



**Next Generation Vital Statistics:
A Hearing on Current Status, Issues, and Future
Possibilities**

Held September 11-12, 2017

Hearing Summary

National Committee on Vital and Health Statistics



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

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Issued May 2018

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Executive Summary

Vital records data are the foundation for essential functions at local, state, territorial, and federal levels but the system is highly vulnerable. Federal leadership is needed to modernize and secure the vital records and vital statistics data collection network as a sustainable, reliable resource.

ES-I. Introduction and Overview of the Hearing

Vital records, the building blocks for vital statistics, are the legal registration of major life events for individuals, including birth, fetal death, marriage, divorce, and death. Vital statistics, the compilation of de-identified vital records, are the quantitative data concerning vital events in a population, such as the number of births and the death rate. Together, the Vital Registration and Statistics System (VRSS), play a critical role in public health surveillance and evaluation of the effectiveness of health care and health financing, and are relied on for identity establishment, research, commerce, and many other essential uses.

The National Committee on Vital and Health Statistics (NCVHS), a Federal Advisory Committee, held a hearing in Washington, D.C., in September 2017 to review the nation's existing VRSS and explore how to transform it into a system that is more robust, integrated, and sustainable. The impetus for the hearing was a combination of concerns about the sustainability of the VRSS and awareness of its great importance to the operation of essential national functions. This report summarizes the hearing testimony and discussion, which focused on identifying the strengths and challenges for data collection, data use, and the viability of the federated VRSS moving forward.

The hearing brought together more than 40 expert stakeholders from 25 organizations within Federal and state government, research, healthcare, commerce, professional associations, and other relevant fields. (The agenda and list of testifiers are in Appendix 1, and presenters' slides are posted on the NCVHS website.) Together, the hearing participants represented both producers and users of vital records data, and through providing these distinct perspectives, they delineated critical elements and challenges facing the VRSS. In two days of testimony and discussion, the participants described the complex work of collecting and reporting information on birth and death records, and reviewed the many essential functions of the aggregated data for public health surveillance, population estimates, identity establishment and verification, death notification and fraud prevention.

The picture of the existing VRSS that emerged from the testimony was of a network of interdependent systems in which vital records data are pulled together from the disparate civil registration laws, practices, and systems of 57 U.S. registration jurisdictions—the 50 states plus New York City, the District of Columbia, and 5 U.S. territories. Sustainable financial support is a fundamental issue: the VRSS is inadequately financed by 57 separate, and in many cases outdated, business models; in addition, many of the entities that use the data do not share the costs of data collection and management. The resulting funding limitations make it very difficult for jurisdictions to invest in improvements that would make their processes more efficient, complete, timely, and precise.

In response to this situation, hearing participants considered what is already being done and what more is needed to transform the current system into a more efficient, sound, and sustainable system that generates timely, high quality, multi-purpose information flows.

ES-II. The Vital Records and Vital Statistics Landscape

The VRSS landscape encompasses the processes, systems, institutions, and records involved in recording vital events and the vital statistics that are derived from vital records data. Vital records are legal documents collected by jurisdictional vital registration offices to document individual vital events. Each jurisdiction owns the data it collects, and its laws and statutes govern the collection, use, sharing, dissemination, and reuse of all vital record information. The 57 jurisdictions in the vital registration system share their vital records data with many different groups: within jurisdictions to inform public health efforts, with each other for notification of events to residents that occur outside jurisdiction boundaries, with the National Association for Public Health Statistics and Information Systems (NAPHSIS), an organization representing the state vital records and public health statistics offices for systems for vital event verification, with the National Center for Health Statistics (NCHS) through the Vital Statistics Cooperative Program for the compilation of detailed data sets in the National Vital Statistics System, and with the Social Security Administration (SSA) to properly administer federal benefits programs.

The box on page 13 provides definitions of the major terms used for elements of the VRSS. Figures 1 and 2 on pages 15 and 16 illustrate the complexity of the flow of birth and death data, respectively, to and through vital records offices (VROs) and to national entities, such as NCHS and SSA for further distribution. They also show some of the important uses of the data and the payments and funding for the operations of vital record production and maintenance.

ES-III. The Uses of Vital Record Data and Vital Statistics

The testimony at the NCVHS hearing highlighted individual and institutional uses of vital records as administrative and legal documents, as well as the wide range of uses of vital statistics. The major areas of use described in the hearing include health care and public health; population estimates; and identity verification, death notification, and fraud prevention. The sidebars throughout this report describe illustrative use cases. Both the immense value of the VRSS and many of the challenges associated with the system stem from the multiple purposes it has evolved to serve, often linked with other data.

The users of VRSS include Federal agencies; local, state, and territorial agencies; researchers; health care providers; commercial entities; and individual Americans. Major areas of use and examples are outlined in Table 1.

Essential Uses of Vital Records and Statistics	
Health Care and Public Health	<ul style="list-style-type: none"> ○ Studying clinical outcomes and disparities ○ Developing performance and outcome measures ○ Populating health registries, e.g., immunization registries ○ Tracking emerging diseases ○ Monitoring trends in community health
Population Estimates	<ul style="list-style-type: none"> ○ Basis for federal funding allocations ○ Denominators for health statistics ○ Controls for government surveys and unemployment rates ○ Basis for projecting Social Security costs and revenue for Congress
Identity Establishment and Verification, Death Notification, Fraud Prevention	<ul style="list-style-type: none"> ○ Required identity verification for passports, drivers' licenses, voter registration ○ Starting and stopping pension benefits ○ Preventing fraud in insurance, financial institutions, reverse mortgages, Social Security ○ Restoring unclaimed property

Table 1

ES-IV. System Challenges

Over the course of the two-day hearing, hearing participants identified challenges in the major areas listed in Table 2, which affect providers and users of VRSS data both within jurisdictions and at the national level.

System Challenges Affecting Producers and Users of the VRSS	
Costs and Financing	
	Existing payment models do not cover the costs borne by jurisdictions for vital records collection, management, and sharing.
	Many data users neither directly nor adequately fund the VRSS.

Complexity, Inefficiency, and Gaps in Technology
Extensive information is requested on birth and death certificates; information is needed from multiple sources.
Certificates are still designed around a paper-based template; electronic modernization is needed.
Digital data sources for vital registration are often inconsistent and not interoperable; vital records are not generally linked to source data such as electronic health records and medical examiner and coroner file management systems.
The centralization of jurisdictional IT process result in the VRSS competing for IT funding and prioritization with other programs.
Variability and Performance Gaps among Jurisdictions
There are disparities among vital records offices, linked to funding, laws, policy, and capacity differences.
Strong jurisdictions want to be allowed to move ahead and model best practices.
Quality Concerns
Large strides have been made to reduce the time lag between vital registration and availability of data for vital statistics surveillance; additional improvement is still needed.
Among quality issues, greater timeliness was hearing participants' top priority, although increased data accuracy is also desired.
Lack of Training for Data Providers and Collectors
Aspects of vital record data entry process are detached from contributors' normal workflow and needs; this limits their appreciation for efficiency, timeliness and data quality.
Data providers need additional training in vital records data assemblage and certificate completion.
Barriers to Data Access
Barriers to access hamper the use of vital records data; these limitations stem from restrictions on data sharing and reuse of vital registration jurisdictions' laws and statutes.
Marked redundancy, overlap and gaps exist in the efforts to aggregate and make the VRSS accessible; multiple federal agencies provide different slices of the data to internal and external users.
Challenges Specific to Mortality Data
Variations among state electronic death registration system capabilities prevent public health officials and health providers from keeping pace with public health problems.
Cause of death data is not well reported due to lack of training, experience and EHR system support for clinicians who certify most deaths as well as the lack of data integration between health care providers and medical examiners'/coroner's systems.
Researchers, healthcare providers and commercial users have difficulty getting timely information on the fact of death.

Table 2

ES-V. Looking to the Future

The question that guided the NCVHS hearing on the next generation of the VRSS was, *“How do we transform today’s vulnerable vital records data collection network into a system that produces accurate and timely information to support a breadth of local, state, territorial, and Federal data needs?”*

Moving toward this goal begins with elaborating the vision for the VRSS of the future. Over the course of the two-day hearing, several speakers shared their respective vision for the next generation of vital registration and statistics and steps that could be taken to move in that direction. A vision emerged for an integrated and accessible system that efficiently provides timely data for use in public health monitoring, community health improvement, national security, and numerous additional important purposes.

The Committee invited hearing participants to suggest possible strategies for transforming the VRSS to alleviate the current vulnerabilities in the system. Table 3 summarizes the major areas in which hearing participants suggested transformative strategies. Presentation of these suggestions does not represent NCVHS endorsement.

Suggested Strategies for Transforming VRSS
➤ Identify, design and deploy a sustainable contemporary business model to enhance systems for vital records data collection and sharing.
➤ Simplify and align practices, and take greater advantage of data interoperability to reduce duplicative data entry.
➤ Expand training for data providers and integrate processes into workflow, with accreditation as a tool.
➤ Advocate for changes to state laws to improve data access.

Table 3

Next Steps

A point made often during the hearing was that the Federal government is heavily reliant on vital records data and bears a special responsibility for supporting and enhancing the system; several speakers urged NCVHS to convene stakeholders and advise HHS in this area. Further, they urged NCVHS to work with stakeholders and subject matter experts to develop a long-term vision—seen as the appropriate context for devising a new business case—and to target short-term opportunities for improvement. There were reminders to involve the entire coalition of stakeholders in efforts to design and advocate for system-wide enhancements, building on the progress already being made in many areas.

