Contents

Contents ................................................................................................................. 3
Agency for Healthcare Research and Quality (AHRQ) ........................................... 1
Healthcare Cost and Utilization Project (HCUP) .................................................... 1
National Consumer Assessment of Healthcare Providers and Systems (CAHPS)
Benchmarking Database ....................................................................................... 5
Centers for Disease Control and Prevention (CDC) .............................................. 7
Behavioral Risk Factor Surveillance System (BRFSS) ......................................... 7
National HIV/AIDS Surveillance System ................................................................. 9
National Ambulatory Medical Care Survey (NAMCS) ......................................... 11
National Hospital Ambulatory Medical Care Survey (NHAMCS) ....................... 13
National Health and Nutrition Examination Survey (NHANES) ......................... 14
National Health Interview Survey (NHIS) ............................................................. 16
National Immunization Survey (NIS) and NIS-Teen ........................................... 20
National Program of Cancer Registries (NPCR) ................................................. 21
National Tuberculosis Surveillance System (NTBSS) ......................................... 23
National Vital Statistics System: Linked Birth and Infant Death Data (NVSS-I) ... 24
National Vital Statistics System: Mortality (NVSS-M) ....................................... 26
National Vital Statistics System: Natality (NVSS-N) ......................................... 29
Centers for Medicare & Medicaid Services (CMS) .............................................. 31
Home Health Care CAHPS Survey ....................................................................... 31
CAHPS® Hospice Survey ...................................................................................... 33
Hospital CAHPS Survey ....................................................................................... 35
Medicare Quality Improvement Organization (QIO) Program - Clinical Data Warehouse (CDW) ........................................................................................................... 37
Health Resources and Services Administration (HRSA) .................................... 39
HRSA, Ryan White HIV/AIDS Program (RWHAP) .............................................. 39
Indian Health Service (IHS) .................................................................................. 40
Indian Health Service (IHS) National Data Warehouse (NDW) ............................ 40
National Institutes of Health (NIH) ..................................................................... 42
United States Renal Data System (USRDS) ........................................................ 42
Substance Abuse and Mental Health Services Administration (SAMHSA) ....... 43
National Survey on Drug Use and Health (NSDUH) ......................................... 43
Substance Abuse Treatment Episode Data Set (TEDS) ........................................ 46
United States Census Bureau ............................................................................... 47
American Community Survey (ACS) .................................................................... 47
Academic Institutions ........................................................................................... 49
University of Michigan Kidney Epidemiology and Cost Center (UM-KECC) ...... 49
Professional Organizations and Associations ...................................................... 51
American Hospital Association (AHA) Information Technology (IT) Supplement ... 51
National Cancer Data Base (NCDB) .................................................................... 52
Multiple-Source Data Sponsors .......................................................................... 54
Medical Expenditure Panel Survey (MEPS) .......................................................... 54
Medicare Patient Safety Monitoring System (MPSMS). ...................................... 57
Agency for Healthcare Research and Quality (AHRQ)

Healthcare Cost and Utilization Project (HCUP)

Sponsor


Description

HCUP databases bring together the data collection efforts of State government data organizations, hospital associations, private data organizations, and the Federal Government to create a national information resource of discharge-level health care data.

HCUP includes a collection of longitudinal hospital care data, with all-payer, discharge-level information beginning in 1988. Four HCUP discharge datasets were used in this report:

1. The HCUP Statewide Inpatient Databases (SID) includes discharges for most, if not all, hospitals from 47 States and the District of Columbia. In aggregate, the SID represents almost 97% of all community U.S. hospital discharges. The SID contains a core set of clinical and nonclinical information on all patients, regardless of payer. In addition to the core set of uniform data elements common to all of the SID, some States report other data elements, such as patient race.

2. Prior to data year 2012, the Nationwide Inpatient Sample (NIS) was a stratified sample of hospitals, drawn from the subset of hospitals in the SID that could be matched to the American Hospital Association (AHA) Annual Survey. Hospitals were stratified by region, location/teaching status (within region), bed size category (within region and location/teaching status), and ownership (within region, location/teaching, and bed size categories). Weights were used to develop national estimates. More than 8 million discharges from more than 1,000 hospitals located in 46 States were represented in the 2011 NIS, approximating a 20% stratified sample of U.S. community hospitals. In 2012, the NIS was redesigned into a sample of discharges (instead of hospitals). For consistent estimates before and after data year 2012, a nationally weighted analysis file was constructed from the SID using a design consistent with the 2011 NIS, but with a 40 percent sampling rate.

3. The Nationwide Emergency Department Sample (NEDS) was constructed using the HCUP State Emergency Department Databases (SEDD) and the SID. The SEDD captures discharge information on emergency department (ED) visits that do not result in an admission (i.e., treat-and-release visits and transfers to another hospital). The SID contains information on patients initially seen in the ED and then admitted to the same hospital. The NEDS is a stratified sample of 20% of U.S. hospital-based EDs. Thirty-four States and the District of Columbia contributed data to the 2015 NEDS: AR, AZ, CA, CT, DC, FL, GA, HI, IA, IL, IN, KS, KY, MA, MD, ME, MN, MO, MT, NC, ND, NE, NJ, NV, NY, OH, RI, SC, SD, TN, TX, UT, VT, WI, and WI.

4. A nationally weighted analysis file was created from SID each data year for two reasons. First, the availability of information on patient race/ethnicity varied across States and
hospitals within States. Second, the 20% sample of the hospitals in the NIS did not provide enough statistical power to detect differences in QI estimates between Whites and the other specific racial groups. In 2015, the file consists of weighted records from a sample of hospitals that have high-quality race/ethnicity data in the following SID: AR, AZ, CA, CO, CT, FL, GA, HI, IA, IL, IN, KS, KY, MA, MD, MI, MO, MS, NC, NJ, NM, NV, NY, OH, OK, OR, PA, RI, SC, SD, TN, TX, UT, VA, VT, WA, WI, and WY in 2012. These 38 States accounted for 91% of U.S. hospital discharges (based on the AHA annual survey).

The HCUP databases combine race/ethnicity categories, resulting in the following subgroups: Hispanic of all races, and non-Hispanic African Americans, Asians and Pacific Islanders, and Whites. Not all States uniformly collect race and ethnicity data; when a State and its hospitals collect Hispanic ethnicity separately from race, HCUP uses Hispanic ethnicity to override any other race category.

Community, nonrehabilitation hospitals from the SID were sampled to approximate a 40% stratified sample of U.S. community hospitals, with stratification based on five hospital characteristics: geographic region, hospital ownership, urbanized location, teaching status, and bed size. Hospitals were excluded from the sampling frame if the coding of patient race was suspect. Once the 40% sample was drawn, discharge-level weights were developed to produce national-level estimates when applied to the nationally weighted analysis file. The 2015 final SID disparities file included about 15 million hospital discharges from more than 2,000 hospitals.

**Primary Content**

The HCUP NIS and SID contain more than 100 clinical and nonclinical data variables, including age, gender, race, ethnicity, length of stay, discharge status, source of payment, total charges, hospital size, ownership, region, teaching status, diagnoses, and procedures.

The QDR measures that use HCUP data are based on Version 4.4 of the AHRQ Quality Indicators (QIs), a set of algorithms that may be applied to hospital administrative data to quantify quality issues among inpatient populations. The QIs fall into four categories:

1. Inpatient Quality Indicators (IQIs) reflect quality of care in hospitals and currently include 15 mortality indicators for conditions or procedures. The IQIs include indicators for 11 procedures for which utilization varies across hospitals or geographic areas and indicators for 6 procedures for which outcomes may relate to the volume of procedures.
2. Prevention Quality Indicators (PQIs) assess hospital admissions for 14 ambulatory care-sensitive conditions that evidence suggests may be avoided, in part, through high-quality ambulatory care.
3. Patient Safety Indicators (PSIs) reflect potential inpatient complications and other patient safety concerns following surgeries, other procedures, and childbirth. The most recent version of the PSI software has 27 measures.
4. Pediatric Quality Indicators (PDIs) examine 18 conditions that pediatric patients experience within the health care system that may be preventable by changes at the system or provider level. In earlier versions of the QI software, some PDI measures were part of the IQI, PSI, and PQI modules. Our application of the QI software to the HCUP
databases did not use indicators of the diagnosis being present on admission (POA) or the POA estimation module for the IQIs, PDIs, and PSIs since POA indicators were not uniformly available from States that contribute to the HCUP databases. Other QI-specific modifications are noted as footnotes.

Population Targeted

The population targeted by HCUP databases includes any person, U.S. citizen or foreign, using non-Federal, nonrehabilitation, community hospitals in the United States as defined by AHA. AHA defines community hospitals as “all non-Federal, short-term, general, and other specialty hospitals, whose facilities and services are available to the public” (Health Forum, LLC ©2017). Included among community hospitals are specialty hospitals, such as obstetrics-gynecology, ear-nose-throat, short-term rehabilitation, orthopedic, and pediatric institutions. Also included are public hospitals and academic medical centers. The NIS and analyses of the SID for this report excluded short-term rehabilitation hospitals, long-term hospitals, psychiatric hospitals, and alcoholism/chemical dependency treatment facilities.

Although not all States participate in the HCUP database, the NIS, the NEDS, and the nationally weighted analysis files are weighted to give national estimates of all U.S. community, nonrehabilitation hospitals in the AHA Annual Survey (Health Forum, LLC © 2017).

Demographic Data

Age, gender, race/ethnicity, expected primary payer, median household income of the patient’s ZIP Code, urbanized location, and region of the United States.

Years Collected


Schedule

Annual.

Geographic Estimates

National, four U.S. Census Bureau regions, States (for States participating in SID that agree to the release).

Contact Information


AHRQ Quality Indicators: https://www.qualityindicators.ahrq.gov.
References


For detailed information about QI measures, refer to the individual guides to the quality indicators listed below, available from the archives at https://www.qualityindicators.ahrq.gov.

