Health Research Databases

Center for Outcomes Research and Policy, Department of Surgery

2023 - 11 - 17

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About

This website has a list of several public-use databases that can be used in research studies. Most of these resources are freely available online. Some will require a study proposal and/or data use agreement be submitted and evaluated.

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Air Quality System (AQS)

1.1 Organization

US Environmental Protection Agency (EPA)

1.2 Website

https://aqs.epa.gov/aqsweb/documents/data mart welcome.html

1.3 Description

- Collects data as part of the national ambient air monitoring program
 - Air pollution data from over thousands of monitors
 - Meteorological data, descriptive information about each monitoring station, data quality assurance and quality control information
- The most commonly requested aggregation levels of data (and key metrics)
 - Sample values as standard units (e.g. 1-hour or 24-hour averages)
 - NAAQS average values (8-hour for ozone and CO, 24-hour for PM2.5)
 - Daily summary values (e.g. observation count, percent, mean, max and time of max, air quality index, number of observations greater than standard)
 - Annual summary values (e.g. observation count and percent, valid days, required/null/exceptional observation counts, mean and standard deviation, maximum observations, percentiles, number of observations greater than standard)
 - Site and monitor information (FIPS state code, FIPS county code, site number, parameter code, parameter occurrence code, latitude,

longitude, measurement method information, owner/operator/data submitter, monitoring network, exemptions from regulatory requirements, operational dates, city and CBSA

- Quality assurance information (for 19 possible QA assessments)

1.4 Vintage/Release Frequency

Database started in 1957, but national consistency begins in 1980. There are weekly updates, however, data is not real time and usually within 6-9 months of collection.

1.5 Observational Unit

Varies (measurements, averages, summaries, etc.)

1.6 Collection Methodology

- Data submitted by tribal, state, and local agencies
- Data subjected to several quality control tests

1.7 Available at

- Pre-generated data files containing 1.5 billion rows of data updated twice a year are available at https://aqs.epa.gov/aqsweb/airdata/download_files.html
- Aggregated or visual data from AQS or large files of pre-extracted data available at https://www.epa.gov/outdoor-air-quality-data
- Row-level data from the AQS database is available with sign up. Single queries must be limited 20 2 million rows. https://aqs.epa.gov/aqsweb/documents/data_api.html.

1.8 User Guide/Data Dictionary

https://www.epa.gov/aqs/aqs-manuals-and-guides

1.9 Cost

Free

1.10 Proposal or Application required?

No

1.11 DUA required?

No

1.12 Special Notes

- No restrictions on data use
- Suggested citation: US Environmental Protection Agency. Air quality System Data Mart [internet database] available at http://www.epa.gov/ttn/airs/aqsdatamart. Accessed Month DD, YYYY

America's Health Rankings

2.1 Organization

United Health Foundation

2.2 Website

https://www.americashealthrankings.org/

2.3 Description

- Measure and ranks the heath of each US state through an annual report (behaviors, policies, community and environmental conditions, and clinical care), a senior report (population aged 65 and older), health of women and children report (women of reproductive age and infants and children under 18 years), and health of those who have served report
- Explores policies and programs; health factors such as physical environment (e.g. air quality, water quality, housing, transit), social and economic factors (e.g. education, employment, income, family and social support, community safety), clinical care (e.g. access to care, quality of care), and health behaviors (e.g. tobacco use, diet and exercise, alcohol and drug use, sexual activity); and, health outcomes such as length of life and quality of life

2.4 Vintage/Release Frequency

Annual since 1989

State

2.6 Collection Methodology

- Use a variety of national and state data sources to gather information about behaviors, community and environment, public and health policies, clinical care, and health outcomes
- Calculates standardized values for each state and measure again the national value
- Eliminate outliers and weight accordingly
- Rank states according to the sum of the standardized scores across all measures

2.7 Available at

https://www.americashealthrankings.org/explore/annual

2.8 User Guide/Data Dictionary

https://www.americashealthrankings.org/learn/reports/2022-annual-report

2.9 Cost

Free

2.10 Proposal or Application required?

NA

2.11 DUA required?

NA

2.12 Special Notes

NA

American College of Surgeons National Surgical Quality Improvement Program Participant Use Data File (ACS-NSQIP)

3.1 Organization

American College of Surgeons (ACS)

3.2 Website

https://www.facs.org/quality-programs/data-and-registries/acs-nsqip/

3.3 Description

- HIPAA-compliant data file
- $\bullet\,$ De-identified, a dult, patient-level, aggregate data
- Major surgical procedures, inpatient and outpatient
- Cases submitted to the ACS NSQIP by participating sites that received risk-adjusted reports
- Over 150 variables, including preoperative risk factors, intraoperative variables, and 30- day postoperative mortality and morbidity outcomes
- Main dataset along with surgical targeted datasets

3.4 Vintage/Release Frequency

Annual since 2005

3.5 Observational Unit

Cases (patient-level) submitted by hospitals

3.6 Collection Methodology

- Data captured by a Surgical Clinical Reviewer through chart abstraction and other methods
- Portions of data may have been automatically populated by software designed to extract from existing hospital information systems
- Auditing performed on a sample of cases at each site; those not meeting certain criteria are not included in the dataset
- Smaller sites may provide all eligible cases; other sites may use systematic sampling

3.7 Available at

https://www.facs.org/quality-programs/data-and-registries/acs-nsqip/participant-use-data-file/participant-use-request-form/

3.8 User Guide/Data Dictionary

 $https://www.facs.org/media/tjcd1biq/nsqip_puf_userguide_2021_202211021\\20632.pdf$

3.9 Cost

Free for download for those with an appointment at a participating site

3.10 Proposal or Application required?

Yes

3.11 DUA required?

Yes

3.12 Special Notes

NA

4CHAPTER 3. AMERICAN COLLEGE OF SURGEONS NATIONAL SURGICAL QUALITY IMPRO

American College of Surgeons National Trauma Data Bank (ACS-NTDB)

4.1 Organization

American College of Surgeons (ACS)

4.2 Website

https://www.facs.org/quality-programs/trauma/quality/national-trauma-data-bank/

4.3 Description

- HIPAA-compliant data file
- Trauma Quality Programs (TQP) PUF contains all records sent to NTDB for specified admission years
- Includes patient-level data on pediatric and adult patients from Level I, II, III, IV, V or undesignated trauma centers

4.4 Vintage/Release Frequency

Annual since 2007

Cases (patient-level) submitted by hospitals

4.6 Collection Methodology

- Data captured by a Clinical Reviewer through chart abstraction and other methods.
- The NTDS Data Dictionary provides over 50 definitions that can be implemented by a trauma registry system. National data elements are defined that must be collected for the National Trauma Database and TQIP.

4.7 Available at

https://www.facs.org/quality-programs/trauma/quality/national-trauma-data-bank/datasets/

4.8 User Guide/Data Dictionary

https://www.facs.org/media/adujvrqx/tqp-puf-user-manual-2021.pdf

4.9 Cost

\$1000 per admission year or free for those with an appointment at a participating site

4.10 Proposal or Application required?

Yes

4.11 DUA required?

Yes

4.12 Special Notes

- Data use is only allowed in relation to the approved proposal
- Data infrastructure changed significantly in 2017
- A TQP PUF Facility Key (facility-level indicator that allows for the grouping of paitents by facility) may be requested and purchased separately (fee is \$200 per admission year)

American Community Survey (ACS)

5.1 Organization

US Census Bureau

5.2 Website

https://www.census.gov/programs-surveys/acs

5.3 Description

- Collects information about social characteristics (e.g. education, marital status, relationships, fertility), economic characteristics (e.g. income, employment, occupation), housing characteristics (e.g. occupancy and structure, housing value and costs, utilities), and demographic characteristics (e.g. sex, age, race, Hispanic origin)
- Used to explore the social and economic needs of communities (e.g. schools, hospital, emergency services)

5.4 Vintage/Release Frequency

Annual since 1996

People or households (micro files) or geographic area (census block to national)

5.6 Collection Methodology

- Two sampling frames (housing unit addresses and residents of group quarters facilities) derived from the Census Bureau's Master Address File
- Multi-phase, multi-stage sampling approach
- Have 1-year, 3-year, and 5-year files available where the multi-year files have been adjusted for weighting and inflation adjustment factors

5.7 Available at

- Summaries by geographic area can be downloaded at https://data.census.gov/
- Public Use Microdata Sample (PUMS) files can be downloaded at https://www.census.gov/programs-surveys/acs/microdata/access.html

5.8 User Guide/Data Dictionary

- \bullet Handbooks: https://www.census.gov/programs-surveys/acs/guidance/handbooks.html
- Technical documentation: https://www.census.gov/programs-surveys/acs/technical-documentation.html

5.9 Cost

Free

5.10 Proposal or Application required?

No

5.11 DUA required?

No

5.12 Special Notes

• Some data tables also accessible via API; for information go to:

- List data sets/years available as well as variables: https://api.cens us.gov/data.html
- List of all data sets and years available by API: https://www.census.gov/data/developers/data-sets.html
- Instructions for developers: https://www.census.gov/data/developers.html
- Data prior to $\sim\!\!2005$ typically needs to be downloaded from an FTP server

American Hospital Association (AHA) Annual Survey Database

6.1 Organization

American Hospital Association (AHA)

6.2 Website

https://www.ahadata.com/

6.3 Description

- Survey of more than 6,200 hospitals in US
- Measures health system performance, patient satisfaction, readmissions, mortality, and quality and includes data on hospital demographics and characteristics, hospital organization, hospital staffing, and other topics such as leadership, strategic planning, and human resources
- Hospital- and system-level data
- \bullet IT supplement added in 2008
- Survey of Care Systems and Payment added in 2013 to capture new systems of care, care coordination functions and payment models

6.4 Vintage/Release Frequency

Annual

6.5 Observational Unit

Hospital

6.6 Collection Methodology

- Survey sent to both AHA-registered and non-registered hospitals
- Historical response rate >75% annually

6.7 Available at

Have to order the data.

6.8 User Guide/Data Dictionary

Not provided on website.

6.9 Cost

Yes, not listed

6.10 Proposal or Application required?

Not stated on website.

6.11 DUA required?

Not stated on website.

6.12 Special Notes

• Several other tools by the AHA that may be useful (e.g. AHA Population Health Survey)

American Housing Survey (AHS)

7.1 Organization

US Census Bureau

7.2 Website

https://www.census.gov/programs-surveys/ahs/

7.3 Description

- Longitudinal survey of occupied and vacant housing units
- Used to monitor housing supply and demand, conditions and costs
- Used to assess housing needs and develop housing policies
- Core data includes housing size, composition, vacancies, fuel usage, physical condition, occupant characteristics, equipment breakdowns, improvements, mortgages, costs, value
- Topical data varies, but recently has included health and safety hazards, food insecurities, housing counseling services, community opportunities, public transportation, neighborhood characteristics, emergency/disaster preparedness, community involvement, doubled-up households

7.4 Vintage/Release Frequency

Annually 1973-2005, Biennially 2005-present

Household, person, mortgage, or home improvement project (4 relational databases or one flat file)

7.6 Collection Methodology

- Nationally-representative longitudinal panel sample with 2-year cycle
- Oversample 15 largest metropolitan areas and HUD-assisted housing units
- Split sample, each sample getting a different set of topical questions, resulting in 3 sets of weights
- Housing units are revisited every two years until a new sample is drawn
- Computer-assisted personal interviewing

7.7 Available at

https://www.census.gov/programs-surveys/ahs/data.html

7.8 User Guide/Data Dictionary

https://www.census.gov/programs-surveys/ahs/tech-documentation.html

7.9 Cost

Free for download

7.10 Proposal or Application required?

No

7.11 DUA required?

No

7.12 Special Notes

- Majorly redesigned in 2015, with a new sample drawn for first time since 1985, along with major modification of questionnaire and methodology
- Topical modules for 2015 (most recent year available) are Arts and Culture, Food Security, Housing Counseling, and Healthy Homes

American Time Use Survey (ATUS)

8.1 Organization

U.S. Bureau of Labor Statistics

8.2 Website

https://www.bls.gov/tus/

8.3 Description

- Measures the amount of time people spend doing various activities, such as paid work, childcare, volunteering, and socializing.
- The survey also provides information on the amount of time people spend in many other activities, such as religious activities, socializing, exercising, and relaxing.

8.4 Vintage/Release Frequency

Annually since 2003

8.5 Observational Unit

Household member

8.6 Collection Methodology

- Individuals are randomly selected from a subset of households that have completed their eighth month of interviews for the Current Population Survey (CPS). ATUS respondents are interviewed only one time about how they spent their time on the previous day, where they were, and whom they were with.
- Civilian noninstitutional population.

8.7 Available at

https://www.bls.gov/tus/data.htm

8.8 User Guide/Data Dictionary

https://www.bls.gov/tus/atususersguide.pdf

8.9 Cost

Free for download

8.10 Proposal or Application required?

No

8.11 DUA required?

No

8.12 Special Notes

• Data collection was suspended in 2020 from mid-March to mid-May for the safety of ATUS staff. Annual 2020 estimates cannot be produced due to the 2-month suspension in data collection, and thus the ATUS Database was not updated with 2020 data.

Area Deprivation Index (ADI)

9.1 Organization

Health Innovations Program (University of Wisconsin-Madison)

9.2 Website

https://www.neighborhoodatlas.medicine.wisc.edu/

9.3 Description

- Area deprivation index is geographic area-based measure of socioeconomic deprivation
- Based on measure originally created by Health Resources & Services Administration (HRSA) and adapted at UW-Madison
- Allows for rankings of neighborhoods by socioeconomic status disadvantage at state or national level
- Factors include income, education, employment, and housing quality

9.4 Vintage/Release Frequency

2015, 2020

Census block group

9.6 Collection Methodology

- Created using American Community Survey 5-yr estimates data
- Two references provided on website describing methodology

9.7 Available at

https://www.neighborhoodatlas.medicine.wisc.edu/login

9.8 User Guide/Data Dictionary

n/a

9.9 Cost

Free for download

9.10 Proposal or Application required?

No

9.11 DUA required?

No

9.12 Special Notes

- Must register and create an account in order to download
- Citation: University of Wisconsin School of Medicine and Public Health. Area Deprivation Index. 2017. Available at: https://www.neighborhood.atlas.medicine.wisc.edu/?

Area Deprivation Index (ADI-3)

10.1 Organization

Cleveland Clinic, Case Western University, MetroHealth

10.2 Website

https://cran.r-project.org/web/packages/sociome/sociome.pdf

10.3 Description

- Variation of Singh's ADI.
- Allows for estimation at the state, county, census tract, or census block group level.
- Allows for using different iterations of data from the American Community Survey (ACS).
- Can customize the desired reference population down to the block group level when calculating ADI

10.4 Vintage/Release Frequency

NA

Geographical unit (available per state, county, ZCTA, census tract and census block group)

10.6 Collection Methodology

Details can be seen at https://doi.org/10.1007/s10742-021-00248-6

10.7 Available at

Calculate using sociome R package

10.8 User Guide/Data Dictionary

https://github.com/NikKrieger/sociome

10.9 Cost

Free

10.10 Proposal or Application required?

No

10.11 DUA required?

No

10.12 Special Notes

Suggested citation: Krieger N., Dalton J., Wang C., Perzynski A. (2021). sociome: Operationalizing Social Determinants of Health Data for Researchers. R package version 2.0.0.

Area Health Resources Files (AHRF)

11.1 Organization

Health Resources and Services Administration (HRSA)

11.2 Website

https://datawarehouse.hrsa.gov/topics/ahrf.aspx

11.3 Description

- Data files on various topics including Health Care Professions, Health Facilities, Population Characteristics, Economics, Health Professions Training, Hospital Utilization, Hospital Expenditures, Shortage Areas, and Environment
- Current and historical on over 6,000 variables for each of the nation's counties

11.4 Vintage/Release Frequency

Annual

11.5 Observational Unit

County, State, National

11.6 Collection Methodology

Data assembled from the American Dental Association, American Hospital Association, American Medical Association, and the American Community Survey

11.7 Available at

https://data.hrsa.gov/data/download

11.8 User Guide/Data Dictionary

Varies by data file and can be found on same download page.

11.9 Cost

Free

11.10 Proposal or Application required?

No

11.11 DUA required?

No

11.12 Special Notes

NA

Behavioral Risk Factor Surveillance System (BRFSS)

12.1 Organization

Centers for Disease Control and Prevention (CDC)

12.2 Website

https://www.cdc.gov/brfss/about/index.htm

12.3 Description

- Health-related telephone survey of U.S. residents established in 1984
- Captures health-related risk behaviors, chronic health conditions, and use of preventive services
- Collects data in 50 states, DC, and 3 U.S. territories
- Used to track state and local health objectives, implement programs and activities, and monitor trends as well as support legislative efforts

12.4 Vintage/Release Frequency

Annual since 1987

Survey respondent

12.6 Collection Methodology

- Cross-sectional telephone survey that state health departments conduct monthly over landline and cellular telephones
- Questionnaire consists of core questions, optional modules, and stateadded questions- complete questionnaire can vary from state to state
- Many questions are taken from national surveys such as NHIS or NHANES. See https://www.cdc.gov/brfss/questionnaires/index.htm
- Sample telephone numbers from households first. Most use disproportionate stratified sampling (high-density and medium-density strata) while a small number use simple random sampling. Also conduct a cell-phone sample.
- Random digit dialing techniques
- Computer-assisted telephone interviews
- Respondent data are forwarded to CDC to be aggregated for each state, returned with standard tabulations, and published at year's end by each state.

12.7 Available at

https://www.cdc.gov/brfss/annual data/annual data.htm

12.8 User Guide/Data Dictionary

https://www.cdc.gov/brfss/annual_data/annual_2021.html

12.9 Cost

Free

12.10 Proposal or Application required?

No

12.11 DUA required?

No

12.12 Special Notes

- Changes were made to weighting methodology (raking) and sampling methodology (addition of cell phone sample) in 2011
- Starting with 2014, all adults contacted through cell phone were eligible regardless of landline use (i.e. complete overlap)
- Suggested citation: Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [appropriate year].
- Prevalence Data and Data Analyis Tools available at: https://www.cdc.gov/brfss/data_tools.htm

 $4 CHAPTER\ 12.\ BEHAVIORAL\ RISK\ FACTOR\ SURVEILLANCE\ SYSTEM\ (BRFSS)$

Big Cities Health Inventory

13.1 Organization

Big Cities Health Coalition & Drexel Urban Health Collaborative

13.2 Website

https://bigcitieshealthdata.org/about/

13.3 Description

- Open access data platform of 30 of the largest, most urban cities in the United States, allowing for comparability across jurisdictions.
- The platform contains over 100,000 data points and 100 metrics across 50 health, socio-economic, and demographic indicators across 11 categories.
- Provide descriptive data of how health outcomes, COVID-19 related outcomes, and especially inequities in these outcomes, are evolving in Big Cities Health Coalition member cities.
- Indicators encompass 9 broad categories of public health importance: Behavioral Health and Substance Abuse; Cancer; Chronic Disease; Environmental Health; Food Safety; HIV/AIDS; Infectious Disease; Injury and Violence; and Maternal and Child Health. Additional categories include demographics and life expectancy/overall death rate.
- CSV files can be downloaded of individual cities or the entire collection of 30 cities.