Given the foundational significance of the VRSS and current system vulnerabilities, the Committee finds that more attention needs to be paid to this critical infrastructure.

Based on the hearing and subsequent analysis, the Committee has determined that federal leadership is needed to:

- Convene the multiple stakeholders to modernize the federated system.
- Develop business models to better align payment with uses and distribution of payment to cost centers;
 - Obtain systematic information regarding the current business model from each vital registration jurisdiction to inform this work¹.
- Modernize laws, technology and process related to vital records and vital statistics;
- Train people collecting and contributing VRSS data and credential the jurisdictional vital registration systems.

¹ Detailed specifics are outlined on page 25 of the NCVHS report, *Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue*. January 10, 2018, available online: <https://www.ncvhs.hhs.gov/vital-records-and-vital-statistics-in-the-united-states-uses-users-systems-and-sources-of-revenue/>.

I. Introduction and Overview of the Hearing

Vital records, the building blocks for vital statistics, are the foundational data source for understanding the U.S. population and are critical for identity verification. They are the product of vital registration and consist of the completed paper or electronic forms that document vital events, such as birth certificates, death certificates, and records of marriage and divorce. Vital statistics, the compilation of de-identified vital records, are quantitative data concerning vital events in a population, such as the number of births and the death rate. These are the building blocks for monitoring population health, e.g., the opioid epidemic, and other fundamental demographic activities such as creating population estimates. They play a critical role in public health surveillance and evaluation of the effectiveness of health care and health financing, and are relied on for research, and many other endeavors. The National Committee on Vital and Health Statistics (NCVHS), a Federal Advisory Committee, held a hearing in Washington, D.C., in September 2017 to review the nation's existing Vital Records and Statistics System (VRSS) and explore approaches to transform it into a system that is more sound, integrated, and sustainable. This report summarizes the hearing testimony and discussion.

The impetus for the hearing was a combination of concerns about the sustainability of the VRSS and awareness of its great importance to the operation of essential national functions. The hearing brought together more than 40 expert stakeholders from 25 organizations within Federal and state government, research, healthcare, commerce, professional associations, and other relevant fields. (The agenda and list of testifiers are in Appendix 1, and presenters' slides are posted on the NCVHS website.) In two days of testimony and discussion, the participants described the complex work of collecting and reporting information on vital records; reviewed the many essential functions of the aggregated data in protecting the nation's health and economic vitality; and considered what is already being done and what more is needed to transform the current system into a more efficient, sound, and sustainable system that will generate timely, high quality, multi-purpose information flows.

The hearing brought together both the producers and users of vital records data to share their distinct, respective perspectives, with the main focus on birth and death record data. These exchanges resulted in clear delineation of the critical elements of and challenges facing the VRSS. Those who use vital records and statistics in their work were enlightened by the perspectives of those who collect and produce these data. For their part, the data producers welcomed the opportunity to see the numerous uses and need for data sets generated by their work. The discussions were also enriched by contributions from seasoned experts such as Delton Atkinson, Director of the National Center for Health Statistics' (NCHS) Division of Vital Statistics, who brought in-depth understanding and clarity to this complex topic.

Use Case: Preventing Fraudulent Use of Identities

Authentication of identity is a critical use of vital records. After death data are obtained by the Social Security Administration, multiple federal, state, and commercial users employ them to prevent fraudulent filings for tax refunds and continued receipt of pensions, annuities, and insurance payments. In addition, death records are linked to birth records at the state level so that any request to validate a person's identity by their birth certificate will be rejected for deceased persons.

The data producers who testified included a hospital-based birth registrar, regional and state vital statistics directors and supervisors, funeral directors, coroners, medical examiners, state health department informaticians, and several leaders of the National Association for Public Health Statistics and Information Systems (NAPHSIS), the national non-profit association that represents vital records and public health statistics offices. The testimony by these experts grounded the discussions in the realities of vital registration and record management processes, with their focus on serving individual Americans at critical moments of their lives. The fact that the hearing occurred as several areas of the United States were coping with the effects of major hurricanes heightened awareness of the challenges vital registrars face in continuously managing these critically important records, regardless of the circumstances.

The users of VRSS data at local and state levels, in both governmental and non-governmental capacities, brought perspectives from research, health care, public policy, public health, immunization registries, and other areas. Federal data users on the panels described their use of the data within HHS operating divisions, including Centers for Medicare and Medicaid Services (CMS), the National Institutes of Health (NIH), the Health Resources and Services Administration (HRSA), and the Centers for Disease Control and Prevention (CDC), as well as in the Social Security Administration, Veterans Administration (VA), Census Bureau, State Department, and Department of Homeland Security. Representatives of several non-governmental organizations and associations also testified and contributed to the discussions. They included three panelists who widened the frame of reference to include commerce by describing the significant uses of vital records in their businesses. Finally, the Chief of Vital Statistics for *Statistics Canada* brought an international lens to the subject, reporting that the Canadian and U.S. vital statistics systems face many of the same issues.

The picture of the existing VRSS that emerged from the testimony was of a network of interdependent systems in which data are pulled together from the disparate civil registration practices and systems of 57 U.S. registration jurisdictions—the 50 states plus New York City, the District of Columbia, and 5 U.S. territories. Financing remains an ongoing challenge: the VRSS is inadequately financed by 57 separate and outdated business models, and many of the entities that use the data do not share the costs of data collection and management. The resulting funding limitations make it very difficult for jurisdictions to invest in the improvements that would make their processes more efficient, complete, and precise. At the front end of the process, most data clerks, health care providers, hospital staff, and others who contribute vital event data lack a complete picture of the multiplicity of uses and enormous benefits derived from the information they provide.

Use Case: Measuring the Opioid Epidemic

In response to the opioid crisis, HHS is focusing on five major priorities, one being strengthening understanding of the epidemic through better public health surveillance. The primary source of data on drug overdoses is emergency department and hospital visit data and mortality data. In 2017, CDC produced its first annual surveillance report on drug-related risks and outcomes. Mortality data were a major source of data used in this publication, detailing death rates by intent, drug class, age, year, and state. The information obtained from vital statistics is essential in the Department's effort to tackle this national crisis.

Besides outlining the functions, uses, and challenges of vital records and vital statistics, the hearing clarified the potential value to be realized from a more stable, connected, and efficient VRSS. A vision began to emerge of a system, built on existing assets, in which vital records and vital statistics are fully used to strengthen public health surveillance, enhance healthcare, inform health finance policy, serve as the foundation for identity establishment, provide information for commercial enterprises, and deliver other important benefits for Americans. The hearing also laid solid groundwork for NCVHS to continue to work with stakeholders to clarify the vision for the next generation of the VRSS and the strategies that could make it a reality.

II. The Vital Records and Statistics System Landscape

The VRSS landscape encompasses the processes, systems, institutions, and records involved in recording vital events and the vital statistics that are derived from vital records data. The box on this page provides definitions of the major terms used for elements of the VRSS.

Vital Event Registration

Vital records are legal documents collected by vital registration offices to document individual vital events such as birth and death. Vital registration is the continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events in a population, in accordance with the law. For birth certificates, hospitals input the vast majority of data, drawing from a detailed worksheet that mothers fill out at the hospital, including paternity establishment and demographic information on the father. This information is augmented by data from other sources such as prenatal care providers. For death certificates, funeral directors are responsible for providing most of the demographic data, generally obtained through consultation with a family member or friend; and medical examiners, coroners, pathologists, or other physicians supply information on the chain of events that is used to define the

Terminology

VRSS, Vital Records and Statistics System, is the term used to describe both the vital records system and the vital statistic system throughout this report.

Vital events are the major life events for individuals and include fetal death, still birth, birth, marriage, divorce, and death. The focus of this report is on two vital events: birth and death.

Vital registration is the process of collecting, recording, and storing specific information on individual vital events. When this process is completed electronically, it is referred to as “electronic [vital event] registration”; examples include electronic birth registration and electronic death registration.

Vital records are the product of vital registration and consist of the completed paper or electronic forms that document vital events, such as birth certificates and death certificates. Vital records may be stored in either a paper or an electronic form.

Vital registration system consists of the various persons, agencies, equipment, forms, rules (standards), and processes that carry out vital registration. When this system completes vital registration electronically, it is referred to as an “electronic [vital event] registration system”; examples include electronic birth registration system (EBRS) and electronic death registration system (EDRS).

Vital records office (VRO) is the government agency or organization within a state, local, or territorial jurisdiction that is responsible for registering vital events, storing vital records, and issuing certified copies of vital records for legal and administrative purposes. In some jurisdictions, the VRO may be referred to as the “vital registration office” or the “vital statistics office.”

Vital statistics consists of quantitative data concerning vital events in a population, such as the number of births and the death rate. Vital statistics are derived from an analysis of vital records data.

(NCVHS. Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue. Washington, DC: NCVHS, January 2018. Page 3-4.)

underlying cause of death. While not discussed in much detail, jurisdictions also create and maintain records on fetal deaths, adoption, marriage, and divorce.

The process of creating a vital record is complex. For example, Kari Guida, an informatician with the Minnesota Department of Health, described an analysis conducted by their office that found that a hospital's workflow and process to search, abstract, and submit birth registration required 17 high-level steps. Death certificate completion, because it is accomplished through the combined efforts of many different contributors, is even more complicated. Furthermore, because of the high turn-over rates among persons involved in the various steps of the data flow, there is a constant need to train staff involved in the vital record creation process.