Sources of HCUP Data

Alaska Department of Health and Social Services
Alaska State Hospital and Nursing Home Association
Arizona Department of Health Services
Arkansas Department of Health
California Office of Statewide Health Planning and Development
Colorado Hospital Association
Connecticut Hospital Association
District of Columbia Hospital Association
Florida Agency for Health Care Administration
Georgia Hospital Association
Hawaii Health Information Corporation
Illinois Department of Public Health
Indiana Hospital Association
Iowa Hospital Association
Kansas Hospital Association
Kentucky Cabinet for Health and Family Services
Louisiana Department of Health and Hospitals
Maine Health Data Organization
Maryland Health Services Cost Review Commission
Massachusetts Center for Health Information and Analysis
Michigan Health & Hospital Association
Minnesota Hospital Association (provides data for Minnesota and North Dakota)
Mississippi State Department of Health
Missouri Hospital Industry Data Institute
Montana Hospital Association
Nebraska Hospital Association
Nevada Department of Health and Human Services
New Hampshire Department of Health & Human Services
New Jersey Department of Health
New Mexico Department of Health
New York State Department of Health
North Carolina Department of Health and Human Services
North Dakota (data provided by the Minnesota Hospital Association)
Ohio Hospital Association
Oklahoma State Department of Health
Oregon Association of Hospitals and Health Systems
Oregon Office of Health Analytics
Pennsylvania Health Care Cost Containment Council
Rhode Island Department of Health
South Carolina Revenue and Fiscal Affairs Office
South Dakota Association of Healthcare Organizations
Tennessee Hospital Association
Texas Department of State Health Services
Utah Department of Health
Vermont Association of Hospitals and Health Systems
Virginia Health Information
Washington State Department of Health
West Virginia Department of Health and Human Resources, West Virginia Health Care Authority
Wisconsin Department of Health Services
Wyoming Hospital Association

National Consumer Assessment of Healthcare Providers and Systems (CAHPS) Benchmarking Database

Sponsor

Consumer Assessment of Healthcare Providers and Systems

U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ) in association with a consortium of public and private organizations.
Description

By responding to a standardized set of questions administered through a mail or telephone questionnaire, health plan members report on their experiences and rate their health plans and providers in several areas. Participation in the CAHPS Database is voluntary.

Medicare Managed Care data were obtained from Centers for Medicare & Medicaid Services (CMS) for survey participants. The 5.0 Medicaid data were obtained from data submitted directly to the CAHPS Database by State Medicaid agencies and individual health plans.

Survey Sample Design

CAHPS surveys are administered to a random sample of health plan members by independent survey vendors, following standardized procedures. Since 1998, health plans, purchaser groups, State organizations and others have participated in this component.

The CAHPS sampling recommendation is to achieve a minimum of 300 completed responses per health plan, with a target response rate of 50%. The plan samples are not adjusted for unequal probabilities of selection. This logic stems from the principle that the precision of the estimates depends primarily on the size of the sample and not on the size of the population from which it is drawn. Therefore, the given sample size will give the same precision for means or rates regardless of the overall size of the population.

Primary Survey Content

The 5.0 version of the CAHPS Adult and Child Health Plan Surveys reporting questions fall into four major “composites” that summarize consumer experiences in the following areas, getting needed care, getting care quickly, how well doctors communicate, and health plan information and customer service.

Population Targeted

CAHPS surveys several different populations, such as adults, children, children with chronic conditions, Medicaid, Medicare, and/or Medicare managed care.

Estimates for tables based on Medicaid CAHPS (Adult and Child) data were calculated using plan weights; i.e., all respondents in a plan received the same weight. In contrast, estimates for tables based on Medicare CAHPS (Fee for Service and Medicare Advantage) data were calculated using person-level weights; i.e., all respondents in a plan received a weight that had been calculated by multiplying the plan weight by a nonresponse adjustment factor based on the respondent’s demographic characteristics, including age, race, and geographic location.

Demographic Data

Age, gender, education, race, ethnicity, region.
Years Collected

Since 1998.

Schedule

Annual.

Geographic Estimates

State; four U.S. Census Bureau regions.

Contact Information


Reference


Centers for Disease Control and Prevention (CDC)

Behavioral Risk Factor Surveillance System (BRFSS)

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), Office of Surveillance, Epidemiology, and Laboratory Services. Currently, there is a wide sponsorship of the BRFSS survey, including most divisions in the CDC National Center for Chronic Disease Prevention and Health Promotion; other CDC centers; and Federal agencies, such as the Health Resources and Services Administration, Administration on Aging, Department of Veterans Affairs, and Substance Abuse and Mental Health Services Administration.

Description

The BRFSS is the Nation’s premier system of health-related telephone surveys that collect State data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 States, BRFSS now collects data in all 50 States, as well as the District of Columbia and 3 U.S. territories. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world.
Survey Sample Design

BRFSS is a State-based system of telephone health surveys of noninstitutionalized adults age 18 and over who reside in households. BRFSS is conducted by landline and cell phone. Random-digit-dialed (RDD) probability design was used initially. Disproportionate stratified sample (DSS) design has been implemented for landline portions of the sample since 2003 and the number of States using DSS is increasing.

In the DSS design most commonly used in BRFSS, telephone numbers are divided into two strata, high density and medium density. Strata are sampled separately. Telephone numbers in the high-density stratum are sampled at the highest rate. In 2011, 50 States and the District of Columbia used DSS design. Guam, Puerto Rico, and the U.S. Virgin Islands used RDD design.

BRFSS piloted the Cell Phone Survey beginning in 2008. By including cell phones in the survey, BRFSS can reach segments of the population that were previously inaccessible, those who have a cell phone but not a landline, and produce a more representative sample and higher quality data.

Cell Phone surveys were included in the public release dataset beginning in 2011. A second important change in 2011 was the move to a new weighting system (ranking) that incorporates cell phone data and includes new variables (education, marital status, and home ownership) as controls.

As BRFSS moved to incorporate cell phone data and changed weighting methods, a review of reliability and validity research indicated that past BRFSS landline-only data were reliable and valid as measured against other surveys. New analyses and comparisons of BRFSS data that include the new methodologies and cell phone data will be needed to ascertain the impact of these changes on estimates in the future. The 2003-2016 QDR only use the BRFSS landline data collected before 2011.

Primary Survey Content

The objective of BRFSS is to collect uniform, State-specific data on preventive health practices and risk behaviors linked to chronic diseases, injuries, and preventable infectious diseases in the adult population.

The survey consists of core questions asked in all States, standardized optional questions on selected topics administered at the State’s discretion, a rotating set of core questions asked every other year in all States, and State-added questions developed to address State-specific needs. Questions cover behavioral risk factors (e.g., alcohol and tobacco use), preventive health measures, HIV/AIDS, health status, activity limitations, and health care access and utilization.

Population Targeted

U.S. civilian noninstitutionalized population, age 18 and over who reside in households.
Demographic Data

Gender, age, educational attainment, race/ethnicity, household income, employment status, and marital status.

Years Collected

Since 1984. The number of States participating in the survey has increased from 15 in 1984 to 50 States, the District of Columbia, Puerto Rico, Guam, and the Virgin Islands since 2001.

Schedule

Annual. Data are collected monthly.

Geographic Estimates

National; State; smaller area estimates possible in some States.

Contact Information


Data system home page: http://www.cdc.gov/brfss.

References


Go to https://www.cdc.gov/brfss/data_documentation/index.htm for a collection of documents and survey data providing technical and statistical information regarding the BRFSS, such as comparability and sampling information.

National HIV/AIDS Surveillance System

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP).
Description

The National HIV Surveillance System is the Nation's source for timely information on HIV infection. CDC funds and assists State and local health departments to collect the information. Health departments report their data to CDC.

Since the epidemic was first identified in the United States in 1981, population-based AIDS surveillance has been used to track the progression of HIV disease. Since 1985, States have gradually implemented a standardized confidential name-based approach for HIV surveillance. By April 2008, all 50 States, the District of Columbia, and 6 U.S. dependent areas had fully integrated HIV and AIDS surveillance and had laws or regulations requiring confidential reporting by name for adults, adolescents, and children with confirmed HIV infection.

All 50 States, the District of Columbia, and U.S. dependent areas report cases of HIV infection to CDC by using a uniform surveillance case definition and case report form. The original definition has been modified several times. The most recent modification was in 2008 when the surveillance case definition for HIV infection among adults and adolescents was revised to incorporate an HIV infection staging system that categorizes AIDS as HIV infection, stage 3.

Primary Content

Mode of exposure to HIV, case definition category, and other clinical and demographic information.

Population Targeted

Entire population of all 50 States, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and other U.S. territories. HIV infection and AIDS data are nationally representative.

Demographic Data

Age, gender, race, ethnicity, State and county of residence, country of birth, and whether alive.

Years Collected

Since 1981.

Schedule

The HIV Surveillance Report is published annually. Supplemental reports are published on an ad hoc basis and are available online at http://www.cdc.gov/hiv/default.htm

Geographic Estimates

National, State, region, and metropolitan statistical area.
Contact Information


References

HIV Surveillance Report Available at:

https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html

National Ambulatory Medical Care Survey (NAMCS)

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS).

Description

NAMCS is an annual survey that collects visit, practice, and provider-level data from office-based physicians and community health center (CHC) providers in the United States. Field personnel meet with participating office-based physicians and instruct them in survey data collection methods. Physicians are asked to complete a 2-page questionnaire (Patient Record Form) on a sample of their office visits during their assigned reporting period. However, more than half of NAMCS Patient Record forms submitted in 2010 (54.6 percent) were abstracted by field personnel from the U.S. Census Bureau rather than by the physician or medical office personnel.

Survey Sample Design

NAMCS has been fielded since 1989. The sampling frame for office-based physicians in NAMCS is derived from the American Medical Association and the American Osteopathic Association master files. Physicians are excluded if they are federally employed, do not provide direct patient care, or specialize in anesthesiology, radiology, or pathology. A special stratum of CHC providers was first added in 2006.

The sampling frame for CHC providers in NAMCS is developed using data from the Health Resources and Services Administration’s Bureau of Primary Health Care Uniform Data System and the Indian Health Service. Each participating CHC provides a list of physicians and mid-level providers who would be available during the predetermined 1-week reporting period. This list becomes the frame for selection of up to three physicians and mid-level providers in each CHC. To maintain consistency with measures included before 2006, this report excludes visits to CHC mid-level providers. In 2009 and 2010, data from a total of 63,510 visits were obtained from 2,585 office-based physicians. Unweighted and weighted response rates in these years ranged from 57% to 62%, respectively.
Primary Survey Content

Data are collected from medical records and include type of provider seen; reason for visit; diagnoses; drugs ordered, provided, or continued; and selected procedures and tests ordered or performed during the visit. Patient data include age, sex, race, and expected source of payment. Data are also collected on selected characteristics of physician practices.

Population Targeted

Sample data are weighted to produce national estimates of office visits. The basic sampling unit is the patient visit. The specialties of anesthesiology, pathology, and radiology are not included. Also not included are contacts by telephone, visits made outside the physician’s office, visits in hospitals or institutional settings, and visits made for administrative purposes only.

Demographic Data

Patient age, gender, race, and ethnicity.

Years Collected


Schedule

Annual.

Geographic Estimates

National; U.S. Census Bureau regions.

Notes

NAMCS is a visit-based survey rather than a population-based survey. Therefore, estimates of incidence and prevalence of disease cannot be computed. The survey is cross-sectional in nature. Multiple visits may be made by the same person within the sample.

Contact Information


References


National Hospital Ambulatory Medical Care Survey (NHAMCS)

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS).

