

# Getting the Right Match: Using and Evaluating NCHS Linked Data Sets

NCHS National Conference on Health Statistics  
August 26, 2015



**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
**Centers for Disease Control and Prevention**  
**National Center for Health Statistics**

**SAFER • HEALTHIER • PEOPLE™**



# An Overview of the NCHS Data Linkage Program

Irma Arispe, PhD

Director, Office of Analysis and Epidemiology



**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**  
**Centers for Disease Control and Prevention**  
**National Center for Health Statistics**

**SAFER • HEALTHIER • PEOPLE™**



# Why link survey to administrative data?

## Administrative data can enhance survey data by

- Expanding the scope or content of the survey
  - Information on eligibility, enrollment, participation in federal programs
  - Information about programs that survey respondent may not otherwise be able to provide
- Expanding the analytic time window, providing a longitudinal dimension
  - Program eligibility, participation may change over time
  - Linked data can provide “outcome”
- Reducing survey burden
  - Considered to help address falling response rates
- Informing improvements in the surveys
  - Information about the sample frame
  - Information relevant to imputation
  - Information on the quality of the survey data

# Why link administrative to survey data?

Survey data can enhance administrative data by

- Providing additional content, otherwise costly or difficult to collect
  - Demographic information, family structure
  - Socioeconomic and educational factors
  - Health characteristics and health behaviors
- Informing program performance
  - Information on the quality of administrative data
  - Information from program participants about their experience
  - Evidence to assess program effectiveness
  - Information about factors that affect program effectiveness
  - Comparison of program participants, non-participants

# Why else does NCHS link?

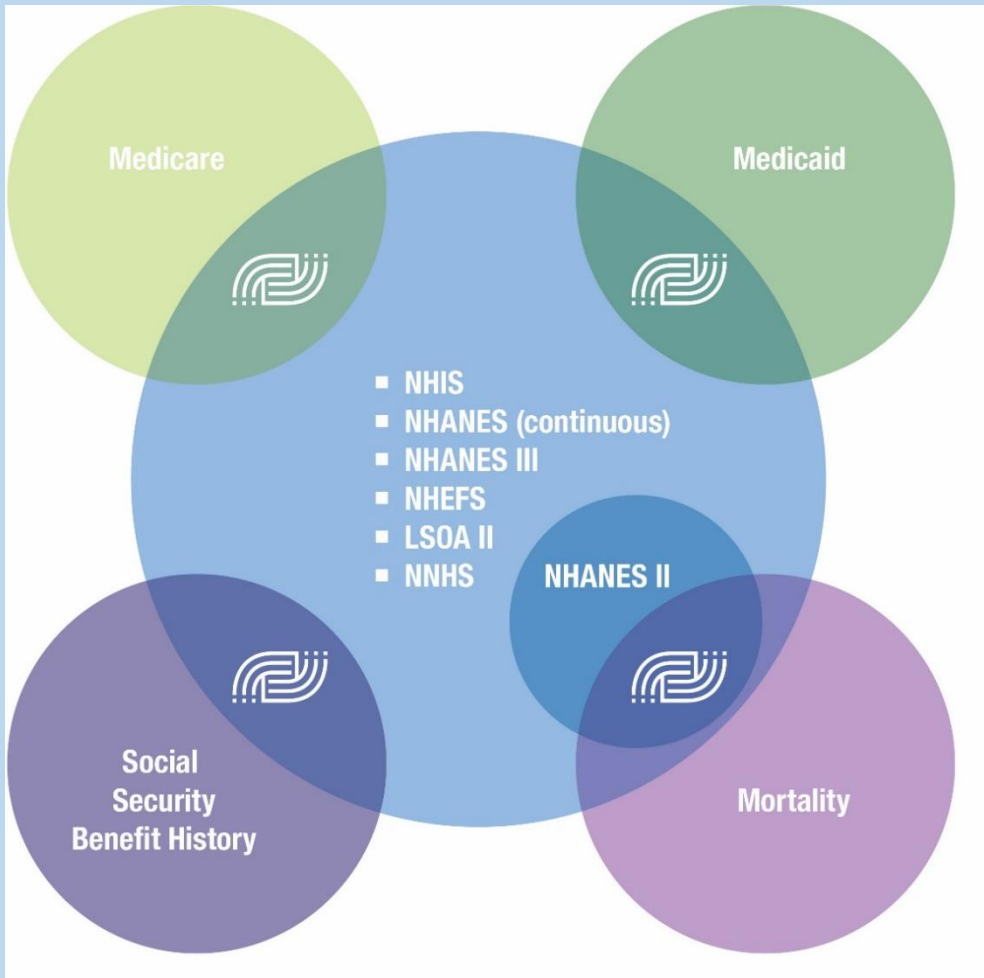
Recognizing data as an asset and recognizing the need to protect privacy

