

The NCHS Data Linkage Program: Leveraging the nation's health data for evidence-based decision making

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National Center for Health Statistics



National Center for Health Statistics (NCHS)

- Nation's principal health statistics agency
- One of 13 federal statistical agencies
- Mission: To provide statistical information that will guide actions and policies to improve the health of the American people. As the Nation's principal health statistics agency, NCHS leads the way with accurate, relevant, and timely data.



Policy Questions Require Evidence-Based Answers

- Many pressing policy questions require complex, detailed data
 - Do Social Security Disability Insurance beneficiaries have access to care during the waiting period before Medicare entitlement?
 - Are there adverse health effects associated with the mandatory folic acid fortification policy for grain products?
 - How effective are health and housing policies in reducing lead exposure?

Data Linkage as a Solution

- Linking data is a powerful mechanism to provide policy relevant information in an efficient way
 - Health survey data are collected to monitor health status, health behaviors and health care access
 - Administrative data are collected for programmatic purposes
- Combining these types of existing data efficiently creates opportunities to answer key health and policy relevant questions



NCHS Surveys Included in Linkages



National Health Interview Survey (NHIS)

A nationally representative, cross-sectional household interview survey that serves as an important source of information on the health of the civilian noninstitutionalized population of the United States



National Health and Nutrition Examination Survey (NHANES)

A nationally representative, cross-sectional sample of the U.S. civilian noninstitutionalized population, which includes an interview in the household followed by an examination in a mobile examination center



National Health Care Surveys

A family of data collection efforts that gather information about providers of health care services and the patients they serve across the spectrum of health care settings from ambulatory and hospital care to long term care settings

NCHS Surveys Collect Information on



Linkage Eligibility

- Only NCHS survey participants who have provided consent as well as the necessary personally identifiable information (PII) are considered *linkage-eligible*
- NCHS survey participants are informed of NCHS' intent to conduct data linkage activities through a variety of informed consent procedures:
 - Advance letters
 - Participant brochures
 - Signed consent forms
 - Questionnaires

Percent of NHIS Participants that are Linkage Eligible



Note: NHIS is the National Health Interview Survey; this graph only includes sample adults/ sample children



Availability of Linked NHIS and NHANES Data



Linked National Hospital Care Survey data

- Linked electronic health records and claims from the National Hospital Care Survey with Medicare data to provide new resources for patient outcomes research, including evaluating treatment effectiveness and post-acute care utilization
- Linked Inpatient and Emergency Department records with death certificate data to assess 30, 60, 90-day post hospitalization mortality



Contextual Information through Geocoding

NCHS Data Linkage Program coordinates geocoding of the Center's survey data and death certificates





Parker, J.D., N. Kravets, and A. Vaidyanathan, Particulate Matter Air Pollution Exposure and Heart Disease Mortality Risks by Race and Ethnicity in the United States: 1997-2009 NHIS with Mortality Followup Through 2011. Circulation, 2017.

Examples of Research using NCHS Linked Data

Over **1,000** publications based on NCHS linked data

Linked Mortality Data

- Deaths Associated with Underweight, Overweight, and Obesity
- Diet quality and all-cause mortality
- Educational Differentials in US Adult Mortality



Linked NCHS-CMS Data

- Characteristics of those who chose Medicare Advantage upon Medicare enrollment
- Health service use among the previously uninsured
- Concordance between survey reported childhood asthma and linked Medicaid



Linked NCHS-HUD Data

- Housing assistance and blood lead levels
- Cigarette smoking and adverse health outcomes among adults receiving federal housing assistance
- Housing assistance associated with insurance rates and unmet medical need



NCHS is Creating Resources that Support Evidence Building



Link NCHS survey data with the National Death Index and other health related administrative data



Provide documentation on linkage methodology, linkage quality and analytic guidelines



Release the curated data files for multiple research projects and to replicate the findings of other researchers

How to Access NCHS Linked Data: Restricted-use Files

 Most linked data products are available through the NCHS and Federal Statistical Research Data Centers

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RDC	Research Data Center (RDC)
Restricted Data	+ The National Center for Health Statistics (NCHS) operates the Research Data Center (RDC) to allow
Location of Access	researchers access to restricted-use data. The RDC is responsible for protecting the confidentiality of survey respondents, study subjects, or institutions while providing access to the restricted-use data for statistical purposes. For access to the restricted-use data, researchers must submit a research proposal outlining the need for restricted-use data. The proposal provides a framework for NCHS to identify potential disclosure risks and how the data will be used.
Proposal Process	
Confidentiality	
Accessing Restricted Data	
Preparing for proposal	1. Preparing for Proposal Submission 1. Restricted Data
Submission	2. Access Modes
Providing the Public Use Data	3. The Proposal Process 4. Consider the American Americ American American
Fees and Invoicing	
Publishing Guidelines	+ 3. Publishing Guidelines

https://www.cdc.gov/rdc/index.htm

Public-use NCHS Linked Data

• Two types of public-use files released by the NCHS Data Linkage Program:



Upcoming NCHS Data Linkages



NCHS Data Linkage Program Future Directions

- Machine learning: Incorporating machine learning techniques to improve linkage accuracy and efficiency
- Encrypted linkage: Assessing privacy preserving record linkage algorithms to increase linkage activities across health care spectrum
- Synthetic data: Piloting innovative methods for public-use linked data files to improve accessibility and reduce disclosure risk

More Information





NCHS Data Linkage Program:

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www.cdc.gov/nchs/data-linkage

Subscribe to our ListServ (updates on program including release dates): Send an email message to list@cdc.gov. Leave the subject line blank. In the body of the message, type or paste: SUBSCRIBE NCHS-DATA-LINKAGE-PROGRAM lastname, firstname where 'lastname, firstname' is your last and first name.

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