Description

NHAMCS collects data on the utilization and provision of medical care services in hospital emergency departments (EDs) and outpatient departments (OPDs). Hospital staff are asked to complete 2-page questionnaires (Patient Record forms, or PRFs) on a sample of their patient visits during an assigned reporting period. However, about one-third of NHAMCS PRFs submitted in 2010 (32% percent) were abstracted by field personnel from the U.S. Census Bureau rather than by hospital staff.

Survey Sample Design

NHAMCS is designed as a national probability sample of visits to EDs and OPDs of non-Federal, short-stay, and general hospitals in the United States. NHAMCS uses a 4-stage probability design that involves samples of primary sampling units (PSUs), hospitals within PSUs, clinics within hospitals, and patient visits within clinics and/or emergency service areas. Hospital staff are asked to complete PRFs for a systematic random sample of patient visits occurring during a randomly assigned 4-week reporting period during the survey year.

About 400 hospitals participate in NHAMCS each year. About 350 hospitals have eligible EDs and 200 have eligible OPDs. In 2009 and 2010, 69,878 PRFs were completed for ED visits and 68,269 PRFs were completed for OPD visits. Response rates in 2009 and 2010 ranged from 73% for OPDs to 87% for EDs.

Primary Survey Content

Information is obtained on various aspects of ED and OPD patient visits, including patient, hospital, and visit characteristics. The survey instrument is redesigned every 2 to 4 years to address changing health data needs. Among the items collected are patient’s age, gender, race, and ethnicity; patient’s expressed reason for visit; intentionality of injury, if any; physician’s diagnoses; diagnostic services ordered or provided; procedures provided; medications; providers seen; visit disposition; immediacy with which patient should be seen; and expected source of payment. Items collected that are specific to the ED include mode of arrival, waiting time, duration of time in the ED, initial vital signs, and cause of injury.

Population Targeted

The survey is a representative sample of visits to EDs and OPDs of non-Federal, short-stay, or general hospitals, exclusive of Federal, military, and Veterans Affairs hospitals, located in the 50
States and the District of Columbia. Telephone contacts and visits for administrative purposes are excluded. NHAMCS is weighted to give national estimates of ED and hospital OPD visits.

**Demographic Data**

Patient age, gender, race, and ethnicity.

**Years Collected**

Since 1992

**Schedule**

Annual.

**Geographic Estimates**

National; U.S. Census Bureau regions.

**Contact Information**


**References**

2010 NHAMCS Emergency Department Web Tables.

2010 NHAMCS Micro-data File Documentation.

NAMCS and NHAMCS Web Tables. [https://www.cdc.gov/nchs/ahcd/web_tables.htm](https://www.cdc.gov/nchs/ahcd/web_tables.htm).

**National Health and Nutrition Examination Survey (NHANES)**

**Sponsor**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS).

**Description**

NHANES is a nationally representative survey of the resident civilian noninstitutionalized population. It consists of questionnaires administered in the home followed by a standardized physical examination in specially equipped mobile examination centers (MECs). The examination includes physical measurements, such as blood pressure and dental examinations, and collection of blood and urine specimens for laboratory testing.
Survey Sample Design

A complex, multistage probability sampling design is used to select a sample representative of the civilian, noninstitutionalized household population of the United States. The four stages of sampling are: first, the primary sampling units (i.e., mostly counties); second, segments within counties; third, dwelling units/households; and fourth, individuals within a household.

Since 1999, the annual sample size has been approximately 5,000 individuals from 15 different county locations selected from a sampling frame that includes all 50 States and the District of Columbia. Oversampled subgroups from 1999-2006 included non-Hispanic Blacks, Mexican Americans, low-income Whites, adolescents ages 12-19 years, and adults age 70 years and over. During 1999-2006 a supplemental sample of pregnant women was also included. Oversampled subgroups from 2007 to 2010 included all Hispanics, non-Hispanic Blacks, low-income Whites, and adults age 80 years and over. From 1999 to 2010, the household interview response rates ranged from 79% to 84%, and the examination response rates ranged from 75% to 80%.

Primary Survey Content

Data collected include information on chronic diseases (including undiagnosed conditions) and health status, dietary intake and nutritional status, infectious disease and immunization status, environmental health and exposures, and related risk factors. Specific survey content may vary by survey cycle.

Population Targeted

NHANES samples the U.S. civilian noninstitutionalized resident population of the United States. NHANES excludes all persons in supervised care or custody in institutional settings, all active-duty military personnel, active duty family members living overseas, and any other persons residing outside the 50 United States and the District of Columbia. Beginning in 1999, NHANES has included people of all ages.

Demographic Data

Gender, age, race and Hispanic origin, educational level, place of birth, income, and occupation.

Years Collected


Schedule

Fielded periodically (1960-1994); annually beginning in 1999, with data releases occurring in 2-year cycles.
Geographic Estimates

National; four U.S. Census Bureau regions (from 1988).

Contact Information


References


National Health Interview Survey (NHIS)

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS).

Description

The National Health Interview Survey (NHIS) monitors the health of the U.S. population through the collection and analysis of data on a broad range of health topics. The survey covers the civilian noninstitutionalized population residing in the United States at the time of the interview. Blacks, Hispanics, and Asians are oversampled. The questionnaire has core questions and supplements. Core questions remain largely unchanged from year to year and allow trend analysis and pooling of data from more than 1 year to increase sample size for analytic purposes.

The core contains four major components: Household, Family, Sample Adult, and Sample Child. The Household component collects limited demographic information on all individuals living in a particular house. The Family component verifies and collects additional demographic information on each member from each family in the house and collects data on topics including health status and limitations, injuries, health care access and utilization, health insurance, and income and assets. The supplements are used to respond to new public health data needs as they arise.

The questionnaires are sometimes fielded only once or are repeated as needed. These questionnaires may be used to provide additional detail on a subject already covered in the core or on a different topic not covered in other parts of NHIS.
Survey Sample Design

Sampling and interviewing are continuous throughout each year. The sampling plan follows a multistage area probability design that allows representative sampling of households. The sampling plan is redesigned after every decennial census. The current sampling plan was implemented in 2006. It has many similarities to the previous sampling plan, which was in place from 1995 to 2005.

The first stage of the current sampling plan consists of a sample of 428 PSUs drawn from approximately 1,900 geographically defined PSUs that cover the 50 States and the District of Columbia. A PSU consists of a county, a small group of contiguous counties, or a metropolitan statistical area.

Within a PSU, two types of second-stage units are used: area segments and permit segments. Area segments are defined geographically and contain an expected 8, 12, or 16 addresses. Permit segments cover housing units built after the 2000 census. The permit segments are defined based on updated lists of building permits issued in the PSU since 2000 and contain an expected four addresses.

The current NHIS sample design continues oversampling Blacks and Hispanics, which was a new feature of the previous sample design. A new feature of the current design is that Asians are oversampled as well. In addition, the adult selection process has been revised so that Black, Hispanic, and Asian people age 65 and over have an increased probability of being selected.

The new sample design is anticipated to result in approximately 87,500 people residing in 35,000 households with completed interviews each year. For 2006-2010, the households and noninstitutional group quarters selected for interview each week in NHIS are a probability sample representative of the target population. Beginning in 2011, the minimum time for a probability sample changed from a week to a month.

Primary Survey Content

After household composition is established, the core family interview asks about everyone in each family within the household. Additional questions are asked of one sample adult and one sample child (under 18 years) per family in the household. The sample adult questionnaire includes chronic health conditions and activity limitations, health behaviors, health care access, health care provider contacts, and immunizations. The sample child questionnaire includes questions about chronic health conditions, activity limitations, health status, behavior problems, health care access and use, and immunizations.

Child data are proxy reported by a parent or other knowledgeable adult respondent. Adult sample person data are self-reported, except in limited instances where a physical or mental impairment prevents the adult from answering for himself/herself. Supplemental modules are fielded periodically and cover areas such as cancer, prevention, disability, and use of complementary and alternative medicine.
Population Targeted

Civilian noninstitutionalized population residing in the United States.

Demographic Data

Gender, age, race/ethnicity, education, income, marital status, place of birth, industry, and occupation.

Years Collected

Continuously, since 1957. Current sample design began in 2006; current questionnaire design began in 1997.

Schedule

Annually.

Geographic Estimates

National; U.S. Census Bureau regions; some of the 10 Health and Human Services regions; some States; metropolitan and nonmetropolitan areas.

Notes

The annual NHIS response rate is close to 90% of the eligible households in the sample.

2006 NCHS Urban-Rural Classification Scheme for Counties, which is based on the Office of Management and Budget’s (OMB) December 2005 delineation of MSAs and micropolitan statistical areas (MISA) (derived according to the 2000 OMB standards for defining these areas) and vintage 2004 postcensal estimates of the resident U.S. population):

- Metropolitan categories:
  - Large Central - Central counties in metro areas of 1 million or more population.
  - Large Fringe - Outlying counties in metro areas of 1 million or more population.
  - Medium - Counties in metro areas of 250,000-999,999 population.
  - Small - Counties in metro areas of 50,000-249,999 population.
- Nonmetropolitan categories:
  - Micropolitan - Counties in areas with an urban cluster of 10,000-49,999 population.
  - Noncore - Nonmicropolitan.

The 2013 NCHS Urban-Rural Classification Scheme for Counties, which is based on the OMB’s February 2013 delineation of MSAs and MISAs (derived according to the 2010 OMB standards for defining these areas) and vintage 2012 postcensal estimates of the resident U.S. population.

Adults with a disability are defined to be those with physical, sensory, and/or mental health conditions that can be associated with a decrease in functioning in such day-to-day activities as bathing, walking, doing everyday chores, and/or engaging in work or social activities.

Limitations in basic activities represent problems with mobility and other basic functioning at the person level. Basic activities include problems with mobility; self-care (activities of daily living, or ADLs); domestic life (instrumental ADLs); and activities dependent on sensory functioning (limited to persons who are blind or deaf).

Limitations in complex activities represent limitations encountered when the person, in interaction with his or her environment, attempts to participate in community life. Complex activities include limitations experienced in work; and in community, social, and civic life. These two categories are not mutually exclusive since persons may have limitations both in basic activities and in complex activities.

Neither basic nor complex activities includes adults with neither basic nor complex activity limitations.

**Contact Information**


**References**

For more details, refer to the NHIS Description documents available from the datasets and documentation section at [https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm](https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm).


National Immunization Survey (NIS) and NIS-Teen

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Immunization and Respiratory Diseases (NCIRD) and National Center for Health Statistics (NCHS).

Description

The NIS is a continuing nationwide telephone sample survey to monitor vaccination coverage rates among children ages 19 to 35 months. Starting in 2006, the NIS-Teen was established to collect similar information for adolescents ages 13-17 years. The NIS-Teen was conducted for a national sample in the 4th quarters of 2006 and 2007 and expanded to an annual sample in each of 56 or more State and local geographic areas starting in 2008.