- Congress asks for data driven results
  - GPRA 1993
  - GPRA Modernization Act of 2010
- The Executive Branch recognizes data as an asset
  - Sharing Data While Protecting Privacy (M-11-02), November 3, 2010
  - Open Data Policy – Managing Information as an Asset (M-13-13), May 9, 2013
  - Next Steps in the Evidence and Innovation Agenda (M-13-17), July 26, 2013
  - Guidance for Providing and Using Administrative Data for Statistical Purposes (M-14-06), February 14, 2014

# Why else does NCHS link? (Continued)

- Studies make recommendations regarding use of these data
  - 1985 Secretary's Report on Black and Minority Health recommends innovative uses of currently available data consistent with the Privacy Act and confidentiality constraints.
  - 2013 Principles and Practices for a Federal Statistical Agency (National Academy of Sciences)
    - Consider upfront investments, cost savings, data quality, and long term improvements
    - Consider means for protecting quality of data files while allowing access for research
    - Consider protocols and criteria for understanding properties (e.g., population coverage, coding error rates, frequency of updating)
  - 2014 Big Data and Privacy: A Technological Perspective (President's Council of Advisors on Science and Technology)

# NCHS Record Linkage Program



## NCHS Population Health Surveys:

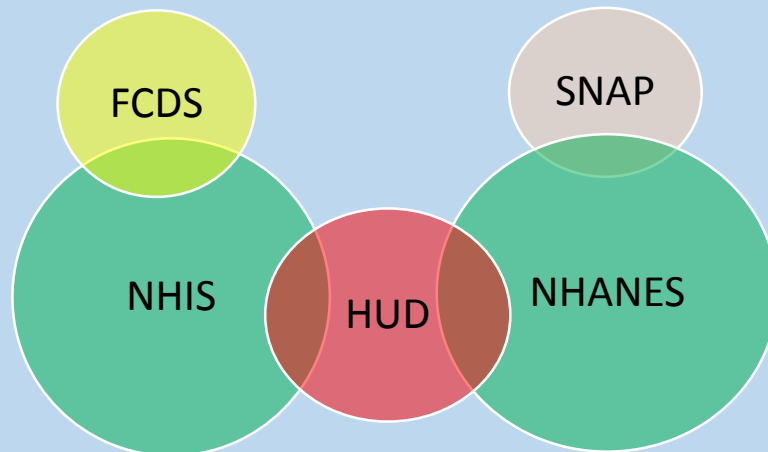
- National Health Interview Survey (NHIS)
- National Health and Nutrition Examination Surveys (NHANES, NHANES III, NHANES II, NHEFS)
- Second Longitudinal Study of Aging (LSOA II)
- National Nursing Home Survey (NNHS)

## Administrative records:

- Medicare (Through 2009)
- Medicaid (Through 2009)
- Social Security Administration (Through 2007)
- National Death Index (Through 2011)

# Recent Pilot Projects

- Florida Cancer Data System (FCDS)
- Supplemental Food and Nutrition Program (SNAP)
- Department of Housing and Urban Development (HUD)





# Why can't NCHS just link everything?

- Agencies have different statutory mandates regarding data ownership, privacy, and data sharing
- Purpose and nature of data collection can affect linkage in very important ways
  - Information for programmatic purposes vs information for research
  - Information about people may be collected in different ways
  - People don't always identify themselves the same way
  - Eligibility, program participation, vary over time
- Not everyone can be linked
  - Consent to participate in survey  $\neq$  consent to be linked
  - Not everyone is linkage eligible
  - Not everyone participating in the program was sampled into the survey
- The act of matching creates different data
  - *How do we protect individual respondents?*
  - *Who do the new data represent?*