Once vital events are registered, this information is shared with a number of different entities for use and distribution. Each jurisdiction has programs within their health departments that use the data. For example birth data are used to create listings of infants and for enumeration purposes. Some of the data are shared with the Social Security Administration, using the birth information to run the Enumeration at Birth process and the death information to create a Death Master File for terminating federal benefits. The information is also given to NAPHSIS to create several systems to share the data both between jurisdictions and to state, federal and commercial users to verify births and deaths. Finally, the data are provided to both state and federal health statistics centers for the development of statistical data files and publications.

Vital Statistics

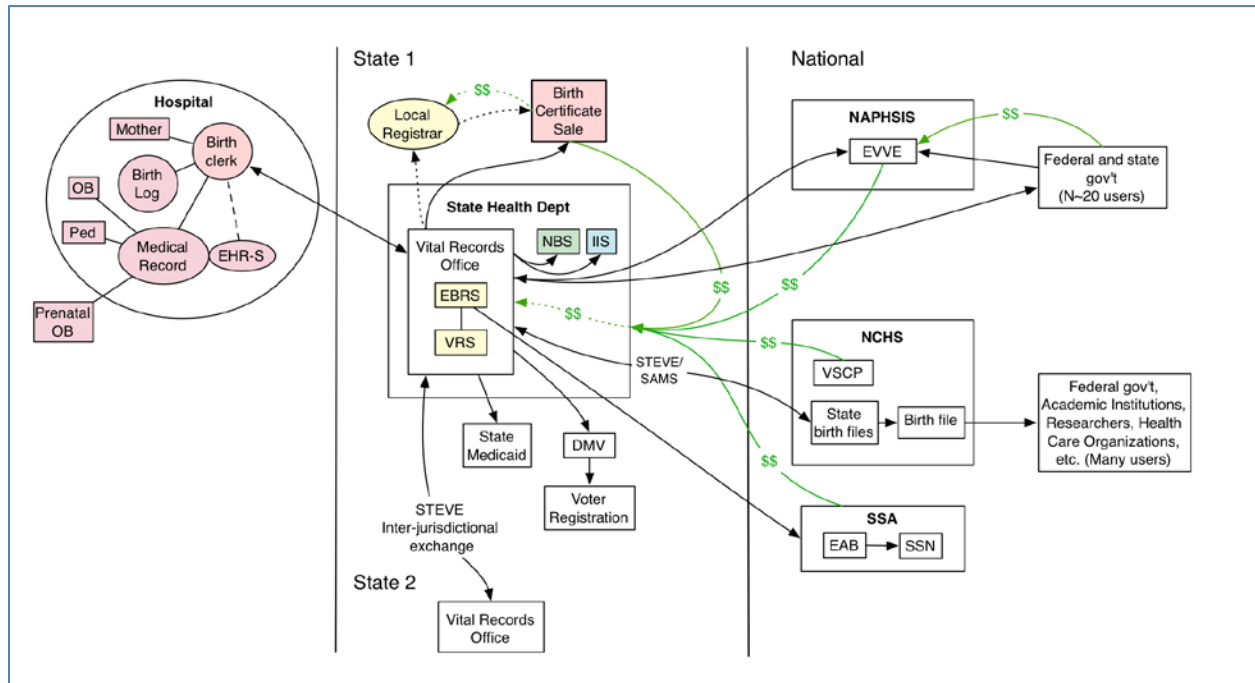
As data providers report vital events by completing standardized data collection forms, they record legal, demographic, and medical data. A subset of these data are issued as part of birth or death certificates and stored as vital records. The rest of the data are used to generate vital statistics. The 57 jurisdictions in the vital registration system share their vital records demographic and medical data with the National Center for Health Statistics (NCHS) through the Vital Statistics Cooperative Program, which compiles detailed data sets on births, deaths, and fetal deaths for the entire U.S. population in the National Vital Statistics System (NVSS). For each event, data are sent to NCHS for coding and editing. Identified errors or incomplete records are sent back to the states for further work; NCHS receives close to 7.5 million transactions in creating the 2.5 million national death records annually. NCHS suspended the collection of detailed records of marriages and divorces in 1996 due to limitations in the information collected by the jurisdictions as well as budgetary considerations and now receives only total counts of these events.

Information Flow in a Federated System

Figures 1 and 2 illustrate the complexity of the flow of birth and death data, respectively, to and through VROs. They also show some of the important uses of the data and the payments and funding. Both figures depict the process of gathering information about the vital event on the left, including the types of people and organizations involved in the process. The middle panels depict the roles of state government in registering the vital event and providing data about vital events to various state and national users. The right panels depict major national agencies and organizations that compile, use, and distribute birth and death records obtained from state vital

records offices. The figures also depict payments made by various users of vital records to state or national organizations for the use of the records. Payments by users to providers of vital records or vital statistics data are shown by green lines with "\$\$."

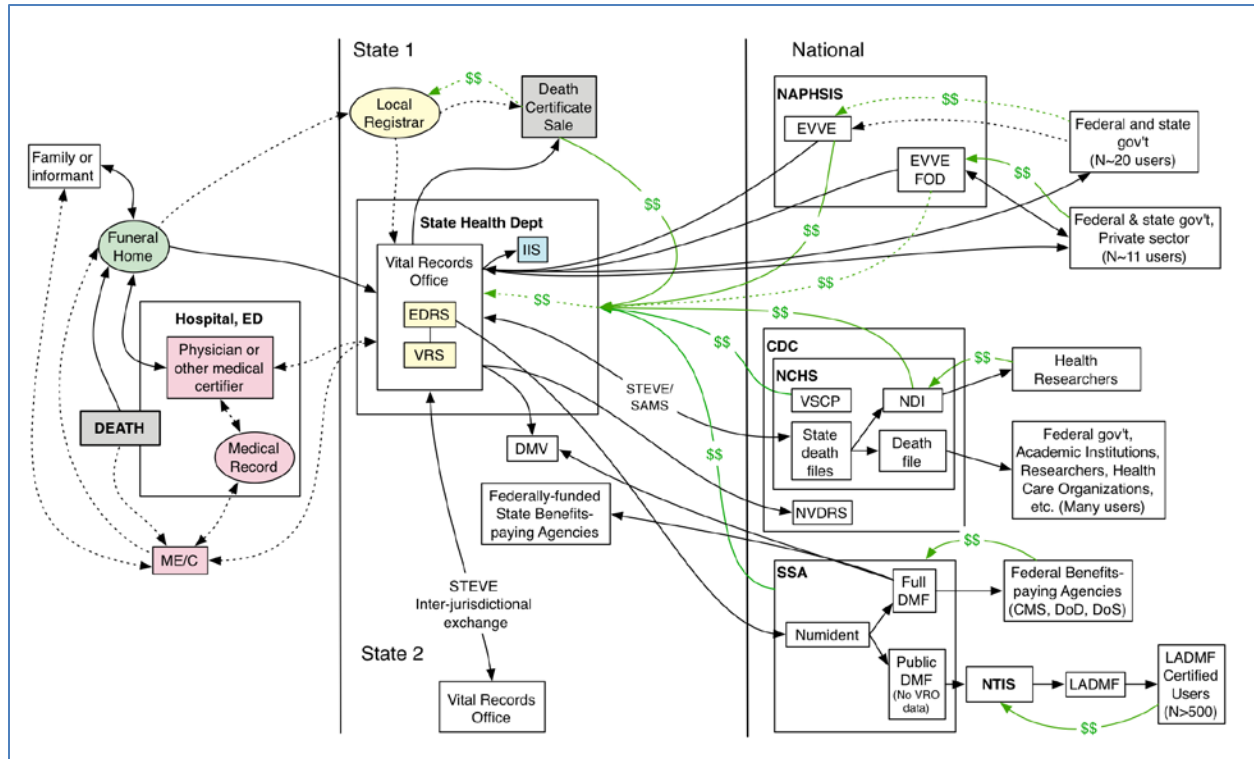
Figure 1. Current Birth Registration Process for a State Vital Records Jurisdiction



- Legend**
 — Solid lines denote typical processes
 - - - Dashed lines denote other, less common processes
- DMV = Department of Motor Vehicles
 EAB = Enumeration at Birth
 EBRS = Electronic Birth Registration System
 EHR-S = Electronic Health Record System
 EVVE = Electronic Verification of Vital Events
 IIS = Immunization Information System
 NBS = Newborn Screening
 NCHS = National Center for Health Statistics
 OB = Obstetrician or comparable health care provider
 Ped = Pediatrician
 SAMS = Secure Access Management Services
 SHD = State Health Department
 STEVE = State and Territorial Exchange of Vital Events System
 VRS = Vital Registration System
 VSCP = Vital Statistics Cooperative Program

Source: NCVHS. Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue. Washington, DC: NCVHS, January 2018
<https://www.ncvhs.hhs.gov/vital-records-and-vital-statistics-in-the-united-states-uses-users-systems-and-sources-of-revenue/>

Figure 2. Current Death Registration Process for a State Vital Records Jurisdiction



Legend

— Solid lines denote typical process
 - - - Dashed lines denote other processes

- CMS = Centers for Medicare and Medicaid Services
- CR = Cancer Registry
- DMF = Death Master File
- DMV = Department of Motor Vehicles
- DoD = U.S. Department of Defense
- DoS = U.S. Department of State
- EDRS = Electronic Death Registration System
- EHR-S = Electronic Health Record System
- EVVE = Electronic Verification of Vital Events
- EVVE FOD = Electronic Verification of Vital Events Fact of Death
- IIS = Immunization Information System
- LADMF = Limited Access Death Master File
- ME/C = Medical Examiner / Coroner
- NCHS = National Center for Health Statistics
- NDI = National Death Index
- NTIS = National Technical Information Service
- NVDRS = National Violent Death Reporting System
- SAMS = Secure Access Management Services
- SHD = State Health Department
- STEVE = State and Territorial Exchange of Vital Events System
- VRO = Vital Records Office
- VRS = Vital Registration System
- VSCP = Vital Statistics Cooperative Program

Source: NCVHS. Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue. Washington, DC: NCVHS, January 2018.