13.4 Vintage/Release Frequency

Annual since 2010

13.5 Observational Unit

City or County Health Department

13.6 Collection Methodology

- Most of the data comes directly from cities. Data also obtained from U.S. Census or other similar publicly available data
- https://bigcitieshealthportal.blob.core.windows.net/data/2022-11-14-BCHI_Technical_Documentation.pdf

13.7 Available at

https://bigcitieshealthdata.org/download/survey/

13.8 User Guide/Data Dictionary

 $https://bigcitieshealthportal.blob.core.windows.net/data/2022-11-14-BCHI_T echnical_Documentation.pdf$

13.9 Cost

Free for download

13.10 Proposal or Application required?

No

13.11 DUA required?

Yes

13.12 Special Notes

- Data dashboard available at https://bigcitieshealthdata.org/
- Watch a webinar describing the big cities health data at https://www.bigcitieshealth.org/webinar-bchi-2022/

- Not all years for all cities are available in the platform, and more recent data are prioritized.
- $\bullet\,$ The data is updated on a rolling basis, when new data is accessible it is added to the platform

Bridged Race Population Estimates

14.1 Organization

National Center for Health Statistics (NCHS), CDC

14.2 Website

https://www.cdc.gov/nchs/nvss/bridged_race.htm

14.3 Description

- Bridged race population estimates.
- Race bridging makes data collected with one set of race categories consistent with data collected using a different set of race categories, allowing for consistent analysis over time.
- The Vintage 2020 bridged-race postcensal population estimates files contain estimates of the resident population of the United States as of April 1, 2010 July 1, 2020 (based on the 2010 census).
- The estimates on these files are based on Census 2010 and result from bridging the Vintage 2020 postcensal estimates with 31 race groups (the 31 race groups used in Census 2010 in accordance with the 1997 Office of Management and Budget (OMB) standards for the collection of data on race and ethnicity) to the four race categories specified under the 1977 OMB standards (3, 4).

14.4 Vintage/Release Frequency

Annual since 2000

14.5 Observational Unit

County level

14.6 Collection Methodology

- Data from the National Health Interview Surveys (NHIS) are used to develop models for bridging
- Use demographic and contextual covariate, both person-level and countylevel
- Probabilities obtained from regression models and applied to Census files to assign multiple-race persons to a single-race category

14.7 Available at

https://www.cdc.gov/nchs/nvss/bridged_race.htm

14.8 User Guide/Data Dictionary

https://www.cdc.gov/nchs/data/series/sr_02/sr02_135.pdf

14.9 Cost

Free for download

14.10 Proposal or Application required?

No

14.11 DUA required?

No

14.12 Special Notes

• Race bridging refers to making data collected using one set of race categories consistent with data collected using a different set of race categories.

- The July 1, 2010-July 2019 intercensal bridged-race population estimates will be released mid to late 2023 and the series will be discontinued afterwards.
- Changes in methodology are detailed at https://www.cdc.gov/nchs/nvss/bridged_race.htm#changes

California Health Interview Survey (CHIS)

15.1 Organization

UCLA Center for Health Policy Research

15.2 Website

https://healthpolicy.ucla.edu/chis/Pages/default.aspx

15.3 Description

- Largest state health survey in the nation.
- CHIS provides representative data on all 58 counties in California and provides a detailed picture of the health and health care needs of California's large and diverse population.
- Especially known for its hard-to-find data on ethnic subgroups and sexual minorities
- Covers numerous health topics such as asthma, diabetes and obesity to immigrant health and health insurance coverage.

15.4 Vintage/Release Frequency

Every other year since 2001 and continually beginning in 2011

Individual, Household

15.6 Collection Methodology

- Population-based survey of California's residential, noninstitutionalized population
- Web or phone Interviews

15.7 Available at

https://healthpolicy.ucla.edu/chis/data/Pages/GetCHISData.aspx

15.8 User Guide/Data Dictionary

 $https://healthpolicy.ucla.edu/chis/analyze/Pages/CHIS-Data-Documentation. \\ aspx$

15.9 Cost

Free for download

15.10 Proposal or Application required?

Only for confidential data

15.11 DUA required?

Only for confidential data

- Need to register to download
- Additional confidential and/or geo-coded data available. Need to submit a research application and data use is tied to that project.

Chronic Disease Indicators

16.1 Organization

Centers for Disease Control and Prevention (CDC) Division of Population Health

16.2 Website

 $https://chronicdata.cdc.gov/Chronic-Disease-Indicators/U-S-Chronic-Disease-Indicators-\ CDI-/g4ie-h725$

16.3 Description

- The Chronic Disease Indicators enable public health professionals and policy makers to retrieve state and selected metropolitan-level data for chronic diseases and risk factors.
- The data contains a set of 124 indicators that were developed by consensus and that allow states and territories and large metropolitan areas to uniformly define, collect, and report chronic disease data that are important to public health practice and available for states, territories and large metropolitan areas.
- Topics groups covered: alcohol; arthritis; asthma; cancer; cardiovascular disease; chronic kidney disease; chronic obstructive pulmonary disease; diabetes; immunization; nutrition, physical activity, and weight status; oral health; tobacco; overarching conditions; and new topic areas that include disability, mental health, older adults, reproductive health, school health, and systems and environmental change.
- Provides crude and age-adjusted rates (overall, by gender & race)

16.4 Vintage/Release Frequency

Varies by indicator/geographic area

16.5 Observational Unit

State, territory or select large metropolitan areas

16.6 Collection Methodology

- Originally there were 73 indicators adopted in 1998.
- CDC, CSTE, and NACDD conducted a preliminary review in 2011 to obtain initial input on the need to update the indicators and to solicit comments from subject-matter experts at CDC and state health departments about the CDI website and the use of the indicators.
- Data is obtained from BRFSS, ACS, NVSS, he State Tobacco Activities Tracking and Evaluation System, the United States Renal Data System, the Youth Risk Behavior Surveillance System, Pregnancy Risk Assessment Monitoring System, the Alcohol Epidemiologic Data System, the Alcohol Policy Information System, alcohol policy legal research, the National Survey of Children's Health, State Emergency Department Databases, State Inpatient Databases, the Centers for Medicare and Medicaid Services Chronic Condition Warehouse and the Medicare Current Beneficiary Survey, the U.S. Department of Agriculture, the CDC School Health Profiles, Achieving a State of Healthy Weight, Maternal Practices in Infant Nutrition and Care, the Breastfeeding Report Card, the Health Resources and Services Administration Uniform Data System, the National Immunization Survey, and the Water Fluoridation Reporting System.

16.7 Available at

https://chronicdata.cdc.gov/Chronic-Disease-Indicators/U-S-Chronic-Disease-Indicators- CDI-/g4ie-h725

16.8 User Guide/Data Dictionary

 $https://chronicdata.cdc.gov/Chronic-Disease-Indicators/U-S-Chronic-Disease-Indicators-\ CDI-/g4ie-h725$

16.9 Cost

Free for download

16.10 Proposal or Application required?

No

16.11 DUA required?

No

- Can access data via API
- CDC reports CDI data using the data quality and sample size thresholds stipulated and implemented by the data providers.
- Only data form the most recent year is presented on the website.

Colorado All Payer Claims Database (CO APCD)

17.1 Organization

Center for Improving Value in Health Care

17.2 Website

https://civhc.org/get-data/whats-in-the-co-apcd/

17.3 Description

- Comprehensive database comprising medical, dental, and pharmacy claims from various payers.
- Captures longitudinal care information on individual and spans diverse care settings.
- Contains demographic, diagnostic, procedural & reimbursement information (total charges, plan paid, and patient responsibility).
- Useful for policy, research, clinical and health system performance, evaluation, population health management, system redesign, payment reform, and more.

17.4 Vintage/Release Frequency

2013 - present (1-2 years lag)

Claim event

17.6 Collection Methodology

- Over 1 billion claims from 40 commercial payers + Medicare & Medicaid (FFS/Advantage)
- Covers about 70% of Covered Lives in Colorado (medical only)

17.7 Available at

- Public Data: https://civhc.org/get-data/public-data/
- Licensed Data: https://civhc.org/get-data/non-public-data/

17.8 User Guide/Data Dictionary

https://civhc.org/get-data/whats-in-the-co-apcd/

17.9 Cost

- Public Data reports can be accessed free of charge.
- Licensed Data pricing: https://civhc.org/wp-content/uploads/2022/07/Non-Public-Data-Release-Options.pdf

17.10 Proposal or Application required?

Yes

17.11 DUA required?

Yes

- Both public-use data and licensed data available
- Does not include Federal Programs (VA, Tricare, Indian Health Services), majority of ERISA-based self-insured empolyers, uninsured and self-pay claims

Common Core of Data, America's Public Schools

18.1 Organization

National Center for Education Statistics (NCES)

18.2 Website

https://nces.ed.gov/ccd/

18.3 Description

- \bullet Primary database on public elementary and secondary education in the US
- Universe surveys provide information such as student membership counts by grade, race/ethnicity, and sex; staff FTE counts by professional category; counts of children with disabilities; counts of English learners; and counts of students eligible for free and reduced-price lunches by state, school district, and/or school
- Dropout and Completers data provide information on the number of dropouts and dropout rates as well as the number of completers, diploma recipients, and averaged freshman graduation rates by state and/or school district.
- Finance data provide information on school revenue and expenditures by state and/or school district

18.4 Vintage/Release Frequency

Annual since 1986

18.5 Observational Unit

State, school-district, and school-level files

18.6 Collection Methodology

Survey with completion by state coordinator

18.7 Available at

https://nces.ed.gov/ccd/files.asp

18.8 User Guide/Data Dictionary

Specifications for each file available at same website as data download

18.9 Cost

Free for download

18.10 Proposal or Application required?

No

18.11 DUA required?

No

18.12 Special Notes

• Data query and mapping tools available on website

Community Resilience Estimates (CRE)

19.1 Organization

U.S Census Bureau

19.2 Website

https://www.census.gov/programs-surveys/community-resilience-estimates/data/datasets.html

19.3 Description

- Estimates community resilience to disasters by using small area estimation (SAE) techniques
- Considers 10 risk factors for households and individuals and provides estimates of the total number of people living in a community by the number of socioeconomic risk factors. In its current data file layout form, the estimates are categorized into three groups: 0 risk factors (low risk), 1-2 risk factors (medium risk) and 3+ risk factors (high risk)

19.4 Vintage/Release Frequency

2019

Geographical unit (available per state, county, ZCTA, and census tract)

19.6 Collection Methodology

See details at https://www.census.gov/programs-surveys/community-resilien ce-estimates/technical-documentation/methodology.html

19.7 Available at

https://www.census.gov/programs-surveys/community-resilience-estimates/data/datasets.html

19.8 User Guide/Data Dictionary

https://www2.census.gov/programs-surveys/demo/technical-documentation/community-resilience/2019/cre quickguide 2019.pdf

19.9 Cost

Free for download

19.10 Proposal or Application required?

No

19.11 DUA required?

No

19.12 Special Notes

Scores range from 0 (most resilience) to 100 (least resilience) Suggested citation: United States Census Bureau Community Resilience 2019 Estimates Datasets. https://www.census.gov/programs-surveys/community-resilience-estimates/data/datasets.html. Accessed on [Insert date].

Consumer Expenditure Survey (CE)

20.1 Organization

U.S. Bureau of Labor Statistics

20.2 Website

https://www.bls.gov/cex/

20.3 Description

- Provides data on expenditures, income, and demographic characteristics of consumers in the United States.
- CE data are collected by the Census Bureau for BLS in two surveys: the Interview Survey for major and/or recurring items and the Diary Survey for more minor or frequently purchased items.
- CE data are primarily used to revise the relative importance of goods and services in the market basket of the Consumer Price Index.

20.4 Vintage/Release Frequency

Annual since 1980

Household

20.6 Collection Methodology

- The Interview Survey is a rotating panel survey in which approximately 10,000 addresses are contacted each calendar quarter that yield approximately 6,000 useable interviews.
- One-fourth of the addresses that are contacted each quarter are new to the survey. After a housing unit has been in the sample for four consecutive quarters, it is dropped from the survey, and a new address is selected to replace it.

20.7 Available at

https://www.bls.gov/cex/pumd_data.htm

20.8 User Guide/Data Dictionary

https://www.bls.gov/cex/pumd_doc.htm

20.9 Cost

Free for download

20.10 Proposal or Application required?

No

20.11 DUA required?

No

- A phased implementation of a re-design is being implemented since July 2022
- Experimental State Weights for 2019, supporting state-level analysis for selected states, are also available with their documentation.
- Public Use Microdata Annual Workshop offered (https://www.bls.gov/cex/ceworkshopthankyou.htm).

County Health Rankings and Roadmaps

21.1 Organization

Robert Wood Johnson Foundation and University of Wisconsin Population Health Institute

21.2 Website

http://www.countyhealthrankings.org/

21.3 Description

- Measure the heath of nearly all US counties and rank them within states (not across states)
- Help communities understand what influences health and length of life
- Explores policies and programs; health factors such as physical environment (e.g. air quality, water quality, housing, transit), social and economic factors (e.g. education, employment, income, family and social support, community safety), clinical care (e.g. access to care, quality of care), and health behaviors (e.g. tobacco use, diet and exercise, alcohol and drug use, sexual activity); and, health outcomes such as length of life and quality of life

21.4 Vintage/Release Frequency

Annual since 2010

County

21.6 Collection Methodology

- Rankings compiled using county-level measures from a variety of national and state data sources
- Measures standardized and combined using scientifically-informed weights
- Measures closely aligned with America's Health Rankings which ranks the health of states

21.7 Available at

https://www.countyhealthrankings.org/explore-health-rankings/rankings-data-documentation

21.8 User Guide/Data Dictionary

Data documentation available at same website as data download

21.9 Cost

Free for download

21.10 Proposal or Application required?

No

21.11 DUA required?

No

21.12 Special Notes

• Separate trends data file available on website

COVID-19 Community Vulnerability Index (CCVI)

22.1 Organization

Surgo Ventures

22.2 Website

https://precisionforcovid.org/

22.3 Description

- Pairs CDC's Social Vulnerability Index data with both epidemiological and healthcare system factors to identify communities in need of additional support and resources during COVID-19.
- It can provide information about the anticipated negative impact at the community level.
- Aggregating dozens of indicators across 6 themes: 1) SES, 2) household composition and disability, 3) minority status and language, 4) housing type and transportation, 5) epidemiologic factors, and 6) health care system factors

22.4 Vintage/Release Frequency

2020

Geographical unit (available per state, county, and census tract)

22.6 Collection Methodology

- Surgo Ventures. COVID-19 Community Vulneratility Index (CCVI) Methodology. https://covid-static-assets.s3.amazonaws.com/US-CCVI/COVID-19+Community+Vulnerability+Index+(CCVI)+Methodology.pdf
- Melvin SC, Wiggins C, Burse N, Thompson E, Monger M. The Role of Public Health in COVID-19 Emergency Response Efforts From a Rural Health Perspective. Prev Chronic Dis 2020;17:200256. DOI: http://dx.doi.org/10.5888/pcd17.200256.

22.7 Available at

https://precisionforcovid.org/ccvi

22.8 User Guide/Data Dictionary

Data explorer at https://precisionforcovid.org/ccvi

22.9 Cost

Free for download

22.10 Proposal or Application required?

No

22.11 DUA required?

No

- National rank: 0 (lesser vulnerability) 1 (greater vulnerability)
- Suggested citation: Surgo Ventures COVID-19 Community Vulnerability Index (CCVI): US Data. Available at https://www.precisionforcoviddat a.org/. Accessed on [Insert date].

Current Population Survey (CPS)

23.1 Organization

US Census Bureau, Bureau of Labor Statistics

23.2 Website

https://www.census.gov/programs-surveys/cps/about.html

23.3 Description

- One of the oldest and largest surveys in the US
- Primary topics include employment, earnings and education
- Supplementary topics include child support, health insurance coverage, school enrollment, and other topics
- Source of monthly labor force statistics, including unemployment rate

23.4 Vintage/Release Frequency

Basic files are released monthly since 1994. Other files are released annually.

23.5 Observational Unit

Household member

23.6 Collection Methodology

- Probability selected sample of about 60,000 occupied households
- Selected households are included in the survey for four consecutive months and then for the same four months the following calendar year
- Administered through personal and telephone interviews using a computerized questionnaire

23.7 Available at

https://www.census.gov/programs-surveys/cps/data/datasets.html

23.8 User Guide/Data Dictionary

Data dictionary available at same website as data download

23.9 Cost

Free for download

23.10 Proposal or Application required?

No

23.11 DUA required?

No

23.12 Special Notes

• Data from the Current Population Survey comes in many forms and release frequencies vary. See website for details on how to obtain the various files.

Distressed Communities Index (DCI)

24.1 Organization

Economic Innovation Group

24.2 Website

https://eig.org/dci

24.3 Description

- DCI examines economic well-being at the zip code level in order to provide a detailed view of the divided landscape of American prosperity
- Combines seven complementary metrics into a broad-based assessment
 of community economic well-being in the United States (no high school
 diploma, housing vacancy rate, adults not working, poverty rate, median
 income ratio, change in employment, change in business establishments)
- Captures 99 percent of the U.S. population and covers more than 26,000 zip codes and more than 3,000 counties (those with over 500 people) as well as nearly 800 cities (those with at least 50,000 people)

24.4 Vintage/Release Frequency

2017, 2020

Geographical unit (available per ZCTA)

24.6 Collection Methodology

- Constructed using data from the U.S. Census Bureau's American Community Survey 5- Year Estimates for 2011-2015 and Business Patterns data from the years 2011 and 2015
- Distress scores are calculated at each scale by ranking geographic units
 on each of the seven metrics, taking the average of those ranks, and then
 normalizing the average to be equivalent to a percentile
- Produces a range of distress scores from 0 to 100

24.7 Available at

https://eig.org/distressed-communities/get-the-data/

24.8 User Guide/Data Dictionary

Methodology available at: https://eig.org/dci/methodology .

24.9 Cost

\$500 for full data, \$100 for scores only

24.10 Proposal or Application required?

No

24.11 DUA required?

Yes

- National rank: 1 (most prosperous) 100 (distressed) or 1 (most prosperous) 5 (distressed)
- Suggested citation: EIG: Economic Innovation Group Distressed Communities Index. http://eig.org/dci Economic Innovation Group Distressed Communities Index. Available at http://eig.org/dci. Accessed on [Insert date].

Drug Abuse Warning Network (DAWN)

25.1 Organization

Substance Abuse and Mental Health Services Administration (SAMHSA)

25.2 Website

https://www.datafiles.samhsa.gov/

25.3 Description

- SAMHSA administered DAWN from 1992 through 2011 (legacy DAWN) and reestablished the current version of DAWN in 2018.
- De-identified, subject-level.
- Nationally represented public health surveillance system that continuously monitors drug-related visits to hospital emergency departments (EDs).
- A DAWN case is any ED visit involving recent drug use that is implicated
 in the ED visit.
- Captures ED visits that are directly caused by drugs and those for which drugs are a contributing factors.
- The dataset includes demographics, drugs involved in the ED visit (up to 16 drugs from 2004 through 2008 and up to 22 drugs from 2009 through 2011), toxicology confirmation, route of administration, type of case, and disposition of the patient following the visit.
- One data file per year

25.4 Vintage/Release Frequency

Annual 2004-2011, 2021

25.5 Observational Unit

Facility-level survey data

25.6 Collection Methodology

- Data is extracted from the medical records
- Stratified simple random sampling with oversampling in selected metropolitan areas is used to select the hospitals
- Target sample are all non-federal, short-stay, general medical and surgical hospitals in the United States that operate one or more EDs 24 hours a day, 7 days a week. Specialty hospitals, hospital units of institutions, long-term care
- All records of ED admissions of sampled hospitals are reviewed to find drug-related visits.
- Major changes to DAWN were instituted during 2003 as the result of a redesign intended to improve the quality and representativeness of DAWN estimates. As a result, comparisons cannot be made between the old DAWN (2002 and prior years) and the redesigned DAWN (2004 and forward). The year 2003 was a period of transition between the old DAWN and the redesigned DAWN. As a result, only interim, half-year estimates were produced for 2003.
- Data processing includes: consistency checks, standardization of missing values, recodes, calculation of derived variables, checks for undocumented or out-of-range codes.