# Getting the Right Match: Session Presentations

- **Differential Linkage by Race/Ethnicity and Availability of a Social Security Number in the Linkage with the National Death Index**  
Eric A. Miller Ph.D.<sup>1\*,2</sup>, Frances McCarty Ph.D.<sup>2</sup>, Jennifer D. Parker Ph.D.<sup>2</sup>
- **Mortality Experiences of National Health Interview Survey Respondents in the 2011 NHIS-Linked Mortality Files**  
Deborah D. Ingram Ph.D.<sup>2</sup>, Eric A. Miller Ph.D.<sup>1\*,2</sup>
- **Evaluation of the 4-Digit Social Security Number Algorithm Used for the 2011 Linked Mortality Files**  
Frances McCarty Ph.D.<sup>2</sup>
- **Characteristics of children in Medicaid Managed Care and Medicaid Fee for Service**  
Patricia C. Lloyd Ph.D.<sup>2</sup>, Alan E. Simon M.D.<sup>2</sup>, Jennifer D. Parker Ph.D.<sup>2</sup>
- **HUD-NCHS Data Linkage**  
Veronica Helms, MPH<sup>3</sup>

<sup>1</sup>ICF International - \*Work conducted while at NCHS

<sup>2</sup>National Center for Health Statistics

<sup>3</sup>US Department of Housing and Urban Development

# Research Data Center

## Research Data Center

RDC Home



What's New

### NCHS Research Data Center (RDC)

Restricted Data +

The National Center for Health Statistics (NCHS) developed the Research Data Centers (RDC) to allow researchers access to restricted data. Today, in addition to providing access to NCHS data, the RDC also hosts restricted data from a variety of groups within the Department of Health and Human Services (HHS).



Access Modes +

Proposal Process +

Confidentiality

The RDC is responsible for protecting the confidentiality of survey respondents, study subjects, or institutions from which data were collected. In order to do this, we request all researchers submit a research proposal outlining the need for this more sensitive data. The proposal provides a framework for us to identify potential disclosure risk. Once approved, we work with you to create a data file specific to your research question. We cannot send you the dataset, but we offer several modes of access.

Using Restricted Data +

Providing the Public Use Data

Publishing Guidelines +

Reference Materials

Directions

RDC Staff

FAQs

#### 1. [Preparing for Proposal Submission](#)

- [1. Restricted Data](#)
- [2. Access Modes](#)
- [3. The Proposal Process](#)

#### 2. [Using Restricted Data](#)

- [1. Confidentiality](#)
- [2. Approved Projects: Next Steps](#)
- [3. Publishing Guidelines](#)

### Related Sites

[National Center for Health Statistics](#)

[U.S. Census Bureau, Center for Economic Studies](#)

[cdc.gov/rdc/](https://cdc.gov/rdc/)



# NCHS/AcademyHealth Fellowship

## 2016 Call for Applications

National Center for Health Statistics (NCHS)  
and AcademyHealth Health Policy Fellowship

### Conduct Research at the National Center for Health Statistics

#### PURPOSE

This Fellowship fosters collaboration between the National Center for Health Statistics (NCHS) staff and visiting scholars on a wide range of health services research topics of mutual concern. The program also offers collective opportunities with AcademyHealth and NCHS.

#### AS A FELLOW, YOU WILL:

- Present research at an NCHS seminar;
- Learn the fundamentals of health policy development and implementation at AcademyHealth's Health Policy Orientation; and
- Attend and present research at AcademyHealth conferences, including the National Health Policy Conference and Annual Research Meeting.

Applications due: **Monday, November 9, 2015**  
Information: <http://www.academyhealth.org/nchs>  
Questions: [nchs@academyhealth.org](mailto:nchs@academyhealth.org)

CS238011 (02/13)



**More information about the  
NCHS data linkage program:**

**[http://www.cdc.gov/nchs/data\\_access/  
data\\_linkage\\_activities.htm](http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm)**