The first stage of survey administration is conducted using telephone interviews with households having age-eligible children. In the second stage, provider reports of vaccination information from the child’s medical record are obtained.

Survey Sample Design

In each of 56 or more State and local geographic areas (which together make up the United States), the NIS draws independent quarterly samples of telephone numbers and then uses random-digit dialing to identify households that have one or more children ages 19 to 35 months or 13-17 years. Until 2011, the NIS surveyed only landline telephones. A cellular telephone sample was added in 2011. In the telephone interview, the interviewer collects vaccination information for each child who meets the age criterion and obtains permission to contact the providers of the child’s vaccinations. In a second phase, a mail survey, the NIS asks providers to report vaccination information from the child’s medical record. This information is generally more accurate and complete than the household information.

Primary Survey Content

Data collected for children ages 19-35 months include vaccination status and timing for diphtheria, tetanus toxoids, and acellular pertussis vaccine (DTP/DT/DTAP); polio vaccine; measles, mumps, and rubella vaccine (MMR); Haemophilus influenzae type B vaccine (Hib); hepatitis B vaccine (Hep B); varicella zoster vaccine; pneumococcal conjugate vaccine (PCV); hepatitis A (Hep A); influenza; and rotavirus vaccine. Data collected for children ages 13-17 years include vaccination status and timing for tetanus, diphtheria, and acellular pertussis vaccine (Tdap), varicella vaccine, meningococcal conjugate vaccine, and human papillomavirus (HPV) vaccine. The data are collected by race and ethnicity, income, location of residence, geographic division, State, and selected urban areas.
Population Targeted

Children ages 1935 months or 13-17 years living in the United States at the time of the interview.

Demographic Data

Gender, race/ethnicity, income, location of residence, four U.S. Census Bureau regions.

Years Collected


Schedule

Quarterly samples, reported annually.

Geographic Estimates

National, State, and local areas.

Contact Information

Agency home page: http://www.cdc.gov/vaccines/.

Data system and information for survey respondents’ home page: https://www.cdc.gov/vaccines/imz-managers/nis/participant/.

References


National Program of Cancer Registries (NPCR)

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion.
Description

NPCR provides funds and guidance to States and U.S. territories to implement and enhance their cancer registries. As of 2015, NPCR supports central registries and promotes the use of registry data in 45 States, the District of Columbia, Puerto Rico, and the Pacific Island jurisdictions. Cancer registry data collected through the NPCR are used to identify and monitor trends in cancer incidence and mortality; guide planning and evaluation of cancer control programs; help allocate health resources; contribute to clinical, epidemiologic, and health services research; and respond to concerns from citizens over the presence of cancer in their communities.

Population Targeted

NPCR registries collect data about cancer cases occurring in approximately 96% of the U.S. population.

Demographic Data

Gender, age, race.

Years Collected

Since 1995.

Schedule

Data collection is ongoing. Reports are published periodically. Since 2001, State registries have been reporting data annually.

Geographic Estimates

National, participating States.

Contact Information


References

National Tuberculosis Surveillance System (NTBSS)

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Division of Tuberculosis Elimination (DTBE).

Description

Reports of verified cases of tuberculosis (RVCT) are submitted to DTBE, CDC, by 60 reporting areas (the 50 States, the District of Columbia, New York City, Puerto Rico, and seven other jurisdictions in the Pacific and Caribbean). In January 1993, an expanded system was developed to collect additional information for each reported TB case in order to better monitor trends in TB and TB control. A software package (SURVS-TB) for data entry, analysis, and transmission of case reports to CDC was designed and implemented as part of the expanded TB surveillance system.

In 1998, the Tuberculosis Information Management System (TIMS) replaced SURVS-TB. Beginning in 2009, case reports no longer had a specific software requirement. Two CDC-sponsored software options—the NEDSS base system (NBS) and the electronic Report of Verified Case of Tuberculosis (eRVCT)—were introduced as two options for reporting TB cases to CDC. In addition, commercial- and State-developed software came into use. TIMS was allowed to be used for reporting 2009 results in cases where other software was not yet available.

TIMS was officially retired for case completion in December 2010 for cases occurring in 2008 and prior. In 2016, the platform for the eRVCT was replaced by the National Tuberculosis Surveillance System for Case Reporting (NTSS-CR), which is a web-based RVCT form to allow data entry for case management and reporting to CDC. All systems reporting TB since TIMS report cases using HL7 messages following the TB Case Notification specification.

In total, 9,550 TB cases were reported in the United States in 2013.

Primary Content

Number of new TB cases, patient management, and program evaluation.

In the expanded system started in January 1993, the RVCT form for reporting TB cases was revised to collect information on occupation, initial drug regimen, HIV test results, history of substance abuse and homelessness, and residence in correctional or long-term care facilities at the time of diagnosis. RVCT Follow up Report-1 was added to collect drug susceptibility results for the initial M. tuberculosis isolate from patients with culture-positive disease. To evaluate the outcomes of TB therapy, RVCT Follow up Report-2 was added to collect information on the reason and date therapy was stopped, type of health care provider, sputum culture conversion, use of directly observed therapy, and results of drug susceptibility testing for the final M. tuberculosis isolate from patients with culture-positive disease.

In 2009, the RVCT form was further expanded to collect variables to reflect the changing field of TB epidemiology and to collect more accurate data on TB cases. New variables include count
status to address TB burden, pediatric TB to collect information on guardians and travel outside the United States, nucleic acid amplification test, initial chest CT scan or other chest imaging study, interferon gamma release assay blood test, primary reason evaluated for TB disease, additional TB risk factors, immigrant status, genotyping accession number, whether or not a patient moved during treatment and where, and reason therapy was extended for more than 12 months. Other variables were modified to include the addition of dates that specimens for diagnostic tests were collected and reported.

**Population Targeted**

Civilian population residing in the United States with a diagnosis of TB.

**Demographic Data**

Age, gender, race, and country of origin.

**Years Collected**

In aggregate form, since 1953; in individual case forms since 1985.

**Schedule**

Annual.

**Geographic Estimates**

National and States.

**Contact Information**


**References**


**National Vital Statistics System: Linked Birth and Infant Death Data (NVSS-I)**

**Sponsor**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS).
Description

NCHS’s Division of Vital Statistics obtains information on births and deaths 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, American Samoa, and Northern Mariana Islands. Data are sent to NCHS through the Vital Statistics Cooperative Program (VSCP). The number of participating States grew from 6 in 1972 to 46 in 1984. Since 1985, all 50 States and the District of Columbia have participated in VSCP.

In the linked birth and infant death dataset, the information from the death certificate is linked to the information from the birth certificate for each infant less than age 1 who dies in the United States, Puerto Rico, Virgin Islands, and Guam. Starting with data year 1995, linked file data are produced in a period data format preceding the release of the corresponding birth cohort format. The 2011 linked file contains a numerator file that consists of all infant deaths occurring in 2011 that have been linked to their corresponding birth certificates, whether the birth occurred in 2010 or 2011.

Other changes to the dataset, starting with 1995 data, include addition of record weights to correct for the 1.0% to 1.4% of records that could not be linked each year as well as an imputation for unstated birth weight.

The vital statistics general mortality data are a fundamental source of geographic and cause-of-death information and some demographic information. The birth certificate is the primary source of demographic information, such as age, race, and Hispanic origin of the parents; maternal education; live birth order; and mother’s marital status; and of maternal and infant health information, such as birth weight, period of gestation, plurality, prenatal care use, and maternal smoking.

Population Targeted

Infants in 50 States and the District of Columbia.

Demographic Data

Age, gender, race, and Hispanic origin of infant and parents, mother’s education and marital status.

Years Collected

Linked data are available for the data years 1983-1991 and 1995-2010.

Schedule

Annual.

Geographic Estimates

National, State.
Place of death is classified by State and county. In residence classification, all deaths are allocated to the usual place of residence as reported on the death certificate and are classified by State, county, and city.

**Notes**

Data on mother’s educational attainment, tobacco use during pregnancy, and prenatal care based on the 2003 revision are not comparable with data based on the 1989 revision of the U.S. Standard Certificate of Live Birth.

**Contact Information**


**References**


**National Vital Statistics System: Mortality (NVSS-M)**

**Sponsor**

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS).

**Description**

NVSS mortality files include data for the 50 States, the District of Columbia, and the territories of Puerto Rico, Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands. All deaths occurring in those areas are included (approximately 2.4 to 2.5 million annually).

By law, registration of deaths is a funeral director’s responsibility. Administrative records (death certificates) completed by funeral directors, physicians, medical examiners, and coroners are filed with State vital statistics offices. Selected statistical information is forwarded to NCHS to be merged into a national statistical file.

States are phasing in the 2003 revision of the standard certificates. Those that have not revised yet are using the 1989 version of the standard certificates. Demographic information on the death certificate is provided by the funeral director and is based on information supplied by an informant. Medical certification of cause of death is provided by a physician, medical examiner, or coroner.
Currently, data are sent to NCHS through the Vital Statistics Cooperative Program (VSCP). All 50 States and the District of Columbia have participated in VSCP since 1985.

**Primary Content**

Demographic and medical information and information about death event such as age at death, Hispanic origin, race, sex, marital status, decedent’s residence, place of birth, educational attainment, underlying and multiple causes of death, injury at work, place death occurred, day of week of death, month of death, and year of death.

**Population Targeted**

U.S. population.

**Demographic Data**

Sex, race, Hispanic origin, age at death, place of decedent’s residence, educational attainment, and marital status.

Race and ethnic origin are separate items on the death certificate. As of 1997, all States report Hispanic origin. The categories reported include Mexican, Puerto Rican, Cuban, Central and South American, and Other Hispanic.

Beginning in 1992, California, Hawaii, Illinois, New Jersey, New York, Texas, and Washington reported expanded Asian and Pacific Islander categories: Asian Indian, Korean, Vietnamese, Samoan, and Guamanian. The rest of the States reported a combined Other Asian and Pacific Islander category in addition to the categories of White, Black, American Indian, Chinese, Hawaiian, Japanese, and Filipino that all States report.

Beginning with data for 2003, multiple-race data are available for selected States and the previous distinction about particular Asian groups is being replaced by the categories available on the 2003 revision of the standard certificate.

**Years Collected**

The mortality reporting data system began in 1880, but not all States participated before 1933. Coverage for deaths has been complete since 1933.

**Schedule**

Annual.

**Geographic Estimates**

National, regional, State, and county but access below national has limitations.
Notes

Beginning with 1989 data, some changes were initiated to increase confidentiality. Identifying information, including date of death and geographic identifiers for counties of fewer than 100,000 persons, was not available for public use. Beginning with 2005 data, geographic identifiers below the national level were removed from the public use data files. Data are still accessible using tools such as WONDER (http://wonder.cdc.gov).