<https://www.ncvhs.hhs.gov/vital-records-and-vital-statistics-in-the-united-states-uses-users-systems-and-sources-of-revenue/>

Significantly, each jurisdiction owns the data it collects, and its laws and statutes govern the collection, use, sharing, dissemination, and reuse of all vital records data. For example, each jurisdiction must approve each use of the NVSS files that include sub-state geographic detail. These varied and complicated jurisdictional rules result in uneven access to data at both state and national levels, exacerbated by capacity differences among the VROs. Starting in 1907, over

100 years ago, and most recently in 2011, federal and state representatives have cooperatively written a Model State Vital Statistics Act and Regulations, known as the Model Law, with the goal of reducing variability across jurisdictions by providing states and territories with a model for modifying their own laws and regulations.² To date, however, the U.S. Department of Health and Human Services has not endorsed the latest (2011) version and only three states have adopted portions of the 2011 version. Three presenters pointed out that without endorsement by the U.S. Department of Health and Human Services, jurisdictional vital records offices have difficulty navigating their state government to advocate for legislative change. This subject is discussed further in Sections IV and V below.

III. The Uses of Vital Record Data and Vital Statistics

The testimony at the NCVHS hearing highlighted individual and institutional uses of vital records as administrative and legal documents, as well as the wide range of uses of vital statistics. In brief, individual Americans use birth certificates to establish and confirm their identity and citizenship, and death certificates to conduct legal and business transactions after the death of a person of whom they are a beneficiary and/or legal agent. Local, state, and territorial jurisdictions, researchers, health care providers, commercial businesses, and other entities use vital records and vital statistics for legal and administrative purposes and in public health surveillance, research, policy creation and evaluation, program management, and more. For example, local, state, and territorial governments use VRSS data for program enrollment and eligibility and to study health care outcomes, monitor community health, and stop services upon death. Federal agencies use individual birth and death data for administrative purposes such as determining citizenship and beginning and ending entitlements, as well as for a host of public health purposes. The aggregate data are

Use Case: Reducing Early Elective Deliveries

Elective deliveries before the gestational age of 39 weeks—that is, early deliveries that are not deemed medically necessary—can lead to preventable neonatal intensive care admissions and increased long-term health risks to infants while providing no known benefits to the mother or newborn. The Centers for Medicare and Medicaid Services and the March of Dimes, along with states and other organizations, used national natality data to demonstrate clear differences in rates of early elective deliveries among states. The data strengthened the momentum for new state and federal policies and generated quality improvement initiatives in this arena. Subsequent natality data are being used to evaluate the impact of these efforts.

² Department of Health and Human Services, Centers for Disease Control and Prevention National Center for Health Statistics, Hyattsville, Maryland 20782. Model State Vital Statistics Act, Model State Vital Statistics Regulations, 2011 Revision. Endorsed by the National Association for Public Health Statistics and Information Systems by resolution; pending Department of Health and Human Services approval. <https://www.naphsis.org/> (click on bottom right corner). Accessed January 18, 2018.

used as some of the inputs for population estimation and projection by the Social Security Administration and the Census Bureau.

Both the immense value of the VRSS and many of the challenges associated with it stem from the multiple purposes it has evolved to serve, often linked with other data. Several of the major areas of use described in the hearing are outlined below, and the sidebars throughout this report describe illustrative use cases.

Health Care and Public Health

The hearing focused particular attention on the current and potential uses of birth and death records for public health work. Several examples concerned maternal and child health. Karen Matsuoka of CMS described linking data on prenatal care and vital records to look at clinical outcomes; Rebecca Russell of the March of Dimes described the use of vital statistics data to examine disparities in birth outcomes among different population groups, to inform the organization's program planning; and Michael Kogan of HRSA said that many of the agency's performance and outcome measures on maternal and child health are derived from vital statistics. In addition, Rebecca Coyle and Mary Beth Kurilo of the American Immunization Registry Association (AIRA) described the use of birth record data to populate immunization registries with demographic birth information, for which they are considered to be the gold standard.

Ursula Bauer of the CDC described the use of vital statistics to track trends in health events over time, to enrich their understanding of low prevalence conditions, such as epilepsy, and to monitor emerging diseases such as Zika and influenza. Carolyn Clancy of the VA described their use of vital records data to search for information on suicides by veterans not receiving care through the Department. John Lumpkin of the Robert Wood Johnson Foundation, a former NCVHS chair, spoke of the uses of vital statistics for monitoring health at the community level. William Riley, NIH Associate Director of Behavioral and Social Sciences Research, represented the perspectives of researchers running clinical trials; he stressed the challenges of obtaining information on deaths of research participants and the impact this has on the quality of research findings. Other testifiers referenced other uses of VRSS data, such as in describing the health of specific population groups,³ monitoring vaccination patterns linked to income, and tracking anti-bacterial drug resistance.

Population Estimates

Hearing participants also testified about the important uses and benefits of VRSS data in non-health areas. Benjamin Bolender of the Census Bureau reported that the Bureau uses vital statistics information along with their own survey data to create detailed population estimates each year between decennial Censuses. The Bureau's population estimates are "the basis for federal funding allocations [totaling] hundreds of billions of dollars. They're used as denominators for health statistics, so for death rates, cancer rates, et cetera. They're used as

³ For example, the notable research by Anne Case and Angus Deaton on trends in white working class male mortality and morbidity. <http://www.pnas.org/content/112/49/15078>

controls for the American Community Survey. They're used as controls for the current population survey for unemployment rates. They're used as controls for most major government surveys that deal with population. They're also used by the public sector, the private sector, and local government leaders." On the same topic, Steve Goss, Chief Actuary for the Social Security Administration, described the critical role of vital statistics data in projecting Social Security costs and revenue for Congress through estimates of the population of the U.S. by demographic characteristics.

Identity Establishment and Verification, Death Notification, Fraud Prevention

Several hearing participants discussed their organization's use of birth and death registration data for identity establishment and verification, death notification and the prevention of fraud. Tara Das, State Registrar and Director of the Vital Statistics for the Texas Department of State Health services pointed out that births and deaths are "marked by legal documents, birth and death certificates, which serve a number of critical government and societal functions by documenting that a vital event has occurred at a specific time, date and place to an individual." Corrynne Carter of the State Department's Office of Passport Services described the use of birth certificates to verify identity before issuing passports—18 million of them in FY2016. Regarding the uses of death certificates, the three speakers representing commercial organizations⁴ explained that death notification is critical not only for terminating Social Security benefits but also for providing survivor benefits and preventing fraud in pensions, insurance, financial institutions, and reverse mortgages as well as in restoring unclaimed property. They also described the challenges they face in gaining access to fact of death information in order to conduct their business due to jurisdictional laws and regulations covering data confidentiality and data sharing.

IV. System Challenges

Over the course of the hearing, participants identified the following major areas of challenge for providers and users of VRSS data, within jurisdictions and at the national level. Corrynne Carter from the State Department observed that although participants' business needs varied, they identified many of the same challenges with the VRSS and needed similar functionality. The ideas they put forward for addressing challenges are summarized in Section V.

Costs and Financing

Across presenters, there was broad agreement regarding the urgent need to rethink how the nation pays for vital event data to be translated into vital statistics and shared with numerous users. Participants spoke of a "tragedy of the commons" in which the VRSS, which contains information of life-saving and life-changing importance to society, struggles for funding and sustainability. In effect, those testifying at the hearing argued for a new business model for the VRSS so that the states have a rational incentive to produce accurate and timely data that can

⁴ Susan McDonald of Pension Benefit Information, LLC; Edward Hall of Verus Financial, LLC; and Steven Emmert of LexisNexis.

be readily shared across a diverse base of users. Testimony indicated that the cost burden of data collection and exchange could be shared more equitably. Furthermore, more revenue is needed to adequately staff vital statistics offices and provide system maintenance, updates, and improvements over time.

Delton Atkinson of NCHS observed that the prevailing fee-for-service model does not work fairly or generate sufficient revenue for the jurisdictions. A core issue is that the costs borne by jurisdictions for vital records collection, management, and sharing—not to mention for system upgrades—are not adequately covered by the existing payment models. He called the current NCHS payments for vital records, which average \$370,000 per jurisdiction, “peanuts relative to the cost of having a top-flight vital statistics system in this country.”

