basis. This deficiency was viewed as critical for state health agencies that have the primary role of targeting resources to reduce behavioral risks and their consequent illnesses. National data may not be appropriate for any given state; however, state and local agency participation was critical to achieve national health goals.

About the same time as personal health behaviors received wider recognition in relation to chronic disease morbidity and mortality, telephone surveys emerged as an acceptable method for determining the prevalence of many health risk behaviors among populations. In addition to their cost advantages, telephone surveys were especially desirable at the state and local level, where the necessary expertise and resources for conducting area probability sampling for in-person household interviews were not likely to be available.

As a result, surveys were developed and conducted to monitor state-level prevalence of the major behavioral risks among adults associated with premature morbidity and mortality. The basic philosophy was to collect data on actual behaviors, rather than on attitudes or knowledge, that would be especially useful for planning, initiating, supporting, and evaluating health promotion and disease prevention programs.

To determine feasibility of behavioral surveillance, initial point-in-time state surveys were conducted in 29 states from 1981–1983. In 1984, The Centers for Disease Control and Prevention (CDC) established the Behavioral Risk Factor Surveillance System (BRFSS), and 15 states participated in monthly data collection. Although the BRFSS was designed to collect state-level data, a number of states from the outset stratified their samples to allow them to estimate prevalence for regions within their respective states.

CDC developed standard core questionnaire for states to use to provide data that could be compared across states. The BRFSS, administered and supported by the Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, CDC, is an ongoing data collection program. By 1994, all states, the District of Columbia, and three territories were participating in the BRFSS. Further information on the history of BRFSS can be found at: http://www.cdc.gov/BRFSS/history.htm

Future Plans: States and urban areas will continue to rely on the BRFSS to gather the high quality data they need to plan and evaluate public health programs and to allocate scarce resources. CDC will work closely with State and Federal partners to ensure that the BRFSS continues to provide data that are useful for public health research and practice and for State and local health policy decisions.

Bibliography:

http://apps.nccd.cdc.gov/BRFSSBib/index.asp

Behavioral Risk Factor Surveillance System (BRFSS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: **http://www.cdc.gov/brfss/***
- *X Some or all public-use files downloadable free from website: **http://www/cdc.gov/brfss/***
- *☐ Data available for free upon order from agency. Order from website*
- *☐ Application process required to obtain some data files*
- *☐ Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *☐ Application process required to obtain data files*
- *☐ Use of Research Data Center required for access to restricted-use data.*
- *☐ Payment required for the preparation / supply of data*

Additional Information:

Surveillance summaries and other relevant reports and information can be accessed at http://www.cdc.gov/brfss/pubs/index.htm

Contact: BRFSS State Coordinator at: http://apps.nccd.cdc.gov/BRFSSCoordinators/coordinator.asp

Email: ccdinfo@cdc.gov

Phone: 770–488–2455

Website: http://www.cdc.gov/brfss

National Center for Health Statistics

Longitudinal Studies of Aging (LSOAs)

Sponsor(s): National Center for Health Statistics (NCHS), National Institute on Aging (NIA)

Data Collection Agency: U.S. Census Bureau and National Opinion Research Center at the University of Chicago

Purpose / Primary Goals: 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 project comprises of four surveys: the 1984 Supplement on Aging, the 1984–1990 Longitudinal Study of Aging, the 1994 Second Supplement on Aging, and the 1994–2000 Second Longitudinal Study of Aging. An overview of each survey is provided below.

Supplement on Aging (SOA)

The SOA was conducted as part of the 1984 National Health Interview Survey (NHIS). The sample is comprised of 16,148 persons 55 years of age and over who were living in the community at the time of the interview. All interviews for this cross-sectional survey were conducted in person by the U.S. Census Bureau. The following topics were covered in the questionnaire:

- 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 (LSOA)

The 1984 SOA served as the baseline for the LSOA, which followed all persons who were 70 years of age and over in 1984 (n=7,527) through three follow-up waves, conducted in 1986, 1988, and 1990. Follow-up interviews were conducted over the telephone by interviewers from the U.S. Census Bureau. The major focus of the 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.

Second Supplement on Aging (SOA II)

The SOA II was conducted as part of the 1994 NHIS. Interviews 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 (LSOA II)

The SOA II serves as the baseline for the LSOA II. The LSOA II followed all 9,447 sample persons through two additional interviews, conducted in 1997–98 and 1999–2000. Follow-up interviews were conducted over the telephone by the National Opinion Research Center at the University of Chicago. The survey design and content of the LSOA II are similar to the first LSOA with improvements and enhancements reflecting the methodological and conceptual developments that have occurred during the intervening decade. The LSOA II data, when used in conjunction with data from the original LSOA, enables researchers to determine whether the prevalence and incidence of functioning, pathology, and impairments in the elderly population have changed over 10 years and whether the change is due to differences in cohort characteristics or to technological and medical advancements. 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.

The 1994–2000 LSOA II interview data have been linked with administrative data from NCHS' National Death Index and multiple cause of death files, with the Centers for Medicare & Medicaid Services, Medicare enrollment and claims data files, and with the Social Security Administration's benefit records.

Survey Universe / Coverage / Census: U.S. civilian non-institutionalized population age 55 years and over (SOA), age 70 years and over (LSOA, SOA II, LSOA II)

Sample or Research Design: The design of the LSOAs is similar to that of the NHIS, from which the baseline samples were drawn. The NHIS relies on a multistage complex sample design, interviewing throughout the year, and personal interviews. Baseline data for the surveys (SOA and SOA II) are cross-sectional household interviews. The LSOA and LSOA II incorporate follow-up interviews conducted via telephone.

Unit(s) of Analysis: Person-level

Mode of Data Collection: In-person (SOA, SOA II), telephone (LSOA, LSOA II)

Topics / Keywords: Functioning, health, aging, longitudinal

Data Years: 1984 (SOA), 1984–1990 (LSOA), 1994 (SOA II) and 1994–2000 (LSOA II)

Linked Data: LSOA II data have been linked to the: National Death Index Mortality Data (1999–2006), Medicare Enrollment and Claims data (CMS-1991–2007), and SSA-RSDI (1962–2003) and SSA-SSI (1974–2007) benefit data. More information about the LSOA II data linkage projects mentioned above and availability of resulting data files may be obtained online from the NCHS Data Linkage Activities website. Interested users are directed to http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm.

Reports: Detailed descriptions of the LSOA survey are published in reports of the Vital and Health Statistics, Series 1, Number 21 and Number 28. The LSOA questionnaires are provided in Appendices III-V of Series 1, Number 28. All LSOA II documentation is available online at http://www.cdc.gov/nchs/lsoa.htm.

Documentation associated with the linked data files is available at http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm.

Future Plans: Data collection for the LSOA cohort is complete. While active data collection of the LSOA II cohort is complete, passive follow up with administrative data sources continues, with periodic release of linked data files, documentation and research are ongoing. Users will find updated items at the LSOAs website: http://www.cdc.gov/nchs/lsoa.htm

Bibliography: n/a

Background / History: n/a

Longitudinal Studies of Aging (LSOAs)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website:* ***http://www.cdc.gov/nchs/lsoa.htm***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- X *Use of Research Data Center required for access to restricted-use data*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

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Health Data Interactive (HDI)

Sponsor(s): National Institute on Aging, National Center for Health Statistics

Data Collection Agency: National Center for Health Statistics; Center for Medicare and Medicaid Services

Purpose / Primary Goals: The National Center for Health Statistics has combined two interactive, web-based applications, Health Data for All Ages and Trends in Health and Aging, to create a new site (http://www.cdc.gov/nchs/hdi.htm). Most of the table topics and many of the previous tables will continue to be featured on HDI. Where possible, age groups have been expanded and the depth of demographic detail increased.

Survey Universe / Coverage / Census: Varies by survey

Sample or Research Design: Varies by survey

Unit(s) of Analysis: Varies by survey

Mode of Data Collection: Varies by survey

Topics / Keywords: Functional status, Health care use and expenditures, Health conditions, Health insurance and access, Mortality, Life expectancy, Pregnancy and birth, and Risk factors and disease prevention

Data Years: n/a

Linked Data: n/a

Reports: n/a

Background / History: n/a

Future Plans: HDI will continue to provide data updates to the various tables as available. New tables will be added as resources allow.

Bibliography: n/a

Health Data Interactive (HDI)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- X *User-specified online data query or table generation possible. Website: http://www.cdc.gov/nchs/hdi.htm*
- X *Some or all public-use files downloadable free.*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
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Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

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Website: http://www.cdc.gov/nchs/hdi.htm

National Ambulatory Medical Care Survey (NAMCS)

Sponsor(s): National Center for Health Statistics, Division of Health Care Statistics (DHCS)

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The National Ambulatory Medical Care Survey (NAMCS) collects data on the utilization and provision of medical care services at visits to office-based physicians. Data are collected on type of providers seen; reason for visit; diagnoses; drugs ordered, provided, or continued; diagnostic and screening services, and therapeutic services ordered or provided during the visit, as well as other visit characteristics. Patient data include age, sex, race, and expected source of payment. Data are also collected on selected characteristics of physicians included in the survey.

Survey Universe / Coverage / Census: The survey is a representative sample of visits to nonfederally employed office-based physicians, not including anesthesiologists, radiologists, or pathologists, who are primarily engaged in direct patient care. Telephone contacts are excluded.

Sample or Research Design: Census field representatives contact sample physicians to determine if they are eligible for survey participation. Visits to eligible physicians are systematically sampled over a 1-week reporting period such that about 30 encounters are selected.

Mode of Data Collection: Physicians are asked to complete Patient Record Forms (PRF) for each sampled visit, but Census field representatives typically abstract data for about thirty percent of these visits.

Unit(s) of Analysis: Visit-level and physician-level.

Topics / Keywords: Medical care, Physician visits, Diagnoses and Prescription drugs

Linked Data: Restricted NAMCS data contain geographical variables such as patient ZIP code and State and county codes. These variables can be linked to other data sources such as U.S. Census Bureau data and the Health Resources and Services Administration's Area Resource File, a national county-level health resources information system, in order to do contextual analysis. Such linking can only be done at NCHS' Research Data Center.

Data Years: 1973–2007

Reports: A list of reports using NAMCS data is available at: http://www.cdc.gov/nchs/ahcd.htm

Background / History: n/a

Future Plans: The NAMCS PRF is modified approximately every 2 years to reflect changes in physician practice characteristics, patterns of care, and technological innovations. Examples of recent changes are the number of drugs recorded on the PRF, and checkboxes of specific tests or procedures performed. Added for the first time in 2006 were a sample of community health centers, a sample of oncologists, and a cervical cancer screening supplement.

Bibliography: A list of publications using NAMCS data is available at: http://www.cdc.gov/nchs/ahcd.htm

National Ambulatory Medical Care Survey (NAMCS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: **http://www.cdc.gov/nchs/ahcd.htm***
- ☐ *Data available for free upon order from agency.*
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Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- X *Use of Research Data Center required for access to restricted-use data Website: **http://www.cdc.gov/nchs/r&d/rdc.htm***
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Annual data collection began in 1973 and continued through 1981. The survey was next conducted in 1985, and resumed an annual schedule in 1989. National and regional (four Census regions) estimates are available.

Public-use data files are available for 1973–2007. In addition, SAS program code is available for survey years 1993–2007; SPSS and Stata code are available for 2002–2006. Data for 1990–2005 are also available on CD-ROM with Statistical Export and Tabulation System (SETS) retrieval software.

Email: nchsquery@cdc.gov

Phone: 1–866–441-NCHS (6247)

Website: http://www.cdc.gov/nchs/ahcd.htm

National Death Index (NDI)

Sponsor(s): National Center for Health Statistics Division of Vital Statistics

Data Collection Agency: National Vital Statistics System

Purpose / Primary Goals: The National Death Index (NDI) is a central computerized index of death record information on file in the State vital statistics offices. Working with these State offices, NCHS established the NDI as a resource to aid epidemiologists and other health and medical investigators with their mortality ascertainment activities. Investigators conducting prospective and retrospective studies can use the NDI to determine whether persons in their studies may have died and to obtain the underlying and multiple causes of death in coded form (for the more probable matches).

It is available to investigators solely for statistical purposes in medical and health research. Not accessible to organizations or the general public for legal, administrative, or genealogy purposes.

Survey Universe / Coverage / Census: Deaths in United States of U.S. residents

Sample or Research Design: n/a

Unit(s) of Analysis: n/a

Mode of Data Collection: A national file of identifying death record information (beginning with 1979 deaths) is compiled from computer files submitted by State vital statistics offices to NCHS' Division of Vital Statistics. Death records are added to the NDI file annually, approximately 12 months after the end of a particular calendar year.

Topics / Keywords: Death and Mortality

Data Years: The NDI currently contains death records from 1979–2006. Death records are added to the NDI file annually, approximately 12–15 months after the end of a particular calendar year. Deaths for 2007 should be available in Fall 2009.

Linked Data: n/a

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

National Death Index (NDI)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data*
- X *Payment required for the preparation / supply of data*

Additional Information:

Refer to the NDI matching criteria (http://www.cdc.gov/nchs/data/ndi/NDICriteria_front.pdf) to see how records are selected as possible matches. NDI users are encouraged to submit as many of the following data items as possible for each study subject: first and last name, middle initial, father's surname, social security number, month, day, and year of birth, race, sex, marital status, State of residence, and State of birth.

Refer to the NDI retrieval report (http://www.cdc.gov/nchs/data/NDI_Retrieval_Back.pdf) for a sample of how possible matches are presented.

Investigators can then make arrangements with the appropriate State offices to obtain copies of death certificates or specific statistical information such as cause of death. Investigators can also obtain cause of death codes directly using the NDI Plus service.

To use the system, investigators first must submit a NDI application form to NCHS. Applicants should allow about 2 months for their applications to be reviewed and approved. Once approved, users may submit their study subjects' names, social security numbers, dates of birth, and related information to NCHS on diskette or CD-ROM.

Contact: n/a

Email: ndi@cdc.gov

Phone: 301–458–4444

Website: http://www.cdc.gov/nchs/ndi.htm

National Health and Nutrition Examination Survey (NHANES)

Sponsor(s): National Center for Health Statistics, Division of Health and Nutrition Examination Surveys

Data Collection Agency: Westat

Purpose / Primary Goals: NHANES is designed to assess the health and nutritional status of the U.S. noninstitutionalized civilian population through direct physical examinations, laboratory tests, and interviews. NHANES collects data on the prevalence of selected disease and risk factors, as well as a range of other topics.

Survey Universe / Coverage / Census: NHANES I included the civilian noninstitutionalized population 1 year of age and over residing in the contiguous United States, except for people residing on any of the reservation lands set aside for the American Indians. NHANES II targeted the civilian noninstitutionalized population 6 months of age and over residing in the United States, including Alaska and Hawaii. The Hispanic Health and Nutrition Examination Survey (HHANES) included three geographically and ethnically distinct populations: Mexican Americans living in Texas, New Mexico, Arizona, Colorado, and California; Cuban Americans living in Dade County, Florida; and Puerto Ricans living in parts of New York, New Jersey, and Connecticut. NHES I, NHANES I, and NHANES II collected information on persons up to 74 years of age. NHANES III and later surveys include people age 75 years and over. In addition, NHANES III and continuous NHANES (1999 and later) provide estimates for the civilian noninstitutionalized population 2 months of age and over in the United States.

Sample or Research Design: This is a cross-sectional survey first conducted in 1960, and has been conducted continuously since 1999. In 1971, the nutritional surveillance component was added, and the survey changed from NHES (National Health Examination Survey) to NHANES.

The survey for the NHANES III was conducted from 1988 to 1994 and consisted of two phases of equal length and sample size. Phase 1 and Phase 2 comprised random samples of the civilian U.S. population living in households. About 40,000 persons 2 months of age and over were selected and asked to complete an extensive interview and an examination. Participants were selected from households in 81 counties across the United States. Children aged 2 months to 5 years and persons 60 years of age and over were oversampled to provide precise descriptive information on the health status of selected population groups of the United States. Beginning in 1999 NHANES oversampled low-income persons, adolescents 12–19 years of age, persons 60 years of age and over, African Americans, and Mexican Americans. The sample is not specifically designed to give a nationally representative sample for the total population of Hispanics residing in the United States.

Over the 6-year survey period of NHANES III, 39,695 persons were selected, the household interview response rate was 86 percent, and the medical examination response rate was 78 percent. In the sample selection for NHANES 1999–2000, there were 22,839 dwelling units screened. Of these, 6,005 households had at least one eligible sample person identified for interviewing. A total of 12,160 eligible sample persons were identified. The overall response rate in NHANES 1999–2000 for those interviewed was 81.9 percent (9,965 of 12,160), and the response rate for those examined was 76.3 percent (9,282 of 12,160). For NHANES 2001–2002 there were 13,156 persons selected in the sample, of which 83.9 percent (11,039) were interviewed and 79.7 percent (10,480) of the 13,156 selected completed the health examination component of the survey.

Unit(s) of Analysis: Person-level data analysis.

Mode of Data Collection: The NHANES includes clinical examinations and selected medical and laboratory tests that are conducted in mobile examination centers (MECs). Prior to 2003, a small number of participants who were unable to come to the MEC received an abbreviated health examination in their homes. In addition, in-home personal interviews are conducted.

Topics / Keywords: Cardiovascular disease, diabetes, environmental exposures, hearing loss, infectious disease, kidney disease, mental health, cognitive functioning, nutrition, obesity, oral health, osteoporosis, physical fitness, physical functioning, reproductive history, sexual behavior, respiratory disease, sexually transmitted diseases, vision.

Data Years: Data have been collected from surveys conducted during 1960–62 (NHES I), 1963–65 (NHES II), 1966–70 (NHES III), 1971–74 (NHANES I), 1976–80 (NHANES II), 1982–84 (HHANES), and 1988–94 (NHANES III). Beginning in 1999, the survey has been conducted continuously.

Linked Data: NCHS has conducted a linkage of NHANES I Epidemiologic Followup Study (NHEFS) with the NCHS National Death Index (NDI). The NHEFS is a longitudinal follow-up study of the adult participants from the first National Health and Nutrition Examination Survey (NHANES I) and includes all participants 25–74 years of age who completed a medical examination during the NHANES I survey period between 1971 and 1975. A linkage is available of the Second National Health and Nutrition Examination Survey (NHANES II) with the NCHS National Death Index (NDI). The NHANES II mortality linkage includes information on 9,252 participants 30–75 years of age who completed a medical examination during the NHANES II survey period between 1976 and 1980. Finally, there is a mortality linkage of the Third National Health and Nutrition Examination Survey (NHANES III) with the NDI. The NHANES III linked mortality file provides mortality follow-up data from the date of NHANES III survey participation (1988–94) through December 31, 2006. NHANES 1999–2004 data have been linked with mortality files through December 31, 2006.

Reports:

- Surveillance for Dental Caries, Dental Sealants, Tooth Retention, Edentulism, and Enamel Fluorosis—United States, 1988–94 and 1999–2002
- Lower Extremity Disease Among Persons Aged greater than/equal to 40 Years With and Without Diabetes—United States, 1999–2002
- Mobility Limitation Among Persons Aged greater than/equal to 40 Years With and Without Diagnosed Diabetes and Lower Extremity Disease—United States, 1999–2002
- Blood Lead Levels—United States, 1999–2002
- Children and Teens Told by Doctors That They Were Overweight—United States, 1999–2002
- DHHS-USDA Dietary Survey Integration—What We Eat In America
- National Center for Environmental Health's Third National Report on Human Exposure to Environmental Chemicals
- Healthy Eating Index, USDA Center for Nutrition Policy and Promotion

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

National Health and Nutrition Examination Survey (NHANES)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website:* ***http://www.cdc.gov/nchs/nhanes.htm***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- X *Use of Research Data Center required for access to restricted-use data. Website:* ***http:// http://www.cdc.gov/nchs/nhanes/genetics/genetic.htm****. Data linkage information at:* ***http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm***
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

National-level data are available and are released in 2 year cycles (1999–2000; 2001–2002; 2003–2004 etc.). Data from NHANES 1999+, NHANES III, NHANES II, and NHEFS are available online via the NCHS website.

Contact: n/a
Phone: 1–866–441-NCHS (6247)
Email: nchsquery@cdc.gov
Website: http://www.cdc.gov/nchs/nhanes.htm

National Health and Nutrition Examination Survey—Epidemiologic Followup Study (NHEFS)

Sponsor(s): National Center for Health Statistics

Data Collection Agency: Westat

Purpose / Primary Goals: NHEFS was designed to investigate the relationships between clinical, nutritional, and behavioral factors assessed in the first National Health and Nutrition Examination Survey (NHANES I) and subsequent morbidity, mortality, and hospital utilization, as well as, changes in risk factors, functional limitation and institutionalization.

Survey Universe / Coverage / Census: Persons 25–74 who completed a medical examination at NHANES I in 1971–1975

Sample or Research Design: The NHEFS cohort includes all persons between 25 and 74 years of age who completed a medical examination at NHANES I in 1971–1975 (n=14,407). It comprises of a series of followup studies, four of which have been conducted to date. The first wave of data collection was conducted for all members of the NHEFS cohort from 1982–1984. It included tracing the cohort; conducting personal interviews with subjects or their proxies; measuring pulse rate, weight and blood pressure of surviving participants; collecting hospital and nursing home records of overnight stays; and collecting death certificates of decedents.

Continued followups of the NHEFS population were conducted in 1986, 1987, and 1992 using the same design and data collection procedures developed in the 1982–1984 NHEFS, with the exception that a 30-minute computer-assisted telephone interview was administered rather than a personal interview, and no physical measurements were taken. The 1986 NHEFS, was conducted for members of the NHEFS cohort who were 55–74 years of age at their baseline examination and not known to be deceased at the 1982–1984 NHEFS (n=3,980). The 1987 NHEFS was conducted for the entire nondeceased NHEFS cohort (n=11,750). The fourth wave of data collection, the 1992 NHEFS, was conducted for the entire nondeceased NHEFS cohort (n=11,195).

Unit(s) of Analysis: Person level data analysis

Mode of Data Collection: In person interview, medical examination, linkage to facility records

Topics / Keywords: Nutrition

Data Years: 1971–1975 with followup through 1992

Linked Data: NCHS has collected mortality data through 2000, Medicare entitlement and utilization data (1991–2000) and Social Security benefit history data (1962–2003) for eligible NHEFS survey participants. For more information visit http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm.

Reports: Descriptions of the study methodologies are available in the NCHS Vital and Health Statistics Series 1 Reports, Numbers 22, 25, 27, and 35. Statistical issues in analyzing NHEFS data are addressed in Series 2 Report, Number 121. See http://www.cdc.gov/nchs/nhanes/nhefs/nhefs.htm.

Background / History: n/a

Future Plans: While no full scale interview recontacts are currently planned for this cohort, NCHS plans to continue to link NHEFS survey data to administrative records on mortality and health care utilization.

Bibliography: n/a

National Health and Nutrition Examination Survey—Epidemiologic Followup Study (NHEFS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free.*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- X *Use of Research Data Center required for access to restricted-use data.*
- X *Payment required for the preparation / supply of data*

Additional Information:

Contact: n/a

Email: nchsquery@cdc.gov

Phone: 1–866–441-NCHS (6247)

Website: http://www.cdc.gov/nchs/nhanes/nhefs/nhefs.htm

National Health Interview Survey (NHIS)

Sponsor(s): National Center for Health Statistics, Division of Health Interview Statistics; special topic questions are sponsored by various agencies

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The NHIS is the principal source of information on the health of the population of the United States. The NHIS monitors the health of the U.S. population through the collection and analysis of data on a broad range of topics and is used to monitor trends in illness and disability and to track progress toward achieving national health objectives. The data are also used by the public health research community for epidemiologic and policy analysis of such timely issues as characterizing those with various health problems, determining barriers to accessing and using appropriate health care, and evaluating Federal health programs.

Survey Universe / Coverage / Census: This survey includes the civilian noninstitutionalized population, excluding patients in long-term care facilities, persons on active duty with the Armed Forces, prisoners, and U.S. nationals living in foreign countries. The institutionalized population of the United States accounts for approximately 2 percent of the total population.