The item on educational attainment was changed on the 2003 revision of the standard certificate. Some States have implemented the 2003 revision, while others still use the 1989 revision of the Standard Certificate of Death. One State does not have either version of the item.

QDR tables report geographic location. Geographic locations are based on the 2006 NCHS Urban-Rural Classification Scheme, which is based on the Office of Management and Budget's 2000 standards for defining metropolitan and micropolitan statistical areas:

- **Metropolitan Areas**
  - Large Central - Central counties in metro areas of 1 million or more population
  - Large Fringe - Outlying counties in metro areas of 1 million or more population
  - Medium - Counties in metro areas of 250,000-999,999 population
  - Small - Counties in metro areas of 50,000-249,999 population

- **Nonmetropolitan Areas**
  - Micropolitan - Counties in areas with an urban cluster of 10,000-49,999 population
  - Noncore - Nonmicropolitan


Contact Information


References


National Vital Statistics System: Natality (NVSS-N)

Sponsor

U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS).

Description

NVSS natality files include approximately 4 million birth records annually, with data for the 50 States, the District of Columbia, and the territories of Puerto Rico, Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Marianas.

State laws require birth certificates to be completed for all births. The reporting of births is the responsibility of the professional attendant at birth, generally a physician or midwife. Federal law mandates national collection and publication of birth and other vital statistics data.

Birth certificates are filed with State vital statistics offices; selected statistical information is forwarded to NCHS to be developed into a national statistical file. Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for State use through cooperative activities of the States and NCHS (the Vital Statistics Cooperative Program).

The most recent revision of the U.S. Standard Certificate of Live Birth was effective in 2003. Implementation of the 2003 revision is being phased in by the States. As of 2011, 36 States and the District of Columbia, representing 83% of 2011 births, had implemented the 2003 revision. Those States that have not yet implemented the 2003 revision are using the 1989 revision. Full implementation of the 2003 revision of the standard certificate was expected by January 1, 2015.

Primary Content

Demographic information about the birth such as year, date, place of birth, age, race and Hispanic origin of mother, and live-birth order.

Maternal and infant health information about the birth such as maternal age, live-birth order, race and Hispanic origin, marital status, attendant at birth, method of delivery, period of gestation, birth weight, plurality, medical risk factors, maternal weight gain, obstetric procedures, characteristics of labor and delivery, and congenital anomalies.

Population Targeted

U.S. resident population.

Demographic Data

Child: Sex.
Mother and father: Race, Hispanic origin (beginning in 1978), age, place of mother's residence, and educational attainment (beginning in 1978) (education of father is currently collected on the 2003 revision of the standard certificate).
Mother: marital status.

Race and Hispanic origin are separate items on the birth certificate. As of 1993, all States report Hispanic origin. The categories reported include Mexican, Puerto Rican, Cuban, Central and South American, and Other Hispanic.

Beginning with 1992 data, California, Hawaii, Illinois, New Jersey, New York, Texas, and Washington have reported expanded Asian and Pacific Islander categories of Asian Indian, Korean, Vietnamese, Samoan, and Guamanian. The rest of the States report a combined Other Asian and Pacific Islander category in addition to the categories of White, Black, American Indian, Chinese, Hawaiian, Japanese, and Filipino that all States report.

Beginning with data for 2003, multiple-race data are available for selected States and the previous distinction about particular Asian groups is being replaced by the categories available on the 2003 revision of the standard certificate.

Years Collected

The national birth registration system was established in 1915. Not all States participated before 1933. Coverage for births has been complete since 1933.

Schedule

Annual.

Geographic Estimates

National, regional, State, county, and city, but access below national has limitations.

Notes

Beginning with 1989 data, some changes were initiated to increase confidentiality. Identifying information, including geographic identifiers for counties of fewer than 100,000 persons, is not available for public use. Beginning with 2005 data, geographic identifiers below the national level were removed from the public use data files. Data are still accessible using tools such as VitalStats (https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm) and WONDER (http://wonder.cdc.gov). In addition, restricted data files with geographic identifiers may be available upon request (http://www.cdc.gov/nchs/nvss/dvs_data_release.htm).

Data on mother's educational attainment, tobacco use during pregnancy, and prenatal care based on the 2003 revision are not comparable with data based on the 1989 revision of the U.S. Standard Certificate of Live Birth.
Contact Information


References


Centers for Medicare & Medicaid Services (CMS)

Home Health Care CAHPS Survey

Sponsor

Centers for Medicare & Medicaid Services (CMS)

Description

The Home Health Care Consumer Assessment of Healthcare Providers and Systems (HHCAHPS) Survey is the first and only national, standardized, publicly reported survey of patients' perspectives of skilled home health care. HHCAHPS (pronounced “HH-caps”) is a 34-item survey instrument and data collection methodology for measuring patients’ perceptions of their home health care experiences.

While many Medicare-certified home health agencies have collected information on patient satisfaction for their own internal usage, until HHCAHPS there were no common metrics and no national standards for collecting and publicly reporting information about home health patients' experiences of home health care. Since October 2010, HHCAHPS has allowed valid comparisons to be made across Medicare-certified home health care agencies locally, regionally and nationally.

The HHCAHPS Survey asks current and discharged home health care patients about aspects of their home health care experiences that they are uniquely suited to address. The core of the survey contains 25 items that ask "how often" or whether patients experienced significant aspects that are expected in their home health care, rather than whether they were "satisfied" with their home health care. Also included in the survey are nine "About You" items about the patients' attributes, some of which are used in patient mix adjustments (e.g., "Do you live alone?" and "What is the Primary Language that is spoken at home?" and the patients' educational levels). Home health agencies may add supplemental questions after the 25 core HHCAHPS items, but
we educate agencies that too many questions on a survey may lower their response rates. Right now, the average response rate is 29.0%.

HHCAHPS is administered to patients age 18 years old and over who have received at least two home health visits in the reference period of the past 2 months. The survey is administered to Medicare-certified agency patients but HHCAHPS is not restricted to Medicare patients. Home health agencies must contract with an approved list of HHCAHPS survey vendors (there are about 30 approved vendors) to conduct the survey on their behalf.

Agencies have a choice of requesting the survey vendor to conduct the HHCAHPS in one of three survey modes: mail only, telephone only, and mixed (mail with telephone followup), each of which requires multiple attempts to contact patients. Home health agencies must survey patients every month of the year.


Survey Sample Design

Official HHCAHPS scores, based on four consecutive quarters of home health care patient surveys, have been publicly reported on the Home Health Compare website (www.medicare.gov/homehealthcompare), since April 2012. HHCAHPS scores are reported four times each year, with the oldest quarter of surveys rolling off as the newest quarter rolls on. A link to the downloadable version of HHCAHPS results is available on this website.

In the most recent data submission covering January-March 2017, which was publicly reported on Home Health Compare, there were 8,395 agencies submitting HHCAHPS data for 309,832 completed surveys. There were 1,070,225 patients sampled in that quarterly period, and there was a response rate of 29.0%.

The average age of the patient respondent on the HHCAHPS is 79 years old, and about 12% of the HHCAHPS surveys are completed by proxy respondents who are related to the patients or friends of the patients, but not home health care personnel.

Primary Survey Content

Since April 2012, five HHCAHPS measures (three summary or composite measures and two global items) have been publicly reported on the Home Health Compare website at http://www.medicare.gov/homehealthcompare. Each of the three summary, or composite, measures is constructed from four or more content-related survey questions. The three composites are named (1) Patient Care (Q9, Q16, Q19, and Q24), (2) Communications between providers and patients (Q2, Q15, Q17, Q18, Q22, and Q23); and (3) Specific care issues (Q3, Q4, Q5, Q10, Q12, Q13, and Q14). The two global ratings are the (1) Overall rating of care
given by the home health agency’s care providers (Q20), and the (2) Patient’s willingness to recommend the home health agency to family and friends (Q25). We publicly report the survey response rates and the number of completed surveys.

**Population Targeted**

HHCAHPS survey-eligible patients at all Medicare-approved home health agencies in the United States.

**Demographic Data**

Nine "About You" questions in the HHCAHPS Survey provide self-reported demographic data about the patients but the home health agencies also provide a lot of this information (such as age, gender, and all of the ICD-10 codes pertaining to the patients' home health care). The HHCAHPS survey questions ask patients: how would you rate your overall health, how would you rate your overall mental or emotional health; do you live alone; what is the highest grade or level of school you have completed; are you Hispanic or Latino/Latina; what is your race; what language do you mainly speak at home; what other language do you mainly speak at home; did someone help you complete this survey; (and if yes) how did that person help you complete this survey?

**Years Collected**

Since October 2010 (for publicly reported data).

**Data Collection Schedule**

Continuous.

**Geographic Estimates**

National and State.

**Contact Information**


Data system home page: [http://www.homehealthcahps.org](http://www.homehealthcahps.org).

HHCAHPS technical assistance, HHCAHPS@RTI.org or homehealthcahps@cms.hhs.gov.

**CAHPS® Hospice Survey**

Sponsor

Centers for Medicare & Medicaid Services (CMS), CAHPS Hospice
Description

The Centers for Medicare & Medicaid Services (CMS) has implemented the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey to measure the experiences that patients and their caregivers have with hospice care. The survey was developed to (1) provide a source of information from which selected measures could be publicly reported to beneficiaries and their family members as a decision aid for selection of a hospice program; (2) aid hospices with their internal quality improvement efforts and external benchmarking with other facilities; and (3) provide CMS with information for monitoring the care provided.

Hospices with fewer than 50 survey-eligible decedents/caregivers during the prior calendar year are exempt from the survey data collection and reporting requirements. Hospices with 50 to 699 survey-eligible decedents/caregivers in the prior year are required to survey all cases (conduct a census) and attempt to obtain as many completes as possible. Hospices with 700 or more survey-eligible decedents/caregivers in the prior year are required to survey a minimum sample of 700 using an equal-probability design.

While there is no requirement for census administration, hospices with 700 or more survey-eligible decedents/caregivers may conduct a census, if desired. Survey-eligible decedents/caregivers are defined as that group of decedent and caregiver pairs that meet all the criteria for inclusion in the survey sample.

Primary Survey Content

The CAHPS Hospice Survey consists of 47 questions and is administered to the primary informal caregiver of the decedent who died while receiving hospice care. The CAHPS Hospice Survey mail materials are available in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish, and Korean. The Chinese mail survey is provided in both traditional and simplified characters and targets both Mandarin and Cantonese speakers. The CAHPS Hospice Survey telephone script is available in English and Spanish.