In addition, there are no mechanisms to enable a significant number of data users to help support the VRSS that supply the data. Some data users, such as health researchers who use National Death Index data,⁵ have to pay significant fees for data, while others pay little or nothing to use vital records data obtained through other mechanisms such as the Limited Access Death Master File. William Riley of NIH noted that to make matters worse, the fees NIH-funded researchers pay end up costing NIH about twice that amount because of associated administrative costs and other factors. This situation was viewed as placing an unfair cost burden on a few payers. Moreover, John Lumpkin of RWJF pointed out that a fee-for-service system of revenue generation slows down data transactions and works against the efficiencies possible in a digital environment. In addition, as one state VRO representative observed, not all payments to states for the use of vital records make it back to the vital records offices from which they originate.

In the face of these realities, hearing participants called for development of a new business model for VRSS, possibly based on a “pay for play” principle; and NAPHSIS Director Shawna Webster called for greater funding from a more diverse set of federal and state agencies who use the data

One State’s Perspective on Funding

“Our Vital Records Office is required to provide data to the immunization registry, cancer registry, birth defects registry, advanced directives registry, organ donor registry, prescription monitoring system, PRAMS [Pregnancy Risk Assessment Monitoring System] ... and I could go on. None of those programs provide any funding to the Vital Records Office.” (Hearing testimony by Richard McCoy, Registrar, Vermont Dept. of Health)

Complexity, Inefficiency, and Gaps in Technology

The challenge of complexity affects VRSS data producers and users at every level of the system. Hearing participants testified about the extensive amount of information requested on birth and death certificates, the number of sources needed to provide the information, the inadequacy and lack of interoperability of digital systems, and the fact that some data providers are not

⁵ The National Death Index (NDI) is a centralized database of death record information on file in state vital statistics offices. Working with these state offices, NCHS established the NDI as a resource to aid health and medical investigators with mortality ascertainment activities.

<https://www.cdc.gov/nchs/ndi/index.htm>. Accessed 1/22/18

adequately trained. Referring to the volume of data collected in vital records, CDC's Ursula Bauer adapted the prevailing metaphor of vital statistics data as a foundation and wondered if "perhaps we're building a house that's too big for the foundation and could collapse."

Testifiers provided many examples of this challenge. After she showed the 17 steps involved in creating a birth certificate in her state, Minnesota informatician Kari Guida pointed out that creating the birth certificate is over and above the hospital's primary job of providing health care. Other speakers noted that the same is true for funeral home directors and physicians providing cause of death information for death certificates. Rebecca Coyle of AIRA reported that the 64 separate immunization programs compile information in a system she described as "clunky" because of the many different approval processes (e.g., Memorandum of Understanding, Data Use Agreement) needed to exchange data between the immunization programs and vital records offices.⁶ NCHS's Delton Atkinson said the 2.5 million mortality records that NCHS collects in a year require an average of three transactions each to complete the process because records are updated and/or corrected multiple times. Terra Abrams, Vital Registrar for the District of Columbia, named redundant processes as one of the chief challenges for data providers, along with aging or obsolete technology, aggressive counterfeiters and fraudsters, and lack of training of data providers.

Strategic use of technology was identified as a major part of the solution throughout the testimony and discussions. Participants observed that while some vital records processes use electronic systems, others do not; some of the technology in use is dated; and not all of the systems are interoperable between jurisdictions or even within them. Jurisdictions may choose to collect somewhat different data from what is included in the U.S. Standard Certificates so that systems must be designed for each jurisdiction to accommodate the differences. Furthermore, efficiencies and important data are missed because vital records in most jurisdictions are not (or are inconsistently) linked to electronic health records (EHRs). Moreover, the information for vital records must be entered as a separate process from data entry for other systems. Disparate message formats and content requirements further complicate the process. A fundamental observation by several hearing testifiers was that some electronic systems as well as the standard birth and death certificates themselves are still designed around a paper-based template, which generally does not use current technology and linkages to more efficiently combine data from multiple sources. Noting the current "patchwork" nature of the electronic birth and death registration system, Shawna Webster of NAPHSIS wondered if there were "something we could do at a higher, national level of standards to encourage more technology sharing, more reuse of technology, versus 57 different pieces of technology." Another issue that arose during several presentations was that jurisdictions have been moving towards centralizing their IT systems. This has resulted in better overall processing abilities but at the expense of focus on each individual need. Funding and prioritization of IT needs for VRSS compete with many other programs, causing delays in the design and implementation of improvements.

⁶ Immunization information services use many different mechanisms to support data exchanges with vital records, including memoranda of understanding, interacting agreements, data use agreements, and state statutes or rules.

Variability and Performance Gaps among Jurisdictions

Participants took it as a given that in a federated system such as this, every jurisdiction is entitled to enact its own laws, statutes, policies, and practices. Still, a major focus of the hearing focused on ways to move the entire national system toward soundness, excellence and efficiency, overcoming the variability and performance gaps that hamper the evolution of a high-functioning system. Minnesota's Kari Guida framed the problem in terms of "disparities between our offices of vital records," linked to the wide differences in funding. She warned that these disparities would "filter down from our offices to our departments of health and to the communities we serve."

To accommodate these differences among jurisdictions, Tara Das, who has VRSS experience in both New York City and Texas, urged that the strongest jurisdictions be allowed to move ahead while the weaker, less resourced ones learn from best practices. She shared her ideas for developing a community of practice among vital records professionals and mobilizing it to help transform the system. Hearing participants agreed on the value of highlighting best practices and providing training to promote capacity-building. Calls for greater standardization by presenters and participants were uniformly balanced by affirmation of the need for locally-tailored solutions.

Quality Concerns

Although they acknowledged the importance of other dimensions of data quality, hearing participants agreed that the first priority in this area is to continue to improve timeliness. The jurisdictions and NCHS have made tremendous progress in timeliness in recent years. For example, between 2011 and 2016 the number of months for release of final mortality data after the close of the data year was reduced from 30 to 10 months. NCHS has set a goal of 80 percent of deaths being reported to NCHS within 10 days of the date of the event—as of the hearing, 55 percent were reported within that period, up from 7 percent in 2010. Still, many testifiers said they needed more timely data. Strategies discussed included reliable sustained funding, modernized technology, and training, each of which would contribute to improved timeliness.

Beyond timeliness, participants described other quality concerns. As mentioned by Linette Scott, Chief Medical Information Officer in the California Department of Health Care Services, the quality of data reporting goes down as the number of data fields requested for birth and death records goes up. Quality of death data, especially the information on underlying cause of death and race and ethnicity of the decedent, is not as precise as needed. Tara Das also inquired that "the gold standard has been 'does it match what is in the medical chart' but are there other standards to look at data quality?"

Lack of Training for Data Providers and Collectors

Some testifiers pointed out that aspects of the vital record data entry process are detached from the normal workflow of data providers, limiting efficiency as well as their appreciation for the importance of their efforts. For instance, those responsible for entering health data into the record in hospital settings may fail to see the meaning of the information they provide for

eventual public health uses. In addition, they may derive no direct work-related benefit or value from their efforts. John Lumpkin observed, "If the vital statistics system is a black hole that they send data to, [health care providers] are not going to care one whit about it." As another example, clerks responsible for data entry and interaction with the public in local VROs may not realize how the data for which they are responsible are ultimately compiled, aggregated, and put to beneficial uses. The lack of perceived value in these and other settings contributes to the varied quality of the resulting data.

Many of the people involved in data creation and collection need additional training. There is a lack of understanding by the vital records staff about the importance of their work, how they serve the public not only through quality customer service by accurate and secure documentation of life events but also through all of the other uses of the data about which they are generally unaware. NAPHSIS representatives reported that VRO staff members, many of whom are nearing retirement, generally were not trained in the latest information technologies. At the same time, VROs can have difficulty attracting IT-proficient individuals who regard the field as a potential career. Training also was mentioned in regard to the physicians who must understand the importance and process of determining the sequence in the cause of death, especially since most deaths are completed by physicians not trained in this task.

Barriers to Data Access

The hearing testimony revealed considerable unrealized potential in access to timely and complete VRSS data for uses such as immunization registries, health care research, and population estimation. Calls by data users for greater access to the data were echoed by calls from some data producers to "let the data flow."

A major factor limiting data availability and access is the restrictions written into the laws and statutes of vital registration jurisdictions regarding data sharing and reuse. Delton Atkinson of NCHS spoke to the frustration about these constraints: "When we are working with researchers, the first thing they will say is, 'NCHS has the records; why can't you give them to us and why can't we use them in the way that we want to use them?' That is not how the system is set up. It's the laws and statutes and regulations at the state level that govern the use of the records, and we have to follow those laws and regulations." Some jurisdictions have open record statutes, which allow virtually any person access to records, while others have stringent restrictions in regard to who may access, utilize or even view records.

As part of the solution, NAPHSIS and many of its members call for HHS endorsement and wider adoption of the Model Law described above (page 16), which NAPHSIS Executive Director Shawna Webster stated "reflects best practices and standards for vital records administration." She and others explained that it is difficult for VROs to navigate the political process and advocate for change in their state legislation, especially without the explicit support that an HHS endorsement would provide.

Marriage and divorce data represent another significant data gap, one with a different cause. As noted, for budgetary reasons as well as limitations in states' data collection, in 1996 NCHS stopped collecting detailed data on marriage and divorce and started collecting only totals. Mark Bye and Karen Glenn, actuaries at the Social Security Administration, testified that this gap,

which includes information on same-sex marriage, has left them without critical information for determining projections and benefits.

Several hearing participants discussed the different sources of the compiled data that through which VRSS data are accessed. There are **seven main overlapping** sources of the data, which have different purposes and so have limitations in access by user affiliation and purpose of use.