Sample or Research Design: The NHIS has been conducted annually since 1957, with a major redesign every 10–15 years. It is a cross-sectional household interview survey; sampling and interviewing are continuous throughout the year. The last major revision to the instrument occurred in 1997 and it divided the survey into three parts. The Basic module consists of the family core, sample adult core, and sample child core. The other two modules are the Periodic module and the Topical module.

Unit(s) of Analysis: Person-level analysis: Self report and proxy report.

Mode of Data Collection: The data are collected through personal household interview surveys conducted by trained interviewers. Prior to 1997, a paper and pencil questionnaire format was used. From 1997 onwards, computer-assisted personal interviewing (CAPI) was used. The last re-engineering of the CAPI occurred in 2004.

Topics / Keywords: Chronic conditions, Demographics, Functional status, Health behaviors, Health care utilization, Health insurance coverage, Health status, Illnesses, Income, Injuries, Marital status, Medicaid, Mental health / behavioral health, Mortality, Program participation, Risk factors, Self report of health status, and Socioeconomic status. Recent supplements have included topics on Complementary and Alternative Medicine, Cancer Prevention, and Healthy People 2010 objectives.

Data Years: Ongoing since 1957, with a major research design every 10–15 years.

Linked Data: Linked Data (available through the NCHS Research Data Center):

Beginning in 1995 (and each subsequent year), a subsample of households that participated in the National Health Interview Survey link to the subsequent year's Medical Expenditure Panel Survey (i.e., a subsample of persons in the 1995 NHIS will link to the 1996 MEPS).

- NHIS 1986–2004 are linked to mortality files from 1986 to 2006
- In 1994, the NHIS data was linked with National Immunization Provider Record Check Study to determine the accuracy of household vaccination reports for children 12–35 months of age
- 1994–1998 NHIS has been linked with 1962–2003 Social Security administrative data

- 1994–1998 NHIS has been linked to 1991–2000 Medicare enrollment and Claims data

Reports: Advance Data Reports, and Vital and Health Statistics, Series 10 Reports are available at: http://www.cdc.gov/nchs/nhis/nhis_products.htm

Background / History: n/a

Future Plans: n/a

Bibliography: An NHIS bibliography via MEDLINE available at: http://www.cdc.gov/nchs/nhis.htm#Publications.

National Health Interview Survey (NHIS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- *X Some or all public-use files downloadable free from*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- *X Use of Research Data Center required for access to restricted-use data. Website:* ***http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm***
- *X Payment required for the preparation / supply of data*

Additional Information:

Contact: n/a

Email: nchsquery@cdc.gov

Phone: 1–866–441-NCHS (6247)

Website: http://www.cdc.gov/nchs/nhis.htm

National Home and Hospice Care Survey (NHHCS)

Sponsor(s):National Center for Health Statistics

Data Collection Agency: Westat

Purpose / Primary Goals: NHHCS, a periodic nationally representative sample, collects data on the characteristics and care provided by home health care agencies and hospices as well as characteristics of patients receiving these services. Data collected at the home health care and hospice agency level include number of clients served, ownership and affiliations, certification status, and services provided. At the home health patient and hospice discharge level, data are collected on demographic characteristics, services received, length of time since admission, diagnoses, medications taken, advance directives, and many other items. In 2007, the survey was redesigned and expanded to include a computer-assisted personal interviewing (CAPI) system, many new data items, and larger sample sizes of current home health patients and hospice discharges. The 2007 NHHCS also included a supplemental survey of home health aides employed by home health and/or hospice agencies, called the National Home Health Aide Survey (NHHAS). NHHAS collected information from a nationally representative sample of home health aides employed by participating NHHCS agencies about job history, organizational commitment and job satisfaction, organizational culture, management and supervision, client relations, recruitment and training, family life, work-related injuries, and demographics.

Survey Universe / Coverage / Census: All agencies that participated in the survey were either certified by Medicare and/or Medicaid or were licensed by a State to provide home health and/or hospice services and currently or recently served home health and/or hospice patients. Agencies that provided only homemaker services or housekeeping services, assistance with instrumental activities of daily living (IADLs), or durable medical equipment and supplies were not included in the survey.

Sample or Research Design: This is a continuing series of cross-sectional surveys.

The sample design for the 1992–94 NHHCS was a stratified three stage probability design. Primary sampling units were selected at the first stage, agencies were selected at the second stage, and up to six current patients and six discharges were selected at the third stage. The sample design for the 1996, 1998, 2000 and 2007 NHHCS was a two-stage probability design in which agencies were selected at the first stage and current patients and discharges were selected at the second stage. Current patients were those on the rolls of the agency as of midnight the day before the survey. Discharges were selected to estimate the number of discharges from the agency during the 12 months before the survey.

The original sampling frame consisted of all home health care agencies and hospices identified in the 1991 National Health Provider Inventory (NHPI). The 1992 sample contained 1,500 agencies. These agencies were revisited during the 1993 survey (excluding agencies that had been found to be out of scope for the survey). In 1994, in scope agencies identified in the 1993 survey were revisited, along with 100 newly identified agencies added to the sample. In 1996, the universe was again updated and a new sample of 1,200 agencies was drawn. In 1998, a sample of 1,350 agencies was selected from a universe of home health agencies and hospices obtained from various national organizations and other sources. In 2000, 1,800 agencies were sampled from the universe that was obtained from SMG Home Healthcare Market Database and the membership list of the National Hospice and Palliative Care Organization. The response rates during the 1992–2000 survey years have been greater than 92 percent at the agency level, mid-90 to mid-80 percent for current patients, and low 90 to low 80 percent for discharges. In 2007, 1,545 agencies were sampled from the universe that was constructed using three sources: (1) The Centers for Medicare & Medicaid Services Provider of Services file of home health agencies and hospices, (2) State licensing lists of home health agencies compiled by a private organization, and (3) The National Hospice and Palliative Care Organization file of hospices. The combined files were matched and identified duplicates were removed, resulting in a sampling frame of 15,488. The total number of agencies that participated in the 2007 NHHCS is 1,036, and data are available on 9,416 current home health patients and hospice discharges from these agencies.

Unit(s) of Analysis: Home health care and hospice care agency level, patient level, and aide level.

Mode of Data Collection: Agency characteristics were obtained through interviews with the agency administrators and staff. Sample patients and discharges were selected, and questionnaires were completed by interviewing the staff member most familiar with the care provided to the patient/discharge. Respondents were requested to refer to the medical records for the patient/discharge.

Topics / Keywords: Home health care, hospice, disability

Data Years: 1992, 1993, 1994, 1996, 1998, 2000, 2007

Linked Data: In the future plan, 2007 NHHCS data from sampled patients and agencies will be linked to the CMS Outcome Assessment Information Set (OASIS) to obtain more clinical data and create episodes of care.

Reports: A list of reports is available at: http://www.cdc.gov/nchs/nhhcs/nhhcs_products.htm

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

National Home and Hospice Care Survey (NHHCS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- *X Some or all public-use files downloadable free from website at **http://www.cdc.gov/nchs/nhhcs.htm***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Initiated in 1992, NHHCS was also conducted in 1993, 1994, 1996, 1998, and 2000. The survey was conducted again in 2007. Data from the 2007 survey were released in the spring of 2009. CD-ROMs are available from National Technical Information Service (NTIS) for 1992–1994, 1996, 1998. Data from 1996–2007 can be downloaded from the NHHCS webpage.

Contact: n/a
Email: nchsquery@cdc.gov
Phone: 1–866–441-NCHS (6247)
Website: http://www.cdc.gov/nchs/nhhcs.htm

National Hospital Ambulatory Medical Care Survey (NHAMCS)

Sponsor(s): National Center for Health Statistics, Division of Health Care Statistics

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The National Hospital Ambulatory Medical Care Survey (NHAMCS) collects data on the utilization and provision of medical care services in hospital emergency and outpatient departments. Data are collected from medical records on type of providers seen; reason for visit; diagnoses; drugs ordered, provided, or continued; diagnostic and screening services, selected procedures and tests ordered or performed during the visit, and other visit characteristics. Patient data include age, sex, race, and expected source of payment. Data are also collected on selected characteristics of hospitals included in the survey.

Survey Universe / Coverage / Census: The survey is a representative sample of visits to emergency departments (EDs) and outpatient departments (OPDs) of non-Federal, short stay, and general hospitals. Telephone contacts are excluded.

Sample or Research Design: Census field representatives contact sample hospitals to determine whether they have a 24-hour ED or an OPD that offers physician services. Visits to eligible EDs and OPDs are systematically sampled over the 4-week reporting period such that about 100 ED encounters and about 200 OPD encounters are selected.

In any given year, the hospital sample consists of approximately 500 hospitals, of which 80 percent have EDs and about half have eligible OPDs. Typically, about 1,000 clinics are selected from participating hospital OPDs.

Unit(s) of Analysis: Hospitals, medical care, diagnoses

Mode of Data Collection: Hospital staff is asked to complete a Patient Record Form (PRF) for each sampled visit, but Census field representatives typically abstract data for more than half of these visits.

Topics / Keywords: Hospitals, medical care, diagnoses.

Data Years: Annually, 1992-present

Linked Data: Restricted NHAMCS data contain geographical variables such as patient ZIP code and State and county codes. These variables can be linked to other data sources such as U.S. Census Bureau data and the Health Resources and Services Administration's Area Resource File, a national county-level health resources information system, in order to do contextual analysis. Such linking can only be done at NCHS' Research Data Center.

Reports: A list of publications and reports using NHAMCS data is available at: http://www.cdc.gov/nchs/ahcd/ahcd_products.htm.

Background / History: n/a

Future Plans: The NHAMCS PRF is modified approximately every 2 years to reflect changes in physician practice characteristics, patterns of care, and technological innovations. Examples of recent changes are the number of drugs recorded on the PRF form, and checkboxes of specific tests or procedures performed. In addition, supplemental studies are conducted periodically to assess topics such as bioterrorism preparedness, hospital staffing and capacity, and ambulance diversions. For 2006, a supplement on emergency pediatric surveillance and equipment and an outpatient cervical cancer screening supplement are being fielded. Data from the supplements are currently available only through NCHS' Research Data Center.

Bibliography: n/a

National Hospital Ambulatory Medical Care Survey (NHAMCS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- *X Some or all public-use files downloadable free from website: **http://www.cdc.gov/nchs/ahcd.htm***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- *X Use of Research Data Center required for access to restricted-use data. Website: **http://www.cdc.gov/nchs/ahcd.htm***
- *X Payment required for the preparation / supply of data*

Additional Information:

Contact: n/a

Email: nchsquery@cdc.gov

Phone: 1–866–441-NCHS (6247)

Website: http://www.cdc.gov/nchs/ahcd.htm

National Hospital Discharge Survey (NHDS)

Sponsor(s): National Center for Health Statistics, Division of Health Care Statistics

Data Collection Agency: NCHS, U.S. Census Bureau

Purpose / Primary Goals: The National Hospital Discharge Survey (NHDS) collects and produces national estimates on characteristics of inpatient stays in non-Federal short-stay hospitals in the United States. Patient information collected includes demographics, length of stay, diagnoses, and procedures. Hospital characteristics collected include region, ownership, and bed size.

Survey Universe / Coverage / Census: The survey design covers the 50 States and the District of Columbia. Included in the survey are hospitals with an average length of stay of less than 30 days for all inpatients, general hospitals, and children's general hospitals. Excluded are Federal, military, and Department of Veterans Affairs hospitals, as well as hospital units of institutions (such as prison hospitals), and hospitals with fewer than six beds staffed for patient use. All discharged patients from in-scope hospitals are included in the universe from which the sample is drawn.

Sample or Research Design: Beginning in 1985, two data collection procedures have been used in the survey. One is a manual system in which sample selection and medical transcription from the hospital records to abstract forms is performed by the hospital's staff or by staff of the U.S. Bureau of the Census on behalf of NCHS. The other data collection procedure is an automated system in which NCHS purchases machine-readable medical record data from commercial organizations, State data systems, hospitals, or hospital associations. The medical abstract form and the automated data tapes contain items that relate to the personal characteristics of the patient. These items include age, sex, race, ethnicity, marital status, and expected sources of payment. Administrative items such as admission and discharge dates (which allow calculation of length of stay), as well as discharge status, are also included. Medical information about patients includes diagnoses and procedures coded to the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM).

A redesign of the NHDS was implemented for the 1988 survey. Under the redesign hospitals were selected using a modified three-stage stratified design.

The NHDS hospital sample is updated every 3 years by continuing the sampling process among hospitals that become eligible for the survey during the intervening years and by deleting hospitals that were no longer eligible. This process has been conducted every 3 years beginning in 1970, and was conducted again in 2006.

In 2006, 501 hospitals were selected: 478 were in scope, 438 participated (92 percent), and approximately 376,000 medical records were abstracted.

Unit(s) of Analysis: The basic unit of estimation for NHDS is a sampled discharge.

Mode of Data Collection: From 1965, the initial year of the NHDS, through 1984, all data collection was conducted by means of manual abstraction of patient information from sampled medical records. Sample selection and transcription of information from inpatient medical records to NHDS survey forms were performed by either hospital staff or staff of the Census Bureau on behalf of NCHS. When the second data collection procedure was introduced in 1985, that is, using automated data, the new method was used in approximately 17 percent of the sample hospitals for 1985–87. Discharges from these data files are selected using the NHDS sampling specifications, and the same computer edits and estimation procedures used for the manual data are also used for the automated data. Two data collection methods, manual and automated, continue to be used in the NHDS. For the 2006 data year, approximately 45 percent of respondent hospitals provided data through the automated system.

Topics / Keywords: Hospitals, inpatients, procedures

Data Years: The NHDS has been conducted annually since 1965. National and regional (four Census regions) estimates, based on the calendar year, are produced.

Linked Data: Linkages of NHDS data to other data files is possible through the National Center for Health Statistics' Research Data Center. Among the data files, which have been linked to the NHDS are area resource file, American Hospital Association (AHA), and U.S. Census Bureau data.

Reports: Reports utilizing data from NHDS can be found at: http://www.cdc.gov/nchs/about/major/hdasd/listpubs.htm.

Background / History: n/a

Future Plans: A pretest study for a redesigned NHDS was conducted from October 2008 – April 2009. Final plans to field the national redesigned NHDS are currently under discussion.

Bibliography: n/a

National Hospital Discharge Survey (NHDS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from wesite: http://www.cdc.gov/nchs/nhds.htm*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Public-use data files are available for download from the website for 1996–2006. NHDS data is also available on CD-ROM's for data years 1970–97.

Contact: n/a

Email: nchsquery@cdc.gov

Phone: 301–458–4321

Website: http://www.cdc.gov/nchs.nhds.htm

National Mortality Followback Survey (NMFS)

Sponsor(s): National Center for Health Statistics, Mortality Statistics Branch, Supplemental questions are sponsored by various agencies

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: To provide information on mortality beyond that routinely collected on the death certificate. Five major subject areas can be examined: (1) socioeconomic differentials in mortality; (2) prevention of premature death by inquiring into the association between risk factors and the cause of death; (3) health care service utilization in the last year of life; (4) disability and medical conditions in the last year of life; and (5) the reliability and validity of certain items reported on the death certificate.

The Mortality Followback Survey Program, begun in the 1960s by NCHS, uses a sample of United States residents who die in a given year to supplement the death certificate with information from the next of kin or another person familiar with the decedent's life history. This information, sometimes enhanced by administrative records, provides a unique opportunity to study the etiology of disease, substance use, demographic characteristics and risk factors in mortality, and other health related issues.

The first mortality followback survey, conducted in 1961, featured information on hospital and institutional care in the last year of life. Information from the 1962–63 survey permitted an extensive analysis of socioeconomic differentials in mortality. Data from the 1964–65 survey included expenditures for health care during the last year of life, sources of payment, and health insurance coverage of decedents. The 1966–68 survey provided information on the link between smoking and cancer mortality. In 1986, the survey provided data on comorbid conditions, disabilities, alcohol use, and access to health care services.

The 1993 survey samples individuals aged 15 years or over who died in 1993. Forty-nine of the 50 State vital registration areas granted approval to sample their death certificates, as well as the independent vital registration areas of the District of Columbia and New York City. (South Dakota declined to participate in the NMFS due to State law restricting the use of death certificate information.)

A sample of 22,957 death certificates from the Current Mortality Sample was drawn. To meet specific research needs, the sample included 9,636 death certificates selected with certainty. There is an over-sample of death certificates to obtain reliable numbers for important population subgroups; persons under age 35, women, and the black population.

The 1993 NMFS focused on five subject areas:

- Socioeconomic differentials in mortality
- Associations between risk factors and cause of death
- Disability
- Access and utilization of health care facilities in the last year of life
- Reliability and validity of certain items reported on the death certificate
- Identifying strategies to prevent deaths due to trauma

The 1993 NMFS is different from the five previous mortality followback surveys in several ways:

- It over-sampled deaths due to homicide, suicide, and unintentional injury.
- The subject areas are considerably broader. However, many previously-surveyed subject areas are included for prevalence analysis from various years.
- The survey is the first national survey to collect information from medical examiner/coroner reports.

- The complexity of the questionnaire necessitated telephone or in person interviews.

Survey Universe / Coverage / Census: Deaths to person 15 and older in the United States in 1993

Sample or Research Design: Sample of resident deaths

Unit(s) of Analysis: Person-level

Mode of Data Collection: Survey and administrative data

Topics / Keywords: Socioeconomic status , Risk factors, Death, Disability, Access to care and Prevention of death

Data Years: 1986, 1993

Reports: Publications using the 1986 NMFS include: Advance Data Nos. 172, 173, and 180. Vital and Health Statistics Series 1, No. 29; Series 2, No. 118; and Series 20, No. 19.

Linked Data: n/a

Future Plans: n/a

Bibliography: n/a

National Mortality Followback Survey (NMFS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: **http://www.cdc.gov/nchs/nvss/nmfs.htm***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Mortality Statistics Branch
Email: nchsquery@cdc.gov
Phone: 301–458–4666
Website: http://www.cdc.gov/nchs/nvss/nmfs.htm

National Nursing Home Survey (NNHS)

Sponsor(s): National Center for Health Statistics, Division of Health Care Statistics

Data Collection Agency: Westat

Purpose / Primary Goals: The NNHS provides information on characteristics of nursing homes and their residents and staff. The NNHS provides information on nursing homes from two perspectives: that of the provider of services and that of the recipient. Data about the facilities include characteristics such as bed size, ownership, affiliation, Medicare/Medicaid certification, specialty units, services offered, number and characteristics of staff, expenses, and charges. Data about the current residents and discharges include demographic characteristics, health status, level of assistance needed with activities of daily living, vision and hearing impairment, continence, services received, sources of payment, and discharge disposition (for discharges). The survey underwent a major redesign in 2004. New content added to the survey included medications, medical, mental health, and dental services offered or provided, end-of-life care and advance directives, education, specialty credentials, and length of service of key staff, turnover and stability of nursing staff, use of contract/agency staff, overtime shifts worked, wages and benefits, facility practices for immunization, dining, and use of mechanical lifting devices.

Survey Universe / Coverage / Census: The initial NNHS, conducted in 1973–1974, included the universe of nursing homes that provided some level of nursing care and excluded homes providing only personal or domiciliary care. The 1977 NNHS encompassed all types of nursing homes, including personal care and domiciliary care homes. The 1985 NNHS was designed to be similar to the 1973–1974 survey in that it excluded personal or domiciliary care homes. The 1995, 1997, 1999, 2004 NNHS also included only nursing homes that provided some level of nursing care and excluded homes providing only personal or domiciliary care, similar to the 1985 and 1973–1974 surveys.

Data were collected from nursing homes in all 50 States and the District of Columbia in the 1995–2004 surveys, but in 1973–1974, 1977, and 1985, data were only collected in the 48 contiguous States and DC. Data on current residents were collected in all surveys; data on discharges were collected in 1977, 1985, 1997, and 1999.

Data were collected from nursing homes in all 50 States and the District of Columbia in the 1995–2004 surveys, but in 1973–1974, 1977, and 1985, data were only collected in the 48 contiguous States and DC. Data on current residents were collected in all surveys; data on discharges were collected in 1977, 1985, 1997, and 1999.

Sample or Research Design: NNHS is a continuing series of cross-sectional surveys. The 2004 NNHS used a self-administered questionnaire to obtain staffing information and a computer-assisted personal interview system (CAPI), which contained seven modules: facility qualification, facility characteristics, resident sampling, nursing assistant sampling, health assessment 1, health assessment 2, prescription medications, and payment.

The 2004 sample consisted of 1,496 nursing homes. In 1995, 1997, and 1999, facility-level response rates were over 93 percent.

Unit(s) of Analysis: Information is collected on the nursing home level and resident level.

Mode of Data Collection: Information on the facility is collected through a personal interview with the administrator or staff designated by the administrator. Resident data were provided by staff familiar with the care provided to the resident. Staff relied on the medical record and personal knowledge of the resident. In addition to employee data that were collected during the interview with the administrator, in several years staffing data were collected via a self-administered questionnaire. Discharge data were based on information recorded in the medical record. Information on discharges was not collected in 1995 and 2004.

Topics / Keywords: Nursing homes, health status, disability, and prescription drugs

Data Years: 1973–1974, 1977, 1985, 1995, 1997, 1999, 2004

Linked Data: The 2004 NNHS data from sampled residents and facilities will be linked to the CMS Minimum Data Set (MDS) to obtain more clinical data and create episodes of care. The NNHS data are also linked to the NDI.

Reports: A list of reports is available at: http://www.cdc.gov/nchs/nnhs/nnhs_products.htm

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

National Nursing Home Survey (NNHS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: **http://www.cdc.gov/nchs/nnhs.htm***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

CD-ROMs are available from National Technical Information Service (NTIS) for 1999, 1997, 1995, 1985, 1977, 1973–1974, and 1969. Data for 1995–2004 can be downloaded from the NNHS Web page.

Contact: n/a
Email: nchsquery@cdc.gov
Phone: 1-866–441-NCHS (6247)
Website: http://www.cdc.gov/nchs/nnhs.htm

National Survey of Ambulatory Surgery (NSAS)

Sponsor(s): National Center for Health Statistics, Division of Health Care Statistics

Data Collection Agency: US Census Bureau

Purpose / Primary Goals: The National Survey of Ambulatory Surgery (NSAS) is the only national study of ambulatory surgical care in hospital-based and freestanding ambulatory surgery centers (ASCs). The NSAS was first conducted from 1994 to 1996, but it was discontinued due to lack of resources. The NSAS was conducted again in 2006.

After nearly ten years of being out of the field, the NSAS data collection instruments were updated to reflect the changing environment in ambulatory surgery. Outside experts from the American College of Surgeons, American Association for the Accreditation of Ambulatory Surgery Facilities (AAAASF), American Association of Ambulatory Surgery Centers (AAASC), the American Academy of Ophthalmology (AAO), the American Hospital Association (AHA), the Society for Ambulatory Anesthesiologists (SAMBA), the Federation of American Hospitals (FAH), the Joint Commission of Accreditation of Healthcare Organizations (JCAHO), the Federated Ambulatory Surgery Association (FASA), and the American College of Obstetrics and Gynecology (ACOG) provided input into updating the data collection tools used for NSAS. Many of the new questions that were asked in the 2006 NSAS were about the facility in which the ambulatory surgery was performed.

Data for the NSAS in 2006 were collected for approximately 52,000 ambulatory surgery visits from a nationally representative sample of hospital-based and freestanding ambulatory surgery centers. These data are used for a variety of planning, administrative and evaluation activities by government, professional, scientific, academic, and commercial institutions, as well as by private citizens.

Beginning in 2009 ambulatory surgery data are being collected in the National Hospital Ambulatory Medical Care Survey (NHAMCS). Hospital-based ASCs was added that first year to the scope of the NHAMCS, and freestanding ASCs will be added in 2010. Annual data collection is planned. The NHAMCS website provides more information on these efforts. Go to: http://www.cdc.gov/nchs/ahcd.htm.

Survey Universe / Coverage / Census: Visits to US hospital-based and freestanding ambulatory surgery facilities.