25.7 Available at

https://www.datafiles.samhsa.gov/dataset/drug-abuse-warning-network-2011-dawn-2011-ds0001

25.8 User Guide/Data Dictionary

https://www.samhsa.gov/data/data-we-collect/legacy-dawn-drug-abuse-warning-network

25.9 Cost

Free for download

25.10 Proposal or Application required?

No

25.11 DUA required?

No

25.12 Special Notes

DAWN does not produce rates (visits per 100,000 population) for race/ethnicity groups

FDA Aderse Event Reporting System (FAERS)

26.1 Organization

U.S. Food & Drug Administration (FDA)

26.2 Website

https://open.fda.gov/data/faers/

26.3 Description

- Database that contains information on adverse event and medication error reports submitted to FDA.
- Designed to support the FDA's post-marketing safety surveillance program for drug and therapeutic biologic products.
- Adverse events and medication errors are coded to terms in the Medical Dictionary for Regulatory Activities (MedDRA) terminology.

26.4 Vintage/Release Frequency

Quarterly since 2004

26.5 Observational Unit

Event

26.6 Collection Methodology

- Healthcare professionals, consumers, and manufacturers submit reports to FAERS.
- FDA receives voluntary reports directly from healthcare professionals (such as physicians, pharmacists, nurses and others) and consumers (such as patients, family members, lawyers and others).
- If a manufacturer receives a report from a healthcare professional or consumer, it is required to send the report to FDA as specified by regulations.

26.7 Available at

https://fis.fda.gov/extensions/FPD-QDE-FAERS/FPD-QDE-FAERS.html

26.8 User Guide/Data Dictionary

File descriptions included in each download

26.9 Cost

Free for download

26.10 Proposal or Application required?

No

26.11 DUA required?

No

- There is no certainty that the reported event (adverse event or medication error) was due to the product. FDA does not require that a causal relationship between a product and event be proven, and reports do not always contain enough detail to properly evaluate an event.
- FDA does not receive reports for every adverse event or medication error that occurs with a product.
- There are also duplicate reports where the same report was submitted by a consumer and by the sponsor.
- FAERS data cannot be used to calculate the incidence of an adverse event or medication error in the U.S. population.

Food Access Research Atlas

27.1 Organization

Economic Research Service (ERS), U.S. Department of Agriculture (USDA)

27.2 Website

https://www.ers.usda.gov/data-products/food-access-research-atlas/

27.3 Description

- The Food Access Research Atlas maps food access indicators for census tracts using ½- mile and 1-mile demarcations to the nearest supermarket for urban areas, 10-mile and 20-mile demarcations to the nearest supermarket for rural areas, and vehicle availability for all tracts.
- Limited access to supermarkets, supercenters, grocery stores, or other sources of healthy and affordable food may make it harder for some Americans to eat a healthy diet.
- Provides information on: food desert, low access, share of population beyond x miles from supermarket, without vehicle (overall, low income, by age, race).

27.4 Vintage/Release Frequency

2010, 2015, 2019

Census tract

27.6 Collection Methodology

- The Atlas is based on 2010 census tract polygons.
- The criteria for identifying a census tract as low income are from the Department of Treasury's New Markets Tax Credit (NMTC) program.
- Spatial analysis, string matching, and manual review methods were used to merge the SNAP and TDLinx data sets to construct a combined store directory.
- For vehicle access, tract-level 2010-2014 estimates of the share of housing units without vehicles is multiplied by the 2010 count of housing units to obtain an estimate of the number of households without vehicles. The share of individuals below 200 percent of poverty is multiplied by the 2010 population to obtain an estimate of the number of people with income at or below 200 percent of poverty. These numbers and shares are then allocated down to the ½-kilometer-square grid level. In previous updates, direct estimates of income and vehicle access were used instead of relying on 2010 population counts for estimation.

27.7 Available at

https://www.ers.usda.gov/data-products/food-access-research-atlas/download-the-data/

27.8 User Guide/Data Dictionary

 $https://www.ers.usda.gov/data-products/food-access-research-atlas/document\ ation/$

27.9 Cost

Free for download

27.10 Proposal or Application required?

No

27.11 DUA required?

No

27.12 Special Notes

- Data webinar available at https://www.ers.usda.gov/newsroom/trendingtopics/data-training-webinars/#FARA_FEA

Food Environment Atlas

28.1 Organization

Economic Research Service (ERS), U.S. Department of Agriculture (USDA)

28.2 Website

https://www.ers.usda.gov/data-products/food-environment-atlas/

28.3 Description

- The objectives of the Atlas are to assemble statistics on food environment indicators to stimulate research on the determinants of food choices and diet quality, and to provide a spatial overview of a community's ability to access healthy food and its success in doing so.
- The objectives are to assemble statistics on food environment indicators to stimulate research on the determinants of food choices and diet quality, and to provide a spatial overview of a community's ability to access healthy food and its success in doing so.
- Food Choices—Indicators of the community's access to and acquisition of healthy, affordable food, such as: access and proximity to a grocery store; number of food stores and restaurants; expenditures on fast foods; food and nutrition assistance program participation; food prices; food taxes; and availability of local foods.
- Health and Well-Being—Indicators of the community's success in maintaining healthy diets, such as: food insecurity; diabetes and obesity rates; and physical activity levels.
- Community Characteristics—Indicators of community characteristics that might influence the food environment, such as: demographic composi-

tion; income and poverty; population loss; metro-nonmetro status; natural amenities; and recreation and fitness centers.

28.4 Vintage/Release Frequency

2011, 2012, 2014, 2015, 2017, 2020

28.5 Observational Unit

County

28.6 Collection Methodology

- In each of the referenced reports, a directory of supermarkets and large grocery stores authorized to accept SNAP benefits was merged with Trade Dimensions' TDLinx directory of stores within the United States, including Alaska and Hawaii, for the years 2010 and 2015.
- Population data are reported at the block level from the 2010 Census
 of Population and Housing, while data on income in 2010 are drawn at
 the block group-level from the 2006-10 American Community Survey, and
 data on income in 2015 are drawn from the 2010-14 American Community
 Survey.
- These population data were aerially allocated down to ½-kilometer-square grids across the United States. For each ½-kilometer-square grid cell, the distance was calculated from its geographic center to the center of the grid cell with the nearest supermarket.
- Rural or urban status is designated by the Census Bureau's Urban Area definition. Low- income is defined as annual family income of less than or equal to 200 percent of the Federal poverty threshold based on family size.

28.7 Available at

 $https://www.ers.usda.gov/data-products/food-environment-\ atlas/data-access-and-documentation-downloads/$

28.8 User Guide/Data Dictionary

https://www.ers.usda.gov/data-products/food-environment-atlas/document at ion/

28.9. COST 3

28.9 Cost

Free for download

28.10 Proposal or Application required?

No

28.11 DUA required?

No

28.12 Special Notes

- Data webinar available at https://www.ers.usda.gov/newsroom/trendingtopics/data-training-webinars/#FARA_FEA

General Social Survey (GSS)

29.1 Organization

NORC at the University of Chicago

29.2 Website

http://gss.norc.org/About-The-GSS

29.3 Description

- Gathers data on contemporary American society
- Standard core of demographic, behavioral, and attitudinal questions
- Additional supplemental content
- Among the topics covered are civil liberties, crime and violence, intergroup tolerance, morality, national spending priorities, psychological well-being, social mobility, and stress and traumatic events.

29.4 Vintage/Release Frequency

Annual from 1972 to 1994 and biennial since 1994

29.5 Observational Unit

Household respondent

29.6 Collection Methodology

- Sampling methodology has changed over time, with a full probability sample implemented in 1977 and changes to the sampling frames were made about every ten years, adapted from updated census information
- Multi-stage area probability sample

29.7 Available at

http://gss.norc.org/get-the-data

29.8 User Guide/Data Dictionary

http://gss.norc.org/Get-Documentation

29.9 Cost

Free for download

29.10 Proposal or Application required?

No

29.11 DUA required?

No

29.12 Special Notes

- Have a tools available for searching and analyzing the data without download
- Citation: Smith, Tom W., Davern, Michael, Freese, Jeremy, and Hout, Michael. General Social Surveys, 1972-2016. [machine-readable data file]. Principal Investigator, Tom W. Smith; Co-Principal Investigators, Peter V. Marsden and Michael Hout, NORC ed. Chicago: NORC, 2017. 1 data file (62,466 logical records) and 1 codebook (3,689 pp).

Global Health Data Exchange (GHDx)

30.1 Organization

Institute for Health Metrics and Evaluation (IHME)

30.2 Website

http://ghdx.healthdata.org/

30.3 Description

- World catalog of surveys, censuses, vital statistics, and other health-related data
- Has many data sources as well as data visualizations and interactive maps and county profiles
- One main IHME project is the Global Burden of Disease (GBD) Study which provides national and state estimates of death, years of life lost, years lived with disabilities, disability-adjusted life years, prevalence, incidence, life expectancy, healthy life expectancy, and maternal mortality ratio
- Other datasets include county-specific mortality rates for infectious disease, substance use, intentional injuries, chronic respiratory disease, cardiovascular disease, cancer as well as overall; life expectancy and age-specific mortality risk; health care and public spending; and countyspecific prevalence of alcohol use, diabetes, smoking, physical activity, obesity, and hypertension; other datasets as well.

30.4 Vintage/Release Frequency

Annual since 1990 for GBD. Other data release might vary by country/type.

30.5 Observational Unit

National, state and county-level for US data

30.6 Collection Methodology

• Data pulled from a variety of sources. Some of data sources used to build the repository are listed at http://ghdx.healthdata.org/data-sites-we-love

30.7 Available at

US data free for download at http://ghdx.healthdata.org/us-data

30.8 User Guide/Data Dictionary

Codebooks are available at same website as data download

30.9 Cost

Free for download

30.10 Proposal or Application required?

No

30.11 DUA required?

No

30.12 Special Notes

NA

Health and Retirement Study (HRS)

31.1 Organization

The University of Michigan

31.2 Website

https://hrs.isr.umich.edu/about

31.3 Description

- Longitudinal panel study supported by the National Institute on Aging and the Social Security Administration of people over age 50
- Core data includes information on income and wealth, health and use of health services, employment, family connections, biomarker health measurements, and psychosocial and lifestyle factors
- Supplemental surveys have included topics such as consumption (time and money), memory, prescription drugs, and diabetes, among others

31.4 Vintage/Release Frequency

Annual from 1992 to 1996 and biennial since 1996

31.5 Observational Unit

Survey respondent

31.6 Collection Methodology

- Longitudinal cohort sample
- Surveys a representative sample of approximately 20,000 people
- Interviews are conducted every two years, with the sample replenished every six years

31.7 Available at

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

31.8 User Guide/Data Dictionary

https://hrs.isr.umich.edu/documentation

31.9 Cost

Free for download

31.10 Proposal or Application required?

Not for public use files but yes for restricted use files.

31.11 DUA required?

Not for public use files but yes for restricted use files.

31.12 Special Notes

- Must register to access public use files
- Off-year and cross-year studies available
- 2020 HRS COVID-19 Project data available
- Restricted/Sensitive data available via application process

Health Data Compass

32.1 Organization

Health Data Compass, University of Colorado

32.2 Website

https://www.healthdatacompass.org/

32.3 Description

• Enterprise health data warehouse for UCHealth and Children's Hospital Colorado.

32.4 Vintage/Release Frequency

NA

32.5 Observational Unit

Patient and/or encouter

32.6 Collection Methodology

• Integrates patient data from the electronic medical records at UCHealth and Children's Hospital Colorado, provider billing data from CU Medicine, and -omics data from the Colorado Center for Personalized Medicine.

• These data are further enriched with a variety of state and public data sources.

32.7 Available at

https://www.healthdatacompass.org/home

32.8 User Guide/Data Dictionary

n/a

32.9 Cost

Not stated

32.10 Proposal or Application required?

Yes

32.11 DUA required?

Yes

32.12 Special Notes

- Can register for a Compass orientation session at https://www.healthda tacompass.org/data-delivery-services/compass-orientation
- Only available for employees of University of Colorado Anschutz Medical Campus, University of Colorado Medicine, UCHealth, and Children's Hospital Colorado

Health Information National Trends Survey (HINTS)

33.1 Organization

National Cancer Institute (NCI), NIH

33.2 Website

https://hints.cancer.gov/default.aspx

33.3 Description

- Nationally-representative survey designed to assess current access to and use of information about cancer by the US public
- Looks at all stages of cancer care from prevention to detection, diagnosis, treatment, and survivorship

33.4 Vintage/Release Frequency

NA

33.5 Observational Unit

Individual

33.6 Collection Methodology

- Methodology varied but most recent is a two-stage survey design (primary sampling unit was residential addresses selected from a database used by a marketing group, stratified by high or low concentrations of minority population; secondary sampling unit was individual within the household)
- Oversampled high-minority stratum
- Survey conducted by mail with prepaid \$2 incentive, four mailings as needed

33.7 Available at

https://hints.cancer.gov/data/download-data.aspx

33.8 User Guide/Data Dictionary

Methodology report available at https://hints.cancer.gov/data/methodology-reports.aspx and questionnaires available at https://hints.cancer.gov/data/survey-instruments.aspx

33.9 Cost

Free for download

33.10 Proposal or Application required?

Not for public use files but yes for restricted use files.

33.11 DUA required?

Yes

33.12 Special Notes

• They have an interactive online tool to develop SAS code to merge multipe iterations of HINTS data

Hospital Compare

34.1 Organization

US Centers for Medicare and Medicaid Services (CMS)

34.2 Website

https://www.medicare.gov/hospitalcompare/About/What-Is-HOS.html

34.3 Description

- Use to find and compare quality of over 4,000 Medicare-certified hospitals in U.S.
- Includes general hospital information such as name and address, survey
 of patients' experiences, as well as information about the timeliness and
 effectiveness of care, complications and deaths, unplanned hospital visits,
 use of medical imaging, and payment and value of care
- Also includes an overall hospital rating designed for comparison across hospitals

34.4 Vintage/Release Frequency

Collection frequency and data refresh varies by data field, but annually available

34.5 Observational Unit

Hospital

34.6 Collection Methodology

- Data sources vary according to data field but include: CMS Certification and Survey Provider Enhanced Reporting (CASPER) system; online data entry tools; CMS Abstraction and Reporting Tool (CART); External Peer Review Program (EPRP); National Healthcare Safety network (NHSN); Medicare enrollment and claims data; Veterans Health Administration (VHA) administrative data; Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey; and, Survey of Healthcare Experiences of Patients (SHEP)
- Overall rating calculated using a latent variable model

34.7 Available at

https://data.medicare.gov/data/hospital-compare

34.8 User Guide/Data Dictionary

Data dictionary and other supporting documentation available at same website as data download

34.9 Cost

Free for download

34.10 Proposal or Application required?

No

34.11 DUA required?

No

34.12 Special Notes

 Within the hospital compare website, they also note the availability of data for comparing nursing homes, physicians, home health, dialysis facilities, hospice, inpatient rehabilitation facilities, long-term care hospitals, and suppliers.

Integrated Postsecondary Education Data system (IPEDS)

35.1 Organization

National Center for Education Statistics (NCES)

35.2 Website

https://nces.ed.gov/ipeds/

35.3 Description

- Information on US colleges, universities, and technical and vocational institutions (post-secondary institutions)
- Institutional characteristics, admissions and test scores, enrollment, program completion and graduation rates, institutional costs, student financial aid, human resources

35.4 Vintage/Release Frequency

Annual since 1984

35.5 Observational Unit

Post-secondary institutions

35.6 Collection Methodology

- Web-based data collection
- Post-secondary institutions mandated to report

35.7 Available at

https://nces.ed.gov/ipeds/use-the-data

35.8 User Guide/Data Dictionary

Supplementary documentation available for download at https://nces.ed.gov/pubsearch/getpubcats.asp?sid=010

35.9 Cost

Free for download

35.10 Proposal or Application required?

No

35.11 DUA required?

No

35.12 Special Notes

n/a

IPUMS

36.1 Organization

University of Minnesota

36.2 Website

https://ipums.org/

36.3 Description

- Provides census, survey, and spatial data from around the world integrated across time and space.
- IPUMS integration and documentation makes it easy to study change, conduct comparative research, merge information across data types, and analyze individuals within family and community contexts.

36.4 Vintage/Release Frequency

Varies by project

36.5 Observational Unit

Varies by project

36.6 Collection Methodology

NA

36.7 Available at

https://ipums.org/

36.8 User Guide/Data Dictionary

Each project has it's own documentation on the same website as data download.

36.9 Cost

Free for download

36.10 Proposal or Application required?

No

36.11 DUA required?

No

36.12 Special Notes

- Requires registration
- Each project has it's separate site and documentation
- \bullet IPUMS USA harmonizes ACS and US Census microdata from 1850 to present.
- IPUMS Health Surveys harmonizes data from NHIS (1963-[resent) and MEPS (1996- present)

Kids' Inpatient Database (KID)

37.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

37.2 Website

https://www.hcup-us.ahrq.gov/db/nation/kid/kiddbdocumentation.jsp

37.3 Description

- Only all-payer (private insurance, Medicaid, Medicare, and uninsured) pediatric inpatient care database in the United States, containing data from two to three million hospital stays
- Sample of pediatric (age 20 or younger at admission) discharges from community, non- rehabilitation hospitals in participating states
- Used for developing national and regional estimates and analyzing rare conditions and uncommon treatments
- Wide range of topics including economic burden, access to services, quality
 of care, patient safety, impact of health policy changes

37.4 Vintage/Release Frequency

Triennial for 1997-2012 and 2016-present

37.5 Observational Unit

Hospital inpatient admission

37.6 Collection Methodology

- Capture four files: inpatient core file containing pediatric discharges sampled from participating HCUP hospitals (contains linkage variables, demographics, clinic information, and payment information); hospital file containing linkage variables and basic information about the hospital; disease severity measures file; and, the diagnosis and procedure group files.
- State-level inpatient databases serve as sampling frame for KID
- Select stratified sample (uncomplicated in-hospital births, complicated in-hospital births, all other pediatric hospital stays), oversampling in last two groups

37.7 Available at

Purchase at https://hcup-us.ahrq.gov/tech_assist/centdist.jsp

37.8 User Guide/Data Dictionary

- $\bullet \ \ Data\ elements\ are\ available\ at\ https://www.hcup-\ us.ahrq.gov/db/nation/kid/kiddde.jsp$
- Also see https://hcup-us.ahrq.gov/db/nation/kid/kiddbdocumentation.jsp

37.9 Cost

Cost varies by year

37.10 Proposal or Application required?

Application form required

37.11 DUA required?

Yes

37.12 Special Notes

• Hospital discharge data uses ICD codes. 2012 and earlier use ICD-9 while 2016 and later years use ICD- 10.

- \bullet KID 2015 was skipped by HCUP due to the transition from ICD-9 to ICD-10 that year; 2016 released instead
- Cannot be used to conduct state-level analyses
- Before publishing with any HCUP database, ensure manuscript follows requirements of the HCUP DUA and includes the appropriate citation (see https://www.hcup- us.ahrq.gov/db/publishing.jsp)

Medical Expenditure Panel Survey (MEPS)

38.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

38.2 Website

https://www.meps.ahrq.gov/mepsweb/

38.3 Description

- Large-scale surveys of families and individuals, their medical providers, and employers across US capturing data on cost and use of health care and health insurance.
- Two major components: household component (all members of selected households), containing demographics, health conditions, health status, use of medical services, charges and sources of payments, access to care, satisfaction with care, health insurance coverage, income, and employment; and insurance component (selected private and public sector employers), containing number and types of plans offered, premiums, contributions by employers and employees, eligibility requirements, benefits associated with plans, and employer characteristics.
- Also has a medical provider component covering hospitals, physicians, home health care providers and pharmacies to supplement information

received through the household component.

38.4 Vintage/Release Frequency

Annually since 1996

38.5 Observational Unit

Person or family

38.6 Collection Methodology

- Household component involves nationally representative subsample of households that participated in prior year National Health Interview Survey
- New panel is selected year; each panel is followed for two years and interviewed 5 times
- Use computer assisted, personal interviewing

38.7 Available at

https://www.meps.ahrq.gov/mepsweb/data_stats/download_data_files.jsp

38.8 User Guide/Data Dictionary

https://www.meps.ahrq.gov/mepsweb/survey_comp/survey_questionnaires.js

38.9 Cost

Free

38.10 Proposal or Application required?

Not for public use files but yes for restricted use files.