- NCHS produces the NVSS and the NDI available for health surveillance and research purposes.
- SSA generates the Death Master File, which is only available for agencies administering federal benefits programs.
- SSA also generates the Limited Access Death Master File, which does not include data obtained from some jurisdictions, but can be used by individuals and organizations who have a certified need to access the data.
- Finally, NAPHSIS supports three different systems to allow users ascertainment or verification of vital events; each of these systems have restrictions on allowable users, acceptable uses, and in two systems, limitations on availability of data from some jurisdictions.

The marked redundancy, overlap and gaps in these systems designed to make VRSS data accessible are in fact prodigal and confusing. Multiple federal agencies aggregate and disseminate different slices of the data for a range of internal and external users. Because of this tremendous complexity and duplication, these systems, including their differences and similarities, were documented in detail in the report commissioned by NCVHS immediately following the hearing on the use and users of the VRSS.⁷

Challenges Related to Mortality

Some hearing participants consider the system that produces and collects mortality data to be the area in greatest need of improvement—including concerns about adequate funding, technology, timeliness, data quality, training, the complexity of data sources, and data access. John Fudenberg, Coroner in Clark County, Nevada, pointed out that the opioid epidemic has generated a tremendous demand for mortality data that it is difficult to meet under these conditions.

At the hearing, funeral directors, coroners, medical examiners, and several expert observers spoke about the issues involved in producing mortality data. For example, Mary Ann Sens, Coroner for Grand Forks County, North Dakota, said this about the multiple sources she must deal with: “Within my own county, I deal with some two dozen or so different funeral homes. There is a bewildering number of different agencies and computer systems that are pouring data into the death certificate.” Several presenters commented on the inadequate training of physicians who provide cause of death information, and on the disconnects between the

⁷ See Appendix C starting on page 32 of the NCVHS report, *Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue*. January 10, 2018, available online: <https://www.ncvhs.hhs.gov/vital-records-and-vital-statistics-in-the-united-states-uses-users-systems-and-sources-of-revenue/>

information sources for the death registration that prevent smooth data flow into the VRSS from those on the front lines.⁸ Eric Hughes of MITRE Corporation has studied ways to improve mortality data for NCHS, under contract to the Center. He described the variations among states in their electronic death registration system capabilities that prevent public health officials and health care providers from keeping pace with public health problems.

On the usage side, researchers and commercial users testified about the difficulty they face in getting timely information on the fact of death. The result, in the memorable words of Susan McDonald of Pension Benefit Information, LLC, is that pension plans “are making payments to dead people.”

V. Looking to the Future

The question that guided this NCVHS hearing on the next generation of VRSS was, *How do we transform today’s vulnerable vital records data collection network into a system that produces accurate and timely information to support a breadth of local, state, territorial, and Federal data needs?*

Vision

Moving toward this goal begins with elaborating the vision for the VRSS of the future. Over the course of the two-day hearing, several speakers shared their respective vision for the next generation of the VRSS and the steps NCVHS and stakeholders could take to move in that direction. For example, William Riley of NIH articulated an ambitious vision for a Public Health Surveillance System—an integrated, accessible system that would allow researchers and public officials to monitor the health of the U.S. population from birth to death in real time. He contrasted today’s “fragmented and disconnected” health surveillance system with the existing examples of integrated systems being used to monitor the weather, aerospace, and tectonics. In this regard, several speakers invoked the foundational vision of a single, integrated record for every individual—one that begins with the birth record, incorporates the EHR, and ends with the death record, all interfacing in real-time, Web-based systems.

John Lumpkin of RWJF sketched a vision for an innovative system that uses the VRSS to understand and improve community health and well-being. “The vital statistics system must transform from answering yesterday’s questions,” he said, “to begin to answer tomorrow’s questions using tomorrow’s tools.” With that end in mind, he urged that data and processes in the VRSS of the future be forward-facing, embedded in the workflow, meaningful to the data generator, timely, integrated, and granular. This wish-list captures many of the key themes of the hearing.

Chesley Richards, Director of CDC’s Office of Public Health Scientific Services, imagined a future in which vital records data are “transmitted to partners, supported by electronic platforms in an

⁸ The sources of death certificate information include funeral homes, coroner and medical examiner offices, hospitals, hospices, and nursing homes.

environment where we can use all the tools at our disposal to make that data move in the ways that it should." He continued,

I think that's critical, [so we can] facilitate the record sharing that needs to occur at the state level.... At the national level, the creation of national datasets and the ability to make that data available to all the appropriate business and research users or partners is really going to hinge on how effectively we can use emerging technologies like block chain for security and natural language processing to really be able to get from the data the things that we're not able to get now.... We need to align policy, resources, and a workforce that's right-sized with the right skills to be able to do the work. The critical piece out of all of this is the business model for vital registration, vital statistics. It needs to be robust. And it needs to be primed not just to operate where we are currently, but to be able to move into the future and take advantage of all the various opportunities we have.

Possible Strategies

The Committee invited hearing participants to suggest possible strategies for transforming the VRSS and realizing its potential. Some suggestions focused broadly on strategy. For example, Minnesota's Kari Guida recommended clearly identifying the essential information needed and engaging VROs in the transformation process from the beginning. John Lumpkin linked vision to hard work: "As we think about the transitions, we have to have a vision of where we want to go but recognize that there is some really hard work about redesigning that business model."

The major areas in which hearing participants suggested strategies for transforming the VRSS are summarized below. Presentation of these suggestions does not signify NCVHS endorsement.

- **Identify and Deploy a Sustainable Business Model to Enhance Systems for Vital Records Data Collection and Sharing**

One of many testifiers to comment on the business model was Eric Hughes of MITRE, who concluded his report on mortality data issues by linking wider uses of the data to funding: "We need a more sustainable funding model, with a public-private partnership to drive support and guide innovation efforts. As part of a new business model, we should explore wider uses of mortality data in addressing public health issues while protecting privacy and confidentiality." Fellow hearing participants also stressed the need to clarify the business case and the return on investments (ROI) in the VRSS, and to use that understanding of the ROI to inform the development of sustainable funding models. CDC's Chesley Richards added that the business model must be sufficiently flexible to evolve. Participants agreed that a high-priority early step should be to learn more about current users, uses, and money flow related to vital records and vital statistics.⁹

⁹ NCVHS moved quickly on this action item. Soon after the hearing, it contracted with R. Gibson Parrish, M.D., to conduct the inventory and prepare a report, which he completed in late 2017. In the present report, Figures 1 and 2 and the sidebar on terminology (page 24) are taken from that report.

- **Simplify and Align Practices, and Take Greater Advantage of Data Interoperability**

A number of suggestions, both conceptual and practical, were put forward for streamlining VRSS processes and systems. Regarding mortality data, for example, John Lumpkin of RWJF challenged the field, in view of the fact that “we don’t live in a paper environment any more... to think about creating this public health information space that health care and funeral directors interface with, and that actually gives them something back that’s meaningful in what they’re attempting to accomplish.” He added that all those involved in the data enterprise should be part of this endeavor, not just government.

Gregory Davis, Medical Examiner for Jefferson County, Alabama, expressed his field’s strong interest in interoperability: “We’re on the cusp of developing a system where we can have data from the various databases being put into the other databases, and share the data. When the time comes to pilot such a system—and I hope it’s sooner rather than later—you’ll find that medical examiner/coroner offices are willing, even eager, to get involved because we see its usefulness and know that that’s the proper future for us.”

On a practical level, NAPHSIS members asked for support for the use of EVVE (Electronic Verification of Vital Events System) and STEVE (State and Territorial Exchange of Vital Events), electronic systems developed by NAPHSIS to facilitate inter-jurisdictional data exchange and access to birth and death information. Additionally, Valerie Gaston of Statistics Canada described how helpful Canada’s National Routing System has been in enabling its federal departments to deal directly with vital registrars while leveraging funding, setting messaging standards, and allowing greater control of data by data providers. While there was broad agreement about the importance of ensuring flexibility for local innovation and problem-solving, several speakers called for exploration of standardization such as standard message formats and common data elements.

A recurring theme was the idea of decoupling the data needed to meet legal and administrative needs from the data needed for public health surveillance. Ursula Bauer of CDC put it this way:

We built this surveillance system, not from scratch...but on the back of a different system that was established for a different purpose. I wonder how streamlined and solvent, even, the vital registration system would be if it were focused exclusively on documenting the fact of the event and weren’t saddled so much with the enormous data collection that the vital statistics system requires as a public health surveillance system. We’re a century removed from when this system was set up, and we have all of these new processes and tools and resources like electronic health records and so on. Were we to build a new kind of freestanding system, might that better meet the needs of our public health surveillance?

Speaking from the perspective of vital registrars, Tara Das of Texas addressed the importance of the information being collected, the burden on those doing the collecting, and the funding implications:

There are both legal and public health purposes to the work we do. Many of our local vital records offices were rooted in health departments, and we see a core public health mission to what we do. But at the same time, I do think that the public health purposes may have become too expansive, particularly on the birth reporting side. Reconsidering how many data items we collect on the birth certificate, particularly in the confidential medical report, would be good. A request from the states to our data partners at the state and federal level is to think about that, think about the demands that you ask of us and increasing them without providing any kind of support, or really also consideration as to whether they are appropriate to ask of us.