Sample or Research Design: A stratified random sample of visits to hospital-based and freestanding ambulatory surgery facilities which is nationally representative

Unit(s) of Analysis: Facility-level, visit level

Mode of Data Collection: Each sampled facility was asked to complete a Facility Questionnaire and return it in the mail.

Topics / Keywords: Outpatient care, Surgery, procedures

Data Years: 1994-1996, 2006. In 2009, data on hospital-based ASC facilities only, but plan to also add freestanding ASC facilities in 2010.

Linked Data: n/a

Reports: Available at http://www.cdc.gov/nchs/nsas.htm

Background / History: Prior to the NSAS no national data were available on ambulatory surgery.

Future Plans: Beginning in 2009, ambulatory surgery data is being collected in the National Hospital Ambulatory Medical Care Survey (NHAMCS). Hospital-based ASCs were added that year to the scope of the NHAMCS, and freestanding ASCs will be added in 2010. Annual data collectionin both settings is planned. The NHAMCS website provides more information on these efforts.

Bibliography: Available at http://www.cdc.gov/nchs/nsas.htm

National Survey of Ambulatory Surgery (NSAS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- *X Some or all public-use files downloadable free from website:* ***http://www.cdc.gov/nchs/nsas.htm***
- *X Data available for free upon order from agency. Order from: 301–458–4321*
- ☐ *Application process required to obtain some data files*
- *X Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files-not for public use data*
- *X Use of Research Data Center required for access to restricted-use data. Website:* ***http://www.cdc.gov/nchs/r&d/rdc.htm***
- *X Payment required for the preparation / supply of data*

Additional Information:

Data files for the 1994–96 and 2006 NSAS can be downloaded from the following website at: http://www.cdc.gov/nchs/nsas.htm

Contact: Marni Hall,
National Center for Health Statistics, CDC
Email: nchsquery@cdc.gov
Phone: 301–458–4321
Website: http://www.cdc.gov/nchs/nsas.htm

National Vital Statistics System (Vital Statistics)

Sponsor(s): National Center for Health Statistics, Division of Vital Statistics

Data Collection Agency: National Center for Health Statistics

Purpose / Primary Goals: Through the National Vital Statistics System, the National Center for Health Statistics collects and publishes data on births, deaths, fetal deaths, and prior to 1996, marriages and divorces, and in the 1970's and 1980's, induced terminations of pregnancy, occurring in the United States based on U.S. Standard Certificates.

The mortality data file is one of the few sources of comparable health-related data available for smaller geographic areas in the United States for a long time period. The data are a fundamental source of cause-of-death information by demographic characteristics and for geographic areas such as states. Mortality data can be used not only to present the characteristics of those dying in the United States but also to determine life expectancy and to compare mortality trends with other countries. Data include events occurring within the United States but are typically displayed by place of residence.

Survey Universe / Coverage / Census: Universe is all deaths occurring in the 50 states, New York City, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, Guam, America Samoa, and Northern Mariana Islands. Geographic coverage for the U.S. has been complete since 1933. More than 99% of all deaths are registered.

Sample or Research Design: The Division of Vital Statistics obtains information from the registration offices of each of the 50 states, New York City, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, Guam, America Samoa, and Northern Mariana Islands. The data are collected on a continuous basis with an administrative record, the death certificate. State laws and regulations require that a death certificate be completed for all deaths.

Unit(s) of Analysis: Decedent

Mode of Data Collection: Demographic information on the death certificate is provided by the funeral director based on information supplied by an informant. Medical certification of cause of death is provided by a physician, medical examiner, or coroner.

Topics / Keywords: Deaths, Life expectancy, Mortality and smaller geographic areas

Data Years: 1933 – present for US (data available for a registration area for 1900–1932)

Linked Data: n/a for this data file; however, many other data files link with mortality data

Reports: Heron MP, Hoyert DL, Murphy SL, Xu JQ, Kochanek KD. Deaths: final data for 2006. National vital statistics reports; vol 57, no 14. Hyattsville, MD: National Center for Health Statistics. 2009.

Background / History: US Vital Statistics System Major Activities and Developments, 1950–1995 http://www.cdc.gov/nchs/data/misc/usvss.pdf

Future Plans: Continue process of implementing electronic death registration and revised certificates.

Bibliography: Other reports can be found at http://www.cdc.gov/nchs/nvss/new_mortality.htm and http://www.cdc.gov/nchs/nvss/mortality_products.htm

National Vital Statistics System (Vital Statistics)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: **http://wonder.cdc.gov** (underlying and multiple causes); **http://www.cdc.gov/injury/wisqars/***
- *X Some or all public-use files downloadable free from wesite: **http://www.cdc.gov/nchs/data_access/Vitalstatsonline.htm***
- *☐ Data available for free upon order from agency.*
- *☐ Application process required to obtain some data files*
- *☐ Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files: see additional information*
- *X Use of Research Data Center required for access to restricted-use data.*
- *☐ Payment required for the preparation / supply of data*

Additional Information:

Contact: Mortality Statistics Branch
Email: nchsquery@cdc.gov
Phone: 1–800–232–4636
Website: http://www.cdc.gov/nchs/deaths.htm

Centers for Medicare & Medicaid Services

Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Surveys

Sponsor(s): Centers for Medicare & Medicaid Services, Medicare Drug Benefit and C & D Data Group, Division of Consumer Assessment and Plan Performance

Data Collection Agency: The CAHPS Survey for Health and Prescription Drug Plans (Wilkerson & Associates and CSS); Hospital CAHPS – (Health Services Advisory Group is the national implementation coordinator over 50 vendors approved to conduct the survey)

Purpose / Primary Goals: The purpose of the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Surveys is to measure experiences of enrollees in their health and prescription drug plans and with fee-for-service Medicare and to measure the experiences of patients in hospitals and other provider settings such as nursing homes, End-Stage Renal disease facilities, and home health agencies. The health and prescription drug plan surveys have been conducted annually by the Centers for Medicare & Medicaid Services (CMS). Hospital CAHPS® was implemented nationally in 2006. The Home Health CAHPS® survey will be implemented in late 2009.

The primary goals of these surveys are to:

- Provide people with Medicare and the general public with information to help them make more informed choices among plans and providers
- Help CMS identify problems and improve the quality of services
- Enhance CMS' ability to monitor the quality of care and performance of its Medicare plans and providers

Survey Universe / Coverage / Census: CAHPS Survey for Health and Prescription Drug Plans - Medicare enrollees in health and prescription drug plans

Hospital CAHPS – Patients 18 and older with an overnight stay in an acute care hospital

Sample or Research Design: Random sample of eligible patients

Unit(s) of Analysis: Patents in hospitals, Medicare enrollees with 6 or more months experience in their health or prescription drug plans.

Mode of Data Collection: CAHPS survey for Health and Prescription Drug Plans – mix mode of mail with telephone follow-up of non-respondents Hospital CAHPS – choice of four modes (mail only, telephone only, mix of mail with telephone follow-up of non-respondents, and active IVR – touch tone)

Topics / Keywords: Access to care, Medicare managed care, Use of health care services. and Use & expenditure for prescription medications

Data Years: CAHPS is conducted annually. Hospital CAHPS was implemented nationally in 2006. The other CAHPS surveys are in different phases of development implementation.

Linked Data: n/a

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Surveys

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

☐ *User-specified online data query or table generation possible.*
X Some or all public-use files downloadable free from website: http://www.hcahpsonline.org/home.aspx
☐ *Data available for free upon order from agency.*
☐ *Application process required to obtain some data files*
☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

X Application process required to obtain data files: Plan Level Data
☐ *Use of Research Data Center required for access to restricted-use data.*
☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Liz Goldstein, CMS
Email: Hcahps@azqio.sdps.org
Phone: n/a
Website: http://www.hcahpsonline.org/home.aspx

Medicaid Analytic eXtract (MAX): Medicaid (Claims and Enrollment) Data

Sponsor(s): Centers for Medicare & Medicaid Services, Office of Research, Development, and Information, Research and Evaluation Group, Division of State Programs and Special Populations

Data Collection Agency: States

Purpose / Primary Goals: The Centers for Medicare & Medicaid Services (CMS) works with its State partners to collect data on persons served by the Medicaid program to produce Medicaid program statistics, monitor and evaluate access and quality of care, trends in program eligibility, characteristics of enrollees, changes in payment policy, and other program-related issues.

Medicaid enrollment data collected include demographic and eligibility characteristics of enrolled persons such as race/ethnicity, age, and basis of eligibility. Enrollee eligibility variables include state, county and ZIP code of residence, although reported ZIP code is of varying quality. Service data include detail on utilization and Medicaid payments for each covered service.

Survey Universe / Coverage / Census: The data include individuals enrolled in the Medicaid program and the Medicaid-covered services they receive.

The CMS Medicaid enrollment and claims data contains information for Medicaid eligibles who actually do enroll in their State's Medicaid program. CMS Medicaid files cannot, therefore, be used to study individuals who are eligible but not enrolled.

Sample or Research Design: The primary data source for Medicaid statistical data is the Medicaid Statistical Information System (MSIS). The Medicaid Analytic eXtract (MAX) data, derived from MSIS, are the primary data used for research and policy analysis. Prior to 1999 the predecessor to MAX was the State Medicaid Research Files (SMRF).

Detailed information on MAX is available on the CMS website at: http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/07MAXGeneralInformation.asp.

MAX files contain person-level enrollment, utilization, and expenditure data on a calendar year basis. For years prior to 1999, they are available for 25–31 States, depending on the year. These are States that chose to participate voluntarily in electronic data submission or the Medicaid Statistical Information System (MSIS). MSIS participation was mandated for all States beginning with 1999. Calendar year MAX and SMRF files are created from the quarterly MSIS files that State Medicaid agencies submit to CMS. MAX and SMRF include one file with enrollment information (Personal Summary File) and four service files (Inpatient, Long Term Care, Prescription Drug, and Other Services) for each year of data. In MAX and SMRF service files, interim claims (originals, voids, and positive or negative adjustments) have been combined so that the records represent final action "events" to the extent possible. While MAX and SMRF data have undergone extensive edit checks, Medicaid programs and data quality vary across States.

Unit(s) of Analysis: Person-level

Mode of Data Collection: MSIS is the basic source of State-reported eligibility and claims data on the Medicaid population, and their characteristics, utilization, and payments. Beginning in FY 1999, as a result of legislation enacted from the Balanced Budget Act of 1997, States are required to submit individual eligibility and claims data tapes to CMS quarterly through MSIS. Prior to FY 1999, States were required to submit an annual HCFA-2082 report, designed to collect aggregated statistical data on eligibles, recipients, services, and expenditures during a Federal fiscal year (October 1 through September 30). The data reported for each year represented people on the Medicaid rolls, recipients of Medicaid services, and payments for claims adjudicated during the year. The data reflected bills adjudicated or processed during the year, rather than services used during the year. States summarized and reported the data processed through their own Medicaid claims processing and payment operations, unless they opted to participate in MSIS, in which case the HCFA-2082 report was produced by the Health Care Financing Administration (the predecessor to CMS).

Topics / Keywords:Medicaid and Quality of care

Data Years: Selected State data are available from 1992 forward. Data for the 50 States and the District of Columbia are available from 1999 forward.

Linked Data: n/a

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Medicaid Analytic eXtract (MAX): Medicaid (Claims and Enrollment) Data

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: Aggregate statistics only – see the web site at* ***http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/07_MAXGeneralInformation.asp****. Statistics on prescribed drugs from MAX are available at:* ***http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/08_MedicaidPharmacy.asp****.*
- ☐ *Data available for free upon order from agency. Order from*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- X *Payment required for the preparation / supply of data*

Additional Information:

MAX and SMRF are research identifiable files. Person-level identifiable information is included in these Medicaid enrollment and utilization files. These data are protected under the Privacy Act of 1974 and other applicable Federal government rules and regulations. A Privacy Act Systems of Records notice (No. 09–70–6001), published in the Federal Register, identifies allowable uses of the data if potential benefits outweigh the risk of disclosure. Research is identified as an allowable use. CMS employs strict security measures to safeguard individual privacy. CMS data release policies seek to ensure that files containing physician and/or beneficiary identifiers are used only when necessary and in accordance with disclosure provisions of the Privacy Act. Researchers need to submit to CMS a data request package containing a written request, study protocol, evidence of funding, and a Data Use Agreement (DUA). The package is reviewed by the CMS Privacy Board. If CMS approves the data file request, researchers need to pay the cost incurred in the processing of data. Only the minimum data necessary for the research study are released to an approved user. Further information is available at the following CMS web addresses: http://www.cms.hhs.gov/PrivProtectedData/ and http://www.cms.hhs.gov/cmsforms/downloads/cms-r-0235.pdf.

Contact: Research Data Assistance Center
Email: resdac@umn.edu
Phone: 888–973–7322
Website: http://www.resdac.umn.edu or
CMS: http://www.cms.hhs.gov/home/medicaidasp

Medicare (Fee-for-Service (FFS) Claims, Part D Events, and Parts A/B/C/D Enrollment) Data

Sponsor(s): Centers for Medicare & Medicaid Services

Data Collection Agency: Centers for Medicare & Medicaid Services

Purpose / Primary Goals: The Centers for Medicare & Medicaid Services (CMS) collects and synthesizes Medicare enrollment, FFS spending, and FFS claims data to monitor and evaluate access to and quality of care, trends in utilization, changes in payment policy, and other program-related issues.

Data include claims information for FFS services furnished to Medicare beneficiaries and Medicare enrollment data. Claims data include type of service, procedures, diagnoses, dates of service, and claim-reported amounts for Medicare spending, for other primary payers, and potential beneficiary liability for deductible and coinsurance. Enrollment data include date of birth, sex, race/ethnicity, state and county of residence, and reason for entitlement.

Survey Universe / Coverage / Census: Enrollment data are for all persons enrolled in the Medicare program (original or FFS Medicare, managed care (Part C), and Part D). FFS claims data include data for Medicare beneficiaries who filed claims or had claims filed on their behalf. Part D event data include selected information extracted from claims by Part D plans and submitted to CMS.

Sample or Research Design: Analysis of the Medicare program and its impact on beneficiaries should start by first focusing on the targeted benefit and the population at risk.

The Denominator File contains demographic and enrollment information about each beneficiary enrolled in Medicare during a calendar year. The information in the Denominator File is "frozen" in March of the following calendar year. Some of the information contained in this file includes the beneficiary unique identifier, State and county codes, Zip code, date of birth, date of death, sex, race, age, monthly entitlement indicators (for Medicare Part A, Medicare Part B, or Part A and Part B), reasons for entitlement, State buy-in indicators, and monthly managed care indicators (yes/no).

The Denominator File is used to determine beneficiary demographic characteristics, entitlement, and beneficiary participation in Medicare Managed Care Organizations. A modification to the Denominator File to include information on enrollees' Part D status, including deemed/low income cost sharing, type of Part D plan, state-reported dual eligibility, and retiree drug subsidy, has also been prepared.

On occasion additional information on enrollees in plans (either managed care organization or Part D plans) is needed. The Management Integrated Information Repository (MIIR) contains data on beneficiaries who are currently enrolled or have ever been enrolled in a Managed Care Organization (MCO) under contract with CMS to provide A/B services and in a Prescription Drug Plan (PDP) or Medicare Advantage Part D (MA PD) Plan to provide prescription drug coverage. The data are individually beneficiary based. Some of the information contained in this file includes the Beneficiary Unique Identifier number, date of birth, date of death, State and County, and managed care/Part D enrollment information such as dates of membership and MCO/PBP contract number. The MIIR File is used to identify the exact MCO/PDP/MA PD in which beneficiaries were enrolled.

The Vital Status File contains demographic information about each beneficiary ever entitled to Medicare. Some of the information contained in this file includes the beneficiary unique identifier, State and county codes, ZIP code, date of birth, date of death, sex, race, and age. Often the Vital Status File is used to obtain recent death information for a cohort of Medicare beneficiaries. This file, like the Denominator File is derived from the Enrollment Data Base (EDB).

Most analyses of the FFS sector involve claims for A/B services. The claims and utilization data files contain extensive utilization information at various levels of summarization for a variety of providers and services. There are many types and levels of these files, including the National Claims History (NCH) files, the Standard Analytic Files (SAF), Medicare Provider and Analysis Review (MedPAR) files, Medicare enrollment files, and various other files.

The National Claims History (NCH) 100 Percent Nearline File contains all institutional and noninstitutional claims and provides records of every Medicare claim submitted, including adjustment claims. The Standard Analytical Files (SAFs) contain final action claims data in which all adjustments have been resolved. These files contain information collected by Medicare to pay for health care services provided to a Medicare beneficiary. SAFs are available for each institutional (inpatient, outpatient, skilled nursing facility, hospice, or home health agency) and noninstitutional (physician and durable medical equipment providers) claim type. The record unit of SAFs is the claim (some episodes of care may have more than one claim). SAF files include the Inpatient SAF, the Skilled Nursing Facility SAF, the Outpatient SAF, the Home Health Agency SAF, the Hospice SAF, the Clinical Laboratory SAF, and the Durable Medical Equipment SAF, all of which are potentially available as 100 percent samples. In addition, representative 5 percent Sample Beneficiary SAF's are created for inpatient hospital, SNF, home health, hospice, outpatient, physician/supplier, and DME.

Medicare Provider and Analysis Review (MedPAR) files contain inpatient hospital and skilled nursing facility (SNF) final action stay records. Each MedPAR record represents a stay in an inpatient hospital or SNF. An inpatient "stay" record summarizes all services rendered to a beneficiary from the time of admission to a facility through discharge. Each MedPAR record may represent one claim or multiple claims, depending on the length of a beneficiary's stay and the amount of inpatient services used throughout the stay.

Because Medicare managed care organizations do not file claims, files based only on FFS claims data will exclude care for persons enrolled in Medicare managed care programs. In addition, to maintain a manageable file size, some files are based on a sample of enrollees, rather than on all Medicare enrollees. Coding changes and interpretation of Medicare coverage rules have also changed over the life of the Medicare program.

Recently, Part D prescription drug data became available in the form of summary records of the Part D claims, called prescription drug events (PDEs). PDE files contain utilization and payment data for prescription drugs paid for under Part D.

Unit(s) of Analysis:Beneficiary, Service, Provider

Mode of Data Collection: Multiple modes

Topics / Keywords: Medicare Managed care

Data Years: Some data files are available as far back as 1987, but CMS no longer provides technical support for files with data prior to 1996.

Linked Data: Multiple surveys and other databases

Reports: Health Care Financing Review Statistical Supplement

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Medicare (Fee-for-Service (FFS) Claims, Part D Events, and Parts A/B/C/D Enrollment) Data

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free.*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- *X Payment required for the preparation / supply of data*

Additional Information:

Contact: Research Data Assistance Center
Email: resdac@umn.edu
Phone: 888–973–7322
Website: http://www.resdac.umn.edu

Medicare Chronic Condition Warehouse (CCW)

Sponsor(s): Centers for Medicare & Medicaid Services, Office of Research, Development, and Information

Data Collection Agency: Centers for Medicare & Medicaid Services

Purpose / Primary Goals: Section 723 of the Medicare Modernization Act of 2003 called for the establishment of a chronic condition data warehouse (CCW) to support the study of chronically ill Medicare beneficiaries and of cost effective and quality improvement options to treat these beneficiaries. The first phase of this work was done at the Iowa Foundation for Medical Care. The next phase will be performed by Buccaneer.

The data warehouse supports:

- Studies for improving the quality of care for chronically ill Medicare beneficiaries
- Studies for reducing the cost of care
- Integration of existing datasets
- Identification of new data needs for research

Data stored in the warehouse have the following features:

- Unique patient ID linked to all CMS program data creating person-level view of data
- Data extraction tools that support
    - — Accessing data by chronic conditions
    - — Complex customized research data requests related to chronic illness

Data included in the warehouse will be a 5 percent sample of all Medicare beneficiaries from CY 1999 through 2003, and a 100 percent sample starting in CY 2004 linking:

- Medicare enrollment data
- Medicare claims
- Medicaid claims
- MDS (nursing facility), OASIS (home health, IRF PAI (rehabilitation facility), and SB (swing bed) assessments
- Beneficiary data and data collected from relevant surveys (e.g., MCBS)

Survey Universe / Coverage / Census: Medicare beneficiaries

Sample or Research Design: 5 percent beneficiary sample CY 1999 through 2003, 100% thereafter

Unit(s) of Analysis: Person level

Mode of Data Collection: n/a

Topics / Keywords: Chronic conditions

Data Years: 1999 – present

Linked Data: 100 percent sample starting in CY 2004 linking to:

- Medicare enrollment data
- Medicare claims
- Medicaid claims
- MDS (nursing facility), OASIS (home health), IRF PAI (rehabilitation facility), and SB (swing bed) assessments
- Beneficiary data and data collected from relevant surveys (e.g., MCBS)

Reports: n/a

Background / History: n/a

Future Plans:

- Expand data sources to include Part D enrollment and drug events
- Enhance data access tools
- Enhance technical support services

Bibliography: n/a

Medicare Chronic Condition Warehouse (CCW)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

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Website: http://www.resdac.umn.edu/

Medicare Current Beneficiary Survey (MCBS)

Sponsor(s): Centers for Medicare & Medicaid Services, Office of Research, Development, and Information

Data Collection Agency: Westat

Purpose / Primary Goals: The Medicare Current Beneficiary Survey (MCBS) produces nationally representative estimates of health status, health care use and expenditures, health insurance coverage, and socioeconomic and demographic characteristics of Medicare beneficiaries. It is used to estimate expenditures and sources of payment for all services used by Medicare beneficiaries, including co-payments, deductibles, and noncovered services; to ascertain all types of health insurance coverage and relate coverage to sources of payment; and to trace processes over time, such as changes in health status, spending down to Medicaid eligibility, and the effects of program changes.

The survey collects data on utilization of health services, health and functional status, health care expenditures, and health insurance and beneficiary information (such as income, assets, living arrangement, family assistance, attitudes, perceptions, knowledge, and quality of life).

Survey Universe / Coverage / Census: The MCBS is a continuous survey of a nationally representative sample of aged and disabled Medicare beneficiaries, living in long-term-care facility and the community.

Sample or Research Design: The longitudinal design of the survey allows each sample person to be interviewed three times a year for 4 years, whether he or she resides in the community or a facility or moves between the two settings, using the version of the questionnaire appropriate to the setting. Sample persons in the community are interviewed using computer-assisted personal interviewing (CAPI) survey instruments. Because long-term-care facility residents often are in poor health, information about institutionalized patients is collected from proxy respondents such as nurses and other primary caregivers affiliated with the facility. The sample is selected from the Medicare enrollment files, with oversampling among disabled persons under age 65 and among persons 85 years of age and over.

Medicare claims are used to supplement survey reported events to produce the Cost and Use file that provides complete expenditure and source of payment data on all health care services, including those not covered by Medicare. The full claims file for the MCBS sample is also available. The Access to Care file contains information on beneficiaries' access to health care, satisfaction with care, and usual source of care. The sample for this file represents the "always enrolled" population—those who participated in the Medicare program for the entire year. In contrast, the Cost and Use file represents the "ever enrolled" population, including those who entered Medicare during the year and those who died.

Each fall, about one-third of the sample is retired and roughly 6,000 new sample persons are included in the survey—the exact number chosen is based on projections of target samples of 12,000 persons with 3 years of cost and use information distributed appropriately across the sample cells. In the community, response rates for initial interviews range in the mid- to high 80s; once respondents have completed the first interview, their participation in subsequent rounds is 95 percent or more. Background data are available on nonrespondents. In recent rounds, data have been collected from approximately 15,000 to 19,000 beneficiaries, with the peaks occurring in fall rounds. Roughly 90 percent of the sample is made up of persons who live in the community, with the remaining persons living in long-term care facilities. Response rates for facility interviews approach 100 percent.

Because only Medicare enrollees are included in the survey, the survey excludes a small proportion of persons age 65 and over who are not enrolled in Medicare, which should be noted when using the MCBS to make estimates of the entire population age 65 and over in the United States.

