Federal Perspective on the National Vital Statistics System and the National Death Index

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National Committee on Health and Vital Statistics September 11, 2017



National Center for Health Statistics

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#### National Vital Statistics System (NVSS) and the National Death Index (NDI)

- Need for the records?
- Governance of the records?
- Financing of the records?
- Collection, processing, management, and protection of the data?
- Sharing and use of the records?
- Timeliness and Quality of the data?

### **National Vital Statistics System**

#### 57 registration jurisdictions

- Includes 50 states, District of Columbia, New York city and the 5 U.S. territories of American Samoa, Guam, Northern Marianas, Puerto Rico, and the U.S. Virgin Islands.
- Complete census----births, deaths, & fetal deaths
- Annually, there are about:
  - 4.0 million birth events
  - 2.6 million death events
  - 26,000 fetal death events (20 weeks or more gestation)

# Why We Need the Records for the NVSS?

- Describe the health status of the Nation
- Surveillance of new and/or emerging diseases
- Program management and policy making
- Health research

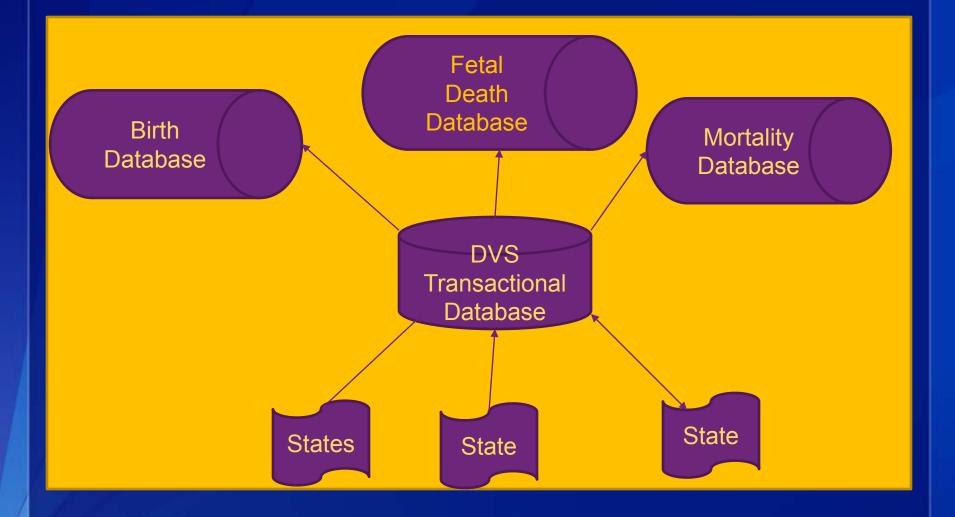
#### How is NVSS financed? (Statistics vs. Civil Registration)

- Vital records financed thru civil registration
  - Civil registration financed through the sale of birth and death certificates, or sale of services.
  - Most states have removed state appropriations from the vital records programs
- NVSS financed through the Vital Statistics Cooperative Program contract (VSCP) with the jurisdictions
  - Support civil registration but do not completely finance it.
- In 2017, the total contract is \$21.1 million per year. Components:
  - Births ----- \$9.5 million
  - Deaths ------ \$8.5 million
  - Fetal Deaths -----\$1.1 million
  - Infant/Death linkages----\$2.0 million

#### Governance of Records for the NVSS

- Vital records are governed by state, not Federal, laws and statutes
  - Laws/regulations about access & use of the records or parts of the records vary.
  - Model vital records and statistics law exist, but is not implemented nationwide
  - Use of the records are outlined in the VSCP contract
  - Participation in the VSCP contract is optional-----100% participation.
- Electronic vital registration systems
  - All jurisdictions have an electronic birth system
  - 46 jurisdictions have an electronic death registration system, not all of which are statewide or have complete coverage
  - 28 jurisdictions have an electronic fetal death system

## Flow of Records from States for NVSS



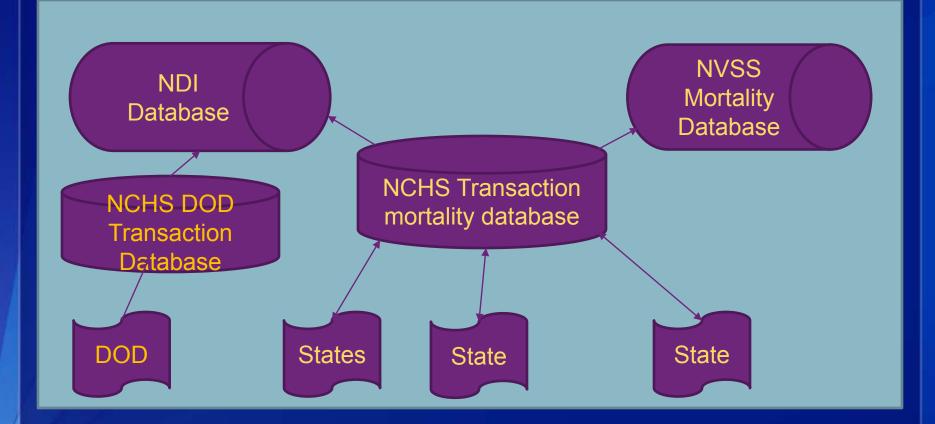
#### **Release of Vital Statistics**

- Annual Vital Statistics publications and topic-based Data Briefs
  - Births
  - Deaths
  - Fetal deaths
- Vital Statistics Rapid Release Program
  - Surveillance data on births and deaths
- Public Use Files births and deaths
- Files on CDC Wonder
- Confidential Research Files (approval of research project)
  - Births
  - Deaths
  - Fetal deaths
- Research Data Centers

#### National Death Index (NDI)

- Comprised of:
  - All deaths occurring within the U.S from 1979 forward
  - All military deaths occurring overseas
- Jurisdictions and DOD owned the records in database
  NCHS/DVS is an intermediary
  - Actions governed through data use agreements
- Used for data matching of researchers' files with death certificates to determine if a person has died, and if so, the cause of death
- Currently over 90 million records in the database

## Flow of Death Records in Creating the NDI and NVSS-Mortality Files



#### Use of the National Death Index

- Researcher must submit an IRB-approved project to NDI
- NDI Advisory Committee (comprised of state vital statistics professionals, & Federal/state/private researchers)
  - Reviews/approves each NDI application
- DVS Director reviews/approves applications approved by Advisory Comm.
- NDI staff matches researchers' records with NDI database using at least one of the following criteria:
  - First and last name and social security number
  - First and last name and month and year of birth
  - Social security and date of birth and sex
- NDI staff provides the results (fact &/or cause of death) to the researcher and assess the fee for matching services

#### Financing of and Access to the National Death Index

- 100% receipt operated----no appropriated dollars.
   Receipts must cover:
  - Payment of states for use of their records
  - NCHS NDI salaries and fringe (100%)
  - NDI operating expenses including:
    - Travel
    - IT/computer costs
    - NAPHSIS Cooperative Agreement
    - NDI Advisory Committee
  - NDI fee structure set by the jurisdictions

NDI access and use rules set by jurisdictions

Must cover the laws in the most restricted states.

What are the challenges and opportunities for the NVSS and the NDI?



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## Thank You!

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