38.11 DUA required?

Not for public use files but yes for restricted use files.

38.12 Special Notes

- Variable search tool and data tools available on website
- Publications search available on website
- Additional restricted data files require access to research data center.

4 CHAPTER 38. MEDICAL EXPENDITURE PANEL SURVEY (MEPS)

Medicare Current Beneficiary Survey (MCBS)

39.1 Organization

US Centers for Medicare and Medicaid Services (CMS)

39.2 Website

 $https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCB \\ S/index.html$

39.3 Description

- Longitudinal survey of nationally representative sample of Medicare population (beneficiaries 65 and over as well as beneficiaries with disabilities under 65)
- Designed to explore expenditures and sources of payment for services (copayments, deductibles, and non-covered services), ascertain all types of health insurance coverage and relate coverage to sources of payment, and trace outcomes over time (health status, Medicaid eligibility, source of care, etc.)

39.4 Vintage/Release Frequency

Annual since 2015

39.5 Observational Unit

Medicare beneficiary

39.6 Collection Methodology

- Three-stage cluster sample design
- Systematic random sampling with probability proportional to the conditional probabilities of selection with independently selection random start within each PSU, stratified by age and ethnicity
- Starting with 2015, beneficiaries eligible for Medicare Part A or B and enrolled anytime during sampling year were eligible for sample
- Hispanic beneficiaries living outside Puerto Rico oversampled
- For each panel sample, respondents are interviewed every 4 months over a 4 year period (maximum of 12 interviews)

39.7 Available at

https://www.cms.gov/research-statistics-data-and-systems/research/mcbs/codebooks

39.8 User Guide/Data Dictionary

Codebook and User Guide for publicly available files available at same website as data download

39.9 Cost

Free for download

39.10 Proposal or Application required?

No

39.11 DUA required?

No

39.12 Special Notes

NA

Medicare Fee for Service Parts A and B (MEDPAR)

40.1 Organization

US Centers for Medicare and Medicaid Services (CMS)

40.2 Website

https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/medicarefeeforsvcpartsab

40.3 Description

- Medicare home health utilization by state
- Medicare ranking for all short stay hospitals by discharges
- Medicare hospice utilization by state
- MEDPAR files by state and diagnosis related group (DRG), including total charges, covered charges, Medicare reimbursement, total days, number of discharges, and average total days for 100% of Medicare beneficiaries using hospital inpatient services
- BETOS
- Top Level II HCPCS Codes by charges and by services
- Expenditures and services by specialty

40.4 Vintage/Release Frequency

Varies, but generally, annual

40.5 Observational Unit

State

40.6 Collection Methodology

- Most hospitals are now paid a fixed amount, determined in advance, for the operating costs of each case according to one of approximately 500 Diagnosis Related Groups (DRGs). A discharge is assigned to a DRG based on diagnosis, surgery, patient age, discharge destination and sex. Each DRG has a weight established for it based primarily on Medicare billing and cost data. Each weight reflects the relative cost, across all hospitals, of treating cases classified in that DRG. The short stay hospital files include PPS exempt units (rehabilitation and psychiatric) and waiver state (Maryland) hospitals not paid under the PPS.
- MEDPAR files contain information for 100% of Medicare beneficiaries using hospital inpatient services.
- Data is provided by state and then by DRG for all short stay and inpatient hospitals for fiscal years 2005-2007.

40.7 Available at

https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/medicarefeeforsvcpartsab

40.8 User Guide/Data Dictionary

n/a

40.9 Cost

Free for download

40.10 Proposal or Application required?

No

40.11 DUA required?

No

40.12 Special Notes

n/a

 $4CHAPTER\ 40.\ \ MEDICARE\ FEE\ FOR\ SERVICE\ PARTS\ A\ AND\ B\ (MEDPAR)$

Metabolic and Bariatric Surgery Accreditation and Quality Improvement Program (MBSA-QIP)

41.1 Organization

American College of Surgeons

41.2 Website

https://www.facs.org/quality-programs/accreditation-and-verification/metabolic-and-bariatric-surgery-accreditation-and-quality-improvement-program/

41.3 Description

- The Participant Use Data File (PUF) is a Health Insurance Portability and Accountability Act (HIPAA)-compliant data file containing cases submitted to the Metabolic and Bariatric Surgery Accreditation and Quality Improvement Program (MBSAQIP®) Data Registry.
- The intended purpose of this file is to provide researchers at participating sites with a data resource they can use to investigate and advance the quality of care delivered to the metabolic and bariatric surgical patient through the analysis of cases captured by MBSAQIP.

41.4 Vintage/Release Frequency

Annual since 2015

41.5 Observational Unit

Patient

41.6 Collection Methodology

- MBSAQIP collects data on over 200 variables including preoperative risk factors, intraoperative variables, and 30-day postoperative mortality and morbidity outcomes for patients undergoing metabolic and bariatric surgical procedures in both the inpatient and outpatient setting.
- Required data elements are entered via a web-based data collection tool.
- Portions of the data may be automatically populated by a software program that was developed to extract data from the participating hospital's existing information systems.
- To ensure the data collected are of the highest quality, the MBSAQIP has
 developed a host of different training mechanisms for the MBSCRs and
 conducts a data integrity audit of selected participating centers, when
 warranted.

41.7 Available at

https://www.facs.org/quality-programs/accreditation-and-verification/metabolic-and-bariatric-surgery-accreditation-and-quality-improvement-program/participant-use-data-file-puf/

41.8 User Guide/Data Dictionary

https://www.facs.org/media/krbickhz/mbsaqip_puf_userguide_2021.pdf

41.9 Cost

No additional cost to employees of MBSAQIP participant centers

41.10 Proposal or Application required?

No

41.11 DUA required?

Yes

41.12 Special Notes

- The PUF does not identify hospitals, health care providers, or patients
- Significant changes to data files/collection were made in 1/2020
- The PUF consists of four distinct datasets which are referred to as main, reoperation, readmission, and intervention, respectively

4CHAPTER 41. METABOLIC AND BARIATRIC SURGERY ACCREDITATION AND QUALITY IM

Minority Health Social Vulnerability Index (MHSVI)

42.1 Organization

U.S Department of Health and Human Services Office of Minority Health & Center for Disease Control and Prevention

42.2 Website

https://www.minorityhealth.hhs.gov/minority-health-svi/

42.3 Description

- An extension of the CDC SVI that combines the 15 social factors included in the original CDC SVI with additional factors known to be associated with COVID-19 outcomes
- Covers 6 themes: Socioeconomic Status, Household Composition and Disability, Minority Status and Language, Housing Type and Transportation, Health Care Infrastructure and Access, and Medical Vulnerability
- The MHSVI expands the SVI's Minority Status and Language theme by including statistics for the five racial/ethnic minority groups currently defined by the 1997 OMB Directive 15 and the top five languages spoken by limited English proficient (LEP) populations at the county level
- Can be used to apply a health equity lens to research, strategic planning, program design, and evaluation related to response and recovery for

COVID-19 and other public health emergencies

42.4 Vintage/Release Frequency

2018

42.5 Observational Unit

Geographical unit (available at county level)

42.6 Collection Methodology

Details can be seen at https://www.minorityhealth.hhs.gov/minority-health-svi/assets/downloads/MH%20SVI%20Overview_11.19.2021.pdf

42.7 Available at

https://www.minorityhealth.hhs.gov/minority-health-svi/

42.8 User Guide/Data Dictionary

 $https://onemap.cdc.gov/Portal/sharing/rest/content/items/b284e468b099404\\ 3b9d1eaf7756aa35b/data$

42.9 Cost

Free for download

42.10 Proposal or Application required?

No

42.11 DUA required?

No

42.12 Special Notes

• 0 (least vulnerable) to 1 (most vulnerable)

• Suggested citation: Centers for Disease Control and Prevention; U.S. Department of Health and Human Services; Agency for Toxic Substances and Disease Registry. Minority Health Social Vulnerability Index 2018. https://www.minorityhealth.hhs.gov/minority-health-svi/. Accessed on [Insert date].

 $4CHAPTER\ 42.\ MINORITY\ HEALTH\ SOCIAL\ VULNERABILITY\ INDEX\ (MHSVI)$

National Adult Tobacco Survey (NATS)

43.1 Organization

Office of Smoking and Health (OSH), CDC

43.2 Website

https://www.cdc.gov/tobacco/data_statistics/surveys/nats/index.htm

43.3 Description

- Used to assess prevalence of tobacco use
- Used to explore factors promoting and impeding tobacco use

43.4 Vintage/Release Frequency

2009-2010, 2012-2013, 2013-2014

43.5 Observational Unit

US adult

43.6 Collection Methodology

- Stratified, national, landline and cell phone survey of non-institutionalized adults aged 18 years and older in the US
- Produces representative and comparable data at national and state levels
- Provides national estimates by gender, age, and race/ethnicity

43.7 Available at

https://www.cdc.gov/tobacco/data_statistics/surveys/nats/index.htm

43.8 User Guide/Data Dictionary

Codebook, questionnaire and other documentation available at same website as data download

43.9 Cost

Free for download

43.10 Proposal or Application required?

No

43.11 DUA required?

No

43.12 Special Notes

n/a

National Ambulatory Medical Care Survey (NAMCS)

44.1 Organization

National Center for Health Statistics (NCHS), CDC

44.2 Website

https://www.cdc.gov/nchs/ahcd/index.htm

44.3 Description

- Information about the provision and use of ambulatory medical care services in US
- Data includes patient characteristics (e.g. age, sex, race/ethnicity), visit characteristics (e.g. reason for visit, diagnosis, services ordered and provided, treatments) and physician and practice characteristics

44.4 Vintage/Release Frequency

Annual 1993-2016, 2018-2019

Visit to described physician

44.6 Collection Methodology

- National sample of visits to non-federally employed office-based physicians who are primary engaged in direct patient care in US
- · Excludes anesthesiology, pathology, and radiology
- Separate sample of community health centers added in 2006 (visits to physicians and non-physician clinicians)
- Each physician reports on a systematic random sample of visits during a randomly assigned 1-week reporting period
- Because of methodology changes, 2017 is still being harmonized. See https://www.cdc.gov/nchs/ahcd/notice.htm

44.7 Available at

https://www.cdc.gov/nchs/ahcd/datasets_documentation_related.htm

44.8 User Guide/Data Dictionary

Documentation available at the same website as data download

44.9 Cost

Free for download

44.10 Proposal or Application required?

No

44.11 DUA required?

No

44.12 Special Notes

- See National Hospital Ambulatory Medical Care Survey (NHAMCS) for related survey directed at the facility rather than the physician.
- — See https://www.cdc.gov/nchs/ahcd/notice.htm for data notices.

National Beneficiary Survey (NBS)

45.1 Organization

Social Security Administration

45.2 Website

https://www.ssa.gov/disabilityresearch/nbs.html

45.3 Description

- The National Beneficiary Survey (NBS), sponsored by our Office of Retirement and Disability Policy, provides SSA, Congress, other policymakers, and researchers with information about key health, employment, and socio-demographic factors that contribute to Social Security Disability Insurance (SSDI) beneficiaries' and Supplemental Security Income (SSI) recipients' successful or unsuccessful employment efforts.
- The NBS collects data on a wide range of variables not available in the agency's administrative systems, including socio-demographic information, health and functional status, health insurance, interest in work, barriers to work, use of services, employment, income, and experience with Social Security programs.

45.4 Vintage/Release Frequency

2004, 2005, 2006, 2010, 2015, 2017 and 2019

SSDI respondent/SSI recipient

45.6 Collection Methodology

- Nationally representative sample of adult SSDI beneficiaries and SSI recipients.
- The survey is conducted using computer-assisted telephone interviewing (CATI). For beneficiaries who do not respond to the CATI interview or who prefer or require an in-person interview, we follow up using computer-assisted personal interviewing (CAPI).

45.7 Available at

https://www.ssa.gov/disabilityresearch/publicusefiles.html#tag2

45.8 User Guide/Data Dictionary

Each round has documentation on the specific download page

45.9 Cost

Free for download

45.10 Proposal or Application required?

No

45.11 DUA required?

No

45.12 Special Notes

n/a

National Cancer Database (NCDB)

46.1 Organization

American College of Surgeons (ACS), American Cancer Society

46.2 Website

https://www.facs.org/quality-programs/cancer/ncdb

46.3 Description

- Clinical oncology database sourced from hospital registry data
- Collected in more than 1500 Commission on Cancer (CoC)-accredited facilities in US $\,$
- Represent more than 70% of newly diagnosed cancer cases nationwide
- Used to analyze and track patients with malignant neoplastic diseases, their treatments, and outcomes
- Used to explore trends in cancer care, create regional and state benchmarks, and serve as basis for quality improvement
- Data includes patient characteristics, cancer staging and tumor histological characteristics, type of first course treatment administered, and outcomes information

46.4 Vintage/Release Frequency

Annual since 2004

Patient

46.6 Collection Methodology

• Data elements are collected and submitted to the NCDB from CoCaccredited cancer program registries using nationally standardized data item and coding definitions and nationally standardized data transmission format specifications coordinated by the North American Association of Central Cancer Registries

46.7 Available at

Participant User Files (PUF) are available upon request, but must coincide with an announced application period. More information can be found here: https://www.facs.org/quality-programs/cancer/ncdb/puf

46.8 User Guide/Data Dictionary

A data dictionary and other documentation are available at the same website as PUF information

46.9 Cost

Free through an application process to investigators associated with CoC-accredited cancer programs

46.10 Proposal or Application required?

Yes

46.11 DUA required?

Yes

46.12 Special Notes

- Data can be queried using the NCBD Public Benchmark Reports for cases diagnosed 2009- 2018 at https://reportsncdb.facs.org/BMPub/
- Data request must coincide with application period

National Crime Victimization Survey (NCVS)

47.1 Organization

Bureau of Justice Statistics (BJS)

47.2 Website

https://www.icpsr.umich.edu/icpsrweb/NACJD/series/95

47.3 Description

- Captures detailed information about the victims and consequences of crime
- Estimates number and types of crimes not reported to police
- Provides uniform measures of selected types of crime
- Data includes type of crime, severity of crime, injuries or losses, time and place of occurrence, medical expenses, characteristics of offender(s), demographic information of respondent

47.4 Vintage/Release Frequency

Annual since 1992

Person

47.6 Collection Methodology

- Stratified, multistage cluster sample of US households
- All persons 12 years of age or older in household are interviewed
- Asked if a victim of a crime (including rape, robbery, assault, burglary, larceny, and motor vehicle theft) during six-months prior to interview date
- Person-level files include full sample of victims and 10% sample of nonvictims for up to four incidents
- 6 quarters of data comprise and annual file (all four quarters of the designated year as well as the first two quarters of the subsequent year

47.7 Available at

- Select specific studies and publications at https://www.icpsr.umich.edu/web/NACJD/series/95 .
- Select data free for download at https://www.icpsr.umich.edu/web/page s/NACJD/discover-data.html

47.8 User Guide/Data Dictionary

Documentation are available at the same website as data download

47.9 Cost

Free for download

47.10 Proposal or Application required?

No

47.11 DUA required?

No

47.12 Special Notes

There is also a learning guide available for the NCVS at https://www.icpsr.umich.edu/icpsrweb/content/NACJD/guides/victimization/index.html and a

resource guide at https://www.icpsr.umich.edu/web/pages/NACJD/NCVS/i ndex.html

4 CHAPTER 47. NATIONAL CRIME VICTIMIZATION SURVEY (NCVS)

National Emissions Inventory (NEI)

48.1 Organization

Environmental Protection Agency (EPA)

48.2 Website

https://www.epa.gov/air-emissions-inventories/national-emissions-inventory-nei

48.3 Description

- Estimate of air emissions of criteria pollutants, criteria precursors, and hazardous air pollutants from air emissions sources
- Emissions estimates from point sources (e.g. large industrial facilities, electric power plants, airports), nonpoint sources (e.g. residential heating, commercial combustion, asphalt paving), onroad sources (e.g. light duty vehicles, heavy duty vehicles), nonroad sources (e.g. construction equipment, lawn and garden equipment, locomotives), and event sources (e.g. fires)

48.4 Vintage/Release Frequency

Annual 1996-2005 and Triennial since 2008

County level

48.6 Collection Methodology

- Data provided by State, Local, and Tribal air agencies for sources in their jurisdictions and supplemented by data developed by the US EPA
- Built using the Emissions Inventory System (EIS) first to collect the data from State, Local, and Tribal air agencies and then to blend that data with other data sources

48.7 Available at

 ${\rm https://www.epa.gov/air-emissions-inventories/national-emissions-inventory-nei}$

48.8 User Guide/Data Dictionary

Supporting documentation available at the same website as data download

48.9 Cost

Free for download

48.10 Proposal or Application required?

No

48.11 DUA required?

No

48.12 Special Notes

n/a

National Environmental Public Health Tracking Network

49.1 Organization

National Center for Environmental Health (NCEH), CDC

49.2 Website

https://ephtracking.cdc.gov/showHome

49.3 Description

- Combines health and environment data from national, state, and city sources
- Information on environments and hazards, health effects, and population health (air quality, asthma, biomonitoring, birth defects, cancer, carbon monoxide poisoning, childhood cancers, childhood lead poisoning, chronic obstructive pulmonary disease, climate change, community characteristics, community design, community water, developmental disabilities, drought, heart disease, heat stress illness, lifestyle risk factors, pesticide exposures, populations and vulnerabilities, reproductive and birth outcomes, sunlight and UV, toxic substances release)

49.4 Vintage/Release Frequency

Annual but varies depending on measures

49.5 Observational Unit

County or census tract, state (geographic unit depending on the measure selected

49.6 Collection Methodology

• Varies https://ephtracking.cdc.gov/indicatorPages

49.7 Available at

Can use the data explorer to generate county-level data that can be downloaded for use at https://ephtracking.cdc.gov/DataExplorer/#/ Downloadable data sets are available at https://ephtracking.cdc.gov/download

49.8 User Guide/Data Dictionary

No data dictionary but can find information for each indicator under https://ephtracking.cdc.gov/indicatorPages

49.9 Cost

Free

49.10 Proposal or Application required?

No

49.11 DUA required?

No

49.12 Special Notes

Fact sheets, infographics, learning resources, publications and data resources are linked at https://www.cdc.gov/nceh/tracking/resources.htm?

National Health and Aging Trends Study (NHATS)

50.1 Organization

Johns Hopkins University Bloomberg School of Public Health

50.2 Website

https://www.nhats.org/scripts/default.htm

50.3 Description

- Used for research to reduce disability, maximize health and independent functioning, and enhance quality of life at older ages
- Allows for study of national disability trends as well as individual trajectories
- Topics include physical, social, technological, and service environment; physical and cognitive capacity; use of assistive devices and rehabilitation; help received with daily activities (self-care, household, medical); participation in valued activities; wellbeing; and, quality of end of life care. Also experiences during COVID outbreak

50.4 Vintage/Release Frequency

annual starting in 2011

Person-level

50.6 Collection Methodology

- Nationally representative sample of Medicare beneficiaries 65 and older
- Stratified three-stage sample (counties or groups of counties, zip codes or zip code fragments, Medicare beneficiary)
- Sample refreshed periodically (2011 and 2015)

50.7 Available at

- Public Use Files (PUFs) are free for download with registration at https://www.nhatsdata.org/
- Sensitive and restricted use data files require an application process described at https://www.nhatsdata.org/ResDataFiles.aspx

50.8 User Guide/Data Dictionary

User guide and other data documentation available at https://www.nhats.org/scripts/dataDocum.htm

50.9 Cost

Free

50.10 Proposal or Application required?

All files require registration. Sensitive and restricted files require an additional application.