Unit(s) of Analysis: Medicare beneficiary

Mode of Data Collection: Computer-assisted personal interview (CAPI)

Topics / Keywords: Insurance plans and their characteristics, Health care utilization, Beneficiary knowledge and perceptions and Longitudinal data

Data Years: The first round of interviewing was conducted from September through December 1991, and the survey has been continuously in the field since then. The data are designed to support both cross-sectional and longitudinal analyses.

Linked Data: Medicare claims files

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: Adler GS. A profile of the Medicare Current Beneficiary Survey. Health Care Finance Rev;15(4):153–163. 1994.

Lo A, Chu A, Apodaca R. Redesign of the Medicare Current Beneficiary Survey Sample, Rockville, MD: Westat, Inc., 2003, found at http://www.amstat.org/sections/SRMS/Proceedings/y2002/Files/JSM2002-000662.pdf.

Medicare Current Beneficiary Survey (MCBS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- X *Application process required to obtain some data files*
- X *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
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- X *Payment required for the preparation / supply of data*

Additional Information:

Contact: Research Data Assistance Center
Phone: 1–888–973–7322
Email: resdac@umn.edu
Website: http://www.resdac.umn.edu
Or, MCBS: http://www.cms.hhs.gov/mcbs/

Medicare Health Outcomes Survey (HOS)

Sponsor(s): Centers for Medicare & Medicaid Services, Office of Research, Development, and Information

Data Collection Agency: National Committee for Quality Assurance

Purpose / Primary Goals: The Medicare Health Outcomes Survey (HOS) is the first outcomes measure used in Medicare managed care. The goal of the Medicare HOS program is to gather valid, reliable, and clinically meaningful patient-reported health status data in Medicare managed care for use in quality improvement activities, plan accountability, public reporting, and improving health. All managed care plans with Medicare Advantage (MA) (formerly Medicare +Choice) contracts must participate. The HOS assesses an MA organization's ability to maintain or improve the physical and mental health of its Medicare members over time.

The Centers for Medicare & Medicaid Services (CMS), in collaboration with the National Committee for Quality Assurance (NCQA), launched the Medicare HOS in 1998. The Medicare HOS is part of the effectiveness of care component of the Healthcare Effectiveness Data and Information Set (HEDIS®). This measure was initially titled Health of Seniors, and was renamed the Medicare Health Outcomes Survey during the first year of implementation. This name change was intended to reflect the inclusion of people with Medicare who are disabled and under age 65 in the sampling methodology.

The HOS measure was developed under the guidance of a Technical Expert Panel comprising individuals with specific expertise in the health care industry and outcomes measurement. The measure includes the most recent advances in summarizing physical and mental health outcomes results and appropriate risk adjustment techniques. In addition to health outcomes measures, the HOS is used to collect height and weight to calculate body mass index, as well as the Urinary Incontinence in Older Adults, Physical Activity in Older Adults, Fall Risk Management, and Osteoporosis Testing in Older Women HEDIS® measures.

Survey Universe / Coverage / Census: Aged and disabled Medicare beneficiaries enrolled in an MA organization. Institutionalized members are eligible. Members with end stage renal disease (ESRD) are excluded.

Sample or Research Design: The HOS is an ongoing longitudinal, nationally representative Medicare managed care survey.

Sample: A random sample of Medicare beneficiaries is drawn from each participating MA organization and surveyed every spring (i.e., a survey is administered to a new baseline cohort, or group, each year). Two years later, the baseline respondents are surveyed again (i.e., follow-up measurement). Participating MA organizations must have a minimum enrollment of 500 at the time of baseline sampling. For data collection years 1998-2006, the MA organization sample size was one thousand. Effective 2007, the sample size increased to twelve hundred. For MA organizations with 1,200 members or less, all eligible members are included in the sample for the baseline survey. Cohort One was surveyed in 1998 and was resurveyed in 2000. During the 2009 HOS administration, Cohort Twelve is being surveyed and Cohort Ten resurveyed. Nearly two million beneficiaries have been surveyed to date.

Unit(s) of Analysis: Medicare managed care (i.e., Medicare Advantage) organization at the contract level.

Mode of Data Collection: The HOS is a mail survey with computer-assisted telephone (CATI) follow up for partial and non-respondents.

Topics / Key Words: Medicare, Managed care, and Longitudinal data

Data Years: 1998–2008

Linked Data: Since 2003, the HOS instrument includes the Healthy Days Measures from the Centers for Disease Control and Prevention's (CDC's) Behavioral Risk Factor Surveillance System (BRFSS). The inclusion of these questions allows a link between HOS and BRFSS results.

In addition, data from HOS Cohorts 1–4 (measurement years 1998–2004) are currently linked with data from NCI's Surveillance, Epidemiology, and End Results (SEER) cancer registry.

Reports: Research utilizing Medicare HOS data has produced a number of technical reports, manuals, and peer-reviewed articles. More information on available HOS publications can be found at http://www.hosonline.org/surveys/hos/hospublications.aspx

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Medicare Health Outcomes Survey (HOS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website:* *(see additional information below)*
- ☐ *Data available for free upon order from agency.*
- X *Application process required to obtain some data files (see additional information below)*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- X *Use of Research Data Center required for access to restricted-use data. Website: http://www.resdac.umn.edu*
- X *Payment required for the preparation / supply of data*

Additional Information:

Baseline Data, Cohorts 1–10 (Baseline Measurement Years 1998–2007) and 2-Year Analytic Cohort Data, Cohorts 1–8 (Follow Up Measurement Years 2000–07) are currently available. Follow up HOS data sets are available only for Cohorts 1–5 (2000–2004). Data for 2008 Cohort 11 Baseline and 2006–2008 Merged Analytic Cohort 9 data will be available later in 2009.

After the administration of each baseline cohort, Quality Improvement Organizations (QIOs) receive beneficiary level data files for each MA organization in their respective States. Beneficiary level performance measurement data are disseminated to all participating QIOs and made available to participating MA organizations after the follow up measurement for each cohort.

Medicare Health Outcomes Survey Modified (HOS-M)

Sponsor(s): Centers for Medicare & Medicaid Services; Office of Research, Development, and Information

Data Collection Agency: National Committee for Quality Assurance

Purpose / Primary Goals: The HOS-M, originally entitled the Program of All-Inclusive Care for the Elderly (PACE) Health Survey, is administered to vulnerable Medicare beneficiaries at greatest risk for poor health outcomes. The HOS-M is a modified version of the Medicare HOS that is administered annually by CMS to frail elderly and dual-eligible beneficiaries (i.e., recipients of both Medicare and Medicaid) for the purpose of adjusting plan payments based on the frailty of their members.

Survey Universe / Coverage / Census: Aged and disabled enrollees in Program of All-inclusive Care for the Elderly (PACE) organizations, as well as Minnesota Senior Health Options, Minnesota Disability Health Options, Wisconsin Partnership Program, and Massachusetts MassHealth Senior Care Options Special Needs Plans (SNPs). Members with ESRD and institutionalized members are excluded from sampling.

Sample or Research Design: Similar to HOS, the HOS-M design is based on a randomly selected sample of individuals from each participating PACE Organization and eligible SNP. A random sample of 1,200 eligible enrollees is selected from managed care plans with at least 1,400 members. For participating managed care plans with less than 1,400 members, all eligible members are included in the sample.

The HOS-M survey is a shorter, modified version of the Medicare Health Outcomes Survey. Unlike the HOS, the HOS-M is a cross-sectional survey that measures the physical and mental health functioning of beneficiaries at a single point in time without a follow-up. The HOS-M instrument contains six Activity of Daily Living (ADL) items as the core items used to calculate the frailty adjustment factor. The survey also includes 12 physical and mental health status questions, one question about memory loss interfering with daily activities, and one question about urinary incontinence. If the participant received assistance completing the questionnaire, the respondent was asked why a proxy was needed, how the proxy assisted the participant and the staff position of the proxy.

Unit(s) of Analysis: Medicare managed care organization at the contract level.

Mode of Data Collection: The HOS-M is a mail survey with telephone (CATI) follow up for partial and non-respondents.

Topics/Key Words: Program of All-inclusive Care for the Elderly (PACE) Program, Managed care and Frail elderly

Data Years: 2005–2008

Linked Data: n/a

Reports: Sample summary reports aggregating 2007 HOS-M results for PACE organizations and participating SNPs are available at http://www.hosonline.org/surveys/hos/hospublications.aspx.

Background / History: n/a

Future Plans: As a result of the transition from Medicare demonstration status to Medicare Advantage SNP, the Minnesota Senior Health Options, Minnesota Disability Health Options, Wisconsin Partnership Programs, and Massachusetts MassHealth Senior Care Options contracts will start collecting HOS data in 2010 and will no longer participate in HOS-M.

Bibliography: n/a

Medicare Health Outcomes Survey Modified (HOS-M)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- *X Use of Research Data Center required for access to restricted-use data. Website: **http://www.resdac.umn.edu***
- *X Payment required for the preparation / supply of data*

Additional Information:

Chris Haffer Ph.D.,

Director, Medicare HOS Program; Sonya Bowen MSW, Program Administrator.

Phone: 410–786–8764 or 410–786–5609

Email: chris.haffer@cms.hhs.gov Email: sonya.bowen@cms.hhs.gov

A general overview of the Medicare HOS program is available at the CMS HOS web address at http://www.cms.hhs.gov/hos/.

Minimum Data Set (MDS)

Sponsor(s): Centers for Medicare & Medicaid Services, Survey and Certification Group

Data Collection Agency: Medicare- and Medicaid-certified Nursing Homes

Purpose / Primary Goals: The Minimum Data Set (MDS) is a uniform set of elements extracted from the Resident Assessment Instrument (RAI), which is a standardized tool for assessing the functional capacity of residents of long term care facilities. On December 23, 1997, the Centers for Medicare & Medicaid Services (CMS) published the final rule that established the guidelines for the use of the dataset and specified the data elements included in the assessment instrument.

The Long Term Care Minimum Data Set (MDS) is a standardized, primary screening and assessment tool of health status, which forms the foundation of the comprehensive assessment for all residents of long-term care facilities certified to participate in Medicare or Medicaid.

The MDS contains items that measure physical, psychological, and psycho-social functioning. The items in the MDS give a multidimensional view of the patient's functional capacities, and can be used to present a nursing home's profile. The MDS can be linked to Medicare claims data and to survey and certification facility data to build a number of resident-level and facility-level analytical datasets. The MDS also now plays a key role in the Medicare and Medicaid reimbursement system and in monitoring the quality of care provided to nursing facility residents.

In the NPRM for the FY 2010 SNF PPS Update, CMS proposed the adoption of a new verison of the MDS, called MDS 3.0, beginning on October 1, 2010. The MDS 3.0 is an update of many of the items contained on the current MDS to reflect changes in clinical assessment.

Survey Universe / Coverage / Census: All residents of Medicare- and Medicaid-certified nursing homes

Sample or Research Design: 100 percent sample

Unit(s) of Analysis: Resident Level, Skilled Nursing Facilities and Nursing Facilities

Mode of Data Collection: Skilled Nursing Facilities and Nursing Facilities are required to complete and transmit MDS data to the designated State agency for all residents as a condition of participation in the Medicare and Medicaid programs. Automated transmission of all MDS data was required beginning in 1998. CMS began collecting MDS data in a national database in July 1998.

Topics / Keywords: Medicare, Medicaid, Long-term care, Functional status and Mental health / behavioral health

Data Years: 1998-present

Linked Data: The MDS can be linked to Medicare and Medicaid claims data and to survey and certification facility data to build a number of resident-level and facility-level analytical datasets. The MDS also now plays a key role in the Medicare and Medicaid reimbursement system and in monitoring the quality of care provided to nursing facility residents.

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Minimum Data Set (MDS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
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- X *Application process required to obtain data files*
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Additional Information:

Contact: Research Data Assistance Center
Email: resdac@umn.edu
Phone: 888–973–7322
Website: http://www.resdac.umn.edu

Outcome and Assessment Information Set (OASIS)

Sponsor(s): Centers for Medicare & Medicaid Services, CMSO, Survey and Certification Group,Division of Continuing Care Providers

Data Collection Agency: Home health agencies

Purpose / Primary Goals: The Home Health Outcome and Assessment Information Set (OASIS) contains data items that were developed for measuring patient outcomes for the purpose of performance improvement in home health care. Medicare certified home care agencies are required to conduct patient-specific comprehensive assessments at specified time points. The assessments for Medicare and Medicaid patients must contain the OASIS data elements. Some data elements are also used to determine Home Health Prospective Payment System reimbursement. This data is used to prepare OASIS Outcome reports for agency performance improvement as well as the reports posted on Home Care Compare.

OASIS data items address sociodemographic, environmental, support system, health status, functional status, and health service utilization characteristics of the patient.

Survey Universe / Coverage / Census: Adult Medicare and Medicaid patients receiving skilled services

Sample or Research Design: Universe of Medicare certified home care agencies

Unit(s) of Analysis: Patient level

Mode of Data Collection: The data are collected at start of care, 60-day follow-ups, and discharge (and transfer to and from an inpatient stay).

Topics / Keywords: Patient outcomes, Health care utilization and Home health care

Data Years: OASIS data from CMS available since 1999

Linked Data: n/a

Reports: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Outcome and Assessment Information Set (OASIS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Home Care Compare at http://www.cms.hhs.gov/OASIS/09a_hhareports.asp*
- *X Some or all public-use files downloadable free from website: http://www.cms.hhs.gov/OASIS/09a_hhareports.asp*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
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Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- *X Use of Research Data Center required for access to restricted-use data.*
- *X Payment required for the preparation / supply of data*

Additional Information:

Contact: Research Data Assistance Center
Email: resdac@umn.edu
Phone: 888–973–7322
Website: http://www.resdac.umn.edu

National Institutes of Health National Cancer Institute

Surveillance, Epidemiology, and End Results (SEER)

Sponsor(s): National Cancer Institute

Data Collection Agency: National Cancer Institute

Purpose / Primary Goals: The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) is an authoritative source of information on cancer incidence and survival in the United States. SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 26 percent of the U.S. population. SEER coverage includes 23 percent of African Americans, 40 percent of Hispanics, 42 percent of American Indians and Alaska Natives, 53 percent of Asians, and 70 percent of Hawaiian/Pacific Islanders.

The SEER Program registries routinely collect data on patient demographics, primary tumor site, tumor morphology and stage at diagnosis, first course of treatment, and follow-up for vital status. The SEER Program is the only comprehensive source of population-based information in the United States that includes stage of cancer at the time of diagnosis and patient survival data.

The SEER Program is considered the standard for quality among cancer registries around the world. Quality control has been an integral part of SEER since its inception. Every year, studies are conducted in SEER areas to evaluate the quality and completeness of the data being reported.

Survey Universe / Coverage / Census: 26 percent of U.S. resident population

Sample or Research Design: Cancer incidence and survival data from population-based cancer registries

Unit(s) of Analysis: de-identified case listing, county, state

Mode of Data Collection: population-based registry

Topics / Keywords: Cancer, population-based, survival, stage

Data Years: SEER began collecting data on cancer cases on January 1, 1973, in the States of Connecticut, Iowa, New Mexico, Utah, and Hawaii and the metropolitan areas of Detroit and San Francisco-Oakland. In 1974–1975, the metropolitan area of Atlanta and the 13-county Seattle-Puget Sound area were added. In 1978, 10 predominantly black rural counties in Georgia were added, followed in 1980 by the addition of American Indians residing in Arizona. Three additional geographic areas participated in the SEER program prior to 1990: New Orleans, Louisiana (1974–1977, rejoined 2001); New Jersey (1979–1989, rejoined 2001); and Puerto Rico (1973–1989).

The National Cancer Institute also funds a cancer registry that, with technical assistance from SEER, collects information on cancer cases among Alaska Native populations residing in Alaska. In 1992, the SEER Program was expanded to increase coverage of minority populations, especially Hispanics, by adding Los Angeles County and four counties in the San Jose-Monterey area south of San Francisco. In 2001, the SEER Program expanded coverage to include Kentucky and the remaining counties in California (Greater California); in addition, New Jersey and Louisiana once again became participants. For the expansion registries (Kentucky, Greater California, New Jersey, and Louisiana), NCI funds are combined with funds from the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries and with funds from the States.

Linked Data: The National Cancer Institute SEER databases are linked with county attributes and populations from the US Census Bureau (http://seer.cancer.gov/resources).

The linked SEER-Medicare data reflect the linkage of two large population-based sources of data that provide detailed information about elderly persons with cancer, which can be used for an array of epidemiological and health services research (http://healthservices.cancer.gov/seermedicare).

The linked SEER-National Longitudinal Mortality Study (NLSM) database is designed to expand opportunities for analyzing socioeconomic differentials in cancer incidence, survival, and tumor characteristics based on self-reported demographic and socioeconomic factors. The NCI encourages interested investigators to utilize the NLMS and SEER-NLMS databases for cancer-related research projects (http://surveillance.cancer.gov/disparities/nlms).

State Cancer Profiles is a web-based tool for public health officials, policymakers, and researchers. State Cancer Profiles provides a user-friendly interface for finding cancer statistics for specific States and counties. This website is a joint project between NCI and CDC and is part of the Cancer Control PLANET website, which provides links to comprehensive cancer control resources for public health professionals (http://statecancerprofiles.cancer.gov/help/about).

The SEER program is developing computer applications to unify cancer registration systems and to analyze and disseminate population-based data. Use of surveillance data for research is being improved through Web-based access to the data and analytic tools, and linking with other national data sources.

Reports: The SEER Cancer Statistics Review (CSR), a report of the most recent cancer incidence, mortality, survival, prevalence, and lifetime risk statistics, is published annually by the Cancer Statistics Branch of the NCI. See http://seer.cancer.gov/csr/1975_2006

The Annual Report to the Nation provides an annual update on cancer occurrence and trends in the United States. It is a collaborative effort of The American Cancer Society, the National Cancer Institute, the Centers for Disease Control and Prevention, and the North American Association of Central Cancer Registries. The current report, published in November 2008, contains a special feature on trends in lung cancer, tobacco use and tobacco control. See http://seer.cancer.gov/report_to_nation

Background / History: n/a

Future Plans: n/a

Bibliography: Search the comprehensive bibliography of SEER Publications produced by registry and program staff; if available, links to PubMed and abstracts will be provided in the search results. http://seer.cancer.gov/pubsearch/

Surveillance, Epidemiology, and End Results (SEER)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

X User-specified online data query or table generation possible. Website: http://seer.cancer.gov/faststats and http://seer.cancer.gov/canques
X Some or all public-use files downloadable free at http://seer.cancer.gov/data.
X Data available for free upon order from agency.
X Application process required to obtain some data files at http://seer.cancer.gov/data/access
☐ Payment required for the preparation/supply of data

Data Access to Non Public-Use data (i.e., data with confidential information)

☐ Application process required to obtain data files
☐ Use of Research Data Center required for access to restricted-use data.

Additional Information:

Contact: Cancer Statistics Branch, National Cancer Institute

Email: seerweb@imsweb.com

Phone: 301–496–8510

Website: http://seer.cancer.gov/

National Institute on Aging

The Aging, Demographics and Memory Study (ADAMS)

Sponsor(s): National Institute on Aging

Data Collection Agency: Institute for Social Research, University of Michigan under a cooperative agreement

Purpose / Primary Goals: The Aging, Demographics, and Memory Study (ADAMS), a supplement to the Health and Retirement Study, has the specific aim of conducting a population-based study of dementia. HRS formed a partnership with a research team led by the Epidemiology of Dementia Program at the Duke University Medical Center. The purpose of this collaboration was to conduct in-person clinical assessments for dementia on selected HRS respondents in order to gather information on their cognitive status. A diagnosis of dementia, cognitive impairment but not demented (CIND), or non-case was assigned on the basis of this assessment. Prior community-based studies of dementia have focused on a particular geographical area or have been based on nationally distributed samples that are not representative of the population. This study is the first of its kind to conduct in-home assessments of dementia in a national sample that is representative of the U.S. elderly population.

Survey Universe / Coverage / Census: US resident, non-institutionalized individuals age 70 or older.

Sample or Research Design: A group of 1,770 HRS respondents, age 70 or older, was selected from the 2000 and 2002 waves based on self or proxy cognitive assessment measures. Assessments were completed with 856 respondents

Unit(s) of Analysis: Individual level

Mode of Data Collection: Five cognitive strata (ranging from "low functioning" to "high normal") were defined based on respondents' performance in the cognitive measures in the most recent HRS interview. In-person evaluation was a 3- to 4-hour structured assessment conducted in the subject's residence by a nurse and neuropsychology technician. In addition, a self-administered paper-and-pencil caregiver questionnaire was completed by informants.

Topics / Keywords: Assets, Caregiving, Chronic conditions, Collection of biological samples, Demographics, Disability, Economics, Functional status, Health behaviors, Health care utilization, Health outcomes, Health status, Illnesses, Income, Insurance plans and their characteristics, Labor force participation, Mental health / behavioral health, Race /ethnicity, Risk factors, Self report of health status, Social characteristics Social security, Socioeconomic status, Use & expenditure for prescription medications and Use of health care services

Data Years: HRS data available on subjects from 2000- (or 2002)- present; ADAMS assessment one time between 2001 and 2005.

Linked Data: Social Security, Medicare, subjects are also part of the Health and Retirement Study and full data are available to approved researchers.

Reports: For full methods report and documentation, visit the website: http://hrsonline.isr.umich.edu/index.php?p=shoavail&jumpfrom=DD&iyear=04

Background / History: n/a

Future plans: n/a

Bibliography: An updated and searchable list of publications and studies using the HRS data can be found at: http://hrsonline.isr.umich.edu/index.php?p=biblio

The Aging, Memory and Demographics Study (ADAMS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

☐ *User-specified online data query or table generation possible.*

*X Some or all public-use files downloadable free from website: **http://hrsonline.isr.umich.edu/index.php?p=shoavail&jumpfrom=DD&iyear=04***

☐ *Data available for free upon order from agency.*

X Application process required to obtain some data files

X Payment required for the preparation/supply of data

Data Access to Non Public-Use data (i.e., data with confidential information)

X Application process required to obtain data files

☐ *Use of Research Data Center required for access to restricted-use data.*

☐ *Payment required for the preparation / supply of data*

Additional Information:

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Website: http://hrsonline.isr.umich.edu

Health and Retirement Study (HRS) and Assets and Health Dynamics of the Oldest Old (AHEAD)

Sponsor(s): National Institute on Aging, Social Security Administration

Data Collection Agency: Institute for Social Research, University of Michigan under a cooperative agreement

Purpose / Primary Goals: 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 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.

Survey Universe / Coverage / Census: US resident, non-institutionalized individuals over 55.

Sample or Research Design: 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

Unit(s) of Analysis: Person level and spouse.

Mode of Data Collection: Baseline: in-home, face-to-face in 1992 for the 1931–1941 birth cohort (and their spouses, if married, regardless of age); in 1998 for 1924–1930 (CODA: Children of the Depression Age) and 1942–1947 (War Babies) birth cohorts; in 2004 for 1948–1953 (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.

Topics / Keywords: Assets, Caregiving, Chronic conditions, Collection of biological samples, Demographics, Economics, Functional status, Health behaviors, Health care utilization, Health insurance coverage, Health status, Income, Insurance plans and their characteristics, Labor force participation, Longitudinal data, Marital status, Mental health / behavioral health, Performance measurement, Race /ethnicity, Risk factors, Self report of health status, Social security, Socioeconomic status, Use & expenditure for prescription medications and Use of health care services

Data Years: 1992-ongoing

Linked Data: Social Security, Medicare

Reports: Growing Older in America: the Health and Retirement Study (available for download at: http://hrsonline.isr.umich.edu/).

For detailed reports on data documentation and methods, please visit the website: http://hrsonline.isr.umich.edu/index.php?p=docfinder&jumpfrom=DD

Background / History: The Health and Retirement Study (HRS) and Asset and Health Dynamics Among the Oldest Old (AHEAD) studies were created as separate but related surveys. The original HRS study was supported by a cooperative agreement between the National Institutes on Aging (NIA) and the University of Michigan, with additional funding from the Social Security Administration, the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services (DHHS), and the Pension and Welfare Benefit Office. It was joined in 1993 by a companion study, Assets and Health Dynamics of the Oldest Old (AHEAD), consisting of persons born before 1924 who were aged 70 and over in 1993. It was funded as a supplement to the HRS.