- **Expand Training for Data Providers and Integrate Processes into Workflow, with Accreditation as a Tool**

Many of the testifiers spoke to a need to provide additional training to data providers, with a particular focus on physicians who certify only a limited number of deaths each year. In addition, hearing participants homed in on the benefit of embedding data collection in workflow and making the data useful to the generators. For example, John Lumpkin talked about integrating VRSS data into the public health enterprise. Several speakers mentioned the potential benefits of using accreditation as a guide and motivator, and the need to develop criteria for the accreditation of vital statistics departments as part of the Public Health Accreditation Board process. Then accreditation could be used as a tool of learning, accountability, and promotion of best practices, furthering many of the improvements under consideration.

- **Advocate for Changes to State Laws to Improve Data Access**

The pressing need to change state laws was a major theme of the hearing, articulated most strongly by Steven Emmert of LexisNexis. He said,

Some of the inconveniences that were built into the system originally [were for reasons that don't] really exist today.... If you look at the underlying structure behind the vital records laws in the states, a lot of those laws were passed about 25 years ago. Many of those laws were written 50 years ago, 75 years ago, before the technology existed to move data as quickly as we can over the Internet. None of the comments I have made are meant to criticize either state custodians or, for instance, the Social Security Administration.... They have all tried very hard within the parameters of the laws they have to be responsible partners. But it's an area where some updating on the laws would facilitate some actions that would have a dramatic public benefit.

Many speakers recommended exploring regulatory changes and standards that could facilitate improvements in data quality, linkage, and re-use while protecting confidentiality and privacy. As noted, the major strategy put forward was to encourage endorsement and support for

implementation of the Model Law. NCHS Director Charlie Rothwell pointed out that private sector representatives such as those present at the hearing could be effective advocates at the state level.

Next Steps

A point made often during the hearing was that the Federal government is heavily reliant on vital records data and bears a special responsibility for supporting and enhancing the system; several speakers urged NCVHS to convene stakeholders and advise HHS in this area. Further, they urged NCVHS to work with stakeholders and subject matter experts to develop a long-term vision—seen as the appropriate context for devising a new business case—and to target short-term opportunities for improvement. There were reminders to involve the entire coalition of stakeholders in efforts to design and advocate for system-wide enhancements, building on the progress already being made in many areas.

Given the foundational significance of the VRSS and current system vulnerabilities, the Committee finds that more attention needs to be paid to this critical infrastructure.

Based on the hearing and subsequent analysis, the Committee has determined that federal leadership is needed to:

- Convene the multiple stakeholders to modernize the federated VRSS.
- Develop business models to better align payment with uses and distribution of payment to cost centers;
 - Systematically obtain information regarding the current business model from each vital registration jurisdiction on costs, revenues, distribution of revenues and relevant laws and statutes to inform this work.¹⁰
- Modernize laws, technology and process related to vital records and vital statistics;
- Train people collecting and contributing VRSS data and credential the jurisdictional vital registration systems.

¹⁰ Detailed specifics are outlined on page 25 of the NCVHS report, *Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue*. January 10, 2018, available online: <https://www.ncvhs.hhs.gov/vital-records-and-vital-statistics-in-the-united-states-uses-users-systems-and-sources-of-revenue/>.

Appendix 1. Hearing Agenda and Panelists

National Committee on Vital and Health Statistics (NCVHS)

Next Generation Vital Statistics: A Hearing on Current Status, Issues and Future Possibilities

Hubert H. Humphrey Building, Room 705A, Washington, DC

September 11-12, 2017

Agenda

Vision

A sustainable, secure and robust U.S. vital records infrastructure that meets the nation’s need for timely and accurate information.

Guiding Question

How do we transform today’s vulnerable vital records data collection network into a network of state systems that produce accurate and timely information supporting a breadth of local, state and federal data needs?

Objectives

Using a multi-stakeholder presentation and generative discussion approach, this hearing will:

- Identify the essential elements of the vital statistics system – the components and as a whole,
- Assess its current status and risks to its viability, and
- Consider what actions are needed both to protect and improve the system.

Monday, September 11, 2017

9:00 am	Welcome and introductions	Bruce Cohen, PhD & Dave Ross, ScD: Hearing Co-Chairs
9:15 am	Overview – Importance and Need for Vital Records: Local, State, Federal, International Committee Q & A	Tara Das, PhD, MPH, MLIS: Texas Dept. of Health Services Valérie Gaston, MA: Statistics Canada, Health Statistics
10:15 am	Panel 1. Current Status for Vital Records: State and Local Data Producers FOCUS: Why do states collect vital records? How are they collected? How are they managed? How and why are they shared? A) Introduction	Shawna A. Webster, CAE: NAPHSIS Richard H. McCoy: Vermont Dept. of Health and NAPHSIS

	<p>B) Births</p> <p>15 minute break</p> <p>C) Deaths</p> <p>D) State/Jurisdictional Health Information Technology and Information Technology:</p> <p>Committee Q & A</p> <p>Audience Input</p>	<p>Angela Shaw-Perkins: Medstar Washington Hospital Center Susan Zannis: Southern NV Health District</p> <p>Robert C. Moore, IV, CFSP, CCO: Funeral director and NFDA John Fudenberg, D-ABMDI: Clark Co. Office of the Coroner/Medical Examiner and IAC&ME</p> <p>Kari Guida, MPH, MS: MN Dept. of Health Linette Scott, MD, MPH: CA Dept. of Health Care Services (by phone)</p>
<p>11:55 am</p>	<p>Discussion and Public Comment</p>	
<p>12:15 pm</p>	<p>Lunch</p>	
<p>1:15 pm</p>	<p>Panel 2. Current Status of Vital Records: Federal Perspective</p> <p>FOCUS: Why do federal agencies need vital records? How are they managed? How and why are they shared and used?</p> <p>A) Federal Data Steward</p> <p>B) Federal Health Users</p> <p>Committee Q&A</p> <p>C) Other Federal Users</p> <p>Committee Q & A</p> <p>Audience Input</p>	<p>Delton Atkinson, MPH, MPH, PMP: NCHS, CDC</p> <p>Karen Matsuoka, PhD: CMCS, CMS Cathy Carter: OIT, CMS William Riley, PhD: OBSSR, NIH Ursula Bauer, PhD, MPH: NCCDPHP, CDC Michael D. Kogan, PhD: MCHB, HRSA</p> <p>Stephen C. Goss, ASA, MAAA: Social Security Administration Corryne Carter, MPA: Dept. of State Carolyn Clancy, MD: Dept. of Veterans Affairs Aaron Firoved, PhD: Dept. of Homeland Security</p>

3:15 pm	Break	
3:30 pm	<p>Panel 3. Current Status for Vital Records: Other Users of Vital Statistics Data</p> <p>FOCUS: Who are other users of vital statistics? What are these data needed for?</p> <p>A) State users</p> <p>B) Researchers</p> <p>Committee Q & A</p> <p>C) Commercial users:</p> <p>Committee Q & A</p> <p>Audience Input</p>	<p>Rebecca Coyle, MEd: AIRA Michael D. Warren, MD, MPH, FAAP: TN Dept. of Health and AMCHP</p> <p>Mohsen Naghavi, MD, PhD: Univ. of Washington Rebecca B. Russell, MSPH: March of Dimes</p> <p>Susan McDonald: Pension Benefits information, LLC Edward Hall, JD: Verus Financial, LLC Steven M. Emmert, JD: LexisNexis Risk Solutions</p>
5:15 pm	Discussion and Public Comment	
5:45 pm	Adjourn	

Tuesday, September 12, 2017

8:30 am	<p>Reconvene & Welcome</p> <p>Framing the Day:</p> <ul style="list-style-type: none"> • Current challenges & barriers regarding the vital statistics system • Potential consequences if current challenges are not addressed • Opportunities available to leverage technology and new innovation to support the vital statistics system 	Dave Ross, ScD and Bruce Cohen, PhD: Hearing Co-Chairs
8:45 am	<p>Panel 4. Challenges and Opportunities: Federal Level</p> <p>FOCUS: What are the current challenges and issues for federal users, and how might they be addressed?</p>	<p>Delton Atkinson, MPH, MPH, PMP: NCHS, CDC Eric Hughes, PhD: MITRE Corp. (under contract w/NCHS) Caitlin Cross-Barnet, PhD: CMMI, CMS</p>

	<p>Committee Q & A</p> <p>Audience Input</p>	<p>Lekisha Daniel-Robinson, MSPH: CMCS, CMS</p> <p>Ursula Bauer, PhD: NCCDPHP, CDC</p> <p>William Riley, PhD: OBSSR, NIH</p> <p>Karen P. Glenn, FSA, EA, MAAA and K. Mark Bye, ASA: Social Security Administration</p> <p>Benjamin Bolender, PhD: Census Bureau, Dept. of Commerce</p> <p>Corryne Carter, MPA: Bureau of Consular Affairs, Dept. of State</p>
10:15 am	Break	
10:30 am	<p>Panel 5. Challenges and Opportunities: State and Local Levels</p> <p>FOCUS: What are the current challenges and issues for State and local users, and how might they be addressed?</p> <p>Committee Q & A</p> <p>Audience Input</p>	<p>Elizabeth W. (Lou) Saadi, PhD: KS Dept. of Health & Environment and NAPHSIS</p> <p>Terra J. Abrams, MBA, BPM: DC Dept. of Health</p> <p>Mary Ann Sens, MD, PhD: Grand Forks County Coroner’s Office, Univ. of ND and NAME</p> <p>Gregory G. Davis, MD, MSPH: Jefferson County AL Medical Examiner’s Office and Univ. of AL at Birmingham</p> <p>Mary Beth Kurilo, MPH, MSW: ARIA</p> <p>Amy Zimmerman, MPH: RI Exec. Office of Health & Human Services</p> <p>Michael Hogarth, MD, FACP, FACMI: UC San Diego Health</p> <p>Janet J. Hamilton, MPH: FL Dept. of Health and CSTE</p>
12:10 pm	Discussion and Public Comment	
12:30 pm	Lunch	