The CAHPS Hospice Survey is administered using three modes: mail only, telephone only, and mixed mode (mail with telephone followup). CAHPS Hospice Survey administration begins 2 months after the month of patient death. The data collection process must be completed within 42 calendar days after initial contact. Submission of data to the CAHPS Hospice Survey Data Warehouse will occur quarterly.

Population Targeted

Decedents age 18 and over in a hospice facility in the United States.

Demographic Data

Gender, race/ethnicity, income, location of residence, four U.S. Census Bureau regions.

Years Collected

Since 2015.
Schedule
Monthly.

Geographic Estimates
National, State, and local areas.


Data system home page: https://www.hospicecahpssurvey.org


Hospital CAHPS Survey
Sponsor
Centers for Medicare & Medicaid Services (CMS)

Description
The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) Survey is the first national, standardized, publicly reported survey of patients' perspectives of hospital care. HCAHPS (pronounced "H-caps"), also known as the CAHPS® Hospital Survey®, is a 32-item survey instrument and data collection methodology for measuring patients' perceptions of their hospital experience. While many hospitals have collected information on patient satisfaction for their own internal use, until HCAHPS there were no common metrics and no national standards for collecting and publicly reporting information about patient experience of care. Since 2008, HCAHPS has allowed valid comparisons to be made across hospitals locally, regionally and nationally.

The HCAHPS Survey asks recently discharged patients about aspects of their hospital experience that they are uniquely suited to address. The core of the survey contains 21 items that ask "how often" or whether patients experienced a critical aspect of hospital care, rather than whether they were "satisfied" with their care. Also included in the survey are four screener items that direct patients to relevant questions, five items to adjust for the mix of patients across hospitals, and two items that support congressionally mandated reports. Hospitals may add supplemental items after the core HCAHPS items.

HCAHPS is administered to a random sample of adult inpatients between 48 hours and 6 weeks after discharge. Patients admitted in the medical, surgical, and maternity care service lines are eligible for the survey; HCAHPS is not restricted to Medicare patients. Hospitals may use an approved survey vendor or collect their own HCAHPS data, if approved by CMS to do so. HCAHPS can be implemented in four survey modes: mail, telephone, mixed (mail with
telephone followup), or active interactive voice recognition (IVR), each of which requires multiple attempts to contact patients.

Hospitals must survey patients throughout each month of the year. HCAHPS is available in official English, Spanish, Chinese, Russian, Vietnamese, and Portuguese translations. The survey and its protocols for sampling, data collection, coding and submission can be found in the HCAHPS Quality Assurance Guidelines (QAG) manual located under the Quality Assurance section of the official HCAHPS website at [www.hcahpsonline.org](http://www.hcahpsonline.org).

Survey Sample Design

Official HCAHPS scores, based on four consecutive quarters of patient surveys, have been publicly reported on the Hospital Compare website, [www.medicare.gov/hospitalcompare](http://www.medicare.gov/hospitalcompare), since 2008. HCAHPS scores are reported four times each year, with the oldest quarter of surveys rolling off as the newest quarter rolls on. A link to the downloadable version of HCAHPS results is available on this website. In April 2017, 4,306 hospitals publicly reported HCAHPS scores based on more than 3.1 million completed surveys. On average, more than 8,500 patients complete the HCAHPS Survey every day.

Primary Survey Content

Eleven HCAHPS measures (seven summary measures, two individual items, and two global items) are publicly reported on the Hospital Compare website at [www.medicare.gov/hospitalcompare](http://www.medicare.gov/hospitalcompare). Each of the seven summary, or composite, measures is constructed from two or three survey questions. The seven composites summarize how well nurses and doctors communicate with patients, how responsive hospital staff are to patients' needs, how well hospital staff help patients manage pain, how well the staff communicate with patients about new medicines, whether key information is provided at discharge, and how well patients understand the type of care they need after leaving the hospital.

The two individual items address the cleanliness and quietness of patients' rooms while the two global items capture patients' overall rating of the hospital and whether they would recommend it to family and friends. Survey response rates and the number of completed surveys are also publicly reported.

Population Targeted

Eligible patients at all acute-care hospitals in the United States.

Demographic Data

The "About You" section of the HCAHPS Survey asks patients whether they were admitted through the emergency room; their overall health; their overall mental or emotional health; highest level of education; ethnicity; race; and language spoken at home. Other demographic and hospital information, such as patient's age, gender, service line, and discharge status, is taken from hospital administrative records.
Years Collected
Since 2006.

Data Collection Schedule
Continuous.

Geographic Estimates
National and State.

Contact Information
Data system home page: www.hcahpsonline.org
Data system email: Hospitalcahps@cms.hhs.gov

References


Medicare Quality Improvement Organization (QIO) Program - Clinical Data Warehouse (CDW)
Sponsor
U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS), Hospital Inpatient Quality Reporting

Description
The QIO Program, created by law in 1982, provides 3-year contracts to organizations throughout the country to assist providers to improve the quality, safety, efficiency, and economy of health care services delivered to Medicare beneficiaries and the public at large.

The QIO Program is administered through 53 performance-based, cost-reimbursement contracts with 41 independent organizations. The QIOs are staffed with physicians, nurses, technicians, and statisticians. QIOs encourage hospitals to submit clinical performance data to the national Clinical Data Warehouse (CDW). Hospitals collect these data using data collection tools.
developed by QIOs or related organizations. Details are in the QIO Statement of Work (https://www.cms.gov/QualityImprovementOrgs/04_9thsow.asp#TopOfPage). Quality performance information collected from the more than 4,000 participating hospitals is reported on Hospital Compare, a website developed by CMS.

Before 2005, CMS had abstraction centers perform the QIO data abstraction, which only included Medicare inpatients. From 2005 on, QIO data are hospital self-reported and include all payers. Hospital self-reported data submitted to the QIO CDW are subject to random validation audits by an independent CMS contractor.

**Primary Content**

Current national priorities include four health care settings: nursing homes, home health agencies, hospitals, and physician offices.

**Population Targeted**

Medicare beneficiaries and non-Medicare beneficiaries required for the relevant measure in each State, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

**Demographic Data**

Age, race, and gender.

**Notes**

From 2002 to 2004, CMS randomly selected 125 medical charts for each topic per quarter and asked clinical data abstraction centers (CDACs) to perform data abstraction. The results were used for QIO program evaluation and measure surveillance. CMS stopped the measure surveillance program for heart attack, heart failure, and pneumonia topics at the end of 2004. The surveillance program for surgery patient safety was stopped at the end of the third quarter of 2005.

Since the 2002-2004 data only reflected Medicare inpatients and these are CDAC-abstracted data and 2005 data are hospital self-reported for all payers, only hospital self-reported data starting from 2005 are reported in the QDR.

In 2011, CMS redesigned its QIO Program to further enhance the quality of services for Medicare beneficiaries.

**Contact Information**


References


Measure Specifications: https://www.jointcommission.org/specifications_manual_for_national_hospital_inpatient_quality_measures.aspx

Health Resources and Services Administration (HRSA)

HRSA, Ryan White HIV/AIDS Program (RWHAP)

Sponsor

U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB).

Description

The Ryan White HIV/AIDS Program (RWHAP) supports direct health care and support services for more than half a million people living with HIV (PLWH), which is more than 50% of all people living with diagnosed HIV in the United States. RWHAP has successfully created effective patient-centered services to support strong provider-patient relationships. RWHAP funds and coordinates with cities, States, and local community-based organizations to deliver efficient and effective HIV care, treatment, and support services for low-income PLWH.

Since it was established, RWHAP has developed a comprehensive system of safety net providers who deliver high-quality direct health care and support services. RWHAP is critical to ensuring that individuals with HIV are linked to and retained in care, can adhere to medication regimens, and remain virally suppressed. These goals are crucial not only to ensuring optimal HIV health outcomes among PLWH, but also to preventing further transmission of the virus and, ultimately, ending the HIV epidemic.

RWHAP-funded grant recipients and providers annually submit client-level data through the Ryan White HIV/AIDS Services Report (RSR). Since 2010, client-level RSR data have been used to assess the numbers and types of clients receiving services and their HIV-related outcomes.

Survey Sample Design

The RSR dataset is HAB’s primary source of annual client-level data collected from more than 2,000 funded grant recipients and subrecipients. The RSR includes clients receiving services from RWHAP-funded recipients and providers during the calendar year, regardless of the
RWHAP funding stream. RSR data do not include information about the AIDS Drug Assistance Program (ADAP); all ADAP-related information is collected through another data system.

**Primary Survey Content**

The RSR includes demographic composition of clients served; socioeconomic factors, such as Federal poverty level, health care coverage, and housing status; and clinical information.

**Population Targeted**

All RWHAP Part A-D recipients and providers submit the annual RSR.

**Demographic Data**

Client-level demographic data include age, race/ethnicity, gender, HIV transmission risk category, Federal poverty level, health care coverage, and housing status.

**Years Collected**

Since 2010.

**Data Collection Schedule**

Annual.

**Geographic Estimates**

National, HHS region, and State.

**Contact Information**

Agency home page: [https://hab.hrsa.gov/data/data-reports](https://hab.hrsa.gov/data/data-reports)

**References**

None

**Indian Health Service (IHS)**

**Indian Health Service (IHS) National Data Warehouse (NDW)**

**Sponsor**

U.S. Department of Health and Human Services, Indian Health Service.
Description

NDW is the national repository for all IHS health care data and includes information on patient registration and visit encounters. Data are derived from various government (Resource Patient Management System or "RPMS") and commercial health care information systems. These are largely transaction-based systems used to support patient care. NDW was upgraded from the National Patient Information Reporting System in 2006.

Primary Content

Registration records and all encounter records (dated October 1, 2000, to the present) are included in the NDW. Registration tables contain patient information, including name, demographic data, medical chart data, aliases, and insurance eligibility data. Encounter tables contain encounter information, including location of treatment, clinic, provider, medications, and diagnosis codes.

Population Targeted

Approximately 1.6 million American Indians and Alaska Natives who belong to 567 federally recognized tribes in 36 States.

Demographic Data

Age, gender, and American Indian and Alaska Native status.

Years Collected

2001 to present.

Schedule

Daily.

Geographic Estimates

National IHS service area estimates are available for the following HIS regions: Aberdeen, Alaska, Albuquerque, Bemidji, Billings, Nashville, Navajo, Oklahoma, Phoenix, and Tucson (excluding the Portland and California service areas where no IHS direct care inpatient facilities exist as of this writing).

Notes

In the calculation of indicators based on hospitalization, since no IHS inpatient facilities are located in either the Portland or California service areas, and hospitalizations from these regions are not present in the data, the denominator is correspondingly reduced.
Contact Information


Data system home page: http://www.ihs.gov/NDW/

Division of Program Statistics home page: http://www.ihs.gov/DPS

References


National Institutes of Health (NIH)

United States Renal Data System (USRDS)

Sponsor

U.S. Department of Health and Human Services, National Institutes of Health (NIH), National Institute for Diabetes and Digestive and Kidney Diseases (NIDDK) in collaboration with the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS).