In its original conceptualization, the HRS study was designed to follow age- eligible individuals and their spouses as they made the transition from active worker into retirement; the AHEAD study was designed to examine the dynamic interactions between health, family, and economic variables, in the post-retirement period at the end of life. The HRS study spanned three waves of data collection: 1992, 1994, and 1996. The AHEAD study included two waves: 1993 and 1995. The HRS and AHEAD sample designs provided for exit interviews with a surviving spouse, child or other informant concerning medical expenditures and family interactions with the deceased during the final stages of life. Exit interviews with survivors also were designed to provide information about the disposition of assets following death.

Both studies obtained detailed information in a number of domains: demographics, health status, housing, family structure, employment of respondent, work history and current employment, disability, retirement plans, net worth, income, and health and life insurance. In addition, there were several important linkages between HRS and AHEAD survey data and information from employers and from administrative data. HRS supplementary data included administrative data from Social Security earnings and benefits records, National Death Index data, Medicare claims record data and employer pension data.

In 1998 the HRS and AHEAD studies were merged, resondents from each forming a cohort in a combined interview. At the same time, two new cohorts were added: the Children of the Depression Era (CODA), born in 1924–30 and War Babies (WB), born in 1942–1947.

Future Plans: The study is currently in the field; future waves are planned.

Bibliography: An updated and searchable list of publications and studies using the HRS data can be found at: http://hrsonline.isr.umich.edu/index.php?p=biblio

Health and Retirement Study (HRS) and Assets and Health Dynamics of the Oldest Old (AHEAD)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website:* ***http://hrsonline.isr.umich.edu/index.php?p=data***
- ☐ *Data available for free upon order from agency.*
- X *Application process required to obtain some data files*
- X *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

For detailed information on data access and available files, please see the HRS website: http://hrsonline.isr.umich.edu/

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National Long Term Care Survey (NLTCS)

Sponsor(s): Assistant Secretary for Planning and Evaluation and National Institute on Aging

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The National Long-Term Care Surveys (NLTCS) was designed to measure the point prevalence of chronic (90 days or more) disability in the U.S. elderly Medicare enrolled population and to provide longitudinal data on the changes (both improvement and decline) in health, chronic disability, and institutionalization. The NLTCS also tracked health expenditures, Medicare service use, and the availability of personal, family, and community resources for caregiving. The survey began in 1982, and follow-up surveys were conducted in 1984, 1989, 1994, 1999, and 2004. The NLTCS were surveys of the entire Medicare enrolled aged population with a particular emphasis on the aged who are functionally impaired. As sample persons were followed through the Medicare record system, virtually 100 percent of cases were tracked longitudinally, providing information on onset and recovery from disability, as well as exact dates of death. NLTCS sample persons were followed until death and were permanently and continuously linked to the Medicare record system from which they were 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.

Survey Universe / Coverage / Census: Aged Medicare beneficiaries in both community and institutional settings.

Sample or Research Design: The 1982 NLTCS sample was randomly drawn from Medicare administrative files. A two-stage procedure identified chronically disabled persons for household interviews. Chronically disabled community residents were interviewed at home. No institutional interviews were conducted in 1982.

The 1984 NLTCS introduced a complete longitudinal design with an institutional component. All persons surviving to 1984 who, in 1982 either reported chronic disability or were in an institution, were re-interviewed in 1984 with either a detailed community or institutional questionnaire. Consequently, not only disabled survivors were tracked, but also formerly disabled survivors who had become nondisabled. Community residents screened in 1982 who were not chronically disabled were rescreened with the same instrument in 1984 to determine new disability incidence. A new sample of persons 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 2-year disability and mortality rates for a longitudinally followed population and representative cross-sectional prevalence estimates of disability and institutional residence for the total 1984 elderly Medicare population. The Next-of-Kin survey was conducted along with this wave.

The methodology in 1989 followed that of 1984, and by following survivors from 1984 provided data on both disability and institutional rates for the 1982–1989 period, and by drawing a new representative sample estimated the crosssectional prevalence of disability and institutional residence in the total 1989 elderly Medicare population. The Informal Caregiver survey was conducted with this wave.

The 1994 NLTCS followed the methodology of the previous two survey waves, to provide precise estimates of disability and institutionalization rates for the 1982–1994 period, and to provide data on the cross-sectional prevalence of disability and institutional residence in the 1994 elderly Medicare population. Furthermore, in 1994, a supplementary group of community interviews were conducted with nondisabled persons (the healthy supplement). This group was followed like all other detailed interview persons in subsequent years. Further, a group of persons age 95 and older were also drawn in 1994 and screened for disability. This supplemental sample greatly increased the precision associated with estimates of the very old.

The 1999 NLTCS was designed to precisely estimate disability and institutionalization rates for the 1982–1999 period. In 1999, Computer-assisted Personal Interviewing (CAPI) was used for the first time. Following the methodology of the 1984, 1989, and 1994), persons in any of the previous surveys who received a detailed interview (in the community or an institution) and survived to 1999 were reinterviewed, and again the "aged-in" sample of people who turned 65 between 1994 and 1999 were screened for disability. Non-disabled survivors from the 1994 "healthy subsample," as well as an additional sample of non-disabled Medicare beneficiaries living in the community, were interviewed to be followed like other detailed interview groups in future survey years. As in 1994, a group of persons age 95 and older were selected in 1999 to provide precise estimates of the very old population. The Informal Caregiver and the Next-of-Kin surveys were conducted with this wave.

The 2004 used the same methodology of the previous surveys to estimate disability and institutionalization rates for the 1982-2004 period, and included an "aged-in" sample to provide cross-sectional estimates of disability and institutionalization. The "healthy subsample" from 1999 was also reinterviewed, and additional sample of non-disabled, non-institutionalized beneficiaries were "aged-in" to this group as well. Again, a sample of persons aged 95 or older was selected in 2004 to provide precise estimates of the very old population. The Informal Caregiver survey was conducted with this wave.

Unit(s) of Analysis: Person-level (self report or proxy report)

Mode of Data Collection: In-person (Computer-assisted personal interview (CAPI) in 1999 and 2004)

Topics / Keywords: Access to care, Caregiving Charges and sources of payment for healthcare, Chronic conditions, Demographics, Disability, Economic, Functional status, Health behaviors, Health care utilization, Health insurance coverage, Health outcomes, Health status, Long-term care, Longitudinal data, Marital status, Mortality, Performance measurement, Race/ethnicity, Risk factors, Self report of health status, Smoking, Social characteristics, Socioeconomic status and Use of health care services.

Data Years: 1982, 1984, 1989, 1994, 1999, 2004

Linked Data: Medicare claims data

Reports: For detailed documentation, and a list of links to published reports on methods and data collection, please see the NLTCS project website: http://www.nltcs.aas.duke.edu/doc.htm.

Background / History: n/a

Future Plan: n/a

Bibliography: A detailed bibliography can be found at: http://www.nltcs.aas.duke.edu/publications/search/search.htm

National Long Term Care Survey (NLTCS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: **http://www.icpsr.umich.edu/cocoon/NACDA/STUDY/09681.xml***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files. For linked Medicare data, contact the Research Data Assistance Center at **http://www.resdac.umn.edu***
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

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Email: patmiosg@nia.nih.gov

Website: http://www.icpsr.umich.edu/cocoon/NACDA/STUDY/09681.xml

National Social Life, Health, and Aging Project (NSHAP)

Sponsor(s): National Institutes of Health (NIH), specifically National Institute on Aging (NIA), Office of Research on Women's Health, Office of AIDS Research. Additional financial support provided by the National Opinion Research Center (NORC).

Data Collection Agency: National Opinion Research Center (NORC)

Purpose / Primary Goals: The health of older adults is influenced by many factors. One of the least understood is the role that social support and personal relationships may play in healthy aging. The National Social Life, Health, and Aging Project (NSHAP) is the first population-based study of health and social factors on a national scale, aiming to understand the well-being of older, community-dwelling Americans by examining the interactions among physical health, illness, medication use, cognitive function, emotional health, sensory function, health behaviors, and social connectedness. It is designed to provide health providers, policy makers, and individuals with useful information and insights into these factors, particularly on social and intimate relationships. The study will be important in finding new ways to reduce morbidity and prevent dysfunction and disease as people age.

Survey Universe / Coverage / Census: Nationally representative sample of community dwelling individuals aged 57–85

Sample or Research Design: NORC, with Principal Investigators at the University of Chicago, conducted more than 3,000 interviews during 2005 and 2006 with a nationally representative sample of adults aged 57 to 85. Face-to-face interviews and biomeasure collection took place in respondents' homes. Data collection elicited: 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, using non-invasive collection techniques and cutting edge technology that minimizes respondent burden. NSHAP plans to conduct follow-up interviews with respondents every five years to collect longitudinal data.

Complex, multi-stage, area probability sample from Inter-University Consortium for Political and Social Research (ICPSR) with the National Archive of Computerized Data on Aging (NACDA) at website: http://www.icpsr.umich.edu/cocoon/NACDA/STUDY/20541.xml)

Unit(s) of Analysis: Individual

Mode of Data Collection: Data collection consisted of three components: in-person questionnaire, biomeasure collection, and a mail-in supplemental self-administered questionnaire.

Topics / Keywords: Aging, Demographics, Emotional health, Health status, Healthy aging, Longitudinal data, Mental health / behavioral health, Older adults, Personal relationships, Social characteristics, Social connectedness, Social factors, Social networks, Social and cultural activity, and Social support

Data Years: Began 2005–2006; follow-up interviews every five years

Linked Data: n/a

Background / History: n/a

Reports: n/a

Future Plans: NSHAP plans to conduct follow-up interviews with respondents every five years to collect longitudinal data

Bibliography: http://www.norc.org/NSHAP/NSHAP+Publications.htm

National Social Life, Health, and Aging Project (NSHAP)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website:* ***http://www.norc.org/nshap through ICPSR at http://www.icpsr.umich.edu/cocoon/ICPSR/STUDY/20541.xml***
- ☐ *Data available for free upon order from agency. Order from*
- X *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

NSHAP data are available to the public through ICPSR (Inter-university Consortium for Political and Social Research).

Users interested in obtaining data from NACDA (National Archive of Computerized Data on Aging) must request and complete the NSHAP Restricted Data Use Agreement form. Users can download this form from the download page associated with this dataset. A copy of this form can also be obtained by contacting ICPSR User Support (734–647–2200). Completed forms with original signature(s) should be mailed to: Director, National Archive of Computerized Data on Aging, Inter-university Consortium for Political and Social Research, Institute for Social Research, P.O. Box 1248, University of Michigan, Ann Arbor, MI 48106–1248.

Some instruments administered as part of this study may contain contents from copyrighted instruments. Reproductions of the instruments are provided solely as documentation for the analysis of the data associated with this collection. Please contact the data producers for information on permissions to use the instruments for other purposes.

Contact: Stephen Smith, Project Director, NSHAP and Kathleen Parks, Senior Vice President, Academic Research Centers, National Opinion Research Center

Email: smith-stephen@norc.org and parks-kathleen@norc.org

Phone: 312–759–4023 and 773–256–6302

Website: http://www.norc.org/nshap

National Survey of Midlife Development in the United States (MIDUS I and MIDUS II)

Sponsor(s): National Institute on Aging and The John D. and Catherine T. MacArthur Foundation

Data Collection Agency: University of Wisconsin

Purpose / Primary Goals: MIDUS (Midlife in the U.S.) is a national study of the role of behavioral, psychological, and social factors in health and well-being, broadly defined, as people age from early adulthood into midlife and old age. It was conceived by a multidisciplinary team of scholars from fields of psychology, sociology, epidemiology, demography, anthropology, medicine, and health care policy. The first wave of data collection utilized survey and questionnaire methodologies. The second wave of the study has incorporated numerous additions, including new measures of cognitive performance, diverse biomarkers, and neurological assessments.

Survey Universe / Coverage / Census: Nationally representative, non-institutionalized, English-speaking adults aged 25 and older

Sample or Research Design: Multi-stage sampling design. At Stage 1, an equal probability sample of telephone numbers was selected. Predesignated households were then selected in random replicates. Information was collected from the contact person regarding household composition to determine the availability of a potential respondent meeting the eligibility criteria stated above. After explaining the study to the informant, a household listing was generated of English-speaking people in the age range 25–74, and a random respondent was selected. Oversampling was conducted in five metropolitan areas (Boston, Atlanta, Chicago, Phoenix, San Francisco). Siblings were identified by members of the national sample and added to the sample, yielded 1,614 sibling pairs. The 998 twin pairs participating in the MIDUS Twin Screening Project represent the first national sample of twin pairs ascertained randomly via the telephone.

Unit(s) of Analysis: Individual

Mode of Data Collection: Telephone and self-response mailed questionnaire; daily diary study; cognitive assessments for the full MIDUS sample, plus longitudinal follow-up for the cognitive subsample from MIDUS I; comprehensive biomarker assessments on a subsample of MIDUS respondents; neuroscience assessments on a subsample of respondents in the biomarker study.

Topics/Key Words: Assets, Chronic conditions, Collection of biological samples, Demographics, Functional status, Health behaviors, Health status, Income, Injuries, Labor force participation, Longitudinal data, Marital status, Mental health / behavioral health, Race /ethnicity, Risk factors, Self report of health status, Smoking, Social characteristics, Socioeconomic status, Substance abuse (drug/alcohol) and Use of health care services

Data Years: MIDUS I was undertaken in 1994–1995. MIDUS II began follow-up on these same individuals and added to the sample in 2002.

Linked Data: n/a

Reports: Detailed documentation and reports on methods and study methodology are available at: http://www.midus.wisc.edu/findings/

Background / History: In 1994–1995, the MacArthur Midlife Research Network carried out a national survey of over 7,000 Americans aged 25 to 74. The purpose of the study was to investigate the role of behavioral, psychological, and social factors in understanding age-related differences in physical and mental health. The study was innovative for its broad scientific scope, its diverse samples (which included twins and siblings of main sample respondents), and its creative use of satellite studies to obtain in-depth assessments in key areas (e.g., daily stress, cognitive functioning). Publications from MIDUS I have since appeared in leading journals in fields of aging, demography, epidemiology, medicine, psychology, and sociology.

Beginning in 2002, the Institute on Aging at the University of Wisconsin-Madison initiated a longitudinal follow-up on all MIDUS respondents. The new initiative includes five research projects, which cover the following topics: Project 1 provides follow-up on the psychosocial, sociodemographic, and health variables assessed in MIDUS I; Project 2 provides follow-up on the daily diary study included in MIDUS I; Project 3 includes new cognitive assessments for the full MIDUS sample, plus longitudinal follow-up for the cognitive subsample from MIDUS I; Project 4 includes comprehensive biomarker assessments on a subsample of MIDUS respondents, collected at one of 3 General Clinical Research Centers around the country; and Project 5 includes neuroscience assessments on a subsample of respondents in the biomarker study.

Future plans: A new wave of data collection is planned.

Bibliography: An updated and searchable bibliography is available at: http://www.icpsr.umich.edu/NACDA/search.html, search term "MIDUS"

National Survey of Midlife Development in the United States (MIDUS I and MIDUS II)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

☐ *User-specified online data query or table generation possible.*

X Some or all public-use files downloadable free from website: http://www.icpsr.umich.edu/NACDA/search.html

☐ *Data available for free upon order from agency.*

X Application process required to obtain some data files

☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

X Application process required to obtain data files

☐ *Use of Research Data Center required for access to restricted-use data.*

☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: MIDUS - A National Study of Health and Well-Being, and University of Wisconsin - Madison Institute on Aging

Phone: 608–262–2056

Email: Helpdesk request form at http://www.midus.wisc.edu/helpdesk.php

Website: http://www.midus.wisc.edu/

New Immigrant Survey (NIS)

Sponsor(s): National Institute on Aging, National Institute of Child Health and Human Development, Office of Behavioral and Social Science Research, National Science Foundation, U.S. Citizenship and Immigration Services, Assistant Secretary for Planning and Evaluation in HHS, Pew Charitable Trusts.

Data Collection Agency: National Opinion Research Center, University of Chicago

Purpose / Primary Goals: The main objective is to provide a public use database on new legal immigrants to the United States 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; evaluate employment situations prior to immigration, i.e., occupation, income, and social assimilation; evaluate the assimilation of immigrants into U.S. society; examine the schooling of immigrants; compare NIS survey instruments with comparable instruments used in major U.S. longitudinal surveys; examine the transition from temporary to permanent citizenship; compare the health and wellbeing of immigrants with native citizens

Survey Universe / Coverage / Census: Nationally representative sample of the electronic administrative records compiled for new immigrants by the U.S. government

Sample or Research Design: 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 83 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 multimodal: 60 percent of adult interviews were administered by telephone; 40 percent 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.

Unit(s) of Analysis: Individual

Mode of Data Collection: Telephone and in-person survey

Topics / Keywords: Assets, Charges and sources of payment for healthcare, Chronic conditions, Demographics, Economics, Health behaviors, Health care utilization, Health insurance coverage, Health status, Housing, Illnesses, Income, Insurance plans and their characteristics, Labor force participation, Language ability, Marital status, Race /ethnicity, Risk factors, Self report of health status, Social characteristics, Socioeconomic status and Use of health care services

Data Years: A pilot was carried out in 1996, NIS-1 was fielded in 2003.

Linked Data: n/a

Reports: Data documentation is available at: http://nis.princeton.edu/documentation.html.

A series of technical papers is available at: http://nis.princeton.edu/papers.html

Background / History: The first full cohort (NIS-2003) sampled immigrants from the seven-month period May to November of 2003. The sampling frame consists of new-arrival immigrants – immigrants arriving in the United States with immigrant documents acquired abroad - and adjustee immigrants - immigrants who are already in the United States with a temporary nonimmigrant visa (or, in some cases, illegally) and adjust to lawful permanent residence. The Adult and Child Samples are defined in terms of immigration category and age. The Adult Sample covers all immigrants who are 18 years of age or older at admission to the Lawful Permanent Residence (LPR) program. The Child Sample covers immigrants with child-of-U.S.-citizen visas who are under 18 years of age and adopted orphans under five years of age.

Future Plans: n/a

Bibliography: An updated bibliography is available at: http://nis.princeton.edu/papers.html

New Immigrant Survey (NIS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: http://nis.princeton.edu/*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

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Panel Study of Income Dynamics (PSID)

Sponsor(s): National Institute on Aging, National Institute of Child Health and Human Development, National Science Foundation, Assistant Secretary for Planning and Evaluation in HHS, U.S. Department of Agriculture.

Data Collection Agency: University of Michigan, Institute for Social Research

Purpose / Primary Goals: The Panel Study of Income Dynamics, 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. The inclusion of supplemental modules has provided information on wealth, health, parental health and long term care, and the financial impact of illness.

Survey Universe / Coverage / Census: Longitudinal, nationally representative sample of U.S. individuals (men, women, and children) and the family units in which they reside.

Sample or Research Design: The PSID sample, originally selected in 1968, consisted of two independent samples: a cross-sectional national sample and a national sample of low-income families. The cross-sectional sample was drawn by the Survey Research Center (SRC). Commonly called the SRC sample, this was an equal probability sample of households from the 48 contiguous states and was designated to yield about 3,000 completed interviews. The second sample came from the Survey of Economic Opportunity (SEO), conducted by the Bureau of the Census for the Office of Economic Opportunity.

Unit(s) of Analysis: Reporting unit is the family: single person living alone or sharing a household with other nonrelatives; 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 black persons (30 percent). Waves 1990 through 1995 included a 20 percent Hispanic oversample; within the Hispanic oversample, Cubans and Puerto Ricans were oversampled relative to Mexicans.

Mode of Data Collection: Telephone interview. Event history calendar methodology added in 2001 to facilitate recall of employment spells.

Topics / Keywords: Assets, Caregiving, Charges and sources of payment for healthcare, Demographics, Disability, Economics, Health behaviors, Health care utilization, Health insurance coverage, Health status, Housing, Housing characteristics, Income, Insurance plans and their characteristics, Labor force participation, Language ability, Long-term care, Longitudinal data, Marital status, Race /ethnicity, Risk factors, Self report of health status, Social characteristics, Social security, Socioeconomic status and Use of health care services

Data Years: 1968-ongoing

Linked Data: Geocode (GIS) file, National Death Index (NDI), Medicare

Reports: Documentation of data is available at: http://psidonline.isr.umich.edu/Data/

Background / History: The PSID sample, originating in 1968, consisted of two independent samples: a cross-sectional national sample and a national sample of low-income families. The cross-sectional sample was drawn by the Survey Research Center (SRC); this was an equal probability sample of households from the 48 contiguous states and was designated to yield about 3,000 completed interviews. The second sample came from the Survey of Economic Opportunity (SEO), conducted by the Bureau of the Census for the Office of Economic Opportunity. In the mid-1960's, the PSID selected about 2,000 low-income families with heads under the age of sixty from SEO respondents. The sample, known as the SEO sample, was confined to Standard Metropolitan Statistical Areas (SMSA's) in the North and non-SMSA's in the Southern region. The PSID core sample combines the SRC and SEO samples.

From 1968 to 1996, the PSID interviewed and reinterviewed individuals from families in the core sample every year, whether or not they were living in the same dwelling or with the same people. Adults have been followed as they have grown older, and children have been observed as they advance through childhood and into adulthood, forming family units of their own.

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 over 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 2001–03 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.

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.

Future Plans: Future waves are planned but not yet funded

Bibliography: A searchable bibliography is available online at: http://psidonline.isr.umich.edu/Publications/Bibliography/default.aspx

Panel Study of Income Dynamics (PSID)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible.*
  Website: http://simba.isr.umich.edu/
- *X Some or all public-use files downloadable free from website*
- *☐ Data available for free upon order from agency.*
- *☐ Application process required to obtain some data files*
- *☐ Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- *☐ Use of Research Data Center required for access to restricted-use data.*
- *☐ Payment required for the preparation / supply of data*

Additional Information:

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Website: http://psidonline.isr.umich.edu/

Wisconsin Longitudinal Study (WLS)

Sponsor(s): National Institute on Aging

Data Collection Agency: University of Wisconsin

Purpose / Primary Goals: The Wisconsin Longitudinal Study (WLS) is a long-term study based on a random sample of 10,317 men and women who graduated from Wisconsin high schools in 1957. A companion sample contains comparable data for a randomly selected sibling of most respondents. WLS data cover social background, youthful aspirations, schooling, military service, labor market experiences, family characteristics and events, social participation, psychological characteristics, health and well-being, and retirement.

Survey Universe / Coverage / Census: Men and women who graduated from Wisconsin high schools in 1957

Sample or Research Design: Longitudinal survey of a random sample of 10,317 men and women who graduated from Wisconsin high schools in 1957 and of their randomly selected brothers and sisters. The survey data from earlier years have been supplemented by mental ability tests (of primary respondents and 2000 of their siblings), measures of school performance, and characteristics of communities of residence, schools and colleges, employers, and industries. The WLS records for primary respondents are also linked to those of three same-sex high school friends within the study population. In 1977 the study design was expanded with the collection of parallel interview data for a highly stratified sub-sample of 2000 siblings of the primary respondents. In the 1992–1993 round of the WLS the sample was expanded to include a randomly selected sibling of every respondent with at least one brother or sister, and the content was extended to obtain detailed occupational histories and job characteristics; incomes, assets, and inter-household transfers; social and economic characteristics of parents, siblings, and children and descriptions of the respondents' relationships with them; and extensive information about mental and physical health and well-being. Brief, close-out interviews were carried out with a relative of respondents who have died, and, in cases in which the selected sibling has died, close-out data from the original respondent were obtained.

Unit(s) of Analysis: Individual level; data is also available for siblings, and husband-wife pairs.

Mode of Data Collection: Data collection – of which the surveys are only the first phase – spans many modes: telephone and mail surveys, brain imaging, personal interviews, anthropometric measurement, bio-indicators, and content analysis of recorded interviews.

