The National Vital Statistics System (NVSS) is a critical data source for understanding the health of the nation, conducting public health surveillance of diseases and epidemics, and understanding the effectiveness of the healthcare and health financing systems. The National Death Index (NDI) is an invaluable tool for facilitating patient-outcomes research. Yet, both of these systems face serious structural and financial challenges.

**Current Situation:** Birth, death, and fetal death records are collected under the auspices of state, not Federal, laws and statutes. The National Center for Health Statistics (NCHS) obtains access to these records through the Vital Statistics Cooperative Program (VSCP) Contract, which provides base funding in return for their “use” for statistical and research purposes, and through the NDI contract which enables the receipt of personally identifiable information for each death event. Through the VSCP contract, NCHS obtains birth, death and fetal death records from the 57 registration jurisdictions, paying a total of $21.1 million per year ($9.5 million per year for births, $8.5 million for deaths, $1.1 million for fetal deaths, and $2.0 million for infant/death linkages). NCHS pays jurisdictions another $1.7 to $2.5 million per year through NDI receipts for the matching of researcher records to the NDI database.

While birth records are generally transmitted to NCHS well within the desired time frames for analysis and surveillance purposes, that is not the case for deaths and fetal deaths. About 44% of death records are transmitted to NCHS within 10 days of the date of death, up from only 7% in 2010. Transmission of fetal death records continue to be lag far beyond the death percentages. Improvements in timeliness performance has primarily occurred through the automation in both NCHS and the jurisdictions and enhancement of the jurisdictions’ business practices. These actions have enabled NCHS to: a) release the mortality statistics and the NDI files much earlier, from 30 months in 2011 to less than 12 months in 2016; b) release the detailed provisional birth measures within 6 months after the close of a calendar year and the final birth file within 9 months, and c) release reliable quarterly provisional rate estimates for mortality including, but not limited to, reliable provisional counts for flu surveillance and monthly surveillance counts of drug overdose deaths.

**Challenge:** While we have achieved a faster reporting system for health status assessment and the surveillance of some births and deaths of immediate public health concern, further steps are needed. Improvements to date have been principally financed through one time receipts, making it imperative that sustainability of these gains be a top priority. Continual gains are critically needed for timely and higher quality birth, death and fetal death data, and for the retrieval of additional information on the death certificate. Finally, we need to make the National Death Index (NDI) more affordable and nimble for health research.

**Opportunities:** To transform the NVSS and the NDI systems even further, we must:

1. Increase the rate of mortality records transmitted to NCHS within 10 days from 44% in 2016 to at least 80% by incentivizing improved state performance and targeting large underperforming jurisdictions;
2. Initiate new special projects at the jurisdictional level to improve data quality of birth, death, and fetal death information on certificates. Projects such as the following need to be implemented:

   o Expansion of the NCHS Validation and Interactive Web Service to more jurisdictions to identify and alert the data provider of problem cause-of-death entries as they are being first entered on an EDRS by the data provider;
   o Implementation and/or enhancement of quality assurance programs in each of the 57 jurisdictions;
   o Establishment of performance-based accreditation program for jurisdiction’s vital records/statistics agencies;
   o Development of a Cause of Death Decision-Support Tool for physicians to assist them in determining cause of death;
   o Implementation of birth, death and fetal death e-learning systems for clinical and non-clinical hospital and medical staffs.

3. Improve the value and use of vital statistics systems by:

   o Expanding the NCHS Vital Statistics Rapid Release Program to include selected health indicators, and weekly counts and/or analyses of drug overdose deaths (including specific drugs involved) and other urgent emerging health threats; and
   o Expanding a rapid release type program using provisional data at the state level.

4. Modernize the NCHS Medical Mortality Coding System to:

   o Code a larger proportion of records electronically;
   o Use machine-learning and natural language approaches to conduct rapid analysis of literal text data for inclusion in the NVSS statistical and NDI databases and to improve the coding of records; and
   o Undertake quicker analysis of drugs and other important health topics.

5. Improve the electronic linkage of jurisdictional vital registration systems with other electronic systems using nationally approved standards including:

   o Linkage of electronic birth systems with electronic medical records to abstract the relevant medical information recorded on birth certificates;
   o Linkage of electronic death registration systems with Medical Examiner and Coroner Case Management System to enable the timely flow of relevant mortality-related information between the two entities;
   o Linkage of electronic death registration systems with hospital-based electronic medical records system.

The electronic transfer of information between electronic medical records and electronic vital registration systems provides an opportunity to improve the quality of medical information on birth and death certificates and the opportunity for physicians to more easily complete the cause of death. The development and national approval of exchange standards for births, deaths, and fetal deaths will be required.
6. Improve NDI by reducing the cost to researchers for data matching services while maintaining NDI payments for states (the charging for services is largest perceived barrier to the use of the NDI for research), minimizing where feasible the barriers to NDI access and use, and creating an NDI Portal to enable electronic processing of applications for the purposes of reducing review time.

7. Expand the financial resources for state vital records/statistics programs. Funding of state vital records/statistics programs beyond NCHS and SSA is critically. Where critical health outcome information is needed for national or state program management and evaluation, Federal agencies should incorporate into their respective corporate agreements or contracts with their state counterparts a priority that their funds can be used to support state vital record/statistics programs. The Office of Public Health Preparedness and Response is an example of this action. With the exploding demands for timely, high quality data, the rising costs for securing and maintaining technology systems, and the increasing proportion of state vital records/statistics programs that must “live or die” on their receipts, Federal entities can no longer assume that the provision of birth, death and fetal death information can or should be free or at very small marginal costs.

8. Improve the performance of state vital records/statistics programs. Wide gaps exist between the highest and lowest performing jurisdictions. Steps should be taken to ensure that a minimal performance level exist across all jurisdictions. Tying contract awards to timeliness and quality performance, initiating an accreditation program of state vital records/statistics agencies, and initiating/targeting performance enhancement projects for poorly performing are some of the initiatives or policy changes that should be considered. These initiatives should be conducted in concert with the state health officers and their association.

**Results:** Undertaking and completing these opportunities will result in a vital statistics system that can be an effective, high quality tool for health status assessment, near real-time surveillance of events of immediate public health importance, and research impacting the health of the nation. Moreover, these opportunities can help minimize the structural and financial plight of this Nation’s state vital records/statistics programs.
Federal Perspective on the National Vital Statistics System and the National Death Index

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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

- 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

- Birth Database
- Fetal Death Database
- Mortality Database

DVS Transactional Database

States → DVS Transactional Database

State → DVS Transactional Database

State → DVS Transactional Database
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

- NDI Database
- NVSS Mortality Database
- NCHS Transaction mortality database
- NCHS DOD Transaction Database
- DOD
- States
- State
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 NVSSS and the NDI?
Thank You!

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