50.11 DUA required?

Restricted files require DUA as noted under https://www.nhats.org/researcher/data-access/sensitive-data-files?id=nsoc_other_sensitive_files

50.12 Special Notes

User registration for access is necessary at https://www.nhats.org/researcher/data-access

National Health and Nutrition Epidemiological Survey (NHANES)

51.1 Organization

National Center for Health Statistics (NCHS), CDC

51.2 Website

https://www.cdc.gov/nchs/nhanes/index.htm

51.3 Description

- Program of studies designed to assess the health and nutritional status of adults and children in the US
- Combines interviews and physical examinations
- Interview topics include demographics, socioeconomics, diet, and health while examination topics include medical, dental, physiological, and laboratory
- Medical conditions and health indicators include anemia, cardiovascular disease, diabetes, environmental exposures, eye diseases, hearing loss, infectious diseases, kidney disease, nutrition, obesity, oral health, osteoporosis, physical fitness and physical functioning, reproductive history and sexual behavior, respiratory disease, sexually transmitted diseases and vision

- Some risk factors include smoking, alcohol consumption, sexual practices, drug use, physical fitness and activity weight, and dietary intake
- Used to estimate number and percentage of US population with diseases and risk factors, monitor trends in risk behaviors and exposures as well as prevalence, control and treatment of outcomes, among other aims

51.4 Vintage/Release Frequency

2-year cycles released every 2 years since 2000

51.5 Observational Unit

Person

51.6 Collection Methodology

- Nationally representative sample of resident, civilian, non-institutionalized US population
- Four-stage sample design
- Questionnaire and health examination using mobile examination center
- Over-sampling was performed but varied from sample to sample
- COVID affected data collection for 2019-2020 cycle collected data are not nationally representative; they've released special 2017-2020 pre pandemic data files that are nationally representative

51.7 Available at

https://wwwn.cdc.gov/nchs/nhanes/default.aspx

51.8 User Guide/Data Dictionary

Available in website by cycle and file/component

51.9 Cost

Free

51.10 Proposal or Application required?

Not for public use files but yes for restricted use files.

51.11 DUA required?

Not for public use files but yes for restricted use files.

51.12 Special Notes

- Other versions of NHANES were conducted prior to 1999. See the website for more details and to access the data.
- Additional restricted data files require access to research data center.

4CHAPTER 51. NATIONAL HEALTH AND NUTRITION EPIDEMIOLOGICAL SURVEY (NHANES

National Health Interview Survey (NHIS)

52.1 Organization

National Center for Health Statistics (NCHS), CDC

52.2 Website

www.cdc.gov/nchs/nhis.htm

52.3 Description

- Used to track health status, health care access, and progress toward achieving national health objectives in US civilian non-institutionalized population
- Includes basic health and demographic items and one or more sets of questions on current health topics with major health topics including physical and mental health status, chronic conditions including asthma and diabetes, access to and use of health care services, health insurance coverage and type, behaviors such as smoking, alcohol use, and physical activity, measures of functioning and activity limitations, and immunizations. Includes race and Hispanic origin, sexual orientation and veterans health information.

52.4 Vintage/Release Frequency

Annual starting in 1997

Family, household, injury episode, person, sample child, sample adult

52.6 Collection Methodology

- Cross-sectional, household interview survey
- Sampling and interviewing continuous throughout each year
- Multistage area probability design (county/county group/metropolitan statistical area, address, adult and child)
- Four separate panels and each panel is representative of the US population

52.7 Available at

https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm

52.8 User Guide/Data Dictionary

Questionnaires and other documentation available at same website as data download $\,$

52.9 Cost

Free

52.10 Proposal or Application required?

No

52.11 DUA required?

No

52.12 Special Notes

Methodology has changed over time. In January 2019, NHIS launched a redesigned content and structure that differs from its previous questionnaire design (1997–2018).

National Hospital Ambulatory Medical Care Survey (NHAMCS)

53.1 Organization

National Center for Health Statistics (NCHS), CDC

53.2 Website

https://www.cdc.gov/nchs/ahcd/index.htm

53.3 Description

- Information about the provision and use of ambulatory medical care services in hospital emergency departments, outpatient departments, and ambulatory surgery centers in US
- Data includes patient characteristics (e.g. age, sex, race/ethnicity), visit characteristics (e.g. reason for visit, diagnosis, services ordered and provided, treatments) and physician and practice characteristics

53.4 Vintage/Release Frequency

Annual since 1992

Visit to described facility

53.6 Collection Methodology

- National sample of visits to emergency departments, outpatient departments, and ambulatory surgery locations in non-institutional, general, and short-stay hospitals in US
- Excludes Federal, military, and Veterans Administration hospitals
- Included only hospital emergency and outpatient departments from 1992-2008, ambulatory survey in hospitals was added in 2009, and ambulatory surgery performed in freestanding ambulatory surgery centers was add in 2010 (but suspended in 2013 to develop a new sampling frame)
- Four-stage probability sampling design used for emergency departments, outpatient departments, and ambulatory surgery locations (geographically defined areas, hospitals, clinics, and patient visits)
- Two-stage list sample design used for freestanding ambulatory survey component (facilities and patient visits)
- Each sampled facility selects systematic sample of patient visits from randomly selected 4-week reporting period

53.7 Available at

https://ftp.cdc.gov/pub/Health Statistics/NCHS/Datasets/NHAMCS/

53.8 User Guide/Data Dictionary

Documentation available at the same website as data download

53.9 Cost

Free for download

53.10 Proposal or Application required?

No

53.11 DUA required?

No

53.12 Special Notes

- See National Ambulatory Medical Care Survey (NAMCS) for related survey directed at the physician rather than the facility.
- $\bullet~$ NHAMCS will cease after the collection and processing of the 2022 annual data file.
- $\bullet~$ See https://www.cdc.gov/nchs/ahcd/notice.htm for data notices.

 $4 CHAPTER\ 53.\ \ NATIONAL\ HOSPITAL\ AMBULATORY\ MEDICAL\ CARE\ SURVEY\ (NHAMCS)$

National Household Travel Survey

54.1 Organization

Federal Highway Administration (FHWA)

54.2 Website

 $\rm https://nhts.ornl.gov/$

54.3 Description

- Data on individual and household travel behavior in the US linked to economic, demographic, and geographic factors
- Includes all modes of travel (private vehicle, public transportation, pedestrian, and cycling) and for all purposes (work, school, recreation, personal/family trips)
- Examples of use include describing current travel and developing trends over time, energy consumption, environmental concerns, travel of specific demographic groups, modeling and planning applications, and safety

54.4 Vintage/Release Frequency

Every few years starting in 1969, ongoing

Household-, person-, worker, vehicle-, and daily-travel level data

54.6 Collection Methodology

- Stratified (by geographic designation) random sample of US households
- Two-phase study (phase 1 household survey, phase 2 personal survey)
- Previous surveys have used random digit dialing telephone sampling and computer- assisted telephone interview data collection
- 2017 survey used address-based sampling with mail-back surveys as the primary mode of completion, and phone or web surveys as secondary modes of completion
- 2020 Origin—Destination (OD) leverage in-vehicle and smartphone application—generated passive mobility data to summarize travel, annualized trip counts for truck and passenger travel.

54.7 Available at

Free for download at https://nhts.ornl.gov/downloads

54.8 User Guide/Data Dictionary

Supporting documentation including data dictionary available at https://nhts.ornl.gov/documentation

54.9 Cost

Free

54.10 Proposal or Application required?

No

54.11 DUA required?

No

54.12 Special Notes

Also have a tool available for exploring data at the bottom of https://nhts.orn l.gov/?

National Immunization Survey (NIS) (Child/Teen)

55.1 Organization

National Center for Immunization and Respiratory Diseases (NCIRD), CDC

55.2 Website

https://www.cdc.gov/vaccines/imz-managers/nis/data-tables.html

55.3 Description

- Used to monitory vaccination coverage among children 19-35 months and teens 13-17 years and flu vaccinations for children 6 months-17 years
- Provides current, population-based state and local area estimates of vaccination coverage in US
- Includes information on type of vaccination, number of doses, dates of administration, and administrative data about the healthcare facility where vaccines provided

55.4 Vintage/Release Frequency

yearly 2008-current (teen), and 1995-current (child)

55.5 Observational Unit

Person-level (child or teen)

55.6 Collection Methodology

- Dual frame random digit dialing telephone survey design, including landline and cell phone numbers along with provider record check survey
- Household telephone survey of parent or guardian
- Mail survey of vaccination provider

55.7 Available at

Free for download at https://www.cdc.gov/vaccines/imz-managers/nis/dataset s.html (child) and https://www.cdc.gov/vaccines/imz-managers/nis/datasets-teen.html (teen)

55.8 User Guide/Data Dictionary

Complete supporting documentation available at same website as data download

55.9 Cost

Free

55.10 Proposal or Application required?

No

55.11 DUA required?

No

55.12 Special Notes

NA

National Inpatient Sample (NIS)

56.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

56.2 Website

https://www.hcup-us.ahrq.gov/nisoverview.jsp

56.3 Description

- Largest publicly available all-payer inpatient health care database in the US
- Allows for national estimates of hospital inpatient stays
- Used to make national estimates of health care utilization, access, charges, quality, and outcomes and explore trends over time
- Topics promoted include utilization of health services by special populations, hospital stays for rare conditions, variations in medical practice, health care cost inflation, regional and national analyses, quality of care and patient safety, impact of health policy changes, and access to care

56.4 Vintage/Release Frequency

Annually since 1988

56.5 Observational Unit

Hospital inpatient admission

56.6 Collection Methodology

- Twenty percent stratified sample of all discharges form US community hospitals (excludes rehabilitation and long-term acute care hospitals)
- Most recently includes 46 states and DC (started with 8 states in first year)
- Includes all patients regardless of payer (Medicare, Medicaid, private, uninsured)
- Sampled from the State Inpatient Databases (SID) now a sample of discharge records from all HCUP-participating hospitals
- Four files: inpatient core file (e.g. age, total charges, expected primary payer); diagnosis and procedure groups file (ICD-9 and ICD-10 codes for diagnosis and procedure); disease severity measures file (ICD-9 and ICD-10 codes for disease severity); hospital weights file (hospital characteristics)

56.7 Available at

https://www.hcup-us.ahrq.gov/tech_assist/centdist.jsp

56.8 User Guide/Data Dictionary

https://www.hcup-us.ahrq.gov/db/nation/nis/nisdbdocumentation.jsp

56.9 Cost

Cost varies by year

56.10 Proposal or Application required?

Application form required

56.11 DUA required?

Yes

- In 2015, the diagnosis and procedure groups file as well as the disease severity measures file are split into two files (January September for ICD-9 codes and October December for ICD-10 codes)
- There was a change in design in 2012; read documentation describing changes in methodology over time if conducting longitudinal data analyses.
- Data Use Training must be completed and must sign Data Use Agreement
- Before publishing with any HCUP database, ensure manuscript follows requirements of the HCUP DUA and includes the appropriate citation (see https://www.hcup- us.ahrq.gov/db/publishing.jsp)

National Longitudinal Survey of Mature and Young Women

57.1 Organization

Bureau of Labor Statistics

57.2 Website

https://www.nlsinfo.org/content/cohorts/mature-and-young-women

- De-identified, patient-level
- Longitudinal survey
- Mature Women's Cohort:
- Born between 1922-1937 (Aged 30-44 when first interviewed in 1967)
- Yong Women's cohort:
- Born between 1943-1953 (Aged 14-24 when first interviewed in 1968)
- Custom data file built using Investigator (query tool) or full data download,
- $\bullet\,$ Some restricted-use data available upon request

57.4 Vintage/Release Frequency

Discontinued study. 1967 to 2003 for older cohort and 1968 to 2003 for younger cohort

57.5 Observational Unit

Cases (patient-level) collected by interviews/questionnaires

57.6 Collection Methodology

• Data collected by interviews and questionnaires. See data collection information in their webpage https://www.nlsinfo.org/content/cohorts/mature-and-young-women/intro-to-the-sample/retention-and-reasons-non-interview

57.7 Available at

Free for download at https://www.nlsinfo.org/investigator/pages/search.jsp? $s{=}NLSW$

57.8 User Guide/Data Dictionary

https://www.nlsinfo.org/content/cohorts/mature-and-young-women/using-and- understanding-the-data

57.9 Cost

Free

57.10 Proposal or Application required?

No

57.11 DUA required?

No

- Active surveying has been discontinued.
- A set of cross-sectional weights for each survey round.

National Longitudinal Survey of Older and Young Men

58.1 Organization

Bureau of Labor Statistics

58.2 Website

https://www.nlsinfo.org/content/cohorts/older-and-young-men

- De-identified, patient-level
- Longitudinal survey
- Older Men's Cohort:
- Born between 1906-1921 (Aged 45-59 when first interviewed in 1966)
- Yong men's cohort:
- Born between 1941-1952 (Aged 14-24 when first interviewed in 1966)
- Custom data file built using Investigator (query tool) or full data download,
- Some restricted-use data available upon request

58.4 Vintage/Release Frequency

Discontinued study. 1966 to 1983 for older cohort (with 1990 widow interview) and 1966 to 1981 for younger cohort

58.5 Observational Unit

Cases (patient-level) collected by interviews/questionnaires

58.6 Collection Methodology

- Data collected by interviews and questionnaires
- Young men were surveyed annually between through 1971 and then were surveyed 3 years out of 5 until 1981.
- Older men were surveyed annually through 1969 and then 3 years out of 5 until 1986. A final interview was conducted in 1990 with living respondents and widows or other family members of deceased respondents.

58.7 Available at

Free for download at https://www.nlsinfo.org/investigator/pages/search.jsp? $s{=}NLSM$

58.8 User Guide/Data Dictionary

 $https://www.nlsinfo.org/content/cohorts/older-and-young-men/using-and-understanding-the-\ data$

58.9 Cost

Free

58.10 Proposal or Application required?

No

58.11 DUA required?

No

- $\bullet\,$ Active surveying has been discontinued.
- A set of cross-sectional weights for each survey round.

4CHAPTER 58. NATIONAL LONGITUDINAL SURVEY OF OLDER AND YOUNG MEN

National Longitudinal Survey of Youth 1979 (NLSY79)

59.1 Organization

Bureau of Labor Statistics

59.2 Website

https://www.nlsinfo.org/content/cohorts/nlsy79

- De-identified, patient-level
- Longitudinal survey
- Respondents were 14-22 years old when first interviewed in 1979
- There are 3 independent probability subsamples:
- cross-sectional sample designed to represent the noninstitutionalized civilians
- a supplemental sample of Hispanic or Latino, black and disadvantaged nonblack/non- Hispanic respondents
- a sample of respondents designed to represent the population serving in one of the four branches of the U.S. military
- Thousands of variables covering topics such as education, training and achievement scores, employment, household, geography, dating, marriage, health, etc.

2CHAPTER 59. NATIONAL LONGITUDINAL SURVEY OF YOUTH 1979 (NLSY79)

- Custom data file built using Investigator (query tool) or full data download
- Some restricted-use data available upon request

59.4 Vintage/Release Frequency

Round 1 (1979) to Round 29 (2020) with annual follow-up for participants

59.5 Observational Unit

Cases (patient-level) collected by interviews/questionnaires

59.6 Collection Methodology

- Nationally representative sample of men and women born between 1957-64
- All youths who completed the 1st round are considered respondents
- During each round, there is an attempt to reach all youths within the active sample
- Data is collected via questionnaires and interviews

59.7 Available at

https://www.nlsinfo.org/content/access-data-investigator

59.8 User Guide/Data Dictionary

https://www.nlsinfo.org/content/cohorts/nlsy79/using-and-understanding-the-data

59.9 Cost

Free for download

59.10 Proposal or Application required?

No

59.11 DUA required?

No

- $\bullet\,$ Registration required for download
- A set of cross-sectional weights for each survey round.
- • Customized weights for longitudinal research can be created online (https://www.nlsinfo.org/weights/nlsy79)

 $4 CHAPTER\ 59.\ \ NATIONAL\ LONGITUDINAL\ SURVEY\ OF\ YOUTH\ 1979\ (NLSY79)$

National Longitudinal Survey of Youth 1979 Child and Young Adult (NLSYCYA)

60.1 Organization

Bureau of Labor Statistics

60.2 Website

https://www.nlsinfo.org/content/cohorts/nlsy79-children

- De-identified, patient-level
- Longitudinal survey
- Respondents are biological children of the women in NLS79
- Child survey:
- Children are assessed and interviewed every 2 years
- The assessments measure cognitive ability, temperament, motor and social development, behavior problems, and self-competence of the children as well as the quality of their home environment
- Data also collected form child's mother
- Young Adult Survey:

- Starting in 1994 children 15 years and older complete interview modeled on NLSY79 questionnaires
- Information collected from these Young Adults includes education, training, employment, health, dating, fertility and parenting, marriage and cohabitation, household composition, and social-psychological indicators
- Custom data file built using Investigator (query tool) or full data download
- Some restricted-use data available upon request

60.4 Vintage/Release Frequency

Biennial (for the most part)

60.5 Observational Unit

Cases (patient-level) collected by interviews/questionnaires

60.6 Collection Methodology

- See Sample Design, and Sample Sizes: Who Was Interviewed in the Current Survey Round? in their webpage https://www.nlsinfo.org/content/cohorts/nlsy79-children/intro-to-the-sample/sample-design
- See Interview Methods https://www.nlsinfo.org/content/cohorts/nlsy79-children/intro-to-the-sample/interview-methods

60.7 Available at

Free for download at https://www.nlsinfo.org/investigator/pages/search.jsp? $s{=}NLSCYA$

60.8 User Guide/Data Dictionary

https://www.nlsinfo.org/content/cohorts/nlsy79-children/using-and-understanding-the-data

60.9 Cost

Free

60.10 Proposal or Application required?

No

60.11 DUA required?

No

- Appropriate sample weights are available in each year to adjust the unweighted sample cases for the minority oversamples and year-to-year sample attrition
- Sample weights for generating population estimates also available.
- There is a mother and a child sampling weight.
- Customized weights for longitudinal research can be created online (https://www.nlsinfo.org/weights/nlscya)
- Beginning in 2002, a new algorithm was used to create weights; there are revised weights for prior years using this same algorithm.
- A child identification code (CPUBID, C00001.00) allows to link children with their siblings in NLSYCY and with their mother in NLSY79.
- The panel dimension of the NLSY79 data collection permits one to cumulate sample cases for children at specified ages across survey points but this limits the ability to follow a particular age cohort across survey years.

4CHAPTER 60. NATIONAL LONGITUDINAL SURVEY OF YOUTH 1979 CHILD AND YOUNG AD

National Longitudinal Survey of Youth 1997 (NLSY97)

61.1 Organization

Bureau of Labor Statistics

61.2 Website

https://www.nlsinfo.org/content/cohorts/nlsy97

- De-identified, patient-level
- Longitudinal survey
- Respondents were 12-17 years old when first interviewed in 1997
- Thousands of variables covering topics such as education, training and achievement scores, employment, household, geography, dating, marriage, health, etc.
- Custom data file built using Investigator (query tool) or full data download
- Some restricted-use data available upon request

61.4 Vintage/Release Frequency

Round 1 (1997-1998) to Round 19 (2019-2020) with annual follow-up of participants

61.5 Observational Unit

Cases (patient-level) collected by interviews/questionnaires

61.6 Collection Methodology

- Nationally representative sample of youths born between 1980-84
- Upon enrollment youth and one parent receive 1-hour long personal interview
- Youths are interviewed on an annual basis after that
- Data is collected via questionnaires and interviews
- After each round, ~10% of interviews are randomly chosen for validation by re- interviewing the subject.