Topics/Key Words: Assets, Caregiving, Chronic conditions, Collection of biological samples, Demographics, Economics, Functional status, Health behaviors, Health status, Income, Labor force participation, Longitudinal data, Marital status, Mental health / behavioral health, Risk factors, Self report of health status, Smoking, Social characteristics, Socioeconomic status, Use of health care services and Veteran status

Data Years: Survey data were collected from the original respondents or their parents in 1957, 1964, 1975, 1992, and 2004; from a selected sibling in 1977, 1994, and 2005; from the spouse of the original respondent in 2004; from the spouse of the selected sibling in 2006; and from widow(er)s of the graduates and siblings in 2006.

Linked Data: n/a

Reports: Supplementary documents can be found at http://www.ssc.wisc.edu/wlsresearch/documentation/

Background / History: Survey data were collected from the original respondents or their parents in 1957, 1964, 1975, and 1992, and from a selected sibling in 1977 and 1993. These data provide a full record of social background, youthful aspirations, schooling, military service, family formation, labor market experiences, and social participation of the original respondents. The survey data from earlier years have been supplemented by mental ability tests (of primary respondents and 2000 of their siblings), measures of school performance, and characteristics of communities of residence, schools and colleges, employers, and industries.

The WLS records for primary respondents are also linked to those of three same-sex high school friends within the study population. In 1977 the study design was expanded with the collection of parallel interview data for a highly stratified sub-sample of 2000 siblings of the primary respondents. In the 1992–1993 round of the WLS the sample was expanded to include a randomly selected sibling of every respondent with at least one brother or sister, and the content was extended to obtain detailed occupational histories and job characteristics, incomes, assets, and inter-household transfers, social and economic characteristics of parents, siblings, and children and descriptions of the respondents' relationships with them, and extensive information about mental and physical health and well-being. As in later, large, longitudinal studies of school-based samples, age variation occurs in repeated observations rather than in cross-section.

Also, siblings cover several adjoining cohorts: they were born primarily between 1930 and 1948. In 1964, 1975, and again in 1992, about two-thirds of the sample lived in Wisconsin, and about one-third lived elsewhere in the U.S. or abroad.

In 1992–1993 a follow-up survey – of about 9,000 men and women who were first interviewed as seniors in Wisconsin high schools in 1957 and have subsequently been followed up in 1957, 1964, and 1975 – was completed. Most respondents were 53 or 54 years old when interviewed. Other members of the original sample who were not interviewed in 1975 (475 of 850 surviving non-respondents) have also been interviewed. In all, 8493 of the 9741 surviving members of the original sample have been interviewed. In 1993–1994 randomly selected siblings of the high school graduates were interviewed. Some 2000 siblings were previously interviewed in 1977, and they and approximately 2800 additional siblings were interviewed in the 1993–1994 round of the study.

Future Plans: An upcoming round of survey data collection is planned.

Bibliography: A searchable bibliography can be found at http://www.ssc.wisc.edu/wlsresearch/publications/

Wisconsin Longitudinal Study (WLS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

☐ *User-specified online data query or table generation possible.*

X Some or all public-use files downloadable free from website: http://www.ssc.wisc.edu/wlsresearch/data/

☐ *Data available for free upon order from agency.*

X Application process required to obtain some data files

☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

X Application process required to obtain data files

☐ *Use of Research Data Center required for access to restricted-use data.*

☐ *Payment required for the preparation / supply of data*

Additional Information:

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Substance Abuse and Mental Health Services Administration

Client/Patient Sample Survey (CPSS)

Sponsor(s): Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), Division of State and Community Systems Development (DSCSD)

Data Collection Agency: SAMHSA/CMHS

Purpose / Primary Goals: To provide national estimates on the number and sociodemographic, clinical, and service use characteristics of persons who receive services in specialty mental health organizations nationwide.

Survey Universe / Coverage / Census: Annual admissions to and persons under care on a single day in specialty mental health organizations that include: State psychiatric hospitals, private psychiatric hospitals, the separate psychiatric services of non-Federal general hospitals and Veterans Administration medical centers, multiservice mental health organizations, residential treatment centers, and freestanding mental health outpatient clinics.

Sample or Research Design: Samples are based on a two-staged, stratified design. For each type of program setting (inpatient, residential, outpatient), clients/patients are systematically sampled from within a sample of specialty mental health organization types. Sample cases are weighted to produce national-level estimates on the number of persons served.

Unit(s) of Analysis: Cross-tabulations of client/patient-level characteristics by type of program setting and type of specialty mental health organization.

Mode of Data Collection: Mailed client/patient questionnaires to programs for completion on a sample of program's caseload; data abstracted from medical records.

Topics/Key Words: Access to care, Charges or sources of payment for healthcare, Chronic conditions, Demographics, Disability, Economics, Functional status, Health behaviors, Health care utilization, Health insurance coverage, Health outcomes, Health status, Housing characteristics, Illnesses, Long-term care, Longitudinal data, Marital status, Medicaid, Mental health/behavioral health, Race/ethnicity, Social characteristics, Substance abuse (drug/alcohol), Use of health care services, and Veteran status

Data Years: 1970, 1975, 1980, 1986, and 1997

Linked Data: The Inventory of Mental Health Organizations (IMHO)

Reports: The most recent analyses of CPSS data can be found in Mental Health, United States, 2000; Mental Health, United States, 2002; and Mental Health, United States, 2004. These publications are available on line at: http://mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics/

Background / History: n/a

Future Plans: A CPSS was conducted in late spring 2007. The outpatient program setting of specialty mental health organizations was surveyed. The 2007 CPSS also included an adult self-report consumer perception of care survey component. Program respondents (and adult consumer respondents) had the option of completing questionnaires on paper or electronically on the web.

Bibliography: n/a

Client/Patient Sample Survey (CPSS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- X *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

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Website: n/a

Drug Abuse Warning Network (DAWN)

Sponsor(s): Substance Abuse and Mental Health Services Administration, Office of Applied Studies

Data Collection Agency: Substance Abuse and Mental Health Services Administration

Purpose / Primary Goals: The Drug Abuse Warning Network (DAWN) is an ongoing, national public health surveillance system that collects data and reports information on adverse health consequences associated with drug use, misuse, and abuse. Specifically, DAWN captures data on drug-related emergency department (ED) visits from a national probability sample of hospitals with oversampling in selected metropolitan areas. DAWN also collects data on drug-related deaths reviewed by medical examiners and coroners (ME/Cs) in participating jurisdictions in selected metropolitan areas and States. DAWN helps communities, member facilities, local public health authorities, as well as Federal agencies and policymakers assess emerging drug problems, improve patient care, and monitor drug trends. The entire DAWN system was recently redesigned to collect better data more efficiently and to serve the information needs of its users more effectively.

Survey Universe / Coverage / Census: Hospitals are selected by scientific sampling. Hospitals eligible for the sample are short-term, general, non-Federal facilities, with 24-hour emergency departments. The sample is stratified based on these hospital characteristics:

- Location (in selected metropolitan areas vs. elsewhere in the United States)
- Ownership (public vs. private)
- Size (small, medium, or large)

ME/Cs are invited to join DAWN based on their location in selected metropolitan areas and States across the country. DAWN invites jurisdictions:

- In the same metropolitan areas where DAWN has oversampled hospitals. With ME/C jurisdictions and hospital EDs covering the same metropolitan areas, so that DAWN can measure drug-related morbidity and mortality for the same population base.
- In States with centralized medical examiner systems.
- In selected metropolitan areas where DAWN does not have an active sample of hospitals. In some instances, this will be the only data on substance abuse readily available for these local areas.

Sample or Research Design: The current DAWN ED sample design consists of a stratified, single-stage cluster sample. The design uses primary geographic strata with as many as eight finer strata within each geographic stratum. The geographic strata represent the selected metropolitan areas and subdivisions and the balance of the United States (“remainder area”). The stratification within each geographic area reflects the public or private ownership of the hospital and the size of the hospital in terms of the number of ED visits. Hospitals are selected with equal probability within stratum and all ED visits, charts reviewed, and DAWN cases are captured within sampled hospitals. In 2007, 207 hospitals submitted data that were used for estimation.

Unit(s) of Analysis: The drug-related ED visit or the drug-related death is the primary unit of analysis used in DAWN. A secondary ED unit of analysis is the drug report. Multiple drugs may be reported for an individual visit or death.

Mode of Data Collection: Drug-related ED visits are found through a process of retrospective chart review. All charts for patients treated in a participating ED are reviewed to find the drug-related visits. Data items are submitted electronically for the drug-related visits found. A comparable process is followed in ME/C jurisdictions where all case files are reviewed to find drug-related deaths. Data items are submitted electronically on the drug-related deaths.

Topics / Keywords: Access to care, Demographics, Health behaviors, Mental health / behavioral health, Mortality, Race / ethnicity, Substance abuse (drug/alcohol), Use of health care services, Nonmedical use of pharmaceuticals and Drug-related deaths

Data Years: Comparative data estimates since 2004

Linked Data: n/a

Reports: DAWN publishes annual estimates of drug-related ED visits for the Nation and for selected metropolitan oversampled areas. Estimates for 2004 were the first to reflect the major redesign of the DAWN system that began in 2003. Therefore, no comparisons of DAWN estimates prior to 2004 are possible. DAWN publishes annual profiles of drug-related deaths for selected metropolitan areas, jurisdictions, and States.

Mortality profiles for 2003 were the first to reflect all the changes from the redesign. Therefore, no comparisons of DAWN mortality data prior to 2003 are possible. The DAWN Report is a series of short publications on special topics that are published periodically from DAWN. Methodology publications are produced periodically to address the statistical design, analyses, and approaches used in DAWN. Website: https://restricted.dawninfo.net/login.asp

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

Drug Abuse Warning Network (DAWN)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: **http://www.dawninfo.samhsa.gov/default.asp***
- *X Some or all public-use files downloadable free from website*
- *☐ Data available for free upon order from agency.*
- *X Application process required to obtain some data files*
- *X Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *☐ Application process required to obtain data files*
- *X Use of Research Data Center required for access to restricted-use data. Website: **https://restricted.dawninfo.net/login.asp***
- *☐ Payment required for the preparation / supply of data*

Additional Information:

Online tables available in 2009.

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Website: https//www.dawninfo.samhsa.gov/default.asp

National Survey on Drug Use and Health (NSDUH)

Sponsor(s): Substance Abuse and Mental Health Services Administration, Office of Applied Studies (OAS)

Data Collection Agency: Office of Applied Studies

Purpose / Primary Goals: The National Survey on Drug Use and Health (NSDUH) has been conducted since 1971 and serves as the primary source of information on the prevalence and incidence of illicit drug, alcohol, and tobacco use in the civilian, noninstitutionalized population aged 12 or over in the United States. Information about substance abuse and dependence, mental health problems, and receipt of substance abuse and mental health treatment also is included. Before 2002, the name of the survey was the National Household Survey on Drug Abuse (NHSDA).

Survey Universe / Coverage / Census: The civilian, noninstitutionalized population aged 12 years old or over residing within the United States. The survey covers residents of households (living in houses/townhouses, apartments, condominiums, etc.), persons in noninstitutional group quarters (e.g., shelters, rooming/boarding houses, college dormitories, migratory workers' camps, halfway houses), and civilians living on military bases. Persons excluded from the survey include homeless people who do not use shelters, active military personnel, and residents of institutional group quarters, such as correctional facilities, nursing homes, and long-term psychiatric hospitals.

Sample or Research Design: A 50-State design has been employed since 1999, where 8 States were designated as large sample States (California, Florida, Illinois, Michigan, New York, Ohio, Pennsylvania, and Texas) with a target sample size of 3,600 per State per year. For each of the remaining 42 States and the District of Columbia, the target sample size is 900 per year.

States were first stratified into a total of 900 State sampling (SS) regions (48 regions in each large sample State and 12 regions in each small sample State). These regions were contiguous geographic areas designed to yield the same number of interviews on average. In each SS region, 8 census tracts were selected with probability proportional to size for inclusion in the survey each year. Within these tracts, adjacent census blocks were combined to form the second-stage sampling units, called area segments. One segment per census tract per year was selected with probability proportional to population size.

These sampled segments were allocated equally into four separate samples, one sample (consisting of 2 segments) for each 3-month period (calendar quarter) during the year, so that the survey is essentially continuous in the field. In each of these area segments, a listing of all addresses is made, from which a sample of about 180,000 addresses are selected each year. Of the selected addresses, about 150,000 are eligible sample units. In these sample units (which can be either households or units within group quarters), sample persons are randomly selected using an automated screening procedure programmed in a handheld computer carried by the interviewers. The number of sample units completing the screening is about 140,000. Youths aged 12–17 years and young adults aged 18–25 years are oversampled at this stage. Because of the large sample size, there no longer is a need to oversample racial/ethnic groups, as was done on surveys prior to 1999. A total of about 85,000 persons are selected nationwide leading to an annual final respondent sample of about 67,500 persons. This sample is representative of the U.S. general population (since 1991, the civilian, noninstitutionalized population) aged 12 and over.

Unit(s) of Analysis: Person-level analysis: Self report.

Mode of Data Collection: The data are collected through in-person interviews with sample persons, incorporating procedures that would be likely to increase respondents' cooperation and willingness to report honestly about their illicit drug use behavior. Confidentiality is stressed in all written and oral communications with potential respondents. Respondents' names are not collected with the data, and CAI (computer-assisted interviewing) methods, including audio computer-assisted self-interviewing (ACASI), are used to provide a private and confidential setting to complete the interview.

Topics / Keywords: Demographic and geographic characteristics, Race/ethnicity, Poverty, Income, Education, Employment Marital status, Living arrangement, Health insurance coverage, Veteran status, Social Environment, Lifetime, past year, and past month illicit drug use: Marijuana/hashish, cocaine (including crack), inhalants, hallucinogens, heroin, and prescription-type drugs used nonmedically (pain relievers, tranquilizers, stimulants, and sedatives), Lifetime, past year, and past month alcohol use, including binge alcohol use and heavy use, Lifetime, past year, and past month tobacco use including cigarettes, chewing tobacco, snuff, cigars, and pipe tobacco, Substance abuse, dependence, prevention, and treatment, Perceived risk of harm from use of illicit drugs, alcohol, and cigarettes, Perceived availability of illicit drugs, Alcohol consumption, Religious beliefs and participation in activities, Lifetime and past year health conditions, Health care utilization, Mental health problems (psychological distress, serious mental illness, and depression), Mental health service utilization, and Source of payment for healthcare

Data Years: Public-use data files for 1979, 1982, 1985, 1988, and annually from 1990 to present are currently available through the Substance Abuse and Mental Health Data Archive (SAMHDA) and the archive's on-line data analysis system (http://www.icpsr.umich.edu/SAMHDA/).

Linked Data: n/a

Reports: A complete listing of previously published NSDUH reports is available from SAMHSA's Office of Applied Studies. Many of these reports are available on the SAMHSA website. The NSDUH Report, published approximately twice a month, presents key findings from the NSDUH. These reports are available by mail and are posted on the SAMHSA website.

Associated with the release of the annual survey findings are detailed tables presenting analyses of substance use and other measures by demographic and geographic characteristics. These are also posted on the SAMHSA website. For More Information go toWebsite at: http://oas.samhsa.gov/nsduh.htm

Background / History: See Website: http://oas.samhsa.gov/nsduh.htm

Future Plans: n/a

Bibliography: See Website: http://oas.samhsa.gov/nsduh.htm

National Survey on Drug Use and Health (NSDUH)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website at http://www.icpsr.umich.edu/SAMHDA/*
- *X Some or all public-use files downloadable free from website: see below*
- ☐ *Data available for free upon order from agency.*
- *X Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Office of Applied Studies (OAS)
Phone: OAS Data Request Line: 240–276–1212
Email: See the web link at: http://www.oas.samhsa.gov/Mail/email.cfm
Website: http://oas.samhsa.gov/nsduh.htm

National Survey of Substance Abuse Treatment Services (N-SSATS)

Sponsor(s): Substance Abuse and Mental Health Services Administration, Office of Applied Studies

Data Collection Agency: Synectics for Management Decisions Inc.and Mathematica Policy Research, under contract with SAMHSA

Purpose / Primary Goals: To collect data on the location, characteristics, and utilization of alcohol and drug treatment facilities.

Survey Universe / Coverage / Census: All facilities, in the United States and its jurisdictions, both public and private, that provide substance abuse treatment.

Sample or Research Design: The N-SSATS is a census.

Unit(s) of Analysis: Substance abuse treatment facility

Mode of Data Collection: Mixed mode, including mail questionnaire, web-based questionnaire and CATI

Topics / Keywords: Buprenorphine, Clients in treatment, Detoxification, Hospital inpatient treatment, Intensive outpatient treatment, Long-term residential treatment, Mental health/behavioral health, Methadone, Opioid Treatment Program, Outpatient treatment, Short-term residential treatment, Substance abuse (drug/alcohol), Substance abuse treatment facility, Substance abuse treatment programs for special groups and Substance abuse treatment services

Data Years: Periodically since the 1970's through 1988. Most years since 1987.

Linked Data: State-level; Metro area

Reports: available at http://www.oas.samhsa.gov/dasis.htm#nssats2

Background / History: The N-SSATS (formerly the Uniform Facility Data Set (UFDS) and the National Drug and Alcoholism Treatment Unit Survey (NDATUS) has evolved from national survey efforts begun in the 1970s by the National Institute on Drug Abuse (NIDA) to measure the scope and use of drug treatment services in the United States. The survey has been conducted most years since 1987.

Future Plans: The N-SSATS is an ongoing data collection

Bibliography: Bibliography available at http://www.oas.samhsa.gov/dasis.htm#nssats2

National Survey of Substance Abuse Treatment Services (N-SSATS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website:* ***http://webapp.icpsr.umich.edu/cocoon/SAMHDA-SERIES/00058.xml***
- *X Some or all public-use files downloadable free from website:* ***http://webapp.icpsr.umich.edu/cocoon/SAMHDA-SERIES/00058.xml***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Office of Applied Studies Helpdesk
Phone: 240–276–1212
Email: oaspubs@samhsa.hhs.gov
Website: http://www.oas.samhsa.gov/dasis.htm#nssats2

National Survey of Mental Health Treatment Facilities (NSMHTF)

Sponsor(s): Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services (CMHS), Division of State and Community Systems Development (DSCSD)

Data Collection Agency: SAMHSA/CMHS

Purpose / Primary Goals: In the rapidly changing health care services delivery environment, timely data on the availability and utilization of organizations and point-of-contact facilities that provide mental health services is needed for policy formulation. In the past, the Center for Mental Health Services (CMHS) has funded a biennial Inventory of Mental Health Organizations (IMHO) to meet information needs. The 2008 NSMHTF expands the scope of the IMHO to address the need to move from an organizational survey to a point-of-contact or facility-based survey fielded among the universe of specialty mental health organizations in addition, become more aligned with the National Survey of Substance Abuse Treatment Services (N-SSATS). This survey is expected to continue to occur biennially on the entire inventory of eligible mental health organizations and point-of-contact facilities.

Survey Universe / Coverage / Census: The NSMHTF includes public and private psychiatric hospitals, general hospitals with separate psychiatric units, residential treatment centers, multiservice setting mental heath organizations, and freestanding mental health outpatient clinics.

Sample or Research Design: Cross-sectional facility survey

Unit(s) of Analysis: Approximately 15,000 point-of-contact facilities nationwide representing approximately 4,400 mental health organizations

Mode of Data Collection: Mailed questionnaire with option for web-based questionnaire completion, and Computer-Assisted Telephone Interview (CATI) follow-up.

Topics/Key Words: Access to care, Charges or sources of payment for healthcare, Chronic conditions, Demographics, Disability, Economics, Health care utilization, Health insurance coverage, Illnesses, Long-term care, Longitudinal data, Medicaid, Mental health/behavioral health, Race/ethnicity, Social characteristics, Substance abuse (drug/alcohol), Use of health care services, and Veteran status

Data Years: Periodically since 1970; most recently in 2000, 2002 and 2004

Linked Data: The Client/Patient Sample Survey (CPSS)

Reports: The most recent analyses of IMHO data can be found in Mental Health, United States, 2000; Mental Health, United States, 2002; and Mental Health, United States, 2004. These publications are available on line at: http://mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics/

Background / History: In prior years, this survey was called the Inventory of Mental Health Organizations (IMHO)

Future Plans: A similarly designed point-of-contact facility survey is planned to be conducted in spring 2010.

Bibliography: n/a

National Survey of Mental Health Treatment Facilities (NSMHTF)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- X *Data available for free upon Public-use data files available upon request.*
- X *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

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Website: n/a

Treatment Episode Data Set (TEDS)

Sponsor(s): Substance Abuse and Mental Health Services Administration, Office of Applied Studies

Data Collection Agency: Synectics for Management Decisions Inc., under contract with SAMHSA

Purpose / Primary Goals: To collect data on the substance abuse, demographic and socioeconomic characteristics of persons admitted to substance abuse treatment. TEDS comprises an admissions data set and a discharge data set which, when linked, can describe complete treatment episodes

Survey Universe / Coverage / Census: Admissions to substance abuse treatment at facilities that are licensed or certified by the State substance abuse agency or are administratively tracked by the State substance abuse agency for other reasons. In general, facilities reporting to TEDS are those that receive State alcohol and/or drug agency funds (including Federal Block Grant funds) for the provision of alcohol and/or drug treatment services. All States participate in TEDS.

Sample or Research Design: TEDS is an administrative data set collected by State substance abuse agencies from the treatment providers that they fund or otherwise monitor. TEDS consists of a Minimum Data Set of admission variables reported by all States, a Supplementary Data Set of admission variables reported by some States, and a Discharge Data Set reported by 50 States or other jurisdictions.

Unit(s) of Analysis: An admission and discharge from substance abuse treatment

Topics/Keywords: Age at first use, Demographics, Detoxification, Frequency of use, Health care utilization, Intensive outpatient, Length of stay, Long-term residential, Medication-asssisted opioid therapy, Number of prior treatment episodes, Outpatient, Reason for discharge, Route of administration, Short-term residential, Source of referral, Substance abuse (drug/alcohol), Substance of abuse, Substance problem (primary, secondary, tertiary), and Socioeconomic status

Data Years: 1992–2007

Linked Data: State-level; Metro area

Reports: Reports available at http://www.oas.samhsa.gov/dasis.htm#teds2

Background / History: In 1988, the Coomprehensive Alcohol Abuse, Drug Abuse, and Mental Health Amendments (P>L> 100–690) established a revised Substance Abuse Prevention and Treatment (SAPT) Block Grant and mandated Federal data collection on clients receiving treatment for either alcohol or drug abuse. The TEDS represents the Federal response to this mandate. TEDS, originally called the Client Data System (CDS), began in 1989 with the issue of 3-year development grants to States.

Future Plans: TEDS is a continuous, ongoing data collection

Bibliography: Bibliography available at http://www.oas.samhsa.gov/dasis.htm#teds2

Treatment Episode Data Set (TEDS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: **http://webapp.icpsr.umich.edu/cocoon/SAMHDA/DAS3/00056.xml***
- *X Some or all public-use files downloadable free from website: **http://webapp.icpsr.umich.edu/cocoon/SAMHDA-SERIES/00056.xml***
- *☐ Data available for free upon order from agency.*
- *X Application process required to obtain some data files*
- *X Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *☐ Application process required to obtain data files*
- *☐ Use of Research Data Center required for access to restricted-use data.*
- *☐ Payment required for the preparation / supply of data*

Additional Information:

Contact: Office of Applied Studies Helpdesk
Phone: 240–276–1212
Email: oaspubs@samhsa.hhs.gov
Website: http://www.oas.samhsa.gov/dasis.htm#teds2

Department of Housing and Urban Development

Office of Policy Development and Research

American Housing Survey (AHS)

Sponsor(s): Office of Policy Development and Research, Department of Housing and Urban Development

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: To provide information on the nation's housing stock and the characteristics of its occupants. Data on the characteristics, condition, financing, and costs of housing in the United States and selected metropolitan areas are made available. Information on the characteristics of the households that reside in the housing units as well as neighborhood conditions and amenities is provided also.

Survey Universe / Coverage / Census: The national sample covers approximately 55,000 to 60,000 homes. Metropolitan area sample covers approximately 2,500 to 6,000 homes.