Description

The USRDS is a national data system that maintains a relational database of diagnostic and demographic characteristics of end-stage renal disease (ESRD) patients. It includes information on the incidence, prevalence, morbidity, and mortality of this population, as well as biochemical lab results, dialysis and other institutional claims, physician/supplier services, treatment histories (useful for modality determination), payer histories, hospitalization and modality events, and details regarding providers. As the ESRD population typically includes Medicare beneficiaries, CMS is the main data source for this database.

These CMS-supplied data are supplemented by data from the Social Security Administration, Organ Procurement and Transplant Network Transplant Database, and U.S. Census. Data include date of onset of ESRD, treatment modality, causes of death, patient survival, hospitalization, cost and cost-effectiveness, and institutional providers of ESRD treatment. Special surveys cover
behavioral risk factors, preventive health measures, health status, activity limitations, and health care access and utilization.

**Population Targeted**

ESRD patients.

**Demographic Data**

Gender, age, race, and ethnicity.

**Years Collected**

Continuously since 1988.

**Schedule**

Annual.

**Geographic Estimates**

National, State, and county.

**Contact Information**


**References**


**Substance Abuse and Mental Health Services Administration (SAMHSA)**

**National Survey on Drug Use and Health (NSDUH)**

**Sponsor**

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Behavioral Health Statistics and Quality (CBHSQ). CBHSQ (formerly the Office of Applied Studies) is the data collection agency.
Description

NSDUH serves as the primary source of information on the prevalence and incidence of illicit drug, alcohol, and tobacco use in the U.S. civilian noninstitutionalized population age 12 and over. In-person interviews with sampled persons and computer-assisted interviewing methods, including audio computer-assisted self-interviewing, are used to provide a private and confidential setting to complete the interview.

Survey Sample Design

NSDUH 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.

NSDUH data are representative of the Nation and States. The survey design includes an independent, multistage area probability sample for each State and the District of Columbia to accommodate State estimates of substance use and mental health. The survey design also oversamples youths and young adults.

In 2014, changes were made in the sample sizes allocated to each state and to different age groups in order to increase the precision of national and many state estimates as well as estimates for older adults. In 2015, changes were made to the survey questionnaire to improve the quality of the data collected, expand the number of prescription drugs covered, and address changing substance use and mental health policy and research needs.

New data collection equipment was introduced in 2015 to replace the older equipment in the field. Respondent materials also were updated.

Primary Survey Content

NSDUH collects a respondent's demographic characteristics; age at first use, lifetime, past-year, and past-month use of the following substances: illicit drugs (marijuana or hashish, cocaine [including crack], inhalants, hallucinogens, heroin, or prescription-type psychotherapeutics used nonmedically [e.g., stimulants, sedatives, tranquilizers, and pain relievers]), alcohol, and tobacco; substance use disorders; substance use treatment; health care; mental health disorders; and mental health service utilization.

Population Targeted

U.S. civilian noninstitutionalized population age 12 and over.
Demographic Data

Age, gender, race/ethnicity, marital status, education, employment status, family income, health insurance, veteran status, and current household composition.

Years Collected

Since 1971.

Schedule

Annual.

Geographic Estimates

National, State, and substate estimates as well as estimates by county type and region.

Notes

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 online data analysis system (http://www.icpsr.umich.edu/SAMHDA/).

Contact Information

Agency home page: http://www.samhsa.gov

Data system home page: http://www.samhsa.gov/data/population-data-nsduh

References


Substance Abuse Treatment Episode Data Set (TEDS)

Sponsor

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Behavioral Health Statistics and Quality (CBHSQ).

Description

TEDS is an admission-based system and is part of SAMHSA’s Behavioral Health Services Information System (BHSIS). TEDS is a compilation of data on the demographic and substance abuse characteristics of admissions to substance abuse treatment. The data are routinely collected by State administrative systems and then submitted to SAMHSA in a standard format.

TEDS does not include all admissions to substance abuse treatment. It includes admissions to facilities that are licensed or certified or funded by the State substance abuse agency to provide substance abuse treatment (or are administratively tracked by the agency for other reasons). TEDS does not include data from facilities operated by Federal agencies. The scope of facilities included in TEDS may differ by State due to differences in State systems of licensure, certification, accreditation, and funds disbursement.

Primary Content

Patient demographics; primary, secondary, and tertiary substance; length of stay; reason for discharge.

Population Targeted

Admissions to substance abuse treatment facilities.

Demographic Data

Age, gender, ethnicity, race, and employment status.

Years Collected


Schedule

Monthly or quarterly submissions from States; annual report.

Geographic Estimates

National, States, and Core Based Statistical Area (CBSA).
Contact Information


United States Census Bureau

American Community Survey (ACS)

Sponsor

The United States Census Bureau, The Census Bureau is part of the United States Department of Commerce

Description

The American Community Survey (ACS) is an ongoing survey that provides vital information on a yearly basis about our nation and its people. Information from the survey generates data that help determine how more than $675 billion in federal and state funds are distributed each year.

Through the ACS, we know more about jobs and occupations, educational attainment, veterans, whether people own or rent their homes, and other topics. Public officials, planners, and entrepreneurs use this information to assess the past and plan the future. When you respond to the ACS, you are doing your part to help your community plan for hospitals and schools, support school lunch programs, improve emergency services, build bridges, and inform businesses looking to add jobs and expand to new markets, and more

Survey Sample Design

ACS forms are not mailed to specific people, but rather to specific addresses. The sample is designed to ensure good geographic coverage and does not target individuals. By focusing on quality geographic coverage, the ACS can produce a good picture of the community's people and housing by surveying a representative sample of the population. The Census Bureau selects a random sample of addresses to be included in the ACS. Each address has about a 1-in-480 chance of being selected in a month, and no address should be selected more than once every 5 years. The Census Bureau mails questionnaires to approximately 295,000 addresses a month across the United States. This is a small number of households considering there are more than 140 million eligible addresses in the United States, and an address that receives ACS instructions will not likely find a neighbor or friend who has also received them.

The responses to the American Community Survey are collected in four different ways: internet, mail, telephone, and in-person interviews.
Primary Survey Content

The most recent census consisted of a short form, which included basic questions about age, sex, race, Hispanic origin, household relationship, and owner/renter status. After the 2000 Census, the long form became the ACS, and this survey continues to collect long-form-type information each year. The ACS includes not only the basic short-form questions, but also detailed questions about population and housing characteristics. It is a nationwide, continuous survey designed to provide communities with reliable and timely social, economic, housing, and demographic data every year. Since its start, the ACS has been providing a continuous stream of updated information for States and local areas and has revolutionized the way we use statistics to understand our communities.

An individual's responses are combined with others' responses to create and publish statistics for communities nationwide, which can then be used by community and local governments and the private sector. ACS estimates are often used to help establish priorities through a needs assessment, to develop general plans, and to further research, education, and advocacy work.

Population Targeted

Civilian population residing in the United States.

Demographic Data

Gender, age, race/ethnicity, education, income, marital status, place of birth, industry, and occupation.

Years Collected

2006 to present.

Schedule

Annually.

Contact Information

Agency home page: https://www.census.gov/

Data system home page: https://www.census.gov/programs-surveys/acs/about.html

References

For more details, refer to the ACS document available at https://www.census.gov/content/dam/Census/programs-surveys/acs/about/ACS_Information_Guide.pdf
Academic Institutions

University of Michigan Kidney Epidemiology and Cost Center (UM-KECC)

Sponsor

University of Michigan with funding from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS).

Description

UM-KECC is an interdisciplinary research group drawing from the Departments of Biostatistics, Health Management and Policy, Surgery, and Nephrology. UM-KECC carries out epidemiologic, clinical, medical outcomes, public policy, and economic research related to end stage renal disease (ESRD), chronic kidney disease (CKD), and organ transplantation.

UM-KECC maintains comprehensive historic patient- and provider-level data on more than 2 million ESRD patients. The UM-KECC ESRD patient database is largely derived from the following sources:

- CMS Consolidated Renal Operations in a Web-enabled Network (CROWN), which includes Renal Management Information System (REMIS) and the Standard Information Management System (SIMS) database.
- National Vascular Access Improvement Initiative’s Fistula First project (in CROWNWeb starting May 2012).
- CMS Annual Facility Survey (Form CMS-2744).
- Medicare dialysis and hospital payment records.
- CMS Medical Evidence Form (Form CMS-2728).
- Transplant data from the Organ Procurement and Transplantation Network (OPTN).
- Death Notification Form (Form CMS-2746).
- Nursing Home Minimum Data Set.
- Dialysis Facility Compare.
- Social Security Death Master File.

The database is comprehensive for Medicare patients. Non-Medicare patients are included in all sources except for the Medicare payment records. SIMS/CROWNWeb provides tracking by dialysis provider and treatment modality for non-Medicare patients.

Primary Content

Data include information about directly actionable practice patterns such as dose of dialysis, vascular access, and anemia management and patient outcomes (mortality, hospitalization, and transplantation) that can be used to inform and motivate reviews of practices.
The information in the report facilitates comparisons of facility data with local and national averages. Available data include patient characteristics (laboratory values, primary cause of ESRD, comorbidities), treatment patterns (dialytic modality, hemoglobin levels, urea reduction ratio), and outcomes (transplantation, wait list, hospitalization, mortality). Facility information provides counts of patients treated, Medicare eligibility, treatment modality, staffing, survey and certification activity, and services provided.

**Population Targeted**

ESRD patients in the United States.

**Demographic Data**

Age, gender, race, and State of residence.

**Years Collected**

1999 to present.

**Schedule**

Annually each July.

**Geographic Estimates**

National, State, network, and regional levels.

**Contact Information**

Organization home page: [http://kecc.sph.umich.edu/](http://kecc.sph.umich.edu/)

Data system home page: [www.dialysisdata.org](http://www.dialysisdata.org).

**References**

UM-KECC. Methodology documents available at [https://dialysisdata.org/content/methodology](https://dialysisdata.org/content/methodology).
Professional Organizations and Associations

American Hospital Association (AHA) Information Technology (IT) Supplement

Sponsor
American Hospital Association

Description
The AHA conducts an annual survey of all hospitals in the United States, including both registered and nonregistered hospitals. The focus is on four main areas, which include organization, facilities, community benefit, and utilization. Since 2008, the AHA has administered a supplemental Information Technology (IT) mail survey to gather information on the extent to which hospitals have fully functional health information systems, the characteristics of these systems, and the functions available and used by hospital staff.