61.7 Available at

https://www.nlsinfo.org/content/access-data-investigator

61.8 User Guide/Data Dictionary

https://www.nlsinfo.org/content/cohorts/nlsy97/using-and-understanding-the-data

61.9 Cost

Free for download

61.10 Proposal or Application required?

No

61.11 DUA required?

No

- A set of cross-sectional weights for each survey round.
- Customized weights for longitudinal research can be created online (https://www.nlsinfo.org/weights/nlsy97)

 $4 CHAPTER\ 61.\ \ NATIONAL\ LONGITUDINAL\ SURVEY\ OF\ YOUTH\ 1997\ (NLSY97)$

National Mental Health Services Survey (N-MHSS)

62.1 Organization

Substance Abuse and Mental Health Services Administration (SAMHSA)

62.2 Website

https://www.datafiles.samhsa.gov/

- Annual collection of information on the services and characteristics of all known mental health treatment facilities in the US
- Biennial collection of information on numbers and demographics of persons served in these treatment facilities, starting in 2015
- Includes public and private psychiatric hospitals, non-federal general hospitals with separate psychiatric units, US Department of Veterans Affairs medical centers, residential treatment centers for children and for adults, community mental health centers, outpatient or day treatment or partial hospitalization mental health facilities, multi-setting (non-hospital) mental health facilities
- Used to populate the mental health component of SAMHSA's online Behavioral Health Treatment Services Locator

62.4 Vintage/Release Frequency

NA

62.5 Observational Unit

Mental health treatment facility

62.6 Collection Methodology

Mail questionnaire

62.7 Available at

https://www.datafiles.samhsa.gov/dataset/national-mental-health-services-survey-2020-n-mhss-2020-ds0001

62.8 User Guide/Data Dictionary

Codebook and questionnaire available at same website as data download

62.9 Cost

Free for download

62.10 Proposal or Application required?

No

62.11 DUA required?

No

62.12 Special Notes

n/a

National Survey of Children's Health (NSCH)

63.1 Organization

US Census Bureau

63.2 Website

https://www.census.gov/programs-surveys/nsch.html

63.3 Description

- De-identified, patient-level, aggregate data
- Survey examines the physical and emotional health of children ages 0-17
- 3 separate files (screener, topical and implicate)
- Data resource center allows to browse and see aggregate data (http://ch ildhealthdata.org/browse/survey)

63.4 Vintage/Release Frequency

Annual since 2016

63.5 Observational Unit

Household and child-level

63.6 Collection Methodology

- Sample of children under the age of 18 was developed from Edited Master Address File Extract and a file of administrative flags that was created by of the Bureau's Center for Administrative Records Research and Applications
- Data collected via paper or web instrument questionnaires filled by parent or guardian
- The household completes one screener questionnaire then 1 child per household is selected to complete the detailed topical questionnaire

63.7 Available at

https://www.census.gov/programs-surveys/nsch/data.html

63.8 User Guide/Data Dictionary

 $https://www.census.gov/programs-surveys/nsch/technical-documentation.ht\ ml$

63.9 Cost

Free for download

63.10 Proposal or Application required?

No

63.11 DUA required?

No

- Through the DCD it seems the survey was also done in 2003, 2007, 2011/12 but these data are not in the census site.
- In 2016 there was a major redesign. As part of this, the National Survey of Children with Special Health Care Needs (NSCSHCN) and NSCH are combined into a single survey.
- CSHCN are oversampled
- Starting in 2016 the data is released annually
- Topical questionnaires are age specific (0-5, 6-11 and 12-17)
- They provide imputed values (multiple imputation)

National Survey of Family Growth (NSFG)

64.1 Organization

National Center for Health Statistics (NCHS), CDC

64.2 Website

https://www.cdc.gov/nchs/nsfg/index.htm

64.3 Description

- De-identified, patient-level
- Gathers information on family life, marriage and divorce, pregnancy, infertility, use of contraception, and men's and women's health
- In addition to the public uses files, there is additional data upon request.

 These files contain interviewer observations data and data about the data collection process

64.4 Vintage/Release Frequency

Annual or bi-annual starting in 1973

64.5 Observational Unit

Respondent-level

64.6 Collection Methodology

- A multi-stage probability-based, nationally representative sample of household population aged 15-44 (changed to 15-49 in later years)
- Data collected via in-person interviews

64.7 Available at

 $Free \ for \ download \ at \ https://www.cdc.gov/nchs/nsfg/nsfg_questionnaires.htm$

64.8 User Guide/Data Dictionary

Technical documentation available at same website as data download

64.9 Cost

Free

64.10 Proposal or Application required?

No

64.11 DUA required?

No

64.12 Special Notes

Certain populations are oversampled each cycle (mainly Blacks, Hispanics and Teens)

National Survey of Substance Abuse Treatment Services (N-SSATS)

65.1 Organization

Substance Abuse and Mental Health Services Administration (SAMHSA)

65.2 Website

https://www.datafiles.samhsa.gov/

- De-identified, center-level
- Collects data from public and private facilities that provide substance abuse treatment
- Data are collected on topics including facility operation, services offered (assessment and pre-treatment, pharmacotherapies, testing, transitional, ancillary), detoxification, primary focus (substance abuse, mental health, both, general health, and other), hotline operation, Opioid Treatment Programs and medications dispensed/prescribed, counseling and therapeutic approaches, languages in which treatment is provided, type of treatment provided, number of clients (total and under age 18), number of beds, types of payment accepted, sliding fee scale, special programs offered, facility accreditation and licensure/certification, and managed care agreements.

- Information on number of beds designated for treatment is collected only in "odd" years.
- One data file per year, some concatenated files are available that combine multiple years

65.4 Vintage/Release Frequency

NA

65.5 Observational Unit

Facility-level survey data

65.6 Collection Methodology

- Survey completed by facility
- In 2019 survey completion rate was 91%
- Data processing includes: consistency checks, standardization of missing values, recodes, calculation of derived variables, checks for undocumented or out-of-range codes.

65.7 Available at

https://www.datafiles.samhsa.gov/dataset/national-survey-substance-abuse-treatment-services-2020-n-ssats-2020-ds0001

65.8 User Guide/Data Dictionary

Dataset documentation available at same websites as data download

65.9 Cost

Free for download

65.10 Proposal or Application required?

No

65.11 DUA required?

No

65.12 Special Notes

 $\operatorname{N-SSATS}$ was called Uniform Facility Data Set (UFDS) in 1997 and 1998

4CHAPTER 65. NATIONAL SURVEY OF SUBSTANCE ABUSE TREATMENT SERVICES (N-SSAT

National Survey on Drug Use and Health (NSDUH)

66.1 Organization

Substance Abuse and Mental Health Services Administration (SAMHSA)

66.2 Website

https://www.datafiles.samhsa.gov/

66.3 Description

- De-identified, patient-level
- Source of statistical information on the use of illicit drugs, alcohol, and tobacco and on mental health issues among members of the U.S. civilian, non-institutional population aged 12 or older.
- The survey tracks trends in specific substance use and mental illness measures and assesses the consequences of these conditions by examining mental and/or substance use disorders and treatment for these disorders.
- One data file per year, some concatenated files are available that combine multiple years

66.4 Vintage/Release Frequency

NA

66.5 Observational Unit

Subject-level survey data

66.6 Collection Methodology

- Sample of civilian, non-institutionalized subjects aged 12 or older
- Sampling design changed in 1999 at which time they started using a 50-state design with an independent, multistage area probability sample for each of the 50 states and the District of Columbia
- There are some sampling changes across years (oversampling, weighting of states, etc.)
- Each NSDUH respondent since 2002 has been given an incentive payment of \$30.
- For selected variables, statistical imputation was performed following logical inference to replace missing responses. Variables are labeled "logically assigned" or "imputation-revised".
- To protect the privacy of respondents, all variables that could be used to identify individuals have been encrypted or collapsed in the public use file. To further ensure respondent confidentiality, the data producer used data substitution and deletion of state identifiers and a subsample of records in the creation of the public use file.

66.7 Available at

https://www.datafiles.samhsa.gov/dataset/national-survey-drug-use-and-health-2021-nsduh-2021-ds0001

66.8 User Guide/Data Dictionary

Dataset documentation available at same websites as data download

66.9 Cost

Free for download

66.10 Proposal or Application required?

No

66.11 DUA required?

No

- $\bullet\,$ NSDUH was called National Household Survey on Drug Abuse up to 2001
- $\bullet\,$ NSDUH restricted-use data files are available for online analysis with the R-DAS
- In 2002 and 2011 new population data from the 2000 and 2010 decennial Censuses, respectively, became available for use in NSDUH sample weighting procedures. Therefore the data from 2002 and later should not be compared with data collected in 2001 or earlier to assess changes over time. ?

 $4 CHAPTER\ 66.\ \ NATIONAL\ SURVEY\ ON\ DRUG\ USE\ AND\ HEALTH\ (NSDUH)$

National Violent Death Reporting System (NVDRS)

67.1 Organization

National Center for Injury Prevention and Control (NCIPC), CDC

67.2 Website

https://www.cdc.gov/violenceprevention/datasources/nvdrs/index.html

67.3 Description

- De-identified, multi-state, case-level microdata
- Uses short narratives to describe the circumstances related to violent deaths, including descriptions from law enforcement and medical examiner or coroner reports

67.4 Vintage/Release Frequency

Ongoing, started in 2002

67.5 Observational Unit

deaths resulting from violence

67.6 Collection Methodology

NVDRS collects facts from death certificates, coroner/medical examiner reports, law enforcement reports, and toxicology reports into one anonymous database. NVDRS data are stored in an incident-based, relational database.

67.7 Available at

Descriptive data is available at https://www.cdc.gov/injury/wisqars/index.h tml. More detailed Restricted Access Data (RAD) is available by request (free of cost); proposal submission/approvals required.

67.8 User Guide/Data Dictionary

https://www.cdc.gov/violenceprevention/datasources/nvdrs/resources.html

67.9 Cost

Free

67.10 Proposal or Application required?

For access to restricted data see https://www.cdc.gov/violenceprevention/datasources/nvdrs/dataaccess.html

67.11 DUA required?

NA

- To request NVDRS RAD the primary investigator must meet all of the following:
- Have a Ph.D., Dr. P.H., M.D., ScD, D.O., or other doctoral level degree
- Hold a research position or faculty appointment at his/her institution
- Home institution must be a research organization, government agency, or institution of higher education. This includes research foundations or grant-making organizations.
- Agreement to comply with NVDRS RAD security, confidentiality, and data protection requirements, as outlined during the review process?

National Vital Statistics

68.1 Organization

National Vital Statistics System (NVSS), CDC

68.2 Website

https://www.cdc.gov/nchs/nvss/index.htm

68.3 Description

- De-identified, patient-level, aggregate data
- Birth, Period-Linked Birth Infant Death, Birth Cohort Linked Birth Infant Death, Mortality Multiple Cause and Fetal Death files are available
- States and U.S. Territories data on separate files
- Request of customized micro-data files is possible by completing a project review form
- WONDER (https://wonder.cdc.gov/) allows querying of data online

68.4 Vintage/Release Frequency

Yearly, availability depends on measure (birth data and mortality data 1968 to current)

68.5 Observational Unit

Cases (patient-level)

68.6 Collection Methodology

- Data obtained from birth and death certificates
- They provide guidelines to jurisdictions on how to complete certificates
- In 2010 they centralized coding at the NCHS

68.7 Available at

Free for download at https://www.cdc.gov/nchs/data_access/vitalstatsonline. htm

68.8 User Guide/Data Dictionary

User guide available at same website as data download. Other documentation available at https://www.cdc.gov/nchs/nvss/mortality_methods.htm

68.9 Cost

Free

68.10 Proposal or Application required?

No

68.11 DUA required?

Implicit DUA when downloaded

68.12 Special Notes

NA

National Youth Tobacco Survey (NYTS)

69.1 Organization

Office of Smoking and Health (OSH), CDC

69.2 Website

https://www.cdc.gov/tobacco/data statistics/surveys/nyts/index.htm

69.3 Description

- Anonymous, respondent-level
- The NYTS was designed to provide national data on long-term, intermediate, and short- term indicators key to the design, implementation, and evaluation of comprehensive tobacco prevention and control programs.
- Items measured as part of the NYTS survey include to bacco-related beliefs, attitudes, behaviors, exposure to pro- and anti-to bacco influences and correlates of to bacco use such as demographics, minors' access to to bacco, and exposure to secondhand smoke.

69.4 Vintage/Release Frequency

1999-2000, 2002, 2004, 2006, 2009 and Annual since 2011

69.5 Observational Unit

Respondent-level survey data

69.6 Collection Methodology

- Sample of all middle and high school students in the 50 states and DC
- Stratified, three-stage cluster sample design. Sampling was probabilistic and without replacement.
- Primary sampling units were county or a group of small counties or part
 of a large county. Secondary units were schools and 3rd sampling unit was
 students within each selected school.
- Students completed an anonymous, self-administered paper questionnaire
- In 2020 school and student participation rates were 49.9% and 87.4%, respectively. Survey administration was stopped early due to widespread school closures as a result of COVID-19.

69.7 Available at

https://www.cdc.gov/tobacco/data_statistics/surveys/nyts/data/index.html

69.8 User Guide/Data Dictionary

Data documentation available at same website as data download

69.9 Cost

Free for download

69.10 Proposal or Application required?

No

69.11 DUA required?

No

69.12 Special Notes

n/a

Nationwide Ambulatory Surgery Sample (NASS)

70.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

70.2 Website

https://www.hcup-us.ahrq.gov/nassoverview.jsp

70.3 Description

- HIPPA-compliant, encounter-level
- Largest all-payer ambulatory surgery database in US. Yields national estimates of major ambulatory surgery encounters performed in hospital-owned facilities
- Three data files per year (Encounter, Hospital, Supplemental)

70.4 Vintage/Release Frequency

Annual since 2016

70.5 Observational Unit

Ambulatory surgery encounter

70.6 Collection Methodology

- Sampled from the State Ambulatory Surgery and Services Databases (SASD).
- Data from 2,699 hospital-owned facilities located in 31 States and the District of Columbia, approximating a 63-percent stratified sample of U.S. hospital-owned facilities performing selected ambulatory surgeries
- Stratification is based on geographic region, trauma center designation, urban-rural location, teaching hospitals and hospital ownership or control.

70.7 Available at

Available for purchase by year. CPHR has 2016-2019 data.

70.8 User Guide/Data Dictionary

https://www.hcup-us.ahrq.gov/db/nation/nass/nassdde.jsp

70.9 Cost

Cost varies by year

70.10 Proposal or Application required?

Application form required

70.11 DUA required?

Yes

- Query and classify patients using ICD-10 and/or CPT
- You cannot track a particular patient across multiple encounters
- All users must complete a Data Use Agreement Training and sign a DUA
- Before publishing with any HCUP database, ensure manuscript follows requirements of the HCUP DUA and includes the appropriate citation (see https://www.hcup- us.ahrq.gov/db/publishing.jsp)

Nationwide Emergency Department Sample (NEDS)

71.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

71.2 Website

https://www.hcup-us.ahrq.gov/nedsoverview.jsp

71.3 Description

- HIPPA-compliant, patient-level
- Discharge data for ED visits from 953 hospitals located in 34 States and the District of Columbia, approximating a 20-percent stratified sample of U.S. hospital-based EDs.
- Includes data on 1ry and 2ry diagnoses and procedures, discharge status, demographics, hospital characteristics, expected payment source, total charges, length of stay and severity and comorbidity measures
- Can be used to study use of and charges of ED services, medical treatment effectiveness, quality of ED care, impact of policy changes, access to care, utilization of services and trends among other things.
- Four data files per year (Core, Hospital, Severity and Diagnosis/Procedure) except for 2015 which has 6 (Severity and Diagnosis/Procedure split into 2 each)

71.4 Vintage/Release Frequency

Annual since 2006

71.5 Observational Unit

Emergency department encounter level

71.6 Collection Methodology

- Sampled from the State Inpatient Databases (SID) and the State Emergency Department Databases (SEDD). SID contains information on patients initially seen in the ED and then admitted and the SEDD captures information on ED visits that do not result in admission.
- 20% stratified sample of hospital-owned EDs in the US (States and DC)
- Stratification is based on geographic region, trauma center designation, urban-rural location, teaching hospitals and hospital ownership or control.
- Data obtained from inpatient discharge abstracts provided by participating organizations and then translated into a uniform format.

71.7 Available at

Available for purchase by year. CPHR currently has 2006-2019.

71.8 User Guide/Data Dictionary

https://www.hcup-us.ahrq.gov/db/nation/neds/nedsdbdocumentation.jsp

71.9 Cost

Cost varies by year

71.10 Proposal or Application required?

Application form required

71.11 DUA required?

Yes

- Query and classify patients using ICD
- Up to the 3rd quarter of 2015, diagnosis and procedure codes are coded using ICD-9. In the 4th quarter of 2015 the transition to ICD-10 is done. Because of this the file structure for 2015 is different than previous years.
- You cannot track a particular patient across multiple admissions
- All users must complete a Data Use Agreement Training and sign a DUA
- Before publishing with any HCUP database, ensure manuscript follows requirements of the HCUP DUA and includes the appropriate citation (see https://www.hcup- us.ahrq.gov/db/publishing.jsp)

 $4 CHAPTER\ 71.\ \ NATIONWIDE\ EMERGENCY\ DEPARTMENT\ SAMPLE\ (NEDS)$

Nationwide Readmissions Sample (NRD)

72.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

72.2 Website

https://www.hcup-us.ahrq.gov/nrdoverview.jsp

72.3 Description

- HIPPA-compliant, patient-level
- Includes data on 1ry and 2ry diagnoses and procedures, discharge status, demographics, hospital characteristics, expected payment source, total charges, length of stay and severity and comorbidity measures.
- The NRD includes discharges for patients with and without repeat hospital visits in a year and those who have died in the hospital.
- Patient linkage numbers allow tracking patients across multiple admissions and hospitals within a State.
- Timing between admissions can be calculated
- Repeat stays may or may not be related
- Four data files per year (Core, Hospital, Severity and Diagnosis/Procedure) except for 2015 which has 6 (Severity and Diagnosis/Procedure split into 2 each)

72.4 Vintage/Release Frequency

Annual since 2010

72.5 Observational Unit

Hospital inpatient admission

72.6 Collection Methodology

- Sampled from the State Inpatient Databases (SID)
- 20% stratified sample of hospital-owned EDs in the US (States and DC)
- Stratification is based on geographic region, trauma center designation, urban-rural location, teaching hospitals and hospital ownership or control.
- Data obtained from inpatient discharge abstracts provided by participating organizations and then translated into a uniform format.

72.7 Available at

Available for purchase by year. CPHR currently has 2010-2019

72.8 User Guide/Data Dictionary

https://www.hcup-us.ahrq.gov/db/nation/nrd/nrddbdocumentation.jsp

72.9 Cost

Cost varies by year

72.10 Proposal or Application required?

Application form required

72.11 DUA required?

Yes

72.12 Special Notes

• Query and classify patients using ICD

- There is a patient linking variable that allows tracking a particular patient across a calendar year
- Up to the 3rd quarter of 2015, diagnosis and procedure codes are coded using ICD-9. In the 4th quarter of 2015 the transition to ICD-10 is done. Because of this the file structure for 2015 is different than previous years.
- Cost-to-Charge Ratio Files enable conversion from the reported charges to costs
- All users must complete a Data Use Agreement Training and sign a DUA
- Before publishing with any HCUP database, ensure manuscript follows requirements of the HCUP DUA and includes the appropriate citation (see https://www.hcup- us.ahrq.gov/db/publishing.jsp)

Panel Study of Income Dynamics (PSID)

73.1 Organization

Institute for Social Research, University of Michigan

73.2 Website

https://psidonline.isr.umich.edu/

73.3 Description

- Longest running longitudinal household survey in the world.
- The study began in 1968 with a nationally representative sample of over 18,000 individuals living in 5,000 families in the United States. Information on these individuals and their descendants has been collected continuously, including data covering employment, income, wealth, expenditures, health, marriage, childbearing, child development, philanthropy, education, and numerous other topics.