Sample or Research Design: The American Housing Survey (AHS) collects detailed information on the nation's housing and the people that reside in the housing units. For housing characteristics, such data as unit size, housing costs, mortgage financing, equipment and fuels, recent movers, neighborhood quality, and commute to work are collected. For characteristics on the individuals in the household, such information as individual and family income, race/ethnicity, age, education, disabilities, and assisted living are obtained. Data is collected on all types of housing, including single-family homes, townhouses, apartments, condominiums, cooperatives, mobile homes, and vacant housing units. National and metropolitan data are currently collected biennially in odd numbered years. Data for each of 21 selected Metropolitan Areas are collected every 6 years.

Unit(s) of Analysis: Housing unit

Mode of Data Collection: The AHS is a household survey that asks questions about the quality of housing in the United States and the characteristics of its occupants. In gathering information, Census Bureau interviewers visit or telephone the household occupying each housing unit in the sample. For unoccupied units, they obtain information from landlords, rental agents, or neighbors.

Topics / Keywords: Housing characteristics, Household characteristics, Housing and Neighborhood quality, Financial characteristics, Alterations and repairs, and Longitudinal data

Data Years: Ongoing since 1973; last major design changes in 1985 and 1997. Public-Use Data Files found at http://www.huduser.org/datasets/ahs.html

Linked Data: n/a

Reports: National and Metropolitan American Housing Survey Reports PDF: http://www.census.gov/hhes/www/ahs.html

- Hardcopy: http://www.HUDUSER.org or the Census Bureau
- Publications based on the American Housing Survey can be found at: http://www.huduser.org/datasets/ahs/ahsprev.html#analyses

Background / History: The American Housing Survey (AHS) was mandated by Congress in 1968 to provide data for evaluating progress toward "a decent home and a suitable living environment for every American family." The AHS was started in 1973, and in 1983 Congress mandated that HUD continue to conduct a survey similar to the 1981 AHS.

Future Plans: Sample will be redesigned and redrawn based on the 2010 Decennial Census.

Bibliography: n/a

American Housing Survey (AHS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: **http://www.census.gov/prod/www/abs/cons-hou.html#house***
- *X Some or all public-use files downloadable free from website: **http://www.huduser.org/datasets/ahs.html***
- *☐ Data available for free upon order from agency.*
- *☐ Application process required to obtain some data files*
- *X Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *☐ Application process required to obtain data files*
- *X Use of Data Center required for access to confidential data. Website: **http://www.ces.census.gov/index.php/ces/researchlocations***
- *☐ Payment required for the preparation / supply of data*

Additional Information:

Contact: n/a

Phone: HUD:1–800–245–2691 or 202–708–1060

Census: 1–888–518–7365 or 301–763–3235

Email: ahsn@census.gov or ahslistserv@huduser.org

Website: http://www.huduser.org/datasets/ahs.html or http://www.census.gov/hhes/www/housing/ahs/ahs.html

Department of Labor
Bureau of Labor Statistics
American Time Use Survey (ATUS)

Sponsor(s): Bureau of Labor Statistics

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The major purpose of the ATUS is to develop nationally representative estimates of how people spend their time. Estimates show the kinds of activities people do and the time spent doing them by sex, age, educational attainment, labor force status, and other characteristics, as well as by weekday and weekend day.

Survey Universe / Coverage / Census: The U.S. civilian noninstitutionalized population. This includes all residents living in households in the United States that are at least 15 years of age, with the exception of active military personnel and people residing in instititutions such as nursing homes and prisons.

Sample or Research Design: ATUS uses a stratified, three-stage, national probability sample. First, a sample is drawn from households that have completed their eighth and final month of interviews for the Current Population Survey (CPS), the monthly labor force survey in the United States. This sample is distributed across the States in approximately the proportion of the national population each one represents. Second, households are stratified based on the race or ethnicity of the householder, the presence and age of children, and the number of adults in adults-only households. Finally, an eligible person is randomly selected from each household; this individual becomes the designated person for an ATUS interview. Respondents are interviewed one time about how they spent their time on the previous day, where they were, and whom they were with.

Survey Mode: All ATUS interviews are conducted using Computer-assisted Telephone Interviewing (CATI). ATUS also has procedures in place to collect information from the small number of households that did not provide a telephone number during the final CPS interview.

Unit(s) of Analysis: Person-level data analysis

Topics / Keywords: Care giving, Demographics, Economics, Health behaviors, Health status, Income, Labor force participation, Marital status, Race /ethnicity, Risk factors, Self report of health status, Social characteristics, Socioeconomic status and Time use

Data Years: The survey has been ongoing since 2003. Data sets are released annually.

Linked Data: The Current Population Survey (CPS) and CPS supplements.

Reports: A list of survey documents and reports is available on the ATUS home page: http://www.bls.gov/tus/.

Background / History: The American Time Use Survey is the Nation's first federally administered, continuous survey on time use in the United States. In the core of the ATUS interview, survey respondents provide information about what they were doing, where they were, and who they were with for a 24-hour period that began at 4 a.m. on the day prior to the interview day and ended at 4 a.m. on the day of the interview. Information about respondents' demographics, household composition, labor force status, and other characteristics also is collected. Data collection began in January 2003.

In addition to the core ATUS interview data, more detailed data about a time use topic are periodically available. The Economic Research Service (ERS) of the U.S. Department of Agriculture sponsored an Eating & Health module from 2006 to 2008 which collected information on eating and drinking as a secondary activity, grocery shopping and food preparation patterns, food stamp eligibility, school meal programs, general health, and height and weight.

Future Plans: ATUS news releases and data files are released annually.

Bibliography: n/a

American Time Use Survey (ATUS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website:* ***http://www.bls.gov/tus***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Data Center required for access to confidential data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

ATUS micro data files and supporting documentation are available for free download from the ATUS website: http://www.bls.gov/tus/. Several tables and charts showing time-use estimates by age, employment status, educational attainment, marital status, presence and age of household children, and other characteristics also are available on the ATUS Web site. Unpublished tables are available upon request by contacting ATUS staff.

Phone: 202– 691–6339
Email: atusinfo@bls.go
Website: http://www.bls.gov/tus/

Consumer Expenditure Survey (CE)

Sponsor(s): Bureau of Labor Statistics, Division of Consumer Expenditure Surveys

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The Consumer Expenditure Survey (CE) program consists of two surveys, the quarterly Interview Survey and the two-week Diary Survey, that provide information on the buying habits of American consumers, including data on their expenditures, income, and consumer unit (families and single consumers) characteristics. CE is the most detailed source of expenditure data collected from households by the Federal government. In addition to providing information for studies in business, academics, and other government agencies, the data are an important input in the Consumer Price Index, which is used to measure inflation in the U.S. economy.

Survey Universe / Coverage / Census: The population represented by the survey is the total U.S. civilian noninstitutional population, both urban and rural. It includes people living in houses, condominiums, apartments, and group quarters such as college dormitories. It excludes people such as military personnel living on base, nursing home residents, and people in prisons.

Sample or Research Design: Interview Survey: Rotating panel survey. Households are visited once every three months for five consecutive quarters, the first of which is a "bounding" interview to derive baseline information, but not for use in computing published expenditure estimates. Approximately 7,000 interviews are completed each quarter.

Diary Survey: Participants receive two separate, one-week diaries in which to record daily expenditure and other information. Approximately 7,000 households participate each year.

Sample design and household selection for each survey: Systematic sample, selected from geographically-defined primary sampling units. For details, see BLS Handbook of Methods in Bibliography section below.

Unit(s) of Analysis: Consumer unit (expenditures, some income sources, assets and liabilities, and certain characteristics, such as region of residence); individual members (most demographics); individual members age 14 or older (working status and some income sources).

Mode of Data Collection: Computer assisted personal interview (CAPI) is primary mode for the Interview. Respondent filled out paper diary is the mode for the Diary.

Topics / Keywords: Consumer spending, Consumer unit, Demographics, including: Age, Family size and composition, Education, Housing tenure, Geography (urban/rural; region; population size of area of residence), Income, Labor force participation (occupation type; hours per week and weeks per year worked), Marital status, Number of earners, Race/ethnicity, Diary, Survey, Expenditure categories (e.g., food; housing; apparel and services), Expenditure for health care (insurance; medical services; prescription and non-prescription medications; medical supplies), Expenditure patterns, Economics, Health insurance coverage, Housing, Housing characteristics, Income, Interview Survey and Reference person

Data Years: 1980 onward: Continual basis; 1950 to 1972–1973: Once every 10 to 12 years (including 1960–1961); 1901 to 1950: As warranted by economic conditions (e.g., 1917–1919; 1935–1936).

Linked Data: n/a

Reports: Annual, biennial, and other reports are available at: http://www.bls.gov/cex/#news. Links to research articles featuring data from the Consumer Expenditure Surveys are available at: http://www.bls.gov/cex/#publications.

Background / History: n/a

Future Plans: n/a

Bibliography: BLS Handbook of Methods, chapter 16 (updated 4/2007), p. 5, on the Internet at http://www.bls.gov/opub/hom/pdf/homch16.pdf. Also see “Reports” above.

Consumer Expenditure Survey (CE)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible.*
  Website: http://www.bls.gov/cex/
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- *X Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Consumer Expenditures
Phone: 202– 691–6900
Email: cexinfo@bls.gov
Website: http://www.bls.gov/cex/

Current Population Survey (CPS)

Sponsor(s): Bureau of Labor Statistics

Data Collection Agency: U.S. Census Bureau

Purpose / Primary Goals: The CPS, a monthly household survey conducted by the Bureau of the Census for the Bureau of Labor Statistics, provides a comprehensive body of information on the employment and unemployment status of the Nation's population, classified by age, sex, race, and a variety of other characteristics.

Survey Universe / Coverage / Census: The CPS collects information on the labor force status of the civilian noninstitutional population 15 years of age and older, although labor force estimates are reported only for those 16 and older. Persons on active duty in the U.S. Armed Forces are excluded from coverage. Also excluded are residents of institutions such as prisons, long-term care hospitals, and nursing homes.

Sample or Research Design: The CPS is a monthly survey conducted in approximately 60,000 households throughout the United States. The CPS is a probability sample based on a stratified sampling scheme. In general, the CPS is selected from lists of addresses obtained from the most recent decennial census and updated for new construction.

For a detailed description of the CPS sample design, see the Technical Note to the survey published in Employment and Earnings, available online at:

http://www.bls.gov/cps/eetech_methods.pdf

Unit(s) of Analysis: Person-level data analysis

Mode of Data Collection: Interviews are conducted using Computer-assisted Telephone Interviewing (CATI) and Computer-assisted Personal Interviewing (CAPI).

Topics / Keywords: Demographics, Labor force, Labor force participation rate, Employment, Employment-population ratio, Labor force participation rate, Unemployment, Unemployment rate, Earnings

Data Years: The CPS has been conducted since 1940.

Linked Data: n/a

Reports: Each month, the employment and unemployment data are published in The Employment Situation news release about 2 weeks after they are collected. The release includes a narrative summary and analysis of the major employment and unemployment developments, together with tables containing statistics for the principal data series. The news release is available on the Internet and can be accessed at: http://www.bls.gov/cps/home.htm

Background / History: In the late 1930s, the concepts of the labor force, employment, and unemployment were developed. The classification of an individual depended principally upon his or her actual activity within a designated period, that is, was the individual working, looking for work, or engaged in other activities? These concepts were adopted for the national sample survey of households, called the Monthly Report of Unemployment, initiated in 1940 by the Work Projects Administration.

The household survey was transferred to the Census Bureau in late 1942, and its name was changed to the Monthly Report on the Labor Force. The name was changed once more, in 1948, to the present Current Population Survey in order to reflect the survey's expanding role as a source for data on a wide variety of demographic, social, and economic characteristics of the population. In 1959, responsibility for analyzing and publishing the CPS labor force data was transferred to BLS; the Census Bureau continues to collect the data.

Future Plans: n/a

Bibliography: BLS Handbook of Methods, Chapter 1, Labor Force Data Derived from the Current Population Survey at: http://www.bls.gov/opub/hom/homch1_itc.htm

Current Population Survey: Design and Methodology (Technical Paper 66) http://www.census.gov/prod/2006pubs/tp-66.pdf

Current Population Survey (CPS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: **http://www.bls.gov/cps/home.htm#data***
- *X Some or all public-use files downloadable free from website: **http://www.bls.census.gov/ferretftp.htm***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Division of Labor Force Statistics (BLS)
Phone: 202–691–6378
Email: CPSinfo@bls.gov
Website: http://www.bls.gov/cps/home.htm

National Longitudinal Surveys (NLS)

Sponsor(s): Bureau of Labor Statistics

Data Collection Agency: Ohio State University Center for Human Resource Research and the National Opinion Research Center at the University of Chicago. Data for the original cohorts were collected by the U.S. Census Bureau.

Purpose / Primary Goals: The National Longitudinal Surveys (NLS) are a set of surveys sponsored by the Bureau of Labor Statistics (BLS) of the U.S. Department of Labor. These surveys have gathered information on the labor market activities and other significant life events of several groups of men and women. The same respondents have been interviewed repeatedly to provide a picture of schooling, work history, retirement preparation, and other events and transitions over the life cycle. For more than 4 decades, NLS data have served as an important tool for economists, sociologists, demographers, and other researchers.

Survey Universe / Coverage / Census:

Table 2. Summary of the National Longitudinal Survey Cohorts

Cohort	*Birth Years*	*Year of first interview (and age at first interview)*	*Number of interview rounds completed*	*Original sample size*	*Status*
Older Men	4/1/1906 to 3/31/1921	1966 (45–59)	**13**	5,020	Ended in 1990
Mature Women	4/1/1922 to 3/31/1937	1967 (30–44)	**21**	5,083	Ended in 2003
Young Men	4/1/1941 to 3/31/1952	1966 (14–24)	**12**	5,225	Ended in 1981
Young Women	1943–1953	1968 (14–24)	**22**	5,159	Ended in 2003
NLSY79	1957–1964	1979 (14–22)	**23**	12,686 (9,964 remain eligible)	Continuing biennally
NLSY79 Child	Birth to age 14	1986	**12**	Varies	Continuing biennally
NLSY79 Young Adult	15 and over	1994	**8**	Varies	Continuing biennally
NLSY97	1980–1984	1997–98 (12–17)	12	8,984	Continuing

Sample or Research Design: The four original NLS cohorts began in the mid-1960s. They are called the NLS of Older Men, Mature Women, Young Men, and Young Women. Screening for these surveys was conducted in early 1966 by the Census Bureau. All residents of a screened household who were eligible for one of the cohorts were included, so the cohorts together include many spouse, parent-child, and sibling combinations. The cohorts of Older Men, Mature Women, and Young Women are particularly useful for conducting research on aging.

Older Men

The NLS of Older Men included men who were ages 45–59 when the survey began in 1966. These men were well into their careers and on the threshold of decisions about the timing and extent of their labor force withdrawal. Data collection focused on work experiences, including job changes, retirement expectations and experiences, and reentry to the labor market after initial retirement.

The survey also included questions about retirement planning, health, insurance coverage, and the ways in which respondents spent their leisure time. Regular interviews with this cohort ceased in 1981. In 1990, respondents were interviewed a final time along with widows or other family members of deceased sample members.

Mature Women and Young Women

The NLS of Mature Women included women who were ages 30–44 when the survey began in 1967. Many of these women were re-entering the workforce following childbearing and were balancing the roles of mother and labor force participant. Respondents were ages 66–81 when interviewed for a final time in 2003.

The NLS of Young Women included women who were ages 14–24 when the survey began in 1968. These women were completing school, making initial career decisions, and starting families. Respondents were ages 49–60 when interviewed for a final time in 2003.

Beginning in 1993, surveys of the mature and young women's cohorts included questions about transfers of time and money to a respondent's parents or children. These questions were added to obtain information about the financial impact aging parents have on their children and to record inheritances and other transfers that respondents received from their parents.

The NLS of Mature Women obtained information in all but two rounds from 1977 to 2003 on respondents' retirement plans, expectations, and eligibility for various pension plans. The NLS of Young Women included questions in 1991 and 1995–2003 on pension coverage and vesting rights for respondents who indicated that their employer provided a pension or other retirement plan. Both surveys of women also included a comprehensive set of health-related questions.

NLSY79

The National Longitudinal Survey of Youth 1979 (NLSY79) includes men and women who were born in the years 1957–1964 and living in the United States when the survey began in 1979. The sample members, who constitute part of the baby boom generation, were ages 14–22 during the first round of data collection. They were ages 43–52 during the 23rd round of data collection in 2008–2009. The NLSY79 was conducted annually from 1979 through 1994 and has been conducted biennially since 1994. A primary focus of the NLSY79 is labor force behavior, but the content of the survey is considerably broader. The NLSY79 includes questions on educational attainment, training, income and assets, participation in government programs, health, workplace injuries, insurance coverage, alcohol and drug use, sexual activity, marital and fertility histories, and other topics. As the sample members enter their 50s, the

NLSY79 will become increasingly valuable as a research tool on aging.

The NLSY79 Child and Young Adult surveys obtain a wealth of information on the children born to female NLSY79 respondents. The collection of data on these children began in 1986 with a battery of cognitive, social, emotional, and physiological assessments administered to NLSY79 children and their mothers. These biennial assessments are administered primarily in person. Beginning in 1988, children age 10 and over have answered a self-administered set of questions about family, friends, jobs, school, after-school activities, religious attendance, smoking, alcohol and drug use, and more. Starting in 1994, children who reach age 15 by December 31 of the survey year complete a questionnaire that is similar to the main NLSY79 and asks about work experiences, training, schooling, health, fertility, attitudes, and work expectations. This "Young Adult" interview, which is conducted primarily by telephone, replaced the child assessments for older adolescents. The data collected about the children and young adults can be linked easily with information collected from their mothers in the main NLSY79.

NLSY97

The National Longitudinal Survey of Youth 1997 (NLSY97) includes men and women born during the years 1980 through 1984. Survey respondents were ages 12–17 when first interviewed in 1997 and were ages 23–29 during the 12th round of interviews in 2008–2009. The survey covers a variety of topics, including labor market status and characteristics of jobs, education, training, aptitudes, health, fertility, marital history, income and assets, participation in government programs, attitudes, sexual activity, criminal and delinquent behavior, household environment, and military experiences. Sample members today are obviously much too young for the NLSY97 to contribute to current research on aging. If the survey is able to continue successfully, however, decades from now it will be a valuable tool for aging-related research.

Unit(s) of Analysis: Person-level; see also Table 2. Summary of the National Longitudinal Survey Cohorts in the preceding Survey Universe / Coverage / census section

Mode of Data Collection: In-person interview, or telephone interview.

Topics / Keywords: Demographics, Economics, Labor force participation, Labor market activity, Life transitions, Longitudinal data, Marital Status, Retirement preparation Schooling, Significant life events and Work history

Data Years: Please see Table 2. Summary of the National Longitudinal Survey Cohorts in the preceding Survey Universe / Coverage / census section.

Linked Data: n/a

Reports: http://www.bls.gov/nls/#publications

Background/History: The National Longitudinal Surveys (NLS) are a set of surveys designed to gather information at multiple points in time on the labor market activities and other significant life events of several groups of men and women. For more than 4 decades, NLS data have served as an important tool for economists, sociologists, and other researchers.

Future Plans: n/a

Bibliography: Over 6,000 NLS-based journal articles, working papers, monographs and dissertations are stored in an electronic NLS database. This is available on the World Wide Web at www.nlsbibliography.org, and allows researchers to search, retrieve, and print customized listings of NLS research.

National Longitudinal Survey (NLS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website:* ***http://www.nlsinfo.org/web-investigator/***
- *X Some or all public-use files downloadable free from website:* ***http://www.bls.gov/nls/home.htm***
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data multi-chorot data on a CD.*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *X Application process required to obtain data files on geocode data (application at website:* ***http://www.bls.gov/nls/geocodeapp.htm****), and other data at* ***http://www.bls.gov/bls/blsresda.htm***
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

The easiest way to obtain NLS data is to visit the NLS website and click on the "NLS Data" link. From there, you can download public-use data files for free. The website also provides information on how to obtain access to geographic variables and other restricted-access NLS data

Contact: For help with NLS data downloads:
usersvc@chrr.osu.edu.
Phone: 202–691–7410
Email: NLS_INFO@bls.gov
Website: http://www.bls.gov/nls/home.htm

Department of Veterans Affairs

National Survey of Veterans (NSV)

Sponsor(s): Department of Veterans Affairs

Data Collection Agency: Department of Veterans Affairs

Purpose / Primary Goals: The 2009 National Survey of Veterans (NSV) will satisfy the requirements detailed in P.L. 108-454, section 805. Information will be collected on awareness, demographics, health care, disability, life insurance, burial benefits, employment, education and training, and vocational rehabilitation.

Survey Universe / Coverage / Census: For the first time, the NSV will include active duty service members, activated National Guard and Reserves, and family members and survivors in addition to veterans. Excludes institutionalized veterans.

Sample or Research Design: Under Section 527, Title 38 U.S. Code, the Secretary of VA is authorized to gather data for the purposes of evaluating programs. This is the sixth in a series of comprehensive nationwide surveys designed to help VA improve services for beneficiaries and their families.

Unit(s) of Analysis: Estimates will be provided at the National level

Mode of Data Collection: Address mailing, internet and phone

Topics / Keywords: National estimates, Awareness of VA benefits and services, Demographics, Heath care, Income

Data Years: 2009

Linked Data: n/a

Reports: Reports and Methodological documents are available on VA's website.

Background / History: The NSV is conducted approximately every 8 to 10 years. The previous NSV was conducted in 2001.

Future Plans: Execution and completion by the end of August 2010.

Bibliography: n/a

National Survey of Veterans (NSV)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- *X Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data multi-chorot data on a CD.*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Maribel Aponte
Phone: 202–461–5790
Email: Maribel.Aponte@va.gov
Website: http://www1.va.gov/vetdata/
NOTE: (click on "Surveys and Studies") this website contains results from the 2001 National Survey of Veterans. The results from the 2009 National Survey of Veterans will be posted on the website when they become available in 2011.

VHA Survey of Veteran Enrollees' Health and Reliance Upon VA (SoE)

Sponsor(s): Department of Veterans Affairs (VA)

Data Collection Agency: ICF Macro conducts the interviews on behalf of the Department of Veterans Affairs(VA)/Veterans Health Administration (VHA)

Purpose / Primary Goals: The Veteran's Health Care Eligibility Reform Act of 1996, Public Law 104-262, mandated that most Veterans must be enrolled in VA to receive care. Since this mandated enrollment began, VHA has collected data regarding utilization of VA and non-VA inpatient and outpatient services. The primary purpose of the VHA SoE is critical as inputs to the Enrollee Health Care Projection Model and the long-term care model. Data from SoE are a reliable source for answering policy questions, Congressional inquiries, expenditure projections, the Secretary's enrollment level decision processes. Data are useful in a variety of strategic analysis areas related to budget, policy, or legislation and inquiries from other agencies and offices. The VHA SoE helps identify not only who VA serves as well as supplementing VA's knowledge of Veteran enrollees' demographic characteristics including household income, health insurance coverage status, perceived health status, their other eligibilities and resources, their use of VA and non-VA health care services, their reliance upon VA, and their potential future use of VA health care services.

The 2008 SoE is the seventh in a series of surveys of Veteran enrollees for VA health care. The survey is conducted by VHA, within the Department of Veterans Affairs, under multi-year OMB authority. All VHA SoE's consist of telephone interviews with stratified random samples of enrolled Veterans. Over the years, modifications are made to the survey instrument to reflect VA management's need for specific data and information on enrolled Veterans.

In the 2008 survey, telephone interviews averaged 17 minutes in length. Interviews were conducted from September through December 2008. Of approximately 7.3 million live, eligible enrollees who had not declined enrollment as of April 30, 2008, 42,460 completed interviews to the 2008 telephone survey.

Survey Universe / Coverage / Census: All Veterans enrolled for VA health care as of a given date, including institutionalized and non-institutionalized Veterans

Sample or Research Design: As with the other surveys in the series, the 2008 Survey of Veteran Enrollees' Health and Reliance Upon VA sample was stratified by Veterans Integrated Service Network (VISN), enrollment priority, and type of enrollee (new or past user). A new stratum for Operation Enduring Freedom/ Operation Iraqi Freedom (OEF/OIF) was added in the 2008 survey.