Survey Sample Design
The 2012 survey for the IT Supplement was sent to 6,241 non-Federal acute care hospitals in the United States, including non-AHA member hospitals. The response rate was 51.9%. If data are missing, the hospital is not included in the numerator or denominator of generated statistics.

Primary Survey Content
The AHA Hospital Survey reports on statistics including current and historical data on utilization, personnel, revenue, expenses, managed care contracts, community health indicators, physician models, technology, electronic record system, number of beds and admissions, and urban/rural status. The 2012 IT supplement queries hospital representatives about the adoption of electronic medical records and the scope of computer functionalities used by the facility.

Population Targeted
All hospitals in the United States.

Demographic Data
Combined with the core survey, information collected includes identifying information about the hospitals, organizational structure, facilities and services, utilization data, community orientation indicators, physician arrangements, managed care relationships, expenses, staffing, use of electronic medical records, use of electronic systems for prescribing, and sharing of patient information across providers.
Years Collected

Since 2008.

Data Collection Schedule

Annual.

Geographic Estimates

National and regional.

Contact Information

Agency home page: http://www.aha.org

References


National Cancer Data Base (NCDB)

Sponsors

Operation of the NCDB is jointly supported by the Commission on Cancer (CoC) of the American College of Surgeons and the American Cancer Society.

Description

The NCDB is a nationwide facility-based oncology database that annually captures approximately 70% of all newly diagnosed cancer cases in the United States from inception, beginning in 1989. The NCDB holds information on more than 29 million cases of reported cancer diagnoses dating back to 1985 and continues to grow.

All CoC-accredited hospital cancer programs are annually required to submit data for all patients diagnosed or treated for a cancer diagnosis. More than 1,500 participating hospitals respond to a call for data, submitting case reports for a specified calendar year approximately 1.5 years after diagnosis.

CoC-accredited cancer program registries collect and submit data elements to the NCDB using nationally standardized data item and coding definitions. These are found in CoC's Facility Oncology Registry Data Standards (FORDS) and the North American Association of Central Cancer Registries' nationally standardized data transmission format specifications.
Primary Survey Content

The NCDB contains standardized data elements on patient demographics, patient insurance status, tumor site, stage and morphology, comorbidities, first course of treatment, disease recurrence, and survival information. In addition, the NCDB contains information on patient ZIP Code and county of residence, which is used to incorporate area-based sociodemographic characteristics. Selected characteristics of the reporting health care facility are also collected.

Population Targeted

Cancer patients in the United States.

Demographic Data

Gender, age at cancer diagnosis, and race/ethnicity.

Years Collected

Continuously since 1989.

Schedule

Annual.

Geographic Estimates

National; nine U.S. Census Bureau regions; metropolitan and nonmetropolitan areas.

Contact Information


References


Multiple-Source Data Sponsors

Medical Expenditure Panel Survey (MEPS)

Sponsor

U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ); and Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS).

Mode of Administration

The MEPS Household Component (HC), the core survey, is an interviewer-administered computer-assisted personal interview household survey. The Self-Administered Questionnaire (SAQ) and Diabetes Care Survey (DCS) are supplementary self-administered paper questionnaires.

Survey Sample Design

The sampling frame for the MEPS-HC is drawn from respondents to the National Health Interview Survey (NHIS), conducted by NCHS. The MEPS-HC augments NHIS by selecting a sample of NHIS respondents, collecting additional data on their health care expenditures, and linking these data with additional information from the respondents' medical providers, employers, and insurance providers.

Each year a new panel of households is selected from among those households that participated in the previous year's NHIS. Data covering 2 calendar years of information are collected for each new annual sample (referred to as a panel), through a series of five rounds of data collection over a 2.5-year period. This series of data collection activities is repeated each year on a new sample of households, resulting in overlapping panels of survey data. MEPS annual data are based on information from two separate panels, the panel that began that year and the panel that began in the previous year.

NHIS provides a nationally representative sample of the U.S. civilian noninstitutionalized population, with oversampling of Hispanics and Blacks. Starting in 2006, NHIS oversamples Asians as well. In addition to the oversampling by NHIS, MEPS oversamples policy-relevant groups such as low-income households.

Primary Survey Content

MEPS consists of three component surveys: the HC, the Medical Provider Component, and the Insurance Component. The MEPS-HC collects detailed data on demographic characteristics, health conditions, health status, use of medical care services, charges and payments, access to care, satisfaction with care, health insurance coverage, income, and employment.
The data for the QDR are primarily from the following sections of the 2002-2015 MEPS-HC:

- **SAQ**: This paper questionnaire collects data on a variety of adult health and health care quality measures.
- **DCS**: This paper questionnaire, given to persons identified as ever having had diabetes, asks about their diabetes care, such as services rendered.
- **Child Health and Preventive Care (CHPR) section**: Starting in 2001, the CHPR section was added to the MEPS-HC interviews during the second half of the year. It included health care quality measures taken from the health plan version of CAHPS® (Consumer Assessment of Healthcare Providers and Systems); the Children With Special Health Care Needs screener questions; children's general health status as measured by several questions from the General Health Subscale of the Child Health Questionnaire; Columbia Impairment Scale questions about possible child behavioral problems; and child preventive care questions. Before 2001, the CAHPS questions and the Children with Special Health Care Needs screener questions had been in the Parent-Administered Questionnaire. Therefore, estimates from 2001 may not be comparable with estimates for 2000 or earlier years.
- **Access to Care**: The Access to Care section of the MEPS-HC gathers information on five main topic areas: family members' origins and preferred languages; family members' usual source of health care; characteristics of usual source of health care providers; satisfaction with and access to the usual source of health care provider; and access to medical treatment, dental treatment, and prescription medicines.
- **Preventive Care**: For each person, a series of questions was asked primarily about the receipt of preventive care or screening examinations.

**Population Targeted**

Like the NHIS population from which its sample is drawn, the MEPS-HC is a nationally representative survey of the U.S. civilian noninstitutionalized population.

**Demographic Data**

The MEPS-HC collects data on demographic characteristics, including age, gender, race, ethnicity, education, industry and occupation, employment status, household composition, and family income. Race and ethnicity variables and categories changed in 2002 in compliance with Office of Management and Budget standards.

**Years Collected**

MEPS is the third in a series of national probability surveys conducted by AHRQ on the financing and use of medical care in the United States. The National Medical Care Expenditure Survey was conducted in 1977, the National Medical Expenditure Survey was conducted in 1987, and MEPS, an annual survey, began in 1996.
Schedule

Annual.

Geographic Estimates

National; four U.S. Census Bureau regions; selected States; metropolitan and nonmetropolitan areas; and urban-rural areas, based on frameworks such as the 2006 Urban-Rural Classification Scheme for Counties (http://www.cdc.gov/nchs/data_access/urban_rural.htm).

Notes

Estimates in the QDR data tables that are based on MEPS data are weighted to reflect the experiences of the U.S. civilian noninstitutionalized population. Standard errors of the estimates were derived using SUDAAN statistical software, which factors in MEPS complex survey design. MEPS estimates are suppressed when they are based on sample sizes of fewer than 100, or when their relative standard errors are 30% or more.

The combined response rate for MEPS, which includes the NHIS response rate, ranged from 57% to 65% during the 2002 to 2009 period.


References


**Medicare Patient Safety Monitoring System (MPSMS)**

**Sponsor**

From its inception in 2001, the Centers for Medicare and Medicaid Services (CMS) led the coordination and development of MPSMS with technical and administrative support from Qualidigm. In 2009, primary coordination of the project was transferred to the Agency for Healthcare Research and Quality (AHRQ). CMS continues as a partner with AHRQ on the project.

**Description**

MPSMS is a nationwide surveillance system that aims to identify rates of specific adverse events, or unintended patient harm, injury, or loss among hospitalized patients. The system tracks and monitors interactions with the health care system rather than health conditions.

MPSMS is composed of 21 measures representing six types of adverse drug events (ADEs); six types of hospital-acquired infections; seven types of adverse events associated with surgery; two types of infections and complications that can occur as a result of different types of catheterization; patient falls; and hospital-acquired pressure ulcers.

Approximately 20,000 to 30,000 records are selected annually as a subset of the CMS Hospital Inpatient Quality Reporting program (IQR) sample, which includes hospitalized patients age 18 years and over whose hospital stays are reimbursed by any payer. The IQR sample represents hospital admissions for four conditions: heart failure (HF), acute myocardial infarction (AMI), pneumonia, and a subset of major surgical procedures (SCIP). In 2013, a global sample was added to the IQR sample and includes patients age 18 years and over hospitalized for all other conditions not included in the four-condition sample.

Records are sent to the Clinical Data Abstraction Center, where trained abstractors abstract each clinical chart by recording predefined questions and responses. The contractor uses algorithms to analyze the abstracted data to identify patient exposure to the processes of care, ascertain the occurrence of specific adverse events, and assess patient risk factors and outcomes. MPSMS data are used to develop a summary Patient Safety Event Rate based on the 21 measures.
**Primary Content**

The purpose of MPSMS is to provide a tool to facilitate improvements in patient safety by gaining an understanding of the magnitude of specific patient safety issues associated with the processes of hospital care delivery. Adverse event categories monitored by MPSMS include the following:

- Adverse Drug Events
- Adverse events associated with surgical procedures.
- Hospital-acquired infections.
- Adverse events associated with the hospital stay and not present on hospital admission (in-hospital falls and pressure ulcers).

MPSMS also collects and examines patient risk factors, such as demographics and comorbid conditions. Data on outcomes, such as length of hospital stay and in-hospital mortality, are also collected.

**Population Targeted**

The four-condition sample includes hospital inpatients age 18 years and over admitted for one of four conditions of interest: heart failure, acute myocardial infarction, pneumonia, and a subset of major surgical procedures, which are covered by any payer. The Global sample includes patients 18 years of age and older hospitalized for all other conditions not included in the four-condition sample.

**Demographic Data**

Age, race, gender, and payment source.

**Years Collected**


**Geographic Estimates**

All States except Maryland.

**Schedule**

Data are submitted and collected monthly and reported annually.
Table 1. MPSMS Measures and Domains by Phase

<table>
<thead>
<tr>
<th>Measure</th>
<th>Primary Domain</th>
<th>Data Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hip Replacement Due to Fractures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hip Replacement Due to Degeneration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Postoperative Cardiac Event After Cardiac Surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Postoperative Cardiac Event After Non-cardiac Surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-Hospital Patient Fall</td>
<td>General</td>
<td>2005-2007 and 2009-2015</td>
</tr>
</tbody>
</table>

Contact Information


References


[1] Only inpatients whose surgical procedures are included in the CMS Surgical Care Improvement Project (SCIP) major surgical procedure category are selected.

[2] In 2009, the sample population changed to the sample described above from the 2002 to 2007 samples that only included Medicare fee-for-service beneficiaries who were admitted for any condition.