73.4 Vintage/Release Frequency

Annually from 1968-1997 and biennially after 1997

73.5 Observational Unit

Family, Individual

73.6 Collection Methodology

See https://psidonline.isr.umich.edu/Guide/default.aspx

73.7 Available at

Data available free of charge at https://simba.isr.umich.edu/data/data.aspx

73.8 User Guide/Data Dictionary

https://psidonline.isr.umich.edu/Guide/default.aspx

73.9 Cost

Free

73.10 Proposal or Application required?

Not for public use files but yes for restricted use files. https://psidonline.isr.u mich.edu/Guide/FAQ.aspx? Type=3

73.11 DUA required?

Only for restricted data

- Registration required
- Additional restricted use data files are available and require a request

PLACES: Local Data for Better Health

74.1 Organization

The Robert Wood Johnson Foundation and the Centers for Disease Control and Prevention (CDC)

74.2 Website

https://www.cdc.gov/places/index.html

74.3 Description

- Provides health data for small areas
- Allows local health departments and jurisdictions, regardless of population size and rurality, to better understand the burden and geographic distribution of health measures in their areas and assist them in planning public health interventions
- 2022 data includes estimates for 29 measures: 13 for health outcomes, 9 for preventive services use, 4 for chronic disease-related health risk behaviors, and 3 for health status

74.4 Vintage/Release Frequency

Yearly since 2020

74.5 Observational Unit

All counties, places (incorporated and census designated places), census tracts, or ZIP Code Tabulation Areas (ZCTAs) across the United States

74.6 Collection Methodology

- Model-based area-level estimates
- In the 2022 release, 25 of the estimates are based on Behavioral Risk Factor Surveillance System (BRFSS) 2020 data and 4 (high blood pressure, taking high blood pressure medication, high cholesterol, and cholesterol screening) are based on 2019 BRFSS data.

74.7 Available at

https://chronicdata.cdc.gov/browse?category=500+Cities+%26+Places

74.8 User Guide/Data Dictionary

https://chronic data.cdc.gov/500-Cities-Places/PLACES-Local-Data-for-Better-Health-County-Data-20/swc5-untb

74.9 Cost

Free for download

74.10 Proposal or Application required?

No

74.11 DUA required?

No

74.12 Special Notes

• This replaces the 500 Cities Project since Dec. 2020

Pregnancy Risk Assessment Monitoring System (PRAMS)

75.1 Organization

Division of Reproductive Health (DRH), CDC

75.2 Website

https://www.cdc.gov/prams/

75.3 Description

- HIPPA-compliant, patient-level
- Joint research project between the state departments of health and the CDC
- Collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy.
- Currently forty-six states, the District of Columbia, New York City, Northern Mariana Islands, and Puerto Rico currently participate in PRAMS, representing approximately 81% of all U.S. live births.
- These data can be used to identify groups of women and infants at high risk for health problems, to monitor changes in health status, and to measure progress towards goals in improving the health of mothers and infants.
- The PRAMS Data Portal has a PRAMS dataset for each year from 2000 2011. For any of these datasets, you can filter, export, create custom

visualizations, view associated metadata, and more.

75.4 Vintage/Release Frequency

Yearly 1988-ongoing

75.5 Observational Unit

Subject-level

75.6 Collection Methodology

- Each month, a stratified sample of women who have recently given birth is drawn from the state's birth certificate files.
- Each participating state samples between 1300 and 3400 women per year.
- Women from higher risk populations are oversampled.
- Women are first contacted by mail. If there is no response after multiple attempts, they are contacted and interviewed by phone.
- Data collection tools are standardized across states.

75.7 Available at

Free but need to submit a proposal. See $\label{eq:https://www.cdc.gov/prams/prams-data/researchers.htm} % \end{submit a proposal.} % \end{submit a propo$

75.8 User Guide/Data Dictionary

See https://www.cdc.gov/prams/prams-data/P6-Core-Codebook.htm

75.9 Cost

Free

75.10 Proposal or Application required?

Yes

75.11 DUA required?

Yes

75.12 Special Notes

There have been some major changes to the question naires over the years. For questions included in each phase see https://www.cdc.gov/prams/questionnaire.htm#current? $4 CHAPTER\ 75.\ PREGNANCY\ RISK\ ASSESSMENT\ MONITORING\ SYSTEM\ (PRAMS)$

Rural-Urban Continuum Codes

76.1 Organization

United States Department of Agriculture (USDA)

76.2 Website

https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/

76.3 Description

- A classification scheme that distinguishes metropolitan counties by the population size of their metro area, and nonmetropolitan counties by degree of urbanization and adjacency to a metro area
- This scheme allows researchers to break county data into finer residential groups, beyond metro and nonmetro, particularly for the analysis of trends in nonmetro areas that are related to population density and metro influence.
- Codes for Puerto Rico are available for 2003

76.4 Vintage/Release Frequency

Decennial

76.5 Observational Unit

County-level

76.6 Collection Methodology

- All U.S. counties and county equivalents were first grouped according to their official metro-nonmetro status, defined by the Office of Management and Budget (OMB) as of February, 2013.
- OMB determined current metropolitan status by applying population and worker commuting criteria to the results of the 2010 Census and the 2006-10 American Community Survey (ACS).
- Metro counties are then divided into three categories according to the total population size of the metro area of which they are part: 1 million people or more, 250,000 to 1 million people, and below 250,000.
- Nonmetro counties are classified along two dimensions. First, they are divided into three urban-size categories (an urban population of 19,999 or more, 2,500 to 20,000, and less than 2,500) based on the total urban population in the county. Second, nonmetro counties in the three urban-size categories are sub- divided by whether or not the county is adjacent to one or more metro areas. A nonmetro county is defined as adjacent if it physically adjoins one or more metro areas, and has at least 2% of its employed labor force commuting to central metro counties. Nonmetro counties that do not meet these criteria are classed as nonadjacent.

76.7 Available at

Free for download

76.8 User Guide/Data Dictionary

https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/documentation/

76.9 Cost

 ${\rm Free}$

76.10 Proposal or Application required?

No

76.11 DUA required?

No

76.12 Special Notes

NA

School Health Policies and Practices Study (SHPPS)

77.1 Organization

Division of Adolescent and School Health (DASH), CDC

77.2 Website

https://www.cdc.gov/healthyschools/data/shpps/

77.3 Description

- District or classroom-level depending on cycle
- National survey periodically conducted to assess school health policies and practices at the state, district, school, and classroom levels.
- Six data files: Health Education, Physical Education and Activity, Health Services, Nutrition Services, Healthy and Safe School Environment and Status.

77.4 Vintage/Release Frequency

1994, 2000, 2006, 2012, 2014, 2016

77.5 Observational Unit

District-level in 2016 but this varies by cycle

77.6 Collection Methodology

In 2016 a stratified random sample of public school districts in US was done and 7 DASH- funded districts selected with certainty were also included. * Previous cycles had different sampling levels (state, district, school and classroom). This can be viewed at: https://www.cdc.gov/healthyyouth/data/shpps/index.htm * Data collected via questionnaires (web-based in 2016). * Web-based data collection system had built-in checks to limit invalid responses

77.7 Available at

- $\bullet \ \ https://www.cdc.gov/healthyyouth/data/shpps/data.htm$
- https://www.cdc.gov/healthyschools/data/shpps/data.htm

77.8 User Guide/Data Dictionary

Data documentation available at same website as data download.

77.9 Cost

Free for download

77.10 Proposal or Application required?

No

77.11 DUA required?

No

- Data for 2012, 2014 and 2016 is available for download.
- Data and documentation for 1994, 2000, and 2006 can be requested by filling out a form (https://www.cdc.gov/healthyyouth/data/shpps/cont act.htm)
- Webpage is archived and the newer webpage (https://www.cdc.gov/heal thyschools/data/shpps/data.htm) only has 2012 and 2014 data.

Scientific Registry of Transplant Recipients (SRTR)

78.1 Organization

Division of Transplantation, HHS

78.2 Website

https://www.srtr.org/

78.3 Description

- All national data on the candidate waiting list, organ donation and matching, and transplantation
- De-identified, adult and pediatric data
- All solid organs

78.4 Vintage/Release Frequency

SAFs are released quarterly (March, June, September, and December of each year) since 1987

78.5 Observational Unit

Candidates for transplant, recipients of solid organ transplants, deceased and living donors, donors procured for the purpose of transplantation, immunosuppression medications

78.6 Collection Methodology

- Primary source of data is the Organ Procurement and Transplantation Network (OPTN)
- OPTN collects data from transplant programs, organ procurement organizations (OPOs), and histocompatibility laboratories
- United Network for Organ Sharing (UNOS), contractor for OPTN, first developed the OPTN data collection system in 1986 under contract with HHS, and the system has since undergone numerous changes

78.7 Available at

https://www.srtr.org/requesting-srtr-data/about-srtr-standard-analysis-files/

78.8 User Guide/Data Dictionary

- Online data dictionary available at https://www.srtr.org/requesting-srtr-data/saf-data-dictionary/
- Overview of data available at: https://www.srtr.org/about-the-data/the-srtr-database/

78.9 Cost

Standard Analysis Files (SAF) cost \$1000; each additional, updated SAF costs \$500

78.10 Proposal or Application required?

Yes

78.11 DUA required?

Yes

- $\bullet\,$ Manuscripts must be sent to SRTR for review prior to submission.

 $4 CHAPTER\ 78.\ SCIENTIFIC\ REGISTRY\ OF\ TRANSPLANT\ RECIPIENTS\ (SRTR)$

Selected Metropolitan/Micropolitan Area Risk Trends (SMART)

79.1 Organization

Centers for Disease Control and Prevention (CDC)

79.2 Website

https://www.cdc.gov/brfss/smart/Smart_data.htm

79.3 Description

- Provides localized health information that can help public health practitioners identify local emerging health problems, plan and evaluate local responses, and efficiently allocate resources to specific needs.
- Uses BRFSS data to provide prevalence rates for selected conditions and behaviors for cities and their surrounding counties.

79.4 Vintage/Release Frequency

Annual since 2006

Metropolitan/micropolitan statistical areas (MMSAs)

79.6 Collection Methodology

CDC analyzes BRFSS data to obtain these estimates. View detailed methodology at https://www.cdc.gov/brfss/annual_data/2021/pdf/2021_SMART_BRFSS_MMSA_Methodology-508.pdf

79.7 Available at

https://www.cdc.gov/brfss/smart/Smart_data.htm

79.8 User Guide/Data Dictionary

Available for each year on same site as data download

79.9 Cost

Free

79.10 Proposal or Application required?

No

79.11 DUA required?

No

79.12 Special Notes

• An aggregated file with data from 2011 to present is available at https://chronicdata.cdc.gov/Behavioral-Risk-Factors/Behavioral-Risk-Factors-Selected-Metropolitan-Area/j32a-sa6u

Small Area Income and Poverty Estimates (SAIPE)

80.1 Organization

US Census Bureau

80.2 Website

https://www.census.gov/programs-surveys/saipe.html

80.3 Description

- Single-year estimates of income and poverty
- Estimates provided are # of people in poverty, # of children under age 5 in poverty (for states only), # of related children ages 5-17 in families in poverty, # of children under age 18 in poverty, median household income

80.4 Vintage/Release Frequency

Yearly since 1995

80.5 Observational Unit

States, counties, school districts

80.6 Collection Methodology

- In 2005, SAIPE began using ACS data for estimates. Before this time, the Annual Social and Economic Supplement to the Current Population Survey was used.
- School district estimates sum to county estimates, county estimates sum to state estimates, and state estimates sum to the national estimate

80.7 Available at

Free for download at: https://www.census.gov/programs-surveys/saipe/data/datasets.html

80.8 User Guide/Data Dictionary

https://www.census.gov/programs-surveys/saipe/technical-documentation.html

80.9 Cost

Free

80.10 Proposal or Application required?

No

80.11 DUA required?

No

80.12 Special Notes

NA

Social Deprivation Index

81.1 Organization

Robert Graham Center

81.2 Website

https://www.graham-center.org/rgc/maps-data-tools/sdi/social-deprivation-index.html

81.3 Description

- Developed to quantify levels of disadvantage across small areas, evaluate their associations with health outcomes, and address health inequities.
- Composite measure of seven demographic characteristics: percent living in poverty, percent with less than 12 years of education, percent single parent household, percent living in rented housing unit, percent living in overcrowded housing unit, percent of households without a car, and percent non-employed adults under 65 years of age.
- Originally developed by Butler et al and calculated at the Primary Care Service Area.

81.4 Vintage/Release Frequency

2012, Annually since 2015

Geographical unit (available per primary care service area, county, ZCTA and census tract)

81.6 Collection Methodology

- $\bullet \ \, \text{https://www.graham-center.org/rgc/maps-data-tools/sdi/social-deprivation-index.html} \\$
- Butler DC, Petterson S, Phillips RL, Bazemore AW. Measures of Social Deprivation That Predict Health Care Access and Need within a Rational Area of Primary Care Service Delivery. Health Services Research. 2013;48(2 Pt 1):539-559. doi:10.1111/j.1475-6773.2012.01449.

81.7 Available at

https://www.graham-center.org/maps-data-tools/social-deprivation-index.html

81.8 User Guide/Data Dictionary

n/a

81.9 Cost

Free for download

81.10 Proposal or Application required?

No

81.11 DUA required?

No

- National rank: 1(least disadvantaged)-100 (most disadvantaged)
- Suggested citation: Social deprivation index (SDI). Robert Graham Center Policy Studies in Family Medicine & Primary Care. (2018, November 5). Retrieved November 29, 2021, from https://www.graham-center.org/rgc/maps-data-tools/sdi/social-deprivation-index.html.

Social Determinants of Health Database

82.1 Organization

Agency for Healthcare Research and Quality (AHRQ)

82.2 Website

https://www.ahrq.gov/sdoh/data-analytics/sdoh-data.html

82.3 Description

- The purpose of the files is to make it easier to find a range of well documented, readily linkable SDOH variables across domains without having to access multiple source files, facilitating SDOH research and analysis.
- Variables in the files correspond to five key SDOH domains: social context (e.g., age, race/ethnicity, veteran status), economic context (e.g., income, unemployment rate), education, physical infrastructure (e.g., housing, crime, transportation), and healthcare context (e.g., health insurance)

82.4 Vintage/Release Frequency

Annual since 2009

County, Zip Code or Census Tract

82.6 Collection Methodology

These SDOH files are curated from existing Federal datasets and other publicly available data sources.

82.7 Available at

https://www.ahrq.gov/sdoh/data-analytics/sdoh-data.html#download

82.8 User Guide/Data Dictionary

https://www.ahrq.gov/sites/default/files/wysiwyg/sdoh/SDOH-Data-Sources-Documentation-v1-Final.pdf

82.9 Cost

Free for download

82.10 Proposal or Application required?

No

82.11 DUA required?

No

82.12 Special Notes

n/a

Social Vulnerability Index (SVI)

83.1 Organization

Centers for Disease Control and Prevention (CDC), Agency for Toxic Substances & Disease Registry (ATSDR)

83.2 Website

https://www.atsdr.cdc.gov/placeandhealth/svi/index.html

83.3 Description

- Social vulnerability refers to the resilience of communities when confronted by external stresses on human health, stresses such as natural or humancaused disasters, or disease outbreaks.
- ATSDR's Social Vulnerability Index uses U.S. census variables at tract level to help local officials identify communities that may need support in preparing for hazards, or recovering from disaster.
- The CDC SVI ranks each tract into four themes: socioeconomic status, household composition, race/ethnicity/language, and housing/transportation. Also, gives an overall SVI.
- Each tract receives a separate ranking for each of the four themes, as well as an overall ranking. Rankings can be US-wide or state-wide.
- Meant to help officials identify communities that may need support before, during, or after disasters.

83.4 Vintage/Release Frequency

2000, 2010 and biennially since 2014

83.5 Observational Unit

Geographical unit (available at county or census tract level)

83.6 Collection Methodology

• The SVI ranks each tract on 15 social factors, including poverty, lack of vehicle access, and crowded housing, and groups them into four related themes: socioeconomic status, household composition, race/ethnicity/language and housing/transportation.

83.7 Available at

 $https://www.atsdr.cdc.gov/placeandhealth/svi/data_documentation_download.html$

83.8 User Guide/Data Dictionary

https://www.atsdr.cdc.gov/place $and health/svi/documentation/SVI_documentation_2020.html$

83.9 Cost

Free for download

83.10 Proposal or Application required?

No

83.11 DUA required?

No

- National rank: 0 (lesser vulnerability) 1 (greatest vulnerability)
- State rank: 0 (lesser vulnerability) 1 (greatest vulnerability)

• Suggested citation: Centers for Disease Control and Prevention/ Agency for Toxic Substances and Disease Registry/ Geospatial Research, Analysis, and Services Program. CDC/ATSDR Social Vulnerability Index [Insert 2018, 2016, 2014, 2010, or 2000] Database [Insert US or State]. https://www.atsdr.cdc.gov/placeandhealth/svi/data_documentation_downlo ad.html. Accessed on [Insert date].

State Ambulatory Surgery and Services Databases (SASD)

84.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

84.2 Website

https://www.hcup-us.ahrq.gov/sasdoverview.jsp

84.3 Description

• SASD include encounter-level data for ambulatory surgeries and may also include various types of outpatient services such as observation stays, lithotripsy, radiation therapy, imaging, chemotherapy, and labor and delivery. The specific types of ambulatory surgery and outpatient services included in each SASD vary by State and data year.

84.4 Vintage/Release Frequency

Annual since 1997 (states available vary by year)

Ambulatory surgery encounter

84.6 Collection Methodology

https://hcup-us.ahrq.gov/db/state/sasddbdocumentation.jsp

84.7 Available at

Available for purchase, contact CORP for current availability and possibility to purchase

84.8 User Guide/Data Dictionary

https://www.hcup-us.ahrq.gov/db/state/sasddbdocumentation.jsp

84.9 Cost

Cost varies by year and state

84.10 Proposal or Application required?

- Application form required
- Some states may require proposal

84.11 DUA required?

Yes

- Query and classify patients using ICD
- Up to the 3rd quarter of 2015, diagnosis and procedure codes are coded using ICD-9. In the 4th quarter of 2015 the transition to ICD-10 is done. Because of this the file structure for 2015 is different than previous years.
- Some states allow tracking a particular patient across multiple events
- All users must complete a Data Use Agreement Training and sign a DUA
- Before publishing with any HCUP database, ensure manuscript follows requirements of the HCUP DUA and includes the appropriate citation (see https://www.hcup- us.ahrq.gov/db/publishing.jsp)

State Emergency Department Databases (SEDD)

85.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

85.2 Website

https://www.hcup-us.ahrq.gov/seddoverview.jsp

85.3 Description

• SEDD captures discharge information on all ED visits in a given State that do not result in an admission.

85.4 Vintage/Release Frequency

Annual starting in 1999 (states available vary by year)

85.5 Observational Unit

Emergency department encounter level

85.6 Collection Methodology

https://hcup-us.ahrq.gov/db/state/sedddbdocumentation.jsp

85.7 Available at

Available for purchase, contact CORP for current availability and possibility to purchase

85.8 User Guide/Data Dictionary

https://www.hcup-us.ahrq.gov/db/state/sedddbdocumentation.jsp

85.9 Cost

Cost varies by year and state

85.10 Proposal or Application required?

- Application form required
- Some states may require proposal

85.11 DUA required?

Yes

- Query and classify patients using ICD
- Up to the 3rd quarter of 2015, diagnosis and procedure codes are coded using ICD-9. In the 4th quarter of 2015 the transition to ICD-10 is done. Because of this the file structure for 2015 is different than previous years.
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State Inpatient Databases (SID)

86.1 Organization

Agency for Healthcare Research and Quality (AHRQ), HHS

86.2 Website

https://www.hcup-us.ahrq.gov/sidoverview.jsp

86.3 Description

 The SID includes inpatient discharge records from community hospitals in that State. The SID files encompass all patients, regardless of payer, providing a unique view of inpatient care in a defined market or State over time.