1:30 pm	<p>Panel 6. Future Directions</p> <p>FOCUS: In light of evolving technology and practice, what are the opportunities to reinforce and strengthen the national vital statistics system?</p> <p>Committee Q & A</p> <p>Audience Input</p>	<p>John R. Lumpkin, MD, MPH: RWJF Calvin Yu, MD: Southern CA Kaiser Permanente Chesley M. Richards, MD, MPH, FACP: OPHSS, CDC</p>
3:00 pm	<p>Discussion and Public Comment</p>	
3:25 pm	<p>Instructions for Audience Input and Break</p>	
3:45 pm	<p>Audience Input</p>	
4:00 pm	<p>Moving Forward: An Integrated Vision – Discussion</p> <p>Focus: Identify key issues and key themes. Formulate framework to synthesize testimony.</p>	<p>R. Gibson Parrish, II, MD, Facilitator</p>
4:45 pm	<p>Wrap-Up</p>	<p>Dave Ross, ScD and Bruce Cohen, PhD</p>
5:00 pm	<p>Adjourn</p>	<p>Dave Ross, ScD and Bruce Cohen, PhD</p>

QUESTIONS FOR DAY 1, PANEL 1**A) NAPHSIS and State Vital Health Registrar**

1. Explain where your role fits into the overall vital statistics system process. What is the workflow of that process at a high level?
2. What are the legal underpinnings of the current system?
3. How is the system financed? How does the financing approach impact your ability to participate in broader electronic data exchange?
4. How are the data used and by whom?

B) Births

1. Explain where your role fits into the overall vital statistics system process. What is the workflow of that process at a high level?
2. How does data sharing and transmission work?
3. How are data protected?
4. How are privacy and confidentiality issues addressed?
5. How are the data used and by whom?

C) Deaths

1. Explain where your role fits into the overall vitals data process. What is the workflow of that process at a high level?
2. How does data sharing and transmission work?
3. How are data protected?
4. How are privacy and confidentiality issues addressed?
5. How are the data used and by whom?

D) State/Jurisdictional IT Lead

1. Explain where your role fits into the overall vitals data process. What is the workflow of that process?
2. How does data sharing and transmission work?
3. How are data protected?
4. How are privacy and confidentiality issues addressed?

QUESTIONS FOR DAY 1, PANEL 2

1. How are vital statistics used by your agency?
2. How important of a role do they play?
3. What are the quality concerns regarding the data?
4. How are the data obtained/managed/shared/protected?
5. How do you verify or confirm the authenticity of birth and death certificates?

QUESTIONS FOR DAY 1, PANEL 3

1. What do you use the data for? Why are they important?
2. What is the current “experience” with vital records?
3. How does data sharing, transmission and protection work?

QUESTIONS FOR DAY 2, PANEL 4

1. From the vantage point of your agency, what are the challenges & barriers you are encountering in your use of vital records and statistics?
2. From your agency’s perspective, what kinds of solutions do you believe would be helpful?
3. What would be some possible consequences if current challenges are not addressed?

QUESTIONS FOR DAY 2, PANEL 5

1. From the vantage point of your organization, what are the challenges & barriers you encounter in your using, accessing, or producing vital records and statistics?
2. From your organization’s perspective, what kinds of solutions do you believe would be helpful?
3. What would be some possible consequences if current challenges are not addressed?

QUESTIONS FOR DAY 2, PANEL 6

1. What opportunities are available to leverage technology/new innovation to support the vital statistics system?
2. How would these opportunities improve the vital statistics system, e.g. data quality and timeliness?
3. What issues and challenges need to be addressed? What are options for approaches?

List of Testifiers

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Panel 1. Current Status for Vital Records: State and Local Data Producers

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Panel 2. Current Status of Vital Records: Federal Perspective

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Panel 3: Current Status for Vital Records: Other Users of Vital Statistics Data

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Panel 4: Challenges, Barriers and Potential Solutions: Federal Level

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Panel 5: Challenges, Barriers and Potential Solutions: Local Level

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Panel 6: e-Health and its Relation to e-Vitals

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Moving Forward: An Integrated Vision

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Appendix 2. Hearing Attendees

NCVHS Next Generation Vital Statistics: A Hearing on Current Issues and Future Possibilities

Attendees

Committee Members

Bill Stead	Linda Kloss	Helga Rippen
Bruce Cohen	Denise Love	David Ross
Lee Cornelius (on phone)	Vickie Mays	Debra Strickland (on phone)
Nick Coussoule	Bob Phillips	Roland J. Thorpe, Jr. (on phone)
Alix Goss		

Staff

Kate Brett	Rashida Borse	Katherine Jones
Suzie Burke-Bebee	Rebecca Hines	Susan Kanaan
Geneva Cashaw	Debbie Jackson	Marietta Squire

Presenters

Terra J. Abrams	Valérie Gaston	Robert C. Moore, IV
Delton Atkinson	Karen P. Glenn	Mohsen Naghavi
Ursula E. Bauer	Stephen C. Goss	R. Gibson Parrish
Benjamin Bolender	Kari Guida	Chesley M. Richards
Mark Bye	Edward Hall	William Riley
Cathy Carter	Janet J. Hamilton (on phone)	Rebecca Baker Russell
Corryne C. Carter	Michael Hogarth	Elizabeth W. (Lou) Saadi
Carolyn Clancy	Eric Hughes	Linette Scott (on phone)
Rebecca Coyle	Ira Katz	Mary Ann Sens
Caitlin Cross-Barnet	Michael D. Kogan	Angela Shaw-Perkins
Lakeisha Daniel-Robison	Mary Beth Kurilo	Michael D. Warren
Tara Das	John R. Lumpkin	Kalvin Yu
Gregory G. Davis	Karen Matsuoka	Shawna A. Webster
Steven M. Emmert	Richard H. McCoy	Susan Zannis
Aaron Firoved	Susan McDonald	Amy Zimmerman
John Fudenberg		

Other Attendees

Jerome Adams	John DeCarlo	Michael Morris
Jeffrey Agnew	Nicole Gardner	Andrea Price
Francis Barbour	Cora Han	Charles Rothwell
Shallendra Bhargava	Lucas Hitt	Susan Roy
Blair Bowers	Betsy Humphries	Loraine Scobedo
Debra Bowers	Lillian Ingster	Meriarad Seercy
John Bowers	Fern Johnson-Clark	Lisa Valente
Patti Brennan	Fatemeh Khatibloo	Margaret Warner
Christopher M. Bryant	Mac McGraw	Erin Weber
Chandra Chaay	Jacqueline Medina	Will Whitman
Susie Cormack	Patricia Moore	Crystal Willis

Appendix 3. One-Page Background on Hearing



National Committee on Vital and Health Statistics Hearing on Next Generation Vital Statistics September 11-12, 2017 Humphrey Building, Washington DC

The National Committee on Vital and Health Statistics (NCVHS) is charged with advising HHS on health data, statistics, privacy, and national health information policy. Because the vital statistics system plays a critical role in public health surveillance, is essential to understanding the effectiveness of the healthcare and health financing system, and is relied upon for business and commerce, the Committee is taking this opportunity to explore the state of the existing national vital statistics system and identify possibilities for improvement.

Realizing the Potential of Vital Statistics

Despite the essential role vital statistics and related administrative data play in protecting a broad range of needs, especially national security and population health, stakeholders at the state and national level have shared concerns that the vital statistics system faces serious structural and resource challenges. As currently constituted, national data are developed through a federated network of data collected by states and territories, with differing laws and parameters on data use, and then shared with the federal government for aggregation.

- Vital statistics are the foundational data source for understanding the U.S. population, including identification of trends in disease and epidemics, e.g., the recent surge in opioid-related deaths.
- Health care providers, businesses, and government agencies at all levels as well as individual citizens, depend on vital records and the vital statistics system for identity establishment and protection, and a host of other critical uses for research, finance, planning, public records and services.
- Resources for vital statistics infrastructure are dependent on the ability of jurisdictions to issue records and assess fees, or secure the minimal funding available via contracts and data sharing agreements and support from the National Center for Health Statistics (NCHS).

NCVHS Hearing

To clearly define the challenges and identify potential approaches to address them, NCVHS is seeking input from key stakeholders from experts at HHS, other Federal agencies, states, and territories, as well as from researchers, healthcare providers, and organizations that rely on vital administrative and statistics data.

The guiding question the Committee will study is:

How do we transform a vulnerable, federated data collection network into a robust timely integrated sustainable multipurpose information system that produces timely data and information flows?

The objectives of this hearing are to:

- Identify the essential elements of the vital statistics system – the components and as a whole
- Assess its current status and risks to its viability
- Consider what actions are needed both to protect and improve the system.

The Committee is studying potential approaches to transform vital statistics and administrative data into a robust and sustainable system that generates timely, secure and integrated information flows to strengthen public health surveillance, enhance healthcare, and provide information for all governmental and private sectors that have come to depend on the system.

www.ncvhs.hhs.gov

Appendix 4. National Committee on Vital and Health Statistics Membership

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