Unit(s) of Analysis: Estimates are provided at the National and Veterans Integrated Service Networks level (VISN) (21 VISNs cover the country)

Mode of Data Collection: Telephone interviews, including a pre-survey notification letter

Topics / Keywords: Reliance, Enrollee, Survey, Veteran

Data Years: 1999, 2000, 2002, 2003, 2005, 2007, and 2008

Linked Data: n/a

Reports: See website for selected reports

Background / History: The SoE was conducted in 1999, 2000, 2002, 2003, 2005, 2007, and 2008

Future Plans: Next survey planned for calendar year 2010

Bibliography: n/a

VHA Survey of Veteran Enrollees' Health and Reliance Upon VA (SoE)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data multi-chorot data on a CD.*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Marybeth H. Matthews
Phone: 414–384–2000 extension 42359
Email: marybeth.matthews@va.gov
Website: http://www.va.gov/vhareorg

Veteran Population Model(VetPop)

Sponsor(s): Department of Veterans Affairs

Data Collection Agency: Department of Veterans Affairs

Purpose / Primary Goals: To provide estimates and projections of the veteran population by age groups and other demographic characteristics at the National, State and County levels.

Sample or Research Design: n/a

Unit(s) of Analysis: Number of veterans by demographic and military characteristics

Mode of Data Collection: Veteran estimates and projections were computed using a cohort-component approach, whereby 2000 Census baseline data were adjusted forward in time on the basis of separations from the armed forces (new veterans) and expected mortality.

Topics / Keywords: Veteran population, Estimates and projections, Demographics, and Military characteristics

Data Years: Latest actual data as of September 30, 2006.

Linked Data: n/a

Reports: See website for several technical documents: executive summary, data sources, and summary overview.

Background / History: The Veteran Population Model is updated approximately every other year. The previous model was the Veteran Population Model 2004.

Future Plans: Incorporate data from the new VA DoD Identity Repository, research methodologies to improve migration and mortality, and continue to research ways of using American Community Survey data.

Bibliography: n/a

Veteran Population Model(VetPop)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible. Website: http://www1.va.gov/vetdata/*
- *X Some or all public-use files downloadable free from website: see below*
- *☐ Data available for free upon order from agency. Order from*
- *☐ Application process required to obtain some data files*
- *☐ Payment required for the preparation/supply of data multi-chorot data on a CD.*

Data Access to Non Public-Use data (i.e., data with confidential information)

- *☐ Application process required to obtain data files*
- *☐ Use of Research Data Center required for access to restricted-use data.*
- *☐ Payment required for the preparation / supply of data*

Additional Information:

National, State and county estimates and projections of veteran population by age groups and other demographic characteristics are available. In addition, custom tables are possible by manipulating Excel pivot tables.

Contact: Hyo Park
Phone: 202–461–5772
Email: Hyo.Park@va.gov
Website: http://www1.va.gov/vetdata/
(click on “Demographics”)

Federal Reserve System Board of Governors

Survey of Consumer Finances (SCF)

Sponsor(s): The study is sponsored by the Federal Reserve Board in cooperation with the Department of the Treasury.

Data Collection Agency: Since 1992, data have been collected by the National Organization for Research at the University of Chicago (NORC).

Purpose / Primary Goals: The Survey of Consumer Finances (SCF) is a triennial survey of the balance sheet, pension, income, and other demographic characteristics of U.S. families. The survey also gathers information on the use of financial institutions. The results of the survey are widely used by researchers and policymakers to examine the effects of economic policies and trends on American households.

Survey Universe / Coverage / Census: Civilian noninstitutionalized population.

Sample or Research Design: The SCF is a triennial, nationally representative survey using a dual frame sample design. One part of the sample is a standard multistage national area probability sample. The second part of the sample employs information from IRS Statistics of Income (SOI), under stringent provisions to protect the privacy of taxpayers, to select a sample with disproportionate representation of families more likely to be relatively wealthy; this sample is stratified by a "wealth index" computed using observed capital income flows and related information. The two parts of the sample are adjusted for sample nonresponse and combined using weights to provide a representation of families overall.

Unit(s) of Analysis: Family

Mode of Data Collection: CAPI

Topics / Keywords: Income, Wealth and Pensions

Data Years: 1962 to present

Linked Data: n/a

Reports: Changes in U.S. Family Finances from 2004 to 2007: Evidence from the Survey of Consumer Finances. Brian K. Bucks, Arthur B. Kennickell, Traci L. Mach and Kevin B. Moore. Federal Reserve Bulletin, vol. 95 (February 2009), pp. A1-A55. at http://www.federalreserve.gov/pubs/oss/oss2/2007/scf2007home.html

Background / History: A 2009 panel (i.e. 2007–2009 panel)

Future Plans: It is expected that the survey will be conducted every 3 years in the future.

Bibliography: See: http://www.federalreserve.gov/pubs/oss/oss2/method.html

Survey of Consumer Finances (SCF)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

☐ *User-specified online data query or table generation possible.*

X *Some or all public-use files downloadable free from website: **http://www.federalreserve.gov/pubs/oss/oss2/scfindex.html***

☐ *Data available for free upon order from agency.*

☐ *Application process required to obtain some data files*

☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

☐ *Application process required to obtain data files*

☐ *Use of Research Data Center required for access to restricted-use data.*

☐ *Payment required for the preparation / supply of data*

Additional Information:

Public versions of the data from the 1962–63, 1983, 1986, 1989, 1992, 1995, 1998, 2001, 2004, 2007 cross-sections and the 1983–89 panels are available online at the website listed above.

Contact: Gerhard Fries and Arthur Kennickell

Phone: 202–452–2578 and 202–452–2247

Email: gerhard.fries@frb.gov and arthur.kennickell@frb.gov

Website: http://www.federalreserve.gov/feedback.cfm

Office of Management and Budget

FedStats

Sponsor(s): Interagency Council on Statistical Policy

Data Collection Agency: n/a

Purpose / Primary Goals: FedStats (http://www.fedstats.gov/) is an interagency web portal that provides access to a full range of official statistical information available to the public from the Federal Government. It allows users to access official statistics collected and published by more than 100 Federal agencies without having to know in advance which agency produces them. FedStats users can utilize the Internet's powerful linking and searching capabilities to track economic and population trends, education, health care costs, aviation safety, foreign trade, energy use, farm production, and more.

FedStats, developed under the auspices of the Interagency Council on Statistical Policy (ICSP), permits easy access via an initial point of entry to the wide array of Federal statistics available to the public. FedStats provides a centralized set of links to the Internet sites that individual agencies maintain for disseminating Federal statistics. The site's primary objective is to help users find the information they need without having to know and understand in advance how the decentralized Federal statistical system is organized or which agency or agencies may produce the data they are seeking. FedStats has logged nearly 22 million user sessions since its release to the public in 1997.

Note: Essentially all of the statistical information available through FedStats is maintained and updated solely by Federal agencies on their own web servers.

FedStats provides information for Federal agencies reporting expenditures of at least $500,000 per year in one or more statistical activities including:

- Planning of statistical surveys and studies, including project design, sample design and selection, and design of questionnaires, forms, or other techniques of observation and data collection.
- Training of statisticians, interviewers, or processing personnel.
- Collection, processing, or tabulation of statistical data for publication, dissemination, research, analysis, or program management and evaluation.
- Publication or dissemination of statistical data and studies.
- Methodological testing or statistical research.
- Data analysis.
- Forecasts or projections that are published or otherwise made available for government-wide or public use.
- Statistical tabulation, dissemination, or publication of data collected by others.
- Construction of secondary data series or development of models that are an integral part of generating statistical series or forecasts.
- Management or coordination of statistical operations.
- Statistical consulting or training.

Survey Universe / Coverage / Census: Varies depending upon data source

Sample or Research Design:Varies depending upon data source

Unit(s) of Analysis: Varies depending upon data source

Mode of Data Collection: Varies depending upon data source

Topics / Keywords: Federal data portal

Data Years: Website started in 1997

Linked Data: The ICSP's Task Force on One-Stop Shopping for Federal Statistics continues to upgrade and expand FedStats' coverage of the government's statistical products. A "MapStats for Kids" section was developed and made available to the public to facilitate the improvement of statistical literacy for young children. The addition to the MapStats section of the site of statistical information for cities with populations of 25,000 or more has been well received by the public, and provides links to the Department of Housing and Urban Development's State of the Cities website for more in-depth statistical information for a locality.

Reports: n/a

Background / History: n/a

Future Plans: FedStats plans to refresh the basic MapStats data during the coming year. Search capabilities continue to be enhanced by indexing the statistics available on nearly all the FedStats agency websites, and exploratory work in the use of the Statistical Data and Metadata Exchange (SDMX) protocol to facilitate updates to information on the site is being conducted. The ICSP task force continues to respond to user requests for a broader scope of subjects, more detailed data on those subjects, and easier overall access to the data, and plans to further improve the public's access to statistical information through revision of the current set of "Topics A-Z" displayed on the site.

Bibliography: n/a

FedStats

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
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Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: n/a
Phone: n/a
Email: n/a
Website: http://www.fedstats.gov

Social Security Administration

New Beneficiary Data System Microdata File (NBDS)

Sponsor(s): Social Security Administration

Data Collection Agency: Temple University Institute of Survey Research

Purpose / Primary Goals: Survey of new (e.g., Social Security) beneficiaries of mid-1980-1981 and reinterview in 1991

Survey Universe / Coverage / Census: Newly awarded beneficiaries in a one year period from selected Social Security programs

Sample or Research Design: Multi-stage sample starting with SSA benefit listing and national area probability sample locations

Unit(s) of Analysis: Beneficiary

Mode of Data Collection: Application to SSA for benefits

Topics / Keywords: Social Security beneficiary benefits and earnings, health status and expenditures, demographic characteristics

Data Years: Oct-Dec. 1982 and 1991

Linked Data: Annual Social Security covered earnings, monthly social Security benefits, and monthly SSI benefits, and Medicare expenditures for hospitalization, outpatient, home health, and hospice

Reports: See website for articles in Social Security Bulletin in the 1980s and early 1990s

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

New Beneficiary Data System Microdata File (NBDS)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- *X User-specified online data query or table generation possible: see website below*
- *X Some or all public-use files downloadable free from website below*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Howard Iams
Phone: 202–358–6217
Email: Howard.M.Iams@ssa.gov
Website: http://www.socialsecurity.gov/policy

OASDI Microdata File 2001

Sponsor(s): Social Security Administration

Data Collection Agency: Social Security Administration

Purpose / Primary Goals: Release data on Old Age Survivors and Disability Insurance (i.e., Social Security) beneficiaries of December 2001

Survey Universe / Coverage / Census: Recipients of OASDI in December 2001

Sample or Research Design: Systematic sample of 5 percent of recipients

Unit(s) of Analysis: Beneficiary

Mode of Data Collection: Application to SSA for benefits

Topics / Keywords: Social Security beneficiary benefits

Data Years: December 2001

Linked Data: n/a

Reports: See website for reports on Social Security beneficiaries

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

OASDI Microdata File 2001

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: see below*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Mike Compson
Phone: 410– 965–3949
Email: Michael.compson@ssa.gov
Website: http://www.socialsecurity.gov/policy

OASDI Microdata File 2004

Sponsor(s): Social Security Administration

Data Collection Agency: Social Security Administration

Purpose / Primary Goals: Release data on Old Age Survivors and Disability Insurance (i.e., Social Security) beneficiaries of December 2004

Survey Universe / Coverage / Census: Recipients of OASDI in December 2004

Sample or Research Design: Systematic sample of 1 percent of recipients

Unit(s) of Analysis: Beneficiary

Mode of Data Collection: Application to SSA for benefits

Topics / Keywords: Social Security beneficiary benefits and earnings

Data Years: December 2004

Reports: See website for reports on Social Security beneficiaries

Linked Data: n/a

Background / History: n/a

Future Plans: n/a

Bibliography: n/a

OASDI Microdata File 2004

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: see below*
- ☐ *Data available for free upon order from agency.*
- ☐ *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Mike Compson
Phone: 410– 965–3949
Email: Michael.compson@ssa.gov
Website: http://www.socialsecurity.gov/policy

SSI Microdata File

Sponsor(s): Social Security Administration

Data Collection Agency: Social Security Administration

Purpose / Primary Goals: Release data used to determine eligibility for Supplemental Security Income for recipients of December 2001

Survey Universe / Coverage / Census: Recipients of OASDI in December 2004

Sample or Research Design: Systematic sample of 5 percent of recipients

Unit(s) of Analysis: Recipient

Mode of Data Collection: Application to SSA for benefits

Topics / Keywords: Supplemental Security Income recipients

Data Years: December 2001

Linked Data: n/a

Reports: See website for reports on Social Security recipients

Background / History: See report to Congress on Supplemental Security Income at the SSA website.

Future Plans: n/a

Bibliography: n/a

SSI Microdata File

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- X *Some or all public-use files downloadable free from website: see below*
- ☐ *Data available for free upon order from agency. Order from*
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- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Contact: Mike Compson
Phone: 410– 965–3949
Email: Michael.Compson@ssa.gov
Website: http://www.socialsecurity.gov/policy

Access to Tabulations and Statistics on Programs Created by the Social Security Act

http://www.socialsecurity.gov/policy/data_type.html

Chartbooks

Using data from statistical publications, such as the Annual Statistical Supplement and Income of the Population 55 or Older, the chartbooks present important information about the people served by the Social Security Administration's programs and the benefits they receive. The information is presented clearly in charts and tables that are easy to understand.

http://www.socialsecurity.gov/policy/docs/chartbooks/index.html

Fact Sheets

http://www.socialsecurity.gov/policy/docs/factsheets/index.html

Program Descriptions

Several Office of Retirement and Disability Policy publications highlight the principal features of social security programs here and abroad. They provide information on such topics as coverage, eligibility, program administration, sources of funding, regulatory framework and applicable legislation, and benefits available under the program.

http://www.socialsecurity.gov/policy/docs/microdata/index.html

Public-Use Microdata Files

Public-use microdata files are subsets of survey or administrative data that are released to the public with all identifying information removed. Those files are valuable because they can be used for statistical analysis and research studies that cannot be carried out using aggregate information. Public-use microdata files enable researchers to create summary information that meets specialized needs and to investigate relations among variables that are not apparent based on aggregate information.

http://www.socialsecurity.gov/policy/docs/microdata/index.html

Statistical Compilations

The Office of Retirement and Disability Policy produces numerous statistical reports that give a broad overview of the scope of the Old-Age, Survivors, and Disability Insurance and Supplemental Security Income programs. The data describe the characteristics of beneficiaries—for example, age, sex, race and ethnicity, income, and type of disability—and the type of benefits they receive (retired-worker, survivors, disabled-worker benefits, and so on). The data are also presented by state and, in some reports, by county or congressional district.

http://www.socialsecurity.gov/policy/docs/statcomps/index.html

International Data Sources

English Longitudinal Study of Ageing (ELSA)

Sponsor(s): National Institute on Aging, UK government agencies

Data Collection Agency: International Institute for Society and Health, University College London (UCL)

Purpose/Primary Goals: The English Longitudinal Study of Ageing is an interdisciplinary data resource on health, economic position and quality of life as people age. ELSA is the first study in the UK to connect the full range of topics necessary to understand the economic, social, psychological and health elements of the aging process. The aim of ELSA is to explore the unfolding dynamic relationships between health, functioning, social networks and economic position. It is in effect a study of people's quality of life as they age beyond 50 and of the factors associated with it.

The survey covers the broad set of topics relevant to a full understanding of the aging process, these include: health, disability, healthy life expectancy; the relationship between economic position and both physical and cognitive health; the determinants of economic position in older age; the timing and circumstances of retirement and post-retirement labor market activity; the nature of social networks, support and participation; household and family structure and the transfer of resources.

Survey Universe / Coverage / Census: English Sample: representative population aged 50 and over

Sample or Research Design: The survey sample is drawn from respondents to the Health Survey for England (HSE) - a study conducted jointly by the Department of Epidemiology and Public Health, UCL, and the National Centre for Social Research, on behalf of the Department of Health. Around 12,000 respondents from three separate years of the HSE survey were recruited to provide a representative sample of the English population aged 50 and over.

Unit(s) of Analysis: Individual

Mode of Data Collection: Face to face interviews and nurse visit

Topics / Keywords: Assets, Chronic conditions, Collection of biological samples, Demographics, Disability, Economics, Functional status, Health behaviors, Health care utilization, Health outcomes, Health status, Housing, Housing characteristics, Income, Labor force participation, Longitudinal data, Marital status, Mental health / behavioral health, Mortality, Performance measurement, Risk factors, Self report of health status, Smoking, Social characteristics, Socioeconomic status and Use of health care services

Data Years: 1998: Initial baseline fieldwork and biomedical tests, 2002: Wave 1; face to face interview , 2004: Wave 2; face to face interviews and nurse visit, 2006: Wave 3; face to face interviews , 2007: Life history interview, 2008: Wave 4; face to face interviews and nurse visit

Linked Data: n/a

Reports: Data documentation and other information on the survey instruments can be found at: http://www.ifs.org.uk/elsa/documentation.php. Publications of early findings and summary reports can be found at: http://www.ifs.org.uk/elsa/publications.php

Background / History: n/a

Future Plans: Wave 4 is in the field. Wave 5 is planned.

Bibliography: A list of publications can be found at: http://www.ifs.org.uk/elsa/publications.php?type_selected=all

English Longitudinal Study of Ageing (ELSA)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency.*
- X *Application process required to obtain some data files*
- X *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- ☐ *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

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Website: http://www.ifs.org.uk/elsa/index.php

Survey of Health, Ageing and Retirement in Europe (SHARE)

Sponsor(s): National Institute on Aging, European Commission

Data Collection Agency: Multiple partners; Coordinating Agency: Mannheim Research Institute for the Economics of Aging

Purpose / Primary Goals: The Survey of Health, Ageing and Retirement in Europe (SHARE) is a multidisciplinary and cross-national panel database of microdata on health, socio economic status and social and family networks of more than 40,000 individuals aged 50 or over. Eleven countries have contributed data to the 2004 SHARE baseline study.

They is a balanced representation of the various regions in Europe, ranging from Scandinavia (Denmark and Sweden) through Central Europe (Austria, France, Germany, Switzerland, Belgium, and the Netherlands) to the Mediterranean (Spain, Italy and Greece). Further data have been collected in 2005–2006 in Israel. Two new EU member states - the Czech Republic and Poland - as well as Ireland have joined SHARE in 2006 and participated in the second wave of data collection in 2006–2007.

Data collected include health variables (e.g. self-reported health, health conditions, physical and cognitive functioning, health behavior, use of health care facilities), bio-markers (e.g. grip strength, body-mass index, peak flow), psychological variables (e.g. psychological health, well-being, life satisfaction), economic variables (e.g. current work activity, job characteristics, opportunities to work past retirement age, sources and composition of current income, wealth and consumption, housing, education), and social support variables (e.g. assistance within families, transfers of income and assets, social networks, volunteer activities).

Survey Universe / Coverage / Census: European Sample: Non-institutionalized population aged 50 and older. Spouses are interviewed if they are younger than 50.

Sample or Research Design: Random probability sample.

Unit(s) of Analysis: Individual

Mode of Data Collection: In most countries there are two separate samples: the main and the vignette sample. Respondents in the main sample complete a CAPI interview and a drop off questionnaire. In the vignettes sample, the respondents answer the CAPI instrument and a vignette module. SHARELIFE (wave 3, ongoing) collects detailed retrospective life-histories.

Topics / Keywords: Assets, Care giving, Chronic conditions, Demographics, Disability, Economics, Functional status, Health behaviors, Health status, Housing, Housing characteristics, Income, Labor force participation, Longitudinal data, Marital status, Mental health / behavioral health, Mortality, Performance measurement, Risk factors, Self report of health status, Smoking, Social characteristics, Social security and Socioeconomic status

Data Years: 2004 Baseline Study (Wave 1): Eleven countries contribute data to SHARE - Austria, Belgium, Denmark, France, Germany, Greece, Italy, The Netherlands, Spain, Sweden and Switzerland. In 2005–2006: Further data are collected in Israel. In 2006–2007 Wave 2: The Czech Republic, Ireland and Poland join SHARE. 2008–2009 SHARELIFE (Wave 3): SHARELIFE collects detailed retrospective life-histories. In 2010–2011 Wave 4: SHARE aims to include all EU member countries. For the fourth wave Finland, Hungary, Portugal and Slovenia are scheduled to participate in data collection.

Linked Data: n/a

Reports: Data documentation and published reports on methods, sample selection and preliminary analyses can be found at: http://www.share-project.org/t3/share/index.php?id=74&L=0. Initial findings can be found at: http://www.share-project.org/t3/share/index.php?id=74&L=0

Background / History: The Survey of Health, Ageing and Retirement in Europe (SHARE) is a multidisciplinary and cross-national panel database of microdata on health, socio economic status and social and family networks of more than 40,000 individuals aged 50 or over. Eleven countries have contributed data to the 2004 SHARE baseline study. The survey's third wave of data collection, SHARELIFE, will collect detailed retrospective life-histories in sixteen countries in 2008–2009, with Slovenia joining in as a new member.

SHARE is coordinated centrally at the Mannheim Research Institute for the Economics of Aging (MEA). It is harmonized with the U.S. Health and Retirement Study (HRS) and the English Longitudinal Study of Ageing (ELSA), and other cross-nationally comparable datasets under development or in the field. SHARE's scientific power is based on its panel design that grasps the dynamic character of the aging process. SHARE's multi-disciplinary approach delivers the full picture of the aging process. Rigorous procedural guidelines and programs ensure an ex-ante harmonized cross-national design.

Data collected include health variables (e.g. self-reported health, health conditions, physical and cognitive functioning, health behavior, use of health care facilities), bio-markers (e.g. grip strength, body-mass index, peak flow), psychological variables (e.g. psychological health, well-being, life satisfaction), economic variables (current work activity, job characteristics, opportunities to work past retirement age, sources and composition of current income, wealth and consumption, housing, education), and social support variables (e.g. assistance within families, transfers of income and assets, social networks, volunteer activities). In addition, the SHARE data base features anchoring vignettes from the COMPARE project and variables and indicators created by the AMANDA RTD-Project. The data are available to the entire research community for no costs.

Future Plans: Wave 3 data is being edited and Wave 4 is planned for 2010–2011

Bibliography: A detailed bibliography can be found at: http://www.share-project.org/t3/share/index.php?id=71

Survey of Health, Ageing and Retirement in Europe (SHARE)

Data Access (Availability and Dissemination):

X is next to all that apply

Data Access to Public-Use data (i.e., deidentified)

- ☐ *User-specified online data query or table generation possible.*
- ☐ *Some or all public-use files downloadable free from website*
- ☐ *Data available for free upon order from agency. Order from*
- X *Application process required to obtain some data files*
- ☐ *Payment required for the preparation/supply of data*

Data Access to Non Public-Use data (i.e., data with confidential information)

- X *Application process required to obtain data files*
- ☐ *Use of Research Data Center required for access to restricted-use data.*
- ☐ *Payment required for the preparation / supply of data*

Additional Information:

Following a short application for data use, a userID will be assigned and data can be downloaded from the SHARE website.

Contact: SHARE Coordination Team, Mannheim Research Institute for the Economics of Aging, University of Mannheim
ELSA, University College London
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Email: share@mea.uni-mannheim.de
Website: http://www.share-project.org/

World Health Organization (WHO)

WHO Statistical Information System (WHOSIS)

http://www.who.int/whosis/en/

WHOSIS, the WHO Statistical Information System, is an interactive database bringing together core health statistics for the 193 WHO Member States. It comprises more than 100 indicators, which can be accessed by way of a quick search, by major categories, or through user-defined tables. The data can be further filtered, tabulated, charted and downloaded. The data are also published annually in the World Health Statistics Report released in May.

Download the detailed data files of the WHO Mortality Database

http://www.who.int/whosis/mort/download/en/index.html