86.4 Vintage/Release Frequency

Annual starting in 1990 (states available vary by year)

86.5 Observational Unit

Hospital inpatient admission

86.6 Collection Methodology

The SID contain the universe of the inpatient discharge abstracts in participating States, translated into a uniform format to facilitate multi-State comparisons and analyses. Together, the SID encompass about 97 percent of all U.S. community hospital discharges. Some States include discharges from specialty facilities, such as acute psychiatric hospitals. *The SID contain a core set of clinical and nonclinical information on all patients, including individuals covered by Medicare, Medicaid, or private insurance, as well as those who are uninsured.

86.7 Available at

Available for purchase, contact CORP for current availability and possibility to purchase

86.8 User Guide/Data Dictionary

https://www.hcup-us.ahrq.gov/db/state/siddbdocumentation.jsp

86.9 Cost

Cost varies by year and state

86.10 Proposal or Application required?

- Application form required
- Some states may require proposal

86.11 DUA required?

Yes

- Query and classify patients using ICD
- Up to the 3rd quarter of 2015, diagnosis and procedure codes are coded using ICD-9. In the 4th quarter of 2015 the transition to ICD-10 is done. Because of this the file structure for 2015 is different than previous years.
- Some states allow tracking a particular patient across multiple events
- All users must complete a Data Use Agreement Training and sign a DUA
- Before publishing with any HCUP database, ensure manuscript follows requirements of the HCUP DUA and includes the appropriate citation (see https://www.hcup- us.ahrq.gov/db/publishing.jsp)

State of Ohio Public Health Data

87.1 Organization

Ohio Department of Health

87.2 Website

http://publicapps.odh.ohio.gov/EDW/DataCatalog

87.3 Description

- Mortality
- Live births
- Cancer Incidence data
- Ohio Onesource: licensed healthcare facilities in the state of Ohio
- OHYES! Ohio Healthy Youth Environments Survey Data Student survey (7th 12th grade) of health risk behaviors assessing physical health, behavioral health, activity and wellbeing, safety, substance use, unintentional and intentional injuries, and environmental factors. This survey is a partnership between ODE, ODH, and OhioMHAS. Data are for schools that volunteered to participate and are not representative of the state as a whole
- Population Data for calculating rates: Bridged-Race County Population data from National Center for Health Statistics (NCHS) to calculate rates at ODH
- Lead data: blood lead test results for Ohio children

• Ohio Lead Hazardous properties: list of properties in Ohio whose owners have refused to comply with an order from the Ohio Department of Health or its delegated local board of health to correct known lead hazards.

87.4 Vintage/Release Frequency

- Live births 2006-present
- $\bullet\,$ Cancer incidence data 1996-present
- Mortality 2007-present
- Lead data 2006-present

87.5 Observational Unit

For mortality data, each person dead in state of Ohio

87.6 Collection Methodology

• Mortality information is collected by the Ohio Department of Health (ODH) and is derived from Ohio Certificates of Death

87.7 Available at

https://publicapps.odh.ohio.gov/EDW/DataCatalog

87.8 User Guide/Data Dictionary

Available on same website as downloads

87.9 Cost

Not stated

87.10 Proposal or Application required?

Yes

87.11 DUA required?

Yes

- Reports freely available online.
- Other data might be available for research through contact with the Ohio Department of Health.
- • MCH reports now housed under http://www.odh.ohio.gov/en/odhprograms/cfhs/cf_hlth/blockgrant

Surveillance, Epidemiology and End Results (SEER)

88.1 Organization

National Cancer Institute (NCI), NIH

88.2 Website

https://seer.cancer.gov/

88.3 Description

- Records for patient tumors, type, staging, demographic data, geographic area, survival, cause of death
- Incidence and population data associated by age, sex, race, year of diagnosis, and geographic areas.
- De-identified, adult and pediatric data

88.4 Vintage/Release Frequency

Annual since 1973

88.5 Observational Unit

Patient tumor

88.6 Collection Methodology

SEER collects data on cancer cases from various locations and sources throughout the United States.

88.7 Available at

https://seer.cancer.gov/data-software/

88.8 User Guide/Data Dictionary

https://seer.cancer.gov/data-software/documentation/seerstat/nov2022/

88.9 Cost

Free for download

88.10 Proposal or Application required?

No

88.11 DUA required?

Yes

88.12 Special Notes

n/a

Survey of Income and Program Participation (SIPP)

89.1 Organization

US Census Bureau

89.2 Website

https://www.census.gov/sipp/

89.3 Description

- Longitudinal survey
- Captures income dynamics and program participation of US individuals and households
- Used to evaluate use of and eligibility for government programs

89.4 Vintage/Release Frequency

Annual since 1984

Household, person, mortgage, or home improvement project (4 relational databases or one flat file)

89.6 Collection Methodology

- Nationally-representative continuous series of panels from 2.5 to 4 years duration per panel
- Multi-stage, stratified sample of US civilian non-institutionalized population

89.7 Available at

https://www.census.gov/programs-surveys/sipp/data/datasets.html

89.8 User Guide/Data Dictionary

- An online codebook is available at: https://www.census.gov/data-tools/demo/uccb/sippdict.
- A description of the methodology can be found at https://www.census.g ov/programs-surveys/sipp/methodology.html.

89.9 Cost

Free for download

89.10 Proposal or Application required?

No

89.11 DUA required?

No

89.12 Special Notes

n/a

Toxics Release Inventory (TRI) Data

90.1 Organization

Environmental Protection Agency (EPA)

90.2 Website

https://www.epa.gov/toxics-release-inventory-tri-program/tri-data-and-tools

90.3 Description

- Quantities of toxic chemicals released into the environment on site at facilities; the quantities transferred off site to other facilities; and summary data concerning releases, recycling, energy recovery and treatment.
- Data is available by year for: state, national data file, federal facility data file, and tribal data file.
- The data contains the facility name, address, latitude and longitude coordinates.

90.4 Vintage/Release Frequency

Annual since 1987

Industrial facilities that meet Toxics Release Inventory (TRI) Program reporting requirements

90.6 Collection Methodology

Industrial facilities report to the EPA using reporting Form R or Form A

90.7 Available at

https://www.epa.gov/toxics-release-inventory-tri-program/tri-data-and-tools

90.8 User Guide/Data Dictionary

A data dictionary and data help center are available at the same website as the data download. Also see https://www.epa.gov/sites/production/files/2016-11/documents/tri basic data file format v15.pdf

90.9 Cost

Free for download

90.10 Proposal or Application required?

No

90.11 DUA required?

No

- In 2013, the TRI program began requiring facilities to submit records electronically using TRI-MEweb, preventing many errors that were common in earlier paper versions
- There are also tools available on the same website using TRI data in conjunction with other EPA data

Treatment Episode Data Sets: Admissions (TEDS-A) and Discharges (TEDS-D)

91.1 Organization

Substance Abuse and Mental Health Services Administration (SAMHSA)

91.2 Website

https://www.datafiles.samhsa.gov/

91.3 Description

- De-identified data for admissions (TEDS-A) to or discharges (TEDS-D) from substance abuse treatment facilities of patients 12 years and older
- Contains all publically funded admissions/discharges (some facilities also report all other admissions but it varies)
- Demographics and substance abuse characteristics
- Discharge data contains demographic and social information, length of stay, service setting, substances abused, number of prior treatments, diagnosis codes, arrests in 30 days prior

91.4 Vintage/Release Frequency

Annual since 1992 for admissions and 2006 for discharges

Admissions (same patient might be admitted multiple times)

91.6 Collection Methodology

- Record abstracts
- Number and client mix depends on availability of public funds to cover treatment
- Files may include multiple admissions for the same client, but the same client cannot be tracked through multiple admissions

91.7 Available at

 $https://www.datafiles.samhsa.gov/dataset/teds-d-2020-ds0001-teds-d-2020-ds0001 \ https://www.datafiles.samhsa.gov/dataset/treatment-episode-data-set-admissions-2020-teds-2020-ds0001$

91.8 User Guide/Data Dictionary

Dataset documentation available at same websites as data download

91.9 Cost

Free for download

91.10 Proposal or Application required?

No

91.11 DUA required?

No

91.12 Special Notes

SAMHSA also contains National Survey on Drug Use and Health (NSDUH), National Mental Health Services Survey (N-MHSS), National Survey of Substance Abuse Treatment Services (N-SSATS), Drug Abuse Warning Network (DAWN)

United Network for Organ Sharing (UNOS)

92.1 Organization

Organ Procurement and Transplantation Network (OPTN), United Network for Organ Sharing (UNOS)

92.2 Website

https://optn.transplant.hrsa.gov/data/

92.3 Description

- All national data on the candidate waiting list, organ donation and matching, and transplantation
- De-identified, adult and pediatric data
- Over 3,500 variables from 26 different form types
- All organs

92.4 Vintage/Release Frequency

NA

92.5 Observational Unit

Wait-listed candidates, living and deceased donors and transplant recipients

92.6 Collection Methodology

Collected via an online Web application by Transplant professionals at hospitals, histocompatibility (tissue typing) laboratories, and organ procurement organizations

92.7 Available at

- Request data at: https://optn.transplant.hrsa.gov/data/request-data/
- In general, SRTR data contains all of UNOS data plus more and is better suited for research. See SRTR data description.

92.8 User Guide/Data Dictionary

- https://optn.transplant.hrsa.gov/data/about-data/
- https://transplantpro.org/technology/data-collection-forms/

92.9 Cost

STAR files are free of charge. Requests for custom limited data, patient-identified datasets and aggregate data can be made and processing fees may apply.

92.10 Proposal or Application required?

Yes

92.11 DUA required?

Yes

- Data released with approximately 1 year lag
- Some data collection has changed over time

United States Mortality Database (USMDB)

93.1 Organization

University of California, Berkeley & National Center for Health Statistics (NCHS)

93.2 Website

https://usa.mortality.org/

93.3 Description

- State-level life tables designed to foster research on geographic variations in mortality across the United States and to monitor trends in health inequalities
- Includes complete and abridged life tables by sex for each of the US 9 Census Divisions, 4 Census Regions, 50 States and the District of Columbia, for each year since 1959 with mortality values up to age 110.

93.4 Vintage/Release Frequency

Annual since 1959

State, Census division or region

93.6 Collection Methodology

- Contains original calculations of death rates and life tables for the United States resident population as well as for the 4 US Census regions, the 9 US Census divisions, the 50 states and the District of Columbia.
- The input data used to construct the mortality series are death counts and birth counts from the US vital statistics system, as well as census counts and population estimates from the US Census Bureau.

93.7 Available at

https://usa.mortality.org/

93.8 User Guide/Data Dictionary

https://usa.mortality.org/uploads/documentation/USMDBcom.pdf

93.9 Cost

Free for download

93.10 Proposal or Application required?

No

93.11 DUA required?

No

- Requires registration
- World data also available at: https://www.mortality.org/

United States Renal Data System (USRDS)

94.1 Organization

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

94.2 Website

www.usrds.org

94.3 Description

- All national data on patients receiving dialysis and kidney transplant
- De-identified, adult and pediatric data
- Additional data available through additional requests: special studies data, CROWNWeb clinical data, ESRD medicare payment data, pre-ESRD medicare payment data, CKD 5% medicare sample SAFs, ESRD clinical performance measures.

94.4 Vintage/Release Frequency

Released since 1998

94.5 Observational Unit

Patients with ESRD and kidney transplant

2

94.6 Collection Methodology

Main data collected in all US dialysis centers for all patients

94.7 Available at

Instructions for obtaining the standard analysis files can be found at https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/usrds/for-researchers/standard-analysis-files

94.8 User Guide/Data Dictionary

https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/usrds/for-researchers/researchers-guide

94.9 Cost

There is no cost for the standard analysis files but other data requests might involve a cost.

94.10 Proposal or Application required?

Yes

94.11 DUA required?

Yes

94.12 Special Notes

• Some data collection forms have changed over time.

US Census Data

95.1 Organization

US Census Bureau

95.2 Website

www.census.gov/

95.3 Description

- Census conducted every 10 years to determine the number of people living in US
- Demographic data, housing, social and economic data

95.4 Vintage/Release Frequency

Decennial since 1790

95.5 Observational Unit

Respondent-level for microdata but various geographic level summaries available

95.6 Collection Methodology

National census

95.7 Available at

https://www.census.gov/programs-surveys/decennial-%20census/data/dataset~s.html

95.8 User Guide/Data Dictionary

https://www.census.gov/programs-surveys/decennial-%20census/data/dataset~s.html

95.9 Cost

Free for download

95.10 Proposal or Application required?

No

95.11 DUA required?

No

95.12 Special Notes

Several tools are available for finding and using census data are available at https://www.census.gov/data/data-tools.html

US Religion Census: Religious Congregations and Membership Study

96.1 Organization

The Association of Religion Data Archives (ARDA)

96.2 Website

http://www.thearda.com/Archive/browse.asp

96.3 Description

- Compiles data on the number of congregations and adherents for 236 religious groups in each county of the United States.
- Participants included 217 Christian denominations, associations, or communions (including Latter-day Saints, Messianic Jews, and Unitarian/Universalist groups); counts of Jain, Shinto, Sikh, Tao and National Spiritualist Association congregations, and counts of congregations and adherents from Bahá'ís, three Buddhist groupings, four Hindu groupings, four Jewish groupings, Muslims and Zoroastrians.

96.4 Vintage/Release Frequency

Varies by file

96.5 Observational Unit

County or State-level

96.6 Collection Methodology

- In 2009, an invitation to participate in the study was sent to every U.S. religious body listed in the Yearbook of American and Canadian Churches. Invitations also were sent to contacts suggested by the Advisory Committee and by members of the ASARB. Several special efforts were made to identify and include data from several religious bodies that have not traditionally participated or been underrepresented in similar past studies.
- Groups agreeing to participate were asked to appoint a contact person. Two forms were sent to the contact person: instructions for reporting data and a transmittal sheet to be signed and sent with the data collected.

96.7 Available at

https://www.thearda.com/data-archive/browse-categories

96.8 User Guide/Data Dictionary

https://www.thearda.com/data-archive/metadata/marc-files

96.9 Cost

Free for download

96.10 Proposal or Application required?

No

96.11 DUA required?

No

96.12 Special Notes

n/a

US Small Area Life Expectancy Estimates Project (USALEEP)

97.1 Organization

Partnership of NCHS, the Robert Wood Johnson Foundation (RWJF) external icon, and the National Association for Public Health Statistics and Information Systems (NAPHSIS) external icon

97.2 Website

https://www.cdc.gov/nchs/nvss/usaleep/usaleep.html

97.3 Description

• Estimates of life expectancy at birth—the average number of years a person can expect to live—for most of the census tracts in the United States for the period 2010-2015

97.4 Vintage/Release Frequency

Single time estimated life expectancy at birth for 2010-2015

97.5 Observational Unit

Census tract

97.6 Collection Methodology

- Deaths occurring in 2010 through 2015 were geocoded using decedents' residential addresses to identify and code census tracts
- Population estimates were produced based on the 2010 decennial census and the 2011–2015 American Community Survey 5-year survey
- A methodology that combined standard demographic techniques and statistical modeling was developed to address challenges posed by small population sizes and small and missing age-specific death counts
- Standard, abridged life table methods were adjusted to account for error introduced by population estimates based on sample data

97.7 Available at

Free for download at https://www.cdc.gov/nchs/nvss/usaleep/usaleep.html

97.8 User Guide/Data Dictionary

Documentation available at same website as data download and at https://www.cdc.gov/nchs/data/series/sr 02/sr02 181.pdf

97.9 Cost

Free

97.10 Proposal or Application required?

No

97.11 DUA required?

No

97.12 Special Notes

NA

Walkability Index

98.1 Organization

U.S. Environmental Protection Agency (EPA)

98.2 Website

https://catalog.data.gov/dataset/walkability-index

98.3 Description

- The Walkability Index dataset characterizes every Census 2010 block group in the U.S. based on its relative walkability.
- Walkability depends upon characteristics of the built environment that influence the likelihood of walking being used as a mode of travel.

98.4 Vintage/Release Frequency

2019

98.5 Observational Unit

Census block

98.6 Collection Methodology

• The Walkability Index is based on the EPA's previous data product, the Smart Location Database (SLD). Block group data from the SLD was the only input into the Walkability Index, and consisted of four variables from the SLD weighted in a formula to create the new Walkability Index.

98.7 Available at

https://catalog.data.gov/dataset/walkability-index

98.8 User Guide/Data Dictionary

Available as part of the download zip file

98.9 Cost

Free for download

98.10 Proposal or Application required?

No

98.11 DUA required?

No

98.12 Special Notes

n/a

Youth Risk Behavior Surveillance System (YRBSS)

99.1 Organization

Division of Adolescent and School Health (DASH), Centers for Disease Control and Prevention (CDC)

99.2 Website

https://www.cdc.gov/healthyyouth/data/yrbs

99.3 Description

- De-identified survey responses from high school students, and in some cases middle school students
- Monitors six categories of health-related behaviors that contribute to the leading causes of death and disability among youth and adults.
- Risk behavior, sexual behavior, alcohol and drug use, tobacco use, dietary behaviors, physical activity, obesity and asthma
- National, state, and large urban school district data from selected surveys as well as a combined dataset
- Combined datasets include sample variables, demographics, BMI, sexual minority, questionnaire and supplemental variables, and risk behavior optional question variables.

99.4 Vintage/Release Frequency

Biennial since 1991

99.5 Observational Unit

Survey record

99.6 Collection Methodology

- National survey with a three-stage cluster sample design to produce a representative sample of 9-12th grade students.
- YRBS combined datasets include survey data from all national and the majority of weighted national, state, and large urban school districts
- Some sites did not grant CDC permission to include their data in the combined datasets

99.7 Available at

https://www.cdc.gov/healthyyouth/data/yrbs/data.htm

99.8 User Guide/Data Dictionary

Documentation available at same website as data download and at https://www.cdc.gov/healthyyouth/data/yrbs/methods.htm

99.9 Cost

Free for download

99.10 Proposal or Application required?

No

99.11 DUA required?

No

99.12 Special Notes

n/a

500 Cities: Local Data for Better Health

100.1 Organization

The Robert Wood Johnson Foundation and the Centers for Disease Control and Prevention (CDC)

100.2 Website

https://chronicdata.cdc.gov/browse?category=500+Cities+%26+Places

100.3 Description

- This dataset includes model-based small area estimates for 27 measures of chronic disease related to unhealthy behaviors (5), health outcomes (13), and use of preventive services (9).
- It includes prevalence estimates (crude and age-adjusted) for the 500 largest US cities and approximately 28,000 census tracts within these cities.
- These estimates can be used to identify emerging health problems and to inform development and implementation of effective, targeted public health prevention activities.
- Because the small area model cannot detect effects due to local interventions, users are cautioned against using these estimates for program or policy evaluations

100.4 Vintage/Release Frequency

Annual from 2016 to 2019

100.5 Observational Unit

US, City or Census Tract-level

100.6 Collection Methodology

- Data were provided by the Centers for Disease Control and Prevention (CDC), Division of Population Health, Epidemiology and Surveillance Branch.
- Data sources used to generate the 2017 release measures include Behavioral Risk Factor Surveillance System (BRFSS) data (2015, 2014), Census Bureau 2010 census population data, and American Community Survey (ACS) 2011-2015, 2010-2014 estimates.
- Includes data from 500 cities consisting of ~28,000 census tracts. The number of cities per state ranges from 1 to 121.
- The project includes a total population of 103,020,808, which represents 33.4% of the total United States population of 308,745,538.

100.7 Available at

https://chronicdata.cdc.gov/browse?category=500+Cities+%26+Places

100.8 User Guide/Data Dictionary

https://chronicdata.cdc.gov/500-Cities-Places/500-Cities-Local-Data-for-Better-Health-2019-relea/6vp6-wxuq

100.9 Cost

Free for download

100.10 Proposal or Application required?

No

100.11 DUA required?

No

100.12 Special Notes